

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

Activity Report 2014/15



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

The International Kidney Cancer Coalition (IKCC) is the global network of independent national patient support and advocacy organisations that each includes a focus on kidney cancer. The IKCC was born from a very strong desire among national patient groups to network and share resources, knowledge, and experiences with one another, with medical experts, and with the healthcare industry, and to work together towards improved outcomes for kidney cancer patients worldwide.

2014 and 2015 have been exciting and transformative years for IKCC. Our collaborative and democratic network was first established in 2009 in Berlin as an informal coalition. In December 2014, our organisation was legally incorporated as a registered foundation in the Netherlands as “Stichting IKCC” according to established practices in The Netherlands.

Back in September 2010, 50 participants attended our first collaborative conference “EXPANDING CIRCLES in Kidney Cancer” in Frankfurt. As the network grew, we welcomed more participants for successful meetings in Rome (2012), in London (2013), in Amsterdam (2014) and in Morristown/NJ USA (2015). Conference Reports from these meetings are available on our website www.ikcc.org. You will find the Conference Report from our 2015 meeting as part of this Activity Report.

During our Annual Conference 2014 in Amsterdam, participants discussed and developed a “Charter for Global Kidney Cancer Care”. This document outlines the universal standards of kidney cancer care that patients should expect. Published in the European Journal of Urology, the Amsterdam Charter for Global Kidney Cancer Care has already been translated into 14 languages. (www.ikcc.org)

In 2014 and 2015, we intensified our efforts to expand our online communication. Our website www.ikcc.org has been completely revised. We started our regular IKCC e-newsletter and are active on Facebook and Twitter as @IKCCORG, using these tools to disseminate research updates and perspectives from medical congresses.

From February until September 2015 we began an ambitious new project to address the emerging need for credible, balanced information about immuno-oncology as it applies to kidney cancer. As a result of a successful grant application, we developed an additional web-platform “www.10forIO.info”. Ten for immuno-oncology (10-for-IO) offers comprehensive, understandable and trusted information for patients about immuno-oncology (IO), with a specific focus on clinical trials in kidney cancer.

Our latest project is the “IKCC Book of Courage and Hope - Kidney Cancer Patient Stories from around the World.” With this book IKCC demonstrates the diversity of the global kidney cancer community, unified in their shared belief “Together we are stronger!” The

IKCC network currently comprises 25 Affiliate Organisations with reach across six continents. Our membership comprises organisations that collectively represent up to half a million kidney cancer patients.

IKCC welcomes every organisation that has an interest in kidney cancer and extends an open invitation to all groups to become a part of this international network. IKCC also welcome individuals who are interested in starting kidney cancer support groups in their own countries.

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

Kidney Cancer Basics – A Global Disease

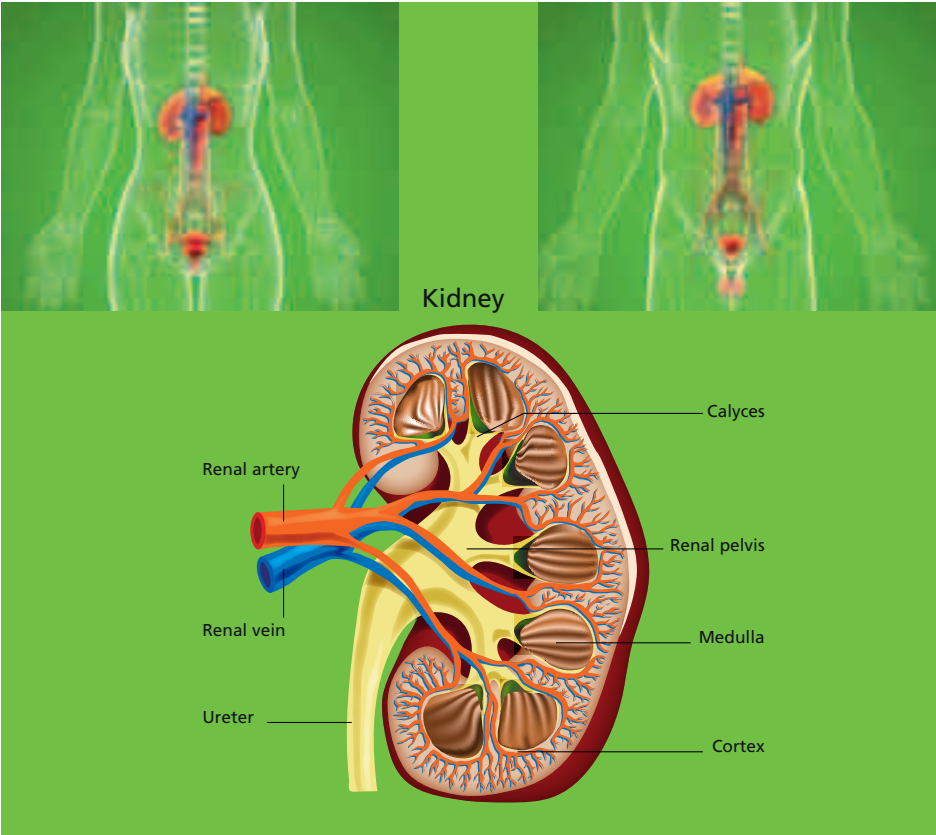
Kidney cancer is considered a rare cancer; worldwide there are about 337,860 new cases of kidney cancer each year, accounting for around 2% of all cancers and making it the 13th most common cancer. Globally, the incidence of kidney cancer has been increasing; in part due to better scanning facilities, 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



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- 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.



