

# Patient organisations working together globally to support those affected by kidney cancer.

Activity Report 2016



Letter from the Board	03
Kidney Cancer Basics	04
Patient Charter for Global Kidney Cancer Care	08
Clinical Trials - A Patient Advocate’s Perspective	10
IKCC Profile	14
IKCC at a Glance	16
IKCC Conference Report 2016	17
IKCC Projects and Activities (Excerpt)	41
IKCC Financial Overview	48
Acknowledgements	49
Joining IKCC	50
IKCC Affiliated Organisations	52
IKCC 2016 Board Members	54

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

Welcome to our Activity Report for the calendar year 2016. 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 2016, we met in the countryside outside of Paris in Chantilly, France. Inspired by a keynote lecture by Dr. Bernard Escudier, founder of ARTuR, we focused on 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 raise awareness of kidney cancer globally. You will find the Conference Report from this meeting as part of this Activity Report.

Following our conference, we began several ambitious projects: Our discussions on shared decision making prompted an ambitious project to develop a Decision Aid for Advanced Kidney Cancer. This project, led by our affiliate organisation in Australia, Kidney Health Australia, aims to ensure that the patient is at the centre of decision making for advanced kidney cancer.

Thanks to your brainstorming efforts on awareness building, we began work on the first-ever World Kidney Cancer Day to be launched on June 22, 2017. This multi-year project has involved medical experts collaborating on an evidence-based paper, along with communications professionals who have provided advice and creative ideas to engage the public, the medical community, and the media.

We continue to publish our work in medical journals, with IKCC listed as a contributing author in the medical database PubMed. This year we co-authored three papers in the number one journal in the field of urology, European Urology. In turn, we **(1)** reviewed the data published about whether taking sunitinib after surgery helps patients; **(2)** looked at all the evidence to treat the approximately 15% of advanced kidney cancer patients that do not have clear cell histology; and **(3)** Considered the best approach to treat advanced kidney cancer patients with tumours that have become resistant to the first-line targeted therapies currently approved. By working with the medical community to generate these papers, 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 worldwide.

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



(1) Bex et al. Updated European Association of Urology Guidelines Regarding Adjuvant Therapy for Renal Cell Carcinoma. Eur Urol. 2016 Dec 13. pii: S0302-2838(16)30886-7.

(2) Fernández-Pello et al. A Systematic Review and Meta-analysis Comparing the Effectiveness and Adverse Effects of Different Systemic Treatments for Non-clear Cell Renal Cell Carcinoma. Eur Urol. 2017 Mar;71(3):426-436.

(3) Powles et al. European Association of Urology Guidelines for Clear Cell Renal Cancers That Are Resistant to Vascular Endothelial Growth Factor Receptor-Targeted Therapy. Eur Urol. 2016 Nov;70(5):705-706.

# Kidney Cancer Basics – A Global Disease

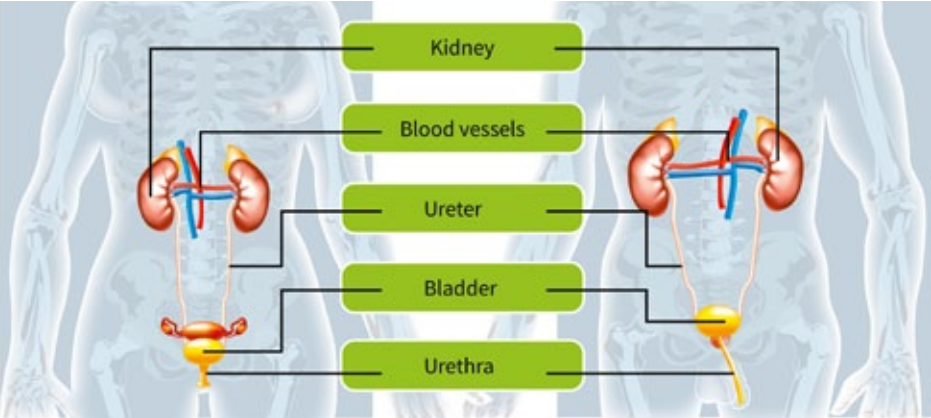
Kidney cancer is considered a rare cancer; worldwide there are about 337,860 new cases of kidney cancer each year, accounting for around 2% of all cancers and making it the 13th most common cancer. Globally, the incidence of kidney cancer has been increasing; in part due to better scanning facilities, although the increase in the prevalence of certain risk factors, such as smoking and obesity, might also contribute.

Cancers of the kidney result from malignant transformation of the urothelium (lining of the collecting system) or renal parenchyma. Cancer of the urothelium is called transitional cell carcinoma (TCC), which is treated in a similar manner as bladder cancer. This article focuses on renal cell carcinoma (RCC) – cancer of the renal parenchyma.

### Types of kidney cancer

There are several different types of kidney cancer. The most common is RCC, which accounts for more than 80% of all kidney cancers. There are eight sub-types of RCC, which are classified according to the appearance of the cancer cells under the microscope:

- Clear cell is the most common sub-type (75-80% of cases)
- Papillary (or chromophilic, 10-15%)
- Chromophobe (5%)
- Collecting duct
- Renal medullary carcinoma
- Mucinous tubular and spindle-cell carcinoma
- Renal translocation carcinoma
- Unclassified RCC (the latter five are very rare and make up the remaining 5-10% of RCC tumours)



Nephroblastoma (or Wilms’ tumour) is a kidney cancer found in children, usually between the ages of 2 and 5.

### Causes

Tumours within the kidney have been found in any age group but are most common in people over 55, and they are more common in men than in women with a ratio of 16:10. The major risk factors for kidney cancer are obesity (70% increased risk) and cigarette smoking (50% increased risk).

Certain medical conditions and treatments, such as cystic kidney disease, dialysis, renal stones, hypertension, and previous abdominal radiotherapy, can increase the likelihood of developing kidney cancer.

There are also some inherited conditions that can give a higher risk of developing kidney cancer. These include von Hippel-Lindau (VHL) syndrome, Birt-Hogg-Dubé syndrome, and hereditary papillary RCC (HPRCC).

### Worldwide Incidence

The highest rates of kidney cancer are in some parts of Europe (16.67 per 100,000 in the Czech Republic, 13.21 per 100,000 in Lithuania, 12.54 in Slovakia and 11.67 in Estonia), and the USA (11.97 per 100,000 people). The lowest rates are in Asia and Africa (ranging from 0.62 per 100,000 people in Central Africa to 4.21 per 100,000 in Eastern Asia).

The incidence of kidney cancer does not vary significantly in the developed countries, with Canada and Australia reporting incidence rates slightly less than the USA and slightly more than Europe (11.97 per 100,000 in USA, 9.29 per 100,000 in Canada, 9.48 per 100,000 in Australia, 8.77 per 100,000 in Europe).

Worldwide, kidney cancer is the 16th most common cause of death from cancer; in 2012, there were more than 143,000 deaths from kidney cancer (2% of the total). Mortality rates are highest in Central and Eastern Europe, and lowest in Micronesia and Polynesia.

### Symptoms

The classic symptoms of kidney cancer are haematuria (blood in the urine), loin pain and abdominal mass, but only 10% of people present with all three of these symptoms together. Back pain, night sweats, polycythaemia, and a left-sided varicocele (in men) can also lead to a diagnosis of kidney cancer.

More than 50% of renal tumours are now detected when using ultrasound for non-specific symptoms, such as general abdominal pain, hypertension, malaise, weight loss, anorexia, anaemia, elevated C-reactive protein, or abnormal liver function tests.

Unfortunately, 25-30% of people with kidney cancer present with symptoms of metastatic disease, such as; a persistent cough, frequent headaches, bone pain, or abnormal liver function tests.

### Methods of Diagnosis

Currently, there are no screening programmes for kidney cancer. The advantage of early detection is successful removal of the affected kidney to prevent the spread of the disease. As the tumour grows and the lymph nodes become involved, the 5-year survival rate decreases from 90% for stage 1 disease to 40-70% for stage 3, and 10-40% for stage 4.

Those who present with haematuria (blood in urine) usually have a urine test to rule out infection. If there is no evidence of infection, or the haematuria continues, the person is usually referred to hospital, and may have a renal ultrasound scan, cystoscopy and/or CT to differentiate between TCC and RCC.



Other tests, such as magnetic resonance imaging (MRI), positron emission tomography (PET), or a bone scan might be undertaken to assess the spread of the disease.

### Staging and Grading

Kidney cancer is graded according to the Fuhrman nuclear grading system as low grade (grade 1; slow growing, less aggressive) through high grade (grade 4; fast growing, extremely aggressive, likely to spread).

Staging using the TNM system is used to describe how big a cancer is and how far it has already spread. T (tumour) indicates the size of the primary tumour (less than or greater than 7 cm) and how far it has grown locally, N (nodes) indicates spread to nearby lymph nodes (1 for a single lymph node, 2 for more than one), and M (metastases) refers to whether the cancer has spread (0 refers to no spread, 1 refers to distant metastases).

Sometimes the cancer is classified as stage 1, 2, 3 or 4 reflecting how large the primary tumour has become, and whether the cancer has spread to lymph nodes or other areas of the body. A stage 4 tumour is often referred to as ‘advanced’ cancer.

### Surgery

Nephrectomy is usually the first thing doctors consider, and it can cure early stage cancer. The tumour can be removed using partial nephrectomy (or nephron-sparing surgery), to remove only the portion of the kidney containing the tumour, or radical nephrectomy, when the whole kidney is removed. Partial nephrectomies are usually only performed for early stage (stage 1) tumours less than 7 cm in size.

Nephrectomies may be carried out using open surgery or laparoscopic (keyhole) surgery, sometimes using a robot to assist the surgeon (robot assisted surgery).

