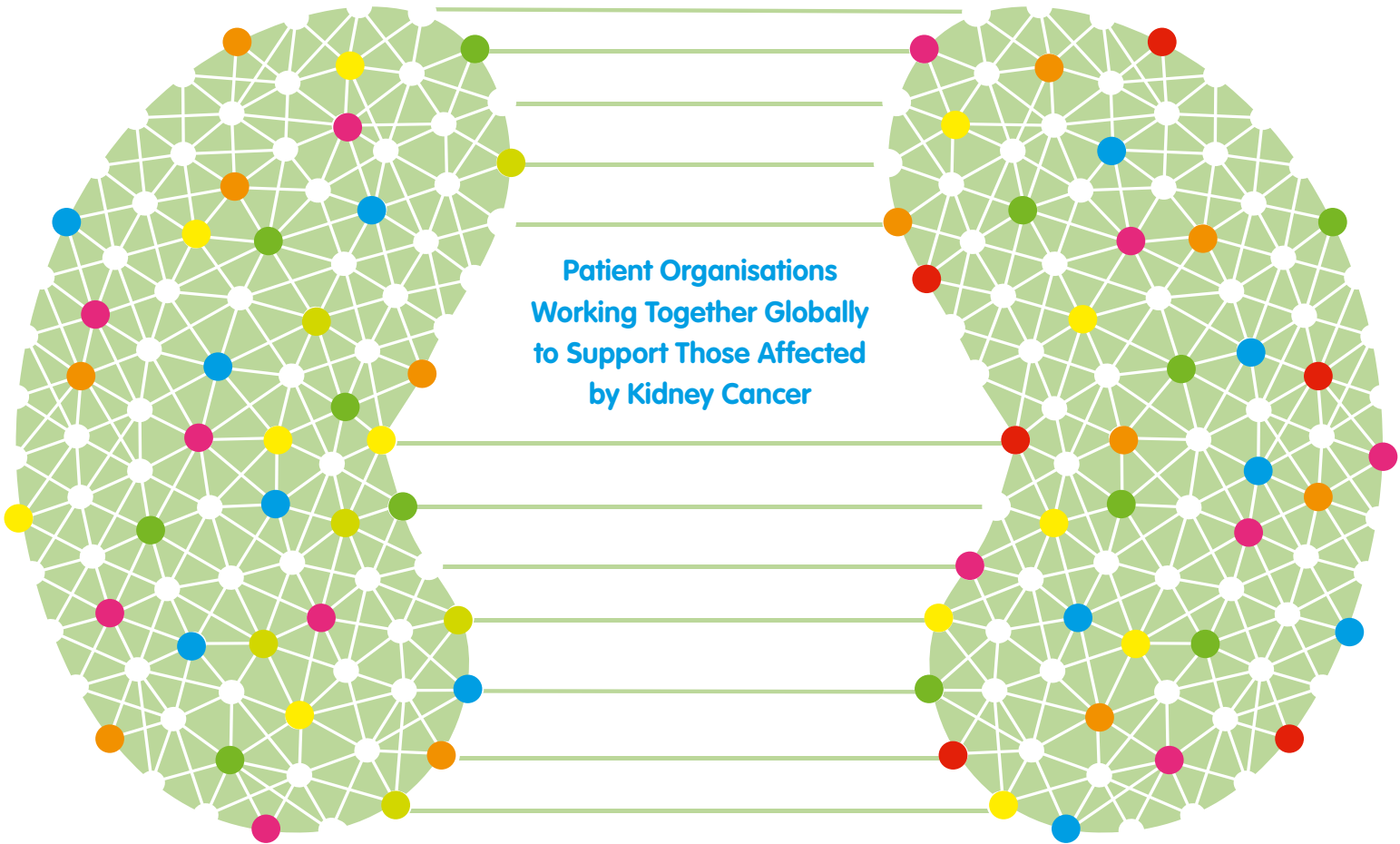


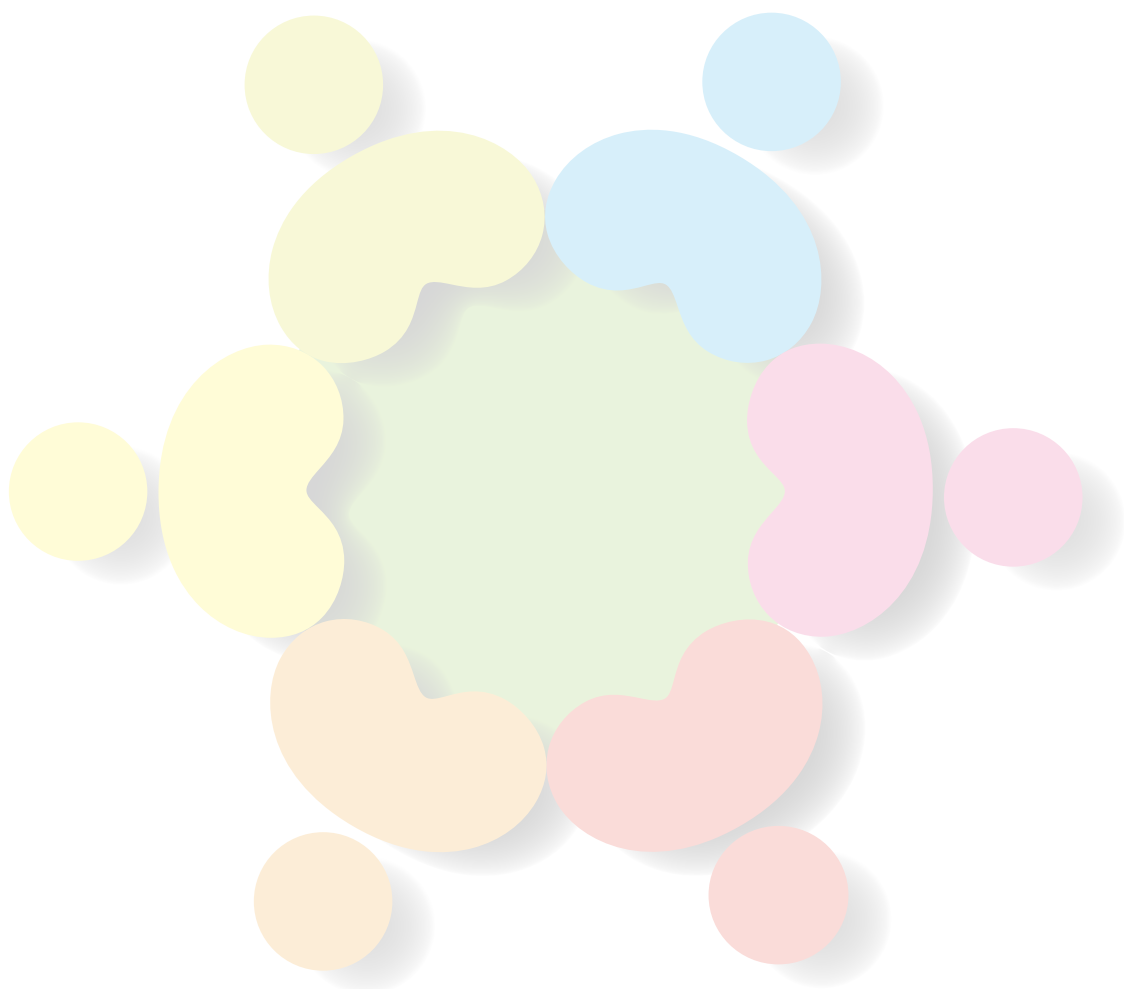


IKCC
International
Kidney Cancer
Coalition

IKCC Annual Report 2021

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





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Message From the Chair



Rachel Giles

Dr Rachel Giles,

Chair of the Board

Without a doubt, 2021 has been another successful year for the International Kidney Cancer Coalition (IKCC) and the kidney cancer community. What has been accomplished in the second year of the pandemic – another year full of change, uncertainty and the inability to physically come together – is something to be proud of. But when I look back on it all, the one thing that stands out consistently, is how important connection is in everything we do.

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 connections we seek, the connections we build, and the connections we maintain with patient organisations, healthcare professionals and associations, researchers and supporters, all sharing a common goal of reducing the burden of kidney cancer worldwide.

World Kidney Cancer Day 2021 was celebrated in June. The theme – We need to talk about how we are feeling – resonated with the patient community and beyond. It gave patients a tool to help them connect with their health team about their mental well-being. This theme, as in previous years, was based on the results of IKCC's 2018 Global Patient Survey – where we heard from nearly 2,000 patients and carers about the kidney cancer experience. Kidney cancer has a remarkable impact on the lives of the patients as well as their family and support team; wellbeing should always be central to care.

Connecting patients and carers with the information they need, when they need it is a key component of patient empowerment. Throughout the year, IKCC has shared information about IKCC-led research on COVID-19 and patients' perspectives on adjuvant treatment with immunotherapy, as well as clinical trial results in easy-to-understand formats. We also talked to kidney cancer patients in a pilot study examining the barriers experienced when in a clinical trial.

IKCC's Global Kidney Cancer Summit 2021 was held over two days in September. The focus of the conference was to build and strengthen the connections throughout the global kidney cancer community. This year, our approach further emphasized our organisational commitment to put Affiliate Organisations at the centre of the Summit. The agenda was created through Affiliate feedback and featured many Affiliate-led sessions, with the focus on collaboration and knowledge exchange.

Beyond the Summit, IKCC is committed to ongoing support in all regions around the world. In 2020, the Board of Directors made the strategic decision to increase efforts to engage with patient organisations in Asia and help strengthen the patient voice in that region. As a result, in November 2021, organisations connected at our first virtual consultation called IKCC Roundtable: Focus on Asia.

Connecting with other global cancer coalitions continues to be a priority for IKCC, and we play an active role in the newly-formed Global Cancer Coalitions Network, a collaboration of nine global cancer coalitions and alliances, representing 750 patient organisations working on behalf of 14 million cancer patients around the world. While the specifics of the work we do is different, there is so much we can learn from each other and there are many opportunities to collaborate on pan-cancer issues. This year, Affiliate Organisations directly heard the expertise of Lorna Warwick from Lymphoma Coalition and Alex Filicevas from World Bladder Cancer Patient Coalition – we look forward to making even more of these connections in the future.

