

EUROPEAN ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS

Annual Report 2022

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PRESIDENT FOREWORD

Dear friends and colleagues,

I am very happy to share with you the 2022 EAHAD Annual Report, containing all the key activities carried out by our association this year. 2022 marked the beginning of the end for the Covid-19 pandemic. Its repercussions could still be felt, but this did not stop us from pursuing our goals of ensuring the provision of the highest quality of clinical care, educating the medical community and the general public, and promoting scientific research.

This year, I officially became the President of EAHAD for 2022-2024. I was joined by Dr Jan Blatny, Vice president, Prof. Wolfgang Miesbach, Treasurer, and Prof. Ana Boban, Secretary. With the support of the Executive Committee members, our standing committees and working groups, our goal is to ensure that EAHAD remains at the top of haemophilia and allied disorders education, science, and research.

Still facing the Covid-19 challenges, our EAHAD 2022 Congress was a fully virtual event. This would be our last online only congress, as in 2022 we decided that our 2023 Congress would take place in Manchester, UK, under the direction and expertise of Congress President Prof. Mike Makris.

In 2022, two new members were added to the EAHAD team, as Giuliana Giardina and Diana Carbonero Alvarez joined as Communications and Events Officer and Project Manager respectively.

In 2022 we established two new working groups: the EAHAD E-Learning Working Group, with the goal

of deepening the knowledge necessary for the management of bleeding pathologies, through the release of monthly E-Learning modules; and the EAHAD Glanzmann Thrombasthenia Working Group, with the goal of improving the care for patients with Glanzmann Thrombasthenia, and sharing knowledge among healthcare practitioners regarding the treatment of this rare disorder.

Our existing Committees and Working Groups continue to be active and productive. Our Gene Therapy Working Group published a paper on the Hub and Spoke Model and released three webinars. Our Coagulation Factor Variant Databases Steering Group updated their Factor VII Gene Variant Database. Our Physiotherapists Committee published two papers in Haemophilia Journal, one of the two being on the European Principles of Physiotherapy Care.

I would like to thank outgoing President Prof. Flora Peyvandi for her invaluable contribution in keeping EAHAD focused and united especially in the unprecedented circumstances of the pandemic. I would also like to thank our Executive Committee members, the committees and working groups, the EAHAD office team, our pharmaceutical industry partners, and everyone else who supports our activities throughout the year. I am certain that, together, we will continue to produce work of the highest order and quality for our community.



"Together, we will continue to produce work of the highest order and quality for our community."

Dr Robert Klamroth
EAHAD PRESIDENT 2022-2024

WHO WE ARE

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, 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.
- 2. **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, psychosocial professionals, 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**, and **Associate members** (new category introduced in the new articles of association adopted in November 2022)



members

1 Junior

4 Honorary 17 AHP

Meet the new members of our team!



DIANA CARBONERO ALVAREZProject Manager

As Project Manager, Diana coordinates the EUHASS Project and the work of the Working Groups and Committees. She works closely with their chairs and members, following their activities and their projects. Diana is supporting all aspects of the management, organisation, and coordination of EUHASS, the European Haemophilia Safety Surveillance Project.



GIULIANA GIARDINACommunications and Events Officer

As Communications and Events Officer, Giuliana is responsible for managing internal and external communication, such as the EAHAD Website and Newsletter, as well as the EAHAD Social Media Channels. Moreover, she supports with the organisation and planning of the EAHAD Annual Congress and all committee and working group meetings.



EAHAD 2022 Virtual Congress

From 1 to 4 February 2022, the EAHAD 2022 Virtual Congress took place. More than 2300 delegates joined and interacted online for our second virtual Congress. Due to ongoing Covid-19 uncertainty, our **15th Annual Congress** remained a fully virtual event under the direction of the Congress Organising Committee, Prof. Flora Peyvandi, Dr Robert Klamroth, and Prof. Michael Makris. Thanks to the diverse, high quality sessions and presentations, EAHAD 2022 was the virtual place-to-be for the latest in the field of haemophilia and allied disorders.

The meeting opened on Tuesday 1 with the Allied Health Professionals Day. For the first time ever, Tuesday hosted a bonus satellite symposium on Gene Therapy, that was extremely well received and surely will spark discussions about this novel haemophilia treatment option.

From 2-4 February, the main scientific programme took place. Wednesday 2 started with the Multidisciplinary Haemophilia Educational Session, which focused on the crucial topic of the MTD team's response in times of disaster/crisis. Different presentations followed, with some highlights being on the immunogenicity of Factor VIII, as well as on thrombosis and novel haemophilia therapies. The day closed with the first of three recap sessions, summarising the content of the day and exploring the issues tackled during the eclectic presentations.

Thursday 3 offered attendees the chance to experience a highly anticipated session on Gene Therapy, as well as very interesting presentations on the European accreditation of haemophilia and gene therapy centres, and the European Haemophilia Safety Surveillance project. The day ended with the second recap session.

Friday 4 hosted two EAHAD Congress staples: the always exciting SLAM session and the Arosenius Lecture. Nevertheless, the crown jewel of EAHAD t2022 was the Latest Clinical Trial Results session. With six not-to-bemissed presentations, the session offered a deep dive into key issues that can potentially transform the future haemophilia and allied disorders landscape.

The EAHAD 2022 Virtual Congress and its sessions and presentations were met with universal acclaim online. We would like to thank everyone who joined and supported us in our second online scientific journey.



Facts & Figures

Congress Organising Committee

Prof. Flora Peyvandi Dr Robert Klamroth Prof. Michael Makris

Dates

1-4 February 2022

Delegates

2384

Countries represented

78

Abstracts

216 submissions

Satellite Symposia

П

Sponsors

EAHAD 2023 Congress goes to Manchester

After two years of online-only meetings, it was decided that our 16th Annual Congress, EAHAD 2023, would take place in Manchester, UK, from 7-10 February 2023.

Under the direction of Congress President Prof. Mike Makris, the Congress will feature high quality sessions, renowned speakers, and interactive presentations. EAHAD 2023 aims to solidify its spot as the place-to-be for anyone wanting to discover and deepen their knowledge on the latest in the field of haemophilia and allied disorders.

The in-person venue for the Congress is the Manchester Central Convention Complex, formerly the Manchester Central railway station. The congress online component will once again be made possible by a cutting-edge virtual platform.







Annual General Meeting 2022

On Thursday 4 February 2022, the EAHAD Annual General Meeting took place virtually. After the approval of the meeting's agenda and the minutes from the 2021 AGM, outgoing EAHAD President Prof. Flora Peyvandi presented the 2021 activities report, before warmly welcoming new President Dr Robert Klamroth.

Dr Klamroth thanked Prof. Peyvandi for her invaluable contributions and proceeded with presenting the association's plans for 2022. Outgoing Treasurer and new Vice-President Dr Jan Blatny presented the 2021 annual accounts and the 2022 budget. Both the 2021 annual accounts and the 2022 budget were unanimously approved.

At the 2022 AGM, one Executive Committee Member and Past President Prof. Mike Makris reached the end of his term. Prof. Peyvandi thanked him for his work and informed the members that he will continue to serve EAHAD as he is the EAHAD 2023 Congress President.

Extraordinary Annual General Meeting 2022

On Thursday 10 November 2022, an Extraordinary Annual General Meeting, chaired by EAHAD President Dr Robert Klamroth, took place. The Extraordinary AGM's goal was for the general assembly to approve the upgrade of EAHAD's statutes in compliance with the new Belgian legislation. The General Assembly decided unanimously to approve and adopt a new and coordinated text of the Articles of Association and that the new and coordinated text of the Articles of Association enters into force immediately after the Extraordinary AGM. The new Articles of Association have since been published in the Official Journal (Moniteur Belge).

E-Learning Working Group founded

EAHAD E-Learning Working Group founded

In March 2022, the EAHAD E-Learning Working Group was formed and had its inaugural meeting. Chaired by Prof. Yesim Dargaud, our E-Learning Working Group will strive to contribute to the training of young physicians and offer a high quality continuous education programme to experienced haematologists and pathologists, who manage patients with bleeding disorders, by producing a variety of online educational materials and items.

Its goals are:

- Deepen the **theoretical and practical knowledge** necessary for the management of pathologies at risk of bleeding.
- · Acquire and master knowledge on procoagulant treatment strategies.
- Provide **practical training** to better understand the problems related to haemostasis pathologies through interactive teaching in the form of clinical cases, MOOCs, and educational games.

Glanzmann Thrombasthenia Working Group founded

In December 2022, the EAHAD Glanzmann Thrombasthenia Working Group was formed. Chaired by Prof. Roger Schutgens, the working group's purpose and goals are:

- · Improvement of care for patients with Glanzmann Thrombasthenia.
- Sharing and dissemination of **knowledge** among European health care practitioners regarding the treatment of patients with Glanzmann's Thrombasthenia.
- · Definition and execution of a pan-European research agenda on the topic of Glanzmann Thrombasthenia.
- Creation of a **European network** that is tightly connected and easily accessible to improve care for patients with Glanzmann Thrombasthenia, with the objective to interact on patient care and coordinate clinical research.

Three EAHAD Gene Therapy Webinars released

In 2022, our Gene Therapy Working Group released three educational webinars:

- **Hub and Spoke Model Webinar,** chaired by Prof. Wolfgang Miesbach and with presentations by Dr Daniel Hart, Dr Robert Klamroth, Prof. Flora Peyvandi, and Declan Noone.
- Gene Therapy AHP Webinar, chaired by Prof. Wolfgang Miesbach, with presentations by Greta Mulders (Nurse), Paul Mclaughlin (Physiotherapist), Gaby Golan (Psychosocial Professional), and Dr Stephen Kitchen (Laboratory Scientist).
- Hub and Spoke Model: Practical Experiences from Europe, chaired by Prof. Flora Peyvandi and Declan Noone, with an introduction by Prof. Wolfgang Miesbach and presentations by Prof. Bulent Zulfikar (Turkey), Prof. Yesim Dargaud (France), and Dr Peter Kampmann (Denmark).

2022 ANNUAL REPORT

"Gene therapy of haemophilia: Hub centres should be haemophilia centres: a joint publication of EAHAD and EHC" paper published

In 2022, our Gene Therapy Working Group, together with the European Haemophilia Consortium, published a letter to the editor of Haemophilia highlighting the **importance and value of the hub-and-spoke model for haemophilia centres especially with the advent of gene therapy**. The authors concluded that a network of centres structured according to the hub-and-spoke model, with both centres acting as haemophilia centres, will optimise patient access to gene therapy and ensure that patients with haemophilia can be adequately informed about haemophilia gene therapy within the standards of care.

Factor VII Gene Variant Database updated to end-2021

In 2022, the EAHAD Coagulation Factor Variant Databases Steering Group updated their <u>FVII Gene Variant Database</u>. 40 new publications covering 2015-2021 have been added, with over 50 new unique variants and over 300 new individual cases.

"European principles of care for physiotherapy provision for persons with inherited bleeding disorders: perspectives of physiotherapists and patients" paper published

In 2022, our Physiotherapists Committee released a joint paper with the European Haemophilia Consortium on the European principles of care for physiotherapy provision for persons with inherited bleeding disorders. The authors noted that physiotherapy should be viewed as a basic requisite in multidisciplinary care. The eight principles developed outline optimum standards of practice in order to advocate personalised patient-centred care for physical health in which both prevention and interventions include shared decision making, and supported self-management.

"Promoting physical activity for people with haemophilia in the age of new treatments" paper published

In 2022, our Physiotherapists Committee together with authors Fionnuala Sayers and Olav Versloot, produced a <u>narrative review</u> aiming to provide a brief overview of what is currently understood regarding physical activity levels and influences for the three broad age groups ottff children and adolescents, adults and older adults. The authors offered recommendations for members of the haemophilia team on important aspects related to promotion of PA in their clinical practice. Finally, the highlighted that PA behaviour is multifactorial and that many PWH still have limited access to adequate care.

2022 EAHAD Research Grants cycle

The objective of the EAHAD Research Grants is to foster pre-clinical and clinical research collaborations in Europe and to support scientific projects aimed at improving the care of patients with inherited and acquired bleeding disorders.

The grant application cycle runs yearly. In 2022, three grants were awarded, two for allied health professionals and one for a young researcher:

DAVID STEPHENSEN, MD

Kent Haemophilia & Thrombosis Centre, Canterbury

"Identifying Performance-based Outcome measures of Physical function in people with haemophilia (IPOP)"

Lay Summary: The current physical assessment of people with haemophilia focuses on 'what joints look like' (joint scores) and includes little information on what activities a person can do and how they might do them. We want to find out what people with haemophilia think about measuring the activities they can do and what the best way of doing this might be. This information could be added to 'what joint looks like' when monitoring the physical health of people with haemophilia to give them more information about their condition.

Project duration: 12 months

Grant amount: € 25.000

ANNA WELLS, PHD

Basingstoke Haemophilia, Haemostasis & Thrombosis Centre

"Exploring Posttraumatic Stress Symptoms and Pain Memories in People with Haemophilia and the influence on current pain experience"

Lay Summary: We are interested in understanding experiences of previous painful events and exploring how these memories may impact on individuals' day to day to life. We aim to gain a greater understanding of factors which may influence people's current pain experience. We hope that what we learn as part of this research can be taken forwards to help develop better pain management within bleeding disorder services.

Project duration: 12 months

Grant amount: € 25.000

HEIKE HAWERKAMP, PHD

Trinity Biomedical Sciences Institute, Trinity College Dublin

"Neutrophils wandering in patients with haemophilia (New path)"

Lay Summary: This project will investigate the role of neutrophils – a specific type of immune cell – and its secreted effector molecules in haemophilia. Detailed knowledge about the function of these circulating immune cells in haemophilia might be highly beneficial in improving patient therapies and healthcare.

Project duration: 10 months

Grant amount: € 50.000

European Haemophilia Centre Certification

The European Haemophilia Centre Certification process remains active with EAHAD administrating the process. In 2022, 4 centres in 4 countries were certified.

- European Haemophilia Treatment Centres (EHTCs): Hungarian National Blood Transfusion Service Regional Centre Gyor Hungary
- European Haemophilia Comprehensive Care Centres (EHCCCs): Lyon Comprehensive Haemophilia Care Centre
 France, Warsaw Department of Pediatric, Oncology, Hematology and Transplantology Poland, Hæmofilicenter
 Rigshospitalet Denmark

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.

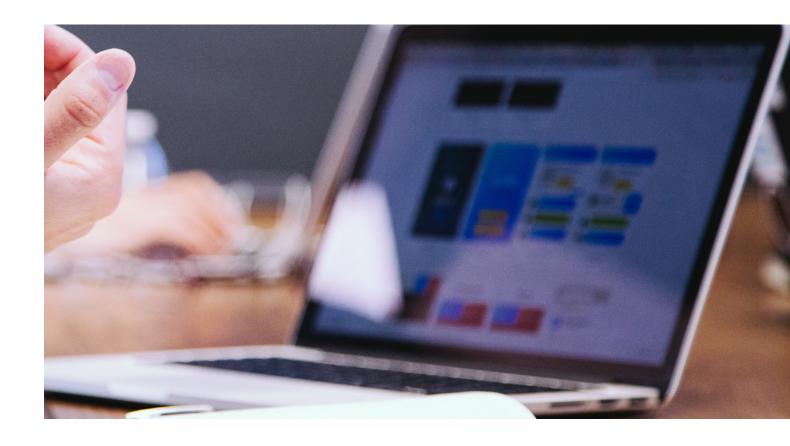
In November 2022, EUHASS published its 13th annual report covering the period 1 October 2008 – 31 December 2021. The report contains events data from 95 centres in Europe.

In 2022, EUHASS also published three quarterly reports covering the period from 1 January to 30 September 2022. These reports contain more condensed information on the events reported whilst the annual reports provide a more detailed analysis.

Until recently the EUHASS project was run from the University of Sheffield in the UK, but now all operating activities are run from the EAHAD office in Brussels, Belgium. The new EUHASS project manager is Diana Carbonero Alvarez.

Another change in the 13th annual report is that centres from The Netherlands are now reporting as a country. Following the reorganisation of the Dutch Haemophilia centres to nine centres at Amsterdam, Leiden, The Hague, Maastricht, Eindhoven, Groningen, Nijmegen, Rotterdam and Utrecht, any adverse events are first reported to the national registry (HaemoNed) and then transferred to EUHASS.

2022 HIGHLIGHTS **EAHAD ACTIVITIES**



Communications

2022 was another very good year for our social media channels in terms of impression and engagement rate, as a **more comprehensive strategy** was implemented with the arrival of Communications and Events Officer Giuliana Giardina. Our tweets earned **more than 150K impressions** (the number of times users saw our tweets in their feeds) and our average engagement rate, which measures how much of our audience actively engages with our content, **increased to 3,7%** from July on. Our LinkedIn page witnessed a **significant boost with 120K impressions** and our average engagement rate was 6,6%.

In 2022 we released two issues of the Nurses Newsletter and one issue of the Physiotherapists Newsletter.

Moreover, we have been working on revamping our website to provide the community with an even better user experience. The new website is set to launch in 2023, promising a significant upgrade in terms of user-friendliness and functionality.

