

Whistleblower Protection Policy

GENERAL

Barth Syndrome Foundation ("BSF") policies require members of BSF's Board, Scientific & Medical Advisory Board ("SMAB"), Committees, employees and other volunteers (the "Responsible Parties") to observe high standards of business and personal ethics in the conduct of their duties and responsibilities. As representatives of BSF, we must practice honesty and integrity in fulfilling our responsibilities, respect each member of our various constituencies including affected individuals, families, physicians, researchers, donors, employees and volunteers and comply with all applicable laws and regulations.

REPORTING RESPONSIBILITY

It is the responsibility of all Responsible Parties to comply with BSF Policies and all applicable laws and regulations and to report employees or others in order to raise any and all serious concerns within BSF prior to seeking resolution outside BSF.

REPORTING VIOLATIONS

This Whistleblower Policy is intended to encourage and enable leaders in the best position to address an area of concern. However, if the individual is not comfortable speaking with their supervisor or leader or is not satisfied with their response, then the individual is encouraged to speak with anyone in management or on the Board with whom they are comfortable speaking. Members of BSF's Board, officers and leaders are required to report suspected violations to BSF's Executive Director or Chairperson who have responsibility to investigate all reported violations.

For issues involving any of the above-named officers or when an individual is not satisfied or uncomfortable with following BSF's open-door policy, then individuals should contact an independent member of the Board of Directors directly.

The Whistleblower Policy addresses BSF's open-door policy and advises that employees and others share their questions, concerns, suggestions, or complaints with someone who can address them properly. It is the responsibility of the person that receives the question, concern, suggestion, or complaint to report it to the Executive Director or Chairperson, who will then notify the Audit Committee. The Audit Committee will manage all reports and ensure that they are appropriately handled. Additionally, it is the responsibility of all leaders of BSF to ensure that those who work with them also are aware of this policy.

Examples of possible violations include without limitation:

• Theft

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- Financial reporting that is intentionally misleading
- Improper or undocumented financial transactions
- Improper destruction of records
- Improper use of assets
- Violation of client protection policies
- Violation of the conflict of interest policy

NO RETALIATION

No individual who in good faith reports a violation of any BSF Policy or any applicable law or regulation shall suffer harassment, retaliation, or adverse employment or association consequence. An individual who retaliates against someone who has reported a violation in good faith is subject to discipline up to and including termination of employment or association with BSF.

ACTING IN GOOD FAITH

Anyone filing a complaint concerning a violation or suspected violation must be acting in good faith and have reasonable grounds for believing the information disclosed indicates a violation of BSF's policies or a state or federal law or regulation. Any allegations for which reasonable grounds are not found and which prove to have been made maliciously or knowingly to be false will be viewed as a serious disciplinary offense.

CONFIDENTIALITY

Violations or suspected violations may be submitted on a confidential basis by the complainant or may be submitted anonymously. Reports of violations or suspected violations will be kept confidential to the extent possible, consistent with the need to conduct an adequate investigation.

HANDLING OF REPORTED VIOLATIONS

The senior officer or Board member receiving the complaint will notify the sender (if identified) and acknowledge receipt of the reported or suspected violation within 5 business days. All reports will be promptly investigated, and appropriate corrective action will be taken if warranted by the investigation.

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