IKCC
International Kidney
Cancer Coalition

IKCC Annual Report 2025

The Only Global Patient-Driven Organisation Dedicated to Kidney Cancer

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Message from the Chair



Over the past year, IKCC entered a period of evolution, marked by leadership transition and organisational growth. Yet at its core, IKCC remained firmly grounded in the values on which it was founded: collaboration, shared purpose, and an unwavering commitment to improving the lives of people affected by kidney cancer worldwide.

It is both an honour and a responsibility to serve as Chair of the Board. I accepted this role because of IKCC's unique global impact. Few organisations are as well-positioned to support and empower kidney cancer patient organisations – and, by extension, the patients and carers they serve. By fostering meaningful partnerships with clinicians and other stakeholders, IKCC helps build the global infrastructure that enables better information sharing, meaningful advocacy, and improved care.

One particularly exciting development has been the growing momentum in the Asia-Pacific region. Recent engagement with patient advocates and healthcare professionals across Asia has highlighted both the unmet need and the strong enthusiasm for developing kidney cancer patient organisations in countries where they do not yet exist. By supporting the formation of these organisations and nurturing partnerships between patients and physicians, IKCC can deliver a measurable and lasting impact. This focus aligns closely with our mission and strategic pillars, and we look forward to expanding this work in the years ahead.

Beyond Asia, Africa and Eastern Europe represent regions of significant potential. These regions report high levels of kidney cancer prevalence alongside lower levels of patient engagement and support. While meaningful progress has been made, substantial gaps remain. Through trusted partnerships and collaboration with individuals and organisations that understand the regional landscape, we aim to develop thoughtful, sustainable, culturally informed approaches to strengthening patient voices and expanding support.

At the same time, our commitment to existing Partner Organisations remains central to everything we do. Success for IKCC is defined not only by geographic growth but also by how well we listen to, understand, and serve our current constituents. Whether organisations are long-established or newly formed, our goal is to strengthen each group's capacity to support patients and advocate effectively within their own healthcare systems. An upward trajectory for all is our measure of progress.

I am grateful to follow in the footsteps of those who have shaped IKCC's strong legacy, and I am equally energized by the strength of our current Board and executive leadership team. With new perspectives, deep expertise, and a shared sense of purpose, we are focused not on radical change, but on consolidation, strengthening, and becoming an even better version of the organisation we already are.

Dr Eric Jonasch

Message from the Executive Director



This year marked my first as Executive Director of IKCC, and it has been a period of discovery, learning, and meaningful progress. While I could not have anticipated everything we would achieve in 2025, the impact of our work is clearly reflected in this Annual Report. We advanced our strategic priorities, anchored by flagship programs that are delivering long-term value to the global kidney cancer community.

2025 was also a year of transition for IKCC as an organisation. Since its founding 16 years ago by a small group of national patient organisations, IKCC has grown into a global coalition of 58 Partner Organisations across five continents. Through this growth, we have deepened our understanding of the experiences and support of patients and carers worldwide. Our sustained investment in patient-experience research and shared decision-making is strengthening evidence-based advocacy and ensuring these insights are represented where decisions about treatment and care are made.

As we enter our next chapter, we are grateful to the leaders who stepped forward this year. Dr Eric Jonasch (US) assumed the role of Board Chair, Claudia Ungarelli (IT) became Vice-Chair, Bart van Goudoever (NL) joined IKCC as Secretary-Treasurer, Carmen Vallejo Auste (PH) joined the Board of Directors, and Prof. Stênio de Cássio Zequi (BR) was appointed Chair of the Medical Advisory Board. Together with an engaged and highly skilled Board of Directors, their leadership enables IKCC to operate with agility and deliver outsized impact in the global oncology space. As they take on a transitional role, I would like to express my sincere gratitude to Dr Michael Jewett (Past Chair, CA), Bryan Lewis (Past Vice-Chair, US), and Anne Wilson (Past Secretary-Treasurer, AU) for their outstanding contributions to the development of IKCC.

This period of transition also included the launch of a refreshed visual identity and communications. Our new logo reflects IKCC's commitment to people affected by kidney cancer, symbolising both the disease and our enduring focus on collaboration, relationships, and trust.

Partnerships remained central to our work this year. We strengthened collaboration with the Global Cancer Coalition Network through an initiative on shared decision-making in oncology and formalised our partnership with The Max Foundation to support access to treatment in low- and middle-income countries. These collaborations exemplify how aligning strengths allows us to work more effectively and efficiently together.

As an agile organisation, IKCC remains committed to responsible resource management, and priority is given to its flagship projects. In an increasingly uncertain funding environment, IKCC combined rigorous management and the consolidation of strategic partnerships with its sponsors. European projects also contributed to revenue diversification and collaborations.

Looking ahead, IKCC will continue to expand its evidence-based advocacy to improve access to treatments, increase its research activities for the benefit of patients, and strengthen its global network, with a focus on Asia, Eastern Europe, and Africa, where the burden of kidney cancer is growing quickly.

Thank you to everyone who contributed to this successful year of transition. I look forward to what 2026 will bring and am grateful to continue this mission together.

Olivier Exertier

About IKCC

International Kidney Cancer Coalition (IKCC) is the only global patient-driven organisation dedicated to kidney cancer. IKCC brings together Partner Organisations from around the world to collaborate, share expertise, and learn from one another, united by a common goal: reducing the global burden of kidney cancer. Through this collective effort, IKCC is driving meaningful global impact across research, treatment, care, and survivorship.

IKCC's work is grounded in robust evidence that reflects the lived experiences of patients, carers, and healthcare professionals. These insights are shared with key stakeholders and incorporated into decision-making related to kidney cancer research, treatment, support and survivorship. This evidence-based approach ensures education, prevention, awareness, and advocacy initiatives are relevant, responsive, and aligned with the real needs of people affected by kidney cancer.

