

**BY-LAWS
OF THE
PKU ORGANIZATION OF ILLINOIS**

ARTICLE ONE

General

1.01 Introduction. These By-Laws constitute the code of rules adopted by the Board of Directors of the PKU Organization of Illinois (hereinafter the "Organization") for the regulation and management of its affairs.

1.02 Purposes and Powers. The Organization has such purposes as are stated in its Articles of Incorporation and such powers as are now or may hereafter be granted by the General Not-For-Profit Corporation Act of Illinois or any successor legislation.

1.03 Objectives. In furtherance of, and pursuant to, the purposes stated in the Organization's Articles of Incorporation, the Organization has the following objectives:

- (a) To promote and support the achievements and services of Illinois PKU Clinics (University of Illinois, Rush-Presbyterian-St. Luke's and Children's Memorial Hospital) and other state, regional or national programs, when feasible;
- (b) To maintain a program for several regularly scheduled family-oriented events each year; to assist in the planning and implementation of the PKU Annual Meeting and other educational projects, and to continue a regular informational newsletter;
- (c) To act as a liaison with other local, state or federal organizations devoted to the study, treatment, and representation of individuals with PKU or other inborn errors of metabolism; and,
- (d) To raise funds to support the activities sponsored by the Organization.

1.04 Limitations on Activities. Notwithstanding any other provision of the Organization's Articles of Incorporation or these By-Laws, the Organization shall not conduct or carry on any activity not permitted to be conducted or carried on by an organization exempt from taxation under Section 501(c) (3) of the Internal Revenue Code of the United States and its Regulations, as they now exist or may hereafter be amended, or by an organization, contributions to which are deductible under Section 170(c) (2) of the Internal Revenue Code of the United States and its Regulations, as they now exist or may hereafter be amended.

ARTICLE TWO

Office and Agents

2.01 Principal office. The principal office of the Organization in Illinois is:

PKU Organization of Illinois
P.O. Box 102
Palatine, Illinois 60067
(630) 415-2219

The principal office of the Organization in Illinois may be located at such places as the Board of Directors from time to time may designate by resolution.

2.02 Location of Registered Office. The registered office of the Organization may, but need not be the same as its principal office. The address of the registered office will be identical to the office of the Registered Agent of the Organization. Such office will be continuously maintained within the State of Illinois for the duration of the Organization's existence. The Board of Directors may from time to time change the address of its registered office by duly-adopted resolution and submission of the appropriate statement to the Secretary of State's office.

2.03 Registered Agent. The Registered Agent of the Organization may be either an individual resident in the State of Illinois or a domestic or foreign corporation, authorized to act as such agent. Such an agent will be continuously maintained by the Organization in the State of Illinois. A new Registered Agent may be appointed if the office becomes vacant for any reason, or such agent becomes disqualified or incapacitated to act, or if the Organization through the Board of Directors revokes the appointment of such agent by duly-adopted resolution and submission of the appropriate statement to the Secretary of State's office. Such Registered Agent will be recognized as an agent of the Organization on whom any process, notice, or demand required or permitted by law to be served on a corporation may be served.

ARTICLE THREE

Membership

3.01 Classes of Members. The Organization shall have two classes of members, which are designated as Voting Members and General Members.

3.02 Qualifications of Members. The qualification of members of the membership classes of the Organization are as follows:

(a) Voting Members. All individuals with phenylketonuria, or one of the following related disorders (Urea Cycle Disorder, Maple Syrup Urine Disease, Homocystinuria, Tyrosinemia, Glutaric Acidemia – Type 1, Methylmalonic Acidemia, Propionic Acidemia, Organic Acidemia) over the age of sixteen (16) residing in Illinois or attending an Illinois PKU Clinic and all members of their immediate families over the age of sixteen (16). For purposes of this subparagraph only, the term "immediate family" shall include parents, step-parents, foster parents, grandparents, legal guardians, spouses, siblings, and children. Voting members shall also include any other person whom the Board of Directors may designate by duly-adopted resolution upon the petition of such person submitted in the form to be designated by the Board. Any person who would otherwise qualify as a Voting Member under this subparagraph but for their having failed to attain the age of sixteen (16) years, shall upon attaining such age, automatically become a Voting Member.

