

THE CANADIAN SOCIETY FOR MUCOPOLYSACCHARIDE & RELATED DISEASES INC.
BY-LAWS NO. 2 AMENDED as of July 18, 2025

CORPORATE SEAL

1. The seal, an impression whereof is stamped in the margin hereof, shall be the seal of the Corporation.

NATIONAL OFFICE

2. The National Office of the Canadian Society for Mucopolysaccharide & Related Diseases Inc., (herein after called the Corporation) shall be located in the city of Uxbridge, in the province of Ontario
Columbia

MEMBERSHIP

3. The members of the Corporation shall consist of those persons *over the age of 18* who have subscribed and paid yearly dues for the newsletter published by the Corporation and whose application for admission as a member has received the approval of the Board of Directors. Each individual shall have the right to vote at any membership meeting of the Corporation.
4. The Board of Directors shall, in its sole discretion and from time to time, determine the amount of the subscription fee paid by members of the Corporation.

MEETINGS

5. The Annual Meeting of the members shall be held at the National Family Conference of the Corporation, or at any other place in Canada as the Board of Directors may determine and on such day as the said directors shall appoint.
6. The Board of Directors shall call a Special General Meeting of members on written requisition of members carrying not less than 5% of the voting rights.
7. Fourteen (14) days written notice shall be given to each voting member of any Annual or Special Meeting. Notice of any meeting where special business will be transacted shall contain sufficient information to permit the member to form a reasoned judgment on the decision to be taken.
8. Each voting member present at an Annual or Special Meeting shall have the right to exercise one vote. Voting will proceed by a show of hands or verbal indication unless otherwise indicated by a duly passed motion. Proxy votes, in the written form attached as Appendix "A", shall be accepted. All members of the Corporation, as described in paragraph 3 herein, shall be entitled to be a proxy holder. A form of a proxy or a reminder of proxy right shall be attached to the notice of an Annual or Special Meeting.
9. Two members or more of the Corporation shall constitute a quorum at an Annual or Special Meeting.
10. A meeting of the Board of Directors shall be held in conjunction with each National Conference at any place to be determined by the Board of Directors.
11. Fourteen (14) days written notice shall be given to each Director or Executive Officer prior to a Board, Executive or Special Meeting. This notice shall include the agenda for the meeting.
12. The Board of Directors and/or Executive Officers shall meet not less than three times per year. Meetings of the Board and/or Executive shall be held at any time and place to be determined by the Board members. Two Officers shall constitute a quorum. (really 2 officers? Not 2/3's or 50% +1?)
13. Various Board and or Executive meetings may be conducted by video meeting, or telephone, when all directors consent thereto generally or in respect of a particular meeting. A Director may participate in

a meeting of the Board by means of such conference video/telephone, as to permit all persons participating in the meeting to hear each other, and a director participating in such a meeting is deemed to be present at the meeting. Prior to meetings an agenda will be distributed via electronic means to each Board or Executive member. Meetings conducted via electronic/telephone entitles each Board member to one vote and requires each voting Board or Executive member to state his/her vote in favour or against. A resolution in writing, signed by all the Directors entitled to vote on that resolution at a meeting of Directors, is as valid as if it had been passed at a meeting of the Directors. Minutes of each meeting of Board of Directors will be recorded and distributed to the Board.

14. Each Director is authorized to exercise one vote. A majority of votes cast shall be sufficient to take or authorize action upon any major matter which may properly arise at a Board of Directors or Executive meeting, unless otherwise specifically provided by statute or by these by-laws.

MINUTES OF BOARD OF DIRECTORS AND EXECUTIVE MEETINGS

15. The minutes of the Board of Directors shall be made available to the general membership of the Corporation upon written request and shall be made available to the Board of Directors, each of whom shall receive a copy of such minutes within thirty (30) days of the said meeting.

