

## ARPKD/CHF ALLIANCE-BY-LAWS

### ARTICLE I-NAME, LOCATION, PURPOSES

Section 1.01: Name. The name of this corporation is ARPKD/CHF Alliance.

Section 1.02: Principle Office. The principal office of the Corporation is in Pennsylvania.

Section 1.03: Purposes. The purposes of the corporation are set forth in its “Articles of Organization”. The ARPKD/CHF Alliance is organized exclusively for charitable purposes, established specifically to “educate, advocate, support and advance research for Autosomal Recessive Polycystic Kidney Disease and Congenital Hepatic Fibrosis” to improve the lives of those affected by ARPKD and CHF.

### ARTICLE 11-MEMBERS

Section 2.01: No Members. The Corporation shall have no “members” and no dues. Actions/votes shall consist by members of the Board of Directors.

### ARTICLE III –MEETINGS

Section 3.01: Organizational meetings. The meeting date, time and place shall be set by the Board of Directors. Every meeting of the Board shall be presided over by the President or Executive Director, or if so decided by Directors, the Vice-President or elected/appointed Chairperson of the Board. In the absence of the President, a chairperson shall preside, chosen by the President. In the absence of the Secretary, a person shall be appointed to act as Secretary and in the absence of the Treasurer, a person shall be appointed as Treasurer, by the person presiding or chairing the meeting. The person presiding or chairing the meeting may prepare an agenda and shall coordinate the meeting. He/she may limit discussion in order to proceed expeditiously with the business of the meeting, to assure that the meetings are effectively conducted and shall cast a deciding vote on deadlocked issues. Directors shall transact business as may properly be brought before the meeting. At such meetings:

(a) Annual and Regular Meetings. Determined by the Board of Directors these may be held at such place and time as designated by standing resolution of the Board. These provide for the election of Directors, the election of Officers, and the transaction of any other business which may be brought before the meeting.

b) Special Meetings. Special meetings may be called by the President, Vice-President, Chairperson, the Executive Committee or by the request of one-third of the Board Directors.

Section 3.02: Notice. Advance notice of Annual and/or Regular meetings is 2 weeks, this shall be given by email, phone call, fax or mail. Notice of each special meeting shall be

given to each Director, either by email, phone call, fax or mail before the meeting at least 24 hours in advance.

Section 3.03: Participation in Meetings. Members of the Board of Directors may participate in a meeting of the Board by means of a teleconference call or similar communications equipment by means of which all persons participating in the meeting can interact, respond and cast vote. Participation by such means shall constitute presence in person at a meeting, so long as proper notice is given.

Section 3.04: Quorum. A majority of the Directors shall constitute a quorum, unless the Directors decide a different quorum percentage is needed prior to a meeting. The acts of a majority of the Directors present at a meeting at which a quorum is present shall be the acts of the Board.

Section 3.05: Voting. What constitutes business to be transacted or motions passed, is a majority vote, unless a different percentage is deemed necessary by the Board of Directors with advance notice. Discussion is always encouraged prior to voting, so all relevant questions, information and concerns have been voiced. Any absent Director entitled to vote at any meeting of the Board may be represented by a proxy vote, per email, fax or mail and must be received prior to a meeting. Such must clearly specify the matter it pertains to, must be dated, with Director's name granting the proxy, and must be filed with meeting minutes.

Section 3.06: Action by Consent. In the interval between meetings, actions may be taken by ballots, received either by email, fax or mail, provided that the majority of return votes are within the stated time frame. These shall be filed with permanent records and shall have the same force and effect as the affirmative ballot at a noticed meeting.

#### ARTICLE IV - BOARD OF DIRECTORS

Section 4.01: Board of Director Role. The terms Board Director and Board Member may be used interchangeably, with the same meaning. The business and affairs of the Corporation shall be managed under the direction of the Board. The powers of the Corporation shall be exercised by, or under the authority of the Board, except as otherwise provided by statute, these Bylaws, or a resolution of the Board. The Board is responsible for overall policy and direction (governance) of the ARPKD/CHF Alliance, and it's delegates responsible for day-to-day operations. The powers of the Board of Directors will include any other powers permitted by law.

Section 4.02: Size, Compensation. The Board shall not have less than one and no more than twelve members. The board receives no compensation other than reasonable reimbursement of expenses for their services as such.

Section 4.03: Board Elections. Election of new Directors or election of current Directors may occur at any meeting of the corporation with advance notice. When a vacancy on the Board exists, Director nominations may be made by any Director or Officer. These

nominations shall be sent out to Board members with Board meeting announcement and agenda, to be voted upon at the next Board meeting. Directors will be elected by a majority vote and may hold consecutive terms.

Section 4.04: Terms and Tenure. All Board members shall commit to serve an initial one-year term, with the potential for a two-year re-election, or length of term determined by Directors, following a self-evaluation after one-year and periodically. Each Director shall be elected to hold office until the expiration of the term for which he or she was elected, or until his or her successor has been elected and qualified, or his/her death, resignation, or removal, determined by Director resolution, and any Director may resign by delivering his/her written resignation to the Corporation at its principal office. Each person elected to replace a Director during a term, shall be a Director to serve for the balance of the unexpired term, with potential for reelection.

Section 4.05: Resignation, Termination/Removal. Resignation shall be effective upon receipt unless it is specified to be effective at some other time or upon the happening of some other event. Resignation from the Board must be in writing and received at the corporate office. A Board Director may be dropped for excess absences from Board meetings. A Board Director may be removed by a majority vote of the remaining Directors at any meeting of the Board with advance notice.

Section 4.06: Vacancies. In the event of vacancy, the remaining Directors may exercise the powers of the full board.

Section 4.07: Enlargement of the Board. The Board of Directors may be enlarged by any meeting by a majority vote of the Directors then in office.

## ARTICLE V-OFFICERS

Section 5.01: Officers. The Officers of the Corporation shall consist of a President/Executive Director, a Treasurer, and a Secretary. Directors may appoint other officers as it shall deem desirable, including but not limited to Vice-President, Chair, Vice Chair, Clerk, Assistant Secretary, Editor. Officers have the authority to perform duties from time to time, those of the Board of Directors, and/or serve as Directors with said responsibilities. Officers may hold more than one office, except President may not be Treasurer.

Section 5.02: Officer Election. The Officers of the corporation shall be elected at any meeting of the Board of Directors during which there is a vacancy for that office. When a vacancy in an Office exists, nominations may be made by a Director or Officer. These nominations shall be sent out to Directors with the Board meeting announcement and agenda, to be voted upon. Vacancies in an Office, including vacancies resulting from an increase in the number of Officers, shall be decided by a majority vote of the current Directors.

Section 5.03: Terms and Tenure. All Officers shall commit to serve an initial one-year

term, with the potential for a two-year re-election, or length of term determined by Directors, following a self-evaluation after one-year and periodically. Each person elected to replace an Officer during a term, shall be an Officer to serve for the balance of the unexpired term, with potential for reelection or until his or her successor has been elected and qualified. Consecutive terms may be served.

Section 5.04: Resignation, Termination/Removal. Resignation shall be effective upon receipt unless it is specified to be effective at some other time or upon the happening of some other event. Resignation as an Officer must be in writing and received either by the President or Secretary. An Officer may be dropped or removed by the Directors at any meeting of the Board with advance notice, by a majority vote. Any Officer may be removed if in the Director's judgment the best interests of the corporation would be served thereby, but such removal will be without prejudice to the contract rights, if any, of the officer so removed.

Section 5.05: Vacancies. In case of a death, absence or incapacity of the President, the Vice-President will assume the role of President, if no Vice-President, Secretary assumes the President's role.

Section 5.06: Duties of Officers. The officers of the Corporation shall serve at the pleasure of the Board.

a) President: The President shall, unless otherwise provided by the Directors, be the Chief Executive Director; these terms may be used interchangeably, unless determined otherwise by the Directors. The Chief Executive Director of the Corporation shall in general, subject to the direction of the Directors, supervise and carry out the day-to-day business operations and corporate affairs, subject to the control of the Board. Including but not limited to provide advertising in publications, participating in events/meetings, advocating/promoting the ARPKD/CHF Alliance's mission statement and purpose, except where the execution is expressly delegated elsewhere by the Board of Directors. He/she has the authority, acting alone or jointly, to sign checks and other documents/contracts on behalf of the Corporation and shall maintain appropriate, complete, and accurate books, or records of account(s) kept at the principal office with summaries provided to the Treasurer. The President shall represent the ARPKD/CHF Alliance to outside agencies and to fulfill the goals of the ARPKD/CHF Alliance, may appoint Professional Advisory Board members, committees and volunteer roles, subject to the direction and control of the Board of Directors, and assures that duties are fulfilled.

