

Annual **Report** 2016



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FOREWORD

Dear colleagues and friends,

It is my pleasure to share with you this report summarising the key activities carried out by EAHAD in 2016. Since its foundation in 2007, less than a decade ago, the European Association of Haemophilia and Allied Disorders (EAHAD) has established itself as a dynamic organization of health professionals involved in haemophilia care.

One of the major ambitions of EAHAD has always been to share and promote expertise in bleeding disorders care across Europe, not only for physicians but also for all other health professionals actively involved in the field. The Physiotherapists and Nurses committees of EAHAD have been very successful in pursuing the creation of dense and productive networks of collaborators in Europe. 2016 saw both of these committees undertake ambitious projects around developing evidence-based practice guidelines (nurses) and drafting a survey to determine the status of services to haemophilia patients throughout the continent (physiotherapists).

Another principal objective of EAHAD is to implement the European Principles of Haemophilia Care and fill the gaps in access to replacement therapy and multidisciplinary care that are still present in Europe, in close collaboration with patients' organisations, in particular the European Haemophilia Consortium (EHC) and the World Federation of Hemophilia. In this context, EAHAD has in 2016

worked actively on initiatives to improve haemophilia care in the Baltic countries and with the EHC in their work around care for people with inhibitors. It is our intention to find ways to support other European regions through similar initiatives in the future.

A third main objective of EAHAD is to promote scientific research. While this has been a focal point in our activities from the outset, through both the annual congress and the ongoing support of a number of working parties, in 2016 EAHAD took the first steps to further encouraging research through the awarding of Research Grants. We look forward to updating you next year on the first projects we are supporting through these grants.

As always a major highlight in the year for our association is the annual EAHAD meeting. This time it was held in Malmö, Sweden under the direction of Prof. Jan Astermark and demonstrated the capacity of EAHAD to attract more than 1500 attendees to what has now become the largest haemophilia meeting organized in Europe.

Finally, 2016 was again a great year of collaboration with the industry, which was valued at the Congress where the most recent innovations in the treatment of haemophilia could be actively communicated. Support from industry also allows EAHAD to launch new activities as the organisation continues to strive to carry out its mission in an inclusive and multidisciplinary fashion. From an organizational standpoint, in 2016 EAHAD made progress in formalizing its administrative structure, relocating its office to new facilities in central Brussels, close to the European Institutions.

As the current President of EAHAD, I would like to thank Aislin Ryan for her continuous commitment to EAHAD as Managing Director; our Vice-President, Professor Mike Makris, for his ongoing support; all committee and working party members for their significant contribution and all members of the haemophilia community for their trust in our organisation, which provides us with a vital source of inspiration and enthusiasm to improve haemophilia care.

Sincerely,

A handwritten signature in blue ink, appearing to be 'C. Hermans', written in a cursive style.

Professor Cedric Hermans
EAHAD President 2016-2018

ABOUT EAHAD

Founded in 2007, the European Association for Haemophilia and Allied Disorders (EAHAD) is a registered charity that seeks to improve care for people with haemophilia and other bleeding disorders through research, knowledge dissemination, and multi-disciplinary collaboration.

Its membership is made up of healthcare professionals from a range of disciplines working in haemophilia-related services, including haematologists, internists, paediatricians, nurses, physiotherapists, psychologists, laboratory scientists, and researchers.

EAHAD's work is guided by three main aims :



Recognising, measuring and addressing the problems of people with haemophilia and allied disorders, protecting their interests and ensuring the provision of the highest quality of care available;

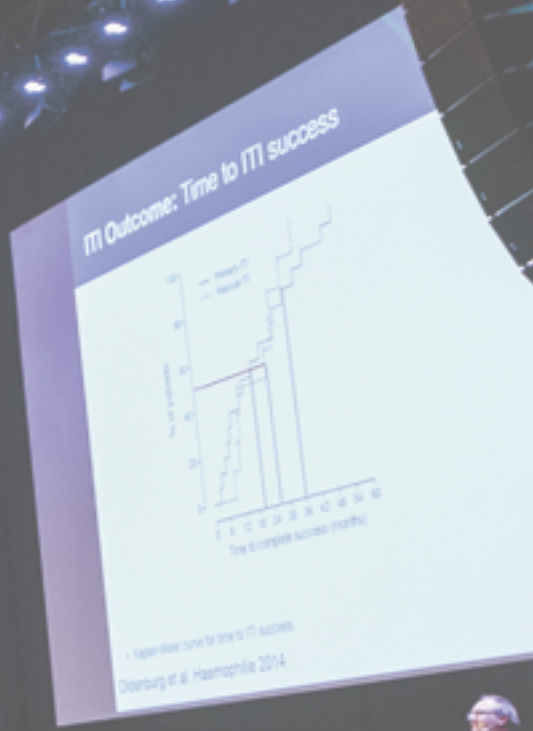


Promoting research in the above areas.



Disseminating knowledge through the appropriate scientific channels and educating practitioners, clinical scientists, professionals allied to medicine and the general public in the knowledge of haemophilia and allied disorders and their treatment.



