

ECPC General Assembly
Friday 3 – Sunday 5 June 2016, Brussels
Advancing the rights of cancer survivors



Joint Action on Rare Cancers (JARC)

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FUNDING UNDER THE 3RD HEALTH PROGRAMME 2014-2020



*Actions co-financed with
Member State authorities
(Joint Actions)*

The Health Programme is about fostering health in Europe by encouraging cooperation between Member States to improve the health policies that benefit their citizens. The programme aims to support and complement Member States health initiatives.

The Programme is translated into annual work programmes defining actions in priority areas set in the Programme Regulation (EU) No282/2014. On this basis the Consumer, Health and Food Executive Agency organises every year calls for proposals.

Joint Actions are one funding instrument under the third EU Health Programme 2014-2020.

WHAT IS A JOINT ACTION?

Joint Actions have a clear EU added value and are co-financed either by competent authorities that are responsible for health in the Member States or in the third countries participating in the Programme, or by public sector bodies and non-governmental bodies mandated by those competent authorities.

Joint Actions' proposals should provide a genuine **European dimension** in order to make sense both technically and in terms of policy. Depending on the scope of the action previous Joint Actions involved on average 25 partners.

HOW TO PARTICIPATE?

The Commission sends invitation letters to all EU Member States and other countries participating in the 3rd Health Programme, asking them to nominate the participants in the Joint Actions listed in the annual work programme.

Rare cancers

Incidence (number of new cases/year < 6/100,000)

Rare cancers

1. **Pediatric cancers**
2. **Haematologic rare neoplasms**
3. **Sarcomas**
4. **Rare thoracic cancers**
5. **Neuroendocrine tumours**
6. **Head & neck cancers**
7. **Central nervous system tumours**
8. **Rare female genital cancers**
9. **Rare urological and male genital tumours**
10. **Endocrine gland tumours**
11. **Digestive rare cancers**
12. **Rare skin cancers & non-cutaneous melanoma**



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Rare cancers are not so rare: The rare cancer burden in Europe

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540,000 new cases/year in Europe (22% of all new tumors)

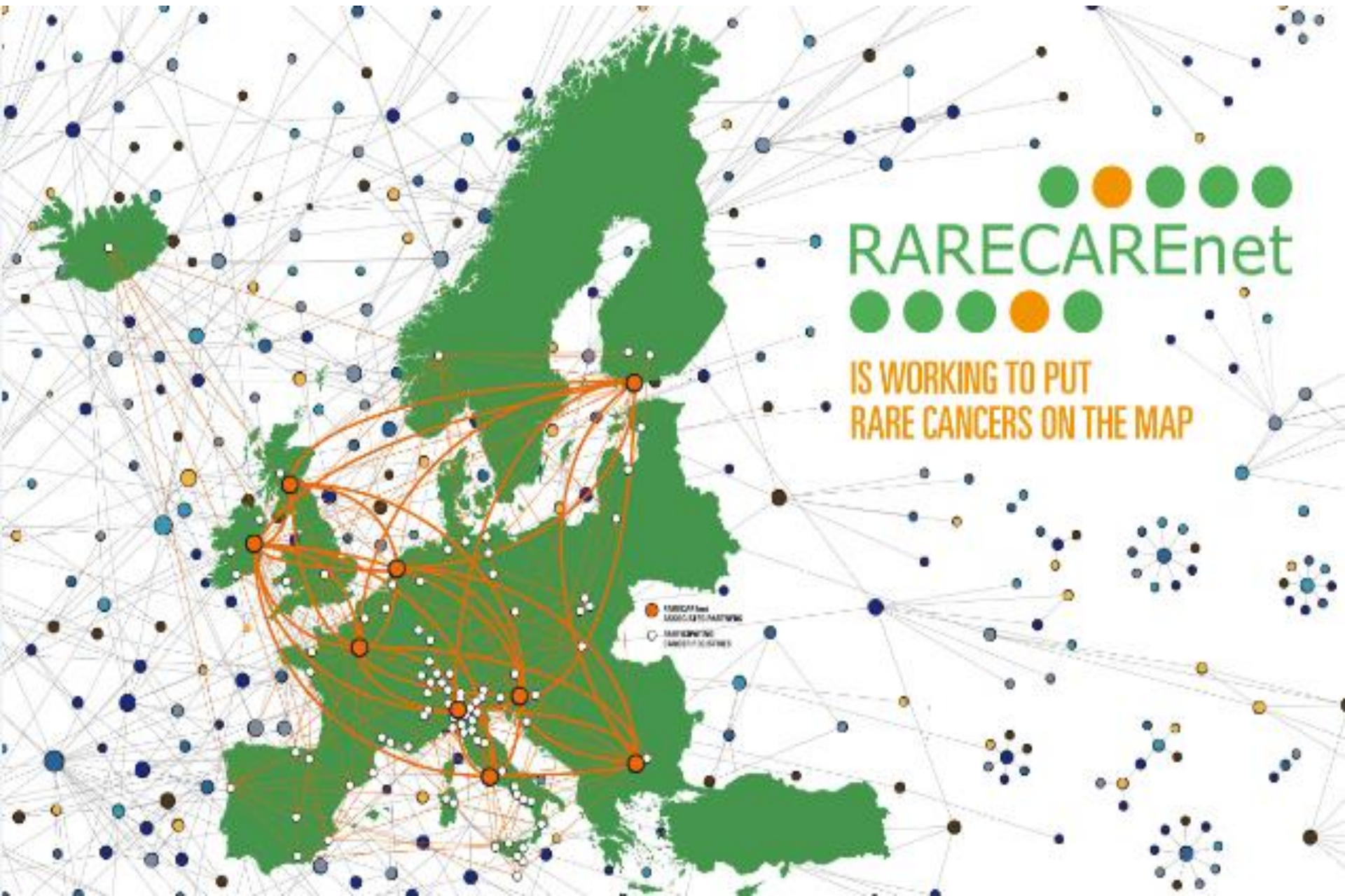
Number of expected cases 2013 for different incidence rates, in EU and selected countries

	incidence rate		
	0.1/100.000 Bone sarcomas	0.45/100,000 Nasal cavity tumors	3.5/100,000 Acute myeloid leukaemia
European Union (28)	558	2,282	17,801
Belgium	12	50	392
Spain	51	210	1,640
France	72	295	2,302
Italy	66	269	2,095
Portugal	12	47	368
Romania	22	90	703
Switzerland	9	36	282

Expertise ??

Centralisation

Network



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RARECAREnet
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IS WORKING TO PUT
RARE CANCERS ON THE MAP

FP6 and the FP7 Programmes

- CONTICANET (CONnective TIssue CAncers NETwork to integrate European Experience in Adults and Children)
- EUROBONET (European network to promote research into uncommon cancers in adults and children: Pathology, Biology and Genetics of Bone Tumours)
- EUROSARC (EUROpean clinical trials in rare SARComas within an integrated translational trial network)
- ENCCA (European Network for Cancer Research in Children and Adolescents)
- PANCARESURFUP (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies)
- PANCARELIFE (impact of treatment regimes on long-term health and quality of life in survivors of cancer diagnosed during childhood or young adulthood)
- IMMOMEK (FIMmune MOdulating strategies for treatment of MErkel cell Carcinoma) under FP7)
- EEC (International Clinical Trials to Improve Survival from Ewing Sarcoma)
- ENS@T-CANCER (network of Biological Resource Centres devoted to research on adrenal tumours)



Show your support and sign the
Call to Action Against Rare Cancers:

www.rarecancerseurope.org

Rare Cancers Europe is a joint initiative based on a partnership between the European Society for Medical Oncology (ESMO), the European Organisation for Rare Diseases (EURORDIS), the European Cancer Patient Coalition (ECPC), the European Organisation for Research and Treatment of Cancer (EORTC), Conticanet, EuroBioNet, the World Sarcoma Network (WSN), the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group, the International Brain Tumour Alliance (IBTA), Orphanet, the Chronic Myeloid Leukaemia Advocates Network, the Sarcoma Patients EuroNet Association (SPAEN), GIST Support UK & PAWS-GIST, Cancer 52, the International Kidney Cancer Coalition (IKCC), the Chordoma Foundation, the Fondazione IRCCS Istituto Nazionale dei Tumori, the European Institute of Oncology (IEO), the European Society for Paediatric Oncology (SIOP Europe), the European Society of Surgical Oncology (ESSO), the Grupo Español de Tumores Huérfanos e Infrecuentes (GETHI), the European School of Oncology (ESO), the European Oncology Nursing Society (EONS), eCancer, the European Society of Pathology (ESP), the European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB), Novartis Oncology (initiating sponsor and industry partner), Pfizer Oncology (industry partner), and Sanofi (industry partner). The campaign is moreover supported by additional corporate supporters, including Amgen (silver industry supporter) and Takeda Pharmaceuticals Europe (silver industry supporter).

RARE CANCERS

More common than you think!



European
Reference
Networks

- promote good **quality and safe care** to patients by fostering proper diagnosis, treatment, follow-up and management of **patients empower and involve patients**
- offer and promote **multi-disciplinary advice** for complex cases
- develop and implement **clinical guidelines** and **cross-border patient pathways**
- exchange, gather and disseminate **knowledge, evidence** and expertise within and outside the Network
- promote **collaborative research** within the Network
- reinforce research and epidemiological surveillance, through setting up of **shared registries**

JARC: objectives

1. prioritise rare cancers in the agenda of the EU and Member States with regard to:
 - national cancer plans
 - funding of research
2. develop innovative and shared solutions so that ERNs can improve:
 - quality of care
 - clinical practice guidelines
 - research
 - medical & patient education
 - epidemiological surveillance

JARC: Work packages

WP number	WP name
1	Coordination
2	Dissemination
3	Evaluation
4	Epidemiology
5	Assuring Quality
6	Clinical Studies
7	Patient empowerment and access to innovation
8	Public education
	Childhood Cancers
1	Rare Cancer Policy

ECPC, EURORDIS

Patient empowerment

Work package 4 Epidemiology

- to agree on an **operational definition of rare cancers**,
- to develop recommendations to improve the quality of rare-cancer registration in population based cancer registries (CRs),
- to propose a model to evaluate the impact of ERNs by linkage of CRs with clinical data.

Work package 5 Quality of Care

- To map the existing networks of care for all 12 families of rare cancers
- To design Quality Assurance systems or processes specific to rare cancers
 - The aim would be to promote and assure the standards will be maintained, a system of continuous quality improvement be established, best practice shared, and equality of care met for rare cancers across Europe
- **Establish PAGs for rare cancers**

Work package 6 Clinical Guidelines

- to map and provide a quality evaluation of existing clinical practice guidelines for rare cancer subtypes;
- to identify open issues about **implementation of clinical practice guidelines at the local level**;
- to work out solutions on how to incorporate clinical practice guidelines within ERNs.