BOARD OF DIRECTORS

16. The Board of Directors shall have the control and management of the affairs and property of the Corporation unless otherwise specifically provided by these by-laws. The Board shall consist of not less than three (3) and not more than twelve (12) Directors of whom two (2) shall constitute a quorum. Directors must be individuals, 18 years of age, with power under law to contract.
17. The applicants for incorporation shall become the first Directors of the Corporation whose term of office on the Board of Directors shall continue until their successors are elected.
18. At the third meeting of the members, the Board of Directors then elected shall replace the provisional Directors named in the Letters of Patent of the Corporation.
19. Directors shall be elected by the members at an annual meeting of the members or be appointed by a majority vote of the Board of Directors and subsequently acknowledged at the next Annual Meeting.
20. Directors nominated must meet the requirements set forth in the job description policies. Nominees shall submit an application in writing to the National Office of the Corporation and the appointment of such nominee may be approved or disapproved by a majority vote of the Board of Directors.
21. The Directors of the Corporation shall hold office **for three (3) years** from the date of appointment or election or until their successors are elected or appointed in their stead. Directors' positions will be reviewed after a one-year period. Any two or more offices may be held by the same person. Directors are eligible to run for consecutive terms of office.
22. The Directors and Officers shall serve as such without remuneration and no Director or Officer shall directly or indirectly receive any profit from his/her position as such; provided that a Director or officer may be paid reasonable expenses incurred by him/her in the performance of his/her duties; and provided further that any Director who is engaged in or is a member of a firm engaged in any business or profession may act in and be paid the usual professional costs and charges for any professional business required to be done in connection with the administration of the affairs of the Corporation.

INDEMNITIES TO DIRECTORS AND OFFICERS

23. Every Director or Officer of the Corporation or other person who has undertaken or is about to undertake any liability on behalf of the Corporation respectively shall from time to time and at all times, be indemnified and saved harmless out of the funds of the Corporation, from and against:

- (a) all costs, charges and expenses whatsoever which such Director or Officer or other person sustains or incurs in or about any action, suit or proceedings which is brought, commenced or prosecuted against him/her or in respect of any act, deed, matter or thing whatsoever, made, done or permitted by him/her in or about the execution of the duties of his/her office or in respect of any such liability so long as such actions were taken under the approval of the Board of Directors; and
- (b) all other costs, charges and expenses which he/she sustains or incurs in or about or in relation to the affairs thereof, except such costs, charges or expenses as are occasioned by his/her own willful neglect or default.
- (c) Insurance – Directors & Officers shall be covered by a comprehensive insurance policy.

POWERS OF DIRECTORS

- 24. The Directors of the Corporation may administer the affairs of the Corporation in all things and make or cause to be made for the Corporation, in its name, any kind of contract which the Corporation may lawfully enter into and, save as hereinafter provided, generally, may exercise such other powers and do all such other acts and things as the Corporation is by its charter or otherwise authorized to exercise and do.
- 25. The Directors shall have power to authorize expenditures on behalf of the Corporation from time to time and may delegate by resolution to an Officer or Officers, including the Executive Director, of the Corporation, the right to employ and pay salaries to employees, and all day to day activities of the corporation.
- 26. The Directors may delegate certain of their duties to the Officers of the Corporation, but such delegation shall not relieve the Board of the responsibilities for any action so taken.
- 27. The Board of Directors shall take such steps as they may deem requisite to enable the Corporation to acquire, accept, solicit or receive legacies, grants, settlements, bequests, endowments and donations of any kind whatsoever for the purpose of furthering the objects of the Corporation.

EXECUTIVE OFFICERS

- 28. The Executive Officers of the Corporation shall constitute the Executive Committee, unless otherwise specifically provided by these by-laws. The Executive Committee shall exercise such powers as are authorized by the Board of Directors.
- 29. The Executive Officers of the Corporation shall be the Chair, the Vice-Chair, the Secretary and the Treasurer. The Board may in its sole discretion, appoint additional Officers who shall be members of the Executive.
- 30. The Chair shall be appointed by the members of the Board of Directors. Executive Officers other than the Chair of the Corporation shall be appointed by the Board of Directors or the Chair.
- 31. The Executive Officers of the Corporation shall hold office for three (3) years from the date of appointment or election or until their successors are appointed or elected in their stead.