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. +150K impressions

on Twitte

3,7% engagement rate

+120K impressions

on LinkedIr

6,6% engagement rate on LinkedIn



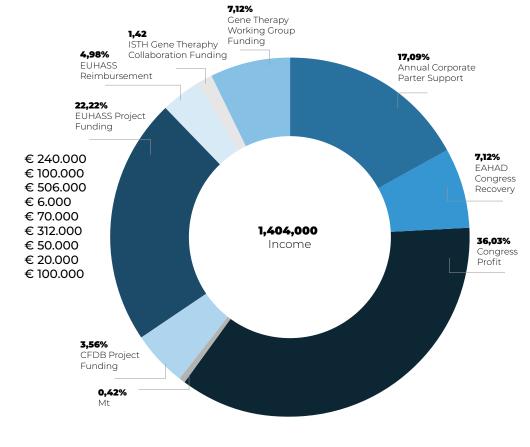
EAHAD's financial year is 1 January - 31 December. A full copy of the annual accounts for 2022 can be consulted on the website of the National Bank of Belgium.

The company number is 0718.594.509.

FINANCES INCOME AND EXPENSES

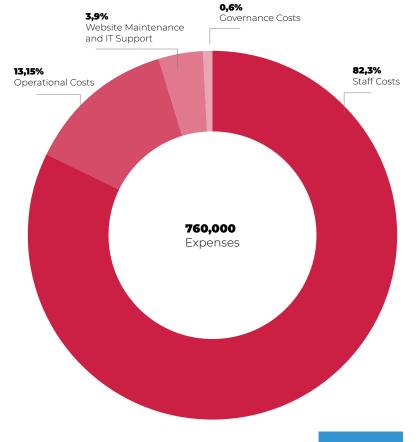


Annual Corporate Parter Support GT WG Funding Congress Profit Membership Income EUHASS Reimbursement EUHASS Project Funding CFDB Project Funding ISTH GT Collaboration Funding EAHAD Congress Recovery



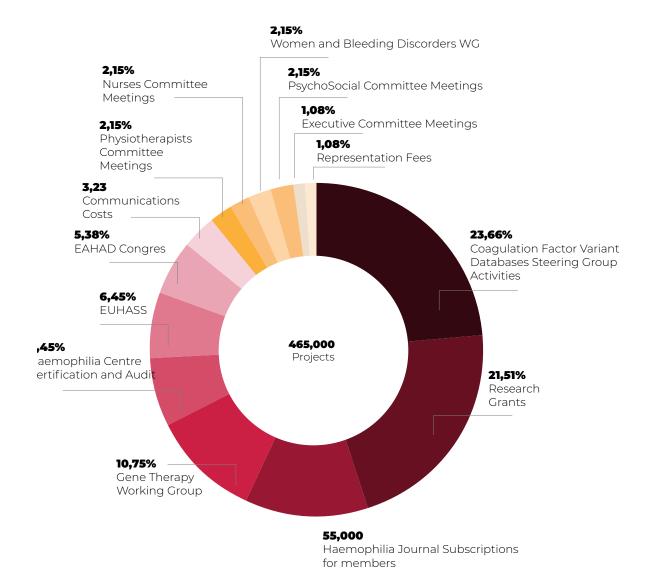


Staff Costs€ 625.000Operational Costs€ 100.000Website and IT Support€ 30.000Governance€ 5.000



FINANCES

INCOME AND EXPENSES



Projects

EAHAD Congress	€ 25.000
Executive Committee Meetings	€ 5.000 € 5.000
5	
Nurses Committee Meetings	€ 10.000
Physiotherapists Committee Meetings	€ 10.000
PsychoSocial Committee Meetings	€ 10.000
Coagulation Factor Variant Databases Steering Group Activities	€ 110.000
Women and Bleeding Discorders WG	€ 10.000
Gene Therapy Working Group	€ 50.000
EUHASS	€ 30.000
Research Grants	€ 100.000
Representation Fees (attendance at other conferences	€ 5.000
Communications Costs	€ 15.000
Haemophilia Journal Subscriptions for members	€ 55.000
Haemophilia Centre Certification and Audit	€ 30.000

179,000 € balance

Organisational Structure Structure



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, Physiotherapists, and Psychosocial Professionals 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, physiotherapy, and psychosocial care initiatives and activities. The Nurses, Physiotherapists, and Psychosocial Professionals Committees report to the Executive Committee and are represented on the latter by their chairs.

