



2022

# ANNUAL IMPACT REPORT



*Strong alone. Unstoppable together.®*



**A MESSAGE FROM**  
**Gretchen E. Vaughan**  
*President and CEO, KCA*



In 2022, we asked you to “Orange Up!” in honor of those with kidney cancer. And wow! The enthusiasm was infectious as you illuminated your cities, got creative with fundraising, dressed your animals in KCA gear, and posted more orange-themed photos than we could count! While “Orange Up!” started in March as part of Kidney Cancer Awareness Month, this energy fueled transformative work throughout the year.

In the past year, we expanded the KCA’s resources to serve more people (including translating some into eight languages!). We created new ways for people impacted by kidney cancer to connect with one another, receive and get financial help through our Patient Assistance Fund.

We also continued to fuel groundbreaking research to drive more treatments, better surveillance, and ultimately, a cure. As the central hub for thought leadership, we brought top experts in research, clinical care, and industry together at two scientific symposiums in the US and Europe. It was awe-inspiring to watch compassionate and determined healthcare providers gather to advance their knowledge in kidney cancer while connecting with one another in our shared vision.

We had the privilege of sharing your stories, too! Through our Honor Wall, personal essays on our blog, and the powers of social media, you demonstrated how kidney cancer is both a unique journey and a shared experience. Thank you for offering your advice and wisdom to those who need it most. We’re grateful for your shared stories, which emphasize the KCA’s most resounding message: no one walks this path alone.

Our whole community remains heavy-hearted about the devastating loss of our co-founder and long-serving board member Dr. Nicholas Vogelzang in November 2022 (read more about him on page 13). I know I’m not alone in saying we will miss him tremendously and pledge our work and commitment even more firmly toward his original mission to serve and support people facing kidney cancer.

I’m incredibly proud of the KCA’s work in the last year. But I’m most proud of our growing kidney cancer community, those champions who fundraise for research, who support others around them, and who make their own pledges to “Orange Up!” and improve the lives of those impacted by kidney cancer. We are proud to work alongside you in pursuit of the ultimate cure.

Warmly,

## A MESSAGE FROM

### Dr. Bradley C. Leibovich

*Chair, Board of Directors, KCA*



This year, I stepped in to fill the large shoes of my good friend and former Chair of the KCA's Board of Directors, Dr. Christopher G. Wood. Chris was passionate about the KCA, and I'm honored to be part of leading this organization in a new way.

It's been my pleasure to lead the KCA's Medical Steering Committee for many years, and I haven't missed an International Kidney Cancer Symposium (IKCS) since 1997. These opportunities showed me the KCA's immense impact in the medical community. In my new role, I'm grateful to have new insight into the KCA's impact on patients and families, too.

In just a year, the KCA has refined many of the flagship programs that provide immeasurable value to the kidney cancer community. As a surgeon, the KCA's patient and healthcare provider resources support me to better care for my patients. I see kidney cancer patients in my clinic every week, and resources like these fulfill a fundamental need for them that I know they could not find elsewhere. It's an honor to be part of an organization that recognizes this and works to meet those needs.

It's also been a pleasure to see colleagues and friends in person once again at IKCS meetings. The ideas that these symposiums foster and the knowledge that they share are vital. I look forward to those days all year.

As we look to the future, I see an exciting path toward fulfilling the KCA's mission to bring the kidney cancer community together as partners in improving the lives of those impacted by this disease. Dr. Wood expected big things from us. It's an honor to be part of this organization, and on this journey with you.

Sincerely,

*Bradley Leibovich*

# Our Mission and Vision

## OUR MISSION

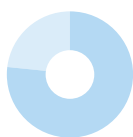
is to be a global community dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education.

## OUR VISION

is to be the universal leader in finding the cure for kidney cancer.

The Kidney Cancer Association (KCA) was founded in 1990 by a small group of patients and doctors in Chicago, Illinois, and has grown into an international non-profit organization. The KCA promotes scientific advances through two annual research symposiums and a robust grant program, participates in legislative advocacy, and seeks to be the trusted source of education and resources for patients, caregivers, and all those impacted by kidney cancer.