Kidney cancer is a growing global health challenge. Since the 1970s[1], the incidence rates have steadily increased worldwide. In 2022 according to IARC-WHO, an estimated 434 840 people were diagnosed globally, and approximately 155 953 people die from kidney cancer each year.[2] Incidence is projected to continue rising, with an estimated 745 791 new cases anticipated by 2050, representing a +72% increase[3]. Strengthening local efforts through a coordinated global action is essential to improving health equity and patient outcomes for people living with kidney cancer.

IKCC is committed to achieving our vision through these strategic pathways, with a focus on key flagship programs:

IKCC MISSION:

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

IKCC VISION:

To reduce the global burden of kidney cancer.

RESEARCH & INFORMATION: Quality assured and credible to drive patient outcomes. → **GLOBAL PATIENT SURVEY**

EMPOWERMENT: Empowering patient organisations to reduce disease burden locally. → **GLOBAL KIDNEY CANCER SUMMIT**

AWARENESS: For kidney cancer and the ways to reduce the burden on patients. → **WORLD KIDNEY CANCER DAY**

ADVOCACY: Improving access to treatment and care for all people with kidney cancer. → **INFOGRAPHICS & PUBLICATIONS**

GLOBAL PATIENT VOICE: Bring patient perspectives to policy-making, healthcare and industry. → **SHARED DECISION-MAKING**

1. J Clin Oncol. 2018 Dec 20; 36(36): 3574–3581.
2. Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, Piñeros M, Znaor A, Soerjomataram I, Bray F (2024). Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer. Available from: https://gco.iarc.who.int/today, accessed 19 February 2025.
3. Global Cancer Observatory. Available from: https://gco.iarc.fr/tomorrow/en/dataviz/tables?cancers=29&years=2050, accessed 19 February 2025.

IKCC Collaborations

When there is collaboration between like-minded organisations with aligned objectives, the potential impact is exponential.

In 2025, IKCC collaborated with the following organisations to help move our strategic pathways forward.

UICC

GLOBAL CANCER COALITIONS NETWORK

european cancer ORGANISATION

European Commission

eau

WECAN
Workgroup of European Cancer Patient Advocacy Networks

The Max Foundation

IKCC by the Numbers

IKCC's Worldwide Network

58 Partner Organisations representing **32 countries** across **5 continents** make up the IKCC global network of patient organisations. Together, we represent **1.37 million kidney cancer patients worldwide**.

Global Kidney Cancer Summit

The 15th Global Kidney Cancer Summit brought together **27 Partner Organisations** from **24 countries**, where **70 participants** collaborated and connected for 3 days in Madrid!

World Kidney Cancer Day

The 9th annual World Kidney Cancer Day campaign reached **112 countries** and generated **76 million impressions on social media**.

14

IKCC represented the kidney cancer community at **14 major medical conferences**.

5

5 editions of the IKCC Newsletter were sent to the global network of the Coalition.

18

In 2025, IKCC generated **18 scientific publications**, including **5 abstracts** with data from the 2025 Global Patient Survey on Kidney Cancer.

3

3 Medical Conference Highlights Reports were developed to share patient-friendly summaries from ASCO GU, ASCO, ESMO.

IKCC's social media reach grew across all platforms:

- +4,750 followers
- +1,000 followers
- +12,000 followers

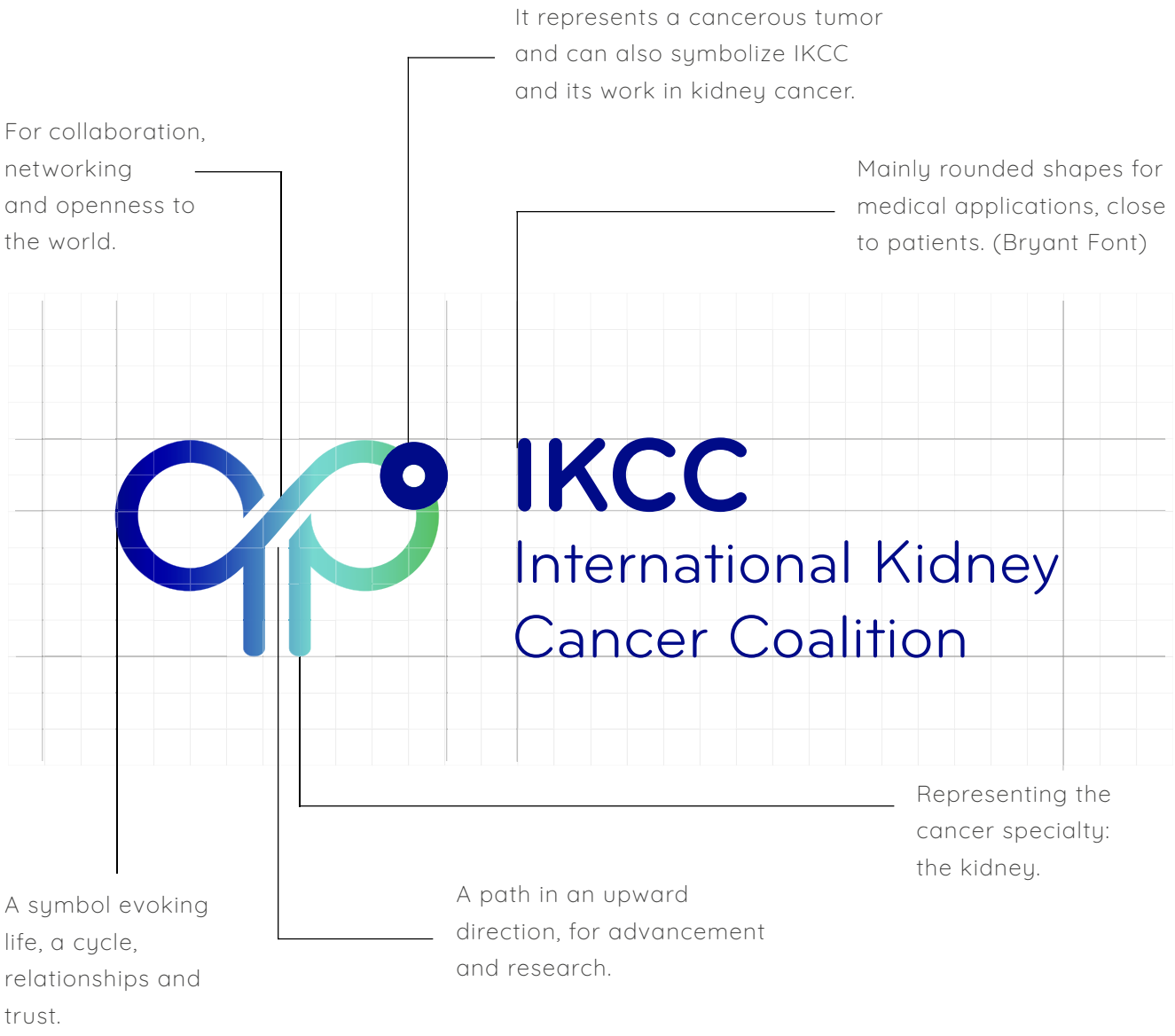
IKCC also expanded social media reach via increased efforts **on Instagram, YouTube and Bluesky!**

