



KidneyCancerAssociation®

2021
**ANNUAL
IMPACT
REPORT**

Strong alone. Unstoppable together.®

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A Note from Our CEO

This year was a year of growth for the KCA. We built on the foundational work from the prior year, in which we launched many new services to support people with kidney cancer and their families, and made them even more comprehensive and robust.

We've also set the stage to expand our reach to different groups of people impacted by kidney cancer who, whether because of where they live or the type of kidney cancer they have or for any other reason, can often miss out on critical opportunities to get involved in clinical trials, access novel treatments, or simply understand they can take a breath before making big decisions. The Kidney Cancer Association Data Federation will be a major part of this moving forward, and you can read about that more on page 14.

We've also grown as a team. Through a pandemic that continues to impact people across the world, I'm lucky to be part of a group of people whose dedication to their work and to this community is like none other. I count our Board of Directors and advisory councils in this group as well, and we've been honored to expand our Medical Steering Committee, Clinical Advisory Board, and Patient & Caregiver Advisory Council with people who are knowledgeable, dedicated, and passionate about the KCA's mission.

But the year was also marked with tragedy. We lost our dear friend and leader, Dr. Christopher G. Wood, last November after an unexplained neurologic condition. The outpouring of grief, support, memories, and gratitude for his gifts as a surgeon and a mentor showed how pivotal Dr. Wood was to the kidney cancer community. Within the KCA, he was a force nearly since its inception, most recently serving as Chairman of the Board of Directors.

Dr. Wood did so much for others, but personally, his greatest gift to me was his unwavering confidence and support. I can think of no better way to honor him than to carry on with our important work and encourage all of us to reach for a cure that, thanks to Dr. Wood's lifetime of service, is closer than ever.

Thank you for joining us on this journey, and as you read about all we accomplished in the past year and all we hope to do in the future, know that we do it all for you but certainly could not do it without you.



Sincerely,

A handwritten signature in black ink that reads "Gretchen".

Gretchen E. Vaughan

President and CEO, Kidney Cancer Association

In Memoriam: Dr. Christopher G. Wood



Dr. Christopher G. Wood, Chairman of the Kidney Cancer Association's Board of Directors, died on November 3, 2021. Beyond the important role he played in championing the kidney cancer community, Dr. Wood was our dear friend, colleague, mentor, and leader.

When the KCA announced Dr. Wood's death on social media, one patient, Henry, gave a touching tribute. His words beautifully convey Dr. Wood's influence.

"Almost 15 years ago, Dr. Wood diagnosed my first run with renal cancer and was my nephrectomy surgeon. He methodically went through all factors for me, then his game plan (surgery first then chemo and radiation) and then we'd see. The disease was very advanced, had really spread and things didn't look good. Straight talker, rigorously honest, focused – everything I needed.

Two things stood out from that surgery. First, as I was wheeled in he slid over in his wheeled chair, grabbed my hand and said, Henry, I'm going to do everything I can for you. We've the best team here for you today and it's going to be alright, and he held my hand until the anesthesia took over. It's been almost 15 years since that moment and I remember it like it was yesterday. As busy as he was, all the activity around us, the workload ahead, and still the humility to hold a patient's hand. Unreal.

The second item from that surgery is that I never had post-surgical chemo or radiation. His skills, focus, effectiveness, and that of the team he surrounded himself with that day gave me close to 12 years of freedom before the disease surfaced again. My most humble and deep appreciation for his dedication to his craft and his patients and to those who helped him on his journey."

The KCA, and all of us who loved him, will continue to work tirelessly to bring awareness and a cure to the disease he treated with humility, compassion, empathy, and extreme precision.

His laugh was deep, his presence large, and his impact was infinite. He will be greatly missed.

