

BY-LAWS OF

ALS Research Group

(hereinafter referred to as the "Corporation")

ARTICLE I

MEMBERS

Section 1. Membership. Membership shall be open to all professionals involved in the care of ALS patients or in the investigation of the cause and cure of ALS. This includes physicians, researchers and allied health professionals located both at academic medical centers and in private practice settings. In addition, membership shall be open to those associated with patient advocacy and ALS funding agencies. In order to become a member, an interested individual should contact the office of the Chair either by email or other written communication, and supply information regarding their involvement in ALS care, research, advocacy or funding. The Board of Directors of the Corporation may establish such other criteria for membership, including a schedule of dues, as they deem appropriate. A call for new membership shall occur annually through all available information dissemination sources, including the ALSRG website, and any list serves that the organization may have access to.

Section 2. Meetings. The annual meeting of the members (the "Annual Meeting") for the election of the Directors and Officers and for the transaction of such other business as may come before the Members shall be held each year at the place (which may be either within or outside the State of New York), time and date, in the 2nd quarter of the year, as may be fixed by the Board of Directors, or, if not so fixed, as may be determined by the Chairperson of the Board of Directors. Special meetings shall be held whenever called by resolution of the Board of Directors, the Chairperson of the Board, the Executive Director, or by a written demand to the Secretary of ten percent of the members eligible to vote.

The Secretary upon receiving the written demand or Resolution shall promptly give notice of such meeting as provided below, or if the Secretary fails to do so within five business days thereafter, any member signing such demand may give such notice.

Section 3. Notice of Meetings. Written notice of the place, date and hour of any meeting shall be given to each member entitled to vote at such meeting by mailing the notice by email, first class mail, postage prepaid, or by personal delivery, not less than ten nor more than fifty days before the date of the meeting. Notice of special meetings shall indicate the purpose for which they are called and the person or persons calling the meeting.

Section 4. Quorum, Adjournments of Meetings. At all meetings of the members, one-third of the members, present in person or by proxy, shall constitute a quorum for the transaction of business. In the absence of a quorum, a majority of the members present in person or by proxy may adjourn the meeting. Notice of the new meeting is not required if the time and place for the new meeting are announced at the meeting at which the adjournment is taken, and at the new meeting any business may be transacted which might have been transacted at the meeting as originally called.

Section 5. Organization. The Chairperson of the Corporation shall preside at all meetings of the members or, in the absence of the Chairperson, an acting Chairperson shall be chosen by the members present. The Secretary of the Corporation shall act as Secretary at all meetings of the members, but in the absence of the Secretary, the presiding officer may appoint any person to act as Secretary of the meeting.

Section 6. Voting. At any meeting of the members, each Member present, in person or by proxy, shall be entitled to one vote. Upon demand of any member, any vote for directors or upon any question before the meeting shall be by ballot. The record eligibility of voting rights shall be set **30** days before the date of the meeting.

Section 7. Action by the Members. Except as otherwise provided by statute or by these by-laws, any corporate action authorized by a majority of the votes cast at a meeting of Members shall be the act of the Members. Action may be taken without a meeting on written consent, setting forth the action to be taken, signed by all of the Members.

Section 8. Special Actions Requiring Vote of Members: The following corporate actions may not be taken without approval of the members:

(a) a majority of the votes cast at a meeting of the members is required for (1) any amendment of or change to the certificate of incorporation, or (2) a petition for judicial dissolution;

(b) two-thirds of the votes cast at a meeting of the members is required for (1) disposing of all, or substantially all, of the assets of the Corporation, (2) approval of a plan of merger, (3) authorization of a plan of non-judicial dissolution, or (4) revocation of a voluntary dissolution proceeding;

provided, however, that the affirmative votes cast in favor of any such action shall be at least equal to the minimum number of votes necessary to constitute a quorum. Blank votes or abstentions shall not be counted in the number of votes cast.

## ARTICLE II

### BOARD OF DIRECTORS

Section 1. Powers and Number. The property, affairs and activities of the Corporation shall be managed and controlled and its powers exercised by the Board of Directors. The number of directors constituting the entire Board after the first annual meeting of the members shall be **13** but in no event shall the entire Board consist of less than three (3) directors. Each Director shall be at least eighteen (18) years of age.

