



# *Overview for ERN- EuroBloodNet actions for health professionals and patients*

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# INTEGRATION OF NEW TEAM MEMBERS FOR EDUCATION

**Christophe Goetghebuer**

**H.U.B. Hôpital Erasme –ULB, Brussels**



**ERN-EuroBloodNet Education for Health Professional and CPMS Manager**

- Organizing and coordinating webinars for health professionals
- Coordinating on-site preceptorships
- Management of the EDU Blood Academy
- Accreditations

**Hiba Aboudaya**

**Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis**



**ERN-EuroBloodNet Educational & Patients Program Manager**

- Organizing and coordinating webinars for patients and patient organisations
- Development and management of patient care pathways
- Management and implementation of advocacy plans
- Organisation of research actions centered on patient needs and support related activities



# Overview of training activities

Collaboration with  
International & European  
Scientific Societies



Health  
profess.

## Target

Health professionals: Physicians, researchers, nurses, laboratory technicians, etc.

## Kind of education

### Continuing Medical Education (CME):

- a) Not accredited
- b) Accredited by CME points issued by the **European Body of Accreditation in Haematology**

## Format online

### a) Thursday Webinars:

- One webinar promoting the interest on very innovative topics in order to stress among health professionals the cutting-edge advances in Rare Haematological Diseases (RHD)
- Addressing very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines.

### b) Topic on Focus & Spotlight with European or International Scientific Societies

- Several webinars promoting CME for Healthcare professionals on a single/group of RHD
- Case study, new treatments, implementation of guidelines, highly specialised procedures.

## Format onsite

Trainings in Health Care Providers for disseminating expertise on RHD. Mixed of theoretical lectures, case study and participating to the service consultations, or laboratory.





# Overview of training activities



## Patients

### Target

Patients, caregivers, siblings, Patients Organizations

### Kind of education

- a) Patient Therapeutic Education
- b) Patient Advocacy Training
- c) Public Patient Involvement in Research

### Format online

- **Patient Webinar:**
  - One webinar providing patients' community with highly specialized knowledge on a specific RHD or groups of disease
- **Topic on Focus & ERN Research Education Initiative**
  - Several webinars promoting Patient Therapeutic Education and wider awareness on a single/group of RHD
  - Quality of life and well being

### Format onsite

- a) Training and/or workshops on Patient Therapeutic Education
- b) Patient Advocacy Training
- c) Public Patient Involvement in Research

## Integrating ERN Research into Education





## Accredited training courses and training curricula - 2025

- **16 accredited trainings courses:** 16 total activities, comprising: 3 sessions on VWD (1 EBAH credit each), 2 sessions on IPFD (1 EBAH credit each), 2 sessions on BMF (1 EBAH credit each), 9 sessions on Thursdays Webinars (1 EBAH credit each)
- **401 trainees:** from them 27 people have received or are eligible for the EBAH CME credit.
- **57 countries of trainees who completed accredited training courses:** 23 EU MS, 1 Norway, 1 UK, 1 Switzerland & 30 non-EU Countries

