



ANNUAL REPORT 2015



TABLE of contents

04 Foreword

O6 About EAHAD

08 Organisational Structure

- Executive Committee
 - Nurses Committee
 - Physiotherapists Committee
 - Staff
- 14 Membership
- 2015 at a glance
- 2015 Activities
 - Congress
 - Working Parties

Coagulation Factor Variant Databases

EUHANET

PRO:RBDD

- Joint Projects
- Communications

Publications

Communications tools

- Operations and Finances
- 36 Acknowledgments
 - Sponsors
 - Partners
 - Service Providers



FOREWORD

Dear EAHAD members and colleagues,

The past year was a busy one for EAHAD. It is my pleasure to share with you some highlights of the activities and developments that took place in 2015.

The year started with a very successful congress held in Helsinki in February. The event, hosted by Professor Riitta Lassila, was EAHAD's largest congress to date with 1276 registered delegates. As part of our ongoing strategy to ensure that EAHAD is inclusive of the multidisciplinary haemophilia care team as a whole, as in Brussels in 2014, the congress kicked off with a Multidisciplinary Educational Session, with interactive presentations from doctors, a nurse, and a physiotherapist. We also introduced a networking lunch for nurses.

In 2015, EAHAD's structure also grew and changed:

- At the beginning of the year, EAHAD hired a permanent staff person to work for us. We are delighted to have Ms Aislin Ryan join the organisation as Managing Director to oversee our day-to-day activities.
- In Helsinki, five new members joined our Executive Committee. I would like to extend a warm welcome to Jan, Karin, Victor, Mike, and Flora, while also thanking departing committee members, Kathelijn, Pål Andre, Angiola, and Elena, for their valuable contributions.
- In September, EAHAD made a further step towards ensuring that the multidisciplinary nature of haemophilia care is reflected in our organisation with the establishment of a Physiotherapists Committee. We are very pleased to be working with key European physiotherapists in the field of haemophilia and look forward to developing a strong network of physiotherapists to help promote this integral aspect of comprehensive care.

There is also very important on-going work being done by EAHAD's existing committees and working parties, including the Clotting Factor Variant Databases Working Party, EUHANET, and the Nurses Committee. In August, the Nurses Committee published "A European curriculum for nurses working in haemophilia." On behalf of the EAHAD Executive Committee, I would like to congratulate our nurses group on this significant achievement in enhancing nursing services for people with haemophilia and allied disorders.

This year we have also collaborated closely with the European Haemophilia Consortium (EHC), joining our efforts in both advocacy initiatives and scientific activities. In late October, our two organisations, along with the World Federation of Hemophilia (WFH), took part in a four-day visit to Estonia and Latvia to meet with key stakeholders in the bleeding disorders community. We believe this strong partnership with the EHC and the WFH demonstrates the value of collaboration between patients and healthcare professionals in the improvement of bleeding disorders care.

You will find more details on the various initiatives and activities that took place within EAHAD throughout this report. As always, we encourage you to share with us your feedback and ideas for how we can best serve you and contribute to securing optimal care for people with bleeding disorders.

Finally I would like to express my sincere gratitude to all our collaborators and partners for your support of EAHAD. We look forward to continuing to work with you in the coming years.

Sincerely,

Professor Philippe de Moerloose

EAHAD President 2014 - 2016

Ple OseAvore

ABOUT EAHAD

The European Association for Haemophilia and Allied Disorders (EAHAD) is a multi-disciplinary association of healthcare professionals who provide care for individuals with haemophilia and other bleeding disorders. Its members include haematologists, internists, paediatricians, nurses, physiotherapists, laboratory scientists, and researchers from across Europe.

Since its establishment in 2007, EAHAD has worked to improve the situation of people living with haemophilia and other bleeding disorders. EAHAD's work is guided by the following three aims:



To ensure the provision of the highest quality of clinical care

By recognising, measuring, and addressing the problems of people with haemophilia and allied disorders in Europe, to protect their interests and to ensure the provision of the highest quality of care available.



To educate the medical community and the general public

By advancing the education of medical practitioners, clinical scientists, professions allied to medicine, and the general public in the knowledge of haemophilia and allied disorders and their treatment.



To promote scientific research

By supporting scientific research and auditing into the causes, prevention, alleviation, and management of haemophilia and allied disorders and to disseminate the useful results of such research.



