Registered Charity: 1181244

bbsuk
Bardet-Biedl Syndrome UK

Newsletter

Spring 2026

Book Now: BBS UK Conference

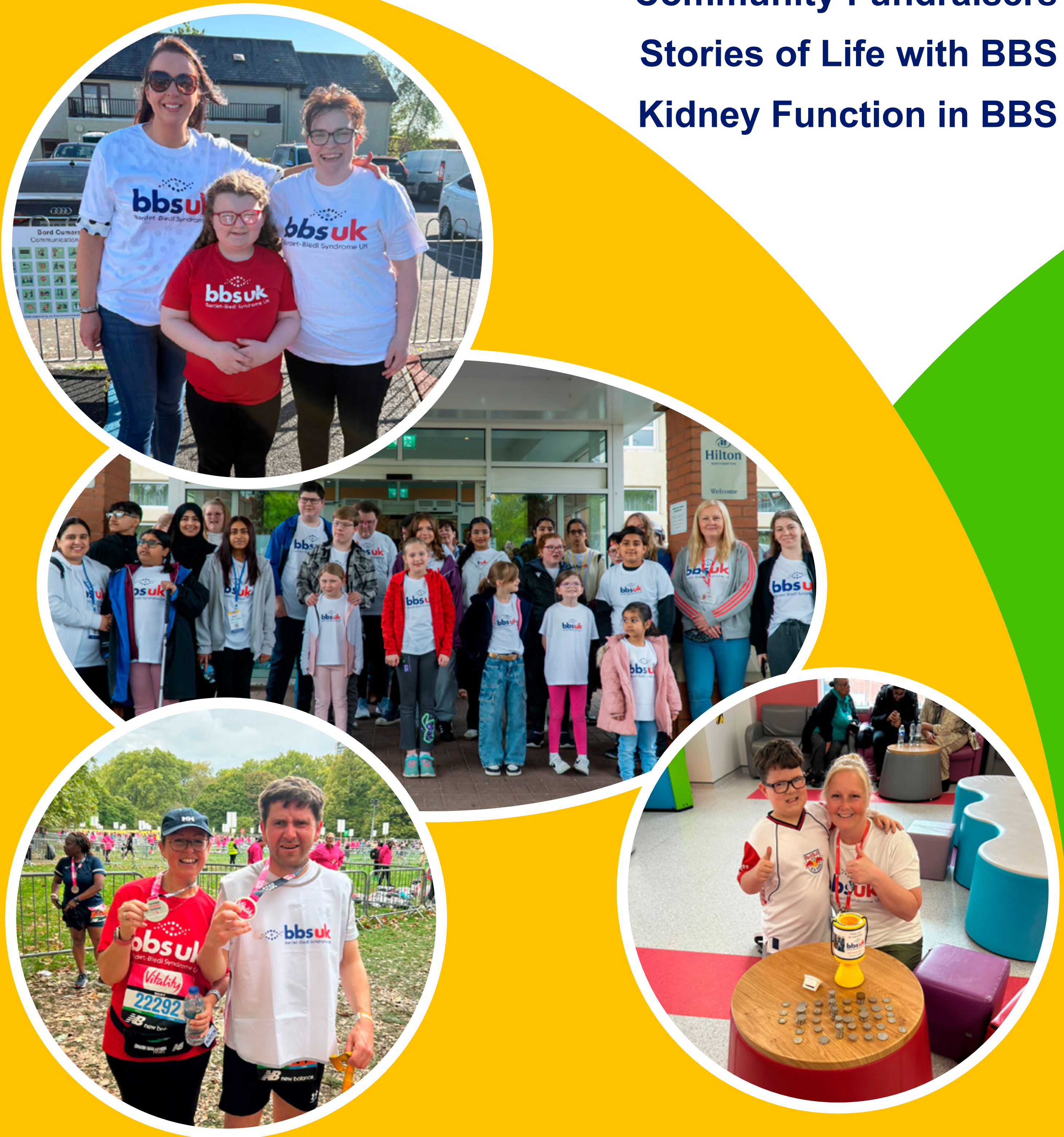
26th September 2026

Registration information inside

Community Fundraisers

Stories of Life with BBS

Kidney Function in BBS



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Foreword

Welcome to a bumper spring newsletter, where we share the Charity's activities, personal stories from people living with BBS, the amazing efforts of our community fundraisers, as well as useful and informative articles to support those living with the Syndrome.

Last April, I attended my first BBS UK conference and was heartened to witness the strength of our community, the willingness to support one another, and the passion shown by professionals in the scientific and vision loss fields as they shared their knowledge and research. I'm sure I'm not alone in looking forward to the next conference in September.

In July, I visited Great Ormond Street Hospital, caught up with Team BBS UK, and spoke to many families attending clinic appointments that day. Thank you to everyone who took the time to share their experiences with me.

In October, I joined staff and volunteers at the Ireland Information Day and was once again struck by the warmth and inclusivity of the community who attended. A special thank you to the Ireland Regional Group volunteers who made the whole day so fantastic from start to finish.

In February this year, the Board of Trustees gathered in London for an in-person meeting. This gave us a much-valued opportunity to share ideas, strengthen relationships, and look ahead to the future of BBS UK. Following the earlier approval of our 2025–2030 strategy, we received a detailed update from the team on progress against our key performance indicators and discussed plans for the second year of delivery. It was encouraging to see that many of our strategic goals are already underway, with strong plans in place for the year ahead.

This is another packed edition of the newsletter. If you would like to share your personal story of living with BBS, your fundraising activity, or have a suggestion for a future article, please email us at admin@bbsuk.org.uk.

Happy reading!

Emma Hughes
Chair, BBS UK

Annual Conference 2026

We are excited to be taking bookings for our Annual Conference, which will once again take place at the Hilton Hotel, Northampton. We look forward to welcoming families, individuals, and professionals from across the UK for another supportive and informative weekend together.

This year's conference theme is **Living Well with BBS.** Our 2026 programme will focus on practical advice and strategies to help individuals and families manage symptoms, improve quality of life and access the right support at every stage of life.

The main conference day will take place on Saturday 26th September 2026, with a full programme of talks, workshops, and opportunities to connect with others in the BBS community. As always, we are working hard to develop a programme that offers something for everyone, including updates on research and clinical care, personal perspectives, and practical information for families and individuals living with BBS.

Date: Saturday 26th September 2026
Location: Hilton Hotel, Northampton

Further information, including how to request a place, can be found on our website or by scanning the QR code.

Booking and costs

Each year, the cost of running the conference increases. However, BBS UK continues to absorb most of these costs to keep attendance as affordable as possible for our community. This year, we have made a small change to the booking process in order to maintain last year's prices, so please read the following information carefully.

Attendance at the main conference day (Saturday) is free of charge for individuals with BBS and their immediate family members. The Children and Young People's trip and the on-site creche are also free of charge.

Attendees are responsible for booking and paying for their own accommodation on a bed and breakfast basis. BBS UK will cover the cost of accommodation for children with BBS and their siblings (up to the age of 18), where applicable.

We have secured favourable rates on a limited number of rooms at the Hilton Hotel, Northampton. Details of how to access these rates will be shared once your conference place has been confirmed.

To help keep costs down, BBS UK is subsidising the evening meals at the Hilton Hotel on Friday and Saturday. Meals can be requested at the time of booking at a cost of £20 per person, per evening. This is a subsidised rate, with BBS UK covering the remaining cost. BBS UK will also cover the cost of children's evening meals.

To request a place, please complete a Booking Request Form as soon as possible. Bookings will be confirmed by email (subject to availability) and will include details of any evening meal costs and how to make payment.

Once your place has been confirmed, you can then arrange your accommodation. As noted above, a block of rooms is available at the Hilton

Hotel, Northampton, on a bed and breakfast (BB) basis. Other hotels are available nearby, although these are not within walking distance of the venue.

For first-time attendees in receipt of means tested benefits, the Chris Humphreys Memorial Fund can provide free accommodation where needed. For more information, please contact admin@bbsuk.org.uk.

Programme

The conference programme is currently in development and will be shared in the coming months. We are pleased to confirm that Professor Phil Beales and Dr Elizabeth Forsythe will be joining us to provide an update on the 'Scientific Progress and the Future of Living Well with BBS'.

