



KidneyCancerAssociation®

IMPACT REPORT 2024

The KCA is the *Heart* of the Kidney Cancer Community

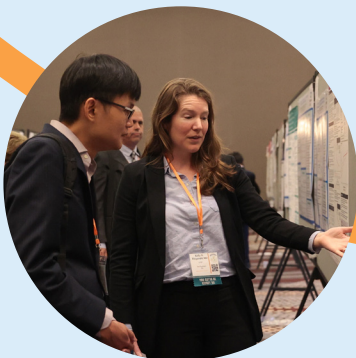


Table of Contents

Introduction Messages — 02

Impact Overview — 04

Supporting Patients — 06

Fueling Research Toward A Cure — 08

Educating Healthcare Providers: Symposia and Beyond — 10

Empowering Women in Kidney Cancer Care — 11

Igniting Community Impact Across the Globe — 12

Affiliates and Partners — 14

Financial Transparency — 15

Introduction Messages

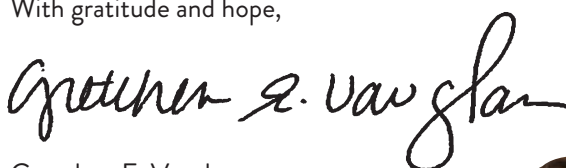
THE HEART OF COMMUNITY

The Kidney Cancer Association is more than just an organization. Together with all of you, we are honored to serve as the heart of the kidney cancer community. We drive passion, resources, and connections throughout an ecosystem of patients, providers, researchers, and advocates. Just as the heart sustains life by circulating what's essential to every part of the body, we ensure that every corner of our community has the support, knowledge, and funding needed to thrive. We are the steady beat that fuels research, empowers patients, and unites partners in our collective mission to conquer kidney cancer.

In 2024, this role as the “heart” of the kidney cancer community inspired all we accomplished. Together, we mobilized local communities to make a global impact, raised vital funds to support groundbreaking projects, and witnessed research breakthroughs that are directly improving lives. We deepened connections with international partners, ensuring more patients than ever had access to critical resources during their cancer journey. We amplified our voice to advocate for increased government research funding and launched transformative collaborative projects, leveraging real-world data in ways no single institution could achieve alone.

Just as every vessel leads back to the heart, we are honored to serve as the unifying force in the fight against kidney cancer. Whether you are a patient, caregiver, industry partner, researcher, or advocate, you are a vital part of this system. Together, we are a living, breathing force for change. And above all else, we have a heart for you.

With gratitude and hope,



Gretchen E. Vaughan
President and CEO



BRIDGES TO BREAKTHROUGHS

As a physician, I've had the privilege of standing alongside patients and their families as they navigate the challenges of a kidney cancer diagnosis. I've seen their courage, their determination, and their unwavering hope. It is this same hope that fuels my work with the Kidney Cancer Association and drives our collective mission to transform the kidney cancer landscape.

At the Kidney Cancer Association, we don't just address today's challenges; we also build the bridges to tomorrow's breakthroughs. In 2024, this has meant advancing research that targets the most urgent gaps in treatment, connecting patients with vital resources, and ensuring that every voice—whether that of a researcher, caregiver, or advocate—is heard and valued.

As a Board member, I've witnessed the profound impact of our programs firsthand. From groundbreaking real-world data initiatives to expanding patient assistance funds, every project reflects our commitment to creating a community that is empowered and informed. Importantly, these efforts are driven by an extraordinary collaboration across disciplines—a true testament to the power of unity in the fight against kidney cancer.

This year's theme focuses on the KCA as the heart of this community, and nothing could resonate more with me. As physicians, we talk about the heart not just as an organ but as a symbol of resilience and connection. That's what the Kidney Cancer Association represents to all of us—a steady, unwavering heartbeat that brings life, hope, and progress to a diverse and interconnected global community.