b) Vice-President: Becomes Acting-President and assumes the duties of President in the event of death, absence, incapacity, resignation, inability or otherwise, and/or other duties assigned by the Board of Directors.

c) Secretary: The Secretary shall be responsible for keeping records of Board meetings and actions, including overseeing the taking of minutes and votes at all board meetings, and if so decided, sends out meeting announcements, distributing copies of minutes and the agenda to each Board members. He/she assures that corporate records are maintained by keeping a copy of all minutes of Board meetings, amendments and annual financial

reports, kept at a location other than that of the principal office for the purpose that a fire would not destroy both original and copies.

In his absence of the Secretary, a temporary or assistant Secretary shall be present, to take minutes of the meeting of the Directors. An Assistant Secretary, if so elected, shall have powers as the Directors may designate.

d) Treasurer. The treasurer shall receive from the Executive Director a yearly summary which will be mailed, emailed or faxed to him/her by the Executive Director. He/she shall make a report at least annually, and if so deemed, at other Board meetings. If such powers are provided by the Directors, the Treasurer may sign checks on behalf of the Corporation, have authority to receive and give receipts for money due and payable to the Corporation, endorse checks, drafts, and warrants in its name, on its behalf and to give full discharge for the same, or deposit funds of the Corporation, except such as may be required for the current use, in such banks or other places of deposit as the Board. Treasurer shall notify the President and/or Board members of any situations that require action, and shall respond to all inquiries from Board Members or Officers regarding the fiscal operation.

Annual reports submitted to the Board are required to show income, assets, liabilities, expenditures, revenue, expenses, disbursements and pending income. The financial records of the organization are public information and shall be made available to the Board Members and the public. The Treasurer may request any financial records from the Executive Director at any time and may require an audit of the books at any time. Treasurer may chair the finance committee, assist in the preparation of the budget, develop fundraising plans, and make financial information available to Board Members and the public. Any major change in the budget must be approved by the Board or the Executive Committee.

Section 5.07: Other Powers and Duties. Each officer shall, subject to these by-laws, have in addition to the duties and powers specifically set forth in these by-laws, such duties and powers as are customarily incident to his/her office, and such duties and powers as the Directors may from time to time designate. Officers shall exercise good conservative judgement in completing duties as accepted or assigned.

## ARTICLE VI-PROFESSIONAL ADVISORY BOARD

Section 6.01: Professional Advisory Board Role. An Advisory Board Member's role and function is to serve the corporation with activities of review, education, resources, research, support, recommendations, articles, awareness, funding, and/or as a consultant with professional or medical information on issues pertaining to ARPKD and CHF. Members must be supportive of the corporation's mission statement; functions provided are dependent on the willingness and expertise of each member.

Section 6.02: Terms. Professional Advisory Board members may be appointed or

elected. There is no limit to the terms a member may serve.

Section 6.03: Removal of Professional Advisory Board Member. Any member of the Advisory Board may be removed from office by a majority vote of the Board at any meeting of the Board.

Section 6.04: Resignations. Any member of the Advisory Board may resign at any time by giving written notice to the Corporation. The resignation shall be effective upon receipt by the Corporation or at such subsequent time as may be specified in the notice of resignation.

## ARTICLE VII – COMMITTEES

Section 7.01: Creation of Committees. The Board or Executive Director, under the direction of the Directors, may create committees, such as Fundraising, Program Development, Marketing, Public Relations, etc. to support the mission statement and purposes of the ARPKD/CHF Alliance. Each committee shall keep minutes of its proceedings, and report to the Board periodically. Any such committee may make rules for the conduct of its business, unless determined otherwise by the Directors, and its business shall be conducted as nearly as may be, in the same manner as is provided by these by-laws. No committee on its own, including the Executive Committee shall have any power or authority as to the following.

