

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

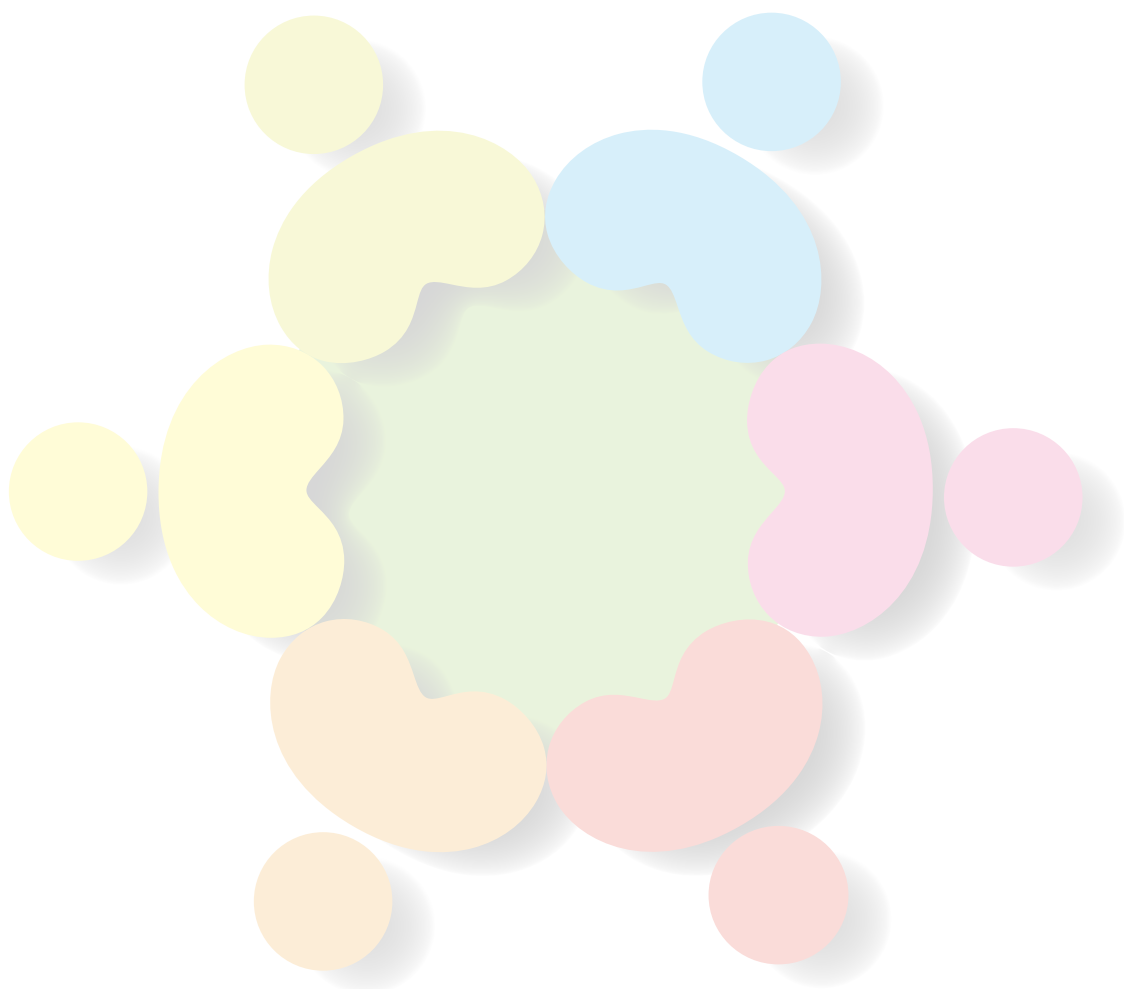
Annual Report 2020



 Global Kidney Cancer
Summit
2020

Updated September 2021

- ➔ Agenda & Presentations
- ➔ Affiliate Booths
- ➔ Networking Lounge
- ➔ Resource Centre
- ➔ Help Desk



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Message from the Chair



Rachel Giles

Dr Rachel Giles,

Chair of the Board

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.

This last year posed unique challenges to most patient organisations, including IKCC. The COVID-19 pandemic drastically increased the need for the paramedical support services that most patient organisations offer, while simultaneously, the resources available to most organisations became scarcer. We all strove to find solutions to work remotely, provide up-to-date medically solid information, and move our projects to reduce the burden of kidney cancer forward.

But despite the challenges, there is much to celebrate as we reflect on 2020. We applaud all Affiliate Organisations, our Medical Advisory Board, our staff, and Board of Directors for their tireless work in this difficult year. We are pleased to present this Annual Report along with the year's highlights.

IKCC worked very hard this year with eight other global cancer coalitions (now called the Global Cancer Coalitions Network) to call attention to the dire situations many patient organisations were facing. We presented the Network's research and action plan at the annual meeting of the European Society for Medical Oncology (ESMO).

In 2020, IKCC's Global Kidney Cancer Summit was to take place in Singapore. However, by February it became evident we had to move it to a virtual platform. Our planning committee did an amazing job turning the meeting into four virtual sessions between 29 October and 30 November, filled with updates from thought leaders in the field of kidney cancer, presentations about how the pandemic is impacting care, research and clinical treatments going forward.

Members of IKCC's Medical Advisory Board have also taken an active role in creating patient-centric language following each of the major scientific conferences throughout the year, bringing this important information to the kidney cancer community.

IKCC launched its second biennial Global Patient Survey in 2020 to better understand the patient experience worldwide. With over 2,000 responses, this rich data set will be guiding our strategy in the coming years. Thank you to everyone who helped gather participants! This year we will be processing the data for dissemination.

In addition to the initiatives highlighted in this report there are ongoing projects with expected deliverables in 2021. In January 2020 in Rome, Italy, I presented the results of the IKCC 'Value of Patient Engagement Research' at a meeting for patient advocates collaborating on academic projects. The final results will be presented at the EAU21 meeting in July. Progress to the Global Kidney Cancer Dashboard were delayed by the pandemic in 2020, but efforts have now resumed with more updates expected in 2021.

It is an organisational priority to bring patients' voices and priorities closer to the implementation of best practices for kidney cancer. This cannot stop in a pandemic and we continue our work on guidelines committees, health technology assessments, and patient involvement in the design of clinical trials. We have co-authored seven papers in medical journals last year and attended and presented at many international conferences.

IKCC has continued to grow and mature as an organisation. In February 2020 the IKCC Board met in San Francisco, following GU ASCO for a strategic planning meeting. Here it was decided to initiate a number of new initiatives that will help extend our reach, better engage and collaborate with stakeholders and Affiliate Organisations and strengthen our impact in the global cancer community.

We recognise that IKCC is merely the sum of our parts that make a global impact. The number of Affiliate Organisations continued to grow this year and we continue to welcome and encourage organisations with an interest in kidney cancer to join our international network.

On behalf of the Board of Directors and the dedicated IKCC staff, we thank each and every person who contributed to the tremendous success in 2020.

About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of over 40 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.

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.



GLOBAL CANCER
COALITIONS NETWORK



WE CAN
Workgroup of European
Cancer Patient Advocacy Networks



**EUROPEAN
CANCER
PATIENT
COALITION**

1) https://gco.iarc.fr/today/online-analysis-table?v=2020&mode=cancer&mode_population=continents&population=900&populations=900&key=asr&sex=0&cancer=39&type=0&statistic=5&prevalence=0&population_group=0&ages_group%5B%5D=0&ages_group%5B%5D=17&group_cancer=1&include_nmssc=1&include_nmssc_other=1

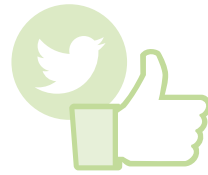
2020: IKCC by the Numbers



46
Affiliate Organisations worldwide



2
new Affiliate Organisations – from Portugal and Spain – joined IKCC



More than **4,000**
Twitter followers and nearly
9,000
likes on Facebook



500,000
social media impressions
worldwide



Over 170 attendees from
20+ countries and
6 continents
attended the first-ever virtual Global Summit



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



IKCC co-authored **7** articles
in medical journals



IKCC presented at
7 international conferences



7 editions of the IKCC Newsletter sent to
nearly **400** subscribers

Lessons Learned and Hope Ahead

It was a year like no other. And while kidney cancer organisations around the world faced unthinkable challenges, the situation created by the global pandemic also led to opportunities. It was a time for collaboration and resilience. And a time to rethink and adapt the ways organisations can support patients and caregivers in their communities into the future.

