

**By-laws of Cornelia de Lange Syndrome Foundation, Inc.
A Massachusetts Nonprofit Corporation**

ARTICLE 1

Name

Section 1. NAME. The name of the organization shall be Cornelia de Lange Syndrome Foundation, Inc., hereinafter referred to as “CdLS Foundation”. CdLS Foundation (the Corporation”) as described in the Articles of Incorporation.

ARTICLE 2

Offices

Section 1. PRIMARY OFFICE. The primary office shall be determined from time to time by the board of directors of the CdLS Foundation. The current address of the corporation is 30 Tower Lane, Suite 400, Avon, CT 06001.

ARTICLE 3

Purpose

Section 1. PURPOSE. The purpose of the Corporation shall be charitable and educational within the meaning of Section 501 (c) (3) of the Internal Revenue Code. The purpose of the Corporation is:

- (a) to receive contributions, make distributions, and conduct operations so as to advance the art of medicine and support persons and caregivers of persons affected with Cornelia de Lange Syndrome; and
- (b) to collect and disseminate information regarding the syndrome to persons and caregivers of persons affected by the syndrome, the medical community, and the general public.

Section 2: The Corporation shall not carry on propaganda or otherwise attempt to influence legislation except as an insubstantial part of its activities. The corporation shall not engage in any transaction or permit any act or omission which shall operate to deprive it of its tax-exempt status under Section 501 (c) (3) of the Internal Revenue Code. The corporation shall not in any manner or to any extent participate in, or intervene in (including the publishing or distribution of statements), any political campaign on behalf of any candidate for public office; nor shall it engage in any “prohibited transaction” as defined in Section 503 (b) of the Internal Revenue Code.

Section 3: In the event of dissolution or liquidation of the corporation, any assets then remaining shall be distributed among such other organizations as shall qualify at the time as exempt organizations described in Internal Revenue Code Section 501 (c) (3)



as the Board of Directors shall determine, such assets to be used for purposes consistent with those described in Section 1.

Section 4: The corporation also has such powers as are now or may hereafter be granted under the laws of the Commonwealth of Massachusetts that are in furtherance of the corporation's exempt purposes within the meaning of Section 501 (c)(3) of the Internal Revenue Code or the corresponding section of any future federal tax code.

ARTICLE 4

Board of Directors

Section 1. GENERAL POWERS. The business and the property of The CdLS Foundation shall be managed and controlled by its board of directors. The directors may exercise all such powers and do all such things as may be exercised or done by The CdLS Foundation subject to the provisions of the Articles of Incorporation, these Bylaws, and all applicable law. The board of directors shall have the power to establish and amend policies and procedures for the operation of the corporation. Directors shall receive no compensation for their services as directors, but can be reimbursed for direct expenses related to participation in board meetings. Directors shall not be precluded from serving the corporation in any other capacity and receiving compensation for any such service.

Section 2. NUMBER. The board of directors shall consist of no fewer than eleven (11) or more than twenty (20) members and shall be divided into three classes, each class consisting of one third of the whole number of the board, as nearly as may be.

Section 3. TENURE. Each elected director of The CdLS Foundation shall be elected to serve for a term of three (3) year with the option of re-election for one (1) consecutive term. Upon the completion of a one-year leave from board directorship, a former director can re-apply for board directorship. The Director's terms shall coincide with the fiscal year (term to expire on December 31 in the third year). Director's terms will be staggered to assure continuity.

Section 4. VACANCIES. Any vacancy occurring in the board of directors may be filled by the affirmative vote of a majority of the current members of the board of directors. A director elected to fill a vacancy not resulting from the normal expiration of office shall be elected for the unexpired term of his predecessor in office.

Section 5. REGULAR AND SPECIAL MEETINGS. The board of directors may hold regular and special meetings. Regular meetings shall be held not less than two (2) times each year, one meeting in the Spring and one meeting in the Fall. Special meetings of the board may be called by the president or by four or more directors. Written notice of the time, place and agenda for both regular and special meetings shall be given to each



director personally or by mail, phone, fax, or electronic mail at least seven (7) days before the meeting.

Section 6. QUORUM. At any duly called meeting of the directors the number of directors present shall constitute a quorum. A majority of the directors present and voting shall decide any question.

Section 7.1 VOTING. Each director shall have one vote in person. At all meetings each director may vote either in person or by proxy. Every proxy must be executed in writing by the director or duly authorized attorney, but no proxy need be sealed, witnessed or acknowledged.

In the event of a tie vote, the executive director's vote will serve as the tie-breaker. The executive director normally does not vote unless there is a tie.

