



EAHAD, EUHANET and EUROPEAN HAEMOPHILIA CENTRES

NORDIC MEETING 2019 | 16 November 2019



ABOUT EAHAD



WHAT IS EAHAD

EUROPEAN ASSOCIATION FOR HAEMOPHILIA AND ALLIED DISORDERS



- Multidisciplinary association of healthcare professionals
- Members include doctors, nurses, physiotherapists, social workers, psychologists, reserachers, etc. from across Europe
- Established in 2007
- Based in Brussels, 3 staff



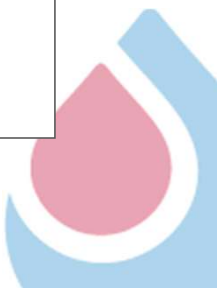
EAHAD IN THE BEGINNING

- 2005: Interdisciplinary Working Group (IWG) established
- Comprised of 45 clinicians from 15 European countries
- Steering Committee members included Jan Astermark (SE) and Jorgen Ingerselv (DK). Patient input from EHC and WFH. Nurse involvement.

Addressing current challenges in haemophilia care: consensus recommendations of a European Interdisciplinary Working Group

C. A. LUDLAM,* P. M. MANNUCCI† and W. G. POWDERLY‡ ON BEHALF OF THE EUROPEAN INTERDISCIPLINARY WORKING GROUP

Haemophilia 2005;11:433



EAHAD IN THE BEGINNING

- IWG decided on 3 areas of focus:
 - ① **Provide care** in an environment of cost constraint
 - *European Principles of Haemophilia Care*
Haemophilia (2008), 14, 361-374 – **free access via EAHAD website**
 - ② Develop the **next generation** of haemophilia specialists
 - *European Curriculum for Thrombosis and Haemostasis*
Haemophilia (2009), 15, 337-344 – **free access via EAHAD website**
 - ③ Reduce the potential **risk of treatments**
 - European Haemophilia Safety Surveillance Scheme (EUHASS)
 - www.euhass.org



EAHAD IN THE BEGINNING

IWG also recommended that a permanent organisation be formed:

Journal of Thrombosis and Haemostasis, 4: 2270–2290

LETTERS TO THE EDITOR

Proposal to establish a European Association for Hemophilia and Allied Disorders

C. A. LUDLAM* and P. M. MANNUCCI†, ON BEHALF OF THE INTERDISCIPLINARY WORKING GROUP
*Haemophilia and Thrombosis Centre, Royal Infirmary, Edinburgh, UK; and †Angelo Bianchi Bonomi Haemophilia Centre, Milan, Italy

To cite this article: Ludlam CA, Mannucci PM, on behalf of the Interdisciplinary Working Group. Proposal to establish a European Association for Hemophilia and Allied Disorders. *J Thromb Haemost* 2006; 4: 2270–1.

The establishment of a European Association for Hemophilia and Allied Disorders is proposed. Its aims would be to promote collaboration in clinical practice, research, pharmacovigilance, dissemination of knowledge, education and training. This proposal emanates from an existing broad-based group of European hemophilia physicians as detailed below.

The background for this proposal is that hemophilia is a relatively uncommon condition that is complex and costly to manage effectively. To ensure high quality of treatment it is essential that there is collaboration between all those involved

examples include: PedNet (Pediatric Network of hemophilia centers particularly assessing inhibitor incidence), European Haemophilia Economic Study Group, The von Willebrand disease prophylaxis network (VWD PN), Type 1 VWD project, European Haemophilia Therapy Standardisation Board, and European Study on Orthopaedic Status (ESOS). These collaborations are costly to organize and are partly supported by European Union, but to a large extent funding from the pharmaceutical industry is necessary.

A further group of 45 established European physicians from 16 countries met recently to consider issues that might

*“Its aims would be to promote collaboration in **clinical practice, research, pharmacovigilance, dissemination of knowledge, education and training.**”*

EAHAD TODAY

- Annual Congress
- Nurses Committee
- Physiotherapists Committee
- Working Groups:
 - Psychosocial Professionals
 - Women and Bleeding Disorders
- Research Grants
- Coagulation Factor Variant Databases
- European Haemophilia Centre Certification
- EUHASS



EAHAD CONGRESS

- Held every year in early February
- 3-day meeting (Wed-Fri) with focus on clinical management
- Single-track of sessions so everyone hears the same message. No exhibition.
- **Pre-Congress Day** for nurses, physiotherapists, and psychosocial professionals since 2017.

AMSTERDAM, 2008: 190 participants



HELSINKI, 2015: 1276 participants



MALMÖ, 2016: 1653 participants



PRAGUE, 2019: 2612 participants

EAHAD 2020 CONGRESS



EAHAD
European Association for Haemophilia
and Allied Disorders
2020

13th ANNUAL CONGRESS
OF THE EUROPEAN ASSOCIATION
FOR HAEMOPHILIA AND ALLIED DISORDERS

THE HAGUE NETHERLANDS
5-7 February 2020



www.eahadcongress.com

- In 2020, specific registration category for **patient advocates** with reduced registration fees.

More info:

www.eahadcongress.com

- Early-bird deadline:
27 November 2019



NURSES COMMITTEE

- Est. 2014
- Publications:
 - European Curriculum for Nurses Working in Haemophilia Care
Haemophilia (2016), 22, 103-109
 - Guidelines on factor administration via IV or CVAC
eahad.org/nurses-guidelines
- European Nurses Network
 - To join, email:
nurses@eahad.org



PHYSIOTHERAPISTS COMMITTEE



- Est. 2015
- European Physio Network
 - Regional coordinators – hub & spoke approach
 - 270+ physios in 29 countries
 - To join, email: physio@eahad.org

- Published “Scope of practice of haemophilia physiotherapists: A European survey”

- *Haemophilia* (2019), 25, 514-520



Findings: Role, autonomy, and training of physios varies greatly across Europe. Impact on patients’ access to care

PSYCHOSOCIAL PROFESSIONALS WORKING GROUP

- Est. 2018
- Psychologists and social workers
- Survey to be sent out this month on access to psychosocial services for bleeding disorders patients



WOMEN & BLEEDING DISORDERS WORKING GROUP



- Est. 2018
- Aims:
 - identify research priorities to address **unmet needs** of women with bleeding disorders
 - Publish *European Principles of Care for Women-Specific Bleeding Disorders*

Multidisciplinary group - haematologists, gynaecologists, nurse, psychologist, patient

RESEARCH GRANTS

- Since 2017, 6 grants awarded, € 300,000 total
- Scientific projects on inherited bleeding disorders
- Topics to date:
 - Inhibitors
 - VWD
 - Fibrinogen disorders
 - Ankle pain
- Effort to support early-career investigators



COAGULATION FACTOR VARIANT DATABASES

Online, publicly available databases listing known genetic variants for:

- FVIII,
- FIX,
- FVII,
- VWF

Visit: dbs.eahad.org

The screenshot displays the EAHAD Factor VIII Gene (F8) Variant Database website. The header includes the EAHAD logo (European Association for Haemophilia and Allied Disorders) and the EAHAD-^{CF}DB logo (Coagulation Factor Variant Databases). The main title is "Factor VIII Gene (F8) Variant Database". A navigation bar contains links for Home, Advanced Search, Variants, AA Alignments, Resources, Structures, and Support.