We asked Affiliate Organisations to reflect on the learnings from the past year and share their hopes for what's ahead.

What did you learn in 2020?



The greatest learning was to focus, slow down and take care of what is possible to control. I can control what I eat, my sleep, my walks... in short, several things related to my well-being, which during the pandemic made a lot of difference.

Luciana Holtz,
Instituto Oncoguia,
Brazil

We've had to become more efficient, agile, and open to adaptation. I think what became clearest as a result of the COVID-19 pandemic was the potential to strengthen connections with our communities virtually through better communication.

Gretchen Vaughan,
Kidney Cancer Association,
United States



In 2020, we learned to keep the essentials and offer valuable services to our members and relatives, adapted to the new reality.

Juan Carlos Julián Mauro,
ALCER,
Spain

No one is an island, and we need others. We learned that our KCSN charity motto remains true – we ARE stronger together.

Rose Woodward,
Founder Kidney Cancer Support Network
and IKCC Board Member,
United Kingdom



ALCER
Federación Nacional



**Click & Chat
Special**

by patients for patients

We found out how valuable online patient groups can be. We do not have in-person groups everywhere and patients suffering from side effects or living far off, especially enjoy the possibility to meet virtually.

The online group was established in March 2020 and is still meeting virtually each month.

Karin Kastrati,
Das Lebenshaus e.V.,
Germany



We really came to understand the benefits of exercising, even for kidney cancer patients, and presented exercises with our Greek swimming champion, Nora Drakou.

Athina Alexandridou,
VHL FA Alliance,
Greece



What is your hope for 2021 and beyond?

In 2021, we hope to bit by bit include face-to-face meetings but will also continue to use a webinar platform so we can reach patients everywhere in our country.

Olle Karlsson,
Kidney Cancer Association of Sweden



I hope that we have learned one important lesson from COVID – that the health of everyone on this planet is interconnected with everyone else. A pandemic cannot be controlled by any one country alone. We need to work together worldwide to end this pandemic, and to make progress also on kidney cancer and indeed all cancers.

Joyce Graff,
Powerful Patient,
United States



Lessons Learned and Hope Ahead

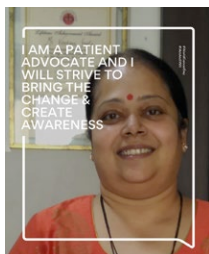
I am looking forward to the projects that can be done non-face-to-face and online with members, especially the new program for psychological support. I would like to create many programs to support the psychological support of patients as it is also linked to the IKCC campaign.

Jinyung Paik,
Korea Kidney Cancer Association,
Korea



*All we need is HOPE & STRENGTH.
Hope that it will get better and strength to hold on until it does.*

Jyoti Patil Shah,
V Care Foundation,
India



My hope is that with COVID behind, with vaccines or herd immunity, we can get back to operating face-to-face with patients. There is no better way to communicate.

Carlos Castro,
Asociación ALE,
Mexico

We have found that we as a foundation are stronger than we thought and are working harder to find ways to reach our audience and then some. We have opened our minds to any potential and idea. Almost can't wait for 2022!!

What a year that will be!

Linda Anderson,
Judy Nicholson Kidney Cancer Foundation,
United States



I hope that we can continue to lead in the field of disease-oriented patient advocacy with in-person interactions.

Dr Michael Jewett,
IKCC Board Member,
Canada



Projects and Activities 2020



Global Kidney Cancer Patient Survey

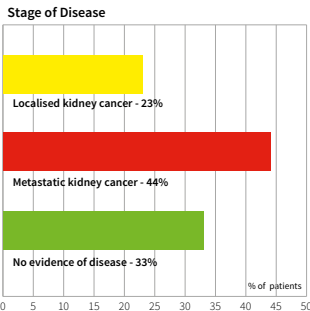
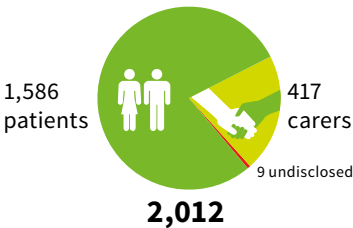


In 2020, IKCC launched our 2nd Global Kidney Cancer Patient Survey. The biennial survey is designed to identify geographic variations in patients' experience and to highlight best practices and unmet needs related to patients' access to care, quality of life, shared decision-making and involvement in clinical trials.

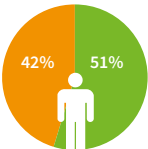
The survey was developed by a multi-country steering group of patient organisations. It was completed by more than 2,000 people from 41 countries around the globe in 13 languages – exceeding participation of the inaugural survey in 2018.

In the months ahead, the survey data will be analysed and reported upon, and will inform IKCC's work to reduce the burden of kidney cancer worldwide.

A huge thank you to all the patient organisations, patients and carers who supported and contributed their experiences and insights. The success of the survey reflects your collaboration and participation, ensuring the results generate a truly global voice.

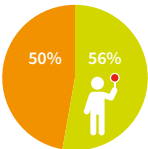


42% reported that the likelihood of surviving their cancer beyond 5 years was not explained



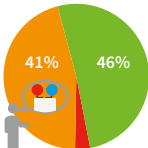
Just over half (51%) reported that they were involved as much as they wanted to be in developing their treatment plan.

50% Younger-onset patients (<46 years) did not know their tumour-subtype



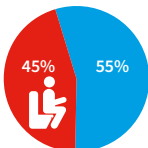
56% experienced barriers to their treatment

41% of respondents indicated that "No one" discussed cancer clinical trials with them



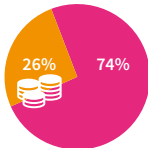
46% of respondents had a biopsy
Only 3% said they were NOT willing to undergo (additional) biopsy if asked

45% of respondents reported that they were insufficiently active



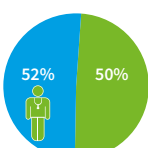
55% of respondents indicated that they 'very often' or 'always' experienced a fear of recurrence

26% of respondents 'very often' or 'always' experienced stress related to financial issues



74% of respondents took <3 months to correct diagnosis

52% of respondents reported having talked to their doctor/healthcare professional about their psychological well-being



50% of respondents indicated that they 'very often' or 'always' experienced disease-related anxiety.

My Treatment, My Choice: Decision Aid for Locally Advanced Disease

IKCC created the fourth module in the My Treatment, My Choice: Decision Aid series, specifically for patients diagnosed with locally advanced stage 3 disease.

A patient decision aid is a particular type of tool, written and evaluated according to international standards. It aims to support patients to be actively involved in decision-making about their own care and treatment. It provides information and sets out treatment choices and options in a structured way, which encourages discussion, understanding and promotes shared decision-making as a means of improving quality of care and patient satisfaction.

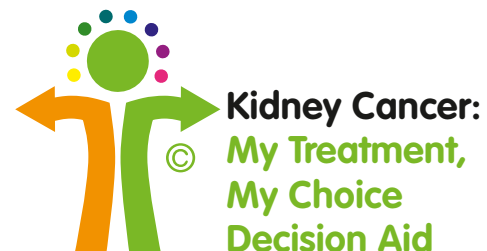
IKCC believes patients have an essential role to play in health-care decisions that affect their lives. Involving patients in decisions has become an important aspect of many health-care systems around the world and has the potential to lead to better health outcomes and improved equity of care.

The majority of RCC patients are initially diagnosed at stages 1-3. Currently, there is huge variation in how these patients are treated, regionally and internationally. Newly diagnosed kidney cancer patients are faced with a bewildering number of treatment choices and need both emotional and practical support.

Our fourth module of the My Treatment, My Choice: Decision Aid series focuses on the critical decisions required in the intermediate, high-risk of relapse, locally advanced stage 3 setting. The booklet introduction clarifies the number of confusing descriptions used for this group of patients. It then explores the principles of active surveillance/close observation and explain the various types of surgery available. It discusses the information contained in a pathology report and the effect that staging and grading and various tumour types will have on future treatment. Finally, the resource outlines choices around neoadjuvant and adjuvant therapy and the role of clinical trials for patients with locally advanced disease.



The IKCC My Treatment, My Choice: Decision Aid for Locally Advanced Disease follows international standards for patient decision aids.



EVOLVE: Giving patients a voice in the design and delivery of care

Clinical practice guidelines are recommendations based on the best available clinical evidence. These guidelines are a tool to support clinicians and patients to make informed healthcare decisions.

Patient involvement in the development of guidelines has been shown to improve the quality and relevance of the guidelines but there is a lack of standard processes for involving patients within guideline development.

