EUROPEAN HAEMOPHILIA CONSORTIUM

ANNUAL REPORT 2014

ACRONYMS

ATMP – Advanced Therapeutic Medicinal Products
CEO – Chief Executive Officer
CFC – coagulation factor concentrates
DG SANCO – European Commission Directorate General for Health and Consumers
EAHAD – European Association for Haemophilia and Allied Disorders
EAHP – European Association of Hospital Pharmacists
EC – European Commission
EDQM – European Directorate for the Quality of Medicines and Healthcare
EHC – European Haemophilia Consortium
ELPA – European Liver Patients Association
EMA – European Medicines Agency
EPF – European Patients Forum
EU – European Union
EUHANET – European Haemophilia Network
EURORDIS – European Rare Diseases Organisation
HTA – Health Technology Assessment
ISPOR – International Society for Pharmacoeconomics and Outcome Research
MAG – Medical Advisory Group
MEP – Member of the European Parliament
MOU – Memorandum of Understanding
NMO – National Member Organisation
PCWP – Patient and Consumers Working Party
PDCO – Paediatric Committee
PLUS – Platform of Plasma Users
SC – Steering Committee
ToR – Terms of Reference
VWD – von Willebrand Disease
VWF – von Willebrand Factor

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About the European Haemophilia Consortium

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

Mission Statement

The EHC was established in 1989 with the mission to:

- Improve diagnostic and treatment facilities
- Ensure adequate supply of – and access to – safe factor concentrates
- 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 rare bleeding disorders

Members

The EHC has 45 National Member Organisations (NMOs) from 27 EU Member States[1], including all acceding countries as well as most of the Council of Europe Member States.

The EHC represents patients with congenital bleeding disorders such as haemophilia A and B, VWD and other rare bleeding disorders. It is estimated that approximately 90,000 people in Europe are affected by these conditions.

In 2014, the EHC General Assembly welcomed the "Community of handicapped – Hemophiliacs" from the Kyrgyz Republic as its 45th member.

Albania
Shoqatës Shqiptare
të Hemofilikëve

Armenia
Armenian Association
of Hemophiliacs

Austria
Österreichischen Hämophilie
Gesellschaft (ÖHG)
www.bluter.at

Azerbaijan
Hemofiliyalı Xəstələrin Respublika Assosiasiyası
www.hemophilia.az

Cyprus
Παγκύπρια Οργάνωση
Αιμορροφιλικών (Π.Ο.Α.)
www.poh.org.cy

Czech Republic
Český svaz hemofiliků
www.hemofilici.cz

Denmark
Bløderforening
www.bloderforeningen.dk

Estonia
Eesti Hemofiliauhing
www.hemofiilia.ee

Hungary
Magyar Hemofília Egyesület
www.mhe.hu

Iceland
Blæðarafélag Íslands
www.hemophilia.is

Ireland
Irish Haemophilia Society
www.haemophilia.ie

Israel
הילופימה ילוחל התומע – הלע
www.hemophilia.org.il

Macedonia
Hemolog
www.hemolog.org

Moldava
Ассоциации Гемофилии
Молдовы
www.hemophilia.ucoz.ru

Montenegro
Montenegrin Association
for Hemophilia

Netherlands
Nederlandse Vereniging van
Hemofilie-Patiënten (NVHP)
www.nvhp.nl

Serbia
Udruženje hemofiličara Srbije
www.hemofilija.org.rs

Slovak Republic
Slovenské hemofilické
združenie
www.shz.sk

Slovenia
Društvo hemofilikov Slovenije
www.drustvo-hemofilikov.si/

Spain
Federación Española
de Hemofilia (FEDHEMO)
www.hemofilia.com

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[1] Malta is no longer a National Member Organisation.

- **Belarus**
  Белорусская Ассоциация
  Больных Гемофилией
  www.belabg.org

- **Belgium**
  AHVH – Hemofilievereniging –
  Association de l’Hémophilie
  www.ahvh.be

- **Bosnia and Herzegovina**
  Udruženje Hemofiličara
  Bosne i Hercegovine
  www.uhbh.org.ba

- **Bulgaria**
  Българска Асоциация
  по Хемофилия
  www.hemo-bg.org

- **Croatia**
  Društvo hemofiličara Hrvatske
  www.dhh.hr

- **Finland**
  Suomen Hemofiliayhdistys
  (SHY)
  www.hemofilia.fi

- **France**
  Association Française
  des Hémophiles (AFH)
  www.afh.asso.fr

- **Georgia**
  Georgian Association
  of Hemophilia and Donorship
  www.gahd.org.ge

- **Germany**
  Deutsche Hämophilie
  Gesellschaft
  www.dhg.de

- **Greece**
  Σύλλογος Προστασίας
  Ελλήνων Αιμορροφιλικών
  (ΣΠΕΑ)
  http://hemophiliasociety.gr

- **Italy**
  Federazione delle Associazioni
  Emofilici (Fedemo)
  www.fedemo.it

- **Kyrgyz Republic**
  Kyrgyz Haemophilia Society
  “Community of handicapped – haemophiliacs”
  http://hemophilia.go.kg

- **Latvia**
  Latvijas Hemofilija Biedrība
  www.hemofilija.lv

- **Lithuania**
  Lietuvos Hemofiljos Associja
  www.hemofilija.lt

- **Luxembourg**
  Association Luxembourgeoise
  des Hémophiles
  www.alh.lu

- **Norway**
  Foreningen for blødere
  i Norge (FBIN)
  www.fbin.no

- **Poland**
  Polskie Stowarzyszenie
  Chorych na Hemofilię
  www.hemofilia.of.pl

- **Portugal**
  APH – Associação Portuguesa
  de Hemofilia e de outras Coagulopatias Congénitas
  www.aphemofilia.pt

- **Romania**
  Asociația Română de Hemofilie
  (ARH)
  www.hemofilic.ro

- **Russian Federation**
  Всероссийского общества
  гемофилии
  www.hemophilia.ru

- **Sweden**
  Förbundet Blödarsjuka
  i Sverige
  www.fbis.se

- **Switzerland**
  Schweizerische
  Hämophilie-Gesellschaft
  www.shg.ch

- **Turkey**
  Türkiye Hemofili Derneği
  www.turkhemoder.org

- **Ukraine**
  Всеукраїнське товариство
  Гемофілії
  www.hemophilia.org.ua

- **United Kingdom**
  The Haemophilia Society
  www.haemophilia.org.uk

Message from the President and Chief Executive Officer (CEO)

Brian O'Mahony & Amanda Bok

2014 marked not only the 25th anniversary of the EHC but also a year that saw an increase in our activities and partnerships. Thanks to the dynamism of its Steering Committee, the fresh spirit, new ideas and passion of its dedicated volunteers and the hard work of its growing staff the EHC continued to build on its strengths to further promote the interest of people with bleeding disorders in Europe.

The year started with a fresh addition to the EHC team: Laura Savini joined the EHC staff as the EHC's first Communications and Public Policy Officer. We also eased three new Steering Committee (SC) members, newly elected in October 2013 – Olivia Romero Lux, Traci Marshall Dowling and Giuseppe Mazza – into their new roles by immediately launching a 2014-2017 Strategic Planning exercise. Thankfully, seasoned Steering Committee members like Radoslaw Kaczmarek (re-elected in 2013) and Jordan Nedevski (who we were pleased to see re-elected in 2014), our Vice-President Finance, were there to help guide them and reassure them that yes indeed, the workload would always stay the same because we were (still) only a few, implementing the aspirations of many.

We finished the Strategic Planning exercise, emerging with a clear vision of our three-year goals and objectives and with the understanding that we would work toward "Shaping the future for people with congenital bleeding disorders in Europe." To do so – and to do it well - we assigned each Steering Committee nine NMOs with whom to liaise regularly in order to ensure that NMOs remain aware of our work and we remain aware of their needs!

The year 2014 saw new and established partnerships being strengthened and bringing meaningful contributions to the work of the EHC. We started by fully implementing the newly signed (2013) Terms of Reference (ToR) of the EHC Medical Advisory Group (MAG). This meant greater engagement between SC and MAG members with MAG members joining all SC meetings to ensure maximum engagement, collaboration and alignment. The EHC also established a small informal support group of Members of the European Parliament (MEPs) to support haemophilia and other rare bleeding disorders in the European legislative process.

We started our work on a patient representative seat with the European Commission' Expert Group for Rare Diseases, which advises the European Commission and Member States on the development and implementation of effective policies to tackle rare diseases. Dr Günter Auerswald was accepted to represent the EHC with the Paediatric Committee (PDCO) of the European Medicines Agency (EMA).

To mark World Haemophilia Day, we partnered with the Paul-Ehrlich-Institut (PEI), a German regulatory agency responsible for research and approval of biological medicinal products, to host an event launching the recommendations for haemophilia treatment emanating from the Wildbad Kreuth III initiative[2]. These recommendations promote the most effective treatment of haemophilia and other rare bleeding disorders with coagulation factor concentrates (CFC). Furthermore, to facilitate the promotion of these recommendations with external stakeholders, we developed an advocacy video, which was translated into multiple languages and used across our membership. Finally, we became a member of the European Patients' Forum (EPF) and added our voice to theirs at the EU policy level.

