

The  
**Kidney Cancer Association**

Presents...



We Have  
**Kidney Cancer**

*Survivors Stories*

Inspiration and advice from patients and caregivers

KidneyCancer.org

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## FOREWORD

I am always thrilled to meet fellow kidney cancer survivors and their families.

When I was diagnosed 18 years ago with Stage III kidney cancer, the only encouragement I received from my surgeon was that he would “make me as comfortable and happy as possible.” As a straightforward New Yorker, I decided that “comfortable and happy” wasn’t going to cut it with me. I very sweetly advised him that I had “comfortable and happy” covered; I needed him to do something more.

Following a radical nephrectomy of a 10 cm tumor (that was classified as papillary), I endured one year of low-dose subcutaneous immunotherapy – at the time, the only FDA approved treatment on the market -- and was pronounced cancer-free.

Six months later, a lymph node surfaced in my neck; it was malignant. What to do? My oncologist put me on a chemotherapy regimen that combined two other chemical agents. It was an extremely challenging treatment, but it seems to have worked.

I have subsequently had all sorts of “quirky” medical issues, but, fortunately, kidney cancer has not been among them. During my experience with cancer, I came to realize that one thing we always need is HOPE. Kidney cancer statistics are daunting and can weigh heavily on one’s state of mind. This is what propelled me to become involved with the Kidney Cancer Association: I wanted to be the voice for those unable to speak up; the shoulder for those who needed a boost; and, most importantly, the one who provided hope when things looked grim.

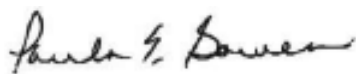
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*“During my experience with cancer, I came to realize that one thing we always need is HOPE.”*

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The courageous survivors and caregivers profiled in this book give us many good reasons to be hopeful. Their inspiring stories remind us of how important it is to keep striving, no matter what the circumstances – and their practical advice and tips for daily living are invaluable.

I would urge anyone who has been impacted in some way by a kidney cancer diagnosis – whether as a patient or a caregiver – to consider offering your services as a patient advocate. Become a volunteer. Join the Kidney Cancer Association’s online community. Share your story with others who may benefit from it. I am confident that you will find reaching out to support other patients as rewarding an experience as I have, and by doing so you help move us closer to our goal of a world without kidney cancer.



**Paula E. Bowen**

Director, Kidney Cancer Association

## Acknowledgments

We gratefully acknowledge the commitment of time and the thoughtful input of the kidney cancer patients and caregivers who offered their stories and advice in this book to help other patients. Your efforts are deeply appreciated.

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## Introduction

For more than a decade, the Kidney Cancer Association has published the book *We Have Kidney Cancer* for patients and families facing a cancer diagnosis. Thousands of copies of the book have been distributed, offering comprehensive background information and resources on every aspect of kidney cancer.

This new companion book, *We Have Kidney Cancer: Survivors Stories*, brings patients and families an additional element of help – the personal stories and advice of kidney cancer patients and caregivers.



The National Cancer Institute estimates that there are between 100,000 and 200,000 kidney cancer survivors living in the United States right now. The good news is that there are more treatment options for patients today than ever before. With recent advances in diagnosis, surgical procedures and drug treatment options it is expected that even more patients will live with kidney cancer in the

future, continuing to maintain their normal schedules and lifestyles.

*We Have Kidney Cancer: Survivors Stories* aims to help these survivors by giving them inspiration and a reason for hope. The patients and caregivers featured on these pages offer a wide variety of viewpoints and backgrounds, but they all have one thing in common: The determination to press on after a kidney cancer diagnosis.

From an 83-year-old great grandfather in Illinois, about to celebrate his 60th wedding anniversary, to a 25-year-old snowboarder in Utah who just graduated from college, each patient offers unique perspectives and practical tips for day-to-day living with kidney cancer.

Most of the common challenges faced by patients and caregivers are covered in these pages – making treatment decisions, choosing a medical team, facing physical limitations, how to talk about illness to friends and family, dealing with side-effects of drugs, and much more.

To watch videos and learn more about these survivors and others, or to order a copy of the book *We Have Kidney Cancer*, visit the Kidney Cancer Association website at [www.kidneycancer.org](http://www.kidneycancer.org).



## *Bob and Carol*

Bob and Carol are Florida residents, with three grown sons. They have been married 26 years. Bob is originally from Pennsylvania and Carol is from Texas. Bob is a sales professional who works from home and Carol is a Pilates instructor and fitness consultant.

Bob was diagnosed with kidney cancer in 2005 during a routine doctor's visit. He had scheduled an appointment after experiencing stomach problems. A CT scan showed a malignant tumor on his left kidney, which was removed laparoscopically a week later. A follow up scan in 2007 showed another tumor, which was again surgically removed, and several months later the disease metastasized to his liver; he then began immunotherapy. He had a third surgery in 2009, to remove a part of his liver.

Bob's experience offers insight into the psychological changes that can occur when kidney cancer metastasizes. "I went from Stage I to Stage IV and that was when a new kind of reality set in," Bob says. He attributes his experience with kidney cancer to helping him change his attitude about life, becoming much more positive as a result. He has also become a strong proponent of meditation, which he says has helped in his recovery from several surgeries and grueling immunotherapy.

In this interview, Bob and Carol offer excellent advice for families and friends providing caregiving help for a hospitalized patient.

### ***Survivor's advice from Bob:***

- "Get the best possible care you can – and that means getting multiple opinions about your options."
- "Become an active part of your medical/caregiving team. Help them help you."
- "It's very important that you believe you can get better. Your attitude will determine a lot of your success."

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**Interviewer:** What were the circumstances of your diagnosis?

**Bob:** I was originally diagnosed with kidney cancer, in January of 2005. And it was actually through a routine examination with my regular doctor. I was complaining a bit about stomach problems. I think at the time I was just having some life issues, feeling a little nervous. And ultimately, he ended up referring me to go get a

CT scan, just simply thought maybe I might have kidney stones. That's when we got the good news and the bad news. The good news is you don't have a kidney stone. The bad news is you've got something more difficult. And that's when I was diagnosed with a kidney tumor.

**Interviewer:** What treatment did you receive?

**Bob:** About two weeks later, I ended up having surgery. I had my left kidney removed. And from that point forward, just through regular recovery – it was done laparoscopically – it was pretty easy for me actually. It was just a matter of getting back on my feet physically, which I did. And I was perfectly fine for a good two years. And actually, I never even thought about it anymore. We started regular CT scans as a follow-up procedure, and about two years and a couple months later I remember walking in the door, and my wife Carol said, “You better call the doctor about the latest scan.” It turned out that they had found another tumor, a second tumor. It was a recurrence in my abdominal area. It was a pretty big tumor. That was removed surgically, and that was in 2007, and I went through a complete recovery again.

**Interviewer:** Then what happened?

**Bob:** About three months later, we did another CT scan and that's when things got really, really tricky. I was diagnosed with tumors that had metastasized to the liver. There were multiple lesions in the liver. And at that point was the first time Carol and I ever went and actually visited an oncologist. Up to this point, everything had been handled at the level of my urologist. That was the first time I ever walked into an oncologist's office, ever. And I think that's when the reality hit me that I really had cancer because all the other things had been surgically addressed – just get rid of it. At that point, we discussed my treatment options. I'm very, very fortunate today – I've had some great doctors who presented the different treatment options available to me. At that time, I was about 46 or 47. So I was in pretty good health. And my doctor gave me several alternatives. One of them was immunotherapy. And the other ones, of course, were the new drugs that were then coming on the market.

**Interviewer:** What did you choose to do?

**Bob:** My doctor referred me to a couple of cancer centers in Miami. And I went to both. And it turned out I was a good candidate for their treatment programs. And then I was on the calendar to actually start immunotherapy, and then I received another opinion

from a doctor in Miami. He said I shouldn't do it – that he thought it was “barbaric.” So I hesitated. But after talking to another doctor about it I started immunotherapy in June of 2007.

**Interviewer:** And what was it in this doctor's advice that made you decide to go ahead?

**Bob:** I trusted this person. I just had really good rapport with him. He said, “Listen, I can't tell you what to do. It's your body. It's your life. But if you've got one shot, even today, at getting some sort of a full response and potentially a cure, why not think about really taking that shot?” So that's really what put me over the edge to try immunotherapy. I think the other doctor had scared me a little bit in terms of the side effects and things that I could anticipate having to go through.

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*“He said, ‘Listen, I can't tell you what to do. It's your body. It's your life. But if you've got one shot, even today, at getting some sort of a full response and potentially a cure, why not think about really taking that shot?’”*

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**Interviewer:** And how did the treatment go?

**Bob:** Well, quite frankly, when I did go in, and after the first treatment, I was in the hospital for about six days. And it was the most brutal thing I could ever, ever go through.

**Interviewer:** Why is that?

**Bob:** Just the side effects. I don't think anybody is really prepared to deal with the treatment. And I don't care what you read, until you physically go through it, you have no idea. And that's why Carol is so important because it wasn't just what I was going through, the rest of my family had to deal with it. That was really difficult. That was probably the most difficult. And actually, what happened was, after I got through the first regimen, we were walking out of the hospital. And I felt like I was brain dead. And I turned to her and I said, “I don't think I want to do this.” I said, “I'm prepared to look at other alternatives.” And at that point, I went back and I met with my oncologist. And he said, “Well, if you don't want to do it, don't do it.” And he got an order started for one of the new drugs. We had it ordered.

**Interviewer:** And did you go on the drug?

**Bob:** No. The doctor who had administered the immunotherapy down in Miami said, “Listen, before you decide to totally throw in, why don't we do a CT scan?” And we did. And the scan actually



showed that there was something biologically happening. There was no question. And it was enough to convince me to go back. And I ended up going back and doing the course – I went through five rounds of immunotherapy. I ended up with a very, very good partial response. All the liver masses were gone. And then we waited a little bit and they decided to do one more consolidation dose of immunotherapy. After that there were still residual tumors in my liver, which, in turn, they decided to remove surgically. So I had liver surgery in 2009, where they removed the balance of the tumors. They removed a pretty big section. And since that point, I've been completely disease-free.

**Interviewer:** You have been active with the Kidney Cancer Association and other projects to help other survivors. How did you become involved?

**Bob:** About five years ago KCA was running a video contest, in which survivors were asked to share their stories. So my son and I did a video and we won a little laptop computer. And now that video has gone incredibly viral. As a result, since doing the video, I've received over 100 e-mails from patients. And among them were some people from a drug development company who saw it and invited us to be part of a patient advisory group in San Diego. So we went out there. They're putting together what I think is terrific patient advisory program, and we're part of that.

**Carol:** They are also creating information for caregivers.

**Bob:** For the caregivers as well. So anybody that might be contemplating immunotherapy will have somebody that they can talk to – not to get any medical advice, but at least have someone that they can talk to that's been there and done it.

**Interviewer:** How involved were you, Carol, during Bob's treatment?

**Carol:** Very involved. There are things you need to know and do when you are the primary caregiver, and I did a lot of reading to learn. At the hospital, they thought I was a nurse. I would say, "OK. He's going to need some blankets heated up. We're going to need this. Then he's going to need ice baths, and stretching him in between." I was lucky because I had my sisters helping me. I could literally write a book now on how to prepare as a caregiver for this.

**Interviewer:** And how did you learn all of this?

**Carol:** I just read everything I could. And I read about the side effects. I'm in the health industry – I'm a Pilates teacher – so I'm a good nurturer. So I was ready for things he was going to need. I knew

that he was going to be stiff so I would have to bring things to help him stretch. And I knew that his skin would be dry and he would need lotion. I had bottles of water there for the fever, and helped him get through the chills. I just kind of in my head thought about what a mom would do for her kid if he was sick, and he had the flu really bad or something.

**Interviewer:** So you worked as a kind of extension to the hospital staff.

**Carol:** As a caregiver you have to be on top of everything. The patient needs someone to be his or her advocate. And we were on it. We were well known, very well known. But they also liked us at the hospital because we were nice.

**Interviewer:** Well, that was going to be my next question. Couldn't a proactive caregiver be alienating to the staff a little bit?

**Carol:** Not if you are organized. I would just help them anticipate what was coming. I'd say, "OK. Here's what happens to him. He starts shaking. Within two hours, you're going to give him a shot. You're going to have to give him something before for nausea. You're going to have to give him this and this." And they would say, "OK." And I was cleaning him up. I was taking him to the bath. I was a good caregiver and he was a good patient, a very good patient, and they loved that. And I wasn't demanding. I never made the nurses mad. If you are helping them, they really appreciate that.

**Bob:** She would bring a gift in for the nurses. So there was appreciation. There was no animosity.

**Carol:** No, and my sisters and I would make them laugh. We had the best nurses.

**Bob:** Most hospitals have a nurse advocate. And that's the one you go to, or the doctor. But we were pretty good patients. I mean, I was really thankful, and we got really good service.

**Interviewer:** What is your treatment regimen today?

**Bob:** I get scanned every three to four months. I had a scan two months ago. And we just keep an eye on things.

**Interviewer:** And right now, nothing?

**Bob:** Nothing. I'm really, really thankful. I think the one thing I'm very fortunate about is that I'm not on any drugs for now. That's obviously one of the things you consider. But I was very, very lucky. Statistically, I was that one guy. And I've been really, really fortunate.

**Interviewer:** How did your children react to all of this? They were all adult age when this was happening, correct?

**Bob:** Yes. Honestly, I don't think they really took it seriously. I don't think they understood the breadth of what was really going on.

**Carol:** Because I think they figured, mom can take care of him. [Laughs] And he's fine. He's always so happy. He's fine.

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*"I appreciate him more. I think he appreciates me and appreciates life more. It's like we look out for each other more. You don't take anything for granted anymore."*

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**Bob:** But the reality is that for the first two or three years even I didn't know how serious it was. I remember the night we went in for the second tumor surgery, going in and saying, "I didn't realize this is serious. I mean, oh, gosh, I have a recurrence. I'm considered Stage IV. I'm one of those guys now."

**Carol:** I didn't get it either.

**Bob:** For me, personally, I think the true realization was when I went to the oncologist, because when you're sitting there in a room with other patients, it's not just kidney cancer patients. It's everybody. You've got people with shaved heads. You've got people getting chemotherapy. They look sick. And you're realizing, I'm part of this club now.

**Interviewer:** If you were to go back to that moment when you first got the diagnosis, what was your emotive state at that moment?

**Bob:** When I first received the diagnosis that I had a tumor, it didn't completely resonate until I actually met with the urologist. Because the doctor said, "You've got a tumor. You've got to go see a urologist." The urologist is the one who said, when he saw it, "It's got to come out. We're taking the kidney out." And he was pretty good about telling me, "Plenty of people live with one kidney. It's OK. Just be careful." And I was fine with that. The cancer part of it didn't have really the kind of impact on me that it should have. But it didn't. It wasn't one of those life-threatening things, I think. I said, "OK. Well, I just go get some surgery done, and I'll be back." I threw it under the table. I really did.

**Interviewer:** How about you, Carol?

**Carol:** Same as Bob. I thought, "Fine. Yeah, we got lucky." We walked out of the hospital saying, "Oh, cool, done."

**Bob:** Yeah. I got out of the hospital in four or five days, and the kidney

is gone. I felt good. I went back to playing a lot of tennis. I got back in shape. I was doing all that.

**Interviewer:** But things changed after the cancer metastasized to the liver?

**Carol:** It was bad for me because I work with a lot of doctors, and I work with a lot of people that have been through similar things, so I didn't take it well. And I was kind of scared, and I was like in a little bit of shock. And I thought, "How am I going to handle this?" And I didn't handle it well at first. I mean, I tried to put on a good front, but I was shaking, crying. I was freaking out. And every day, somebody would tell me, "You need to just get your things in order. And your husband is going to die. You're going to be alone. You won't be alone for long, don't you worry." And I'm thinking, "What?" Too many people were telling me bad news, and I would try to hide it from Bob. I just got lost and started listening to everyone tell me different things. And I looked at statistics. He's not a statistic, and that's one thing you have to know. Your husband is not a statistic, he's an individual. But it didn't look good.

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*"I didn't handle it well at first. I mean, I tried to put on a good front, but I was shaking, crying. I was freaking out."*

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**Interviewer:** How were you able to emerge from this?

**Carol:** I started watching what Bob was doing. He was meditating. He was getting back in shape – so I started going back to my working out again. I started getting back to being healthy, back to being positive. Our son kept sending us material on meditation. And I started doing that, too. And then I thought, "You know, everything they said doesn't have to happen." And then I just kind of started listening. Bob had such a positive attitude. So then I started thinking, "You know what, we don't have to be like what happens to everybody else." When I started doing that, I started seeing that in a way, everything had gotten better. I'm a better wife. He's a better husband.

**Interviewer:** And why is that? Why does it make you a better wife or a better husband?

**Carol:** I appreciate him more. I think he appreciates me and appreciates life more. It's like we look out for each other more. You don't take anything for granted anymore.

**Bob:** I have a whole different perspective now. I found a whole different way of doing things. When I grew up I always was worried about things. And I think that's one of the reasons, maybe that's the

reason this all happened. I was always wanting to be an achiever, wanting to make things happen. But the reality is that after all these things happened, I began to accomplish more, spiritually, financially, and we accomplished more as a family. I just began to become more conscious about things. And I have a whole different perspective. I just have a better appreciation now than I had before the disease. I mean, as Carol said, I'm a much better person today than I was, say six or seven years ago.

**Carol:** I think being a proactive patient made him a proactive person in his own life. Like, you know what, I'm going to find out. I'm going to make this work. And then I think that he just carried that on to everything else.

**Bob:** I didn't dwell on things. When people ask me about what's made a difference and how I've gotten through and maybe how she's gotten through, I became very focused on the positive side. I made a decision early on to become very focused. One of the things I mentioned on the video I did with the Kidney Cancer Association is to visualize things being good, look at the good side of things. I started looking for a sense of humor, a good side to things, and not being impacted by either negative things or negative people. I thought that would allow me to focus and began to meditate, as Carol said, and just concentrate on things that I felt were going to be proactive. And since that point, I swear by it. That's what I do, that's how I live my life. It's my own personal religion. I'm not a very religious person. If there was any one recommendation to people, I'd say, "Don't let other people hinder what you can do yourself."

**Interviewer:** You seem like a very positive person to me. You must have been somewhat positive before this.

**Carol:** He was a worrier.

**Bob:** I was one of those guys that would say, "You know, I could do that," but I never did. So you get a lot of people that never get over the finish line, the wanna-bes, the think-you-cans, maybes, should-bes, and all that. But you just never take it to the edge. And after all this you realize there's a finite side to things, you say, "What have I got to lose?" The worst possible thing that could happen in my life just happened, so why not take that shot? Or why not do this or that? It's just a different way. I'm not saying I'm ready to go out there and jump out of airplanes. But, to me, there's always something you can do or try.

**Interviewer:** Some kidney cancer survivors attribute their success in life directly to the disease.

**Bob:** Absolutely. I couldn't agree more.

**Interviewer:** You said you have become more active in interacting with other kidney cancer survivors through KCA's online forum, partly as a result of the video you posted. What do you find appealing in that?

**Bob:** I didn't start tapping into the resources of the Kidney Cancer Association until after the second tumor was discovered. After the second diagnosis, I started going on the forum. That's where I began to meet these survivors for the first time. When I get e-mails from other kidney cancer patients, I welcome it. It's not always joyful, of course. Unfortunately, there are a lot of people out there that don't have results like I've had. And it just is what it is. But it's a good feeling to help somebody.

**Interviewer:** Tell me about some of the specific strategies you have used for coping with kidney cancer. You mentioned meditation and exercise. What about diet?

**Carol:** He's always been really, really healthy. We both were chefs before, and so we both cook. We always are proactive about our food.

**Interviewer:** And what do you do specifically with diet?

**Carol:** We eat a lot of organic food. We stay away from a lot of carbs, starches and sugars.

**Bob:** We cook healthy. But we're not to the point where we say, "Oh, I can't drink," or any of that. We enjoy wine.

**Interviewer:** So a common sense approach to nutrition – not anything really extreme?

**Carol:** Exactly.

**Bob:** Yeah. We're not over the top.

**Interviewer:** And you meditate every day?

**Bob:** Yes, every day. Meditation is about learning to quiet your mind because in a single day you can have tens of thousands of thoughts going through your mind. It's very hard for people to concentrate. And that was the thing that I first learned to do, be quiet. Twenty minutes, and I feel great.

**Interviewer:** What other kinds of things do you do? Are there other things that you adopted that others might learn from?

**Bob:** Oh, speaking for myself, I started listening to a lot of really good audio books. And I walk my dog every morning, and it's a really good time for me to listen to it. Whether it's spiritual, or whether it's business, it's always positive. It's a great way to start my day. And that started me on a path, that's what actually started me towards meditation. I listened to some good authors that made a big difference in the way I perceive things.

**Interviewer:** What is your advice about finding the right medical team? What do you say to other patients who have just been diagnosed?

**Bob:** I really lucked out with the doctors. I've had some great ones. But having talked to other people and seeing other situations, your doctor is basically your treatment, so take care in choosing. It's critically important. I had a great team. I think building a trusting, open relationship with your doctors is the key. From a patient perspective, don't be afraid to ask questions. And if you're not happy with the questions and the answers that you're getting, find another doctor.

**Carol:** And also don't go by yourself to the doctor. Take somebody with you because you're going to hear something, and they're going to hear something, and in between you'll find what really was said. You have to listen together. And that has been super important for us.

**Bob:** It's critical. Your doctors are your lifeline.

## *Ed and Mary Lou*

Ed and Mary Lou are residents of Illinois who have been married for 59 years. They have nine children, 22 grandchildren and five great-grandchildren. The couple, who will celebrate their 60th wedding anniversary in 2012, live in a suburb of Chicago; all of their children also live in the Chicago area, creating a tight-knit family.

Ed spent his professional life managing line crews for a phone company. At 81 he is robust and hearty, with a firm handshake and intense blue eyes. He works extensively around the house and plays golf regularly. He and Mary Lou like a good chuckle and have many humorous stories to tell – of family life and the twists and turns of a long marriage. They are devout Catholics and say faith has been an important part of their lives.

Ed's experience with cancer began in 1998, when, at age 69, he was diagnosed with bladder and kidney cancer. After a nephrectomy and treatment for his bladder cancer, Ed went back to his life as a retiree and busy grandfather. But in 2004, cancer returned – this time invading his pancreas. He had surgery on his pancreas and a series of treatments followed; today, Ed is in good health, overall, though still coping with his disease. He is on a drug regimen, which is currently keeping his tumor growth in check.

Both Ed and Mary Lou admit now that they underestimated the impact of the disease on their lives. But they have persevered, counting each day of life as a gift.

### *Survivor's advice from Ed:*

- “Find the right doctors and the right hospital – right away.”
- “Write everything down – you'll need to keep track of what's going on while you are getting treatment.”
- “Don't forget to ask the medical staff for copies of your records. Ask while you are right there in the office.”

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**Interviewer:** What were the circumstances of your diagnosis?

**Ed:** We were up at our cottage in Door County, Wisconsin and I noticed blood in my urine.

**Mary Lou:** I called our internist. And he said, “Come home right away, you'll need to see a urologist.” We returned right away, and they did a CT scan. And they said, “Well, you have bladder cancer. But you



have a worse problem. You have a tumor on your kidney, and you'll have to have that removed." And that was the beginning of our journey.

**Interviewer:** And how did you feel at that moment when you heard that news?

**Ed:** To tell you the truth, I thought, no problem. I said let's get on with it – move forward.

**Interviewer:** And how did you feel, Mary Lou?

**Mary Lou:** Well, I thought once the kidney was out that would be the end of that. And the bladder cancer we could deal with. And I felt positive about it. But I was totally unprepared for the journey to follow – totally.

**Interviewer:** What was it about the journey that you were unprepared for?

**Mary Lou:** I didn't know that the kidney cancer would return in such a vicious way. We were very positive after the diagnosis, very upbeat.

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*"We say the things we think are important now. You know – "I really love you." "I really care." Because we know how fragile life is now."*

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**Interviewer:** When did things start to get to be more challenging for you emotionally?

**Ed:** For me it was when all the side effects mounted.

**Mary Lou:** I think it started getting tough for me, and for both of us, in 2004, when they found a new tumor on Ed's pancreas and they said that he needed Whipple surgery. That was devastating. *[Note: Whipple surgery consists of removal of a portion of the stomach, the gall bladder and its cystic duct, the common bile duct, the head of the pancreas, parts of the small intestine, and some associated lymph nodes.]*

**Mary Lou:** The success rate of that operation is not as high as others. So that really brought us to our knees, literally. We had a hands-on prayer meeting. We have wonderful family, a lot of support. And all of our grandchildren were there. We were all in tears. But after it was over, we felt like we were prepared for the rest of the journey. And it worked out well. That's when we began treatment at an academic medical center in Chicago.

**Ed:** We have a priest in our bridge group, and we got a hold of him. And he got it set up our prayer meeting at a friend's house. There must have been 50 of us there – all holding hands and praying.

**Interviewer:** Have you been people of faith all your lives?

**Mary Lou:** Yes, all our lives.

**Interviewer:** And how has that been impacted by your experience with cancer? Has it been bolstered by this or strengthened in some way? Or challenged?

**Ed:** I would say it has been strengthened.

**Mary Lou:** Yes. There are other benefits as well. Now we don't bicker so much because we know we're on a short string. [Laughs] And we say the things we think are important now. You know – "I really love you." "I really care." Because we know how fragile life is now.

**Interviewer:** You both seem very optimistic. Have you been that way over the course of your lives?

**Mary Lou:** Yes. I'm optimistic to the point of being foolish. [Laughs] I mean, I can be foolishly optimistic. I am optimistic when I have no right to be.

**Interviewer:** Would you say the same, Ed, about yourself? You're an optimist as well?

**Ed:** Yes.

**Interviewer:** What about your children? How did they respond to this?

**Mary Lou:** They were very supportive. Some of our kids work in health care. When we got the diagnosis of the kidney cancer, my daughter was a radiographer, and we were at her hospital. She was right there during the testing. And together the kids saw to it that we were at the right hospital and getting the right surgeons. You know, there were some times when things weren't so wonderful. But our family has been there for us, and in the end, it all turned out pretty well.

**Interviewer:** Tell me about the treatment, the various treatments that you received.

**Ed:** Well, along with the kidney problem we had to take care of my bladder cancer. That was six years of treatment and it was successful.

**Interviewer:** So almost like they predicted, your bladder cancer wasn't the big problem. It turned out to be true.

**Ed:** Yes, that's right.

**Interviewer:** Then what about the kidney cancer? What kind of treatment did you undergo for that?

**Ed:** There were three tumors that had to be treated. After my Whipple procedure, I went through several protocols, including immunotherapy and some of the new drugs that came out in the last few years.

**Interviewer:** And did you respond to the treatment? Did you respond well?

**Ed:** The last drug I was on did a really good job, but the other protocols didn't work as well.

**Interviewer:** How did you cope during those early stages, let's say the first couple of years, when various treatments weren't providing results? What did you do to kind of keep your spirits up during that time?

**Ed:** We just never faltered. We just stayed solid. We put it in God's hand, and we had a lot of faith in God. And we prayed that God would steer the hands of the doctors and guide them through any surgery that might be required.

**Interviewer:** How about on a day-to-day basis? When you go to the hospital, the report maybe is not great. It doesn't seem like you're making much progress. Or you get the new news that you've got a tumor on your pancreas. How did the two of you work together to try to keep your spirits up during that? Or did you even think about it?

**Ed:** You just do it. You don't worry about it.

**Mary Lou:** Like I say, I'm optimistic. I'm always telling him everything is going to be all right, you know.

**Interviewer:** You were diagnosed at a time when the Internet was still growing and developing. How did you get information to learn more about the disease?

**Ed:** Our daughters went on the Internet right off the bat, and that's how we got to the medical center in Chicago. I had seen a doctor at another hospital, but he wasn't the right doctor.

**Mary Lou:** The first doctor had done only three Whipples. And the doctor we eventually found had done hundreds of them. And he said, "That's all I do."

*[At this point in the interview, Ed referred to a notebook to refresh his memory about his various treatments.]*

**Interviewer:** You seem very organized. Have you always been that way?

**Mary Lou:** He's a paper person! [Laughs]

**Interviewer:** He writes everything down?

**Mary Lou:** He never met a paper he didn't like. And he saves them all. He gets a report every time he has a CT scan, a blood test or anything else. And he keeps all of those records.

**Ed:** There's a lot.

**Interviewer:** So when you are in a medical office, you always say, "Can you make a copy of that for my records?"

**Ed:** Yes, I ask for my copy.

**Interviewer:** Right there, when you're in the office?

**Ed:** Yes, right away.

**Interviewer:** Let me ask you this, what would your advice be for somebody who has just been diagnosed? You've been through that experience. You received the news. What do you say to people?