A New Look for IKCC

In September, IKCC unveiled a refreshed visual identity. This update reflects not only our growth in size and impact over the past 16 years, but also our evolving approach to achieve our mission to improve the lives of kidney cancer patients worldwide.

The new design incorporates the current global standards of accessibility and features two stylised kidneys – one with a tumour – symbolising our unwavering focus on kidney cancer. The elliptical shapes highlight our commitment to collaboration, trust, and relationships with individuals and organisations in the global cancer community, and the upward path through the design represents a dedication to advancing research.

The visual identity roll-out began with social media and digital communications, with further updates planned in 2026, culminating in the launch of a new website that will fully showcase our new creative direction, dedicated to patient-centricity.



Research & Information

Quality assured and credible to drive patient outcomes.

2025 Global Patient Survey on Kidney Cancer

To strengthen collective understanding of the lived experience of people with kidney cancer, IKCC collaborates with Partner Organisations to develop and administer its biennial Global Patient Survey on Kidney Cancer (GPS). The survey captures insights of people diagnosed with kidney cancer, providing a global evidence base to inform education, awareness, and advocacy initiatives. GPS findings enable patient organisations at a local level, and IKCC globally, to design programs that meaningfully respond to the needs of those affected by kidney cancer.

2025 Highlights Report: Mapping the Kidney Cancer Patient Experience Worldwide

Findings from the 4th IKCC Global Patient Survey on Kidney Cancer were published in the Mapping the Kidney Cancer Patient Experience Worldwide: 2025 Highlights Report in April 2025. It was based on the results from 2,677 patients and carers from 46 countries who completed the survey between September and November 2024.

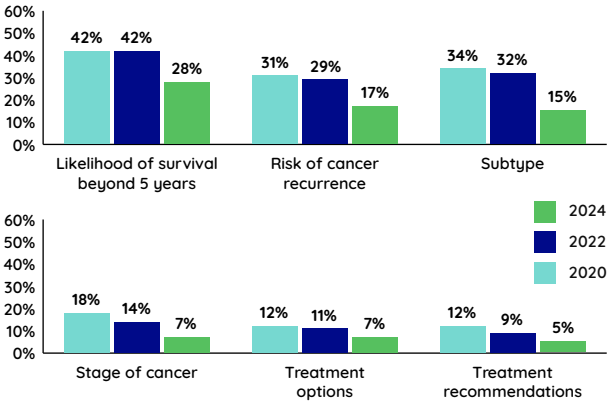
The Highlights Report examined key aspects of the kidney cancer journey, including diagnosis, patient knowledge, quality of life, shared decision-making, participation in clinical trials, and awareness of biomarker testing and kidney health.

Encouragingly, there was a significant improvement in patients' knowledge and understanding of their diagnosis. The survey also recorded the most positive global response about shared decision-making since the GPS began, driven by notable improvements in several countries.

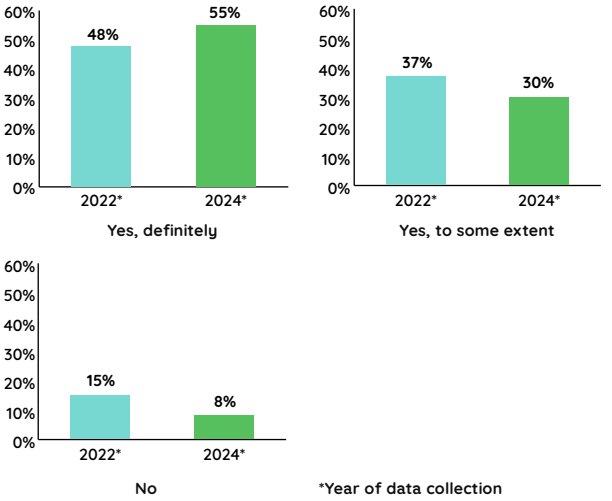
At the same time, the findings highlighted areas requiring further attention, including geographic disparities in access to treatment and gaps in education related to biomarker testing and kidney health following a cancer diagnosis.

In addition to the IKCC Global Highlights Report, 11 country reports were published for countries with a significant number of GPS participants: Canada, France, Germany, India, Italy, Japan, Mexico, Korea, Turkey, the United Kingdom, and the United States.

The following were NOT explained to patients in a way they could understand:



Were you involved as much as you wanted to be in decisions about your treatment plan?