We've also been connecting beyond the kidney cancer community with the broader urology and oncology professional community. For example, when the European Association of Urology held its Annual EAU Conference in July, IKCC was there representing the kidney cancer community with 11 presentations and five posters, two of which won awards. In 2021, we were also authors on nine publications in peer-reviewed medical journals.

In 2021, we were also happy to make some new additions – expanding our circle of connection. We're pleased to have welcomed a new Affiliate Organisation – Polish Amazons Social Movement. And we are thrilled to have three new members on the Board of Directors. Margie Hickey (U.S.) brings extensive experience from her impressive career as a nurse and professional health communicator. Christine Collins (CA) and Liz Leff (U.S.) join the Board for 1-year terms representing Affiliate Organisations.

It's been another successful year. And no matter where you are in the world, or what you call it – conexión, lien, verbinding, 關係, or połączenie – connection is what's been at the centre of it all.

*On behalf of the Board of Directors,
and the dedicated IKCC staff, we thank
every single person who was a part
of what was accomplished this year.
We are grateful.*

About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of over 45 patient organisations that focus exclusively, or include a specific focus, on kidney cancer. Based in Amsterdam, the Netherlands, the organisation was born from a very strong desire among various national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences around the world.

Kidney cancer is a global issue. Every year, an estimated 431,000 people worldwide will be diagnosed with kidney cancer.¹ Research and clinical trials in kidney cancer take place across continents and many kidney cancer experts sit on international panels. 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:

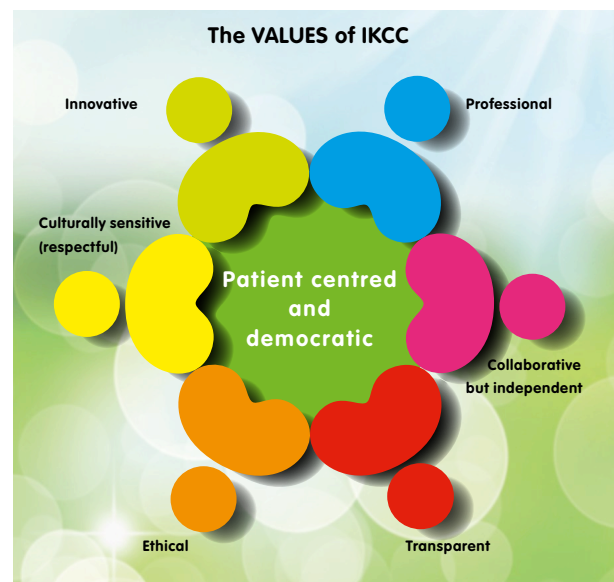
IKCC is a global collaboration of patient organisations that empowers and represents the kidney cancer community through advocacy, awareness, information and research.

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 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

2021: IKCC by the Numbers



47

Affiliate Organisations worldwide



1

new affiliate member from Poland
joined IKCC



More than **4,500**
Twitter followers and nearly
9,000

likes on Facebook
A **12.5%** increase of followers
on Twitter!



Over 100 attendees from
20+ countries and
6 continents
attended the
2-day virtual Global Summit



The World Kidney Cancer Day campaign
achieved more than
9.5 million
impressions globally across all program
elements.

The campaign page saw
152,000 clicks and
24,000 landing page views.



IKCC co-authored **9** articles
in medical journals

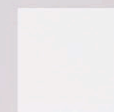


IKCC presented at
11 international conferences



7 editions of the IKCC Newsletter sent to
nearly **450** subscribers

Projects and Activities 2021



2020 Global Patient Survey – Exploring the Kidney Cancer Experience



IKCC launched the 2nd Global Patient Survey late in 2020, and in 2021 the survey results were analysed and shared. The biennial survey heard from more patients and carers than in the inaugural year, with more than 2,000 people from 41 countries sharing their experiences.

The 2020 Global Patient Survey explored many of the same areas as the first survey, but also examined some areas more deeply and considered how experiences are interconnected and affect patients' outcomes. Patients were asked about their knowledge and understanding of their diagnosis and treatment, and also explored their thoughts regarding biopsies. Individuals' quality of life was assessed, but also the role physical activity plays in their physical and emotional well-being. IKCC partnered with the Università Cattolica del Sacro Cuore in Italy to incorporate the Patient Health Engagement Scale, which assessed patients' psychosocial state as it relates to living with kidney cancer.

While some differences were observed between the first and second surveys, overall, a consolidated baseline of information from the two surveys was demonstrated. With this understanding of the gaps in care and patients' needs, IKCC and Affiliate Organisations will plan and execute activities and initiatives that support the kidney cancer community.

The results of the 2020 survey can be viewed in a variety of ways:

- A complete report with all the survey findings and breakdowns
- A 16-page summary report with key findings and highlights and accompanying infographic
- Country reports, where more than 100 people completed the survey

All reports can be found at ikcc.org/global-patient-survey.

Results were also presented at the following medical conferences:

- American Society of Clinical Oncology (ASCO), June 2021
- European Association of Urology (EAU), July 2021
- European Society of Medical Oncology (ESMO), September 2021

Thank you to everyone who participated in the Global Patient Survey – including its development, translation, promotion and completion. In 2022, IKCC will work with a multi-country steering group of Affiliate Organisations to design and launch the next Global Patient Survey and continue the evidence-based research of the kidney cancer patient experience.



“Participating in the Global Patient Survey has allowed me, along with thousands of other patients around the world, to have our real-life experiences heard, counted and considered to improve the lives of people with kidney cancer. That is the very definition of patient-centred healthcare.”

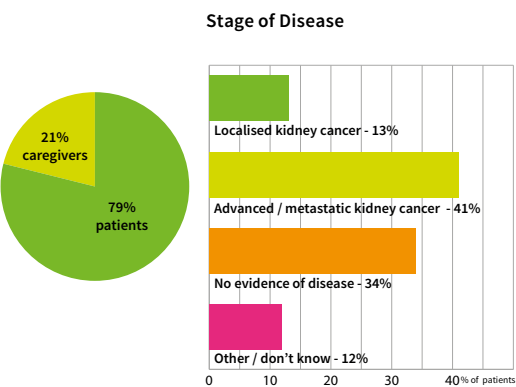
*Subbegowda Tammegowda,
V Care Foundation, India.*

2020 Global Patient Survey – Exploring the Kidney Cancer Experience

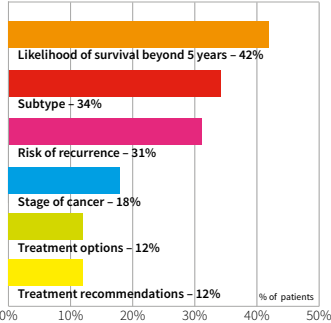
The survey included 2,012 respondents in 41 countries

IKCC’s Global Patient Survey is designed to identify geographic variations in patients’ education, experience and awareness and highlight best practices and unmet needs related to care, quality of life and clinical trials.

Understanding the details of their disease at diagnosis allows patients to participate in the treatment process in an informed way and help reduce the psychosocial effect of the diagnosis.

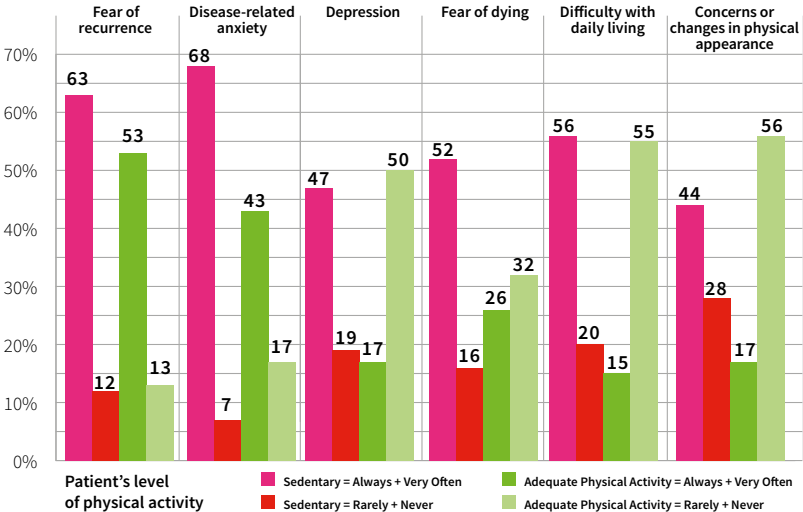
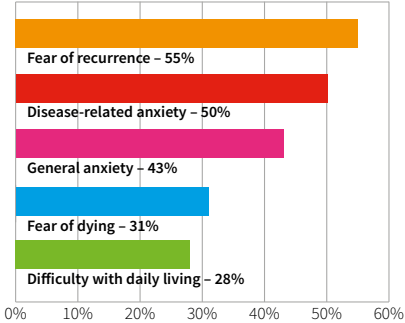


At the time of diagnosis, the following were **not** explained to patients in a way they could understand:

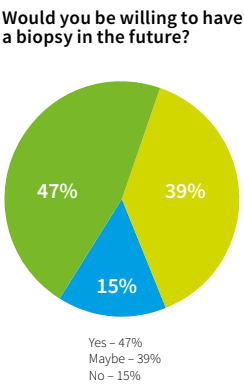
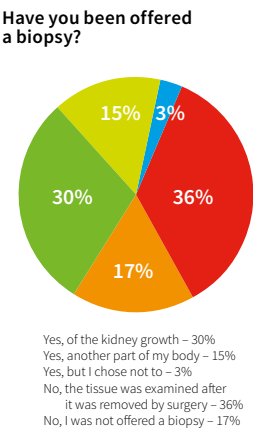


96% of patients are living with one or more psychosocial issues related to kidney cancer. However, making regular exercise a part of an individual’s treatment plan from diagnosis through to survivorship is a safe and effective way to manage the psychosocial impacts of cancer.

Most common psychosocial issues included:

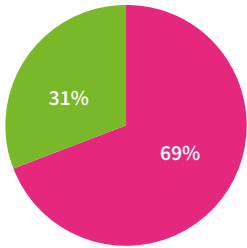


With a refusal rate of 3% and only 15% of patients saying they would refuse a biopsy in the future, there is an opportunity to offer biopsies more consistently to better understand and treat individuals' masses.



