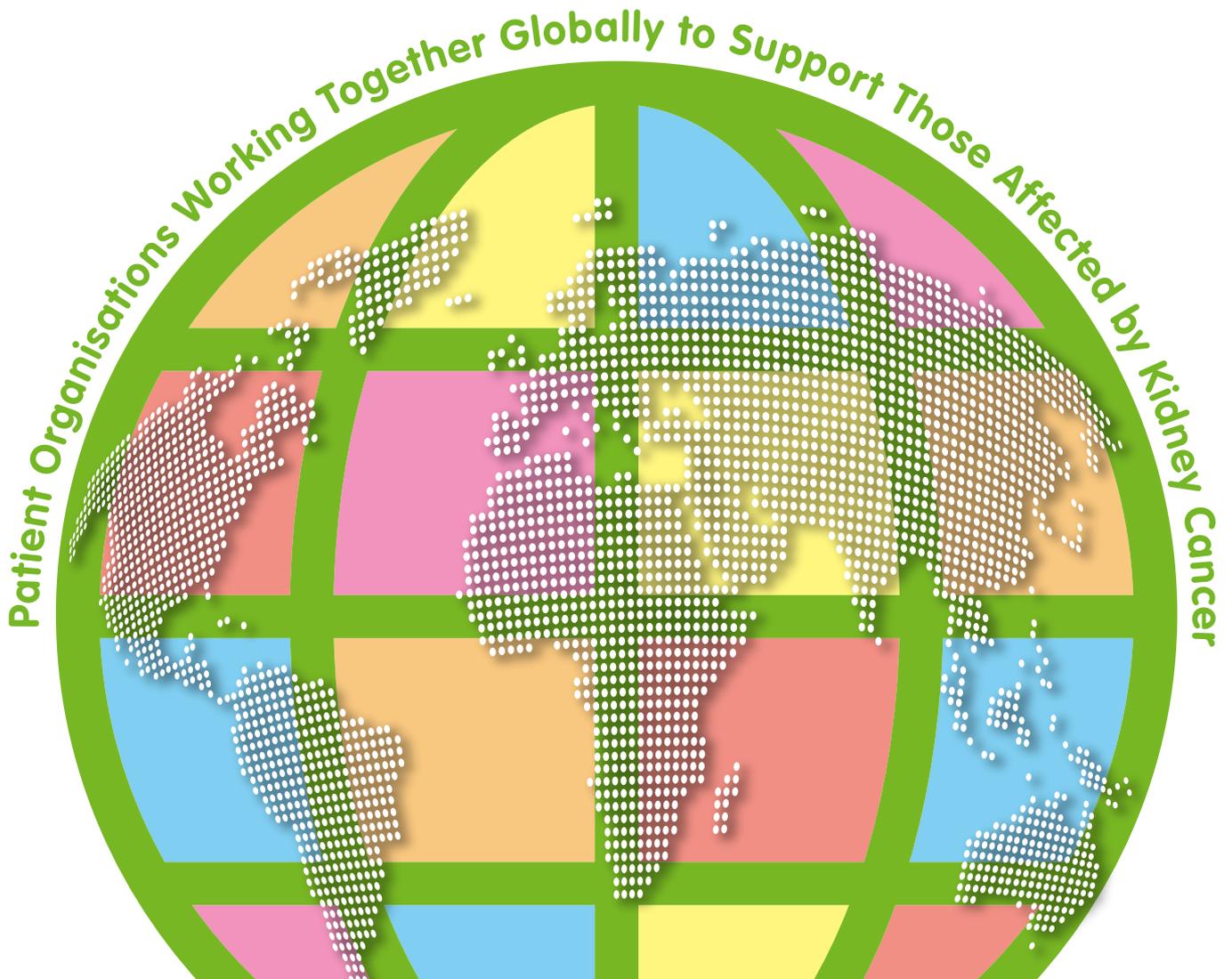
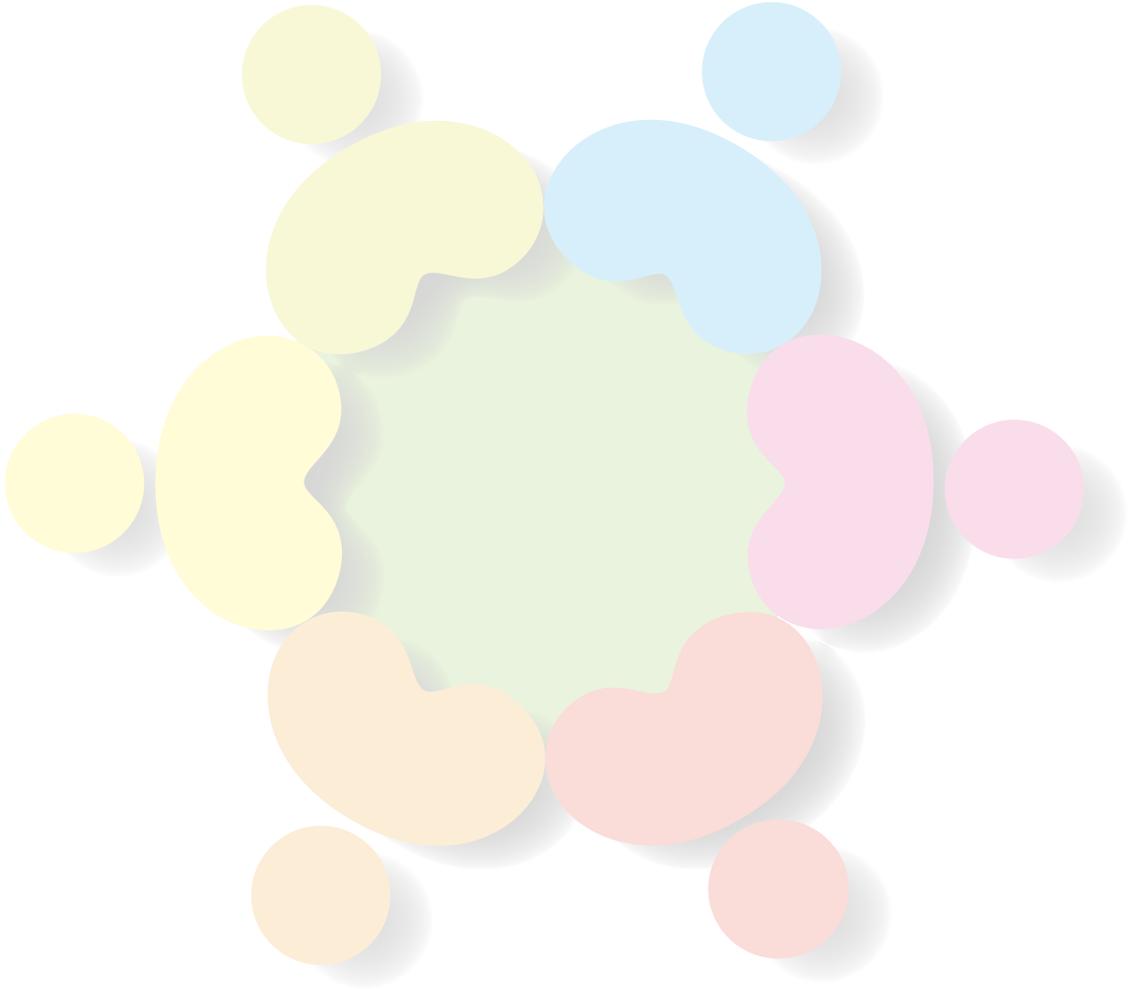




