2018
ANNUAL REPORT

EUROPEAN HAEMOPHILIA CONSORTIUM

EHC
european haemophilia consortium

ACRONYMS

CEO: Chief Executive Officer

EAHAD: European Association for Haemophilia and Allied Disorders

EASL: European Association for the Study of the Liver

EMA: European Medicines Agency

ePAG: European Patient Advocacy Group

EIN: European Inhibitor Network

EPF: European Patients' Forum

ERN: European Reference Network

HCV: hepatitis C virus

HTA: Health Technology Assessment

ISTH: International Society for Thrombosis and Haemostasis

IWG: Inhibitor Working Group

MEP: Member of the European Parliament

NMO: National Member Organisation

PARTNERS: Procurement of Affordable Replacement Therapies/ Network of European Stakeholders

PLUS: Platform of Plasma Users

UKHCDO: United Kingdom Doctors' Haemophilia Organisation

VP: Vice-President

WBD: Women and Bleeding Disorders

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ABOUT THE EHC

The European Haemophilia Consortium (EHC) is a non-profit, non-government organisation that works to improve the quality of life of people with haemophilia, Von Willebrand Disease and other rare bleeding disorders in Europe.

MISSION STATEMENT

The EHC was established in 1989 with the mission to:

- Ensure adequate supply – and access to – safe factor concentrate treatments,
- Improve diagnostic and treatment facilities,
- Promote patients’ rights and raise ethical issues,
- Follow and influence developments in European health policy,
- Monitor the status of haemophilia care in member countries, and
- Stimulate research in all fields related to haemophilia and other rare bleeding disorders.

IN 2018, THE EHC FOCUSED ITS ACTIVITIES ON:

Raising awareness and providing information,

Building advocates,

Empowering communities,

Maintaining EHC long-term sustainability.

MESSAGE FROM THE PRESIDENT AND CEO

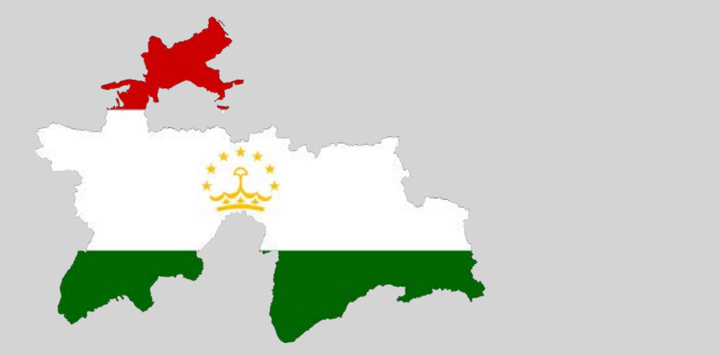
"Our growing number of volunteers from across the patient and healthcare provider spectrum are a testament to the power of the European community."

"The EHC's partnership approach across sectors continued to bear fruits in 2018 and is a model we will continue to build on!"

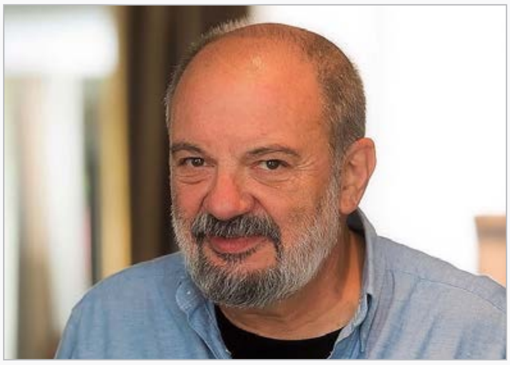
"A strong, committed and highly flexible staff base continued to support the valuable work of our volunteers and empower our patient community to further grow in 2018."

A QUICK OVERVIEW OF 2018

MINETTE VAN DER VEN BECAME EHC VICE-PRESIDENT FINANCE, SUCCEEDING JORDAN NEDEVSKI.
MINETTE VAN DER VEN IS FOURTH FROM THE LEFT.



TAJIKISTAN JOINED THE EHC COMMUNITY.



THE EHC WISHES TO THANK JORDAN NEDEVSKI, THE OUTGOING EHC VICE-PRESIDENT FINANCE FOR SERVING ON THE EHC BOARD FOR ELEVEN YEARS.

PROFESSOR (PROF.) FLORA PEYVANDI BECAME THE CHAIR OF THE EHC MEDICAL ADVISORY GROUP (MAG) TAKING OVER FROM PROF. PAUL GIANGRANDE

THE EHC WISHES TO THANK PROF. PAUL GIANGRANDE, THE OUTGOING CHAIR OF THE EHC MAG, FOR HIS SUPPORT, ADVICE AND FRIENDSHIP TO THE EUROPEAN BLEEDING DISORDER COMMUNITY.

OVER SEVENTY VOLUNTEERS DEDICATED 8540 HOURS TO EHC ACTIVITIES. THAT IS, ON AVERAGE, THREE WEEKS OF FULL-TIME WORK PER YEAR!

The EHC was also delighted to welcome over 850 participants to its events in 2018. Amongst those, 250 patients that attended and trained at our EHC events. The EHC warmly thanks all the participants to its events!

EHC STARTED A COMMITTEE FOR WOMEN AND BLEEDING DISORDERS (WBD).

> ***"In many countries in Europe, both the medical and psychosocial support for women with haemophilia is very low. Especially the medical aspect. Female carriers are completely on the lowest level of treatment, and in many countries, they aren't recognised as a category at all. It is very important that we have a committee that can help women all over Europe, whether it is through their patient organisations or personally. Finally, women have a home and someone to turn to for support and to ask questions."***
>
> Tatjana Markovic, WBD Committee member, Serbia

EHC STARTED A NEW PRODUCT COMMITTEE TO HELP DEVELOP A NEW NEWSLETTER ON DEVELOPMENTS IN NOVEL THERAPIES FOR HAEMOPHILIA AND OTHER RARE BLEEDING DISORDERS.

EHC STARTED THE YOUTH FELLOWSHIP PROGRAMME.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RAISING AWARENESS AND PROVIDING INFORMATION

One of the missions of the EHC is to ensure that the European community is visible at the European level so that issues faced by the community are addressed in a broader European context.

