

Introduzione e focus sulla partecipazione in Lombardia alle Reti di Riferimento Europee (ERN) per le Malattie Rare

Luca Barcella

Centro Emostasi e Trombosi &
Immunoematologia e Medicina Trasfusionale
ASST Papa Giovanni XXIII, Bergamo
ERN EuroBloodNet



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network
Hematological
Diseases (ERN EuroBloodNet)

DIRECTIVE 2011/24/UE

4.4.2011

EN

Official Journal of the European Union

L 88/45

DIRECTIVES

**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**

DIRECTIVE 2011/24/UE

Articolo 1

*La presente direttiva stabilisce norme volte ad agevolare l'accesso a un'**assistenza sanitaria transfrontaliera** sicura e di qualità e promuove la cooperazione tra gli Stati membri in materia di assistenza sanitaria, nel pieno rispetto delle competenze nazionali relative all'organizzazione e alla prestazione dell'assistenza sanitaria [...]*

DIRECTIVE 2011/24/UE

Articolo 12

*La Commissione sostiene gli Stati membri nello sviluppo delle **reti di riferimento europee** (European Reference Networks, ERN) tra prestatori di assistenza sanitaria e centri di eccellenza negli Stati membri, **soprattutto nel settore delle malattie rare***

[...]

RARE DISEASES IN THE EUROPEAN UNION

5 000 – 8 000

RARE DISEASES INCLUDING

300

RARE CANCERS AFFECT

30

MILLION PEOPLE IN THE EU



DIRECTIVE 2011/24/UE of 9 March 2011

Obiettivi delle ERN:

- *cooperazione in materia di assistenza sanitaria altamente specializzata*
- *condivisione di conoscenze*
- *migliorare diagnosi e assistenza sanitaria per le malattie rare*
- *uso economicamente efficiente delle risorse, concentrandole laddove opportuno*
- *rafforzare ricerca, sorveglianza epidemiologica, formazione dei professionisti sanitari*
- *agevolare la mobilità delle competenze, virtualmente o fisicamente*
- *sviluppo di parametri di riferimento in materia di qualità e sicurezza*
- *aiutare gli Stati membri a fornire servizi altamente specializzati di alta qualità*

DIRECTIVE 2011/24/UE of 9 March 2011

Criteria per le ERN e per gli HCP (Health Care Providers)

- *conoscenza e competenze in materia di diagnosi, controllo e gestione dei pazienti*
- *impostazione multidisciplinare*
- *capacità di produrre orientamenti in materia di buona pratica clinica*
- *contributo alla ricerca*
- *attività didattiche e di formazione*
- *collaborare strettamente con altri centri di eccellenza e reti a livello nazionale e internazionale*

2014: CRITERIA FOR ESTABLISHING AN ERN

17.5.2014

EN

Official Journal of the European Union

L 147/71

COMMISSION DELEGATED DECISION

of 10 March 2014

setting out criteria and conditions that European Reference Networks and healthcare providers wishing to join a European Reference Network must fulfil

(Text with EEA relevance)

(2014/286/EU)

2016: CALL FOR PROPOSALS

To achieve ERN status, network members respond to a call from the European Commission, following which an Independent Assessment Body (IAB) assesses their application and compiles a report.

The Board of Member States (BoMS) then decides whether or not to approve the ERN application.

ERNs must fulfil certain key criteria:

- > Patient-centred and clinically led
- > A minimum of **10 members** in at least **8 countries**
- > Strong, independent assessment
- > Fulfilment of Network and Member criteria
- > Endorsement and approval by national authorities

March 2017: 24 EUROPEAN REFERENCE NETWORKS (ERN)

ERN BOND

ERN CRANIO

Endo-ERN

ERN EpiCARE

ERKNet

ERN-RND

ERNICA

ERN LUNG

ERN Skin

ERN EURACAN

ERN EuroBloodNet

ERN eUROGEN

ERN EURO-NMD

ERN EYE

ERN GENTURIS

ERN GUARD-HEART

ERN ITHACA

MetabERN

ERN PaedCan

ERN RARE-LIVER

ERN ReCONNET

ERN RITA

ERN TRANSPLANT-CHILD

VASCERN



November 2019: CALL FOR MEMBERSHIP TO THE EXISTING ERNs

ERN BOND
ERN CRANIO
Endo-ERN
ERN EpiCARE
ERKNet
ERN-RND
ERNICA
ERN LUNG
ERN Skin
ERN EURACAN
ERN EuroBloodNet
ERN eUROGEN

ERN EURO-NMD
ERN EYE
ERN GENTURIS
ERN GUARD-HEART
ERN ITHACA
MetabERN
ERN PaedCan
ERN RARE-LIVER
ERN ReCONNET
ERN RITA
ERN TRANSPLANT-CHILD
VASCERN





NETWORK COORDINATOR

Dr Luca Sangiorgi
*Rizzoli Orthopaedic Institute,
Bologna, Italy*

ERN BOND brings together all rare bone diseases (congenital, chronic and of genetic origin) that affect cartilage, bones and dentin.

The network is focusing initially on osteogenesis imperfecta (OI), X-linked hypophosphataemic rickets (XLH) and achondroplasia.

Congenital craniofacial anomalies include children born with underdeveloped or maldeveloped parts of their brain, skull and/or face that result in significant functional problems and psychosocial challenges.

Patients require follow-up and treatment from birth into adulthood.

Clinical and public knowledge of many of these presentations is low, and diagnosis can be extremely challenging.



NETWORK COORDINATOR

Professor Alberto M. Pereira
*Leiden University Medical Center,
The Netherlands*

Rare endocrine conditions include too much, too little or inappropriate hormonal activity, hormone resistance, tumour growth in endocrine organs, or diseases with consequences for the endocrine system.

The epidemiological distribution is highly variable from ultra-rare, rare, to low-prevalence conditions.



