

AMENDED AND RESTATED BY-LAWS
OF
LOWE SYNDROME ASSOCIATION, INC.
As Amended Through June 19, 2025

ARTICLE I

Mission and Vision

Section 1. Vision. The Lowe Syndrome Association, Inc. (“LSA” or the “Corporation”), envisions a world where the challenges of Lowe syndrome are met with healing solutions or no longer exist.

Section 2. Mission. The mission of LSA is to improve the lives of persons with Lowe syndrome and their families through fostering communication, providing education, and supporting research so that individuals can attain their highest potential. LSA will do this by:

- (a) Fostering communication among families who have a member with Lowe syndrome,
- (b) Promoting medical and educational information,
- (c) Promoting a better understanding of Lowe syndrome and the potentials of individuals with this condition, and
- (d) Encouraging and supporting research relating to Lowe syndrome.

ARTICLE II

Members

Section 1. Voting Members. The Corporation shall have but one class of voting members (the “Members”), which shall consist, at any particular point in time, solely of those persons who are then members of the Corporation's Board of Directors. Termination of a person's status as a

Director of the Corporation shall automatically terminate such person's status as a Member of the Corporation and such terminated member shall have no voting rights.

Section 2. Meetings of Members. An annual meeting of the Members shall be held each year within six months after the close of the fiscal year, concurrently with the annual meeting of the Board of Directors. Any notice of a Directors' meeting shall be deemed also to constitute notice of a Members' meeting, if any reason for a Members' meeting exists. The annual meeting of Members shall be held on the last Friday of June in each year, unless the Board of Directors selects another date in any particular year. Special meetings of Members shall be held only in such instances in which the law of the State of Indiana requires membership action to accomplish the purpose for which the meeting is held. The Board of Directors may designate any location, either within or without the State of Indiana, as the place of meeting for any meeting of Members. The President shall serve as Chair of any meeting of the Members.

Section 3. Quorum and Voting. A majority of the actual number of Members then serving shall constitute a quorum for the transaction of business at any meeting of the Members, but if less than a majority of the Members are present at said meeting, a majority of the Members present may adjourn the meeting from time to time without further notice. Each Member shall have one vote. Meetings of Members shall be conducted according to the current revision of Robert's Rules of Order.

Section 4. Virtual and Conference Call Meetings. One or more Members may participate in meetings of the Members by any means of which all participating Members can simultaneously speak and hear each other during the meeting, including teleconference or virtual conduct through online conferencing, such as Zoom or Teams or similar online platforms, or by

means of a conference telephone or similar communications equipment. Participation by a Member in such manner in a meeting shall constitute personal attendance at such meeting.

Section 5. Manner of Acting. The act of a majority of the Members present at a meeting at which a quorum is present shall be the act of the Members, unless the act of a greater number is required by law or by these By-Laws.

Section 6. Action Without Meeting. Any action required or permitted to be taken at any meeting of the Members may be taken without a meeting if prior to such action a written consent to such action is signed by all of the Members and such written consent is filed with the minutes of the proceedings of the Members. An email or other electronically transmitted writing by a Member to the President confirming such consent shall constitute a sufficient written consent.

Section 7. Supporting Members. Supporting membership shall be open to all persons who annually make a monetary contribution to the Corporation in one of several categories established from time to time by resolution of the Board of Directors. Supporting Members shall be without a right to vote and without entitlement to notice of meetings of the Members or the Board of Directors, without a right of attendance at meetings of the Members or the Board of Directors, or a right to certificates of membership in the Corporation. A subscription to or online access to the Corporation's newsletter shall be provided to all Supporting Members. Upon written request to the Board of Directors, any Supporting Member may request a copy of the most recent meeting minutes of the Members or of the Board of Directors within a reasonable time of any such meeting.

Section 8. Honorary Members. Any person or organization who, in the opinion of the Board of Directors, has made an outstanding contribution to the work of the Corporation may be

designated an Honorary Member of the Corporation. Honorary Members shall have the same rights and restrictions as Supporting Members.

ARTICLE III

Board of Directors

Section 1. General Powers. The affairs of the Corporation shall be managed by the Board of Directors, consistent with these By-Laws, the Articles of Incorporation, and other applicable law.

