

## European VHL (von Hippel-Lindau) Federation

### Society Statutes

#### European VHL (von Hippel - Lindau) Federation (VHL Europa)

##### § 1: Name, Registered Office and Field of Activity

(1) The Association, having full legal capacity, is named "European VHL (von Hippel - Lindau) Federation, abbreviated to "VHL Europa", and shall be referred to in the statutes and by-laws as "the Association".

(2) The Association has its registered office in The Netherlands, and extends its activities throughout Europe.

(3) The setup of subsidiary Associations is not foreseen.

(4) The financial year runs from January 1st to December 31th.

##### § 2: Objectives

(1) Supporting existing national VHL patient organisations and helping to set up new and foster cooperation between these national organizations in Europe and develop a common policy, if possible, between them, and to do everything that is related to this in the broadest sense, either directly and indirectly,

(2) Improving situation of people affected with VHL in Europe

(3) Promoting and sustaining research

##### § 3: Means to Achieve the Objectives of the Association

(1) The purpose of the Association shall be achieved by the immaterial and material means listed in section 2.

(2) These are:

a) Promoting and supporting the interests of VHL patient organisations in Europe

b) Promoting and supporting the interests of all VHL patients and their carers in Europe

c) Acting as interlocutor to the European Union and other European institutions for all matters relating to VHL patient organizations, patients, carers;

d) Acting as interlocutor for and on behalf of VHL patient organisations to scientific societies, political parties, (commercial) organisations, national health services, health insurers, the pharmaceutical industry and other institutions that influence or can influence the interests of VHL patients and their carers;

##### § 4: Use of Funds

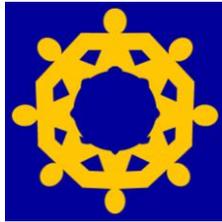
Association funds may only be used for the purposes stipulated in the statutes. Upon their resignation from the Association, or in the event that the Association is disbanded or dissolved, Members revoke the right to receive any more than the invested capital and the total value of their share, which will be calculated according to the performance value of the investment. No person shall receive expenses not relating to the purposes of the Association.

##### § 5: Types of Membership

VHL Europa has the following sorts of members:

a) Full members, being national VHL organisations recognized in their country as non profit associations within Europe, independent of authorities, political parties, the pharmaceutical industry and commercial organizations

b) Affiliated members are individuals from European countries where no National Association for VHL is in existence. An affiliated member may attend all VHL-Europa meetings as observer without the right to vote. The Chairman may permit an affiliated member to address the meeting.



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c) Sponsoring members, members can be individuals who support the goals of VHL Europa. They may attend all VHL-Europa meetings as observer without the right to vote

### **§ 6: Membership Eligibility**

Application for membership must be submitted in writing to the Board. The General Assembly decides upon the application.

#### **1. Full Members**

European non-profit VHL organisations registered in the individual countries.

These organisations can apply for membership by writing to the Board and the General Assembly will decide to accept or refuse their admission. Once accepted, they are represented in the General Assembly and have the right to vote in Association elections. Founding Members automatically gain full membership status and need not apply for membership.

#### **2. Affiliated Members and sponsoring members**

Affiliated members and sponsoring members do not have voting rights in Association elections. Membership applications can be submitted to the Board in writing and the General Assembly will decide to accept or refuse their admission.

### **§ 7: Termination of Membership**

(1) Membership is terminated upon death, with regard to juristic persons and legal partnerships upon loss of their juridical personality, upon voluntary resignation or expulsion.

(2) Membership termination and reasons thereof must be submitted to the Board in writing. The Board can exclude a Member after hearing the defense case of the concerned party.

Such exclusions will be announced by the General Assembly having reached an appropriate verdict with a two-thirds majority of attending Members or their named representatives.

(3) The expulsion of a Member of the Association can be ordered by the Board for gross breach of other Membership duties or dishonorable behavior.

### **§ 8: Rights and Duties of Members**

(1) All Members have the right to participate in all Association events and to make use of Association facilities. The right to vote in the General Assembly and the entitlement to elect and stand for election is only granted to Full Members.