IKCC Annual Report 2022





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Message from the Chair



Dr Michael Jewett

Board Chair

What an exciting time for the International Kidney Cancer Coalition (IKCC). We are growing, we are changing, and we are stronger. We've been through some challenging years – navigating a global pandemic and virtually supporting the global kidney cancer community through significant uncertainty. Yet, here we are now, well positioned to make the leap into the next phase of the organisation.

The IKCC Board of Directors is thrilled Dr Rachel Giles has accepted the role of Chief Executive Officer beginning in January, 2023. The growth and organisational maturity that IKCC has experienced over the past several years has been under Rachel's strategic guidance, first on the Leadership Team since 2010, and after 2014, as Board Chair. She brings both personal and professional experience and insights to this work. As Rachel takes on a more substantive role, the goal is to accelerate the impact IKCC has in the global cancer community.

As a result, there are changes to the IKCC Board of Directors. I have moved into the position of Board Chair, and Dr Eric Jonasch has moved from Vice Chair to replace me as Chair of the IKCC Medical Advisory Board, and Prof Axel Bex has agreed to serve as the Vice Chair of the Medical Advisory Board.

Outside of the leadership changes, IKCC's community continues to grow with three new Affiliate Organisations joining in 2022. European Kidney Patients' Federation in Austria, Wilms Cancer Foundation in Canada, and Association for VHL Affected Families in Germany – your partnership makes us stronger.

IKCC began nearly 14 years ago with the idea to bring together like-minded organisations focused on kidney cancer to connect, share and collaborate. Look where we are today, but more importantly, look where we have the potential to go!

On behalf of the Board, thank you to everyone who contributed to the success of 2022 – we are honoured, grateful and inspired by your partnership.

Sincerely,

Michael Jewett

Chair, IKCC Board of Directors



**Patient Organisations Working Together Globally
to Support Those Affected by Kidney Cancer**

Message from the CEO



Dr Rachel Giles

Chief Executive Officer

When we look back on 2022, it was a year of many things. It was a year of recovery and re-establishing our bonds. Strengthening and expanding our presence, both regionally and globally. It was also a time to look at what we've accomplished, where we have the most impact, and how can we continue – and even boost – our impact.

The International Kidney Cancer Coalition (IKCC) is the only global network of independent national kidney cancer patient organisations. We represent the perspectives, insights and experiences of kidney cancer patients around the world and empower the kidney cancer community through advocacy, awareness, information and research. Our strength is in the power of our network of patient organisations, healthcare professionals and associations, researchers and supporters, all sharing a common goal of reducing the burden of kidney cancer worldwide.

One of the most important roles IKCC plays is representing the perspectives of kidney cancer patients in many forums. Ensuring the patient perspective is not only considered, but given substantial importance, helps improve research, clinical care and support. In 2022 alone, IKCC representatives served on the National Comprehensive Cancer Network (NCCN) and European Association of Urology (EAU) guideline panels for kidney cancer, published 20 papers and presented at 12 national or international conferences. To help even more healthcare professionals get involved in patient engagement and advocacy, in partnership with the IKCC Medical Advisory Board, we hosted the IKCC Clinical Leadership Workshop in Paris, France, empowering more clinicians to get involved in advocacy in their home countries.

IKCC's biennial Global Patient Survey on Kidney Cancer is foundational to all the work we do. Accurately understanding patients' experiences and insights allows us to better represent patients' needs and values. In 2022, more than 2,200 people from 39 countries completed the 3rd survey. We are looking forward to sharing the results later in 2023.

Another highlight of 2022 was the 12th Global Kidney Cancer Summit in October. For the first time in three years, Affiliate Organisation met in Orta San Giulio, Italy. Together we celebrated successes, learned from each other's challenges and collaborated on how to locally and globally support people with kidney cancer. I know I craved being with the IKCC community in person and the three days together didn't disappoint.

World Kidney Cancer Day continues to be an important annual milestone where the global network of Affiliate Organisations comes together to raise awareness for the disease. In 2022, the campaign theme – ***We need to talk about treatment options*** – addressed the gaps in knowledge patients face related to the full range of treatments available, including clinical trials, and encouraged more communication between patients and healthcare teams.

In addition, important educational and support information is made available for Affiliates to cascade to patients and carers around the world, including the newest My Treatment, My Choice decision aid and the translated Kidney Cancer Diet & Nutrition Resource.

As we reflect on all that was accomplished in the past year – and as you read the report that follows – you will see there is so much more. I am excited to take on my new role as the Chief Executive Officer of IKCC. I'm looking forward to building and strengthening partnerships with Affiliate Organisations, medical experts, health organisations and other healthcare stakeholders. There is so much more to do to improve the lives of people with kidney cancer and we are well positioned to do it together.

In partnership,



Chief Executive Officer, IKCC

About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of 48 patient-focused Affiliate Organisations that focus on kidney cancer. Based in Amsterdam, The Netherlands, the organisation was born from a strong desire among multiple national kidney cancer patient groups to network, collaborate and share knowledge and experiences to ultimately magnify the voices of kidney cancer patients globally.

