

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

Activity Report 2018





Content

Letter from the Board	04
IKCC Profile	06
IKCC at a Glance	08
IKCC Projects and Activities 2018 (Excerpt)	09
IKCC Conference Report 2018	21
IKCC Financial Overview	53
Joining IKCC	54
IKCC Affiliated Organisations	56
IKCC 2018 Board Members	58
Acknowledgements	62

Letter from the Board

Dear Readers, Representatives of our Affiliated Organisations, Supporters and Friends of IKCC,

Welcome to our Activity Report for the calendar year 2018. With thanks to all of you, and a dedicated Board of Directors, the International Kidney Cancer Coalition continues to grow in reach and impact with many shared accomplishments. As the global network of independent national patient organisations, we celebrate each of your individual organisations and your initiatives for kidney cancer patients in your country. Together we strive for ONE shared goal: to reduce the global burden of kidney cancer.

Each year at our annual conference, we come together as a global network to share resources, knowledge and experiences with one another, with medical experts, and with the healthcare industry. In April 2018, we met in Mexico City, Mexico. We focused on access to care, shared decision making, clinical trials, and unmet medical needs. Alongside expert medical sessions, we spent time on capacity building, on risk management for our organisations, and we brainstormed ways to improve the patient journey after surgery. You will find the Conference Report from this meeting as part of this Activity Report.

Thanks to your brainstorming efforts on awareness building from the annual meeting in 2016, we celebrated the second World Kidney Cancer Day on June 21, 2018. This year will see the third World Kidney Cancer Day on June 20, 2019, and preparations are well underway with input from a global steering group of Affiliate Organisations. See www.worldkidneycancerday.org for further information.

We continue to publish our work in medical journals, with IKCC listed as a contributing author in the medical database PubMed. In 2018 we co-authored six papers, three of which were published in the number one journal in the field of urology, European Urology, and another in the prestigious journal Nature Reviews in Urology.

- Firstly, we worked together with a group of expert patient advocates to ensure patient value is included in current and future value frameworks which we justified on compassionate and economic grounds¹.
- We also updated guidelines reflecting the newest information from a large trial which showed that patients do not always benefit from surgery (cytoreductive nephrectomy) for metastasised kidney cancer before they start systemic therapy, suggesting that surgery should be considered only after start of systemic therapy and that patients' psychological burden for poor risk disease should be taken into account².
- Because trials in patients with localised RCC had provided contradictory data as to whether better outcomes could be achieved with adjuvant VEGF-TKI therapy after surgery, we worked with the main leaders of those trials and the EAU RCC Guideline Panel to perform a pooled analysis of all the data³. The pooled data provided clear conclusions; VEGF-TKI therapy after nephrectomy for localized kidney cancer is not associated with consistent improvements in delaying cancer recurrence or prolonging life and comes at the expense of potentially significant side effects.
- We also looked at all the evidence to treat the approximately 65% of advanced kidney cancer patients that will develop bone metastases and concluded that there was very little strength in the available data, and that many patients were being treated inappropriately as a result. We then brought together the various global experts to review the evidence available and to add their "eminence-based" experience where evidence was not available to generate recommendations (as opposed to guidelines) for the management of bone metastases from kidney cancer⁴.

- Similarly, the IKCC worked with senior members of the European Association for Urology RCC Guideline Panel as well as other radiological experts to perform a systematic review of the best imaging approaches and the timing of follow-up scans for RCC⁵.
- Lastly, when the European Medicines Agency did not approve the combination of nivolumab and ipilimumab for first-line treatment of metastasised RCC, despite very promising data from the Checkmate-214 trial in intermediate and poor-risk mRCC, we collaborated with the EAU Guideline Committee to publish a letter openly challenging this decision and holding fast to evidence-based guidelines⁶. We are grateful that our advocacy efforts, combined with those of our European Affiliate Organisations, led to a reversal of this decision and prompted a follow-on clinical trial to resolve any uncertainties in risk/benefit for this treatment option.

In summary, the landscape for kidney cancer treatment is changing rapidly and it is important that the patient perspective is meaningfully incorporated in the process of adaptive care.

On an ongoing basis, through our work with the medical community, we hope to bring the patients' voice and priorities closer to the implementation of best practices for kidney cancer. We continue our work on guidelines committees, health technology assessments, and patient involvement in the design of clinical trials for kidney cancer worldwide. In 2018, we incorporated a searchable database of kidney cancer specific clinical trials that is updated daily into our website, and made this tool available to the community. Coupled with our social media campaign "Think Treatment, Think Trials!" we hope to inform our affiliates of the possibilities available to patients in many countries and simultaneously help the trials that are running meet meaningful endpoints that are useful and relevant for patients worldwide.

In 2018, we also attended a Policy Roundtable in Brussels with members of the European Parliament in a full-day discussion about the allocation of funds for promoting awareness and research in kidney cancer.

And most importantly, we continue to extend a warm welcome to every organisation that has an interest in kidney cancer. We are happy to reach out to organisations whose mission includes a focus on kidney cancer to become part of this international network. Where no group exists, we also welcome individuals who are interested in starting a kidney cancer support group or growing that expertise within an existing organisation.

With all the best wishes for a healthy 2019, on behalf of the IKCC Board of Directors

Rachel

1. Addario BJ, Fadich A, Fox J, Krebs L, Maskens D, Oliver K, Schwartz E, Spurrier-Bernard G, Turnham T. **Patient value: Perspectives from the advocacy community.** *Health Expect.* 2018 Feb;21(1):57-63.

2. Bex A, Albiges L, Ljungberg B, Bensalah K, Dabestani S, Giles RH, Hofmann F, Hora M, Kuczyk MA, Lam TB, Marconi L, Merseburger AS, Fernández-Pello S, Tahbaz R, Abu-Ghanem Y, Staehler M, Volpe A, Powles T. **Updated European Association of Urology Guidelines for Cyoreductive Nephrectomy in Patients with Synchronous Metastatic Clear-cell Renal Cell Carcinoma.** *European Urology* 2018 Dec;74(6):805-809.

3. Sun M, Marconi L, Eisen T, Escudier B, Giles RH, Haas N, Harshman L, Quinn D, Larkin J, Pal S, Powles T, Ryan C, Sternberg C, Uzzo R, Choueiri T, Bex A. **Adjuvant vascular endothelial growth factor (VEGF) targeted therapy in renal cell carcinoma: a systematic review and pooled-analysis.** *European Urology.* 2018 Nov;74(5):611-620.

4. Grünwald V, Eberhardt B, Bex A, Flörcken A, Gauler T, Derlin T, Panzica M, Dürr HR, Grötz KA, Giles RH, Falck Cv, Graser A, Muacevic A, Staehler M. **An interdisciplinary consensus on the management of bone metastases from renal cell carcinoma.** *Nature Reviews Urology* 2018; 15(8), pages 511–521.

5. Vogel C, Ziegelmeüller B, Ljungberg B, Bensalah K, Bex A, Canfield S, Giles RH, Hora M, Kuczyk MA, Merseburger AS, Powles T, Albiges L, Stewart F, Volpe A, Graser A, Schlemmer M, Yuan C, Lam T, Staehler M. **Imaging in Suspected Renal Cell Carcinoma: A Systematic Review** *Clinical Genitourinary Cancer* 2018; Aug 11, doi: 10.1016/j.clgc.2018.07.024.

6. Bex A, Albiges L, Staehler M, Bensalah K, Giles RH, Dabestani S, Hofmann F, Hora M, Kuczyk MA, Lam TB, Marconi L, Merseburger AS, Fernández-Pello S, Tahbaz R, Abu-Ghanem Y, Volpe A, Ljungberg B, Escudier B, Powles T. **A Joint Statement from the European Association of Urology Renal Cell Cancer Guidelines Panel and the International Kidney Cancer Coalition: The Rejection of Ipilimumab and Nivolumab for Renal Cancer by the Committee for Medicinal Products for Human Use Does not Change Evidence-based Guideline Recommendations.** *European Urology* 2018 Dec;74(6):849-851.

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer.

It is legally incorporated as a Foundation in 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.

IKCC is governed by a volunteer Board of Directors with members from a minimum of four countries. The Coalition is run according to democratic principles and is not bound by national, political, religious or economic interests. Organisations may apply to become Affiliate Organisations.

Together we are Stronger

Kidney cancer knows no country boundaries. We all live in a globalised world. Research and clinical trials in kidney cancer are spread across continents and many kidney cancer experts are working on international panels. By working together as patient organisations, we are able to speak as ONE VOICE to represent the perspectives, insights and experiences of kidney cancer patients from around the world. This is empowering to individual patients and also patient organisations.

We have seen from the experience of other rare cancers that this type of an international network can be very valuable, supportive and inspiring. A lot of groups and organisations, especially in rare cancers have limited capacity and resources and they embrace the opportunity to be part of a larger stronger network which allows them to share best practice, information, and to cooperate and work on similar projects.

The VALUES of IKCC

Innovative

**Culturally sensitive
(respectful)**

Ethical

**Patient
and
demo**



Patient-centred
and
democratic

Professional

Collaborative
but independent

Transparent

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

- Values are an integral part of every culture – they are central to any organisation. 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. We are:
 - Patient-centered and democratic
 - Collaborative – but independent
 - Culturally sensitive and respectful
 - Ethical and transparent
 - Professional and innovative.

Our Code of Conduct

- The International Kidney Cancer Coalition (IKCC) welcomes corporate donations, grants and sponsorship to fund certain projects and to enable the Coalition to

grow and develop. IKCC has developed a transparent and robust Code of Conduct to guide the relations between patient organisations and the healthcare industry (including their representatives and consultants).

Our Objectives

- To strengthen the capacity of current and emerging organisations in their support for patients with kidney cancer
- To advocate for access to best care
- To increase awareness of kidney cancer globally
- To be an authority in the provision of kidney cancer information
- To foster projects promoting the voice of kidney cancer patients in research activities worldwide.

Our Positioning

- A comprehensive global network of kidney cancer patient groups.
- A peer-to-peer partner with a strong and influential voice to represent the voices of kidney cancer patients worldwide.

Name:	IKCC International Kidney Cancer Coalition The Global Collaboration of Patient Groups Supporting Those Affected by Kidney Cancer. www.ikcc.org www.worldkidneycancerday.org Facebook IKCC Twitter @IKCCorg Twitter @IKCCtrials
Initiated:	September 2009
Registered:	December 2014
Legal Entity:	Foundation registered in The Netherlands under: Stichting Intl. Kidney Cancer Coalition, Reg.-No. KvK 62070665
Board Members:	R. Giles (NL) (Chair) • D. Maskens (CAN) (Vice-Chair) • B. Eberhardt (DE) • M. Jewett (CAN) • E. Jonasch (USA) • B. Lewis (USA) • E. Perdeaux (UK) • A. Wilson (AUS) • R. Woodward (UK)
Medical Advisory Board:	M. Jewett (CA) (Chair); E Joansch (USA) (Vice Chair); A. Bex (NL) D. Heng (CA), J. Larkin (UK)
Registered Office:	't Ven 30 1115HB Duivendrecht, The Netherlands
Services:	Operations Manager: Julia Black (UK) julia@ikcc.org
Collaborations:	IKCC is a proud member and participant of the following regional and international coalitions:



Projects and Activities 2018

(Excerpt)



World Kidney Cancer Day – 21 June 2018

On 21 June, 2018, together with our Affiliate Organisations worldwide, the IKCC celebrated our second official World Kidney Cancer Day. Over the past two years the impact of World Kidney Cancer Day has spread far and wide. IKCC affiliates across 29 countries have had the opportunity to participate locally in awareness raising, advocacy and activities aimed at improving knowledge of kidney cancer, its causes, treatments and challenges. Our consistent theme of Questions and Answers through “Q&A” day has shone light on the many unanswered questions related to kidney cancer and the need for more research.

