

AMENDED AND RESTATED
BYLAWS
OF
EVERYLIFE FOUNDATION FOR RARE DISEASES

A District of Columbia Nonprofit Corporation

TABLE OF CONTENTS

ARTICLE I PRINCIPAL OFFICE	4
ARTICLE II MEMBERSHIP	4
ARTICLE III BOARD OF DIRECTORS	4
Section 3.01 Powers.	4
Section 3.02 Number of Directors.	4
Section 3.03 Limitation on Interested Persons.	4
Section 3.04 Election and Term of Office of Directors.	4
Section 3.05 Vacancies.	5
Section 3.06 Resignation.	5
Section 3.07 Removal.	5
Section 3.08 Annual and Regular Meetings.	5
Section 3.09 Special Meetings.	5
Section 3.10 Notice.	5
Section 3.11 Waiver of Notice.	5
Section 3.12 Action at a Meeting.	6
Section 3.13 Action without a Meeting.	6
Section 3.14 Telephone and Electronic Meetings.	6
Section 3.15 Standard of Care.	6
Section 3.16 Investments.	7
Section 3.17 Inspection.	7
Section 3.18 Compensation.	7
ARTICLE IV COMMITTEES	8
Section 4.01 Board Committees.	8
Section 4.02 Advisory Committees.	8
Section 4.03 Audit Committee.	8
Section 4.04 Meetings of Board Committees.	9
Section 4.05 Meetings of Advisory Committees.	9
ARTICLE V OFFICERS	9
Section 5.01 Officers.	9
Section 5.02 Election.	9
Section 5.03 Vacancies.	9
Section 5.04 Resignation.	9
Section 5.05 Removal.	9

Section 5.06	Chair.....	10
Section 5.07	Vice Chair.....	10
Section 5.08	Secretary	10
Section 5.09	Treasurer.....	10
Section 5.10	Executive Compensation Review.....	10
Section 5.11	Standards of Conduct	10
ARTICLE VI CERTAIN TRANSACTIONS.....		11
Section 6.01	Loans.....	11
Section 6.02	Conflicting Interest Transactions.....	11
Section 6.03	Approval.....	11
ARTICLE VII INDEMNIFICATION AND INSURANCE.....		13
Section 7.01	Right of Indemnity.....	13
Section 7.02	Approval of Indemnity.....	13
Section 7.03	Selection of Counsel.....	13
Section 7.04	Not Exclusive Right.....	13
Section 7.05	Advancing Expenses.....	13
Section 7.06	Insurance.....	13
ARTICLE VIII GRANTS.....		13
Section 8.01	Purpose of Grants.....	13
Section 8.02	Board of Directors' Review.....	13
Section 8.03	Refusal and Withdrawal.....	13
Section 8.04	Periodic Accounting.....	14
Section 8.05	Restricted Contributions.....	14
ARTICLE IX MISCELLANEOUS.....		14
Section 9.01	Fiscal Year.	14
Section 9.02	Contracts, Notes, and Checks.....	14
Section 9.03	Representation of Corporate Shares	14
Section 9.04	Annual Reports to Directors.	14
Section 9.05	Required Financial Audits.....	15
Section 9.06	Electronic Transmissions.....	15
Section 9.07	Maintenance of Certain Records.	15
Section 9.08	Amendments.....	16
Section 9.09	Governing Law.	16
Section 9.10	Severability.....	16

**AMENDED AND RESTATED BYLAWS
OF
EVERYLIFE FOUNDATION FOR RARE DISEASES**

**ARTICLE I
PRINCIPAL OFFICE**

The principal office of this corporation is located in Washington, D.C.

**ARTICLE II
MEMBERSHIP**

This corporation shall have no voting members. The Board of Directors may, by resolution, establish one or more classes of nonvoting members.

**ARTICLE III
BOARD OF DIRECTORS**

Section 3.01 Powers. This corporation shall have powers to the full extent allowed by law. All powers and activities of this corporation shall be exercised and conducted by or under the direction of the Board of Directors. The Board may delegate the management of activities of this corporation to any person or persons, management company, or committee however composed, provided that the activities and affairs of the corporation shall be managed and all corporate powers shall be exercised under the ultimate direction of the Board.

Section 3.02 Number of Directors. The Board shall consist of Voting Directors, Non-Voting Directors, and a Young Adult Rare Representative (YARR) Director, as described below.

(a) The number of Voting Directors shall be not less than 8 nor more than 15 with the exact authorized number of Voting Directors to be fixed, within these limits, by resolution of the Board.

(b) The Chief Executive Officer shall be an *ex officio* Non-Voting Director. Non-Voting Directors are not vested with any powers of management on the Board and do not have the right to vote as a member of the Board or any of its committees. Non-Voting Members are entitled to attend meetings of the Board and its committees and participate in discussions at such meetings, subject to the right of the Board to hold all or a portion of a Board meeting in executive session, without some or all of the Non-Voting Members present.

(c) The YARR Director shall be a member of the Corporation's Young Adult Rare Representative program, and shall have the same voting rights as the Voting Directors.

Section 3.03 Limitation on Interested Persons. No more than 49% of the Voting Directors of this corporation may be considered interested persons of a for-profit pharmaceutical, biotechnology, or medical device development or manufacturing company when participating in decision-making activities. An interested person is any person currently serving as an executive officer, major shareholder (owning more than 10% of shares), primary officer, or owner of such a company.

Section 3.04 Election and Term of Office of Directors. Except for the initial directors named by the incorporator, the Voting Directors of this corporation shall elect their successors, subject to the power of the Board to fix the number of Voting Directors as provided in Section 3.02 above. Terms of Voting Directors shall be staggered such that there are three (3) classes of Voting Directors. Each Voting Director shall hold office for three (3) years and until a successor has been elected. Voting Directors may serve no more than three (3) consecutive three-year terms and any person who has served such three (3) consecutive three-year terms (for a total of nine consecutive years) shall be eligible for reelection after a one-year absence. The term of a Voting Director elected to fill a vacancy expires at the end of the unexpired term that the Voting Director is filling. Notwithstanding the foregoing, the YARR Director shall serve a single, three (3) year term without the possibility for renewal.

Section 3.05 Vacancies. A vacancy shall be deemed to exist on the Board whenever the actual number of Voting Directors is less than the authorized number for any reason, including a vacancy resulting from an increase in the number of Voting Directors. Vacancies for the unexpired portion of the term may be filled by a majority of the directors remaining in office even if they constitute less than a quorum. A vacancy that will occur at a specific later time, by reason of a resignation effective at a later time or otherwise, may be filled before the vacancy occurs, but the new director shall not take office until the vacancy occurs.

Section 3.06 Resignation. Resignations shall be effective upon receipt in writing by the Chair, the Secretary, or the or to another executive officer of the Board, unless a later effective date is specified in the resignation.

Section 3.07 Removal. The Board of Directors, by the vote of a majority of the directors then in office, may remove any Voting Director at any time, with or without cause. The Superior Court may also remove a director from office in a proceeding commenced by or in the right of the corporation pursuant to D.C. Code § 29-406.09.

Section 3.08 Annual and Regular Meetings. Annual meetings of the Board of Directors shall be held at least once a year. Annual meetings shall be called by the Chair, or any two Voting Directors, and noticed in accordance with Section 3.10. Regular meetings of the Board may be held without notice if the date, time, and place of the meetings are fixed by resolution of the Board. One (1) annual meeting and one (1) regular meeting shall be held in person unless notice is given otherwise. Any change in the date, time, or place of a regular meeting shall be noticed in accordance with Section 3.10. Voting Directors may be absent from two (2) annual or regular meetings per term.

Section 3.09 Special Meetings. Special meetings of the Board may be called by the the Chair or any two directors, and shall be noticed in accordance with Section 4.10.

