

The VHL Family Alliance, Inc.

By-laws

ARTICLE I -- NAME, INCORPORATION, OFFICERS

Section 1. Name: The name of the corporation is: The VHL Family Alliance, Inc. referred to hereinafter by that name or the "Alliance", or the "Corporation".

Section 2. Incorporation: The VHL Family Alliance is organized as a not-for-profit corporation under the laws of the Commonwealth of Massachusetts.

Section 3. Principal Office: The principal office of the VHL Family Alliance shall be located at 171 Clinton Road, Brookline, Massachusetts, or at such other place as the Board of Directors may from time to time determine.

The VHL Family Alliance shall maintain a registered office in the Commonwealth of Massachusetts as required by the General Laws of the Commonwealth of Massachusetts, Chapter 180. The VHL Family Alliance may also maintain other offices at such other places as the Board of Directors may determine or as the purpose of the VHL Family Alliance may require.

ARTICLE II -- PURPOSES

The purposes for which the VHL Family Alliance is formed, as set forth in its Articles of Organization, are to conduct the following activities which are exclusively charitable, educational, and scientific within the meaning of Section 501 (c) (3) of the Internal Revenue Code of 1986, as amended, including:

1. To disseminate timely and accurate information about von Hippel-Lindau Syndrome to patients, family members, physicians, and other interested parties.
2. To provide means for patients and relatives to share experiences, support one another, and improve their medical care.
3. To encourage, advise, and establish standards for clinics specializing in the diagnosis and treatment of von Hippel-Lindau Syndrome.
4. To encourage and foster biomedical and other pertinent research on von Hippel-Lindau Syndrome.

5. To aid and encourage formation of Chapters and to provide assistance and guidance to enhance their effectiveness.

6. To undertake all actions as deemed appropriate by the Board of Directors to carry out the foregoing purposes to the extent permitted under state and federal law.

ARTICLE III -- MEMBERSHIP

The Alliance may have members who are individuals, institutions, and corporations. Membership in the Alliance shall be determined as follows.

Section 1. Individual Members: Any person who completes an initial membership application and pays individual dues on an annual basis to the VHL Family Alliance shall be an individual member and have the benefits, privileges, and obligations provided in the By-laws and Policies of the VHL Family Alliance and its Chapters. Persons and family members affected by von Hippel-Lindau Syndrome who are unable to pay dues but notify the Alliance of their desire to be counted as members and complete an initial membership application will have regular membership status.

Section 2. Family Members: Each family who completes the membership application and pays dues at the family rate on an annual basis shall have the same privileges of membership as the individual member. Each family membership has one vote and receives one mailing to one address. Families affected by von Hippel-Lindau Syndrome who are unable to pay dues but notify the Alliance of their desire to be counted as members and complete an initial membership application will have regular membership status subject to the provisions of this Section.

Section 3. Professional Membership: Physicians and other health care professionals who complete an initial membership application and pay dues on an annual basis at the professional rate shall have the same privileges of membership as the individual member.

Section 4. Corporate or Institutional Members: Each corporation or institution shall designate one individual as its representative. Corporate or Institutional members shall consist of representatives of organizations and facilities with an interest in or relationship to the Alliance. Institutional members have no vote and are not eligible to hold office. Dues and other requirements may be imposed by the Board of Directors. Corporate or Institutional members may request up to six copies of membership materials, and are authorized to make photocopies of Alliance materials for distribution to others within the Corporation.

Section 5. Honorary Members: Honorary members may be designated by the Board of Directors. Such members shall pay no dues, have no vote, and are not eligible to hold office.

Section 6. Non-U.S. Members: Persons and family members affected by von Hippel-Lindau Syndrome who reside outside the United States may be counted as Members of the VHL Family Alliance, but do not have voting powers on matters regarding the disposition of funds collected within the United States.

Section 7. Term: Membership in the VHL Family Alliance shall be for a term of one year from January 1 through December 31 of each year. Dues are due and payable on January 1 of each year. Members who join for the first time after September 1 will remain in good standing through December 31 of the following year.

Section 8. Expulsion: Membership may be terminated at any time, with cause, after providing notice and the opportunity of a hearing to the member, by affirmative vote of two-thirds of the Board of Directors.

Section 9. Reinstatement: On written request filed with the Secretary, the Board of Directors may, by affirmative vote of the majority of the members of the Board, reinstate a former member to membership on such terms as the Board of Directors may deem appropriate.

