ERN | EuroBloodNet

ePAGS bi-annual meeting

EHA 2026 - Stockholm
12 June 2026

Agenda

- ToR Update on the signature
- Some relevant actions with ePAGs
- Upcoming actions (education and patient versions of guidelines)
- Update on the HLM by Mar
- Engagement of ePAGs in ERN Scientific & strategic Committee
- Free debate

ToR Update on the signature

Missing ePAGs:

•**Jan Geissler (Leukemia Patient Advocates Foundation):** Jan is no longer active in the role and has decided to step down from his position. In line with the ToR, he is required to identify a new ePAG representative to succeed him and complete the replacement process according to the established ToR procedure.

•**Ananda Plate (Myeloma Patients Europe):** Ananda has not been active for over a year and has now been replaced by Monica, who will sign the ToR on behalf of Myeloma Patients Europe.

MPE ePAGs representation update

- PhD in Global Social Sciences from Doshisha University, Japan
- Comes from Romania and currently resides in UK
- Worked on science and health policy issues in academia, international development or consultancy in Italy, Austria and the UK.
- Access and Policy Manager at MPE

Educational activities: patients

- **Session 1: Strong at Any Age - Redefining Frailty Together**
  - Date: 22 January 2026
  - Speakers: Dr William McKeown (EHC Steering Committee, Queen's University Belfast, UK) and Prof Susie Shapiro (Oxford University Hospital, UK).
- **Session 2: Von Willebrand factor and von Willebrand Disease in ageing: mechanisms, evolving phenotypes, and clinical implications**
  - Date: 09 March 2026
  - Speakers: Prof Flora Peyvandi (Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan, Italy) and Cathy Verbraeken (EHC VWD Committee)
- **Session 3: Bleeding Disorders and Ageing - Shall I bleed less with age?**
  - Date : 27 April 2026
  - Speakers : Prof Yesim Dargaud (Hôpital cardiologique Louis-Pradel de Lyon, France), Prof Sophie Susen (CHU de Lille, France) and Dr William McKeown (EHC Steering Committee, Queen's University Belfast, UK).
- **Session 4: Cardiovascular Issues and other comorbidities**
  - Date: 18 May 2026
  - Speakers: Prof Roger Schutgens (University Medical Center Utrecht, Germany), Prof Bruna Gigante (Karolinska University Hospital, Stockholm, Sweden) and Prof Alison Dougall (Dublin Dental University Hospital, Ireland).

Manuscript prepared for submission

Co-branded with ERN GUARD Heart

Ongoing activities patients

Topic on Focus: EU Health Policy for patients organizations

Angelo Loris Brunetta

Thalassaemia International Federation

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.Valutazione delle Tecnologie Sanitarie (HTA)
→ Prezzi e rimborso dei farmaci dopo l'autorizzazione dell'EC
Relatrice : Anna Ponzianelli
4.Nuova Legislazione Farmaceutica Europea
→ Processo di approvazione, accesso equo, incentivi, terapie avanzate
Relatore (da confermare): **to be confirmed**

Upcoming: Repeating same webinar series in English for a wider audience

Upcoming activities for patients - Autumn 2026

EDU | BloodAcademy

Topic on Focus: TTP

Online comprehensive educational program on Thrombotic Thrombocytopenic Purpura (TTP) for Patients.

(Information coming soon)

Ioana Todorova-Yanakieva

Bulgarian TTP Patient organization

Two other educational webinars for patients:

- Webinar for patients on VWD in Collaboration with EHC on September 10th: **Updated global prevalence and ethnic diversity of von Willebrand disease based on population genetics analysis.**
- Webinar on MaTCL for patients (Imune T- ME project experts) in 2027

Program coordinators: Flora Peyvandi and Paul Coppo
ePAG: Ioana Tadarova
7 modules: 1 module/ month starting October 2026 until April 2027

Designing Patient-Centered Care

Patient Journeys from Educational Programs, pilot of von Willebrand Disease

Patient Versions of Guidelines, pilot of Burkitt Lymphoma

Patient Journeys

- A visual or narrative tool that maps the typical steps a patient takes through a disease: from first symptoms to diagnosis, treatment, daily management, and long-term care
- Includes clinical, emotional, and social experiences
- Developed with patients, caregivers, and clinicians, highlighting needs, barriers, and goals

Patient Versions of Guidelines

- A simplified, accessible version of evidence-based clinical guidelines
- Written for patients, not for doctors
- Explains e.g.: What care to expect, which options exist
- Always aligned with official recommendations
- Ideally, it should be developed with patients, but this is not yet standard practice. Within the ERN, however, it has been developed in collaboration with patients.

Preparation: A Patient Journey Built *from* Educational Program

1. The educational program was designed following the structure of a patient journey, all critical health stages for vWD

2. Each webinar tackled a specific stage, identified through collaborative work with: Patient support groups (to reflect lived experiences and needs) Expert health professionals (to align with clinical pathways and guidelines)

Outcome:

The program naturally evolved into a structured patient journey,
with learning objectives and take-home messages mirroring real-life care phases

ERN-EuroBloodNet Topic on Focus: von ...

by ERN-EuroBloodNet's EDU

Playlist · Public · 13 videos · 26 views

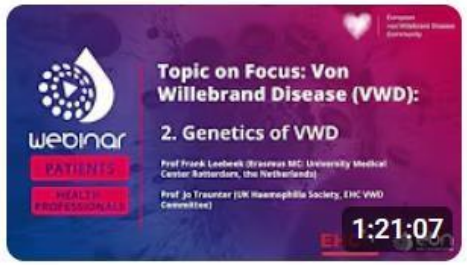
ERN-EuroBloodNet "Topic on Focus: von Willebrand Disease (VWD) for patient organizations and healt ...more

Play all

Sort | All | Videos | Shorts

ERN-EuroBloodNet Topic on Focus on VWD - VWD is not hemophilia

ERN-EuroBloodNet's EDU • 93 views • 4 months ago



ERN-EuroBloodNet Topic on Focus on VWD - Genetics of VWD

ERN-EuroBloodNet's EDU • 77 views • 4 months ago

ERN-EuroBloodNet Topic on Focus on VWD - Type doesn't define...