DUTIES OF OFFICERS AND DIRECTORS

- 32. The Chair shall preside at all the meetings of the Corporation and the Board of Directors. He or she shall supervise the affairs of the Corporation. He or she shall see that all orders and resolutions of the Board are carried into effect. He or she shall be a non-voting member of all committees except when a tie in votes has been cast.

33. The Vice-Chair shall act in the absence or disability of the Chair and shall exercise the powers of the Chair and shall perform such other duties as shall from time to time be imposed upon him or her by the Board. Should both the Chair and Vice-Chair be absent or disabled, the performance of their powers and duties shall be delegated to an interim Chairperson appointed by the Board.

The Treasurer shall have the responsibility of reviewing and affirming that all transactions have followed procedures, been reviewed and approved prior to distribution of assets or funds. The Treasurer is also responsible for the yearly audit of the corporation. To ensure that the Accounts maintained in such depository shall be in the name of The Canadian Society for Mucopolysaccharide & Related Diseases Inc. He or she shall be designated as one of the signing Officers of the Corporation in any financial transaction. He or she shall perform such other duties as may be prescribed by the Board of Directors or Chair under whose supervision he or she shall be. In conjunction with the appointed Executive Director the Executive Director will be responsible for the day to day operations and is responsible to report to the Treasurer any risks or contracts that are being entered into on behalf of the corporation. The Executive Director will have the right to bind the corporation on behalf of the Treasurer if so appointed.

34. The Secretary shall preside at all meeting of the Board of Directors and record the minutes of said meetings. The Secretary shall transcribe said minutes and distribute them to the Board of Directors within thirty (30) days of said meeting.
35. In all cases of death, resignation, retirement or removal from office of an Officer or Director, all books, papers, vouchers, money and other property of whatever kind in his or her possession or under his or her control belonging to the Corporation shall be delivered to the Executive Director on behalf of the Board of Directors. Any actions taken in the name of the Society must be first cleared by the Board of Directors.

VACANCY OR REMOVAL FROM OFFICE

36. Any Office or Board position shall be automatically vacated:
- (a) if by notice in writing to the Corporation an officer or director resigns his or her office;
 - (b) if at any Special Meeting of members a resolution is passed by a majority of the members present at the meeting that an Officer or Director should be removed from office; or
 - (c) if at any Special Meeting of the Board of Directors or Executive, a majority of the members present so decide that an Officer or Director should be removed from Office, provided that if any vacancy shall occur for any reason in this paragraph, the Directors or Executive may fill the vacancy with any person who should qualify for the position.
37. In addition to any provision provided by law, the Directors of the Corporation may, by vote of no fewer than two-thirds of the Board of Directors, remove a Director from the Board before the expiration of their term, if they fail to attend **four (4) consecutively** scheduled meeting of the Board of Directors, without proper reason, or they demonstrative a dereliction of duty that puts the interests of themselves before the interests of the Corporation. In the case where there has been illegal activities or any disparaging situations that could harm the Society, an immediate expulsion shall be immediately executed by the Executive Committee.

EXECUTIVE DIRECTOR

38. The Board of Directors is responsible for the hiring of an Executive Director. The Executive Director is managed by the Executive Committee. The Executive Director shall be responsible for delivering the Board of Directors' vision and mission of the organization.
- The Executive Director shall:
- (a) oversee the administrative activities of the Corporation;
 - (b) implement Board policies and directives.
 - (c) co-ordinate the activities of the Board, the Executive and the committees of the Corporation;
 - (d) develop, in co-operation with the Treasurer, and oversee the budget as approved by the Executive;

- (e) The Executive Director will be one of the signing officers of the corporation. Managing the financial commitments of the corporation and has the right to bind the corporation in contracts. The Executive Committee (or part there-of) will also be signing officers for the corporation and any one officer can sign on behalf of the corporation as long as procedures are in place and followed.
- (f) attend meetings of the Executive and Board of Directors; and
- (g) perform such other duties as may be prescribed by the Board of Directors or Executive under whose supervision he or she shall be.