To strengthen our advocacy activities, we surveyed our NMOs on national systems of tenders and public procurement, and their involvement in the process – which resulted in key data that will be instrumental to our community for years to come. An additional survey was done on how our NMOs fund themselves. The results of this survey were presented during a parallel workshop at our Annual Conference, held in Belfast, United Kingdom – itself a great success. The EHC will also continue to build on this data.

2014 saw the EHC diversifying its activities to be more inclusive and representatives of the various disorders and types of volunteers covered by the EHC's mandate. We started a new programme on youth and we hope it began to plant the seeds for future generations of leaders in our community. The programme kicked off with our very first youth leadership workshop, held in Amsterdam, the Netherlands, which resulted in both an exciting and fruitful experience. But we did not leave it at that, in fact, we invited talented young participants to continue the conversation started in Amsterdam during a conference workshop on youth-led strategies for engagement held at our Annual Conference, where we also organised a debate between young volunteers and eminent clinicians in front of 300 participants – our young volunteers stole the show!

We also organised two Round Tables on rare bleeding disorders and Von Willebrand Disease (VWD) to bring the latest clinical and scientific knowledge to our members but also to explore strategies to raise awareness about these conditions and to facilitate the marketing of novel technologies in Europe for the most rare conditions covered by our mission. This was a direct follow-up of our advocacy activities of 2013.

In terms of advocacy, we continued our long-standing campaign with the EU institutions against marketing exclusivity for the first longer-acting haemophilia product to come to the European market. We have reason to believe that we made inroads. But we also invested in our community's understanding of those products with the introduction of a New Technologies workshop. It was held in Dublin, Ireland, and trained multiple stakeholders – including patients, clinicians and regulators – on the science and mechanisms behind PEGylated, FC- and albumin-fusion products as well as on the new bi-specific antibody.

Finally, we continued our work in training NMOs on economic concepts in haemophilia and how to get involved and actively participate in their national Health Technology Assessment (HTA) processes. This workshop took place in Riga, Latvia, and focused on Central European countries. We concluded the year with a final Round Table, held at the European Parliament, on haemophilia councils followed by a small reception to celebrate the EHC's 25th anniversary.

In between all that, we changed offices – moving into the EU quarter in order to be a short distance from the institutions and our European partners, and to allow room for more staff to arrive in the future. We revamped our website to make it more user-friendly and useful to our NMOs and for all other visitors. We updated our statutes to reflect the reality of our new working methods and directions. And we changed our logo!

It was an incredibly busy, fruitful and exciting year – and it would not have been possible without the support of our volunteer community, key partners and staff. In particular, it would not have been possible without an expanded funding base. We worked closely, openly and transparently with our corporate partners. We shared our vision and they supported our independent work to translate our ideas into reality. Our collective work is not done yet; it has only just begun!

Brian o Mahony

Brian O'Mahony
President

Amanda Bok
Chief Executive Officer

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[2] The Wildbad Kreuth III initiative is a joint initiative organised by the European Directorate for the Quality of Medicines and Healthcare (EDQM), the Rudolf Marx Foundation and the University of Munich that seeks to promote effective use of coagulation factor concentrates and immunoglobulins.

EHC 2014 at-a-glance

Marked 25th anniversary (1989-2014)
Welcomed Kyrgistan as a new member and increased membership to 45 members
Annual Conference in Belfast, Northern Ireland, UK

MEDICAL AND SCIENTIFIC UPDATE ON:

- Von Willebrand Disease and Factor
- Rare Bleeding Disorders
- Hepatitis C treatment
- Physiotherapy
- Reproductive and genetic issues
- New Technologies in haemophilia treatment

PROVIDING TRAINING AND SHARING BEST PRACTICES IN:

- Healthcare services organisation and patient involvement
- Haemophilia Centres and Patient Groups relations
- Youth engagement
- Mild and moderate haemophilia
- Health economics

DATA COLLECTION:

- NMO funding
- Purchase of coagulation factors

World Haemophilia Day: promoting guidelines on optimal treatment of haemophilia
Continued EUHANET Project
Became a member of EPF
Grew the EHC team and moved office

Activity Report

In 2014 the EHC Steering Committee (SC) set its 2014-2017 Strategic Plan objectives, which seek to:

- Support and empower NMOs
- Promote access to optimal treatment and comprehensive care for people with congenital bleeding disorders in Europe
- Ensure constructive engagement with key stakeholders
- Increase its influence on the European policy-making environment
- Ensure the good governance and sustainability of the organisation

These strategic objectives maintain the spirit of the original EHC mission while also taking into account the changing environment in which the EHC operates.

SUPPORT AND EMPOWER NMOs

One of the primary roles of the EHC is to support and strengthen the work of its NMOs at national and European levels.

Communications

The EHC strives to provide its members with the type of communication that they need for their own work at national and European levels. This is done through timely communication of EHC activites and developments in European health policy as well as through targeted training and the dissemination of educational materials. Additionally, the EHC promotes the diffusion of the latest scientific and clinical knowledge, while collecting data on different aspects of comprehensive care for haemophilia in Europe. Finally, the EHC encourages NMOs to exchange on best practices across Europe.

QUARTERLY HEALTH POLICY UPDATE

The EHC produces four NMO-only analytical reports on European health policies and legislation. These reports also outline the legislative process in the European Union (EU) and the roles of other key institutions in European healthcare decision-making.

NEWSLETTER

The EHC Newsletter is produced three times a year and features information about the EHC activities, news from its NMOs and feature articles covering current issues in haemophilia and other bleeding disorders.

ROUND TABLE REPORTS

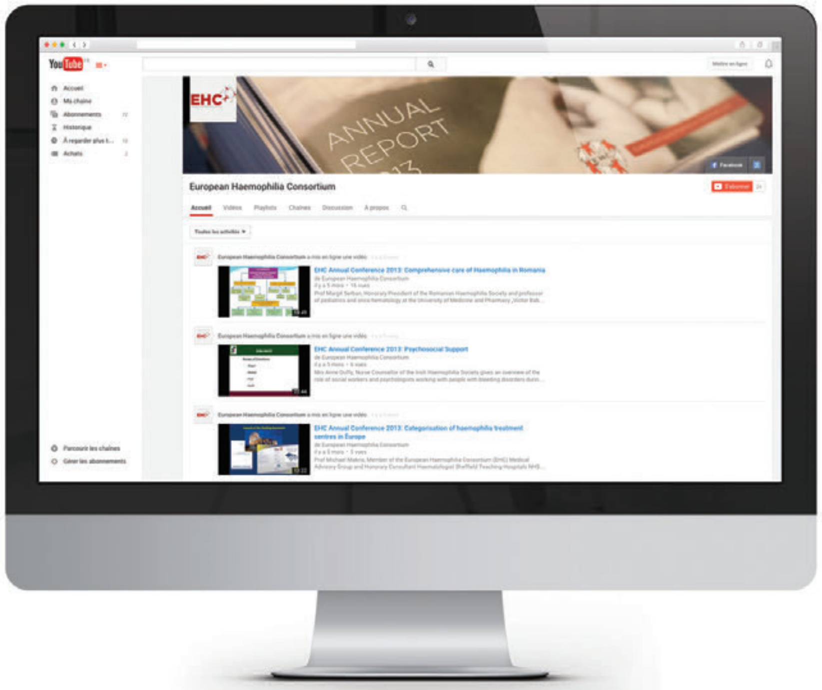
Following each Round Table, the EHC produces detailed reports of the event and their findings and recommendations.

WEBSITE

In 2014, the EHC revised and updated its website to meet the needs of its NMOs and users. The website was reviewed with a double objective: to be an information resource on EHC activities and to give the wider public an introduction about rare bleeding disorders and how these conditions affect people living with them. The revision of the website was made possible by an educational grant from Pfizer.

FACEBOOK PAGE

In 2014, the EHC increased the level of visibility and activity of its official Facebook page. The page got an additional 210 likes during the year and was visited more than 1,800 times. The EHC also increased its posting frequency and uses its Facebook page to provide information about EHC activities, positions, news and other items.



YOUTUBE PAGE

In 2014, the EHC created a YouTube page to publish EHC-produced videos such as advocacy videos and webcasts from the EHC Annual Conferences and other events. The EHC uploaded its video on Wildbad Kreuth III recommendations (see pg 10) that gathered over 1 ,000 views.

EHC EVENTS WEBCASTING

The EHC develops webcasts of scientific content presented during its Annual Conference and workshops. The content is released on the EHC YouTube Channel.

Education and training

The EHC provides targeted training to its NMOs each year and also promotes their participation in multiple other events by providing travel and accommodation grants, including to its Brussels-based Round Tables, Annual Conference and World Haemophilia Day event.

YOUTH LEADERSHIP WORKSHOP

In July 2014, the EHC held its first Youth Leadership Workshop, titled 'Turning motivation into action: communicating your ideas into reality' in Amsterdam, the Netherlands. It brought together 15 young volunteers (between the ages of 20 and 31) from 12 European countries[3] and trained them on how to engage more effectively with their national patient communities. The programme focused on volunteerism, communications, strategic planning and project management. This workshop was made possible by educational grants from Baxter, Bayer and Novo Nordisk.

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[3] Albania, Belgium, Denmark, France, Germany, Greece, Ireland, the Netherlands, Norway, Portugal, Serbia and Sweden.

ECONOMICS AND HTA WORKSHOP

In September 2014, the EHC held its second in a three-year series of Economics and Health Technology Assessments (HTA) Workshops. It took place in Riga, Latvia, and brought together 14 participants from 12 countries[4] to provide specific training in economic concepts relevant to haemophilia care and to equip them to actively participate in current or future HTA processes in their countries to ensure patient access to adequate treatment and care. The last workshop of the series will take place in St. Petersburg, Russia, in 2015 and bring together Eastern European countries. This workshop series was made possible through an educational grant from Pfizer.

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[4] Austria, Belgium, Croatia, Ireland, Latvia, Lithuania, Romania, Poland, Slovenia, Switzerland, Turkey and United Kingdom.

> « The EHC provides its members with state of the art information on policy, medical and scientific developments relevant to the bleeding disorders community. »

Scientific knowledge

Through the communication tools[5], the EHC provides its members with state of the art information on policy, medical and scientific developments relevant to the bleeding disorders community.
During its Annual Conference EHC members also receive updates from experts on the latest medical and scientific developments. Finally, EHC representatives regularly help to advance the evidence base and disseminate information through speaking engagements and publication in scientific journals like *Haemophilia* and *Nature*.

In 2014, the EHC organised its Annual Conference in Belfast, United Kingdom. This was an opportunity for over 300 participants from 37 countries, including medical, scientific and patient experts, to present and discuss the latest medical and scientific advances in the area of haemophilia and other bleeding disorders. The programme included topics such as Hepatitis C, physiotherapy, state-of-the-art and novel treatments for haemophilia, reproductive and genetic issues. The conference was held in English with simultaneous Russian interpretation.

Following a successful 2013 pilot, four parallel capacity-building workshops were again held in 2014 of which two were NMO-only and two were open to all delegates. These focused on:

- Challenges in mild and moderate haemophilia (open to all delegates) (see pg 27).

- Youth-led strategies for engagement (open to all delegates) (see pg 27).

- Haemophilia treatment centres and NMOs working together (open to NMOs only) (see pg 28).

- Financing haemophilia societies: A survey-based workshop (open to NMOs only) (see pg 28).

The EHC would like to thank the Haemophilia Society UK for co-hosting the event.

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[5] Outlined in section 1.1

Data collection

The EHC understands that sound scientific evidence is the bedrock of its advocacy efforts. This is why the EHC conducts annual surveys of its NMOs to collect data on various aspects of access to treatment and care in Europe. The collected data is compiled, analysed and interpreted by the EHC. The results are frequently published in scientific journals such as *Haemophilia* and adapted by the EHC for advocacy purposes to be used by NMOs at national levels.

In 2014, the EHC conducted two surveys. The first focused on the organisation of tenders and procurement for coagulation factor concentrates in Europe and its purpose was to gain a better understanding of how medicinal products for haemophilia and other bleeding disorders are purchased and whether patients and healthcare professionals are involved in the purchasing process. The second survey explored how EHC NMOs are funded. The results of this survey were presented and discussed during the EHC Annual Conference Workshop (see pg 27).

NMO liaison and assistance

In 2014, the EHC launched an initiative through which to ensure regular, direct and personalized contacts with all of its NMOs on national issues and developments. To this end, each EHC SC member was assigned nine NMOs with which to liaise.

In addition to providing information and targeted advocacy materials to its NMOs, the EHC also supports individual NMOs in their national advocacy work on an ad hoc basis and as needed. In 2014, the EHC provided specific assistance to NMOs from Estonia, Latvia, Poland, Portugal, Spain, Ukraine and the UK.

Jordan Nedevski	Radoslaw Kaczmarek	Traci Marshall Dowling	Giuseppe Mazza	Olivia Romero Lux
Armenia	Czech Republic	Denmark	Albania	Austria
Azerbaijan	Estonia	Finland	Bosnia-Herzegovina	Belgium
Belarus	Hungary	Iceland	Croatia	France
Bulgaria	Latvia	Ireland	Cyprus	Germany
Georgia	Lithuania	Israel	Greece	Luxembourg
Kyrgyzstan	Moldova	Netherlands	Italy	Portugal
Russia	Poland	Norway	Macedonia	Slovenia
Turkey	Romania	Sweden	Montenegro	Spain
Ukraine	Slovakia	UK	Serbia	Switzerland

Best practice

In 2014, the EHC organised several events aimed to support and facilitate the exchange of best practices between its NMOs.

EHC ANNUAL CONFERENCE WORKSHOPS

During the 2014 EHC Annual Conference (see pg 23), four parallel workshops (each attended at full capacity by over 40 participants) enabled NMOs to exchange best practices and to discuss and define common approaches in the below areas:

▷ Challenges in mild and moderate haemophilia

Mild and moderate haemophilia are often overlooked conditions, which nonetheless carry similar problems as severe haemophilia. People affected by the milder versions of haemophilia are, for example, also at risk of developing inhibitors and receiving inadequate treatment by non-expert health practitioners. Furthermore, some patients with mild and moderate haemophilia also experience more severe bleeds. These patients are often disengaged from the patient community and the haemophilia treatment centre as they do not view their condition as being serious. During the workshop participants explored strategies on how to better engage with this sub-group of patients.

▷ Youth-led strategies for engagement

This workshop built on the experience gained by the EHC Youth Leadership Workshop (see pg 20) and featured a wide selection of panellists, including two youth representatives, to discuss a range of questions regarding youth involvement in NMOs. The debate between panellists was followed by an interactive discussion with the participants present in the workshop.

▷ Haemophilia treatment centres and NMOs working together

Collaboration between NMOs and haemophilia treatment centres can be mutually beneficial and provide added value to both sides as these groups often share common objectives. However, good working relations between patients and clinicians can take time to develop and challenges may arise along the way. During this workshop, participants explored strategies for how patient groups and clinicians can best engage with one another to ensure successful collaborations.

▷ Financing haemophilia societies: A survey-based workshop

Securing funds to sustain patient organisations' activities is one of the biggest challenges faced by NMOs. During this workshop, the EHC presented the results of its survey on how European NMOs are financed. This led to discussions on strategies for securing public and private funding in different European contexts, as well as how to create and implement ethical and transparent funding policies.

ROUND TABLE ON 'NATIONAL HAEMOPHILIA COUNCILS: FROM CONCEPT TO REALITY'

In December 2014, the EHC held a Round Table of Stakeholders in the European Parliament on the concept of national haemophilia councils and the importance of patient involvement in the organisation of healthcare nationally. The Round Table was co-chaired by Members of the European Parliament Nessa Childers (Ireland) and Dr Cristian Silviu Bușoi (Romania). Presentations showcased examples from the UK, Romania and Poland outlining both best practices and current challenges. Key recommendations from the event included that patient representatives should be formally involved in national haemophilia councils/committees that manage haemophilia programs and budgets.

> *« The EHC Round Table on national haemophilia councils highlighted the importance of patient involvement in the organisation of healthcare at national level. »*


Traci MARSHALL-
WLING
member
Toon DIGNEFFE
Baxter

PROMOTE ACCESS TO TREATMENT AND COMPREHENSIVE CARE

There is widely disparate access to optimal treatment and comprehensive care in different European countries. Even where optimal levels are achieved, they often become vulnerable to economic and political factors. In 2014, the EHC met this strategic objective by organising a series of scientific events targeting specific medical issues that would result in a series of recommendations to support national advocacy. The EHC also contributes towards the development of a European system for pharmacovigilance in the area of rare bleeding disorders and towards the certification of haemophilia treatment centres.

Targeted advocacy tools

In 2014, the EHC organised a series of events and generated subsequent advocacy materials to be used by NMOs in their countries.

EHC ROUND TABLE ON RARE BLEEDING DISORDERS AND ORPHAN DRUGS

In March 2014, the EHC held a Round Table in the European Parliament, co-chaired by Members of the European Parliament Dr Miroslav Mikolášik (Slovakia) and Dr Paul Rübig (Austria), on orphan drugs for the treatment of rare bleeding disorders. These disorders are caused by the lack of one of the proteins active in the coagulation cascade (excluding coagulation FVIII and FIX, which cause haemophilia A and B respectively) and are extremely rare, ranging from an estimated prevalence of 1 in 100,000 for factor XI deficiency to 1 in 3,000,000 million for factor XIII deficiency. People with these disorders face many obstacles, including the lack of diagnosis and treatment.

This Round Table examined novel pipeline products targeting rare bleeding disorders such as FV, FX and FXIII deficiencies and featured discussions about the development and regulatory framework, pricing and patient access. Participants concluded that patients should be more involved in the whole development process including in pricing discussions as they provide a unique perspective on the impact of a medicinal product not only on the specific disease but on all aspects of the patient's life. The EHC also called on regulators to make a distinction between rare diseases such as haemophilia, which are well understood and have access to many therapeutic products and other rare bleeding disorders where no medicinal product exist. The EHC noted that the Orphan Medicinal Product Regulation (EC No 141/2000) and its benefits, such as marketing exclusivity, was originally designed to facilitate the marketing of novel treatments and not to hinder innovation.

EHC ROUND TABLE ON VON WILLEBRAND DISEASE AND FACTOR: CURRENT CLINICAL ISSUES

In June 2014, the EHC organised a Round Table on von Willebrand Disease (VWD) and von Willebrand Factor (VWF) with the dual objectives of exploring best practices for the clinical care of this disorder and discussing the latest findings on the role played by VWF in the prevention of inhibitor development. Although VWD is the most common bleeding disorder in Europe, it is often improperly diagnosed and different European countries use different diagnosis criteria, thereby leading to a lack of appropriate treatment in many countries. The Round Table featured discussions on the appropriateness and cost of prophylaxis in VWD, acquired VWD, a comparison between recombinant VWF and combined FVIII/ VWF. It also looked at the issue surrounding the immunological mechanisms of VWF in preventing the development of inhibitors in people with haemophilia.

NEW TECHNOLOGIES WORKSHOP

In November 2014, ahead of novel longer-acting haemophilia treatment products coming to the European market, the EHC organised a workshop in Dublin, Ireland, to train 25 participants from 15 countries[6] on the different mechanisms behind the various types of longer-acting products under late-stage development, namely those using PEGylation and glycopegylation technologies, FC- and albumin-fusion technologies as well as bi-clonal antibodies. Participants also heard from patient representatives from North America who already had access to these therapies and shared their experiences, including on the prioritisation of access. The main workshop sessions were filmed in order to be subsequently webcast. This workshop was made possible by an unrestricted grant from Sobi.

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[6] Austria, Canada, Croatia, France, Germany, Ireland, the Netherlands, Poland, Portugal, Slovakia, Spain, United States, Norway, Switzerland and the United Kingdom.


Business Centre


European
Haemophilia
Consortium
EHC
www.ehc.e

WORLD HAEMOPHILIA DAY

In April 2014, the EHC marked World Haemophilia Day with an event hosted by the German regulatory agency, the Paul-Ehrlich-Institut, in Langen, Germany, to officially launch the recently published recommendations coming out of the 2013 Kreuth III initiative. The recommendations were a joint initiative of the University of Munich, the Rudolf Marx Foundation and the European Directorate for the Quality of Medicines and Healthcare (EDQM), to reach clinical consensus on the optimal use of coagulation factor concentrates and immunoglobulins. The 2013 consensus exercise resulted in seven recommendations for the optimal treatment of haemophilia and other rare bleeding disorders, which were published in the scientific journal *Haemophilia* in early 2014. The EHC also created an advocacy video on the recommendations to promote their implementation across Europe. This video was made public, circulated to all stakeholders and can be found on the EHC's YouTube Channel. This World Haemophilia Day activity was made possibly by an unrestricted grant from Sobi.

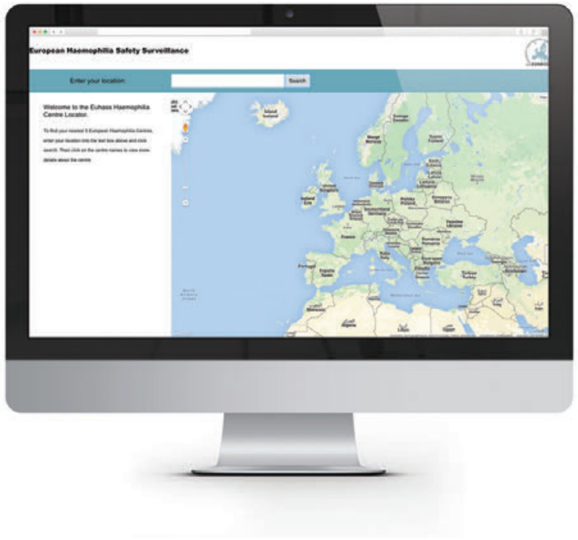
Paul-Ehrlich-Institut

Pharmacovigilance

The European Haemophilia Safety Surveillance (EUHASS) system is a pharmacovigilance programme within a European network that monitors the safety of treatments for people with congenital bleeding disorders in Europe and reports adverse events to clinicians and regulators, among others. Since its inception the EHC has been one of the implementing partners of the programme, which is now a component of EUHANET (see 2.5) in which the EHC is also actively involved.

Certification of Haemophilia centres

In 2012, the EHC together with EAHAD and others, and with co-funding from the European Commission and industry, partnered to create and implement the European Haemophilia Network (EUHANET) – a project with various elements including EUHASS (see above) as well as the standardization and certification of haemophilia treatment centres across Europe. The EHC led the development of the certification guidelines and in 2014 the certification process began. By the end of the year, more than 100 centres were certified as either European Haemophilia Comprehensive Care Centres (EHCCC) or European Haemophilia Treatment Centres (EHTC) and their details were published online in a web tool (www.hclocator.org) that helps patients locate the five treatment centres nearest to their current location and access information about the services they provide and their contact details.



Ensure political support for optimal treatment and comprehensive care

The EHC actively works to encourage the development of appropriate principles and guidelines on optimal treatment and comprehensive care across Europe. It contributes to the evidence base by generating its own data (see pg 24) in order to inform and support the development of these standards. Once published, it helps to promote such standards through position taking, advocacy videos and other activities (see pg 19), and it builds them into nationally tailored advocacy tools for NMOs to use in their own countries. It does all of this because ensuring political support requires constant effort at national and European levels.

ENSURE CONSTRUCTIVE ENGAGEMENT WITH KEY STAKEHOLDERS

The EHC operates in a complex environment where many other stakeholders carry out parallel actions that have an impact on haemophilia, rare bleeding disorders and EHC activities generally. As only one piece of a larger puzzle, the EHC works closely with key partners such as patient organisations, medical and professional societies, to ensure collaboration and alignment.

Patient organisations

EUROPEAN RARE DISEASE ORGANISATION (EURORDIS)

The EHC is a long-standing member of EURODIS, an international organisation representing over 600 patients groups active in the area of rare diseases. In 2014, the EHC was an active participant of EURORDIS' Rare Disease Day activities, the European Conference on Rare Diseases and EURORDIS' members' meeting. The EHC also worked closely with EURORDIS within the newly established European Commission's Expert Group for Rare Diseases.

WORLD FEDERATION OF HEMOPHILIA (WFH)

The EHC and the WFH share the same European NMOs and, as a result, they work closely together. In 2012, the EHC and the WFH updated their MOU, originally signed in 2004, to reflect the changing environment in Europe. The two organisations continue to stay in close contact, attending each other's conferences and speaking at each other's executive meetings. The EHC and the WFH also coordinate joint positions at European and international levels, when necessary and appropriate, and implement joint work as needed.

EUROPEAN PATIENTS' FORUM (EPF)

In 2014, the EHC became a member of EPF, an umbrella organisation representing chronic and lifelong conditions across Europe. The EHC took active part in their work on access to healthcare and interfaced on EPF projects at European and national levels.

PLATFORM FOR PLASMA USERS (PLUS)

The EHC is a founding member of PLUS, an organisation representing patient groups that rely fully or partially on plasma-derived medicines. In 2014, PLUS members took part in the consultation organised by the Alliance of Blood Operators (ABO) on a framework for risk-based decision making for blood safety. The framework was designed to provide guidance on how to evaluate and manage risk, and how to communicate and engage with stakeholders involved in blood donations. It also looks at risk assessment and tolerability. In 2014, PLUS also met with representatives from the European Commission Directorate General for Health and Consumers (DG SANCO) to discuss the potential revision of the Blood Directive (2002/98/EC), which sets standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components.

EUROPEAN LIVER PATIENTS ASSOCIATION (ELPA)

ELPA is a patient organisation promoting the interests of people living with liver diseases. In 2014, the EHC participated in an international training day organised by ELPA on Hepatitis C. This is an area of great importance to the rare bleeding disorders community as many of whom were infected by contaminated blood products 20 to 30 years ago.

Medical and professional Societies

EUROPEAN ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS (EAHAD)

In 2013, the EHC and EAHAD signed a Memorandum of Understanding (MOU) to formalise their relationship and collaboration. In 2014 the organisations implemented this collaboration by speaking on key issues at each other's scientific conferences, aligning on key advocacy positions and collaborating on the European Haemophilia Network (EUHANET) project, in particular the certification of treatment centres (see pg 36). They also discussed launching new initiatives for 2015, which include a joint staff resource and a pilot project to conduct joint advocacy and educational visits to key countries in Europe.

EUROPEAN ASSOCIATION FOR HOSPITAL PHARMACISTS (EAHP)

In addition to working closely with EAHAD, in 2014 the EHC engaged in activities organised by the EAHP, who launched a consultation process to develop hospital pharmacist practice standards for Europe, and also ensured EAHP participation in EHC events such as Round Tables.

INTERNATIONAL SOCIETY FOR PHARMACOECONOMICS AND OUTCOME RESEARCH (ISPOR)

ISPOR is an international multidisciplinary professional membership society that advances the policy, science, and practice of pharmacoeconomics (health economics) and outcomes research. In 2014, ISPOR organised its Annual European Conference and hosted a Patient Round Table to discuss the current state of patient involvement in HTA, which the EHC attended.

INCREASE INFLUENCE ON EUROPEAN POLICY-MAKING ENVIRONMENT

Intricate and complex, the European policy-making environment is a layered arena of multiple decision-making bodies and diverse experts. The mission of the EHC is to inform all relevant stakeholders about the specificities of both haemophilia and other rare bleeding disorders, in order to ensure that appropriate decisions are made. For this purpose, the EHC is in regular contact with key institutions with decision-making roles in health policy and legislations, such as the European Commission, the European Medicines Agency (EMA), the European Parliament and the Council of Europe’s European Directorate for the Quality of Medicines and Healthcare.

EUROPEAN MEDICINES AGENCY (EMA)

As a patient organisation recognised by the EMA, in 2014, EHC representatives participated in various EMA meetings and workshops, including on Hepatitis E, Advanced Therapeutic Medicinal Products (ATMP) and Patient and Consumers Working Party (PCWP) sessions, among others. The EHC also provided patient input in the review of EMA communications, including package leaflets and Committee decisions. In addition, in 2014, Dr Günter Auerswald was appointed to the EMA Paediatric Committee (PDCO) as a representative of the EHC.

EUROPEAN PARLIAMENT

In 2014, the EHC launched an informal MEP support group for rare bleeding disorders. Chaired by Member of the European Parliament, Nessa Childers (Ireland), in 2014 the group also included Dr Paul Rübig (Austria), Dr Miroslav Mikolášik (Slovakia) and Dr Cristian Silviu Bușoi (Romania). In addition to working closely with this group and holding Round Tables in the European Parliament (see pgs 28, 31, 32), the EHC also met with other MEPs to discuss various advocacy efforts.

EUROPEAN COMMISSION

In addition to the aforementioned collaborations, the EHC also maintains close communications with various Directorates General (DG) of the European Commission, including DG SANCO, DG Growth and DG Market to keep the Commission informed and engaged on the various aspects of importance to our community.

EUROPEAN DIRECTORATE FOR THE QUALITY OF MEDICINES AND HEALTHCARE (EDQM)

The EDQM, a Directorate of the Council of Europe, is responsible for protecting public health by enabling the development, supporting the implementation and monitoring the application of quality standards for safe medicines and their safe use.

It is one of the main partners of the Wildbad Kreuth initiatives and the EHC works with them closely on the development and promotion of standards and recommendations (see pg 10).

ENSURE GOOD GOVERNANCE AND SUSTAINABILITY

The EHC maintains open and transparent relations with all stakeholders, including pharmaceutical companies, payers and regulators. The EHC is an eligible patient organisation associated with the EMA and is also on the Transparency Register of the European Parliament. The EHC receives, amongst others, financial support from the pharmaceutical industry in accordance to a strict policy published on its website. All EHC staff, consultants and elected volunteers as well as the members of the Medical Advisory Group have to adhere to a code of conduct and declare conflicts of interest. The EHC is also exploring opportunities to diversify its source of funding in order to better represent its independence.

SOUND AND TRANSPARENT FINANCIAL POLICIES AND PROCEDURES

As the staff and activities of the EHC grow, sound and transparent financial management must be ensured to maintain good governance and sustainability. To this end, the EHC built on previous practices by fine-tuning its annual budget exercise, updating its travel and reimbursement policies and ensuring robust checks and balances between staff and volunteers on all payment approvals and transfers. In 2014, the EHC also worked closely with an external accountant, reported monthly cash flow to the Steering Committee and submitted its annual accounts to a voluntary external audit, which is made public and published on the EHC website and annual reports, as well as submitted to key partners such as the EMA.

NEUTRAL AND TRANSPARENT CORPORATE SPONSORSHIP POLICY

Much of the EHC's work is made possible by generous support from its corporate partners. In order to ensure ethical and transparent relationships, the EHC accepts corporate funding in strict compliance with its 'Policy on Financial Support from Corporate Sponsors,' which is published on the EHC's website, and which outlines the terms and conditions relating to such funding, including that the EHC shall exercise full independence, accountability and transparency.

CLEAR AND ETHICAL CODES OF CONDUCT

In order to ensure the clear and ethical behaviour of all staff and volunteers, the EHC requires everyone who collaborates with the organisation (paid or unpaid) to complete and sign codes of conduct as well as declaration of interest forms.

PARTNERSHIP AND ENGAGEMENT BETWEEN THE EHC SC AND THE MAG

As complementary bodies in the governance and strategic work of the organisation, the EHC takes care to ensure a constructive and ongoing dialogue between the elected members of the Steering Committee – composed of patients or their family members – and the appointed members of the Medical Advisory Group – composed of clinicians. To this end, each body has a dedicated Terms of Reference and in 2014, the groups started to have joint meetings to ensure maximum dialogue, mutual engagement and alignment on key issues.

OPERATIONAL RESERVE

Operating in the uncertain financial environment of a European recession, in 2014 the EHC took the strategic decision to accrue a minimum of six-month operational reserve in the short-term and a one-year operational reserve in the longer-term in order to weather possible future funding cuts without damaging the work and activities of the organisation in the short-term.

DIVERSIFICATION OF FUNDING

In order to further protect the organisation from financial instability, as well as to ensure clear recognition by all stakeholders of the EHC's absolute independence as a patient organisation, in 2014 the EHC initiated efforts towards the diversification of its funding base.

STRUCTURE AND GOVERNANCE

Governance

The EHC is governed by the General Assembly of all NMOs, which typically meets once a year during the EHC Annual Conference. The SC is elected by the General Assembly and oversees the EHC yearly activities. The SC is composed of a President, Vice-President Finance and four to six lay Members. The EHC has a small office based in Brussels, Belgium, which implements the organisation's day-to-day work and activities.

Steering Committee

In 2014, the General Assembly re-elected Mr Jordan Nedevski as Vice-President Finance. The Steering Committee is composed of :

- Brian O'Mahony, EHC President, Irish Haemophilia Society
- Jordan Nedevski, EHC Vice-President Finance, Bulgarian Haemophilia Association
- Radoslaw Kaczmarek, EHC Steering Committee Member, Polish Haemophilia Society
- Traci Marshall Dowling, EHC Steering Committee Member, Irish Haemophilia Society
- Giuseppe Mazza, EHC Steering Committee Member, Italian Haemophilia Society
- Olivia Romero-Lux, EHC Steering Committee Member, French Haemophilia Association
- Alain Weill, Ex-Officio, President of the World Federation of Hemophilia

Medical Advisory Group (MAG)

Established in 2009, the MAG provides high-level medical and scientific support to the SC and EHC staff. It is composed of European medical and scientific experts in haemophilia and other congenital bleeding disorders. The MAG is composed of:

- Prof Paul Giangrande (Chairperson), Oxford University
- Prof Angelika Batorova, Medical Director of the National Hemophilia Center and the Hemostasis and Thrombosis Unit, University Hospital, Bratislava
- Prof Michael Makris, Honorary Consultant Haematologist, Sheffield Teaching Hospitals NHS Trust
- Prof Flora Peyvandi, Director of the Department of Internal Medicine, RCCS Maggiore Hospital, University of Milan

EHC Committees

DATA AND ECONOMICS

The Data and Economics Committee (DEC) was created to support the EHC's work in the area of health economics and HTAs. The DEC is composed of:

Chair – Declan Noone	Irish NMO
Amanda Bok	EHC staff
Mariëtte Driessens	Dutch NMO
Michael Makris	MAG member / University of Sheffield
Giuseppe Mazza	SC member / Italian NMO
Jamie O'Hara	UK NMO
Brian O'Mahony	EHC President / Irish NMO
Laura Savini	EHC staff
Uwe Schlenkrich	German NMO
Keith Tolley	Tolley Health Economics

YOUTH COMMITTEE

The Youth Committee supports the EHC's initiatives for youth such as the development and implementation of youth leadership trainings. It is composed of:

Chair – Michael van der Linde	Dutch NMO
Amanda Bok	EHC staff
Tracy Marshall Dowling	SC member / Irish NMO
Olivia Romero Lux	SC member / French NMO
Federico Ruiz Garcia	Spanish NMO
Laura Savini	EHC staff

WEBSITE COMMITTEE

In 2014 the Website Committee continued its work to revamp the EHC Website, which was launched in December 2014. The Website Committee is composed of:

Amanda Bok	EHC staff
Jo Eerens	EHC staff
Dan Farthing	EHC website consultant
Steffen Hartwig	EHC webmaster / German NMO
Traci Marshall Dowling	SC member / Irish NMO
Jordan Nedevski	Vice-President Finance / Bulgarian NMO
Olivia Romero-Lux	SC member / French NMO
Laura Savini	EHC staff

NEWSLETTER EDITORIAL COMMITTEE

The Newsletter Editorial Committee was created to support the EHC with the conception, planning, content and production of its newsletter; it is composed of:

Amanda Bok	EHC staff
Jo Eerens	EHC staff
Radoslaw Kaczmarek	SC member / Polish NMO
Olivia Romero Lux	SC member / French NMO
Laura Savini	EHC staff

Volunteers

With the exception of the EHC staff and consultants, unpaid volunteers carry out all of the other above-mentioned roles and responsibilities. These individuals work extremely hard to help advance the EHC’s activities and we thank them most sincerely for their time, dedication, patience and passion! In addition to the volunteers named above, we also express our thanks to those individuals who provided ad hoc support for the EHC in 2014:

- Katja Kirchkevitch (for her Russian translation of the website and other materials)
- Lucia Prihadova (for her contribution to the development and analysis of the EHC survey)

The EHC also extends its tahnks to all Members of the European Parliament and their staff who supported the EHC's work in 2014 as well as to all speakers, facilitators and chairs of EHC Round Tables, training workshops and the Annual Conference in 2014. The EHC would also like to extend its thanks to all volunteers that ensured smooth running of its Annual Conference, including local volunteers and the nurses manning the treatment room. Finally, the EHC would like to thank all the contributors to the EHC newsletter.

Service Providers

The EHC would like to thank the Conference Organisers for their help in the logistical organisation of the EHC events; Toast for their help with visual and print communication tools; Rohde Public Policy for their support of our EU-level work; BDO for their accounting services; Stéphane Rosier, our external auditor; Ethical Properties for making it possible for NGOs to be in the European Quarter; and last but not least Mrs Olga Miniuk and Mrs Julia Krivkina for their support with all Russian translations and interpretation at EHC events.

« The EHC would like to thank the Conference Organisers for their help in the logistical organisation of the EHC events. »


University of Amsterdam
European Haemophilia Consortium

Financial
Report

Message from the Vice-President Finance

In 2014 the European Haemophilia Consortium (EHC) was able both to continue to grow its activities for the European rare bleeding disorders community and to further strengthen the funding base and financial health of the organisation.

In 2014 the EHC achieved a 73% growth in income over the previous year and implemented pre-existing but also many new areas of work not just with one additional new staff person, but also with a team of hard working and committed volunteers. On behalf of the organisation, I take a moment to thank our corporate and other partners for their growing support, trust and collaboration. I also give a special thanks to our volunteers. To capture just how much our volunteers have done for the EHC in 2014, we carried out an economic evaluation of their unpaid time dedicated to implementing our programmes and activities. This resulted in a financial value of X [1], which is reflected in our income on pg 60.

Placing a financial value on the time and efforts of our volunteers is something the EHC began to do for 2014 and will continue to do in future years. We do this because it more accurately reflects the financial but also the human resources that go into – and come out of – our organisation. It more accurately reflects who we are as an organisation and how we work as a collective of patients and family members – together with our external partners – but independently and true to our mission. Therefore from 2014 forward, our funding overview (pg 64) will feature this figure even if it cannot be captured in our official financial accounts (pg 70) under Belgian regulations.

Importantly, the 2014 EHC Conference in Belfast, UK, also had a very positive financial result, which significantly contributed to the EHC's budget.

Due to all of the above in 2014 the EHC was able to generate a surplus of approximately €200,000, which it has put towards an important and growing operational reserve. The EHC's objective is to achieve a one-year operating reserve in order to ensure the sustainability of its core activities in times of financial difficulties.

Finally, in line with the EHC's commitment to external financial oversight, our 2014 accounts were independently audited under Belgian Audit Standards and the results are published on pg 62.

In conclusion, the year 2014 represented a very important step, one of many more to come as the EHC continues to work towards meeting the needs of the European rare bleeding disorders patient community.

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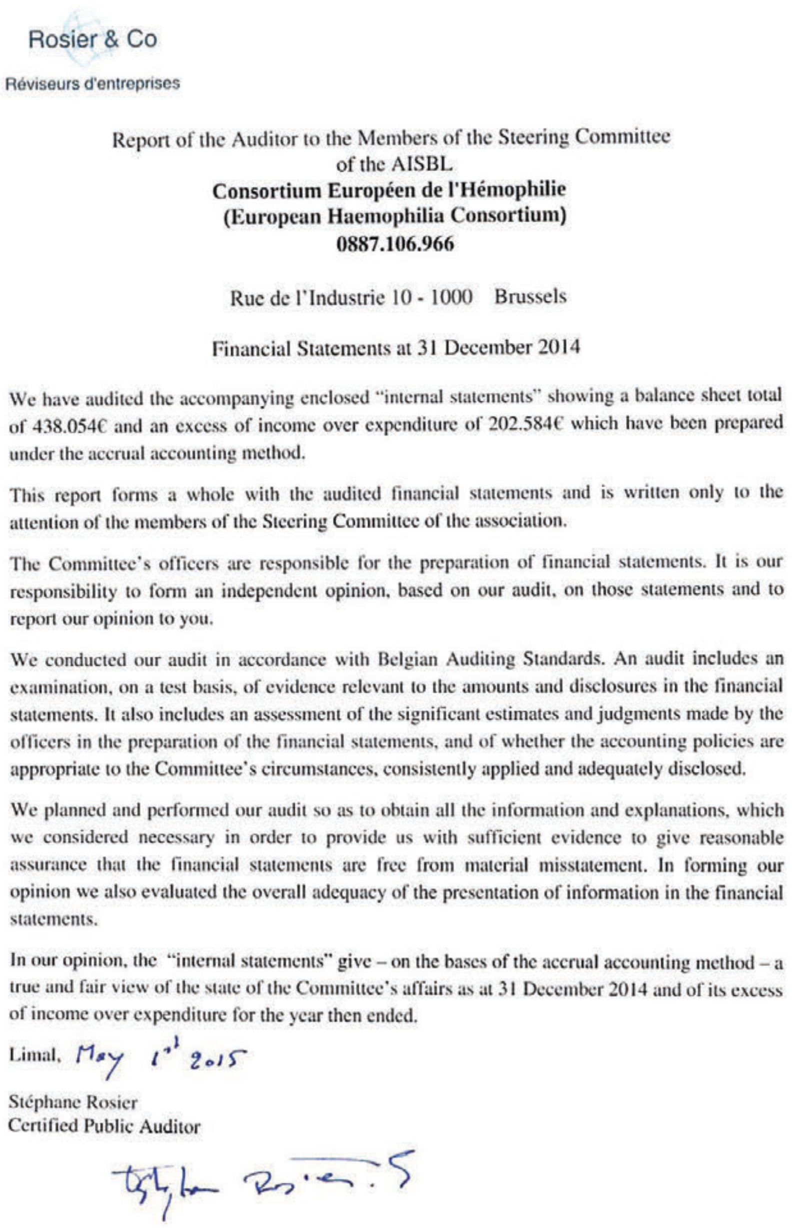
[1] The EHC used the same formula as Eurordis (of which the EHC is a member organisation) for this calculation.

Report of the auditor



Rosier & Co
Réviseurs d'entreprises

Report of the Auditor to the Members of the Steering Committee
of the AISBL
Consortium Européen de l'Hémophilie
(European Haemophilia Consortium)
0887.106.966

Rue de l'Industrie 10 - 1000 Brussels

Financial Statements at 31 December 2014

We have audited the accompanying enclosed "internal statements" showing a balance sheet total of 438.054€ and an excess of income over expenditure of 202.584€ which have been prepared under the accrual accounting method.

This report forms a whole with the audited financial statements and is written only to the attention of the members of the Steering Committee of the association.

The Committee's officers are responsible for the preparation of financial statements. It is our responsibility to form an independent opinion, based on our audit, on those statements and to report our opinion to you.

We conducted our audit in accordance with Belgian Auditing Standards. An audit includes an examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgments made by the officers in the preparation of the financial statements, and of whether the accounting policies are appropriate to the Committee's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations, which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

In our opinion, the "internal statements" give – on the bases of the accrual accounting method – a true and fair view of the state of the Committee's affairs as at 31 December 2014 and of its excess of income over expenditure for the year then ended.

Limal, May 1st 2015

Stéphane Rosier
Certified Public Auditor

Balance sheet

		YEAR 2014	YEAR 2013
FIXED ASSETS	**20/28**	**6.405,12**	**1.727,27**
Tangible assets	22/27	4.279,42	338,70
Furniture and vehicles	24	4.279,42	338,70
Fully owned by the association	**241**	**1.185,75**	**338,70**
241000 Computer equipment		2.230,88	751,88
241009 Depreciation / Computer equipment		**(1.045,13)**	**(413,18)**
Other	242	*3.093,67*	
242000 Office furnitures		**3.867,09**	
242009 Depreciation / Computer equipment		*(773,42)*	
Financial assets	28	2.125,70	1.388,57
Other financial assets	284/8	2.125,70	1.388,57
Amount receivable in cash garantees	**285/8**	**2.125,70**	**1.388,57**
288000 Cash garantees		2.125,70	1.388,57
CURRENT ASSETS	**29/58**	**431.649,52**	**271.280,84**
Amounts receivable within one year	40/41	24.568,89	11.806,84
Trade debtors	40	16.578,56	(74.155,18)
400000 Customers		**419,86**	**120,00**
404400 Credit notes to be received		16.158,70	5.724,82
407000 Doubtful amounts		**2.100,00**	**2.100,00**
409000 Amounts written off		(2.100,00)	(82.100,00)

		YEAR 2014	YEAR 2013
Others amounts receivable	41	7.990,33	85.962,02
411200 C/A V.A.T. ADMINISTRATION		7.990,33	5.962,02
416000 SUNDRY AMOUNTS			80.000,00
Cash at bank and in hand	54/58	346.207,44	205.425,99
550000 KBC 736-0015727-77 (SIGHT ACCOUNT)		14.356,39	65.492,60
550001 KBC 746-0011961-78 (SAVING ACCOUNT)		323.174,93	129.573,51
550002 KBC 746-0001443-54 (COMPTE EPARGNE EUHAN	242	8.226,81	8.692,70
550003 KBC 736-002608-76 (COMPTE A VUE EUHANET)		449,31	1.667,18
Deferred charges and accrued income	490/1	60.873,19	54.048,01
490000 DEFERRED CHARGES 1.048,01			1.048,01
491000 ACCRUED INCOME		60.873,19	53.000,00
TOTAL ASSETS		***438.054,64***	***273.008,11***
SOCIAL FUNDS	**10/15**	**360.976,40**	**158.391,89**
Associative funds	10	9.419,96	9.419,96
Permanent means	101	9.419,96	9.419,96
101100 PERMANENTLY FUNDS IN CASH		9.419,96	9.419,96
Accumulated profits	140	148.971,93	148.971,93
140000 ACCUMULATED PROFITS (LOSSES -)		148.971,93	148.971,93

		YEAR 2014	YEAR 2013
*** 149999 Solde entre 6 et 7		202.584,51	
AMOUNTS PAYABLE	**17/49**	**77.078,24**	**114.616,22**
Amounts payable within one year	42/48	73.467,99	38.698,94
Trade debts	44	67.974,86	29.906,86
Suppliers		67.974,86	29.906,86
440000 SUPPLIERS		56.666,87	8.443,73
444000 INVOICES TO BE RECEIVED		11.307,99	21.463,13
Taxes, remunerations and social security	45	5.493,13	8.792,08
Taxes	450/3		2.330,81
453000 TAXES WITHHELD			2.330,81
Remunerations and social security	454/9	5.493,13	6.461,27
454000 SOCIAL SECURITY CONTRIBUTIONS			2.391,16
455000 REMUNERATIONS TO BE PAID		2.064,11	4.070,11
456000 HOLIDAY PAY		3.429,02	
Accrued charges and deferred income	492/3	3.610,25	75.917,28
492000 ACCRUED CHARGES		3.610,25	3.610,25
493000 DEFERRED INCOME			72.307,03
TOTAL LIABILITIES		***438.054,64***	***273.008,11***

INCOME STATEMENT

		YEAR 2014	YEAR 2013
Operating income	**70/74**	**652.639,23**	**376.400,38**
Contributions, donations, legacies and subsides	73	505.273,81	343.370,00
730000 NMO MEMBERSHIP FEES		8.980,00	8.370,00
730010 CORPORATE GIVING PROGRAM MEMBERSHIP		104.500,00	77.000,00
730020 ROUND TABLE MEMBERSHIP		152.500,00	140.000,00
730030 RESTRICTED GRANTS		23.420,62	5.000,00
730040 EHC ANNUAL CONFERENCE		60.873,19	53.000,00
730050 SPONSORSHIP OTHER		155.000,00	60.000,00
Other operating income	74	147.365,42	33.030,38
740010 EUHANET PROJECT		132.307,03	29.782,83
743200 RECHARGE OF EXPENSES		14.851,71	2.917,89
743900 SOCIAL WITHHOLDING TAXES REFUND		206,68	329,66
Operating charges	**60/64**	**(454.013,91)**	**(302.428,83)**
Services and other goods	61	(420.876,95)	(266.365,07)
610100 OFFICE RENT		(8.871,40)	(7.200,00)
610110 RENTAL CHARGES OFFICE		(2.872,79)	
610120 RENT OF MEETING ROOM		(436,89)	
611300 CLEANING AND REPAIRS OFFICES		(501,03)	(127,65)
612100 RENT CAR		(41,39)	(118,24)
612130 POSTAGE		(1.445,98)	(1.003,88)

	YEAR 2014	YEAR 2013
612140 MOBILE COSTS	(1.274,24)	(2.261,39)
612150 TELEPHONE AND INTERNET COSTS	(2.082,98)	(1.977,44)
612200 DOCUMENTATION	(532,15)	
612300 OFFICE EQUIPMENT	(3.337,62)	(2.253,06)
612310 COPIER AND PRINTING SUPPLIES	(2.275,95)	
612400 PRINTING	(509,88)	(1.207,99)
612610 WEBSITE	(13.545,48)	(2.895,00)
612620 IT SUPPLIES	(6.603,08)	(167,73)
612900 REIMBOURSED EXPENSES	(14.851,71)	
613100 FIRE INSURANCE (BUILDING)	(152,46)	(150,45)
613160 INSURANCE PR	(624,28)	(624,28)
613170 TRAVEL INSURANCE	(11,53)	(49,73)
613200 ADMB FEES	(711,15)	(644,30)
613211 AUDITORS FEES	(1.547,25)	(3.094,50)
613212 ACCOUNTANCY FEES	(9.807,63)	(10.329,59)
613213 ADVISORY FEES	(940,20)	
613214 FEES MEAL VOUCHERS	(113,13)	(94,67)
613215 CONSULTANCY PUBLIC AFFAIRS	(35.206,50)	(56.890,00)
613216 CONSLUTANCY	(76.499,61)	(90.771,39)
613217 LAURA SAVINI FEES	(42.581,36)	
613219 TRANSLATIONS	(631,00)	
613220 CONFERENCE ORGANISERS FEES	(63.089,51)	
613402 TRANING COST	(1.534,84)	
613410 TRAVEL COSTS	(21.865,26)	(14.934,82)

		YEAR 2014	YEAR 2013
613420 RESTAURANT		(5.000,66)	(4.121,65)
613430 PARKING		(595,51)	(708,34)
613440 TRANSPORTATION - URBAN TRANSPORT		(3.502,06)	(3.276,08)
613450 HOTEL		(23.547,84)	(50.500,14)
613460 CADEAUX			(62,50)
613470 COSTS OF MEETINGS CATERING		(5.734,34)	(3.801,21)
613480 TAXI		(4.060,51)	(3.718,49)
613500 MEMBERSHIP FEES		(437,75)	(3.380,55)
615100 SPECIFIC PROJECT		(63.500,00)	
Remuneration; social security costs and pensions (+)(-)	62	(31.629,59)	(33.580,48)
612051200 GROSS SALARIES BELGIUM		(19.896,21)	(32.061,54)
621200 O.N.S.S. CONTRIBUTIONS		(4.463,85)	(5.297,56)
623001 LEGAL WORKERS INSURANCE		(215,07)	(329,13)
623003 EMPLOYEE URBAN TRANSPORT COST		(704,62)	(389,69)
623101 CATERING COSTS		(1.822,73)	(219,98)
623211 PREVENTION		(120,59)	(120,59)
623900 MEAL VOUCHERS		(977,50)	(904,23)
625000 PROVISION PECULE DE VACANCES		(3.429,02)	
625010 REPRISE PROVISION PECULE DE VACANCES (-)			5.742,24
Depreciation of and other amounts written off formations expenses; intangible and tangible fixed assets	630	(1.405,37)	(189,86)
630200 DEPRECIATION OF TANG. FIX. ASS		(1.405,37)	(189,86)

		YEAR 2014	YEAR 2013
Amounts written off stocks; contracts in progress and trade debtors: appropriations (write-backs) (+)(-)	631/4	80.000,00	(2.100,00)
634000 AM. WRITTEN OFF TRADE DEBT -1			(2.100,00)
634100 REP DEP. ON AMOUNTS REC.TRAD DEBT-1YEAR		80.000,00	
Other operating charges	640/8	(80.102,00)	(193,42)
642000 Deprecation on the customers		(80.000,00)	
643050 Other taxes		(102,00)	
643105 WITHHOLDING TAXES /INTERESTS			(193,42)
POSITIVE (NEGATIVE) OPERATING RESULT (+)(-)		***198.625,32***	***73.971,55***
Financial income	**75**	**1.344,66**	**1.348,41**
Income from current assets	751	1.343,96	1.333,31
751010 Interests / Bank accounts		1.343,96	1.333,31
Other financial income	752/9	0,70	15,10
754000 Exchange differences			0,05
754010 Payment differences		0,70	15,05
Financial charges	**65**	**(661,04)**	**(606,81)**
Other financial charges	652/9	(661,04)	(606,81)
654010 PAYMENT DIFFERENCES		(22,78)	(17,00)
654100 OTHER REALIZED EXCHANGE LOSSES		(9,89)	(4,09)
657000 BANK CHARGES		(628,37)	(585,72)

		YEAR 2014	YEAR 2013
POSITIVE (NEGATIVE) RESULT ON ORDINARY ACTIVITIES		***199.308,94***	***74.713,15***
Extraordinary income	**76**	**4.069,94**	
Other extraordinary income		4.069,94	
764000 OTHERS EXTRAORDINARY INCOME		4.069,94	
Extraordinary charges	**66**	**(600,00)**	**(2.348,20)**
Others Extraordinary charges	664/8	(600,00)	(2.348,20)
664000 Others extraordinary charges	**9903**	(600,00)	(2.348,20)
Profit (Loss) for the current financial year	67	**202.778,88**	**72.364,95**
Income taxes	670	(194,37)	(8,21)
Belgian taxes on the income of the current financial year		(194,37)	(8,21)
670300 Withholding TAX		(194,37)	(8,21)
Profit (Loss) for the financial year	**9904**	**202.584,51**	**72.356,74**

APPROPRIATIONS AND TRANSFERS

Profit (Loss) to be appropriated	**9906**	**202.584,51**	**148.971,93**
Profit (Loss) for the period avail. for appropr.	9905	202.584,51	72.356,74
Profit (Loss) brought forward	14P		76.615,19
790000 Profit brought forward			76.615,19
Profit (Loss) to be carried forward	**(14)**		**148.971,93**

ACCOUNTS OFF BALANCE SHEET

149999 - BROUGHT FORW. PROVIS. RESULT		202.585	

« In 2014 the EHC achieved a 73% growth in income over the previous year and implemented pre-existing but also many new areas of work »

SPONSORS

The EHC would like to acknowledge and thank its 2014 corporate sponsors:

PLATINUM SPONSOR:
Baxter, CSL Behring, Sobi, Pfizer

GOLD SPONSOR:
Bayer and Novo Nordisk

SILVER SPONSOR:
Biotest

The EHC would also like to thank the European Commission for its financial contribution to the EUHANET Project.

