

DELIVERABLE 6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD

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 6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD - REPORT ON THE ACTIVITIES IMPLEMENTED IN COLLABORATION WITH EDUCATIONAL BODIES (EHA AND ESH) FOR THE PROMOTION OF CME ON RHD

Report document

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Short Description

Report on activities implemented for the Continuing Medical Education for Health Professionals and for patients including: educational workshops and webinars, results from surveys conducted on educational expectations and needs, creation of educational repository.

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1. INTRODUCTION

1.1. RATIONALE AND BACKGROUND

The promotion of continuing medical education (CME) for both professionals and patients the ERN's most ambitious objectives, especially that they focus on rare diseases (RD).

The reason of it is the fact that it is very difficult to produce and/or find educational material due to the orphan character RD . Therefore, there are not so many scientific congresses or sessions devoted to the Rare Hematological Diseases (RHD), due to the low number of patients affected by RHD the expertise is heterogeneously distributed across the EU, due to lack of standardized access to advanced tools it is hard to apply the right therapy, diagnostic tools therefore it is extremely difficult to develop guidelines and launch clinical trials. Moreover, many patients are undiagnosed or misdiagnosed is difficult to identify patients' cohorts'.

The same challenges in the production of educational materials can be applied to both for patients' community and for health professionals.

There almost none nor easy accessible educational programs for health professionals in the field of 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, and moreover if they exist they are very expensive due to the limited source of experts and tools.

In this context, the ERN-EuroBloodNet via the Transversal Field of Action on CME joined the efforts of the fourth year activity of the network to build comprehensive online educational programs covering existing gaps. 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 in the field of RHD across the EU countries.

Promotion of education for patients and patients associations targeting rare diseases is one of the key objectives for the ERN-EuroBloodNet. 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. Therefore, patients could not receive an adequate education with respect to the pathology they suffer from. They are not aware of the daily management of their disease nor of the good practices for improving their quality or life. 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). Finally, patients do not receive an adequate formation for advocate for their rights and needs. This situation is due to a low prevalence of rare diseases themselves but also to the lack of patients associations that serve as an info point, the lack of expert centers that could help patients in receiving information.

The educational opportunities for an interested patient are more developed for those suffering from rare onco- hematological disease rather than people affected by conditions belonging to non-oncological hematology's clinical domain, or to ultra-rare conditions. In addition, the organization of patients training is very expensive since the available resources of experts from which to draw knowledge are not extensive, making necessary the co-participation of a board of international experts and the use telematics tools (online courses, webcasting, etc). Only if an experienced patient association covers a disease or a group of diseases there is the possibility to find highly quality validated educational documents and get the patient empowered.

This is the reason why the ERN-EuroBloodNet is fruitfully investing on educational projects addressed to both health professional and patients. As 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" and "6.4. Patients Actions" in the previous period of network implementation.

Education is the major basis for increasing patients' empowerment. The pedagogical plan, from the ERN-EuroBloodNet perspective should include giving visibility and representation of rare disease in Europe, promoting advocacy training and educational training, creating educational material repositories, encouraging the establishment of patients associations, strengthen the collaboration between physicians and patients, etc. This is the reasons why the ERN-EuroBloodNet is coordinating different joint projects for reaching the objective of improving rare disease patients' empowerment.

In this section, the ERN-EuroBloodNet' educational actions are described, both past projects and ongoing projects that are specifically addressed to patients, caregivers, patients advocates and patients organizations

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, the following objectives were identified for this action:

- 1) To continue dissemination of most innovative topics among health professionals and patients’ advocates 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 organisations by creating accredited and non-accredited webinar cycles programs focused on specific type of disease.
- 3) To organise on-site trainings for health professionals, patients’ community, and patients’ organizations (such as preceptorships and educational trainings) within highly specialized ERN-EuroBloodNet Healthcare Provider (HCPs) and coordinated by ERN experts.

This deliverable describes all the ERN-EuroBloodNet actions developed and continued by the Network after the third and fourth year reporting period, addressing the identified educational gaps described in the “Deliverable 5.1 report on educational gaps” of 2019 and started initiatives described in ‘Deliverable 6.1 Actions for the promotion of CME on RHD ’of 2020.

The different actions reported include the following sections:

- Rationale
- Objectives
- Methods
- Results
- Next steps

2. EDUCATIONAL ACTIONS IMPLEMENTED FOR HEALTH PROFESSIONALS

2.1. ONSITE TRAININGS

2.1.1. PRECEPTORSHIPS FOR HEALTH PROFESSIONALS CARRIED OUT ON HCPS SITES AND COORDINATED BY ERN-EUROBLOODNET EXPERTS

2.1.1.1. UPDATE on ERN-EuroBloodNet Preceptorship for Health Professional Programs

Onsite Trainings, in the framework of an exchange mobility program addressing health professionals, are an important part of the ERN-EuroBloodNet Continuing Medical Education Objectives. The idea is to promote 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 major aim is not only to promote cutting edge-knowledge but to spread expertise in countries where expertise on specific RHD is scarce or not easily accessible. Those trainings would not be only theory and scientific background oriented but they would also experience the insight into practical management of patients with rare hematological diseases at the highly specialized RHD centres - from the early diagnosis to treatment of complicated cases.

Preceptorship for health professional are part of ERN-EuroBloodNet Continuing Medical Education Plan. Intense short stays tackling RHDs are addressed as Training Mobility Programme to hematologist, pediatricians, biologist and health professionals at large. Participants coming from European Members States could benefit from a training in an highly expert ERN member and/or Affiliated Partner, assisting at the daily life of the service and acquiring cutting-edge knowledge on RHDs.

The first Preceptorship experience, as explained in the “Deliverable 6.1. Actions for promoting the CME” has been concluded successfully in February 2020. The Preceptorship program for AA and PNH has gathered a total of 13 Participants from 8 Member States (Czech Republic, Germany, Italy, Lithuania, Netherlands, Portugal, Spain and United Kingdom) attending to:

- 3 Participants selected for Preceptorship 1 (Paris, AP-HP hôpital Saint Louis)
- 5 Participants selected for Preceptorship 2 (Naples, AOU Federico II)
- 5 Participants selected for Preceptorship 3 (Genoa, IRCCS Institute Giannina Gaslini)

The three ERN-EuroBloodNet Preceptorships have been successfully accredited by EBAH (European Board for Accreditation in Hematology). Each preceptorship has obtained 18 credits.

Feedback reported for both, participants and professionals hosting, have reported wonderful comments on the experience. The comments received from the first preceptorship hosted by AP-HP, Hôpital Saint-Louis, Paris, France under the coordination of Prof Regis Peffault de la Tour during 13-16 January 2020 were compiled and published at the piece of news:

- ["The majority of continuing education events I have ever attended were much more theoretically orientated. EuroBloodNet preceptorship was totally different." Read the testimonies of the first PNH and AA program!](#)

The second Preceptorship program promoted by the ERN-EuroBloodNet is dedicated to SCD and hosted in 5 highly specialized HCPS, members of the ERN-EuroBloodNet, as previously described in the Deliverable 6.1. Actions for promoting the CME”.

Main objective in endorsing a training program on SCD is to increase awareness of current management of sickle cell disease, delivering excellence in patient care education, clinical audit and stimulate research interests. Due to the COVID-19 Outbreak Pandemic, this program has been postponed. As the ERN-EuroBloodNet is joining the ERN Exchange Program for Health Professionals promoted by the European Commission in collaboration with the agency Ecorys, this short stays on SCD will be part of the mentioned ERN Mobility Plan.

2.1.1.2. Draft Proposal for Health Professional Exchange Program 2021-2022

Rationale

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 will run 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 start depending on the COVID19 pandemic situation.

Identified Medical Interventional Area

The educational actions undertaken by the network so far have allowed to deeper analyze the educational area of RHD by the compilation of the existing educational material for health professional and patients and the identification of the educational requirements for health professional and patients. In turn, the analysis of the educational needs has provided the evidence base required for defining the strategic plan and starting specific targeted-actions to address gaps with the following expected long-term results:

- 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 haematological diseases among health professionals in UE.

Each CME training of the ERN Mobility Program, from ERN-EuroBloodNet 'perspective, will include those interventional medical areas:

- Highly specialized procedures in rare hematological disorders
- Diagnosis and clinical management of hematological rare diseases, consisting of the integration of the following two formats :
 - Theoretical academic courses (formal lectures, informal discussion)
 - Practical exercises held in expert centers, either in the laboratory and or in clinical consultations (direct tutorial activity)
- 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
 - Cases shared in the Clinical Patients Management System

Please, see the proposed models of CME Exchange program in ANNEX I_Exchange CME Programs.

Already identified clinical area

Those 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.
- New clinical areas could be identified as part of the program. Indeed the online platform provided by Ecorys could be used for exploring if other domains require CME intervention. Also, if during the last of this program some educational needs are covered by other organizations, the ERN will not duplicate the program but identify other niches.

• **Cutaneous Lymphoma**

Main objective is to disseminate very innovative topics among health professionals in order to give visibility to the last cutting-edge advances in the field of Cutaneous Lymphoma. This objective responds to the need for in-depth knowledge sharing by international experts of this rare malignancy. In fact there are several differentiations in Cutaneous Lymphoma sub-categories that require a specific educational knowledge from a clinical, pathological, etiological and phenotypic point of view. Finally an educational program dedicated to this very rare malignancy would clarify the role of hematologists and dermatologists in the clinical managing of Cutaneous Lymphoma patients as this disease requires a multidisciplinary approach because it manifests itself on the skin level.

• **Sickle Cell Disease**

Due to a number of factors, Sickle Cell Disease is on the rise Europe and therefore the need to increase expertise in clinicians responsible for patient care in areas of high and low prevalence. A number of countries like the UK and France traditionally have high SCD prevalence in the range of 14-20,000 people living with the disorders respectively, while others like Spain, Italy and Germany have seen a more steep rise in the affected people in their midst recently. All patients with SCD irrespective of where they live are entitled to receive high quality care that is able to meet their needs for emergency treatment, surveillance and rehabilitation where necessary. This is the driving force for the current service review across Europe, leading to the emergence of Haemoglobinopathy Coordinating Centres, Specialist Treatment Centres and National Clinical Reference Group to ensure equity of provision and high quality care.

• **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.

• **Thrombotic Microangiopathies**

The main objective for this program is to disseminate very innovative topics among hematologists, internists, nephrologists, pediatricians, or other health care providers interested in the topic in order to give visibility to the last cutting-edge advances in the field of Thrombotic Microangiopathies (TMAs). This objective responds to the need for in-depth knowledge sharing by international experts of this rare group of diseases. Thrombotic Microangiopathies require a specific educational knowledge from a clinical, pathological, etiological and phenotypic point of view due to the low prevalence of the disease and multi-level clinical manifestations. Finally, this educational program would clarify the role of hematologists, nephrologists, and pathologists in the clinical management of patients with TMAs, as this disease requires a multidisciplinary approach due to variety of symptoms like hemolytic anemia, low platelets, and organ damage as a result of the formation of microscopic blood clots in capillaries and small arteries of most organs.

Criteria for CME Mobility Program Priorities

Benefit of the program by experts coming from ERN members or affiliated members in those EU MS with scarce cutting-edge knowledge on a RHD.

Benefit of disseminate cutting edge knowledge on RHDs in those country where expertise is scarce by implementing services and highly specialized procedures where lacking. It is also a way of encouraging the Cross Border Health cooperation among ERN-EuroBloodNet HCPs.

Urgency of consultation about RHDs complex cases.

CME Mobility Program Timeline and logistic informations

- The ERN-EuroBloodNet Mobility Program will start as soon as the COVID19 pandemic crises will be under control.
- 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.

CME accreditation

The ERN-EuroBloodNet CME Mobility program addressed to health professionals will be accredited by the European Board for Accreditation in Hematology <https://ebah.org>

Next steps

- Submit the completed initial agreement template for the ERN exchange program
- Organize and coordinate together with Ecorys Ltd the 55 ERN exchange program packages allocated

2.2. ONLINE TRAININGS

2.2.1. WEBINAR PROGRAMS FOR HEALTH PROFESSIONALS ON RARE HEMATOLOGICAL DISEASES

Webinars are online educational sessions led by the international top experts in the field of Rare Hematological Diseases. Each webinar is conducted using the Webex Platform provided to ERN-EuroBloodNet by the European Commission. 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.

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, webinar 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.

2.2.1.1 "EuroBloodNet Thursdays Webinars". Transversal program for health professional covering all RHDs

Objective

Main objective of the Webinar "EuroBloodNet Thursdays Webinars" is continuing promotion of the innovative topics in order to stress among health professionals the cutting-edge advances in the field of Rare Hematological Diseases. Webinars are mainly addressed the very rare diseases, complex disorders, highly specialized procedures and implementation of guidelines. Apart from defining a focus of interest that could be neglected because too specialized or dedicated to ultra-rare diseases, webinars give also visibility to upcoming educative events organized by EHA and ESH with respect to each session's topic. Continuation of the objectives identified in the previous report:

1. Enhance the dissemination of the Program aiming to increase the number of participants by the diffusion among National Scientific Societies contact persons identified.
2. Creation of a repository of questions rose each session.
3. Continue programming the calendar to organize further educational sessions by taking into consideration the 23 topics proposed by the Board of Network.

Methods

The list of potential webinar topics was identified during the ERN-EuroBloodNet Board of Network in November 2019 in Barcelona. Thursday Webinars were officially launched in January 2020, with the first webinar taking place the 6th of Feb. This established list with webinars was described in the previous deliverable report.

Thursday Webinars are opened to every haematologist, paediatrician, or other health care providers interested in the topic, within and outside the ERN-EuroBloodNet. Speakers are identified among ERN-EuroBloodNet members.

Each Webinar last 45 minutes: 30 minutes for the expert's presentation and the last 15 minutes for questions from the audience. Session are conducted using the Webex Platform provided to the ERN-EuroBloodNet by the European Commission, and based on the Thursday Webinars 'powerpoint template. The PowerPoint presentation should include: diagnostic tools, process of the differential diagnosis and treatment algorithms with expert recommendation. In addition, they are always held in the same day of the week and time slot (Thursdays at 17:00). ERN-EuroBloodNet aims to implement 2 webinars per month.

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:

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)

Results

- **Thursdays Webinars Logo and Theme**

To promote better recognition of EuroBloodNet’s Thursday 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. Pic. 1 and Pic. 2 present the powerpoint presentation template and logo of Thursdays’ Webinars respectively.



Pic.1. Thursdays Webinars Powerpoint template and logo

- **List of Webinars taken place in 2020**

In the frame of building the repository of educational material in the field of Rare Hematological Diseases EuroBloodNet’s published the recorded Thursday Webinars on the [EuroBloodNet’s EDU YouTube channel](#) launched in May 2020 to promote increased and open access to educational material on rare diseases. The list of all the sessions published in 2020 can be found in the ANNEX II_EuroBloodNet’s Thursdays Webinars for Health Professionals in 2020.

- **Registration and online visibility of the Thursday’s Webinars**

Campaigns for dissemination of the whole program and for the specific webinars have been launched through ERN-EuroBloodNet communication channels, including pieces of news, dedicated Newsletters, tweets, facebook and LinkedIn posts. Furthermore, a total of 26 dedicated Newsletters have been launched for the dissemination of the program, with the following average rates:

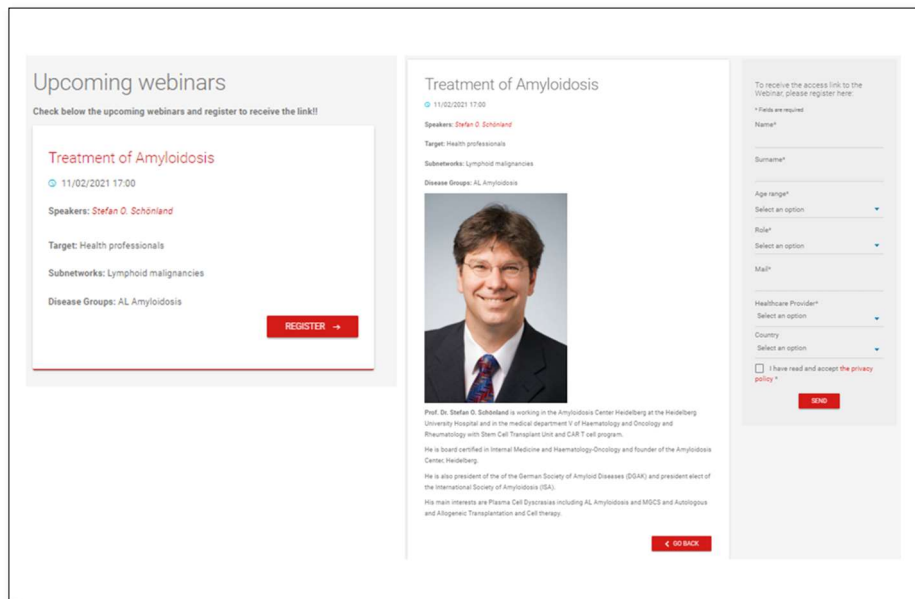
Dissemination Campaigns	Total emails sent (medium rates)	Opened (medium rates)	Open rate %	Clicked	Click rate %
Thursdays webinars	357,92±18,98	88,02±11,48	26,81±10,14	8,84±3,50	4,04±7,54

Table 1. Dissemination Newsletter campaign results

The description of the [Thursday Webinars](#) can be found in the special section of the network’s website dedicated to this specific program. To enable the monitoring of participants and dissemination of the access link to Webex platform, EuroBloodNet created a dedicated registration form for each Thursday Webinar at ERN-EuroBloodNet website (picture 2), together additional short biography and profile of the Speaker can be found.

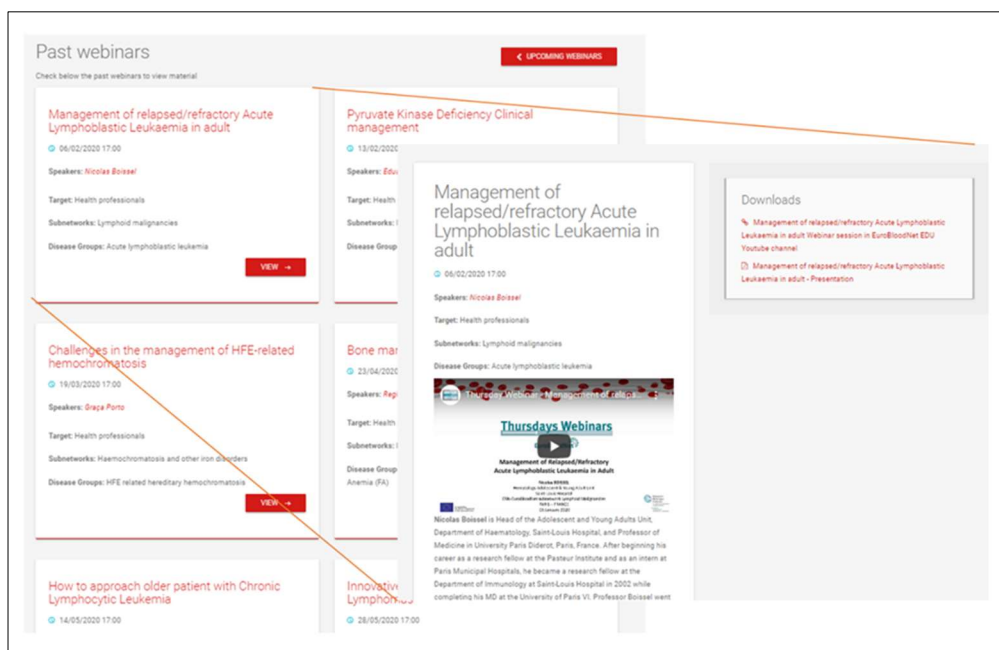
Registration form includes the following fields mandatory to receive the link for connection:

- Name
- Surname
- Age range
- Role
- Mail
- Healthcare Provider (list of ERN-EuroBloodNet members and "Other" option for free text)
- Country
- Checkbox "I have read and accept the privacy policy"



Pic. 2. Thursdays Webinars registrations and overview of the available sessions

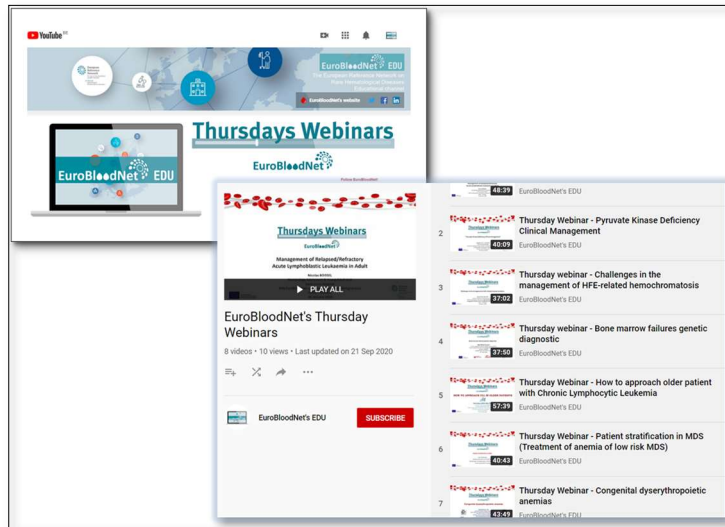
The recorded session is being published on EuroBloodNet’s EDU and it is also visible in the EuroBloodNet’s website section ‘past webinars’ where the video together with presentation’s pdf is intergated (picture 3).



Pic. 3. Past sessions of the Thursdays Webinars with recorded videos and pdfs.

To increase the publicity of the Thursdays Webinars, all the recorded videos are published on the EuroBloodNet’s EDU YouTube channel in a dedicated ‘Thursdays Webinars’ playlist (Picture 4).

All the published webinars together with number of views are presented in the Table number 2.



Pic. 4. Overview of the EuroBloodNet's EDU YouTube channel's playlist with Thursdays Webinars.