- a.) The filling of vacancies in the Board.
- b.) The adoption, amendment, or repeal of the Bylaws.
- c.) The amendment or repeal of any resolution of the Board
- d.) Action on matters committed by the Bylaws or by resolution of them

Section 7.02: Executive Committee. Officers serve as the members of the Executive Committee, unless deemed differently by the Directors. Except for the power to amend the Articles of Incorporation and Bylaws, the Executive Committee shall have the power and authority of the Board of Directors in the intervals between meetings of the Board of Directors, subject to the direction and control of the Board of Directors.

## ARTICLE VIII-MISCELLANEOUS PROVISIONS

Section 8.01: Headings. In interpreting these Bylaws, the headings of articles shall not be controlling.

Section 8.02: Fiscal Year. The fiscal year of the Corporation shall be the twelve (12) months beginning on the first day of January and end on the last day of December.

Section 8.03: Corporate Records. The original, or attested copies, of the Articles of Organization, Bylaws, amendments and records of all meetings shall be kept at the principal office of the Corporation or at an office of its transfer agent. Additionally the corporation shall keep correct and complete books and records of account(s). Said copies

and records need not all be kept in the same office. They shall be available at all reasonable times to the inspection of any Director for any proper purpose but not to use the same for a purpose other than in the interest of the applicant, relative to the affairs of the Corporation.

Section 8.04: Articles of Organization. All references in the Bylaws to the Articles of Organization shall be deemed to refer to the Articles of Organization of the Corporation, as amended and in effect from time to time.

Section 8.05: Limitation on Amendments. Notwithstanding the foregoing, no amendment shall authorize or permit the Corporation to be operated other than exclusively for charitable purposes as will permit the Corporation to continue to qualify for exemption from taxation under Section 501(c)(3) of the Internal Revenue Code of 1986 as now in force or hereafter amended.

Section 8.06: Sponsors, Benefactors, Contributors, Advisers, Friends of the Corporation. Certain persons or groups of persons may be designated as sponsors, benefactors, contributors, advisers, or friends of the Corporation or such other title as deemed appropriate. Such persons shall serve in an honorary capacity and, except as otherwise designated, shall in such capacity have no right to notice of or to vote at any meeting, shall not be considered for purposes of establishing a quorum, and shall have no other rights or responsibilities.

Section 8.07: Indemnification.

Each Director and Officer of the Corporation, and any person who, at the request of the Corporation, serves as a Director or Officer of another organization, shall be indemnified by the Corporation. This is against costs/expenses, attorney's fees, judgment, liability and or amount paid in settlement, reasonably incurred by or imposed upon him/her in connection with any action, suit, or proceeding (including any proceeding before any administrative or legislative body or agency), to which he/she is made party or otherwise involved or with which he/she is threatened, by reason of Director or Officer status, (whether or not he/she continues to be an Officer or Director of the Corporation), so long as such person did not act with recklessness or willful misconduct in their performance, but in good faith and in the best interests of the Corporation, in the absence of fraud and not opposed to the Corporation. Such person is to repay such payment if it is determined that such person is not entitled to indemnification. This section shall not affect any rights to indemnification to which corporate personnel other than Directors and officers may be entitled by contract or otherwise under law. This section shall be subject to amendment or repeal by action of the Directors.

Section 8.08 Nondiscrimination. The ARPKD/CHF Alliance shall not discriminate against any person(s) based on race, ethic, religious or sexual orientation.

## ARTICLE VIII – AMENDMENTS

Section 9.01: Amendment of Bylaws. These by-laws may be amended or repealed, in whole or in part, and new by-laws adopted if so authorized by the Board of Directors at any meeting of the Board with advance notice, by a majority vote of the Directors then in office. Proposed amendments must be submitted and sent out with advance notice.

Bylaws of the ARPKD/CHF Alliance adopted March 2001

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Addendum, October 27, 2005

Upon the dissolution of the corporation, the ARPKD/CHF Alliance shall, after paying or making provisions for the payment of all the liabilities of the corporation, dispose of all assets of the corporation exclusively for the purposes of the corporation in such a manner, or to such organizations organized and operated exclusively for charitable, educational, religious, or scientific purposes as shall at the time qualify as an exempt organization or organizations under section 501c3 of the Internal Revenue Code of the 1986, as the Board Members shall determine. Any such assets not so disposed of shall be disposed of by the Court of Common Pleas of the county in which the principle office of the corporation is then located, exclusively for such purposes or to such organization or organizations, as said court shall determine, which are organized and operated exclusively for such purposes.