

## VIII

### SCIENTIFIC ADVISORY BOARD

#### A. Membership

The Board of Directors shall appoint a Scientific Advisory Board from the professional membership of the organization. The Board shall be comprised of *up to fifteen* professionals representing physicians who care for *individuals* having Glycogen Storage Diseases, nutritionists who are concerned with nutritional therapy for these disorders, and *scientists/health care professionals actively engaged in clinical care/research* (10/10) pertaining to the genetics or the metabolic disruptions associated with Glycogen Storage Diseases.

#### B. Tenure

Each appointment will be *for a minimum of three (3) years*, with the consent of the appointee. (10/10)

#### C. Chairman of the Scientific Advisory Board

The membership of the Scientific Advisory Board shall elect a Chairman of this group by plurality vote. The Chairman shall represent the Scientific Advisory Board at meetings of the Board of Directors of the Association for Glycogen Storage Disease, and it shall be the duty of the Chairman to advise the Board of Directors regarding medical, nutritional, and scientific matters relating to the Glycogen Storage Diseases.

#### D. Duties

The Scientific Advisory Board shall prepare reviews of current reports on diagnosis, treatment, or research regarding Glycogen Storage Diseases to be published in the Newsletter as requested by the Chairman of the Newsletter Committee. The Chairman of the Scientific Advisory Board shall appoint various members of this Board to prepare such reviews, or may invite contributions from professionals not specifically present on the Board as dictated by the specifics of the topics to be covered. This Board will recommend research projects for financial support and the amounts of money to be spent, in conjunction with the approval of the Board of Directors. (9/89)

## **IX**

### **MEETINGS OF THE CORPORATION**

#### **A. Annual Meeting**

An annual meeting of the corporation shall generally be held in September of each year, and will be called by the President and announced to the membership at large via the Newsletter. The announcement will precede the meeting date by not less than 90 days. At this annual meeting the general business meeting for the corporation as well as the annual Board of Directors meeting shall be held.

The meeting shall be held at a location and time to be designated by the Board of Directors.

Any issues discussed by the Board that need approval shall be voted upon at the General meeting by those in attendance. Any new issues presented at the meeting may be acted upon by a special meeting of the Board the day after the annual meeting. (9/83)

Active members of the organization may submit items for the agenda of the corporation's meetings. Such items shall be submitted in writing to the President of the corporation not later than 120 days before the next scheduled meeting. The President shall place all such items of organizational interest on the agenda as time allows. Items not placed on the agenda by the Board of Directors shall be returned to the members who submitted them with explanations regarding why they could not be placed on the agenda. (9/83)

#### **B. Special Meetings**

Special meetings of the members, for any purpose or purposes, may be called by the President or the Board of Directors. The same rules governing the annual meeting shall apply to the special meetings.

## X

### COMMITTEES

The Association of Glycogen Storage Disease shall have the following standing committees: A. Nominating Committee; B. Program Committee; C. Newsletter Committee.

#### A. Nominating Committee

The Nominating Committee shall consist of at least two and not more than five active members. The Chairman of this committee and the members shall be appointed by the President.

The appointees shall be representative of the membership as a whole. The Chairman will coordinate the activities of the committee in its responsibility to solicit the membership for nominations of Officers and/or Board of Directors of the Association for Glycogen Storage Disease. It shall be the responsibility of the Nominating Committee to validate all nominations and prepare voting material and mail to the active membership. (9/83)

The material which the Nominating Committee shall prepare for the Secretary shall include 1) instructions, 2) an official statement from each candidate or the qualifications thereof, 3) an official ballot, 4) a special sealable ballot envelope to receive the marked ballot, and 5) an addressed envelope for mailing the ballot envelope containing the marked ballot back to the Treasurer.

The Treasurer of the organization shall inform the Nominating Committee of the number of ballots required to be sent to the active membership, and shall also receive the sealed ballot envelopes from the voting membership. After validating all sealed ballots from the voting membership, the Treasurer shall send the ballots in their sealed ballot envelopes to the Nominating Committee for the final tally.

To help in the validating procedure, voting members shall sign the addressed mailing envelope returning the sealed ballot envelope and ballot to the Treasurer and the Treasurer shall use the signature to verify the ballot cast. The Nominating Committee shall report the winner (4/98) of the election to the membership via the Newsletter and shall retain all ballots for a minimum of three months before they are destroyed.

B. Program Committee

The Program Committee shall consist of at least 2 and not more than 5 active members who have been appointed by the President. The President shall designate one of the appointees to serve as Chairman of the committee. This committee shall provide the Board of Directors with a list of recommended locations, sites, and dates for the annual meetings 12 months in advance of the proposed meeting dates. The committee shall assist the President and/or the Board in preparing for the meeting by arranging for speakers, assuring accommodations for the meeting and the membership and providing hospitality arrangements and recreational activities for members and their families while attending the meetings. The Program Committee shall take responsibility for arranging the annual dinner for the organization. The committee shall have all details of its plans in regards to the aforementioned in the hands of the Board of Directors 120 days in advance of the next annual meeting so that this information may be distributed to the membership 90 days prior to this meeting

C. Newsletter Committee

Membership shall consist of at least 2 and not more than 5 members appointed by the President of the corporation. The committee shall select a chairman who shall coordinate the activities of the group.