Section 3.10 Notice. Notice of the annual meeting and any special meetings of the Board shall state the date, time, and place of the meeting and shall be given to each director at least ten (10) days before the meeting if given by first-class mail or forty-eight hours before the meeting if delivered personally or by telephone, including a voice messaging system, or by other electronic transmission such as e-mail.

Section 3.11 Waiver of Notice. Notice of a meeting need not be given to any director who, either before or after the meeting, signs a waiver of notice, a written consent to the holding of the meeting, or an approval of the minutes of the meeting. All such waivers, consents, and approvals shall be filed with the corporate records or made a part of the minutes of the meeting. A director's attendance at or participation in a meeting will also waive any required notice to the director of the meeting, unless the director at the beginning of the meeting, or promptly upon arrival, objects to holding the meeting or transacting at the meeting and does not thereafter vote for or assent to action taken at the meeting.

Section 3.12 Action at a Meeting. A majority of the total number of Voting Directors then in office shall constitute a quorum of the Board for the transaction of business. However, in no event shall the required quorum be less than one-third of the authorized number of Voting Directors or two directors, whichever is larger. Every action taken or decision made by a majority of the directors present at a meeting at which a quorum is present shall be the act of the Board, except as otherwise provided in Section 3.05 (filling board vacancies), Section 3.07 (removing directors), Section 3.13 (taking action without a meeting), Section 4.01 (appointing Board Committees), Section 6.03 (approving self-dealing transactions), Section 7.02 (approving indemnification), and Section 9.08 (amending Bylaws), of these Bylaws or in the District of Columbia Nonprofit Corporations law. Directors at a meeting at which a quorum is initially present may continue to transact business, despite the withdrawal of directors, if any action taken or decision made is approved by at least a majority of the required quorum for such meeting, or a greater number as required by law or by these Bylaws.

Section 3.13 Action without a Meeting. Any action that the Board is required or permitted to take may be taken without a meeting if all Board members individually or collectively consent in writing to such action. Such action by unanimous written consent shall have the same force and effect as the unanimous vote of the directors at a meeting. The written consents shall be filed with the minutes of the proceedings of the Board.

Section 3.14 Telephone and Electronic Meetings. Directors may participate in a meeting through use of conference telephone or video screen communication so long as all participating directors can hear each other. Directors may participate in a meeting through the use of other electronic transmission so long as all of the following apply:

(d) each director participating in the meeting can communicate concurrently with all of the other directors, and

(e) each director is provided with the means of participating in all matters before the Board, including the capacity to propose, or to interpose an objection to, a specific action to be taken by the corporation.

The Board shall receive planning and program activity updates by electronic transmission during fiscal year quarters in which an Annual or Regular meeting is not held.

Section 3.15 Standard of Care. A director shall perform the duties of a director, including duties as a member of any Board Committee, in good faith, in a manner such director believes to be in the best interest of this corporation and with such care, including reasonable inquiry, as an ordinary prudent person in a like position would use under similar circumstances.

In performing such duties of a director, a director shall be entitled to rely on information, opinions, reports, or statements, including financial statements and other financial data, in each case prepared or presented by:

(a) one or more officers, employees, or volunteers of this corporation whom the director reasonably believes to be reliable and competent in the functions performed or the information, opinions, reports, or statements provided;

(b) legal counsel, public accountants, or other persons retained by the corporation as to matters involving skills or expertise the director reasonably believes are matters within such person's professional or expert competence or as to which the particular person merits confidence; or

(c) a Board Committee upon which the director does not serve, as to matters within its designated authority, provided that the director believes such Committee merits confidence;

so long as in any such case, the director acts in good faith after reasonable inquiry when the need therefor is indicated by the circumstances and without knowledge that would cause such reliance to be unwarranted.

A director shall not be a trustee with respect to the nonprofit corporation or with respect to any property held or administered by the corporation, including property that may be subject to restrictions imposed by the donor or transferor of the property.

Except as provided in District of Columbia Code Section 29-406.31, a person who performs the duties of a director in accordance with this Section shall not be liable to the corporation or its members for any decision to take or not take action or any failure to take any action, as a director, including, without limiting the generality of the foregoing, any actions or omissions which exceed or defeat a public or charitable purpose to which this corporation, or assets held by it, are dedicated.

