



EAHAD ANNUAL REPORT 2020

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President's Foreword

Dear friends and colleagues,

I am very happy to share with you the 2020 EAHAD Annual Report, containing all the key activities carried out by our association this year. 2020 was a very difficult year for everyone around the world, due to the Covid-19 pandemic. Nevertheless, that did not deter us from striving to improve the care for persons with bleeding disorders. We continue to bring together multidisciplinary professionals, whose expertise supports patients, enhances education, and helps promote scientific research.

This year, I officially became the President of EAHAD for 2020-2022. I was joined by Dr Robert Klamroth, Vice president, Dr Jan Blatny, Treasurer, and Prof. Dr. Karin Fijn van Draat, Secretary. With the support of the Executive Committee members, our subcommittees and working groups, our goal is to cement EAHAD as the hub in Europe where education, science, and research flourish for the benefit of every person with bleeding disorders.

In light of the Covid-19 pandemic, in 2020 we decided that the EAHAD 2021 Congress would be a fully virtual event. Our top commitment was and still is that high quality scientific content would reach our members and partners in Europe and around the world in a safe and accessible manner.

In 2020, a new member joined the EAHAD team, as Pascale Blaes became our interim Chief Executive Officer. Pascale oversaw all organisational and administrative processes and projects, while CEO Aislin Ryan is on leave until December 2021.

One of our priorities going forward is focusing on various activities and structures to support the development of gene therapy. In 2020, we partnered with the International Society on Thrombosis and Haemostasis (ISTH) on a series of educational projects to collaborate on components of the ISTH Gene Therapy in Hemophilia Education Initiative.

In 2020 we have established a new working group, the EAHAD Haemophilia Centre Certification & Audit Working Group, with the goal of updating the current guidelines on the certification of European Haemophilia Centres to include monitoring of novel treatment products and establishing an audit procedure across European haemophilia centres to improve patient care. This committee will also work closely with the Gene Therapy Working Group to facilitate the definition of a European Hub and Spoke model for gene therapy.

Like previous years, our Physiotherapists and Nurses Committees remained at the educational forefront of their disciplines. Our Physiotherapists Committee published in *Haemophilia* a letter to the editor titled "Comprehensive care on paper only? The challenge for physiotherapy provision in day to day haemophilia practice", while our Nurses Committee released their most recent project, the "Adjustable surgery workflow in patients with bleeding disorders".

2020 was another year of fertile collaboration with our pharmaceutical industry partners. Their support doesn't go unnoticed as it helps us initiate new activities, further establishing our role as the leading European scientific voice in haemophilia and allied bleeding disorders.



Our biggest project in 2020 was of course our Annual Congress. With its theme of "A Golden Age of Treatment Choice" and under the direction of Congress President Prof. Dr. Karin Fijn van Draat, EAHAD 2020 was the place-to-be for more than 2,300 delegates, who experienced diverse sessions and presentations of the highest caliber.

As the new EAHAD President for 2020-2022 I would like to thank outgoing President Prof. Michael Makris for his excellent work and remarkable commitment to the goals of the association. I would also like to thank our Executive Committee members, the subcommittees and working groups, the EAHAD office team and everyone else who supports our activities throughout the year. I am positive that our community is more dedicated than ever to accomplish outstanding achievements for haemophilia and bleeding disorders care in the future.

Sincerely,

Professor Flora Peyvandi
EAHAD President 2020-2022

EAHAD - Who we are

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.

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, laboratory scientists, and researchers.