The main content area is divided into several sections:

- F8 Gene Variants:** A red header bar. Below it, text states: "Haemophilia A is caused by variants in the gene that codes for coagulation factor VIII. There are currently 2634 unique variants in the F8 gene compiled within this database corresponding to 8601 individual cases."
- Citing us:** A red header bar. Below it, text asks for a reference to the website address (f8-db.eahad.org) and the parent organization (EAHAD-DB at dbs.eahad.org).
- What can you do in this database?:** A red header bar. Below it, text describes search capabilities for variants from 1986-2017 and 2019, and mentions the ability to submit new mutations/variants.
- F8 Variants at LOVD:** A red header bar. Below it, text states: "The basic F8 case data in this database are mirrored at LOVD: go here for [F8 at LOVD](#)."

On the right side, there are four search boxes:

- Simple Nucleotide Search:** Includes a "Nucleotide" dropdown menu and a "GO" button.
- Simple Amino Acid Search:** Includes "HGVS" and "Legacy" dropdown menus and "GO" buttons.
- Variant type Search:** Includes a "Type" dropdown menu and a "GO" button.
- Exon and Intron based search:** Includes "Exon" and "Intron" dropdown menus and "GO" buttons.

EAHAD & EHC

- Partner organisations representing healthcare professionals and patients, respectively
- Close collaboration, MoU
- Joint publications & positions statements
 - European Principles for Inhibitor Management
 - Statement on novel therapies & on Brexit
- Joint advocacy visit to Baltic countries in 2015
- Collaborators on EUHANET, EUHASS, and European Centre Certification



**EAHAD-EHC Joint Statement on:
Promoting central role of haemophilia comprehensive care centres
in the treatment of haemophilia and rare bleeding disorders using
novel non-replacement therapies**

ABOUT EUHANET



WHAT WAS EUHANET?

- Project funded by European Commission from 2012-2015
- Co-funding from pharmaceutical industry
- EAHAD, EHC + many other partners
- 4 projects in 1:
 - Haemophilia Central website
 - Including Haemophilia Centre Locator
 - Certification of European Haemophilia Centres
 - EUHASS
 - Rare Bleeding Disorders Database



EUHANET

Improving the care of European citizens with inherited bleeding disorders.

Download information leaflet [here](#)

Download lay version of final project report [here](#)



Haemophilia Central Website

The Haemophilia Central website has been set up to provide information about Haemophilia.

[Haemophilia Central website \(opens up in new window\)](#)



Certification of European Haemophilia Centres

Certification of European Haemophilia Centres.

[European Haemophilia Centres Map \(opens up in new window\)](#)



EUHASS Website

EUHASS is a pharmacovigilance program to monitor the safety of treatments for people with inherited bleeding disorders in Europe.

[EUHASS website \(opens up in new window\)](#)



Rare Bleeding Disorder Database

International registry of rare bleeding disorders.

[Rare Bleeding Disorder Database website \(opens up in new window\)](#)

HAEMOPHILIA CENTRAL



Haemophilia Central

Bringing together patients and health professionals
to provide a better service to everyone...

Home

News

Info

Guidelines

Trials

EUHASS

Travel

Products

Organisations

Genes

QC

FAQs

About

Links

Welcome

Haemophilia Central is a new service designed as a focal point for the haemophilia community, providing key information for patients and doctors alike. In the coming weeks and months we will be bringing you all the latest haemophilia news, a comprehensive 'Frequently Asked Questions' section for patients, a mobile phone 'Haemophilia Centre Locator' application and the Haemtrack telemedicine home treatment management system, allowing remote review of patients home treatment. If you would like further information on Haemtrack please click [here](#).

The site will also act as a central resource for: Information and professional opinion, Guidelines, Clinical trials, Treatments and Documentation

Haemophilia Central is being developed as part of the [EUHANET](#) project.

Want To Know More?



Ask a question about EUHANET



Haemophilia Centre Locator



Search for Haemophilia Centres
using the centre locator



European Council Recommendation



Watch the European Council
Recommendation on Haemophilia
video



www.haemophiliacentral.org

HAEMOPHILIA CENTRAL

News

Produced in collaboration with Dr. Uwe Schlenkrich ([HaemophiliaNews](#))

HERO Research Grant 2014 - a funding opportunity for projects concerned with the psychosocial challenges of living with haemophilia

Tue, 12 Aug 2014 09:18:05 GMT

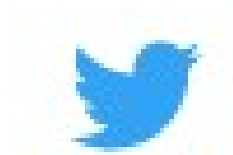
[HERO Research Grant 2014 - a funding opportunity for projects concerned with the psychosocial challenges of living with haemophilia](#)

Extended deadline for the call for posters for the EHC Annual Conference

Mon, 07 Jul 2014 12:13:54 GMT

[Extended deadline for the call for posters for the EHC Annual Conference](#)

< - Previous Next - >



EAHAD
@EAHADnews

EAHAD seeks to improve care for people with haemophilia and other bleeding disorders through research, education and multidisciplinary collaboration.

📍 Brussels, Belgium [eahad.org](#) 📅 Joined January 2017

341 Following 1,042 Followers



Following

Michael Makris

@ProfMakris Follows you

Professor of Haemostasis and Thrombosis at The University of Sheffield. EAHAD president. EUHASS lead. Opinions are my own.