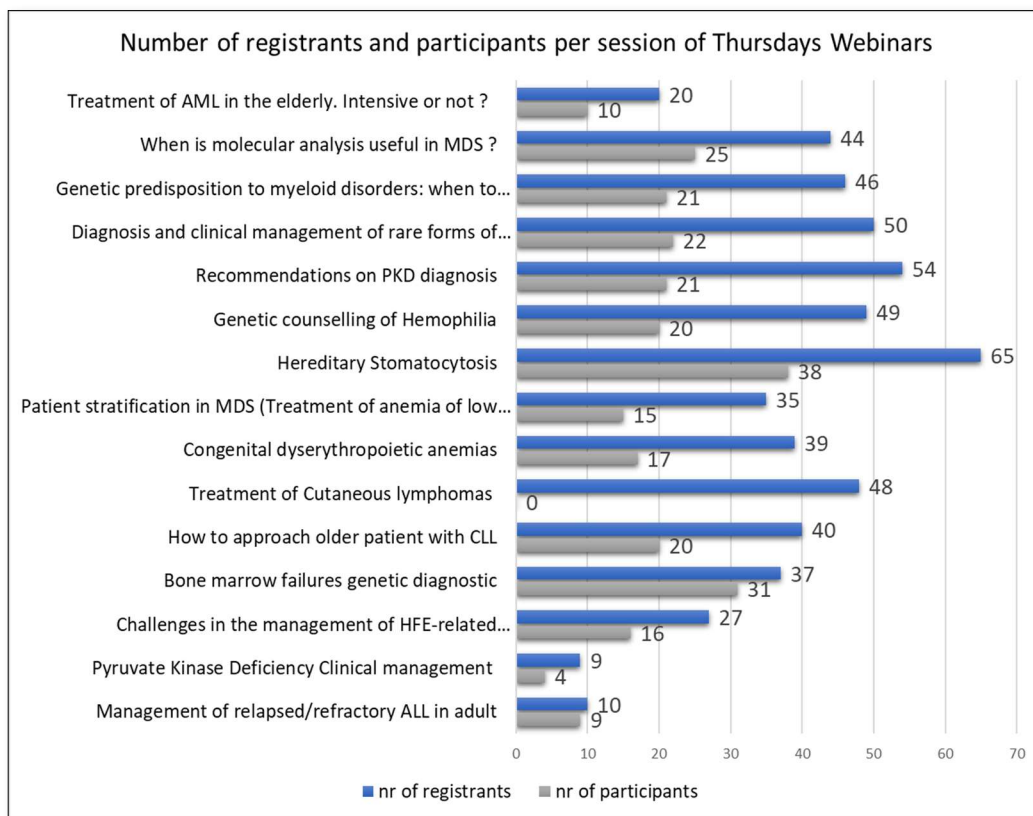
Title	Link to EuroBloodNet's EDU YouTube channel	Nr of views
Management of relapsed/refractory ALL in adult	https://youtu.be/hY4kWNJ2hwM	85
Pyruvate Kinase Deficiency Clinical management	https://youtu.be/RWmuHK-_5fs	69
Challenges in the management of HFE-related hemochromatosis	https://youtu.be/ZF14eGQ8NOc	53
Bone marrow failures genetic diagnostic	https://youtu.be/kC0zkqR7Qvs	60
How to approach older patient with CLL	https://youtu.be/oz89GdVpxWM	33
Treatment of Cutaneous lymphomas	https://youtu.be/wtLLyFkUMe4	81
Congenital dyserythropoietic anemias	https://youtu.be/JnnLz7ogPJA	183
Patient stratification in MDS (Treatment of anemia of low risk MDS)	https://youtu.be/ZfjkwbOkprk	43
Hereditary Stomatocytosis	https://youtu.be/qjfwJIRB1Ow	23
Genetic counselling of Hemophilia	https://youtu.be/XPG2FakCc9E	18
Recommendations on PKD diagnosis	https://youtu.be/sdD86-odFRY	30
Diagnosis and clinical management of rare forms of Hemochromatosis	https://youtu.be/k3Ilc1wF5Ow	23
Genetic predisposition to myeloid disorders: when to analyze it	https://youtu.be/7-QjHm8p3HY	21
When is molecular analysis useful in MDS ?	*	*
Treatment of AML in the elderly. Intensive or not ?	*	*

Tab. 2. List of Thursdays Webinars available on the EuroBloodNet's EDU YouTube channel from the sessions taken place in 2020. * under development.

- **Statistical overview of the Thursday Webinars program in 2020**

Registrations and participants

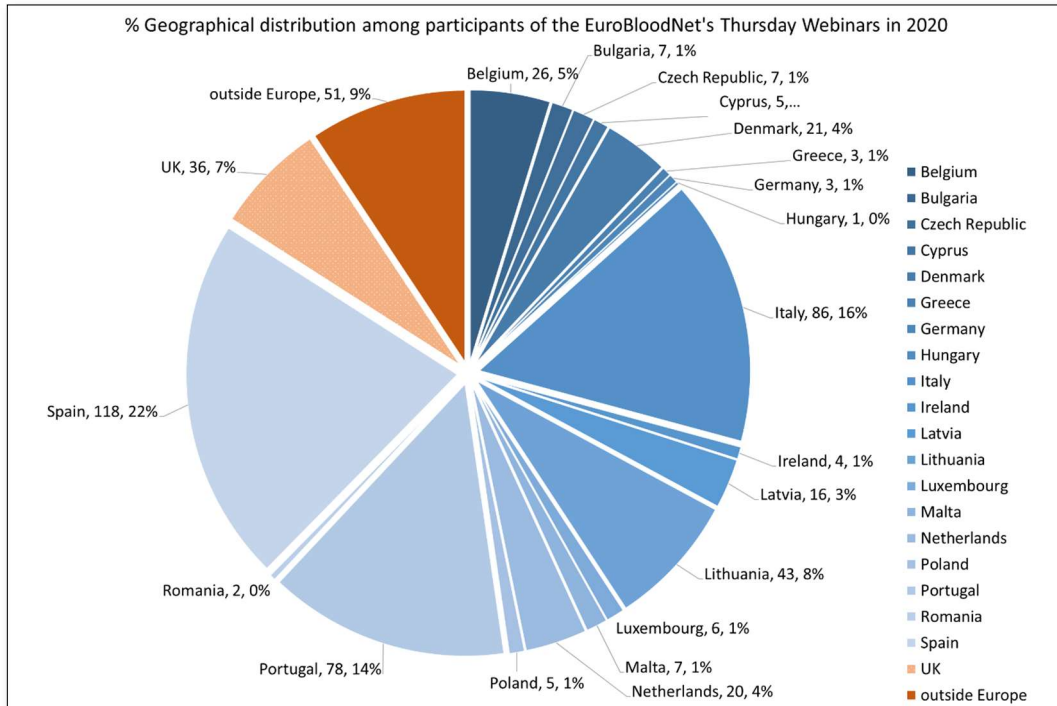
Through the 15 sessions of Thursday Webinars taken place in 2020, the general trend can be observed that the number of registrants was mostly double-fold higher than the actual number of participants (Graph 1.). The higher number of registrations was for the webinar on 'Hereditary Stomatocytosis – '65 and the lowest for the PKD Deficiency Clinical Management – 9. The number of participants for these webinars were 38 and 4 respectively, also indicating the most and least attended Thursdays' Webinars in 2020. For the rest of the webinars the number of participants was between 10 and 31.



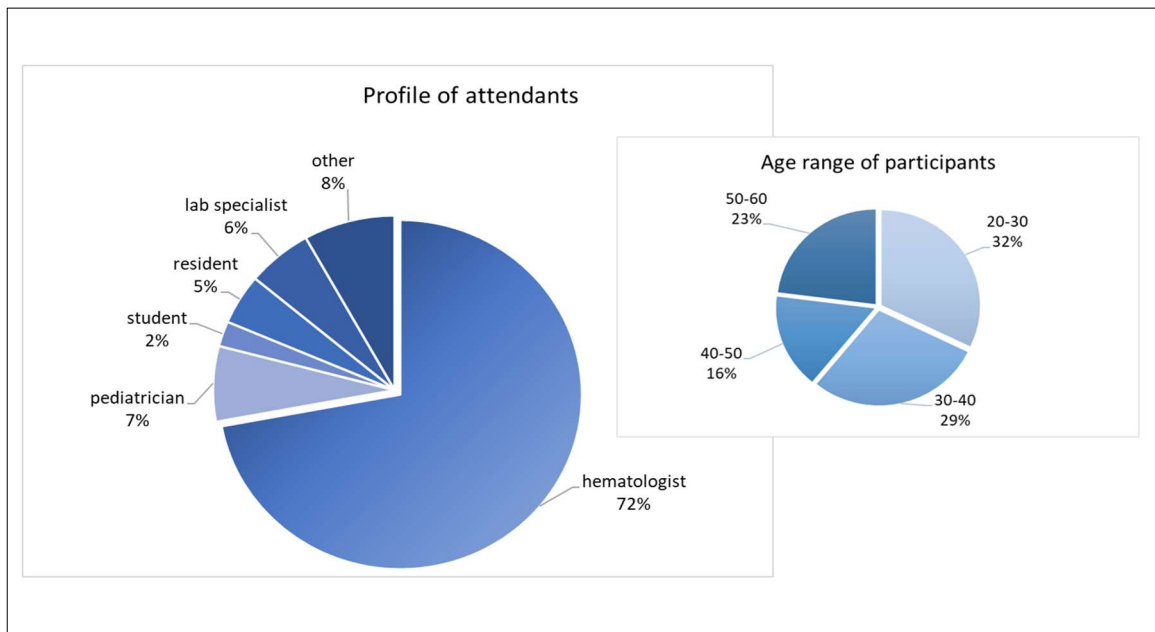
Graph 1. Registration v. participation in Thursday Webinars in 2020.

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 19 EU countries, moreover from UK and outside Europe. The majority of attendants were from Spain (22%), Italy (16%), Portugal (14%) and Lithuania (8%) and UK (7%). Whereas 51 participants (9%) were from outside Europe. Majority of the audience were hematologists (72%) and young professionals in a group between 20-40 (together 61%). Detailed overview is presented in graph 2 and 3.



Graph 2. Geographical distribution among Thursday Webinars' audience.

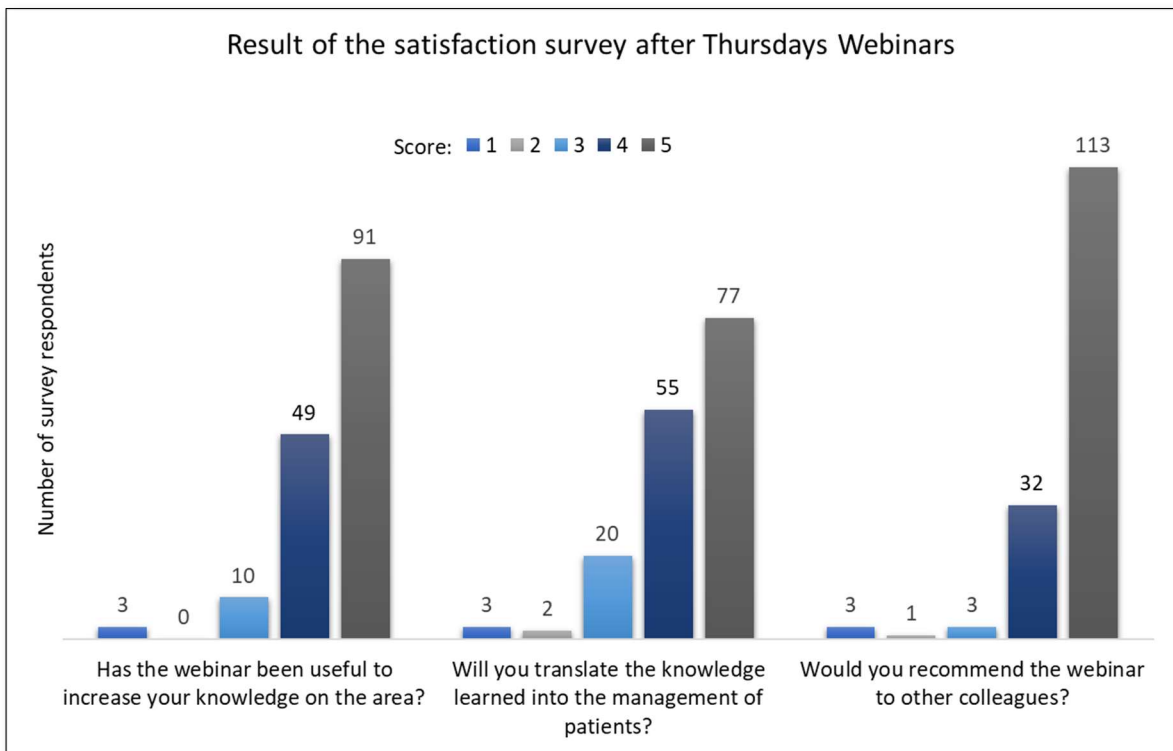


Graph 3. Profession and age of Thursday Webinars' audience.

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 in 2020, majority of the participants claimed that the webinar was useful to increase

their knowledge on the area (91 responders), they will translate the knowledge learned into the management of patients (77), and that they will recommend the webinar to other colleagues (113). The overview of the survey is presented in the Graph 4.



Graph 4. 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. The list is presented in the table 3.

T/NK cell lymphoma, monoclonal gammopathy of renal significance, management of CART toxicity

Myelodysplastic syndromes in children

Diffuse Large B Cell Lymphoma, new drugs

Treatment of aplastic anemia, Pediatric myeloproliferative disorders
Pediatric myelodysplastic syndromes

I expected more info about geriatric assessment and how to adapt therapy in older patients with hematological malignancies, Low grade Hodgkin's Lymphoma , Management of Aggressive Lymphomas especially relapsed refractory

Lymphoma DLBCL, myeloma, other lymphomas, leukemia, Keratinocyte carcinoma, Excellent Webinar

Iron metabolism in RBC, very good

How to plan transfusions in MDS patients

Non transfusion dependent thalassemia, sideroblastic anemias, Hereditary Spherocytosis, Hemoglobinopathy thalassemia, immune hemolysis, PNH, marrow failure syndrome, megaloblastic anemia, NK/T cell lymphoma

Hemoglobinopathy, Diamond Blackfan anemia, Fanconi anemia, practical management of severe iron overload in children in hemolytic anemia, Hexakinase deficiency clinic and diagnosis

I am board member of Danish Haemacromatosis Association, and it was interesting to hear, management of iron overload related to NASH and metabolic causes, congenital dyserythropoietic anemia, GATA-2 deficiency

pediatric myelodysplastic syndromes, Myelodysplastic syndromes, somatic variant interpretation in myeloid neoplasms, familiar lymphoid disease, Excellent overview! It was great!

Inherited thrombocytopenias, Lymphocytic HES

Table 3. Comments and suggestions gathered through the satisfactory survey.

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.

2.2.1.2 Accredited Topic on Focus: Cutaneous Lymphoma for Health Professionals

After the good results and experience from ERN-EuroBloodNet Thursdays Webinars, a new program called "ERN-EuroBloodNet Topic on Focus Webinars program on Cutaneous Lymphoma for health professionals" has been defined aiming to disseminate very innovative topics among health professionals in order to give visibility to the last cutting-edge advances in the field.

The program has been developed under the frame of Connecting EuroBloodNet II, with the definition of 9 sessions accredited by European Board for Accreditation in Hematology (EBAH) with 7 credits to the participants to all the webinars.

ERN-EuroBloodNet Topic on Focus Webinars program on Cutaneous Lymphoma for health professionals program started in May 2020 and ended in December 2020.

Campaigns for dissemination of the whole program and for the specific webinars have been launched through ERN-EuroBloodNet communication channels, including pieces of news, tweets, facebook and LinkedIn posts. Furthermore, a total of 11 dedicated Newsletters have been launched for the dissemination of the program, with the following average rates:

Dissemination Campaings	Total emails sent (medium rates)	Opened (medium rates)	Open rate %	Clicked	Click rate %
Topic on Focus: Cutaneous Lymphoma	357,11±10,74	80,22±7,66	22,52±1,72	2,71±3,83	1,76±1

Table 4. Results from the dissemination of the program through the dedicated Newsletters

Objectives of the program, methodology and results from each of the Webinar will be detailed in the frame of the Connecting EuroBloodNet II (Cef Telecom grant).

2.2.1.3. Accredited Topic on Focus: Thrombotic Microangiopathies for Health Professionals

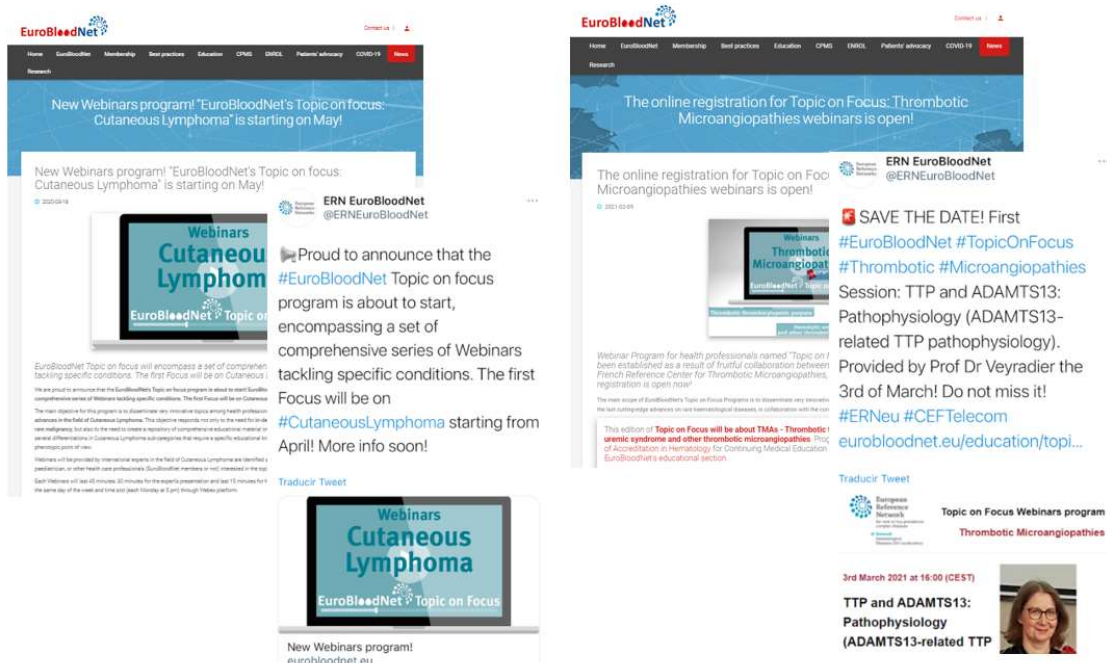
Given the success experienced on ERN-EuroBloodNet Topic on Focus Webinars program on Cutaneous Lymphoma the structure has been replicated for the organization of ERN-EuroBloodNet Topic on Focus Webinars program on Thrombotic Microangiopathies with the aim to disseminate very innovative topics among health professionals in order to give visibility to the last cutting-edge advances in the field.

This webinar program is a response to the need for in-depth knowledge sharing by international experts of this rare group of diseases, but also to the need to create a repository of comprehensive educational material on all types of Thrombotic Microangiopathies.

The program has been developed under the frame of Connecting EuroBloodNet II, with the definition of 15 sessions, and has been submitted for the CMA accreditation to the European Board for Accreditation in Hematology (EBAH).

The program will start in March 2021. Dissemination campaign has been launched through ERN-EuroBloodNet communication channels, including pieces of news, tweets, facebook and LinkedIn posts. A dedicated Newsletter for the first webinar has been launched to a total of 386 recipients (21,67% opened and 1,57% clicked).

Objectives of the program, methodology and results from each of the Webinar will be detailed in the frame of the Connecting EuroBloodNet II (Cef Telecom grant).



Pic 5. Some examples of the dissemination campaigns for Topic on Focus Webinars

3. EDUCATIONAL ACTIONS IMPLEMENTED FOR PATIENTS

SICKLE CELL DISEASE RELATED ACTIONS

3.1. ONSITE TRAININGS

3.1.1. NATIONAL TRAININGS FOR PATIENTS ADVOCACY

Rational

The ERN-EuroBloodNet together with EURORDIS is establishing the European Network of Sickle Cell Disease Patients' Organisations aiming to provide a centralized European point of contact for patients and caregivers. It will be a bottom-up umbrella network of national and local organizations of SCD patients' advocates. Each Country is represented by two spokespersons. A spokesperson is a national representative that advocate on behalf of all the national SCD patients' organizations. The role is the mediation among the European Network of SCD Patients' Organisations and the national patients support groups. Among all spokespersons, a representative one will become ePAG for the ERN-EuroBloodNet.

Objective

The ERN-EuroBloodNet decided to act at the local level inviting Patients support group and/or motivated patients to National Meetings. National Meeting' objectives are:

- Training in patient advocacy.
- Listening to SCD patients' needs and expectation.
- Encourage, if not existent yet, to form a national association/federation/group

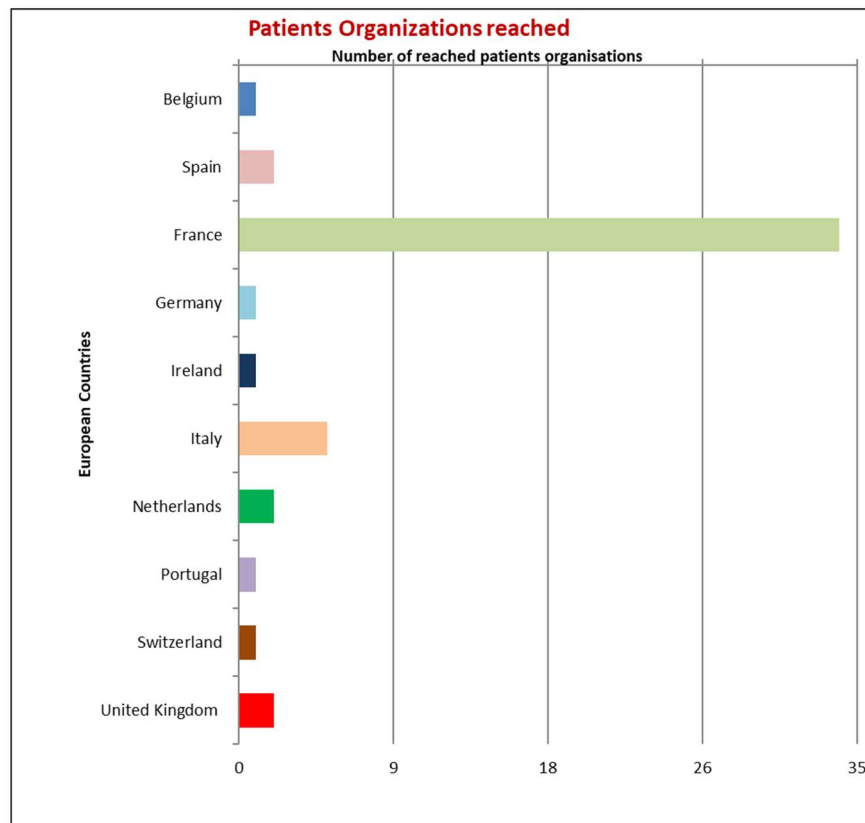
The training dedicated to advocacy consists of different parts:

- What is a patients representative?
- What is a Patient association ? (scopes, types, actions)
- Eurordis and the role of ePAGs in the ERNs
- Other possibilities to train in patients advocacy (Eupati, Eurordis Summer and Winter School, TIF training, etc.).

Results

1. Advocacy representation:

- More than 50 SCD patients association have been reached in Europe and are constantly in contact with the ERN-EuroBloodNet ongoing actions dedicated to SCD.
- Patients Associations and patients motivated to contribute to the cause of SCD advocacy in Europe in contact with the Coordination Team of the ERN-EuroBloodNet belong to 12 European Countries: Spain, Portugal, Italy, France (France metropolitan and France Overseas), Cyprus, Belgium, Germany, Ireland, UK, Austria, Netherlands, Switzerland.
- Also Patients associations and patients motivated to contribute to the cause of SCD advocacy outside Europe have been reached. For instance, the Australian Sickle Cell Advocacy or the GASCDO, the Global Alliance of SCD organisations. Other countries reached are: USA, India, Ghana, Kenya, Abuja.
- Meeting outcomes in "ANNEX III_National Trainings for patients advocacy".



Graph 5. Showing the 12 European countries representing 50 patients associations dedicated to SCD.

2. A total of Four National trainings to patients advocacy (Italy, France, Spain&Portugal and Belgium) have been held during third year of the ERN-EuroBloodNet.