ARTICLE IV -- MEMBERSHIP MEETINGS

Section 1. Regular meetings: An annual meeting, open to Members, shall be held at a time, place, and date as determined by the Board of Directors and such meeting shall be for the purpose of electing Members to the Board of Directors and for the transaction of other business as may come before the meeting. The annual membership meeting shall be held in conjunction with the annual meeting of the Board of Directors and will include reports by both the Medical Director and the Executive Director.

Section 2. Special meetings: Special meetings of the members may be called by the Chairperson of the Board, or on the written request of a majority of the Board of Directors, at a place designated by such notice. If no designation is made, the place of the meeting shall be the principal office of the Corporation. In the case of a special meeting, the purpose(s) for which the meeting is called shall be placed in the notice.

Section 3. Notice of Meetings: Written notice setting the place, day, and hour of any meeting shall be mailed to each regular member, or notice placed in the Alliance's newsletter, no less than thirty (30) or more than one hundred twenty (120) days before the date of such meeting. If mailed, the notice of a meeting shall be deemed to be delivered when deposited in the United States mail addressed to the member at his/her address as it appears on the records of the Alliance, with postage thereon prepaid.

Section 4. Quorum: A quorum shall consist of a minimum of ten percent (10%) of the regular membership present or represented by proxy.

Section 5. Required Vote: A vote of a majority of those regular members present or represented by proxy shall be necessary to approve or disapprove any action presented at the meeting. The Secretary shall mail proxies to members at least 45 days prior to the annual meeting and members shall return the proxies at least 10 days before the annual meeting. Proxies must be given to the Secretary of the Corporation for examination prior to a regular or special meeting of the members. The decision of the Secretary as to whether such proxies are valid shall be final. The Secretary may rely on legal advice from counsel of the Corporation as to the validity of proxies.

Section 6. Rules of Order: Meetings of the VHL Family Alliance shall be governed by Roberts Rules of Order, as last revised.

ARTICLE V -- BOARD OF DIRECTORS

Section 1. Powers and Duties: The Board of Directors shall have general power to manage and control the affairs and property of the Corporation and shall have full power, by majority vote, to adopt rules and regulations governing the action of the Board and shall have full power and complete authority with respect to the distribution or payment of the moneys received by the Corporation from time to time.

Section 2. Number, Composition, and Term of Office:

- a. The Board of Directors shall consist of not less than five (5) or more than nineteen (19) directors. The number of directors may be changed by vote of a majority of the entire Board but no decrease may shorten the term of any incumbent director(s). Not less than fifty percent of the Directors shall be representatives of families affected by VHL.
- b. Directors shall be elected by majority vote of the membership at its annual meeting for a term of three years. Beginning upon election, each Director shall serve for said term and until his/her successor shall have been duly elected and qualified.
- c. No Director shall serve more than two consecutive terms as Director, except that if a Director is elected an officer and the term as an officer extends beyond the two consecutive term limit, such Director's term shall be extended to allow completion of the term as an officer. A Director who has served two consecutive terms shall be eligible for re-election one year after expiration of his/her second term.
- d. Each year, one-third of the Directors shall be elected. At the first election following adoption of these By-laws, one-third of the Directors shall be elected for one year, one-third for two years, and one-third for three years. Beginning at the second annual meeting, and thereafter, elections of Directors shall be for terms of three years.

Section 3. Nomination and Election of Directors: The Nominating Committee shall decide upon a slate of directors and shall present such slate to the Board of Directors not less than twenty (20) days prior to the VHL Family Alliance regular annual membership meeting. Upon written request of at least one member of the Board made to the Nominating Committee not less than ten (10) days prior to the said annual meeting, additional names may be placed in nomination and presented to the Directors of the Corporation. The Nominating Committee shall thereafter present such slate or slates to the regular members of the Corporation for election at the Annual Meeting.

Section 4. International Liaison. Each year, the Board of Directors shall appoint a member of the Board of Directors to be international liaison to the VHL Family Alliance affiliates in other countries.

Section 5. Qualifications: Directors shall be members of the Alliance in good standing. Members of a Director's immediate family shall not be elected to serve during the term of a Director. Immediate family shall include the Director's parents, spouse, children, brothers and sisters, aunts and uncles, domestic partners or members of the household.

Section 6. Vacancies: In case of any vacancy on the Board of Directors, a successor to fill the unexpired portion of the term may be elected by a majority of the remaining Directors.

Section 7. Removal or Resignation: Following written notice, a member of the Board of Directors may be removed by approval of two-thirds of the Directors whenever such member has failed to attend three consecutive meetings of the Board without justifiable cause or when his/her actions have not been in the best interests of the VHL Family Alliance. Any director who decides to resign prior to the end of their term shall notify the Chairperson of the Board in writing of the resignation with an effective date of resignation provided in the notice. The resignation shall be voted on by the Board of Directors with a simple majority required for the acceptance of a resignation.