The giving patients a **mEaningful VOice in the design and deLiVery of care (EVOLVE)** study is a unique collaboration between the European Association of Urology (EAU) Guideline Panels, researchers, clinicians and patient associations. The study aims to develop a framework of meaningful patient involvement in guideline development to address which stakeholders to involve, how to involve them and at what stage of the process.

The EVOLVE study began with a systematic review of the literature to identify existing models of patient involvement in guideline development. Next, interviews were carried out with key stakeholders, including patient and clinician members of European genitourinary cancer Guideline Panels, to find potential processes for patient involvement. Finally, patients living with genitourinary cancers and urologists, oncologists and nurses were invited to take part in an international Delphi survey to achieve consensus on which guideline development and implementation processes to involve patients. The Delphi study identified 16 areas of guideline development that are important for involving patients (Figure 1).



FIGURE 1. Guideline processes considered important for including patients (processes highlighted in blue were included and processes highlighted in grey excluded). Key stakeholders, including IKCC, are shown in green.

Based on findings from the Delphi study, evidence from the systematic review and interviews with key stakeholders, the EVOLVE framework for patient involvement in guideline development and implementation was designed. The EVOLVE framework includes recommendations around areas integral to patient involvement in guideline development: collaboration with patient networks; recruitment and retention of patient members; training and support for patient members and integrating patient members within all relevant guideline development and implementation processes.

The EVOLVE study team will continue to work with EAU Guideline Panels and patient organisations to implement these recommendations. Key findings from the EVOLVE study will be shared in various presentations and publications to come.

IKCC has been integral to the study, including participating in the study concept and design, conducting the study, recruiting participants and interpreting study findings.

The EVOLVE study is led by researchers at the University of Aberdeen and funded by North East Scotland urological cancer charity UCAN.

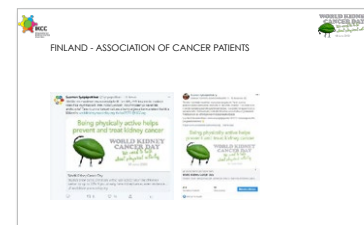
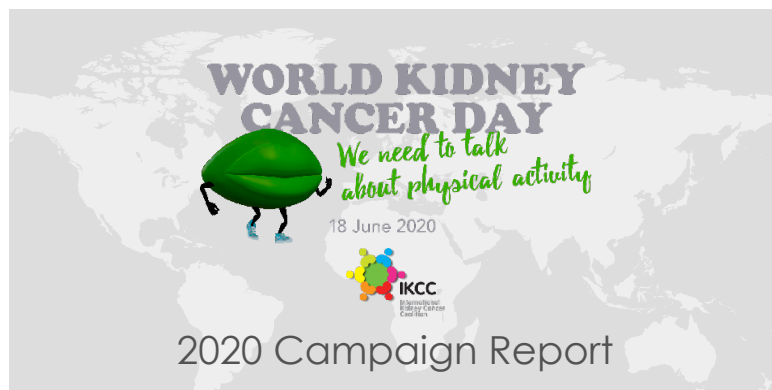
World Kidney Cancer Day 2020

World Kidney Cancer 2020 day was celebrated on 18 June by patients, friends, carers, health professionals, researchers and Affiliate Organisations around the world. The theme – We need to talk about physical activity – highlighted the importance of gentle exercise for preventing kidney cancer and helping people living with it at every stage of treatment.

The campaign was built upon the research of Dr Linda Trinh, Assistant Professor, Exercise and Cancer Survivorship at the University of Toronto, Canada. It included an informational website with practical tips, a YouTube video featuring Dr Trinh, and her *Get Active Sit Less* book, available for download.

With the combined efforts of Affiliate Organisations around the world, the campaign generated more than 2.5 million impressions, raising awareness for the importance of physical activity and kidney cancer. Affiliate Organisations celebrated World Kidney Cancer Day with traditional and social media campaigns, virtual education sessions, a virtual flash mob and more!

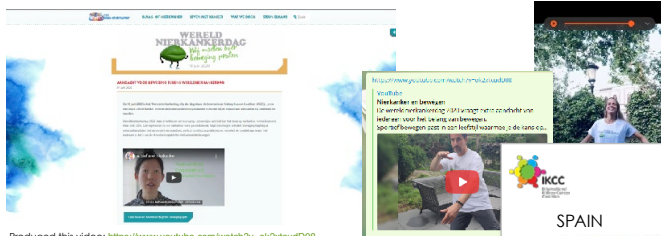
Thank you to everyone who took part in World Kidney Cancer Day 2020 – together we are stronger! Special thanks are extended to our sponsors and partners for supporting this important global public health and awareness initiative.





NETHERLANDS- DUTCH VHL ORGANISATION

Used a combination of WhatsApp and Youtube to share a video promoting physical activity and raising awareness of World Kidney Cancer Day 2020.



Produced this video: <https://www.youtube.com/watch?v=ok2xtciud08>



NETHERLANDS- DUTCH VHL ORGANISATION

The video was featured on Vimeo:



KOREA - KKCA

Used Facebook and Instagram, the KKCA online community, and the President of KKCA's Facebook.

운동은 신장암 예방과
치료에 도움이 됩니다



세계 신장암의 날
관장을 위한 운동
우리 함께 이야기해요.



세계 신장암의 날
관장을 위한 운동
우리 함께 이야기해요.



6월18일



*Localized Korean calligraphy version



GERMANY - DAS LEBENSHAUS e.V

Online patient group focussing on the importance of physical activity.

Schritte für Nierenkrebs-Patienten

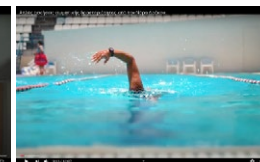


Schritte für Nierenkrebs-Patienten (steps for kidney cancer patients)

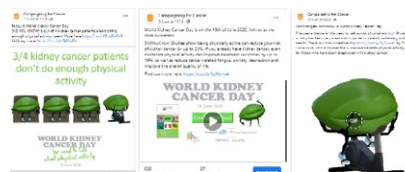


GREECE - VHLFA ALLIANCE GREECE

A month-long TV and radio campaign that delivered the Dr Trih messages, and was supported by a web event hosted by a national swimming champion that showed a number of physical activity exercises that are designed to activate patients. These are moderate water based exercises for everyone that can be adapted according to a patient's strength and doctor's advice.



SOUTH AFRICA - CAMPAIGNING FOR CANCER



AURORAX-0087A (AUR87A): A pioneering study to help people with kidney cancer detect disease recurrence

AURORAX-087A (or AUR87A) is an international study aiming to confirm the usefulness of a new blood and urine test for the early detection of RCC recurrence after curative surgery for localised kidney cancer. IKCC is a partner in this trial, in which patients and researchers have worked together to explore potential improvements to kidney cancer surveillance.

Even after curative surgery for localised kidney cancer, 20% of patients will see their cancer recur within five years. In standard practice, patient follow-up is performed using regular imaging scans. Not only is imaging not optimised for the early detection of recurrence, but having frequent scans increases the patient's exposure to radiation and can be associated with physical and emotional burden, also known as *scanxiety*. A test using a marker found in the blood and/or urine could be used instead to more easily determine if and when the kidney cancer recurs.

Glycosaminoglycans (GAGs) represent a new potential biomarker of kidney cancer. Measurements of blood and/or urine GAGs can be condensed in GAG scores. GAG scores were distinctively different in any stage of clear cell renal cell carcinoma (ccRCC) compared to controls. However, GAG scores have not been validated prospectively for detection of recurrence.

Therefore, a European Union Horizon 2020 funded, multi-national clinical trial called AURORAX-0087A was launched in 2019. AUR87A plans to validate the use of GAG scores in detecting ccRCC recurrence after curative surgery and thereby address the unmet need experienced by patients.

AUR87A aims to enrol 280 non-metastatic ccRCC patients curatively treated with surgery, with intermediate to high risk of recurrence (Leibovich Points ≥ 5). Patients are followed-up for between 12 to 18 months, with blood and urine sampling preoperatively and every 3 months for GAG score assessment, alongside current standard of care follow-up imaging as reference standard comparator for recurrence detection (Figure 1). The primary endpoint is the sensitivity and specificity analyses of GAG score to detect a recurrence compared to the reference standard. Sixteen international sites are currently involved in the study.

IKCC and patient representation has been involved throughout the study and is included on the trial Steering Committee to monitor both interim and final result presentation as co-investigator. Following enrolment of the first patient in February 2020, to date the study has screened 219 and enrolled 82 patients (Figure 2). The trial will close in 2023.

