

PRESS RELEASE

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



IKCC (International Kidney Cancer Coalition) launches www.10forIO.info, a new web-based resource for kidney cancer patients: trusted, evidence-based, patient-focused and understandable.

Amsterdam/The Netherlands, September 25, 2015

The International Kidney Cancer Coalition (IKCC) today announced the launch of 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. The new website “10-for-IO” (www.10forIO.info) aims to address many questions kidney cancer patients around the world are asking. The platform also tries to address potential misinformation and exaggerated expectations shown in the lay media and various online communities.

“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 achieves long-term responses. Therefore the aim of current studies is to combine different IO 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. The website was initially launched in English but other languages such as German, French, Spanish, and Portuguese will follow in the coming months.

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 recognized 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."

Visit us online: www.10forIO.info
See us on facebook: www.facebook.com/IOkidney
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BACKGROUND

About KIDNEY CANCER

Kidney cancer is diagnosed in over 300,000 people worldwide every year. It is the 12th most common cancer in the world, the same numbers as pancreatic cancer. Fewer than 1 in 20 people with cancer have kidney cancer, meaning that it is quite a rare disease. There is no known cure for advanced kidney cancer though treatments can extend survival for many patients.

About IMMUNO-ONCOLOGY

Immuno-oncology (IO) therapy is a way to treat cancer by activating the immune system in the hope that it will attack the tumour. Recently, newer types of immune therapies (also called immuno-oncology or IO therapies) have been proving successful in some types of cancer. For example, results from early trials of immune therapy for advanced skin cancer (melanoma) and lung cancer have been encouraging, and some of these drugs have already been approved for use in some countries. Immuno-oncology is currently being evaluated in trials worldwide for kidney cancer.

About IKCC

The International Kidney Cancer Coalition (IKCC), a registered Foundation based in The Netherlands, is an independent, patient-centred network comprising over 20 Affiliate Organisations from around the world. The organization was born from a very strong desire among various national patient groups to network, cooperate and share experiences. The IKCC has previously published a Global Charter for Kidney Cancer Care that is now available in 14 languages.

For more information please view the IKCC-website www.ikcc.org

About The University Medical Center Utrecht (UMCU)

With approximately 12,000 employees, the University Medical Center Utrecht is one of the largest public health care institutions in the Netherlands. It collaborates closely with the Netherlands Cancer Institute for Integrated Cancer Care.

For more information please view www.umcutrecht.nl