

CYSTINOSIS RESEARCH NETWORK, INC.

BYLAWS

Revisions January 2026

Article I: Name and Location

Section 1 – Name. The name of this corporation is the **Cystinosis Research Network, Inc.**, (CRN). Cystinosis Research Network is a non-profit tax-exempt organization founded in 1996.

Section 2 - Principal Office. The principal office of the Cystinosis Research Network is located at PO Box 702, Lake Forest, IL 60045.

Article II: Vision, Mission and Purpose

Section 1 – Vision and Mission. The Cystinosis Research Network’s vision is the discovery of improved treatments and ultimately a cure for cystinosis. The Cystinosis Research Network (CRN) is a volunteer, non-profit organization dedicated to advocating and providing financial support for research, providing family assistance and educating the public and medical communities about cystinosis.

Section 2 - IRC Section 501 (C) (3) Purposes. The Cystinosis Research Network is organized exclusively for one or more of the purposes as specified in Section 501 (C) (3) of the Internal Revenue Code. The Cystinosis Research Network may make disbursements in the form of grants or contracts to organizations that qualify as exempt under Section 501(c) (3) of the Internal Revenue Code of 1996 (or the corresponding provision of any future United States Internal Revenue law.) The Cystinosis Research Network, its directors and its officers shall not be empowered to engage in any objectives other than as described herein. Notwithstanding any other provision of these articles, the corporation shall not carry on any other activities not permitted to be carried on: (A) by a corporation exempt from Federal income tax under section 501(c)(3) of the Internal Revenue Code of 1996 (or the corresponding provision of any future United States Internal Revenue law) or B) by a corporation, contributions to which are deductible under Section 170 of the Internal Revenue Code of 1996 (or the corresponding provision of any future United States Internal Revenue law

Section 3 - Statement of Purpose. The following highlight key elements of the Cystinosis Research Network’s purpose:

- a) To further the advancement of study, research, therapy and cure of cystinosis;

- b) To collect and disseminate accurate and objective information regarding the cause, identification, treatment, prediction, prognosis, analysis, prevention and cure of cystinosis;
- c) To develop the understanding and awareness of cystinosis;
- d) To promote the general welfare of those with cystinosis;
- e) To support individuals and families in coping with cystinosis;
- f) To conduct other activities aimed at the prevention, treatment, and eradication of cystinosis.

Article III: 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. All Board members shall be required to actively serve on at least one standing committee. Board members who reside outside the United States do not have input on matters regarding the disposition of funds collected within the United States.

Section 2. Membership. The Board of Directors (the “Board”) shall consist of Board members and Officers who constitute the Executive Committee. Each director shall be of good moral character and have the skills, commitment, and dedication necessary to promote the mission of the Cystinosis Research Network. The Board of Directors hierarchy is: The Executive Committee and The Board Members/Directors.

Section 3. Executive Committee: Officers. The Officers shall consist of the:

- a) President
- b) Vice President for Research
- c) Vice President for Development
- d) Vice President for Education and Awareness
- e) Vice President for Family Support
- f) Secretary
- g) Treasurer

Section 4. 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 cystinosis.

- b. The term of service of the Officers and Board Members will be staggered. The initial terms for the President, Vice President for Education and Awareness, Vice President of Family Support and the Treasurer shall be three years. After the first term, the second term will be for two years. The term of office will continue to stagger from three years to two years. The initial terms for the Vice President for Research, Vice President for Development and Secretary shall be for two years. The subsequent term will be for three years. The term of office will continue to stagger from three years to two years. A vacancy on the Board of Directors and Executive Committee shall be filled by appointment of the President in consultation with the Executive Committee. Board Members or Officers shall be limited to two consecutive terms of three years. If there is a need that supersedes this limitation, then a Director may succeed for a third term by majority approval of the Executive Committee and the Board of Directors.