SIGNING OFFICERS

39. The Chair, Vice-Chair, Treasurer or any other Board member appointed by the Board of Directors, shall be designated signing officers for the Corporation for all banking procedures, contracts and documents of the Corporation. The Executive Committee will appoint the Executive Director to sign on behalf of the corporation and has the right to bind the corporation. All such business of the corporation will have a policy and procedure to follow prior to funds being distributed on behalf of the corporation..

REGIONAL CONTACT PERSONS

40. From time to time, and as they are available, the Board of Directors shall appoint a Regional Contact Person for the following regions: British Columbia, Prairies (Alberta, Manitoba, Saskatchewan), Ontario, Quebec, Newfoundland & Labrador, Atlantic (P.E.I, Nova Scotia, New Brunswick), and Northern Territories (Yukon, Northwest Territories, & Nunavut). The following guidelines shall govern the selection and conduct of such Regional Contact Persons:
- (a) An MPS individual or family member may apply to the Board of Directors to hold the position of Regional Contact Person for a particular region;
 - (b) The Board of Directors will examine all such applicants. Upon the approval of such applicant by the Board of Directors, the Regional Contact Person for that region will become a member of the Board and shall adopt and abide by the aims, policies and by-laws of the Corporation. These Directors shall not operate a separate corporation or organization from the National Corporation and shall not maintain separate bank accounts or separately incorporate;
 - (c) Regional Contact Persons shall strive to further the objectives and aims of The Canadian Society for Mucopolysaccharide & Related Diseases, Inc.;
 - (d) The Regional Contact Person shall be the main contact person for that Region. The Regional Contact Person shall organize and preside at all Regional meetings, formal or informal, called for the purpose of providing information and/or support to patients, families or physicians in the Region;
 - (e) Any fund-raising to be undertaken by the Regional Chapter, in the name of The Canadian Society for Mucopolysaccharide & Related Diseases, Inc. must be approved **by the Board of Directors of the Society**. The Board of Directors of the Corporation may, in its sole discretion, approve or disapprove any such application;
 - (f) If at any time a Regional Chapter fails or appears to fail to adopt or abide by the aim, by-laws, regional policies, rules or procedures of the Corporation, or carries on activities determined by the Board of Directors to be detrimental to the Corporation, the Board of Directors may, by a majority vote, remove the said person from the office of Regional Contact Person; and
 - (g) All administration of funds shall be dealt with through the National Office.

COMMITTEES

41. The Board of Directors or Executive and or their designate, may at any time, establish or dissolve such committees as is deemed necessary and may confer upon such committees appropriate mandates as they see fit. The committee will be the responsibility of the Executive Directors management as the designate of the Board the Executive Director can remove a committee member if the committee

member is deemed to be a risk to the society. Committee members shall receive no remuneration for serving as such but are entitled to reasonable expenses incurred in the exercise of their duty.

MEDICAL ADVISORY BOARD

42. The Medical Advisory Board shall be appointed by the lay Board of Directors.
43. The Corporation shall consult with the Medical Advisory Board prior to any dispersal of research funds.
44. A position on the Medical Advisory Board shall be automatically vacated:
 - (a) if by notice in writing to the Corporation a member resigns his or her office;
 - (b) if at any Special Meeting of the Corporation a majority of the members present so decide that such a member should be removed from the Advisory Board; provided that if any vacancy shall occur for any reason in this paragraph, the Directors may fill the vacancy with any person who would qualify as a Medical Advisor;
45. The Medical Advisory Board shall consist of no less than three (3) and no more than ten (10) positions.
46. No Medical Advisor shall directly or indirectly receive any profit from his/her position; provided that an Advisor may be paid reasonable expenses incurred by him/her in the performance of his/her duties.