European Board for Accreditation  
in Hematology (EBAH) → CME  
Credits







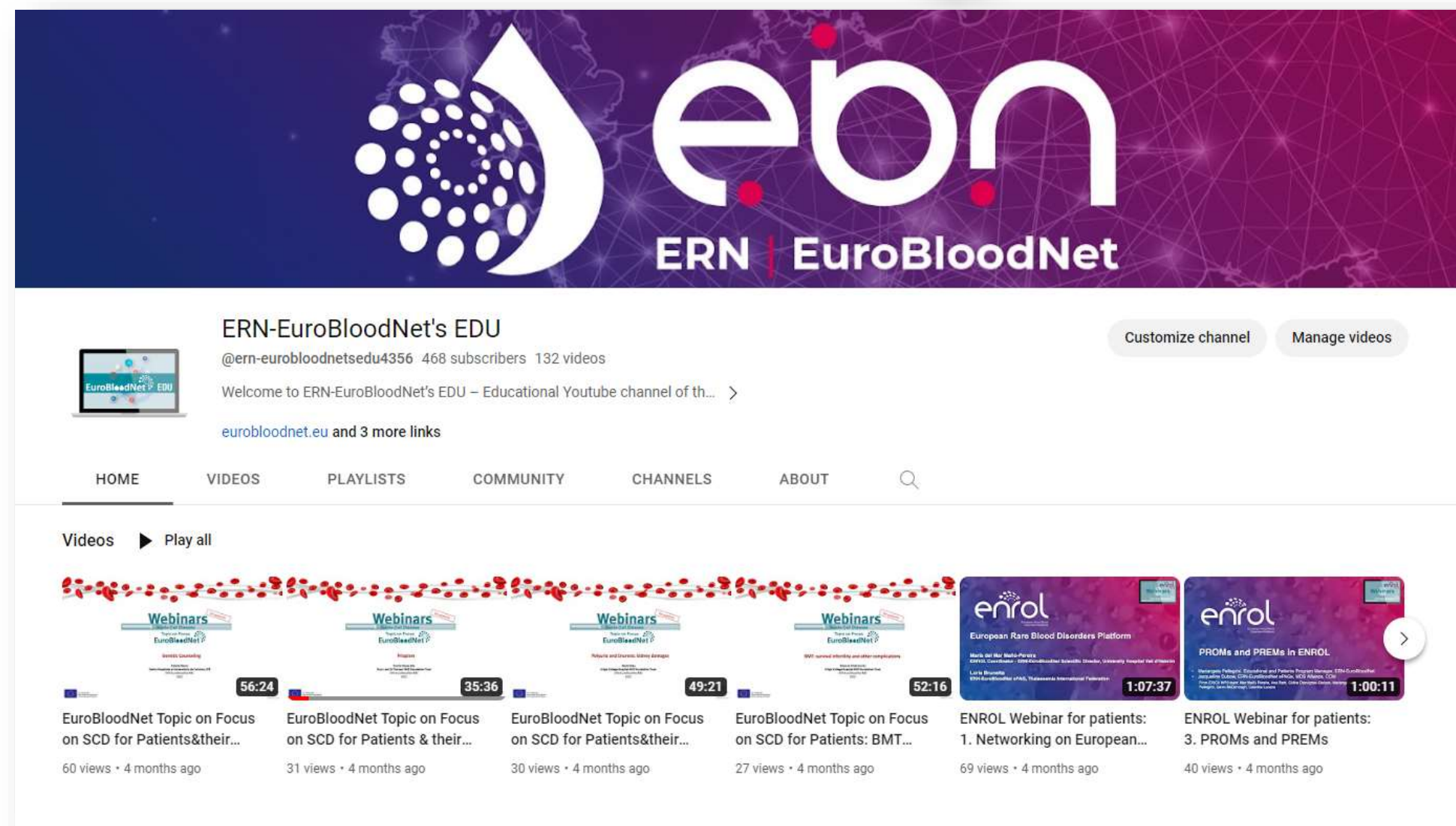
## Non-accredited training courses and activities - 2025

- 134 non-accredited courses comprising: 134 coordinated by the ERN-EuroBloodNet comprising: 3 webinars for patients and 3 for Health Professionals; 128 videos comprising: 16 videos published for Health Professionals, 3 for both and 109 for patients.
- 703 trainees considering 6 webinars.
- 74 countries of trainees who completed training courses and activities: 23 EU MS, 1 Norway, 1 UK, 1 Switzerland and 48 non-EU countries.

# Recalling the model of the ERN-EuroBloodNet for Online Education:



- **Online live program:** speaker presentation & interaction with the audience
- **Recorded videos** implemented on the e-learning platforms (website, Youtube) with the PDF of the PPT presentation
- **Worldwide free open access** both for live sessions (after registration) & recorded videos
- **Dissemination** plan via mailing list, scientific society and social media
- **AI tool for interactive interpretation** of the lecture into national languages



# Great news!

OUR EDUCATIONAL WEBINARS  
ARE EMPOWERED WITH AI  
**TRANSLATED CAPTIONS** VIA  
ZOOM, MAKING LEARNING  
MORE ACCESSIBLE WORLDWIDE.

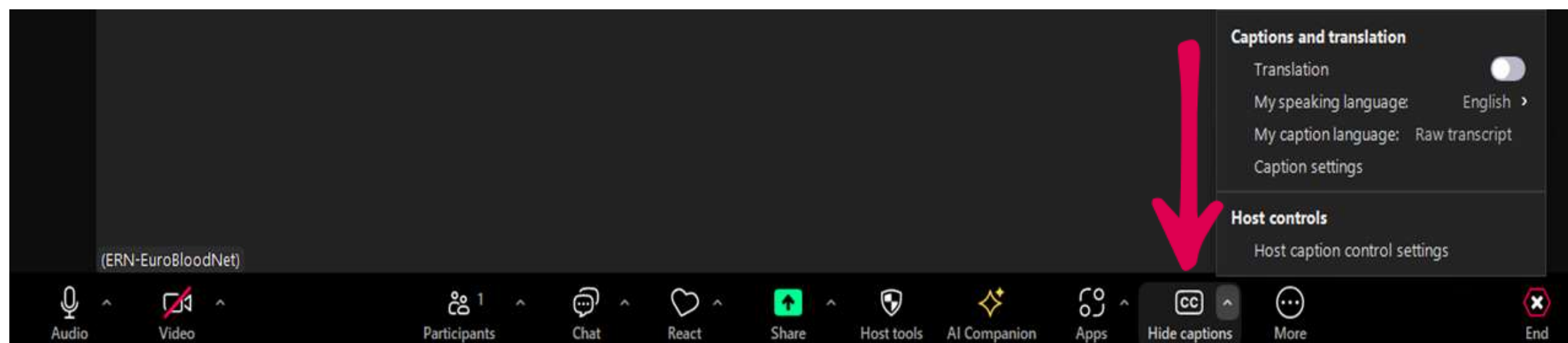
AVAILABLE IN OVER  
36 LANGUAGES!



