

Bylaws

American ALS Research Group

ARTICLE I: NAME

This organization shall be known as the American ALS Research Group. The American ALS Research Group shall hereafter be referred to as the “ALSRG.”

ARTICLE II: MISSION

The mission of the ALSRG is to foster communication, collaboration and research in North America into the cause and treatment of ALS.

To achieve this mission, the following objectives are identified:

1. To enhance free and full communication among North American ALS researchers.
2. To foster the development of new clinical investigators in ALS.
3. To facilitate conduct of genetic, proteomic and metabolomic research in ALS.
4. To facilitate involvement of study coordinators and allied health professionals in ALS clinical research.
5. To promote development of a unified natural history database of ALS patients in North America.
6. To facilitate the design and conduct of clinical trials testing new therapies for patients with ALS.

ARTICLE III: MEMBERSHIP

Any interested professional involved in the care of ALS patients or in the investigation of the cause and cure of ALS is eligible for membership. This includes physicians, researchers, and allied health professionals located both at academic medical centers in private practice settings. In addition, membership is offered to those associated with patient advocacy and ALS funding agencies. In order to become a member, an interested individual should contact the Membership committee, and supply information regarding their involvement in ALS care or research to the committee.

Thus, the membership of ALSRG will comprise of scientific investigators, clinicians, clinical evaluators and research coordinators from academic clinical centers, as well as interested individuals from the lay public and ALS advocacy groups and support agencies. The different members of ALSRG shall hereafter be collectively referred to as the “Membership.”

ARTICLE IV: ORGANIZATION

The ALSRG is an independent, nonprofit consortium of clinical and scientific investigators who conduct research at their affiliated institutions. Membership in ALSRG does not alter the responsibilities of individual investigators or institutions to obtain appropriate approval from the appropriate institutional review boards, or to conduct research according to the standards of the individual institutions. ALSRG headquarters will reside at the institution of the elected Chair, and will rotate to the location of the chair at the time of new elections.

ARTICLE V: OFFICERS

Section 1

Officers of the ALSRG shall consist of a Chair, Chair-Elect, Treasurer and Secretary.

Section 2

The ALSRG shall be governed primarily by 2 elected officers (Chair and Chair-Elect) in consultation with the Steering Committee. The initial term of the Chair, Chair-Elect and current steering committee members shall be 3 years, to commence in April, 2004. The next election for these offices will be held in January, 2007. For this election, nominations will be sought for the position of ALSRG Chair. The winner of the this election will be chair, to serve a 2 year term; the individual with the second highest vote total will be Chair-Elect, also to serve a 2 year term. To ensure continuity of leadership, subsequent elections to be held at 2 year intervals will be for the purpose of electing a new Chair-Elect, as the vacating Chair-Elect will assume responsibility of Chair for the next 2 year period. The Chair cannot succeed himself or herself. The outgoing Chair will remain as a member ex officio of the Steering Committee for the two years following their term in office.

Section 2

A Treasurer will be appointed by the Chair, to serve a term coincident with that of the chair. The function of the Treasurer will be to maintain and organize financial books, and to participate in fund raising activities as determined by the Finance committee. In addition, a Secretary will be appointed by the Chair, to assist in maintenance of the organization's communication records, recording minutes of meetings and to facilitate communication with the Membership.

ARTICLE VI: COMMITTEES

Section 1 – Standing Structural Committees

The following committees shall be constituted, to perform both administrative and substantive functions critical to the development and success of the ALSRG.

- A. Membership Committee - A Membership Committee shall be established to further define the criteria for membership, potentially to include continued interest and participation in ALSRG related activities; to maintain an accurate list of the Membership, categories of Membership, Membership dues; and to address other issues relating to dues, qualifications, categorizations etc. that may arise.
- B. Steering Committee - The Steering Committee shall consist of 8 members elected at large. The function of the Steering Committee shall be to provide guidance and governance of the ALSRG. The Chair and co Chair will also be members of the Steering Committee. In addition to the at large Steering Committee members, 2 additional Steering Committee members will be designated from specific groups. One position will be reserved for an allied health professional, while the other for an investigator under the age of 40. Nothing precludes young investigators or allied health professionals from being elected to the at large positions as well. The Steering Committee shall have major responsibility for approval of ALSRG-related research and teaching activities. Monetary expenditures of greater than \$1000 also must be approved by a majority vote of the Steering Committee. The Steering committee shall meet regularly throughout the year by conference call, and at least twice per year in person.
- C. Constitution and Bylaws Committee – The Constitution and Bylaws Committee shall create the bylaws and take responsibility for updating and modifying the existing bylaws, as appropriate
- D. Website Committee – The Website Committee shall develop and maintain an ALSRG website which will promote the functions of communication between members and of members and the public at-large
- E. Financial Committee – The Financial Committee shall be responsible for overall financial oversight, and to oversee fundraising and other funding activities
- F. Publication Committee – The Publication Committee shall be responsible for creating guidelines for publications, and to ensure that such guidelines are followed by organization members

