

## **Barth Syndrome UK Social Media Policy**

Last Reviewed: **March 2026**

Barth Syndrome UK (BS UK) seeks to use all relevant, accessible means of communication, including social media.

### **Responsibilities for input**

Social media accounts for BS UK will be set up by a designated person. Upkeep, maintenance and input of profiles and entries will only be carried out by approved persons.

### **Password protection**

Gaining access to social media accounts requires the inputting of a correct email address and user password. The password will be changed if there is any reason to believe that someone other than an approved person knows it.

### **Privacy protection**

BS UK will always consider the privacy of colleagues and others and will never broadcast open details that may reveal personal information such as home address, date of birth, street name, car number plate or other similar information without prior permission.

### **Monitoring content**

Nothing detrimental to BS UK will be posted by staff or volunteers on the BS UK social media sites.

Wall posts and other comments posted by others will be monitored. If posts are deemed unsuitable they will be deleted. Postings from people who frequently post unsuitable comments will be blocked.

### **Personal social media**

On personal social media sites: -

- If you mention BS UK or anything connected to BS UK, you should identify that you are an employee or volunteer of BS UK and that the views expressed are yours alone and do not necessarily represent the views of the organisation.
- Unless given permission by the Chief Executive Officer or a Board Member, you are not authorised to speak on behalf of BS UK, nor to represent that you do so.
- You may not share confidential information about BS UK.
- You should exercise good judgement and post nothing detrimental to BS UK on these sites.

### **Social Media Groups**

The WhatsApp Group set up in response to COVID-19 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. BSUK 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.