The EHC has also put in place mechanisms to continually bring the latest medical, scientific, and health policy information to its members.

WORLD HAEMOPHILIA DAY CELEBRATION: MARKING 10 YEARS OF THE EUROPEAN PRINCIPLES OF CARE

April 2018 – Brussels, Belgium

For the past ten years, the European Principles of Haemophilia Care have not only set a gold standard for haemophilia care in Europe but they have also been used as a tool to evaluate the quality of haemophilia care in European countries. These principles have also inspired the development of principles of care in other disease areas such as inhibitors.

Dr. Brian Colvin, Chair of the United Kingdom Doctors' Haemophilia Organisation (UKHCDO) and one of the leading figures behind the principles said: "These Principles have now been looked at all over the world. It was a European initiative, it was designed to bring Europe together." On the role of principles with novel treatments, he noted that: "The new treatments for haemophilia will need to be looked at very carefully, they will need to be regulated, rolled out in the right way, and then properly assessed. Any adverse events must be recorded. All that work will continue to be under the influence of the European Principles."

2018 was also the year in which the EHC launched its fourth survey on "The state of haemophilia care in Europe," which was based on criteria established the European Principles of Care and the Council of Europe Resolutions on principles concerning haemophilia therapies. The survey's objective is to evaluate the progress made by individual countries in terms of access to treatment and care. This survey also marks ten years of EHC data collection on the state of haemophilia care with surveys published in 2009, 2012 and 2015.


EHC

Haemophilia Care in Europe

A Survey of 35 European Countries
Produced in 2012

Brian O'Mahony

The European Principles of Care in Haemophilia and the results of the EHC surveys have also inspired the PARTNERS programme, which aims at increasing levels of treatment and care to the minimum European standards.

EHC CONFERENCE

October 2018 – Brussels, Belgium

The EHC 2018 Conference was meant to be set in Baku, Azerbaijan, but technical issues had it moved to Brussels where it attracted a record number of over 350 delegates. The Conference is an opportunity to provide a place to our community to meet, exchange and learn new information about clinical and scientific developments in haemophilia treatment and care.

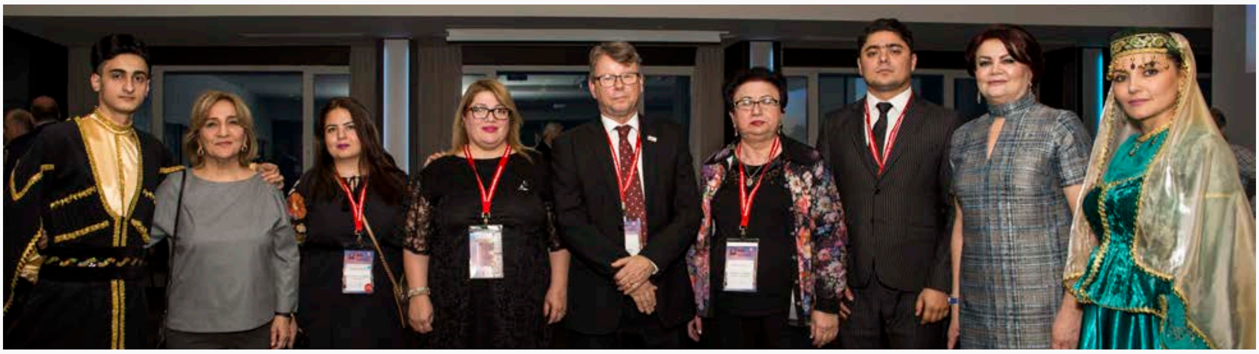
What have participants said about this Conference:

"The EHC Conference was well organised, and the venue was excellent. It was great to have the meeting in Brussels, which is a very central city easily accessible from across all of Europe. With almost 360 participants, the Conference is growing in size."

"As a patient, I can say that the research being done is remarkable."

"Dr Alison Dougall's enthusiasm rocked! And Prof Mike Makris is just a legend. No more needs to be said!"

"Just happy to be alive at this point in history when so many new cures are being developed."



WORKSHOP ON NOVEL TECHNOLOGIES IN HAEMOPHILIA CARE & NEW PRODUCT REVIEW

November 2018 – Sofia, Bulgaria

With so many new medicinal products for haemophilia in the pipeline, it is challenging to keep abreast of every latest development. To ensure EHC members receive the most recent information the EHC holds each year a workshop on New Technologies in Haemophilia Care. Also, the EHC started to publish a Periodic Review of Advances in Haemophilia Treatment.

What participants said about the EHC Workshop on New Technologies in Haemophilia Care:

"The data and the debates will help me prepare tools for advocacy at the national level."

"Huge amount of information for two days, still very well done."

"The gene therapy panel had very dynamic discussions!"

ROUND TABLES OF STAKEHOLDERS

Held in February, June and November 2018 at the European Parliament in Brussels

Each year the EHC organises three Round Tables of Stakeholders on some of the 'hot topics' in the haemophilia community. These events are an opportunity for various stakeholders to meet, review issues and discuss potential solutions.

In 2018 the EHC held Round Tables on the topics of:

ECONOMICS AND ACCESS, HEALTH CARE SYSTEMS AND NOVEL THERAPIES

"With novel therapies, we need to work together to make sure they don't come on top of inequalities, but rather are received in a timely manner all over Europe." Dr. Miroslav Mikolášik, Member of the European Parliament (MEP).

WOMEN AND RARE BLEEDING DISORDERS

"We don't treat, we don't speak, we don't support women with rare bleeding disorders!" Mrs. Norica Nicolai, MEP.

"It is a common mistake to consider bleeding disorders as only affecting male patients." Dr. Miroslav Mikolášik, MEP.

"I'm here exposing myself and my family in the hope that the people in this room will hear me and help me make a change." Mrs. Ana Pastor, WBD Committee member, Portugal.

SWITCHING FROM STANDARD THERAPIES, WHERE DO NOVEL THERAPIES FIT IN?

"European payers finding no clinically significant benefit does not equal lack of additional value! We need to move to multi-criteria decision analysis!" Mr. Declan Noone, EHC PARTNERS Programme consultant.

"Patients should be the final decision-makers when it comes to switching, and for this, they must be well informed, well trained and have a high level of trust in their clinicians." Mr. Edouard Hamelin, France.