Section 8. Compensation: No Director shall receive compensation or salary in any form for his/her services but shall be reimbursed for authorized and documented expenses.

ARTICLE VI -- BOARD MEETINGS

Section 1. Regular Meetings: The Board of Directors shall meet at least three (3) times per year. The annual meeting shall be held in conjunction with the VHL Family Alliance annual membership meeting. Other meetings may be held by means of telephone conferences or equipment of similar communications by means of which all Directors participating in the meeting can hear each other. Participating in this type of meeting shall constitute presence in person. Directors shall be notified in writing of the time, place, and agenda for regular meetings at least fourteen (14) days in advance of said

meetings. The Board by majority vote may close any meetings or parts of meetings to persons other than the Directors.

Section 2. Special Meetings: Special meetings of the Board of Directors may be held at any time and place upon call of the Chairperson of the Board, or by the Secretary upon written request of a majority of the Directors. Special meetings may be held by means of telephone conference or similar communication equipment. Notice at least 48 hours before of the time, place, and purpose of the Special meeting(s) shall be given to each Director.

Section 3. Quorum: A quorum shall consist of a majority of the Directors.

Section 4. Required Vote: An affirmative vote of a simple majority of those present shall be necessary for the passage of any resolution. A Director may not vote by proxy.

Section 5. Action Without Meeting: If Directors shall vote by unanimous written consent to any action to be taken by the Board of Directors, such vote shall have the same force and effect as if taken at a duly called meeting.

Section 6. Rules of Order. All meetings of the Board of Directors shall be governed by the most current edition of Roberts Rules of Order.

ARTICLE VII -- OFFICERS

Section 1. Number and Qualification: The officers of the Corporation shall consist of the Chairperson of the Board, one or more Vice Chairpersons, Secretary, and Treasurer, together with such other officers, if any, the Board of Directors may from time to time designate. Officers must be elected from among the Board of Directors. No person may hold more than one office in the Corporation concurrently.

Section 2. Election and Term of Office: The officers shall be elected for two year terms by the Directors.

Section 3. Vacancies: In the case of any vacancy in any office, a successor to fill the unexpired term may be elected by the Board of Directors.

Section 4. Other agents, etc.: The Board of Directors may appoint or employ, from time to time, such agents or employees as it shall deem necessary and shall have such authority and perform such duties and receive such reasonable compensation as the Board of Directors may determine.

Section 5. Removal: All Officers and Agents of the Corporation shall be subject to removal at any time by the affirmative vote of a two-thirds majority of the whole Board of Directors.

Section 6. Powers and Duties of the Chairperson of the Board: The Chairperson of the Board is the Chief Executive Officer of the Corporation and shall have general charge and control of all its business affairs and properties. S/he shall have the power to call special meetings and to constitute special committees and make appointments to standing committees. S/he shall preside at all meetings of the Board of Directors; sign and execute all authorized bonds, contracts, and other obligations in the name of the Corporation; and be an ex-officio member of all committees.

Section 7. Powers and Duties of the Vice Chairperson(s) of the Board: The Vice Chairperson(s) of the Board shall have such powers and shall perform such duties as may be assigned to him/her/them by the Board of Directors. S/he shall act in the role of Chairperson of the Board in the Chairperson's absence or disability.

Section 8. Powers and Duties of the Secretary: The Secretary shall act as a secretary of all meetings of the members and the Board of Directors and shall keep the minutes of all such meetings. S/he shall attend to the giving and service of all notices of the Corporation and shall perform all the duties customarily incident to the office of Secretary, subject to the control of the Board of Directors, and shall perform such other duties as shall be assigned to him/her from time to time by the Board of Directors.

Section 9. Powers and Duties of the Treasurer: The Treasurer shall have custody of all funds and securities of the Corporation which may come into his/her hands. S/he shall keep or cause to be kept full and accurate accounts of receipts and disbursements of the Corporation, and shall deposit all moneys and other valuable effects of the Corporation in the name and to the credit of the Corporation in such banks or depositories as the Board of Directors may designate. Annually and whenever else required by the Board of Directors, the Treasurer shall render a statement of accounts. S/he shall at all reasonable times exhibit the VHL Family Alliance's books and accounts to any Officer or Director of the Corporation and shall perform all duties incident to the position of Treasurer subject to the control of the Board of Directors and shall, when required, give such security for the faithful performance of duties as the Board of Directors may determine.

