

WFH By-Laws

Constitution

Article 1. Definitions

In this by-law and all other by-laws of the WFH, unless the context otherwise requires:

“**ACT**” means the Canada Not-For-Profit Corporation Act S.C. 2009, c.23 including the Regulations made pursuant to the Act, and any statute or regulations that may be substituted, as amended from time to time;

“**Assessment**” means annual subscription amount that NMOs must pay to maintain its membership;

“**by-law**” means this by-law, including the constitution, rules of procedure, and any other by-law of the WFH as amended and which are, from time to time, in force and effect;

“**board**” means the Board of Directors of the WFH;

“**Director**” means a member of the board;

“**General Assembly**” means the body of National Member Organizations;

“**Headquarters**” means the head office of the World Federation of Hemophilia;

“**Meeting of the General Assembly**” includes a regular meeting of members or a special meeting of the members;

“**National Member Organization**” (NMO) means a national organization representing people with hemophilia and other inherited bleeding disorders that have met the accreditation criteria and have been voted in by the General Assembly;

“**Ordinary resolution**” means a resolution passed by a majority of not less than 50% plus 1 of the votes cast on that resolution;

“**Special resolution**” means a resolution passed by a majority of not less than two-thirds (2/3) of the votes cast on that resolution;

“**WFH**” means the World Federation of Hemophilia, a corporation incorporated under the Canada Not-For-Profit Corporations Act S.C. 2009, c.23

Article 2. Status and Mission

The WFH is a benevolent and charitable organization.

The mission of the WFH, which acts in accordance with its member organizations and through them, is to advance and stimulate services for people with hemophilia and other inherited bleeding disorders world-wide, thus enabling them to participate fully in the activities of their communities. It will:

- 2.1 Encourage and foster the highest possible levels of diagnosis, comprehensive care and support for people with hemophilia and other inherited bleeding disorders, for all countries throughout the world;
- 2.2 Help, initiate and assist programs to address the local factors which restrict access to areas of comprehensive care for people with hemophilia and other inherited bleeding disorders and their families in the developing world;
- 2.3 Encourage the education and training of direct care givers as well as people with hemophilia and other inherited bleeding disorders, their families, concerned organizations and the general public, using the most appropriate means;
- 2.4 Promote research and development of the technology base for this support;
- 2.5 Encourage the formation and development of national and regional organizations throughout the world and assist and stimulate such organizations through the exchange of information.

The WFH acts, where appropriate, with other organizations at global, regional, and national levels.

Article 3. Objectives

In particular, the WFH shall serve to:

- 3.1 Act as a medium for deliberation, for exchange of ideas, knowledge, skills, and experience, and for compiling and disseminating information;
- 3.2 Organize international and regional congresses, conferences, seminars, and courses of instruction;
- 3.3 Encourage, by all means at its disposal, research in the genetics of hereditary disorders of blood coagulation as well as measures suitable for their prevention and cure;
- 3.4 Encourage the formation and development of national and regional organizations throughout the world, and assist and stimulate such organizations through the exchange of skills and knowledge;

- 3.5 Assist National Member Organization (NMOs) in establishing and developing programs which will further the attainment of its objective, in co-operation with government agencies and other private and public bodies;
- 3.6 Co-operate with other international organizations, both governmental and non-governmental, in advancing the welfare of people with hemophilia and other inherited bleeding disorders;
- 3.7 Establish and maintain such administrative services as may be required to carry out its objectives;
- 3.8 Receive, hold, administer and use according to the budget any funds received by contributions, bequests or endowments, or the proceeds thereof;
- 3.9 Contract, acquire and dispose of moveable and immovable property, to institute legal proceedings;
- 3.10 Co-operate with any person or body with the ability to help further the objectives of the WFH, provided this co-operation is consistent with the benevolent character of the WFH;
- 3.11 Generally take all necessary action to carry out the mission and reach the objectives of the WFH.

Article 4. Membership

Membership of the WFH shall consist of one NMO in each country. The NMO shall be the voting member at the meeting of the General Assembly. The NMO shall represent the best interests of people with hemophilia and other inherited bleeding disorders, and their families in that country. Accreditation as an NMO shall be decided by the General Assembly of the WFH based on the criteria set out in the Rules of Procedure.

In addition to NMOs, WFH recognizes as non-voting members, Associate NMOs and Affiliated Members, who subscribe to the mission of WFH and pay annual subscriptions. Membership is as follows:

4.1 Voting Members

4.1.1 National Member Organizations

These members shall have the right to vote at the meeting of the General Assembly.

4.2 Non-voting Members

The level of dues and privileges attached to such membership shall be determined by the Board of Directors. These members shall not have the right to vote at the meeting of the General Assembly.

4.2.1 Associate National Member Organizations

This category is reserved to national hemophilia associations which are not yet eligible for NMO status or that otherwise do not currently fulfill the criteria for an NMO.

