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European Reference Network for rare or low prevalence complex diseases
Network Hematological Diseases (ERN EuroBloodNet)

European Reference Networks

DELIVERABLE 6.3 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD 3

ERN-EuroBloodNet European Reference Network on Rare Hematological Diseases

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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DOCUMENT INFORMATION

DELIVERABLE 6.3 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD 3

Report document

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

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

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Short Description

Report on activities implemented for the Continuing Medical Education for Health Professionals including: workshops and educational online webinars programs on Continuing Medical Education and ERN Exchange Program

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1. INTRODUCTION

1.1. RATIONALE AND BACKGROUND

Promoting Rare Diseases' Continuing Medical Education (CME) and Patient Therapeutic Education (TPE) for health professional and patients' community is one of the most ambitious goal of the ERNs.

Due to the law number of rare diseases patients' cohorts and its heterogeneous incidence in Europe, education of Orphan conditions is lacking in many clinical area of the medicine because it is complicated to produce educational material. Information on RDs is scattered, which causes a lack of research productions, standardized access to advanced tools, treatment and diagnostic tests, lack of guidelines development and launch of clinical trials. Very often patients affected by a rare disease do not have easily access to educational material nor have the possibility to participate to Patients Therapeutic Educational trainings, not receiving an adequate formation of the pathology they suffer from. They could lack of knowledge about the daily management of their disease nor he good practices for improving their quality or life and wellbeing. Sometimes they are not aware of health related services and their rights to access to them. In addition, awareness of public patients' involvement in research is scarce, causing a lack of patients' engagement in research processes (such as participation in clinical trials and peer review or identifications of topics to be addressed by research). Also, patients do not receive an adequate formation for advocate for their rights and needs.

Therefore, due to the limited sources of repository of educational material, expert trained in highly specialized centers and lack of above mentioned services and tools, there are almost none nor easy accessible educational programs for health professionals in the field of Rare Hematological Diseases (RHD). When it is coming to benign hematological disorders, or to ultra-rare conditions both oncological and non-oncological, continuing medical educational programs are even scarcer.

In this context, the ERN-EuroBloodNet for the five years of its activity has invested a lot on CME and TPE education, building comprehensive online educational programs, workshops and training covering existing gaps for health professionals, patients, their families and patients associations, stated in the deliverables:" Deliverable 5.1 Report of educational gaps" of 2018 and " 6.1 ERN-EuroBloodNet Report on Actions for the promotion of continuing medical education on RHD", "Deliverable 6.2 Report on promotion of CME on RHD" and "Deliverable 6.4 ERN-EuroBloodNet report on actions for the promotion of Patients' empowerment" in the previous period of network implementation.

Due to the Covid – 19 circumstances, all the programs were developed in the form of online trainings, supporting the same way the equal access to education for health professional community and TPE for patients in the field of RHD across the EU countries.

1.2. OBJECTIVE AND STRUCTURE

Taking into consideration the results of the identified gaps expressed in the "Actions for the promotion of the CME on RHD" in the previous period of network implementation, and the first actions overtaken for tackling those gaps, the following objectives were identified for the last year of the ERN:

1) To continue dissemination of most innovative topics among health professionals, patients' advocates and patients community and their families in order to gain insight into the last cutting-edge advances in the field of RHDs, focusing on: Very rare diseases, Complex disorders, highly specialized procedures, Implementation of guidelines by organizing online sessions dedicated to different groups of rare blood diseases.

2) To continue the promotion of equal access to knowledge and training on very innovative topics among health professionals, patients' community and organizations by creating accredited and non-accredited webinar cycles programs focused on specific type of disease.

3) To organize on-site trainings for health professionals, (such as preceptorships) within highly specialized ERN-EuroBloodNet Healthcare Provider (HCPs) and coordinated by ERN experts.

4) To organize patients' therapeutic educational workshops for patients and their family on clinical patients management, patients empowerment and starting talking about stigmatic topics, full of cultural reticence as: mental health and racism in rare diseases.

In this context, **this deliverable describes all the ERN-EuroBloodNet actions developed and continued by the Network after fourth and last year reporting period addressing the identified educational gaps for health professionals. All the educational actions addressing Patients, Patients advocates y Patients organizations can be found at Deliverable 6.5 ERN-EuroBloodNet report on actions for the promotion of Patients' empowerment 2, February 2022.**

The different actions reported include the following sections: Rationale, Objectives, Methods, Results, Next steps

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2. EDUCATIONAL ACTIONS IMPLEMENTED FOR HEALTH PROFESSIONALS

2.1. UPDATE ON HEALTH PROFESSIONAL' S EXCHANGE PROGRAM

Rationale

The promotion of continuing medical education (CME) for RHDs via onsite trainings, in the framework of an exchange mobility program for health professionals is one of the ERN's goal. Due to the Covid – 19 circumstances, since March 2020 all the programs were developed in the form of online trainings, supporting the same way the equal access to education for health professional community in the field of RHD across the EU countries. A part of planning online trainings on the most innovative topics among health professionals in order to gain insight into the last cutting-edge advances in the field of RHDs, focusing on very rare diseases, Complex disorders, highly specialized procedures, implementation of guidelines, the ERN has started planning an Exchange Program Comprehensive Strategy.