Global awareness days take years to establish and become recognised worldwide. Through our combined efforts, World Kidney Cancer Day is now embedded into the World Health Calendar of events with planning for future years designed to increase access to increasing numbers of people through IKCC Affiliated Organisations, individuals and partners. Green lips have become the symbol of World Kidney Cancer Day with ever-increasing numbers of supporters posting Green Lips on social media and in local media.

Over the first two years, some 20,000 people have completed our Q & A Day Quiz in multiple languages and over 650,000 social media impressions have been measured specifically related to this awareness day.

In 2018 our worldwide campaign featured:

- Over 30 video posts of celebrities, experts, ambassadors, and organisations
- 250 press releases, radio interviews, blogs and local social media
- Global media shared in 8 languages
- Fundraising events and challenges
- Patient education events
- Food sales including green jelly beans, kidney-shaped biscuits, and one green lips cake-baking event
- Fabulous photo sharing of supporters in green lips, green nails and green hair!

We are thrilled with the creative approaches to raise awareness in each country under our common umbrella of World Kidney Cancer Day.

Beyond awareness raising, our advocacy in Europe resulted in a European Roundtable meeting held in Brussels with members of the European Parliament.

The IKCC thanks all of our official World Kidney Cancer Day sponsors for supporting our campaign in 2018:

Gold Sponsors: BMS, Novartis, Pfizer

Silver Sponsors: Exelixis, Ipsen

Bronze Sponsors: Roche



World
Kidney
Cancer

Q&A Day

21 June
2018



KCC shared a post.
Published by Rose Housheer on June 19 at 9:07 AM

More coverage from the Korean Kidney Cancer Organization for the 2nd World Kidney Cancer Q&A Day on Thursday 21st June. Thank you so much for sending this mail and see how great in the T shirts. I am sure they caught everyone's attention. Thank you from everyone here at the KCC for supporting what will be a very important day for kidney cancer patients everywhere. <http://tkcancer.or.kr/>



World Kidney Cancer Q&A Day
June 19 at 7:11 AM



Global Patient Survey

At our Annual Conference in 2018, the International Kidney Coalition (IKCC) offered our Affiliate Organisations the opportunity to participate in our first-ever Global Patient Survey. The purpose of the global survey is to improve our collective understanding of patient experiences worldwide, look for best practices, and to empower patient organisations with information they can act upon.

Initially we had planned to survey 5 or 6 countries, but we were astounded with the tremendous interest and enthusiasm. The project was expanded to include the preparation and distribution of surveys to patients with kidney cancer and their caregivers in 14 languages (including English UK & US, French and Canadian French, Portuguese and Brazilian Portuguese), through 30 of IKCC's Affiliate Organisations and social media, resulting in responses from 43 countries around the world. We are grateful to the many patient organisations worldwide who stepped up to review translations and promote the survey online. Thanks to your efforts, we achieved almost 2,000 survey responses! To the best of our knowledge, this makes our first survey the largest survey of kidney cancer patients ever conducted!

A professional data analysis agency has prepared a Global Report that highlights geographic variations in patient education, experience and awareness, access to care, quality of life, and their involvement in clinical trials and shared decision making. Nine countries with a minimum of 100 responses have also received a detailed report of their findings, including comparison to global data. Countries with 30-99 responses have also received summary charts of responses as directional findings.



We look forward to sharing the key findings of our 2018 Global Patient Survey at our 2019 Conference and in various presentations and publications to come.

Going forward, our intent is that we will conduct a global survey every two years so that together we can identify best practices, monitor trends, and explore topics of special interest to our Affiliate Organisations, both within country and on a global basis. We look forward to your feedback and hope that you will join us in the next Global Survey in 2020!



Top countries in our global #kidneycancer patient survey currently include France, India, Japan, South Korea, UK, and USA. 11 languages. 1 challenging cancer for all. Add your voice: bit.ly/Survey-IKCC



"Today is the last day to complete our first-ever Global Patient Survey. Thanks to the more than 1,600 patients and caregivers who responded!" <http://bit.ly/Survey-IKCC> #kidneycancer

05.30 - 28. Sep. 2018

1 Retweet · 4 „Gefällt mir“-Angaben
1 HeartConnectEurope @HeartC... · 1st October 2018



Almost 1600 patients and caregivers have completed our global #Kidneycancer survey! Add your voice by October 15: <http://bit.ly/Survey-IKCC>.



Survey: What barriers (if any) have you experienced in receiving quality treatment for your #Kidneycancer?



IKCC Global #KidneyCancer Patient Survey @IKCCOrg

IKCC.ORG

Global Patient Survey

Together with 26 patient organisations around the world, the IKCC is...



¿Eres cuidador de un paciente con #CáncerdeRiñón? Ayúdanos a conocer las carencias que enfrentas. <http://bit.ly/IKCC-Survey>

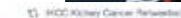


Patients with rarer cancers like #Kidneycancer face unique challenges throughout the world. Complete our Global Patient and Caregiver Survey to highlight the real world experiences of patients. bit.ly/Survey-IKCC. #Kidneycancer #GlobalCancer #2018IKCC



RareCancersAustralia at Cancer Australia

4 · 3



Ünaufrufen (Übersetzen) - 30 Sep 2018

Die 1. globale Umfrage für Nierenkrebs-Patienten ist noch bis zum 15.10. offen. bit.ly/Nierenkrebs_Umfrage... Bitte unterstützt diese Initiative der @IKCCOrg - auf der Konferenz der DGHG haben wir alle Anwesenden gebeten diese Umfrage an Ihre Nierenkrebs-Patientin weiterzuleiten.

Global Patient Survey

• Bis zum 15.10. läuft die erste globale Nierenkrebs-Patienten-Umfrage!



• Zusammen mehr erreichen - 2018erpatienten - 1 Sprache - 1 Hashtag

• http://bit.ly/Nierenkrebs_Umfrage



Scan me



Deb Maskers @DebMaskers - 24 Sep 2018

Pleased to report that we've well over 1,000 responses now to our Global #KidneyCancer patient survey. There's still time to be included in this 1st-ever global view of patient/survivor experiences. 11 languages. Thanks for RTs. [@ikccorg](https://www.instagram.com/ikccorg/) @anoreu @EUPatient #PatientExperience



IKCC Kidney Cancer @IKCCOrg

Take our survey: How involved were you in deciding your treatment plan with your doctor? bit.ly/Survey-IKCC #Kidneycancer

4 · 3

Addressing an Evidence Gap: What is the Value of Patient Advocacy on Patient Outcomes?

As an international coalition focused on reducing the global burden of kidney cancer through patient organisations worldwide, we believe that patients derive clear benefits by being connected to patient organisations to receive information, education, and assistance in navigating their care pathway. Collectively we believe these patients have improved quality of life and quite possibly that their engagement leads to improved clinical outcomes. That said, outside of the strongly held views of the patient advocacy community and evidence of psychosocial benefit, there is little evidence in the cancer literature that supports the quantitative outcome benefits of engaging and activating patients. In short, to much of the clinical community, there is no ‘Kaplan-Meier survival curve’ type data to show that the interventions from patient organisations to encourage engagement leading to patient activation, make a clear difference to overall and progression free survival quantitative outcomes. A clinician practicing evidence medicine might therefore ask why refer a patient to a patient organisation?

While to patient organisations our value might seem self-evident, we believe that studying and reporting evidence of impact could make a tremendous difference with policy makers, government bodies, industry, and clinicians globally. Evidence will support further acceptance of patient organisations, both in developed and developing countries, and support their role in helping patients achieve the best outcomes possible. For example, with evidence of interventional value in improving patient outcomes, in some countries patient organisations may then be able to seek national/regional government funding, influence research allocations, instigate policy and guideline changes, as well as generating valid metrics to convince individual clinicians of the value of referring their patients to their local patient organisation.

Our “Value of Patient Engagement” Research Project

The IKCC Project Team began with a literature review and meetings with survivorship experts and academics focusing on patient activation, engagement, and health behaviour change. We have reviewed examples of clear benefits of referrals to patient organisations for education, rehabilitation, survivorship care in other chronic disease areas such as diabetes, cardiac care, and mental health conditions. Our literature review found few parallels in cancer.

Key Terms

- **Patient Engagement** = “actions people take for their health and to benefit from care”
- **Patient Activation** = “understanding one’s own role in the care process and having the knowledge, skills, and confidence to take on that role”

Judith Hibbard et al. Health Affairs. 2013;32



**Kidney Cancer:
My Treatment,
My Choice
Decision Aid**



Key Questions:

- Does *'increased' patient engagement + 'increased' patient activation = improved patient outcomes?*
- What roles do patient organisations play in this process?

Together with researchers in Italy, Canada and the United States, we have begun a multi-year project that will include a mapping of the different kinds of interventions that can be used to engage patients with cancer – with a special focus on outcomes related to patients with kidney cancer.

The first findings will be presented at our annual Conference on April 4, 2019 with our first report to be submitted for publication by October 2019. After developing a clear map of the various patient engagement interventions reported by the scientific literature, in 2019 we will investigate whether those specific interventions have been shown to impact the clinical as well as the psychosocial outcomes of cancer patients. Finally, this project will shed light on the role of cancer patient organisations in enhancing patient engagement/activation and clinical outcomes.

Refreshed! Our Website Now Features an E-Atlas and InfoHub

E-Atlas

Did you know? The IARC (International Agency for Research on Cancer <https://www.iarc.fr/>) updated its global statistics for all types of cancer in 2018. We were quick to seize the opportunity to share the kidney cancer data for all countries reported in this GLOBOCAN database.

The IKCC E-Atlas is the beginning of a global resource we plan to build upon to collect and share information about kidney cancer information, resources, trials, and patient organisations in every country.

Please take a look for your country on the map – and then explore other countries. There are many countries yet where we have not identified patient organisations. We aim to build on this data to help patients find quality care for kidney cancer in their country or region.

In 2019, our focus region for greater exploration will be Latin America to see how much information about kidney cancer care and support for patients in each country we can provide. We look forward to partnering with LARCG (Latin American Renal Cancer Group) to further this work!

The image displays two screenshots of the IKCC E-Atlas website. The top screenshot shows a world map with Brazil highlighted in blue. A pop-up window titled "Kidney Cancer in Brazil" is overlaid on the map, displaying the following data:

Kidney Cancer in Brazil			
Overview	Clinical Trials	Patient Organisations	Discovery
Incidence			
Age-standardised rate of kidney cancer (per 100,000 persons per year) (2018)			
Men	3.3		
Women	2.2		
Men & Women	4		
Mortality			
Age-standardised kidney cancer death rate (per 100,000 persons per year) (2018)			
Men	2.2		
Women	1		
Men & Women	1.6		
Prevalence			
Estimated number of prevalent kidney cancer cases (prevalence per 100,000 per year) (2018)			
Estimated Prevalence (0 year)			
Prevalence is defined as the number or percent of people who live in a population who previously had a diagnosis of the disease. It includes new incident and pre-existing cases and is a function of both past incidence and survival.			