CSL Behring

European Hemophilia Consortium (EHC) Annual Report CSL Behring Article

CSL BEHRING: PARTNERING WITH THE GLOBAL BLEEDING DISORDERS COMMUNITY

As a leader in the global bleeding disorders community, CSL Behring is committed to meeting the needs of people with hemophilia, von Willebrand disease, and other rare bleeding disorders. It's this commitment that led CSL Behring to renew its pledge to the World Federation of Hemophilia to donate bleeding disorder protein therapy International Units (IUs) to the WFH Global Alliance for Progress (GAP) Program and other WFH programs, as well as to make significant financial contributions.

As part of the new agreement, CSL Behring will provide 10 million IUs of one or more of its products from its broad portfolio of bleeding disorder protein therapies to the WFH over the period of three years, beginning in 2016. The GAP Program strives to improve diagnosis and treatment of bleeding disorders in developing countries. In 2009, CSL Behring was the first biotherapies company in the world to make a multiyear commitment to WFH to aid the GAP Program with humanitarian aid coagulation factor donations over an extended period of time. CSL Behring will also provide $1.1 million in financial support to WFH's Corporate Partner and GAP programs over the three year period.

COMMITMENT TO ADVANCING COAGULATION SCIENCE

CSL Behring's commitment to innovation and meeting the needs of patients led the company to develop and advance its recombinant factor development program.

The AFFINITY clinical development program is studying CSL Behring's recombinant Factor VIII SingleChain (rVIII-SingleChain) to treat hemophilia A and the PROLONG-9FP clinical trial program is studying the company's recombinant fusion protein linking recombinant coagulation factor IX with recombinant albumin (rIX-FP) to treat hemophilia B. Regulatory submissions for rIX-FP are currently being reviewed by the European Medicines Agency and U.S. Food and Drug Administration.

CSL Behring also funds promising research that happens outside of its own labs. In 2008 the company began the annual CSL Behring Professor Heimburger Award, which helps to support pioneering coagulation factor research from across the globe. In 2015 CSL Behring awarded five researchers with 20,000 euro start-up grants to advance preclinical and/or clinical work in their highly specialized field of coagulation research.

For more information about CSL Behring, please visit www.cslbehring.com

Co-creation

Building programmes together

We believe that we can only build programmes that add real value to our communities when we listen carefully and when we create together. We call this "co-creation" and it is a cornerstone of how we work at Sobi. By listening carefully to our partners and members of the community, we can be guided by first-hand experience of people with haemophilia, their treaters, families and other key thought leaders. Together we can create meaningful approaches that will support better outcomes for people with haemophilia.

www.sobi.com

"While the economic support from industry is obviously important, we are strongly convinced it's not the only possible contribution, and constantly try to involve companies in our projects. Sometimes projects can even be a co-creation. This is the case for the programme we are launching for teenagers, the result of a course we charted together with Sobi."

Andrea Buzzi, President of the Paracelso Foundation

Feel The Gap: Transition from adolescence to young adulthood is a critical phase in life. For people with haemophilia this phase is even more delicate. Feel The Gap is the name of a project in Italy co-created together with Sobi to allow small groups of adolescents and young adults with haemophilia to share their feelings, experiences and doubts, to help them face this difficult passage together.

"For children with haemophilia, breaking the stigma and being able to live as normal a life as possible is as important as an effective treatment. The app is a great initiative, and I am very happy that it is now available."

Dr Kate Khair, Consultant Nurse Haemophilia GOSH

Magic Movie Maker: Children living with haemophilia sometimes have a hard time talking about their condition. Sobi has, with the support of Consultant Nurse Dr Kate Khair and her team at the Great Ormond Street Hospital for Children, developed the Magic Movie Maker – a free iPad app created to enable children to enlighten others about what it means for them to live with haemophilia.

"Sobi has been very respectful of our independence and the editorial angle of the project. This multidisciplinary project is a result of close collaboration with medical professionals, Sobi and ourself, where mutual respect for each other's objectives has been a key to the success."

Thomas Sannié, Président de l'Association française des hémophiles

The French Haemophilia association (AFH): AFH is committed since October 2012 to provide information to patients on research activities on rare bleeding disorders and to make sure patients acquire knowledge in this field. One of the project aimed to create a better understanding of clinical trials for patients and their families, and to raise awareness about their important role in clinical research thereby helping them to make informed decisions about participation in clinical trials. The brochure called "Patient Guide - Participating in a clinical trial" was developed in partnership with Sobi.

THE
HAEMOPHILIA
SOCIETY

"We find Sobi an excellent collaborator as we have similar goals and ambitions for people with haemophilia. We find this collaboration a synergistic way of working and supporting people with haemophilia."

Christina Burgess, Head of Membership and Planning, the Haemophilia Society UK

sobi
Pioneer in Rare Diseases

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From Baxter's BioScience to Baxalta...

Baxter's BioScience is expected to become Baxalta in mid-2015.

At Baxter's BioScience, we see a world of endless possibilities for you. And although our name may be changing to Baxalta, our commitment to you is as strong as ever. At our foundation is an enduring heritage of innovation and advocacy. Your life is our inspiration to make a meaningful difference, so you can dream big, and experience life. We are excited about the future and hope you are too!

Baxter

Pfizer Haemophilia

Partnering to *Change the World* for People with Haemophilia

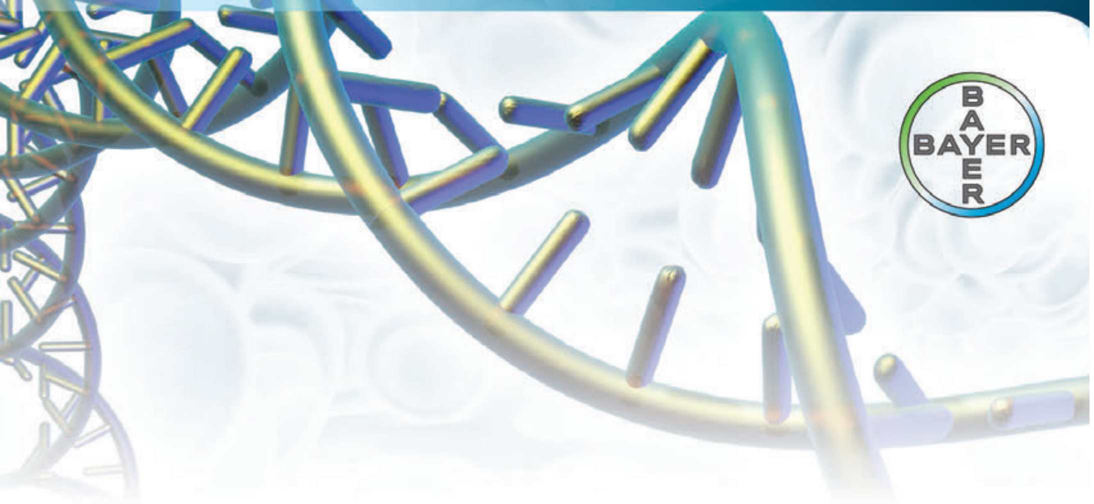
Pfizer is committed to the improvement of long-term outcomes for people with haemophilia and the support they receive to manage their condition

MILES FOR HAEMOPHILIA
YOUR PERSONAL BEST!

Haemoassist®

Pfizer
Ultrasound
Programme
Innovation and
Imaging in Haemophilia

Date of preparation: August 2015
REFEU403



EHC ANNUAL REPORT 2014, NOVO NORDISK INPUT, APRIL 2015;

Novo Nordisk is a proud supporter to the EHC

Novo Nordisk is committed to Changing Possibilities in Haemophilia®. We believe that multidisciplinary, expert care in haemophilia is key to achieve optimal outcomes based on a clear understanding of the physical, emotional and social well-being of people with haemophilia. We know that our products only get us part of the way, and we work with partners across the haemophilia community, such as the EHC, in order to reach our goals.

Our Joint Health initiatives such as TalkingJoints™ and the Novo Nordisk Haemophilia Fitness Camp raise awareness that joint functionality is essential to people living with haemophilia: TalkingJoints™ provides information, education and support on joint function as it aims to help individuals detect changes to their joints early: feel something, and act accordingly: do something. The Novo Nordisk haemophilia fitness camp is a programme created for HCPs, people with haemophilia and their caregivers. It highlights the importance of physical activity and how it can be safely introduced into the everyday lives of people with haemophilia. It aims to provide HCPs with materials and training to run Fitness Camps in their haemophilia treatment centres and/or region.

Through the HERO initiative we work to create a better understanding of the psychosocial needs of people with haemophilia. The insights generated can help patient organisations and other stakeholders in the haemophilia community advocate for better expert care in haemophilia. In 2014, the HERO Research Grant programme was launched, and we are delighted to announce that we will provide the Grants again in 2015: 4 project grants are available for award. The amount will be up to EUR 75,000 for each.

Learn more about how Novo Nordisk is Changing Possibilities in Haemophilia® everyday on changingpossibilities.com and herostudy.org

EHC

european haemophilia consortium