European Cancer Patient Coalition

CHALLENGE CANCER
EU PARLIAMENTARY INTERGROUP

Public event of the EU Parliamentary Intergroup on Cancer: "EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030"

February 2021

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Register here

Draft agenda

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Dear Colleagues,

We are happy to invite you to our next public event: ***"EU Joint Action on Rare Cancers (JARC) recommendations towards implementing the Rare Cancer Agenda 2030"*** that will take place on Wednesday, ***24th of February 2021*** from ***16:00 to 17:00 CET.***

This event, hosted by the Challenge Cancer Intergroup, is an interesting opportunity to discuss about the **implementation of the Rare Cancer Agenda 2030 in the EU**.

Despite the rarity of each of the 198 identified rare cancers, collectively they represent 24% of all new cancer cases diagnosed in the EU28 each year. Five-year relative survival is worse for rare cancers (47%) than for common cancers (65%), and differences in survival exist across European countries, therefore suggesting the **existence of inequalities in healthcare.**

The EU created the **European Reference Networks** (ERNs) in 2017 on several rare diseases, including four related to rare cancers: ERN on rare adult cancers (ERN EURACAN), ERN on haematological diseases (EuroBloodNet), ERN on paediatric cancer (ERN PaedCan), ERN on genetic tumour risk syndromes (ERN GENTURIS). The shortcoming of these ERNs is the **lack of awareness among patients** and, as a result, the **lack of access to the benefits offered** by these networks because access is strictly linked to hospitals.

Also following this evolution in the perception of rare cancers as a distinct issue in the world of oncology, the EU prompted **JARC (Joint Action on Rare Cancers)**. JARC gathered around the same table all stakeholders in the field of rare cancers and rare diseases. The goal of JARC was to contribute to **improve health outcomes for patients with rare cancer**s in the EU maximizing chances of ERNs on rare cancers to be successful.

An agenda on rare cancers was perceived as instrumental to **prioritise rare cancers in the agenda of the EU** and Member States to minimise the risk that rare cancer patients may be discriminated against simply because of the numbers of the disease they suffer from.

Objectives:

- **raise awareness** about the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030
- **open the debate about their implementation at the national level** and the need to activate the ERNs network to make it more accessible for patients.

Please register here to ensure your participation in the event.

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