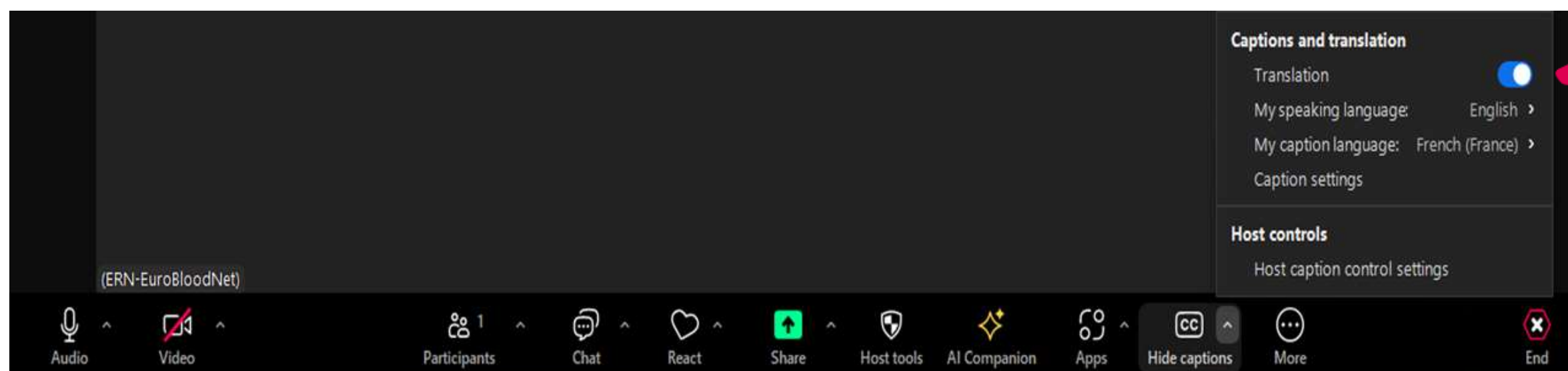


# How to turn on Zoom AI Translated Captions?

1. Click on the 'Show Captions' or 'CC (Closed Caption)' button in the Zoom toolbar at the bottom (right hand side) of your screen.



2. Click the small arrow next to 'CC' to turn on Translation. Next, select your speaking language (English) as well as your caption language.



# HCPs focus





## Health professionals - focus

Thursday webinars  
are now accredited!

Create your profile  
on EBAH portal



This program is accredited by the **European Board of Accreditation in Hematology (EBAH)**, allowing participants to earn **1 Continuing Medical Education (CME)** points when they take part in each online webinar.

Don't have an EBAH account yet? Create one now to ensure your accreditation credits are properly assigned!



# ERN-EuroBloodNet Topic on Focus: Inherited Platelet Function Disorders



**CRPP**  
Centre de Référence  
Pathologies Plaquettaires

**MHEMO**  
La Filière des maladies rares de l'hémostase

- **Session 1: Mechanisms of platelet activation**, Speaker: Loredana Bury, 24 Septembre 2025
- **Session 2: Platelet aggregation - investigating a suspected platelet function disorder**, Speaker: José Rivera, 12 November 2025
- **Session 3: When to suspect an inherited platelet function disorder - differential diagnoses**, Speaker: Paolo Gresele, Date: 17 December 2025
- **Session 4: Flow cytometry for IPFD - advantages and limits**, Speaker: Sofia Ramstrom, Date: 21 January 2026
- **Session 5: Genetic testing for IPFD - Advantage, limitations and future perspectives of for platelet dysfunction**, Speaker: Kathleen Freson, Date: 11 February 2026
- **Session 6: Inherited thrombocytopenias associated with platelet dysfunction - NBEAL2 and others**, Speaker: Agnès Ribes, 18 March 2026 (TBC)
- **Session 7: Diagnostic and management of dense granule deficiency including Hermansky-Pudlak syndrome**, Speaker: Manal Ibrahim, 8 April 2026
- **Session 8: Pediatric-specific aspects and transition of care in inherited platelet function disorders**, Speaker: Céline Falaise: 13 May 2026
- **Session 9: Glanzmann thrombasthenia - general aspects of diagnosis and follow-up**, Speaker: Mathieu Fiore, 24 June 2026
- **Session 10: Glanzmann thrombasthenia - general aspects of treatment (platelet transfusion, rFVIIa, innovative therapies, HSCT)**, Speaker: Suthesh Sivapalaratnam, 16 September 2026
- **Session 11: Women with Glanzmann thrombasthenia - management of abnormal uterine bleeding and pregnancy (maternal and fetal aspects)**, Speaker: Roseline d'Oiron, 14 Octobre 2026
- **Session 12: Glanzmann thrombasthenia - management of gastrointestinal bleeding**, Speaker: Paolo Gresele, 18 Novembre 2026
- **Session 13: Glanzmann thrombasthenia - surgery and invasive procedures**, Speaker: Roger Schutgens, 16 Decembre 2026





Webinars for Health Professionals

## ERN-EuroBloodNet Preceptorships in Aplastic Anemia



**Coordination**  
**Prof. Carlo**  
**Dufour**

Preceptorship 1 - Aplastic Anemia in children and adolescents at the IRCCS Istituto Giannina Gaslini, Genoa, Italy.