4.2.2 Affiliated Members

This category is for individuals, organizations, and corporations who subscribe to the mission of WFH and pay annual subscriptions.

Affiliated Members shall not have the right to receive notice of meetings of the General Assembly or to vote at such meetings.

Article 5. Organization

The bodies of the WFH shall be:

5.1 The General Assembly.

5.2 The Board of Directors.

Article 6 The General Assembly

6.1 The General Assembly is the supreme body of the WFH.

6.2 The General Assembly shall be composed of one voting delegate from each NMO.

6.3 The General Assembly shall meet in regular session on the occasion of a World Congress.

6.4 Special meetings may be convened by the Board of Directors at its discretion or by Members according the rules prescribed in the “Act”.

6.5 The Board of Directors shall also call annual meetings of the General Assembly in accordance with the Act. Each such meeting shall be called not later than 15 months after the last preceding annual meeting but not later than six months after the end of the WFH’s financial year. It may be held at the occasion of the World Congress if such congress falls within the above deadlines.

6.6 The General Assembly in accordance with the mission and objectives of the WFH, shall exercise all functions arising from the responsibilities allocated to members by the law.

6.7 Voting

6.7.1 Each NMO which is up to date with the payment of its annual assessment shall have one vote in the meeting of the General

- Assembly which may be cast only by a delegate duly appointed under a written and non-transferable proxy deposited with WFH;
- 6.7.2 The quorum for the meeting of the General Assembly shall be one-third of the current NMO membership;
- 6.7.3 If the necessary quorum is not attained at the opening of the meeting of the General Assembly, the NMOs present may adjourn the meeting to a fixed time and place but may not transact any other business;
- 6.7.4 At the meeting of the General Assembly, all questions shall be decided by the simple majority of valid votes from accredited voting NMO delegates present unless otherwise provided by law;
- 6.7.5 Amendments of the Constitution shall be adopted according to the procedure set down in the Constitution itself.

Article 7. The Board of Directors

7.1 The Board of Directors, elected by the General Assembly, shall be the executive body of the WFH, responsible to the General Assembly of the WFH. It shall consist of not more than fourteen (14) voting members, namely;

- 7.1.1 The President of WFH who shall be elected for four (4) years and shall be the legal representative of the WFH, The President shall be a person with hemophilia or other inherited bleeding disorders, or the parent of such a person.
- 7.1.2 The Vice-President Medical.
- 7.1.3 The Vice-President Finance.
- 7.1.4 Eight (8) other members.
- 7.1.5 The Board of Directors shall have the power to co-opt up to three (3) additional members who shall hold office for a term expiring not later than the close of the next meeting of the General Assembly.

7.2 Further Vice Presidents shall be appointed from within and by the Board of Directors from amongst its members. Their specific roles will be agreed by the Board of Directors in accordance with the strategic objectives of the WFH.

7.3 The Board of Directors shall be chaired by the President.

7.4 The Board of Directors shall be responsible for all affairs between meetings of members and shall in particular be responsible for the execution of the decisions taken

by the General Assembly and hold such powers as are delegated to it by the General Assembly or this Constitution.

7.5 The Board of Directors may also establish Regional Offices.

Article 8 Amendments to this Constitution

8.1 The General Assembly shall decide on the amendment of this Constitution.

8.1.1 The text of any proposed amendment shall be sent by the Headquarters to all NMOs between twenty-one (21) and sixty (60) days prior to the meeting of members at which it is to be considered;

8.1.2 Any NMO may move an amendment to the constitution. Any such amendment proposal must be sent by the NMO to the Headquarters within ninety (90) to one hundred and fifty (150) days before the next meeting of the General Assembly in order for such amendment proposal to be the considered.

8.2 An amendment shall be adopted if:

8.2.1 Two-thirds of the sum of votes cast by the NMOs present and voting at the meeting of the General Assembly and proxy votes endorsed by the President and Secretary of the NMO addressed to the Chairperson of the meeting of the General Assembly are in favour of the amendment; or

8.2.2 One hundred percent of the NMOs indicate their assent by postal vote within sixty (60) days of notice being given of the text of the amendment, if the Board of Directors decide that this method of voting be adopted between meetings of the General Assembly.

Article 9 The Dissolution of the WFH

9.1 The General Assembly shall decide on the dissolution of the WFH.

9.2 The liquidation shall be controlled by the Board of Directors or by any person or persons designated by the Board of Directors.

9.3 In the event of dissolution, or winding up of the WFH, all its remaining assets after payment of its liabilities shall be distributed to one or more organizations that are qualified donees pursuant to the Income Tax Act (Canada) carrying on similar activities.

Article 10 Governing Authority

Unless otherwise required by the Act, the Constitution and the Rules of Procedure presented in the following section shall be the governing documents of the WFH.

Article 11 The Rules of Procedure

The business of the WFH shall be conducted according to the Rules of Procedure of the WFH which are described in the following section.

