



Barth Syndrome
Foundation

BARTH SYNDROME FOUNDATION POLICY ON CONFIDENTIALITY

Reviewed and Approved – May 15, 2019

BARTH SYNDROME FOUNDATION (“BSF”) is aware that individuals involved with BSF as Directors, officers, employees, committee members and volunteers may see, become aware of, or possess information of a private or confidential nature to BSF, families affected by Barth syndrome, researchers, physicians or donors. The Covered Persons (as defined below) may have a legitimate need to know and make use of such confidential or private information in the course of fulfilling their responsibilities on behalf of BSF. To ensure that the confidentiality of the information will be maintained, the following Policy on Confidentiality (the “Policy”) is adopted.

1. Applicability. This Policy applies to BSF’s Board of Directors, officers, employees (present or former), committee members, advisory board members, and all lay and scientific members of any committee or advisory board, and other volunteers who receive Confidential Information (collectively, “Covered Persons”).
2. Definition of Confidential Information. “Confidential Information” means all written or oral business, financial, technical, health and scientific information relating to BSF which is not public information, including but not limited to, (i) information related to the identity, health, treatments or condition of an individual or family affected by Barth syndrome; (ii) unpublished information related to research; (iii) the identity of physicians who may be treating someone affected by Barth syndrome; (iv) information related to donors; and (v) confidential information provided to BSF from third parties; and which BSF or the owner of the Confidential Information has (a) marked conspicuously or otherwise designated as “CONFIDENTIAL,” “PROPRIETARY,” or a similar marking, or (b) which a reasonable person

would understand to be confidential or proprietary information. "Confidential Information" excludes information which (i) is in the public domain at the time of disclosure; and (ii) becomes part of the public knowledge through no fault of BSF (including any Covered Person), as of the date of its becoming part of the public knowledge.

3. Nondisclosure of Confidential Information. From the date of receipt of any Confidential Information and thereafter, each Covered Person agrees not to disclose to any person any Confidential Information, except as provided below. Each Covered Person agrees that he or she will use the Confidential Information only for the purpose provided and for no other purpose. Notwithstanding the foregoing, a Covered Person may disclose the Confidential Information (i) to other Covered persons who have a need to know and who have agreed to be bound by this Policy on Confidentiality, or (ii) to other persons approved in advance in writing by an officer of BSF; or (iii) to the extent required by a court order or by law. Each Covered Person shall use the same degree of care, but not less than a reasonable degree of care, that he or she uses to protect his or her own most highly confidential information to prevent any unauthorized or inadvertent disclosure of Confidential Information.

Any individual having question(s) concerning this policy or its applicability in a given situation(s) should address those question(s) to the appropriate BSF officer.

4. Return of Confidential Information. Upon request of BSF, each Covered Person agrees to (i) return to BSF official(s) all tangible materials incorporating Confidential Information made available or supplied to such Covered Person and all copies and reproductions thereof, and (ii) sign and deliver to BSF a verification statement, in the form provided by BSF, certifying the Covered Persons compliance with this Section 4.
5. Implementation. Each Covered Person, other than an employee, shall execute a written statement provided by BSF stating that such Covered Person has read this Policy on Confidentiality, understands its terms and agrees to be legally bound by the provisions hereof. With respect to employees, each employee shall execute a written statement provided by BSF stating that such employee has read the Employee Handbook, understands its terms and agrees to comply with the provisions thereof. Such written statements

shall be signed by an individual upon his or her appointment or other act in his or her being a Covered Person, and periodically thereafter at such times as the Chairman of the Board or other officer of BSF determines.

CERTIFICATION REGARDING CONFIDENTIALITY OF INFORMATION

I have read and understand the above Policy on Confidentiality and agree to be legally bound by its terms.

Name (please print)

Signature

Date