



2019

ANNUAL
REPORT

TABLE OF CONTENTS



Page 4
FOREWORD



Page 5
ABOUT EAHAD



Page 6
MEMBERSHIP



Page 8
**2019 AT
A GLANCE**



Page 10
2019 HIGHLIGHTS



Page 16
COMMUNICATIONS



Page 18
FINANCES



Page 19
**ORGANISATIONAL
STRUCTURE**



Page 23
ACKNOWLEDGMENTS





FOREWORD

Dear colleagues and friends,

I am happy to share with you the 2019 EAHAD Annual Report, in which you will find all the key activities carried out by EAHAD this year. Once again, 2019 was dedicated to the improvement of care for persons with bleeding disorders. Our association continues to bring together professionals whose diverse expertise supports patients and helps scientific research grow.

A substantial development in 2019 was that EAHAD officially transferred its legal base from the United Kingdom to Belgium. The decision was taken due to our office and staff being based in Brussels and the uncertainty around Brexit. We decided that running the association from the continent would provide more stability and sustainability.

EAHAD has been one of the main partners of the EUHASS Project since the beginning. In 2019, we have facilitated access to information about EUHASS by creating a direct link to the EUHASS website on the EAHAD website, now listed under the Projects tab.

Our Physiotherapists and Nurses Committees continue to be prolific. Our Physiotherapists Committee published "Scope of practice of haemophilia physiotherapists: A European survey" in the *Haemophilia* Journal. Our Nurses Committee established their dedicated European Nurses Network.

Our Psychosocial Professionals Working Group conducted a survey on the "Access to psychosocial services for patients with bleeding disorders" and our Women and Bleeding Disorders Working Group conducted one on the "Clinical Management of Women-Specific Symptoms in Inherited Bleeding Disorders among the certified hemophilia treatment centers in Europe". 2019 also saw the creation of an EAHAD Gene Therapy Working Group, with the goal of providing information to physicians and patients about the practicability and safety of this new treatment option.

2019 was another fruitful year for collaboration with our partners from the pharmaceutical industry. Their support is always appreciated since it helps us start new initiatives and enhances our role as the leading scientific voice in the field of haemophilia in Europe.

It goes without saying that once again this year our biggest project was the Annual Congress. EAHAD 2019, the 12th iteration of our congress, surpassed all expectations and became the most successful to date. It took place in Prague, Czech Republic, under the direction of Dr Jan Blatny. Its diverse sessions and presentations highlighted why our Congress is the place to be for everyone involved in haemophilia and bleeding disorders in Europe.

As EAHAD President for the period 2018-2020, I would like to thank my fellow Executive Committee members, the sub-committees and working groups, the staff and everyone else who contributes to our activities throughout the year. I am certain that the community we have created will help make haemophilia and allied disorders care attain new heights in the future.

Sincerely,

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 multidisciplinary association of healthcare professionals that seeks to provide care for individuals with haemophilia and other bleeding disorders, based on research, collaboration, and knowledge dissemination. Its members include haematologists, internists, paediatricians, nurses, physiotherapists, psychosocial professionals, laboratory scientists, and researchers.

EAHAD'S WORK IS GUIDED BY THE FOLLOWING THREE 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.

There are four membership categories:



