

Amsterdam Patient Charter for Global Kidney Cancer Care (April 2014)

Original Version (English)

The International Kidney Cancer Patient Charter was created by the International Kidney Cancer Coalition (IKCC) to ensure that the more than one million people living with kidney cancer worldwide (338 000 diagnoses in 2012 alone, http://www.wcrf.org/cancer_statistics/data_specific_cancers/kidney_cancer_statistics.php) have access to the best available treatment, care, information, and support.

It is our aim to assist national kidney cancer patient organizations in helping patients and their families worldwide to obtain the information necessary to play 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.

This charter was developed in April 2014 in Amsterdam, The Netherlands, at a meeting of kidney cancer patient advocates from diverse geographic regions convened by the IKCC. For a period of 4 years, the IKCC has used web-based search engines and personal networks to contact all patient organizations globally with a stated interest in kidney cancer. In several countries, general cancer or kidney organizations only have a kidney cancer chapter or contact person; however, many countries have independent organizations dedicated specifically to kidney cancer patient support, including Canada, the USA, the UK, The Netherlands, Germany and Ghana. More than 40 organizations have been contacted by the IKCC and invited to attend annual meetings. The 34 patient group representatives present at the Amsterdam meeting, coming from 20 countries spread over six continents, identified the hurdles met by kidney cancer patients worldwide 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. The charter contends 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. This charter is entirely driven by patient organizations and is intended to underscore the global need for equity of care and access to expertise.

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Collectively, the global kidney cancer community declares that patients have the following rights:

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 multidisciplinary 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 psychosocial support;
5. Access to medical records, including pathology and imaging reports, if requested;
6. Provision of information on all available support systems, including patient support tools and local patient support and advocacy organizations;
7. An active role in 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 with survivorship information, including medical and lifestyle recommendations; and
10. Recognition that up to 10% of all kidney cancer tumours are hereditary in nature as part of familial syndromes, and that these patients require specialized and coordinated care over their entire lifetime.

The charter was signed by the participants of the 4th IKCC Annual Conference EXPANDING CIRCLES in Amsterdam.

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