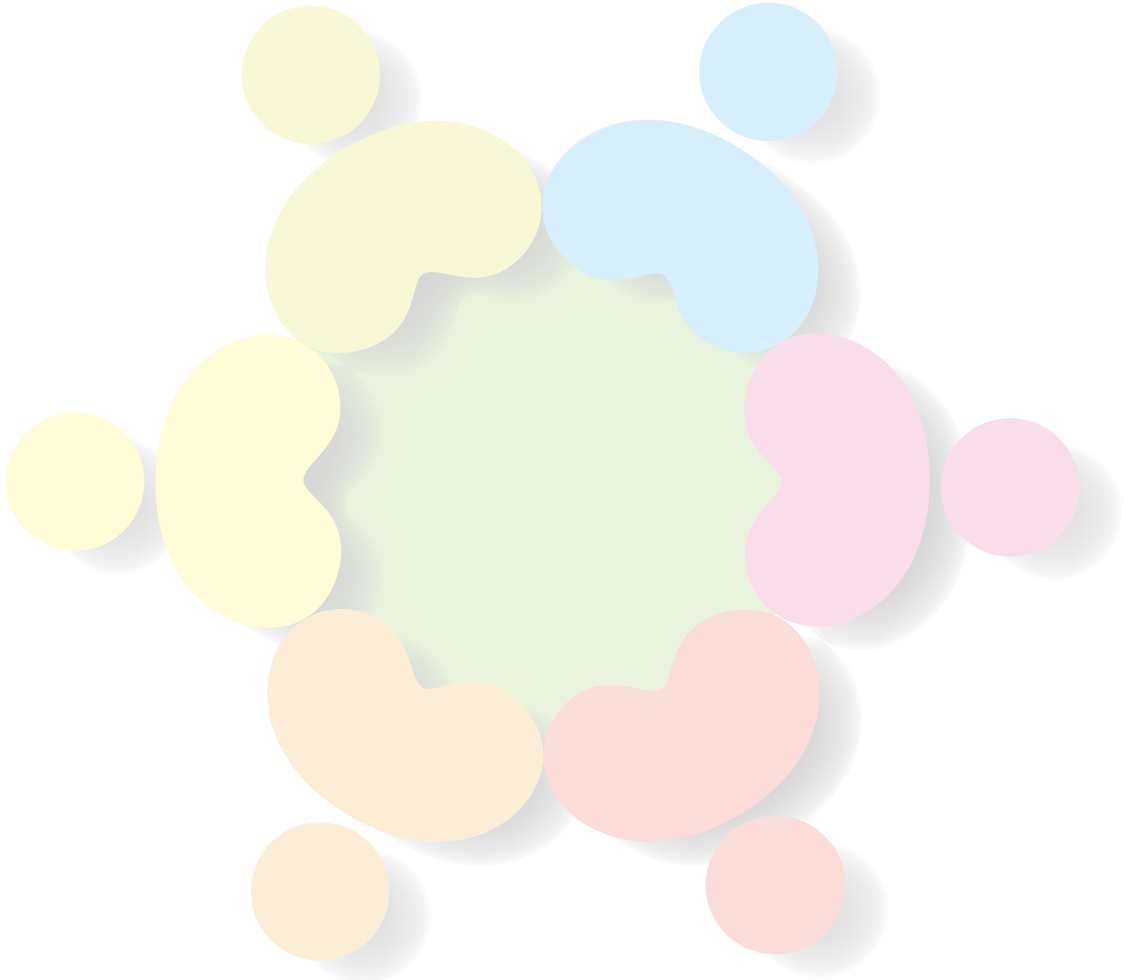


# IKCC Annual Report 2023



**The only global  
patient-driven organisation  
focused on improving  
kidney cancer research,  
treatment, care  
and survivorship.**



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# Message from the Chair



**Dr Michael Jewett**

*IKCC Board Chair*

I have always sought to be part of positive change in any organisation that I have been part of. As a clinician, I am hardwired to try to make things better. So, I am particularly happy to report that 2023 brought many positive changes in IKCC, and I'm confident that we will look back on this year as an even bigger positive inflection point than past years. Like a snowball rolling downhill, we will continue to get stronger at an ever increasing rate in the forthcoming years.

Between 2020 and 2022, like nearly all organisations, IKCC was operating in uncharted territory due to the upheaval of the global pandemic. Our strategic aspirations were put aside as we focused on supporting patients, Partner Organisations, and the global kidney cancer community as best we could. Like a snowball rolling downhill, we will continue to get stronger at an ever increasing rate in the forthcoming years.

The Board was finally able to complete the IKCC strategic plan that is presented here (a process which began in January 2020). It will guide us through the next evolution and build on our strong foundation established in 2009.

At the heart of everything we do, we are focused on Empowering Patient Organisations. We are not in the business of direct patient interaction or support but aim to pave the way for the network of Partner Organisations connected through IKCC to do this locally. We promote the Patient Voice, globally and regionally, provide Research and Information that is evidence-based, and Advocate for Access to Treatments for all people living with kidney cancer, no matter where they live.

To pursue these strategic directions, we focused on improving governance, increasing communication, and strengthening our operational capacity.

# Empowering Patient Organisations



Patient  
Voice



Research &  
Information



Advocacy



Awareness

Communications



GOVERNANCE



OPERATIONS



Look for how IKCC's Strategic Priorities come to life  
in the work we do throughout this report.

## Message from the Chair

In January, we hired our former Board Chair Rachel Giles to be the CEO and lead the organisation. Increasing our bench strength with a more robust and expanded team has helped move our strategic directions forward in a more systematic way. This has included improving transparency and communications and diversifying our income. For the first time in 2023, a new significant source of our income came from European grants for projects that have a global impact on the experiences and outcomes of (kidney) cancer patients.

We have improved our communications, creating more opportunities for connection and touch points with the IKCC network of patient organisations. These efforts are intended to make sure the work being done around the world is shared with Partner Organisations. It is this sharing, learning and connection that is at the heart of how we are stronger together as a Coalition.

In 2021, we added rotating patient and carer representative positions to the Board to firmly entrench the patient voice in our deliberations. These Board members are selected for their firsthand personal experience as patients or carers. Christine Colins (CA) and Liz Leff (US), the inaugural representatives, completed their terms on the Board – we deeply thank them for all their contributions. In November, we welcomed two new patient representatives to the IKCC Board – Claudia Ungarelli from Anture in Italy and Caleb Egwuenu from Move Against Cancer Africa (MACA) in Nigeria. Based on patient representative and Board feedback, we have refreshed the onboarding and established a Board mentoring process. This is just one way we are addressing improved governance, and you can expect to hear more on this in 2024.

