

ERN-EuroBloodNet 4th Progress Meeting

7th of November 2022

Outcomes

On the 7th of November 2022, the [ERN-EuroBloodNet](#) held its bi-annual Progress Meeting online, gathering almost 150 participants from 19 European countries. It was a great pleasure to welcome our ERN members, [ePAGs](#), [EURORDIS](#), and other invited stakeholders to this event, as the [European Hematology Association \(EHA\)](#).

The event kicked off with a welcome message provided by the ERN co-coordinators who presented the new ERN logo and visual identity. Alexis Arzimanoglou, coordinator of the [ERN EpiCare](#) and Chair of the ERN coordinators' group, presented lessons learnt from the past and suggestions for the future of the ERNs. Franz Schaefer, coordinator of the European Rare Kidney Network ([ERKNet](#)), presented an update on the ERN's Registries.

The audience was then split into five different parallel sessions according to [subnetworks](#) for assessment of current performance based on indicators and discussion on ongoing and new actions in different transversal fields of actions: Cross border health, Best practices, Education and training, Telemedicine ([Clinical Patient Management System - CPMS](#)) and Research (clinical trials, registries and translational research).

Finally, an update on the evaluation process was delivered to members.

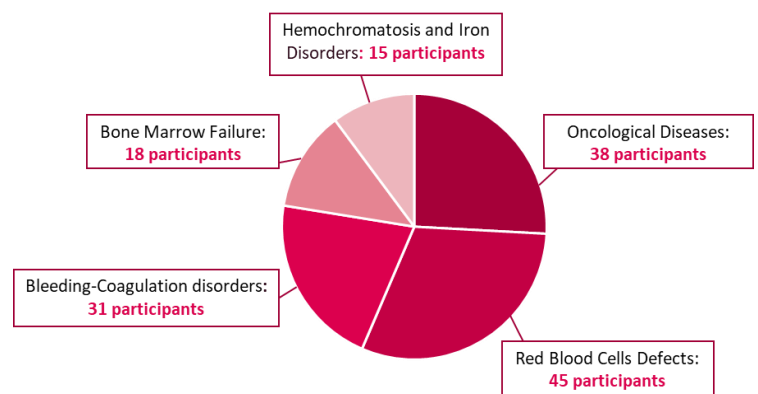
Here are new proposals and conclusions from the groups:

All subnetworks

Cross Border Health:

- Identification of new centers outside [ERN-EuroBloodNet](#) for promoting their engagement in the network actions and potentially their participation in the next call for new membership. Special efforts will be devoted in countries without any representation (ie. Croatia, Latvia and Romania), and in terms of country coverage per subnetwork. This should also include possibilities for current members to extend their disease coverage.

147 Participants from 19 European Countries !



Research:

- The first contract for EuroBloodNet sponsored clinical trial, SATISFY, has been signed. [ENROL](#) registry has active collaborations for specific subregistries on rare anemia disorders – [RADeep&GenoMed4All](#), dendritic cell leukemia – EU-Blast, von Willebrand disease - TWIST, myelodysplastic syndromes – [Genomed4All](#), and acute myeloblastic leukemia – IMPACT proposal submitted.
- Efforts are needed to promote new clinical trials and disease specific subregistries under [ENROL](#).

Oncological subnetworks (38 participants in 9 European countries)

Cross border health:

- The main cross border health activity of this year has been focussed on supporting Ukrainian patients fleeing the war that allowed various patients with haematological malignancies to go in France (Paris, Lille) and Italy (Florence).
- Survey to identify gaps in continuity of cares when haemato-oncological patients change country within the European Union (EU). It will result on a map of standards of cares, basket of health services and access to treatments in member states (MS). Short statements should be written with the support of clinical partners and patient associations; this concerns in particular countries for which diagnosis and treatment(s) of certain haematological diseases are not available.

Best practices:

- Clinical practice guidelines on Burkitt lymphoma and recommendations on VEXAS syndrome are ongoing.
- In order to promote best practices, algorithms and tools for clinical decision support and therapeutic management will be promoted or created. This will be a key action disseminated using short statements that will enable the implementation of best practices.
- Development of new Guidelines and/or updates of existing ones by [ERN-EuroBloodNet](#) members is welcome, avoiding duplication of existing ones. [ERN-EuroBloodNet](#) can provide support.

Education and training:

- Short stays (preceptorships) are being restarted after their interruption by the COVID-19 crisis. Targets are particularly cutaneous lymphoma and myelodysplastic syndrome.
- An educational program for general practitioners and nurses was identified as a priority e.g. early detection of symptoms in haemato-oncology.
- A meeting will be dedicated to determining the strategy to be implemented for patient webinar programs, in particular concerning the target audience and the languages to be offered.

Telemedicine (CPMS):

- Efforts need to be done to include multidisciplinary teams in virtual panels in [CPMS](#).
- The virtual board on cutaneous lymphoma successfully, established for the training of experts on the use of [CPMS](#) and sharing of complex cases on this disease, will be promoted for the engagement of new health professionals and enrolment of new cases.
- Creation of the new virtual board on blastic plasmacytoid dendritic cell and Langerhans cell histiocytosis was proposed based on the new pilot scheme for reimbursement.