(b) General Members. General Members shall include any person who would qualify as a Voting Member but for their having failed to attain the age of sixteen (16) years, and any other member of the general public who is so designated by duly-adopted resolution of the Board of Directors

following notification to the Board of Directors by such person of his or her desire to become a member.

3.03 Members' Dues. The Board of Director's, by duly-adopted resolution may from time to time, at its discretion, impose membership dues upon either the Voting Members or the General Members, or both, to support the purposes and goals of the Organization upon a determination that voluntary contributions and funds from other sources are insufficient to support such purposes and goals; provided, however, that such dues may not be imposed upon any member more than once during any calendar year.

3.04 Annual Meeting. The annual meeting of Members shall be held on the first Saturday of November of each year, or if such date is impracticable, then on such date within either one month before or after that date as determined by the Board of Directors, at a location determined by the Board of Directors, for the purposes of electing Directors and for the transaction of such other business as may come before the meeting.

3.05 Special Meetings. Special Meetings of the Members may be called only upon a duly-adopted resolution of the Board of Directors supported by a majority of sixty (60) percent of the Directors, or by a number or proportion of Voting Members having at least two-fifths of the votes entitled to be cast at such meeting.

3.06 Notice of Meetings. Written or printed notices of the Annual Meeting, stating the place, date and hour of the meeting will be published in the PKU Press or any successor newsletter, and/or may be specially noticed by mail, which shall be delivered not less than thirty (30) days prior to the date of such meeting. Written or printed notices of any special Meeting, stating the place, date, hour and the purposes of such meeting shall be published in the PKU Press or any successor newsletter, or noticed specially by mail, and must be delivered not less than fifteen (15) days before the date of such meeting. Notices of special meetings may be given to the entire membership or only the Voting Members at the discretion of the Board of Directors. If notice of any meeting is given in the PKU Press or any successor newsletter, the notice shall be deemed to be delivered three weeks (21 days) following deposit in the United States mail, postage prepaid, addressed to the Member at his or her address as it appears on the records of the Organization. Notices sent first class mail shall be deemed delivered five days after such deposit. If any matter is to be submitted to the Voting Members for approval, the notice of Annual or Special Meeting shall include a proxy for such vote.

3.07 Voting Rights of Members. Each Voting Member shall be entitled to one vote on each matter submitted to a vote of Members. General Members shall not be entitled to vote.

3.08 Members' Proxy Voting. A Voting Member may vote at any Annual or Special Meeting either in person, or by proxy executed in writing by the Member or by his or her duly-authorized attorney in fact which proxy must be delivered in person or by mail to the President at or before such meeting. No proxy will be recognized as valid after ten months from the date of its execution.

3.09 Voting by Ballot or Acclamation. Any matter may be voted upon by casting of ballots or by acclamation.

3.10 Quorum of Members. No minimum number or percentage of Voting Members need be present in person or by proxy to constitute a quorum at a meeting of Members. The vote of a majority of the votes entitled to be cast by the Voting Members present or represented by proxy at a meeting shall be necessary for the adoption of any matter voted on by the Voting Members, unless a greater proportion is required by the General Not-For-Profit Corporation Act or any provision of these By-laws.

3.11 Elections by Mail. In the election of Directors of the Organization, such election may be conducted by mail according to any procedure instituted and adopted by the Board of Directors.

ARTICLE FOUR

Directors

4.01 General Powers. Management of the affairs of the Organization shall be vested in its Board of Directors.

4.02 Qualification. Only Voting Members of the Organization may be elected to the Board of Directors.

4.03 Number and Tenure. The number of Directors of the Organization shall be eleven, until increased or decreased by amendment of these By-laws. Each director shall serve for a term of two years or until his or her successor shall be elected and shall have qualified. The terms of the Directors will be staggered as follows: five positions on the Board of Directors shall be filled by the vote of the Voting Members in even numbered years, and six positions in odd numbered years. No director may serve more than three consecutive terms, provided further that no director may hold the same office or position on the Board of Directors for more than two consecutive terms.