Section 3.16 Investments. Except with respect to assets held for use or used directly in carrying out this corporation's public or charitable programs, in investing, reinvesting, purchasing, acquiring, exchanging, selling, and managing this corporation's investments, the Board shall avoid speculation, looking instead to the permanent disposition of the funds,

considering the probable income, as well as the probable safety of this corporation's capital. No investment violates this Section where it conforms to provisions authorizing such investment contained in an instrument or agreement pursuant to which the assets were contributed to this corporation.

Section 3.17 Inspection. Every director shall have the absolute right at any reasonable time to inspect and copy all books, records, and documents, and to inspect the physical properties of this corporation.

Section 3.18 Compensation. No compensation shall be paid to a director for services as a director. The Board may authorize the advance or reimbursement to a director of actual reasonable expenses incurred in carrying out his or her duties as a director, including expenses for attending meetings of the Board and Board Committees.

ARTICLE IV COMMITTEES

Section 4.01 Board Committees. In addition to the Standing Committees specified in Section 4.03, the Board may, by resolution adopted by a majority of the directors then in office, create one or more ad-hoc Board Committees, each consisting of two or more directors, and only of directors, to serve at the pleasure of the Board. The appointment of chair and other members of such ad-hoc committees shall be by a majority vote of the directors then in office. Board Committees may be given all the authority of the Board, except for the powers to:

- (a) set the number of directors within a range specified in these Bylaws;
- (b) elect directors or remove directors without cause;
- (c) fill vacancies on the Board or any Board committee;
- (d) fix compensation of directors for serving on the Board or any Board Committee;
- (e) amend or repeal these Bylaws or adopt new Bylaws;
- (f) adopt amendments to the Articles of Incorporation;
- (g) amend or repeal any resolution of the Board which by its express terms is not so amendable or repealable;
- (h) create any other Board Committees or appoint the members of any Board Committees; or
- (i) approve any merger, reorganization, voluntary dissolution, or disposition of substantially all of the assets of this corporation.

Section 4.02 Advisory Committees. The Board may establish Advisory Committees to the Board. The members of any Advisory Committee may consist of directors or non-directors and may be appointed as the Board determines. Advisory Committees are not Board Committees and may not exercise the authority of the Board to make decisions on behalf of this corporation, but shall be restricted to making recommendations to the Board or Board Committees, and implementing Board or Board Committee decisions and policies under the supervision and control of the Board or Board Committee.

Section 4.03 Standing Committees. There shall be the Standing Committees specified in this Section 4.03. The chairs and other members of each Standing Committee shall be appointed annually by the Chair of the Board upon recommendation by the Governance Committee and with the approval of the Board and in consultation with the Chief Executive Officer. The Chief Executive Officer shall be an ex-officio member of all standing committees without power to vote. The four Standing Committees shall be the Executive Committee, the Governance Committee, the Finance Committee, and the Audit Committee. Each Standing Committee shall have a charter specifying the criteria for membership in the committees, a description of the operations of the committee, and the responsibilities of the committee. Committee charters must be approved by the Board.

Section 4.04 Meetings of Board Committees. Meetings and actions of Board Committees shall be governed by the provisions of Article IV of these Bylaws concerning meetings and actions of the Board of Directors. Minutes shall be kept of each meeting of a Board Committee and shall be filed with the corporate records.

Section 4.05 Meetings of Advisory Committees. Advisory Committees may determine their own meeting rules and whether minutes shall be kept, subject to the authority of the Board of Directors.

ARTICLE V OFFICERS

Section 5.01 Officers. The officers of this corporation shall be a Chair, a Vice Chair, a Secretary, a Treasurer, and such other officers with such titles and duties as shall be determined by the Board. Any number of offices may be held by the same person, except that neither the Secretary nor the Treasurer may serve concurrently as the Chair of the Board, if any.

