



KidneyCancerAssociation®



*Full of
Impact*



*Uniting Healthcare
Providers*

IMPACT REPORT 2023

THE KCA IS...

*Supporting
and Empowering
Patients*



*Fueling Research
Toward a Cure*



*Igniting
our Global
Community*



THE KCA IS

Full of *Impact*

316

Virtual Patient
Symposium participants

15 countries • 40 states

100+ PEOPLE ADVOCATED FOR



\$50M

in federal kidney cancer
research funding



2023 IKCS:
North America and
2023 IKCS: Europe

794

Participants

25

Countries

20

support group
meetings

\$16K

was distributed via the KCA's
Patient Assistance Fund to
63 people with \$250 gift cards

2023
82K
CHALLENGE

179 + 612 = \$111,307

participants

donors

raised



Caregiver
Connections



Patient
Perspectives



1,495

Just Diagnosed
Toolkits distributed

475

patients/caregivers
assisted through the
Patient Navigator
Program

2,465

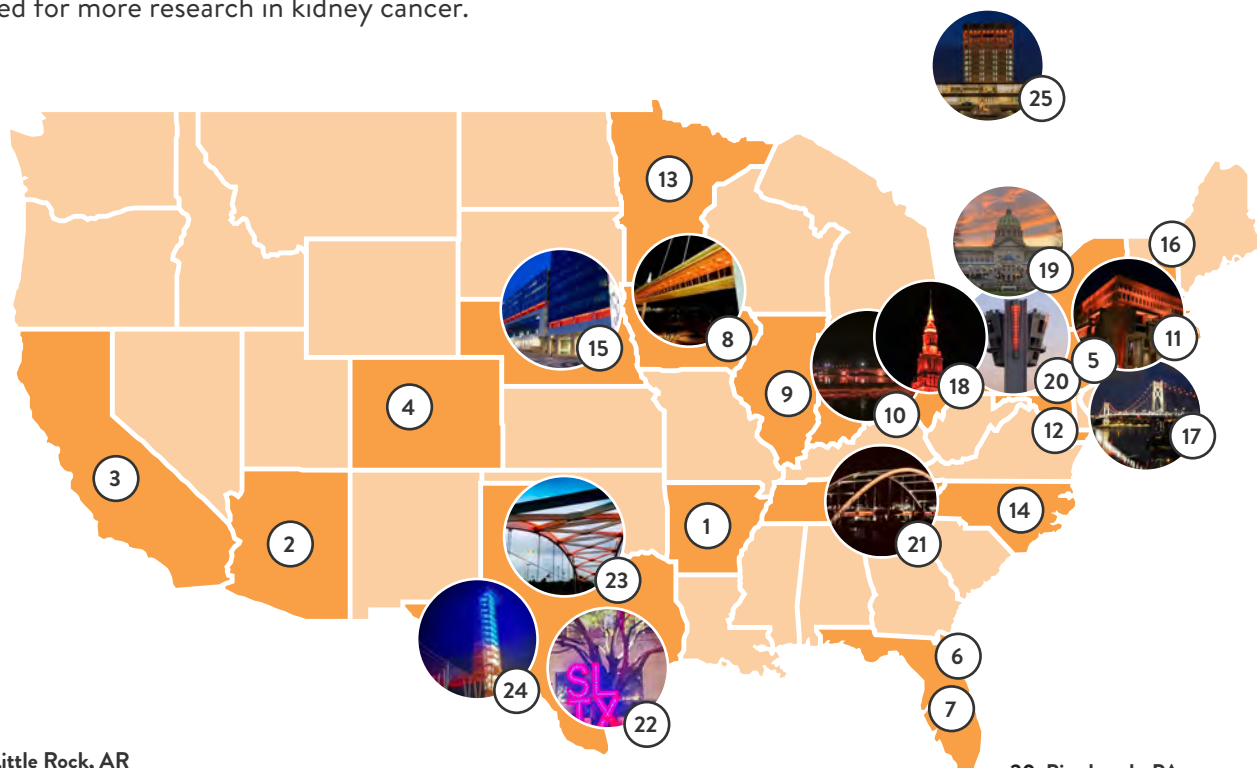
patients impacted through
KCA resources



THE KCA IS

Full of *Impact* in Your Communities!

