



Privacy Policy

What Information Do We Collect? When you visit our website or contact us by telephone or mail, you may provide us with two types of information: personal information you knowingly choose to disclose that is collected on an individual basis and website use information collected on an aggregate basis as you and others browse our website.

1. **Personal Information You Choose to Provide.** We may request that you voluntarily supply us with personal information, including your name, email address, postal address, phone number(s) and other personal information for such purposes as correspondence or participating in online surveys. If you choose to correspond with us through email, we may retain the content of your email messages together with your email address and our responses. We provide the same protections for these electronic communications that we employ in the maintenance of information received by mail and telephone.
2. **Website Use Information.** Similar to other websites, our site may utilize a standard technology called "cookies" (see explanation below, "What Are Cookies?") and web server logs to collect information about how our website is used. Information gathered through cookies and server logs may include the date and time of visits, the pages viewed, time spent at our website, and the sites visited just before and just after ours. This information is collected on an aggregate basis. None of this information is associated with you as an individual.

How Do We Use the Information That You Provide to Us? Broadly speaking, we use personal information for purposes of administering our charitable activities, such as improving our website and the information and communications that we offer, and providing service and support to our Barth syndrome community. We also use such information to detect security incidents and to protect against malicious, deceptive, fraudulent, or illegal activity and to comply with laws, rules and regulations.

Occasionally, we may also use the information we collect to communicate with you and notify you about important changes to our website and/or important information that we think you will find valuable. The lists used to send you these communications are developed and



managed under our traditional standards designed to safeguard the security and privacy of all personal information provided by our users. You may at any time notify us of your desire not to receive these communications by checking or clicking on a response box when you receive such a communication or by sending us an email request.

What Are Cookies? Cookies are a feature of web browser software that allows web servers to recognize the computer used to access a website. Cookies are small pieces of data that are stored by a user's web browser on the user's hard drive. Cookies can remember what information a user accesses on one web page to simplify subsequent interactions with that website by the same user or to use the information to streamline the user's transactions on related web pages. This makes it easier for a user to move from web page to web page and to complete commercial transactions over the Internet. Cookies should make your online experience easier and more personalized.

How Do We Use Information Collected From Cookies? We use website browser software tools such as cookies and web server logs to gather information about our website users' browsing activities, in order to constantly improve our website and better serve our users. This information assists us to design and arrange our web pages in the most user-friendly manner and to continually improve our website to better meet the needs of our users and prospective users. Cookies help us collect important business and technical statistics. The information in the cookies lets us trace the paths followed by users to our website as they move from one page to another. Web server logs allow us to count how many people visit our website and evaluate our website's visitor capacity. We do not use these technologies to capture your individual email address or any personally identifying information about you.

How Do We Secure Information Transmissions? When you send confidential personal information to us on our website, such as when making a donation, a secure server software which we have licensed encrypts all information you input before it is sent to us. The information is scrambled en route and decoded once it reaches our website. Other email that you may send to us may not be secure unless we advise you that security measures will be in place prior to your transmitting the information. For that reason, we ask that you do not send confidential information such as Social Security, credit card, account numbers or personal medical information to us through an unsecured email.



How Do We Protect Your Information?

1. *Information Security* -- We utilize encryption/security software to safeguard the confidentiality of personal information we collect from unauthorized access or disclosure and accidental loss, alteration or destruction.
2. *Evaluation of Information Protection Practices* -- Periodically, our operations and business practices are reviewed for compliance with organization policies and procedures governing the security, confidentiality and quality of our information.
3. *Employee Access, Training and Expectations* -- Our organization's values, ethical standards, policies and practices are committed to the protection of user information. In general, our business practices limit employee access to confidential information to only that for which the employee has a legitimate need to know in the conduct of their assigned work, and limit the use and disclosure of such information to authorized persons, processes and transactions.

How Can You Access and Correct Your Information? You may request access to all your personally identifiable information that we collect and maintain in our database, or you may request that we correct your personal information, by emailing us using the contact form provided to you within the site structure of our website, by sending a letter to: 2005 Palmer Avenue #1033, Larchmont, NY 10538, Attn: Executive Director or by calling 914-303-6323.

Do We Disclose Information to Outside Parties? We may provide aggregate information about our community, website traffic patterns and related website information to our affiliates or reputable third parties, but this information will not include personally identifying data, except as previously authorized in writing or otherwise provided in this privacy policy.

What About Legally Compelled Disclosure of Information? We may disclose information when legally compelled to do so, in other words, when we, in good faith, believe that the law requires it, are compelled by a legitimate legal authority or for the protection of our legal rights.

Permission to Use Materials. The right to download and store or output the materials in our website is granted for the user's personal use only, and materials may not be reproduced in any edited form. Any other reproduction, transmission, performance, display or editing of these materials by any means mechanical or electronic without our express written permission



is strictly prohibited. Users wishing to obtain permission to reprint or reproduce any materials appearing on this site may contact us directly.

Personally Identifiable Information from Children or Minors. Our website is not intended for individuals under 13 years of age. No one under age 13 may provide any personally identifiable information to or on the website. We do not knowingly collect personally identifiable information from individuals under 13 years of age. If you are under 13, do not provide any personally identifiable information on our website or on or through any of its features, register on the website, make any purchases or donations through the website, use any of the interactive or public comment features of this website or provide any information about yourself to us, including your name, address, telephone number, email address, or any screen name or username you may use. As a parent or legal guardian, please do not allow your children to submit personally identifiable information without your permission. If we learn we have collected or received personally identifiable information from an individual under 13 without verification of parental consent, we will delete that information. If you believe we might have any personally identifiable information from or about an individual under 13, please contact us by emailing us using the contact form provided to you within the site structure of our website, by sending a letter to: 2005 Palmer Avenue #1033, Larchmont, NY 10538, Attn: Executive Director, or by calling 914-303-6323.

Third Party Links. Throughout the website, links have been provided to third party sites that may be of special interest to our users, and the website may include third-party integrations or offer a co-branded or third-party-branded service. Through these links, third-party integrations, and co-branded or third-party-branded services, you may be providing information directly to the third party, us, or both. In particular, if you choose to make a donation or make a payment, you may provide payment card information via the website into a third-party payment processing service to which we subscribe. In using such links, you should be aware that each third party site or service operates under its own privacy guidelines, and we do not take responsibility for the privacy policies of these sites or services. You acknowledge and agree that we are not responsible for how those third parties collect, use or disclose your information. We encourage you to review the privacy policies of every third-party service that you visit or use, including those third parties you interact with through our services or the website.

Policy Modifications. We may modify this Privacy Policy from time to time to reflect changes in the law, our information collection, use and disclosure practices, features of the website, or

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technology, or for any other reason. When we make material changes to this policy, we will post the revised policy on the homepage of our website. You can tell when this Privacy Policy was last updated by looking at the date at the bottom of the Privacy Policy. Any changes to our Privacy Policy will become effective upon posting of the revised Privacy Policy on the website. Use of the website following such changes constitutes your acceptance of the revised Privacy Policy then in effect.