

**BY-LAWS  
OF  
THE BARTH SYNDROME FOUNDATION, INC.  
(Amended January 14, 2014)**

**ARTICLE I  
Organizational Purpose and Location**

Section 1. Purpose of the Organization. The Barth Syndrome Foundation, Inc. (the "Corporation") is a not-for-profit organization dedicated to: 1) promote awareness of Barth syndrome; 2) assist in the support of families with children suffering from Barth syndrome; 3) assist in the support of research centers and organizations addressing the causes, diagnosis, treatment and cure of Barth syndrome; and 4) such other charitable, scientific and educational purposes within the meaning of Section 501(c)(3) of the Code as may be determined by the Board of Directors of the Corporation.

Section 2. Registered Office. The registered office of the Corporation in Delaware is located at 1209 Orange Street, in the City of Wilmington, County of New Castle, State of Delaware 19801. The registered agent of the Corporation at such address is the Corporation Trust Company.

Section 3. Other Offices. The Corporation may also maintain offices at such other places both within and without the State of Delaware as the Board of Directors of the Corporation may from time to time determine or the business of the Corporation may require.

**Article II  
Members and Supporters**

Section 1. Who Shall Be Members. The Corporation shall not be a membership organization.

Section 2. Criteria for Supporter Status. The Supporters of the Corporation (individually a "Supporter" and in the plural "Supporters") shall be the contributing supporters who shall receive the Corporation's newsletter and invitations to special events sponsored by the Corporation. Supporter status in the Corporation shall be on an annual basis and be granted to all individuals, corporations and foundations that have been deemed to have made contributions of value, including but not limited to financial assistance, to the Barth Syndrome Foundation within that fiscal year. The Board may also grant special, permanent supporter status to individuals and/or institutions that it deems to have made significant contributions to the Barth Syndrome Foundation. The annual supporter list shall be kept by the Secretary or such other officer as the Board directs.

### **Article III Board of Directors**

Section 1. General Authority. The business and affairs of the Corporation shall be managed by or under the direction of a governing body of persons (individually designated as “Directors” and collectively as the “Board of Directors” or “Board”), which may exercise all powers of the Corporation and do all acts and things permitted by law to be done by a Delaware non-stock corporation.

Section 2. Expenditure Responsibility.

- (a) In furtherance of the purposes of the Corporation, only the Board of Directors shall have the power to make grants and contributions to other organizations and only where such grants are exclusively for charitable, scientific, or educational purposes within the meaning of the Internal Revenue Code of 1986 (or the corresponding provision of any future United States internal revenue law).
- (b) The Board of Directors shall have the power and responsibility to review and approve proposed plans and budgets for programs operated directly by the Corporation, as well as the Corporation’s annual operating budget.
- (c) The Board of Directors shall review all requests for funds from other organizations, as well as for programs operated directly by the Corporation. The Board of Directors shall require that all such requests or proposals specify the use for which such funds shall be put, and, if the Board of Directors approves the request shall authorize payment of such funds to such grantee or authorize program implementation and such oversight procedures as it deems to be prudent with respect to such internally operated programs.
- (d) The Board of Directors shall require that such grantees and internal program directors furnish periodic accounting to the Corporation to indicate that the funds were expended for the purposes approved by the Corporation.
- (e) The Board of Directors may, in its sole discretion, refuse to make any grants or contributions or otherwise render financial assistance to or for any or all of the purposes for which such funds are requested.

Section 3. Number, Election and Term. The Corporation shall be governed by a Board of Directors consisting of not less than eight (8) nor more than twenty-one (21) Directors. The number of directors may be increased or decreased at any time and from time to time by amendment to these By-Laws or by majority vote of the entire Board, except that in no case may any decrease in the number of directors shorten the term of any incumbent director. The first Board shall consist of five Directors named in the Certificate of Incorporation. At the first annual meeting of the Board of Directors, the Directors then holding office shall elect three classes of Directors, each class consisting of not less than one (1) nor more than seven (7)

