



Three Year Strategy

2022 - 2025





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Foreword

Bardet-Biedl syndrome (BBS) is a rare, recessively inherited disorder which affects approximately 1 in 100,000 babies born. Symptoms of this condition are numerous. Rod-cone dystrophy, a progressive eye disorder that leads to blindness, is a primary feature of the syndrome and has the biggest impact on those diagnosed. Other features of the syndrome are renal abnormalities; learning difficulties, speech and language difficulties; developmental delay; and obesity, often causing long term health problems including diabetes and metabolic syndrome.

BBS UK was founded as the Laurence-Moon-Bardet-Biedl Society (LMBBS) in the mid-1980s by a group of parents looking to find ways of bringing together, and providing support and information, to those living with the syndrome, their families and carers. During the early 1990s, LMBBS was registered as a charity and the annual conference was established in 1995, supported by funding from

the very first National Lottery. The ethos, services and information resources that were established at the beginning, continue to inform the charity today, such as the quality, attention to detail and understanding of the needs of the BBS community.

As a charity, to date we have been primarily patient support focused, and are only just starting to develop our role with regards to research and collaboration with scientific and medical professionals across the globe. To provide a mechanism and support for this, the BBS UK Scientific Advisory Board was established in 2018.

Our aim is to engage with rare disease research, to share experience and knowledge of our genetic condition with others, and to network with similar organisations.



Today, BBS UK remains the only UK registered charity supporting people with Bardet-Biedl syndrome (BBS), their families and carers.

We are a user-led organisation, managed by a board of trustees including those who have lived experience of the syndrome.

The charity has a contract with NHS England to provide support, facilitation and advocacy services to specialised multi-disciplinary clinics that are held in London and Birmingham. This enables us to directly influence the quality of care for those with BBS and to improve the understanding of this complex condition among the medical professionals involved in their care.

“BBS UK is an excellent organisation with excellent staff and volunteers. They have given us tremendous support since diagnosis. I don't know what we would have done without BBS UK...”

Our community's experiences have enabled us to become experts in our own condition. This has a major impact on future health and wellbeing; it strengthens our knowledge and the support that we can give to each other.

We understand each other and the struggles we face. We are a community that is inclusive, accepting and appreciative. We are resilient and we engage to create positive relationships that both motivate and encourage. We have the foundations and building blocks for learning and success; and we have strong internal and external networks that come together to facilitate social change, perception, knowledge and understanding, both nationally and locally within our communities.

“I am very grateful for the support I have from the liaison officer. I can call her any time and talk to her.”





Our vision:

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

Our 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 Bardet-Biedl syndrome.

Our values:

Committed and Passionate: We are committed to achieving the best possible outcomes for our community and are passionate about improving the lives of those affected by BBS.

Inclusive and Community Minded: We value diversity and strive to ensure opportunities are available and open to all.

Experienced and Understanding: We have deep experience and understanding of Bardet-Biedl syndrome and the impact it has on our community; we understand the needs of our membership.

Positive and Forward Looking: We take a positive attitude towards challenges; we stride forwards with optimism and we are open to opportunity.

Collaborative: The voice of our membership is at the heart of our work; we seek out and listen to their experiences and to the expertise of others and we share best practice.

Our members say:

BBS UK works hard to improve the lives of those with BBS...

...thanks to BBS UK, we understand our condition more fully...

...and we are better informed about research into our condition.

“Without the support of BBS UK, life would be more difficult.”

Our work so far:

We have worked hard over the past five years, strengthening our organisational structure, governance and financial position and developing our core services and activities. We have updated our name and logo, developed a comprehensive range of information resources and have updated our website.

Core services and activities include:

- BBS clinic support team providing support, facilitation and advocacy services to NHS multi-disciplinary clinics
- Advice service supporting members with accessing local support across the areas of health, education, social care and benefits
- Information booklets available in multiple formats, including:
 - Medical Information Booklet
 - Introducing Bardet-Biedl Syndrome
 - Booklet for Schools and Colleges
 - My Life, My Future (Transition Handbook)
 - Who We Are and How We Can Help



Other core services and activities:

- Annual family conference weekend bringing beneficiaries together with interested professionals and experts, to provide access to the latest research and to participate in tailored workshops
- BBS UK website: www.bbsuk.org.uk
- Regular newsletters and an annual conference report
- Social media (including Facebook, Twitter, YouTube) in order to facilitate the development of an online community
- Young People's Group (YPG) and Adult Focus Group (AFG)



Our members say:

BBS UK information resources are excellent...