**Ed:** Well, the first thing is to find the right hospital and the right doctors.

**Mary Lou:** Another thing is to be tuned in to your body. The one thing that's a good side of having cancer is that then you become more aware of your body and looking for the next shoe that might drop. And you get to being able to identify things pretty quickly at the onset.

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*"I was totally unprepared for the journey to follow – totally."*

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**Interviewer:** Tell me a little bit about the things that you do to stay active, given your health challenges? What kinds of things do you do?

**Ed:** Well, I do everything around the house, including keeping up the grounds.

**Mary Lou:** We have a large lot, and it's a lot of work. A lot of yard work.

**Interviewer:** Is it hard work?

**Ed:** Yes, but I'm used to work. I've been working since I was six years old.

**Mary Lou:** He makes work sometimes.

**Interviewer:** So you find that physical work helps you?

**Ed:** Yeah, sure. I like to keep busy.

**Interviewer:** What other kinds of things?

**Ed:** I like to play golf and bridge.

**Interviewer:** Did you have the opportunity to be on a clinical trial? Did they ever give you that option?

**Ed:** I was in three of them.

**Interviewer:** Tell me about that process. Were you concerned about it? How did you feel about being in a clinical trial when you first heard about it?

**Ed:** Well, I was a little skeptical from the onset. But then I thought about it. And I said, “Well, you know, why not?” Somebody has to do it.

**Mary Lou:** And they learn a lot from those studies so it’s a very positive thing, maybe helping somebody else down the line.

**Interviewer:** Let me ask you a little bit about side effects from the various treatments that you’ve had.

**Ed:** I started making a list of all the side effects years ago and trying things to cope with them.

**Interviewer:** Any examples you would like to share?

**Ed:** Well, I’ve had a serious problem with cramping, especially leg cramps, and the advice of one of my doctors was that I should try tonic water to help. And I’ve been taking tonic water ever since.

**Interviewer:** It has helped you?

**Ed:** Oh, yes.

**Mary Lou:** We have tonic water in every room of the house. [Laughs].

**Interviewer:** What other kinds of things have you had to do to cope with side effects? Any other strategies that you can share?

**Mary Lou:** Ed sleeps a lot. The drug treatments can make you very tired. He’ll get up early, but he’ll take maybe two or three naps in a day. He has a lot of fatigue. I think that’s the biggest thing. The biggest challenge.

**Ed:** But we keep moving forward.

**Mary Lou:** That’s right.

**Ed:** Ever forward.

**Interviewer:** How long of a nap do you take?

**Ed:** A couple hours.

**Mary Lou:** I was wondering if you were going to be honest about it. [Laughs]

**Interviewer:** Well, I would think that would be hard for somebody who clearly likes to work and has been very active his entire life. It must be frustrating.

**Ed:** Yes, that's true.

**Interviewer:** Have you made changes to your diet since your diagnosis?

**Mary Lou:** He doesn't eat hardly as much as he used to. He's more like a grazer now, snacks, rather than having a meal.

**Interviewer:** How did you learn about the Kidney Cancer Association?

**Mary Lou:** Someone mentioned a meeting being hosted by the Kidney Cancer Association that we should attend.

**Interviewer:** Tell me about your impressions so far now that you've been interacting with the Kidney Cancer Association. What are your feelings about it?

**Mary Lou:** Well, as I mentioned, we were not prepared for anything further with Ed's kidney problem. We thought when the kidney was out everything would be over and done. So problems later came totally out of the blue and were a big shock to us. And now we see, through the Kidney Cancer Association, that there are so many other people with the same problem.

## **EMPOWERING STEPS FOR PATIENTS**

*Additional tips and advice from the Kidney Cancer Association*

### **Don't Rush**

Do not rush into surgery or treatment without getting some basic facts about your specific type of cancer. Your doctor and your emotions may be telling you to act quickly. But your tumor has been part of you for months, perhaps even years. Not all types of cancer are fast growing. Take your time to get a few basic facts so you can make informed decisions. First steps might impact your disease course or future treatment options.

Time is important, but it is more important to get the right care than to save a few days or a week.

### **Get the Facts**

It's important to become informed about your diagnosis and options as early as possible. A good first step is to go to libraries or search the Internet for disease information. Visit a hospital patient library or a medical school library. Read medical journals if you have a technical background. Or get your local public library to do a computerized literature search for information on your disease. Many libraries will search for you free of charge. You can see which doctors are doing the most research, and you can consider getting a second opinion regarding treatment options. Be sure to review the patient resources section included in this book.

The Internet is a great source of information, but remember that some of what you may find could be inaccurate. You may find information that is taken out of context or may not apply to your situation. This can lead to both false hope and unfounded fear. As you search, rely on sites that are known for providing accurate, credible information. Every patient is an individual and the course of your disease will not be exactly like that of other patients. Be wary of making comparisons between yourself and others with the same diagnosis while searching online. Checking facts and validating understanding is important.

## *Beata and Jim*

Beata is a 42-year-old mortgage broker who is studying to become a financial advisor. She is a native of Poland. Her husband, Jim, is a magazine editor. The couple, who have three children, live in Florida.

Beata and Jim met in Poland while Jim was on a newspaper professional exchange in the early 1990s. After living in Poland for two years, they came to the United States and began their family.

In July 2008, Beata was experiencing symptoms of being “tired and achy,” but thought she was simply working too hard and out of shape. An episode of bleeding, requiring a trip to the emergency room, however, led to an x-ray that confirmed she had kidney cancer.

Beata and Jim’s story illustrates how quickly cancer can change the complexion of family dynamics: Before her diagnosis, she says she was living the American dream, with everything she could ever have hoped for. In one day, her outlook on life changed radically.

Jim and Beata openly discuss their somewhat different approach to cancer: He has tended to be more of an “activist,” more closely engaged with details, while Beata has taken an approach that is more accepting and philosophical. They say their relationship has benefited from their experience with cancer.

After immunotherapy treatment, Beata is disease-free after nearly three years.

### ***Survivor’s advice from Beata:***

- “Think about what’s most important in your life – don’t get stressed out about things that don’t matter.”
- “It’s a challenge, but at some point it’s important to relax and stop worrying. Your emotional or spiritual healing is part of recovering.”
- “Don’t dwell on questions like, ‘Why did this happen to me?’ Learn to accept things and move on.”

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**Interviewer:** How were you diagnosed?

**Beata:** Basically, my life was going great until the summer of until 2008. We had three great kids. We had just bought our dream house. I had a very nice husband. I even had just gotten my dream car.



I felt I had it all. I remember I was looking back at my life as I was driving my new car, and I actually started to cry. I just was overcome with emotion and I remember thinking to myself, “God, here I am, a humble person from Poland, and I have all this stuff. I never thought in my life I would have all of this.” And then, one week later, I was diagnosed with cancer.

**Interviewer:** You had reached a kind of pinnacle in your life?

**Beata:** Yes. We all have our dreams. And I started crying. “My God, I never thought I will have it all.” A week later, I was in the emergency room, bleeding, and they told me I had cancer. I’ll always remember that day.

**Interviewer:** How old were your children at the time?

**Beata:** Very young. Five, nine, and twelve.

**Interviewer:** And how was it for you, Jim, to learn of the diagnosis?

**Jim:** Well, she called and said she was bleeding badly. And so I left work immediately. It didn’t sound good, no matter what. We didn’t suspect that it was cancer, though. I thought, probably kidney stones or something. And then she went to the emergency room. And the doctors came out and were very hushed and serious.

**Beata:** It was strange. After they confirmed the cancer, the doctor very simply said, “OK, well, you’re staying. You have cancer.”

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*“We didn’t dwell on it. We went on with life: We went to the mountains, had normal holidays. There was no sense of breaking out the black drapings. There was nothing like that.”*

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**Interviewer:** How did you feel at that moment?

**Beata:** I have cancer running in the family. And actually, a least a year and a half prior to my diagnosis, I had started to do some checking on myself. I did two blood tests, looking for cancer markers. I was not feeling good. My father died of brain tumor at 40, and my brother had cancer around 40. I was not thinking that for sure it was going to happen to me, but I did think there was a good chance. So I was trying to be proactive. The problem was that the cancer I had didn’t show up in blood markers. So actually half a year before I found I had it, in looking for cancer markers, nothing showed. So when they did tell me that I do have cancer, I thought, “OK, I’ve got it. Here we go.” It wasn’t a major surprise.

**Interviewer:** You were somewhat calm about it, then?

**Beata:** Yes.

**Jim:** When the worst happened, she was prepared for it.

**Beata:** I didn't throw my hands in the air and start crying. I tried to adjust and think about it very calmly, even though lots of emotions came through. I never asked "Why me?" If you are going to ask that question you have to also ask "Why not me?" Because realistically, this is something that can happen to any of us.

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*"The doctors said I had early Stage IV cancer and I asked 'How many stages are there?' And they said 'four.' At that point I knew it was serious."*

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**Interviewer:** Did you find a period where it did hit you harder emotionally?

**Beata:** Yes, I think at the point of realizing that we have three small children and this is going to have a major effect. And we don't have family nearby.

**Interviewer:** How about you, Jim? Did your feelings change?

**Jim:** I was shocked and devastated the first two days. Early on, the doctors thought they saw some evidence of cancer in the lungs and I remember going online at 2:00 in the morning and seeing some references to Stage IV cancer in the lungs having a five percent survival rate. So for a couple of days it was just misery. But then, at some point, I switched into the now-what-do-we-do-to-try-to-fix-it mode, where you are calling around and scheduling surgery and taking care of other details. I switched into the mode of attacking it. But the first 48 hours was horrible.

**Interviewer:** How did you deal with it with the kids? What was your strategy?

**Beata:** I tried not to scare them. They did know I had cancer, but I didn't tell them much beyond that. Not with what the outcome could or could not be. But they knew I was sick. And of course, I tried controlling myself. There were days when I was crying, and I was distressed. But I tried never to show this to the kids.

**Interviewer:** So the children knew it was cancer?

**Jim:** Yes.

**Beata:** At the same time, because we didn't know what was going to happen, we didn't see any point in stressing them.

**Jim:** We didn't dwell on it. We went on with life: We went to the mountains, had normal holidays. There was no sense of breaking out the black drapings. There was nothing like that. We were just normal and tried to keep our minds off it.

**Beata:** Partly because my faith and I like working and staying busy.

**Jim:** Part of the reason we responded this way was tied to the doctors' approach. They were methodical. Before you go to the next stage of treatment, you have to watch to see what the tumors were doing. If they're stable, you keep watching. It's the watch-and-wait method. If they're growing, then you move on to the next treatment. For us, it was a matter of waiting along with them, and we thought, during that process, why be miserable?

**Interviewer:** So in your case, a nephrectomy was recommended, but there was evidence the cancer had metastasized?

**Beata:** Yes. I had the nephrectomy and was ready to move on, but there was still more treatment to come.

**Jim:** I had done research online and so I knew that there would have to be additional treatment.

**Beata:** The doctors said I had early Stage IV cancer and I asked "How many stages are there?" And they said "four." At that point I knew it was serious. I started immunotherapy six months later and I did that for three months off and on.

**Interviewer:** You mentioned a moment ago how you informed your children. What did you tell the rest of the family?

**Beata:** All my family is in Poland. And my sister specifically asked me not to tell our mother because she wouldn't be able to handle it. I couldn't tell my mother. My father died of cancer at 40, my brother had throat cancer, she was fixated on cancer and we thought it might be difficult for her. What's ironic is that not long after that my sister in Poland was diagnosed with breast cancer, and it was impossible for her to keep it from my mother, who lived ten minutes away. My sister died a year ago, so now, my mother has had three kids diagnosed with cancer and one has died from it, along with her husband. Eventually we had to tell her because she scheduled a visit to the United States just about the time I was beginning my immunotherapy treatment. During my treatment, as I was getting better, my sister Margaret was getting worse. There are no words to describe how I felt. She was amazing – she never complained and was grateful for every day, and helped me so much.

**Interviewer:** Going back to those three months when you were getting immunotherapy, what do you remember during that period as being the toughest thing that you had to deal with? And then what would you say in that three-month period was the most important?

**Beata:** I think dealing with the question: What's going to happen to my children? And then my sister's illness.

**Interviewer:** How about for you, Jim?

**Jim:** For me, it was just dealing with sleeplessness. That was a first. I have never experienced those kind of emotions before because my grandparents had died at an older age. I had never dealt with the prospect of young death. My parents and my brothers and their families are fine. So this was the biggest shock of my life. It knocked my equilibrium off for a couple of months.

**Interviewer:** How did you cope emotionally while all this was happening?

**Beata:** Other than my husband I really didn't have anyone to talk to about it. I've always been religious so, of course, I turned to God. I had been going to a Bible study group. And I was not advertising that I have cancer there, because I don't really like talking that much about myself, trying to be more humble. But some people knew and I got strong support there, especially from my friend Adriana. Because of deep faith, at some point I became completely relaxed. I stopped worrying. Call it emotional healing, spiritual healing, whatever you want to call it. I have reached complete peace.

**Jim:** I believe her focus on spirituality helped a lot with her treatment. She was very placid.

**Beata:** But of course in the beginning it was very difficult. I was not sleeping. I couldn't show emotion to my kids. My family wasn't there. When you lie down on the bed at night, you obviously wonder, what's going to happen? We have three kids and bills to pay. But somehow I got to the point of feeling, whatever happens, happens. God is with me.

**Interviewer:** During your experience with the disease, what, if any, Kidney Cancer Association resources did you utilize?

**Jim:** Well, I wanted to get the scientific stuff about all the odds and the charts, and that was available through the association. But I also wanted to find stories about kidney cancer patients to see how much they matched our own. I just wanted to hear what the options were because in the beginning you're so confused. And I was looking to find something a little more uplifting, not just uplifting but constructive. What can I do now? Because not only did I not know anything about the disease, I didn't know about cancer in general.

**Interviewer:** What have you done during the course of your illness from a

physical standpoint to stay healthy? Has exercise been a part of your lifestyle, for example?

**Beata:** We always do lots of walks, and find that it helps. Before I was diagnosed I joined a gym because I had high blood pressure and my lower back hurt. I used to joke that I was like a 70-year-old father-in-law with a bad back and high blood pressure. So I decided I needed to get in shape at the gym. Of course, we now know it was the cancer that was the problem, not that I was out of shape. But since the surgery it has really just been regular walking, nothing major other than that.

**Interviewer:** What about diet?

**Beata:** I didn't want to do any diets. I didn't want to take any major vitamins. I decided to keep things the way they were, day to day.

**Interviewer:** You didn't change your diet significantly?

**Beata:** Nothing.

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*“For me, it was just dealing with sleeplessness. That was a first. I have never experienced those kind of emotions before because my grandparents had died at an older age. I had never dealt with the prospect of young death.”*

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**Interviewer:** Has anything else changed in terms of your lifestyle?

**Jim:** Beata was blessed after the immunotherapy with what they call a 100 percent remission response. And there's been no recurrence since then. So that allowed us to at least to say we're on a plateau that could eventually be a permanent cure. We know we aren't home-free for life yet, but they told us that after a certain period of time, recurrence is much less likely. She's over the first two years. So the result is that we are transitioning from “cancer patient” status to being able to put it on the back shelf until further notice. And that is helping us get on with our lives.

**Interviewer:** So there really haven't been any lingering sort of changes to your family structure from the experience, other than the change of mindset?

**Beata:** If you asked me five years ago the question: If you had ten days to live, what would you do? I would have said, “Nothing.” That's what I always said. What do you change? You just live until your time comes. No regrets. And that's the way I still feel.

**Jim:** With cancer, there are some people who want to know every detail and obsess over everything, and then become a vegetarian and do anything possible. And then the other approach is ignore it

and be natural – don't get all tensed up about it. And maybe that can be just as beneficial – it's really to each his own. I think that's more Beata's approach.

**Beata:** You do what you can do. And what will happen, will happen. I went to get the treatment. But I wasn't thinking that if I do A, B, C and D, I'll have a certain outcome.

**Jim:** While she might not have felt that way, though, I think I did to a large extent. So someone who was close to her was tracking the options. If one thing doesn't work you do this. And if that doesn't work, you do this other thing.

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*“Because of deep faith, at some point I became completely relaxed. I stopped worrying. Call it emotional healing, spiritual healing, whatever you want to call it. I have reached complete peace.”*

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**Interviewer:** That's very interesting. You had two very different approaches to the disease.

**Jim:** Yes, I think so.

**Beata:** I view what has happened to me as a major transition in my life. But I live very much as I did. The one thing that has changed is that the things I was stressing about before I'm certainly not stressing about anymore.

**Interviewer:** What would be an example of something you're not stressing about anymore?

**Beata:** Money. I was always trying to succeed and was always worried about what's next. I was very focused on making money and being successful. But that's not the priority now. I still want to be successful, but now not by all means. I believe my work may have contributed to my health problems. I was so stressed out, with so many clients, so much to do. And they say that does affect your immune system. It was exhausting emotionally because I'm one of those people who wants to do a really good job. I don't slack off, and then it really takes a toll on you. I know as strange as it sounds, in some ways it was the biggest blessing I ever had, to get cancer, because it helped change my viewpoint this way.

**Interviewer:** Has there been a positive impact for you, Jim?

**Jim:** I can say that it was the best part of our marriage. It was the smoothest and most calm and the most pleasant we ever were with each other. It brought us together. It was almost like we threw out the extra irritants about it and we kind of focused on the core of life. And a lot of that's carried over, I think, as well. So in a strange way, it has had a positive effect.

## **EMPOWERING STEPS FOR PATIENTS**

*Additional tips and advice from the Kidney Cancer Association*

### **Get a Second Opinion**

Finding a doctor who specializes in your type of cancer is a good idea. Your doctor may be an excellent physician, but some types of cancer are very rare so your doctor may not see enough cases to be good at treating your disease. In medicine, practice makes perfect.

Start by asking your doctor for a referral for a second opinion. Don't hesitate to take this step – doctors aren't upset if you get a second opinion, and this is your right and responsibility. You can find an expert doctor by asking the Kidney Cancer Association for the names and phone numbers of experts in your area. Call one or two expert doctors and make appointments to see them. Sometimes, these "super doctors" are very busy and you may need a referral from a cancer patient organization. Ask for this help.

### **Keep Good Records**

Get in the habit of collecting reports and records at the time of visits to doctors or other health professionals, and keep everything organized. You will want to keep pathology reports from all surgeries and/or biopsies, reports from scans and CDs of images and other tests, and records of any treatments given. A binder with separation tabs is an ideal way to organize your health information and medical or surgical reports.

Bring these records to any new appointment, especially one in which you are receiving a second opinion. Take films or a CD with your most recent scans to the visit (don't leave them there unless the doctor asks you to). Keep an updated, legible list of all your medications, and provide the doctor with a copy. Be sure to include any "over the counter" medications and complementary therapies.

You are entitled to copies of your medical, surgical, and pathology records. Do not be surprised if the doctor asks you to sign a receipt for your x-rays or charges you for copying documents. A receipt is simply a written record that you were given the materials you requested. Don't hesitate to ask for your records. If you have any trouble obtaining them, contact the hospital ombudsman.

# Paul and Marilyn

Paul and Marilyn are Illinois residents who recently celebrated their 40th wedding anniversary. After a long career with a heavy equipment manufacturer, Paul decided to retire early in 1999.

Just before his retirement day, not feeling well, Paul scheduled a visit with his doctor; an x-ray revealed a large tumor on his kidney and tumors in his lungs. Despite the bleak news, Paul consulted with a specialist who was optimistic and suggested an experimental treatment that would be available in a few months.

Miraculously, just two months later – without the benefit of surgery or drug treatment – a follow-up CT scan showed no evidence of tumors in Paul’s body. He was cancer free. He had experienced what the medical profession calls “spontaneous remission” – a rare, but well documented cancer phenomenon in which the body heals itself.

13 years later, Paul remains cancer-free and he and Marilyn are deeply grateful for their good fortune, which they share with their children and grandchildren. They say the experience has brought them closer together.

## *Survivor’s Advice from Paul:*

- “I was lucky – I didn’t have to go through what so many kidney cancer patients experience. My message is to be hopeful and keep living your life.”

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**Interviewer:** You have a very interesting story – one of the very rare cases of spontaneous remission. What happened to you?

**Paul:** I was getting ready to retire in 1999, and I was not feeling very well. I was losing weight. But I never thought anything about it, until I finally decided to retire on April 1 of that year. Marilyn was concerned and wanted me to go to the doctor. So I went in for a check-up, and that’s when I found out, through an x-ray, that I had a tumor the size of a baseball on top of my right kidney that had metastasized to both lungs.

**Interviewer:** What was your treatment plan?

**Paul:** We didn’t know what to do. I went to a local doctor who said “It’s too much for me.” He suggested a couple of medical centers. So I got in touch with one of the specialists there. And I’m telling you, he just changed my life. He was so positive: Where everybody else



told me there wasn't much that could be done, he told me there were different plans we could try, and he said "We're going to beat it."

**Interviewer:** So there was some optimism, but still, you were very sick.

**Paul:** Yes.

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*"He just changed my life. He was so positive: Where everybody else told me there wasn't much that could be done, he told me there were different plans we could try, and he said 'We're going to beat it.'"*

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**Interviewer:** So at that point, you were in a "watch and wait" mode, anticipating an experimental treatment that would be available in a few months?

**Paul:** Yes. Then, in June of 1999, I went down to a church in Streator, Illinois – St. Stephen's, where supposedly somebody took a picture at a celebration, and a picture of Christ appeared on the right shoulder of this person. And so my wife said "Let's go down to St. Stephen's for a service." So we went down to St. Stephen's and the place was packed. We were about five, ten minutes late, but there was a parking spot right in front. Unbelievable. Then we went inside, and there were no seats, except for two, right up front. So we got up there, and sat down. This nun came out and she said, "Now we can start." And it kind of gave me chills. So we said the rosary. And as we were saying the rosary, a feeling came over me. It was just a calmness. An unbelievable feeling. When we were walking out, Marilyn said, "Did you feel anything?" I said, "Yeah, I really did." And she said, "Well I didn't." [Laughs]

**Interviewer:** So then what happened?

**Paul:** The next week, we went to the medical center for a CT scan. I was going in regularly to be checked. I had the CT scan and came back the next week to get the results. And I was expecting to get bad results. Well, there were five doctors in the room when I got there, and they were laughing and joking. And they had a picture of the before and after, the latest film from the CT scan. And the cancer was gone. I mean, the lungs were clear. There was a scab on my right kidney on top, that's all. And to this day: no tumors. I'm still healthy, 13 years later, and I haven't had a CT scan now in probably four or five years. And they said, "If you feel sick, you'll be the first one to know it and to come back." And now all I'm doing is baby-sitting with my great granddaughter.

**Interviewer:** Your cancer diagnosis must have been a great shock to you – especially since you were just getting ready for retirement, which a lot of people really look forward to.

**Paul:** I used to get up at 5:00 every morning and lift weights at the gym. And I played softball three nights a week, and we played a lot on the weekends, tournaments and things like that. I was always very active with the kids. So I mean, I was in perfect shape, and that's one reason why I don't think I really accepted my cancer.

**Marilyn:** Our granddaughter is a dancer and we used to travel with the kids a lot. We would go back and forth to Las Vegas and New York, Florida, different cities all over the country. We had a very active life.

**Interviewer:** After your diagnosis, how long was it before it went into remission? How long did that take?

**Paul:** Probably from April, when I was diagnosed, until the end of June.

**Interviewer:** So literally just a few months?

**Paul:** Yes.

**Interviewer:** Tell me about that period though from April to June, the period where you were sick and didn't know what was going to happen. What was going on?

**Paul:** Marilyn probably could answer that.

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*“I was in perfect shape, and that’s one reason why I don’t think I really accepted my cancer.”*

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**Marilyn:** He was sick for about a week, really sick. He would be in bed, and he would just shake, physically shake. And I would get close to him and lay on top of him and give him my body warmth. And still, he was so cold. And then we were on a trip out of town and he just couldn't get warm. We had to leave and go get him coffee, hot coffee. And I said, “You're anemic or you've got the flu. You've got pneumonia. You need to go and see the doctor.” That's when he decided to make an appointment.

**Paul:** And ten minutes later, I would be burning up. But the doctor said that was my immune system kicking in. That's what they told me.

**Marilyn:** So that's when we went to our family doctor – who happens to be my cousin. And he just looked at Paul and he knew what he had. And he said he almost quit his practice because he didn't want to be the one to tell Paul what he had.

**Paul:** He was upset.

**Interviewer:** Once you were diagnosed, how would you describe your feelings for those several months? How did you feel emotionally?

**Paul:** Well, I was pretty depressed. And the doctors told me that I had to stop lifting weights. I had to stop playing softball because they wanted to give me radiation and then cut the tumor out. So I was pretty down. I mean, I had to tell the guys on the softball team I couldn't play. I was their pitcher. It was pretty touch and go for a while.

**Interviewer:** How did it affect your relationship with Marilyn?

**Paul:** We were probably both pretty unhappy, and we weren't speaking much.

**Marilyn:** We didn't talk. We were very quiet with each other. I didn't know what to say. I mean, small talk, like, "What do you want to eat?" I just didn't know what to say to him.

**Paul:** Maybe she was scared to upset me. I don't know.

**Interviewer:** Did you try to be a kind of cheerleader for Paul, Marilyn?

**Marilyn:** No, because I felt that was wrong. I don't think people like to hear that.

**Interviewer:** What was Paul's attitude like?

**Marilyn:** He was more positive, I think, than I was. I was quiet, and I didn't say anything. But he would say, "It's going to be OK." He never broke down and cried at all. He was very strong. We just kept going. We went shopping and did our normal activities.

**Paul:** We just continued on with our life.

**Interviewer:** What about trying to learn more about the disease itself? Did you do much in terms of researching it?

**Paul:** A little bit, but not too much. It all happened so fast. You know, three months and it was gone.

- Interviewer:** So they didn't start the radiation. They hadn't even started it yet?
- Paul:** No. I did not get a single treatment. And people cannot believe that. You know, mostly people who've had cancer and hear my story say, "Well, you had to have an operation or you've had to have some type of a drug or something." Nothing. The doctors showed me film from my scans, and they showed that the tumors, which were confirmed by a biopsy, were gone. The one that was on my kidney had been 8 cm.
- Interviewer:** So your remission occurred somewhere in the space of roughly three months?
- Paul:** Yeah.
- Interviewer:** How did the doctors explain it to you?
- Paul:** They just said it was a spontaneous remission and that my immune system kicked in.
- Interviewer:** Did you talk to people about all of this? Who knew about what was happening?
- Paul:** At first, nobody other than our family.
- Marilyn:** Later, I wrote a letter to all my friends and I told them to pray for us. And then I got to write another letter to tell them what happened, and thank them for the prayers.
- Paul:** I had a lot of support. As Marilyn said, we had a lot of people praying for us. So, of course, when the cancer went away I thought it was a miracle. The doctors at the hospital, they really didn't accept that. They thought it was the immune system kicking in and that's all it was. But to me, it was a miracle. It really was. Anybody, I think, that believes would probably feel the same way.
- Interviewer:** Now that this is 13 years behind you, how do you feel it has impacted your lives as a couple?
- Marilyn:** I think we've become closer, but I don't know because we were always close before. So I'm not sure. But I think the thought that I might not always have him has made me take today as it is and enjoy it more.

**Paul:** I think I'm more patient now than I was before. I try to look at the good in people instead of being negative. I try to be more positive about everything in life.

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*"The thought that I might not always have him has made me take today as it is and enjoy it more."*

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**Marilyn:** You were always pretty positive.

**Paul:** I was, but I think I'm more so now.

**Marilyn:** Maybe we would have been close anyway, but you get so tied up in your everyday life. "I don't have time for you. I have to do this. I have to do that." Now we do everything together. In fact, my dad and my sister tease us, "They're like a set, a matched set." We do everything together. If I run to the store, he'll drive me. He's my best friend. I want to be with him.

**Interviewer:** Paul, how has it impacted you personally?

**Paul:** Mixed feelings. Like a lot of times, I'll go to a wake where somebody died of cancer or something like that. And I really feel guilty. The first time I ever had that feeling was when Walter Payton of the Chicago Bears got sick and died. He had liver cancer. And it really bothered me because he was diagnosed about the same time I was. I got really depressed. And even to this day sometimes I'll go to a wake where somebody died of cancer, and it just bothers me, you know. It's probably survivor's guilt. In some ways I didn't want to participate in this interview, because, you know, I never went through what most of these people went through. I was lucky to have experienced a miracle. I really think that's what it was. I was talking to a guy from a pharmaceutical company who told me that the chances of spontaneous remission are about one-tenth of one percent. It's so rare that you just don't hear about it very often. I've even had people tell me, "You were misdiagnosed." But I've got the CT scans at home to prove it.

