



DELIVERABLE 2.3 ANNUAL DISSEMINATION REPORT 3

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 2.3 ANNUAL DISSEMINATION REPORT 3

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

28/02/2022

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 ERN-EuroBloodNet communication channels

2.2 Expansion of ERN-EuroBloodNet website

2.3 Promotion of the use of the ERN collaborative platform

2.4 Dissemination at European rare diseases meetings and workshops

Task 3. Relations with third parties

3.1 Promotion of collaborations 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 ERN-EuroBloodNet communication channels

2.2 Expansion of ERN-EuroBloodNet website

2.3 Promotion of the use of the ERN collaborative platform

2.4 Dissemination at European rare diseases meetings and workshops

Linked to Task 3. Relations with third parties

3.1 Promotion of collaborations with third parties

3.2 Promotion of relations with National Scientific Societies of Hematology

5. Conclusions & 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 because 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.

Nowadays, ERN-EuroBloodNet has increased its coverage with 36 new Members from 11 MS and with 7 APs from 6 MS, therefore an upgrade of the inventory has been implemented for their proper inclusion.

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

2.1 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, including:

- 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



Fig 1. ERN-EuroBloodNet Newsletter

SOCIAL NETWORKS EXPANSION: TWITTER, FACEBOOK AND LINKEDIN

The presence of the network in social media increases the impact of the messages launched by the network. ERN-EuroBloodNet has the account [@ERNEuroBloodNet](#) in Twitter since the initial steps of the Network. The communication channels have been expanded during the last period of network implementation in order to improve the outreach of network actions:

1. Facebook ([Eurobloodnet - European Reference Network on Rare Hematological Diseases](#)), as one of the major social networks mainly addressing general audience
2. LinkedIn ([EuroBloodNet - European Reference Network on Rare Hematological Diseases](#)), as one of the major social networks connecting professionals.

Nowadays, the three social media channels are essential tools for the dissemination of the actions because within the ERN-EuroBloodNet and for the communication with the rare disease community.

ERN-EUROBLOODNET EDU YOUTUBE CHANNEL

[EuroBloodNet's EDUcational Youtube channel](#) was launched during the previous period of implementation for the inclusion of educational videos created/endorsed by the network for the benefit of the ERN-EuroBloodNet community (patients and experts) by providing a direct and open access to the knowledge in the field of rare blood diseases. Nowadays a total of 72 videos have been published and 262 subscribers has been gained.

ERN-EUROBLOODNET PROGRESS MEETINGS

ERN-EuroBloodNet face-to-face social events have been adapted to the current COVID-19 situation. Therefore, the two habitual established meetings per year in ERN-EuroBloodNet have been held online, becauseh makes them more accessible to the community and increases the outreach of the ongoing actions.

The meetings 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.

- The **1st ERN-EuroBloodNet Progress Meeting** was held on the 20th of May 2021. The meeting was divided into 5 topics:
 1. Cross Border Health
 2. Continuing Medical Education
 3. Best Practices
 4. Telemedicine
 5. Clinical Trials and Research
- The **2nd ERN-EuroBloodNet Progress Meeting** was held on the 28th October 2021. This edition was organized in different areas:
 1. Introduction: A new framework for the ERN-EuroBloodNet
 2. Session I: Diseases on Focus
 3. Session II: Guidelines & Continual Medical Education
 4. Session III: Innovation & Research

Major outcomes of both editions 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:

- [The 1st ERN-EuroBloodNet Progress meeting took place on 20th May with more than 140 participants thanks to all!](#)
- [The 2nd edition of the ERN-EuroBloodNet Progress meeting took place on 28th October!](#)

2.2 EXPANSION OF ERN-EUROBLOODNET WEBSITE

[ERN-EuroBloodNet website](#) is the main 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 becaused by the networks.

In line with the previous presented concept, ERN-EuroBloodNet website has been designed as the on-line platform that provides not only the door of access to ERN-EuroBloodNet dynamic and public inventory of Members, experts and Patients Organizations but also to the main tools becaused and implemented during the running time of the network.

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

- As the main tool for dissemination of the ongoing actions, achievements and related events to promote public awareness of the network.
- ERN-EuroBloodNet website as the infrastructure (web portal and database) for accessing the Inventory of ERN-EuroBloodNet profiles

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

2.3 PROMOTION OF THE USE OF THE ERN COLLABORATIVE PLATFORM

The platform becaused by the EC is an ideal tool for communication, dissemination of activities and sharing of documents among ERN-EuroBloodNet members. Since its implementation, it has been promoted and used in ERN-EuroBloodNet by uploading of exclusive material of interest for our community.

2.4 DISSEMINATION AT EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

Online and virtual relations promote collaboration, especially under the current pandemic situation. Activities becaused by ERN-EuroBloodNet members have been reported to the coordination team and, since this period, also published on the ERN-EuroBloodNet website.

