



# EHC ANNUAL REPORT 2019



**EHC**  
30th anniversary

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

## VWD

von Willebrand Disease

## WBD

Women and Bleeding Disorders





## ABOUT 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.

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.

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.

## Strategic Objectives

In 2019 EHC worked towards specific strategic objectives:



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



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



Empower NMOs and support their future development.



Ensure EHC's organisational health and secure its future development.





**“Our vision is clear, and our European community has never been stronger, more united and more empowered to face the important yet exciting challenges ahead.”**

**Amanda Bok, EHC CEO**



**“2019 was a year of continued growth, innovation and increased influence for the EHC. I completed my second and final term as President. I am proud of this great organisation and community and confident about their future strength, direction and leadership.”**

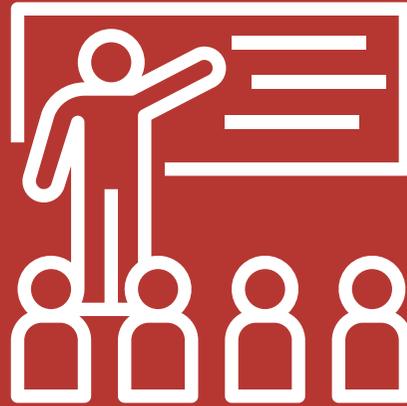
**Brian O'Mahony, former EHC President (2011-2019)**



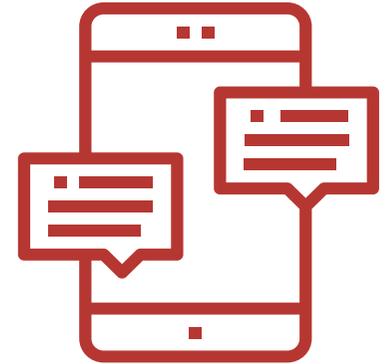
**“I am honoured to have been elected EHC President, and to have run along such competent fellow patient advocates. I look forward to building on the EHC's strong foundations and working for all the bleeding disorders our community represents.”**

**Declan Noone  
EHC President (2019-)**

**p6** EHC held 15 international events – conferences, workshops, round tables and other – with close to 1200 participants attending in total. It was energetic, inspiring and productive!



**p11** EHC ran a successful social media strategy reaching 1291 followers on Twitter, almost doubling the followers from the previous year, 2348 page likes on Facebook and more than 400 connections on LinkedIn.



**p12** EHC is grateful for the amazing efforts of its volunteers – more than 60 volunteers dedicated 6438 hours this year to the EHC. That's more than 3.5 years of one person's full-time work!



**p16** The already-large EHC family grew by an additional member – welcome Uzbekistan!



**p17** In 2019, the EHC team continued to grow and diversify to better serve our community.



**p17** EHC released numerous publications, films and videos.



**p22** EHC continued to strive for financial stability and transparency.



**p25**  
EHC continued to work with a number of great professionals!



**p20** The EHC was represented at events and meetings of other major bleeding disorder and rare disease organisations by members of its Steering Committee and staff.



# 2019

## IN BRIEF

**p21** EHC ran several programmes to support and empower its NMOs and volunteers – Activity Grant and Physical Activity Grant programmes, as well as its Youth Fellowship programme.



**p25** The EHC is grateful for the support of its Corporate Giving Partners and other sponsors that enabled its 2019 work.



**FOLLOW THE PAGE NUMBERS TO READ MORE ABOUT THE THINGS THAT INTEREST YOU!**



# 2019

## 25-27 JANUARY

### EHC Youth Leadership Workshop Alumni Event

📍 Amsterdam, The Netherlands

“It was very relevant and inspiring. I’ve heard lots of new ideas what we could achieve in our NMO. The whole weekend encouraged me to do more and be more active. Getting together different generations of youth leadership alumni was great and beneficial for me!

**Anonymous workshop participant**”

Following a survey and needs assessment of our youth leadership workshop alumni in 2018, in January 2019, we invited them together again for a follow-on workshop focusing on advocacy, with practical and pragmatic exercises, which complemented and expanded on the five-year history of the EHC’s Youth Leadership Workshop. Twenty-six participants registered for the event, which was led by EHC advocates and staff.

The intensive three-day workshop was a ‘hands-on’ opportunity to gain more knowledge as well as an opportunity to further network and strengthen our young community’s ties to each other.

## 20 FEBRUARY

### Round Table of Stakeholders on the Future of Comprehensive Care and Outcomes

📍 Brussels, Belgium

“The true value of the EU is demonstrable in rare diseases.”

**Gesine Meissner, German MEP**”

Two main themes came out from the expert discussions around the table. Firstly, a transition to novel therapies, such as non-replacement therapies and gene therapy, will require a whole new set of outcome measures. Secondly, while it may seem that there are viable alternatives, the long-term effects of circumventing or reducing Comprehensive Care Centres would lead to increased costs and negative outcomes.

The Round Table was hosted at the European Parliament by Honourable MEPs Gesine Meissner (Germany) and Norica Nicolai (Romania).

## 5-7 APRIL

### Youth Leadership Workshop

📍 Amsterdam, The Netherlands

“I think this workshop is also very good for NMOs not only youth. Thank you for calling us youth of the future and investing in us. Please keep doing and telling us about the importance of youth involvement. It may not always be seen by NMOs.”

**Anonymous workshop participant**

The EHC held its 6<sup>th</sup> Youth Leadership Workshop in Amsterdam from 5-7 April 2019, to which we welcomed 15 participants from Albania, Austria, Bulgaria, Croatia, France, Kyrgyz Republic, North Macedonia, Romania, Serbia and the United Kingdom (including Northern Ireland), all aged under 30, who have made the decision to be patient advocates and continue their lifelong process of developing and fine-tuning advocacy skills. The future leaders of our community gathered to gain tools and information to encourage greater participation in their NMOs and their community. Using a combination of short lectures and extensive interactive techniques, including ice-breakers, case studies and role-plays, the programme covered volunteering, communicating and collaborating internally and externally, and offered an overview of medicines development and the role of industry.



“ This is the place I have to be. ”  
 Karola Diosi, Hungary

2019

## 16 APRIL

### World Haemophilia Day event

📍 Dublin, Ireland

“ Joint bleeds still happen! We need to ensure that novel treatments will prevent all bleeds and protect joints for a life-time for all patients. This will be real progress! ”  
 Thomas Sannié, EHC Steering Committee

On 16 April 2019 members of the EHC community gathered to honour not only World Haemophilia Day, but also to officially mark the beginning of the EHC's 30<sup>th</sup> anniversary year.

The programme of the event included presentations from healthcare professionals, as well as insights and reflections from patient representatives on different aspects of past and desirable outcomes for haemophilia treatment and care, including the role of patients and patient organisations.

## 24-26 MAY

### 1<sup>st</sup> European Conference on Women and Bleeding Disorders

📍 Frankfurt, Germany

It was an idea that was long overdue: a conference, a space where women with bleeding disorders could discuss and share information. Abounding with misconceptions, general disregard and a lack of information, women with bleeding disorders have been sadly ignored and underrepresented in our communities. The 1<sup>st</sup> European Women and Bleeding Disorders (WBD) Conference was an unqualified success. With over 30 countries represented, including the United States and Canada, as well as partner organisations such as the World Federation of Hemophilia (WFH) and the National Hemophilia Foundation (NHF), the event went far beyond European borders. Recurring themes of the 1<sup>st</sup> European Women and Bleeding Disorders Conference included: lack of diagnosis or under-diagnosis, lack of information generally, and the need for much more efforts from all bleeding disorder organisations, treatment centres and NMOs to ensure awareness, education and appropriate advocacy tools. If there was a primary takeaway from the Conference, it was the establishment of an anthem for women with bleeding disorders: *'you are not alone.'* The sense of *'finally being heard and listened to'* was immeasurable: stronger, together. The future started to look a little bit brighter after this Conference and the EHC is committed to keeping it that way.

