



The Barth Syndrome Foundation Privacy & Disclaimer Statement

The Barth Syndrome Foundation, Inc. (BSF), while designing and maintaining a website on the internet that provides educational information to those in need, does not intend to provide medical advice. Also, BSF highly respects the privacy of each and every individual affiliated with our organization. Accordingly, BSF sought legal advice to compose the following Disclaimer and Privacy Policy statements outlining BSF's role in complying with said issues.

Disclaimer The Barth Syndrome Foundation website is designed for educational purposes only and is not intended to serve as medical advice. The information provided on this site should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. If you suspect you or your child(ren) may have Barth syndrome, you should consult your health care provider.

Members of the Barth Syndrome Foundation are those families who have received a confirmed genetic diagnosis for Barth syndrome. Follow the link for more information on how to go about receiving an [accurate diagnosis](#).

Web-Site Privacy Policy The Barth Syndrome Foundation is committed to protecting your privacy. We have summarized our policies and procedures below. Your privacy is important to us. To better protect your privacy, we provide this notice explaining our on-line information practices and choices you can make about the way your information is collected and used. To make this notice easy to locate, we make it available as a link on our home page, and at every point where personal information may be requested. We define personal information to include: name, e-mail name, web address, physical address, phone number, survey responses, registry information and the content of your correspondence with us.

Disclosure When you contact us, your e-mail address, web name and other information included in your e-mail may be forwarded through the site to the appropriate person(s) within The Barth Syndrome Foundation, Inc. for a response. Copies of your correspondence may be retained at the BSF home office and by the responding individual. The Barth Syndrome Foundation, Inc. will establish and maintain lists of our members including families, physicians, scientists, contributors and others interested in Barth syndrome to allow us to communicate with you. These lists will not be sold, rented or given to any third party for commercial use, nor do we currently expect to release these lists to any third party for any reason. However, if The Barth Syndrome Foundation sees a need or a possible benefit to you of making your personal information available to a third party, we will not do so without first identifying the recipient and providing a full explanation to you, and receiving your permission to do so in advance of each instance.

Name and Address We use some of the information included in your e-mail message (e.g. your web name and address, including your internet service provider) to track usage of our web site and improve its value to you. We compile statistics that show the daily number of visitors to our site, the daily requests for particular files on the site, the countries that requests are coming from, and browser and operating systems used. These statistics are used internally to help us improve the content and scope of the site. These statistics contain no personal information and cannot be used to gather such information. We may use this information to communicate with you, but will not distribute this information outside of BSF or use it for any other purpose without your permission.

Other Sites The Barth Syndrome Foundation links to other sites that may be of interest to those who use our site. BSF is not responsible for the privacy practices or the content of such Web sites.

Confidentiality The Barth Syndrome Foundation is firmly committed to maintaining the confidentiality of your personal information in all of our activities and programs. Every reasonable effort will be made to maintain the security of all personal information in our possession. Access to personal information will be limited to BSF Board members and officers and to individuals who have a need to use such information in the course of their work on approved projects for, and overseen by the Barth Syndrome Foundation, and who have been instructed in the confidentiality requirements of the organization.

Security We take precautions to protect your information. When you submit sensitive information via the website, your information is protected both online and offline. Wherever we collect sensitive information (such as credit card data), that information is encrypted and transmitted to us in a secure way. You can verify this by looking for a closed lock icon at the bottom of your web browser, or looking for "https" at the beginning of the address of the web page. While we use encryption to protect sensitive information transmitted online, we also protect your information offline. Only employees who need the information to perform a specific job (for example, billing or customer service) are granted access to personally identifiable information. The computers/servers in which we store personally identifiable information are kept in a secure environment.

Contact

If you have questions about your personal information provided through the BSF website, please us at bsfinfo@barthsyndrome.org.