TASK 3. RELATIONS WITH THIRD PARTIES

3.1 PROMOTION OF COLLABORATIONS WITH THIRD PARTIES

The collaboration among ERNs, projects, and initiatives seeking equal objectives to those established in ERN-EuroBloodNet is of major importance in a networking environment. As in the previous period, ERN-EuroBloodNet has consolidated collaborations 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, the list of National Societies of Hematology Associations created is continuously updated 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 resolution of the Assessment of the call for new ERNs members has allowed the integration of 36 new ERN-EuroBloodNet members. Accordingly, their new profiles for Healthcare providers, Departments and Experts (representatives, substitutes and Multidisciplinary teams) have been created on the [ERN-EuroBloodNet website](#).

Moreover, the repository's back office has been technically upgraded to allow the creation of profiles for Experts, Departments and HCPs profiles for the [Affiliated Partners](#) and [Supporting Partners](#). The design ensures the same structure as for the creation of ERN-EuroBloodNet Members profiles, including the selection of the diseases of expertise based on ORPHA classification.

In addition, these profiles are also findable through [the search tool](#) implemented on the website:

Results:

Austria

Medical University of Vienna <

Ordensklinikum Linz Elisabethinen <

Belgium

Institut Jules Bordet <

Denmark

Aarhus University Hospital <

France

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

-  Nicolas Boissel
-  David Boutboul
-  Adèle De Masson
-  Léa Margot
-  Bagot Martine
-  Eric Oksenhendler
-  Mariangela Pellegrini

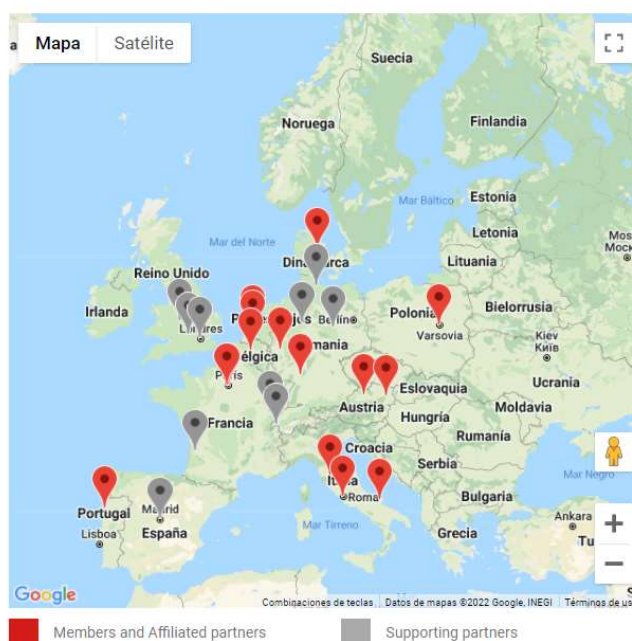


Fig 2. ERN-EuroBloodNet upgraded Search Experts tool

In addition, because upgrade performed on the repository's back office during the present period of implementation has been the creation of profiles for [Patients Organizations Supporting Groups](#) including the Country, geographical coverage, diseases groups covered by the organization (to be selected from RHD disease groups), Umbrella linked to the organization and links. The design ensures the same structure as for the creation of ERN-EuroBloodNet Members profiles, including the selection of the diseases of expertise based on ORPHA classification, therefore ensuring an interlink with all the existing profiles with ORPHA classification as common codification element.

Full details on the upgrades implemented and analysis of the state of the art of the repository can be found at Deliverable 4.3 ERN-EuroBloodNet Repository of members 3 (February 2022).

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

2.1 ERN-EUROBLOODNET COMMUNICATION CHANNELS

ERN-EUROBLOODNET MONTHLY NEWSLETTER AND OTHER SPECIFIC NEWSLETTERS

Since the launch of the ERN-EuroBloodNet Newsletter in October 2019 all the issues are visible at the [ERN-EuroBloodNet website dedicated section](#). During this interval two different types of newsletters have been because:

1. Monthly Newsletter: Disseminated the last day of the month (Table 1)
2. Newsletters devoted to concrete actions related to ongoing projects (Table 2)

	Total emails sent	Opened (medium rates)	Open rate %	Clicked (medium rates)	Click rate %
March 2021	398	133	33,42	19	4,77
April 2021	401	111	27,68	14	3,49
May 2021	406	114	28,08	16	3,94
June 2021	412	112	27,18	10	2,43
July 2021	412	109	26,52	12	2,92
August 2021	414	112	27,05	15	3,62
September 2021	422	113	26,84	12	2,85
October 2021	427	141	33,1	20	4,69
November 2021	429	123	28,6	14	3,26
December 2021	432	138	32,02	23	5,34
January 2022	435	135	31,03	23	5,29
February 2022*					
Medium rates (without Feb.)	417,09	121,91	29,23	16,18	3,87
Und deviation	±12,71	±12,42	±2,64	±4,47	±1,01

* The results of the Newsletter of February can not be included becausee during the analysis of this deliverable it has not been disseminated yet.

