



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA



European Haemophilia Consortium

MEMORANDUM OF UNDERSTANDING

Between the WFH and the EHC

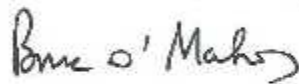
The World Federation of Hemophilia (WFH) represents the interests of National Member Organisations (NMOs) worldwide. The European Haemophilia Consortium (EHC) represents the interests of NMOs in Europe, which are the countries as defined by the World Health Organisation to belong in the European region. This Memorandum of Understanding (MOU) between the WFH and the EHC replaces in full the 2004 MOU and its subsequent 2010 and 2012 amendments.

1. The MOU specifies the modalities of cooperation between the WFH and the EHC to optimise the impact of our work to improve the welfare of people with haemophilia and other rare bleeding disorders in Europe.
2. The WFH recognises the EHC as a separate organisational entity of European NMOs while recognising that the EHC's NMOs are also NMOs of the WFH, and that the EHC's NMO membership rules follow the WFH's NMO membership rules.
3. The WFH represents the view of the global haemophilia community on regulations, guidelines and directives from all regions and regulatory authorities that have a global impact. The EHC represents the view of the European haemophilia community on regulations, guidelines and directives in Europe. The WFH and the EHC will communicate closely on the above.
4. The WFH and the EHC agree to carry out their respective activities as outlined in the annex and that these activities will not be duplicated.
5. The WFH and the EHC both collect annual data from their respective countries and agree to communicate closely with each other in this regard.
6. Best efforts will be undertaken to establish and maintain regular communication (i.e. 2-4 times annually) between peers of both organisations – e.g. Presidents, CEO, Medical lead and/or Data and Safety leads to align and avoid duplication of activities, as well as to liaise on regulatory and other policy-related affairs.
7. To facilitate and foster collaboration between the WFH and the EHC, both organisations agree to invite and support the mutual participation of the other as follows:
 - a. The President of the EHC, or his/her designee when so approved, will be invited annually to participate in a meeting of the WFH Board of Directors to report on EHC initiatives. Costs associated with participation will be paid by the WFH in accordance with the WFH travel policy.
 - b. The President of the WFH, or his/her designee when so approved, will be reimbursed for expenses for travel and hotel for one EHC Steering Committee meeting annually.

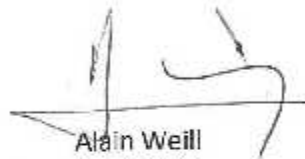
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- c. During the WFH World Congress and the EHC Annual Conference, the WFH and the EHC will offer each other complimentary registration for three delegates.
- d. The WFH and the EHC will facilitate for each other a 30-60 min meeting slot for European NMOs at, respectively, the WFH World Congress and the EHC Annual Conference.
- e. One or the other organisation may provide, from time to time, other meeting, travel and participation support as agreed by both organisations.

Signed on: Oct 6th, 2016



Brian O'Mahony
President
European Haemophilia Consortium



Alain Weill
President
World Federation of Hemophilia

Annex

**Memorandum of Understanding between the WFH and the EHC
2016**

Activities exclusive to the WFH

Development programme including:

1. Country development programmes
2. Twinning programmes
3. Fellowships
4. Product donations

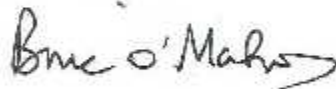
Activities exclusive to the EHC

1. Annual meetings of the EHC's NMOs
2. Fundraising to EU institutions and the Council of Europe
3. Advocacy and representation with EU institutions and the Council of Europe
4. European communication materials
5. European youth leadership development

Activities on which there is no exclusivity but cooperation is encouraged to avoid duplication.

1. NMO training activities
2. Data collection

Signed on: *Oct 6 2016*



Brian O'Mahony
President
European Haemophilia Consortium



Alain Weill
President
World Federation of Hemophilia