📍 Sheffield, UK [euhonet.org](#) 📅 Joined October 2009

566 Following 2,878 Followers

👤 Followed by April Jones, David Lillicrap, and 159 others you follow

HAEMOPHILIA CENTRAL

The screenshot displays the Haemophilia Central website interface. At the top, a dark blue navigation bar contains the following menu items: Home, News, Info (highlighted), Guidelines, Trials, EUHASS, Travel, Products, Organisations, Genes, QC, FAQs, About, and Links. Below the navigation bar, the 'Info' section is active, featuring a heading 'Info' and a welcome message: 'Welcome to the information pages about inherited bleeding disorders. The information below is provided in association with the Rare Bleeding Disorders Resource Room (www.rarecoagulationdisorders.org) and the Mary M. Gooley Hemophilia Center (<http://www.hemocenter.org>)'. A prompt 'Click on the disorder below to get more specific information.' is followed by a list of links: Haemophilia, von Willebrand Disease (VWD), Fibrinogen deficiencies, Factor II deficiency, Factor V deficiency, Factor VII deficiency, Factor X deficiency, Factor XI deficiency, Combined factor V and VIII deficiency, Congenital vitamin K factor deficiency, Alpha-2 antiplasmin deficiency, Plasminogen deficiency, PAI-1 deficiency, and Congenital Platelet function defects. On the right side, there are three promotional boxes: 'Want To Know More?' with a question mark icon and the text 'Ask a question about EUHANET'; 'Haemophilia Centre Locator' with a target icon and the text 'Search for Haemophilia Centres using the centre locator'; and 'European Council Recommendation' with a YouTube icon and the text 'Watch the European Council Recommendation on Haemophilia video'. Each box includes a right-pointing arrow icon.

Home News **Info** Guidelines Trials EUHASS Travel Products Organisations Genes QC FAQs About Links

Info

Welcome to the information pages about inherited bleeding disorders. The information below is provided in association with the Rare Bleeding Disorders Resource Room (www.rarecoagulationdisorders.org) and the Mary M. Gooley Hemophilia Center (<http://www.hemocenter.org>)

Click on the disorder below to get more specific information.

- [Haemophilia](#)
- [von Willebrand Disease \(VWD\)](#)
- [Fibrinogen deficiencies](#)
- [Factor II deficiency](#)
- [Factor V deficiency](#)
- [Factor VII deficiency](#)
- [Factor X deficiency](#)
- [Factor XI deficiency](#)
- [Combined factor V and VIII deficiency](#)
- [Congenital vitamin K factor deficiency](#)
- [Alpha-2 antiplasmin deficiency](#)
- [Plasminogen deficiency](#)
- [PAI-1 deficiency](#)
- [Congenital Platelet function defects](#)

Want To Know More?
Ask a question about EUHANET

Haemophilia Centre Locator
Search for Haemophilia Centres using the centre locator

European Council Recommendation
Watch the European Council Recommendation on Haemophilia video

HAEMOPHILIA CENTRAL

Home News Info Guidelines **Trials** EUHASS Travel Products Organisations Genes QC FAQs About Links

Clinical Trials

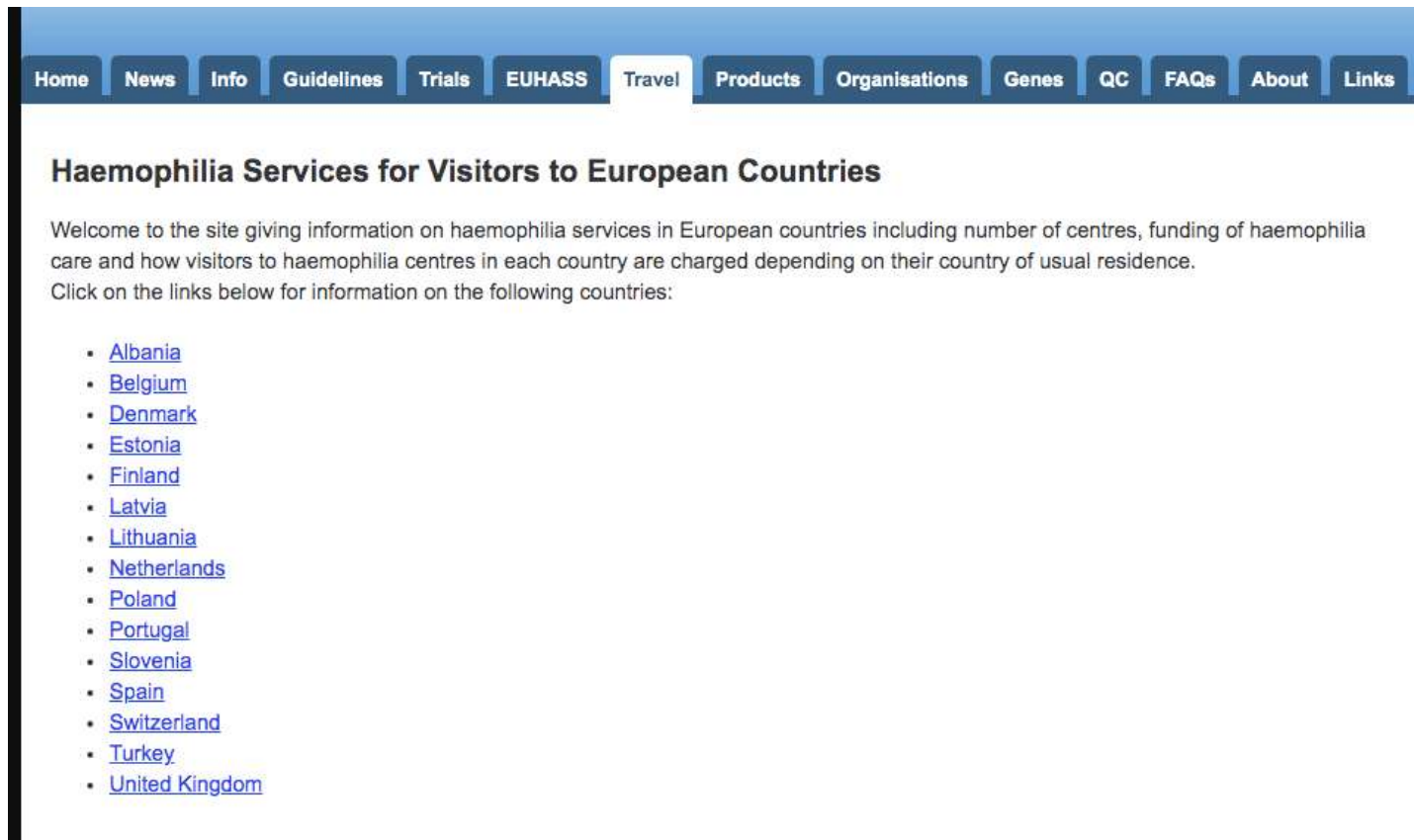
Below is a list of active clinical trials worldwide which involve patients with inherited bleeding disorders. The link from each study title will take you to ClinicalTrials.gov which gives you more information about the trial.

To see a list of trials for a particular bleeding disorder use the drop-down list below to select the condition you're interested in. A new window will open up with a list of trials for this condition only.