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide will be diagnosed with kidney cancer.¹ By working together and collecting the experiences of many patients in different countries, we represent the perspectives, insights and experiences of kidney cancer patients around the world and empower the kidney cancer community through advocacy, awareness, information and research.

Priority areas of focus include:

- Strengthening the capacity of current and emerging Affiliates in their support for patients with kidney cancer
- Advocating for access to the best care
- Increasing awareness of kidney cancer globally
- Being a global authority in the provision of credible and up-to-date kidney cancer information
- Fostering projects promoting the voice of kidney cancer patients in research activities worldwide

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.

Our Values:

IKCC has defined core values that form the basis for the culture, the behaviour, the cooperation, the decision-making process and the activities of IKCC.



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



¹ Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality world-wide for 36 cancers in 185 countries. *CA Cancer J Clin.* 68(6):394–424. <https://doi.org/10.3322/caac.21492> PMID:30207593

2022: IKCC by the Numbers



48

Affiliate Organisations worldwide



World Kidney Cancer Day 2022

4.2+ million impressions

6,864 website clicks

570 downloads of the 6-question resource

374 video views

234 webinar registrations



3

new Affiliates in 2022

 European Kidney Patients Federation in Austria

 Wilms Cancer Foundation in Canada

 Association for VHL Affected Families in Germany



IKCC published **20** papers in medical journals – up **113%** from 2021!



Growing Social Media Community

4,631 Twitter followers

8,657 Facebook likes



IKCC presented at

12 national and international conferences and shared **4** posters



At the 2022 Global Kidney Cancer Summit

62 delegates from

21 countries and

6 continents spent

3 days together!



4 editions of the IKCC Newsletter were sent to **481** subscribers

4 conference highlight summaries shared from GU ASCO, ASCO, EAU, ESMO

2022 Projects and Activities



Global Patient Survey on Kidney Cancer 2022



In September 2022, the 3rd Global Patient Survey (GPS) on Kidney Cancer was launched and kidney cancer patients, carers and survivors from around the world were asked to share their individual lived experiences and insights about living with the disease.

This was the third iteration of the biennial survey, which studies the ways patients' experiences change over time. The survey assesses access to care, information needs, quality of life and the prevalence of shared decision-making, as well as identifies geographical differences, best practices and unmet needs.

More than 2,200 people from 39 countries participated in the 2022 GPS. This represents approximately a 10% increase in the number of respondents from 2020. The survey results will be analysed and shared in 2023.

The success of the survey depends on the participation of patients and carers from around the world taking the time to share their experience and insights, which then informs the work of IKCC and Affiliate Organisations worldwide. Thank you to everyone who participated in the Global Patient Survey – including its development, translation, promotion and completion.



WORLD KIDNEY CANCER DAY 2022

We need to talk
about treatment options

16 June 2022

On 16 June 2022, Affiliate Organisations and the global kidney cancer community came together for World Kidney Cancer Day to say – We need to talk about treatment options. The campaign was created to address the gaps in knowledge patients face related to the full range of treatments available, including clinical trials. When patients know more, they are in a better position to be an active partner in their care and treatment and share in the decision-making process with their healthcare team.

The global campaign kick-off featured an online expert panel webinar with healthcare and patient leaders. Clinicians were asked to talk about shared decision-making best practices as they relate to kidney cancer treatment options and the importance of clinical trials. The patient panel shared their experiences living with kidney cancer and talking about treatment options. The event was recorded and shared with subtitles in 12 languages making it accessible to the global community.

A variety of World Kidney Cancer Day-branded multi-language campaign elements were available so Affiliates could customise the campaign for their region: logos, graphics, animated videos, social media content, and a downloadable patient resource of 6 questions to ask a healthcare team.

Affiliate Organisations from six continents participated in the campaign and raised awareness for the disease and encouraged conversations between patients and healthcare teams. Overall, the campaign materials achieved 4.2+ million impressions, 6,864 website clicks, 570 resource downloads, 374 video views and

234 webinar registrations. The overall success and increased awareness of the campaign was achieved through the combined efforts of the many participating Affiliate Organisations around the world, together with the local activities and media they generated. Thank you!

By the Numbers:

- 4.2+ million impressions
- 6,864 website clicks
- 570 resource downloads
- 374 video views
- 234 webinar registrations

<u>Host and moderator</u>	<u>Medical Panellists</u>	
Dr Rachel Giles	Dr Eric Jonasch	Dr Poovan Govender
		
Chair, IKCC, Associate Professor, Internal Medicine, University Medical Centre Utrecht, Netherlands. Medical Science Officer, Medicom Medical Publishers, Netherlands.	Professor, Department of Genitourinary Medical Oncology, Division of Cancer Medicine, MD Anderson Cancer Center, The University of Texas, Houston	Specialist Oncologist, Durban, Kwazulu Natal, South Africa
<u>Patient Panel</u>		
Our medical panellists will be joined by a panel of patients and caregivers from around the world.		



OncoDebate 30 JUN / 17h

Junho: mês de conscientização sobre o **câncer de rim**

LUCJANA HOLTZ
Procedente do Oncologia

ANDRE FAY
Oncologista, membro do IBCO do Brasil, fundador do IBO e professor de oncologia da medicina da FUCRS

EVELIN SCARELLI
Neurocientista, professora de oncologia e radioterapeuta do Oncologia

HELENA ESTEVES
Coordenadora do Oncology do Oncologia

LEIDIENE ALVES
Procedente do Oncologia do rim e vertebroplastia do Oncologia

Oncoguia IKCC IPSEN

ΠΑΓΚΟΣΜΙΑ ΗΜΕΡΑ ΚΑΡΚΙΝΟΥ ΤΟΥ ΝΕΦΡΟΥ 2022

Watch on YouTube

Stowarzyszenie Gladiator, Główny Zarząd z siedzibą w Warszawie

16 Jun ·

Dołącz do wydarzenia. Rak nerki może dotyczyć również Ciebie. Dowiedz się więcej! See Translation

THURS, 16 JUN
WORLD KIDNEY CANCER DAY 2022

Like Comment Share

JOURNÉE MONDIALE DU CANCER DU REIN

La version sous-titrée du webinar est en ligne!

