

## **How We Look After and Safeguard Information About You**

### **Introduction**

BBS UK is a registered charity primarily supporting individuals with Bardet-Biedl syndrome, their families, and carers.

To provide high-quality support, we may need to record and retain information about you and the support we have provided or plan to provide.

We understand how important your privacy is and are committed to protecting the personal information we hold about you.

### **What Information Do We Collect?**

We may record and retain information such as:

- Basic contact details: name, address, phone number, email address, date of birth, and names of family members;
- Education, health, welfare benefits, and social care information where relevant and provided;
- Referral details, which may include information about symptoms or treatments.

This information helps us provide you with appropriate support and may also include referrals made to other professionals or services. We will not share your information except in the circumstances outlined as follows:

### **Sharing Your Information**

We will only share your personal information:

- With your explicit permission;
- If you request us to do so;
- When required by law;
- When permitted by law in situations where the public interest overrides confidentiality.

With your consent, we may share information with professionals such as GPs, hospital teams, social workers, or occupational health staff.

Anyone receiving your information from us is legally required to keep it confidential, subject to the exceptions above.

### **Your Data Protection Rights**

You have the right to confidentiality under the:

- ✓ UK General Data Protection Regulation (UK GDPR)

- ✓ Data Protection Act 2018
- ✓ Human Rights Act 1998
- ✓ Common law duty of confidence

Other legislation, such as the Equality Act 2010, may also apply.

We follow the NHS Code of Practice on Confidentiality.

All staff are contractually required to protect your personal information and treat it confidentially.

Our guiding principle is that we handle your information with the highest level of care and respect.

### **Your right to view your information**

You have the right to request a copy of the personal information we hold about you, free of charge in most cases.

To make a request:

- Please submit it in writing (via email or post – see our contact details below or on our website);
- Include your full name, address, date of birth, and details of the information you wish to access;
- We may ask you to provide two forms of identification;
- We will respond within one calendar month from the date we receive your request and ID.

If you think any information we hold is inaccurate or incorrect, please let us know.

### **Lawful Basis for Processing**

We process your personal data:

- Based on your consent (which you can withdraw at any time);
- As part of our legitimate interest in supporting individuals with Bardet-Biedl syndrome and their families;
- To comply with our legal obligations.

### **Data Retention**

We will retain your data only for as long as it is necessary to support you and to meet any legal or regulatory requirements. Information is securely deleted when no longer required.

## Privacy Notice

For full details on how we collect, use, store, and protect your personal data, please refer to our Privacy Notice, available on our website or upon request.

## Contact Us

To make a data request, update your information or withdraw your consent, please contact:

Tonia Hymers  
BBS UK Information Governance Lead  
43 Balton Way  
Dovercourt  
Harwich  
Essex  
CO12 4UP

tonia.hymers@bbsuk.org.uk  
www.bbsuk.org.uk  
admin@bbsuk.org.uk

If you are unhappy with how we have handled your personal data, you have the right to contact the Information Commissioner's Office (ICO):

Website: <https://ico.org.uk>

Helpline: 0303 123 1113