

Welcome affiliates, breaking news

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Dear \*[SALUTATIONI]\*:

# Welcome Affiliates

## 23 organisations from 18 countries, 6 continents



Since the announcement in April of our new Foundation structure, 23 organisations have enrolled as affiliates of the International Kidney Cancer Coalition. Altogether we represent six continents, from developing nations to industrialized nations, with varying needs and readiness to deal with kidney cancer. [Click here for the growing list of our affiliates.](#)

We look forward to working together to improve diagnosis, treatment, and quality of life for everyone with kidney cancer worldwide. By working to find ways to improve early diagnosis in countries with smaller budgets, we have the opportunity to lower cost and improve early diagnosis worldwide. Established organisations may have materials and experiences to help newer organisations grow. And organisations of all sizes can create exciting ideas to improve services everywhere.

If your organisation is not already an Affiliate, [please click here for information](#) on what that means and how to apply. We welcome applications from all organisations who have a focus on kidney cancer.

## News from our Affiliates: Kure It, USA

*From Alison Hahn, Kure It (USA):* We have good news to share - Kure It will be granting another \$250,000 grant for Kidney Cancer Research focused on an immunologic approach to the disease through the American Association



of Cancer Researchers (AACR). The grant will be for 2016-2017 and will run concurrently with the grant we funded in 2015 to Dr. Elizer Van Allen at Dana Farber Cancer Institute in Boston. It is a two year grant for 2015-2017. In addition to the \$250,000 that goes directly to the selected grantee, Kure It funds a 10% administration fee to the AACR to cover their costs, therefore allowing the full \$250k to go directly to the research project. This is the second grant we will be funding related to immunology and the way it can work with Kidney Cancer. [See other funded projects.](#)

We will be making a similar grant next year. We will be sure to send the grant information to the IKCC community so that any researchers we are connected with worldwide will have the opportunity to apply for the grant. It will be an international Request for Proposal (RFP).

## News from our Affiliates: Kidney Health Australia



*From Anne Wilson, KHA, Australia:* Following the last IKCC meeting it has been a busy time for Kidney Health Australia, with a number of kidney cancer projects either underway or in the planning phase. Very shortly our new website will be launched with a fresh update on kidney cancer information. We have also been surveying kidney cancer patients to gain an understanding of information and support needs. This information will help to inform future resource development. We will be able to report on our survey in future newsletters.

## News from our Affiliates: Spain

*From Juan Carlos Julián Mauro, Director General, Federación Nacional ALCER, Madrid, Spain:* ALCER held its annual meeting in Madrid, at which we announced our new affiliation with IKCC. [Read more](#)



## U.S. Trends in treating small renal masses

A recent study published in JAMA Surgery shows that through 2009 the use of partial nephrectomy has grown, mostly in an effort to reduce the risk of chronic kidney disease. Cryotherapy and Radio Frequency Ablation (RFA) are generally reserved for people who are poor surgical risks. [Read more.](#)

## EAU Guidelines amended

The publication in 2015 of results of two pivotal clinical trials were sufficiently compelling that the Guidelines Committee of the European Association of Urology has modified its Guidelines. IKCC plays an important role on the Guidelines Committee to ensure the patient perspective is incorporated. The modified advisory was published in *European Urology*. [Read more](#)



## Curious about Immuno-Oncology?

IKCC has launched [www.10forIO.info](http://www.10forIO.info), a new web-based resource for kidney cancer patients: trusted,

evidence-based, patient-focused, and understandable. THANK YOU to all the patient organisations and advocates worldwide who have shared in the development of this new resource. [See Press Release](#). Follow us on Facebook and Twitter as @IOKidney.

The 10forIO site is being translated now and will soon be available in German, French, Spanish, and Portuguese. New agents for immuno-oncology are nearing approval for kidney cancer, so this information will be vital to your constituents. [Read more and hear an interview](#) with Deb Maskens on the Powerful Patient.

## Role of Patient Advocates at Medical Meetings

While attending the 2015 European Cancer Congress (ECC) and the European Society for Medical Oncology (ESMO), Deb Maskens (Kidney Cancer Canada) participated in an interview with Bettina Ryll, MD, PhD, chair of the ESMO Patient Advocacy Working Group and a founding member of the Melanoma Patient Network Europe. [Read more and listen](#).



There is a transcript of the interview which can be used to translate it into languages other than English.



Please SAVE THE DATE for our next Expanding Circles conference - **14th to 16th April 2016 in Chantilly, near Paris, France.**

[Please write to Julia Black for details.](#)

[Read more.](#)

We send you all good wishes for the holiday season and for a healthy and happy year ahead. We look forward to working with you to further improve diagnosis, treatment, and quality of life for people with kidney cancer throughout the world, and to empower them to be partners in their healthcare.

*Rachel, Deb*

Rachel Giles, M.D., Ph.D., Chair

Deb Maskens, Vice Chair

and the [Board of Directors, Stichting IKCC](#)

The IKCC is dedicated to global collaboration to raise awareness, promote research and empower organisations to support those affected by kidney cancer.



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