If the primary endpoint is met, patients and researchers will have co-created a practice-changing methodology for recurrence detection which will benefit the majority of kidney cancer patients, both in the management of their disease, as well as their psychosocial impact.

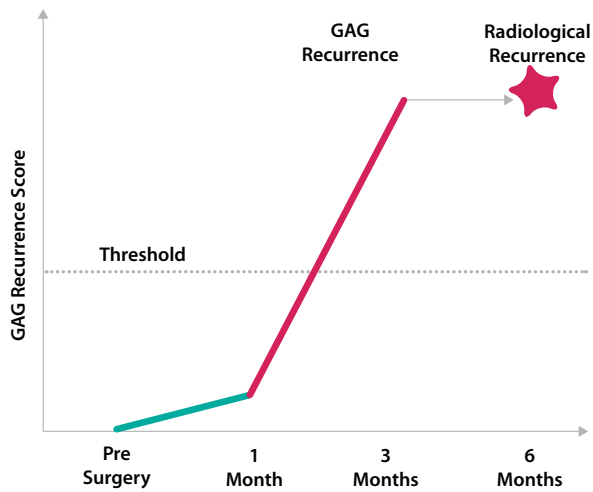


Figure 1. Hypothesis tested in AUR87A.
An increase in GAG score during follow-up is indicative of M0 ccRCC recurrence.

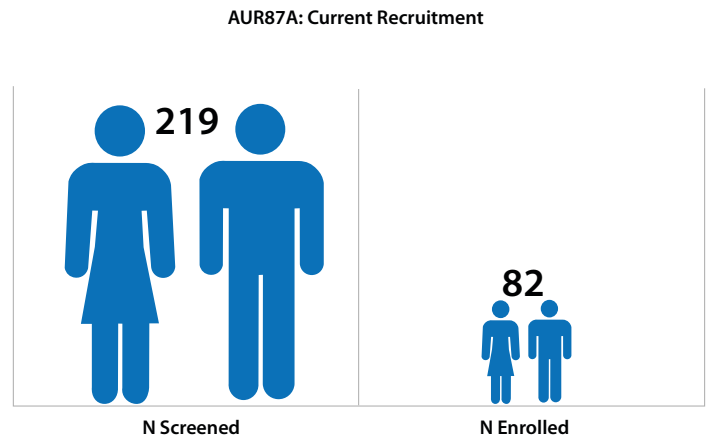


Figure 2. AUR87A recruitment: to date 219 patients have been screened, of which 82 have met eligibility and thus enrolled.

The Global Cancer Coalitions Network

In response to concerns about the impact of COVID-19 on member organisations, IKCC along with eight other global cancer patient coalition groups came together to form the Global Cancer Coalitions Network (GCCN). The collaboration was initiated when patient organisations around the world were sharing many of the same issues created by the pandemic to facilitate collaboration and sharing of best practices.

Together, GCCN represents 750 cancer patient advocacy and support organisations that are working on behalf of over 14 million patients around the world.

In the spring of 2020, GCCN assessed the ways the pandemic had affected cancer patients and the organisations which support them. Based on survey findings of the global cancer community, a united statement was developed calling for a global plan of action for cancer to meet the challenges of future pandemics or health crises. It includes specific recommendations to help ensure patients maintain access to the treatment and supportive care they need.

The study was accepted by the European Society of Medical Oncology (ESMO) and was presented at the virtual conference in September 2020. As well, the study findings were covered in the July issue of Lancet Oncology. The complete statement can be found on the IKCC website.

The GCCN consists of leaders from the following cancer groups:

- Advanced Breast Cancer Global Alliance
- Global Colon Cancer Association
- Global Lung Cancer Coalition
- International Brain Tumour Alliance
- International Kidney Cancer Coalition
- Lymphoma Coalition
- World Bladder Cancer Patient Coalition
- World Ovarian Cancer Coalition
- World Pancreatic Cancer Coalition



Global Kidney Cancer Summit 2020



Global Kidney Cancer
Summit
2020

- ➔ Agenda & Presentations
- ➔ Affiliate Booths
- ➔ Networking Lounge
- ➔ Resource Centre
- ➔ Help Desk

Working together
to reduce
the global burden
of kidney cancer



Contact: [@IKCC](#) [@IKCC](#) [@IKCC](#) [@IKCC](#)

Bem-vindo

Bienvenido Welcome Bienvenue



IKCC Global Kidney Cancer Summit 2020

In 2020, IKCC hosted the 10th Global Kidney Cancer Summit – the only international conference for organisations representing patients with kidney cancer. It was also the first-ever virtual Summit due to the COVID-19 pandemic.

More than 100 members of the worldwide kidney cancer community came together virtually over four days showing their commitment to improving the lives of people with kidney cancer.

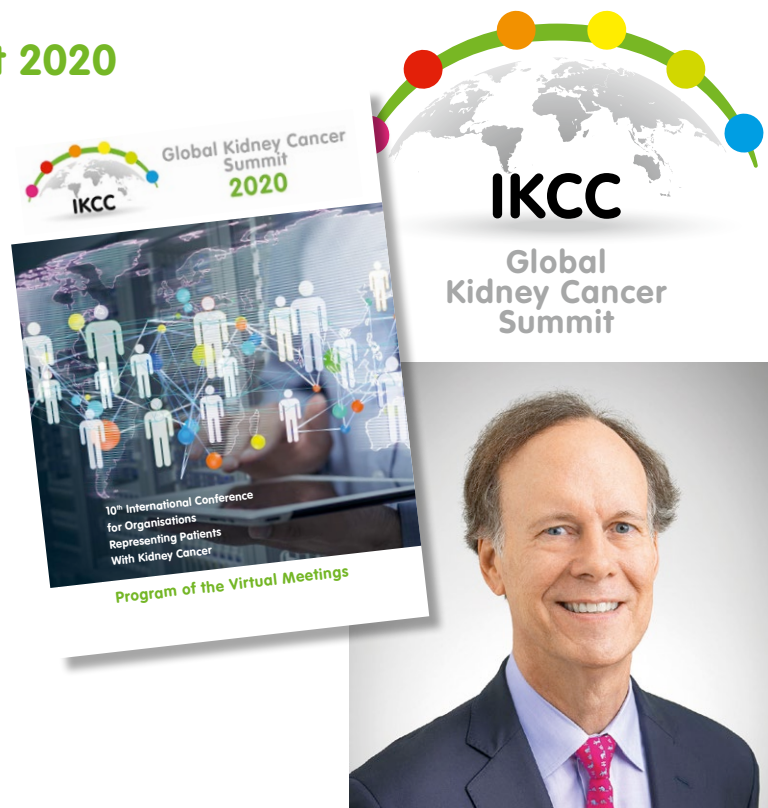
The Summit began with a keynote address from William G. Kaelin Jr., MD, from Dana Farber Cancer Institute in Boston. Dr Kaelin presented his Nobel Prize-winning research on the importance of oxygen in the VHL (Von-Hippel Lindau) gene and how this impacts the growth of kidney cancer tumours.

Other keynote presentations and panel discussions over the four days updated the patient advocate community with new developments in the field of kidney cancer, including new research findings, treatment advances and side-effect management. In addition, a multi-disciplinary discussion focused on the impact of COVID-19 on the kidney cancer community and shared experiences from a leading clinician, an infectious disease expert, a researcher and a kidney cancer patient, all focused on the lessons learned and plans for the future.

A special thank you to the Kidney Cancer Association (US), who extended an invitation to all IKCC Affiliate Organisations to join their annual International Kidney Cancer Symposium. The day-long event featured patient-centred panel discussions about diagnosis, treatment, side effects and living beyond kidney cancer.

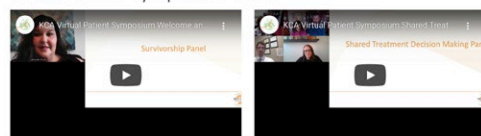
We also thank the planning committee and members of the Medical Advisory Board who did an immense amount of work – both in the original planning of the in-person Global Summit in Singapore and then bringing the virtual event to the global audience. IKCC remains committed to growing the kidney cancer patient voice in Asia and acknowledges the ongoing contributions of researchers and patient organisations in the region.

For a complete summary of the Global Kidney Cancer Summit 2020, visit the IKCC website.