**Coordination**  
**Prof. Régis Peffault de**  
**la Tour**

Preceptorship 2 - Acquired and Inherited Aplastic Anemia in pediatric and adult at the Assistance Publique Hôpitaux de Paris, Hôpital Saint Louis, Paris



**Coordination**  
**Prof. Jens**  
**Panse**

Preceptorship 3 - Bone marrow failure syndromes (BMFS) with a focus on aplastic anemia in adults and pediatrics at the University Hospital RWTH Aachen

- 3 webinars in collaboration with ISLH on Rare constitutional coagulation factor bleeding disorders

# EHA & ERN-EuroBloodNet Spotlight on Rare Hematological Diseases

**2022**

*Castleman Disease*

Prof Eric Oksenhendler France

Prof Kai Hübel Germany

Prof Simone Ferrero Italy

Mark Bower United Kingdom

David Boutboul France

Elena Sabatini Italy

>100 live participants

**2024**

*Hypereosinophilic Syndrome*

Prof Massimo Breccia Italy

Prof Florence Roufosse Belgium

>300 live participants

**2025**

*BMF Syndromes*

**Prof. Régis Peffault de Latour,**  
France

**Prof Achille Iolascon,** Italy

**Prof Carlo Dufour,** Italy

**Prof Thierry Leblanc,** France

**Prof Lidye Da Costa,** France

**Prof Prof. Roberta Russo,** Italy

**Prof. Kathleen Freson,** Belgium

**Dr. Erika Massaccesi,** Italy

**> 125 live participants**



## Focus education HCPs: upcoming

- **Next Thursday webinars**
- **EHA & ERN-EuroBloodNet  
Spotlight on Hemophilia**

- **Preceptorship for AA**
- **Hosting UA Hematologists**



# Patients focus





# New strategy for patients Education

- **Integrate Education with Research** : Equip patients with evidence-based information, the latest research findings, and cutting-edge tools to support informed decision-making and enhance their care experience.



Trainings for SCD patients at ASCAT



- **ENROL webinars**
  - 3 webinars & 3 videos
- **16 videos on ENROL Registries and PROMs available in 8 languages**



- **Genomed4all 1st wave**
  - 4 webinars & 4 video
- **Genomed4all 2nd wave**
  - 6 webinars & 6 videos



