FACTS

198 different types of cancer, including all childhood cancers, affect only a small number of patients each. 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 access to appropriate therapies and clinical expertise,
- late or incorrect diagnosis,
- few available registries (clinical registries mostly) and tissue banks.

FOCUS ON

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

The JARC will focus on the 12 families of rare cancers following the “Surveillance of rare cancers” (RARECARE - www.rarecare.eu)

1. Head and neck cancers
2. Thoracic rare cancers
3. Male genital and urogenital rare cancers
4. Female genital rare cancers
5. Rare skin cancers and non-cutaneous melanoma
6. Tumours of the endocrine organs
7. Central Nervous System tumours
8. Female reproductive cancers
9. Male reproductive cancers
10. Central Nervous System tumours
11. Rare skin cancers and non-cutaneous melanoma
12. Thoracic rare cancers

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

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
• Providing operational solutions & professional guidance
• Improving lives of EU patients

“All 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
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.

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, cancer patient organisations) recognised the need for an integrated system immortalising the expertise required to provide high-quality care. This has been possible through the integration of ERNs in national health systems. In this context, the JARC has been instrumental in promoting the integration of rare cancer care into national health systems, and the development of national networks for rare cancers.

ERNs for researchers

The Joint Action on Rare Cancers (JARC) is a multistakeholder collaboration between 18 Member States and the European Commission, coordinated by 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 – SIOP, and the European Organisation for Research and Treatment of Cancer - EORTC).

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 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