# Laura and Scott

Laura and Scott live in a small town in southwestern Michigan. Laura, 47, is a day-care provider and Scott a contractor. Laura, an energetic blonde who is quick to laugh, has three grown children from a previous marriage and a granddaughter, Naomi. Scott, quiet and thoughtful, is clearly devoted to his wife and has played a key role in helping organize her treatment.

Like some couples interviewed for this book, Laura's cancer created strong burdens that created challenges for her relationship with Scott; they had been married for only a short time when she was diagnosed. And like others, a correct diagnosis eluded physicians for many months before her tumor was discovered.

After initial success with a nephrectomy, her cancer returned and metastasized to her liver; in 2005, doctors turned to chemotherapy, ablation and treatment with new drugs for kidney cancer patients in response. The treatments produced results; today she is in remission.

Laura and Scott speak candidly about the peaks and valleys in a long-term battle with cancer. There have been times when Laura says she was "tired of being sick and tired" and just didn't want to continue to fight, days when she couldn't fathom one more day of illness or of being a burden to her family.

Though she is in remission now, the emotional and psychological toll has been significant. Laura credits Scott's unflinching commitment to her care, and her personal faith, as key factors in her recovery. Her work with young children also helped keep her spirits up.

## *Survivor's advice from Laura:*

- "Don't be afraid of new drugs or treatments."
- "Don't hesitate to ask questions and advocate for yourself. If you don't understand what the doctor just told you, ask him to slow down and keep asking for more information until you understand."
- "Getting your nutrients is important – and sometimes that's hard to do. I use a juicer and it really helps."

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**Interviewer:** When were you diagnosed with kidney cancer?

**Laura:** November of 2001.

**Interviewer:** How were you diagnosed? What were the circumstances?

**Laura:** Well, prior to the diagnosis, I was having dizzy spells. I had

no pain whatsoever. I remember having some dizzy spells and thinking this is just an equilibrium problem, that's it. I wasn't alarmed since it wasn't continuous. Then one day at work one of my colleagues said, "Hey, Campbell," and I turned around to respond and ended up hitting the ground.

**Interviewer:** Literally?

**Laura:** Yes, everything was spinning and I fell to the ground. That told me that something was really wrong. So I went to the doctor. And that started a long process of misdiagnosis, which went on for five months. I kept saying, "Something is wrong." And they would tell me, "Oh, no, you're just over-worked," since at the time I was working 60 to 70 hours a week. But I persisted and kept telling them that something was wrong. And I remember one day I had a sensation inside that felt almost like an explosion – it felt like being shot. And at that point I finally got to a gynecologist who scheduled a CT scan.

**Interviewer:** How did that go?

**Laura:** Well, I remember lying there before the scan and saying, "Okay, Lord, I know it's cancer." Somehow I just knew.

**Interviewer:** You were having premonitions that it was going to be serious?

**Laura:** Yes.

**Interviewer:** Is that unusual for you?

**Laura:** No, I've been that way since I was five.

**Interviewer:** Really? You have a feeling about something and –

**Laura:** And it usually happens. I used to run from it. Now I kind of understand it.

**Interviewer:** So you went in and it turned out exactly as you thought it was.

**Laura:** Yes.

**Interviewer:** Did that help you to prepare?

**Laura:** Yes, I think it did. You do what you have to do in life. I was able to cope and do what I had to do.

*[Laura's doctors recommended a radical nephrectomy, and a surgery was scheduled.]*

**Interviewer:** How did the surgery go?

**Laura:** Not well. I was hemorrhaging on the table, and it turned out I had

a 10.7 cm tumor. But we got through it. The doctors believed all of the cancer had been caught and removed. But it came back.

**Interviewer:** What year was that?

**Laura:** I found out it had returned on November 10, 2005 – my birthday.

**Scott:** What a birthday present. [Laughs]

**Interviewer:** What clinical approach did your physicians try with the second diagnosis?

**Laura:** On January 16, 2006, I had an ablation and chemotherapy. [Note: ablation is a surgical process that removes tissue by heating or freezing it – sometimes with the aid of lasers.] The surgery seemed to be a success, but in December of 2007, in a follow-up test, the doctors noticed that there were spots throughout my liver.

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*“They would tell me, ‘Oh, no, you’re just over-worked,’ since at the time I was working 60 to 70 hours a week. But I persisted and kept telling them that something was wrong.”*

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**Interviewer:** What was the medical approach after this diagnosis?

**Laura:** My surgeon came out and said “That’s it. There’s nothing else we can do surgically.” So they put me on one of the new drugs, which worked for about four months.

**Scott:** Unfortunately, the side effects of the drug were horrible for her.

**Laura:** Terrible.

**Scott:** Extremely bad. She had trouble staying out of bed, throwing up...

**Laura:** Losing patches of hair.

**Scott:** She had a lot of trouble with it.

**Laura:** Then I started a new drug that was in development. I had two tablets every night.

**Scott:** And again, side effects. Her triglycerides and blood pressure both skyrocketed.

**Laura:** We got those down with other medications and a change of diet – I went from red meat to chicken, fish, lots of vegetables and juicing – and I was stabilized. With that, I was able to stay on the drug for four years.

**Interviewer:** Let’s talk for a moment about your interactions with the doctors during all of this. You said your surgeon came out at one point



and said “That’s it. There’s nothing else I can do.”

**Laura:** Right.

**Interviewer:** How did you feel receiving that kind of information?

**Laura:** Well, when I started seeing a lot of doctors as a result of my cancer, I asked them to be straightforward with me. I don’t like sugarcoating. I feel lucky in that my doctors were straightforward, but also caring at the same time.

**Scott:** I think they still tried to occasionally float over a lot of stuff and make it look good, but when we felt that was happening, we would always say, “Wait: What exactly does that mean?”

**Laura:** Yeah, we made them work. [Laughs]

**Scott:** We definitely learned to stop them and ask questions, as soon as there was anything we didn’t understand.

**Laura:** It’s okay to do that.

**Scott:** If you don’t understand anything, you have to stop the doctor and ask. And they’re always more than happy to explain it back to you. You don’t want to just nod your head as they walk out the door.

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*“If you don’t understand anything, you have to stop the doctor and ask. And they’re always more than happy to explain it back to you. You don’t want to just nod your head as they walk out the door.”*

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**Interviewer:** Which is really easy to do because you’re thinking, “I don’t want to waste this person’s time. I know they got a lot going on. I’m not really sure, but I don’t know if I should really push it here.” But what you are saying is that you shouldn’t hesitate.

**Laura:** Right. It’s your life.

**Laura:** It’s your life. These are the people with the knowledge, and you have a trust, but you need to fight for yourself.

**Interviewer:** What else did you do to educate yourself about cancer?

**Laura:** The Kidney Cancer Association book *We Have Kidney Cancer* was my start. And then from there I went on the Internet. And then I would get overwhelmed by information and had to back away from it.

**Interviewer:** You have participated in a clinical trial. How was that experience? Did you have to be convinced to do it? Or were you eager to do it?

**Scott:** When the first drug she was on turned out to be ineffective, we

wondered, okay, now what do we do? Where do we go? So we looked at a couple of the clinical trials that were going on. One, she couldn't do because of the type of kidney cancer she had. The other one was a blind trial and we were reluctant to participate in a blind trial. [Note: a blind trial is a clinical trial in which patients don't know if they are receiving a test drug or a placebo.] And then we found a non-blind trial that looked good and that her doctor recommended.

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*“There have been times throughout all of this that I felt like giving up. And I could hear Scott’s voice because he just has this calmness within him.”*

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**Laura:** At that point, with the cancer in my liver, and me being out of options, the feedback from the liver specialist helped convince me to try a trial. He said, “Hey, you’re fighting. What do you have to lose? You have a choice. You can sit back and do nothing or do this.”

**Scott:** They couldn't operate on the liver, so what were our options at that point? Do you give up, throw the towel in and just let it take you? Or do you fight back?

**Interviewer:** Scott has clearly been deeply involved in the questions about your treatment. Tell me about his impact in your care.

**Laura:** There have been times throughout all of this that I felt like giving up. And I could hear Scott’s voice because he just has this calmness within him. It’s one of the things that made me fall in love with him. He’d look me straight in the eye, and he’d say, “You can do this. You’re going to fight. You’re going to live longer than I am.” And he always stayed strong. He was always strong for me. I know deep down inside he was hurting. He was scared. But he never let me see it.

**Scott:** Laura is an extreme optimist most of the time, so that helps. But cancer creates waves of emotion, with highs and lows.

**Laura:** There were those times that I felt so tired of being tired and tired of swallowing the pills. You just find yourself saying “I’m tired of feeling this way.” And then a lot of times I felt guilty about how this was affecting Scott. This happened not long after we were married and I even tried to give him an out because I didn’t think it was fair for him. He didn’t sign up for this. He looked at me and said “I’m in it for the long haul.” And my kids were in high school at the time. That was tough for them, too. And then you feel guilty about the bills. There’s a lot of guilt. You feel like you’re putting a burden on everybody.

**Interviewer:** What about other people in your family, besides the two of you? Tell me a little bit about their role in your experience so far.

**Laura:** I think one of the things that impacted me the most was having my son, at the age of 21, saying to me, “Mom, it is what it is. It’s cancer. You need to embrace it.” That stayed with me. Instead of hating it, I thought, okay, this is what I have. And my daughter kept saying “Mom, you know you’re a fighter. You can’t give up.” They all stayed strong around me.

**Interviewer:** Let me ask you some specific questions about the kind of lifestyle and diet. You already talked a little bit about cutting out red meat. Any other changes you’ve made?

**Laura:** Juicing has been a big help in getting nutrients. One thing you have to do is watch your nutrition. I’ve really had to make myself eat because sometimes I just don’t feel like it. If I don’t have an appetite it helps me to eat at the same time every day. And if you can’t eat, at least get a cracker with peanut butter, something like that.

**Scott:** Eating was a constant battle for her. I had to fight that battle a lot to make her eat.

**Laura:** All the time. Yes. And if he didn’t, I don’t know where I’d be.

**Scott:** Part of the problem was nausea. On one of the drugs she tried, it was every day, every night, non-stop.

**Laura:** One little tip that was amazing: My mother-in-law called me and said, “Honey, trying chewing spearmint gum. I want you to get two pieces. I want you to chew it, build up the saliva. Don’t swallow the gum.”

**Scott:** That did help you.

**Laura:** It stopped the vomiting and helped me get an appetite.

**Interviewer:** What about other activities of life? How have they been impacted by your cancer?

**Laura:** I found that working was a big help to me. I have loved working in child care.

**Scott:** Being able to work has helped a lot, but she also lost a lot of the activities she did before getting sick. Some outdoor things – for example, softball, canoeing.

**Laura:** Dancing.

**Interviewer:** And are any of those activities coming back? Are you thinking about those kinds of things?

**Laura:** When you are putting all of your energy into fighting cancer – that’s all there is every day – and then you get past it and start getting back to living life, you feel off balance. What I’m struggling with right now is feeling like I was in a relationship with something, and it was there all the time, and now it’s gone. And now I need to find my identity again.

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*“When you are putting all of your energy into fighting cancer – that’s all there is every day – and then you get past it and start getting back to living life, you feel off balance.”*

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**Interviewer:** Are the psychological issues of being a cancer survivor difficult for you?

**Laura:** To get going again after all the surgery and treatment is rough. I spent five years on medication, plus chemotherapy. And sometimes I just don’t want to put the effort in. I don’t want to eat. And I don’t want to take the medication. Psychologically, you just get tired of it. You feel like you are not in control of your body, this medicine is. That can be a big issue. And then there is this feeling of being tired. I want to get up, I want to do this or that, but I feel like I can’t.

**Scott:** There are huge problems getting back to normal life, wanting to get up and do something. The tumor is removed, you go on a drug and think “OK, I’m free. I’m good. I’m healthy.” But you still have struggles. It can be a lot more difficult than people realize. Getting Laura to do the things she needs to do – eating, and so on – can be a challenge. There were times where I was making no progress with her – getting her to do what she had to do – and I would have to call her best friend, Leanne, to help me. We would sort of take turns. If I got to the point where I couldn’t get any further, I’d call Leanne and say, “she’s acting up again, can you help?”

**Laura:** Right. I found that out later. [Laughs] And my brother Ron was a huge help, too. He moved here from California and was right there with us in the midst of chemotherapy and everything else. He really helped Scott and was there for me whenever I needed him.

**Scott:** At critical points in her recovery, we’d have to sort of gang up on her to keep her going.

**Interviewer:** So a support network outside a spouse or significant-other is important?

**Scott:** Yes, very important.

**Interviewer:** Any other advice you would give kidney cancer patients?

**Laura:** My best advice to others is: Don't be afraid to ask questions and advocate for yourself. This disease can be overwhelming as news is delivered so it is important to have someone there with you – to ask questions, to be your advocate and help you understand. Keep fighting and don't be afraid of new drugs or treatments.

## Billy and Renee

Billy is a teacher, musician and jazz pianist from Indiana. Over the course of his career, he taught music for elementary-school students as a part of the public school system, jazz piano for students at a major four-year university, and private lessons, while leading a band. He retired in 2004 after 35 years of service as an elementary school music teacher and continues to teach jazz at the university. He and his wife Renee – who is also a musician, as well as a culinary artist – have been married for 14 years.

Billy, 64, was originally diagnosed with kidney cancer in 1996 and underwent a radical nephrectomy. He then lived 11 years cancer free before the cancer was discovered to have metastasized in his lungs and liver. Additional lesions were found in his brain.

Billy has received a variety of treatments, ranging from gamma-knife surgery for his brain lesions to drug regimens. [Note: *gamma-knife technology allows doctors to deliver beams of radiation directly to tiny tumors in the brain.*] Though tumors remain, he has been stable for several years and continues an active lifestyle (with a few concessions to the disease and ongoing treatments) – teaching, performing, recording a radio show in his private studio and broadcasting live from a radio station in Gary, Indiana.

A slender, soft-spoken man, Billy says that side effects of some of the drugs – including the effect on his eating habits – have been a challenge, but that he is able to maintain a busy schedule in spite of them. He says kidney cancer has not diminished in any way his abilities as a musician or his enjoyment of his craft; he intends to keep working. Renee has been a very strong advocate and she and Billy agree that part of the role of a caregiver is making sure that the patient’s needs are expressed and heard by the medical team.

### ***Survivor’s advice from Billy:***

- “Remember that you can’t control everything in life. At some point you have to accept things as they are.”
- “Pray – God is supremely in control of all”
- “Friendships can help to sustain you.”
- “Let your care-giving team have lots of input – they can help.”
- “Seek out the best doctors and medical team you can find”

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**Interviewer:** What were the circumstances of your kidney cancer diagnosis?

**Billy:** I found out I had kidney cancer in 1996. In the summer of 1995 I was on my way to New York, alone, and I stopped to go to the restroom in Pennsylvania and had blood in my urine. So I

found the nearest hospital and checked in. This was in Sharon, Pennsylvania. It turned out it was kidney stones, but the doctor thought it might be something more than kidney stones because I was bleeding too much. So I spent four days there. I came back home and went to the hospital for more tests and they couldn't find anything else. So I was fine until February 1996, when the bleeding recurred. And that's when they found that I had a cancerous tumor in my right kidney. The doctors were surprised by the size of it. I had a nephrectomy. From that point until 2007, which was 11 years later, I was okay. I thought that when I passed the five-year mark, I was in good shape. But then I started coughing –

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*“I guess I now look at my life as having a limit. And so I'm just trying to get as much done as I can. I don't think I'll be around until I'm 90, though I might be. And I'll just get that much more done.”*

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**Renee:** He was coughing, and he didn't look right.

**Billy:** And so they did an x-ray and my doctor told me he saw something. He sent me to an oncologist who did some further investigation and found that I had cancer in my lungs and liver. And my family doctor, who had just had treatment at a medical center in Chicago for prostate cancer, said, “Do you want me to call and see if I can get you an appointment?” And so he did, and I was able to get right in. And within a week, I was there and getting started with my treatments. They sent me to a lung cancer specialist. They thought that if the cancer was located in just one spot, they could cut off that third of the lung and I would be good to go. Unfortunately, when they opened me up, there were spots of it all over the place so that wasn't an option. In the beginning the cancer didn't appear to be moving so they left it untreated for about three months. I took this opportunity to try some things myself. One was an all-raw diet. I lost close to 30 pounds and I went down to 130 and my normal weight was around 159. So I went off that.

The size of the tumors eventually started to increase and at that time, the doctors started me on one of the newer drugs for kidney cancer. In the meantime, I was having some trouble with my vision, so I went in for an MRI of my brain. And it turned out that I had three lesions in my brain. So my next treatment was to have gamma-knife surgery. This was successful in removing the lesions. I continued with the drug treatment for the lungs and liver at the medical center in Chicago, but I was having a hard time with side

effects, including very high blood pressure, coughing up blood and on top of that, it didn't work. [Laughs] At that time I was offered the opportunity to participate in a clinical trial. I would be a part of a group testing what was a new drug at that time. Given prior results, I was happy to consent.

**Interviewer:** And are you on that drug now?

**Billy:** Yes – I take it every night and have been on it for three years.

**Interviewer:** And what is the status of your tumors?

**Billy:** Some of the tumors have reduced in size since the beginning of this, which was an unexpected result.

**Interviewer:** And how are the side effects for this one?

**Billy:** Well, at first, they started at a fairly high dosage, I guess, and I was getting more side effects. But over time we got that adjusted.

**Interviewer:** What was it doing to you?

**Billy:** Well, I couldn't eat. Everything tasted horrible. My stomach was hurting every time I ate something, fatigue would set in and I had a sore on the bottom of one of my feet caused by the medicine. With the sore on my foot I would put a salve recommended by the doctors and a foot patch on to cushion it.

**Renee:** And I had to learn new recipes for him in order for him to eat. For example vegetable stir-frys, assorted juices, vegetarian meals. I would read about the significance of vitamin supplementation in order to help strengthen the body, what would help cleanse the body and what could help fight the cancer.

**Billy:** I remember, too, one of the things at the beginning of this is if I ate anything that was just a little hot it would set my tongue on fire. I was playing somewhere, and I ate something with a little bit of pepper. And I spent the rest of the night drinking milk trying to cool it down. The doctors gave me something to deaden my tongue for this. Currently, I have high blood pressure, a thyroid condition and bouts of diarrhea. These are caused by the medicine I take. I have some weak spots in my bones so I also take an infusion of a medicine for that. The side effects are just something you have to deal with. I also take medication for my thyroid condition and for diarrhea. When my stomach's upset I eat candied ginger or drink ginger ale.

**Interviewer:** Let me go back to when you were first diagnosed, when you first got the news that you had cancer. What went through your mind? What were your feelings and thoughts?



**Billy:** Well, that was a depressing night. My first thought was that I wanted to get it out as fast as we could. But by the next morning I was doing much better.

**Interviewer:** That's interesting. That's a pretty quick recovery.

**Billy:** I don't do a lot of moping.

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*"He doesn't base his life on what somebody else does or how they deal with things."*

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**Interviewer:** And have you always been that way, a positive person?

**Billy:** Yeah.

**Renee:** He's been an independent kind of person. He doesn't base his life on what somebody else does or how they deal with things. It's based on what he wants and how he goes after it. The other thing is this is a person that has always done the things he really wanted to do. Billy has been fortunate to love music, share with others and students his love of music, with a career teaching music and a profession performing jazz music. Most people, with jobs, you know, move from job to job. Billy has loved playing piano since the age of seven. This is his gift, and he has a passion for his music.

**Interviewer:** You always knew what you wanted to do?

**Billy:** Yes.

**Renee:** So he had a love. And I told him the piano may be your first love, but I'd better be the second! [Laughs] When a person has a passion for something this beautiful and they are gifted, this is a way that they can express themselves, and this becomes an extension of their total being. That's what helps sustain them. He truly has a passion for his music – it takes you into another zone. I can understand, because I am also a musician. Billy is a great man, and I believe Billy's love of music has helped to save his life.

**Interviewer:** Has your illness affected your playing, Billy? Have you noticed any effects?

**Billy:** It hasn't affected my ability to play. Occasionally, I get on a gig and have to run to the restroom, you know, that kind of thing. As I said, the medicine sometimes causes diarrhea. But, I'll still play, in spite of everything, even if I'm sick to my stomach.

**Interviewer:** Is it pleasurable for you still to play music?

**Billy:** Oh, sure.

**Interviewer:** So your music is still thriving. Have there been any other positives

– things that have benefited either of you while coping with Billy’s cancer?

**Billy:** Well, I guess I now look at my life as having a limit. And so I’m just trying to get as much done as I can. I don’t think I’ll be around until I’m 90, though I might be. And I’ll just get that much more done. Renee has some health issues and I have tried to be there for her also. We know that we are good support for each other. I believe that it’s important to know that you have someone you can lean on and that will be there for you no matter what.

Teaching students, doing my radio show, playing gigs and occasionally doing clinics – I’ll continue all of that.

**Renee:** And then in between, he writes music, he helps other musicians or students when they have problems with their own music or writing, or they have questions, that kind of thing. All of this is part of Billy’s life, along with the rigors of going to the doctors, having tests, blood work, and going through the bouts with the various side effects from the medicines. This is not to say that Billy has not suffered, he has. Billy has had tremendous hardships, along with good and bad days mixed in with some of the worst days in his life. We have – with prayer, great doctors, medical teams and a whole lot of hope – managed to move on. Of course his pace has to slow down when he has to and when he can’t do things, but in spite of it, he continues to push forward.

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*“I think another one of the things that can be a positive is that you see your friends and family in a new light – you learn new things about them in the way they deal with you.”*

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**Billy:** I think another one of the things that can be a positive is that you see your friends and family in a new light – you learn new things about them in the way they deal with you. Fortunately, for me, I’ve been blessed with good family and good friends.

**Renee:** Yes, our friends and family and those who know us through our performing throughout the Midwest have done so much. Sending cards, e-mail jokes, they’ll say, “I’m sorry Billy has cancer and I’m going to pray for you. Or I’m putting you on our prayer list.” A reverend friend of ours said, “I’m going to have to send up some heavy timbers for you, Billy.” And we even had one friend who found out how to send a petition to the Vatican so that the Pope could pray for Billy. It’s amazing how God sends people into your life that offer inspiration.

**Interviewer:** What would you say is something that hasn’t helped either of

you from the standpoint of people responding to Billy's cancer? Is there anything that people do that is bothersome to you? Things you wish they wouldn't do?

**Renee:** I did have a situation where a friend would call the house and start crying over the phone. This happened more than once. This was in the beginning when we were being told that Billy's situation was extremely serious, so at that time our emotions were also being tested. I realize that everyone copes with these things in a different manner, but even the most well-meaning friends should be careful not to cause more stress to the family than necessary. Community hospitals usually have support groups and educational help classes. As a suggestion, rather than further upset the family, perhaps one could attend a session and become more aware of how to be of some constructive assistance.

**Interviewer:** How about talking about cancer? Tell me, how do you deal with that? When do you bring it up?

**Billy:** Yes, all my close friends, people who are around me, they all know. And I'll talk to anybody about it. But I don't just bring it up on my own.

**Interviewer:** Renee, as the chief caregiver for Billy, what would be your advice to relatives and friends of patients who will be providing care-giving help?

**Renee:** You really have to speak up and be an advocate. When Billy went on the first drug, the dosages were way too high. And so I explained to them that Billy never took medicine, not even an aspirin, and that if perhaps they started off with smaller increments of whatever it was rather than higher dosages perhaps he could tolerate it better. And after some trial, it did work. The patient needs to be comfortable giving you permission to speak up as their advocate. That's important because sometimes the patient is going to be out of it – not thinking right. If there is something that's wrong with Billy, he has to say so – but he may not do it. Sometimes I would be with him and the doctors or nurses would ask him how he was, and he'd say, "Oh, I'm fine." And I'd say, "Well, what about when you said you didn't feel good and you looked kind of yellow earlier?" Sometimes you have to stand up and advocate for them. Read as much as you can, remain an observer, and don't forget to take care of yourself – because you cannot help someone if you are ill yourself. Make sure that you get your medical checkups and have breaks in between what has to be done. Ask for help and make sure that your support group is in place.

**Interviewer:** Has the cancer diagnosis changed your outlook or philosophy of life?

**Billy:** Before cancer, I figured I could control everything. You think you are in charge. But you're not in charge of anything. God is. You're just kind of along for the ride. So when you have a situation like this you need to learn how to put up with and deal with it.

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*“The patient needs to be comfortable giving you permission to speak up as their advocate. That’s important because sometimes the patient is going to be out of it – not thinking right.”*

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**Renee:** You need to learn as either the patient or the person that’s the advocate, to let go sometimes. Because the same schedule you had when everything was fine and it was a sunny day is not the same schedule you have, based upon that illness. And then it takes a little more time, perhaps, or it takes a little bit more understanding of how to actually do things, practical things like putting on your clothes, side affects from the medicine, preparation of food, or preparation for travel. You have to learn to make adjustments. One learns that through it all there is a higher power, and surely as we live and die, we learn to become active participants in life, love and the pursuit of happiness and peace. The caring and sharing in life. The giving and the taking.

**Billy:** I had plans for living into my 90s because all of my relatives lived into their late 80s. And I had an uncle that just died a few years ago – he was 96. When I first got my kidney taken out in 1996, I was talking to my uncle. He must have been 80-something at the time. And I was saying, “Uncle Harry, you know, I had to have my kidney taken out.” He said, “Oh, I had my kidney taken out when I was 60-something.” And I said “Oh, sorry to hear that.” [Laughs] This was the best “bad” news I’d ever heard. I think watching relatives and others work through their health problems has helped me deal with this a little bit better. My motto now is “Don’t let what you can’t do stop you from doing what you can.” This is how I end each radio show and I take it to heart.

I have to thank all the doctors and nurses and the many others who have helped me through these very challenging and interesting years of my life. This has been an education in many ways and not all bad.

We would also like to thank the Kidney Cancer Association for the opportunity to share our story and to meet other wonderful and inspiring kidney cancer patients. We wish them all the best.

## **EMPOWERING STEPS FOR PATIENTS**

*Additional tips and advice from the Kidney Cancer Association*

### **Hire an Expert**

Get the most qualified doctor to treat you. Do not confuse “bedside manner” with true expertise. You want to be given the most appropriate treatment, not be charmed.

You are more likely to find an expert doctor at a comprehensive cancer center associated with a university medical center, particularly for a rare type of cancer. However, there are many excellent doctors in community hospitals. Do not hesitate to be treated by them if they have experience with your type of disease. Simply ask your doctor how many patients with your type of cancer he or she has treated in the past 12 months. Then compare this number with the other doctors you are researching.

Some medical centers are famous. However, when it comes to rare cancers, a less well-known cancer center may offer more advanced care and have more doctors who are experts in your type of cancer. Be sure to ask for statistics measuring surgical success, morbidity, and rates of complications associated with treatments.

# Jessica

Jessica is an energetic 25-year-old from a small community about an hour north of New York City. Naturally athletic, she grew up playing hockey, skiing and other sports. She recently earned a bachelor's degree in psychology and took time off after graduation to snowboard – one of her great passions – in Utah.

Jessica was a junior in college when she learned of her diagnosis – but the diagnosis itself didn't emerge easily. She estimates that she saw at least six doctors before the kidney cancer was discovered. While doctors early on suspected a kidney stone or cyst, she intuitively thought it might be more serious and kept pressing her doctors to be more proactive.

To lessen the impact of her illness on her family (Jessica has an older brother and younger sister in addition to her parents) and on her friends, Jessica adopted a very determined and upbeat mindset in the face of her diagnosis that she says has changed her overall outlook on life. She says she is happier than she has ever been.

Jessica underwent no additional treatment for her kidney cancer after a partial nephrectomy, though she has had several other surgeries for other health problems. Like many patients, she has become active in the community of kidney cancer survivors, interacting with others at the Kidney Cancer Association website and its Facebook page.

Jessica's story illustrates how difficult it can be, in some cases, to detect kidney cancer definitively – and why it's a good idea to be your own advocate. As she puts it, “advocating for myself, in my case, literally saved my life.”

## *Survivor's Advice from Jessica*

- “Your life isn't over. Think objectively about what is before you today and plan what you are going to do next.”
- “Humor is important, for both patients and caregivers. Learn how to poke fun at yourself, and let others know it's OK to joke.”
- “Go on with your daily activities as much as you can – don't let cancer change the way you do things.”

