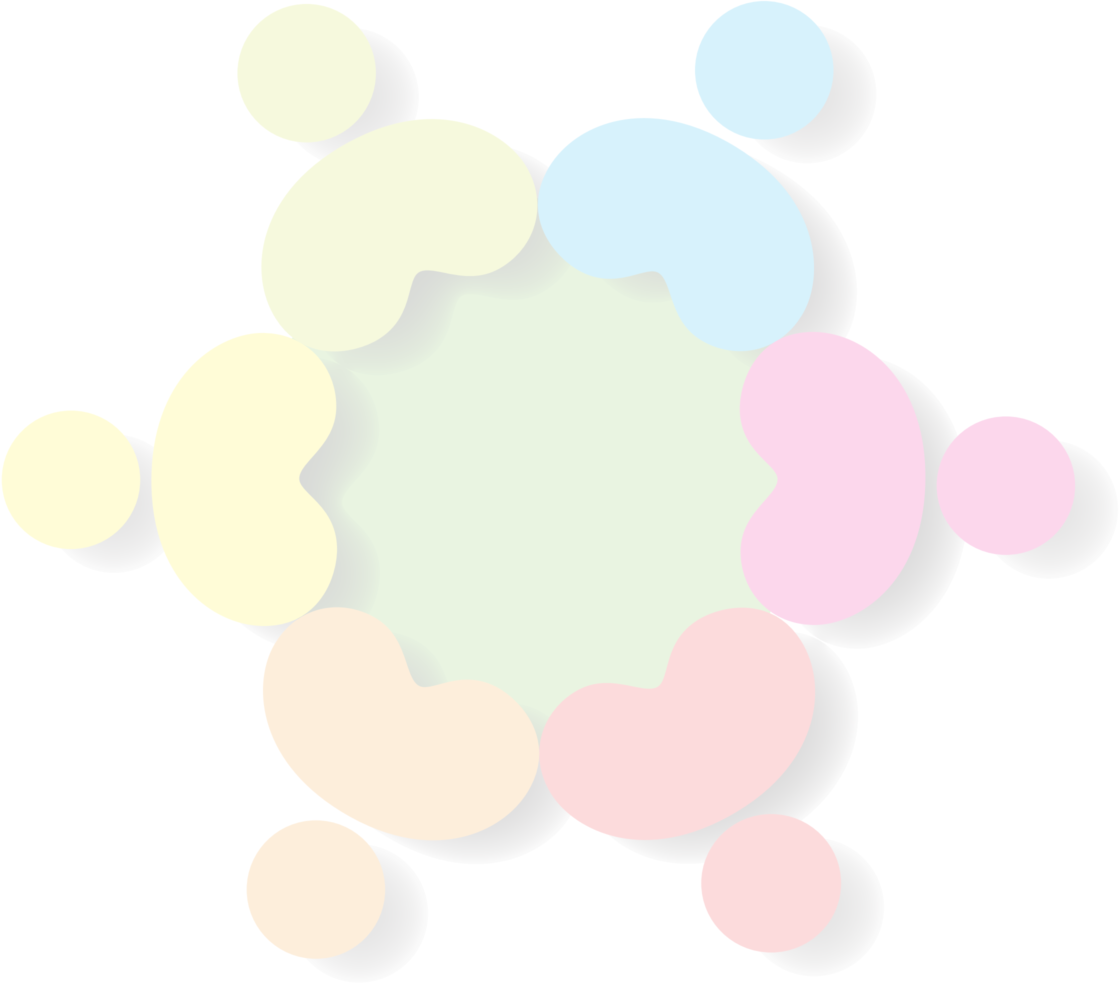
IKCC
International
Kidney Cancer
Coalition

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

Activity Report 2017



Content

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 2017. 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 are working on 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 2017, we met in Warsaw, Poland. Inspired by the high incidence and prevalence of kidney cancer in Eastern Europe, we focused on access to care, shared decision making, clinical trials, and unmet medical needs. Alongside 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 first-ever World Kidney Cancer Day on June 22, 2017. In addition to efforts worldwide to raise awareness, the online quiz developed by our communications team also raised $25,000 for kidney cancer research which we awarded to a peer-reviewed grant application to initiate a new Decision Aid tool for localised kidney cancer. We hope to present the results next year. This year will see the second World Kidney Cancer Day on June 21, 2018, and preparations are well underway.
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 2017 we co-authored or were lead authors for five papers in the number one journal in the field of urology, European Urology. We updated the newest information about patients' response to treatment.(1) We also looked at all the evidence to treat the approximately 15% of advanced kidney cancer patients that do not have clear cell histology and concluded that there was very little strength in the available data, and that many patients were being treated inappropriately as a result; (2) and consequently 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 rare kidney cancers.(3) The IKCC worked with senior members of the European Association for Urology to share a vision statement of stakeholder involvement to improve guideline development and implementation.(4) Lastly, we participated in a review of studies using systemic therapy after surgery (adjuvant) for localised kidney cancer.(5) The landscape for kidney cancer treatment is changing rapidly and it is important that the patient perspective be meaningfully incorporated in the process of adaptive care.

By working with the medical community, we hope to bring the patients' voice and priorities closer to the implementation of best-practice 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 world-wide. In 2017, we built a searchable database of kidney cancer-specific clinical trials that is updated daily. Coupled with our social media campaign "Think Treatment, Think Trials!" we hope to inform our affiliates of the possibilities available to them and simultaneously help the trials that are running meet meaningful endpoints useful for patients worldwide. In 2017, we also produced fact sheets about kidney cancer with graphics and text freely available to our affiliate organisations to use for their own purposes.

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 best wishes,
on behalf of the IKCC Board of Directors**

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IKCC Profile

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

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.

IKCC at a Glance

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) • J. Graff (USA) • M. Jewett (CAN) • E. Jonasch (USA)• E. Perdeaux (UK) • A. Wilson (AUS) • R. Woodward (UK)
Registered Office:	't Ven 30 1115HB Duivendrecht, The Netherlands
Services:	Project Manager: Julia Black (UK) julia@ikcc.org Management Services : Markus Wartenberg (DE) ikcc@daswissenshaus.de
Collaborations:	IKCC is a proud member and participant of the following regional and international coalitions:

Projects and Activities 2017

(Excerpt)

NEW: Kidney Cancer Fact Sheets

One of our core objectives is to strengthen the capacity of patient organisations worldwide in their support for patients with kidney cancer.

As part of this objective, the IKCC published a series of eight fact sheets on kidney cancer and launched them at the ESMO 2017 conference in Madrid last September. The fact sheets cover all aspects of kidney cancer such as causes, diagnosis, types of kidney cancer, treatment options, and clinical trials.

Each single-page fact sheet has been designed to provide information in an easy-to-read format using simple graphics.

These fact sheets are available for patient organisations to use, translate, and adapt to local needs. We have included a 'Distributed by:' box on the back that allows you to easily personalise any fact sheet with your organisation's logo and stamp.

The fact sheets are available to download on the IKCC website www.ikcc.org

Files and graphics are available at no cost. Your feedback is most welcomed!

Kidney Cancer Diagnosis

IKCC

- **Blood tests:** Chemical tests of the blood can detect findings associated with kidney cancer.
- **Bone scan:** A small amount of radioactive material is injected into a vein and travels through the bloodstream to the bones so the scanner can detect if cancer has spread to the bones.

CT-Scan

The majority of kidney cancers are initially discovered by scans (ultrasound, CT scan, or MRI), showing something like a "lump" on the kidney. This does not prove it is kidney cancer however, and it must be examined under the microscope to be sure.

Sometimes your doctor may be so suspicious they recommend immediate surgery; other times your doctor might order a biopsy. During a biopsy, a thin needle is used to remove some cells from the tumour. A doctor will then look at the cells to see if they are cancerous or not. Up to 20% of small kidney masses (or lumps) are non-cancerous.

