ERN | EuroBloodNet

12th June 2026 - EHA Congress

Workforce development & capacity building for rare diseases

ERN infrastructure on education for patients and professionals & best practices

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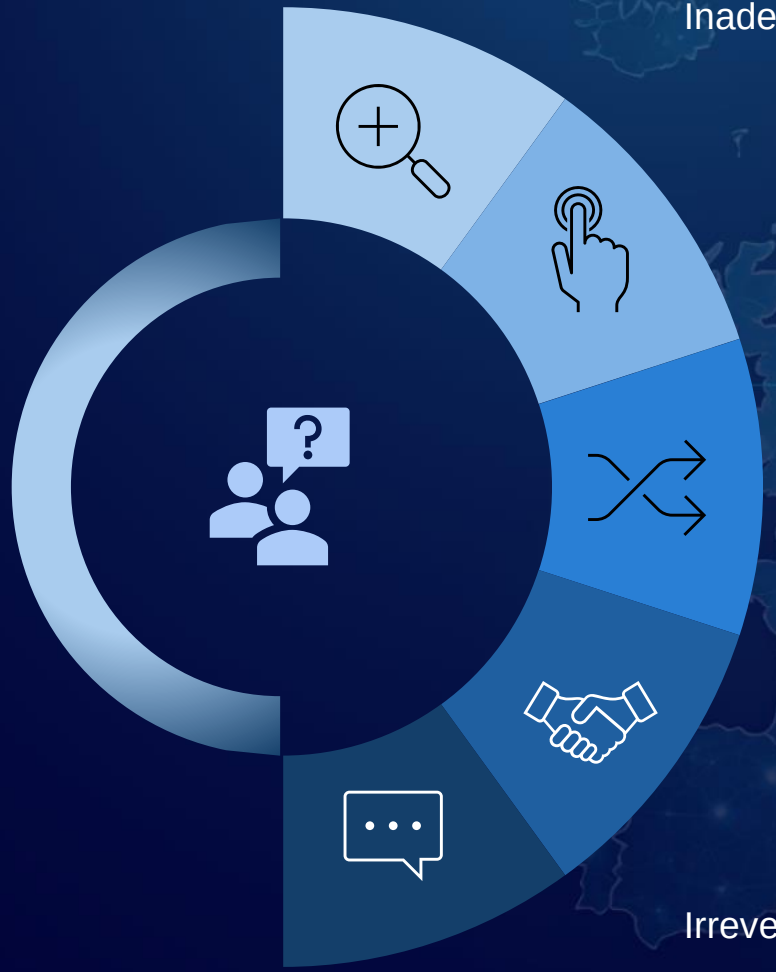
European Reference Network | Hematological Diseases (ERN EuroBloodNet)

Funded by the European Union

WHY EDUCATION MATTERS

If education reduces average diagnostic delay by just one year, the potential savings are massive, given 7.6× cost differentials across 30 million EU patients.

This reduction is achievable through systematic curricular integration, without additional training years.



Inadequate medical education

Failure to recognize RD signs

Prolonged diagnostic odyssey

Avoidable healthcare costs

Irreversible disease progression

THE RARE DISEASES REALITY IN EUROPE

65.9% of medical students rate their rare disease knowledge as 'Poor' or 'Very Poor’.

Only 6% of known rare conditions have approved treatments.

Sources: EURORDIS Rare Barometer 2024; Öztürk et al. 2025; EURORDIS/Draghi Report 2024

SESSION 1: EU ACTION PLAN FOR RARE DISEASES

PRIORITY ACTION 2: WORKFORCE DEVELOPMENT

EUROPEAN PRIORITY FOR RARE DISEASES

HLM4RARE WG2 : Strengthen workforce development and capacity building for rare diseases and formalise the ERN Academy

CHALLENGES

- Rare disease **expertise remains unevenly distributed across Europe**, limiting equitable access to specialized knowledge and care.
- **Rare diseases** are not yet systematically embedded in medical, nursing, scientific and allied **health curricula**.
- Structured training for professionals, patients and families, **including digital and AI skills**, remains insufficiently recognized at EU level.

