



Kidney Cancer Association®

2021 VIRTUAL PATIENT SYMPOSIUM

Resources and Takeaways



Thank you for joining the Kidney Cancer Association's 2021 Virtual Patient Symposium on September 17-18, 2021. Here are the key takeaways and resources from each presentation.

TOPICS

Kidney Cancer Treatment Approaches

Speaker: *Dr. Ulka Vaishampayan*

Shared decision making

Moderator: *Zita Lim, PA-C*

Panelists: *John Ferrell, Bruce Hill, Dr. Chung-Han Lee*

Genetics And Kidney Cancer

Moderator: *Sallie McAdoo, MS, CGC*

Panelists: *John Lee, Genetic Counselor*

Understanding A New Diagnosis

Moderator: *Nancy Moldawer, RN, MSN*

Panelists: *Chapmann Cheung, Dawne Gee, Laura Esfeller, Marissa Willis*

Living With Kidney Cancer (Early Stage Diagnosis)

Moderator: *Dr. Stephanie Berg*

Panelists: *Jason Hinojosa, Ryan Natzke, Annamarya Scaccia*

Living With Kidney Cancer (Advanced Stage Diagnosis)

Moderator: *Deborah Maskens*

Panelists: *Steven Edwards, Matty McClain*

Caregiving

Moderator: *Sarah Rosner*

Panelists: *Kathleen Campbell, Milton Wade*

Disparities And Access

Moderator: *Ritchie Johnson, RN*

Panelists: *Dr. Pedro Barata, Dr. Pavlos Msaouel, Dr. Melanie Royce*

Financial Toxicity

Speaker: *Monica Bryant, Triage Cancer*

Diet and Nutrition

Speaker: *Brittany Finley, RD*

What I Learned From Kidney Cancer

Moderator: *Salima Witt*

Panelists: *Megan Conley, Ritchie Johnson, Peggy Zuckerman*

Kidney Cancer Treatment Approaches

Understanding Diagnosis

(Look for some of these words to appear in your pathology report)

CLEAR CELL

- Multiple therapy options
- TKI/targeted options: (VEGF is most common.)
- IO+IO
- VEGF + IO

NON-CLEAR CELL

- Papillary most common
- Cabozantinib is preferred therapy for papillary
- Look for clinical trials

SARCOMATOID

- Immune based therapy

Treatment Options

VEGF THERAPIES

- Starving cancer cells by blocking blood flow
- Usually oral
- Usually have higher chances of shrinking cancers
- Very small chance of complete response or long term response. (“Response” primarily means there are indications that the tumor has decreased in size.)
- Most side effects are short lived, reverse after you stop therapy

IMMUNE THERAPIES

- Stimulate immune therapy to attack the cancer
- Usually IV
- Smaller chance of response
- Long lasting or durable remissions
- Side effects can be long lasting, and may be lifelong even if you stop therapy

Summary

Immune checkpoint-based combinations have demonstrated tremendous promise in advanced renal cancer: IO+ IO or IO + VEGF-TKI. Median survival of 4 years, and ongoing durable responses were demonstrated

In favorable risk disease, consider surveillance or VEGF-TKI based combo.

PD-1 inhibition is the backbone of future combination regimens in RCC

PD-L1 expression was not predictive of clinical outcomes with immune checkpoint therapies in RCC

Sarcomatoid RCC: Immune checkpoint-based regimens, ipilimumab+nivolumab and axitinib + pembrolizumab have shown superior outcomes to front line therapy.

Papillary RCC: Standard therapy was established by PAPMET S1500 trial. Cabozantinib is a standard treatment.

For those presenting with primary tumor and metastases, start with systemic therapy. Consider participation in S1931/PROBE trial with randomization to nephrectomy or not.

RESOURCES

1. **Exploring your treatment options:** [kidneycancer.org/explore-your-treatment-options/](https://www.kidneycancer.org/explore-your-treatment-options/)
2. **Treatment summary sheets:** [kidneycancer.org/drug-information/](https://www.kidneycancer.org/drug-information/)

Shared-Decision Making

Defining the Importance of Shared Decision Making

- It's a **process** essential to all the decisions that come in the aftermath of diagnosis
- Make health care decisions **together**, including medical team, patient, and caregiver/family
- Importance of **valuing** the patient's values and preferences
- Medical care teams need to honor the patient's right to be fully **informed** of all care options.