- First national meeting in Milan, the 29th of March 2019
- Second National Training, in Paris, the 29th of June 2019
- Third National Training, in Madrid, gathering Spanish and Portuguese patients, 18th February 2020
- Four National Training, in Brussels, the 3rd of December 2020

3. The following points, based on the meetings held between France, Italy, Spain, Portugal and Belgium are common points raised by those countries and would be translated into first concrete actions at European level:

- Recognition of Sickle Cell Disease as recognized disability in the National Table of Disabilities.
- Fight against Stigmatization
- Fight against patient isolation
- Improving best practices and patients' pathways
- Awareness raising on the importance of receiving psychological help
- Neonatal and prenatal screening programs
- Improving the visibility of the disease during the International Sickle Cell Disease Awareness day.
- Repository of Educational Material for patients.

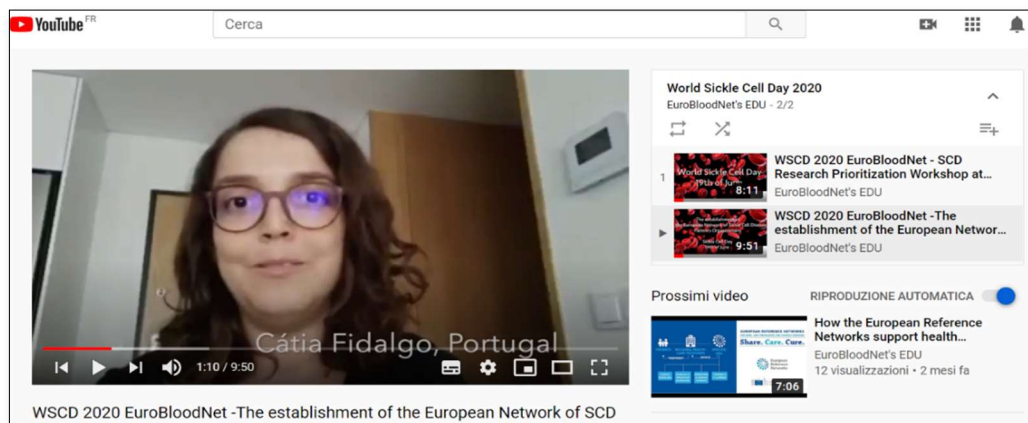
4. One of the relevant results to underline from the national meetings are the effects those had at the national level on local patients organisations:

- In France the election of National Representatives for the European Network of SCD Patients Organisations has strength the collaboration between the associations belonging to the France overseas and the France metropole; as for the associations belonging to Parisian territory and extra urbans territories

- In Italy the patients associations got to know each other and choose to collaborate together. They also have elected two national patients representatives for the European Network of SCD Patients Organisations.
- In Spain, no SCD patients associations existed. After the meeting held by the ERN-EuroBloodNet a National patients association was founded: the ASAFE 5 Asociación Española de Enfermedad Falciforme; Two national patients representatives have been elected for the European Network of SCD Patients Organisations.
- In Portugal new patients representatives joined the existing National patients association: the APPDH. Two national patients representatives have been elected for the European Network of SCD Patients Organisations.
- In Belgium an informal national group of patients representative has been created. Two national patients representatives have been elected for the European Network of SCD Patients Organizations.

5. Testimony Video

- Production, editing and publication of The video described in the paragraph of Patients Video, 1st Testimonies Video, the establishment of the European Network of SCD POs of this Deliverable.



Pic. 6. Videos of SCD patients testimonies on EuroBloodNet's EDU YouTube channel.

Next steps

- SCD patients reached by the ERN-EuroBloodNet Coordination team are invited to the part to the Educational Session organized by the Network addressed at people living with SCD at ASCAT (2019, 2020 and forthcoming 2021)

3.1.2. EDUCATIONAL PATIENTS SESSION AT CONGRESS

Rationale

ERN-EuroBloodNet is promoting educational activities taking place during International Scientific Congress and targeting people living with SCD in order to encourage their training and develop their skills as advocates and expert patients. First reason for coordinating this project is that when it comes to SCD in Europe is frequent to face patients' isolation. Indeed, there are few existing SCD patients' associations. In addition, most of the patients do not have an adequate educational level as they come from third countries and suffer from immigration burdens. Therefore, the ERN-EuroBloodNet considers those events as an occasion for SCD patients to meet each other in a dedicated space for them and sharing experience and expectations. Finally, the ERN-EuroBloodNet's model of educational sessions at International Scientific Congress is a way to make visible to scientific community what patients would prioritize as research topics and tackle gaps to address. Indeed, SCD patients could present the outcomes of the educational sessions they took part to, at the plenary session of International Scientific Congress.

SICKLE CELL DISEASE PATIENTS EDUCATIONAL SESSION AT ASCAT 2020

Objective

Considering the success of the SCD patients' session at ASCAT 2019 as described in previous Deliverables ("6.1 ERN-EuroBloodNet Report on Actions for the promotion of continuing medical education on RHD" and "6.4. Patients Actions"), it has been decided to repeat the experience by organizing another educational event addressed to SCD patients in the framework of the 15th Annual Sickle Cell and Thalassaemia Conference (ASCAT). This year the ASCAT Conference has been organized in collaboration with the European Hematology Association (EHA) and the British Society of Haematology (BSH), held from the 26th to 31st of October 2020, on an online virtual platform as a result of Covid19 Pandemic Outbreak.

A part letting SCD patients participating to the Educational Online session specifically addressed to them, the ERN-EuroBloodNet Coordination Team and the ASCAT members have also given the possibility to assist to the whole ASCAT Congress event. This has been an important opportunity for SCD patients and parents patients for learning more and discuss the latest advances in terms of diagnosis, treatment and emerging new therapies in the field of the haemoglobinopathies as the ASCAT 2020 is dedicated this year to: 'Haemoglobinopathies: Emerging Challenges and Future Therapies'.

Methods

An online Educative Session has been programmed on three different days. A team of SCD experts belonging to ERN-EuroBloodNet and ASCAT committee has planned the program.

Task force

ERN-EuroBloodNet, ASCAT Steering Committee, British Society of Hematology

- Prof. Beatrice Gulbis, from Hôpital Erasme/LHUB-ULB in Belgium;
- Prof Mariane de Montalembert, from AP-HP hôpital Necker, in France;
- Dr. Noemy Roy from Oxford University Hospitals NHS Foundation Trust,
- Dr Baba Inusa from Guy's and St Thomas' NHS Foundation Trust,
- Dr Raffaella Colombatti, from AO Padua in Italy,
- Dr CHAKRAVORTY, Subarna, from King's college Hospital NHS Foundation Trust
- Dr Maria del Mar Manu Pereira, from VHIR Hôpital,
- Dr Mariangela Pellegrini, from AP-HP Saint Louis Hospital,

Program

The above-mentioned group together with the ERN-EuroBloodNet coordination team has decided the topics to address during the online educational session this year. Program has been decided based on some evidences:

- The result of the past' year edition: Top 10 topics from SCD Research Prioritization Workshop ASCAT 2019, the list of topics SCD patients would like that the research addressed
- the feedbacks' survey from participants of ASCAT 2019, the ERN-EuroBloodNet's Survey for prioritizing SCD topics to be addressed by Educational Videos, as described in the paragraph dedicated to SCD Educational video of this deliverable. Identified topics for the "meet the expert" session are:
 - Newborn and infant SCD Screening
 - Neurological Complications in SCD
 - Adult people affected Quality of Life
 - BMT: survival infertility and other complications
 - New therapies for SCD

The SCD Patients Educational Session involves three major sessions:

- Living with SCD and coping with COVID19 Pandemic Outbreak, (access to hospitals, management of crisis, receiving information about Covid, etc.)
- The participations of SCD patients to Research and Peer Reviewing.
- Three panels. One "meet the experts" and two "meet the patients' session". There has been also the possibility for patients to raise dedicated questions to physicians and for physicians and young patients, the possibility to raise questions to adult patients.
- Living with SCD as pediatric or young adult patients.

As visible in the "Annex IV_ASCAT 2020", presenting the program of the ASCAT 2020 patients'session, a duo made by physician and patient representative has moderated each topic session. Their role has been presenting the topic, gathering key messages and collecting questions raised by hearers in the platform's chat. For some topics, pre-recorded session made by patients' testimonies have been shared. For better shaping the framework of each specific session, the ERN-EuroBloodNet Coordination Team has

collecting questions from patients to physicians and from physicians to patients launching a survey among participants, and key messages belonging to each session too before the official day of the Educational SCD session at ASCAT.

Format of the program:

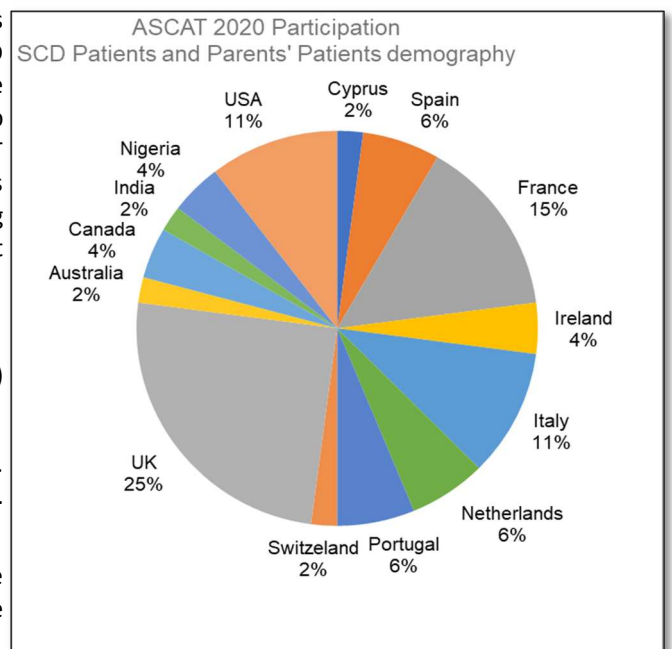
- Online session
 - pre-recorded and live session
 - interaction by live and questions in the chat
 - panel of experts physicians/adult patients/parents patients
 - participants can have access to all the ASCAT
 - Each day, the program last 2 hours and 40 minutes (breaks included), held late in the afternoon for reaching a bigger number of participants.
 - Moderation of the program (duo of physician and SCD patient or parent' patient)
- The Educational Online Session has been fully recorded. For this, an inform consent, in line with the GDPR Regulation has been produced and signed by participants. Inform consent in "ANNEX IV_ASCAT 2020". Those videos will be available on the YouTube Educational channel, [EuroBloodNet Edu's](#) . Subtitles in different languages will be edited to the video

Identification of participants

- SCD Patients associations in contact with ERN-EuroBloodNet. Countries: France, Italy, Spain, Portugal, Cyprus, Belgium, Germany, Austria, Ireland, UK, Netherlands, Switzerland.
- At least 60 patients from Europe (12 country), 5 from Kenya, Nigeria, Ghana, India (20 persons, 1 person per country to speak) + GASCCO governance patients representatives + PESCA and EFSC patients governance.
- Participants and invited patients to ASCAT 2019

Results

- A SCD patients forum has been created with patients coming from European countries and in a smaller part, SCD patients coming from extra communitarian countries. The creation of such a group (moreover if a part of this group had already the opportunity to get in touch thank to ASCAT past event) is capital for patients empowerment. It means more specifically: sharing opinion on burdens regarding living with SCD, sharing best practices and advocating at European and global level.
- 48 Patients and parents patients registered to the event
- 20 Health professionals (physicians, Eurordis, ERN, others) registered to the Event
- Feedback' survey from participants ASCAT 2020 is excellent. Program had a great educational impact on participants. Results on the survey in "ANNEX IV_ASCAT 2020"
- New educational needs have been identified during the whole session, as visible in the presentation of the outcomes. As said the presentation has been written by participants and two people living with SCD has exposed it during the Plenary session of the ASCAT 2020. Results are in the "ANNEX IV_ASCAT 2020. SCD patients and parents patients would like to have access to valuable information on:
 - Mental health
 - Pregnancy
 - BMT side effects
- Another relevant main outcome is that: involving SCD patients in research and care is difficult and not often done. This disenfranchised group is typically challenging to engage. With our model of Educational training, we show to patients



Graph 6. Geographical distribution of participants to SCD educational session at ASCAT 2020.

community and scientific community that it is possible and meaningful, it makes a difference to the patient group and it strength the relation among physicians and patients. Finally, it has been highly appreciated from scientific and patients community to hear patients perspective during international scientific conferences.

- Patients group required a Webinar dedicated to COVID 19. As described in “Patients Webinars” section of this deliverable, it has been conducted the 14th of Decembers 2020. Results are also in the mentioned paragraph.
- Envisaged obstacles have been the different levels of patients’ educations and the language fluency, as the whole conference was held in English. Whereas the online format has been appreciated by patients. There are no burden for family care of days of work, no fatigue of travelling, patients felt free to raise questions thanks to the comfortable situation for addressing questions in the chat. Those elements are visible in the survey feedback presented in the ANNEX IV ASCAT 2020”

3.2. ONLINE TRAININGS

3.2.1. PATIENTS WEBINARS

Objective

EuroBloodNet’s Patients Webinars are led by experts in the field of Rare Hematological Diseases, health professionals and/or patients representatives. This program consist of one webinar that provides patients community, patients’ organisations, caregivers and health professionals with highly specialized knowledge on a specific Rare Hematological disease or groups of disease. In addition, it allows to tackle questions gathered from the audience in real time, providing the perfect environment to benefit from the most outstanding experts in the field.

Method for EuroBloodNet Patients Webinar session

Patients’ representatives or health professionals that collaborates with the Network propose topics to the ERN-EuroBloodNet. So, webinar should tackle an identified educational need. In addition, a survey could be conducted among those associations that collaborate with the ERN in order to identify possible topic to be addressed by a webinar. Webinar target is: patients community, patients’ organizations, caregivers and non expert health professionals. Speakers are identified among ERN-EuroBloodNet members (ePAGS, physicians and active patients associations)

Webinar structure

Each Webinar lasts 45 minutes: 30 minutes for the expert’s presentation and last 15 minutes for hearers’ questions.

In the webinars dedicated section on the ERN-EuroBloodNet website, will be soon placed, in educational section: a brief introduction and aims of the patients’ 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 (when those will be available).

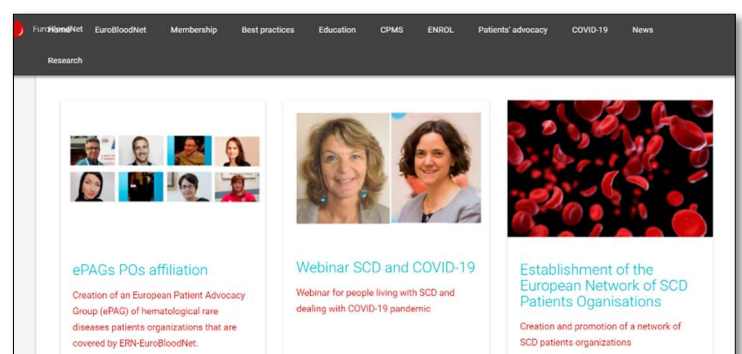
Waiting for the IT team implementing this section, the webinar program is advertised in the section dedicated to Patients Organizations actively involved in the ERN

Registration form includes the following fields mandatory to receive the link for connection:

- Name
- Surname
- Age range
- Role (Student/ Hematologist/ Pediatrician/ Laboratory specialist / Nurse/ Patient/ Parent patient/ Other)
- Mail
- Patients Associations (yes/no) (please, specify if yes)
- Checkbox "I have read and accept the privacy policy"

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

- Role:
 - (Student/ Hematologist/ Pediatrician/ Laboratory specialist / Nurse/ Patient/ Parent patient/ Other)



Pic. 7. Patients’ dedicated sections on ERN-EuroBloodNet website.

- From 1 (Not at all) to 5 (Absolutely yes!)
 - Has the webinar been useful to increase your knowledge on the area?
 - Will you disseminate the knowledge among the local patients and parents patients community?
 - Would you recommend the webinar among other people living with the same condition?

To promote better recognition of EuroBloodNet's Patients Webinars, a unique theme was developed including the logo, the look of the powerpoint templates, and videos intro and outro integrating visually this webinars' cycle.

Additionally the webinars are published on the EuroBloodNet's EDU YouTube channel launched in May 2020 under the CEF grant II to promote increased and open access to educational material on rare diseases.
<https://www.youtube.com/channel/UC7011seQKL7STmLpWPmUFig>

Results

1. Patients Webinars Logo and Theme



Pic. 8. Logo and theme of the Patients' Webinars.

2. 1st Webinar: SCD and COVID-19 infections addressed to people living with SCD

The ERN-EuroBloodNet is facing unprecedented challenges to gather and spread information on the correct treatment and management of infection by Coronavirus (COVID-19) in patients affected by Rare Hematological Diseases. Information gathered are accessible on the [Network's Website](#). The ERN is also helping patients affected by Red Blood Cell Disorders who are also infected with the new coronavirus to receive care and cure adequate to their specific situation by establishing a **ERN-EuroBloodNet Collaborative Platform on Red Blood Cell and COVID-19 patients**. Finally, the ERN has dedicated a specific **educational session on COVID-19 addressed to Sickle Cell Disease patients and parents' patients during ASCAT 2020**.

During this experience, that has gathered more than 40 SCD patients representative worldwide, the ERN-EuroBloodNet has reached the outcomes that patients find difficult to know who/what information to trust about COVID-19 infection. They felt fear and anxiety about how to handle the daily life and respect the barriers gestures, and even they did not know if getting hospitalized during vaso-occlusive crises would have been good or bad for them in the context of the coronavirus pandemic. Finally they wished to know the data on people with SCD getting affected.

This is the reasons why the ERN-EuroBloodNet has organized a webinar dedicated to SCD and COVID-19 infections addressed to SCD Patients and parents patients.

Webinar was led by two clinicians at the front line dealing with the COVID-19 pandemic and **SCD adult and paediatric patients, Prof Mariane de Montalembert** (SCD paediatric specialist) and **Dr Noemi Roy** (SCD adult specialist). The aim is to support people living with SCD, families and caregivers that are currently dealing with COVID-19 case.

Questions patients community would like to addressed to physicians related to COVID-19 have been previously collected during the SCD Patient Educational Session at ASCAT 2020 (event described in a dedicated paragraph of this deliverable). Additional questions have been gathered via a survey circulated among SCD patients community before the webinar.

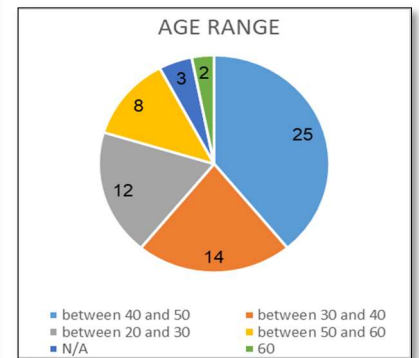
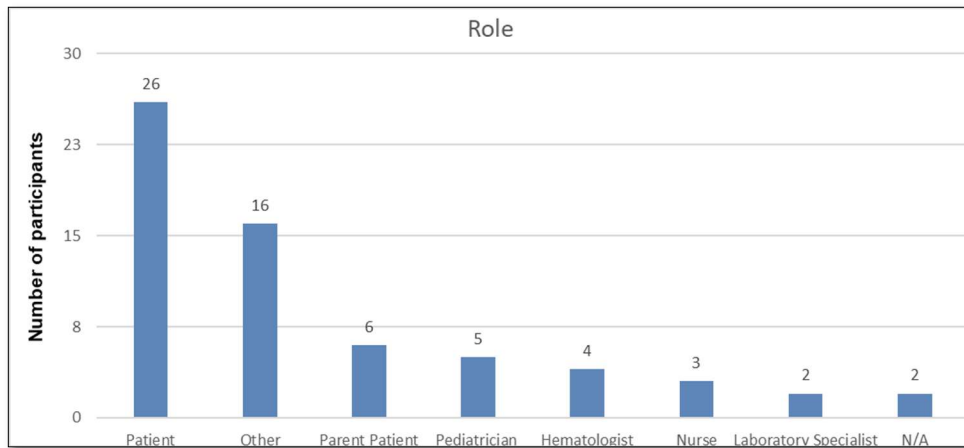
Content of the Webinar

- Symptomatic and asymptomatic cases of COVID19 in children and adults affected by SCD
- Risks for children and adults affected by SCD
- How to live and deal with barrier gestures for children and adult affected by SCD

- Vaccination on COVID19 for children and adults affected by SCD

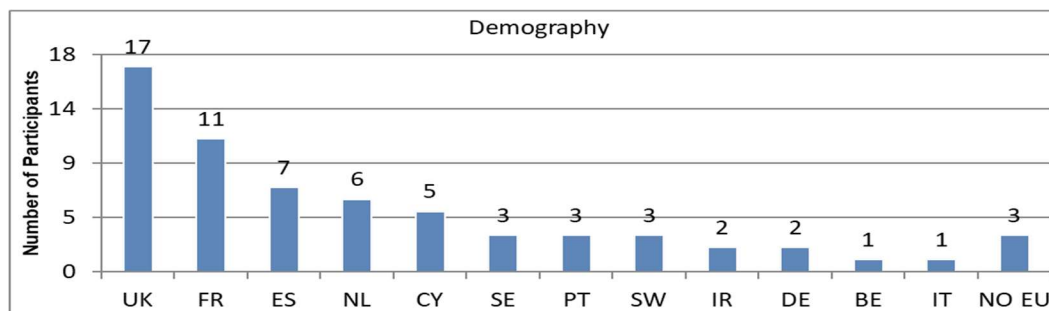
Participants

- 40 participants followed the webinars
- 64 registered to the event
- 29 patients associations registered to the event



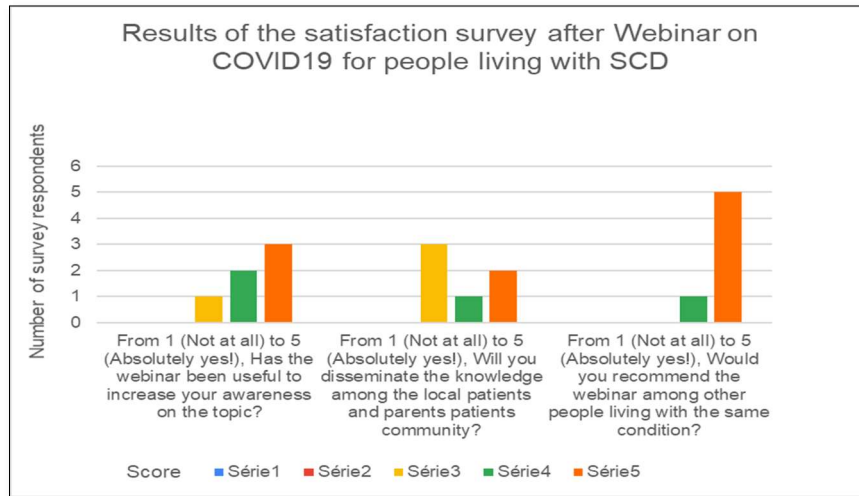
Graph 7. Role of the attendance. The majority of participants were SCD patients (26), followed by other roles (6 participants, as Rare Disease Network project manager), 5 people parents patients, 9 physicians (5 pediatrician and 4 hematologist), 3 nurses, 2 Laboratory Specialist and 2 N/A.

Graph 8. Details of the number of attendants per age range. Attending to age range, the higher representation at the webinars are participants between 40 and 50 age range.