Good to know!

Biopsy
The removal of cells or tissues for examination by a pathologist.
The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue.

Pathologist
A doctor who identifies diseases by studying cells and tissues under a microscope.

Radiologist
A doctor who specializes in diagnosing disease by using procedures such as x-rays, ultrasounds, CT scans and MRI.

Surgery
A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.

Symptom
An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

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IKCC International Kidney Cancer Coalition

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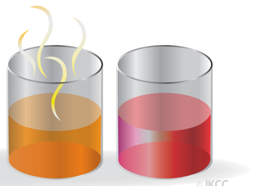
- Lower back, abdominal or flank pain which is not linked to an injury
- Abdominal pain (stomach area)
- Weight loss
- Newly developed high blood pressure
- Constant tiredness
- Fever or night sweats which are not linked with any other conditions

All of these symptoms can also be caused by other diseases. If you have any of these symptoms it is important to see your doctor so you can find out what's causing them.

Ultrasound

- **MRI / CT Scans:** Computed tomography (CT) scan or magnetic resonance imaging (MRI) scans can be used to get detailed pictures of organs in the body. This can help characterise a lump in the kidney if one is found.
- **Chest x-ray:** An x-ray of organs and bones within the chest.
- **Urine test (urinalysis):** The most common symptom and sign of a kidney tumour is blood in the urine. This test can also detect other irregularities in the urine such as protein.



Advanced Kidney Cancer

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International Kidney Cancer Coalition

My kidney cancer has spread to other parts of the body: what treatment could I take?

In people with advanced kidney cancer, where the cancer has spread to distant organs, the cancer is usually not completely curable. The goal of treatment is therefore to make life as long and as normal as possible. Combinations of different treatments may be recommended by different doctors, including urologists, medical oncologists who prescribe anti-cancer medications, and radiation oncologists who treat people with radiation. Throughout, this team of specialists will work with you and your family doctor to help you control your symptoms and live as normal a life as possible.

Treatments for advanced kidney cancer include:

Active Surveillance (Observation): In some people in whom the kidney cancer has spread, the cancer might be growing so slowly that the right first option is to watch carefully. This is especially the case when the cancer has been discovered by accident. If the cancer starts to grow quickly or cause symptoms then active treatments will be recommended. A small percentage of patients might live without symptoms from the cancer for a very long time, sometimes years, so your doctor might advise you to observe for a period of time.

Surgery to remove cancer that has spread: In a very small number of people, the cancer spreads to only one or two places; if this is the case it can be possible to try to cut out all the metastatic cancers (a “metastectomy”). Some patients can live a very long time in these circumstances, but it really only applies to patients where there is only one or two spots elsewhere and they can all be safely removed.

Surgery to remove cancer in the kidney: If your health is otherwise good, there is evidence that removing the original cancer in the kidney improves survival and helps other treatments work better. This “cytoreductive” nephrectomy would be performed by your urologist (or uro-oncologist).

Clinical Trials: A clinical trial is sometimes erroneously perceived as a “last resort”, but with rapidly improving treatments it should be considered the “first port of call”. A clinical trial is a way of testing new treatments, or older treatments used in a new way. Clinical trials are not right for every person; not every person is right for a clinical trial. If a clinical trial is available it can be an interesting opportunity to consider. For more information about clinical trials, see: www.ikcc.org.

Radiation therapy: A Radiation Oncologist uses high-energy radiation to kill cancer cells. Radiation can be very helpful if the cancer causes a lot of problems in one location, e.g. cancer in the bone causing pain, cancer in the kidney causing bleeding, cancer in the brain causing swelling. Radiation is used as a means of controlling symptoms (e.g. pain). SBRT (stereotactic body radiation therapy) is increasingly used to control kidney cancer growth..

Palliative care: Palliation doesn’t mean the “end of the road” or that the cancer is in its terminal stages. Palliative care is all the treatments that your team recommends to improve your symptoms and improve your quality of life. Your family doctor, your medical oncologist and your other doctors will help you with this. Sometimes palliative care physicians and nurses are consulted, and they can often provide specialised advice. Palliative treatment can improve quality of life by alleviating symptoms associated with advanced cancer.

Advanced Kidne

Alternative Therapies: Everyone wants the best health ca for themselves and their loved one If there are no suitable standard medical therapies available, “alternative” therapies might be proposed by well-intentioned friends, relatives or internet web-pages.

These are called “alternative” because they have not been scientifically proven to shrink cancers or help patients. Worse still, they might have been proven not to help or to even cause harm. Examples of unhelpful or harmful alternative “treatments” include mega-dose vitamins, herbal products or extreme diets.

Some alternative therapies can interfere with medicines normally prescribed by a doctor, causing harm to the patient. So it’s important to inform your doctor or nurse if you are considering these therapies.

Complementary Therapies: On the other hand, complementary therapies can “complement” established medical treatments, improving quality of life and symptoms. These include mindfulness meditation, relaxation techniques, remedial massage therapy, psychotherapy, prayer, yoga, acupressure and acupuncture. If there were any chance that the kidney cancer has spread to bones, chiropractic or osteopathy would not be a good idea.

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International Kidney Cancer Coalition

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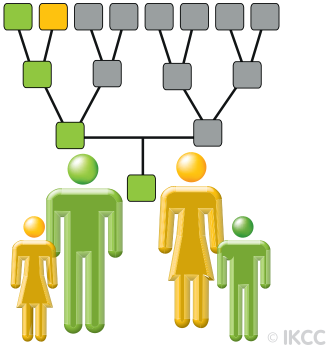
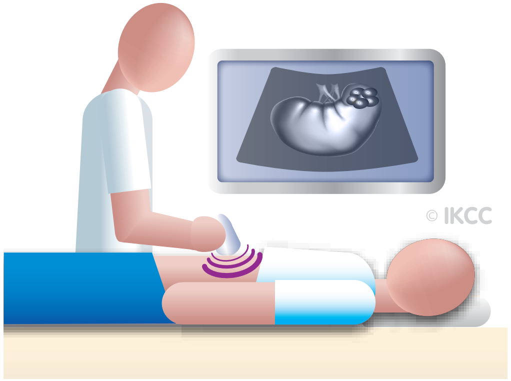




Our Commitment to Supporting Clinical Trials in Kidney Cancer

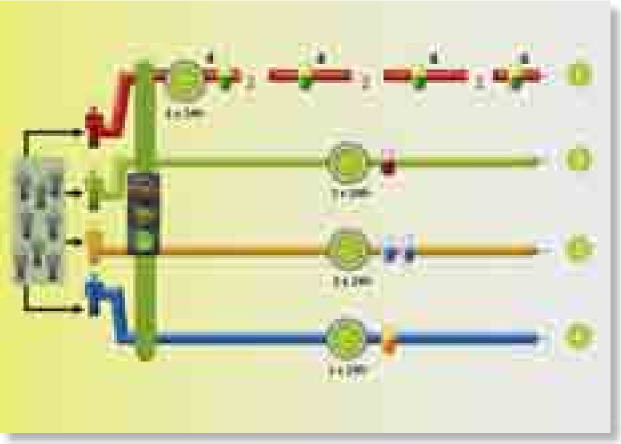
Improving outcomes for kidney cancer patients worldwide depends upon clinical trials that will evaluate better ways to screen, diagnose, treat and potentially cure the disease. For this reason, the IKCC remains firmly committed to shaping research priorities so that they are based upon real patient and carer priorities and unmet medical needs. Ideally all kidney cancer patients worldwide would have the opportunity to participate in a clinical trial so that we can learn faster, share results, and make significant improvements in survival for more patients. We have made progress, but we have a long way to go!

Supporting research takes many forms. Many IKCC Affiliate Organisations are involved in funding kidney cancer research in their countries. Others are involved in clinical trial awareness by providing listings of clinical trials to patients in their countries and patient navigation services. Many patient organisations find the clinical trials landscape challenging to navigate, especially in local languages.

