



## Confidentiality Policy

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, individuals affected by Barth syndrome, their families, researchers, physicians or donors. The Covered Persons (as defined below) may have a legitimate need to know and make use of such Confidential Information (as defined below) in the course of fulfilling their responsibilities on behalf of BSF. To ensure that the confidentiality of the information will be maintained, the following Confidentiality Policy (the “Policy”) is adopted.

1. **Applicability.** This Policy applies to BSF’s Board of Directors, officers, employees (present and 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related to the identity, health, treatments or condition of an individual or family affected by Barth syndrome; (ii) unpublished information related to research; (iii) the identity of physicians who may be treating someone affected by Barth syndrome; (iv) information related to donors;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 to treat such Confidential Information as strictly confidential and not to disclose to any person any Confidential Information, except as provided below. Each Covered Person agrees that they 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, 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 a reasonable degree of care 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 / Destruction of Confidential Information. Upon request of BSF, each Covered Person agrees to (i) return to BSF all tangible materials incorporating Confidential Information made available or supplied to such Covered Person and all copies and reproductions thereof, (ii) permanently delete any Confidential Information and (iii) sign and deliver to BSF a verification statement, in the form provided by BSF, certifying the Covered Person's compliance with this Section 4.
5. Implementation. Each Covered Person, shall execute a written statement provided by BSF stating that such Covered Person has read this Policy, understands its terms and agrees to be legally bound by the provisions hereof. Such written statements
6. shall be signed by an individual upon their appointment or other act in their 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 Confidentiality Policy and agree to be legally bound by its terms.

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**Name (please print)**

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**Signature**

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**Date**