ERN-EUROBLOODNET RESPONSE

Continuing Medical Education

Best Practices

KEY INITIATIVES

ITN-Marie Curie, Preceptorships
EDIT-SCD, Edu programs in GENOMED4ALL & SYNTHEMA

EU ACTION PLAN FOR RARE DISEASES

- WG1 Governance & Action Plan
- WG2 Workforce Development
- WG3 Diagnostics & Early treatment
- WG4 Clinical Trials
- WG5 National Infrastructure
- WG6 Real-World Evidence
- WG7 Equitable access to therapies
- WG8 Funding & Sustainability

SESSION 1: EU ACTION PLAN FOR RARE DISEASES

PRIORITY ACTION 2: WORKFORCE DEVELOPMENT

KEY TAKE-AWAYS from HLM Rare 2025

- **Skills gaps drive delayed diagnosis**, uneven care, weaker registries, fewer trials and slower research transaction
- ERN education already exists but is fragmented. This is why the **ERN Academy is needed** to unify and certify it
- **Talent retention** needs clear career paths and support
- **GPs** need rare-disease awareness and “red flags” **training,** as well as clear pathways
- **Digital and data competencies** are now essential, but clinicians must be appropriately trained guide, validate and implement these tools

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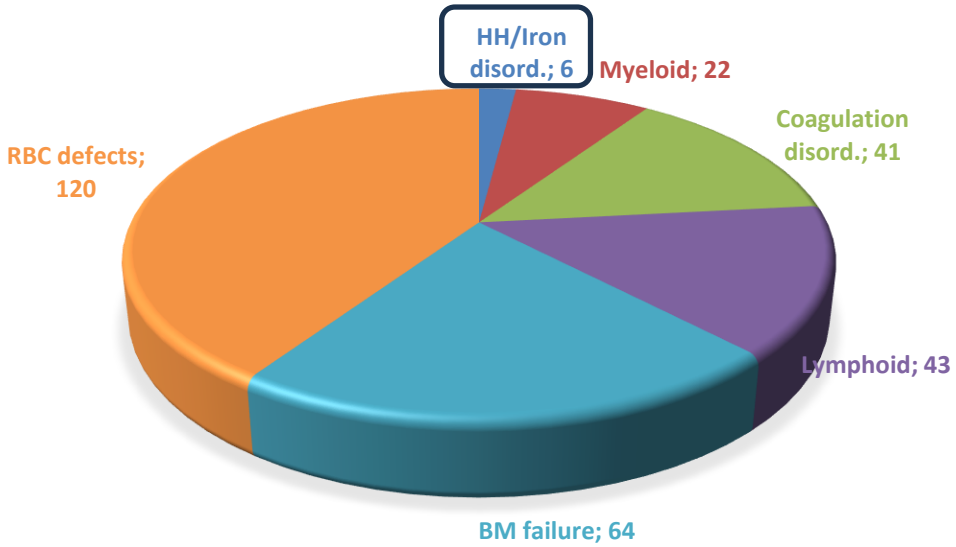
ACTION PLAN TOPICS
Translated for ERN-EuroBloodNet

- **What role can we further play in reducing disparities in rare diseases expertise?**
- How can we attract and retain the next generation of specialists in rare haemotological diseases?
- How can we better support the upskilling of general practitioners to improve early recognition and referral of people with rare hematological diseases?
- Digital and data competencies are now essential: what is currently needed to improve rare-disease specialists’ and patients’ skills and to better support their needs?

Educational activities Oct 2023-Dec 2025

Connecting expertise. Advancing knowledge. Improving lives across Europe.

CONTINUING MEDICAL EDUCATION



+ For all rare haematological disorders; 41

What strategies can be used to promote and harmonize education across all rare hematological disease subnetworks?

