



**IKCC**

International  
Kidney Cancer  
Coalition

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





## Our Global Network

The IKCC (International Kidney Cancer Coalition) 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 as Stichting [Foundation] IKCC, or simply "IKCC". The organisation was born from a very strong desire among various national patient groups to network, cooperate and share materials, knowledge, and experiences.

IKCC is governed by a 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.

### Who Can Join the IKCC?

We welcome every organisation that has an interest in kidney cancer and extend an open invitation to all groups to become a part of this international network. We also welcome individuals who are interested in starting kidney cancer support groups in their own countries. Affiliate Organisations are listed, along with an application form, on our website: [ikcc.org](http://ikcc.org)

Join IKCC as an Affiliate Organisation, an Associated Individual, or as a Supporter.

### Why an International Coalition?

Global experience with other rare cancers proves that this type of an international network can be very valuable, supportive and inspiring. A lot of associations, especially in rare cancers have limited resources and welcome the opportunity to share information, cooperate and work on similar projects.

Kidney cancer knows no country boundaries. We all live in a globalised world. Research and clinical trials in kidney cancer are globalised 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.



## Our Mission

- Global collaboration to raise awareness,
- Promote research and empower organisations to support people affected by kidney cancer.

## Our Vision

- Empowering organisations to improve the lives of people affected by kidney cancer worldwide.

## Our Core 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 our work together.

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

The Code of Conduct outlines IKCC's policy on commercial funding and provides a set of principles that are used to guide decisions related to funding of specific projects, meetings and activities.



## Our Objectives

### 1 Raising awareness of kidney cancer as a significant and increasing health issue

As a rarer cancer, kidney cancer is often not on the “agenda” of different stakeholders including healthcare systems, national cancer societies or cancer institutes. We need to bring attention to kidney cancer as a significant and increasing health issue. We need to raise the awareness of kidney cancer regarding unmet needs of patients, the gaps in research and access to and quality of treatment & care. This applies in particular for low and middle income countries.

### 2 Encouraging early detection and access to quality care

Successful outcomes for kidney cancer patients is dependent upon early detection, access to qualified treatment, care, and follow up. Quality care requires identification of national and international data, clinical guidelines, access to quality care including multi-disciplinary care in centres of excellence, access to treatments and to clinical trials.

### 3 Enhancing the exchange of information and best practices

Around the world, kidney cancer patient organisations often provide the same services and have similar information needs. At the same time they have limited personnel and financial resources. IKCC is actively enhancing the exchange of information by encouraging organisations to share best practices, materials and to collaborate on common projects.

### 4 Promoting collaboration and patient involvement in clinical research

Patient organisations are able to offer a unique, invaluable contribution to the clinical research process – ensuring that the global patient perspective is incorporated from the very outset. A patient-centric approach to designing, implementing and evaluating kidney cancer research will make studies more effective, more credible and more cost-efficient. In addition to supporting the general approach of “Patient Involvement in Clinical Research” - IKCC is fostering pilot projects to involve the kidney cancer patient voice and is able to bring relevant people together to develop and prioritise key research questions and find better answers for patients worldwide.

### 5 Supporting existing patient organisations and encouraging the creation of new groups

The whole is more than the sum of its parts. As a global network of kidney cancer patient groups, we are stronger working together as peers with a strong and influential voice. Together we are working to empower one another, provide education, training and capacity building, and to find opportunities to create new resources where needed.

We welcome new organisations working in kidney cancer to reach out to us, whether they are focused on kidney cancer specifically, or more generally as organisations supporting rare cancers, kidney diseases, cancer or related healthcare challenges.



### Join the IKCC Network!

Under the constitution of IKCC, organisations and individuals are cordially invited to join the Foundation as:

- Affiliate Organisations OR
- Associated Individuals OR
- Supporters

### Please go to our website: [www.ikcc.org](http://www.ikcc.org)

Our website lists various documents such as

- Our legal constitution in Dutch and English (Deed of Incorporation),
- Conference reports and activity reports,
- Documents and forms – including how to join IKCC.

## Our Board of Directors

The IKCC Board of Directors consists of representatives of Affiliate Organisations. Each is appointed for a three-year term and serves as a volunteer, without remuneration. Board Directors are appointed by the Board with the approval of the Council of Affiliates.

**Chair: Dr. Rachel Giles,**  
Dutch von Hippel-Lindau, The Netherlands

**Vice-Chair: Deb Maskens**  
Kidney Cancer Canada

#### Board Directors:

**Anne Wilson**  
Kidney Health Australia

**Berit Eberhardt**  
Das Lebenshaus e.V. Germany

**Prof. Dr. Michael Herbst**  
Cancer Assoc. of South Africa (CANSA)

**Rose Woodward**  
Kidney Cancer Support Network UK

**Joyce Graff**  
Powerful Patient Inc. United States

#### Management Services:

Markus Wartenberg (Germany)  
Julia Black (UK)



## Our Annual Conferences “EXPANDING CIRCLES”

Our collaborative network of independent kidney cancer organisations was established in 2009 in Berlin. In September 2010, 50 participants attended our first collaborative conference “EXPANDING CIRCLES” 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, New Jersey (USA) in April 2015.

The Conference Programmes are developed by Conference Committees comprised of volunteers from the IKCC network. In planning the conferences, our goals are to address the varied needs and interests of the global kidney cancer patient advocacy community. Each IKCC conference has demonstrated the tremendous value of bringing together patient support and advocacy groups from around the world to share their ideas and experiences and to get the latest updates from medical professionals.

**For more information about past and future conferences, please visit our website: [www.ikcc.org](http://www.ikcc.org)**

## Our Charter for Global Kidney Cancer Care

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. IKCC aims to assist national kidney cancer patient organisations serving patients and their families all over the world, to get the necessary information to take an active role in the management of their kidney cancer and to understand what they can expect from their treatment and care. Published in the European Journal of Urology, the Amsterdam Charter for Global Kidney Cancer Care has already been translated into 12 languages and more are being added.

**Please see our website: [www.ikcc.org](http://www.ikcc.org)**



# IKCC

International  
Kidney Cancer  
Coalition

**Working together we can help one another  
achieve the best support, care and treatment  
for kidney cancer patients and their families.**

**IKCC International Kidney Cancer Coalition  
The Global Collaboration of National Patient Organisations  
Supporting Those Affected by Kidney Cancer.**

Legal Entity: IKCC Foundation  
Registered in The Netherlands under:  
Stichting IKCC - Intl. Kidney Cancer Coalition  
Reg.-No. KvK 62070665

Established: 2009  
Registered: 2014  
Address: t Ven 30  
1115HB Duivendrecht  
The Netherlands

Website: [www.ikcc.org](http://www.ikcc.org)  
Email: [contact@ikcc.org](mailto:contact@ikcc.org)

Member of: Rare Cancers Europe (RCE)  
[www.rarecancerseurope.org](http://www.rarecancerseurope.org)

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