Section 7.2 ELECTRONIC VOTING. Electronic voting may be used in connection with both meetings of the board of directors and the solicitation of written consents as follows:

- (a) Meetings. For purposes of soliciting electronic votes in connection with a meeting of the board of directors at which a quorum was present, the requisite number of votes that would have been required at such meeting to pass an action shall be required to pass an action via this electronic voting provision. Only those directors in attendance of the meeting shall be permitted to vote with respect to this section. The deadline for receipt of electronic votes with respect to any such vote shall be no sooner than one (1) week from the date of the meeting, as announced prior to adjournment of such meeting. This subsection shall apply equally to the Executive Committee.
- (b) Action Without Meeting. For purposes of taking action without a meeting, solicitation via electronic balloting and voting shall be permitted hereunder. Such procedure shall be initiated by the electronic distribution of ballots and all related materials for consideration to all of the directors. Thereafter, the directors shall be permitted to cast their votes electronically in response to the distributed ballots. The deadline for receipt of such electronic votes cast by the directors shall be no less than one (1) week from the date of distribution of the balloting materials, as set forth therein. This subsection shall apply equally to the Executive Committee.

Section 8.1 ELECTRONIC MEETINGS AND COMMUNICATIONS.
A conference among directors by any means of communication, or through which the directors can simultaneously hear each other during the conference, constitutes a board meeting, subject to the notice requirements of Section 5 of this Article. This section shall apply equally to the Executive Committee.



Section 8.2 APPEARANCE VIA ELECTRONIC COMMUNICATION.

Directors may appear at a meeting of the board of directors by any means of communication through which all directors can simultaneously hear each other during the conference. Participation in a meeting in this manner shall constitute presence in person at the meeting. Furthermore, a director appearing at a meeting of the board of directors via this medium shall also be allowed to vote via this medium. This section shall apply equally to the Executive Committee.

Section 9. MANNER OF ACTING. Any action required or permitted to be taken at any meeting of the board of directors may be taken without a meeting, if all members of the board consent thereto in writing, setting forth the action so taken, and the writing or writings are filed with the minutes of the proceedings. Such consent shall have the same force and effect as a unanimous vote of the board.

Section 10. RESIGNATION/REMOVAL OF DIRECTORS. Any board member, elected or appointed, may resign by submitting written notice to the secretary. Any director may be removed by the board of directors whenever, in its judgment, the best interest of the CdLS Foundation would be served.

Section 11. EXECUTIVE COMMITTEE. The Executive Committee shall be composed of the President, Vice President(s), Secretary and Treasurer of the Board of Directors, as well as the Executive Director and Medical Director, both of whom shall serve ex officio without vote. The Executive Committee shall have and may exercise all the necessary powers of the Board of Directors in the governance of the Foundation during the intervals between the meetings of the Board of Directors; provided, however, that the Executive Director may request that any decision of the Executive Committee be voted upon by the Board of Directors prior to implementation. Minutes shall be kept of all Executive Committee actions and reported to the Board of Directors immediately. Meetings of the Executive Committee may be called at any time by the President and shall be called by the President within seven (7) days upon the request of three or more members of the Executive Committee. All meetings of the Executive Committee shall be held on at least three (3) days' written notice or one-day notice by telegram, cable, fax, or electronic mail. A majority of the members of the Executive Committee shall constitute a quorum. In addition to meeting in person, the Executive Committee may act pursuant to unanimous written consent or by any means of communication in which all members may simultaneously hear and be heard by all of the participating members.

Section 12. COUNCILS/COMMITTEES. The board may, from time-to-time, appoint councils, committees or task forces as deemed appropriate for such purposes as the board may designate.



Section 13. HONARARY MEMBERS: The Board may appoint one or more honorary members in recognition of distinguished services rendered to the CdLS Foundation.

Section 14. MEDICAL DIRECTOR. The position of medical director is self-perpetuating and shall serve until a successor is appointed.

ARTICLE 5

Officers

Section 1. NUMBER. The officers of the corporation shall be elected by the board of directors annually and shall include a president, vice president(s), a secretary, a treasurer.

Section 2. ELECTION AND TERM OF OFFICE. Each elected officer of the CdLS Foundation shall be elected to serve for a term of one (1) year with the option of re-election for one (1) consecutive term. By majority vote of the board, the President and Treasurer may serve up to 1 additional term.

Section 3. REMOVAL AND VACANCIES. Any officer elected by the board of directors may be removed from office with or without cause at any time by the vote of a majority of the board of directors. Any vacancy in any office of the CdLS Foundation shall be filled by the board of directors.

Section 4. PRESIDENT. The president shall preside at all business meetings, but may at his or her discretion or at the suggestion of the directors arrange for another officer to preside at the meetings. The president shall be responsible for the active executive management of this corporation under direction of the directors. The president shall review all proposals for appropriation of funds, and submit them with recommendations to the directors. The president shall be responsible for the execution of the full details of the various programs which shall be determined from time to time by the directors. The president shall sign or countersign all instruments that require an officer's signature, and shall make such reports and perform such other duties incident to the office as are required by the board of directors

Section 5. VICE PRESIDENT. There are one or more vice presidents that have such powers and perform such duties as the president or the board of directors may from time-to-time prescribe. In the absence of the president or in the event of his death, inability or refusal to act, one of the vice presidents 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 assures the integrity of board of director's documents, compliance with board policies and shall have such other powers and perform such other duties as the board of directors may from time-to-time prescribe.



Section 7. TREASURER. The treasurer shall maintain in good order all financial records of the CdLS Foundation. The treasurer shall also have such other duties as may be assigned by the membership or the board of directors. The treasurer shall render such reports relating to the monies, funds, securities, investments, and fiscal affairs of the corporation as may be required from time to time by the board of directors.