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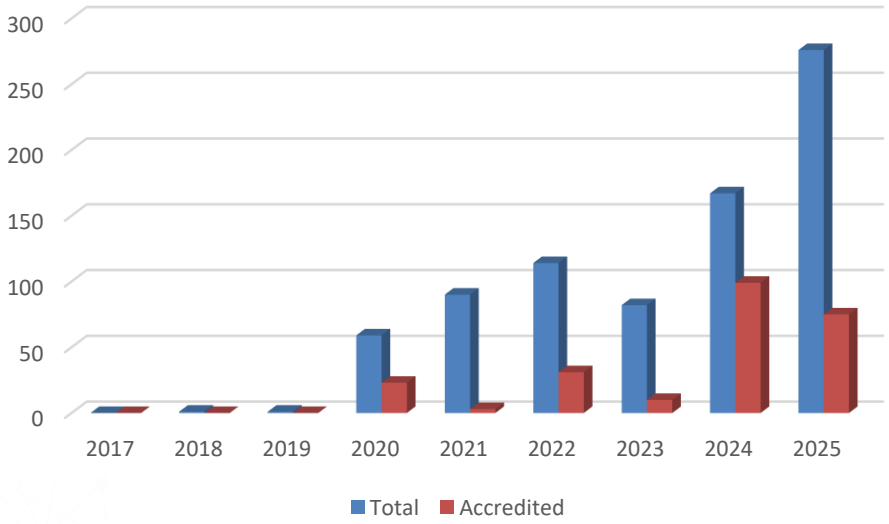
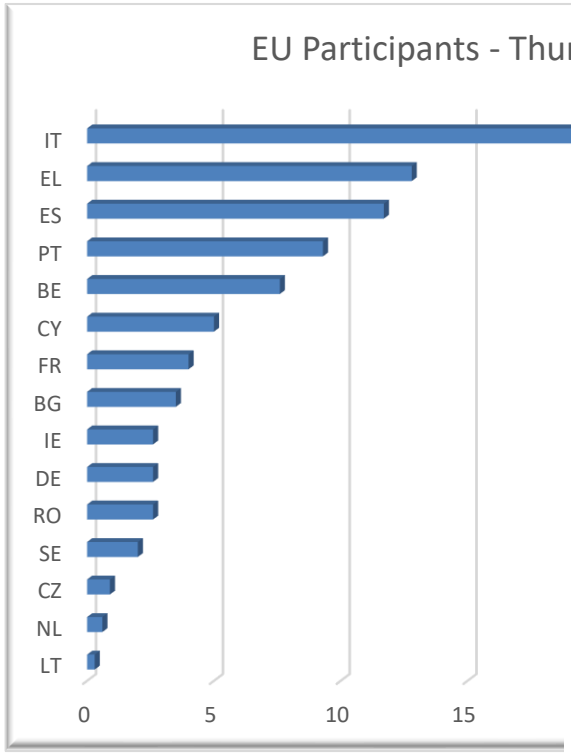
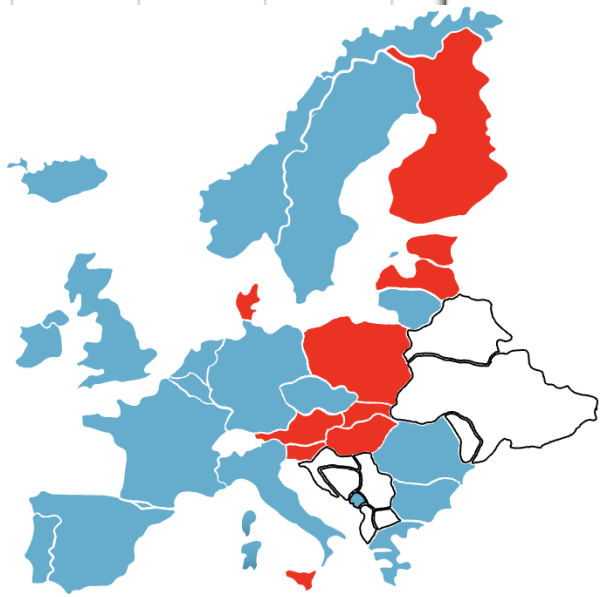
CONTINUING MEDICAL EDUCATION







How to reach health care providers in East and North EU member states?