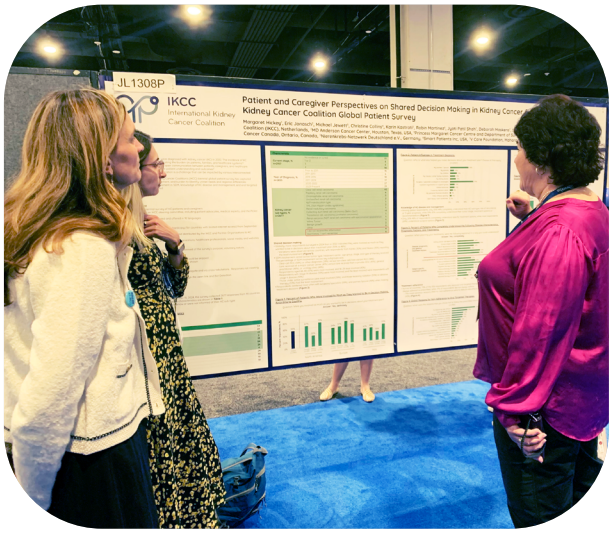
GPS Publications and Presentations

Bringing evidence-based patient insights into scientific dialogue and decision-making remains a core focus of IKCC. In 2025, the IKCC Publication Committee, with contributions from the Medical Advisory Board, continued in-depth analysis of the GPS data and identified key trends and findings for dissemination across urology and oncology conferences through abstracts, posters, presentations, and other channels.

Five abstracts highlighting GPS data were accepted for poster or oral poster presentations in major scientific congress such as the Kidney Cancer Research Symposium, ESMO (European Society of Medical Oncology), JADPRO Live Annual Meeting (Journal of the Advanced Practitioner in Oncology), the International Kidney Cancer Symposium – North America, and ESMO Asia Congress.









Funding for the Global Patient Survey on Kidney Cancer and its reporting was provided by the following companies in full compliance with the IKCC Donors Policy:

AstraZeneca
Bristol Myers Squibb
Debiopharm WE DEVELOP FOR PATIENTS
Eisai
IPSEN Innovation for patient care
Roche

Research Initiatives

Kidney cancer research can lead to more effective treatment, improved patient care, and ambitious health policies. Partnerships and collaborations that bring patients' experiences and values to research initiatives help accelerate this understanding and make meaningful change in the lives of people living with kidney cancer.

The DISCERN Project

IKCC is a proud partner of the DISCERN Project – Discovering the Causes of Three Poorly Understood Cancers in Europe. It is a five-year project of the European Commission Cancer Mission to understand the causes of kidney (renal), pancreatic, and colorectal cancer in Europe and to help explain the geographical distribution of these cancer types, including their high incidence in Central and Eastern Europe.

In addition to the ongoing role in ensuring patients and caregivers are represented, and ensuring project results are relevant to the patient community and communicated in plain language, in 2025 IKCC supported the DISCERN Project in the following ways:

- IKCC helped improve visibility of the DISCERN Project with key audiences through an ongoing communication campaign. The research initiative was profiled in IKCC's newsletter, its website, and on social media for major cancer awareness events.

- Aida Ferreiro (ES), a co-Principal Investigator of the DISCERN Project, addressed delegates at the IKCC Global Kidney Cancer Summit in Madrid (ES) in April to share the benefits and challenges of the research initiative with Partner Organisations, healthcare professionals, and the global kidney cancer community.

- IKCC promoted the patient voice and highlighted DISCERN-related activities at oncology-focused meetings. IKCC presented at the 3rd Annual DISCERN Meeting in Brno (CZ) in June and the Annual meeting of European Cancer Research Consortia in Barcelona (ES) in October.





CARE1 Pragmatic Clinical Trial

IKCC is a full member of the Management Board of CARE1 Pragmatic Clinical Trial, a European phase III multi-centre study of first-line treatment for metastatic kidney cancer. Coordinated from France and involving eight European countries, the study seeks to establish treatment guidelines based on biomarkers such as PD-L1, aiming to enhance kidney cancer care, improve patient outcomes, and support oncologists in selecting the most effective treatment combination for each kidney cancer patient.

IKCC continues to represent the perspectives, insights, and experiences of kidney cancer patients within the project. Specifically, IKCC oversees patient-facing materials (including digital resources) to ensure patient needs are met and manages a Patient Advisory Board for the project.



IKCC Board Ambassador, Rose Woodward (UK), represents kidney cancer patients in the CARE 1 Pragmatic Clinical Trial.

CARE 1
PRAGMATIC CLINICAL TRIAL

Empowerment

Empowering patient organisations to reduce disease burden locally.

2025 Global Kidney Cancer Summit: Empowering Advocacy and Collaboration

The 15th Global Kidney Cancer Summit convened 70 participants in Madrid, Spain, from 4 – 6 April 2025, bringing together 27 Partner Organisation delegates from 24 countries. This diverse gathering fostered learning, sharing, and capacity building across the global kidney cancer community.

Summit Theme: Building Evidence-Based Advocacy Skills

This year's summit focused on **"Building Evidence-Based Advocacy Skills,"** marking a strategic evolution for patient organisations, from primarily educating patients to actively advocating for policy change. Internationally recognised leaders in patient advocacy, both from the kidney cancer field and beyond, led discussions on generating and disseminating evidence to influence health policy. The Summit also featured group activities designed to strengthen connections and foster a spirit of collaboration.

Interactive and Impactful Programming

Interactive and Impactful Programming

- **Engagement:** 19 expert presenters facilitated four roundtable groups and 12 interactive discussions, enabling delegates to explore topics in depth and collaborate on practical solutions for their organisations.
- **Clinical Focus:** Dedicated sessions addressed the unmet needs of kidney cancer patients and clinical hot topics, including immuno-oncology, primary renal mass management, and shared decision-making in adjuvant treatment.
- **Satisfaction:** 100% of participants reported that their expectations were met or exceeded each day.