Ablative techniques, such as cryotherapy (freezing), radiofrequency ablation (heating) and high intensity ultrasound can be used to treat small kidney tumours. These techniques are less invasive than surgery, and have shorter recovery times; however, they are not widely used and their success is yet to be proven.

# Kidney Cancer Basics – A Global Disease

## Biological and Targeted Therapies

A number of biological and targeted therapies are used for the treatment of advanced kidney cancer, including immunotherapies, targeted therapies and monoclonal antibodies.

Immunotherapies, such as interferon and interleukin 2 (cytokines), stimulate the immune system to attack the cancer cells. Cytokines were the first systemic treatments for advanced kidney cancer in the early 1990s; however, in recent years they have been superseded by targeted therapies.

A small minority of patients (about 5%) have a long-term durable response to high doses of interleukin 2. This proportion is increased to around a quarter in carefully selected patients. Interleukin 2 therefore still has a place in the treatment of a small percentage of patients where it offers the hope of durable remission.

New immunotherapies, such as PD-1 and PD-L1 inhibitors, and vaccines are now becoming available for kidney cancer, having been proven effective for melanoma and non-small cell lung cancer.

In most countries, targeted therapies are used in the treatment of advanced kidney cancer. These drugs block the pathways involved in new blood vessel growth (angiogenesis) essential for cancer cells to proliferate. They also block signals within the cancer cells that trigger cell growth and division.

Targeted therapies include vascular endothelial growth factor receptor (VEGFR) inhibitors (tyrosine kinase inhibitors), mTOR inhibitors, and monoclonal antibodies.

## Radiotherapy

While kidney cancer is widely regarded to be less sensitive to radiation than other types of cancer, recent advances in this field are revisiting the value of radiotherapy in RCC; for example, radiotherapy can be very successful at controlling symptoms and slowing down the growth of metastases in the brain, liver, lung and pancreas. Stereotactic radiotherapy (also called stereotactic radiosurgery or SRS, Gamma Knife®, CyberKnife®, or Stereotactic Body Radiotherapy or SBRT) uses high doses of radiation directed at the cancer using a frame to increase precision and reduce damage to surrounding tissue.

## Access to treatment

Although these treatments are licensed in many countries around the world, access remains a problem. Due to the high cost of medicines approved for kidney cancer, some government reimbursement schemes will only fund first and possibly second-line treatment. After this, the patient must pay for treatment privately or through insurance, enrol on a clinical trial, or obtain treatment through compassionate use programmes. Some countries have introduced systems to alleviate this problem, such as patient access schemes; however, as development costs soar and kidney cancer becomes a chronic condition, the issue of drug access will be a continuing problem for many patients.

## Research

Research into new treatments for kidney cancer is currently very exciting, especially with the resurgence of immunotherapy in recent years. Checkpoint inhibitors bring renewed hope for the treatment of advanced RCC, and clinical trials with cancer vaccines and more potent targeted therapies show promise. Clinical trials are ongoing in a number of countries with these products. Some of these drugs are being used in combination with other immunotherapies or targeted therapies to boost their effectiveness.

## National Guidelines for Treatment of Kidney Cancer

A number of countries have developed guidelines for the treatment of kidney cancer, which help to provide a more consistent approach to treating this disease. These guidelines are reviewed at least annually in most countries. When a country doesn't have guidelines, they might choose to adopt those of another country where the guidelines are established. Guidelines for the treatment of kidney cancer can be found for Canada, the European Union, Mexico, Ukraine, United Kingdom, and United States.

Global kidney cancer statistics can be found at: Cancer Incidence and Mortality World-wide: GLOBOCAN 2012, International Agency for Research on Cancer: Available from: [www.globocan.iarc.fr](http://www.globocan.iarc.fr)

Further information about kidney cancer can be found on the IKCC website: [www.ikcc.org/types-of-kidney-cancer/](http://www.ikcc.org/types-of-kidney-cancer/)

Information about the new immunotherapy (immuno-oncology) drugs for kidney cancer can be found on the “Ten for IO” website: [www.10forio.info](http://www.10forio.info).

Information about national kidney cancer guidelines can be found on the IKCC website [www.ikcc.org/kidney-cancer-demographics/national-guidelines-and-standard-of-care/](http://www.ikcc.org/kidney-cancer-demographics/national-guidelines-and-standard-of-care/)



Approved Medications for Kidney Cancer (mRCC) – in alphabetical order:					
Active Agent	Brand Name	Research Code	Dosage Form	Company	Approval by FDA/EMA
Aldesleukin/IL-2/Interleukin	Proleukin™		Intravenous Infusion	Novartis (formerly: Chiron Corp.)	1992
Axitinib	Inlyta™	AG-013736	Tablets	Pfizer	2012
Bevacizumab (in combination with interferon alpha)	Avastin™		Concentrate for Infusion	Roche / Genentech	2009/2007
Cabozantinib	Cabometyx™	XL184	Tablets	Exelixis / Ipsen	2016
Everolimus	Afinitor™	RAD001	Tablets	Novartis	2009
Interferon alpha-2a	Roferon Alpha™		Injection (Subcutaneous)	Roche / Genentech	1987
Lenvatinib (in combination with Everolimus)	Kisplyx™ (EU) / Lenvima™	E7080	Capsules	Eisai	2016
Nivolumab	Opdivo™	ONO-4538 BMS-936558 MDX1106	Concentrate for Infusion	BMS Bristol-Myers Squibb	2015/2016
Pazopanib	Votrient™	GW786034	Tablets	Novartis (formerly: GSK)	2009/2010
Sorafenib	Nexavar™	BAY43-9006	Tablets	Bayer	2005/2006
Sunitinib	Sutent™	SU11248	Capsules	Pfizer	2006
Temsirolimus	Torisel™	CCI-779	Concentrate for Infusion	Pfizer (formerly: Wyeth)	2007



Patient Charter for Global Kidney Cancer Care

The International Kidney Cancer Patient Charter was created by the International Kidney Cancer Coalition (IKCC.org) to ensure that the more than one million people living with kidney cancer worldwide<sup>1</sup> have access to the best available treatment, care, information and support. It is our aim to assist national kidney cancer patient organisations help patients and their families all over the world, get the necessary information to take an active role in the management of their kidney cancer and to gain a better awareness of what they can expect from their treatment and care.

The Charter is based on a survey extended to 34 patient group leaders with a special interest in kidney cancer, located in 20 countries spread over 6 continents. Based on the 22 responses, this charter represents the global response that all kidney cancer patients should be entitled to, in order of reported importance.

The Charter was developed in Amsterdam in April 2014, when the IKCC convened a meeting of leading kidney cancer experts and advocates from diverse geographic regions. This group discussed the issues surrounding kidney cancer and outlined the universal standards of care that patients should expect, with the goal of enabling patients to become active, informed and empowered participants at every stage of their treatment. All parties noted that the current situation could be improved if those involved in the care and treatment of patients adopted the principles outlined in the Charter on a global scale.

1.	Timely investigation and accurate diagnosis by medical experts with experience in treating kidney cancer
2.	Patient-oriented information and education concerning all treatments including quality of life, side-effect management, pain control, and palliative care
3.	Access to optimal, current evidence-based treatment as suggested by a multi-disciplinary team of medical professionals possessing specialist knowledge about kidney cancer
4.	Regular follow-up care concordant with national and/or international guidelines including appropriate and culturally sensitive psycho-social support
5.	Access to their medical records, including pathology and imaging reports, if requested
6.	Be informed of all available support systems, including patient support tools and local patient support and advocacy organisations
7.	An active role in the decision-making concerning the management of their kidney cancer, e.g. patients should be offered a choice, whenever possible, in the surgical and medical management of their kidney cancer
8.	Information regarding the availability of clinical trials in their country/region
9.	Recognition that kidney cancer can have long-term effects, including heart disease and kidney function insufficiency. Patients should be provided survivorship information, including medical and lifestyle recommendations
10.	Recognition that up to 10% of all kidney cancer tumours are hereditary in nature, as part of familial syndromes, and these patients require specialised and coordinated care over their entire lifetime

<sup>1</sup>338,000 diagnoses in 2012 alone, source: [www.wcrf.org/cancer\\_statistics/data\\_specific\\_cancers/kidney\\_cancer\\_statistics.php](http://www.wcrf.org/cancer_statistics/data_specific_cancers/kidney_cancer_statistics.php)

Signed in 2014 by:

Anne Wilson  
*(Managing Director and CEO), Kidney Health Australia, Australia  
(www.kidneycancer.org.au)*

Luciana Holtz  
*(President and CEO), Instituto Oncoguia, Brazil (www.oncoguia.org.br)*

Deborah Maskens  
*(Co-Founder), Kidney Cancer Canada, Canada (www.kidneycancercanada.ca)*

Timo Koponen  
*(Patient Advocate, Support Group of the Kidney and Bladder Cancer),  
The Association for Finnish Cancer Patients, Finland (www.syopapotilaat.fi)*

Denis Brezillon  
*(Volunteer Patient Advocate), Association pour la Recherche  
sur les Tumeurs du Rein, France (www.artur-rein.org)*

Berit Eberhardt  
*(Manager Kidney Cancer), Das Lebenshaus eV, Germany  
(www.lh-nierenkrebs.org)*

Kinga Mathe  
*(Patient Advocate), Das Lebenshaus eV, Germany (www.lh-nierenkrebs.org)*

Athina Alexandridou (Chairman),  
*VHLFA Alliance Affiliate in Greece, Greece (www.vhlgr.blogspot.gr/)*

Jolan Demeter  
*(Vice President), Hungarian League Against Cancer, Hungary (www.rakliga.hu)*