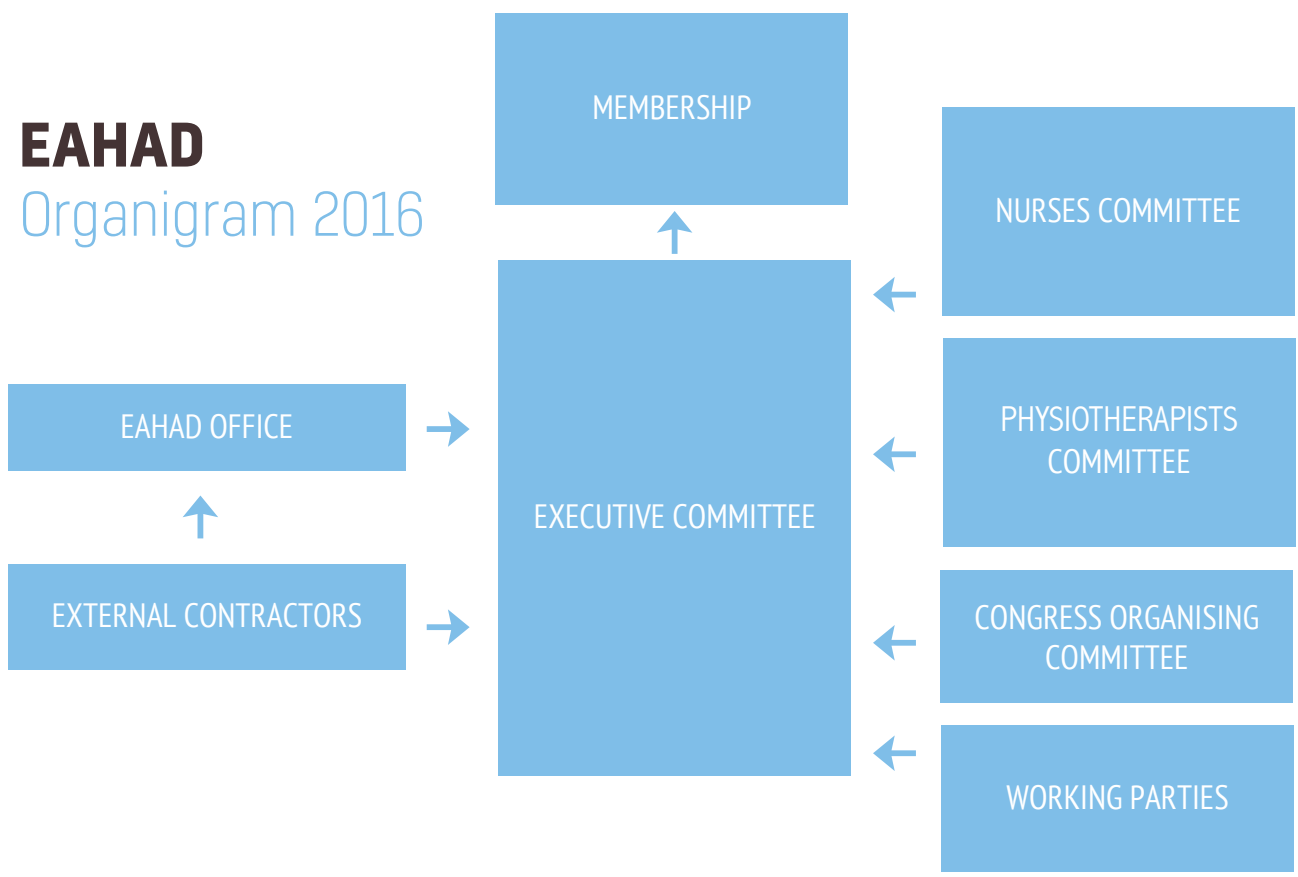


ORGANIZATIONAL STRUCTURE

The policy and general management of EAHAD is directed by the charity's trustees, the Executive Committee. Members of the Executive Committee are elected by the association's ordinary members. The Executive Committee presents activity and financial reports to EAHAD's members during its Annual General Meeting.

The Nurses and Physiotherapists Committees are comprised of professionals working in these respective disciplines of haemophilia care and are charged with advancing their profession as an integral part of comprehensive haemophilia care through the development and implementation of nursing and physiotherapy initiatives and activities. The Nurses and Physiotherapists Committees report to the Executive Committee and are represented on the latter by their chairs.