Virtual Patient Symposium Videos



Welcome and Survivorship Panel

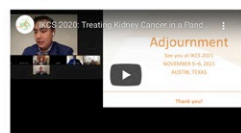
Moderated by: Laura Wood, RN, MSN, OCN

Panelists: John Ferrel, Brian Moran, Michelle Piccolo, Cathy West, and Salma Witz

Shared Decision Making Panel

Moderated by: Courtney Firsi, MPH

Panelists: Pedro Barata, MD, MSc and Katy Beckerman, MD, PhD
Bruce and Susan Hill, patient and caregiver



Treating Kidney Cancer in a Pandemic: Lessons from COVID-19

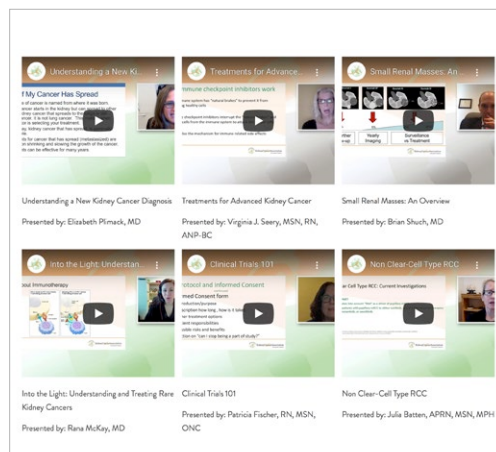
Moderated by: Matt Campbell, MD, MS and William C. Huang, MD

Panelists: Brian Shinder, MD, Martin H. Vos, MD and Megan Conley, patient



Side Effect Management

Presented by: Kira Kahoe, RN, BSN, CCRN



Understanding a New Kidney Cancer Diagnosis

Presented by: Elizabeth Pimmack, MD

Treatments for Advanced Kidney Cancer

Presented by: Virginia J. Seery, MSN, RN, ANP-BC

Small Renal Masses: An Overview

Presented by: Brian Shuch, MD

Into the Light: Understanding and Treating Rare Kidney Cancers

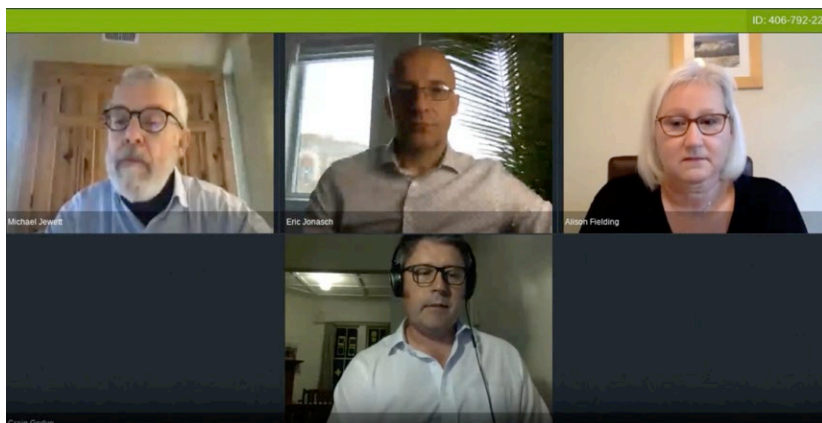
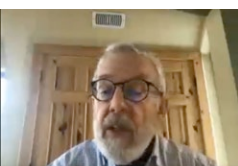
Presented by: Rana McKay, MD

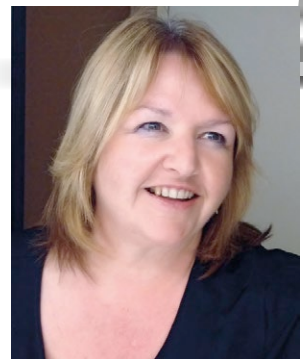
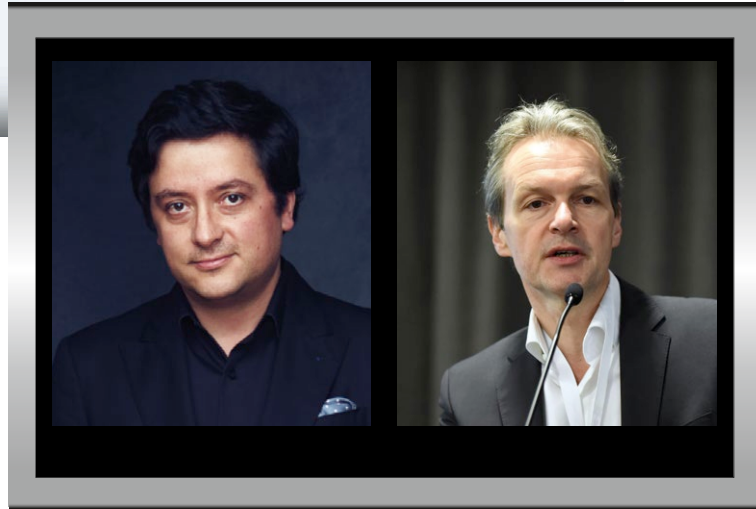
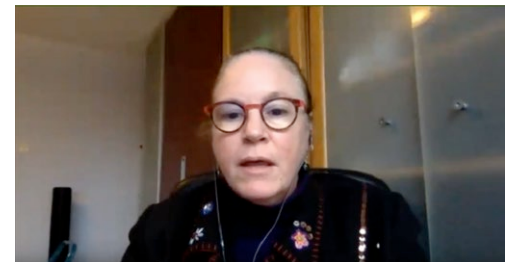
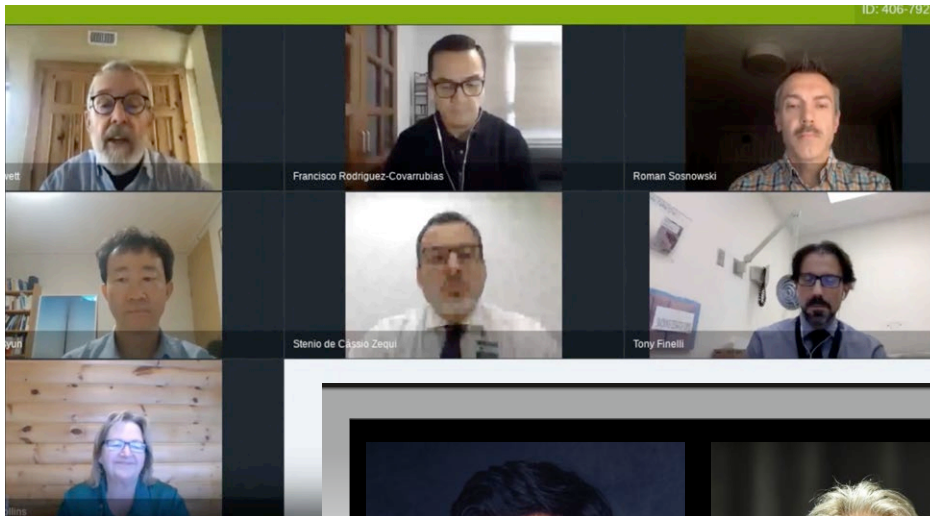
Clinical Trials 101