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
- Allied Health Professionals
- Junior
- Honorary

2019-2020 Membership Numbers:
165 members from **28** countries

- 126 Ordinary Members
- 24 Allied Health Professional Members
- 10 Junior Members
- 4 Honorary Members



2015-2016
164 members
28 countries

2016-2017
168 members
29 countries

2017-2018
142 members
28 countries

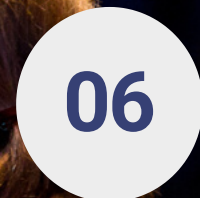
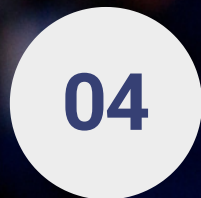
2018-2019
153 members
27 countries

2019-2020
165 members
28 countries

2020 at a glance

- Pascale Blaes joins EAHAD as Interim CEO

JAN



FEB

- Executive Committee 2020 Elections
- 13th Annual Congress of EAHAD (The Hague, Netherlands)
- EAHAD 2020 Pre-Congress Day
- EAHAD Annual General Meeting
- 2020 Research Grant Recipients announced

- Coagulation Factor Databases Steering Group new publication

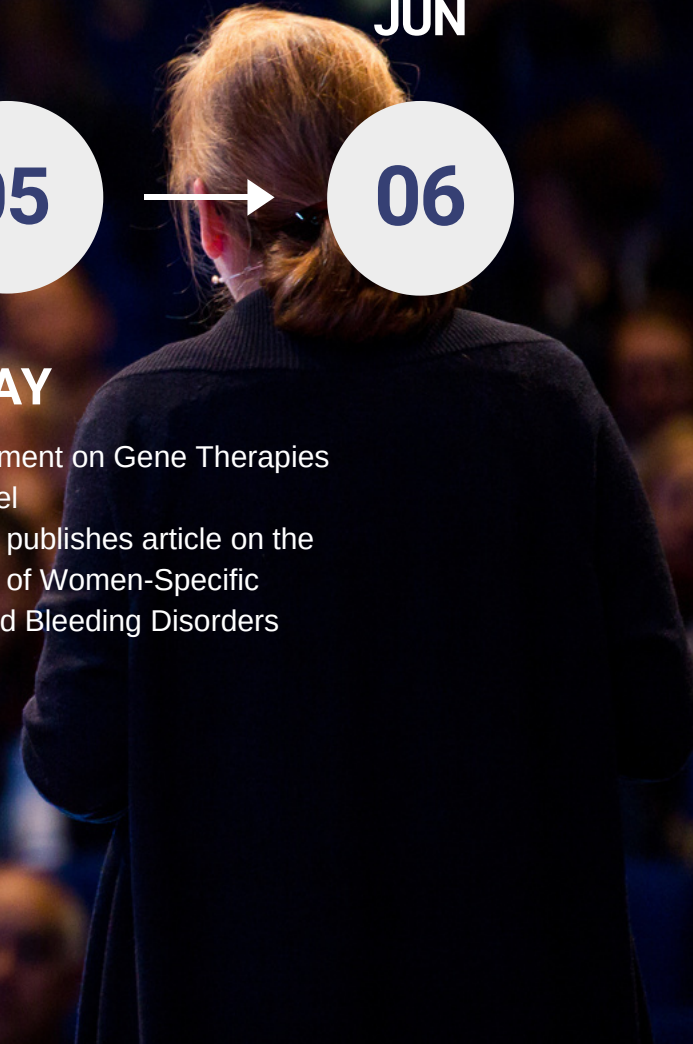
APR

MAY

- EAHAD – EHC Statement on Gene Therapies Hub-and-Spoke Model
- WBD Working Group publishes article on the Clinical Management of Women-Specific Symptoms in Inherited Bleeding Disorders

- EAHAD Webinar: Covid-19 and Haemophilia
- Covid-19 recommendations and survey from the Psychosocial Professionals Working Group
- EAHAD – EHC Joint statement on AAV8-based ASPIRO clinical trial

JUN



2020 at a glance

- EAHAD 2019 Annual Report published
- EAHAD co-signs ISTH Covid-19 Consensus Statement
- EAHAD 2021 Virtual Congress Announcement

- ISTH and EAHAD Educational Partnership on Gene Therapy announced
- EAHAD Physiotherapists Committee Letter to the Editor published in Haemophilia
- Haemophilia Centre Certification & Audit Working Group formed

- EAHAD co-signs Covid-19 vaccination guidance
- EUHASS 11th annual report published