"Progress in therapies has been amazing, but increased budgets have not led to increased consumption in Romania. There is a need to re-think haemophilia and identify obstacles to access!" Mr. Daniel Andrei, Romania.

HERE IS WHAT ELSE THE EHC DID IN 2018 TO RAISE AWARENESS AND PROVIDE INFORMATION

EHC CEO, Amanda Bok, has sat and was actively involved with the Patient Advisory Group (PAG) of EuroBloodNet, the European Reference Network focused on blood disorders.

The EHC developed a movie on the contamination with hepatitis C (HCV) of people affected by rare bleeding disorders. This movie is a call to action to provide curative treatments to people with haemophilia and HCV.

The European Medicines Agency (EMA) appointed Dr. Günter Auerswald as a patient representative to its Paediatric Committee. Dr. Auerswald is serving his second term in this role.

The EHC continued to grow its group of MEPs 'Friends of Haemophilia.'

The EHC provided its members with regular updates on European health policy, through its European Health Policy Quarterly Reports.

EHC provided travel grants to its members to attend the Annual Conference of the European Association for Haemophilia and Allied Disorders (EAHAD).

EHC had an active presence and held exhibition stands at the Congresses of the International Society on Thrombosis and Haemostasis (ISTH) and the World Federation of Hemophilia (WFH).

EHC took part in activities led by PLUS, the platform of plasma users. An informal patient group representing patients relying solely or partially on plasma-derived treatments.

The EHC signed a Memorandum of Understanding with the EASL Foundation, an organisation committed to combatting HCV.

The EHC provided travel grants for participants to attend its Round Tables of Stakeholders as well as Annual Conference.

EHC continued to be a member of EURORDIS – Rare Disease Europe – and the European Patients' Forum, two umbrella patient organisations representing the interests of patients with rare and chronic conditions. Mr. Declan Noone joined the EURORDIS HTA Task Force as EHC representative.

" I know that we need a better understanding economically and politically in order to improve the quality of life of people with rare bleeding disorders. We have many opportunities here, but we also have a lot of challenges, a lot of complicated situations, mostly in Central and Eastern European countries. I believe we can improve the situation for haemophilia and other rare bleeding disorder patients only if we have a vision and only if we truly understand the needs of patients before anything else."

Dr. Cristian Busoi, MEP

"I am proud to serve this community because I understand people. All of us need to have the right to a normal life and for me, as a politician, it's normal to support this necessity of the people." Mrs. Norica Nicolai, MEP

BUILDING ADVOCATES

The EHC strives to provide its members with adequate tools and skills to become the most effective advocates for their community. So that they can volunteer both within their NMO at a national level as well as internationally.

EUROPEAN INHIBITOR NETWORK

Started in 2016, the European Inhibitor Network (EIN) aims at providing a support network to people with rare bleeding disorders and inhibitors to their treatment. Inhibitor development is currently the most severe complication in haemophilia. It can leave affected people very isolated and with no or very little (and highly expensive) treatment choices. In 2018, EHC, led by its Inhibitor Working Group (IWG), continued its work to support community members affected by inhibitors through several initiatives and events.

EHC INHIBITOR SUMMIT

December 2018 - Barretstown, Ireland

This event is the culmination of the work carried out by the IWG. In 2018, 150 participants (including families with children), speakers and moderators from across Europe came together for three days to follow a mix of scientific and practical sessions. During these three days they learned more about managing inhibitors and becoming better patient advocates.
The event also left plenty of room for discussions and exchanges amongst delegates, which will ultimately lead to the development of a peer-to-peer network.

What participants have said of the summit:
"It is an exceptional achievement; I wish I had heard of this years ago. I feel as though I have struggled alone for such a long time."

"Thank you for an amazing couple of days! Attending the summit has been life-changing. There are so many uniquely different "experiences" of living with an inhibitor, but also so many similarities; it is quite powerful to see how families in other countries cope with life with an inhibitor. I will take what I have learnt here and implement it into our programming."

"I am meeting the most wonderful people every year, and it is amazing :) Thank you!"

"Excellent summit. I love that all the summits have been fantastic and the EHC takes on the feedback and suggestions each year to improve the event, even though it was already good. Well done!"

PRE-CONFERENCE WORKSHOP ON "FINDING WAYS FOR BETTER INCLUSION OF PEOPLE WITH INHIBITORS IN THE LIFE OF NATIONAL MEMBER ORGANISATIONS"

October 2018 – Brussels, Belgium

People with inhibitors are a minority within a rare disease group. So, often, it is difficult for patient groups with limited resources to focus their activities on something that may only concern a handful of people within their membership. This situation only leads to further isolation and feeling of loneliness amongst inhibitor patients. How to integrate these individuals in the life of the NMO was the focus of this pre-Conference workshop.

What participants said about this event:
"This workshop was relevant and had high importance for the inhibitor community."

"Traditionally, there hasn't been any focus on people with inhibitors within my NMO, so this workshop provides me with information on where and how to start developing new activities."

Besides all of these activities, in 2018, the EHC IWG collaborated with key clinicians to develop ten European Principles of Inhibitor Management complementary to the European Principles of Care (see pg13). This document serves as a benchmark to improve the multidisciplinary and practical management of patients with inhibitors.
The European Inhibitor Network was also actively present at the EHC stand during EHC and other international events.

HAPPY ½ HOUR WITH AN EXPERT IN HAEMOPHILIA CARE

October and November 2018 – Online

In October 2018 a series of 'Happy ½ Hour with an Expert in Haemophilia Care' was started.

These 30-minute monthly videoconferences allow participants to ask questions to experts in one of the areas of multidisciplinary care. Participants can learn more about specialties such as haematology, physiotherapy, nursing care or psychosocial care, from the comfort of their home in a small group of peers. A variety of themes – venous access, dental care and physiotherapy – have already been covered under these series.

Following the event, EHC staff transcribes and publishes these discussions in the 'Ask the Expert' section on the European Inhibitor Network website (inhibitor.ehc.eu).

YOUTH PROGRAMME

In the past five years, the EHC has put its focus on ensuring continuity in its community by training young volunteers. These young members of EHC NMOs were trained on how to become more effective within their NMOs and also how to navigate the haemophilia landscape in Europe and interact with various stakeholders. The Youth programme is traditionally composed of a Youth Leadership Workshop and Youth Debates, however, in 2018 the EHC also developed a new initiative: the EHC Youth Fellowship Programme.

