



## DELIVERABLE 2.2 ANNUAL DISSEMINATION REPORT

### ERN-EuroBloodNet

### European Reference Network on Rare Hematological Diseases

## EUROPEAN REFERENCE NETWORKS FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

# Share. Care. Cure.



Co-funded by  
the Health Programme  
of the European Union

## Disclaimer:

**The content of this deliverable represents the views of the authors only and it is their sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (Chafea) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.**

## DOCUMENT INFORMATION

### DELIVERABLE 2.2 ANNUAL DISSEMINATION REPORT

Report Document

ERN: **ERN-EuroBloodNet (European Reference Network on Rare Hematological Diseases)**

Call: **HP-ERN-SGA-2018**

Type of action: **HP-SGA-PJ**

Authors:

**Victoria Gutierrez Valle – ERN-EuroBloodNet Dissemination & IT Manager**

**Maria de los Ángeles Rodríguez Sánchez- ERN- Project Manager**

**María del Mar Mañú Pereira – ERN-EuroBloodNet Scientific Director**

**Béatrice Gulbis - ERN-EuroBloodNet co-Coordinator and non-Oncological Hub chair**

**Pierre Fenaux - ERN-EuroBloodNet Coordinator and Oncological Hub chair**

#### Short Description

Dissemination report including all the activities done for increasing the critical mass of stakeholders and target groups involved.

Publication Date

26/02/2021

# TABLE OF CONTENTS

## 1. Introduction

## 2. Objectives

## 3. Tasks

Task 1. Upgrade of the ERN-EuroBloodNet repository of experts

Task 2. Upgrade and development of new ERN-EuroBloodNet communication tools and channels

2.1 Update of ERN-EuroBloodNet communication material

2.2 ERN-EuroBloodNet communication channels

2.3 Expansion of ERN-EuroBloodNet website

2.4 Promotion of the use of the ERN collaborative platform

2.5 Dissemination at European rare diseases meetings and workshops

Task 3. Relations with third parties

3.1 Promotion of collaboration agreements with third parties

3.2 Promotion of relations with National Scientific Societies of Hematology

## 4. Results

Linked to Task 1. Upgrade of the ERN-EuroBloodNet repository of experts

Linked to Task 2. Upgrade and development of new ERN-EuroBloodNet communication tools and channels

2.1 Update of ERN-EuroBloodNet communication material

2.2 ERN-EuroBloodNet communication channels

2.3 New sections on the ERN-EuroBloodNet website

2.4 Promotion of the use of the ERN collaborative platform

2.5 Dissemination in European rare diseases meetings and workshops

Linked to Task 3. Relations with third parties

3.1 Promotion of collaboration agreements with third parties

3.2 Promotion of relations with National Scientific Societies of Hematology

## 5. Next steps

## 1. INTRODUCTION

The design and implementation of a robust communication strategy and plan is cornerstone to creating a critical mass of interests necessary for the upgrading of services provided by the experts and expert centres included in ERN-EuroBloodNet, and to increase public awareness of rare hematological diseases (RHD) and of network goals and achievements.

The bidirectional communication of the network requires permanent contacts between the board of ERN-EuroBloodNet and different target groups including a) National and EU health authorities and policy makers b) Healthcare Providers, universities and research centres c) Scientific and national bodies at the national, EU level and international d) Patients' associations, patients and relatives.

Liaison with third parties outside Europe are also promoted since this will add value to the network by enhancing the development and use of registries as well as disseminating information on RHD in neighbouring countries. Both European Hematology Association (EHA) and EURORDIS Rare Disease Europe have links outside of EU that will be informed regularly and invited to dialogue through the communication tools of ERN-EuroBloodNet. This provides a means to strengthen networking and international collaborations, and ensure sustainability of the network.

ERN-EuroBloodNet Dissemination strategy was described in the Dissemination plan defined during the first year of the network aiming to set the basis for the overall strategy to promote and expand the knowledge of ERN-EuroBloodNet to the different stakeholders already identified for the five years of implementation, including five main objectives to be achieved:

- To define and establish a dissemination plan including creation of the dissemination material (ie Leaflets, slide presentations...) and creation of a Dynamic Stakeholders Directory
- To develop and stimulate ERN-EuroBloodNet social media channels as the main powerful tools for dissemination, including ERN-EuroBloodNet website, ERN Collaborative platform, newsletter and social networks.
- To promote collaboration agreements with third parties: other ERNs, European Research Infrastructures Consortiums.
- To increase awareness and knowledge on RHD through the organization of European Symposia for health professionals and patients.
- To disseminate reports on ERN-EuroBloodNet outcomes via website and ERN Collaborative platform to improve clinical care and increase public awareness, together with a final publication.

This document describes the activities implemented as part of Work Package 2 “Dissemination” aiming to promote and to expand the knowledge of ERN-EuroBloodNet among the Health and legal authorities, scientific community, patients' organizations and public in general.

## 2. OBJECTIVES

ERN-EuroBloodNet's dissemination includes all the activities aiming to expand knowledge of the ERN in RHDs, its website and its activities and services in order to get the necessary critical mass to make the network fully successful and ensure its long-term sustainability.

