

AMENDED AND RESTATED
BYLAWS OF
NATIONAL MPS SOCIETY INC.

Revised April 20, 2024

ARTICLE I HEADQUARTERS

The National MPS Society, Incorporated (hereinafter called the "Society") headquarters shall exist for the purposes described herein and in the Certificate of Incorporation. The headquarters shall be located and shall carry out such other activities as determined by the Board of Directors.

ARTICLE II PURPOSE AND MISSION AND VISION

Section 1. Purpose Statement

In February of 1974 a group of parents and professionals, with the objective of creating a greater understanding of mucopolysaccharidosis ("MPS") and mucopolidosis ("ML"), met at Johns Hopkins Hospital. As a result of that meeting, the Society was established.

Section 2. Mission Statement

The National MPS Society exists to cure, support, and advocate for MPS and ML.

Section 3. Vision Statement

Our vision is to be recognized as the global leader in MPS and ML research funding and support for those impacted by MPS and ML.

ARTICLE III MEMBERSHIP

Section 1. Membership and Voting Rights

Members shall be persons having satisfied registration requirements as established and published by the Board of Directors who shall be entitled to vote on all matters coming before the membership. Each Member shall have one vote.

Section 2. Meetings

The Society will hold at least one annual membership meeting during the calendar year. The committees or work groups of the Society will conduct meetings as necessary. All membership meetings of the Society are public and shall be preceded by a 30-day notice to the membership of the meeting.

Special meetings of the Society membership may be held at such time and place as the Executive Committee, Board or Directors or Chairman of the Board may order on a thirty (30) day notice to the membership.

A quorum is not required for the annual membership meeting or other committee meetings. No member may vote for, on behalf of, or in any way exercise the vote of another.

The date, time, and place for the succeeding membership meeting will be announced at each membership meeting. The meeting will convene at the time and place unless proper notice is given to all members that the meeting will be rescheduled.

Meeting notices shall state the agenda or the purpose of the meeting. All membership meetings will be held in accessible and barrier-free buildings or virtually, through an online meeting platform that provides accessible communication aids.

ARTICLE IV BOARD OF DIRECTORS

Section 1. General Powers

The Board of Directors shall be the governing body, and as such, is responsible for the property and affairs of the Society. The Board may perform such acts and make such rules, regulations, and decisions and repeal, alter, or amend same, consistent with Articles of the Society, and/or bylaws as may be necessary to promote the interests of the Society and carry on its business. The Directors may delegate certain responsibilities of their duties to the officers of the Society, but such delegation shall not relieve the Board of the responsibility for any action so taken.

The Board of Directors is responsible to the membership and is expected to work within the mission and goals of the Society.

The Board of Directors shall exercise the governance of the organization, subject to these bylaws, the Certificate of Incorporation, and any vote at the annual or other membership meeting.

The Board of Directors shall establish an annual income and expense budget.

Section 2. Number and Term

The total number of Director positions shall be not fewer than nine (9) or more than fifteen (15). Up to one-third (1/3) of the Director positions may be appointed by the Board of Directors. The remaining Director positions shall be elected at the annual meeting of members or by formal ballot. The number of total Director positions, appointed positions, and elected positions will be set by Board Resolution.

The term of office of each Director shall be two (2) years or until a Director's successor is qualified and appointed or elected. The terms of the Directors shall be staggered so that approximately one-half (1/2) of the terms expire each year.

A married couple may choose to run for or be appointed to the same Director position. The couple shall have one vote and would count as one position towards the Director position count. Only one individual of the couple may hold an officer position at the same time.

The President/CEO and other Chief Officer level employees identified by the Board of Directors may serve as nonvoting ex-officio Directors, not subject to term limits and not subject to the maximum Director count.

One member of the Scientific Advisory Board elected by the Scientific Advisory Board may serve as a nonvoting ex-officio Director, not subject to term limits and not subject to the maximum Director count.

Section 3. Qualifications

Director candidates, as of the deadline for accepting nominations and during their term of office, must be members in good standing of the Society, at least twenty-one (21) years of age, and residents of the United States. Director candidates, as of the deadline for accepting nominations and during their term of office, shall not be employees of the Society.

