

European Association for Haemophilia and Allied Disorders

Annual Report

2023



Robert **Klamroth**
EAHAD President



Foreword

Dear friends and colleagues,

I am very happy to share with you the EAHAD Annual Report, containing all the key activities carried out by our association in 2023. Together with my fellow Executive Committee members, as well as with the support of our committees and working groups, we continued to pursue our goals of ensuring the provision of the highest quality of clinical care, educating the healthcare professionals and the patient communities, and promoting scientific research. 2023 marked the triumphant return to in-person EAHAD congresses, with the EAHAD 2023 Congress taking place in Manchester, UK, under the direction and expertise of Congress President Prof. Mike Makris.

In 2023, two new members joined the Executive Committee, Niamh O'Connell from Ireland, and Samantha Gouw from the Netherlands. Our Executive Committee also elected for the period 2024-2026 Ana Boban as EAHAD Vice President, and appointed Niamh O'Connell as Treasurer and Wolfgang Miesbach as Secretary.

This year, we launched the EAHAD Academy, our platform for all EAHAD educational material, and we joined the Health Technology Assessment Stakeholder Network, hoping to contribute in the discussion around novel treatments and be an involved stakeholder on the EU level.

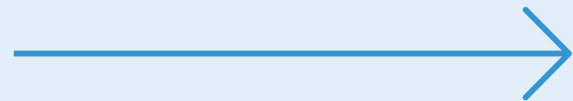
Our E-Learning Working Group was extremely prolific, releasing nine educational modules with renowned speakers, as well as launching the EAHAD Podcast. Our Gene Therapy Working Group finally launched its Gene Therapy Trials Database containing the most up-to-date information and results on gene therapy studies and safety issues.

Our Committees and Working Groups continued to be productive, releasing webinars, publishing scientific papers, and coordinating significant projects. You can read more about all our initiatives in the following pages.

I would like to once again thank the Executive Committee, our standing committees and working groups, the EAHAD office team, our pharmaceutical industry partners, and everyone else who provides support for our activities. I am proud for the great work we've achieved together for the benefit of our community.

01

About 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, laboratory scientists, and researchers.

EAHAD's work is guided by the following three aims:

1. Recognising, measuring, and addressing the problems of people with haemophilia and allied disorders, protecting their interests, and ensuring the provision of the **highest quality of care available**.
2. **Promoting research** in the aforementioned areas.
3. **Disseminating knowledge** through the appropriate scientific channels and educating practitioners, clinical scientists, professionals allied to medicine, and the general public in the knowledge of haemophilia and allied disorders and their treatment.

Membership at a glance

Membership

Membership in EAHAD is open to all professionals working in the area of haemophilia and allied disorders.

173

Total members

Become a member

→ [Click here to access the portal](#)

116

Ordinary members

41

AHP members

7

Junior members

5

Associate members

4

Honorary members



2023 Highlights

02

→ EAHAD 2023 Congress

From 7 to 10 February 2023, the EAHAD 2023 Congress took place in Manchester and online. More than 2200 delegates from 92 countries, of which only about 400 attended remotely, joined us for the first on-site congress since the COVID-19 pandemic hit Europe in 2020.

Under the direction of Congress President Prof. Mike Makris and thanks to high-quality sessions, renowned speakers, and interactive presentations, EAHAD 2023 solidified 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 meeting opened on Tuesday 7 with the Allied Health Professionals Day with streams dedicated to physiotherapists, nurses and psychosocial professionals.

From 8-10 February, the main scientific programme took place. Wednesday 8 started with the Multidisciplinary Haemophilia Educational Session, focusing on the role of sports in Haemophilia. Different satellite symposia followed and the day closed with the Poster Networking Reception, with delegates exploring the poster area and having the chance to talk directly to the authors.

Thursday 9 offered attendees the chance to experience a vast array of interesting sessions and presentations. Some of the highlights were the highly anticipated session on Gene Therapy, as well as insightful presentations on topics like the role of a hepatologist in haemophilia centres, future therapies for von Willebrand Disease, and dealing with steroid side effects and withdrawal.