Section 2. Number and Qualifications. The number of Directors shall be no less than nine (9) and no more than fifteen (15), with the exact number of Directors to be determined from time to time by the Board of Directors at its annual meeting, or at such special meeting as may be called for such purpose. Each Director shall be a Member of the Corporation. A majority of the Board of Directors shall be persons who are related by blood, marriage, adoption, or through foster care to an individual with Lowe syndrome, whether that individual is living or deceased.

Section 3. Term and Election. Subject to Section 4 of this Article, the Directors shall be elected by the Members at the annual meeting of the Members. Except for Directors elected to fill an unexpired term, each Director shall serve a term of either two (2) or three (3) years as determined by the Members from time to time but assuring a minimum of nine (9) active Directors at all times, with each Director serving until his successor shall have been elected and qualified. Unless and until these By-Laws are amended to provide for fewer than nine (9) Directors, the terms of one third (1/3) of the Board of Directors shall expire at each annual meeting of the Members, at which time the Directors' successors shall be elected. A Director may succeed himself in office with no term limits. New Directors shall be elected, whether by the Members or the Board of Directors, only upon the recommendation of the Nominating

Committee and following such review as the Board of Directors deems necessary to assess the Director candidate's qualifications, expertise, strengths and commitment to advancing the interests of LSA. The Nominating Committee shall assess each candidate and make recommendations to the Members and the Board of Directors as to the potential election of a candidate, in accordance with Article VI, Section 1(c) these By-Laws.

Section 4. Vacancies. Any vacancy occurring in the Board of Directors and any Directorship to be filled by reason of an increase in the number of Directors may be filled by the Board of Directors for the unexpired portion of the term.

Section 5. Director's Responsibilities. Directors are expected to actively participate in organizational oversight, strategic planning, and fiduciary duties. Without limitation, each Director shall:

- (a) Regularly attend meetings;
- (b) Support LSA's mission, activities, and financial status;
- (c) Participate in committee work when appropriate;
- (d) Support LSA's fundraising and outreach efforts; and
- (e) To the extent possible, exercise a skillset to assist the Board of Directors to carry out the LSA's mission.

Section 6. Regular Meetings. Regular meetings of the Board of Directors shall be held no less than quarterly and as scheduled by the President, and more frequently if and as the President may determine. The annual meeting of the Board of Directors shall be held on the last Friday of June in each year, unless the Board of Directors selects another date in any particular year. The Board of Directors may designate any location, within or without the State of Indiana, as the place of meeting for any annual meeting.

Section 7. Special Meetings. Special meetings of the Board of Directors may be called by or at the request of the President or any three (3) Directors at such time and place as is specified in the notice of such special meeting.

Section 8. Virtual and Conference Call Meetings. One or more Directors may participate in meetings of the Board of Directors or a committee thereof by any means of which all participating Directors can simultaneously speak and hear each other during the meeting, including teleconference or virtual conduct through online conferencing, such as Zoom or Teams or similar online platforms, or by means of a conference telephone or similar communications equipment. Participation by a Director in such manner in a meeting shall constitute personal attendance at such meeting.

Section 9. Notice of Meetings. The Secretary shall give written notice of each regular meeting to all Directors at least ten (10) days prior to the meeting date specifying the time and place of the meeting. Notice of all special meetings shall include the purpose of such meetings and shall be given by telephoning, telegraphing, emailing, cabling or delivering in hand or by mail or by electronic delivery at least three (3) days in advance. Notice of any meeting may be waived by any Director by written instrument delivered before, at the time of, or following such meeting. Attendance at a meeting shall constitute a waiver of notice of that meeting.

Section 10. Order of Business. Meetings of the Board of Directors or any committee thereof shall be conducted according to the current revision of Robert's Rules of Order. The order of business at any meeting shall be, so far as possible, as follows:

- Roll Call
- Proof of Notice of Meeting
- Reading and Approval of Unapproved Minutes

- Reports of Officers and Committees
- Unfinished Business
- New Business
- Adjournment

Section 11. Quorum. A majority of the actual number of Directors elected, qualified and serving shall constitute a quorum for the transaction of business at any meeting of the Board of Directors, but if less than a majority of the Directors are present at said meeting, a majority of the Directors present may adjourn the meeting from time to time without further notice.

