



2018
**ANNUAL
REPORT**

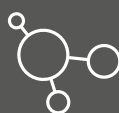


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FOREWORD

Dear colleagues and friends,

It is a great pleasure to share with you the 2018 EAHAD Annual Report, where you will find all the key activities carried out by our association throughout the year. In 2018, we continue to be active and more involved than ever in improving the care of persons with bleeding disorders. By bringing together the many multidisciplinary disciplines involved in the clinical care of these patients and promoting scientific research in the field, our goal remains to be a hub where expertise can flourish, and a channel for quality communication and dialogue.

To achieve this, we felt that putting all our major projects under one roof was the way to move forward. 2018 was the year we consolidated the work around the EUHANET and EUHASS programmes. Whilst these remain multi-stakeholder projects, EAHAD will house these projects going forward, providing staff support and serving as the communications platform for the resources developed under EUHANET.

A major highlight this year was the addition of two staff members to the EAHAD Office. With the EUHASS project being moved to Brussels under the EAHAD umbrella and the retirement of Dr. Estelle Gilman who served as EUHASS Project Manager from the project's beginnings at the University of Sheffield, Livia Boagiu was hired in April as the new EUHASS Project Manager. Also, as the EAHAD Congress becomes bigger and the Pre-Congress Day more elaborate, Angelos Athanasopoulos took on the role of Communications and Events Officer in June 2018, providing social media & communications support, as well as logistical assistance to our committees and working groups. We welcome the two new members, who, together with our Managing Director, Aislin Ryan, are now the core team that takes care of the association's day-to-day operations in Brussels.

Our Physiotherapists and Nurses Committees continue to be very successful and active in their respective fields. Our Physiotherapists Committee saw a significant rise in members in their network, reaching by the end of the year almost 280 physiotherapists from around Europe. The year was especially productive for our Nurses Committee, as they published the first set of their practical guidelines, with more to come in the future.

2018 also saw the launch of two new EAHAD Working Groups, one for psychosocial professionals and one on women and bleeding disorders. The purpose of the groups is to, respectively, improve the psychosocial quality of care for patients with haemophilia and allied disorders throughout



Europe and address the unmet needs in the clinical management of women living with bleeding disorders.

This past year was another fruitful one for collaboration with our industry partners. Their support is always appreciated, as it helps EAHAD to continue launching new projects and becoming a recognisable staple in the field of haemophilia.

Of course, I would be remiss not to mention EAHAD 2018, the 11th iteration of our annual congress with the biggest attendance to date. This year, the Congress took place in Madrid, Spain, under the direction of Dr Jiménez Yuste. The different sessions and diverse activities that took place further proved why the EAHAD Congress is an unmissable opportunity for everyone involved in the field of haemophilia and other bleeding disorders in Europe.

Much attention throughout the year was also spent behind-the-scenes doing the preparatory work to transfer EAHAD's legal base from the UK to Belgium. With the recent developments around Brexit, it became increasingly difficult to keep the status-quo, especially with our members, funding, and staff being based in Europe. Thus, a decision was made to move EAHAD to Belgium, the heart of Europe. This does not mean that our work will change. Conversely, we will be more efficient and more productive in our pursuit of improving haemophilia care. EAHAD was and will continue to be a European association covering all European countries and not just those in the European Union.

As EAHAD President for the period 2018-2020, I would like to thank my fellow EC members, our committees and working groups, the staff and everyone else who contributes to our activities throughout the year. 2018 being my first year as President, I am more enthusiastic and confident than ever that, together, we can make haemophilia and allied disorder care better for everyone.

Sincerely,

A handwritten signature in blue ink, appearing to read 'M Makris'.

Professor Mike Makris
EAHAD President 2018-2020



EAHAD | WHO WE ARE

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 multi-disciplinary collaboration. Its members include haematologists, internists, paediatricians, nurses, physiotherapists, laboratory scientists, and researchers.

EAHAD's work is guided by the following 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 aforementioned 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.



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. The membership cycle runs from October to September each year.