Friday 10 hosted the always exciting SLAM session and the crown jewel of EAHAD 2023, the Latest Clinical Trial Results session, which offered a deep dive into key issues that can potentially transform the future haemophilia and allied disorders landscape.

Congress Facts & Figures

Congress President

Prof. Mike Makris

Dates

7-10 February 2023

Abstracts

362 submissions

Delegates

2214

Countries represented

92



Annual General Meeting 2023

On Thursday 9 February 2023, the EAHAD Annual General Meeting took place in Manchester, UK. After the approval of the meeting's agenda and the minutes from the 2022 AGM, EAHAD President Dr Robert Klamroth presented the 2022 activities report, as well as the association's plans for 2023. EAHAD Treasurer Prof. Wolfgang Miesbach presented the 2022 annual accounts and the 2023 budget. Both were unanimously approved.

At the 2023 AGM, two Executive Committee members, Prof. Karin Fijnvandraat and Prof. Hervé Chambost reached the end of their term. Dr Klamroth thanked them for their work.

In order to ensure the continuation of the current presidency, vice-presidency and secretary positions, the General Assembly resolved to re-elect as member of the Executive Committee Dr Robert Klamroth, Dr Jan Blatny, and Prof. Ana Boban.

In 2022, EAHAD launched a call for nominations for four positions on the Executive Committee. Eight applications were received. At the 2023 AGM, after a written secret ballot, the General Assembly resolved to re-elect Dr Fariba Baghaei and Dr Pratima Chowdary, and elect Dr Samantha Gouw and Prof. Niamh O'Connell.

All aforementioned terms are for three years.



Appointment of 2024-2026 Vice President, Treasurer, and Secretary

At its September 2023 meeting, the Executive Committee elected Prof. Ana Boban as Vice President and appointed Prof. Niamh O'Connell as Treasurer, and Prof. Wolfgang Miesbach as Secretary for the period 2024-2026. They will officially take on their positions in February 2024.

→ EAHAD Academy launched

In February 2023, we launched a very important new initiative, the EAHAD Academy. The EAHAD Academy is the home for all of our educational material, including E-learning modules, Webinars, Live events, Congress recordings, and interviews.

In 2023, we uploaded on the Academy:

9 E-Learning Modules

2 E-Learning Live Events

3 Webinars

2 Meet the Author Interviews

The EAHAD 2023 Congress recordings (*available for members*)





EAHAD E-Learning Working Group releases nine educational modules

In 2023, the EAHAD E-Learning Working Group released nine modules on three different topics:

1. What's new in haemophilia? [▶ Watch](#)

- **How to manage acute cardiovascular disorders in haemophilia**
Robert Klamroth, Cedric Hermans
- **ITI in the era of Emicizumab**
Carmen Escuriola-Ettingshausen
- **FVIII inhibitors during non-replacement therapy**
Jan Astermark, Christoph Königs

2. von Willebrand disease [▶ Watch](#)

- **von Willebrand disease**
Luciano Baronciani, Omid Seidizadeh
- **Prophylactic management of patients with VWD**
Roberta Gualtierotti, Flora Peyvandi
- **How to manage Gastrointestinal bleeding in patients with VWD**
Sophie Susen, Camille Paris

3. Women Health Issues and Bleeding Disorder [▶ Watch](#)

(in collaboration with the EAHAD Women and Girls with Bleeding Disorders Working Group)

- **Menstrual problems and inherited bleeding disorders**
Karin Van Galen
- **Glanzmann Thrombasthenia and pregnancy**
Roseline d'Oiron
- **Peripartum management of women with von Willebrand Disease**
Michelle Lavin

Each module features self-evaluation quizzes and consists of three parts: state of art, "hands-on" session: practical clinical casea and recent literature.

A special module titled "[Conversation with Prof. Pier Mannuccio Mannucci: Innovations in Haemophilia Treatment, 50 Years of Progress and Beyond](#)" was also released. Prof. Cedric Hermans, vice-chair of the Working Group interviewed EAHAD Honorary Member Prof. Pier Mannuccio Mannucci.