JUL

07



09



10



11



12

SEP

- EAHAD co-signs bureaucracy in clinical trials statement

OCT

NOV

- 2021 Research Grant cycle launches
- EAHAD Nurses Committee publish Adjustable Surgery Workflow

DEC



2020 HIGHLIGHTS



2020 Highlights

EAHAD 2020 Congress The Hague, Netherlands



From 4 to 7 February, the EAHAD 2020 Congress took place in The Hague, Netherlands. Its theme was “A Golden Age of Treatment Choice” and, indeed, more than 2300 delegates experienced diverse sessions and presentations of the highest caliber. The 13th Annual Congress took place at the World Forum, under the direction of Congress President, Prof. Dr. Karin Fijn van Draat and was the place to be for innovative discussions on the latest developments in the haemophilia and bleeding disorders field.

We kicked off the meeting with our Pre-Congress Day on Tuesday 4 February. Physiotherapists, nurses and psychosocial professionals were present to share their expertise and show just how crucial the multidisciplinary approach in haemophilia care really is. Our opening session highlighted the importance of the joint effort between different health professionals by looking into the multidisciplinary and interdisciplinary care of patients with rare bleeding disorders in the Netherlands.

From 5-7 February, attendees had the opportunity to experience diverse presentations ranging from the current and modern haemophilia therapeutic landscape, gene therapy, uncertainties for patients in the era of new treatments, to vWF dilemmas. On Friday, delegates attended the exciting oral abstract SLAM presentations, as well as the Hot Topics session, covering cutting-edge developments in treatment that will definitely affect the future bleeding disorders landscape.

The feedback received for the scientific content of the EAHAD 2020 Annual Congress was extremely positive and we would like to thank all of you who joined us.

CONGRESS FACTS AND FIGURES

CONGRESS PRESIDENT

Prof. Dr. Karin Fijn van Draat

DATES

5-7 February 2020

COUNTRIES REPRESENTED

82

ABSTRACTS

338 submissions, 308 posters presented, 10 oral abstract presentations

SPONSORS

14

VENUE

World Forum

DELEGATES

2,367

TRAVEL GRANTS

27

SATELLITE SYMPOSIA

12

POSTER PRIZE WINNERS AND TOP SLAM PRESENTATION



First Prize

V.J. Strijbis et al. "Evaluation of a blood coagulation factor IX variant that functions independently of factor VIII as an alternative treatment of Hemophilia A"



Second Prize

F.Atiq et al. "VWF and FVIII levels after desmopressin, mimicking hemostatic response during hemostatic challenges, are associated with the bleeding phenotype in type 1 VWD patients"



Third Prize (tied)

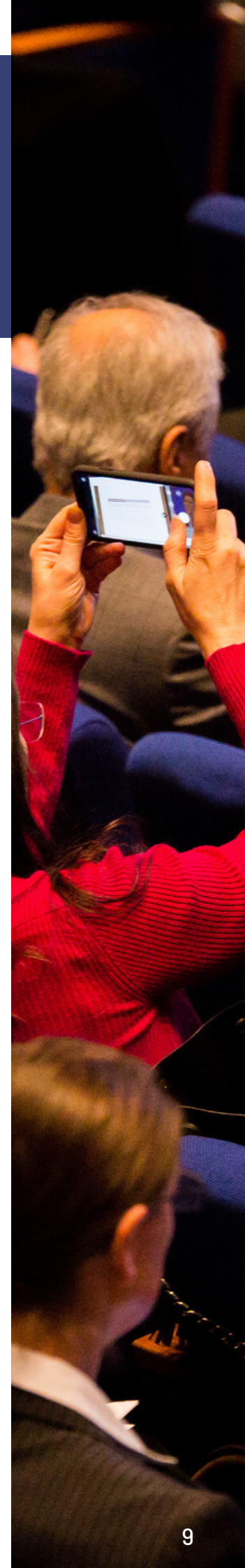
M.Heesterbeek et al. "Measuring anxiety and depression in young adult men with haemophilia using PROMIS"

M. Kennedy et al. "Physical activity and cardiometabolic risk profiles amongst Irish adults with severe haemophilia: The Irish Personalised approach to the treatment of Haemophilia (IPATH) study"



Top SLAM presentation

F. R. Kloosterman et al. "The treatment history of non-severe haemophilia A"



EAHAD RECOGNITION AWARDS



EAHAD Recognition Award recipients

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

In 2020, the awards were presented to Professor Wolfgang Schramm, Emeritus Professor of Haematology, from the Ludwig-Maximilians-University of Munich, Germany, Mr Brian O'Mahony, Chief Executive Officer, from the Irish Haemophilia Society, Ireland, and, posthumously, to Professor Jørgen Ingerslev, from Denmark, world leading specialist in the haemophilia and bleeding disorders field and a founding member of EAHAD.

2020 Highlights

Executive Committee 2020 Elections

On Thursday 6 February 2020, the EAHAD Annual General Meeting took place in The Hague, Netherlands. During the meeting, the EAHAD members resolved to re-elect Prof. Flora Peyvandi, EAHAD President (Feb 2020-Feb 2022), as Member of the Executive Committee (Feb 2020-Feb 2023), re-elect Dr Robert Klamroth, EAHAD Vice-President (Feb 2020-Feb 2022), as Member of the Executive Committee (Feb 2020-Feb 2023), re-elect Dr Jan Blatny, Treasurer (Feb 2020-Feb 2022), as Member of the Executive Committee (Feb 2020-Feb 2023), re-elect Prof. Karin Fijn van Draat, Secretary (Feb 2020-Feb 2022), as Member of the Executive Committee (Feb 2020-Feb 2023) and re-elect Prof. Hervé Chambost as Member of the Executive Committee (Feb 2020-Feb 2023).

New members also joined the Executive Committee during the 2020 AGM. The EAHAD members resolved to elect Dr Fariba Baghaei from Sweden, Prof. Ana Boban from Croatia, and Dr Daniel Hart from the United Kingdom as Members of the Executive Committee (Feb 2020-Feb 2023).

Newly appointed chairs Dr David Stephensen and Mary Kavanagh will represent the Physiotherapists and Nurses Committees respectively.

With their expertise and knowledge in the field of haemophilia and bleeding disorders, we are sure that they will positively contribute to our association's work.

Pascale Blaes joins EAHAD as Interim CEO

In 2020, a new member joined the EAHAD team, as [Pascale Blaes](#) became our interim Chief Executive Officer. Pascale comes to EAHAD with over 15 years' experience in the not-for-profit health sector and has held various managerial and directorial positions throughout her career with a focus on policy and EU affairs. She trained as a lawyer, is a Brussels native, and is fluent in English, French, and Dutch.

As Interim Chief Executive Officer, Pascale is responsible for the smooth continuation of EAHAD's organisational and administrative processes. She oversees all projects and planned activities, working closely with the Executive Committee and the sub-committees, while CEO Aislin Ryan is on leave until December 2021.

EAHAD 2021 Congress goes virtual

After careful consideration, the Executive Committee decided to make the [EAHAD 2021 Congress](#) a fully virtual event, taking place from 3 until 5 February 2021.

Everyone at EAHAD was fully committed to creating an excellent virtual learning experience and strived to ensure that high quality scientific content will be able to reach our members and partners in Europe and around the world, in a safe and accessible manner.

Like our previous Congresses, EAHAD 2021 offers original scientific sessions and presentations, showcasing the latest innovations and advances in the field of haemophilia and bleeding disorders.

EAHAD and ISTH announce Educational Partnership on Gene Therapy

This past year, together with the International Society on Thrombosis and Haemostasis (ISTH), we started an educational partnership to collaborate on components of the ISTH Gene Therapy in Hemophilia Education Initiative.

EAHAD, ISTH, and The France Foundation will develop and distribute tailored educational materials for the primarily European haemophilia practice community, including a survey for allied health professionals, train-the-trainer workshops, podcast episodes, an EAHAD 2021 conference briefing and other learning sessions.

All resources will be available through the [ISTH Gene Therapy in Hemophilia Education Initiative](#) website.

2020 Highlights

EAHAD Physiotherapists Committee Letter to the Editor published in *Haemophilia*

In October 2020, our Physiotherapists Committee published in *Haemophilia* a letter to the editor titled "[Comprehensive care on paper only? The challenge for physiotherapy provision in day to day haemophilia practice](#)". The Committee called upon funders, medical professionals, centre directors, and patient organisations to collaborate in the development and enhanced provision of physiotherapy care.

The committee members, together with the Chief Executive Officer of the Irish Haemophilia Society, Brian O'Mahony, asked clinicians to look into new ways of working with physiotherapists, learning from each other and understanding how the two roles can raise the quality of patient care.

EAHAD Nurses Committee publish Adjustable Surgery Workflow

In 2020, our Nurses Committee released their most recent project, the "[Adjustable surgery workflow in patients with bleeding disorders](#)". The detailed workflow addresses the different phases, tasks, and responsibilities regarding surgery in patients with a bleeding disorder.

It is accompanied by a checklist, which must be adapted based on local circumstances, guidelines and practice.

New article by the Women and Bleeding Disorders Working Group

After presenting the results of their 2019 survey on the Clinical Management of Women-Specific Symptoms in Inherited Bleeding Disorders at EADAD 2020, the Working Group published in *Haemophilia* in May 2020 an [article](#) describing them.

The article provides some insight into the organisation of care for women with bleeding disorders and shares identified knowledge gaps and research priorities in WBD clinical management.

EAHAD Coagulation Factor Variant Databases Steering Group release new publication

After moving the databases at a new [address](#) last year, in 2020 the EAHAD CFVD Steering Group published an original article titled "[The European Association for Haemophilia and Allied Disorders \(EAHAD\) Coagulation Factor Variant Databases: Important resources for haemostasis clinicians and researchers](#)", describing the valuable work done by the members of the group on the project, that has improved the quality and quantity of information available to the haemostasis research and clinical communities.

In 2020, the Working Group also worked on expanding the existing databases, as a new variant database for Factor V is nearing completion, followed in early 2021 by a database for Factor X.

Covid-19 recommendations and survey from our Psychosocial Working Group

Our Psychosocial Working Group released a [letter on Covid-19 and psychosocial care](#), presenting specific aspects of working as a psychosocial professional during the pandemic and offering recommendations for treatment.

Included in the letter is also a short survey on psychosocial work during the Covid-19 pandemic.



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 2020, EUHASS published its 11th annual report covering the period 1 January to 31 December 2019. The report contains events data from 76 centres in Europe.

In 2020, EUHASS also published 3 quarterly reports covering the period from 1 January to 31 September 2020. These reports contain more condensed information on the events reported whilst the annual reports provide a more detailed analysis.

European Haemophilia Centre Certification

The European Haemophilia Centre Certification process remains active with EAHAD administrating the process. In 2020, 12 centres in 6 countries were certified, bringing the total count of certified centres to 159 in 34 countries.

European Haemophilia Treatment Centres (EHTCs)

- North Estonia Centre for Bleeding Disorders - Tallinn, Estonia
- HaemoCenter Hildesheim - Hildesheim, Germany
- MVZ für Blutgerinnungsstörungen und Gefäßkrankheiten Limbach Magdeburg - Magdeburg, Germany
- Hemophilia Center RPL Mainz - Mainz, Germany
- Bleeding Disorders' Centre for Children and Adolescents - Thessaloniki, Greece
- Department of Pediatrics, Mohács Hospital - Mohacs, Hungary

European Haemophilia Comprehensive Care Centres (EHCCCs)

- University Hospital Leipzig, Centre for Haemostaseology - Leipzig, Germany
- Haemophilia and Haemostasis Center Heidelberg - Heidelberg, Germany
- The National Hemophilia Center - Ramat Gan - Israel, Ramat Gan, Israel
- Ankara City Hospital Pediatric Hematology Unit - Ankara, Turkey
- Gaziantep University Pediatric Hemophilia Center - Gaziantep, Turkey
- Erciyes Üniversitesi Tıp Fakültesi Çocuk Hemofili Merkezi - Kayseri, Turkey

Haemophilia Centre Certification & Audit Working Group formed

In 2020, EAHAD started developing the next phase of European haemophilia centre certification in two steps: first, updating the current guidelines on the certification of European Haemophilia Centres to include monitoring of novel treatment products and, second, to establish an audit procedure across European haemophilia centres to improve patient care.

To facilitate this, in October, the EAHAD Certification and Audit of Haemophilia Centres Working Group was formed. The Working Group will strive to establish and coordinate the audit process across European haemophilia centres.



COMMUNICATIONS

2020 was another very good year regarding EAHAD social media follower numbers. On Twitter, we went from 1,079 followers in 2019 to 1,572 in 2020. Our LinkedIn page also witnessed a significant boost with 816 followers in 2020, compared to 602 in 2019.

In 2020 we released three issues of the EAHAD Newsletter, as well as two issues of the Physiotherapists Newsletter and two of the Women and Bleeding Disorders (WBD) Newsletter. We remain committed to our goal of having a continuous and open conversation with all our members and partners, providing them with the latest information in the field of rare bleeding disorders.

TWITTER

1,079



2019

45.6 % increase

1,572



2020

LINKEDIN

602



2019

35.5 % increase

816



2020

NEWSLETTERS

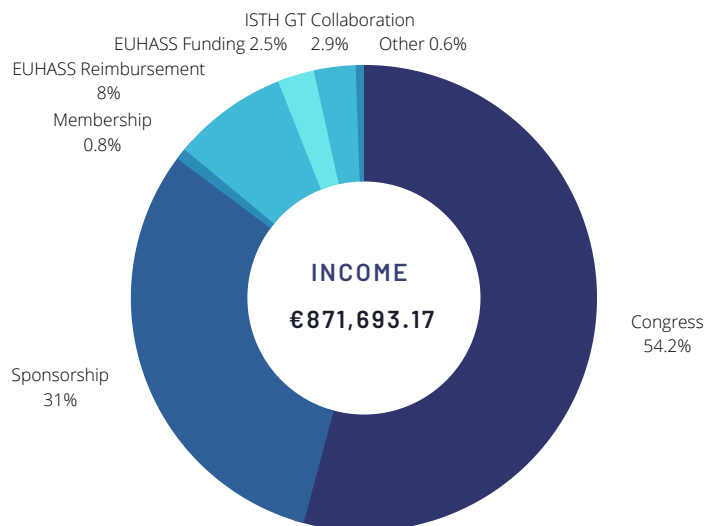
3 EAHAD NEWSLETTERS

2 PHYSIO NEWSLETTERS

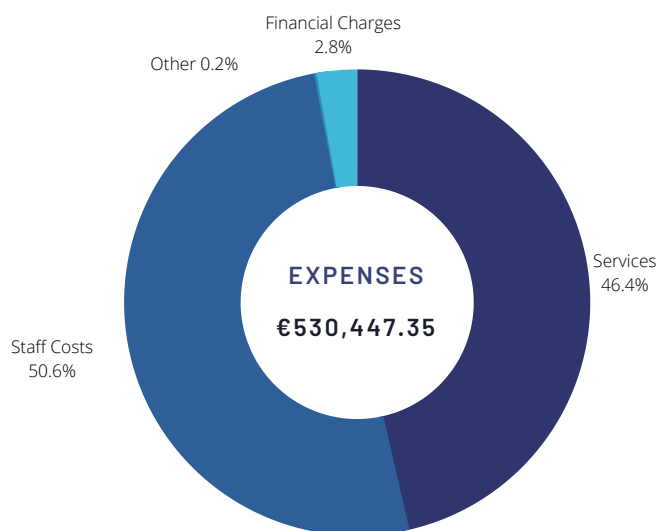
2 WBD NEWSLETTERS

FINANCES

EAHAD's financial year is 1 January – 31 December. A full copy of the annual accounts for 2020 can be consulted on the website of the National Bank of Belgium. The company number is 0718.594.509.



Annual Congress	€467,721.53
Sponsorship	€268,000
Membership Income	€6,874.92
EUHASS Project Reimbursement	€69,005.86
EUHASS Project Funding	€22,000
ISTH Gene Therapy Collaboration	€24,937.43
Other Income	€4,936.39



Services and other goods	€246,118.72
Staff Costs and Expenses	€268,544.31
Depreciation	€915.68
Financial Charges	€14,796.14
Other Operating Costs	€72.5



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.

Our activities are supported by a multitude of Working Groups:

- Coagulation Factor Variant Databases Steering Group
- Gene Therapy Working Group
- Haemophilia Centre Certification & Audit Working Group
- Psychosocial Professionals Working Group
- Women and Bleeding Disorders Working Group

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).

The EUHASS Steering Committee manages the EUHASS Project, implementing its aim of being a prospective adverse event reporting system for Europe.

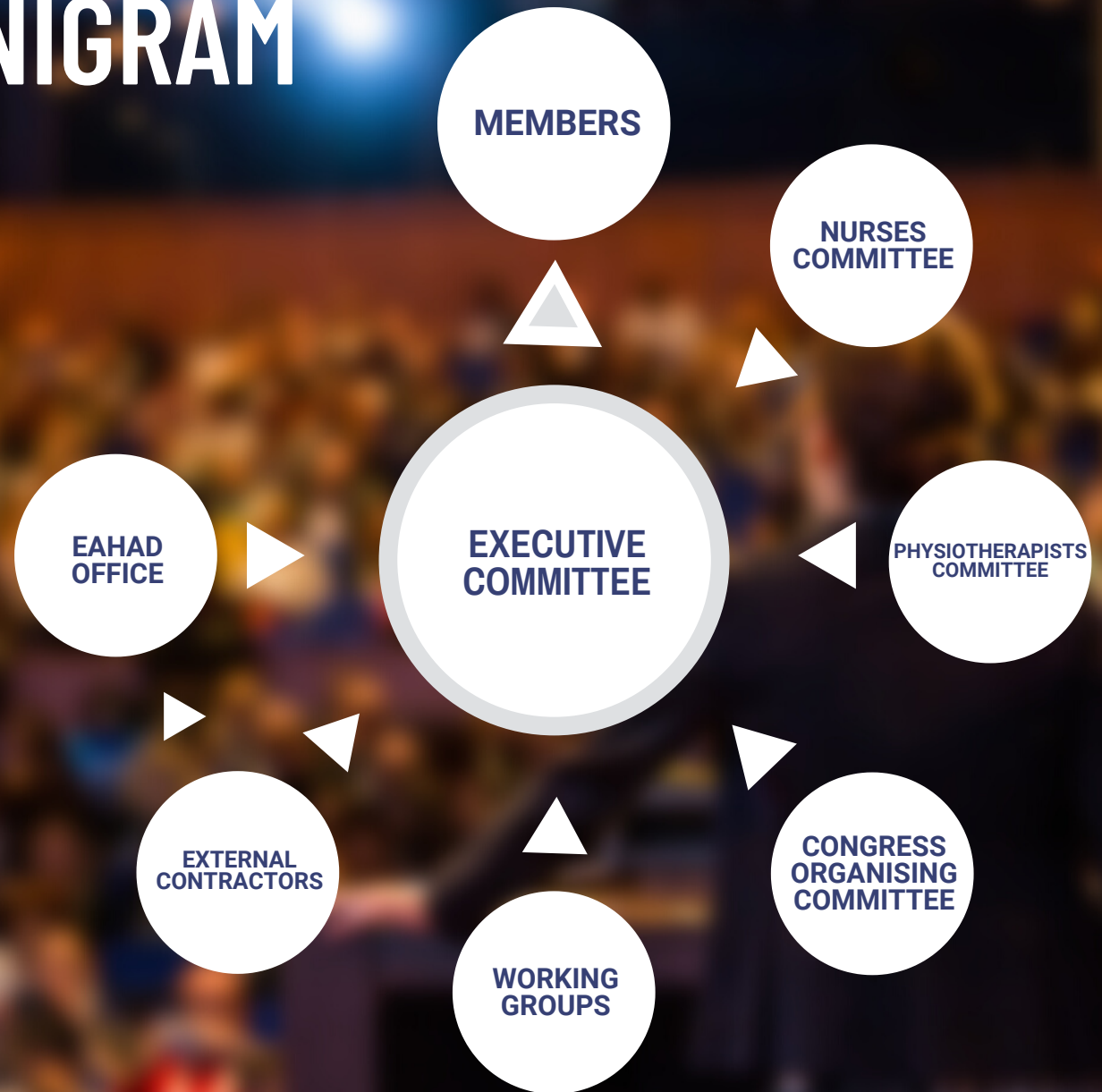
EAHAD's day-to-day operations are managed by its Chief Executive Officer, under the direction of the Executive Committee.