The bottom screenshot shows the "Patient Organisations" section for Brazil, listing several organizations:

- IKCC Affiliate Organisations**
- Instituto Espanol de Nefrologia (Instituto de Nefrologia)**
- Instituto Brasileiro de Nefrologia (IBN)**
- Instituto Brasileiro de Nefrologia (IBN)**
- Associação Brasileira de Nefrologia (ABN)**
- Associação Brasileira de Nefrologia (ABN)**
- Associação Brasileira de Nefrologia (ABN)**

Other Organizations section includes a link to "Other Organizations" and a note: "We are not aware of any other organizations serving kidney cancer patients in this country. Please refer to our global network to identify affiliate organizations (listed by other in our global network)." and "If you are aware of an organization that serves kidney cancer patients in this country please send the organization's details to: info@ikcc.org."

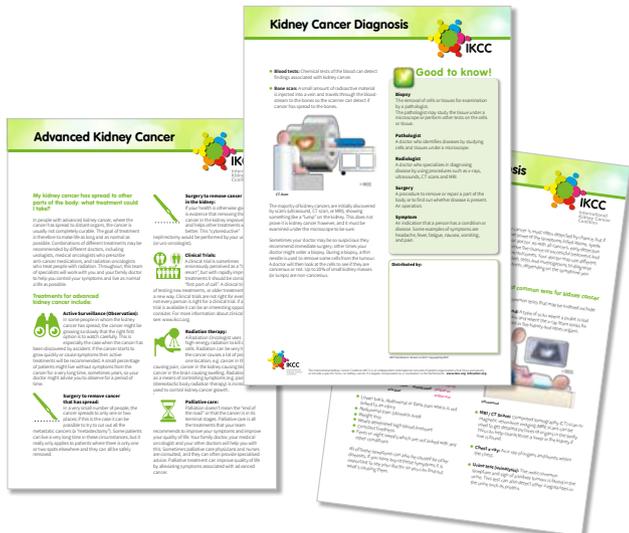
IKCC InfoHub

Do you need illustrations of kidneys? Of stages of kidney cancer? Of surgical procedures?

Please feel free to use, adapt, and translate any of the graphics or texts in the IKCC InfoHub of shareable information. We ask only that you cite the original graphic was courtesy of IKCC. There is no charge and no delay in getting these to you in the formats you need.

If your country or organisation needs some quick Fact Sheets about kidney cancer, please feel free to download, translate, and put your own organisation's logo at the top!

The entire idea of the InfoHub is to share what we have. If you're looking for something that's not there, please let us know and perhaps we can make it available for everyone.



Step 1

Before treatment	Yes (1) / No (0)
Time from initial diagnosis to treatment < 1 Year	1 / 0
Karnofsky Performance Score (KPS) < 80%	1 / 0
Low Hemoglobin < LLN	1 / 0
High Calcium > 10mg/dL	1 / 0
High Platelet > ULN	1 / 0
High Neutrophil > ULN	1 / 0
Total	

Step 2

Favourable Risk	0
Intermediate Risk	1 - 2
Poor Risk	≥ 3

Step 3



About IMDC Risk Categories
75-80% of patients selecting 1st line mRCC treatment options have at least 1 of these risk factors, therefore classifying their mRCC as intermediate/poor risk. Risk classification may change over time and may help in selecting treatments such as immunotherapy.

Legend: KPS = Karnofsky Performance Score (e.g., are cancer symptoms affecting normal activities?)
LLN = Lower Limit of Normal
ULN = Upper Limit of Normal
IMDC = International Metastatic Renal Cell Carcinoma Database

© IKCC = International Kidney Cancer Coalition, www.ikcc.org

Search for us on Facebook as: ikcc
Follow us on Twitter: @IKCCtrials @IKCCorg

Supporting Clinical Trials for Kidney Cancer Worldwide

The IKCC remains firmly committed to shaping research priorities so that they are based upon real patient and carer priorities and the unmet medical needs of real-world patients with kidney cancer globally. We are pleased to be involved early in the design of many clinical trials to ensure they are patient-focused, and will deliver results that matter most to patients and carers, but also to governments and healthcare agencies who play a role in the adoption of new therapies.

Well-designed clinical trials can offer patients the opportunity for expert care and monitoring while moving kidney cancer treatments for all other patients forward. But... finding an appropriate clinical trial for a patient at the right moment can be challenging in any country!

Many IKCC Affiliate Organisations keep track of clinical trials in their own country. However, this can often be an enormous task for small, resource-limited organisations or for those whose mission is to support a wider range of disease conditions. To meet that need, we are pleased to offer our automated Country Reports that list all clinical trials for kidney cancer in the selected country. Trial information is updated every 24 hours from www.clinicaltrials.gov

Country Reports

The IKCC Clinical Trials database (<https://ikcc.org/clinical-trials-search/>) can help organisations assist patients in navigating the ever-changing landscape of clinical trials. For example, to find all trials for kidney cancer patients in Poland, you can export a Microsoft® Excel or PDF document listing just those trials that are currently recruiting in Poland. The trials listed will be all those that meet all of our linguistic search terms, have at least one clinical trial site in Poland, and are currently recruiting patients.

The screenshot displays the 'Clinical Trials Search' interface. At the top, there is a green header with the text 'Clinical Trials Search'. Below this, a white box contains introductory text: 'Clinical trials are research studies that test the idea that a new treatment or other healthcare intervention is better than the existing drug or practice. Keeping track of ongoing clinical trials for kidney cancer in each country can be a difficult task for patient organisations. The IKCC clinical trials database lists the majority of clinical trials available worldwide that are focused on kidney cancer. Information in this database is automatically updated daily and reviewed weekly.' Below this text, there is a section titled 'About the clinical trials database' with a 'Disclaimer' link and the text 'Last updated: February 28, 2019'. The main interface features three tabs: 'Search', 'Reports', and 'Results'. Under the 'Reports' tab, there is a 'Country' dropdown menu with a list of countries, including Algeria, Argentina, Australia, Austria, Belgium, Bosnia and Herzegovina, Brazil, Bulgaria, Cameroon, Canada, Chile, China, Colombia, Croatia, Czech Republic, Denmark, Ecuador, Egypt, and Ethiopia. To the right of the country list, there is a 'Type of kidney cancer (per pathology report)' dropdown set to 'all kidney cancer subtypes', a 'Status of trials' dropdown set to 'recruiting', and a 'Phase of trials' dropdown set to 'all phases'. The interface is clean and user-friendly, with a green and white color scheme.

Study Results Javelin Renal 101

A study of avelumab with axitinib versus sunitinib in advanced renal cell cancer

source : www.esmo.org/Press-Office/Press-Releases/Javelin101-renal-cancer-immunotherapy-Motzer



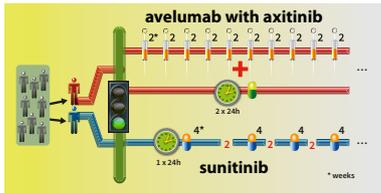
886
Patients



273
Trial Sites



Trial Design



Objective Response Rate (ORR)



Patients with PD-L1+ tumours



Progression Free Survival (Median PFS)



Patients with PD-L1+ tumours



Complete Response (CR)



Patients with PD-L1+ tumours

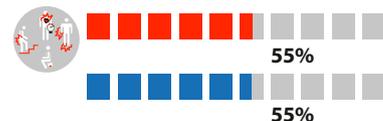


Overall Survival (OS)



Side Effects

Grade 3 or Grade 4



© IKCC = International Kidney Cancer Coalition, www.ikccc.org, www.10for10.org

* Overall Survival Data Has Not Yet Matured



Share our Infographics

When major trials report, our infographics help explain key findings in a neutral, consistent, visual language that helps highlight progress in patient-relevant endpoints such as Progression Free Survival, Overall Survival, and Side Effect Profile. To see our most recent study infographics, visit the IKCC InfoHub here: <https://ikcc.org/infohubpost/graphic-trial-results/>

Note that all text visuals in the InfoHub are available for your use. A very popular infographic in 2018 was our visualisation of IMDC Risk Classification to illustrate the differences between Favourable, Intermediate, and Poor Risk disease characteristics of metastatic RCC. The IMDC Infographic is already available in English, French, and German.

Understanding IMDC Criteria for Metastatic RCC (Heng criteria)

Step 1

Before treatment	Yes (Y) / No (N)
Time from last diagnosis to treatment	< 1 Year / 1 / 0
Hemoglobin	> 10g/dL / 1 / 0
Performance	> 80% / 1 / 0
Neutrophils	< 1000/mm ³ / 1 / 0
Platelets	> 150,000/mm ³ / 1 / 0
High lactate	< 1.5 mmol/L / 1 / 0
High bilirubin	< 1.5 mg/dL / 1 / 0
High creatinine	< 1.5 mg/dL / 1 / 0
High hemoglobin	> 15g/dL / 1 / 0
High neutrophils	> 1500/mm ³ / 1 / 0
High platelets	> 400,000/mm ³ / 1 / 0
High lactate	> 1.5 mmol/L / 1 / 0
High bilirubin	> 1.5 mg/dL / 1 / 0
High creatinine	> 1.5 mg/dL / 1 / 0
Total	0-9

Step 2

Risk Categories	Score
Favourable Risk	0-3
Intermediate Risk	4-6
Poor Risk	7-9

Step 3

Treatment Selection

About IMDC Risk Categories
Y: Yes or partial response to prior IMDC treatment options have an impact on these risk factors. Hemoglobin, neutrophils, platelets, lactate, bilirubin, creatinine, and performance may change over time and may help in selecting treatment such as immunotherapy.

Legend: Y/N = Karnofsky Performance Scale; LLN = Lower limit of normal; ULN = Upper limit of normal; IMDC = International Metastatic Renal Cell Carcinoma Database

© IKCC = International Kidney Cancer Coalition, www.ikccc.org

Search for us on Facebook or on Twitter. Follow us on Twitter. @IKCC @IKCC

Comprendre les critères de l'IMDC pour le carcinome métastatique à cellules rénales (critères de Heng)

Étape 1

Avant le traitement	Oui (O) / Non (N)
Temps écoulé depuis le dernier diagnostic	< 1 an / 1 / 0
Hémoglobine	> 10 g/dL / 1 / 0
Performance	> 80% / 1 / 0
Neutrophiles	< 1000/mm ³ / 1 / 0
Plaquettes	> 150 000/mm ³ / 1 / 0
High lactate	< 1,5 mmol/L / 1 / 0
High bilirubin	< 1,5 mg/dL / 1 / 0
High creatinine	< 1,5 mg/dL / 1 / 0
High hemoglobin	> 15 g/dL / 1 / 0
High neutrophils	> 1500/mm ³ / 1 / 0
High platelets	> 400 000/mm ³ / 1 / 0
High lactate	> 1,5 mmol/L / 1 / 0
High bilirubin	> 1,5 mg/dL / 1 / 0
High creatinine	> 1,5 mg/dL / 1 / 0
Total	0-9

Étape 2

Catégories de risque	Score
Groupes à faible risque	0-3
Groupes à risque intermédiaire	4-6
Groupes à risque élevé	7-9

Étape 3

Sélection du traitement

À propos des catégories de risque de l'IMDC:
Y: Oui ou réponse partielle à un traitement antérieur. L'hémoglobine, les neutrophiles, les plaquettes, le lactate, le bilirubine, la créatinine et la performance peuvent changer au fil du temps et peuvent aider à sélectionner un traitement tel que l'immunothérapie.

