



EUROPEAN REFERENCE NETWORKS: HOPES & DREAMS: LETS MAKE IT HAPPEN!

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EURORDIS.ORG

European Reference Networks

European Reference Networks (ERNs)

ERNs aim to **improve access to diagnosis and treatment** by providing high-quality healthcare to patients who have conditions requiring a particular concentration of resources or expertise, such as rare diseases.

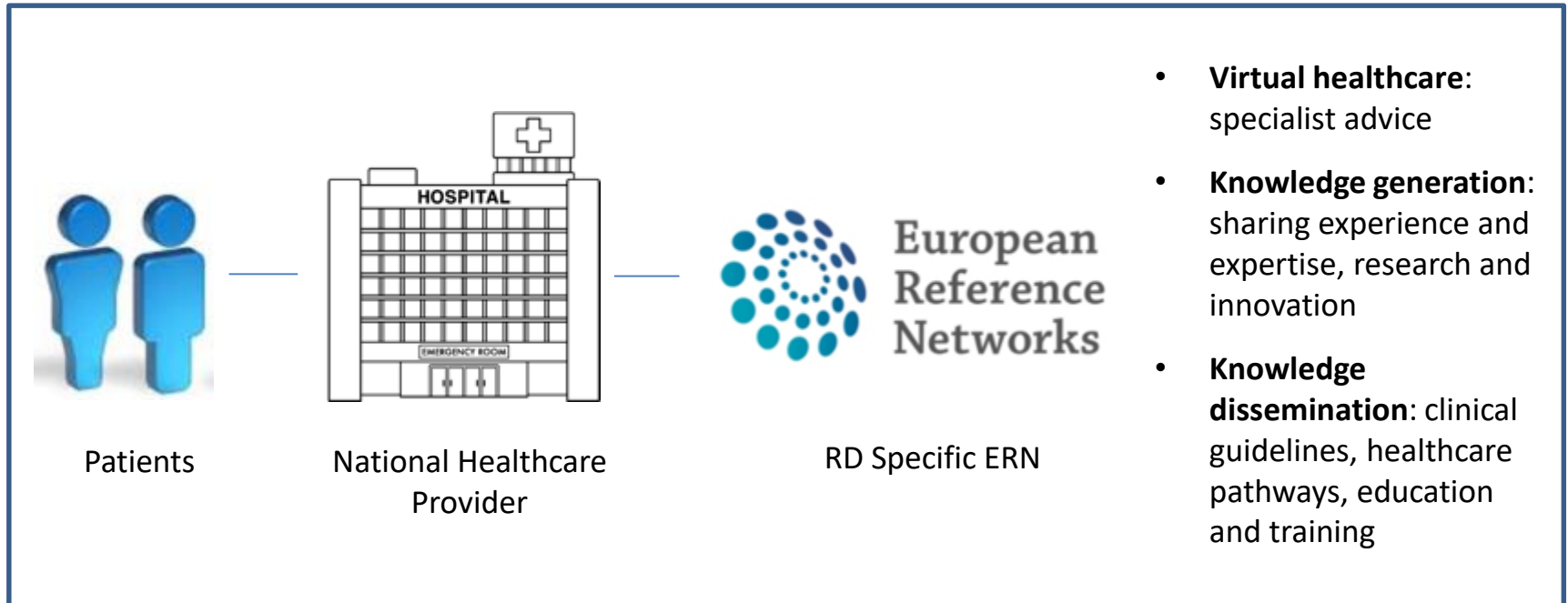
ERNs are networks of centres of expertise, healthcare providers and laboratories that are organised across borders

Expertise travels across borders, rather than the patient



- **Patient-centred**, involving patients from the start and as equal partners in all ERNs
- **Optimal framework** for multisystem rare diseases, every patient with a rare disease has a home under an ERN, leaving no one behind
- **Connect expert, expertise and creating a critical mass of cases and data**
- **Anchored into national health systems**
- Vehicle that will pave the way for **faster diagnosis and access to expert care**

European Reference Network



Note: Slide inspired from Dr Enrique Terol, DG SANTE

ERN Launch Conference, Vilnius

9-10 March 2017



Patient & Clinical Partnership, Vilnius

+50 number. ePAG Representatives attended Vilnius, funded by the EC as ERN representatives

9-10 March 2017



Application Overview (revised)

Member State	No. ERNs / 24	No. Hospitals	Number HCP	Member State	No. ERNs / 24	No. Hospitals	Number HCP
Italy	23	66	186	Bulgaria	6	6	7
France	ALL	38	111	Romania	6	6	7
Germany	23	42	121	Slovenia	9	3	9
UK	22	35	112	Estonia	3	2	3
Netherlands	ALL	13	90	Croatia	2	1	2
Belgium	19	10	36	Austria	2	1	2
Spain	19	16	42	Norway	3	2	3
Czech Republic	18	8	28	Ireland	3	1	3
Sweden	20	6	30	Latvia	2	1	2
Portugal	16	8	29	Luxembourg	1	1	1
Poland	17	12	21	Cyprus	2	2	2
Denmark	11	4	20	Malta	-	-	-
Finland	12	4	14	Greece	-	-	-
Hungary	10	4	14	Slovak Rep.	-	-	-
Lithuania	12	2	12	Total	-	>300	>900

Useful websites

European Commission ERN webpage

http://ec.europa.eu/health/ern/policy_en

RD Action (Joint Action for Rare Diseases)

Network Name	Thematic Grouping	Coordinating HCP	Name of Coordinator	Website
BOND	Rare Bone Disorders	Istituto Ortopedico Rizzoli, ITALY	Luca Sangiorgi	ERN-BOND
CRANIO	Rare Craniofacial anomalies and ENT disorder	Erasmus Medical Centre, Rotterdam - THE NETHERLANDS	Irene Mathijssen	ERN-CRANIO
ENDO-ERN	Rare Endocrine Diseases	Leiden University Medical Centre - THE NETHERLANDS	Alberto Pereira	ENDO-ERN
EpiCARE	Rare and Complex Epilepsies	UCL Institute of Child Health - UNITED KINGDOM	Helen Cross	EpiCARE
ERKNET	European Rare Kidney Diseases Reference Network	Heidelberg University Hospital - GERMANY	Franz Schaefer	ERKnet
ERN-RND	Rare Neurological Diseases	University Hospital Tubingen - GERMANY	Hans Graessner	ERN-RND
ERNICA	Rare Gastrointestinal Diseases (Rare Inherited & Congenital Anomalies)	Erasmus Medical Centre, Rotterdam - THE NETHERLANDS	Rene Wijnen	ERNICA

<http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease-erns/>

Patient Involvement in ERNs

Patient Centre & Empowerment

European Reference Networks (ERNs) created on founding principles of patient-centred care, patient advocate empowerment, patient engagement



European Patient Advisory Groups (ePAG):

- **24 forums** for dialogue, unity & solidarity to optimise involvement of patients
- **Represent** patients to engage in application process & governance of RD ERNs
- **Open** to members & non-member patient groups in EU
- **Aligned** with RD ERN scope
- **Composed of c.150 elected ePAG representatives & <1000 ePAG member organisations**
- Democratically established & progressively expanded with agreed Terms of Reference
- Processed launched in May 2015, Announcement in May 2016

European Patient Advocacy Group Satellite Meeting



ERN Governance Structure

	Group	Number	ePAG Representatives	Gaps
Overarching ERN	Network Boards	24	2 – 3 per Network Board	tbc
Disease specific networks	Clinical committees	115	++150	23

- **Network Boards:** Patient representatives are voting members of ERN Network Boards
- **Patient Boards** are being established with terms of reference
- **Thematic topics:** In process of identifying patient representatives for the ERN transversal working groups for:
 1. Research and Registries
 2. eHealth and virtual healthcare
 3. Education & Training
 4. Quality, Outcomes & Guidelines

Agenda

09:45 – 11:00	Workshop 1: Session 1 Turning ERNs into a Reality: A New Era for Rare Diseases	Presenter
	Diagnosis: Rare Malformations & Intellectual Disabilities ERN	Sofia Douzgou
	Treatment: Rare Metabolic ERN	Maurizio Scarpa
	Research: Rare Bone ERN	Luca Sangiori

Ask the Experts Roundtable Discussion : Panelist:

- Matt Bolz-Johnson, EURORDIS (chair)
- Sofia Douzgou, Rare Malformations & Intellectual Disabilities ERN
- Maurizio Scarpa, Rare Metabolic ERN
- Luca Sangiori, Rare Bone ERN

11:00 – 11:30 Coffee break

Roundtable Discussion

Key topics:

- Access ERNs and highly specialised advice, treatment: how will I benefit from an ERN?
- Challenges facing ERNs
- What is the true potential ERNs offer?

Session 3: ERN Specific Focus Groups

Focus Group	Lead	Room
Rare Malformation & Intellectual Disabilities ERN	Lead: Sofia Douzgou Co/lead: Dorica Dan Rapporteur: Ariane Weinman	Helia
Rare Bone ERN	Lead: Luca Sangiori Co/lead: Rapporteur: Lenja Wiehe	Saturnus
Rare Metabolic ERN	Lead: Maurizio Scarpa Co/lead: Anne-Sophie Lapointe Rapporteur: Matt Bolz-Johnson	Venus

14:00 – 15:30 ERN Specific Focus Groups

15:30 – 16:00 Panel Discussion, Victoria Hedley & Matt Bolz-Johnson

Thank You