Directors are to chair or actively participate on a minimum of one standing committee as directed by the Chairman of the Board.

Section 4. Removal

The Board of Directors may by a two-thirds (2/3) vote at a meeting called pursuant to this Section, censure or dismiss a director under the following conditions: failure to attend two (2) or more Board of Directors meetings in a given term, intentional misrepresentation of the actions or stated position of the Board of Directors, or violation of the Society's confidentiality or ethics policy. (For the purposes of this Section, censure is defined as a formal reprimand of the Director with notification to the general membership via the Society's official journal and dismissal is defined as removal from

office). Censured Directors shall be ineligible for service as an officer of the Society for the remainder of their current and one future term. Dismissed Directors are barred from Board service for the remainder of their current and one future term.

Section 5. Regular Meetings

A regular meeting of the Board of Directors shall be held at least twice (2) during each calendar year at the office of the Society or at such other place as the Chairman of the Board may determine.

Section 6. Special Meetings

Special meetings of the Board of Directors may be called by or at the request of the Chairman of the Board or a majority of Directors and shall be held at the Headquarters of the Society or at such other place as the Directors or Chairman of the Board may determine.

Section 7. Notice

Notice of any special meeting of the Board of Directors shall be given ten (10) days prior to a teleconference or thirty (30) days prior to a face to face meeting and shall be written, electronic, or oral, delivered personally to each Director or to such person as the Chairman may designate to receive such notice.

Section 8. Quorum

A simple majority of the Board of Directors shall constitute a quorum for the transaction of business at any meeting of the Board; but if less than a quorum of the Directors is present at any meeting, an informational meeting may be held with no votes taken.

Section 9. Board Decisions

The act of a majority of the Directors present at a meeting, at which a quorum is present, shall be the act of the Board of Directors, unless a greater number is required by law or by these bylaws.

Section 10. Vacancies

Any vacancy occurring on the Board of Directors may be filled by the Board of Directors by a simple majority vote. A Director appointed to fill a vacancy shall serve for the remaining term of the predecessor.

Section 11. Compensation, Per Diem, and Expenses

Directors shall not receive any stated salary and shall not receive any compensation, direct or indirect, for their services. This bylaw cannot be amended except by amendment of the Certificate of Incorporation of the Society. Directors are volunteers and not employees but are entitled to per diem and reimbursement for travel and other expenses as authorized by the Executive Committee or Board of Directors.

Section 12. Directors' Adherence to Director Responsibilities

Directors, in accordance with their term of service, shall abide by the confidentiality and ethics policies of the Board of Directors.

ARTICLE V OFFICERS

Section 1. Officers Specified

Only Directors may serve as Officers of the Society. Any Director is eligible to hold office subject to office term limitations, one officer per Director position limitation, and censure limitations. Officers shall include the Chairman of the Board, Vice-Chairman of the Board, Secretary, Treasurer, and such other officers as the Board of Directors may elect. See the discussion of officers-elect at Section 2.

Section 2. Election and Terms of Office

The Officers shall be elected at a duly called meeting of the Board of Directors for a two (2) year term by a majority vote of the Board of Directors. Terms begin January 1 of the calendar year following the year of election and shall continue until a successor shall have been chosen and qualified. Officers shall be elected approximately three months in advance and shall serve in an ex-officio status until the Officer has been installed. No officer shall serve for more than two consecutive terms in the same office. In the event the Board of Directors determines that a suitable candidate is not available, an officer may succeed for a third term by majority approval of the Board of Directors. In no event shall an officer serve for more than three consecutive terms in the same office. No person may hold more than one office simultaneously.

Section 3. Resignation and Removal of Officers

In the event of the resignation, death, or removal from office of the Chairman of the Board, the Vice-Chairman of the Board shall succeed to the office of the Chairman of the Board. In the event of the resignation, death, or removal of the Chairman of the Board and Vice-Chairman of the Board, the Secretary shall succeed to the office of the Chairman of the Board. Any vacancy occurring in the offices of the Vice-Chairman of the Board, Secretary, or the Treasurer, shall be filled by another Board member upon a majority vote of the Board of Directors to serve the remainder of the current term.

