



ANNUAL REPORT 2021

ACRONYMS

ASH

American Society of Hematology

ISTH

International Society for Thrombosis and Haemostasis

PoC

Principles of Care

CEO

Chief Executive Officer

IWG

Inhibitor Working Group

PwVWD

People with von Willebrand Disease

EAHAD

European Association for
Haemophilia and Allied Disorders

MAG

Medical Advisory Group

SC

Steering Committee

EMA

European Medicines Agency

MASAG

Medical and Scientific Advisory Group

VWD

von Willebrand Disease

EHC

European Haemophilia Consortium

MEP

Member of the European Parliament

WBD

Women and Bleeding Disorders

EIN

European Inhibitor Network

MoU

Memorandum of Understanding

WHD

World Haemophilia Day

EU

European Union

NHF

National Hemophilia Foundation

WFH

World Federation of Hemophilia

NMO

National Member Organisation

INTRODUCTION

MESSAGE FROM THE PRESIDENT AND THE CEO

During the year, 2021 felt like an unending tunnel of screens filled with societal angst and unknowns, and marred by individual fatigue and burn-out. 'The great resignation' was the theme of the year as people looked for new challenges or just something different. Yet no matter the mood of the times, the EHC stayed prolific throughout.

Where for many years the EHC delivered 15 face-to-face events per annum, in 2021 we delivered 54 online. We worked hard to keep our community 'feeling' connected through virtual tools. We learned a lot about the psychology of online engagement, about pacing, and about connecting virtually in the 'right' ways for the 'right' audiences. All of this is learning we can take forward to serve our communities differently in our new future.

Yet we also worked hard because we wanted to keep many critical issues of the day (novel therapies, vaccinations, therapeutic shortages, to name a few) moving forward - and with you and the EHC staff, we did!

Collectively, we launched a systems change Think Tank. We examined new ideas for delivering differently on registries, hub-and-spoke models, and increasing patient agency. We rolled out a free educational app. We welcomed much-needed European principles for women and girls with inherited bleeding disorders, and international guidelines for the management of von Willebrand Disease (VWD).

Most importantly, the EHC strengthened the power of dialogue: dialogue internally within our own communities, reaching deeper to serve more bleeding disorder cohorts; and dialogue externally with the EMA (European Medicines Agency) on vaccinations, trials, and approaching novel therapies; with the EAHAD (European Association for Haemophilia and Allied Disorders) on the future structure of and relationship between treatment centres in a world of gene therapy (and other novel products); and with the EU (European Union) institutions on unmet paediatric health and medical needs.

2021 also saw important legislation reviews coming through. The EU legislation on blood, tissues and cells (which has historical ties to the origin of the EHC in 1989), and the paediatric and orphan medicinal product regulation (which underpins Europe's rare disease framework), both came into public consultations.

Perhaps it was indeed a tunnel year in the sense of being acutely focused. All the while we were closer to the light than we often realised. Reconnecting face-to-face in November at the New Technologies workshop, we married the forces of rekindled community with those of a changing world - and we re-emerged, ready for 2022.

"Still physically apart but mentally connected, 2021 saw us advance one step closer to our vision for future healthcare, and we couldn't have done it without the passion and commitment of our staff and volunteers."

Declan Noone, EHC President (2019-)

"2021 was a year of stark contrasts for staff and volunteers. On the one hand, possibly the toughest year of the past decade. On the other, it gave flight to innovative and inspiring work that will mark the next decade to come!"

Amanda Bok, EHC CEO

EHC



european haemophilia consortium

Advocating for people with haemophilia and congenital bleeding disorders

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

The EHC was established in 1989 with the mission to:

- Ensure adequate supply of – and access to – safe therapies;
- 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;
- Stimulate research in all fields related to haemophilia and other rare bleeding disorders.

The EHC draws on the knowledge of patients, healthcare professionals, the scientific community, European institutions, and the pharmaceutical industry to share expertise within Europe. The EHC also collaborates closely with other European patient organisations to ensure a strong collective voice for people with rare bleeding disorders.

ABOOUT

STRATEGIC OBJECTIVES

The EHC's key role consists in shaping the quality of life of all people with congenital bleeding disorders in Europe, through partnership and advocacy: in substance, in form, and into the future.

Our strategic objectives for 2021 were:

1 

ADVOCACY AND AWARENESS

To advocate and partner effectively towards improving quality of life for all people with congenital bleeding disorders in Europe.

- World Haemophilia Week
- EHC Conference
- EHC Think Tank
- New Technologies Workshop
- New Memorandum of Understanding (MoU) with the World Federation of Hemophilia (WFH)
- Principles of Care (PoC) for Women and Bleeding Disorders (WBD)

2 

EDUCATION, ENGAGEMENT AND DEVELOPMENT

To ensure state-of-the-art knowledge and relevant skills for National Member Organisation (NMO) representatives to help them achieve better treatment and comprehensive care nationally.

- Educational app EHCucate
- Novel Treatment Products Newsletter
- Youth Leadership Workshop and related activities
- Economics Workshop

3 

COMMUNITY EMPOWERMENT AND SUPPORT

To empower NMOs and support their future development.

- EHC Leadership Conference
- EHC Leadership Academy
- Community calls
- EHC Activity Grants and EHC Physical Activity Grants
- WBD workshops
- VWD platform
- Inhibitor Summit
- Happy 1/2 Hour with an Expert in Haemophilia Care
- Peer-to-Peer sessions
- #thisway campaign

4 

SUSTAINABILITY

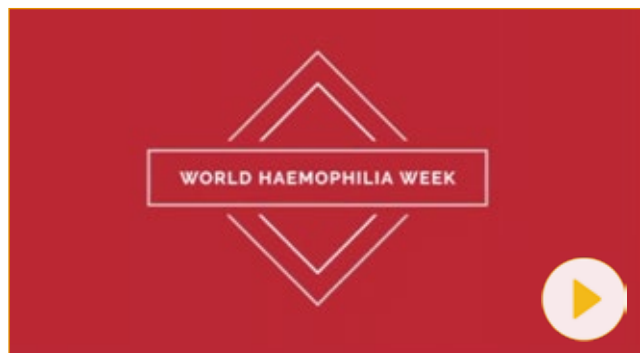
To ensure proof of EHC's organisational health and secure its future development.

- EHC Income and Expenditure
- Independent Auditor's Report
- Balance Sheet

WORLD HAEMOPHILIA WEEK 2021

ADVOCACY AND AWARENESS

In 2021, the EHC marked World Haemophilia Week (WHW) in advance of World Haemophilia Day (WHD) with consecutive discussions on topics related to the EHC community. Each of the five days had its own theme:



PREVIEW

WELCOME

A welcome message and introduction to World Haemophilia Week 2021 by Jo Eerens.



MONDAY

COMMUNITY DAY

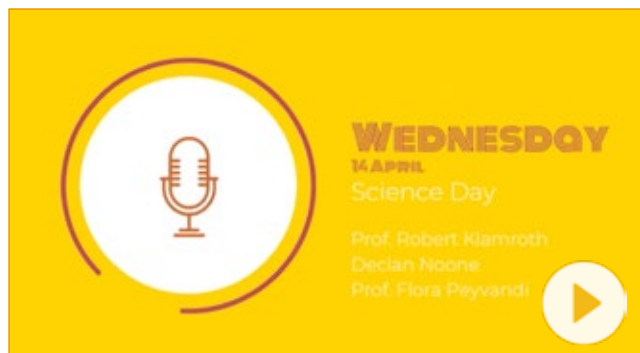
A focus on community with one particular part in the spotlight - VWD!



TUESDAY

TECHNOLOGY DAY

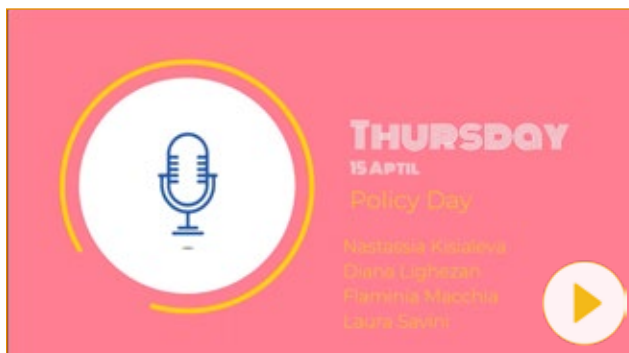
An exploration of the future of technology and access to healthcare.



WEDNESDAY

SCIENCE DAY

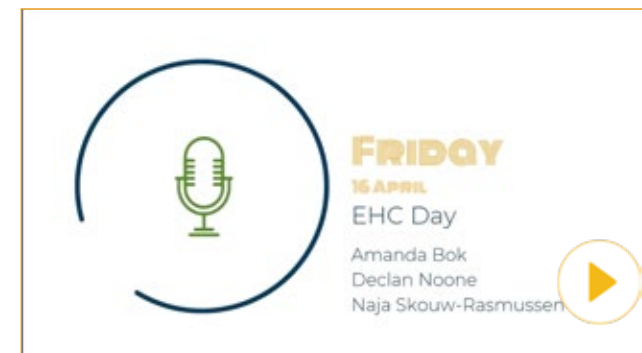
A scientific discussion on the latest from the field.



THURSDAY

POLICY DAY

A look to public policy and the EHC's organisational directions.



FRIDAY

EHC DAY

A presentation of the EHC's Think Tank and its role in advocacy.

EHC CONFERENCE

3-8 OCTOBER 2021

From 3-8 October 2021, the EHC held its second virtual conference and General Assembly. This event is traditionally an occasion for the European bleeding disorders community to meet, learn about the latest medical, scientific, and community developments, and exchange on ongoing issues in their countries.

Due to the pandemic, the EHC had to hold this event online for the second year. Nonetheless, we were able to provide our members with a diverse and engaging programme covering a range of topics such as:

- Women and Bleeding Disorders;
- Von Willebrand Disease;
- Pipeline perspectives;
- Patient choices and preferences;
- Transformation in healthcare.

Each day concluded with a virtual networking event in which participants had a chance to meet with EHC volunteers, speakers, and moderators. We wish to thank the conference sponsors for helping us continue to serve our membership despite the challenging situation.