As part of our strategy to enhance our online presence and expand our community, we have adopted a comprehensive multichannel strategy, integrating podcasts into our digital framework. To this end, the Working Group launched the **EAHAD Podcast** to coincide with the release of each module and to provide more concisely valuable insights, discussions and updates on the latest developments in the field of haemophilia and allied disorders. It is hosted by Prof. Hermans and is available on [Spotify and Apple Podcast.](#)

→ EAHAD joins the Health Technology Assessment Stakeholder Network

In 2023, EAHAD joined the Health Technology Assessment Stakeholder Network. The aim of the HTA Stakeholder Network is to engage and consult widely with stakeholder organisations with an interest in European Union cooperation on HTA, including patient associations, consumer organisations, health technology developer associations, health professional organisations and other relevant non-governmental organisations in the field of health, including clinical and learned societies. EAHAD is represented by Dr Robert Klamroth and Dr Jan Blatny. In 2023, two meetings took place.

→ EAHAD Gene Therapy Trials Database launched

In 2023, our Gene Therapy Working Group finally launched its [Gene Therapy Trials Database](#) containing the most up-to-date information and results on gene therapy studies and safety issues. The Database is user-friendly and publicly accessible, and will be regularly maintained and updated, with the goal to eventually expand beyond the haemophilia.

→ Two EAHAD Gene Therapy Webinars released

In 2023, our Gene Therapy Working Group released two educational webinars:

1. Relevance of anti-AAV antibodies testing in haemophilia gene therapy [▶ Watch](#)

Chair: Wolfgang Miesbach

Speakers: Flora Peyvandi, Robert Klamroth, Alok Srivastava, Michiel Coppens

2. Liver health in Gene Therapy: what you need to know [▶ Watch](#)

Chair: Flora Peyvandi

Speakers: Graham Foster, Wolfgang Miesbach, Greta Mulders, Declan Noone

→ “Accreditation model of European Haemophilia Centres in the era of novel treatments and gene therapy” paper published

In 2023, our Accreditation and Audit Working Group, together with the European Haemophilia Consortium, published an [original article](#) on Haemophilia noting the importance of updating the European certification guidelines to accreditation guidelines now including all the requirements regarding facilities, laboratory and personnel needed for optimal management of novel treatment options. This novel accreditation protocol, now introducing the hub-and-spoke model for delivery of gene therapy, aims to further improve the quality of care for patients with haemophilia and other inherited bleeding disorders.

→ “How to write an abstract” webinar by the our Nurses Committee

Our Nurses Committee together with the Nurses Committees of the International Society on Thrombosis and Hemostasis (ISTH), and the World Federation of Hemophilia (WFH) worked together to increase the active participation of nurses in bleeding disorder care during congresses. To this end, they released a webinar titled “How to write an abstract”. This is the first webinar of a three-part series, aiming to help nurses with writing an abstract. It was chaired by Kate Khair, with presentations by Marcela Sisdelli and Femke Yspeerd. [▶ Watch](#)

→ Two publications from our Psychosocial Professionals Committee

In 2023, our Psychosocial Professionals Committee released two letters to the editor of Haemophilia. The [first letter](#) was on the results of their survey about psychosocial care throughout Europe, showing that psychosocial care is considered important in haemophilia centres but should be implemented in a more comprehensive and consistent way in the future. The [second letter](#) was on the impact of COVID-19 on professionals and patients in haemophilia care noted that while the tele-medicine model worked, it cannot replace face-to-face interaction, in order to ensure and enhance trust, empathy, and commitment within the community.