Talking about clinical trials helps patients learn more about the process of advancing cancer care and be active partners in their own care.

31% of patients were asked to participate in a clinical trial. Of those asked, **62%** agreed and the majority were satisfied with their experience.



69% of patients had never been asked to participate in a clinical trial. Of those, **65%** said it was likely they would have participated if they had been asked

World Kidney Cancer Day 2021: We need to talk about how we're feeling



17 June 2021

IKCC and Affiliate Organisations celebrated another successful World Kidney Cancer Day raising awareness for kidney cancer and the unique challenges patients face. The 2021 campaign theme, We need to talk about how we're feeling, was built on the results of the 2018 Global Patient Survey which revealed that 96% of patients experience psychosocial issues related to their cancer, yet approximately half do not discuss the issues with family, friends or their healthcare team.

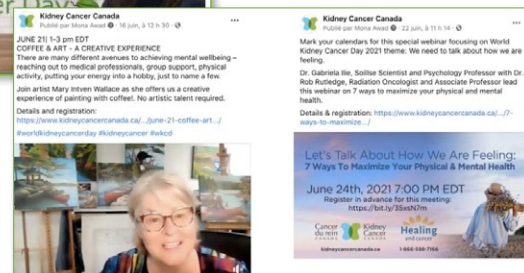
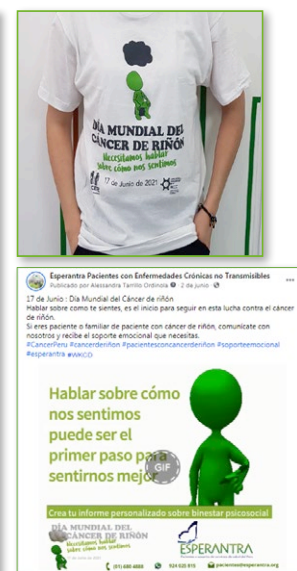
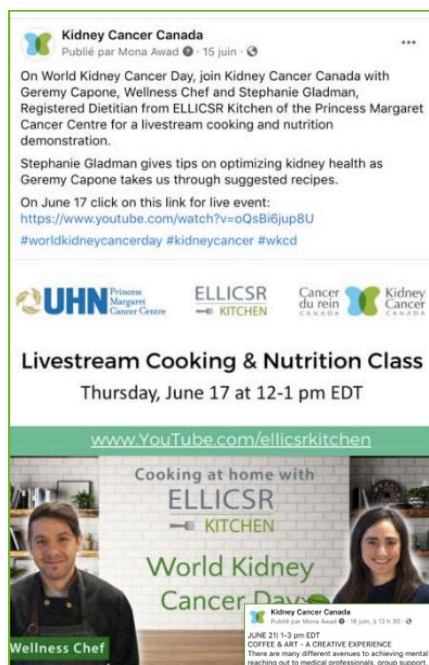
In addition to raising awareness for the mental burden of kidney cancer and the importance of seeking support, the campaign encouraged kidney cancer patients to create their own Personalised Psychosocial Wellbeing Report by answering a short survey about their experience. The clinically credible tool was designed to help people better understand their own situation and start conversations with others, including their healthcare team, about how they are feeling.

Beyond the global campaign, Affiliate Organisations on 6 continents hosted local activities including online education and support events, community communications, healthcare professional outreach, media coverage, the launch of a book sharing group, and more!

The success of World Kidney Cancer Day is a credit to everyone who got involved to talk about how we're feeling – thank you!

By the Numbers:

- 9.5 million impressions of campaign materials
- 152,000 clicks and 24,269 landing page views
- 712 Personalised Psychosocial Wellbeing Reports submitted
- Online wellbeing survey in 14 languages



IKCC Roundtable: Focus on Asia

In 2020, the Board of Directors made the strategic decision to increase efforts to engage with patient organisations in Asia and help strengthen the patient voice in that region. As a global collaboration of patient organisations, supporting all regions around the world is a priority.

As a result, on 29 November 2021, IKCC hosted a virtual consultation called *IKCC Roundtable: Focus on Asia*. Patient organisations from across the region came together to learn and discuss the region's unique needs.

The virtual event began with a presentation from Dr Ravi Kanesvaran, head of medical oncology at the National Cancer Center in Singapore. He summarised the highlights from the ESMO Asia Virtual Oncology Week 2021, which he also chaired.

Next, Lorna Warwick, CEO of Lymphoma Coalition, shared the organisation's experience and lessons learned in Asia-Pacific lymphoma care. The presentation included a discussion about the heterogeneity of the region, the varied barriers to care, and how many best-practices around the world don't easily translate to countries in the region.

The session concluded with a roundtable discussion amongst participants where each organisation's representative shared their experiences and challenges working in the healthcare, oncology and kidney cancer spaces specifically.

Throughout the day, the engaged group participated in meaningful discussions that helped identify key issues and areas for additional discussion and a path forward to work together in the future.



Participating Organisations

AVEC, Japan

Bangladesh Community Oncology Trust, Bangladesh

Bec's Troops, Australia

Korean Kidney Cancer Association, South Korea

The Max Foundation, Malaysia

Philippine Alliance of Patient Organizations, Philippines

V-Care Foundation, India

Clinical Trial Retention Program:

Why kidney cancer patients leave clinical trials

Clinical trials are the cornerstone of advancing treatment for kidney cancer and they provide evidence about which treatments work. It is a core belief of IKCC that every patient deserves access to the highest quality care and the opportunity to participate in research through clinical trials.

Research has shown that compared with all clinical trials, clinical trials in cancer have a lower rate of completion, which could be related to their longer duration, greater cost to patients, travel requirements, and serious side effects. These factors can add up to the unfortunate consequence of having patients leaving the trial before it is completed. Furthermore, although initial research has explored the barriers to patient retention in clinical trials, none have been specific to kidney cancer patients. As well, most of the studies in this area have focused on barriers to patients completing questionnaires and not on trials where visits and follow up are required, which have a higher burden on the patient.

When a kidney cancer patient has taken the careful decision to join a clinical trial, and then later chooses to withdraw from that trial, that trial has somehow failed the patient. We need to understand the barriers and other considerations to that important decision in order to better support patients currently in clinical trials, or those considering joining one.

To define the barriers to patients, and potentially suggest interventions to minimise impact, IKCC launched a Clinical Trial Retention Project. The pilot project employed a theory-informed approach to understand the specific barriers kidney cancer patients face to remain on a clinical trial once they are enrolled.



Eight of the 14 domains within the Theoretical Domains Framework, developed by behavioural scientists, were identified as important to patient retention in clinical trials for kidney cancer, namely: knowledge, skills, social influences, environmental context and resources, beliefs about capabilities, reinforcements, beliefs about consequences and emotion.

The pilot project highlighted the role patient organisations play in relation to patients' participation and staying enrolled in clinical trials by increasing awareness of trials and providing practical and emotional support.

The findings also suggested that there is a need to explore how kidney cancer clinical trials can be improved by including patient values into their design, with a particular focus on patients' information needs and the real burden that patients participating in trials face.

IKCC's abstract on ***Why patients leave clinical trials: the kidney cancer patient perspective*** has been accepted for the Patient Poster Session at the 37th Annual EAU Congress.

The next step in this project is to conduct a literature review to investigate retention in clinical trials beyond kidney cancer and to explore whether there are existing interventions to improve retention that may be applied for kidney cancer trials. The full report will be available in 2022.

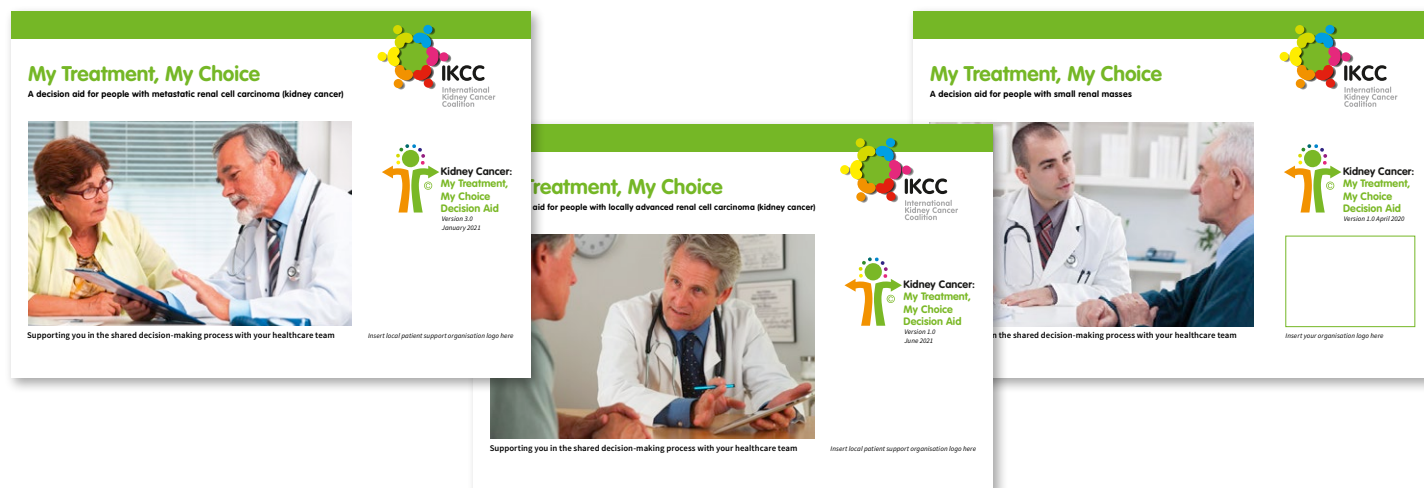
My Treatment, My Choice: Decision Aid Series – Updates

One of IKCC's core beliefs is patients and their families have an essential role to play in the healthcare decisions that affect their lives – a concept known as shared decision making. However, to be active participants in their care, patients and families must be supported with accurate, accessible and up-to-date information about treatment and care options, as well as an understanding of how their decisions will affect their quality of life.