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Methods of Diagnosis

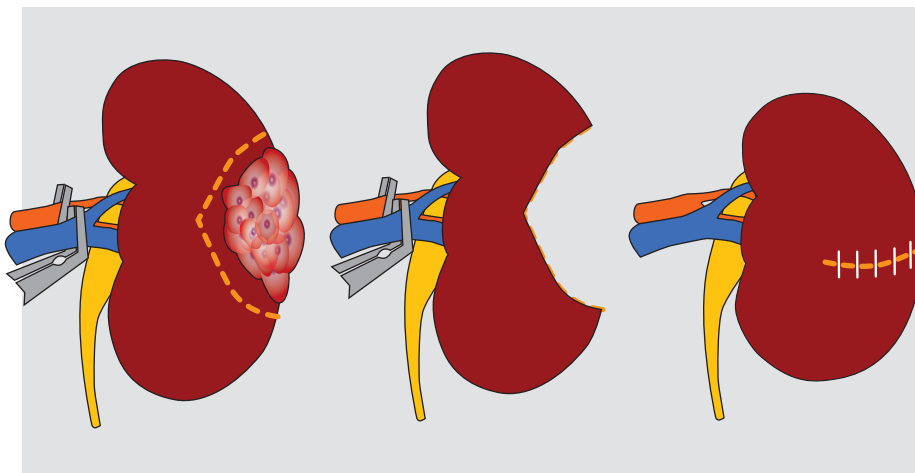
Currently, there are no screening programmes for kidney cancer. The advantage of early detection is successful removal of the affected kidney to prevent the spread of the disease. As the tumour grows and the lymph nodes become involved, the 5-year survival rate decreases from 90% for stage 1 disease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



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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.

Biological and Targeted Therapies

A number of biological and targeted therapies are used for the treatment of advanced kidney cancer, including immuno-therapies, 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 undergoing clinical trials for kidney cancer, having been proven effective for melanoma and non-small cell lung cancer.

The development of targeted therapies has been one of the most promising advances in the treatment of advanced kidney cancer, and is now standard treatment. 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 Worldwide: GLOBOCAN 2012, International Agency for Research on Cancer: Available from: www.globocan.iarc.fr

Further information about kidney cancer can be found on the IKCC website: 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 10" website: www.10for10.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/

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 worldwide¹ 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 |

¹338,000 diagnoses in 2012 alone, source: www.wcrf.org/cancer_statistics/data_specific_cancers/kidney_cancer_statistics.php

Signed:

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

Luan Percuku
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Rose Woodward (Founder and Patient Advocate),
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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)

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 to raise awareness, promote research and empower organisations to support people affected by kidney cancer.

Our Vision

- To empower patient organisations to improve the lives of people affected by kidney cancer worldwide.

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.

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

- Raising awareness of kidney cancer as a significant and increasing health issue
- Encouraging early detection and access to quality care
- Enhancing the exchange of information and best practices
- Promoting collaboration and patient involvement in clinical research
- Supporting existing patient organisations and encouraging the creation of new groups



Name: **IKCC International Kidney Cancer Coalition**
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) *
A. Wilson (AUS) • R. Woodward (UK)

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5th International Conference
for Organisations
Representing Patients
with Kidney Cancer
16th – 18th April 2015
Hyatt Hotel, Morristown,
New Jersey, USA

Conference
Report

Day 1 – Thursday, 16th April



09:00 – 09:15

START OF THE CONFERENCE
Welcome To The 5th IKCC EXPANDING CIRCLES
In Supporting Kidney Cancer

Speakers: Joyce Graff (USA) & Deb Maskens (CAN)

Joyce Graff (USA) and Deb Maskens (CAN) welcomed the representatives of more than 20 countries on six continents to New Jersey for the first North American conference of the IKCC. They shared some history of Morristown, its role in the American Revolution, and its position between New York City to the east and the rolling hills of Pennsylvania to the west. They also introduced the audience response system and asked some demographic questions. Many present were from Europe; most were attending their first IKCC meeting.

09:15 – 10:45

Kidney Cancer - Updates for 2015
Moderator: Joyce Graff (USA)
Patient Perspective - Speaker: Denis Brezillon (FRA)
Medical and Surgical Oncology - Speaker: Dr. Jonathan Coleman (USA)
Q & A Session

While incidence of most cancers has leveled off, the rate of kidney cancer continues to rise, especially among women and African Americans. Because there is no screening test available, most kidney cancers are identified when they are already symptomatic and quite frequently after metastasis. Surgery is the “gold standard” treatment, and more conservative techniques are being used in order to preserve maximum working nephrons and retain good kidney function throughout the patient’s lifetime. A number of treatments are now available, but we are still working to find the optimal treatment recommendations for specific cell types. The situation is compounded by the high cost and limited access to the latest treatments.