IKCC 2025 Summit: At a Glance

- **70** participants
- **27** Partner Organisation
- **24** countries represented
- **19** presenters
- **4** roundtable groups and **12** roundtable discussions
- **100%** of participants said their expectations were met or exceeded every day

Highlights and Acknowledgments

- A keynote address by Neil Bertelsen (DE), a renowned patient advocate, illustrated the transformative power of grassroots activism in shaping clinical trial protocols and regulatory processes for life-saving medicines.
- The event was made possible through the dedication of the 2025 Conference Committee, Margie Hickey (Chair, US), Flávia Kavalec (BR), Elżbieta Majewska (PL), Karin Kastrati (DE), Juan Carlos Julian Mauro (ES), Jyoti Patil Shah (IN), and Claudia Ungarelli (IT) and the invaluable assistance of Julia Black and Rebecca Cubbage.



Keynote speaker, Neil Bertelsen (DE), a long-time patient advocate leader in the HIV/AIDS community, shared how grassroots activism in the 1980s changed protocols for clinical trials and led to new regulatory processes for life-saving medicines.

















While in Madrid, IKCC partnered with Dr Ignacio Duran to convene a meeting of Spanish medical experts to discuss ways to accelerate access to combination treatments with immunotherapies for advanced kidney cancer.

The 2025 Global Kidney Cancer Summit was funded by the following companies in full compliance with the IKCC Donors Policy:

EXELIXIS® MSD Pfizer

Connect and Share Webinar Series

Since the launch in 2023, the Connect and Share Webinars have created ongoing opportunities for the IKCC network of Partner Organisations to meet virtually and sustain connection despite geographical distance. Under the coordination of Margie Hickey (US), the online discussion forum allows all Coalition members to come together regularly to share best practices on topics of interest.

Topics in 2025 included:

- A meet and greet with IKCC's new Executive Director, Olivier Exertier
- Sharing best practices for World Kidney Cancer Day
- Aligning Patients' Needs and Future Funding Opportunities

Over three years, IKCC has hosted a total of nine Connect and Share Webinars. Attendance continues to grow steadily, and a WhatsApp group has been formed to continue conversations between webinars, meeting Partner Organisations' desires to connect more often and learn from each other's experiences.

> "*As a new member of the IKCC community, the regular opportunities through the* Connect and Share Meetings, *allowing me to connect, share ideas, tackle challenges, and learn from other IKCC Partner Organisations, have been invaluable.*"
>
> **— Maria Hannah Azul, Kidney Alliance Philippines (PH)**

Awareness

For kidney cancer and the ways to reduce the burden on patients.

World Kidney Cancer Day 2025



World Kidney Cancer Day 2025 was celebrated around the world on 19 June. Held each year on the third Thursday of June, the day brings together patients, carers, healthcare professionals, and advocacy organisations to unite in improving the lives of people affected by kidney cancer. Its goals are to provide education and support for people impacted by kidney cancer, raise awareness of the disease's local and global burden, and inform the broader public about kidney cancer.

The 2025 campaign theme, **Show Your Kidneys Some Love**, highlighted the importance of kidney health for people living with kidney cancer. The theme was inspired by findings from the 2025 IKCC Global Patient Survey, which revealed that 39% of patients were always or almost always concerned about their kidney function. However, only 27% reported feeling they had sufficient information on how to manage kidney health following their kidney cancer diagnosis.

The global online campaign included:

- Educational resources about kidney health, including lifestyle guidance and tests to assess kidney function
- A downloadable checklist to help patients prepare questions for their healthcare providers
- Campaign logos and social media toolkits available in 13 languages
- A Global Patient & Carer Symposium exploring practical ways to maintain kidney health while living with kidney cancer
- A video created in partnership with DISCERN Project partner, IARC-WHO, to share the main global kidney cancer statistics, reaching more than 1000 online participants.

World Kidney Cancer Day is made possible through the dedication of the global kidney cancer community. Across five continents, campaign content was widely shared on social media, and Partner Organisations hosted online and in-person events, encouraging individuals everywhere to show their kidneys some love!

World Kidney Cancer Day 2025 Results

- Campaign reached **112 countries and generated 76 million impressions on social media worldwide**
- Online educational event was viewed by nearly **1,000 participants globally**
- **100% of Partner Organisations** reported that World Kidney Cancer Day is important to their organisation

World Kidney Cancer Day 2025 was funded by the following companies in full compliance with the IKCC Donors Policy:

Silver Sponsor:

IPSEN Innovation for patient care

Bronze Sponsors:

AstraZeneca MERCK

Advocacy

Improving access to treatment and care for all people with kidney cancer.

IKCC advanced strategic partnerships with organisations committed to enhancing the lives of people impacted by cancer.

WECAN Academy

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) is a consortium of 24 umbrella cancer patient advocacy organisations operating across Europe. IKCC has been a member since its inception in 2015, collaborating with like-minded organisations to advance meaningful improvements for people affected by cancer.

The WECAN Academy, WECAN's annual flagship programme, delivers intensive training for patient advocates in three core areas: Advocacy Tools & Skills; Healthcare Systems, Policy & Access; and Research & Data.

In June 2025, IKCC Executive Director, Olivier Exertier, was joined by IKCC representatives Claudia Ungarelli (IT), Karin Kastrati (DE), and Stephanie Bonn (SE) at the WECAN Academy in Fiumicino, Italy. Together, they strengthened their knowledge, exchanged best practices with peers from across Europe, and further developed their advocacy capabilities.

"It was energising spending three immersive days collaborating with and learning from peers from across Europe who share the common goal of improving the lives of people affected by cancer. It is the boost needed to keep moving forward to help drive meaningful change both in Sweden and around the world."

– Stephanie Bonn (SE)



Union for International Cancer Control – World Cancer Leaders' Summit

In November 2025, the Union for International Cancer Control (UICC) convened its biennial World Cancer Leaders' Summit in Melbourne, Australia. This global policy meeting brings together UICC members and partners from across the cancer and global health communities to share expertise, strengthen collaboration, and shape coordinated efforts to reduce the burden of cancer worldwide.

IKCC was represented by Executive Director, Olivier Exertier, and Board Member, Anne Wilson (AU). Alongside 130 UICC members and partners, IKCC endorsed the World Cancer Declaration 2025 – 2028, a framework for coordinated international action to integrate cancer control into national health and development agendas.