There are four membership categories:



Ordinary



Allied Health Professional



Associate



Honorary

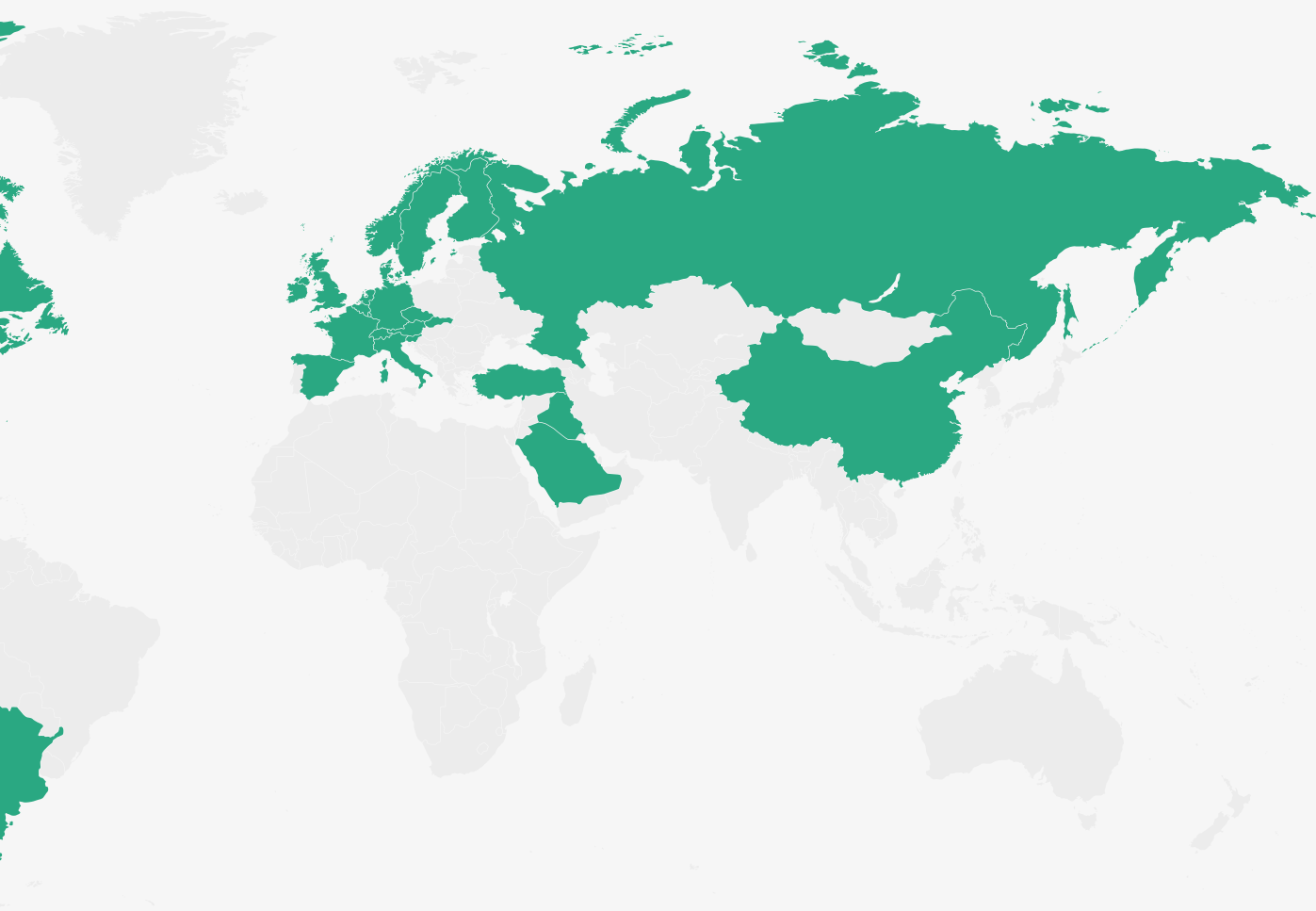
New membership platform launched

With the 2017-18 membership cycle, a new, more intuitive, and easier to use membership platform was launched. By logging in with their individual username and password, all members can register with a reduced fee to the EAHAD Annual Congress; access *Haemophilia* journal and other EAHAD publications; and stay informed about future EAHAD opportunities, events, and activities.

142
members

28
countries

2017-2018 MEMBERSHIP NUMBERS:



2014-2015	2015-2016	2016-2017	2017-2018
125 members	164 members	168 members	142 members
24 countries	28 countries	29 countries	28 countries



2018 AT A GLANCE

JANUARY

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



MARCH

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

APRIL

European Physiotherapists Newsletter published

Livia Boagiu joins EAHAD as EUHASS Project Manager

World Haemophilia Day 2018 Event, in collaboration with the EHC (Brussels, Belgium)

"European Principles of Inhibitor Management in Patients with Haemophilia" published

JUNE

Angelos Athanasopoulos joins EAHAD as Communications and Events Officer

Presentation at the Annual Congress of the French Haemophilia Association – AFH (Nancy, France)