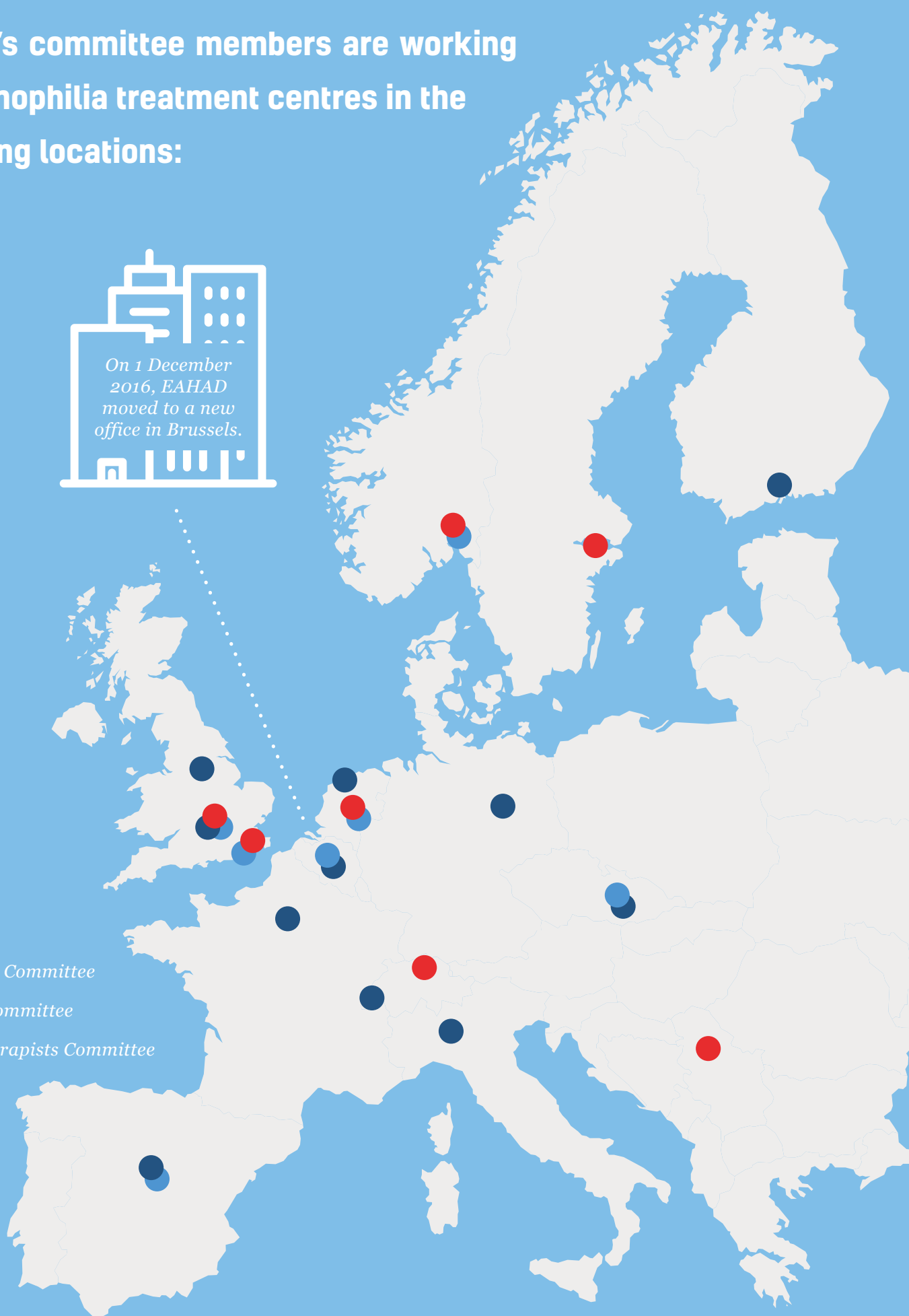
EAHAD's day-to-day operations are managed by its Managing Director, under the direction of the Executive Committee.



EAHAD's committee members are working in haemophilia treatment centres in the following locations:



- Executive Committee
- Nurses Committee
- Physiotherapists Committee



Executive Committee



Cedric Hermans *(President)*



Michael Makris
(Vice-President)



Philippe de Moerloose
(Past-President)



Piet de Kleijn
*(Physiotherapists
Committee Chair)*



Roseline d'Orion
(Congress President)



Gerry Dolan
(Treasure)



Riitta Lassila
(Secretary)



Jan Blatny
(Member)



Karin Fijnvandraat
(Member)



Víctor Jiménez Yuste
(Member)



Robert Klamroth
(Member)



Flora Peyvandi
(Member)



Martin Bedford
(Nurses Committee Chair)



Nurses Committee

Martin Bedford *(Chair)*

Elsbeth Müller-Kägi *(Vice-Chair)*

Petra Elfvinge *(Secretary)*

Alpha Barrie *(Member)*

Ljiljana Rakic *(Member)*

Siri Grønhaug *(Member)*

Marlies Schrijvers *(Member)*



Physiotherapists Committee

Piet de Kleijn *(Chair)*

Sébastien Lobet *(Vice-Chair)*

David Stephensen *(Secretary)*

Rubén Cuesta Barriuso *(Member)*

Ruth Elise Dybvik *(Member)*

Marie Katzerova *(Member)*

Paul McLaughlin *(Member)*



Staff

Aislin Ryan *(Managing Director)*

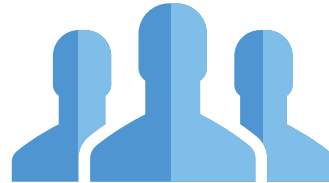


MEMBERSHIP

Membership in EAHAD is open to all healthcare professionals, including physicians, nurses, physiotherapists, and clinical scientists, who are working in the area of haemophilia and allied disorders.

There are three membership categories: Ordinary, Associate, and Honorary Members.