Our activities are supported by a multitude of expert groups:

- · Coagulation Factor Variant Databases Steering Group
- · Gene Therapy Working Group
- · Haemophilia Centre Certification & Audit Working Group
- · Women and Bleeding Disorders Working Group
- · E-Learning Working Group
- · Glanzmann Thrombasthenia Working Group
- · European Haemophilia Centre Certification Panel
- · EUHASS Steering Committee
- · Research Grants Review Panel

Executive Committee

Robert Klamroth President

Jan Blatny Vice President

Flora Peyvandi Past President

Wolfgang Miesbach Treasurer

Ana Boban Secretary

Maria Teresa Alvarez Roman Member

Fariba Baghaei Member

Hervé Chambost Member

Karin Fijnvandraat Member

Nanda Uitslager Nurses Committee Chair and representative

Paul Mclaughlin Physiotherapists Committee Chair and representative

Lotte Haverman Psychosocial Professionals Committee Chair and representative

ORGANISATIONAL STRUCTURE

Nurses Committee

Nanda Uitslager Chair

Maj Friberg Birkedal Vice Chair

Mary Kavanagh Past Chair

Renester Fenton Secretary

Greta Mulders Gabriella Nicolò

Linda Myrin Westesson

Physiotherapists Committee

Paul McLaughlin Chair

Ruth Elise Dybvik Vice Chair
David Stephensen Past Chair
Marie Katzerova Secretary

Magnus Aspdahl Nathalie Grinda Paula Loughnane Merel Timmer Merel Timmer

Psychosocial Professionals Committee

Lotte Haverman Chair

Christina Burgess Vice Chair Petra Bučková Secretary

Gaby Golan Gloria Rooney Ana Torres-Ortuño

Coagulation Factor Variant Databases Steering Group

Christopher Ludlam Chair

Mathilde Fretigny

Muriel Giansily-Blaizot

Keith Gomez

Daniel Hampshire

Geoffrey Kemball-Cook

John McVey

Gene Therapy Working Group

Wolfgang Miesbach

Chair

Ana Boban

Pratima Chowdary Michiel Coppens

Robert Klamroth Michael Makris Greta Mulders

Declan Noone Flora Peyvandi

Víctor Jiménez Yuste

Haemophilia Centre Certification & Audit Working Group

Fariba Baghaei Co-chair Ana Boban Co-chair

Miguel Crato

Karin Fijnvandraat

Mary Kavanagh

Robert Klamroth

Paul Mclaughlin

Wolfgang Miesbach

Declan Noone

Flora Peyvandi

Women and Bleeding Disorders Working Group

Karin van Galen Chair

Rezan Kadir Vice chair

Michelle Lavin Vice chair

Roseline d'Oiron Petra Elfvinge

Keith Gomez

Naja Skouw-Rasmussen

Gaby Golan

ORGANISATIONAL STRUCTURE

E-Learning Working Group

Yesim Dargaud Chair

Cedric Hermans Vice chair

Cihan Ay

Roberta Gualtierotti Pål André Holme Robert Klamroth Christoph Königs

Jerzy Windyga

Víctor Jiménez Yuste

Glanzmann Thrombasthenia Working Group

Roger Schutgens Chair

Roseline d'Oiron Mathieu Fiore Robert Klamroth

Andrea Artoni

Mary Mathias

Minette van der Ven

European Haemophilia Centre Certification Panel

Michael Makris Lead

Philippe de Moerloose

Brian O'Mahony Martin Bedford

EUHASS Steering Committee

Michael Makris Chair/Project Lead

Kathelijn Fischer

Alex Gatt

Rob Hollingsworth Radoslaw Kaczmarek

Thierry Lambert

Riitta Lassila

Flora Peyvandi

Research Grants Review Panel

Karin Fijnvandraat Lead

Jan Blatny

Robert Klamroth Wolfgang Miesbach

Flora Peyvandi

Staff

Pascale Blaes, Chief Executive Officer
Angelos Athanasopoulos Chief Operations Officer

Diana Carbonero Alvarez Giuliana Giardina Project Manager
Communications and

Events Officer

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In 2022, we received funding for our Congress from:





CSL Behring





















In 2022, we received corporate support from:















In 2022, we received funding for the EUHASS activities from:



B<u>OMARIN</u>

















In 2022, we received funding for our Gene Therapy activities from:



ACKNOWLEDGEMENTS PARTNERS

EAHAD collaborates with the following organisations:







European Haemophilia Consortium (EHC)

International Society for Thrombosis and Haemostasis (ISTH)

World Federation of Haemophilia (WFH)

ACKNOWLEDGEMENTS 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 our Congress organisational support
- 5 O'Clock for administrative and bookkeeping support
- Medical Data Solution & Services for IT support
- · BOFIDI Accountants and Advisors for accounting support
- · EY Law for legal support

CONTACT

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