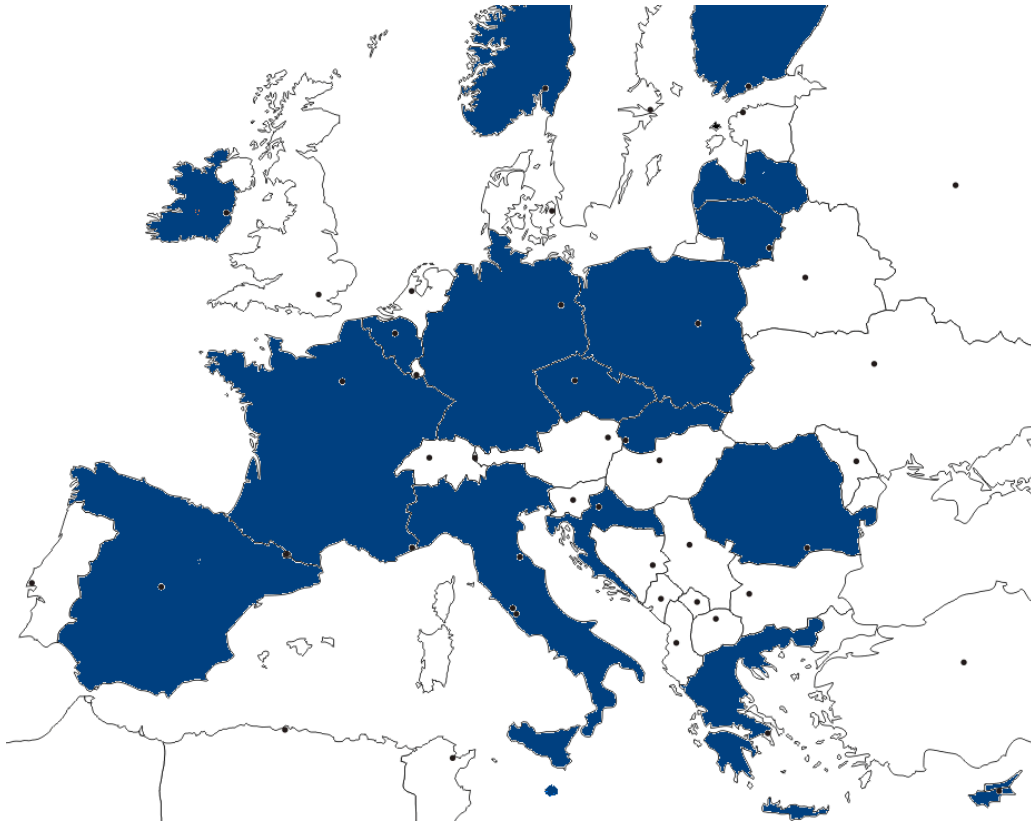
Work package 8 **Medical education**

- to promote the improvement of European medical expert training,
- to provide recommendations on education of non-medical experts,
- identify the needs for educational tools and learning programme of the rare cancer patient communities,
- work out criteria for educational tools and learning programmes for patient advocates and patient communities **to reinforce patients and carers' capacity and enable them to participate in the design of clinical trials, in research projects, in scientific and /or regulatory, ethics committees.**

Work package 10 Rare cancer policy

- to propose a core set of strategies and measures to **accommodate rare cancers-specific needs in the national cancer plans and rare disease plans** across the EU Member States;
- to analyze current problems in the **designation of orphan drug medical products** and in **marketing of medicinal products for rare cancers** to identify possible ways to address the major issues;

Partnership



- 18 MS
- 35 partners
8 Ministry of Health/cancer control programme (Cyprus, Czech Republic, France, Ireland, Italy, Malta, Poland, and Spain)

27 universities, public health institutions, cancer registries, oncological institutes, patients associations (EURORDIS, **ECPC**), other societies/organisation (OEI, SIOPE)

Collaborating partners

European Cancer Patients Coalition (ECPC)

University College of London-Institute of Child Health (UCL-ICH)

European School of Oncology (ESO)

European Medicine Agency (EMA)

European Network of Cancer Registry (ENCR)

Joint Research Centre (JRC)

Belgian Cancer Registry (BCR)

Italian National Institute of Health (Istituto Superiore di Sanità)

European Society for Medical Oncology (ESMO)

Istituto Superiore di Sanità (ISS - Rare Best Practice)

European Organisation for Research and Treatment of Cancer (EORTC)

Anticancerfund

Association of European Cancer Leagues (ECL)

European Society of Surgical Oncology (ESSO)

Childhood Cancer International (CCI-Europe)

St. Anna Children's Cancer Research Institute' (CCRI)

Rare Cancer Europe (RCE)

EFPIA-EuropaBio

VERY CHALLENGING

Looking forward to working with you

meeting of rare cancer patient organisations

17:00 – 18:00