Section 5. Nomination and Appointment to the Board of Directors:

- a. Nomination: Any member in good standing may nominate a member in good standing for consideration for appointment to the Board of Directors. Members will review the qualifications of the candidate and forward the nomination, along with any pertinent information about the candidate, to the Nomination Committee of the Board of Directors. This nomination can take place at anytime during the year. The membership will be notified as board positions expire or otherwise become available via the CRN website (www.cystinosis.org), or in writing if requested.
- b. The Nominating Committee will provide the Board with a slate of candidates for consideration for appointment to the Board of Directors as vacancies occur. The Board will review the slate of candidates and appoint qualified members to the Board of Directors based upon the needs of the Cystinosis Research Network. This process will take place during the month of July, unless circumstances dictate otherwise.
- c. The Board of Directors will appoint by majority vote, new members to the Board based upon the needs of the organization. This process will take place on an annual basis if necessary in the month of July. However, based upon the needs of the organization, this process can be altered. The primary goal of the appointment process is to ensure that the Board has the appropriate number of qualified members to manage the affairs and meet the goals and mission of the Cystinosis Research Network. The Board will post the names of the new Directors to the CRN website (www.cystinosis.org) after their appointment.

Section 6. Qualifications: Directors shall be members of the Cystinosis Research Network in good standing. They will be of good moral background and possess the skills required by the position or office that they hold. They must not participate in, or have previous involvement in activities that would discredit or detract from the stated mission of the Cystinosis Research Network.

Section 7. Vacancies: At any time during year, the Board may appoint, by majority vote, a replacement or new Director. This expedited process should only take place in situations where the needs of the organization outweigh following the traditional process.

Section 8. 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 Cystinosis Research Network. Any director who decides to resign prior to the end of their term shall notify the Secretary in writing of the resignation with an effective date of resignation provided in the notice.

Section 9. Advisors to the Board of Directors

The Board shall appoint Professional and Medical Advisory Committees and a Scientific Review Board and any other advisors it deems necessary who will be indemnified in the same manner as the directors. Duties as assigned by the Board.

Section 10. Indemnification. The Cystinosis Research Network shall indemnify any board member made a party to any proceeding by reason of service as a board member if the director acted in good faith and, in the case of conduct as a director, that such conduct was in the best interest of the Cystinosis Research Network and in all other cases, that the conduct was not opposed to the best interest of the Cystinosis Research Network. However, there shall be no indemnification if it is proved that (a) the act or omission of the board member was material to the cause of action adjudicated in the proceeding and (b) was committed in bad faith, or was the result of active and deliberate dishonesty, or the board member actually received an improper personal benefit in money, property, or services or, in the case of any criminal proceeding, the board member had reasonable cause to believe that the act or omission was unlawful. The board members and officers of the Cystinosis Research Network shall not be liable to the Cystinosis Research Network or its members for money damages (a) except to the extent that it is proved that the board member or officer actually received an improper benefit or profit in money, property, or services or (b) except to the extent that a judgment or other final adjudication adverse to the person is entered in a proceeding based on a finding that the person's action or failure to act was the result of active and deliberate dishonesty and was material to the cause of action adjudicated in the proceeding.

Section 11. Conflict of Interest. Board members and staff are expected to avoid even the appearance of a conflict of interest and shall excuse themselves from involvement in any decision where a conflict might appear to exist

Section 12. 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 IV – Board Meetings

Section 1. Regular Meetings: The Board of Directors shall meet at least three (3) times per year, with one (1) meeting per year in person when funding and timing considerations allow. 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 and place 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 President, 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. All meetings of the Board of Directors shall be governed by the most current edition of Roberts Rules of Order.

Article V: Executive Committee

Section 1. Membership. The Executive Committee shall consist of the seven Officers of the Cystinosis Research Network.

Section 2. Duties

A. Executive Committee - The Executive Committee shall oversee the affairs of the Cystinosis Research Network during periods between meetings of the Board. The Executive Committee shall do such acts and perform such duties as shall be specified in these bylaws, together with such other acts and duties as are not otherwise provided for herein to be performed by other persons. The Executive Committee shall at all times be responsible to the Board. The Executive Committee shall review the annual budget presented by the Treasurer. The Executive Committee shall serve without compensation. However, they may be reimbursed for their documented expenses on behalf of the Cystinosis Research Network, funds and budget permitting.

B. Executive Director- The Executive Director is the chief administrator of the Cystinosis Research Network and is primarily responsible for the overall operation of the Cystinosis Research Network and supervision of its staff and programs. The Executive Director is not

a member of the Board of Directors. The Executive Director position may however be held concurrently by a member of the Board of Directors or may be filled separately. The Executive Director carries out day to day administrative requirements of the organization, implements policies set by the Board, promotes achievement of the Cystinosis Research Network mission objectives and is directly responsible to the Board.