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**Interviewer:** Tell me about how you discovered that you had kidney cancer.

**Jessica:** I was 23 when I found out. I've worked for a long time for an organization that helps people with developmental disabilities. And I was helping put a disabled girl on a carousel one day at the mall. Somehow I threw out my back. I had shooting pains in my hip and pelvic bone, in my lower back. It was terrible. Very bad

pain. I called my mom and asked where I should go for help since this was the first time I'd ever had any medical issue. I'd had no previous medical problems whatsoever. She suggested I go to an orthopedist, so I went in. The doctor just gave me a bunch of pain medicine and said, "Come back in two weeks." But I ended up coming back in a week and half because the pain was so bad.

This time I went back in with my mom. They did an MRI and the doctor said, "We have your results. You have a bulging disc in your lower back." I was about to leave – I was starting to stand up to go – and he said, "I have one more thing to show you." He showed me an MRI and he said, "Here are normal kidneys." Then he showed me my MRI and said, "Now, these are yours." I didn't know what to look for, but he pointed out a dark shadow – like a big black blob. I thought to myself, "OK, that's not good." I had this funny intuition. I knew right then and there it was going to be something serious.

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*"I didn't know what to look for, but he pointed out a dark shadow – like a big black blob. I thought to myself, 'OK, that's not good.' I had this funny intuition. I knew right then and there it was going to be something serious."*

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He said, "It's probably just a kidney stone" and sent me to a urologist, who ordered even more tests of various kinds, which was very discouraging. At this point it had been three weeks since my original injury. When I went back to the urologist for a second visit, he said nothing had shown up in the tests. He didn't want to do anything more invasive at that point, so a week later we tried an ultrasound. This time I'm sitting there with both my mom and my dad. And this time the doctor said he didn't know definitively but that his best educated guess was that it was an abscess or cyst. By this time there had been probably six doctors involved in trying to figure this out. And now they wanted me to just take an antibiotic and let it go for six weeks and then check again. And at that point, I don't know why exactly, but I just kind of snapped. I said, "You can't tell me that it's not cancer." And the doctor said, "No, that's right. I can't tell you that it's not." So I said, "You really have no idea then, do you?" And he said, "No, but in my professional opinion, it's a cyst." And I said, "OK, well, in my professional opinion, I'd like a referral." My dad was so mad at me for talking like that to him. [Laughs] But I was being my own advocate.

**Interviewer:** That's understandable. You must have been frustrated by then.

**Jessica:**

Yes, very. So I finally got a referral to a cancer specialist. He was the chair of his department at a medical center in Connecticut. It took two and a half more weeks just to get an appointment. At this point I just wanted to know what the hell was going on. So I went to see him. He looked at everything and said he didn't know 100 percent either. But his attitude was more questioning. He said, "I really want to know what's going on, and I'm going to give you an answer." He believed it was a benign tumor. He ruled out a cyst or a kidney stone immediately. I came back a second time and the still didn't have an answer. So now, he started asking about symptoms. He wanted to know if I had experienced any of them. And it was a long list. It seemed like there were millions of them. I just kept answering, "No, no, fine, no." And finally he got to night sweats. There, I paused and I said, "You know, this whole past summer I was sweating through my sheets. It was awful." When I told him that, he changed immediately. He said, "OK, I want to do a biopsy." My mom and I just looked at each other.

**Interviewer:**

And how did that go?

I had it that same week. I remember sitting there as they were doing the biopsy – two young doctors were there and they were making it easy for me – "We all think it's nothing. We're betting on you." Because it didn't make any sense that a 23-year-old with no health problems would be sick. "It's probably benign if it's a tumor at all." The doctor came to me afterwards and said that in no more than five to seven days he would have an answer for me. He said the office secretary would call as soon as they had results. I literally called her every day, the poor woman. And she would say, "Sorry, no results yet." After seven days it seemed weird. And after a week and half had gone by I called again. The secretary said, "Let me check and see what's going on." And she came back and said they were sent in for confirmation, and she named the hospital they were sent to. Well, I looked up that hospital, which was very well known as a cancer center. And I thought, "Well I guess that solves it. Cancer." Four or five days later the doctor called me, just as I was walking into a statistics final at school. It was Dec. 21. He said, "The slide confirms that you have Papillary Renal Carcinoma type 1."

**Interviewer:**

That must have been a difficult blow

**Jessica:**

I just said, "OK, I'll call you later." I had to get through the rest of my day. I got off the phone, tuned it out and after my finals I went to see my parents. They said, "Any news?" And I said, "Yup. It's cancer." How do you tell your family? There's no "right" way to say it.



**Interviewer:** How did your parents react?

**Jessica:** My parents' reaction was vastly different than mine. It was very difficult for them. I was actually more collected than they were. We went to see the doctor on Christmas Eve day at 8 a.m. It was a gloomy morning. Snowing. There was hardly anybody at the hospital. They said I had only two options. I could have partial nephrectomy or full nephrectomy. I couldn't do laparoscopy because of where my tumor was, embedded in the urinary tract. I remember I was pacing the hallway because he was graphically detailing the surgery – talking about cutting me open – and I was thinking, “Oh, my god, it's gross.” I thought I was going to throw up. It was my decision but at the time I'm not sure I was capable of making a good decision. We decided on a partial because then there would be at least some good tissue left if something happened with the other kidney.

**Interviewer:** How did the surgery go?

**Jessica:** I had the surgery on Dec. 30 2009. It was an awful experience in terms of pain. The hospital was great. I had exceptional care. But when I woke up out of surgery I couldn't breathe. It was the shock of the pain I was in and also that it turned out I was allergic to morphine. I was in the hospital for five days. My mom stayed with me the whole time. She had a bed next to mine. And thank God. It was miserable. I couldn't have done it without her. On the first day they wanted me to get out of the hospital bed. And I couldn't even imagine walking to the door. I said, “No way. That's not happening.” I didn't really want to leave the bed at all. On the third day I started walking around. It was very surreal. I had to stay home for six weeks after I got out of the hospital, and then, eight weeks later, I started spring semester at school.

**Interviewer:** Your response was interesting to the diagnosis. It seems less emotional than most others I've spoken with. Why do you think you didn't have a stronger emotional reaction?

**Jessica:** There was a reason that I responded the way I did. First, I had two solid months to prepare for bad news. During that time, everyone kept saying, “You are going to be fine, it's nothing,” but I kept thinking, “I don't think so.” I was more emotional the day I saw my first MRI than the day I found out I had cancer. I cried, not because of the pain, but because of what I saw on my kidney. And then as far as being incapacitated or slowed down after the surgery, I said, “Screw this, I'm not going to let this ruin my life.” I didn't want it to change my perspective. I had prepared myself. If it's cancer, it's cancer. I'll just have to deal with it, just like

anything in life. Having had the time to prepare myself helped, I think. When I finally found out I had cancer I think I was relieved in a way, because all I really wanted was an answer. The not knowing is the worst part.

**Interviewer:** Did you have any other treatments in addition to the nephrectomy?

**Jessica:** I didn't go on any drugs or have any other treatment. I've had additional surgeries, including an operation to remove a portion of my lung that showed four tiny tumors. I also had a cyst removed and most recently I had an operation to address a heart arrhythmia that developed over this last year. But no other treatment for the cancer. I'm now hoping after all these things, I'm now done with medical issues for awhile. It's been like a Pandora's Box of medical problems. I know that I've have been lucky – I didn't have to do chemotherapy or radiation.

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*“On the first day they wanted me to get out of the hospital bed. And I couldn't even imagine walking to the door. I said, ‘No way. That's not happening.’”*

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**Interviewer:** You have a brother and sister. How did they react to all of this?

**Jessica:** I was the only one living at home at the time. My brother had long moved out. So he was gone. And my sister was away at college, in Pennsylvania. We decided not to tell Kristen, since she was in finals. And she was going on a ski trip after that. And when I did tell her, I said, “Don't worry about it. I'm OK.” It was funny, because you would think the person being sick would be falling apart, but I was being strong for everyone else. I knew my brother and sister would feel guilty they weren't there, and if I convinced them that I was OK, they would be OK as well.

**Interviewer:** What are you doing now that you have finished school?

**Jessica:** Well, over the first part of this year, I was a ski bum. I finally graduated in December 2011 with a bachelor's degree in psychology. I'm now thinking about getting a masters degree in social work. But in the meantime, I decided to take a break and just not do anything. I went to Utah in January and spent the winter there. I'm going to have to work the rest of my life, so why not? I started skiing when I was 4 or 5 and have been snowboarding now for about 15 years and I love it.

**Interviewer:** Has your cancer impacted your athletic ability?

**Jessica:** Yes – definitely. That's 100 percent true. After I had my nephrectomy, the doctor said I should be careful about sports. I

just started going back to the gym this summer. I was weak on that side of my body. The muscle had atrophied. I knew I had a weak core and after the surgery it got worse. I've had physical therapy to strengthen my core and really have had to work from

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*“When I finally found out I had cancer I think I was relieved in a way, because all I really wanted was an answer. The not knowing is the worst part.”*

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the bottom up to repair my body again. It has impacted me in that sense because I have always been involved in sports. Having cancer has affected my mobility and my strength, but I'm slowly getting it back. I knew it would take time.

**Interviewer:** What were your first steps after the diagnosis? What did you do to deal with all that was happening around you? Is there anything someone who has been newly diagnosed can learn from your experience?

**Jessica:** There's one thing I just can't stress enough: You have to advocate for yourself. When you get diagnosed with cancer you have to pick up your game. It's one of those things you just have to do. You don't have a choice. I have tried to look at things objectively, and that has helped me: I try to think of what's going to happen next, what I'm going to need to do and how I'm going to do it. As an example, if I had just sat back and expected things to happen during the time the doctors were trying to figure out what was wrong with me, they wouldn't have happened. There would have been a stalemate. Advocating for myself, in my case, literally saved my life.

**Interviewer:** Any other advice for those who have been diagnosed?

**Jessica:** First, remember that your life is not over. It sounds like a cliché, but it's the truth. One of the best things I got when I was sick was a music CD from a friend, called the Bright Side of Life. And I thought, “This is right, there's way too much about life to be happy about for this to ruin it.” If I let it, it will.

**Interviewer:** How about advice for caregivers and others who are interacting with a young kidney cancer patient? You are much younger than the typical kidney cancer patient.

**Jessica:** Most of my friends knew that something was going on. A lot of them didn't say much because they really didn't know what they could say. I ended up being the one telling them it was going to be OK. It was funny being the one who was consoling other people. But in a way, that's kind of what I needed – I didn't want people talking about it a lot. My friends were awesome. They didn't call

me up and say, “How are you feeling?” Instead, they would call me up and say, “Do you want to go out and do something?”

**Interviewer:** What did you need most during the time you were dealing with all of this?

**Jessica:** I think in general, patients need someone to be there with them – someone who will hang out with them. They want someone who will do regular everyday things with them. You don’t want to feel that things have changed. You want to go about things the way you always do. I personally didn’t want to dwell on it or talk about it. The best thing for me was to ignore it and do things like I would do any other day.

One thing I think is important is humor. I think humor is very important to people who are sick. As an example, a friend of mine nicknamed my tumor “Toomy.” He made it funny – “How’s Toomy doing?” And I enjoyed things like that. If there was no joking, or no making fun of me or my situation, it would have been terrible. Then I wouldn’t have been able to be strong for anyone.

**Interviewer:** Did religious faith play a role?

**Jessica:** Not as much for me as for other people. I grew up in a religious family – my mom is Catholic and my dad is Episcopalian – but I don’t turn to faith so much to cope. Doing what I love to do is more how I cope.

**Interviewer:** So you found strength in the daily activities of living.

**Jessica:** Yes, and those are things that are even more special to me now. I’m appreciating life more now. Honestly, that’s what it really comes down to. Prior to this, most of my life, prior to getting sick, I was not the happiest kid. I was a depressed teenager. A lot of people don’t really know that, but it’s something I don’t mind disclosing because it’s true. It was a big part of me. I was never really happy and could never figure out why. And then, you know, after getting cancer, going through it and being OK, it changed everything.

You get that feeling of your life flashing before your eyes. And I’m pretty sure every cancer patient has that. You say, “Oh my God, how much time do I have left?” You hear those words, “You have cancer” and you say, “What am I going to do now? What’s going to happen?” Things have changed, big time, in my life. I’m a much happier person than I ever was. In a way, I’m not happy that I had to go through cancer – nobody would be. But it’s given me a different view on life, one that I didn’t have before. I’m realizing how precious it truly is. And how many things you have to be

thankful for. The little things in life, the simple things. While I was in Utah it was enjoying the scenery. Every day in Utah I got to look at mountains when I opened the door.

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*“I think in general, patients need someone to be there with them – someone who will hang out with them. They want someone who will do regular everyday things with them. You don’t want to feel that things have changed.”*

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**Interviewer:** What advice would you have for people who want to get involved and give back to the kidney cancer community?

**Jessica:** It’s 100 percent worth it to share your experiences with others. I want to do whatever I can to give back. After my diagnosis I started going online to learn as much as I could. And I really didn’t have any intention of joining anything online. But then I found the Kidney Cancer Association Facebook page and started posting something there every now and then. The folks at KCA asked me if I would be interested in telling my story in a podcast, which I did. And then I started thinking about other ways I could share and ended up submitting a photo that won their Denise Richards contest. [Note: Actress and celebrity Denise Richards’ mother died of kidney cancer; she has been an active supporter of KCA causes and special events.] A friend did a black and white photo of me that showcases my scars in a way that is beautiful. We wanted to convey that life is not over. So the KCA has been a kind of catalyst for me to be able to share my story, hopefully to help other people.

The KCA’s Facebook page and online forums have so many benefits. You can meet so many people there and they are incredibly helpful and supportive. It’s very homey and welcoming. I don’t know of any other network or community like it. It has enriched my life and been very rewarding to be a part of it.

## María Teresa

María Teresa, 44, is a native of Bogota, Colombia, who has lived in Illinois since 2010. She and her husband Robert, who works for a Fortune 500 food products company, have a 16-year-old son and a 14-year-old daughter. The family has lived all over the world, including France and Switzerland. Trained as a microbiologist, María Teresa has worked as a Spanish teacher and private tutor while raising her children.

Just a few months after moving to Illinois from Switzerland, María Teresa's father, José María – whose nickname is “Chema” – was diagnosed with kidney cancer. He still lived in Colombia with his wife of more than 40 years. One of María Teresa's two sisters, María José – a doctor living in Colombia – was able to help her father and mother cope with the diagnosis. María Teresa, meanwhile, became the family's information gatherer and researcher as they tried to learn everything they could about the disease.

Chema's cancer had metastasized to his lungs, and because they were so compromised by the time his cancer was diagnosed, surgery was not possible. Doctors started drug therapy, but side effects forced him to stop taking them in the summer of 2011. He died shortly after, with his family at his side.

Her father's cancer diagnosis propelled María Teresa and her family to become active fund raisers for the Kidney Cancer Association. “It gave me a way of contributing and fighting for my dad, even though I couldn't be with him,” she says. Even after her father's death, “Team Chema” – comprised of María Teresa, her husband, children, mother, sisters and other family members – is still very involved with the Kidney Cancer Association.

The story of María Teresa and her family's fundraising efforts is a great example of how caregivers can get involved in the kidney cancer community in a way that can have a tangible impact on progress towards a cure. As fund raisers and organizers, many caregivers – across the United States and the world – are making a difference.

### *Caregiver's advice from María Teresa:*

- Take one step at a time. Worry about today only – not yesterday or tomorrow.”
- Visit the Kidney Cancer Association website right away, and read the book *We Have Kidney Cancer*.
- “Consider joining an online chat to connect with other patients and caregivers. You will be amazed by the relationships you build.”

**Interviewer:** Tell me about your father's diagnosis.

**María Teresa:** The doctors found tumors in his lungs in November 2010. Then they did a biopsy and an abdominal MRI and found a tumor in his kidney, as well. The biopsy showed it was kidney cancer. Unfortunately, he couldn't have surgery because of his lung condition. So on December 24, 2010, he started taking one of the kidney cancer drugs. At first, it worked for him, then it stopped. So we went to the next drug option, and then to a third when that one stopped working. Last July, he decided he wanted to stop treatment because the side effects were too hard for him. I flew to Colombia with the kids so we could see him. I had to bring the kids back to the United States on August 9 so they could start school, then I went back by myself on August 20 and he died on August 28.

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*"After an experience like this, you truly live with a hole in your soul. I realize nothing will be like before. It's different, and that's just the way it is."*

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**Interviewer:** So the family was with him?

**María Teresa:** Yes, my mother, my sisters and me. It was very peaceful for him at the end.

**Interviewer:** This is still a very fresh memory for you – what has been the impact on you and your family?

**María Teresa:** When he was diagnosed, it was the worst moment of my life so far. I couldn't believe it. You never think it's going to happen to you or someone you love. My dad was a real hero. He never complained. He showed us the way, we just followed him. He was a real example. And we feel we can't be less than the example he showed us.

We are a Catholic family and we prayed a lot. We got together and prayed with him every night by speaker phone. And of course I cried a lot. It has been very hard on my mother, who was 11 years younger than my father. She's very tough, but it's painful for her. It's hard to see her as a widow, without him. They were married when she was 16, so her whole life was my dad. They had their 45-year anniversary last July.

After an experience like this, you truly live with a hole in your soul. I realize nothing will be like before. It's different, and that's just the way it is. But I'm so grateful for my father. Team Chema is our way to keep him alive. Like the priest said at his funeral: "You only die when you are forgotten." He is, and will always be, with us. My kids adored him. His last words were for them.

**Interviewer:** Your story is interesting for families dealing with kidney cancer because it shows how involved a caregiver can become with the kidney cancer community. You don't have to be a patient to make strong connections with people who are going through what your family went through.

**María Teresa:** That's right. Because my sister and my mother were in Colombia doing what I think was the really hard work of caregiving for my dad, while my sister Beatriz was in Atlanta and I was in Chicago, our contribution was to do as much of the research as we could for our family – and that's what really got me online. My sister Beatriz started a blog with my dad's story, which we called "The Blue Crab," and I started researching. I got involved right away with the Kidney Cancer Association because, like so many people, I went to their website and their Facebook page to get more information. I was reading as much as I could, and when I saw all the things going on there I sent them a note. And then that led to getting involved with the KCA and going to a KCA conference, where I met a bunch of other survivors. And I started getting to know the KCA staff. They were all so friendly and helpful to me. I told them "I want to help – I need to do something." The waiting, not knowing what was going to happen with my father, was very difficult for me. I needed an outlet. And they were encouraging people to run in the Chicago Marathon to raise money for kidney cancer, so I signed up. Beatriz pushed me to do it, so I did. I really

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*"I really wondered if I would be able to complete a marathon because I really don't like to exercise. It took me 7 hours and 14 minutes, but I did it. I had my dad's photo on my shirt. And I raised \$1,600 for kidney cancer."*

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wondered if I would be able to complete a marathon because I really don't like to exercise. It took me 7 hours and 14 minutes, but I did it. I had my dad's photo on my shirt. And I raised \$1,600 for kidney cancer. My dad was already in heaven but at the same time he was the one giving me the strength to do it. Now I'm getting ready for my second marathon.

**Interviewer:** And that experience led to many other fundraising activities – tell us about some of the other things you have done since getting involved in this way.

**María Teresa:** Well, our family organized ourselves right away. And then I started creating other small fundraisers. We did a little fundraiser during the Christmas Bazaar at my daughter's school and we raised more than \$200. My daughter and I sold the KCA's orange wrist bands and crocheted "scrunchies" (accessories for tying hair). Our



mission was to raise awareness and spread the word about kidney cancer and KCA. Then I organized a little fundraiser in my house, for my neighbors and friends, and then another one in the home of a friend. Another friend was doing crochet scarves, gloves and orange jewelry. We sold these things and I also had a KCA poster and the KCA book. We had wine and food. It didn't matter to us how many people came, because we figured that if only one person learned about kidney cancer and the KCA, they would spread that information multiple times to others.

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*"I'm a pretty intense person, and I needed some way of contributing, of giving something, since I couldn't be there with my dad in Colombia."*

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Earlier this year I was in a store, shopping, and got to talking with one of the staff people there and told them my story and they said, "Why don't you do a fundraiser here?" And so we organized a special Team Chema event in honor of his birthday on February 2 – "Fighting Back" day. I sold Team Chema orange wrist bands, and anyone who brought one into the store got a discount. And everyone wore orange.

My daughter Rebecca suggested a Kidney Cancer Day at her school and she helped get it organized. Everybody in the school wore orange and we raised another \$300. It was a very emotional day, but also rewarding. Everybody knew they were helping to raise awareness of kidney cancer.

My son Robert also organized a fundraiser at his high school and they raised \$250. Next year, his lacrosse team will have a part of their uniforms in orange, in recognition of kidney cancer awareness. And I'm continuing to organize events. I've started discussing with my local park district the idea of organizing a "Chema-thon" – a two-mile event around my favorite lake to celebrate my father's life, on the anniversary of his death. We'll walk around the lake and everyone will wear orange.

Getting my kids and husband involved has been great, and I would suggest that for kids who have a parent or grandparent who is sick.

**Interviewer:** What advice would you offer to other caregivers who are dealing with kidney cancer in their family or with a close friend?

**María Teresa:** I was long-distance caregiver, and that can be hard. All you can do is offer your love and support, and take one step at a time. My advice to others is: Worry about the worries you have today only – nothing else. Tomorrow will be another day. That's very hard to do,

but when you think only about today, it helps. It's easier that way.

If you are spiritual, pray a lot. We are Catholic. And every time my dad would start a new treatment, we would get on the speaker phone and pray with him. So even though he was far away, we were able to be together in that sense.

Never lose hope. That's important. We continued to hope for my father, even in his last days.

I'm very lucky. My husband Robert and my children are amazing. I couldn't have done it without them. They were, and they are, always there for me. Our infinite love as a family and the strong bonding with my parents and sisters, even over a great distance, is our most precious treasure. In April 2012, I participated in a poster session at the American Association for Cancer Research – representing the KCA and Team Chema – and in the poster that I designed I described it by writing, “Advocacy is a mission for life inspired in the infinite power of love.”

I've also been blessed with very good friends around the world and they have made a big difference in the way they supported me and my cause. They were always there for me in every way.

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*“KCA involvement gave me something that was very calming and positive. Working with them and doing fundraising gave me the chance to fight in my own way.”*

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**Interviewer:** Tell me more about your experience with the Kidney Cancer Association and why you think it's important for family members and other caregivers to connect with the kidney cancer community in addition to patients.

**María Teresa:** Well, the people there just changed my life. I will always be grateful for them. I'm a pretty intense person, and I needed some way of contributing, of giving something, since I couldn't be there with my dad in Colombia. My mother Johanna and sister María José did all the hard work down there. After my dad was diagnosed I was very upset, and KCA involvement gave me something that was very calming and positive. Working with them and doing fundraising gave me the chance to fight in my own way. My dad was fighting and this gave me a way to fight, too. He was very proud of my fundraising.

**Interviewer:** You have been very active in online forums hosted by KCA. Why would you suggest those for other caregivers?

**María Teresa:** For me, the KCA online chats are one of the best resources of all. Until you experience them, you can't understand how great they

are. They are just amazing. It's difficult to explain – you become so close, and yet you don't really know each other. There are people who are very active there and they are very supportive. I later met some of them at a KCA conference and it was great to meet them in person. Connecting with other people allows you to make something beautiful out of the ugliness of this disease. Chats are important because they can lead you in new directions. You will very quickly meet lots of people in the community – both patients and caregivers. And they will give you great advice. You won't find this kind of bond anywhere else.

**Interviewer:** How should people get started with KCA?

**María Teresa:** I always suggest visiting the website first, and the online forums, then read the KCA's book *We Have Kidney Cancer*. It's an amazing resource. You get all of the answers in one place. Everything that I needed was in that book. And then I would suggest visiting the KCA Facebook page. Sooner or later you will find someone you can connect with.

## Joyce

Joyce, 67, lives in Boston, Mass. She is one of the founders of the VHL Family Alliance, a not-for-profit organization that provides resources for families impacted by a hereditary disorder called von Hippel-Lindau (VHL) disease. VHL is one of the genetic factors that has been linked to an increased risk of developing kidney cancer.

Scientists have isolated the gene responsible for VHL, which involves the abnormal growth of blood vessels in some parts of the body that are particularly rich in blood vessels. Research into VHL has played an important role in the development of many of the drugs currently used to fight kidney cancer.

Joyce's experience with VHL – and kidney cancer – is extensive and personal. Her late husband died of complications related to VHL, including kidney cancer, in 1977 and her son was diagnosed with VHL and kidney cancer at the age of 15. As a caregiver, Joyce still faces many challenges: The emotional burden of losing a husband to kidney cancer and the continuing struggle of helping a son who has faced major health burdens of his own (VHL caused him to lose his sight and both kidneys; after three years of dialysis, he received a kidney transplant, donated by Joyce, and is doing well today).

In addition to providing background about VHL and the VHL Family Alliance in her interview, Joyce also provides perspectives on why it is important for patients and caregivers to learn as much as possible about their disease and their treatment options after a diagnosis. She offers an inspiring example of how cancer patients and those who love them can overcome even the most daunting of physical challenges.

### *Caregiver's advice from Joyce:*

- “Remember whose body this is. You can do research and provide perspective, and voice your opinion, but the owner of the body makes the final decision.”
  - “When caring for your child, remember that they will soon turn 18 or 21 and be in charge. Are you training your child to be his or her own best advocate? Are you prepared to turn over control?”
  - “It is hard for people ‘in the hot seat’ to absorb all the difficult information in a doctor's visit. You can play an invaluable role by listening, taking notes, and helping the patient review the information later, to absorb it in smaller doses over time.”
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**Interviewer:** Though you personally don't have kidney cancer, your connection with the von Hippel–Lindau (VHL) gene is unique and important to the kidney cancer community. And you have an inspiring story to share about being a caregiver for someone with kidney cancer. Tell us about that.

**Joyce:** I met my husband in college. And during our college years, he went blind. He had VHL. While we were earning our five academic degrees between the two of us, he was also dealing with his disease, during which he had three brain surgeries, three spinal surgeries, and eventually went blind as a junior in college. After graduating from the University of Michigan, we moved to Boston. He had had a very nasty spinal surgery there. And while he was in the hospital, they said, "Oh, we should check your kidneys." And we said, "What do you mean? There can't be an issue with the kidneys. We have enough problems with the eye and the brain and the spinal cord." They said, "No, we need to check his kidneys." And they found multiple kidney cancer tumors on both kidneys.

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*"I went over to my boss and I said, 'Something is going on with my son's health, and I need to go be a patient advocate for a while. And frankly, I don't know how long this is going to take.' And bless her heart, she said, 'Well, just do what you have to do, but stay in touch with me.'"*

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**Interviewer:** What was the prognosis?

**Joyce:** A young urologist recommended surgery on both kidneys and said, "We can cure him." And I said, "I have no doubt that you have the talent – that if this were anybody else walking off the street, you could cure him. But look at this man. I mean, he's been through all these brain tumors and spinal tumors. He's paraplegic. He's half deaf. He's blind. The word 'cure' has no meaning for us." They had a summit meeting at the hospital with the neurologist and the neurosurgeon. And they both said, "Leave the poor man alone." And the urologist again said, "We can cure him." My husband, who had been an aspiring marathon runner, signed up for the surgery, and within two years he was gone. It just deflated what was left of his quality of life. So that was my introduction to kidney cancer. I was royally mad at that urologist for a long time. It took me almost ten years to get over it. But anyway, it's now water under the bridge. I mean, my husband, with the extent of his disease, was headed that way anyway. And being who he was, he had to try.

**Interviewer:** When did you start to become so involved in researching and understanding VHL?

**Joyce:** My husband died in 1977. And nine years later, my son was diagnosed with VHL. He had wanted to get contact lenses so he went to a new ophthalmologist that we hadn't seen before because the ophthalmologist I had taken him to since the age of three was retiring. And the older ophthalmologist had told me three times, "Oh, he doesn't have VHL, mother. You can stop worrying now." He'd pat me on the head, you know. "I'd see it by now if he were going to have it." And he went in for these contact lenses and came home with a note that said we should see a retinal specialist. And you can imagine, the bottom fell out of my world.

So he went to see the retinal specialist, who diagnosed him with VHL. And the doctor said to me, "Well, we'll do a little bit of laser treatment, and then he'll be fine and we'll see him in three years." And I said, "Three years sounds like a long time to me. Shouldn't we be doing some other testing here? Because if there's any other non-invasive testing we can do, I would really like to know what ballgame we're playing."

