

By-laws of the
Spastic Paraplegia Foundation, Inc.

(Revised August 28, 2007)

Section 1. Name, Purposes, Locations, Corporate Seal and Fiscal Year

1.1 Name and Purposes. The name and purposes of the corporation shall be as set forth in the Articles of Organization. These By-laws, and the powers of the corporation and of its directors and officers, shall be subject to the Articles of Organization.

1.2 Location. The principal office of the corporation in the Commonwealth of Massachusetts shall initially be located at a place set forth in the Articles of Organization of the corporation. The directors may change the location of the principal office in the Commonwealth of Massachusetts effective upon filing a certificate with the Secretary of the Commonwealth of Massachusetts.

1.3 Other Locations. The corporation may also have other offices in locations within or without the Commonwealth of Massachusetts, as the directors may from time to time designate.

1.4 Gender. The pronouns "he" or "his", when appropriate, shall be construed to mean also "she" or "her".

1.5 Corporate Seal. The directors may adopt and alter the seal of the corporation.

1.6 Fiscal Year. The fiscal year of the corporation shall begin on the first day of January and end on the last day of December in each year.

Section 2. Members

2.1 No Members. The corporation shall not have any voting members. Any action or vote permitted to be taken by members pursuant to Massachusetts General Laws, chapter 180 shall be taken by action or vote of the same percentage of the directors of the corporation.

Section 3. Board of Directors

3.1 Management of the Corporation. The general management of the affairs of this corporation shall be vested in the board of directors. The board of directors shall fix its policies, have the power to employ and discharge necessary staff and other help, authorize expenditures, and take all necessary and proper steps to carry out the purposes of this corporation and promote its best interests.

3.2 Number and Election. There shall be seven initial directors, and they shall be those persons named as directors in the Articles of Organization. Thereafter, *there shall be no more than thirteen¹ directors and no less than seven, and they²³* shall be elected by vote of a majority of the directors then in office at the annual meeting. The number of directors may be increased or decreased from time to time by a vote of a majority of the directors then in office.

3.3 Term of Office. The term of office for a director shall be two years. Notwithstanding the previous sentence, the four initial directors who are also the four initial officers shall serve a three-year term for their initial term only. Thereafter, the terms of all directors shall be two years, but the terms shall be staggered. Each director shall hold office until his successor is appointed by a vote of the majority of the directors.

3.4 Compensation. Directors shall serve without compensation as directors, except that they shall be allowed reasonable advancement or reimbursement of expenses incurred in the performance of their duties. Notwithstanding the previous sentence, directors shall not be allowed reasonable advancement or reimbursement of expenses incurred in attending, and travelling to and from meetings of the board of directors, *except that a member who could not otherwise attend such a meeting may apply for a travel allowance in an amount up to three hundred dollars (\$300.00), which shall be approved or denied by the President.*⁴

3.5 Restriction Regarding Interested Directors. Notwithstanding any other provision of these By-laws, not more than forty-nine percent (49%) of the persons serving on the board may be interested persons.

For purposes of this section, "interested persons," means either:

a) any person currently being compensated by the corporation for services rendered it at any time within the previous twelve (12) months, whether as a full- or part-time officer or other employee, independent contractor, or otherwise; or

b) any brother, sister, ancestor, descendant, spouse, brother-in-law, sister-in-law, son-in-law, daughter-in-law, mother-in-law, or father-in-law of any such person.

3.6 Resignation of Directors. Any director may resign at any time by giving written notice to the corporation at its principal office, or to the president or secretary of the corporation. The acceptance of a resignation shall not be necessary to make it effective, but no resignation shall discharge any accrued obligation or duty of a director.

¹ Maximum number of directors raised to thirteen (13) by an amendment adopted by the Board of Directors on February 25, 2006.

² Maximum number of directors raised to nine (9) by an amendment adopted by the Board of Directors on April 12, 2003.

³ Maximum number of directors raised to eleven (11) by an amendment adopted by the Board of Directors on December 11, 2004.

⁴ Amendment adopted by the Board on March 2, 2004.

3.7 Removals. A director may be removed with or without cause by the vote of a majority of the directors. A director may be removed for cause only after reasonable notice and opportunity to be heard before the board.

3.8 Vacancies. Any vacancy in the board of directors may be filled by vote of the remaining directors at any meeting. Each successor shall hold office for the unexpired term or until his successor is chosen, or until he sooner dies, resigns, or is removed. The directors shall have and may exercise all of their powers notwithstanding the existence of one or more vacancies in their number.