Graph 9. Country coverage of the attendants to the webinar on Covid19 for people living with SCD. Most of participants came from UK, following France, Spain and Netherland. 3 participants were from USA, Israel and Trinidad and Tobago

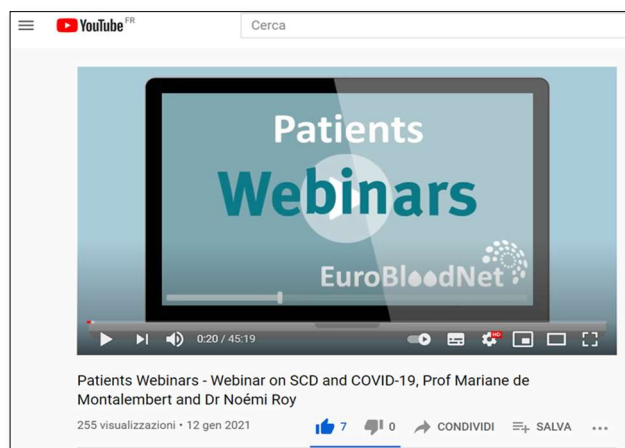
Surveys feedbacks



Graph 10. In the table you can see that 6 participants answered to the satisfactions survey. Feedback in general terms was excellent. A total of three "9" rates were received.

3. Video of the Patients Webinar: SCD and COVID-19 infections addressed to people living with SCD

The recorded webinar is publicly accessible on the [ERN-EuroBloodNet YouTube Channel](#).



Pic. 8. Webinar on EuroBloodNet's EDU channel.

Results:

Webinar on SCD and COVID-19				From 12th January to 4th Feb 2021
Views	Like	View's hours	Interactions	
241	7	21,9	1820	

Tab. 5. Video has obtained an excellent visibility: 241 numbers of views.

Next steps

- Identify other topics addressed to RHDs patients community that could be part of the ERN-EuroBloodNet Patients Webinars Plan.

3.2.2. SICKLE CELL DISEASE PATIENTS TESTIMONIES VIDEOS

Rationale

When it comes to rare diseases, patients and patients' families could face isolation. This situation is due to the: scarce access to information, lack of patients' associations and finally sometimes an approximate disease's management.

Because of this ground, the ERN-EuroBloodNet has started playing a key role in Europe for making rare diseases patients' burdens visible to scientific community, public-at large and policymakers. The ERN-EuroBloodNet could achieve good goals in those domains thanks to the close collaboration with expert HCPs, EURORDIS, ePAGS and European, National or Local patient's representatives groups too.

Objective

Given visibility to patients' voice by publishing a video on our ERN-EuroBloodNet Educational YouTube Channel is a cardinal educational action aiming to:

- Training patients in public speaking
- Raise awareness in patients community about a rare disease
- Raising awareness on Patient Educational Therapy and Public Patients Involvement in research
- Strength the collaboration between patients and health professionals by including videos on patient's expectations/needs during International Congress and/or International Awareness Day.

Patients Testimonies for the Sickle Cell Disease International World Awareness Day.

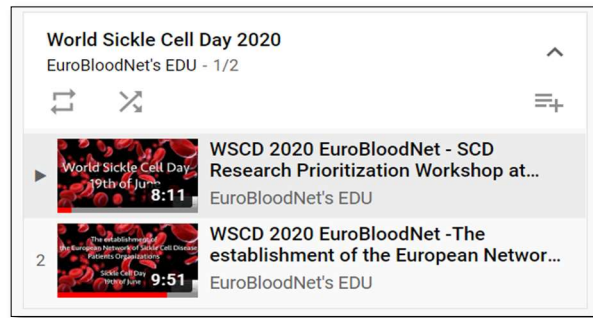
In Europe, people living with SCD mainly belong to ethnic and social minorities. Therefore, they are more isolated, have a lower level of health education, poorer adherence and disease management compared with patients with other hematologic diseases. Those conditions make the disease invisible to the society. The ERN-EuroBloodNet could provide a worldwide visibility to Sickle Cell Disease and correlated patients' needs, by monitoring and reporting patient expectations thanks to the results obtained by the several projects dedicated to the SCD the ERN have launched. The ERN-EuroBloodNet has considered a fundamental action to contribute to the WSCD2020 by giving voice to SCD patients. Main aim was indeed to train patients in giving testimonies, spread patients' needs and expectation by giving to patients the possibility of expressing themselves and providing editing and recording solutions, media channels and logistics assistance.

Methods

The ERN- EuroBloodNet has first contacted the SCD patients and parent's patients that have taken part to the 2 Educational events: SCD Research Prioritisation Workshop at ASCAT 2019 and to the National meetings for the establishment of the European Network on SCD Patients Organisations, by sharing the idea of producing a testimony video for the International Day of SCD. To those patients willing to participate, the ERN-EuroBloodNet has given the following instructions:

1. Video duration should be less than 1 minute
2. Language should be English
3. Video's testimony could be developed in those suggested frameworks:
 - a. National meetings: "What do you expect from an European common patient's voice?" Or "How did you felt in having the opportunity to share your experience and concerns with other patients?", "How do you imagine will be the opportunity to exchange with patients coming from other EU countries?"
 - b. ASCAT 2019: "What do you expect from Research and/or what do you expect from patients' involvement in Research?" Or "How did you felt in having the opportunity to take part to the SCD Research Prioritization workshop and share your thoughts and needs with patients from other EU countries?".
4. Video should be recorded in horizontal
5. Consent form signed by each testimony for sharing the video for the International day of the SCD published on ERN-EuroBloodNet website and social channels.

Secondarily, the ERN-EuroBloodNet have done an editing work of video received. Technical support has been provided by Dr Julia Dominika Zajac ERN-EuroBloodNet CPMS & e-learning Manager, as part of a new Grant by the EC for the CPMS and eLearning platforms that has been officially launched 1st October 2019. The Educational channel launched on YouTube by the ERN-EuroBloodNet is indeed part of the development of the e-learning platform of the ERN-EuroBloodNet.



Pic.9. The two videos’ testimonies published for the WSCD 2020

1st Testimonies Video, the establishment of the European Network of SCD POs

The ERN-EuroBloodNet together with EURORDIS is establishing the European Network of Sickle Cell Disease Patients' Organisations aiming to provide a centralized European point of contact for patients and caregivers. Secondary objective is to create synergies among existing national patients support groups and finally objective is to encourage the creation of national patients association in those country where patients association do not exist yet.

A total of four National meetings (Italy, France, Spain&Portugal and Belgium) has been held during third and fourth year of the ERN-EuroBloodNet.

For the World Sickle Cell Disease Awareness Day 2020 (WSCD) two SCD patients’ testimony videos have been published on the EuroBloodNet's YouTube Educational Channel, the 19th of June 2020. [A first video is about the national meetings for the establishment of the European Network on SCD Patients Organisations](#)

Results:

- 9 patients from Portugal, Italy, Spain, France have given testimony on the video.
- 6 Patients Associations involved: Drépvie, SOS GLOBI Aquitaine, United Onlus, Libera Associazione contro la Talassemia CATANIA, ASAFE - Asociación Española Enfermedad FALCIFORME, APPDH Associação Portuguesa de Pais e Doentes com Hemoglobinopatias
- Here follows some rates obtained from the YouTube EuroBloodNet EDU Channel:

WSCD 2020 EuroBloodNet -The establishment of the European Network of SCD PO				From 18th June 2020 – 04th Feb 2021
Views	Like	View's hours	Interactions	
323	10	10,7	806	

Tab.6. Youtube statistics on the video.

2nd Testimonies Video. World Sickle Cell Disease International Awareness Day.

Another important result to be underlined as patients’ testimonies video also for World SCD International Awareness Day is the patients’ voice collected in a second Video published on the ERN-EuroBloodNet Youtube Channel: [WSCD 2020 EuroBloodNet - SCD Research Prioritization Workshop at ASCAT Video](#).

The SCD Research Prioritisation Workshop at the Annual Scientific Conference on Sickle Cell and Thalassemia (ASCAT 2019) was a joint project of the ERN-EuroBloodNet together with ASCAT members aiming to

- Engage patients’ thoughts in research
- Train patients to Public Patient Involvement in Research
- Train health professionals on a patient research centred approach

The workshop group included 28 participants coming from 7 EU countries, 5 non-EU countries. The group was made up of patients living with SCD, relatives looking after children with SCD and representing at least 10 National patient organizations.

The patients presented the workshop outcome, that is to say a top 10 list of topics that what people living with sickle cell disease would like the research community to focus on, to the plenary session of the ASCAT congress, demonstrating that healthcare professionals are willing to change and listen to the patient voice. Testimonies of this experience were gathered in the above mentioned second video.

Results

- 5 patients from: Portugal, USA, Italy, Netherland, Cyprus have given testimony on the video.
- 4 Patients Associations involved: I-X-L, ASAFE - Asociación Española Enfermedad FALCIFORME, APPDH Associação Portuguesa de Pais e Doentes com Hemoglobinopatia, Associazione Pazienti Drepanocitici Padova (AMD)

Here follows some rates obtained from the YouTube EuroBloodNet EDU Channel:

WSCD 2020 EuroBloodNet - SCD Research Prioritization Workshop at ASCAT				From 18th June 2020 – 04th Feb 2021
Views	Like	View's hours	Interactions	
251	3	8,1	713	

Tab.7. Youtube statistics on the video.

3.2.3. SICKLE CELL DISEASE PATIENTS EDUCATIONAL VIDEO

Rationale

The Spanish SCD patients association (Asociación Española de Enfermedad Falciforme, ASAFE) has proposed to the ERN-EuroBloodNet to develop Educational Video that would last between 5 and 10 minutes and whose speech would have been exposed by a SCD expert member of the Network. ASAFE had identified among its members 11 SCD related topics they considered needed to be addressed by visual pedagogical content.

The 11 identified topics were:

1. New therapies for SCD
2. Adult Patients Quality of Life
3. BMT: survival infertility and other complications
4. Neurological Damages in SCD
5. Neonatal Screening
6. Gestational Risk
7. SCD and immune disease
8. Genetic Counselling...
9. Hydroxurea and fertility
10. Polynuria and Enuresis: kidney damages
11. Priapism

Objective

To keep the educational action at European level (and not simply targeted at Spanish level), the ERN-EuroBloodNet has launched a survey among all the European SCD Patients Associations in its contacts, in order to prioritize the 11 pre-identified topics and to give the possibility to other associations to propose new topics too. The main goal was to produce educational video that consider educational patients needs at European level.

Method

1. Prioritize the 11 SCD topics via a survey (ERN-EuroBloodNet's Survey for prioritizing SCD topics to be addressed by Educational Videos) to be conducted among SCD patients associations reached by the ERN-EuroBloodNet by previous actions.
2. Survey has been conducted by ERN-EuroBloodNet Coordination Team via EU Survey platform. Survey was available at the following link: <https://ec.europa.eu/eusurvey/runner/EuroBloodNetSurveySCDvideoTOPICS>
3. Each topic could be rated by a score from 1= not very important to 5= very important
4. ERN-EuroBloodNet SCD experts will perform the video in their native languages. Then subtitles in other European languages will be edited in order to reach the SCD patients community at large.

Results

“ERN-EuroBloodNet’s Survey for prioritizing SCD topics to be addressed by Educational Videos” has gathered 24 answers expressed by SCD from: France, Italy, Spain, Portugal, Cyprus, USA, Belgium.

AVERAGE SCORE		
1	New therapies for SCD	4,56
2	Adult Patients Quality of Life	4,5
3	BMT: survival infertility and other complications	4,045
4	Neurological Damages in SCD	4
5	Neonatal Screening	3,85
6	Gestational Risk	3,6
7	SCD and immune disease	3,56
8	Genetic Counselling...	3,52
9	Hydroxurea and fertility	3,47
10	Polynuria and Enuresis: kidney damages	3,4
11	Priapism	3,1

Tab.8. Results from the Survey, by order of prioritization and average score.

Next steps

Video will be recorded in expert native language and subtitled with several European languages. First 5 topics will be integrated in a SCD Topic on Focus for Patients Associations.

CUTANEOUS LYMPHOMA RELATED ACTIONS

3.2.4. COMPREHENSIVE WEBINAR PROGRAM ON CUTANEOUS LYMPHOMA FOR PATIENTS ORGANIZATIONS

Webinars targeting patients' organizations is coordinated in collaboration with the Lymphoma Coalition, France Lymphoma Espoir, Cutaneous Lymphoma Foundation and Eurordis.

Objective

It aims to disseminate very innovative topics related to Cutaneous Lymphoma among patients' organizations in order to give the visibility to the medical services available in Europe, last quality of life cutting-edge advances in the field of this very rare condition and its treatments options.

Methods

Webinars are online educational activities conducted using the Webex Platform provided to ERN-EuroBloodNet by the EC. It allows full audio and visual communication, as well as interaction between webinar's speaker and participants.

Webinars are led by the speaker with the visual aid of a Power Point presentation and recorded by the coordination team. The mp4 audio got by the session and the power point presentation will be uploaded and made available on the ERN-EuroBloodNet webpage. At the end of the Patients webinar program a Power Point Presentation slide will mention the upcoming events organised by Patients associations, Networks, etc. with respect to the topic of the session.

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. 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.

Webinar target

Webinars will be opened to patient's advocates, but also to relative patients and caregiver interested in the topic. Despite the program is open to every interested person, the target for structuring the program should be: expert patients and patients associations. So, the webinars can get more technical; introduce the scientific and clinical aspects of the Cutaneous Lymphoma.

Result

1. Program

- Six sessions, once per month on Monday, from 5 pm to 6 pm (CET), starting from April 2021.
- 25 min of presentation + 35 min for questions (written in the chat)
- On Virtual Platform
- Program will be recorded and part of the ERN-EuroBloodNet Edu YouTube channel

Each session will be moderated by a duo of an expert physician and a patient representative, who will elaborate the session together. The physician will first introduce the topic and share the clinical knowledge. The patient representative will ensure that information provided can be well addressed to patients organizations, and will also highlight which are the key crucial concepts for patients to the expert and asking to clarify them to the webinar audience. The patient representative will also moderate the Q&A session. Please find the draft of the program in the ANNEX V_EuroBloodNet's Topic on Focus: Cutaneous Lymphoma for Patients' Organizations.

Next steps

- Identify patients representatives as speakers of the program and fixing the calendar.
- Finalize the inform consent to be shared with patients representative with the role of speakers.
- Organize Topic on Focus on other identified clinical areas. SCD, as described in the paragraph of "SCD educational video" of this document will be the next RHDs addressed by a Topic on Focus.
- Make videos available at ERN-EuroBloodNet e-Learning platform developed in the frame of Connecting EuroBloodNet II (Cef Telecom grant)



Pic. 10. Logo for the Topic on Focus: CL for Patients' Organizations.

3.2.5. CUTANEOUS LYMPHOMA REPOSITORY OF EDUCATIONAL MATERIAL FOR PATIENTS

Rationale

As stated in previous introduction, the ERN-EuroBloodNet is creating in the context of Connecting EuroBloodNet II (Cef Telecom grant) an e-learning platform that will incorporate educational material dedicated to some specific Rare Hematological Disorders and targeted for health professionals and patients. Within this framework it is foreseen the creation of the repository of Cutaneous Lymphoma (CL) educational material for patients.

Objectives

The repository material has a double utility:

- a) A landscape analysis for understanding which pedagogical areas of CL have already been covered and identifying the gaps. The Cutaneous Lymphoma Webinar comprehensive program, described in the previous paragraph could address eventual identified gaps.
- b) Make the educational material accessible for patients through the repository itself.

Methods

ERN-EuroBloodNet Coordination Team, CL or Lymphoma patients associations (Europe Lymphoma Coalition, France Lymphoma Espoir, Cutaneous Lymphoma Foundation) and EURORDIS have conducted a first analysis of the existing available educational material for CL. A first list of the educational material was collected and classified on an Excel file and shared with the CL task force for a second revision. This list was created by collecting material from: Cutaneous Lymphoma Foundation, Lymphoma Coalition Europe, France Lymphoma Espoir.

Material has been distinguished between:

- CL subtype/Generic CL
- Title of the educational material
- Topic Category: (quality of life/treatment/Diagnosis, etc)
- Adult/Pediatric/Young adult/all
- Type of document (PDF, PPT, Leaflet, Book, etc)
- Language/s of the material available
- ink or indicate annex (PDF, PPT)
- Contact the organisation (if material is not on the repository)
- All the material collected were documents approved by CL experts and CL patients advocates.

Results

A total of 53 educational material have been collected and will be made available through ERN-EuroBloodNet e-learning platform (Connecting EuroBloodNet II, Cef telecom grant)

Next steps

- Organizing a second revision of the repository adding the CL educational Material for patient produced by Lymphoma Action in the UK and Lymphoma Switzerland.
- Adding the video recorded from the Comprehensive Webinar program
- Integrating of the material compiled on the e-learning platform

4. 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 Feb 2020 and ongoing
- Topic on Focus: Cutaneous Lymphoma for health professionals to disseminate very innovative topics among health professionals in order to give visibility to the last cutting-edge advances in the field finished in Dec 2020
- Topic on Focus: Thrombotic Microangiopathies for health professionals to disseminate very innovative topics among health professionals in order to give visibility to the last cutting-edge advances in the field, starting March 2021
- 3 preceptorships on AA and PNH accredited finished in Feb 2020 and establishment of the ERN Mobility Program for CME training for 2021/2022

By using an online video platform tool webex, 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. Although it can be suspected that the hectic circumstances at many European HCPs could have had ambivalent influence on the number of participants. Nevertheless, the statistical analysis of two established webinar cycles for health professional, using two different educational strategies – diverse topics' program and program devoted to one disease, shows that the objectives of EuroBloodNet to disseminate cutting-edge knowledge and facilitate continuous medical education (CME) in the field of RHD were met. In this context is worthy to mention the success of the ERN-EuroBloodNet Thursdays webinar program with more than 260 participants and on the Topic on Focus Cutaneous Lymphoma webinars program implemented under the frame of Connecting EuroBloodNet II (Cef Telecom grant), with more than 600 participants and finally 24 health professionals who were granted with 7 CME points for their attendance to the program. Also the 3 preceptorships on AA and PNH were accredited with 18 CME points by the EBAH. As a result 13 Participants from 8 Member States (Czech Republic, Germany, Italy, Lithuania, Netherlands, Portugal, Spain and United Kingdom) attended the program receiving 18 points for their medical education.

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, what indicates a great interest in such educational initiatives across EU. Based on closer analysis identified geographical gaps will be addressed in the next period, by e.g. adjusting the advertisement strategy or contacting RHD societies from the missing countries. EuroBloodNet will continue the dissemination of cutting-edge knowledge and facilitate continuous medical education CME by further development of Thursday Webinars, running the Topic on Focus in connection with Connecting EuroBloodNet (Cef Telecom Grant): Thrombotic Microangiopathies, and launching the new Topic on Focus: Aplastic Anaemia, and establishing the strategy for the next two years ERN Mobility Exchange Program. Moreover these results will be ever further potentiated with the release of the ERN-EuroBloodNet eLearning platform under the Connecting EuroBloodNet II grant.

For reaching excellent outcomes in the promotion of the education for people living with Rare Hematological Diseases (targeting patients, patients associations and caregivers), in the field of the RHDs is essential the collaboration with EURORDIS, European Patients Networks, Patients organizations at National and local level. This cooperation is essential not only for identifying educational niches, but mainly for the analysis and development of patients-centered projects'. Excellent results has been achieved by the ERN-EuroBloodNet, as follows:

- Patients Advocacy

Four national trainings organized for the establishment of the European Network of Sickle Cell Disease Patients organizations. This project allows the important effect of introducing patients in the "advocacy" and make them aware of realities such as ERN and Eurordis, giving to them an European Perspective of patients representations. Indeed, after the intervention of the ERN in those reached countries (Italy, Spain, Portugal, France and Belgium), many national patients groups (formal and informal) have been created.

- SCD related actions

Sickle Cell Disease Patients Educational OnSite Trainings: an important opportunity for SCD patients and parents patients to learn more about the latest advances in terms of diagnosis, treatment and emerging new therapies in the field of the haemoglobinopathies, creating a global patients group that can share opinion on burdens of living with SCD, sharing best practices and advocating at European and Global level. It could be an emulative model in the field of patients community education. In addition excellent results have been achieved by the ERN in the domain of advocacy trainings changing the setting of national SCD patients community, giving the possibility to create a national group where not existing yet.

Sickle Cell Disease Patients Educational Video that will increase SCD patients awareness by creating videos and make the disease visible at public at large, scientific community and people living with SCD.

Patients Webinar: important results have been achieved by the webinar dedicated to COVID-19 for people living with SCD that has registered an high presence of participant and an high score on view on YouTube.

Conducting exercises for prioritizing educational patients needs (as surveys or workshop) is essential for guarantee a patient-centered educational plan.

- Cutaneous Lymphoma related actions

Definition of Webinars program on Cutaneous Lymphoma for patients' advocates and patients association in order to understand diagnosis, treatments and management of specific type of Cutaneous Lymphoma to be better prepared to support within his/her patients' organization newly and already diagnosed patients.

Cutaneous Lymphoma Repository of Educational Material for patients that will establish an accessible list of multilingual educational document on Cutaneous Lymphoma related educational topics.

In conclusion, ERN-EuroBloodNet Patients education strategy has allowed to directly promoting patient-centred projects. Nevertheless, it has produced different educational programs addressed to patient community at large and patients associations. ERN's Patients' Plan has also initiated SCD patients in the advocacy environment, and increased the European Patients Group Representation within the Network. Considering those fruitful results and outcomes obtained from the initiatives, same actions coverage will be applied to other RHD areas already identified as urgent targets to be tackled. In addition new actions has been proposed for integrate an exhaustive strategy of patients' education i.e. the educational session at ASCAT 2021 or other identified clinical areas to be tackle by online and onsite programs.

ANNEX I_EXCHANGE CME PROGRAM

6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD -



- **1st CME Mobility Program's model**

- **Preceptorship: participants going in an expert HCP, member of the ERN-EuroBloodNet**

- EuroBloodNet's experience and lessons learned from Preceptorship Program on AA and PNH of 2020, as described in the paragraph Rational and Background of this document, are integrated in the exchange program ERN Mobility Exchange program, as follow:
 - Intense training from 2 to 5 days, cases based, with theoretical and practical courses/exercises on diagnosis/management or highly specialized procedure on RHD. Finally a session coordinated by a patient advocate explaining patients needs could be encouraged.
 - From 3 to 10 participants
 - Carried out in one or more EuroBloodNet HCPs experts of one RHD or RH group of diseases
 - Coordinated by EuroBloodNet members
 - Open to any hematologist, pediatrician, biologist or other health professionals affiliated in a ERN-EuroBloodNet HCPs. Under the agreement of ERN-EuroBloodNet Coordinator and in line with a concrete CME need, also Affiliated Partners could benefit from the program.
 - A call for participants will be launched and candidates will be chosen by a jury according to: CV+ cover letter + follow-up with education projects and activities on medical education. The expected participant profile is
 - Hematologists, pediatrician, biologist or other health professionals
 - Interest in developing their medical competences in the clinical area of RHDs.
 - In a position to follow-up the preceptorship with education projects and activities on medical education.
 - Available for the whole duration of the preceptorship.
 - Resident in a European Member State at the moment of the signature of the Application Form.
 - One of the Preceptorship objective is to disseminate medical knowledge in countries where this knowledge is scarce and foster the dissemination of knowledge/expertise and Cross Border Health cooperation among European Member States. Priority would be given to participants affiliated to HCPs whose country has lack of knowledge on the program's related RHD.