Specific objectives for the third year of implementation of ERN-EuroBloodNet are:

1. To expand and upgrade the ERN-EuroBloodNet Repository of experts
2. To increase awareness on ERN-EuroBloodNet actions and results by the update and upgrade of the ERN-EuroBloodNet's website, stimulation of social media channels and participation in RHD events
3. To promote collaboration agreements with third parties and strengthen the existing ones

### 3. TASKS

## TASK 1. UPGRADE OF THE ERN-EUROBLOODNET REPOSITORY OF EXPERTS

As starting point for the mapping of experts, an inventory of [ERN-EuroBloodNet inventory of members and experts](#) was created during previous period of the network implementation (2017-2018) for creating a public and accessible repository of the expertise available in the network. ERN-EuroBloodNet inventory is based on Experts, Departments, and Members profiles. Profiles are editable through a set of applications forms allocated in the private area and integrate the ORPHA classification for RHD in its back office, allowing the selection of health professionals' specific area of expertise as well as for the diseases covered. In addition, a [Disease Search tool](#) has been implemented to exploit the data gathered through the inventory, making the expertise available in the network findable and searchable to the public.

From their establishment on 2017, ERNs are currently experiencing the enlargement of the number of types of members of the networks through a) the designation of Affiliated Partners (APs), and b) the launch of the call for new ERNs members.

As a result, ERN-EuroBloodNet has increased its coverage with [10 Affiliated Partners from 8 countries](#), and have received a total of 38 applications for new members from 11 countries (Assessment ongoing - Expected date for official membership Q2 2021), therefore an upgrade of the inventory is being implemented for their proper inclusion.

## TASK 2. UPGRADE AND DEVELOPMENT OF NEW ERN-EUROBLOODNET COMMUNICATION TOOLS AND CHANNELS

### 2.1 UPDATE OF ERN-EUROBLOODNET COMMUNICATION MATERIAL

Presentation slides are constantly evolving depending on the audience or the subject of the meetings. Having an extensive reference presentation is useful in order to use the most relevant parts for a given audience in every talk where ERN-EuroBloodNet is introduced.

### 2.2 ERN-EUROBLOODNET COMMUNICATION CHANNELS

#### NEWSLETTER

The objective of the ERN-EuroBloodNet newsletter is to inform stakeholders about the relevant RHD news and to updated them about the development of the different projects carried on by ERN-EuroBloodNet, increasing the visibility of ERN-EuroBloodNet activities. After the first designed version of the ERN-EuroBloodNet newsletter during the 2nd year of Implementation and its improvement during 2019, the final version has been finally released in October 2019. Nowadays we are using the same designed structure described below:

- Introductory header with ERN-EuroBloodNet logo and Month of newsletter
- Two emphasized pieces of news, including title, subtitle, picture and link to the piece of news
- Unlimited number of pieces of news in a smaller size, including title, subtitle, picture and link to the piece of news
- Footer with ERN-EuroBloodNet logo and EC recognition
- Privacy policy disclaimer, including the link to unsubscribe



#### SOCIAL NETWORKS EXPANSION: TWITTER, FACEBOOK AND LINKEDIN

ERN-EuroBloodNet has an account in twitter since the first year of the Network. The presence of the network in this social media increases the impact of the messages launched by the network.

Dissemination and communication channels have been expanded during this period of network implementation in order to increase the outreach of network actions. New channels include Facebook, as one of the major social networks mainly addressing general audience and LinkedIn, as one of the major social networks connecting professionals.

#### NEW ERN-EUROBLOODNET EDU YOUTUBE CHANNEL

EuroBloodNet's EDUcational Youtube channel has been created for the inclusion of educational videos created/endorsed by the network for the benefit of the EuroBloodNet community (patients and experts) by providing a direct and open access to the knowledge in the field of rare blood diseases.

## 4TH EUROBLOODNET BOARD OF NETWORK MEETING

The 4th EuroBloodNet Board of Network meeting was planned to be held in Paris, unfortunately, due to the COVID-19 the meeting has been performed online the past 22nd of October. In spite of the actual circumstances, this edition had a notable participation with 120 attendees. Among them member representatives, patients' organizations, candidates for new members, affiliated partners, collaborating stakeholders including the European Hematology Association (EHA) or International Quality Expertise (UKNEQAS) and as a novelty, new members candidates currently under assessment.

This year the meeting has been divided in 5 sections. The first section included three different talks: an overview of the past and future of ERN-EuroBloodNet to the audience, the progress of the process of the second call for new members and the third one showing up updates on the website design.

The following 4 sections were named according to the four main areas in which EuroBloodNet is working on:

1. Cross border health, mapping expertise and inter-professional consultations
2. ERNs future consolidation
3. Educational activities and Webinar programs
4. Clinical practice guidelines and Patients' Registries

The meeting provided the whole overview of the status of the ongoing projects undertaken by the network while enhanced discussion on important questions risen after the sessions, leading to a) reaching consensus for upcoming next steps on the methodological approach for the ongoing projects, while b) creation of new projects proposed to be implemented in needs identified.

Major outcomes were distributed by mail to ERN-EuroBloodNet stakeholders through a [dedicated piece of news](#) including the key points discussed and links to the [ERN Collaborative platform](#) for downloading the slides presentations.

## 2.3 EXPANSION OF ERN-EUROBLOODNET WEBSITE

ERN-EuroBloodNet website is the principal tool of dissemination of the network, providing the skeleton of the complex structure that ERN-EuroBloodNet represents by endorsing specific dedicated sections to the all the activities and tools developed by the networks.

ERN-EuroBloodNet website has been conceived as the on-line platform that provides not only the door of access to ERN-EuroBloodNet dynamic and public inventory of members and experts but also to the main tools developed and implemented during the running time of the network.

