

# **Patient organisations at the heart of a European network**

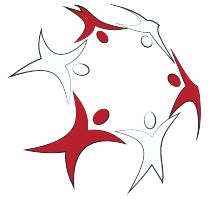
## **The haemophilia experience**

Amanda Bok

CEO

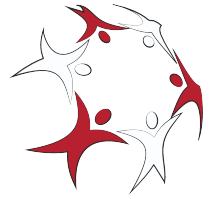
European Haemophilia Consortium

# Overview



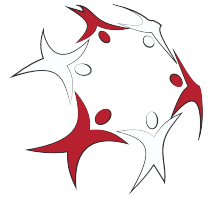
1. About EHC
2. Our network experience: EUHANET
3. Building legitimacy
4. Creating value & leveraging your expertise
5. Being an equal partner
  - And taking the lead if necessary

# About EHC



- Founded 25 years ago
- Haemophilia, von Willebrand Disease, other Rare Bleeding Disorders
- 45 national member organisations (NMOs)
- 27 EU MS + most Council of Europe MS
- 90,000 people in Europe
- Elected Steering Committee, appointed Medical Advisory Group, staff, volunteers

# European Haemophilia Network (EUHANET)



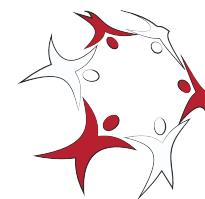
- Aim
  - To establish a network of haemophilia centres to work together on a number of related projects to improve the care of European citizens with inherited bleeding disorders
- Funding
  - European Commission (60%), industry (40%)
- Duration
  - June 2012-May 2015

# EUHANET



- Partners
  - University of Sheffield (project lead)
  - **EHC**
  - European Association for Haemophilia and Allied Disorders (**EAHAD**)
  - University Medical College Utrecht
  - Medical Data Solutions and Services, Ltd.
  - Fondazione IRCCS Ca'Grande Milan

# State of care (2012)

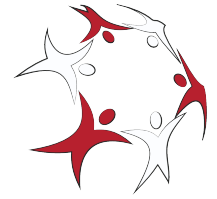


- Survey of haemophilia care in 35 European countries
  - 22 countries had no classification system for treatment centres
  - 17 countries had no recognised national treatment centre

**Haemophilia Care in Europe 2012**

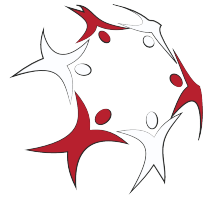
Country	Austria	Belgium	Denmark	France	Germany	Greece	Ireland	Italy	Latvia	Lithuania	Netherlands	Poland	Portugal	Romania	Slovakia	Spain	Sweden	Switzerland	Turkey	UK	Ukraine
Classification system for treatment centres	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Recognised national treatment centre	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Number of treatment centres	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia A patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia B patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia C patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia D patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia E patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia F patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia G patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia H patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia I patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia J patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia K patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia L patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia M patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia N patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia O patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia P patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia Q patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia R patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia S patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia T patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia U patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia V patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia W patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia X patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia Y patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Number of haemophilia Z patients	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1

# EHC's role in EUHANET



- Assessment and standardisation of the quality of care of haemophilia centres
  - Developed a system for the certification of the delivery of haemophilia care in Europe
    - European guidelines for the certification of Haemophilia Centres
  - Defined two levels of haemophilia care
    - European Haemophilia Comprehensive Care Centres
    - European Haemophilia Treatment Centres
  - Led 'Haemophilia Centre Locator' website (see slides)
  - Review applications (EHC has 1 vote on selection board)

# Benefits of certification

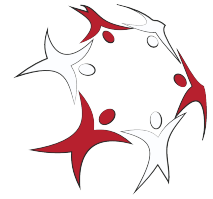


- Patients informed about services available
- Resources / expertise can be allocated based on centre type & number of patients treated
- Designation of primary (comprehensive) and secondary (treatment) centres allows for appropriate availability of specialist services
  - Example: orthopaedic surgery or genetics may only be available at comprehensive centres