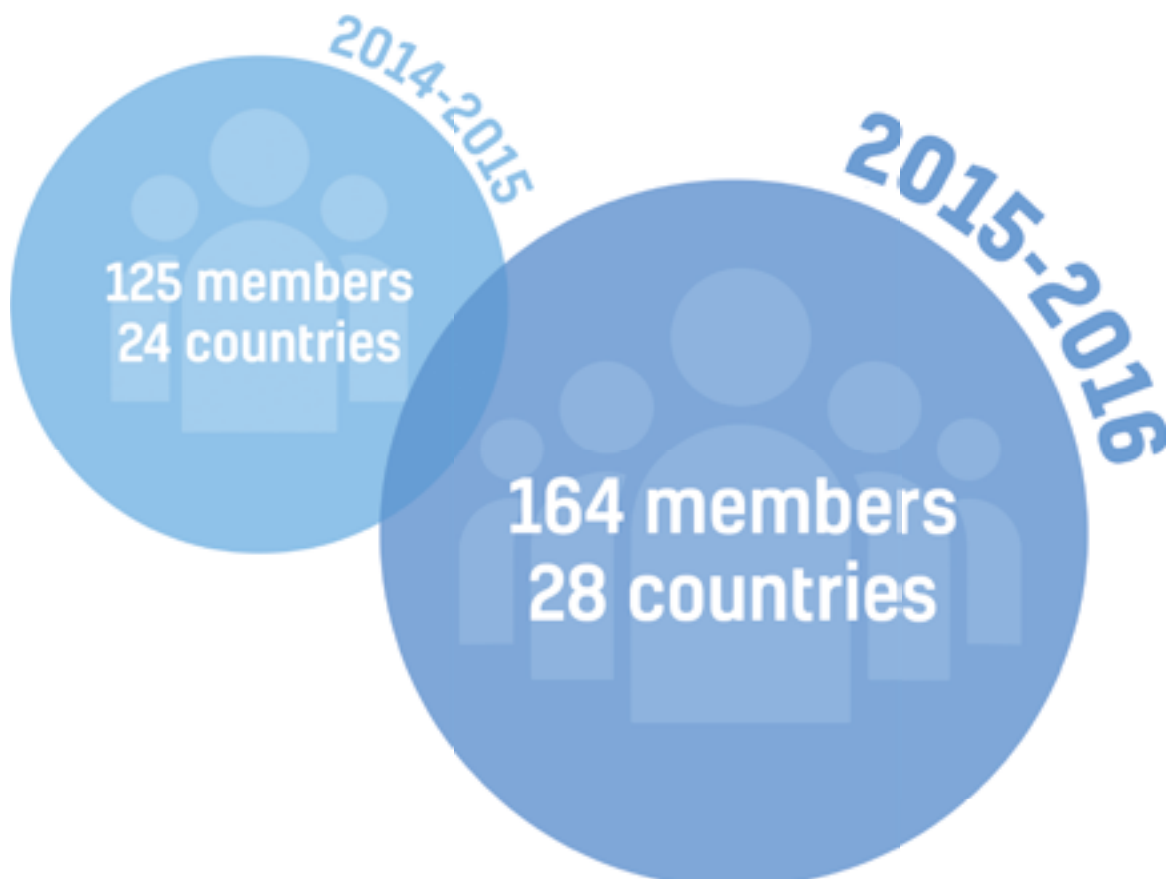
In November, EAHAD introduced a new category under Ordinary Membership for Allied Health Professionals to encourage the involvement of a greater array of healthcare professionals in the organisation. These members are entitled to the same benefits as Ordinary Members, but pay a lower membership fee.



In 2015-2016, EAHAD had
74 Ordinary Members
86 Associate Members
4 Honorary Members



The membership cycle runs from
November 1 to October 31 of each year.



2016 at a glance



- 9th Annual EAHAD Congress (Malmö, Sweden)



- Certification of 3 new European Haemophilia Comprehensive Care Centres (EHCCC) and 1 European Haemophilia Treatment Centres certified (EHTC)



- EAHAD Coagulation Factor Databases Steering Group Meeting (London, UK)



- Nurses Committee and Guidelines Development Meeting (Utrecht, the Netherlands)



- Presentation on “Physiotherapy for older people with haemophilia” by Piet de Kleijn at the European Haemophilia Consortium (EHC) Round Table on Ageing and Haemophilia (Brussels, Belgium)



- 2 EHTCs certified



- Multidisciplinary Baltic Update Meeting (Helsinki, Finland)



- EAHAD-EHC Inhibitor Meeting (Brussels, Belgium)

- Statements on the SIPPET study results and Brexit published

February

March

April

May

June

July



- 1 EHCCC certified
- Spring Newsletter published



- Executive Committee Meeting (Brussels, Belgium)