4.04 Vacancies. Any vacancy occurring in the Board of Directors shall be filled by appointment of the Board of Directors and such appointee shall serve until the expiration of the term of the Director whom he or she replaced.

4.05 Regular Meetings. The Board of Directors shall meet at, or within one month of, the Annual Meeting of Members for the purposes of electing the Officers. Regular meetings of the Board of Directors shall be held at such time as the Board of Directors may by resolution provide. To facilitate the participation of all interested members, the Board shall publish a schedule of Regular Meetings for the next calendar year in the final issue of the PKU Press or any successor newsletter for the previous calendar year. The Board of Directors shall endeavor to hold Regular Meetings at locations where teleconferencing is available so as to permit any member to attend the Regular Meeting in person or via telephone or teleconference.

4.06 Special Meetings. Special Meetings of the Board of Directors may be called at the request of any five directors or at the request of any Voting Members. Such requests shall be in writing and delivered to the Secretary of the Organization.

4.07 Notice of Meetings. Notice of the place, day and hour of any meeting of the Board of Directors and/or its Officers, other than the scheduled Regular Meetings, may be by telephone or by mail, and shall be accomplished by the Secretary of the Organization. Notice of a Special Meeting shall state the purpose of the meeting.

4.08 Quorum. A majority of the whole Board of Directors shall constitute a quorum. Except for the election of Officers, the act of a majority of the Directors present at a meeting at which a quorum is present will be the act of the Board of Directors unless a greater number is required under the provisions of the General Not-For-Profit Corporation Act, the articles of Incorporation of the Organization, or any provision of these By-laws.

4.09 Informal Action by Consent. Except for the annual election of Officers, any action which the Board of Directors may be empowered to take under law, the Articles of Incorporation of the Organization, these By-laws, or at a meeting of the Board of Directors, may be taken without a meeting if a consent in writing, setting forth the action so taken, is signed by all of the Directors.

ARTICLE FIVE

Officers

5.01 Number. The Officers of the Organization shall be a President, a Vice President, a Secretary and a Treasurer.

5.02 Selection and Tenure. The Officers of the Organization shall be elected annually by the Board of Directors from the membership of the Board of Directors at, or within one month of, their meeting held at the Annual Meeting of Members. A minimum of five votes shall be necessary to elect any officer. Each officer shall hold office until his or her successor shall have been elected and shall have qualified. No one individual may serve more than two consecutive terms in the same elective office. No one individual may serve more than three consecutive terms on the Board of Directors.

5.03 President. The President will be the principal Executive Officer of the Organization. Subject to the direction and control of the Board of Directors, he or she shall be in charge of, supervise and control the affairs of the Organization. The President may execute on behalf of the Organization any contract, other instrument or document which the Board of Directors has authorized. The President shall perform all duties as may be prescribed in these By-laws or from time to time by the Board of Directors.

5.04 Vice President. The Vice President shall perform all duties and exercise all powers of the President when the President is absent or is otherwise unable to act. The Vice President shall assist the President in the discharge of his or her duties and perform such other duties as from time to time may be assigned to him or her by the President or the Board of Directors.

5.05 Secretary. The Secretary shall: (a) record the minutes of the meetings of Members, the Board of Directors, or the Officers in one or more books provided for that purpose; (b) see that all notices are duly given in accordance with the provisions of these By-laws or as required by law; (c) be custodian of the corporate records and of the seal, if any, of the Organization; (d) keep a register of the post-office address of each Member which shall be furnished to the Secretary by such Member; (e) co-sign with the President, or Vice President, or any other Officer thereunto authorized by the Board of Directors, any contract, other instrument or document which the Board of Directors has authorized to be executed; (f) perform all duties incident to the office of Secretary and such other duties as from time to time may be assigned to him or her by the President or by the Board of Directors.