Légende: O/N = Karnofsky Performance Scale; LLN = Limite inférieure de la normale; ULN = Limite supérieure de la normale; IMDC = International Metastatic Renal Cell Carcinoma Database

© IKCC = International Kidney Cancer Coalition, www.ikccc.org

Search for us on Facebook or on Twitter. Follow us on Twitter. @IKCC @IKCC

Die IMDC-Kriterien für das metastasierte Nierenzellkarzinom verstehen (Heng Kriterien)

Schritt 1

Vor der Behandlung	Ja (J) / Nein (N)
Zeit seit dem letzten Diagnosezeitpunkt	< 1 Jahr / 1 / 0
Hämoglobin	> 10 g/dL / 1 / 0
Leistungsfähigkeit	> 80% / 1 / 0
Neutrophile	< 1000/mm ³ / 1 / 0
Thrombozyten	> 150 000/mm ³ / 1 / 0
High lactate	< 1,5 mmol/L / 1 / 0
High bilirubin	< 1,5 mg/dL / 1 / 0
High creatinine	< 1,5 mg/dL / 1 / 0
High hemoglobin	> 15 g/dL / 1 / 0
High neutrophils	> 1500/mm ³ / 1 / 0
High platelets	> 400 000/mm ³ / 1 / 0
High lactate	> 1,5 mmol/L / 1 / 0
High bilirubin	> 1,5 mg/dL / 1 / 0
High creatinine	> 1,5 mg/dL / 1 / 0
Summe	0-9

Schritt 2

Risikoklassen	Score
Gute Prognose	0-3
Intermediäre Prognose	4-6
Schlechte Prognose	7-9

Schritt 3

Wahl der Behandlung

Zu den IMDC-Risikogruppen:
Y: Ja oder partielle Antwort auf eine frühere IMDC-Therapie. Hämoglobin, Neutrophile, Thrombozyten, Laktat, Bilirubin, Kreatinin und die Leistungsfähigkeit können sich über die Zeit ändern und können bei der Wahl der Behandlung, wie zum Beispiel einer Immuntherapie, hilfreich sein.

Légende: J/N = Karnofsky Index; LLN = Limite inférieure de la normale; ULN = Limite supérieure de la normale; IMDC = International Metastatic Renal Cell Carcinoma Database

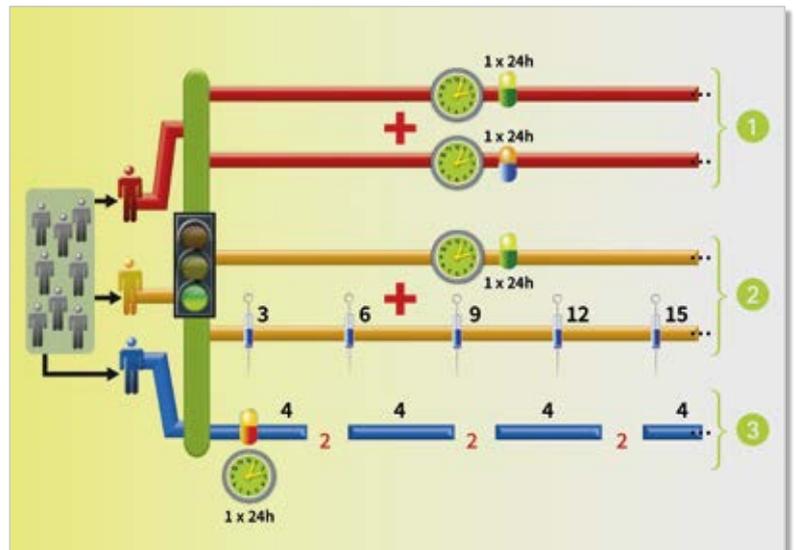
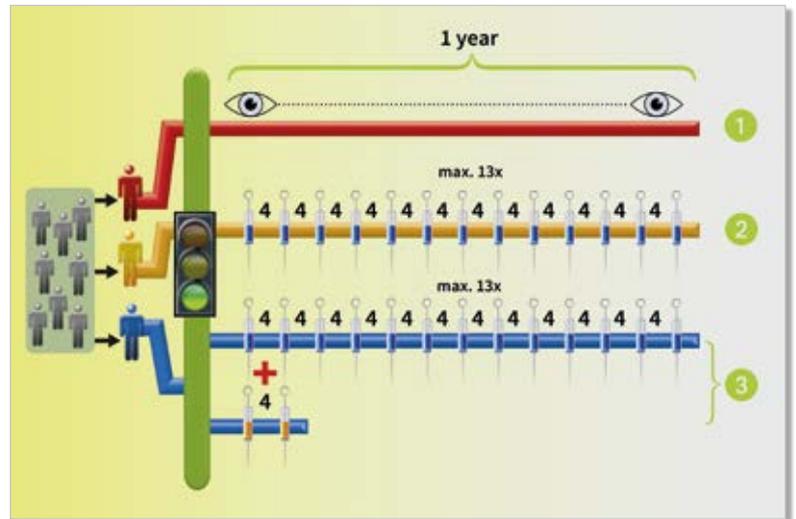
© IKCC = International Kidney Cancer Coalition, www.ikccc.org

Search for us on Facebook or on Twitter. Follow us on Twitter. @IKCC @IKCC

New Trials

As major trials open, the IKCC develops a patient-friendly summary and visual schematic to show how the trial has been designed. Patient organisations can use, adapt, and translate these materials as necessary. For example, the RAMPART clinical trial (Renal Adjuvant Multiple Arm Randomised Trial) aims to recruit 1750 patients worldwide. Patients can inquire about this trial or others before or immediately after surgery (nephrectomy) for kidney cancer.

Phase 3 clinical trials are often global in nature and offer an important opportunity for patients worldwide. One example of a truly global clinical trial is the CLEAR Phase 3 trial for metastatic kidney cancer patients who have not had any prior treatments. This study is recruiting over 1,000 patients across 217 sites in the following countries: Australia, Austria, Belgium, Canada, Czechia, France, Germany, Greece, Ireland, Israel, Italy, Japan, South Korea, Netherlands, Poland, Russia, Spain, Switzerland, UK and USA.





8th

**International Conference
for Organisations
Representing Patients with Kidney Cancer
12th – 14th April 2018
Crowne Plaza Hotel De Mexico,
Mexico City, Mexico**

Conference Report

DAY 1 - Thursday 12th April 2018



Welcome to the 8th IKCC Expanding Circles in Supporting Kidney Cancer

Dr Rachel Giles (NL), Carlos Castro Sanchez, Asociación Ale IAP (MX)

Patient perspective: Herrera Tayo

The IKCC welcomed over 50 patient advocates from 25 countries and 6 continents to the 8th Expanding Circles Conference in Mexico City. We were pleased to have new participants from Latin America and to offer our conference for the first time with simultaneous translation in Spanish. Other delegates travelled from as far away as Australia, Ghana, India and South Africa. Following last year's focus on Eastern Europe, this year's conference highlighted the particular issues for kidney cancer patients in Latin America.

Carlos Castro Sanchez represented the local affiliate organisation in Mexico, Asociación Ale IAP. His organisation hosted a breakfast meeting for health officials in Mexico to bring attention to the plight of kidney cancer patients, and to bring together urological, oncological, and government representatives along with patient representatives.



The opening of our conference brought together clinical experts from a parallel meeting organised by LARCG (Latin American Renal Cancer Group) and offered the opportunity for clinicians and patient advocates to co-present, co-mingle and foster collaboration.

Opening our IKCC conference, Dr Giles introduced the interdisciplinary format and our commitment to patient-centricity in the joint program. Mr Sanchez then introduced Mr. Herrera Tayo, a patient from Mexico, who shared his experience with the diagnosis and treatment of type 2 metastatic papillary renal cell carcinoma (pRCC).





Keynote Address 1: Closing the cancer divide: An equity imperative in expanding access to cancer care and control to developing countries

Dr Felicia Marie Knaul (USA/MX)

Moderator: Dr Rachel Giles (NL)

The first keynote address came from internationally renowned global cancer researcher, Dr Felicia Marie Knaul, a health economist and professor at the University of Miami, with dual residence in Mexico and the USA. Dr Knaul shared her perspectives on reducing fundamental disparities in cancer care and expanding access to affordable and achievable cancer care in developing countries. Dr Knaul suggested that it is both necessary and appropriate to review current access to treatments, since cancer deaths continue to rise. With global collective action to reduce the price of treatments, and financial coverage schemes such as Mexico's Seguro Popular, cancer treatment can be affordable and possible. Her most important take-home message to IKCC delegates was that we need both 'evidence-based advocacy' and 'advocacy-inspired evidence'.



Controversies in kidney cancer: Clinician and patient advocate perspectives

Moderator: Deb Maskens (CA)

1. Active surveillance: is there a role for watching small renal masses?

Clinician: Dr Michael Jewett (CA)

Patient advocate: Dena Battle (USA)

Dr Jewett reviewed the management of small renal masses (SRMs), RCC tumours less than 4cm and stage T1a and presented the rationale for active surveillance. Most SRMs are detected asymptotically, do not metastasise, and 20-30% are not RCC. Mortality due to SRMs is stable, despite an increasing incidence of stage T1 RCC tumours being detected on imaging. Active surveillance or ablation of SRMs is recommended for older patients with comorbidities to reduce the impact of surgery, especially where the SRM is slow-growing. Dr Jewett cited studies recommending needle biopsy to characterise and grade SRMs, and to help to determine treatment options.

DAY 1 - Thursday 12th April 2018



Patient advocate Dena Battle presented the patient and caregiver perspective on the use of active surveillance given that biopsy is not routinely used and that many patients are in fact fearful of renal tumour biopsy. Over time, the majority of renal masses do grow and most are malignant, so patients are understandably anxious regardless of the size of the tumour. Patients are very stressed when diagnosed with cancer and many cannot live with the ongoing anxiety. Without adequate information and counselling, patients don't feel safe. They want to actively fight the disease and find it difficult to wait without having active treatment. Overall, patients need better techniques to identify benign from malignant tumours, and better ways to reassure patients to reduce anxiety.



2. Should a partial nephrectomy always be the goal?

Clinician: Dr Fernando Gabilondo Navarro (MX)

Patient advocate: Hans Hofman (NL)

Dr Navarro spoke about radical nephrectomy as the traditional approach for the treatment of RCC; however, there are risks, such as chronic renal disease, stroke and cardiovascular impairment. Partial nephrectomy requires more technical knowledge and is more complex than radical nephrectomy. The location and size of the tumour are important, and partial nephrectomy needs careful planning to avoid renal damage from ischaemia. However, the use of partial nephrectomy is increasing as technical knowledge increases.





For the patient perspective on this topic, Mr Hofman spoke about patient anxiety regarding surgery. Patients need to be informed of all their treatment options, including the pros and cons of each option, in language that they can understand. With radical nephrectomy, the patient needs to know the implications of being left with only one kidney. With partial nephrectomy, renal function is conserved which is important for survival, but the patient might experience more surgical complications. Radical nephrectomy is a simpler operation for the surgeon, with fewer complications, shorter recovery time and faster return to work. However, many patients like the idea of only taking away the tumour, and for people with familial disease loss of an entire kidney can be very serious. Shared decision-making between surgeon and patient builds trust. The surgeon needs to listen to the preferences of the patient. This requires a different mindset for both patient and surgeon.