Importance of Shared-Decision Making

- **Increased confidence** in treatment path
- Allows for patients/caregivers to be **better advocates** for themselves because they feel part of the process and **understand** their options enough to ask questions

Red Flags When Choosing a Medical Provider

- They are against second opinions (*They should encourage it!*)
- They don't allow time for questions or to explain discrepancies in treatment recommendations from second opinions

RESOURCES

1. **Questions to ask your doctor:** [kidneycancer.org/wp-content/uploads/2020/07/Questions-to-ask-my-doctor.pdf](https://www.kidneycancer.org/wp-content/uploads/2020/07/Questions-to-ask-my-doctor.pdf)

Genetics and Kidney Cancer

Cancer is Either Hereditary or Sporadic

- The majority being sporadic

Genetic Counseling Defined

- Process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease
 - When being genetically tested, it's primarily a two-visit model. First is data gathering and second visit is interpretation of genetic test results, risk assessment, and management and screening recommendations
 - Genetic testing can be done through saliva or blood
- Analysis of genes for germline mutations
 - Usually most informative when performed on family member when cancer
 - Germline testing is done on cells that do not have cancer. It is done to see if a person has a gene mutation that is known to increase the risk of developing kidney cancer. They are often hereditary germline mutations which is why it's useful for heirs.

Genetics and Kidney Cancer

- Genes currently associated with hereditary RCC
 - VHL, MET, FH, TSC1, TSC2, FLCN, SDHA, SDHB, SDHC, SDHD, BAP1, CDC73, MITF, PTEN
 - Identification of several new genes/syndromes related to hereditary RCC over past few years
 - Many syndromes have specific connection with certain histology of RCC (clear cell, papillary type 1, papillary type 2, chromophobe, SDH deficient, etc.)
- Higher percentage of patients with advanced RCC carry germline mutations
 - First ever consensus panel for renal cell carcinoma genetic risk assessment.
Areas of consensus:
 - └ Patient with renal tumor and a first degree relative or 2 second degree relatives with RCC
 - └ Specific RCC histology
 - └ Bilateral or multifocal renal tumors
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Genetics knowledge is advancing rapidly. Just because you don't qualify for genetic testing now, keep checking back!

RESOURCES

1. Find a Genetic Counselor: findageneticcounselor.nsgc.org/
2. KCA blog post on the first consensus statement on genetic risk assessment for inherited RCC: kidneycancer.org/stories/this-month-in-kidney-cancer-research-6/

Understanding a New Diagnosis

- **Understand** your histology, subtype, and stage because it's important when investigating treatment options.
- **Slow down!** You don't need to decide on a treatment/ surgery the hour you get a diagnosis. Your immediate decision could affect future treatment decisions.
- **Advocating for yourself** is so important. KCA has a list of "Questions to ask your doctor" that is a good place to start.
- Mental health is so important. **Endorphins** from working out and staying active were helpful to this panel.
- **Clinical trials can be very important** and aren't "last chance". They may offer the best first-line treatment.
- Palliative care and supportive care can be useful at any point in your care journey and does not signal end-of-life. **Use your palliative care team early-on**, as they're best with helping with pain management and mental coping skills.
- **Ask** your medical care team about mental health services that are offered.

RESOURCES

1. **KCA Just Diagnosed Toolkit:** [kidneycancer.org/just-diagnosed/](https://www.kidneycancer.org/just-diagnosed/)
2. **Questions to ask your doctor:** [kidneycancer.org/wp-content/uploads/2020/07/Questions-to-ask-my-doctor.pdf](https://www.kidneycancer.org/wp-content/uploads/2020/07/Questions-to-ask-my-doctor.pdf)

Living With Kidney Cancer (Early Stage Diagnosis)

- A significant challenge is learning to keep your own identity but having a shifting perspective with a cancer diagnosis.
- Second opinions and shared-decision making are very important. Your doctor and medical care team should encourage second opinions.
- Everyone has a different perspective on check-ups and scans. Some find encouragement from them, and sometimes they provide only anxiety. Talk to your health care team about what works best for your treatment, with your mental health in mind.
- A community was important, especially for people who are diagnosed at younger ages who may not know other cancer patients. Online forums like SmartPatients, which the KCA partners with, is a good resource, as is KCA Connect for monthly virtual support meetings.
- When telling your family and friends about diagnosis, set appropriate boundaries. Ideas include to set virtual sign-ups for ways to help, so you aren't being bombarded with people helping in ways that are stressful.

Living With Kidney Cancer (Advanced Stage Diagnosis)

Advocating for yourself is important. Ideas include:

- Knowledge is power! Educate yourself about your own cancer and biology so you can have productive discussions with doctors/healthcare providers (*asking why a certain course of action is recommended, or not, for me and my specific biology*)
- Set goals for yourself outside of cancer. (*A trip, a fitness goal, etc.*)

Mental health with a long term diagnosis.

- Set a time on your calendar to worry. During that time you can research, read Smart Patients, blogs, etc. But after that, put it away.
- The focus needs to be on **LIVING** with kidney cancer. Focus on what we need to do **LIVE**.

Your goals for a metastatic diagnosis may be different from a non-metastatic diagnosis.

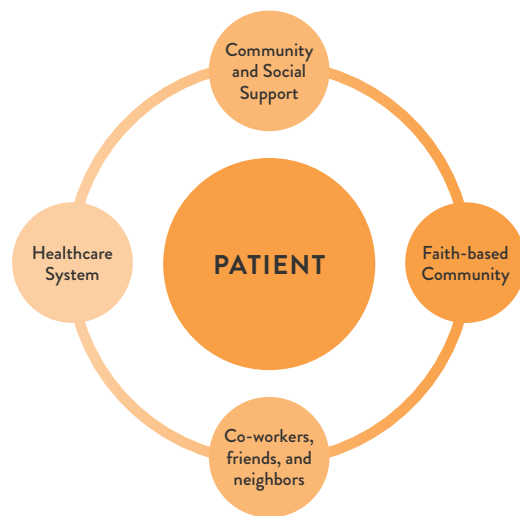
- We do not have to only focus on NED or a cure.
- There is a whole spectrum in which to LIVE between “terminal” and “cure”.
- Goals can be a travel, seeing kids grow up, etc. Communicate these goals to your doctor and your care team.
- **You are not cancer.**
You are a person LIVING with cancer.

RESOURCES

1. **Smart Patients:** [kidneycancer.org/support-community/](https://www.kidneycancer.org/support-community/)
2. **KCA Connect:** [kidneycancer.org/kca-connect/](https://www.kidneycancer.org/kca-connect/)

Caregiving

- There are many styles of caregiving and many roles a caregiver can fill. Some of these include being an advocate, being a key support person, and being a buffer between the patient and wider communities of friends and families.
- The KCA encourages engaging caregiving communities rather than relying on singular caregivers to support patients.
- In addition, caregivers need their own dedicated networks of support that may be separate from the patients.
- As possible, caregivers should invest in personal time and self-care.
- Develop a go-to list of ways people who want to help can help. And practice telling people what you do and do not need.



SOURCE Caregivers: Creating A Support System, National Brain Health Center for African Americans: brainhealthcenterforafricanamericans.org/169-2/

KCA RESOURCES

1. **Patient Navigator Program** A 1:1 person you can call or email to help walk with you through questions. If she doesn't know the answer, she'll help you find them! She can also refer you to oncology nurse call center. kidneycancer.org/patient-navigator-program/
2. **Just Diagnosed Toolkit** A virtual or physical toolkit (can be mailed or accessed online) to walk with you to know what to expect. kidneycancer.org/just-diagnosed/
3. **KCA Connect** An online support community that meets virtually once a month. kidneycancer.org/kca-connect/
4. **Smart Patients** A free online support community to engage with others impacted by kidney cancer. kidneycancer.org/support-community/
5. **Patient Video Library** Kidney cancer experts answer common questions in a video format. kidneycancer.org/video-library/

Disparities and Access

- Advocacy is a vital part of increasing awareness about health disparities and of mitigating the systemic barriers and subconscious biases preventing optimal care.
- Find a community within your diagnosis to help armor you with knowledge.
- Project Equity: A public health initiative by the FDA Oncology Center of Excellence (OCE) to ensure that the data for approval of oncology medical products adequately reflects the patients for whom the medical products are intended. The aim is to ensure that FDA-approved medical products work for all.
- Project Community: An FDA initiative to increase minority participation in clinical trials and to increase knowledge and minority participation in genetic databases.
- Project Facilitate: A single point of contact where FDA oncology staff will help physicians and their healthcare team through the process to submit an Expanded Access request for an individual patient with cancer.
- Kidney Cancer Association’s Project Echo (*Extension for Community Healthcare Outcomes*):
 - └ Kidney cancer experts at major care centers provide medical education to doctors in community settings so they may offer expert-level care to their patients, wherever they live.
 - └ KCA works with Dr. Pedro Barata at Tulane University and the community providers at Northshore Oncology Associates and Northshore + Our Lady of the Lake in Louisiana.