11:15 – 12:00

Keynote Address: Cancer Challenges in Mexico and the Global Perspective
Moderator: Dr. Rachel Giles (NL)
Speaker: Dr. Harold Varmus (USA), Director of the National Cancer Institute and co-recipient of a Nobel Prize (1989) for studies of the genetic basis of cancer.
Q & A Session

We were extremely honoured to have an inspirational keynote address by Nobel Laureate Dr. Harold Varmus, former director of the NIH and National Cancer Institute (USA), who talked about global challenges in health care. Dr. Varmus pointed out that cervical cancer caused by HPV virus is a considerable burden worldwide despite a vaccine being available. As an example of how government policy can influence cancer outcomes, “Rwanda has a better uptake of HPV vaccines in girls than the USA.” He also discussed the collaboration between the US National Cancer Institute in managing EBV virus (Burkitt’s lymphoma) in Africa, especially Uganda. He concluded with inspiring words from Robert Browning: “Our reach should exceed our grasp”.

13:30 – 15:00

Sharing Best Practices In Kidney Cancer Support & Advocacy
Moderator: Rose Woodward (UK)
James Whale Fund for Kidney Cancer, UK
VHL Alliance
V Care Foundation, India
The Judy Nicholson Foundation for Kidney Cancer Research, USA
Kidney Health Australia
Q & A Session

We genuinely love to share ideas and experiences and to learn from each other’s successes at the “sharing best practice” session. Delegates learn about other groups’ successful projects which they can take back to their own countries to help improve the lives of kidney cancer patients. We heard from five organisations who shared their best ideas with us: Karen McNee from the James Whale Fund for Kidney Cancer (UK) discussed starting a patients’ buddying scheme; Damien McDonnell from Ireland explained why Ireland needs to set up a Centre of Excellence for VHL patients; and Yashwant Sawant from India told how V Care Foundation helped hundreds of patients receive sunitinib through an assistance programme.

Day 1 – Thursday, 16th April



15:00 – 15:30

Global Kidney Cancer Patient Charter

Moderators: Deb Maskens (CAN) & Dr. Rachel Giles (NL)
Speaker: Dr. Rachel Giles (NL)

Amsterdam Charter for Kidney Cancer Care: The Global Patient Charter for Kidney Cancer Care was developed during last year's annual conference in Amsterdam and has since been published in the very prestigious Journal of European Oncology. The charter promotes the global need for diagnostics, quality of care, and access to expertise for patients throughout the world. The charter has already been translated into 14 languages, the latest being Arabic thanks to our representative from Morocco. During the conference participants rated each charter statement against the current reality in their country. Results of this survey each year will help the IKCC direct its efforts wherever possible to close gaps in information, support, and care for kidney cancer patients.



Kirren Grennan from Kidney Health Australia shared her project about setting up a Clinical Trial Register for kidney cancer patients in Australia. Karen Gibson from The Judy Nicholson Foundation (U.S.A.) described how her organisation helps kidney cancer patients with a Patient Financial Help Fund.



16:00 – 17:30

How Can Kidney Cancer Patient Groups Best Address Psychosocial Issues?

Moderator: Robin Martinez (USA)
Speaker: Kathleen Nugent, Licensed Clinical Social Worker (LCSW) (USA)
Discussion Panel:
Timo Koponen - The Association for Finnish Cancer Patients, Finland
Vandana Gupta - V Care Foundation, India
Karen McNee - James Whale Fund for Kidney Cancer, UK
Q & A Session

Psychosocial issues are often neglected in providing services to kidney cancer patients and families. This is an area where patient groups can shine. Social worker Kathleen Nugent (USA) says a cancer diagnosis creates an existential plight in which patients question the meaning, purpose, and value of their lives. Both the patient and family struggle to maintain their psychological balance, to build a support network among their contacts, and to get the help they need. Timo Koponen (Finland) told us about providing kidney cancer patients and caregivers with information and a sense of community with others in the same situation. Vandana Gupta described overcoming challenges in India where cancer is often seen as



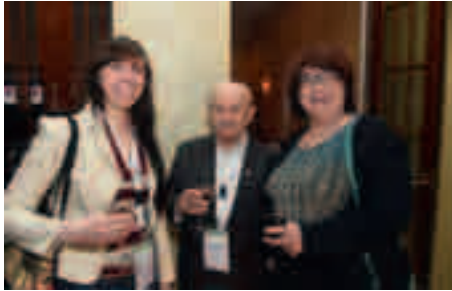
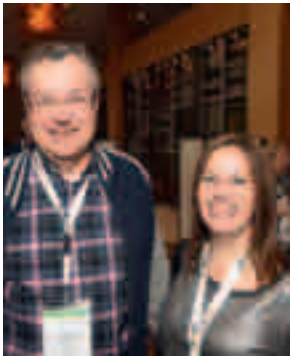
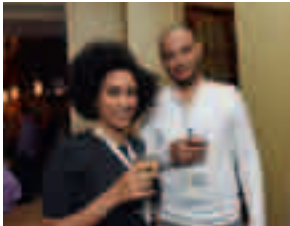
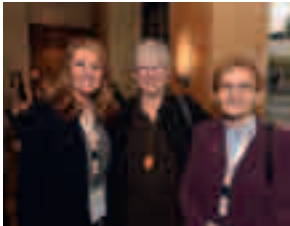
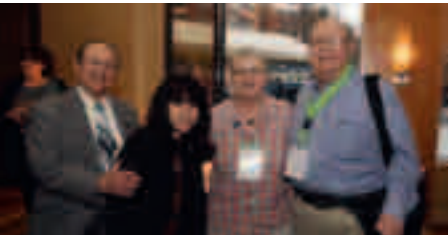
punishment from God, patients often travel long distances to receive treatment, and many struggle just to afford adequate food. Scotland's Karen McNee (UK) shared a patient's moving account of the many fears and problems that accompany cancer diagnosis and treatment.

