Barth Syndrome UK Safeguarding Policy

Last Reviewed: **August 2026**

Intent

This policy exists to ensure employees, trustees, volunteers or anyone else connected to BS UK understands their obligations with regard to the safeguarding of children, young people, adults at risk, staff, volunteers and anyone else with whom we may work; that any user/beneficiary of the charity understands (i) what they should do if they feel something isn't right (ii) understands the process that will be followed should a safeguarding issue be raised and (iii) how BS UK will protect and respond to anyone who raises a safeguarding issue.

BS UK acknowledges and fully accepts its' duty to act appropriately to any allegations, reports or suspicions of abuse.

The Policy Statement and Procedures have been drawn up in order to enable BS UK to: -

- Promote good practice and work in a way that prevents harm, abuse and coercion occurring and to provide a safe and trusted environment for all.
- Ensure all volunteers are suitable for working with children, young people and adults at risk.
- Ensure any event organised by BS UK is delivered safely, with the needs of children, young people and adults at risk being uppermost when planning.
- Ensure that any allegations or suspicions of abuse are dealt with appropriately, in accordance with the law and in line with best practice.
- Ensure the person experiencing abuse is henceforth protected and supported, and to stop further abuse occurring.

The policy applies to all BS UK trustees, paid staff, volunteers, and anyone else working on behalf of BS UK.

BS UK acknowledges that the welfare of all people, and specifically children, young people and adults at risk, is paramount, and that they have the right to be protected from harm and exploitation.

As an internet-based rare disease charity, trustees, volunteers and staff typically work from their own homes and do not come into regular contact with each other. Trustees, staff and volunteers have little or no unsupervised contact with children and adults at risk. The only exception to this could be during Family Outreach events when children and families might mingle. However, during these events, parents/carers are responsible for the care of their children and are always present.

Trustees, staff and volunteers who are at such events will ensure that they are not alone with other children and/or adults at risk, unless they have successfully passed a Disclosure and Barring Service (DBS) check.

In order to implement the policy, BS UK will work to: -

- Promote the rights of all people to live free from abuse, exploitation and coercion.
- Manage our services in a way which promotes safety and helps to prevent abuse, exploitation and coercion.

- Recruit trustees and volunteers safely, ensuring all necessary background and assurance checks are made.
- Ensure the safety and wellbeing of people who do not have the capacity to decide how they want to respond to the abuse being experienced.
- Promote the freedom and dignity of the person who has or is experiencing abuse.

BS UK will: -

- Ensure that all trustees, volunteers, and anyone working on behalf of BS UK, are familiar with this policy and procedures (where relevant).
- Ensure all trustees, volunteers, and anyone working on behalf of BS UK have undertaken the relevant safeguarding training appropriate to their role and potential interactions.
- Act within its confidentiality policy and will typically gain permission from service users before sharing information about them with another agency or third-party.
- Alert all concerned parties (where possible) of their responsibilities to act and intervene where it appears that a child, young person or adult at risk is at risk.
- Respond in a timely manner to any concerns raised, or allegations received and ensure that appropriate and confidential records are kept.
- Inform the appropriate services where a child, young person or adult at risk is (or appears to be) in danger or at risk, including the passing of such information to another agency without that person's consent.
- Endeavour to keep abreast of developments nationally relating to the prevention of abuse and welfare of children, young people or adults at risk, and to regularly review this policy.
- Ensure that the Designated Named Person understands his/her responsibility to refer incidents of all abuse to the relevant statutory agencies (Police/Social Services, Health Agencies and Charity Commission).

The Designated Named Person with regards to this Safeguarding Policy for BS UK is the Chairperson (Ralph Easterbrook); the deputy Designated Named Person is Susan Williams.

They should be contacted (see www.barthsyndrome.org.uk for contact details) for support and advice on implementing this policy and procedures.

This policy should be read in conjunction with Barth Syndrome Trust's policies on:-

- Anti-Harassment & Bullying.
- Confidentiality.
- Trustee Code of Conduct.
- Volunteer Policy.
- Whistleblowing.

Useful Contacts

Children

NSPCC 0808 800 5000 https://www.nspcc.org.uk/keeping-children-safe/reporting-abuse/report/

ChildLine 0800 1111 (24/7 telephone counselling for children and young people) www.childline.org.uk

Kidscape 02077 303 300 (helpline for parents concerned about bullying) www.kidscape.org.uk

Children's Commissioner's Office 0808 801 1000 https://www.childrenscommissioner.gov.uk/about-us/contact/

Adults

The National Careline 0800 069 9784 (information about care and support for older people, their carers and their families) www.thenationalcareline.org

Age Concern 0800 022 3444 (information, support and advice for older people) www.ageuk.org.uk

Action for Elder Abuse 080 8808 8141 www.elderabuse.org.uk

Older People's Commissioner's Office 08442 640 670