Barth Syndrome UK Confidentiality Policy

Last Reviewed: **November 2026**

General principles

Barth Syndrome UK (BS UK) recognises that employees, volunteers and trustees gain information about individuals and organisations during their work or activities. In most cases such information will not be stated as confidential, and colleagues may have to exercise common sense and discretion in identifying whether information is expected to be confidential. This policy aims to give guidance but if in doubt, seek advice from the Chief Executive or Chair.

Colleagues can share information in order to discuss issues and seek advice.

Colleagues should avoid exchanging personal information or comments (gossip) about individuals with whom they have a professional relationship.

It is not appropriate to discuss a person's sexuality (i.e., 'outing' a gay person) without their prior consent.

Colleagues should avoid talking about organisations or individuals in social settings.

Information given to staff members or volunteers acting on behalf of BS UK is considered to be given to BS UK as an agency rather than to the individual staff member or volunteer. To give the best possible service to users of BS UK, it is sometimes desirable to share information with other colleagues within the organisation and affiliate organisations.

Constructive liaison with other agencies is sometimes essential if individuals and groups are to be offered an effective service by BS UK. However, confidential matters must not be discussed without the prior permission of the individual or organisation. Third party disclosees will be informed of the confidential nature of the information shared.

Where there is a legal duty on BS UK to disclose information, the person to whom the confidentiality is owed will be informed that a disclosure has been or will be made, to the extent permitted by the applicable law.

Why information is held

Most information held by BS UK relates to affected individuals, their families, friends, volunteers and donors, or the services which support them.

Information may be kept to enable BS UK to provide the highest level, most appropriate, relevant services to its users.

BS UK has a role in putting people in contact with each other to share information and provide support for mutually beneficial purposes.

Access to and sharing of information

The WhatsApp Group set up in response to COVID-19 is not owned, operated or moderated by BS UK and by group consensus, there is currently no policy in force surrounding its use. Its aim is to share information and support. 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. Personal Information is confidential to BS UK as an organisation, but de-sensitised or anonymised information may be passed to colleagues, support services or trustees to ensure the best quality service for users.

Where information is sensitive, i.e., it involves disputes or legal issues, it will be confidential to the employee dealing with the case and the Chair. Such information should be clearly labelled 'Confidential' and should state the names of the colleagues entitled to access the information and the name of the individual or group who may request access to the information.

Colleagues will not withhold information that is necessary for the proper functioning of the Charity unless it is purely personal.

Users may have sight of BS UK records held in their name or that of their organisation. The request must be made in writing to the Chair giving 28 days' notice and be signed by the individual, or in the case of an organisation's records, by the Chair. Sensitive information will only be made available to the person or organisation named on the file.

When photocopying or working on confidential documents, colleagues must ensure they are not overlooked by people in passing. This also applies to information on computer screens.

Storing information

BS UK keeps information using paper files and computers. Confidential information is maintained with an appropriate level of security, in accordance with the Data Protection Act and this policy, which will adequately protect information about individuals that is held in the systems.

Information about volunteers and other individuals will be kept by the colleague directly responsible. These colleagues must ensure the Board know how to gain access.

Employees' personnel information will be kept in filing cabinets and will be accessible to the Chair or to those who are entitled to see it as part of their duties.

In an emergency situation, the Chair may authorise access to files by other people.

Duty to disclose information

There is a legal duty to disclose some information including:

- Child abuse will be reported to the Children, Schools and Families Department (Local Authority where child resides)
- Drug trafficking, money laundering, acts of terrorism or treason will be disclosed to the police

In addition, a colleague believing an illegal act has taken place, or that a user is at risk of harming themselves or others, must report this to the Chief Executive Officer or Chair who will report it to the appropriate services. *See Safeguarding policy for more details.*

Users should be informed of this disclosure unless it is deemed unsafe to do so.

Disclosures

BS UK complies fully with the DBS Code of Practice regarding the correct handling, use, storage, retention and disposal of Disclosures and Disclosure information.

Disclosure information is always kept separately from an applicant's personnel file in secure storage with access limited to those who are entitled to see it as part of their duties. It is a **criminal offence** to pass this information to anyone who is not entitled to receive it.

Documents will be kept for a year and then destroyed by secure means. Photocopies will not be kept. However, BS UK may keep a record of the date of issue of a Disclosure, the name of the subject, the type of Disclosure requested, the position for which the Disclosure was requested, the unique reference number of the Disclosure and the details of the recruitment decision taken.

Breach of confidentiality

Employees who are dissatisfied with the conduct or actions of other colleagues or of BS UK should raise this with the Chair using the grievance procedure, if necessary, and not discuss their dissatisfaction outside of BS UK.

Colleagues accessing unauthorised files or breaching confidentiality will face disciplinary action. Ex-employees breaching confidentiality may face legal action.

This policy is to be read in conjunction with the following policies:

- *Data Retention Policy*
- *Privacy Policy*
- *Safeguarding Policy*
- *Social Media Policy*