Rules of Procedure

Article 12 Conditions for Membership and Responsibilities of a National Member Organization

12.1 A National Member organization (NMO) must agree, if its application for membership is accepted, to pay to the WFH such annual assessments as are determined by the Board of Directors of the WFH and, according to the Constitution, conform with all other provisions of the Constitution which are applicable to it.

12.2 It must supply with its application such evidences as the WFH may require substantiating the status of the applicant and its entitlement to be elected as a National Member Organization in accordance with the NMO accreditation criteria. Membership dues and privileges shall be determined by the Board of Directors.

12.3 It shall inform the Headquarters of the WFH the name and address of the President or Chairperson of the NMO who shall be considered responsible for maintaining contacts with WFH, unless the NMO informs the Headquarters of WFH that this task has been entrusted to another duly designated person.

Article 13 Membership

13.1 WFH recognizes as members: the NMOs; the associate NMOs (in accordance with the attached criteria) and as Affiliated Members the following: individuals, organizations, corporations, who subscribe to the mission of WFH and pay annual subscriptions.

13.2 The level of dues and privileges attached to such membership shall be determined from time to time by the Board of Directors.

13.3 Membership is as follows:

13.3.1 VOTING MEMBERSHIPS

13.3.1.1 National Member Organizations

13.3.1.2 These members shall have the right to vote at the General Assembly.

13.3.2 NON-VOTING MEMBERSHIPS

13.3.2.1 Associate NMO

This category is reserved to national hemophilia associations which do not currently fulfill the criteria for NMOs

13.3.2.2 Affiliated Members

This category is for individuals, organizations, and corporations who subscribe to the mission of WFH and pay annual subscriptions.

13.3.2.3 Associate NMO and Affiliated Members shall not have the right to vote at the meeting of the General Assembly.

Article 14. Honorary Life Members

14.1 Any person, who by reason of outstanding service rendered to the cause of hemophilia, may be elected to Honorary Life Membership by the General Assembly following recommendation by the Board of Directors.

14.2 An Honorary Life Member shall not have the right to vote at the meeting of the General Assembly.

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Article 15. Termination of Membership of National Member Organizations and Associate NMOs

Subject to confirmation by the General Assembly, membership of an NMO or of an Associate NMO of WFH shall cease:

15.1 By resignation addressed to the Headquarters of WFH in which case it shall take immediate effect.

15.2 By dissolution of the organization, in which case it shall take immediate effect.

15.3 If an NMO or Associate NMO no longer fulfills the criteria for WFH membership (see Appendix 1).

Article 16. Termination of Memberships of Affiliated Members

Memberships shall cease:

16.1 By resignation addressed to the Headquarters of the WFH, with immediate effect.

16.2 By dissolution of the affiliated organization.

Article 17 General Assembly

17.1 If the Board of Directors or members call a meeting of the General Assembly, those directors, or members, as the case may be, may determine that the meeting shall be held entirely by means of telephonic, and electronic or other communication facility that permits all participants to communicate adequately with each other during the meeting.

17.2 Prior to each meeting of the General Assembly, each NMO must advise the Headquarters of the name of its voting delegate and alternate delegate as per the procedures specified by the Board of Directors.

17.3 Only the named delegate or in his/her absence the alternate delegate may vote and speak on behalf of their NMO.

17.4 The Board of Directors shall select a Chairperson for each meeting of the General Assembly.

17.5 Other individuals may address the General Assembly at the invitation of the Chairperson.

17.6 The place and date of any meeting of the General Assembly, as well as the proposed Agenda, shall be notified to NMOs during a period of twenty-one (21) to sixty (60) days before the day on which the meeting is to be held.

17.7 Notice of any meeting of the General Assembly specifying the place, day and hour of the meeting shall be given in accordance with the Act.

17.8 Notice of any meeting of the General Assembly where special business is to be transacted shall (a) state the nature of that business in sufficient detail to permit a member to form a reasoned judgment on the business; and (b) state the text of any special resolution to be submitted to the meeting.

17.9 Member Proposals

17.9.1 A NMO may (a) submit to WFH notice of any matter that the NMO proposes to raise at the regular or special meeting of the General Assembly, referred to in this section as a “proposal”; and (b) discuss at the meeting any matter with respect to which the NMO would have been entitled to submit a proposal.

17.9.2 Subject to section 17.9.4 hereof, WFH will include the proposal in the notice of meeting of the General Assembly.

17.9.3 If so, requested by the NMO who submits a proposal, WFH shall include in the notice of meeting a statement in support of the proposal by the NMO and the name and address of the NMO. The statement and the proposal shall together not exceed 500 words.