Table 1. Results from the Monthly Newsletters campaigns

Specific newsletters devoted to concrete actions are disseminated with the purpose to boost their visibility among the rare hematological community. During this period, [ERN-EuroBloodNet](#) considered important to disseminate 10 different campaigns to promote:

- The achievements obtained in the network thanks to the collaboration of the community : Presentation of two projects related to [ERN-EuroBloodNet](#) at the 63rd ASH Annual Exposition
- The boost of awareness on Sickle Cell Disease
- The outcomes fruit of the 1rst Progress Meeting held on the 20th May 2021
- Newsletters of educational actions for Patients and Healthcare professionals.

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 Campaign	Number of Newsletters	Total emails sent	Opened (medium rates)	Open rate %	Clicked (medium rates)	Click rate %
WSCD2021 Awareness Day ERN-EuroBloodNet Poster	1	412	112	27,18	10	2,43
1rst Progress Meeting (Outcomes)	1	413	114	27,6	15	3,63
ERN-EuroBloodNet present in the 63rd ASH Annual Meeting and Exposition	1	430	136	31,7	24	5,59
Happy Holidays and Happy New Year 2022!	1	431	133	30,93	10	2,33
ERN-EuroBloodNet Thursdays webinars program	22	417,36±14,39	108,32±23,54	26,99±2,51	17,09±20,75	3,24±1,50
ERN-EuroBloodNet Topic on Focus: Thrombotic Microangiopathies	26	411,46±12,06	78,85±32,40	19,36±8,08	8,73±4,11	2,11±0,95
ERN-EuroBloodNet Topic on Focus: Bone Marrow Failures Syndromes	3	434,66±1,53	58,66±69,57	13,54±16,08	23±7,81	5,3±1,81
ERN-EuroBloodNet Topic on Focus on Sickle Cell Disease for Patients and their Families	4	436,5±1,54	14,5±5,07	3,35±1,21	14,5±5,07	3,35±1,21
ERN-EuroBloodNet Topic on Focus Myélodysplasies : un sujet d'intérêt pour les patients et leurs familles	16	421,69±9,30	94,69±10,02	22,48±2,10	6,25±3,89	1,48±0,91
EHA & ERN-EuroBloodNet Spotlight on Castleman Disease	6	435,83±1,17	131,17±10,15	30,35±2,36	11,6±3,93	2,7±0,92

Table 2. Results from the Newsletters campaigns during the period of March 2021 to February 2022

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

From March 2021 to February 2022, the number of subscribers has increased to 437 (51 new subscribers). Among the subscribers there are health professionals with profile created in ERN-EuroBloodNet repository of members and experts, 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 17-28%.](#)
- [Average click-through rate should be about 2-5%.](#)

According to the established parameters, the ERN-EuroBloodNet Newsletters campaigns can be defined as a powerful tool to maintain update and engaged our community. The figures shown that The [ERN-EuroBloodNet present in the 63rd ASH Annual Meeting and Exposition](#) campaign has capted more attention than the others during this period. The Last periods, the pieces of news with higher number of clicks were:

1. [ERN-EuroBloodNet Board of Network meeting](#) (March 2019 to January 2021)
2. [ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients](#) (March 2021 to January 2022)

ERN-EUROBLOODNET SOCIAL NETWORKS: TWITTER, FACEBOOK, LINKEDIN

[@ERN-EuroBloodNet Twitter](#) account registers more than 2170 Tweets, 1154 followers (705 more than the first year, as shown in Fig 3) and 236 followed. Active interactions are given among the rest of ERNs, [EU Health](#), projects as [EJP on RDs](#), [Genomed4all](#), patients' associations as [EURORDIS](#) or [Myeloma Patients Europe](#), and scientific associations as ESH (European School of Hematology) or [EHA \(European Hematology Association\)](#). During this period ERN-EuroBloodNet has established a direct collaboration with the EHA for the dissemination of ERN-EuroBloodNet actions.