As the global umbrella network, IKCC aims to support organisations and provide resources that can be used, adopted, translated to help bring relevant, current, and understandable clinical trials information to those who need it.

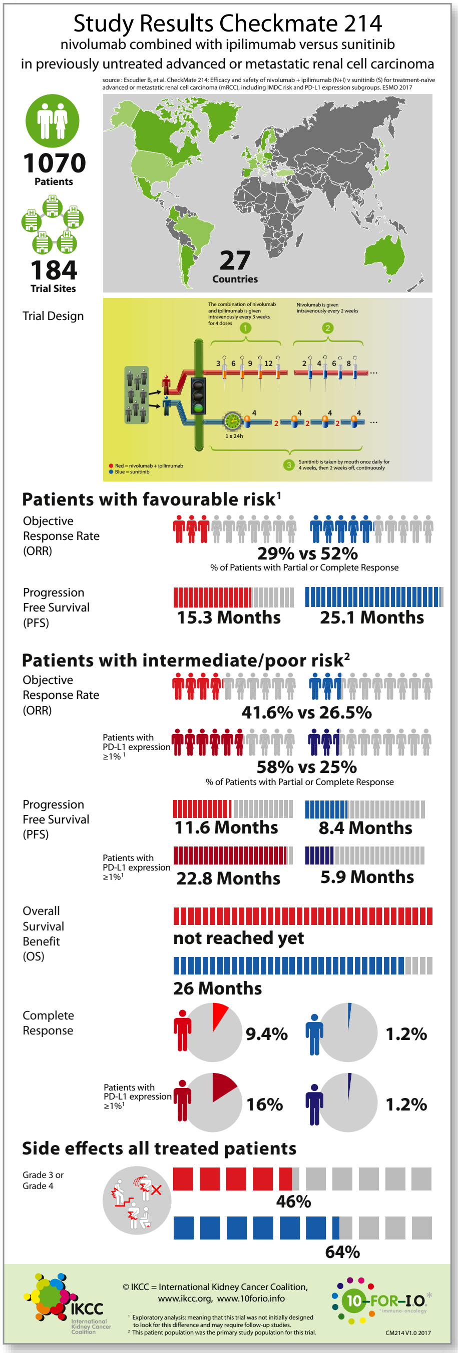
Lay Summaries

Descriptions of clinical trials are often written by researchers for other researchers. For major trials in kidney cancer, the IKCC develops a patient-friendly summary complete with visual trial design:



Infographics of Clinical Trial Results

As major clinical trials report, Press Releases often provide mixed messages for patients. Our approach to infographics shows the results in plain language visual format:



Study Results Checkmate 214

nivolumab combined with ipilimumab versus sunitinib
in previously untreated advanced or metastatic renal cell carcinoma

source : Escudier B, et al. CheckMate 214: Efficacy and safety of nivolumab + ipilimumab (N+I) v sunitinib (S) for treatment-naïve advanced or metastatic renal cell carcinoma (mRCC), including IMDC risk and PD-L1 expression subgroups. ESMO 2017

1070 Patients

184 Trial Sites

27 Countries

Trial Design

The combination of nivolumab and ipilimumab is given intravenously every 3 weeks for 4 doses ①

Nivolumab is given intravenously every 2 weeks ②

③ Sunitinib is taken by mouth once daily for 4 weeks, then 2 weeks off, continuously

● Red = nivolumab + ipilimumab
● Blue = sunitinib

Patients with favourable risk[1]

Objective Response Rate (ORR)
29% vs 52%
% of Patients with Partial or Complete Response

Progression Free Survival (PFS)
15.3 Months **25.1 Months**

Patients with intermediate/poor risk[2]

Objective Response Rate (ORR)
41.6% vs 26.5%

Patients with PD-L1 expression ≥1% [1]
58% vs 25%
% of Patients with Partial or Complete Response

Progression Free Survival (PFS)
11.6 Months **8.4 Months**

Patients with PD-L1 expression ≥1%[1]
22.8 Months **5.9 Months**

Overall Survival Benefit (OS)
not reached yet
26 Months

Complete Response
9.4% **1.2%**

Patients with PD-L1 expression ≥1%[1]
16% **1.2%**

Side effects all treated patients

Grade 3 or Grade 4
46%
64%

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www.ikcc.org, www.10forio.info

[1] Exploratory analysis: meaning that this trial was not initially designed to look for this difference and may require follow-up studies.
[2] This patient population was the primary study population for this trial.

CM214 V1.0 2017

Database of Kidney Cancer Clinical Trials Worldwide

In 2017, we launched a new clinical trials database that is automatically updated every 24 hours with current and kidney cancer relevant trials from the world's largest database of trial information, clinicaltrials.gov

Patient organisations can produce a country-specific trials report based upon search criteria – for example, to produce a custom report of trials currently recruiting in any country. ***See: http://ikcc.org/clinical-trials-search***

Work is ongoing to integrate lay summaries and graphics into the trial database. We look forward to sharing progress.

First-Ever: World Kidney Cancer Day – June 22 2017

We did it! Together with Affiliate Organisations around the globe, in 2017 the IKCC launched the first-ever World Kidney Cancer Day. To address the need for increased awareness of kidney cancer, the IKCC Project Team developed the World Kidney Cancer Q&A Day Quiz, an interactive, seven-question quiz highlighting what is known and what people need to know – about kidney cancer.

As a result of the combined efforts of our worldwide network of Affiliate Organisations, medical experts and societies, and our partners, over 11,000 people completed the World Kidney Cancer Q&A Day Quiz across nine languages: English, French, Spanish, Portuguese, German, Dutch, Polish, Greek and Arabic. Many more were engaged in social media, events, fundraisers, and traditional media.

Global Ambassador Juliet Ibrahim, celebrity and humanitarian, conceptualised the ***#greenlipstickchallenge*** which helped raise further awareness by encouraging everyone to ‘pucker up’ with green lips and show their support for kidney cancer by ‘going green’ for the cause

Key outcomes

- IKCC engagement on Twitter during the campaign achieved nearly 200,000 impressions
- IKCC’s Facebook community increased by 96% to 9,032 likes
- IKCC’s Twitter following increased by 46% to a total of 2,327 followers
- Engagement on Facebook during the campaign reached nearly 95,000 people
- Our Thunderclap virtual online flash mob resulted in a combined social media reach of 230,000.

230 K
PEOPLE

20
COUNTRIES

72
CITIES

In addition, the reach was magnified by each of the participating organisations, sponsors and medical associations creating a significant worldwide online presence, sharing the Quiz and information with patients, physicians and the general public through social media, pamphlet distribution, events and more!

Press Releases from IKCC announcing World Kidney Cancer Q&A Day was shared globally across nine languages and was posted to 439 news websites with a potential combined audience of 81.6 million people.

World Kidney Cancer Day is now embedded on the global health calendar of disease specific events. IKCC intends to grow this event significantly each year.

We thank our sponsors and partners for helping us bring World Kidney Cancer Day to fruition and for working so collaboratively to raise awareness at the local level to bring information about kidney cancer to each corner of the globe.

World
Kidney
Cancer
Q&A
Day
22 June
2017

$25,000 Donated to Patient-Centred Kidney Cancer Research

To boost the uptake of our first World Kidney Cancer Q&A Day Quiz, the IKCC offered a $5 incentive donation for each Quiz completed, to a maximum of $25,000 USD. These funds were granted in 2017 to support a research project entitled: ***“A patient-centered decision aid and experience survey for choosing between partial and radical nephrectomy for complex localized renal tumors”***. Principal Investigator: Dr. Luke T. Lavallée MDCM MSc FRCSC, Urologic Oncology, Ottawa Hospital Research Institute. We look forward to sharing the results of this important research in shared decision making with the IKCC community.