- 17.9.4 WFH may decide not to include the proposal and/or statement in support of the proposal in the notice of meeting in the cases provided for under the Act.
- 17.9.5 If WFH refuses to include a proposal in a notice of meeting, it shall within 21 days after the day on which it receives the proposal, notify in writing the member submitting the proposal of its intention to omit it from the notice of meeting and of the reasons for the refusal.
- 17.10 The General Assembly shall:
 - 17.10.1 At each meeting at which an election of the Board of Directors is required, elect the member of the Board of Directors;
 - 17.10.2 Decide on membership and termination of membership of NMOs;
 - 17.10.3 Decide of recommendations by the Board of Directors for the admission of Honorary Life Members;
 - 17.10.4 Approve the audited annual accounts in accordance with the Act;
 - 17.10.5 Appoint the public accountant;
 - 17.10.6 Deal with any other matter with the agreement of the Chairperson.
- 17.11 Voting
 - 17.11.1 NMOs which have not paid their annual assessments by the required date shall not be entitled to vote.
 - 17.11.2 Voting at any meeting of the General Assembly may be by show of hands, or by ballot, which may be secret as may be determined at any meeting. During the interim between meetings of the General Assembly, questions may be resolved by postal, electronic, or facsimile ballot.

17.2 In lieu of a meeting of members, a resolution in writing may be signed by all the members entitled to vote on that resolution at a meeting of the General Assembly. Such written resolution shall be as valid as if it had been passed at a meeting of the General Assembly. A copy of every such resolution shall be kept with the minutes of the meetings of the General Assembly.

Article 18. The Board of Directors of the WFH

18.1 General

As stated in the Constitution, the Board of Directors shall consist of:

- 18.1.1 President.
- 18.1.2 Vice President Medical.

18.1.3 Vice President Finance who shall act as WFH Treasurer.

18.1.4 Eight (8) other members

18.1.5 Up to three (3) co-opted members.

18.2 Further Vice Presidents shall be appointed from within and by the Board of Directors from amongst its members. Their specific roles will be agreed by the Board of Directors in accordance with the strategic objectives of the WFH. There must, however, be at least two (2) members of the Board of Directors who are not officers or employees of WFH.

18.3 The nomination and election procedure for the Board of Directors shall take place as follows:

18.3.1 The WFH nominations and election process will be conducted by the WFH Headquarters under the supervision of the Chairperson of the General Assembly.

18.3.2 Only NMOs who have paid their assessments at the last WFH World Congress and who meet the WFH membership criteria may nominate people to stand for election to the Board of Directors.

18.3.3 No person shall serve for more than two (2) consecutive terms of four (4) years as member of the Board of Directors, except that

- (a) Where such person has served as a co-opted member prior to his/her election on the Board of Directors, such limit shall be extended to a maximum of ten (10) years,
- (b) if such person is elected as officer of the WFH as Medical VP, Financial VP or President, such limit shall be extended by the term of such officer's position in the same capacity, but only for up to two (2) additional terms of four (4) years,
- (c) No person shall serve for more than eighteen (18) years as member of the Board of Directors,
- (d) Such limit shall not be applied retroactively and will begin to be counted for all mandates initiated after its approval, that is, as of June 18, 2021, without taking into consideration for this purpose the mandates prior to this date

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18.4 Nomination Process

18.4.1 Eligibility for nomination by NMOs for members of the Board of Directors:

18.4.1.1 Medical doctors.

18.4.1.2 Lay membership may be granted;

1) to a person with hemophilia or other inherited bleeding disorder;

2) to a parent of such person;

3) to a married, civil union, or de facto spouse of such person. De facto spouses are persons who have lived in a conjugal union relationship for at least three years or for one year if a child was born or adopted by such persons.

18.4.1.3 Others with specific expertise may be appointed to the Board of Directors as co-opted members.

18.4.2 One hundred and fifty (150) days prior to the meeting of the General Assembly a call shall be made to all eligible NMOs to submit nominations as follows:

18.4.2.1 Regional Lay Nominees

Each NMO may nominate two (2) people:

- i. One (1) from their own country or from within their own region.
- ii. One (1) from their own region or from anywhere else in the world.

18.4.2.2 Regional Medical Nominees

Each NMO may nominate two (2) doctors:

- i. One (1) from their own country or from within their own region.
- ii. One (1) from their own region or from anywhere else in the world.

18.4.2.3 Nomination of Officers (takes place every four (4) years

Each NMO may submit one (1) nomination for each of the following positions:

- i. WFH President
- ii. Vice President Medical
- iii. Vice President Finance

18.4.2.4 To be eligible to appear on the final election slate at the meeting of the General Assembly, a candidate must receive at least the following number of nominations:

- i. WFH President – five (5) nominations

- ii. Vice President Medical – three (3) nominations
- iii. Vice President Finance – three (3) nominations

18.4.2.5 Nomination forms for all nominees must be signed by the Presidents of the nominating NMOs.

18.4.2.6 In the event that no candidate receives the required number of nominations, the Board of Directors will appoint someone- either from within their number or by co-option, pro tem until the next meeting of the General Assembly

18.5 Election Process

The process for selecting the candidates who will appear on the final election slate at the meeting of the General Assembly is as follows:

Ninety (90) days prior to the meeting of the General Assembly the nominations will close, and the Headquarters will:

18.5.1 Prior to the election every two (2) years:

18.5.1.1 Select one lay and one medical candidate from each region with the highest number of nominations to be put forward as the regional lay and medical nominees for the Board of Directors election at the meeting of the General Assembly.