Best practices 2017 - 2025

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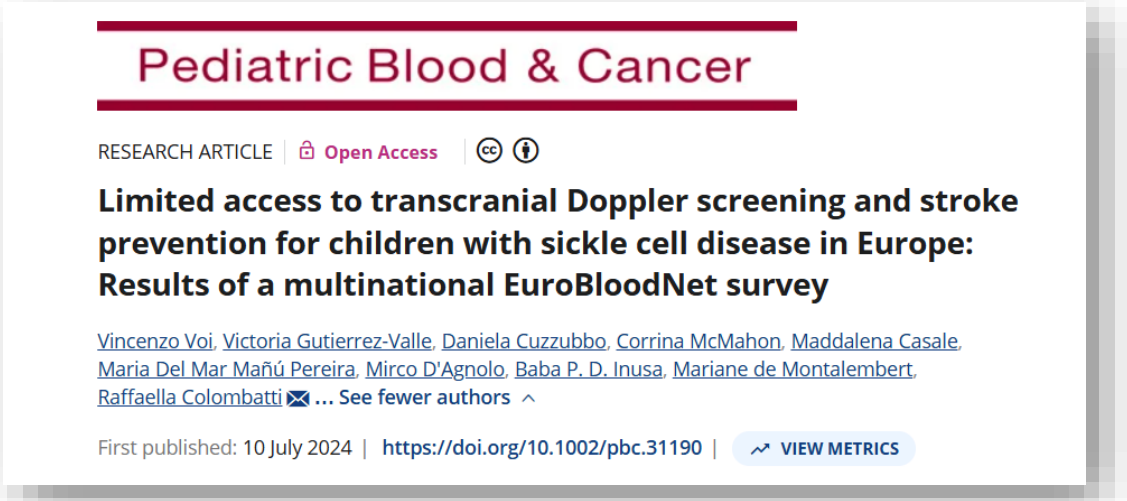
BEST PRACTICES



Pediatric Blood & Cancer

RESEARCH ARTICLE | Open Access

Limited access to transcranial Doppler screening and stroke prevention for children with sickle cell disease in Europe: Results of a multinational EuroBloodNet survey

Vincenzo Voi, Victoria Gutierrez-Valle, Daniela Cuzzubbo, Corrina McMahon, Maddalena Casale, Maria Del Mar Mañú Pereira, Mirco D'Agnolo, Baba P. D. Inusa, Mariane de Montalembert, Raffaella Colombatti ... See fewer authors

First published: 10 July 2024 | https://doi.org/10.1002/pbc.31190 | VIEW METRICS

Best practices & education 2017 - 2025

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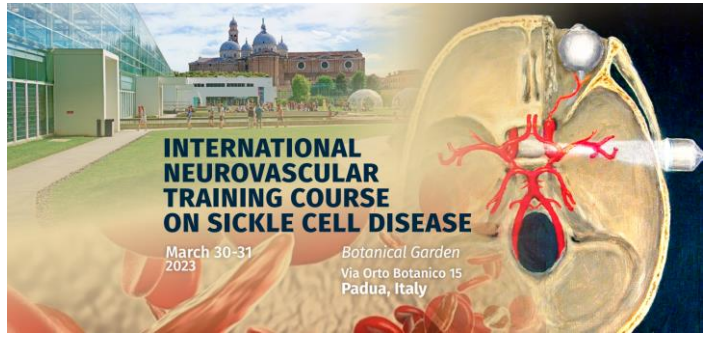
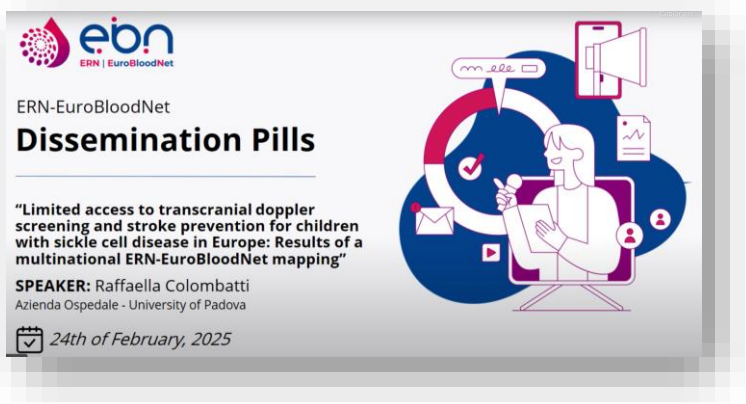
BEST PRACTICES

CONTINUING MEDICAL EDUCATION

Translate guidelines into education activities





Translate guidelines into clinical practice

Best practices 2017 - 2025

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Collaborations +++

European Reference Network for rare or low prevalence complex diseases
Network Paediatric Cancer (ERN PaedCan)

ASCAT

European Reference Networks

ERN RARE-LIVER

EBAH
European Board for Accreditation in Hematology

eha

AETSA
Evaluación de Tecnologías Sanitarias de Andalucía

EHC
european haemophilia consortium

European von Willebrand Disease Community

ISLH
INTERNATIONAL SOCIETY FOR LABORATORY HEMATOLOGY

CNR MAT
Centre National de Référence sur les Microangiopathies Thrombotiques

EAHAD

CRPP
Centre de Référence Pathologies Plaquettaires

MHEMO
La Filière des maladies rares de l'hémostase

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SESSION 1: EU ACTION PLAN FOR RARE DISEASES