5.06 Treasurer. The Treasurer shall be the principal accounting and financial Officer of the Organization. He or she shall (a) have charge of and be responsible for the maintenance of adequate books of account for the Organization; (b) have charge and custody of all funds and securities of the Organization, and be responsible therefor, including for the receipt and distribution thereof; and (c) perform all the duties incident to the office of Treasurer and such other duties as from time to time may be assigned to him or her by the President or by the Board of Directors.

5.07 Honorary and Ex Officio Board Members. Beginning in 1998 and continuing thereafter, the Board of Directors shall include nonvoting Honorary Director positions, which shall be reserved for representatives from the Illinois PKU Clinics or other community-based organizations. The Board of Directors may appoint any retiring Officer or Director to a nonvoting honorary director ex officio position

for a period not to exceed one year for the purpose of providing a sufficient time for transfer and transition of all duties of such Officer or Director and to maintain and enhance continuity of such programs as may be on-going within or on behalf of the Organization. The number of Honorary and Ex Officio Board positions shall not exceed five. Honorary and Ex Officio Board Members shall have no authority to execute on behalf of the Organization any contract, other instrument or document.

5.08 Meeting of the Officers. The Officers of the Board of Directors may, from time to time, meet via telephone or in person to conduct such business as is authorized by the Articles of Incorporation or the Bylaws. All Officers must be in attendance at such meetings. Minutes of such meetings shall be kept and shall be communicated to the full Board of Directors prior to the next Regular or Special Meeting and all action taken by the Officers at such meeting shall be submitted to the full Board of Directors for ratification.

ARTICLE SIX

Committees

6.01 Authorization of Committees. The Organization may have one or more Committees as may be from time to time established by resolution of the Board of Directors. Each such committee shall consist of at least one Director and any number of other interested Voting or General Members and may have and exercise whatever prescribed authority may be designated by the Board of Directors. However, no such Committee will have the authority of the Board in reference to affecting any of the following: Articles of Incorporation; By-laws; resolution of the Board of Directors which by its terms provides against such action by a Directorial Committee; or voluntary dissolution or plan of asset distribution of the Organization.

6.02 Nominating Committee. The Nominating Committee shall constitute the sole Standing Committee of the Organization. It shall be the function of the Nominating Committee to present the slate of directors to the Voting Members for election. The slate may consist of one or more names for each director's position available. The Nominating Committee shall consist of a Chair and four additional Members selected by the Board of Directors from the Voting Membership, giving due regard to geographical representation and clinic affiliation. The Chair of the Nominating Committee shall be the most recent past president who is still a qualified Voting Member. If there is no person in this capacity who is able or willing to serve as Chair, then the most recent past vice president who is qualified shall serve. If there is no person in either capacity who is able or willing to serve, then the current president shall serve as Chair. The Board of Directors shall solicit nominations for and appoint the Membership of the Nominating Committee at the Annual Meeting. The Nominating Committee shall present to the Voting Members its slate of nominees for the Board of Directors as well as additional nominations by petition, by the date, and in the manner, as shall be designated by resolution of the Board of Directors. Such resolution of the Board of Directors shall be communicated to all Voting Members by July 15 of each year by publishing such resolution in the PKU Press or any successor newsletter.

6.03 Committee Chair - Duties and Removal.

(a) It shall be the duty of each Committee Chair to preside over the meetings of such Committee; to submit a written report to the President of the proceedings of each meeting of the Committee; to present to the President an annual report of the Committee's activities and accomplishments no later than the date of each Annual Meeting of Members, and to ensure that the Committee faithfully carries out the duties and responsibilities imposed upon it by these By-laws or the Board of Directors.

(b) The President may ask a Chair to resign before the expiration of the period for which he or she was appointed, if he or she is remiss to carrying out his or her duties. If such Chair refuses to resign, the President may, with the approval of a majority of the Board, remove such Chair from office. No such removal may be accomplished unless the Chair sought to be removed has been given an opportunity to be present at the Board Meeting at which reasons for his or her removal are discussed and to present rebuttal.