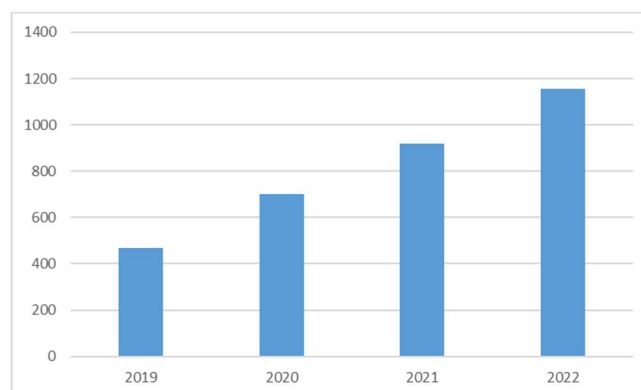


Fig 3. Progression of the number of twitter followers

Number of visits	Number of Tweets	Mentions
4028±1820	27±15	27±17

Table 3. Monthly estimation of the Activity in Twitter (March 2021-January 2022)

The material disseminated in ERN-EuroBloodNet twitter account since 2020 are also posted in Facebook and LinkedIn:

[ERN-EuroBloodNet Facebook](#) as one of the major social networks mainly addressing general audience. The profile has 197 followers.

[ERN-EuroBloodNet LinkedIn](#) as one of the major social networks connecting professionals. The profile accounts with 260 followers (180 followers more than the first year).

ERN-EUROBLOODNET EDU YOUTUBE CHANNEL

Since [the EuroBloodNet's EDUcational Youtube channel lauchment](#), this tool has become the ERN-EuroBloodNet repository of videos that have been created or are endorsed by ERN-EuroBloodNet together with the ERN-EuroBloodNet website.

Nowadays a total of 79 videos (57 more videos than the first year) have been published on the platform. The diversification of the hematological topics of the videos has promoted a ratio of increase of 2,5 on the number of subscribers. The diversification is due to a) the enlargement of the targeted audience by starting the production of videos for Patients Organizations and for Patients and Families of Patients and b) the establishment of new educational programs focused on several diseases.

Further details on the Educational Programs addressing health professionals are detailed on Deliverable 6.3 ERN-EuroBloodNet report on actions for the promotion of Continuing medical education on RHD 3 (February 2022), and addressing patients on Deliverable 6.5 ERN-EuroBloodNet report on actions for the promotion of patients' empowerment 2 (February 2022).

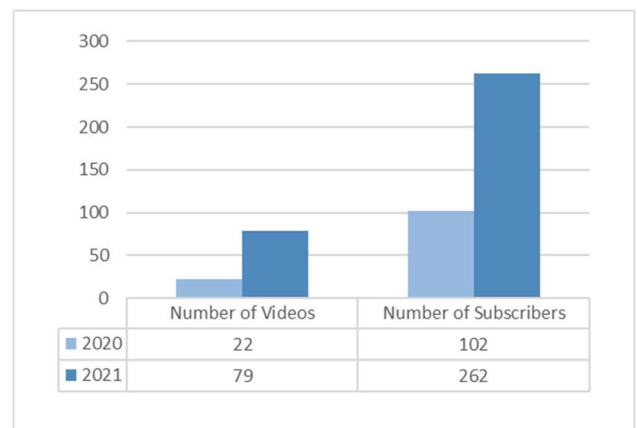


Fig 4. Progression the ERN-EuroBloodNet's YouTube channel over the years

With the aim to give higher visibility to communication channels in the ERN-EuroBloodNet website, a specific icon image has been created and added in the footer menu with a direct link to facebook, Twitter, linkeding and youtube.

2.2 EXPANSION OF ERN-EUROBLOODNET WEBSITE

HOME PAGE UPDATE

Aiming to give a simplified but concrete overview of the ongoing actions and achieve goals of ERN-EuroBloodNet a new structure of the Home Page has been designed for the inclusion of "Highlights"

In this section, 5 different topics can be included with the following structure: Title, Description text and an Image. The information devoted to each section is directly managed by the IT and Dissemination manager allowing its continuous update on the key actions, results and news willing to promote under the umbrella of the network

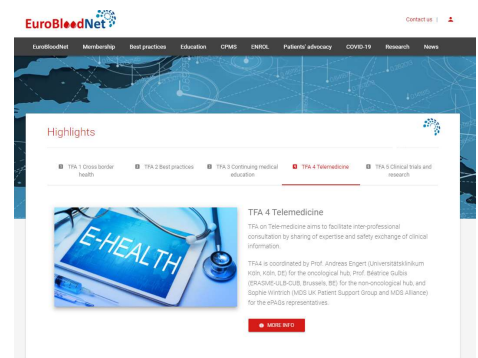


Fig 5. Highlights at Home page

"WHO WE ARE?" SECTION UPDATE

According to the incorporation of 36 new Members, an update on the description included in the [Who we are?](#) section has been performed.

