



# 2017 ANNUAL REPORT

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## FOREWORD



Dear colleagues and friends,

It is with great pleasure that I share with you this Annual Report, where you will find all the key activities carried out by EAHAD in 2017. This year marks the 10<sup>th</sup> anniversary of the association. Since its establishment in 2007, EAHAD has worked to improve the situation of people living with haemophilia and other bleeding disorders and, a decade later, we are an established, successful and more-active-than-ever organisation of professionals working in the aforementioned fields. From an open meeting in Vienna on 7 June 2007, where 120 individuals were eager to form the association, EAHAD has grown into a mature organisation with an annual congress that, in 2017, attracted more than 1800 participants.

EAHAD has always been on the forefront of disseminating and promoting knowledge in bleeding disorders care across Europe. We strive to be a platform, where expertise can be shared, dialogue can flourish and all health professionals active in the field can become better. Our Physiotherapists and Nurses Committees continue to be very successful in creating productive and dense networks of colleagues. It was an especially fruitful year for our Physiotherapists Committee, as they launched the [European Physiotherapists Network](#). With the goal of connecting physiotherapists working in this specialised area and facilitating the exchange of knowledge between them, the network managed to gather more than 200 members in its first year.

EAHAD is always aiming to further promote scientific research. 2017 saw the launch of the [Factor VII Variant Database](#) by the EAHAD-DB group. A proud moment for everyone involved, the launch of this complex and comprehensive database shows the association's stability and focus on long term and ambitious scientific projects. This focus on high-quality scientific knowledge was also demonstrated during our annual meeting where for the first time Research Grants were awarded, positioning EAHAD as a major stakeholder and promoter of highly advanced research in haemophilia.

As with every year, a major highlight for EAHAD is the association's annual congress. The [EAHAD 2017 Congress](#) took place in Paris, France, under the direction of Dr. Roseline d'Oiron. The presentations

and activities of the congress further demonstrated why it is the place to be for all haemophilia and bleeding disorders related matters in Europe. The 10<sup>th</sup> edition of the annual EAHAD Congress was not only a milestone occasion but also the first one to feature the Pre-Congress Day for Nurses and Physiotherapists, providing a platform for disseminating knowledge and experience for all experts involved.

2017 was another successful year of collaboration with our industry partners. Their support is always greatly valued, allowing EAHAD to continue launching new initiatives and becoming more stable and recognised.

Furthermore, in 2017, EAHAD made many of the necessary preparations for transferring its legal base to Belgium, one year after relocating its office to Brussels. This huge undertaking is being handled meticulously by EAHAD's Managing Director, Aislin Ryan.

As the President of EAHAD for the period 2016-2018, I would like to thank Aislin Ryan for her commitment, tenacity and sense of professionalism; our Vice-President, Prof Mike Makris for always being ready and available to provide support; our committee and working party members, whose contributions are EAHAD's real added value and, of course, all members of the haemophilia community for their continuous feedback and trust. For my second year as President, I could not ask for a better source of satisfaction and enrichment, both scientifically and socially. Thanks to you, we are more inspired than ever to move forward with even more ambitious projects and genuine enthusiasm in improving haemophilia care for everyone involved.

Sincerely,

**Professor Cedric Hermans**

*EAHAD President  
2016-2018*



## ABOUT EAHAD

Established in 2007, the European Association for Haemophilia and Allied Disorders (EAHAD) is a registered charity and multidisciplinary association of healthcare professionals that seeks to provide care for individuals with haemophilia and other bleeding disorders, based on research, knowledge dissemination, and multidisciplinary collaboration. Its members include haematologists, internists, paediatricians, nurses, physiotherapists, laboratory scientists, and researchers.

### EAHAD'S WORK IS GUIDED BY THE FOLLOWING THREE AIMS

1

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;

2




Promoting research in the aforementioned areas.

3

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.