Section 2 – Ad Hoc Committees

Nominating Committee – The Nominating Committee shall oversee all elections of the organization, as discussed below

Section 3 – Content Committees

A. Clinical Research Committee – The Clinical Research Committee shall oversee and guide the research activities of the organization. This committee will be divided into working groups, to include but not be limited to:

- Genetic studies
- Biomarkers
- Natural history/ outcomes database

Clinical trial issues

B. Clinical Education Committee – The Clinical Education Committee shall oversee and guide educational and training activities of the organization. This committee will be divided into working groups to include but not be limited to:

- Investigator training and mentoring
- Evaluator/coordinator training
- Clinical management/standard of care

Section 4 – Special Committees

The Chair may appoint committees to assist in conducting the affairs of the ALSRG as deemed necessary and as defined by the Membership.

ARTICLE VII: ELECTIONS AND NOMINATIONS

All elections shall proceed by mail ballot. The next election for chair and Chair-Elect, as well as for the 4 at-large Steering Committee members and 2 designated Steering Committee members, shall be held in January 2007, with nominations solicited in November, 2006. Subsequent elections shall occur in 2-year cycles, to elect the Chair-Elect, 4 at-large Steering Committee members, and 2 designated Steering Committee members. A Nominating Committee shall be constituted to oversee these elections.

Elections of the Steering Committee shall be held in concert with elections for the Chair-Elect; at each election cycle, 4 positions of the Steering Committee will up for election. Thus, each Steering Committee member will be elected for a 4-year term. Steering Committee members will be able to stand for re-election. In addition to the at-large Steering Committee members, 2 additional Steering Committee members shall be elected at each election to serve for a 2-year term. One position shall be reserved for an allied health professional, while the other shall be reserved for an investigator under the age of 40. Nothing precludes young investigators or allied health professionals from being elected to the at-large Steering Committee membership positions as well. Term limits will be established, so that no steering committee member will be eligible to serve more than 2 consecutive terms. Thus, maximum duration of steering committee tenure will be 8 years for at large members, and 4 years for designated members. Term limits apply only to consecutive service; members may be reelected to the Steering Committee even if they have served two terms, as long as there has been an interval during which they are not serving.

ARTICLE VIII: INCOME AND EXPENSES

All funds garnered by ALSRG shall be accounted for by the Treasurer of the group, and will be deposited in an account designated by the name of the group. All funds received shall be applied solely towards the promotion of ALSRG objectives. These objectives include the planning and implementation of ALSRG related activities including but not limited to meetings, support of research projects, creation and maintenance of web site design , and the support of approved organizational objectives, such as the establishment of a central office. A complete financial report will be prepared by the Treasurer and submitted to the ALSRG membership annually.

ARTICLE IX: AMENDMENTS

The bylaws of ALSRG may be revised or expanded in response to unforeseen events, or for the purposes of clarity of language. The Steering Committee will review a proposed change or addition to the bylaws, and then vote to recommend ratification. Written notice of the substance of the proposed amendment shall be sent to all members by the Secretary at least thirty (30) days prior to the meeting at which action is to be taken. Final decision regarding change in bylaws will rest with a majority vote of all Membership.

ARTICLE X: ANNUAL MEETING

The ALSRG shall meet at least annually, to conduct the organizations business, address educational and research issues and to plan future activities. The Chair, Chair-Elect and Steering Committee shall organize the annual meeting and determine the time and place of this meeting. Other meeting as needed to conduct ALSRG related business will be scheduled as needed.

ARTICLE XI: PUBLICATION GUIDELINES

The ALSRG strongly supports the publication of data generated from its related activities. A publication policy shall encourage publications and prevent conflicts about publication priorities and details. The guidelines governing authorship and acknowledgement in publications will be determined by the Publications Committee.

Ammendment #1 to Article 1 (approved by membership 12/13/2010):

New Member Application Process.

An application portal will be developed on our web site. Prospective members must agree that they are: A health care professional or scientist and Involved in ALS research, patient care, teaching.

Prospective members must submit their CV which will be used by the ALSRG BOD to verify the above. If verified, prospective members can be admitted by majority vote of the ALSRG BOD”.