Section 4. Duties and Powers

The officers shall perform the following duties and others as may be prescribed by the Board of Directors:

(A). Chairman of the Board

Call all meetings and set agenda.

Preside at all meetings.

Establish committees and work groups as appropriate to meet the goals and objectives of the Society.

Appoint the Chairs of the standing committees and work groups.

Appoint one member at large from the Board of Directors to serve on the Executive Committee.

Appoint Society members and other public members to the committees and work groups.

Serve as ex-officio (non-voting) member of all committees.

Serve as the Society's official representative during the Chairman's term.

Operate and conduct the business and affairs of the Society according to the orders and resolutions of the Board of Directors.

Perform other duties described in these bylaws or assigned by the Board of Directors.

(B). Vice-Chairman of the Board

Assist the Chairman of the Board in the discharge of his or her duties and preside at meetings in the absence of the Chairman of the Board.

Monitor the record of actions taken by motions at each meeting and items requiring follow-up on the agenda for the next meeting.

Act as the parliamentarian for the Society.

Perform other duties in accordance with the orders and resolutions of the Board of Directors.

(C) Secretary

Coordinate and administer to the needs of the Executive Committee and Board of Directors as directed by the Chairman of the

Provide oversight to the President/CEO for the development and orientation manual for the new Board of Directors. Distribute to the membership notice of all membership meetings of the Society.

Take minutes of all meetings of the members and of the Board of Directors and Executive Committee.

Be responsible for presenting the agenda and minutes of the Executive Committee and Board of Directors meetings in collaboration with the Chairman of the Board and President/CEO.

(D). Treasurer

It shall be the duty of the Treasurer to oversee the preparation and maintenance of the financial records and reports of the Society (including arranging for the annual audit of the Society's records), to establish (with the approval of the Executive Committee) depositories for the Society's funds, to oversee collection of moneys due the Society, to oversee the payment of bills, and to prepare and report, in conjunction with the President/CEO, the financial status of the Society at each regularly scheduled meeting of the Board of Directors.

Further duties of the Treasurer include ensuring that all tax forms, or other such forms required by regulatory bodies, are properly filed on a timely basis, reviewing and approving of all binding contracts greater than \$100,000 along with the President/CEO, and chairing the budget committee that develops the annual budget for submission to the Board of Directors for approval.

The Treasurer shall perform such other duties and have such other powers as the Board may prescribe.

ARTICLE VI EMPLOYEES

Section 1. President/CEO and Staff

The Board of Directors may hire a President/CEO. The President/CEO of the Society shall be selected by a majority vote of the Board of Directors. The President/CEO employed by the Society shall:

Provide staff support for the Board of Directors and Executive Committee.

Develop and maintain the orientation manual for the new Board of Directors. Include Board of Directors policies and procedures. Orientate new Directors to the Society and to their Board Member responsibilities.

Prepare, file, copy, and submit all reports as required by law to state and local governments for proper operation of the Society and register the Society for any and all charity status.

Coordinate and support the fundraising activities.

Write and oversee the grant writing activities.

Work under the primary supervision of the Chairman of the Board as directed by the Executive Committee.

Be responsible for the Society's communications, with the concurrence of the Chairman of the Board or Board of Directors.

Prepare the financial report of the Society in conjunction with the Treasurer.

Carry out and achieve the financial objectives in the annual budget.

Maintain a roster of members of the Society, including the names and mailing addresses of all members, affected family members, affected family member birth date or date of death, as well as other information necessary for the operation of the Society and to keep such information confidential as required by the Society's Confidentiality Policy and applicable law.

Attest to the authenticity of Society resolutions and orders.

Send notices of committee meetings or work groups of the Society and the agenda of such meetings to all participants.

Hire staff as necessary if approved by the Board of Directors, to ensure that the Society has the capacity to fulfill its responsibilities.