## Kidney Cancer Facts



**76%**

5-year Relative Survival Rate (2010–2016)



**13,920**

Estimated deaths in the US in 2022



**79,000**

Estimated number of new diagnosed cases in the US in 2022



**582,727**

Number of people living with kidney and renal pelvis cancer



**RCC**

The medical term for kidney cancer is Renal Cell Carcinoma (RCC)



**75%**

of kidney cancer diagnoses are Clear Cell RCC



Kidney cancer is more common in African Americans and American Indian/Alaska Natives



**Types of RCC:** Clear Cell, Papillary, Chromophobe, Wilms Tumor (pediatric kidney cancer), Translocation, and Renal Medullary Carcinoma

*Key Statistics about Kidney Cancer, American Cancer Society, 2022*



# OUR IMPACT

*this year*



KCA CONNECT  
*Care to Share*

**12**  
virtual support meetings  
held this year



Total research projects  
funded to further  
advancements in a cure  
for kidney cancer



Virtual Patient  
Symposium reached

**214**  
People  
*11 countries • 32 states*

Just Diagnosed Toolkit is now available in 8 languages

ENGLISH

CHINESE

FRENCH

GERMAN

RUSSIAN

SOMALI

SPANISH

SWAHILI

**50+**

People advocated for

**\$50M**

in federal kidney cancer  
research funding



Proved  
federated learning  
success in kidney cancer  
data model through our  
**Kidney Cancer Data  
Federation**

**\$31,000**

was distributed via  
KCA's Patient Assistance  
Fund to **195 people** who  
received a \$25, \$50, or  
\$250 gift card

2022  
**79K**  
CHALLENGE

**105**  
Participants

**+** **494** **=**  
Donors



**\$91,989**  
Raised in the 79K Challenge

2022 IKCS Europe and 2021 IKCS: North America

**913** People in **26** Countries



**436**  
Patients and caregivers  
assisted by Patient Liaison

# How We Help

SUPPORT AND EMPOWER

EDUCATION

RESEARCH

ADVOCACY AND AWARENESS



Kelly Hudak is a wife, mother, and medical device rep based in Charlotte, North Carolina. Spring 2022 was an exciting time for her and her family; she celebrated her daughter's 1st birthday and her 33rd birthday, and she and her husband were discussing the expansion of their family.

At her next appointment, Kelly's obstetrician ordered an ultrasound and incidentally discovered a 4-cm mass on her right kidney. Within a few days, a nephrectomy was performed to remove her right kidney. A few days later, pathology came back confirming the mass was cancer: grade 2 clear cell RCC.

Fortunately, her doctor considered her "in no need of treatment." However, in such a short amount of time, her world was turned upside down. She was told to stay positive, which made her feel like she needed to be brave, but she was really struggling. It was the words from her mother that she really needed to hear, "Kelly, it's okay to cry. You're allowed to be sad."

*"Grief doesn't just apply to death; it applies to other types of loss as well."*

"Grief doesn't just apply to death; it applies to other types of loss as well," Kelly says while processing her diagnosis and making space to grieve. Some days are better than others, but she has utilized several resources to help her navigate, such as her faith, therapy, and her efforts to foster connections by meeting people through social media who are similar in age, live similar lifestyles, and were diagnosed with kidney cancer. All have given her encouragement and hope.

## KCA's Patient Resources

Patient Navigator Program

Just Diagnosed Toolkit

Financial Assistance

KCA Connect

Patient Video Library

Virtual Patient Symposium

KCA Ambassador Program

Health Insurance Guides

Patient Second Opinion Service

Side Effects Tracker

Oncology Nurse Consultant

Ask INA® The Virtual Nutritionist

SmartPatients Online Community

Caregiving Support and Resources



# How We Help: International Kidney Cancer Symposium

SUPPORT AND EMPOWER

EDUCATION

RESEARCH

ADVOCACY AND AWARENESS



*“IKCS is my favorite meeting of the year for kidney cancer. It is filled with dynamic discussions, fuels collaboration, and furthers best practices in our field. This is the premier event for kidney cancer, and I’m thrilled to be part of it.”*

— Dr. Tian Zhang, Co-Chair 2022 IKCS: North America

## 2022 IKCS: North America

NOV 4-5 | AUSTIN, TEXAS

484

Participants

## 2022 IKCS: Europe

22-24 APRIL | ANTWERP, BELGIUM

352

Participants



# How We Help

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**Dr. David Braun received a 2022 KCA Trailblazer Award for his research on “Dissecting the immunobiology of chromophobe renal cell carcinoma using single-cell transcriptomics.” Dr. Braun is a medical oncologist and an Assistant Professor of Medicine, Pathology, and Urology, and the Goodman and Gilman Yale Scholar at the Yale School of Medicine. We spoke with Dr. Braun about his work and the impact it can have on people with kidney cancer.**

The goal of this project is to improve our understanding of Chromophobe tumors at the bench that can then be translated into new therapies at the bedside and ultimately improve the outcomes of patients with advanced Chromophobe Renal Cell Carcinoma (RCC). The revolution we’ve seen for patients with kidney cancer has touched the lives of so many people with clear cell RCC and with a lot of other different histologies and RCC subtypes – unfortunately, with the exception of most Chromophobe kidney cancers.

