

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE

BYLAWS

I

NAME

The name of the organization is Association for Glycogen Storage Disease. It shall be incorporated under the provisions of the laws of the State of Iowa, pursuant to provision of Section 501(c)(3) of the Internal Revenue Code for the purpose of non-profit corporation recognition.

II

FUNCTIONS

The purpose of the organization shall be to protect and promote the best interests of all persons affected by Glycogen Storage Disease; to act as a vehicle of communication on Glycogen Storage Disease related matters and to publish and distribute such material to all members of the organization (but not necessarily restricted to members of the organization); to promote the establishment and improvement of facilities and the management of such facilities for the treatment, study, education, shelter, recreation, recuperation and other general benefit to Glycogen Storage Disease affected persons; and to act as a focus for scientific, educational, and charitable activities related to the disease.

III

AREAS OF OPERATION

The areas of operation are not restricted to any location in any State of the United States or any foreign country. It is the intent of the organization to serve all races, creeds and nationalities throughout the world for the purposes stated in Article II.

IV

MEMBERSHIP

A. Types of Membership:

The Association for Glycogen Storage Disease shall have two types of membership as follows:

- 1) Active Membership – Active members shall be limited to persons affected with Glycogen Storage Disease, parents of affected persons, health professionals actively engaged in the treatment of Glycogen Storage Disease affected persons, scientists actively involved in Glycogen Storage Disease research, immediate relatives of Glycogen Storage Diseases affected persons (limited to siblings and grandparents), and spouses of affected persons. (9/96) Active members enjoy the rights, privileges, and responsibilities of the Association including the right to vote and hold office provided their dues have been received by the Treasurer of the corporation by March 1st. In the case of divorce between an affected person and his/her spouse, the membership status of the spouse will revert to an Associate Membership. (9/96).
- 2) Associate Membership - Associate members include all others not included under the definition of active membership and any member unable to become an active member by March 1st. Associate members enjoy the rights, and privileges of the Association excluding the right to vote and hold office.
- 3) Honorary Lifetime Membership - Individuals designated to personal, professional, and humanistic service to this organization with patients of GSD, will become honorary lifetime members, free from paying dues. These individuals would be able to participate in meetings at their discretion. These people would be chosen by the Board. (10/93)

B. Application for Membership

Application for either active or associate membership shall be made by forwarding a completed and signed application form and one year's membership dues to the Treasurer of the corporation. Applicants choosing to be active members must have paid their dues to the Treasurer by March 1st.

Applicants wishing to be active members who are not able to meet the March 1st deadline will automatically be associate members until the following year when the appropriate membership dues must be paid by March 1st.

C. Eligibility

Membership all be open to all persons 18 years of age or older, families (including minors), institutions, organizations etc., that pay the yearly membership dues regardless of location, race, creed, nationality or other qualifications that could be considered discriminative or restrictive.

V

OFFICERS

A. Number

The officers of the corporation shall be a President, a Vice-President, a Secretary, and a Treasurer all of whom are active members and are elected by the active membership.

B. Election and Term of Office

The slate of candidates for each office shall be formulated by a nominating committee that certifies the qualification of each candidate and his/her willingness to accept the duties of the office sought. The slate of candidates shall initially be presented at the annual meeting which immediately precedes the next election. At the time of this presentation the President shall have the authority to accept additional nominations from the floor. The Treasurer at that time shall certify that any nominations made are made from the list of active members of the organization.

Upon completion of the list of all candidates seeking office, the nominating committee shall prepare a brief resume of each candidate, and shall submit this resume to the Secretary for use in the voting procedure.

The term of all officers shall be three (3) years.

Each officer shall hold office until a successor to that office has been duly elected and instated (subject to conditions of section C). Each term of office shall begin on January 1 of the year following the election.

C. Vacancy of an Office

An office of the corporation shall become vacant if the officer holding the same dies during the term of office or resigns the office through the submission of a formal letter of resignation to the Board of Directors of the corporation.

Any officer shall be subject to dismissal who fails to uphold the bylaws of the corporation and/or fails to carry out the duties as prescribed for the office held. In such case the Board of Directors shall receive any complaints in regard to any officers of the corporation, and shall fairly evaluate the complaint(s) through the examination of evidence gathered from all parties concerned.

If, after examination of all evidence, the Board of Directors decides by majority vote that any officer is not carrying out the duties of his/her office in the best interest of the corporation, the Board may request the resignation of said officers by written letter. If the officer fails to resign by letter within one month of reception of the letter requesting resignation, the Board shall act unilaterally to dismiss the officer from further duties in the corporation.