## 11 JUNE

### Round Table of Stakeholders on Pain Management in Haemophilia

📍 Brussels, Belgium

“ It is great that somebody speaks of pain! In a lot of countries everybody speaks about the level of treatment and nobody speaks about pain, but pain is central. Why? Because if you are a parent of a kid who has pain, it is the most important thing in your life because: Your – Kid – Has – Pain. This is the problem. The session was great! ”  
 Tatiana Markovic, Serbia

The Round Table on Pain Management in Haemophilia took place in the Renaissance Hotel in Brussels, Belgium, and brought together over 40 participants representing patient, clinicians, academia and industry.

The event clarified that pain is a complex physical process as well as a clinical issue, which demands proper and individualised management to achieve satisfactory treatment for the patient. Participants asked for concrete European policies to make improved pain management accessible for all people with bleeding disorders in Europe.



21-23 JUNE

### EHC Leadership Conference

📍 Brussels, Belgium



6-8 SEPTEMBER

### Workshop on Tenders and Procurement

📍 Istanbul, Turkey



2019

3 OCTOBER

### European Inhibitor Network Pre-Conference Workshop

📍 Skopje, North Macedonia

“The dynamic here is different. EHC holds many events to encourage young people to come through, but here the young people and established leaders get to see each other in action, in a dynamic and fluid situation, where they are ‘workshopping’, solving problems and real issues. It is an opportunity perhaps for the established leaders to see their own young leaders in a different light.”

**Brian O’Mahony, Ireland**

The purpose of the Leadership Conference is to bring together the full EHC community through different generations and types of key NMO leaders to exchange and engage on shared issues and challenges. Alongside EHC updates, the programme of the 2019 Leadership Conference included medical sessions on von Willebrand Disease, as well as insights into novel treatments and discussions on ensuring patient access. Most importantly, it included ample exchange between the EHC NMOs, their good practices in a variety of fields and their joint challenges. The highlight of the Conference was the interactive session ‘Building a Synergy Machine,’ dedicated to NMOs internal workings.

“Very relevant workshop, encourages to do tenders for rare bleeding disorders!”

**Anonymous workshop participant**

The EHC workshop on Tenders and Procurement was attended by 30 participants, speakers and moderators. Participants gathered from Albania, Bosnia and Herzegovina, Belgium, Bulgaria, Switzerland, Cyprus, Estonia, France, Greece, Croatia, Hungary, Ireland, Latvia, the Netherlands, North Macedonia, Poland, Romania and Serbia. The programme consisted of interactive sessions including case studies and role-plays, which helped participants understand the complex economic concepts involved in ensuring access to treatment for people with bleeding disorders throughout Europe.

“Thank you for all your hard work! It inspires me to do something more in my own National Member Organisation!”

**Anonymous workshop participant**

The aim of the EIN Pre-Conference Workshop is to bring together people with inhibitors (PWI) and the leadership of the EHC National Member Organisations (NMOs) to jointly address and tackle obstacles that may impede the participation of PWI in the life of NMOs. The programme of the workshop also included information on novel treatments already available for PWI, as well as the options in the pipeline. Special attention was paid to haemophilia B and inhibitors, a topic that is often left undiscussed. The practical part of the programme was dedicated to working with haemophilia centres and including PWI in the NMO’s strategic planning. The Pre-Conference workshop took place prior to the EHC Conference and brought together more than 40 participants.



## 3 OCTOBER

### Youth Leadership Pre-Conference Workshop

📍 Skopje, North Macedonia

“I understood the presentations on medicines and procurement in a different way this time - really helpful and so important for us to know.”  
Anonymous workshop participant

The EHC held a Youth Leaders' Pre-Conference Workshop on October 3<sup>rd</sup> as part of a Youth Fellowship Project (YFP). The project aims to reach out to selected established youth, recruited from the Youth Leadership Alumni, who are interested in stepping into leadership roles in their NMOs. A total of ten volunteers from nine countries were nominated and invited to attend the training, which aimed at improving their collaboration and involvement in the decision-making process of their organisations.

The workshop focused on access to new therapies, strategic planning and governance. The selected youth continued their engagement with this YFP project through online webinars in 2019 & 2020.



“It removed some concerns I have had about treating these patients, it corrected some myths and gave me confidence, which will help those I treat”  
Anonymous workshop participant

## 4 OCTOBER

### Dental Workshop

📍 Skopje North Macedonia

#### Oral Hygiene Booth during the EHC Conference 2019

In October 2019 the EHC held its first Dental Workshop & Oral Hygiene Booth during the EHC Conference in Skopje, North Macedonia. The purpose of the workshop was to train, educate, and empower dentists and give them confidence to treat all patients with rare bleeding disorders. Meanwhile, the booth focused on better educating patients, families and caregivers on safe oral hygiene. The workshop took place on Friday 4 October 2019, bringing together over 30 professionals from the dental community, from nine countries in the Balkan region.

The Oral Hygiene Booth was visited by EHC Conference participants who sought advice and received education in relation to the management of their oral health. Following the workshop, a private forum and network was established for dentists to share educational material and to seek support and advice from their peers. The EHC is exceptionally proud of the impact this initiative has had so far on patients' health and wellbeing, and will continue to work in this area.



## 4-6 OCTOBER

### EHC Conference

📍 Skopje, North Macedonia

“Despite one of the main airline carriers servicing Skopje going bankrupt a few days before the start of the event, the EHC 2019 conference saw a record number of attendance. This is a testament to the dedication of our community towards our work.”  
Amanda Bok, EHC CEO

The EHC Conference 2019 and the three Pre-Conference Workshops brought together more than 400 participants. The programme was jam-packed with the medical sessions, focusing on novel therapies not only for haemophilia, but also other bleeding disorders and various considerations around those. In addition to the scientific programme, discussions were held around the safety, quality of life, as well as health economics questions. Also, the work of the EHC in various areas was showcased during the conference sessions and sponsored symposia. This conference edition couldn't have missed yet again another youth debate, which is by now a well-established tradition of any EHC Conference. As with every conference, participants could access the exhibition area featuring a variety of stands including those from corporate partners, NMOs bidding to host future conferences, EHC - showcasing the work from its numerous committees and other partner organisations.



“ Love it here! Magic in the air!  
Anonymous participant ”



2019

## 22-24 NOVEMBER

### Workshop on New Technologies in Haemophilia Care

📍 Athens, Greece

The EHC workshop on New Technologies in Haemophilia Care was attended by 70 participants, speakers and moderators from Albania, Bulgaria, Croatia, Czechia, Denmark, Estonia, Finland, France, Greece, Hungary, Ireland, Israel, Latvia, Lithuania, the Netherlands, North Macedonia, Poland, Portugal, Romania, Serbia, Slovakia, the United Kingdom and, exceptionally, the United States. The programme consisted of sessions on licensed therapies, clinical trials and gene therapies.

The setting and programming of the workshop allow for honest and frank discussions about novel therapies in haemophilia. Participants benefit from direct access to key healthcare professionals and clinicians and can also share national experiences.

## 28 NOVEMBER- 1 DECEMBER

### Inhibitor Summit

📍 Barretstown, Ireland

The purpose of the Summit is to offer a special time and space for people with haemophilia who have inhibitors, as well as their family members and caregivers, to build a community, educate and empower themselves to improve the quality of their lives. It is traditionally held in the venue of Barretstown – a facility founded by the American actor Paul Newman as a place designed for children living with a serious illness and their families. It offers 24-hour on-site medical and nursing care and complete disability access throughout its property. Even more importantly, it offers tailored activities that all children and adults with a serious illness/disability can participate in, and excellent and experienced support staff onsite.

This year, participation again reached the full capacity (150 people) of the Barretstown facilities, with 60% of attendees being first-timers to the Summit – an excellent recruitment achievement by the EHC’s NMO Inhibitor Ambassadors – thus further expanding the European inhibitor community. This also demonstrated that the need for continued support at the European level for people with inhibitors. 2019 also saw much higher attendance by siblings, partners and caregivers, revealing these groups’ equally-important needs and hunger for meaningful support.

