



ERN-EuroBloodNet Website navigation

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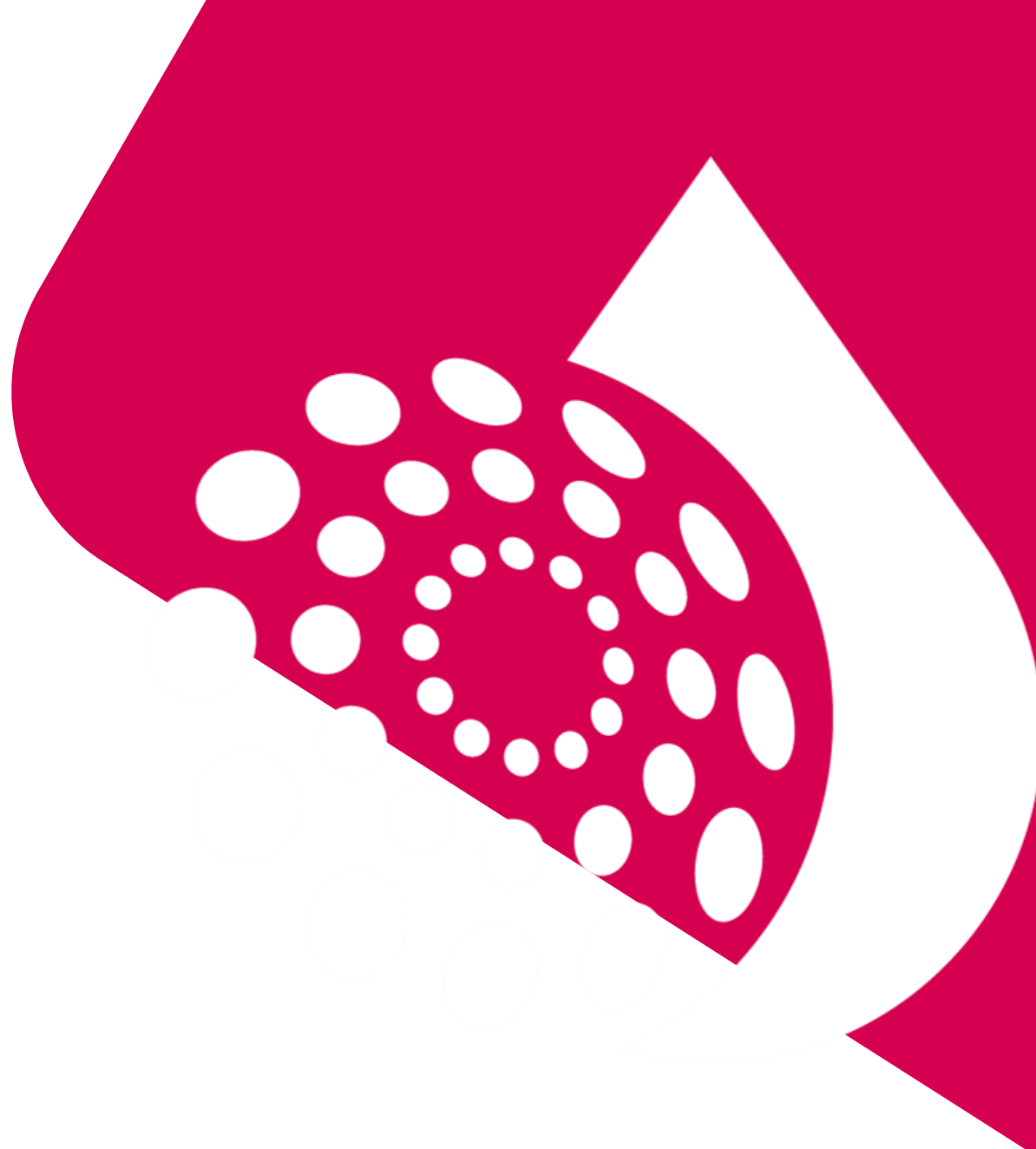
TOPICS FOR TODAY

- ERNEuroBloodNet TFAs (Transversal Fields of Action):

- Edu Blood Academy
- Clinical Practice Guidelines

- Repository of Experts

- Why update your profile
- How to edit your profile





ERN-EuroBloodNet WEBSITE

We encourage everyone to explore the website and take full advantage of all the available tools and information. It is not only a comprehensive repository but also a dynamic platform featuring valuable resources such as Disease Cards, the EDU Blood Academy, the Expert Repository, Best Practice Guidelines, and much more.

ebn
ERN | EuroBloodNet

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ERN-EuroBloodNet Membership Best practices EDU Blood Academy CPMS ENROL Patients' advocacy Disease cards Research News #ERNcare4Ua

HIGHLIGHTS

vidéo 3

Copy enl...

“Sickle cell disease landscape and challenges in the EU: the ERN-EuroBloodNet perspective” has been published at The Lancet Haematology!