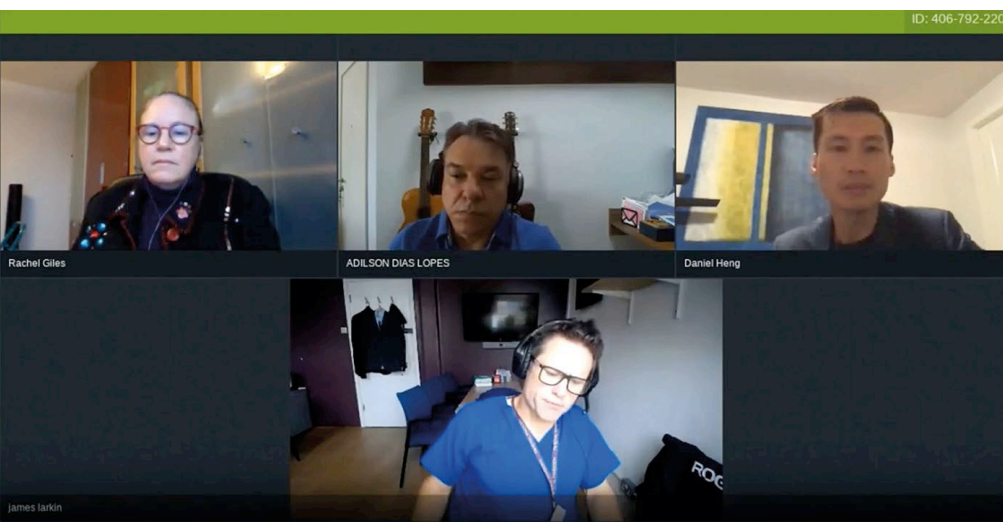
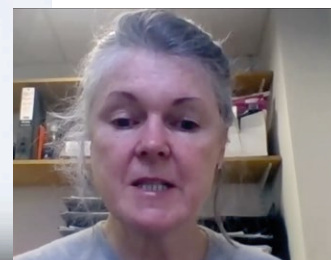
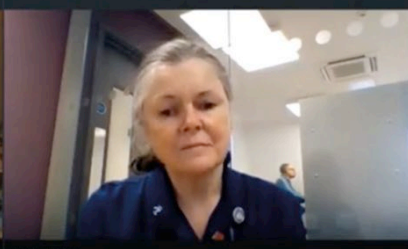
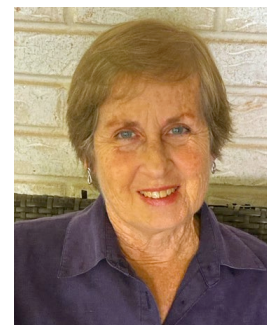
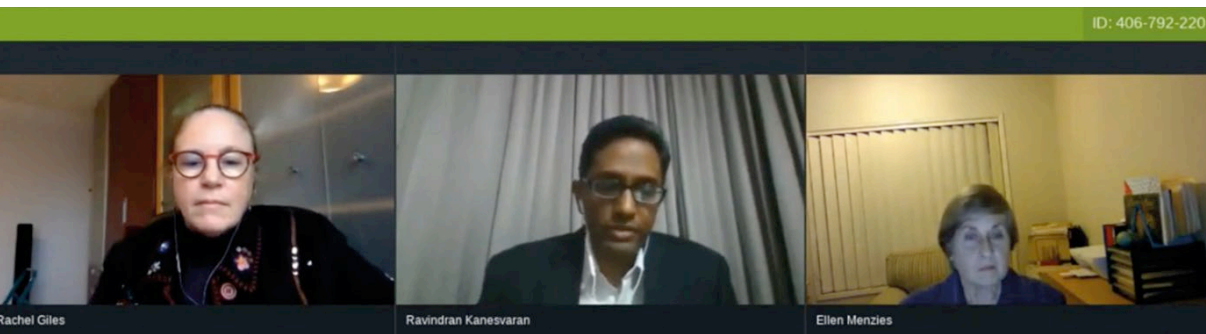
Presented by: Patricia Fischer, RN, MSN, ONC

Non Clear-Cell Type RCC

Presented by: Julia Bates, APRN, MSN, MPH







The Cecile and Ken Youner International Kidney Cancer Coalition (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.

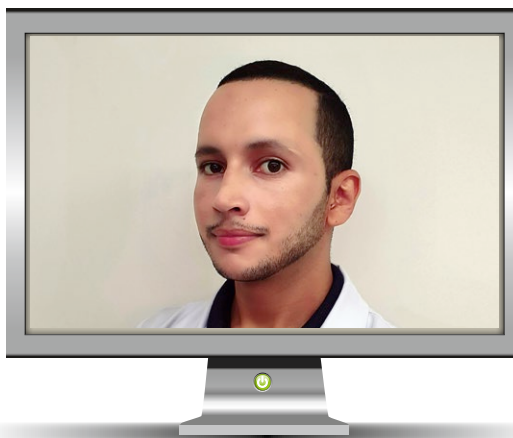
The inaugural Cecile and Ken Youner International Kidney Cancer Coalition (IKCC) Scholarship was awarded to Dr. Lewis Au, MD, FRACP (UK).

*Adriano Beserra,
A.C.Camargo Cancer Centre,
São Paulo, Brazil*

Scholarship Recipient 2020

IKCC is pleased to announce the 2020 recipient of the Cecile and Ken Youner IKCC Scholarship for 2020 is Adriano O. Beserra.

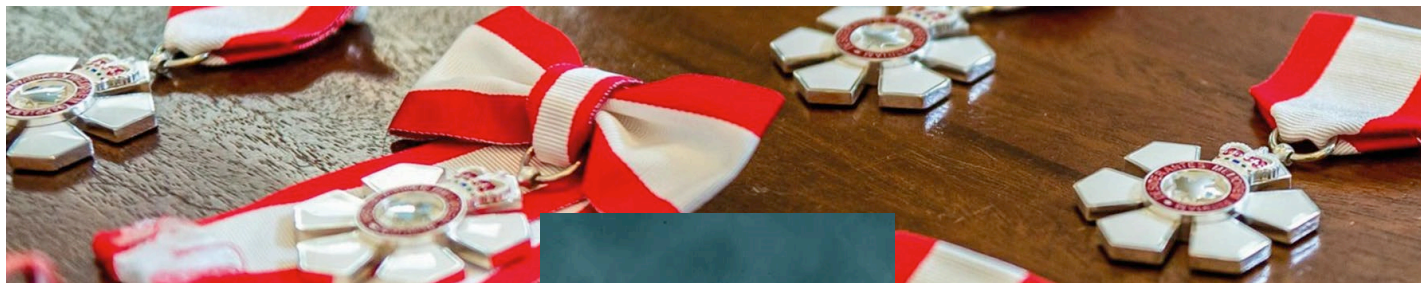
Adriano Beserra is a PhD student in oncology at A.C.Camargo Cancer Center in São Paulo, Brazil, working with xenografts of human renal cell carcinoma.



Area of Study:

Patient-derived xenografts (PDX) are an attractive experimental platform for cancer research due its capacity to capture specific characteristics in patients' tumours. A study platform was established using this model with the aims to identify therapeutic vulnerabilities. Currently, we carry out analysis of sequencing, complete exome and morphological characterization by immunohistochemistry between primary tumours and tumours generated in PDX. Preliminary results suggest that the CCR xenograft model represents an adequate tool for the study of tumour biology, once which was effective in to preserve the major characteristics of the primary tumour in the animals.

Dr Michael Jewett Appointed to the Order of Canada



The Board of IKCC and Affiliate Organisations around the world share in congratulating Dr Michael Jewett on the occasion of his recent appointment to the Order of Canada. This prestigious honour was granted in recognition of his life-saving innovations in surgical oncology and advocacy of patient-centred clinical care.

For more than two decades, Dr Jewett has demonstrated and strongly advocated for patient inclusion, adopting the *Nothing About Them, Without Them* philosophy. He has volunteered countless hours in Canada and internationally to ensure the patient voice is appropriately heard, represented, and included in healthcare decision making.

Dr Jewett is currently a Director on the Board of IKCC and Chair of its Medical Advisory Board. He also played a pivotal role in encouraging and actively supporting the creation of three national patient organisations: Bladder Cancer Canada, Testicular Cancer Canada and Kidney Cancer Canada.

Dr Jewett also currently holds the role of Co-Chair of the National Cancer Institute Renal Task Force (USA and Canada) where he has expanded the role of patient advocates and continues to foster collaboration on clinical trial design, patient-reported outcome measures, and patient-relevant research endpoints.

“Having known Michael for many years, I can attest to his role as a catalyst and a champion of improving outcomes for kidney cancer patients around the world,” said Deb Maskens, Co-Founder of Kidney Cancer Canada and Founding Board Director of IKCC.

The Order of Canada was established in 1967 by Her Majesty Queen Elizabeth II. It is the cornerstone of the Canadian Honours System and recognises outstanding achievement, dedication to the community and service to the nation.

Treasurer's Report 2020

It gives me great pleasure to present our Annual Financial Overview for 2020. The Board has worked consistently with our accounting team and auditors to deliver the audited financial statements that indicate the IKCC is in a healthy and well-managed financial position with funds appropriately allocated to projects that fulfil the IKCC mission and vision.

The impact of COVID-19 has meant that some of our regular activities have either had to be postponed or events pivoted in some areas resulting in less expenditure than initially budgeted. As a consequence, funds have been released from our reserves delivering an operating surplus of Euro 210,501 and our Balance Sheet has been further strengthened.

The ongoing support of our Sustaining Partners under challenging circumstances has ensured that the work of IKCC in supporting those with kidney cancer globally has continued and strengthened with work having been completed across a number of critical projects including delivery of our annual Global Kidney Cancer Summit, promotion of World Kidney Cancer Day and the launch of our second Global Patient Survey. We thank our Partners for your ongoing support of our critical work globally.