IKCC has created a series of Decision Aids, called **My Treatment, My Choice**, which are tailored to provide the specific information needed at every stage of kidney cancer. The series includes a booklet with basic information about kidney cancer for people who are newly diagnosed, as well as booklets to support people diagnosed with a small renal mass, locally advanced renal cell carcinoma, and metastatic renal cell carcinoma. Each decision aid is written in patient-friendly language by a global team of patients, advocates and medical professionals who have supported thousands of kidney cancer patients around the world.

This is a very exciting time in kidney cancer research. New and effective targeted treatments are being discovered and clinicians are gaining experience with new drug combinations and sequences. In addition, there is a better understanding of the role of surgery at all stages and how to manage side effects, which can improve quality of life. As advances in research are translated into clinical practice, IKCC regularly updates this valuable resource to make sure patients and families have accurate and current information when making decisions about their treatment options.

In 2021, the decision aid for metastatic renal cell carcinoma was reviewed and updated to include the very latest combination treatment options because it is important for patients to have access to the very best information in an easy-to-understand format. We will continue to review and update all our decision aid booklets as research provides us with ever more effective treatment options.



Spotlight on New Research: Infographics

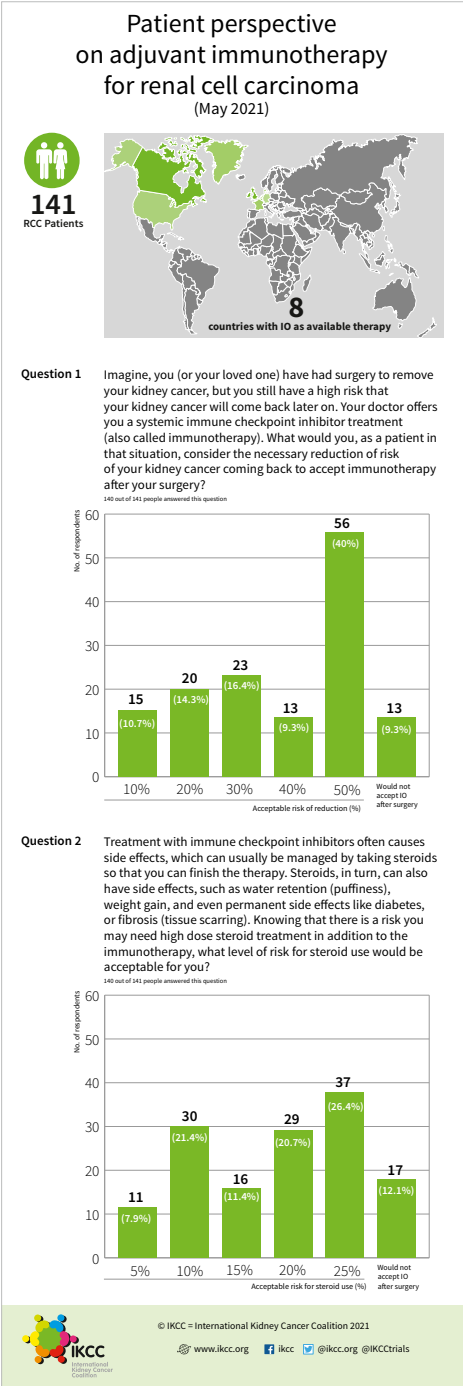
When patients can access and understand information about research, they are better prepared to be active participants in their own care. For this reason, IKCC creates easy-to-understand visual infographics outlining the findings of newly published data about kidney cancer. Affiliate Organisations, as well as other interested organisations and medical professionals, are invited to use the infographics (with permission) provided IKCC is cited as the source.

IKCC created three new infographics in 2021:

Patient perspective on adjuvant immunotherapy for renal cell carcinoma

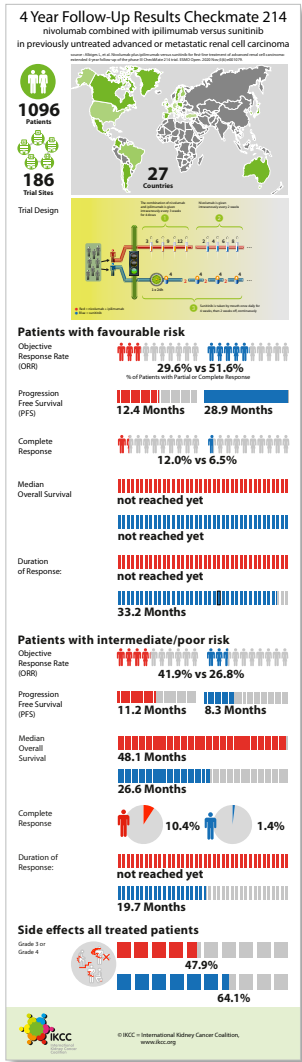
IKCC conducted a short poll of kidney cancer patients to gauge their attitudes towards post-surgery (adjuvant) treatment with immunotherapy (IO) to reduce the chance that their tumour will come back. Specifically, the poll asked people about the level of risk reduction of recurrence to accept immunotherapy after surgery, as well as the acceptable level of risk for steroid use to manage side-effects from immunotherapy.

The poll found that 40% of patients would take adjuvant IO treatment after surgery if there was a 50% reduction in the risk of the cancer returning. Only 9% said they would not take adjuvant IO at all. Regarding steroid use, over a quarter of patients were willing to accept a 25% risk of having side-effects to adjuvant IO that required treatment with steroids. We thank the 141 patients who completed this poll!



Study Results: CheckMate 214 - 4-Year Follow Up

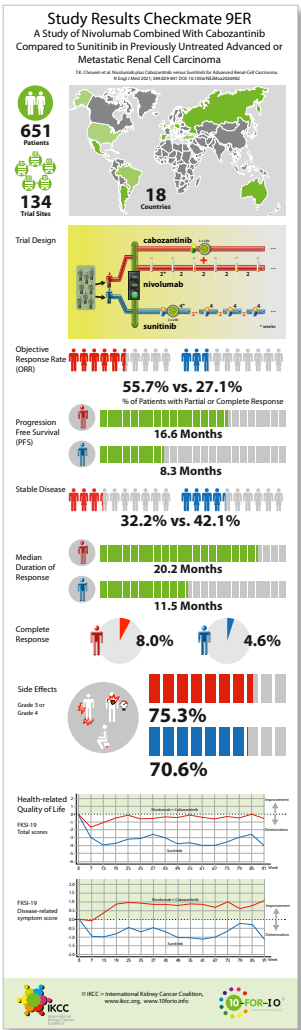
CheckMate 214 is a study that compares nivolumab combined with ipilimumab with sunitinib in previously untreated advanced or metastatic renal cell carcinoma. The infographic captures the 4-year follow-up, specifically reporting on study participants' demographics, trial design, objective response rate, progression-free survival, complete response, median overall survival, duration of response and side effects.



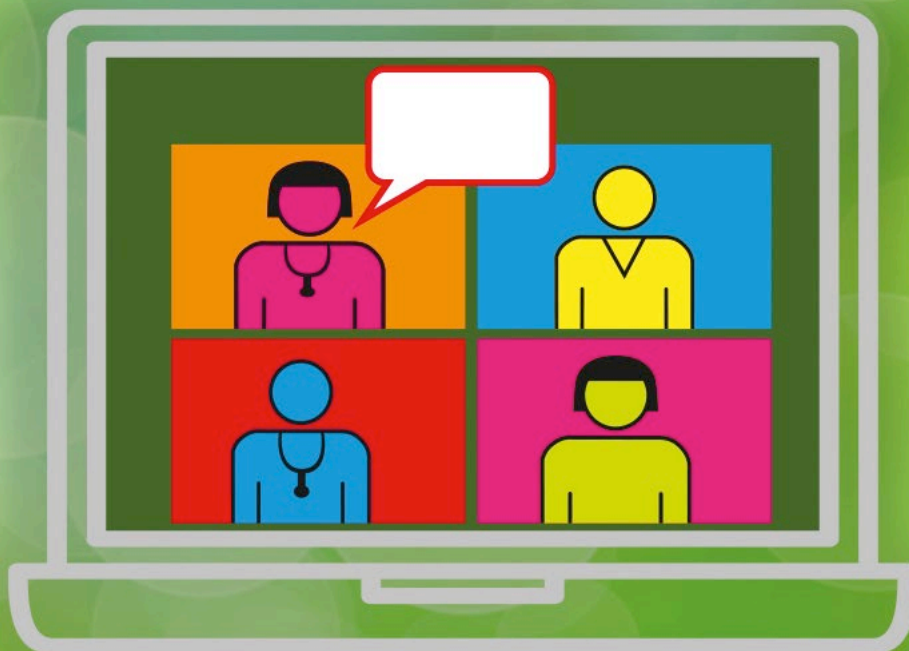
All of IKCC's infographics are available on the website.
ikcc.org/infohubpost/graphic-trial-results/

Study Results: CheckMate 9ER

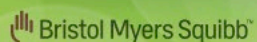
CheckMate 9ER is a study that compares nivolumab combined with cabozantinib to sunitinib in previously untreated advanced or metastatic renal cell carcinoma. The infographic reported on the study participant's demographics, trial design and results, including objective response rate, progression-free survival, stable disease, median duration of response, complete response and side effects. In addition, this trial reported extensive quality of life data, which is included in the infographic.



Global Kidney Cancer Summit 2021



Sustaining Partners 2021:



MERCK

 **NOVARTIS**


EXELIXIS

 **MSD**
INVENTING FOR LIFE

 **Pfizer**

 **Roche**

Project Sponsors 2021:

 Bristol Myers Squibb

EXELIXIS

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 **IPSEN**
Innovation for patient care

 **Pfizer**





24th and 25th September

Global Kidney Cancer Summit 2021: Connecting the Kidney Cancer Community

IKCC hosted its 11th Global Kidney Cancer Summit in September 2021. It is the only international conference for organisations representing patients with kidney cancer. The focus of the 2021 virtual conference was building and strengthening the connection

throughout the global kidney cancer community.

More than 100 members of the worldwide kidney cancer community representing 23 countries came together virtually showing their commitment to improving the lives of people with kidney cancer.

During the two-day online conference, delegates had the opportunity to learn from each other, share successes and challenges and help build capacity across the kidney cancer network. The agenda was created through Affiliate feedback and featured a variety of Affiliate-led sessions.