And so he sent us to a pediatric neurologist, and my son passed all the tests for neurology. Two weeks later, the neurologist called me back, and he said, "You know, we also ought to check his kidneys." I said, "OK. Fine." And they said, "We'll do an ultrasound." My 15-year-old son, who didn't want his mother to go to all his doctor appointments, took a friend and went for the ultrasound. [Laughs] After he came back, I got a call at the office. And this resident, I still don't know his name, said to me, "We need you to come in. We need to talk about these pictures." And I said, "What did you find?" And he said, "Oh, the doctor will tell you when you meet with him." I said, "I don't think I'll live that long. What did you find?" And he said, "Now, I don't want you to worry about this. We've got this down to a science these days. We found tumors on both his kidneys. And we'll just take out both his kidneys and wait for a transplant." I said, "That may not sound like a problem to you, but that sounds like a problem to me."

**Interviewer:** That must have been very difficult.

**Joyce:** Yes. I got off the phone, and you can imagine the waterworks started at this point. So I went over to my boss and I said, "Something is going on with my son's health, and I need to go be a patient advocate for a while. And frankly, I don't know how long this is going to take." And bless her heart, she said, "Well, just do what you have to do, but stay in touch with me." So I did.

The doctors were saying, “We’ll take out both his kidneys.” And I said, “Can’t we let this poor guy get through puberty first? We don’t need to do these now. They didn’t even look at my husband’s kidneys until he was 32. And, yeah, he has tumors on both sides, but he didn’t have any metastasis. And why are we rushing to do this in his teens?”

**Interviewer:** How did the doctors react?

**Joyce:** They kept pressing me. But I wanted to learn more, so I went to a medical school library and I looked for articles about VHL. And I found an article about 16 families or something like that, that had been done by a doctor in Texas about ten years before. And I said, “Good, good. I’ll get follow-up information about their treatment. How did they do ten years later?” So I called him, and he was retired. I called the second author on the paper, who was a genetic counselor in Kansas. And she said, “Take out his kidneys? We almost never take out kidneys.” “Oh, thank you,” I said. So hope bloomed.

I also checked with my own oncologist. [*Note: Joyce was treated for breast cancer in 1979.*] I told her the story and I said, “Am I doing the wrong thing? The doctors are pressing me. Should I just say, yes, sir, doctor, and do it?” She said, “No, you’re doing exactly the right thing. And anytime you need your backbone strengthened, you just call me.” I had good coaches on my side. But the Boston medical community pushed me very hard.

So I kept looking. And at one point, I took my son’s scans to Germany and met with a leading researcher who had been working with kidney cancer and VHL for a long time. We sat in his living room, and he put the CT up to the light. And I was getting more and more encouragement to just postpone action. Eventually he did have surgery at ages 15 and 16 in Boston. And the agreement with the surgeon was that he would take out what he needed to, but no more than that. Somewhat fearfully, I agreed.

**Interviewer:** So he had a partial nephrectomy?

**Joyce:** Yes, partial on both sides. And then when he was 19, he had new growth, and they wanted to do another surgery. So they went in to do another partial, and the kidney died during the surgery. He lost that one kidney when he was 19. And at that point, I said, “You know what? We’re not going to do anything with that other kidney until we get pushed to the wall.” And that’s when I really started doing intensive research.

**Interviewer:** So you became an expert in VHL?

**Joyce:** Well, one of the things that occurred to me that day in the medical school library was this: I had these huge reading tables, completely covered with old journals and some of them were in German. And I sat back and I said to myself, “You know what? You’re doing what a doctor would have to do to find out about VHL. And the reality is, they don’t have the time to do this.” So that was the birth of the idea that we, as patients, need to take some responsibility for getting our doctors up to speed on this disease. You know, there are some 7,000 rare diseases. And if you go to a doctor with a rare disease, you’re lucky if he remembers one paragraph about it from medical school. That’s the reality. You can’t ask this doctor to have a catalog like that in his or her brain. Thank God now we have the Internet. But we didn’t have the Internet in 1986. So that struck a bell for me. I started writing what became *The VHL Handbook* in 1992, and we published the first edition in ’94.

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**Interviewer:** How is the handbook doing today?

**Joyce:** Well, it is now available in nine languages on the Internet. It has become the main source for patients and for doctors, where they can look up and find an easy “patient digestible” version of the impact of VHL on the various organ systems of the body. And when we were putting that together, we said, “Oh, my God, should we tell everybody all this? Because they’re going to get terrified!” And then we said to each other, “You know, if we don’t tell them, they can’t protect themselves.” As an example, VHL can impact the inner ear. And that information now becomes extremely valuable to patients who are having hearing problems. They now have some new information for the doctor. We can say, “Just to be safe, let’s rule out an endolymphatic sac tumor. And this is what it looks like. This is how you test for it.” Now the patient and his or her medical team are empowered to do that. We can help people understand what their symptoms might imply. And in the case of VHL and the inner ear, we save a lot of people’s hearing because of that.

**Interviewer:** Continue the narrative about your son. What happened after the surgery at 19?



**Joyce:**

He lost one kidney. And then meanwhile, he was having eye issues. And around the age of 20, somewhere in that general vicinity, he lost an eye. And then he needed surgery on the second kidney. His tumor was about 3.5 cm. And they said, “You know, we really need to get it out of there.” And we were really terrified. And so we went to the National Institutes of Health,

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*“It’s a genetic alteration, and of the people who have this alteration, almost all of them will have at least one symptom of VHL. According to a calculated genetic projection, it affects one person in 32,000. But the truth is we don’t know what the general percentage of who will develop it.”*

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which, at the time, was supposed to have the best surgeon in the United States. The surgeon came to us the night before and said, “We have probably an 85 percent chance of success here. I’ve done lots of these. And I really expect it to go fine.” They started into the surgery, and about half way through the estimated operating time that they had given me, suddenly there was silence. They had been giving me little updates from the operating room, but then there was nothing. Now I’m chewing my fingernails. And later, I found out that the kidney died during surgery. They tried to revive it, and they couldn’t. They even brought people over from the Naval Hospital across the road. All these kidney experts tried to wake it up, and it just wouldn’t wake up. So finally, they just had to give up on it, and they removed his only remaining kidney. He went on dialysis immediately.

The chief surgeon came to me and he said, “I want to show you something. If you were anybody else I wouldn’t do this. But I know who you are, and I think you need to see this.” So he took me down to the lab, and they had his kidney on the table. And they had it sliced in half. And he said, “I want you to see this.” And down deep inside the kidney there was another 3-centimeter tumor. “If that kidney had woken up,” he said, “we would have sewn him back up with another dangerous 3-centimeter tumor in place. So the good Lord was looking out for us.”

**Interviewer:**

A little bit of a silver lining, anyway.

**Joyce:**

Yes. So at least we don’t have to worry about kidney cancer anymore. That’s the good news. Now we have to worry about dialysis, which was another story. My son spent two and a half years on dialysis. And then he and I did a kidney transplant in 2001. I gave him a kidney. And that was a wonderful experience. It was just great. You don’t know until you go through that experience the difference that it makes. By the time of the

transplant his demeanor had toned way down. He was on low speed. And he'd always cracked jokes, and he was very quick witted. But now his jokes were very dark. Dialysis is a tough experience. You know, it's a part-time job. It's 20 hours a week, four and a half hours per session, three times a week, plus transportation time. So it's basically a part-time job. And three times, the guy in the next bed to him coded. So it's life on the edge. And it was a pretty depressing experience for all of us. Anyway, three days after the transplant, his demeanor and jokes changed. The color of his face changed. The way he walked changed. It was just amazing. So it was such a gift to watch that.

**Interviewer:** How is he today?

**Joyce:** He's doing well. It's been ten years, but there have been other complications. At 27, he lost his vision. So now he's blind. He has a kidney transplant. And he's had one brain surgery and two spinal surgeries. He has ten brain tumors, which are not growing at this point. They did do full-brain radiation for him to try to keep them from growing. But at some point, we know one of these guys is going to grow. And we need a new drug to attack these tumors.

**Interviewer:** I know that one of your activities is advocating for more research into VHL, the development of new drugs and facilitating support groups for VHL families. How did you get started with that?

**Joyce:** In all the time I was dealing with my husband's and son's health issues, I had never met another VHL family. In one of my conversations with that genetic counselor in Kansas, she said, "There ought to be an organization for this." She introduced me to another woman whose husband had VHL. And we got together for lunch and shared our experiences. At the end of an hour, the two of us sat back and said, "This conversation has been just incredible!" We both felt like we'd learned more in that one conversation than we had in the previous five years. So we said, "What if we could get all the families together and throw all our information in one pile? Maybe we could help the doctors fix this." So that was the beginning of the idea of the VHL Family Alliance.

**Interviewer:** What year was that?

**Joyce:** The organization was actually born at the beginning of 1993.

**Interviewer:** Tell me a little bit about the evolution of the Alliance and what happened after you started that in '93.

**Joyce:** First I looked up everybody who had published anything about VHL in the previous 20 years, and I wrote to all of them. [Laughs] That was a lot of faxing. Not so much e-mail in those days. Nobody had e-mail. But it was a lot of fax, a lot of telephone calls, a lot of paper mail. And just reaching out to whoever we could to try to find people, families, but also to find doctors who knew anything about VHL, and try to put that information together. We started this around sort of a virtual kitchen table. We were all over the United States.

**Interviewer:** Tell me a little bit about its growth since then. Where are you now? How many people are part of the Alliance?

**Joyce:** We're now in touch with almost 17,000 people in 108 countries. And most of it is in English, but whenever we develop a sister group in another country, we agree that we're going to exchange information and that they have license to localize it. The handbook now is in nine languages. And we have local support groups officially registered in the countries, in 18 countries, and there are plenty more that are very small. For example, there's a group in Croatia that's just two families. And there are two families in Hungary and so forth. There are several families in Greece, but that hasn't coalesced yet. We have groups in Chile, Brazil, Colombia, and South Africa. We're on six continents.

**Interviewer:** What kind of progress is being made now with VHL?

**Joyce:** A tremendous amount is being done at the molecular level. And in terms of diagnosis and treatment, there's better imaging now. As I mentioned earlier, we now know, A, that there is such a thing as an endolymphatic sac tumor, and, B, how to look for it. You do an MRI of the internal auditory canal. Would I have ever known that? No. It's a partnership with the doctors. They figure it out. Here's an example: Early on, we put in an 800 telephone number. We noticed we were getting an awful lot of calls from people with hearing loss. We looked at the percentage of calls with hearing loss and it was 30 to 35 percent – that's higher than the general population. So I called a prominent researcher in Germany. I said, "What do you know about hearing in VHL?" He said, "Oh, nothing." And I called another researcher in England, "No, no connection." My husband had been partially deaf, and they said that was because of all the medication he was on. And I called the NIH, and said, "What do you know about that?"

Next thing we know, there's a researcher at the NIH who is calling all their patients. We heard about it through the grapevine. He called and interviewed all their patients about hearing

loss. In 1996, NIH came out with a paper that talked about endolymphatic sac tumors in VHL. And they have pioneered better diagnosis and treatment since then. Doctors at NIH have figured it all out and figured out that there is such a tumor – a tiny little tumor – in that little sac where Meniere’s disease goes wrong. It has to do with your vestibular control and also with hearing. So you get this itty bitty tumor in there, and that’s enough sometimes to interrupt your vestibular canal. Then sometimes it will leak and cause an infection. It’s the inflammation and the infection that actually destroy the hearing nerve.

We take some credit for having helped alert them and make the connection. That’s the sort of partnership that we’ve tried to foster right from the very beginning. Since 1994, we’ve held annual patient-provider meetings, both for patients and doctors. We do ask the doctors to tone down the language so that patients can understand it. The patients who come are a relatively well-informed audience. They have their little handbook and their glossary. We want them to learn the language that the doctors are going to use, but we do ask the doctors not to get too very technical.

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*“We said, ‘What if we could get all the families together and throw all our information in one pile? Maybe we could help the doctors fix this.’ So that was the beginning of the idea of the VHL Family Alliance.”*

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**Interviewer:** I understand the Alliance has also done a lot of working in fostering the development of clinical care centers?

**Joyce:** Yes, that’s another major focus – putting together a program of clinical care centers. We create partnerships with major institutions around the country and the world. There are almost 40 now altogether. Two-thirds of them are in the U.S., and the other third are outside the U.S. And part of our thinking was that it takes a team to manage this team. People will call me and say, “Where can I find a specialist in VHL?” And to do that you need a team. If you’re looking for endolymphatic sac tumor, you’ve got to find an ENT who has done inner-ear surgery before, and this is a rare beast. So where do you find all these specialists? You’re probably going to find them at a major medical center, large teaching hospital, something like that, and especially if you want to do brain stem surgery or something, you know. You not only need a really good surgeon, you need a certain amount of technology, which probably is only going to be at a big medical center.

So we targeted first the medical centers where we knew they

already had some expertise in VHL. And then little by little, we've grown. And now hospitals are coming to us and saying, "Can we be a clinical care center?"

**Interviewer:** Is there a number that would give some sense of the percentage of people who will develop or will have VHL? Is there any kind of a figure?

**Joyce:** It's a genetic alteration, and of the people who have this alteration, almost all of them will have at least one symptom of VHL. According to a calculated genetic projection, it affects one person in 32,000. But the truth is we don't know what the general percentage of who will develop it. How many people in the United States are affected? At least 10,000, but possibly more. There has never been a population-wide screening. We do know that 20% of the people we are in touch with are the first ever in their family to have VHL. It's not all inherited; something is causing new mutations to occur today.

**Interviewer:** How is your VHL research advocacy going?

**Joyce:** Well, we know that we need a new drug. We need a drug badly that's going to attack VHL-related tumors. All of the new drugs for kidney cancer are based on VHL research, and they're doing great things for kidney cancer, but there are two reasons why they're not good for VHL: What you can take for a couple months to kill one tumor is different from what you would take as a preventative for the rest of your life. That's the first thing. And secondly, the new drugs don't do anything for brain and spinal tumors, the central nervous system (CNS) tumors. They don't control those tumors at all. So we still need something that's going to control the CNS tumors and the eye tumors. Having a tumor near the optic nerve, which is what my son had, is one of our most intractable problems. The tumors on the periphery of the eye, you can treat with laser – and they generally are well controlled with laser – but the ones that are near the optic nerve are different. All the currently available treatments will stop the tumor but they also damage the optic nerve and cause loss of vision. We've tried various of the new drugs and so far they don't work. So we're still desperately hunting the right drug to control VHL.

## *Julie and Art*

Julie is a 70-year-old retiree who worked in the aircraft industry in the Pacific Northwest. She met her husband, Art, 65, in 1983 through the organization Parents Without Partners. Both have children from previous marriages, and Julie has seven grandchildren and one great-grandchild.

Julie's father died of kidney cancer in 1974. She was diagnosed in 2000, with tumors on both kidneys. She has had three surgeries for her cancer, including two partial nephrectomies and one cryosurgery. She has not had a recurrence of cancer since 2003, but has a number of other health problems – including pancreatic cysts, that have complicated her recovery from kidney cancer.

As is the case with some of the couples interviewed for this book, Art's contribution, in addition to emotional support, has been to help Julie by researching treatment options, gathering information and helping to coordinate her care.

As a couple, Julie and Art are great examples of the national community that the Kidney Cancer Association has fostered through its development of local support groups and online forums. Several years after her diagnosis, they started a support group in the state of Washington that has been very active and successful. Additionally, they have traveled extensively to KCA meetings nationally.

They say that social support and learning from others is one of the best ways to speed along personal recovery after a kidney cancer diagnosis.

### *Survivor's advice from Julie:*

- “Buy a medical dictionary and make sure you understand everything the doctor is saying.”
- “If you get discouraged, turn your focus within – most of us can find the answers we need deep within ourselves.”
- “Get involved in organized kidney cancer groups. The more you share with others, the better you will feel.”

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**Interviewer:** Tell us the story of your diagnosis with kidney cancer.

**Julie:** On December 7, 2000, I was diagnosed. At first they thought

I had a kidney stone, but later, after a CT scan, they could see a tumor. And about three or four months after that, I had my first surgery, which was a hand-assisted, laparoscopic partial nephrectomy. And then a couple months later, I had cryosurgery. When the doctors found out that my father had died of kidney cancer they thought it might be familial. So I was sent for some testing. And they found another tumor growing. They couldn't tell if it was incidental or familial. So then I came back home, and I had yet a third surgery, an open, partial nephrectomy. I have been cancer-free ever since.

**Interviewer:** Let's go back to the diagnosis, when you first found out in 2000. Not a great time to hear something like that, right before the holidays.

**Julie:** Yes, December 7, Pearl Harbor Day – kind of an auspicious date. [Laughs]

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*“Lobbying was wonderful. I really enjoyed it. I got to see the legislative process and it was very interesting.”*

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**Interviewer:** Now it has double meaning for you.

**Julie:** Yes.

**Interviewer:** Can you describe your feelings when you got the diagnosis?

**Julie:** When they first suspected I had a tumor, I immediately thought that I was going to die because my father died of kidney cancer. Just 18 months after diagnosis he was gone. And I thought, “Oh, my God, this is going to happen to me.” I was just terrified, and I was absolutely depressed.

**Interviewer:** Art, tell me about your experience with the diagnosis.

**Art:** The very first time that she was diagnosed, the December 7 meeting, I was not with her when she went to the urologist. She told me afterwards she walked in there and there was a waiting room full of nothing but men waiting to hear about their prostates. It was a male nurse. And the doctor was kind of pompous. And he took a look at her scan and said, “Oh, you've got this tumor in the middle of your kidney. We can watch it. But what I really think we ought to do is take that whole kidney out.” Well, she thought that wasn't such a good thing and she wanted to go see a female urologist. So she did – but the female urologist was also very pompous. She had kind of an attitude of “we know it all.” So Julie went to see a second female urologist, who turned

out to be a cohort of the first one and wasn't about to contradict her. So at this point, very frustrated, she went back to the first doctor – the one she didn't like in the first place – and scheduled the surgery. She went in for the pre-surgical meeting and the doctor wasn't there. It turns out he had an emergency surgery, so he had to postpone the meeting where she was going to sign up to have her kidney removed. It's now weeks since her diagnosis and she was getting a little desperate. And this is where the story gets interesting. She made a call to an academic medical center in our region.

**Julie:** That's right. And I asked for a urologist. Instead, I was misdirected to the head of the urology department and the research department for kidney cancer. My call went right through to his desk phone. And he actually talked to me for an hour. He said, "Tell me about it." And so I did. I told him all the details. And he said, "Oh, well, I know this doctor. He's kind of a young doctor, but he's doing laparoscopic surgery. Maybe he could just take a portion laparoscopically, and you'd still have part of your kidney." So I went to him.

**Art:** When we met with him to sign up, the very first meeting, we were there for about 45 minutes. And he explained what he was going to do and how it all worked out. And then he said, after looking at the scans of her kidneys, "By the way, what's that on your other kidney?" He took us down the hall and showed us these slides up there on the screen. And on her left kidney was a two-centimeter tumor. So what happened is all the other doctors had fixated on the first tumor and missed the other one.

**Interviewer:** Nobody had really paid attention to it?

**Art:** We carried the slides to three different doctors.

**Interviewer:** Well, that must have felt better after your experience with the other physicians.

**Art:** The urology clinic is where she got the very best advice and treatment from a doctor that actually specialized in kidney cancer.

**Interviewer:** Let me ask you, Art, how you felt when she gave you the news.

**Art:** I was devastated. At that point, we had only been married for a year. We had been together for many years and finally got married in 1999. I felt guilty that I had not been with her at her December 7 meeting with the urologist. So since then I've been with her to every doctor's meeting. And that's something that we've learned – you really need to have somebody with you to take notes.



- Julie:** Yes.
- Art:** It's not just the convenience of having someone to take notes, it's the fact that when the patient gets the emotional impact of a diagnosis, they kind of shut down. Julie remembers selectively a lot of things.
- Julie:** Yes, and then the terminology sometimes we didn't understand. So we had to buy a medical dictionary to go back home and look up some of the things.
- Art:** We actually learned that at one of the Kidney Cancer Association conferences. One of the long-term survivors told us, "The first thing you need to do is buy a medical dictionary."
- Interviewer:** It sounds like you both were depressed about this. What did you do to cope?
- Art:** Well, I tend to be more analytical and scientific. I'm actually a finance manager at work – I add up numbers and track progress against plans, so I tend to try and concentrate on that sort of thing. And Julie probably tends more toward the emotional side. So that's one of the reasons why we thought the KCA survivors meeting would be a good idea – and then the various other KCA meetings we went to. We gained a lot every time we went to one of those because we heard survivor stories. We heard progress being made. Julie's mantra, right at the very beginning, when she was told that she had essentially only months to live and that she should go home and put her affairs in order, was, "I just need something to create hope."
- Julie:** The meetings provided that. And then later, in 2003, we went to Washington D.C. to lobby for kidney cancer research. They just needed a few people to talk a couple of minutes and tell their stories, and make a plea for kidney cancer research and for changes in Medicare to provide better coverage for kidney cancer patients. Lobbying was wonderful. I really enjoyed it. I got to see the legislative process and it was very interesting.
- Interviewer:** Julie, what kind of tactics or strategies have you used to deal with the physical effects of having cancer?
- Julie:** What I do is I go within myself. I've always talked to myself, given myself a pep talk. "You're going to do this. You're going to get over it. You're going to get through it." And that's how I've gone through life. You know, a lot of people focus on something "out there," but really the focus should be within. That's where your focus should be. If you go within yourself, you will find answers.

You don't really have an answer when you're talking to somebody. It's their opinion. That's the way I look at things.

**Interviewer:** How did your children react to all this? And how did they deal with it?

**Julie:** They were pretty upset. They were very, very concerned. Of course, they couldn't all be there. But my youngest son was, and he was very supportive. They all keep in touch. And then I have grandchildren. And my grandchildren also are very supportive. So I've had quite a bit of family support. And friends, lots of friends. I belong to lots of groups, organizations and book clubs, and what not.

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*“What I do is I go within myself. I've always talked to myself, given myself a pep talk. ‘You're going to do this. You're going to get over it. You're going to get through it.’ If you go within yourself, you will find answers.”*

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**Interviewer:** It sounds like the social part of your recovery is very important to you.

**Julie:** Yes.

**Interviewer:** And in fact, you have been very active in creating a kidney cancer survivors support group in Seattle, with the help of the Kidney Cancer Association, correct?

**Julie:** Yes. My involvement with the KCA began somewhere around 2001 or 2002, when my husband found out about a meeting in Seattle that they were hosting, and we went. It was a very small meeting. There were probably five or six people, but it was very informational, and we learned a lot. That helped. Then I met a couple of survivors who really influenced my life. They were long-time survivors, and they said to me, “Never give up; keep fighting the fight.” They were very encouraging. Then a little later on, we went to a convention KCA was hosting in Washington D.C. And we were so impressed with all the people we met. We were all kind of in a little community. We felt at home with these other people.

**Interviewer:** How did the support group get started?

**Julie:** Art and I have been to eight KCA meetings, all over the country, since that first one, and we enjoyed all of them. We met a lot of people and got a lot of information. Somewhere during that time, we were encouraged by my oncologist and others to start a support group, which we did, and we have been leading that for eight years. The KCA helped us set it up. And we're doing really well. We have about 20 people or more and we host them

five to seven times a year. We talk about everything. We have speakers, doctors and nutritionists, and sometimes we just have a roundtable. And it's been very uplifting for me. It really has helped me over the years to get through the periods of depression that occasionally pop up.

**Interviewer:** So you are the prime coordinators and organizers in Seattle for the group?

**Julie:** We are. I do most of the organizing. I stand at the door. I greet people. I give them hugs. Art stands up there because he can speak louder than me. So he does the narrating. [Laughs]

**Art:** One of the things we have made clear about our support group meetings for kidney cancer is that they are not pity parties. We're all there to help. Just bringing survivors together, that's probably the single biggest thing that comes from the meetings that we host. We bring information from the national meetings, and updates on the latest drugs, things like that, bring some information for them, but that's just the basic groundwork to get the meeting started. When they start sharing with each other, that's when the good stuff happens.

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*“One of the things we have made clear about our support group meetings for kidney cancer is that they are not pity parties. We're all there to help. Just bringing survivors together, that's probably the single biggest thing that comes from the meetings that we host.”*

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**Interviewer:** What are the things that you would suggest to caregivers and supporters of those who have been diagnosed with kidney cancer? As a patient, what are the most helpful things they can do?

**Julie:** One thing is avoid giving too much advice – “don't do this and don't do that” and so on. Be there for them, just give your phone number and call them occasionally. Make sure you're in the loop. Our support group works a lot by e-mail. And I do have phone numbers of people that I call occasionally. But we try not to interfere with their lives. We just want them to help themselves more than anything. Everybody's life is so different, and you can't really tell everybody, “Here's how you should do it.”

**Art:** There is a dichotomy. You find a lot of people that will say, “Oh, yeah, you've got cancer. Well, my friend had cancer, and she took mega-doses of vitamins and it all went away, and she was cured.” And the general, generic type stuff like that isn't very helpful. On the other hand, when we have our support group meetings, we

have people that say, “Oh, yeah, I was on this drug, and here’s what happened to me and how I dealt with the side effects.” That is very helpful. So we find that at the support group, when you’ve got somebody that has specific, relevant information, it can be very helpful.

**Julie:** And I always encourage hobbies. Some people knit and crochet, and some carve wood. Some are artists. One person had bought a sailboat, and he said, “You know, I’m going to be starting treatment, and I am not sure I should take the family up to the San Juan Islands.” [Note: *The San Juan Islands are located off the coast of Washington.*] And I said, “What are you waiting for? Go.” I encourage everybody to do whatever makes them happy. I’m not biased, and I say, “Do it now.” If you want to travel, travel.

**Art:** We’ve seen that several times – where people who are just starting into one or another phase of treatment are really looking for somebody to give them permission. They’re looking for somebody who is more of a veteran, and Julie, of course, is an 11-year veteran. We’re fortunate that we had two people in our group that were long-term survivors. One person is now at 21 years of survivorship. And another was, I think, at 16 or 17 years when he died. And he died not of the kidney cancer, but an aortic embolism. You develop a friendship with these folks.

**Julie:** We also visit them in the hospital if we know about it. And they think, oh, my gosh, this is wonderful.

**Interviewer:** What would you say to someone in another city thinking about starting a support group? What is the benefit to them in starting a group?

**Julie:** It would be healing. That would be healing for everybody, I think. Healing for them and healing for the other people.

**Art:** Every time we have one of these meetings, Julie comes away pumped up. And for me, my home life improves for a period of time. [Laughs]

**Julie:** I knew you were going to say that! [Laughs]

**Interviewer:** Let’s stay on that topic for a moment. Has dealing with cancer been difficult on your relationship?

**Art:** Yes. You have to realize, people that are going through kidney cancer have a lot of things to deal with. It’s not just the cancer. Julie’s had eight abdominal surgeries, not all of them cancer related, but some are. And that means that she’s got a lot of other problems. Her back is out of whack. Her organs are not doing

well. She has a lot of other health problems. So there are times when she gets kind of nasty to deal with. And that's going to be true of almost anybody that's going through some of this cancer and the kind of treatments that we have. For the caregivers, that can be a problem. In fact, we had a lady at our last meeting in September who told us that her husband, who was with her when we first met her for one of these meetings, had left her because he just couldn't deal with it. And apparently, that's not uncommon. So it's tough on caregivers, too. And I find that the caregivers take away a lot from coming to the meetings because they're meeting other caregivers. For the most part, most of them don't talk a lot. But most of them are there and very supportive of their patient. And hearing other people that are doing OK years down the road helps them say, "I can deal with this. I can get through it."

**Interviewer:** And if somebody wanted to start a support group, what's the first thing that they should do?

**Julie:** First, talk to KCA and find a local meeting room or somebody who can supply one free that you don't have to pay for. I asked doctors. That's what I would suggest. A lot of them have meeting rooms that are available. Hospitals are also a good reference.

**Art:** We know that KCA has limited resources. But they helped us with sending us some literature and some of their KCA wristbands and things like that. The wristbands are very popular. When people leave our meetings, almost every one of them takes a wristband.

**Interviewer:** How are the meetings structured?

**Art:** We furnish light refreshments. We schedule the meetings for two hours. Frequently, they run long because people are talking and enjoying it. And frequently, after the meeting officially ends, they'll stand around talking for another 45 minutes to each other, exchanging telephone numbers. Several of them have made fast friendships. So we've had people come from as far away as Hood River, Oregon, which is about 200 miles. Bellingham, quite frequently, that's about 150 miles. Port Angeles, that's about 120 miles and across the Puget Sound. So we've had them come from all over because we're the only support group in the Northwest. For someone just getting started, it probably would be helpful to have a doctor or a nurse come and be a speaker at the first meeting.