Please select the category:

<p>Inter Individual Variability in Initiation Pathway Activation and Regulation and Phenotypic Heterogeneity in Patients With Haemophilia A and B</p> <p>Condition: Haemophilia</p> <p>Interventions: Diagnostic Test: Thrombophilia screen; Diagnostic Test: Initiation pathway analysis</p> <p>Sponsor: Royal Free Hospital NHS Foundation Trust</p> <p>Recruiting</p>
<p>Performance Evaluation of Von Willebrand:Collagen-Binding Assays to Diagnose Von Willebrand Factor Deficiency in Patients With Increased Risk of Bleeding</p> <p>Condition: Von Willebrand Disease</p> <p>Intervention: Other: Non interventional study</p> <p>Sponsor: Nantes University Hospital</p> <p>Recruiting</p>
<p>UK - EHL Outcomes Registry</p> <p>Conditions: Hemophilia A; Hemophilia B</p> <p>Intervention:</p> <p>Sponsor: Royal Free Hospital NHS Foundation Trust</p> <p>Recruiting</p>

HAEMOPHILIA CENTRAL



The screenshot shows a website with a blue header containing a navigation menu with the following items: Home, News, Info, Guidelines, Trials, EUHASS, Travel, Products, Organisations, Genes, QC, FAQs, About, and Links. The 'Travel' item is highlighted. Below the menu, the page title is 'Haemophilia Services for Visitors to European Countries'. The main content area contains a welcome message and a list of countries with blue underlined links.

Haemophilia Services for Visitors to European Countries



Welcome to the site giving information on haemophilia services in European countries including number of centres, funding of haemophilia care and how visitors to haemophilia centres in each country are charged depending on their country of usual residence. Click on the links below for information on the following countries:

- [Albania](#)
- [Belgium](#)
- [Denmark](#)
- [Estonia](#)
- [Finland](#)
- [Latvia](#)
- [Lithuania](#)
- [Netherlands](#)
- [Poland](#)
- [Portugal](#)
- [Slovenia](#)
- [Spain](#)
- [Switzerland](#)
- [Turkey](#)
- [United Kingdom](#)

HAEMOPHILIA CENTRAL

[Home](#) [News](#) [Info](#) [Guidelines](#) [Trials](#) [EUHASS](#) [Travel](#) [Products](#) [Organisations](#) [Genes](#) [QC](#) [FAQs](#) [About](#) [Links](#)

European Database of Haemophilia Centres and Other Organisations



Use this database to search for details of haemophilia centres, patient organisations, doctor organisations, etc. in Europe.
Just click on the appropriate tab below, type your search criteria into the box and press the Search button

Please type in a search criteria
e.g. **Country, City** or **Centre Name**

Haemophilia Centres [Patient Organisations](#) [Doctor Organisations](#) [Nurse Organisations](#) [Physio Organisations](#)

Please click on desired centre to show details

Country	City	Centre Name	Director	Telephone
Albania	Tirana	Hospital and University Center of Tirana	Dr. Keti Pojani	+355 422 5417
Armenia	Yerevan	Center of Hematology	Dr. Smbat Daghbashyan	+374 10 283 800
Australia	Adelaide	Women's and Children's Hospital McGuiness-McDermot Foundation Children's Clinic	Dr Ram Suppiah	08 8161 7411
Australia	Adelaide	Royal Adelaide Hospital Oncology Day Centre		08 8222 0029 / 4396, Emergency 08 8222 4000
Australia	Brisbane	Royal Brisbane and Women's Hospital Queensland Haemophilia Centre	Dr John Rowell	07 3646 5727
Australia	Brisbane	Royal Children's Hospital (Children's Health Service), Queensland Haemophilia Centre	Dr Simon Brown	07 3636 9030 mobile: +61 438 792 063

HAEMOPHILIA CENTRAL

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Just click on the appropriate tab below, type your search criteria into the box and press the Search button

Please type in a search criteria
e.g. Country, City or Centre Name

DENMARK

Search

Haemophilia Centres

Patient Organisations

Doctor Organisations

Nurse Organisations

Physio Organisations

Please click on desired centre to show details

<u>Country</u>	<u>City</u>	<u>Centre Name</u>	<u>Director</u>	<u>Telephone</u>
Denmark	Aarhus	Centre for Haemophilia and Thrombosis, Aarhus University Hospital	Dr. Lone Hvitfeldt Poulsen	+45 7845 5182 (secretary), Nurse +45 7845 5199 (weekdays daytime)
Denmark	Aarhus	Western Denmark: Children, Børnehæmofilicenter Vest,	Dr. Niels Clausen	+45 8949 9031
Denmark	Copenhagen	Hemophilia Centre Copenhagen	Dr. Peter Kampmann (Administration), Dr. Marianne Hoffmann (Pediatrics), Dr. Eva Funding (Adults)	+45 354222 (secretary), +45 3545 9868 (nurse, adults), +45 3545 1070 (nurse, children)

HAEMOPHILIA CENTRAL

European Database of Haemophilia Centres and Other Organisations



Use this database to search for details of haemophilia centres, patient organisations, doctor organisations, etc. in Europe.

Just click on the appropriate tab below, type your search criteria into the box and press the Search button

Please type in a search criteria
e.g. Country, City or Centre Name

DENMARK

Search

Haemophilia Centres

Patient Organisations

Doctor Organisations

Nurse Organisations

Physio Organisations

Please click on desired patient organisation to show details

<u>Organisation Name</u>	<u>Country</u>	<u>Centre Telephone</u>	<u>Centre Email</u>
The Danish Haemophilia Society	Denmark	0045 3314 5505	dbf@bloderforeningen.dk

HAEMOPHILIA CENTRAL

Use this database to search for details of haemophilia centres, patient organisations, doctor organisations, etc. in Europe.

Just click on the appropriate tab below, type your search criteria into the box and press the Search button

Please type in a search criteria
e.g. **Country, City** or **Centre Name**

DENMARK

Search

Haemophilia Centres

Patient Organisations

Doctor Organisations

Nurse Organisations

Physio Organisations

Please click on desired nurse organisation to show details

No Nurse Centres found. Please try searching by country



EUHANET

Improving the care of European citizens with inherited bleeding disorders.

Download information leaflet [here](#)

Download lay version of final project report [here](#)



Haemophilia Central Website

The Haemophilia Central website has been set up to provide information about Haemophilia.

[Haemophilia Central website \(opens up in new window\)](#)



Certification of European Haemophilia Centres

Certification of European Haemophilia Centres.

[European Haemophilia Centres Map \(opens up in new window\)](#)



EUHASS Website

EUHASS is a pharmacovigilance program to monitor the safety of treatments for people with inherited bleeding disorders in Europe.

[EUHASS website \(opens up in new window\)](#)



Rare Bleeding Disorder Database

International registry of rare bleeding disorders.