Vandana Gupta (Founder),  
*V Care Foundation, India (www.vcarecancer.org)*

Luan Percuku  
*(Medical Doctor), Kosovo Association for Cancer Care, Kosovo*

Lisa Bracht (Chair),  
*Dutch Kidney and Bladder Cancer Association, the Netherlands  
(www.waterloop.nfk.nl)*

Rachel H. Giles (Chair),  
*Dutch VHL Organisation, the Netherlands (www.vonhippellindau.nl)  
and International contact for Dutch Kidney and Bladder Association  
(www.waterloop.nfk.nl)*

Barbara Bezemer (Coach and Writer, Board Member),  
*Dutch VHL Organisation, the Netherlands (www.vonhippellindau.nl)*

Tadeusz Wlodarczyk (President),  
*Association Gladiator, Poland (www.gladiator-prostata.pl)*

Michael Herbst (Head of Health),  
*Cancer Association of South Africa, South Africa (www.cansa.org.za)*

Inna Krulko (Head of Projects),  
*Ukrainian Union of Patients Organisations, Ukraine (www.patient.in.ua)*

Rose Woodward (Founder and Patient Advocate),  
*Kidney Cancer Support Network, UK (www.kidneycancersupportnetwork.co.uk)*

Barry L Hoeven (Director),  
*Kure It Cancer Research, USA (www.kureit.org)*

Joyce Graff (Founder),  
*VHL Family Alliance, USA; (Director) Powerful Patient Inc., USA  
(www.powerfulpatient.org)*

Ilene Sussman (Executive Director),  
*VHL Family Alliance, USA (www.vhl.org)*

(Reviewed: Oct 2014)

# Clinical Trials - A Patient Advocate’s Perspective

Clinical trials are an essential step in the development of novel treatment methods for cancer and other diseases. They show researchers what works for the welfare of patients and what does not. In addition to safety and effectiveness, they also determine whether the side effects of a new treatment are acceptable and, increasingly, what quality of life for patients is associated with a new therapy. Clinical trials are an important component of treatment concepts for rare forms of cancer because the standard forms of therapy are often limited. Nevertheless, only up to 5% of cancer patients actually participate in clinical trials. Recent studies show that 3 out of 5 phase III trials are not able to recruit the necessary number of patients. Many experts now criticize the high costs of trials, the long duration, the unrealistic design and lack of consideration for patient needs.

The following interview offers the perspective of Markus Wartenberg from Germany about clinical trials from the point of view of patients and patient support groups. Markus is one of the Co-Founders of IKCC and an advisor to the IKCC-Board of Directors. He is also the current President of SPAEN Sarcoma Patients EuroNet Assoc. – the international network of Sarcoma, GIST and Desmoid Patient Advocacy Groups.

## What are the most important aspects of clinical trials from the point of view of patients?

This topic is an extremely important and complex one from the point of view of patient organisations. The first thing to realize is that people who are diagnosed with cancer and who become patients hardly ever know anything at all about clinical trials. Only a few of them will know what clinical trials are, how they are carried out, and what benefits and risks they have, and few are able to understand the terminology that is commonly used in clinical trials. When they are diagnosed, many patients do not even realize that the treatments they are undergoing are based on clinical trials which other patients before them participated in and which they may have benefitted from or not. Society as a whole and the health care systems in particular make far too little effort to inform people about clinical research. As a result it is quite common to encounter patients who think that clinical trials involve “experiments” and who thus refuse to serve as “guinea pigs”. Or patients think that participating in a clinical trial is something you do as a “last resort”; they think that only when nothing else helps, maybe a trial will help them. And yet patient organisations have been educating patients about clinical trials for years and providing valuable support.



## As previously mentioned, many clinical trials have difficulties recruiting patients, and only up to 5% of all cancer patients take part in clinical trials. What is the reason for this?

For years, clinical trials have been developed **for** patients, but not developed **with** them. Unfortunately, the perceptions, needs, and reality of the patients rarely play a role in the design and implementation of clinical trials. Many researchers think they know what is best for patients, instead of involving patient groups in the early planning stages of a trial. There is no discussion of study endpoints that would be relevant to patients. A few simple factors are often the ones that determine whether a patient participates in a study or not.

During recruitment, numerous clinical trials lose many patients who would have been eligible for the trial. Studies have shown that clinical trials can have “leaks”, like a water pipe, that can lead to one patient after another getting lost to the trial. One study showed that of 276 patients who were eligible for a trial, only 39 (14%) were included in that trial. The loss of patients was mainly due to three factors:

1. **Awareness:** 38% of the patients were not referred to the study centres.
2. **Design:** 56% were supposedly not eligible for the study.
3. **Information:** 49% were not willing to give their written consent to the study.

## Does that correspond to your experience and do you have any practical examples?

Absolutely! It all begins with finding out about a trial. Where should patients find information about clinical trials? On sites like [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or on the websites of pharmaceutical companies? That is completely unrealistic. Patients rely on their own doctors, or look for information in networks related to their disease at university centres or on websites, or they get information from other patients or from patient advocacy groups. In the case of rare cancers, the cooperation between patient groups, experts, and the pharmaceutical industry is particularly important. When it comes to communicating with the patients about the few clinical trials that are available, it has to be done in a timely and easily understandable manner.

Timely means not too early, for example, so as not to awaken great hopes that may later be disappointed as a result of delays. Another problem occurs when patients are referred to university centres: We have often experienced cases where even the doctors were not informed about the study or were not willing to get information about a study or to refer patients to the study centres because they were afraid they would lose their patient.

Clinical Trial Design. We could talk about this topic for hours. The central question is what new findings can be expected and how can patients really benefit from the trial. There are far too many trials that simply reaffirm something already known or that attempt to

confirm questionable hypotheses or that are carried out for strategic, marketing-related reasons. Very often the design of the trial – for a variety of reasons – is far removed from the day to day reality of the clinic or from patients’ needs. Or too much importance is placed on the opinions of statisticians or of the authorities or on concerns related to the approval process or to the question of funding. Trials often entail emotional, physical, and cognitive stress for patients, a fact which should be taken into consideration in the design of the trial. Particularly clinical trials for rare cancers require innovative, methodologically different approaches which are commensurate with the rarity of these diseases. In October 2014, Rare Cancers Europe, a multi-stakeholder initiative, presented a consensus paper that contains the commonly shared ideas of doctors, researchers and patient representatives. Essentially it deals with the creation of new approaches for generating evidence about rare cancers. These include the factorization of pre-clinical data, evidence, and analyses of retrospective or anecdotal cases as well as new forms of randomized clinical trials. In practice, the information provided about trials often leaves much to be desired. Some patients are recommended for trials that have no rationale for their situation. When giving their consent, patients may feel under time pressure, or may not have properly understood what the study is about or may not even be aware of the fact that they are participating in a study. A very problematic issue that persists concerns the information material available for patients. The goal of the process of informed consent should actually be that patients give their consent after

# Clinical Trials - A Patient Advocate's Perspective

having been fully informed. Yet it is unreasonable to expect that patients can be fully informed after reading page after page of text written in specialist medical and legal jargon and featuring tables and graphs that are completely inaccessible and incomprehensible to patients. In such matters patient advocacy groups provide valuable support – which unfortunately often remains unappreciated by those who carry out the studies.

**You mentioned emotional, physical and cognitive stress for patients. What exactly do you mean by that?**

It is well known that a cancer diagnosis is a great shock for patients and their loved ones. Life changes suddenly and dramatically after a cancer diagnosis. The initial shock then gives way to enormous physical, emotional, and everyday challenges. In this respect a clinical trial represents a further, new challenge to overcome.

The **emotional aspect** plays an important role here. For most patients, clinical trials are something unknown, a new territory. The patient may feel afraid, confused, and suddenly unable to carry on and to make decisions. What's more, they often are urgently in need of a solution, and invest a great deal of hope in the trial.



The **physical aspects** pertain to questions related to the way the study is organized and how the patient's everyday life can be accommodated with regard to such matters as distance, mobility, expenses, scheduling, missing work days and undergoing additional testing and examinations. There may also be new and unfamiliar side effects and changes in quality of life to contend with.

The third aspect involves **cognitive stress**. What previous experiences with trials are there? What image does a therapy have in the market or in its use for other indications? What is the relation between risks and benefits? Another issue is the patient's worry that he or she will be assigned to the placebo arm or will receive a "non-innovative" therapy. Patients also often wish to have contact with other participants in the trial. There is also the important question: If the new medication works for me, how long will I be able to take it? These questions and many others must be taken into account in the design and implementation of clinical trials.

**Which approaches do you think could lead to better, more patient-centred trials and higher participation rates?**

As previously mentioned, the solution lies in closer cooperation, i.e. in developing clinical trials from the perspective of the patient and in close collaboration with patient organisations. I'd like to address my appeal to two groups: On the one hand, doctors, principal investigators, researchers, and representatives of the pharmaceutical industry are called on to involve patient representatives in the early stages of a trial and to make use of their knowledge. On the other hand, patient groups and patient support groups should be emboldened to demand involvement in clinical research, and to become involved in a competent way, and to educate themselves. Some initiatives have already been launched for patients to learn more and to educate themselves, such as the European Patients Academy on Therapeutic Innovations (EUPATI). We urgently need patient advocates to be involved in clinical trials, not as researchers, but as patient representatives who are well acquainted with the reality of the patients' situation.





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.



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

- Our coalition welcomes donations, grants and sponsorship to fund specific projects and to enable the IKCC to grow and develop.

IKCC has developed a transparent and robust Code of Conduct to guide the relationships between patient organisations, the healthcare industry and the Clinicians and Healthcare Professionals we work with. The IKCC Code of Conduct outlines our policy on commercial funding and grants and provides a set of firm principles that are used to guide all decisions related to funding of specific projects, meetings and activities.