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

In accordance with Dutch audit law, we report the IKCC by-laws have been amended and accepted by Affiliates. The Board has designated that IKCC reserves be earmarked for the following projects in 2021 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 45,000 COVID-19: Impact on future care for kidney cancer patients
- Euro 44,000 Dashboard Project
- Euro 42,000 Global Patient Survey Communications
- Euro 39,000 Clinical Trial Retention Problems
- Euro 20,000 Decision Aid: Clinical Trials Basics

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

We thank all those who have enabled IKCC to spread its messages of courage and hope around the world. With your support, IKCC will continue to expand its reach globally in 2021 and beyond.

Anne Wilson

*Secretary-Treasurer
IKCC Board*

2020 Financial Statements

These figures are extracted from the 2020 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 2020	
CURRENT ASSETS	
Other prepayments and accrued income	€ 88,174
Liquid assets	€ 868,061
TOTAL CURRENT ASSETS	€ 956,235
CURRENT LIABILITIES	
Creditors and borrowings	€ 17,868
Accrued liabilities	€ 156,166
TOTAL CURRENT LIABILITIES	€ 174,034
NET ASSETS	€ 782,201
ACCUMULATED FUNDS	
Reserves	€ 425,709
Last year surplus/(deficit)	€ 145,991
Current year surplus/(deficit)	€ 210,501
TOTAL ACCUMULATED FUNDS	€ 782,201

Joining IKCC



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

- Has 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.
- Is recognised and/or registered as a non-profit organisation.
- Is 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.
- Is willing to work with and co-operate with other organisations having the same objectives.



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 activities of the IKCC but have no voting rights.

Please see the IKCC website for further information:

www.ikcc.org/about-ikcc/join-the-network/

New Affiliate Organisations in 2020

Portugal:

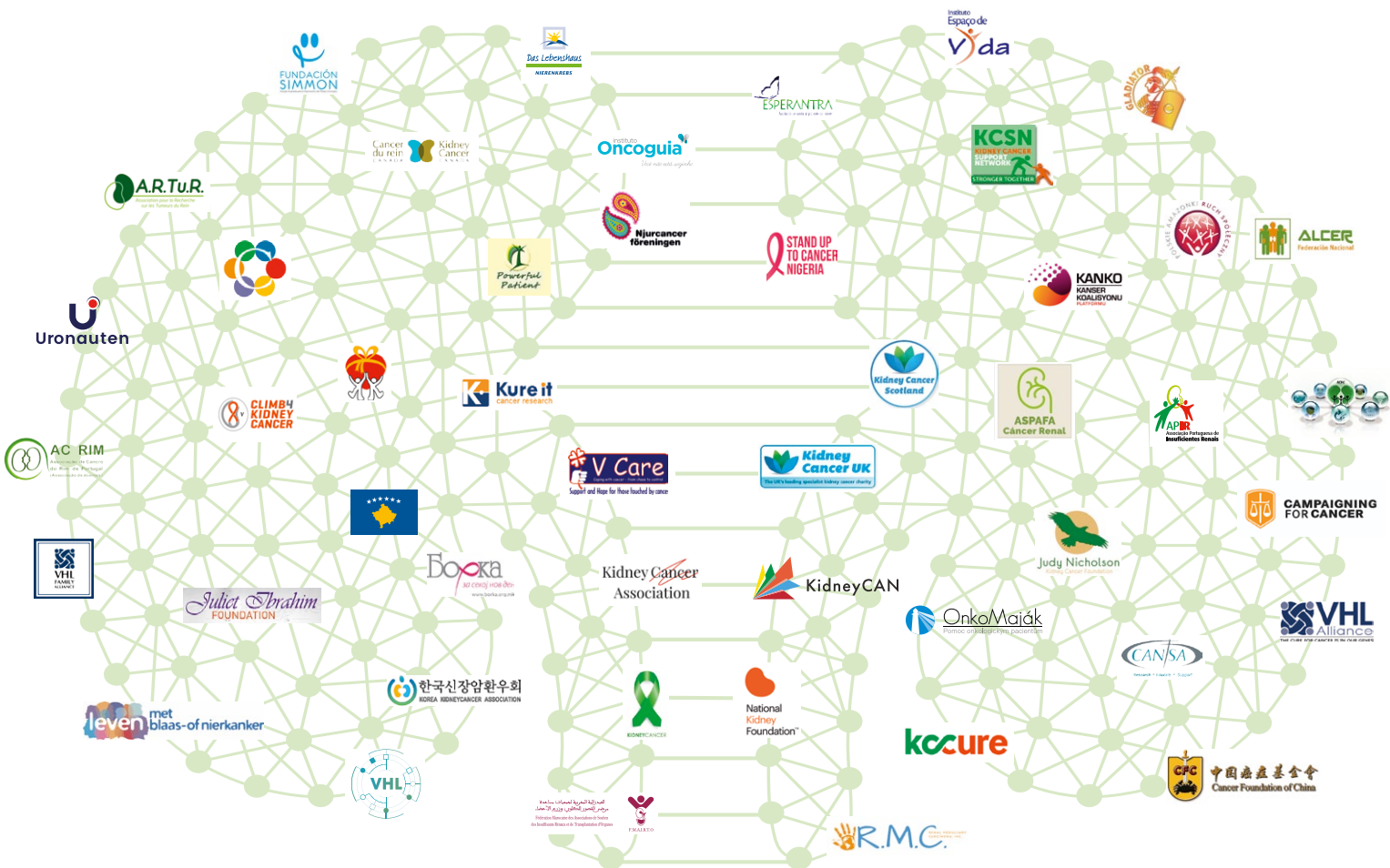
AC Rim

www.ac-rim.org

Spain:

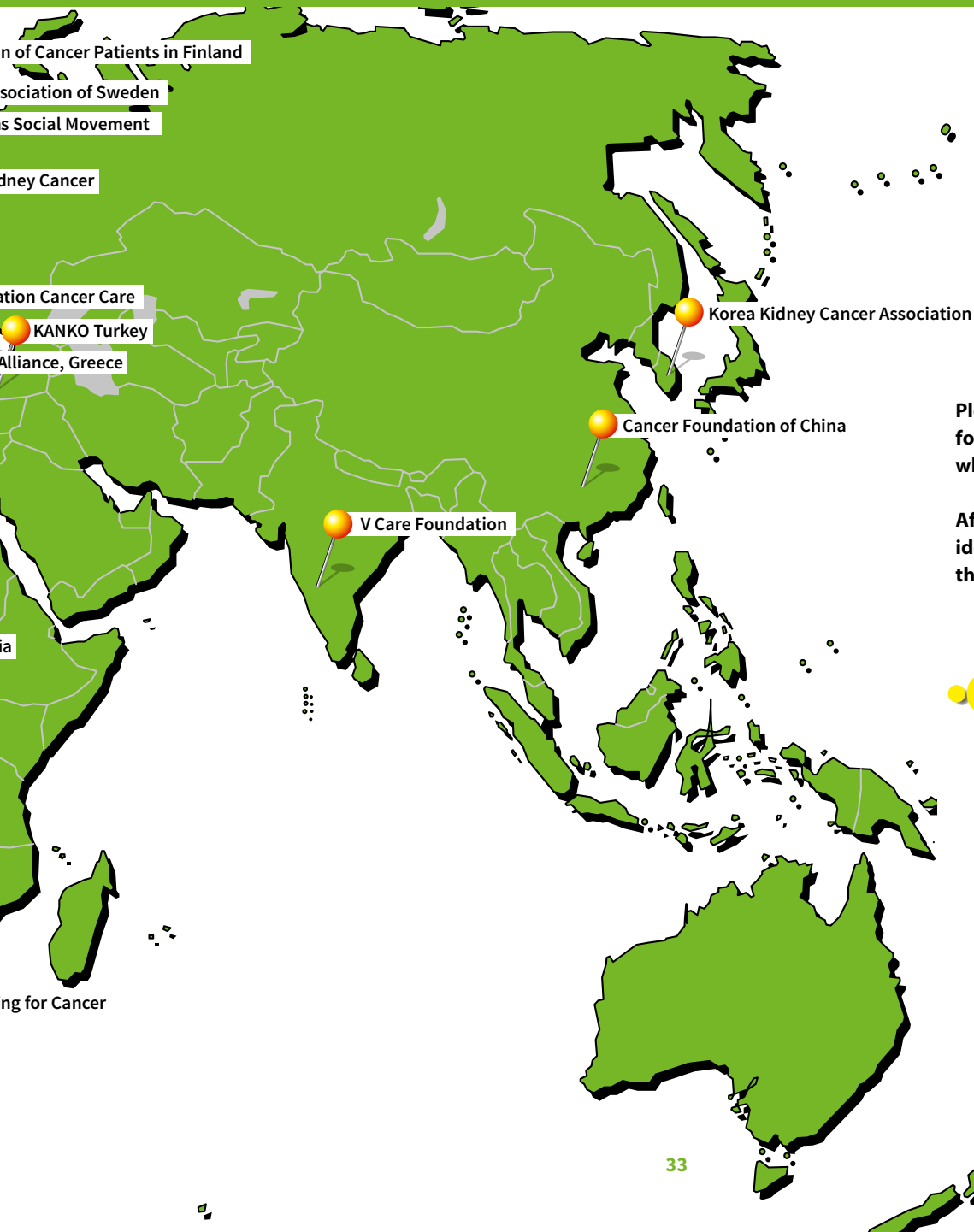
AsPaFa Renal Cancer

www.asociacion-de-pacientes-y-familiares-de-cancer-renal-2015.webnode.es/sobre-nosotros/