18.5.1.2 In alternate elections, collate and check the nominations received for the position of President or Vice Presidents Medical and Finance.

18.5.1.3 Request CVs of the nominees being put forward for election and their signed consent to appear on the slate.

18.5.2 In the event of a tie when deciding upon the names of nominated lay or medical nominees to appear on the final election slate from each region, the following procedures shall apply:

18.5.2.1 The person who has the largest number of nominations from NMOs outside their own region shall be selected. If the tie remains:

18.5.2.2 Nominations which may have been received for the person for an officer position shall count, if those nominations are from NMOs other than those who made the nominations for the person as lay or medical representative. If the tie remains:

18.5.2.3 Selection by lot shall be made by persons nominated by the General Assembly Chair as scrutineers.

18.5.3 Sixty (60) days prior to the meeting of the General Assembly when an election takes place, the WFH Headquarters will circulate to all NMOs for their consideration the final list of candidates together with CVs for:

- 18.5.3.1 President, if applicable
- 18.5.3.2 Vice President Medical, if applicable
- 18.5.3.3 Vice president Finance, if applicable
- 18.5.3.4 Two (2) other lay positions
- 18.5.3.5 Two (2) other medical positions

18.6 Election Process – General Assembly

At the meeting of the General Assembly all NMOs in good standing will vote on the final election slate.

18.6.1 For Officer Positions. The successful candidate must receive more than fifty per cent (50%) of the votes cast. If there are more than two (2) candidates for President, Vice President Medical or Vice President Finance and if no candidate achieves this on the first ballot, the candidate with the least number of votes is eliminated and a second ballot is taken. This procedure is repeated until a candidate has more than fifty percent (50%) of votes cast.

18.6.2 For Directors: There shall be only one (1) ballot. The candidates receiving the highest number of votes are deemed elected.

18.6.3 In the event of a tie vote at the meeting of the General Assembly for Officer or Directors positions, the following procedure shall apply:

18.6.3.1. The General Assembly will vote again among the number of candidates who are tied, but each NMO may vote only for one person regardless of the number of tied candidates.

18.6.3.2.: If the tie persists a selection by lot shall be made by persons nominated by the General Assembly Chair as scrutineers.

18.6.4 Persons elected to the Board of Directors shall serve a four (4) year term, being eligible for a maximum of two (2) consecutive four (4) year terms or, exceptionally, a maximum of ten (10) years. Such exceptions will be dictated by rule 18.3.3 above.

18.6.4.1 As an exception to 18.6.3.1, the term of office for the Vice President Medical and Finance for the 2012 election process shall be for two (2) years only. In 2014, the term of office shall revert back to four (4) years. This two (2) year term shall not be counted toward the maximum limit specified in rule 18.3.3.

18.6.5 Additional appointments

18.6.5.1 Co-option of up to three (3) additional Directors by the Board of Directors may take place following a meeting of the General Assembly. In deciding on the co-options, the Board of Directors will have regard to ensure that specific expertise is included, and the Board of Directors shall be as representative as is practicable. Co-opted members shall serve for a term expiring not later than the close of the next meeting of the General Assembly. In no case, may Co-opted members hold office for more than ten (10) years, as indicated in rule 18.3.3.

18.6.5.2 Further Vice presidents shall be appointed from within and by the Board of Directors from amongst its members. Their specific roles will be agreed by the Board of Directors in accordance with the strategic objectives of the WFH.

18.6.6 Regions

18.6.6.1 The WFH regions listed in Appendix 2 are to be based on WHO regions with the exception of the changes outlined.

NOTE: These regions are solely for voting purposes. Smaller groups of countries will be grouped together for all other WFH activities, allowing more practical action to take place.

18.6.6.2 Eight Regions:

Africa
Americas – North
Americas – South
Asia – Southeast
Europe East
Europe West
Eastern Mediterranean
Western Pacific

18.7 Terms of Reference of the Board of Directors

18.7.1 The Board of directors shall be chaired by the President. In the absence of the President, the Board of Directors shall elect an Acting Chairperson.

18.7.2 A minimum of one (1) Board of Directors meeting must take place during each calendar year.

18.7.3 The quorum of the Board of Directors is a majority of the Members of the Board.

18.7.4 Decisions shall be taken by the simple majority of members present and voting or, if the quorum is not attained at a given meeting, by a simple

majority of all members of the Board of Directors, obtained through direct communication.

18.7.5 A member of the Board of Directors may, in accordance with the regulations, if any, and if all the members of the Board of Directors of WFH consent, participate in a meeting of the Board of Directors or of a committee of directors by mean of a telephonic, an electronic or other communication facility that permits all participants to communicate adequately with each other during the meeting.