In March, for Kidney Cancer Awareness Month, you made your cities #OrangeUp! 25 cities illuminated orange to spread awareness and the need for more research in kidney cancer.



1. Little Rock, AR
Union Plaza Building
March 1

2. Gilbert, AZ
Water Tower Plaza
March 4

3. San Diego, CA
Convention Center
March 4

4. Denver, CO
Wynkoop Walkway
March 1-5

5. Hartford, CT
The Stilts Building
March 1-31

6. Jacksonville, FL
Acosta Bridge
March 4-8

7. Orlando, FL
The Wheel at ICON Park
March 11

8. Davenport, IA
Davenport Bridge
March 12

9. Chicago, IL
BCBS Tower
March 8

10. South Bend, IN
River Lights Plaza
March 4

11. Boston, MA
City Hall
March 4

12. Baltimore, MD
City Hall Dome
March 1-3

13. Minneapolis, MN
I-35 W St. Anthony Falls
Bridge
March 4

14. Charlotte, NC
Wells Fargo
March 4

15. Omaha, NE
Fred and Pamela
Buffett Cancer Center
March 3-15

16. Concord, NH
The Hotel Concord
March 4

17. Highland, NY
Mid-Hudson Bridge
March 6

18. Cleveland, OH
Terminal Tower
March 4

19. Harrisburg, PA
City Hall Dome
March 3-5

20. Pittsburgh, PA
Gulf Tower and Koppers
Building
March 4

21. Nashville, TN
Korean War Veterans
Memorial
March 4

22. Sugar Land, TX
Sugar Land Town Square
March 5-10

23. Houston, TX
Montrose Bridges and City
Hall
March 29-31

24. Austin, TX
Fairmont Austin and Circuit
of the Americas
March 4

25. Queenston, Ontario, Canada
Arthur Schmon Tower
March 1

THE KCA IS

Fueling *Research* Toward A Cure

In 2023, we awarded six innovative researchers a total of **\$412,500** in research funding. In the past five years, we have impacted 32 research projects for a total of \$4.9 million.

KCA TRAILBLAZER AWARD



Maria Carlo, MD, Memorial Sloan Kettering Cancer Center
Role of germline and somatic variants in NRF2 pathway genes in renal cell carcinoma



Rana McKay, MD, UC San Diego
Dissecting predictors of response to immunotherapy in patients with renal cell carcinoma

CHROMOPHOBE RCC FOCUS AWARD



Niki Zacharias Millward, PhD, MD Anderson Cancer Center
Leveraging patient-derived xenograft models to identify and therapeutically target metabolic hallmarks of chromophobe renal cell carcinoma

TRANSLOCATION RCC FOCUS AWARD

in partnership with Joey's Wings Foundation



Prateek Khanna, MD, Dana-Farber Cancer Institute
Therapeutic targeting of cell surface antigens in translocation renal cell carcinoma

INTERDISCIPLINARY RCC FOCUS AWARD

supported by the Michael and Ina Korek Foundation Trust



Brendan Guercio, MD, University of Rochester Medical Center
Associations of diet with the gut microbiome among patients with advanced/metastatic RCC receiving immune checkpoint inhibition

UNCLASSIFIED/PAPILLARY RCC FOCUS AWARD

supported by Brandon Butera and Maggie Valdes



Shinji Ohtake, MD, UCLA School of Medicine
Development of Models of NF2 loss in papillary and unclassified variant of kidney cancer

Grant Winner Spotlight



Prateek Khanna, MD
Dana-Farber Cancer Institute

Dr. Prateek Khanna received a 2023 KCA Translocation RCC Focus Award for research on “Therapeutic targeting of cell surface antigens in translocation renal cell carcinoma.” This award was given in partnership with Joey’s Wings Foundation, a KCA Affiliate Partner. Dr. Khanna is a Hematology/Oncology Fellow at the Dana-Farber Cancer Institute in Boston, Massachusetts. We spoke with Dr. Khanna about his research and the impact it can have on people with kidney cancer.