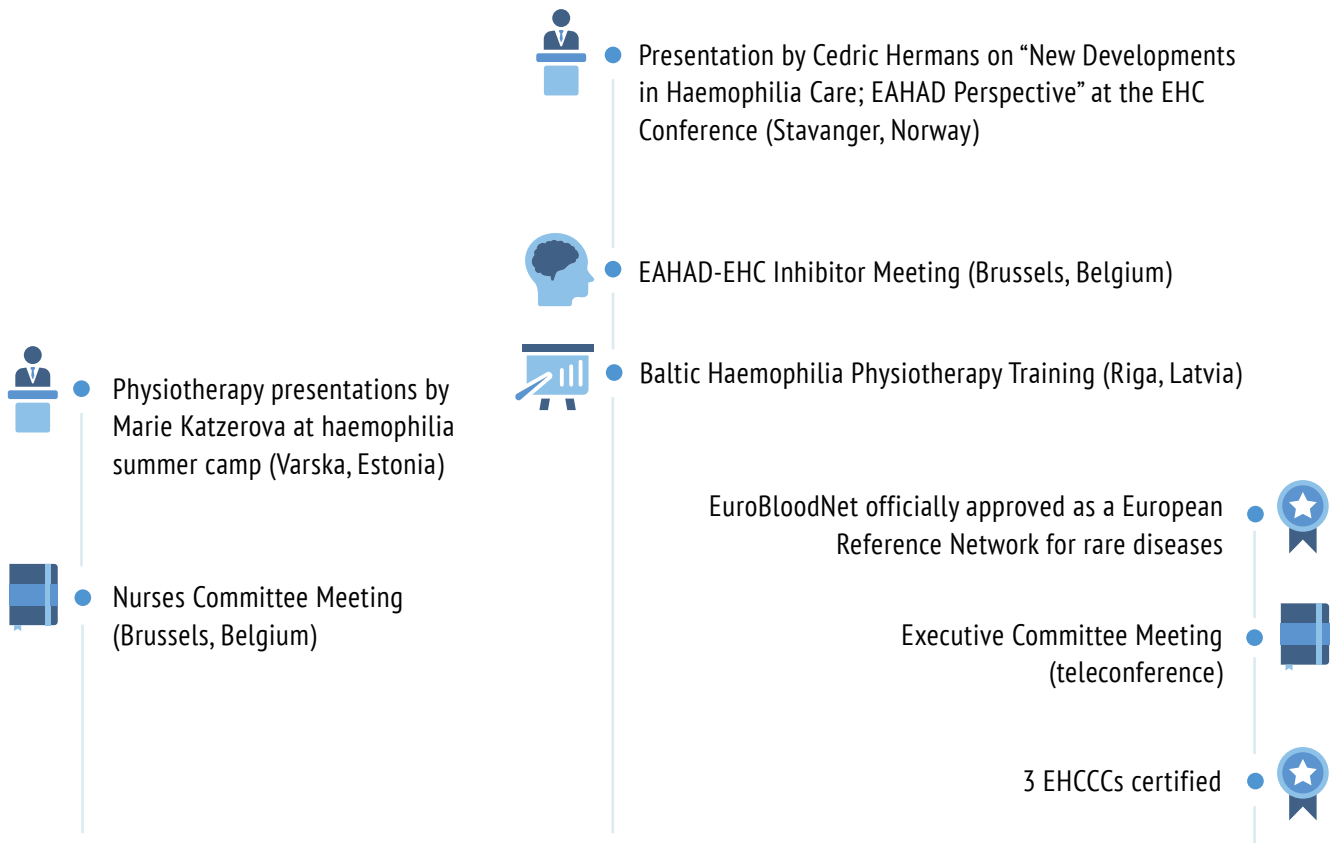


- EAHAD Coagulation Factor Databases Steering Group Meeting (London, UK)



- 1 EHTC certified





August

September

October

November

December

Physiotherapists Committee Meeting (Orlando, USA)

EAHAD Coagulation Factor Databases Steering Group Meeting (London, UK)

Launch of Call for Applications for 2017 EAHAD Research Grants

Executive Committee Meeting (Brussels, Belgium)

EAHAD Coagulation Factor Databases Steering Group Meeting (London, UK)

Nurses Committee Meeting (Hamburg, Germany)

EAHAD Coagulation Factor Databases Steering Group Meeting (London, UK)

Fall Newsletter published

EAHAD-EHC Inhibitor Meeting (Brussels, Belgium)

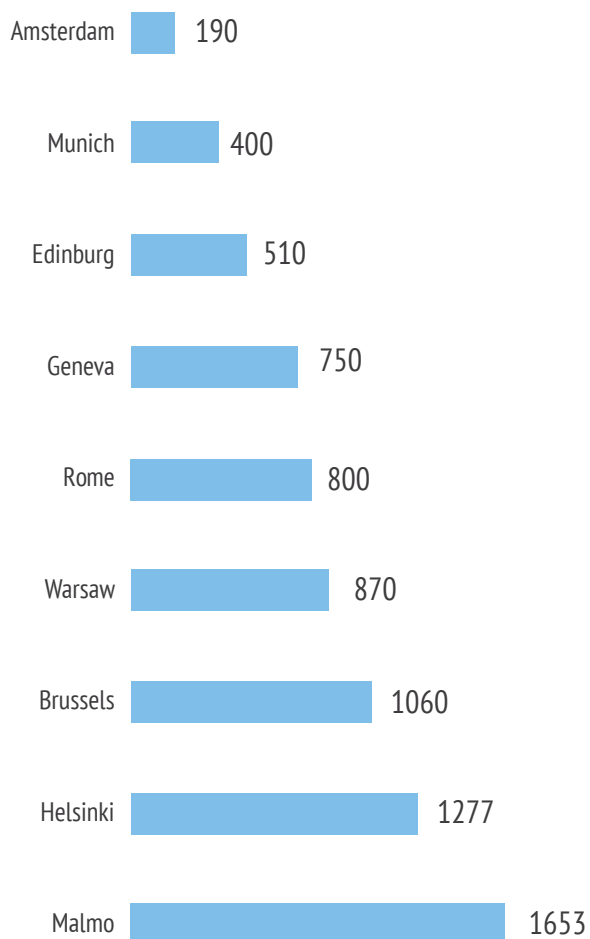
Physiotherapists Committee Meeting (Brussels, Belgium)

2016 ACTIVITIES

Congress

The 9th edition of the Annual EAHAD Congress was held from 3-5 February in Malmö, Sweden, a city that has fostered some of the most important developments in research on inherited bleeding disorders. It was hosted by EAHAD Past-President Prof Jan Astermark.