NETWORK COORDINATOR

Alexis Arzimanoglou
*Centre Hospitalier Universitaire de
Lyon, CHU Lyon, France*

Traditionally, epilepsy has been treated as a single disease, but these conditions are increasingly viewed as a group of rare and complex diseases.

ORPHANET lists 137 disorders with epilepsy as the predominant symptom, however many patients remain undiagnosed and without access to treatment.



NETWORK COORDINATOR

Professor Franz Schaefer
*Universitätsklinikum Heidelberg,
Germany*

Rare and complex kidney diseases comprise a wide range of congenital, hereditary and acquired disorders.

It is estimated that at least 2 million Europeans are affected by rare kidney diseases, with glomerulopathies and congenital kidney malformations each accounting for 1 million cases.

In addition, inherited tubulopathies, tubulointerstitial diseases and thrombotic microangiopathies represent a number of rare and ultrarare diseases of high clinical relevance.

The European Reference Network on Rare Neurological Diseases (ERN-RND) aims to address the unmet needs of more than 500.000 people living with RNDs in Europe.

Due to significant phenotype and genotype heterogeneity of RND patients, 60 % of those affected are still undiagnosed.



European
Reference
Networks

ERNICA

NETWORK COORDINATOR

Professor Rene Wijnen
*Erasmus Medical Center Rotterdam,
The Netherlands*

ERNICA is the European Reference Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies.

The network deals with malformations of the digestive system, malformations of the diaphragm and abdominal wall, malformations of the oesophagus, and gastroenterological and intestinal diseases.

For some of these rare diseases, mortality rates can be as high as 50%.

ERN LUNG addresses all rare and complex diseases of the respiratory system, including interstitial lung diseases (ILD); cystic fibrosis (CF); non-CF bronchiectasis (nCF-BE); pulmonary hypertension (PH); primary ciliary dyskinesia (PCD); alpha-1 antitrypsin deficiency (AATD); mesothelioma (MSTO); and chronic lung allograft dysfunction (CLAD).



NETWORK COORDINATOR

Professor Christine Bodemer

*Assistance Publique-Hôpitaux
de Paris, Hôpital Necker-Enfants
Malades, France*

ERN Skin brings together leading experts in the field of rare child and adult skin diseases to exchange knowledge, update and develop best practice guidelines, improve professional training and patient education, and set up research programmes.



NETWORK COORDINATOR

Professor Dr. Jean-Yves Blay

Centre Léon Bérard, Lyon, France

Rare cancers are malignant disorders with an incidence of fewer than six per 100,000 per year. They account for around 20-25 percent of all new cancer diagnoses and 30 percent of cancer deaths.

EURACAN covers more than 300 rare adult solid cancer types.



NETWORK COORDINATOR

Professor Pierre Fenaux

Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis, Paris, France (Oncological Hub Chair)

Professor Béatrice Gulbis

Hôpital ERASME-CUB, LHUB-ULB, Brussels, Belgium (Non-oncological Hub Chair)

Haematological diseases involve abnormalities of blood and bone marrow cells, lymphoid organs and coagulation factors, and almost all of them are rare.

They can be subdivided into six categories: rare red blood cell defects; bone marrow failure; rare coagulation disorders; haemochromatosis and other rare genetic disorders of iron synthesis; myeloid malignancies; and lymphoid malignancies.



European
Reference
Network

eUROGEN
Urogenital Diseases

NETWORK COORDINATOR

Wout Feitz

*Radboud University Medical
Center, Amalia Children's Hospital,
Nijmegen, The Netherlands*

Rare and complex uro-recto-genital conditions can require surgical correction, often during the neonatal period or in childhood.

Urinary and faecal incontinence are a heavy burden on paediatric, adolescent and adult patients.

Affected individuals require life-long care provided by multidisciplinary teams of experts who plan and perform surgery and provide post-operative care.

EURO-NMD

Building bridges and breaking barriers
in rare neuromuscular diseases

NETWORK COORDINATOR

Dr. Teresinha Evangelista

Sorbonne University - Pitié

Salpêtrière Hospital - Assistance

Public Hopitaux de Paris, France

Neuromuscular diseases (NMDs) occur from early childhood to late adulthood and are characterised by muscle weakness and wasting.

They may also be associated with other symptoms including fatigue, pain, numbness, blindness, swallowing difficulties, breathing difficulties and heart disease. Most NMDs are progressive and debilitating, with reduced lifespan and quality of life.



NETWORK COORDINATOR

Professor H el ene Dollfus
*H opitaux Universitaires de
Strasbourg, France*

Rare Eye Diseases (REDs) are the leading cause of visual impairment and blindness for children and young adults in Europe.

More than 900 REDs are listed in ORPHANET, including more prevalent diseases such as retinitis pigmentosa - which has an estimated prevalence of 1 in 5,000 - as well as some very rare conditions described only once or twice in medical literature.

Genetic tumour risk syndromes are disorders in which inherited genetic variants strongly predispose individuals to the development of tumours.

The lifetime risk of cancer can be as high as 100 percent.

At present, only a small minority of people with genetic tumour risk syndromes has been diagnosed as such.

NETWORK COORDINATOR

Professor Arthur A.M. Wilde
*Amsterdam University
Medical Centre, Amsterdam,
The Netherlands*

Rare cardiac diseases can present throughout a person's life, and most of them are usually either genetic (inheritable) disorders or those which develop during embryogenesis (congenital heart defects).

Most of these cardiac diseases carry a unique susceptibility to sudden death at a young age, and may occur in otherwise healthy people.



NETWORK COORDINATOR

Professor Alain Verloes

*Université de Paris & Assistance
Publique-Hôpitaux de Paris,
Hôpital Universitaire Robert-Debré,
Paris, France*

ERN ITHACA (Intellectual disability, TeleHealth, Autism and Congenital Anomalies) echoes the diagnostic ‘odyssey’ experienced by so many patients with developmental anomalies.