Section 9. EXECUTIVE DIRECTOR. The board of directors may appoint an executive director to serve at the will of the board. The executive director is the person duly qualified to operate and administer the affairs of the CdLS Foundation. This person shall be responsible for the daily affairs of the CdLS Foundation, subject to policy as established by the board of directors. The executive director will serve as a key advisor to the board of directors and a key link to the CdLS Foundation's programs, staff and operations. The executive director will have full authority in regard to staff and will be responsible to use that authority in compliance with Board policies to meet the defined outcomes of the organization. The executive director shall receive for his or her services such compensation as may be determined by the board of directors.

ARTICLE 6

Financial Oversight and Management

Section 1. CONTRACTS. The board of directors may authorize any officer or officers, agent or agents, to enter into any contract or execute and deliver any instrument in the name of and on behalf of the CdLS Foundation, and such authority may be general or confined to specific instances.

Section 2. LOANS. No loans shall be contracted on behalf of the CdLS Foundation and no evidences of indebtedness shall be issued in its name unless authorized by a resolution or board policy. Such authority may be general or confined to specific instances.

Section 3. CHECKS, DRAFTS, ETC. All checks, drafts or other orders for the payment of money, notes or other evidences of indebtedness issued in the name of the CdLS Foundation, shall be signed by such officer or officers, agent or agents of the CdLS Foundation and in such manner as shall from time-to-time be determined by resolution of the board of directors.

Section 4. FINANCIAL POLICIES. The board will convey to the executive director policies regarding financial expectations and limitations and will monitor the policies as to compliance. This includes defining the role of the executive director and the board in the areas of loans, contracts, investments, accounts and other financial oversight and management obligations.

Section 5. CONFLICT OF INTEREST. Prior to board or committee action on a contract or transaction involving a conflict of interest, a director having a conflict of interest and who is in attendance at the meeting shall disclose all facts material to the conflict of



interest. Such disclosure shall be reflected in the minutes of the meeting. A person who has a conflict of interest shall not participate in or be permitted to hear the board or committee's discussion of the matter except to disclose material facts and to respond to questions. Such person shall not attempt to exert his or her personal influence with respect to the matter, either at or outside the meeting, and shall decline from voting on any or all decisions related to the conflict of interest and shall not be present in the meeting room when the vote is taken. In the event it is not entirely clear that a conflict of interest exists, the individual with the potential conflict of interest shall disclose the circumstances to the board president or the president's designee, who shall determine whether there exists a conflict of interest that is subject to this.

ARTICLE 7

Indemnification of Directors and Others

Section 1. INDEMNIFICATION. The CdLS Foundation shall, to the extent legally permissible, indemnify any person serving or who has served as a director, trustee, officer, employee or other agent of the CdLS Foundation, against all liabilities and expenses, including amounts paid in satisfaction of judgments, in compromise or as fines and penalties, and counsel fees, reasonably incurred by him in connection with the defense or disposition of any action, suit or other proceeding, whether civil or criminal, in which he may be involved or with which he may be threatened, while serving or thereafter, by reason of his being or having been such a director, officer, trustee, employee or agent, except with respect to such matter as to which he shall have been adjudicated in any proceeding not to have acted in good faith in the reasonable belief that his action was in the best interests of the CdLS Foundation; provided, however, that as to any matter disposed of by a compromise payment by such director, officer, trustee, employee or agent, pursuant to a consent decree or otherwise, no indemnification either for said payment or for any other expenses shall be provided unless:

- (a) such compromise shall be approved by a disinterested majority of the board of directors as in the best interests of the CdLS Foundation, after notice that it involves such indemnification; or
- (b) in the absence of action by disinterested directors, there has been obtained at the request of the majority of the directors then in office.

Section 2. INSURANCE. The CdLS Foundation will purchase board of director's insurance and may purchase and maintain insurance on behalf of any person and such person's official capacity against any liability asserted against and incurred by such person in or arising from that capacity whether or not the CdLS Foundation would otherwise be required to indemnify the person against the liability.

ARTICLE 8



Miscellaneous

Section 1. FISCAL YEAR. The fiscal year of the Corporation shall begin on January 1 and end on December 31 in each year.

Section 2. SEAL. The Corporate seal shall be circular in form, and have inscribed thereon the name Cornelia de Lange Syndrome Foundation, State of Massachusetts, and the year of incorporation.

Section 3. AMENDMENTS. These Bylaws may be altered or amended by the board of directors at any regular or special meeting of the directors to the full extent permitted by law.

Section 4. RULES OF ORDER. The deliberations of the members and the board of directors shall be governed by Robert's Rules of Order unless suspended by a vote of the members or directors.

Adopted this 13th day of November 2010 by the CdLS Foundation Board of Directors.

Amendments:

- October 24, 2014: Article 4, Section 11 (new) approved by the board of directors.
- April 24, 2015: Article 4, Section 7.2, 8.1 and 8.2 (new) approved by the board of directors.
- December 15, 2020 Article 2, Section 1 and Article 5, Section 2 (updated) approved by the board of directors.