PARLER DES TRAITEMENTS WEBINAIRE MONDIAL

Kidney Cancer Canada

WOW! The CN Tower in Toronto dressed in green for World Kidney Cancer Day. Thank you for supporting the global kidney cancer community!

A special thank you to our Executive Director's sister, Susan, for the great photo!

2 491 Personnes atteintes 321 Interactions

V Care @vcare24

Around the world, many #kidneycancer patients aren't aware of the treatment options that are available to them. We need to talk about treatment options. Join us on World Kidney Cancer Day 16 June #WKCD2022 #IKCC #WKCD2022 #CancerCare #India #VCare #Mumbai

वर्ल्ड किडनी कैंसर डे 2022

Tweet your reply

ARTUR Association pour la recherche sur les tumeurs et les cancers du rein

Événement ARTUR - Table ronde

414 Personnes touchées 59 Interactions

Weltweber & Partner

WELTNIERENKREBSTAG 2022 16. JUNI

Wie wird es mir unter dieser Behandlung gehen?

251 Besuche Personen 32 Interaktionen

3

한국신장암환우회 Korea Kidney Cancer Association

6월 8일

6월 16일은 세계신장암의 날입니다.

#WorldKidneyCancerDay #kidney... 더 보기

WORLD KIDNEY CANCER DAY 2022

Let's work to talk about treatment options

World Kidney Cancer Day

WORLD KIDNEY CANCER DAY 2022

Let's work to talk about treatment options

世界腎がんデー2022

治療の選択肢について話しましょう

2022年6月16日

세계 신장암의 날 2022

치료 환경, 우리 함께 이야기 해봐요.

2022년 6월 16일

두 분이 한자리에 모인 이유?

IKCC Clinical Leadership Workshop



In September 2022, IKCC hosted a first-of-its-kind patient engagement-focused workshop for members of the IKCC Medical Advisory Board (MAB) and potential candidates who will be invited to join the MAB. The IKCC Clinical Leadership Workshop, held in Paris, France following the European Society of Medical Oncology (ESMO) conference, was designed to foster a better understanding of the role for clinicians to promote patient advocacy and accelerate patient engagement.

An international roster of experts – including patients advocates and clinicians – shared their experiences and expertise. Over the course of the two-day workshop, presenters and participants explored a number of ways to elevate the patient experience and values into the clinical and supportive settings. The first day focused on the ways involving patients and patient organisations can improve clinical research. The second day focused on ways to support shared decision-making, involving patients in clinical guidelines and understanding patients' needs across the cancer journey.

In total, 41 clinicians, patient advocates and IKCC members from 21 countries attended the inaugural workshop and participants were armed to go back to their home countries and encouraged to share their learnings with colleagues and trainees.



“Patient engagement is a potential blockbuster treatment that urologists should prescribe for their cancer patients.”

Dr Michael Jewett,

IKCC Board Chair and Professor of Surgery, Toronto, Canada

Kidney Cancer Roundtable with the European Union Parliament

IKCC hosted its first Kidney Cancer Roundtable with the European Union Parliament in Brussels, Belgium on 29 November 2022. During the event, policy makers, patients and clinicians came together to highlight the need to address EU funding for kidney cancer research, which is currently not in line with the incidence or burden of the disease.

The day of education and engagement kicked off with a welcome from event sponsor and Member of European Parliament, Nicolás Casares. He reviewed the current state of kidney cancer in Europe – where cases are on the rise and have been increasing for several decades.

Other presenters included:

- Claudia Ungarelli, from ANTURE in Italy, shared the importance of the patient voice
- Dr Rachel Giles, Chair of IKCC, presented how research has advanced the treatment of metastatic kidney cancer
- Eveline Scheres, MBA, from European Kidney Health Alliance, spoke about the connection between chronic kidney disease and kidney cancer
- Mónica Suengas, from ALCER in Spain, presented a case study outlining the impact of delayed access to innovative kidney cancer treatments
- Prof Christine Chomienne, from Mission Cancer Board, and Kay Duggan Walls, from Cancer Mission Team, reviewed what is happening at a European level, including highlighting ways for patient organisations to become involved
- Prof Dr Hein Van Poppel, the European Association of Urology (EAU) Policy Office Chair, discussed the importance of early detection and treatment of kidney cancer

Following the presentations, the 20 participants engaged in a productive discussion, which culminated with draft recommendations to improve the lives of people living with kidney cancer in Europe. A Roundtable Report will be created and shared, and IKCC will work closely with the EAU Policy Office to ensure they are part of the discussion related to the Europe's Beating Cancer Plan and the Cancer Research Mission. In addition, Affiliate Organisations across Europe will be able to use the recommendations to improve funding and access issues locally.



Kidney Cancer Diet & Nutrition: A guide for patients and families

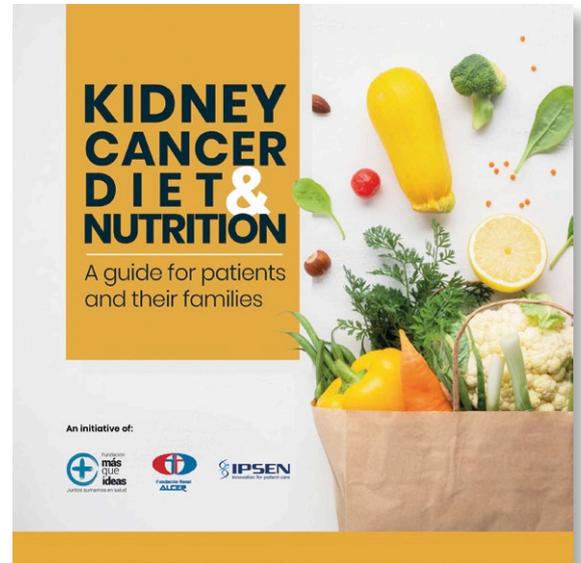
A new resource, specifically for people with kidney cancer, was created to help explain the effect of food and nutrition on the body. Kidney Cancer Diet & Nutrition: A guide for patients and their families, it was created to provide practical health and dietary information and to help people enjoy food and its related social experiences.