**Julie:** That's what we did.

**Art:** Yes. But we find the nurses sometimes are even better speakers

because they can talk about things like side effects and how you can deal with them – the practical aspects.

**Art:** We've tried all kinds of different things. We've had speakers from the drug companies before. Another thing we try to encourage people is to think about getting into medical trials. This is the time to think about helping find the next miracle drug that will be the cure. So it gets people involved in the trials.

**Interviewer:** What about navigating the health care system? Do you have any new perspective about the health care system as a result of your experience? You've had a lot of medical experiences now of various kinds.

**Julie:** It's really changing.

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*“You find a lot of people that will say, ‘Oh, yeah, you’ve got cancer. Well, my friend had cancer, and she took mega-doses of vitamins and it all went away, and she was cured.’ And the general, generic type stuff like that isn’t very helpful.”*

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**Art:** One of the things we picked up on early in the process was that you want to keep your own records, keep notes, get copies of all the lab tests, get copies of everything because you can't always count on the doctors to coordinate with each other accurately.

**Julie:** Yes. And make sure you understand what they're saying. That's why we got the medical dictionary – because they would start explaining things in “doctor-ese,” which we didn't always understand.

**Art:** Another thing that can help you navigate the health care system is the Kidney Cancer Association forum online. I'm on there daily. I don't participate in the online discussions all the time, but one of the things I like to try and get “newbies” involved with right away is the *We Have Kidney Cancer* book from KCA. When that came out, I thought that was just a fantastic resource because it puts information together in one place. It's a basic text. It's not an answer to all your questions about the health care system, but if you are new into the whole thing, there are some answers there that'll get you started, places where you need to go and find out more answers.

**Interviewer:** What about insurance and the cost of treatment?

**Art:** We found that you have to be little bit careful about the insurance aspects. When you have \$90,000 or \$100,000 in costs, it scares the dickens out of you. And in some cases, the insurance companies won't cover some things. You have to have a doctor

that will go to bat for you.

**Julie:** One thing to remember is that the drug companies have special programs to help people who have high expenses. But a lot of people don't know about that.

**Art:** Back to insurance: Julie is 70 years old, and I'm now 65. If I had retired from my company, the way things work, her primary coverage would have been Medicare. Medicare is good, but not great. My company's insurance is better. So I'm still working full time. Thankfully, I have good insurance.

**Interviewer:** You said that the doctors came in and said you had a limited time to live. How did they express that to you? Was it done in a compassionate way? Or was it more clinical?

**Julie:** The doctor was really compassionate. And he said, "Remember, this is according to statistics."

**Interviewer:** So he gave you some hope still?

**Julie:** Yes. He said, "I don't know what to tell you except keep doing scans, and see what happens. You could live five years."

**Interviewer:** What else have you done to keep your spirits up in the face of your diagnosis?

**Art:** Julie mentioned hobbies. We have lots of hobbies. Our big one of course is our flower garden. We have 750 dahlias that we enter in shows competitively, and we win a lot of prizes. Julie hasn't done much the last year or two because she's been hurting a lot. But she used to enter in several different categories, like dried dahlias and arrangements and baskets. She became expert at dried dahlias and won all the prizes, and eventually they ended up eliminating that category from the shows.

**Julie:** Hobbies are very helpful to people I think.

**Art:** We have worked closely with the KCA for years, and that has helped. I think that's been very empowering for Julie and certainly we've been able to make things better for some other people. I think it's been very helpful not only to get hope but to create hope for others. That's been very important.

**Julie:** That was my theme. [Laughs]

**Art:** Yeah, that was the theme. Because at first she thought there was no hope.

## Mac and Debbie

Mac and Debbie are residents of St. Thomas in the Virgin Islands. Mac, who was diagnosed with kidney cancer in 1997, is a 60-year-old attorney who has lived in the Virgin Islands since arriving there with his parents at the age of nine. He and Debbie have been married 35 years. They are proud parents of three children: Joseph, Elizabeth, and Elliott.

Mac and Debbie's story offers insights for those dealing with the practical aspects of finding doctors or treatment centers nearby. In their case, travel for medical treatment to and from the Virgin Islands has been a significant challenge. Mac was accepted into a clinical trial for one of the new drugs that was emerging in the early to mid 2000s – but the trial was located in Nashville, Tennessee, requiring twice-a-month travel back and forth between the islands and the U.S. mainland.

Mac's determination to experience as much living as possible in the face of his disease has helped him compress an extraordinary amount of activity into the last decade – including running the New York City marathon five times and leading an effort to raise funds for a modern cancer center in the Virgin Islands. As a part of that effort, he created a nine minute fundraising video that chronicles his fight against kidney cancer. With the help of the video, he eventually raised \$200,000 for the cancer center. The center opened in St. Thomas, VI, in 2005, and now offers the kinds of services Mac had to travel thousands of miles to receive when he was diagnosed with kidney cancer.

### *Survivor's advice from Mac:*

- “Establish goals and milestones that give you something to strive for.”
- “Live for today. Remember: Yesterday is history, tomorrow's a mystery, and today is a gift – make the most of it.”
- “Exercise and eat right. Physical fitness will sustain you and enable you to recover more quickly.”

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**Interviewer:** Tell me about your diagnosis.

**Mac:** I was a long-time blood donor to the American Red Cross. And when they developed a screening test for hepatitis C, I tested positive. They notified me and said, “Thanks but no thanks. We don't want your blood anymore.” So I went to my doctor who retested me, and confirmed that I had been exposed to the virus.



He told me there was no treatment for it and that I should just go and live my life. And I did. And then about five years later, I saw an article in *USA Today* about hepatitis C, and how it was now being called the silent killer. I took it to my family physician – this would have been around 1997. He ran blood tests and my liver enzymes were elevated so he told me I should see a specialist. There being none in my island home, I went to a hepatologist at a university in Miami who was doing a clinical trial of a treatment for hepatitis C. He said I qualified for the trial, but that I had to have biopsy-confirmed hepatitis C to participate. Because I lived far away, he squeezed me into the schedule for a laparoscopic biopsy the next day. Before the biopsy I had to have a sonogram of my abdomen, which he sent me for that day. The young technician was performing my sonogram when, all of a sudden she got very quiet, excused herself, and came back with a doctor. He said, “You have a 7.5-centimeter mass on your kidney.”

**Interviewer:** What was the recommended treatment?

**Mac:** I had a radical nephrectomy ten days thereafter. About three months later, after I recovered from the surgery, I went back to begin to participate in the clinical trial for hepatitis. The nephrologist sadly advised that now, “Since you’ve had cancer, you no longer qualify.” He was sympathetic to my plight and, after reflecting for a few moments said, “I can prescribe you interferon,” which is one of the two drugs they were using at the time. He said “The other drug is available from its Mexican production facility and I can supply you with their contact information.” Thus commenced a year of treatment with the two drugs, one from my pharmacist, the other shipped to me directly from the Mexican plant. After one year of the treatment, I tested negative for hepatitis C. I’ve since been repeatedly tested negative so I consider myself cured of the disease.

**Interviewer:** So that took care of one disease but left you to deal with another.

**Mac:** The doctors in Miami just said, “Well, there’s not really any treatment for the kidney cancer. After the radical nephrectomy, we’ll follow you.” So they did just that for five years. First, every three months, then every six months. In 2002, at five years of no recurrence, a milestone when most laymen consider the cancer cured, I was expecting them to tell me I was OK, but the doctor said, “You have two spots in your pancreas. Plus, they were actually there a year ago, but we just didn’t see them.”

“What should I do?” I asked. “I’ll refer you to a surgeon who will consider whether they can be removed,” he replied. That surgeon

scheduled me for surgery several weeks later, but I had a change of heart after consulting him, gathered all my test results and left that hospital, never to return. I went to a cancer center in New York City, where they tested me further and said, “It is not just two tumors in your pancreas. It’s three tumors in your pancreas, one in your kidney, and one in your lung. It is inoperable, and incurable.” I was told the average survival for someone with Stage IV kidney cancer was 18 months, and the chance of living five years only one in ten. At this point, at the recommendation of others, I sought care at another cancer center in Texas. I connected with the doctor who I was assigned to immediately, and I loved everything about the center: much more patient-oriented, cutting-edge, everything, just the best in every way. The doctors there concurred that the only available treatment then was high-dose immunotherapy with

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*“The young technician was performing my sonogram when, all of a sudden, she got very quiet, excused herself, and came back with a doctor. He said, “You have a 7.5-centimeter mass on your kidney.””*

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another agent that was being used in a few locations around the country. I chose one in New York City and underwent two cycles of the treatment. But after testing, they found that it had not worked. Moreover, my tumors had progressed. Meantime, my doctor had just come back from a seminar in Amsterdam, where he had heard about a clinical trial of two new drugs being tested. The clinical trial was in Nashville, Tennessee, and after being accepted, I began commuting from St. Thomas, Virgin Islands to Nashville every other week for two years.

**Interviewer:** That must have been terribly expensive.

**Mac:** I was able to do it through contributions of over a half a million frequent flyer miles donated to me by family, friends and colleagues, just people who were really helpful.

**Interviewer:** How did the trial go?

**Mac:** There were 57 of us in the study, and seven of us had the best response. I was one of the seven. All the tumors were reduced. But after two years, the treatment became too toxic for my remaining kidney so I had to drop out of the experimental trial. I remained stable for maybe two years longer. And then the tumors began to grow again.

**Interviewer:** Was more treatment recommended?

**Mac:** By this time, the first of the several drugs that were approved by

the FDA in the mid 2000s was on the market. So I went on one of them for nine months and I had good response from it. But then my doctor again took me off the drug treatment because it too was too toxic for my kidney. I was stable for about 18 months, and then the tumors started to grow again. Once more, a new drug appeared on the market and I was able to switch to it. I'm now on that drug and have been taking it for a little over two years. My hair is white, as that is one of the side effects of the treatment. After two years on this drug, new tumors have appeared in my kidney and on one of my ribs, so even though I'm still on the drug, we're anticipating that I will switch soon to another of the drugs that the FDA has recently approved.

**Interviewer:** You've been on a long journey with your cancer: 15 years and a lot of stops along the way, a lot of drugs, a lot of treatments, a lot of travel.

**Debbie:** Yes, partly because there wasn't anybody to treat it in the Virgin Islands.

**Interviewer:** With three children, Debbie, dealing with the disease must have been traumatic over the course of all this time. How did it feel to you when Mac was diagnosed and given such bleak odds?

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*"I kept thinking, 'Oh, it's just a tumor. It's not going to be cancer. I mean, he's perfectly healthy.' He didn't feel sick. And I was like Miss Positive."*

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**Debbie:** Well, I remember getting the call from him when they found the tumor in his kidney. When he called me, I was standing in the front hall and I sat on the step, and I said, "Really?" I kept thinking, "Oh, it's just a tumor. It's not going to be cancer. I mean, he's perfectly healthy." He didn't feel sick. And I was like Miss Positive. And I said, "So, doctor, what do you think about this?" And he said, "Well, I'm almost..."

**Mac:** "Ninety percent sure."

**Debbie:** "...ninety percent sure it's cancer." And I just lost it. I got very upset.

**Mac:** She just collapsed.

**Debbie:** Because I couldn't believe it. You feel like it's an out-of-body experience. Mac was so young – only 46. I remember thinking, "This can't be possible." I'm getting goose bumps talking about it. I don't know how some people feel being married as long as I have, but I remember saying to the doctor, "Listen. Let me tell you something. This is the love of my life, and you better take care of him."

**Interviewer:** Mac had to travel a lot for treatment. How did that impact you?

**Debbie:** It's wonderful to live in the Virgin Islands, but it's terrible when you're sick and you have to travel. You're away from your support group. We live in a small place. We're well-known. Our mothers, our families are there, our kids. Everyone knows you and looks after you, and all of a sudden you're in another place – on your own.

**Mac:** She slept in my hospital room.

**Debbie:** Slept in the hospital room in a chair.

**Mac:** She was my advocate.

**Debbie:** We were at the hospital for weeks. You feel very lonely. And he was in a lot of pain. But we thought that was going to be it because they said, "Oh, we got everything. It's going to be fine." Later that year, our son had to have open-heart surgery. Our 16-year-old. So it began to feel like it was going to be the year from hell, going through all of that. Then I remember distinctly again, five years later, when Mac went for his check-up, and he called me and said, "It's metastasized in my pancreas." And I just went, "Oh, my God, it's like a nightmare." So then began the next phase of all of this, which started with an insensitive doctor coming out and telling Mac "You'll be lucky if you have 18 months."

**Interviewer:** So there was no kind of bedside manner?

**Debbie:** No. No. "You'll be lucky. There's nothing we can do."

**Interviewer:** And what year was that?

**Debbie:** The summer of 2002.

**Interviewer:** It must have been difficult to remain positive.

**Debbie:** Yes, it's a challenge. You're trying to be "up" for the kids, and we didn't want Elliott, then only 11 years old, our youngest, to be afraid. So we were trying not to talk about it around him, and everyone wanted to know. And the one other thing I remember about that summer was I was just having a melt down, and I tried not to do that very often. And I don't do it very often. I am pretty positive, too. But he was gone and I was in St. Thomas. He was in New York with a friend looking in on him. And one afternoon, the kids were home and I went into our bathroom and sat in the shower fully clothed and just broke down. And then I could hear the kids going, "Mom. Mom." I'm not answering because I couldn't answer. And then having them finally find me in the shower and say, "Mom?" And I remember saying to them, "Look,

can I just break down one damn day? Can I just fall apart? Just let me fall apart for 15 minutes. Leave me alone, and then I'm going to be OK."

**Interviewer:** So how do you keep positive?

**Debbie:** I think I've always had this faith. At various times Mac has said things like, "Oh, I'll never see grandchildren. I won't see my daughter get married," which we did. There are all of these little milestones. So we have kept making these deals. "Let me see my son graduate from high school. "And we've made it through all those things so far.

**Mac:** The latest one is, "I want to hold my grandchildren."

**Debbie:** Now, he wants to have grandchildren and hold grandchildren. And he will say, "I may never have grandchildren." But I say "Of course, you will."

**Mac:** But it's still there, you know. I'm not cured.

**Debbie:** It's there, yeah, right. It's there.

**Mac:** Those tumors are all there, except for one I had removed laparoscopically later on.

**Interviewer:** It must have been difficult explaining all of this to your kids.

**Mac:** By the time my cancer had metastasized, we were very concerned about our 11-year-old, because he's a very sensitive kid. And he's sort of like an only child. He's seven years younger than his sister, and ten years younger than his brother. We finally decided that we needed to tell him because he was sensing it, you know. So we

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*"He thought a minute – he's a very thoughtful kid – and he said, 'Are you going to die?' And that was the one question I was totally not prepared for. So I said, 'I'm going to try really hard not to. I can't promise you that I won't, but I'm going to promise you that I'll go down fighting.'"*

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sat him down. You say, in 11-year-old terms, what's happening. I remember explaining what the situation was. And when I was done, I said, "Now do you have any questions?" It was one of those snapshot moments where you remember where everybody is sitting, you know. And he thought a minute – he's a very thoughtful kid – and he asked, "Are you going to die?" And that was the one question I was totally not prepared for. So I said, "I'm going to try really hard not to. I can't promise you that I won't, but I'm going to promise you that if I do, I'll go down fighting. And I feel like I'm going to survive."

**Interviewer:**

Do you have advice for other people with cancer who have kids?

**Mac:**

Well, when you have kids, or at least when I had kids, I discovered at a certain age that they don't listen to what you say. What they really model themselves on is what you do. They watch how you perform. They watch how you behave. And that's how they behave. You can say all you want, but if you behave differently than what you say they're not going to do what you say. When I got that metastatic diagnosis, my older son was with me, because I scheduled a check-up for me to coordinate with his cardiologist check-up. He'd been followed every six months since he was two because of this heart condition. This was the same day that they told us he was going to need open-heart surgery some time soon, instead of some day. It was like probably in the next six months or so. And so you have to be open to gifts coming to help you. You know, if you're all closed in you can't be open to things that you weren't expecting to help you. What I was open to was that he was watching me. And when you have a child with a condition that would later require the implantation of an artificial aorta – an artificial aortic valve that you can hear clicking – and he's thriving, it does something to you. I mean, he's thriving. He's a lawyer for an international law firm. He's about to marry a lovely girl. His life is wonderful. But he's had to deal with this stuff. And I was thinking, "He's going to watch how I go through this." So even when he wasn't in the room or in the same city or anything else, that gave me a subliminal message that this child, who I adore and who is going to have to go through difficult problems, is modeling me, is helping me stay strong. One of the hardest things about kidney cancer is the pain you inflict on your loved ones, and watching them have to watch you go through it. And I mean, it's irrational. If you explain it to somebody, they say, "Well, you shouldn't feel that way." But you do. You just do, you know.

**Interviewer:**

What are some of your coping mechanisms – things that help you deal with both the physical and emotional aspects of cancer?

**Debbie:**

Mac's always run marathons – staying in shape helps. He's always working out at the gym. He's missed very little work. I've told him I don't know if I could do some of the things he does. Even when he's sick, with headaches, bad headaches or feeling sick to his stomach or feeling weak, still managing to get up and go on and live his life. And I realize that that is better for him when he does that because sometimes, lately, he hasn't felt as good. On Saturdays, he'll be in bed a long time with headaches. And I'll go out and come back and go, "Are you still in bed?" And I'll say "Just get up." Once he gets up and goes and futzes with his orchids or

does a project, you can see he starts to feel better. So, in terms of coping with cancer, I think it's about action and living. We have a little bear that someone gave us that says "Cancer Sucks." And the person who gave it to us said "You're not dying with cancer. You're living with cancer."

**Mac:** Yes, living with it.

**Debbie:** And I feel that it's been very much a part, a center of our lives for 15 years. But we're living with it. It's like having some kind of a chronic disease. It's scary. It's very scary because you wonder what's going to happen next. But you just have to live your life. And Mac lives for today – that's his motto.

**Mac:** When I post on Facebook, 90 percent of the time, I post something beautiful I've seen or something inspirational someone said to me. And my tag line is always, "And to think I might have missed this." Because that's sort of the way I live, you know.

**Debbie:** He's never given up.

**Interviewer:** What kind of advice, in general, would you give someone who has just been diagnosed with kidney cancer?

**Mac:** I would say, "Educate yourself." Use available resources to establish a fundamental understanding of the implications of your disease, the treatment options available and the best medical facilities in your area or otherwise, where you can be treated. Be prepared to get a second opinion if you are dissatisfied with the advice you are getting. And become expert in what your insurance will cover – which facilities, co-payments, and so on.

Equally important is staying in the moment. Take it one day at a time. Regretting the past or worrying about the future is futile. Make a decision to focus on doing the next right thing. Force yourself not to worry about the next 2, 10, 50, or 100 "right things." Above all, choose to be positive, because it is a choice. Becoming depressed or overwhelmed with self-pity is your worst enemy because it paralyzes you from gearing up to fight your disease, and make no mistake, the fight is a marathon and not a sprint. No one has a bigger stake in success than you do, so you must reach deep down within and summon up a courage you perhaps may not have known you have. Now is the time to demonstrate it.

**Interviewer:** Do you have any specific advice regarding subjects like sleep, diet, and work-life balance?

**Mac:** Sleep is essential. Do what you must to assure the necessary hours

of it, because deprivation of sleep diminishes your overall ability to address the challenges that life presents on a daily basis. I have continued to work full time in a fairly demanding professional position throughout my 15 years of battling this disease – with relatively brief exceptions only when I was physically incapable of doing so. It maintains a sense of normalcy, precludes too much introspection and self-sympathy, and provides the economic foundation and health insurance for seeking and obtaining the best doctors and treatments available.

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*“Make a decision to focus on doing the next right thing. Force yourself not to worry about the next 2, 10, 50, or 100 ‘right things.’ Above all, choose to be positive, because it is a choice.”*

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**Interviewer:** What would you say to the family and friends of someone who has kidney cancer? What is the best way they can support their loved one?

**Mac:** Strive to maintain a sense of “life going on,” as there is a tendency for the patient to think that nothing will ever be the same. Continue to celebrate holidays, birthdays, occasions, and the like. Try to maintain normal routines as much as the situation allows, and when it doesn’t try to reestablish them as soon as possible. Another issue with me at least, is that I never liked being, or being treated like, an invalid. Even when the patient is sick, do whatever you can to encourage them to recover and reclaim their sense of normalcy. Sometimes it requires gentle encouragement, sometimes it requires tough love.

**Interviewer:** Have you changed or grown in any way as a result of this experience? If so, how?

**Mac:** I choose to view my cancer as a gift. Nothing else could have enabled me to appreciate as I do every additional day living my life, loving with whom I live, loving where I live, loving my daily interactions with others, loving the fragrance of a flower, the feel of a cool breeze on sweaty skin, loving sunrises, sunsets, and on and on. I think those of us fighting a deadly disease that is relentless in seeking to extinguish our flame of life may be able to appreciate the gifts of life more in a single day than most “normal” people do in a lifetime.



## **EMPOWERING STEPS FOR PATIENTS**

*Additional tips and advice from the Kidney Cancer Association*

### **Communicate Professionally With Your Doctor**

Establishing good communications with your doctor is essential to a good outcome, and good communication is a shared responsibility. Ask your doctor for a “point person” in the office for your questions, and determine the preferred method – e-mail, fax, phone, etc.

If you use a phone to communicate with your doctor or nurse and deliver a message, be proactive and call back if you have not received a response in a reasonable amount of time. Phone messages sometimes do not go through or the voice mail may not be clear and your message may not be heard. Do not assume that your message is being ignored. Call back to double check that your message got through. If you leave a message on a voice mail, include as much identifying information as you can.

It’s always a good idea to have questions written down before your visit. Be honest and clear with your questions, and be straightforward in all of your communications with your doctor. You have the right to expect honest, clear responses. If possible, take an advocate with you to help with note taking and for support.

## Frank and Patricia

Frank is a 73-year old plumbing contractor who has run a family-owned business in the Midwest for 30 years. He and his wife Patricia have three sons and a daughter, who all live nearby. Their sons are all employed in the family business.

Like many kidney cancer patients, Frank was in good health and had no pain or discomfort before his diagnosis in 1998 – it came as a complete surprise. Within three weeks of a partial nephrectomy of his right kidney, Frank had a heart attack and underwent quadruple bypass surgery. He then began a long series of treatments using various drugs that continued for more than a decade.

He had surgery to remove a tumor in his shoulder in 2003, a stroke in 2005, and radiation therapy to treat additional tumors in 2011.

Despite his many health complications, Frank continues to work every day in his plumbing business and he and Patricia remain optimistic – part of which they attribute to having a closely knit family and part to their shared faith.

### *Survivor's advice from Frank:*

- “Spend time with your family. They can make all the difference in the world.”
- “Realize that you have options with kidney cancer. There are reasons to be optimistic. You may have more time to decide what to do and how to treat it.”
- “Work is good therapy – it can help take your mind off the cancer.”

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**Interviewer:** Let's start out by going back to your diagnosis. Tell me the story of when you were diagnosed and kind of how it all unfolded.

**Frank:** I was preparing to go to a dentist visit. I had an appointment. I had to urinate before I went there and I had blood in my urine. It was the first time I knew something was wrong, and it was very shocking. I had no pain, no pre-warning at all. And that was the first contact with anything being wrong.

**Interviewer:** When did this happen?

**Frank:** That was in February, 1998. I went to my own personal physician, and he made arrangements with a kidney specialist. And at that point they did whatever tests were necessary to determine that

I had a tumor in my right kidney. And then three weeks after I started this, after the first appearance of a problem, I had my right kidney removed, along with my right adrenal gland. And then the next thing is, in post-op, they found a tumor in my left adrenal gland. And my doctor said, "I'd like to get you to follow up for another opinion. Let's see where we're going with this." And then I went there and I'm at the appointment with the other doctor, and he said, "Well, yeah, we can take out your adrenal gland." When I went back to my own doctor, he said, "I don't know if we should do this right away. Let's be a little patient. Let's see if we have time. I don't think it's that critical right now to have your left adrenal gland operated on immediately." So we waited.

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*"That's the value of being with a clinical program like the academic medical center I've been treated at. With the research going on today, it seems like they always have something else to suggest to you – something else they can try if this one doesn't work."*

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**Interviewer:** How long did you wait?

**Frank:** Well, in the meantime, I had a heart attack – about three weeks after my kidney removal. And they did a quadruple bypass. And after they did that, these questions surfaced about the kidney again. In my conversation, my own personal doctor – who was a cardiologist by trade before he became a general practitioner – said: "Before we go ahead and schedule anymore work for cancer, let's give it some time. It's too close – two major surgeries are too close." He thought another opinion would be a good idea, so I went to one of the major national clinics that specialize in kidney cancer. They agreed to take my case and I went there on and off for about a year and a half, making visits on a regular basis. On the last visit I had there, they found another tumor that was in my left kidney. And they discussed a couple of methods of what they could do. One of which was cryoablation. But it turned out that because of the location of the tumor, cryoablation was not an option after all. So they suggested putting me on a drug therapy program. So I went on drug therapy in a program at a local academic medical center. Since then I have been on several therapies.

**Interviewer:** How many drug therapies?

**Frank:** I was on the first drug for a couple of years, and some tumors showed up again. And then they put me on another drug, which I was on for another year or two. And then I had a stroke. And

when I had the stroke, they looked at me and they said, “We don’t know if we want to keep you on this program because we think it may have contributed to your stroke. So we’re going to let you slide for a while.” So I took about a year hiatus, I think, seeing if my own immune system would kick in. It didn’t. And then they put me on another drug. And I was on that for a while. And probably two years after that, I had some other tumors show up again in my collarbone and in my neck. And at that point in time, they said, “Well, we better do something else “Let’s take it easy for a while.” And then for about a year, I was just on a monitor program. And then I had another tumor show up in my collarbone. They checked that out and determined it was a cancerous tumor. So they started me on yet another drug at that point, in the fall of 2009. I was on that drug for about two months, and then more tumors showed up. And at that point they said, “Let’s try and use radiation on these.” So I had ten sessions of radiation. And after that we did another CT scan. And after that CT scan, the doctor said the latest drug had not done what they had hoped it would do. So they have now started me on another drug. I’m on that drug now, and I have been for several months. And I’ll be getting monitored. Probably in another few weeks, they’ll do another CT scan and see where I’m at.

**Interviewer:** And how is it going with the new drug?

**Frank:** It’s hard to tell. I think I have some of the symptoms that they say could happen, like a loss of appetite. It has raised my blood pressure. Those are two of the side effects and I am experiencing those.

**Interviewer:** Compared to some of the other treatments you’ve tried, how is this one in terms of your being able to tolerate it?

**Frank:** You know, I’ve been very fortunate. All the drugs I’ve been on have been tolerable to me. The only one that I wasn’t really tolerable of was the very first one. I got sick on that once in a while. But all the other ones have been OK. The trouble is they haven’t completely worked.

**Interviewer:** It sounds like there’s always been something else to try.

**Frank:** Well, that’s the value of being with a clinical program like the academic medical center I’ve been treated at. With the research going on today, it seems like they always have something else to suggest to you – something else they can try if this one doesn’t work.

**Interviewer:** Let me go back to the diagnosis, when it first happened. Describe how you felt when you were diagnosed.

**Frank:** I was scared as hell. I think that anybody that goes through this can quickly think, “This is the end.” Anytime you hear “cancer,” especially in the society that we grew up in. We were very fortunate in our family. I am the first one to have cancer that I know of. It just scared the hell out of me. And then not knowing where you’re going to go to get help – that was tough. You need to have some consultation with people. And luckily, I had some pretty good people at the national clinic and at the local medical center – program specialists who always gave me hope. “There’s something we can do,” they would say. “Come on, don’t give up. Keep going.” And I guess I had to make that part of my outlook. Otherwise, I probably could’ve given up.

**Interviewer:** How long did it take you to get back on your feet emotionally after that first diagnosis? It sounds like you were scared and concerned about it.

**Frank:** To tell you the truth, I’m not sure I’ve ever gotten rid of that. I haven’t reached a milestone where I’ve been cancer-free. So I think I always have it in the back of mind.

**Interviewer:** That’s a pretty long time. Fourteen years now for you.

**Frank:** Yeah, 14 years now. And I mean, it’s never totally out of my mind.

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*“Quite frankly, I was 60 years old, when I was diagnosed. It was just about the time that the older guys started developing other habits or interests. I never developed a fishing habit or a golfing habit. All I did was work. So if I hadn’t worked, I would have had nothing.”*

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**Interviewer:** You had a little different circumstance than some people because some people have had a situation where the tumors went away, or they did surgery and they were removed, and then came back. So at least they had that time where everything seems OK. But in your case, the tumors have always been there.

