ESMO Rare Cancers Working Group statement on Rare Disease Day, 29 February 2024

The European Society for Medical Oncology's (ESMO) Rare Cancers Working Group (RCWG) is a multi-stakeholder partnership which brings together scientific societies, patient and research organisations, healthcare and education providers, and industry.

Rare Disease Day, marked on the last day of February every year, is a vital initiative that brings much-needed attention to rare diseases of which rare cancers are an often-overlooked subset and can be overshadowed by more prevalent cancers. By raising awareness, advocating for research and funding, providing support, encouraging early detection and by reducing stigma, such an initiative plays a pivotal role in improving the lives of those affected by rare cancers.

ESMO RCWG's key objectives are to support the rare cancers community towards the effective implementation of the **Rare Cancer Agenda 2030** and advocate for fostering rare cancers research and improving care.

Rare and ultra-rare cancers have an annual incidence of less than 6 per 100.000 people, and they correspond to 650.000 new diagnosis annually in Europe. Thus, rare cancers are not so rare, as 5.1 million people live with a rare cancer in Europe, and they represent the 24% of all new cancer diagnoses, including all cancers in children which have additional specificities, as outlined in the dedicated chapters of the Rare Cancers Agenda 2030.

Rare cancers are the rare diseases of oncology - they share the specificities of both cancer and rare diseases. These specificities require a tailored policy approach to overcome their challenges. Rare cancers face difficulties linked to access to early and correct diagnosis, lack of access to cancer care, including treatment and development of new therapies, lack of feasibility in developing new therapies and difficulties in conducting well-powered clinical studies which lead to a need for the development of methodological research applicable to rare cancers given the low numbers. It is also crucial to have properly educated health care professionals, including nurses, to provide adequate rehabilitation, support and symptom management in all phases of disease.

EU's flagship initiatives in the field of cancer, such as Europe's Beating Cancer Plan (EBCP) and the EU Cancer Mission, are clear illustrations of the positive strides the EU can take in improving the lives of cancer patients. It is crucial that rare cancers are addressed in further key policy files, such as the ongoing revision of the EU general pharmaceutical legislation and the legislative proposal for the European Health Data Space. The latter is pivotal to sharing data on rare cancers across Europe to deliver innovative care for all patients.

While recognising EU's many achievements and attention to rare cancers, the very nature of rare cancers adds a layer of complexity to overcoming the challenges they pose to patients, researchers and healthcare professionals. Given the disparities in the standards of treatment between EU Member States, patients with rare cancers face a unique set of challenges, and successful approaches can be substantially strengthened by developing an EU-wide rare diseases strategy. Built on the EBCP, Cancer Mission, European Reference Networks (ERNs) and the European Parliament's report **'On strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy',** such an EU-wide strategy should properly and distinctly address issues around both rare adult and paediatric cancers.

In addition, facilitating the interplay between registries and clinical trials would provide significant potential to ensure better documentation of practices, stimulating studies documenting natural history of rare cancers and raising hypothesis for clinical research questions towards improving the standards of care.

Going forward, the RCWG is committed to working with EU institutions after the EU 2024 elections to ensure that rare cancers' specificities continue being part of the EU health agenda and accelerate momentum to deliver improved health outcomes to rare cancers patients.