We would also be remiss not to take a moment to acknowledge the many years of service from founding IKCC Board member Rose Woodward (UK). Rose generously contributed her personal and professional expertise to IKCC. Specifically, she brought her passion for advocacy and amplifying the patient voice to the work we do. We are very happy Rose has agreed to stay involved as an IKCC Board Ambassador and will continue to generously support the global patient community. Thank you Rose!

We are also very pleased that ANTURE in Italy, the Canadian VHL Alliance in Canada and Vicare in Argentina have joined the Coalition, bringing our network of Partner Organisations to a total of 51! As of now, together IKCC is representing 1.2 million people living with or affected by kidney cancer worldwide.

I'm proud of what IKCC has achieved this year, and I am honoured to be part of this important inflection year for our organisation. But even more so, I'm excited by where we are going and how we as an organisation and a Board continue to mature and evolve.

On behalf of the Board, a tremendous thank you to each person who contributed to this year – together we are making a global impact.

Sincerely,



*Chair, IKCC Board of Directors*

# About IKCC

International Kidney Cancer Coalition (IKCC) is the only global patient-driven organisation focused on kidney cancer. The Coalition of more than 50 patient organisations connected through IKCC collaborate, share and learn from each other with the goal of reducing the burden of kidney cancer worldwide. Together we are making a global impact by improving research, treatment, care and survivorship.

Our work is grounded in evidence that reflects the experiences of patients, carers and healthcare professionals. This information is shared and incorporated when decisions are made about kidney cancer research, treatment and support. This knowledge and understanding also ensures education, awareness and advocacy programs respond to the needs of people living with kidney cancer.

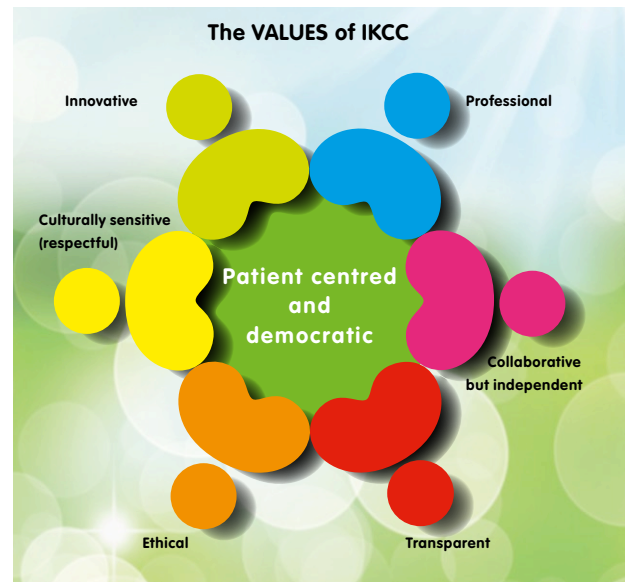
Kidney cancer is a global issue. Since the 1970s, the global incidence rates of kidney cancer have been increasing<sup>1</sup>. Currently, it is estimated around the world more than 431,000 people are diagnosed with kidney cancer<sup>2</sup> and approximately 180,000 people die from the disease every year<sup>3</sup>. However, when local efforts are coupled with a global approach, we can have the greatest impact on improving health equity and patient outcomes for people with kidney cancer.

**Our Mission:** IKCC is a global collaboration of patient organisations that empowers and represents the kidney cancer community through advocacy, awareness, information and research.

**Our Vision:** To reduce the global burden of kidney cancer.

IKCC is committed to achieving our vision through these strategic pathways:

- Empowering patient organisations to reduce the disease burden for local patient populations
- Promoting patient voice with global policy-making, healthcare and industry audiences
- Providing research and information that is quality-assured, strengthening our influence and has impact for patients
- Advocating for access to treatments for all people, no matter where they live
- Raising awareness of kidney cancer and the best ways to reduce the global burden of disease



IKCC works in partnership with the following international organisations, collaborating to help improve the lives of cancer patients around the world.



1) *J Clin Oncol.* 2018 Dec 20; 36(36): 3574–3581. 2) Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, Bray F. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2021 Feb 4. doi: 10.3322/caac.21660. Epub ahead of print. PMID: 33538338. 3) World Cancer Research Fund International website. Accessed October 23, 2023. <https://www.wcrf.org/cancer-trends/kidney-cancer-statistics/>






# 2023: IKCC by the Numbers



**51** IKCC patient organisations worldwide are connected through IKCC. Together we are representing **1.2 million** kidney cancer patients globally!



**3** new Partner Organisations in 2023

-  Vicare Argentine Association of patients and relatives with kidney and bladder cancer
-  Canadian VHL Alliance
-  ANTURE - Italian Kidney Cancer Association



Growing IKCC's Social Media Community

- 4,729** X followers (Twitter)
- 8,944** Facebook likes
- 246** LinkedIn followers



At the 2023 Global Kidney Cancer Summit **71** delegates from **23** countries spent **3** days together!



World Kidney Cancer Day 2023

- 3.2+ million** impressions
- 2.5 million** video views
- 62K+** website visits
- ~ 600** symposium attendees



IKCC represented people living with kidney cancer at **29** national and international conferences and meetings



IKCC published **14** papers in medical journals



**5** editions of the IKCC Newsletter were sent to **490** subscribers

ASCO Genitourinary  
Cancers Symposium

2023 ASCO  
ANNUAL MEETING

MADRID 2023 ESMO congress

**3** Conference Summaries shared from GU ASCO, ASCO, ESMO. The EMSO Summary was shared in **3** languages!



# Global Patient Survey on Kidney Cancer – Sharing the 2022 Results

IKCC's work is grounded in evidence that reflects the experiences of people impacted by kidney cancer. Central to this commitment is conducting the biennial Global Patient Survey on Kidney Cancer. Every two years the data that identifies geographic variations in patients' education, experience and awareness are collected and the following year the results are analysed and shared.

In 2023, the results of the 3rd Global Patient Survey (GPS) held at the end of 2022 were shared, highlighting unmet needs and global benchmarks related to patients' access to care, quality of life, involvement in clinical trials and shared decision-making.