- **2nd CME Mobility Program's model**

- **A senior expert member of the ERN-EuroBloodNet bringing expertise on a EU MS HCPs for a specific consultation**

- One or more days of training and/or consultations, with theoretical and practical courses and exercises on diagnosis/management or highly specialized procedure on RHD
 - A senior expert, member of the ERN-EuroBloodNet bringing cutting-edge knowledge in another HCP

- Open to ERN-EuroBloodNet HCPs. Under the agreement of ERN-EuroBloodNet Coordinator and in line with a concrete CME need, also Affiliated Partners could benefit from the program. Priority would be given to those countries needing to access to cutting-edge knowledge with respect to a RHD or RH group of diseases.
- The online platform provided by Ecorys could be used for understanding which are the clinical domain that required an CME intervention and which are the EU MS in which this clinical domain is lacking of Educational trainings.
- Requests of organizing a specific Mobility Program could be also collected via CPMS submitted cases.

- **3rd CME Mobility Program's model**

Any other possible model:

- Based on Network's members proposal according to specific needs defined within a clinical area framework, as for example, a program organized only at national level, that is to say an ERN-EurobloodNet HCPs that are willing to host a fellow for training in a highly specialized clinical service at national level. Or a program targeting other health professionals categories such as: nurses, psychologist, etc

ANNEX II

EUROBLOODNET'S THURSDAYS WEBINARS FOR HEALTH PROFESSIONALS IN 2020

6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION



List of webinars sessions by subnetworks in 2020 (HH-Iron: Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis, BMF: Bone marrow failures, Bleed-Coag: bleeding-coagulation disorders, RBC: Red blood cell disorders, MYEL: myeloid disorders, lymph: lymphoid disorders) including the date, speaker, title and link to the EuroBloodNet's website with past webinars where the pdf as well as integrated recorded video can be found.

date of the webinar	speaker	title	subnetwork		link to website
06 February 2020	NICOLAS BOISSEL	Management of relapsed/refractory ALL in adult	ONCO	MYEL	Management of relapsed/refractory ALL in adult
13 February 2020	EDUARD VAN BEERS	PKD Clinical management	NON ONCO	RBC	PKD Clinical management
19th March 2020	GRAÇA PORTO	Challenges in the management of HFE-related hemochromatosis	NON ONCO	HH-IRON	Challenges in the management of HFE-related hemochromatosis
23d April 2020	REGIS PEFFAULT DE LA TOUR	BMF genetic diagnostic	NON ONCO	BMF	BMF genetic diagnostic
14 May 2020	DOMINIQUE BRON	How to approach older patient with CLL	ONCO	lymph	How to approach older patient with CLL
28th May 2020	MARTINE BAGOT	Treatment of Cutaneous lymphomas	ONCO	lymph	Treatment of Cutaneous lymphomas
25th June 2020	ROBERTA RUSSO	Congenital dyserythropoietic anemias	NON ONCO	BMF	Congenital dyserythropoietic anemias
9th July 2020	UWE PLATZBECKER	Treatment of anemia of low risk MDS	ONCO	MYEL	Treatment of anemia of low risk MDS
24 September 2020	IMMACOLATA ANDOLFO	Hereditary Stomatocytosis	NON ONCO	RBC	Hereditary Stomatocytosis
1st October 2020	PATRICIA AGUILAR MARTINEZ	Genetic counselling of Hemophilia	NON ONCO	Bleed-coag	Genetic counselling of Hemophilia
8th of October 2020	PAOLA BIANCHI	Recommendations on PKD diagnosis	NON ONCO	RBC	Recommendations on PKD diagnosis

29th October 2020	DOMENICO GIRELLI	Diagnosis and clinical management of rare forms of Hemochromatosis	NON ONCO	HH- IRON	Diagnosis and clinical management of rare forms of Hemochromatosis
5th of November 2020	JUDE FITZGIBBON	Genetic predisposition to myeloid disorders: when to analyze it	ONCO	MYEL	Genetic predisposition to myeloid disorders: when to analyze it
26th of November 2020	VALERIA SANTINI	When is molecular analysis useful in MDS ?	ONCO	MYEL	When is molecular analysis useful in MDS ?
3d of December 2020	GERT OSSENKOPPELE	Treatment of AML in the elderly. Intensive or not ?	ONCO	MYEL	Treatment of AML in the elderly. Intensive or not ?

ANNEX III

NATIONAL TRAININGS FOR PATIENTS ADVOCACY

6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD -

Establishment of a European Network of Sickle Cell Disease Patients Associations across EU MS Meeting with Italian PO's

National Advocacy Trainings

- First national meeting in Milan, the 29th of March 2019
- Second National Training, in Paris, the 29th of June 2019
- Third National Training, in Madrid, gathering Spanish and Portuguese patients, 18th February 2020
- Four National Training, in Brussels, the 3rd of December 2020

**Establishment of a European Network of Sickle Cell Disease Patients Associations across EU MS
Meeting with Italian PO's
29th of March 2019**

Venue: Aula Polo Scientifico, Fondazione Ca' Granda Ospedale Maggiore Policlinico (IRCCS), Via Francesco Sforza, 35 , 20122 Milano

AGENDA

- **10.00-10.30** Welcome coffee
 - **10.30-10.45** Tour de table of the participants
 - **10.45-11.00** Introduction of ERN-EuroBloodNet (Mariangela Pellegrini)
 - **11.00-11.30** ePAGs role in RDs panorama (Loris Brunetta)
 - **11.30-11.45** Physicians engagement for the ERN EuroBloodN (Raffaella Colombatti)
 - **11.45-12.00** Coffee break
 - **12.00-12.30** Characteristic of the European Network of SCD patients association
 - Network description (Mariangela Pellegrini)
 - Objectives and added values of having an European Network (Loris Brunetta)
 - Network's patient representatives "should have" criteria (Loris Brunetta)
 - Training with... (Eupati, Eurordis, EuroBloodNet ePAGs) (Loris Brunetta)
 - **12.30-13.30** Lunch break
 - **13.30-14.45** PO's presentation: organizations and actions for SCD, *15 min*
 - United Onlus
 - Associazione Fondazione Italiana 'L.Giambrone' for Thalassemia
 - Associazione Malattia Drepanocitica
 - EXPO IME EKEMINI
 - Associazione Italiana Drepanocitici di Torino
 - **14.45-16.00** PO's feedbacks and questions
 - **16.00-16.30** Contacts of those PO's which are interested being engaged in the project
- Next steps:** Italian patients associations communicate who is their national representative and substitute.

Discorso introduttivo

- **Presentazione dell'ERN-EuroBloodNet:** come nasce l'iniziativa, obiettivi e progetti, la focalizzazione sulla drepanocitosi.
Presentazione ppt in allegato.
- **Presentazione del ruolo dei pazienti all'interno dell'ERN:** il compito degli ePAG, qual è il valore aggiunto di un'iniziativa centrata sul punto di vista del paziente, la formazione degli ePAG, la voce della comunità europea dei pazienti rappresentata dagli ePAG
Presentazione ppt in allegato
- **Presentazione del ruolo dei medici all'interno dell'ERN EuroBloodNet:** la collaborazione per lo stabilimento del registro di anemie rare, l'utilizzo della piattaforma di telemedicina CPMS, l'analisi della direttiva sulle cure transfrontaliere (il caso del trapianto di midollo osseo tra Italia e Irlanda per pazienti drepanocitici di fascia pediatrica), il raggruppamento di linee guida e buone pratiche, l'educazione medica continua e l'educazione terapeutica del paziente.
Presentazione ppt in allegato.
- **Sito Web EuroBloodNet:** www.eurobloodnet.eu Siamo presenti anche su twitter

Presentazione del progetto: Rete europea di associazioni di pazienti drepanocitici

- **Come sarà la rete europea di associazioni di pazienti drepanocitici?**
 - La rete unirà le associazioni nazionali, regionali, locali che vorranno far parte della rete europea.
 - EuroBloodNet darà l'endorsement EuroBloodNet alla rete, ma qualora la rete voglia costituirsi in un'alleanza o una federazione, e avere quindi uno statuto legale di associazione sarà libera di farlo, autonomamente.
- **Che cosa chiede EuroBloodNet alle associazioni nazionali dei vari paesi?**
 - Obbligatorio. Le modalità per identificare i due rappresentanti saranno scelte dalle associazioni italiane. EuroBloodNet raccomanda che siano persone motivate, capaci di parlare in inglese e che conoscano la realtà sociale, giuridica e clinica in Italia, per i pazienti drepanocitici. Perché questo avvenga è in atto un percorso di formazione condiviso.
 - Facoltativo. Alle associazioni nazionali, regionali o locali di un dato paese europeo EuroBloodNet suggerisce che vengano federate, formalmente o no, a livello nazionale per facilitare il flusso delle comunicazioni e la concentrazione delle risorse e delle conoscenze. Questo passaggio è facoltativo.
 - Obbligatorio. I rappresentanti nazionali di tutte le associazioni europee (il comitato della rete europea) dovranno scegliere chi sarà il rappresentante europeo dell'associazione, che diverrà inoltre ePAG per EuroBloodNet. Le modalità di selezione saranno liberamente scelte dal comitato della rete europea delle associazioni di pazienti affetti da

drepanocitosi. Ciò avverrà entro il termine del percorso di formazione in tutti i paesi europei (tre anni).

- **Come contribuirà EuroBloodNet alla rete europea?**

- EuroBloodNet si occupa della creazione della rete europea delle associazioni di pazienti drepanocitici. Organizza i primi meeting nazionali, mette in contatto le realtà nazionali e raggruppa i rappresentanti nazionali nel primo meeting europeo. Queste azioni sono coperte finanziariamente da EuroBloodNet. Una volta che la rete sarà lanciata, dovrà essere autonoma.
- EuroBloodNet offre lo spazio alla rete europea delle associazioni di pazienti drepanocitici sulla sua pagina web
- EuroBloodNet offre visibilità sui suoi social media
- EuroBloodNet offre dei seminari formativi con gli ePAGs di EuroBloodNet e altre organizzazioni internazionali e nazionali, che saranno in grado di spiegare: come gestire un'associazione europea dalla comunicazione alla ricerca dei finanziamenti, come formarsi al ruolo di advocate, come interagire con le ERN.
- EuroBloodNet offre l'informazione sul panorama europeo delle malattie rare.

- **Come contribuirà la rete europea di associazioni di pazienti alla causa della drepanocitosi?**

- La rete europea delle organizzazioni di pazienti affetti da drepanocitosi potrebbe avere un ruolo chiave da svolgere nel settore sanitario europeo e di liaison con la comunità medico-scientifica.
- Aiuterebbe i pazienti e le persone che li assistono a comprendere i migliori percorsi dei pazienti e le buone pratiche.
- Sarebbe un infopoint per diffondere informazioni su come e dove ottenere l'accesso alle migliori cure e promuovere la consapevolezza dei diritti dei pazienti e l'accesso alle cure sanitarie in quanto cittadini europei. Infine divulgerebbe conoscenza su come muoversi nel sistema sanitario per ottenere i migliori risultati possibili a livello nazionale ed europeo.
- Funterebbe da punto di contatto centralizzato a livello europeo per i pazienti, i familiari e i professionisti della sanità.
- Infine, attuerrebbe la relazione sulle politiche sulle malattie rare per garantire che tutte le politiche sanitarie e la ricerca rispondano alle esigenze e alle priorità dei pazienti.

- **Bisogni e aspettative espressi dai pazienti delle associazioni italiane durante la riunione**

- È stata espressa vivamente la necessità di un maggior dialogo e confronto sulla malattia e sulle necessità dei pazienti, con i medici curanti e la comunità medico-scientifica del centro di cura, così come con quella nazionale ed internazionale. È auspicata la definizione nel prossimo futuro di iniziative congiunte pazienti-medici/operatori sanitari, anche in collaborazione con le società scientifiche nazionali

- - È stato condiviso l'isolamento che i pazienti sentono nei vari centri, nei quali spesso manca un ambulatorio dedicato per i pazienti drepanocitici che vengono visitati in day hospital o ambulatori insieme con pazienti oncologici o emato-oncologici, con cui non condividono bisogni e problematiche. Viene suggerita una maggiore specificità e viene richiesta una maggiore collaborazione da parte del personale sanitario per mettere in comunicazione i pazienti tra di loro e avvicinarli alle associazioni, lì dove presenti.
 - Combattere gli stereotipi legati allo stigma del paziente drepanocitico, in Italia e in Africa. Questo vuol dire lottare contro l'idea che la malattia sia una vergogna o una maledizione, informare sulle nuove aspettative di vita e il miglioramento della qualità di vita del paziente, informare sul fatto che non è semplicemente una patologia africana ma che è presente sul territorio mondiale. Sensibilizzare i familiari, insegnanti e datori di lavoro sulle implicazioni di questa patologia.
 - Informare sui diritti in materia sanitaria del paziente drepanocitico. Come per esempio l'articolo sui permessi retribuiti: legge 104 articolo 3, comma 3.
 - Promuovere la transizione dall'età pediatrica all'età adulta in ogni ambito: servizi clinici, strutture ospedaliere, materiale informativo per i pazienti, materiale informativo per i medici.
 - Migliorare il percorso di presa in carico del paziente, soprattutto per l'urgenza/emergenza e l'accesso al Pronto Soccorso. Spesso il paziente con crisi dolorosa vaso-occlusiva viene fatto attendere per ore, non viene riconosciuto il codice giallo, non esiste percezione della gravità delle complicanze acute da parte del personale sanitario. Vengono proposte alcune idee: survey sull'accesso alle urgenze da condurre in collaborazione con le società scientifiche, una tessera di identificazione paziente da mostrare ai professionisti della sanità dove viene spiegata brevemente la presa in carico da eseguire, etc.
 - Sensibilizzare all'accompagnamento psicologico.
 - Promuovere azioni mirate in Africa tramite fondi europei.
 - Creare nuove associazioni di pazienti a livello locale e regionale.
- **Prossimi passi**
 - A partire dai contatti inviati da Mariangela Pellegrini, ERN project manager, dei partecipanti alla riunione di Milano, creare una mailing list.
 - Comunicare a Mariangela Pellegrini, ERN manager, se ci sono altre associazioni italiane che andrebbero inserite nella mailing list.
 - Diffondere il verbale tra le associazioni nazionali, regionali, locali di pazienti drepanocitici al fine di informarli sulla creazione della rete europea. Inoltre il verbale sarà inviato alle società scientifiche italiane: SITE e AIEOP .
 - Organizzare una teleconferenza delle associazioni italiane, al fine di decidere come portare avanti il progetto. Mariangela Pellegrini, ERN project manager, si occuperà della organizzazione della teleconferenza.
 - Creare una eventuale federazione informale o formale italiana.
 - Facoltativo Partecipazione agli eventi dedicati alla drepanocitosi in quando gruppo delle associazioni di pazienti italiani (per esempio il 19 giugno, giornata internazionale della drepanocitosi).

Création d'un réseau européen d'associations de patients atteints de drépanocytose dans les États membres de l'UE

Rencontre avec les organisations françaises de patients
29 juin 2019

Lieu

Hôpital Saint-Louis, 1, Avenue Claude Vellefaux, Paris 75010.
Salle de réunion Trèfle 3, PLOT B, troisième étage.

ORDRE DU JOUR

- 9.00-9.30 Café de bienvenue
 - 9.30-9.45 Tour de table des participants
 - 9.45-10.10 Introduction d'ERN-EuroBloodNet (Mariangela Pellegrini, ERN EuroBloodNet chef de projet)
 - 10.10-10.30 Caractéristiques du Réseau européen des associations de patients SCD et les critères des représentants des patients (Mariangela Pellegrini)
- 10.30-10.45 Pause-café
- 10.45- 11.15 Formation avec... (Eupati, Eurordis, EuroBloodNet ePAG) (Ariane Weinman, EURORDIS)
 - 11.15-11.45 Rôle des ePAGs dans le panorama des MR (Jean-Philippe Plançon, ePAG dans l'ERN EURO-NMD)
 - 11.45- 12.15 Présentation de comment la filière représente les associations au niveau national (Sonia Pavan, Chef de projet Filière de Santé MCGRE)
- 12.15-13.15 Pause déjeuner
- 13.15-16.00 Présentation des associations présentes : organisations et actions, 10 min
- *Présentations des associations*
 - 16.00-16.30 Commentaires et questions des associations
 - 16.30-17 Contacts des organisations intéressées par le projet

Discours d'introduction

- Présentation d'ERN-EuroBloodNet : Origine des ERNs, Structure et acteurs d'EuroBloodNet, objectifs et projets, accent sur les activités en faveur des patients atteints de drépanocytose.
Présentation ppt en pièce jointe.
- Présentation du rôle des patients au sein de l'ERN : Missions de l'ePAG, formation de l'ePAG, témoignage de la communauté européenne des patients représentée par les ePAGs, valeur de la représentation du patient au niveau européen. Le porte-parole européen du Réseau européen des associations de patients atteints de drépanocytose pourra devenir ePAG pour l'ERN-EuroBloodNet.
Présentation ppt en pièce jointe
- Présentation d'EURORDIS : Naissance et développement d'Eurordis au fil des ans. Rôle, missions et actions menées par Eurordis. Formations possibles offertes par Eurordis et EUPATI pour devenir un patient expert et agir dans le paysage européen. Eurordis participe avec EuroBloodNet à la création d'un réseau européen de patients atteints de drepanocytose.
Présentation ppt en pièce jointe
- Présentation de la filière MCGRE : Organisation de la filière, missions, présentation des groupes de travaux, relations et actions avec les associations des patients, nouveau site web. Le réseau a coordonné la réunion des associations françaises avec EuroBloodNet. La filière MCGRE veillera à l'harmonisation des actions des associations de patients au niveau français et européen. La filière accompagnera les actions des associations françaises au sein du réseau européen et veillera à ce que les communications du réseau européen des associations de patients soient également réparties entre les associations françaises.
Présentation ppt en pièce jointe
- Site Internet d'EuroBloodNet : www.eurobloodnet.eu
- Site Internet Eurordis <https://www.eurordis.org/>
- Site Internet ERN EURO-NMD <https://ern-euro-nmd.eu/>
- Site Internet filière MCGRE <https://filieres-mcgre.fr/>

Présentation du projet : Réseau européen d'associations de patients atteints de drépanocytose

A quoi ressemblera le réseau européen des associations de patients drépanocytaires? Le réseau rassemblera les associations nationales, régionales et locales qui souhaitent faire partie du réseau européen. EuroBloodNet donnera son aval au réseau de patients EuroBloodNet, mais si le réseau veut former une alliance ou une fédération et donc avoir un statut juridique d'association, il sera libre de le faire. Il est souhaitable que chaque pays ait un (ou deux) porte-parole et un (ou deux) suppléants en représentation de toutes leurs organisations nationales de patients. Parmi tous les porte-paroles, un représentant du réseau européen sera élu et deviendra ePAG pour le réseau ERN EuroBloodNet.

Comment le réseau européen des associations de patients contribuera-t-il à la cause de la drépanocytose ?

- Le réseau européen des associations de patients atteints de drépanocytose pourrait jouer un rôle clé dans le secteur européen de la santé et dans la liaison avec la communauté médicale et scientifique.
- Le réseau européen des associations de patients atteints de drépanocytose veillera que toutes les politiques européennes et la recherche en santé en Europe répondent aux besoins et aux priorités des patients.
- Le réseau européen des associations de patients atteints de drépanocytose sera un point de contact centralisé au niveau européen pour les patients, leurs familles et les professionnels de la santé.
- Le réseau européen des associations de patients atteints de drépanocytose pourra aider les patients et leurs soignants à comprendre les meilleures pratiques des patients et les meilleures pratiques des professionnels de la santé.
- Le réseau européen des associations de patients atteints de drépanocytose contribuera à améliorer l'accès aux meilleurs soins et à promouvoir la sensibilisation aux droits des patients en tant que citoyens européens.

Comment EuroBloodNet contribuera-t-il au réseau européen ?

- EuroBloodNet est responsable de la création du réseau européen des associations de patients drépanocytaires. EuroBloodNet organise les premières rencontres nationales, identifie les réalités nationales et réunit les représentants nationaux lors de la première rencontre européenne. Ces actions sont couvertes financièrement par EuroBloodNet. Une fois le réseau lancé, il devra être autonome.
- EuroBloodNet accompagnera les actions du réseau européen des associations de patients atteints de drépanocytose.
- EuroBloodNet offre l'espace au réseau européen des associations de patients drépanocytaires sur sa page web.
- EuroBloodNet offre une visibilité sur ses médias sociaux.
- EuroBloodNet propose des séminaires de formation avec les ePAGs d'EuroBloodNet qui pourront expliquer : comment gérer une association européenne (communication, financement, organisation, etc.), comment interagir avec les ERNs, etc.
- EuroBloodNet offre l'expertise sur le paysage européen des maladies rares.

Besoins et attentes exprimés par les patients des associations françaises lors de la réunion

La nécessité d'un dialogue et d'une confrontation accrue sur la maladie et les besoins des patients a été fortement exprimée, tant avec les médecins traitants et la communauté médico-scientifique du

centre de traitement, qu'avec la communauté nationale et internationale. Le rôle des associations de patients peut être le fondement pour garantir une médiation entre le patient et le médecin au niveau national et européen.

- Avoir une permanence des associations de patients atteints de drépanocytose au sein des hôpitaux.
- Plaidoyer au niveau européen.
- Former des patients experts.
- La création au niveau national d'une Fondation de Recherche dédiée à la drépanocytose.
- La généralisation du dépistage néonatal au niveau national.
- Sensibiliser à l'accompagnement psychologique.
- Sensibiliser à l'écoute du corps : par exemple aborder les crises avec des approches non pharmacologiques (massages, sophrologie, etc.).
- Lutter contre l'isolement des patients.
- Favoriser les rencontres entre patients drépanocytaires.
- Aider les migrants sans abris atteints de drépanocytose.
- Reconnaissance de la drépanocytose en tant que maladie lourde au niveau national et européen.
- Reconnaissance de la journée mondiale de la drépanocytose + création d'une journée européenne de la drépanocytose.
- Promouvoir des actions ciblées en Afrique.
- Lutter contre la stigmatisation du patient.
- Sensibiliser le milieu scolaire.

Les points suivants, basés sur les réunions tenues en France, en Italie et en Belgique, sont communs entre les pays et peuvent être traduits en actions concrètes au niveau européen

→ PLAIDOYER AU NIVEAU EUROPEEN

1. Axe Politique de la Santé : reconnaissance de la drépanocytose en tant que pathologie lourde (le passage d'un handicap invisible à une pathologie lourde implique des effets dans tous les milieux sociaux : médical, scolaire, lieu de travail, etc.).
2. Axe sociétal : lutter contre la stigmatisation.
3. Axe social : lutter contre l'isolement des patients.
4. Axe bonnes pratiques :
 - 4.1. Utilisation de la carte d'urgence française (Filière MCGRE) au niveau européen (traduction dans les langues officielles de la EU).
 - 4.2. Sensibilisation à l'aide psychologique.
 - 4.3. Programmes de dépistage néonatal + prénatal.
5. Axe communication : Journée mondiale de la drépanocytose + Journée européenne.
6. Axe éducatif : Matériel d'information pour les patients et les professionnels de la santé. L'ERN-EuroBloodNet est en train de créer un répertoire de matériel éducatif, cette action peut être menée en commun.

Prochaines étapes

- A partir des contacts de la filière MCGRE (membres et non membres de la filière MCGRE) des associations des patients atteints de drépanocytose qui souhaitent participer au réseau européen, Mariangela Pellegrini, chef de projet ERN EuroBloodNet, va créer une liste de diffusion.
- Diffuser les conclusions auprès des associations nationales, régionales et locales de patients drépanocytaires afin de les informer de la création du réseau européen.
- Organiser les élections des 2 représentants et les 2 suppléants.