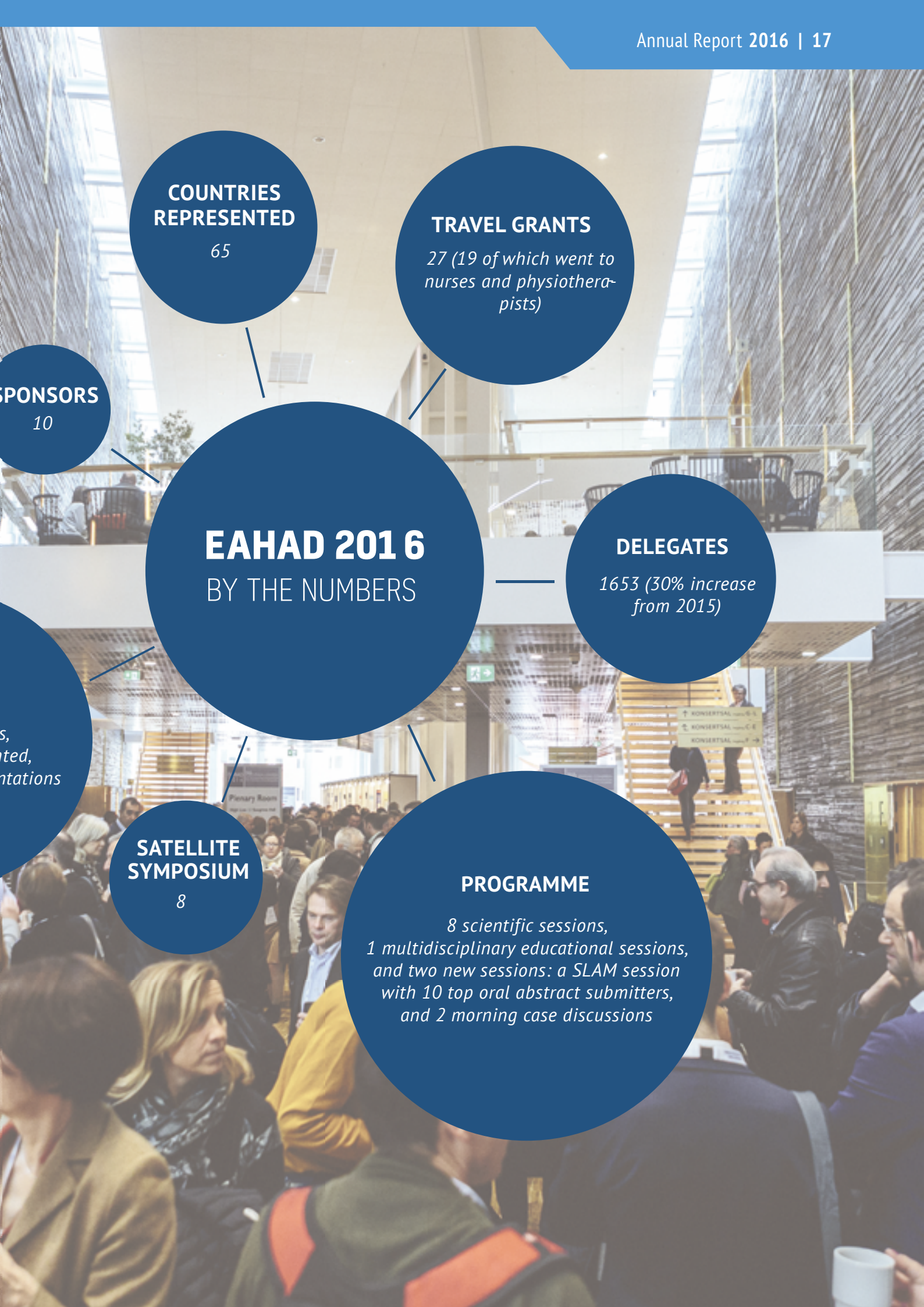
Growth in Congress Registration :



ABSTRACTS

159 submissions
146 posters presented
10 oral abstract presentations





COUNTRIES REPRESENTED

65

TRAVEL GRANTS

27 (19 of which went to nurses and physiotherapists)

SPONSORS

10

EAHAD 2016
BY THE NUMBERS

DELEGATES

1653 (30% increase from 2015)

SATELLITE SYMPOSIUM

8

PROGRAMME

8 scientific sessions, 1 multidisciplinary educational sessions, and two new sessions: a SLAM session with 10 top oral abstract submitters, and 2 morning case discussions

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Primary Room

*KONSERTAL
KONSERTAL
KONSERTAL*

Working Parties and Projects

EAHAD Coagulation Factor Variant Databases

The EAHAD Coagulation Factor Variant Databases project constructs and maintains publicly accessible web-based coagulation factor variant databases. It is the most comprehensive global source of known causative mutations for coagulation factors VII, VIII, IX and VWD (www.eahad-db.org/index.php).



