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World Cancer Day 2015:

Specific European Reference Networks for rare cancers, help us meet the challenge!

RARE CANCERS EUROPE

Joining forces for action

On World Cancer Day, Rare Cancers Europe would like to highlight the specific battles that rare cancer patients face and underline the need for dedicated European Reference Networks for rare cancers.

20 % of all cancer cases diagnosed in Europe annually are rare so, taken together, they are not so rare. Every year, over four million Europeans are diagnosed with a rare cancer.

Rare cancers pose a unique set of challenges including:

- Late or incorrect diagnosis
- Difficulties in finding clinical expertise and accessing appropriate treatments
- Difficulties in carrying out clinical studies due to the small number of patients
- Funding research for innovative therapies due to small markets
- Uncertainty in clinical decision-making
- Scarcity of registries, guidelines and tissue banks

Rare cancers bring great distress to patients and their caregivers. Due to the particular difficulties they pose, rare cancer patients face an additional burden of uncertainty. Access to expert opinion is crucial and may entail travelling long distances, often across national borders.

The EU has decided to provide support to rare diseases across the EU and to set up European Reference Networks (ERNs) focusing specifically on improving care and quality of life of patients. The Cross-border Healthcare Directive (2011/24/EU) gave the Commission the mandate to support Member States in developing ERNs between healthcare providers and centres of expertise.

About the author:

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By connecting highly qualified health professionals from across the EU, the aim of ERNs is to advance highly specialised healthcare and provide a concentration of knowledge and resources, especially in areas where resources are scarce, such as rare cancers.

The burden of rare cancers on society has not yet been adequately estimated but is recognised as a major public health problem. Rare cancers include all childhood cancers, most hematologic malignancies and several types of adult solid cancers. Over 186 rare cancers have been identified and grouped into 10+ "families".

One way to improve diagnosis, treatment and quality of care for rare cancer patients is to concentrate treatment in specialised centres. Once identified, they can be linked through reference networks.

ERNs dedicated to rare cancers allowing a centralised review system, would contribute to decrease the number of pathologic misdiagnoses and improve quality of treatment. ERNs would also allow progress on registries, clinical trials and sharing of knowledge about rare cancers between doctors (oncologists and pathologists) and patients alike.

Rare Cancers Europe (a multi-stakeholder initiative including doctors, patients, academic institutions, oncology societies, and the industry) is therefore calling for the **creation of specific ERNs for each of the 10+ identified families of rare cancers.**

Let's not miss this opportunity to offer hope, support and novel solutions to rare cancer patients. Join forces with us to call for the prompt creation of European Reference Networks dedicated to rare cancers!

For more information visit www.rarecancerseurope.org or write to rarecancerseuropenews@esmo.org