Section 5.02 Election. Except for the initial officers appointed by the incorporator, the officers of this corporation shall be elected by the Board and shall serve for 3 years, at the pleasure of the Board and subject to the rights of any officer under any employment contract.

Section 5.03 Vacancies. A vacancy in any office for any reason shall be filled in the same manner as these Bylaws provide for election to that office.

Section 5.04 Resignation. Any officer may resign at any time by giving written notice to the Board. The resignation shall take effect on the date the notice is received or at any later time

specified in the notice. If a resignation is made effective at a later time and the Board accepts the future effective time, the Board may designate a successor before the effective time if the Board provides that the successor does not take office until the effective time. An officer's resignation shall not affect the corporation's contract rights, if any, with the officer.

Section 5.05 Removal. The Board may remove any officer with or without cause. An officer's removal shall not affect the officer's contract rights, if any, with the corporation.

Section 5.06 Chair. The Chair shall preside at all meetings of the Board. In collaboration with the Vice Chair, the Chair acts as a liaison between the Board and the Chief Executive Officer to help ensure the Board's directives and resolutions are carried out. The Chair shall determine the order of business and has the authority to establish rules for the conduct of the meeting. Any rules adopted for, and the conduct of, the meeting shall be fair to the attendees. The Chair shall evaluate the annual performance of the Chief Executive Officer. The Chair shall appoint Board and Advisory committee chairs.

Section 5.07 Vice Chair. The Vice Chair performs the responsibilities of the Chair when the Chair cannot be available. In collaboration with the Chair, the Vice Chair acts as a liaison between the Board and the Chief Executive Officer to help ensure the Board's directives and resolutions are carried out. The Vice Chair participates closely with the Chair to determine the order of business of the meeting. The Vice Chair shall have such other powers and duties as may be prescribed by the Board or these Bylaws.

Section 5.08 Secretary. The Secretary shall keep or cause to be kept a full and complete record of the proceedings of the Board and its committees, shall supervise the giving of such notices as may be proper or necessary, shall keep or cause to be kept the minute books of this corporation, and shall have such other powers and duties as may be prescribed by the Board or these Bylaws.

Section 5.09 Treasurer. The Treasurer shall be the chief financial officer of this corporation and shall keep and maintain, or cause to be kept and maintained, adequate and correct books and accounts of the corporation's properties and transactions. The Treasurer shall supervise the charge and custody of all funds of this corporation, shall supervise the deposit of such funds in the manner prescribed by the Board, shall render reports and accountings as required, and shall have such other powers and duties as may be prescribed by the Board or these Bylaws.

Section 5.10 Executive Compensation Review. The Board or a Board Committee shall review any compensation packages, including all benefits, of the Chief Executive Officer and the Treasurer or Chief Financial Officer, regardless of job title, and such other officers as may be required by law or which shall be so designated by resolution of the Board, and shall approve such compensation only after determining that the compensation is just and reasonable. The review and approval shall occur when such officer is hired, when the term of employment of such officer is renewed or extended, and when the compensation of such officer is modified, unless the modification applies to substantially all of the employees of this corporation.

Section 5.11 Standards of Conduct. An officer with discretionary authority shall discharge his or her duties under that authority in good faith, with the care an ordinarily prudent person in like position would exercise under similar circumstances, and in a manner the officer reasonably believes to be in the best interests of the corporation.

The duty of an officer shall include the obligation to inform:

(a) the superior officer to whom, or the Board or Board Committee to which, the officer reports of information about the affairs of the corporation known to the officer, within the scope of the officer's functions, and known to the officer to be material to the superior officer, Board, or Board Committee; and

(b) his or her superior officer, another appropriate person within the corporation, the Board, or a Board Committee of any actual or probable material violation of law involving the corporation or material breach of duty to the corporation by an officer, employee, or agent of the corporation, that the officer believes has occurred or is likely to occur.