Section 3. Meetings and Quorum. The Executive Committee shall hold such meetings as it deems necessary upon such notice as it shall from time to time determine necessary and three members shall constitute a quorum for the transaction of all business of the committee. A majority of votes of those casting a ballot at any meeting shall be the act and deed of the Committee.

Section 4. Acts without a Meeting. The Executive Committee may, under such rules as it may from time to time prescribe, perform any or all of its acts or duties by mail, electronic communication or telephone without the necessity of a face-to-face meeting.

Article VI: Officers

Section 1. Order of Succession. In case of unexpected vacancy, immediate order of succession to the Presidency until such times that the Executive Committee can meet to appoint a successor will be:

- a) The Vice President for Research
- b) The Vice President for Development
- c) The Vice President for Education and Awareness
- d) The Vice President for Family Support
- d) The Secretary; and
- e) The Treasurer

Section 2. Duties

a) The President

1. shall preside at all meetings of the members, meetings of the Board and the Executive Committee;
2. shall appoint all ad hoc committees;
3. shall call emergency meetings and/or Executive Committee meetings; and
4. shall be an ex officio member of all committees.
5. shall oversee all Executive Committee member and Executive Director activities

b) The Vice President for Research

1. shall represent research interests on the Executive Committee and Board;
2. shall be responsible for strategic direction of all areas of research;
3. shall provide assistance and serve in an advisory capacity on Cystinosis Research Network assigned projects/activities at the request of the President;

4. shall collaborate with the Vice President for Education and Awareness, the Vice President for Family Support, and the Vice President for Development in building professional relationships;
5. shall oversee the Research Committee;
6. shall oversee activities of the Scientific Review Board;
7. shall oversee activities of the Medical Advisory Committee and the Professional Advisory Committee; and
8. shall oversee organization of the biennial Family Conference.

c) The Vice President for Development

1. shall represent development interests on the Executive Committee and Board;
2. shall be responsible for strategic direction of all areas of marketing and fundraising;
3. shall provide assistance and serve in an advisory capacity on Cystinosis Research Network assigned projects/activities at the request of the President;
4. shall collaborate with the Vice President for Research, the Vice President for Education and Awareness, and the Vice President for Family Support in building family and professional relationships; and
5. shall oversee the Development Committee.

d) The Vice President for Education and Awareness

1. shall represent the interests of individuals and families affected by cystinosis on the Executive Committee and Board;
2. shall provide assistance and serve in an advisory capacity on Cystinosis Research Network assigned projects/activities at the request of the President;
3. shall collaborate with the Vice President for Research, the Vice President for Development, and the Vice President for Family Support in building professional relationships; and
4. shall be responsible for all public relations, corporate alliances, and strategic partnerships with other advocacy organizations.
5. shall oversee the Education and Awareness Committees; and
6. shall oversee organization of the biennial Family Conference.

e) The Vice President for Family Support

1. shall represent the interests of individuals and families affected by cystinosis on the Executive Committee and Board;
2. shall function as the family liaison to coordinate the Cystinosis Research Network's interactions with families;
3. shall provide assistance and serve in an advisory capacity on Cystinosis Research Network assigned projects/activities at the request of the President;
4. shall collaborate with the Vice President for Research, the Vice President for Education and Awareness, and the Vice President for Development in building professional relationships;
5. shall oversee the Family Support Committee and the Membership Committee; and
6. shall oversee organization of the biennial Family Conference.

f) The Secretary

1. shall be responsible for presenting the agenda and minutes of the Executive Committee and Board meetings in collaboration with the Board President or designated staff;
2. shall be responsible for coordination and administrative functions of the Executive Committee and the Board as directed by the President;
3. shall be responsible for orientating new directors to the Cystinosis Research Network and to Board responsibilities;
4. shall develop and maintain an orientation manual for new directors;
5. shall keep track of all Board member terms and initiate and oversee nomination and appointment of new board members and officers; and
6. shall oversee the Nominating Committee.

h) The Treasurer

1. shall be responsible for presenting the current financial statement to the Executive Committee and the Board;
2. shall present to the Executive Committee the annual budget proposal for eventual presentation to and approval by the Board;
3. shall assure that full and complete records of all the Cystinosis Research Network's financial transactions and of all monies received and disbursed are kept;
4. shall review and assure the filing of annual reports necessary with the state of incorporation at the end of each fiscal year;
5. shall assure the filing of all tax reports as necessary on a timely basis;
6. shall review the annual audit report; and present to the Board.
7. shall oversee the Finance Committee.
8. shall insure Executive Board Members and Executive Director receive corporate credit cards.