EAHAD ORGANIGRAM 2020

Executive Committee

Flora Peyvandi	President
Robert Klamroth	Vice President
Michael Makris	Past President
Jan Blatny	Treasurer
Karin Fijn van Draat	Secretary, EAHAD 2020 President
Fariba Baghaei	Member
Anna Boban	Member
Hervé Chambost	Member
Daniel Hart	Member
Wolfgang Miesbach	Member
Mary Kavanagh	Nurses Committee Chair
David Stephensen	Physiotherapists Committee Chair



Nurses Committee

Mary Kavanagh	Chair
Nanda Uitslager	Vice Chair
Elsbeth Müller-Kägi	Secretary
Simon Fletcher	Member
Kristian Juusola	Member
Greta Mulders	Member
Linda Myrin Westesson	Member

Psychosocial Professionals Working Group

Lotte Haverman	Chair
Gaby Golan	Vice Chair
Christina Burgess	Secretary
Petra Bučková	Member
Gloria Rooney	Member
Ana Torres-Ortuño	Member
Karen Vandenabeele	Member

Gene Therapy Working Group

Wolfgang Miesbach	Chair
Pratima Chowdary	Member
Daniel Hart	Member
Robert Klamroth	Member
Michael Makris	Member
Declan Noone	Member
Flora Peyvandi	Member
Víctor Jiménez Yuste	Member

Coagulation Factor Variant Databases Steering Group

Christopher Ludlam	Chair
Muriel Giansily-Blaizot	Member
Keith Gomez	Member
Daniel Hampshire	Member
Daniel Hart	Member
Geoffrey Kembal-Cook	Member
John McVey	Member

EAHAD Office Staff

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

Physiotherapists Committee

David Stephensen	Chair
Paul McLaughlin	Vice Chair
Ruth Elise Dybvik	Secretary
Magnus Aspdahl	Member
Nathalie Grinda	Member
Marie Katzerova	Member
Sébastien Lobet	Member

Women and Bleeding Disorders Working Group

Karin van Galen	Chair
Petra Elfvinge	Member
Romana Gerychova	Member
Eva Ivanova	Member
Rezan Kadir	Member
Michelle Lavin	Member
E.P. Mauser-Bunschoten	Member
Roseline d'Oiron	Member
Naja Skouw-Rasmussen	Member

Haemophilia Centre Certification & Audit Working Group

Ana Boban	Chair
Fariba Baghaei	Member
Karin Fijn van Draat	Member
Robert Klamroth	Member
Wolfgang Miesbach	Member
Brian O'Mahony	Member
Flora Peyvandi	Member
David Stephensen	Member
Mary Kavanagh	Member

European Haemophilia Centre Certification Group

Michael Makris	EUHANET Project Leader
Philippe de Moerloose	Member
Brian O'Mahony	Member
Martin Bedford	Member

EUHASS Steering Committee

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

Acknowledgements

Funding

EAHAD is grateful for the unrestricted financial support it receives from its sponsors. In 2020, we received funding for our non-Congress related activities from:



Acknowledgements

Partners

EAHAD collaborates with the following organisations:



Service Providers


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


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



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