Barth Syndrome UK Privacy Policy

Last Reviewed: **January 2026**

We at Barth Syndrome UK (BS UK) take your privacy seriously and we never share any personal data for marketing purposes.

This privacy policy applies to the website of BS UK at www.barthsyndrome.org.uk (the "website").

This policy covers the collection, processing and other use of personal data under the Data Protection Act 2018 ("DPA").

For the purpose of the DPA we are the data controller and any enquiry regarding the collection or processing of your data should be directed to info@barthsyndrome.org.uk.

We work closely with the Barth Syndrome Foundation, Inc (BSF) located in the USA and other Barth Syndrome patient support groups in Canada, France and Italy.

Some of the resources we offer our UK members are hosted by BSF in the USA and we direct you to their website – www.barthsyndrome.org – for further information.

By accessing and using our website, you consent to this policy.

What information do we collect?

We collect several different types of information.

Your browsing

We collect information about the users of our website. This information is non-personal. Whenever you access our website or download information, the web server automatically records the following non-personal information: the date and time you accessed our website, how long you were on the site, your Internet domain name and the internet browser you use. This information helps us to improve our website service.

We make use of cookies. A cookie is a series of characters that is generated by our website and stored on your computer when you visit our site. The cookie does not collect or contain personal information about you but allows us to track how often you return to our site. The cookie does not track your movements on other websites. You do not have to accept our cookie in order to be able to use our website.

Your contact with us

If you contact us by telephone, email, through our website or by letter, we retain a record of your contact to help us respond to your enquiry and improve our service. This typically might include your name and contact details as well as sensitive medical information that you include. We only share this information with designated staff, authorised medical professionals and/or volunteers in order to provide you with the service or information you seek. We limit the people who have access to personal data, all of whom sign a confidentiality agreement. We take precautions to ensure that your information is kept securely.

We use Google Analytics to analyse the audience of the website and improve our content. No personal information is collected from Google Analytics. For further information on the privacy policy concerning Google Analytics, please go to

http://www.google.com/intl/en/analytics/privacyoverview.html

Your donations

We collect information about our sources of income to produce accurate financial statements.

We also collect information supplied by users of our website who donate funds to us online. This information would include your name, address, and donations made. Where a donation is made using a specialist third party company such as PayPal, Just Giving etc. some of this information is shared with them in order to process on-line financial transactions. Your credit/debit card details may be recorded on their sites, and we recommend that you consult with their data protection policies. If you make a payment or a donation by any other method e.g. post, debit order, we retain a paper record of your financial transaction only for as long as is necessary. By voluntarily submitting your personal information to us, you are consenting to the use of your personal information for effecting a payment or donation.

If you submit a signed Gift Aid Declaration to us, we retain it for HM Revenue & Customs purposes.

Your membership details

We collect information about our members.

In order for our members to receive our newsletters – and other similar literature relevant to the services we provide - we hold records of their names, addresses, telephone numbers and email addresses. However, we only collect this information from you if you choose to provide it to us and we only share your name and contact details with other member families with your clear consent. You may ask us to stop sending you information, or to change the format in which we send it (e.g. change from a printed newsletter to an email format) at any time and we will act upon your instruction.

Your medical history and other personal details

We collect some information about our members and their families' medical history and the lifetime effects of this rare genetic disorder.

We only collect this information from you if you choose to provide it to us. As the information you provide is sometimes of a very personal nature, we safeguard your privacy by storing this information in a secure database and regularly review the security measures in place. Currently, only designated senior members of staff/volunteers have access to this database.

The purpose of collecting this information is primarily: -

- to provide a service to you.
- to give you the relevant information to help you to manage and understand Barth syndrome as it affects you.
- to enable BS UK, BSF and affiliates, medical professionals and scientists to learn more about Barth syndrome and how it affects families.
- to send you newsletters and other relevant literature.

- to invite you to relevant events, such as clinics and family days.
- to enable you to have contact with other families who are affected by Barth syndrome through our private email forum for research.

Our staff and volunteers

We hold some personal information about our staff, trustees and volunteers.

Transfer of Data to Third Parties and/or outside the UK

As part of the services offered to you, the information you provide to us may be transferred to, processed and stored by designated staff and volunteers of the BSF in USA or to other licensed affiliates. This may be offline or in 'the Cloud'. If we transfer or store your personal data outside of the UK in this way, we will take steps to ensure that your privacy rights continue to be protected, as outlined in this privacy policy and in accordance with the DPA.

If you use our service while you are outside the UK, your personal data may be transferred outside the UK in order to provide you with these services.