PRIORITY ACTION 2: WORKFORCE DEVELOPMENT

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Educational activities Oct 2023-Dec 2025

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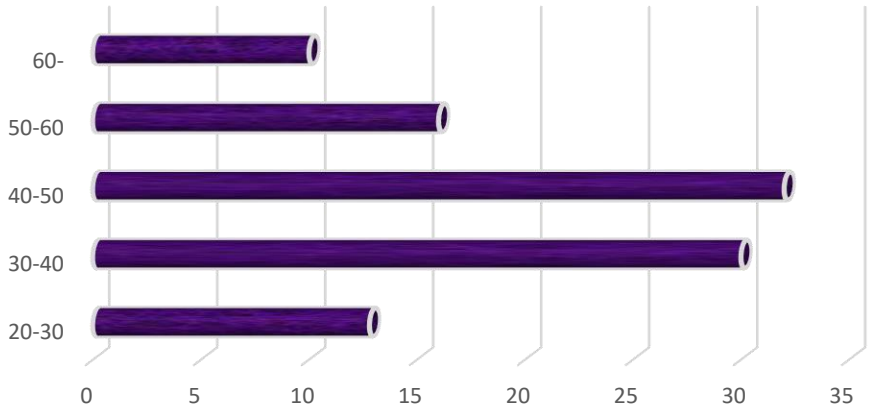
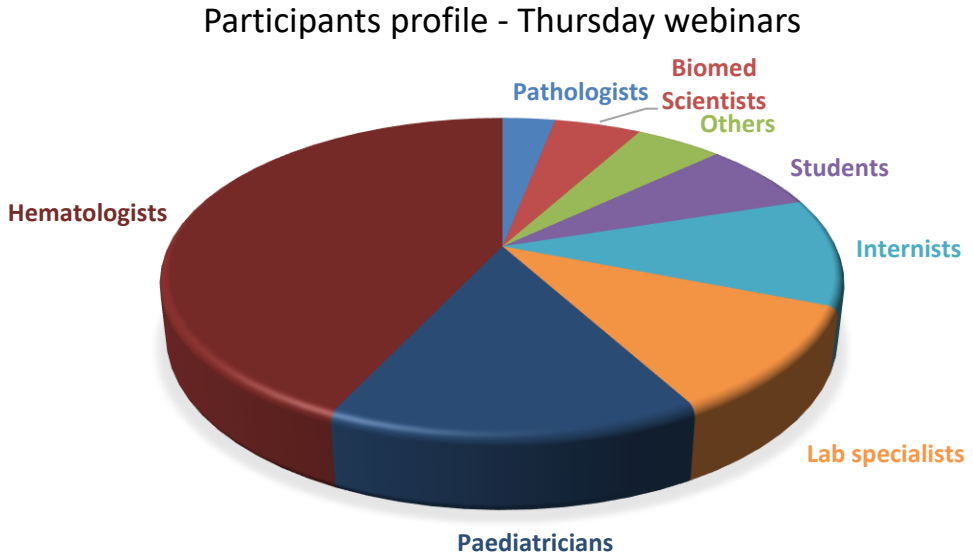
CONTINUING MEDICAL EDUCATION





How can the next generation of healthcare providers be effectively attracted and engaged?