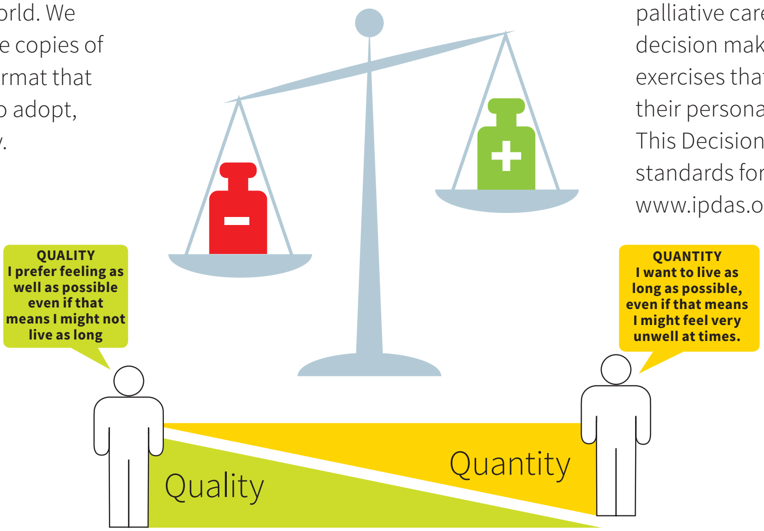
UPDATE: Decision Aid for Advanced Kidney Cancer

One year ago, the IKCC celebrated the publication of our first Decision Aid for Advanced Kidney Cancer. We asked the IKCC community, particularly our Affiliate Organisations, patients, medical experts, and academics experienced in patient decision aid standards to review the first edition and provide detailed feedback.

Thank you to everyone who provided suggestions. And thank you to those of you who ordered copies, distributed them to patients, and urged us to finalise this important new tool to support shared decision making between kidney cancer patients and their healthcare teams.

The IKCC Decision Aid Team has incorporated feedback from all corners of the world. We look forward to releasing the online copies of the 2nd Edition in a new modular format that will enable patient organisations to adopt, translate, and print or share locally.

©
Kidney Cancer:
My Treatment,
My Choice
Decision Aid



About My Treatment; My Choice

Decisions for any advanced cancer diagnosis are difficult and often need to be made during an incredibly stressful time for a patient, their carer, and extended family. While some patients prefer for their physician to make all of the decisions for them, increasingly, many patients worldwide expect to play a partnership role in treatment decisions in conversations with their healthcare team.

The IKCC Decision Aid for Advanced Kidney Cancer presents an unbiased presentation of the many options for treatment of advanced disease ranging from surgery to radiation to medical treatment to active surveillance and palliative care. In support of patient-centred decision making, it includes questions and exercises that prompt patients to explore their personal values, goals and preferences. This Decision Aid follows international standards for patient decision aids (IPDAS: www.ipdas.ohri.ca).

7th International Conference for Organisations Representing Patients with Kidney Cancer

6th – 8th April 2017
Mercure Warsaw Centrum Hotel,
Poland

Conference Report

7th IKCC Expanding Circles in Supporting Kidney Cancer

The International Kidney Cancer Coalition Conference brings together patient organisations, advocates, medical experts, and key stakeholders for a uniquely collaborative conference. Key objectives of this conference include:

- Capacity building for patient organisations and advocates in areas of common interest and emerging needs
- Updates in kidney cancer research, treatments, and new developments
- Fostering collaboration to raise awareness of kidney cancer and support the needs of patient organisations worldwide.

From 6th - 8th April 2017, over 80 representatives from 26 countries met to share best practices, discuss common needs, and work together. In 2017, new attendees were welcomed from Latvia, Macedonia, South Korea, Turkey and USA.

Start of the conference

Speakers: Dr. Rachel Giles (NL), Katarzyna Teodorczyk, Gladiator (PL)
Patient perspective: Marcin Wlodarczyk, Gladiator (PL)

Dr. Giles opened the 7th Expanding Circles Conference and welcomed representatives from 26 countries on 6 continents to Warsaw, Poland. More than 80 delegates attended the conference, with new IKCC affiliates from Latvia, Macedonia, South Korea, Turkey and USA. The main topic of this year's conference was the global burden of kidney cancer. There are almost 400,000 new cases of kidney cancer per year, most of which are renal cell carcinoma (RCC); it is the ninth most common cancer in men. Of the ten countries with the highest incidence, nine are in Eastern Europe. For this reason, we chose to highlight the particular struggles this part of the world has with kidney cancer. Our local affiliate, Gladiator, introduced Marcin Wlodarczyk who shared his kidney cancer experience.

Kidney cancer update 2017

Introductory session

Speakers: Dr. Roman Sosnowski (PL), Dr. Jakub Dobruch (PL)

Drs. Sosnowski and Dobruch gave an introduction to kidney cancer: incidence, risk factors, diagnosis and treatment. Clinicians are seeing many more cases of kidney cancer, the majority of which are confined to the kidney itself. Surgical removal of small kidney tumours has a high cure rate. Active surveillance is increasingly used for small, slow-growing tumours. European Association of Urology (EAU) guidelines are used worldwide (except USA) to guide the management of kidney cancer. Patient advocacy groups could encourage adoption of EAU guidelines in their respective countries to reduce worldwide variations in care.

Advanced session

Speakers: Dr. Michael AS Jewett (CA), Dr. Eric Jonasch (USA)

Drs. Jewett and Jonasch used a case study to demonstrate the real world management of a metastatic kidney cancer (mRCC) patient in North America. Initial diagnosis was made using ultrasound and confirmed with contrast-enhanced CT and image-guided percutaneous needle biopsy. At the time of diagnosis more than 50% of patients have a T1 kidney tumour, while about 25% have a tumour that has spread (T3 or T4). This patient had high grade kidney cancer and an open partial nephrectomy. When deciding on the type of surgery, patients should opt for the best surgeon, not the best procedure! Number of procedures performed is a good quality marker for surgeons. Follow-up after surgery is dependent on stage of disease and risk of recurrence. There are three main systemic treatments available to people with advanced RCC; anti-angiogenic therapies; immunotherapies and mTOR inhibitors. The benefit of adjuvant treatment to prevent recurrence following surgery remains questionable. Active surveillance can be used for patients at low risk of spread. Sunitinib or pazopanib are recommended as first-line systemic treatments for advanced RCC; nivolumab, axitinib, everolimus and cabozantinib are second or third-line treatments.

DAY 1 - Thursday 6 April 2017

Keynote Address: Global burden of kidney cancer - Are we facing an epidemic of kidney cancer?

Speaker: Professor Dr. Hendrik Van Poppel (BE)

Professor Van Poppel, the EAU Adjunct Secretary General, reminded us that we are all working together to reduce the global burden of kidney cancer. Worldwide incidence of kidney cancer is 338,000 new cases/year, and is predicted to rise by 22% by 2020 due to an aging population, and an increase in hypertension and obesity. Diagnosis, treatment and follow-up are expensive.. Incidence is highest in developed countries (Europe and USA) and the elderly (>75 years). Mortality is dependent on access to treatments. The drugs for mRCC are expensive and the cost of RCC treatment is increasing. Smoking and obesity are the main risk factors. Clear cell RCC is most prevalent (75-85%), while collecting duct RCC has the worst prognosis. Typical symptoms are flank pain, gross haematuria, and a palpable mass in the abdomen. Screening the general population for kidney tumours would be too costly.

To tackle the global burden of kidney cancer, there needs to be improvement in diagnosis and treatment through clinician training. Policy-makers need to be engaged for allocation of resources and support for research. Prevention strategies need to be improved, such as promotion of healthy lifestyles, and identification of high-risk populations for screening. Disparities in kidney cancer care across the world need to be eliminated. Patient organisations can help achieve this through dissemination of kidney cancer guidelines. A patient-centered, multidisciplinary approach should be used to decide optimal treatment.