The Viewpoint summarizes the role of ERN-EuroBloodNet to improve the overall approach and management of Sickle cell disease patients in EU through key actions developed by the network. The manuscript is the result of the joint work within 12 EU Member States, a total of **26 ERN-EuroBloodNet health professionals and patients representatives have contributed.**

Ver en YouTube

MORE INFO



TRANSVERSAL FIELDS OF ACTION (TFAs)

Five Transversal Fields of Action (TFAs) were defined aligned with the objectives in order to implement target driven actions to ensure their achievement:



Cross border health



Best Practices



**Continuing Medical
Education**



Telemedicine



**Clinical Trials &
Research**



TRANSVERSAL FIELDS OF ACTION (TFAs)

Five Transversal Field of Actions (TFAs) were defined aligned with the objectives defined in order to implement target driven actions to ensure their achievement:



Cross border health



Best Practices



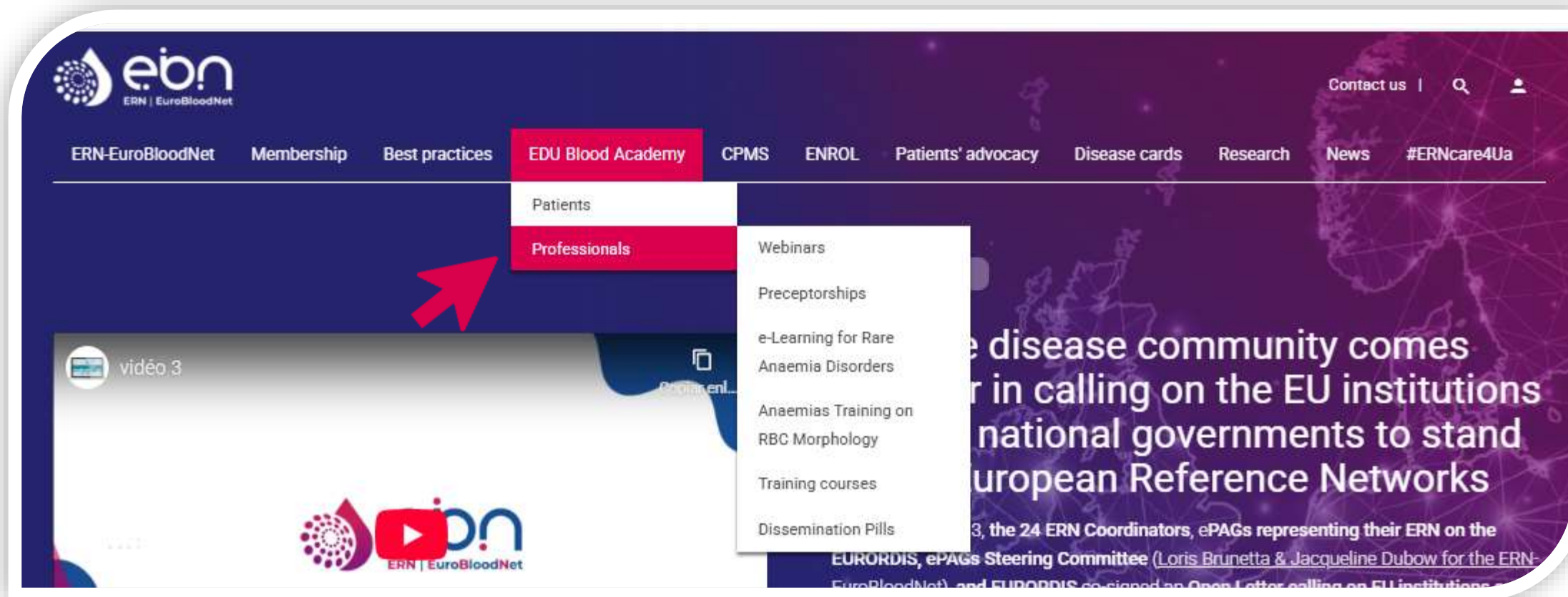
**Continuing Medical
Education**



Telemedicine



**Clinical Trials &
Research**





ERN-EuroBloodNet EDU Blood Academy

The educational space dedicated to the rare hematological community! Discover the content created by the ERN-EuroBloodNet that targets your profile.



Co-financed by the Connecting Europe
Facility of the European Union



Patients

Patients & Patients'
Organizations



**Health
Professionals**

Health Professionals





Educational Section for Health Professionals

Click on the different boxes to discover more information about the educational actions available in ERN-EuroBloodNet for health professionals!



Webinars for Health Professionals

Three different webinar programs are available



Preceptorships

Short stay programs organized in the frame of ERN-EuroBloodNet



e-Learning for Rare Anaemia Disorders

Dedicated section for the learning of Rare Anaemia Disorders



Anaemias Training on Red Blood Cell Morphology

A course for the learning of Anaemias and Red Blood Cells abnormalities



Training courses

Endorsed by the ERN for health professionals carried out on HCPs sites and coordinated by ERN-EuroBloodNet experts



Dissemination Pills

The ERN-EuroBloodNet Dissemination webinar program has been created to increase awareness of concrete ERN actions and results.



