



European Action Against Rare Cancers

PRESS RELEASE



24 June, 2009: *European Action Against Rare Cancers* is a new campaign that has been launched today to coincide with the publication of the European Commission's Communication on Cancer. The new campaign urges European policy-makers to prioritise better treatment and care for patients with rare cancers within the framework of the new Commission Communication on cancer and other recent policy initiatives such as the Council Recommendation on Rare Diseases.



Nearly half a million Europeans live with a rare cancer. Despite the rarity of each individual cancer type, rare cancers represent in total about 20% of all cancer cases, including all cancers in children. Rare cancers are classified in the group of rare diseases which is defined in the European Union as diseases with a prevalence of fewer than 5 cases out of a population of 10,000. As such, patients with rare cancers are faced with the same problems as other patients with a rare disease, such as lack of information, inefficient detection and practical obstacles to treatment and care, just because their condition is rare.



With this background, we have established a **Call to Action** – an international petition to be endorsed by organisations and private individuals. The Call to Action appeals to policy-makers and all other relevant stakeholders to initiate targeted actions and policies that will address the challenges that rare cancers entail for the patients who are living with the disease, for the physicians who are treating the patients, and for the researchers who are working to acquire more knowledge in this field.



Sandy Craine, Director of the Chronic Myeloid Leukaemia Support Group states: *"Facing a rare cancer as a patient has great challenges: to get the proper diagnosis, to find a doctor with medical expertise in that specific rare cancer, and to access an effective therapy, if it exists."*



Paolo Casali, medical oncology expert on rare cancers and representative of the European Society for Medical Oncology (ESMO) states:



"Policy makers are realizing the enormous public health threat of cancer and the need to address issues that relate to all patients, not only those with the most common cancer types. However, effective solutions require a broad European-based forum to discuss them. ESMO understood this need and organised a conference with the major European stakeholders in both rare diseases and rare cancers. The outcome of this conference is a united collaborative effort called 'European Action Against Rare Cancers'. This campaign is extremely valuable to the entire oncology community because it clearly identifies the challenges of rare cancers and outlines concrete, integrated and sustainable solutions which the various stakeholders can implement to help solve them."



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Guido Guidi, Head of Novartis Oncology Region Europe, adds to this:

"The fight against cancer relies on commitment from all relevant stakeholders working in partnership with open dialogue. Equally, the political and regulatory framework should work to ensure all cancer patients in Europe have access to the highest attainable standard of cancer care. We all recognize that to reconcile sustainable financing with improved patient access to optimal care, the whole EU system needs to work more effectively and efficiently. Improved cooperation among all stakeholder groups, as well as recognition of how each can contribute, is a precondition. The 'European Action Against Rare Cancers' initiative is an excellent example of a partnership involving many stakeholders working to reach a common goal".



About European Action Against Rare Cancers



European Action Against Rare Cancers is a joint initiative based on a partnership between the European Society for Medical Oncology (ESMO), European Organisation for Rare Diseases (Eurordis), European Cancer Patient Coalition (ECPC), Conticanet, the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group, the International Brain Tumour Alliance (IBTA), Orphanet, Chronic Myeloid Leukaemia Advocates Network and the European Institute of Oncology (EIO), and as well as Novartis Oncology as the initiating sponsor. The organisations collaborate as equal partners and all decisions are made on the basis of consensus. The campaign is moreover supported by eight corporate supporters.

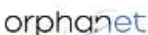


For more information please visit: www.rarecancers.eu



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