As more immunotherapy trials in non-clear cell RCC have come out, the data is really encouraging for many subtypes, but Chromophobe RCC patients consistently seem to benefit less from these therapies.

That’s really the motivating factor for this particular work. I’m interested in tumor immunology and kidney cancer biology broadly, and we’ve applied single-cell methods in clear cells and found some interesting things that helped us understand disease progression and gave us some new targets. That naturally led to using similar methods to better understand Chromophobe and why this histology isn’t responsive to immunotherapy and how we can rethink these types of therapy and what’s needed for this type of tumor.

There are tremendous advances in kidney cancer therapy. Chromophobe has not been at the forefront of that because of the lack of investment in general. Hopefully, we’re at a point where that’s starting to change. There are more people in Chromophobe biology. We have a wonderful toolkit we didn’t have five years ago to dissect the biology of Chromophobe and make those next advances. Now we have an interest in it. And if we’re able to partner with patients who support it, that is the combination that helps to make the big moves.

Read more on [kidneycancer.org](https://www.kidneycancer.org).



# How We Help

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## KCA Trailblazer Award Winners



**David Braun, MD, PhD**  
*Yale School of Medicine*

**RESEARCH:** Dissecting the immunobiology of chromophobe renal cell carcinoma using single-cell transcriptomics



**Nazli Dizman, MD**  
*Yale School of Medicine*

**RESEARCH:** Impact of CBM588 on metabolomic profile in patients with metastatic renal cell carcinoma (mRCC)



**Pooja Ghatalia, MD**  
*Fox Chase Cancer Center*

**RESEARCH:** Comparison of immune microenvironment between patients of African and European ancestry with renal cell carcinoma



**Sheldon Holder, MD, PhD**  
*The Legorreta Cancer Center at Brown University*

**RESEARCH:** Exploration of the causes and effects of increased PIM1 kinase activity in renal cell carcinoma



**Srinivas Viswanathan, MD, PhD**  
*Dana-Farber Cancer Institute*

**RESEARCH:** Advancing a cell surface therapeutic target in translocation renal cell carcinoma



**Yufei Wang, PhD**  
*Dana-Farber Cancer Institute*

**RESEARCH:** Design of CAIX targeted fine-tuned immune restoring safe (FIS) CAR T-cell therapy for metastatic clear cell renal cell carcinoma