(2) Every Member has the right to request a printed copy of the statutes.

(3) At least one tenth of the Members may request the Board to call a General Assembly.

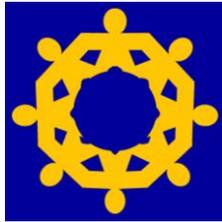
(4) In the course of each General Assembly the Board shall inform the Members about the activities and the financial bearing of the Association. Upon reasoned request of at least one tenth of the Members, the Board has to provide those Members with the respective information within four weeks time.

(5) The Board shall have to inform the Members about the audited final account. In case respective information is given in the course of a General Assembly this shall be made in the presence of the Auditors.

(6) Members are obliged to further the interests of the Association to the best of their abilities and to refrain from any action that could harm the reputation and purpose of the Association. Members shall have to observe the statutes of the Association and the resolutions of its executive bodies. Standard and Non-Standard Members are obliged to pay their admission and membership fees on time and to the sum resolved in the General Assembly.

Members have no right to claim financial compensation for their duty-bound actions.

Only costs incurred on behalf of VHL Europa may be reimbursed, and the relevant receipts must be presented where possible. This includes travel expenses and accommodation costs. The details are set forth in the Association Rules.



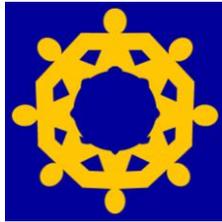
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### **§ 9: Association Bodies**

The bodies of the Association shall be the General Assembly, the Board, the Auditors, the Medical and Scientific Advisory Board.

### **§ 10: General Assembly**

- (1) The General Assembly shall be the highest governing body of the Association.
- (2) The General Assembly is the Meeting of Members according to the terms of the Association and is held annually. The General Assembly is chaired by the President or a person designated by him/her in the seat or office specified on the written invitation.
- (3) This written invitation is sent with the agenda by the Board 30 days prior to the date set for the General Assembly.
- (4) The President must convoke a special General Assembly if this is requested by the Board or one tenth of the membership represented at the General Assembly.
- (5) Members and/or their representatives attend the General Assembly. Every Member is responsible for the votes of their single state Association.
- (6) Every country represented at the VHL Europa General Assembly has one seat and one vote.
- (7) Absent Members can be represented by another Member equipped with a written power of attorney. However, one Member – himself included – may represent no more than two Members.
- (9) The General Assembly approves the accounts of the past year and, on the Board's proposal, the budget for the coming year by a single majority of votes.
- (9) The General Assembly decides, on the Board's proposal, by a single majority of votes:
  - on resolutions regarding the strategic policy of VHL Europa
  - on annual membership fees
  - on the Board's annual reports and agenda
  - on the admission or refusal of Members
  - on amendments to statutes as voted for by two thirds of all Association Members.
- (10) The General Assembly elects the President and Vice President, the Treasurer and and the Secretary for a three-year term of office. These positions are elected in an absolute majority vote cast by the Members. Members of the Board can be re-elected.
- (11) The votes cast by VHL Europa Members are submitted either in VHL Europa's annual General Assembly or prior to the annual General Assembly on ballot papers, which Members receive well in advance either by post, fax or email or a combination of the three, giving all Members the right to vote. If the votes are tied, there must be a second vote held for the office in question.
- (12) If a second or further assemblies need to be called, a majority of a third of VHL Europa's Members is required.
- (13) With the exception of special cases mentioned in these statutes, resolutions are passed in the General Assembly by a single majority of the votes of Members eligible to vote (or their named representatives) and communicated to all Members.
- (14) The General Assembly shall form a quorum, regardless of the number of attendees.
- (15) Resolutions may only be adopted when included in the agenda. The resolutions passed in the General Assembly are recorded in the minutes, which are signed by the President and then retained by the Secretary who forwards them on to the Members.