Lower-Risk Myelodysplastic Syndrome

25/09/2025 17:00

Speakers: *Pierre Fenaux*

Target: Health professionals

Subnetworks: Myeloid malignancies

Disease Groups: Myelodysplastic syndrome



Downloads

Recent progress in the treatment of lower risk MDS in ERN-EuroBloodNet EDU Youtube channel

Recent progress in the treatment of lower risk MDS - Presentation

Upcoming webinars or programs

Upcoming webinars

Check below the upcoming webinars and register to receive the link!

← PAST WEBINARS

Cutaneous T-Cell Lymphomas: Bridging Gaps in Therapy and Patient Care

13/11/2025 17:00

Speakers: *Maarten Wemmer*

Target: Health professionals

Subnetworks: Lymphoid malignancies

Disease Groups: Primary cutaneous lymphoma

REGISTER →

Comprehensive Overview of Mantle Cell Lymphoma: Diagnosis, Treatment, and Emerging Therapies

11/12/2025 17:00

Speakers: *Olivier Hermine*

Target: Health professionals

Subnetworks: Lymphoid malignancies

Disease Groups: Mantle cell lymphoma

REGISTER →

Newborn screening for sickle cell disease: what can we learn from the practice in the European Union?

25/01/2026 17:00

Speakers: *Elisavete Gullik*

Target: Health professionals

Subnetworks: Red blood cell defects

Disease Groups: Sickle cell disease and related disorders

REGISTER →

Advancing Diagnostics and Therapeutic Strategies in Paroxysmal Nocturnal Hemoglobinuria: A Comprehensive Guide to Managing a Complex Disorder

19/02/2026 17:00

Speakers: *Jeroen Panzer*

Target: Health professionals

Subnetworks: Bleeding - Coagulation disorders

Disease Groups: Paroxysmal nocturnal hemoglobinuria

REGISTER →

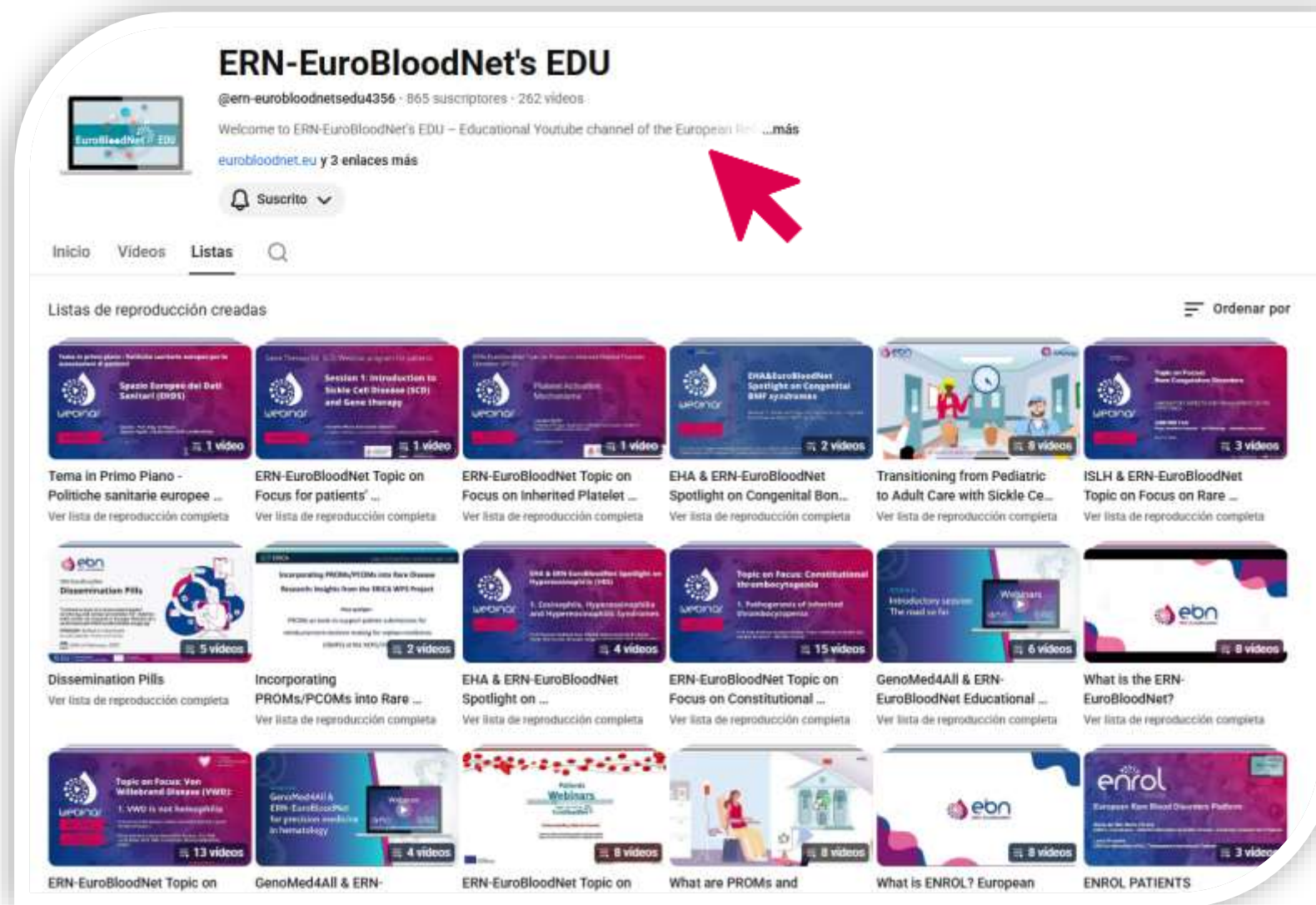
Past webinars: all the material available to watch on demand on YouTube and download the documents.