In this context, ERN-EuroBloodNet website can be understood as two-side online platform with two main objectives:

- ERN-EuroBloodNet website as the main tool for dissemination of the goals and achievements to boost public awareness of the network.
- ERN-EuroBloodNet website as the infrastructure (web portal and database) for accessing the Inventory of ERN-EuroBloodNet members and experts' profiles

New sections and specific target-actions engines have been implemented in this period for the exploitation of the data collected while keeping the website in an evolving environment attending to the network's need.

## 2.4 PROMOTION OF THE USE OF THE ERN COLLABORATIVE PLATFORM

The platform developed by the EC is an excellent platform for communication and sharing of documents among ERN-EuroBloodNet members. As in previous periods, its usage has been promoted by uploading of exclusive material of interest for our community.

## 2.5 DISSEMINATION AT EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

Online and virtual relations make cooperation easier, specially under current pandemic situation. All the activities developed by ERN-EuroBloodNet members have been reported to coordination team.

## TASK 3. RELATIONS WITH THIRD PARTIES

### 3.1 PROMOTION OF COLLABORATION AGREEMENTS WITH THIRD PARTIES

In order to create a real network it is essential to create synergies with other ERNs, projects and initiatives working towards objectives complementary to those of ERN-EuroBloodNet. Links for collaborative agreements have been already established and consolidated during this year of implementation, eg. Orphanet, EURORDIS, patients' associations and National and International Scientific organisations.

### 3.2 PROMOTION OF RELATIONS WITH NATIONAL SCIENTIFIC SOCIETIES OF HEMATOLOGY

National Scientific Societies of Haematology in Europe as major channels of the hematology stakeholders at the national level. In an effort to increase the outreach of the ERN-EuroBloodNet activities and results of the network, a list of National Societies of Hematology Associations have been created in order to be approached, including the following details:

- Country
- Subnetwork/RHD
- Coverage of Pediatric/ Adults/Both
- Name of Society
- Contact
- Website
- Contact Person and mail
- Post address



## 4. RESULTS

### LINKED TO TASK 1. UPGRADE OF THE ERN-EUROBLOODNET REPOSITORY OF EXPERTS

The current structure implemented for the full ERN-EuroBloodNet members, including their dedicated: a) Healthcare provider profile, b) Departments profiles and c) Experts profiles, is being technically upgrading to allow the new representatives and multidisciplinary teams from Affiliated partners and future new members to create the public profiles.

Moreover, the search tool is being upgraded in order to show in a visual-appealing design the different types of profiles matching with the concrete disease of expertise search and/or any other of the filters available in the profiles.

Further details can be found at Deliverable 4.2 ERN-EuroBloodNet Repository of members.

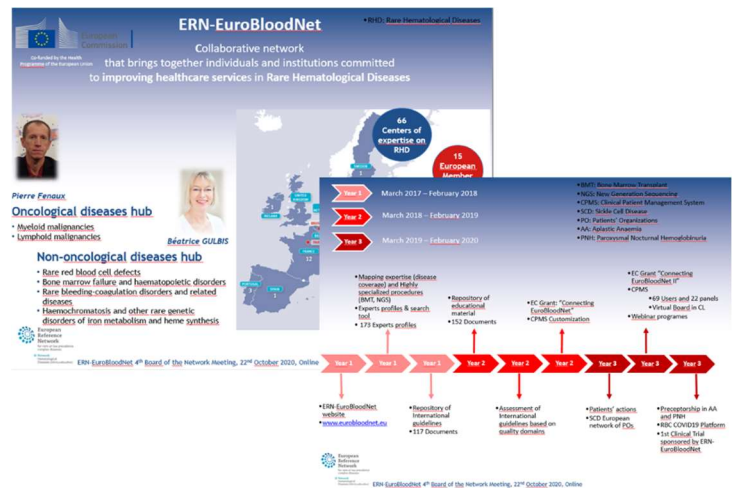
### LINKED TO TASK 2. UPGRADE AND DEVELOPMENT OF NEW ERN-EUROBLOODNET COMMUNICATION TOOLS AND CHANNELS

#### 2.1 UPDATE OF ERN-EUROBLOODNET COMMUNICATION MATERIAL

An updated power point presentation on ERN-EuroBloodNet ongoing projects was presented and shared through the ERN Collaborative Platform after the Board of the Network meeting (October 2020) in order to facilitate the dissemination of the network to a wide range of public by summarizing most relevant challenges and achievements.

Different from the general presentation produced during the third year of the network, this power point includes the current active lines of work under the each of the specific TFAs, the main outcomes achieved in the 3 years of network implementation through a visual chart, and the mention of the current new membership applications under assessment. Contacts for the coordination team are also provided. Official ERN EuroBloodNet and Chafea logos visibility have also been ensured.

Additionally it is important to mention that members are welcomed to contact Coordination team in case specific information or slides on the specific actions are required to be presented in their talks.



#### 2.2 ERN-EUROBLOODNET COMMUNICATION CHANNELS

##### ERN-EUROBLOODNET MONTHLY NEWSLETTER AND OTHER SPECIFIC NEWSLETTERS

ERN-EuroBloodNet Newsletter was launched in October 2019 and since then all the different editions are visible at [ERN-EuroBloodNet website dedicated section](#). During this period two different kinds of newsletters have been developed, the monthly newsletter and specific ones for concrete actions of the ongoing projects (Table 1 and 2).