3. What are the current indications for adjuvant therapy in renal cell carcinoma?

Clinician: Dr Maria Teresa Bourlon (MX)

Patient advocate: Deb Maskens (CA)

Dr Bourlon explained that adjuvant therapy may be considered for localised RCC after surgery to reduce the risk of recurrence. The use of adjuvant therapy depends on the size of the tumour, the grade, and performance status of the patient. Clinical trial results with targeted therapies are not conclusive (ASSURE, S-TRAC, PROTECT). Only S-TRAC showed a benefit for intermediate-high risk patients with sunitinib. However, cost-benefit and risk-benefit for targeted therapies in the adjuvant setting need to be carefully considered. Adjuvant therapy using TKIs is not indicated. Immunotherapy is currently being assessed in the adjuvant setting for RCC.



DAY 1 - Thursday 12th April 2018



Ms Maskens added a patient perspective to this topic noting that RCC patients do indeed want adjuvant therapy, but only one that has shown clear benefit to overall survival. Currently, the standard of care for patients after nephrectomy for stage 1-3 RCC in most of the world is close observation. In the USA sunitinib is approved as adjuvant therapy, but its use remains controversial. Clinical trials are ongoing to assess immunotherapy in the adjuvant setting. Ultimately what patients need is objective, unbiased evidence to support decision-making regarding adjuvant treatments. Patients with localised disease also need psychological support for anxiety regarding the prospect of recurrence. Risks (toxicity) and financial burden (to the individual and health care system) of current adjuvant treatment need to be considered when assessing any potential benefits.



4. Should a cytoreductive nephrectomy always be offered to patients who present with metastatic disease?

Clinician: Dr Samuel Rivera-Rivera (MX)

Patient advocate: Mike Lawing (USA)

Dr Rivera stated that while nephrectomy generally improves overall survival for RCC, the benefit is not so pronounced for patients with metastatic RCC. Cytoreduction can provide symptom relief. However, removing the primary tumour may also reduce the antigens present in the blood that stimulate the immune system to attack the cancer. Results of clinical trials are contradictory – some show benefit of cytoreduction, others show an increase in morbidity. In conclusion, patients need to be carefully selected for cytoreductive nephrectomy based on clinical characteristics and number of metastases.





As a patient advocate, Mr Lawing reminded the audience that cytoreductive nephrectomy is not always offered to patients with metastatic disease, but should be discussed so that patients are aware of the potential risks and benefits. De-bulking surgery could be beneficial for relatively fit and well patients. If patients start first with targeted systemic therapies, there is no guarantee that the tumour size will decrease and the treatment may decondition the patient from surgery at a later date. Patients will often seek a second opinion for de-bulking surgery based upon other patients' feedback and the psychological burden.



Rights of cancer patients (Latin America)

Moderator: Dr Stênio de Cássio Zequi (BR)

Dr Stênio de Cássio Zequi (BR) - clinician

All RCC patients have the right to a prompt diagnosis and fast, high quality treatment with follow-up in accordance with international guidelines. Patients should be actively involved in decision-making and informed about clinical trials. They should also be provided with survivorship information and the long-term effects of RCC, especially those with hereditary RCC. In Latin America, there is a lack of treatment options for public patients. Treatments are very expensive, and physician education is poor. Chemotherapy is still used for RCC, and few patients receive second- and third-line treatments. Access to state-of-the-art treatments is a global challenge. Cultural, socioeconomic and spiritual hurdles need to be overcome. Patient groups need to act together to improve access to treatments.



DAY 1 - Thursday 12th April 2018



Dr Marcos Paulo Falcone Patullo (BR) - lawyer

The Brazilian healthcare system is very litigious, with expenditure on health litigation having risen 800% in 5 years (to \$300m in 2015). In Brazil, healthcare is a fundamental right, and it is the duty of the state to fulfill this right. Drugs are appraised for cost-effectiveness before being recommended on the national dispensing list. Patients can successfully sue the government for access to any approved cancer medication. Judicial activism is harmful to the state healthcare budget, and makes the system inefficient and unequal. This contrasts with the culture of the British system, which is not litigious, and the courts do not interfere with public policy. In Brazil, the Supreme Court advises on policy and the public litigates to change policy. In contrast, in Colombia the Supreme Court is extremely active and determined to reformulate public policy. Colombia has one of the best universal healthcare systems in Latin America insuring more than 80% of the population.



Carlos Castro Sanchez (MX) - patient advocate

Patient advocates can help to protect the rights of patients in Mexico, such as the right to information, choice, respect, participation, confidentiality, appeals, and access to treatment, and can act to influence public health policy. Currently, 49% of Mexicans do not have access to healthcare, and only 2% have medical insurance. Advocates need to be the public voice for about 80% of the population. Patients need education to understand and use health information, and to participate in shared decision-making. This is difficult when 50% of the population lives in poverty. There is no universal health plan in Mexico. The government is focused on cost-savings and does not invest in health. The Health Ministry must coordinate efforts to reduce risk factors for cancer, use health budgets more effectively, and break health inequalities.





Management of RCC in countries with limited access to treatments and diagnostics

Moderator: Joyce Graff (USA)

Natalia Rosa, Instituto Oncoguia (BR)

Ms Rosa spoke about the provision of quality information, and the role of advocacy in protecting patients' rights. The main challenges for RCC are lack of public data (patient registries), lack of awareness about prevention and symptoms, and poor access to treatment. In Brazil, more than 50% of patients are diagnosed with advanced RCC. Oncoguia helps patients with information about treatments and diagnosis, and advocacy for access to drugs. They provide specialised information to patients and are gathering data on access to healthcare. They have prepared a guide to help RCC patients communicate with their physicians.



Vandana Gupta, V Care Foundation (IN)

More than 40% of Indian patients need to borrow money for medical care. Available records indicate that there are about 40,000 RCC patients in India (3,000 cases/year) and around 60–70% have surgery. RCC is often diagnosed late due to lack of awareness and superstitious beliefs. Treatment costs are high and 80% of the population of 1 billion is below the poverty line, 70% live in rural areas, and only 13% of the rural population has access to primary healthcare. There are cultural barriers to seeking treatment: Many feel that cancer is a punishment for wrongdoing earlier in life (karma). V Care creates awareness of RCC and provides funds for travel, medical tests, and nutritional support, and helps with documents to verify income. They can recommend specialists for second opinions, places to stay while visiting the hospital, and emotional counselling.



DAY 1 - Thursday 12th April 2018



Jin-Young Paik, Korean Kidney Cancer Association (KR)

South Korea has had a National Health System since 1989 serving 52 million people, and a national cancer-screening programme. KKCA aims to improve access to treatment for kidney cancer patients, especially for metastatic patients and the medical poor. There are only one first-line and one second-line drug eligible for reimbursement. Patients must pay up front and wait for reimbursement which can take more than a year. Their new President Moon has declared a policy to shorten reimbursement rates and times and improve care. Pharmaceutical companies help with co-payment. KKCA stresses that patient advocates must work together to achieve common goals through alliance platforms, compelling evidence, patient voice, social consensus, patient stories, and policy setting.



*Addressing the gaps:
Megan Mager, MAX Foundation (USA)*

Ms Mager spoke about improving global access to cancer treatment, care and support for people living with cancer in low and middle-income countries (LMICs). Barriers to access include lack of government reimbursement; financial constraints within the country; drug importation taxes; unlicensed drugs; affordability of drugs and tests; and limited diagnostic capability. She proposed the Max access solution model: a patient-centered system of access to oncology treatment, that includes healthcare providers, procurement, logistics and distribution, and patient support via partnerships with pharmaceutical companies. She discussed how this model has greatly increased access to targeted therapies for chronic myeloid leukaemia (CML) in LMICs. Commitment across pharmaceutical companies and across disease-specific areas is critical to the success of this model.





Keynote Address 2: DePICThealth^{RB} to support global teamwork towards ZERO (0) deaths from childhood eye cancer

Dr Brenda Gallie (CA)

The second keynote address was from Dr Brenda Gallie, Professor of Ophthalmology and Vision Sciences, Hospital for Sick Children (SickKids), Toronto, specializing in the diagnosis and treatment of retinoblastoma (RB), a childhood cancer. Dr. Gallie's presentation focused on an innovative point-of-care database platform to foster global collaboration in care for children with a rare childhood cancer retinoblastoma. The online system, DePICThealth^{RB}, is scalable for other cancers and is a model for collaborative cancer care across geographies.

Childhood retinoblastoma is very rare, and drugs have been difficult to develop. Most cases occur in countries with high birth rates (e.g., India, China). There are around 8,000 cases worldwide. In most of the world, retinoblastoma is detected at stage 4 and 70% of children die (by comparison, in North America, where retinoblastoma is detected early, only 3% die). DePICThealth^{RB} collects data from individual patients (parents) and physicians at 178 treatment centres globally, and represents this on a clinical timeline as a treatment pathway, along with diagnosis, staging, images, outcomes, and vector coordinated diagrams.



DePICThealth^{RB} enhances communication across the multi-disciplinary team including the family, GP and paediatrician to improve understanding of the treatment course, and to support life-long care. DePICThealth^{RB} also captures high quality data that can be used to inform global research and achieve high-level evidence-based care. Ultimately, DePICThealth^{RB} will use artificial intelligence to generate a global Learning Health System to improve care and make retinoblastoma a zero death cancer.



Evening Reception





DAY 2 - Friday 13th April 2018



Breakfast session: Capacity building 1

Moderator: Deb Maskens (CA)

Social media training for patient organisations

Deb Maskens (CA), Emmi Toivonen (FI), Juan Carlos Julián Mauro (ES), Juliet Ibrahim (GH)

Ms Maskens provided an overview of the various uses of social media by patient organisations. Social media can be used to support core objectives and strategic plans regarding awareness, advocacy, sharing information and fundraising. Around 40% of the world's population is active on social media, and Facebook remains the largest social network (although not available in Russia and China). About 87% of people use the Internet for healthcare information. Urologists and oncologists love Twitter and use common hashtags such as #kidneycancer for conferences. Patient organisations need to be mindful about sharing information that is not evidence-based or from objective, trusted sources, particularly in relation to cancer treatments.

Ms Toivonen spoke about her organisation's use of Facebook in Finland for sharing information with patients, pharmaceutical companies, NGOs and government. Closed Facebook groups are used to provide a place for peer discussion, secret groups for volunteers for sharing ideas and discussing good practice, and instant messenger for patients in crisis. Facebook is not very flexible and managing her organisation's 23 groups is a lot of work! Facebook is the most popular social media in Finland, while Twitter is seen as elitist and is used mainly to connect with decision-makers. YouTube is used to share events with people who are unable to attend in person. LinkedIn is used for working life and WhatsApp for one-on-one contact with patients.





Mr Mauro described how ALCER uses social media in Spain to communicate among their 51 member associations, and 2 associated entities. Social media is used for staff and patient training/mentoring (Facebook, Twitter). Social media is combined with traditional communication channels (press releases, articles, debates, events, etc.) and used to promote research projects and distribute information. Social media feeds are displayed on the ALCER website. World Kidney Cancer Day provided a great example of how ALCER used its many associations to amplify social media engagement across multiple accounts.



Ms Ibrahim spoke about the power of images and videos on social media. Her Foundation based in Ghana uses YouTube video campaigns to raise awareness of kidney cancer on all social media platforms with appropriate hashtags. The videos have global reach. Social media is a very powerful tool when used by celebrities (followers are keen to see pictures) and this enables the Foundation to build a rapport with followers. Hashtags are key for trending posts. Influencers are creative online and develop a large number of followers. Celebrities can provide a social media push. Social media is mobile-driven, and partnerships with local mobile operators can reach millions of users with key health messages. Live broadcasting on Instagram and Facebook is important for patient group meetings and live events.



DAY 2 - Friday 13th April 2018



Cancer and the media

Moderator: Stephen Andrew (CA)

Valéria Hart (BR)

Journalist and oncology blogger Valeria Hart presented a compelling case for more balanced information about cancer in the public domain. This requires additional work by patient advocates and journalists alike. As we know, the media plays an important role in influencing public perceptions of cancer. Some cancers are over-represented in the media, while others are under-represented. This often mirrors the degree of celebrity endorsement, which has an effect on the use of health services. Prevention gets little attention in the media, but aggressive treatment successes (miraculous cures) are frequently discussed. Many news stories reflect an overly optimistic view of medical research creating an unrealistic expectation of healthcare systems. There is an absence of stories about treatment failures, palliation and end of life care, giving patients an unrealistic view of cancer treatment. News blogs and social media posts are often based on sharing one-sided press releases which omit key information and fail to acknowledge important study limitations.

Ms. Hart urged us to work within our organisations and partners to improve the readability of press releases and to ensure that authors are accessible to the media for questions. All of us in the oncology community can help to address sensationalist reporting through media forums and patient education.





Raising awareness of kidney cancer globally and locally

Anne Wilson (AU)

Following the success of the first World Kidney Cancer Q&A Day (WKCD) last year, Ms Wilson launched WKCD 2018 on 21 June 2018. The aim of the day is to raise global awareness of kidney cancer, its prevalence, symptoms, and risk factors, through IKCC Affiliated Organisations and the use of an interactive quiz and a green lips campaign. As a global day, World Kidney Cancer Day is becoming established as an annual event with a consistent visual appearance, yet with flexibility for each country to adapt the theme and materials and build their participation into their annual plans.



Kidney cancer refresh 2018 - English

Moderator: Dr Michael Jewett (CA)

Dr Jaime Omar Herrera Cáceres (CA/MX), Dr Danny Heng (CA) used case studies to demonstrate the real world management of a metastatic kidney cancer patient in North America.

Case study 1

Dr Cáceres walked us through the case of a 58-year-old male who had no risk factors for kidney cancer (smoking, obesity or hypertension), but had a father with RCC (3-5% is hereditary). The patient was initially diagnosed with locally advanced clear cell RCC with tumour necrosis according to findings on CT scan. The patient had an open radical adrenal-sparing nephrectomy, followed by adjuvant pazopanib for one year (on clinical trial). Disease recurrence was subsequently detected in the lung and contralateral kidney on CT, and patient had haematuria (blood in urine). Biopsy showed a very aggressive grade 4 clear cell RCC. The remaining kidney was left in situ and the patient was started on sunitinib as his first-line treatment. The cancer progressed, sunitinib was stopped due to side effects, and the patient was started on a second line treatment.

DAY 2 - Friday 13th April 2018



Dr. Cáceres emphasized that patients must feel comfortable and be able to trust their healthcare team – if not, seek a second opinion. Patients need to be informed about treatment options, and each treatment decisions should be shared between patient and physician. Patients should be active participants in their own healthcare.



Case study 2

Dr Heng presented the case of a 55-year-old male with left flank pain. CT scan showed a 10cm mass on the left kidney, and lung nodules. A laparoscopic radical nephrectomy confirmed a pT3a tumour, grade 4, with invasion into the renal vein. Biopsy of lung nodules confirmed clear cell RCC. His patient started targeted therapy and a CT scan showed pleural nodules. He then enrolled in the CheckMate 214 trial and was randomised to receive the ipilimumab/nivolumab combination. He came off the trial due to severe diarrhoea, for which he was hospitalised. CT scan in June 2015 showed the pulmonary nodules had disappeared, and the pleural nodules reduced. He started sunitinib in September 2015 and had a complete response in December 2015. It is unknown whether this was a delayed effect of immunotherapy or the sunitinib. He continued on sunitinib maintenance therapy, and in September 2016 was diagnosed with a solitary brain metastasis on MRI, which was resected by left frontal craniotomy followed by stereotactic radiosurgery. He is doing well on sunitinib and is currently NED (no evidence of disease). Key take-away messages from this case are that treatment algorithms for metastatic RCC are changing with the advent of combination therapies in the first-line. Clinical trials are important to test new therapies, and particularly to help determine biomarkers that will help us select which treatment is best for each individual patient.





Kidney cancer refresh 2018 - Spanish

Moderator: Carlos Castro Sanchez (MX) moderated a parallel session in Spanish

Dr. Francisco Rodríguez-Covarrubias (MX),

Dr. María Teresa Bourlon (MX)

Dr Rodríguez mentioned that in Mexico there are 4,000 new cases of kidney cancer each year, in which RCC is the most common type of cancer (90%). The four types of kidney cancer treatments are: active surveillance, radical nephrectomy, ablative therapy and partial nephrectomy. This last one provides a better functional outcome than radical nephrectomy and a lower risk of renal failure. It is ideal for patients with a tumour <4cm and possibly in some larger tumours.



Dr Bourlon talked about the stages of metastatic kidney cancer, which is the spread of tumour cells to other organs. Potentially the cells can be disseminated to any organ, the most frequent sites being lung, bone, liver and brain. The steps of the treatment are to remove the tumour from the kidney and to consider metastasectomy and systemic treatment.

In Mexico, kidney cancer is often diagnosed late due to the fact that it does not present symptoms until advanced stages. Having access to imaging studies such as ultrasound and CT tomography have allowed detection at earlier stages.

Currently in Mexico, treatment options have increased, with greater survival and better quality of life for people, as well as access to more multidisciplinary treatments.

DAY 2 - Friday 13th April 2018



Real world evidence in kidney cancer and how patient organisations can use it

Moderator: Deb Maskens (CA)

UK patient survey

Lucy Willingale (UK)

Ms Willingale presented the results from an annual online survey of UK patients conducted by Kidney Cancer UK. The aims of the survey were to improve awareness and patient outcomes. The main findings from the survey were: 51% of patients were diagnosed incidentally; there is a need for a simple screening test to identify high-risk patients; there is a need for better information and support for patients; every patient needs a specialist nurse for information and support; and awareness needs to be improved among GPs for earlier diagnosis. Kidney cancer patient quality improvement groups have been implemented in England, Scotland and Wales to address patient experience, improve service standards and reduce local variation.



Regional registries

Dr Diego Abreu Clavijo (UY)

Dr Abreu Clavijo reported on a Latin American renal cancer database to highlight specific challenges and geographic and social factors influencing RCC diagnoses. In 2012, worldwide there were 338,000 new cases of RCC; 70% in developed countries, the highest incidence being in Czechia, North America, North/Eastern Europe and Australia, the lowest in Africa. The incidence of kidney cancer is rising. By 2020 there are expected to be 620,500 new cases of kidney cancer every year; 60% of which will be in developing countries like those in Latin America.

Dr. Abreu Clavijo presented findings that suggest some of the biggest risk factors for RCC in Latin America are agro-toxins and transgenic foods. A high proportion of food is contaminated with pesticides, some of which have been banned in Europe due to their carcinogenic nature. Pesticide exposure is potentially associated with a 15% increase in incidence of RCC. Lack of clinical service in poor areas, low income and reluctance to use services, limited access to healthcare professionals, and poor availability of diagnostic tests contribute to an underestimation of RCC incidence and mortality in Latin America.



There is a need for more epidemiology studies to ascertain risk factors. Alternative forms of agriculture should be considered, as well as a cost-effective screening test using abdominal ultrasound for early diagnosis.



Emerging evidence from international registries

Dr Danny Heng (CA)

The International mRCC Database Consortium (IMDC) is used for the collection of real world data. Databases are important because they collect information on real world experience, they include patients that are ineligible for clinical trials, they help to find rare patients, identify trends in practice, answer important clinical questions, and are becoming important for health technology assessment (HTA) and reimbursement decisions to corroborate clinical trial findings. IMDC started about 10 years ago with a study to evaluate sunitinib. The database now holds data from 9,200 patients from 39 international institutions. Dr Heng presented a case example highlighting the use of the data to corroborate clinical trial data. He then described how IMDC data is being used to identify prognostic risk factors and potential biomarkers.

DAY 2 - Friday 13th April 2018



Management of kidney cancer in the elderly

Moderator: Sarper Diler (TR)

Medical perspective

Dr Francisco Rodríguez-Covarrubias (MX)

Worldwide incidence of RCC is increasing with age. Surgery is the standard of care, although active surveillance and ablation might be better options for elderly, frail patients with co-morbidities, short life expectancy and high general anaesthetic risk. Location of the tumour is a consideration for ablation. The benefits of ablation are low complication rates, short hospital stay and preservation of renal function. Studies have shown there is no survival advantage of surgery over active surveillance for small renal masses; however, larger masses should undergo active treatment in properly selected patients. Disease and patient characteristics, patient expectations, desires, and knowledge should be taken into account when making shared decisions about treatment options.

Advocate perspective

Berit Eberhardt (DE)

Ms Eberhardt questioned whether it was age that really mattered, or the condition of the person (comorbidities, nutrition, activity, cognition, social circumstances, environment). Every patient is different and the term 'elderly' does not impart valid health information; a geriatric assessment is needed. In the elderly, impaired kidney function, kidney abscess, drug interactions and toxicities, deterioration in organ function and geriatric events need to be considered during diagnosis and treatment. Medical treatments may need support and dose adaptation. Patient preferences need to be taken into account, and patients involved in decision-making regarding treatment options. Information about impact of age and comorbidity on treatment effects and toxicity is lacking. There is a difference between being elderly and being frail. Risk assessment should be undertaken for every elderly RCC patient.

Impressions



DAY 3 - Saturday 14th April 2018



Breakfast session: Capacity building 2

Moderator: Robin Martinez (USA)

Special topic: Unique challenges for serving the paediatric/young adult kidney cancer patient and family

Belinda Jago (AU)

Ms Jago gave a very moving account of her daughter's experience with kidney cancer and reflected on the different needs of paediatric and young adult patients. Bec was only 13 when she was diagnosed. Due to the rarity of RCC in adolescents and young adults (AYAs, 15-25), her cancer was diagnosed in the late stages. She had a nephrectomy and was diagnosed with inoperable lung metastases 11 months later. Because of her age, Bec could not be prescribed systemic treatment nor could she access new treatments through clinical trials. Manufacturers provided access to treatments on compassionate grounds, but she had to have dose reductions due to toxicity. Bec died at age 19, but leaves behind a tremendous legacy known as Becs Troops, an organisation committed to raising funds for young cancer patients in Australia.



AYAs need psychosocial support services tailored for AYAs, appropriate rooming in hospital (with others of similar age), multidisciplinary approach to treatment of rare cancers, clinical trials, maintaining a balanced family life, and support for carers.





Hot topics in kidney cancer

Moderator: Dr Rachel Giles (NL)

Follow-up after surgery: When and how?

