The challenge of accurately diagnosing rare cancers

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Inaccurate diagnosis is a major obstacle for the proper treatment of patients with rare cancers. A Consensus on Improving the Pathologic Diagnosis of Rare Cancers was presented today by Rare Cancers Europe, together with the European Society for Medical Oncology (ESMO) and the European Society of Pathology (ESP) in Brussels. The recommendations aim to help rare cancer patients get a timely and accurate diagnosis.

The statement is the result of a two-day workshop, where the particular challenges for each type of rare cancer were discussed.

"Inaccurate diagnosis means inappropriate treatment," said Paolo G Casali, from the Istituto Nazionale Tumori, Milan, Italy and ESMO Coordinator of the Rare Cancers Europe Initiative. "Pathological diagnosis is everything in oncology. There is an urgent need for solutions in health organization across Europe to facilitate referrals in order to ensure an accurate first diagnosis for rare cancer patients."

Angelo Dei Tos, ESP Co-Chair of the workshop, said, "During this workshop, pathologists and clinicians have worked together to highlight challenges for each type of rare cancer. Diagnosing and treating cancers should always be a multidisciplinary effort."

Rare cancers affect over four million people in the EU and, taken together, represent 20% of all cancer cases and a huge burden on healthcare.

Zofija Mazej Kukovič, Member of the European Parliament (MEP) and former Minister of Health of Slovenia said: "When it comes to rare cancers, there is a clear need for European Reference Networks (ERN). These diseases affect large numbers of people, even though their prevalence is low. Patients have to tackle many difficulties, most of the time without the right support.There is a strong need for more collaboration among experts, especially in small member states, as Slovenia. We, the decision-makers, need to work for our patients. The cross border healthcare directive gives us the opportunity to be more efficient when it comes to rare diseases. Cancer is a distant topic for many of us, but when it comes to our home, things change. At the end of the day, we are all patients. "

Kathy Oliver from the International Brain Tumour Alliance (IBTA) declared: "Every rare cancer patient in Europe should have equal access to the best healthcare. This includes the right to a second (reimbursed) opinion. If the best treatment is not available close to the patient's home, they should be able to contact the closest centre of excellence very quickly. ERNs are being established under the Cross Border Healthcare Directive but there is still a lot of red tape. In cancer, timely treatment is everything."

Industry representatives also attended the workshop. The Rare Cancers Europe initiative has called on them to prioritise the development of medicines for these diseases and will hold another workshop in October to address the methodological barriers to rare cancer care.

Casali concluded: "We have worked hard on the items for this vital consensus, but the important part comes now. The implementation of the recommendations we will release is crucial to improve the lives of rare cancer sufferers."

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