Directors. The term of office of the Class A Directors shall expire at the second annual meeting, of the Class B Directors at the third annual meeting, and of the Class C Directors at the fourth annual meeting. After the first annual meeting, one class of Directors shall be elected at each annual meeting for a three-year term. Subject to the provisions of this Section, Directors shall be elected by action of the Directors then holding office and shall serve as Directors until their successors are elected and qualified or until their earlier resignation or removal. All Directors (regardless of class affiliation) may vote at the election of each and any class of Directors. A Director may serve for no more than three consecutive terms of office, following the annual meeting in 2006, if so elected by the Board. The Executive Director shall be a non-voting *ex-officio* member. At no time shall the Board of Directors have fewer than 50% of its members who have or are directly related (i.e. parents, siblings, grandparents or children) to someone who has Barth syndrome.

Section 4. Vacancies. Any vacancy occurring in the Board of Directors may be filled by the affirmative vote of the majority of the members of the Board of Directors present at a meeting at which a quorum is present. A Director elected to fill a vacancy shall be elected for the unexpired term of his predecessor in office.

Section 5. Removal. Any Director elected to the Board of Directors may be removed at any time, with or without cause, by the affirmative vote of two-thirds (2/3) of the members of the Board of Directors then in office or as permitted by and in accordance with the laws of the State of Delaware.

Section 6. Resignation. Any Director may resign at any time by giving written notice to the Board of Directors. Such resignation shall take effect at the time specified therein, and the acceptance of such resignation shall not be necessary to make it effective. If any Director shall tender his resignation to take effect at a future time, then the Board of Directors shall have the power to elect a successor to take office at such time as the resignation shall become effective. No director may resign if the Corporation would then be left without a duly elected Director or Directors in charge of its affairs, except upon notice to the Office of the Attorney General or other appropriate agency of the State of Delaware.

Section 7. Meetings of the Board of Directors. The Board of Directors of the Corporation may hold meetings, both regular and special, either within or without the State of Delaware as may be fixed by the Board from time to time or as shall be specified in the respective notice or waivers of notice thereof.

Section 8. Annual Meeting. The annual meeting of the Board of Directors for the election of Directors and the transaction of such other business as may properly come before the meeting shall be held in April of each year at the time and place designated by the Executive Director. Notice of the annual meeting, stating the place, date and time of the meeting, shall be served on each Director at least ten (10) business days before the date on which said meeting is to convene, and shall conform to the requirements for notice and waiver of notice set forth in

Article IV of these By-Laws. The notice of the annual meeting need not specifically state the business to be transacted thereat.

Section 9. First Meeting. The first meeting of the Board of Directors may be held immediately after the annual meeting of Directors and at the same place, and no notice of such meeting shall be necessary to the newly elected Directors in order legally to constitute the meeting, provided that a quorum shall be present. In the event such a meeting is not held at that time and place, the meeting may be held at such time and place as shall be specified in a notice given as hereinafter provided for special meetings of the Board of Directors, or as shall be specified in a written waiver signed by all of the Directors.

Section 10. Regular Meetings. Regular meetings of the Board of Directors or any committee thereof may be held with ten (10) days notice at such times and at such places as shall from time to time be determined by the Board or committee, as the case may be.

Section 11. Special Meetings. Special meetings of the Board of Directors or any committee may be called by the Chairman or Executive Director on notice to each Director at his last known residence or place of business, either personally, or by telephone, telegram, or other means of wire communication, at least one (1) day prior to such meeting or by mail at least ten (10) business days prior to such meeting. Special meetings shall be called by the Chairman, Executive Director or Secretary in like manner and on like notice at the request of one or more of the Directors.

Section 12. Quorum and Required Vote. Unless a greater proportion is required by law, by the Certificate of Incorporation, or by a section of these By-Laws, at all meetings of the Board, a majority of the entire Board of Directors shall constitute a quorum for the transaction of business, and the act of the majority of the Directors present at any meeting at which there is a quorum shall be the act of the Board of Directors, except as may be otherwise specifically provided by statute or these By-Laws. If a quorum shall not be present at any meeting of the Board of Directors, the Directors present thereat may adjourn the meeting from time to time, without notice other than announcement at the meeting, until a quorum shall be present.

