

# FACTS

**198 different types of cancer,** including all childhood cancers, affect only a small number of patients each.

**24% of new diagnosis of cancers** are of rare cancers

Patients struggle with:

- late or incorrect diagnosis,
- lack of access to appropriate therapies and clinical expertise,
- lack of scientific studies due to the small number of patients,
- lack of interest in developing new therapies due to limitations in the market,
- few available registries (clinical registries mostly) and tissue banks.

# FOCUS ON

## The JARC will focus on the 12 families of rare cancers

For the purposes of JARC, the following “families” of rare cancers will be singled out, following the “Surveillance of rare cancers” (RARECARE - [www.rarecare.eu](http://www.rarecare.eu)) list of rare cancers:

- 1 Head and neck cancers
- 2 Thoracic rare cancers
- 3 Male genital and urogenital rare cancers
- 4 Female genital rare cancers
- 5 Neuroendocrine tumours
- 6 Tumours of the endocrine organs
- 7 Central Nervous System tumours
- 8 Sarcomas
- 9 Digestive rare cancers
- 10 Rare skin cancers and non-cutaneous melanoma
- 11 Haematological rare malignancies
- 12 Pediatric cancers (all)

## Associated Partners

1. Fondazione IRCCS Istituto Nazionale Dei Tumori (INT), Italy
2. Ethniko Kai Kapodistriako Panepistimio Athinon (UoA), Greece
3. Organisation Of European Cancer Institutes (OEI), Belgium
4. Institut Scientifique De Sante Publique (WIV-ISP (IPH)), Belgium
5. Pecs Tudományegyetem - University Of Pecs (UP), Hungary
6. SIOP Europe ASBL (SIOPE), Belgium
7. Institut Catala D'Oncologia (ICO), Spain
8. Suomen Syöpäyhdistys - Cancerforeningen I Finland RY – Cancer Society Of Finland CSF (CSF), Finland
9. Hrvatski Zavod Za Javno Zdravstvo (CNIPH), Croatia
10. Escuela Andaluza De Salud Publica (EASP), Spain
11. Eurordis - European Organisation For Rare Diseases Association (EURORDIS), France
12. Fundacion Para La Formacion E Investigacion Sanitarias De La Region De Murcia (FFIS-CARM), Spain
13. Institut National Du Cancer (INCA), France
14. Institut National De La Sante Et De La Recherche Medicale (INSERM), France
15. National Cancer Registry Board (NCRB), Ireland
16. Szegedi Tudományegyetem (USZ), Hungary
17. Országos Onkológiai Intézet (OOI), Hungary,
18. Universitat De Valencia (UVEG), Spain
19. Viesoji Istaiga Vilniaus Universiteto Ligonines Santariskiu Klinikos (VULSK), Lithuania
20. Fundacio Hospital Universitari Vall D'Hebron - Institut De Recerca (VHIR), Spain
21. Ministerstvo Zdravotnictvi Ceske Republiky (MoH), Czech Republic
22. Aristotelio Panepistimio Thessalonikis (AUTH), Greece
23. Fundacion Para El Fomento De La Investigacion Sanitaria Y Biomedica Dela Comunitat Valenciana (FISABIO), Spain
24. GPOH Gemeinnutzige GmbH (GPOH), Germany
25. Ministero Della Salute (MIN SALUTE), Italy
26. Universitatea Babes Bolyai (UBB), Romania
27. Ministry Of Health Of The Republic Of Cyprus (MoH CYPRUS), Cyprus
28. Health Service Executive (HSE), Ireland
29. Lietuvos Sveikatos Mokslu Universiteto Ligonine Kauno Klinikos (ISMU), Lithuania
30. The Ministry Of Health Of The Republic Of Poland (MZ), Poland
31. Pancare (PANCARE), Sweden
32. Ministry For Health - Government Of Malta (MFH), Malta
33. Deutsche Krebsgesellschaft EV (DKG), Germany
34. Oslo Universitetssykehus HF (OUS-KSSB), Norway

## Collaborating Partners

1. European Cancer Patients Coalition (EPCP), Belgium
2. University College Of London - Institute Of Child Health (UCL-ICH), United Kingdom
3. European School Of Oncology (ESO), Italy
4. European Medicine Agency (EMA), United Kingdom
5. European Network Of Cancer Registry (ENCR), Italy
6. Joint Research Centre (JRC), Italy
7. Belgian Cancer Registry (BCR), Belgium
8. Italian National Institute Of Health (Istituto Superiore Di Sanità), Italy
9. European Society Of Medical Oncology (ESMO), Switzerland
10. European Organisation For Research And Treatment Of Cancer (EORTC), Belgium
11. Anticancerfund, Belgium
12. Association Of European Cancer Leagues (ECL), Belgium
13. European Society Of Surgical Oncology (ESSO), Belgium
14. Childhood Cancer International (CCI-EUROPE), The Netherlands
15. St. Anna Children's Cancer Research Institute (CCRI), Austria
16. Rare Cancer Europe (RCE), Switzerland
17. EFPIA-Europabio, Belgium
18. University Of Milan, Italy
19. Hospital Universitario Y Politécnico La Fe. Gic-Càncer IIS La Fe, (CICT), Spain
20. Rīgas Stradiņa Universitāte, Latvija
21. European Hematology Association, The Netherlands
22. Directorate General Of Health, Portugal
23. Ospedale Pediatrico Bambino Gesù, Italy

For further information and contact <http://jointactionrarecancers.eu/>

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# PUTTING PATIENT CARE FIRST

EU Joint Action on Rare Cancers (JARC)

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

**- Commissioner Vytenis Andriukaitis**



# JARC

The **Joint Action on Rare Cancers** is a multistakeholders collaboration between 18 EU Countries and the European Commission, coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan, which will run for 3 years (2016-2019).

There are 34 partners involved in the JARC including Ministries of Health/Cancer Control Programmes representatives (Cyprus, Czech Republic, France, Ireland, Italy, Malta, Poland, and Spain), universities, public health institutions, population-based cancer registries, Cancer Institutes, patients' associations (ECPC, EURORDIS, CCI-Europe) and other societies/organisations (including the Organisation of European Cancer Institutes - OEI, and the European Society for Pediatric Oncology - SIOPE).





## Objectives

This EU Joint Action on Rare Cancers should be viewed as a natural framework for all stakeholders to work together to:

- prioritise rare cancers, in the agenda of the EU and Member States, with a view to national cancer plans and quality of healthcare, harmonization of clinical practice, innovation through promotion of clinical and translational research.
- develop innovative and shared solutions, mainly to be implemented through the future European Reference Networks (ERNs) on rare cancers, in the areas of quality of care, research, education and state of the art definition on prevention, diagnosis and treatment of rare cancers.

## Our Goal: To provide expertise to European Reference Networks (ERNs)

Many of the rare cancers are simply too rare for individual countries to invest into the much needed expertise to diagnose and treat them. European Reference Networks can help solve this problem by pooling expertise from different EU countries. They will facilitate access to diagnosis, treatment and provision of affordable, high-quality and cost-effective healthcare for rare cancer patients of all ages.

## Ten Work Packages (WP)

The JARC will achieve these aims through a series of seven core WPs and three cross cutting WPs that include those addressing epidemiology, quality of care, clinical practice guidelines, access to innovation, childhood cancers, education, and rare cancer policy.

# Six Specific Objectives of what JARC will do

**1.**

Improving epidemiological surveillance of rare cancers in the EU

**2.**

Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking

**3.**

Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancers

**4.**

Promoting integration of translational research innovations into rare cancer care

**5.**

Improving education on rare cancers for medical and non medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU

**6.**

Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs

