

Rare Cancers Europe: joining forces to tackle a common problem

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Rare cancers are not rare at all: they account for more than 20% of all cancers and affect more than 4 million people in the European Union. Every year, more than 500,000 people in the EU are diagnosed with a rare cancer.¹ Evidence suggests that survival rates for rare cancers are lower than for common cancers² and that cancer patients across Europe do not have equal access to cancer drugs.^{3,4}

Rare cancers pose significant challenges to patients, their families and all parties involved in cancer care. These challenges include:

- late or incorrect diagnosis
- lack of access to appropriate therapies and clinical expertise
- very limited number of clinical studies due to the small number of patients
- lack of interest in developing new therapies due to limitations in the market
- few available registries and tissue banks

Major European stakeholders in rare cancers and rare diseases came together for a European conference in November 2008. Thirty-nine political and stakeholder recommendations, addressing issues of particular relevance in rare cancers, were developed. These included methodological and regulatory barriers in rare cancer care, the need for centres of expertise and European reference networks, barriers to patients' access to care, education of healthcare professionals and access to information on rare cancers.

This was the starting point for Rare Cancers Europe, a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and advocating for the implementation of the 39 recommendations. Based on these recommendations, a public *Call to Action Against Rare Cancers* was launched in June 2009, calling on European governments, the European Union institutions and other international governmental organisations, the research community, the pharmaceutical industry, medical professionals and members of the society to give a high priority to addressing the specific challenges associated with rare cancers and to work towards:

- substantially improved equity of rare cancer care across borders
- the development of new effective therapies for rare cancers
- facilitating more clinical studies in rare cancers with greater flexibility
- balanced, timely and transparent assess-

ment of new therapies

- building a knowledge-base through clinical database networks, rare cancer registries and tissue banks
- increased sharing of knowledge across borders through centres of expertise and reference networks
- timely and accurate detection and provision of care through appropriate referral of patients to centres of expertise and reference networks.

All readers of the Rare Tumors online medical journal are encouraged to show their support for the initiative by signing the *Call to Action* at www.rarecancerseurope.org, where you will also find the full text. Together with the 39 recommendations, it is an integral part of Rare Cancers Europe's ongoing activities, which can be grouped under three main goals:

1. to improve the methodology of clinical research on rare cancers
2. to improve the organisation of health care in rare cancers
3. to improve access of rare cancer patients to new therapies in the EU

To achieve the first goal, an ongoing multi-stakeholder consensus discussion process was launched in November 2011. This also includes a consensus meeting and a related Rare Cancers Conference held in Brussels in February 2012. The aim is to develop and publish a widely-endorsed consensus document that can then be used for advocacy purposes.

Activities related to the second goal include an exemplary survey on clinical practice guidelines for selected rare cancers to better understand the reasons for discrepancies and develop recommendations for harmonising existing rare cancer guidelines across Europe. This could be done in close collaboration with the European Partnership for Action Against Cancer (EPAAC), in which several Rare Cancers Europe partners are also involved.

Rare Cancers Europe has also recently joined the EU Commission-funded RARECARENet project as a collaborating partner. This new three-year project aims to identify clinical centres of expertise for rare cancers and establish a related information network across Europe. In collaboration with the European Society for Medical Oncology (ESMO), the project also foresees the development of new clinical practice guidelines on rare cancers, which have not yet been addressed.

Finally, Rare Cancers Europe aims to develop a *horizontal* index measuring access to rare cancer treatment and care in the 27 EU Member States (goal 3). The index will include data on a pre-defined set of indicators, of which many will also reflect the aforementioned 39 recommendations. The data generated will help to better assess and compare the situations in individual countries and can be

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used to encourage high-performing countries (through public recognition) and low performers to provide optimal access to rare cancer treatment and care. In addition, the findings of the index report will be illustrated by a series of comparative text and video case studies. These will cover rare adult solid, haematological and childhood cancers and can be used by all stakeholders for advocating at European and national levels.

Rare Cancers Europe is an ongoing partnership initiative of professional societies, cancer and rare disease associations, cancer research organisations, cancer institutes, rare cancer networks and reference centres, professional education and training organisations, patient advocacy groups, and the industry. The following partners are involved in the initiative:

- European Society for Medical Oncology (ESMO)
- European Organisation for Rare Diseases (EURORDIS)
- European Cancer Patient Coalition (ECPC)
- European Organisation for Research and Treatment of Cancer (EORTC)
- Conticanet
- EuroBoNeT
- World Sarcoma Network (WSN)
- Association of European Cancer Leagues (ECL)
- Chronic Myeloid Leukaemia Support Group
- International Brain Tumour Alliance (IBTA)
- Orphanet
- Chronic Myeloid Leukaemia Advocates Network
- Sarcoma Patients EuroNet Association (SPAEN)
- GIST Support UK & PAWS-GIST
- Cancer 52
- International Kidney Cancer Coalition (IKCC)
- Chordoma Foundation
- Fondazione IRCCS Istituto Nazionale dei Tumori
- European Institute of Oncology (IEO)
- European Society for Paediatric Oncology

(SIOP Europe)

- Grupo Español de Tumores Huérfanos e Infrecuentes (GETHI)
- European School of Oncology (ESO)
- European Oncology Nursing Society (EONS)
- European Society of Pathology (ESP)
- European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB)
- Novartis Oncology (initiating sponsor and industry partner)
- Pfizer Oncology (industry partner)
- Sanofi (industry partner)

The campaign is also supported by additional corporate supporters. More information on Rare Cancers Europe is available at

www.rarecancerseurope.org. The partners involved in Rare Cancers Europe thank the Rare Tumors online medical journal for the opportunity to inform your readers about our initiatives and activities.

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