Chafea and DG SANTE are providing the 24 ERNs with the support for programs on capacity and knowledge sharing through short term mobility and exchanges of healthcare professionals. In a nutshell: an ERN Exchange program. Ecorys Ltd, the agency contacted by the European Commission runs the logistics of the program for the 24 ERNs. The ERN-EuroBloodNet has been allocated with 55 exchange packages. Each package has a duration of an average of 5 days (including travel and €200 per day allowance for accommodation and other related expenses). The ERN-EuroBLoodNet Mobility Program will restart depending on the COVID19 pandemic situation in March 2022.

Objective

Organization of ERN Exchange Program in order to promote:

- The facilitation of the harmonization of the haematology and paediatric (haematology) specialities curricula throughout the EU - European haematology curriculum/passport.
- The improvement of continuing medical education on ultra-rare RHD among health professionals in UE.

Methods

The educational plan conducted during the first years of the network included the analysis of those disease's area to tackle with education, obtaining the evidence required for defining the targeted-actions to address gaps by organizing a short stay.

Clinical area have been identified via different methods: ERN-EuroBloodNet Questionnaire on CME, Educational niches identified during Scientific and Strategic Board meetings, already ongoing educational projects, CPMS Virtual Boards opinions, ePAGs and patients representatives opinions. The clinical area identified and prioritized are: Cutaneous Lymphoma, Bone Marrow Failure Syndromes, Thrombotic Microangiopathies, and Hemolytic Anemias.

Each Exchange training of the ERN Mobility Program include those interventional medical areas:

- Highly specialized procedures in rare hematological disorders
- Diagnosis and clinical management of hematological rare
- Clinical cases based to experience via face to face interaction the insight into practical management of patients 'concrete RHDs cases from the early diagnosis to treatment of complicated conditions (Cases proposed by participants and/or cases shared in the Clinical Patients Management System).

Specifically the CME Mobility Program is addressed to ERN members or affiliated partners in those EU MS with scarce cutting-edge knowledge on a specific RHD and requiring training. It is also a way of encouraging the Cross Border Health cooperation among ERN-EuroBloodNet HCPs.

The ERN-EuroBloodNet has been allocated with 55 exchange packages. Each package has a duration of an average of 5 days (including travel and €200 per day allowance for accommodation and other related expenses). Ecorys, the agency contacted by the European Commission will run the logistics of the program for the 24 ERNs. The ERN-EuroBloodNet CME Mobility program addressed to health professionals will be accredited by the European Board for Accreditation in Hematology

Results

Planning the laboratory training for diagnosis of hereditary haemolytic anaemia. Specifically this exchange program will consider from theory to laboratory practice, from phenotype to genotype for hereditary haemolytic anaemias (haemoglobinopathies, RBC membrane pathologies and enzymopathies).

Educational objectives

1. Acquire the theoretical and practical basis for the use of diagnostic tools and follow-up of patients with suspected hereditary haemolytic anaemia
2. Know the diagnostic and monitoring tools, their limitations and the interpretation of the results

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3. Be able to propose a change in his/her own laboratory, to make adaptations or to propose that analyses in a particular field be sent to a reference centre
4. Propose a rational approach/algorithm to a haemolytic anaemia based on national/international recommendations

Exchange program will run in 4 different host centers, members of the ERN-EuroBloodNet: 1) CUB-Hôpital Erasme in Belgium, 2) CHU de Montpellier in France, 3) AOU Federico II – Naples in Italy and finally 4) Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan also in Italy.

Each site is specialized in different aspects of hereditary haemolityc anemias diagnosis.

The draft of the proposal to be submitted for the launching of this exchange program is presented in ANNEX I_Exchange CME Program hereditary haemolytic anaemia.

Next steps

- Submit the completed initial agreement template for the ERN exchange program and launch the program on rare hemolytic anemias in laboratories
- Organize and coordinate together with Ecorys Ltd the ERN exchange program

2.2. Online Continuing Medical Education Programs

Rationale

Webinars are online educational sessions led by the international top experts in the field of Rare Hematological Diseases. Each webinars is conducted using the Zoom Platform. Thanks to this format the full audio and visual communication between speaker and audience is possible. Lecture is based on the visual aid of a Power Point presentation and recorded by the EuroBloodNet's coordination team. Recorded video is edited and then published together with lecture slides on the EuroBloodNet's website and EuroBloodNet's EDU YouTube channel launched in May 2020.

According to the directive of the GDPR, speakers are requested to sign a presentation publishing agreement to authorize the publication of the webinar recorded together with the slides presentation on the ERN-EuroBloodNet website and YouTube. Also, webinars hearers are requested to sign consent through a checkbox in the registration form on ERN-EuroBloodNet website, by joining the webinar the participant accepts the possibility of being recorded if comments/questions are made and understand that those will be publicly available at the website.

2.2.1. ERN-EuroBloodNet Thursdays Webinars: Transversal program for health professional covering all RHDs

The program ERN-EuroBloodNet Thursday webinars have been presented already in the Deliverable 6.2 Report on promotion of CME on RHD of February 2021 together with its: methodology, dissemination campaign, registration and online visibility on ERN-EuroBloodNet Website, list of webinars held until December 2020 and statistical overview of the program until December 2020. In this deliverable it will be presented the results from January 2021 until February 2022.