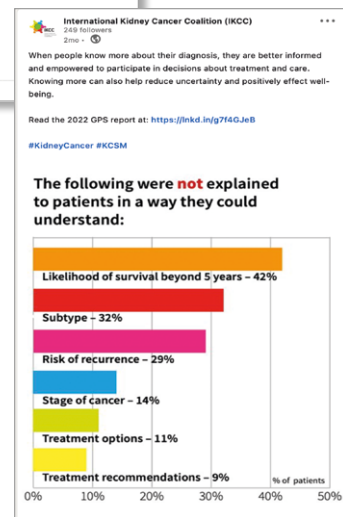
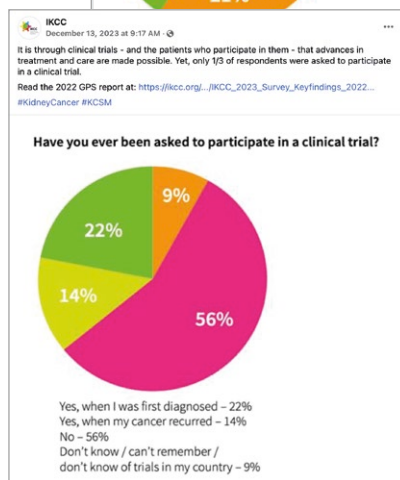
**The results of the 2022 GPS are available on the IKCC website in various formats:**

- [2022 GPS Highlights Report](#)
- [2022 GPS Infographic](#)
- [2022 GPS Report \(Global\)](#)

In addition, Country-Specific Reports are made available when more than 100 people in one country complete the survey. Country-Specific Reports were created for Canada, France, Germany, India, Japan, Mexico, the Republic of Korea, South Africa, the United Kingdom and the United States – more than any previous year!

The survey results are foundational to the work we do to respond to and represent the needs of people living with kidney cancer. The data are incorporated into education, awareness, and advocacy programs, both at a global level and those led locally by patient organisations connected through IKCC.

Thank you to everyone who played a part in making the Global Patient Survey 2022 a success. We are grateful to the global network of patient organisations who helped create, adapted and promoted the survey. We also thank all the patients and carers who completed the survey and shared their insights and experiences. Together we are helping to improve the experience of people affected by kidney cancer.





## Kidney Cancer Advocacy Feasibility Pilot

In 2023, IKCC sought to answer the following questions: Does kidney cancer have advocacy training needs that are unique from other cancers? And, if so, how can we address these needs?

To find out, IKCC hosted the Kidney Cancer Advocacy Feasibility Pilot Program the day before ESMO 2023 in Madrid (ES). The program was led by Rachel Giles, CEO of IKCC, with the help of Dr Ana Amariutei of the European Patient Advocacy Institute, and cancer advocates were invited to attend to provide their perspectives. The pilot program assessed the learning needs for kidney cancer advocates and discussed potential opportunities for future advocacy training programs.

The day-long session began with education about kidney cancer and IKCC. Then the group focused on advocacy topics such as kidney cancer patients' unmet needs, funding gaps in kidney cancer, and evidence-based advocacy. The session also included two interactive, hands-on exercises that taught participants how to prepare country-specific fact sheets about kidney cancer and navigate academic databases to support advocacy efforts.

Participants were surveyed at the beginning and the end of the session to assess the pilot program and evaluate the value of disease-specific advocacy training. The overall response from the participants was enthusiastic. The feedback was clear about the high value of kidney cancer-specific training to support patient organisations and direction on how to create training programs to initiate and sustain regional advocacy efforts. IKCC will move forward in exploring how these needs can best be met.

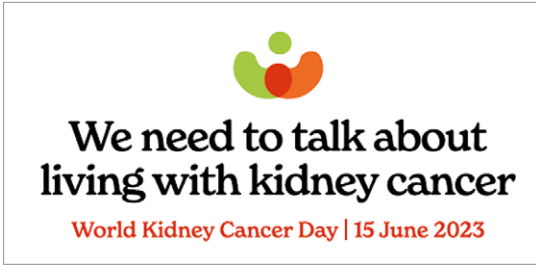


***“It was a very practical and useful workshop. I learned a lot of new things. I would be very interested in delving deeper into the processes of evidence-based advocacy and grassroots advocacy, particularly through case studies related to access to treatment and learn how we can contribute to designing clinical trials that are beneficial to patients.”***

*Claudia Ungarelli, ANTURE, Italy*



# World Kidney Cancer Day 2023:



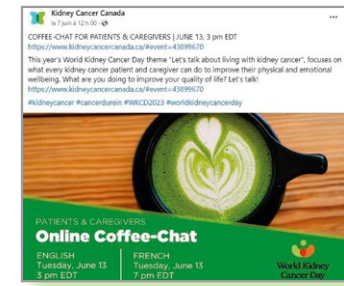
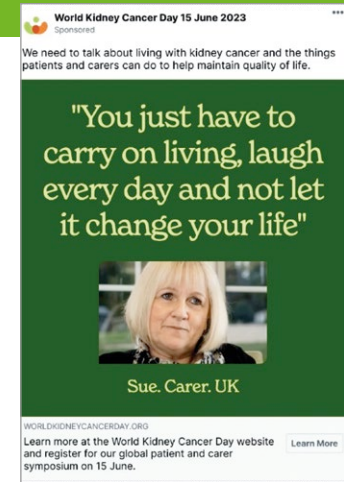
The importance of survivorship was the focus of World Kidney Cancer Day 2023. The campaign theme – *We need to talk about living with kidney cancer* – aimed to educate patients, survivors and caregivers about how to live their best life possible.

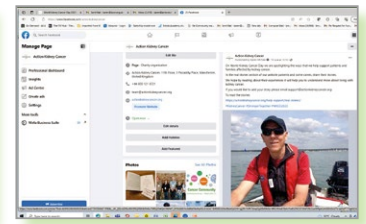
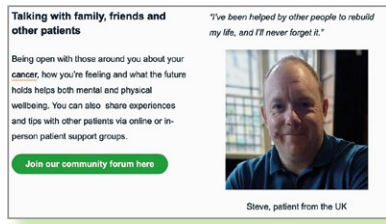
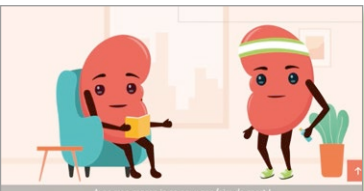
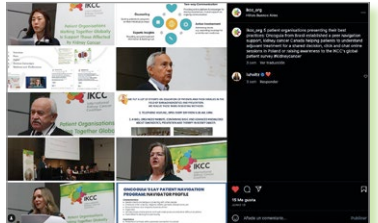
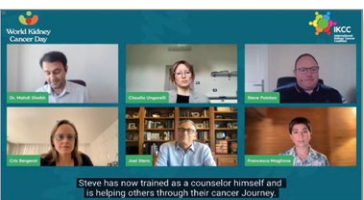
Patient voice and the lived experiences of those affected by kidney cancer were central to the awareness campaign and patients and carers from the United Kingdom, the United States and Italy were interviewed to inform the program.