EDU Blood Academy

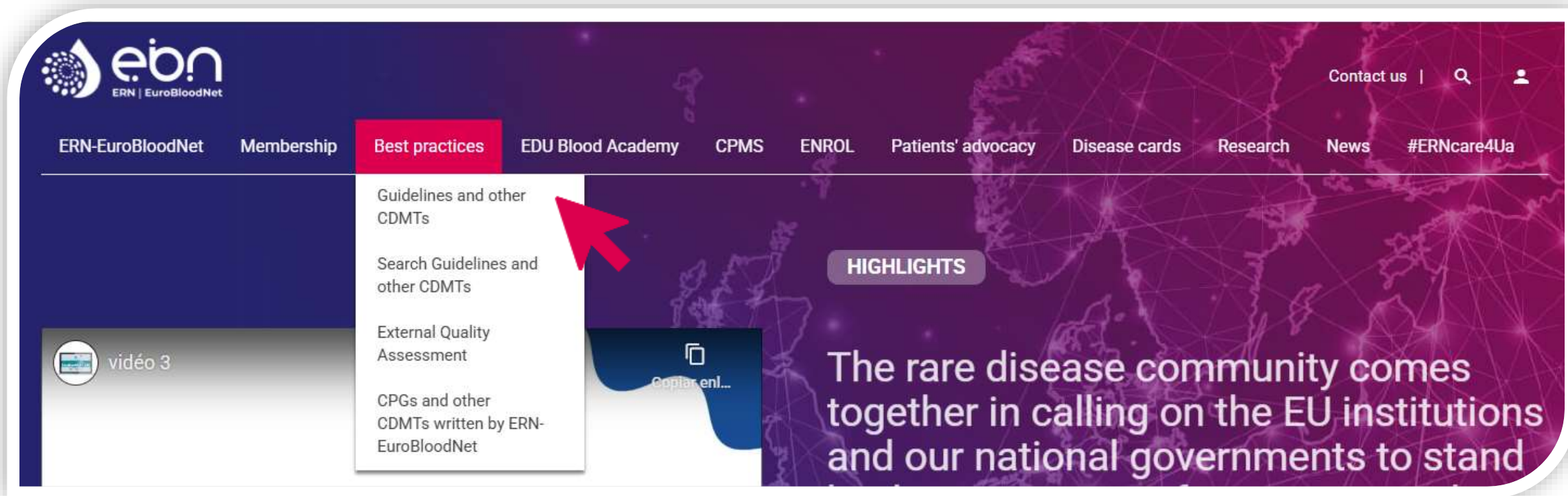
The YouTube Channel has **865 subscribers & 262 videos**.

You can find **webinars, patients's testimonies** and other **informative/educational** videos developed by the network.





BEST practices

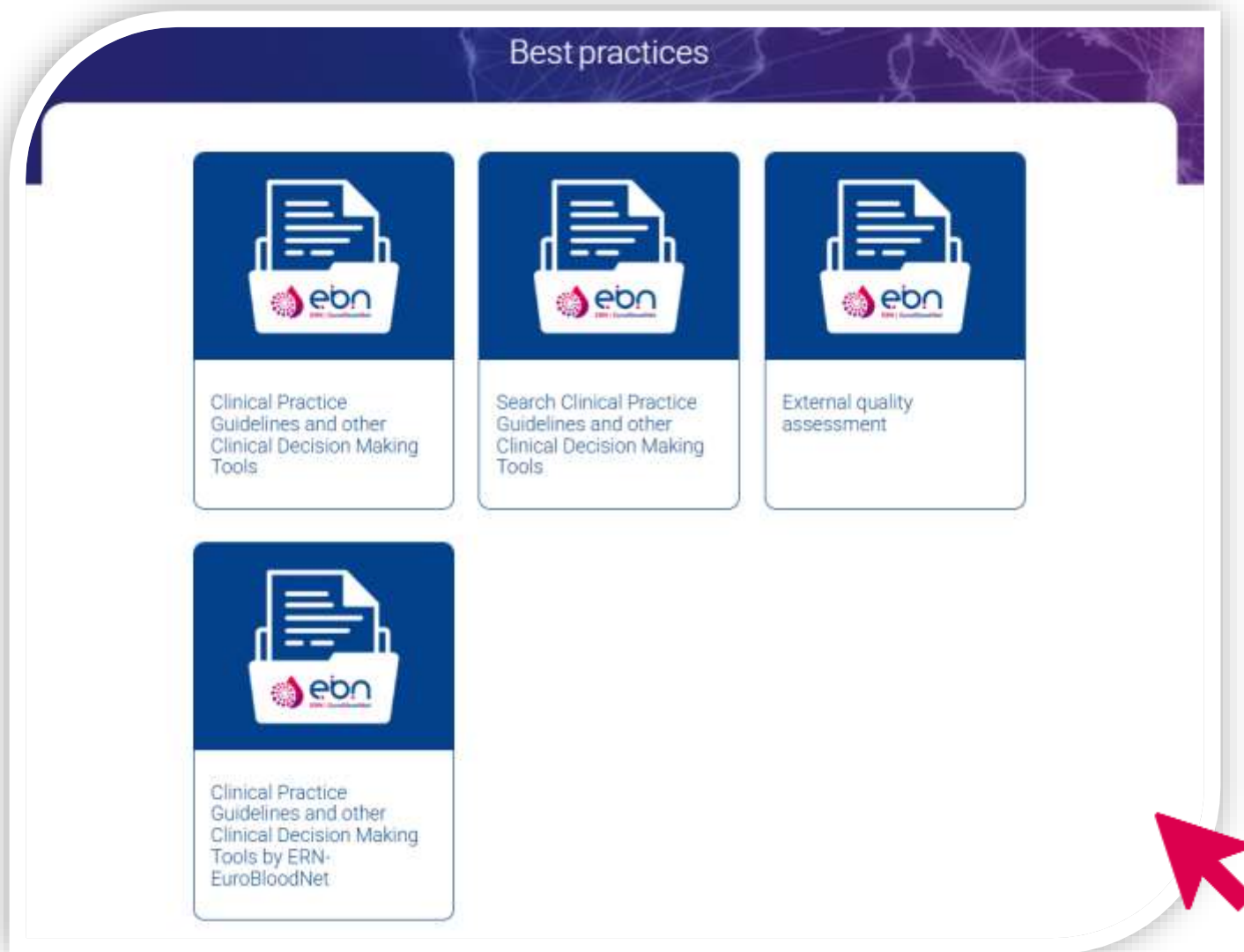


A number of international **Clinical Practice Guidelines (CPGs)** and other **Clinical Decision Making Tools (CDMTs)** have been published so far on prevention, diagnosis, and clinical care in RHD.

ERN-EuroBloodNet aimed to create a comprehensive repository of CPGs and CDMTs classified by Quality Domains and to identify gaps for promoting the creation of new ones on areas where they are lacking.



BEST practices





BEST practices

You will find the list of **Clinical Practice Guidelines (CPGs)** and other **Clinical Decision Making Tools (CDMTs)** compiled and classified on Quality Domains.

In this section you will find the list of Clinical Practice Guidelines (CPGs) and other Clinical Decision Making Tools (CDMTs) compiled and classified on Quality Domains. Please go to **Guidelines and other CDMTs** Section to see the methodology followed.

*Please note that classification for CPGs and other CDMTs on Bleeding and Coagulation disorders and Lymphoid malignances on ongoing. Documents will be searchable soon.

Search guidelines

Disease group

All

Scope and Purpose

All

Rigour of development

All

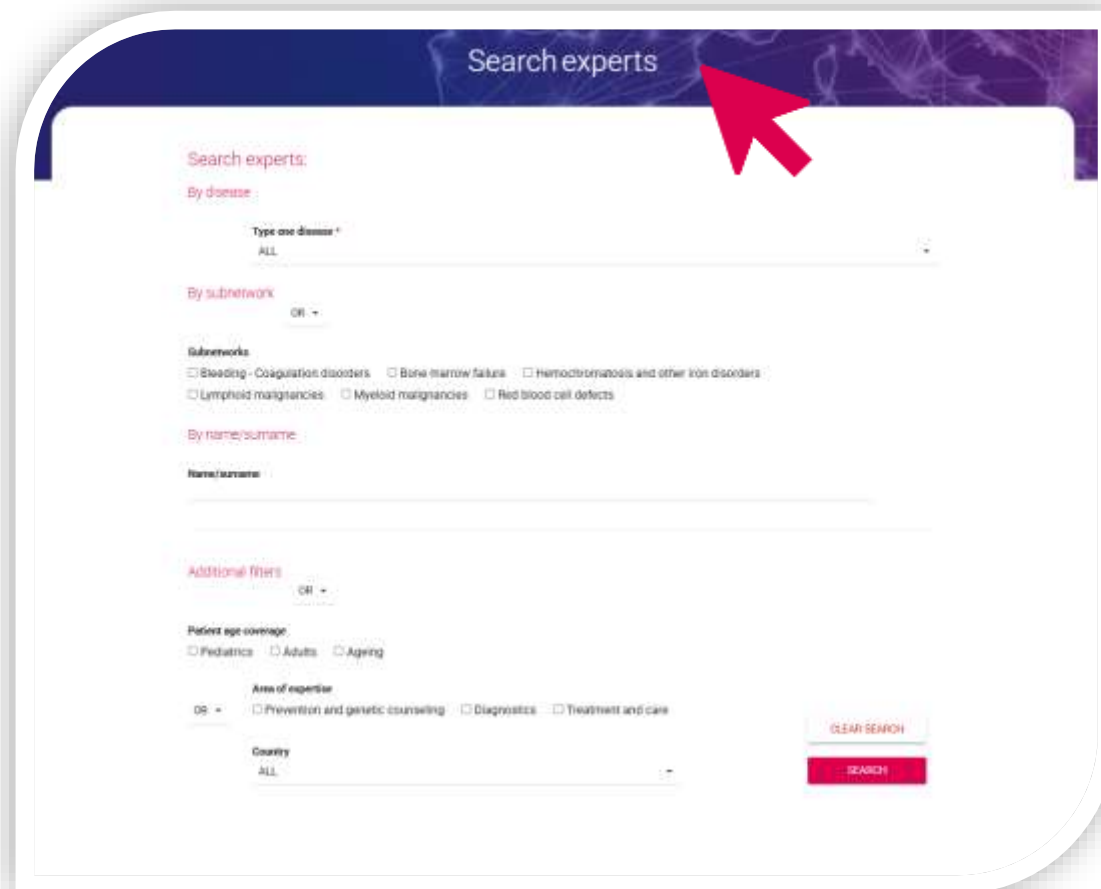
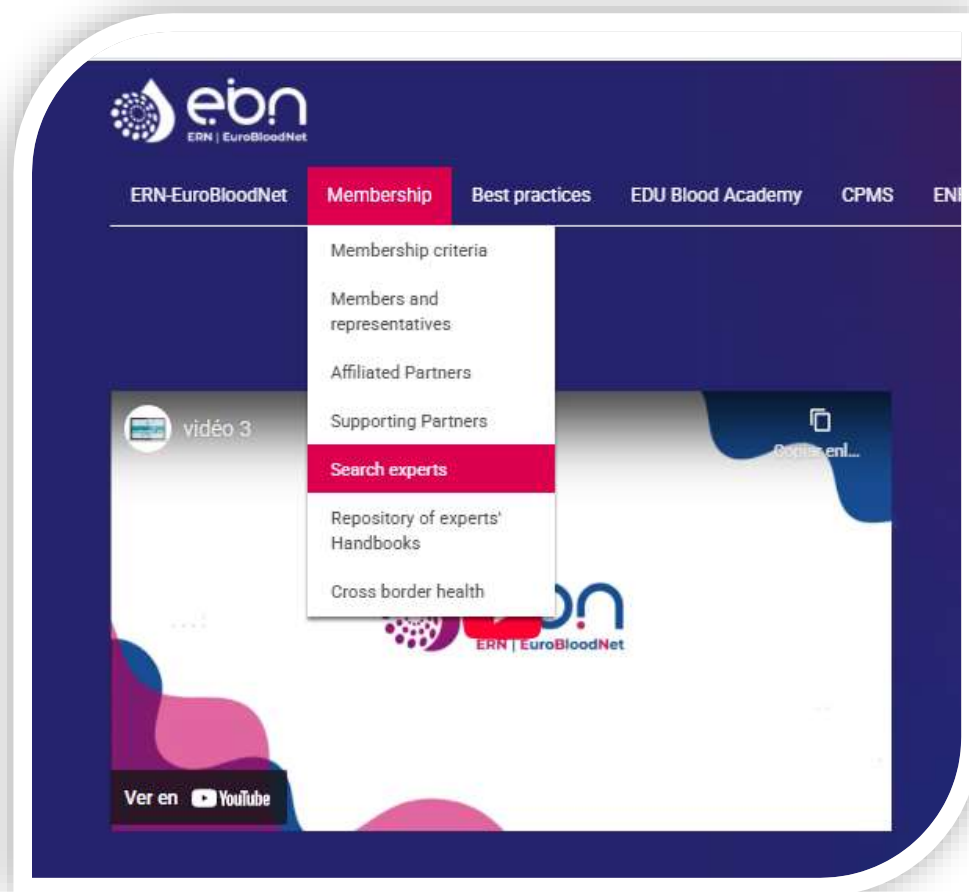
SEARCH

CPGs and other CDMTs written by ERN-EuroBloodNet

List of Clinical Practice Guidelines (CPG) and Clinical Decision Support Tools (CDST: clinical consensus statements or consensus recommendations), developed by the ERN-EuroBloodNet involving at least two Health Care Providers from two different Member States within the ERN. All of them include the **acknowledgement of the ERN**, for diseases within the scope of the ERN where no guidelines existed previously and be according to an evidence-based recognized methodology.



Very linked to the production of Clinical Practice Guidelines is the “Experts repository” on our website:

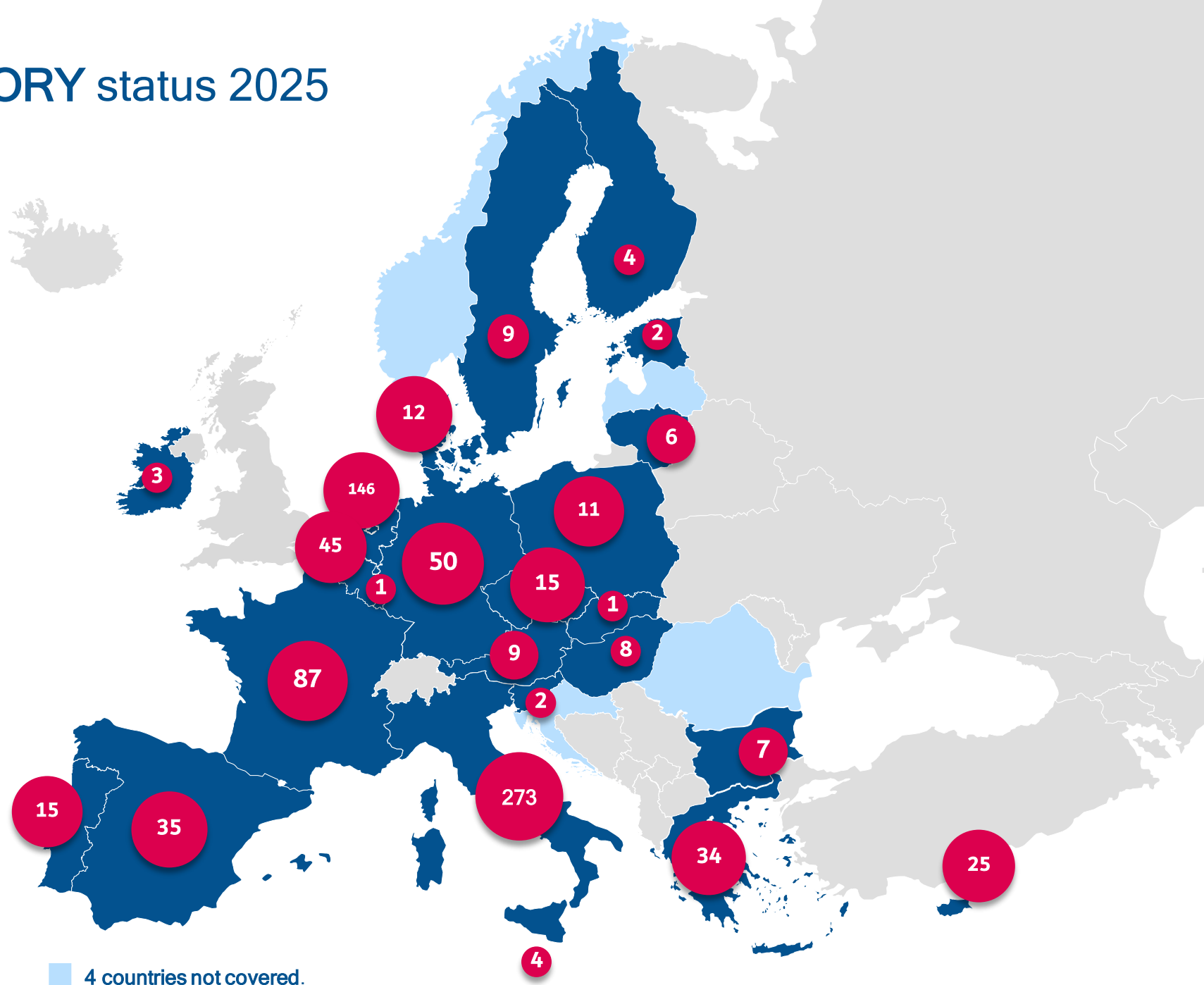




EXPERTS REPOSITORY status 2025

Italy	273
The Netherlands	146
France	87
Germany	50
Belgium	45
Spain	35
Greece	34
Cyprus	25
Czech Republic	15
Portugal	15
Denmark	12
Poland	11
Austria	9
Sweden	9
Hungary	8
Bulgaria	7
Lithuania	6
Finland	4
Malta	4
Ireland	3
Estonia	2
Slovenia	2
Luxembourg	1
Slovakia	1


804 Experts from 24 Member States.





An example of **Expert profile** complete with all the information.

Information



About me

Name: Maria del Mar

Surname: Mafú Pereira

Academic title: BsC, PhD

Charge: Head of Research Lab in rare anemia

Which is your area of expertise for the "Disease/group of diseases"?

- Prevention and genetic counseling
- Diagnostics

Specify your expertise for the "Disease/group of diseases" (eg SCT, Molecular diagnosis):

Integrative diagnosis of rare anemia disorders combining conventional and innovative methodologies including x-OMICs for personalized medicine

Disease groups:

Alpha- thalassaemia diseases, Beta-thalassemia and related diseases, Hemoglobinopathy (Other than THAL and SCD), Hereditary elliptocytosis, Hereditary spherocytosis, Hereditary stomatocytosis, Porphyrias, Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD), Rare constitutional hemolytic anemia due to pyruvate kinase deficiency, Sickle cell disease and related diseases

Which is your patient age coverage?

- Pediatrics
- Adults

Scientific and Strategic Board member

Coordination team

TFA coordinator

Webinars:

- ENROL: Networking on European Registries in Rare Hematological Disorders
- Use cases challenges: MDS, SCD and MM
- Use case SCD overview of results (both from a technical and clinical perspective) + specific onboarding requirements (e.g. minimal dataset).

Member [Go to Member](#)

Name english: Vall d'Hebron Barcelona Hospital Campus

Name original: Hospital Universitari Vall d'Hebron

Healthcare provider [Go to healthcare provider](#)

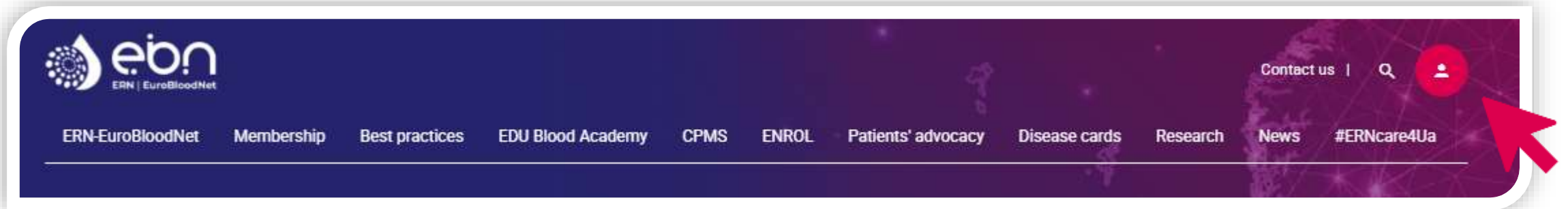
Name english: Vall d'Hebron Barcelona Hospital Campus

Name original: Hospital Universitari Vall d'Hebron

Why is it important to keep your Expert Profile complete and up to date?

- It serves as our **main reference list** for consultations and collaborations.
- When developing **new guidelines**, we use the Expert Repository to identify and contact experts by subnetwork and disease area.
- A recent example is a **request from the European Medicines Agency (EMA)**, where updated expert information was essential for regulatory procedures related to the authorization of a new therapy.

How to update your Expert profile?



Login

E-mail *

Password *

LOGIN →

[Forgot your password?](#)

[LINK](#) to access.

The user is your mail and if you don't remember the password you can **reset password**.

* If you have any questions or technical issues, please contact us:
daiana.lopez@vhir.org



** If you have any questions or technical issues, please contact us:*

Daiana Natali Lopez

[Professional information](#)[Healthcare providers](#)[Departments](#)[Experts](#)[Invite](#)

EDIT EXPERT

Start

Departments

Subnetworks

Diseases

Level 1

Finish

Change password

Healthcare provider

VALL D'HEBRON BARCELONA HOSPITAL CAMPUS

Name *

Daiana Natali

Surname *

Lopez

Academic title

Charge

ERN-EuroBloodNet Dissemi

Email *

daiana.lopez@vhir.org

Telephone

Load your photo

Recommended size:

SAVE & NEXT



KEY points

- **Take full advantage of the website**, it's a living platform that grows and stays relevant thanks to your contributions.
- **Explore and use the educational materials**, a valuable resource for on-demand learning and for sharing with patients.
- **Use the CPGs/CDSTs repository**. Explore it and disseminate it to colleagues and other experts.
- **The Expert Repository** is our main tool to identify and extract expert lists by subnetwork and disease area.
- When institutions such as the European Medicines Agency (EMA) request expert lists, **we rely on the data available on the website**.
- It is essential to **keep your Expert Profile updated**, especially the subnetwork and disease information.
- Without this information, experts will not appear in the **Disease Cards or in the search filters**.

Thank you!