Provide research grant administration support. involving direction, policy formation, and oversight, either directly or through identified staff. This may include working with both formal and informal groups of individuals with biomedical or other relevant expertise, such as members of the Scientific Advisory Board (SAB). Duties and responsibilities include management of proposal submission and review (including Conflict of Interest issues, contract negotiation, and signatory approval of awards approved by the Board of Directors).

Be responsible to the Society for performance of his or her duties and subsequently responsible for the actions of the staff.

Prepare quarterly President/CEO report for distribution to the Board of Directors, and any regular member requesting it, to include staff activities, fundraising activities, research activities, committee work in progress, pertinent correspondence and any action items recommended. Prepare reports to the Executive Committee at meetings at least three times per year.

Obtain office space adequate for conducting Society business.

Perform other duties as directed by the Board of Directors or Executive Committee.

ARTICLE VII COMMITTEES

Section 1. Executive Committee

The Society's Executive Committee shall consist of five voting members comprised of the four (4) officers and one (1) Director-at-Large. The Director-at-Large is appointed by the Chairman of the Board.

Any officers-elect (Article V, Section 2) and the chairs of the six standing committees (unless otherwise serving on the Executive Committee) will serve as ex-officio nonvoting members. For one year following the transition of Chairman of the Board, the immediate past-Chairman of the Board shall serve as an ex-officio nonvoting member, subject to retaining his or her seat on the Board of Directors.

The Executive Committee shall have full authority, within the limits of established Society priorities, policies, and procedures, to act on behalf of the Board between regularly scheduled Board meetings.

The Executive Committee shall prepare the Society meeting calendar, fix the time and place of meetings, call special meetings, and assist the Chairman of the Board in preparing Society agendas.

The Executive Committee shall consider the appointment of all chairs and members of committees or work groups made by the Chairman of the Board and coordinate and review activities of committees or work groups.

The Executive Committee shall supervise and evaluate the President/CEO, supervise implementation of the Society work plan, and assure that the Society fulfills its duties, purpose, and responsibilities.

The Executive Committee shall recommend the Society's operating budget and present it to the Board of Directors.

The Executive Committee shall monitor expenditure of Society funds.

To conduct official Society business, a quorum must be present. A quorum is three voting Executive Committee members. If less than a quorum is present at any meeting, an informational meeting may be held with no votes taken.

The Executive Committee shall meet at least three times a year unless otherwise agreed by a majority of the Executive Committee members.

The Executive Committee may refer matters to other committees or work groups for reports to the Society or the Executive Committee. In assigning tasks to committees or work groups, the Executive Committee shall at their discretion, delegate authority to the committee or work group.

The Executive Committee may assemble and review reports of other committees for inclusion on the agenda of Society meetings and request expansion or clarification of reports that are inadequate.

The Executive Committee shall oversee the preparation of periodic or annual reports described in law or submitted by the President/CEO or Treasurer.

The Executive Committee shall prepare and submit Society comment to all private sector and private institutional entities on issues that impact people with MPS and ML and their families. The Executive Committee shall edit, review, and approve by simple majority vote or unanimous consent, Society public policy statements and recommendations directed to legislative, executive (regulatory), and judicial branches of the state and federal governments with the appropriate consultation with the Advocacy Committee.

Section 2. Standing Committees

The Chairman of the Board shall appoint at the first regular meeting of the Board of Directors following the Chairman taking office, subject to approval of the Board of Directors, the following standing committees, including Chairs. Committee chairs set the committee yearly work plan with the approval of the Board and have authority to implement such work plans.

(A). Family Support

Shall coordinate and support the activities of the contact families.

Shall plan and monitor all Family Support activities, programs, and conferences.

Shall plan and schedule all educational and professional seminars.

Shall work to recruit new and retain ongoing members.

(B). Fund Raising

Shall be responsible for creating a development plan/calendar and coordinating all fundraising activities with the staff support of the Development Director, including the annual fund, annual fundraising events, planned giving, endowment growth, marketing & technology where applicable to fundraising efforts, and annual walk/runs.

(C). Advocacy

Shall track, report and advocate action on significant legislation pertaining to MPS and ML related medical research, health services, special education, and disabilities policy.

Shall report quarterly on significant legislation of interest and advocacy efforts.

Shall assist members in advocacy efforts and shall monitor and report these efforts to Directors.

Shall advocate on public policy issues in the form of personal contact, correspondence, and testimony. Shall report activities to the President/CEO, Executive Committee and or Board of Directors on a regular basis. The Chair will represent the Society's policies and issues as directed by the Board of Directors.

(D). Education/Communication

Shall be responsible for the content of Society's newsletter.

Shall be responsible for updating informational brochures and other Society educational publications in concert with the President/CEO.

Shall be responsible for other publication and public information distributed by the Society

(E). Research

Shall be responsible for the oversight of research funding and grant solicitation. Ensure grant administration and management of proposals and review will be conducted on a global platform.

Shall review research funding proposals, including evaluations and comments by the SAB and Society staff, and make funding recommendations to the Board or Executive Committee.

Maintain an ongoing working relationship and network with the Scientific Advisory Board.

Oversee research public communications and ensure such are disseminated to members and published.

(F). Governance

The Governance Committee is responsible for ongoing review and recommendations to enhance the quality and future viability of the Board It focuses on the following areas, with specific duties dependent on Board needs at any specific time, as well as evolving practice:

1. Board Role and Responsibilities

Shall lead the Board in regularly reviewing and updating the Board's statement of its role and areas of responsibility, and the expectations of individual Directors.

Shall assist the Board in periodically identifying, updating, and clarifying primary areas of focus for the Board; the Board's agenda for the next 1-2 years based on the strategic plan.

2. Board Composition

Shall lead in assessment of the current and anticipated needs for Board composition. Determine the knowledge, attributes, skills, abilities, influence, and access the Board will need to consider addressing issues that will arise in the foreseeable future.

Shall develop a profile of the Board as it should evolve over time.

Shall identify potential Director candidates, present them as possibilities, and explore their interest and availability (i.e., establish a pool of candidates).

Shall serve as the Election Sub Committee to oversee the nomination and election process for the Board of Directors.

Shall nominate qualified Director candidates under criteria to be added to the election ballot with Board approval.

Shall nominate qualified individuals to be appointed as Directors based upon needs for Board composition with Board approval.

Shall in cooperation with the Chairman of the Board, contact each Director to assess a Director's continuing interest in Board membership and the term of service. Work with each Director to identify the appropriate post (Director's role) to assume.

3. Board Knowledge

Shall design and oversee a process of orientation, including information prior to election and during first cycle of Board activity for new Directors (usually one year).

Shall design and implement an ongoing program of Board development and education.

4. Board Effectiveness

Shall initiate the periodic assessment of the Board's performance. Propose, as appropriate, changes in Board structure, roles, and responsibilities.

Shall provide ongoing counsel to the Chairman of the Board, Officers, and Committee Chairs on steps the Governance Committee might take to enhance Board effectiveness.

Shall regularly review the Board's practices regarding Director participation, conflict of interest, confidentiality, etc., and suggest improvements as needed.

Shall serve as the Audit Committee to review audit results with the auditors.

Shall periodically review Board's policy guidelines, bylaws and practices, and propose updates to the full Board.

5. Board Leadership

Shall take the lead in succession planning, e.g., recruit and prepare for future Board leadership.

6. Other

Shall serve as the Personnel Committee, reviewing compensation and personnel changes recommended by the President/CEO to the Board.

Section 3. Other Ad Hoc Committees or Work Groups

The Chairman of the Board, subject to the approval of the Board of Directors, shall appoint such other ad-hoc committees or work groups as necessary for the orderly conduct of its business, such as the following:

(A). Resource Board

Shall focus on time-limited projects or programs, either individually or as a group, as determined by the Board of Directors, e.g. fundraising, staff mentoring.

(B). Honorary Board

Shall perform duties in accordance with the orders and resolutions of the Board of Directors.

ARTICLE VIII CONTRACTS, CHECKS, DEPOSITS, AND FUNDS

Section 1. Contracts

The Chairman of the Board and President/CEO are so authorized by these bylaws, to enter into any contract or execute and deliver any instrument in the name of and on behalf of the Society, and such authority may be general or may be confined to specific instances.

Section 2. Checks, Drafts, or Orders

All checks, drafts, or orders for payment of money, notes or other evidence of indebtedness issued in the name of the Society, shall be signed by an authorized signor as indicated in the Society's cash management policies and procedures, and in such manner as shall be determined by resolution of the Board of Directors.

Section 3. Deposits

All funds of the Society shall be deposited to the credit of the Society in such banks; trust companies or other depositories as the Board of Directors may elect.

Section 4. Gifts

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

ARTICLE IX FISCAL YEAR

The fiscal year of the Society shall commence January 1 of each year.

ARTICLE X NON-DISCRIMINATION

The members, officers, directors, committee members, employees and persons served by this Society shall be selected entirely on a non-discriminatory basis with respect to age, sex, race, religion, and national origin.

ARTICLE XI SEAL

The seal of the Society shall be circular in form and shall bear the name of the Society.

ARTICLE XII CONFIDENTIALITY

All records, transaction and membership lists of the Society are confidential. No information, of any kind, may be released without the express consent of the individuals involved.

ARTICLE XIII CHAPTERS

Local Chapters will be determined and established by the Board of Directors. The purpose and activities of the Chapter will be at the direction of the Board.

ARTICLE XIV WAIVER NOTICES

Whenever any notice of any meeting of the members of the Board of Directors is required to be given under provision of law or under the provisions of these by-laws, a waiver thereof in writing, signed by the person or persons entailed to such notice and filed with the records of the meeting, whether before or after the holding thereof, shall be equivalent to the giving of such notice.

ARTICLE XV RECORDS AND PROCEDURES

The Society shall keep correct, complete financial reports and minutes of the proceedings of the Society, the Executive Committee, and any other committees or work groups. The financial reports and other records of the Society shall be maintained by the Society's President/CEO.

All records of the Society shall be available to the members unless otherwise prohibited by law or parliamentary authority.

ARTICLE XVI PARLIAMENTARY AUTHORITY

Robert's Rules of Order, as revised, shall govern the Society meetings when not inconsistent with these bylaws, or with special rules of order adopted by the Society. Suspension of the Rules is permissible by vote of the Society members.

ARTICLE XVII ETHICS AND CONFLICT OF INTEREST

A member of the Society who has a conflict of interest shall not be eligible to vote on any action in which the member has a monetary interest or may receive some special compensation different from regular members of the Society.

A member of the Society shall not be eligible to participate in a discussion of a matter in which the member has a conflict of interest. However, a member who has a conflict may speak on the matter, as a member of the public would do, once the member declares that a conflict exists.

Persons who believes they have a conflict of interest shall disclose the matter on the public record and in writing to the appropriate committee or work group Chair.

Any person who believes that a member of a committee or work group has a conflict of interest may so advise the Chairman of the Board of the Society. The matter shall be decided by a vote of a majority of the members of the Executive Committee excluding that person and any other members who may have already been disqualified for conflict of interest.

ARTICLE XVIII NONPROFIT OPERATION

The Society will not have or issue shares of stock. No dividends will be paid. No part of the income or assets of the Society will be distributed to the members, directors, or officers without full consideration of the entire membership. No member has any vested right, interest, or privilege in or to the assets, property, functions, or activities of the Society. The Society may contract in due course with its members, directors, and officers without violating this provision.

ARTICLE XIX INDEMNIFICATION

The Secretary shall indemnify each office and director, including former officers and directors, to the full extent, permitted by New York's Not-For-Profit Corporation Law and its general corporate laws.

ARTICLE XX AMENDMENT OF BYLAWS

These Bylaws may be amended, repealed or altered, in whole or in part, and additional Bylaws may be adopted, by a two-thirds (2/3) vote of the Board of Directors, following a 30-day written notice to all Board members of the proposed amendment.

IN WITNESS THEREOF, the foregoing bylaws are hereby adopted as the bylaws of the Society, to be effective as of April 20, 2024.

Lisa P. Todd Chairman of the Board

Steve Holland, Vice-Chairman of the Board