YOUTH LEADERSHIP WORKSHOP

April 2018 – Amsterdam, the Netherlands

Sixteen volunteers from across Europe gathered for two days in Amsterdam for an interactive training including role-plays, presentations and case studies. This training aims to equip young volunteers with the necessary tools and skills to become more active and navigate the haemophilia space in Europe. Therefore, the training focuses both on the internal functioning of the NMO as well as external relations. Topics such as the fundamentals of volunteering and strategic planning, medicines development and external communications are presented and discussed at length.

What participants have said about this training:

- ***"I am a new youth coordinator, so all the knowledge I'll take home will be the perfect tool to orient myself and my peers."***
- ***"Very relevant, especially in regard to being heard within our NMO to drive youth's projects."***
- ***"The workshop opened my eyes to areas that I didn't think about before. I liked that it was as interactive as possible. Hence we had to apply what we learned in practice."***
- ***"The Youth Leadership Workshop makes a real difference to our community, our NMO community and the wider community. It has inspired me to be a positive change!"***
- ***"It was a tremendous experience for our NMO. I gained a lot of information, and I will apply it in our NMO to engage with young people, our youth committee and the broader community."***

YOUTH DEBATE

The EHC believes that training youth to become the advocates of tomorrow should not just be a once-off exercise. Young volunteers should be offered the opportunity to take the initiative, utilise their skills and blossom within the community. Since the beginning of its youth training, the EHC organised youth debates during its scientific Conference. Young volunteers are up against established leaders and healthcare professionals within the community, and they are asked to debate controversial topics. Throughout the years, this has become a favourite session of the scientific Conference.

YOUTH FELLOWSHIP PROGRAMME

In the spirit of continuing to provide a platform for youth to utilise their skills and blossom into the leaders of tomorrow, the EHC launched in 2018 a new initiative: The Youth Fellowship Programme. This unique programme targets Youth Leadership Workshop alumni who will be offered support (both financial and logistical) to develop projects within their community. The programme also focuses on enhancing European cooperation. Proposed projects will need to involve volunteers from two or more countries. The EHC anticipates that this will be particularly beneficial for smaller countries with smaller patients' populations and limited resources.

In 2018, the EHC also worked towards preparing a five-year reunion for Youth Workshop alumni, which took place on January 2019.

What our participants have said about the Youth Fellowship Programme:
"All of us had ideas, but none of us dared to do it on our own. You don't need any special skill, there is no secret, you need to be motivated, and we can help you learn the rest - you can be trained by the EHC, by the NMO. The EHC brought us together and gave us the tools to do what we need to do to help continue our community well into the future."

WOMEN AND BLEEDING DISORDERS

Despite common misconception, women are also affected and suffer from bleeding disorders. As EHC Women and Bleeding Disorders (WBD) Committee Chair, Naja Skouw-Rasmussen, puts it:

"From the many years of being in the bleeding disorders community, I keep coming across many women who keep saying that they actually don't know much about their bleeding disorder, that they keep being discriminated against in getting the right education, getting the right treatment, not being taken care of in the proper way. Many of these women are mothers of kids with a bleeding disorder as well."

Led by a passionate and productive committee, the WBD Committee, the EHC took on several initiatives to address challenges faced by women with rare bleeding disorders. The objective of these inititatives was to raise awareness and identify ways to improve access to treatment and care for women affected by bleeding disorders.

EHC WBD COMMITTEE

The EHC WBD Committee was established in late 2017 and immediately developed an ambitious working programme that would culminate with a first European Conference for Women and Bleeding Disorders. The first point of order was to raise awareness and identify the women within the community.

"I really would like to raise awareness about women with bleeding disorders because I have learned that it's not really something people know about. This statement also includes doctors, and I would like to change that with the help of the committee."

Marion Braüer, WBD Committee member, Austria

"It is important to get together and share our information and knowledge that we already have. If you do it on a European level, I think we can arrange and accomplish more than if you do it just on a national basis."

Evelyn Grimberg, WBD Committee member, The Netherlands

The committee was instrumental in carrying out the activities outlined in the following pages.

EHC SURVEY ON WOMEN AND RARE BLEEDING DISORDERS

Before acting, it was important for EHC to understand the challenges faced by the WBD community. This knowledge would be paramount to define actions to support the community. Therefore, EHC surveyed the community. The survey got over 750 individual responses and shed much light on the difficulties experienced by these women. The results of the survey were submitted for publication and published in 2019 in *Haemophilia*.

The survey shows that women experience severe bleeding symptoms. For instance, these women get monthly bleeds with their menses, and that they often struggle to get properly recognised by healthcare professionals and to access adequate treatment and care.

These statements are some of the respondents' testimonials on everyday issues:

"I needed a transfusion of two blood units, and as a result, I missed out on a new career."

"I have to plan my bathroom times between professional appointments because I need to change up to 40 times per day during my period."

"I had severe bleeding for over ten years resulting in a hysterectomy at 38."

Did you know?

Women can have bleeding disorders too.

10 % of women go to the doctor with heavy blood loss.

29 % of these women may have a bleeding disorder.

But only 2 % of these women get tested for bleeding disorders.

WOMEN & BLEEDING DISORDERS

#caughtredhanded
#EHCWomensCommittee

MOVIE ON WOMEN AND BLEEDING DISORDERS

To better illustrate the hurdles faced by women with bleeding disorders to a broader audience, the EHC decided to develop a movie telling their stories. The documentary, directed by Goran Kapetanovic, was shot in 2018 in various locations across Europe and was then released in 2019.

ROUND TABLE ON WOMEN AND RARE BLEEDING DISORDERS

June 2018 – Brussels, Belgium

This Round Table allowed patients and healthcare professionals to present to various stakeholders' issues faced by women in this community.

As Prof. Paul Giangrande, former chair of the EHC MAG said of the Round Table: ***"The key messages of the event, were: 1) there is an unmet need for women with bleeding disorders; 2) women who are carriers should be actively referred to as people with mild haemophilia; and 3) they're no different from men with mild haemophilia.***

He continued: ***"I think there are several treatments that are under-utilised. That's because they are not promoted for carriers of haemophilia and women with Von Willebrand Disease."***

Finally, the EHC WBD Committee developed many informative materials. Members of this committee and their activities were put forward at the EHC stand during EHC and other events.