**Frank:** Yeah. There’s always been something. Never been free of it.

**Interviewer:** Patricia, how did you feel at the diagnosis? What was your emotional feeling?

**Patricia:** Oh, for three days I did nothing but cry. I mean, I couldn’t even talk to the kids or anything. It was shocking. I thought, “No – we’re too young.” But then I had time to think a lot afterwards:

“OK. You’ve got it pretty good.” So I think that’s when I finally started pulling myself together again and saying, “Come on, we’re going to work through this.”

**Frank:** She’s been a trooper. She’s really been there.

**Patricia:** Like he was saying, there was one thing after another, and I think you feel so fortunate because there are other types of cancer that he could be dealing with.

**Frank:** I guess if I were going to say if you’re going to get kidney cancer or another kind of cancer, at least kidney cancer seems to give you a longer period of time to decide what to do. Whether you can completely cure it or not, I guess that remains to be seen.

**Interviewer:** But it gives you more options.

**Frank:** Yeah.

**Interviewer:** And how did this affect your children?

**Patricia:** Well, I know my daughter took it the same way I did. The boys, I think, felt it, but didn’t show their emotions like my daughter did.

**Frank:** It was probably less of an impact on them because I’m a contractor, a plumbing contractor. And they all work for me. So we’ve had a day-by-day relationship. It’s just one more difficulty, like a broken pipe or something. “Dad got cancer – we’ll pick up the pieces and move on.” They adapted to it fairly well.

**Interviewer:** Are you still working?

**Frank:** Yes.

**Interviewer:** So do you think that that has helped you in terms of kind of dealing with your diagnosis?

**Frank:** Absolutely. Because I never developed other hobbies or interests outside of work. Quite frankly, I was 60 years old, when I was diagnosed. It was just about the time that the older guys started developing other habits or interests. I never developed a fishing habit or a golfing habit. All I did was work. So if I hadn’t worked, I would have had nothing.

**Interviewer:** And so you found that the work took your mind off of it, basically?

**Frank:** Yes. Probably for a couple of years now. We’re in the bottom of a deep recession right now. We’re feeling it just as much as anybody in the construction industry. Union contractors are having a much more difficult time in trying to survive. I have on my shoulders

the responsibility for my kids and ten grandkids. We've got to keep the business going. So it becomes another struggle, trying to keep the doors open on a company in a very difficult time.

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*“Oh, for three days I did nothing but cry. I mean, I couldn't even talk to the kids or anything. It was shocking. I thought, 'No – we're too young.' But then I had time to think a lot afterwards: 'OK. You've got it pretty good.'”*

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**Interviewer:** A lot of challenges right now.

**Frank:** Yeah.

**Interviewer:** What are some of the things that help you get through all that? What do you find has been comforting?

**Frank:** Good family. We have a lot of personal relationships, both with my immediate family and our brothers, sisters and sisters-in-law and brothers-in-law. We do a lot of things together. I mean, we're a pretty close-knit family. And I think that helps because nobody wants to hear your problems. [Laughs] So you think you've got problems ... quite frankly, there are other people in the family that have had problems, too. I can't really tell them about mine and feel good about it.

**Interviewer:** So there some other health issues in the family?

**Frank:** Probably within the last four years, we lost four very close members.

**Interviewer:** So family is a big part of it. What other kinds of practical things keep your spirits up? Is there anything else? Any tips or things that have helped you over this time?

**Frank:** One thing is that Patricia won't let me feel sorry for myself. I think that has helped.

**Patricia:** And yet I know he's got to let his feelings out and everything. And I'll listen.

**Frank:** Probably more than the health issues, my business issues bother me more than anything because that's the immediate thing that affects me every day. The health issue has been going on for 14 years, and I guess I have a little more tolerance to work with that.

**Interviewer:** What about your connection with friends through your illness? What have they done that has been helpful?

**Patricia:** I think keeping in touch and then calling him – that has been a big help.

**Frank:** Yes. To tell you the truth, though, I didn't think I needed any help. I didn't ask my friends for any. I tried to fight it all through myself, between my wife and myself and our immediate family.

**Patricia:** They were always concerned and asking about him all the time.

**Frank:** They're concerned. If anything, they'd give me prayers. I get a lot of prayers.

**Patricia:** Well, I think another important thing is to have laughter. You know, times when you can really laugh out loud. And I think that helps. You've got to cry. And I really think you've got to laugh. It must do something to your brain. You have to stop and say, "Come on. Are you going to go down? Or are you going to enjoy what you've got left?" So a lot of talking to yourself, I think, can help.

**Interviewer:** Really?

**Patricia:** Yes. A lot.

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*"Well, I think another important thing is to have laughter. You know, times when you can really laugh out loud. And I think that helps."*

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**Interviewer:** Do you mean literally? Or just kind of in your mind, kind of sorting things out? What do you mean by that?

**Patricia:** I think in my mind, and just trying to say, "It's going to be all right. It's going to be all right." Follow through with that because sometimes you get that depressed feeling. And, boy, you really have to talk yourself out of it.

**Interviewer:** How do you relax, Frank?

**Frank:** My brother and I are pretty close. My brother has been very successful. And we've taken a lot of trips. We went to Ireland and to Mexico and to the Bahamas, and a lot of different places around the country. We've taken those trips with him. Neither one of us are very enchanted with traveling anymore, with the rigmarole that you go through. So recently, we haven't been doing much. But up until two or three years ago we traveled.

**Interviewer:** What about your diet and lifestyle in general? Has anything changed as a result of your cancer?

**Frank:** Yes. I don't drink much beer anymore. I cut back on martinis. At one point in time, I was a big beer drinker.



- Interviewer:** And is it because you don't tolerate it? Or because you just feel better?
- Frank:** Well, it's because I think it's counterproductive to all the medicine I'm taking. Alcohol doesn't mix with a lot of the other stuff so I put myself on a self-restricted diet. Every once in a while, I do still like to have a beer. You know, when you're Irish, there's no such thing as one. You've got to have that second, third, fourth, fifth and sixth, or you're not living up to your heritage. [Laughs]
- Interviewer:** Is there a silver lining in any of this? And if there is, what is it? Is there something positive that you've been able to gain from it?
- Frank:** I think the silver lining is that at least if you have good family and good support, it helps you get through. In my particular case, I have not had any evidence to the fact that I'll be cured. So I can't say the silver lining is I know I'm going to be cancer-free some day, but the support that I receive from people has been wonderful. And still, I have the ability, thank God, to use most of my parts. I have neuropathy right now, which starts to affect my balance and my walking a little bit. So I am not as physically active as I should be. I guess just the fact that we have good, close family, who are always there – that's the most important thing. We do a lot of things together. I mean, I can look at my sons at work all day long. We can fight like hell, which we do on occasion. And when we go home at night, we're able to have a party and everything is just fine. We adapt well.
- Interviewer:** How about for you, Patricia? Any new way of thinking that has come out of this experience that is good? Or anything that has changed you for the better in dealing with it?
- Patricia:** I think every day has been such a different day, but I think overall, faith has been important.
- Frank:** We have a lot of faith. I can't say we're really spiritual, but we do practice our faith every week.

## *Mike and Yvonne*

Mike and his wife, Yvonne, are residents of Western North Carolina who have been dealing with kidney cancer for a long time. Like many patients, Mike's kidney cancer was discovered when doctors looked for something else – in this case, kidney stones. He remembers vividly the diagnosis, which occurred just a week before Thanksgiving, 1997. Yvonne (who was interviewed separately) offers the viewpoint of a caregiver which is often quite different from that of a survivor.

After a nephrectomy, Mike returned to an almost normal life, but three years later, his cancer had metastasized to distant lymph nodes. He underwent immunotherapy, had lymph node surgery in 2005, and in 2007 began a regimen on one of the new drugs for kidney cancer. At the time of his interview with the Kidney Cancer Association he had been taking the drug for more than four years and his lymph nodes had been stabilized and some had begun shrinking or returning to normal size.

Mike retired from the pest control industry in 1998, and tried his hand at several other professions. In 2006 he retired completely and now devotes a great deal of his spare time working as a volunteer for the Kidney Cancer Association and other cancer related organizations; offering help, information, and encouragement to survivors and caregivers of kidney and other cancers.

Mike and Yvonne have experienced the emotional roller coaster of kidney cancer but he says that over the last decade he has been guided by a simple philosophy gleaned from Dr. Norman Cousins' writings: "Don't deny the diagnosis; but try to defy the outcome."

"I resolved to figure out the limitations that I had as a result of the cancer, and then I was determined to live as normal a life as possible," he says.

Mike is a very active participant in the KCA's online patient forums and has connected closely with other kidney cancer survivors throughout the United States. He offers an excellent example of how volunteering and connecting with others who have faced the same challenges can be a positive outgrowth of a kidney cancer diagnosis.

"I have the opportunity to share some of my fears and failures as well as my successes with others," he says. "No matter what the diagnosis, there are those who have overcome the odds."

Since his interview with the KCA, Mike had a scan that indicated additional progression of disease. He enrolled to participate in a clinical trial, and stopped taking the targeted-therapy drug he had been taking after 39 rounds. A final CT scan prior to the start of the clinical trial showed that the enlarged lymph nodes had gotten smaller;

and participation in the trial did not take place. Currently Mike is not on any cancer medication, and is scheduled to have another CT scan soon.

At that time, depending on the scan results, Mike, Yvonne, and his medical team will decide on which of several options to pursue next.

***Survivor's advice from Mike:***

- “A diagnosis is not automatically a death sentence; nor is a statistic or a doctor’s opinion that a person has a specific amount of time to live necessarily correct.”
- “Don’t be afraid to ask questions or to seek support in areas where it is needed. Counselors, massage therapists, dieticians, exercise coaches and other resources can greatly increase the quality of life and ability to survive.”
- “Despite all the advice and inspiration in the world, people still die from kidney cancer; if this is the apparent situation someone is facing, I pray that they will be able to make the most of the time remaining.”

***Caregiver's advice from Yvonne:***

- “Allow the survivor to do as much on their own as they safely can; let them regain as much independence and freedom as possible.”
- “Be supportive of the survivor during doctor visits helping to take notes and also making sure that information is given to medical team about side effects or unusual situations, which may affect the course and quality of treatment.”
- “Realize that your perspective and understanding of events in this journey will vary greatly from that of the survivor. Keep a line of communication open to be able to share important things.”
- “Remember to take care of yourself as well; a martyred caregiver can do little to assist others.”

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**Interviewer:** Tell me about the course of your disease, the diagnosis and treatment, and how your story unfolded.

**Mike:** My story begins in November 1997. I woke up in the middle of the night in extreme pain and went to the hospital. I was told I had kidney stones. And they gave me the normal strainer, an x-ray,

some pain medicine, and sent me back home. A day and a half later, they called me and said, “We found something. We think you need to come back.” We received a diagnosis the week before Thanksgiving. The emergency room was crowded. It was late on a Friday afternoon: it was raining – just terrible weather, a doctor came out and knelt down beside us and said, “I’m afraid you’ve got a large tumor on your kidney. And we don’t know how bad it is, but it’s bad.” In the next few days, we ran all sorts of tests, and saw a lot of people. We finished up on Wednesday, and my surgeons said, “Go home and enjoy Thanksgiving. Be here Friday morning ready for surgery.” We didn’t know if I’d make it or not; that’s how bad it was. I had surgery with a complete removal of the kidney. The tumor was the size of a dinner plate, completely enveloping my right kidney. In addition to the huge, ugly tumor, my surgeons removed my gallbladder, which contained inflamed gallstones; the initial source of my pain.

We did well for three years after the kidney was removed. But I have had confirmed active metastatic disease since September, 2000. I was referred to a specialist, and I had immunotherapy. Basically, since 2000, it’s been a journey of learning, applying knowledge and trying to stay ahead of the game.

**Interviewer:** Have any of the new drugs for kidney cancer been part of your treatment regimen?

**Mike:** Yes – we’ve been on one of the new drugs for over four years.

**Interviewer:** And how has that gone for you?

**Mike:** It’s going well. I haven’t had any significant progression. We’ve had some fluctuations. If we need to make a change, we’ll do it. If not, we’ll stay the course. My medical team has been very proactive in addressing side effects of the medication I am on, and we have resisted the tendency to switch from one medication to another when a scan shows progression; we have found that the next scan may show a decrease in size.

**Interviewer:** In the early stages of your disease, did you work with a specialist?

**Mike:** No. The reason we didn’t is that there weren’t that many specialists in the Carolinas. We tried to find information about kidney cancer. My wife and I looked. We couldn’t find anything except from our initial surgeon, who was fairly knowledgeable. He said it was something we needed to keep a close eye on the rest of our lives. And he made a promise that if we had metastatic disease in the future, he would find us a specialist, and that’s what he did.

**Interviewer:** How did you determine that your cancer had metastasized?

**Mike:** I felt a lump in my neck in September 2000; I went back to my medical team, and they removed the swollen lymph node, as opposed to doing a biopsy, because it was just as simple to remove it. The pathology report indicated it was “consistent with renal cell carcinoma.” After having been referred to a specialist as my doctor promised, a scan in late spring 2001 indicated we also had involvement in some abdominal lymph nodes.

**Interviewer:** You were saying that you couldn’t get information about kidney cancer.

**Mike:** Right.

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*“The Internet was in its infancy back then; there was very little information available. We called the American Cancer Society, and they sent us a booklet. There weren’t a lot of details as far as clinical trials, or how to contact a specialist or anything like that.”*

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**Interviewer:** How did you go about trying to find it?

**Mike:** The Internet was in its infancy back then; there was very little information available. We called the American Cancer Society, and they sent us a booklet. There weren’t a lot of details as far as clinical trials, or how to contact a specialist or anything like that. We had a lot of confidence in my initial urologist; he was a good surgeon, had set up a reasonable follow-up protocol and explained a lot of things to us.

**Interviewer:** The lack of information must have been frustrating for you, I would think.

**Mike:** Oh, yes. You know, the Kidney Cancer Association was in business. They were doing a good job. But you look back 15 years and you realize there wasn’t a lot of information about them back then. Few people we knew had Internet access, and even that was local networks; and we did not know of very many people who had even heard of kidney cancer much less knew someone who had it. In retrospect, Yvonne and I have come to realize how blessed we were that my initial surgeon had the level of knowledge and commitment to our care that he had.

**Yvonne:** I remember not being able to find more than a sentence or two, or perhaps a pamphlet that had information on kidney cancer. Once, when Mike was in the hospital taking immunotherapy treatments, someone told me about a book that was probably out of print,

written by someone familiar with kidney cancer. I made numerous calls all over town searching for the book, and finally found a copy at a used bookstore. I was very unfamiliar with the roads in that town, and this was before the days of cell phones and GPS devices, but I managed to find the store and get the book. Information was almost non-existent.

It would have been such a wonderful thing back then to have had a book available such as this collection of survivor stories, or *We Have Kidney Cancer*, or to have had access to the resources available through the Kidney Cancer Association's website.

**Interviewer:** The Internet has expanded so much you can now find a lot more.

**Mike:** Right; but something to keep in mind is that there is a lot of misinformation out there as well as information that is out-of-date. Cancer research and treatment procedures are moving forward so rapidly that many sites do not reflect the most recent knowledge or applications. It's always a good idea to consult with your medical team or a trusted organization such as the Kidney Cancer Association about information you might find on the Internet.

**Interviewer:** Let's go back to the treatments. So you started immunotherapy. How did that go?

**Mike:** I was part of a clinical study on low-dose immunotherapy. It wasn't a blinded clinical trial, but it was a study group to test how people would respond to lower dose immunotherapy in terms of remission, response and side effects. I got some response and wound up taking eight weeks of therapy, 96 doses, over a period of about ten months. I had to go into the hospital eight separate times to get all the treatments in. At the end of the eighth week I felt like I had taken all I could stand. At that point, we kept an eye on the tumors and after about six months or so, they started to grow again very slightly. So at that point, we elected to take the high-dose immunotherapy. I went through four weeks of that. My body reacted more quickly and severely to it because it had already received the low dose. I got some response that stabilized my condition for about a year and a half. Then we had additional surgery because one of the enlarging lymph nodes was so close to one of the major blood vessels that we were afraid it was going to wrap around it. We knew it was a risky surgery with only a slim chance of removing the lymph nodes. While they couldn't take the lymph nodes out, they were able to drastically reduce their blood supply. That caused shrinkage, which lasted about three years. At that point I found another enlarged lymph node in my

neck which showed presence of RCC, and that's when we started on one of the new drugs.

**Interviewer:** The immunotherapy treatment must have been pretty tough to go through.

**Mike:** Yes, it was. It's amazingly tough, but in 2001 it was the only therapy that was available that worked besides surgical removal of tumors. Conventional chemotherapy and the radiation therapies that were available did not work. It is still the only therapy for kidney cancer that has produced complete and durable responses at this time. Only a small percentage of those who receive immunotherapy have a complete response and those who have a partial response have a slightly higher percentage. Still, despite the targeted-therapy and other options available today, I would recommend people who are diagnosed with kidney cancer to at least consider immunotherapy as a possible treatment. While not everyone can or should have that procedure, it may be a good option for some.

**Interviewer:** What was the worst part of it for you?

**Mike:** Well, with the low dose, there were some weeks I couldn't even tell I was taking the medication as far as vomiting or diarrhea. I felt bad, became irritable, and was unable to rest; I had the swelling and the redness, and some weeks had more challenges than others. At the end of a week of treatment I was worn out. On the high dose, I was out of it.

**Interviewer:** What do you mean by "out of it?"

**Mike:** I was fairly unresponsive as far as being able to communicate with the nurse who was in the room asking questions. And I was very agitated. If the sun would be shining in my eyes in the afternoon, I'd want the blinds closed. But when they came in to ask if I needed anything, I couldn't remember to tell them.

**Interviewer:** Any other difficult side effects?

**Mike:** I had nausea, but we kept it abated. I would have high blood pressure. My respiration would slow way down. Oxygen levels were getting low. I would be very lethargic. Electrolytes and blood chemistry constantly needed adjusting. I didn't have an appetite. But when they would take me off the medication and we would start to use the diuretic to get rid of the fluid buildup, within two or three days I was fine. All the side effects subsided rapidly. That's why I kept going back – because you endure it for a week, and then a week later you're fine.

**Interviewer:** What helped you get through those difficult side effects?

**Mike:** Well, I had a very proactive medical team. They had medications already pre-prescribed on the floor for just about every side effect I could possibly experience. When the nurses, who were all specially trained in this procedure, would see an issue, a lot of times they would go ahead and give me something to help with the side effects and then call the doctor. Those nurses took such great care of those who were undergoing immunotherapy. When

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*“This guy was on call literally 24/7 the whole time I was in the hospital. He would be in there at 6:00 in the morning or before that checking my blood work and everything. A lot of times he would be in there at 8:00 or 9:00 that night checking on me and often one or two others who were taking immunotherapy.”*

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it was time for an immunotherapy dose, we only had one doctor in the hospital that approved it. If I needed a dose in the middle of the night, he got a phone call at home. This guy was on call literally 24/7 the whole time I was in the hospital. He would be in there at 6:00 in the morning or before that checking my blood work and everything. A lot of times he would be in there at 8:00 or 9:00 that night checking on me and often one or two others who were taking immunotherapy. On rare occasions he would have someone to fill in for him once the dosing was complete and I was in the “recuperation phase,” but he was deeply committed to his patients.

**Interviewer:** That must give you a whole new perspective and appreciation for the medical profession, I would think.

**Mike:** Absolutely. On low-dose immunotherapy, my wife stayed with me. A lot of times, especially on his last round late in the evening, we would tell the doctor, “Come in and sit down,” because we had a couch in the room. He would actually come in and sit down and take his shoes off. He was so exhausted he didn’t feel like driving home. It takes a lot of dedication to do what they do. We are not only placing our lives in their hands, for many of them their commitment to the welfare of the individual patient is very important. It does put the medical team in a different perspective. In this journey of fifteen years there are only a few out of the countless numbers of the team members that have attended to us that we have been dissatisfied with.

**Interviewer:** Let’s talk a little bit about your emotive state when you got the news. Do you remember what you felt? What feelings were going through your mind when you heard for the first time that you had cancer?



**Mike:**

Well, just a month before, I had passed a state-licensing exam to start our own business in pest control. And we already had a customer base lined up. We had the financing available. We had everything available to go into our own business. And we were very good at that business. My wife was very good at it. She was one of the few ladies that could run a pest control service route and out-service and out-sell the guys. And so when this diagnosis came, we knew that was going to change. I honestly did not know if I was going to make it out of surgery or not. It was that bad. And I can remember, and here's some religious slant, I can remember lying on the bed in the emergency room probably 45 minutes after I got the diagnosis. And my wife is sitting there holding my hand with neither of us knowing if I was going to be alive a week from then. And I said, "You know, I'm glad I got this kidney cancer instead of somebody else that didn't know how to deal with the hereafter." That was kind of a girding for me. I knew that in my case, no matter what happened, everything was all right. And I got a confirmation of that when I was going into surgery. I'd left my wife and my son; an orderly was wheeling me down a long corridor on the gurney, and this wave of peace came over me. And I knew if I woke up or if I died, I would be OK. And that peace, which occurred 15 years ago, has basically never left me since. Now when I get bad news I say "Oh well, what are we going to do about it?"

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*"I knew that in my case, no matter what happened, everything was all right. And I got a confirmation of that when I was going into surgery. I'd left my wife and my son; an orderly was wheeling me down a long corridor on the gurney, and this wave of peace came over me. And I knew if I woke up or if I died, I would be OK."*

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**Interviewer:**

So you're attributing that attitude to your faith then?

**Mike:**

That has a lot to do with it. But there's more. Years ago, when I grew up, I had one of the most negative attitudes on the face of the earth. And through a process of changes, I developed an extremely positive attitude. One of the things I did along the way was teaching a continuing education class at a local prison camp – a behavior modification class. And basically, that behavior modification class was 12 weeks long, and it revolved around Earl Nightingale's tapes. He had 12 tapes in the Lead the Field series, and that's what we used. We would go through one tape a week and just sit down and talk about it for the whole week. For some of the guys that class literally meant their lives wound up being changed. But picking up those positive things and then

reinforcing them, teaching them to other people – that helped me to internalize many important concepts. It was automatic at the diagnosis to realize we're either going to beat this thing or we're going to die trying.

**Interviewer:** So it's a combination for you of faith and also human-based positive thinking?

**Mike:** Right; but the positive thinking aspect is an outgrowth of my faith; they are both intertwined.

**Interviewer:** What about Yvonne? How did she respond? What were her feelings?

**Mike:** Well, she was devastated. Her mother had died of lung cancer. And she and her mother were very close. Her mother had died when she was 19, and my wife was pretty much on her own after that. She was the one that was caregiver for her mother before she graduated from high school. She's the one who took her to all the appointments and everything. At the time of my diagnosis we'd been married just a few years. And now she's saddled with a guy that's got cancer.

**Yvonne:** My response and feelings, especially at first were quite different. My husband, who had never been sick, who never went to doctors, was doubled up in pain, insisting he would be OK, and was rapidly getting sicker. It took some convincing to get him to go to the emergency room of our local hospital. A few days later when they requested he come back, I called my family physician, who Mike had never seen, and had to get him worked in and to go to another hospital that was covered by our insurance. He slept all the way to the hospital; the weather was terrible and it was the longest, loneliest trip I have ever made. At the hospital, the emergency room was packed with accident victims and crime victims, and it took forever for us to receive service. As the doctor knelt beside Mike and basically said for us to get our affairs in order, that we had five years at most, I kept saying to myself, "This can't be right... he's healthy and never sick... he's my soul mate; you have no right to be rocking my world like this." As we were placed in a room awaiting additional tests, and I held the hand of my very sick husband and he began talking about being glad that he had the cancer instead of someone who didn't know how to deal with the hereafter, I wanted to knock him out of the bed. I was confused, lost, devastated, alone, and if he died, perhaps he would be OK; but I would not.

**Interviewer:** So you were diagnosed soon after your marriage?

**Mike:** Right. We got married in 1994, and I was diagnosed in 1997. But we'd been together for a lot longer than that. Yvonne and I both had to come to grips with the diagnosis in our own way. We decided to get as much information as we could, and whatever opportunities we had, we were going to make the best of them. We'd made our mind up when I started going to the doctor after the surgery that while he was very positive about our prospects, for the next five years or so, the lack of treatment options and the long term survival figures spurred us to look for future options. We decided if we had to go to Houston, if we had to go New York, wherever we had to go, we were going to get treatment. And it turned out the best treatment option for our situation was an hour and a half from home.

**Interviewer:** Mike, did Yvonne become depressed? What happened with her?

**Mike:** Well, she dealt with it very well. It did depress her, just as a diagnosis is going to depress just about everybody. I mean, if they really understand what's going on it can depress them. But she had that same faith that I had. She and I both knew that we had limited options. And she later said "Well, if we have to come back every year to have surgery to keep you alive, we'll do it." And I said, "What's this 'we' stuff?" [Laughs]

**Interviewer:** Yvonne, what is your version of what was happening?

**Yvonne:** While I had the same faith that Mike had that if he died he would be OK, but we were worlds apart in our approach to a number of things. He was very calm about scans and results, and about death and dying, but on a daily basis, especially at first, I faced the dark tunnels of the unknowns of finances, the future without my spouse or with him having a steadily progressing disease and a host of other challenges. I wasn't depressed, but the prospect of perhaps five years at most of a reasonable quality of life for my husband and for us was a serious challenge to cope with.

**Interviewer:** Mike, I have noticed that when you talk about your cancer, you use the word "we" a lot.

**Mike:** Yes.

**Interviewer:** That suggests to me that you consider it truly a team approach with your wife.

**Mike:** It is. It really is. She is very supportive of everything we've had to do. In a broader perspective, while my wife and I are extremely close in this journey and are the main team, there are other teams

involved in this process as well – medical teams, support group teams, family teams are just a few of them.

**Interviewer:** How would you say the two of you were different in the way you approached the disease? It sounds like some things are really similar, the faith-based sort of thing, but what else? Anything different?

**Mike:** Well, she's been a driving force. At the times when I would be low, she would pick me up. She is extremely protective of me from the standpoint of making sure I don't overdo some things or miss appointments, and countless other caregiver concerns. She's always there. Even if I just go to a doctor's appointment, she's usually there with me in case, just in case.

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*“She is extremely protective of me from the standpoint of making sure I don't overdo some things or miss appointments, and countless other caregiver concerns. She's always there.”*

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**Yvonne:** The biggest difference has been our view on dealing with the diagnosis and our approach to the quarterly scan and exams. Mike has literally taken it in stride, while I wasn't as quick to do so. As we moved further away from the time of the initial surgery and got to a facility where specialists were located; as new treatments came available, and as we began to survive past the dire prediction of possibly five years to live, things have become much easier. I appreciate the fact that we not only got those five years, but we have gotten three times that. While Mike and I both realize that something can happen tomorrow, we are very optimistic and appreciative of the fact that we weathered this together.

**Interviewer:** How has this impacted your work, your ability to work?

**Mike:** Well, when I had the initial surgery I knew I needed to get out of the pest control business because when you've got an abdominal incision all the way around, you are not going to crawl under many houses. And I also knew that even though I couldn't pin the cancer on the pesticides, I probably didn't need further exposure to them.

**Interviewer:** And had you been in that business for a long time?

**Mike:** I'd been in it three separate times. I started in the 1970s in Florida. There were very few regulations. There were all kinds of things that later were banned. But I'd also been to Vietnam. I worked in the textile and plastic industries. I worked in construction industries. I've been around all kinds of chemicals

all my life, so as far as putting the blame on any one thing, there's no way you can do that. After getting out of the pest control business I tried a variety of different jobs, including working for a steel-bearing manufacturer and being a maintenance director at an assisted living facility. Then I went to work for a large printing plant. That's where I was when I went through the immunotherapy. But after my 2005 surgery, the doctor said, "Look, you're not going back to work anymore. Work is contributing to this somehow." So I've actually been officially retired for six years. And helping other kidney cancer survivors is now my hobby.

**Interviewer:** What about you Yvonne, are you still working?

**Yvonne** I am a support facilitator at a local manufacturing plant.

**Interviewer:** Let me ask you about things that you've developed just to help you cope at various times. What about your physical well-being? Is there anything that you do on a day-to-day basis, to stay physically fit?