The Nutrition Guide is an initiative of IKCC Affiliate Organisation ALCER Renal Foundation (ES), Fundación MÁS QUE IDEAS and Ipsen. Originally created in Spanish for the kidney cancer community in Spain, the Guide has been translated into English to help more people living with kidney cancer and their families understand the relationship between food, nutrition, the kidneys and kidney cancer.

The English translated guide is available on the IKCC website: www.ikcc.org.

“Food is such an important part of our culture in Spain – sharing food together is so often the way we connect with the people we love. That’s why we created this resource – so people living with kidney cancer can be empowered to understand the role food plays in their health, and ways to continue to enjoy it.”

Juan Carlos Julián Mauro, ALCER Renal Foundation, Spain.



The Kidney Cancer Diet & Nutrition Guide includes information about:

- Kidney cancer, including potential treatments
- Nutrition as it relates to kidney cancer
- Maintaining a balanced diet when diagnosed with kidney cancer (including specific information for localised and metastatic kidney cancer)
- Managing symptoms and side-effects
- Food and drug interactions
- And...recipes!

My Treatment, My Choice: Clinical Trial Basics

It is a guiding principle of IKCC that patients, along with families and carers, have an essential role to play in healthcare decision-making that affects their lives – a concept known as shared decision-making.

Each year IKCC reviews and expands the series of patient-focused Decision Aids, called **My Treatment, My Choice**. The series of resources help patients and their families to understand, navigate and participate in their healthcare decisions with practical, credible and accessible information in a format designed for patients.

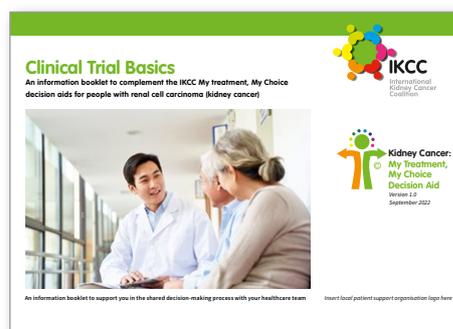
In 2022, the newest decision aid for patients was launched focusing on research and clinical trials. It introduces the basic information and will be useful for all patients who may be considering joining a clinical trial, regardless of cancer subtype or stage.

The Clinical Trials Basics decision aid was created to help patients and carers prepare for and have conversations with their healthcare teams. Specifically, it focuses on:

- What is a clinical trial?
- Information about why we need to test new treatments and interventions in clinical trials
- Information about the funding and ethics of clinical trials
- Explanations about the different types of clinical trial and research studies
- Information about who conducts clinical trials and where
- Information about data management and reporting

A collaborative team of patients, patient advocates and medical professionals who have supported thousands of kidney cancer patients worldwide wrote the resource with the patient and their needs in mind.

The Clinical Trial Basics decision aid is available on the IKCC website (www.ikcc.org), along with the other editions of the **My Treatment, My Choice** series.



“Kidney cancer medicine is rapidly changing with many new treatments on the horizon. It is through research and clinical trials that these achievements are possible and we are especially grateful to the patients who take part in clinical trials, which will benefit so many patients in the future.”

Rose Woodward, IKCC Board Member and lead for the My Treatment, My Choice Decision Aids.

IKCC's Response to the Crisis in Ukraine

As the humanitarian crisis in Ukraine unfolded in the spring of 2022, there was great international concern about the significant impact on cancer patients fleeing the country, as well as those who cannot. This includes disruptions to diagnostic evaluations, cancer treatment and supportive care.

IKCC made a commitment to support patients and healthcare professionals in Ukraine and bordering countries that are receiving refugees to help ensure cancer patients get the continued care and support they need.

IKCC became involved in supporting cancer patients from Ukraine in collaboration with the European Cancer Patient Organisation WECAN (involving daily coordination calls to share resources), the European Cancer Organisation, other European networks and the Rakiety Foundation. We also worked with local clinicians, cancer and urological societies, and patient groups to help patients access the care they needed. In total, 32 medical translators were engaged to translate hundreds of faxed medical records to Polish and English to help ease and expedite the transition. IKCC also translated kidney cancer-specific resources into Ukrainian, which were shared by Affiliate Organisations in the region, and posted on the European Association of Urology (EAU) website.

In addition, IKCC made a financial donation to the Rakiety Foundation, a charity based in Poland working directly with refugees who are cancer patients. This charity continues to focus on providing medical transport from the border, facilitating continuity of care and treatment in Poland, providing psychosocial and basic needs support, and managing a 24-hour Info-line.

While it is all of our hopes that the conflict in the region comes to an end soon and patients' safety is restored, until it does, we encourage kidney cancer patients to reach out to IKCC and Affiliate Organisations in the affected regions to help them navigate the local health systems and access care.

Що таке рак нирки?

Що таке рак?
Рак, пухлина, новоутворення, формування, ушкодження, ураження... Можливо, ви чули кілька цих слів, які означають рак. Медичні експерти стверджують більш формальними термінами: неоплазма, що досконало перекладається як новий ріст. З наукової точки зору, рак трапляється як несподівана аномальна генерація, що призводить до некоректного росту клітин і не координується з ними. Відбувається те, що ми уявляємо смертю для її зростання.

Наша тіла складається з клітин. Кожна клітина, кожна частина нашого тіла - це скупчення клітин, які за своєю природою думати, замислювати або не робити. Більше того, наш тіла завжди виробляють нові клітини: щоб ми могли рости, щоб замінити зношені клітини або відновити пошкоджені після травми. Відновлення клітин відбувається аналогічно їх пошуку. Наприклад, у разі порузу, клітини шкіри отримують сигнал "пошукайте для пошуку пошуку". Коли поріз загоється, вони отримують сигнал "зупинитися" і перестають ділитися.

Цей процес контролюється механізмами всередині клітин, так званими генами. Як і люди, раку викликають змінами цих генів, які називаються мутаціями. Зміни в генах, які викликають рак, зазвичай відбуваються протягом нашого життя, хоча невелика кількість людей успадковують мутації від батьків.

Діагностика раку нирки

Як люди дізнаються, що вони хворі на рак нирки?
Більшість ракових захворювань нирок на ранніх стадіях протікає безсимптомно, що є головною причиною, чому основні види нирки часто діагностують вже на пізніх стадіях.

Часто пухлику виявляють абсолютно випадково - при профілактичному обстеженні або під час сканування, рентгенологічного чи ультразвукового дослідження органів черевної порожнини (УЗД) з приводу могого іншого захворювання.

Слід обов'язково звернутися до лікаря у разі будь-яких з нижчеперелічених симптомів:

- Кров'яні сечі або зміна її кольору до темного, червоного або коричневого кольору (гематурія)

Найпоширеніші види обстежень на рак нирки
Залежно від симптомів, фази захворювання, різні види обстежень для діагностики раку нирки, які спрямовані на встановлення і підтвердження або виключення діагнозу, уточнення типу пухлики і ступеня ураження нирки. До основних методів діагностики належать наступні:

- **Ультразвукове дослідження.** Тип сканування, коли зонд ковзає по шкірі, і дослідники виявляють порушення в роботі нирок та інших органів.

Як лікувати розповсюджений рак нирки

Таргетна терапія
Хіміотерапія не застосовується при раку нирки. Таргетна терапія базується на руйнуванні ліній (зв'язки) між клітинами. Таргетні препарати пригнічують кровотворення пухлики, що уповільнює або зупиняє ріст пухлики, а іноді й призводить до її зменшення. (див. графік №1).

Ці препарати спрямовані на конкретні діючі речовини всередині раку, і тому їх називають "таргетною терапією". Препарати таргетної терапії ще називають ангіогенними або інгібіторами тирозинкінази.

Для лікування нирково-клітинного раку використовуються наступні таргетні препарати: аксизатиніб, кабозатиніб, леватиніб, пазопаніб, сорafenіб, сунітиніб.

Ще один препарат, бевасизумаб, відноситься до антиангіогенних таргетних препаратів.

Ліки, які блокують ріст раку
Друга група ліків від раку нирки діє шляхом блокування іншого сигналу (інгібітори mTOR). Інгібітори mTOR (див. графік № 2), що використовуються для лікування раку нирки, є еверолімусом і темсиролімусом.

Імунотерапія із застосуванням цитотоксичних
До 2006 року імунотерапія цитотоксичними, такими як іперицидин 2 (I-2) та альфа-інтерферон, переважно використовувалася для лікування метастатичного раку нирки.

Ці ліки діють на деяких людей, антумічні клітини Т-клітери, які є частинкою імунної системи організму, що знищують ракові клітини. Нові види імунної терапії стали доступними і їх тестують під час спільних випробувань.

Імунотерапія з використанням інгібіторів контрольних точок
Інгібітори контрольних точок, які ще називають імунотерапією, блокують регуляторні імунні клітини з контрольними точками імунної відповіді, які допомагають регулювати роботу імунної системи. При заході імунної регуляції імунна система стає надзвичайно активною і атакує організм, в результаті чого виникає його ракове захворювання, при заході високій регуляції - імунні функції порушуються і, іноді, виникають інфекції та рак.

Global Kidney Cancer Summit 2022



2022 Global Kidney Cancer Summit

The 12th Global Kidney Cancer Summit 2022 – the International Conference for Organisations Representing Patients with Kidney Cancer – was held in beautiful in Orta San Giulio, Italy in October 2022. At the in-person meeting we welcomed 28 Affiliate Organisations from 21 countries. Additionally, Affiliates had the opportunity to join the conference virtually. Over the three days together, we learned from each other, shared our successes and challenges and helped to build capacity across the kidney cancer network.

This was the first in-person Summit in three years and once again there was a very robust agenda. Medical experts shared clinical updates for adjuvant and metastatic treatment. A panel discussion explored what to consider when communicating a kidney cancer diagnosis to a patient. A variety of ways to support patients – from support programs to better nutrition – were discussed. As well, guest presenters spoke about the benefits of mindfulness and living with meaning in cancer care.

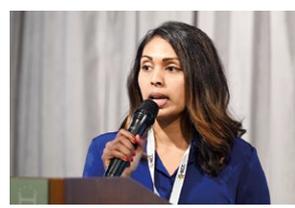
There was also a special focus on the Evolution of Patient Organisations that considered the varying stage and circumstances of organisations across the network of Affiliates and set the stage for sharing best practices, key learnings and mentorship.

Thank you to everyone who presented and shared during the Global Kidney Cancer Summit, as well as those who helped to moderate the discussions. We also thank the 2022 Conference Committee for all their efforts to plan the event. Committee members included Christine Collins (CA), Dr Rachel Giles (NL), Dr Michael Jewett (CA), Liz Leff (US), Brian Lewis (US). Grazie!









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 attends conferences, participates on committees and advisory groups and publishes 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.

2022 IKCC Presentations and Conference Participation

February

Board Vice Chair Bryan Lewis spoke at the Cancer Survivors Day for VCare in India.

IKCC staff and Board members attended and presented a poster at ASCO Genitourinary Cancers Symposium (GU ASCO) in San Francisco, US.

March

Dr Rachel Giles presented at the Dutch Renal Cancer Group.

April

IKCC made a presentation and shared a poster at the International Kidney Cancer Symposium: Europe.

May

Board Ambassador Deb Maskens presented at the American Society of Clinical Oncology (ASCO) conference in Chicago, US.

Board Vice Chair Bryan Lewis presented at the VHL Virtual Meeting (GR).

July

Drs Rachel Giles and Michael Jewett presented at the European Association of Urology (EAU) Congress in Amsterdam, NL. A poster was shared.

September

IKCC staff and Board members attended the European Society of Medical Oncology (ESMO) conference and shared a poster.

Dr Rachel Giles was a panelist at the European Medicines Agency multi-stakeholder workshop: Patient experience data in medicines development and regulatory decision-making.

October

Dr Rachel Giles was a clinical keynote speaker at the EMBO Cilia 2022 meeting in Cologne, DE.

IKCC represented kidney cancer patients and gave a presentation at the World Cancer Congress in Geneva, CH.

November

IKCC attended the virtual VHL International Medical Symposium.

Dr Rachel Giles was a speaker at the European Cancer Summit in Brussels, BE.

Dr Eric Jonasch, Vice Chair of the Medical Advisory Board, presented at the International Kidney Cancer Symposium in Austin, US.

