



**BYLAWS OF
INTERNATIONAL MPS NETWORK, INC.
(CANADA Registrar No. 1202623-6)
MAY, 2020**

ARTICLE I HEADQUARTERS

The International MPS Network, Incorporated (hereinafter called the "IMPSN") headquarters shall exist for the purposes described herein and in the Certificate of Incorporation. The headquarters is located in the country of Canada and shall carry out such other activities as determined by the Board of Directors. The IMPSN is registered in CANADA with a registrar No. 1202623-6 Certificate of Incorporation.

ARTICLE II MISSION, VISION, OBJECTIVES, and GOALS

In the year 2000, a group of MPS Society professionals gathered with the objective of creating a greater global understanding of mucopolysaccharidosis ("MPS") and related lysosomal diseases. In 2008, global MPS organizations gathered in Vancouver, Canada to forum the first Memorandum of Understanding. Over the past two decades, an annual meeting brought together a growing number of countries to discuss critical global MPS issues, and access to therapies.

SECTION 1. Mission

The International MPS Network exists to be the primary platform for the MPS and Related Diseases. IMPSN is a global community of informed and empowered organizations, who promote access to medicines, new research, advocacy, and programs that lead to better quality of lives for patients and those affected by these diseases.

SECTION 2. Vision

Our vision is to facilitate the continual development of informed MPS and Related Diseases communities. To serve as a resource for stakeholders in challenges from political, social, and health issues for the global community. To advocate policy, action, and awareness by those affected by MPS and Related Diseases and help deliver fair and equitable access to education, medicines, and clinical trials.

SECTION 3. Objectives



- a. Develops relationships and partnerships with national MPS Societies for the purpose of collaboration and joint learning.
- b. Identify potential communication partners in countries without established national MPS societies or organizations that are not members of the IMPSN.
- c. Support establishing MPS Societies in countries with nonexistent support.
- d. Share information and the latest knowledge and achievements in science and medicine about early diagnosis, clinical management, interventions, treatment, clinical studies and standards of care for MPS and sRelated Diseases by improving information flow.
- e. Support access to treatment and care for all MPS patients
- f. Support International MPS Societies in advocating access to medicines
- g. Work collaboratively with key industry stakeholders to develop partnerships for patient advocacy organizations.
- h. Develop cooperation and information exchange with experiences within International organizations and actively participate in their efforts.
- i. To oversee the management and delivery of the International MPS Symposium with the Host country. To award the “Life for MPS” award at each IMPSS in order to recognize those who have made significant contributions to the international community.

SECTION 4. Goals

- a. Act as an independent and supportive forum for MPS Societies and relevant patient associations, including emerging new MPS Societies at a global level.
- b. Promote the well-being of those affected by Mucopolysaccharide and Related Diseases through best practices of diagnosis, clinical management and treatment
- c. Promote public and professional awareness of Mucopolysaccharides and Related Diseases.
- d. Uphold human rights, eliminate discrimination and promote equality and social inclusion for all persons affected with MPS and Related Diseases.



Provide expert representation of interests of persons affected with MPS and Related Diseases in front of decision and policy makers.

- e. Lobby for adoption and implementation of standards, principles and documents for MPS and Related Diseases in order to provide highest possible quality of life for persons affected.
- f. Identify research priorities and potential collaborations and where appropriate, work in partnership with the academic community and the pharmaceutical industry.
- g. Oversee and support the organization of the biannual International Symposium on MPS and Related Diseases.

ARTICLE III MEMBERSHIP

SECTION 1. Membership

The IMPSN is a global not-for-profit organization. Membership is open to the one nationally recognized MPS Society or relevant patient association as established by the IMPSN and Board of Directors. Two representatives from each membered organization may attend the IMPSN meetings. If there is more than one MPS Society within a governing country, they must agree and notify who will represent the country and notify, in writing, the IMPSN.

Priority for becoming a full member of the IMPSN will be given to the organization working most closely to and effectively with the MPS Community. Affiliate membership can be given to other organizations representing MPS or relevant patient associations, without a right to vote. Observers and translators may attend by prior agreement of the IMPSN. Emerging new MPS Societies should apply for membership through the IMPSN directly. A final decision will be rendered by the IMPSN.