Section 13. Majority. In the event that the Board or any committee thereof present at any meeting consists of an even number of persons, a majority means one-half of the number of such persons plus one.

Section 14. Action without Meeting. To the fullest extent permitted by the Delaware General Corporation Law as it presently exists, or hereafter may be amended, any action permitted to be taken at a meeting of the Board of Directors or committee thereof may be taken without a meeting if a majority of the members of the Board of Directors then in office or members of a committee thereof, as the case may be (or a two-thirds majority, where required under these By-Laws), consent thereto in writing. Such writing or writings shall be submitted to the Secretary and shall be filed with the minutes of proceedings of the Board of Directors or committee thereof. No action may be taken by the Board of Directors or committee thereof

without a meeting unless all Directors or committee members, as the case may be, are informed before any voting is scheduled to occur on the action being contemplated.

Section 15. Telephone Meetings. Unless otherwise restricted by the Certificate of Incorporation or these By-Laws, any or all Directors may participate in a meeting of the Board of Directors or committee thereof by means of a conference telephone or by any means of communication by which all persons participating in the meeting are able to hear one another. Such participation shall constitute presence in person at the meeting.

Section 16. Executive Committee. The Executive Committee of the Board of Directors shall be comprised of the Chairman, Treasurer, Secretary, and the Executive Director (non-voting *ex-officio*). The Executive Committee may also include the Board liaison representing families and the Board liaison representing science/medicine. The minimum number of members present to form a quorum is 2/3 of the voting members.

Section 17. Finance and Audit Committee. The Finance and Audit Committee shall be comprised of the Chairman, Treasurer, Secretary, and Executive Director (non-voting *ex-officio*). The Committee is responsible for overseeing investments, assets, audits, and risk management.

Section 18. Other Committees. The Board of Directors may, by resolution passed by a majority of the Board of Directors then in office, designate committees, each committee to consist of three or more of the Directors of the Corporation. Such committees may include, without limitation, an Executive committee, a Finance committee, and a Nominating committee. The Board may designate one or more Directors as alternate members of any committee, who may replace any absent or disqualified member at any meeting of the committee. In the event of the absence or disqualification of a member of a committee, the member or members thereof present at any meeting and not disqualified from voting, whether or not they constitute a quorum, may unanimously appoint another member of the Board of Directors to act at the meeting in the place of the absent or disqualified member. Any such committee, to the extent provided in the resolution of the Board of Directors or in the By-Laws, shall have and may exercise all the powers and authority which may be delegated by statute or the Board of Directors in the management of the business and the affairs of the Corporation and may authorize the seal of the Corporation, if any, to be affixed to all papers which may require it; but such committee shall not have any power of authority in reference to: (a) amending the Certificate of Incorporation or amending the By-Laws, (b) adopting an agreement of merger or consolidation, (c) selling, leasing or exchanging all or substantially all of the Corporation's property or assets, or (d) adopting a resolution to dissolve the Corporation. Each committee shall keep regular minutes of its meetings and report the same to the Board of Directors, when required.

Section 19. Compensation of Directors. The Directors of the Corporation shall serve in their capacity as Directors or committee members without compensation, but may be reimbursed for reasonable expenses, if any, incurred in carrying out the purposes of the Corporation.

Section 20. Annual Report of Directors. The Board of Directors shall present at its annual meeting a report, verified by the Executive Director and Treasurer or by a majority of the directors, or certified by an independent public or certified public accountant or a firm of such accountants selected by the Board, showing in appropriate detail the following:

- 1) the assets and liabilities, including the trust funds, of the Corporation as of the end of a twelve-month fiscal period terminating not more than six months prior to said meeting;
- 2) the principal changes in assets and liabilities, including trust funds, during said fiscal period;
- 3) the revenue or receipts of the Corporation, both unrestricted and restricted to particular purposes, during said fiscal period;
- 4) the expenses or disbursements of the Corporation, for both general and restricted purposes during said fiscal period; and
- 5) the number of directors of the Corporation as of the date of the report, together with a statement of increase or decrease in such number during said fiscal period, and a statement of the place where the names and places of residence of the current directors may be found.