IKCC special announcement: World Kidney Cancer Day

Speaker: Anne Wilson (AU)

Anne Wilson announced the first World Kidney Cancer Day (WKCD), to take place on 22 June 2017. The aim of the day is to raise global awareness of kidney cancer, its prevalence, symptoms, and risk factors, through IKCC affiliated organisations. Anne Wilson outlined the theme, design and elements of the day, along with the toolkit and kidney cancer quiz that will be made available to affiliate organisations. Juliet Ibrahim (GH) was welcomed as the first global ambassador for World Kidney Cancer Day.

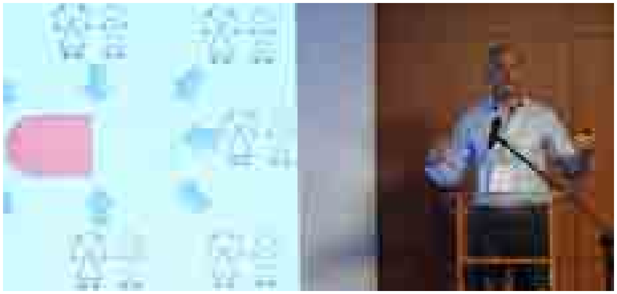
Surveillance: Putting the patient voice into guidelines

Moderator: Dr. Rachel Giles (NL)

Speaker: Prof. Dr. Michael Staehler (DE)

Dr. Staehler talked about the work of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group; an informal collaboration of people with an interest in addressing the shortcomings of grading systems in health care. The working group has developed an approach to grading quality of evidence and strength of recommendations, including patients' ideals, values, and preferences, to address the benefits and harms of assessment from a patient's perspective. Current surveillance guidelines were described and survival benefits discussed. Surveillance protocols for kidney cancer are not standardised globally and the duration of follow-up is unclear.

DAY 1 - Thursday 6 April 2017



Think treatment, Think trials

Moderator: Deb Maskens (CA)

Researcher's perspective: The importance of clinical trials

Speaker: Dr. Eric Jonasch (USA)

Dr. Jonasch explained that patient participation in clinical trials is critical to the development of new therapies. To improve cancer treatment, researchers need to understand cancer mutations and how these affect the immune system. Researchers need to improve how information is collected from patients, and treatment needs to be personalised for specific patients in real time by assessing changes in tumours. Trials need to move from a drug-centric to a patient-centric research model based on needs and wellbeing of patients.

Patient advocacy perspective

Speaker: Berit Eberhardt (DE)

Berit Eberhardt said that patient advocates are key to accessing innovative treatments. Patient organisations can provide basic education and act as navigators to help reduce anxiety. They can help trial recruitment through advertising and involvement in trial design, including design/translation of informed consent forms. Patient organisations can support collection of real world data and assist with dissemination of trial results. They can also facilitate communication among patients, and help improve the experience of patients coming off trials.

Patient perspective

Speaker: Deb Maskens (CA)

Deb Maskens spoke about her own experience of clinical trials and how patient organisations can help with clinical trial design. She has taken part in two clinical trials, with very different experiences. Her first trial was in 2006 in Canada. She was very motivated to take part, but her experience differed significantly from her expectations due to severe side effects and quality of life issues. In 2009, she enrolled in her second trial at the National Cancer Institute (NCI), and this time expected the worst. However, with support from the medical team and other patients, she was on the drug for 3 years with barely any side effects. The drug stopped growth, with long-term stability. Patients shouldn't expect their medical team to be aware of all available trials, or to refer them. Patient organisations are in the best position to help patients find trials. Patient advocates can help researchers design better trials and improve the patient experience. They can also support researchers by making patients aware of clinical trials. When trials report, they can help to share both positive and negative results.

Impressions from the networking dinner

DAY 2 - Friday 7 April 2017

Kidney cancer survivorship: Coping with 'we got it all'

Moderator: Dr. Rachel Giles (NL)

Dr. Giles talked about how cancer patients cope after finishing treatment. Patients live in a “world of cancer shock”: anxiety regarding follow-up scans (“scanxiety”); fear of recurrence; feelings of abandonment following discharge from hospital. Patients will have had to confront their own mortality, and might feel that their body has let them down. Patients sometimes need emotional support to help cope with these feelings. Online support groups and facilitated discussions with other patients can help with feelings of isolation. Discharge summaries/care pathways in patient-friendly language can help with feelings of abandonment. A diagnosis of cancer can also affect family, work and self-image. Caregivers and family members may also need emotional support.

Components of supportive care: Advanced kidney cancer

Moderator: Rose Woodward (UK)

IKCC decision aid tool: My Treatment, My Choice

Speaker: Deb Maskens (CA) presenting Dr. Lisa Murphy's slides

Deb Maskens formally launched the first version of the IKCC decision aid tool, which is designed to help kidney cancer patients participate in decisions about their own health. It empowers patient/caregiver/family to make decisions that are right for the patient by taking into account the patient’s values and lifestyle. The decision aid does not advise people to choose one option over another, or replace the professional consultation. It is hoped the decision aid will ultimately change the face of decision-making in kidney cancer. While this is an international project, shared decision-making is not a reality in some healthcare systems and all treatments mentioned will not be available in every country.

Supportive/palliative care

Speaker: Prof. Dr. Saskia Teunissen (NL)

Dr. Teunissan spoke about palliative care and demonstrated the hopelessness felt by some during the transition from curative/restorative treatment to the palliative phase of disease where it is difficult to set goals, discuss effective treatments and prognosis. Palliative care is an approach that improves the quality of life of patients facing life-threatening illness and their families through the prevention and relief of suffering. There are four dimensions of palliative care: physical, psychological, spiritual, and social. The aim of palliative care is a better quality of life, a better quality of death, and a better quality of bereavement for the family. Palliative care is about resilience, and about hope.

New roles for radiation therapy in kidney cancer

Moderator: Joyce Graff (USA)

Warsaw is the birthplace of Marie Skłodowska- Curie, the first woman to win a Nobel Prize (in 1903) and the only woman to win it twice and in two different sciences (physics and chemistry). She was the first person to carry out studies into the radiation treatment of tumours.

Different types of radiotherapies

Speaker: Dr. Mateusz Spałek (PL)

Dr. Spałek spoke about the different types of radiotherapy and its mechanism of action. The aim of modern radiotherapy is to precisely deliver a radiation dose to the target tissue with minimal damage to surrounding healthy tissues. New techniques for increasing precision include gating (4D radiotherapy) and gold markers to follow organ movement. Radiotherapy can be curative, palliative, anti-inflammatory,and can prolong life.

DAY 2 - Friday 7 April 2017

Role of radiotherapy in advanced kidney cancer

Speaker: Susan Poteat, M.S. (USA)

Susan Poteat focused on radiotherapy for mRCC. Traditional radiotherapy has limited use in RCC since RCC was considered to be 'resistant'. She described modern radiotherapy techniques (stereotactic radiosurgery (SRS), stereotactic body radiotherapy (SBRT), and hippocampus-sparing whole brain radiotherapy (WBRT) which require advanced radiotherapy equipment not accessible to all patients. Palliative radiotherapy can be useful for symptom control (pain relief). SBRT is effective for bone metastases, especially in the spine, and SRS is common for solitary brain metastases. The use of WBRT is controversial, but is sometimes used for multiple metastases to the brain. Hippocampus-sparing WBRT can reduce the neurological side effects of WBRT. Kidney cancer patients may benefit from multi-modality treatment with immunotherapy. Patient groups can inform and educate others about radiotherapy options.

World cafe

Moderator: Professor Michael Herbst (ZA)

Reports from small group discussions:

What do you plan to do for kidney cancer patients when you get home?