"We are very pleased to be working with key European physiotherapists in the field of haemophilia and look forward to developing a strong network of physiotherapists to help promote this integral aspect of comprehensive care"

Ph de Moerloose



ORGANIZATIONAL STRUCTURE

Executive Committee

Our Executive Committee is composed of medical professionals from across Europe who are experts in the field of haemophilia and allied disorders. Their role is to direct the policy and general management of EAHAD.

In 2015, we also formalized the inclusion of the chair of the Nurses Committee as an ex-officio member of the Executive Committee, with Marlies Schrijvers joining the committee. In November, the chair of the newly established physiotherapy committee, Piet de Kleijn, also joined the Executive Committee. Following the conclusion of their three-year term of office, Dr Kathelijn Fischer, Dr Pål Andre Holme, Dr Angiola Rocino, and Dr Elena Santagostino stepped down from the Executive Committee in February 2015.



Victor Jimenez-Yuste
Associate Professor in the Haematology Department at the Autónoma University and Head of the Haematology Department at La Paz University Hospital in Madrid, Spain

In February 2015, five new members were elected to the committee at our Annual General Meeting



Jan Blatny
Consultant Haematologist and Lead
Clinician at the Department of Paediatric Haematology, Centre for Thrombosis and Haemostasis, Children's
University Hospital Brno, Czech Re-

public



Karin Fijnvandraat
Professor of Paediatric Haematology
at the University of Amsterdam and
Consultant Paediatric Haematologist
in Emma Children's Hospital, at the
Academic Medical Center in Amsterdam, the Netherlands



Michael Makris
Professor of Haemostasis and Thrombosis at the University of Sheffield,
Honorary Consultant Haematologist
at The Sheffield Teaching Hospitals
NHS Trust and Director of the Sheffield Haemophilia and Thrombosis
Centre in Sheffield, United Kingdom



Flora Peyvandi
Associate Professor of Internal Medicine and Head of the Department
Angelo Bianchi Bonomi Hemophilia
and Thrombosis Center, Fondazione
IRCCS Cà Granda, Ospedale Maggiore
Policlinico, University of Milan, Italy

They joined current members:

Philippe de Moerloose (President)

Professor in the Department of Internal Medicine, Head of the Haemostasis Unit and Adjunct Chef de Service for the Division of Angiology and Haemostasis at the University Hospital in Geneva, Switzerland





Cedric Hermans (Vice-President and Treasurer)
Head of the Division of Haematol-

ogy, the Haemostasis and Thrombosis Unit and the Haemophilia Centre of the Saint-Luc University Hospital in Brussels, Belgium



Jan Astermark

Associate Professor at Lund University, Head of the Department for Hematology and Vascular Diseases at the Skane University Hospital in Lund/Malmö and Director of the Centre for Thrombosis and Haemostasis in Malmö, Sweden



Gerry Dolan

Consultant Haematologist at Nottingham University Hospitals and Head of the Haemostasis and Thrombosis Service in Nottingham, United Kingdom



Robert Klamroth

Head of the Department of Internal Medicine Angiology and Coagulation Disorders and Director of the Comprehensive Care Haemophilia Treatment Center and the Haemostasis and Thrombosis Unit at the Vivantes Klinikum im Friedrichshain in Berlin, Germany



Roseline d'Oiron (ex-officio)

Clinician investigator at the Reference Centre for Haemophilia and Other Congenital Rare Bleeding Disorders, Congenital Platelets Disorders and von Willebrand disease at Bicêtre Hospital AP-HP – Paris XI University, Le Kremlin-Bicêtre, France



Riitta Lassila (ex-officio)

Professor of Coagulation Medicine at Helsinki University and the head of Coagulation Disorders Unit both in Laboratory Services, HUSLAB and the Hematology and Cancer Center in Helsinki University Central Hospital, Helsinki, Finland



Nurses Committee

The purpose of EAHAD's Nurses Committee is to improve the quality of care to patients with haemophilia and allied disorders throughout Europe by enhancing nursing services as a core component of the comprehensive care team.

The committee is composed of registered nurses from at least five European countries with experience in haemophilia.

The 2015 Nurses Committee members:

Marlies Schrijvers (Chair)

PhD, Registered Nurse, and Post-Doc Nursing Science, Van Creveldkliniek, University Medical Center Utrecht and Lecturer at the Department of Nursing Science, Utrecht University, the Netherlands

Martin Bedford (Vice-Chair)

Senior Lecturer, School of Nursing, Faculty of Health and Wellbeing, Canterbury Christ Church University, Canterbury, United Kingdom

Petra Elfvinge (Secretary)

Registered Nurse, Coagulation Unit, Karolinska University Hospital, Stockholm, Sweden

Alpha Barrie

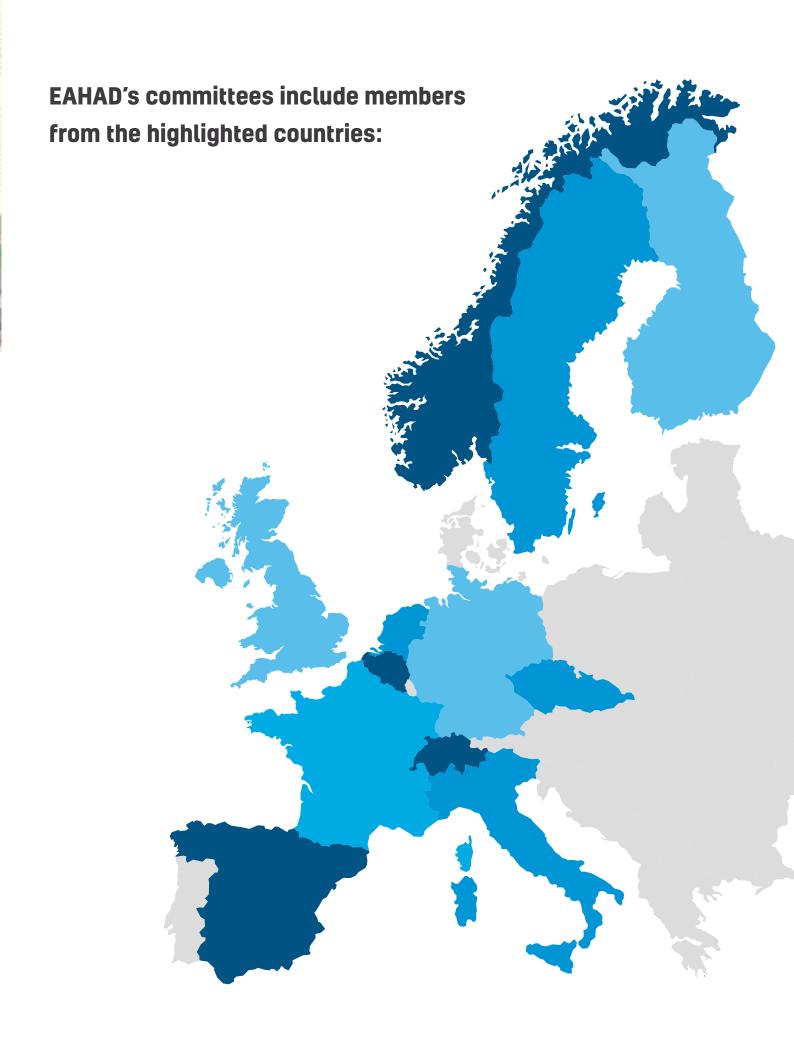
Clinical Nurse Specialist and Research Nurse, Haematology and Oncology Department at Great Ormond Street Hospital, London, United Kingdom

Siri Grønhaug

Registered Nurses, Department of Haematology, Rikshospitalet, Oslo University Hospital, and Senior Adviser, Centre for Rare Disorders, Oslo, Norwa

Elsbeth Müller-Kägi

Advanced Practice Nurse, Zürich Hemophilia Comprehensive Care Center, University Children's Hospital Zürich, Zürich, Switzerland



Physiotherapists Committee

In July 2015, the first meeting was held in view of developing a Physiotherapists Committee within EAHAD. The Committee was officially established following approval by the Executive Committee in September.

The objective of the committee is to improve the provision and quality of musculoskeletal care to patients with haemophilia and associated bleeding disorders throughout Europe by promoting physiotherapy and musculoskeletal services as a core component of comprehensive care.

The founding members of the Physiotherapists Committee are:

Piet de Kleijn (Chair)

Physiotherapist, Van Creveldkliniek at the University Medical Center Utrecht, the Netherlands

Paul McLaughlin

MSc, MMACP, Clinical Specialist Physiotherapist in Haemophilia at The Katharine Dormandy Haemophilia Centre and Thrombosis Unit,

Royal Free London NHS Foundation Trust in London, United Kingdom

Sébastien Lobet

PhD, Physiotherapist and Researcher at the Haemostasis and Thrombosis Unit at the Cliniques Universitaires Saint-Luc in Brussels, Belgium

David Stephensen

PhD, Physiotherapist, Kent Haemophilia & Thrombosis Centre, Canterbury and Haemophilia Centre, Royal London Hospital, London, United Kingdom



Staff

In January 2015, EAHAD hired a permanent staff person to work for the organisation, Aislin Ryan. Starting in the role of EAHAD-EHC Project Consultant, in the first half of the year, Aislin's work was focused on implementing the joint EHC-EAHAD Baltic country visit and other joint EAHAD-EHC projects. Based on the increased need for more day-to day support to the Executive Committee in the general management of EAHAD, in the fall of 2015, Aislin transitioned to the role of Managing Director of EAHAD.

The mandate for this role include formalizing EAHAD's organisational structure and administrative processes, overseeing our communications strategy, increasing the involvement of healthcare professionals from different disciplines and from across Europe in our work, and collaborating with other organizations working in bleeding disorders care, namely, the European Haemophilia Consortium (EHC). Aislin is based in Brussels where she works in the offices of the EHC.



MEMBERSHIP

Membership in EAHAD is open to all healthcare professionals, including physicians, nurses, physiotherapists, and clinical scientists, who are working in the area of haemophilia and allied disorders.



The membership cycle runs from **November 1 to October 31 of each year.**



In 2014-2015, EAHAD had **125 members from 24 countries.**





2015 at a glance

- 8th Annual EAHAD Congress(Helsinki, Finland)
- Annual General Meeting
 (Helsinki, Finland)
 Executive Committee Meeting
 (Helsinki, Finland)

- Coagulation Factor Databases
 Steering Group Meeting
 (London, United Kingdom)
- Nurses Committee Meeting
 (Utrecht, the Netherlands)

February
March
April
May
June
June
Coagulation Factor Databases
Steering Group Meeting
(London, United Kingdom)

- EUHANET Steering Committee
 Meeting (Manchester, United Kingdom)
- Coagulation Factor Databases Steering
 Group Meeting (London, United Kingdom)
 - Executive Committee Meeting (Brussels, Belgium)

Meeting with Industry Partners (Brussels, Belgium)

- Participation in 2nd Conference on
 European Reference Networks
 (Lisbon, Portugal)
- Nurses Committee Meeting (Stockholm, Sweden)
- Joint EAHAD-EHC-WFH Baltic Country Visit
 (Tartu and Tallinn, Estonia and Riga, Latvia)
 - Executive Committee Meeting
 by Teleconference
 - Coagulation Factor Databases

 Steering Group Meeting

 (London, United Kingdom)

"A European curriculum for nurses
 working in haemophilia"
 published online in Haemophilia journal

Coagulation Factor Databases

Steering Group Meeting

(London, United Kingdom)

August

September

October

Novembe

December

Physiotherapists Committee Meeting (Brussels, Belgium)

 Physiotherapists Committee Meeting (Brussels, Belgium)

- Executive Committee Meeting(Geneva, Switzerland)
- EUHANET Steering Committee Meeting
 (Manchester, United Kingdom)
- Coagulation Factor Databases
 Steering Group Meeting
 (London, United Kingdom)



2015 ACTIVITIES



Congress

Our 8th Annual Congress was held in Helsinki, Finland, from 11-13 February 2015. Chaired by congress president, Professor Riitta Lassila, the three-day meeting attracted a record number of over 1270 delegates.

For the second year running, the congress started with a multidisciplinary session where hematologists, nurses, and physiotherapists discussed challenges in the care of bleeding disorders patients across the lifespan from each of their unique perspectives.

The congress concluded with a late-breaking session on how to interpret current evidence on inhibitor development, which analysed the latest data from a number of recent studies.

Much of 2015 was also spent preparing the 9th Annual Congress taking place in Malmö, Sweden from 3-5 February 2016.

The main programme of the congress featured 26 scientific presentations on a variety of topics including:



Cost of haemophilia care



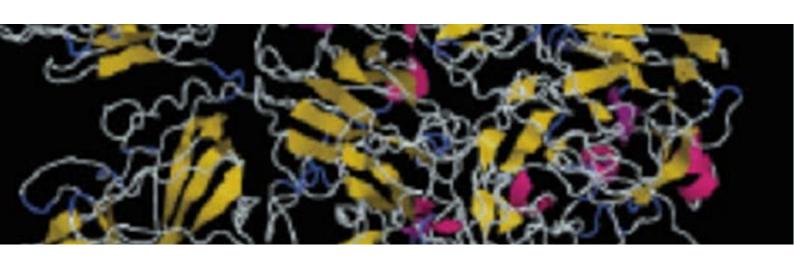
Emerging therapies for bleeding disorders



Management of pregnancy and birth in carriers

In 2015, EAHAD contributed to the following projects:

- Coagulation Factor Variant Databases
- European Haemophilia Network (EUHANET)
- Prospective Rare Bleeding Disorders Database (PRO-RBDD)



Working Parties

EAHAD supports a number of working parties investigating various aspects of the diagnosis, treatment, and management of rare bleeding disorders.

Coagulation Factor Variant Databases

The Coagulation Factor Variant Databases project gathers together single gene variant databases involved in clinical bleeding disorders, principally haemophilias A and B and von Willebrand disease, as well as other rarer coagulation factor variants.

A Steering Group chaired by Professor Christopher Ludlam leads the project. In the past year, their work has focused on consolidating the EAHAD database portal arrangements. This portal gives

access to the Factor VIII, Factor IX and VWF databases, where users can view a wealth of structural and clinical information about each variant. This includes an 'In Depth Mutation Analysis' of each variant that reveals the features of each mutation and predicts its consequences. The databases are free to use and of value to both clinicians and researchers.

In 2015, the group also made substantial progress in the establishment of factor VII and factor XI databases.

Coagulation Factor Variant Databases website: http://www.eahad-db.org/



Pictorial representation of the mutation site on the factor VIII molecule

EUHANET

EUHANET was a European Commission-funded project aimed at establishing a network of haemophilia centres that could work together on a number of related projects to improve the care of European citizens with inherited bleeding disorders.

The project was led from Sheffield in the United Kingdom by Professor Michael Makris and involved five associated partners: the European Haemophilia Consortium (EHC), University Medical College Utrecht, Medical Data Solutions and Services Ltd (MDSAS), Fondazione IRCCS Ca' Granda, and EAHAD.

While the European funding finished in May 2015, EAHAD is committed to working with the EHC to continue this work going forward. At present, this includes the continuation of the European haemophilia centre certification process.

EUHANET website: www.euhanet.org

- ► Certification of 113 European haemophilia centres in 31 countries
- ▶ Development of the comprehensive Haemophilia Central website
- Expansion of the EUHASS project, which now includes 86 centres from 26 countries
- Collection of prospective data on fibrinogen and FXIII deficiencies through the PRO-RBDD project

Prospective Rare Bleeding Disorders Database (PRO-RBDD)

Following the conclusion in May of the EUHANET project, the EAHAD Executive Committee voted to provide one-year transitional funding to the Prospective Rare Bleeding Disorders Database (PRO-RBDD) project led by Professor Flora Peyvandi.

PRO-RBDD collects data on patients with the most severe types of rare bleeding disorders, fibrinogen and factor XIII deficiencies, using a prospective observational cohort design. It aims to better identify the number of affected individuals worldwide and make use of the data collected to optimise the clinical management of patients and therapy modalities.

Thanks to the development of an international network of care providers and to the use of a web-based database, the PRO-RBDD is collecting prospective data on laboratory and clinical manifestation of disease, efficacy, and safety of treatment. Genetic characterisation of patients and external quality control assessment of laboratory assays for fibrinogen and FXIII are also carried out.

The findings observed so far confirmed the previously reported association between fibrinogen or FXIII plasmatic levels and clinical severity of patients. Further analysis aims at establishing a cut-off level of activity capable of discriminating patients who may have spontaneous major bleedings.

PRO-RBDD website: eu.rbdd.org

Participation in PRO-RBDD:

- ► 62 centres involved (38 from Europe)
- ▶ 19 centres actively entering data (16 from Europe)
- ➤ The database currently stores data on 140 patients with fibrinogen deficiency (114 from Europe) and 64 patients with FXIII deficiency (51 from Europe)

Joint Projects

In October 2015, EAHAD partnered with the European Haemophilia Consortium (EHC) and the World Federation of Hemophilia (WFH) to conduct a fourday visit to Estonia and Latvia to discuss the situation of haemophilia care in both countries.

The purpose of the visit was to combine the collective strengths of our three organisations to provide advocacy and educational support to both the patients and healthcare professionals in each country.

Over the course of the four days, we met with patients, clinicians and government officials to discuss the current status of haemophilia treatment and future steps for the improved organisation of care at the national level in both countries.

In Estonia, this involved meeting with key stakeholders, including the Minister of Health, to discuss strategies for how to structure haemophilia care across Estonia's three main hospitals in order to ensure that it both serves the patients as efficiently and effectively as possible and guarantees optimal sharing of knowledge and resources.

In Latvia, we participated in an interview with local media aimed at raising awareness about the situation of people living with bleeding disorders in the country and conducted a half-day educational workshop focused on multidisciplinary care and the treatment of haemophilia through the life course.



Communications

Publications

In August 2015, "A European curriculum for nurses working in haemophilia", a publication written by EAHAD's Nurses Committee, was published online in *Haemophilia* journal. The publication was developed by the committee to describe the skills and knowledge needed for a nurse to work in this specialty. Going forward, the committee will be developing a number of initiatives to use the document as a resource for facilitating haemophilia nurse education.

The European Nurses Curriculum can be accessed here: http://onlinelibrary.wiley.com/doi/10.1111/hae.12785/epdf

Communications tools

This year we undertook an initiative to update EAHAD's communication tools to give them a refreshed look and also make them more user-friendly for our members.

This included working with graphic and web designers to come up with a new logo for EAHAD and redesign the website to include more up-to-date information that is easier to access.

While the majority of the work completed in 2015 was done behind the scenes and out of view, the changes made will be reflected more widely in 2016 with the launch of the website and logo, and with more frequent updates to our members on our website and through our newsletters.



OPERATIONS and Finances

Report of the trustees

For The Year Ended 30 September 2015

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 30 September 2015. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number	Trustees	Independent examiner
06373427 (England and Wales)	Prof J Astermark	Atkinson Donnelly LLP
	Dr K Fischer - resigned 12.2.15	1 Cambuslang Court
Registered Charity number	Prof C Hermans	Cambuslang
1125081	Dr R D'Oiron - resigned 12.2.15	Glasgow
	Dr P A Holme	Strathclyde
Registered office	Dr R PT Lassila - resigned 12.2.15	G32 8FH
Fifth Floor	Dr A Rocino - resigned 12.2.15	
100 Victoria Street	Prof P De Moerloose	
Bristol	Dr R Klamroth	
England	Dr G Dolan	
BS1 6HZ	Dr J Blatny - appointed 12.2.15	
	Dr F Peyvandi - appointed 12.2.15	
	Prof M Makris - appointed 12.2.15	
	Dr V Jimenez-Yuste - appointed 12.2.15	
	Dr C J Fijnvandraat - appointed 12.2.15	

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

European Association for Haemophilia and Allied Disorders is a company limited by guarantee and is governed by its Memorandum and Articles of Association dated 17 September 2007 as amended by special resolution dated 23 June 2008.

Recruitment and appointment of new trustees

Directors (who are also Trustees) other than the initial directors, will be appointed by way of an election process involving a ballot of the ordinary members of the charity. The election process will be carried out in such a way as to ensure that the board of Directors has a balanced reflection of the professional diversity of the field of haemophilia and allied disorders.

Directors may be elected to the following offices: President, the President elect (known as the Vice-President), the Treasurer and the Secretary.

Directors will hold office for three years, except for the President and Vice-President who will hold office for two years. The Vice-President will automatically be appointed to the office of President on the expiry of his term of office as Vice-President.

If the Directors are of the opinion that the board does not contain an adequate number of Directors who are medical practitioners, clinical scientists or related persons, they may co-opt members who are willing to act. Any Director appointed in this way will automatically be deemed to retire at the next following Annual General Meeting of the charity.

In the event of a casual vacancy, the Directors will take all necessary steps to arrange the election of a replacement Director to hold office for the remainder of the term.

Organisational structure

The board of Directors (who are also Trustees) administers the charity. There are a minimum of four, and a maximum of 10 Directors.

The Board meets several times a year to discuss the charity and its activities.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to help those people suffering from haemophilia and allied disorders throughout Europe. This is to be achieved by firstly recognising, measuring and addressing the problems of people with haemophilia and allied disorders. The charity will strive to protect their interests and ensure the provision of the highest quality of care available. Secondly to promote research in haemophilia and the various allied disorders. Thirdly to disseminate knowledge through the appropriate scientific channels and educate practitioners, clinical scientists, professionals allied to medicine and the general public in the knowledge and treatment of haemophilia and allied disorders.