Objective

Main objective of the Webinar "EuroBloodNet Thursdays Webinars" is disseminate the promotion of the innovative topics in order to stress among health professionals the cutting-edge advances in the field of Rare Hematological Diseases. Webinars tackled topics as: the very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines. Also for the 5th year of the ERN, it has been chosen the continuation of the objectives identified in the previous report:

- Organizing new webinars keeping the run of the program, in order to tackle all the educational niches related to RHD areas.
- Enhance the dissemination of the Program aiming to increase the number of participants by the diffusion among National Scientific Societies contact persons identified.
- Continue programming the calendar to organize further educational sessions by taking into consideration the 23 topics proposed by the Board of Network.

Results

List of webinars held

- 21st January 2021, Marina Kleanthous, Preimplantation genetic testing for rare anaemias
- 11th of February 2021, Stefan Schönland, Treatment of Amyloidosis
- 15th of April 2021, Thierry Leblanc, Management of Blackfan Diamond anemia in adults

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- 13th of May 2021, Mike Makris, Vaccine-induced Immune Thrombocytopenia and Thrombosis (VITT)
- 27th of May 2021, Raffaella Colombatti, Newborn screening for sickle cell disease in Europe: recommendations
- 24th of June 2021, Gian Luca Forni, Selecting β-thalassemia Patients for GeneTherapy: A Decision-making Algorithm
- 1st of July 2021, Carole Soussaine, CNS and/or Ocular lymphoma
- 23rd of September 2021, Holger Cario, Pathogenesis, clinical presentation and management of congenital erythrocytosis
- 30th September 2021, Lionel Ades, Treatment of higher risk MDS after hypomethylating agent failure
- 7th of October 2021, Mariane de Montalembert, SCD New traitements revision
- 13th January 2022, Jaccard, Arnauld Daratumumab-Based Treatment for Immunoglobulin Light-Chain Amyloidosis
- 10th of February 2022, C. Thieblemont, Marginal zone lymphomas
- 24th of February 2022, Elena Corradini, Current concepts and controversies on aceruloplasminemia

List of upcoming webinars

- 31st March 2022, Serge Pissard , The rare haemoglobin variants of clinical significance
- 7th of April 2022, KILADJIAN Jean-Jacque , Primary myelofibrosis: diagnosis and treatment
- 21st of April 2022, Richard van Wijk, Pathophysiology and diagnosis of rare enzyme disorders
- 26th of May 2022, Olivier Tournilhac, Lymphoplasmacytic lymphoma (T-LPL)

Representation of ERN-EuroBloodNet Subnetworks in this program dedicated to all RHDs:
Distribution of webinars subnetwork coverage can be found at Fig 1. It has been underlined the necessity of covering the BMF and HH-IRON subnetwork. Accordingly, two Topic on Focus comprehensive program will be dedicated to those subnetwork. The one on BMF Syndrome is currently ongoing and the one on HH-IRON disorders is under preparation (see next section).

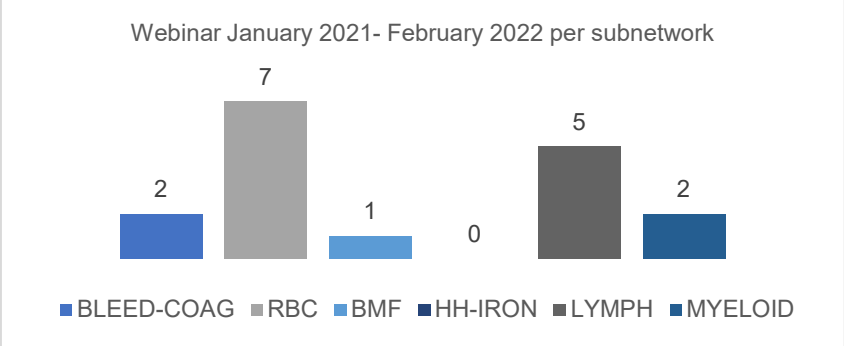

Fig.1 distribution of webinar per ERN-EuroBloodNet subnetworks (BLEED-COAG: Rare bleeding-coagulation disorders and related diseases subnetwork, RBC: Rare Red blood cell defects subnetwork, BMF: Bone marrow failure and hematopoietic disorders, HH-IRON: Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis subnetwork, LYMPH: Lymphoid malignancies subnetwork, Myeloid: Myeloid malignancies subnetwork).

Statistical overview of the Thursday Webinars program from January 2021 until February 2022

Registrations and participants

Through the 12 sessions of Thursday Webinars taken place from January 2021 to February 2022, the general trend can be observed that the number of registrants was mostly double-fold higher than the actual number of participants (Fig below.). The higher number of registrations was for the webinar on VITT -271 and the lowest for the CNS and/or Ocular Lymphoma– 21. The number of participants for these webinars were 122 and 13 respectively, also indicating the most and least attended Thursdays 'Webinars from the indicated perdios. For the rest of the webinars the number of participants was between 56 and 23.