D. Filling of Vacancies

A vacancy in any office during an unexpired term because of death, resignation, or dismissal may be filled by the Board of Directors for the unexpired portion of the term, except in the case of the Presidency. Vacancy in the Office of the President shall automatically be filled by the Vice-President.

E. President Ex-Officio

The immediate past President of the Organization shall become President Ex-Officio for 1 year as an advisor to the Board of Directors and the newly elected President as needed.

F. Compensation of Officers

No officer shall receive compensation for any services that he/she may render to the corporation in the capacity of officer. Each officer, however, may be reimbursed for any actual expenditure reasonably incurred in connection with carrying out the business of the corporation.

VI

DUTIES OF OFFICERS

A. President

1. Calls the annual meeting of the corporation and any other meeting deemed necessary.
2. Presides over all meetings of the corporation and presents a report of the stated of the corporation at the annual meeting.
3. Insures that the agenda for the annual meeting is published in the newsletter no later than 90 days prior to the meeting.
4. As the principal executive officer of the corporation, supervises the business affairs of the corporation and solicits and appoints members to committees established to effectively carry out new programs or other functions of the corporation not specified delineated in the bylaws.
5. Authorizes, with the Board of Directors' approval, expenditure of corporation funds. Cosigns together with the Treasurer checks written against the corporation's funds for amounts equal to or greater than \$750.00. (10/10)
6. Signs, together with the Secretary or any other officer of the corporation thereunto authorized by the Board of Directors, contracts or other instruments which the Board of Directors has authorized to be executed, except in cases where the signing and execution thereof shall be expressly delegated by the Board of Directors or by these bylaws to another officer or agent of the corporation, or shall be required by law to be otherwise signed or executed.
7. Performs all duties incident to the office of President and not specifically delegated to other officers of the organization. Performs such other duties as may be prescribed by the Board of Directors.

B. Vice-President

1. In the event of the President's death or inability to act, or at the request of the President or Board of Directors, the Vice-President shall perform the duties of the President, subject to the powers and restrictions granted to the office of the President.
2. Acts as parliamentarian at the annual meeting and any other meeting deemed necessary by the President or Board of Directors.
3. Performs such duties as may be assigned by the President and/or Board of Directors, and upon request may assist in the appointment and/or supervision of standing committees of the organization or other committees deemed necessary for the efficient functioning of the organization [i.e. Newsletter Committee, Publicity Committee, Ways & Means Committee, Nominating Committee, etc.]

C. Secretary

1. Keeps minutes of the proceedings of the Board of Directors on permanent file.
2. Is the custodian of all papers, letters, and transactions of the corporation and is responsible for filing such articles in a manner easily retrievable for reference as required by the Board of Directors. The Secretary maintains the updates list of all members of the organization.
3. Delegates to the Newsletter Editor: The assembling and mailing (8/88) of the Newsletter of the organization to all members (active and associate); mails all other notices to the membership as may be deemed necessary by the President or Board of Directors.
4. Delegates to the Election Committee to use the active membership list from the Treasurer to assemble and mail out voting information and ballots to the active membership for all elections. (9/83)
5. In general performs all duties incident to the Office of Secretary and such other duties as from time to time may be assigned by the President or Board of Directors.

D. Treasurer

1. The Treasurer shall collect, receive, and have charge of all funds of the corporation, shall deposit such funds at banks, trust companies or other depositories designated by the Board of Directors, and shall provide for the expenditure of such funds. The Treasurer shall be responsible for maintaining accurate records relative to the functions of the office as stipulated.
2. If required by the Board of Directors, the Treasurer shall post bond for the faithful discharge of his/her duties in such sum and with such sureties as the Board of Directors shall determine.
3. In providing for the expenditure of the corporation's funds, the Treasurer and President or other officer designated by the Board of Directors shall each sign any checks to be drawn on the corporation's funds for amounts of \$750.00 or more. (10/10)
4. The Treasurer shall bill all members of the organization for annual dues as of December 1, and shall keep records relative to the collection of dues from all participating members. Dues not received from members as of January 15 shall be marked as delinquent and such members will be sent a second notice. Members whose dues have not been received by March 1 shall be dropped from membership.
5. The Treasurer shall make the current list of active and associate members available to the Officers of the organization by March 15 of each year.
6. The Treasurer shall receive new applications for membership together with requisite fees. Upon receipt and deposit of membership fees, the Treasurer shall send the completed application to the Secretary.
7. The Treasurer shall receive all sealed ballots from the voting membership during elections, and shall certify those who have voted. The Treasurer shall send sealed, unmarked ballots to the Nominating Committee for tabulation of results.
8. In general the Treasurer shall perform all of the duties incident to the Office of the Treasurer and such other duties as from time to time may be assigned by the President or by the Board of Directors.