EDUCATION SECTION RESTRUCTURING AND UPDATE

ERN-EuroBloodNet education section has been upgraded and restructured during this period of implementation in order to include the expansion to activities addressing Patients, Families of Patients and Patients Organizations.

a) The [Educational Section for Health Professionals](#) is divided into several sections and are included in the new website dedicated page. Each box includes an image created exclusively for it and a direct link to the section:

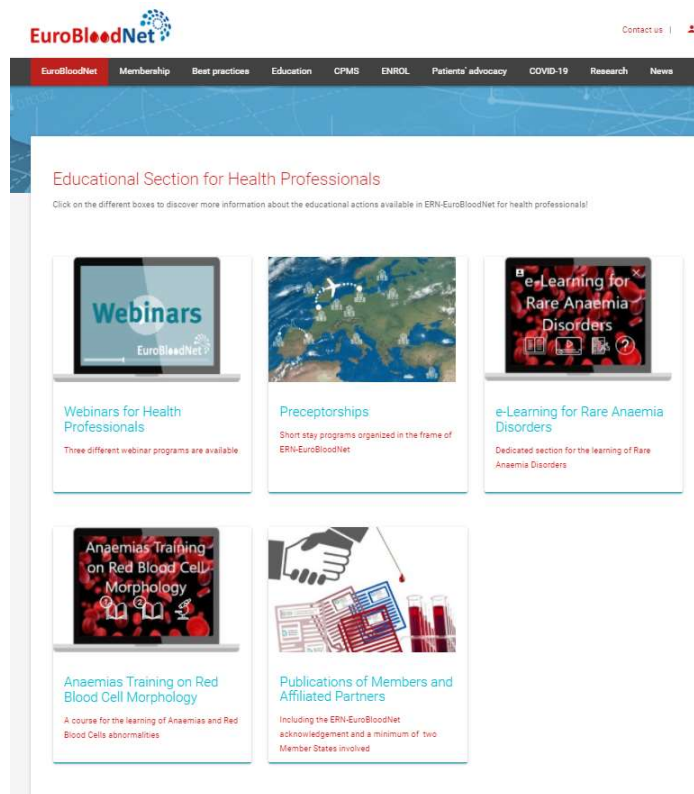


Fig 6. Education section for health professionals

WEBINARS: Three types of programs are included in this section.

1. [Thursdays webinars program](#) has been launched at the beginning of 2020 with the aim of promoting the interest In 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 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 of a specific rare hematological disease among patients' advocates and patients associations.
2. [Topic On Focus](#): This year two now Topics have been launched.
3. [EHA&ERN-EuroBloodNet Spotlight on Castleman Disease](#): This educational program has been launched and created in collaboration with the European Hematology Association this year.

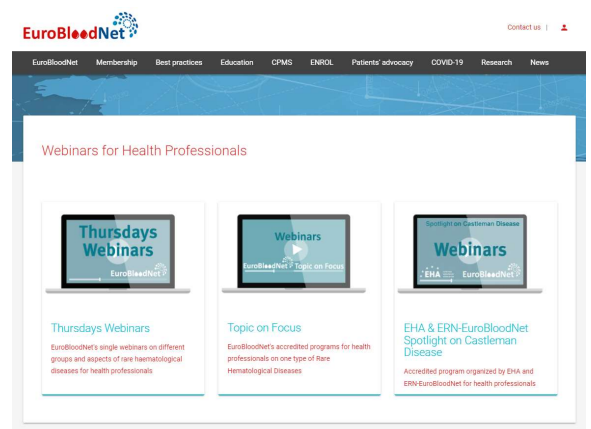


Fig 7. Webinars programs for health professionals

PRECEPTORSHIPS: Short stay programs organized in the frame of ERN-EuroBloodNet are included in this section.

E-LEARNING FOR RARE ANEMIA DISORDERS: This section has been created with the aim to update the rare disease community about the soon launch of the e-Learning content for Rare Anemia Disorders.

ANEMIAS TRAINING ON RED BLOOD CELL MORPHOLOGY: A course for the learning of Anaemias and Red Blood Cells abnormalities is now online available (in English and French) on the ERN-EuroBloodNet website thanks to the transfer work performed by the University of Montpellier. The course was produced by O. Fenneteau ([Hôpital Robert Debré, Paris](#)), V. Latger-Cannard (CHU de Nancy), J. Buisine (CHU de Nancy), F. Mielot (Hôpital Kremlin Bicêtre), T. Cynober (Hôpital Kremlin Bicêtre), P. Aguilar-Martinez ([CHU de Montpellier](#)), M. Maier-Redelsperger (Hôpital Tenon, Paris), R. Girot (Hôpital Tenon, Paris) and edited by Pr. Georges Flandrin.