ADVOCACY AND AWARENESS

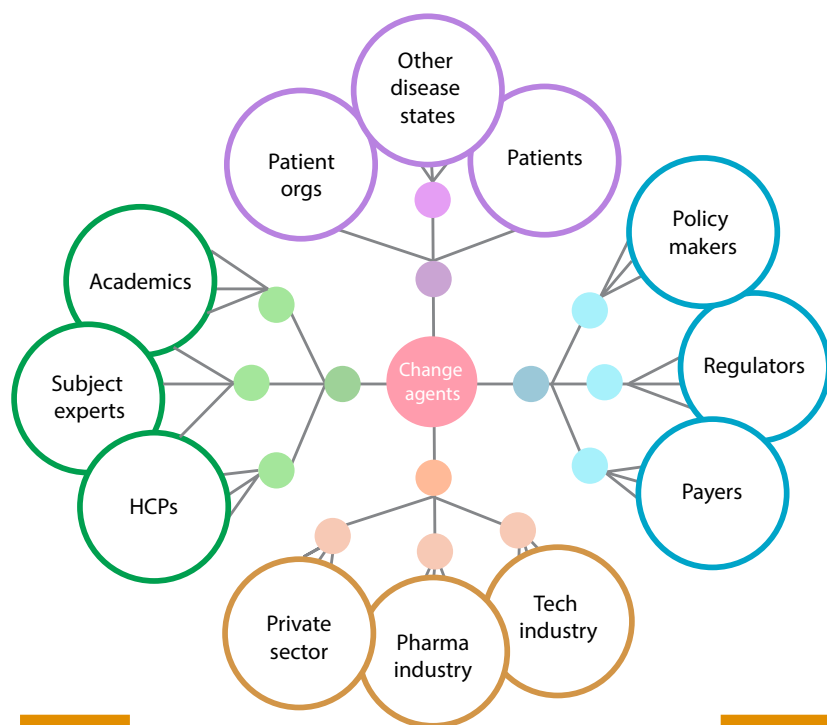


EHC CONFERENCE IN NUMBERS



EHC THINK TANK

The EHC Think Tank is a new initiative launched in June 2021. The aim is to adapt advocacy to our complex world by working from a systems change approach.



WHY

The EHC Think Tank works in parallel with EHC's long-standing traditional advocacy efforts. By targeting 'systems change', the EHC Think Tank seeks to mobilise the agency and purpose that all stakeholders in our healthcare system naturally have, to co-identify given problems from all of our and their collective perspectives, and to co-design potential solutions and trajectories of positive future change, that will then be co-championed, co-owned and co-implemented – thereby creating an 'inside-out' advocacy and multiplying its effect.

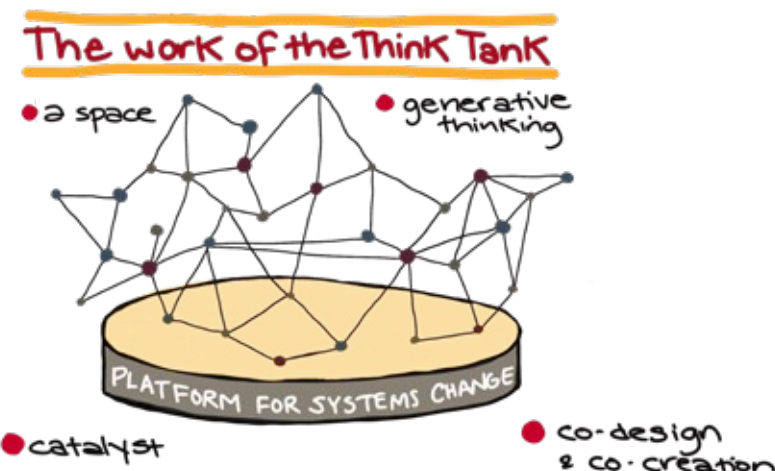
HOW

Shifting from a purely project-based to a more people-driven approach requires a cultural and mindset shift, a longer time horizon, and the right conditions. For this reason, the Think Tank employs methodologies that support genuine bottom-up co-creation and is run under strict terms of reference and codes of conduct that capture Chatham House and other compliance and engagement standards.

PUBLIC LAUNCH EVENT

The EHC Think Tank was publicly launched at a virtual event on 25 June 2021. More than 85 participants from over 25 countries, counting representatives from patient organisations, pharmaceutical industry, healthcare professionals, and external partners attended the 1,5-hour event with live music and presentations to learn more about the Think Tank and celebrate this new initiative.

ADVOCACY AND AWARENESS



Credit: la Brix Ohmann, Overlap

WORKSTREAMS

In 2020, the EHC ran a horizon scanning process resulting in the following three themes to commence its work in 2021:

- **Workstream One: Registries** - this workstream seeks to untangle the complexities of registries, find common ground, and co-construct a collectively endorsed forward direction. It focuses on challenges such as data sharing, the multiplicity of registries, ownership, and the overall purpose of registries.
- **Workstream Two: Hub & Spoke Model** - this workstream explores future treatment and care pathways, building on international calls for a hub-and-spoke model approach.
- **Workstream Three: Patient Agency** - this workstream addresses how to meaningfully embed and integrate patient expertise up-front and throughout the design, organisation, implementation, and evaluation of treatment and care as well as capturing and utilising patient preferences, for example, the unmet needs of women with bleeding disorders, remains challenging.

GOVERNANCE

The EHC Steering Committee (SC) oversees the Think Tank's work as a whole, while a designated Think Tank Council offers strategic advice, guidance, and input on its externally-facing work, particularly on the focus and composition of workstreams. Beyond clinical, academic, and patient perspectives from the bleeding disorder community, the Council includes patient and industry perspectives from non-bleeding disorder disease areas and seeks geographically balanced representation.

Members of the Think Tank Council in 2021:

- **Lara Bloom** - Patient expert / academic (United Kingdom);
- **Michael Makris** - Chair, EHC MAG and haematologist (United Kingdom);
- **Geoff McDonough** - Industry expert (United States);
- **Cees Smit** - Patient expert (The Netherlands);
- **Brian O'Mahony** - CEO, Irish Haemophilia Society (Ireland);
- **Debra Pollard** - Member, EHC MASAG and Director of Education, Haemnet (United Kingdom);
- **Thomas Sannié** - Member, EHC SC (France);
- **Yuri Zhulyov** - President, Russian Haemophilia Society (Russia);
- **Declan Noone** - President, EHC SC (Ireland).

EHC THINK TANK FACULTY

The Think Tank Faculty meets with the Think Tank leaders roughly twice a year to review new learnings and developments, and advise potential new and bespoke approaches and methodologies. Furthermore, the Faculty engages before and after relevant workstream meetings to ensure adequate preparation, learning and adaptation to the culture and methodologies of engagement, where needed.

This 'behind-the-scenes' Faculty team in 2021 consisted of:

- Behavioural scientist: Mark Lightowler;
- Systems change practitioner: Anna Birney;
- Group and visual facilitator: la Brix Ohmann.



EHC

WORKSHOP ON
NEW TECHNOLOGIES IN HAEMOPHILIA CARE
AND OTHER RARE BLEEDING DISORDERS

19 - 21 NOVEMBER 2021 | DOLCE LA HULPE HOTEL, BRUSSELS

WWW.EHC.EU

WWW.EHC.EU

WWW.EHC.EU

NEW TECHNOLOGIES WORKSHOP

19-21 NOVEMBER 2021

The 2021 EHC Workshop on New Technologies in Haemophilia and Other Rare Bleeding Disorders was the first hybrid event held by the EHC.

Over two days, 50 participants gathered in La Hulpe, near Brussels, Belgium, and another 40 joined online. The event featured lectures on replacement and non-replacement therapies and gene therapy.

This workshop is key to providing EHC members with education and information on the latest developments in novel therapies.

This workshop was also the occasion for the EHC and the EAHAD to hold a joint roundtable on the 'Hub and Spoke' model for gene therapy in haemophilia. These multi-stakeholder discussions are crucial to preparing gene therapy's smooth arrival in Europe and ensuring patients' adequate follow-up.

ADVOCACY AND AWARENESS



50
participants
on-site

40
joined
online

EUROPEAN PRINCIPLES OF CARE FOR WOMEN AND GIRLS WITH INHERITED BLEEDING DISORDERS

ADVOCACY AND AWARENESS

In 2021, the Principles of Care for women and girls with inherited bleeding disorders were officially launched at the 2021 EAHAD Congress.

These principles were developed jointly by members of the EHC WBD Committee and the EAHAD Working Group on WBD and were subsequently published in the scientific journal *Haemophilia*.

To learn more about Women and Girls with Bleeding Disorders:
www.ehc.eu/bleeding-disorders/women-with-bleeding-disorders

EAHAD European Association for Haemophilia and Allied Disorders

EUROPEAN PRINCIPLES OF CARE FOR WOMEN AND GIRLS WITH INHERITED BLEEDING DISORDERS

Women and Girls with Bleeding Disorders (WGBD) face unique challenges. In order to optimise diagnosis, care and management of WGBD, the EAHAD Women and Bleeding Disorders Working Group have developed the following Principles of Care (PoC):

- Equitable access and quality of care for all individuals with bleeding disorders, irrespective of gender
- Timely and accurate diagnosis of bleeding disorders in women and girls
- Awareness of the additional challenges faced by WGBD throughout life
- Comprehensive care of bleeding disorders requires a family centred approach which includes WGBD
- Inclusion of a dedicated obstetrician and gynaecologist in the multidisciplinary team
- Education of WGBD and their families regarding the menstrual cycle and management
- Early recognition and optimal management of heavy menstrual bleeding
- Provision of preconception counselling and access to prenatal diagnostics
- Provision of a patient centred comprehensive management plan throughout pregnancy and the post partum period
- Involvement of WGBD in registries, clinical research and innovation

THESE PRINCIPLES OF CARE SERVE AS A FRAMEWORK TO GUIDE HAEMOPHILIA TREATMENT CENTRES WITH THE AIM OF POSITIVELY IMPACTING ON THE HEALTH, WELLBEING AND QUALITY OF LIFE OF WGBD

EHC **EAHAD**

EHC-WFH MEMORANDUM OF UNDERSTANDING (MOU)

In 2021, the EHC and the WFH signed a new MoU to update how both organisations work together.

The EHC and the WFH serve the same members in Europe, and through this updated MoU, they wish to improve the welfare of people with haemophilia and other rare bleeding disorders covered by their membership.

The WFH and the EHC have worked together for over 30 years, and this updated MoU respects their independence and underlines the importance of collaboration at all levels.