ERN-EuroBloodNet's EDU • 121 views • 4 months ago

ERN-EuroBloodNet Topic on Focus on VWD - People with VWD ble...

ERN-EuroBloodNet's EDU • 92 views • 4 months ago

Phases 1 & 2: Mapping and Structure

1. Extract "take-home messages" from each webinar
2. Generate and cluster key concepts by disease stage: *Awareness, Diagnosis, Psychosocial Adaptation, Daily Management, Female Life Stages, Emergency, Ageing*
3. Tag each concept by:Type (clinical, psychosocial, etc.), *Target population, Stakeholders involved*
4. Steering Commitee validated the journey
5. Final format (video, flyer, interactive map…)

Key aspect:

- ✓ Validation of clusters/tags by session speakers (experts via ERN + patients via EHC)
- ✓ Literature review planned for benchmarking with other chronic diseases
- ✓ ERNs expert centers and National Patients Organisations focusing on vWD will be added in the journey

Patient Versions of Guidelines

Pilot of Burkitt Lymphoma

Diagnosis and treatment of Burkitt lymphoma in adults: clinical practice guidelines from ERN-EuroBloodNet

Vincent Ribrag, MD [a,b] · Prof Dominique Bron, MD, PhD [c] · Grzegorz Rymkiewicz, MD, PhD [d] · Prof Dieter Hoelzer, MD, PhD [f] · Judit Jørgensen, MD [g] · Aythami de Armas-Castellano, BS [h] · Maria Trujillo-Martín, PhD [h,i] · Prof Pierre Fenaux, MD, PhD [j,k] · Prof Luca Malcovati, MD, PhD [l,m] · Natacha Bolaños [n] · Prof Josep-Maria Ribera, MD, PhD [o] · Prof Charles Herbaux, MD, PhD [p] · Clémentine Sarkozy, MD, PhD [q] · Prof Pier Luigi Zinzani, MD, PhD [r] · Prof Jan Walewski, MD, PhD [e] · Prof Martine E D Chamuleau, MD [s] Show less

LYMPHOMA COALITION

Collaborative Planning & Patient-Centered Drafting

Steering Commitee: From guideline authors identify 4 health professionals, Patient advocates

Lived Experience Council: Identify patients with Burkitt Lymphoma Ensuring EU geographical representation

Begin Co-Creation Process

- Identify key patient-relevant recommendations
- Simplify complex content; use plain language
- Consider FAQ/narrative style, short paragraphs, bullets
- Conduct feedback sessions with patient advocates

Validation, Accessibility & Sustainable Impact

Validate the Draft

- Clinical accuracy check
- Readability & relevance reviewed by patient advocates
- Optional: testing with external patient group

Ensure Accessibility

- Visual aids, icons, accessible fonts
- Screen reader compatibility, translations
- Decide the format & translate the document in different languages

Dissemination Strategy

- Share via websites, clinics, social media, patient organisations
- Include a link to the full clinical guideline
- For booster CBH: Include a list of expert centers in Europe via ERN, and a list of Patients organisations in Europe via Lymphoma Coalition

ERN | EuroBloodNet

www.eurobloodnet.eu

@ERNEuroBloodNet

eurobloodnet-european-reference-network-on-rare-hematological-diseases

Eurobloodnet - European Reference Network on Rare Hematological Diseases

ERN-EuroBloodNet's EDUcational Youtube channel

European Reference Network | Hematological Diseases (ERN EuroBloodNet)

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.

Funded by the European Union

PVGs: Challenges and Recommendations:

Barriers

- Limited resources (time & funding)
- Lack of standardized methodologies
- Access to a clear, high-quality clinical guideline to base the PVG
- Difficulties in reaching consensus among stakeholders.

Developped & Endorsed by the ERN-EuroBloodNet

Easy accessibility and right to develop PVGs

dissemination and implementation of PVGs to reach the target patient population.

Patient Journeys from Educational Programs

Pilot of von Willebrand Disease

European
von Willebrand Disease
Community

EHC
european haemophilia consortium
Advocating for people with haemophilia and congenital bleeding disorders

Steering Committee:

Mariangela Pelligrini
ERN-EuroBloodNet

Sophie Susen
CHU de Lille, France

Jeroen Eikenboom
Leiden University Medical Center, the Netherlands

Flora Peyvandi
Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan, Italy

Daria Camilli
European Haemophilia Consortium (EHC)

VWD Committee
European Haemophilia Consortium (EHC)

Marius Tanase
ERN-EuroBloodNet ePAG, European Haemophilia Consortium (EHC)

European
von Willebrand Disease
Community

EHC
european haemophilia consortium
Advocating for people with haemophilia and congenital bleeding disorders

Steering Committee:

Mariangela Pelligrini

(ERN-EuroBloodNet)

Natacha Bolaños

(ERN-EuroBloodNet ePAGs, Lymphoma Coalition)

Vincent Ribrag

(Gustave Roussy Hospital, France)

LYMPHOMA COALITION