[Rare Bleeding Disorder Database website \(opens up in new window\)](#)

RARE BLEEDING DISORDER DATABASE

- Prospective study on fibrinogen and FXIII deficiency
- Run from Milan

Visit:
eu.rbdd.org



[Home](#)

[Project](#)

- [Overview](#)
- [Steering Committee Fibrinogen](#)
- [Steering Committee FXIII](#)

[News](#)

[Join](#)

[Contact](#)

Prospective data collection on patients with Fibrinogen and Factor XIII deficiencies: design of the PRO-RBDD project

The cross-sectional project entitled "Establishment of an European Network of the Rare Bleeding Disorders (EN-RBD)" (www.rbdd.eu) funded in 2007 by the European Community was established to answer unmet questions on rare bleeding disorders (RBDs). The results of this project increased knowledge on frequency and distribution of each coagulation defect. The EN-RBD database enabled to explore the relationship between the laboratory phenotype and clinical severity of each deficiency, showing that only observed in fibrinogen, FX and FXIII deficiencies there is strong association between plasmatic factor levels and bleeding severity.

The main limitation of this retrospective study was the lack of detailed data on the diagnosis setting and the chronology between diagnosis and bleeding episodes. Therefore there is still a gap in knowledge of annual incidence of either disorders and the bleeding manifestations as well as on what is the minimum coagulant activity level able to prevent spontaneous and trauma/surgery/pregnancy related bleeding and provide an adequate hemostasis.



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Rare Bleeding Disorder Database
International registry of rare bleeding disorders.
[Rare Bleeding Disorder Database website \(opens up in new window\)](#)

EUHASS

EUROPEAN HAEMOPHILIA SAFETY SURVEILLANCE

- Pharmacovigilance program to monitor the safety of treatments for people with inherited bleeding disorders in Europe.
- Haemophilia treatment centres report adverse events directly to the EUHASS website and regular surveillance reports are produced.
 - 4 quarterly reports
 - 1 annual report

EUHASS

AIMS:

- Monitor safety of treatments for PWH and other inherited bleeding disorders in Europe.
- Inform clinicians, regulators and other interested parties of the treatment patterns and adverse events reported for these patients in Europe.
- Set up a publicly available directory containing information and publications lists for all the clotting factor products used in Europe to treat haemophilia and other inherited bleeding disorders.

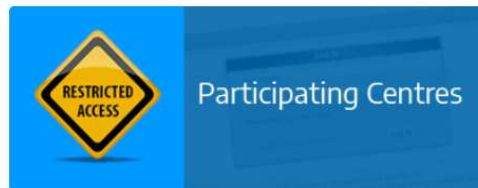
EUHASS

FUNDING:

- Not-for-profit
- Initially 60% EU funded
- Now 100% industry funded
- Funding cycle 2019-2021:
Continued funding from 10 companies: Takeda, Bayer, BPL, CSL
Behring, Kedrion, Novo Nordisk, Octapharma, Pfizer, Sobi and Roche

AGGREGATED DATA

Event Type	Reported
Allergic/Other Acute	200
Transfusion Transmitted Infections	0
Inhibitors - first occurrence	539
Inhibitors - recurrence	62
Thrombosis	284
Malignancy	705
Deaths	1285
Total Adverse Events (Since October 2008)	3075



PARTICIPATING CENTRES

Participating Haemophilia treatment centres report adverse events directly to the EUHASS web application. (Restricted Access)

[Event Reporting Login](#)



ABOUT EUHASS

EUHASS is a pharmacovigilance program to monitor the safety of treatments for people with inherited bleeding disorders in Europe. Haemophilia treatment centres report adverse events directly to the EUHASS website and regular surveillance reports are produced.

[More Information](#)

euass.org

EUHASS EVENT REPORTING

AGGREGATE DATA FROM 2008 TO 13 NOVEMBER 2019

		Events reported	
Centres participating	94	Allergic reactions	200
Countries participating	30	Transfusion transmitted infections	0
Patients	44,306	New inhibitors	601
		Thromboses	284
		Malignancies	705
		Deaths	1285
		TOTAL	3075

EUHASS PARTICIPANTS – NORDIC COUNTRIES

- **Denmark** – 2 centres: **Aarhus** and **Copenhagen**
 - Centre for Haemophilia and Thrombosis Aarhus University Hospital
 - Hemophilia Centre Copenhagen
- **Estonia** – no centre
- **Finland** – 1 centre: **Helsinki**
 - Coagulation Disorders Centre, Helsinki
- **Iceland** – no centre
- **Latvia** – 1 centre: **Riga**
 - Latvia National Centre of Haematology
- **Norway** – no centre
- **Sweden** – 3 centres: **Gothenburg**, **Malmö** and **Stockholm**
 - Coagulation Centre, Sahlgrenska University Hospital, Gothenburg
 - Koagulationscentrum Malmö
 - Coagulation Unit, Karolinska University Hospital, Stockholm

Info on how to join:

livia.boagiu@eahad.org

HC LOCATOR

Haemophilia Centre Locator

An EAHAD and EHC project



Enter your location:

Search

Welcome to the Haemophilia Centre Locator.

To find your nearest 5 European Haemophilia Centres, enter your location into the text box above and click search. Then click on the centre names to view more details about the centre.



HOW IT WORKS

- ① Visit: hlocator.org
- ① Type in your location: country, city or street address. The more precise the better!
- ① The 5 closest European Haemophilia Centres will appear (listed by proximity)

Welcome to the Haemophilia Centre Locator.

To find your nearest 5 European Haemophilia Centres, enter your location into the text box above and click search. Then click on the centre names to view more details about the centre.