They will be part of a wider line up of experienced professionals, alongside what are always the most important contributions of the day: the personal perspectives from members of the BBS community. Together, these sessions will combine professional insight with real life experience.

The morning will consist of keynote talks bringing everyone together for shared learning and discussion.

In the afternoon, there will be a range of workshops designed to provide more interactive and focused sessions, giving attendees the opportunity to explore topics in greater depth and ask questions in a smaller group setting.

The BBS UK Annual General Meeting will be held at the start of the Saturday programme.

Children and young people

For children and young people (accompanied by a parent or responsible adult), we have planned a trip to Whipsnade Zoo. This will offer a fun and engaging day out in a spacious outdoor environment. Whipsnade Zoo has a strong focus on accessibility, and we will work closely with families to support individual needs.

For younger children, an on-site creche will be available at the conference venue. Further details about the children and young people's trip will be shared nearer the time.

Livestream

For those unable to attend in person, we plan to livestream the morning conference programme and make recordings available afterwards. More information will be shared closer to the event.

Donations

BBS UK is committed to keeping the annual conference as accessible as possible. Donations are very welcome and help us continue to subsidise the conference, support families, and fund our wider work. Donations can be made via our website.

Contact information

If you have any questions about the conference, please email admin@bbsuk.org.uk.

We're really looking forward to bringing the BBS UK community together again in September, to connect, learn, and share. We hope you'll be able to join us.

Team BBS UK Updates

Welcome to the team

We are delighted to welcome Beatrice Adeogun, Vicky Harman, and Natasha Murray to Team BBS UK!

Beatrice Adeogun:
Advice Service

Beatrice joined BBS UK in June 2025 as a registered Social Worker, working alongside Advice Service Manager Rebecca Perfect. She supports individuals and families across a wide range of issues, including accessing health, education, and social care services, negotiating care packages, addressing housing concerns, benefits applications, and planning for the future.

She brings both professional expertise and valuable personal insight to her role, with a background in social care and lived experience as a parent of a child with disabilities.

"I'm really enjoying my time so far as an Advice Worker at BBS UK. No two days are the same, and I love supporting children, adults and families affected by Bardet-Biedl syndrome with practical advice, listening support and guidance. It's a privilege to be part of a team that helps people feel supported, understood and less alone."

Shirin Memi:
Advice Service

Shirin has returned to the Advice Service in her role as a registered Social Worker, after previously working as a Patient Liaison Officer in the London service.

Shirin's experience in the clinic setting has given her valuable insight into the challenges families face when navigating health and social care systems.

Vicky Harman:
Patient Liaison Officer,
GOSH

We're very pleased to share that Vicky Harman will be joining BBS UK in April as Patient Liaison Officer for the Great Ormond Street BBS Clinics Service. Vicky brings a wealth of experience in providing emotional and practical support to people living with complex, long-term health conditions. We're very much looking forward to welcoming Vicky to the team and working alongside her to support our London clinic families.

New Trustee:
Natasha Murray

We're delighted to welcome Natasha Murray as a new trustee. Natasha has been co-opted onto the Board and will stand for election at our AGM in September 2026.

Natasha lives in North London with her two daughters, Ella and Amber, and became involved with BBS UK when her daughter Amber was diagnosed with BBS.

With over 30 years' experience in media and marketing, Natasha is "delighted to be part of the team" and looks forward to using her professional skills to help raise awareness, understanding and funding for BBS UK.

Thank you and goodbye

We would like to thank Tazeem Abbas, who retired as Trustee and Treasurer at our latest AGM. Tazeem's financial expertise, attention to detail and commitment played a key role in strengthening the Charity's financial governance. We are very grateful for her time and dedication.

We also say thank you and goodbye to Alis Stevens, who worked with the Advice Team from June to December 2025. We wish Alis all the very best for the future.

Congratulations

Last but by no means least, our warmest congratulations to Natalie, our Operations Officer, who got married last August. Natalie is now Natalie Elsawy, and her new email address is natalie.elsawy@bbsuk.org.uk.

Clinic Support Service

For many patients and families, attending a specialist multidisciplinary BBS clinic brings reassurance and clarity, but it can also feel overwhelming, with multiple appointments and tests scheduled throughout the day.