The annual report of the Directors shall be filed with the records of the Corporation, and either a copy or an abstract thereof entered in the minutes of the proceedings of the annual meeting of the Board of Directors. The annual report shall be made available to any member of the public upon written request.

Section 21. Purchase, Sale, Mortgage and Lease of Real Property. No purchase of real property shall be made by the Corporation, and the Corporation shall not sell, mortgage or lease real property unless authorized by the vote of two-thirds of the entire Board of Directors; provided, however, that if there are twenty-one or more directors, the vote of a majority of the entire Board shall be sufficient.

#### **Article IV Notices**

Section 1. Notices. Whenever the Certification of Incorporation, By-Laws, Board resolutions, or provision of statute require that notice be given, such notice shall be construed to mean written notice by mail addressed to the person to be notified at his address as it appears on the records of the Corporation, with postage thereon prepaid, and such notice shall be deemed to have been given at the time when the same shall have been deposited in the United States mail. Notice may also be given by overnight delivery service, telephone, telegram, telefax, facsimile, personal delivery, or other forms of transmission generally available to the public reasonably designed to convey such notice within the time frame(s) set forth elsewhere in the

By-Laws, Board resolutions, or provisions of statute. Notice shall have been deemed to have been given when sent.

Section 2. Waiver of Notice. Whenever any notice is required to be given under the Certificate of Incorporation, the By-Laws, Board resolutions, or provisions of statute, a waiver of notice in writing that is signed by the person(s) entitled to such notice before or after the time of the event for which notice is required shall be deemed equivalent to notice. Attendance of a person at a meeting shall constitute waiver of notice of such meeting, except when the person attends a meeting for the express purpose of objecting, at the beginning of the meeting, to the transaction of any business because the meeting is not lawfully called or convened. Neither the business to be transacted at, nor the members of a committee of Directors need be specified in any written waiver of notice unless so required by the Certificate of Incorporation or these By-Laws.

## **Article V**

### **Officers**

Section 1. Positions. The Board shall appoint the officers of the Corporation. The officers of the Corporation shall be a Chairman, a Secretary, a Treasurer, the Executive Director and such other officers as the Board from time to time may appoint. Two or more offices may not be held simultaneously by the same person. No officer shall execute, acknowledge or verify any instrument in more than one capacity.

Section 2. Term of Office. Other than the Executive Director, who is *ex-officio*, the officers of the Corporation shall hold office for a term of three (3) years, concurrent with their Director terms, or until their successors are chosen and qualified.

Section 3. Compensation. The salaries of all officers and agents of the Corporation shall be determined by the Board of Directors.

Section 4. Removal. Any officer may be removed, with or without cause, at any time by an affirmative vote of two-thirds (2/3) of the members of the Board of Directors then in office.

Section 5. Chairman. The Chairman is elected by the Directors from among their number, and is responsible for convening and managing all meetings of the Board of Directors. The Chairman is expected to attend and chair all meetings of the Board, and, in conjunction with the Executive Director, is responsible for setting the agenda for all meetings of the Board. In the absence of the Chairman, the Executive Director shall preside at all meetings of the Board of Directors.

Section 6. Executive Director. The Executive Director is a non-voting *ex-officio* officer and shall ensure that all orders and resolutions of the Board are carried into effect, and in general all duties normally incident to the office of Executive Director and such other duties as may be prescribed by the Board of Directors from time to time. In furtherance, but not in limitation of

the duties and responsibilities herein described, the Executive Director , together with such officer or officers as may be authorized by special resolution of the Board, may sign and execute any deeds, mortgages, bonds, contracts, or other instruments which the Board of Directors has authorized to be executed or have delegated to his discretion to execute on behalf of the Corporation, except in cases where the signing and execution thereof shall be expressly delegated by the Board of Directors or by these By-Laws to some other officer or agent of the Corporation, or shall be required by law to be otherwise signed or executed.