18.7.6 Vacancies

18.7.6.1 Vacancies occurring in the Board of Directors between sessions may be filled by a quorum of the Board of Directors who shall appoint persons to fill that vacancy until the next session of the General Assembly.

18.7.6.2 In the case of a vacancy of the President, the vacancy shall be filed by the Board of Directors from amongst its own membership, until the next meeting of the General Assembly.

18.8 The Board of Directors shall:

18.8.1 Supervise and instruct on the work of the Headquarters through the Executive Director.

18.8.2 Prepare for General Assembly meetings and supervise the organization of Congresses.

18.8.3 Take all necessary steps and initiatives within the context of the Constitution and Rules of Procedure in the interest of the objectives of the WFH.

18.8.4 Decide on assessment fees for NMOs, membership dues and privileges of individual, associate, organization, and corporate members.

18.8.5 Be entitled to organize fund raising campaigns.

18.8.6 Decide on the acceptance of gifts, bequests, or endowments to the WFH.

18.8.7 Maintain relations with other organizations and bodies.

18.8.8 Appoint a Medical Advisory Board and assign responsibilities to same.

18.9 To assist in carrying out its functions and performing the duties for which it is responsible, the Board of Directors may as it considers necessary:

18.9.1 Establish Committees comprising either some of its members or other persons or representatives of NMOs in order to pursue particular tasks within the context of the objectives of the WFH.

18.9.2 Allocate particular functions to its members or other suitable persons (including but not limited to corporations, organizations, trusts, or associations).

18.9.3 Appoint Regional representatives.

18.9.4 Appoint representatives to other organizations.

18.10 The Executive Director shall, following input from NMOs, Medical Advisory Board, stakeholders, and Board of Directors, develop a strategic plan outlining goals and objectives. This strategic plan will be forwarded to the Board of Directors for modification and approval.

18.11 The members of the Board of Directors shall serve as such without remuneration and shall not directly or indirectly receive any profit from their position; however, a member of the Board of Directors may be paid reasonable expenses incurred in the performance of his/her duties. Nothing herein shall be construed to preclude a member of the Board of Directors from serving the WFH as an officer or in any other capacity and receiving compensation, therefore.

Article 19. The Medical Advisory Board

19.1 This Board shall consist of persons appointed by the Board of Directors of the World Federation of Hemophilia. The Medical Advisory Board will be chaired by the Vice President Medical and additional members will be selected by the Board of Directors on the basis of expertise and/or to give regional balance.

19.2 The Medical Advisory Board shall undertake responsibilities assigned to them by the Board of Directors.

Article 20 The Headquarters

20.1 The Headquarters shall manage the affairs of the WFH.

20.2 The Headquarters is headed by the Executive Director who is contracted by and whose conditions of employment are determined by the Board of Directors. The Executive Director reports to the Board of Directors through the President.

20.3 The Executive Director is the chief administrative officer of the WFH and is responsible for managing the organization and achieving organizational objectives to fulfill the WFH mission, policies, and programs, as set forth by the Board of Directors and the General Assembly.

20.4 The responsibilities of the Executive Director are established by the Board of Directors which annually sets out specific goals and objectives and reviews performance.

20.5 The Executive Director shall attend all meetings of the Board of Directors and all regular and special meetings of the General Assembly and shall be responsible for the recording of all votes and minutes of all proceedings in the books to be kept for these purposes. The Executive Director shall give or cause to be given notice to all such meetings.

Article 21. Finances

21.1 The financial year of the WFH shall be from January 1 to December 31.

21.2 The WFH shall be financed by:

21.2.1 Gifts, bequests, endowments to the WFH from NMOs, public and private bodies and persons, provided that they are consistent with the objectives of the WFH and do not impede its freedom of action.

21.2.2 Annual subscription of individual, associate, and corporate members.

21.2.3 The financial assessments of NMOs and Associate NMOs.

21.2.4 Other means as approved by the Board of Directors.

21.3 The Executive Director will prepare a budget each year. The budget will be approved by the Board of Directors.

21.4 Annual assessments become due on the first day of each financial year and shall be paid in the course of that year.

21.5 WFH may raise funds through public appeals. Appeals by the WFH for funds shall be made in any country only after consultations with the corresponding NMO.

21.6 The Vice President Finance shall have particular responsibility for the assessment and collection of assessments from NMOs and Associate NMOs.

21.7 The Executive Director shall under the supervision and direction of the Board of Directors, and in consultation with the Vice President Finance, be responsible for the administration of the funds of the WFH. The Board of Directors shall adopt policies as required on such matters as investments, signatories to WFH accounts, travel allowances.

21.8 The Headquarters shall, under the supervision of the Vice President Finance, submit an annual audited financial report to NMOs.