Dena Battle (USA)

Most patients surveyed by KCCure have significant anxiety; about 20% suffer post-traumatic stress disorder (PTSD), and most (78%) worry about the cancer coming back, regardless of stage. In the US, almost 20% of patients were not sure about their follow-up schedule, and follow-up CT scans did not reduce anxiety about recurrence. A new paradigm for communicating and managing follow-up needs to be established. Counselling and psychological support are needed for PTSD and anxiety. A surveillance plan will help alleviate anxiety and make patients feel safe with the care team. At diagnosis, doctors should acknowledge anxiety and provide access to psychological support; empower patients with knowledge to actively participate their care decisions; and support patients by connecting them with patient communities.



Immuno-oncology: Is it for everyone?

Dr Eric Jonasch (USA)

Immuno-oncology (IO) therapy works through harnessing the immune system. Immune T cells recognise cancer cells to trigger an attack. Immune checkpoints (PD-1 and CTLA-4) block the action of T cells. Checkpoint inhibitors release the brakes on the system to enhance the T cell response. However, IO does not help everyone and we are not yet able to identify those who will benefit. Around 25% of patients have tumour shrinkage on nivolumab (CheckMate 025) and 16% of intermediate/poor risk PD-L1 positive patients had a complete response (CheckMate 214) with the combination ipilimumab/nivolumab. Among patients with favourable risk, tumour shrinkage and disease control is actually better with sunitinib. IO toxicities include colitis, pneumonitis, and hepatitis, which can be managed with steroids. Patients with suppressed or hyperactive immune systems should avoid IO therapy. IO is a significant advance for the treatment of RCC, but is not a panacea.

DAY 3 - Saturday 14th April 2018



Increasing participation in clinical trials

Dr Sharon Deveson Kell (UK)

In the UK, cancer clinical trial participation has increased four-fold since the introduction of Clinical Research Networks, and around 16% of all patients take part in clinical trials. However, only 14% of urological cancer patients are told about research. The aims of the KCSN Patient Champion Programme are to improve awareness and knowledge of UK RCC clinical trials, improve communication between patients and the trial team, and increase recruitment and retention of patients. KCSN Clinical Trials Hub holds a database for UK RCC studies and general information about clinical trials. Patient champions are educated about clinical trials through training workshops. They raise awareness of new trials in their region, act as a liaison between trial team and patients, and support their local kidney cancer community through sharing experiences, networking, buddying and mentoring.



Evidence-based decision-making in kidney cancer

Moderator: Dr Michael Jewett (CA)

Evidence gaps in early stage

Dr Michael Jewett (CA)

For clinicians, an evidence gap is when there is no or weak scientific evidence. Patients need to be aware of and understand scientific evidence. An evidence gap is when a patient is unaware of or doesn't understand evidence. Dr Jewett went on to describe evidence gaps in early stage RCC (confined to the kidney without spread, 60%), such as: recognition that a small renal mass (SRM) is not cancer; the role for renal tumour biopsy; indication for active surveillance for a new SRM; ablation versus surgery; treatment of benign cysts/tumours; radical versus partial nephrectomy and how (open, laparoscopic, or robotic); the role for adjuvant/neo-adjuvant therapy; and the best follow-up protocol. Decision aids are helpful tools for patients to digest evidence that exists and choose treatment options.



Evidence gaps in advanced stage

Dr Eric Jonasch (USA)

Dr Jonasch described evidence gaps in advanced stage RCC as being: an unmet need for treatments for rare kidney cancer subtypes (papillary, chromophobe, medullary, etc.); better understanding of rare subtypes; better treatments for brain metastases, which react differently to systemic drugs; identification of a biomarker to improve treatment and understand the biology of RCC; improved collection of clinical trial data, e.g. liquid biopsies, molecular imaging, and genomic analysis; and more information about IO toxicities. Researchers are making progress and we need to continue to gather information for research as a community. Input from the kidney cancer patient community is critical for success.



Evidence gaps in patient engagement

Joyce Graff (USA)

Ms Graff chose not to list things that “we know we don’t know,” but rather asked us to focus on the realm of things “we don’t know we don’t know.” That is the area where collaboration between patients and physicians is critical. She gave examples of things the VHL community learned over the past 25 years that both the patients and the doctors didn’t know were there. Patients reported their experiences, physicians added their expertise, and together they discovered symptoms, treatments, and strategies that have increased life expectancy for someone with VHL by at least 17 years over the last 25 years. One key factor was the recognition that a diagnosis of VHL means that individual is at 60% risk of developing kidney cancer. Similarly, a tool to do early screening for kidney cancer could be expected to save thousands of lives. We can only understand what we don’t know through partnership between patients and physicians.

DAY 3 - Saturday 14th April 2018



Announcement: Global Patient Survey

Deb Maskens (CA)

The main aim of the IKCC global patient survey is to identify geographic variations in RCC patient experience, awareness, access to care, quality of life, and clinical trials. Survey results will provide global and country-specific data to inform participating country organisations; and build IKCC programmes around unmet needs/survey findings. The survey is intended to be conducted every 2 years and is open to all patient organisations and to patients/carers worldwide.



Capacity building 3:

How advocates can make an impact in kidney cancer

Moderator: Bryan Lewis (USA)

Patient engagement in clinical trials

Belinda Jago (AU)

Ms Jago spoke about her involvement with the consumer (patient) advisory panel on the Australia and New Zealand Urogenital and Prostate Clinical Trials Group (ANZUP). This volunteer group advises on clinical trials to improve outcomes for kidney, bladder, testicular, and prostate cancer. The National Framework for Consumer Involvement in Cancer Control facilitates a consistent approach to consumer engagement to ensure consumers feel included and supported through committed organisations, capable consumers, inclusive groups, and a shared focus. All consumers have had their lives affected by cancer. Tasks include review of patient information and treatment plans for clinical trials. Taking on an advocacy role can be scary but a mentor/buddy will help with confidence. Be clear about the role and what is expected; take on what you can do and do it well.



Patient engagement in access to treatment (HTA)

Deb Maskens (CA)

Health technology assessment (HTA) is the systematic evaluation of properties, effects and/or impacts of health technology. It is a multidisciplinary process to evaluate the social, economic, organisational and ethical issues of a health intervention/technology, used to inform policy decisions regarding cost-benefit and budget impact for government. A number of countries conduct HTA for new health technologies, and the UK (NICE, SMC), Australia and Canada are models for good HTA processes with patient input. All HTA decisions are subject to political, public and stakeholder scrutiny, and patients will be most impacted by HTA decisions. Every decision to fund a drug should be subject to transparency and political scrutiny. Clinicians/academics/health system experts should not try to represent patients. Patient input must be relevant, fair and equal, legitimate and build capacity for patients and HTA organisations to work together. IKCC can collaborate internationally towards global patient evidence collection with local adaptation per HTA requirements.



Patient engagement in guidelines development

Dr Rachel Giles (NL)

Dr Giles is the patient advocate representative on the European Association of Urology (EAU) RCC guideline panel. She is required to attend two 2-day meetings a year, have a good understanding of clinical trials, basic statistics, and understand medical papers and levels of evidence. Patient advocates are experts! Advice to others considering a similar role included: follow the etiquette set by the committee and speak their language (medical jargon). Request training and argue your points with supportive materials (studies). If you don't know the answer to a question, always follow it up. Try not to be overly casual, emotional, or angry, and don't swear or interrupt. Personal experience is relevant, but try to represent ALL patients. Don't pretend to understand things; ask or look it up! Patient representatives are integral to guideline panels, and if the evidence is weak, the patient preference has a lot of weight. There is an opportunity to really make a change that matters.

DAY 3 - Saturday 14th April 2018



Increasing stakeholder engagement

Stephen Andrew (CA)

Mr Andrew gave some tips on how to increase stakeholder engagement through effective communication, using the right language, and knowing your audience. Social media can be used for engagement activities by targeting appropriate audiences and actively measuring engagement and interaction. Headline grabbers and newsletters increase engagement for various activities, e.g. WKCD. Examples of increasing engagement activities in 2018 are: vital information toolkit for new members; video knowledge library; medical community engagement via conferences, exhibitions, webinars, medical advisory board, and direct contact; and general engagement with the public via fundraising activities.



Closing Remarks

Dr Rachel Giles (NL), Carlos Castro Sanchez (MX)

Dr Giles and Mr Sanchez thanked everyone for their active participation in the meeting, especially the translators and audio-visual technicians, and Julia Black for organising such a successful meeting. There is a lot of sentiment in the work that IKCC does; thank you for sharing experiences. The medical perspective is particularly useful for meetings with stakeholders in low and middle-income countries. Dr Giles also thanked Mexico for hosting this event and wished everyone a safe journey home and much success implementing the many ideas shared at IKCC 2018!

2018 Conference Feedback

This has been an outstanding conference, thanks to everyone for their dedication and hard work in planning, organising and executing this conference.

It was such a great conference, is the first time I see so many physicians so interested in hearing the patient and organisation voice. This networking is not so common in other diseases. It was so well organised. Congratulations!

It was indeed a privilege and an honor to be able to attend the Conference

Congrats for the wonderful conference!! Well done!! I also would like to say that it was such a pleasure to be with you in Mexico City. Thank you for all!

Thanks again for the IKCC 2018 organisation. It was a wonderful conference well prepared. This gave me confidence to continue my treatment when I see how all these clinicians are devoted to the IKCC and how we can help patients.

Congratulations to you and the team for this outstanding meeting



2018 Conference Feedback

This year's IKCC was so wonderful that I learned and shared great and useful things. I would like to express my appreciation for IKCC

I'm new in KC world, for me, knowing what associations are doing worldwide was super interesting.

Thank you for all your kind attentions during the Conference, and congratulations again on a great event!

The conferences just keep getting better. Enjoyed the deep value on patient involvement! And how our organisations can promote this.

As in 2017 it was a fine learning and networking event, and as usual you were on top of your game - well done.

We truly appreciated the opportunity to join this meeting, and you did an excellent job in all of the execution!

Financial Overview

2018 Financial Statements

These figures represent a summary of the financial statements of IKCC. To view our independently audited financial statements, please visit our website: www.ikcc.org.

Financial Services

Administratiekantoor Boekjwinst.nl BV, Computerweg 22,
3542DR Utrecht, The Netherlands

Independent Auditor

FlanQ, Accountants & Adviseurs
Jan Valsterweg 87, 3315 LG Dordrecht; Netherlands, www.flanq.nl

IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2018	
CURRENT ASSETS	
Funds to receive	€ 1.216
Liquid assets	€ 524.877
TOTAL CURRENT ASSETS	€ 526.093
CURRENT LIABILITIES	
Creditors and borrowings	€ 100.384
TOTAL CURRENT LIABILITIES	€ 100.384
NET ASSETS	€ 425.709
ACCUMULATED FUNDS	
Reserves	€ 89.675
Last year surplus/(deficit)	€ 104.788
Current year surplus/(deficit)	€ 231.246
TOTAL ACCUMULATED FUNDS	€ 425.709

Accountability and Transparency

The IKCC is committed to transparency and accountability according to laws governing patient organisations in the Netherlands. The IKCC Code of Conduct is available to view on our website: www.ikcc.org

Please contact us if you have any questions info@ikcc.org

Treasurer's Report 2018

It gives me great pleasure to present our Annual Financial Overview for 2018. The Foundation continues to be well managed and remains in a healthy financial position with funds appropriately allocated to projects that fulfil the Mission and Vision of our organisation.