	Total emails sent	Opened	Open rate	Clicked	Click rate
<a href="#">March 2020</a>	329	118	35,87%	22	6,69%
<a href="#">April 2020</a>	330	82	24,85%	14	4,24%
<a href="#">May 2020</a>	352	100	28,49%	20	5,70%
<a href="#">June 2020</a>	349	102	29,23%	17	4,87%
<a href="#">July 2020</a>	368	100	27,55%	9	2,48%
<a href="#">August 2020</a>	366	116	32,04%	19	5,25%
<a href="#">September 2020</a>	370	103	28,07%	12	3,27%
<a href="#">October 2020</a>	367	96	27,95%	9	2,74%
<a href="#">November 2020</a>	372	111	29,92%	17	4,58%
<a href="#">December 2020</a>	374	96	25,81%	15	4,03%
<a href="#">January 2021</a>	381	118	31,05%	20	5,26%
February 2021					
Medium rates (without feb)	359,82	103,82	29,17%	15,82	4,46%
Standard deviation	±17,54	±11,11	±0,03	±4,45	±0,01

Table 1. Results from the Monthly Newsletters campaigns

Some concrete actions of the network are disseminated independently of the newsletter in order to increase the visibility of them. During this period, ERN-EuroBloodNet considered important to disseminate newsletters to promote the European mapping procedures carried on in the network, new projects and also newsletters of educational actions.

The following table contains the figures of the mediums rates obtained in each campaign, and link to one of the newsletters disseminated as an example of each campaign. Notice that those campaigns with less than two e-mails no present SD.

Dissemination Campaigns	Total emails sent (medium rates)	Opened (medium rates)	Open rate %	Clicked	Click rate %
<a href="#">ERN-EuroBloodNet European mapping for intraocular lymphoma</a>	368±1,41	90±5,65	24,6±1,45	1,5±0,71	0,41±0,19
<a href="#">ERN-EuroBloodNet European Mapping of Transcranial Doppler for children with Sickle Cell Disease</a>	386	88	22,92	1	0,26
<a href="#">European Rare Blood Disorders Platform (ENROL) Kick off Meeting</a>	362,67±7,51	104,33±4,51	29,18±1,47	8,33±7,02	2,35±2
<a href="#">Board of Network meeting</a>	382	102	26,91	9	2,37
<a href="#">ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients</a>	343,60±20,45	107,60±12,34	31,48±4,01	16±11,75	5,09±3,48
<a href="#">New repository of Guidelines &amp; other CDMTs and search tool!</a>	371	98	26,42	11	2,98
<a href="#">Topic on Focus: Cutaneous Lymphoma</a>	357,11±10,74	80,22±7,66	22,52±1,72	2,71±3,83	1,76±1
Thursdays webinars	357,92±18,98	88,02±11,48	26,81±10,14	8,84±3,50	4,04±7,54
Clinical Patient Management System (CPMS)	365	95	26,03	9	2,47

Table 2. Results from the Newsletters campaigns

All the newsletters are sent via the General Data Protection Regulation-compliant email platform [MailerLite](#).

During this period, the number of subscribers has increased to 386, including health professionals with profile created in ERN-EuroBloodNet repository of members and experts, candidates, ePAGs, National Societies and the new subscribers via web at the dedicated section of [ERN-EuroBloodNet website](#).

Considering the generally accepted measures for an email campaign success (source: [Campaign Monitor](#)):

- [Average email open rate should be between 15-25%.](#)
- [Average click-through rate should be about 2.5%.](#)

In line with this measures and the results obtained, the ERN-EuroBloodNet Newsletters campaigns can be defined as a powerful tool to maintain update and engaged our community. The figures shown that the higher impact on the subscribers has been the campaign of the ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients. The Last period the piece of news with higher number of clicks was the related to the [ERN-EuroBloodNet Board of Network meeting](#). During the actual one is the campaign of the [ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients](#) which capted more attention.

## ERN-EUROBLOODNET SOCIAL NETWORKS: TWITTER, FACEBOOK, LINKEDIN

[@ERN-EuroBloodNet Twitter](#) account registers more than 1400 Tweets, 920 followers (220 more than last year and 453 more than the first year) and 185 followed. Active interactions are given among the rest of ERNs, EU Health, projects as EJP on RDs, ELIXIR or RD-Connect, patients' associations as EURORDIS or Myeloma Europe, scientific associations as EHA or ESH (European School of Hematology) among many others.

Moreover, ERN-EuroBloodNet presence on social networks was increased with the creation of the following two new social profiles:

[ERN-EuroBloodNet Facebook](#) as one of the major social networks mainly addressing general audience. The profile has obtained more than 60 followers and obtained 60 likes on the 197 published posts.

[ERN-EuroBloodNet LinkedIn](#) as one of the major social networks connecting professionals. The profile accounts with 80 followers and 197 posts with 108 likes.