Consult the MoU here: www.ehc.eu/wp-content/uploads/2021_MOU_EHC-WFH_Signed.pdf

EHCUCATE APP

An educational app that evolves with the treatment landscape

The treatment landscape of inherited bleeding disorders is evolving rapidly with advances in the half-lives and administration of clotting factor concentrates, increasingly widespread use of the first non-factor replacement therapy for haemophilia A, and gene therapies for haemophilia A and B potentially on the horizon. The EHC set out to develop an accessible patient-centred novel therapies educational resource that would evolve with the treatment landscape.

The EHC community working group prioritised the creation of a mobile phone app to leverage state-of-the-art technology in the personalisation of novel therapies for patient education. A development team of learning design experts, medical writers/editors, a medical illustrator, and an app technology group was recruited to work in tight collaboration, integrating feedback from a beta launch to the community.

In October 2021, the app was launched both for Android and iOS users. All topics were divided into three groups: basic information, non-factor replacement therapy, and gene therapy, with the first five topics being available as of December 2021.

The EHCucate app features multiple learner-driven content exploration pathways that offer foundational knowledge and progressively more advanced topics. A diversity of interactive features such as gamification elements, self-assessments, custom animations, medical illustrations, deep-dive resources, and personalised quick reference collections incentivise and enhance learner engagement.



EDUCATION ENGAGEMENT DEVELOPMENT

NOVEL TREATMENT PRODUCTS NEWSLETTER

With so much change in the therapeutic landscape in rare bleeding disorders, it is critical to ensure that EHC members are kept abreast of with all relevant scientific and clinical developments. The newsletter covers recent major developments and is divided into different types of disorders for which there is an update to report. The information provided in this newsletter is compiled from multiple sources, including presentations at recent scientific meetings, websites, financial information and by writing directly to pharmaceutical companies. It is then redrafted and presented in easy-to-understand language. The EHC issues this publication twice a year in English.

The EHC is grateful for the work and support of the New Products Working Group, which has overseen the content and production of this newsletter. The EHC also wishes to give EHC President Declan Noone special thanks for his work on these publications. The EHC greatly welcomes all treatment developments that may benefit patients in the future. The EHC takes no position on any product type or class reported in this newsletter.

Consult all the issues of the newsletter here:
www.ehc.eu/novel-treatment-products-newsletter

for Android



For iOS



INSPIRATION FROM OUR YOUTH



EHC YOUTH LEADERSHIP WORKSHOP

23-25 APRIL 2021

The EHC held its seventh edition of the Youth Leadership Workshop which is the one EHC event designed to bring together only youth participants from across our European NMOs to exchange, learn, and engage with each other for the first time at a European level.

Therefore, this important event was maintained for 2021, held virtually, and in total there were eight registrations from seven NMOs represented.

The workshop took place over three days from April 23 to April 25, 2021, focusing on a variety of themes and employing a spectrum of methodologies adapted to an online setting – these included presentation-style lectures, interactive group work, case studies, and role-plays, and also included informal activities such as icebreakers and team building activities. The EHC Youth Leadership Workshop aims to focus on the core modules of Fundamentals of Patient Organisations in the European Context, Interaction with Stakeholders, and Volunteering.

A major benefit of the EHC Youth Leadership Workshop is the ability to bring participants together with the Youth Committee and specifically the Youth Ambassadors for a process of mentorship and sharing of experiences. In the absence of a face-to-face meeting, it was planned to offer each youth participant a series of individual peer-to-peer sessions over the course of 2021. This follow-up encouraged participants to implement the information and tools shared during the workshop.

YOUTH FELLOWSHIP PROGRAMME

Despite the challenges of the COVID-19 pandemic and associated confinement, the EHC felt strongly that we needed to continue to engage with and invest in our youth and the future generations of leadership for our community and NMOs. Our Youth Fellowship Programme is intended to bring youth representatives in our community

to work together cross-nationally on common projects. We encouraged our youth to engage with each other and stay connected online when face-to-face encounters were not possible. We held several virtual calls throughout the year with the purpose of touching base, connecting, and planning for future programmes.

EDUCATION ENGAGEMENT DEVELOPMENT

YOUTH DEBATE AT THE EHC CONFERENCE

As is EHC tradition, we identified four Youth Leadership Workshop participants to take part in the much-coveted EHC Youth Debate which is held at the EHC Conference each year. The purpose of the EHC Youth Debate is to train and empower our youth to further explore areas relevant to our community. The EHC staff provides training in public speaking, argument modelling, and counter argumentation. We then pair our youth with esteemed professionals to prepare a debate. For the first time in the EHC Youth Debate history, we held an English-speaking and a Russian-speaking debate. The topic for debate in 2021 was: 'Curating my treatment plan, is Shared Decision-Making the best option?'



Listen here for an engaging and insightful conversation:

<https://bit.ly/3G3BzLm>

ECONOMICS WORKSHOP

6, 9, 14, 15 SEPTEMBER 2021


With novel therapies in the pipeline and increased pressure on health systems due to the COVID-19 pandemic, the importance of talking about economics and purchasing mechanisms for treatment has never been more critical.

In 2021, the EHC continued with its training on health economics with a series of four webinars for countries outside the EU, using Russian as the main language to deliver these webinars. The training consisted of giving an update on novel therapies, current mechanisms for pricing and reimbursement, and practical exercises on advocating for improved access to treatment in participants' home countries.

This training aims to empower our members to become better advocates and improve access to treatment in their communities.


EDUCATION
ENGAGEMENT
DEVELOPMENT

EHC virtual workshop on
Tenders and Procurement 2021



Join us during the 4 sessions on :

MONDAY, 6 SEPT
THURSDAY, 9 SEPT
TUESDAY, 14 SEPT
WEDNESDAY, 15 SEPT

 <https://www.ehc.eu/events/ehc-workshop-on-tenders-procurement/>

EHC LEADERSHIP CONFERENCE

24-26 JUNE 2021

COMMUNITY
EMPOWERMENT

The EHC Leadership Conference is an irreplaceable get-together of EHC membership in an informal setting, where different key figures of EHC NMOs, such as senior NMO leaders, young NMO leaders, and NMO staff meet to discuss issues that are important to them and jointly find better ways to work.

For the second consecutive year, the EHC organised this event in a virtual setting, on EHC Conference Platform over three days, each day consisting of 2,5-hour sessions.

The programme of the event incorporated various elements allowing for learning and exchange, such as several thematic sessions featuring expert inputs that were complemented by semi-interactive sessions of panel discussions as well as hands-on breakout sessions. Over the three days, three thematic blocks were explored: looking into the future, the psychology of online engagement, and speaking with one voice.

The first thematic block featured both an update on the latest in bleeding disorder treatment and a discussion on what the future may look like for different groups within the bleeding disorders community. It was important to have this discussion with different bleeding disorder cohorts as the treatment and care options available for each of these are radically different, thus, having an impact on their vision of the future.

The second thematic block focused on the timely discussion of the way forward in the the post-pandemic reality for the EHC and its NMOs. It featured an interactive presentation on the psychology of online engagement that outlined the effects of prolonged

exposure to online meetings as well as offered tips to improve these experiences. To illustrate how this impact is different in different contexts, three patient organisation representatives from different contexts were invited to share their experiences on patient-specific online engagement.

This was followed by a very important discussion on seeking medical advice online. Different aspects of this, such as the source credibility, reliability, relativity of personal advice, and the responsibility of NMOs towards the medical literacy of their members were raised by the two panellists.

The final thematic block of the conference programme was designed to consolidate the elements discussed so far and build them into the vision of NMOs. This work was done taking into account the discussions and information from the previous sessions, especially when it comes to the different groups of people with bleeding disorders.

An overarching element of the conference was the hands-on part at the end of each of the thematic blocks so that the participants could practically envisage their contribution to the development/resolution of the discussed issues in their NMOs.



DAY 1: LOOKING INTO THE FUTURE

EHC ^{Virtual} LEADERSHIP CONFERENCE 2021

Conclusions of the day by EHC President **Declan Noone**

The conversation was about all the new therapies that are coming - there are so many different options and new ways of thinking - there are expectations from patients on lower bleeding rates...

But the one thing that came through from the discussions is that it is not just about bleed rates, it is not just about factor expression, it is about living a life choosing to not having to think about having a bleeding disorder, choosing to be able to be mobile and not have to worry about the joints in the future, choosing to get pregnant or achieve a goal of climbing a mountain.

And that brings us to a very different place, because one thing that we have to work on as NMCs is the ability to measure - because not everything that we can measure is important, but the things that are important are very difficult to measure! We need to get this aspect into how therapies are viewed and accessed.

Another aspect that was mentioned is being heard as a patient and that there is a plan in place for the treatment of all bleeding disorders, so that the above mentioned aspects of life can happen.

DAY 2: PSYCHOLOGY OF ONLINE ENGAGEMENT

EHC ^{Virtual} LEADERSHIP CONFERENCE 2021

Conclusions of the day by EHC President **Declan Noone**

The conversation identified that some people have really struggled in the pandemic and the restrictions have been an issue for them. Some have found ways to move on and get through it, and some have maybe even liked it a little bit, because they have had time to think and to recalibrate, and approach things in a new way.

It really **makes us think about all the individual patients** within the community. Because everybody is different - there are introverts, there are extroverts, there are people who want to engage physically, and there are people who want to engage online.

Going forward we really have the **capacity to create the freedom** to engage in whatever is the best way with the tools that we have - Zoom, Remo, Gather etc. These are incredible tools that we can use quite well. I think that everybody is already working really hard - and it is working well - on engaging the patients in a way that works for them.

We also need to keep in mind the time that it takes to maintain this online engagement, and to **keep it in our budgets as well!**

We are very good at engaging online, but we are still struggling with **"hallway conversations"**, so we need to figure out how to do better in the future.

DAY 3: SPEAKING WITH ONE VOICE

EHC ^{Virtual} LEADERSHIP CONFERENCE 2021

Conclusions of the day by EHC President **Declan Noone**

This weekend was all about quotes, so here are some more:

Recently I heard a couple of conversations around the idea that "The person with a spreadsheet in the room usually wins the argument", and **that is not actually a good thing**, not a good place to be.

And then there is another quote - **"The best arguments in the world won't change a person's mind. The only thing that can do that is a good story."** (Richard Powers) - I think that is the vision we are looking for! We need to be getting that across, getting it concise, and putting it forward.

I do want to end with one more quote - **"The strength of the TEAM is each individual member. And the strength of each member is the TEAM!"** (Phil Jackson)

LEADERSHIP ACADEMY

26 AUGUST & 23 NOVEMBER 2021

24 FEBRUARY 2022

A journey toward better inclusion of people with all bleeding disorders.