Host: Prof. Michael Herbst (ZA)

The most popular take-home activity was to advertise the World Kidney Cancer Q&A Day 22nd June locally via various media, while at the same time build awareness of the local affiliate organisation. The importance of collaboration with the IKCC, other patient groups, the medical community and patients/carers/families was also stressed.

Improving patient centricity in your country

Host: Vandana Gupta (IN)

Patient-centred care puts the patient at the focus of decisions concerning treatment/care. Advocates/educators are needed to empower patients with relevant information to supplement what the doctor has time to provide. Clinical trials and patient information sheets need to be patient-centred and incorporate the needs, wants and experience of patients. Pharmaceutical companies should involve patients in the design of clinical trials. Patient centricity improves outcomes for patients; patients feel more secure, patients and families feel empowered.

Save the kidneys!

Host: Joyce Graff (USA)

Often the signs and symptoms related to problems with the kidneys are not an emergency situation and there is time to seek a second opinion. People should know the risks of recurrence of kidney cancer, especially genetic risks, and understand and use them to benefit their health.Campaigns for kidney care can be linked to other conditions, e.g., diabetes, hypertension, and in resource-limited areas/countries, non-verbal materials can be used e.g., cartoons can be used to help people appreciate what the kidneys do for us.

Building awareness of kidney cancer

Host: Anne Wilson (AU)

This workshop focused on methods to build awareness of kidney cancer, such as social media campaigns, target patient populations e.g., people over 65, people at high risk, engagement of global ambassadors, use of a common symbol for kidney cancer in media releases, posters and flyers in public places/waiting rooms/clinics, viral media, radio and TV commercials/public awareness campaigns. Campaigns need to focus awareness on risk factors for kidney cancer along with early signs and symptoms.

DAY 2 - Friday 7 April 2017

Capacity building

Moderator: Berit Eberhardt (DE)

Connecting to kidney cancer experts/ medical societies

Speaker: Dr. Michael AS Jewett (CA)

Dr. Michael Jewett encouraged organisations to engage with kidney cancer experts and professional medical societies. Potential gains from the relationship include access to reliable and up-to-date scientific/medical information, and access to appropriate care/innovative treatment. Patient-centred care is not a universal concept and evidence of the impact of advocacy on patient outcomes will help in the development of the collaboration. The partnership should be on a level playing field, and the right key opinion leaders need to be on board. No money should exchange hands. Work together in a partnership, and focus on the positive and the importance of the patient journey.

Kidney cancer research: Projects and funding

Speaker: Bryan Lewis (USA)

Bryan Lewis talked about capacity building and campaigns to fund kidney cancer research from a U.S. perspective. Kidney cancer deserves equitable treatment with other cancers with respect to research funding. Identify political stakeholders and use emotional and economic arguments, such as incidence rates, and the impact of the disease on patients and family. Personal stories have a strong impact and make connections to stakeholders. Email campaigns can be used to engage legislators. To be successful, you need to be persistent with your campaign.

Bringing kidney cancer experts together for policy change: Mexico

Speaker: Carlos Castro Sanchez (MX)

Carlos Castro Sanchez presented his experience of bringing kidney cancer experts together for policy change. The objectives were to raise awareness of kidney cancer; discuss what is being done and what is needed; and make policy proposals to stakeholders. The strategy was to hold a breakfast press conference with government representatives, media, and medical experts to discuss treatments, disease burden, health policy and challenges, followed by an academic discussion involving medical experts from the most prestigious private hospitals in Mexico. Collaboration with the Latin America Renal Cancer Group (LARCG) strengthened the case for health coverage for kidney cancer.

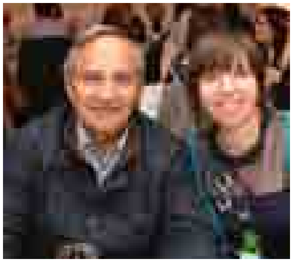
Meeting with government - advocacy/activism/action

Speaker: Deb Maskens (CA)

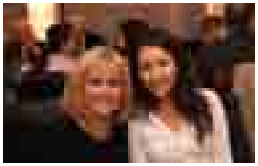
Deb Maskens shared her experience of meeting with government in Canada to influence health policy change, along with some ideas for how to make it happen. Activism (marching and protesting) is not necessarily effective in the modern world. Patient organisations need to come to the table with evidence and budgets to influence policy change. Go armed with background on the disease, what you are proposing, who is involved, who to advocate with, and when. Face-to-face meetings, handwritten letters and telephone calls have the greatest impact; e-advocacy campaigns have low impact. Choose a tangible ‘ask’ and keep it simple, achievable and action-oriented. Remain firm and persistent with the ‘ask’, look for opportunities, stay focused, anticipate objections and provide new information. Build a relationship as a trusted partner.

DAY 2 - Friday 7 April 2017

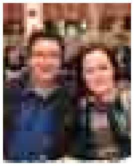
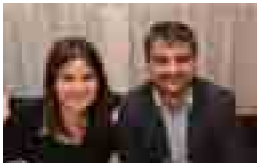
Group photo and impressions from the external networking dinner

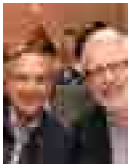








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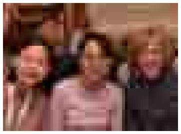
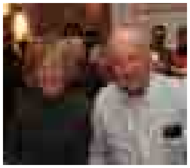
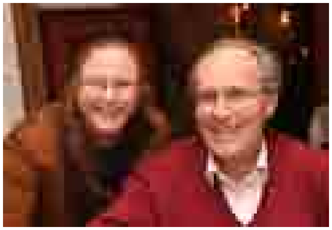
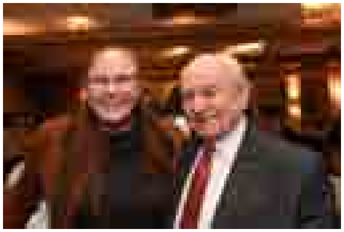




DAY 3 - Saturday 8 April 2017

Kidney cancer risk factors: Prevention including practicalities of screening

Moderator: Dr. Rachel Giles (NL)

Speaker: Professor Joanna Didkowska (PL)

Professor Didkowska opened the third day with a presentation about kidney cancer risk factors. The incidence of kidney cancer by age peaks at 65-80 years, and there are twice as many men as women with the disease. Cigarette smoking increases the risk twofold, while obesity increases risk fourfold. Physical activity has a positive effect. Other risk factors include genetic/hereditary risk factors; some chemicals used in industry (e.g. dry cleaners, trichloroethylene); certain medical conditions (e.g. kidney dialysis, hypertension); and some medicines (e.g. paracetamol, diuretics, NSAIDs). Survival rates are dependent on stage of disease. Primary prevention, (e.g. smoking cessation, maintaining a healthy weight, and controlling blood pressure) reduces the risk by 20-40%. Ultrasound screening is recommended for patients with hereditary syndromes.

Building real world evidence

Moderators: Dr. Rachel Giles (NL), Berit Eberhardt (DE)

Patient reported outcomes

Speaker: Professor N Cem Sönmez (TR)

Professor Sönmez spoke about patient reported outcomes (PROs) using health-related quality of life (HRQoL) instruments. Standardised, self-report instruments are used to measure symptoms, and how they affect the patient's capacity to function. These instruments give a unique insight into how therapy can affect how the patient feels and functions, their wellbeing, emotional state, ability to live a full life, level of comfort, and the impact of illness on loved ones. Self-report instruments capture information that needs to be measured specifically and objectively; deciding what to measure is critical. Many health technology appraisals (HTAs) are now asking for real world evidence. Patient input is essential to ensure HRQoL instruments measure outcomes important to patients. There needs to be more collaboration between researchers and patients. HRQoL should make sense to patients; this could mean the difference between positive and negative HTA decisions.