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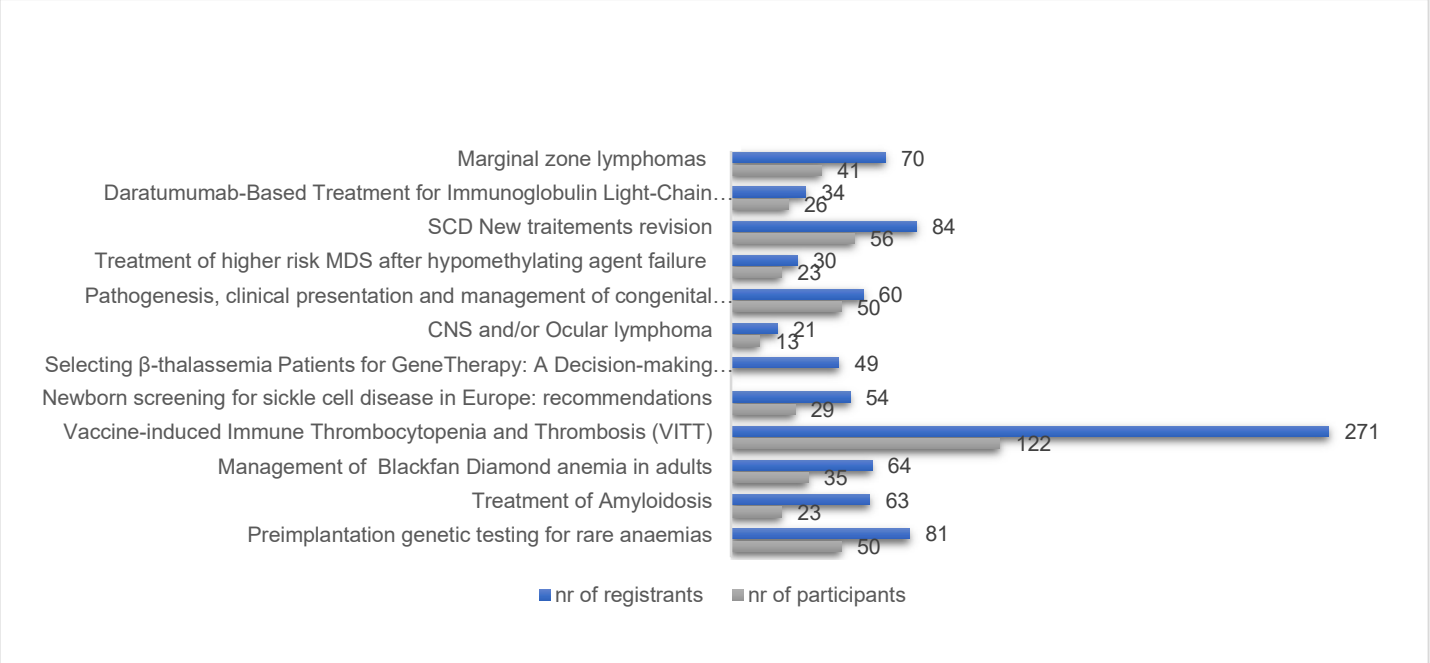

Fig 2. Registration v. participation in Thursday Webinars between January 2021 and February 2022.

Comparing to the data of the last year reported in the previously Deliverable (6.2 of February 2020) the number of participants and registered people has increased. As follow in the figure

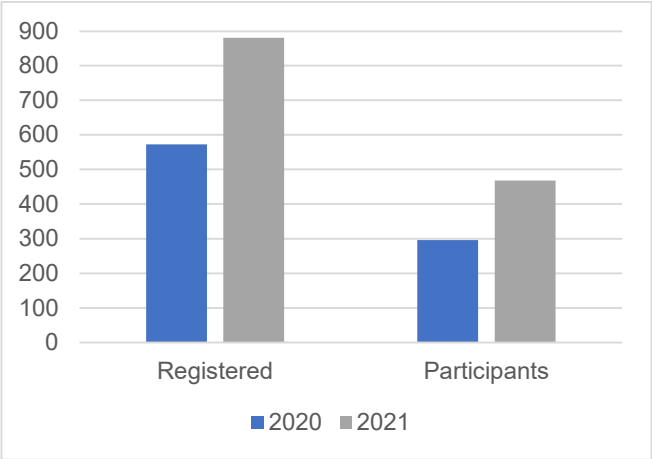

Fig. 3 Comparison of Attendance (Registered and Participant) of year 2020 and 2021

Audience's profile

Based on the registration form and survey, the gathered data could provide an overview on the profile of the Thursdays Webinars audience: geographical coverage, profession and age. Thursdays Webinars reached the audience coming from 23 EU countries, moreover from UK and outside Europe. The majority of attendants were from Italy (15%), Spain (12%) and France (5%). Whereas 123 participants (14%) were from outside Europe. Majority of the audience were hematologists (49%) and age rage was quite equal. Detailed overview is presented in the following figures:

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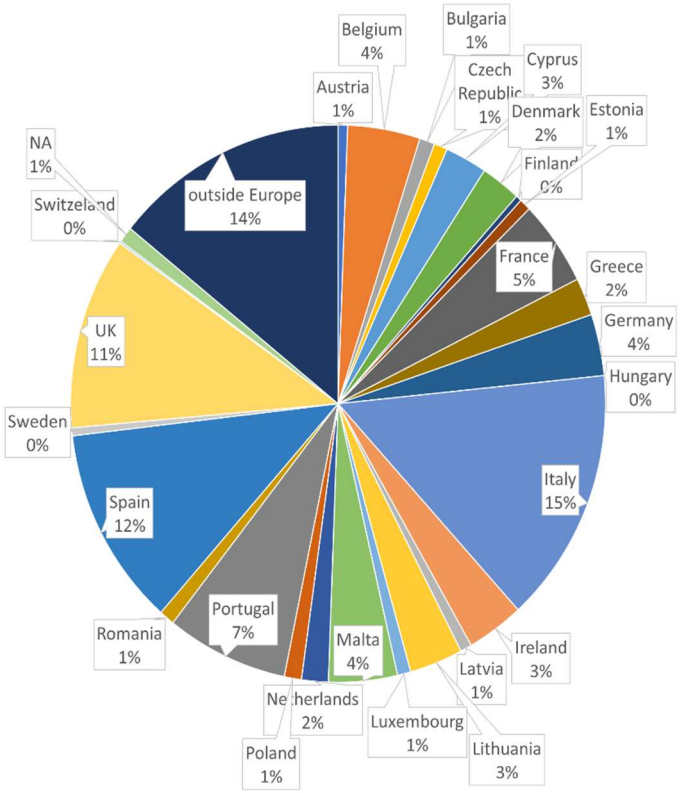

Fig. 4. Geographical distribution among Thursday Webinars' audience.

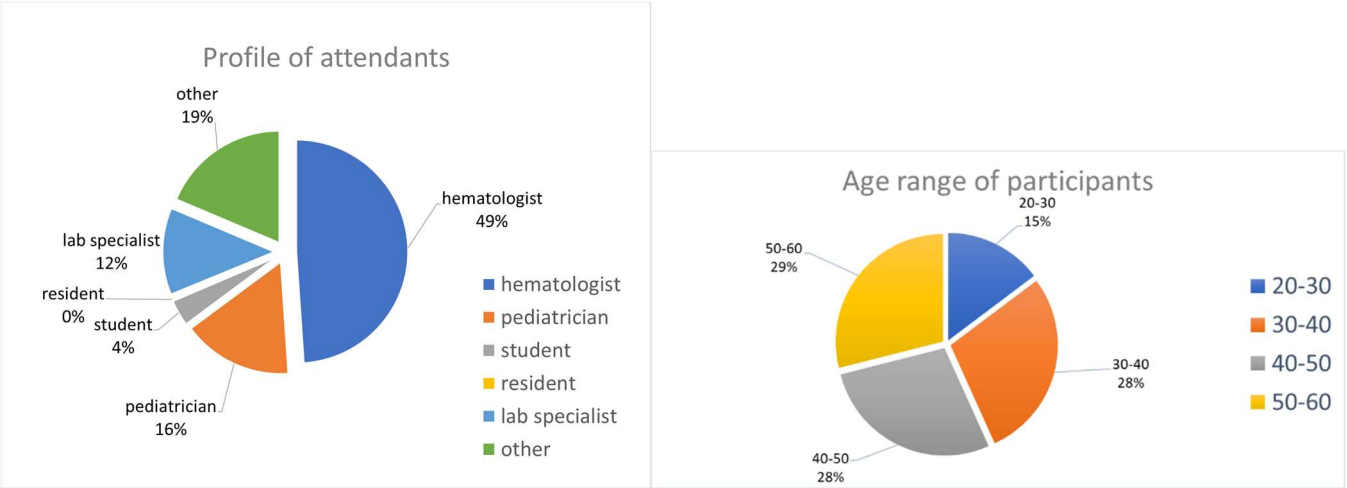

Fig 5 and fig 6 Profession and age of Thursday Webinars' audience.

Satisfaction Survey

After each session the webinar attendants were asked to fill in the short survey to provide their feedback and impressions on the webinars. Based on the results collected, majority of the participants claimed that the webinar was useful to increase their knowledge on the area (211 responders), they will translate the knowledge learned into the management of patients (123), and that they will recommend the webinar to other colleagues (163). The overview of the survey is presented in the following figure:

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Fig 7 Results of the satisfactory survey after Thursday Webinars.

Also, through the survey a repository of suggestions on topics for the next webinars and comments from the audience gathered, ie: Mantle cell lymphoma, Rare coagulation disorders, Thrombophilia, Epo and receptor in different diseases, among many others.

Videos have been edited and implemented in the EuroBloodNet' EDU YouTube Channel and ERN-EuroBloodNet website.

Next steps

1. Invitation of the next guest Expert speakers
2. Updating the dedicated section at ERN-EuroBloodNet website, including speakers' introduction and registration.
3. Continuous analysis of webinars' participants to adapt the dissemination strategy to reach geographical gaps.
4. Edition of the recorded videos and upload them on the EuroBloodNet's EDU YouTube channel.

2.2.2. EHA & ERN-EuroBloodNet Spotlight on Castleman Disease

Rationale

EHA & ERN-EuroBloodNet Spotlight on Castleman Disease is an accredited European online educational program targeting health professionals organized by the European Hematology Association (EHA) and ERN-EuroBloodNet.

This program is accredited by the European Board of Accreditation in Hematology. Participants will receive 1 Continuing Medical Education points when they take part in one online webinar, or 4 taking part to the full program.

This program has been launched the 25th of January 2022 and is still ongoing.