In order to give our NMOs more time and space to engage with each other and exchange information, knowledge and best practices also in the virtual environment, the EHC offered to the community an add-on to the Leadership Conference in the format of Leadership Academy – three short online workshops. As one of the recurring themes in the discussion during the Leadership Conference 2021 was about the ways to include all bleeding disorders in the conversation, it was decided to dedicate the Academy sessions to the integration of all people with bleeding disorders into the work of the NMOs.

The first session, entitled ‘Departure point: changing the perspective of looking at inclusion’ took place in August 2021, and explored different ways of looking at inclusion through the Human Rights-Based Approach (HRBA) and Non-Violent Communication (NVC). The participants shared their observations about the bleeding disorder community on different levels and discussed the impact of unmet needs.

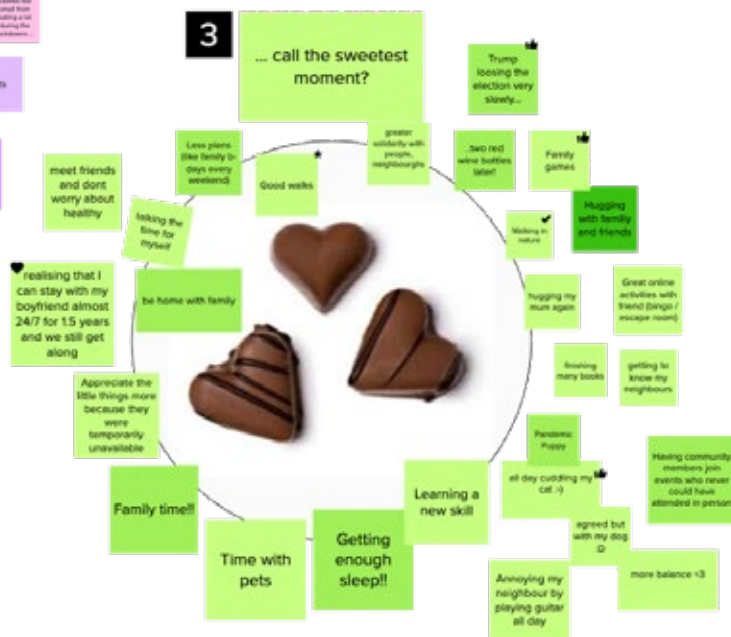
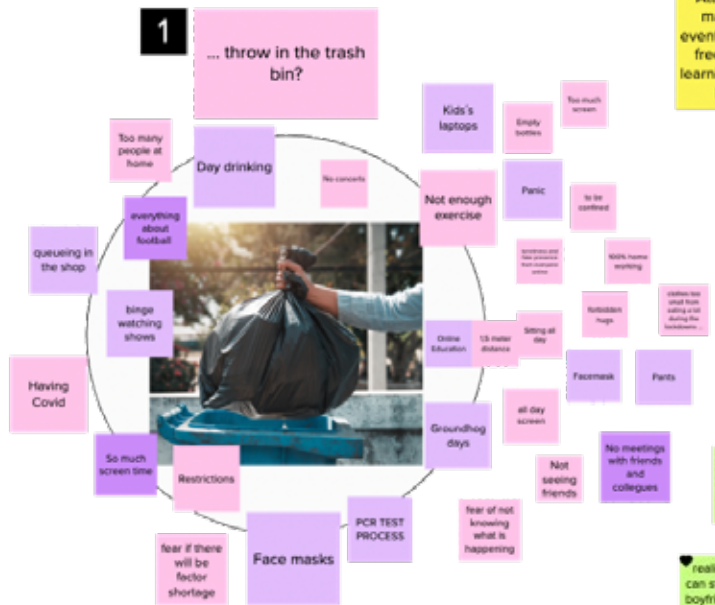
During the second session entitled ‘First stop: Who are the people in my community and outside my community,’ which took place in November 2021, the main focus was on filmed interviews with people with a variety of bleeding disorders. That unveiled the misconceptions these people have encountered with regard to their bleeding disorder as well as their most urgent unmet needs. This was a good starting point for the discussion on the needs of various groups within the community and the deeper root causes of why those needs are not met.

Finally, the last session of the EHC Leadership Academy 2021/2022 was entitled ‘Next stop: finding ways to work together towards inclusion of all people with bleeding disorders’. It took place in February 2022 and focused on different groups of needs as identified in the previous sessions, e.g., treatment, diagnosis, psychosocial support, knowledge, and information, and also sought to collect various ideas and experiences on how those needs can be met. Besides that, the time was allocated to discuss what can be the value of collaboration on the European level and within the bleeding disorders community as a whole.

COMMUNITY EMPOWERMENT



From your experiences during the pandemic what would you....?



COMMUNITY CALLS

Building on the good practice that started in 2020, the EHC continued organising Community Calls where necessary to update our NMOs on COVID-19-related questions. These calls provided space for our community to discuss the challenges our members were facing during this time.

The information collected by EHC COVID-19 tracker was fed back to the NMOs, this enabled a timely exchange of information and good practices in facing the pandemic nationally, as well as giving EHC insights of the support measures that were needed to be taken.

Relevant experts were invited to provide the latest update on the situation regarding COVID-19 and its potential implications for people with rare bleeding disorders and space was given for discussion and addressing the concerns of the community.

The EHC also kept the COVID-19 resource page up to date and together with the WFH, the National Hemophilia Foundation (NHF), and the EAHAD issued joint guidance on COVID-19 vaccination.

EHC ACTIVITY GRANTS AND EHC PHYSICAL ACTIVITY GRANTS

The EHC provides support options to our NMOs who wish to implement various activities but lack the financial resources to do so. In 2021, the EHC was delighted to continue to offer this service to our members in particular to support our community in getting together face-to-face again at the national level.

WOMEN WITH BLEEDING DISORDERS WORKSHOPS

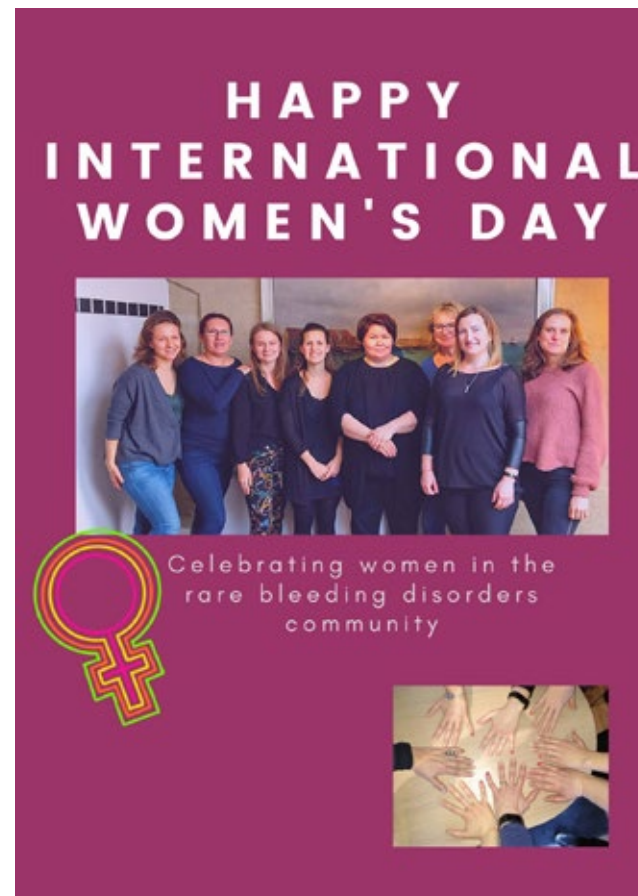
In 2021, the EHC Women and Bleeding Disorders Committee continued to provide a space for women and girls with bleeding disorders to meet, learn, and exchange through four online webinars. Following a strategic retreat in 2020, the committee set its objective to improve the quality of life for all women with bleeding disorders. This objective encompassed three areas of work: improving the general knowledge of women and bleeding disorders within the bleeding disorders community, improving access to treatment and diagnosis, and highlighting the link between infertility/fertility and bleeding disorders.

Four webinars took place in January, March, May, September, and November. They covered the following topics:

- community call to meet and present the committee's strategic objectives;
- raising awareness about issues faced by women and bleeding disorders and providing basic advocacy training;
- preparing for menarche;
- fertility and bleeding disorders;
- preparing for older age as a woman with a bleeding disorder;
- psychosocial issues;
- sexual health and intimacy;
- family planning;
- treatment protocols for women and bleeding disorders;
- underdiagnosis and inclusivity.

Each webinar featured patient and medical experts, presentations, and interactive discussions on their issues and how to address them within the NMO.

COMMUNITY EMPOWERMENT



VWD PLATFORM

The EHC von Willebrand Disease Working Group continued to focus their work on outreach and creating a European community for patients with VWD. Firstly, the VWD Working Group worked to provide feedback on the newly published American Society of Hematology (ASH) International Society for Thrombosis and Haemostasis (ISTH) NHF WFH 2021 Guidelines on the Management of von Willebrand Disease. The working group reviewed the guidelines and provided important patient perspectives. It then began work on developing patient-friendly summaries of the Guidelines to distribute to NMOs.

Along with developing tools and resources such as podcasts, information sheets, and a VWD booklet for our NMOs, the group also worked on providing the European community with a series of webinars with the aim of increasing education for patients and with the ultimate goal of improving the quality of life for all patients with VWD in Europe. The webinars covered topics such as updates on clinical treatments for VWD, behavioural economics, patient preferences, need analysis, and integration of patients with VWD into the tapestry of NMOs.