Article 22. WFH Committees

22.1 Chairs of WFH Committees will be chosen or ratified by the Board of Directors and/or Executive Director. Membership should be as regionally representative as is practicable.

22.2 Committee chairs will be appointed for a two (2) year term, subject to a maximum of four (4) consecutive two (2) year terms.

22.3 Each Committee's official designation and terms of reference are determined by the WFH Board of Directors and/or Executive Director. The Committee's terms of reference must be filed with Headquarters.

Article 23. World and Regional Congresses

23.1 A World Congress on Hemophilia and other inherited bleeding disorders shall, if possible, be held at intervals not exceeding three (3) years, in the manner hereinafter provided. In the event that no bid from an NMO to host a World Congress on Hemophilia meets the pre-specified criteria, the Board of Directors may select a place for holding of a World Congress and direct the Headquarters to organize it.

23.2 The Board of Directors:

23.2.1 May organize World or Regional Congresses.

23.2.2 The World Congress will follow a rotation pattern starting in 2024 that will award the Congress to Americas-North, Europe East and -West and other countries outside of Americas-North and Europe East and -West. The Board of Directors may receive and examine proposals from NMOs desiring to act as host for certain World Congress from the region selected.

23.2.3 The Board of Directors will accept bids from NMOs desiring to act as host for the World Congress from the region selected by the Board of Directors according to 23.2.2 (Americas-North, Europe East and -West and other outside of Americas-North and Europe-East and -West) The Board of Directors shall select, from among the bids, the two (2) strongest bids which meet the pre-specified criteria and present them to the General Assembly for their consideration and decision.

23.3 The holding of Regional Congresses shall be authorized by and shall be the responsibility of the Board of Directors and jointly organized with the NMO concerned.

Article 24. Conflict of Interest Declaration

All members of the WFH Board of Directors, all officers and all WFH Committee Chairs will complete and sign a Conflict-of-Interest declaration at least every year or when a situation requires an update to the declaration.

Article 25. Amendments to the Rules of Procedure

25.1 These shall be determined by the Board of Directors of the WFH and ratified at the next meeting of the General Assembly or by written resolution signed by all NMOs.

Appendix 1

Criteria for Accreditation as WFH National Member Organization or Associate National Member Organization

1. WFH CRITERIA FOR RECOGNITION OF A COUNTRY

The WFH recognizes any country that is accepted by either the United Nations or World Health Organization.

2. WFH CRITERIA FOR RECOGNIZING WHICH NATIONAL GROUP SHOULD REPRESENT A COUNTRY

Only one national Organization can represent any one country.

- ✓ If two or more qualifying organizations exist in a country, they need to negotiate WFH membership between themselves.
- ✓ If such an agreement cannot be reached, the WFH Board of Directors will assist in the determination of membership by granting National Member Organization (NMO) status to the Organization which best satisfies the criteria for accreditation.

3. CRITERIA FOR A NATIONAL GROUP TO BECOME A WFH NATIONAL MEMBER ORGANIZATION (NMO)

To become an NMO an Organization must first be an associate NMO and fulfill the following criteria:

- The Organization must represent the best interests of the majority of people with hemophilia and other inherited bleeding disorders and their families in that country. This will generally be an organization consisting primarily of people with hemophilia and other inherited bleeding disorders and their

families. The Organization must be committed to the patients and patients must be involved in the Organization.

- The Organization must be in a country recognized by either the United Nations or the World Health Organization (see 1).
- The goals and aims of the Organization must be similar to, and not in conflict with, those of the WFH.

4. **WFH CRITERIA FOR A NATIONAL GROUP TO BECOME AN ASSOCIATE NATIONAL MEMBER ORGANIZATION (ASSOCIATE NMO)**

To become an associate NMO and Organization must apply for accreditation and complete the application process as outlined in the WFH Guidelines for Accreditation.

Organizations whose membership or <management board> is made up solely of or by a majority of doctors or other healthcare professionals, not primarily people with hemophilia and other inherited bleeding disorders, are eligible for associate NMO status.

Organizations that have met all other criteria for WFH NMO accreditation with the exception of their country being officially recognized as a country by either the United Nations or the World Health Organization are eligible for associate NMO status.

The WFH shall assist Associate NMOs to reach full NMO status.

5. **CRITERIA FOR A NATIONAL MEMBER ORGANIZATION TO MAINTAIN ITS STATUS INCLUDE BUT ARE NOT EXCLUSIVE TO:**

The NMO must work towards developing comprehensive care for all people with hemophilia and other inherited bleeding disorders.

The NMO must work towards establishing self-help support groups for people with hemophilia and other inherited bleeding disorders and their families.

The NMO must assume responsibilities regarding WFH, such as paying membership fees by the due date to keep its voting status, submitting regular reports, and actively participating in WFH affairs.

The NMO must act ethically and in accordance with WFH values.

6. **ACCREDITATION OF NEW NMOS**

Accreditation of full and associate NMOs is decided by vote at the General Assembly of the WFH, based on the recommendation of the Accreditation Committee and approval of the Board.