IKCC Partners with The Max Foundation

In 2025, IKCC formalised a strategic partnership with The Max Foundation through the signing of a memorandum of understanding. This collaboration marks an important step toward improving outcomes for people living with kidney cancer in low- and middle-income countries (LMICs).

Expanding impact in LMICs has been a long-standing priority for IKCC. However, meaningful progress in these settings can be challenging due to limited infrastructure, restricted access to care, and significant resource constraints. Partnering with The Max Foundation addresses these challenges by combining complementary strengths and shared commitment to health equity.

The Max Foundation is a global nonprofit organisation dedicated to accelerating health equity by delivering life-saving medicines, technology, and services to patients facing cancer and critical illness in LMICs. Access to early detection, accurate diagnosis, effective treatment, and ongoing support – key drivers of positive patient outcomes – remains a substantial unmet need for people with kidney cancer living in low-resource settings.

Through this collaboration, each organisation contributes its unique expertise. IKCC will focus on strengthening patient advocacy, education, and healthcare professional knowledge, while The Max Foundation brings extensive operational experience in opening access to treatment and supportive care to cancer patients in need.

By aligning efforts and working collaboratively, IKCC and The Max Foundation aim to extend the reach of kidney cancer support and improve patient outcomes in some of the world's most underserved hard-to-reach regions.



David Palacios of the Max Foundation and Olivier Exertier of IKCC.

The Max Foundation

Global Patient Voice

Bringing patient perspectives to policy-making, healthcare and industry audiences.

Shared Decision-Making

Evidence Generation Project to Quantify Benefits of SDM for Urologists and Patients

Shared decision-making (SDM) is a core pillar of patient-centred healthcare, central to the notion that patients should have the opportunity to be involved in their treatment decision-making as much as they want.

IKCC partnered with Dr Katharina Beyer (NL) to study the question of why SDM is lagging in kidney cancer clinical practice. The qualitative research project, titled *Empowering Choices: Insights from Healthcare Professionals on Shared Decision-Making in Kidney Cancer*, interviewed healthcare professionals in urology clinics in the United Kingdom, the Netherlands, and Germany to explore their perspectives as they relate to SDM, with a focus on early-stage kidney cancer.

In 2025, the research findings were published in a manuscript and presented at IKCS EU 25, as well in a poster at EAU25 winning the 1st prize for the best patient abstract.



The Evidence Generation Project to Quantify Benefits of SDM for Urologists, Patients was funded by the following companies in full compliance with the IKCC Donors Policy:

Eisai IPSEN Innovation for patient care Telix

GLOBAL CANCER COALITIONS NETWORK

IKCC and the Global Cancer Coalitions Network

Since its establishment in 2020, IKCC has been an active member of the Global Cancer Coalitions (GCCN) Network, to address collectively the impact of COVID-19 on cancer patient organisations worldwide. This network of 9 global cancer coalitions continues to foster collaboration, share best practices, and advance joint pan-cancer initiatives that strengthen patient advocacy across disease areas.

In October, during the congress of the European Society for Medical Oncology (ESMO) in Berlin (DE), IKCC co-organised a roundtable event on shared decision-making in oncology with the GCCN and Ipsen. Shared decision-making reflects the principle that patients should be provided the opportunity to participate in treatment decisions to the extent they desire.

The roundtable featured patient survey data from Lymphoma Coalition, World Bladder Cancer Patient Coalition, World Lung Cancer Coalition, and IKCC. Findings consistently showed that while many patients felt adequately involved in decision-making, a substantial proportion would like greater involvement in treatment decisions. Evidence indicates that clearer, more accessible information about treatment options, along with decision-support tools, can significantly improve shared decision-making.

Following the presentations, the GCCN members collaborated with Ipsen to co-create a practical framework to support the implementation of shared decision-making in oncology care globally. A comprehensive report from the event is planned for publication in 2026.



2025 IKCC Medical Conference Participation Highlights

IKCC represented patient voices and values at major international cancer conferences, contributing to key discussions that influence kidney cancer treatment and care worldwide.

2025 Urology and Oncology Conferences:

- **ASCO Genitourinary Cancers Symposium** (San Francisco, US)
- **European Association of Urology Annual Congress** (Madrid, ES)
- **American Urological Association Annual Meeting** (Las Vegas, US)
- **International Kidney Cancer Symposium: Europe** (Amsterdam, NL)
- **American Society of Clinical Oncology Annual Meeting** (Chicago, US)
- **Kidney Cancer Research Symposium** (Boston, US)
- **European Society of Medical Oncology Congress** (Berlin, DE)
- **International Kidney Cancer Symposium: North America** (Denver, US)
- **Congress of the CUA Confederation Americana de Urologia** (Panama City, PA)
- **Journal of the Advanced Practitioner in Oncology - Live Annual Meeting** (Maryland, US)
- **European Cancer Summit** (Brussels, BE)
- **UICC World Cancer Leaders' Summit** (Melbourne, AU)
- **ESMO Asia Congress** (Singapore)
- **Latin American Renal Cancer Group Conference** (Panama City, PA)

In 2025, IKCC collaborated with the American Association for Cancer Research on the AACR Scholar-in-Training Award. The award supports early-career researchers from around the world in attending the AACR Annual Meeting in Chicago (US). This collaboration aligns with IKCC's strategic focus on kidney cancer research and knowledge transfer, as well as supporting opportunities for researchers from lower- and middle-income countries.

Congratulations to Stefano Clerici of A.C. Camargo Cancer Center (BR) who was awarded the 2025 scholarship for his work titled, *Establishing patient-derived xenograft organoids (PDXOs) from renal cell carcinoma for drug screening and identification of treatment-induced vulnerabilities.*



2025 Medical Advisory Board Update

The IKCC Medical Advisory Board (MAB) is composed of leading clinical experts from around the globe who provide scientific and clinical guidance to IKCC. In April, I assumed the role of MAB Chair in a broader governance transition, in which Dr Eric Jonasch, became the Chair-elect of the IKCC Board.

In 2025, MAB activities focused on education, scientific knowledge exchange, and ensuring patient perspectives are reflected across care delivery and research. These efforts are central to IKCC's mission of driving patient advocacy through credible, clinically grounded information.

Again, MAB members were guest editors for IKCC's Medical Conference Highlights Reports, translating learnings from leading kidney cancer and oncology conferences into accessible summaries for Partner Organisations and their patient communities. Meeting Highlight Reports were published for ASCO GU, ASCO, and ESMO, focusing on practice-changing data and emerging research.

A major milestone was the MAB's collaboration with the IKCC Publication Committee. For the first time, MAB members worked closely with patient advocates to bring evidence-based patient experience data from the Global Patient Survey to the medical community. Five IKCC abstracts were accepted, with poster presentations delivered at the Kidney Cancer Research Symposium, ESMO, JADPROLive Annual Meeting, and the International Kidney Cancer Symposium – North America, and an oral presentation at the ESMO Asia meeting.

Inspired by The Cecile and Ken Youner IKCC Scholarship, the IKCC Allied Healthcare Professional Scholarship Award was developed in 2025. The new award focuses on the important work of allied healthcare professionals, including nurses, physiotherapists, psycho-oncologists, occupational therapists, dietitians, pharmacists, and social workers. In 2026, we will seek nominations of colleagues who significantly enhance the quality of life and care experience of kidney cancer patients.

In 2026, the MAB will continue its core activities while contributing to the upcoming Global Patient Survey on Kidney Cancer, marking ten years of data. Members will also support updates to IKCC's decision aids and clinical trial infographics. To further strengthen its multidisciplinary and global reach, the MAB will expand its specialised complementary expertise (e.g., radiation oncology, nephrology, cardiology) and recruit members from regions with high kidney cancer incidence, including Eastern Europe, the Middle East, and Africa.

We extend our gratitude to the physician experts who completed their MAB terms in 2025 for their dedication and contributions: James Larkin (UK), Yoshi Tomita (JP), Francisco Rodríguez-Covarrubias (MX), and Roman Sosnowski (PL). We also welcome two new members: Shankar Siva (AU), a radiation oncologist, and Ala Abudayyeh (US), an onco-nephrologist. We look forward to collaborating with you!

I am proud of all we have accomplished in 2025. Through deliberate, strategic efforts, we are expanding our reach and deepening our impact. These incremental advances collectively strengthen patient knowledge, elevate patient voices, and reinforce IKCC's role as a trusted bridge between patients, clinicians, and global stakeholders.

Prof. Stênio de Cássio Zequi
Chair, Medical Advisory Committee

2025 IKCC Medical Advisory Board

Prof. Stênio de Cássio Zequi (BR), Chair
Prof. Axel Bex (NL/UK), Vice Chair
Dr Daniel Heng (CA), Executive Member
Prof James Larkin (UK), Executive Member
Prof. Laurence Albiges (FR)
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Dr Roman Sosnowski (PL)
Dr Eric Singer (US)
Dr Yoshi Tomita (JP)
Prof. Yüksel Ürün (TR)

The Cecile and Ken Youner IKCC Scholarship

Since 2018, IKCC has run The Cecile and Ken Youner IKCC Scholarship, an annual award honouring Emeritus Founding Member Dr Ken Youner. The scholarship aims to engage with medical students and early-career physicians, encouraging them to pursue careers in kidney cancer and to become future leaders in the field. The award includes a travel grant to attend the Global Kidney Cancer Summit and an invitation to present their work to the international delegates.

In 2025, IKCC's Medical Advisory Board awarded the 7th Youner Scholarship to Dr Hatice Bölek of Türkiye.

Dr Bölek is an internal medicine specialist and medical oncology fellow. She received her medical degree from Hacettepe University in 2015 and completed her internal medicine residency there in 2020. After two years of consulting as an internal medicine specialist, she began her medical oncology fellowship at the Ankara University Faculty of Medicine in September 2022. In 2024, she was recognised with the International Development and Education Award (IDEA) by Conquer Cancer, American Society of Clinical Oncology (ASCO).

At the Global Kidney Cancer Summit in Madrid, Spain, Dr Bölek presented her current research: *Enhancing Quality of Life and Symptom Management in Metastatic Renal Cell Carcinoma Through a Web-Based eHealth Application.*



Dr Hatice Bölek receiving The Cecile and Ken Youner IKCC Scholarship from Dr Eric Jonasch, at the Global Kidney Cancer Summit in Madrid.

Financial Overview

Treasurer's Report 2025

On 1st November 2025, I had the honour of taking on the role of IKCC's Secretary-Treasurer, succeeding Anne Wilson. I would like to thank her for the time and energy she has invested in IKCC over her tenure. She will remain on the Board as past Secretary-Treasurer to ensure a smooth transition.

IKCC's work is largely supported by the pharmaceutical industry, in accordance with the IKCC Donors Policy. We thank them for their contributions and hope they will continue to be committed to our objectives and activities that support people affected by kidney cancer for a long time to come.

IKCC experienced a decline in revenue due to the uncertain global funding environment in 2025. As expenditures exceeded income, the organisation reported a deficit of approximately €383,000. IKCC utilised a portion of its reserves to bridge the gap, while maintaining a prudent reserve level to maintain operations. To address this trend, a plan has been implemented to strengthen and diversify revenue streams, implementing enhanced cost-management measures to reduce expenditures. The impact of these initiatives is expected to become evident in 2026.

We would like to thank our new accountants, AMA, and new auditors, Accent on Audit B.V., for their support in establishing robust and precise financial dashboards and helping to guide the organisation forward.