**Mike:** Unfortunately, with the drug I am currently on, walking can be a challenge.

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*"As new treatments came available, and as we began to survive past the dire prediction of possibly five years to live, things have become much easier. I appreciate the fact that we not only got those five years, but we have gotten three times that."*

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**Interviewer:** Is it? What happens? What's the problem?

**Mike:** Well, I have what they refer to as foot syndrome. Some days I would love to walk, but I'm just not up for it because of the pain. But I try to stay active. I ride my bicycle a fairly good amount. I try to watch and keep a good diet. I'm mindful of these things. I haven't gotten on the extreme edge of nutrition, but I do watch it. One of the things my doctor told me, during my treatment, was "I'm going to be mighty ticked off with you if you die of a heart attack after all I'm doing to keep you alive." So, you know, that sunk it, and I watch what I eat.

**Interviewer:** So you're paying attention to cholesterol and things like that?

**Mike:** Yeah. My cholesterol is good. Everything is good. I've got just a touch of cancer, that's all. [Laughs]

A few moments ago we were talking about my ability to work, and mentioned some of the different things I had been exposed

to. I think it is important to note that I also had a terrible diet and eating habits leading up to my diagnosis. My meals were consumed on the run for the most part between service calls while I was driving. Sandwiches, sodas, and snacks were the mainstays of my diet. After work, we usually ate fast food because of our very hectic lifestyle. The one thing that I was doing that may have actually helped to save my life was that I had been going to a gym on a regular basis for about ten months before my diagnosis. I was overweight, but the gym visits helped to control more weight gain and increased my stamina.

**Interviewer:** So your advice to other cancer patients would be to pay attention to these lifestyle factors?

**Mike:** Yes. There really is a lot that people can do to help their situation, whatever it may be – from making sure you drink plenty of water to eating right. Even with all of the many medical treatment options for kidney cancer, we personally play a vitally important role through our diet, exercise, mental and spiritual conditions. For stress, for example, you can practice positive visualization, stress reduction, and learn how to develop an expectation of successful outcomes. You can definitely have an impact.

**Interviewer:** What about other activities, other things that you like to do? What do you like to do when you're just having a good time?

**Mike:** I don't look at myself as a person that has cancer. But I'm usually involved on the periphery of some kind of support group, and that's almost a hobby for me, as I mentioned. I also enjoy playing the guitar and singing gospel music. I go to a lot of rest homes. I go to the local Hospice House and I'll sit down and sing and play the guitar in the patients' rooms. I have the tremendous privilege of visiting and sharing something that is very meaningful with people and families at that time of transition in their lives. I do a lot of projects around the house. Right now, I'm renovating a bathroom and a laundry room. I stay busy.

**Interviewer:** Any other activities?

**Mike:** I also work with a church for the mentally and physically handicapped. I've been volunteering with them for about 34 years. It's the only church of its kind in North Carolina that's devoted exclusively to physically and mentally handicapped people. We have anywhere from 50 to 60 handicapped people that come to the service. We have them very involved in the service. They light the candles, carry in the altar Bible, and participate in many other activities. It is very touching and inspiring to see these folks who

most of society passes by being able to worship according to their own individual abilities.

**Interviewer:** Because you are very involved with KCA in organizing and coordinating activities for survivors, do you have any feelings about what needs to happen in terms of our national effort to find cures for cancer? What do we, as a country, need to do, or what you'd like to see happen more in the way we approach cancer?

**Mike:** I have a lot of opinions about that subject. The first thing that everybody should be doing is to become proactive about cancer before it develops. We need to be aware of our environment, our diet, our body, mental state, and being aware of exercise – all of that comes into play. That's my take on it. I heard Dr. Anna Barker, who at the time was the Deputy Director of the National Cancer Institute, declare that, "Cancer is complicated." And the medical community is just finding that out. President Nixon declared war on cancer in 1971. Some people thought we'd beat it in five years – and we're still working on it. They didn't know what they didn't know back then. Because it is so complicated, and because we have so much work still do to, the biggest thing is education of people before they ever get cancer in the first place. We should be pushing for greater awareness and more prevention. That is true not only with kidney cancer, or other cancers; it is true of our entire concept of health.

## *Rick and Mac*

Rick, 68, retired from his position as CEO of a rehabilitation agency for the blind a year after he was diagnosed with kidney cancer in 2002. He and his wife Mary Nelle, who goes by the nickname “Mac,” had been married 6 months at the time of diagnosis – a second marriage for both. Rick has three adult children from his previous marriage. The couple resides in Pennsylvania, Rick’s home state. Mac is from Tennessee.

They had known each other professionally for years and both have been deeply involved as leaders in the professional community that offers education and rehabilitation services for the blind. Both have received professional honors for their work, and Rick is the author of an influential university textbook that is in its third edition.

Rick’s story offers insights into the challenges faced by patients whose cancer never goes into remission and who must try multiple treatments and drugs as they battle the disease. He has been on nine different treatments and has been prescribed almost all of the new drugs that are available to kidney cancer patients.

Maintaining hope and optimism over the course of a decade of treatment can be a challenge, but Rick and Mac provide thoughtful advice that can help – including a step they found critically important: Finding a doctor who would become a strong and equal partner in their efforts to fight the disease.

### *Survivor’s Advice from Rick*

- “When you choose an oncologist, find one who specializes in kidney cancer.”
- “Join an online community that specializes in kidney cancer and start making connection with others. You’ll learn a lot and get great support.”
- “If you are having a hard time keeping your spirits up, concentrate not on what you have lost, but what you still have. Focus on today and make the most of it.”

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**Interviewer:** When were you diagnosed with kidney cancer?

**Rick:** I was diagnosed on June 21, 2002 – I remember it well because it was on the 6-month anniversary of our marriage. We had both been married before and had found each other. And we were looking forward to a new life together and all of the sudden we were confronted with this serious diagnosis. Mac had given up a significant executive position in Louisville and moved to Pittsburgh to be with me here.



I started with pain in my back, combined with nausea. It reminded me of the pain I had experienced with a kidney stone back in the 1980s. I went in and they did urinalysis. That then led to three months of ever more sophisticated testing. CT scans, MRIs, and so on, till we finally got to the diagnosis. The tumor had grown out of the kidney through the renal vein and into the vena cava. It looked like very complicated surgery was going to be required. They also found spots on the lung, so we were dealing with metastatic disease right from the beginning. Later on there were also metastases in my brain.

**Interviewer:** What was your treatment?

**Rick:** In July of 2002 I had an 8-hour combined nephrectomy and thrombectomy (*Note: a thrombectomy is a surgical procedure that removes blood clotting or cancerous tissue invading the vena cava.*) I spent eight days in the hospital. In August, a lung resection confirmed that renal cell cancer was in my lungs. In September, I started systemic treatment.

Originally, my first oncologist suggested high dose immunotherapy. But then he changed direction and said, let's go with a milder immunotherapy instead. If we knew then what we know now, we would have put our foot down and said "No way." But at the time we were traditional patients so we said "OK, you're the boss."

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*"Getting the right oncologist who knows his stuff was important, but also getting someone who seemed to genuinely care about what happened to us."*

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**Mac:** But we're not traditional patients anymore! [Laughs]

**Rick:** Yes, we've overcome that. [Laughs]

The point I wanted to make with that is that the milder immunotherapy didn't accomplish much. After we tried it, we were ready to go to the more aggressive immunotherapy, but I had developed a heart rhythm problem by then. We found out that the first immunotherapy had knocked out my thyroid, and that led to heart palpitations. And that eliminated us from consideration for high-dose immunotherapy, which at the time was our only chance for a total cure. And at that point, in my disappointment I asked the oncologist, "What if we did nothing else at this point?" And he said very matter-of-factly, "you'd have nine months to a year."

**Mac:** That's all he said, no emotion. He was so clinical, so matter of fact. Just – boom, there it is.

**Rick:** We decided that we really needed a different doctor on our team.

We had been taking referrals from our other medical providers up to that point. We stayed within the “system.” So we took it into our own hands. Through personal contacts I had, we found someone on our own. I get a little emotional when I talk about this... [Rick’s voice trails off.]

**Mac:** I’ll take it over, from here. We went to the person who was recommended to us. And during our first meeting we asked the same question we had asked the other doctor. “What if we just do nothing?” And – just within weeks of hearing what we heard from the other doctor – this man literally leapt up from his chair and in a very animated way said, “We don’t want to do that. My job is to keep you in the game till some of these other medicines that are coming down the pike are approved and are available to you.”

So there we had two ends of the spectrum. At one end was someone who was cold and clinical and at the other end was someone who really believed in both his patient and his ability to help his patient. We had a partner at that point – and we’ve maintained a wonderful relationship for nine years.

**Rick:** Getting the right oncologist who knows his stuff was important, but also getting someone who seemed to genuinely care about what happened to us.

**Interviewer:** When was all this happening?

**Rick:** This would have been right after Christmas in 2002. At that point we started a very long list of treatments. We went back and forth between two immunotherapies and two chemotherapies and then on to several of the newer targeted therapies, including a drug I’m just starting this week, which will be the ninth treatment.

**Interviewer:** What were the other treatments?

**Rick:** After the first immunotherapy, I participated in a clinical trial for a chemotherapy using two drugs that were intended to interfere with the development of blood vessels that grow the cancer. But this treatment didn’t have a positive result for me – I was left with neuropathy (*Note: neuropathy is a medical condition in which nerves to the peripheral nervous system have been damaged*) in my feet and lower legs. That’s remained with me all these years. I also had gamma-knife surgery for my brain tumors.

We then tried a low-dose immunotherapy, before trying a chemotherapy approach. In 2005, I went on one of the first targeted therapies that was just being approved by the FDA. After six weeks, we saw a sharp shrinkage of tumors. Everything up to

that point had kept things steady, but not dramatic in terms of reduction. That lasted for about six months. And then in January 2006 things started growing again.

By that time, I had become involved in online community specializing in kidney cancer and I learned through it that a prominent research doctor was starting a large clinical trial in Cleveland for an experimental drug. I emailed him, he responded the next day, and the day after that I was sitting in his office talking to him about the trial. A week later we were in the trial. That was a real blessing. That was a turning point for me. That drug was very successful. It produced shrinkage of my tumors of about 65 percent and held me stable for four and a half years – even though there were a lot of side effects along the way.

**Interviewer:** So you had good results in the clinical trial?

**Rick:** Yes. In addition to the shrinkage and subsequent stability, I had no new brain metastases for those 4 ½ years. I became a patient of one of the leading researchers in the field of renal cell carcinoma. One of the most important benefits was that his research nurse is an expert in managing the side effects of all of these newer treatments and she has been a godsend during the past six years. But I had a serious heart attack in 2010 and had to leave the trial. So we tried two more targeted therapies – one in the fall of 2010 and the other in 2011. I had to go off of both of those because of the side effects. Now I'm preparing to go on one of the other new drugs. The problem is that I've had a lot of side effects which seem to have been aggravated by adrenal insufficiency. As an example, I've had eight or nine dehydration episodes, where I get a sudden loss of fluids through vomiting and diarrhea, a rise in my heart rate, and a dangerous drop in my blood pressure. So I've had eight or nine trips to the hospital for that.

It's going on 10 years, now, and I've never been without disease and never without treatment for more than four or five weeks. It's been quite a ride. Sometimes it's almost unbelievable how much we've been through and how we're still here.

**Interviewer:** And how are your spirits, given all you have been through?

**Rick:** Well, over the last year I've had a little "patient fatigue." If I have to have one more doctor's appointment or one more drug, I'm just going to scream.

**Interviewer:** When you have a bad day, how do you cope?

**Rick:** When I have a bad day, I grumble and I complain and I express

a lot of that to Mac, and then I decide to do something positive. Whether it's setting up the next appointment or researching a drug, or doing something in my profession, or just doing something around the house. I grumble and complain and then I move on. So far, that has worked. I haven't had more than a day or two at a time of being down in the dumps.

**Mac:** Rick has been one of the most courageous people I know. One thing he has taught me is that every time we get another round of bad news – and gracious knows, we've had plenty of those – his whole attitude toward this is that it's "just another problem to be solved." It's nothing to panic about. Let's take it step by step and solve the problem. Sometimes it can feel like Chinese water torture. You think you are going to get a break and then the other shoe drops.

**Rick:** When others around us respond more emotionally, I sometimes feel that it's my job to take a more rational approach and get beyond that. While we all can feel emotions, I've taken on that role of saying, "OK, what are we going to do about this now?"

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*"Sometimes we wonder, 'What if this diagnosis had occurred before we got married? Would I have been willing to bring Mac into this frightening and unpredictable situation?' I'm glad I did not have to make that decision."*

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**Interviewer:** How did you feel when you were first diagnosed with kidney cancer?

**Rick:** Well, I first felt numb – it was sort of a reaction where you don't let all the emotion in right way, because you can't handle it all. But also, I was uninformed. I spent the following weeks on the Internet trying to learn all I could on my own. And the more I learned, the more frightened I became.

The second major feeling I had was that we had just gotten married, Mac had given up a lot to come to Pittsburgh, and now our future was uncertain. On the one hand I felt bad about it, but it was great to have her on board. I really needed her. Sometimes we wonder, "What if this diagnosis had occurred before we got married? Would I have been willing to bring Mac into this frightening and unpredictable situation?" I'm glad I did not have to make that decision.

**Interviewer:** How did this impact your children, Rick?

**Rick:** They sort of take their cues from us. They have lives of their own, kids of their own. They have not been as caught up in it as some

families have. When I have needed them, they have been there. The kids took it in stride.

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*“There is more hope than ever before. The first thing is getting the right medical team and the second thing is getting the opportunity to interact with people who have been there.”*

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**Interviewer:** What advice would you give to someone who had just been diagnosed?

**Rick:** It depends on a lot of things – what kind of cancer you have and how serious it is. But in general, you are going to need an oncologist and you should find a specialist. We’ve seen so many stories online from people who went to a general oncologist and that person said, “Go home and get your affairs in order.” Kidney cancer is rare enough that some generalists may not know about all of the many options that kidney cancer patients now have. So get in touch with someone who has experience with this disease.

The second thing is to join an online community that specializes in kidney cancer. I wish I would have known about that sooner. It’s a great source of information. You can go online and say, “My doctor says there is no hope for me” and you’ll get people responding to you right away who say, “There is hope” and provide suggestions. Now, there is more hope than ever before. The first thing is getting the right medical team and the second thing is getting the opportunity to interact with people who have been there.

The third thing is that it’s extremely important that everybody get a good baseline from tests. The sooner you find out if your cancer has metastasized the sooner you can get the right treatment. If you are going to be serious about fighting the disease, you need to know what you are dealing with.

**Interviewer:** Those are all good, practical tips – what about advice about the emotional side of a cancer diagnosis? What can people do to keep their spirits up?

**Rick:** It has been very important to stay positive during this. With all the negative things going on, you have to try to keep that positive focus. I remember reading an article about statistics. A statistic might tell you that a certain percentage of people die within a certain amount of time after being diagnosed. But you really have to understand the difference between a group statistic and an individual experience. It has been helpful to me to understand that even though the majority of people in a bell curve are in the middle section, there are people at both ends – the positive and

the negative end. Somebody's got to be at the positive end of a bell curve – so why not me? The statistics may be lousy, but they don't define your experience.

The other thing I've found helpful is being very actively involved in the research and decision making. That has motivated me and encouraged me. As an example, when we were weighing the options of having a second gamma knife surgery or whole brain radiation for my second group of brain tumors, my neurosurgeon was leaning toward the whole brain radiation, but I did some research and found three studies that indicated that whole brain radiation did not help with renal cell metastases in the brain and that gamma knife was the best way to go. I expressed that preference and so we did it. And we had good success. After six gamma knife treatments, he's actually using my case now in some of his lectures.

It can be difficult staying positive, especially if other things are happening with your family. In my case, I had just lost my sister to cancer in December 2000, so when I was diagnosed, I thought "Here we go again." And then I lost my younger brother to a brain aneurysm four years later.

**Interviewer:**

Mac, what about you? Any advice for families and other caregivers of cancer patients?

**Mac:**

I echo what Rick said about being your own advocate and doing the research. I started out from the very beginning keeping journals – a systematic set of notes for every appointment, every scan, every medical intervention that we have, every hospitalization – everything. I've kept these since he was diagnosed. I think I'm on my eleventh journal. I put all kinds of notes to myself. You would be amazed by how many times the journal has served us well – the times when I've been able to correct something, determine the right dosage, or provide some technical detail the doctors needed to know. That's a technical piece that has served us very well. It keeps me involved too, so I'm not just idly sitting there.

One thing that is great about keeping a journal is that it allows you to challenge authority, but do it in a positive way. You shouldn't hesitate to question a treatment or medical suggestion from a team, but if you have been keeping a journal, with all the test results and everything, you can do it in a way that is backed up with data.

Another thing I do is I give hugs liberally. I treat people on the

medical team in their human role – not just their medical role. I try to get to know the nurses and doctors and their families. And I think that has helped.

I actually have a list of things for families, after all we've been through. Remember – it is about the patient, but it's about you, too, as a family member. I actually have a list of things I suggest that families keep in mind as they go through a cancer diagnosis. [Reads list]

- Be honest.
- Be present.
- Be realistically positive.
- Reside in the moment.
- Control what you can.
- Enjoy something beautiful each day. Find something that refreshes you and do it daily.
- Remain curious and ask a lot of questions.
- Push your luck.
- Acknowledge your pain.
- Never give up hope.
- Give hugs liberally.
- And fight like hell.

**Interviewer:** Rick, you were at the peak of your career when you were diagnosed, in your fifties. How did this impact your work life?

**Rick:** I wasn't even close to thinking about retiring at the time I was diagnosed. But after the first year, I began to realize that the physical impact and time away from work made it hard for me to continue on as head of the agency – I just didn't have the energy or time to provide the leadership that was needed. If I had been further down in the ranks I might have been able to continue. So I went on disability retirement about a year into my diagnosis.

**Mac:** That was a difficult decision because both Rick and I have loved our work.

**Interviewer:** Rick, you had a high visibility position and a lot of people were concerned about your health and wanted to know what was going on as your treatments progressed. How did you keep them aware?

**Rick:** A couple of my colleagues came to the hospital during my

surgery and the two of them started a group email to keep other colleagues around the country apprised of what was happening. And Mac continued sending a group email after that. The list started to grow. Once I was up to it, I took it over. Every six months or so, I'd send a health update. It grew to about 80 people. Many people came to appreciate that. We got great feedback from it. We tried to put some humor into it and people said they enjoyed that. I found that keeping friends in the loop turned out to be a very positive thing for me. It made me realize that we weren't alone in this. There were lots of people in lots of different faiths remembering us in their prayers.

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*“You would be amazed by how many times the journal has served us well – the times when I’ve been able to correct something, determine the right dosage, or provide some technical detail the doctors needed to know.”*

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**Mac:** Rick’s health update was very self-revealing and inspirational, and it got forwarded a lot. People posted it online. It was literally being read all over the world. People have written us to say things like “You’ve helped me not be afraid of cancer.”

**Interviewer:** What would you say to someone who is feeling defeated by the struggle against cancer, or who is starting to run out of hope?

**Rick:** From my work in rehabilitation services for the blind, I have found that frequently, if people have a disability, they spend time struggling and being depressed about what they have lost. The turning point you see in people who make a successful transition during the loss of vision is when they focus not on what they have lost, but what they still have. Then they move forward.

If a person is depressed about his cancer and the entire focus is on what he is losing, rather than what he has – you can understand why he would be feeling low. So my advice would be to focus on the things you still have, today, and make the most of those things. Don’t give up on your life any sooner than is necessary. Continue to focus on the life you have. Live it to the fullest.



## **EMPOWERING STEPS FOR PATIENTS**

*Additional tips and advice from the Kidney Cancer Association*

### **Be a Skeptic**

Your surgeon will not be able to guarantee that “I got it all.” If you are treated surgically, you should be skeptical of such a claim. What the surgeon really means is that he or she removed all of the tumor that could be seen. If your surgeon did not see it, it wasn’t removed.

Some tumors have many blood vessels. Tiny bits of tumor or even a few cancer cells can drift off in the bloodstream and settle elsewhere in your body. Years after your primary tumor is removed, these cells can form new tumors and kill you. You will need regular medical check-ups. If a new tumor starts up, you want to catch it early and treat it promptly. Never let your guard down. Make sure you get regular follow-up care.

### **Be Accountable for Your Follow-up**

Don’t assume that someone at your doctor’s office is responsible for your follow-up. You should take responsibility for getting a follow-up visit scheduled and for keeping the appointment.

Get regular follow-up testing, which might include CT scans, bone scans, and blood tests. Get the results of these tests in writing, and ask for a referral or see an expert for abnormal findings. If you are uncomfortable with abnormal findings that your doctor is not treating, ask for a second opinion.

## Larry

Larry is a 70-year-old retiree who was born and raised on the southeast side of Chicago. He and his wife, Marilyn, have two daughters who live in California and one grandson, recently born.

Larry was first diagnosed with kidney cancer in 1994; he had a nephrectomy but no additional treatment. He was pronounced cancer-free and for the next 12 years had no problems. In 2006, a CT scan intended to search for a hernia turned up cancerous growths in his lungs – evidence that his kidney cancer had returned.

After a period of “watchful waiting,” Larry began drug treatment in 2009. The drugs have kept his cancer under control three years later.

Larry’s story is a good illustration of the importance of good communication with the medical team – and the need for patients to ask the right questions. Looking back at his own experience with kidney cancer, he says communication with his medical team broke down at a key moment of his diagnosis and treatment.

Today he is grateful for the effectiveness of the drug he takes, and is enjoying a retirement that he says keeps him very busy, including travel with his wife.

### *Survivor’s Advice from Larry:*

- “Ask a lot of questions and that you understand exactly what the doctor is telling you.”
- “Always get a second opinion.”
- “Learn to adapt, especially if you are taking a drug. You can live with the side effects.”

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**Interviewer:** Tell me about your diagnosis and treatment. How did you find out you had cancer?

**Larry:** Well, the first indication I had that there was something wrong was blood in my urine. So I went in for tests and an ultrasound. They found a growth on my right kidney. They told me it was encapsulated – covered over by the membrane. I subsequently had surgery to have it removed, and they told me that I was “cured.” I didn’t have any treatment other than surgery, and I was fine for quite a long time.

**Interviewer:** Then what happened?

**Larry:** In 2006, I was complaining to my doctor about a hernia, but he couldn't feel it. He said, "Let's do a CT scan to see what's going on there." And, fortunately or unfortunately, when I went in to have the procedure done, the device operator, started the scan too high. He started at my neck instead of starting at the waist. And what ended up happening is that the scan showed I had some growths in my lungs, which they said was metastasized Renal Cell Carcinoma. So I went to see a lung specialist, who didn't think much of it, and he sent me to another guy, who thought we should do a biopsy. So they cut me open to do a biopsy of the lung – and this resulted in a lot of miscommunication.

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*"In my case, I was told by a doctor that I was 'cured.' I had no additional treatment, no therapy. And then I was told later, 'No, you're not cured.'"*

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**Interviewer:** What happened?

**Larry:** I believed that they were going to go after the largest of the tumors and cut them out. Upon waking up I said, "Did you get it?" and the doctor said, "Yeah, we got it" – but I was referring to the tumor and he was referring to the biopsy. I thought they had removed the tissue they needed to remove, but that wasn't the case. They confirmed that I had kidney cancer and that I would need to see a kidney cancer specialist in Chicago. So we basically watched it for a couple of years to see what it was going to do. The doctor was saying, "Eventually we're going to have to do something about this." But for awhile we just did CT scans. I didn't have any symptoms.

After a couple of years of watchful waiting, the cancer was slowly growing and he decided we needed to start some therapy. But I wasn't convinced, so I got a second opinion at another clinic out of state. I took in all my records and they confirmed the diagnosis and that watchful waiting had been the right approach. So in 2009 we agreed to start treatment and I started taking one of the new drugs.

**Interviewer:** And how is that going?

**Larry:** It's working. We had to modify the recommended dosage – originally I was supposed to be on it for four weeks at a time, then off for another two weeks. But we changed it to three weeks on and three weeks off.

**Interviewer:** Why is that?

**Larry:** When I'm off it grows but not to the extent to where it is larger than when I started. As soon as I start taking it again it knocks it down. I just can't withstand physically the negative effects of a full four weeks at a time on the drug.

**Interviewer:** A lot of other survivors may be getting started on drug therapy and wonder how their experience compares to others. Can you describe what it's like for you, as you regularly take the drug?

**Larry:** Well, for me, the first week is piece of cake, the second week a little shaky, and in the third week it gets a lot more difficult.

**Interviewer:** What happens during those last days to make it difficult?

**Larry:** My side effects are that I have poor appetite and no strength. I'm always tired. I stop doing normal activities – I don't cut the grass, I don't really want to go out, I'm not interested in talking to people, that sort of thing. Everything is an effort. If you are in a chair you don't want to get up because it's too hard. There is a tremendous amount of fatigue and a litany of side effects, which are never the same. Each one, by itself, is not too bad, but in combination they can be depressing. You can lose your taste, or you may not be able to eat food that is spicy. Your lips crack, your skin peels. There's no rhyme or reason for when the symptoms occur. Sometimes you get them, sometimes you don't.

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*"I think she was initially apprehensive. But when she saw that the drug was working, it gave her some confidence, as it did me. We have both learned how to adapt and live with it."*

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**Interviewer:** Do the symptoms go away when you are between treatments?

**Larry:** Oh yeah. The first week, the bad stuff goes away, the second week you are feeling better, and by the third week you are feeling good again. Nothing is permanent. It's all reversible.

**Interviewer:** How did you feel when you got your diagnosis?

**Larry:** I didn't see the freight train coming. I was erroneously led to believe, either by my inattention or not knowing how to ask the questions, that I was cured. And then all of a sudden I hear, "You've got kidney cancer in your lungs." It's a hell of a shock, and you don't react too kindly to it. It would have been a hell of a shock even if I didn't have these preconceived notions that I was OK.

**Interviewer:** Especially since during those years following your first surgery, everything was OK.

**Larry:** Yes. If that CT scan had started at my waist, instead of my neck, I would never have known. Believe me, I know how to ask questions now.

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*“Basically you have to do anything you can to keep your mind off your temporary problem. So, have some reading materials. Watch something mindless on TV. Remember, though, that it is temporary. Focus on the positive.”*

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**Interviewer:** What have you done to cope with some of the emotions you have felt as a result?

**Larry:** Well, it does affect you. You start weighing everything and questioning things. The fact that the drug is working is a great motivating factor. But I was told that at some point my body might figure out what the drug is doing and it will stop working. And they don't know if that might be months, or years. Because everybody is different, the doctors really can't give you a simple answer. Maybe it will stop working in 5 years, maybe 10 years. We just don't know. When I express that to the doctor, he says, “But remember, there are five other drugs we can use.” So that makes you feel better – there is some light at the end of the tunnel and it might not be a freight train. You learn to live and you learn to adapt. In my opinion, you have two choices – you can lay down and give up or you can say, “I'm going to keep on going.”

**Interviewer:** How did your wife handle the stress?

**Larry:** She adapted. I think she was initially apprehensive. But when she saw that the drug was working, it gave her some confidence, as it did me. We have both learned how to adapt and live with it. We've learned to plan our lives around the rest periods – the time I'm not on the drug – rather than when I'm taking it. So, as an example, we plan our trips around that schedule. And the nice thing about this drug is that there is some flexibility. Recently we had a trip planned and I asked if we could lay off the drug for an extra week, and the doctor said, “Sure.”

**Interviewer:** Do you have any specific advice for other cancer patients who are taking a drug to fight their cancer?

**Larry:** You might have to make some adjustments, but basically, live your life. You might have to stay away from spicy food, or foods you can't tolerate, or adapt to some of the side effects, and you will. We don't have any big strategy. Just try to keep on living life.

**Interviewer:** What about on the emotional side? What should patients keep in mind?

**Larry:** Well, there's good and bad. The first thing to keep in mind is that coming back from a nephrectomy can be painful, so you have to be ready for that. The other thing is that you never really know what's going to happen with your treatment, and that can lead to some emotional challenges. In my case, I was told by a doctor that I was "cured." I had no additional treatment, no therapy. And then I was told later, "No, you're not cured." It can put you on a roller coaster. You need to be aware of that. Fortunately I had 14 years before I had to do something about it.

**Interviewer:** What do you do when you are having a bad day?

**Larry:** I take a nap. [Laughs] Basically you have to do anything you can to keep your mind off your temporary problem. So, have some reading materials. Watch something mindless on TV. Remember, though, that it is temporary. Focus on the positive – especially when you are having a bad day due to side effects from drugs. I always say, "The alternative is a lot worse."

**NOTES**

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