As such, the focus was on the many aspects of living with the disease, including quality of life, social supports, physical activity and nutrition. The campaign culminated on 15 June where these topics and more were discussed at a virtual Global Patient and Carer Symposium and patients, carers and healthcare professionals shared their expertise and practical advice.

World Kidney Cancer Day campaign materials were available in **15 languages** and patient organisations connected through IKCC had the opportunity to engage local communities in the campaign in a variety of ways.

Overall, the campaign materials achieved ~ **3.2 million impressions**, **62,854 website visits**, more than **2.5 million views of the videos**, and nearly **600 people** attended the symposium. In addition, local activities by national patient organisations reached many more people with this important information and overall raised awareness for kidney cancer.





## New in 2023: Connect and Share Webinar Series

The Coalition of patient organisations connected through IKCC is a global collaboration working together to reduce the burden of kidney cancer through sharing and learning from each other. Based on feedback asking for more regular contact, the Connect and Share Webinar series was launched.

The online facilitated discussion forum is an opportunity for all Coalition members to connect with each other and share best practices. In 2023, two Connect and Share Webinars took place. In May, the open-house format allowed participants to get to know the IKCC Board and CEO Rachel Giles. In September, the focus was on peer support programs and Kidney Cancer Canada and the Instituto Oncogua in Brazil shared their experiences.

*Connect and Share Webinars* will continue on a quarterly basis in 2024.



***“A valuable part of being part of IKCC over the years is having the opportunity to learn and share with others who are having similar experiences or have already crossed the hurdles we are facing as an organisation. Connect and Share offers that type of collaboration more often, helping to make each one of our organisations stronger, but together.”***

*Caleb Egwenu Move Against Cancer Africa, Nigeria*





## Representing the Voice and Values of Kidney Cancer Patients

IKCC is a global collaboration of patient organisations that both empowers and represents the kidney cancer community through advocacy, awareness, information and research to generate evidence to further our advocacy efforts. As part of this commitment, IKCC via members of its Board of Directors and Medical Advisory Board attend conferences, have a seat at the table among major healthcare decision-makers, participate on committees and advisory groups including guideline development, and publish in scientific journals, newsletters and other medical-based outlets.

Through these efforts, the voice and values of kidney cancer patients are included in places where research, treatment, and care decisions are made.



## 2023 IKCC Presentations and Conference Participation Highlights

### On the cutting edge of new research

IKCC staff and Board members attended major international cancer conferences including American Society Clinical Oncology Annual Meeting (Chicago, US), European Society of Medical Oncology Congress (Madrid, ES), ASCO Genitourinary Cancers Symposium (San Francisco, US), and the European Association of Urology Annual Congress (Milan, IT).

### Advocating for better patient outcomes

IKCC is at the table making sure the voices and values of people living with kidney cancer are represented, including UICC Cancer Leadership Meeting (Long Beach, US), WECAN Academy (Frankfurt, GR) and the Cancer Drug Development Forum (Amsterdam, NL).

### Collaborating with others

IKCC works in partnership with other cancer coalitions to learn and share, and together improve the lives of people affected by cancer. In 2023, IKCC participated with the members of the Global Cancer Coalition Network and presented at the annual meetings of World Bladder Cancer Patient Coalition and Myeloma Patients Europe.

### Inspiring future kidney cancer leaders

We are committed to ushering next-generation leaders through education and mentorship. IKCC presented at a meeting of the Young Urologists and hosted the Clinical Leadership Workshop at the EAU Annual Congress (Milan, IT).

## 2023 Global Kidney Cancer Summit

The 13th Global Kidney Cancer Summit was held in Buenos Aires, Argentina on 18th – 20th June 2023. Representatives from 33 patient organisations from 23 countries came together to collaborate, share, and learn more about kidney cancer genetics, diagnosis, treatment and support. The Global Kidney Cancer Summit is the only international conference for organisations representing patients with kidney cancer.

This year the conference programme took a new direction and reflected the kidney cancer patient pathway. The goal was to touch on all aspects of a kidney cancer pathway, bringing patients' perspectives and professionals' expertise to the forefront. The Summit began with discussions about diagnosis and early detection. It then transitioned to robust discussions about early- and then late-stage approaches to treatment. Finally, the Summit concluded with an expert panel about survivorship.

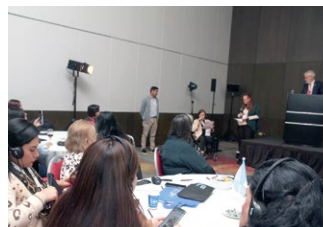
For the first time the Global Kidney Cancer Summit was held in South America. We were thrilled to welcome many new partners from organisations across Central and South America. The entire Summit was presented with simultaneous translation in Spanish, creating an environment of cross-cultural sharing and learning from each other.

Thank you to everyone who contributed to the Global Kidney Cancer Summit and making the time together interesting, educational, and inspiring! A special shout out to the presenters and moderators. And thank you to those who joined us online from around the globe too!

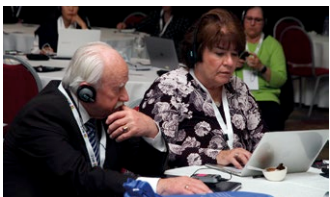
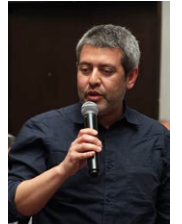
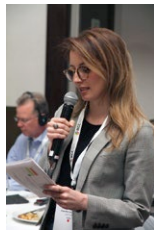
We also thank the 2023 Conference Committee for all their efforts to plan the event: Christine Collins (CA), Rachel Giles (NL), Margie Hickey, (US), Luciana Holtz, (BR), Liz Leff (US), Jin Young Paik, (KR), Ariel Park, (KR). The Conference Committee was supported by Julia Black and Rebecca Cabbage. **Gracias!**

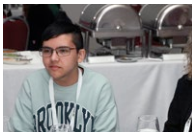
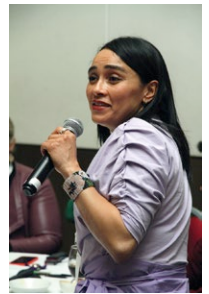
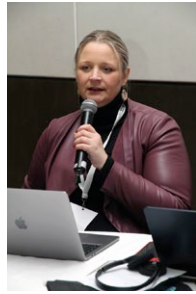
### 2023 Global Kidney Cancer Summit 2023 Objectives:

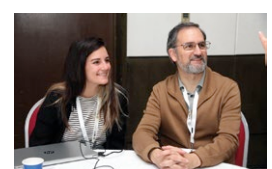
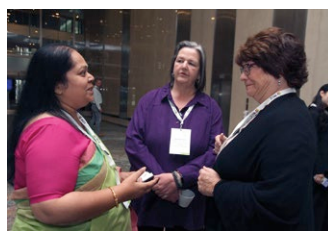
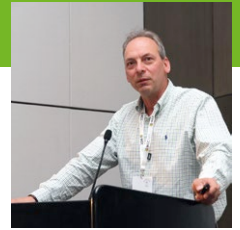
- To update the patient advocate community with new developments in the rapidly-changing field of kidney cancer treatments
- To learn from one another and build new skills in key areas for patient involvement including research, clinical trials, guidelines development and real-world evidence
- To include the patient perspective – both personal and organisational – in every session across the programme
- To build and strengthen relationships across the global kidney cancer network, and to stimulate and foster relationships, partnerships, learning opportunities and idea generation











## 2023 IKCC Publications



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Capitanio, U., Bedke, J., Albiges, L., Volpe, A., Giles, R. H., Hora, M., Marconi, L., Klatte, T., Abu-Ghanem, Y., Dabestani, S., Fernández-Pello, S., Hofmann, F., Kuusk, T., Tahbaz, R., Powles, T., Ljungberg, B., & Bex, A. (2023). A Renewal of the TNM Staging System for Patients with Renal Cancer To Comply with Current Decision-making: Proposal from the European Association of Urology Guidelines Panel. *European urology*, 83(1), 3–5. <https://doi.org/10.1016/j.eururo.2022.09.026>

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Links to all of IKCC's 2023 publications can be found at <https://ikcc.org/publications/>



## Medical Advisory Board Update

The role of the Medical Advisory Board (MAB) is to provide scientific and clinical expertise to IKCC and support the organisation's commitment to evidence-based leadership and activities. Over the past several years, based on the feedback from the kidney cancer community, the MAB has expanded to include 14 clinicians from across five continents to help ensure perspectives and experiences reflect the patient organisations and patient communities we support.

A guiding principle of the MAB activities is that engaging with patients and empowering them with quality information leads to better outcomes. As such, we believe it's our duty through education and advocacy to foster this approach with healthcare professionals and highlight the importance of shared decision-making and including the patient voice in all aspects of care, research and guideline development.

In 2023, the MAB continued to focus on helping healthcare professionals understand the value of patient engagement and advocacy. The goal is to inspire this audience to be more involved – this could include increasing shared-decision making in their clinical practice, getting involved with patient organisations and much more. IKCC leaders, Rachel Giles, CEO, and Dr Michael Jewett, Chair, gave a presentation at EAU 2023 based on the 2022 IKCC Clinical Leadership Workshop – more fondly known as Flip the Classroom. We continue investing in this important program and will host the next Clinical Leadership Workshop at GU ASCO 2024 in San Francisco (US).

The MAB also plays a role in disseminating the latest clinical and research advances as it arises at major conferences and medical meetings. MAB members serve as guest editors to create the IKCC Meeting Summaries that synthesise the information presented and draw attention to new and important updates for kidney cancer patients and carers. While this isn't a new practice, we have taken steps to evolve the process to make the Summaries easier to understand and allow patient

organisations to share directly with their communities. In 2023, Summaries were published from three conferences – ASCO GU, ASCO and ESMO. And for the first time in addition to English, the ESMO Summary was also made available in Portuguese and Spanish!

With the goal of engaging young kidney cancer leaders into the IKCC community, the MAB oversees the Cecile and Ken Youner Scholarship, an annual student scholarship created to honour the IKCC Emeritus Founding Member, Dr Ken Youner. In 2023 the scholarship was awarded to Dr Yuly Remolina Bonilla from Mexico and Ph.D. candidate Amanda Ikegami from Brazil. The two winners shared their research with IKCC at the Global Kidney Cancer Summit in Buenos Aires.

Thank you to all the members of the Medical Advisory Board for your time, expertise, and commitment to the global kidney cancer community.

### **Dr Eric Jonasch**

*Chair, IKCC Medical Advisory Board*

### **2023 IKCC Medical Advisory Board**

Dr Eric Jonasch (US), Chair

Prof. Axel Bex (NL/UK), Vice Chair

Dr Daniel Heng (CA), Executive Member

Prof James Larkin (UK), Executive Member

Prof. Stênio de Cássio Zequi (BR), Executive Member

Dr Cristiane Bergerot, (BR)

Dr María Teresa Bourlon (MX)

Prof. Craig Gedye (AU)

Nikki Hunter, RN, BSc, MSc (UK)

Dr Ravindran Kanesvaran (SG)

Dr Fransisco Rodríguez-Covarrubias (MX)

Dr Roman Sosnowski (PL)

Dr Yoshi Tomita (JP)

Dr Jin Zhang (CN)

## The Cecile and Ken Youner IKCC Scholarship

The Cecile and Ken Youner International Kidney Cancer Coalition (IKCC) Scholarship is an annual student scholarship created to honour the IKCC Emeritus Founding Member, Dr Ken Youner, who contributed so much to the establishment of IKCC. It is awarded annually to a student (undergraduate, graduate, resident or fellow) who intends to practice medicine, hopefully in the field of kidney cancer.

IKCC's Medical Advisory Board awards the prestigious scholarship, and the winners are invited to attend the IKCC Global Kidney Cancer Summit and present their work to the conference delegates.

**In 2023, the 5th Youner Scholarship was awarded to two deserving students:**

Dr Yuly Remolina Bonilla is a medical oncologist at Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubrian in Mexico. She graduated from Universidad Nacional Autónoma de México and is currently pursuing her Master of Science. She is passionate about patient care and clinical research in genitourinary neoplasms. She presented her work about the existing healthcare-system inequities in Mexico and its impact on survival outcomes in Mexican patients with metastatic renal cell carcinoma (mRCC) at the IKCC Global Kidney Cancer Summit in Buenos Aires.