## 3 DECEMBER

### Round Table of Stakeholders on Markets and Access

📍 Brussels, Belgium

The Round Table of Stakeholders on the topic of ‘Markets and Access: Bridging the Gap between People and Innovative Treatments’ took place at the European Parliament in Brussels, Belgium, and brought together over 40 participants representing patients, clinicians, industry, academia and policy-makers.

The Round Table discussions highlighted the difficulties in access to current therapies and concerns regarding access to novel therapies in the future. The event raised more questions than it provided answers and showed the need for continued discussion and exchange in this area. Take aways included the need to move beyond Annual Bleeding Rates (ABR), use data collection systems able to capture real-world evidence, move away from the notion of ‘convenience’ when describing lower infusion rates or subcutaneous administrations, increase personalisation of treatment and address budget impacts. The event was hosted by Honourable MEP Kateřina Konečná (Czechia).

## #THISWAY

To give visibility to the EHC Physical Activity Grant programme among the NMOs, we linked it to our social media and movement campaign #thisway that is designed to promote the importance of physical activity for people with bleeding disorders. Unlike in the 1970s when physical activity was not recommended for people with bleeding disorders, nowadays physical activity is seen as an essential part of wellbeing for people with haemophilia and other bleeding disorders, and is being actively promoted for its benefits in terms of joint health, coordination, general fitness, body weight and self-esteem.

During the #thisway campaign the EHC keeps track of the kilometres covered by any physical activity and anyone in the community - in 2019 the EHC #thisway campaign tallied a total of 10,596.4 KM!!!!

**10,596km**  
Tallied over the course  
of the EHC #thisway  
2019 campaign



## EHC NOW!

As part of its social media strategy, the EHC maintains a weekly news highlight – EHC Now! – with an aim to offer a more profound insight into various themes related to bleeding disorders and multidisciplinary care, as well as to deliver relevant breaking news and feature the work of NMOs.



## WWW

In addition to its upgraded social media activity, the EHC also updated and modernised its websites in 2019 including [www.ehc.eu](http://www.ehc.eu) and [www.inhibitor.ehc.eu](http://www.inhibitor.ehc.eu).

# EHC VOLUNTEERS AND COMMITTEES

“Volunteers don't get paid, not because they're worthless, but because they're priceless”  
Sherry Anderson, Community leader



## STEERING COMMITTEE (SC)

The Steering Committee is the democratically-elected guiding force of the EHC. In 2019 the Steering Committee met face-to-face three times, in February, May and October, as well as once virtually in August.

The EHC Steering Committee is composed of:

- **Brian O'Mahony, Declan Noone** | President, Irish NMO
- **Minette van der Ven** | Vice-President Finance, Dutch NMO
- **Miguel Crato** | Portuguese NMO
- **Radoslaw Kaczmarek** | Polish NMO
- **Olivia Romero-Lux** | French NMO
- **Naja Skouw-Rasmussen** | Danish NMO
- **Thomas Sannié** | French NMO
- **Michael van der Linde** | Dutch NMO
- **Amanda Bok, Ex-Officio** | EHC CEO
- **Alain Weill, Ex-Officio** | World Federation of Hemophilia

During the EHC General Assembly in October 2019 presidential elections were held. Brian O'Mahony stepped down following a two-term Presidency (2011-2019) and Declan Noone, Irish NMO, was elected to a first four-year term.

The EHC is grateful to Brian for his contributions towards building the EHC into what it is today and for the enormous heritage he leaves the European bleeding disorders community. The EHC is delighted to keep him as an active volunteer!



## MEDICAL ADVISORY GROUP (MAG)

The Medical Advisory Group (MAG) provides high-level medical and scientific support, guidance and strategic input to the EHC and its Steering Committee. The MAG is mobilised throughout the year and meets virtually as well as face-to-face.

The EHC Medical Advisory Group is composed of:

- **Prof Flora Peyvandi, Chair** | Italy
- **Prof Michael Makris** | UK
- **Prof Johannes Oldenburg** | Germany
- **Dr Jan Blatný** | Czechia

## MEDICAL AND SCIENTIFIC ADVISORY GROUP (MASAG)

Close collaboration with a comprehensive team of scientific as well as medical experts is essential to the work of the EHC. The MASAG ensures a multidisciplinary approach to the work of the EHC, provides advice and guidance on specific areas of EHC engagement, as well as strategic input into specific event programmes and activities as necessary, and hands-on, in-person support in key events as needed.

Even though MASAG did not hold a specifically dedicated meeting in 2019, their strong influence could be felt in all of the EHC events in 2019!

The MASAG is composed of: Rezan Abdul-Kadir, Massimo Colombo, Piet De Kleijn, Roseline d'Oiron, Alison Dougall, Carmen Escuriola-Ettinghausen, Albert Farruggia, Dan Hart, Anneliese Hilger, Vince Jenkins, Evelien Mauser-Bunschoten, Giuseppe Mazza, Alec Miners, Beatrice Nolan, Cristina Novembrino, Jamie O'Hara, Brian O'Mahony, Debra Pollard, Frits Rosendaal, Glenda Silvester, Luigi Solimeno and Thierry VandenDriessche

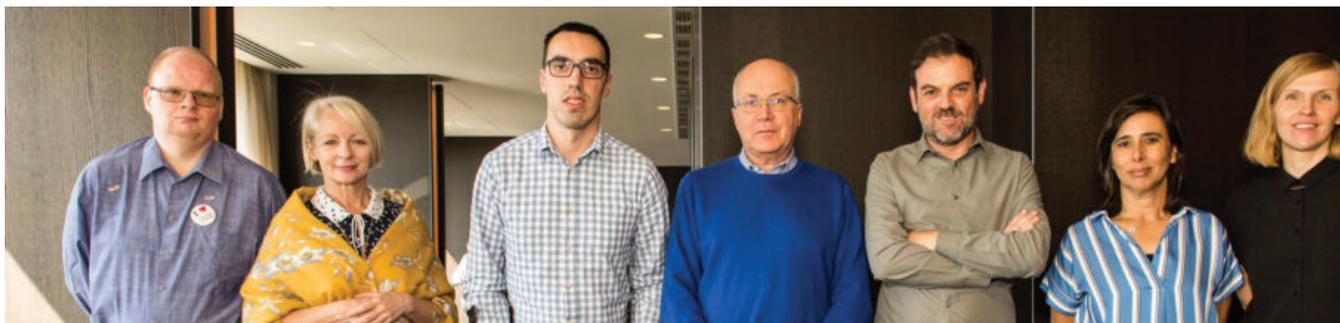
## NEW PRODUCTS COMMITTEE

The EHC New Products Committee has the objective of supporting the production of the EHC New Products Review Newsletter. This is a publication covering all the latest developments in medicinal products for haemophilia and other rare bleeding disorders.

In 2019, the EHC produced two newsletters.

This committee is composed of:

- **Mariëtte Driessens** | Dutch NMO
- **Radoslaw Kaczmarek** | EHC Steering Committee, Polish NMO
- **Declan Noone** | EHC President, Irish NMO
- **Brian O'Mahony** | EHC MASAG, Irish NMO
- **David Page** | Canadian Hemophilia Society
- **Flora Peyvandi** | MAG Chair, Italy
- **Geneviève Piétu** | French NMO
- **Uwe Schlenkrich** | German NMO



## INHIBITOR WORKING GROUP

The Inhibitor Working Group plans and carries out a variety of projects in the framework of the European Inhibitor Network (EIN). The most visible work is done online through the EIN online platform ([inhibitor.ehc.eu](http://inhibitor.ehc.eu)). A particular highlight are the monthly “Happy 1/2 with an expert in haemophilia care” sessions. These live, 30-minute videoconferences allow participants to ask questions directly to multidisciplinary experts without leaving their homes. A variety of themes were addressed in 2019, including physiotherapy, surgery, psychosocial issues, home treatment and self-infusion, employment issues, parenting a child with inhibitors and pain management. Following the video conferences, the discussions are converted into short articles and published online.

The IWG also worked closely with the EHC NMOs through national Inhibitor Ambassadors who serve as the active link between people with inhibitors in their country and the EIN at a European level. Another important element of this cooperation are the local visits with NMOs, where IWG members take part in national inhibitor-related events and present the work of the EIN, as well as meeting with healthcare professionals to spread the European Principles of Inhibitor Management (EPIM). In the first half of 2019, the IWG met with the Portuguese NMO and visited a treatment centre in Lisbon, attended an Inhibitor Information & Support meeting organised by the UK NMO and attended the 7<sup>th</sup> national and 1<sup>st</sup> regional Inhibitor Camp, organised by the Serbian NMO.

In the light of the recent clinical developments in the field of inhibitor treatment, it was decided to update the European Principles of Inhibitor Management (EPIM) and resubmit the updated article for publication to the *Orphanet Journal of Rare Diseases*. The work on updating the EPIM took place during the summer of 2019 and the article was resubmitted in September 2019 and published in 2020.

The most notable achievement of the IWG in the 2019 was the publication of the **Handbook for better inclusion of people with inhibitors in the life of the National Member Organisation**. (See p. 19)

The EHC Inhibitor Working Group is composed of:

- **Christina Burgess** | UK
- **Miguel Crato** | EHC Steering Committee, Portugal
- **Paul Giangrande** | UK
- **Steffen Hartwig** | German NMO
- **Mirko Jokic** | Serbian NMO
- **Jim O’Leary** | Irish NMO
- **Teresa Pereira** | Portuguese NMO

At the end of the year Prof Giangrande retired from his role in the IWG. We are grateful for all the invaluable support and advice during his involvement in the IWG!



## YOUTH COMMITTEE

A newly formed Youth Committee hit the ground running in 2019 and focused not only on the traditional EHC Youth Leadership Workshop held in April but also a Leadership Alumni Event held in January. The committee works hands-on in developing content and steering the direction of the EHC’s youth strategy. The EHC is grateful to the fantastic members who have been full of energy and ideas!

The EHC Youth Committee is composed of:

- **Valentin Brabete** | Youth Ambassador, Romania
- **Stefan Radovanovic** | Youth Ambassador, Serbian NMO
- **Olivia Romero-Lux** | EHC Steering Committee, French NMO
- **Clive Smith** | Youth Advisor, UK NMO



## WOMEN AND BLEEDING DISORDERS COMMITTEE

The EHC Women and Bleeding Disorders Committee works with the objective of developing activities to raise awareness about women affected by rare bleeding disorders.

In 2019, the Committee developed and held the first EHC Conference on Women and Bleeding Disorders, a three-day event that gathered close to 150 participants from all over Europe for scientific and interactive sessions on issues faced by women with bleeding disorders.

The Committee also presented the movie **Women and Bleeding Disorders: Untold Stories** (See p.18). A movie depicting the daily struggles of women affected by rare bleeding disorders. The committee chair also continued her mandate with the working group on women and rare bleeding disorders of the European Association for Haemophilia and Allied Disorders (EAHAD), further strengthening the EHC committee relationship with healthcare professionals.

The committee also held booths at various international events to present their activities and attended a number of local NMO events to raise awareness about women with bleeding disorders.

The EHC wishes to thank the fantastic members of this group for their contributions to EHC activities. In 2019, these were:

- **Marion Bräuer** | Austrian NMO
- **Yannick Colle** | French NMO
- **Evelyn Grimberg** | Dutch NMO
- **Ulla Hakkarainen** | Finnish NMO
- **Tatjana Markovic** | Serbian NMO
- **Ana Pastor** | Portuguese NMO
- **Naja Skouw-Rasmussen** | Chair of the Committee, EHC Steering Committee, Danish NMO

# THANK YOU.

EHC is grateful to the Members of the **European Parliament (MEP) Rare Bleeding Disorders Group** that supports the work of the EHC, especially in the organisation of the Round Tables of Stakeholder in the European Parliament:

- **MEP Dr Cristian-Silviu Buşoi** | European People's Party (EPP), Romania
- **MEP Dr Biljana Borzan** | Socialists and Democrats (S&D) Vice-President, Croatia
- **MEP Sirpa Pietikäinen** | European People's Party (EPP), Finland

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 other volunteers for their energy, time, ideas, commitment and drive to support the work of the EHC!

Aizat Aidarbekova, Sviatlana Anischiuk, Enea Atroce, Eugenia Biguzzi, Greig Blamey, Jan Blatny, Valentin Brabete, Marion Brauer, Christina Burgess, Daryl Butler, Liz Carroll, Cristina Catarino, Ivana Chandogova, Yannick Collé, Peter Collins, Piet de Kleijn, Hortensia de la Corte Rodriguez, Philippe de Moerloose, Manon Degenaar-Dujardin, Karola Diosi, Mariette Driessens, Gaetan Duport, Marija Dzmanoska, Els Eerens, Paul Giangrande, Jenny Goudemand, Anna Griesheimer, Evelyn Grimberg, Steffen Hartwig, Lotte Haverman, Mirko Jokic, Michael Laffan, Michelle Lavin, Sebastien Lobet, Maria Elisa Mancuso, Evelien Mauser, Declan Noone, Jim O'Leary, David Page, Ana Pastor, Teresa Pereira, Geneviève Pietu, Debra Pollard, Stefan Radovanovic, Olivia Romero-Lux, Glenda Silvester, Naja Skouw-Rasmussen, John Stack, Adam Sumera, Anna Tollwé, Ioannis Tsimpanakos, Michael van der Linde, Minette van der Ven, Karin Van Galen, Alain Weill, Camilla Wensing, Xhulio Xhaferaj, Barretstown volunteers, EHC Conference volunteers

**In 2019, the organisations here below were part of the EHC membership:**

<b>Albania</b>	Shoqatës Shqiptare të Hemofilikëve
<b>Armenia</b>	Armenian Association of Hemophiliacs
<b>Austria</b>	Österreichische Hämophilie Gesellschaft (ÖHG)
<b>Azerbaijan</b>	Hemofilialı Xəstələrin Respublika Assosiasiyası
<b>Belarus</b>	Белорусская Ассоциация Больных Гемофилией
<b>Belgium</b>	Association de l'Hémophilie - Hemofilievereniging (AHVH)
<b>Bosnia and Herzegovina</b>	Udruženje Hemofiličara Bosne i Hercegovine
<b>Bulgaria</b>	Българска Асоциация по Хемофилия
<b>Croatia</b>	Društvo hemofiličara Hrvatske
<b>Cyprus</b>	Παγκύπρια Οργάνωση Αιμορροφιλικών (Π.Ο.Α.)
<b>Czech Republic</b>	Český svaz hemofiliků
<b>Denmark</b>	Bløderforening
<b>Estonia</b>	Eesti Hemofiliaühing
<b>Finland</b>	Suomen Hemofiliayhdistys (SHY)
<b>France</b>	Association Française des Hémophiles (AFH)
<b>Georgia</b>	Georgian Association of Hemophilia and Donorship
<b>Germany</b>	Deutsche Hämophilie Gesellschaft
<b>Greece</b>	Σύλλογος Προστασίας Ελλήνων Αιμορροφιλικών (ΣΠΕΑ)
<b>Hungary</b>	Magyar Hemofília Egyesület
<b>Iceland</b>	Blæðarafélag Íslands
<b>Ireland</b>	Irish Haemophilia Society
<b>Israel</b>	הייליפומה ילוחל התומע – הלע
<b>Italy</b>	Federazione delle Associazioni Emofilici (Fedemo)
<b>Kyrgyz Republic</b>	Kyrgyz Haemophilia Society “Community of handicapped – haemophiliacs”
<b>Latvia</b>	Latvijas Hemofilijas Biedrība
<b>Lithuania</b>	Lietuvos Hemofilijos Asocija