During the past 12 months:

- The Steering Group has met on five occasions.
- The principal activity has been the construction of a database of factor VII variants. This has now been completed and is available at www.factorvii-db.org.
- The factor VIII variant database (www.factorviii-db.org) has many users as evidenced by approximately 8000 hits in the past year. We have been very fortunate to have the collaboration of Dr Barbara Konkle who has submitted data from 4,000 haemophilia A cases from the US My Life, Our Future programme.
- The factor IX variant database (www.factorix-db.org) is being well used as reflected by almost 3,000 hits. Dr Konkle has also submitted data from over 1,000 haemophilia B cases.
- The VWF variant database (www.vwf.group.shef.ac.uk) continues to be widely consulted.
- Collaboration has been established with Dr Michel Hanss in relation to the GFHT fibrinogen variant database.

Coagulation Factor Variant Databases Steering Group members:

- Prof CA Ludlam: (Chairman) Emeritus Professor of Haematology and Coagulation Medicine, Edinburgh, UK
- Dr G Dolan: Consultant Haematologist
Nottingham University Hospitals, UK
- Dr M Giansily-Blaizot: Hematologie Biologique
CHU Montpellier, France
- Dr K Gomez: Senior Lecturer and Consultant in Haemostasis
Royal Free Hospital London, UK
- Prof A Goodeve: Haemostasis Research Group
University of Sheffield, Sheffield, UK
- Dr D Hampshire: Haemostasis Research Group
University of Sheffield, Sheffield, UK
- Dr G Kemball-Cook: (Secretary) Hon. Associate
Royal Free Hospital London, UK
- Prof J McVey: Molecular Medicine Research Group
University of Surrey, UK
- Dr J Oldenburg: Institute of Exp. Haem. & Transfusion Medicine,
University Clinic Bonn, Germany
- Prof S Perkins: Research Dept of Structural & Molecular Biology,
University College London, UK

EUHANET

EAHAD continues to support the European Haemophilia Network, including through the administration of the European Haemophilia Centre Certification process.

Over the past years, EAHAD has been closely following the development of the European Reference Networks (ERNs) by the European Commission in the view of continuing EUHANET within this new framework.

On 15 December 2016, the Board of Member States approved the application of the EuroBloodNet ERN, in which many haemophilia treatment centres are participating.



 > **300**
HOSPITALS

 > **900**
HEALTHCARE UNITS

 **THOUSANDS OF**
PATIENTS HELPED
BY **2020**

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



In 2016, 11 centres in 7 countries were certified

European Haemophilia Comprehensive Care Centres (EHCCCs)



European Haemophilia Treatment Centres (EHTCs)

Erasmus University Medical Centre,
Haemophilia Treatment Centre
(Rotterdam, the Netherlands)

Center for Bleeding Disorders,
Careggi University Hospital
(Florence, Italy)

Centro Emofilia, Emostasi e Trombosi
(Catanzaro, Italy)

Centre de traitement de l'hémophilie et de
la maladie de Willebrand
(Caen, France)

Centre d'accueil et de traitement des
hémophiles de l'hôpital Cochin
(Paris, France)

Centre de traitement de l'hémophilie et
des maladies hémorragiques
(Saint-Étienne, France)

Paediatric Haemophilia Centre Budapest;
Onco-Hematology Department named by
Dr. Kemeny Pal
(Budapest, Hungary)

Complejo Hospitalario Universitario A
Coruña (A Coruña, Spain)

Hemophilia and Coagulopathies Center of
Lithuanian University of Health Sciences
Kauno Klinikos
(Kaunas, Lithuania)

Centro Emofilia e Coagulopatie Congenite
(Pavia, Italy)

Hemophilia Treatment Centre Liberec
(Liberec, Czech Republic)

NURSES GUIDELINES

One of the strategic goals of the Nurses Committee for 2014-2018 is the development of guidelines for haemophilia nursing care.

Following preparatory work to scan the literature, collate national and local protocols, and evaluate them using the AGREE II tool, the committee along with four invited experts met in Utrecht, the Netherlands in April to develop and achieve consensus on the following three guidelines:

1. Intravenous administration of clotting factor (peripheral infusion and CVAD)
2. Education of self-management skills for patients with a bleeding disorder
3. Nursing care during surgery on a patient with a bleeding disorder

They are now in the process of finalizing the guidelines and looking at ways to disseminate them.







PHYSIOTHERAPISTS NETWORK

In its first full year in operation, the Physiotherapists Committee worked to expand its reach across the continent. The first step in this was the addition of three new committee members from the North, Centre, and South of Europe: Ruth Elise Dybvik (Norway), Marie Katzerova (Czech Republic), and Rubén Cuesta Barriuso (Spain).

In the second half of the year, the committee worked to establish a larger network of physiotherapists working in haemophilia in Europe, identifying regional coordinators across Europe to put in place a hub-and-spoke method, with regional coordinators identifying and building relationships with physiotherapists in their region.



INTERDISCIPLINARY COLLABORATIONS

Baltic Regional Activities

On 7 June, EAHAD, in collaboration with the Helsinki University Central Hospital Coagulation Disorders Unit and with support from the World Federation of Hemophilia (WFH) Twinning Program, held a day-long multidisciplinary update meeting for haemophilia healthcare professionals from the Baltic region. Thirty-eight participants attended the meeting including members of the multidisciplinary teams from nine centres treating bleeding disorders patients in Estonia, Finland, and Lithuania.

The morning featured parallel sessions, with physiotherapists discussing three difficult cases with practical demonstrations, and the nurses engaging in a planning session focused on setting objectives for haemophilia nursing care over the next four years.



