



## An Open Letter to the Kidney Cancer Community

Bad Nauheim/Germany the 8th of March 2010

Association:  
Registration pending.

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### Dear Patients, Caregivers, Patient Group Leaders, Medical Experts and Industry Sponsors!

The purpose of this "Open Letter" is provide more information about our new international network of kidney cancer patient groups and provide some important background information about participation and industry funding of this initiative.

### *What are the objectives of IKCC?*

IKCC stands for "International Kidney Cancer Coalition". IKCC will be an international network of independent Kidney Cancer Patient Support Groups from around the world. The organization was born from a strong desire among various national patient groups to network, cooperate and share experiences.

We would like to emphasize very clearly: IKCC is not a coalition against any existing organization, nor does it intend to replace any existing organization or duplicate the great work of any other organization. Rather, IKCC will meet the unmet needs expressed by patient groups to network, share resources, and promote best practices in patient support and patient advocacy from around the world. We welcome every organization that has an interest in kidney cancer and will continue to 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.

### *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. So it makes absolute sense to share information, to cooperate and to work on similar projects. Examples of successful international coalitions include:

- International Lymphoma Coalition – a worldwide network of lymphoma groups
- International Brain Tumour Alliance – an international brain tumour advocacy group
- Myeloma Euronet – European network of 42 groups from 20 countries
- Sarcoma Patients EuroNet Assoc. – European coalition of 17 groups from 13 countries

We all live in a globalized world - research and business is global. Most pharmaceutical companies are global players, research and clinical trials in Kidney Cancer are globalized and experts are working on international panels.

The preliminary mission of IKCC is: **"Networking, collaborating and advocating on a global level to better support patients at each national level."** We believe that together we will be able to speak as one voice to expert panels and the industry on behalf of many Kidney Cancer Patient Support Groups.



### **How will IKCC be funded?**

The IKCC funding policy is based on the well known Code of Practice Between Patients' Organisations and The Healthcare Industry from ECPC (The European Cancer Patient Coalition.) ECPC is a well established organization comprising over 300 national and European umbrella cancer patient organizations acting on this "Code of Practice". IKCC is already acting on this Code of Practice and, after registration as a legal entity, IKCC will be a member of ECPC. In the meantime, each organization involved in IKCC is governed by the rules of transparency and ethical relations within their own countries.

The idea of building the future association IKCC was not initiated or pushed by the industry. The idea was voluntarily developed by several patient group leaders in 2009, who are strongly interested in working closer together. From the very beginning we made our position clear that IKCC would only work on a multi-sponsored, equal sponsorship basis.

### **Our First Conference – May 14-16, 2010**

The main objectives of the conference in Frankfurt is to learn more from each patient organization and to evaluate the future objectives and role of IKCC.

All the work for the conference has been done on a voluntary basis beside our daily work for our national organizations. To cover the costs for such a global conference, we asked different pharmaceutical companies to support this international project with unrestricted educational grants. We are pleased to have their support. When the final agreements are made, we will be absolutely happy to announce these companies and to be fully transparent to the global kidney cancer patient community.

At the end of our letter we would like to make this absolutely clear:

The members/people of IKCC are friendly-minded and positive people with a central and common focus: Every day we see patients dying from Kidney Cancer. We would like to do our very best to achieve the best support, care and treatment for kidney cancer patients and their families.

We hope that this letter helps to bring more transparency to our activities.  
On behalf of the IKCC Steering Committee –

#### **Steering Committee:**

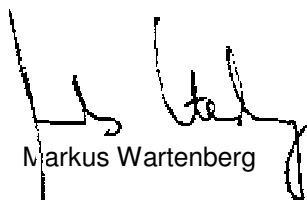
Dr. Marion Beier (DE)  
Vandana Gupta (IND)  
Andrew Wilson (UK)  
Markus Wartenberg (DE)

Tony Clark (CDN)  
Deborah Maskens (CDN)  
Rose Woodward (UK)

with best regards



Dr. Marion Beier



Markus Wartenberg