<b>Luxembourg</b>	Association Luxembourgeoise des Hémophiles
<b>North Macedonia</b>	Hemolog
<b>Moldova</b>	Асоциация Гемофилии Молдовы
<b>Montenegro</b>	Montenegrin Association for Hemophilia
<b>Netherlands</b>	Nederlandse Vereniging van Hemofilie-Patiënten (NVHP)
<b>Norway</b>	Foreningen for blødere i Norge (FBIN)
<b>Poland</b>	Polskie Stowarzyszenie Chorych na Hemofilię
<b>Portugal</b>	Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas (APH)
<b>Romania</b>	Asociația Română de Hemofilie (ARH)
<b>Russia</b>	Всероссийское общество гемофилии
<b>Serbia</b>	Udruženje hemofiličara Srbije
<b>Slovak Republic</b>	Slovenské hemofilické združenie
<b>Slovenia</b>	Društvo hemofilikov Slovenije
<b>Spain</b>	Federación Española de Hemofilia (FEDHEMO)
<b>Sweden</b>	Förbundet Blödarsjuka i Sverige
<b>Switzerland</b>	Schweizerische Hämophilie-Gesellschaft
<b>Tajikistan</b>	Republic of Tajikistan Public Organisation “Hemophiles”
<b>Turkey</b>	Türkiye Hemofili Derneği
<b>Ukraine</b>	Всеукраїнське товариство Гемофілії
<b>United Kingdom</b>	The Haemophilia Society
<b>Uzbekistan</b>	Узбекское общество гемофилии

*The EHC is delighted to welcome the Haemophilia Association of Uzbekistan to our family of NMOs! During its 2019 General Assembly, EHC members voted to accept the Haemophilia Association of Uzbekistan as its 47th member. The association was founded in 2001 and does not yet have many volunteers. For example, a youth group has just recently been created there. The NMO is hoping that its joining the EHC will help to further develop its activities. In Uzbekistan there are 1887 bleeding disorder patients - haemophilia A and B, as well as other bleeding disorders, including VWD patients.*

# STAFF

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

In February 2019 the EHC welcomed Mr Charles Kinney as Communications Officer, but sadly this cooperation lasted only until the end of June 2019. Mr Kinney worked on a major update of the EHC website and boosted the EHC's social media work. The EHC thanks Mr Kinney for his contributions to the community.

After working full time with the EHC on remote contract from Ireland, the EHC Community Programmes Officer **Ms Fiona Brennan** moved to Brussels in 2019 to be based with the rest of the EHC staff.

In June 2019, Mr Thierry Hoppe joined the EHC team as EHC Office Administrator in charge of finances and human resources. Thierry came to the EHC with a long management background in other health-related organisation.

In 2019 the EHC also said a few good-byes, amongst these to the first employee of the EHC, Mr Jo Eerens, who retired in the end of 2019. The EHC wishes to thank Jo for all of his work and support during the past ten years. Jo will be certainly missed but the EHC is delighted that he will continue to volunteer with the organisation.

In the summer of 2019 the EHC office also said a staff team goodbye to Mr Declan Noone, who left his paid position to run for the unpaid, volunteer role of EHC Presidency – a position he was subsequently elected to.

# EHConversations

## european haemophilia consortium

### GENE THERAPY SERIES

In February 2019, the EHC released the first educational videos in its **EHConversations** Series – informative, patient-focused discussion and education about gene therapy and haemophilia.

This first series of five videos on the subject, from both patient and expert points of view, was created to help patients and the general public understand and demystify some of the concepts related to gene therapy in haemophilia.

The following themes are discussed in the videos:



**What is gene therapy?** with Prof Flora Peyvandi



**An overview in gene therapy for haemophilia A and B** with Prof Paul Giangrande



**How does a clinical trial in gene therapy for haemophilia work?** with Dr Dan Hart



**Safety and gene therapy** with Prof Michael Makris



**Gene therapy: A patient's perspective** with Mr Jack Grehan



## CONTACT FOR THE MULTIDISCIPLINARY CARE TEAM

### Common symptoms of bleeding disorders in women include

- Long-lasting bleeds (after a cut, a surgery ...)
- Long-lasting and heavy nose bleeds (+10 min)
- Long-lasting bleeds of the gums or after a tooth extraction
- Family history of bleeding disorders
- Heavy and/or long-lasting (+ 7 days) menstrual bleeds
- Frequent and/or large bruises
- Post-partum bleed
- Lack of iron, anaemia
- Need of a transfusion

## EUROPEAN PRINCIPLES OF INHIBITOR MANAGEMENT IN VIDEO FORMAT

In February 2019, the EHC released the *European Principles of Inhibitor Management* in video format, following the original article published in April 2018.

This video is intended to serve the EHC membership as an advocacy tool to assist in their work to receive the care that their inhibitor population is entitled to. Management of inhibitors extends well beyond the clinical treatment of inhibitors, even with novel treatment options available. Inhibitor management unequivocally requires support such as specialist nursing care, individually tailored physiotherapy, psychosocial support, advice on employment and social security benefits, as well as on maintaining healthy relationships.

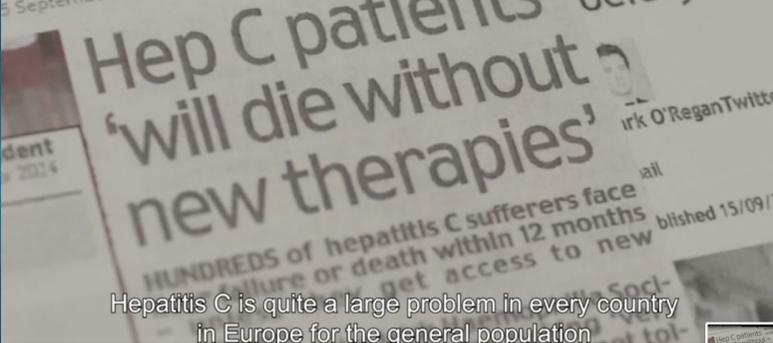
Even though the Principles were updated to include novel treatment products, this tool remains powerful. In fact, in many EHC NMO countries immune tolerance induction (ITI), bypassing agents or important components of comprehensive care are often unavailable.

## WOMEN AND BLEEDING DISORDERS: UNTOLD STORIES

In May 2019, the EHC premiered its movie **Women and Bleeding Disorders: Untold Stories**. In creating this ground-breaking film, the EHC began the process of shedding light on these often neglected but valued members of the bleeding disorders community. The film gives an important voice to many women who have long been in the shadows and will be in the shadows no more.

This film supports the EHC's commitment to women with bleeding disorders. Made in cooperation with the EHC's Women and Bleeding Disorders Committee as well as Medical and Scientific Advisory Groups, the film underscores alarming statistics for women in the bleeding disorders community, including that 10% of all women who go to the doctor with heavy blood loss, 29% may have a bleeding disorder, yet only 2% of them will get tested for a bleeding disorder. This film begins to shed light on the ramifications and real-world experiences of women who live these statistics.

The film is part of the EHC Stories series and continuation of work in partnership with director Goran Kapetanović who has directed and produced the other parts of the series: Haemophilia Stories and Inhibitor Stories. In addition, the EHC published five short clips highlighting difficulties and issues faced by women with bleeding disorders in its EHConversations series on Women and Bleeding Disorders. The clips were made from the longer Women and Bleeding Disorders: Untold Stories film.



## LIVING WITH HEPATITIS C AND HAEMOPHILIA IN EUROPE

In June 2019, the EHC released its film *Living with hepatitis C and haemophilia in Europe* for worldwide distribution. With this film, the EHC calls on European governments to provide access to hepatitis C virus (HCV) treatment with direct-acting antivirals (DAAs) to all patients with haemophilia who were contaminated through government-provided treatment. This initiative is part of the EHC's commitment to continue to highlight this injustice and call for governments to make amends and rid people with haemophilia of HCV.

The film is part of the EHConversations series and continuation of work in partnership with director Goran Kapetanović who has directed and produced Women and Bleeding Disorders: Untold Stories, Haemophilia Stories and Inhibitor Stories with the EHC.

This film was entirely financed by EHC's own funds.



## NOVEL PRODUCTS REVIEW

This periodic review of novel treatments in haemophilia and other bleeding disorders is a newsletter entirely developed by the EHC to help educate NMOs about the rapidly changing landscape of medicinal treatment in rare bleeding disorders. The EHC encourages its NMOs to use and adapt this newsletter to their national needs.