→ Our Physiotherapists Committee releases two “Meet the Author” interviews

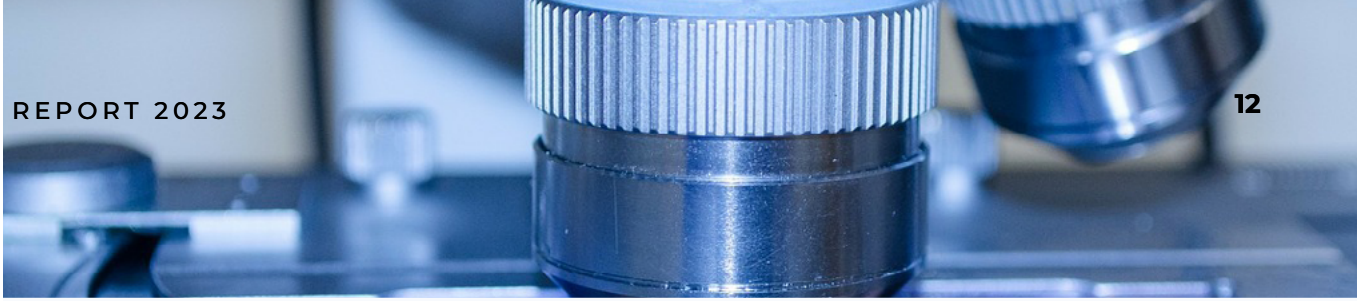
In 2023, our Physiotherapists Committee released two “Meet the Author” interviews:

1. Promoting physical activity for people with haemophilia in the age of new treatments [▶ Watch](#)

Merel Timmer interviews Ruth Elise Dybvik Matlary

2. Monitoring recovery of joints after bleeding: Physical examination and ultrasound are complementary [▶ Watch](#)

Magnus Aspdahl interviews Floor van Leeuwen



Esra Kiraz

Goethe University Frankfurt

Analysis of FVIII reservoirs on cell surfaces and their potential impact on coagulation

Project duration: 12 months
Grant amount: € 47.990

Routinely the activity of coagulation FVIII is measured in patients' plasma for the diagnosis and to guide treatment in patients with haemophilia A. However, for some patients the tendency to bleed cannot be explained by the measured FVII activity levels only. Based on the preliminary findings, we are expecting a role of FVII bound to blood cells not detected by current coagulation assays. Thus, we are aiming to analyse how much FVIII is bound to cells in the blood of haemophilia A patients and healthy controls. Our results might lead to further understand and especially to personally tailor haemophilia A treatment.

Lotte Haverman

Amsterdam UMC

Sexual functioning in men with haemophilia: measurement and communication

Project duration: 24 months
Grant amount: € 25.000

One can assume sexuality is a crucial component in the life of every human being. Sexual functioning and satisfaction is an important aspect of health-related quality of life. In general, patients think sexuality and intimacy is an important topic to discuss with their healthcare professional. More knowledge and skills to discuss problems in sexual functioning is important, especially in MWH considering the problems they may experience. Therefore, this study aims to get more insight into the sexual functioning and satisfaction of men with haemophilia by developing a valid and reliable measure that can be used in clinical practice.

Louise Crossley

Cardiff University

Examination of the acceptability of digitalisation of the Timed Up and Go test for remote assessment in people with haemophilia

Project duration: 10 months
Grant amount: € 21.184

The Timed Up and Go test (TUAG) evaluates mobility, gait and balance and is widely used to evaluate falls risk in the general population and in other health conditions. This project will establish the acceptability and practicality of collecting this information from people with a bleeding disorder remotely at home via movement analysis software, and establish the views of participants on the use of this technology. If acceptable to patients, this approach will reduce the burden of hospital visits, provide valuable feedback to the patient increasing efficiency and effectiveness of the rehabilitation, and allow physiotherapists to potentially identify people at risk of falling so that appropriate interventions can be implemented earlier.





EUHASS

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

In October 2023, EUHASS published its 14th annual report covering the period 1 October 2008 – 31 December 2022. The report contains events data from 95 centres in Europe.

In 2023, EUHASS also published three quarterly reports covering the period from 1 January to 30 September 2023. These reports contain more condensed information on the events reported whilst the annual reports provide a more detailed analysis.

In 2023 the EUHASS software was rewritten to make it more user friendly and easier to analyse. The new “EUHASS 2.0” software would be launched officially in early 2024 with a Gene Therapy module to follow.



European Haemophilia Centre Certification

The European Haemophilia Centre Certification process remains active with EAHAD administrating the process. In 2023, 14 centres in 10 countries received certificates.

European Haemophilia Treatment Centres (EHTCs)

- Eskisehir Haemophilia Centre, Turkiye (original application)
- MVZ für Blutgerinnungsstörungen und Gefäßkrankheiten Limbach Magdeburg, Germany (renewal)
- National Centre of Hemostasis and Thrombosis, Department of Hematology and Transfusiology, Slovakia (renewal)
- Haemophilia Center Ticino, Switzerland (renewal)

European Haemophilia Comprehensive Care Centres (EHCCCs)

- Istanbul University, Istanbul School of Medicine, Division of Pediatric Hematology & Oncology, Turkiye (original application)
- Hemophilia Treatment Center Clinical Center University of Sarajevo, Bosnia (original application)
- Uludag University Medical Faculty, Department of Pediatric Hematology, Turkiye (original application)
- Department of Hematology, Blood Neoplasms, and Bone Marrow Transplantations, Wroclaw Medical University, Poland (original application)
- Department of Paediatric Bone Marrow Transplantation, Oncology and Haematology Supraregional Centre for Pediatric Oncology “Cape of Hope”, Poland (original application)

- Haemophilia and Bleeding Disorders Care Centre, Paediatric and Adults Units, Switzerland (renewal)
- Haemophilia Centre Rhine Main – HZRM GmbH, Germany (renewal)
- Centre de Ressources et Compétences des Maladies Hémorragiques Constitutionnelles, France (renewal)
- Coagulation Centre, Sahlgrenska University Hospital, Sweden (renewal)
- Centre for Benign Haematology, Thrombosis and Haemostasis Van Creveldkliniek, The Netherlands (renewal)

2023 marked the final year that the original European Haemophilia Centre Certification Panel helmed the application review process. We would like to thank Prof. Mike Makris, Prof. Philippe De Moerloose, Brian O'Mahony and Martin Bedford for their dedication and contributions. The project continues under the guidance of our Certification and Audit Working Group.

Communications

Twitter/X

Our tweets reached a peak of 45.5K impressions (the number of times users saw our tweets in their feeds) between July and September, averaging 500 impressions per day, with an engagement rate of 3.5%, which measures how much of our audience actively engage with our content. Among our posts, the promotion of the collaborative project between the Nurses Committees of EAHAD, ISTH, and WFH, with the participation of Kate Khair from Haemnet, stood out as the most successful. It garnered 1,926 impressions and a total engagement of 74.

LinkedIn

On LinkedIn, our most impactful post earned 2.728 impressions, showcasing compelling findings from an article published on the Haemophilia Journal. Our page registered an increase of over 500 new followers.

Community

In 2023, we released two issues of the Nurses Newsletter. Additionally, we launched the EAHAD Monthly Recap, a resource designed to ensure that our members remain updated on the most recent EAHAD developments for each month.

EAHAD Podcast

In line with our goal of enhancing our online presence and expanding our audience, our communication strategy continues to evolve. In addition to LinkedIn and Twitter/X, we've now expanded our presence to platforms such as Spotify and Apple Podcast.

In 2023, our social media channels experienced yet another successful year in terms of both impressions and engagement rates.

+500

Followers on LinkedIn

3,5%

Engagement rate

+1900

Impressions on
Twitter/X

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 and physiotherapy 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 Girls with Bleeding Disorders Working Group
- E-Learning Working Group
- Glanzmann Disease 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 T. Alvarez Roman	Member
Fariba Baghaei	Member
Pratima Chowdary	Member
Samantha Gouw	Member
Niamh O'Connell	Member
Nanda Uitslager	Nurses Committee Chair
Paul McLaughlin	Physiotherapists Committee Chair
Lotte Haverman	Psychosocial Professionals Committee Chair

Nurses Committee

Nanda Uitslager	Chair
Maj Friberg Birkedal	Vice Chair
Mary Kavanagh	Past Chair
Renester Fenton	Secretary
Malin Axelsson	
Greta Mulders	
Gabriella Nicolò	
Linda Myrin Westesson	

