



Joint Action on Rare Cancers Launch



The Joint Action on Rare Cancers (JARC) is coordinated by the Italian Fondazione IRCCS Istituto Nazionale dei Tumori, with the aims of prioritising rare cancers within the national and European agenda, and improving the [European Reference Networks](#)' ability to tackle rare cancers. **JARC** will achieve these aims through a series of work packages that include those addressing epidemiology, quality of care, research, childhood cancers, and rare cancer policy.

The European Cancer Patient Coalition (ECPC) has a horizontal role representing the voice of the rare cancer patients across all the work packages.

The official launch of the European Commission's **Joint Action on Rare Cancers** took place on the 7th of November 2016 in the Neumunster Abbey in Luxembourg. **EU Commissioner for Health and Food Safety, Dr. Vitenis Andriukaitis** and **Ms. Lydia Mutsch, Luxembourg's Minister of Health** were present at the event .

Mr. Antoni Monsterrat (DG SANTE) introduced the **JARC** and highlighted the important role of the ECPC and the European Organisation for Rare Diseases (EURORDIS) in the success on the work to be done.

'A total of 24% of all people living with cancer in the EU have a rare cancer and their survival is much lower than people affected with a common cancer type.' Dr. Gemma Gatta, coordinator of the [RARECARE](#) and [RARECARENet](#) EU funded projects, stated.



Mr. Yann le Cam (EURORDIS) and Prof. Francesco de Lorenzo (ECPC) both shared their thoughts from the rare disease and rare cancer patient perspective respectively. Their common goal is to *'ensure that the needs and rights of rare cancer patients are incorporated in the work of JARC'*. ECPC and EURORDIS will have a synergistic collaboration.



Commissioner Andriuskaitis provided his full support and commitment. *'Working together is the best means to address rare cancers. Let us then work together to help provide diagnostics, healthcare and support to all our citizens who suffer from rare cancer – across the European Union'* stated the Commissioner.

He added that *'in addition to this Joint Action, the Commission will also support research into rare diseases, including rare cancers, via Horizon 2020 and through our Joint Research Centre's patient registries'*.

[Link to full speech](#)

Dr. Paolo Casali ([ESMO](#), [Rare Cancers Europe](#)), coordinator of the JARC, talked about the key issues faced by the rare cancer community such as the lack of medical and patient education, the lack of referral and the lack of available funds. He addressed the issue of clinical studies stating that *'in rare cancers we must tolerate a higher level of uncertainties'*. He concluded that *'We are here in the name of rare cancer patients and will serve for them over these three years to the best of our ability'*.

The meeting was followed by a [Rare Cancers Europe](#) panel discussion facilitated by Annie Pannelay (Economist Intelligence Unit) on the opportunities and the challenges of the [European Reference Networks \(ERNs\)](#).



Background

The Joint Action on Rare Cancers (JARC) is a multistakeholder collaboration between **18 Member States** and the **European Commission**, coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan. There are 34 partners involved in the JARC including 8 Ministries of Health/Cancer Control Programmes representatives (Cyprus, Czech Republic, France, Ireland, Italy, Malta, Poland, and Spain) and 26 universities, public health institutions, cancer registries, oncological institutes, patients' associations (ECPC, EURORDIS) and other societies/organisations (including the [Organisation of European Cancer Institutes](#) – OECI, and the [European Society for Pediatric Oncology](#) - SIOPE).

JARC should be viewed as the natural framework to bring together all the stakeholders at the EU level in order to:

- Prioritize all rare cancers in the agenda of the EU and the Member States with regards to national cancer plans, harmonization of practices and funding of research.
- Develop innovative and shared solutions, to be recommended for implementation mainly through the future ERNs on rare cancers, in the areas of: quality of care, clinical practice guidelines, innovation and research, medical & patient education and epidemiological surveillance.

The final goal of the **The Joint Action on Rare Cancers** will be to contribute to **improve health outcomes for patients with rare cancers and to decrease health inequalities for rare cancer patients across Europe**.

ECPC is involved in all the work packages of the JARC, which will run for 3 years (2016-2019). In order to better represent patients within the **JARC**, the European Cancer Patient Coalition has set up a **Working Group on Rare Cancers (WGRC)** where members can share their knowledge and cooperatively generate expertise to better respond to ECP's activities under the to **JARC**. For more information kindly contact Isabelle Manneh (isabelle.manneh@ecpc.org), European Cancer Patient Coalition's Head of Health & Research Programmes.