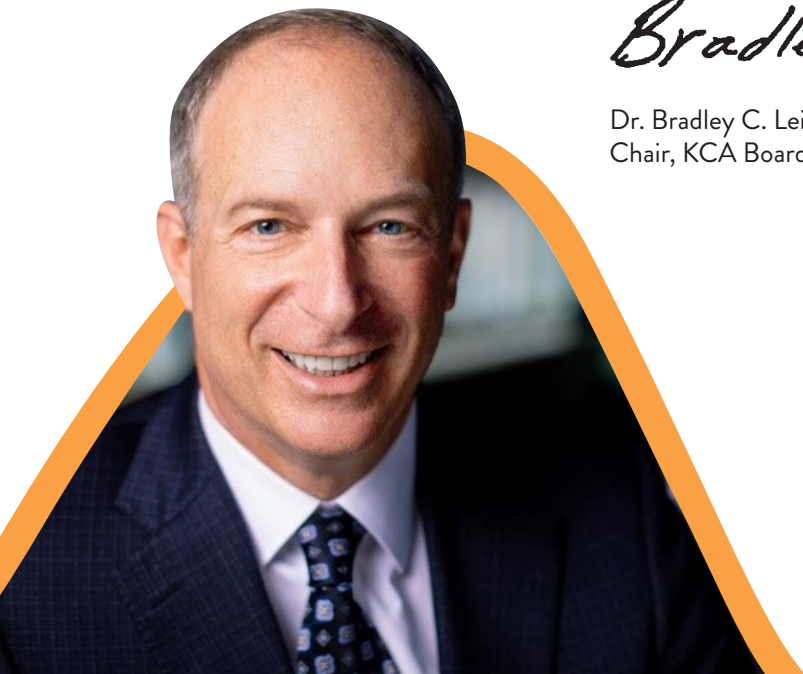
To every patient, family member, researcher, and partner reading this: You are an indispensable part of this journey. Together, we are making strides not just toward better treatments but toward a world where kidney cancer no longer takes lives. Thank you for being a part of this mission.

Gratefully,



Bradley Leibovich

Dr. Bradley C. Leibovich
Chair, KCA Board of Directors



Impact Overview

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.

1

WHERE WE'VE BEEN

Building the Foundation (2019-2023)



Grew our team with 15+ new hires, under leadership of a new CEO.



Enhanced patient educational opportunities through new website content and virtual meetings.



Launched a Legislative Advocacy strategy with a letter-writing portal to connect directly with legislators.



Established expert advisory groups including the Medical Steering Committee, Clinical Advisory Board, Patient and Caregiver Advisory Council, and expanded Board of Directors.



Built community programs: #OrangeUp during Kidney Cancer Awareness Month in March, KCA Challenge annual fundraiser, KCA Ambassadors, and patient storytelling.



Expanded research funding with Trailblazer Awards, Advanced Discovery Awards, and Young Investigator Awards.

2

WHERE WE ARE PATIENT PROGRAMS

Prioritizing Patients and Caregivers



Introduced a Patient Navigator Program.



Developed virtual support groups for patients and caregivers.



Established the Patient Assistance Fund to support financial needs.



Created the Kidney Cancer Unfiltered podcast.



Provided Care Packs for patients and caregivers.

3

WHERE WE ARE RESEARCH INITIATIVES

Addressing Research Gaps



Launched Women in RCC, advancing efforts for women in kidney cancer research and care.



Initiated collaborative research projects focused on kidney cancer knowledge gaps, driving innovation and discovery.

4

WHERE WE'RE GOING A Bold Vision for the Future



Patient Programs

Continue to expand in-person education meetings to generate additional learning and networking opportunities for patients and caregivers with support from the Joel Stern Endowment for Patient Resources.

Create new educational resources for populations at higher risk of being diagnosed with kidney cancer.

Build a long-term survivorship program, with an emphasis for individuals living with one kidney.



Research Initiatives

Fund grants targeting research gaps.

Develop a Mentorship Academy.

Develop Real-World Data research projects.

Host specialized professional workshops and community hackathons.

Explore and develop solutions for complex kidney cancer topics.



Community

Expand Regional Ambassador Events and strengthen involvement in key communities.

Increase focus on local oncology outreach.

Grow Chalk Your Walk to support pediatric initiatives.

Strengthen legislative advocacy efforts with Patient and Caregiver Advisory Council-led committee.

WHY IT MATTERS



This roadmap reflects the lives we've touched and the progress we've made together. Each milestone represents a step closer to a cure. With a strong foundation, we're making strides in patient care and research but the journey ahead is just as critical. Your support keeps us moving forward, ensuring every patient, caregiver, and healthcare provider feels the impact of our mission.

Supporting Patients

"The writing exercise was out of my comfort zone but as soon as I started writing I started crying... As my husband's caretaker, these exercises were an opportunity to just reflect on how this last year has impacted both of our lives."

-Participant from the Virtual Patient Retreat, Co-sponsored by KCA and Respite Retreats

"I am so blessed to have found this group. From what everybody's going through to what I have gone through and I'm still going through...but we're doing the best we can, which is what all of us can do."

-Patient Perspectives virtual support group member

"I liked hearing the doctors discuss how they approach & decide upon treatment. I am encouraged by advances made in treatment options. I am also encouraged by stories from survivors & caregivers."

-Virtual Patient Symposium attendee


WHY IT MATTERS

Behind every number is a person—a patient navigating the challenges of a kidney cancer diagnosis or a caregiver looking for answers. When we provide financial assistance, we're not just covering bills; we're lifting the emotional weight of financial stress. When we distribute toolkits, we're empowering patients with knowledge to make informed decisions. This work ensures that no one faces kidney cancer alone, and it's all possible because of your support.

Patient Assistance Fund

120 Patients **Received** \$250 Visa Gift Cards = \$30,000 Distributed

Patient Navigator Program

445 Inquiries  **Types of Assistance Provided**
Financial, Educational, and Emotional/Psychosocial

CARE PACKS LAUNCHED

28 for Caregivers
25 for Patients

Patient Education Events

VIRTUAL PATIENT SYMPOSIUM: SEPTEMBER

 **349** Registrants


 **132** Unique Users Live

Registrants Represented

17
Countries

43
US States and Territories

Top Sessions

-  Understanding Your Kidney Cancer Radiology Reports
-  How Doctors Decide How To Treat Your Cancer

Faculty

13
Institutions

20
Faculty Members



Amount of Patient Materials distributed

 **845** Downloads

 **1,159** Print-outs

HOUSTON: JUNE



Top Sessions

-  Kidney Cancer 101
-  Patient Stories

Held in conjunction with MD Anderson Cancer Center

NEW ORLEANS: OCTOBER

Top Sessions

-  Kidney Cancer 101
-  Liquid Biopsies: Another Way to Detect Kidney Cancer

Participating institutions: Ochsner Health, LSU, LCMC Health

Virtual Monthly Support Groups

177 
Patient Perspectives attendees

57 
Caregiver Connections attendees

Treatment Center Finder

577
Providers Listed

201
Institutions Promoted

Clinical Trial Finder



Search by **kidney cancer type, stage, and location of trials**

 **Podcast**
2 Seasons Launched



SEASON 1: Jan 30, 2024–Mar 5, 2024

1,153
Downloads

Top Rated Episodes
Cancer at a Young Age (Part I & II)

384
Listeners

The Collective Cancer Experience

Managing Emotions (Part I & II)

SEASON 2: Sep 24, 2024–Nov 26, 2024

Fueling Research Toward a Cure

GRANT RECIPIENTS



Elizabeth Ellis, MD, MS
MD Anderson Cancer Center

Chromophobe RCC Focus Award, in partnership with the Chromophobe and Oncocytic Tumor Alliance (\$75,000)

Evaluating the response of chromophobe renal cell carcinoma to novel targeted metabolic therapies