Dr Bart van Goudoever
Secretary-Treasurer, IKCC Board of Directors

Financial Statements 2025

Statement of Financial Position	31-Dec-25	31-Dec-24
ASSETS		
Fixed assets		
Tangible fixed assets	694	-
Total fixed assets	**694**	-
Current Assets		
Funds to receive	-	2,566
Prepaid expenses and other receivables	47,778	65,159
Liquid assets	774,319	1,132,626
Total current assets	**822,097**	**1,200,351**
TOTAL ASSETS	**822,791**	**1,200,351**

Statement of Financial Position	31-Dec-25	31-Dec-24
Current liabilities		
Creditors and accrued expenses	93,959	88,114
Total current liabilities	**93,959**	**88,114**
NET ASSETS	**728,832**	**1,112,237**
ACCUMULATED FUNDS		
Reserves	1,309,167	1,286,251
Previous year surplus/ (deficit)	(196,930)	22,916
Current year surplus/ (deficit)	(383,405)	(196,930)
TOTAL ACCUMULATED FUNDS	**728,832**	**1,112,237**

Partner Organisations

IKCC is an independent network of 58 patient organisations from around the world, united by a shared commitment to improving the lives of people affected by kidney cancer. While advocacy begins locally – within individual countries and communities – our collective strength enables a far-reaching global impact. Together, Partner Organisations dedicated to kidney cancer amplify patient voices, share knowledge, and drive meaningful change worldwide.

Partner Organisations

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

- Have a clear focus on supporting people affected by kidney cancer through patient services, awareness-raising, research promotion, and/or organisational empowerment.
- Are formally recognised and/or registered as a non-profit organisation in their respective countries.
- Committed to abiding by the IKCC Code of Conduct and adhering to the strict ethical guidelines governing charities and non-profit organisations within their national contexts.
- Demonstrate a willingness to collaborate, share expertise, and work cooperatively with other organisations within the IKCC network.

Please see the IKCC website for a complete and up-to-date list of Partner Organisations: https://ikcc.org/about-ikcc/our-affiliates/partner-organisations/

Supporters

Supporters are individuals or organisations who share an interest in the work of IKCC but do not meet the criteria for Partner Organisation status. This group may include emerging organisations, advocates, or individuals with a strong interest in kidney cancer support and advocacy who wish to engage with IKCC through meetings, events, or communications.

New in 2025

In 2025, we welcomed Cancer Warriors Foundation Inc. in the Philippines to the IKCC family. Founded in 1991, initially the organisation focused on raising awareness of childhood cancers and supporting affected children and their families. In recent years, Cancer Warriors Foundation, Inc. has expanded its mission to serve all people diagnosed with cancer in the Philippines, strengthening patient support and advocacy efforts nationwide.

Cancer Warriors Foundation, Inc.

IKCC Board of Directors

The IKCC Board of Directors is a volunteer-based working Board that brings together people with a variety of experiences, perspectives and skills. This diversity ensures a collective experience and management expertise needed for the leadership, sustainability and ongoing growth of the global organisation. The Board sets the organisational strategic direction towards the vision of reducing the global burden of kidney cancer for patients.

According to the IKCC Deed and Regulations the Board is made up of five to ten Directors, and must include a minimum of two Directors from Partner Organisations to provide input from patient organisations and personal experience with kidney cancer, up to two Directors from the IKCC Medical Advisory Board and specific Office Bearers, Chair, Vice-Chair, and Secretary-Treasurer.



Dr Eric Jonasch
Chair
United States



Claudia Ungarelli
Vice-Chair
Italy



Dr Bart van Goudoever
Secretary/Treasurer
The Netherlands



Professor Stenio de Cassio Zequi
Chair, IKCC Medical Advisory Board
Brazil



Caleb Egwuenu
Board Member,
Patient Organisation Representative
Nigeria



Margaret (Margie) Hickey
Board Member
United States



Steve Pointon
Board Member,
Patient Organisation Representative
United Kingdom



Carmen Vallejo Auste
Board Member
Philippines



Dr Michael A.S. Jewett
Past Chair
Canada



Bryan Lewis
Past Vice-Chair
United States



Anne Wilson
Past Secretary / Treasurer
Australia

IKCC Leadership



Olivier Exertier
Executive Director
France



Julia Black
Chief Operating Officer
United Kingdom



Rebecca Cubbage
Projects Assistant
United Kingdom

We would also like to express our gratitude to the IKCC team, whose efforts enable us to carry out our mission.

- **Rebecca Bigelow**
  Epion Medical Communications
  Medical Writer
- **Jorge and Arthur da Silva**
  AMA Accountants
  Accounting Support
- **Sharon Deveson Kell**
  Medical Writer
- **Charlie Douglass**
  Douglass Digital
  Website Hosting
- **Karin Kastrati**
  Technical Support
- **Jilda Lazer**
  Reverb Consulting Group
  Communications Support
- **Laurine Robinn**
  Graphic Designer
- **Jay Strauss**
  Social Media Support

Acknowledgements

2025 Sponsors

We thank the following organisations that have supported IKCC in 2025.

Public/Institutional Support:

European Commission

Industry Support:

ARCUS BIOSCIENCES

AstraZeneca

Eisai

EXELIXIS

IPSEN Innovation for patient care

MERCK

MSD

Pfizer

Roche

Telix

IKCC is committed to open and transparent partnerships with the healthcare industry in accordance with the IKCC Donors Policy (www.ikcc.org) updated in 2025. Multi-sourced funding allows us to maintain our independence and integrity as a patient organisation and remain focused on our mission to reduce the global burden of kidney cancer.

IKCC
International Kidney Cancer Coalition

Registered Address:
Stichting International Kidney Cancer Coalition
Computerweg 22, 3542 DR Utrecht,
The Netherlands

Email: info@ikcc.org
Website: www.ikcc.org

Search for us on
Facebook: @ikcc
Instagram: @ikccfoundation
X: @IKCCorg
YouTube: @ikccorg
LinkedIn: International Kidney Cancer Coalition (IKCC)
BlueSky: @ikccorg.bsky.social

Registered in the Netherlands under:
No. KvK 62070665

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