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:	<b>IKCC International Kidney Cancer Coalition</b> The Global Collaboration of Patient Groups Supporting Those Affected by Kidney Cancer.  www.ikcc.org Facebook IKCC Twitter @IKCCORG
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) • J. Graff (USA) • M. Herbst (ZA) • M. Jewett (CAN) • A. Wilson (AUS) • R. Woodward (UK)
Administration Office:	Management Services & Financial Operations c/o Das Wissenshaus GmbH Caspar-Bender-Weg 31, 61200 Wölfersheim-Södel/Germany
Services:	Project Manager: Julia Black (UK) julia@ikcc.org Management Services / Financial Operations: Markus Wartenberg (DE) ikcc@daswissenshaus.de





**Welcome**

*Denis Brézillon (FR) and Dr Rachel Giles (NL)*

Denis Brézillon from ARTuR organisation in France, and Dr Rachel Giles, Chair of IKCC opened the 6th Expanding Circles Conference and welcomed everyone to the Dolce Chantilly Hotel in France.



**Keynote address: Kidney cancer perspectives in 2016 - how far have we come?**

*Speaker: Dr Bernard Escudier (FR)*

*Moderator: Denis Brézillon (FR)*

Noted kidney cancer expert, Dr Bernard Escudier, founder and president of ARTuR and Oncologist at the Institute Goustave Roussy, Paris, France provided a stimulating and thought-provoking opening to the conference. While he acknowledged the significant advances in kidney cancer treatment since the 1980s, he stressed the need for individualized patient care, further research collaboration, and a strong role for patient advocacy.

Dr Escudier emphasized the heterogeneous nature of kidney cancer – some cases are indolent (slow growing), while others are very aggressive. Today, surgery remains the most effective treatment for metastatic renal cell carcinoma (mRCC) and IL 2 is active in very small groups of pre-selected patients. Anti-vascular endothelial growth factor (VEGF) drugs have improved survival and will remain a treatment option. Due to the heterogeneous nature of RCC, identification of biomarkers remains very challenging, and biomarkers are yet to be identified for VEGF, cytokines and checkpoint inhibitors.



Dr Escudier indicated that randomised clinical trials are absolutely key for the development of new treatments, and international collaboration is paramount. Combinations of drugs for mRCC have so far failed due to unacceptable toxicity. He cautioned that the current enthusiasm for checkpoint inhibitors has to be reasonable; about 30% of patients have rapid progression of their cancer while on nivolumab, and some side effects are very severe and unknown.

Dr Escudier concluded by suggesting that patients should be involved in decisions about their treatment, since they are the most important people in the treatment process.

**“International collaboration is paramount”**

**Conference Report 2016:  
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 14<sup>th</sup> - 16<sup>th</sup> April 2016, 68 representatives from 26 countries met to share best practices, discuss common needs, and work together. In 2016, new attendees were welcomed from Brazil, the Czech Republic, and Sweden.



Day 1 – Thursday, 14<sup>th</sup> April



**Dr Laurence Albigès**, Oncologist and Head of the Genitourinary Tumour Board at Institute Gustave Roussy, Paris, France, followed by talking about the challenges currently facing medical oncology research. Medical oncology needs to balance quality of life, risk of toxicity and survival, and oncologists need to ‘... make the most of treatments we have to save time to move forward’. One of the main obstacles for medical oncology is being able to understand the biology behind drug resistance; if resistance can be characterised, alternative pathways can be targeted with different drugs.

Dr Albigès also talked about integrating patient views on quality of life into clinical trials, collaborating internationally for rare tumour research, learning from mistakes, the use of real world data (more health authorities are now asking for this), new innovative clinical trial designs, e.g. addition of new arms to test new hypotheses as trial progresses, and making the most of existing trials. Underlying all this, oncologists need to incorporate the patient perspective through working with patient groups.



**Kidney cancer research priorities – where do we go from here?**  
*Moderator: Rose Woodward (UK)*

During this session, three clinical experts presented their perspectives on research priorities for kidney cancer in terms of surgical research, medical oncology and clinical research.

**Dr Michael AS Jewett**, Professor of Surgery (Urology) from the University of Toronto, Canada, opened the session with a presentation about the work of the Kidney Cancer Research Network of Canada. This network was formed with the help of Kidney Cancer Canada and the Kidney Foundation of Canada. In Canada, patients, carers, clinicians and patient groups worked together using the James Lind Alliance methodology to develop research priorities that are grounded in what matters to them jointly.

Dr Jewett then turned to issues that could impact kidney cancer surgery in the foreseeable future, such as; the role of renal tumour biopsy for small renal masses; refinement of competing risk assessments; indications for partial versus radical nephrectomy; minimally invasive surgery and ablation; and the integration of surgery in treatment for advanced disease.



**Dr James Larkin**, Consultant Medical Oncologist, Royal Marsden Hospital, London, UK provided an update on clinical research for kidney cancer treatments. He talked about current research priorities as being the role of nephrectomy, variability of practice, sequential therapy, adjuvant and neoadjuvant therapy, novel dosing schedules, e.g. standard versus interrupted treatment, selection of drug therapy, mechanisms of response, and drug resistance.

He touched on the search for predictive biomarkers, which is yet to yield a candidate for kidney cancer. The benefits of biomarkers will be more effective use of drugs; reduced side effects; cheaper Quality Adjusted Life Years (QALYs); and greater understanding of kidney cancer biology.

Dr Larkin emphasized that there has been significant progress in the development of new treatments and new targets (e.g. lenvatinib, cabozantinib, nivolumab) since 2011. He finished by saying that the immune checkpoint inhibitors are very promising for the treatment of kidney cancer.



**Sharing best practices in kidney cancer awareness, support and advocacy**  
*Moderator: Denis Brézillon (FR)*

**Spain: Federación Nacional de Asociaciones ALCER - Juan Carlos Julian Mauro**  
Federación Nacional ALCER provides health education, emotional and social support, advocacy of patient rights, psychological services, and social activities for patients with kidney disease living in Spain. For kidney cancer patients, ALCER provides information, promotes research, publishes personal stories, and supports patients and families. Recent activities organised by ALCER for kidney cancer patients in Spain include; a presentation by a kidney cancer expert at a national conference; an article in a journal about kidney cancer; and a kidney cancer meeting and workshop planned for this year.

**Brazil: Instituto Espaco de Vida - Isabel Marcal**  
Instituto Espaco de Vida’s mission is to improve quality of life of cancer patients while working towards prevention and cure. In Brazil, kidney cancer is diagnosed late and access to drugs in the public health system is difficult. It is also difficult to access drugs in the private sector. Instituto Espaco de Vida has run two campaigns recently: ‘Take care of your kidneys’ and ‘Every kidney has its story’. ‘Take care of your



Day 1 – Thursday, 14<sup>th</sup> April



kidneys’ focused on how to prevent kidney disease and used social media, TV, radio, and a one-day educational event at the railway station in São Paulo. ‘Every kidney has its story’ focused on kidney cancer. There was a meeting with the state department of health, information folders for kidney cancer, an awareness campaign in the public square in Fortaleza, a medical workshop with 15 key opinion leaders, and an educational event in a subway station in São Paulo.

**Morocco: FMAIRTO - Said El Kharrazi**

FMAIRTO is a new organisation that supports people with chronic kidney disease and organ transplant. They are collaborating with colleagues in The Netherlands to run a training programme and workshop about kidney cancer, and they have a medical team of voluntary doctors to build awareness of kidney cancer and screening.

**Germany: Das Lebenshaus e.V. - Dr Kinga Mathe**

Das Lebenshaus described an innovative and cost-effective campaign called ‘Time2talk about kidney cancer’. The campaign consists of local events that enable patients to communicate directly with the medical experts around the table. Each of 15 sessions to date have provided patients with time to question experts and time to network with other patients and families. A ‘buddy system’ has been developed; patients listen directly to other patients asking questions,



identify with similar situations, and learn from the answers. Benefits of this format is that meetings are inexpensive, encourage closer cooperation with the experts, stimulate the development of regional support groups, and help to advertise Das Lebenshaus. Last year, Das Lebenshaus ran 15 Time2talk events across Germany.

**Canada: Kidney Cancer Canada - Heather Chappell**

Kidney Cancer Canada ran a national kidney cancer patient survey to gain new insights into the state of kidney cancer care across Canada. Key areas of inquiry were: treatment and clinical trials awareness; frequency of multidisciplinary team meetings; financial and other barriers to care; awareness of Canadian guidelines for treatment, surveillance and genetic screening; treatment adherence and barriers to adherence; and sources of and expectations around information and support. The survey was conducted with help from a university research team, who developed the survey instrument, obtained ethics approval (increases credibility of survey and allows peer reviewed publication), collected and analysed the data, and shared the findings. The survey was promoted to patients and key stakeholders via website, e-blasts, discussion forum, and social media. The data will be used for a public awareness campaign and to inform priorities related to advocacy, information and support.



**Shared Decision Making**

*Moderator: Anne Wilson (AU)*

During the final session of day 1, the concept of shared decision-making was discussed from the perspective of a psychology expert, a nurse and a kidney cancer patient.

**Expert perspective**

**Dr Hilary Bekker**, Associate Professor in Psychology and Medicine at the University of Leeds, UK, talked about understanding how people make decisions, and how to use this within the healthcare setting. She discussed the use of shared decision making/decision aids, and how these impact on care. Patients need to be active, informed and empowered participants at every stage of treatment, with information that is patient-oriented, evidence-based, timely and relevant. In practice, there is a lot of variation between centres (doctor preference driving choice, not patient), whether patients want to make treatment choices, and information is not designed to support people making informed decisions. When making health decisions, patients use their experiences, knowledge, motivation, skills, culture to make informed decisions. Practitioners make evidence-based decisions, based on their experiences, knowledge, motivation, skills, and culture. Shared decision-making about health and treatment is a consultation process; an exchange of understanding, preferences and personal choice.



