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) 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. FFONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI INT, Italy
2. ETHNIKO KAI KAPODISTRIAKO PANEPISTIMIO ATHINON UOA, Greece
3. ORGANISATION OF EUROPEAN CANCER INSTITUTES OECI, Belgium
4. INSTITUT SCIENTIFIQUE DE SANTE PUBLIQUE WIV-ISP, Belgium
5. PECSI TUDOMANYEGYETEM - UNIVERSITY OF PECS UP, Hungary
6. EUROPEAN SOCIETY FOR PAEDIATRIC ONCOLOGY - SIOP EUROPE ASBL SIOPE, Belgium
7. INSTITUT CATALA D'ONCOLOGIA ICO, Spain
8. SUOMEN SYOPAYHDISTYS -CANCERFORENINGEN I FINLAND RY - CANCER SOCIETY OF FINLAND CSF, Finland
9. HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO CNIPH, Croatia
10. ESCUELA ANDALUZA DE SALUD PUBLICA SA 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 TUDOMANYEGYETEM USZ, Hungary
17. ORSZAGOS ONKOLOGIAI INTEZETORSZAGOS ONKOLOGIAI INTEZET 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, Czech Republic
22. ARISTOTELIO PANEPISTIMIO THESSALONIKIS AUTH, Greece
23. FUNDACION PARA EL FOMENTO DE LA INVESTIGACION SANITARIA Y BIOMETICA DELA COMUNITAT VALENCIANA FISABIO, Spain
24. GPOH GEMEINNUTZIGE GMBH GPOH, German
25. MINISTERO DELLA SALUTE MIN SALUTE, Italy
26. UNIVERSITATEA BABES-BOLYAI UBB, Romania
27. MINISTRY OF HEALTH OF THE REPUBLIC OF CYPRUSMINISTRY OF HEALTH OF THE REPUBLIC OF CYPRUS MoH Cyprus, Cyprus
28. HEALTH SERVICE EXECUTIVE HSE HSE, Ireland
29. LIETUVOS SVEIKATOS MOKSLU UNIVERSITETO LIGONINE KAUNO KLINIKOS LSMU, Lithuania
30. THE MINISTRY OF HEALTH OF THE REPUBLIC OF POLAND MZ, Poland
31. PANCARE PanCare, The Netherlands
32. MINISTRY OF HEALTH - GOVERNMENT OF MALTA MFH, Malta
33. DEUTSCHE KREBSGESELLSCHAFT EV DKG, Germany
34. OSLO UNIVERSITETSSYKEHUS HF OUS, Norway

Collaborating Partners

1. Pediatric Oncology Unit "Marianna V. Vardinoyannis - ELPIDA'' of "Aghia Sophia" Children's Hospital ELPIDA, Greece
2. EXPERT GROUP http://www.raretumors-children.eu/ -
3. EUROPEAN CANCER PATIENTS COALITION ECPC, Belgium
4. UNIVERSITY COLLEGE OF LONDON - INSTITUTE OF CHILD HEALTH UCL-ICH, United Kingdom
5. EUROPEAN SCHOOL OF ONCOLOGY ESO, Italy
6. EUROPEAN MEDICINE AGENCY EMA, United Kingdom
7. EUROPEAN NETWORK OF CANCER REGISTRY ENCR, Italy
8. JOINT RESEARCH CENTRE JRC, Italy
9. BELGIAN CANCER REGISTRY BCR, Belgium
10. ITALIAN NATIONAL INSTITUTE OF HEALTH Istituto Superiore di Sanita, Italy
11. EUROPEAN SOCIETY FOR MEDICAL ONCOLOGY ESMO, Switzerland
12. EUROPEAN ORGANISATION FOR RESEARCH AND TREATMENT OF CANCER EORTC, Belgium
13. ANTICANCERFUND Belgium
14. ASSOCIATION OF EUROPEAN CANCER LEAGUES ECL, Belgium
15. EUROPEAN SOCIETY OF SURGICAL ONCOLOGY ESSO, Belgium
16. CHILDHOOD CANCER INTERNATIONAL CCI-Europe, The Netherlands
17. ST. ANNA CHILDREN'S CANCER RESEARCH INSTITUTE CCRI, Austria
18. RARE CANCER EUROPE RCE, Switzerland
19. http://www.efpia.eu/EFPIA - EuropaBio Belgium
20. UNIVERSITY OF MILAN Italy
21. HOSPITAL UNIVERSITARIO Y POLITECNICO LA FE GIST-CANCER IIS LAFE CICT, Spain
22. RIGAS STRADINA UNIVERSITATA Latvia
23. EUROPEAN HEMATOLOGY ASSOCIATION The Netherlands
24. DIRECTORATE GENERAL OF HEALTH Portugal
25. OSPEDALE PEDIATRICO BAMBINO GESU Italy
26. UNIVERSITA DEGLI STUDI DI PADOVAUNIVERSITA DEGLI STUDI DI PADOVA Italy
27. INSTITUT CURIEINSTITUT CURIE France

