



Bardet-Biedl Syndrome UK

# How can we help?

**BBS UK is the only registered charity in the UK dedicated to supporting people affected by Bardet-Biedl syndrome (BBS).**

**We aim to ensure that everyone living with BBS has access to the information, care, and support they need to understand their condition, feel valued, and live the life they choose.**

## Advice Service

The BBS UK Advice Team supports with access to local services across health, education, and social care, including support for sight and sensory needs, learning disability and special educational needs provision, benefits and housing applications, and mental health and wellbeing. We also work alongside professionals, increasing their understanding of BBS so they can better meet the needs of those affected.



## Clinic Support Service

The BBS UK Clinic Support Team supports with access and attendance at NHS multi-disciplinary BBS Clinics in Birmingham and London. Providing information, advocacy, and support before, during, and after appointments, the team helps patients navigate services and engage confidently in their healthcare.



## Annual Family Conference

Our highly regarded annual conference, usually held in the autumn, provides a weekend of learning, sharing, and connecting with researchers, professionals, and those living with BBS and their families. Live-streamed via Zoom for full accessibility, past recordings are available on our website.

## Information Resources

We have a range of information resources available via our website. BBS UK holds the PIF TICK quality mark, which means our publications are accurate, practical, and contain evidence-based information.

## IT Equipment Fund

We provide support to access laptops, tablets, or other devices, where needed for use across education, virtual appointments, and social connections, for children and adults.

## Rareminds Counselling Service

We are working with Rareminds to offer specialist counselling for adults (18+) with BBS, delivered by trained therapists with experience of rare conditions.

## Service User Groups

We offer a range of opportunities to share experiences and influence BBS UK's work:

- Service User Advisory Group (SUAG)
- Zoom Social Groups
- Ireland Regional Group

## Social Media

We are on Facebook, Instagram, X, and LinkedIn. Our private Facebook pages offer a closed forum for our community to connect and support each other.





## How you can support BBS UK

- Fundraising events or challenges
- Donations, one-off or regular
- Sharing your story to raise awareness
- Volunteering
- Participating in research or surveys

## We're here for you

Whether you need practical advice, emotional support, or to connect with others, BBS UK is here every step of the way – we are stronger together.



## Contact us

Bardet-Biedl Syndrome UK (BBS UK)

Registered Charity No. 1181244

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Alternatively, use this QR code to visit our contact us page.