Article VII: Committees

Section 1. Standing Committees. The standing committees of the Cystinosis Research Network shall be:

- a) The Development Committee
- b) The Research Committee
- c) The Finance Committee
- d) The Family Support Committee
- e) The Education and Awareness Committee
- f) The Advisory Committees

The Vice President of Development will serve as chair of the Development Committee, the Vice President of Research will serve as chair of the Research Committee and will serve as liaison with the Advisory Committees, the Treasurer will serve as chair of the Finance Committee, the Vice President of Family Support will serve as chair of the Family Support Committee, and the Vice President of Education and Awareness will serve as chair of the Education and Awareness Committee.

Section 2. Ad Hoc Committees. Ad hoc committees and chairpersons may be created by the President as the need arises.

Section 3. Committee Members. Each committee chairperson, with the approval of the President, shall appoint other individuals to assist as necessary to carry out the work of the committee.

Section 4. Standing Committee Duties

a) The Development Committee

1. Fundraising: shall be responsible for identifying potential sources of income to support the mission of the Cystinosis Research Network along with long-term financial goals and projections and shall provide support and oversight to those conducting fundraising activities in support of CRN; and
2. Marketing: shall be responsible for all areas of branding, production of collateral materials, and special events.
3. Corporate Alliances: shall be responsible for building and maintaining partnerships and securing funds from corporate and other sources to support the mission of Cystinosis Research Network
4. shall be responsible for oversight of membership/donor database along with Family Support Committee

b) The Research Committee

1. shall be responsible for identifying and prioritizing research activities;
2. shall be responsible for managing the Professional Advisory Committee, the Medical Advisory Committee, and the Scientific Review Board;
3. shall be responsible for identifying and requesting grant applications from researchers interested in conducting research projects that will lead to improved treatments and / or a cure for cystinosis;
4. shall be responsible for reviewing grant proposals with the Scientific Review Board;
5. shall assist with organization of the biennial Family Conference.

c) The Finance Committee

1. shall be responsible for financial management and accountability;
2. shall review and present the annual budget to the Board;
3. shall review the audit report and tax filings; and
4. shall draft a fiscal plan for the year and long term financial needs.

d) The Family Support Committee

1. shall implement and recommend the Family Support programs of the Cystinosis Research Network;
2. shall assist with organization of the biennial Family Conference.
3. shall administer the Cystinosis Research Network internet support group; and
4. shall welcome new families by providing means of support such as access to internet support group and CRN website, written materials, referral to other families, etc.
5. shall be responsible for oversight of membership/donor database along with Development Committee.

e) The Education and Awareness Committee

1. shall implement and recommend education/ awareness programs of the Cystinosis Research Network;
2. shall assist with organization of the biennial Family Conference.
3. Strategic Alliances: shall be responsible for all partnerships aimed at enhancing the Cystinosis Research Network's mission (i.e. NORD, charitable group affiliation, like foundations, etc.);
4. Public Relations: shall be responsible for all publicity, media relations, and corporate communication matters.
5. shall publish the CRN newsletter and be responsible for upkeep and oversight of the CRN website.

g) The Advisory Committees

1. are the primary medical and professional advisory bodies of the Cystinosis Research Network and include the Professional Advisory Committee, the Medical Advisory Committee, and the Scientific Review Board;
2. shall report directly to the Executive Committee;
3. members shall either have expertise in the various medical disciplines relating to cystinosis such as genetics, nephrology, neurology, endocrinology, gastroenterology, molecular biology, pulmonary, orthopedics, and more, or shall have expertise in other professional disciplines such as finance, business, law, social services, education, and more; shall submit their most current curriculum vitae upon nomination to provide documentation of their qualifications;
4. By agreeing to serve on one of the advisory committees, members give permission for their names to be printed on Cystinosis Research Network materials where appropriate, such as on letterhead, website, and more.