Section 12. Executive Session. Any portion of a meeting of the Board of Directors may be conducted in executive session, when determined by the Board of Directors that executive session is necessary to preserve confidentiality or non-disclosure concerns, such as legal matters, negotiations, employee issues, or confidentiality or anonymity requirements of donors and donations. In such event, the discussions, disclosures, and decisions made in executive session shall not be included or described in the minutes of the meeting.

Section 13. Manner of Acting. 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 the act of a greater number is required by law or by these By-Laws. Each Director shall have one vote.

Section 14. Action Without Meeting. Any action required or permitted to be taken at any meeting of the Board of Directors or of any committee thereof may be taken without a meeting if prior to such action a written consent to such action is signed by all of the Directors or members of such committee, as the case may be, and such written consent is filed with the minutes of the proceedings of the Board of Directors or of said committee. An email or other

electronically transmitted writing by a Director to the President confirming such consent shall constitute a sufficient written consent.

Section 15. Executive Director. The Board of Directors may from time to time assess the need for and approve by resolution the hiring of an Executive Director based on financial and Lowe syndrome community growth, regulatory considerations, or other key changes affecting the Corporation. The duties, responsibilities, and authorities of any such Executive Director, which may be a full-time or part-time position, shall be set forth in an employment agreement approved by the Board of Directors. Any Executive Director shall be an ex-officio member of the Board of Directors but shall have no voting rights.

Section 16. Compensation of Directors. Directors shall receive no compensation for their services as such, but they may be reimbursed for reasonable expenses incurred in the performance of their duties, as considered and approved by the Compensation Committee from time to time.

Section 17. Removal and Resignation. Any Director may be removed from his office with or without cause and for any reason whatsoever by the Board of Directors whenever in its judgment the best interests of the Corporation will be served by such removal. A Director may resign at any time by providing written notice of such resignation to the President or Secretary. Resignation is effective upon receipt of such notice by the President or Secretary unless stated otherwise in the notice.

ARTICLE IV

Officers

Section 1. Officers. The officers of the Corporation shall be a President, a Vice-President, a Secretary, and a Treasurer, all of whom shall be Directors. Any two or more offices may be

held by the same person, except the offices of President and Secretary. If the Secretary is unavailable at any meeting of the Members, the Board of Directors, or any committee thereof, the President may prepare the minutes of such meeting, in which event another Director present at such meeting shall review and by affidavit attest and certify to the accuracy of the minutes prior to the minutes being approved and recorded in the Corporation's records. Any such attestation and certification shall be retained with the minutes.

Section 2. Term and Election. The officers of the Corporation shall be elected by the Directors at the annual meeting of the Board of Directors. The Vice-President, Secretary, and Treasurer shall hold office until their respective successors have been elected and qualified. The President shall hold office for a term of three (3) years and until the President's successor has been elected and qualified.

Section 3. Vacancies. Any vacancy occurring in any office may be filled by the Board of Directors for the unexpired portion of the term.

Section 4. President. The President shall be the principal executive officer of the Corporation and shall in general supervise and control the business and affairs of the Corporation, subject to the authority of the Board of Directors and the provisions of the Articles of Incorporation and these By-Laws. He shall preside at all meetings of the Members and of the Board of Directors and shall be a member of all Board of Directors' Committees and all Non-Board Committees. He shall execute such instruments as may be necessary and proper in the transaction of the Corporation's business, and in general he shall perform all duties incident to the office of President and such other duties as may be prescribed by the Board of Directors from time to time.

Section 5. Vice-President. The Vice-President shall have such powers and duties as may be assigned to him by the President or by the Board of Directors. In the absence of the President, the Vice-President shall perform the duties of the President, and when so acting shall have all the powers of and be subject to all the restrictions upon the President.

Section 6. Secretary. The Secretary shall issue or cause to be issued notices of all meetings of the Members and of the Board of Directors, and shall keep or cause to be kept all minutes of such meetings. The Secretary shall have responsibility and authority for supervision of the records of the Corporation and shall at all times maintain or cause to be maintained a list of Members entitled to vote. The Secretary shall sign, with the President, such instruments as may require his signature and shall make such reports and perform such other duties as are incidental to his office or are properly required of him by the Board of Directors.

