2022
ANNUAL IMPACT REPORT

Strong alone. Unstoppable together.®
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,

Gretchen

A MESSAGE FROM

Gretchen E. Vaughan  
President and CEO, 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**
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**
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

7
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

KCA CONNECT
Care to Share
12 virtual support meetings held this year

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

Just Diagnosed Toolkit

$31,000 was distributed via KCA’s Patient Assistance Fund to 195 people who received a $25, $50, or $250 gift card

2022 IKCS Europe and 2021 IKCS: North America
913 People in 26 Countries

2022 79K CHALLENGE
105 Participants + 494 Donors = $91,989 Raised in the 79K Challenge

436 Patients and caregivers assisted by Patient Liaison
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.
How We Help: International Kidney Cancer Symposium

“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
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.
How We Help

SUPPORT AND EMPOWER
EDUCATION
RESEARCH
ADVOCACY AND AWARENESS

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

#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**

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<th>Category</th>
<th>Total</th>
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<tr>
<td>Education Programs</td>
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<tr>
<td>General and Administrative</td>
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<td>Research Programs</td>
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<td>Patient Programs</td>
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**TOTAL REVENUE**

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**ASSETS**

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<th>As of Oct 31, 2021 (PY)</th>
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<td><strong>Total Assets</strong></td>
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**LIABILITIES AND EQUITY**

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<th>Liabilities</th>
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<th>As of Oct 31, 2021 (PY)</th>
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<td><strong>$23,316,300</strong></td>
<td><strong>$30,008,000</strong></td>
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</tbody>
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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
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Tian Zhang, MD

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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
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.