In discharging his or her duties, an officer who does not have knowledge that make reliance unwarranted may rely on information, opinions, reports, or statements, including financial statements and other financial data, if prepared or presented by:

(a) one or more officers or employees of the corporation whom the officer reasonably believes to be reliable and competent in the functions performed or the information, opinions, reports, or statements provided; or

(b) legal counsel, public accountants, or other persons retained by the corporation as to matters involving skills or expertise the officer reasonably believes are matters within the particular person's professional or expert competence or as to which the particular person merits confidence.

ARTICLE VI CERTAIN TRANSACTIONS

Section 6.01 Loans. This corporation shall not lend any money or property to, or guarantee the obligation of, any director or officer of the corporation, except as permitted by District of Columbia Code Section 29-406.32(b). This corporation may, however, advance money to a director or officer of this corporation or of its parent or any subsidiary for expenses reasonably anticipated to be incurred in the performance of the duties of such director or officer so long as such individual would be entitled to be reimbursed for such expenses absent that advance.

Section 6.02 Conflicting Interest Transactions. The Board shall not approve or permit the corporation to engage in any conflicting interest transaction, except as provided in Section 6.03 below. A conflicting interest transaction is a contract or transaction between this

corporation and one or more of its directors or officers, or between this corporation and any other entity in which one or more of its directors or officers hold a similar position or have a financial interest.

Section 6.03 Approval. Pursuant to District of Columbia Code Section 29-406.70, this corporation may engage in a transaction that would otherwise be a conflicting interest transaction if:

- (a) the material facts as to the relationship or interest and as to the contract or transaction are disclosed or are known to the Board and the Board in good faith authorizes the contract or transaction by the affirmative votes of a majority of the disinterested directors even though the disinterested directors are less than a quorum; or
- (b) the contract or transaction is fair as to the corporation as of the time it is authorized, approved, or ratified by the Board.

The director's interest in the contract or transaction must be disclosed to the Board within three (3) business days in order to make a determination. Such determinations must be made by the Board in good faith, with knowledge of the material facts concerning the transaction and the director's interest in the contract or transaction, and by a vote of a majority of the directors then in office, without counting the vote of the interested director or directors.

Where it is not reasonably practicable to obtain approval of the Board before entering into a self-dealing transaction, a Board Committee may approve such transaction in a manner consistent with the requirements above; provided that, at its next meeting, the full Board determines in good faith that the Board Committee's approval of the transaction was consistent with the requirements above and that it was not reasonably practicable to obtain advance approval by the full Board, and ratifies the transaction by a majority of the directors then in office without counting the vote of any interested director.

ARTICLE VII INDEMNIFICATION AND INSURANCE

Section 7.01. Right of Indemnity. To the fullest extent allowed by law, this corporation shall indemnify its directors, officers, employees, and other agents, including persons formerly occupying such positions, against all expenses, judgments, fines, settlements, and other amounts actually and reasonably incurred by them in connection with any proceeding by reason of the fact that such person is or was an agent of the corporation. "Proceeding" includes any threatened, pending, or completed proceeding; investigations; or proceedings brought by the Attorney General. "Expenses" shall include attorneys' fees.

Section 7.02. Approval of Indemnity. On written request to the Board by any agent seeking indemnification, to the extent that the agent was successful, on the merits or otherwise, the Board shall promptly authorize indemnification in accordance with District of Columbia Code Section 29-406.52. Otherwise, the Board shall promptly determine, by a majority vote of a

quorum consisting of directors who are not parties to the proceeding, whether the agent has met the applicable standard of conduct stated in District of Columbia Code Section 29-406.51, and, if so, shall authorize indemnification to the extent permitted thereby.

Section 7.03. Selection of Counsel. The corporation shall have the right to select attorneys and to approve any legal expenses incurred in connection with any suit, action or proceeding to which this indemnification applies. Unless the corporation waives such right, the corporation shall not be required to indemnify any director, officer, employee, and other agent for expenses of counsel not selected by the corporation.

Section 7.04. Not Exclusive Right. The indemnification provided by these Bylaws shall not be deemed exclusive of any other rights which a director, officer, employee, and other agent may have under any agreement with the corporation or otherwise.