The Summit began with highlights from ESMO 2021. Dr Andreas Michael Schmitt, Clinical Research Fellow at the Royal Marsden

Hospital in London (UK), presented clinical trial results related to new treatment approaches in locally advanced and metastatic kidney cancer, as well as ways to manage side effects of treatment.

The following sessions were driven by the experiences and insights of Affiliate Organisations who, in the spirit of learning and collaboration, recounted their success, challenges and best practices in the areas of engaging new patients and carers, strengthening patient support programs, supporting carers and the impact of the pandemic on patient organisations.

Thank you to all who presented and shared during the conference, and to those who helped moderate the discussions. We also thank the 2021 Conference Committee for their dedication to the planning and organisation of this year's Global Summit. Committee members included Linda Anderson (US), Vandana Gupta (IN), Dr Michael Jewett (CA), and Linda Ostoski (US) – we are grateful!

For a complete summary of the Global Kidney Cancer Summit 2021 and details from the presentations, visit the IKCC website.

In a time when being together still wasn't possible, Affiliate Organisations came together virtually to build, maintain, and strengthen connections throughout the global kidney cancer community.

Welcome to the 2021
Virtual Global Kidney Cancer Summit



Sustaining Partners 2021:
Bristol Myers Squibb, EXELUXIS, MERCK, MSD, NOVARTIS, Pfizer, Roche

Project Sponsors 2021:
Bristol Myers Squibb, EXELUXIS, IPSEN, MERCK, Pfizer




100% of attendees said the conference fulfilled their reason for attending and the majority said they connected with the kidney cancer community throughout.



Andreas Michael Schmitt, MD, United Kingdom

After finishing Medical School at the Johannes Gutenberg-University in Mainz, Germany, Dr Schmitt started training in General Internal Medicine, which he then completed at the University Hospital Basel Switzerland and then began training in Medical Oncology. Since 2018, he has also worked as a Clinical Research Fellow; he is very interested in decision-making in oncology and which methods are best to generate the most useful evidence for the treatment of our patients. In February 2021, Dr Schmitt started his work as a Clinical Research Fellow at the Royal Marsden Hospital in London in the Melanoma, Skin and Renal group of Prof James.



Study Design

Key Eligibility Criteria


- Advanced or metastatic cRCC
- Being treatment naïve or having previously received immunotherapy and IC regimens for locally advanced or metastatic RCC
- ECOG PS 0 or 1
- All IMDC risk categories (resectable/intermediate/poor) allowed

Cohort 1: Treatment naïve, baseline T2b/T3a/T3b/T4a/T4b/T4c/T4d/T4e/T4f/T4g/T4h/T4i/T4j/T4k/T4l/T4m/T4n/T4o/T4p/T4q/T4r/T4s/T4t/T4u/T4v/T4w/T4x/T4y/T4z/T4aa/T4ab/T4ac/T4ad/T4ae/T4af/T4ag/T4ah/T4ai/T4aj/T4ak/T4al/T4am/T4an/T4ao/T4ap/T4aq/T4ar/T4as/T4at/T4au/T4av/T4aw/T4ax/T4ay/T4az/T4aa/T4ab/T4ac/T4ad/T4ae/T4af/T4ag/T4ah/T4ai/T4aj/T4ak/T4al/T4am/T4an/T4ao/T4ap/T4aq/T4ar/T4as/T4at/T4au/T4av/T4aw/T4ax/T4ay/T4az

Cohort 2: Prior immunotherapy treatment with or without prior systemic treatment, baseline T2b/T3a/T3b/T4a/T4b/T4c/T4d/T4e/T4f/T4g/T4h/T4i/T4j/T4k/T4l/T4m/T4n/T4o/T4p/T4q/T4r/T4s/T4t/T4u/T4v/T4w/T4x/T4y/T4z/T4aa/T4ab/T4ac/T4ad/T4ae/T4af/T4ag/T4ah/T4ai/T4aj/T4ak/T4al/T4am/T4an/T4ao/T4ap/T4aq/T4ar/T4as/T4at/T4au/T4av/T4aw/T4ax/T4ay/T4az


Joshua Mann, MPH United States

Joshua Mann joined the VHL Alliance in May of 2017. In his role as the Director of Health, Josh provides patient support, works with VHL Clinical Care Centers, serves as the Principal Investigator for the MyVHL Patient Natural History Study, and more. Josh earned his Masters of Public Health degree in Health Care Policy and Management at New York Medical College and his Bachelors of Science degree in Business Administration and Health Care Policy and Management at Carnegie Mellon University. He has devoted his career to improving the patient experience through a variety of endeavors including entrepreneurial pursuits, nonprofit work and collaborating with leaders in the field. Apart from his work with the VHL Alliance, Josh serves as the Vice-Chair of his municipality's Board of Health, volunteers as a Vice-Chair of the HL/RCC Family Alliance, and volunteers as an Artistic Advisor for the Jewish Arts Collaborative.



VHL Alliance

- Who we are:
 - 501(c)(3) nonprofit organization founded in 1993 dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
- What is VHL?
 - Rare hereditary tumor predisposition syndrome causing those affected to be at risk for tumors to grow in up to 10 different parts of their body throughout their life.
- Organizational Success
- Challenges
- Key Initiatives



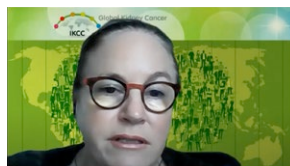
Elshad Hasanov, MD Turkey

Dr Elshad Hasanov is a medical oncology fellow at the University of Texas MD Anderson Cancer Center. He received MD and PhD in Tumor Biology and Immunology from the Hacettepe University Faculty of Medicine in Turkey. He subsequently completed the Internal Medicine Residency training at the University of Texas Houston McGovern Medical School. His current research focuses on understanding the unique clinical and biological features of brain metastasis in renal cell carcinoma patients with the goal of developing better treatments.



Molecular characterization of renal cell carcinoma brain metastases

Elshad Hasanov, MD PhD
Medical Oncology Fellow

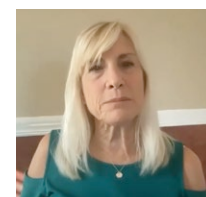
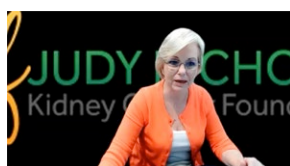
VHL

Implementation in University Hospitals: 2021-2022

- Patient-initiated
- Reflects patient preferences
- Standardized care
- Ensure quality


Summary

Conclusion: Patients have co-created the first care pathway for a complex tumor syndrome being implemented at the national level


Understanding Histological:Genomic Relationships in Kidney Cancer: TRACERx Renal

Dr Charlotte Spencer
Group Leader: Dr Samra Turajlic
Cancer Dynamics Laboratory



IKCC

The Royal Marsden
NHS Foundation Trust




Dena Battle United States

Dena Battle is the co-founder and President of KCCure, a non-profit organization dedicated to evidence based, patient driven advocacy for kidney cancer. Launched in 2016, KCCure has raised over \$1.5 million for kidney cancer research, established a peer reviewed research grant program, and created a patient centered research program aimed at providing quantitative information about patient preferences and desires related to care and treatment. KCCure communities provide a platform for patients to connect with others, share their stories and have their voice represented in research.

In 2009, at the age of 40, Dena's husband, Chris Battle was diagnosed with metastatic kidney cancer. Together, they began a quest for the best care possible to combat the disease. Chris was treated at four different comprehensive cancer centers, participated in multiple clinical trials, and endured nine different therapies, including off-label treatment. They co-authored the blog Kidney Cancer Chronicles, which was widely read by patients from around the world. After Chris's death in 2013, Dena remained active as a patient advocate.

She began her career in Washington, DC, as a congressional aide, and spent nearly two decades working in economic and health care policy. She has policy expertise in health care reimbursement, tax treatment of benefit plans, and corporate research and development policy.



Social Media and Cancer Patients

80% of cancer patients reported using social media to connect with peers


49% reported starting a social media account as a result of their cancer diagnosis

kccure

Source: JCO Journal of Cancer Research and Clinical Oncology 2019

Emma Andersson Finland

Emma Andersson works as an Advocacy Specialist at the Association of Cancer Patients in Finland. She is interested in survivorship and return-to-work issues after cancer. Her academic background is in international relations and she holds a Master's degree in Political Science from the University of Helsinki. Professionally, she has been working on project management and communications, both in Finland and abroad in Germany, Kenya, Sweden, Vietnam and the USA. She loves running and reading.




Reaching out to patients – Story of the kidney cancer patient guide

Global IKCC Summit, 24 Sept 2021

Emma Andersson
Advocacy Specialist


Suomen Syöpäpotilaat
www.syopapotilaat.fi



Day 1_Presentations


Global Kidney Cancer Summit
2021

Strengthening Patient Support Programs
to Cope with Diagnosis:
Global Experiences & Perspectives
A Discussion of Recommended Practices
Moderator: Bryan Lewis (USA)



Global Themes: Recommended Practices


1. Encourage Self Advocacy for Patients
2. Help Identify Good Care Options
3. Provide Current Information and Education
4. Provide Support for the Whole Patient
5. Find a "Kidney Cancer Focused" Cancer Resource Center for Personalized Help
6. Increase Public Education-Awareness and Reduce Stigma
7. Engage in Public Policy Initiatives
8. Access: Assist with Challenges of Dealing with Multiple Health Systems within Each Country



Global Kidney Cancer Summit September 24-25, 2021


Meredith H. Kruse, MSc, MPH
Brazil

Meredith is an interdisciplinary global health professional and Project Analyst with Oncoguia, an internationally recognized cancer advocacy organization in Brazil where she supports the Patient Navigation Program. She has expertise in research, community-based programs, and advocacy with extensive experience developing, implementing, and providing technical support to global health research for change and program interventions to improve cancer prevention, screening, diagnosis, access, and adherence to treatment.



Oncoguia
Don't make the road

IKCC Global Kidney Cancer Summit 2021
Strengthening patient support programs to cope with diagnosis
24-25/2021



Athina Alexandridou
Greece

VHL Family Alliance-Greece was founded and is led by Athina oz Alexandridou, whose family carries the von Hippel Lindau (VHL) gene that causes kidney cancer in some family members. The organisation started as a patient support group, helping patients access genetic tests for VHL. The Alliance also advocated on behalf of VHL patients to have VHL recognised as a rare, incurable disease.

