



BBS UK Strategy 2025–2030

Foreword from the Chair

Over the past three years, we've achieved extraordinary things as a community. We strengthened our core services, adapted through challenges and changes, and made sure lived experience continues to guide everything we do.

This new strategy is shaped by your voices. It is based on extensive stakeholder engagement and analysis, including a community audit, and sets clear priorities for reaching more people, strengthening mental health support, reducing isolation and amplifying the lived experience of those affected by BBS.

Our goal is simple: by 2030, everyone who needs BBS UK will know who we are and feel part of a connected, empowered community.

This strategy is more than a plan for what we will do. It is a shared commitment to what we can achieve together.

Thank you to our members, families, staff, trustees, clinicians and funders for your continued support, trust and belief in BBS UK. Together, we will continue to build a brighter, more connected future for everyone affected by BBS.

Emma Hughes Chair of Trustees, BBS UK

About BBS UK

BBS UK was founded in the 1980s by parents who wanted connection and support. Today, we are the only UK charity dedicated to people with Bardet-Biedl syndrome, their families and carers. We are a user-led charity governed by trustees with lived experience and contracted by NHS England to deliver specialist support at clinics in London and Birmingham.

Our services include an Advice Service, Clinic Support Service, information resources, an annual family conference, online social groups, and a Scientific Advisory Board linking families with research and rare disease networks.



Our Vision, Mission, Values

Vision

Our unique experience, knowledge and understanding of BBS will ensure that everyone who accesses our services is supported, connected and informed about BBS and empowered to achieve the best possible outcome.

Mission

We are committed to promoting positive health and wellbeing within the BBS community; to improving knowledge and understanding amongst those affected, the medical and educational professionals and the wider public; and to supporting research and raising awareness of BBS.

Values

Committed and Passionate: We are committed and passionate about supporting and empowering those affected by BBS to achieve the best possible outcomes.

Inclusive and Community Minded: We value diversity and ensure our services are inclusive and accessible to everyone in the BBS community.

Experienced and Understanding: The voice of our community is at the heart of our work. We use our deep experience and understanding of BBS and its impact to inform our services.

Positive and Forward Looking: We maintain a positive attitude towards challenges, and stride forwards with optimism and open to opportunity.

Collaborative: We actively seek opportunities to connect, engage and partner with others, nationally and internationally, sharing best practices to enhance our work and strengthen our impact.



Our Priorities for 2025–2030

1. Reach More People and Raise Awareness

Launch a 'Know Your Services' campaign, ensure online content is accessible and easy to navigate, and increase awareness of BBS across specialized clinics.

2. Strengthen and Sustain Core Support Services

Achieve Advice Quality Standard accreditation; develop multi-year Advice Service funding; measure impact effectively; audit Clinic Support Services; and develop our Transition Service for young people.

3. Support Mental Health and Emotional Wellbeing

Develop Rareminds counselling project, offer peer support and self-help tools, and embed emotional support at diagnosis and transition points.

4. Reduce Isolation Through Inclusive Connection

Develop online social groups, maintain an inclusive conference, and ensure digital connections are open to all.

5. Amplify the Voice of Lived Experience

Share personal stories, train speakers, place representatives on external panels, and grow international partnerships.

6. Strengthen Governance and Leadership

Recruit Trustees with key skills, implement a succession plan, and invest in training and wellbeing.

7. Collaborate and Support Research

Partner in new research projects, publish easy-read updates, and connect the community with research opportunities and registries.



Themes That Guide Our Work

Equity, Diversity & Inclusion

Ensure accessible and representative services for all members of our community.

Collaboration & Co-Production

Work with our community at every stage of programme design and delivery.

Environmental & Ethical Practice

Operate sustainably and ethically across all areas of our work.

Financial Sustainability

Diversify income and focus on impact-based reporting to strengthen resilience.

Looking Ahead

By 2030, BBS UK will be a more visible, resilient and impactful charity. We'll reach more families, enhance mental health support, and influence research and policy so the voice of lived experience continues to shape better understanding of BBS.

Get Involved

Join us as a member or volunteer, take part in our events, share your story, or help us fundraise. Together we can make it happen.

Contact us:

admin@bbsuk.org.uk
www.bbsuk.org.uk

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