Day 1 – Thursday, 16th April

19:00 – 23:00

Conference Welcome Dinner
and Networking

Concord Room, Hyatt Morristown at
Headquarters Plaza



Day 2 – Friday, 17th April

07:30 – 08:30

Early Breakfast Session (optional)
Joining the IKCC

Facilitators: Anne Wilson (AUS) & Markus Wartenberg (DE)
Information Session: Joining the IKCC as an Affiliate or
Associated Individual

Please find more information about joining IKCC
on pages 38 and 39.



09:00 – 10:30

Challenges and Opportunities for Non Clear Cell RCC

Moderator: Deb Maskens (CAN)
Patient Perspective - Speaker: Alison Hahn (USA)
Surgical Oncology Perspective - Speaker: Dr Gennady Bratslavsky (USA)
Medical Oncology Perspective - Speaker: Dr. Ram Srinivasan (USA)
Q & A Session

In the session on Challenges and Opportunities for Non Clear Cell RCC, Alison Hahn of Kure It presented the story of Barry Hoeven, an inspirational patient who has been treated for a mix of papillary and clear cell rcc for 17 years and who founded Kure It. Dr. Gennady Bratslavsky presented the surgical management of non-clear cell RCC, stating “just because it appears in the kidney doesn’t mean it’s the same disease.” The role of the surgeon is to know when to observe and when to act aggressively. Dr. Ram Srinivasan’s call to action was that patients with non-clear cell RCC should be directed to highly specialised centres where pathology can be re-reviewed. Specifically on papillary, Dr. Srinivasan is seeing very encouraging results in his ongoing clinical trial of bevacizumab plus erlotinib. Most important to conference attendees, Dr. Srinivasan confirmed his willingness to offer an opinion and help non-clear cell patients worldwide whenever possible.

Day 2 – Friday, 17th April



11:00 – 12:30

Kidney Cancer, Kidney Disease and the Role of the Nephrologist:

Moderator: Anne Wilson (AUS)

Speaker: Prof. Allan J. Collins (USA)

Discussion Panel:

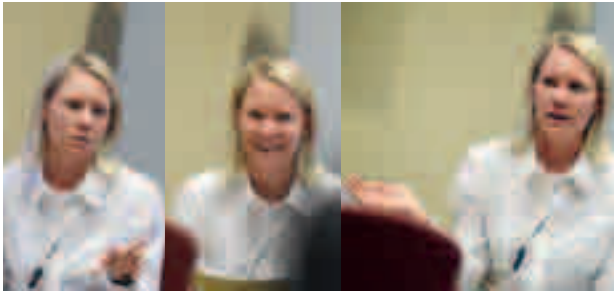
Patient Perspective – Frederick L. Atkin (USA)

Kidney Disease Organisation - Carlos Castro Sanchez (MEX)

Kidney Cancer specialist – Dr. Fabio A. B. Schutz (BRA)

Q & A Session

In the session entitled Kidney Cancer; Kidney Disease and the Role of the Nephrologist, we were reminded of the importance of considering what else may be happening in and to the kidney. Kidney cancer should not be considered in isolation from the impact of potential co-morbid conditions such as diabetes and hypertension, often prevalent in patients with chronic kidney disease (CKD). From Prof. Allan Collins, Nephrologist, we learned about the need to balance kidney cancer treatment against the importance of preserving kidney function and the need for regular monitoring of kidney function for early diagnosis and management of CKD in those with kidney cancer. We celebrated individual successes and achievements and were inspired by stories where tragedy was overcome by triumph.



14:00 – 15:30

The Marketplace Session: Capacity Building and Organisational Issues For Patient Groups

The Marketplace session allows delegates to meet in small groups with individual speakers for fast-paced knowledge exchange.

Delegates chose a maximum of three sessions to attend from the following topics:

- Working in a non-profit organisation: funding top level research
- Building effective relations with medical experts
- Using surveys, online polls and databases to learn more about your patient needs
- Using social media strategically to further your organisation's goals
- Working with the pharmaceutical industry on projects.