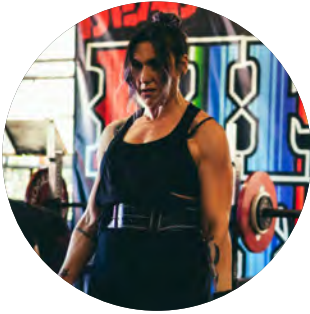
Research Project Summary

Translocation renal cell carcinoma (tRCC) is a rare but aggressive subtype of kidney cancer that constitutes 50% of pediatric and 5% of adult kidney cancer. tRCC is treated with therapies that were developed and tested for other subtypes of kidney cancer and are usually not very effective in tRCC. In this project, we aim to develop a treatment for tRCC directed against a molecular target unique to cell surface of tRCC. This idea is rooted in previous research done by his mentor—Dr. Srinivas Viswanathan (2022 KCA Trailblazer Award recipient)—who identified a surface molecule expressed uniquely in tRCC cells. Dr. Khanna now aims to develop a therapy that engages patients’ own immune T cells to recognize tRCC cancer cells, thereby causing immune mediated cancer cell death.

tRCC is a rare subtype of kidney cancer that was first classified by the WHO as a unique subtype of RCC in 2004. Since then, we have discovered that the biology of tRCC is driven by chromosomal translocations unique to this type of kidney cancer. However, we need to understand in more detail how these chromosomal abnormalities contribute to malignant biology of tRCC and identify potential drug targets. In the meantime, a cell surface-based therapy holds promise since these therapies are based on immune cell biology and have been shown to be beneficial in other cancer types.

The proposed cell surface therapy holds potential as first targeted treatment specifically for tRCC patients. Dr. Khanna is excited about the potential this project has. If we are successful, the treatment could quickly be brought to clinical trials and help patients. It is also a proof of concept to identify more cell surface targets in tRCC and other kidney subtypes, allowing us to develop a depth of targeted therapies for our patients.

Supporting and Empowering Patients



Annamaria's Story

Certified fitness and nutrition coach, KCA Ambassador, kidney cancer survivor

Annamaria Scaccia was diagnosed with kidney cancer in 2020. She is a KCA Ambassador and certified fitness and nutrition coach who helps kidney cancer survivors optimize their performance without sacrificing their health.

Annamaria didn't know it at the time, but when she was diagnosed with kidney cancer in late 2020, her dreams of being an amateur Muay Thai fighter would later shatter. Her urologist hoped to perform a partial nephrectomy, but after cutting into her body and seeing the tumor's location on her left kidney, the urologist decided the whole organ had to go. This meant she couldn't fight in any ring. She traded her gloves for weights and dove headfirst into the world of natural bodybuilding, competing in her first show back in November 2021.

She has been very open and honest about her story on social media, and over the last 2.5 years, she's had several kidney cancer survivors, as well as people with kidney health issues, reach out to her to learn more about her story. They told her that they would "love to be a bodybuilder," but now they "can't" because they've lost a kidney. They recount stories of coaches and doctors who tell them they could never compete again because they can't eat all the protein in the world. And with every conversation, her response was always the same:

"I didn't become a bodybuilder until after I lost my left kidney—and until after my protein intake was cut considerably."

Being a one-kidney bodybuilder is not easy. Bodybuilding is a humbling sport in and of itself, but when you've had a kidney removed, it can feel completely intimidating. Bulking is even slower, nutrition is even harder, and you long for protein fiercely. Where other natural bodybuilders may knock out five shows in a year, you may only be able to compete in two, because you need to be cognizant of putting too much strain on your remaining kidney. Not to mention all the mindset work you need to do to heal, both from the trauma of cancer and how that cancer has altered your body and entire life. Dealing with scanxiety in the middle of prep magnifies the stress of the experience.

But even with the added challenges, it is possible to be a bodybuilder with one kidney. It takes honesty, diligence, resilience, time, and intention.

This past year, Annamaria joined the KCA's Patient & Caregiver Advisory Council (PCAC). She was motivated to get involved because joining the council felt like a natural progression from her advocacy work as a KCA Ambassador. From her early days of survivorship, she focused her advocacy work primarily on nutrition and fitness. As a one-kidney bodybuilder, she couldn't find any real, meaningful information on how to adjust her active lifestyle to her new reality. As a fitness and nutrition coach, she's worked hard to close the gap by providing information, support, and guidance to fitness enthusiasts with kidney health concerns. As a member of the KCA's PCAC, she knows she can continue this mission by teaming up with experts to create science-backed, publicly available resources tailored to patients and survivors interested in fitness and nutrition.

"Just wanting to thank you for all the effort you put into getting me assistance. It's greatly appreciated and actually hard to believe that there are still people in today's society that truly will go above and beyond to get others help these days. Without your help and calls, it wouldn't have been possible for me to have received this. You are truly an angel."

—Patient Assistance Fund Recipient

KCA's Patient Resources

Patient Navigator Program

Just Diagnosed Toolkit

Financial Assistance

KCA Support Groups

Clinical Trial Finder

Patient Video Library

Virtual Patient Symposium

KCA Ambassador Program

Side Effects Tracker

Oncology Nurse Consultant

Ask INA® The Virtual Nutritionist

Smart Patients Online Community

Uniting Together Healthcare Providers



THE KCA NICHOLAS J. VOGELZANG HUMANITARIAN AWARD

This inaugural Award is presented to the late Dr. Nicholas J. Vogelzang, co-founder and long-serving board member of the KCA. It recognizes an individual who has made great impact in highlighting kidney cancer advocacy and made strides to raise awareness and resources to advance kidney cancer treatment and patient care. 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. Dr. Vogelzang died on September 20, 2022.

"Nick was the reason I went into GU Oncology. His energy, charisma, and staunch patient advocacy drew me to him and this specialty. He has arguably had the greatest impact on kidney cancer of anyone, considering his academic accomplishments, mentoring, and co-founding of KCA. Many renal cell carcinoma (RCC) researchers, including myself, owe our success in RCC and contributions in patient care to Nick. I spoke with Nick on the phone and promised him we would keep fighting for better treatments for RCC."

–Dr. Brian Rini, member of the KCA's Medical Steering Committee and Professor of Medicine at the Vanderbilt-Ingram Cancer Center

"I got to know Nick when I joined the KCA's board back in 2000. He was very helpful in choosing which direction the KCA was taking and how we should manage the Association, how we would be able to grow it. I recommended a couple of patients to him in the last few years. He was a great director, very easy to get to know, and I have a lot of respect for him."

–William Perry, kidney cancer patient and member of the KCA's Board of Directors from 2000–2021

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,” 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.”

NEW HEALTHCARE PROVIDER PROGRAM LAUNCHED

Women in RCC empowers and elevates female physicians in kidney cancer to lead and succeed through trainings, mentorship, open forums, and camaraderie. The KCA is proud to be a leader in bringing these woman together.