TRAINING IN HEALTH ECONOMICS

In 2018, the EHC closed its second series of training in health economics, focusing on tenders and procurement. Despite being a rare disease, haemophilia has multiple treatment options available, and many innovative medicinal products are being developed. However, like many other disease areas, haemophilia also faces increased financial pressures from cost-containment measures imposed on national healthcare systems.

This economic training aims at providing participants with information on the safety and efficacy of haemophilia therapies. It also offers models for the safe and effective procurement of these medicines and finally, tools on how to contribute towards a meaningful evaluation of therapies' benefits from a patient's perspective.
The 2018 training was given to patient representatives from Western European countries.

What participants said of this workshop:

"The workshop was very relevant! We are ready to suggest to our government some big changes."

"In our country, we do not use a tender system, and I think we will not change that in the future for various reasons. However, this training was beneficial because you never know what happens in the future, and you should be prepared to take action!"

EMPOWERING COMMUNITIES

Ultimately one of the most important goals of the EHC is to enable national communities to advocate for themselves. Besides raising awareness, providing information and training volunteers, the EHC also has specific initiatives to support local ecosystems. These initiatives will allow the development, engagement, growth and empowerment of volunteers who advocate for a better life for people with bleeding disorders.

LEADERSHIP CONFERENCE

June 2018 – Brussels, Belgium

The EHC Leadership Conference brings together established volunteers, young volunteers and staff members from their National Member Organisations (NMOs). Participants spend three days to learn how to ensure the long-term sustainability of NMOs through lectures and interactive workshops. This event aims at providing a space where members from across Europe come together to meet, learn and exchange on common issues.

What participants said of our event:

"The Leadership Conference was practical, with a lot of new ideas and information that can be applied to my country."

"The event was on topics I work on, and it gave me more insights, but also a lot to think about on how to give this information back to members."

"Very relevant, it was motivating and inspiring to get back and grow your NMO with this information."

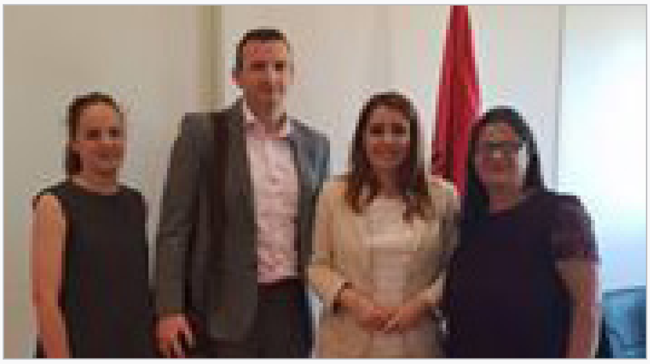
PARTNERS PROGRAMME

The PARTNERS Programme (Procurement of Affordable Replacement Therapies/ Network of European Relevant Stakeholders) was born out of a desire to improve access to therapies and care for countries who continuously were below the minimum level of care as recommended by the Council of Europe.

The PARTNERS programme will bring together all stakeholders involved in the organisation of haemophilia care. Then, all of these actors can identify ways to purchase treatment products more cost-effectively way. The idea of the programme is to utilise treatment products in a more effective, yet personalised, manner and to widen access to multi-disciplinary care. PARTNERS establishes target countries based on the results of the EHC surveys. It also incorporates treatment best practices, as outlined by the uropean Principles of Haemophilia Care and Council of Europe Resolutions on haemophilia therapies.

IN 2018, THE EHC LED BY ITS PARTNERS CONSULTANT CONTINUED TO EXPLORE POSSIBILITIES OF IMPLEMENTING THE PROGRAMME IN SEVERAL EUROPEAN COUNTRIES.

"We very much welcome the creation of such an innovative and much-needed programme towards addressing the needs of patients with haemophilia both inside and outside of the European Union in accessing adequate supply of clotting factor concentrates." Yann Le Cam, CEO of Eurordis.



"We commend the programme for prioritising the involvement of clinicians and patient representatives in the national procurement process as this is essential in order improve overall treatment quality as well as assisting healthcare systems toward achieving sustainability in the future."

Marco Greco, President of EPF.

ACTIVITY AND PHYSICAL ACTIVITY GRANTS

It can be challenging to start an activity from scratch without any financial support. Therefore, EHC developed two grants.

The first is to help NMOs to start new activities. The second is to promote physical activity, which plays an essential role in the management of haemophilia.

Some of the projects financed by these grants include:

- Translation of the EHC Novel Treatment Newsletter (Greece & Israel),
- Training of local clinicians (Kyrgyzstan),
- Support of a basketball camp (Lithuania),
- Development of a women and bleeding disorders strategy (Portugal),
- Support of a youth leadership camp (Romania).

MAINTAINING EHC LONG-TERM SUSTAINABILITY

A word on finances…
…is also a word about the people behind them.

Those people include Jordan Nedevski who for eleven years, since 2007, was part of the EHC's leadership, and for eight of those, the EHC's Vice-President (VP) Finance. In October 2018 Jordan handed his role over to Minette van der Ven, and thus the EHC closes its 2018 accounts and this annual report in a tripartite.

Jordan and Minette both equally committed to the European community, outgoing and incoming VPs Finance had a productive hand-over towards the end of 2018 and enabled the EHC as an organisation to continue to grow on the strong foundations laid before them, thanks to our deep and meaningful collaborations.

Nowhere is the strength of these collaborations seen best as amongst our volunteers, particularly so in 2018. In this year, the efforts that volunteers were dedicating of themselves to the EHC completely free of charge - their time, their input and their expertise - rose by nearly 70% over the previous year. Namely, this meant that in-kind contributions rose from 302,000 Euros in 2017 to 512,400 Euros in 2018! That puts volunteer time at a solid quarter of the EHC's financial and non-financial income of 2018, and is a testament to the drive, power and passion of our European bleeding disorders community!

External partnerships too offered the other critical three-quarters of the EHC's 2018 work, stabilising as previously predicted, at levels similar to 2017. EHC was able to slowly taper off our previous growth and focus on our consolidation.