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 (IKCC Chair)**

**Von Hippel-Lindau
Organisation / Living with
Bladder or Kidney Cancer
Netherlands**

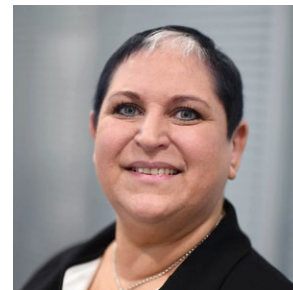
Dr Rachel Giles has experience as Associate Professor of Internal Medicine at the University Medical Center Utrecht in the Netherlands and is the Science Officer and Medical Education Specialist at Medicom Medical Publishers in Baarn, the Netherlands. She has been active in advocacy for patients with inherited kidney cancer since 2003 and has been chair of the Dutch VHL Organisation since 2009. Rachel is Chair of IKCC and represents IKCC on the EAU Guidelines Committee for renal cell carcinoma.



**BRYAN LEWIS,
J.D. (IKCC Vice Chair)**

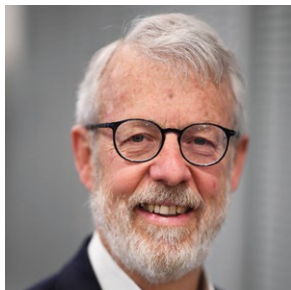
KidneyCAN, USA

Bryan Lewis has led the advocacy and Research Summit efforts for KidneyCAN (www.kidneycan.org). 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. Most recently, he helped spearhead a community effort to obtain \$50 million annually for the Kidney Cancer Research Program (www.cdmp.army.mil/kcrp/). Bryan has also been appointed to the National Comprehensive Cancer Network's Kidney Cancer Guidelines Panel and the GU Steering Committee Renal Task Force, U.S. National Cancer Institute. Previously, he held the positions of Vice President, Operations for Brand USA, and as Chief of Staff & General Counsel, U.S. Travel Association.



BERIT EBERHARDT
Uronauten e.V., Germany

Berit Eberhardt has been connected to 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 patients after her partner died. Being a cancer survivor herself, she is committed to bringing the patient perspective into various projects and publications (e.g. the German RCC guidelines and scientific publications). Berit has been involved with IKCC since 2010.



**MICHAEL A.S. JEWETT,
MD, FRCSC, FACS, CM**
Canada

Dr Michael Jewett is a Professor of Surgery (Urology) at Princess Margaret Cancer Centre and the University of Toronto. He supported the founding of Kidney Cancer Canada, and was the founding and immediate past-Chair of the Kidney Cancer Research Network of Canada. Dr Jewett was awarded the Canadian Cancer Research Alliance Award for Exceptional Leadership in Patient Involvement in Cancer Research in 2017 and made a member of the Order of Canada in recognition of his innovations in cancer surgery and support of patient-centred care. He serves as Surgical Co Chair, GU Steering Committee Renal Task Force, U.S. National Cancer Institute and holds Honorary Membership in the European Association of Urology and American Urology Association. He is a leader in academic urology, published 350+ peer-reviewed papers and is a frequent guest at international meetings and universities.



ERIC JONASCH, MD
Professor of Medicine
USA

Dr Eric Jonasch is a Professor in the Department of Genitourinary Medical Oncology at the University of Texas MD Anderson Cancer Center in Houston, Texas. He performs clinical, translational and basic research in kidney carcinoma and VHL disease. Dr Jonasch has authored over 200 articles published in peer-reviewed journals and is editor of the textbook: Kidney Cancer, Principles and Practice. Dr Jonasch has a long history of service in the kidney cancer community. He serves as Vice Chair of the National Comprehensive Cancer Network's Kidney Cancer Guideline Panel, and is a member of the GU Steering Committee Renal Task Force, U.S. National Cancer Institute.



ANNE WILSON

**Anne Wilson & Associates,
Australia**

Formerly CEO and Managing Director of Kidney Health Australia – Anne Wilson has been a member of the IKCC Board for the last four years. Since stepping down as CEO in May 2016, she has consulted to a number of not-for-profit organisations in Australia. Anne pioneered Kidney Health Australia's work in advocacy and support for Australians and families affected by kidney cancer and oversaw the development of resources, a website, telephone information service and promotion of information about access to relevant clinical trials in Australia. As a Social Worker, Anne is passionate about equitable access to service delivery and the latest and most up-to-date information about kidney cancer and patient support. Anne is Secretary/Treasurer of IKCC and has been the Board lead for the management of World Kidney Cancer Day since its inception.



ROSE WOODWARD

**Kidney Cancer Support
Network, UK**

Rose Woodward is a patient survivor of kidney cancer and a passionate and committed patient advocate. She became involved in advocacy and patients' rights in 2006 when she led the successful "Fight for Life" campaign to get kidney cancer drug treatments funded in the United Kingdom. Rose and her team manage the Kidney Cancer Support Network charity which is the UK's largest patient-led kidney cancer community working to support, inform and empower patients to become equal partners in their care and treatment. Rose is involved in clinical trials and research at various levels in the UK having served 10 years at the National Cancer Research Institute as part of the Renal and Bladder Cancer Clinical Studies Group. Rose is one of the founding volunteer members of the IKCC Board.



Recognising Deb Maskens: IKCC Founding Member, Board Vice Chair and International Patient Advocate

It is with tremendous gratitude that the IKCC Board recognises Deb Maskens for her decade-long contributions to IKCC as a Board Member as she transitions to her new role as an IKCC Ambassador.

Deb Maskens is a founding member of IKCC. She was one of the original Steering Committee members and was Vice Chair of the Leadership Team. After IKCC was incorporated, Deb served as Vice Chair of the IKCC Board from 2014 – 2019, for a total Board tenure of 10 years.

A long-time kidney cancer patient herself, she is a champion of evidence-based advocacy and including patients' values in all aspects of care and treatment. Specifically, Deb led the development and implementation of the first IKCC Global Patient Survey and helped organise many of IKCC's Global Kidney Cancer Summits.

Before her work with IKCC, Deb co-founded Kidney Cancer Canada with the late Tony Clark. Through their own experiences, they saw a significant gap in the healthcare system and created an organisation that offered much-needed support and education and advocated for access to high-quality treatments for kidney cancer. In 2016, Deb was recognised with the Meritorious Service Medal by Canada's Governor General, the Queen's representative in Canada, for her role in establishing Kidney Cancer Canada.

"The commitment and expertise Deb has brought to IKCC has been invaluable. She has encouraged us to grow and to do more for patients at every step and has helped shape IKCC into the organisation that it has become," said Dr Rachel Giles, Chair of IKCC.

Deb will remain involved with IKCC projects and collaborate as needed, and will continue her advocacy work both nationally in Canada, and internationally. The Board wishes her well on her new endeavours and thanks her for her extraordinary contributions to IKCC and its mission of improving the lives of people with kidney cancer worldwide.

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 2020 with Sustaining Partnerships and Project Sponsorships.

Sustaining Partners 2020



Project Sponsors 2020





IKCC Annual Report 2020 – Imprint:

Text:	IKCC Board and Julia Black (UK)
Graphic Design:	Herbert Thum, www.visKon.de (DE)
Photos:	Fotolia, Adobe Stock



International Kidney Cancer Coalition

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The Netherlands

Email: info@ikcc.org

Website: www.ikcc.org

www.worldkidneycancerday.org



Search for us on Facebook as: [ikcc](#)



Follow us on Twitter: [@IKCCorg](#)
[@IKCCtrials](#)

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