**Nurse perspective**

**Lynda Pyle**, Research Nurse at the Royal Marsden Hospital in London, UK, defined shared decision-making as a conversation that happens between the patient and healthcare professional to reach a healthcare choice together. Shared decision-making requires patients and professionals to understand what is important to the other person when choosing a treatment – this can be difficult and technical.

Shared decision making begins with information exchange between the patient (knowledge and beliefs) and the clinician (evidence-based information, options, outcomes, uncertainties and risks), deliberation, and decision-making. Shared decision-making points occur at the time of diagnosis, progression/relapse of the disease, and at the end of available treatment. It is important to remember that the patient’s decision is the correct decision at that time, whatever the decision, and the patient needs support for this.

**“It is important to remember that the patient’s decision is the correct decision at that time, whatever the decision.”**

Day 1 – Thursday, 14<sup>th</sup> April



Patient perspective

Rose Woodward, Founder of the Kidney Cancer Support Network and kidney cancer survivor, spoke about decision-making from a patient’s perspective.

Rose emphasized that while doctors are expert in treating disease; patients are expert at living with it. Shared decision-making should be an equal partnership between doctors and patients; a collaborative process that allows patients and clinicians to make healthcare decisions together, taking into account the best scientific evidence available as well as the patient’s values and preferences. Patients need resources to enable them to feel confident and knowledgeable enough to be part of the shared decision making process.

In summary, Rose talked about the UK NHS ‘Ask 3 questions’ campaign:

- 1. What are my options?
- 2. What are the possible benefits and risks of those options?
- 3. How do I get support to help me make a decision that is right for me?

Rose added a fourth question and suggested patient organisations could help with this:

- 4. Where can I find enough information to enable me to make an informed choice?

Day 1 – Thursday, 14<sup>th</sup> April

Conference and Networking







Kidney cancer and immuno-oncology (IO)

Moderator: Berit Eberhardt (DE)

Immuno-oncology (IO) is a very exciting area of research for new kidney cancer treatments. During this session, three experts gave updates on the IO clinical trials, IO research activities, and management of side effects.

Update in IO clinical trials

**Dr James Larkin**, Consultant Medical Oncologist, Royal Marsden Hospital, London, UK, opened the session with an update on IO clinical research. Immunotherapy is not a new treatment for kidney cancer; cytokines, such as interferon and IL 2, are types of immunotherapy that stimulate the immune system. Immune checkpoint inhibitors are new types of IO that remove inhibition of the immune system by the cancer - they block antibodies and release the brakes on T cells to enable them to destroy cancer cells.

In kidney cancer specifically, checkpoint inhibitors seem to work in aggressive, high volume disease. There also seems to be a residual effect of treatment, with some patients continuing to respond for up to 1 year after 3 months of dosing. These drugs are well tolerated, with 15-20% of patients experiencing severe side effects. In combinations, the toxicity of these drugs is increased. The FDA has already



Capacity building for organisations:  
Preparing for the unexpected (risk management)

Speaker: Dr Erik Briers, BE

**Dr Erik Briers** gave a thought-provoking presentation about risk management for patient organisations.

Dr Briers emphasized the importance of statutes, of transparency, and of leadership qualities to realise the goals and objectives of the organisation. Many organisations fail to plan for succession planning for long-term sustainability of the organisation. Organisations that depend on a few people are not sustainable and succession plans are needed for everyone – staff and Board members alike.

Dr Briers finished by talking about possible funding sources, such as membership fees, industry sponsors, foundation/trust grants, and government/statutory funding. Dr. Briers recommended obtaining advice from others who have experience such as those present at this conference.



approved nivolumab for kidney cancer, and the European agency, the CPHMP, is currently reviewing the nivolumab application. However, these drugs are very expensive (approximately £600 per month) and the cost needs to reflect the benefit to patients.

The main strategy going forward is to combine agents such as nivolumab with anti-VEGF drugs and with ipilimumab. Anti-VEGF combinations are better tolerated than ipilimumab plus nivolumab, but if the combinations work, will the cost of the drugs double? Most importantly, there needs to be more understanding of tumour biology to be able to pre-select those patients who will benefit the most from these combinations.

Update in IO

**Professor Dr Viktor Grünwald** from the Medical University of Hannover, Germany, gave an update on the IO research and the mechanism of action of IO drugs. During an immune response, immune cells, called T cells, process antigens (foreign protein from cancer cells) on receptors and become activated. An immune checkpoint protein called CTLA-4, tightly controls this initial immune response and dampens the activation of T cells to maintain a consistent level. This is called the first signal.



During an immune effect (e.g. inflammation), T cells recognise antigen on tumour cells and kill them. An immune checkpoint protein called PD-1/PD-L1, which dampens the activity of T cells, tightly controls this immune effect. This is called the second signal. The dead cancer cell releases antigen again and the cycle starts over. The immune response is a balance between the effects of the first and second signals and is very tightly regulated by checkpoint proteins. Inflamed (hot) tumours have been invaded by T cells – this is the PD1/PD-L1 cycle. Non-inflamed (cold) tumours do not contain T cells – this is the CTLA-4 cycle. Checkpoint inhibitors release the control on the immune system to allow T cells to attack cancer cells.

Dr Grünwald mentioned that PD-1/PD-L1 expression varies within individual tumours because kidney cancer tumours are heterogeneous. Researchers are still unsure how to assess PD-1/PD-L1 positivity as a biomarker for a response to checkpoint inhibitors.

Dr Grünwald summarised by saying that the immune system was tightly regulated and there are multiple layers of intervention. IO therapies are individualist, i.e. they work in some people, but not others. Combinations of IO drugs are likely to succeed, and combinations may vary. The main goal of IO treatment is long-term remission (chronic disease/cure).





Update in how to manage IO side effects

**Lynda Pyle**, Research Nurse from the Royal Marsden Hospital, London, UK went on to describe the management of side effects to IO drugs. Her experience has been with nivolumab in patients with kidney cancer and melanoma. Nivolumab is administered as a 60 min infusion every two weeks. Treatment continues until the cancer grows or side effects become too severe. Once inside the body, the drug cannot be stopped; side effects can happen at any time during treatment, or may occur after treatment has finished. Side effects may affect the lungs, intestines, liver, thyroid, pituitary, kidney, and brain.

The side effects to nivolumab are usually very mild. About 80-90% of people report side effects, and most are mild and not serious, such as fatigue, pruritis (itchy skin), diarrhoea, constipation, nausea, loss of appetite, rash, and anaemia. Rare, but more severe side effects include colitis, pneumonitis, hepatitis, and hypothyroidism. Patients should be aware of the possible side effects to nivolumab, and report side effects early to prevent worsening of symptoms. Patients should not try to treat side effect symptoms themselves.



If a patient experiences a side effect, treatment with nivolumab will continue and the side effect will be treated. Treatment might be delayed for severe side effects and stopped permanently for rare side effects, such as very severe diarrhoea that could indicate colitis. Treatment for autoimmune/immune-related side effects is steroids. Fatigue can be severe and may influence mood and ability to cope, resulting in frustration and lower activity levels. Fatigue is the most common side effect to anti-cancer treatment, and can be exacerbated by pain, emotional distress, anaemia, and sleep disturbances.

Lynda concluded by saying that IO drugs were generally very well tolerated, usually with very mild side effects. Early reporting of side effects is vital, and communication with all concerned is crucial to their effective management.



Addressing healthcare policy issues in your country

*Moderator: Vandana Gupta*

During this session, delegates from Australia, Nigeria, Peru and India addressed healthcare policy issues that were facing kidney cancer patients in their respective countries.



Kidney Health Australia

**Debbie Fortnum** described the main healthcare policy issues facing kidney cancer patients in Australia. There are just over 3000 new cases of kidney cancer in Australia each year, and the incidence has been rising since the early 1980s. Kidney cancer is a rare and forgotten cancer; people feel overwhelmed and alone, and there is rarely a specialised nurse to guide them through their journey. Targeted therapies, such as sunitinib, pazopanib, axitinib, everolimus, and sorafenib are all available in Australia, and nivolumab is available on a compassionate use programme. The Australian kidney cancer registry for outcomes is currently not very useful, and healthcare providers have difficulty understanding the key needs of consumers and health professionals.

Kidney Health Australia is addressing these issues by providing resources and support to those diagnosed with kidney cancer, and delivering education to patients and health professionals via their website, fact sheets, newsletter, handbooks etc. They provide support via their kidney health information service and online forum, and assistance with locating clinical trials. They also provide advocacy to help patients claim reimbursement of drugs. Education about the disease is a key area to making a difference.



**Stand up to Cancer Naija, Nigeria**

**Caleb Egwuenu** talked about Stand up to Cancer Naija as being a community-based organisation that has a mission to reduce the burden of cancer through community awareness campaigns, early detection via screening programmes, outreach or hospital facilities, and health professional training/support. Cancer is the second cause of death after cardiovascular disease in Nigeria. There is a lack of oncology specialists and less than 10 specialist centres in a country of 170 million people (most professionals go to Europe and North America). Treatment is expensive and health insurance does not cover cancer – only a few people have health insurance. There is poor drug supply chain management, treatment adherence is poor, 60-70% of people present late, and the majority of patients are lost to follow-up. There is also high use of alternative medicine and many patients die before receiving medical treatment.

Many patients have difficulty accessing and navigating the health care delivery system, and have to travel many miles to specialist centres for screening and treatment. Stand up to Cancer Naija plans to address this with the use of patient navigators – people who sit with the patient during consultations to help them navigate the system. They currently have 6 patient navigators in teaching hospitals around Nigeria, with plans to expand this project.



**Esperantra, Peru**

**Karla Ruiz de Castilla** described the situation in Peru with respect to healthcare policy issues. In Peru, cancer is the cause of death in about 8% of cases, and around 20% of the population does not have health insurance. The social plan, which applies to the 80% of population with health insurance, includes treatment for cancer of the cervix, breast, colon, prostate, lymphoma, and stomach – none of the other cancers are covered. For kidney cancer (1.7% of cancer cases), the cost of diagnosis is covered, but treatment is not.

Esperantra addresses this issue through the provision of information and advocacy, and promotes changes in health care policies. Esperantra are working with global networks to exchange information and help patients to access treatment. They are also trying to persuade the government to include the 20% of the population without health insurance in the social plan.



**V Care Foundation, India**

**Jyoti Patil** talked about the situation in India with respect to health care policies. Around 49,000 patients in India are supported financially and with treatments. The incidence of kidney cancer is low, but mortality rate is high. The government spends 1% of Gross Domestic Product (GDP) on cancer, and there are lots of patients who are not covered by insurance or on the national cancer control programme. Access to treatment is difficult and there is a lack of trained health professionals. Cancer centres are only in major cities, and patients have to travel long distances for diagnosis and treatment. There are financial constraints to travel and the costs of diagnosis and treatment, and many patients turn to traditional treatments instead.

V Care are trying to address these issues by providing information and support to patients and health professionals via the use of government schemes, Non-Governmental Organisations (NGOs), trusts, and charities. They help patients with the cost of transportation and hotel accommodation, and provide a dedicated helpline for patient support.



**Discussion**

IKCC can help countries access treatment for kidney cancer by bringing countries together to exchange experiences, and mentor organisations in developing countries to help them implement projects to improve access through NGOs and other means. They can help organisations show local experts and authorities what is happening elsewhere in the world.



## Day 2 – Friday, 15<sup>th</sup> April



### Breakout discussions

*Moderator: Berit Eberhardt (DE)*

Three breakout groups discussed various topics to do with kidney cancer, and fed back to the rest of the delegates in an interactive session. The key themes are summarised below:



### Issues for kidney cancer patient organisations worldwide

During the discussion, the following main issues were identified:

1. Professional management – most patient organisations are run by volunteers and part time staff who are not always committed for the long term.
2. Funding/finding resources – fundraising and finding resources to enable the organisation to provide its services to patients
3. Outreach difficulties – some delegates talked about the technical, regional (travel) and psychological barriers disrupting outreach programmes
4. Communication – there was discussion about communication of global messages to patients and doctors, cooperation/collaboration with professional bodies/societies and other organisations, and the ability to communicate the larger impact of organisation's work
5. Language translations – the need for multi-language materials to reach ethnic minorities.

### Opportunities for global collaborations

1. Communication - sharing resources and collaboration. Cultural issues need to be taken into account. Some countries might push back against ideas from other countries and would prefer to do it their own way. Can be challenging to raise the issue of kidney cancer with the governments in developing countries, since they have more pressing health-related issues to deal with, e.g. zika virus
2. IKCC conference - workshops for regional groups to share ideas and obtain support. IKCC to attend regional conferences to present its work and how IKCC can support other organisations
3. Economic modeling - burden of disease and cost to government can be used to leverage governments for funding. Identify what patient groups in other countries are doing to address kidney cancer and use this data to inform advocacy approaches
4. Sharing of best practices - all organisations have same tools/information for support of patients, which can be shared globally
5. Reimbursement across borders - reimbursement from own country for treatment in a different country takes time, especially if going to a more expensive country



6. Union for International Cancer Control (UICC) – IKCC can develop links with the UICC to take advantage of the tools and information available through this global organisation, and to promote its work.



### Raising awareness of kidney cancer globally

Visibility for a forgotten cancer: Raising awareness leads to earlier detection of kidney cancer.

1. Raising awareness of kidney cancer - issue a global challenge. Ideas included an IKCC water bottle - answer a question about kidney cancer to be awarded with a water bottle
2. Funding – funds are required to support raising awareness, research and screening tests, and kidney cancer is underfunded globally. Can we come together to raise funds?
3. Global spotlight – ‘a story to share’. Identify the most important facets to share globally, the key facts that are important globally and of interest to politicians etc. to raise awareness with governments
4. Global awareness campaigns for a kidney cancer awareness day/week using global brands displaying a label containing information about kidney cancer. IKCC could develop guidelines for a globally coordinated campaign (funds to stay in local country)
5. Rare cancers working together worldwide – e.g., urological cancers such as kidney, bladder, and prostate.



Day 2 – Friday, 15<sup>th</sup> April



External Dinner





Day 3 – Saturday, 16<sup>th</sup> April



Different ways for patients to access treatments

Speaker: Deb Maskens (CA)

**Deb Maskens**, Vice Chair of IKCC, opened the third day with a presentation about international variation in the methods to access kidney cancer treatments, and a big divide between low/middle income countries and the developed world.

In the developed world, access to treatments depends on whether the drug is pre- or post-market. If pre-market, access can be via clinical trials (2-20% of kidney cancer patients), ‘named patient’ programmes, early access schemes, compassionate use, e.g. ‘right to try’ legislation in US, and off-label (difficult in most countries). Post-market, early access schemes often end. Treatments can be accessed via private insurance, public (government) insurance, compassionate use and self pay, but only a small minority of patients can afford these drugs (\$6-10,000/month USD).

In developing countries NGOs can help patients access treatment, but it is time consuming. Patient organisations need to know the landscape and government priorities for health care. They also need to be aware of what is possible and partner with health care providers/advocates. Patient organisations need to provide guidance/advice to patients, and be able to work at the individual and health system level.



Deb’s closing thoughts were that “free medications” are never really free (doctor’s time, infrastructure, blood work etc.). Patients need to travel, take time off work, and be aware of their own quality of life and safety issues on treatment. Corruption and distributor diversions can be issues in some countries, and culture issues. IKCC can help by acting as knowledge brokers, and by building relationships with NGOs, healthcare industry, global medical societies, and patient groups.

During the subsequent discussions, most patient organisations cited finance and cost of drugs as the biggest barrier to access to treatments. Crowd funding was cited as a potential means to access funding; however, there was some scepticism about this method of fundraising at the individual level.



Who is listening to the patient voice?

Moderator: Joyce Graff (USA)

**Joyce Graff**, Powerful Patient, USA, opened this session by talking about communication between patient and doctor, and the factors that impact the effectiveness of communication. Communication is a two-way process, but can be influenced by context, level of authority and knowledge of each person, culture, jargon, and language. Both participants need to be active and engaged for effective communication to happen.



**Beate Bartès**, President of Vivre sans Thyroïde and a thyroid cancer patient, suggested that patients take checklists into their consultation, and take notes of the discussion with their doctor. In France, doctors are very paternalistic and many patients complain that doctors don’t listen. Doctors are suspicious of patients going on the Internet for information; however, patients are now generally more informed, and some have started to go to conferences and are asking more pertinent questions. Doctors now appreciate more informed patients, but it has taken a few years to get to this point. Beate mentioned that it is very important for patients to have support from other patients, and doctors are starting to suggest this to boost recruitment into clinical trials. In France, patients still don’t have the opportunity to participate in guideline committees, but some groups are trying to change the environment.

Day 3 – Saturday, 16<sup>th</sup> April



**Denise Silber**, President of Basil Strategies, is an American living in France. In France, medicine is very hierarchical and doctors are paternalistic. Doctors can’t make a decision without knowing all the details about a patient, so they need to listen to the patient. However, listening is not always effective due to interruptions during consultations. If the patient does not feel they are being listened to and treated like a whole person, it can make them feel miserable. There needs to be collective action to ensure the patient voice is heard. Denise commented on ‘social listening’ - listening to patients on social media - and under-reporting of side effects to drugs. Denise also suggested that there is the impression that data collected from patients has less value than data collected by the doctor. She talked about using an app for the collection of patient-generated data for chronic diseases. She finished by saying that patients must listen to themselves, and know their own value - healthcare makes no sense without patients.



**Erik Briers** concluded this session by speaking about patient involvement in the regulatory process and engaging with government agencies. Patients need to learn the rules of engagement, and develop relationships with the regulatory agencies. In Europe, patient organisations have been directly involved with the European Medicines Agency (EMA), which advises the European Commission on the licensing of new treatments, since 1996. At the EMA, there is patient involvement throughout the medicines lifecycle from pre-submission (ethics committees), through evaluation, and post-marketing authorisation in various committees (e.g. CHMP), and preparation of documents for the public (e.g. package leaflets). After marketing authorisation, each member state has its own health technology appraisal process to determine the cost-benefit of the treatment, with patient input. Patient experts are also involved in guideline committees in some countries. Patients are key to research; however, there is concern whether there are enough patient advocates to engage in R&D, and Dr Briers recommends training patients to become advocates. Dr Briers touched upon the need for patient organisations to work with the pharmaceutical industry in partnership on clinical trial design and drug development strategy. Some pharmaceutical companies are bringing patients in-house for this specific role, and changing the mind-set of how they work.



**Kidney cancer under the microscope**  
*Moderator: Dr Rachel Giles (NL)*

**Dr Eva Comperat**, Associate Professor Pathology, from the Pitié-Salpêtrière Hospital in Paris, France, gave a presentation on the histology of kidney cancer. Imaging techniques for the diagnosis of cancer are improving, but 100% of kidney cancer is still diagnosed by a pathologist. Tumour biopsies are taken and immune-histological staining is used to identify tumour subtypes by looking at the shape of the cells and nuclei, the membrane, and cell architecture. The new WHO classification, which was published in January 2016, identifies 55 different subtypes of RCC, most of which are extremely rare.

Dr Comperat went on to explain the pathological tumour-node-metastasis (pTNM) staging system and the ISUP grading system. Staging is based on size of the tumour and extent of spread of the cancer. The ISUP grading system is replacing the Fuhrman grading system, and is based on the size of the nuclei (small = grade 1, large = grade 4).

Dr Comperat went on to discuss each RCC subtype in turn, based upon the new WHO classification. The most frequent subtypes are ccRCC, papillary RCC, chromophobe RCC and oncocytoma. She also discussed each of the less common (less than 5% of RCC cases) subtypes from a histological perspective.



**Close of conference**  
*Speakers: Denis Brézillon (FR), Dr Rachel Giles (NL)*

Denis Brézillon and Dr Rachel Giles closed the conference by thanking everyone for their active participation and for coming together to contribute to the international kidney cancer community.

As a follow on to the conference, each patient organisation was tasked to take what they have learned over the past few days back to their organisations and to think about what they want to do for kidney cancer patients in their own countries in the next year. Dr. Giles commented that not only is kidney cancer an heterogeneous disease, but patient organisations are also heterogeneous in the way they provide support. This heterogeneity needs to be celebrated in patient organisations.

**Vive les différences!**



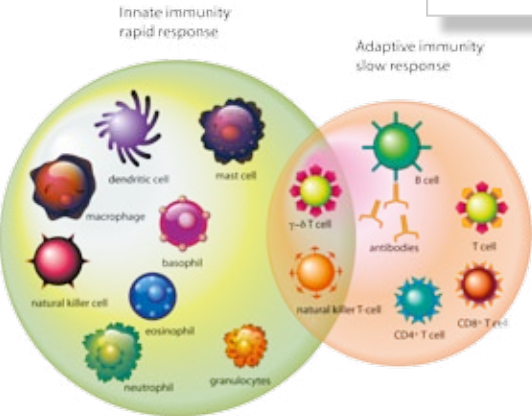
Feedback



Projects and Activities  
(Excerpt)

# Understanding immuno-oncology in kidney cancer: IKCC website responds to strong demand from patients worldwide

A year ago, in September 2015, IKCC launched a new internet platform “10-for-IO” – Ten for immuno-oncology (IO) – offering comprehensive information about immuno-oncology (IO), with a specific focus on kidney cancer. IO is an innovative therapeutic approach currently being tested in various types of cancer including metastatic renal cell carcinoma (mRCC). The prospect of immuno-oncology has raised high expectations among both the medical and the kidney cancer patient community. This IKCC website “10-for-IO” (www.10forIO.info) aims to address many questions kidney cancer patients around the world are asking. The platform includes information about global clinical trials for kidney cancer patients and patient-friendly summaries of trials that have reported results.



“While the early data for IO certainly looks very encouraging for advanced kidney cancer patients, we also need to be mindful that there is much yet to be learned”, says Professor Viktor Grünwald, MHH Hannover, Germany. “Many of these therapies are currently being studied in clinical trials worldwide. As of today, only a fraction of patients achieve long-term responses. Therefore the aim of current studies is to combine different treatments and explore novel targets in order to enrich the fraction of responding patients. We still have a great deal to learn about long-term efficacy, suitability of patients for IO, and combining medications. In the meantime, our patients are seeking information online. The website “10-for-IO” is a great tool to support patients looking for clinical trials and learning more about IO for this disease.”

At the global level, the IKCC worked to coordinate efforts of patient organisations around the world: “We did so by collaborating on a truly international basis: We worked with kidney cancer patient organisations and with medical experts around the world to address common questions”, explains Dr. Rachel Giles, Chair of the IKCC Board, in The Netherlands. “We began with the top 10 most frequent questions from all over the world – and set out to answer those 10 questions with medically-reviewed answers now available on this website.” The content has been written in a straightforward patient-language by medical writers and

expert patients. It was reviewed by medical experts who have in-depth knowledge of both kidney cancer and immuno-oncology.

Clinical trials for IO are rapidly recruiting patients around the world. The website “10-for-IO” highlights some of the major IO clinical trials being conducted globally in renal cell carcinoma. While other resources list clinical trials for clinicians, the focus is to explain these trials in patient-friendly language. The website also addresses common questions about clinical trials and provides information to help patients evaluate options. In the future, the new website will provide patient-written summaries of the results of IO clinical trials in kidney cancer.

The 10forIO website has already been recognised as an important step forward in patient engagement in an area of emerging scientific discovery. Deans of the University Medical Center Utrecht (www.umcutrecht.nl) fully support and endorse this patient-led initiative: “I think this example of patient empowerment is definitely what Science in Transition advocates. We would be proud to share this initiative through our online channels.”

The website is currently available in English, German, French, Spanish, Portuguese, Dutch, Arabic and very soon in Russian.

## User Statistics “10-for-IO”: 25th of Sept. 2015 (launch) to 31st of Dec. 2016 (= 15 months):

- Number of users:**
- 27.421 users
  - 69.343 page views in 34,562 sessions
  - 20.6% returning visitors
  - 79.4% new visitors

## Top 10 countries – most visitors: (from all continents)

Country		% Sessions	
1.	United States	<div></div>	13.60
2.	Canada	<div></div>	10.90
3.	Germany	<div></div>	10.61
4.	France	<div></div>	8.93
5.	United Kingdom	<div></div>	6.58
6.	Russia	<div></div>	6.17
7.	Mexico	<div></div>	2.97
8.	India	<div></div>	2.44
9.	Brazil	<div></div>	2.20
10.	Australia	<div></div>	2.16

- How users reached the website:**
- Organic search: 51.9%
  - Direct access: 19.4%
  - Referral: 16.0%
  - Social Media: 12.7%



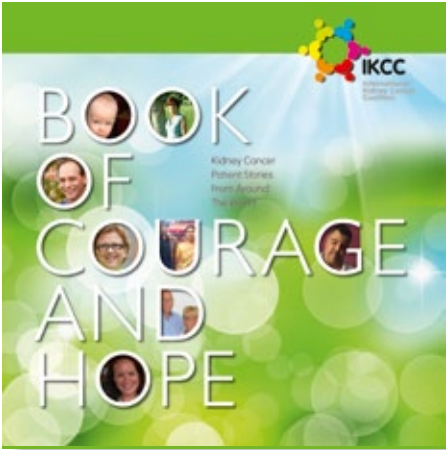
“Life is beautiful and worth fighting for!”  
Kidney cancer patients worldwide share their stories  
in the “IKCC Book of Courage and Hope”.

IKCC demonstrates the diversity of the global kidney cancer community, unified in their shared belief that “Together we are stronger” in our new “Book of Courage and Hope – Kidney Cancer Patient Stories from Around the World.”

Being diagnosed with kidney cancer changes everything, not only for the patient, but also for family and friends. Kidney cancer makes you want to cry, to wail, to hit something or to hide in a corner – and it makes you hope and want to fight. Eighteen kidney cancer patients from all over the world share their stories in the “Book of Courage and Hope” launched by the International Kidney Cancer Coalition (IKCC).

Researchers have long known that kidney cancer is a diverse set of cancers that can occur in the kidney. This unique collection of emotional and moving stories speaks to that diversity, and the diversity of kidney cancer experiences – from the one-year-old Freddie in Australia to Mercedes, a mother of two and grandmother of four, in Colombia. But no matter where the patients live and which obstacles they have had to overcome, they all come to the same conclusion, perfectly summarised by Dipankar Bhattacharjee, kidney cancer patient from Mumbai, India: “Life is beautiful and worth fighting for!”

Around the world, kidney cancer patients face a wide range of challenges – not only with different subtypes and stages of disease,



but often with inequitable and complex health systems in their home countries. Many patients and families search for information and support from patient organisations, both national and international. The IKCC, as an international coalition, connects patients with regional and national organisations wherever they exist. The Coalition also serves as an important resource to patient organisations providing information about clinical trials, and working with international experts, guidance panels, and research teams.

“The IKCC ‘Book of Courage and Hope’ illustrates our belief that being a part of a cancer patient support group and sharing knowledge and experiences with each other not only helps individual patients, but can also serve more broadly to increase knowledge of unmet medical needs,

raise awareness, and foster further research in kidney cancer”, explains Rachel Giles, Chair of the Board of the IKCC. “The Book of Courage and Hope” clearly demonstrates that shared conviction of the IKCC and their Affiliate Organisations: “Together we are stronger”.

“Each of the stories is an amazing testimony to the courage and unique challenges faced by kidney cancer patients and their care-givers”, summarises Rachel Giles. On behalf of the International Kidney Cancer Coalition (IKCC), we owe these patients and their families our deepest gratitude.”

The book is available as a download on the IKCC website [www.ikcc.org](http://www.ikcc.org). Hardcopies can be requested via the IKCC website.



Think Treatment? Think Trials!

The international kidney cancer community has come together as the IKCC with the mission to reduce the global burden of kidney cancer. Many of our Affiliate Organisations actively raise funds for research with the knowledge that kidney cancer is on the rise worldwide and sadly, for advanced kidney cancer, there is no known cure.

Research and clinical trials are the only way to move forward towards improvements in prevention, screening, diagnosis, treatment, and ultimately a cure. As research ideas move from the lab, clinical trials are designed to answer key research questions and move our collective understanding of kidney cancer forward. But as advocates, we know too well that many patients are never told about clinical trial opportunities in their country, and many more have a misunderstanding about what these trials are about or why they might want to participate.

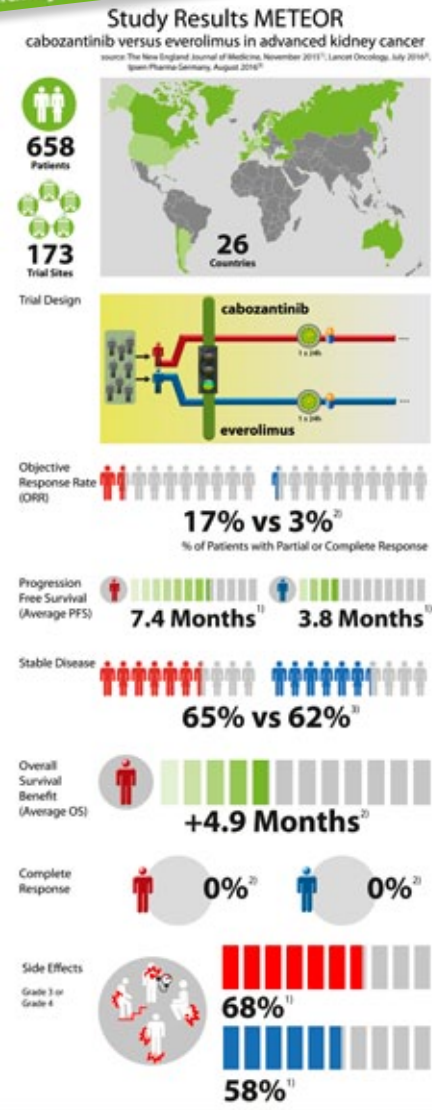
Our “Think Treatment? Think Trials!” campaign aims to get the word out about open clinical trials through social media channels. Our trial descriptions use clear visuals and plain language. Our messages help to dispel the myths that keep patients from asking their doctor about trial opportunities.



When clinical trials report, our infographics explain the results in visual language that shows the results in terms of Who, What, Where, When, and How? What did we learn from that trial?

Kidney cancer patients around the world need better answers. As patient organisations, we can help patients help other patients by growing the awareness of clinical trials. We welcome you to join us online as we promote clinical trials through our social media accounts and websites. As always, our work is open for you to adapt or translate for your country.

We hope to see the day when joining a clinical trial or long-term study is just an accepted and normal extension of cancer care for all patients -- from the moment of diagnosis right through to end of life. Thank you for your ongoing support of these efforts to promote clinical trials. Together we can get the word out!



Visit us online:  
[www.ikcc.org](http://www.ikcc.org)

See us on facebook:  
[www.facebook.com/IKCC](https://www.facebook.com/IKCC)

Follow us on twitter:  
[@IKCCorg](https://twitter.com/IKCCorg)





Decision Aid for Advanced Kidney Cancer

Advanced kidney cancer is a complex disease that is difficult to treat. As advocates we have seen a number of new therapies and treatment options emerge over the past decade. While these new options are very much needed, we also recognise that patients diagnosed with advanced kidney cancer today face a more complex and daunting journey of decision making than ever before.

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. Many factors come into consideration: including medical information such as the type and stage of the kidney cancer, the patient’s age, overall health, and the treatment availability. Equally important are the patient’s preferences, values, and personal goals for treatment. 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.

My Treatment; My Choice

As kidney cancer patient advocates, we believe that patients need to be empowered with information about all of the treatment options before they can make a choice about what best suits their preferences, their values, and their very individual life circumstances.



Kidney Cancer: My Treatment, My Choice Decision Aid

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.

We look forward to your comments on this first stage of the Decision Aid project and to building on this first edition.

Towards the First-Ever: World Kidney Cancer Day

Following our discussions in April 2016 about the challenges of raising awareness of kidney cancer in our respective countries, the IKCC Board approved a global project that will be launched and offered to all of our affiliate organisations in 2017.

The aim of World Kidney Cancer Day is to start the journey of raising awareness of kidney cancer, its prevalence, symptoms, risk factors, and the need for additional research to reduce the global burden of kidney cancer.

Worldwide, kidney cancer is the 12<sup>th</sup> most common cancer with 338,000 new cases diagnosed in 2012. Over 100,000 people die of kidney cancer each year. And yet, we know that if you asked 100 people on the street to name six cancers, it’s unlikely ‘kidney cancer’ would appear even a handful of times.

Before we can make significant inroads to promote prevention, early detection, patient support or fundraising, we must first **PUT KIDNEY CANCER ON THE MAP**



By implementing an annual World Kidney Cancer Day, IKCC aims to:

- Raise global awareness of kidney cancer as a significant health issue
- Provide a dedicated focus on kidney cancer its detection, treatment, risk factors, and need for research
- Deliver a global advocacy platform for IKCC affiliated organisations
- Galvanise clinical societies, patient organisations, media, advocacy groups, governments, industry and people with kidney cancer around a common goal and theme
- Develop tools to inform and support patient organisations and people with kidney cancer and their families at the grassroots level
- Provide a platform that can enhance the potential for individual country fundraising.

We look forward to sharing more about our plans for World Kidney Cancer Day during the Warsaw Conference and hope that you will join us in raising awareness!



IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2016	
CURRENT ASSETS	
Cash	76.880,00 €
TOTAL CURRENT ASSETS	76.880,00 €
TOTAL ASSETS	76.880,00 €
CURRENT LIABILITIES	
Creditors and borrowings	- 12.797,00 €
TOTAL CURRENT LIABILITIES	- 12.797,00 €
TOTAL LIABILITIES	- 12.797,00 €
NET ASSETS	64.083,00 €
ACCUMULATED FUNDS	
Reserves	
Last year profit/(loss)	6.360,00 €
Current year profit/(loss)	83.315,00 €
TOTAL ACCUMULATED FUNDS	89.675,00 €

Audited Financial Statements

These figures represent a summary of the financial statements of IKCC. To view our full independently audited financial statements please visit our website: [www.ikcc.org](http://www.ikcc.org)

Independent Financial Auditor  
Administratiekantoor APN  
(Administration for Patient organisations in the Netherlands)  
S. van Haarlemstraat  
4003VG Tiel  
Netherlands  
[www.stichtingapn.nl](http://www.stichtingapn.nl)

IKCC STATEMENT OF SURPLUS AND DEFICIT FOR THE YEAR ENDED 31 DECEMBER 2016	
INCOME	
Partnership Income	417.039 €
Other Income	56.554 €
TOTAL REVENUE	473.593 €
EXPENSES	
Labour Costs	57.875 €
Conferences & Meetings	19.494 €
Travel Expenses	41.759 €
Legal Expenses	0 €
Consulting Expenses	11.975 €
Board Expenses	61.880 €
General Expenses	7.481 €
Bank Charges Expenses	756 €
Printing & Stationery Expenses	8.089 €
Book of Courage & Hope	10.691 €
Clinical Trial Database	5.533 €
Project WKCD	82.483 €
Website / Social Media	57.092 €
Creditors	7.736 €
Delayed payments previous fin. Year	17.434 €
TOTAL EXPENSE	390.278 €
Result from Operating Activity	83.315 €
NET PROFIT / (LOSS)	83.315 €

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](http://www.ikcc.org)  
Please contact us if you have any questions [info@ikcc.org](mailto:info@ikcc.org)

We would like to thank the following funders who have supported IKCC in 2016 with Sustaining Partnerships or Sponsorships:



The idea, conception, planning, preparation, realisation, management and dissemination of materials, projects, activities are the responsibility of the IKCC Board without any influence from the sponsors/funders.

We are looking forward to continuing these open and transparent partnerships with the healthcare industry. This will help us achieve our goal of collaboration with independent kidney cancer patient organisations on a global level, to improve the lives of kidney cancer patients at a national level.

Under the Constitution of the International Kidney Cancer Coalition, organisations and individuals 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.



Associated individuals may be clinicians or allied health care professionals working in the field of kidney cancer, onco-nephrology or urology.

Associated individuals have voting rights and are invited to meetings of the Council of Affiliates.



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/](http://www.ikcc.org/about-ikcc/join-the-network/)



# 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.



IKCC 2016: 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 currently Chair of the IKCC and represents the IKCC on the EAU Guidelines Committee for renal cell carcinoma.



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

Dr. Jewett is Professor of Surgery (Urology) at Princess Margaret Cancer Centre and the University of Toronto where he holds the Farquaharson Clinical Research Chair in Oncology. He has been a member of the US NCI Renal Task Force since its inception and is currently Co-Chair. 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 holds peer reviewed funding and 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.



**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.



**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.



**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.



**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 two 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. As Secretary/Treasurer of the IKCC Anne is also overseeing the development of the first World Kidney Cancer Day in 2017 and is a member of the International Decision Aid Steering Committee.



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

Joyce Graff 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) and four years on the Director’s Consumer Liaison Group (DCLG) of the US National Cancer Institute. 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 weekly internet radio show. She is currently the Executive Director of the New England Regional Genetics Group.



**MICHAEL C. HERBST,  
PH.D.**  
Cancer Association of  
South Africa (CANSA)

Author and co-author of a large number of scientific papers and various books, Michael has written numerous scientific papers, both nationally and internationally. He was editor of Curationis, the Africa Journal of Nursing and Midwifery, and Nursing Update, a professional journal. Michael was a member of staff of the Potchefstroom University for Christian Higher Education and University of South Africa. At the University of Venda, he was the first Professor and Head of the Department of Nursing Science and Acting Dean of the Faculty of Science. His advanced degrees include D Litt et Phil, D. N. Ed., and Dip. Occ. Health. Michael is currently Head of Health at the Cancer Association of South Africa. Michael has been accredited to provide online training to medical doctors, professional nurses, pharmacists and clinical social workers in oncology by the Health Professions Councils of Namibia.



### **International Kidney Cancer Coalition**

Administrative Office  
Caspar-Bender-Weg 31  
61200 Wölfersheim-Södel  
Germany  
Email: [info@ikcc.org](mailto:info@ikcc.org)  
Website: [www.ikcc.org](http://www.ikcc.org)



Search for us on Facebook as: [ikcc](https://www.facebook.com/ikcc)



Follow us on Twitter: [@IKCCORG](https://twitter.com/IKCCORG)

Registered in the Netherlands under:  
Stichting IKCC  
Reg.-No. KvK 62070665