

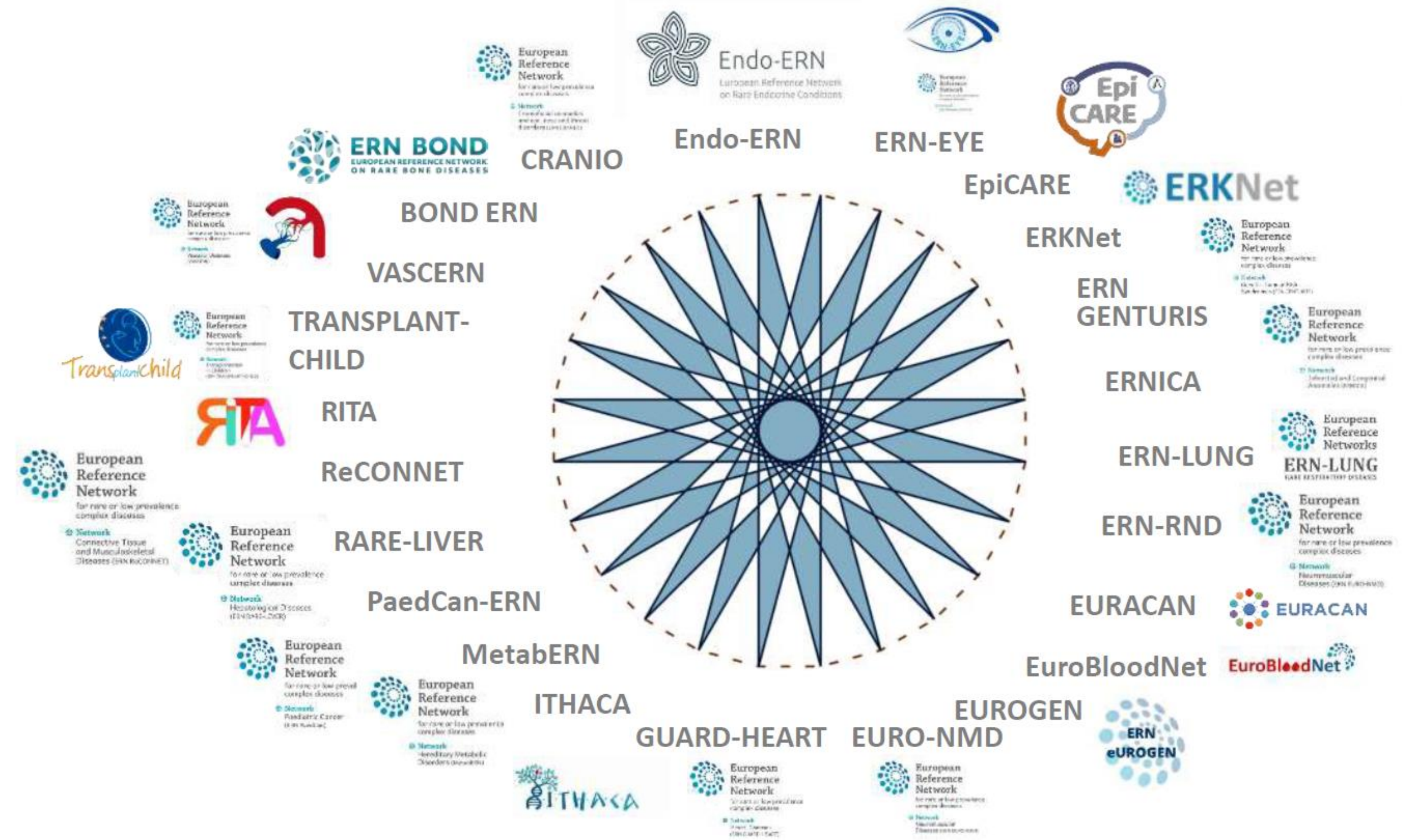
European Reference Networks



European Reference Networks

- Operational since 2017
- As of 2024, the ERNS include 1,619 specialised centres in 382 hospitals across 27 Member States and Norway.
- Focus on healthcare
- Created under [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare.

24 ERNs– Thematic networks



European Reference Networks created added value



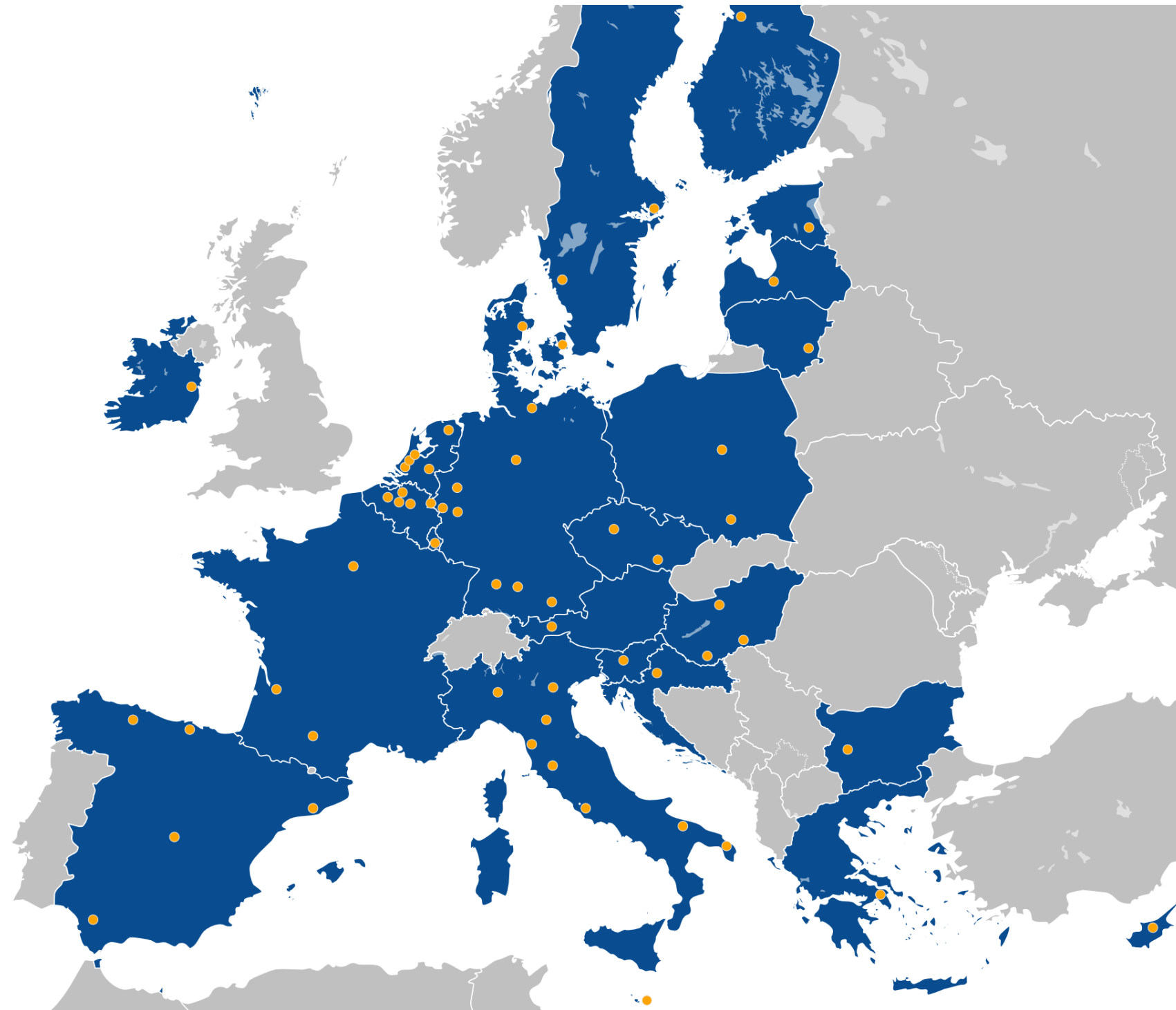
- European partnership
- Structural integration of patient organisations
- Knowledge and standards: Collect, make available
- Produce new knowledge, standards and data
- Increase equity of care
- E-health for cross-border care (“knowledge travels, not the patient”)

24 ERNs have been established in 2017

- 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

ERN-RND – European Reference Network for rare neurological diseases

- 68 expert centres in 24 EU countries (medium large ERN)
 - + supporting partners
- > 44.000 patients per year (adults and paediatric)



Country	N members	Country	N members
Austria	1	Greece	1
Belgium	4	Hungary	3
Bulgaria	1	Ireland	1
Croatia	1	Italy	9
Cyprus	1	Lithuania	1
Czech Republic	4	Netherlands	6
Denmark	2	Poland	2
Finland	1	Slovenia	1
France	6	Spain	8
Germany	9	Sweden	2

Country	N members
Estonia	1
Latvia	1
Luxembourg	1
Malta	1

Governance

- ERN-RND Board
- ERN-RND ePAG
- ERN-RND Management Team
- ERN-RND Advisory Board
- ERN-RND Coordination Office

- Disease Expert Groups and Working Groups
- Cross-ERN working groups

Cross-ERN working groups

Cross-cutting themes: Joint training curriculum, NGS, Registry and European health data space, Genetic therapy and stem-cell transplantation, Surgical therapies

Disease overarching themes: Mitochondrial diseases, Channelopathies, Neurophysiology / myoclonus, Neurometabolic diseases

ERN-RND transversal working groups

Neuropediatric issues

Neurorehabilitation

ERN-RND disease groups

Ataxia and HSP

Dystonia, paroxysm.
Disorders, NBIA

Huntington's disease
and choreas

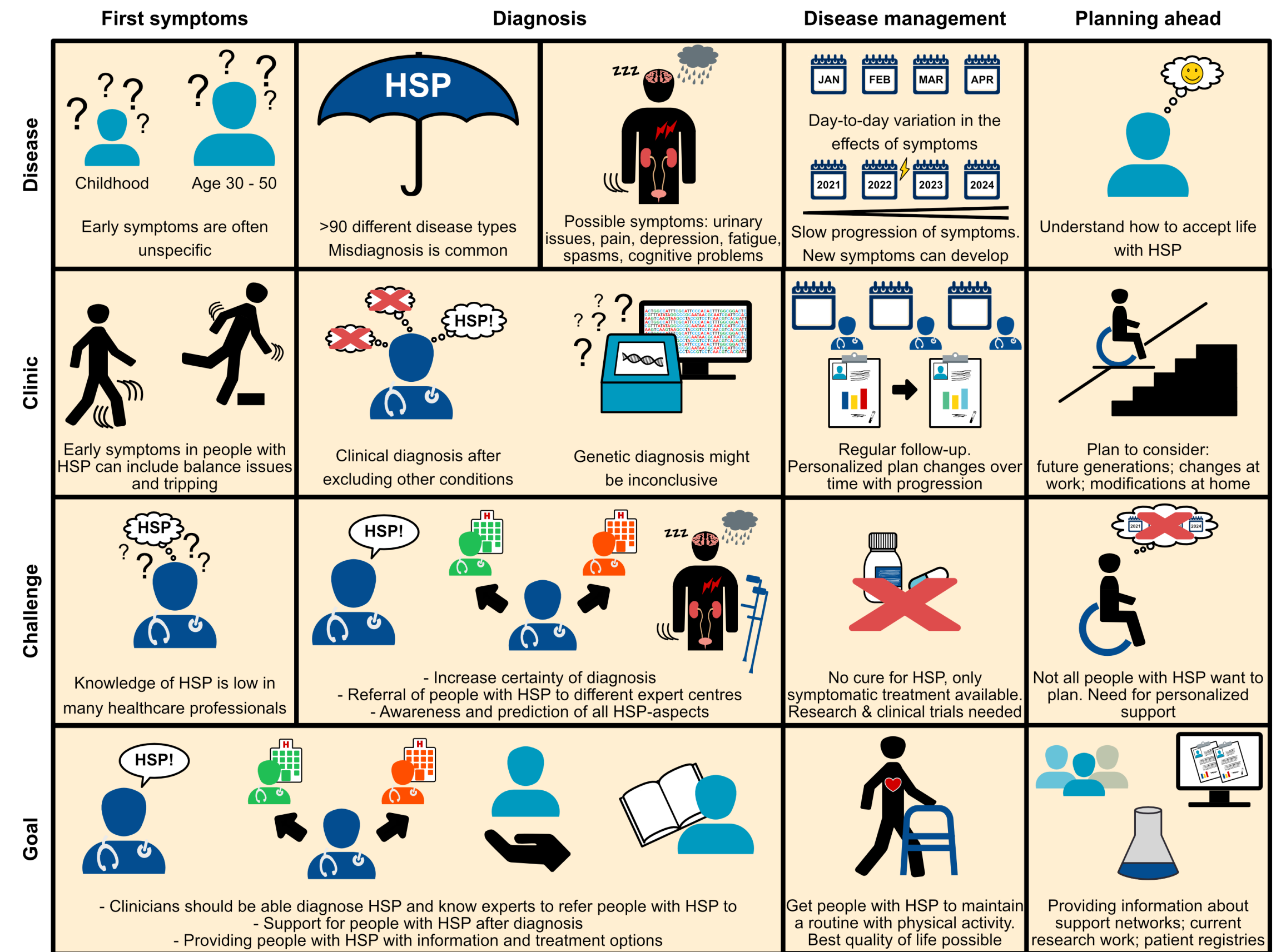
Atypical parkinsonian
syndroms

Leuko-
encephalopathies

Frontotemporal
dementias

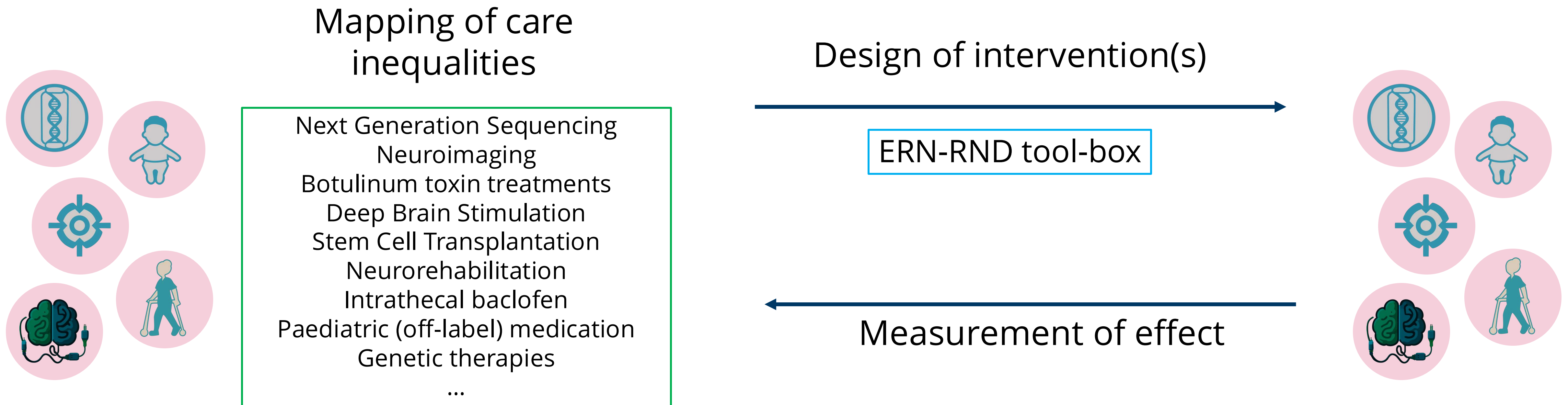
Core activities of ERN-RND

- Crossborder healthcare / CPMS
- Training and education of health professionals
- ERN-RND registry
- Guidelines and Clinical Decision Support Tools / care standards
- Patient journeys
- Dissemination



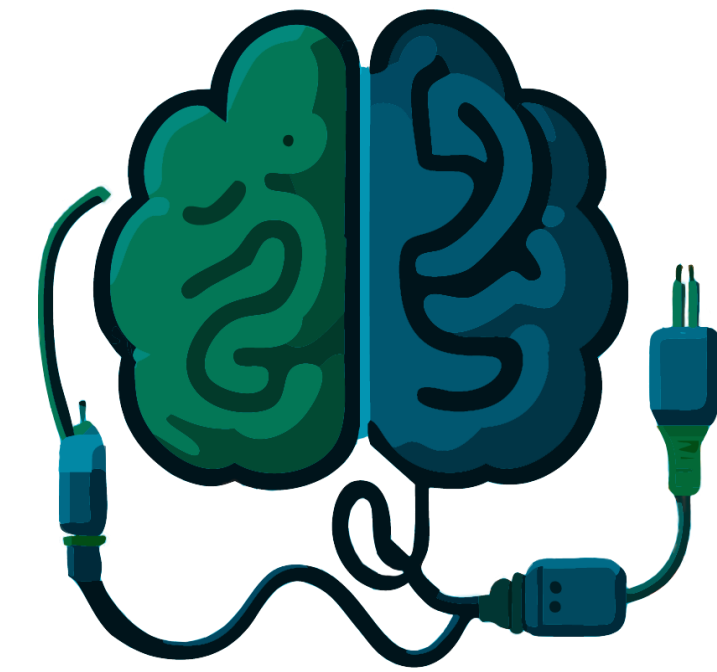
Example: Patient Journey for Hereditary Spastic Paraplegia

ERN-RND - mode of action for improvement of care equity



Cross-Border healthcare pathway: DBS in Dystonia

Standard pathway for harmonizing & optimizing DBS management decisions in Dystonia patients.