ARTICLE SEVEN

Operations

7.01 Fiscal Year. The fiscal year of the Organization shall end on December 31 of each year.

7.02 Contracts. The Board of Directors may authorize any Officer or Officers, agent or agents, to enter into any contract, or execute and deliver any instrument in the name of and on behalf of the Organization and such authority may be general or confined to specific instances.

7.03 Loans. No loans shall be contracted on behalf of the Organization and no evidences of indebtedness shall be issued in its name unless authorized by a resolution of the Board of Directors. Such authority may be general or confined to specific instances.

7.04 Checks. Drafts. etc. All checks, drafts or other orders for the payment of money, notes or other evidences of indebtedness issued in the name of the Organization, shall be signed by such Officer or Officers, agent or agents of the Organization and in such manner as shall from time to time be determined by resolution of the Board of Directors.

7.05 Deposits. All funds of the Organization not otherwise employed shall be deposited from time to time to the credit of the Organization in such banks, trust companies or other depositaries as the Board of Directors may select.

7.06 Books and Records. The Organization will keep correct and complete books and records of account, including minutes of meetings of Members, Board of Directors and Directorial Committees. The Organization will keep at its principal office a record giving the names and addresses of its Voting and General Members.

7.07 Seal. The corporate seal, if any, shall have inscribed thereon the name of the Organization and the words "Corporate Seal, Illinois". The seal may be used by causing it or a facsimile thereof to be impressed, affixed or in any manner reproduced.

ARTICLE EIGHT

Removal

8.01 Removal proceedings against any elected officer must originate within the Board of Directors and shall be passed by a vote of seventy-five percent of the total Board serving at the time of the vote in favor of removal.

8.02 Removal proceedings against any other members of the Board of Directors may originate within the Board of Directors or may be requested by the motion of any Voting Member. Within thirty days of receipt of the motion to remove, the Board of Directors shall conduct removal proceedings. Removal proceedings may be conducted at a Regular Meeting or at any Special Meeting. A vote of seventy-five percent of the total Board serving at the time of the vote shall be required to remove.

8.03 Removable Offenses. For purposes of these Bylaws, removable offenses shall include the following: (i) the continued willful or deliberate failure of the Officer or Director to perform his or her duties in a manner substantially consistent with the manner prescribed by the Board, (ii) the engaging by the Officer or Director of willful misconduct materially and demonstrably injurious to the Organization, or (iii) the Officer's or Director's failure to attend three consecutive Board Meetings, unless such absences are excused. With reference to any removal under clauses (i) or (iii) of this Section, the continued willful and deliberate failure of the Officer or Director to perform his or her duties or to attend Board Meetings shall not be deemed to have occurred unless and until the Officer or Director has been given written notice by the Board describing such failure(s) and the Officer or Director does not cure such failure(s) within thirty (30) days of such notice.

ARTICLE NINE

Amendment

9.01 The power to make, alter, amend or repeal these By-laws of the Organization shall be vested in the Board of Directors, provided that, these By-laws may be amended by a two-thirds vote of those Voting Members present in person or by proxy at the Annual Meeting of Members. Any Voting Member may propose an Amendment, provided however, that any proposed amendment must be submitted in writing to the Secretary of the Association no later than July 15 for publication in the PKU Press.

ARTICLE TEN

Parliamentary Procedures

10.01 In all cases not covered by the General Not-For-Profit Corporation Act of the State of Illinois, the rules contained in Roberts Rules of Order, Revised, shall govern this corporation's meetings when applicable.

ARTICLE ELEVEN

Amendments

11.01 These bylaws may be amended by a two-thirds vote of those members in good standing present and voting at a general meeting after proper notice has been given. Any member can propose an amendment.

ARTICLE TWELVE

Interpretation

12.01 Where appropriate, words of masculine gender include the feminine and words used in the plural of collective sense include the singular and vice versa.

The foregoing By-Laws of the PKU Organization of Illinois, as revised, were adopted by the unanimous approval of the Directors in attendance at the Annual Meeting held on the 12th day of November 2005, as attested by their individual signatures below.

Revised 2005