# Current Centres

On 25-05-2015



## EUHANET Certified Centres



Last Updated: 21/05/2015

📍 - EHCCC (European Haemophilia Comprehensive Care Centre) - 📍 - EHTC (European Haemophilia Treatment Centre) - 🔴 - Under Review

### Certification Count

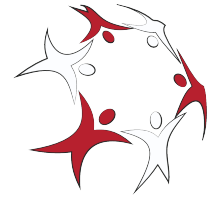
EHCCC	85
EHTC	20
UNDER REVIEW	1

### Applications By Country

United Kingdom	22
Germany	12
Italy	7
Portugal	7
Switzerland	7
France	6
Czech Republic	5
Belgium	5
Netherlands	3
Greece	3
Turkey	3
Sweden	3
Slovakia	2
Ireland	2
Spain	2
Romania	2
Bulgaria	2
Austria	2
Belarus	1
Finland	1
Georgia	1
Serbia	1
Norway	1
Poland	1



<http://www.euhanet.org/MappedCentres.aspx>



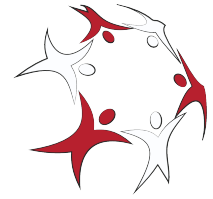
- Only website patients need to remember in order to find access to specialist care
- Next year: to contain worldwide centre information

Enter your location:

**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.

- 1 Centro de Hemostasia, Hospital Universitario La Paz
- 2 Hospital del Río Hortega
- 3 Hospital Universitario Salamanca
- 4 Complejo Asistencial de Palencia
- 5 Hospital General Yague



## European Haemophilia Safety Surveillance



Enter your location:

Madrid

Search

### 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.

#### 1 Centro de Hemostasia, Hospital Universitario La Paz

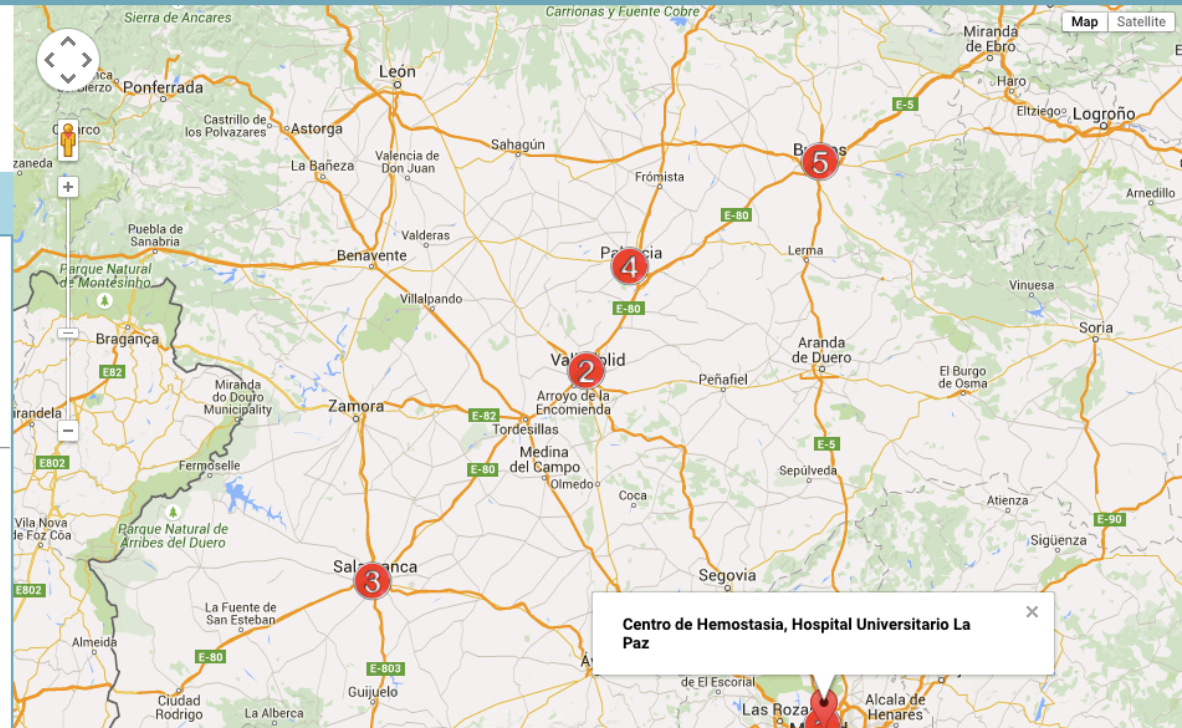
**Address:** Paseo de la Castellana 261  
**City:** Madrid  
**Country:** Spain  
**Postal/Zip:** 28046  
**Code:**  
**Telephone No.:** +34 912071945  
**Fax No.:** +34 913582211  
**Email Address:** talvarezman@gmail.com  
**Website:** www.madrid.org/hospitalapaz/