Results of National Kidney Cancer Patient Survey (Canada)

Speaker: Stephen Andrew (CA)

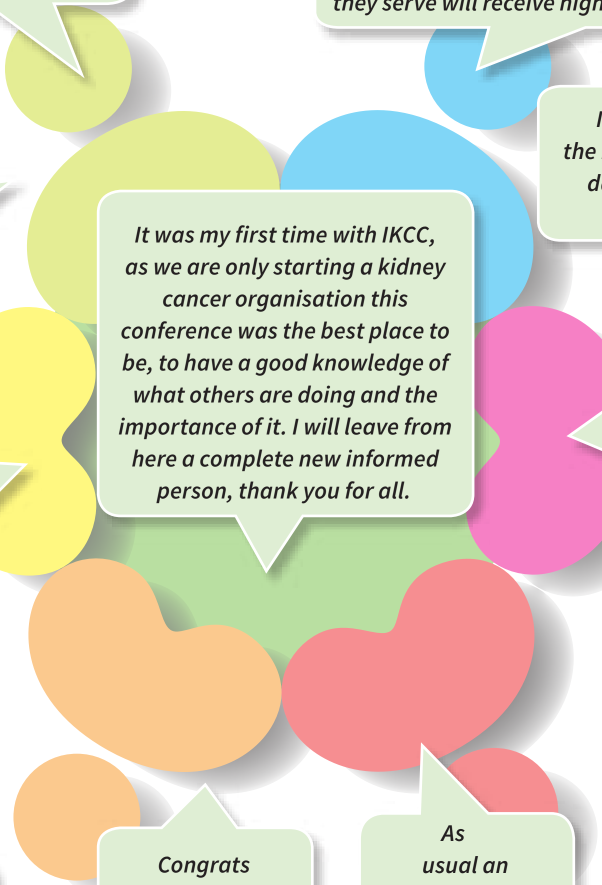
Stephen Andrew presented a Canadian national kidney cancer patient survey conducted in collaboration with the Princess Margaret Cancer Centre in Toronto. The objectives of the survey were to explore treatment awareness and choice, barriers to care, supportive care needs, unmet needs, and access to information. The questionnaire-based needs assessment was directed at both patients and caregivers. Participants were invited via email, clinics, physicians and via social media. Most patients received information about kidney cancer from their oncologist/urologist. Other sources of information were Kidney Cancer Canada and family doctors. Information from oncologist/urologist and Kidney Cancer Canada was rated most helpful. More than half of all respondents did not receive information about clinical trials and only 20% enrolled in clinical trials. Barriers to care included side effects to treatment, health system delays, access to treatment, and financial burden. Real word evidence provides an opportunity to match evidence with action plans; a worldwide survey would be very useful.

End of conference

Moderators: Dr. Rachel Giles (NL),
Katarzyna Teodorczyk, Galdiator (PL)

Dr. Giles and Ms. Teodorczyk closed the conference by thanking everyone for their active participation and for coming together to contribute to the international kidney cancer community. It was a great honour that IKCC decided to hold the conference in Warsaw, Poland. Meeting friends from around world provides the incentive needed to help patients with kidney cancer and to tackle the global burden of this disease. Patient organisations can go home with the knowledge and ideas imparted by the many magnificent speakers.

2017 Conference Feedback



Attending the annual conference last year as a speaker and meeting so many people working to improve care in 3rd world countries was one of the most moving experiences I have ever had.

I was very impressed by the passion, diversity and expertise of the IKCC Board and members. It is clear that the patient groups they serve will receive high quality resources.

The professional presentations were sensational as were the insights from individual affiliates.

I think this has been one of the best IKCC annual meetings to date. Congratulations to the organising committee.

It was my first time with IKCC, as we are only starting a kidney cancer organisation this conference was the best place to be, to have a good knowledge of what others are doing and the importance of it. I will leave from here a complete new informed person, thank you for all.

Thank you so much for organising the conference. I thought it was excellent and it was lovely to see all the other delegates.

Thank you very much for a great conference and for the practical take-home tools such as the Decision Making Aid & Kidney Cancer Data Toolkits. These are very valuable, not only for kidney cancer issues but as examples to replicate in other diseases.

*I want to thank you for inviting me to the 7th International Conference on the fight against kidney cancer.
I'm very glad that there is such a world organization that helps people cope with the disease of kidney cancer.*

As usual an excellent meeting.

Congrats to all the IKCC organizers for the 2017 Conference.

It was very nice and interactive. Nice to know all the participants and to have network groups. Very busy three days.

2017 Financial Statements

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

Independent Financial Office
Administratiekantoor APN
(Administration for Patient organisations in the Netherlands)
S. van Haarlemstraat
4003VG Tiel
Netherlands
www.stichtingapn.nl

IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2017		
CURRENT ASSETS		
Prepayments	€	**49.267**
Liquid assets	€	**254.814**
TOTAL CURRENT ASSETS	€	**304.081**
CURRENT LIABILITIES		
Creditors and borrowings	€	**(110.143)**
TOTAL CURRENT LIABILITIES	€	**(110.143)**
NET ASSETS	€	**414.224**
ACCUMULATED FUNDS		
Reserves	€	**6.360**
Last year profit/(loss)	€	**83.315**
Current year profit/(loss)	€	**104.788**
TOTAL ACCUMULATED FUNDS	€	**194.463**

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 2017

On the recommendation of the IKCC Board to streamline financial operations, in 2017 the IKCC began a transition of management services from Das Wissenshaus in Germany to the Netherlands, resulting in a transition of financial management.

As Secretary/Treasurer of IKCC it gives me great pleasure to present our Annual Financial Overview for 2017. The organisation is well managed and remains in a healthy financial position with funds appropriately allocated to the Mission and Vision of the organisation.

The independently reviewed financial statements for 2017 are to be presented at our Annual General Meeting and subsequently posted on our website www.ikcc.org.

We continue to be indebted to our Sustaining Partners whose support of our work on behalf of those with kidney cancer allows us to deliver significant outcomes through the important projects we continue to deliver as demonstrated in this Activity Report.

In 2017 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 2018 and beyond.

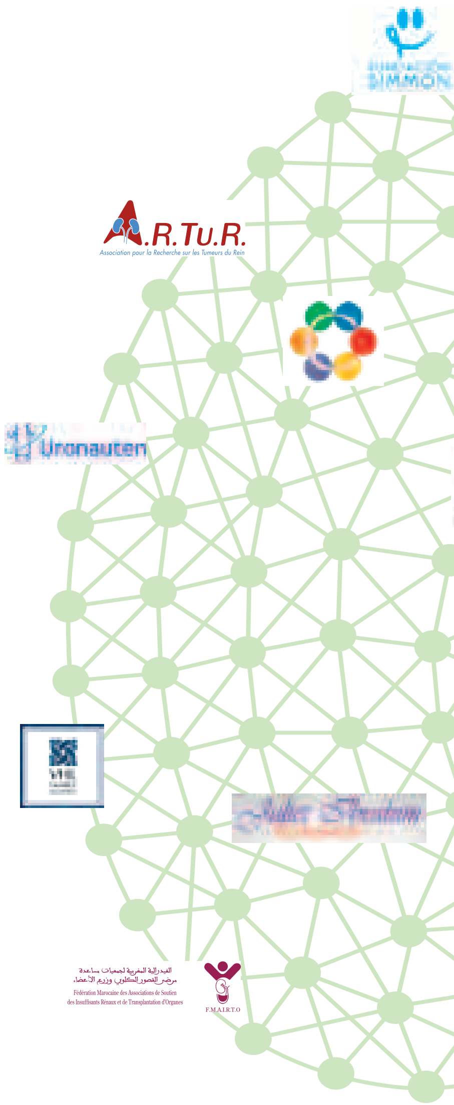
Anne Wilson

Secretary-Treasurer
IKCC Board

Joining IKCC

AFFILIATED
ORGANISATION
of
IKCC
International
Kidney Cancer
Coalition

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



AFFILIATED ORGANISATION

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.