These clinics bring together experts in ophthalmology, nephrology, endocrinology, genetics, psychology, speech and language therapy, and dietetics, providing coordinated care within one service.

Clinic days are carefully structured so patients can meet each member of the multidisciplinary team, ask any questions they may have, and agree next steps, which may include referrals for local health or social care support.

This is where BBS UK aims to make a difference, working in partnership with the NHS to support patients attending the clinics in London and Birmingham. Our Patient Liaison Officers are available before, during, and after clinic appointments, to help patients and their families prepare, welcome them on the day, and support conversations where needed, ensuring that concerns are addressed and questions answered.

> "This is an excellent support for us - the specialist help and advice is very much welcomed when the vast majority of local medical people don't know much about BBS and therefore can't answer the questions we have or offer the reassurance we need."

We are also available to provide support beyond clinic days, helping patients and families understand clinic letters, liaise with hospital teams, and access local support services.

Hamza Hussain, an adult living with BBS, said:

> "My experience with the BBS team has been exceptionally great, and having support from everyone helps me to feel more confident, safe, valued and listened to."

A parent of a child with BBS said:

> "The most reassuring appointment I've ever experienced. It was detailed and impressive and made me feel safe and supported."

Between April 2025 and March 2026, the service continued to grow, delivering:

- 34 face-to-face clinics
- 34 telemedicine clinics
- Support for 488 patients

We continue to see a steady rise in referrals, meaning more people with BBS are accessing specialist care. While this is positive, increased demand can affect waiting times between appointments. BBS clinic appointments are a precious and limited resource. If you need to cancel or rearrange your appointment, please let us know as soon as possible. This allows us to offer the appointment to another patient and helps reduce waiting times for everyone.

Transition and continuity

Moving from children's to adult services can feel especially daunting. We provide dedicated transition support to help young people and their families feel prepared and confident.

Before each transition clinic, young people can meet the adult clinic team, ask questions, and build confidence ahead of their first appointment. There is also time to socialise and connect with other young people, while parents can meet and share experiences.

Visit from BBS UK's Chair

BBS UK Chair, Emma Hughes said this about her visit:

"I was delighted to visit the GOSH clinic and meet the fantastic BBS UK staff team, Shirin and Angela, the medical team at GOSH and some inspiring young people and their families. It was clearly evident that the support provided through the clinics is crucial and much appreciated by those receiving it. I am extremely proud of our clinic service and the high-quality support that it provides."

Rare Disease Day

We celebrated in Ireland, London and Birmingham to join the rare disease community for Rare Disease Day 2026.

These events brought together charities, advocates and champions to raise awareness of the conditions we represent and the realities faced by our communities.

In London at Guy's and St Thomas' Hospital, our CEO Tonia Hymers and Patient Liaison Officer Angela Scudder spoke with MP Ben Coleman and Chief Executive Amanda Pritchard about the challenges of living with BBS.

In Birmingham, Patient Liaison Officer Amy and Laura spoke with clinicians, patients and interested professionals, raising awareness of BBS and the challenges facing rare disease families.

In Derry, our Ireland Regional Group volunteers Lindsay and Carole attended the Northern Ireland Rare Disease Partnership conference, enjoying a packed programme and making valuable new connections.

A special thank you to Mahir and Aneeba for representing the BBS community so brilliantly, and to Dr Shehla Mohammed and Dr Elizabeth Forsythe for championing our charity and support services.

We are proud to support the BBS community and grateful to stand alongside the wider rare disease community, 300 million people worldwide.

We're here to support you

The NHS BBS clinics provide holistic, gold standard, multidisciplinary health care to patients living with BBS. The role of BBS UK is to support patients and their families to prepare for, and make the most of their appointment, and to ensure they have the local support they need, across health, education, and social care.

If you have any questions about the clinics or would like support before, during, or after your appointment, please get in touch with your Patient Liaison Officer, or email us at admin@bbsuk.org.uk

Advice Service Update

In June 2025, Beatrice joined the Advice Team, strengthening our capacity to respond to a growing caseload and the increasing number of people seeking support, following the allocation of additional funding. Alis was also part of the team during 2025, and we thank her for her contribution to the service. At the end of the year, Shirin moved across from the Clinics team, and we are very pleased to welcome her back to the Advice Service as an Advisor. If you feel you would benefit from our support, please do not hesitate to contact us.