7. **SUSPENSION OR TERMINATION OF NMO ACCREDITATION**

Under Article 15.3 of the WFH by-laws – Termination of Membership of National Members Organizations and Associate NMOs:

Subject to confirmation by the General assembly membership of an NMO or of an Associate NMO of WFH shall cease:

7.1 By resignation addressed to the Headquarters of WFH in which case it shall take immediate effect.

7.2 By dissolution of the organization, in which case it shall take immediate effect.

7.3 If an NMO or Associate NMO no longer fulfils the criteria for WFH membership.

In the event that the Board of Directors determines that an NMO should be suspended or terminated from membership in the WFH, The President, or such other officer as may be designated by the Board of Directors, shall provide sixty (60) days' notice of suspension or termination to the NMO, and shall provide reasons for the proposed suspension or termination. The NMO may make written submissions to the President, or such other officer as may be designated by the Board of Directors, in response to the notice received within such sixty (60) day period. In the event that no written submissions are received by the President, the President, or such other officer as may be designated by the Board of Directors, may proceed to notify the NMO that the NMO is suspended or terminated from membership in the WFH. If written submissions are received in accordance with this section, the Board of Directors will consider such submissions in arriving at a final decision and shall notify the NMO concerning such final decision within a further sixty (60) days from the date of receipt of the submissions. The Board's decision will be confirmed by the General Assembly at the next meeting. The decision shall be final and binding on the NMO, without any further right of appeal.

Appendix 2

WORLD FEDERATION OF HEMOPHILIA

WHO REGIONS / WFH NMOs and Associate NMOs

WHO Regions

Africa

Americas

Asia Southeast

Europe

Eastern Mediterranean

Western Pacific

WFH Regions

Africa
Americas - North
Americas - South
Asia – South East

Europe - East
Europe - West
Eastern Mediterranean
Western Pacific

WFH Countries are listed below in their regions. Please see the “WFH NMO Accreditation Criteria” regarding those listed as National Member Organizations (NMOs) and those listed as Associate NMOs.

The table below reflects the accreditation vote by the General Assembly on April 21, 2024 which now comprises of 152 NMOs

AFRICA

NMOs

Benin
Burkina Faso
Cameroon
Cote D’Ivoire
Eritrea
Ethiopia
Ghana
Kenya
Lesotho
Madagascar
Mali
Mauritius
Nigeria
Rwanda
Senegal
South Africa
Sudan
Tanzania
Uganda
Zambia
Zimbabwe

Associate NMOs

Angola
Botswana
Burundi
Dem Rep Congo (Kinshasa)
Gabon
Gambia
Guinea
Malawi
Mauritania
Mozambique
Namibia
Republic of Congo (Brazzaville)
Sierra Leone
Togo

AMERICAS – NORTH (NAFTA Countries)

NMOs

Canada
Mexico
USA

Associate NMOs

AMERICAS – SOUTH

NMOs

Argentina
Belize
Bolivia
Brazil
Chile
Colombia
Costa Rica
Cuba
Dominican Republic
Ecuador
El Salvador
Honduras
Jamaica
Nicaragua
Panama
Paraguay
Peru
Suriname
Trinidad / Tobago
Uruguay
Venezuela

Associate NMOs

Bahamas
Barbados
Guyana

ASIA – SOUTHEAST

NMOs

Bangladesh
India
Indonesia
Maldives
Nepal
Sri Lanka
Thailand

Associate NMOs

EUROPE - EAST

NMOs

Albania
Armenia
Azerbaijan
Belarus
Bosnia & Herzegovina
Bulgaria
Croatia
Czech Republic
Estonia
Georgia

Associate NMOs

Kosovo
Montenegro
Tajikistan

Hungary
Israel
Kazakhstan
Kyrgyzstan
Latvia
Lithuania
Macedonia
Moldova
Poland
Romania
Russia
Serbia
Slovakia
Slovenia
Turkey
Ukraine
Uzbekistan

EUROPE - WEST

(Includes EU and EFTA Countries)

NMOs

Austria
Belgium
Cyprus
Denmark
Finland
France
Germany
Greece
Iceland
Ireland
Italy
Luxembourg
Netherlands
Norway
Portugal
Spain
Sweden
Switzerland
United Kingdom

Associate NMOs

Malta

EASTERN MEDITERRANEAN

NMOs

Algeria
Egypt
Iran
Jordan
Kuwait
Lebanon
Morocco
Oman
Pakistan
Qatar
Saudi Arabia
Syria
Tunisia

Associated NMOs

Afghanistan
Bahrain
Djibouti
Iraq
Libya
Palestine
United Arab Emirates

WESTERN PACIFIC

NMOs

Australia
Cambodia
China
Japan
Malaysia
Mongolia
New Zealand
Philippines
Singapore
South Korea
Vietnam

Associated NMOs

Fiji
Myanmar