There is no membership fee; however, member organizations are responsible for meeting the costs of their representatives' attendance of the IMPSN annual meetings. During the IMPSS, bursaries will be provided to reduce financial impact.

SECTION 2. Voting Rights

Each country represents one member. Each member represents one vote and decisions are made by an approved vote by simple majority. Voting is completed by show of hand, unless a member asks for a ballot. All elections are conducted by a secret ballot, proxy or electronic vote.



SECTION 3. Meetings

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

Special meetings of the IMPSN membership may be held at such time and place as the Board or Directors or Chair 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 shall be held on a secure virtual platform.

In-person meetings shall take place in any Country in which a registered member of the IMPSN has its registered office or domicile.

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 day-to-day operations of the IMPSN. The Board may perform such acts and make such rules, regulations, decisions and repeal, alter or amend same, consistent with Articles of the IMPSN, and/or bylaws as may be necessary to promote the interests of the IMPSN 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 IMPSN. The Board of Directors shall exercise the



governance of the organization, subject to these bylaws, the Not-for-profit Incorporation and any vote at the annual or other membership meeting.

The Board of Directors shall establish an annual income and expense budget to be voted on by membership.

SECTION 2. Number and Term

The total number of Director positions shall be not fewer than five (5) or more than nine (9). The 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 new board may be nominated within 8 weeks prior to an AGM or at the AGM meeting. The executive positions will be voted on by the board at the AGM.

The term of office of each Director shall be two (2) years or until his/her successor is qualified and appointed or elected. Where possible, the terms of the Directors shall be staggered so that approximately one-half (1/2) of the terms expire each year. Directors can serve a maximum of three (3) terms.

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 IMPSN, at least twenty-one (21) years of age, and residents of their country where their organization resides. Director candidates, as of the deadline for accepting nominations and during their term of office, shall not be employees of the IMPSN.

Directors are to chair or actively participate on a minimum of one standing committee as directed by the Chair and/or Co-Chair of the Board.

SECTION 4. Nomination Process

IMPSN request for nominations will be announced to the membership four months prior to the election period. Each nominee will submit a nomination with references, electronically and be made available for Interview with members of the Board of Directors.

The nomination documents will be emailed to all membership, and available online at www.impsnetwork.org/election



SECTION 5. 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 four (4) 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 IMPSN's confidentiality or ethics policy. Censured Directors shall be ineligible for service as an officer of the Society for the remainder of their current and one future term.

SECTION 6. Regular Meetings

A regular meeting of the Board of Directors shall be held in conjunction with the regular membership meeting and thereafter at least six (6) times during each calendar year online through a software program accessible by each Board of Director, or at such other place as the Chair of the Board may determine.

SECTION 7. Special Meetings

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

SECTION 8. Quorum, Decisions, Vacancies

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.

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.

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 his/her predecessor.



SECTION 9. 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 not-for-profit incorporation. Directors are volunteers and not employees, but are entitled to per diem and reimbursement for travel and other expenses as authorized by the Board of Directors.

Section 10. 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 IMPSN. 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 Chair of the Board, (if necessary, Co-Chair of the Board), Vice-Chair of the Board, Secretariat, and Treasurer. All other Board of Directors, are also named "Directors At Large".

SECTION 2. Election and Terms of Office

The Officers shall be elected at a duly called meeting of the Board of Directors for an option of a one (1) or two (2) year term by a majority vote of the Board of Directors. Terms begin August 1 of every other calendar year, following the year of election and shall continue until a successor shall have been chosen and qualified. Officers shall be elected approximately one week in advance and shall serve in an ex-officio status until he or she 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 Chair of the Board, the Vice-Chair of the Board shall succeed to the office of the Chair of the Board. In the event of the resignation, death, or removal of the Chair of the Board and Vice-Chair of the Board, the Secretariat shall succeed to the office of the Chair of the Board. Any vacancy occurring in the offices of the Vice-Chair 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 Officer Responsibilities

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

a. Chair and (Co-Chair) of the Board

The board chair is responsible for leading the board in the oversight and support responsibilities that are critical to good governance. Serving the IMPSNs' interests and needs, is the foundation from which the board chair operates. The chair position is one of servitude, guidance, and authority.