Amanda Ikegami is a Ph.D. candidate at A.C. Camargo Cancer Centre in Brazil. Her research is focused on the biological mechanisms involved in the formation of tumor thrombi in kidney cancer. She achieved her Master of Science from the Institute of Energy and Nuclear Research at the University of São Paulo, Brazil. Ms Ikegami has a background in Biological Sciences and experience in kidney cancer research, with specific training in molecular and functional techniques that aim to understand tumor biology. This work supports her ambition to expand on and apply academic generated knowledge to benefit patients.

***“It is IKCC’s philosophy that engaging with patients is a potential blockbuster treatment that healthcare professionals should subscribe to in their practice to improve outcomes. It’s our hope that inviting next-generation medical leaders to share and collaborate with the global patient community at the Summit, they will then take these foundational learnings into their future practices.”***

*Dr Eric Jonasch, Chair, IKCC Medical Advisory Board*



Dr Eric Jonasch presents the Cecile and Ken Youner IKCC Scholarship to Dr Yuly Remolina Bonilla (above) and Ms Amanda Ikegami (below).



### Treasurer's Report 2023

On behalf of the IKCC Board of Directors, I am pleased to present our Annual Financial Overview for 2023.

IKCC continues to maintain a strong financial status. This allows us to underpin our operations and move forward with key strategic activities which support IKCC Partner Organisations despite posting a reduced result to 31 December 2023 compared to the previous year. This is largely as a result of a resumption of normal activity associated with attendances at various conferences, project participation and having the IKCC Annual Global Summit in Argentina in 2023.

The IKCC is appreciative of the loyal support received from our Sustaining Partners, as well as our specific Project Partners, for their ongoing investment in IKCC and for sharing our vision that seeks to grow, build and empower the global kidney cancer community through advocacy, awareness, information and medical research. This support builds sustainability for the IKCC at a time when there have been several market fluctuations impacting our funding portfolio.

The IKCC reserves funds annually to underpin our operations and key projects delivered on behalf of our affiliated patient organisations, while forging ahead with new strategic initiatives and plans to expand into geographic regions where there are no established kidney cancer patient organisations.

As part of good governance and stewardship of our funds, the IKCC Board developed an Investment Policy that is designed to deliver long-term financial sustainability to our work globally. In 2022, IKCC invested Euro 400,000 in sustainable low-risk investments with a defensive risk profile, striving for a balanced distribution in the coming years.

As per our policy, we have added Euro 50,000 to our portfolio quarterly with the Board's approval and subject to availability of funds will continue to do so up to an amount of Euro 700,000. Quarterly reviews are undertaken prior to investment of any funds. There will be no investments made into any funds relating to tobacco, arms or pharmaceutical industries.

We acknowledge and thank our Sustaining Partners and Project Partners for your ongoing investment in the IKCC and for sharing our global vision that seeks to grow, build and empower the global kidney cancer community through advocacy, awareness, information and medical research.

It is also important to note a new source of income in 2023. This year, IKCC received funding from European grants awarded to projects that have a global impact on cancer patients.

We thank our Audit firm Van Hoesel De Blaey Accountancy B.V. of Rotterdam of the Netherlands who have once again worked with the Board and management to deliver fully independently audited financial statements.

**With your ongoing support, IKCC will continue its reach and desire to support and empower patient organisations in all corners of the globe in our mission to reduce the burden of kidney cancer and help to improve the lives of those impacted.**

**Anne Wilson**

*Secretary-Treasurer  
IKCC Board*



## 2023 Financial Statements

These figures are extracted from the 2023 financial report of Stichting International Kidney Cancer Coalition in Ouder-Amstel, audited by Van Hoesel De Blaey Accountancy B.V. To view the full financial report, please visit [www.ikcc.org](http://www.ikcc.org).

### Independent Auditor

Van Hoesel De Blaey Accountancy B.V.  
Brouwerstraat 6  
3364 BE Sliedrecht  
The Netherlands

### Financial Services

Administratiekantoor Boekjwinst.nl B.V.  
Computerweg 22  
3542DR Utrecht  
The Netherlands

<b>IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2023</b>	
<b>CURRENT ASSETS</b>	
Funds to receive	€ 3,006
Liquid assets	€ 1,367,310
<b>TOTAL CURRENT ASSETS</b>	<b>€ 1,370,316</b>
<b>CURRENT LIABILITIES</b>	
Creditors and borrowings	€ 61,149
<b>TOTAL CURRENT LIABILITIES</b>	<b>€ 61,149</b>
<b>NET ASSETS</b>	<b>€ 1,309,167</b>
<b>ACCUMULATED FUNDS</b>	
Reserves	€ 1,113,380
Last year surplus/(deficit)	€ 172,871
Current year surplus/(deficit)	€ 22,916
<b>TOTAL ACCUMULATED FUNDS</b>	<b>€ 1,309,167</b>



## IKCC Partner Organisations



### Partner Organisations

Partner Organisations\* are registered patient organisations that meet the following criteria:

- Have a focus on providing services and/or supporting patients with kidney cancer and raising awareness, promoting research, or empowering organisations that are focused on supporting those affected by kidney cancer.
- Are recognised and/or registered as a non-profit organisation.
- Are willing to abide by the IKCC Code of Conduct in addition to adhering to the strict ethical guidelines for charities and non-profits according to their own national contexts.
- Are willing to work with and co-operate with other organisations.

\* Previously known as Affiliate Organisations

### Supporters

Supporters are interested in the work of IKCC and may include organisations who do not yet fulfil the criteria of a Partner Organisation or are individuals with an interest in kidney cancer who may wish to attend future meetings or join our mailing list.

Supporters also include individuals who may be strongly motivated to start kidney cancer groups in their own countries.

Supporters are kept informed of IKCC activities but have no voting rights.