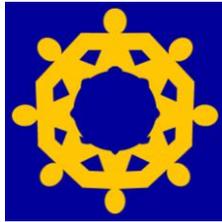
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### **§ 11: Board of Directors**

- (1) The Board shall be composed of four Members at least; the President and Vice Presidents, Secretary and Treasurer. The Board can have a maximum of seven Board Members.
- (2) The Board is elected by the General Assembly. In the absence of an elected Member, the Board has the right to co-opt another eligible Member in their place, which must subsequently be approved in the next General Assembly.
- (3) The Board's functional term is three years; re-election is possible. Every function on the Board must be carried out in person.
- (4) The President, or in his/her absence, Vice President, convenes the Board in writing or verbally. If the President is unavailable for a long period of time, any other Member of the Board may convene the Board.
- (5) The Board shall form a quorum if all Members of the Board were invited to the meeting and at least half are present.
- (6) The Board finalizes its resolutions by a single majority of the votes; should the votes tie the President casts the deciding vote.
- (7) The Board is chaired by the President, or in his/her absence, Vice President. If he/she is also unavailable, the Board shall be chaired by the Board Member with the highest number of years in service from all those present at the meeting, or the Member who receives the majority vote from the other Board Members.
- (8) With the exception of death or expiration of the term of office (section 3) a Board Members' role is revoked through dismissal (section 9) or resignation (section 10).
- (9) The General Assembly may dismiss the entire Board or individual Members thereof at any time. Dismissal, except in cases of misconduct, does not become effective until the appointment of a new Board or Board Member.
- (10) Board Members may submit their resignation at any time in writing. Letters of resignation must be addressed to the Board; in the case of the entire Board resigning letters should be addressed to the General Assembly. The resignation only becomes effective once a successor is elected or co-opted (section 2).

### **§ 12: Special Duties of Individual Members of the Board**

- (1) The President shall be responsible for the ongoing business of the Association and shall be assisted by the Secretary.
- (2) The President shall represent the Association publicly. Written documents of the Association shall become valid upon signature by the President and the Secretary in financial matters (fund deposits), the signatures of the President and the Treasurer is required. Legal transactions between Members of the Board and the Association shall be subject to the approval of another Member of the Board.
- (3) Legal powers to represent the Association publicly or to sign on its behalf can be granted only by the two Board Members named in section 2.
- (4) In case of extraordinary circumstances, the President shall be entitled to take measures independently, even in matters falling within the competence of the General Assembly or the Board; such measures shall, however, require the subsequent approval of the relevant body of the Association.
- (5) The President directs the Board in the General Assembly and in the Board office.
- (6) The Secretary is responsible for the minutes taken in the General Assembly and in Board meetings.
- (7) The Treasurer shall be responsible for the financial bearing of the Association.



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### **§ 13: Auditors**

(1) Two Auditors shall be elected by the General Assembly for a period of two years.

Reelection is possible.

(2) The Auditors are to audit the current business and the financial bearing of the Association for the proper character of accounting and to examine whether the funds are used as provided for in the statutes. The Board has to provide the Auditors with the necessary documents and to give the required information. The Auditors shall have to report to the Board about the results of their audit.

(3) Legal transactions between the Auditors and the Association are subject to the approval of the General Assembly. All other matters concerning Auditors are subject to the stipulations set forth in § 11 section 8 to 10 mutatis mutandis.

### **§ 14: Scientific and Medical Committee**

The General Assembly may set up a European scientific committee, composed of doctors and scientist specialized in VHL. The scientific committee shall have a consulting role without voting rights.

The scientific committee shall assist the organization and give advice in the following areas:

- through their contacts with the media, patients and the general public
- in consulting patients
- in general in all its objectives

### **§ 15: Liquidation of the Association**

(1) The voluntary liquidation of the Association may only be decided in a specially convened General Assembly and requires a majority of two third of the valid votes cast by all Members presents or represented. Invitations to this Assembly shall be issued three months in advance.

(2) This General Assembly shall also pass a resolution concerning the assets of the Association, if such assets exist. The General Assembly shall appoint a liquidator and pass a resolution to whom it is to transfer the assets of the Association remaining after the payment of its debts.

(3) In the case of liquidation or dissolution of the Association or the discontinuation of its previously beneficial purpose, the remaining assets shall be transferred to a receiver pursuing objectives for the promotion of non-profit, charitable purposes.