DUTIES OF MEDICAL ADVISORS

47. The Medical Advisors of the Corporation shall be responsible for reviewing applications for research funds and deciding which research projects to support financially. The Board of Directors will have final approval of the delegation of such funds.
48. The Medical Advisors will be required to answer all inquiries from the Board of Directors concerning medical information.

RESEARCH FUNDING

49. All applications for research funding under the Summer Studentship Program must be received no later than March 1 of each year (as long as the funds are available), with the winning Studentships being awarded during May or June of the same year.

PHARMACEUTICAL ADVISORY BOARD

50. A pharmaceutical advisory board shall be appointed by the lay Board of Directors.
51. A position on the Pharmaceutical Advisory Board shall be automatically vacated:
 - (a) if by notice in writing to the Corporation a member resigns his or her office;
 - (b) if at any Special Meeting of the Corporation a majority of the members present so decide that such a member should be removed from the Advisory Board; provided that if any vacancy shall occur for any reason in this paragraph, the Directors may fill the vacancy with any person who would qualify as a Pharmaceutical Advisor;
52. The Pharmaceutical Advisory Board shall consist of no less than two (2) and no more than five (5) positions.
53. No Pharmaceutical Advisor shall directly or indirectly receive any profit from his/her position; provided that an Advisor may be paid reasonable expenses incurred by him/her in the performance of his/her duties.

DUTIES OF PHARMACEUTICAL ADVISORS

54. The Pharmaceutical Advisors will be required to answer all inquiries from the Board of Directors concerning pharmaceutical information. The Board of Directors of the Corporation will have final authority to make any and all decision regarding the advertisement, endorsement or promotion of pharmaceutical products.

AUDITOR

55. The members shall, at each Annual General Meeting, appoint an auditor to audit the accounts of the Corporation for report to the members at the next Annual General Meeting. The auditor shall hold office until the next Annual General Meeting provided that the Directors may fill any casual vacancy in the office of the auditor.

FISCAL YEAR

56. Unless otherwise ordered by the Board of Directors the fiscal year-end of the Corporation shall be March 31.

AMENDMENT OF BY-LAWS

57. The by-laws of the Corporation not embodied in the letters patent may be amended, repealed or altered, in whole or in part, and additional by-laws may be adopted, by a majority of the Directors at a meeting of the Board of Directors and sanctioned by an affirmative vote of at least two-thirds (2/3) of the members present at a meeting duly called for the purpose of considering the said by-law, provided that the repeal, or amendment of such by-laws shall not be enforced or acted upon until the approval of the Minister of Industry.

BOOKS AND RECORDS

58. The Directors shall see that all necessary books and records of the Corporation required by the by-laws of the Corporation or by any applicable statute or law are regularly and properly kept.

MISCELLANEOUS

59. No service clubs or organizations may raise funds under the name of The Canadian Society for Mucopolysaccharide & Related Diseases Inc. and/or its Regional Chapters unless authorized to do so by the Board of Directors of the Corporation and unless general plans for the fund-raising project have been approved by the Corporation.
60. The decision to affiliate or disaffiliate the Corporation with any other group, movement, association or corporation will be taken by resolution at a meeting of the Board of Directors.

DISSOLUTION

61. In the event of dissolution of the Corporation and after the payment of all its debts and liabilities the remaining property of the Corporation shall be distributed by the Board of Directors to one or more recognized charitable organizations which carry on their work solely in Canada.

DATED at the City of North Vancouver in the Province of British Columbia, this _____ day of _____ 2005

APPENDIX “A”

PROXY

I, _____ (*insert name*), a member of the Canadian Society for Mucopolysaccharide & Related Diseases Inc., hereby appoint _____, or failing him or her, _____ as proxyholder for me, to attend, act and vote for and on my behalf at the annual general meeting to be held on _____ (*insert date of meeting*), including any adjournments, and I hereby revoke all proxies previously given by me.

I authorize and direct proxyholder:

(list all matters for which proxyholder is authorized to act)

DATED this day of , 20__.

(signature)

Name: