



## Code of Ethics (the “Code”)

### Introduction

Barth Syndrome Foundation’s (BSF) mission is to save lives through education, advances in treatment, and finding a cure for Barth syndrome. In carrying out our work, we are guided by our core values:

- We ensure that BSF stands for: Credibility, Integrity, Professionalism, and Compassion.
- We are respectful of the time and talents we are offered and are good stewards of the resources we are given.
- We value collaboration and constantly seek to improve by listening to and learning from others.
- We encourage diversity within our Board and committees, and strive to be inclusive in all program areas.
- We recognize the unique and personal challenges of every person and family affected by Barth Syndrome and pledge to them our commitment, compassion and respect.
- When representing BSF we place the interests of all those affected by Barth syndrome above the interest of any one individual.
- We will never ever give up until a cure and effective treatments have been made available to all individuals affected by Barth syndrome!

In keeping with these principles, we have adopted the following policy regarding potential “conflict of interest” situations with the purpose of assuring a high level of organizational integrity on behalf of members of our Board, SMAB, Committees, employees and other volunteer leadership. A primary goal of BSF’s Code of Ethics is that we do not permit personal interests to conflict, or even appear to conflict, with the interests of the Foundation. We are resolute in our commitment to the highest standards of ethical and legal behavior.

On or around January 1st of each year (or upon such later date as the applicable

engagement with BSF begins), each member of the Board, SMAB, Committees, employees and volunteer leaders shall be required to sign a written acknowledgment affirming that they have received and reviewed the Code.

We expect BSF's employees and volunteers to act in accordance with these standards:

**We comply with laws and regulations.**

We strive to comply with all laws and regulations that are applicable to BSF, including the laws governing nonprofit organizations and workplace behavior. Although laws and regulations may sometimes be ambiguous and difficult to interpret, as a good citizen, BSF emphasizes good faith efforts to follow the spirit and intent of the law. We understand that, as a charity, we operate exclusively for public benefit and not for private purposes, and we are subject to stringent rules relating to conflicts of interest and political activities.

**We respect privacy and confidentiality.**

We may have access to sensitive and proprietary information about our clients, donors, grantees, grant applicants, partners, volunteers, employees, marketing plans, strategies, and technical matters. We do not disclose or use that information except as appropriate in our work, and we comply with applicable privacy laws. We only retain the information that is needed to help fulfill our mission and vision.

**We manage our resources prudently.**

We protect our assets, both physical and intellectual, and use them in furtherance of our charitable purposes in line with our mission of advancing treatments and identifying a cure for Barth syndrome. We do not use the BSF name, reputation, or other property for our own or others' personal financial benefit.

**We work respectfully and collaboratively.**

We maintain a productive and diverse work environment intended to foster teamwork, ongoing learning, and creativity. We appreciate the contributions of all. We work cooperatively and respectfully, acting with courtesy and tact in all our interactions with clients, grantees, partners, donors, volunteers, members of the public, and colleagues. To ensure that we take the various special needs of every individual with Barth syndrome into consideration, we encourage and promote the inclusion of members in all leadership rolls regardless of age, gender, geographic location, culture, race or ethnic origin, or medical needs.

**We carry out our organizational policies.**

We comply with our organizational policies, including those relating to nondiscrimination, workplace conduct, conflicts of interest, use of assets, financial reporting, confidentiality and social media.

**We speak up and hold ourselves accountable.**

We promote trust by being responsible, transparent and accountable for our actions. We pay attention to our conduct and honestly report internal activities that may be unethical or violate law or policy. We address concerns promptly and prohibit retaliation against those who raise issues and hold us accountable.

**We look to our values in making decisions.**

We recognize that not every situation we face in the workplace is covered by a law or policy. We expect ourselves to always be guided by the standards set out in this Code of Ethics in making decisions, taking actions, and interacting with others.

**We do not allow our personal interests to cloud our judgment.**

We never allow personal gains or interests to threaten the wellbeing of the Foundation. Nor do we accept gifts (other than of nominal value) directly or indirectly, in any form, from a third party or fees or commissions in connection with any transaction on behalf of BSF. The acceptance of payments for personal consulting or other professional services requires the prior approval of the Board.

**Employee or Volunteer Certification**

I have read and accept the Code of Ethics at BSF. I understand that my violation of the Code of Ethics may lead to appropriate disciplinary action, up to and including grounds for dismissal from my role in the Foundation. I am expected to act fairly and honestly in all transactions with BSF and with others to maintain the high ethical standards of BSF. If a situation arises where I am unsure whether there may be a violation of the Code of Ethics, I agree to contact the Chairperson of the Board and Executive Director for guidance.

Signature: \_\_\_\_\_

Print Name: \_\_\_\_\_ Date: \_\_\_\_\_