ANNUAL REPORT 2013

EUROPEAN HAEMOPHILIA CONSORTIUM

SUMMARY

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 for 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:

1. Improve diagnostic and treatment facilities
2. Ensure adequate supply of – and access to – safe factor concentrates
3. Promote patients' rights and raise ethical issues
4. Follow and influence developments in European health policy
5. Monitoring the status of haemophilia care in member countries
6. Stimulate research in all fields related to haemophilia and rare bleeding disorders

Members

The EHC has 44 National Member Organisations (NMOs) from 27 EU Member States, including all acceding countries as well as most of the Council of Europe. It represents approximately 90,000 people with congenital bleeding disorders such as haemophilia A and B, VWD and other rare bleeding disorders.

EHC members are located in: Albania, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Heerzegovenia, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, Macedonia, Moldova, Montenegro, Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine, United Kingdom

Partnerships

The EHC works closely with other key organisations in Europe and globally including: the European Commission, the European Parliament, European Medicines Agency (EMA), the Council of Europe, the World Federation of Hemophilia (WFH), the European Association for Haemophilia and Allied Disorders (EAHAD), the International Patient Organisation for Primary Immunodeficiencies (IPOPI), the European Patients' Forum (EPF), Eurordis and EPPOSI. The EHC is also a founding and active member of the Platform of Plasma Protein Users (PLUS) and works closely with four other implementing partners on the European Commission co-funded project EUHANET.

Message from the President Brian O'Mahony and CEO Amanda Bok

For the EHC, 2013 was a year of solid achievement based on collaboration, alliance-building and defined programme work. Our organisation grew in strength and influence through more formalised collaboration with and integration of our Medical Advisory Group (MAG) into the work of the Steering Committee (SC). Our collaboration with the World Federation of Hemophilia (WFH) was strengthened by an updated Memorandum of Understanding (MOU) and our collaboration with the community of European Haemophilia treaters was greatly increased by the signing of a MOU with the European Association for Haemophilia and Allied Disorders (EAHAD). As part of this collaboration, for the first time, the EHC delivered a lecture at the EAHAD conference on our view of the regulatory environment in Europe. At a policy level, we had increased contact with the European Medicines Agency (EMA) including a formal meeting with six EMA committees, more meetings with Members of the European Parliament (MEPs) and engagement with the Council of Europe through the European Directorate for the Quality of Medicine and Healthcare (EDQM). The EHC has become formally involved in the new European Commission Expert Group on Rare Diseases as an alternate member. We worked to increase our involvement with the fledgling EU Health Technology Assessment (HTA) network and started to build a relationship with the European Patients Forum (EPF).

The increased collaboration and alliance-building were important, not only in the context of building sustainable long-term relationships, but also in the pursuit of short- and medium-term goals. At EU level, we had concerns relating to the impact of the Clinical Trial guidelines and the requirement for the completion of paediatric studies on new products prior to their licencing in adults. These guidelines are resulting in delays of approximately two years in the licencing of new factor concentrates in the EU compared to regions outside of Europe. A more serious concern was the possibility of a severe limitation in the availability of new therapies due to the potential granting of market exclusivity to specific factor concentrates under the Orphan Medicinal Product Regulations (OMPR). The EHC with the active participation of our MAG worked hard during 2013 to ensure that the views on these issues of the European haemophilia patient community were heard by the EMA, the European Commission and MEPs. The formal meeting with the EMA on these issues was ground-breaking and established the EHC as a serious partner for consultation. Our work in these vital issues also included speaking with the European clinical community through EAHAD, with the global clinical community at the Scientific and Standardisation Committee (SSC) conference of the International Society for Thrombosis and Haemostasis (ISTH) and informing and advocating with influential MEPs on these issues. An article authored by MAG member Flora Peyvandi with myself was published in the prestigious Journal *Nature* on this issue.

The data collected by the EHC from 35 of our NMOs in 2012 formed the basis of our World Haemophilia Day activity in 2013. The data, published as a paper in *Haemophilia* and as a Monograph by the EHC was a comprehensive examination of every aspect of comprehensive care in the 35 countries who answered the detailed survey. Our 43 members received an individually-tailored PowerPoint presentation demonstrating the current status of haemophilia treatment in their country or region in relation to the rest of Europe. We hope and believe that these presentations were useful tools for our NMOs in their ongoing advocacy work.

The data was also useful in our efforts to influence the new recommendations on haemophilia care in Europe produced by the EDQM in 2013. A total of seven new recommendations were agreed at a meeting of experts attended by the EHC. These new recommendations included minimum factor use in countries, formal involvement of haemophilia patient organisations in national haemophilia committees, prophylaxis in adults and the prevention of market exclusivity for haemophilia therapies.

These recommendations are very important tools for the EHC and for all NMOs as they are promulgated by an official European body and therefore should carry weight with governments.

Our three Round Tables were very successful and well-attended. We organised two of them in the European Parliament on the 'Implications of the EU Cross-Border Healthcare Directive for People with Haemophilia' and 'Towards Haemophilia Centres of Expertise in Europe'. One of them was organised outside the European Parliament on 'Access to New Therapies: Opportunities, Challenges and Barriers.' We greatly appreciate the ongoing collaboration with MEPs on these events, including Nessa Childers (Ireland), Miroslav Mikolasic (Slovakia) and Rebecca Taylor (UK).

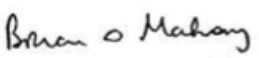
The growing importance of HTAs and economic evaluation in haemophilia resulted in the first of a series of EHC workshops on HTAs and Economics, which was held in London. Attended by 16 participants from 14 NMOs, the workshop was a practical and very constructive event, which gave attendees a clear grounding in economic concepts. As a result of the success of this workshop, an EHC Data and Economics Committee was established later in 2013. Chaired by Declan Noone from Ireland, this committee will work on issues relating to these vital areas and play an ongoing role in our future HTA workshops.

Assistance, advice and support was provided to a number of NMOs during the year. Advice or assistance on issues requiring a clinical input or opinion was provided by our active and engaged MAG chaired by Prof Paul Giangrande. A specific visit was also made to Estonia during 2013 to assist the NMO and clinicians in their ongoing efforts to achieve a meaningful participation in their national tender process for factor concentrates.

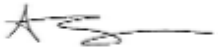
Following the establishment of selection criteria for European Haemophilia Comprehensive Care Centres (EHCCC) and European Haemophilia Treatment Centres (EHTC), which were developed by an EHC working group, we set out with the certification process for centres as part of the working group established for this process. This process gives the EHC an important role in the certification of centres and in the future may allow for an expanded role in external audits of centres.

The EHC had a good year financially with income up by 89% compared to 2012. We continue to grow our finances in a measured way in line with our increased activity in terms of workshops, data collection and advocacy.

Finally, we want to express our thanks to the EHC SC, MAG, staff and volunteers for their continued and increasing commitment and hard work on behalf of the haemophilia community in Europe.