This publication 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 requesting updates directly from pharmaceutical companies. It is then redrafted and presented in easy-to-understand language.

In 2019, two issues of the Novel Products Review were released, as well as one issue adapted for the inhibitor population and published on the EIN website.



## A HANDBOOK FOR BETTER INCLUSION OF PEOPLE WITH INHIBITORS IN THE LIFE OF THE NATIONAL MEMBER ORGANISATION

In 2019 a long-standing goal of the EIN was reached and a substantial publication was finalised in September.

**Are you in? A handbook for better inclusion of people with inhibitors in the life of the National Member Organisation** was presented at the EIN Pre-Conference workshop and is designed to offer hands-on tips and useful information to help NMOs better integrate people with inhibitors (PWI) into their day-to-day activities and decision-making.

Containing medical information about inhibitors and profiles of those affected by an inhibitor, as well as practical tips and useful methodologies for PWI inclusion, the handbook is based on information-exchange and best practice collected since the inception of the EIN programme.

# REPRESENTATION

**6-8 February 2019**

EHC was strongly represented at the 2019 Congress of the European Association for Haemophilia and Allied Disorders (EAHAD) in Prague, Czechia.

**13-14 April 2019**

EHC representatives took part in the **General Assembly of the European Patients' Forum (EPF)**, held in Brussels, Belgium.

**13-16 June 2019**

EHC representatives attended the **Congress of the European Hematology Association (EHA)** held in Amsterdam, The Netherlands.

**6-10 July 2019**

EHC representatives attended the **Congress of the International Society of Thrombosis and Haemostasis (ISTH)** held in Melbourne, Australia. EHC hosted a booth to promote its activities.

**3 September 2019**

Brian O'Mahony, EHC President, was featured in a **media campaign on Blood Health**.

**14 September 2019**

EHC representatives attended the **Workshop on Novel and Gene Therapies organised by the National Hemophilia Foundation (NHF)**. The event took place in Washington, DC, United States. Attending this meeting allowed EHC staff and steering committee members to keep abreast of the latest medicinal products development in haemophilia.

**19-20 March 2019**

EHC representatives attended the **International Plasma Protein Congress (IPPC)** held in Amsterdam, The Netherlands.

**13 May 2019**

EHC CEO Amanda Bok attended and spoke at the World Orphan Drug Congress in Maryland, USA.

**7-8 June 2019**

EHC representatives took part in the European Directorate for the Quality of Medicines (EDQM) meeting - **the Wildbad Kreuth Initiative V: Optimal Treatment of Haemophilia** – in Schloss Hohenkammer, Germany. Traditionally EHC takes part in this meeting that develops recommendations for haemophilia treatment in the countries of the Council of Europe by actively engaging and putting forward recommendations.

**1-4 August 2019**

EHC representatives attended the **Boston Inhibitor Summit** organised by the National Hemophilia Foundation (NHF) in the United States. EHC and NHF have been inviting representatives from the other organisation to their respective inhibitor events since 2015 in order to foster education and learn from each other on common issues faced by inhibitor patients and how best to tackle them.

**6-8 September 2019**

EHC representatives attended the 10th edition of the **BIC International Conference**, which was held in conjunction with the **third edition of the International Conference on Inhibitors in Haemophilia**. EHC representatives learned about the latest scientific and medical data on inhibitor treatment.

## Have you heard about EHC Physical Activity Grants?



### ACTIVITY GRANTS

NMOs have important work to do but don't always find the funding they need, when they need it. When this occurs, NMOs can apply to the EHC for co-funding to initiate or allow continuation of a required project, programme or other initiative.

In 2019 the EHC were proud to support a number of projects through Activity Grants:

- Organisation of the Nordic Conference by the Danish NMO
- 50<sup>th</sup> Anniversary event of the Finnish NMO
- Talking Red Information Day for women with bleeding disorders by the Irish NMO
- Women with bleeding disorders programme by the Portuguese NMO
- Projects on advocacy activities and supporting change

in haemophilia health policies as well as prevention and treatment of musculoskeletal complications in persons with haemophilia by the Romanian NMO

- First Regional Inhibitor Camp by the Serbian NMO
- Participation of Ukrainian volunteers in the Lithuanian Basketball Camp

#### Physical Activity Grants

With the Physical Activity Grant, the EHC wants to support its NMOs in organising physiotherapy and physical activities.

In 2019 EHC proudly supported the International Basketball Camp for people with haemophilia of the Lithuanian NMO through its Physical Activity Grant.

### YOUTH FELLOWSHIP PROGRAMME

The Youth Fellowship Programme is designed to encourage, enable and empower the EHC youth leadership and other young EHC alumni to stay actively engaged with each other and to contribute to the European community in tangible ways by working together across borders on projects of their own interest and choosing, which also benefit the full community.

To date the EHC has approved five youth fellowship projects, which include volunteers from over 15 countries. The projects, which vary in focus and objectives, represent several important areas of work and aim to explore and improve some of the significant challenges the community faces.

Amongst the approved and ongoing projects, some areas youth fellows are addressing include sustainable youth outreach and engagement, enabling youth involvement in the decision-making process of NMOs, the importance and need for safe physical activity, outreach and education for people with VWD and women with bleeding disorders.



# REPORT OF THE AUDITOR



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België

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www.bakertilly.be

## 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 2019, 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 € 2.367.992,11 and a loss for the year of € 85.453,41.

#### 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.



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#### 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 2019, and its financial performance and cash flows for the year then ended, in accordance with the financial-reporting framework applicable in Belgium.