PUBLICATIONS OF MEMBERS AND AFFILIATED PARTNERS: A new section has been created to include the list of Publications accredited by ERN-EuroBloodNet.

b) The [section devoted to the educational Patients webinar programs](#) is divided in three sections:

1. **Patients Webinars:** Punctual webinars providing patients' community highly specialized knowledge on a specific RHD or groups of disease. To different webinars are included in this section until now: [Webinar SCD and COVID-19, CDA I and CDA II](#)

2. **Topic on Focus for Patients:** The program promoting the awareness on a Rare Hematological disease or groups of disease targeting patients. Two different topics have been launched:

- [ERN-EuroBloodNet Topic on Focus Myélodysplasies : un sujet d'intérêt pour les patients et leurs familles](#)
- [ERN-EuroBloodNet Topic on Focus on Sickle Cell Disease for Patients and their Families](#)

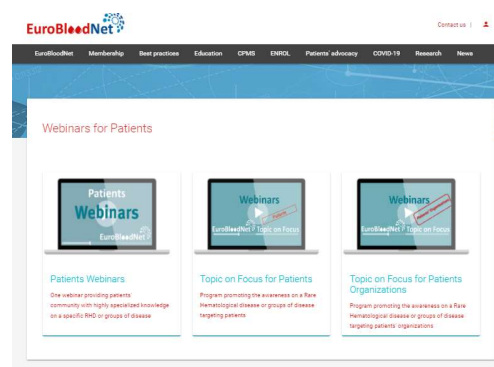


Fig 8. Webinars programs for patients

3. **Topic on Focus for Patients Organizations:** The Program promoting the awareness on a Rare Hematological disease or groups of disease targeting patients' organizations. This year has been held the [ERN EuroBloodNet Topic on Focus for Patients' Organizations: Cutaneous Lymphoma](#)

Each educational webinar program (including the dedicated to both Professionals and Patients) incorporated in the ERN-EuroBloodNet website is developed and structured in the back-office. Visual material has been produced by recording each webinar. According to this, each video session is uploaded in [ERN-EuroBloodNet YouTube channel](#) and linked in each corresponding section within [Past webinars](#), together with the slides in PDF.

BEST PRACTICES SECTION UPDATE

One of the principal goals of ERN-EuroBloodNet is to promote best practice sharing in RHD. 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 repository has been actualized with the inclusion of new material. Further details can be found at Deliverable 5.3 ERN-EuroBloodNet repository of clinical practice guidelines and other clinical decision making tools on RHD 3 (February 2022).

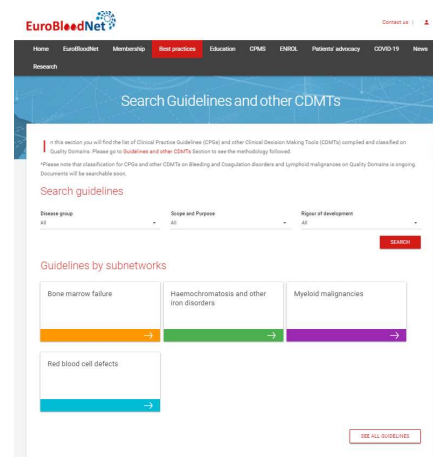


Fig 9. CPGs and other CDMTs search tool

EUROPEAN RARE BLOOD DISORDERS PLATFORM (ENROL) SECTION UPDATE

[ENROL, the European Rare Blood Disorders Platform](#), has been developed 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.

During this period a new section has been included in the ENROL section related to the collaborations established with new/existing registries within the umbrella of ENROL: a) EuroBNet: The registry devoted to Dendritic Cell Leukaemias will be launched soon. The information related to the registry and link to it will be included in this section, b) [RADeep](#): 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.

PATIENTS' ADVOCACY UPDATE

EUROPEAN PATIENTS ADVOCACY GROUP (EPAG)

The ePAG of the hematology group is nominated to represent their disease area in the ERN-EuroBloodNet as well as the interests of the wider patient community affected by rare hematological diseases. They are the voice of the patients in the EuroBloodNet Board of Network. EURORDIS - Rare Diseases Europe ensures transversal coordination as well as provides specific training programmes.

This year [Natascha Bolaños from Lymphoma Coalition](#) has joined the group for representing Lymphoma patients. Her profile has been included in the dedicated section. Nowadays 9 ePAG are involved in ERN-EuroBloodNet.

Furthermore, an update on the organizations related to the ePAG representing Lymphoma patients, Pierre Aumont, have been performed.

PATIENTS ORGANIZATIONS ERN ACTIONS

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

Nowadays there are 9 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.

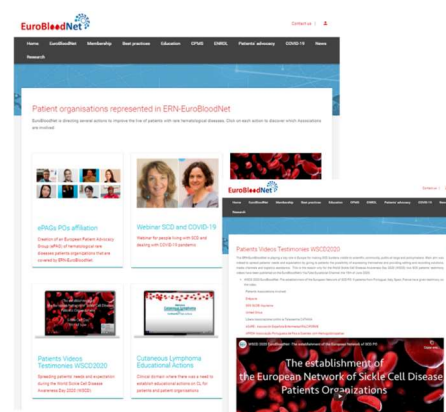


Fig 10. Patient organisations represented in ERN section

2.3 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 two ERN-EuroBloodNet Progress Meetings organized in 2021 (20th of May and 28th of October).