2022 IKCC Publications



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Links to all of IKCC's 2022 publications can be found at <https://ikcc.org/publications/>

The IKCC Medical Advisory Board: 2022 Update

The Medical Advisory Board (MAB) provides high-level scientific and clinical expertise to IKCC. This ensures the organisation provides evidence-based leadership within the international kidney cancer community.

In addition, the MAB supports the IKCC vision to reduce the global burden of kidney cancer and represents and advocates for patient values and perspectives in major scientific committees and expert groups at both national and international levels. In 2022, the group produced highlight summaries from three major medical conferences: GU ASCO, ASCO, and ESMO.

A new program was launched in 2022 - the IKCC Clinical Leadership Workshop - was designed to help members of the IKCC Medical Advisory Board and candidates who will be invited to join the MAB get involved in patient engagement and advocacy. The inaugural workshop was facilitated in September in Paris, France and the European Association of Urology (EAU) is running a small workshop in 2023 based on the initial success.

To great anticipation, members of the MAB met in person for the first time in three years for their Annual Meeting in September 2022 in Paris (before the Clinical Leadership Workshop). Nine members from seven countries were present.

This year brought some changes to the MAB. Dr Eric Jonasch (US) has taken on the role of Chair, and Prof Axel Bex (NL/UK) is now Vice Chair. New MAB members include Dr Cristiane Bergerot (BR) and Dr Maria Teresa Bourlon (MX). We also thank Dr Fernando Maluf (BR) and Dr Kumar Prabhaskar (IN) for their service on the MAB as they conclude their terms.

To view the complete membership of the IKCC Medical Advisory Board, visit the IKCC website at <https://ikcc.org/about-ikcc/ikcc-medical-advisory-board/>



The Cecile and Ken Youner IKCC Scholarship 2022



In 2018, IKCC established an annual student scholarship known as The Cecile and Ken Youner International Kidney Cancer Coalition (IKCC) Scholarship. The award honours the IKCC Emeritus Founding Member, Dr Ken Youner, who contributed so much to the establishment of IKCC. It is to be awarded annually to a student (undergraduate, graduate, resident or fellow) who intends to practice medicine, hopefully in the field of kidney cancer. The award includes the presentation of their work at the annual IKCC Global Summit.

IKCC's Medical Advisory Board awarded the 4th Cecile and Ken Youner IKCC Scholarship at the Global Patient Summit in October 2022 to Dr Jesus Cendejas-Gomez. His work evaluates the impact of the Covid pandemic on kidney cancer care in Canada.

Dr Cendejas-Gomez has been involved in different research projects focusing on kidney, prostate, testicular and urothelial cancers throughout his career. He graduated from the Faculty of Medicine at the National Autonomous University of Mexico in 2015. He then completed his urology residency at the National Institute of Medical Sciences and Nutrition in Mexico City in 2021 and completed a urologic oncology fellowship at National Institute of Cancer in Mexico City in 2022. Currently, Dr Cendejas-Gomez is part of the Society of Urologic Oncology accredited fellowship program of urologic oncology at University of Western Ontario in London, Canada.

Congratulations Dr Cendejas-Gomez!



Treasurer's Report 2022

On behalf of the IKCC Board of Directors, I am pleased to present our Annual Financial Overview for 2022.

As the world emerges from the global pandemic, it is pleasing to report that IKCC has been able to return to some of our annual activities. Being able to run our annual Global Kidney Cancer Summit in 2022 was a huge achievement and meant many Affiliate Organisations were able to travel again and attend meetings.

As a result of the loyal support of our Sustaining Partners, as well as Project Partners, our financial position continues to remain strong and our accounts remain in a healthy position. Our sustainability is ensured by reserving funds for projected expenses across our operations and key projects. This allows IKCC to forge ahead with new strategic projects that will allow for further expansion in the coming years.

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.

We aim to add Euro 50,000 to our portfolio quarterly with the Board's approval and subject to availability of funds up to a total maximum amount of Euro 700,000. Quarterly reviews will be 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 partners for their ongoing support of our important work that empowers the global kidney cancer community through advocacy, awareness, information and research.

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

Moving forward, IKCC will continue to expand its reach to all corners of the globe in our quest to reduce the burden of kidney cancer and help improve the lives of those impacted.

Anne Wilson

*Secretary-Treasurer
IKCC Board*



2022 Financial Statements

These figures are extracted from the 2022 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.

Independent Auditor

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

Financial Services

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

IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2022	
CURRENT ASSETS	
Funds to receive	€ 62,074
Liquid assets	€ 1,354,081
TOTAL CURRENT ASSETS	€ 1,416,155
CURRENT LIABILITIES	
Creditors and borrowings	€ 129,904
TOTAL CURRENT LIABILITIES	€ 129,904
NET ASSETS	€ 1,286,251
ACCUMULATED FUNDS	
Reserves	€ 782,201
Last year surplus/(deficit)	€ 331,179
Current year surplus/(deficit)	€ 172,871
TOTAL ACCUMULATED FUNDS	€ 1,286,251



Affiliate 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.



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

Supporters 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 Affiliate Organisation in 2022

Austria:

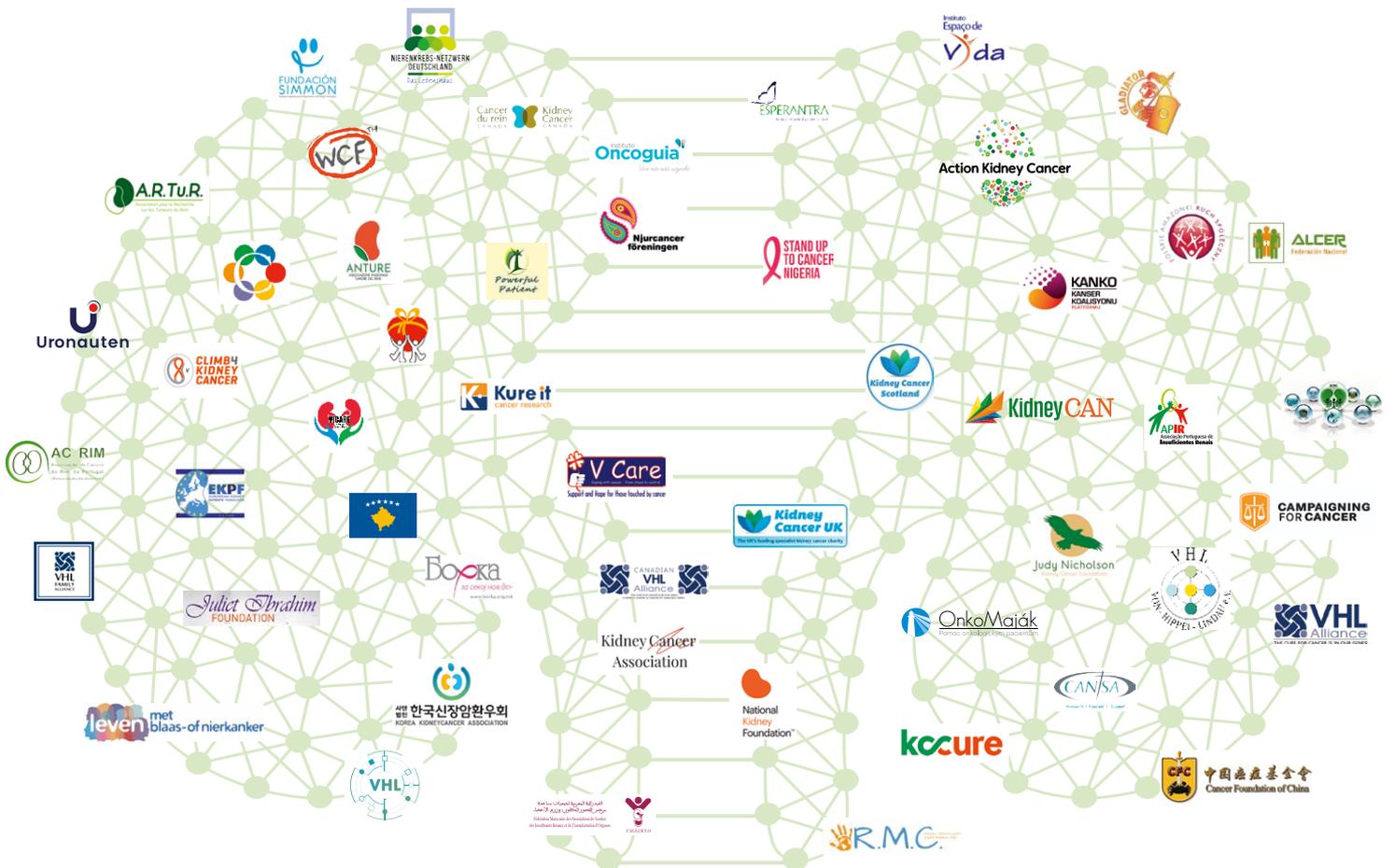
European Kidney Patients' Federation
www.ekpf.eu

Canada:

Wilms Cancer Foundation
www.WilmsFoundation.org

Germany:

Association for VHL Affected Families
in Germany
www.hippel-lindau.de



IKCC Affiliate Organisations





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.





Rachel Giles, MD, PhD, Chair
The Netherlands

Dr Rachel Giles was appointed Associate Professor of Internal Medicine at the University Medical Center Utrecht in 2006. She came from a family with an inherited tumour syndrome and has been active in advocacy for patients with inherited kidney cancer since 2003. She researches how kidney cells are regulated and what goes wrong in the very early steps of kidney cancer.

Rachel is the Medical Science Officer at Medcom Medical Publishers since 2019. She has been Chair of the Dutch VHL Organisation since 2009, and an international contact point for Living with Bladder or Kidney Cancer since 2010. Rachel has been Chair of the IKCC since 2014 and represents the IKCC on the EAU Guidelines Committee for renal cell carcinoma.



Bryan Lewis, Vice-Chair
United States

Bryan Lewis has led the advocacy efforts for KidneyCan – 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.



Berit Eberhardt

Germany

Berit Eberhardt has been involved in kidney cancer since 2009 following her partner's diagnosis with papillary type II renal cell carcinoma. To support him she researched the disease and its treatment. Knowing the needs of patients and caregivers in the same situation, she established a patient support group and became an advocate for kidney cancer after her partner died. Berit is an active networker, connecting people with existing resources and highlighting gaps in services.

Being a cancer survivor herself, Berit is committed to sharing her experience, bringing the patient perspective into various publications (e.g., the German RCC guidelines but also scientific publications) and projects, as well as speaking at local, national and international meetings. Berit has been involved with IKCC since 2010. In 2017 she initiated a non-profit patient advocacy organisation Uronauten e.V., helping patients and caregivers with rarer genitourinary cancers to navigate their disease.



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 currently serving as Editor in Chief of the official journal of SOHN, ORL-Head and Neck Nursing.

IKCC Board of Directors 2022



Michael Jewett, MD, FRCSC, 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.



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 Anderson 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.



Liz Leff
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). Achieving multi-sourced funding helps us meet our goal of collaborating with all stakeholders including patient organisations, medical experts, and the healthcare industry while maintaining our independence and integrity as a patient organisation. Such funding allows our organisation to focus on our mission – to reduce the global burden of kidney cancer.

We thank the following funders who have supported IKCC in 2022 with Sustaining Partnerships and Project Sponsorships.

Sustaining Partners 2022



Project Sponsors 2022





We also extend our gratitude to the team of people who support IKCC to make the work we do to help reduce the burden of kidney cancer worldwide possible.

Rachel Giles – IKCC Chief Executive Officer

Julia Black – IKCC Chief Operating Officer

Rebecca Cabbage – IKCC Project Assistant

Annika Marshall – IKCC Administration Assistant

Charlie Douglass, Douglass Digital – Website Hosting

Paul Fishlock, Behaviour Change Partners – World Kidney Cancer Day

Steve Gray, GrayMatter Marketing & Technology – World Kidney Cancer Day

Karin Kastrati – Technical Support

Jilda Lazer, Reverb Consulting Group – Communications Support

Luci McCann – World Kidney Cancer Day

Diego Somer and Jelle Eissens – Administratiekantoor Boekjewinst.nl BV, Financial Services,
Herbert Thum, VisKon – Graphic Design



IKCC

International
Kidney Cancer
Coalition

International Kidney Cancer Coalition

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Website: www.ikcc.org

www.worldkidneycancerday.org



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[@IKCCtrials](#)

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