**Please see the IKCC website for further information:**

<https://ikcc.org/about-ikcc/our-affiliates/>

### New Partner Organisations that Joined IKCC in 2023

#### **Argentina:**

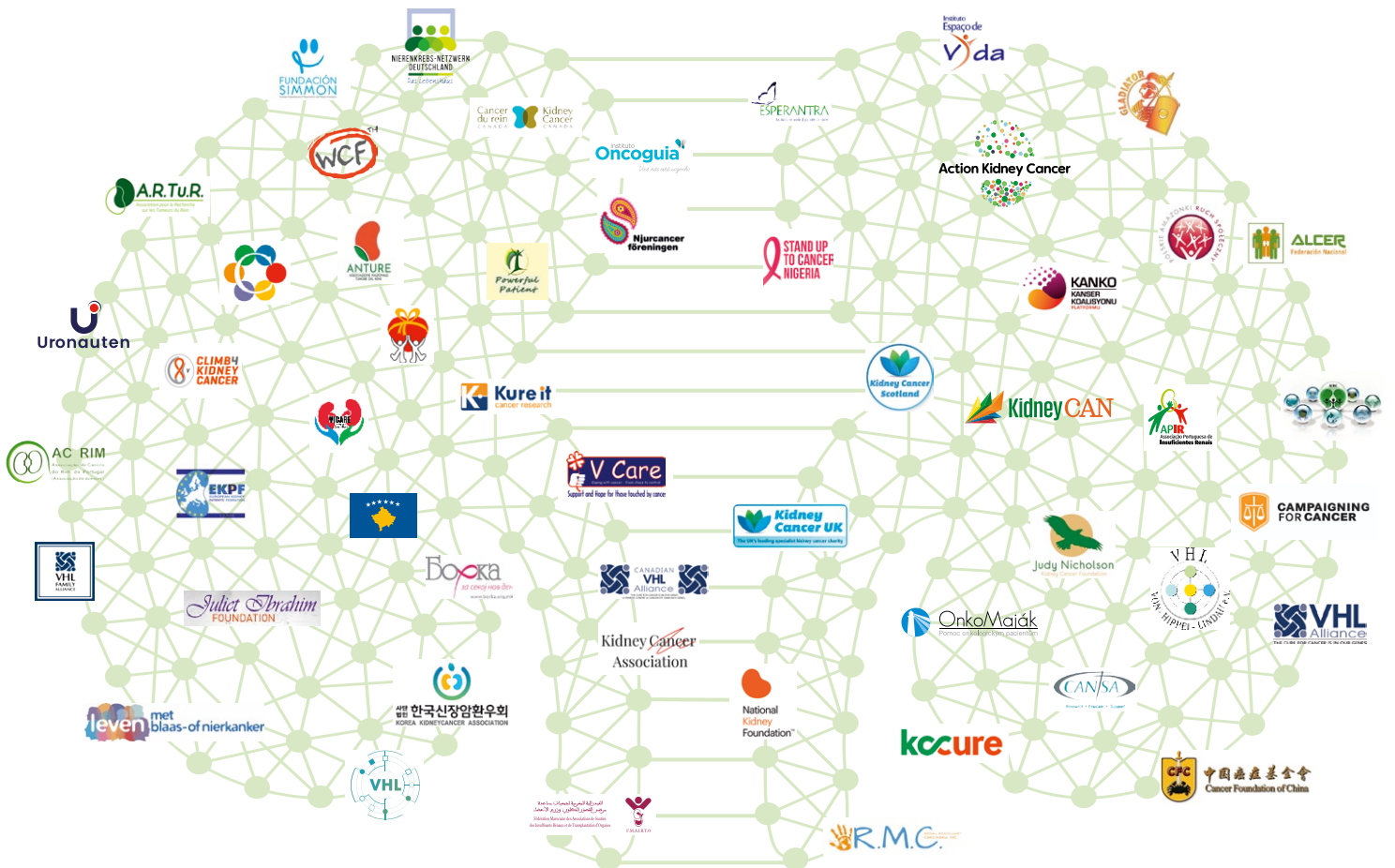
Vicare Argentine Association of patients and relatives with kidney and bladder cancer  
<https://vicare.ar>

#### **Canada:**

Canadian VHL Alliance  
[www.cvhla.ca](http://www.cvhla.ca)

#### **Italy:**

ANTURE - Italian Kidney Cancer Association  
[www.anture.it](http://www.anture.it)



# IKCC Partner Organisations





Association of Cancer Patients in Finland

Cancer Association of Sweden

Amazon Social Movement

...er  
...y Cancer Patient Association

... von-Hippel-Lindau e.V.

...werk Deutschland e.V.

...ssociation Cancer Care

... KANKO Turkey

... Family Alliance, Greece

Korea Kidney Cancer Association

Cancer Foundation of China

V Care Foundation

Africa

USA  
...aigning for Cancer

**Please check our website  
for the latest list of organisations  
who have joined IKCC.**

**Affiliate Organisations can be  
identified by this logo displayed on  
their website and materials.**



## Board of Directors 2023



**Michael Jewett, Chair  
MD, FRCS, FACS, CM**

### Canada

Dr Michael Jewett is Professor of Surgery (Urology) at Princess Margaret Cancer Centre and the University of Toronto. He was an enthusiastic supporter of the founding of Kidney Cancer Canada and was the founding and immediate past-Chair of the Kidney Cancer Research Network of Canada. He was awarded the Canadian Cancer Research Alliance Award for Exceptional Leadership in Patient Involvement in Cancer Research in 2017 and was named a member of the Order of Canada in 2020 for his contributions to patient-centred care and innovation in urological surgery.

Dr Jewett is the immediate past Surgical Co-Chair on the USA National Cancer Institute's Renal Task Force. He has published more than 450 peer reviewed papers, many about kidney cancer. He has had a long interest in many aspects of kidney cancer research, patient care and knowledge transfer. He is a leader in academic Urology, has received many awards and is a frequent guest at national and inter-national urological associations. He has been a visiting professor in 25 countries to more than 100 university departments and institutions.



**Bryan Lewis, Vice-Chair  
United States**

Bryan Lewis has led the advocacy efforts for KidneyCan – [www.kidneycan.org](http://www.kidneycan.org) – a US-based patient advocacy organisation. As a kidney cancer survivor, he has been an active legislative advocate and policy spokesman for the kidney cancer community in Washington, D.C., devoting most of his efforts to policy advocacy in the United States Congress and regulatory agencies. Most recently, Bryan led a grassroots advocacy campaign that successfully obtained \$50 million for the KCRP – Kidney Cancer Research Program

Bryan also serves on the National Comprehensive Cancer Network (NCCN) Kidney Cancer Guidelines Panel, the National Cancer Institute Renal Task Force, and the ASCO Guidelines Panel for Metastatic RCC. Previously, he held the positions of Vice President, Operations for Brand USA, and as Chief of Staff & General Counsel, U.S. Travel Association, a Washington, D.C.-based trade association.



**Christine Collins  
Canada**

Christine Collins' work with Kidney Cancer Canada began after her diagnosis in 2010, in a commitment to give back to the organisation that supported her. She began volunteering at patient education events and in peer support services, and then served as a Director and Vice Chair of the Board. In 2020, Christine moved to the frontlines as the Executive Director at Kidney Cancer Canada.