Third party links

You might find links to third party websites on our website. These websites should have their own privacy policies, which you should check. We do not accept any responsibility or liability whatsoever for these other policies as we have no control over them. These third-party providers may change from time-to-time depending on the requirements of the charity at particular times.

Social Media

We are not responsible for the information which is posted on various open and closed social media groups. Please visit the sites (facebook.com, WhatsApp etc) for details of their current privacy policies and ensure that you update your privacy settings in accordance with your wishes.

The WhatsApp Group set up at the beginning of the COVID-19 pandemic is not owned, operated or moderated by Barth Syndrome UK and by group consensus, there is currently no policy in force surrounding its use. Membership is restricted to affected individuals and immediate family members (parents/guardians) and trustees who actively volunteer within the sphere of Family Services. No-one will be added to the group without their consent. The charity is not responsible for any perceived or actual breach of confidentiality arising from any information shared on this forum. However, as part of the Code of Conduct, and in adherence with BS UK's Confidentiality Policy, trustees, employees and/or volunteers will not share information from this platform with individuals or organisations who do not meet the criteria for inclusion in the group, nor take actions based on such information, without the prior permission of the individual(s) concerned. BS UK will use this and other available forums to inform users of upcoming events and important news, in the wider best interests of the group, as long as no personal information is being shared.

Newsletters and leaflets

We sometimes publish information leafletsand newsletters for our members, and these may contain images and personal information of ~~our~~ member families. We never publish any image of or anything about you or your family without your clear informed consent.

How long do we keep your information?

We keep your information for only as long as is necessary. You may ask us to destroy any personal information that we hold about you so that you receive no further information or contact from us. If you are a member you may ask at any time to be provided with a complete copy of the information we hold about you and/or your family, to amend, update, add or delete as required.

We will undertake to ensure that written consents from members are refreshed at least every 5 years.

Should you wish to restrict the use of your personal information, please contact us via email at info@barthsyndrome.org.uk.

Who has access to your information?

Our members of staff/volunteers and trustees have access to your personal information. Only designated senior level staff members/volunteers have access to members' medical database information.

We may use third parties (companies or volunteers) to provide services on our behalf, including packaging, mailing and delivering purchases, answering questions about services, sending postal mail, e-mails and text messages, analysing data and processing credit card payments. We will only provide those third parties with the information they need to deliver the service and they are prohibited from using that information for any other purpose. We require all such third parties to treat your personal information as fully confidential and to fully comply with all applicable UK Data Protection legislation.

More specifically, we use MailChimp for the purpose of sending out news via email. Please see their website for details of their Privacy policy and DPA compliance https://mailchimp.com/legal/privacy/.

We may disclose personal information if we receive a complaint about any content you have posted or transmitted to or from one of our sites, if required to do so by law or if we believe that such action is necessary to protect and defend the rights, property or personal safety of BS UK, our members, any child or vulnerable adult, our staff or any visitor.

When legally required, we may disclose your information to regulatory or other official bodies.

Except as indicated above we will not use or transfer this data to any third parties (apart from BSF and licenced affiliates) without your prior permission.

Can you access the information we hold about you?

Yes, you have the right to access information stored about you by us. You need to contact us via email at info@barthsyndrome.org.uk. We will then provide you with the following information within one month of your requesting the data: -

- What personal data is stored.
- The purposes for which your data is being processed.
- Who has access to your data.

What security measures do we have?

We have implemented technology and policies to protect your privacy from unauthorised access and improper use and will update these measures as new technology becomes available. While we cannot ensure or guarantee that loss, misuse or alteration of data will not occur, we use reasonable endeavours to prevent this.

Where is the information stored?

Information which you submit via our website is held in the UK, although it may be temporarily processed by trusted providers operating in the UK, EU, and (briefly) the USA, with appropriate safeguards in place.

Do we collect information about children and vulnerable adults?

Yes, we collect personal and medical information provided to us by members about children or vulnerable adults in their care. We place great importance on the security and accuracy of this information and only store this information in a secure database. Whenever possible, we get the consent of the guardian or responsible adult before collecting information about children and/or vulnerable adults. Our staff will make all reasonable attempts to ascertain whether a person has the necessary capacity to consent to submit their information to us. Only designated senior members of staff have access to this information.

Changes to this policy

We may update these policies to reflect changes to the website and feedback. Please regularly review these policies to be kept informed of how we are protecting your personal data.

We welcome any queries, comments or requests you may have regarding this Privacy Policy. Please do not hesitate to contact us via email at info@barthsyndrome.org.uk.