Section 10. Compensation: No officer shall receive compensation for service but shall be reimbursed for authorized and documented expenses.

Section 11. Executive Director. Pursuant to Section 4 of this Article, the Corporation may employ an Executive Director. The Executive Director shall serve as the chief operating officer of the Corporation and shall not be a member of the Board. The Executive Director shall be employed by the Corporation and be subject to the direction and control of the Board of Directors. The Executive Director shall direct, manage and oversee the daily business and affairs of the Corporation and shall have the power to perform such additional acts and execute such documents or contracts as are approved, authorized, or directed by the Board of Directors. The Executive Director shall be an ex-officio non-voting member of all standing committees except the Executive Committee.

ARTICLE VIII -- COMMITTEES

Section 1. Standing and Other Committees: The Board of Directors may, by resolution, designate committees, including committees not referred to in these By-laws. Each committee shall be chaired by a Director of the Corporation. In addition to such Special Committees as the Chairperson of the Board and/or Board of Directors may from time to time authorize, there shall be the following Standing Committees: Executive; Nominating; Development; Membership; Chapter; Professional Education; Public Awareness; Medical Advisory; and By-laws.

Section 2. Executive Committee: The Executive Committee has the authority to act on behalf of the Board and shall meet at the discretion of the Chairperson of the Board. The Executive Committee shall be comprised of the officers of the Board and may include one or more other Directors as selected by the Board of Directors.

Section 3. Nominating Committee: The Nominating Committee shall consist of the Chairperson of the Board, Vice Chairperson(s) of the Board, and two (2) other members elected by the Board of Directors at the regular meeting of the Board following the annual meeting. The Nominating committee shall present for approval by the Board and election by the membership a slate of nominees for Directors.

Section 4. Development Committee: The Development Committee's responsibility is to assure that existing and new programs are adequately funded to assure the viability of the organization over the long term. Toward that end, the committee is responsible for

- A. Fund-raising programs
- B. Grants management
- C. Management of fund-raising special events
- D. Input to the Board of Directors in drafting long-range organizational plans.

Section 5. Membership Committee: The Membership Committee shall attempt to increase membership in the Corporation and shall act as a liaison between the Membership and the Board.

Section 6. Chapter Committee: The Chapter Committee shall assist in the formation of chapters and help chapters to conduct their affairs. The Committee shall also act as a liaison between VHL Family Alliance Chapters and the Board of Directors.

Section 7. Professional Education Committee: The Professional Education Committee shall attempt to increase awareness of members of the Medical and other professional communities about von Hippel-Lindau Syndrome. It will also work with the Medical Advisory Board toward establishing clinics with expertise in VHL and maintaining relationships between each clinic and the VHL Family Alliance.

Section 8. Public Awareness Committee: The Public Awareness Committee is responsible for programs designed to make the general public and specifically targeted audiences aware of von Hippel-Lindau Syndrome and of the VHL Family Alliance's resources for dissemination of information, general and scientific, about VHL.

Section 9. By-laws Committee: The By-laws Committee shall prepare By-laws for the Corporation and amendments of such By-laws for approval and adoption by the Board of Directors and provide opinions to the Board as to the interpretation of the By-laws.

Section 10. Medical Advisory Committee: The Medical Advisory Committee shall recommend to the Board of Directors appointments to the Medical Advisory Board, shall act as liaison with the Medical Advisory Board, and shall perform such other functions relating to medical concerns that may be assigned to the Committee by the Chairperson of the Board, the Executive Director, or the Board of Directors.

ARTICLE IX -- ADVISORY AND HONORARY BOARDS

Section 1. Medical Advisory Board: The Board of Directors may designate one or more persons (including physicians, researchers, psychologists, social workers, or counselors) who are significantly involved in the treatment of those affected by von Hippel-Lindau Syndrome and/or their families, to act as a Medical Advisory Board to the Alliance, to make recommendations regarding the VHL Family Alliance Research Grants Program, and to make recommendations and provide opinions as to Clinical Care Centers. The Chairperson of the Medical Advisory Board shall be a non-voting member of the VHL Family Alliance Board of Directors. No dues are required to be paid by these members.

Section 2. Advisory Council: The Board of Directors, may by resolution designate one or more persons who are significantly interested in the welfare of those affected by von Hippel-Lindau Syndrome or their families to act as an Advisory Council to the Alliance. Members of this Council may be persons of talent, special skills or experience, position, rank, influence, connection or demonstrated interest in VHL. Recommendations to the Board may come from Directors, members of the Medical Advisory Board, Chapters, staff, and members. No dues are required to be paid by these members. This Council is advisory in function. Members may be asked to assist in any program of the Alliance, to give professional guidance, counsel, or advice.