Board of Directors

Lisa Alderson

*Co-Founder and CEO, Genome Medical, Inc.
San Francisco, California*

Ronald M. Bukowski, MD

*Bukowski Consulting LLC
Emeritus Staff, Cleveland Clinic Taussig
Cancer Center
Cleveland, Ohio*

Noah Buntman (Treasurer)

*Operations Program Manager, Apple Inc.
San Francisco, California*

Tessa Churchill, MD, MBA

*Resident Physician, Anesthesiology,
Northwestern Medicine
Chicago, Illinois*

Craig DePriester (Vice Chair)

*Vice President of Clinic Operations,
Optum Care
Los Angeles, California*

Jamie Graves (Secretary)

*Director, State and Local Affairs, BP America
Chicago, Illinois*

Bradley Leibovich, MD, FACS

*Chair, Department of Urology,
Mayo Clinic Cancer Center
Rochester, Minnesota*

Ryan Natzke

*Chief External Affairs Officer,
Marshfield Clinic Health System
Madison, Wisconsin*

Eric Perakslis, PhD

*Rubenstein Fellow, Duke University
Hingham, Massachusetts*

David Perry, Esq.

*Retired, formerly a partner of K&L Gates LLP
Irvine, California*

Shelley Robson

*Senior Director of Trusts, Estates and Gift
Planning, MD Anderson Cancer Center
Houston, Texas*

Gretchen E. Vaughan

*President and Chief Executive Officer,
Kidney Cancer Association
Houston, Texas*

Nicholas J. Vogelzang, MD

*Medical Oncologist, Comprehensive
Cancer Centers of Nevada
Las Vegas, Nevada*

Laura Wood, RN, MSN, OCN

*Research Coordinator, Cleveland Clinic
Taussig Cancer Center
Cleveland, Ohio*

Ruben Ybarra

*Installation Lead/Project Engineer,
Poseidon Services Inc.
Houston, Texas*

Christopher G. Wood, MD, FACS (Chair)

*Professor of Urology and Deputy Chairman,
MD Anderson Cancer Center
Houston, Texas*

Our Mission and Vision

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.

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.

Kidney Cancer Facts



75.2%

5-year Relative Survival
Rate (2010–2016)



13,780

Estimated deaths in
the US in 2021



76,080

Estimated number of
new diagnosed cases in
the US in 2021



558,023

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), and Renal
Medullary Carcinoma

Our Impact This Year



Over **300** patients and caregivers were assisted by our **Patient Liaison**



Launched **KCA Connect: Care to Share**, a virtual monthly support group



Launched **Patient Assistance Fund** to aid patients with financial burden



Advocated to boost federal funding to **\$50M**



73 participants and over **200** donors in annual **76k Challenge**



Funded **\$1,375,000** in kidney cancer research



Over **70+** institutions received **Just Diagnosed Toolkits** to aid their patients



Launched first-of-its-kind grant focused on **psychosocial health**



Virtual Patient Symposium reached **252** people from **14** countries and **41** states



Launched first-of-its-kind **Kidney Cancer Data Federation**



We went virtual! **IKCS 2020: North America** reached **576** people from **39** states and **21** countries. **IKCS 2021: Europe** reached **621** people from **36** countries



Launched **Project Echo** for community practitioners to participate in virtual education and mentorship provided by world-renown kidney cancer experts

How We Help: Support and Empower

Support and Empower • Education • Research • Advocacy and Awareness

PATIENT RESOURCES

When someone receives a kidney cancer diagnosis, they're scared and overwhelmed. But patients and caregivers are not alone. The Kidney Cancer Association is here to walk with patients through the process. Every resource was created to support and empower patients and caregivers.



Patients like...

KENNETH WINTERS

Kenneth G. Winters is a retired US Navy Chaplain and served two tours with the Marine Corps. Physical health has always been important to him, which made his cancer diagnosis a shock when he was diagnosed with stage IV kidney cancer in April 2018. The cancer had also spread to his bones. His oncologist shared gently, “I have to tell you that you are a very sick man.”

Since that day, Kenneth has received a full series of radiation treatments and is now being guided through ongoing immunotherapy. It is “working beyond our best hopes.” Kenneth believes that “Life is meant to be lived, not just survived.”



Caregivers like...

SARAH ROSNER

Sarah Rosner helped care for her father, Stanley. Sarah described her father as “a girl dad, for sure.” As a kid, they would go to the movies together and play card games. When Sarah moved to Chicago as an adult, Stanley would drive in from their family home in Milwaukee, Wisconsin, to visit and go to the zoo or out to lunch for dedicated father-daughter time.