Ordinary



Junior



Allied Health Professional

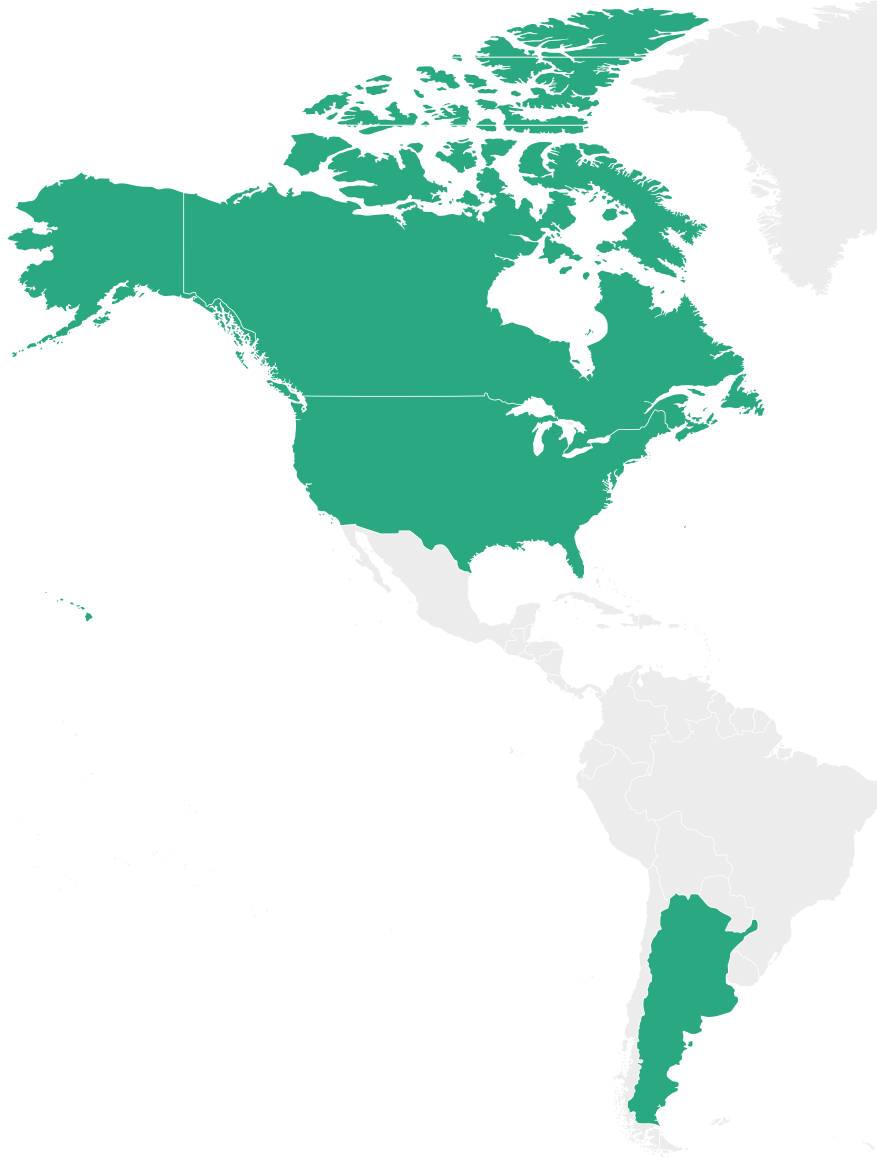


Honorary

Discontinuation of Associate Membership and introduction of Junior Membership

Following a restructuring of the membership categories in conjunction with the transfer of EAHAD's legal base from the United Kingdom to Belgium, the category of Associate Member was discontinued.

In 2019, EAHAD introduced the Junior Membership, with a discounted fee available to students, trainees, post-doctoral fellows, or allied health professionals younger than 35 years old, from any country, who demonstrate an active interest in the field of haemophilia and allied disorders.