Responsibilities include:

1. Call all meetings and set agenda.
2. Preside at all meetings.
3. Establish committees and work groups as appropriate to meet the goals and objectives of the IMPSN.
4. Appoint the Chairs of the standing committees and work groups.
5. Appoint IMPSN members and other public members to the committees and work groups.
6. Serve as ex-officio (non-voting) member of all committees.
7. Serve as the Society's official representative during term.
8. Operate and conduct the business and affairs of the IMPSN. According to the orders and resolutions of the Board of Directors.
9. Act as official signor for the IMPSN
10. Perform other duties described in these bylaws or assigned by the Board of Directors.

b. Vice-Chair of the Board



The Vice-Chair's role is to be available to replace the board's Chair in the event he or she is unable to act in his/her role as the Chair either temporarily or permanently. The Vice-Chair is to oversee meetings, in the absence of the Chair. The Vice-Chair will oversee the Secretariat and Treasurer Board functions are resourced and fulfilled.

Responsibilities include:

1. Oversee and certify the election of the Board of Directors as mandated in the bylaws.
2. Assist the Chair of the Board in the discharge of his or her duties and preside at meetings in the absence of the Chair of the Board.
3. Monitor the record of actions taken by motions at each meeting and items requiring follow-up on the agenda for the next meeting.
4. Act as the parliamentarian for the IMPSN.
5. Perform other duties in accordance with the orders and resolutions of the Board of Directors.

c. Secretariat

1. Coordinate and administer to the needs of the Board of Directors as directed by the Chair of the Board.
2. Orientate new Directors to the IMPSN and to their Board member responsibilities.
3. Distribute to the membership notice of all membership meetings of the IMPSN. Take minutes of all meetings of the members and of the Board of Directors.
4. Be responsible for presenting the agenda and minutes of the Board of Directors meetings in collaboration with the Chair(s) of the Board.

d. Treasurer

It shall be the duty of the Treasurer to oversee the preparation and maintenance of the financial records and reports of the IMPSN (including arranging for the annual audit of the IMPSN records, if required), to establish (with the approval of the Board of Directors) depositories for the IMPSN funds, to oversee collection of moneys due the IMPSN, to oversee the payment of bills, and to prepare and report, in conjunction with the Chair of the Board, 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 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 COMMITTEES

Committees and working groups may be created as needed for the purpose of assisting and providing advice in the context of specific activities or projects of IMPSN. The size and lifespan of these entities will vary according to the tasks entrusted to them and their creation is validated by the Officers of the Board of Directors. The participants of these entities must report to Officers of the Board of Directors. Standing Committees will include, but not be limited to:

- a. Governance
- b. Communication
- c. Fund Development
- d. Fiscal Reporting
- e. IMPSS Planning
- f. Election Process

ARTICLE VII CONFLICT OF INTEREST

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

A member of the IMPSN shall not be eligible to participate in a discussion of a matter in which he or she 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.



A person who believes he or she has 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 Chair of the Board of the IMPSN. The matter shall be decided by a vote of a majority of the members of the Board of

Directors excluding that person and any other members who may have already been disqualified for conflict of interest.

ARTICLE VIII RECORD KEEPING/FISCAL YEAR

IMPSN shall keep complete financial reports and minutes of the proceedings of the not-for-profit, the Managing Director, and any other committees or work groups. The financial reports and other records of the not-for-profit shall be maintained by IMPSN Chair of Board and the Treasurer.

All records of the not-for-profit must be available to the members unless otherwise prohibited by law.

The fiscal year of the IMPSN shall commence on January 1 each year.

ARTICLE IX CONFIDENTIALITY

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

ARTICLE X 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 NOT-FOR-PROFIT ORGANIZATION'S OPERATIONS



The IMPSN will not have or issue shares of stock. No dividends will be paid. No part of the income or assets of the IMPSN 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 IMPSN. The IMPSN may contract in due course with its members, directors, and officers without violating this provision.

ARTICLE XII 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, cast by written ballot, 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 _____