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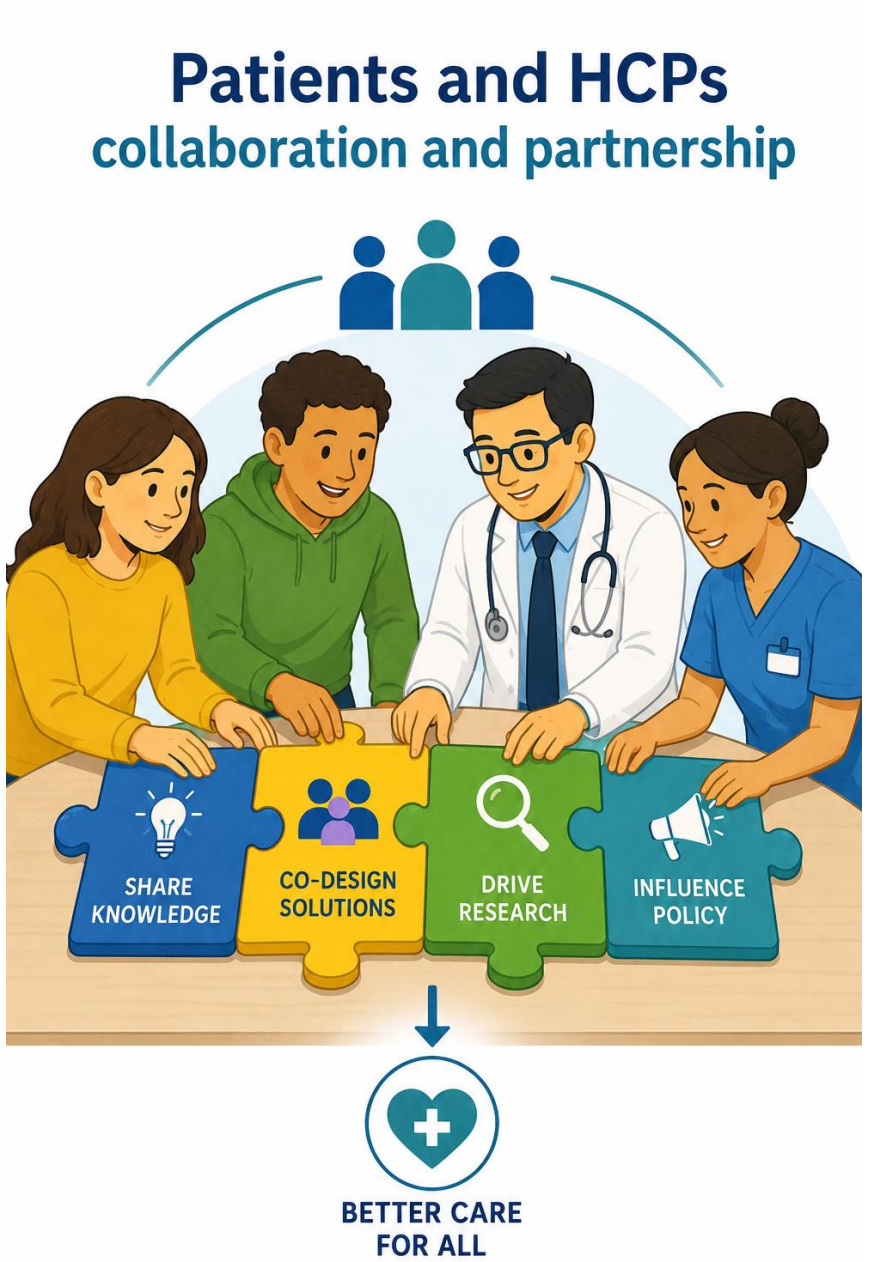

- ✓ **The future ERN Academy cannot be built only for professionals.**
- ✓ **Most successful educational initiatives are those developed *with* patients, not only *for* patients:**
  - **Patients' sessions during meetings**
  - **Regular surveys listening to the patients' perspective**

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Actions to promote more effective educational activities

- ✓ To engage GP: webinars or other resources in **local languages**; certification of attendance officially recognized as valid for Continuing Medical Education **(CME) credits**.
- ✓ A similar policy might help engage hospital doctors more widely in countries where expert centers for a given disease group are too few or absent (e.g., disorders of iron metabolism).
- ✓ Structured collaboration with other ERNs for overlapping disease groups (e.g. iron disorders and ERN-RARE-LIVER/ ERN-RND – rare neurological diseases).

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From successful projects to sustainable infrastructure

WHAT SHOULD EUROPE BUILD NEXT?

1

Formal recognition of the ERN Academy

Recognize education and training delivered within ERNs as a European standard of excellence.

2

European certification pathways for rare disease expertise

Create harmonized, transparent and portable pathways to recognize rare disease expertise across Europe.

3

Dedicated and protected funding for education and capacity building

Ensure stable, long-term investment in education and training within ERNs, linked to the MFF 2028–2034.

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Best practices & Education

Connecting expertise. Advancing knowledge. Improving lives across Europe.

How can we improve communication and engagement with general practitioners?