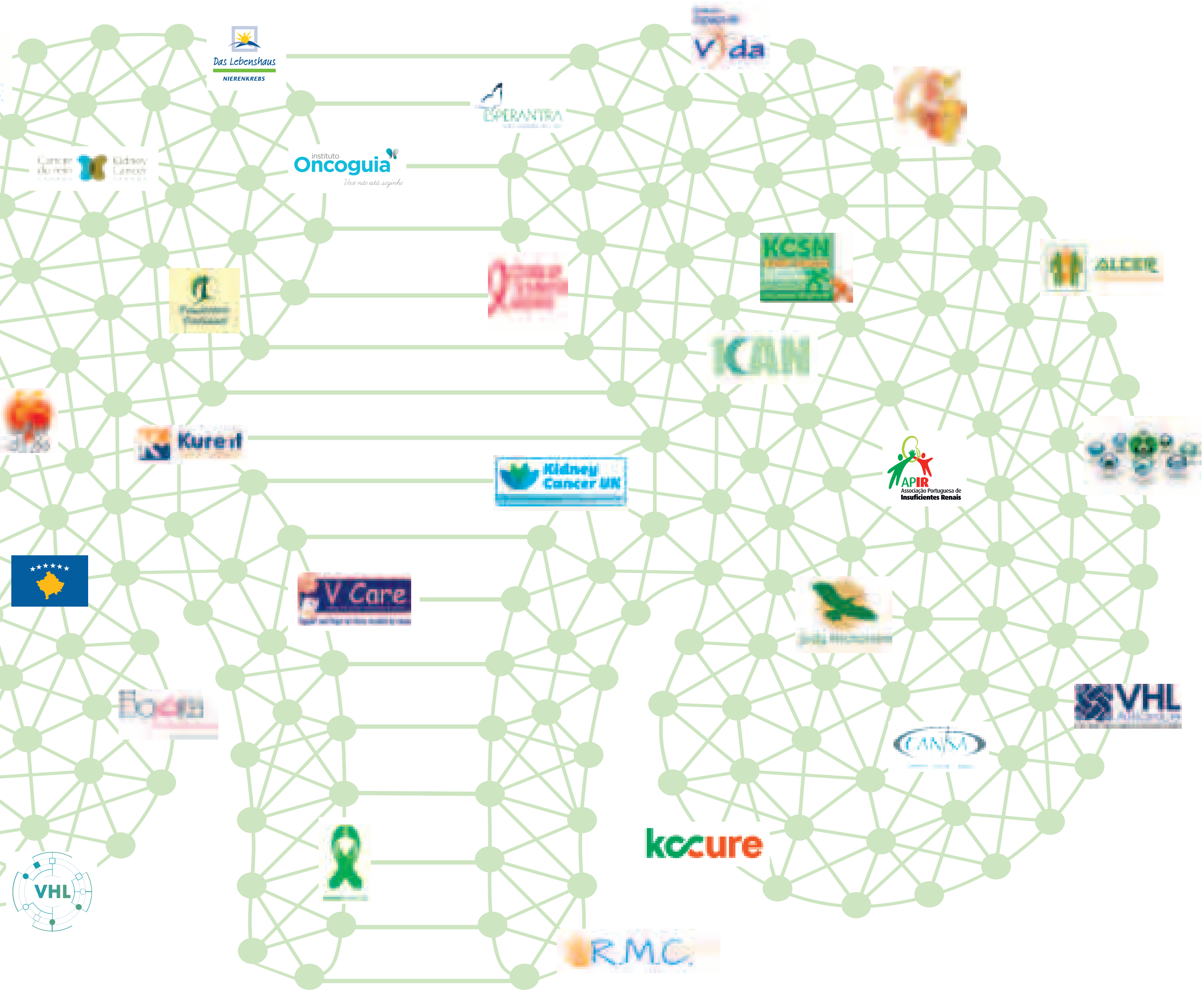
SUPPORTER

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/


Das Lebenshaus
NIERENKREBS
ESPERANTRA
instituto Oncoguia
Você não está sozinho
Cancer du rein
Kidney Cancer
Vida
KCSN
ALCER
ICAN
Kure it
Kidney Cancer UK
APIR
Associação Portuguesa de Insuficientes Renais
V Care
VHL
VHL
kccure
RMC

IKCC Affiliated Organisations

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

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

AFFILIATED
ORGANISATION
of
IKCC
International
Kidney Cancer
Coalition

IKCC 2017: Board Members

RACHEL GILES, MD, PhD (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.S.M. (Vice Chair)

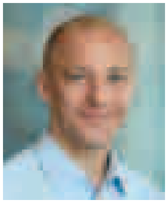
Kidney Cancer Canada

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 is leading a successful coalition campaign of 35 cancer organisations (CanCertainty) toward full public coverage of oral cancer medications. Deb is a founding member and Vice-Chair of the IKCC.

BERIT EBERHARDT

Das Lebenshaus e.V., Germany

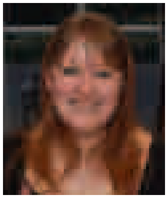
Berit was caregiver to her significant other who died at age 39 just one year after diagnosis with kidney cancer. She learned about the disease, its treatment and the needs of patients and caregivers in the same situation. She shared her knowledge by establishing a patient support group in her home town. Shortly after, she became manager of kidney cancer of Das Lebenshaus e.V. Berit's interest in kidney cancer propels her to raise awareness, connecting people with existing resources and highlighting gaps in services.She works persistently to establish new ideas, materials, and support for those affected by kidney cancer. She provided the patient perspective for the German Kidney Cancer Guidelines, represents the IKCC on the Patient Advisory Committee of the ECCO (European CanCer Organisation) speaks on kidney cancer topics at German and EU meetings, and is IKCC co-lead for medical treatment and care.



Eric Jonasch, MD

Professor of Medicine

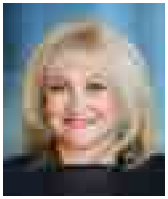
Dr. Jonasch is Professor in the Department of Genitourinary Medical Oncology, Division of Cancer Center at the University of Texas M. D. Anderson Cancer Center in Houston, Texas. He is director of the VHL Clinical Center at the MD Anderson Cancer Center, co-Director of the MD Anderson Kidney Cancer Research Program, and performs clinical, translational and basic research in kidney carcinoma and VHL disease. Dr. Jonasch has authored over 180 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 is a member of the National Cancer Centers PDQ Kidney Cancer Genetics Board, 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.



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 three 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 is also overseeing project management of World Kidney Cancer Day.

ROSE WOODWARD

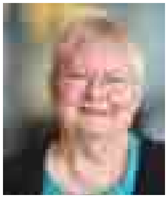
Kidney Cancer Support Network (UK)

Rose is a patient survivor of kidney cancer. She founded the Kidney Cancer Support Network in 2006 to provide much needed information, support and advocacy for kidney cancer patients, their carers and families. The organisation has grown to become the most widely used and most active patient-led charity in the UK supporting people affected by kidney cancer. Rose enjoys a very active life as a committed and experienced patient advocate dedicated to empowering patients to play a full role in all aspects of their own care. Rose serves as a full member of the National Cancer Research Institute renal cancer studies group where she works hard to promote the proven benefits of patient involvement in all aspects of research ranging from clinical trial design through to survivorship studies. Rose is proud to be a founding member of the IKCC and honoured to be a Board Member to help improve the lives of kidney cancer patients wherever they live in the world.

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. His research is currently focused in kidney cancer but he has published extensively in other UroOncology subjects, clinical trials, technology assessment and medical informatics. He has had a long interest in many aspects of kidney cancer research, patient care and knowledge transfer. He has been 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.



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.

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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.

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