EXAMPLE 1





Enter your location: **Toldbodgade 24-28, 1253 Køb** Search

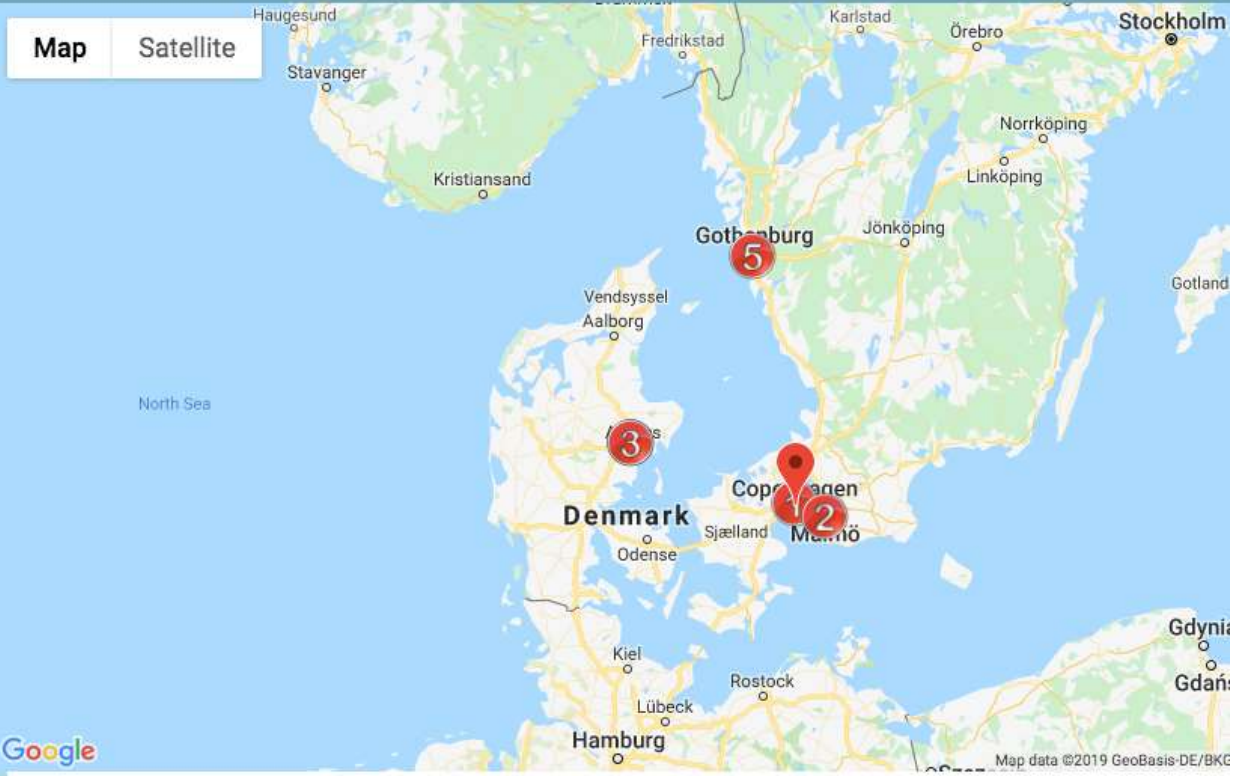
EHCCC (European Haemophilia Comprehensive Care Centre) [What Is This? \(Opens in New Window\)](#)
EHTC (European Haemophilia Treatment Centre) Children treated

Search Results

Click on a centre for more information

All information is accurate at the time of publication, but may become out of date over time.
Please email any changes to livia.boagiu@eahad.org

- 1 Hemophilia Centre Copenhagen
- 2 Koagulationscentrum Malmö  
- 3 Centre for Haemophilia and Thrombosis, Aarhus University Hospital
- 4 Western Denmark: Children, Børnehæmoflicenter Vest,
- 5 Coagulation Centre, Sahlgrenska University Hospital  



Map data ©2019 GeoBasis-DE/BKG

EXAMPLE 1

1 Hemophilia Centre Copenhagen

Address: Finsen Centeret, Afdeling 4222, Blegdamsvej 9
City: Copenhagen
Country: Denmark
Postal/Zip: DK-2100 København Ø
Code:
Telephone No.: +45 354222 (secretary), +45 3545 9868 (nurse, adults), +45 3545 1070 (nurse, children)
Fax No.: +45 3545 4772
Email Address:
Website: www.riget.dk
Centre Director: Dr. Peter Kampmann (Administration), Dr. Marianne Hoffmann (Pediatrics), Dr. Eva Funding (Adults)

During Normal Working Hours:
By telephone +45 354222 (secretary), +45 3545 9868 (nurse, adults) +45 3545 1070 (nurse, children)

Outside Normal Working Hours:
The patients can go to the emergency center or call +45 35451359 (Doctor on call, Hematology)

[Get Directions to this Centre](#)


The screenshot shows a navigation app interface. The starting point is Toldbodgade 24, 1253 København. The destination is Inge Lehmanns Vej 7, 2100 København. The app displays three route options:

- via Blegdamsvej: 8 min, 3.7 km. Best route now, avoids road closure on Inge Lehmanns Vej.
- via Øster Voldgade: 8 min, 3.8 km.
- via Sølvgade: 8 min, 3.1 km.

The map on the right shows the routes in blue and red lines, with the destination marked by a red pin. The map includes labels for various locations in Copenhagen, such as Zooologisk Museum, Telia Parken, Fælledparken, and Blegdammen.






EXAMPLE 1

Enter your location: **Toldbodgade 24-28, 1253 Køb** Search

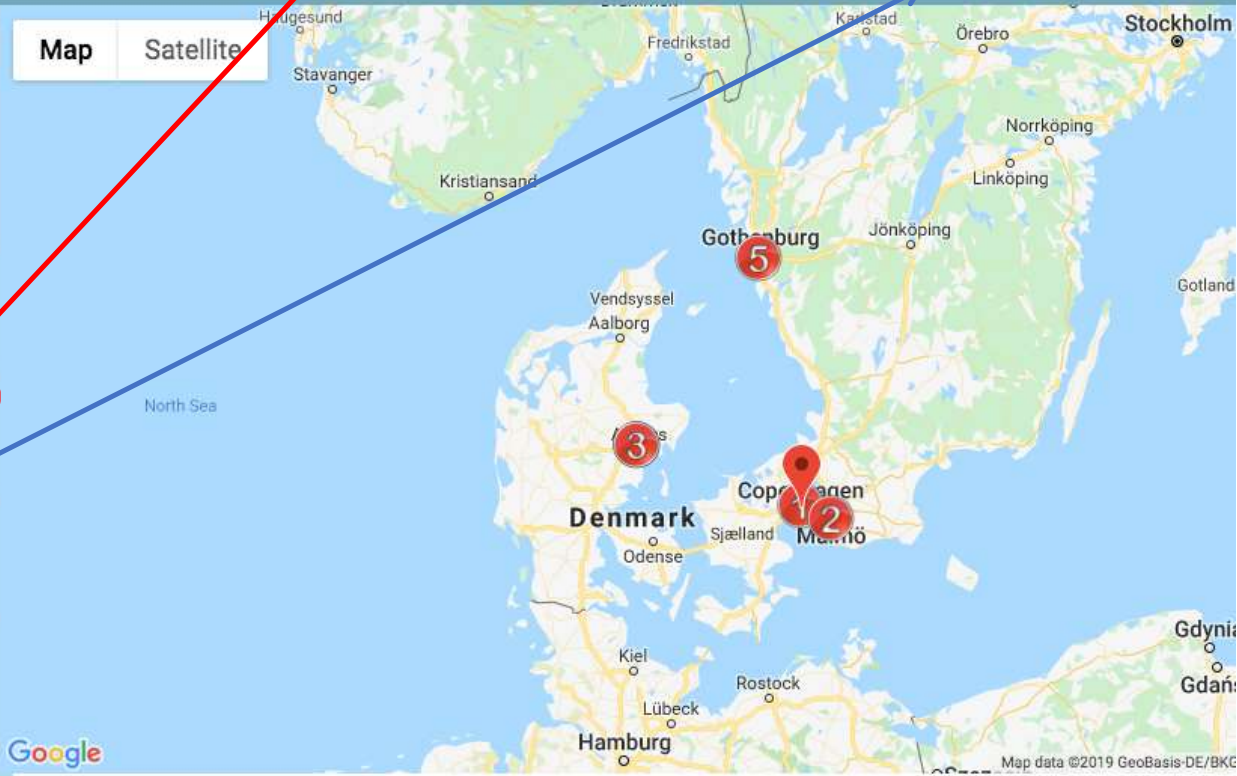
EHCCC (European Haemophilia Comprehensive Care Centre) [What Is This? \(Opens in New Window\)](#)
EHTC (European Haemophilia Treatment Centre)  Children treated