BEST PRACTICES

Topic on Focus: EU Health Policy for patients organizations

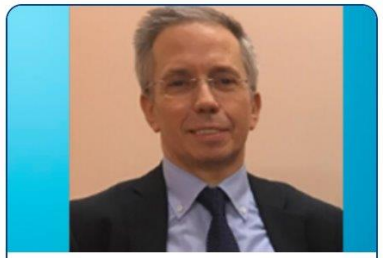
FITHAD
FONDAZIONE ITALIANA TALASSEMIA E DREPANOCITOSI
LEONARDO GIAMBRONE

European Reference Network
for rare or low prevalence complex diseases
Network Hematological Diseases (ERN EuroBloodNet)

CONTINUING MEDICAL EDUCATION

1.Spazio Europeo dei Dati Sanitari (EHDS)
→ Registri, dati dei pazienti, aspetti etico-legali della governance
Relatore: Iñigo de Miguel (esperto legale, collaboratore ERN-EuroBloodNet)
2.Regolamento sulle Sostanze di Origine Umana (SoHO)
→ Sangue, plasma, sistemi di emovigilanza, raccolta e distribuzione
Relatrice : Gabriella Peluso Cassese
3.…

ePAG

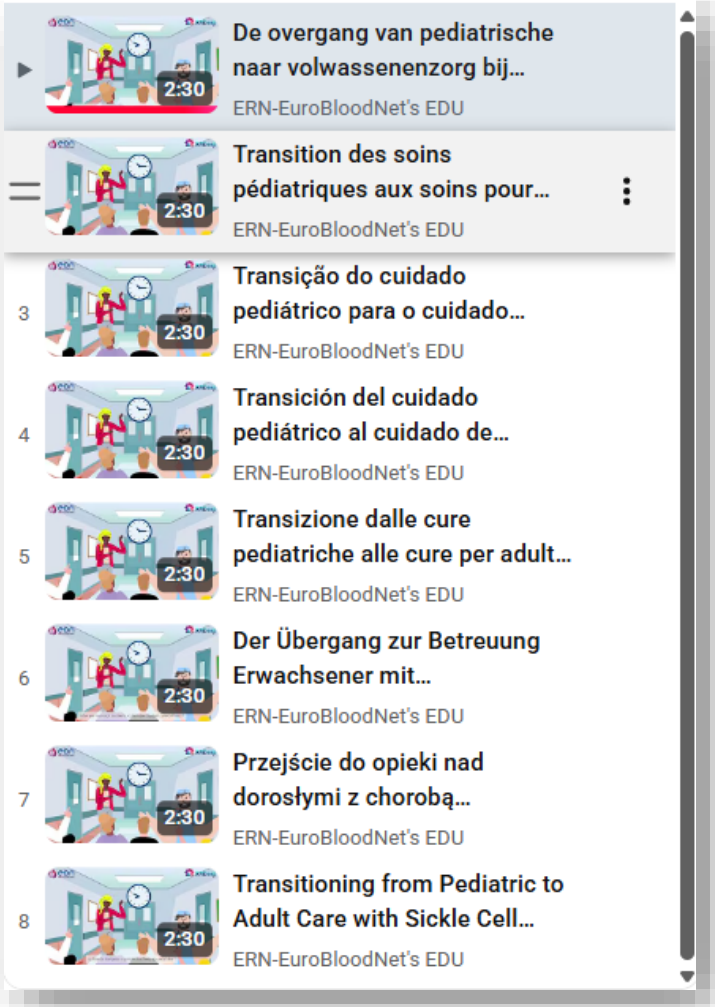


Angelo Loris Brunetta
Thalassaemia International Federation

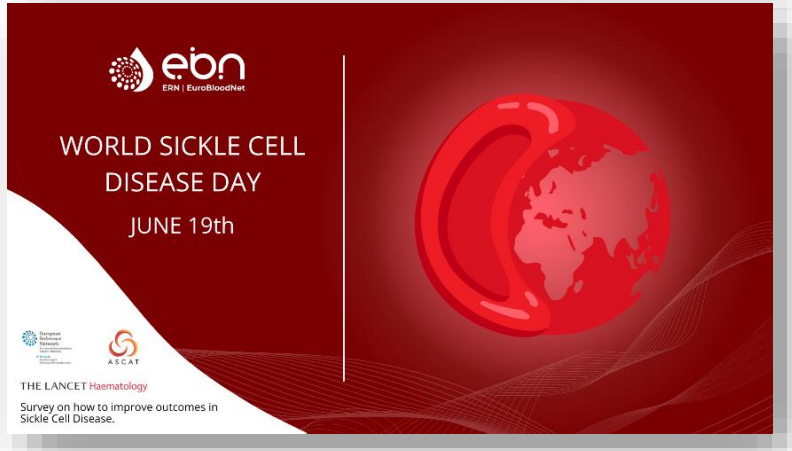
Upcoming: same webinar series in English for a wider audience