Mitchell Hayes, MD
H. Lee Moffitt Cancer Center & Research Institute

Trailblazer Award, in partnership with the Michael and Ina Korek Foundation (\$75,000)

Tracing the Seeds of Progression: Spatial Transcriptomic Analysis of Immunoresistant Kidney Cancer



Kaushal Asrani, MBBS, PhD
Johns Hopkins University School of Medicine

Trailblazer Award, in partnership with Joey's Wings Foundation (\$75,000)

Therapeutic Targeting of EGFR and HER2 in Translocation Renal Cell Carcinoma





Yuexin Xu, PhD
Fred Hutchinson Cancer Center

Trailblazer Award (\$75,000)
Characterization of tumor endothelial STAB1-mediated Treg recruitment into renal cell carcinoma



Angela Cappello, PhD
University of Bari "Aldo Moro"

Trailblazer Award (\$39,625)
Drug resistance mechanisms guided by amino acids catabolism in ccRCC



Laura Bukavina, MD, MPH, Msc
Cleveland Clinic

Trailblazer Award (\$75,000)
Assessing the Presence and Impact of Micro- and Nanoplastics Role in Renal Cell Carcinoma

Research Breakthroughs



WHY IT MATTERS



Research is the key to unlocking better treatments and, ultimately, a cure. The grants we fund aren't just investments in science—they're investments in hope. They pave the way for groundbreaking discoveries, like targeted therapies for rare kidney cancer subtypes, which mean longer, healthier lives for patients. Our grants also give researchers a lifelong appreciation for patient advocacy. Every project and every person we support brings us closer to a future where no family has to endure the pain of losing a loved one to kidney cancer.

RESEARCH COLLABORATIONS

TEMPUS

xCures

pattern.org

Celebrating 25 Years of IKCS

The KCA celebrated 25 years of hosting International Kidney Cancer Symposia, recognizing the organization's role fostering collaboration and advancing cutting-edge research for the kidney cancer community with the theme "Bridges to Cure: Innovating Kidney Cancer Care."

Expanded KCA Research Partnerships

Collaborations with organizations like the Cancer Research Institute, American Brain Tumor Association, Chromophobe and Oncocytic Tumor Alliance, American Association for Cancer Research, and co-organizing kidney cancer sessions at events like the 2024 European Multidisciplinary Congress on Urological Cancers have amplified research, advocacy, education, and patient support efforts.

Women in RCC Initiative

This initiative empowers women physicians in kidney cancer through mentorship, networking, and professional development, showcasing their leadership and research contributions. It has grown from a handful of physicians to over 100 participants.

Mentorship Programs

The Kidney Cancer Association Mentorship Academy (KCAMA) and the Dr. Nizar Tannir Rare Kidney Cancer Scholar program connect early-career oncologists with expert mentors, fostering expertise and next-generation leadership in the kidney cancer field.

Innovative Research Projects Funded by KCA

Six KCA-funded research initiatives have tackled critical topics, including rare subtypes like chromophobe RCC, translocation RCC, and the impact of microplastics on cancer, driving novel approaches to kidney cancer treatment and understanding.

Patient-Centered HRQOL Measures for mRCC

Through KCA funding, Dr. Cristiane Bergerot of Grupo Oncoclinicas in Brazil has developed a patient-centered health-related quality of life (HRQOL) measure tailored to metastatic renal cell carcinoma (mRCC) patients. This initiative ensures that patient-reported outcomes, often overlooked in research, are integrated into care delivery. By prioritizing patient needs and experiences, this tool enhances care strategies and supports quality of life improvements.

Single-Cell mtDNA Dynamics in Tumor Research

Supported by a KCA Young Investigator Award, Dr. Ed Reznik of Memorial Sloan Kettering Cancer Center published a study in Nature Genetics exploring the co-regulation of nuclear and mitochondrial genomes in tumors at the single-cell level. This cutting-edge research provides a foundational understanding of tumor biology, paving the way for highly targeted therapies and potential breakthroughs in personalized medicine for kidney cancer patients.

Pathogenic Role of RNASET2 in Clear Cell RCC

KCA-funded investigator Dr. Brandon Manley of Moffitt Cancer Center has uncovered the pathogenic roles of RNASET2 in clear cell renal cell carcinoma, the most common RCC subtype. This research identifies novel mechanisms underlying the disease, creating opportunities for innovative therapeutic approaches that could improve survival and overall patient outcomes.

Think Tank: Coalition for a Cure

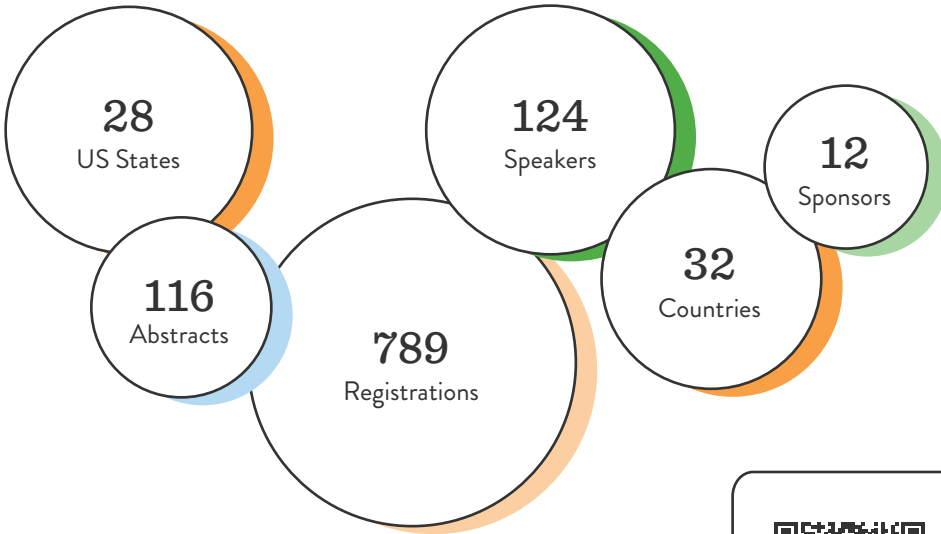
Collaborative forums have united international experts to address key challenges, prioritize research, and advance clinical care in kidney cancer, identifying research gaps for the KCA to target.

Access to AI tools and data to Fuel RCC Advancements

A partnership with philanthropic donors and Tempus focuses on analyzing clinico-genomic data in RCC, chromophobe RCC, and Native American populations to uncover disparities and refine care strategies.

Educating Healthcare Providers

IKCS MEETINGS EUROPE + NORTH AMERICA



Successful Think Tanks: Highlighting key discussions and advancements:



Current State of Digital Pathology and Molecular Diagnostics Consensus Statement.



Featured article in Surgical Oncology Clinics of North America



2024 IKCS: Europe Conference Proceedings: Published for the first time!



WHY IT MATTERS



Every healthcare provider we educate becomes a powerful advocate for improved patient care. Programs like IKCS bring the latest innovations from research to clinics and hospitals, enhancing outcomes for kidney cancer patients. By empowering providers, we create a ripple effect that transforms lives—building a more inclusive, informed, and innovative field of medicine. These efforts ensure a brighter future for patients worldwide.

Empowering Women in Kidney Cancer Care



“These sessions brought us all together and made me realize how all of us are struggling with similar issues. I found tips and tricks to deal with these struggles, and I am hoping to put everything I learned to great use.”

–Women in RCC leadership coaching participant

WHY IT MATTERS



When women succeed, the entire kidney cancer community benefits. Programs like Women in RCC create pathways for mentorship, leadership, and innovation, ensuring diverse perspectives shape the future of research and treatment. This isn't just about equity—it's about unleashing the full potential of the brightest minds to make the biggest impact for patients.