Despite this positive news, 2018 was not without its challenges. Chief amongst these was the last-minute relocation of the 2018 EHC Conference venue due to the intransigence of some politicians. The EHC took that difficult decision collectively, collaboratively and democratically. We were proud to have enabled an outcome that was in the best interest of our broad patient community, even if it meant absorbing a financial end-of-year loss.

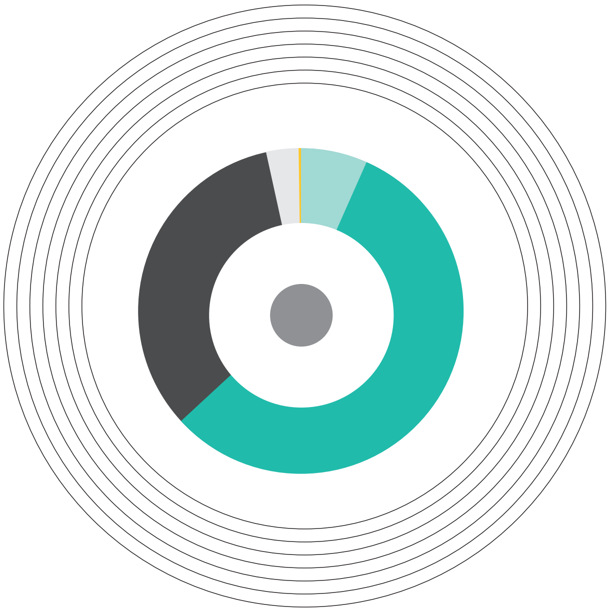
Happily, that didn't happen.

It is with great pleasure that we report closing our 2018 accounts, in spite of these financial turbulences, with a surplus of 160,000 Euros to put towards our operational reserves. We could not have done it without all the extra hands-on-deck and out-pouring of support of everyone in this community, from our youth leaders to our NMOs' membership base, to our external partners. We thank you.

And so, it is, with one word of goodbye, one word of hello, and many words of gratitude, that we close our accounts and financial report of 2018, humbled, moved and at your continued service.

EHC INCOME AND EXPENDITURE 2018

TOTAL INCOME 2018	1,391,101
NMO Membership	11,050
Sponsorship	1,296,886
EHC Conference	65,890
Others	7,544
Book Profit from Last Year	9,731



TOTAL EXPENDITURE 2018	1,182,915
Operationnal Expenses	91,528
Wages and Fees	678,622
Meetings and Events	397,847
Contributions and Affiliations	11,787
Depreciation	3,131

BALANCE 2018	208,186
Volunteer In-Kind contribution	512,400

INDEPENDENT AUDITOR’S REPORT TO THE STEERING COMMITTEE OF THE AISBL

Consortium Européen de l’Hémophilie (European Haemophilia Consortium) 0887.106.966
FOR THE YEAR ENDED 31 DECEMBER 2018

As required, we report to you in the context of our appointment as the association’s independent auditor. This report includes our opinion on the “internal statements”

Report on the annual accounts – Unqualified opinion

We have audited the internal statements of the AISBL Consortium Européen de l’Hémophilie for the year ended 31 December 2018, prepared in accordance with the financial-reporting framework applicable in Belgium, which show a balance sheet total of € 2.183.681 and a positive result for the year of € 208.186.

Responsibility of the board of Directors for the preparation of the annual accounts

The board of Directors is responsible for the preparation of annual accounts that give a true and fair view in accordance with the financial-reporting framework applicable in Belgium, and for such internal control as the board of Directors determines is necessary to enable the preparation of annual accounts that are free from material misstatement, whether due to fraud or error.

Responsibility of the statutory auditor

Our responsibility is to express an opinion on these annual accounts based on our audit.
We conducted our audit in accordance with International Standards on Auditing (ISAs).
Those standards require that we comply with the ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the annual accounts are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the independent auditor's judgment, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the independent auditor considers the company’s internal control relevant to the preparation of annual accounts that give a true and fair view, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity’s internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the board of Directors, as well as evaluating the overall presentation of the annual accounts.

We have obtained from the board of Directors and company officials the explanations and information necessary for performing our audit.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Unqualified opinion

In our opinion, the internal statements of the AISBL’s give a true and fair view of the association’s equity and financial position as at 31 December 2018, and of the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

Limal, project September 2019
Rosier & Co, Independent auditor's
represented by Stéphane Rosier Certified Public Auditor

EHC BALANCE SHEET 2018

FIXED ASSETS	**4,000**
IT and Furniture	4,000
FINANCIAL ASSETS	**2,091,000**
Amount receivables from clients	464,000
Bank account	1,612,000
Guarantee paid	5,000
VAT to recover	11,000
DEFERRED CHARGES	**89,000**
Charges related to 2019	89,000
TOTAL ASSETS	**2,184,00**

EQUITY	**1,810,000**
DEBTS	**349,000**
Amount to pay suppliers	319,000
Tax	1,000
Social debts (Salary)	29,000
DEFERRED INCOME	**25,000**
Income related to 2019	25,000
TOTAL LIABILITIES	**2,184,00**

MEMBERS

In 2018, the organisations here below were part of the EHC membership:

Albania / Shoqatës Shqiptare të Hemofilikëve
Armenia / Armenian Association of Hemophiliacs
Austria / Österreichische Hämophilie Gesellschaft (ÖHG)
Azerbaijan / Hemofiliyalı X□st□l□rin Respublika Assosiasiyası
Belarus / Белорусская Ассоциация Больных Гемофилие
Belgium / Association de l’Hémophilie - Hemofilievereniging (AHVH)
Bosnia and Herzegovina / Udruženje Hemofiličara Bosne i Hercegovine
Bulgaria / Българска Асоциация по Хемофилия
Croatia / Društvo hemofiličara Hrvatske
Cyprus / Παγκύπρια Οργάνωση Αιμορροφιλικών (Π.Ο.Α.)
Czech Republic / Český svaz hemofiliků
Denmark / Bløderforening
Estonia / Eesti Hemofiliauhing
Finland / Suomen Hemofiliayhdistys (SHY)
France / Association Française des Hémophiles (AFH)
Georgia / Georgian Association of Hemophilia and Donorship
Germany / Deutsche Hämophilie Gesellschaft
Greece / Σύλλογος Προστασίας Ελλήνων Αιμορροφιλικών (ΣΠΕΑ)
Hungary / Magyar Hemofília Egyesület
Iceland / Blæðarafélag Íslands
Ireland / Irish Haemophilia Society
Israel / עלה – עמותה לחולי המופיליה
Italy / Federazione delle Associazioni Emofilici (Fedemo)
Kyrgyz Republic / Kyrgyz Haemophilia Society “Community of handicapped – haemophiliacs”
Latvia / Latvijas Hemofilijas Biedrība
Lithuania / Lietuvos Hemofiljos Associja
Luxembourg / Association Luxembourgeoise des Hémophiles
North Macedonia / Hemolog
Moldova / Ассоциации Гемофилии Молдовы
Montenegro / Montenegrin Association for Hemophilia
Netherlands / Nederlandse Vereniging van Hemofilie-Patiënten (NVHP)
Norway / Foreningen for blødere i Norge (FBIN)
Poland / Polskie Stowarzyszenie Chorych na Hemofilię
Portugal / Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas (APH)
Romania / Asociația Română de Hemofilie (ARH)
Russia / Всероссийское общество гемофилии
Serbia / Udruženje hemofiličara Srbije
Slovak Republic / Slovenské hemofilické združenie
Slovenia / Društvo hemofilikov Slovenije
Spain / Federación Española de Hemofilia (FEDHEMO)
Sweden / Förbundet Blödarsjuka i Sverige
Switzerland / Schweizerische Hämophilie-Gesellschaft
Tajikistan / Republic of Tajikistan Public Organisation “Hemophiles”
Turkey / Türkiye Hemofili Derneği
Ukraine / Всеукраїнське товариство Гемофілії
United Kingdom / The Haemophilia Society

VOLUNTEERS

The work of the EHC couldn't be done without the support of our volunteers. For their commitment, time and effort, the EHC wishes to thank the following volunteers from our **Steering Committee, advisory bodies, working groups** and **other volunteers**. The EHC also wishes to thank **events' speakers** and **Members of the European Parliament** for their support of our activities. We truly couldn't achieve all of it without your help!

Rezan Abdul-Kadir, Daniel Andrei, Günter Auerswald, Angelika Batorova, Heinz Becker, Valentin Brabete, Marion Bräuer, Christina Burgess, Cristian Silviu Bușoi, Darryl Butler, Nessa Childers, Pratima Chowdary, Panagiotis Christoforou, Miranda Cole, Yannick Collé, Massimo Colombo, Brian Colvin, Lindsey Connolly, **Miguel Crato,** Roseline d'Oiron, Piet De Kleijn, Hortensia de la Corte Rodriguez, Patrick De Smet, Alison Dougall, Mariëtte Driessens, Nicola Dunn, Carmen Escuriola-Ettinghausen, Elmira Gadimova, Frédéric Gagnon-Lebrun, Paul Giangrande, Nicolas Giraud, Jack Grehan, Evelyn Grimberg, Ulla Hakkarainen, Edouard Hamelin, Peter Hanlon, Dan Hart, Steffen Hartwig, Cedric Hermans, Anneliese Hilger, James Hunt, Guillaume Janin, Vince Jenkins, Mirko Jokic, Radoslaw Kaczmarek, Jo Kroll, Frank Leebeek, Bert Leenders, Michael Makris, Maria-Elisa Mancuso, Tatjana Markovic, Evelien Mauser-Bunschoten, Giuseppe Mazza, Seamus McDonald, Miroslav Mikolasik, Danjiela Mikovic, Alec Miners, Amit Nathwani, **Jordan Nedevski,** Norica Nicolai, Beatrice Nolan, Cristina Novembrino, Niamh O'Connell, James O'Donnell, Jamie O'Hara, Jim O'Leary, **Brian O'Mahony,** Johannes Oldenburg, Rose Ozdemir, David Page, Ana Pastor, Ria Peake, Luke Pembroke, Teresa Pereira, Flora Peyvandi, Geneviève Piétu, Debra Pollard, Stefan Radovanovic, An Reniers, Sebastian Rohde, **Olivia Romero-Lux,** Frits Rosendaal, **Thomas Sannié,** Uwe Schlenkrich, Ivan Sebest, Martin Sedmina, Glenda Silvester, **Naja Skouw-Rasmussen,** Clive Smith, Luigi Solimeno, Craig Upshaw, **Michael van der Linde, Minette van der Ven,** Karin van Galen, Thierry Vanden Driessche, Caroline Voltz-Girolt, Barretstown volunteers, EHC Conference volunteers, **Alain Weill,** Jana Žitňanská

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SERVICE PROVIDERS

The work of the EHC couldn't happen without the support of our service providers:

Conference Organisers, TOAST, RPP Group, Ethical Properties, Goran Kapetanovic, Elliott Laub, Olga Miniuk and Julia Krivkina. Thank you for supporting the European bleeding disorder community.

EHC staff

The daily work of the EHC is carried out by a Brussels-based team of dedicated staff composed of Amanda Bok, Fiona Brennan, Jo Eerens, Kristine Jansone, Raia Mihaylova, Declan Noone, Saskia Pfeyffer and Laura Savini.

EHC 2018 CORPORATE GIVING PARTNERS

THE EHC WISHES TO ACKNOWLEDGE AND THANK ITS 2018 CORPORATE SPONSORS FOR MAKING ITS WORK POSSIBLE.

● PLATINUM SPONSORS:

Bayer, BioMarin, CSL Behring, Novo Nordisk, Pfizer, Roche, Shire (now Takeda), Sobi

● SILVER SPONSORS:

Alnylam/Sanofi, Biotest, Kedrion, UniQure, Spark

The EHC also wishes to thank the following companies for supporting individual 2018 activities:

BioMarin, CSL Behring and Shire (now Takeda) kindly sponsored the Youth Leadership Workshop.

Alnylam kindly supported World Haemophilia Day.

Pfizer, Roche, Shire (now Takeda) and Sobi kindly supported the Leadership Conference.

Pfizer kindly supported the Workshop on Tenders and Procurement.

BioMarin, Shire (now Takeda) and Spark kindly supported the Workshop on New Technologies in Haemophilia Care.