For further information and contact **http://jointactionrarecancers.eu/**

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The JARC is coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (Italy).

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DEDICATED COLLABORATION FOR RESEARCH & HEALTH CARE

EU Joint Action on Rare Cancers (JARC)

- **Pooling expertise**
- **Sharing knowledge**
- **Obtaining a correct diagnosis**
- **Providing operational solutions & professional guidance**
- **Improving lives of EU patients**

> *"No country alone has the knowledge and capacity to treat all rare and complex conditions, but by cooperating and exchanging life-saving knowledge at European level through European Reference Networks (ERNs), patients across the EU will have access to the best expertise available."*
>
> **- Commissioner Vytenis Andriukaitis**

JARC
JOINT ACTION ON RARE CANCERS

www.jointactionrarecancers.eu

JARC

The **Joint Action on Rare Cancers** is a multistakeholder collaboration between 18 Member States and the European Commission, coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan, which started in 2016 and about to end in 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, oncological institutes, patients' organisations (ECPC, EURORDIS, CCI-Europe) and other societies/organisations (including the Organisation of European Cancer Institutes – OECI, the European Society for Pediatric Oncology – SIOPE, and the European Organisation for Research and Treatment of Cancer - EORTC).

Rare Cancers. A disease requesting highly specialised healthcare

Each year in the EU, around 640,000 people are diagnosed with rare cancers (24% of all cancers diagnosed in EU28). Patients with rare cancers often experience late diagnosis or misdiagnosis, they have limited treatment options, limited access to clinical expertise, few opportunities to access clinical trials for new treatments, and difficulty finding relevant information and support.

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
- develop innovative and shared solutions, mainly to be implemented through the ERNs on rare cancers

Our Goal: To provide operational solutions and professional guidance to European Reference Networks (ERNs)

JARC works to integrate and maximise the efforts of the European Commission, Member States and all other stakeholders with the aim of improving quality of care, and research on rare cancers. Many of the rare cancers are simply too rare for individual countries to invest into the much needed expertise to diagnose and treat them.
ERNs can help solve this problem. They will facilitate access to diagnosis, treatment and provision of affordable, high-quality and cost-effective healthcare for rare cancer patients of all ages.
JARC has decided to shape its efforts around the ERNs. Following the first call for proposals in July 2016, the first ERNs were approved in December 2016 and launched in March 2017, in Vilnius, where their kick off meeting took place. At their inception, the networks comprised more than 900 highly specialised healthcare units located in 313 hospitals in 25 Member States (plus Norway). Three devoted to rare cancers ERNs have been activated, and the JARC will be instrumental to make them grow up the best way possible.

Halfway done

How JARC has contributed.

Guidelines. Promoted the collaboration between ERNs and the dedicated scientific societies, to develop clinical guidelines on rare cancers.
Medical education. Promoted and tested models of education for patients and clinicians involving the ERN experts.
Research. Discussed models for performing collaborative trials at low cost, taking advantage of the ERN framework.
Policy. Advocated to integrate the ERNs into national health care systems, and thus to have a national plan for rare cancers, and national networks as members of ERNs.

ERNs for patients

The rare cancers patient community (including both adults and children affected by rare cancers and their families, carers) perceive ERNs as an extremely important opportunity to improve and speed up access to timely and accurate diagnosis, as well as adapted treatments to all EU citizens wherever they live in a equitable manner. Another key benefit of ERNs is to facilitate access and enrollment in clinical trials. ECPC, EURORDIS and CCI-E are active partners of the JARC and deeply involved in the development of ERNs for rare cancers in adults and in children.

Six Specific Goals 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 accross 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 accross EU MSs