## KCA Psychosocial Focus Winner



**Erin Tagai, PhD, MPH**  
*Fox Chase Cancer Center*

**RESEARCH:** Improving patient-reported outcomes for renal cancer patients on active surveillance

# How We Help

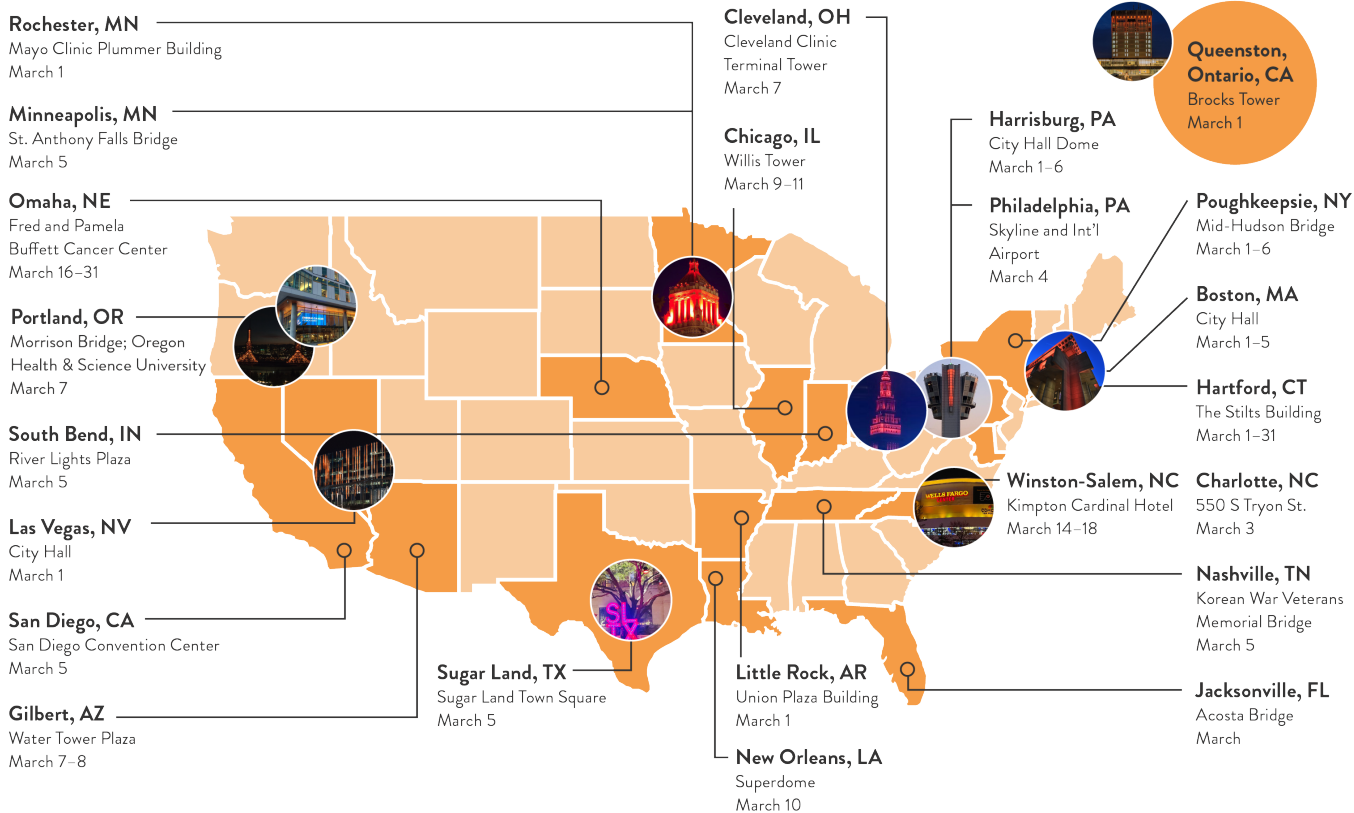
SUPPORT AND EMPOWER

EDUCATION

RESEARCH

ADVOCACY AND AWARENESS

## #OrangeUp for Kidney Cancer Awareness Month!



## Ways we got involved

 Order a free orange awareness ribbon	 Honor a loved one	 Share an awareness graphic
 Sport the orange	 Illuminate your city	 Write an advocate letter
 Fundraise	 Donate	 Be a KCA Ambassador