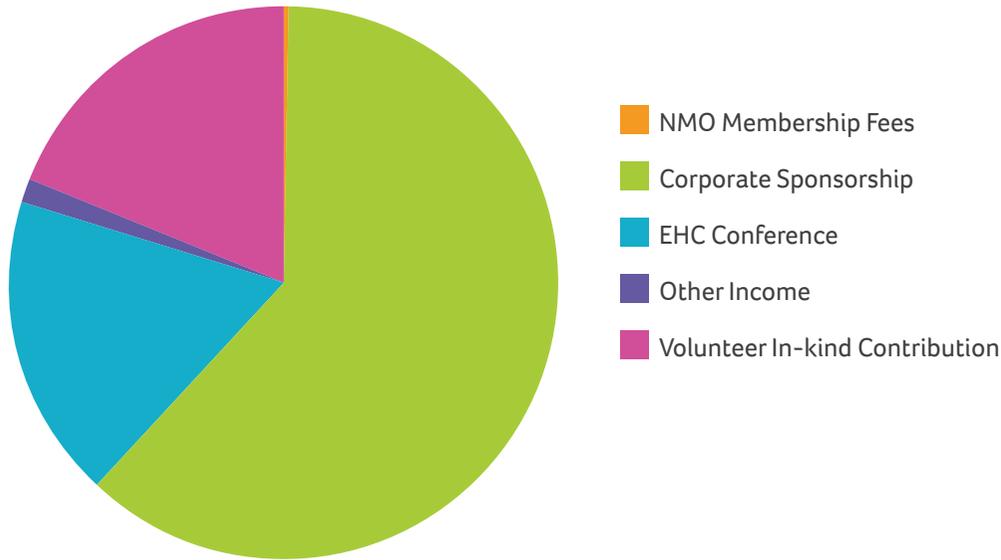
Melle, June 8, 2020

Baker Tilly Belgium Bedrijfsrevisoren CVBA  
Represented by

Jan Smits  
Audit Partner

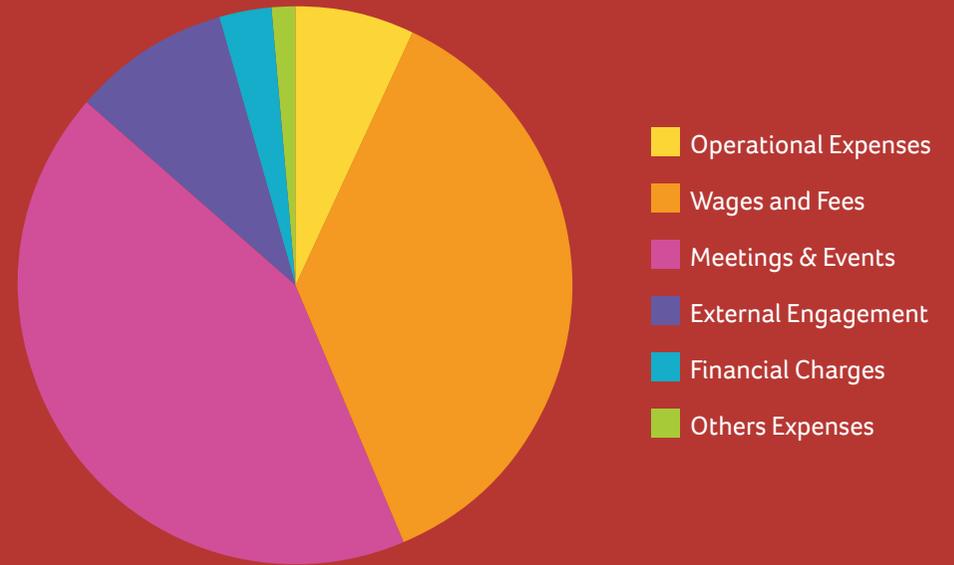
EUROPEAN HAEMOPHILIA CONSORTIUM  
2

# INCOME



INCOME	FINALS (€)
NMO Membership Fees	11,100
Corporate Sponsorship	1,262,125
EHC Conference	376,835
Other Income	27,948
<b>TOTAL INCOME</b>	<b>1,678,008</b>
Volunteer In-kind Contribution	386,200

# EXPENDITURE



EXPENDITURE	FINALS (€)
Operational Expenses	124,952
Wages and Fees	646,902
Meetings & Events	755,710
External Engagement	162,029
Financial Charges	53,464
Others Expenses	20,406
<b>TOTAL EXPENDITURE</b>	<b>1,763,462</b>

# BALANCE SHEET 2019

IT & Furniture	1.909	Patrimony 2018	1.810.159
New Offices	379.200	Balance 2019	-85.453
<b>FIXED ASSETS</b>	<b>381.109</b>	<b>EQUITY</b>	<b>1.724.705</b>
Amounts Receivable	507.830	Amounts to Pay	542.408
Bank Accounts	1.352.905	Taxes	2.986
VAT Current Account	63.230	Social Debts (Salary)	22.893
<b>FINANCIAL ASSETS</b>	<b>1.923.965</b>	<b>DEBTS</b>	<b>568.287</b>
Charges related to 2020	62.918	Income related to 2020	75.000
<b>DEFERRED CHARGES</b>	<b>62.918</b>	<b>DEFERRED INCOME</b>	<b>75.000</b>
<b>TOTAL ASSETS</b>	<b>2.367.992</b>	<b>TOTAL LIABILITIES</b>	<b>2.367.992</b>

# EHC 2019

## CORPORATE GIVING PARTNERS

The EHC wishes to acknowledge and thank its 2019 corporate giving partners for making its work possible.

### SERVICE PROVIDERS

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

- Conference Organisers
- TOAST
- RPP Group
- Ethical Properties
- Design-Plus
- Yaska
- Voilà
- Barretstown
- Goran Kapetanovic
- Joseph Carr
- Elliott Laub
- Caroline Lemay
- Jens Steen Larsen from Larsen & Co
- Olga Miniuk
- Julia Krivkina.

Thank you for supporting the European bleeding disorder community!

The EHC is also particularly grateful for the fully pro-bono legal services and supported provided by Covington.

### PLATINUM SPONSORS:

Bayer | BioMarin | CSL Behring | Novo Nordisk | Pfizer | Roche | Sobi | Takeda

### GOLD SPONSORS:

Sanofi | Spark | UniQure

### SILVER SPONSORS:

Biotest | Kedrion

The EHC also wishes to thank the following companies for supporting individual 2019 activities: BioMarin, CSL Behring and Takeda kindly sponsored the Youth Leadership Workshop, while BioMarin and Sanofi supported the Youth Fellowship Programme.

Pfizer, Roche, Sobi and Spark kindly supported the Leadership Conference, and CSL Behring and Novo Nordisk did contribute to success of the First European Conference on Women and Bleeding Disorders.

Takeda made the release of the Women and Bleeding Disorders: Untold Stories film possible, while BioMarin, Pfizer, Spark and UniQure supported the development of the EHC conversation educational videos on gene therapy.

Pfizer, Roche and Sanofi kindly supported EHC Economics Workshop, while BioMarin enabled the Workshop on New Technologies in Haemophilia Care to happen.

Kedrion, Roche and Sobi supported EHC PARTNERS Programme.

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

The Round Tables of Stakeholders in European Parliament were kindly supported by Bayer, Biotest, BioMarin, CSL Behring, Novo Nordisk, Pfizer, Roche, Sanofi, Sobi, Spark and Takeda.

And finally the EHC Conference received support from Bayer, BioMarin, CSL Behring, Novo Nordisk, Roche, Sanofi, Sobi, Spark, Takeda and UniQure.



## Better Health, Brighter Future

Takeda congratulates the European Haemophilia Consortium on 30 years of successful advocacy for the rare bleeding disorders community.

We are proud to have supported EHC's journey. In 2019, we supported the Roundtables, the Youth Workshop, the Annual Conference and the European Inhibitors Network, as well as the new Women and Bleeding Disorders project.

We will join the journey onward, driven by our belief that every bleed matters. Everyone is unique and every experience of rare bleeding disorders is different. All persons with bleeding disorders, wherever they live, deserve a high standard of comprehensive, personalized care.

[www.takeda.com](http://www.takeda.com)

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July 2020 C-ANPROM/INT//7947



# Treatment

*for those who need it most*



Roche is committed to supporting  
**rapid, broad and sustainable access**  
to treatments...

... for  
**all people with haemophilia A**  
around the world...

... to help **you live the life you want**

Find out more at

[www.roche.com/haemophilia](http://www.roche.com/haemophilia)



## Putting hemophilia patients first

*yesterday, today, tomorrow*

At Bayer, we're all about helping people with hemophilia to break boundaries, thrive and achieve their full potential.

We've been doing this for nearly 30 years and are proud to work with patients, caregivers and treaters to help create a strong community dedicated to reaching these goals.

But we never stop.

Our portfolio of innovative recombinant FVIII therapies is currently setting new standards of care. And, our evolving patient support programs and tireless research into gene therapy and bleeding disorders, is helping redefine what it means to live with hemophilia.



**Breaking boundaries in hemophilia**

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August 2020. PP-PF-HEM-ALL-0401-1

# 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 are proud to support the following patient / physician tools and educational activities in 2020



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

The **Haemoassist<sup>®</sup> 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<sup>®</sup> 2 tool supports people with haemophilia regardless of their choice of clotting factor concentrate.†



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.‡

Throughout 2020, Pfizer will continue to support the European Haemophilia Consortium (EHC) by contributing funding towards the following EHC-organised activities:§



\*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<sup>®</sup> 2 and Pfizer holds sole distribution rights. Haemoassist<sup>®</sup> 2 is a CE-marked medical device in Europe, currently available in Germany and Spain, with planned additional launches in 2020. It is currently neither registered nor available in other regions. Haemoassist<sup>®</sup> 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 Haemoassist<sup>®</sup> 2.

‡The Pfizer Ultrasound Programme is initiated and funded by Pfizer.