#### During Normal Working Hours:

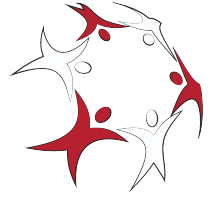
Normal working hours are considered from 8- 15h from Mondays to Fridays. Telephone number: +34 912071945. To access emergency haemophilia care patients should go to the Haemophilia Unit of Hospital Universitario La Paz. Address: Paseo de la Castellana 261. 28046 Madrid.

#### Outside Normal Working Hours:

Telephone number: +34 917 27 70 00. That's the hospital telephone number, where patients should ask to get contact to the haematology specialist. To access emergency haemophilia care patients should go to the emergency of Hospital Universitario La Paz to the

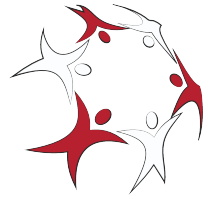


# Next steps

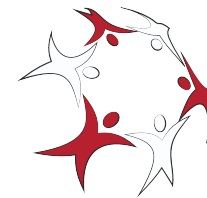


- EU Project now closed
- EHC and EAHAD to continue certification work
  - Joint work
  - Joint staff resource
- Upcoming objectives
  - Develop an accreditation system
  - Introduce peer-reviewed, external audits

# Peer-reviewed audits



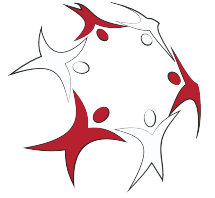
- Audits currently carried out in UK and Ireland
- Teams: haematologist, **patient**, nurse, geneticist
- Scope of patient representative's involvement:
  - Audit of physical facilities & services provided
  - Discussion on patient needs
  - Discussion on HR (policies, procedures) with individual staff
- Patient representative's contribution
  - Completes the picture: brings different experience / perspective to the team of auditors, increases the confidence of other patients in the audit process



# The future

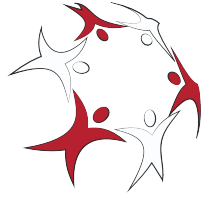
- Maybe: application to become an ERN
- But questions remain:
  - Haematology network
  - Sub-networks?
  - Reconciling EUHANET with ERNs
  - Funding?
  - Structures and sustainability

# Discussion points



1. Build your legitimacy
2. Create value & leverage your expertise
3. Be an equal partner
  - And take the lead if necessary

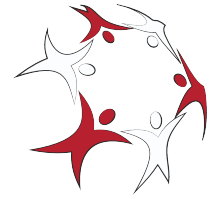
# 1 – Build legitimacy



- Who do you represent?
  - Democratic, accountable, transparent
  - 360° communication with patients, clinicians, sponsors and other stakeholders
- How do you represent them?
  - Elected & appointed
  - Steering Committee & Medical Advisory Group



# 2 – Create value (1/2)



- Bring patient expertise to bear...
- Contribute to the evidence base, ex:
  - Patient reported outcomes
  - “State of...” patient organisation surveys
    - Tenders & procurement systems
    - Haemophilia care

## Haemophilia

The Official Journal of the  
World Federation of Hemophilia,  
European Association for Haemophilia and  
Allied Disorders and the Hemostasis &  
Thrombosis Research Society