This committee shall develop a format for the official publication of the corporation, The Ray. Such format, subject to the approval of the Board of Directors, shall provide for a quarterly publication to be mailed to all the membership on the 15<sup>th</sup> day of February, May, August, and November. It shall also provide a mechanism of communication for the membership which allows the dissemination of information relative to the operation of the Association, its ongoing activities, the various activities of the membership, and the current activities in research, nutrition, and medicine that pertain to the study, treatment or cure of Glycogen Storage Diseases.

The committee shall be responsible for requesting and assimilating information relative to the aforementioned topics, editing the same and providing the Newsletter Editor (8/88) with the finished publication ready for reproduction and mailing at the times indicated. The Ray shall be proofread by two (2) people active in the organization. (4/88) In carrying out the above duties the committee may establish its own deadlines for receiving material for The Ray.

D. Fund Raising Committee

Fund raising is the function of a committee appointed by the Board of Directors. The fund raising drive is limited to active U.S. families residing in the United States of America. Any fund raising activities must be approved by the Board (9/86).

E. Other Committees

The President shall designate one or more other committees as he/she feels are necessary to carry out the functions of the Association. Each such committee shall have an appointed chairman. The committees, to the extent provided by the Board of Directors in said resolution and not restricted by law, shall have and exercise the authority of the Board of Directors. The designation of such committees and delegation thereto of authority shall not operate to relieve the Board of Directors, or any individual Director, of any responsibility imposed upon it of him/her by these bylaws.

F. Removal of a Member of a Committee

Any member of the organization appointed to a committee may be removed from said committee by the President whenever, in his/her judgment, the best interests of the Association for Glycogen Storage Disease shall be served by such removal.

G. Committee Tenure

Each member of a committee shall continue until the next annual meeting of the members of the Association for Glycogen Storage Disease, or until his/her successor is appointed, unless the committee shall be sooner terminated, or unless such member be removed from the committee, or unless such member shall cease to qualify as a member thereof.

H. Vacancies

Vacancies in the membership of any committee may be filled by appointments made in the same manner as provided in the case of the original appointment.

I. Quorum

Unless otherwise provided in the resolution of the Directors designating a committee, a majority of the whole committee shall constitute a quorum and the act of a majority of the members shall be the act of the committee.

## XI

### DUES AND FINANCES

A. Membership Dues

The amount of annual dues will be *\$20.00 for an active membership and \$15.00 for an associate membership.*(9/02) Dues can be increased or decreased by majority vote of the Board of Directors. All membership dues shall be payable annually and shall be due on January 1 of each calendar year. The Treasurer shall bill and receive all dues as defined under duties of the Treasurer. In case of financial hardship an active member may defer payment of annual dues, without loss of active membership, through a request as given on the annual dues statement.

B. Fiscal Year

The fiscal year of the corporation shall be the calendar year.

C. Contracts

The Board of Directors may authorize any office or officers, agent or agents, to enter into any contracts or execute and deliver any instrument in the name of and on behalf of the corporation, and such authority may be general or confined to specific issues.

D. Loans

No loans or extensions of credit of any kind shall be contracted on behalf of the corporation and no evidences of indebtedness shall be issued in its name unless authorized by a resolution issued by a majority of the Board of Directors.

E. 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 corporation shall be signed by such officer or officers of the corporation and in such manner as shall be from time to time determined by resolution of the Board of Directors; all authorizations for the expenditure of \$150.00 (9/87) or more shall be signed by the Treasurer and countersigned by the President or other officer authorized by the Board of Directors.

F. Deposit of the Corporation's Monies

Monies of the corporation shall be deposited by the Treasurer to the credit of the corporation in such banks, trust companies, or other depositories as the Board of Directors selects.

G. Gifts

The Board of Directors may accept on behalf of the corporation any contribution, gift, bequest or device for the general purpose or for any specific purpose of the corporation.

## **XII**

### **AMENDMENT TO THE BYLAWS**

Any active member (including officers of the corporation and members of the Board of Directors) may submit to the Board of Directors bylaw revision(s) for consideration, action and approval at the annual meeting at least 120 days in advance of the date of the annual meeting. (9/83)

## **XIII**

### **BOOKS AND RECORDS**

Books and records of the corporation shall be kept on file by the Secretary and Treasurer of the corporation as indicated under Article VI. All books and records of the corporation shall be available for inspection by any member or his agent or attorney for any proper purpose at a reasonable time. The Treasurer's books are to be reviewed either every three (3) years or with a change in Treasurer, which ever comes first. (9/86)

## **XIV**

### **EARNINGS**

No part of the funds of the corporation shall inure to the benefit of or be distributable to its members, trustees, officers, or other private persons, except that the corporation shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in Article II hereof. No funds may be used for nor will the corporation participate in carrying on propaganda activities to influence legislation, and the corporation shall not participate in, or intervene in (including the publishing or distribution of statements) any political campaign on behalf of any candidate for public office. 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 1954 (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(c)(2) of the Internal Revenue Code of 1954 (or corresponding provision of and future United States Internal Revenue Law).



## **XV**

### **DISSOLUTION OF THE CORPORATION**

Upon dissolution of the corporation, the Board of Directors shall, after paying or making provisions for the payment of all liabilities of the corporation, dispose of all the assets of the corporation exclusively for the purposes of the corporation in such manner, or to such organization or organizations organized and operated exclusively for charitable or educational purposes as shall at the time qualify as an exempt organization or organizations under Section 501(c)(3) of the Internal Revenue Code of 1954 (or the corresponding provisions of any future United States Internal Revenue Law), as the Board of Directors shall determine. Any of such assets not so disposed of shall be disposed of by the District Court of the County in which the principal 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.

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