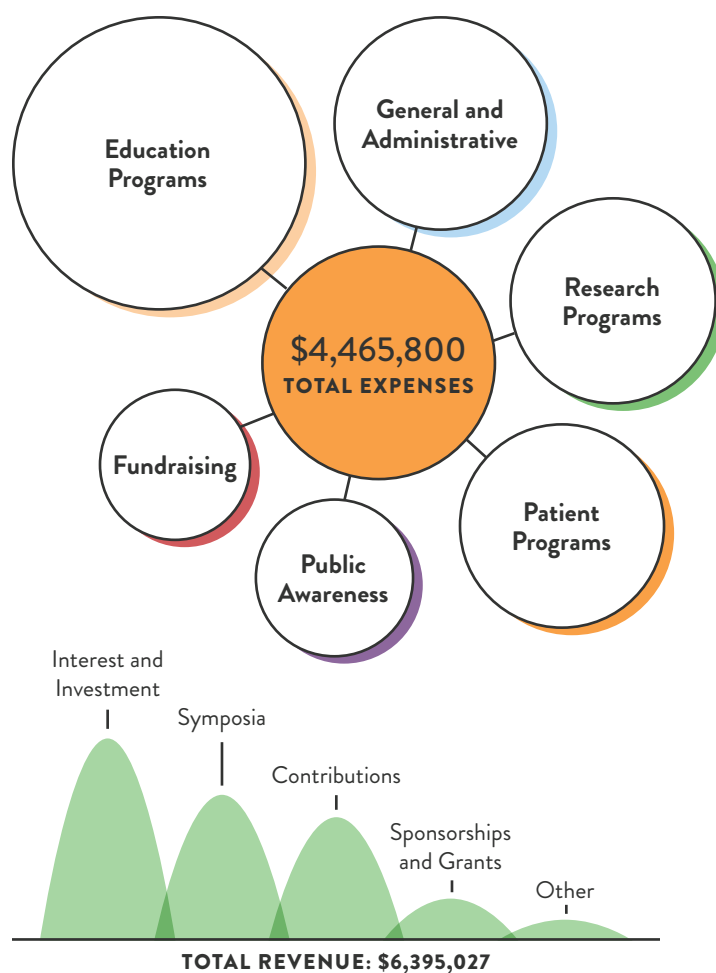
# Financials

## TOTAL EXPENSES

Category	Total
Education Programs	\$1,365,200
General and Administrative	\$874,300
Research Programs	\$774,400
Patient Programs	\$705,000
Public Awareness	\$413,800
Fundraising	\$333,100
<b>Total Expenses</b>	<b>\$4,465,800</b>

## TOTAL REVENUE

Category	Total
Interest and Investment	\$3,404,200
Symposia	\$1,630,600
Contributions	\$941,600
Sponsorships and Grants	\$406,700
Other	\$11,900
<b>Total Revenue</b>	<b>\$6,395,000</b>



## ASSETS

Current Assets	As of Oct 31, 2022	As of Oct 31, 2021 (PY)
Total Bank Accounts	\$590,800	\$1,025,600
Total Accounts Receivable	\$40,000	\$62,000
Total Other Current Assets	\$22,170,300	\$28,283,000
<b>Total Current Assets</b>	<b>\$22,801,100</b>	<b>\$29,370,600</b>
Total Fixed Assets	\$10,500	\$12,800
Total Other Assets	\$504,700	\$624,600
<b>Total Assets</b>	<b>\$23,316,300</b>	<b>\$30,008,000</b>

## LIABILITIES AND EQUITY

Liabilities	As of Oct 31, 2022	As of Oct 31, 2021 (PY)
Accounts/Grants Payable & Accrued Expenses	\$834,300	\$1,079,700
Other Liabilities	\$1,205,400	\$1,116,000
<b>Total Liabilities</b>	<b>\$2,039,800</b>	<b>\$2,195,700</b>
Total Equity	\$21,276,500	\$27,812,400
<b>Total Liabilities and Equity</b>	<b>\$23,316,300</b>	<b>\$30,008,000</b>

# Who We Are

## KCA STAFF

Gretchen E. Vaughan  
President & CEO  
Houston, Texas

Kendall Monroe  
Chief Advancement Officer  
Houston, Texas

LaRanda Burke  
Chief Financial and Operating Officer  
Houston, Texas

Susan Alanis  
Director of Gift Operations  
Houston, Texas

Christina Bargas  
Manager, Events and Education  
Denver, Colorado

Ryan Cerezo  
Development Manager  
Lathrop, California

Radha Chitale  
Senior Director of Communications  
Washington, D.C.

Rosemary Chustak  
Patient Liaison  
Milwaukee, Wisconsin

Christine Kelly-Weaver  
Executive Assistant  
Houston, Texas

Melissa Lopez  
Gift Operations Associate  
Houston, Texas

Amy Marbaugh  
Director of Patient Programs  
Cleveland, Ohio

Emely Rodriguez  
Accountant  
Houston, Texas

Stephanie Shirley  
Director of Advancement Services  
Harrisburg, Pennsylvania

Jeanette Stensgaard  
Senior Director of Events and Education  
Aurora, Colorado

Sarah Tuck  
Program Manager  
Langhorne, Pennsylvania

Maggie Valdes  
Manager of Corporate Partnerships  
Houston, Texas

Angela Washington  
Director of Operations  
Houston, Texas

## BOARD OF DIRECTORS

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Ronald M. Bukowski, MD

Tessa Churchill, MD, MBA

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Daniel J. George, MD

Ryan Natzke

Eric Perakslis, PhD

David Perry, Esq.