Research:

- Clinical research is generally well covered in haematological malignancies by industry sponsored trials. However, academic trials through EuroBloodNet association are needed for smaller disease areas (niches).
- In addition to the ongoing blastic plasmacytoid dendritic cell neoplasm subregistry under [ENROL](#) registry frame, [ERN-EuroBloodNet](#) is open to suggestions for new disease specific subregistries on niches identified for onco-haematological diseases.
- Development of patient reported outcome measures (PROMS) to assess benefits from treatment with Luspatercept (intercrossing myelodysplastic syndrome and thalassaemia) has recently started under the frame of [ERN-EuroBloodNet](#).

Red blood cell subnetwork (45 participants in 14 European countries)

Cross border health:

- Survey on Transcranial Doppler (TCD) for stroke prevention in adults with sickle cell disease.
- Survey to assess bone marrow transplant performance in terms of types and protocols (avoiding overlapping with the [European Society for Blood and Marrow Transplantation \(EBMT\)](#)).
- Definition of standards of care, minimal requirements, for devices and treatment.

Best practices:

- Development of a new guideline through [European Commission](#) support on chronic complications (osteoporosis and liver disease) in adults with sickle cell disease.
 - Development of European guidelines are crucial in some member states specially when they lack of national guidelines. Guidelines are also needed for discussion with national authorities on the need of availability of new drugs coming into the market.
 - European guidelines should be built based on existing national ones in order not to duplicate efforts.

Education and training:

- New educational action to improve performance and quality of TCD for stroke prevention for both, paediatrics and adults in EU centres.
- Links should be promoted with other educational repositories, e.g. with [Thalassaemia International Federation \(TIF\)](#).
- Support patients advocacy & education, e.g. sickle cell disease patients in Germany.

Telemedicine (CPMS):

- Sharing images within the [CPMS](#) can be useful for educational purposes, e.g. with TCD for stroke prevention.
- [CPMS](#) can be used at the national level for regular meetings, including the activation of guest users accounts for non-ERN-EuroBloodNet members.

Research:

- Creation of a group focussed on next-generation sequencing (NGS) for anaemia disorders covering red blood cell, bone marrow failures and iron related anaemias.

Bone marrow failure subnetwork (18 participants in 9 European countries)

Cross border health:

- Proposal of mapping NGS and whole exome sequencing (WES) as well as specific tools for diagnosis like functional tests.
- Not as an outcome from the meeting but as consequence of the discussion: a meeting with high level stakeholders is aiming to be held under the frame of [ERN-EuroBloodNet](#) to lobby for the access to paroxysmal nocturnal hemoglobinuria drugs like Eculizumab, Ravulizumab and anti-complement drugs. For this, two actions are going to be launched shortly:
 - Mapping the countries in the EU with access to paroxysmal nocturnal hemoglobinuria drugs.
 - Preparing a short consensus document for Eculizumab, Ravulizumab and anti-complement drugs with the effectiveness of the treatments, the indications of treatment, etc.

Education and training:

- Proposal was made to work on the inclusion of subtitles on the new videos and webinars recording addressing patients.

Telemedicine:

- [CPMS](#) virtual board for the interpretation of NGS/WES.

Bleeding-coagulation subnetwork (31 participants in 12 European countries)

Cross border health:

- Proposal to map reference centers for NGS testing to unify diagnosis, collect and adapt informed consents, and optimize genotyping/phenotyping.
- Actions at the European level in the area of thrombosis should be promoted.

Best practices:

- Proposal to develop documents for travelling patients (e.g. for ERASMUS students).
- Guidelines compiled should be analyzed and published on the [ERN-EuroBloodNet website](#).

Education and training:

- Education on Von Willebrand disease should be developed, e.g. with preceptorship.

Hemochromatosis and iron metabolism subnetwork (15 participants in 8 European countries)

Cross border health:

- Update the [ORPHANET classification](#) and criteria for the definition of each disorder.
- Survey on availability of molecular testing across EU-MS.
- Survey on access to magnetic resonance imaging (MRI) for monitoring iron overload.

Best practices:

- To endorse a new guideline developed by the [International Society for the Study of Iron in Biology and Medicine \(BioIron\)](#) and the [European Association for the Study of the Liver \(EASL\)](#).
- To promote the development of recommendations for the diagnosis and treatment of iron overload disorders other than HFE haemochromatosis.
- Promote consensus meeting in order to standardize reporting of iron overload measured by MRI.

Education and training:

- Organize a webinar to disseminate the results of the consensus meetings on MRI.
- Survey to identify topics for a new webinar program for patients.

Research:

- Facilitate the involvement of local authorities to implement the registries according to national regulations (e.g. HFE Registry).
- Need to expand registries to cover iron related anaemias and haemochromatosis.

Thank you all for your active participation!



Presentations are available on
the European Collaborative
Platform and on demand by
contacting lea.margot@aphp.fr