7 webinars focusing Gene Therapy for SCD patient



How to read a scientific paper in Hemoglobinopathies



Work in progress



# Patients Actions in collaboration with International stakeholders

## Best Practices – CDSTs for patients



- Development of Patient Journey in vWD



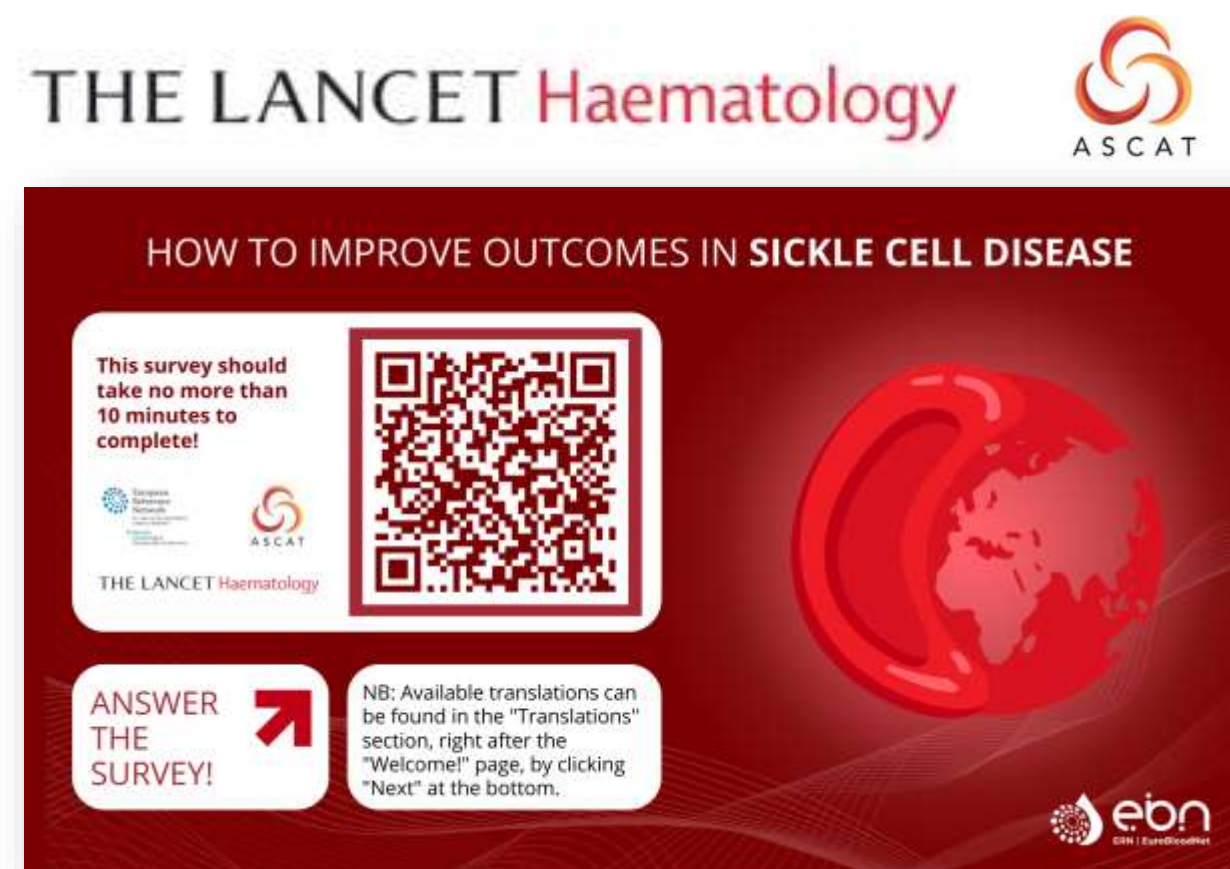
- Development of Patient Version of Guidelines in Burkitt Lymphoma



- Development of the Charter for optimal care transition between paediatric and adult care in sickle cell diseases

## Shaping Patient Driven Global strategy in Public Health

- Global survey assessing the perspectives of people living with SCD on how to improve outcomes in SCD







## ERN-EuroBloodNet & RADeep at ASCAT – Past Editions

2019

### LONDON

- Research Prioritization Workshop: Top 10 SCD Patient Priorities

2020

### ONLINE

- Coping with COVID-19 as an SCD patient
- Patients' role in research & peer reviewing
- Meet-the-experts & patient panel discussions

2021

### ONLINE

- Racism in healthcare
- Mental health
- Pregnancy & SCD
- Bone marrow transplant

2022

### HYBRID - LONDON

- Tips for transition
- Aging well
- Embryonal selection, Prenatal Diagnosis & Preimplantation
- Patient-doctor dynamics & assertiveness training
- Understanding PROMs
- Spreading ERN-EuroBloodNet insights nationally (patient testimony)

2023

### HYBRID - LONDON

- Focus on Transition: Discrepancies in disease perception Adult patients mentoring teenagers
- Global SCD strategy with the Lancet Commission
- AI applications in SCD
- Patient-doctor dynamics through role-playing

2024

### LONDON

- Adult SCD patients mentoring teenagers
- Parent-teen communication for autonomy (PROMs)
- Patient storytelling on transition across cultures

## Sickle cell disease: embedding patient participation into an international conference can transform the role of lived experience

[Mariangela Pellegrini](#) , [Subarna Chakravorty](#), [Maria del Mar Manu Pereira](#), [Beatrice Gulbis](#), [Catriona Gilmour-Hamilton](#), [Sandy Hayes](#), [Mariane de Montalembert](#), [Baba Psalm Duniya Inusa](#), [Raffaella Colombatti](#) & [Noémi BA Roy](#)

*Orphanet Journal of Rare Diseases* **18**, Article number: 341 (2023) | [Cite this article](#)

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Hematological Diseases  
(ERN EuroBloodNet)



Hematological  
Diseases (ERN EuroBloodNet)