Significant activities

The main activities of the charity are the organisation of conferences and meetings to assist in discussion and the dissemination of knowledge and experience.

FINANCIAL REVIEW

Reserves policy

The Directors recognise that there will be fluctuations in the charity's income. It is the policy of the Directors to build up and maintain a sufficient level of reserves to enable the organisation to continue, and to explore and secure alternative levels of funding should unexpected events occur. The Directors consider that the reserves should be held at a level to enable the organisation to continue for a minimum of twelve months without additional sources of income.

Principal funding sources

The principal funding sources are donations from pharmaceutical companies and membership subscription.

Approved by order of the board of trustees on 9 december 2015 and signed on its behalf by:

Prof J Astermark - Trustee

I report on the accounts for the year ended 30 September 2015 set out on pages four to nine.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. The charity's trustees consider that the audit requirement of Regulation 10(1)(a) to (c) of the Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under Section 44(1) (c) of the Act and to state whether particular matters have come to my attention.

Basis of the independent examiner's report

My examination was carried out in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements

Fiona Struthers

- to keep accounting records in accordance with Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records and to comply with Regulation 8 of the 2006 Accounts Regulations

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Fiona Struthers

Chartered Accountant

Atkinson Donnelly LLP

1 Cambuslang Court - Cambuslang

Glasgow - Strathclyde

G32 8FH

Date: 3rd February 2016

Statement of Financial Activities

For The Year Ended 30 September 2015

	Notes	30.09.15 Unrestricted Fund / £	30.09.14 Total Funds / £
INCOMING RESOURCES			
Incoming resources from generated funds			
Voluntary income		159,932	131,475
Investment income	2	534	9
Incoming resources from charitable activities			
Charitable		174,709	98,873
Other incoming resources		653	2,526
TOTAL INCOMING RESOURCES		335,828	232,883
RESOURCES EXPENDED			
Charitable activities			
Charitable		117,805	45,103
Governance costs		40,640	39,780
Other resources expended		2,076	23,195
TOTAL RESOURCES EXPENDED		160,521	108,078
NET INCOMING RESOURCES		175,307	124,805
RECONCILIATION OF FUNDS			
Total funds brought forward		659,795	534,990
TOTAL FUNDS CARRIED FORWARD		835,102	659,795

Balance Sheet

At 30 September 2015

	Notes	30.09.15 Unrestricted Fund / £	30.09.14 Total Funds / £
FIXED ASSETS			
Tangible assets	5	460	-
Investments	6	140,252	-
		140,712	-
CURRENT ASSETS			
Debtors	7	4,526	117,780
Cash at bank		708,597	547,812
		713,123	665,592
CREDITORS			
Amounts falling due within one year	8	(18,733)	(5,797)
NET CURRENT ASSETS		694,390	659,795
TOTAL ASSETS LESS CURRENT LI- ABILITIES		835,102	659,795
NET ASSETS		835,102	659,795
FUNDS			
Unrestricted funds	9	835,102	659,795
TOTAL FUNDS		835,102	659,795

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30 September 2015.

The members have not required the charitable company to obtain an audit of its financial statements for the year ended 30 September 2015 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Board of Trustees on 9th december 2015 and were signed on its behalf by:

Prof J Astermark -Trustee

Prof C Hermans -Trustee

Notes to the Financial Statements

For The Year Ended 30 September 2015

1. ACCOUNTING POLICIES

Accounting convention

The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), the Companies Act 2006 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities.

Incoming resources

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Resources expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery etc - 33% on cost

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees. Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes. Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rates of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of transaction. Exchange differences are taken into account in arriving at the operating result.

2. INVESTMENT INCOME

	30.09.15 Unrestricted Fund $/£$	30.09.14 Total Funds / £
Deposit account interest	534	9

3. NET INCOMING/(OUTGOING) RESOURCES

Net resources are stated after charging/(crediting):

	30.09.15 Unrestricted Fund / £	30.09.14 Total Funds / £
Depreciation - owned assets	226	-

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 30 September 2015 nor for the year ended 30 September 2014 .

Trustees' expenses

Expenses totalling £5,249 (2014 - £9,191) were reimbursed to trustees during the year.