INHIBITOR SUMMIT

3-5 DECEMBER 2021

COMMUNITY EMPOWERMENT

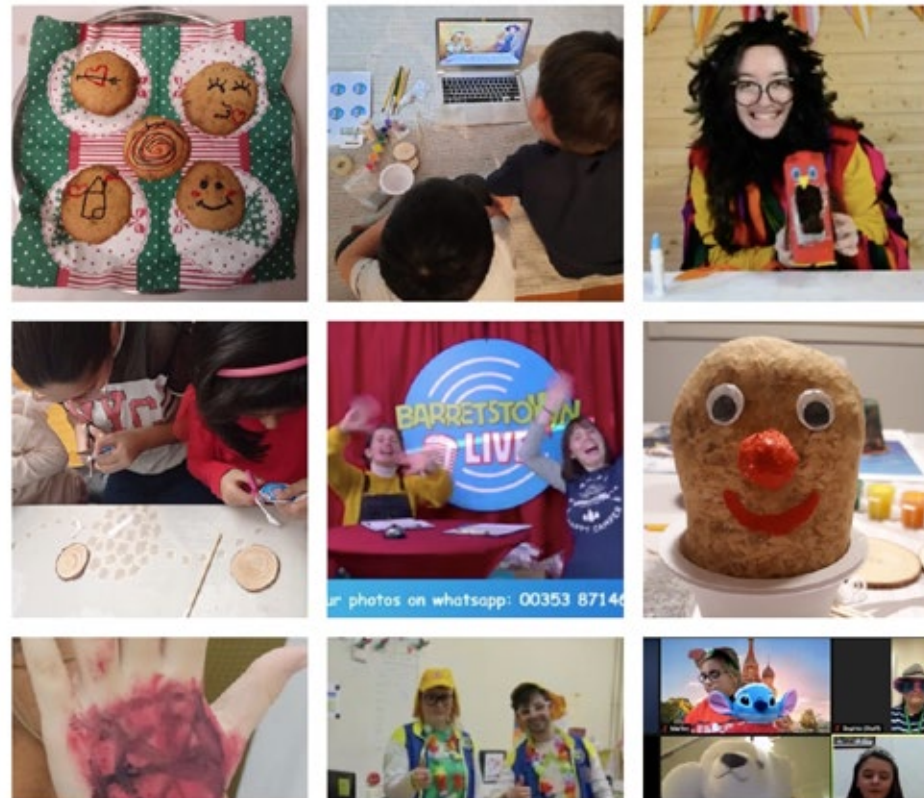
For the second year in a row, the EHC Inhibitor Summit was held online. Despite these settings, the aim and spirit of the Inhibitor Summit remained unchanged – the magic of Barretstown was in the air!

The objective of the Summit was to offer special time and space for people with haemophilia who have inhibitors as well as their family members and caregivers, to build a community, to help educate and empower themselves and to improve the quality of their lives.

In 2021, the Summit programme included various elements focusing beyond inhibitor treatment. Alongside the latest medical updates for both haemophilia A with inhibitors and haemophilia B with inhibitors, the programme also included a session on physiotherapy and shared decision-making as an important element of inhibitor care.

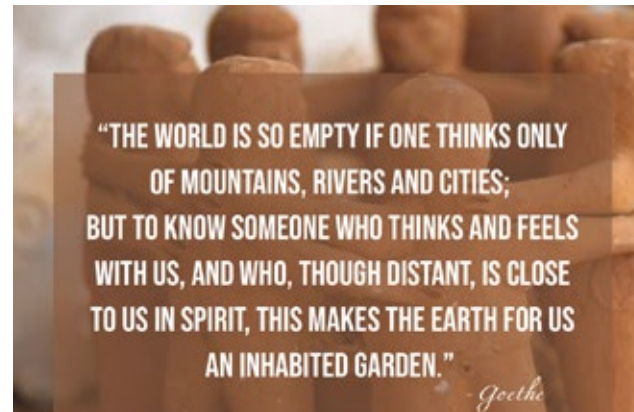
As usual, the important aspect of the Summit was the community building which was carried out through Inhibitor Ambassador networking, peer-to-peer sessions, and various Barretstown activities.

The sessions of the Summit were organised at specifically dedicated hours throughout the weekend, allowing participants to join the sessions of their choice. Every family received a package from Barretstown with all the necessary materials to take part in the various group activities.



EHC VIRTUAL INHIBITOR SUMMIT 2021

Thank you! This was great fun!



HAPPY 1/2 HOUR WITH AN EXPERT IN HAEMOPHILIA CARE

In 2021, the European Inhibitor Network (EIN) continued to organise monthly events with multidisciplinary experts in haemophilia care with seven virtual meetings held during the year. These events are a unique opportunity for the members of the inhibitor community to ask questions to experts in one of the areas of multidisciplinary care: haematology, physiotherapy, nursing care or psychosocial care – from the comfort of their home in a small group of peers. Some of the past “Happy ½ Hour with an Expert in Haemophilia Care” sessions were offered in a podcast format and are available on the EHC SoundCloud channel.



Listen here on Souncloud:

<https://soundcloud.com/european-haemophilia-consortium/sets/happy-1-2-hour-with-an-expert>

PEER-TO-PEER SESSIONS

Each year during the peer-to-peer sessions at the EHC Inhibitor Summit, when it was held face-to-face in Barretstown, it was possible to witness a magical interaction between the participants who are in similar situations. It was clear that during the pandemic, there was an even greater need for this kind of connection.

Therefore, in 2021, the EIN launched online peer-to-peer sessions for the various groups of the inhibitor community: adults with inhibitors, parents of children with inhibitors, and partners of people with inhibitors.

Each peer-to-peer group met four times during the year and the conversation was moderated by a member of the Inhibitor Working Group, who is also in the same peer category, or EHC staff where relevant. Translation into Russian was available during the sessions.

#THISWAY CAMPAIGN

After a year in confinement and exercising with the support of online guidance, the EHC decided to take its #thisway campaign back outdoors. Not only was it a great reminder of the importance of physical activity for people with bleeding disorders, but also a great way to reconnect and spend time together for the EHC team.

In 2021, #thisway consisted of a different challenge every month between WHD and the EHC Conference in October. The EHC challenged the community to cycle, walk or jog, swim outdoors, and play ping pong!

STEERING COMMITTEE

In January, the EHC staff and SC members met online. It was the first and only time that the EHC had a strategic retreat online due to the COVID-19 restrictions. Despite the new format, during this two-day online retreat, the EHC held fruitful brainstorming sessions on the Mural platform to define the values and assets of the organisation, established and reinforced its strategic planning for the coming years, and of course, had some good team-building time.

The EHC 2021 SC members were:



Declan Noone
EHC President, Irish NMO



Minette van der Ven
EHC Vice-President Finance, Dutch NMO



Miguel Crato
EHC Steering Committee Member, Portuguese NMO



Naja Skouw-Rasmussen
EHC Steering Committee Member, Danish NMO (till March 2021)



Thomas Sannié
EHC Steering Committee Member, French NMO



Manon Degenaar-Dujardin
EHC Steering Committee Member, Dutch NMO (from March 2021)



Stefan Radovanovic
EHC Steering Committee Member, Serbian NMO



Jo Eerens
EHC Steering Committee Member, Belgian NMO



Diana Lighezan
EHC Steering Committee Member, Romanian NMO



Amanda Bok
Ex-Officio Member, EHC CEO



Amanda Bok



Saskia Pfeyffer



Fiona Brennan



Daria Mironova



Nastassia Kisialeva



Naja Skouw-Rasmussen



Kristine Jansone



Laura Savini



Rumana Molla



Thierry Hoppe

EHC STAFF & ORGANISATION

In 2021, the daily work of the EHC was carried out by a team of dedicated professionals composed of Amanda Bok, Fiona Brennan, Thierry Hoppe, Kristine Jansone, Saskia Pfeyffer, and Laura Savini.

In March 2021, Naja Skouw-Rasmussen, former EHC SC Member, Danish NMO, joined the EHC team as its Think Tank Officer to lead the activities of the EHC Think Tank.

In September, Rumana Molla joined the EHC as the Executive Assistant to the EHC CEO and EHC President. She supports Amanda Bok and Declan Noone in their day-to-day activities and communications.

In December 2021, Daria Mironova also joined the team to work on Public Policy and Communications together with Laura Savini. Additionally, Daria manages the EHCucate project. She took over the responsibilities from Nastassia Kisialeva who stepped down in October 2021.



MEDICAL ADVISORY GROUP (MAG)

The EHC MAG is composed of experts who assist the EHC with high-level medical and scientific support and guidance and provide strategic input to the EHC SC and staff. The MAG is consulted on ad hoc matters and is a valued source of expertise and know-how.

In 2021, the MAG members were:

- **Michael Makris** (Chairperson) | United Kingdom
- **Flora Peyvandi** | Italy
- **Jan Blatný** | Czechia
- **Johannes Oldenburg** | Germany

MEDICAL AND SCIENTIFIC ADVISORY GROUP (MASAG)

The MASAG forms a comprehensive team of medical and scientific experts, providing the EHC with advice and guidance on specific areas of EHC activities with a multidisciplinary approach. The MASAG is a strong network of professionals ensuring strategic input into our programmes and activities, and assisting the EHC with hands-on and personalised support during specific events and activities. The MASAG is also consulted on some legislative matters to provide the EHC with reliable and relevant expertise on key areas of work.

Members of the MASAG were:

- **Rezan Abdul-Kadir** | United Kingdom
- **Massimo Colombo** | Italy
- **Piet De Kleijn** | The Netherlands
- **Roseline d'Oiron** | France
- **Alison Dougall** | Ireland
- **Carmen Escuriola-Ettinghausen** | Germany
- **Albert Farruggia** | Australia
- **Dan Hart** | United Kingdom
- **Anneliese Hilger** | Germany
- **Vince Jenkins** | United Kingdom
- **Radoslaw Kaczmarek** | USA
- **Evelien Mauser-Bunschoten** | The Netherlands
- **Giuseppe Mazza** | United Kingdom
- **Beatrice Nolan** | Ireland
- **Cristina Novembrino** | Italy
- **Jamie O'Hara** | United Kingdom
- **Brian O'Mahony** | Ireland
- **Debra Pollard** | United Kingdom
- **Frits Rosendaal** | The Netherlands
- **Glenda Silvester** | United Kingdom
- **Luigi Solimeno** | Italy
- **Thierry Vanden Driessche** | Belgium

NEW PRODUCTS WORKING GROUP

The role of the New Products Working Group is to support the production of the EHC Novel Treatment Products Newsletter which is published twice a year to provide the latest updates on novel therapies in haemophilia and other rare bleeding disorders. In 2021, the following volunteers were members of this committee:

- **Mariëtte Driessens** | Dutch NMO
- **Radoslaw Kaczmarek** | Polish NMO
- **Ilmar Kruis** | Dutch NMO
- **Declan Noone** | EHC President, Irish NMO
- **Brian O'Mahony** | EHC MASAG, Irish NMO
- **David Page** | Canadian Hemophilia Society
- **Geniève Piétu** | French NMO
- **Flora Peyvandi** | EHC MAG, Italy
- **Uwe Schlenkrich** | German NMO
- **Michael Makris** | Chair, EHC MAG, United Kingdom
- **Dan Hart** | EHC MASAG, United Kingdom

In addition to these volunteers, the EHC Novel Treatment Products Newsletter is also edited by some of the EHC MAG and MASAG members. The work of this committee is supported by Laura Savini, EHC Public Policy and Communications Officer.