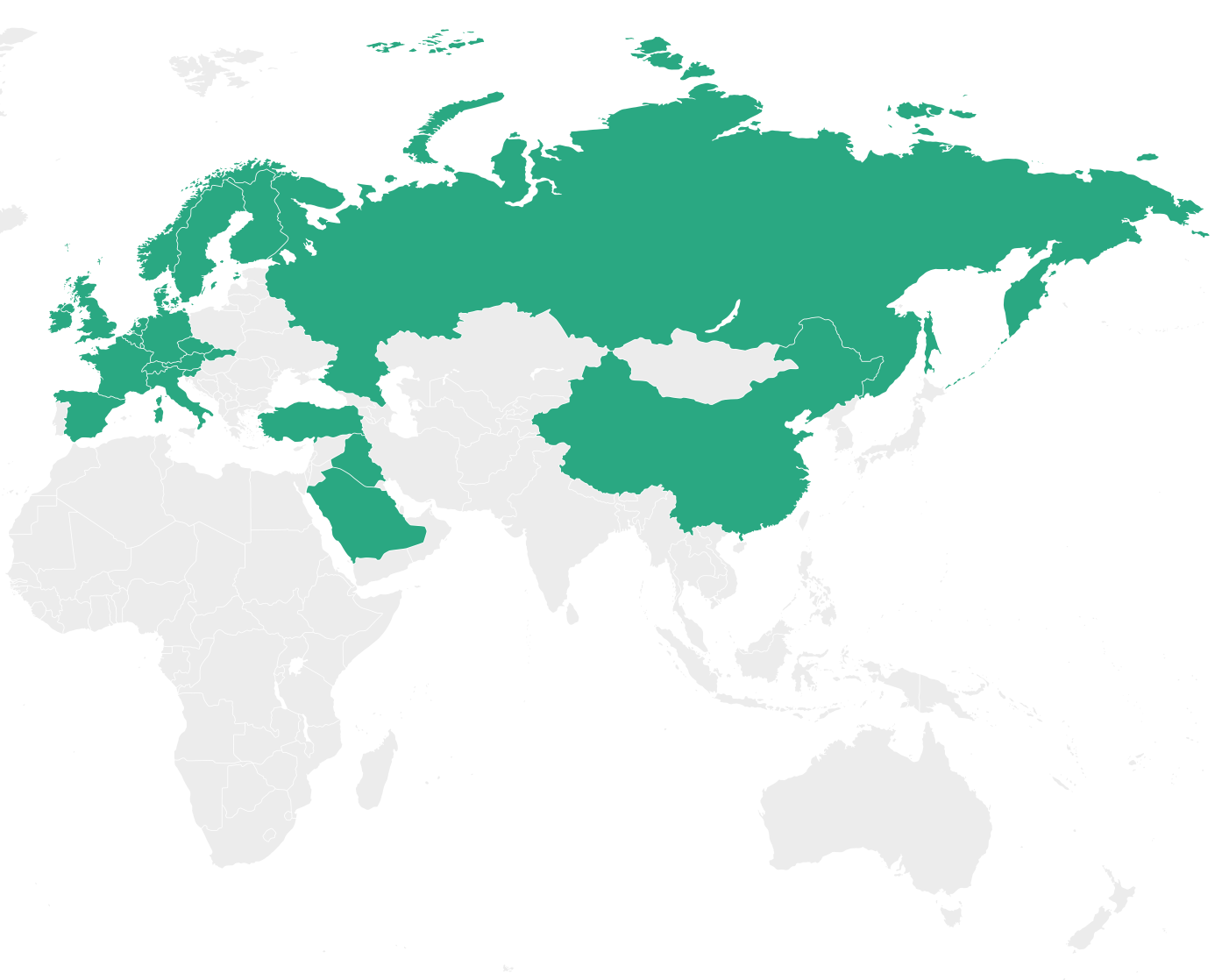


151
members



27
countries

2018-2019 MEMBERSHIP NUMBERS:



2014-2015	2015-2016	2016-2017	2017-2018	2018-2019
125 members	164 members	168 members	142 members	151 members
24 countries	28 countries	29 countries	28 countries	27 countries

114
Ordinary
Members

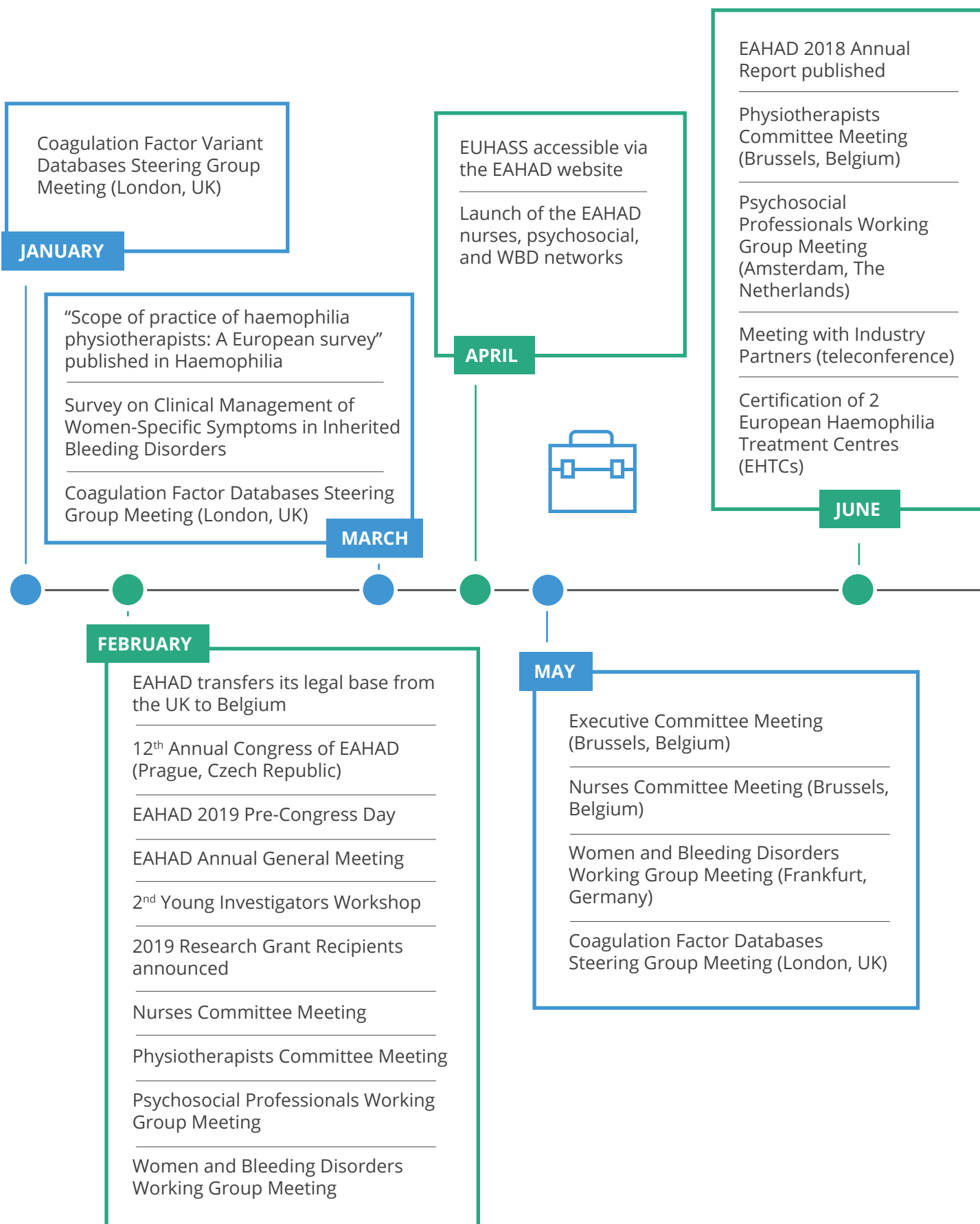
31
Allied Health
Professional Members

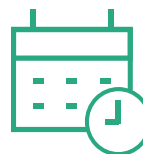
2
Junior
members

4
Honorary
members



2019 AT A GLANCE





JULY

Coagulation Factor
Databases Steering Group
Meeting (London, UK)

AUGUST

EAHAD Coagulation
Factor Databases new
website

OCTOBER

Psychosocial Professionals
Working Group Meeting
(Brussels, Belgium)

Survey on access to
psychosocial services for
patients with bleeding
disorders

SEPTEMBER

Executive Committee Meeting (Brussels, Belgium)
Nurses Committee Meeting (Brussels, Belgium)
Coagulation Factor Databases Steering Group
Meeting (London, UK)
Launch of EAHAD Gene Therapy Working Group

NOVEMBER

Physiotherapists Committee
Meeting (Brussels, Belgium)
EAHAD Coagulation Factor
Databases Steering Group
Meeting (London, UK)

DECEMBER

EUHASS 10th Annual Report
published

European Physiotherapists
Newsletter published

Women and Bleeding Disorders
Newsletter published

Certification of 1 EHTC





2019 HIGHLIGHTS

EAHAD 2019 Congress in Prague, Czech Republic

From 5 to 8 February 2019, held under the auspices of the Czech Minister of Health, the EAHAD 2019 Congress took place in Prague, Czech Republic. The 12th iteration of our Congress welcomed more than 2600 delegates from 80 countries for an unforgettable scientific experience. It took place at the Prague Congress Centre, with a beautiful view over the historic city, and was the place to be for discussions on the latest treatment developments and ongoing clinical challenges in managing haemophilia and other related bleeding disorders.

The meeting started with the Multidisciplinary Pre-Congress Day on 5 February, which emphasised the importance of comprehensive care for people with bleeding disorders. Nurses, physiotherapists, and psychosocial professionals shared their knowledge and expertise to further promote the multidisciplinary approach in haemophilia care. On the same day, young investigators had the chance to discuss their research projects and learn from distinguished professionals during an interactive half-day early career professionals' workshop.

Carefully designed by Congress President Dr Jan Blatny from the Children's University Hospital Brno, the main programme included topics like the near and more distant future of haemophilia treatment, the monitoring of haemophilia treatment and the advantages and challenges of registries and real-world data.



Congress Facts & Figures



CONGRESS PRESIDENT

Dr Jan Blatny



VENUE

Prague Congress Centre



DATES

6-8 February 2019



DELEGATES

2,612

ABSTRACTS

338 submissions | 307 posters presented | 16 oral abstract presentations

80

Countries represented

27

Travel Grants awarded

11

Satellite Symposia

12

Sponsors

POSTER PRIZE WINNERS



S. Bouttefroy et al. "Congenital factor XIII deficiency: Demographic and clinical description of the French cohort from the FranceCoag network"



D. M. Monroe et al. "In the presence of emicizumab, factor VIIa activation of factor IX contributes to factor Xa generation"



B. Tardy et al. "Revised pharmacokinetics of Benefix"

TOP SLAM PRESENTATION



"Intracranial haemorrhage in haemophilia – A systematic review" - A. F. Zwagemaker et al

EAHAD RECOGNITION AWARD RECIPIENTS



Prof Edward Tuddenham
Mr Piet de Kleijn

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

In 2019, the awards went to **Prof. Edward Tuddenham**, leading haematologist from the Royal Free Hospital in London, and **Mr Piet de Kleijn**, expert physiotherapist and past chair of the EAHAD Physiotherapists Committee. Their contributions to the global haemophilia community cannot be overstated.

EAHAD transfers its legal base from the UK to Belgium

Following a unanimous decision on 7 February 2019 at the Annual General Meeting, [EAHAD officially transferred its legal base from the United Kingdom to Belgium](#). EAHAD is now [an international non-profit association \(AISBL\) under Belgian law](#).

This decision was taken due to operational considerations as both EAHAD's office and much of its activity is based in and around Belgium and the Eurozone. At the same time, with the uncertainty around Brexit and potential implications for European funding opportunities in the future, it was felt that running the organisation from the continent would provide more stability and sustainability.

Despite this development, our mission to improve the situation of people living with haemophilia and other bleeding disorders across Europe, including the United Kingdom, remains the same.

EAHAD Physiotherapists Committee survey published in *Haemophilia*

In March 2019, "[Scope of practice of haemophilia physiotherapists: A European survey](#)" was published in *Haemophilia*. Developed by the EAHAD Physiotherapists Committee, the web-based survey was conducted with the aim to quantify the role and scope of practice of physiotherapists involved in haemophilia care. It included questions concerning work practices, assessment and treatment activities, and level of autonomy.

Eighty physiotherapists from twenty-four European countries replied to the survey. Their responses showed a considerable diversity regarding physiotherapists' roles, responsibilities, and clinical practice from one country to the next. The heterogeneity was particularly evident in patients' access to physiotherapy services and the type of physiotherapy treatment provided. There was also variability in physiotherapists' skill set and autonomy to make independent assessments and treatment decisions.