Working in a non-profit organisation: funding top level research

Alison Hahn (USA)

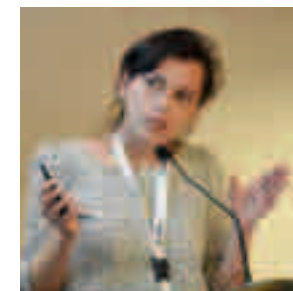
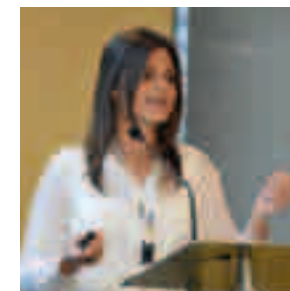
Kure It Cancer Research succeeds in fundraising by educating donors, supporters, and friends about the current state of research funding. Kure It works with Comprehensive Cancer Centers, directing funds for critical research projects that are translational, collaborative, innovative, and novel. Other cancer support organisations can learn from this model to raise funds by focusing on crowdfunding, the latest frontier for igniting potential supporters via online sites including Kickstarter, Indiegogo, Crowdrise, and Crowdfunder. The goal is to create enthusiasm for your cause by connecting with your audience: communicate your mission clearly and concisely, ensure your message is engaging, and include an emotional tie to garner support. A successful crowdfunding campaign capitalises on your organisation's positive public image, creates a call to action to motivate involvement, expands your outreach, and empowers supporters to become activists for your charity.



Building effective relations with medical experts

Kirren Grennan (AUS)

The gold standard practice of cancer care in Australia now advocates for a multidisciplinary team (MDT) approach. The Australian MDT includes a range of health professions, whilst in other countries the patient is included at the MDT discussion. More and more the “patient voice” is being recognised as a critical insider experience. Health experts are working with patients/representatives to achieve mutual goals and have something to offer one another in advancing optimal outcomes in the cancer space. To ensure that we as patient organisations are enabling optimal relationship building with health experts, a few suggestions were noted: clear and achievable goal setting, upfront role expectations, preparation and research as with any business meeting, and mutual respect.



Using surveys, online polls and databases to learn more about your patient needs

Ilene Sussman (USA)

Surveys, polls, and databases are important tools to learn more about your constituents, including their demographics, medical information, needs, etc. A poll is an activity in which several or many people are asked a question or a series of questions in order to get information about what most people think about something. A vote is an example of a poll. A survey is an activity in which many people are asked a question or a series of questions in order to gather information about what most people do or think about something. It is also an act of studying something in order to make a judgment about it or determine next steps. A database is a usually large collection of data organised especially for rapid search and retrieval (as by a computer). There are a number of online resources available. These include www.surveymonkey.com; www.constantcontact.com; www.freeonlinesurveys.com

Using social media strategically to further your organisation's goals

Bryan Lewis (USA)

This session on utilising social media strategically to support an organisation's goals was interesting from two perspectives: One - U.S. attendees asked very specific questions surrounding the efforts Action to Cure Kidney Cancer (ACKC) has been using in Washington, DC, to strive for kidney cancer research funding. Several participants wanted to learn more about what we do, how we do it, and hopefully become engaged to learn more about how to use social media to engage decision-makers, fellow advocates, and patients. Two - international representatives centered their questions and dialogue on how we utilised social media efforts. Social media is just one aspect of most organisations' communication and outreach efforts – another tool in your organisational toolbox to use. There also must be a coordinated effort to communicate messages via many traditional methods such as letter writing, website presence, phone calls and face-to-face meetings.

Working with the pharmaceutical industry on projects

Eva Maria Ruiz de Castilla (PER)

Patients' organisations share the aim of improving health and quality of life for patients with many other stakeholders. Building relationships with these other stakeholders can be valuable and mutually beneficial. As in all relationships, there are also challenges. One way to support the development of effective partnerships and overcome these challenges is to have a framework for interaction. IAPO has developed a toolkit iapo.org.uk/working-partners-and-stakeholders-toolkit which provides examples and guidance on how to develop long-term partnerships with these stakeholders while retaining independence. The toolkit also provides tips and information to help with some of the challenges that can occur when working with external partners. Areas covered include raising disease awareness, advocacy, strategic planning, fundraising, and effective communication.

16:00 – 17:30

Drug and Treatment Access in the Emerging Countries (Focus on Latin America)

Moderator: Prof. Michael Herbst (ZA)

Speaker: Dr. Fabio A. B. Schutz (BRA)

Discussion Panel:

Luiza Cecilio - Instituto Oncoguia, Brazil

Juanita Ruiz - Fundación SIMMON, Colombia

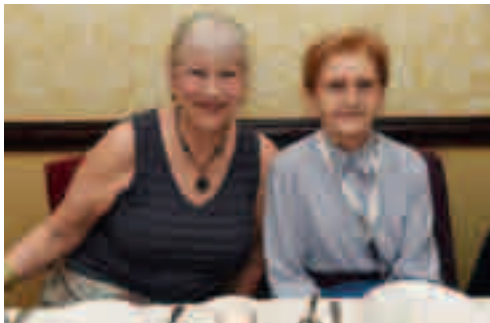
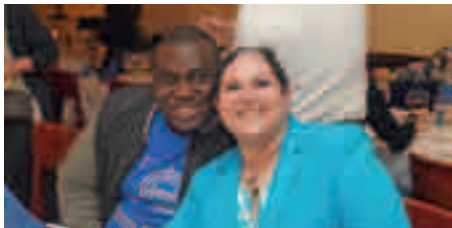
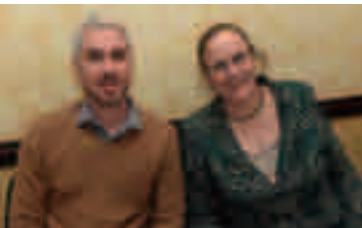
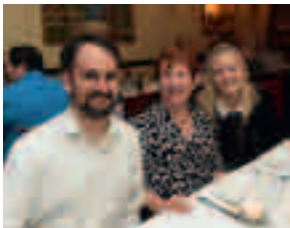
Carlos Castro Sanchez - Asociación Ale IAP, Mexico