Elections des représentants nationaux

- Compte tenu de la fréquence de la drépanocytose en France, il a été choisi par l'ERN-EuroBloodNet, la filière MCGRE et Eurordis que la France **ait 2 représentants et 2 suppléants nationaux.**
- Comme convenu lors de l'assemblée du 29 juin 2019, un délégué de l'Outre-mer et un délégué de la métropole devraient être représentants à égalité. Pour cette raison, seront élus : 1 représentant et 1 suppléant pour le territoire d'outre-mer et 1 représentant et 1 suppléant pour le territoire métropolitain.

Obligations des représentants et suppléants

- 1) Les représentants et suppléants s'engagent à représenter toutes les associations françaises. L'information devra être distribuée également à toutes les associations locales, régionales et nationales. Les représentants et suppléants nationaux doivent veiller à ce que l'ensemble de la communauté française soit représentée et entendue. Aucune association ne doit prendre le pas sur une autre ou empêcher la participation de certains membres.
- 2) Les personnes élues ne pourront, en aucun cas, se prévaloir de leur statut pour faire valoir des actions personnelles et/ou promouvoir l'action de l'association dont elles sont membres. Ce mandat a une visée de représentation strictement collective des associations de patients atteints de drépanocytose.
- 3) Les représentants et suppléants s'engagent à coopérer avec le réseau MCGRE, même si le représentant élu est membre d'une association qui n'est pas membre de la filière MCGRE. Si tel est le cas, l'association n'est pas obligée de devenir membre de la filière.
- 4) Les représentants devront participer aux réunions européennes et veiller à ce que la France soit représentée au sein du Comité européen (représentants nationaux d'autres pays).

- 5) Les représentants devront coordonner un plan stratégique national, en accord avec les associations françaises et en collaboration avec la filière MCGRE. Les choix stratégiques nationaux seront portés au niveau européen.
- 6) Les représentants français doivent coopérer avec les autres représentants nationaux et réaliser les missions et objectifs du réseau européen.
- 7) S'assurer qu'un représentant français est présent à un nombre minimum de réunions ou de téléconférences (80%).
- 8) Participer aux groupes de travail qui seront établis.
- 9) Participer à la rédaction des rapports annuels ou de planning annuels.
- 10) Participer activement à la vie du réseau européen des associations de patients atteints de drépanocytose.
- 11) Si les règles suivantes ne sont pas respectées, le rôle du représentant sera révoqué.

Qui peut se présenter comme candidat ?

- 1) Un patient ou parent d'un patient.
- 2) Une personne qui fait partie d'une association française dédiée à la drépanocytose. L'association peut être membre ou pas de la filière MCGRE.
- 3) Une personne motivée.
- 4) Capable de parler anglais.
- 5) Avec expérience de plaidoyer par exemple dans l'un de ces domaines : service sociale, santé publique, droit ou soins holistique, milieu clinique, accompagnement psychologique en France ou en Europe.
- 6) Intérêt pour participer aux formations pour les patients experts.
- 7) Le candidat ne doit pas avoir de conflits d'intérêt (ex: contrat avec l'industrie pharmaceutique)
- 8) Etre à l'aise avec la prise de parole en public
- 9) Intérêt pour le panorama européen de maladies rares

Comment les élections seront-elles gérées ?

- 1) La filière MCGRE demandera aux associations dont elle a connaissance (membres et non membres de la filière), si un de leurs adhérents souhaitent se présenter en tant que candidat.
- 2) Les candidats seront rendus publics par la filière MCGRE. Le candidat pourra présenter une lettre de motivation à sa participation (facultatif, mais encouragé parce que les

votants ne vont pas forcément connaître les candidats, et donc auront peut-être du mal pour faire leur choix).

- 3) Les élections seront gérées par la filière MCGRE via SurveyMonkey ou Google Form. Il y aura une élection pour le candidat de la France Outremer et une élection pour le candidat de la France métropole. Un vote pour associations. La date pour présenter sa candidature et pour voter vous sera communiquée à la rentrée.

Politique de référence pour le Conflit d'Intérêt

- 4) Les représentants nationaux doivent se conformer à la politique sur les conflits d'intérêts des ERNs.
- 5) Le candidat ne doit pas présenter de conflits d'intérêt, comme par exemple être employé par une société pharmaceutique.

Establecimiento de una Red Europea de Asociaciones de pacientes con anemia falciforme

Meeting con los pacientes de Portugal y España
18 de Febrero 2020

Lugar:

Hospital materno infantil, planta 0, Aula 1
Hospital G. Universitario Gregorio Marañón. C/ Maiquez 5, 28007 Madrid.

AGENDA

- 10.00-10.30 Café de bienvenida
- 10.30-10.45 presentación de los participantes
- 10.45 a 11.00 Introducción de la ERN-EuroBloodNet
- 11.00 a 11.15 Panorama general de los proyectos dedicados a la Anemia falciforme
- 11.15-11.30 ¿quién son los ePAGs y Eurordis?

- 11.30-12.20 Pausa

- 12.20 a 13.00 Característica de la Red Europea de Asociación de Pacientes de Anemia Falciforme
 - Descripción de la red
 - Objetivos y valores añadidos de tener una Red Europea
 - Los criterios para ser representantes de los pacientes de la red
 - Cursos para el empowerment del paciente (Eupati, Eurordis, EuroBloodNet ePAGs)

- 13.00-14.00 Pausa Comida

- 14.00-14.45 Presentación de las organizaciones de pacientes

- 14.45-16.00 Necesidades y expectativas de los pacientes hacia la red europea

- 16.00-16.30 Comentarios y preguntas

Introducción

Las presentaciones power point están en adjunto del email

- **Presentación de ERN-EuroBloodNet:** Origen de las ERN, Estructura y actores de la ERN-EuroBloodNet, objetivos y proyectos, presentación de las actividades dedicadas a la anemia falciforme.
- **Presentación del rol de los pacientes dentro de la Red:** Misiones de los ePAGs, formación de los ePAGs, valor de la representación de los pacientes a nivel europeo. El portavoz europeo de la Red Europea de Asociaciones de Pacientes de Anemia Falciforme podrá convertirse en ePAG de la ERN-EuroBloodNet.
- **Presentación de EURODIS:** Nacimiento y desarrollo de Eurordis a lo largo de los años. Rol, misiones y acciones llevadas a cabo por Eurordis. Posibles cursos de formación ofrecidos por Eurordis y EUPATI para convertirse en un paciente experto y actuar en el panorama europeo. Eurordis participa con EuroBloodNet en la creación de una red europea de pacientes que sufren de anemia falciforme.

Presentación del proyecto: Red Europea de Asociaciones de Pacientes de Anemia Falciforme

- **¿Cómo será la Red Europea de Asociaciones de Pacientes con Anemia Falciforme?**

La red reunirá a las asociaciones nacionales, regionales y locales que deseen formar parte de la red europea. EuroBloodNet respaldará la red de pacientes de EuroBloodNet, pero si la red quiere formar una alianza o federación y, por lo tanto, tener un estatus legal de asociación, será libre de hacerlo. Es deseable que cada país tenga un (o dos) portavoz y un (o dos) suplente que represente a todas sus organizaciones nacionales de pacientes. De entre todos los portavoces, se elegirá un representante de la red europea que se convertirá en el ePAG de la ERN EuroBloodNet.
- **¿Cómo contribuirá la red europea de organizaciones de pacientes a la causa de la anemia falciforme?**
 - La Red Europea de Organizaciones de Pacientes con Anemia Falciforme podría desempeñar un papel clave en el sector sanitario europeo y en el enlace con la comunidad médica y científica.
 - La red europea de organizaciones de Pacientes con Anemia Falciforme vigilará que todas las políticas europeas y la investigación sanitaria en Europa respondan a las necesidades y a las prioridades de los pacientes.
 - La Red Europea de Asociaciones de Pacientes con Anemia Falciforme será un punto de contacto central a nivel europeo para los pacientes, sus familias y los profesionales de la salud.
 - La Red Europea de Organizaciones de Pacientes con Anemia Falciforme podrá ayudar a los pacientes y a sus cuidadores a comprender las mejores prácticas para los pacientes y las mejores prácticas para los profesionales de la salud.

- La Red Europea de Asociaciones de Pacientes con Anemia Falciforme contribuirá a mejorar el acceso a la mejor atención y a promover la conciencia de los derechos de los pacientes como ciudadanos europeos.
- **¿Cómo contribuirá EuroBloodNet a la red europea?**
 - EuroBloodNet es responsable de la creación de la Red Europea de Asociaciones de Pacientes con Anemia Falciforme. EuroBloodNet organiza los primeros encuentros nacionales, identifica las realidades nacionales y reúne a los representantes nacionales en el primer encuentro europeo. Estas acciones están financieramente cubiertas por EuroBloodNet. Una vez que la red sea lanzada, debería ser autónoma.
 - EuroBloodNet acompañará las acciones de la red europea de asociaciones de pacientes con anemia falciforme.
 - EuroBloodNet ofrece un espacio a la red europea de asociaciones de pacientes de anemia falciforme en su página web.
 - EuroBloodNet ofrece visibilidad en sus medios sociales.
 - EuroBloodNet ofrece seminarios de formación con los ePAGs de EuroBloodNet que explicarán: cómo gestionar una asociación europea (comunicación, financiación, organización, etc.), cómo interactuar con las ERNs, etc.
 - EuroBloodNet ofrece de desarrollar experiencia en el panorama europeo de las enfermedades raras.

Las necesidades y expectativas expresadas por los representante de pacientes durante la reunión

- Se ha subrayado la importancia de tener una asociación nacional para que los pacientes tengan una referencia y una representación a nivel nacional.
 - **ES:** Se ha elegido de fundar una asociación nacional (y ha sido fundada, la ASAFE)
 - **PT:** Una asociación nacional existe ya desde 27 años pero falta de voluntarios para ser activa y operativa en el territorio. El presidente de la asociación pide nuevos miembros para que la asociación no termine.
 - Necesidad de desarrollar un plan de sostenibilidad de la asociación
 - Necesidad de desarrollar un plan de visibilidad de la asociación
 - Necesidad de desarrollar una colaboración entre representantes de pacientes, médicos, psicólogos y asistentes sociales
- La promoción de los exámenes de despistaje neonatal y prenatal a nivel nacional.
- Sensibilización hacia los temas de la enfermedad en los entornos escolares.
- Sensibilización hacia la importancia de un apoyo psicológico.
- Luchar contra el aislamiento de los pacientes.
- Reconocimiento de la anemia falciforme como una enfermedad discapacitante a nivel nacional y europeo.
- Luchar contra la estigmatización del paciente.
- Tener más informaciones accesibles para el paciente, y específicamente:
 - Sexualidad, fertilidad y embarazo

- Trasplante de medula ósea
- Dolor crónico y concepto de cronicidad
- Mapeo de la evolución de la enfermedad de la diagnosis a la edad adulta (Patient Journey).
- La posibilidad de poder viajar o quedarse en otro país teniendo la posibilidad de acceder a centros expertos en anemia falciforme (por ejemplo facilitar la posibilidad de tomar parte a programas europeo de formación como el Erasmus para los jóvenes pacientes).
- Tener centros equipado para trasplante de medula ósea que no sea centros dedicados a enfermedades oncológicas.
- Han sido propuestos un programa de webinar educativos para pacientes y para profesionales de la sanidad.

Los siguientes puntos, basados en las reuniones celebradas con los representantes de pacientes de España, Portugal, Francia, Italia y Bélgica, son comunes a todos los países y pueden traducirse en medidas concretas a nivel europeo

1. Eje de política sanitaria

Reconocimiento de la anemia falciforme como patología discapacitante (el paso de una condición invisible a una patología discapacitante implica efectos en todos los entornos sociales: médico, escolar, laboral, etc.).

2. Eje social:

- a. Lucha contra la estigmatización.
- b. Lucha contra el aislamiento de los pacientes.
- c. Lucha para el reconocimiento de los “caregivers”.

3. Buenas prácticas :

- a. Sensibilización sobre la asistencia psicológica.
- b. Programas de exámenes neonatal + prenatal.

4. Eje de comunicación:

Mayor visibilidad a la enfermedad (por ejemplo tomando parte a iniciativas para el día Mundial de la Anemia Falciforme)

5. Eje educativo:

Tener más material informativo para pacientes y profesionales de la salud.(La ERN-EuroBloodNet está creando un directorio de material educativo, esta acción puede llevarse a cabo conjuntamente)

Próximos pasos

- Difundir las conclusiones a las asociaciones nacionales, regionales y locales de enfermos y/o otros pacientes con anemia falciforme afín de informarles sobre la creación de la red europea de asociaciones de pacientes con anemia falciforme.
- Elegir los representantes nacionales.

Criação de uma Rede Europeia de Associações de Doenças de Drepanocitose

Encontro com doentes de Portugal e Espanha
18 de fevereiro 2020

Lugar: Hospital materno infantil, planta 0, Aula 1
Hospital G. Universitario Gregorio Marañón. C/ Maiquez 5, 28007 Madrid.

ORDEM DO DIA

- 10.00-10.30 Café de boas-vindas
- 10.30-10.45 introdução dos participantes
- 10.45 - 11.00 Introdução da ERN-EuroBloodNet
- 11.00-11.15 Visão geral dos projectos de drepanocitose
- 11.15-11.30 Quem são as ePAGs e Eurordis?

- 11.30-12.20 Intervalo

- 12.20 - 13.00 Rede Europeia de Associações de Doentes com drepanocitose
 - Descrição da rede
 - Objectivos e valor acrescentado de dispor de uma rede europeia
 - Os critérios para ser um representante dos doentes na rede
 - Cursos de capacitação dos doentes (Eupati, Eurordis, EuroBloodNet ePAGs)

- 13.00-14.00 Pausa para almoço

- 14.00-14.45 Apresentação das associações de doentes

- 14.45-16.00 Necessidades e expectativas dos doentes em relação à rede europeia

- 16.00-16.30 Comentários e perguntas

Introdução

As apresentações em Power Point estão em anexo ao e-mail

- **Apresentação da ERN-EuroBloodNet:** Origem da ERN, Estrutura e actores da ERN-EuroBloodNet, objectivos e projectos, apresentação das actividades dedicadas à drepanocitose.
- **Apresentação do papel dos doentes no âmbito da Rede:** Missões da ePAG, formação da ePAG, valor da representação dos doentes a nível europeu. O porta-voz europeu da Rede Europeia de Associações de Doentes com drepanocitose pode tornar-se um ePAG da ERN-EuroBloodNet.
- **Apresentação da EURORDIS:** Nascimento e desenvolvimento da Eurordis ao longo dos anos Papel, missões e acções realizadas pela Eurordis Possíveis cursos de formação oferecidos pela Eurordis e pela EUPATI para ser tornar um doente especializado e actuar na cena europeia. A Eurordis está envolvida com a EuroBloodNet na criação de uma rede europeia de doentes com drepanocitose

Apresentação do projecto: Rede Europeia de Associações de Doentes com Drepanocitose

- **Como será a Rede Europeia de Associações de Doentes com Drepanocitose?**

A rede reunirá as associações nacionais, regionais e locais que desejem fazer parte da rede europeia. A EuroBloodNet irá apoiar a rede de doentes da EuroBloodNet, mas se a rede quiser formar uma aliança ou federação e, portanto, ter um estatuto legal de associação, será livre de o fazer. É desejável que cada país tenha um (ou dois) porta-voz e um (ou dois) suplente para representar todas as suas organizações nacionais de doentes. De todos os porta-vozes, será escolhido um representante da rede europeia para se tornar o ePAG da ERN EuroBloodNet.
- **Como irá a rede europeia de organizações de doentes contribuir para a causa da drepanocitose?**
 - A Rede Europeia de Associações de Doentes de drepanocitose poderia desempenhar um papel fundamental no sector da saúde europeu e na ligação com a comunidade médica e científica.
 - A Rede Europeia de Associações de Doentes para a drepanocitose velará por que todas as políticas europeias e a investigação no domínio da saúde na Europa respondam às necessidades e prioridades dos doentes.
 - A Rede Europeia de Associações de Doentes com drepanocitose será um ponto de contacto central a nível europeu para os doentes, as suas famílias e os profissionais de saúde.
 - A Rede Europeia de Associações de Doentes com drepanocitose poderá ajudar os doentes e os seus prestadores de cuidados a compreender as melhores práticas para os doentes e as melhores práticas para os profissionais de saúde.

A Rede Europeia de Associações de Doentes com drepanocitose contribuirá para melhorar o acesso aos melhores cuidados e promover a consciência dos direitos dos doentes enquanto cidadãos europeus.

- **Como irá a EuroBloodNet contribuir para a rede europeia?**
 - A EuroBloodNet é responsável pela criação da Rede Europeia de Associações de Doentes com drepanocitose. A EuroBloodNet organiza as primeiras reuniões nacionais, identifica as realidades nacionais e reúne os representantes nacionais no primeiro encontro europeu. Estas acções são financeiramente cobertas pela EuroBloodNet. Uma vez lançada a rede, esta deverá ser autónoma.
 - A EuroBloodNet acompanhará as acções da rede europeia de associações de doentes com drepanocitose.
 - EuroBloodNet oferece um espaço para a rede europeia de associações de drepanocitose no seu sítio Web.
 - A EuroBloodNet oferece visibilidade nas suas redes sociais.
 - EuroBloodNet oferece seminários de formação com a EuroBloodNet e PAGs que explicarão: como gerir uma associação europeia (comunicação, financiamento, organização, etc.), como interagir com as ARN, etc.
 - A EuroBloodNet oferece-se para desenvolver conhecimentos especializados no panorama europeu das doenças raras.

As necessidades e expectativas expressas pelos representantes dos doentes durante a reunião

- Foi sublinhada a importância de ter uma associação nacional para que os doentes tenham uma referência e uma representação a nível nacional.
 - ES: Foi escolhida uma associação nacional para ser fundada (e foi fundada a ASAFE)
 - PT: Há 27 años que existe uma associação nacional, mas faltam voluntários para serem activos e operacionais no território. O presidente da associação pede novos membros para que a associação não cesse.
 - Necessidade de desenvolver um plano de sustentabilidade para a associação
 - Necessidade de desenvolver um plano de visibilidade da associação
 - Necessidade de desenvolver a colaboração entre representantes dos doentes, médicos, psicólogos e assistentes sociais
- A promoção do rastreio neonatal e pré-natal a nível nacional.
- Sensibilização para as questões da doença em contextos escolares.
- Sensibilização para a importância do apoio psicológico
- Luta contra o isolamento do paciente.
- Reconhecimento da drepanocitose como uma doença incapacitante a nível nacional e europeu
- Luta contra a estigmatização do doente

Para ter mais informação acessível ao paciente, e especificamente

- Sexualidade, fertilidade e gravidez
 - Transplante de medula óssea
 - Dor crónica e conceito de crónica
 - Mapear a progressão da doença desde o diagnóstico até à idade adulta (Patient Journey).
- A possibilidade de poder viajar ou permanecer noutro país, tendo acesso a centros especializados em drepanocitose (por exemplo, facilitando a possibilidade de participar em programas de formação europeus como o Erasmus para jovens doentes)
 - Ter centros equipados para transplante de medula óssea que não sejam centros dedicados a doenças oncológicas.
 - Foi proposto um programa de webinars educativos para doentes e profissionais de saúde.

Os seguintes pontos, baseados em reuniões com representantes dos doentes de Espanha, Portugal, França, Itália e Bélgica, são comuns a todos os países e podem ser traduzidos em medidas concretas a nível europeu

1. Eixo da política de saúde
 - Reconhecimento da drepanocitose como patologia incapacitante (a transição de uma condição invisível para uma patologia incapacitante implica efeitos em todos os ambientes sociais: médico, escolar, laboral, etc.).
2. Eixo social:
 - Combater a estigmatização.
 - Lutar contra o isolamento do paciente.
 - Lutar pelo reconhecimento dos prestadores de cuidados.
3. Boas práticas :
 - Sensibilização para a assistência psicológica.
 - Programas de rastreio neonatais + pré-natais.
4. Eixo de comunicação:
 - Aumento da visibilidade da doença (por exemplo, participando em iniciativas para o Dia Mundial da drepanocitose)
5. Eixo educativo:
 - Dispor de mais material informativo para doentes e profissionais de saúde (a ERN-EuroBloodNet está a criar um directório de material educativo, esta acção pode ser realizada em conjunto)

Próximos passos

- Divulgar os resultados junto das associações nacionais, regionais e locais de drepanocitose e/ou outros doentes com drepanocitose, a fim de os informar sobre a criação da rede europeia de associações de drepanocitose
- Eleger representantes nacionais.

Création d'un réseau européen d'associations de patients atteints de drépanocytose dans les États membres de l'UE

Rencontre avec les organisations des patients de la
Belgique
3 décembre 2020
18h-20h

Lieu
On Webex Platform

L'ERN-EuroBloodNet organise avec la BHS une rencontre des patients atteints de drépanocytose en Belgique pour :

- Comprendre les besoins des patients en Belgique
- Identifier les représentants de patients qui aimeraient prendre parti au Réseau européen des associations drépanocytaires. Il s'agit d'un groupe formé par les organisations et les associations nationales et locales de patients atteints de drépanocytose qui vont représenter la maladie à niveau européen.

ORDRE DU JOUR

- Tour de table des participants
- Introduction d'ERN-EuroBloodNet (Prof Béatrice Gulbis, Coordinateur de l'ERN-EuroBloodNet et Mariangela PELLEGRINI, cheffe de projet de l'ERN-EuroBloodNet)
 - Caractéristiques du Réseau européen des associations de patients SCD et les critères des représentants des patients
 - Formation avec... (Eupati, Eurordis, EuroBloodNet ePAG)
 - Rôle des ePAGs dans le panorama des MR

Pause

- Présentation des associations présentes : organisations et actions, 10 min
 - Commentaires et questions des associations
 - Contacts des organisations intéressées par le projet
 - Comment organiser les élections à niveau européen

Discours d'introduction

- Présentation d'ERN-EuroBloodNet : Origine des ERNs, Structure et acteurs d'EuroBloodNet, objectifs et projets, accent sur les activités en faveur des patients atteints de drépanocytose.
Présentation ppt en pièce jointe.
- Présentation du rôle des patients au sein de l'ERN : Missions de l'ePAG, formation de l'ePAG, témoignage de la communauté européenne des patients représentée par les ePAGs, valeur de la représentation du patient au niveau européen. Le porte-parole européen du Réseau européen des associations de patients atteints de drépanocytose pourra devenir ePAG pour l'ERN-EuroBloodNet.
Présentation ppt en pièce jointe
- Présentation d'EURORDIS : Naissance et développement d'Eurordis au fil des ans. Rôle, missions et actions menées par Eurordis. Formations possibles offertes par Eurordis et EUPATI pour devenir un patient expert et agir dans le paysage européen. Eurordis participe avec EuroBloodNet à la création d'un réseau européen de patients atteints de drepanocytose.
Présentation ppt en pièce jointe
- Site Internet d'EuroBloodNet : www.eurobloodnet.eu
- Site Internet Eurordis <https://www.eurordis.org/>

Présentation du projet : Réseau européen d'associations de patients atteints de drépanocytose

A quoi ressemblera le réseau européen des associations de patients drépanocytaires? Le réseau rassemblera les associations nationales, régionales et locales qui souhaitent faire partie du réseau européen. EuroBloodNet donnera son aval au réseau de patients EuroBloodNet, mais si le réseau veut former une alliance ou une fédération et donc avoir un statut juridique d'association, il sera libre de le faire. Il est souhaitable que chaque pays ait un (ou deux) porte-parole et un (ou deux) suppléants en représentation de toutes leurs organisations nationales de patients. Parmi tous les porte-paroles, un représentant du réseau européen sera élu et deviendra ePAG pour le réseau ERN EuroBloodNet.