2.4 DISSEMINATION AT EUROPEAN RARE DISEASES MEETINGS AND WORKSHOPS

ERN-EuroBloodNet members are devoted to disseminated messages and services of the network in every forum that is related to the hematological topic. Conferences on RHDs are frequent around Europe and the ERN-EuroBloodNet members work to have a presence in the most relevant ones. As a novelty, [a dedicated section including the list of the congresses/meetings/workshops where ERN-EuroBloodNet is involved has been published in the ERN-EuroBloodNet website](#).

Detailed information is included: Date of the event, Slot in the Agenda, Name of the Event, Emplacement of the event (Country or on-line) and Name and Surname of the Representatives (including link to the ERN-EuroBloodNet expert profile).

LINKED TO TASK 3. RELATIONS WITH THIRD PARTIES

3.1 PROMOTION OF COLLABORATIONS 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 fifth year it works under the coordination of Prof H el ene Dollfus (ERN EYE).

ERN-EuroBloodNet 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. Moreover, in order to address the different frames of action, Working Groups (WG) were established, where each ERN could participate, through their coordinators or any of their members. ERN-EuroBloodNet actively contributes to WGs on Research and Knowledge generation, currently integrated in ERICA, and Monitoring.

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.

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 has been extended to ENROL for the implementation of ORPHA and HPO codifications in the registry dataset.

EUROPEAN HEMATOLOGY ASSOCIATION (EHA)

The [European Hematology Association \(EHA\)](#) promotes excellence in patient care, research, and education in hematology.

During this period ERN-EuroBloodNet has straightened the collaboration with the EHA in several ongoing actions. Regarding the educational area, a newly accredited webinar program for health professionals has been co-organized [EHA & ERN-EuroBloodNet Spotlight on Castleman Disease](#).



Fig 11. EHA & ERN-EuroBloodNet Spotlight

A dissemination campaign has been coordinated and co-disseminated among both communities. ERN-EuroBloodNet has included EHA's activities in the dissemination campaigns, such as: [Apply to the 5th edition of the Clinical Research Training in Hematology organized by the European Hematology Association!](#)

EURORDIS

[EURORDIS](#) represents more than 988 rare disease organizations from 74 countries, 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.

Since the beginning of ERN-EuroBloodNet, the relationships between ERN-EuroBloodNet and EURORDIS has facilitate the collaboration 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](#)
- [Participate in the EURORDIS Photo Award!](#)

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 Social Media channels 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!](#)
- [Participate in The Black Pearl Awards 2022!](#)
- [The nomination period of the EURORDIS Black Pearl Awards is open!](#)

In the previous period, 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 previous 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 since its establishment in 1995). The Agency is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. The 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.

The EMA initiated collaborations with ERNs in order to discuss the role of registries in the monitoring of cancer therapies and to agree on recommendations about: a) Core data elements that should be collected in cancer registries to support regulatory assessment of the safety and effectiveness of new cancer treatments; b) Quality assurance measures necessary to ensure registry data are of suitable quality to support regulatory assessments and to permit registries interoperability; and c) Practical considerations for accessing/sharing data to be used for regulatory purposes.

In this context, EMA organized a multi-stakeholders workshop at Amsterdam in 2019 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 ENROL and ERN-EuroBloodNet as ERNs WG on registries .

ERN-EuroBloodNet has also collaborated in the dissemination of actions where the EMA is involved:

- [Accelerating Clinical Trials in the EU \(ACT EU\): The new initiative to optimise the environment for clinical research in Europe!](#)

EUROPEAN JOINT PROGRAMME (EJP) ON RARE DISEASES

The [European Joint Programme \(EJP\) on Rare Diseases](#) brings over 130 institutions from 35 countries, 26 of them are EU Member States, 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).

Moreover, EJP, together with ERICA and the Joint Research Center (JRC) are promoting synergies among ERNs for the definition of Domain specific Common Data Elements (DCDEs) with the objective to be able to share domain specific data between ERNs, data that is not currently covered by the Common Data Elements (CDEs). At this stage, the first of a short series of online meetings have been held including representatives from all the ERNs to finalize the DCDEs.