Eva Maria Ruiz de Castilla - Esperantra, Peru

Q & A Session

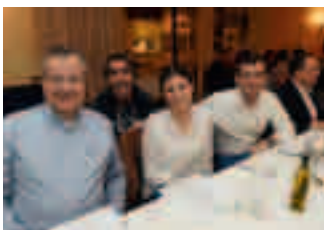
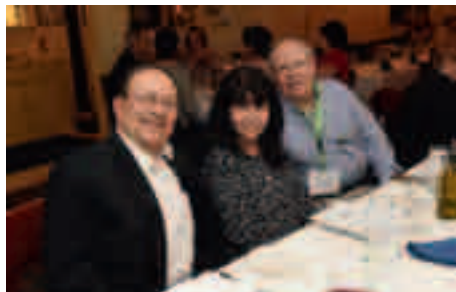
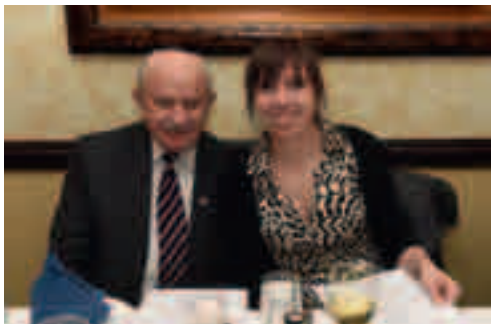
In most of the Latin American countries, health is a constitutional right. However, it would appear there are not enough funds to care for those who need it most. In general, rare cancers like kidney cancer fall outside the health conditions for which 'universal coverage' is available. There are also major differences between private and public healthcare with the majority of the people being dependent on public healthcare. Individuals with private health insurance have access to prompt and more complete care than those who depend on the public healthcare system. Very little coverage is available for specialist care needed by kidney cancer patients. To gain access to adequate treatment, one must sue the Health Department. This boils down to no money = no legal action = no treatment.

Day 2 – Friday, 17th April



19:00 – 23:00

External Dinner – Chef Fredy’s Table



Day 3 – Saturday, 18th April



07:30 – 08:30

Early Breakfast Session (optional)

Moderator: Joyce Graff (USA)

Doctor/Patient Communication:

USA Perspective - Speaker: Dr. Kent Bottles (USA)

China Perspective - Speaker: Zhenxi Zhong (CHN)

Q & A Session

Ms. Zhong shared her perspectives of the situation in China, where patients and doctors are affected affected by long-term cultural factors such as general suspicion, frustration, and anger. Patients may wait to get appointments, time is short, and the doctor tends to make quick judgments due to lack of time and overwork. The role of a patient advocate in China is to help patients optimise their outcomes within the existing healthcare system.

Dr. Bottles explained that in the U.S. we are moving from a “sickness system” to a “wellness system,” focusing on management of chronic disease in order to avoid acute disease, and from a doctor-centric system to a patient-centric system. It is not easy to change the culture, but patients who are involved in shaping the treatment plan are more likely to carry it out as planned. “Useful knowledge plus clinical experience plus what the patient wants leads to best care.”



09:00 – 09:45

Keynote Address: How Healthcare Systems are beginning to Listen

Moderator: Dr. Rachel Giles (NL)

Speaker: Dave deBronkart (USA), ‘e-Patient Dave’, stage IV kidney cancer survivor; now the Mayo Clinic’s 2015 visiting Professor in Internal Medicine
Q & A Session

With the outspoken philosophy that “Doctors are not hosts in the hospitals but guests in their patients’ bodies”, our second keynote speaker was kidney cancer survivor “e-patient Dave” (Dave deBronkart). Dave discussed his personal history and how he came to be a co-founder of the Society for Participatory Medicine to support patient engagement. Using examples ranging from heart patient Laura, who convinced a world-famous hospital to launch research on her rare and deadly heart condition, to Dr. Bennick at Yale University who defends the patient experience locally by using courtesy and common sense (for example, that patients’ blood should not be drawn before 4am to allow sleep), e-patient Dave supports all efforts towards improving patient and family-based management of health care.