Certification of 2 new EHCCCs and 2 new EHTCs

FEBRUARY

11th Annual Congress of EAHAD (Madrid, Spain)

EAHAD 2018 Pre-Congress Day

EAHAD Annual General Meeting

Inaugural Young Investigators Workshop

2018 Research Grant Recipients announced

Nurses Committee Meeting

Physiotherapists Committee Meeting

Certification of 1 European Haemophilia Treatment Centre (EHTC)

MAY

Nurses Committee Meeting (Brussels, Belgium)

Executive Committee Meeting (Brussels, Belgium)

Physiotherapists Committee Meeting (Glasgow, Scotland)

Meeting with Industry Partners (Glasgow, Scotland)

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

Certification of 1 new European Haemophilia Comprehensive Care Centre (EHCCC) and 1 new EHTC



JULY

EAHAD-EHC Joint Statement on novel non-replacement therapies published

Prof Cedric Hermans appointed new Editor-in-Chief of *Haemophilia*

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



OCTOBER

Nurses Committee Meeting (Prague, Czech Republic)

EUHASS 9th Annual Report published

DECEMBER

European Physiotherapists Newsletter published

Guidelines for haemophilia nursing care on Factor administration via Intravenous (IV) or Central Venous Access Device (CVAD) Infusion published

Certification of 1 new EHCCC

SEPTEMBER

Executive Committee Meeting (Brussels, Belgium)

Working Group on Women and Bleeding Disorders launches

Psychosocial Professionals Working Group launches

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

EuroBloodNet Meeting (Brussels, Belgium)

NOVEMBER

EuroBloodNet meeting (Paris, France)

Physiotherapists Committee Meeting (Brussels, Belgium)

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

EAHAD 2017 Annual Report published



2018 HIGHLIGHTS

EAHAD 2018 brings bleeding disorders community together in Spain

The 11th iteration of the annual EAHAD Congress took place in Madrid, Spain from 7-9 February 2018. Dr Víctor Jiménez Yuste, from the city's La Paz University Hospital, designed a programme with forward-thinking and innovative presentations.

The Madrid meeting was EAHAD's biggest and most successful yet with 2,076 participants from 74 countries in attendance. The programme included insightful sessions with topics like product type and inhibitor development, laboratory monitoring of new therapies, the pharmacoeconomics of haemophilia care, ageing and haemophilia, as well as how to deal with new products and what are the rules for switching treatment products.

EAHAD 2018 was preceded by the 2nd edition of the Pre-Congress Day, on 6 February featuring simultaneous interpretation into Spanish and dedicated sessions for physiotherapists, nurses, and, for the first time, psychosocial professionals.

Also on the Pre-Congress Day, EAHAD launched a new initiative, the Young Investigators Workshop. The theme was "Finding the answer to your question – a workshop on study design". The workshop started with a presentation on study design by EAHAD Executive Committee member Prof Karin Fijnvandraat. Following this, each of the participants had the opportunity to present their ongoing research projects and converse on any challenges they were facing. The gathering closed with a presentation by Prof Mike Makris, who offered tips on submitting a paper to a journal and responding to reviewer and editor feedback.



Congress Facts & Figures



CONGRESS PRESIDENT

Dr Víctor Jiménez Yuste



VENUE

Palacio Municipal de
Congresos de Madrid



DATES

7-9 February 2018



DELEGATES

2,076

ABSTRACTS

240 submissions | 213 posters presented | 14 oral abstract presentations

74

Countries
represented

15

Travel Grants
awarded

9

Satellite
Symposia

11

Sponsors

POSTER PRIZE WINNERS



A. Bowyer et al. "The FIX C assessment of extended half-life recombinant factor IX products in clinical practice"



C. Bidlingmaier et al. "Prevalence of overweight in young patients with severe hemophilia and its economic burden in Germany"



H. Pergantou et al. "Application of paediatric bleeding score (ISTH-BAT) in children with von Willebrand disease (preliminary study)"

TOP SLAM PRESENTATION



"Implementation of the French primary long-term prophylaxis guidelines: A real-world prospective study of the FranceCoag PUPs cohort" - Paul Saultier

EAHAD RECOGNITION AWARD RECIPIENTS



Prof Cristopher Ludlam
Prof Pier Mannucci
Dr Brian Colvin

The EAHAD Recognition Awards go to professionals whose accomplishments in haemophilia and allied disorders care have undeniably shifted the paradigm in the field.

In 2018, the awards went to the association's founders, Prof Cristopher Ludlam, Prof Pier Mannucci, and Dr Brian Colvin, for their progressive thinking and initiative in finding new ways of collaborating and promoting haemophilia activities across Europe. Their contributions to the global haemophilia community cannot be overstated.

EAHAD would not be where it is today without their dedication and commitment in its early years as well as their tireless engagement in the association.



Guidelines for Haemophilia Nursing Care now online

One of the strategic goals of the EAHAD Nurses Committee is to produce an evidence-based set of practical guidelines for haemophilia nursing care. Thus, a committee including haemophilia nurses from across Europe, a patient, and a physician/epidemiologist representative was created.

By the end of 2018, the first set of guidelines was published. These first guidelines address the topic of intravenous (IV) and central venous access device (CVAD) factor administration. They are an up-to-date review of the current evidence in haemophilia care focused on the nurse's central role in the treatment of patients with bleeding disorders both in administering clotting factor concentrates and educating patients about self-managing their bleeding disorder.

The guidelines, together with two accompanying videos, are available on the EAHAD website.

European Physiotherapists Network update

Launched in 2017, the goal of the European Physiotherapists Network is to connect physiotherapists working in this specialised area and to facilitate the exchange of knowledge between them. With their network, the members aim to improve the provision and quality of musculoskeletal care to patients with bleeding disorders throughout Europe. After a very successful first year, 2018 was also quite productive for the European Physiotherapists Network, reaching by the end of the year almost 280 physiotherapists from around Europe, publishing two newsletters for its members, and surveying the group to determine the current position of physiotherapy services for haemophilia patients throughout the continent.

Two new staff members join EAHAD

In order to provide the best possible service to our members, one of EAHAD's main goals in 2018 was to increase its employee base. To this end, two new staff joined the EAHAD team this year. In April, Livia Boagiu was hired as EUHASS Project Manager and, in June, Angelos Athanasopoulos took on the role of Communications and Events Officer.

As EUHASS Project Manager, Livia Boagiu is responsible for all aspects of the management, organisation, and coordination of the European Haemophilia Safety Surveillance (EUHASS) project. She also supports the European Haemophilia Centre Certification process, maintains and further develops the Haemophilia Centre Locator, and contributes to the EuroBloodNet activities.

As Communications and Events Officer, Angelos Athanasopoulos manages the EAHAD website and social media channels. At the same time, he oversees the EAHAD newsletters, organises committee meetings, assists with preparations for the annual Congress and is the main contact point for the EAHAD members.

EAHAD introduces two new Working Groups

In 2018, two new EAHAD Working Groups were created: the Psychosocial Professionals Working Group and the Women and Bleeding Disorders Working Group.

The purpose of the Psychosocial Professionals Working Group is to improve the psychosocial quality of care of patients with haemophilia and allied disorders throughout Europe. The members aim to have the group eventually join the two existing EAHAD committees, as a Psychosocial Professionals Committee.

A corollary initiative to the efforts of the European Haemophilia Consortium's Women's Committee to bring to the forefront the unmet needs of women living with bleeding disorders, the aim of the EAHAD Women and Bleeding Disorders Working Group is to gather, concentrate, and disseminate knowledge amongst European healthcare providers on the diagnosis and treatment of women-specific bleeding symptoms in inherited bleeding disorders; to define research priorities in this area within the European medical society; and to diminish the misdiagnosis and under-treatment of women.

EAHAD and EHC release Joint Statement on Novel Non-Replacement Therapies

In July, EAHAD and the European Haemophilia Consortium (EHC) published a **joint position statement** on the crucial role of comprehensive care centres in the era of novel non-replacement therapies. As these therapies are becoming available, potentially significantly impacting the clinical care and quality of life of patients, EAHAD and the EHC highlight how important it is that patients and clinicians are well educated and informed about the modalities of these new therapies. In this joint statement, EAHAD and the EHC call for all novel therapies to be prescribed, managed, and monitored exclusively by haemophilia comprehensive care centres.

European Principles of Inhibitor Management in Patients with Haemophilia published

In April, the **"European Principles of Inhibitor Management in Patients with Haemophilia"** was published in the *Orphanet Journal of Rare Diseases*. A collaboration between EAHAD and the EHC, the purpose of the principles is to be a benchmark for improving the multidisciplinary and practical management of inhibitors in haemophilia. The 10 principles were defined by a multidisciplinary group of health professionals and patients and emphasise the importance and benefits of a centralised, multidisciplinary, expert, and holistic approach in addressing this most serious complication in haemophilia.