INHIBITOR WORKING GROUP

The Inhibitor Working Group (IWG) coordinates the activities of EIN. This is a group of volunteers, consisting of patients, parents, healthcare professionals, and patient organisation representatives. The IWG is in charge of overseeing the EIN programme, and it collaborates closely with EHC NMOs. In 2021, the IWG regularly met online to plan, implement, and evaluate the activities carried out for the inhibitor community.

The IWG is composed of the following volunteers:

- **Enea Atroce** | Swiss NMO
- **Christina Burgess** | United Kingdom
- **Miguel Crato** | EHC SC, Portuguese NMO
- **Mirko Jokic** | Serbian NMO
- **Ioana Malita** | Romania
- **Dr Maria Elisa Mancuso** | Italy
- **Jim O'Leary** | Irish NMO
- **Teresa Pereira** | Portuguese NMO

The work of the EHC IWG is supported by Kristine Jansone, EHC Community Programmes Officer.

YOUTH COMMITTEE

The EHC Youth Committee provides strategic guidance to the EHC on its Youth Programme. The Youth Committee also develops and delivers the agendas and content of the EHC's youth training programmes and supervises EHC Youth Fellowship Programmes. In 2021, the EHC Youth Working Group was composed of:

- **Aizat Aydarbekova** | Kyrgyz NMO
- **Marija Aloa Vera Drzmanoska** | North Macedonian NMO
- **William McKeown** | UK NMO
- **Olivia Romero-Lux** | EHC Youth Expert, French NMO
- **Stefan Radovanovic** | EHC SC, Serbian NMO

The work of the EHC Youth Working Group is supported by Fiona Brennan, EHC Community Programmes Officer.

THE VON WILLEBRAND DISEASE WORKING GROUP

The VWD Working Group was set up in 2020 to lead the EHC VWD Platform for Europe. This platform promotes the formation of a European community of People with von Willebrand Disease (PwVWD) enabling them to find support and 'identity' while also promoting, building and maintaining a network of European VWD advocates. The Working Group also aims to increase and improve diagnosis and treatment options nationally and enable those VWD advocates to work at the European level and with other European partners towards improving access to treatment and care for all PwVWD.

The EHC VWD Working Group was composed of in 2021:

- **Shannon Carey** | Irish NMO
- **Manon Degenaar-Dujardin** | Dutch NMO
- **Marianna Kladi** | Greek NMO
- **Donal McCann** | Irish NMO
- **Julia Rauscher** | Austrian NMO
- **Joanne Traunter** | UK NMO
- **Baiba Ziemele** | Latvian NMO
- **Sunny Mainir** | UK NMO

The work of the VWD WG is supported by Fiona Brennan, EHC Community Programmes Officer.

WOMEN AND BLEEDING DISORDERS COMMITTEE

The EHC Women and Bleeding Disorders Committee's objective is to improve the quality of life of women and girls impacted by bleeding disorders.

In March 2021, Naja Skouw-Rasmussen (Denmark) stepped down as Chair of this Committee as she joined the EHC as Think Tank Officer. Evelyn Grimberg (The Netherlands) became the Committee's new Chair, and Marion Bräuer (Austria) joined the Committee as a new member. We were also sorry to see Ana Pastor (Portugal) step down but welcomed Karola Diósi (Hungary) who took her place.

We wish to thank the following volunteers for their work on the Women and Bleeding Disorders Committee in 2021:

- **Naja Skouw-Rasmussen (Chair)** | Danish NMO
- **Evelyn Grimberg (Chair)** | Dutch NMO
- **Marion Bräuer** | Austrian NMO
- **Yannick Collé** | French NMO
- **Karola Diósi** | Hungarian NMO
- **Diana Lighezan** | EHC SC, Romanian NMO
- **Tatjana Markovic** | Serbian NMO
- **Ana Pastor** | Portuguese NMO
- **Katja Peltoniemi** | Finnish NMO
- **Anna Tollwé** | Swedish NMO

The work of the EHC WBD Committee is supported by Laura Savini, EHC Public Policy and Communications Officer.

MEMBERSHIP

In 2021, the organisations here below were part of the EHC membership:

Albania / Shoqatës Shqiptare të Hemofilikëve

Armenia / Հնժնֆիլիայով և թրոմբոֆիլիով հիվանդների հայկական ասոցիացիայի - Armenian Association of Hemophilia and Thrombophilia

Austria / Österreichische Hämphilie Gesellschaft (ÖHG)

Azerbaijan / Hemofiliyalı Xəstələrin Respublika Assosiasiyası - Azerbaijan Hemofilia Association

Belarus / ОО Белорусская Ассоциация Больных Гемофилией

Belgium / Association de l'Hémophilie, von Willebrand et autres pathologies de la coagulation - Vereniging van hemoflie-, von Willebrand en andere stollingsstoornissen (AHVH)

Bosnia and Herzegovina / Udruženje Hemofličara Bosne i Hercegovine - Bosnia and Herzegovina Hemofilia Society

Bulgaria / Българска Асоциация по Хемофилия (БАХ) - Bulgarian Haemofilia Association

Croatia / Društvo hemofličara Hrvatske

Cyprus / Παγκύπρια Οργάνωση Αιμορροφιλικών (Π.Ο.Α.)

Czechia / Český svaz hemofiliků - Czech Hemophilia Society

Denmark / Danmarks Bløderforening

Estonia / Eesti Hemofiliaühing - Estonian Haemophilia Society

Finland / Suomen Hemofiliyhdistys (SHY)

France / Association Française des Hémophiles (AFH)

Georgia / საქართველოს ჰემოფილიისა და ღონისძიების ასოციაცია

Germany / Deutsche Hämphiligesellschaft zur Bekämpfung von Blutungskrankheiten e.V.

Greece / Σύλλογος Προστασίας Ελλήνων Αιμορροφιλικών (ΣΠΕΑ) - Greek Haemophilia Society (GHS)

Hungary / Magyar Hemofília Egyesület

Iceland / Blæðarafélag Íslands

Ireland / Irish Haemophilia Society

Israel / העלע – התומע ילוחל היליפומה - Amuta leholei haemophilia

Italy / Federazione delle Associazioni Emofilici (FedEmo)

Kyrgyz Republic / Общественное объединение больных гемофилией Кыргызской Республики

Latvia / Latvijas Hemofilijas Biedrība - Latvia Hemophilia Society

Lithuania / Lietuvos žmonių sergančių hemofilija asociacija / Lithuanian Hemophilia Association

Luxembourg / Association Luxembourgeoise des Hémophiles a.s.b.l. (ALH)

North Macedonia / Национално Здружение на Граѓани со Хемофилија и ретки коагулопатии на Р.М-Хемолог - Bleeding Disorder Society of North Macedonia - Hemolog

Malta / Malta Bleeding Disorders Society

Moldova / Ассоциация Гемофилии Молдовы - Moldovan Hemophilia Society

Montenegro / Crnogorsko društvo za hemofiliju - Montenegrin Hemophilia Society

The Netherlands / Nederlandse Vereniging van Hemoflie-Patiënten (NVHP)

Norway / Foreningen for blødere i Norge (FBIN)

Poland / Polskie Stowarzyszenie Chorych na Hemofilię - Polish Hemofilia Society

Portugal / Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas (APH)

Romania / Asociația Română de Hemofilie (ARH) - Romanian Hemofilia Association

Russia / Всероссийское общество гемофилии

Serbia / Udruženje hemofličara Srbije - Serbian Hemophilia Society

Slovakia / Slovenské hemoflické združenie (SHZ) - Slovak Hemophilia Society

Slovenia / Društvo hemofilikov Slovenije

Spain / Federación Española de Hemofilia (FEDHEMO)

Sweden / Förbundet Blödarsjuka i Sverige

Switzerland / Schweizerische Hämphilie Gesellschaft - Association Suisse des Hémophilies - Società Svizzera Emofilia

Tajikistan / Republic of Tajikistan Public Organisation “Hemophiles”

Turkey / Türkiye Hemofili Derneği

Ukraine / Всеукраїнське товариство Гемофілії

United Kingdom / The Haemophilia Society

Uzbekistan / Gemofiliya Jamiyati O'zbekiston Respublikasida

PUBLIC POLICY CORNER

Regarding its policy work, in 2021, the EHC carried out the following activities:

ON EUROPEAN HEALTH POLICY AND LEGISLATION

- Responded to European Commission targeted consultation on the legislation on blood tissues and cells.
- Participated in the TRANSFORM Alliance, a multi-stakeholders initiative considering issues on advanced therapy medicinal products (ATMP) safety and access to be addressed during the revision of the pharmaceutical legislation.

ON COVID-19

- Surveyed NMOs on the COVID-19 vaccination.
- Published a **joint paper** with the WFH recommending COVID-19 vaccination, outlining that the benefits outweighed the risks for the bleeding disorders community.