The independently audited financial statements for 2018 are to be presented at our Annual General Meeting and subsequently posted on the IKCC website www.ikcc.org.

We are indebted to our Sustaining Partners whose support of our work allows us to deliver on a range of critical projects on behalf of our Affiliated Organisations and people with or affected by kidney cancer around the world.

In 2018 we continued to improve upon our overall financial position enabling IKCC to advocate for better health outcomes around the globe while delivering our Annual Expanding Circles in Kidney Cancer Conference and continuing to liaise with and support our Affiliate Organisations internationally.

We thank all those whose support has 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 2019 and beyond.

Anne Wilson

Secretary-Treasurer
IKCC Board

Joining IKCC

Under the Constitution of the International Kidney Cancer Coalition, organisations may apply for Affiliate status.



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 interested in the work of IKCC, may include organisations who do not yet fulfill 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.

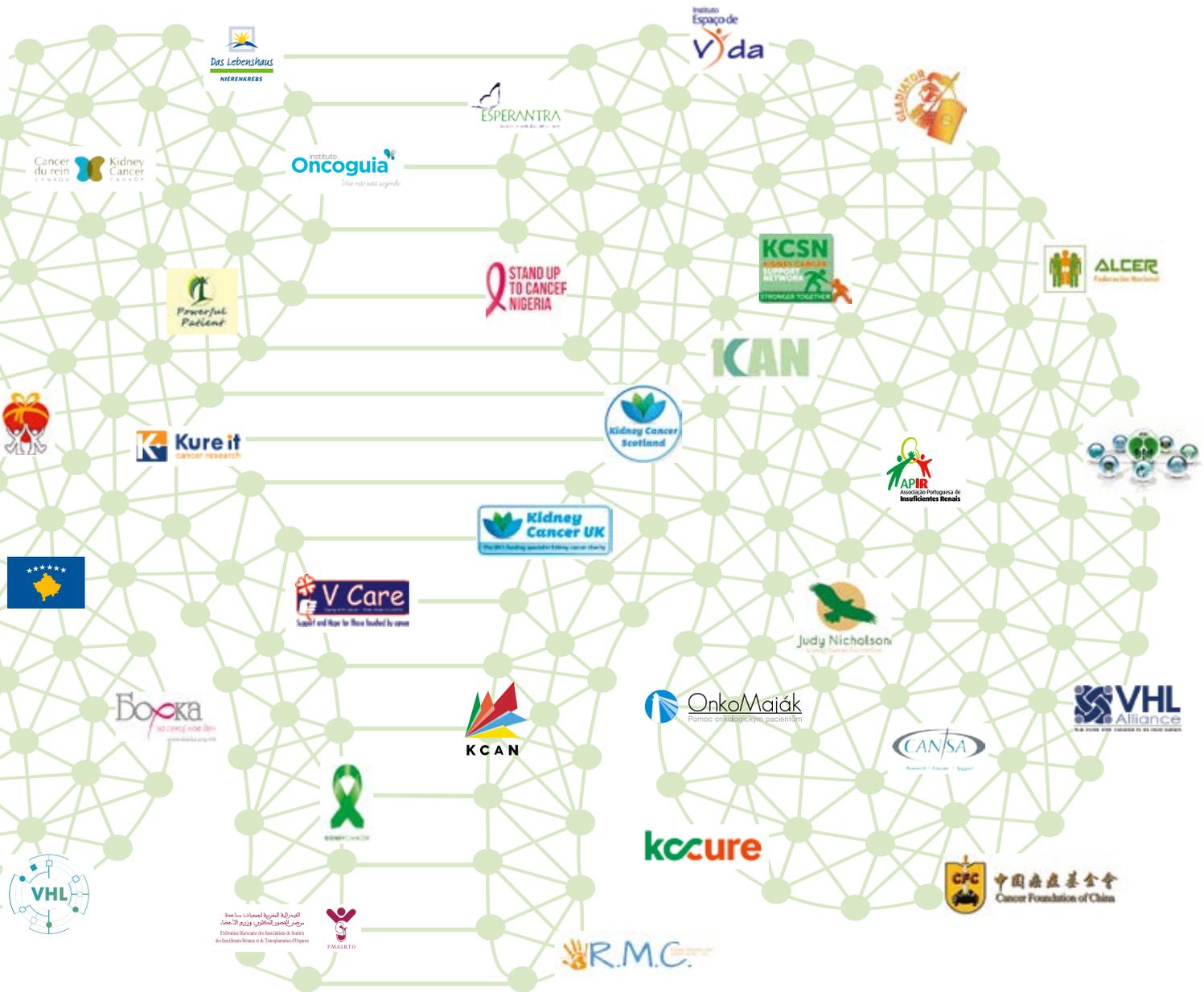
Supporters include individuals who may be strongly motivated to start kidney cancer groups in their own countries.

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/





IKCC Affiliated Organisations



Association of Cancer Patients in Finland

Association for Kidney Cancer

Association Cancer Care

KANKO Turkey

Renal Cancer Alliance, Greece

Association of Nigeria

V Care Foundation

Cancer Foundation of China

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 2018: Board Members



**RACHEL GILES,
MD, PhD (IKCC Chair)**
Von Hippel-Lindau
Organisation (NL) / Living
with Bladder or
Kidney Cancer (NL)

Rachel is a staff/faculty member of Internal Medicine at the University Medical Center Utrecht. 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 is running a research lab that is dedicated to understanding how kidney cells are regulated and what goes wrong in the very early steps of kidney cancer. 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 is Chair of the IKCC and represents the IKCC on the EAU Guidelines Committee for renal cell carcinoma.



**DEBORAH MASKENS,
M. A., M.S.M.**
(IKCC Vice Chair)
Kidney Cancer Canada

As co-founder of Kidney Cancer Canada (KCC), Deb has worked tirelessly to ensure equal access to high quality care for kidney cancer patients across Canada. A long-time kidney cancer patient herself, she is a frequent speaker at national and international cancer meetings where she provides the patient voice perspective along with sound advocacy knowledge and experience. For her role in establishing Kidney Cancer Canada, Deb has been recognised with the Meritorious Service Medal by Canada's Governor General, the Queen's representative in Canada. She serves as a Patient Advocate on the U.S.-based National Cancer Institute (NCI) Renal Task Force. In Canada, she co-leads a coalition campaign of 35 cancer organisations (CanCertainty) toward full public coverage of take-home cancer medications. Deb is a founding member and Vice-Chair of the IKCC.



BERIT EBERHARDT
Uronauten e.V. (DE)

Berit 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 she 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 the International Kidney Cancer Coalition 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.



JOYCE GRAFF, M.A.
Powerful Patient Inc., USA

Joyce founded in 1993 the VHL Family Alliance, a national non-profit organisation focused on von Hippel-Lindau (VHL). Over the next 20 years she oversaw its growth into an international network of patient support groups for VHL and other hereditary kidney cancer syndromes. A cancer survivor herself (breast cancer, 1979), she has been the primary researcher and advocate for her husband and son with VHL since 1963. She has written extensively on VHL, HLRCC, and pheochromocytoma. She served 10 years on the board of the National Organisation for Rare Disorders (NORD), four years on the Director's Consumer Liaison Group (DCLG) of the US National Cancer Institute, two years as Executive Director of the New England Regional Genetics Group (NERGG), and 12 years as consumer advocate for the kidney program of Dana Farber/Harvard Cancer Center. She has been a reporter for the Kidney Cancer Association International Symposia in Chicago (2011, 2012, and 2015). A frequent speaker at national and international cancer meetings, Joyce continues her patient advocacy work through the Powerful Patient and its internet radio show.



Michael A.S. Jewett,
MD, FRCSC, FACS

Dr. Jewett is Professor of Surgery (Urology) at Princess Margaret Cancer Centre and the University of Toronto. He was an enthusiastic supporter of the founding of Kidney Cancer Canada and was the founding and immediate past-Chair of the Kidney Cancer Research Network of Canada. He was awarded the Canadian Cancer Research Alliance Award for Exceptional Leadership in Patient Involvement in Cancer Research in 2017. He serves as Surgical Co-Chair on the USA National Cancer Institute's Renal Task Force. He has published more than 350 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 and has been a visiting professor in 25 countries to more than 100 university departments and institutions.



Eric Jonasch, MD
Professor of Medicine

Dr. 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, co-Director of the MD Anderson Kidney Cancer Research Program, and performs clinical, translational and basic research in kidney carcinoma and VHL disease. Dr. Jonasch has authored over 190 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 NCCN Kidney Cancer Guideline Panel, is a member of the U.S. NCI Renal Task Force and is a Board member of the VHL Alliance.

IKCC 2018: Board Members



BRYAN LEWIS,
Kidney Cancer Action
Network (USA)

Bryan Lewis has led the advocacy efforts for KCAN – the Kidney Cancer Action Network – www.kcan.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 in the United States Congress & regulatory agencies. Most recently, he was successful in obtaining \$20 million for the KCRP – Kidney Cancer Research Program (www.cdmp.army.mil/kcrp/). Bryan has also been appointed to the NCCN (National Comprehensive Cancer Network) Kidney Cancer Guidelines Panel. 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.



Dr. Elizabeth Perdeaux
Oxford PharmaGenesis

Lizzie Perdeaux is a medical writer at Oxford PharmaGenesis, a HealthScience communications consultancy based in Oxford, UK. Lizzie previously worked at the Myrovlytis Trust, a medical research charity for Birt–Hogg–Dubé (BHD) syndrome, a rare, genetic kidney cancer predisposition syndrome. Whilst there, she was the main point of contact for patients seeking information about BHD and developed an interest in communicating health information to patients and the public. Lizzie completed her undergraduate degree and PhD research, both in genetics, at the University of Cambridge, and undertook her Post-Doctoral research at the Institute of Cancer Research in London.



ANNE WILSON
Anne Wilson & Associates

Formerly CEO and Managing Director of Kidney Health Australia – Anne has been a member of the IKCC Board for the last four years. Since stepping down as CEO in May 2016, Anne has consulted to a number of not for profit organisations in Australia as well as having completed various projects in the health consumer space. 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. As a Social Worker, Anne is 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
Kidney Cancer
Support Network (UK)

Rose 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 KC treatments. She now runs the Kidney Cancer Support Network which is a grassroots patient led charity providing practical support and advocacy for the kidney cancer community in the UK. She enjoys a very busy life running 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 is committed to open and transparent partnerships with the healthcare industry according to our Code of Conduct (www.ikcc.org) and in accordance with international standards. Achieving balanced and multi-sourced funding helps us to achieve our goals of collaboration with all stakeholders including medical experts, patient organisations, and the healthcare industry. Such funding allows our organisation to focus on this worthwhile mission – to reduce the global burden of kidney cancer.

We would like to thank the following funders who have supported IKCC in 2018 with Sustaining Partnerships or Project Sponsorships:

Sustaining Partners (2018)



Project Sponsors (2018)





IKCC Activity Report 2018 – Imprint:

Text: IKCC Board and Julia Black (UK)
2018 Conference Report: Dr. Sharon Deveson Kell (UK) and Joyce Graff (USA)
Graphic Design: Herbert Thum, www.VISKON.de, (DE)
Photos: Gareth Davies Photography (MX)
Printing: Englam & Partner (DE)



International Kidney Cancer Coalition

Registered Office:

't Ven 30

1115HB Duivendrecht,

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](#)

Registered in the Netherlands under:

Stichting IKCC

Reg.-No. KvK 62070665