Section 7.05 Advancing Expenses. The Board may authorize the advance of expenses incurred by or on behalf of an agent of this corporation in defending any proceeding prior to final disposition, if the Board finds that:

- (a) the requested advances are reasonable in amount under the circumstances; and
- (b) before any advance is made, the agent submits a written undertaking satisfactory to the Board to repay the advance unless it is ultimately determined that the agent is entitled to indemnification for the expenses under this Article.

Section 7.06. Insurance. This corporation shall have the power to purchase and maintain insurance on behalf of an individual who is or was a director or officer of the corporation, or who, while a director or officer of the corporation, serves or served as the corporation's request as a director, officer, partner, trustee, employee, or agent of another domestic or foreign corporation, partnership, joint venture, trust, employee benefit plan, or other entity, against liability asserted against or incurred by the individual in that capacity or arising from the individual's status as a director or officer, whether or not the corporation would have power to indemnify or advance expenses to the individual against the same liability.

ARTICLE VIII GRANTS

Section 8.01 Purpose of Grants. This corporation shall have the power to make grants and to provide other financial assistance for the public or charitable purposes described in its Articles of Incorporation.

Section 8.02 Board of Directors' Review. The Board shall establish grant review and approval procedures and shall exercise ultimate control over grants and other financial assistance provided by this corporation. The Board's review and approval procedures shall require that grantees specify the proposed use of the funds and that the Board regularly reviews all grants made.

Section 8.03 Refusal and Withdrawal. The Board, in its absolute discretion, shall have the right to refuse to make any grant, or to render other financial assistance, for any or all of the purposes for which the funds are requested. In addition, the Board shall have the right to withdraw its approval of any grant at any time and use the funds for other purposes within the scope of the public or charitable purposes expressed in this corporation's Articles of Incorporation, subject to any rights of third parties under any contract relating to such grant.

Section 8.04 Periodic Accounting. The Board shall determine under what circumstances to require that grantees furnish a periodic accounting to show that the funds granted by this corporation were expended for the purposes that were approved by the Board.

Section 8.05 Restricted Contributions. Unless otherwise determined by resolution of the Board in particular cases, this corporation shall retain complete discretion and control over the use of all contributions it receives, and all contributions received by this corporation from solicitations for specific grants shall be regarded as for the use of this corporation and not for any particular organization or individual mentioned in the solicitation. This corporation may accept contributions earmarked by the donor exclusively for allocation to one or more foreign organizations or individuals only if the Board has approved in advance the charitable activity for which the donations were made.

ARTICLE IX MISCELLANEOUS

Section 9.01 Fiscal Year. The fiscal year of this corporation shall end each year on December 31.

Section 9.02 Contracts, Notes, and Checks. All contracts entered into on behalf of this corporation must be authorized by the Board or the person or persons on whom such power may be conferred by the Board. Such authority may be general or confined to certain instances. Except as otherwise specifically determined by resolution of the Board, or as otherwise required by law, every check, draft, promissory note, money order, or other evidence of indebtedness of this corporation shall be signed by the Chief Executive Officer, Chief Financial Officer, or Treasurer of this corporation, except that all checks or other payments of more than \$75,000 shall be signed by the Chief Executive Officer and countersigned by the Treasurer of this corporation. Unless so authorized, no officer, employee, and other agent shall have any power or authority to bind the corporation by any contract or engagement or to pledge its credit or to render it liable monetarily for any purpose or in any amount.

Section 9.03 Representation of Corporate Shares. The Chief Executive Officer and Treasurer of this corporation are each authorized to vote, represent, and exercise on behalf of this corporation all rights incident to any and all shares of any other corporation standing in the name of this corporation. The authority hereby granted to these officers may be exercised either by such officers in person or by any other person authorized to do so by proxy or power of attorney duly executed by said officers.