Comment le réseau européen des associations de patients contribuera-t-il à la cause de la drépanocytose ?

- Le réseau européen des associations de patients atteints de drépanocytose pourrait jouer un rôle clé dans le secteur européen de la santé et dans la liaison avec la communauté médicale et scientifique.
- Le réseau européen des associations de patients atteints de drépanocytose veillera que toutes les politiques européennes et la recherche en santé en Europe répondent aux besoins et aux priorités des patients.
- Le réseau européen des associations de patients atteints de drépanocytose sera un point de contact centralisé au niveau européen pour les patients, leurs familles et les professionnels de la santé.
- Le réseau européen des associations de patients atteints de drépanocytose pourra aider les patients et leurs soignants à comprendre les meilleures pratiques des patients et les meilleures pratiques des professionnels de la santé.
- Le réseau européen des associations de patients atteints de drépanocytose contribuera à améliorer l'accès aux meilleurs soins et à promouvoir la sensibilisation aux droits des patients en tant que citoyens européens.

Comment EuroBloodNet contribuera-t-il au réseau européen ?

- EuroBloodNet est responsable de la création du réseau européen des associations de patients drépanocytaires. EuroBloodNet organise les premières rencontres nationales, identifie les réalités nationales et réunit les représentants nationaux lors de la première rencontre européenne. Ces actions sont couvertes financièrement par EuroBloodNet. Une fois le réseau lancé, il devra être autonome.
- EuroBloodNet accompagnera les actions du réseau européen des associations de patients atteints de drépanocytose.
- EuroBloodNet offre l'espace au réseau européen des associations de patients drépanocytaires sur sa page web.
- EuroBloodNet offre une visibilité sur ses médias sociaux.
- EuroBloodNet propose des séminaires de formation avec les ePAGs d'EuroBloodNet qui pourront expliquer : comment gérer une association européenne (communication, financement, organisation, etc.), comment interagir avec les ERNs, etc.
- EuroBloodNet offre l'expertise sur le paysage européen des maladies rares.

Besoins et attentes exprimés par les patients des associations de la Belgique lors de la réunion

La nécessité d'un dialogue et d'une confrontation accrue sur la maladie et les besoins des patients a été fortement exprimée, tant avec les médecins traitants et la communauté médico-scientifique du

centre de traitement, qu'avec la communauté nationale et internationale. Le rôle des associations de patients peut être le fondement pour garantir une médiation entre le patient et le médecin au niveau national et européen.

- Avoir une permanence des associations de patients atteints de drépanocytose au sein des hôpitaux.
- Plaidoyer au niveau national, pour ce faire, il a été exprimé le besoin d'un groupe formel ou informel nationale.
- Plaidoyer au niveau européen.
- Former des patients experts.
- La création au niveau national d'une Fondation de Recherche dédiée à la drépanocytose.
- La généralisation du dépistage néonatal au niveau national.
- Sensibiliser à l'accompagnement psychologique.
- Lutter contre l'isolement des patients.
- Favoriser les rencontres entre patients drépanocytaires.
- Aider les migrants sans abris atteints de drépanocytose.
- Reconnaissance de la drépanocytose en tant que maladie lourde au niveau national et européen.
- Promouvoir des actions ciblées en Afrique.
- Lutter contre la stigmatisation du patient.
- Sensibiliser le milieu scolaire.

Les points suivants, basés sur les réunions tenues en France, en Italie et en Belgique, sont communs entre les pays et peuvent être traduits en actions concrètes au niveau européen

→ PLAIDOYER AU NIVEAU EUROPEEN

1. Axe Politique de la Santé : reconnaissance de la drépanocytose en tant que pathologie lourde (le passage d'un handicap invisible à une pathologie lourde implique des effets dans tous les milieux sociaux : médical, scolaire, lieu de travail, etc.).
2. Axe sociétal : lutter contre la stigmatisation.
3. Axe social : lutter contre l'isolement des patients.
4. Axe bonnes pratiques :
 - 4.1. Utilisation de la carte d'urgence française (Filière MCGRE) au niveau européen (traduction dans les langues officielles de la EU).
 - 4.2. Sensibilisation à l'aide psychologique.
 - 4.3. Programmes de dépistage néonatal + prénatal.
5. Axe communication : Journée mondiale de la drépanocytose + Journée européenne.
6. Axe éducatif : Matériel d'information pour les patients et les professionnels de la santé. L'ERN-EuroBloodNet est en train de créer un répertoire de matériel éducatif, cette action peut être menée en commun.

Elections des représentants nationaux

- Les associations de patients et les représentantes de patients ont autonomamente organisé les élections des représentants nationaux du réseaux européen des associations des patients.
 - 4 associations qui ont participé à l'élection
 - Le petit prince de Montzen
 - Sang pour Sang

▪ Abed

▪ Le collectif drépanocytose

▪ 10 représentants de patients non affiliés à une organisations.

- 1 association (AB Drepa) est venue s'ajouter au groupe mais n'a pas participé à l'élection.

- 2 représentants des patients drépanocytaires belges seront chargés de cette mission.
- Un groupe à été crée en vue d'une "filiale" réunissant l'ensemble des ASBL ainsi que des patients belges afin de soutenir les représentants.

ANNEX IV_ASCAT 2020

6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD -



AGENDA

SCD PATIENTS' EDUCATIONAL SESSION ASCAT 2020 (26th – 31st October)

26th of October 2020

5 pm- 7.40 pm (PARIS CET Time)

1. (5pm - 5.10 pm) Welcome&Opening

Moderated by Raffaella Colombatti, Mariangela Pellegrini and Agnes Nsofwa

- a. Recap on last year's meeting including ASCAT video produced by EuroBloodNet containing participants' testimonies and workshop results.

2. (5.10 pm – 6.30 pm) Webinar

Moderated by Noemi Roy and Funmi Dasaolu

- a. **(5.10 pm – 5.20 pm) Pre-recorded session** with the COVID patients experience from London
→ 3 patients testimonies from London :
Reia Costa (UK)
Ayodele Ibidapo-Obe (UK)
- b. **(5.20 pm – 5.30 pm) Pre-recorded session** with EuroBloodNet representatives about how patients with SCD coped during the lockdown, access to treatment, services, follow up
→ 3 patients testimonies from Europe
Andreas Athanasiou (CY)
Diabana BA (FR)
Decio Temporario (PT)
- c. **(5.30 pm - 5.40 pm) Live Session Voluntary/Third sector**
Discussion on the role of Voluntary/Third sector during the pandemic (10 minutes).
→ 1 SCD patients representative testimonies
N' Zallah B. Zamani (Nigeria)

(5.40 pm- 5.50 pm) 10 min break

- d. **(5.50 pm – 6.30 pm) Debate** (Summary of key messages + questions raised during testimonies + moderators gather questions written in the chat)

3. **(6.30 pm – 6.45 pm) Peer reviewing experience in UK**
Moderated by Noemi Roy and Sharon Brown-Peters
 - a. **Pre-recorded session** by a patient who would like to share their experience (5 min).
→2 SCD patients representative testimonies

Vanessa Wills (UK)
June Okochi (UK)

 - b. **Q&A session.** (Summary of key messages +pre-identify questions raised by testimonies +some questions in the chat) (10 min).

(6.45 pm – 6.55 pm) 10 min break

4. **(6.55 pm - 7.25 pm) Why I took part in research)**
Moderated by Noemi Roy and Miriam Santos
 - a. **Pre-recorded session** by a patient who would like to share their experience
→3 SCD patients testimonies

Kuseke Sona Luce (FR)
Miriam Santos (Portugal)
Oluyemi Moses (USA)

 - b. **(7.25 pm – 7.40 pm)Q&A Session** (Summary+ Q&A pre-identify questions raised by testimonies +some questions in the chat). (15 min)

28th of October 2020

5 pm – 7.40 pm (PARIS CET Time)

5. **(5pm – 5.50 pm) “Meet the expert” session with live Q&A**
Moderated by: Raffaella Colombatti, Subarna Chakravorty, Esther Owuta Pepple Onolememen

Panel of physicians: 2 paediatricians, 2 adults haematologist

- a. **Topics identified with a survey submitted to SCD patients**
- Newborn and infant SCD Screening, **Stephan Lobitz, Germany**
 - Neurological Complications in SCD, **Maddalena Casale, Italy**
 - Adult Patients Quality of Life, **Jeremy Anderson, UK**
 - BMT: survival infertility and other complications, **Jean-Hugues Dalle, France**
 - New therapies for SCD, **John Brewin, UK**

50) m – 6 pm) ***10 min break***

6. (6 pm – 6.50 pm) “Meet the patient” 2 parallel sessions with live Q&A

1st Parallel session “Meet the patient”: Physicians addressing questions to adult patients

Moderated by: Subarna Chakravorty and Biba Tinga

Panel of Patients:

Ibidapo-Obe (UK)

Kuseke Sona Luce (FR)

Cassandra Timnel (USA)

2nd Parallel session “Meet the patient”: Teenagers patients addressing questions to adult patients

Moderated by: Raffaella Colombatti and Wilhermina Naa Koshie Lamptey

Panel of Patients:

Awa Kekeh (FR)

Marsha Mothersill (UK)

Michele Nkoudou (IT)

(6.50 pm - 7 pm) ***10 min break***

7. (7 pm – 7.40 pm) ‘My life, my word’

Moderated by: Mariane de Montalembert and Sola Njoku

- a. **Pre-recorded session:** paediatric or young patients express their view/ questions about their life with SCD.

Devard Jones (UK)

Kaltouma MAHAMAT NOUR (FR)

Judy Grandison (Canada)

Gutam Dongre (India)

- b. **Q&A session** (pre-identify questions raised by testimonies +some questions in the chat 15 min)

31st of October 2020

Moderated by: Beverley Francis-Gibson and Anie Kofi

8. **(2 pm- 3.15 PARIS CET time pm) Q&A session** (Question raised in previously sessions but not enough addressed + new questions and comments) (1h)

9. **Plenary session (18.30 PARIS CET Time – 21.10 PARIS CET Time)** (Presentation of key messages and results of the SCD Patients Educational Session at ASCAT 2020 Plenary Session as conclusion of the Congress.) (10 min)

Consent form

for

ASCAT 2020 SCD Patients Educational Session

**The session will be recorded and video will be shared on ASCAT and ERN-
EuroBloodNet website and social channels**

This Form is for a patient's consent to:

- If you have shared a **video testimony** for the ASCAT 2020 SCD Patients Educational Session
 - you consent to share the video during the ASCAT 2020 SCD Patients Educational Session on the online platform
 - you consent to the publication of the video recorded and sent to ERN- EuroBloodNet on ASCAT and ERN EuroBloodNet website and social channels with your information (name, country, affiliation to a patient association – if any)
- If you have been a **panelist or a moderator** for the ASCAT 2020 SCD Patients Educational Session
- If you have been in the **audience** of the ASCAT 2020 SCD Patients Educational Session
 - You consent to record the video's caption of the ASCAT 2020 SCD Patients Educational Session
 - You consent to publish the recorded ASCAT 2020 SCD Patients Educational Session. Your personal information (name, country, affiliation to a patients association) may appear. Your interventions (if you raise questions/comments) may appear.

I give consent at the above mentioned points:

[first name, last name].....

As Patient

Parent Patients, Legal representative* of (name, last name)

.....

Country: _____

Affiliation to a Patient Association (if any)

I understand the following:

- Video and video capture of the ASCAT 2020 SCD Patients Educational Session can be published by ASCAT and ERN-EuroBloodNet on its internet website www.eurobloodnet.eu and linked social media channels.
- I confirm that I have the right to record and publish the video on any electronic media and the rights to permit its use, reproduction, transmission and display by ERN-EuroBloodNet pursuant to the terms of this Agreement, if you have shared a patient's recorded testimony.
- ERN-EuroBloodNet and ASCAT have no obligation to publish the video record or any portion thereof
- I/the patient will not receive any financial benefit from publication of the video.
- I can revoke my consent at any time before publication of the video on the website and social media channels, but once the video has been officially published on the ASCAT and ERN-EuroBloodNet website and social media, it will not be possible to revoke the consent.
- The personal data gathered through this form aims exclusively to express consent of the author for the publication above mentioned, and will in any case be shared to other third parties. Assistance Publique – Hôpitaux de Paris is responsible of the file storing this information and registered on 14th February 2018, before the French Data Protection Agency (nr.2153057) in the agreement with the General Data Protection Regulation, and with relevant national legislation.

Signature: _____

Date:

Details of person who has explained and administered the form to the patient or their representative

Name: MARIANGELA PELLEGRINI

Position: ERN-EuroBloodNet Educational & Patient program Manager

Institution: ERN-EuroBloodNet

Address: Service d'hématologie seniors, AP-HP Hôpital Saint Louis,

Email address: Mariangela.pellegrini@aphp.fr

Date: 02/10/2020


** Patients not able to consent by their own (age or mental impairment) must be also involved in the process of information to the extent permitted by their comprehension grade and maturity.*

Feedback on ASCAT patient sessions 2020

18 participants

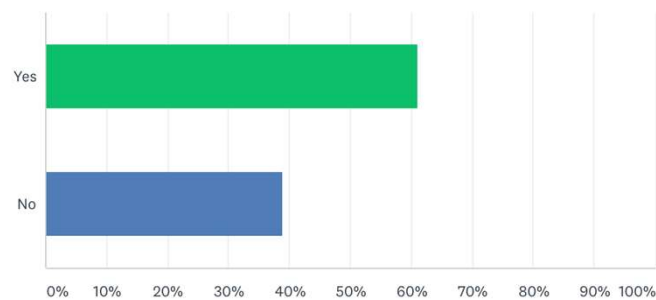
1

Q1

 Customize  Save as ▼

Was this your first time at ASCAT?

Answered: 18 Skipped: 0



ANSWER CHOICES	RESPONSES	
▼ Yes	61.11%	11
▼ No	38.89%	7
TOTAL		18

2

Q2



Customize

Save as ▾

What is your overall feedback on the 3 days?

Answered: 17 Skipped: 1

4.5★
average rating



	1	2	3	4	5	TOTAL	WEIGHTED AVERAGE
★	0.00% 0	0.00% 0	5.88% 1	41.18% 7	52.94% 9	17	4.47

3

Q3



Customize

Save as ▾

What did you think of the way things were organised (emails, contacts, etc)

Answered: 18 Skipped: 0

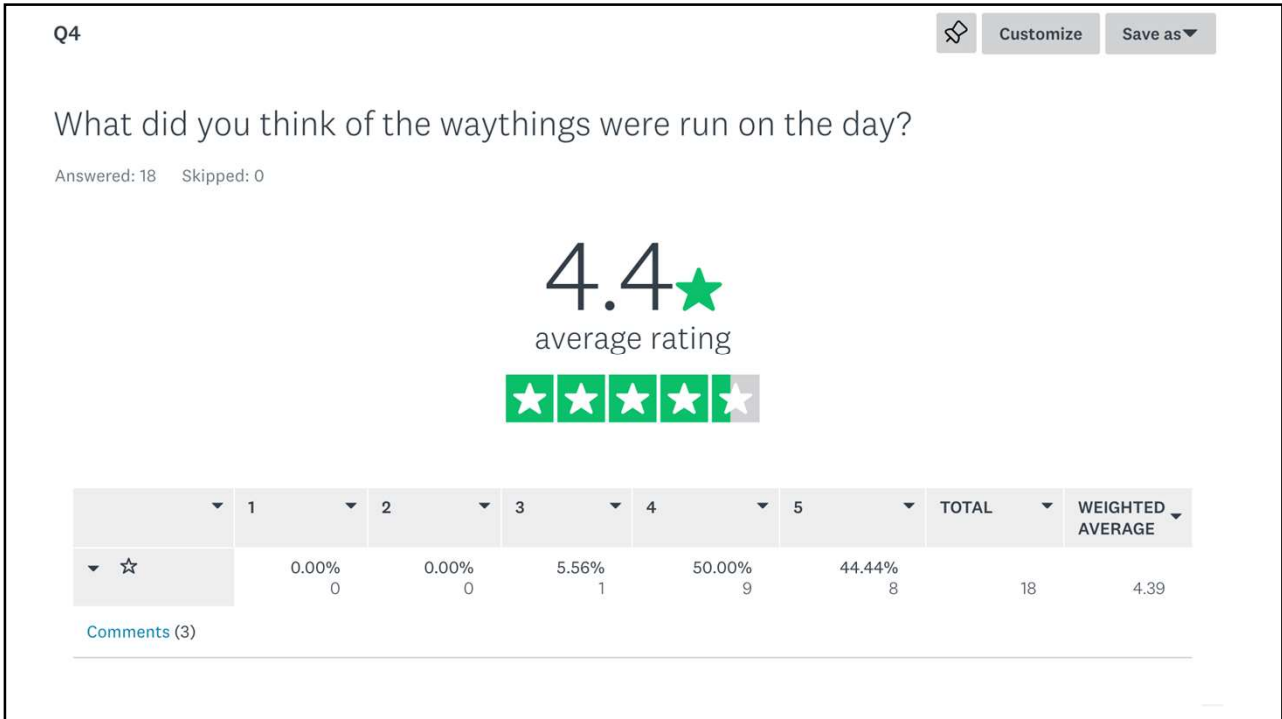
4.3★
average rating



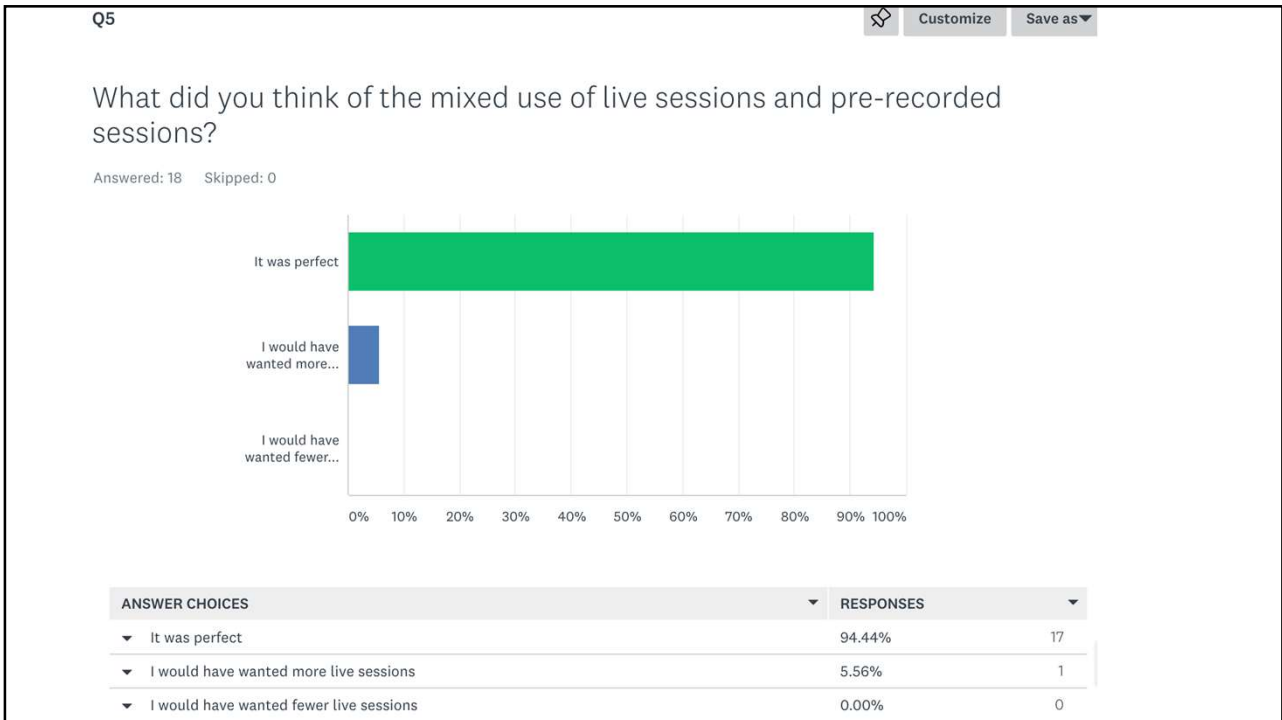
	1	2	3	4	5	TOTAL	WEIGHTED AVERAGE
★	0.00% 0	0.00% 0	11.11% 2	44.44% 8	44.44% 8	18	4.33

[Comments \(2\)](#)

