

How long for European Reference Networks?



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Declaration of «interests»...

Receipt of grants/research supports	Amgen, Bayer, Glaxo, ImClone, Infinity, Janssen Cilag, Lilly, Merck SD, Molmed, Novartis, Pfizer, PharmaMar, Sanofi Aventis, Schering Plough
Receipt of honoraria or consultation fees	Amgen, Ariad, Bayer, Glaxo, Infinity, Janssen Cilag, Merck SD, Novartis, Pfizer, PharmaMar
Participation in a company sponsored speaker's bureau	Bayer, Glaxo, Novartis, Pfizer, PharmaMar
Stock shareholder	no
Spouse/partner	no
Medical meeting coverage	PharmaMar, Novartis

DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL
of 9 March 2011
on the application of patients' rights in cross-border healthcare

- **No reimbursement upfront**
- **Reimbursement at the level of the home country (if no exemptions) and subject to the National Contact Point for expensive treatments**
- **National additional mechanisms possibly in place**
- **.....**

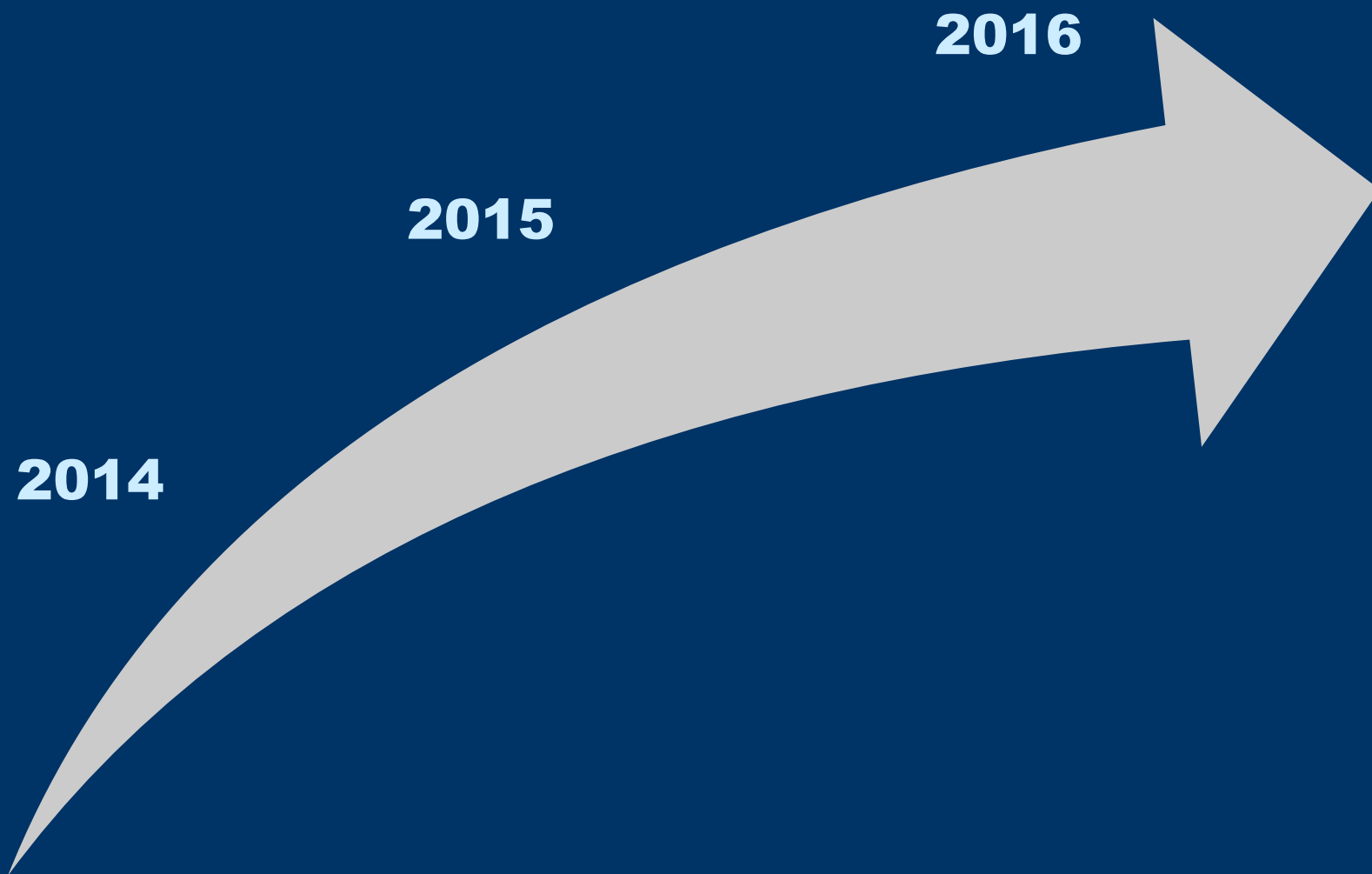
The Commission shall support Member States in the development of ERNs amongst healthcare providers and centres of expertise in the Member States