EAHAD Nurses Committee establishes European Nurses Network

In 2019, our Nurses Committee created their dedicated [European Nurses Network](#). Its purpose is to connect nurses specialising in haemophilia care in Europe and to facilitate the exchange of knowledge, in order to provide better care for patients with bleeding disorders.

Apart from individual nurses, the Committee also invites national haemophilia nurses networks to join, as they are interested in collaborating on an organisational level, by providing the national organisations with information they can disseminate to their members.

Psychosocial Professionals Working Group conducts survey on access to psychosocial services for patients with bleeding disorders

In October 2019, our Psychosocial Professionals Working Group conducted a survey on the "Access to psychosocial services for patients with bleeding disorders". The Working Group sent out the survey to the European Comprehensive Care Centres to establish the level of psychological support available at each of them.

43 Centres responded, 80% of which think that psychosocial provision is important in the care of patients and psychosocial professionals must be an integral part of the comprehensive care team from the beginning.

Women and Bleeding Disorders Working Group disseminates survey on the Clinical Management of Women-Specific Symptoms in Inherited Bleeding Disorders

In March 2019, our WBD Working Group conducted a survey on the Clinical Management of Women-Specific Symptoms in Inherited Bleeding Disorders. The survey received responses from 59 haemophilia centres in 26 different countries.

The results will be presented at EADAD 2020 in The Hague and, as a next step, the Working Group will publish them in a paper to provide some insight into the organisation of care for women with bleeding disorders in Europe and to share identified knowledge gaps and research priorities in the clinical management of WBD within Europe.

Launch of the EAHAD Gene Therapy Working Group

Following the approval of a proposal to the Executive Committee in September, [the EAHAD Gene Therapy Working Group was launched](#). Chaired by Prof. Dr Wolfgang Miesbach, the Working Group will have a mandate of two years and will be comprised of six to eight members.

The tentative goals of the Working Group are to investigate gene therapy safety and its outcome parameters, to provide updates on recent developments in terms of alanine aminotransferase (ALT) results and safety outcomes, to collect data on the different gene therapy trials, tests, and adverse events, and to inform patients and medical professionals.

The EAHAD Coagulation Factor Databases hosted at a new website

In 2019, The EAHAD Coagulation Factor Databases were enhanced with new features and a greatly increased number of listed variants. The databases are now hosted [at a new address](#), where visitors can review the variant lists, clinical information and find additional information on the individual clotting factors, with comprehensive references and graphic display on molecular models.

In order to guarantee the future availability of the databases for coagulation factor deficiencies in FVII, FVIII, FIX and vWF to the clinical and research communities, the EAHAD-DB Coagulation Factor Variant Database Steering Group brought the websites directly under the EAHAD domain. The transfer facilitated improvements in website function and secured the continuing addition of more cases by the EAHAD database curators.



Research Grants



The 2019 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 16 applications from 11 countries.

Following a multi-step review process, 2 projects were selected, and the recipients were announced at the EAHAD 2019 Congress. They are:



Samantha Gouw MD, PhD
Amsterdam University Medical Center,
Amsterdam, The Netherlands

“Getting GRIP on Tolerance: The role of Fc Gamma Receptors in Immune tolerance to Protein therapeutics”

Project duration July 2019-January 2021

Grant amount € 50,000



Nathalie Roussel, PhD, MSc, PT
Faculty of Medicine & Health Sciences,
University of Antwerp, Belgium

“Towards a better understanding of ankle pain in haemophilia patients: A study examining the relationship between structure and function, taking pain mechanisms into account”

Project duration April 2019-April 2020

Grant amount € 50,000

Also, in 2019, two Research Grants from previous years were concluded. 2017 recipient, Roberta Palla, PhD, submitted her final report on the project “*High throughput analysis of antibody binding profiles in previously untreated patients with severe haemophilia A*”. 2018 recipient Alessandro Casini, MD, submitted his final report on the project “*Interactions between fibrinogen variants and blood cells: towards a predictive model in congenital fibrinogen disorders*”.

PROJECT TITLE	PRINCIPAL INVESTIGATOR	INSTITUTION	START DATE	END DATE
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
Interactions between fibrinogen variants and blood cells: towards a predictive model in congenital fibrinogen disorder	Alessandro Casini, MD	University Hospitals of Geneva, Geneva, Switzerland	October 2018	September 2019
Getting GRIP on Tolerance: The role of Fc Gamma Receptors in Immune tolerance to Protein therapeutics	Samantha Gouw, MD, PhD	Amsterdam University Medical Center, Amsterdam, The Netherlands	July 2019	January 2021
Towards a better understanding of ankle pain in haemophilia patients: A study examining the relationship between structure and function, taking pain mechanisms into account	Nathalie Roussel, PhD, MSc, PT	Faculty of Medicine & Health Sciences, University of Antwerp, Belgium	April 2019	April 2020



EUHASS

The **European Haemophilia Safety Surveillance System (EUHASS) project** is an adverse event reporting system for European patients with inherited bleeding disorders. EUHASS officially started collecting adverse event data on 1 October 2008.

In December 2019, EUHASS published its 10th annual report covering the period 1 January to 31 December 2018. The report contains events data from 86 centres in 27 countries.

In 2019, EUHASS also published four quarterly reports covering the period from 1 January to 31 December. These reports contain more condensed information on the events reported whilst the annual reports provide a more detailed analysis.

In 2019, the **EUHASS website became accessible via the EAHAD website**, under the Projects tab.

European Haemophilia Centre Certification

The European Haemophilia Centre Certification process remains active with EAHAD administrating the process. In 2019, 3 centres in 3 countries were certified, bringing the total count of certified centres to 144 in 33 countries.

EUROPEAN HAEMOPHILIA TREATMENT CENTRES (EHTCs)

Tallinn Children's Hospital, Hematology and Oncology department - *Tallinn, Estonia*

Haemophilia and Bleeding Disorders Care Centre, Paediatrics and Adults Units - *Lausanne, Switzerland*

Hungarian National Blood Transfusion Service Regional Centre Győr - *Győr, Hungary*

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.



COMMUNICATIONS

2019 was a great year in terms of follower numbers on the EAHAD social media accounts. On Twitter, our account jumped from 671 followers in 2018 to 1,079 in 2019. Our LinkedIn page also saw an increase in numbers with 602 followers in 2019, compared to 332 in 2018.

In 2019 we released three issues of the [EAHAD Newsletter](#), as well as one issue of the Physiotherapists Newsletter and one of the Women and Bleeding Disorders Newsletter. We aim to support a continuous and open dialogue with all our members and partners, providing them with the latest information in the field of rare bleeding disorders.

