

MEMORANDUM OF UNDERSTANDING

Between the WFH and the EHC

The World Federation of Hemophilia (WFH) and the European Haemophilia Consortium (EHC) are separate organisations.

The WFH and the EHC, for historical reasons as well as for alignment purposes, share the same National Member Organisations (NMOs) in Europe.

The WFH represents the interests of NMOs worldwide. The 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 – or as defined by the WFH accreditation criteria.

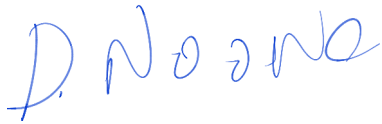
This Memorandum of Understanding (MOU) between the WFH and the EHC replaces in full all previous MOUs or amendments (i.e., 2004, 2010, 2012, 2016).

This 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.

1. The WFH and the EHC manage national patient organisation membership as follows:
2. The WFH manages all NMO accreditation. The WFH agrees to consult the EHC for new accreditation, evaluation, probation, and de-accreditation of European members. Both organizations will try to reach consensus however the final decision of WFH accreditation remains the WFH Board of Directors and ultimately the WFH General Assembly.
3. On matters such as regulations, guidelines, and directives, the WFH represents the view of the global bleeding disorder community; the EHC represents the view of the European bleeding disorder community. Accordingly, the WFH manages contacts with global organisations (e.g., UN, WHO...) and the EHC manages contacts with European institutions (e.g., EU, CoE).
4. On matters involving international collaboration with potential third parties (e.g., UNDP) on initiatives that have regional importance for Europe or for which European experience may benefit other regions, the WFH and EHC will share contacts, expertise and seek to build synergies wherever possible.
5. On matters affecting all patients, such as safety or access issues, the WFH and the EHC seek to coordinate and align as much as possible on position-taking such as public statements.
6. The WFH and the EHC agree to communicate closely on activities of similar scope (e.g., data collection, educational efforts, etc.) in order to ensure complementarity, and on activities of dissimilar scope (e.g., Twinings, product donations, etc.) in order to avoid duplication.

7. To facilitate and foster collaboration between the WFH and the EHC, both organisations agree to the following:
- a. The Presidents and CEOs of both organisations to have regular strategic and coordination calls (at least twice a year).
 - b. The staff of both organisations, on a peer-to-peer basis, to have regular information and coordination exchange on thematic topics (at least every quarter).
 - c. During the WFH World Congress and the EHC Annual Conference, the WFH and the EHC to offer each other complimentary registration for three delegates as well as facilitate for each other a 30-60 min meeting slot and room (at the expense of the beneficiary organisation) for European NMOs at each event.
 - d. During their respective strategic planning, the WFH and the EHC to invite 2 representatives of the opposite organisation to actively contribute in the process where relevant to that organisation, as well as relevant reviews of the respective strategic plans.

Signed on: 14 July 2021



Declan Noone
President
European Haemophilia Consortium



Cesar Garrido
President
World Federation of Hemophilia

Annex
Memorandum of Understanding between the WFH and the EHC
2021

To ensure effective collaboration, the WFH and EHC will maintain regular coordination activities:

Annually (in Q4) an alignment meeting will be organized with 3-4 participants from each organization to discuss and where possible agree on each other's work plans for the region for the year to come.

Quarterly operational calls will be organized between the staff of both organizations to give each other updates and update respective work plans as relevant.

Key activities:

1) Accreditation:

The EHC will be consulted by the WFH for any accreditation-related decision applicable to the region. The WFH will be receptive to and prioritize any accreditation-related issues that the EHC raises for the region.

New accreditation:

When deemed mutually necessary, accreditation visits will be performed by a representation of both the WFH and EHC. Both organizations will try to reach consensus, if not the WFH accreditation committee will be informed of the disagreement and a representative of the EHC will be invited to the accreditation committee to share the EHC's position.

Review:

The EHC will be informed of any country put under review and consulted on the action plan put in place by the WFH. The EHC can also formally ask that a country belonging to Europe be put under review. Both organizations will seek to reach a consensus on the issues and the way both organizations will manage the review.

New criteria:

The EHC will be consulted each time the WFH will change its criteria for membership.

2) Education:

An annual education and training plan will be discussed strategically and operationally every year at the management meetings between both organizations with a view to share resources and avoid duplication.

3) Advocacy:

Advocacy and representation with EU institutions and the Council of Europe will be driven by the EHC. Country advocacy support can be offered by both organizations but needs to be coordinated. Frequent consultations will take place to ensure best practices are shared.

4) Product donation:

Product donations remain the exclusive domain of the WFH – coordination with the actions undertaken by the EHC with international organizations (i.e., UNDP) and advocacy will be sought to maximize leverage.

5) Direct funding to NMOs and HCPs:

Each organization will be informed of the grants given to the NMOs and HCPs in the region.

6) Scientific statements:

Although it will not always be possible to align on scientific statements, parties will try their best to coordinate these.

7) Data collection:

The WFH and the EHC will be supportive of each other's data-related work, and feedback and exchange will be sought to make sure data collection performed by both organizations is complementary.

8) Fundraising in Europe

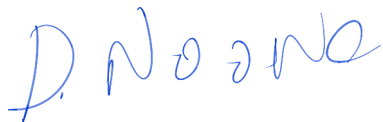
Fundraising to pan-European public institutions having a European geographic scope (e.g., EU, Council of Europe) remains exclusive to the EHC; fundraising to public institutions having a global geographic scope (e.g., UN, foundations) remains exclusive to the WFH; both parties are also willing to work together on fundraising proposals of mutual interest. Corporate and community fundraising is non-exclusive to both parties.

9) Other

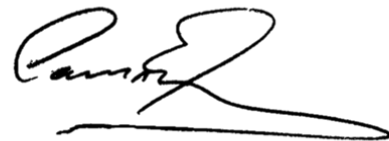
WFH programs that were established in the region prior to this MOU (e.g., Twinnings, Medical Fellowships) shall continue to be driven exclusively by the WFH. The EHC will be informed about the European NMOs and HTC's participating in these programs.

Both parties are encouraged to inform each other about any new areas of work arising after this MOU has taken effect, with a view to seek feedback and potential synergies.

Signed on: 14 July 2021



Declan Noone
President
European Haemophilia Consortium



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