

Making the most of European Reference Networks for patients with rare cancers

Thursday, 25th February 2021

EU Parliamentary Intergrup Challenge Cancer hosted a public event [“EU Joint Action on Rare Cancers \(JARC\) recommendations towards implementing the Rare Cancer Agenda 2030”](#) on Wednesday 24th February 2021. Following the launch of the EU’s Beating Cancer Plan, the event was a timely opportunity to discuss the implementation of the Rare Cancer Agenda 2030 in the EU.

Having rare cancer is challenging due to difficult diagnosis and less treatment options available. Despite the rarity of each of the 198 identified rare cancers, collectively they represent 24% of all new cancer cases diagnosed in the European Union 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.

In 2017, the EU created the European Reference Networks (ERNs) on several rare diseases including paediatric and adult rare cancers with aim to facilitate discussion on conditions requiring highly specialised treatment, and extensive knowledge and resources. 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. Mainly ERN’s implementation at national level and their accessibility for patients was the main objective of the debate.

“ERNs are a unique example of cooperation across EU on healthcare and also a model for any future similar attempt in other areas of healthcare in the future. After more than three years from their creation, ERNs should now be ready for next challenges and express fully their potential to the benefit of EU citizens,” said MEP Alessandra Moretti, Co-Chair of the Intergroup, and she declared her support in this matter: *“We have the chance with the new EU’s Beating Cancer Plan to further develop ERNs in the field of health and particularly oncology with an objective on recognising them as central players in the fight against cancer.”*

“Funding allocated to ERNs is exceedingly limited. Especially at a time of a pandemic, when cancer patients may suffer from difficulties to access normal health services, networking is vital. Networking always requires additional resources. The EU and the Member States should provide cancer institutions appointed to belong to ERNs with proper regular funding. In Eu for Health programme I recommended to increase financing for ERNs and we will also strengthen their prerogatives. A “Call to Action” will be sent by the Intergroup to the Commissioner Stella Kyriakides to implement selected Recommendations of the JARC Agenda 2030,” said the Chair of the Intergroup Cristian Busoi.

“We, cancer patients’ advocates, must address the barriers to an appropriate functioning of the ERNs and we must ensure that all EU rare cancer patients have access to the existing ERNs network and that ERNs have now financial support for the infrastructure,” explained Francesco de Lorenzo, President of the Italian Federation of Cancer Patients Organisations (FAVO).

European Cancer Patient Coalition (ECPC), the Secretariat of the Intergroup, has utmost interest to represent and empower cancer patients with all types of cancer, not excluding rare cancers. Therefore, ECPC established a Working Group on Rare Cancers to improve early, timely and correct diagnosis and to empower patients with information on rare cancers and how to get in touch with Contact Points at the national level.

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About the European Cancer Patient Coalition and Parliamentary Intergroups

The European Cancer Patient Coalition (ECPC) is the voice of cancer patients in Europe. With over 450 members, ECPC is Europe’s largest umbrella cancer patients’ association, covering all 28 EU member states and many other European and non-European countries. ECPC represents patients affected by all types of cancers, from the rarest to the most common.

A Parliamentary Intergroup is an informal group of cross-party MEPs who wish to highlight and promote shared ideas. It serves as a forum, usually in close cooperation with external stakeholders, where expertise can be shared, and legislative work can be advanced on certain topics.

About ERNs

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). More information can be found here: https://ec.europa.eu/health/ern_en

Notes to editors

For more information please contact:

paulina.gono@ecpc.org; +32 494 34 54 82

adela.maghear@ecpc.org/ +32 488 80 03 81

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