VII

BOARD OF DIRECTORS

A. Duties

Except as otherwise required by law or provided by these bylaws, the control and responsibility of the affairs of business of this corporation shall be vested in its Board of Directors. The Board of Directors shall transact the business of the corporation, establish major administrative policies governing the affairs of the corporation, establish committees and their guidelines not otherwise specified in these bylaws, and review the performance of any officer of the corporation and request resignation from office if such officer has not consistently performed duties as stated in these bylaws or has acted in such manner as to consistently misrepresent the goals and ideals of the corporation as specified in Articles I, II, III, and IV of these bylaws. The Board of Directors shall review requests for funds from those seeking assistance and act upon such requests as they best serve the goals of the corporation.

B. Number-Tenure-Qualifications

The voting members of the Board of Directors shall be as follows: 1) President, 2) Vice-President, 3) Treasurer, 4) to 8) five members elected from the active membership, and 9) the Chairman of the Professional and Science Advisory Board. The Secretary and President Ex-Officio shall be non-voting members of the Board of Directors and will serve as advisors to the Board of Directors as needed.

All voting members of the Board of Directors, excepting the Chairman of the Scientific Advisory Board, shall be elected from the active membership. The President Ex-Officio will serve in his/her advisory capacity for one year following his/her term.

The term of the Directors shall be staggered. During the first 3 years of the operation of the corporation under these amended bylaws 3 Directors (officers) and 3 Directors (elected) shall have a 3-year term and 2 Directors (elected) shall have a 2-year term.

C. Chairman of the Board

One member of the Board of Directors shall be elected by plurality vote of the Board to serve as Chairman of the Board of Directors. It shall be the responsibility of the Chairman to call the annual meeting of the Board and other meetings deemed necessary. The Chairman shall prepare the agenda for all Board meetings and shall conduct such meetings.

D. Meetings of the Board of Directors

1) Annual Meeting

The annual meeting of the Board of Directors shall be held each year at a place and time which is coordinated with the annual meeting of the Association for Glycogen Storage Disease. Notice of the date, place and time of the annual Board meeting shall accompany the posting of the date, place and time of the Association for Glycogen Storage Disease, which shall be published in the newsletter not less than 90 days prior to these meetings.

Yearly recommendations for location of the annual Association meeting shall be proposed by the Program Committee and presented to the Board of Directors by the Program Committee Chairman at least two years in advance allowing for a six-month start-up time for the committee to be established and begin operations. Minutes shall be recorded for each annual meeting by the Secretary of the organization.

2) Special Meetings

Special Meetings of the Board of Directors may be called by the Chairman of the Board. The Chairman shall be responsible for fixing a time and place for the meeting that is agreeable to a majority of the Board members, and shall be responsible for preparing the agenda for that meeting. In all cases a written record of the meeting shall be taken, and the results of any votes recorded by the Secretary, or, in the Secretary's absence, an appropriate Officer appointed to take the minutes.

3) A Conference call will be scheduled six (6) months after the general meeting. Minutes shall be recorded for this meeting by the Secretary of the organization. (4/86)

E. Quorum

A majority of the Board members shall constitute a quorum for the transaction of business at any meeting of the Board of Directors. A Director shall be considered present at a meeting of the Board of Directors if he/she participates in such meeting by conference telephone or similar communications equipment by means of which all persons participating in the meeting can freely communicate.

F. Actions Undertaken by the Board of Directors

The act of the majority of Directors present at a meeting at which quorum is present shall be the act of the Board of Directors.

G. Vacancies

A vacancy occurring on the Board of Directors as the result of the death or resignation of a Board Member during his/her term of tenure shall be filled by the Board of Directors at any meeting thereof. Director so appointed shall fill the unexpired term of his/her predecessor in office.

H. Compensation

By resolution of the Board of Directors each Director may be reimbursed for any expenditure reasonably incurred in connection with the business of the corporation. No Director shall be entitled to any salary or other compensation for services rendered the corporation, however.