IMPACTFUL FAST FACTS: INTERNATIONAL KIDNEY CANCER SYMPOSIUM (IKCS) EUROPE AND NORTH AMERICA

89 abstract
submissions

82 posters

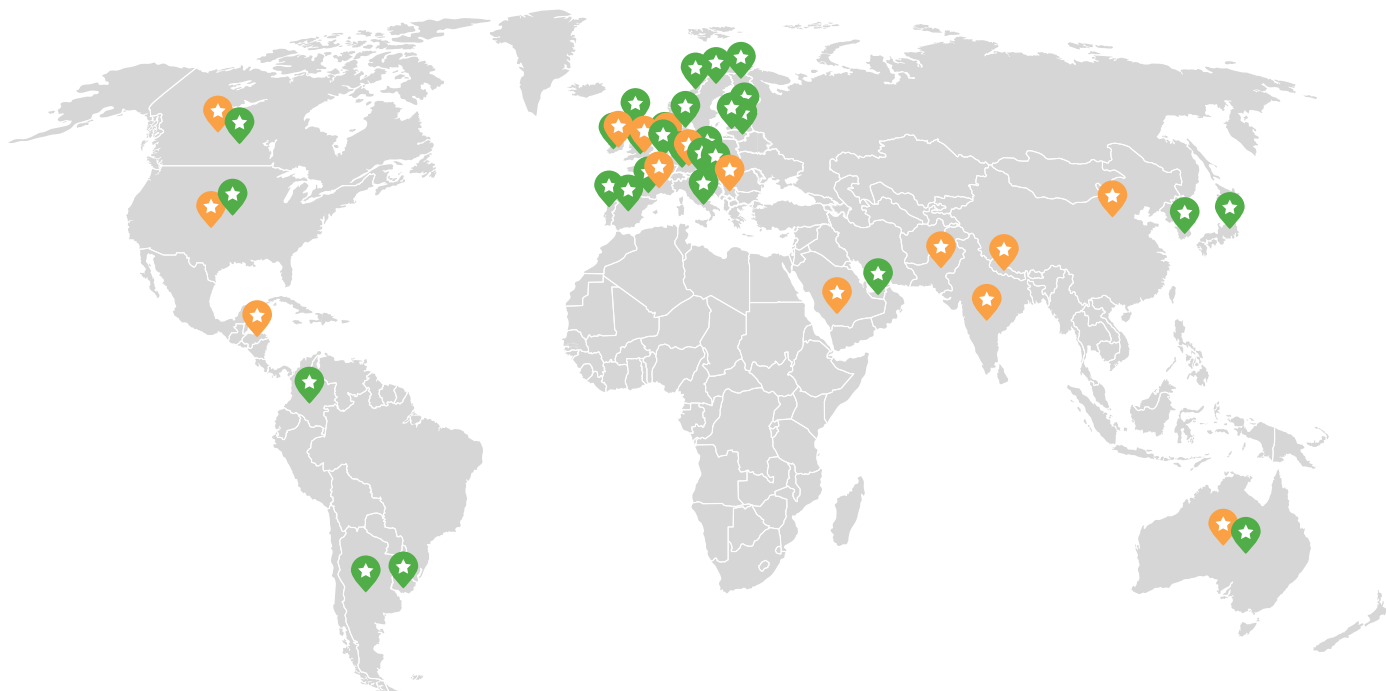
8 oral abstracts
presented

796 total registrants

117 faculty
presented

THE KCA IS

Igniting our Global Community



The KCA works outside the US to assist patients, share educational resources, fund research, and collaborate with physicians.

GLOBAL PATIENT IMPACT



- We assisted 12 people internationally through our Patient Navigator Program
- Wilms Cancer Foundation (Canada) became a KCA Affiliate
- We are active members of the International Kidney Cancer Coalition, representing the KCA and US kidney cancer patients at their meeting in Buenos Aires, Argentina
- Virtual kidney cancer education through our online resources remains high

GLOBAL PHYSICIAN IMPACT



- Led a panel on Advanced RCC management in Argentina, Uruguay, and Korea
- Attendees from 25 countries represented at IKCS: NA and IKCS: EU
- New engagements with five urology societies from Latin America, Europe, the Middle East, and Asia

INTERNATIONAL AWARDEES

- Dr. Robert Jones, Scotland
Keynote Speaker IKCS: EU
- Dr. Arnaud Mejean, France
Fitzpatrick Award IKCS: EU
- Gemma E. Davies, BSc, MSc, United Kingdom
1st place abstract merit award IKCS: NA

Our Affiliate Program

The KCA welcomed six kidney cancer-focused organizations as Affiliate Partners. The KCA's Affiliate Partner program expands the support networks available to people impacted by kidney cancer and allows for strategic collaborations to make advances in research, advocacy, and education.