Section 7. Secretary. The Secretary may be an elected member of the Board. The Secretary is responsible for the recordation of all proceedings of the meetings of the Board, and a book shall be kept for that purpose. The Secretary shall also perform like duties for the committees of the Board, when so requested. The Secretary may delegate the taking of minutes, but is ultimately responsible for them. The Secretary shall see that all notices are duly given in accordance with the provisions of these By-Laws, or as required by law, or as directed by the Board or the Executive Director. The Secretary shall see that the books, reports, statements certificates, and all other documents and records required by law are properly kept and filed, and shall perform such other duties as may be prescribed by the Board or by the Executive Director. The Secretary or his designee shall have custody of the corporate seal of the Corporation, if any and the Secretary shall have authority to affix the same to any instrument requiring it, and when so affixed it may be attested by the signature of the Secretary. The Board may give general authority or specific authority to any other officer to affix the seal of the Corporation and to attest the affixing by such officer's signature. The Secretary may also attest all instruments signed on behalf of the Corporation by the Executive Director. The Secretary shall in general perform all duties incident to the office of Secretary.

Section 8. Treasurer. The Treasurer may be an elected member of the Board. The Treasurer, in conjunction with the Executive Director, shall be responsible for all corporate funds of the Corporation and shall keep full and accurate accounts of receipts and disbursements in books belonging to the Corporation, and is expected to deposit all moneys and other valuable effects in the name and to the credit of the Corporation in such depositories as may be designated by the Board. The Treasurer, in conjunction with the Executive Director, shall disburse the funds of the Corporation as ordered by the Board, taking proper vouchers for such disbursements. The Treasurer, in conjunction with the Executive Director, shall render to the Board, at its regular meetings or when the Board so requires, an account of all financial transactions of the Corporation and of the financial condition of the Corporation. The Treasurer shall perform all other duties incident to the office of Treasurer and such other duties as from time to time may be assigned by the Board.

Section 9. Vacancies. A vacancy in any office of the Corporation because of death, resignation, removal, disqualification, or otherwise, may be filled for the unexpired portion of the term of that office by the Board of Directors.



Section 10. Agents and Employees. The Board of Directors may appoint agents and employees who shall have such authority and perform such duties as may be prescribed by the Board. The Board may remove any agent or employee at any time with or without cause. Removal without cause shall be without prejudice to such person's contract rights, if any, and the appointment of such person shall not itself create contract rights.

Section 11. Compensation of Officers, Agents and Employees. Officers may receive reasonable compensation for operational services rendered to the Corporation as established by the Board, including the reimbursement for expenses incurred in the performance of their duties to the Corporation, in reasonable amounts as approved by the majority of the entire Board.

The compensation of agents and employees appointed by the Board shall be fixed by the Board, but this power may be delegated to any officer, agent or employee as to persons under that person's direction or control. The Board may require officers, agents or employees to give security for the faithful performance of their duties.

## **Article VI**

### **Indemnification and Related Matters**

Section 1. Indemnification. To the fullest extent permitted and in the manner prescribed by the laws of the State of Delaware as those laws presently exist or hereafter may be amended, the Corporation shall (a) indemnify any person (including the estate of any person) who was or is a party or is threatened to be made a party to any action or proceeding or suit other than one by or in the right of the Corporation to procure a judgment in its favor, whether civil, criminal, administrative or investigative, by reason of the fact that such person is or was a Director, officer, employee or agent of the Corporation or is or was serving at the request of the Corporation as a Director, officer, employee or agent of another corporation, partnership, joint venture, trust or other enterprise, may advance such person's related expenses to the fullest extent permitted by law. The Corporation shall pay attorneys' fees, judgments, fines and amounts paid in settlement (except judgments, fines and amounts paid in settlement in connection with an action or suit by or in the right of the Corporation) actually and reasonably incurred by such person in connection with such action, suit or proceeding and (b) pay expenses incurred by any Director, officer, employee or agent in defending a civil or criminal action, suit or proceeding in advance of the final disposition of such action, suit or proceeding.

The indemnification provided herein shall not be deemed to be exclusive of any other rights to which persons seeking indemnification may be entitled under any agreement or vote of disinterested Directors, including rights under any insurance policy that may be purchased by the Corporation to the extent permitted by the Delaware General Corporation Law.

Section 2. Liability to the Corporation. No Director shall be personally liable to the Corporation or any of its Members for monetary damages for breach of fiduciary duty as a Director, except (a) for any breach of the Director's duty of loyalty to the Corporation or its Members, (b) for

acts or omissions not in good faith or which involve intentional misconduct or knowing violation of law or (c) for any transaction from which the Director derived an improper personal benefit.

Section 3. Insurance. The Corporation may purchase and maintain, to the fullest extent permitted by the laws of the State of Delaware as they presently exist or hereafter may be amended, insurance on behalf of any officer, Director, employee, trustee or agent of the Corporation and any person who is or was serving at the request of the Corporation as an officer, Director, employee, partner (general or limited), trustee or agent of another enterprise against any liability asserted against him or incurred by him in any such capacity or status.

## **Article VII General 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 unless otherwise determined by the Board.

Section 2. Contracts, Checks, Notes, etc. All contracts and agreements authorized by the Board, and all notes, drafts, checks, acceptances, orders for the payment of money, and negotiable instruments obligating the Corporation for the payment of money shall be signed by at least one officer of the Corporation or by such other number of officer or officers or employee or employees as the Board may from time to time direct.

Section 3. Corporate Seal. The Corporate seal shall have inscribed thereon the name of the Corporation, the year of its organization, the words "Corporate Seal" and "Delaware" and the year the Corporation was formed in the center. The Corporation may use the seal by causing it or a facsimile to be affixed or impressed or reproduced in any manner.

Section 4. Deposits. All funds of the Corporation not otherwise employed shall be deposited promptly to the credit of the Corporation in such banks, trust companies, or other depositories as the Board, or, if authorized by the Board to do so, the Executive Director, Chairman, or Treasurer may direct. For the purpose of making such deposits, checks, drafts, and other orders for the payment of money that are payable to the Corporation may be endorsed, assigned, and delivered by the Executive Director, Chairman, or Treasurer, or in such manner as may from time to time be determined by resolution of the Board of Directors.

Section 5. Certificates Representing Stocks, Bonds, or Other Securities. The Chairman, Treasurer, and Executive Director are authorized to buy, sell, assign and transfer, across Barth Syndrome Foundation accounts, certificates representing stocks, bonds, or other securities registered in the name of the Barth Syndrome Foundation.

Section 6. Loans. No loans shall be contracted for or on behalf of the Corporation and no evidence of indebtedness shall be issued in the name of the Corporation unless authorized by a resolution of the Board. Such authority may be general or may be confined to specific instances.

Section 7. Voting Securities of other Corporations. The Board shall have the authority to vote those securities of any other corporation which are owned or held by the Corporation and may attend meetings of stockholders or execute and deliver proxies for such purpose.

Section 8. Form of Records. The Corporation shall maintain records in the regular course of its business, including its books of account and minute books of the proceedings of its Board of Directors and any committee of the Corporation. A current list or record containing the names and addresses of all Directors, all officers, all committee members, and all volunteers of the Corporation may be kept in any information storage device, provided that the records so kept can be converted into clearly legible written form within a reasonable time. The Corporation shall so convert any records so kept upon the request of any person entitled to inspect the same.

Section 9. Amendments. The Certificate of Incorporation may be amended by a majority of the Board. The By-Laws may be amended or repealed and new By-Laws may be adopted by the affirmative vote of a majority of the Board of Directors then in office, providing that prior notice has been given to all members of the Board of Directors in accordance with the notice provisions set out in Article IV herein.

Section 10. Meaning of Certain Words. Whenever references are made in the Certificate of Incorporation, these By-Laws or Board resolutions to more than one incorporator, Director or Corporation, such reference shall be construed in the singular rather than the plural in the event of a sole incorporator, Director, or Corporation, and all provisions dealing with majorities for purposes of quorums or otherwise shall be deemed to mean the action of the one person constituting the Corporation. Where words of masculine gender are used, they shall be understood as synonymous with the feminine gender for all purposes.