Section 9.04 Annual Reports to Directors. The Chief Executive Officer or Chief Financial Officer shall provide an annual written report to all of the directors within 120 days after the end of this corporation's fiscal year. The report shall contain the following information:

- (a) the assets and liabilities, including the trust funds, of this corporation as of the end of the fiscal year;
- (b) the principal changes in assets and liabilities, including trust funds, during the fiscal year;
- (c) the revenue or receipts of this corporation, both unrestricted and restricted to a particular purpose, for the fiscal year;
- (d) the expenses or disbursements of this corporation, for both general and restricted purposes, for the fiscal year;
- (e) any transaction during the previous fiscal year between this corporation (or its parent or subsidiaries, if any) and any of its directors or officers (or the directors or officers of its parent or subsidiaries, if any) or any holder of more than ten percent of the voting power of this corporation or its parent or subsidiaries, if any, involving (i) more than \$50,000 or (ii) any of a number of such transactions, which in the aggregate involved more than \$50,000, in which the same person had a direct or indirect material financial interest. For each transaction, the report must disclose the names of the interested persons involved in such transaction, stating such person's relationship to this corporation, the nature of such person's interest in the transaction and, where practicable, the value of such interest; and
- (f) the amount and circumstances of any indemnifications or advances aggregating more than \$10,000 paid during the fiscal year to any director or officer of this corporation.

This annual report shall be accompanied by any report thereon of independent accountants or, if there is no such report, the certificate of an authorized officer of this corporation that such statements were prepared without an audit from the books and records of this corporation.

Section 9.05 Required Financial Audits. This corporation shall obtain a financial audit by an independent certified public accountant for any tax year in which it receives or accrues gross revenues of two million dollars (\$2,000,000) or more, excluding income from any governmental entity for which the governmental entity requires an accounting. Any audited financial statements obtained by this corporation shall be made available for inspection by the Attorney General and the general public within nine months after the close of the fiscal year to which the statements relate.

Section 9.06 Electronic Transmissions. Subject to procedures that the Board may adopt, the term "written" and "in writing" as used in these Bylaws includes electronic transmissions, such as facsimile or e-mail, provided that: (i) for electronic transmissions from the corporation, the corporation has obtained an unrevoked written consent from the recipient to the use of such

means of communication; (ii) for electronic transmissions to the corporation, the corporation has in effect reasonable measures to verify that the sender is the individual purporting to send the transmission; and (iii) for electronic transmissions both from and to the corporation, the transmission creates a record that is capable of retention, retrieval, and review, and may be rendered into clearly legible tangible form.

Section 9.07 Maintenance of Certain Records. This corporation shall keep at its principal office the original or a copy of its Articles of Incorporation and Bylaws as amended to date. This corporation shall keep its accounting books and records, and minutes of the proceedings of the Board and Board Committees at its principal office or at such other place as designated by the Board. The minutes shall be kept in printed form, and the accounting books and records shall be kept either in printed form or in any other form capable of being converted to printed form within a reasonable time.

Section 9.08 Amendments. Amendments to these Bylaws may be adopted by the vote of a majority of the directors then in office or the unanimous written consent of the directors. Proposed bylaw amendments shall be submitted in writing to each director at least one week prior to their vote on or written consent to such amendments.

Section 9.09 Governing Law. In all matters not specified in these Bylaws, or in the event these Bylaws shall not comply with applicable law, the District of Columbia Nonprofit Corporations law as then in effect shall apply.

Section 9.10 Severability. If any competent court of law shall deem any portion of these Bylaws to be invalid or inoperative, then insofar as is reasonable the remainder of these Bylaws shall be considered valid and operative and effect shall be given to the intent manifested by the portion deemed invalid or inoperative.

CERTIFICATE OF SECRETARY

I, the undersigned, certify that I am presently the duly elected and acting Secretary of EveryLife Foundation for Rare Diseases, a District of Columbia nonprofit corporation, and that the above Bylaws, consisting of 16 pages, are the Bylaws of this corporation as adopted by the Board of Directors on December 2, 2024.

Jennifer Bernstein

Jennifer Bernstein, Secretary



Michael Pearlmutter, Chief
Executive Officer