RESOURCES

1. **RMC Support:** rmcsupport.org/
2. **Chris “CJ” Johnson Foundation:** chrisjohnsonfoundation.org/
3. **FDA Project Equity:** fda.gov/about-fda/oncology-center-excellence/project-equity
4. **FDA Project Community:** fda.gov/about-fda/oncology-center-excellence/project-community

Financial Toxicity



Find a summary and additional resources [here](#).

Diet and Nutrition

- Eating a healthy, balanced diet is important for anyone living with kidney cancer.
- Your nutritional needs depend on what type of treatment you're on and the stage of your cancer.
- Eat small, frequent meals during active treatment
- Include fruits, vegetables, whole grains, and lean protein in your diet.
- Try plant-based protein sources.
- Be mindful of fluid restrictions and work with your doctor and/or dietician on this.
- Although some foods can affect cancer risk, there is no evidence that specific foods can cause or cure cancer.
- There is no strong evidence that fasting or specific diets improve detox process.
- All cells, including cancer cells, need sugar (glucose) for energy, but sugar does not cause cancer.
- Weight is not a behavior.
- Behaviors you can modify include movement, increasing nutrient-dense foods, adequate hydration, and stress management.
- Reduce salt intake.

RESOURCES

1. American Institute for Cancer Research: [aicr.org](https://www.aicr.org)

VOICES OF KIDNEY CANCER

What I Learned From Kidney Cancer

Prevention/Screening/Early Diagnosis

Why isn't there a way to diagnose this earlier?

After initial diagnosis, answering
"What do I do now? What options do I have?"

I'd want to know what factors predispose a person to kidney cancer and whether or not changes can be made to decrease the chance of recurrence.

I wish I had known how to be a better self advocate. Because my Crohn's was in remission and I appeared to be very healthy, I did not feel I was taken seriously.

I wish I had known whether my doctor had diagnosed me properly and was knowledgeable about kidney cancer.

I wish I'd known if I was genetically predisposed.

Wish I knew about the likelihood of small renal masses being benign and about diagnostic tools such as biopsy and sestamibi scan.

I learned that carrying sickle cell trait is not entirely benign and that it is associated with renal medullary carcinoma (RMC). I learned that having a history of high-intensity exercise puts a person with sickle cell trait at greater risk for developing RMC.

That my local urologist did not know nearly enough about kidney cancer!
Wish I had seen an expert sooner!

Treatment

That cancer is so very complex in its treatment process.

Learned that there are major developments taking place with immunotherapy and monotherapy.

I wish I'd known more about surveillance protocols as they seem to vary with different doctors and localities. There are no standards.

That there were/are many treatment options but few cures.

Quality of Life

I learned that I can still live a full life with kidney cancer.

I learned how to live a full life with kidney cancer rather than waiting to die from it. At first I was afraid to make any plans more than a month out. Once I started living my life I have made 3 overseas trips traveling to different countries, and got married! Life is good!

Difficulties encountered regarding emotions and depression. And daily challenges of socialization. Living with metastatic kidney cancer.

Living in the unknown is the challenge. Anticipation of pain and suffering is itself very real suffering. Getting to cooperate with so many very intelligent doctors has positives and negatives.

How devastating the effects would be after a radical nephrectomy.

I wish I'd known that this could be with me for many years to come.

I wish I knew how to cope after/ what to do with my life/how to move on after surviving kidney cancer.

That I am incredibly lucky to live in an area with excellent treatment resources, that I really need to appreciate every day and am better able to appreciate every day than I ever was before being diagnosed, that the power of faith and prayer is incredibly important in my life.



KidneyCancerAssociation™

This information is not intended to be a substitute for professional medical advice or clinical therapy. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

CONTACT THE KCA'S PATIENT LIAISON

1-800-544-3KCA | patients@kidneycancer.org

THE KIDNEY CANCER ASSOCIATION

The global community dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education in order to be the universal leader in finding a cure for kidney cancer.

KIDNEYCANCER.ORG

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