Section 7. Treasurer. The Treasurer shall have the custody of all funds and securities of the Corporation and shall receive and give receipts for monies due and payable to the Corporation in such banks, trust companies or other depositories as shall be selected by the Board of Directors. The Board of Directors may at any time by resolution provide for the manner and method of drawing checks thereon. In the absence of any such resolution, only checks drawn by the Corporation upon such bank accounts and signed by the President and the Treasurer shall be duly honored as the acts of the Corporation. The Treasurer shall monitor the overall fiscal health of the Corporation, and shall be responsible for assuring all necessary state and federal tax reports are timely filed. The Treasurer shall keep correct and complete records of accounts showing accurately at all times the financial condition of the Corporation, including a record of the contributions of each member, whether voting or non-voting. Whenever required by the Board of Directors, he shall render a statement of the financial condition of the

Corporation. He shall at all reasonable times exhibit his books and accounts to any Officer or Director of the Corporation, and he shall give such security for the faithful performance of his duties as the Board of Directors may require. The Treasurer shall also perform all other duties incident to the office of Treasurer and as may be required by these By-Laws or the Board of Directors.

Section 8. Annual Reports to Board of Directors. At each annual meeting of the Board of Directors, the President and Treasurer shall present a report, approved by the President and Treasurer, or by a majority of the Board of Directors, or certified by an independent public or certified public accountant or a firm of such accountants selected by the Board of Directors, showing in appropriate detail the following:

- (a) The assets and liabilities of the Corporation as of the end of the preceding fiscal year;
- (b) The changes in assets and liabilities during the preceding fiscal year;
- (c) The revenue or receipts of the Corporation, both unrestricted and restricted to particular purposes, during the preceding fiscal year;
- (d) The expenses or disbursements of the Corporation for both general and restricted purposes, during the preceding fiscal year.

The annual report shall be filed with the minutes of the annual meeting of the Board of Directors.

Section 9. Compensation. Officers serving under this Article IV of these By-Laws may receive reasonable compensation for the performance of the duties of their office, in the event and to the extent that such performance exceeds reasonable volunteer hours, under terms

considered and recommended by the Compensation Committee and under employment agreements approved by the Board of Directors. They may also receive reimbursement for their reasonable expenses pursuant to Article III, Section 16, of these By-Laws.

Section 10. Removal. Any Officer may be removed from his office with or without cause and for any reason whatsoever by the Board of Directors whenever in its judgment the best interests of the Corporation will be served by such removal.

ARTICLE V

Conflicts of Interest and Confidentiality

Section 1. Conflicts of Interest Policy and Procedure. 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) abstain and withdraw from discussion, lobbying, and voting on the matter. Any transaction or other matter involving a potential conflict of interest shall be approved only when upon full disclosure of the conflict a majority of disinterested Directors determine and vote that the transaction or other matter is fair, reasonable, and in the best interests of LSA before proceeding. The minutes of meetings at which such votes are taken shall record such disclosure, abstention and rationale for approval.

Section 2. Conflict of Interest Disclosure Required. All Directors, Officers, and key volunteers must disclose any actual or potential conflicts of interest as soon as they arise. Each Director shall sign an annual statement affirming his understanding and agreement to disclose any potential conflicts.

Section 3. Confidentiality and Non-Disclosure. It is the policy of LSA that Directors and other committee members will not disclose confidential information belonging to or obtained through their affiliation with LSA to any person, including their relatives, friends, and business

and professional associates, unless the Board of Directors has authorized such disclosure. This policy is not intended to prevent disclosure where disclosure is required by law. Directors and other committee members may be required from time to time to execute a Confidentiality and Non-Disclosure Agreement in such form as the Board of Directors may require.

Section 4. Whistleblower Policy. To encourage and protect individuals who report in good faith any suspected wrongdoing or unethical behavior within LSA, the Corporation adopts the following policies and procedures:

- (a) Reporting Concerns – Concerns may be reported verbally or in writing to the President or any Officer.
- (b) Protection from Retaliation – Retaliation against good faith reporting is prohibited and may result in removal.
- (c) Confidentiality – Reports may be anonymous and will be handled confidentially.
- (d) Investigation and Resolution – The President (or the President’s designee) will conduct an investigation and report all findings to the Board of Directors as appropriate.