CHRIS "CJ" JOHNSON FOUNDATION

- In contact with 23 patients who are living with renal medullary carcinoma (RMC)
- Remained in contact with 16 families that have lost loved ones to RMC
- Donated \$10,000 to individuals diagnosed with RMC
- Saw 250 people participate in our in-person 5K Keepin' It Renal event and 150 participate virtually from around the world including Greece, Colombia, Canada, the UK (Ricky Casey Trust Foundation) and the USA. The KCA served as a silver sponsor again.



HLRCC FOUNDATION

- Impacted more than 1,100 patients and families affected by HLRCC through various outlets
- Raised approximately \$3,000 for research and other activities
- Spoke at IKCS to increase knowledge of and attention to HLRCC among healthcare providers
- Reached nearly 1,200 patients and families on social media



CHROMOPHOBE AND ONCOCYTIC TUMOR ALLIANCE

- Raised \$34,700+ for research
- Was supported by 10 businesses "Going Orange" for kidney cancer awareness month
- Partnered with Pattern.org to allow patients to donate their tissue/tumors to research



JOEY'S WINGS

- Raised \$56,000 for research
- Donated \$87,500 to translocation renal cell carcinoma research, including partnership with the KCA's grant
- Co-hosted the Inaugural International Symposium of Translocation Renal Cell Carcinoma
- Financial support given to 22 pediatric kidney cancer families (\$1,000/family)



JUDY NICHOLSON FOUNDATION

- Held 2nd Regional Symposium in Chicago and gained substantial traction, amassing 33,000 views and significantly surpassing average viewership
- Instagram audience expanded by 50%
- Hosted Joel Stern's Virtual "JNF Patient Open Forum" to share experiences and find mutual understanding while navigating the challenges of a kidney cancer diagnosis. Average of 30–50 kidney cancer patients for each monthly gathering
- Held the JNF "Celebrate Life Dinner" on September 22nd which brought together over 50 patients and caregivers from the USA and Canada, representing diverse stages and subtypes of RCC. Hosted in San Antonio, TX, the event encouraged direct interactions between patients and various KCA affiliates, including COA, Joey's Wings Foundation, KCCURE, ThriveWell, and others



THE WILMS CANCER FOUNDATION

- Concluded stage-one initiation of first AI-driven genomic research study into Nephroblastoma (Wilms)
- Shortlisted designation as a "Non-State Actor" by the WHO to provide specialist guidance (to WHO) in the fight against pediatric renal cancer
- Initiated operational launch of key financial support program at 10 sites across eight Sub-Saharan Africa countries

Thank you to our affiliates for representing the KCA as we continue to unlock the cure for kidney cancer together. To learn more about our affiliates visit their websites:



chrisjohnsonfoundation.org



kidneycoa.org



hlrccinfo.org



joeywings.org



jnfkidneycancer.org



wilmsfoundation.org



THE KCA IS

ALL OF YOU

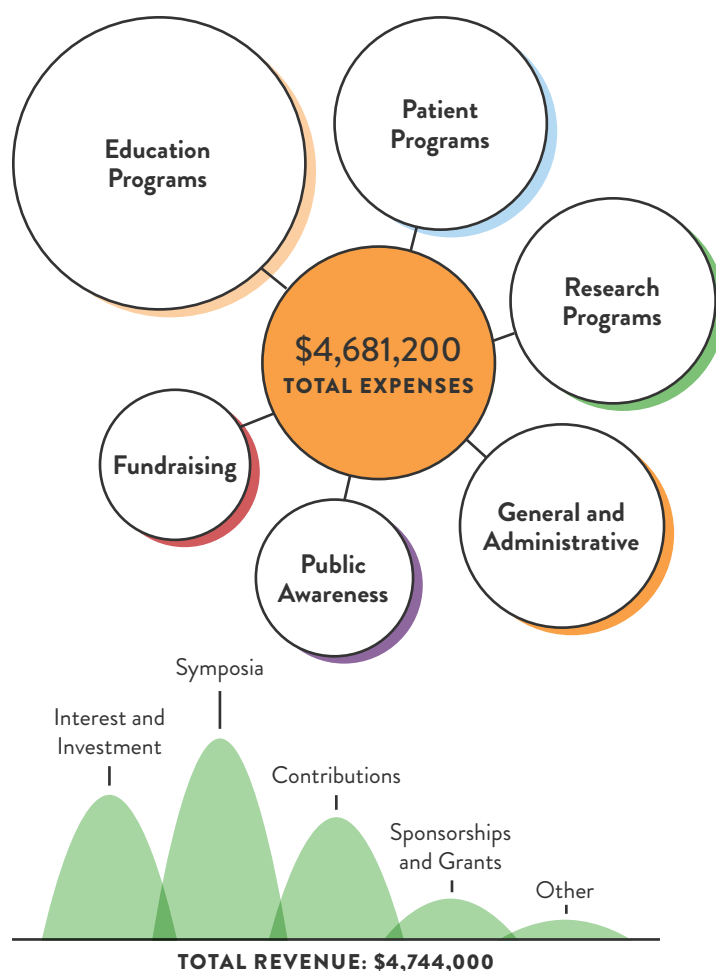
Financials

TOTAL EXPENSES

Category	Total
Education Programs	\$1,526,800
Patient Programs	\$764,500
General and Administrative	\$717,800
Research Programs	\$699,900
Public Awareness	\$440,500
Fundraising	\$531,500
Total Expenses	\$4,681,200

TOTAL REVENUE

Category	Total
Interest and Investment	\$1,528,300
Symposia	\$1,751,500
Contributions	\$968,200
Sponsorships and Grants	\$385,600
Other	\$109,800
Total Revenue	\$4,744,000



ASSETS

Current Assets	As of Oct 31, 2023	As of Oct 31, 2022 (PY)
Total Bank Accounts	\$1,562,700	\$590,800
Total Accounts Receivable	-	\$40,000
Total Other Current Assets	\$21,582,200	\$22,170,300
Total Current Assets	\$23,144,900	\$22,801,100
Total Fixed Assets	\$8,100	\$10,500
Total Other Assets	\$493,300	\$504,700
Total Assets	\$23,646,500	\$23,316,300

LIABILITIES AND EQUITY

Liabilities	As of Oct 31, 2023	As of Oct 31, 2022 (PY)
Accounts/Grants Payable & Accrued Expenses	\$891,500	\$834,300
Other Liabilities	\$1,418,100	\$1,205,400
Total Liabilities	\$2,309,600	\$2,039,800
Total Equity	\$21,338,800	\$21,276,500
Total Liabilities and Equity	\$23,648,500	\$23,316,300

Our Mission and Vision

OUR MISSION

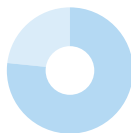
is to be a global community dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education.