The network brings together more than 70 clinical genetics department across EU academic hospitals, including experts in rare neurodevelopmental disorders (NDDs) – mainly intellectual disability (ID) and autism spectrum disorder (ASD) - as well as rare multiple congenital anomalies.



European
Reference
Network

MetabERN

NETWORK COORDINATOR

Professor Maurizio Scarpa

*Udine University Hospital, Udine,
Italy*

Rare inherited metabolic diseases (IMDs), of which there are more than 1400, are individually rare but collectively frequent.

Many metabolic diseases have severe - sometimes life-threatening - implications for patients.

These conditions include disorders of all organs, can affect people of any age, and require multidisciplinary collaboration between a range of professionals



European
Reference
Networks

ERN PAEDCAN

NETWORK COORDINATOR

Professor Dr. Ruth Ladenstein
*St. Anna Kinderspital & St. Anna
Kinderkrebsforschung, Austria*

Each year across Europe, 35,000 children and young people are diagnosed with cancer and 6,000 paediatric cancer patients die - the leading fatal disease for children aged over one.

More than half a million long-term survivors of childhood cancer are alive today in Europe, with two-thirds of them experiencing long-term health and psycho-social problems due to their disease.

ERN RARE-LIVER addresses three disease themes: autoimmune liver disease; metabolic, biliary atresia and related liver disease; and structural liver disease.

For the first time in liver disease, the network fully integrates adult and paediatric care with a focus on the needs of transitional populations and the implications for families with a genetic diagnosis.

NETWORK COORDINATOR

Professor Marta Mosca

*Azienda Ospedaliero Universitaria
Pisana, Italy*

Rare connective tissue and musculoskeletal diseases (rCTDs) comprise different diseases and syndromes which have a considerable impact on patient well-being.

They include hereditary conditions; systemic autoimmune diseases such as systemic sclerosis; mixed connective tissue diseases; inflammatory idiopathic myopathies; undifferentiated connective tissue diseases; and anti-phospholipid syndrome.



NETWORK COORDINATOR

Professor Nico Martinus Wulffraat
*University Medical Center Utrecht,
The Netherlands*

ERN RITA brings together the leading European centres with expertise in the diagnosis and treatment of rare immunological disorders.

The network divides these conditions into four sub-themes or work streams: primary immunodeficiency (PID), autoimmune disorders, paediatric rheumatological disorders and autoinflammatory disorders.



NETWORK COORDINATOR

Dr. Paloma Jara Vega

*Hospital Universitario La Paz,
Madrid, Spain*

Paediatric transplantation (PT) includes both solid organ transplantation (SOT) and haematopoietic stem cell transplantation (HSCT), and is the only curative procedure for several rare diseases.

After transplantation, patients face chronic immunosuppression to avoid rejection, which requires monitoring for post-transplant complications in order to extend children's lifespans and improve their quality of life.



NETWORK COORDINATOR

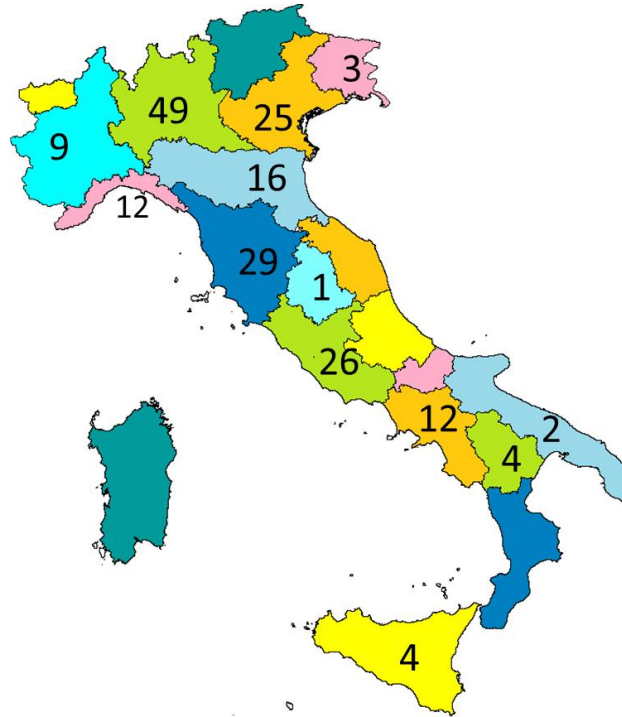
Professor Guillaume Jondeau
*Assistance Publique-Hôpitaux
de Paris, Hôpital Bichat, France*

Rare multisystemic vascular diseases include disorders which affect all types of blood vessels, with consequences for several body systems which require a multidisciplinary approach to care.

VASCERN comprises six rare disease working groups on hereditary haemorrhagic telangiectasia; heritable thoracic aortic diseases; medium sized arteries (vascular Ehlers Danlos Syndrome); paediatric and primary lymphedema; vascular anomalies; neurovascular diseases.

ERN IN ITALIA – marzo 2017

24
European
Reference
Networks
ERNs



192
Partecipazioni
Centri Italiani

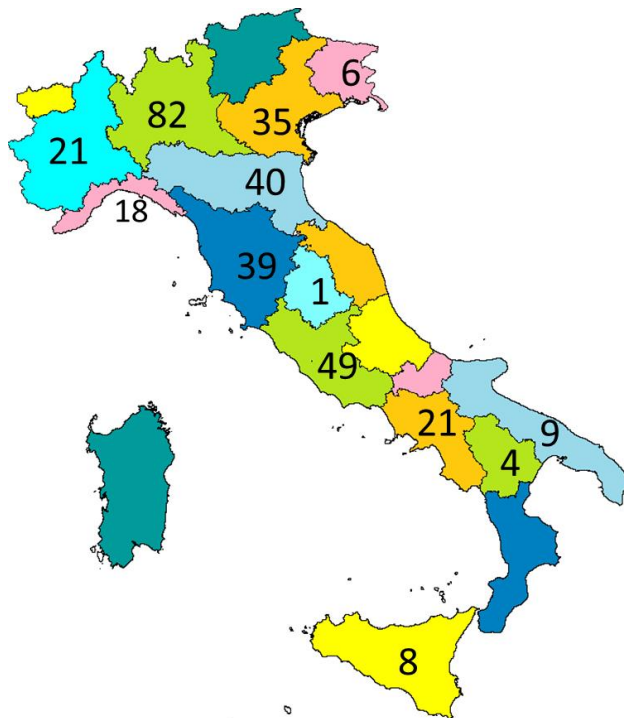
49
Partecipazioni
Centri lombardi

https://ec.europa.eu/health/ern_en

ERN IN ITALIA – gennaio 2022

24

European
Reference
Networks
ERNs



336

Partecipazioni
Centri Italiani

82

Partecipazioni
Centri lombardi

https://ec.europa.eu/health/ern_en

EUROPEAN REFERENCE NETWORKS (ERN) IN LOMBARDIA

ERN	N. PRESIDI	ERN	N. PRESIDI
ERN BOND	1	ERN EURO-NMD	6
ERN CRANIO	3	ERN EYE	2
Endo-ERN	3	ERN GENTURIS	3
ERN EpiCARE	3	ERN GUARD-HEART	4
ERKNet	3	ERN ITHACA	2
ERN-RND	2	MetabERN	3
ERNICA	2	ERN PaedCan	4
ERN LUNG	4	ERN RARE-LIVER	5
ERN Skin	2	ERN ReCONNET	5
ERN EURACAN	8	ERN RITA	4
ERN EuroBloodNet	8	ERN TRANSPLANT-CHILD	1
ERN eUROGEN	2	VASCERN	3

EUROPEAN REFERENCE NETWORKS (ERN) IN LOMBARDIA

	2017	2019 call	2022
Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico di Milano	8	+ 7	15
Fondazione IRCCS Policlinico San Matteo di Pavia	7	-	7
Fondazione IRCCS Istituto Neurologico Carlo Besta di Milano	5	+ 4	9
Ospedale S. Gerardo di Monza	5	-	5
IRCCS Istituto Auxologico Italiano di Milano	3	+ 1	4
IRCCS Istituto Clinico Humanitas di Rozzano	3	-	3
IRCCS Ospedale San Raffaele di Milano	3	+ 3	6
Ospedale Papa Giovanni XXIII di Bergamo	3	+ 3	6
Ospedale S. Paolo di Milano	3	+ 1	4
Spedali Civili di Brescia - Ospedale dei Bambini	3	+ 6	9
Centro Clinico Nemo - Fondazione Serena Onlus di Milano	1	-	1
Fondazione IRCCS Istituto Nazionale dei Tumori di Milano	1	+ 2	3
IRCCS Fondazione Istituto Neurologico Nazionale C. Mondino di Pavia	1	-	1
IRCCS Fondazione Salvatore Maugeri di Pavia	1	-	1
Ospedale di Crema	1	-	1
Ospedale San Giuseppe di Milano	1	-	1
Ospedale Niguarda di Milano	-	1	1
IRCCS Istituto Europeo di Oncologia di Milano	-	1	1
Ospedale di Circolo e Fondazione Macchi di Varese	-	1	1
IRCCS Policlinico San Donato, San Donato Milanese (MI)	-	1	1
Presidio Ospedaliero Gaetano Pini di Milano	-	1	1
Fondazione CNAO - Centro Nazionale di Adroterapia Oncologica di Pavia	-	1	1

EUROPEAN REFERENCE NETWORKS (ERN) ASST PG23



 Ospedale
Papa Giovanni XXIII

Sistema Socio Sanitario



Regione
Lombardia

ASST Papa Giovanni XXIII

Dal 1 marzo 2017

ERN	REPARTO
ERKNet	SC Nefrologia
ERN EuroBloodNet	SC SIMT
ERN TRANSPLANT-CHILD	SC Pediatria

Dal 1 gennaio 2022

ERN	REPARTO
ERNICA	SC Chirurgia Pediatrica
ERN eUROGEN	SC Chirurgia Pediatrica
ERN RARE LIVER	SC Pediatria

ASST PG23 e Malattie Rare Ematologiche

CODICE MR	DESCRIZIONE	REPARTI DI RIFERIMENTO		
RC0220	SINDROME DA ANTICORPI ANTIFOSFOLIPIDI (FORMA PRIMITIVA)	SC SIMT		
RCG070	DIFETTI CONGENITI DEL METABOLISMO DELLE LIPOPROTEINE	SC SIMT	SC PATOLOGIA NEONATALE	SC ENDOCRINOLOGIA
RCG100	DIFETTI CONGENITI DEL METABOLISMO E DEL TRASPORTO DEL FERRO	SC SIMT		
RD0020	EMOGLOBINURIA PAROSSISTICA NOTTURNA	SC EMATOLOGIA		
RD0070	ANEMIE APLASTICHE ACQUISITE	SC EMATOLOGIA		
RD0080	SHWACHMAN-DIAMOND SINDROME DI	SC EMATOLOGIA		
RDG010	ANEMIE EREDITARIE	SC SIMT	SC EMATOLOGIA	
RDG020	DIFETTI EREDITARI DELLA COAGULAZIONE	SC SIMT		
RDG030	PIASTRINOPATIE EREDITARIE	SC SIMT		
RDG031	PIASTRINOPATIE AUTOIMMUNI PRIMARIE CRONICHE	SC SIMT	SC EMATOLOGIA	
RDG040	TROMBOCITOPENIE EREDITARIE	SC SIMT	SC EMATOLOGIA	
RDG050	SINDROMI MIELODISPLASTICHE	SC EMATOLOGIA		
RDG051	NEUTROPENIE CONGENITE	SC EMATOLOGIA		
RGG010	MICROANGIOPATIE TROMBOTICHE	SC SIMT	SC EMATOLOGIA	SC NEFROLOGIA

Malattie Rare Ematologiche seguite presso il SIMT: DGR XI/7753 del 28/12/2022 – CENTRI MEC

Presidi per Difetti ereditari trombofilici e Malattie emorragiche congenite
(Centri MEC Spoke):

Fondazione IRCCS Policlinico San Matteo di Pavia

IRCCS Istituto Clinico Humanitas di Rozzano

Ospedale di Cremona

Ospedale L. Sacco di Milano

Ospedale Niguarda di Milano

 Ospedale Papa Giovanni XXIII di Bergamo

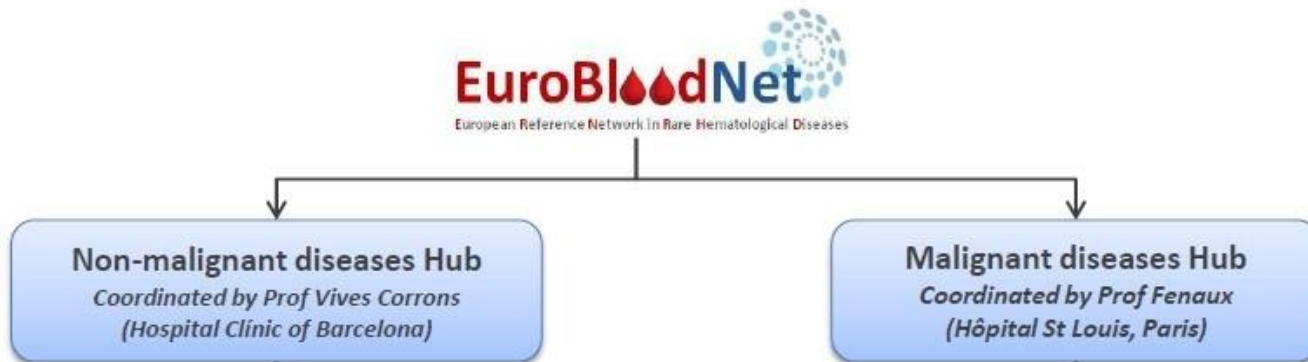
Spedali Civili di Brescia – Ospedale dei Bambini;

ERN EuroBloodNet: Background and Beginning

2016



2017



66 members HCP from 15 EU Member States (MS)

ERN EuroBloodNet: 2022



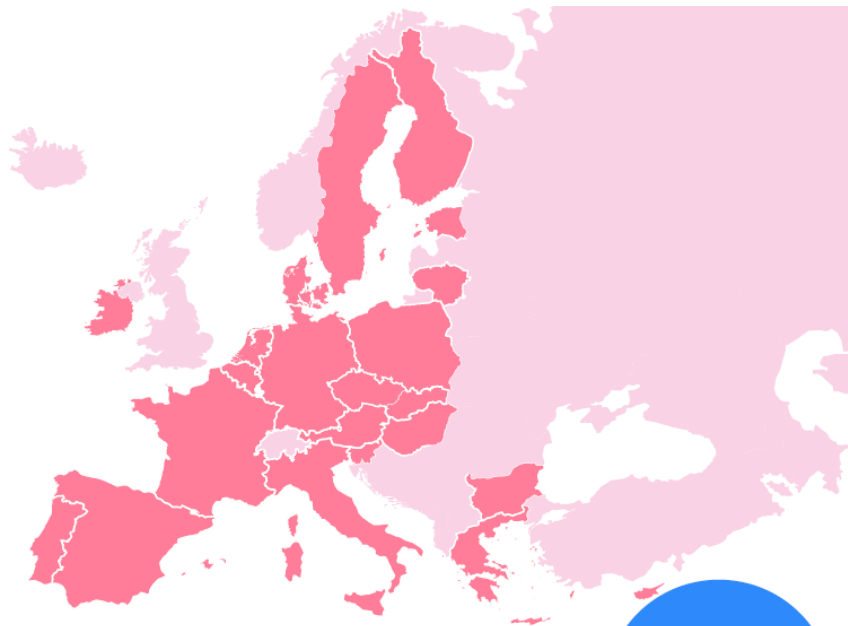
Collaborative network that brings together individuals and institutions committed to **improving healthcare services** in **Rare Hematological Diseases**

Oncological Hub

- Myeloid Malignancies
- Lymphoid Malignancies

Non-Oncological Hub

- Rare red blood cell defects
- Bone marrow failure and haematopoietic disorders
- Rare bleeding-coagulation disorders and related diseases
- Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis



10
EPAGs

24
Member
States

103 Centers
of expertise
across
Europe

7 Affiliated Partners from 6 EU MS

ERN EuroBloodNet: Coordination



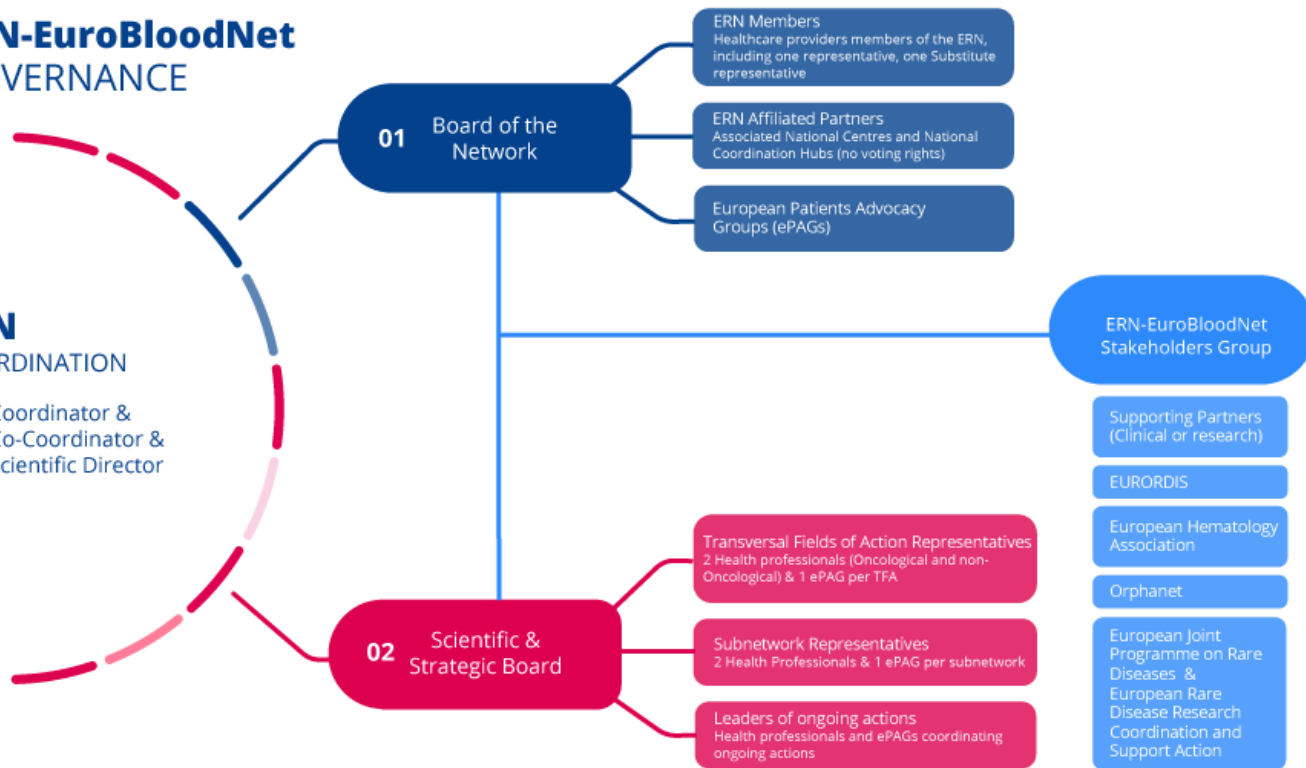
ERN EuroBloodNet: Governance



ERN-EuroBloodNet GOVERNANCE

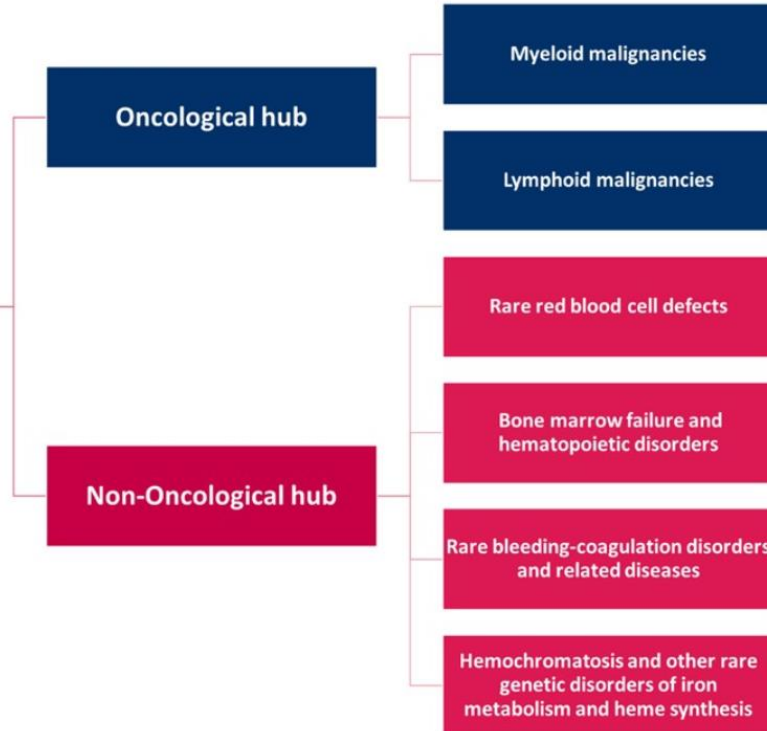
ERN COORDINATION

ERN Coordinator &
ERN Co-Coordinator &
ERN Scientific Director



ERN EuroBloodNet: Subnetworks

More than 450 RHDs according to ORPHA classification



Prevalences range from 1 patient affected in 2.032 individuals to 1 patient affected in 101.600.000 individuals

ERN EuroBloodNet: Objectives



Objective 1: Improve equal access to highly specialized healthcare delivery for RHD across Europe.



Objective 3: Disseminate cutting-edge knowledge and facilitate continuous medical education in the field of RHD



Objective 5: Foster European cooperation in highly specialized procedures for diagnosis, innovative treatments and research



Objective 2: Promote the best practices in prevention, diagnosis and safe clinical care across Europe



Objective 4: Provide inter-professional consultation by sharing of expertise and safe exchange of clinical information



Cross-border health



Best practices



Continuing medical education



Telemedicine



Clinical trials and research



ERN EuroBloodNet: Cross-Border Health

- Repository of Experts and Health Care Providers
- Repository of Patients' Organizations on RHDs
- Mapping of Highly Specialized Procedures
 - *Next generation sequencing for non oncological RHDs*
 - *Bone marrow transplantation for non oncological RHDs*
 - *Diagnostic procedures of primary vitreo-retinal lymphomas*
 - *Transcranial Doppler for Sickle Cell Disease*
- Bilateral agreement for bone marrow transplant for Sickle Cell Disease pediatric patients between two european member states (Ireland and Italy)
- Survey on the accessibility to transfusions and related treatments
- Infopoint for patients dealing with Cross Border Health Rights

ERN EuroBloodNet: Best Practices

- Repository of clinical practice guidelines and other clinical decision making tools on RHD
- Assessment of RHD guidelines awareness and implementation
 - *Pyruvate Kinase Deficiency (PKD) diagnosis*
 - *Sickle Cell Disease management*
- Recommendations for diagnosis and treatment of methemoglobinemia, with the support of the EHA Guidelines Committee (published, AJH, 2021)
- Guideline for Adult Burkitt Lymphoma, with the support of DG SANTE (ongoing)
- Guideline for Long-term complications of haemoglobinopathies , with the support of DG SANTE (ongoing)

ERN EuroBloodNet: Continuing Medical Educations

Educational Section for Health Professionals

Click on the different boxes to discover more information about the educational actions available in ERN-EuroBloodNet for health professionals!



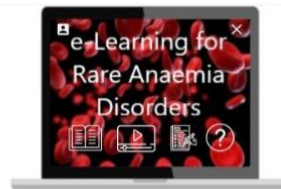
Webinars for Health Professionals

Three different webinar programs are available



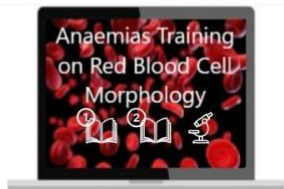
Preceptorships

Short stay programs organized in the frame of ERN-EuroBloodNet



e-Learning for Rare Anaemia Disorders

Dedicated section for the learning of Rare Anaemia Disorders



Anaemias Training on Red Blood Cell Morphology

A course for the learning of Anaemias and Red Blood Cells abnormalities



Publications of Members and Affiliated Partners


Including the ERN-EuroBloodNet acknowledgement and a minimum of two Member States involved

Webinars program on Cutaneous Lymphoma, Thrombotic Microangiopathies, Bone Marrow Failure Syndromes, Castleman Disease (EBAH accredited)

Available on EuroBloodNet EDU Youtube channel


ERN EuroBloodNet: Continuing Medical Educations

Webinars for Patients



Patients Webinars

One webinar providing patients' community with highly specialized knowledge on a specific RHD or groups of disease




Webinars

Patients

EuroBloodNet Topic on Focus

Topic on Focus for Patients

Program promoting the awareness on a Rare Hematological disease or groups of disease targeting patients



Webinars

Patients Organizations

EuroBloodNet Topic on Focus

Topic on Focus for Patients Organizations

Program promoting the awareness on a Rare Hematological disease or groups of disease targeting patients' organizations

Webinars program on Myelodysplastic syndromes, Sickle Cell Disease, Patients Organizations, Cutaneous lymphoma

Available on EuroBloodNet EDU Youtube channel

ERN EuroBloodNet: Telemedicine

European Reference Networks CPMS | Global Dashboard

EU Login succeeded. Welcome, n0021tiv.

- Dashboard
- EuroBloodNet
- Hospital P...
- Map
- Training
- Preferences

Upcoming Meetings in the next 14 days

No upcoming meetings available.

Meeting Invites

No meeting invitations available.

Panel Activity in the last 14 days

No updates in your panels available.

Panel Invites

No panel invitations available.



ERN EuroBloodNet: Clinical Trial and Research

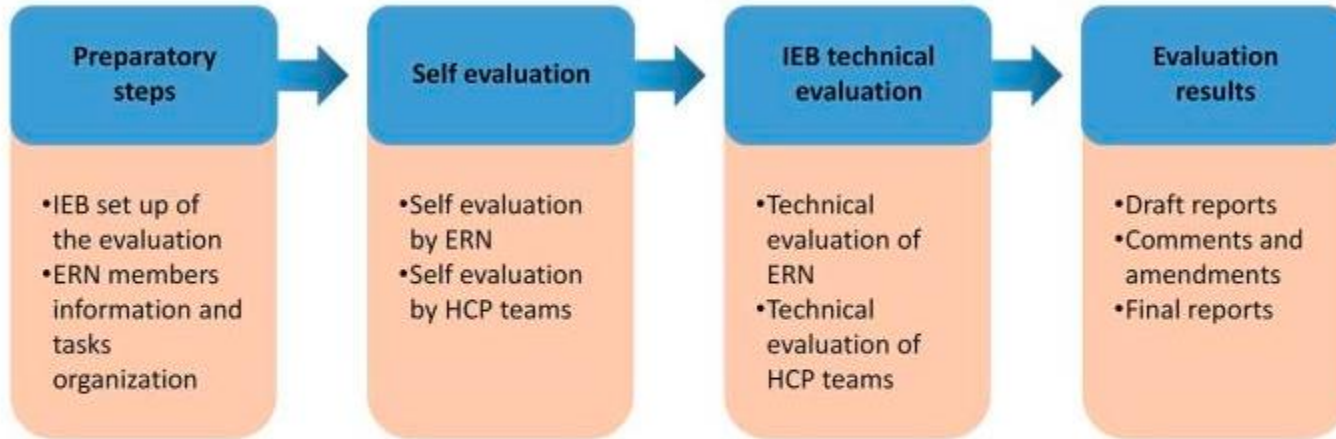


ERN EuroBloodNet: Annual Meeting



3rd ERN-EuroBloodNet Board of the Network meeting, November 2019, Barcelona

5-YEAR EVALUATION OF ERNS AND MEMBER HCPS



Timeline of the evaluation process: IEB (Independent Evaluation Body); ERN (European Reference Network for Rare Diseases); HCP (Health Care Provider)

OBJECTIVES OF THE HCPS' EVALUATION

To assess:

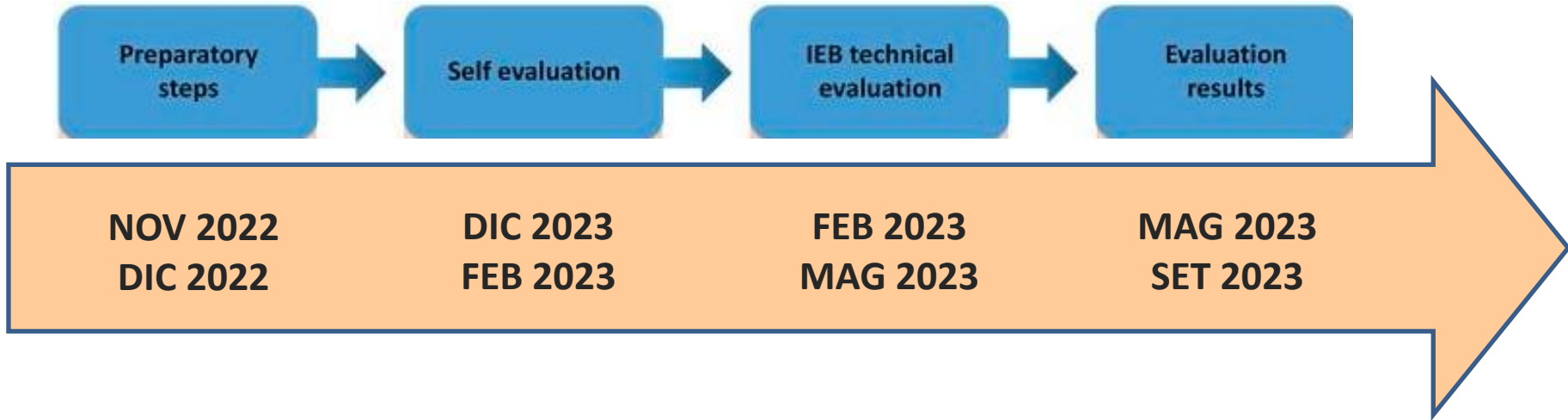
- If the HCP continues to provide specialized and quality care
- If the HCP team maintains the necessary levels of activity and experience
- What has been the contribution of the HCP team to the Network
- The value of the ERN for the HCP

SELF-EVALUATION

64 measurable elements (of which 29 core elements) related to the following areas:

- *patient -centred care*
- *organisation and management*
- *research and training*
- *exchange of expertise and e-health*
- *quality and safety*
- *competence and outcomes of care*
- *human resources*

TIMELINE



EVALUATION RESULT

Outcomes:



Continuation of the ERN membership

OR



Improvement Plan

OR



Termination of the ERN membership

Per ulteriori approfondimenti ...

Public Health

[Home](#) > [European Reference Networks](#)

European Reference Networks

Overview

[Evaluation of the European Reference Networks](#)

Board of Member States

The Board of Member States, as laid out in the European Commission implementing decision, was set up on 5 February 2014. The main tasks of the Board...

Work of the ERNs

To review a patient's diagnosis and treatment the members of an ERN consult, exchange information and share knowledge with other members in their...

ERNs and COVID-19

In the context of the fight against the coronavirus pandemic, the European Commission launched the COVID-19 Clinical Management Support System (CMSS)...

Networks

The first 24 ERNs were launched in 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States.

Projects

Rare Diseases pilot Networks: These pilot projects have been financed by the Public Health Programme before the legal framework of the Cross-border...

https://health.ec.europa.eu/european-reference-networks_en



malattierare.gov.it

insieme nel mondo delle malattie rare

MALATTIE RARE

CENTRI DI DIAGNOSI E CURA

ASSOCIAZIONI

 / A CHI PUOI RIVOLGERTI - Reti di riferimento europee – ERN

RETI DI RIFERIMENTO EUROPEE – ERN

La cooperazione tra i sistemi sanitari europei

Nel marzo 2011 è stata adottata la Direttiva Europea (2011/24/UE) sui diritti dei pazienti all'assistenza sanitaria transfrontaliera che ha istituito un quadro giuridico per assistenza sanitaria transfrontaliera all'interno dell'Unione europea. La direttiva chiarisce le regole di accesso all'assistenza sanitaria in un paese dell'UE diverso dal paese di origine del paziente e specifica le regole per il rimborso.

Uno degli obiettivi principali della direttiva è quello di promuovere la cooperazione tra i sistemi sanitari degli Stati membri attraverso l'istituzione delle Reti europee di Riferimento (ERN), vale a dire reti di centri di expertise e prestatori di cure sanitarie organizzate a livello transfrontaliero.

<https://www.malattierare.gov.it/ern/ricerca>

COVID-19

Regione Lombardia

AIFA

La Rete

Rete Malattie Rare

Normativa

Malattie Rare Esenti

Coordinamento

Referenti Rete MR

Modulistica

Reti ERN

Consulta i Database

Malattie Rare Esenti e Relativi Presidi di Rete

Schede Informative sulle Malattie Rare

Associazioni di Pazienti

Ricerca per Malattia Rara - Risorse Disponibili

European Reference Networks - ERNs



In data 1 marzo 2017 hanno ufficialmente avviato le loro attività le prime 24 Reti di Riferimento Europee (European Reference Networks - ERNs), che hanno coinvolto complessivamente oltre 300 Centri in 25 Paesi dell'Unione Europea ([link al sito dell'Unione Europea](#)).

Il 26 novembre 2021 il Board degli Stati Membri ha approvato un ampliamento delle ERNs con la selezione di un ulteriore gruppo di Centri partecipanti.

GRAZIE PER L'ATTENZIONE !

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



XXIII Ospedale
Papa Giovanni XXIII

Sistema Socio Sanitario

 Regione
Lombardia

ASST Papa Giovanni XXIII



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)