Section 3. Honorary Board: An Honorary Board of former members of the VHL Family Alliance Board of Directors and others whose name would lend influence to the VHL Family Alliance may be appointed to an Honorary Board by the VHL Family Alliance Board of Directors.

Section 4. Chapter Council: The Alliance may have a Chapter Council to work with the Directors and the Alliance for the purpose of encouraging the establishment and viability of Chapters in the United States in accordance with these By-laws and the policies of the

Alliance. Each Chapter shall designate a representative to serve as a member of the Chapter Council. The Chapter Council will meet in person, by telephone or electronically as needed to share ideas and support one another in the fulfillment of its goals. The Chapter Council may work with the Alliance and its Board of Directors to:

1. Establish, develop, or maintain Chapters in the United States.
2. Define the number and composition of groupings of Chapters;
3. Plan and conduct meetings and programs;
4. Plan and conduct an annual meeting of the Chapter Council;
5. Develop and implement programs of the Alliance in accordance with these By-laws, Alliance policies and standards, and under the direction of the Board of Directors;
6. From time to time review and evaluate the programs, policies, and activities of the Chapters and to facilitate the development of programs, policies and activities among the Chapters;
7. Transmit to the Board of Directors recommendations concerning programs, policies, and activities designed to further the purposes and goals of the Alliance.

ARTICLE X -- CHAPTERS

Section 1. Formation: The Board of Directors shall be empowered to designate one or more groups of interested people to act as Chapters of the Alliance. A Chapter is a local unit with a specific area designated by the Board of Directors.

Section 2. Purpose: A Chapter is organized and operated exclusively to act locally for the benefit of, to perform the functions of, and to carry out the purposes of the national VHL Family Alliance, Inc.

Section 3. Responsibilities: A Chapter will conduct all activities in an ethical manner as mandated in the VHL Family Alliance Chapter Guidelines, Affiliation Agreement, and other binding documents between the VHL Family Alliance and its Chapters.

Section 4. Non-U.S. Chapters and Affiliates: Chapters and Affiliates outside the United States may be authorized from time to time. A Chapter or Affiliate outside the United States will conduct all activities in an ethical manner as mandated in the VHL Family Alliance Chapter Agreement, Chapter By-laws, and other binding documents between the VHL Family Alliance and its Chapters, and in accordance with applicable local law. Membership moneys do not cross national boundaries, and will be used within the country in which they were collected.

ARTICLE XI -- CONTRACTS AND COMMITMENTS

Section 1. Authority: Unless specifically authorized by resolution by the Board of Directors or as authorized by Board policy, no officer, agent, employee, or member of the Board of Directors, shall have the power or authority to bind the VHL Family Alliance by any contract or engagement or pledge its credit or financially obligate it for any purpose in any amount.

Section 2. Signatories: All checks or drafts drawn on the VHL Family Alliance accounts shall be signed in accordance with the resolutions of the Board of Directors.

ARTICLE XII - CORPORATE SEAL

Section 1. Seal: The seal of the Corporation shall be circular in form and shall have inscribed thereon the name of the Corporation, the year of its organization, and the word "Massachusetts". Duplicate copies of the corporate seal may be provided for use in the different offices of the Corporation, but each copy shall be in the custody of the Secretary of the Corporation.

ARTICLE XIII - FISCAL YEAR

Section 1. Dates: The fiscal year of the Corporation shall begin on July 1 and end on the last day of June.

ARTICLE XIV -- RESTRICTIONS

Section 1. Activities: The Corporation shall neither have nor exercise any power, nor shall it engage directly or indirectly in any activity that could invalidate its status as a corporation exempt from Federal Income Taxation, as described by section 501(c)(3) of the Internal Revenue Code of 1986; or as a corporation, contributions to which are deductible under section 170(c)(2) of the Internal Revenue Code of 1986.

Section 2. Funds: No part of the net earnings of the VHL Family Alliance shall inure to the benefit of, or be distributable to its members, Directors, officers, or other private persons, except that the Board of Directors shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in the VHL Family Alliance Certificate of Incorporation.

ARTICLE XV -- AMENDMENTS

The Board of Directors shall have the power and authority to amend, alter, or repeal these By-laws or any provisions thereof, and may from time to time make additional By-laws.

As amended and approved by the Board of Directors on the 20th day of June, 2003.