Harmonizing care

Consensus on best practice and minimum requirements (standard operating procedure)

Cross-border healthcare

Online multidisciplinary Board for DBS in Dystonia

Online Learning

Expert webinars and post-graduate curriculum

F2F Exchange
Symposium in Würzburg, Germany 2025

Hands-on training
Exchanges to DBS expert centers


Impact on patient care – Success Story – Patient journeys

- Led by ePAGs
- All ERN-RND disease areas
- Main European languages
- Goal: hand out a suitable patient journey to all newly diagnosed patients

Patient Journeys are info-graphical overviews that visualize patients' needs in the care of their rare disease.

Because Patient Journeys are designed from the patient's perspective, they allow clinicians to effectively address the needs of rare disease patients.


A detailed version of this patient journey is available on our website.




PATIENT JOURNEY

Hereditary Spastic Paraplegias

by PATIENTS for PATIENTS



Was this patient journey helpful? Help us improve patient care and participate in our short survey!



European Reference Network for Rare Neurological Diseases
Coordinator: Dr. Holm Graessner
University Hospital Tübingen




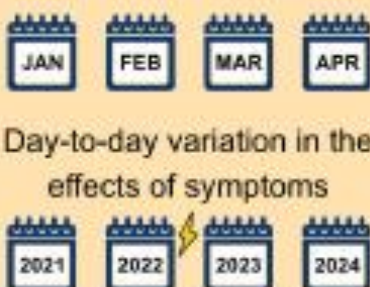













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European Reference Network
for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

Euro-HSP
Federation of European HSP Associations

Hereditary Spastic Paraplegias
ERND
Taking Steps Toward a Cure

	First symptoms	Diagnosis	Treatment	Monitoring	
Disease	 <p>Childhood Age 30 - 50</p> <p>Early symptoms are often unspecific</p>	 <p>90+ different disease types. Misdiagnosis is common</p>	 <p>Possible symptoms: fatigue, urinary issues, pain, depression, spasms, cognitive problems</p>	 <p>Day-to-day variation in the effects of symptoms</p> <p>Slow progression of symptoms. New symptoms can develop</p>	 <p>Understand how to accept life with HSP</p>
Clinic	 <p>Early symptoms in people with HSP can include balance issues and tripping</p>	 <p>Clinical diagnosis after excluding other conditions</p>	 <p>Genetic diagnosis might be inconclusive</p>	 <p>Regular follow-up. Personalized plan changes over time with progression</p>	 <p>Plan to consider: future generations; changes at work; modifications at home</p>
Challenges	 <p>Knowledge of HSP is low in many healthcare professionals</p>	 <p>- Increase certainty of diagnosis - Referral of people with HSP to different expert centres - Awareness and prediction of all HSP aspects</p>	 <p>No cure for HSP, only symptomatic treatment available. Research & clinical trials needed</p>	 <p>Not all people with HSP want to plan. Need for personalized support</p>	
Goals	 <p>- Clinicians should be able diagnose HSP and know experts to refer people with HSP to - Support for people with HSP after diagnosis, including physiotherapy and stretching - Providing people with HSP with information and treatment options</p>	 <p>Get people with HSP to maintain a routine with physical activity. Best quality of life possible.</p>	 <p>Providing information about support networks; current research work; patient registries</p>		

HSP Hereditary Spastic Paraplegias

Please note that specific terms (e.g. home care services, general physician, physiotherapy) do not include the same services in all EU countries and might differ from country to country. Patient advocacy groups can often provide support and resources for patients and families.

Disclaimer
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Registry

	2021	2022	2023
No of centers sent data	8	28	37
No of datasets received	1872	4960	7922

No of centers signed Data Sharing Agreement: 47

Further activities during the last year:

- Data monitoring and upload into the REDCap database
- Data Quality Report for all HCPs who have submitted data
- Data analysis
- Data Access Committee and Process up and running
- Survey of other ERN registries: codification and numbers of patients without determined diagnosis

Data access:



Summary

- ERNs are cross-border collaborative patient-centered networks that bring together European hospital centres of expertise and reference
- ERNs create value for rare, low prevalence and complex diseases and conditions requiring highly specialised healthcare
- ERNs facilitate research



**European
Reference
Networks**

Centers of Excellence



**SJD Barcelona
Children's Hospital**

European Reference Networks

Centers of Excellence



**NoRo Center
Romania**



NoRo Rare Disease Centre

Interview with Dorica Dan, Psychologist,
Parent of daughter with Prader-Willi
syndrome and Founder of NoRo Center
– the Pilot Reference Center for Rare
Diseases in Zalău





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Canadian Organization
for Rare Disorders