Objective

The main objective of this program is to disseminate up-to-date knowledge among interested haematologists, internists, paediatricians, or other health care providers in order to give visibility to cutting-edge advances in the field of Castleman Disease. Castleman Disease has a low prevalence and multiple clinical manifestations, hence the need for education addressing, physiopathology, etiologym diagnosis and treatment. Ultimately, this approach supports better patient care. Webinars will be recorded and the videos will be integrated in the EHA and ERN-EuroBloodNet e-learning environments to create enduring educational material on all types of Castleman disease

Methods

The program consisting of a cycle of 4 Webinars focused on Castleman Disease was developed in collaboration with three experts, all members of the EHA and the ERN-EuroBloodNet: Prof Oksenhendler Eric, Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis, Prof Kai Hübel, Universitätsklinikum Köln, and Prof Simone Ferrero, AOU S.Luigi Gonzaga.

In the webinars dedicated section on the ERN-EuroBloodNet website, are placed: a brief introduction and aims of the program and methods, together with a) specific informative boxes for each of the upcoming webinars and direct link for registration and b) Link to past webinars.

A brief anonymous survey is conducted among the attendants following the end of the Webinar, which includes the following questions:

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From 1 (Not at all) to 5 (Absolutely yes!), how would you rate the webinar?

- Has the webinar been useful to increase your knowledge on the area?
- Will you translate the knowledge learned into the management of patients?
- Would you recommend the webinar to other colleagues?
- Would you suggest any other topic you would like to have as a Webinar session? (free text)

In addition a dissemination plan was established among EHA and EuroBloodNet in order to advertise the program via respective Newsletter, website and social media, with respect to the Network: (Newsletter, Twitter, LinkedIn, Facebook). ERN-EuroBloodNet videos will be integrated in EuroBloodNet' EDU YouTube channel and in the website at the section dedicated to the program.

Finally, the program will be implemented in both ERN-EuroBloodNet and EHA e-learning environment.

Results

Logo and Theme

Fig. 8. and fig.9 Logo and theme of EHA&ERN-EuroBloodNet Spotlight on Castleman Disease to promote better recognition of Webinars the unique theme was developed including the logo, the look of the powerpoint templates, and videos intro and outro integrating visually this webinars 'cycle.

Program

- **N°1 Overview of Castleman Disease (pathophysiology excluded)** provided by Kai Hübel and Elena Sabatini – 25th of January 2022. Content: History / Classification / Pathology / Diagnosis
- **N°2 Unicentric Castleman Disease** provided by Eric Oksenhendler – 1st of February 2022. Content: Imaging (cases) / Diagnosis and initial assessment / Complications / Pathophysiology / Treatment.
- **N°3 Idiopathic multicentric Castleman Disease** provided by Simone Ferrero - 15th of February 2022. Content: Clinical phenotypes of the disease / Differential diagnosis (including cases) / Relationship with TAFRO, IgG4RD, and POEMS / Pathophysiology / Treatment.
- **N°4 Kaposi sarcoma herpes virus-associated multicentric Castleman disease and HHV-8-associated multicentric Castleman disease (KSHV/HHV8 MCD)** provided by Mark Bower and David Boutboul - 8th of March 2022. Content: Diagnosis / Complications / Pathophysiology / Treatment
- First three webinar have been already held:
    - N°1 Overview of Castleman Disease gathered : 77 participants
    - N°2 Unicentric Castleman gathered : 51 participants
    - N°3 Idiopathic multicentric Castleman gathered 62 participants

Next step

- Following the organization of the programs: 1 upcoming webinar
- Editing and publishing the recorded webinars in order to implement EuroBloodNet' EDU YouTube Channel and the ERN-EuroBloodNet e-learning environment, under the CEF grant III
- Elaborate the analysis of the statists of this program once it is finalized

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2.2.3. ACCREDITED TOPIC ON FOCUS FOR HEALTH PROFESSIONALS IN CONNECTION WITH CEF TELECOM GRANT

The program Topic on Focus for Health Professionals are organized under the umbrella of the CEF Telecom Grant Connecting EuroBloodNet. Detailed description of the programs, methods, structures, objectives and analysis of the results can be found at Connecting EuroBloodNet II final report. Main results summarized below:

- 2 accredited Topic on Focus finalized and 1 ongoing
    - First finalized focused on Cutaneous Lymphoma consisting of 9 sessions and accredited with 7 CME EBAH
    - Second finalized on Thrombotic Microangiopathies (TMAs) with a total of 15 sessions and accredited with 11 CME EBAH
    - One ongoing on Bone Marrow Failure Syndromes consisting of 18 sessions and accredited with 18 CME EBAH

For each session, in the ERN-EuroBloodNet Topic on Focus Website' Section there is the biography and headshot of the speaker, the video registered. The same video is then integrated in EuroBloodNet' EDU YouTube channel and the presentation.

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3. CONCLUSIONS

The educational activities for health professionals undertaken by the network during this period, promoted an equal access to knowledge in the field of rare diseases, allowing health professionals develop further under the frames of CME:

- EuroBloodNet Thursdays webinars for transversal knowledge on very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines launched in February 2020 and ongoing
- Health Professional's Exchange Program: a proposal for a short stays in laboratories for the diagnosis of hereditary hemolytic anemia has been written
- EHA & ERN-EuroBloodNet Spotlight on Castleman Disease, a first European online program launched in collaboration with the European Hematology Association

By using an online video platform tool Zoom, the network enabled cost-free, easy and time effective access to the training sessions for every health professional interested in the subject. Additionally, due to the restrictions related to covid-19 pandemics, webinars offered a form of CME for all the health professionals without a need to travel.

In this context is worthy to mention the success of the ERN-EuroBloodNet Thursday's webinar program with more than 400 participants and 800 registered people. Also the ongoing program on Castleman Disease reached an important participation considering the very rare condition focusing the program.

These results can be completed by the outcomes of the satisfaction surveys coming from online and onsite programs, showing a great reception by the audience. Moreover, the geographical distribution covered majority of the European Countries (23), what indicates a great interest in such educational initiatives across EU. ERN-EuroBloodNet will continue the dissemination of cutting-edge knowledge and facilitate continuous medical education CME by further development of online programs and establishing the strategy for the next two years ERN Mobility Exchange Program.

In conclusion, ERN-EuroBloodNet Educational Projects achieved good outcomes in promoting CME among health physicians and in empowering people living with RHDs (see details for Patients educational actions at "Deliverable 6.5 ERN-EuroBloodNet report on Actions for the promotion of patients' empowerment 2, February 2022"). All in all, several diseases' areas have been tackled by addressing educational programs, by organising online programs. Several ambitious projects have been launched: Topic on Focus programs and single webinars for health professionals, patients' community or patients' organizations, ERN Exchange program or facilitating the creation of a European Network of Sickle Cell Disease Patients organization. In addition, the ERN-EuroBloodNet has increased its area of Patient Therapeutic Education interventions by creating a new project on mental health too.

Finally, the strategy of the ERN of identifying educational gaps and addressing them by direct specific program will be maintained for the next period of the Network. Moreover these results will be ever further potentiated with the release of the ERN-EuroBloodNet eLearning platform under the Connecting EuroBloodNet III grant.

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ANNEX I

EXCHANGE CME PROGRAM HEREDITARY HAEMOLYTIC ANAEMIA

DELIVERABLE 6.3 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD 3

European Reference Network
for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)

Logistics informations:

Program

The ERN Exchange Mobility Program is coordinated by Ecorys Agency and aims to organize short stays in ERN's HCPs for disseminating expertise on Rare Diseases among Network's members.

(**Program suspended until March 2022)**

This **fellowship includes** the cost coverage for participants of:

- A training of maximum 5 days per participants (flexible if justified by pedagogical needs)
- Daily allowance to cover subsistence, accommodation and travel insurance for professional that travels
- Travel costs

<u>Not included</u>:

- Compensation for centres and professionals hosting the visit
- Insurance for professional liabilities

1. Laboratories that could host this preceptorship: **more or less 5 centres**, if this number is overpassed and more than one centre per country is willing to participate, those need to be organized at national level (so maximum 1 preceptorship per hosting country).

- **Duration of stay:** ideally from 3 to 5 days, to be defined according to the pedagogical project

- **Number of participating per laboratories**: ideally from 2 to 5 participants (flexible according to each host centre needs)

- **The logistics** (travel and hotel reservations, reimbursements, etc.) are organised by the Ecorys agency, contracted by the Commission.

- The **selection of candidates is based on CV and motivation letter.**

Mandatory criterion: participants must be from a HCP member or Affiliated partner of ERN-EuroBloodNet and preferably permanent staff (so interns are not a priority). **A call for participant will be opened. Priority will be given to those cover letters that stand the willing of replicate, disseminate or using what learned in their centre.**

Each preceptorship will be submitted to the process for getting EBAH CME accreditation

Identified Clinical AREA:

Diagnosis of haemolytic anaemia (Laboratory Training)

Very often Rare Anemias are undiagnosed or misdiagnosed, causing severe consequences as: stress and anxiety in patients and their families, the impossibility of conducting a good quality life, to receive an appropriate treatment and to screen the population for pregnancies. Haemolytic rare anaemia could require for its identification highly specialized diagnosis through laboratory diagnostic test and clinical manifestations.

A correct diagnosis means to prescribe the most adequate treatment for a patient.

A ERN mobility program would be addressed to the classifications, genetics, pathophysiology, clinical presentation, laboratory investigations including rational steps of diagnosis and therapy of Rare Anemias, such as: CDA, Diamond Blackfan Anaemia, Fanconi Anemia, hereditary microcytic anaemia.

1st EXCHANGE: ERN-EuroBloodNet HCP CUB-Hôpital Erasme Brussels (Belgium)
5 PACKAGES

Pedagogical project

- **Context:** from theory to laboratory practice, from phenotype to genotype for hereditary haemolytic anaemias (haemoglobinopathies, RBC membrane pathologies and enzymopathies).

Educational objectives

1. Acquire the theoretical and practical basis for the use of diagnostic tools and follow-up of patients with suspected hereditary haemolytic anaemia
2. Know the diagnostic and monitoring tools, their limitations and the interpretation of the results
3. Be able to propose a change in his/her own laboratory, to make adaptations or to propose that analyses in a particular field be sent to a reference centre
4. Propose a rational approach/algorithm to a haemolytic anaemia based on national/international recommendations

Contextualised teaching (practical experience)

- **Introductory theoretical part/reminders:** Joint clinico-biological presentation max 2H and by theme according to the developments of the host laboratory.
- **Practical experience**

- Integration into the laboratory practice (alongside the technologist, biologist, geneticist,...) and explanation of local technological choices in relation to market possibilities;
- Learning to reason on the basis of clinical cases allowing to approach the different haemolytic anaemias;

From autumn 2022 (4 days)

Host Center: Hospital University Laboratory (LHUB-ULB) – Brussels – Belgium

Number of participants: 5
Participants selected via a call for participants

Coordinated by: Prof Béatrice GULBIS

Teachers:

- Prof Béatrice Gulbis
- Dr Phar Biol Anne-Sophie ADAM
- Prof Samantha BENGHIAT
- Prof Martin Collard
- Dr Sci Xavier Peyrassol

Day 1 : Membranopathies

8H30 – 12H30
2H: Clinical approach (1H) – laboratory tools (1H)
3H: practical approach in the laboratory

13H30 – 17H30
Clinical cases and integration in decisions algorithms, tip and tricks, recommendations available

Day 2: Enzymopathies

Idem

Day 3: Haemoglobinopathies – first- and second-line tests
Idem

Day 4: Haemolytic anaemia - Genetic tests

8H30 – 12H30
2H: techniques available and their places
3H: practical approach in the laboratory

13H30 – 16H30

Clinical cases: from simple cases to mendeliome.

2nd EXCHANGE: ERN-EuroBloodNet HCP AOU Federico II Napoli (Italy) 3 PACKAGES

Pedagogical project

Context from theory to clinics to laboratory practice, from phenotype to genotype of hereditary hemolytic anemias and iron metabolism defects (red blood cell membrane defects; congenital dyserythropoietic anemias; enzymatic defects; iron deficiency anemias; hemochromatosis; sideroblastic anemias; erythrocytosis).

Educational objectives
1. Acquire the theoretical and practical basis for the use of diagnostic tools and follow-up of patients with suspected hereditary hemolytic anemia and iron metabolism defects.
2. Know the genetic diagnostic and monitoring tools, their limitations and the interpretation of the results
3. Be able to propose a change in his/her own laboratory, to make adaptations or to propose that analyses in a particular field be sent to a reference center
4. Propose a rational approach/algorithm for hemolytic anemias and iron metabolism defects based on national/international recommendations

Contextualized teaching (practical experience)
Introductory theoretical part: joint clinic-biological presentation (6h subdivide into 3 days).
Practical experience into the laboratory practice (alongside the technologist, biologist, geneticist) and explanation of local technological choices in relation to market possibilities; or learning to reason on the basis of clinical cases allowing to approach the different hemolytic anemias;

Program
From 20 to 22 July 2022 (3 days)
Host Center: University of Naples Federico II, and CEINGE, Biotecnologie Avanzate, Naples, Italy

Number of participants: 3
Participants selected via a call for participants

Coordinated by: Prof Achille Iolascon
Teachers:
- Prof Achille Iolascon
- Prof. Roberta Russo
- Prof Immacolata Andolfo
- Prof Mario Capasso
- Prof Michele Pinelli

• Dr Barbara Rosato Eleni
• Dr Roberta Marra

Day 1: Red blood cells membrane defects

- 9-30 – 12-30

3h: Clinical approach (1h) – laboratory tools and genetic testing (2h)

- 14-30 – 17-30

3h: Laboratories tools and clinical cases and integration in decisions algorithms, tip and tricks, recommendations

Day 2: Congenital dyserythropoietic anemias

- 9-30 – 12-30

3h: Clinical approach (1h) – laboratory tools and genetic testing (2h)

- 14-30 – 17-30

3h: Laboratories tools and clinical cases and integration in decisions algorithms, tip and tricks, recommendations

Day 3: Other hemolytic anemias

- 9-30 – 12-30

3h: Clinical approach (1h) – laboratory tools and genetic testing (2h)

- 14-30 – 17-30

3h: Laboratories tools and clinical cases and integration in decisions algorithms, tip and tricks, recommendations

3rd EXCHANGE: ERN-EuroBloodNet HCP CHU Montpellier (France) 5 PACKAGES

Pedagogical project

Context: from theory to laboratory practice, from phenotype to genotype for hereditary haemolytic anaemias (haemoglobinopathies, RBC membrane pathologies and enzymopathies).

HOST CENTER : CHU Montpellier, France

COORDINATOR: Prof Patricia Aguilar Martinez

NUMBER OF PARTICIPANTS:
5 participants

Specific and detailed agenda for this short stay is under organization

4th EXCHANGE: ERN-EuroBloodNet Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan (Italy)
5 PACKAGES

Pedagogical project

Context: from theory to laboratory practice, from phenotype to genotype for hereditary haemolytic anaemias (haemoglobinopathies, RBC membrane pathologies and enzymopathies).

HOST CENTER : Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan

COORDINATOR: Prof Giovanna Graziadei

NUMBER OF PARTICIPANTS:
5 participants

Specific and detailed agenda for this short stay is under organization

European Reference Networks

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

European Reference Network
for rare or low prevalence complex diseases
Network Hematological Diseases (ERN EuroBloodNet)

www.eurobloodnet.eu

Co-funded by the European Union

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