Physiotherapists Committee

Paul McLaughlin	Chair
Ruth Elise Dybvik Matlary	Vice Chair
David Stephensen	Past Chair
Marie Katzerova	Secretary
Magnus Aspdahl	
Nathalie Grinda	
Paula Loughnane	
Merel Timmer	

Psychosocial Professionals Committee

Lotte Haverman	Chair
Christina Burgess	Vice Chair
Petra Bučková	Secretary
Karolien Bartels	
Gaby Golan	
Gráinne O' Brien	
Gloria Rooney	
Ana Torres-Ortuño	

Coagulation Factor Variant Databases Steering Group

Christopher Ludlam	Chair
Mathilde Fretigny	
Muriel Giansily-Blaizot	
Keith Gomez	
Daniel Hampshire	
Geoffrey Kembball-Cook	
John McVey	
Niamh O'Connell	

Gene Therapy Working Group

Wolfgang Miesbach	Chair
Ana Boban	
Pratima Chowdary	
Michiel Coppens	
Miguel Crato	
Robert Klamroth	
Mike Makris	
Greta Mulders	
Declan Noone	
Flora Peyvandi	
Víctor Jiménez Yuste	

Accreditation & Audit of Haemophilia Centres Working Group

Fariba Baghaei	Co-chair
Ana Boban	Co-chair
Miguel Crato	
Karin Fijnvandraat	
Mary Kavanagh	
Robert Klamroth	
Paul Mclaughlin	
Wolfgang Miesbach	
Declan Noone	
David Stephensen	

Women and Girls with Bleeding Disorders Working Group

Karin van Galen	Chair
Rezan Kadir	Vice chair
Michelle Lavin	Vice chair
Roseline d'Oiron	
Petra Elfvinge	
Keith Gomez	
Samantha Gouw	
Naja Skouw-Rasmussen	
Gaby Golan	

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 Disease Working Group

Roger Schutgens	Chair
Giancarlo Castaman	
Roseline d'Oiron	
Mathieu Fiore	
Andrea Artoni	
Robert Klamroth	
Mary Mathias	
Suthesh Sivapalaratnam	
Minette van der Ven	
Lena Bilet	NHS Project Manager

European Haemophilia Centre Certification Panel

Mike Makris Lead

Philippe de Moerloose

Brian O'Mahony

Martin Bedford

As of 31 May 2023:

Fariba Baghaei Lead

Ana Boban Lead

Wolfgang Miesbach

Nanda Uitslager

Miguel Crato

Paul Mclaughlin

EUHASS Steering Committee

Mike Makris Chair and Project Lead

Kathelijn Fischer

Alex Gatt

Rob Hollingsworth

Radoslaw Kaczmarek

Thierry Lambert

Riitta Lassila

Flora Peyvandi

Research Grants Review Panel

Pratima Chowdary Lead

Robert Klamroth

Wolfgang Miesbach

Flora Peyvandi

Staff

Pascale Blaes Chief Executive Officer

Angelos Athanasopoulos Chief Operations Officer

Diana Carbonero Alvarez Project Manager

Giuliana Giardina Communications and Events Officer

Acknowledgements

→ Funding

In 2023, we received funding for our Congress from:



BIOMARIN

CSL Behring



ISTH
International Society on
Thrombosis and Haemostasis



LFB
ETHICAL COMMITMENT

octapharma



sobi
rare strength

Spark
THERAPEUTICS



In 2023, we received corporate support from:

BIOMARIN

CSL Behring



octapharma



sobi
rare strength

Spark
THERAPEUTICS

In 2023, we received funding for the Gene Therapy activities from:

BIOMARIN

CSL Behring



Spark
THERAPEUTICS

In 2023, we received funding for our EUHASS activities from:



BIOMARIN

bpl
Bio Products Laboratory

CSL Behring



SANOFI GENZYME

sobi
rare strength



→ Partners

EAHAD collaborates with the following organisations:



European Hematology
Association (EHA)



European Haemophilia
Consortium (EHC)



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:

- **MCI Suisse** 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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