A dedicated piece of news on the launching of the new social networks is available at:

- [ERN-EuroBloodNet new social networks! Follow us on Facebook and LinkedIn!](#)

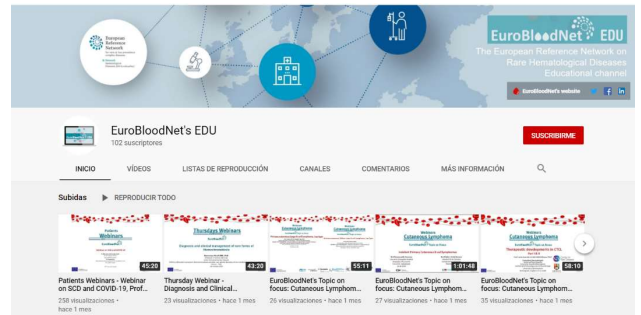
## ERN-EUROBLOODNET EDU YOUTUBE CHANNEL

[EuroBloodNet's EDUcational Youtube channel](#) has been created for the inclusion of educational videos created/endorsed by the network for the benefit of the EuroBloodNet community (patients and experts) by providing a direct and open access to the knowledge in the field of rare blood diseases.

The ERN-EuroBloodNet account, includes to date a total of 22 videos and has 102 subscribers.

The launch of the channel was announced through the dedicated piece of news:

- [EuroBloodNet's EDU YouTube channel has been launched!](#)



## 2.3 NEW SECTIONS ON THE ERN-EUROBLOODNET WEBSITE

### ACTUALIZATION OF THE GOVERNANCE SECTION

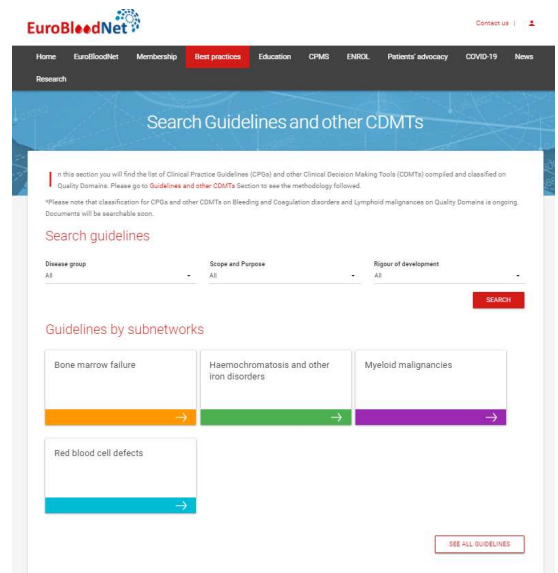
The visualization of the ERN-EuroBloodNet Coordination team in the website is to maintain a communication between the community. For this reason, [the Governance dedicated section](#) has been updated and visually improved.

### BEST PRACTICES SECTION

One of the key objectives established by ERN-EuroBloodNet is to foster best practice sharing in RHD by creating a comprehensive public repository of reliable evidence based guidelines, ranging from prevention, diagnostic tests and treatments to the organisation of patient-centred management in multidisciplinary teams.

The main actions devoted to this objective has been detailed in [Guidelines and Recommendations section](#), including the number of documents compiled and the exercise performed for their classification. The [repository of Clinical Practice Guidelines and other Clinical Decision Making Tools](#) classified based on Quality Domains are available at the dedicated section.

During this period the registry has been created and a dedicated section to find the list of Clinical Practice Guidelines (CPGs) and other Clinical Decision Making Tools (CDMTs) compiled and classified on Quality Domains has been launched and a dedicated newsletter has been disseminate among the ERN-EuroBloodNet community: [New repository of Guidelines & other CDMTs and search tool!](#)



### EDUCATION SECTION

[Thursdays webinars program](#) has been launched at the beginning of 2020 with the aim of promoting the interest on very innovative topics in order to stress among health professionals the cutting-edge advances in the field of Rare Hematological Diseases. Webinars are mainly addressed on very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines. At the same time, webinars' programs that are specifically addressed to patients intends to increase the awareness on a specific rare hematological disease among patients' advocates and patients associations.

Visual material has been produced by recording each webinar. According to this, each video session is uploaded in YouTube and linked in each corresponding section within [Past webinars](#), together with the slides in PDF.

### EUROPEAN RARE BLOOD DISORDERS PLATFORM (ENROL) SECTION

ENROL, the European Rare Blood Disorders Platform, has been conceived in the core of ERN-EuroBloodNet as an umbrella for both new and already existing registries on RHDs. A first ENROL one-page-section was released for offering an overview of the aims of the platform and structure until the official start of the project in June 2020.

ENROL section was subsequently upgraded in the context of the registry grant (HP-PJ-2019 on Rare disease registries for the European Reference Networks, GA number 947670) by the creation of the informative subsections displayed when accessing to [ENROL](#) in the main menu of ERN-EuroBloodNet website. Specific mention to Chafea co-funding is included.

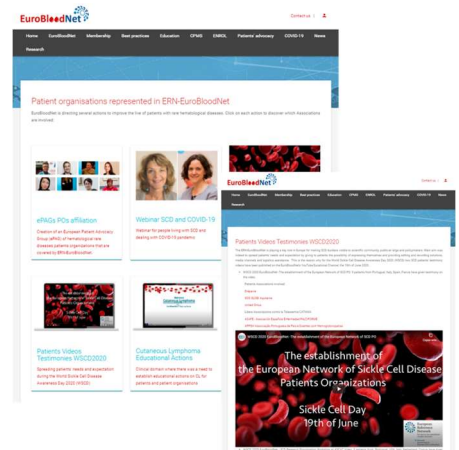
## PATIENTS' ADVOCACY

### PATIENTS ORGANIZATIONS ERN ACTIONS

ERN-EuroBloodNet is directing several actions to improve the live of patients with rare hematological diseases. All the actions are collected in the section named [Patients Organizations ERN actions](#).

Nowadays there are 7 different actions in this section. By selecting each action a new webpage is opened with further details, the concrete material produced and the list of organizations involved in this concrete action.

In order to give visibility to the different organizations the name is linked to its official webpage.



## COVID-19 SECTION

The ERN-EuroBloodNet has established a [European collaborative platform](#) to pool information in a collaborative way aiming to quickly identify the impact of COVID-19 on patients with red blood cell disorders and to understand the impact of risk factors such as prior disease complications. The dedicated section of this platform is divided in three sections:

### ABOUT THE PLATFORM

Description of the objectives of the platform, Research Protocol, Legal and Ethics and the Scientific Committee involved in the project are included in [this section](#).

### ACCES THE PLATFORM

[This section](#) included the direct links to the two steps needed to participate in this platform: Form to complete and link to the REDcap platform registry.

### USEFUL LINKS

During this period of COVID-19 efforts are being devoted by different initiatives for the generation of documents with indications for the clinical care of patients with rare hematological diseases. [This section](#) includes some of the documents produced with the participation of EuroBloodNet members, including language and target (health professionals or patients).

## RESEARCH SECTION

ERN-EuroBloodNet is also involved in five projects, that are described and linked in the dedicated sections. According to this a new botton in the menu has been created in which are included 5 tabs related to the 5 projects. A 6th project is the ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients, due to the relevance of the topic in the present, the section has been designed independently.

### EVIDENCE

The objective of [EVIDENCE](#) project (Erythrocytes properties and viability in dependence of flow and extra-cellular environment) is the exploration of the properties and behavior of RBCs under flow conditions and in vivo to understand pathophysiology and to design novel diagnostic devices.

### ERICA

The [European Rare disease research Coordination and support Action \(ERICA\)](#) project aims to establish a structural framework in support of the research activities of the ERNs. ERICA will promote inter-ERN research activities and establish firm collaborative ties with existing European and international infrastructures and consortia involved in rare disease research and innovation. The formation of this coordinated support structure will stimulate clinical research activities and leverage the cost efficiency of rare disease research in Europe and beyond, contributing to earlier diagnosis and better management for patients with rare diseases and conditions.

### GENOMED4ALL

[Genomics and Personalized Medicine for all though Artificial Intelligence in Haematological Diseases \(GENOMED4ALL\)](#) project proposal has been invited for the grant preparation phase under the call H2020 "DT-TDS-04: AI for Genomics and Personalised Medicine" for supporting the pooling of genomic, clinical data and other "-omics" health data (clinical data from Electronic Health Record, PET, MRI and CT, Next Generation Sequencing, etc.) through a secure and privacy respectful data sharing platform based on the novel Federated Learning scheme, to advance research in personalised medicine in haematological diseases thanks to advanced Artificial Intelligence (AI) models and standardized interoperable sharing of cross-border data, without needing to directly share any sensitive clinical / patients' data.

## INHERENT

The [International Hemoglobinopathy Research Network \(INHERENT\)](#) is an international network that focuses on the study of genetic modifiers for hemoglobinopathies through a large-scale multi-ethnic genome-wide association study (GWAS).

## RADEEP

[RADeep is the acronym for the Rare Anaemia Disorders European Epidemiological Platform](#). RADeep is an initiative for pooling data from patients affected by a rare anaemia disorder, built in line with ENROL and the EU-RD-Platform recommendations for patients' registries on rare disorders. RADeep contributes to ENROL sharing pseudonymised data of patients affected by a rare anaemia disorder.

## 2.4 PROMOTION OF THE USE OF THE ERN COLLABORATIVE PLATFORM

The [ERN-EuroBloodNet dedicated section in the ERN Collaborative Platform](#) has been used in order to share with ERN-EuroBloodNet members the following outcomes and Slides presented during the 4th Board of the Network meeting held the 22 October 2020.

A total of 54 ERN-EuroBloodNet users are active in the ECP.

## 2.5 DISSEMINATION AT EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

ERN-EuroBloodNet members are devoted to spread the messages and services of the network in every forum that might be relevant to strengthen the network. Meetings on RHDs are frequent around Europe and the ERN-EuroBloodNet members work to have a presence in the most relevant ones. Due to the COVID-19 pandemic, the number of activities have been reduced during this period, even so, some of the congresses/meetings/workshops where ERN-EuroBloodNet have been involved are:

- Thalassaemia International Day, organized by Malta Association of Biomedical Scientists, 5th May 2020, " The role of ERNs in enabling cross border (clinical) research on Rare Diseases " by Maria del Mar Mañú Pereira
- Maladies Rares: Point de vue de l'Europe, 4th November 2020, "Filière MARIH: RENCONTRE INTER-ASSOCIATIVE MARIH5, Meeting annuel Nationale" by Mariangela Pellegrini.
- Le réseau européen EuroBloodNet et les patients, 14th November 2020, "Filière MCGRE: Journée des associations, Meeting annuel Nationale" by Mariangela Pellegrini.
- Preparing Europe for novel cell and gene therapies - Launch Event of the European Alliance for Transformative Therapies, 8th December 2020, "Panel discussion: Bridging the Gap Between Innovation and Patients" by Béatrice Gulbis
- Diagnóstico y manejo de las enfermedades raras en eritropatología, abordaje multidisciplinar. Modelo de atención en un centro de referencia, 16th December 2020, "Modelo europeo de unidades referencia (ERN-EuroBloodNet)" by María del Mar Mañú Pereira
- IV Italian Meeting of HCP participating in EuroBloodNet, 23rd February 2021, "IV Italian Meeting of HCP participating in EuroBloodNet" by the participation of multiple ERN-EuroBloodNet italian experts: A. Iolascon - R. Colombatti - L. Malcovati - P Bianchi - GL Forni / U Ramenghi / C Dufour - L Brunetta - A Piga - M della Porta -MD Cappellini - D Girelli - F Longo.

## LINKED TO TASK 3. RELATIONS WITH THIRD PARTIES

### 3.1 PROMOTION OF COLLABORATION AGREEMENTS WITH THIRD PARTIES

#### EUROPEAN COMMISSION AND ERNs COORDINATORS GROUP

After the official approval for the 24 ERNs, a supra level group of coordinators was created for facilitating the gathering of different needs on common issues across the ERNs, sharing different points of view and facilitate the bidirectional communication with the EC.

The ERNs coordinators groups (ERNs CG) is formed by the 24 coordinators of ERNs, and during the third year it works under the coordination of Prof Nicoline Hoogerbrugge (ERN Genturis).

ERN-EuroBloodNet Coordination team has been present in all the ERNs CGs meetings organized by the EC aiming to update coordinators in the main issues concerning the operational management of the networks. ERN CGs meetings organized in this period have been the following:



- 10th meeting of the ERNs CG, 17th June 2020, online
- 11th meeting of the ERNs CG, 27th November 2020, online
- 12th meeting of the ERNs CG, 27th January 2021, online

In order to address the different frames of action, 6 Working Groups (WG) were established, where each ERN could participate, through their coordinators or any of their members, up to 3 WG. Given their high level of implication and constant increase of activity, during this period some of the representatives of the WGs for EuroBloodNet were changed. Accordingly:

- WG on Research presents two major subgroups, namely a) the registries represented by Maria del Mar Mañú Pereira, Eduard van Beers and Matteo della Porta and b) for basic and translational research, EuroBloodNet is represented by Richard van Beers, Paola Bianchi and Eduard van Beers.
- WG on Cross border health and brexit is represented by Raffaella Colombatti
- WG on Knowledge generation, including Taxonomy of Clinical Practice Guidelines and other related documents, represented by Maria del Mar Mañú, Luca Malcovati and Achille Iolascon
- WG on Monitoring, represented by María del Mar Mañú and Victoria Gutierrez Valle.

## ORPHANET

Orphanet is the reference portal for information on rare diseases and orphan drugs, for all audiences aiming to help the improvement of the diagnosis, care and treatment of patients with rare diseases. ENERCA project was previously in tight collaboration with Orphanet for the preparation of the International Classification of Rare Diseases (ICD+11).

ERN-EuroBloodNet has established a collaboration for the implementation of ORPHA classification for RHD at the back office of ERN-EuroBloodNet website prior revision of the classifications by subnetworks coordinators. Collaboration will be strengthened with the aim of contributing to the improvement of the Orphanet nomenclature.

## EURORDIS

EURORDIS represents more than 270 rare disease organisations from 32 countries, 19 of which are EU member states, and thereby reflects the voice of an estimated 30 million patients affected by rare diseases in the EU. One of its most important activities was the promotion of national centres of expertise and European Reference Networks.

ERN-EuroBloodNet has strengthened its relationships with patient associations through a close collaboration of EURORDIS ePAGs. In addition, the generation of contents for social networks consolidates and creates new contacts with patients through these organizations. Some of the actions promoted in this period have been:

- [EURORDIS publishes "No time to lose: Building a data strategy for the European Reference Networks" EURORDIS Rare Barometer survey infographic on Rare Disease perspectives on data sharing and data protection is now available in 23 languages!](#)
- [ERN-EuroBloodNet and EURORDIS working for the establishment of the European Network of Sickle Cell Disease Patients Organizations](#)
- [EURORDIS Recommendations to achieve a mature ERN system in 2030](#)

ERN-EuroBloodNet has also collaborated in the dissemination of the activities organized by for the Annual Rare Diseases Day. The dissemination has been mainly done through ERN-EuroBloodNet website and twitter by posting news and contributing to the Rare Disease Day movement.

- [Submit your nominations for the 10th edition EURORDIS Black Pearl Awards!](#)
- [Join the Annual Convention on Rare Diseases - Padova with the participation of ERN-EuroBloodNet!](#)

In addition, ERN-EuroBloodNet participated at the biennial European Conference on Rare Diseases and Orphan Products organized by EURORDIS that was held on 14-16 May 2020 online, with the presentation of 2 posters on “ENROL: The European Rare Blood Disorders Platform” and “ERN-EuroBloodNet: Establishment of the European Network of Sickle Cell Disease Patients Organizations”:

- [ERN-EuroBloodNet will be presenting two posters at European Conference on Rare Diseases & Orphan Products \(ECRD\) 2020!](#)

ERN-EuroBloodNet also contributed to the dissemination of the congress:

- [European Conference on Rare Diseases & Orphan Products \(ECRD\) 2020 moves online next 14-16 May](#)
- [Register until 1st May to the European Conference on Rare Diseases & Orphan Products \(ECRD\) 2020!](#)

## EUROPEAN MEDICINES AGENCY (EMA)

The European Medicines Agency (EMA) is a decentralised agency of the European Union (EU). It began operating in 1995. The Agency is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. EMA protects public and animal health in EU Member States, as well as the countries of the European Economic Area, by ensuring that all medicines available on the EU market are safe, effective and of high quality.

EMA has established collaborations with ERNs in order to discuss the role of registries in the monitoring of cancer therapies based on genetic and molecular features and agree on recommendations about:

- Core data elements that should be collected in cancer registries to support regulatory assessment of the safety and effectiveness of new cancer treatments;
- Quality assurance measures necessary to ensure registry data are of suitable quality to support regulatory assessments and to permit registries interoperability; and
- Practical considerations for accessing/sharing data to be used for regulatory purposes.

In this context, EMA organized a multi-stakeholders workshop on the 29th November at Amsterdam with the participation of Regulators, Registry holders/representatives, Academia, Industry, Patients/HCP organisations, and Health Technology Assessment bodies.

Matteo della Porta attended in representation of ERN-EuroBloodNet as ERNs WG on registries representative for the oncological hub.

- [Report of the "Workshop on the use of registries in the monitoring of cancer therapies based on tumours' genetic and molecular features" hosted in November 2019 by the EMA](#)

## EUROPEAN JOINT PROGRAMME (EJP) ON RARE DISEASES

The [European Joint Programme \(EJP\) on Rare Diseases](#) brings over 130 institutions from 35 countries to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation. EJP has been established to further help in coordinating the research efforts of European, Associated and non-European countries in the field of rare diseases and implement the objectives of the International Rare Disease Research Consortium (IRDiRC).

ERN-EuroBloodNet has established official collaborations to participate in four of its pillars by ERN-EuroBloodNet representatives: [Achille Iolascon](#), [Marina Kleanthous](#), [Patricia Aguilar Martinez](#) and [Paola Bianchi](#).

Following the ERNs Conference (15/01/2021), EJP has started a fruitful initiative called "Tuesday Afternoon ERN Coffee Rounds". These talks are held as Microsoft Teams meetings on Tuesdays from 16:00 to 17:00 CET dealing with key transversal topics concerning all ERNs, as practical steps for ERN registries implementation, and where ERN-EuroBloodNet has participated.

In addition, the following pieces of news has been published for promoting the different actions provided by EJP:

- [The EJP-RD ERN Research Training Workshops Call is now open!](#)
- [Attend the EJP RD Information Webinar for the JTC2021](#)
- [The EJP RD has launched an Internal Call for Innovation Project in Clinical Trials Methodology in Limited Populations!](#)
- [EJP RD has produced a Short guide on patient partnerships in rare diseases research projects](#)

## PATIENT'S ASSOCIATIONS

Patients are one of the main motor of the ERN-EuroBloodNet. The network seeks direct contact with those organizations supporting patients living with RHDs and their families. The cooperation with these entities includes listing a growing number of Associations in the ERN-EuroBloodNet website.

## 3.2 PROMOTION OF RELATIONS WITH NATIONAL SCIENTIFIC SOCIETIES

Contacts have already been established with National Scientific Societies identified for the dissemination of specific actions implemented by the network, ie. ERN-EuroBloodNet Thursdays webinars.

## 5. NEXT STEPS

During the fourth year of ERN-EuroBloodNet implementation, activities have been successfully addressed aiming to increase the outreach of the ERN-EuroBloodNet outcomes. For the prioritization of activities to be implemented during next period, feedback from ERN-EuroBloodNet members has been analysed in order to identify the more weaknesses and urgent actions to be undertaken in the dissemination field. Accordingly, some of the needs identified and dedicated actions that will be undertaken in the coming period are:

### IMPROVEMENT ON THE DISSEMINATION AT NATIONAL LEVEL

A list of contact points for the National Scientific Societies of Hematology has been created identifying the key actors in each of the organizations. All the newsletters and major pieces of news distributed among ERN-EuroBloodNet members and newsletter subscribers are in addition sent to them in order to allow their re-distribution among their community of stakeholders.

Updates will be performed in the coming months in order to ensure having the correct contact persons for distributing the ERN-EuroBloodNet actions among the targeting communities.

Through this methodology the key activities and outcomes launched by the network will be much targeted distributed among the different societies at the national and European level increasing significantly the impact of the dissemination actions.

### EXPANSION OF ERN-EUROBLOODNET WEBSITE SECTIONS

ERN-EuroBloodNet website is defined by its dynamism not only in its content, but also in the evolution of its structure in the flexible way that a complex network as ERN-EuroBloodNet requires for covering its needs.

In this context, next steps foreseen are:

1. Implementation of directories created under the frame of specific Transversal field of actions, eg. existing registries on RHD...
2. Finalize the implementation of experts profiles for the recent incorporation of Affiliated partners and future new members.
3. Creation of the new "Disease cards" website section where each disease group will have its own "card", showing all the interrelated actions/documents tagged in the website for the specific group. Each card will be composed by the following sheets: Reference centers and experts, Patients associations, Guidelines and other Clinical Decision Making Tools, Educational actions, observational studies and clinical trials, and ongoing projects.

### ERN-EUROBLOODNET PLAN FOR PUBLICATIONS

It is undeniable the impact that the peer-review publications have on the health community. For this reason, it is essential to ensure the maximum level of resonance of all the actions and results obtained through the network by assuring the highest numbers of publications as possible.

In line with the ERNs monitoring indicators, ERN-EuroBloodNet is working on the definition of the strategy to improve the first results obtained through the monitoring exercises conducted, including a plan for publications.





[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)



[www.eurobloodnet.eu](http://www.eurobloodnet.eu)

Co-funded by the European Union