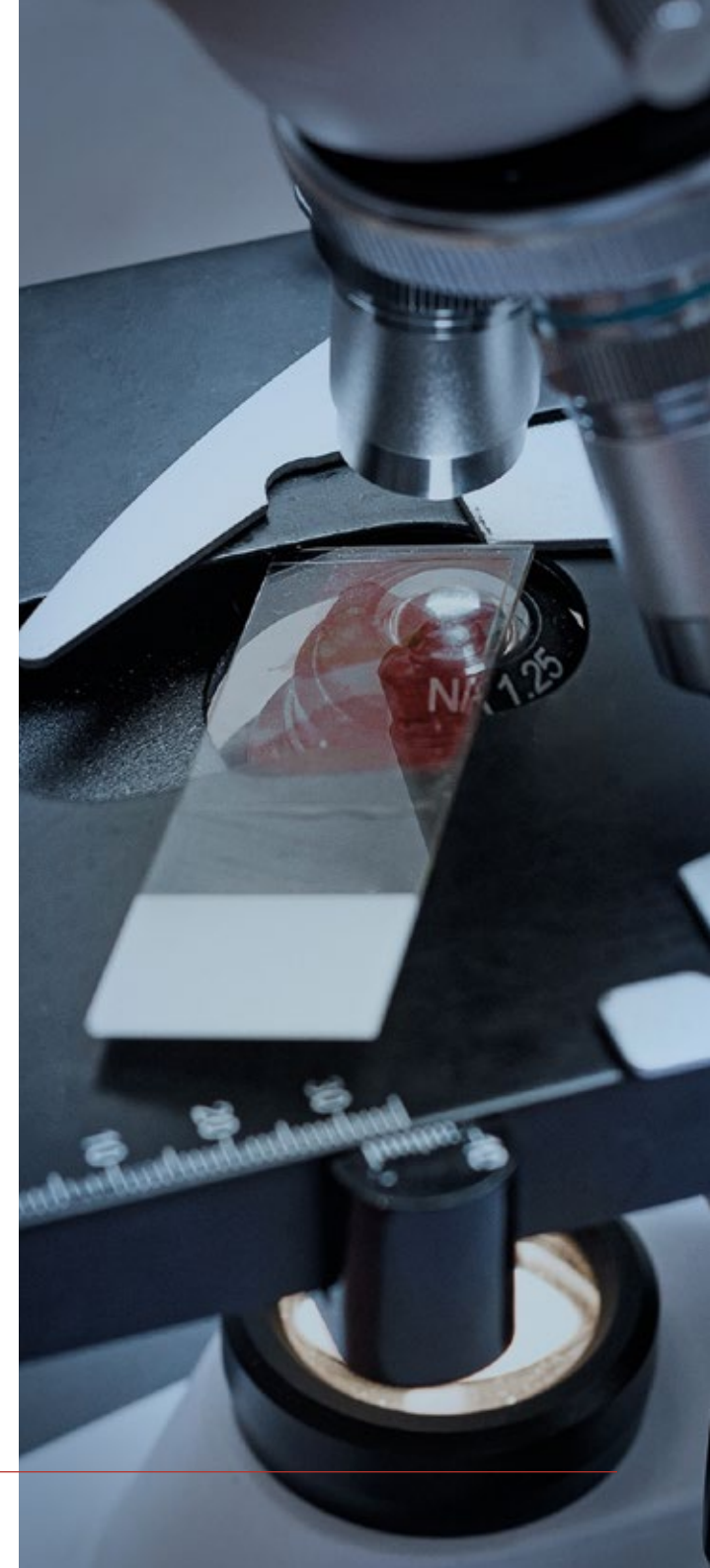
ON ADVERSE EVENTS AND MEDICINES SHORTAGES

On supply chain interruptions to five formulations of desmopressin the EHC liaised closely with manufacturers, regulators, health care providers, and the patient community, and issued numerous communications ([available here](#)).

On adverse events in novel product clinical trials, the EHC liaised closely with trial sponsors, regulators, health care providers, and the patient community, and issued public statements and numerous patient-facing communications ([available here](#)).

On product recalls regarding FIX replacement therapies, the EHC liaised closely with the manufacturer and regulators, and issued a patient-facing statement ([available here](#)).

On the future arrival of advanced medicinal treatment products (ATMPs), including gene therapies, the EHC liaised closely with regulators and other stakeholders on optimal delivery and monitoring systems.



REPRESENTATION AND PARTNERSHIPS

The EHC works closely with key European and international partners, including other patients' groups and medical associations:



World Federation of Hemophilia (WFH)

www.wfh.org



European Association for Haemophilia and Allied Disorders (EAHAD)

www.eahad.org



EURORDIS–Rare Diseases Europe

www.eurordis.org



European Patients' Forum (EPF)

www.eu-patient.eu



European Association for the Study of the Liver (EASL)

easl.eu/patient-synergies



International Society on Trombosis and Haemostasis (ISTH)

www.isth.org



Platform of Plasma Protein Users (PLUS)

plasmausers.org



European Hematology Association (EHA)

ehaweb.org



Transform Alliance
transformalliance.eu

In 2021, the EHC attended the following key events:



THANK YOU!

VOLUNTEERS

The work of the EHC would not be possible without the enormous support from our volunteers, all those mentioned above and many, many others. We are endlessly grateful to all our volunteers from the committees, advisory bodies, working groups, events' speakers, and others for their energy, time, ideas, commitment, and drive to support the work of the EHC!

Flora Peyvandi, Jan Blatný, Johannes Oldenburg, Mike Makris, Enea Atroce, Mirko Jokic, Jim O'Leary, Teresa Pereira, Mihaela Iona Malita, Maria Elisa Mancuso, Christina Burgess, Evelyn Grimberg, Yannick Collé, Anna Tollwé, Ana Pastor, Marion Bräuer, Katja Peltoniemi, Tatjana Markovic, Karola Diósi, William McKeown, Marija Aloa Vera Drmanoska, Aizat Aidarbekova, Milica Dimic, Donal McCann, Julia Rauscher, Baiba Ziemele, Joanne Traunter, Marianna Kladi, Shannon Caery, Sunny Maini, Cees Smit, Lara Bloom, Geoff McDonough, Yuri Zhulyov, Rezan Abdul-Kadir, Massimo Colombo, Piet de Kleijn, Roseline d'Oiron, Alison Dougall, Carmen Escuriola-Ettingausen, Albert Farruggia, Dan Hart, Anneliese Hilger, Vince Jenkins, Evelien Mauser-Bunschoten, Giuseppe Mazza, Beatrice Nolan, Cristina Novembrino, Jamie O'Hara, Brian O'Mahony, Debra Pollard, Frits Rosendaal, Glenda Silvester, Luigi Solimeno, Thierry Vanden Driessche, Eric Lux, Michael van der Linde, Valentin Brabete, Luke Pembroke, Mariëtte Driessens, Uwe Schlenkrich, David Page, Ilmar Kruis, Miranda Cole, Paul Giangrande, Michelle Lavin, Maria Elisa Mancusso, Karin van Galen, Milovan Kumovic, Joyce Steenbergen, Nicolas Giraud, Kate Nammacher, Marko Marinic, Gaetan Dupont, Waander van Heerden, Kate Khair, Robert Klamroth, Flaminia Macchia, Levan Makhaldiani, Paul Batty, Aldo Golja, Lotte Haverman, Radek Kaczmarek, Christoph Koenings, Frank Leebek, Wolfgang Miesbach, Glenn Pierce, Robert Sidonio, Mark Skinner, Clive Smith, Jeff Stonebraker, Renske ten Ham, Roberta Gualtierotti, Sophie Susen, Bülent Zulfikar, Lindsey George, Mark Lightowler, Cedric Hermans, Caterina Casari, David Stephensen, Nurbek Orozaliev, Timur Narbekov, Marjon Cnossen, Sebastien Lacroix-Desmazes, David Silva, Karin Fijnvandraat, Mirna van Steenbergen, Ilzat Gapparov.

SERVICE PROVIDERS

The work of the EHC would not be possible without the support of all of its service providers including:

- Advantage Point
- Alina Oleksienko
- Art of e-Learning
- Assembly Voting
- Barretstown
- Breex
- Brenda Cecilia Padilla Rodriguez
- CitrusSuite
- Conference Organisers
- EASY Noise Control
- Elliott Laub
- Fiona Robinson
- Gabi Witthaus
- Goran Kapetanovic
- Haemnet
- Heather Mason
- la Brix Ohmann
- Jeff Stanford
- Jens Steen Larsen from Larsen & Co
- Joseph Carr
- Julia Krivkina
- Matt Evans
- Olga Miniuk
- Sherpah Video Projects
- Voilà
- Volodymyr Zhyvytskyi
- Weichie
- Yaska

Thank you for supporting the European bleeding disorders community!

The EHC is also particularly grateful for the fully pro-bono services and support provided by Covington & Burling LLP, and for the support ensured by MURAL.



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INDEPENDENT AUDITOR'S REVIEW REPORT

REVIEW REPORT TO: EUROPEAN HAEMOPHILIA CONSORTIUM

Report on the Financial Statements

We have reviewed the accompanying financial statements of European Haemophilia Consortium, which comprise the statement of financial position as at 31 December 2021, and the statement of comprehensive income, statement of changes in equity and statement of cash flows, and a summary of significant accounting policies and other explanatory information. The balance sheet shows a total of € 2.917.410,41 and a profit for the year of € 579.992,99.

Managements Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with the financial-reporting framework applicable in Belgium, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. Based on our review nothing has come to our attention that causes us to believe that the accompanying financial statements do not give a true and fair view.

Auditor's Responsibility

Our responsibility is to express a conclusion on the accompanying financial statements. We conducted our review in accordance with International Standard on Review Engagements (ISRE) 2400 (Revised). ISRE 2400 (Revised) requires us to conclude whether anything has come to our attention that causes us to believe that the financial statements, taken as a whole, are not prepared in all material respects in accordance with the applicable financial reporting framework. This Standard also requires us to comply with relevant ethical requirements.

A review of financial statements in accordance with ISRE 2400 (Revised) is a limited assurance engagement. The auditor performs procedures, primarily consisting of making inquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing. Accordingly, we do not express an audit opinion on these financial statements.

Baker Tilly Belgium Bedrijfsrevisoren CVBA trading as Baker Tilly is a member of the global network of Baker Tilly International Ltd., the members of which are separate and independent legal entities.
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KBC: BE78 4483 6315 /186 / BIC: KRFDBE33



Conclusion

Based on our review, nothing has come to our attention that causes us to believe that these financial statements, in all material respects, do not give a true and fair view of the Financial position of European Haemophilia Consortium as at 31 December 2021, and its financial performance and cash flows for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

Melle, June 28, 2022

Baker Tilly Belgium Bedrijfsrevisoren CVBA
Represented by

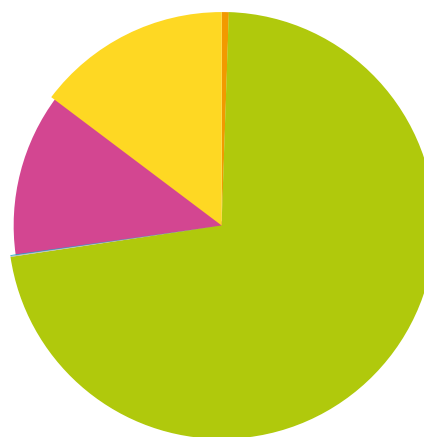
Jan Smits
Audit Partner

EUROPEAN HAEMOPHILIA CONSORTIUM
2



INCOME

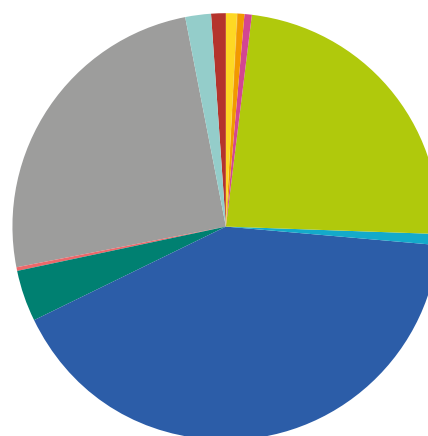
INCOME	FINALS (€)
NMO Membership Fees	11.500
Sponsorships	1.542.164
Grants	315.000
Other Sources of Support	1.841
Other Operating Income	1.137
TOTAL INCOME	1.871.642
Volunteers' contribution	267.000