Section 4. Meetings of the Board of Directors

4.1 Annual Meeting. The annual meeting of the board of directors shall be held on the second Saturday in February and shall be called by the president, secretary, or any director. In the event the annual meeting is not held on such date, a special meeting in lieu of the annual meeting may be held with all the force and effect of an annual meeting. At the annual meeting, or the special meeting held in lieu of the annual meeting, the directors shall elect the president, vice-president, treasurer and secretary, and any directors whose term of office has expired.

4.2 Regular Meetings. In addition to the annual meeting, or the special meeting held in lieu of the annual meeting, there shall be three regular meetings of the board of directors yearly. Regular meetings of the directors may be held at such places and at such times as the directors or the president may determine.

4.3 Special Meetings. Special meetings of the directors may be held at any time and at any place when called by one or more directors, or by the president.

4.4 Place of Meetings. All meetings of the directors shall be held at the principal office of the corporation in the Commonwealth of Massachusetts or at such other place within or without the Commonwealth of Massachusetts as shall be fixed by the directors or the president.

4.5 Notice of Meetings. Notice of the time and place of each meeting of the directors shall be given to each director by first class mail at least five days or by facsimile or e-mail or other electronic means at least forty-eight hours before the meeting, addressed to him at his usual or last known business or residence address, or in person or by telephone at least forty-eight hours before the meeting. Notice need not specify the purposes of the meeting unless required by law, or unless there is to be considered at the meeting (i) contracts or transactions of the corporation with interested persons, or (ii) removal of an officer or director.

4.6 Quorum. At any meeting of the directors, a majority of the directors then in office shall constitute a quorum, but if less than such majority is present at a meeting, a majority of those present may adjourn a meeting from time to time without further notice.

4.7 Action by Vote. When a quorum is present at any meeting, a majority of the directors present and voting shall decide any question, including election of officers and appointment or election of committees, unless otherwise provided by law, the Articles of Organization, or these By-laws.

4.8 Action by Writing. Any action required or permitted to be taken at any meeting of the directors may be taken without a meeting if all the directors consent to the action in writing and the written consents are filed with the records of the meetings of the directors. Such consents shall be treated for all purposes as a vote at a meeting.

4.9 Presence Through Communications Equipment. Unless otherwise provided by law, directors may participate in board meetings 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, and participation by such means shall constitute presence in person at a meeting. Notwithstanding the above sentence, directors must attend at least *one*⁵ meeting per year without the use of communications equipment.

Section 5. Officers and Agents.

5.1 Number and Qualification. The officers of the corporation shall be a president, vice-president, treasurer, secretary and such other officers, if any, as the directors may determine. The corporation may also have such agents, if any, as the directors may appoint. An officer may but need not be a director. The clerk shall be a resident of Massachusetts unless the corporation has a resident agent duly appointed for the purpose of service of process. A person may hold more than one office at the same time.

5.2 Election. The president, vice-president, treasurer and secretary shall be elected annually by the directors at the annual meeting as set forth in section 4.1 of these By-laws.

5.3 Term. The president, vice-president, treasurer and secretary shall each hold office until the next annual meeting and until his successor is chosen and qualified, or until he sooner dies, resigns, or is removed. Each agent shall retain his authority at the pleasure of the directors.

5.4 President. The president shall be the chief executive officer of the corporation and shall, subject to the control of the board of directors, supervise and control the affairs of the corporation and the activities of the officers. He shall perform all duties incident to his office and such other duties as may be required by law, by the Articles of Organization of this corporation, or by these By-laws, or which may be prescribed from time to time by the board of directors. Unless the board of directors decide otherwise, he shall preside at all meetings of the board of directors.

⁵ Changed from two in-person meetings per year to one such meeting, by vote of the Board on March 2, 2004.

5.5 Vice-President. In the absence of the president, or in the event of his inability or refusal to act, the vice-president shall perform all the duties of the president, and when so acting shall have all the powers of, and be subject to all the restrictions on, the president. The vice-president shall have other powers and perform such other duties as may be prescribed by law, by the Articles of Organization, or by these By-laws, or as may be prescribed by the board of directors.

5.6 Treasurer. The treasurer shall be the chief financial officer and the chief accounting officer of the corporation.

Subject to the provisions of section 8 of these By-laws relating to the "Execution of Papers," the Treasurer shall:

Have charge and custody of, and be responsible for, all funds and securities of the corporation, and deposit all such funds in the name of the corporation in such banks, trust companies, or other depositories as shall be selected by the board of directors.

Receive, and give receipt for, or cause a receipt to be given for, monies due and payable to the corporation from any source whatsoever.

Disburse, or cause to be disbursed, the funds of the corporation as may be directed by the board of directors, taking proper vouchers for such disbursements.

Keep and maintain adequate and correct accounts of the corporation's properties and business transactions, including accounts of its assets, liabilities, receipts, disbursements, gains and losses.

Exhibit, or cause to be exhibited, at all reasonable times the books of account and financial records to any director of the corporation, or to his or her agent or attorney, on request therefor.

Render to the president and directors, whenever requested, an account of any or all of his transactions as treasurer and of the financial condition of the corporation.

Prepare, or cause to be prepared, and certify, or cause to be certified, the financial statements to be included in any required reports.

Prepare or cause to be prepared all reports and filings required by the Commonwealth of Massachusetts, the Internal Revenue Service, and other governmental agencies.

In general, perform all duties incident to the office of treasurer and such other duties as may be required by law, by the Articles of Organization of the corporation, or by these By-laws, or which may be assigned to him from time to time by the board of directors.

5.7 Secretary. The Secretary shall:

Record and maintain records of all proceedings of the directors in books kept for that purpose, which shall be kept within the Commonwealth at either (1) the principal office of the corporation or (2) at the office of its secretary or of its resident agent. Such books shall also contain records of all meetings of incorporators and the original, or attested copies, of the Articles of Organization, the By-laws as amended or otherwise altered to date, and the names of all directors and the address of each. If the secretary is absent from any meeting of directors, a temporary secretary chosen at the meeting shall exercise the duties of the secretary at the meeting.

See that all notices are duly given in accordance with the provisions of these By-laws or as required by law.

Be custodian of the seal of the corporation, if any, and, if there is a seal, see that the seal is affixed to all duly executed documents, the execution of which on behalf of the corporation under its seal is authorized by law or these By-laws.

Keep in the Commonwealth of Massachusetts at either (1) the principal office of the corporation, or (2) at the office of its secretary or of its resident agent, a book containing the name and address of each and every contributor of any donation or gift to the corporation.

Exhibit, or cause to be exhibited at all reasonable times to any director of the corporation, or to his or her agent or attorney, on request therefor, the By-laws, the contributors book, and the minutes of the proceedings of the directors of the corporation.

In general, perform all duties incident to the office of secretary and such other duties as may be required by law, by the Articles of Organization of this corporation, or by these By-laws, or which may be assigned to him from time to time by the board of directors.

5.8 Removals and Resignations. Any officer may be removed, at any time either with or without cause, by a two-thirds vote of the entire board of directors. Any officer may resign at any time by giving written notice to the corporation at its principal office, or to the president or the secretary. Any such resignation shall take effect at the date of receipt of such notice or at any later date specified therein, and, unless otherwise specified therein, the acceptance of such resignation shall not be necessary to make it effective. The above provisions of this section shall be superseded by any conflicting terms of a contract which has been approved or ratified by the board of directors relating to the employment of any officer of the corporation.

5.9 Vacancies. Any vacancy caused by the death, resignation, removal, or otherwise, of any officer shall be filled by the board of directors, except that a vacancy in the office of the president shall be filled by the vice-president. In the event of a vacancy in any office other than that of president, such vacancy may be filled temporarily by appointment by the president until such time as the board of directors shall fill the vacancy. Each such successor officer shall hold office for the unexpired term, and in the case of the president, vice-president, treasurer and secretary until his successor is elected and qualified, or in each case until he sooner dies, resigns, is removed or becomes disqualified. Vacancies

occurring in offices of officers appointed at the discretion of the board may or may not be filled, as the board shall determine.

5.10 Compensation. The salaries of the officers, if any, shall be fixed from time to time by resolution of the board of directors, and no officer shall be prevented from receiving such salary by reason of the fact that he is also a director of the corporation, provided, however, that such compensation paid a director for serving as an officer of this corporation shall only be allowed if permitted under the provisions of article 3, section 6 of these By-laws. In all cases, any salaries received by officers of this corporation shall be reasonable and given in return for services actually rendered for the corporation as officers which relate to the performance of the charitable or public purposes of this corporation.

Section 6. Committees

6.1 Executive Committee. The board of directors may, by a majority vote of directors, designate two or more of its members (who may also be serving as officers of this corporation) to constitute an executive committee and delegate to such committee any of the powers and authority of the board in the management of the business and affairs of the corporation, except with respect to:

- (a) The filling of vacancies on the board or on any committee which has the authority of the board of directors.
- (b) The amendment or repeal of the By-laws or the adoption of new By-laws.
- (c) The amendment or repeal of any resolution of the board of directors which by its express terms is not so amendable or repealable.
- (d) The appointment of committees of the board of directors.
- (e) The approval of any transaction to which this corporation is a party and in which one or more of the directors has a material financial interest.
- (f) The issuance of a grant of money to be used to conduct scientific research to find a cure for hereditary spastic paraplegia, primary lateral sclerosis, Pelizaeus-Merzbacher disease, Silver syndrome, Troyer syndrome, or any related disorder.

By a majority vote of its members then in office, the board of directors may at any time revoke or modify any or all of the authority so delegated, increase or decrease but not below two the number of the members of the executive committee, and fill vacancies therein from the members of the board. The executive committee shall keep regular minutes of its proceedings, cause them to be filed with the corporate records, and report the same to the board from time to time as the board may require.

6.2 Other Committees and Task Forces. The corporation shall have such other committees and task forces as may from time to time be designated by resolution of the

board of directors. Such other committees and task forces may consist of persons who are not also directors. These additional committees and task forces shall act in an advisory capacity to the board of directors, except that the board of directors may delegate certain limited powers to a committee or task force. In all cases, these committees and task forces shall report to the board of directors and shall be under their ultimate direction.

6.3 Meetings and Action of Committees. Meetings and action of committees shall be governed by, noticed, held and taken in accordance with the provisions of these By-laws concerning meetings of the board of directors, with such changes in the context of such By-law provisions as are necessary to substitute the committee and its members for the board of directors and its members. The board of directors may also adopt rules and regulations pertaining to the conduct of meetings of committees to the extent that such rules and regulations are not inconsistent with the provisions of these By-laws.

Section 7. Sponsors and Other Supporters of the Corporation

7.1 Sponsors and Other Supporters of the Corporation. The board of directors may designate certain persons or groups of persons as sponsors, benefactors, contributors, advisors or friends of the corporation or such other title as they deem appropriate. Such persons shall serve in an honorary capacity and, except as the directors shall otherwise designate, shall have no right to attend meetings, to have notice of or to vote at any meeting; shall not be considered for purposes of establishing a quorum; and shall have no other rights or responsibilities.

Section 8. Execution of Papers

8.1 Execution of Instruments. Except as the board of directors may generally or in particular cases authorize otherwise, all deeds, mortgages, leases, transfers, contracts, bonds, notes, checks, drafts and other obligations made, accepted or endorsed by the corporation shall be signed by the president, vice-president or the treasurer. Unless so authorized, no officer, agent, or employee shall have any power or authority to bind the corporation by any contract or engagement or to pledge its credit or to render it liable monetarily for any purpose or in any amount.

8.2 Checks and Notes. Except as otherwise specifically determined by resolution of the board of directors, or as otherwise required by law, all checks, drafts, promissory notes, orders for the payment of money, and other evidence of indebtedness of the corporation in an amount of twenty-five thousand dollars or more shall be signed by the treasurer and countersigned by the president or vice-president of the corporation.

8.3 Deposits. All funds of the corporation shall be deposited from time to time to the credit of the corporation in such banks, trust companies, or other depositories as the board of directors may select.

8.4 Gifts. The board of directors may accept on behalf of the corporation any contribution, gift, bequest, or devise for the charitable, scientific and educational purposes of this corporation.

Section 9. Miscellaneous Provisions

9.1 Conflict of Interest Policy. Subject to the Articles of Organization and any applicable law, the board of directors shall adopt a conflict of interest policy covering the corporation's directors, officers, agents and such staff as may be specified in the policy.

9.2 Inspection Rights. Every director shall have the absolute right, upon reasonable notice and at any reasonable time to inspect and copy all books, records and documents of every kind and to inspect the physical properties of the corporation.

9.3 Amendment of the By-laws. The By-laws may be altered, amended, or repealed, in whole or in part, by a majority of the entire board of directors at any meeting, the notice of which contains a statement of the proposed alterations or amendments, and further provided that the notice of such meeting be given to each of the directors at least seven days prior to the meeting at which the proposed action is to be considered.

Section 10. Conflicts of Interest

Whenever a director or officer has a financial or personal interest in any matter coming before the board of directors, the affected person shall:

- a) fully disclose the nature of the interest, and
- b) withdraw from discussion, lobbying, and voting on the matter.

Any transaction or vote involving a potential conflict of interest shall be approved only when a majority of disinterested directors determine that it is in the best interest of the corporation to do so. The minutes of meetings at which such votes are taken shall record such disclosure, abstention and rationale for approval.

For the purposes of this section of the by-laws, "personal interest" shall not include the fact that a director or officer has a particular disorder, or that their disorder is caused by a

mutation in a particular gene.

Revised August 28, 2007

A true copy attest,

Frank Davis, Secretary