EAHAD and EHC celebrate World Haemophilia Day 2018 together

With it being the 10-year anniversary of the publication of the "European Principles of Haemophilia Care", 2018 was the perfect occasion for EAHAD and the EHC to celebrate World Haemophilia Day together. Held in Brussels, Belgium, the World Haemophilia Day 2018 joint event was a great opportunity to look back at the progress made over the last 10 years, but also forward to the many potential initiatives for future collaboration and partnership in the delivery of haemophilia care.

Cedric Hermans becomes the new Editor-in-Chief of *Haemophilia* Journal

In July, **Wiley appointed Prof Cedric Hermans as the new Editor-in-Chief of *Haemophilia***, the official journal of EAHAD. EAHAD's past President, Prof Hermans replaced current President Prof Mike Makris and Dr Craig Kessler. Thanks to the contributions of the previous editors and Prof Cedric Hermans' skills and expertise, the future of the journal is surely going to be even brighter.

Research Grants

The 2018 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 13 applications from 6 countries.

Following a multi-step review process, 2 projects were selected, and the recipients were announced at the EAHAD 2018 Congress. They are:



Alessandro Casini, MD

University Hospitals of Geneva, Geneva, Switzerland

Interactions between fibrinogen variants and blood cells: towards a predictive model in congenital fibrinogen disorders

Project duration

October 2018-September 2019

Grant amount

€ 45,000



Sébastien Lacroix-Desmazes, PhD

INSERM, Centre de Recherche des Cordeliers 15, Paris, France

High throughput generation and characterization of monoclonal anti-FVIII IgG from patients with hemophilia A

Project duration

March 2018-February 2020

Grant amount

€ 50,000



Also in 2018, the first of the 2017 Research Grants were concluded with Dr Johan Boender from Erasmus University Medical Center in Rotterdam, the Netherlands submitting the final report on his project "Does ADAMTS13 influence the bleeding phenotype in von Willebrand disease?"



2017 Research Grant recipients

PROJECT TITLE	PRINCIPAL INVESTIGATOR	INSTITUTION	START DATE	END DATE
Does ADAMTS13 influence the bleeding phenotype in von Willebrand disease?	Johan Boender, MD, PhD Student	Erasmus University Medical Center (Rotterdam, the Netherlands)	April 2017	March 2018
High throughput analysis of antibody binding profiles in previously untreated patients with severe haemophilia A	Roberta Palla, PhD	Fondazione Luigi Villa, Angelo Bianchi Bonomi Haemophilia and Thrombosis Centre (Milan, Italy)	April 2017	March 2019

EUHASS

The European Haemophilia Safety Surveillance System (EUHASS) project is an adverse event reporting system to monitor the safety of treatments for people with inherited bleeding disorders in Europe. EUHASS officially started collecting adverse event data on 1 October 2008, having its 10-year anniversary in 2018.

In October 2018, EUHASS published its 9th annual report covering the period 1 January to 31 December 2017. The number of participating centres continues to grow, with this report containing events data from 86 centres in 27 countries.

In 2018, EUHASS also published four quarterly reports covering the period from 1 January to 31 December. These timely reports include more condensed information on the events reported whilst the annual reports provide a more detailed analysis.

The EUHASS website provides live updates with aggregated data of the total events reported since the launch of the project.

European Haemophilia Centre Certification

The European Haemophilia Centre Certification process remains active with EAHAD administrating the process. In 2018, 7 centres in 5 countries were certified, bringing the total count of certified centres to 140 in 33 countries.

EUROPEAN HAEMOPHILIA COMPREHENSIVE CARE CENTRES (EHCCCS)

Centro Emofilia - Diagnostica Speciale e Terapia delle Malattie dell'Emostasi e della Trombosi – Rome, Italy

Haemophilia Centre Charité Berlin – Berlin, Germany

Ege Adult Haemophilia and Thrombosis Center – Izmir, Turkey

Gazi University Faculty of Medicine – Ankara, Turkey

EUROPEAN HAEMOPHILIA TREATMENT CENTRES (EHTCS)

Haemophilia Treatment Centre of Tartu University Hospital – Tartu, Estonia

Turku University Hospital – Turku, Finland

Tampere University Hospital – Tampere, Finland

For more information on the classification of centres and how the certification process takes place and for a list of all of the certified haemophilia centres in Europe, please visit the Centre Certification website.

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.

During the past year:

- The Steering Group has met on five occasions where it was agreed that the technical oversight of the databases should move to be under the supervision of Medical Data Solutions and Services (MDSAS). This resulted in the incorporation of several enhancements to the databases.
- The **factor VII** database has been enhanced to now display considerable detail on individual variant combinations as well as graphic representation of summary data. In total there are 242 variants on 729 case reports.
- The **factor VIII** variant database has also been enhanced to facilitate the presentation of the data for users. The database has details of 2,015 different variants from 5,450 different case reports and will shortly be expanded with the addition of a further 3000 individual reports from the US.
- The **factor IX** variant database has information on 1,094 separate variants in 3,713 cases. It has also recently been enhanced to allow a user-friendly display of information.
- The **VWF** variant database continues to be widely consulted and is a valuable asset to a broad range of clinicians and researchers.
- Work of the development of databases for **factor X and XI** has progressed.
- The Coagulation Factor Variant Databases receive financial support from EAHAD, BioMarin, Pfizer, and Sobi.



COMMUNICATIONS

2018 saw a significant increase in the number of followers on the EAHAD social media accounts. On Twitter, after reaching 308 followers within the first year on the platform, in 2018 this number more than doubled reaching 671 followers by December 2018. At the same time, our LinkedIn page also saw a substantial boost in numbers with our followers increasing from 154 in 2017 to 332 by the end of 2018.

In 2018 we also launched a completely revamped version of the **EAHAD Newsletter** and are constantly striving to improve communication with our members, as well as professionals and organisations active in the field of rare bleeding disorders. At the same time, with 2018 ushering in new European regulations on data protection and privacy, we made a conscious effort to ensure that our mailing lists were GDPR-compliant.

Twitter



Increase of 118%



LinkedIn



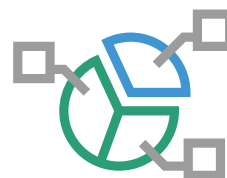
Increase of 116%



Website

Users: 20.797

New Visitors	19.870
Returning Visitors	5.311



	Views	Users
2018	63.490	20.797
	8,11% increase	24,13% increase
2017	58.727	16.754

Top Countries	Users
USA	3.313
United Kingdom	2.721
Spain	1.594
Switzerland	1.219
Germany	1.171

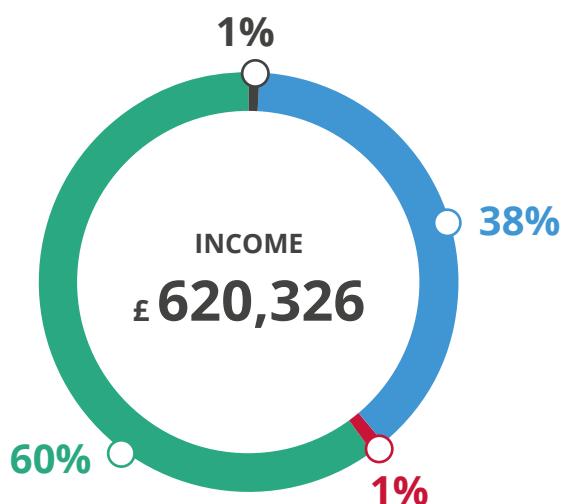




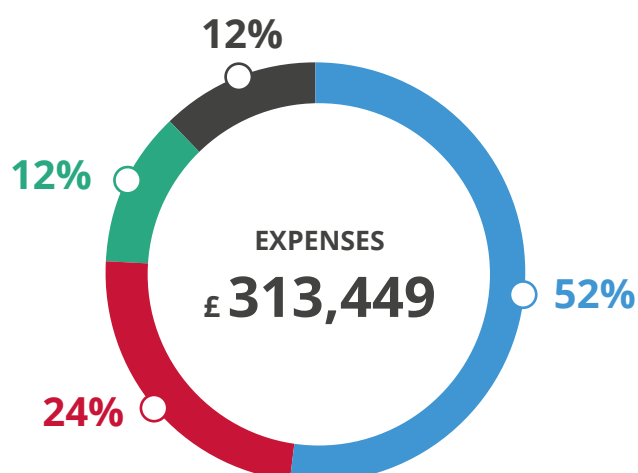
FINANCES

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 2018 can be consulted on the website of the **Charity Commission for England and Wales**.

1 October 2017 to 30 September 2018



Sponsorship	£234,035
Membership fees	£4,785
Congress Revenue	£372,300
Foreign Currency Exchange Gain	£9,206
TOTAL INCOME	£ 620,326



Wages and consultancy fees	£164,308
Research grants	£76,002
Meeting expenses	£37,268
Operational expenses	£35,871
TOTAL EXPENSES	£313,449



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 Women and Bleeding Disorders Working Group aims to gather, concentrate and disseminate knowledge amongst European healthcare providers, define research priorities, and diminish misdiagnosis and under treatment of women with bleeding disorders in Europe. This multidisciplinary group launched in late 2018 with three founding members, but intends to expand its scope to include not only haematologists and obstetrician-gynaecologists, but also nurses, patient representatives, and other multidisciplinary team members.

The Psychosocial Professionals Working Group is composed of psychologists and social workers working in haemophilia centres. Its purpose is to improve the psychosocial quality of care for patients with haemophilia and allied disorders by promoting psychosocial services as part of comprehensive care, supporting research in this field, and forming international standards of psychosocial care.

The Coagulation Factor Variant Databases Steering Group is responsible for the administration of the Coagulation Factor Variant Databases project. This long-running project has as its goal to gather together single gene variant databases involved in clinical bleeding disorders, include haemophilia A, B, von Willebrand disease, and factor VII deficiency. It is comprised of clinicians and scientists from around Europe working in the field of haemophilia and allied bleeding disorders.

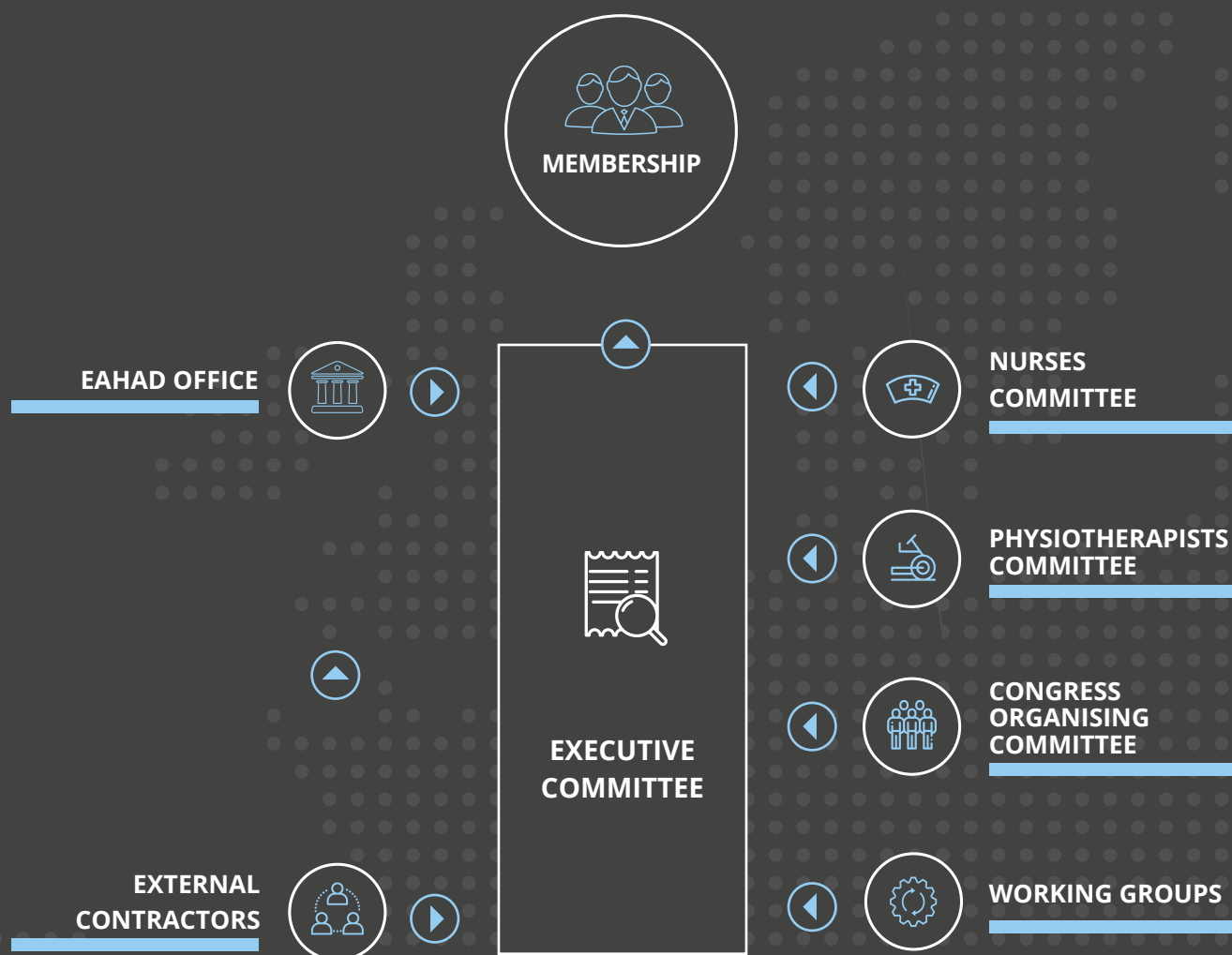
The European Haemophilia Centre Certification Group has the task of reviewing all applications for certification and designating haemophilia centres as either European Haemophilia Comprehensive Care Centres (EHCCCs) or European Haemophilia Treatment Centres (EHTCs). It is comprised of two physicians,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

The EUHASS Steering Committee manages the EUHASS Project, implementing its aim of being a prospective adverse event reporting system for Europe. The Committee includes representatives from the EHC, Medical Data Solutions and Services, the University Medical Centre Utrecht, and four participating haemophilia centres.

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



EAHAD Organigram 2018





EXECUTIVE COMMITTEE

Mike Makris	President
Flora Peyvandi	Vice President
Cedric Hermans	Past President
Víctor Jiménez Yuste	EAHAD 2018 Congress President
Gerry Dolan	Treasurer
Riitta Lassila	Secretary
Jan Blatny	EAHAD 2019 Congress President
Karin Fijnvandraat	Member
Hervé Chambost	Member
Robert Klamroth	Member
Wolfgang Miesbach	Member
Elsbeth Müller-Kägi	Nurses Committee Chair
Sébastien Lobet	Physiotherapists Committee Chair

NURSES COMMITTEE



Elsbeth Müller-Kägi	Chair
Mary Kavanagh	Vice Chair
Kristian Juusola	Secretary
Siri Grønhaug	Member
Martin Bedford	Member
Petra Elfvinge	Member

PHYSIOTHERAPISTS COMMITTEE



Sébastien Lobet	Chair
David Stephensen	Vice Chair
Paul McLaughlin	Secretary
Ruth Elise Dybvik Matlary	Member
Marie Katzerová	Member
Piet de Kleijn	Member

PSYCHOSOCIAL PROFESSIONALS WORKING GROUP



Lotte Haverman	Chair
Petra Bučková	
Ana Torres-Ortuño	
Karen Vandenabeele	
Gaby Golan	
Christina Burgess	(ex-officio)

WOMEN AND BLEEDING DISORDERS WORKING GROUP



Karin van Galen	Chair
Rezan Kadir	
Roseline d'Oiron	

COAGULATION FACTOR VARIANT DATABASES STEERING GROUP



Christopher Ludlam	Chair
Geoffrey Kemball-Cook	Secretary
Keith Gomez	Treasurer
Gerry Dolan	
Muriel Giansily-Blaizot	
Anne Goodeve	
Daniel Hampshire	
John McVey	
Johannes Oldenburg	
Stephen Perkins	
Flora Peyvandi	

EUROPEAN HAEMOPHILIA CENTRE CERTIFICATION GROUP



Mike Makris	EUHANET Project Leader
Philippe de Moerloose	EAHAD Past President
Brian O'Mahony	EHC President
Martin Bedford	Nurse representative

EUHASS STEERING COMMITTEE



Mike Makris	Chair and Project Leader
Kathelijn Fischer	
Alex Gatt	
Rob Hollingsworth	
Radoslaw Kaczmarek	
Thierry Lambert	
Riitta Lassila	
Flora Peyvandi	

EAHAD OFFICE STAFF



Aislin Ryan	Managing Director
Livia Boagiu	EUHASS Project Manager
Angelos Athanasopoulos	Communications and Events Officer





ACKNOWLEDGEMENTS

Funding

In 2018, EAHAD received funding for its non-Congress related activities from:



BIOMARIN



CSL Behring
Biotherapies for Life™

GRIFOLS



octapharma



Shire



EAHAD is grateful for the unrestricted financial support it receives from these sponsors.

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 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 the organisation of our Annual Congress
- **5 O'Clock** for the administrative support
- **Medical Data Solution & Services** for IT support
- **Atkinson Donnelly LLP** for their accounting services
- **Koan Law Firm** for their legal services
- **AdGrafics Agency** for creating visual content for our publications



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