ARTICLE VI

Committees

Section 1. Board of Directors’ Committees.

(a) Executive Committee. An Executive Committee may be created or abolished by the Board of Directors. The membership of the Executive Committee shall consist of no fewer than three (3) and no more than five (5) Directors elected by the Board of Directors. The President of the Corporation shall serve as Chairman of the Committee. When the Board of Directors is not in session, the Executive Committee shall have and exercise all of the authority

of the Board of Directors in the management of the Corporation, except as such authority is limited by statute or by resolution creating or otherwise controlling the Executive Committee, provided, however, that said Executive Committee shall not have the authority of the Board of Directors in reference to amending, altering, or repealing the By-Laws, amending or restating the Articles of Incorporation, or electing, appointing, or removing any member of a Board of Directors' Committee, any Directors, or any officer of the Corporation. The designation of such committee and the delegation thereto of authority shall not operate to relieve the Board of Directors or any member thereof of any responsibility imposed upon it or him by law. The actions of the Executive Committee shall be reported to the Board of Directors at its next meeting.

(b) Compensation Committee. The Corporation shall maintain as a standing committee a Compensation Committee, which shall be comprised of the three longest serving Directors from time to time, but excluding any Director serving as an Officer under Article IV of these By-Laws and who is receiving or seeking to receive compensation for services under an employment agreement with the Corporation. The Compensation Committee shall consider and recommend to the Board of Directors the terms and conditions for each employment agreement to be entered into between the Corporation and any Officer or an Executive Director, which employment agreement shall require approval by the Board of Directors. The Compensation Committee shall consider and shall have the authority to approve all requests for reimbursement of reasonable expenses by any Director under Article III, Section 16, of these By-Laws. The Compensation Committee shall be chaired by the longest serving of those Directors on the Committee.

(c) Nominating Committee. The President shall from time to time appoint a Nominating Committee, to be composed of a minimum of three (3) Directors, to identify and vet potential candidates for election as a Director. The Board of Directors from time to time shall establish protocols and procedures for the Nominating Committee to utilize in performing its functions.

(d) Other Board of Directors' Committees. Additional Board of Directors' Committees may from time to time be created by the Board of Directors from among the Directors, or abolished. Each resolution creating an additional Board of Directors' Committee shall designate the authority which such Committee shall have and the functions which such Committee shall discharge.

Section 2. Non-Board of Directors Committees.

(a) Medical and Science Advisory Board. A Medical and Science Advisory Board (the "MSAB") may be created or abolished by the Board of Directors. The MSAB shall be composed of as many members as the Board of Directors shall from time to time deem appropriate, and shall be comprised of medical doctors, scientists or other persons deemed qualified and chosen by the Board of Directors. In addition, the President shall be an ex officio member of the MSAB and shall report to the Board of Directors the activities of the MSAB from time to time. Except for the President, members of the MSAB shall not be Directors and shall serve for terms of three (3) years. Any vacancy occurring on the MSAB may be filled by the Board of Directors for the unexpired portion of the term. Members of the MSAB may serve consecutive terms. The purpose of the MSAB shall be to advise and assist the Board of Directors regarding the granting of the Corporation's funds for research relating to Lowe syndrome, to advise and assist the Board of Directors regarding medical, scientific, and other matters relating

to Lowe syndrome, and to advise and assist the Board of Directors in other ways as requested by the Board of Directors from time to time.

(b) Other Non-Board of Directors Committees. Other Non-Board of Directors Committees may be created or abolished by the Board of Directors from time to time.

ARTICLE VII

Additional Organizations

Section 1. Additional Organizations. The Board of Directors may authorize the formation of such auxiliary and associated organizations as would in the opinion of the Board of Directors assist in the fulfillment of the purposes of the Corporation.

ARTICLE VIII

Books and Records

Section 1. Document Maintenance. The Corporation shall maintain and keep correct and complete books and records of accounts and shall also keep minutes of the proceedings of its Members, Board of Directors, and any committees having any of the authority of the Board of Directors, and shall keep at its principal office a record giving the names and addresses of the Members entitled to vote. All books and records of the Corporation may be inspected by any Member, or his agent or attorney, for any proper purpose upon reasonable notice and at any reasonable time.