200+
participants supported through all programs



14
women physicians and researchers participated in group leadership coaching that guides career advancement and helps navigate the work environment



3 in-person events hosted

1 virtual event hosted

Igniting Community Impact Across the Globe

A GLOBAL PATIENT STORY

My 2.5-year Journey with Translocation Renal Cell Carcinoma

This is a guest post by Dawn Dyson, 37, who was diagnosed with translocation renal cell carcinoma in 2022. Dawn was a recent speaker at the KCA's 2024 International Kidney Cancer Symposium: Europe in Sitges, Spain, on April 18-20, sharing her own kidney cancer story.

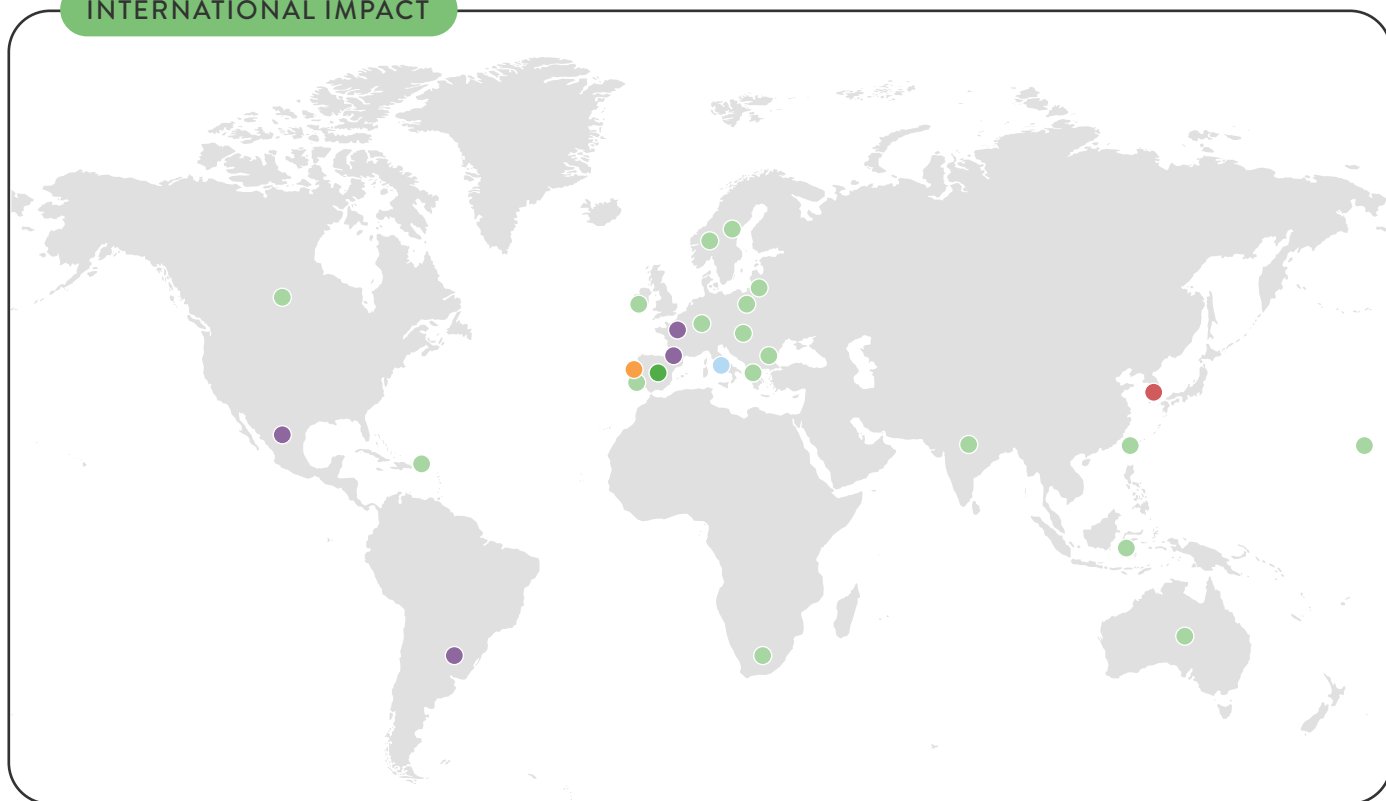
Read more at [kidneycancer.org/stories/dawn-dyson](https://www.kidneycancer.org/stories/dawn-dyson)