Shelley Robson

Brian Shuch, MD

Joel Stern

Laura Wood, RN, MSN, OCN

Nicholas Vogelzang, MD

Ruben Ybarra

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Brian Rini, MD (Vice Chair)

Laurence Albiges, MD, PhD

Axel Bex, MD, PhD

Ronald M. Bukowski, MD (Emeritus)

Jose A. Karam, MD, FACS

Chung-Han Lee, MD, PhD

Bradley C. Leibovich, MD

Pavlos Msaouel, MD, PhD

Sumanta Pal, MD

W. Kimryn Rathmell, MD, PhD

Walter M. Stadler, MD, FACP (Emeritus)

Nizar M. Tannir, MD, FACP (Emeritus)

Tian Zhang, MD

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Nancy Moldawer, RN, MSN (Co-Chair)

Nancy Ainslie, RN, BSN

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Patricia Fischer RN, MSN, OCN

Jan Jackson, RN

Kiran Virdee, RN, BSN, CCRN

Zita Lim, PA-C

Kathryn Nelson, RN

Virginia J. Seery, MSN, RN, ANP-BC

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Kathleen Campbell

Steven Edwards

John Ferrell

Bruce Hill

Susan Hill

Vineeta Hiranandani

Ritchie Johnson

Benjamin Lundin

Deb Maskens

Marissa Willis

Salima Witt

Peggy Zuckerman



# In Memory of Dr. Nicholas Vogelzang

Dr. Nicholas J. Vogelzang, the co-founder and longest-serving board member of the Kidney Cancer Association, died on September 20th, 2022. The KCA became a reality around Dr. Vogelzang's kitchen table in 1990, and he remained a dynamic and steadfast supporter of the organization and its mission throughout his life. As one of the few oncologists working on kidney cancer at the time, Dr. Vogelzang was a beacon for those who were otherwise offered few choices and little hope for their diagnosis. His care and medical prowess helped countless patients and families and his advocacy will help countless more. He was one of a kind.



Dr. Vogelzang was a world-renowned genitourinary (GU) oncologist who specialized in rare cancer types. The KCA honored his legacy and presented him with the inaugural “Kidney Cancer Association Nicholas J. Vogelzang Humanitarian Award.” Dr. Vogelzang's wife, Diane Vogelzang, accepted the award on her husband's behalf during a ceremony at the KCA's 2022 International Kidney Cancer Symposium (IKCS): North America held on November 4–5 in Austin, Texas.

“Improved outcomes for his patients drove him every single day,” Diane said. Recalling a conversation with him not long before his death, Diane said her husband came to realize “[his] legacy wasn't in the boxes they packed for me. It's in the people.”

“Nick was truly a giant in GU medical oncology. He distinguished himself by always going above and beyond for his patients and colleagues with compassion and seemingly endless energy and enthusiasm,” said Dr. Bradley C. Leibovich, Chair of the KCA's Board of Directors and a urologic oncologist at the Mayo Clinic.

“When you consider all the patients he cared for over the years, physicians he taught, and the impact of founding the KCA with Eugene Schonfeld, among many other major accomplishments in oncology, it is clear that he will have a perpetual impact on improving the lives of our patients.”

Dr. Vogelzang spoke often about the importance of putting key resources into the hands of patients and providers alike, knowing that they must work together to solve problems. His work with the KCA to put these ideas into practice was a natural extension of his clinical practice and his personal values.

“My dad was a pastor and my mom a teacher, so service to others was a big part of my family. Church was a big part of our lives, academic excellence was strongly emphasized, and curiosity was always encouraged. My siblings and I share a deep commitment to service to others,” Dr. Vogelzang said, prior to his retirement from the KCA's Board of Directors.

“I have great pride in what the KCA has accomplished thus far and, though I know our important work is not over, I have great hope for the future. The KCA will remain a trusted resource that I'll continue to share with my own patients and fellow medical professionals, and it will always hold a special place in my heart.”



**Dr. Vogelzang also holds a special place in our hearts. We will always remember these words of encouragement as we continue to carry out his vision each day.**

We are able to advocate, support patients, educate families, connect health care professionals, and fuel research to find a cure because of you. Thank you for another unstoppable year!

FROM THE KCA





# KidneyCancerAssociation®

The Kidney Cancer Association is a 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.



**MORE ONLINE  
RESOURCES**

[kidneycancer.org](http://kidneycancer.org)

**KIDNEYCANCER.ORG**

**[office@kidneycancer.org](mailto:office@kidneycancer.org) | 800-850-9132**

**MAILING ADDRESS**

9450 SW Gemini Drive #38269

Beaverton, OR 97008-7105

**DONATION ADDRESS**

PO Box 676226

Dallas, TX 75267-6226

**HQ IN HOUSTON TEXAS**

**@KidneyCancer | #UnstoppableTogether**