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](#)
- [The EJP RD Rare Disease Day Video is online!](#)
- [EJP RD call for Research Mobility Fellowships will open on 15th of March!](#)
- [The EJP RD Research Mobility Fellowships funding opportunity is now open!](#)
- [EJP RD's ERN Workshop: "Clinical Research: The Basics & Beyond"](#)
- [Strategy Meeting: Alignment of national rare diseases strategies with the EJP RD](#)
- [The International Summer School on Rare Disease Registries and FAIRification call is opened until 11th July 2021!](#)
- ["Quality assurance, variant interpretation and data management in the NGS diagnostics era" a new training activity proposed by the EJP RD](#)
- [GATA2-related Myelodysplastic Syndromes workshop is a new training activity offered by the EJP RD](#)
- [The European Joint Programme on Rare Diseases has launched the ERN Research Training Workshops!](#)
- [The next EJP RD Resource Webinar is dedicated to European Paediatric Translational Research Infrastructure!](#)
- [EJP RD ERN Research Training Workshops Funding Opportunity: Deadline extended to October 22nd!](#)
- [The EJP RD Research Mobility Fellowships funding opportunity is now open until November 28th!](#)
- [Get EJP RD's support on your application for the Horizon Europe Call for Proposals: Development of new effective therapies for rare diseases](#)
- [The EJP RD Joint Transnational Call 2022 has been pre-announced!](#)
- [Do not miss the webinar focused on Domain specific Common Data Elements \(DCDEs\) Curation!](#)
- [EJP RD is glad to announce the upcoming launch on December 14th of the fourth EJP RD Joint Transnational Call \(JTC\) 2022!](#)
- [EJ PRD has announced the official launch of the Joint Transnational Call 2022!](#)
- [Apply to the EJ PRD Joint Transnational Call 2022!](#)
- [EJ PRD has announced the official launch of their Instagram account](#)

EUROPEAN COMMISSION – EU RD PLATFORM

In order to support the interoperability of data in RD registries, the Directorate F (Health, Consumers and Reference Materials), the Health in Society Unit (F.1) developed in collaboration with DG SANTE, the EU Platform on Rare Disease Registration (EU RD Platform).

[The EU RD Platform](#) copes with the fragmentation of RD patients data contained in hundreds of registries across Europe. This is ensured by the European RD Registry Infrastructure (ERDRI), composed of (1) the European Directory of Registries (ERDRI.dor), a key element in the provision of a web hub for RD registries, (2) the Central Metadata Repository (ERDRI.mdr) and (3) the pseudonymisation services. Altogether, they make for the first time RD registries' data searchable and findable at EU level. Therefore, the implementation of technological solutions allowing both the collection and exchange of patient data within registry networks will be facilitated.

ENROL is closely collaborating with the EU RD Platform and the standards developed, including the Common Data Set for Rare disease registration implemented in ENROL dataset, and the implementation of the pseudonymisation tool once it is released by the EC.

EUROPEAN RARE DISEASE RESEARCH COORDINATION AND SUPPORT ACTION (ERICA)

[The European Rare disease research Coordination and support Action \(ERICA\)](#) project has been established as the structural framework to support of the research activities of the 24 ERNs. ERICA promotes inter-ERN research activities and establish firm collaborative ties with existing European and international infrastructures and consortia involved in rare disease research and innovation.

WP2 supports concrete actions on the harmonization of ERNs registries procedures, as the development of Informed consent and data sharing agreement templates. ENROL has actively contributed to the discussion and revision of the templates generated by the participation in online meetings organized by ERICA and provision of feedback on the key points for harmonization across ERNs that have been also considered in the production of ENROL templates.

WP3 is led by ERN-EuroBloodNet Scientific director and co-led by ORPHANET and aims to promote the use of validated tools for patient reported outcomes (PRO) in RDs.

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 established with National Scientific Societies identified for the dissemination of specific actions during the previous period of implementation has been strengthened during this period for a direct promotion of key specific actions ie. promotion of ERN-EuroBloodNet webinars programs.

5. CONCLUSIONS & NEXT STEPS

During the fifth year of ERN-EuroBloodNet development, the established milestones have been successfully achieved regarding the boost of the outreach of the ERN-EuroBloodNet outcomes. As performed during the previous years, the feedback from ERN-EuroBloodNet members will be taken in consideration 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 on the contact persons are being performed continuously in order to reinforce the efficacy of the dissemination of 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: the inclusion of the Twits posted on the @ERNEuroBloodNet account in the ERN-EuroBloodNet section, promotion of the creation of profiles related to the multidisciplinary teams of ERN-EuroBloodNet Members and the update the visual material (i.e. leaflets and brochures) within the new period of ERN-EuroBloodNet implementation.

ERN-EUROBLOODNET PLAN FOR PUBLICATIONS

It is undeniable the impact that 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. Publications on the outcomes achieved in the first five years of network implementation as well as on the ongoing actions are envisaged to be published within the new period of ERN-EuroBloodNet implementation.



https://ec.europa.eu/health/ern_en



www.eurobloodnet.eu

Co-funded by the European Union