2019 Newsletters

3

EAHAD
Newsletters

1

Physiotherapists
Newsletter

1

Women and Bleeding
Disorders Newsletter

Twitter

671



2018

1,079



2019

Increase of 61%

LinkedIn

332



2018

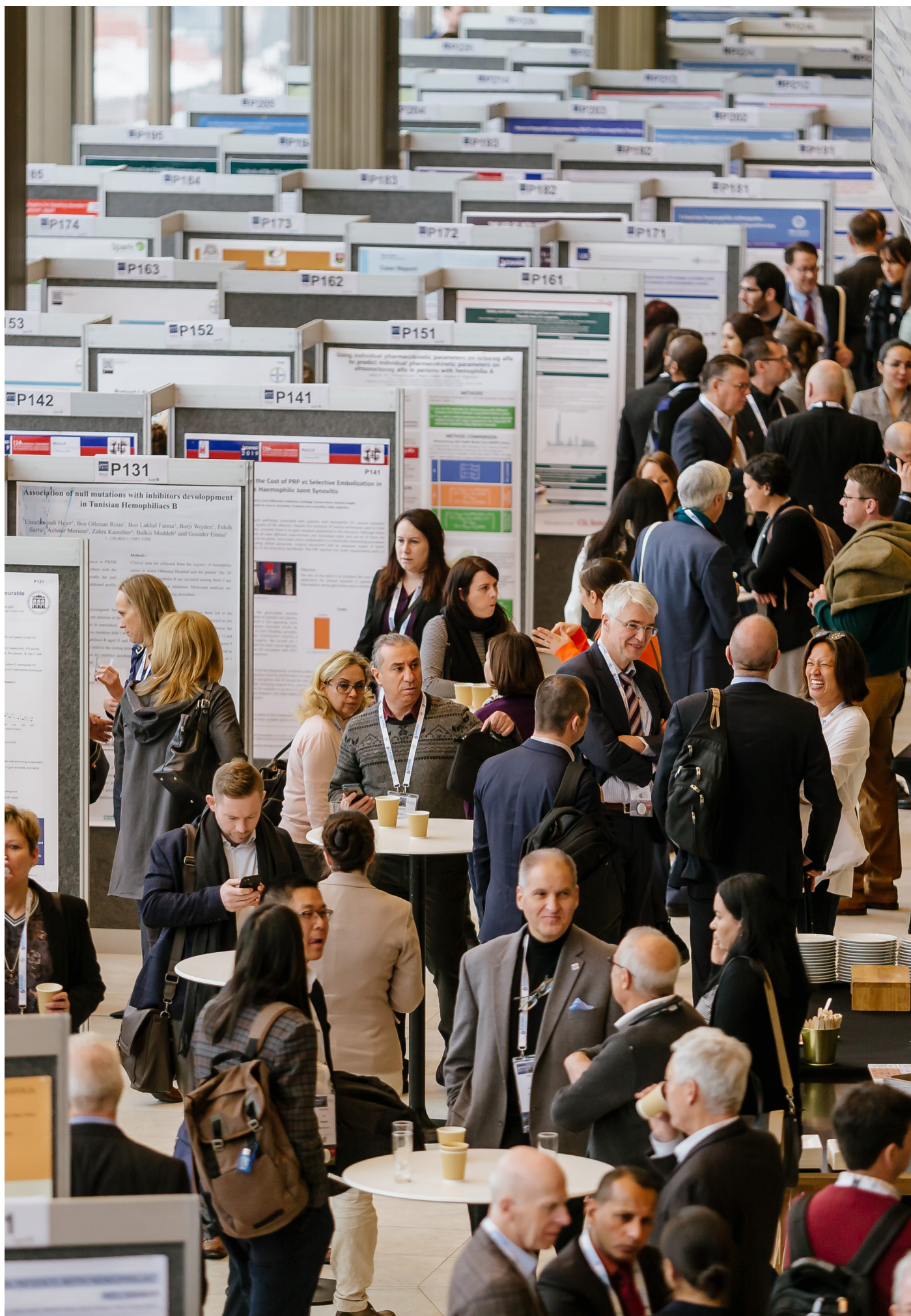
602



2019

Increase of 81%

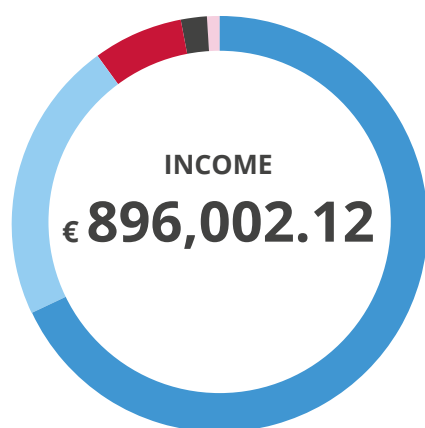




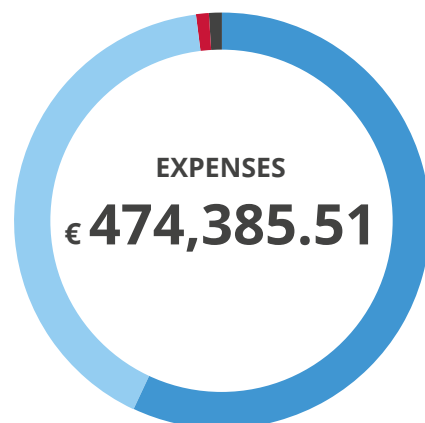


FINANCES

EAHAD's financial year is 1 January – 31 December. A full copy of the annual accounts for 2019 can be consulted on the website of the National Bank of Belgium. The company number is 0718.594.509.



● Annual Congress	€623,461.98
● Sponsorship	€195,000
● Membership Income	€5,927.01
● Reimbursement from EUHASS project	€66,676.74
● Other Income	€4,936.39
Total	€896,002.12



● Services and other goods	€276,577.22
● Staff Costs and Expenses	€195,184.88
● Depreciation	€915.68
● Financial charges	€1,707.73
Total	€474,385.51



ORGANISATIONAL STRUCTURE

The policy and general management of EAHAD is directed by 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 includes 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 Gene Therapy Working Group aims to investigate gene therapy safety and its outcome parameters, to provide

updates on recent developments in terms of alanine aminotransferase (ALT) results and safety outcomes, to collect data on the different gene therapy trials, tests, and adverse events, and to inform patients and medical professionals.

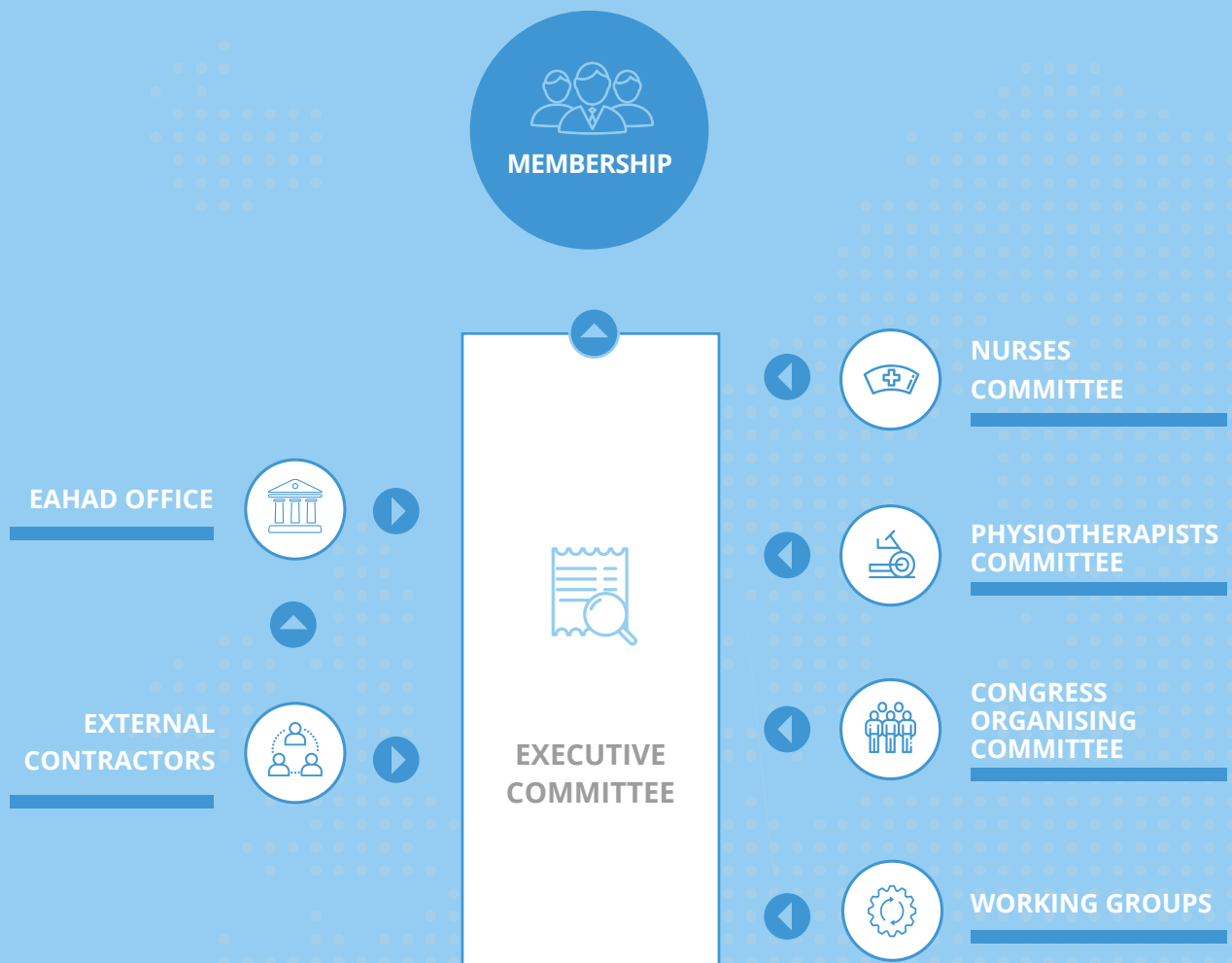
The Coagulation Factor Variant Databases Steering Group is responsible for the administration of the Coagulation Factor Variant Databases project. This long-running project has as its goal to gather together single gene variant databases involved in clinical bleeding disorders, include haemophilia A, 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 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 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 Chief Executive Officer, under the direction of the Executive Committee.





EXECUTIVE COMMITTEE



Mike Makris
 Flora Peyvandi
 Cedric Hermans
 Jan Blatny
 Gerry Dolan
 Riitta Lassila
 Karin Fijnvandraat
 Hervé Chambost
 Robert Klamroth
 Wolfgang Miesbach
 Víctor Jiménez Yuste
 Elsbeth Müller-Kägi
 Sébastien Lobet

President
 Vice President
 Past President
 EAHAD 2019 Congress President
 Treasurer
 Secretary
 EAHAD 2020 Congress President
 Member
 Member
 Member
 Member
 Nurses Committee Chair
 Physiotherapists Committee Chair

NURSES COMMITTEE



Elsbeth Müller-Kägi	Chair
Mary Kavanagh	Vice Chair
Kristian Juusola	Secretary
Simon Fletcher	Member
Siri Grønhaug	Member
Nanda Uitslager	Member

PSYCHOSOCIAL PROFESSIONALS WORKING GROUP



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

GENE THERAPY WORKING GROUP



Wolfgang Miesbach	Chair
Pratima Chowdary	
Mike Makris	
Declan Noone	
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	

PHYSIOTHERAPISTS COMMITTEE



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

WOMEN AND BLEEDING DISORDERS WORKING GROUP



Karin van Galen	Chair
Rezan Kadir	
Roseline d'Oiron	
Petra Elfvinge	
Romana Gerychova	
Eva Ivanova	
Naja Skouw-Rasmussen	
Evelien Mauser Bunschoten	
Michelle Lavin	
Ellen van Loon	

COAGULATION FACTOR VARIANT DATABASES STEERING GROUP



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

EAHAD OFFICE STAFF



Aislin Ryan	Chief Executive Officer
Angelos Athanasopoulos	Communications and Events Officer
Livia Boagiu	Project Manager

ORDERS

PUBLIC
January 2019



ACKNOWLEDGEMENTS

Funding

In 2019, EAHAD received funding for its non-Congress related activities from:



B:OMARIN



CSL Behring
Biotherapies for Life™

GRIFOLS



octapharma



SANOFI GENZYME



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
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 the organisation of our Annual Congress
- **5 O'Clock** for the administrative support
- **Medical Data Solution & Services** for IT support
- **BOFIDI Accountants and Advisors** for their accounting services.
- **Koan Law Firm** for legal services.
- **Adgrafics Agency** for creating visual content for our publications.







EAHAD office

📍 Cours Saint Michel, 30B
Securex Building/Hive5
1040 Brussels, Belgium

More information

✉ info@eahad.org
🌐 www.eahad.org

European Association for Haemophilia and Allied Disorders aisbl
Company number: 0718.594.509