Search Results
Click on a centre for more information

All information is accurate at the time of publication, but may become out of date over time.
Please email any changes to livia.boagiu@eahad.org

- 1 Hemophilia Centre Copenhagen
- 2 Koagulationscentrum Malmö 
- 3 Centre for Haemophilia and Thrombosis, Aarhus University Hospital 
- 4 Western Denmark: Children, Børnehæmofili center Vest, 
- 5 Coagulation Centre, Sahlgrenska University Hospital 


Map Satellite



Google

Map data ©2019 GeoBasis-DE/BKG

EXAMPLE 2

Haemophilia Centre Locator

An EAHAD and EHC project



Enter your location:

- EHCCC (European Haemophilia Comprehensive Care Centre) [What Is This? \(Opens in new window\)](#)
 - EHTC (European Haemophilia Treatment Centre) - Children treated

Search Results
Click on a centre for more information

All information is accurate at the time of publication, but may become out of date over time.
Please email any changes to livia.boagiu@eahad.org

	Oulu University Hospital	
	Kuopio University Hospital, Paediatric Haematology and Haematology Units	
	Tampere University Hospital	
	Turku University Hospital	
	Coagulation Disorders Centre	

EXAMPLE 3

Enter your location:

- EHCCC (European Haemophilia Comprehensive Care Centre) [What Is This? \(Opens In New Window\)](#)
 - EHTC (European Haemophilia Treatment Centre) - Children treated

Search Results

Click on a centre for more information

All information is accurate at the time of publication, but may become out of date over time.
Please email any changes to livia.boagiu@eahad.org

- 1 Inverness Haemophilia Centre
- 2 NHS Grampian Haemophilia Centre
- 3 Dundee Haemophilia Centre
- 4 Yorkhill Haemophilia Centre
- 5 Haemophilia & Thrombosis Centre (Adults)

Google

Map data ©2019 Google

HC LOCATOR ON THE ROAD



Planning a holiday?


HC Locator includes centres across Europe (426), in Canada, Australia, and New Zealand (38).



HOMWORK ASSIGNMENT

- ① Visit HC Locator and look up your country/city
- ① Is the information there? Is it correct? Is it complete?
- ① If not, please send us an email at info@eahad.org
- ① We will then send you a form with the information we need

Haemophilia Centre Contact Details	
Information in bold will be published on the Haemophilia Centre Locator website www.hclocator.org	
Please send a scan copy of this form to livia.bogatu@eahad.org	
Name and email of person completing this application	
Haemophilia Centre name	
Children treated (YES/NO)	
Centre address	
City	
Country	
Postal/Zip code	
Centre telephone number	
Centre fax number	
Centre email address	
Centre website	
Centre Director name	
Centre Director telephone	
Centre Director fax number	
Centre Director email address	
Names of other Haemophilia Doctors at centre	
Names of Haemophilia Nurses at centre	
Names of Haemophilia Physiotherapists at centre	
How to obtain haemophilia care during normal working hours (Please give contact phone number, what hours and email days and normal working hours and location where should patients go to access emergency haemophilia care)	

 September 2018

How to obtain emergency/out of hours haemophilia care (if offered) (Please give phone number and location of centre where patients should go for emergency haemophilia care)	
---	--

 September 2018



EUHANET

Improving the care of European citizens with inherited bleeding disorders.

Download information leaflet [here](#)

Download lay version of final project report [here](#)



Haemophilia Central Website

The Haemophilia Central website has been set up to provide information about Haemophilia.

[Haemophilia Central website \(opens up in new window\)](#)



Certification of European Haemophilia Centres

Certification of European Haemophilia Centres.

[European Haemophilia Centres Map \(opens up in new window\)](#)



EUHASS Website

EUHASS is a pharmacovigilance program to monitor the safety of treatments for people with inherited bleeding disorders in Europe.

[EUHASS website \(opens up in new window\)](#)



Rare Bleeding Disorder Database

International registry of rare bleeding disorders.

[Rare Bleeding Disorder Database website \(opens up in new window\)](#)

HAEMOPHILIA CENTRE CERTIFICATION

BACKGROUND:

- Aimed at establishing a **network of haemophilia centres** to work together on a number of related projects to improve the care of European citizens with inherited bleeding disorders.
- Started in 2013 with the development of a standards document:
 - Collection of available documents from Member States
 - Review of literature
 - Consultation on key issues
 - Validation of criteria and principles for the production of the standards
 - Standards production and further consultation
 - Approval of the standards

HAEMOPHILIA CENTRE CERTIFICATION

WHAT IS A HAEMOPHILIA CENTRE?