In the afternoon, the groups came together for a series of presentations, which included reports from the haemophilia centres in Tallinn, Tartu, and Vilnius; updates from the Nurses and Physiotherapists Committees; a review of the morning case discussions; and short updates from local sponsors.

This activity served as a follow-up to the October 2015 joint visit of EAHAD, the European Haemophilia Consortium (EHC), and the WFH to Estonia and Latvia.

Following this, two smaller actions were carried out later in the year focused on supporting physiotherapy initiatives in the region:

1. [Presentation and demonstration at haemophilia summer camp in Varska, Estonia by Marie Katzerova \(August\)](#)
2. [Physiotherapy Workshop for Baltic Countries, Riga, Latvia led by Piet de Kleijn \(October\)](#)





ABOUT EAHAD | CONTACT | PRESS | PARTNERS | NEWS AND RESOURCES



EAHAD 2017 Congress | 1-3 February
Revisit your favourite moments from EAHAD 2017

[View the Photo Gallery](#)

About EAHAD

The European Association for Haemophilia and Allied Disorders (EAHAD) is a multi-disciplinary association of healthcare professionals who provide care for individuals with haemophilia and other bleeding disorders. Its members include haematologists, nurses, physiotherapists, laboratory scientists and researchers from across Europe.



COMMUNICATIONS

EAHAD was proud to launch a new website and logo at the 2016 Congress.

The impetus behind this change was to both improve our communication with EAHAD members, by making the website more comprehensive and user-friendly, but also to give EAHAD more visibility in the wider bleeding disorders and rare disease communities.

We have been pleased to see notable growth in website visitors and to those following EAHAD, either on social media or by signing up to receive our newsletter.

EAHAD also worked to strengthen its communications with stakeholders through the publication of two statements on events of significant relevance to the European bleeding disorders community:

1. [EAHAD statement on the publication of the SIPPET study results \(published on 27 June 2016\)](#)
2. [Letter from the Presidents: No Brexit for EAHAD and the EHC \(published on 28 June 2016\)](#)



Web

Page views: 51,839 (+ 102%)
Users: 13,975 (+ 94%)



LinkedIn

Followers: 41



Newsletter

266 subscribers (+56%)

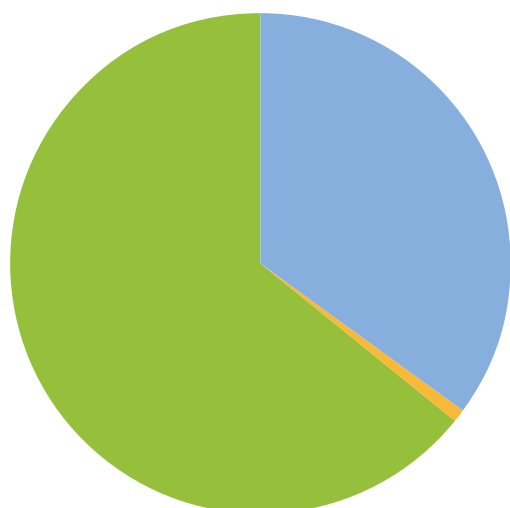
FINANCES

EAHAD's financial year runs from October 1 to September 30. A full copy of the annual accounts for the year ending on 30 September 2016 can be consulted on the website of the Charity Commission for England and Wales.

1 October 2015 to 30 September 2016

Income

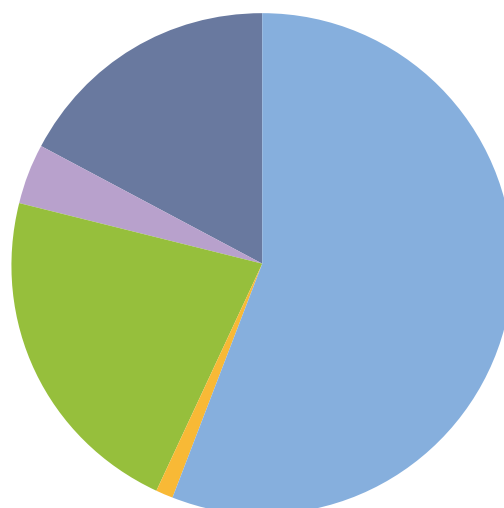
£475,406



- Donations
- Membership fees
- Annual Congress

Expenses

£211,428



- Management
- Journal Subscriptions
- Research Projects
- Administrative Costs
- Meeting and Travel Expenses

ACKNOWLEDGEMENTS

FUNDING

EAHAD is grateful for the funding it receives in support of its various activities from the following industry partners:













In 2016, EAHAD also received support from the Dutch government for the Nursing Guidelines project.

PARTNERS

EAHAD has an official collaboration agreement with: European Haemophilia Consortium (EHC)

EAHAD also collaborates with related organisations:
International Society for Thrombosis and Haemostasis (ISTH)
World Federation of Haemophilia (WFH)

SERVICE PROVIDERS

EAHAD works in cooperation with a number of companies that provide valuable services in order to make our work possible.

We would like to thank MCI Geneva Office for their organisation of our Annual Congress, Northern Networking Events Ltd for the administrative, financial and IT support they provide, Atkinson Donnelly LLP for their accounting services, the PRG Partnership for legal services, Toast Agency for creating visual content for our website and publications, and Cremer Consulting SARL, Alejandro Caffarini, and Bellis Translations sprl for their translation services.



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