Christine's personal experience combined with her background in education, health, and corporate work, along with her commitment to Kidney Cancer Canada, has enabled her to better serve and support the kidney cancer community. Christine has always advocated that kidney cancer is a global disease and that when we collaborate at that scale, we can not only discover better diagnosis opportunities, treatment options and support, but also a cure.



**Eric Jonasch, MD**  
**United States**

Dr Eric Jonasch is Professor in the Department of Genitourinary Medical Oncology, Division of Cancer Center at the University of Texas MD Andersen Cancer Center in Houston, Texas. He is director of the VHL Clinical Center at the MD Anderson Cancer Center, leads the national Kidney Cancer Research Consortium, and performs clinical, translational and basic research in kidney cancer and VHL disease.

Dr Jonasch has authored over 250 articles published in peer-reviewed journals, including papers in Nature Medicine, The Lancet Oncology and The New England Journal of Medicine. Dr Jonasch has a long history of service in the kidney cancer community. He serves as Vice-Chair of the NCCN Kidney Cancer Guideline Panel, is a member of the U.S. National Cancer Institute Renal Task Force, and is a past Board Member of the VHL Alliance.



**Margaret Hickey, MSN, RN, MS**  
**United States**

Margie Hickey is an oncology nurse with more than 40 years of experience and holds Master of Science degrees in both Nursing and Human Resource Administration from LaRoche University of Pittsburgh, PA. She is currently a Medical Education and Communications Consultant. Margie was a Clinical Director at the Pittsburgh Cancer Institute and Tulane Cancer Center, with responsibilities for inpatient and outpatient programs. In 2000, Margie moved to the pharmaceutical sector and specialized in clinical research, medical communication, and patient advocacy.

Margie is a champion for nursing, holding several elected and voluntary positions in local, regional, and national nursing organisations. Margie is a member of Oncology Nursing Society and the Society of Otorhinolaryngology and Head-Neck Nursing (SOHN) and has published as an author and / or editor for several nursing publications including Editor in Chief of the official journal of SOHN, ORL-Head and Neck Nursing.



**Liz Leff, BA**  
**United States**

Liz Leff has led advocacy efforts for NKF – the National Kidney Foundation – in the United States for the past 6 years. As a kidney cancer survivor, Liz has been involved in the kidney cancer community in devoting efforts to patient education, clinician education, trial recruitment, legislative policy support, and bringing together investigators and industry to progress clinical trials. Currently at NKF, Liz’s role is to identify, initiate, and manage relationships with corporations within the healthcare industry sector. She focuses in the areas of co-morbidities of chronic kidney disease and leads all kidney cancer business development, partnerships, and initiatives. Liz has grown the kidney cancer area significantly in the past few years, and has implemented patient education programs, clinician education programs, trial recruitment activities, patient/health care professional focus group surveys, and more.

Previously, Liz held business development positions at a clinical research organisation, and human tissue blood sample company. She also held positions in managed care at Pfizer for over ten years.



**ANNE WILSON**  
**Australia**

Anne Wilson has worked in the area of patient advocacy, public awareness and management of patient organisations for over 25 years. She is currently the CEO of Emerge Australia, working on behalf of patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and other post-viral conditions such as Long COVID.

Anne pioneered Kidney Health Australia’s work in advocacy and support for Australians and their families affected by kidney cancer as well as having overseen the development of specific resources, a website, telephone information service and promotion of information about access to relevant clinical trials in Australia. With her background in Social Work, Anne continues to be passionate about equitable access to service delivery and the latest and most up-to-date information about all aspects of kidney cancer and patient support. Anne is Secretary/Treasurer of the IKCC and has been the Board lead for the management of World Kidney Cancer Day since its inception.



**ROSE WOODWARD**  
**United Kingdom**

Rose Woodward is a long-term patient survivor of kidney cancer and a passionate and active patient advocate. She became involved in advocacy and patients’ rights in the UK in 2003 and later led the “Fight for Life” campaign for NHS-funded kidney cancer treatments. She now runs Action Kidney Cancer (previously Kidney Cancer Support Network), which is a grassroots patient-led charity providing practical support and advocacy for the kidney cancer community in the UK. She enjoys a very busy life running Action Kidney Cancer and is still dedicated to helping empower patients to play a full role in all aspects of their care.

Rose has just retired after serving 10 years as a full member of the National Cancer Research Institute Renal Cancer Group where she worked hard to establish meaningful patient involvement in all aspects of kidney cancer research ranging from clinical trial design through to survivorship studies. Rose is a founding member of IKCC and is also a Board Member, which gives her the opportunity to help improve the lives of kidney cancer patients wherever they live in the world.





## Acknowledgements

IKCC is committed to open and transparent partnerships with the healthcare industry in accordance with our Code of Conduct ([www.ikcc.org](http://www.ikcc.org)). Multi-sourced funding allows us to maintain our independence and integrity as a patient organisation while collaborating with stakeholders including patient organisations, medical experts, and the healthcare industry and focus on our mission – to reduce the global burden of kidney cancer.

We thank the following organisations that have supported IKCC in 2023 with Sustaining Partnerships and Project Sponsorships.

### Sustaining Partners 2023



### Project Sponsors 2023





We also extend our gratitude to the team of people who support IKCC to make the work we do possible.

Rachel Giles – IKCC Chief Executive Officer  
Julia Black – IKCC Chief Operating Officer  
Rebecca Cabbage – IKCC Project Assistant  
Sharon Deveson Kell – IKCC Medical Writer  
Annika Marshall – IKCC Administration Assistant  
Sara McCans – IKCC Project Manager

Charlie Douglass, Douglass Digital – Website Hosting  
Paul Fishlock, Behaviour Change Partners – World Kidney Cancer Day  
Steve Gray, Luci McCann, GrayMatter Marketing & Technology – World Kidney Cancer Day  
Karin Kastrati – Technical Support  
Jilda Lazer, Reverb Consulting Group – Communications Support  
Diego Somer and Jelle Eissens – Administratiekantoor Boekjewinst.nl BV, Financial Services,  
Jay Strauss – Social Media Support  
Herbert Thum, VisKon – Graphic Design



### **International Kidney Cancer Coalition**

Registered Address:  
Computerweg 22  
3542 DR Utrecht  
The Netherlands  
Email: [info@ikcc.org](mailto:info@ikcc.org)  
Website: [www.ikcc.org](http://www.ikcc.org)  
[www.worldkidneycancerday.org](http://www.worldkidneycancerday.org)



Search for us on Facebook as: [ikcc](https://www.facebook.com/ikcc)



Follow us on X (Twitter): [@IKCC](https://twitter.com/IKCC)

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