- NMO Membership Fees
- Sponsorships
- Grants
- Other Sources of Support
- Other Operating Income
- Volunteers' contribution

OPERATING COSTS

EXPENDITURE	FINALS (€)
Occupancy	11.823
Travel expenses	83
Office costs	8.769
Insurances	5.448
Community services	296.019
Advisors	10.412
Sales costs	516.032
Outsourcing	48.314
General costs	1.983
Payroll costs	312.153
Other personnel costs	24.312
Other operating costs	11.815
TOTAL EXPENDITURE	1.247.163



- Occupancy
- Travel expenses
- Office costs
- Insurances
- Community services
- Advisors
- Sales costs
- Outsourcing
- General costs
- Payroll costs
- Other personnel costs
- Other operating costs

BALANCE SHEET 2021

AS AT 31 DECEMBER 2021



ASSETS	Debit	%
Buildings and land	502.503,76	17,2
Furniture and equipment	3574,77	0,1
TOTAL FIXED ASSETS	506.078,53	17,3
Amounts receivable within one year	36.559,04	1,3
- Trade receivables	11.100,00	0,4
- Other receivables	25.459,04	0,9
Current Investments	202.084,01	6,9
- Other investments	202.084,01	6,9
Cash and cash equivalents	2.108.550,75	72,3
Transitory Assests	64.138,08	2,2
TOTAL CURRENT ASSETS	2.411.331,88	82,7
TOTAL ASSETS	2.917.410,41	100,0

LIABILITIES	Credit	%
Equity	2.833.194,70	97,1
Amounts payable within one year	54.555,86	1,9
- Trade payables	14.783,74	0,5
- Taxes, remuneration and social security	39.772,12	1,4
TOTAL DEBTS	84.215,71	2,9
Transitory Liabilities	29.659,85	1,0
TOTAL LIABILITIES	2.917.410,41	100,00

EHC 2021

CORPORATE GIVING PARTNERS

The EHC wishes to acknowledge and thank its 2021 corporate giving partners for making its work possible.

PLATINUM SPONSORS:

Bayer | BioMarin | Roche | Sanofi | Sobi | Takeda

GOLD SPONSORS:

Novo Nordisk | Spark

SILVER SPONSORS:

Biotest | LFB | Sigilon

The EHC also wishes to thank the following companies for supporting individual 2021 activities and projects:

Sanofi and Sobi kindly sponsored the Youth Leadership Workshop, while Sobi also supported the Youth Fellowship Programme.

Virtual World Haemophilia Week was made possible thanks to the support of Sanofi and Sobi.

The Leadership Conference was kindly sponsored by BioMarin, Sanofi and Sobi, meanwhile, CSL Behring, Novo Nordisk, Takeda, and Vifor contributed to the success of the webinar series for Women and Bleeding Disorders.

The VWD Platform received support from Takeda.

Support from BioMarin, Pfizer, Roche, Spark, and Takeda made the EHCucate educational app project come to fruition.

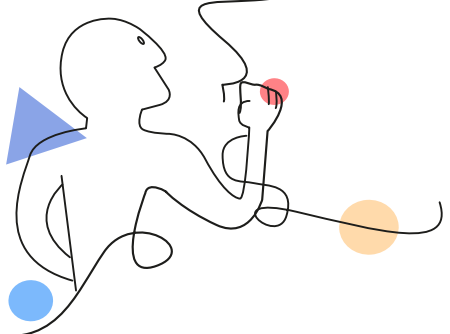
Roche, Sanofi, and Sobi kindly sponsored the EHC virtual Economics Workshop, while Sanofi and Sobi also enabled the online Workshop on New Technologies in Haemophilia Care to happen.

The European Inhibitor Network, including the Inhibitor Summit, couldn't have been carried out without the support of Roche and Sanofi.

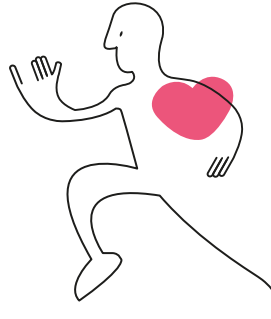
The Think Tank activities were made possible by hands-off grants from Bayer, BioMarin, CSL Behring, Novo Nordisk, Roche, Sanofi, Sobi, and Takeda.

Finally, the EHC 2021 Conference received support from CSL Behring, Roche, Sanofi, Sobi, and Takeda as Platinum sponsors; BioMarin, Novo Nordisk, and Pfizer as Gold Sponsors; and Bayer, Kedrion, Spark, and UniQure as Silver Sponsors.

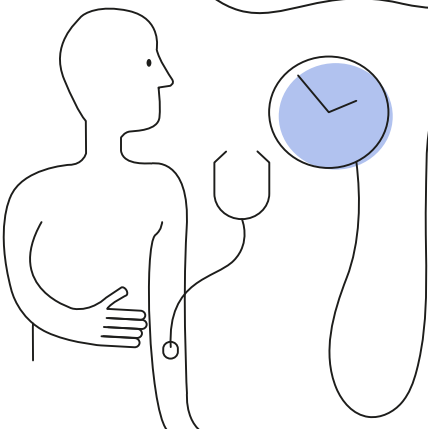
Defining the severity of haemophilia A



The severity of haemophilia A is not always reflective of bleeding behaviour. All severities of haemophilia A can **significantly reduce the quality of life** for people affected, as well as their family and caregivers.¹



While the treatment and management of severe haemophilia A are well-established, there is **less information** and treatment guidance on **moderate and mild haemophilia A**. Due to the **more ambiguous symptoms**, these patients are often not included in clinical trials or other disease burden or quality of life studies.²



Considering this population may not use preventative treatments, they may experience **worsened clinical burden**, with less than **30% of people with moderate or mild haemophilia A living a bleed-free life**.^{2,3}

References

1. Flood E, et al. Illustrating the impact of mild/moderate and severe haemophilia on health-related quality of life. *EJH* 2014; 93: Suppl. 75, 9–18.
2. Walsh C et al. Identified unmet needs and proposed solutions in mild-to-moderate haemophilia. *Haemophilia*. 2021 February 01; 27(S1):25-32.
3. Nissen F, et al. An Insight into clinical outcomes in mild, moderate, and severe hemophilia A (HA):CHESS II study. *2020 Congress*, 12-14 July, 2020; Abstract OC 09.3.

LIBERATE
LIFE

Living life beyond haemophilia

Explore what liberation
means for you

At Sobi, we strive to empower every person with haemophilia to live the life they want.

Liberation Map is a tool created together with the haemophilia community that may help people with haemophilia to pursue what matters most to them.

Liberation Map helps people identify possible health and life goals, share them with their care team and discuss how to achieve them.



You can access the **Liberation Map** in the below countries by clicking on the relevant flag:



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Date of preparation: April 2022. NP-21487



Scan here for further information
about the Liberation Map

Keep track of your factor levels with myWAPPS

The mobile phone app that is helping people with hemophilia to **Aim Higher**

- With myWAPPS you can monitor your PK profile and check your estimated factor level at any time
- You can use this data to tailor your treatment to your needs, in collaboration with your physician
- Ensuring your factor levels are right for you and your lifestyle.

Learn more on www.aimhigherforlife.com



Aim Higher with myWAPPS.
Speak to your doctor and
visit mywapps.org





Better Health, Brighter Future

At Takeda we believe every bleed matters, and that all men and women with a rare bleeding disorder, wherever they live, should have access to comprehensive, personalized care. We are committed to raising the voices of people living with rare bleeding disorders to ensure their meaningful involvement in decision making.



EHC Think Tank



Patient education
app EHCucate



Symposium
during EHC 2021



VWD platform

Takeda is proud to support the European Haemophilia Consortium (EHC) and was privileged to continue supporting the rare bleeding disorders community throughout the COVID-19 pandemic in 2021 through the above initiatives.

Takeda is committed to raising expectations for the future for persons living with rare bleeding disorders by championing early diagnoses, effective bleed protection and personalized care, and we look forward to continuing to support the work of the EHC throughout 2022.

Learn differently.
Engage differently.
HaemDifferently.

Visit HaemDifferently.eu
to learn about the science
behind ongoing research
in **gene therapy**

B:OMARIN[®]

Let's  **Haem**differently

HaemDifferently is built to be a website that provides accurate information in a way that helps you understand the science behind ongoing research in gene therapy. So whether you're a person with haemophilia, a caregiver, or a healthcare provider looking to help educate the bleeding disorder community—HaemDifferently is here to keep you in the know.

Clinical trials are being conducted in gene therapy for a range of genetic disorders including haemophilia.



•
We never
settle
•

We are an innovative global healthcare company, driven by one purpose: we chase the miracles of science to improve people's lives.

We are dedicated to transforming the practice of medicine by working to turn the impossible into the possible. We provide potentially life-changing treatment options and life-saving vaccine protection to millions of people globally, while putting sustainability and social responsibility at the center of our ambitions.

sanofi

Leandro Kuster
Leandro has haemophilia A

we care

Our Changing Haemophilia community provides vital help and support to everyone living with or caring for a loved one with a bleeding disorder.

Discover useful tools, tips, and information about everything from joint health, exercise, and mental health to relationships, travel, and where to find support groups.

Learn more at changinghaemophilia.com

Creating a path for education about the science of gene therapy research in haemophilia



You are invited to explore and advance your knowledge at your own pace. Visit HaemophiliaForward.com

For residents of Europe only.



Available in four languages:



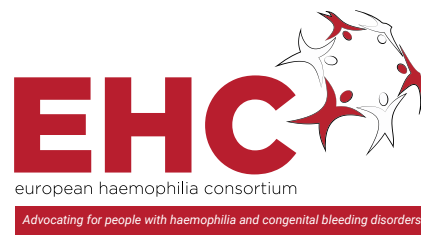
Be informed. Feel empowered.



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