“It didn’t matter if I was doing a play, a musical, or a sport, he and my mom were right there in the front row,” she said. “He was a fun dad, a hard worker, and provided positive energy to everyone around him.”

Stanley’s time facing kidney cancer was swift – he died on March 3, 2016, at age 60, just two months after an unexpected stage IV kidney cancer diagnosis in January.

Patient Resources

- Just Diagnosed Toolkit
- Patient Navigator Program
- Unstoppable Together Newsletter
- Patient Video Library
- KCA Blog
- Ask Ina®: The Intelligent Nutrition Assistant
- KCA Connect: Care to Share
- Virtual Patient Symposium

Just Diagnosed Toolkit

This toolkit aims to help patients and their families make important decisions about their care when they are overwhelmed from just receiving a kidney cancer diagnosis.

→ kidneycancer.org/just-diagnosed/

“My doctor joked that he didn’t know that all he needed to do to get me to talk was point me in the direction of the KCA. Because of the KCA’s Just Diagnosed Toolkit on your website, I felt like I finally knew what questions to ask and how to ask them. I left knowing more about my own cancer after one meeting than I had in months.”

Mike

Living with kidney cancer



Patient Navigator Program

The Patient Navigator Program was launched June 2020 as a place for anyone affected by kidney cancer to receive personalized information, resources, education, and support. A dedicated Patient Liaison responds to inquiries from the kidney cancer community about a recent diagnosis, how to find an expert, questions about treatment, or finding support, in a compassionate and empathetic way.



Rosemary Chustak
KCA's Patient Liaison

→ Contact the Patient Liaison today!
patients@kidneycancer.org or call 1-800-544-3KCA

“On top of becoming the mother of a baby... I had a cancer diagnosis. [My husband] had to quit his job to take care of both the baby and me during this hard time. I am grateful for the KCA’s Patient Liaison, Rosemary, and am so appreciative of the support received through the KCA’s Patient Navigator Program.”

Kayla

Living with kidney cancer

Unstoppable Together Newsletter

The Unstoppable Together Newsletter includes updates from the KCA, stories from the KCA blog, and important news for the whole kidney cancer community.

→ Sign up for our newsletter: secure.kidneycancer.org/np/clients/kca/survey.jsp?forwardedFromSecureDomain=1&surveyId=6

Patient Video Library

Patients, caregivers, and family members can access short videos that answer common questions about kidney cancer explained by kidney cancer specialists.

→ kidneycancer.org/video-library/

KCA Connect: Care to Share

This is the KCA’s virtual peer-led support group for people living with and affected by kidney cancer to connect and learn from each other.

→ kidneycancer.org/kca-connect/

KCA Blog

Check out the KCA blog for patient stories, kidney cancer news stories, conference highlights, and interviews with key KCA stakeholders.

→ kidneycancer.org/blog

Ask Ina®: The Intelligent Nutrition Assistant

Ina® helps people with cancer eat healthy, manage nutrition-related treatment side effects, and stay well-nourished throughout their treatment and beyond.

→ kidneycancer.org/ina-by-savor-health/

Virtual Patient Symposium

This free event is an opportunity for patients and caregivers to learn about kidney cancer from medical professionals and fellow patients, caregivers, and survivors.

→ kidneycancer.org/virtual-patient-symposium/

A patient called the KCA’s Patient Navigator Program. She was frustrated because she was unable to reach her specialist and was concerned with how the lack of communication might affect her treatment. Rosemary, our Patient Liaison, discussed the importance of asking the right questions at each appointment, some specific questions she could ask to address her current concerns, and provided her the [Questions to Ask Your Doctor](#) tip sheet for future reference. The patient was more equipped and empowered with this 1-on-1 assistance!

WE WENT VIRTUAL!

Education: International Kidney Cancer Symposiums

2020 IKCS: NORTH AMERICA REACHED

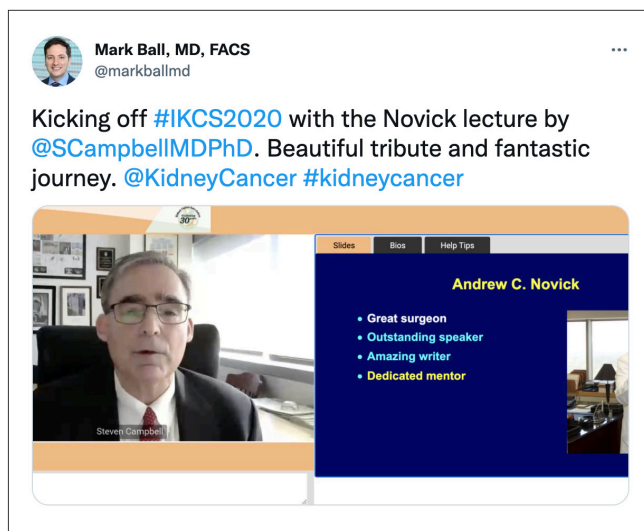
576 people

from 39 states and 21 countries

2021 IKCS: EUROPE REACHED

621 people

from 36 countries



Research: Grants and Data Federation

“Advancing kidney cancer research is integral to moving the needle in kidney cancer and finding new pathways toward a cure. Fueling research is a pillar of the KCA’s mission.”

Gretchen E. Vaughan
KCA President and CEO

GRANT PROGRAM

\$1.375M in Research Awards

The KCA granted two **Advanced Discovery Awards** (ADA), four **Young Investigator Awards** (YIA), and one **Focus Award: Psychosocial** — a total of \$1.375 million in funding— to researchers from around the world who are working to advance early detection of and discover new treatments for kidney cancer.

The Psychosocial Focus Award was a special category introduced in 2021 in response to the need from both patients and researchers for a better understanding of the psychosocial issues facing people impacted by kidney cancer such as mental and emotional health. ADAs support collaborative research between established clinicians and basic scientists while YIAs fund promising new researchers.

2021 Advanced Discovery Award Recipients



Toni Choueiri, MD
Rizwan Romee, MD
Dana-Farber Cancer Institute

Research project: Adoptive cytokine-induced memory-like NK cell therapy alone or in combination with avelumab for immunotherapy-refractory advanced renal cell carcinoma



Jianjun Gao, MD, PhD
Pavlos Msaouel, MD, PhD
*The University of Texas MD
Anderson Cancer Center*

Research project: Identification of tumor frameshift neoantigens to accurately predict response to immune checkpoint therapy in renal cell carcinoma

2021 Young Investigator Award Recipients



Elshad Hasanov, MD, PhD
Eric Jonasch, MD (Mentor)

*The University of Texas MD
Anderson Cancer Center*

Research project: Investigating genomic drivers of immune checkpoint inhibitors resistance in RCC brain metastasis: implications for immunotherapy



Eric C. Kauffman, MD
James Mohler, MD (Mentor)

*Roswell Park Comprehensive
Cancer Center*

Research project: Biology of spontaneously regressing renal cell carcinoma primary tumors



**Nirmish Singla, MD,
MSCS**
**Chetan Bettgowda, MD,
PhD (Mentor)**

Johns Hopkins University

Research project: Tumor evolution of brain-specific tropism in metastatic renal cell carcinoma



Yuexin Xu, PhD
Edus H. Warren, MD, PhD (Mentor)

*Fred Hutchinson Cancer
Research Center*

Research project: Transcriptomic single-cell and spatial mapping of immune cell infiltration and tumor-associated endothelial cell heterogeneity in renal cell

2021 Focus Award: Psychosocial Recipients



Cristiane Bergerot, PhD
*Instituto Unify de Ensino e
Pesquisa, Centro De Cancer de
Brasilia*

Research project: Redefining quality of life assessments in metastatic renal cell carcinoma

“I am immensely grateful and indebted to the Kidney Cancer Association for its generous support in advancing research efforts. I am excited to embark on our next project and hope to pay the investment forward!”

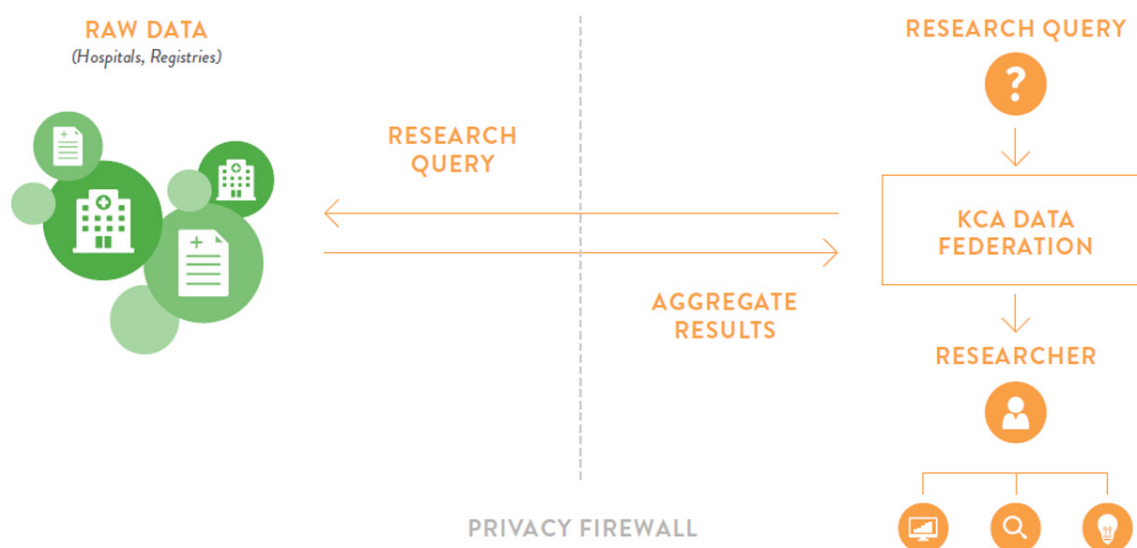
Dr. Nirmish Singla
2021 Young Investigator Award winner

The KCA Data Federation

When it comes to research, data is power. The more we know about the collective medical history, demographics, lifestyle, tumor types, treatments, and other outcomes among people with kidney cancer, the more powerful the toolbox for answering a wider variety of cancer questions.

The KCA Data Federation was launched to help kidney cancer researchers access a larger, more diverse set of data quickly and efficiently through a collaborative, first-of-its-kind model that keeps patients' personal information private. People with kidney cancer can also take an active role in the KCA Data Federation. By contributing their medical information for use in research, patients get the opportunity to help move the needle for others who face the disease.

The KCA Data Federation addresses a trio of obstacles – siloed data, limited data, and maintaining patient privacy – and the resulting research has the potential for unprecedented breakthroughs that will make a meaningful difference to patients and families.



“Despite tremendous advances in the past few decades, many kidney cancer patients don’t respond to treatment and are counting on research breakthroughs to ensure longer, better lives. The KCA Data Federation aims to solve key issues of data quantity and quality facing kidney cancer researchers.”

Sallie McAdoo, MS, CGC
Medical Director, KCA

Advocacy and Awareness

Through legislative advocacy, being a KCA Ambassador, or fundraising in your communities, 2021 was a great year to **Orange Up!**



LEGISLATIVE ADVOCACY

Under the leadership of the American Urological Association, the Kidney Cancer Impact Alliance was created in 2021 to bring together like-minded patients, physicians, and researchers who collaborate to raise awareness, advocate, and increase access for patients and caregivers impacted by kidney cancer and associated conditions.

The KCA participated in this new unified legislative strategy with scheduled meetings with our representatives in addition to our new online letter-writing portal!

Whether you're a patient, caregiver, family member, or friend, you can let your representatives know how kidney cancer affects you. Through our website, the kidney cancer community can stay top-of-mind to legislators by encouraging them to continue funding research.

Our portal provides you a template you can send or edit with your own story. Then, you can send it to House Committee on Appropriation's Chairwoman, Rosa L. DeLauro. Additionally, you can put in your ZIP code to send to your specific congressperson!

In 2021, over 60 people participated in these lobbying efforts to help increase federal research funding for kidney cancer from \$40M to \$50M!

KCA AMBASSADORS

KCA Ambassadors are passionate about kidney cancer and about sharing their passion with others. The KCA relies on Ambassadors to be our eyes, arms, and voice in their communities.

"The new Kidney Cancer Impact Alliance and KCA's letter-writing portal have been crucial in allowing kidney cancer patients to have a voice, even in the middle of a pandemic. It's an easy way to get involved in something that really drives change."

Ryan Natzke
*Chair, KCA Patient & Caregiver
Advisory Council*

MEET KCA AMBASSADOR JASON HINOJOSA

Jason Hinojosa became a KCA Ambassador to further the impact in his own community. As a patient, he knows well the need for resources and awareness in his hometown.



‘You have a mass on your kidney, and I recommend speaking with a urologist ASAP.’ Those words changed my life forever. [After] a full nephrectomy of my right kidney, I was diagnosed with renal cell carcinoma but was lucky that they found it in early stage. I spent the next 6 months recovering, but overall, I was in good spirits. I was only 27.”

Read more about Jason’s story on our [KCA Blog](#).

COMMUNITY FUNDRAISING

In 2021, the kidney cancer community created their own fundraisers all over the country and participated in our KCA’s signature 76k Challenge!

An estimated 76,000 patients were diagnosed with kidney cancer in 2021. In honor of each of them, the KCA’s 76k Challenge asked people to create their own challenge. Participants were creative and set goals like riding a bike 7.6 miles, running for 76 minutes, or spending 7.6 hours meditating. A total of 73 participants and over 200 donors participated!



76k Challenge: Betsey’s Story

Betsey Utter participated in the 76k Challenge for the second year! This time, she and her team planned three walks for 76 minutes each in honor of her dear friend and neighbor, Jane Killam, who has had kidney cancer for 11 years. Her team, Rock Creek Resort, decorated their walk with signs and wore their orange!

CREATE YOUR OWN FUNDRAISER

Ben Lundin created a fundraiser through our easy-to-use portal. He ran 30 miles for his 30 years, all in memory of his dad. “I know that running 30 miles pales in comparison to battling cancer. But I figured this can be my way to say, Thank you, to my dad, who accomplished so much during his lifetime.”

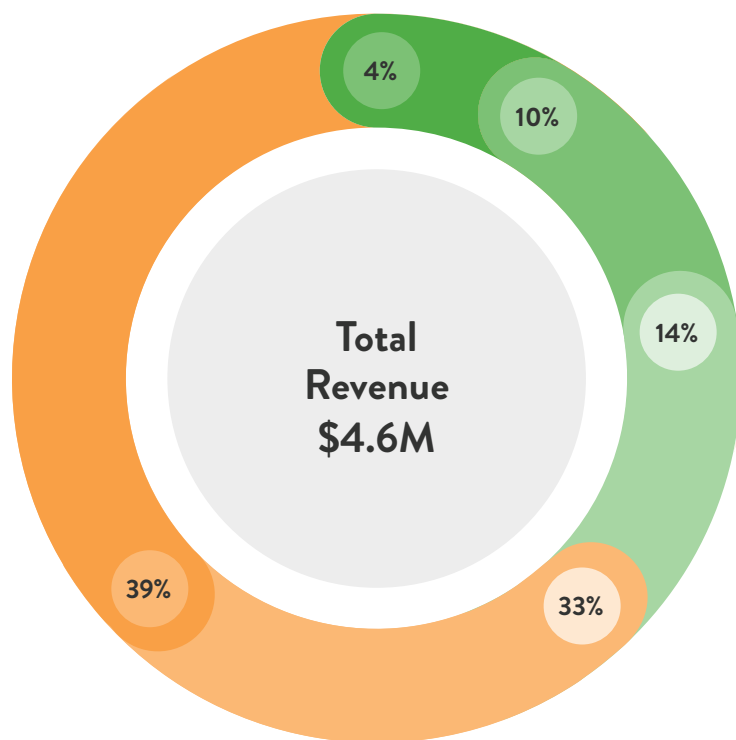
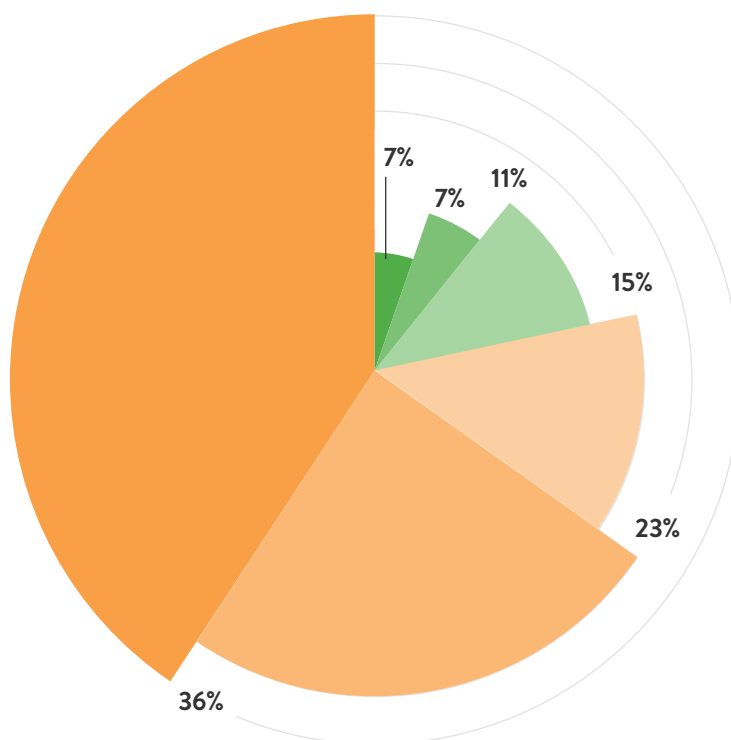