Section 2. Document Retention. The Corporation shall maintain the following records in accordance with applicable legal, financial, and ethical standards:

(a) Permanent Records (to be retained indefinitely):

1. Articles of Incorporation and amendments
2. By-Laws and amendments

3. IRS determination letters (e.g., 501(c)(3) status)
 4. Meeting minutes of the Board of Directors and Executive Committee
 5. Resolutions of the Board of Directors
 6. Key legal contracts and grant agreements
 7. Intellectual property documentation (e.g., trademarks, logos)
- (b) Financial Records (to be retained for a minimum of seven (7) years):
1. Annual financial statements and audits
 2. IRS Form 990 and related tax filings
 3. Bank statements and reconciliations
 4. Donation records and grant disbursements
 5. Payroll and expense reports (if applicable)
- (c) Operational and Lowe Syndrome Community Data:
1. Donor records shall be retained for at least seven (7) years after the last contribution or interaction.
 2. Lowe syndrome community data collected for programming, outreach, or support shall be retained only for as long as necessary for programming or historical purposes, and handled in accordance with any applicable privacy laws or internal data policies.

Section 3. Digital Storage of Corporate Records. All records and official documents shall be maintained and filed digitally and must reside within the LSA cloud-based system, provided that those documents described in Article VIII, Sections 2(a)(1) through 2(a)(5) above shall also be maintained in hard copy and available for examination at the Corporation's principal office upon reasonable notice by any person permitted by law or these By-Laws for

such examination. Copies or exports of any record or document may be made for temporary use, if permitted by the President or Secretary, or such other person designated under Article VIII, Section (6) below, but the official editable version must remain on LSA's platform. Access to the LSA cloud document storage system shall be restricted to the Corporation's Officers and such additional individuals as shall be approved from time to time by the President.

Section 4. Digital Storage of LSA Brand Assets. All documents, data, media and other intellectual property that are branded with the LSA name or logo, or are created in the name of LSA, shall be stored within LSA's designated cloud-based file system. This system must provide version control and full editing capabilities to ensure continuity and security of organizational knowledge.

Section 5. Destruction of Documents. Upon the expiration of the applicable retention period, documents may be destroyed in a secure manner, unless they are subject to pending litigation, audit, or investigation. Destruction of documents must be consistent with any adopted LSA Document Retention Policy.

Section 6. Oversight and Responsibility. The Secretary, or another Officer designated from time to time by the President, shall ensure compliance with this Article VIII, including the organization and accessibility of records and the secure disposal of outdated documents. The President may appoint a Records Manager if the President deems necessary.

ARTICLE IX

Certificates of Membership

Section 1. Membership Certificates. In its discretion the Board of Directors may, but shall not be required to, create membership certificates, in which event the form of a membership certificate shall be determined by the Board of Directors. If certificates are created, each

certificate shall be signed by the President of the Corporation, manually or by facsimile signature, and no certificate shall be transferable.

ARTICLE X

Miscellaneous Provisions

Section 1. 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. Gender and Plural. Wherever the context requires, the gender of all words used in these By-Laws shall include the masculine, feminine, and neuter, and the number of all words shall include the singular and the plural.

Section 3. Principal Office. The Corporation's principal office shall be designated by the President from time to time such that the office may be most convenient to the President and the Corporation's administration.

Section 4. Legacy Gifts. In the event a donor of a legacy gift fails to direct how the donation is to be allocated for expenditure, the Executive Committee, if then serving, or in its absence the Board of Directors, shall determine how a legacy gift is to be allocated, ensuring that the majority of the donation funding supports research and the pursuit of a treatment or cure for Lowe syndrome, while also considering the evolving needs of the Lowe syndrome community.

ARTICLE XI

Amendments

Section 1. Amendment. These By-Laws may be altered, amended or repealed and new By-Laws may be adopted at any regular meeting or at any special meeting of the Board of

Directors, if at least three (3) days' notice is given of intention to alter, amend or repeal or to adopt new By-Laws at such meeting.

Adopted: As of June 19, 2025.