09:45 – 11:00

Clinical Trials in Immuno-oncology (patient perspective)

Moderator: Deb Maskens (CAN)

Speaker: Peggy Zuckerman (USA)

Advances in Immuno-oncology for Kidney Cancer
Speaker: Dr. Janice P. Dutcher (USA)
Q & A Session

Peggy Zuckerman, stage IV kidney cancer survivor and blogger (PeggyRCC.com) gave an inspirational account of having a 10cm tumour and “too many lung mets to count” – and then a complete remission as a result of high-dose Interleukin 2 (HD-IL2) treatment that activated her body’s immune system to fight the cancer. Dr. Janice Dutcher, renowned expert in immunotherapy for kidney cancer, reviewed previous data for HD-IL2, citing response rates of up to 41 percent in carefully selected patients. Dr. Dutcher then described the challenges and opportunities for the next generation of checkpoint inhibitors, reviewing clinical trials to date. The next generation of trials will need to work towards minimizing toxicity. Patients will need to be managed at expert centres where the entire team is trained to expect and manage a wide range of toxicities that may occur between treatments. Much is yet to be learned. Patients should be directed to clinical trials in major cancer centres whenever possible.



11:30 – 12:15

IKCC Global Projects for 2015/2016

Speakers: Markus Wartenberg (DE)

Markus Wartenberg (DE) presented current/ongoing projects for the group’s input, suggestions, and involvement. Projects included:

- Book of Courage and Hope (global)
- Immuno-oncology website (in multiple languages)
- Position papers on unmet medical needs worldwide.

Many of these projects have since been delivered as collaborative efforts among IKCC groups and are described further in this Activity Report.

Day 3 – Saturday, 18th April



12:15 – 12:30

End Of Conference, Summary, Feedback-Forms, Closing Remarks, Thanks To The Presenters & Sponsors

Speakers: Anne Wilson (AUS) & Prof. Michael Herbst (ZA)

The 2015 IKCC conference inspired us to speak with one voice, raise global awareness of kidney cancer, and work to improve health outcomes at the local level for all affected by kidney cancer. We shared best practices from around the world and were introduced to remarkable work being undertaken across more than 20 countries. We were inspired by stories where tragedy was overcome by triumph and encouraged to be equipped, engaged, empowered, and enabled. We were reminded of the social determinants of health and their impact on disease development and progression as well as the importance of preserving kidney function when balancing the impact of treatment regimes. We were educated from a clinical perspective on the latest in treatment and management of kidney cancer and were urged "to beg, borrow and steal" ideas and programme outlines from each other for local implementation on return to our home countries.

A truly remarkable conference!



Feedback



First of all, I want to thank you for this, once again, very well organized IKCC Conference. As always, it was a pleasure to participate and meet all so fantastic people.

I was really delighted and honored by attending the 5th IKCC Conference in New Jersey. It was an occasion to meet lovely people and committed associations focusing on kidney cancer all over the world.

What a wonderful time I had with some of the most kindest, bravest, passionate and hard working people I have ever met.
Thank you for the opportunity to share, learn, collaborate, and meet other kidney cancer patients and advocates making a difference in lives all over the world. Please tell everyone at IKCC how much I appreciate being able to attend and how grateful I am for all I came away with. I just wanted to take a moment to thank you for all the great work you accomplished at the recent 5th IKCC conference in New Jersey.

This is an incredibly well designed conference and meeting. Such an honour and a pleasure to be here and to participate. I have learned so very much! My sincere thanks.

Congratulations for this conference! This conference make me realise the parallel universe of patients. I won't feel alone in this journey anymore.

Feedback

Very well organised, networking was easy with small intimate group. Invaluable and essential info received.

Again, thanks for a great conference. I learned a lot, made some good connections, and I found the speakers inspiring.

Very well organised and well looked after so thank you. Delighted to have been invited and to have found the event, very beneficial but I have so much to learn!!


Thank you for the perfect organisation. Thanks for being able to put in the same room, so many persons from everywhere in the world.

The conference was wonderful, and though the topic of expanding and improving access to kidney cancer care throughout the world is the most important, I was personally so pleased to serve with people whom I have admired for years. The sincere appreciation for your work was voiced many times, but it was not enough to thank you for putting together this remarkable group of people.



I knew of IKCC but not what it does, we must get the word out.

Congratulations to the Board, Markus and Julia for a very well organised meeting. Is it possible that we have smaller meetings/trainings in emerging countries, so more people benefit and are motivated to do more work?


This has been an amazing experience, I feel empowered to help my patients more! The standard of speakers, food, hotel has been excellent. Well done to the organisers and thank you.



Understanding
Immuno-oncology
for kidney cancer



Search



2
Understanding
Immuno-
Oncology

Immuno-oncology (IO) therapy is a new (and old) way to treat cancer by activating your immune system.


Read on

1

10 Steps To
Understanding
Therapy Options
in Kidney Cancer

Learn the basics of kidney cancer and current therapy options in 10 steps.

Read on




8
Finding Patient
Support Globally


Read on

9

News

Read on to get the latest news on IO in kidney cancer







Home About Us Kidney Cancer Global Info News

Curious about Immuno-oncology?

IKCC has launched [www.10for10.org](#), a new web-based resource for kidney cancer patients, medical professionals, patient advocates and underserved. It takes you to all of the patient resources and advocates worldwide who have shared in the development of this new resource. [See Press Release](#)



Delegates gathered from more than 60 countries. Leaders of kidney cancer support groups came to share ideas.



For further information about our global conference visit [www.10for10.org](#)

IKCC is an independent and non-profit network of patient support and advocacy organisations established with the mission of improving the quality of life of patients and their families living with kidney cancer. IKCC provides information, support and assistance to national kidney cancer organisations. All organisations are welcome to participate.

Projects and Activities
(Excerpt)

30

www.ikcc.org

Relaunch of our website - introduced in early 2015.

As one component of our outreach to very different stakeholders worldwide, we undertook to make our website more modern, more pictorial, and easier to use.

The main goal of our site is to empower our Affiliated Organisations to provide information to their own patients and constituents. As such we work not so much to generate original information ourselves but to collect authoritative information from medical sources and make it available in patient-approachable language to kidney cancer patient groups for potential translation into their local languages.

Similarly, we gather good models of information generated by our Affiliates and provide a platform where they can be shared among the Affiliates, either openly on the open website or privately among the Affiliate members themselves. Affiliates are provided with password-protected access to the resources area of the site, where they can interact and share ideas.

Our site also provides information about the IKCC, its new organisational structure, its Board Members, and its programmes, and connection to its Affiliates worldwide.



“Life is beautiful and worth fighting for!”

Kidney cancer patients worldwide share their stories in the new “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 their 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 new “Book of Courage and Hope” recently 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. Hardcopies can be requested via the IKCC website.



Understanding immuno-oncology in kidney cancer: IKCC launched new website in response to strong demand from patients worldwide

On the 25th of 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 new 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 new 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 was 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 three languages: English, German and French with Spanish, Portuguese and Dutch soon to be announced.



| IKCC STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 31 DECEMBER 2015 | |
|--|---------------|
| CURRENT ASSETS | |
| Cash | 71.805,42 € |
| TOTAL CURRENT ASSETS | 71.805,42 € |
| TOTAL ASSETS | 71.805,42 € |
| CURRENT LIABILITIES | |
| Creditors and borrowings | - 30.645,59 € |
| TOTAL CURRENT LIABILITIES | - 30.645,59 € |
| TOTAL LIABILITIES | - 30.645,59 € |
| NET ASSETS | 41.159,83 € |
| ACCUMULATED FUNDS | |
| Reserves | |
| Last year profit/(loss) | |
| Current year profit/(loss) | 41.159,83 € |
| TOTAL ACCUMULATED FUNDS | 41.159,83 € |

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

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

| IKCC STATEMENT OF SURPLUS AND DEFICIT FOR THE YEAR ENDED 31 DECEMBER 2015 | |
|---|-----------|
| INCOME | |
| Partnership Income | 194.957 € |
| Other Income | 34.800 € |
| TOTAL REVENUE | 229.757 € |
| EXPENSES | |
| Project Management | 44.781 € |
| Sponsor Meetings | 2.626 € |
| Conferences & Meetings | 91.924 € |
| Travel Expenses | 15.575 € |
| Legal Expenses | 3.860 € |
| Consulting Expenses | 6.236 € |
| Board Expenses | 19.842 € |
| General Expenses | 890 € |
| Bank Charges Expenses | 126 € |
| Printing & Stationery Expenses | 2.737 € |
| TOTAL EXPENSE | 188.597 € |
| Result from Operating Activity | 41.160 € |
| NET PROFIT / (LOSS) | 41.160 € |

Accountability and Transparency

The IKCC is committed to transparency and accountability according to laws governing patient organisations in the Netherlands. The IKCC Code of Conduct is available to view on our website www.ikcc.org
Please contact us if you have any questions info@ikcc.org

We would like to thank the following funders who have supported IKCC in 2014 and/or 2015 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/

IKCC Affiliated Organisations



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.



**DEBORAH MASKENS,
M.A. (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 has previously served on the board of the Canadian Cancer Advocacy Coalition (CACC) and chaired the Drug Access Working Group, Canadian Cancer Action Network. Most recently 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.



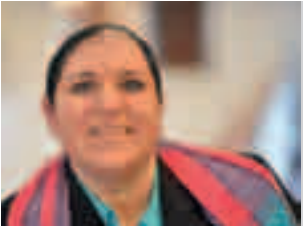
**MICHAEL C. HERBST,
PH.D.**
**Cancer Association of
South Africa (CANSa)**

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.



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.



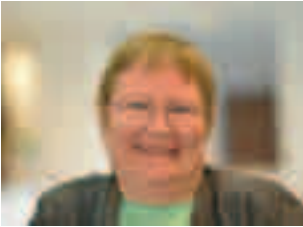
BERIT EBERHARDT
**Das Lebenshaus e.V.,
Germany**

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
Kidney Health Australia

Anne is CEO and Managing Director of Kidney Health Australia – the national peak body committed to saving and improving the lives of Australians affected by kidney disease. Over the past 4 years, Kidney Health Australia has taken on advocacy and support for Australians and their families affected by kidney cancer, developing specific resources, a blog, website and telephone information service as well as promoting information about access to clinical trials. She knows several people who have kidney cancer and whilst she has no other personal experience of the disease she is passionate about the need for those with kidney cancer and their families to have equity of access to the latest and most up-to-date information about all aspects of this disease.



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.



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