Funded by  
the European Union

# Sickle Cell Disease



 Orphanet Journal of Rare Diseases

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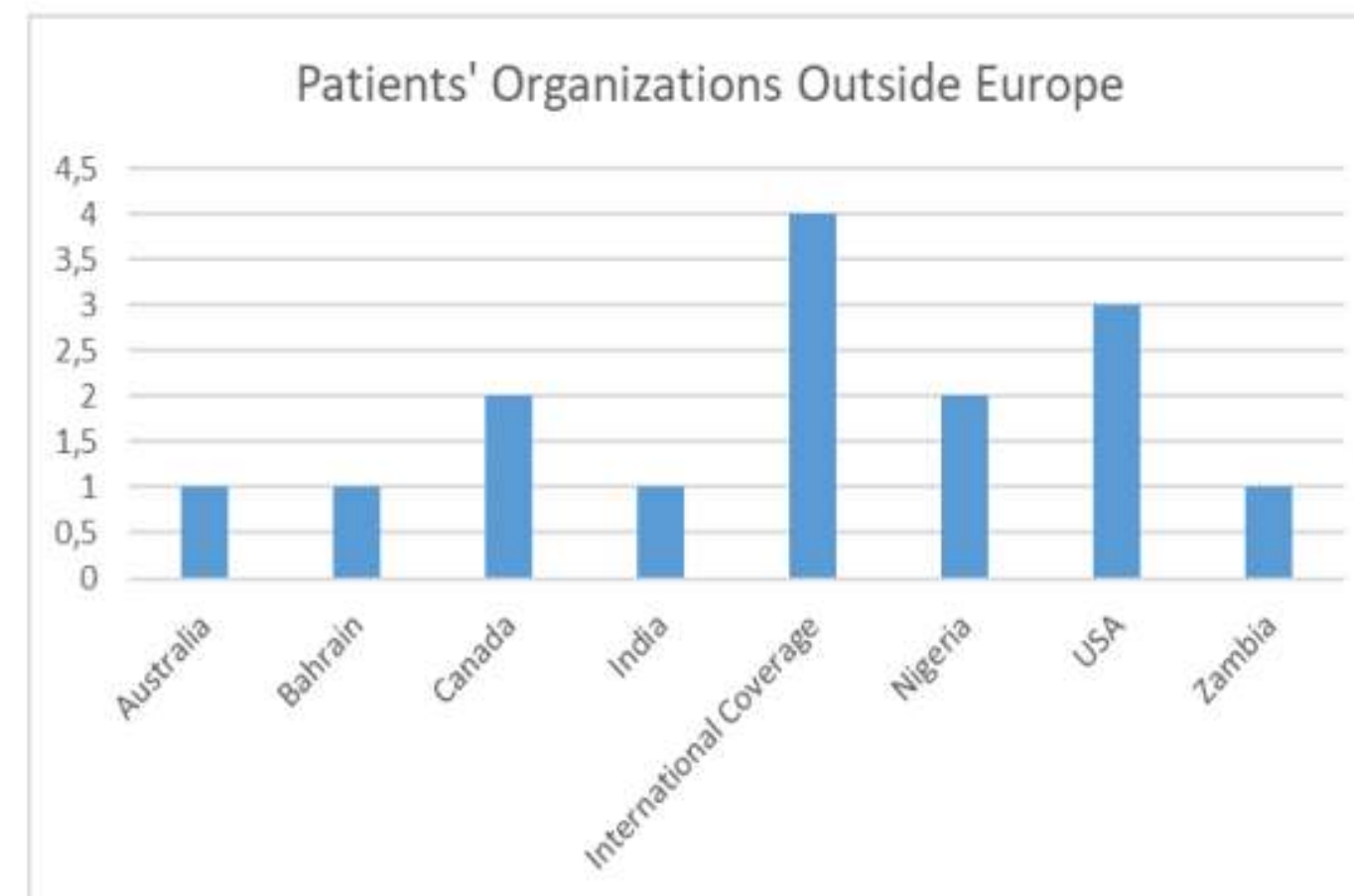
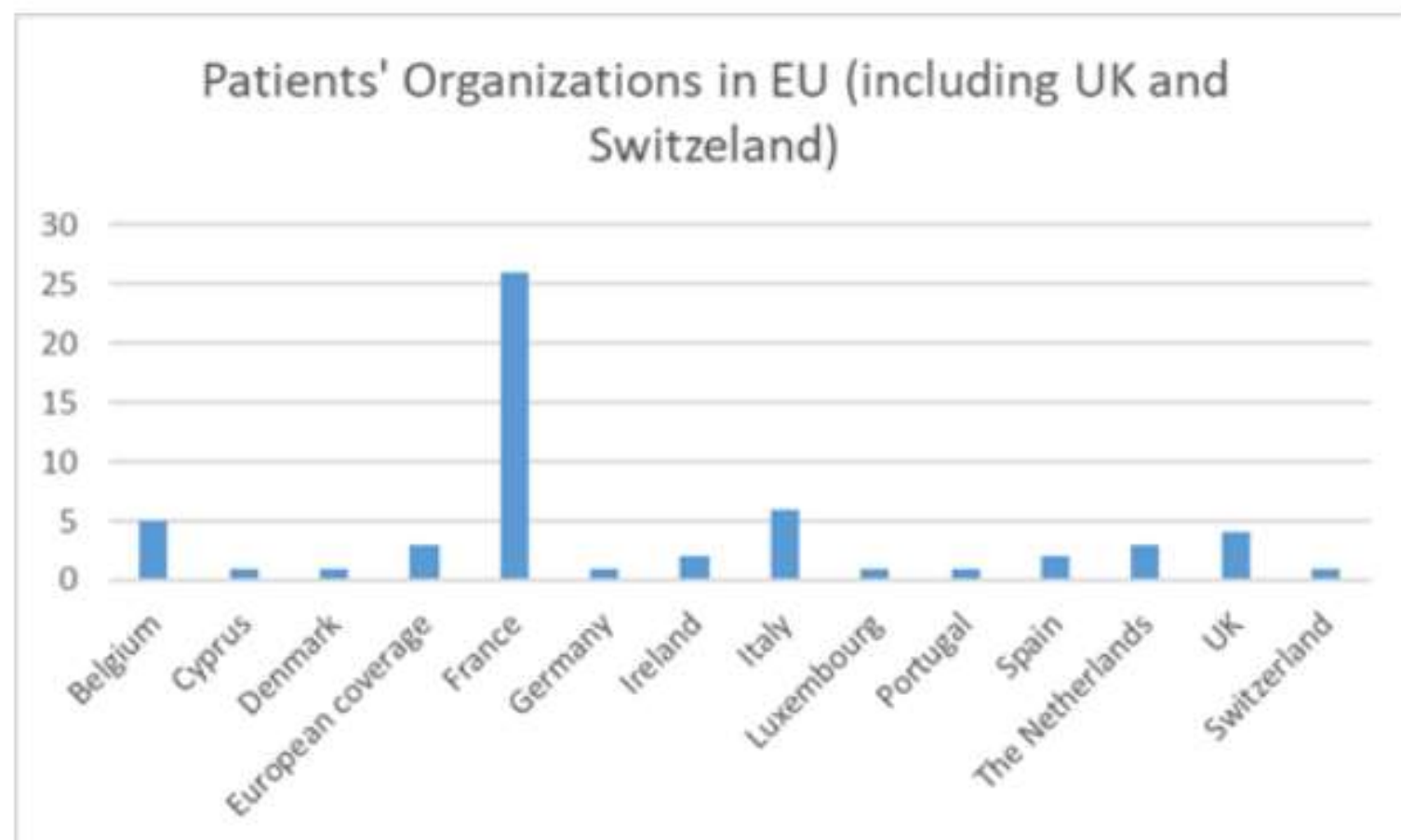
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- Part of a bigger capacity building project: facilitating the establishment of a bottom-up patient driven EU Network
- Patient education is integrated at the core of the scientific congress.
- Patient groups from at least 10 different countries participate.
- Patient groups contribute to the selection of the topic and co-design the activity.
- An international key expert, a member of ERN-EuroBloodNet, contributes to the educational session.
- Patient groups present the results of the training in front of the plenary session of ASCAT.