### Original Article

#### Survey of coagulation factor concentrates tender and procurement procedures in 38 European Countries

B. O'Mahony<sup>1,2,3,\*</sup>, D. Noone<sup>1,2</sup> and L. Prihodova<sup>2,4</sup>

Article first published online: 20 MAY 2015

DOI: 10.1111/hae.12720

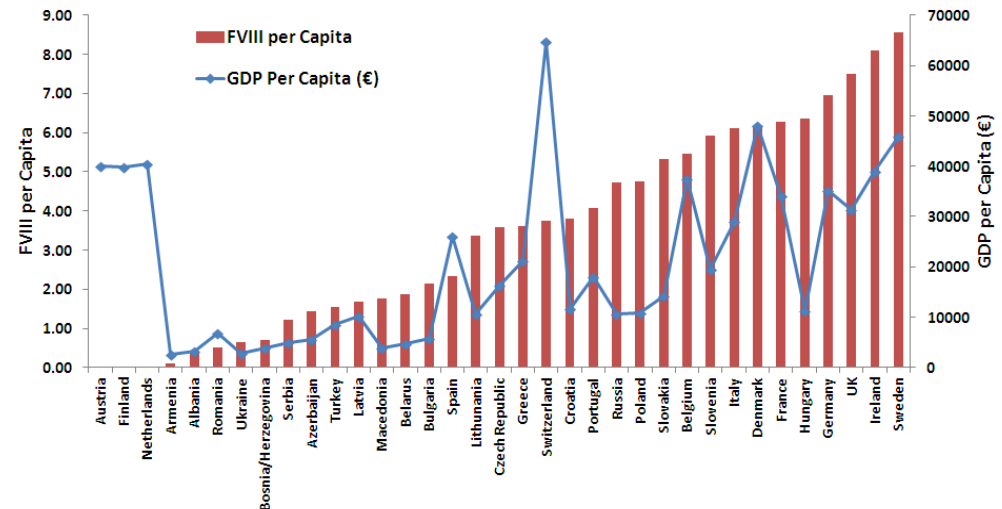
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### Issue

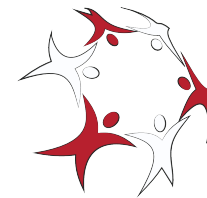


### Haemophilia

Early View (Online Version of  
Record published before  
inclusion in an issue)



## 2 - Create value (2/2)



- Contribute to the policy & regulatory environment, ex:
  - Recommendations, guidelines, etc.
  - Adverse event reporting, assessment of actual value, post marketing reporting, etc.

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

[17 April), the Council of Europe's Committee of Ministers representing  
poration of a European Pharmacopoeia [1] took the Wildbad Kreuth III  
the governments of those State Parties "take appropriate measures  
:

, a system should be established in each member State to allow the  
or the treatment and care of patients (for example by setting up an  
evant clinicians, national haemophilia bodies, patients' organisations,  
establishments and the regulatory authorities or by setting up centres of

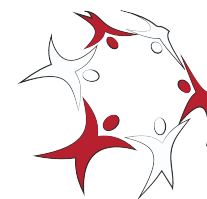
ilisation level should be at least 3 International Units (IU) per capita;  
e product should be based on evidence of safety and effectiveness and

reatment regimes should be strengthened. Prophylaxis is currently  
with severe haemophilia. Ongoing prophylaxis for adults should be  
n by the clinician in consultation with the patient;

uld be offered to haemophiliac children who have developed inhibitors  
as failed or was unsuitable;

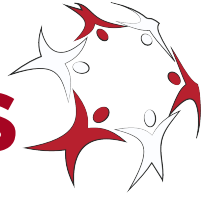
e used as therapy wherever possible in patients with rare bleeding

# 3 – Be an equal partner

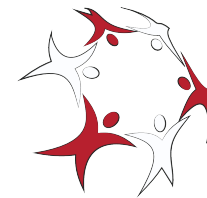


- Institutionalize
  - Agreements, Memoranda of Understanding, etc.
    - EHC-EAHAD
    - EHC-WFH
- Communicate
  - Meetings, Minutes, information exchange
- Align
  - Patients and clinicians speaking with one voice
  - Joint decision-making
    - National Haemophilia Councils / Committees
    - Joint formal involvement in tenders or procurement systems

# Opportunities & challenges



- ‘Professionalize’ your voice
  - Build credibility, expertise, added-value
  - Stay accountable to, representative of, members
- Invest in long-term collaboration
  - Build relationships of trust & partnership
  - Stay independent, never stop consulting members
- Build sustainability
  - Invest in patients, staff and other representatives
  - Have strong funding policies & a thick skin!



Thank you!

**ANY QUESTION?**