The Inhibitor Summit couldn't have been done without the support of Alnylam, Roche and Shire (now Takeda).

Alnylam kindly supported the EHC's website, its Youth Fellowship Programme and patients to attend the EAHAD Congress for their further education.

Roberta Smith
Living with VWD

Driven by Our Patients

CSL Behring is proud to work together with the European Haemophilia Consortium to help ensure patients' needs are met.

CSL Behring
Biotherapies for Life™


changing haemophilia®
~~limited~~ improved
treatment choice


changing haemophilia®
~~limited~~ increased
mobility


changing haemophilia®
~~limited~~ improved
access to care

Global commitment to patients through community initiatives

At Pfizer, we are proud of our heritage of innovation through collaboration and partnerships in haemophilia care. Through working with the haemophilia community and as part of our ongoing commitment to the field, we have been proud to support the following patient / physician tools and educational activities in 2019

In 2018, we launched the **Ready Rufus** board game, developed with leading educational gaming experts, healthcare professionals and patients for children 6–10 years old, with mild, moderate and severe haemophilia. We hope it helps kids, adults, friends and family learn more about haemophilia in a fun and interesting way.[*]

The **Haemoassist® 2** patient app is a smartphone app and website designed as an advanced alternative to paper-based diaries, enabling reporting and documentation of bleeds and factor infusions at the touch of a button. The Haemoassist® 2 tool supports people with haemophilia regardless of their choice of clotting factor concentrate.[†]

Haemoassist® 2

PHYSIOTHERAPY SCHOOL FOR HAEMOPHILIA

Physiotherapy School for Haemophilia is an educational programme that has been running since 2016. Through collaboration with an expert physiotherapy team, our goal has been to advance the science and understanding of the role of physiotherapy in improving outcomes for people with haemophilia.[‡]

With over 600 healthcare professionals trained over the last 6 years, the **Pfizer Ultrasound Programme** aims to support initiatives to provide education, awareness, research support and hands-on training in the use of point-of-care ultrasound in people with haemophilia around the globe.[‡]

Pfizer Ultrasound Programme
Innovation and Imaging in Haemophilia

Throughout 2019, Pfizer will continue to support the European Haemophilia Consortium (EHC) by contributing funding towards the following EHC-organised activities:[§]

- Economic workshops
- Round tables
- Leadership conferences

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[*] Ready Rufus was initiated and funded by Pfizer as part of their mission to change the world for people with haemophilia. The game was designed in collaboration with experts in gaming and healthcare, and with the patients it is intended to serve. Ready Rufus is currently only available in the UK.

[†] StatConsult is the legal manufacturer of Haemoassist® 2 and Pfizer holds sole distribution rights. Haemoassist® 2 is a CE-marked medical device in Europe, currently available in Germany and Spain, with planned additional launches in 2019. It is currently neither registered nor available in other regions. Haemoasssist® 2 is not intended for curing, treating, seeking treatment for, managing or diagnosing a specific disease or any specific health condition. Pfizer will not have access to any personal information entered into Haemoasssist® 2.

[‡] These programmes have been initiated and funded by Pfizer.

[§] These activities are initiated and organised by EHC. The content and activities described are independently developed by the society. Pfizer is not the sole commercial sponsor for EHC.

To find out more about our support service and tools, contact your local Pfizer team.

PP-HEM-GLB-0043
Date of preparation: September 2019

Roche

Being a

Community Partner

for all who are touched by haemophilia

Ensuring ***Treatment for All****, by partnering with patient organisations to help make better treatments available to all people with haemophilia A who need medication.*

Supporting the Person *with local programmes that aim to improve health and well-being of people with haemophilia A, their families and caregivers.*

Furthering the Science *by reaching beyond the status quo to deliver medical innovations that matter.*

ZINC number: NP/HEM/1907/0046 Date of preparation: July 2019

LIBERATE
LIFE

unlocking a world of possibilities for people with haemophilia

Close collaboration with the haemophilia community remains an integral part of Sobi's work, which is why we were so proud to support EHC's priorities again in 2019. There were several highlights throughout the year, all of which have contributed to the strength of our ongoing partnership.

Sobi's research revealed true unmet needs among people living with haemophilia

Ethnographic research presented by Sobi at the 2019 EHC Congress found that despite developments in approaches to treatment in recent years, people living with haemophilia (PwH) still carry burdens of the condition on a daily basis.

The study, conducted among 51 people living with haemophilia in several EU countries and 18 healthcare professionals revealed that there is still an unmet need for more flexible and personalised approaches to care to allow PwH to lead lives beyond the bleeding disorder.

The research was presented at the Sobi symposium during the 30th anniversary EHC Congress in Skopje.

"The research shows that most people with haemophilia still live a life far from normal. For people with haemophilia, a 'normal life' involves living with restrictions and regular burdens of the condition. This is a result of conservative approaches to treatment aiming to achieve basic protection rather than overcoming limitations and expanding possibilities. The study also found that some current treatment approaches may not even be sufficient to deliver basic protection," - Philip Wood, Head of Haemophilia Senior Vice President at Sobi.

Liberate Life: a new vision of living life beyond haemophilia

The ethnographic research conducted by Sobi exposed many challenges, aspirations and unmet needs related to life with haemophilia. Inspired by these insights, Sobi then launched a new vision to coincide with World Haemophilia Day 2019 called Liberate Life.

Such vision symbolises Sobi's intentions and actions and embodies our dedication to working for people living with haemophilia, enabling them to be protected from bleeds, joint damage, pain and mental burdens – helping them feel safe so they can live the life they want, with more possibilities.

"Liberate Life not only spells out our vision for the future of haemophilia care but also serves as a call to action for involvement from patients, advocates and healthcare professionals." – Guido Oelkers, Sobi President and CEO

Liberate Life is a vision made effective through partnership with everyone living with haemophilia, their family members and friends, and the professionals who care for them. By encouraging and motivating the broader haemophilia community across the globe to expect more from life and to reach for the many possibilities that advances in care have made possible, Sobi believes that we can challenge the status quo of today's haemophilia care together.

Swedish Orphan Biovitrum AB (publ) SE-112 76 Stockholm, Sweden +46(0)8 697 20 00

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sobi
rare **strength**

EHC

european haemophilia consortium