## ERN-EuroBloodNet & RADeep patients organization capacity building



**The ERN-EuroBloodNet** maintains in 2025 in total a contact network of 72 patients' organizations covering SCD across European Union and beyond.



# ASCAT 2025 Sexual health

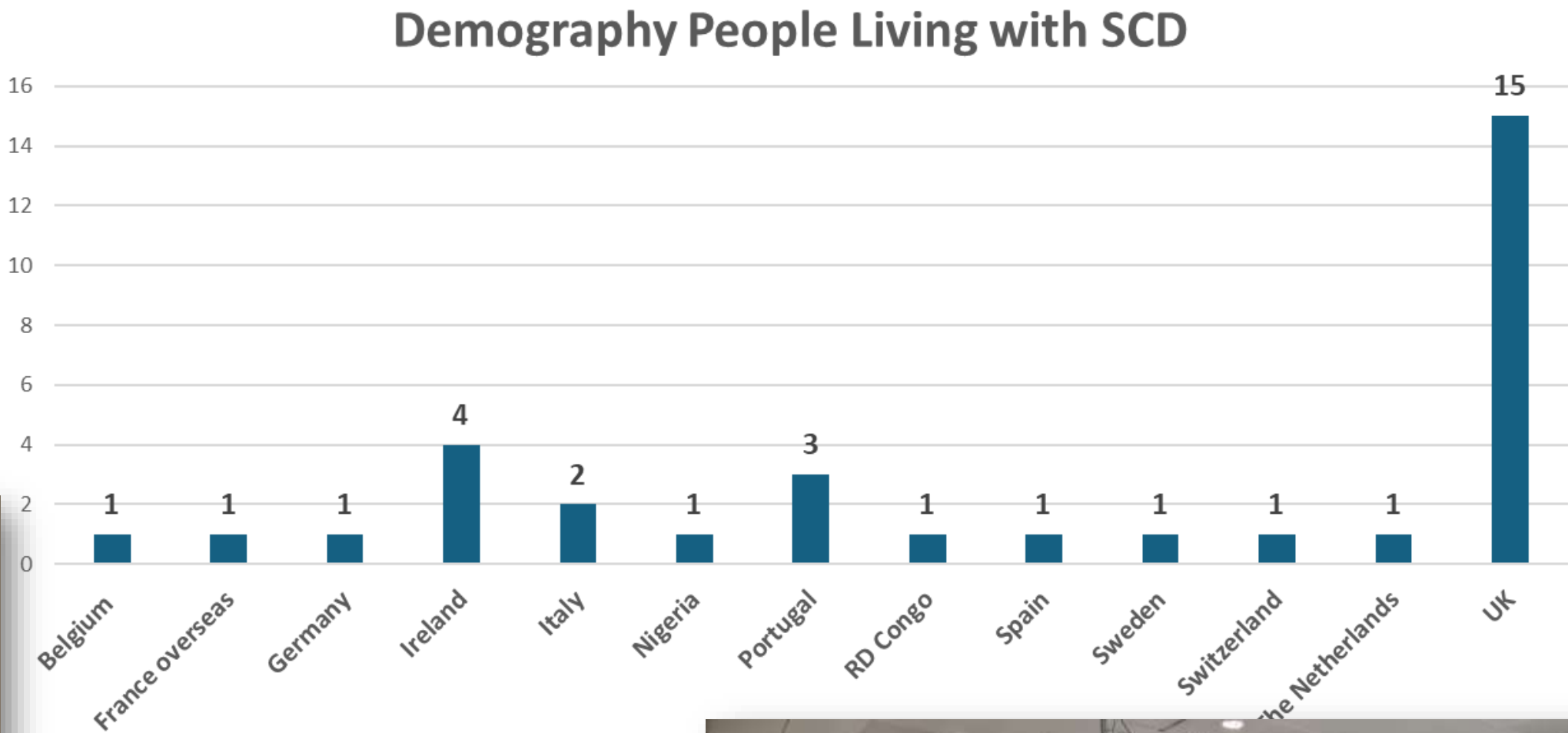
Day 1: Medical & General Aspects

Day 2: Gender-Specific Sessions

Day 3: Practical Approaches & Advocacy







The Teaching Faculty

Belgium	Haematologist
France	Obstetrician
Italy	Internist
Italy	Haematologist
Spain	Psychologist
UK	Psychologist







# Short animated videos on Transition for SCD



Transição do cuidado pediátrico para o cuidado adulto na doença...

75 views • 3 months ago



Transición del cuidado pediátrico al cuidado de adultos con...

42 views • 3 months ago



Transizione dalle cure pediatriche alle cure per adulti con la malattia...

45 views • 3 months ago



Der Übergang zur Betreuung Erwachsener mit...

46 views • 3 months ago



Cosa sono i PROMs e PREMs?  
Come possono essere collegati ai...

69 views • 1 year ago



Qué son los PROMs y PREMs? se pueden conectar a los Registros...

182 views • 1 year ago



Que sont les PROM et PREM?  
Peuvent-ils être connectés aux...

32 views • 1 year ago



Was sind PROMs und PREMs? Wie können sie als ENROL mit...

85 views • 1 year ago





## EU Policy for POs



**FITHAD**  
FONDAZIONE ITALIANA TALASSEMIA E DREPANOCITOSI  
LEONARDO GIAMBRONE



### EU Health Policy

This program is designed to empower patient organisations across Italy (Italian) and Europe (English) with a comprehensive understanding of the key **European health policies** currently under development or recently adopted.

### Struttura

#### 1. Spazio

→ Regis

Relatore: M

TO EVALUATE PRO  
AND CONS FOR  
PROGRAM IN  
NATIONAL  
LANGUAGES

governance

atore ERN-EuroBloodNet)

#### 2. Regolamento S (SoHO)

→ Sangue, plasma, sistemi di sorveglianza, raccolta e distribuzione

Relatrice (da confermare): to be confirmed

#### 3. Nuova Legislazione Farmaceutica Europea

→ Processo di approvazione, accesso equo, incentivi, terapie avanzate

Relatore (da confermare): to be confirmed

#### 4. Valutazione delle Tecnologie Sanitarie (HTA)

→ Prezzi e rimborso dei farmaci dopo l'autorizzazione dell'EC

Relatrice (da confermare): to be confirmed

**EDITSCD: how to explain  
gene therapy research  
to patients**

**A SOLID METHOD FOR  
DEVELOPPING THE  
PROGRAM**

It will be  
explained by  
Annarita  
Miccio in the  
next speech





## Focus education patients: upcoming



Ioana Todorova-Yanakieva

Bulgarian TTP Patient organization

**Topic on Focus on TTP**



Angelo Loris Brunetta

Thalassaemia International Federation

**Topic on Focus EU policy English**





**Topic on Focus on the use of  
synthetic data in Hematology**

**For mixed audience: experts and  
public at large**



## Future outlooks

- Potential for the future :

- Joint preceptorships with other ERNs to promote cross-disciplinary learning.
- Partnerships with medical societies, patient organizations, and academic institutions

- Big Dream:

- Becoming a CME Provider
- Recognition as a **European reference model** for specialist trainings

- Potential game-changers:

- Creation of a preceptorship alumni network to foster long-term collaboration and peer learning
- Integration with career development pathways within EuroBloodNet and ERNsA dedicated digital platform to manage applications, learning materials, and follow-up tracking

# Thank you!