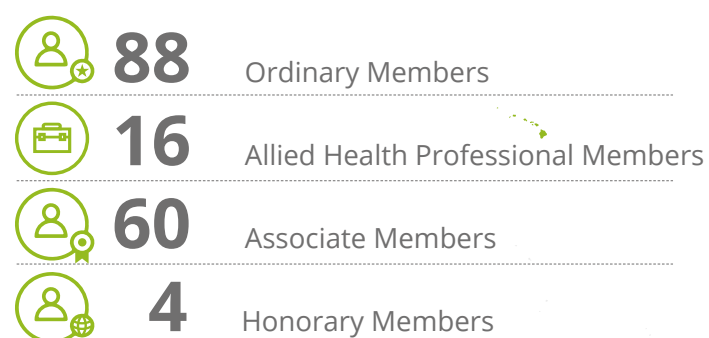




	_____ Ordinary
	_____ Associate
	_____ Honorary

168  
members

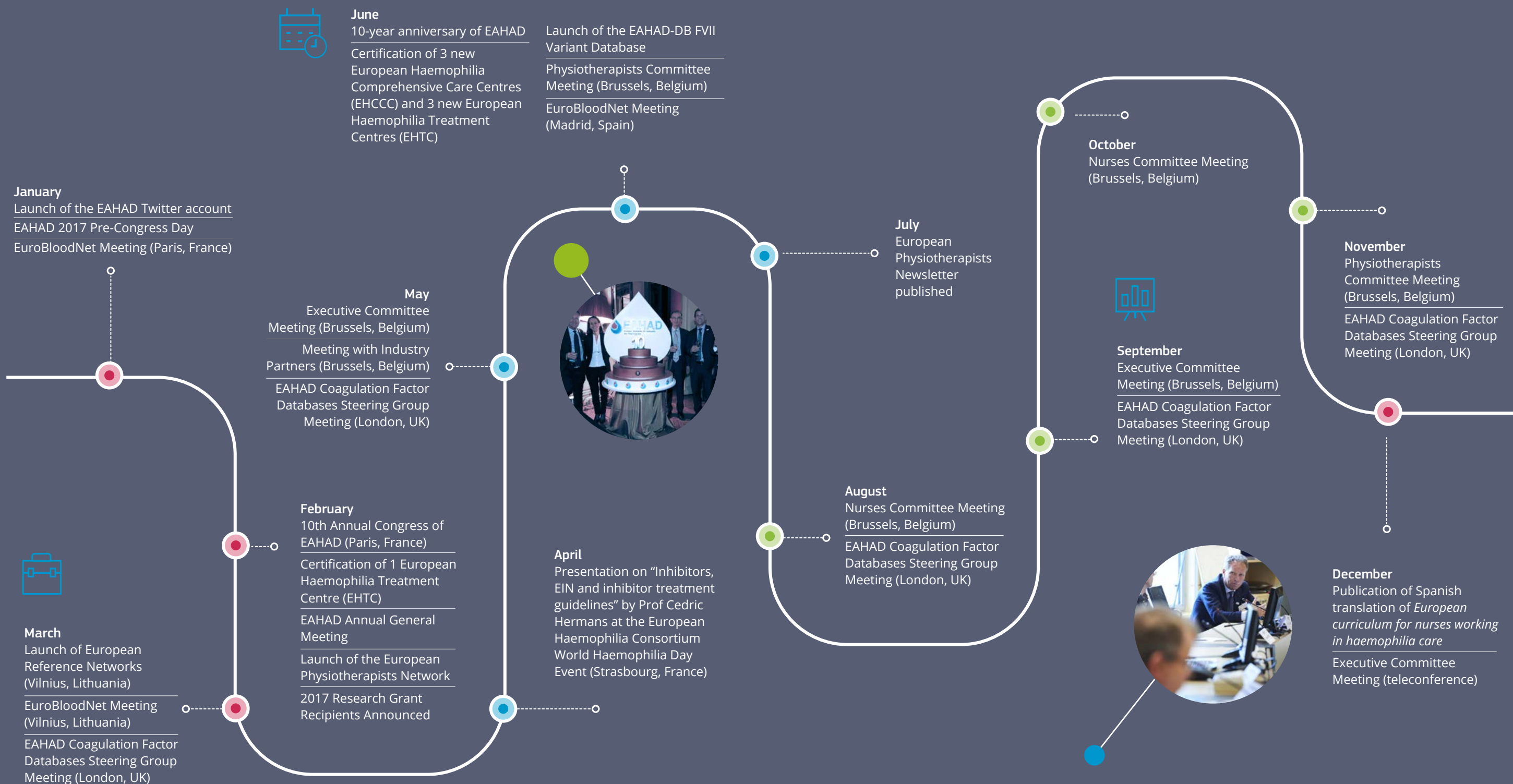
29 countries



2014-2015	2015-2016	2016-2017
125 members	164 members	168 members
24 countries	28 countries	29 countries



## 2017 AT A GLANCE







## 2017 Highlights

### EAHAD 2017

The 10<sup>th</sup> edition of the annual EAHAD Congress was celebrated in Paris, the city of lights. Dr. Roseline d'Oiron, from the city's Bicêtre hospital, put together a programme featuring innovative topics and showcasing speakers from France – many of whom were new to the audience.

This milestone anniversary in EAHAD's development was also marked by the awarding of the first-ever, EAHAD Recognition Award, which went to Dr Assad Haffar from the World Federation of Hemophilia in appreciation of his commitment to the haemophilia community through his tireless work towards making haemophilia treatment available in the most under-served areas of the world.

EAHAD's birthday was also celebrated with an unforgettable Networking Reception held at the Jacquemart-André Museum complete with speeches by each of EAHAD's past presidents and a birthday cake.

### Pre-Congress Day

The EAHAD 2017 Congress in Paris saw the first-ever edition of the Pre-Congress Day for Nurses and Physiotherapists.

Set one day before the official Congress kick-off, on 31 January, the day focused on European nurses and physiotherapists involved in bleeding disorders care. The joint morning session allowed each discipline to highlight their specific skills and showed the crucial role of interaction between all members of a haemophilia treatment centre. In the afternoon, the nurses and physiotherapists broke off into separate sessions where they delved more deeply into current topics in their respective fields.

The aim behind having a Pre-Congress Day was to disseminate knowledge and experience, as well as provide a platform for dialogue helping collaborative research to flourish, both at the national and international level. To this end, simultaneous interpretation into French was provided to attract a maximum number of participants from the host country.

Spearheaded by the Nurses and Physiotherapists Committees, the inaugural Pre-Congress Day was met with such enthusiasm and active participation that there was no question it would become a staple of the annual EAHAD Congress.



# CONGRESS FACTS & FIGURES

**DR ROSELINE D'OIRON**  
CONGRESS PRESIDENT



**PARIS MARRIOTT RIVE GAUCHE HOTEL**  
& CONFERENCE CENTRE

**1-3**

February 2017

**1882**

Delegates (+14%)

**73**

Represented  
countries

**16**

Travel Grants  
awarded

## PROGRAMME

8 scientific sessions including a SLAM session with oral presentations from the top 10 abstract submitters, 1 multidisciplinary educational session, and 2 morning case discussions

**201**  
abstract  
submissions

**185**  
posters  
presented

**10**  
oral abstract  
presentations

**8**

Satellite  
symposia

**5**

Award  
recipients

**11**

Industry  
sponsors

## POSTER AWARDS



**Poster 181:** Is Point-Of-Care Ultrasound an Accurate Alternative For MRI In Haemophilia Patients with Limited Arthropathy? (W Foppen)



**Poster 34:** Benefit of The Study of F8 Gene Transcription In Hemophilia A Patients And Carriers Unsolved By Next Generation Sequencing (C Costa)



**Poster 122:** Weekly Benefix Prophylaxis For Severe Haemophilia B In Normal Clinical Practice: Data From Ukhcd0 And Finland (M Scott)



## TOP SLAM PRESENTATION

In Vitro Characterization Of F376A/M388A-Solulin, a New Promising Antifibrinolytic for Severe Haemophilia A (Y Repessé)

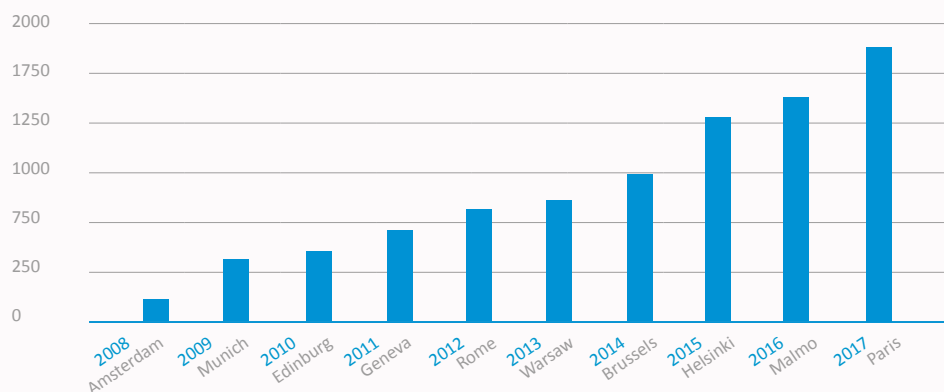
## EAHAD RECOGNITION AWARD



Dr Assad Haffar, World Federation of Hemophilia



## GROWTH IN CONGRESS REGISTRATIONS



## European Physiotherapists Network

In February 2017 during the 10<sup>th</sup> Annual Congress of EAHAD, the Physiotherapists Committee launched the [European Physiotherapists Network](#).

Its goal is to connect physiotherapists working in this specialised area and facilitate the exchange of knowledge between them with the end goal of improving the provision and quality of musculoskeletal care to patients with bleeding disorders throughout Europe. Regardless of where in Europe they are based, physiotherapists can now become more involved and learn about other colleagues working in their area, thanks to the network's coordinators, operating in more than 15 regions in Europe and serving as local knowledge hubs. By the end of 2017, there were more than 200 physiotherapists from 26 countries included in the network.

## Research Grants

In September 2015, the Executive Committee decided that part of EAHAD's surplus from its annual Congress would be dedicated to awarding [Research Grants](#). The Research Grants were first announced during the 9th Annual Congress of EAHAD in February 2016 in Malmö and the Call for Applicants launched in early September 2016.

The call for pre-clinical and clinical scientific projects aimed at improving the care of patients with inherited and acquired bleeding disorders was met with great enthusiasm. EAHAD received 23 applications from 11 countries.

Following a multi-step review process, 2 projects were selected and the recipients were announced at the EAHAD 2017 Congress. They are:

Johan Boender, MD | *Erasmus University Medical Center, Rotterdam, the Netherlands*

**"Does ADAMTS13 influence the bleeding phenotype in von Willebrand disease?"**

**Project duration:** April 2017-March 2018  
**Grant amount:** €47,950

Roberta Palla, PhD | *Fondazione Luigi Villa, Angelo Bianchi Bonomi Haemophilia and Thrombosis Centre, Fondazione IRCCS Ca' Granda, Ospedale Maggiore Policlinico, Milan, Italy*

**"High throughput analysis of antibody binding profiles in previously untreated patients with severe haemophilia A"**

**Project duration:** April 2017-March 2019  
**Grant amount:** €50,000

## FVII Database Launch

In 2017, the EAHAD [FVII Database](#) was launched. A major and complex project, getting the database online was for the EAHAD DB Steering Group a proud moment.

The FVII database was brought to fruition thanks to the effort and support of Dr Pavi Rallapalli, Dr Muriel Giansily-Blaizot, Professor John McVey, and Dr Geoff Kemball-Cook.

The database includes a wide range of available information on factor VII. It is free to the public and is accessible via the EAHAD Coagulation Factor Variant Databases website.

## European Reference Networks and EuroBloodNet

An initiative of the European Commission, the [European Reference Networks \(ERNs\)](#) are networks of healthcare professionals and centres of expertise with the goal of improving quality, safety, and access to highly specialised healthcare in Europe.

Starting its activities on 1 March 2017, [EuroBloodNet](#) ERN was among the first 22 ERNs to be approved by the European Commission. It encompasses rare haematological diseases, including haemophilia and other inherited bleeding disorders. EuroBloodNet is a joint effort of the European Hematology Association (EHA), the European Network on Rare and Congenital Anaemias (ENERCA), the European haematology patient organisations represented in both the EURORDIS European Patient Advocacy Groups (ePAGS) and the EHA Patient Organisations Workgroup.

With the goal of improving the healthcare and overall quality of life of patients with a rare haematological disease, EuroBloodNet includes 66 partners from 15 countries and 35 of its health care providers are haemophilia centres. The majority of these are certified EUHANET centres. EuroBloodNet has under its umbrella 6 sub-networks, including one about Rare bleeding-coagulation disorders and related diseases, whose clinical coordinators are Prof Mike Makris and Prof Flora Peyvandi from EAHAD's Executive Committee.

## European Haemophilia Centre Certification

The [European Haemophilia Centre Certification](#) process remains active with EAHAD administrating the process. In 2017, 7 centres in 6 countries were certified bringing the total count of certified centres to 135 in 32 countries.

European Haemophilia Comprehensive Care Centres (EHCCCs)	European Haemophilia Treatment Centres (EHTCs)
Centre Regional d'Hémophilie Hôpital Purpan – Toulouse – France	Haemophilia Centre Ticino – Bellinzona -Switzerland
Haemophilia Treatment Center Academic Medical Center – Amsterdam - Netherlands	Kuopio University Hospital, Paediatric Haematology and Haematology Units – Kuopio – Finland
Haemophilia Centre Banja Luka – Banja Luka – Bosnia and Herzegovina	Medical Centre Cristian Serban Buzias – Buzias – Romania
	Service d'hémophilie de Chambéry – Chambéry -France



## Communications

In 2017 EAHAD launched its official Twitter account. Reaching 300 followers within the first year on the platform, Twitter is another step for EAHAD to improve communication with its members, as well as professionals and organisations active in the field of rare bleeding disorders. Thanks to interacting with other users and providing up-to-date information to followers, the account has the potential to quickly become the main focus of EAHAD's communications strategy. At the same time, EAHAD continues to reach out to the community through other channels including LinkedIn and its website.

EAHAD also worked in 2017 to provide more opportunities to non-English speaking nurse professionals by translating the *European Curriculum for Nurses Working in Haemophilia* into [French](#) and [Spanish](#). Developed by the EAHAD Nurses Committee to describe the skills and knowledge needed for a nurse to work in this specialty, and published in English in *Haemophilia* in 2016, the [Curriculum](#) is to be used as a strategic resource to outline education for the haemophilia nurse and contribute to the standardisation and benchmarking of haemophilia nursing care.

**308**

[Twitter](#)

**154**

[LinkedIn](#)

Website

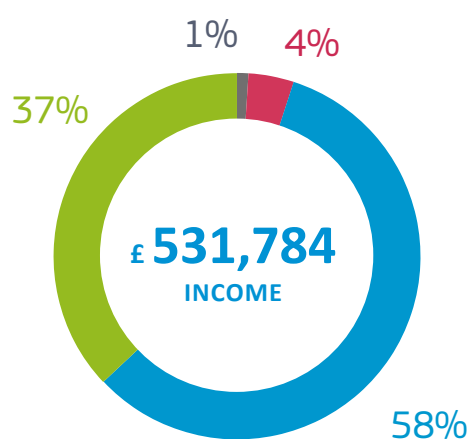
	Views	Users
<b>2017</b>	58,727	16,754
	13.2% increase	19.9% increase
<b>2016</b>	51,839	13,975

Top pages	Pages views
<b>EAHAD 2017</b>	12,086
<b>EAHAD 2018</b>	11,340
<b>Membership</b>	1,014
<b>Past Congresses</b>	990
<b>EAHAD 2019</b>	889

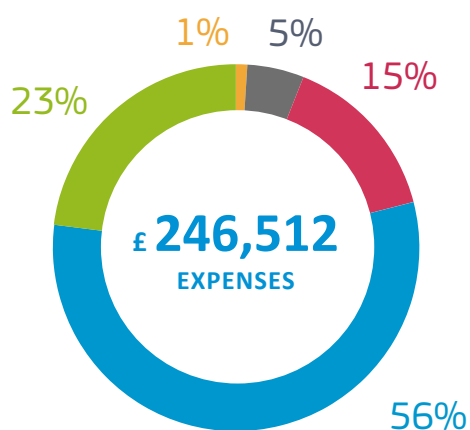


## Finances

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 2017 can be consulted on the website of the [Charity Commission for England and Wales](#).

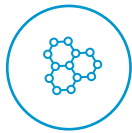


Congress Revenue	£310,866
Donations	£196,825
Foreign Currency Exchange Gain	£19,997
Memberships	£4,096
<b>TOTAL INCOME</b>	<b>£531,784</b>



Professional fees	£138,522
Research grants	£55,434
Meeting expenses	£37,864
Operational expenses	£13,040
Journal subscriptions	£1,652
<b>TOTAL EXPENSES</b>	<b>£246,512</b>





## Organisational 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 their respective disciplines of haemophilia care. They are responsible for advancing their profession as an integral part of comprehensive haemophilia care by developing and implementing 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.

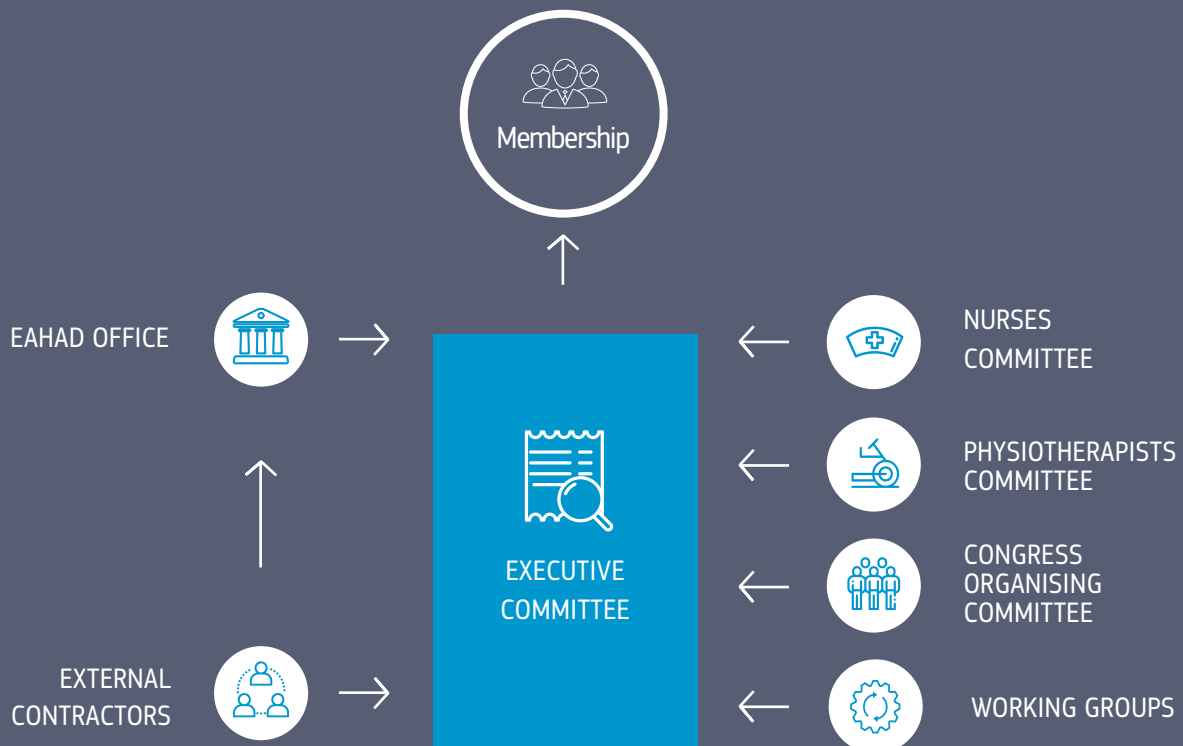
The Coagulation Factor Variant Databases Steering Group is responsible for the administration of the

[Coagulation Factor Variant Databases](#) project. It is comprised of clinicians and scientists working in the field of haemophilia and allied bleeding disorders.

The European Haemophilia Centre Certification Group has the task of reviewing all applications for certification and designating haemophilia centres as either European Haemophilia Comprehensive Care Centres (EHCCCs) or European Haemophilia Treatment Centres (EHTCs). It is comprised of 2 physicians, a nurse, and a patient representative from the European Association for Haemophilia and Allied Disorders (EAHAD) and the European Haemophilia Consortium (EHC).

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

### ORGANIGRAM 2017





## EXECUTIVE COMMITTEE

- Cedric Hermans, President
- Michael Makris, Vice-President
- Philippe de Moerloose, Past-President
- Víctor Jiménez Yuste, 2018 Congress President
- Gerry Dolan, Treasurer
- Riitta Lassila, Secretary
- Jan Blatny, Member
- Karin Fijnvandraat, Member
- Hervé Chambost, Member
- Robert Klamroth, Member
- Flora Peyvandi, Member
- Martin Bedford, Nurses Committee Chair
- Piet de Kleijn, Physiotherapists Committee Chair



## NURSES COMMITTEE

- Martin Bedford, Chair
- Elsbeth Müller-Kägi, Vice-Chair
- Petra Elfvinge, Secretary
- Siri Grønhaug, Member
- Mary Kavanagh, Member (joined in 2017)
- Kristian Juusola, Member (joined in 2017)



## PHYSIOTHERAPISTS COMMITTEE

- Piet de Kleijn, Chair
- Sébastien Lobet, Vice-Chair
- David Stephensen, Secretary
- Rubén Cuesta Barriuso, Member
- Ruth Elise Dybvik Matlary, Member
- Marie Katzerova, Member
- Paul McLaughlin, Member



## COAGULATION FACTOR VARIANT DATABASES STEERING GROUP

- Prof CA Ludlam, Chairman
- Dr G Kemball-Cook, Secretary
- Dr G Dolan
- Dr M Giansily-Blaizot
- Dr K Gomez
- Prof A Goodeve
- Dr D Hampshire
- Prof J McVey
- Dr J Oldenburg
- A Osborne
- Prof S Perkins
- Prof Flora Peyvandi
- Dr PM Rallapalli, Senior Advisor to the Steering Group



## EUROPEAN HAEMOPHILIA CENTRE CERTIFICATION GROUP

- Michael Makris, EUHANET Project Leader
- Philippe de Moerloose, EAHAD Past-President
- Brian O'Mahony, EHC President
- Martin Bedford, Nurse Representative



## STAFF

- Aislin Ryan, Managing Director



## Acknowledgements

### Funding

EAHAD is grateful for the unrestricted financial support it receives from the following industry partners:



*New*



*New*

Partners

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

EAHAD also collaborates with the International Society on Thrombosis and Haemostasis (ISTH) and the World Federation of Hemophilia (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 their administrative, financial and IT support
- Atkinson Donnelly LLP for their accounting services
- Koan Law Firm for their legal services
- MDSAS for their IT services
- Toast Agency for creating visual content for our publications
- Mr Ben Beemsterboer for graphic design support for the Physiotherapists Newsletter





Registered Charity Number: 1125081

## More information