ERNs are networks of specific diseases or healthcare areas in which Member States can cooperate and share expertise



Closely linked are the Centres of Excellence, which will be national centres where knowledge is pooled together on a specific disease or disease area

Aim to achieve better and quicker diagnosis of patients across Europe and increase cooperation



2014

2015

2016

EXPO-r-NET

*European Expert
Paediatric Oncology
Reference Network
for Diagnostics and Treatment*

European Reference Networks awareness conference

Brussels 23 June 2014

Draft Agenda (version 10.06.14)

Time	Activity	Speakers
08.00-09.00	Registration and welcome coffee	
09.00-09:15	Welcome address: European Reference Networks: Dr Andrzej Rys, Director DG SANCO Health Systems	
9.15-10.05	MORNING PLENARY SESSION	
Keynote Speakers		
09.15-09.40	Only Connect: What ICT networks can do for society	Mr Robert Madelin; Director-General for DG CONNECT: Communications Networks, Content and Technology
09.40-10.05	Complex Systems and Networks	Professor Yamir Moreno; Institute for Biocomputation and Physics of Complex Systems (BIFI). University of Zaragoza
10.10-12.20	Roundtable: Highly specialised healthcare: framework for the establishment of ERNs: Dr Paolo G. Casali, Istituto Nazionale Tumori, Italy	
10.15-10.30	Past, present and future of centres of expertise and European reference Networks	Dr Till Voigtländer; Clinical Institute of Neurology, Medical University of Vienna, Austria
10:30- 10.45	<i>The importance of sharing expertise and the challenge to manage the exchange of knowledge in highly specialised healthcare.</i>	Dr Josep Maria Borras; Coordinator of EPAAC on Healthcare.
10.45-11.00	<i>Research priorities and Networks</i>	Ms Irene Norstedt; Philippe Cupers (RTD)
11:00-11:25	<i>The ERN model: Criteria and conditions for Networks and providers.</i> Implementation of Networks: organisation framework	Dr Enrique Terol; DG SANCO
11.25-12.00	<i>Debate & Questions</i>	Chair – all speakers



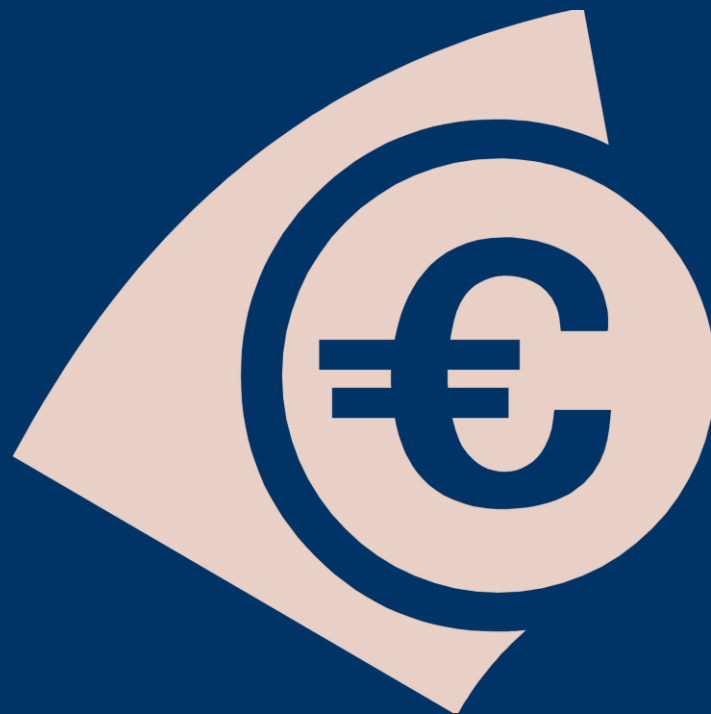
**“will provide
highly specialised healthcare
for rare or low prevalence
complex diseases or conditions”**



- **promote good quality and safe **care** to patients by fostering proper diagnosis, treatment, follow-up and management of patients across the Network**
- **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**
- **exchange and disseminate knowledge and best practices, in particular by supporting **national centres and networks****







«Families» of rare cancers

- **NON CUTANEOUS MELANOMA**
- **SKIN - Rare**
- **THORACIC - Rare**
- **UROGENITAL - Rare**
- **FEMALE GENITAL - Rare**
- **MALE GENITAL**
- **NEUROENDOCRINE**
- **ENDOCRINE ORGAN**
- **CNS**
- **SARCOMAS**
- **DIGESTIVE - Rare**
- **HEMATOLOGICAL - Rare**
- **HEAD & NECK - Rare**
- **PEDIATRIC**



Information Network on Rare Cancers



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www.rarecarenet.eu



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, EuroBoNeT, 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!



Rare Cancers Consensus Meeting: Pathology in Rare Cancers



10 – 11 February 2014, Brussels



- **Referral** to expert rare cancer pathologists is crucial for appropriateness
- **Networks** are the best tool for proper referral
- **Multidisciplinary** is the best environment for rare cancer patient healthcare



Rare Cancers Consensus Meeting: Pathology in Rare Cancers



10 – 11 February 2014, Brussels

Conference Objective: Consensus Statement on Improving Pathological Diagnosis of Rare Cancers

Recommendations stemming from this consensus statement will be crucial in making sure that the Cross-Border Healthcare Directive has the right impact on the lives of patients suffering from rare cancers, through effective use of European Reference Networks.





- **Clinical decision-making**
- **Methods to combine evidence**
- **New study designs**
- **Surrogate end points**
- **Organization of studies**



How can we help you ?

SEARCH

REPORTS FROM PAST EVENTS / Rare Cancers Conference 2012

Rare Cancers Conference 2012



Exploring ways to improve clinical research on rare cancers

Date : 01 Mar 2012

Organised by the [European Society for Medical Oncology \(ESMO\)](#) and [Rare Cancers Europe](#), the Rare Cancers Conference, held on 10 February 2012 in Brussels, provided a multi-stakeholder platform for rare cancer and rare disease experts from across Europe to exchange views and share insights into what can be done to improve the methodology of clinical research on rare cancers.

The first two conference sessions offered an overview of rare cancers and associated challenges for clinical research and drug development and also presented a variety of (potential) solutions as well as best practice examples. Where traditional frequent clinical research approaches are not possible, due to the small numbers of patients, it is particularly challenging to make sure that rare cancer patients are not being left without appropriate clinical research and therapeutic progress.

The third session of the conference therefore also highlighted the need for reaching a broad multi-stakeholder consensus on a set of recommendations on improving the methodology of clinical research on rare cancers. These recommendations will be the product of an ongoing multidisciplinary and multi-stakeholder online consensus discussion, promoted by Rare Cancers Europe. They will focus on best methods, including innovative ones, for clinical research on rare cancers, and rare subgroups of frequent cancers, with the goal of encouraging:

- clinical researchers to exploit innovative solutions for the design and analysis of clinical studies;
- clinicians to exploit innovative solutions for the combination of all available knowledge;
- regulators to accept evidence built through these solutions;
- clinicians' and patients' communities to exploit all forms of collaboration to put together as large series as possible for prospective and retrospective clinical and translational research;
- methodologists to advance research into new methodological solutions better fitting the needs of studies on small series

All interested stakeholder groups are encouraged to actively participate in this open discussion, the result of which will be a consensus paper to be publicly presented in autumn 2012. This paper could then be used for related advocacy efforts. All parties interested in joining this discussion are invited to [contact Rare Cancers Europe](#).

17.

Call for increased integration of local, national and European centres of expertise into **European reference networks**, based on specific criteria as set out in the Commission's proposed Directive on the application of patients' rights in cross-border healthcare , in order to provide the necessary sound organisational structures for more efficient clinical research and early transfer of research data into clinical practice, thus improving the clinical management of rare cancers.

R CANCERS EUROPE E

Joining forces for action



European Society for Medical Oncology

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