ΟΜΙΑΟΣ ΑΣΘΕΝΩΝ ΜΕ V.H.L.
ΕΛΛΑΔΟΣ
(FAMILY ALLIANCE-GREECE)

Tel: no 6944-969003 & 210-2711306
E-mail: athina@vhl.gr

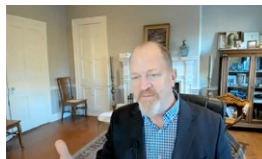
Our VHL:
www.vhl.gr

Members:
www.vhl.org & vhl-europe.org
and affiliates of
www.ikcc.org




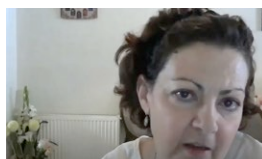
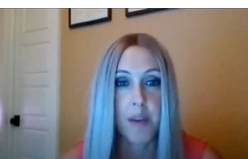
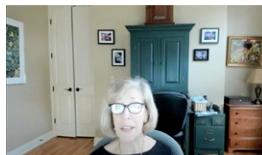
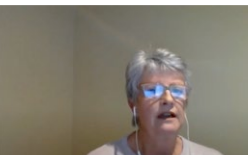

Day 2 Presentations

Together for bladder cancer patients




Alex Filicevas
Executive Director




Global Kidney Cancer Summit 2021



Christine Collins Canada



Christine joined the Kidney Cancer Canada Board in March 2014 after several years of volunteering and participation with Kidney Cancer Canada. Christine is under active surveillance, and as a patient is committed to "giving back" after receiving information, education and support from Kidney Cancer Canada when first diagnosed. She started her Kidney Cancer Canada "career" with Peer Support services and Patient Education events. In July 2020, Christine stepped down from her position as Vice Chair on the Board of Directors and is now the Executive Director of Kidney Cancer Canada.

Christine's background in education, non/not for profit and health and office administration along with her Kidney Cancer Canada "career" all help to serve and support patients with kidney cancer, their family members, and caregivers

THE CANADIAN CONNECTION
HOW WE GOT STARTED



TOGETHER!
FOR KIDNEY CANCER PATIENTS



"Kidney cancer is a global disease."
Working together toward strengthening patient support programs

Susan Poteat, MS, DABR United States





Susan Poteat is a volunteer serving as our liaison with the medical and scientific community. In her professional career, Susan worked first as a teacher and then for 25 years as a medical physicist in radiation oncology before retirement. Since her husband's diagnosis with kidney cancer in 2007, Susan has served the kidney cancer community as a volunteer patient navigator on SmartPatients.com, particularly in patient education. Her special interest is in clinical trials.

Growing the connection with the medical and research community


Another Caregiver, Another Mission

- 25 years in medical physical in radiation oncology and imaging
- Previous career as an educator
- Lots of medical project management
- 20 years on SmartPatients forum communicating with patients
- Retirement career: Medical Science Liaison
- Kidney Cancer Research Summit coordinator

Global Kidney Cancer Summit September 24-25, 2021

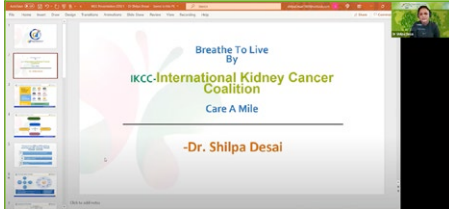
Kidney Cancer Research Summit 2019:
Connecting translational and clinical researchers



Kidney Cancer Research Summit
Global Kidney Cancer Summit September 24-25, 2021

Dr. Shilpa N. Desai
MD And Founder
Ph.D. Health
Psychologist and
wellness expert

Dr. Shilpa Desai is an established health psychologist, scientist & Wellness expert with over two decades of experience in bringing holistic wellness to people of all ages. Known for her contributions in the Public healthcare & Hygiene with Scientific result oriented Wellness, she founded, C4 Integrated Wellness, a company that works on the concept of offering Complete Care to Cure solutions. Her belief that "a healthy mind residing in a healthy body, is the core to happy and successful living", has been the guiding principle of her revolutionary work. Her active contributions are highly regarded in the industry. Thus, She is also a part of several groups as a Trustee and Board Member. She Promote "Atmanirbhar Bharat" by her project consultation to create new innovation to make life sustainable. She has extended her vision to "Swasthya Nirbhar Bharat". **She has been appointed as Covid Officer for VIVO – IPL 2021, Mumbai by MCA.**


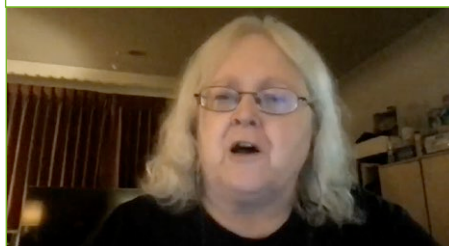


Robin Martinez
United States

Robin Martinez began guiding kidney cancer patients in 1997 with the Association of Cancer Online Resources (ACOR). She has been coordinating the online communities at Smart Patients since the website opened in 2013. The Smart Patients website (www.smartpatients.com) hosts the world's largest interactive online community for kidney cancer patients and caregivers.

Robin's late husband was diagnosed with kidney cancer in 1998 and was told he had only months to live. By the time he died ten years later, they had learned a lot and Robin was co-administering ACOR's large online group for kidney cancer. She has been doing this for over 20 years now believing their experience is too expensive to waste.

Robin also enjoys co-hosting the PowerfulPatient.org podcast with Joyce Graff and Mike Lawing. The three met online as kidney cancer patient advocates.

Kidney Cancer Support Network





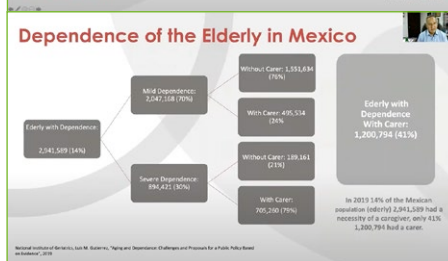

Lic. Carlos A. Castro
Mexico

He has a bachelor's degree in economics from (ITESM) Monterrey Institute of Technology.

Upon the death of his grandson Alejandro, along with his daughter Adriana, the husband of her, and his wife, founded Asocacion ALE, I.A.P., a non-profit organization that promotes organ donor culture (public awareness), provides financial assistance for Mexican population, that doesn't have medical aid, for access to transplant medicine. The institution is actively participating influencing public policies, in kidney and cardiovascular diseases, and to have in Mexico, universal health care and that this be provided in quality and opportunity.


He has participated in numerous Congress and Forum, nationally and internationally, speaking as the Voice of the Patient as an important stakeholder in decisions on Public Health.

He is co-author of a book "Política Nacional de Fomento a la Salud Renal" a proposal of public policy for Kidney Disease for Mexico.

Ankita Ambolkar
India

Ankita Ambolkar holds a Masters Degree in business administration (MBA) in Finance and a Web Designer certification. She has been working with V Care for the last six years under the Patient Assistance Program and managing all the social media platforms. Ankita attended the 5th Asia Pacific Stakeholder Forum in Singapore on Patients Centrality and Patient Journey and Survivorship.



Ways to Support Carers

Presented by: Ankita Ambolkar
V Care Foundation, India



8 tips for caregiver on self-care

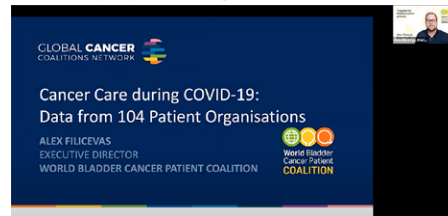
- Understand your new role as a caregiver
- Learn to ask for help
- Understand the diagnosis
- Stay organized
- Stay positive
- Communicate and accept
- Be aware and understand your feelings
- Take care of yourself



Alex Filicevas
Belgium


Alex Filicevas is a passionate cancer patient advocate focused on driving meaningful change in cancer research, policy and care. Alex is Executive Director of World Bladder Cancer Patient Coalition, Global Cancer Coalitions Network member representative, President of All.Can International and EUPATI fellow. He leads the efforts to foster an international community of strong bladder cancer patient advocates and organisations around the world, empowering patient voices across research and care continuum. Passionate about high-quality, equitable cancer care for all, and the role of efficiency in achieving it, he champions evidence generation and sharing, and multi-stakeholder collaboration.

Prior to his current roles, he was leading EU affairs work at Europe's largest cancer patient umbrella organisation, where he focused on advocacy activities, capacity building and policy initiatives with a particular focus on overarching issues faced by cancer patients and their carers in Europe. As a healthcare consultant, Alex has supported a number of private and non-governmental organisations in successful advocacy efforts at the EU level on a range of disease areas and issue-specific public health challenges.

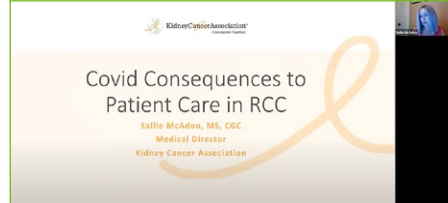
Sallie McAdoo, MS, CGC
United States

Sallie McAdoo is the Medical Director at Kidney Cancer Association. As a genetic counselor, she has always maintained a focus on patient education and empowerment, making her role at the KCA a perfect fit. By bridging together healthcare provider and patient resources, she hopes her role at KCA will lead to earlier means of disease detection, increased awareness for rare kidney cancer types and populations, and multicenter collaboration efforts in research and care. Prior to taking on her role at the KCA, Sallie cared for patients at various academic and private institutions, before switching to a medical affairs role at various diagnostic companies specializing in thyroid and lung cancer, idiopathic pulmonary fibrosis, stem cell research, and reproductive genetics. She has authored multiple scientific abstracts and papers and given over 400 talks worldwide.