ERN-EuroBloodNet actions on SCD awareness day

Every **19 June** marks **World Sickle Cell Disease Day**, and ERN-EuroBloodNet complementary



2025. Animated video co-created with patients about transitioning from pediatric to adult care (in 8 languages)



2024. Launch of a global survey to gather the voices of people living with SCD.

2023. Poster gathering ERN-EuroBloodNet's multi-level actions in the field of Sickle Cell Disease (SCD)

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HLM 4RARE

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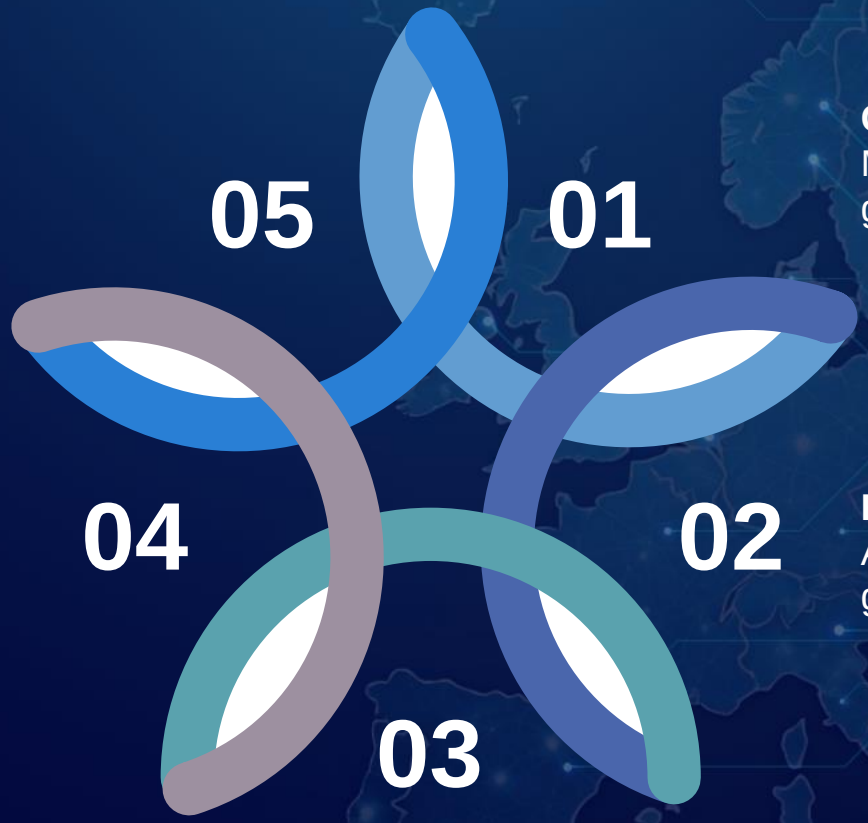
AI: TRANSFORMING RARE DISEASE EDUCATION

Adaptive learning
AI-personalized training platforms for rare disease curricula

Diagnostic decision support
DDSS reducing income losses through earlier correct diagnosis



Genomic analysis
ML/DL for variant interpretation and phenotype-genotype correlation

Facial phenothyping
AI tools analyzing facial features to suggest genetic diagnoses

NLP on Health Records
Identifying undiagnosed patients from clinical text in EHR systems

Best practices & education

Observations

- A robust infrastructure has been established.
- Education, a mechanism for translating knowledge *(best practices, research findings, and evidence-based approaches)* into practice.

Perspectives

- Reducing disparities in expertise
  - Translate existing models to all rare hematological subnetworks
  - Pursue/expand collaborations
- Tackle next generations
- Include multidisciplinary team and patients
  - Focus on language barrier and national health care pathways
- AI
  - Use modern tools for training
  - Include AI into education programmes and update of guidelines

THANK YOU!

Best practices & Education team





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