Financials

TOTAL EXPENSES

Cost distribution by category
(numbers in thousands)

Category	Expense
● Research Programs	\$1,480,779
● General and Administrative	\$942,375
● Education Programs	\$629,443
● Patient Programs	\$467,468
● Fundraising	\$307,652
● Public Awareness	\$308,479
Total Expenses	\$4,136,196



TOTAL REVENUE

By sources

Source	Revenue
● Symposia	\$1.8M
● Interest & Investment Income	\$1.5M
● Contributions, Companies	\$641.7K
● Contributions, Individuals	\$462.1K
● Other Income	\$164.7K
Total Revenue	\$4.6M

*Figures presented are accurate as of 12/15/2021 and may be slightly adjusted during final year-end financial review and audit.



Statement of Financial Position

ASSETS

Current Assets	2021	2020
Total Bank Accounts	\$1,020,126	\$5,996,034
Total Accounts Receivable	\$272,000	\$30,376
Other Current Assets	\$28,273,856	\$19,786,108
Total Current Assets	\$29,565,982	\$25,812,518
Total Other Assets	\$624,595	\$558,965
Total Fixed Assets	\$12,797	\$15,124
Total Assets	\$30,203,374	\$26,386,607

LIABILITIES AND EQUITY

Liabilities	2021	2020
Accounts / Grants Payable and Accrued Expenses	\$1,002,727	\$1,128,823
Other Liabilities	\$1,325,988	\$468,600
Total Liabilities	\$2,328,715	\$1,597,423
Total Equity	\$27,874,659	\$24,789,183
Total Liabilities and Equity	\$30,203,374	\$26,386,607

Financial figures are accurate as of 12/15/21.

**Thank you for another
unstoppable year together!**

FROM THE KCA



The KCA Team

Gretchen E. Vaughan

*President & CEO
Houston, Texas*

Kendall Pace Monroe, MPPA

*Chief Advancement Officer
Houston, Texas*

Susan Alanis

*Director of Gift Operations
Houston, Texas*

LaRanda Burke

*Director of Finance
Houston, Texas*

Radha Chitale

*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*

Sallie McAdoo, MS, CGC

*Medical Director
Houston, Texas*

Emely Rodriguez

*Accountant
Houston, Texas*

Ashley Ruggieri

*Director of Patient Advocacy and Partnerships
Philadelphia, Pennsylvania*

Stephanie Shirley

*Director of Advancement Services
Harrisburg, Pennsylvania*

Jeanette Stensgaard

*Director of Conferences and Events
Aurora, Colorado*

Jennifer Vitek

*Director of Conferences and Events
Denver, Colorado*

Angela Washington

*Director of Operations
Houston, Texas*



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

9450 SW Gemini Drive #38269

Beaverton, OR 97008-7105

DONATION ADDRESS

PO Box 676226

Dallas, TX 75267-6226

HQ IN HOUSTON TEXAS

@KidneyCancer | #UnstoppableTogether