Covid Consequences to Patient Care in RCC


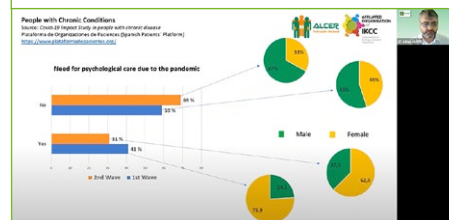
Sallie McAdoo, MS, CGC
Medical Director
Kidney Cancer Association



Juan Carlos Julián Mauro
Spain

Juan Carlos Julián Mauro has been the Managing Director of the Spanish Kidney Patients' Federation (ALCER) since 2006. ALCER began its work with kidney cancer patients in 2015 and today has a specific program for them.

Juan Carlos holds a Bachelor's in Psychology and is currently a doctoral student in the field of Methodology and Health Psychology.

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 treatment and care decisions are made.



2021 IKCC Presentations

2021 ASCO[®] ANNUAL MEETING

American Society of Clinical Oncology (ASCO) in June 2021

- Results from the IKCC 2020 Global Patient Survey



European Association of Urology (EAU) Virtual Conference in July 2021

- Patient Quality Criteria for a Multidisciplinary Integrated Care Pathway for von Hippel-Lindau Syndrome
- Cancer Care during COVID-19: Data from 157 Patient Organisations
- Patient-Reported Experience of Diagnosis, Management, and Burden of RCC: Results from a Global Patient Survey in 41 countries
- Patient engagement interventions not only improve health but survival in patients with cancer: A scoping review
- Patient perspective on serving on the steering committee of the AURORAX-0087A trial for non-metastatic clear cell RCC



European Society of Medical Oncology (ESMO) Virtual Conference in September 2021

- Results from the IKCC 2020 Global Patient Survey

2021 IKCC Publications



Giles RH, Maskens D, Martinez R, Kastrati K, Casto C, Mauro J CJ, Bick R, Packer M, Heng DY, Larkin J, Bex A, Jonasch, MacLennan SJ, Jewett MAS. Patient-Reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas: Results from a Global Patient Survey in 43 countries. Accepted Dec 2021, European Urology Open Science (in press)

Bedke J, Albiges L, Capitanio U, Giles RH, Hora M, Lam TB, Ljungberg B, Marconi L, Klatte T, Volpe A, Abu-Ghanem Y, Dabestani S, Fernández-Pello S, Hofmann F, Kuusk T, Tahbaz R, Powles T, Bex A. 2021 Updated European Association of Urology Guidelines on the Use of Adjuvant Pembrolizumab for Renal Cell Carcinoma. *Eur Urol*. 2021 Dec 14:S0302-2838(21)02198-9.

Choueiri TK, Albiges L, Atkins MB, Bakouny Z, Bratslavsky G, Braun DA, Haas NB, Haanen J, B, Hakimi AA, Jewett MAS, Jonasch E, Kaelin WG, Kapur P, Labaki C, Lewis B, McDermott DF, Pal SK, Pels K, Poteat S, Powles T, Rathmell WK, Rini BI, Signoretti S, Tannir NM, Uzzo RG, Hammers HJ. From Basic Science to Clinical Translation in Kidney Cancer: A Report from the Second Kidney Cancer Research Summit. *Clin Cancer Res*. 2021 Dec 29:clincanres.3238.2021.

Motzer RJ, Jonasch E, Agarwal N, Alva A, Baine M, Beckermann K, Carlo MI, Choueiri TK, Costello BA, Derweesh IH, Desai A, Ged Y, George S, Gore JL, Haas N, Hancock SL, Kapur P, Kyriakopoulos C, Lam ET, Lara PN, Lau C, Lewis B, Madoff DC, Manley B, Michaelson MD, Mortazavi A, Nandagopal L, Plimack ER, Ponsky L, Ramalingam S, Shuch B, Smith ZL, Sosman J, Dwyer MA, Gurski LA, Motter A. Kidney Cancer, Version 3.2022, NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw*. 2022 Jan;20(1):71-90.

Bedke J, Albiges L, Capitanio U, Giles RH, Hora M, Lam TB, Ljungberg B, Marconi L, Klatte T, Volpe A, Abu-Ghanem Y, Dabestani S, Pello SF, Hofmann F, Kuusk T, Tahbaz R, Powles T, Bex A. The 2021 Updated European Association of Urology Guidelines on Renal Cell Carcinoma: Immune Checkpoint Inhibitor-based Combination Therapies for Treatment-naïve Metastatic Clear-cell Renal Cell Carcinoma Are Standard of Care. *Eur Urol*. 2021 Oct;80(4):393-397.

Björkqvist J, Giles RH, Cornford P, Makaroff LE, Van Hemelrijck M, Darraugh J, Cowl J, MacLennan S, MacLennan SJ. Providing a Framework for Meaningful Patient Involvement in Clinical Practice Guideline Development and Implementation. *Eur Urol Focus*. 2021 Sep 28:S2405-4569(21)00264-9.

Herrera-Caceres JO, Ajaj R, Leão R, Barello S, Rodriguez-Covarrubias F, Zequi SC, Maskens D, Giles RH, Lavallée LT, Jewett MAS. Patient-centered care can be improved by joint meetings between cancer patient group leaders and health care providers. *Patient Educ Couns*. 2021 Jul 16:S0738-3991(21)00482-1.

Vat LE, Finlay T, Robinson P, Barbareschi G, Boudes M, Diaz Ponce AM, Dinboeck M, Eichmann L, Ferrer E, Fruytier SE, Giles RH, Hey C, Broerse JEW, Schuitmaker-Warnaar TJ. Evaluation of patient engagement in medicine development: A multi-stakeholder framework with metrics. *Health Expect*. 2021 Apr;24(2):491-506.

Bedke J, Albiges L, Capitanio U, Giles RH, Hora M, Lam TB, Ljungberg B, Marconi L, Klatte T, Volpe A, Abu-Ghanem Y, Dabestani S, Fernández-Pello S, Hofmann F, Kuusk T, Tahbaz R, Powles T, Bex A. Updated European Association of Urology Guidelines on Renal Cell Carcinoma: Nivolumab plus Cabozantinib Joins Immune Checkpoint Inhibition Combination Therapies for Treatment-naïve Metastatic Clear-Cell Renal Cell Carcinoma. *Eur Urol*. 2021 Mar;79(3):339-342.



Links to all of IKCC's 2021 publications can be found at <https://ikcc.org/publications/>

Supporting the Kidney Cancer Community During the COVID-19 Pandemic

For two years, people affected by cancer and patient organisations have been impacted by the global COVID-19 pandemic. Specifically, kidney cancer patients need up-to-date and evidence-based information about their treatment, follow-up care, vaccination and other cancer-specific details about managing health during the pandemic, and patient organisations have worked tirelessly to support their community's needs.

In the spirit of knowledge-exchange and collaboration, IKCC created an information hub on its website with credible resources. At the Global Kidney Cancer Summit, Affiliate Organisations shared their successes and challenges in managing patient programs and changing information needs during the pandemic.

In 2021, IKCC also published a new report entitled *The impact of COVID-19 on the kidney cancer community*. Based on experiences and learnings from a multidisciplinary group of experts, the paper highlights the many ways the pandemic has affected patients and the kidney cancer community. This includes changes to healthcare systems and the ways kidney cancers have been diagnosed and treated, the effect on kidney cancer research and the impact on patient organisations.

The report also looked at the ways that patients have been affected directly and indirectly, including their lifestyle, mental health and their cancer treatment experiences.

The impact of COVID-19 on the kidney cancer community report, as well as COVID-19 resources, can be found on the IKCC website. We will be presenting this report as a poster at the 2022 European Association of Urology Annual Meeting, in Amsterdam, the Netherlands.

In addition, the Global Cancer Coalitions Network, of which IKCC is a part, hosted two virtual meetings focused on the pandemic. Coalition Connection: COVID-19 in February and Coalition Connection 2: COVID-19 Vaccines & Cancer in November.



The IKCC Medical Advisory Board

Board members and Medical Advisory Board co-chairs, Drs Michael Jewett and Eric Jonasch held the annual meeting of the Medical Advisory Board (MAB) virtually with the 12 members representing clinicians from 10 countries and four continents.

The MAB members have again demonstrated their enthusiasm and support for our organisation. They have embraced our values by editing Highlights of major clinical meetings for the Affiliates Organisations, as well as providing expertise to produce infographics and other materials.

Members of the MAB are currently engaged in developing a novel program to increase engagement of clinicians in patient advocacy in their home countries, as well as supporting an annual IKCC sponsor lectureship at a major clinical meeting. The first lecture will be delivered at the 2022 EAU Congress to be held in Amsterdam, the Netherlands. Dr Jewett was invited to address the topic “Patient engagement is a potential blockbuster treatment that urologists should prescribe for their cancer patients.”

The MAB plans to meet in person in 2022 after two years of meeting virtually. At that time, the terms of the members will be reviewed as they are time limited.

To view the members of the IKCC Medical Advisory Board, visit the IKCC website:

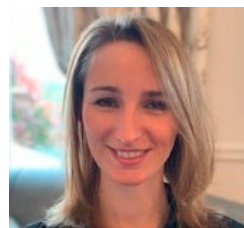
ikcc.org/about-ikcc/ikcc-medical-advisory-board/

The Cecile and Ken Youner IKCC Scholarship

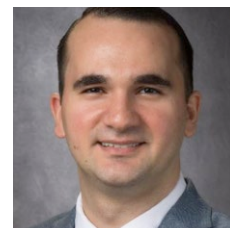
In 2018, IKCC established an annual student scholarship known as The Cecile and Ken Youner International Kidney Cancer Coalition (IKCC) Scholarship. The award honours the IKCC Emeritus Founding Member, Dr Ken Youner, who contributed so much to the establishment of IKCC. It is to be awarded annually to 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 awards the prestigious scholarship and in 2021 awarded the 3rd Youner Scholarship to two deserving students to share and enable them to continue their vital research:

Dr Charlotte Spencer from The Francis Crick Institute in London, UK was awarded the prize for her work on the characterisation of the histological appearance of genomic alterations in clear cell RCC, and harnessing machine learning to predict genetic mutations to ultimately predict patient outcomes.



Dr Elshad Hasanov from the University of Texas MD Anderson Cancer Center in the United States was awarded the prize for his work on the molecular characterisation of RCC brain metastases from genomic features and nucleus sequencing and comparing them with other metastatic sites.