Brian O'Mahony
President



Amanda Bok
Chief Executive Officer

Activity Report

1. DIAGNOSTIC AND TREATMENT FACILITIES

Congenital bleeding disorders are rare and complex conditions to manage. In Europe there are great disparities between countries in terms of access to diagnosis and treatment facilities, as well as between treatment facilities themselves. In 2013, the EHC worked with key partners to start standardising and certifying the delivery of haemophilia care throughout Europe. This will help people with bleeding disorders to have a clear idea of what to expect in terms of diagnosis, treatment and care in a transparent and harmonised manner.

EUHANET

As part of the European Haemophilia Network (EUHANET) project – which runs from 2012-2015, is co-funded by the European Commission and is led by the University of Sheffield – the EHC produced and delivered the European guidelines for the certification of haemophilia centres. This document set the standards and criteria for the designation of haemophilia centres within Europe as either European Haemophilia Comprehensive Care Centres (EHCCC) or European Haemophilia Treatment Centres (EHTC). The objective of these guidelines was to promote the standardisation of care as well as to ensure equity of treatment throughout Europe's diverse countries and regions. The document was drawn up in close consultation with the European Association for Haemophilia and Allied Disorders (EAHAD) – one of the four other implementing partners on the EUHANET team.

EUHANET Project Components

Haemophilia Central Website

Haemophilia Central is a service designed as a focal point for the haemophilia community, providing key information for patients and doctors alike. The website provides the latest haemophilia news, a comprehensive 'Frequently Asked Questions' section for patients, a mobile phone 'Haemophilia Centre Locator' application and the Haemtrack telemedicine home treatment management system, allowing remote review of patients' home treatment. The site also provides information on Clinical Guidelines, Clinical Trials, available treatment and other information.

Certification of European Haemophilia Centres

EUHANET developed a system for certification of the delivery of haemophilia care in Europe. During the first year of the project criteria defining 2 levels of haemophilia care were created through extensive consultation. Treatment centres have now been invited to apply for certification and their level of service is currently being assessed according to which criteria they satisfy.

EUHASS Website

EUHASS is a pharmacovigilance programme to monitor the safety of treatments for people with haemophilia and other inherited bleeding disorders in Europe. It started in 2008 and currently has 80 centres reporting from 26 European countries caring for almost 30,000 people with bleeding disorders. It will be expanded to include reporting of adverse events in acquired haemophilia, acquired von Willebrand's disease and severe inherited platelet disorders. Data on the management of thrombotic events will also be collected.

Rare Bleeding Disorder Database

The RBDD was set up by the European Network of Rare Bleeding Disorders (EN-RBD) and has retrospective information on the non-haemophilia rare bleeding disorders. The database will be extended to allow the collection of prospective data on the bleeding and natural history of afibrinogenemia and factor XIII deficiency. Central specialised coagulation factor and genetic testing will be offered and an external quality assessment scheme will be established.

Round Table of Stakeholders – 'Towards Haemophilia Centres of Expertise in Europe'

The European guidelines for the certification of haemophilia centres, produced by the EHC under the EUHANET project (P.12), were launched at the EHC Round Table of Stakeholders held in the European Parliament and co-hosted by two Members of the European Parliament, Ms Nessa Childers (Ireland) and Ms Rebecca Taylor (UK). The objective of this Round Table was to introduce the guidelines to a broad EU audience and to link them into the wider EU work being done on European Reference Networks and Centres of Expertise. The guidelines were also launched separately in Rome, Italy, with a more comprehensive audience of stakeholders. In addition to benefiting patients by promoting quality standards and a certification process for two tiers of haemophilia centres in Europe, the guidelines also benefit treatment centres by enabling them to advocate for greater resources when needed. Close to 50 people attend the Brussels-held Round Table; all materials from the event as well as a final meeting report are available on the EHC website.

Memorandum of Understanding – Romanian Ministry of Health

Following intensive and long-standing efforts from the Romanian Haemophilia Association (ARH – Asociaia Român de Hemofilie), with support from the EHC, the Romanian Ministry of Health together with the ARH and the EHC signed a joint Memorandum of Understanding (MOU) on 'Haemophilia, a priority for public health in Romania' on 7 October 2013. A detailed, two-page document, the MOU listed key responsibilities for all parties and, notably, commits the government to 1) making haemophilia a national health priority, 2) establishing a haemophilia council, i.e. a body representing the government, the insurance fund, physicians and the NMO to evaluate the state of haemophilia care and to identify appropriate measures to improve it, and 3) preparing the necessary legal framework for the establishment, organisation and functioning of haemophilia treatment centres, amongst others. This was an historic event and is the first time that the EHC signs an MOU with a national Ministry of Health.

2. ADEQUATE SUPPLY OF – AND ACCESS TO – SAFE FACTOR CONCENTRATES

Ensuring that patients across Europe receive safe factor concentrates has been a cornerstone of the EHC's mission since its inception in the wake of the 1980s blood contamination scandals. In 2013 the EHC worked specifically on issues of access, as recent economic pressures in Europe have begun to threaten adequate supply and choice of products. The EHC also focused attention on key European regulations, which have the potential to hinder or significantly delay patients' access to treatment.

NMO Workshop Economics and Health Technology Assessments (HTAs)

In 2013 the EHC held the first in a three-year series of Economics and HTA workshops for all NMOs. The 2013 workshop targeted NMOs from Western EU Member States with subsequent workshops targeting the remaining EU Member States and non-EU countries. These workshops are designed to equip all NMOs with a sound understanding of the economics behind haemophilia care and with the ability to actively participate in and influence current or future HTA processes in their countries to ensure that patients get proper access to the treatment products that they need. The 2013 workshop provided rigorous training to 14 participants from 12 EU Member States, some of whom subsequently joined the EHC's new Data and Economics Committee (see P.38). Further 'down-streaming' activities within individual NMOs following the training were planned and are in various stages of implementation.

Advocacy campaign EU Orphan Medicinal Product Regulation and Market Exclusivity

In 2013, clinical trial results from novel technologies continued to demonstrate that in some cases the half-life of haemophilia treatment products could be significantly prolonged in patients – a development that seemed increasingly poised to revolutionise haemophilia treatment and care by reducing the frequency of needed infusions. Initial advocacy efforts conducted in 2012 with the European Commission and the European Medicines Agency (EMA) continued in 2013 as all pipeline products had received orphan drug designation under the EU Orphan Medicinal Product Regulation (141/2000, OMPR). As such, only the first to receive marketing authorisation would benefit from 10-year marketing exclusivity and enter the European market. Alarmed by the consequences (particularly the creation of a monopoly and the lack of access to other possibly superior technologies for patients) the EHC heightened its advocacy campaign in 2013. It requested and was granted a high-level meeting with 19 EMA representatives from six committees to discuss these (and other, see P.22) issues in depth. The EHC also met with the European Commission and started advocating bilaterally with the relevant pharmaceutical companies. Although many stakeholders agreed with the EHC's position in principle, they did not take clear positions in practice, and the EHC's advocacy campaign was carried forward into 2014.

Round Table of Stakeholders – 'Access to new therapies: opportunities, challenges and barriers'

A detailed overview of the science behind the different protein modification methods of novel longer-acting products was given during the EHC's Round Table of Stakeholders on 'Access to new therapies: opportunities, challenges and barriers.' Held in Brussels and chaired by EHC Steering Committee member Radoslaw Kaczmarek, this Round Table was attended by more than 40 participants and also examined the economic and regulatory barriers to timely, cost-effective and sustainable access in Europe, as well as the potential role and impact of the OMPR (see above). All materials from the event as well as a final meeting report are available on the EHC website.

3. PATIENTS' RIGHTS AND ETHICAL ISSUES

The EHC works to ensure that ethical issues and the rights of its patient community are properly disseminated, understood and respected in all areas of decision-making relevant to their treatment, care and quality of life.

Round Table of Stakeholders
‘The implications of the EU Cross-Border Healthcare Directive for people with haemophilia’

Six months ahead of its agreed national implementation date, the EHC held a Round Table of Stakeholders on the ‘EU Cross-Border Healthcare Directive.’ Held in the European Parliament and co-hosted by Members of the European Parliament Nessa Childers (Ireland) and Rebecca Taylor (UK), the objective of the event was to inform patients and other stakeholders about how the Directive really works and what to expect when it enters Member States’ national laws. In the discussions between more than 40 participants, the conclusion ensued that the legislation would likely have a minimal impact on haemophilia but could potentially benefit people with rare bleeding disorders. Participants also forecast that the Directive would impact the ongoing harmonisation of Health Technology Assessments (HTAs) in Europe. All materials from the event as well as a final meeting report are available on the EHC website.

Paediatric requirements of the Guidelines on Clinical Investigation of Recombinant and Human Plasma-Derived Factor VIII and Factor IX Products

With the first in the pipeline of novel, longer-acting haemophilia treatment products set to enter the market in North America in 2013-2014, it became clear that patients in Europe would face an additional delay in access of up to three years due to different paediatric requirements in the EU's Guidelines on Clinical Investigation of Recombinant and Human Plasma-Derived Factor VIII and Factor IX Products (EMA/CHMP/BPWP/144533/2009) compared to the requirements of the US Food and Drug Administration (FDA). Concerned about the potential consequences – including disadvantaging adult patients, compromising the future affordability of products, and further delaying pediatric access – the EHC, which had begun a letter-writing campaign in 2012, requested and was granted a high-level meeting with 19 EMA representatives from six committees to discuss these (and other, see P.18) issues in depth. During the meeting the EHC engaged fully with the EMA on these Guidelines, on the EU's Paediatric Regulation and on the legislation's unrealistic enrolment requirement for previously untreated children in a rare disease context. The EHC recommended a number of alternative solutions, including a two-step marketing authorisation process with a mandatory risk management plan to minimise off-label paediatric use – as allowed for in EU pharmaceutical legislation. The EMA – though empathetic to the issue – did not move on its position and the EHC's advocacy efforts continue.

PLUS
PLATFORM OF PLASMA PROTEIN USERS

PLUS and the EU 'Blood Directive'

In anticipation of a potential revision of the EU 'Blood Directive' – the EU Directive on 'Setting Standards of Quality and Safety for the Collection, Testing, Processing, Storage and Distribution of Human Blood and Blood Components' (Directive 2002/98/EC) – in the next few years, the European Commission initiated a fact-finding mission and commissioned an analytical report to determine the plasma-derived therapies' supply chain in Europe. The EHC through the Platform of Plasma Protein Users (PLUS), of which it is a founding and central member, actively and formally contributed to this process in 2013. The European Commission is expected to announce in 2015 whether or not this Directive will be revised. In addition to working in this area, the EHC meets with other PLUS member regularly to monitor the quality and safety of plasma-derived therapies and their adequate and regular supply.

4. DEVELOPMENTS IN EUROPEAN HEALTH POLICY

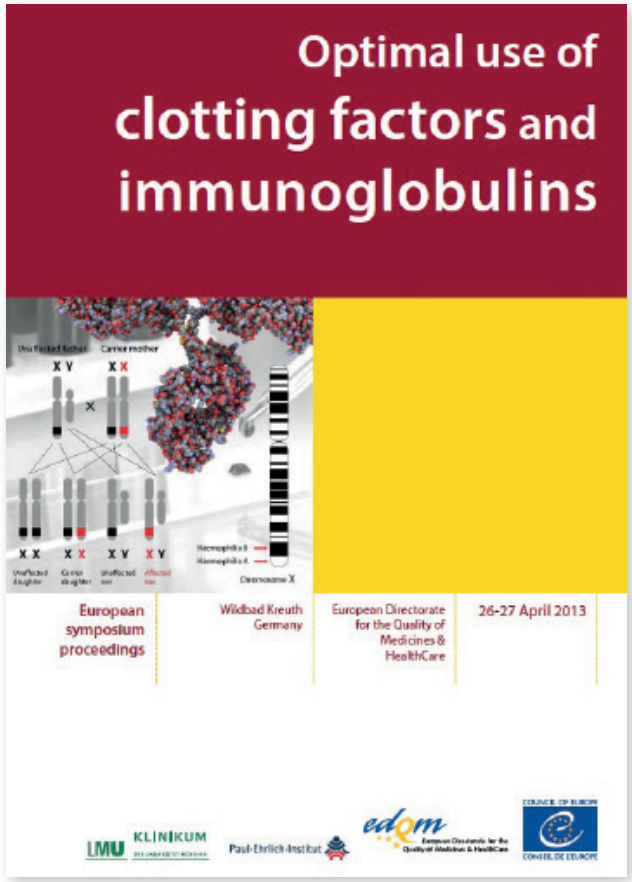
The EHC closely follows developments in European health policy both inside and outside of the European Union, and regularly provides its NMOs with reports. The EHC also works closely with other key stakeholders in healthcare to monitor and when necessary advocate on key policy developments.

Quarterly Policy Reports

In 2013 the EHC produced four quarterly policy reports for its NMOs covering developments in health policy and legislation at a European level – including EU institutions, the Council of Europe, the World Health Organisation (WHO) and other key policy-making organisations that impact all of Europe.

Wildbad Kreuth Initiative / Council of Europe

The Council of Europe through its European Directorate for the Quality of Medicines and Healthcare (EDQM), in partnership with the Paul-Ehrlich-Institut and the University of Munich, held a high-level consensus meeting on the "Optimal use of clotting factors and immunoglobulins" in Wildbad Kreuth, Germany, in April 2013. This meeting brought together more than 100 experts from 36 countries to discuss current clinical practices for the use of coagulation clotting factors for haemophilia and other bleeding disorders. The EHC contributed to this meeting through presentations given by its President and two members of its Medical Advisory Group (MAG). The EHC delegation provided a patients' perspective on access and unmet needs, and presented on 'Benefits and limitations with innovative clotting factor preparations' and 'Clinical challenges and access to clotting factor concentrates in haemophilia in Europe.' The Wildbad Kreuth meeting produced seven key recommendations that set the new minimum standards of treatment and care for people with bleeding disorders in Europe.



European Medicines Agency

In 2013 the EHC successfully applied and became officially associated with the European Medicines Agency (EMA) as a 'patient organisation eligible to be involved in EMA activities.' During the year, EHC representatives participated in the following key EMA meetings:

- Patients' and Consumers' Working Party (PCWP) meeting with all eligible patient organisations, held in London in December. This meeting provided updates on the year's regulatory activities including from the Pharmacovigilance Risk Assessment Committee (PRAC), adverse drug reaction (ADR) reporting and the EMA's collaboration with Health Technology Assessments (HTA).

- Scientific Committees' Working Party.

- Workshop on the characterisation of new clotting factor concentrates with respect to potency assays used for labelling and testing of post infusion samples

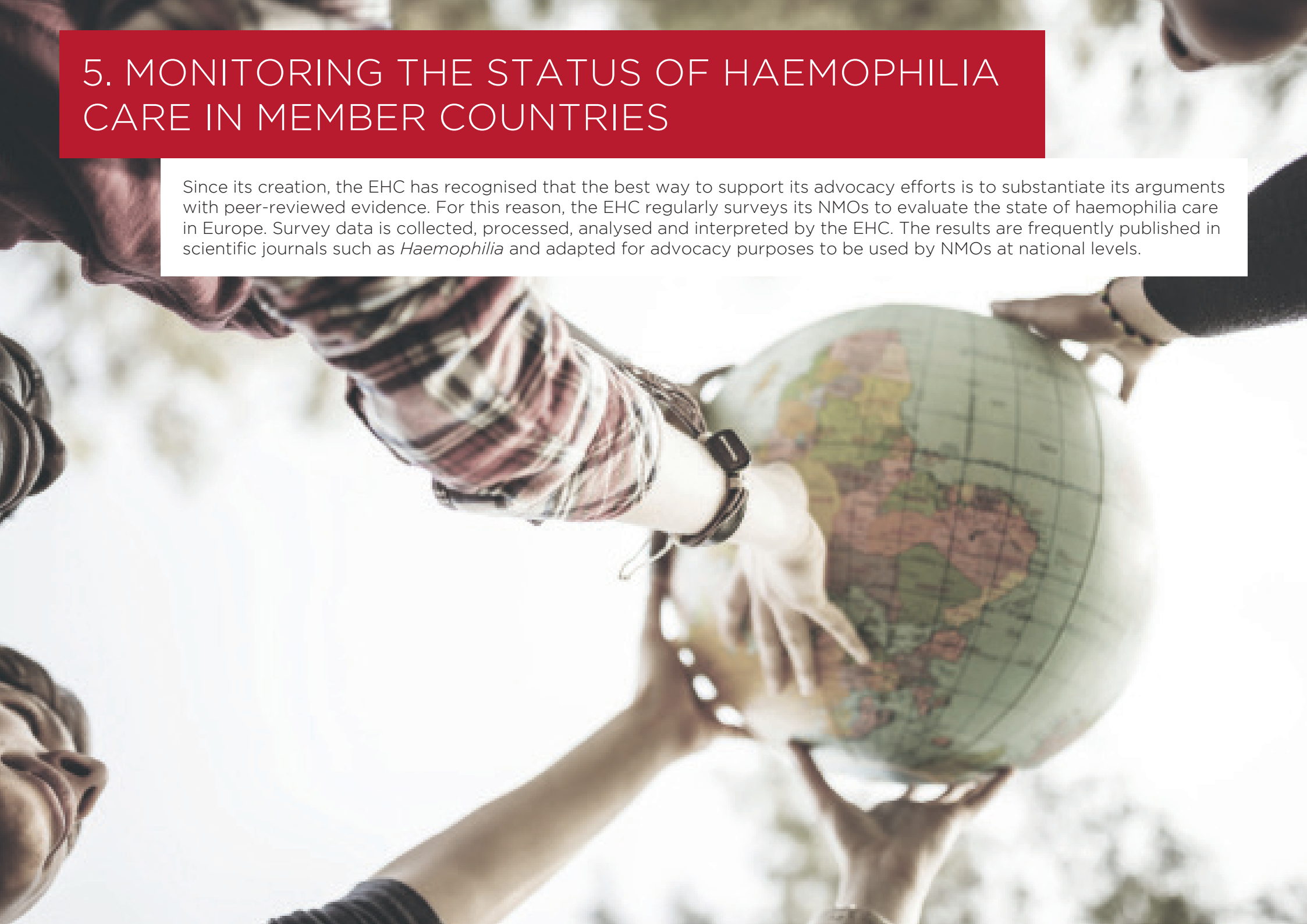
  On 28th and 29th November 2013 Professors Mike Makris and Flora Peyvandi represented the EHC at a workshop in London organised jointly by the European Medicines Agency and the European Directorate for the Quality of Medicines and Healthcare. This workshop explored the methods by which the new long acting FVIII and IX concentrates will be labelled and what assays clinical laboratories will need to be using to manage patients.

- Joint EMA-EUnetHTA workshop

  EUnetHTA is a European project created in 2006 to develop a long term strategy for Health Technology Assessment (HTA) cooperation in Europe. To further this project, a joint EMA – EUnetHTA workshop in took place in November 2013. Mr Declan Noone, Chair of the EHC Data and Economics Committee attended this meeting on behalf of the EHC. The focus of the meeting was earlier involvement of Health Technology Assessment (HTA) agencies in conjunction with EMA when assessing new technologies. To this end, EUnetHTA is working closely with the European Medicines Agency (EMA) to streamline the process. This would mean that collaboration between HTA authorities and EMA may begin after Phase II clinical trials where information required for the final submissions for licensing and reimbursement will be recommended. After clinical trials are complete, a submission will be made to the EMA and HTA authorities concurrently and licensing and HTA report will be made at the same time. Unfortunately as of yet, there is no recommendation of patient involvement during the early engagement with the EMA and HTA authorities. The meeting also discussed the difficulty in assessing the added value of new health technologies, mostly due to lack of assessment of endpoints that are considered in a HTA other than just clinical trial endpoints.
  The EHC will become more involved in future steps of the development of EUnetHTA as well as any further co-operation with EMA. The area of HTA will be increasingly important as healthcare systems in Europe aim to become more sustainable as well as being based on evidence-based practices and transparency in reimbursement decisions.

5. MONITORING THE STATUS OF HAEMOPHILIA CARE IN MEMBER COUNTRIES

Since its creation, the EHC has recognised that the best way to support its advocacy efforts is to substantiate its arguments with peer-reviewed evidence. For this reason, the EHC regularly surveys its NMOs to evaluate the state of haemophilia care in Europe. Survey data is collected, processed, analysed and interpreted by the EHC. The results are frequently published in scientific journals such as *Haemophilia* and adapted for advocacy purposes to be used by NMOs at national levels.



Haemophilia care in Europe: a survey of 35 countries

Building on its 2009 survey of haemophilia care in 19 European countries, a 2012 survey examined the real-world implementation status, three years on, of the Principles of Haemophilia Care and some of the Council of Europe's Recommendations for Haemophilia in EHC member countries. This survey examined the existence of patients' registries, the organisation of national procurement, coagulation factor concentrate consumption in relation to Gross Domestic Product (GDP) and different types of treatments available to people with bleeding disorders, amongst others. The survey was carried out in 2012 and its results were published in 2013 the scientific journal *Haemophilia* as well as in an EHC monograph. With these survey results, the EHC also produced 43 nationally tailored advocacy toolkits for use by all of its members.

Brian O'Mahony – 2012 , brian@haemophilia.ie

6. RESEARCH IN FIELDS RELATED TO HAEMOPHILIA

The EHC promotes research in the areas of haemophilia and other congenital bleeding disorders, and works towards this in collaboration with key partners.

EUHANET

The EHC supported the creation of the Rare Bleeding Disorders Database (RBDD) to collect clinical and laboratory data of patients with coagulation factor deficiencies in order to evaluate prevalence, bleeding frequency and management, as well as consumption of treatment products and related complications. The RBDD was established through the joint EUHANET project (see P.12) that is co-funded by the European Commission and of which the EHC is one of five implementing partners.

Memorandum of Understanding with EAHAD

In 2013, the EHC and the European Association for Haemophilia and Allied Disorders (EAHAD) entered into a formal collaboration with the signing of a Memorandum of Understanding (MOU). Already partners on the EUHANET project (see P.12), amongst others, this MOU set out the terms for a long-term and official collaboration, which includes consulting one another on key topics of mutual interest, including research, as well as aligning advocacy, training and other actions as relevant.

Memorandum of Understanding with the WFH

Building on an already strong relationship, in 2013 the EHC and the World Federation of Hemophilia (WFH) agreed to revise and update their Memorandum of Understanding (MOU) to better reflect the new scope and reach of the distinct organisations, and to better serve the wide-ranging needs of European patient organisations, that separately are members of both organisations.

EHC ANNUAL CONFERENCE

In 2013 the EHC's annual conference, held in Bucharest, Romania, and hosted by the Romanian Haemophilia Society, was a landmark event.

Opened by the Minister of Health, the conference began with the signing of the first ever Memorandum of Understanding (MOU) between a Ministry of Health, an NMO and the EHC. The signing of this MOU was a milestone in the advancement of haemophilia care in Romania, as it specifically promised to involve the Romanian Haemophilia Society in the national decision-making process on haemophilia and to increase the IU/capita FVIII use to the new minimum recommendation of 3 IU/capita, amongst others.

Attended by close to 300 participants from the patient and scientific/medical community as well as regulators and industry, the conference also featured the latest clinical developments and policy initiatives through the following sessions:

- Comprehensive care in developed and developing countries
- Aspects of comprehensive care of haemophilia
- Treatment of rare bleeding disorders
- Access to new treatment for haemophilia – opportunities, challenges and barriers

Finally, as a pilot initiative, the conference also featured four parallel NMO capacity building workshops on:

- Treatment and compliance strategies
- How to choose treatment products for your country
- Communication between doctors and patients
- Family dynamics and siblings

Held in English, the conference provided simultaneous Russian interpretation.

EHC BUCHAREST 2013

COMMUNICATION MATERIALS

The EHC uses various communication tools to keep its members and stakeholders informed and involved.

Newsletters

In 2013, the EHC produced three newsletters covering current affairs, EHC activities, NMO developments and scientific advancements of relevance to the European bleeding disorders community. The newsletters were widely distributed. Readership included NMOs, the scientific/medical community, other patient organisations, key partners, policy-makers, regulators, payers and industry.

Quarterly policy report

In 2013, the EHC published four European policy reports (see P.24) the European Union, the Council of Europe, the World Health Organisation and other relevant policy-making bodies in Europe. It was distributed to all NMOs.

Website

In 2013, the EHC launched a revision process of its website to ensure that it continues to meet the needs of its community. The revision process began with a comprehensive survey of all website users and resulted in the need to streamline content and simplify usability. The revision process is ongoing.

Monograph and Advocacy Toolkit

The EHC published the results of its 35-country survey of haemophilia care in Europe both as a monograph as well as in the scientific journal *Haemophilia*. On the occasion of World Haemophilia Day, it produced 43 nationally tailored advocacy toolkits, comprised of PowerPoint presentations, a briefing document and data analysis as well as a large wall poster of the data, for use by all of its NMOs at national level (see P.27).

Conference Webcast

In 2013, the EHC piloted an initiative to webcast the scientific sessions of its Annual Conference, held in Bucharest, Romania. This was particularly useful for EHC members who could not attend the event but still wanted to benefit from treatment, clinical and policy updates.

Scientific journals

In 2013, EHC volunteers and staff authored or co-authored the following articles and publications:

- The Dublin Consensus Statement 2012 on optimised supply of plasma-derived medicinal products. O'Mahony B. *Blood Transfus*. 2013 Oct;11(4):623-6. doi: 10.2450/2013.0044-13. Epub 2013 Jul 26.

- Haemophilia care in Europe - a survey of 35 countries. O'Mahony B, Noone D, Giangrande PL, Prihodova L. *Haemophilia*. 2013 Jul;19(4):e239-47. doi: 10.1111/hae.12125, Epub 2013 Apr 4

- Treatment for life for severe haemophilia A- A cost-utility model for prophylaxis vs. on-demand treatment. Farrugia A, Cassar J, Kimber MC, Bansal M, Fischer K, Auserswald G, O'Mahony B, Tolley K, Noone D, Balboni S. *Haemophilia*. 2013 Jul;19(4):e228-38. doi: 10.1111/hae.12121. Epub 2013 Mar 28

- A survey of the outcome of prophylaxis, on-demand treatment or combined treatment in 18-35-year old men with severe haemophilia in six countries. Noone D, O'Mahony B, van Dijk JP, Prihodova L. *Haemophilia*. 2013 Jan;19(1):44-50. doi: 10.1111/j.1365-2516.2012.02934.x. Epub 2012 Aug 23.

Structure and Governance

Governance

The EHC is governed by a General Assembly of all NMOs. A Steering Committee (SC) that is elected by the General Assembly oversees the EHC's 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, which implements the organisation's day-to-day work and activities.

Steering Committee

In 2013, the General Assembly re-elected one previous and elected three new SC members:

Radoslaw Kaczmarek, re-elected (Polish NMO)
Olivia Romero Lux, newly elected (French NMO)
Traci Marshall Dowling, newly elected (Irish NMO)
Giuseppe Mazza, newly elected (Italian NMO)

The EHC thanked outgoing Steering Committee members:
Gabriele Calizzani (Italian NMO),
Chris James (UK NMO)
and Gabor Varga (Hungarian NMO).

Medical Advisory Group

Established in 2009, the Medical Advisory Group (MAG) of the EHC 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. In 2013, the General Assembly adopted new Terms of Reference (TOR) for the MAG and the SC invited a fourth member into the group. The MAG is composed of:

Prof Paul Giangrande (Chairperson)
Consultant Haematologist and Director Oxford Haemophilia & Thrombosis Centre, Churchill Hospital, Oxford

Prof Angelika Batorova
Medical Director of the National Haemophilia Centre and the Haemostasis and Thrombosis Unit University Hospital, Bratislava

Prof Michael Makris – joined in 2013
Honorary Consultant Haematologist, Sheffield Teaching Hospitals NHS Trust

Prof Flora Peyvandi
Director of the Department of Internal Medicine, RCCS Maggiore Hospital, University of Milan

The EHC thanked outgoing MAG members:
Profs Alessandro Gringeri and Wolfgang Schramm.

Data and Economics Committee

The Data and Economics Committee (DEC) was created to support the EHC's work in the area of economics and Health Technology Assessments (HTAs); it 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 was created to support the EHC's growing initiatives for youth, including youth engagement, training and other activities; 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

The Website Committee was created to support the revision of the EHC's website; it 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 (NEC) was created to support the EHC with the conception, planning, content and production of its newsletters; 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

LIAISON WITH NMOs

In late 2013 the new SC started a pilot initiative to maintain equal contact with all NMOs. To this end each SC member and the Vice-President Finance regularly touch base with their assigned NMOs:

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

*Not currently an official NMO

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 sincerely. In addition to the volunteers named above, we also express our thanks to those individuals who provided ad-hoc support to the EHC in 2013:

Katja Kirchkevitch
(for her Russian translation of the website and other materials)

Dorothée Fournier de Saint-Jean
(née Pradines, for her contribution to the youth project proposal)

Lino Hostettler
(for his contribution to the youth project proposal)

Nadège Pradines
(for her contribution to the youth project proposal)

Lucia Prihodova
(for her contribution to the WHD advocacy tool kit)

The EHC also extends its thanks to all the Members of the European Parliament and their staff who supported the EHC's work in 2013, as well as to all speakers, facilitators and chairs of EHC Round Tables, training workshops and the Annual EHC Conferences in 2013. Also, we would like to thank all the contributors to the EHC Newsletter.
The EHC would also like to thank Rohde Public Policy and the Conference Organisers for their support in the organisation of various EHC activities.

Michael van der Linde

Lucia Prihodova

Katja Kirchkevitch

Keith Tolley

Dan Farthing

Jamie O'Hara

Mariëtte Driessens

Federico Ruiz-Garcia

Dorothée Fournier de Saint Jean (Pradines)

Steffen Hartwig

Declan Noone

Uwe Schlenkrich

New NMO

In 2013, the General Assembly accepted the Montenegrin Haemophilia Society – Crnogorsko Društvo za Hemofiliju – as the 44th member of the EHC.

Financial Report

Message from the Vice-President Finance

The year 2013 was another positive and productive one for the European Haemophilia Consortium (EHC) in terms of its financial performance and its ability to increase and manage more activities.

The EHC successfully rolled out its new Corporate Giving Programme, which allowed the organisation to have a small but vital amount of unrestricted funding to put towards core operations such as data collection and NMO advocacy.

The organisation's increased professionalism led in turn to increased financial support. The EHC was able to implement more NMO-related activities in 2013 than ever before, including five NMO-specific workshops. The EHC was also able to successfully adapt to the increased challenges of managing more and diverse programmes and activities.

In line with its policy and commitment to transparency and accountability, the EHC reported financial developments to the Steering Committee on a monthly basis. Also, at the closing of the financial year the EHC engaged in an annual and voluntary external audit of its accounts in full compliance with Belgian Audit Standards and in line with its commitment to performing an external audit every year. The audit results are included in this report on page 49.

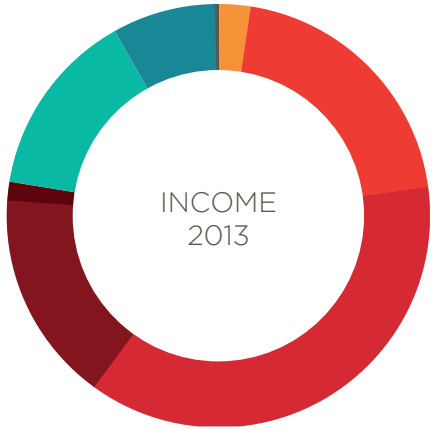
The 2013 EHC Conference in Bucharest, Romania, was a tremendous success not only in terms of political achievements with the first-ever signing of a Memorandum of Understanding between the government, the national patient organisation and the EHC, but also in terms of the surplus generated, which significantly contributed to the EHC's budget.

Finally but crucially, due to all of the above in 2013 the EHC was able to generate a surplus of slightly more than €70,000, which it has put towards a small but important operational reserve. To ensure the financial health and sustainability of the organisation as well as to safeguard its core activities in times of financial difficulties, the EHC is working towards building a full one-year operating reserve.

In conclusion this year 2013 was critical in laying the right financial foundation and we achieved that goal. We can meet the challenge of continuing to grow in a professional manner and of ensuring that a sound and sustainable organisation meets the needs of our European patient community for years to come.

Jordan Nedevski,
Vice-President Finance

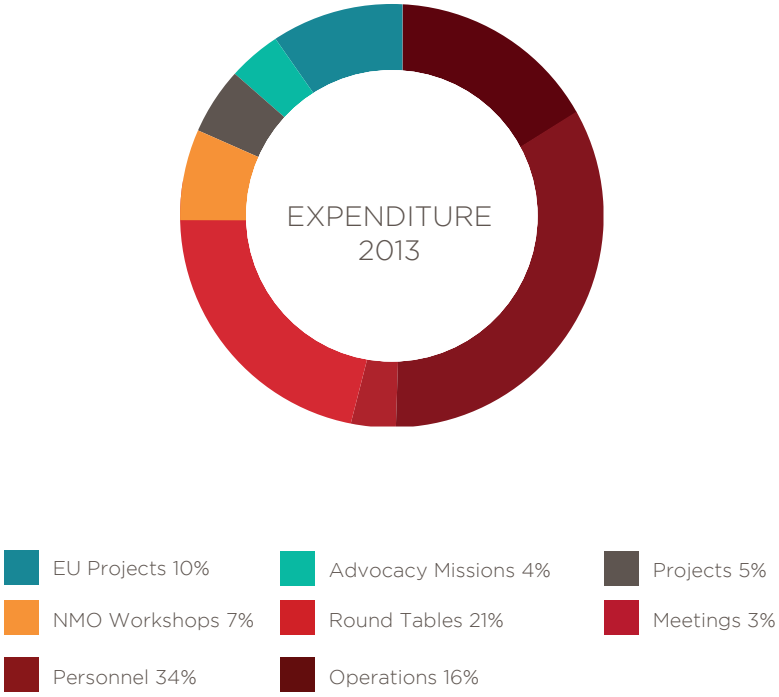
Income



Annual Conference 14%
Grants 1%
Workshops 16%
Round Tables 37%
CGP 21%
NMO Membership 2%
Other 0,3%
EU Projects: 8%

INCOME	BUDGET	FINALS
NMO Membership	9.000	8.370
Sponsorship	190.000	282.000
CGP	*60.000*	*77.000*
Round Tables	*115.000*	*140.000*
Workshops	*0*	*60.000*
Grants	*15.000*	*5.000*
Annual Conference	40.000	53.000
EU Projects	25.000	29.783
Other	4.500	1.301
TOTAL INCOME	**268.500**	**374.454**

Expenditure



EXPENDITURE	BUDGET	FINALS
Operations	60.400	48.753
Personnel	70.000	103.740
Meetings	29.000	10.220
Round Tables	57.000	62.430
NMO Workshops	15.000	20.329
Projects	5.000	14.449
Advocacy Missions	0	11.692
EU Project	25.000	29.783
TOTAL EXPENDITURE	261.400	301.400

Rosier & Co

Réviseurs d'entreprises

Report of the Auditor to the Members of the council committee of the ASBL
Consortium Européen de l'Hémophilie

0887.106.966

Rue du Marché aux Herbes 105/14
1000 Brussels

Financial Statements at 31 December 2013

We have audited the accompanying the joined "internal statements" showing a balance sheet total of 273.008€ and an excess of income over expenditure of 72.364€ which have been prepared under the accrual accounting method.

This report forms a whole with the audited financial statements and is only at the attention of the members of the council committee of the association.

The Council'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 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 judgements made by the officers in the preparation of the financial statements, and of whether the accounting policies are appropriate to the Council'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.

The "internal statements" give in our opinion – on the bases of the accrual accounting method – a true and fair view of the state of the Council's affairs as at 31 December 2013 and of its excess of income over expenditure for the year then ended.

Limal, June 5th 2014

Stéphane Rosier
Certified Public Auditor

Balance Sheet

	Notes	Period	Previous Period
ASSETS			
FIXED ASSETS		1.727,27	1.461,70
Formation expenses			
Intangible fixed assets	5.1.1		
Tangible fixed assets	5.1.2	338,70	111,70
Land and buildings			
Owned by the association or foundation in full property			
Other			
Plant, machinery and equipment			
Owned by the association or foundation in full property			
Other			
Furniture and vehicles		338,70	111,70
Owned by the association or foundation in full property		338,70	111,70
Other			
Leasing and other similar rights			
Other tangible fixed assets			
Owned by the association or foundation in full property			
Other			
Assets under construction and advance payments			
Financial fixed assets	5.1.3/ 5.2.1	1.388,57	1.350,00

ASSETS

	Notes	Period	Previous Period
CURRENT ASSETS		**271.280,84**	**195.631,38**
Amounts receivable after more than one year			
Trade debts			
Other amounts receivable			
of which non interest-bearing amounts receivable			
or with an abnormally low interest rate			
Stocks and contracts in progress			
Stocks			
Contracts in progress			
Amounts receivable within one year		11.806,84	67.700,82
Trade debts		5.844,82	65.240,00
Other amounts receivable		5.962,02	2.460,82
of which non interest-bearing amounts receivable			
or with an abnormally low interest rate			
Current investments	5.2.1		
Cash at bank and in hand		205.425,99	67.405,59
Deferred charges and accrued income		54.048,01	60.524,97
TOTAL ASSETS		**273.008,11**	**197.093,08**

Balance Sheet

	Notes	Period	Previous Period
LIABILITIES			
EQUITY		**158.391,89**	**86.035,15**
Association or foundation funds		9.419,96	9.419,96
Opening equity			
Permanent financing		9.419,96	9.419,96
Revaluation surpluses			
Allocated funds	5.3		
Accumulated positive (negative) result (+)/(-)		148.971,93	76.615,19
Investment grants			
PROVISIONS	5.3		
Provisions for liabilities and charges			
Provisions for repayable grants and legacies and for gifts with a recovery right			
AMOUNTS PAYABLE		**114.616,22**	**111.057,93**
Amounts payable after more than one year	5.4		
Financial debts			
Credit institutions, leasing and other similar obligations			
Other loans			
Trade debts			
Advances received on contracts in progress			
Other amounts payable			
Interest-bearing			
Non interest-bearing or with an abnormally low interest rate			
Cash deposit			

LIABILITIES

	Notes	Period	Previous Period
Amounts payable within one year		38.698,94	16.918,92
Debts payable after one year falling due within one year	5.4		
Financial debts			
Credit institutions			
Other loans			
Trade debts		29.906,86	8.030,31
Suppliers		29.906,86	8.030,31
Bills of exchange payable			
Advances received on contracts in progress			
Taxes, remuneration and social security		8.792,08	8.888,61
Taxes		2.330,81	1.579,48
Remuneration and social security		6.461,27	7.309,13
Other amounts payable			
Debentures and matured coupons, repayable grants and cash deposit			
Miscellaneous interest-bearing amounts payable			
Miscellaneous non interest-bearing amounts payable or with an abnormally low interest rate			
Accrued charges and deferred income		75.917,28	94.139,01
TOTAL LIABILITIES		**273.008,11**	**197.093,08**

Balance Sheet

INCOME STATEMENT

	Notes	Period	Previous Period
Operating income and charges			
Gross operating margin ....(+)/(-)		110.035,31	79.753,19
(+)/(-)		376.400,38	260.692,58
Turnover *....			349,00
Contributions, gifts, legacies and grants *		343.370,00	231.671,97
Raw materials, consumables, services and other goods *		266.365,07	180.939,39
Remuneration, social security costs and pensions ....(+)/(-)	5.5	33.580,48	46.252,72
Depreciation and amounts written down on formation expenses, on intangible and tangible fixed assets		189,86	111,66
Amounts written down on stocks, on contracts in progress and on trade debts appropriations (write-backs)....(+)/(-)		2.100,00	80.000,00
Provisions for risks and charges: appropriations (uses and write-backs) .(+)/(-)			
Other operating charges		201,63	21,93
Operation charges carried to assets as restructuring costs ....(-)			
Positive (negative) operating result ....(+)/(-)		**73.963,34**	-46.633,12
Financial income	5.5	1.348,41	740,04
Financial charges	5.5	606,81	446,77
Positive (negative) result on ordinary activities ....(+)/(-)		**74.704,94**	-46.339,85
Extraordinary income			80.000,00
Extraordinary charges		2.348,20	
Positive (negative) result for the period ....(+)/(-)		**72.356,74**	**33.660,15**

*Optional statement

APPROPRIATION ACCOUNT

	Notes	Period	Previous Period
Positive (negative) result to be appropriated .....(+)/(-)		148.971,93	76.615,19
Positive (negative) result to be appropriated for the period .....(+)/(-)		72.356,74	33.660,15
Accumulated positive (negative) result for the previous period .....(+)/(-)		76.615,19	42.955,04
Deduction from equity			
from association or foundation funds			
from allocated funds			
Addition to allocated funds			
Positive (negative) result to be carried forward .....(+)/(-)		148.971,93	76.615,19

Balance Sheet

	Notes	Period	Previous Period
TANGIBLE FIXED ASSETS			
Acquisition value at the end of the period		XXXXXXX	335,02
Movements during the period			
Acquisitions, including produced fixed assets		416,86	
Sales and disposals			
Transfers from one heading to another (+)/(-)			
Acquisition value at the end of the period		751,88	
Revaluation surpluses at the end of the period		XXXXXXX	
Movements during the period			
Recorded			
Acquisitions from third parties			
Cancelled			
Transferred from one heading to another (+)/(-)			
Revaluation surpluses at the end of the period			
Depreciations and amounts written down at the end of the period		XXXXXXX	223,32
Movements during the period			
Recorded		189,86	
Written back			
Acquisitions from third parties			
Cancelled owing to sales and deposals			
Transferred from one heading to another (+)/(-)			
Depreciations and amounts written down at the end of the period		413,18	
NET BOOK VALUE AT THE END OF THE PERIOD		338,70	
WHERE OF			
Owned by the association or foundation in full property		**338,70**	

FINANCIAL FIXED ASSETS

	Notes	Period	Previous Period
Acquisition value at the end of the period		XXXXXXX	1.350,00
Movements during the period			
Acquisitions		38,57	
Sales and disposals			
Transfers from one heading to another (+)/(-)			
Other movements (+)/(-)			
Acquisition value at the end of the period		1388,57	
Revaluation surpluses at the end of the period		XXXXXXX	
Movements during the period			
Recorded			
Acquisitions from third parties			
Cancelled			
Transferred from one heading to another (+)/(-)			
Revaluation surpluses at the end of the period			
Amounts written down at the end of the period		XXXXXXX	
Movements during the period			
Recorded			
Written back			
Acquisitions from third parties			
Cancelled owing to sales and deposals			
Transferred from one heading to another (+)/(-)			
Amounts written down at the end of the period			
Uncalled amounts at the end of the period		XXXXXXX	
Movements during the period (+)/(-)			
Uncalled amounts at the end of the period			
NET BOOK VALUE AT THE END OF THE PERIOD		1.388,57	

Balance Sheet

	Notes	Period	Previous Period
RESULTS			
PERSONNEL AND PERSONNEL CHARGES			
Employees for whom the association or foundation has submitted a DIMONA declaration or are recorded in the general personnel register			
Total number at the closing date			
Average number of employees calculated in full-time equivalents			
Number of actual worked hours			
Personnel costs			
Remuneration and direct social benefits		32.061,54	46.252,72
Employers' social security contributions		5.297,56	
Employers' premiums for extra statutory insurances			
Other personnel costs		-3.778,62	
Pensions			
FINANCIAL RESULTS			
Intercalary interests recorded as assets			
Amount of the discount borne by the association or foundation as a result of negociating amounts receivable			
Balance of accounts, provisions of a financial nature formed (used or reversed) (+)/(-)			

Sponsors

The EHC would like to acknowledge and thank its 2013 corporate sponsors:

- Platinum Sponsor: Baxter, Sobi, Pfizer
- Gold Sponsor: Bayer, CSL Behring, Novo Nordisk
- Silver Sponsor: Biotest

The EHC would also like to thank the financial support provided by the European Commission for the EUHANET Project.


PURSUING A LIFE
WITHOUT BLEEDS
ONE PERSON AT A TIME

Talking from experience

– a view from the team at Sobi on working together with the Haemophilia community

www.sobi.com

"We are energised by the possibility to re-enter the haemophilia community. We are focused on listening for how we can contribute to the well-being of people living with haemophilia today and in the future."

Dr. Geoffrey McDonough, CEO & President

"Long-acting treatments may offer another option for doctors to individualise a treatment regime for each patient. Our job is to continue to provide robust data that will allow doctors and patients to make informed decisions."

Krassimir Mitchev, Head of Medical, Haemophilia

"National Member Organisations of the EHC work every day to improve quality of life for people with haemophilia. For me in France, Association française des hémophiles is one of our most important partners. I trust them to guide me to do the right thing for the shared goal of better outcomes for the people they represent."

Valérie Bastard, Patient Access Lead, France

"It seems a long time ago that I was tasked with looking at Factor VIII to find a new way to make it possible to manufacture in large quantities through recombinant technology. It also feels like just yesterday. What we did back in 1989 has allowed thousands of people to have access to recombinant therapy, and our team is still working today on doing even better."

Peter Lind, Principal Scientist, R&D

"When people with haemophilia have access to effective treatments, they can make choices that enable them to live healthy and fulfilled lives. It is our job to secure that as many people as possible are able to access treatment in a way that governments can support in the long term."

Philip Wood, Global Head Haemophilia

sobi

Pioneer In Rare Diseases

CSL Behring

Biotherapies for Life™

Novo Nordisk is proud to support the EHC

Novo Nordisk is committed to Changing Possibilities in Haemophilia®. Our key contribution is to discover and develop safe, innovative biological medicines and make them accessible to reach our goal of improving access to care. We know that our products only get us part of the way, and we work with partners across the haemophilia community wherever possible, in order to reach our goals.

We believe that multidisciplinary 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 are therefore committed to improve expert care for people with haemophilia. For example, 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.

HERO Research Grant 2014 received numerous applications

The HERO Research Grant encourages and seeks to foster more in-depth, evidence-based understanding of the challenges faced by people living with haemophilia. The goal is to obtain evidence that can support advocacy aiming to improve care for people with haemophilia, with a focus on psychosocial care.

The application round for the grant has now closed. Many interesting applications from a total of 13 countries have been received and are now being evaluated. The winners will be announced during December 2014. Learn more about the HERO on www.herostudy.org.

Learn more about how Novo Nordisk is Changing Possibilities in Haemophilia® everyday on www.novonordisk.com/about_us/improving_haemophilia/improving-haemophilia.asp

EUROPEAN HAEMOPHILIA CONSORTIUM
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