WHY IT MATTERS

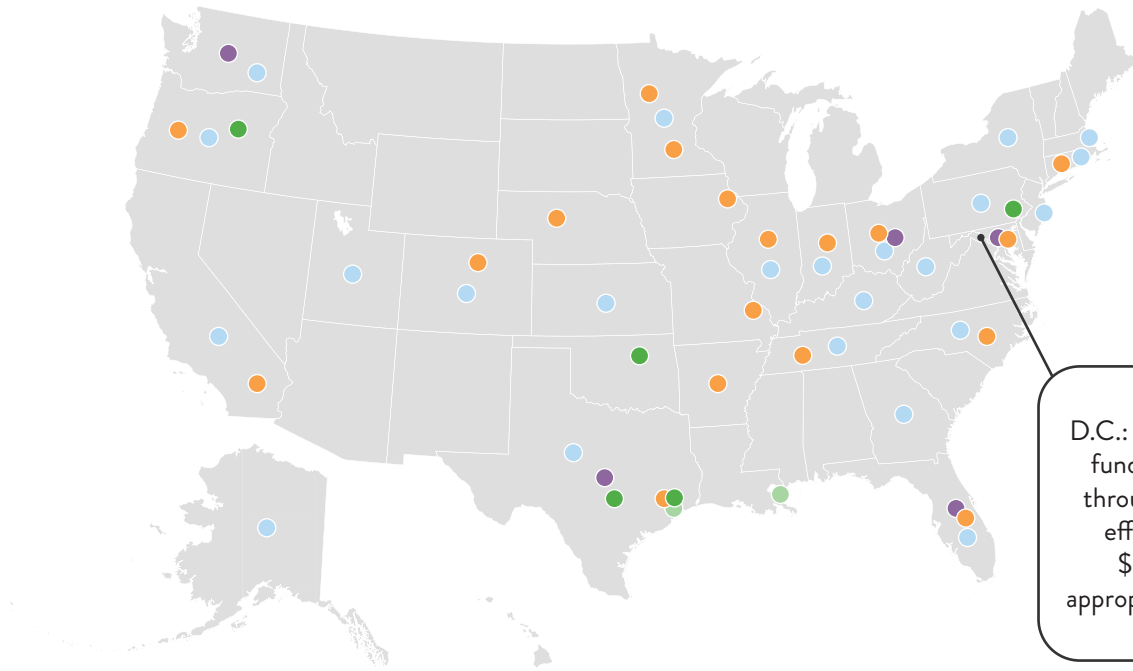
Kidney cancer doesn't stop at borders, and neither do we. Through international partnerships, research, and initiatives, we're ensuring that patients everywhere have access to the resources and support they need. Every global connection we make brings us closer to our ultimate goal: a world free of kidney cancer.

INTERNATIONAL IMPACT



- 2024 IKCS: Europe
- Countries with registered attendees for the Virtual Patient Symposium
- Women in RCC participants
- International Kidney Cancer Coalition meeting
- 2024 European Multidisciplinary Congress on Urological Cancers (EMUC)
- 2024 KCA Trailblazer Award

U.S. IMPACT



D.C.: Federal research funding influenced through community efforts: In FY24 \$50Million in appropriations secured.

● Research Funded
● Patient Symposiums

● 57 letters written by constituents in 23 states

● Cities that #OrangeUp
● 82K Challenge Regional Events

Affiliates and Partners

WHY IT MATTERS



Our affiliates and partners amplify everything we do. They extend our reach, deepen our impact, and bring critical resources to patients in need. Whether it's funding life-saving research or providing direct support to families, these collaborations prove that we're stronger together. By working with others who share our mission, we're accelerating the pace of progress in ways we never could alone.

Supporting Patient Advocacy Partners

Patient Empowerment Network (PEN) – Digitally Empowered®

Cancer + Careers Conferences

American Brain Tumor Association (ABTA) Webinar

Caregiver Action Network – National Family Caregiver Month

Imerman Angels Mentor Program

Respite Retreats Virtual Patient Retreat

Triage Cancer Conferences

Top 5 Accomplishments with Affiliates in 2024



In 2024, we established the Pediatric Renal Tumor Coalition with the goal to elevate childhood cancer research and advocacy in collaboration with Joey's Wings (affiliate), Wilms Tumor Foundation (affiliate), and Elevate Childhood Cancer Research and Advocacy.

Led collaboration to fund the AACR Scholar In Training Program, with Joey's Wings, Chris "CJ" Johnson Foundation, and COA.

2024 KCA Trailblazer Award in partnership with COA.

2024 KCA Trailblazer Award in partnership with Joey's Wings Foundation.

KCA and Judy Nicholson Foundation co-hosted in-person educational symposium for patients in NOLA.

Financial Transparency *Accurate as of 10/31/2024 (unaudited)*



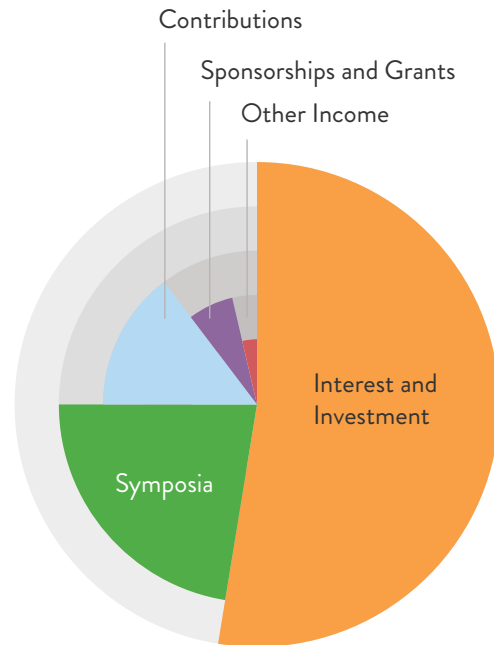
TOTAL EXPENSES

Category	Total
Education Programs	\$1,379,954
Research Programs	\$1,058,405
General and Administrative	\$1,006,959
Patient Programs	\$840,434
Public Awareness	\$579,640
Fundraising	\$370,700
Total Expenses	\$5,236,092

Total Revenue: \$8,744,797

TOTAL REVENUE

Category	Total
Interest and Investment	\$4,989,108
Symposia	\$1,981,125
Contributions	\$1,309,737
Sponsorships and Grants	\$427,068
Other Income	\$37,758
Total Revenue	\$8,744,797



WHY IT MATTERS



We know your trust is invaluable, and we take that responsibility seriously. That's why all philanthropic funding goes directly to programs that make a difference for patients and families. Our endowment covers our operating expenses. Every dollar given is a step closer to a cure, and this report shows exactly how your contributions are transforming lives. Together, we're building a brighter future for everyone impacted by kidney cancer.

KCA STAFF

Gretchen E. Vaughan

President & CEO
Houston, Texas

Salvatore La Rosa, PhD

Chief Scientific Officer
New York, New York

Kendall Monroe

Chief Advancement Officer
Houston, Texas

Ryan Cerezo

Development Manager
Lathrop, California

Radha Chitale

Senior Director of Communications
Washington, D.C.

Rosemary Chustak

Patient Liaison
Milwaukee, Wisconsin

Gabriela Galvan

Program Coordinator
Houston, Texas



M. Nathaniel Haubrich

Director of Finance
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Christine Kelly-Weaver

Executive Assistant
Houston, Texas

Melissa Lopez

Gift Operations Associate
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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