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

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

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PP-HEM-GLB-0123

Date of preparation: July 2020

# Driven by **Our Patients**

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

**CSL Behring**





**BRIAN SOUCY**  
Brian lives in the USA  
and has factor VIII deficiency



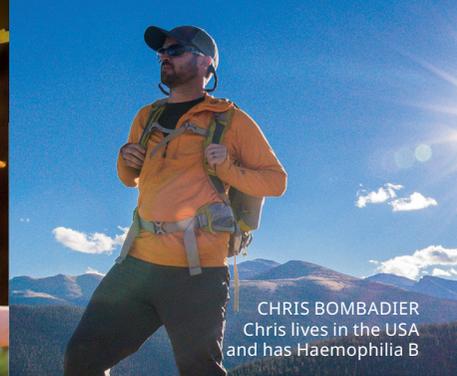
**ABDUL AZIZ AL-ARMALLY and  
SHAHEEN ALMAJED**  
Abdul and Shaheen live in Kuwait and have  
Haemophilia A



**LINDA TAYLOR**  
Linda lives in the USA  
and has Haemophilia B



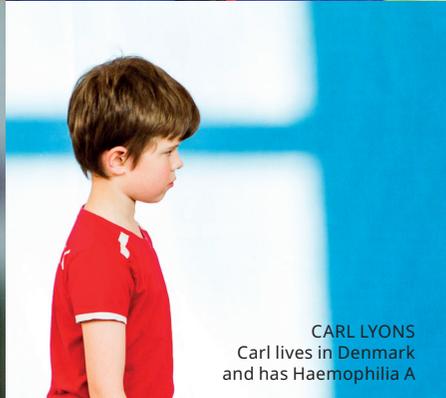
**LIAM CLEMENS**  
Liam lives in the USA  
and has Haemophilia



**CHRIS BOMBADIER**  
Chris lives in the USA  
and has Haemophilia B



**OLIVIA OSBORNE** parent of **HARRY OSBORNE**  
Harry lives in the UK and has severe Haemophilia B



**CARL LYONS**  
Carl lives in Denmark  
and has Haemophilia A



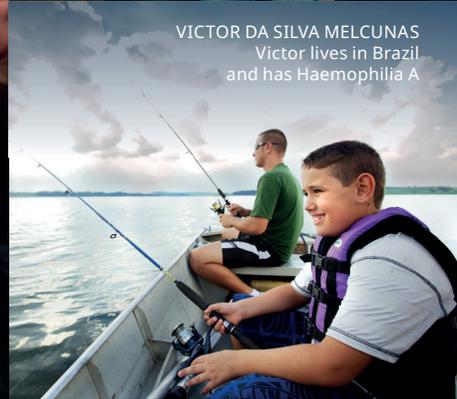
**ZIHAO LI**  
Zihao lives in China  
and has Haemophilia A



**HARRY OSBOURNE**  
Harry lives in England  
and has Haemophilia B



**LEANDRO KUSTER**  
Leandro lives in Switzerland  
and has Haemophilia A

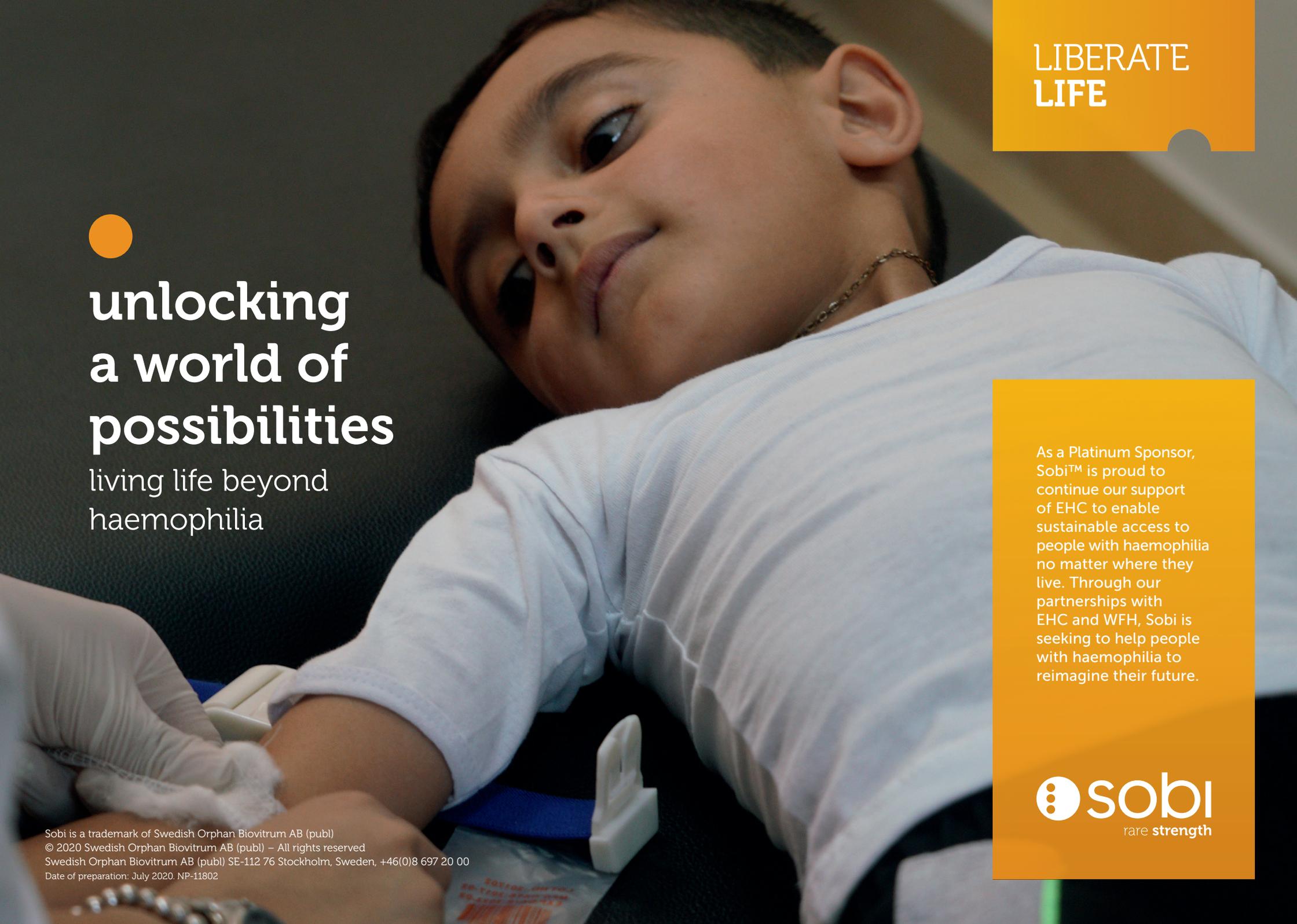


**VICTOR DA SILVA MELCUNAS**  
Victor lives in Brazil  
and has Haemophilia A

## With You at Every Step

We have a life-long commitment to the haemophilia community. To support your journey we provide actionable lifestyle support and guidance for living with haemophilia.

Find out more at [www.novonordisk.com](http://www.novonordisk.com)



LIBERATE  
LIFE

●  
**unlocking  
a world of  
possibilities**

living life beyond  
haemophilia

As a Platinum Sponsor, Sobi™ is proud to continue our support of EHC to enable sustainable access to people with haemophilia no matter where they live. Through our partnerships with EHC and WFH, Sobi is seeking to help people with haemophilia to reimagine their future.

 **sobi**  
rare strength

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Learn differently.  
Engage differently.  
HaemDifferently.

Visit [HaemDifferently.eu](https://HaemDifferently.eu)  
to learn about the science  
behind ongoing research  
in **gene therapy**

B:OMARIN®

Let's  **Haem**differently

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

HaemDifferently is built to be a resource 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.

Learn differently at  
[HaemDifferently.eu](https://HaemDifferently.eu)

# thank you

## To all healthcare workers everywhere

*For your courage in being on the front line,  
saving lives and keeping everyone safe during  
the COVID-19 pandemic*

## And to patients

*For continuing to inspire us with your resilience  
and bravery during these unprecedented times*

**From everyone at Spark Therapeutics**

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FOCUSED ON  
DEVELOPING  
SPECIALTY  
TREATMENTS

At Sanofi Genzyme, you are  
at the center of all that we do.

We've listened and we're  
committed—to breaking  
boundaries with scientific  
innovation, so you can focus  
less on living with hemophilia,  
and more on living.

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MAT-GLB-2001063 August 2020



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