1. Professional Advisory Committee

- a) shall be asked to provide professional guidance, council, and advice according to each member's particular area of expertise with regards to the various programs of the Cystinosis Research Network in order to carry out its stated mission;
- b) members shall be appointed by the Board of Directors and shall serve a three-year term. There is no limitation on the number of terms one may serve;
- c) members shall be asked to provide guidance and information on an as-needed basis in lieu of formally scheduled meetings; members shall be invited to attend the annual conferences.

2. Medical Advisory Committee

- a) shall be asked to provide professional guidance, council, and advice according to each member's particular area of expertise with regards to the various programs of the Cystinosis Research Network in order to carry out its stated mission;
- b) members shall be appointed by the Board of Directors and shall serve a three-year term. There is no limitation on the number of terms one may serve;

c) members shall be asked to provide guidance and information on an as-needed basis in lieu of formally scheduled meetings; members shall be invited to attend the annual conferences.

3. Scientific Review Board

a) shall provide recommendations to the Board of Directors regarding research grant funding proposals; may also be asked to provide scientific guidance concerning the various programs of the Cystinosis Research Network in order to carry out its stated mission;

b) shall consist of no less than five and no more than fifteen members; members shall be appointed by the Board of Directors and shall serve a three-year term; there is no limitation on the numbers of terms one may serve;

c) members shall excuse themselves during any time period in which they have submitted grant proposals for review in order to avoid conflict of interest;

d) Chairman shall be appointed by the Executive Committee to provide membership, policy and procedure advice, guide meetings, and present the Scientific Review Board's funding recommendations to the Board of Directors; shall work in conjunction with the Research Committee chair; shall serve a three-year term with no limitation on the number of terms;

e) members shall provide independent, objective review and recommendations regarding each research proposal according to the stated mission of the Cystinosis Research Network with prioritization being given to interventional research, both clinical and basic, that will lead to improved treatments for cystinosis; consideration will be given to both new and established investigators; a call for proposals will take place in May with a review meeting to take place in July; the review meeting will take place in person in conjunction with the biennial conference or by conference call during years when the conference is not held; an optional September call for proposals and November review meeting will be held only at the discretion of the Board of Directors in the event that additional funds become available and outstanding qualified proposals remain unfunded; the Chairperson shall summarize the Scientific Review Board's recommendations and present them to the Board of Directors, which then votes on each proposed project.

Section 5. Task Force

a) Nominating Task Force

1. shall be appointed by the President and consist of the chair and two directors.

Directors up for election cannot serve on the Nominating Task Force;

2. together with the Executive Committee, will determine the Cystinosis Research Network organizational needs;

3. shall identify potential nominees whose skills and interest meet these needs;

4. shall provide the Board of Directors with a slate of qualified candidates for consideration for appointment to the Board of Directors; and

5. the Nominating Committee shall coordinate with the Secretary regarding the orientation of new board members to the Cystinosis Research Network and to board responsibilities.

Article VIII: Fiscal and Administrative Years

Section 1. Fiscal Year

The fiscal year shall be from January 1 to December 31.

Section 2. Administrative Year

Officers and Directors shall take office on the date designated by the Board of Directors.

Article IX: Amendments

Section 1. These bylaws may be amended by the Board at any meeting provided that the resolution for amendment shall have been submitted to all board members thirty (30) days prior to the vote.

Section 2. To become effective, any amendment adopted by the Board must receive a two-thirds vote of the members voting.

Section 3. Amendments to these bylaws shall become effective immediately upon approval, or as specified in the amendment.

Section 4. Grammatical, punctuation and correlative corrections in these bylaws and/or amendments thereto, shall be affected by the bylaw chairperson at the time said bylaws or amendments were adopted, subject to the approval of the Executive Committee.

Article X: Rules of Order. Roberts Rules of Order, latest revision, shall be the guide for conduct of all meetings where not in conflict with these bylaws.

Article XI: Dissolution. Upon the dissolution of the corporation, the Board shall, after paying or making provision for the payment of all liabilities of the corporation, dispose of all of the Assets of the corporation exclusively for the purposes of the corporation in such manner, or to such organization(s) organized and operated exclusively for charitable, education, or scientific purposes as shall at the time qualify as an exempt organization(s) under Section 501(c)(3) of the International Revenue Code of 1996 (or the corresponding provision of any future United States Internal Revenue law) as the directors 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 principal office of the corporation is then located, exclusively for such purposes or to such organization(s) as said court shall determine which are organized and operated exclusively for such purposes.