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 symposia 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



77%

5-year Relative Survival Rate (2012–2018)



14,890

Estimated deaths in the US in 2023



81,800

Estimated number of new diagnosed cases in the US in 2023



628,355

Number of people living with kidney and renal pelvis cancer



RCC

2/3 of RCC cases are diagnosed early (stage I or II)



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, Collecting Duct, Renal Medullary Carcinoma, Translocation, Unclassified

Key Statistics about Kidney Cancer, American Cancer Society, 2023

Who We Are

KCA STAFF

Gretchen E. Vaughan
President & CEO
Houston, Texas

Kendall Monroe
Chief Advancement Officer
Houston, Texas

Dr. Salvatore La Rosa
Chief Scientific Officer
New York, New York

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
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Lathrop, California

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Washington, D.C.

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Patient Liaison
Milwaukee, Wisconsin

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President and CEO
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Gift Operations Associate
Houston, Texas

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Program Manager
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Maggie Valdes
Manager of Corporate Partnerships
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Angela Washington
Director of Operations
Houston, Texas

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Bruce Hill

Susan Hill

Vineeta Hiranandani

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Matt McClain

Annamaria Scaccia

Cludia Tatum

Marissa Willis

Salima Witt

Peggy Zuckerman

Message from Gretchen E. Vaughan, President and CEO, KCA



As we reflect on 2023 at the KCA, there is one word that seems to encapsulate our year the most: collaboration. This year, more than ever, we've witnessed the strength of unity within the KCA and kidney cancer community. Our shared vision and collective efforts have been pivotal in extending our reach and deepening our impact.

The cornerstone of our collaborative spirit was the launch of our new Affiliate Program. We welcomed six remarkable patient-focused organizations into our fold. This expansion is not just about numbers; it's about the people behind these organizations joining together in a common cause. Together, we have broadened our horizons to reach more patients, amplify our voice, and unify in our mission to conquer kidney cancer.

Our partnerships have also allowed us to amplify voices that offer resources and hope. We've seen firsthand how collaboration can transcend barriers and magnify efforts toward a shared goal. So many of you in our community have contributed to amazing work through cooperation and mutual support.

As I look back on this year, I am filled with immense gratitude and pride for so much. The KCA's journey is a testament to what can be achieved when we come together, combining our strengths and visions. And while we have accomplished much, we look down the road at how much more we still need to do. With your support, we're determined to conquer what's ahead.

Thank you for being an integral part of this journey. Together, we are stronger, louder, and closer to a world free of kidney cancer. Together, we are unstoppable.

With heartfelt thanks,

Gretchen E. Vaughan
President and CEO, Kidney Cancer Association

Message from Dr. Bradley C. Leibovich, *Board Chair*



2023 has been a testament to the relentless need for advancements in kidney cancer research. At the KCA, we stand as the largest organization solely dedicated to bridging the gaps in kidney cancer research and treatment. This year, we've reinforced our commitment to making significant strides in this field.

Our focus has always been clear: to accelerate research breakthroughs and improve patient outcomes. The biggest strides in kidney cancer research and treatment are only possible through collaborative efforts. The KCA has been at the forefront, bringing together the brightest minds and the most passionate hearts in this quest.

Our role as the premier organization in this field comes with a great responsibility: to nurture and foster collaboration among researchers, clinicians, patients, and advocates. We have seen the power of collective effort in driving progress and innovation. It is through our united efforts that we can confront the challenges of kidney cancer, pushing the boundaries of what is possible. We saw this in 2023 through the phenomenal research that was funded.

As we look toward the future, our resolve is stronger than ever. The path ahead is filled with potential, and it is through our collaborative spirit that we will continue to make monumental advances in kidney cancer research.

Thank you for joining us in this vital mission.

With determination and hope,

A handwritten signature in black ink that reads "Bradley Leibovich". The script is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Dr. Bradley C. Leibovich
Board Chair, Kidney Cancer Association



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

KIDNEYCANCER.ORG

office@kidneycancer.org | 800-850-9132

MAILING ADDRESS

2777 Allen Parkway Suite 424

Houston, TX 77019

DONATION ADDRESS

PO Box 676226

Dallas, TX 75267-6226

HQ IN HOUSTON TEXAS

@KidneyCancer | #UnstoppableTogether