The inaugural Cecile and Ken Youner IKCC Scholarship was awarded to Dr Lewis Au, MD, FRACP (UK).

Treasurer's Report 2021

It gives me great pleasure to present our Annual Financial Overview for 2021 on behalf of the IKCC Board of Directors.

The global pandemic has meant that yet again in 2021 regular IKCC activities such as our face-to-face Annual Global Summit, attendance at various clinical conferences and other travel have impacted our bottom line delivering a surplus of Euro 331,179. This an improvement on previous years placing IKCC in a strong financial position to address capacity building while holding funds in reserve to cover organisational operations and key programs going forward. This is an ideal position for the organisation to be in financially and provides optimal flexibility for the selection of strategies and programs to benefit all Affiliates.

The ongoing support of our Sustaining Partners under challenging circumstances has ensured our work to empower the global kidney cancer community through advocacy, awareness, information and research has continued and strengthened. We acknowledge and thank our loyal Partners for your ongoing support of our critical work.

Van Hoesel De Blaey Accountancy B.V. of Rotterdam in the Netherlands have once again worked with the Board and management to deliver independently-audited financial statements.

The Board has designated that IKCC reserves be earmarked for the following projects in 2022 to enable us to deliver on our business objectives, mission and vision. These projects are:

- Euro 120,000 World Kidney Cancer Day
- Euro 116,000 Global Kidney Cancer Summit
- Euro 100,000 PAG Incubator
- Euro 90,000 Global Patient Survey
- Euro 44,000 Dashboard Project
- Euro 25,000 Decision Aid: Clinical Trial Participation

The Board has estimated that Euro 200,000 should be kept in IKCC's unrestricted reserves to cover yearly recurring overhead expenses.

We thank all those who have contributed to IKCC and made our work to reduce the burden of kidney cancer worldwide possible. With your support, IKCC will continue to help improve the lives of people with kidney cancer globally in 2022 and beyond.

Anne Wilson

*Secretary-Treasurer
IKCC Board*

2021 Financial Statements

These figures are extracted from the 2021 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 BV,
Computerweg 22,
3542DR Utrecht,
The Netherlands

IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2021	
CURRENT ASSETS	
Funds to receive	€ 52,936
Liquid assets	€ 1,192,753
TOTAL CURRENT ASSETS	€ 1,245,689
CURRENT LIABILITIES	
Creditors and borrowings	€ 132,309
TOTAL CURRENT LIABILITIES	€ 132,309
NET ASSETS	€ 1,113,380
ACCUMULATED FUNDS	
Reserves	€ 571,700
Last year surplus/(deficit)	€ 210,501
Current year surplus/(deficit)	€ 331,179
TOTAL ACCUMULATED FUNDS	€ 1,113,380



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.

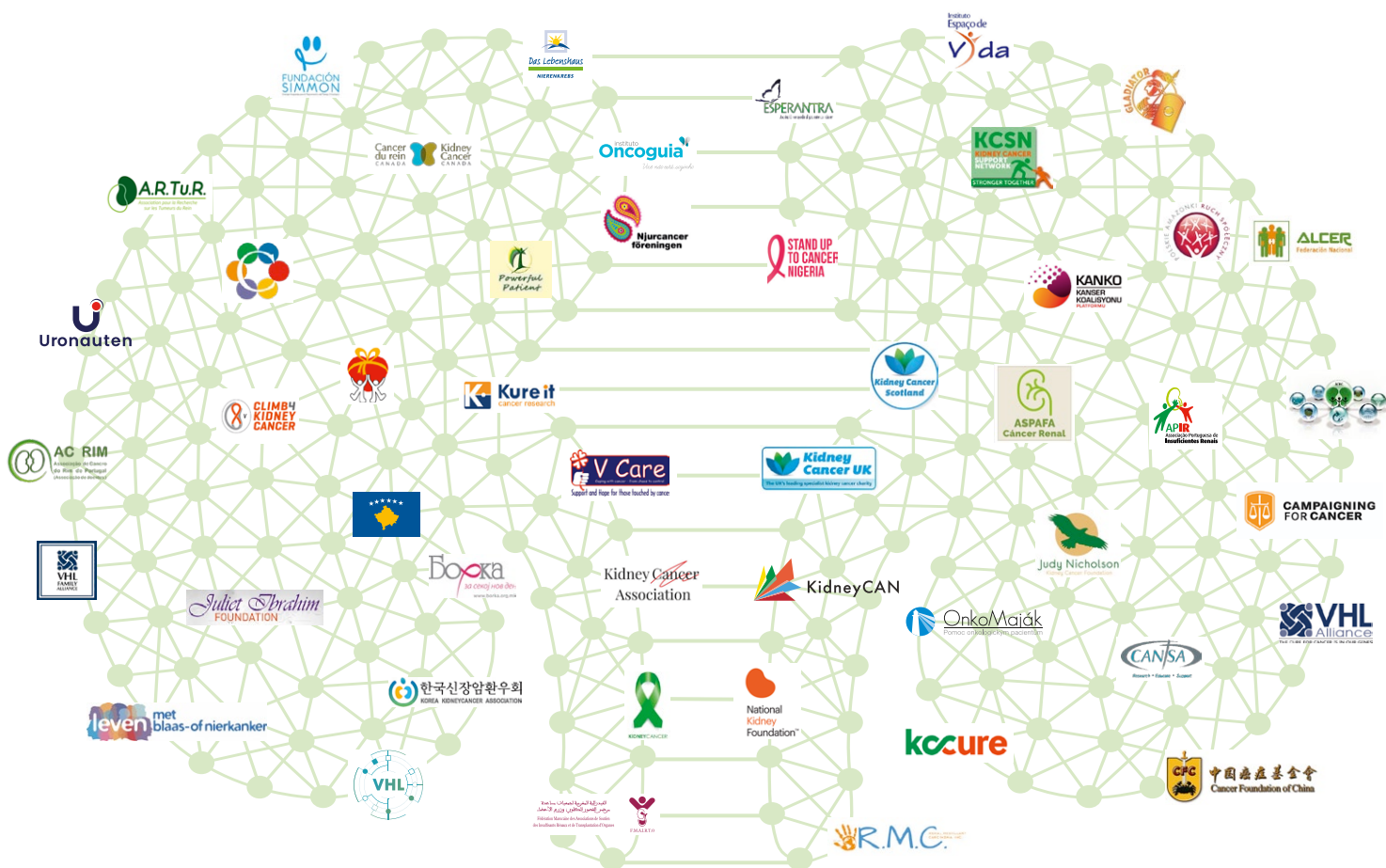
Supporters include individuals who may be strongly motivated to start kidney cancer groups in their own countries.

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

New Affiliate Organisation in 2021

Poland:
Polish Amazons Social Movement
www.ruchspoleczny.org.pl

Please see the IKCC website for further information:
<https://ikcc.org/about-ikcc/our-affiliates/>



IKCC Affiliate Organisations

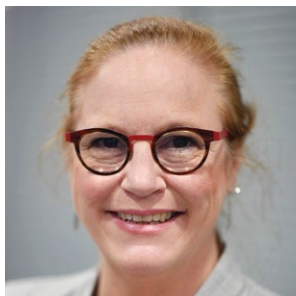


Please check our website for the latest list of organisations who have joined IKCC.

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



IKCC Board of Directors 2021



Dr Rachel Giles, 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 Medicom 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, he was successful in obtaining \$50 million for the KCRP – Kidney Cancer Research Program (www.cdmp.army.mil/kcrp/).

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 in 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.

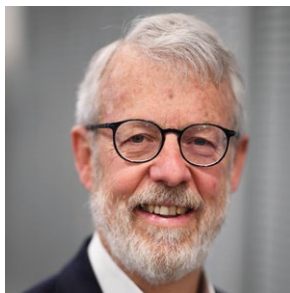


Margaret Hickey, MS, MSN, RN
United States

Margie Hickey is an advanced practice nurse, with more than 40 years of experience. She holds Master of Science degrees in both Nursing and Human Resource Administration from LaRoche College in Pittsburgh, PA in the US. She is a Medical Education and Communications Consultant and serves as the Executive Director of the Society of Otorhinolaryngology and Head-Neck Nurses (non-profit) and the Ear, Nose and Throat Nursing Foundation (charity). Margie was the Clinical Director at the Pittsburgh Cancer Institute of the University of Pittsburgh Medical Center and Tulane Cancer Center in New Orleans, where she was responsible for establishing and managing inpatient and outpatient programs. In 2000, Margie moved to the pharmaceutical sector, specializing in clinical research, medical communication, and patient engagement.

Margie is an active member of Oncology Nursing Society and has published as an author and editor for several nursing publications.

IKCC Board of Directors 2021



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 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 to 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 international 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 M. D. 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, BA
United States

Liz Leff has led advocacy efforts for NKF – the National Kidney Foundation – in the United States for the past 6 years. As a kidney cancer survivor, Liz has been involved in the kidney cancer community 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 the Kidney Cancer Support Network (KCSN), which is a grass-roots patient-led charity providing practical support and advocacy for the kidney cancer community in the UK. She enjoys a very busy life running the KCSN charity 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

The IKCC Board of Directors is committed to open and transparent partnerships with the healthcare industry in accordance with our Code of Conduct (www.ikcc.org) and international standards. Achieving balanced and multi-sourced funding helps us meet our goal of collaborating with all stakeholders including patient organisations, medical experts, and the healthcare industry. 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 2021 with Sustaining Partnerships and Project Sponsorships.

Sustaining Partners 2021



Project Sponsors 2021



**Partial sponsor*



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.

Julia Black – IKCC Chief Operating Officer
Josefine Bjorkqvist – IKCC Science and Policy Consultant
Rebecca Cubbage – IKCC Project 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
Karen Kastrati – Technical Support
Jilda Lazer, Reverb Consulting Group – Communications Support
John Luck – Global Patient Survey Support
Luci McCann – World Kidney Cancer Day
Diego Somer and Jelle Eissens – Administratiekantoor Boekjewinst.nl BV, Financial Services,
Herbert Thum, VisKon – Graphic Design



International Kidney Cancer Coalition

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The Netherlands

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Website: www.ikcc.org

www.worldkidneycancerday.org



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Stichting IKCC

Reg.-No. KvK 62070665