- 409 “haemophilia centres” in Europe
- No acceptable definition
- Great variability
 - Severe haemophilia patients per centre: >350 vs <5
 - Laboratory: 24hr inhibitors vs no FVIII even during day
 - On call care: 24hr every day vs no emergency care
- Centres per country: 80+ vs 1
- Names: Haemophilia centre, Comprehensive care centre, Expert centre, Centre of Expertise, Reference centre

ESTABLISHING CERTIFICATION PROCESS

- Review of all available standards and national schemes
- Extensive consultation
- Agreement on EHCCC and EHTC
- Development of a standards document
- Development of pro-forma for submission



- Review of applications by panel of doctors, nurses and patients
- Decision on satisfaction of criteria
- Certificate issued



European guidelines for the certification of Haemophilia Centres

07 June 2013



Contents

Introduction	4
Background	4
Target patient group	4
Methodology	5
Delivery of haemophilia care	5
Standard requirements	7
1. General requirements	7
1.1 Facility.....	7
1.2 General policy and objectives.....	7
1.3 Information about the Centre.....	7
1.4 Organization and staffing.....	7
1.5 Policies and procedures.....	8
1.6 Record-keeping and data collection.....	8
1.7 Personnel appraisal and continuing education.....	9
1.8 Supply and management of therapeutic products, reagents and medical devices.....	10
1.9 Quality planning, evaluation and improvement.....	10
1.10 Participation in registries related to inherited and acquired bleeding disorders.....	11
1.11 Participation in clinical research.....	11
2. Patient care	11
2.1 Awareness, information and education of patients and their families.....	11
2.2 Diagnosis of haemophilia and other related bleeding disorders and all forms of acquired haemophilia.....	12
2.3 Therapy of haemophilia and other related bleeding disorders and all forms of acquired haemophilia.....	12
2.3.1 Treatment programme.....	12
2.3.2 Prophylaxis.....	12
2.3.3 Home treatment plan.....	13
2.3.4 Treatment of acute bleeds and prevention.....	13
2.3.5 Emergencies, treatment outside normal working hours.....	13
2.3.6 Elective surgery.....	13
2.3.7 Treatment of patients with inhibitors, including immune tolerance.....	14
2.3.8 Treatment of patients with chronic viral infections.....	14
2.3.9 Treatment of patients with acquired haemophilia and acquired vWD.....	14
2.4 Periodic clinical and multi-disciplinary review.....	14
2.5 Genetic services.....	15
2.6 Outcome indicators.....	16
3. Advisory service	16
4. Network of clinical and specialised services in conjunction with the haemophilia team	17
References	19
Authors and Contributors	19

CERTIFICATION GUIDELINES

- Available at www.euhanet.org.
 - Soon will be available on eahad.org under “Projects”
- Comprehensive
- Covers all areas of haemophilia care
- Defines what is expected from EHCCC and EHTC
- Key areas:
 - Number of patients
 - Range of expertise
 - 24/7 care
 - Laboratory support

HAEMOPHILIA CENTRE CERTIFICATION

Two categories of centre:

European Haemophilia Comprehensive Care Centre (EHCCC)

- 40+ severe patients*
- 24/7 haemophilia specialist care
- Specialist laboratory
- Specialist nurses, doctors and physiotherapists

European Haemophilia Treatment Centre (EHTC)

- 10-40 severe patients

* Patients should be seen at least once annually and normally followed up by that centre to be included in the count

24-HOUR CARE

- It is expected to be offered by EHCCC
- Haemophilia expert on call
- Definition of “expert” difficult
- Centres asked to list the individuals (medical team)
- The experts providing the 24/7 will be listed on the web.

APPLICATION PROCESS

- ① Centres can download the application form at www.euhanet.org. (Soon to be at www.eahad.org)
- ② The application must be filled in completely and signed. Certain sections (indicated on the form) are made available publicly.
- ③ Completed forms must be sent to certification@euhanet.org
- ④ Applications are then reviewed by a multidisciplinary review committee:
 - EUHANET representative
 - EAHAD representative
 - EHC/Patient representative
 - Nurse representative
- ⑤ The review committee will come back with an answer:
 - EHCCC designation – **Certificate issued**
 - EHTC designation – **Certificate issued**
 - Refusal



20 page document with many sections for comments

APPLICATION FORM
FOR EUROPEAN HAEMOPHILIA CENTRE CERTIFICATION

Please submit the completed form to certification@euhanet.org



APPLICATION FORM
FOR EUROPEAN HAEMOPHILIA CENTRE CERTIFICATION

The information in the coloured boxes will be made publicly available on a new website listing all the EHTC and EHCC certified centres



SECTION 1 – CONTACT DETAILS

1.1

Country	
City	

1.2

Centre name in English	
Centre name in own language	
Centre address	
Telephone	
Fax	
Email	
Centre website (if available)	

1.3

Hospital/Institute name	
Centre address	
Telephone	
Hospital/Institution website (if available)	

1.4 Centre Director

Title	
Name	
Address if different to Haemophilia centre address:	
Telephone	
Fax	
Email	

CURRENT SITUATION

- In **2019**, 2 centres were certified, bringing the total count of certified centres to **144** in **33** countries:
 - **36 EHTCs** - European Haemophilia Treatment Centres
 - **108 EHCCCs** - European Haemophilia Comprehensive Care Centres
- **1** centre is currently under review

LIVE MAP OF CERTIFIED CENTRES

Certification Count

EHCCC	108
EHTC	36
UNDER REVIEW	1

Applications By Country

United Kingdom	22
France	16
Germany	14
Italy	11
Switzerland	8
Portugal	7
Netherlands	6
Turkey	6
Czech Republic	6
Belgium	5
Finland	4
Ireland	4
Romania	3
Spain	3
Sweden	3
Greece	3
Hungary	2
Lithuania	2
Austria	2
Estonia	2
Bulgaria	2
Serbia	2
Slovakia	2
Slovenia	1
Norway	1
Poland	1
Ukraine	1
Croatia	1
Belarus	1
Bosnia and Hercegovina	1
Macedonia	1
Malta	1
Georgia	1



CERTIFIED CENTRES - NORDIC COUNTRIES

Applications By Country

United Kingdom	22
France	16
Germany	14
Italy	11
Switzerland	8
Portugal	7
Netherlands	6
Turkey	6
Czech Republic	6
Belgium	5
Finland	4
Ireland	4
Romania	3
Spain	3
Sweden	3
Greece	3

Hungary	2
Lithuania	2
Austria	2
Estonia	2
Bulgaria	2
Serbia	2
Slovakia	2
Slovenia	1
Norway	1
Poland	1
Ukraine	1
Croatia	1
Belarus	1
Bosnia and Hercegovina	1
Macedonia	1
Malta	1
Georgia	1

RE-CERTIFICATION

- Initial certificates were for 3 years – started to expire in 2017
- Annual extension until new system in place
 - Ask centres to check and re-confirm publicly available information before re-certification
- Will continue to be managed by EAHAD and the EHC
- Applications still accepted and reviewed

FUTURE PLANS

- Implement audit visits to certified centres
- Will begin with a pilot project to be launched in 2020 or 2021
- Centres that already have national audits in place will not be included in pilot

WHY CENTRE CERTIFICATION MATTERS

- Patient safety – novel therapies – need expertise and 24-hour laboratory – should be managed in a CCC
- Participation in surveys – sent out to certified centres – countries without these centres & their patients get left out
- Funding considerations / Recognition of European body may have impact

COMMENTS?

QUESTIONS?

SUGGESTIONS?

THANK YOU FOR LISTENING!