## **Article VIII**

### **Prohibition and Limitation**

#### Section 1. Prohibition Against Sharing in Corporate Earnings

(a) No part of the earnings of the Corporation shall inure to the benefit of or be distributable to its incorporators, Directors, officers, or other private persons except that the Corporation shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in the Certificate of Incorporation.

(b) All Directors and officers of the Corporation shall be deemed to have expressly consented and agreed that, upon dissolution or winding up of the affairs of the Corporation, the Board of Directors shall, after paying or making provision for the payment of all the liabilities of the Corporation, dispose of the remaining assets of the Corporation exclusively for the purposes and in the manner set out in the Certificates of Incorporation.

Section 2. Exempt Activities. In all events and under all circumstances, and notwithstanding merger, consolidation, reorganization, termination, dissolution, or winding up of the Corporation, voluntary or involuntary or by operation of law:

- (a) The Corporation shall not have or exercise any power or authority either expressly or by interpretation or operation of law, nor shall it directly or indirectly engage in any activity, that would prevent it from qualifying (and continuing to qualify) as a corporation described in Section 501 (c) (3) of the Internal Revenue Code of 1986 (or the corresponding provision of any future United States internal revenue law), contributions to which are deductible for federal income tax purposes.
- (b) No substantial part of the activities of the Corporation shall consist of carrying on propaganda, or otherwise attempting to influence legislation; nor shall it in any manner or to any extent participate in, or intervene in (including the publishing or distributing of statements) any political campaign on behalf of or in opposition to any candidate for public office.
- (c) Neither the whole, nor any part or portion, of the assets or net earnings of the Corporation shall be used, nor shall the Corporation ever be organized or operated, for objects or purposes other than those set out in the Certificate of Incorporation.

## **ARTICLE IX**

### **Construction and Terms**

If there is any conflict between the provisions of these By-Laws and the Certificate of Incorporation of this Corporation, the provisions of the Certificate of Incorporation shall govern.

Should any of the provisions or portions of these By-Laws be held unenforceable or invalid for any reason, the remaining provisions and portions of these By-Laws shall be unaffected by such holding.

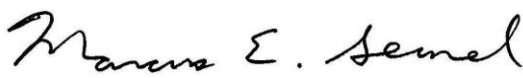

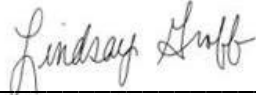
All references in these By-Laws to the Certificate of Incorporation shall be to the Articles of Incorporation, Articles of Organization, Certificate of Incorporation, Organizational Charter, Corporate Charter, or other founding document of this Corporation filed with an office of the State of Delaware and used to establish the legal existence of this Corporation.

All references in these By-Laws to a section or sections of the Internal Revenue Code shall be to such sections of the Internal Revenue Code of 1986 as amended from time to time, or to corresponding provisions of any future federal tax code.

### **ADOPTION OF BY-LAWS AS AMENDED, January 14, 2014**

We, the undersigned, are the current directors of this Corporation, and we consent to, and hereby do, correct and amend in their entirety the By-Laws of the Barth Syndrome Foundation, Inc., and adopt the foregoing By-Laws as amended on November 14, 2009, consisting of the 12 preceding pages, as the By-Laws of this Corporation.

Dated as of: **January 14, 2014**

1.   
\_\_\_\_\_  
Marcus E. Sernel, Chairman
2. \_\_\_\_\_  
David Axelrod, MD
3. \_\_\_\_\_  
Randy Buddemeyer, Treasurer
4. \_\_\_\_\_  
Stephen Kugelman
5.   
\_\_\_\_\_  
Susan A. McCormack, Secretary
6. \_\_\_\_\_  
Katherine R. McCurdy
7. \_\_\_\_\_  
Susan S. Osnos
8. \_\_\_\_\_  
Catharine Lynne Ritter
9. \_\_\_\_\_  
John Wilkins
10. \_\_\_\_\_  
Susan V. Wilkins
11.   
\_\_\_\_\_  
Lindsay Groff, Executive Director, *ex-officio*