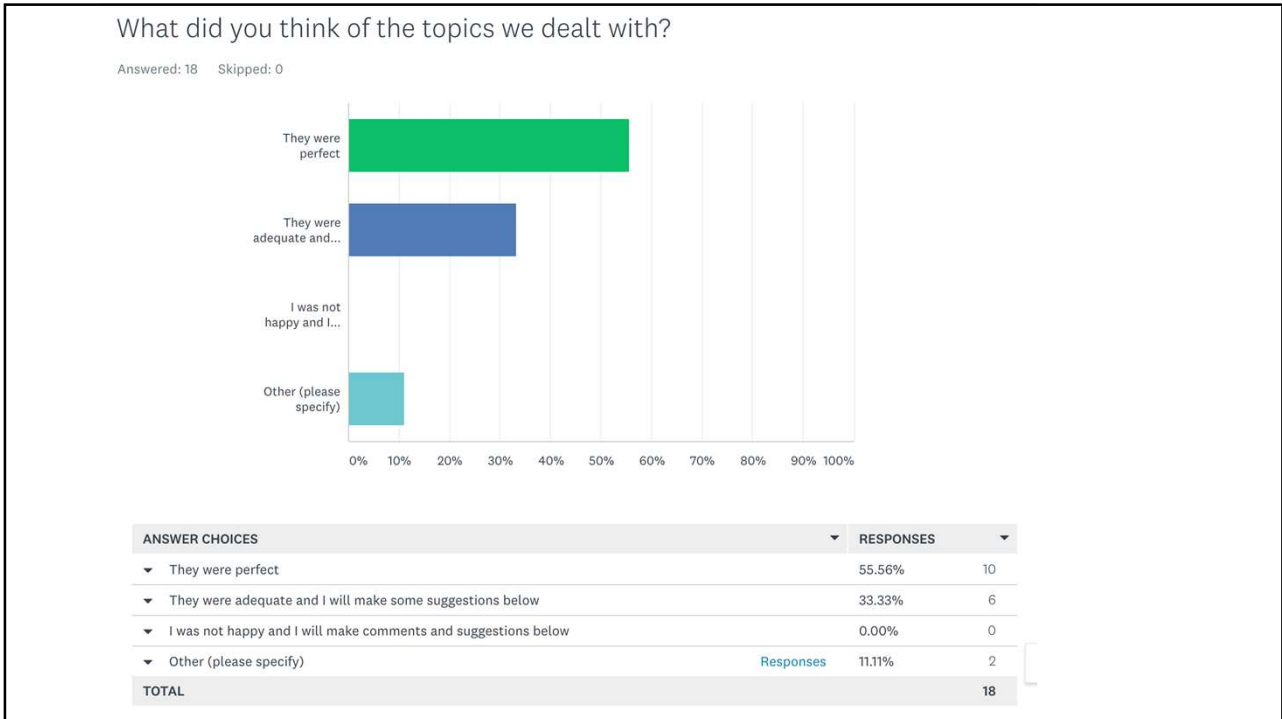
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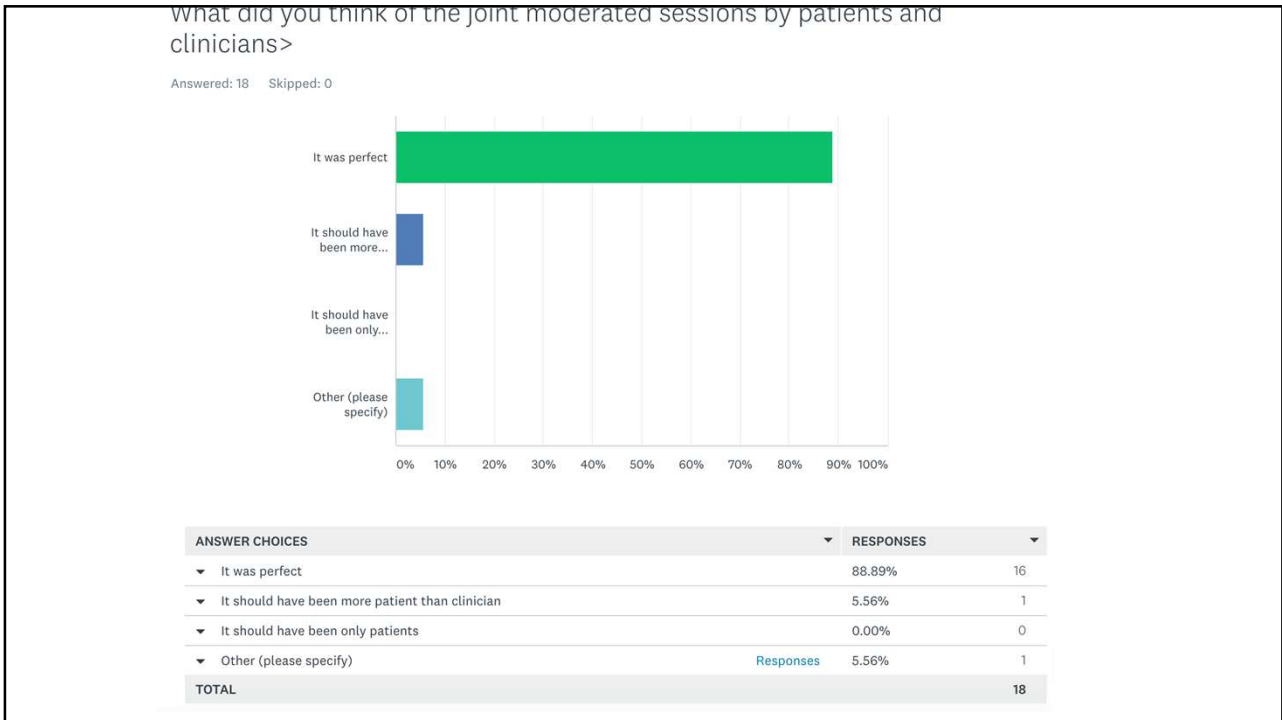
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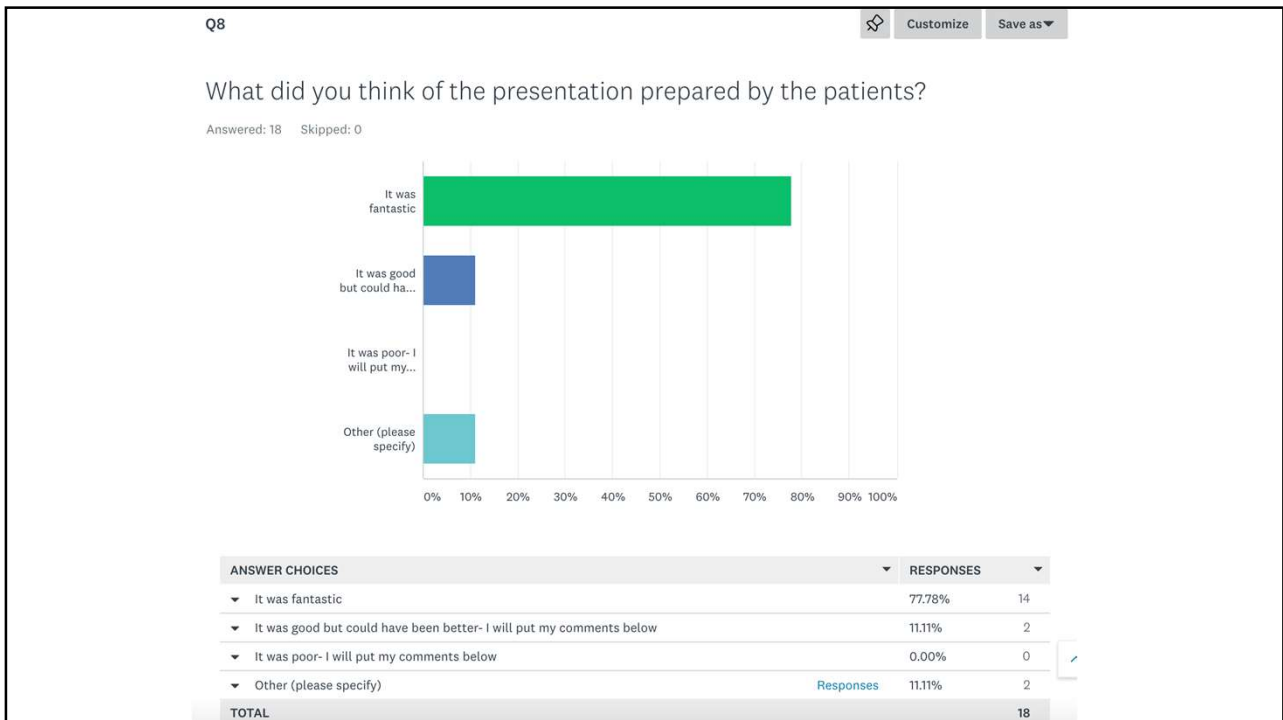
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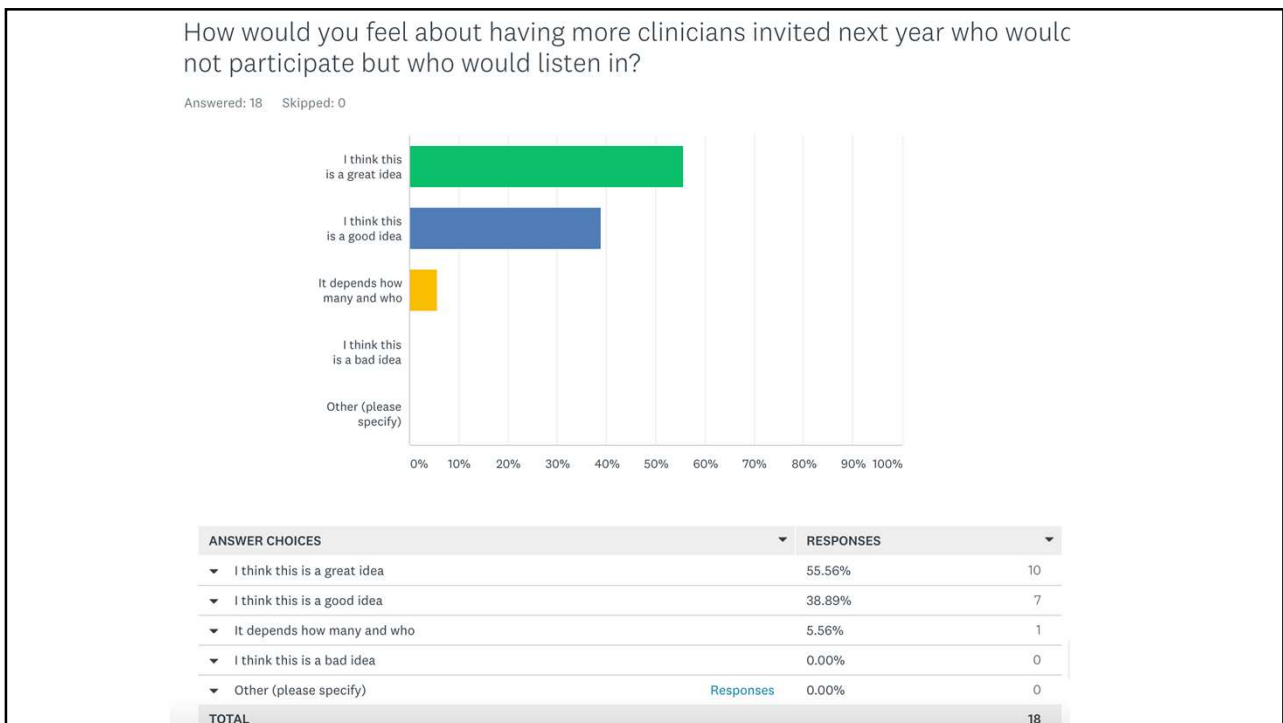
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8



9



10

Q10 Save as ▼

Any other comments? Tell us what you liked most, what you liked least, what we should do differently next year? Was it too short? Too long?

Answered: 13 Skipped: 5

RESPONSES (13) WORD CLOUD TAGS (0) Sentiments: OFF

PAID FEATURE
Text Analysis lets you search and tag comments and see word clouds of frequent words and phrases. To get this feature, upgrade to a paid plan. ✕

UPGRADE [Learn more »](#)

Apply to selected ▼ Filter by tag ▼

Showing 13 responses

All were absolutely fine
12/9/2020 10:06 AM [View respondent's answers](#) [Add tags ▼](#)

It will be great if the conference were a litte bit translated.
12/8/2020 7:26 PM [View respondent's answers](#) [Add tags ▼](#)

11

Showing 13 responses

I totally enjoyed every session and currently looking forward to the next ASCAT.
12/8/2020 4:05 PM [View respondent's answers](#) [Add tags ▼](#)

From the beginning we were told it would be after working hours and that was not the case. It was difficult to attend any sessions before 17:00 GMT. It would be better to have sessions every day but less time each day.
12/7/2020 8:44 PM [View respondent's answers](#) [Add tags ▼](#)

Weekday sessions started at 5pm UK time which is still working time for most. Difficult to make some sessions. Other than that just not enough time, it flew by
12/4/2020 9:39 AM [View respondent's answers](#) [Add tags ▼](#)

I would like to give more time and more topics for discussions sessions between patients-parents / adults patients-young patients / patients-clinicians
12/3/2020 9:06 PM [View respondent's answers](#) [Add tags ▼](#)

12

Showing 13 responses

- Betting more in patient opinions
 12/2/2020 10:34 PM [View respondent's answers](#) [Add tags](#) ▼
- THANK YOU - I APPRECIATE ALL OF THE HARD WORK IN MAKING THIS HAPPEN. Please ensure the questions raised, and outcomes agreed are actioned and answered, and continual feedback and updates are received.
 11/30/2020 8:23 PM [View respondent's answers](#) [Add tags](#) ▼
- Perfect opportunity for patients. Please invite more from all parts of the world
 11/29/2020 1:15 PM [View respondent's answers](#) [Add tags](#) ▼
- patients involvement - participation and the way that good medical practice from doctors have met patients needs
 11/29/2020 11:26 AM [View respondent's answers](#) [Add tags](#) ▼

13

- I enjoyed it but it was obviously limited to an online experience due to the corona virus. I do hope that next year we will be able to meet face to face again. Many thanks.
 11/27/2020 8:44 AM [View respondent's answers](#) [Add tags](#) ▼
- Great organization. Thanks a lot, I really enjoyed this conference.
 11/26/2020 8:17 PM [View respondent's answers](#) [Add tags](#) ▼
- A session to prep both patient and physician moderators on roles beforehand, better clarity to be provided to patients to record testimonials on topic and audio visual quality, greater attendance of physicians to listen in,
 11/26/2020 5:26 PM [View respondent's answers](#) [Add tags](#) ▼

14

**“We can’t do this without you,
you can’t do this without us”**
(From G. Eda Ömür testimony)

Participants of the ASCAT SCD 2020 people affected Session





1

Last Year

- A wonderful group of clinicians from all around Europe who support the **meaningful involvement** of people affected worldwide
- Capacity to improve information, build collaborations, influence research and impact on care models
- Presentation of the results of the SCD Research Prioritization Workshop at the audience of ASCAT 2019






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2

This Year

2020.....Not in person.....





.....BUT.....
**STILL CONNECTED
AND
NOT ALONE**




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3

**49 people affected and
Parents:**





- 1 CYPRUS
- 4 SPAIN
- 7 FRANCE
- 2 IRELAND
- 5 ITALY
- 2 NETHERLANDS
- 3 PORTUGAL
- 1 SWITZELAND
- 13 UK
- 1 AUSTRALIA
- 2 CANADA
- 1 INDIA
- 2 NIGERIA
- 5 USA

38 from European countries



13 experts: physicians, nurses, psychologist; Eurordis and ERN representatives

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4



5

Key features of the patient workshop

- Legacy from 2019 ASCAT - we are building on strong foundations
- Moderators included healthcare professionals *and people affected*
- **Topics chosen:**
 - Had been identified by people affected as being important for research at the 2019 ASCAT
 - Had been prioritized by people affected as requiring more information from a EuroBloodNet Survey
- “Meet the expert” was not only meeting medical professionals but also people affected as experts of their condition
- All people affected who participated had opportunities to ask questions in chat and/or live
- Mixture of live and pre-recorded presentations

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6

Day 1-26th October

- COVID session
 - Testimonies from different countries
 - Live Q&A
- PEER REVIEW session
 - Testimonies from UK patient participants
 - Live Q&A
- WHY I TOOK PART IN RESEARCH session
 - Testimonies from different countries
 - Live Q&A

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7

COVID session outcomes




- Experience varied between countries (shielding vs not)
- Quality of care varied between countries
- Some experienced the “best treatment ever” in hospitals!
 - Direct phone access to clinicians
 - Rapid clinical assessment
 - Admission to correct (haematology) ward
- Some employers were surprised to see SCD on the list of high risk
 - it was validating for a lot of people to have the seriousness of condition finally recognized by government, employers, colleagues, friends
- Fear and anxiety was commonplace
- Use of telehealth- quite a good legacy for the future
- Role of social media in staying informed
 - Access to information – but what/who do you trust?

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8

PEER REVIEW session outcomes

- What is peer review?
 - UK system for quality assessment of services- healthcare providers assess each other's services
 - Patient representatives are included- they review the documents, speak to healthcare providers and to users of that service to get a subjective view
- Testimony from 2 people who had been patient reps on peer review process
- Lots of curiosity about the process from those who were not familiar with it
 - Other countries
 - People in the UK as well did not know
- We liked that we can hold stakeholders accountable
- How can we spread this practice of Peer Review?
 - could this be done elsewhere as well?
 - Could EuroBloodNet be able to spread this practice
- Key messages from peer review:
 - How do we advertise this?
 - How do we share good practice?
 - Why do people still not have good care when we have this process (sometimes due to resources)


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WHY I TOOK PART IN RESEARCH session outcomes

- 4 testimonies from people who had participated in different types of research (BMT, new drug, 'old drug', telephone questionnaire)
- Strong message:
 - The heavy emotional and psychological toll on research participants
 - Even the clinicians in the room were surprised- it made them think *how to do this better in future and support people affected better when they are research participants*
- Lack of advertising:
 - how do you find out and get involved?
 - How do you spread awareness about research
 - What about countries where there is research but poor access
 - What about countries where there is no or little research happening?
- People struggle with the idea of placebo
- Two main problems:
 - Far fewer trials in children
 - Mental health- we need more research!









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Day 2 - 28th October

- Meet the **medical expert** sessions
 - Newborn and infant SCD Screening, **Stephan Lobitz, Germany**
 - Neurological Complications in SCD, **Maddalena Casale, Italy**
 - Adult people affected Quality of Life, **Jeremy Anderson, UK**
 - BMT: survival infertility and other complications, **Jean-Hugues Dalle, France**
 - New therapies for SCD, **John Brewin, UK**
- Live Q&A
- Parallel Meet the expert session: moderators 1 physician/1patient
 - **Young people affected** addressing questions to adult people affected
 - **Physicians** addressing questions to adult people affected
- SCD: "My life, My words"
 - Testimonies from pediatric patient and parents from different countries (France, India, Canada, UK).

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11

Meet the medical expert session outcomes

- Not enough time!
 - People had many questions
 - Lots of unanswered questions- still in the chat.
 - People would like more opportunities to ask questions to the experts





EuroBloodNet will start some seminars

- We know there is a concrete need
- We know what topics are important
- We can run them with subtitles
- We can run some in other languages

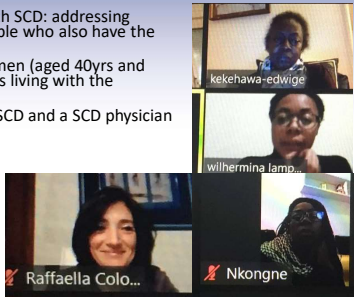



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Meet the expert patient session outcomes YOUNG PEOPLE

- Young people living with SCD: addressing questions to adult people who also have the condition
- Adults with SCD: 2 women (aged 40yrs and 60yrs) who are mothers living with the condition
- A teenager living with SCD and a SCD physician as moderators



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13

Meet the expert patient session outcomes (7 questions)

What are the 3 things you would change in your life going back?

« I would do more sports. From the beginning of my SCD follow up pediatricians always tell me not to do sport, that it is dangerous, that it is a risk for your joints. But sport practice is efficient and complementary to SCD treatments.»

« I would have done the bone marrow transplant, now it's too late»

« I would have chosen a better job, for finding a balance between profession and private life »

What is the most important problem being an ageing adult?

«FATIGUE and finding ways to cope with it »

What about mental health?

«Being a child with sickle cell disease is so difficult on your mental health, you always feel like a burden»

«We need better access to tailored mental health services for SCD– it's important»

« Teenager and children know that their parents also need help in dealing with the condition »

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Other questions....


- Do you have to take medications your entire life?
- Pregnancy (Can I become pregnant? How was your pregnancy?)
- Hope
- Socializing, relationships
- New drugs
- Acceptance by society
- Stigma

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15

As someone living with SCD when you have a painful crisis what do you want your doctor to ask you?

- Your doctor should EXPLORE with you what you need, and together agree on treatments
- Your doctor should LISTEN to you and your partner/parent!
- Your doctor should BELIEVE you
- Your doctor should FOLLOW your lead
- Your doctor should ASK how this will affect your work



When the doctor asks what I need, it's a quick admission. When they don't listen, I know I will end up here for days...

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16

What feature in any new therapy would make you agree to adopt it?

- The RISKS are more important to me than the BENEFITS
- What do I have to LOSE rather than GAIN?
- Will there be any permanent damage?
- How invasive will it be?



How will this fit into the rest of my life- work, family, activities?

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17

What better ways are there for your doctor to communicate with you?

- No time limit
- Honest conversation
- Put me in touch with other people on the same medication

What is the right term- patient? Person living with sickle cell disease?


- Person!!! Not patient!
- Ban the term "sickler"
- "disease" makes people worry about contagion

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18

How do you tackle racism and stigma affecting your care?

- People don't know about SCD or they don't care
- Policies would need to change to reduce racism and inequalities
- Access to care in Africa and India is also a massive problem due to stigmatization
- There are lots of assumptions about skin colour and requirements for testing
- We need to educate society, especially medical students and junior doctors
- Systemic racism in UK means prescription charges not free like in other chronic health conditions



Can we produce some educational material together?

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SCD: My life, My words

Testimonies from pediatric patient and parents of people affected from different countries (France, India, Canada, UK).

UK patient- 9 years old "SCD is Hard but manageable"

Canada- Unexpected diagnosis; Fear and expectations
Answering questions 'why me?' and dealing with emotional consequences of dealing with limitations, pain and setbacks

Africa
Focus on the positives- you can live a normal life
We need more research to stop pain
Lots of new treatments coming along

India
Lack of education
Effect on whole family
Burden on whole population as well (e.g. birth controls??)
Living in remote areas means poor access to treatment

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We leave you with our final key messages

- We need to improve access to care in Africa and India. It is OUR responsibility- all of us
- We have a life outside hospital!
- Global Awareness on SCD and research availability on SCD
- Racism and stigma affects our health everywhere and all the time. What will you do about it?
- How do we improve psychological and mental wellbeing?
- Please LISTEN to us

European Reference Network logo and ASCAT logo are present at the bottom.

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Thanks to Participants and Coordinators of the SCD Patient Educational Meeting at ASCAT 2020

Ascat Steering Committee
BSH
ERN-EuroBloodNet

Sessions and videos WILL BE UPLOADED

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ANNEX V_EUROBLOODNET TOPIC ON FOCUS ON CUTANEOUS LYMPHOMA FOR PATIENTS ORGANIZATIONS

6.2 ERN-EUROBLOODNET REPORT ON ACTIONS FOR THE PROMOTION OF CONTINUING MEDICAL EDUCATION ON RHD -



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

Cutaneous Lymphoma Topic on Focus for Patients Organizations

Topic on Focus webinar targeting patients' organizations is coordinated in collaboration with the Lymphoma Coalition, France Lymphoma Espoir, Cutaneous Lymphoma Foundation and Eurordis.

It aims to disseminate very innovative topics related to Cutaneous Lymphoma among patients' organizations in order to give the visibility to the medical services available in Europe, last quality of life cutting-edge advances in the field of this very rare condition and its treatments options.

PROGRAM

- Six sessions, once per month on Monday, from 5 pm to 6 pm (CET), starting from April 2021.
- 25 min of presentation + 35 min for questions (written in the chat)
- On Virtual Platform
- Program will be recorded and part of the ERN-EuroBloodNet Edu YouTube channel

Each session will be moderated by a duo of an expert physician and a patient representative, who will elaborate the session together. The physician will first introduce the topic and share the clinical knowledge. The patient representative will ensure that information provided can be well addressed to patients organizations, and will also highlight which are the key crucial concepts for patients to the expert and asking to clarify them to the webinar audience. The patient representative will also moderate the Q&A session.

1. How to connect patients in Europe to CL experts via the ERN

(Services available at national or European level, Virtual Board, CPMS).

- **Month:** April 2021
- **Speakers:** Pr Martine Bagot and Pierre Aumont

2. Introduction to cutaneous lymphomas, the two prevalent subtypes: MycosisFungoides and Sézary Syndrome, Diagnosis and staging.

- **Month:** May 2021
- **Speakers:** *proposed* Dr.Maarten Vermeer and *a proposal for patient representative*

3. Introduction to Cutaneous Lymphomas, other subtypes, diagnosis and staging.

- **Month:** June 2021
- **Speakers:** *proposed* Werner Kempf and *a proposal for patient representative*

4. Treatment options available in Europe : Skin directed therapy, Systemic therapy, Clinical trials

- **Month:** July 2021
- **Speakers :** *proposed* Rudolf Stadler and *a proposal for patient representative*

5. Quality of life: Fatigue, Itch and Skin care, Psychological impact

- **Month:** September 2021
- **Speakers:** *proposed* Julia Scarisbrick and *a proposal for patient representative*

6. Impact of treatments on quality of life

- **Month:** October 2021
- **Speakers** *proposed* Dr. Pietro Quaglino and *a proposal for patient representative*



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



www.eurobloodnet.eu

Co-funded by the European Union