... BBS UK is ambitious on behalf of people affected by the syndrome...

...we trust BBS UK to do what it says it will do.

"BBS UK is my second family. Thank you so, so much for all your support."

Impact of Bardet-Biedl Syndrome

Results from 2021 BBS UK Membership Audit

88%

describe the overall impact of BBS as moderate to **very severe**

More than

60%

experience **anxiety**, **loss of confidence** and **stress** as a result of having BBS

68%

describe the impact of BBS on education as moderate or severe

70%

BBS impacts moderately or severely on day to day routines

75%

BBS has a moderate to severe impact on mobility and getting around

81%

BBS impacts on relationships with family and friends

Our members say:

58%

have greater awareness of the support available thanks to BBS UK...

48%

feel more confident in managing BBS

96%

general contact and support is 'good' or 'excellent'

Member Engagement with BBS UK:

75% access information and/or support

60% attend events

35% donate or raise funds

"From the moment we contacted the society, 19 years ago, the service and support we have received has been fantastic and a lifesaver."

Looking ahead:

Covid-19 has had a significant impact on the BBS community and we expect this impact to be felt across the coming three-year period. Key areas of focus will include improving communication with, and easing the isolation of, our community; enhancing our information, advice and support provision; and empowering our membership to achieve and to self-advocate. In support of this, we will continue to strengthen our governance and we will endeavour to raise the profile of BBS UK and of the lived experiences of our community. We will continue to support the medical and research community with their understanding and research of BBS and we will prepare our organisation for future partnership working. Finally, BBS UK is committed to embedding inclusivity, environmental sustainability and ethical practice throughout our work.

Our work for 2022-2025

1: Improve communication with our service users: We will develop an accessible and inclusive communications strategy to enable us to reach all members of our community in a way that is appropriate, relevant, timely and fit for purpose.

2: Develop our support services and reduce isolation: We will develop and grow our Advice and Support Service and develop a network of volunteers to provide peer support when needed. We will develop support services for those most isolated and struggling with anxiety and low mood, for carers and for siblings. We will build communities including regional groups and online social groups, and review and redevelop our activities and events to ensure that they are accessible and inclusive to all. We will develop our 'Initial Contact' / 'New Member Pathway' to ensure ease of, and equal access to, all of our services and resources.



“When my son had a diagnosis of BBS it was so reassuring to have an organisation to turn to for further information, support and to meet other families who had been/were going through the same as us.”

3: Empower our membership to achieve: We will develop a transition service for young people and look for ways to engage them in social groups to develop their friendships within the community. We will look for ways to support our community with improving self-advocacy skills and with accessing volunteering opportunities and employment. In addition, we will develop focus groups to enable our community to directly influence the work of the Charity.

4: Strengthen governance and raise profile: We will continue developing our board of trustees, with a focus on improving diversity and filling gaps in the skills/experience needed for the Charity to provide the services and support its membership needs. We will simplify our organisational structure and continue offering excellent training and development opportunities to our valued team members. We will develop a 'Professionals Supporting BBS' group, bringing together a network of professionals who have the skills to assist BBS UK in supporting our community. In addition, we will join external steering groups to extend the reach of our membership voice. We will attend relevant events and create training webinars to educate interested professionals, and the wider public, about the lived experience of BBS.

5: Support research and understanding of BBS: Our aim is to engage with rare disease research and to share experience and knowledge of our genetic condition with others. The BBS UK Scientific Advisory Board will provide a useful mechanism to assist the collaboration with others in the national and international research community, which in turn will allow the Charity to learn more about this complex condition, in the hope that it can improve the quality of life for those living with Bardet-Biedl syndrome.

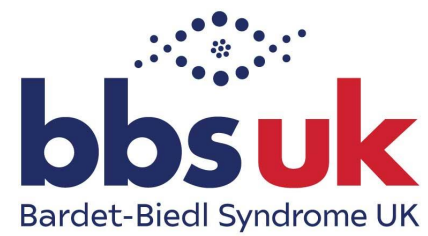
“BBS UK had a positive impact on how we adjusted to my son’s diagnosis.”



Together we can make it happen!

Words that feature prominently in this document are 'support' and 'community'. Team BBS UK is made up of trustees, staff, volunteers, members, supportive professionals, fundraisers, donors, campaigners, supporting charities and organisations and that is how we will make this plan happen: by continuing to work together, and developing new ways of working, in order to improve the lives of all those living with Bardet-Biedl syndrome.





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