5. TANGIBLE FIXED ASSETS

	Plant and Machinery £
COST	
Additions	686
DEPRECIATION	
At 1 October 2014	226
NET BOOK VALUE	
At 30 September 2015	460
At 30 September 2014	-

6. FIXED ASSET INVESTMENTS

	Plant and Machinery £
MARKET VALUE	
Additions	140,252
NET BOOK VALUE	
At 30 September 2015	140,252
At 30 September 2014	-

The investments are maintained by a broker based in Geneva.

7. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	30.09.15 Unrestricted Fund / £	30.09.14 Total Funds / £
Other debtors	106	98,979
Prepayments and accrued income	-	15,578
Prepayments	4,420	3,223
	4,526	117,780

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	30.09.15 Unrestricted Fund $/£$	30.09.14 Total Funds / £
Accrued expenses and deferred income	18,733	5,797

9. MOVEMENT IN FUNDS

	At 1.10.14 £	Net Movement in funds £	At 30.9.15 £
Unrestricted funds			
General fund	659,795	175,307	835,102
TOTAL FUNDS	659,795	175,307	835,102

The investments are maintained by a broker based in Geneva.

	Incoming Resources	Resources expended £	Movement in Funds £
Unrestricted funds			
General fund	335,828	(160,521)	175,307
TOTAL FUNDS	335,828	(160,521)	175,307

10. PROVISIONS AVAILABLE TO SMALLER ENTITIES

In common with many other businesses of our size and nature we use our independent examiners to prepare and submit returns to the tax authorities and assist with the preparation of the financial statements.

	30.09.15	30.09.14 £
INCOMING RESOURCES		
Voluntary income		
Donations	157,711	128,633
Memberships	2,221	2,842
	159,932	131,475
Investment income		
Deposit account interest	534	9
Incoming resources from charitable activities		
Conferences	174,709	98,873
Other incoming resources		
Other Income	174,709	98,873
TOTAL INCOMING RESOURCES	335,828	232,883
Charitable activities	206	
Insurance	806	-
Telephone and IT	1,071	-
Postage and stationery	2,914	-
Sundries	13	260
Travelling Expenses	18,960	22,627
Conference Expenses	780	-
Research Projects	6,100	10,535
Subscriptions	-	750
Consultancy Fees	26,184	-
Printing	936	2,408
Catering	599	878
Accommodation	2,363	1,280
Meals/Refreshments	237	1,164
Venue Hire	2,513	4,705
	63,476	44,607

	30.09.15	30.09.14
Governance costs		
Secretarial Service Fees and Expenses	38,876	38,052
Accountancy	1,764	1,728
	40,640	39,780
Other resources expended		
Bank charges	2,076	711
Support costs		
Management		
Gain/loss on foreign currency	53,893	21,906
Professional Fees	210	1,074
	54,103	22,980
Information technology		
Computer equipment	226	-
TOTAL RESOURCES EXPENDED	160,521	108,078
NET INCOME	175,307	124,805

AKNOWLEDGMENTS

SPONSORS

EAHAD is grateful for the funding it receives in support of its various activities from the following industry partners:

















GRIFOLS







PARTNERS

Since 2013, EAHAD has had a Memorandum of Understanding with the European Haemophilia Consortium (EHC), which represents European national patient organisations for people with rare bleeding disorders. This agreement guides our collaboration with the EHC in a number of relevant areas including advocacy, data collection, and joint initiatives such as the EUHANET project. In 2015, our collaboration with the EHC increased with regular meetings, presentations at each other's conferences and events, and the Baltic visit undertaken in October.

We would like to thank the EHC for their efforts in continuing to strengthen this relationship and generously providing EAHAD with a workspace in their offices in Brussels.

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 their organisation of our Annual Congress, Northern Networking Events Ltd for the administrative, financial, and IT support they provide, Atkinson Donnelly LLP for their accounting services, the PRG Partnership for legal services, and Toast Agency for creating visual content for our website and publications.





European Association for Haemophilia and Allied Disorders Ltd (EAHAD)

Registered Company Number: 06373427 (England and Wales) Registered Charity Number: 1125081

Registered address:

Fifth Floor, 100 Victoria Street Bristol BS1 6HZ United Kingdom Brussels office: Rue de l'Industrie 10 1000 Brussels Relaium T +32 2 893 24 89 info@eahad.org www.eahad.org