Section 2. Election and Term of Office. The initial Directors shall be the persons named in the Certificate of Incorporation. Directors shall be elected to 4 year terms, with elections occurring by mail ballot in the first quarter of even numbered years. There shall be 13 directors, including the Chair and Vice Chair. An approximately equal number of directors will be elected in each 2 year cycle. Of the 11 directors not including the Chair and Vice Chair, one position shall be designated for and held by a non-physician allied health professional, while another position shall be designated for and held by a "young" member of the ALSRG. "Young" is defined as either age less than 40 years at time of election, assistant professor rank, or involvement in the field of ALS research or care for less than 5 years at the time of election.

Nominations for Vice Chair and all available director positions shall be solicited by email in January of the year of election. A two week period shall be designated as an open nomination period. Nominees for both the young director position or the allied health professional director position should be specifically designated. All nominees shall be placed on a mail ballot, which will be mailed to all ALSRG members in the 2nd month of each election year. A 21 day voting period will be established, commencing with date of ballot

mailing. The outgoing Chair will coordinate the election process, and be responsible for vote counting and certifying elections. Election results will be disseminated by email, and formally announced at the Annual Meeting.

Section 3. Newly Created Directorships and Vacancies. Newly created directorships and vacancies among the directors for any reason may be filled by vote of a majority of the directors then in office, regardless of their number, and the directors so elected shall serve until the next annual meeting of the members.

Section 4. Resignations. Any director may resign from office at any time. Such resignation shall be made in writing, and shall take effect at the time specified therein, and if no time be specified, at the time of its receipt by the Corporation or its Chairperson. The acceptance of a resignation by the Board of Directors shall not be necessary to make it effective, but no resignations shall discharge any accrued obligation or duty of a Director.

Section 5. Removal. Any director may be removed at any time with cause by a majority of the Board of Directors then in office at any special meeting of the Board called for that purpose, provided that at least one week's notice of the proposed action shall have been given to the entire Board of Directors then in Office. Any director can be removed at any time with or without cause by a vote of the members.

Section 6. Meetings. Meetings of the Board may be held at any place within or without the State of New York as the Board may from time to time fix, or as shall be specified in the notice or waivers of notice thereof. The annual meeting of the Board of Directors in each year shall be held immediately following the annual meeting of the members. Other regular meetings of the Board shall be held no less than **[number]** times during the year. Special meetings of the Board shall be held whenever called by a majority of the Board of Directors, the Chairperson of the Board, or the Executive Director, in each case at such time and place as shall be fixed by the person or persons calling the meeting.

Section 7. Quorum and Voting. Unless a greater proportion is required by law, a majority of the entire Board shall constitute a quorum for the transaction of business or of any specified item of business. Except as otherwise provided by statute or by these by-laws, the vote of a majority of the directors present at the time of the vote, if a quorum is present at such time, shall be the act of the Board. If at any meeting of the Board there shall be less than a quorum present, the Directors present may adjourn the meeting until a quorum is obtained.

Section 8. Action by the Board. Any action required or permitted to be taken by the Board or any committee thereof may be taken without a meeting if all members of the Board or the committee consent in writing to the adoption of a resolution authorizing the action. The resolution and the written consents thereto by the members of the Board or committee shall be filed with the minutes of the proceedings of the Board or committee. Any one or more members of the Board or any committee thereof may participate in a meeting of the Board or committee by means of a conference telephone or similar communications equipment by means of which all persons participating in the meeting can hear each other at the same time. Participation by such means shall constitute presence in person at a meeting.

Section 9. Notice of Meetings. Notice of the time and place of each regular or special meeting of the Board, together with a written agenda stating all matters upon which action is proposed to be taken and, to the extent possible, copies of all documents on which action is proposed to be taken, shall be mailed to each director, postage prepaid, addressed to him or her at his or her residence or usual place of business (or at such other address as he or she may have designated in a written request filed with the Secretary), at least seven days before the day on which the meeting is to be held; provided, however, that notice of special meetings to discuss matters requiring prompt action may be sent to him or her at such address by telegram or cablegram or given personally or by telephone, no less than forty-eight hours before the time at which such meeting is to be held, unless the meeting must be held within forty-eight hours. Notice of a meeting need not be given to any director who submits a signed waiver of notice whether before or after the meeting, or who attends the meeting without protesting, prior thereto or at its commencement, the lack of notice to him or her. No notice need be given of any adjourned meeting.

Section 10. Compensation. **No compensation shall be paid to Directors.**

### ARTICLE III

#### OFFICERS, EMPLOYEES AND AGENTS

Section 1. Number and Qualifications. The Officers of the Corporation shall be a Chairperson, (the "Chair"), a Vice-Chairperson (the "Vice-Chair"), a Secretary, a Treasurer and such other officers, if any, including one or more Vice Chairpersons, as the Board of Directors may from time to time appoint. One person may hold more than one office in the Corporation except that no

one person may hold the offices of Chair or Chair-Elect and Secretary. The Chair and Vice Chair shall be a Director of the Corporation; the other Officers need not be Directors of the Corporation. No instrument required to be signed by more than one officer may be signed by one person in more than one capacity.

Section 2. Election and Term of Office. Initially, the Corporation shall be managed primarily by the Chair, the Vice Chair and the steering committee (the "Steering Committee"). The initial term of the Chair, the Vice Chair and Steering Committee shall commence in April, 2004. The initial Chair and Vice-Chair will serve until the 2007 Annual Meeting. Thereafter, the Corporation shall be managed primarily by the Chair, Vice-Chair and the elected Board of Directors. The Vice-Chair of the Corporation shall be elected prior to the annual meeting of the Members, beginning with the 2007 Annual Meeting (see Section 2). Elections will be for vacant Board of Directors positions and for the Vice Chair; the outgoing Vice Chair will assume the position of Chair and hold that position for two years, until the next election. Other members of the Board of Directors, whether elected at the Annual Meeting or to fill a vacancy or otherwise, shall hold office for a period of 4 years until the close of the election of Officers or until a successor shall have been elected and qualified, or until the death, resignation or removal of such Officer, whichever is earlier. The outgoing Chair shall serve as ex officio (non-voting) member of the board of directors for two years.

Section 3. Employees and Other Agents. The Board of Directors may appoint from time to time such employees and other agents as it shall deem necessary, each of whom shall hold office at the pleasure of the Board, and shall have such authority and perform such duties and shall receive such reasonable compensation, if any, as a majority of the Board of Directors may from time to time determine. To the fullest extent allowed by law, the Board of Directors may delegate to any officer or agent any powers possessed by the Board of Directors and may prescribe their respective title, terms of office, authorities and duties.

Section 4. Removal. Any officer, employee or agent of the Corporation may be removed with or without cause by a vote of the majority of the entire Board of Directors.

Section 5. Vacancies. In case of any vacancy in any office, a successor to fill the unexpired portion of the term may be elected by the Board of Directors.

Section 6. Chairperson: Powers and Duties. The Chairperson shall preside at all meetings of the members and of the Board of Directors. The Chairperson shall have general supervision of the affairs of the Corporation, and shall keep the Board of Directors fully informed about the activities of the Corporation. He or she has the power to sign and execute alone in the name of the Corporation all contracts authorized either generally or specifically by the Board, unless the Board shall specifically require an additional signature. The Chairperson shall perform all the duties usually incident to the office of the Chairperson, and shall perform such other duties as from time to time may be assigned by the Board of Directors.

Section 7. Vice-Chairperson: Powers and Duties. The Vice Chairperson(s) shall have such powers and duties as may be assigned to them by the Board of Directors. In the absence of the Chairperson, the Vice Chairperson(s), in the order designated by the Board of Directors, shall perform the duties of the Chairperson.

Section 8. Secretary: Powers and Duties. The Secretary shall keep the minutes of the Annual Meeting and all meetings of the Board of Directors in books provided for that purpose. He or she shall be responsible for the giving and serving of all notices of the Corporation and shall perform all the duties customarily incident to the office of the Secretary, subject to the control of the Board of Directors, and shall perform such other duties as shall from time to time be assigned by the Board of Directors.

Section 9. Treasurer: Powers and Duties. The Treasurer shall keep or cause to be kept full and accurate accounts of receipts and disbursements of the Corporation, and shall deposit or cause to be deposited all moneys, evidences of indebtedness and other valuable documents of the Corporation in the name and to the credit of the Corporation in such banks or depositories as the Board of Directors may designate. At the annual meeting of the Board of Directors and whenever else required by the Board of Directors, he or she shall render a statement of the Corporation's accounts. He or she shall at all reasonable times exhibit the Corporation's books and accounts to any officer or director of the Corporation and shall perform all duties incident to the position of Treasurer subject to the control of the Board of Directors, and shall when required, give such security for the faithful performance of his or her duties as the Board of Directors may determine.

Section 10. Compensation. No officer shall receive compensation for services. Other employees of the corporation may receive compensation for duties deemed essential to the management of the corporation.

## ARTICLE IV

### COMMITTEES

Section 1. Committees of the Board. The Board may, by resolution adopted by a majority of the entire Board, establish and appoint certain standing committees. The Chairperson of the Board of Directors shall appoint the chairperson of each committee. Each committee so appointed shall consist of three or more directors and, to the extent provided in the resolution establishing it, shall have all the authority of the Board except as to the following matters:

- a. the filling of vacancies on the Board or on any committee;
- b. the amendment or repeal of the by-laws or the adoption of the new by-laws;
- c. the amendment or repeal of any resolution of the Board which by its terms shall not be so amendable or repealable;

Special committees may be appointed by the Chairperson of the Board of Directors with the consent of the Board and shall have only the powers specifically delegated to them by the Board.

Section 2. Committees of the Corporation. The Board or the members may create committees of the corporation. Committees created by the Board shall be appointed by the Chairperson of the Board of Directors with the consent of the Board. Committees created by the members shall be elected by the members, unless the members authorize the Chairperson to appoint said committees with the consent of the Board.

## ARTICLE V

### CONTRACTS, CHECKS, BANK ACCOUNTS AND INVESTMENTS

Section 1. Checks, Notes and Contracts. The Board of Directors is authorized to select such depositories as it shall deem proper for the funds of the Corporation and shall determine who shall be authorized in the Corporation's behalf to sign bills, notes, receipts, acceptances, endorsements, checks, releases, contracts and documents.

Section 2. Investments. The funds of the Corporation may be retained in whole or in part in cash or be invested and reinvested from time to time in such property, real, personal or otherwise, including stocks, bonds or other securities, as the Board of Directors may deem desirable.

## ARTICLE VI

### OFFICE AND BOOKS

Section 1. Office. The office of the Corporation shall be located at such place as the Board of Directors may from time to time determine.

Section 2. Books. There shall be kept at the office of the Corporation correct books of account of the activities and transactions of the Corporation including a minute book, which shall contain a copy of the certificate of incorporation, a copy of these by-laws, and all minutes of meetings of the members and of the Board of Directors.

## ARTICLE VII

### FISCAL YEAR

The fiscal year of the Corporation shall be determined by the Board of Directors.

## ARTICLE VIII

### INDEMNIFICATION

The Corporation may, to the fullest extent now or hereafter permitted by and in accordance with the standards and procedures provided for by sections 721 through 726 of the Not-for-Profit Corporation Law and any amendments thereto, indemnify any person made, or threatened to be made, a party to any action or proceeding by reason of the fact that he, his testator or intestate was a director, officer, employee or agent of the Corporation, against judgments, fines, amounts paid in settlement and reasonable expenses, including attorneys' fees.

## ARTICLE IX

### AMENDMENTS

These by-laws may be amended or repealed by the affirmative vote of a majority of the entire Board at any meeting of the Board of Directors, or by the members of the Corporation at a meeting duly called for the purpose of altering these by-laws, providing notice of the proposed alteration has been included in the notice of meeting.