Virtual Meetups

We have been offering virtual meetups to help people with BBS connect more regularly.

We currently run:

- A BBS UK Adults Zoom group
- A BBS UK South Asian group

These sessions are proving popular and are wonderfully facilitated by volunteers with lived experience. If you would benefit from socialising with others who understand life with BBS, we would love you to join us. We hope to expand our virtual meet ups over the coming year.

Top Tips for Completing Benefit Renewals

We are currently seeing an increase in the number of people being asked to renew their Personal Independent Payment (PIP) entitlement. Here are some important things to keep in mind when completing the review paperwork:

- ✓ **Contact us early if you need support**
  We're here to help, but renewal forms often have strict deadlines. Getting in touch as soon as possible gives us more time to support you properly.
- ✓ **Keep copies of all benefit applications**
  Reviews and renewals are becoming more frequent. Having copies of previous applications can be extremely helpful when completing new paperwork.
- ✓ **Be mindful of deadlines**
  Make sure you return forms on time. If you need an extension, contact the relevant agency straight away.
- ✓ **Provide supporting evidence**
  Keep copies of any medical or professional evidence that supports your claim and submit copies (not originals) with your renewal form.
- ✓ **Report any changes**
  Make sure you inform the benefit agency about any changes in your circumstances since your last claim.

Call for Volunteers

Do you have a few hours to spare and experience with the EHCP process?

Have you applied for an Education, Health, and Care Plan (EHCP) in recent years, or worked within the education system? Perhaps you've supported a family member through the EHCP journey and developed a strong understanding of how the process works. If so, we would love to hear from you.

We are looking for individuals who can mentor and support another family in a professional and empathetic way, sharing insight and experience to help ensure a child's EHCP is truly fit for purpose.

If you feel you could offer guidance and support to a parent and child with BBS, please get in touch with Rebecca by emailing Rebecca.perfect@bbsuk.org.uk.

BBS UK is delighted to have received a three-year grant from BBC Children in Need to support our work with children and families. This generous support will help us continue making a meaningful difference, and we are truly grateful for their belief in our work.

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Share Your Story with BBS UK

Every person and family living with BBS has a unique story to tell, and your experience matters. We are inviting members of our community to share their personal stories of living with BBS and using BBS UK's services. Whether it's about attending clinics, receiving support from our Advice Service, coming to conference, joining a social event, fundraising for us, or simply what day-to-day life looks like for you, your voice can make a real difference.

Why share your story?

- ✓ **To raise awareness of BBS**
  Personal stories help others understand what it's like to live with BBS, beyond the medical description, and strengthen our ability to advocate for greater awareness and support.

- ✓ **To support newly diagnosed families**
  For families who have just received a diagnosis, reading about others navigating life with BBS can provide comfort, reassurance, and a powerful reminder that they are not alone.

- ✓ **To strengthen funding applications**
  When applying for grants and funding, we are often asked to include real-life case studies. Your story helps us demonstrate the true impact of our work and secure vital funding to continue and grow our services.

You can choose how much you share, and whether you would like your name and photo included or remain anonymous. We will always discuss and agree wording with you before anything is published.

If you would like to share your story, please email admin@bbsuk.org.uk or speak to a member of the team. We would love to hear from you.

Living with BBS

By Shazia Sadiq

My name is Shazia, and I have BBS which affects many aspects of my health. Reflecting on my 35-year journey, I've faced numerous challenges, but I've also discovered strengths and resilience that have shaped me into who I am today.

Early Struggles and Late Diagnosis

From birth, I displayed symptoms of BBS, such as polydactyly (extra fingers), obesity, and developmental delays. Despite these signs, my condition went undiagnosed until I was 30. As a child, my vision problems were significant but not fully understood. I struggled with tasks that required coordination, such as reading, writing, and even walking without stumbling. These difficulties were often misunderstood as clumsiness or intellectual incompetence, which led to bullying by my peers and misjudgements by teachers.

During my early years, I visited ophthalmology clinics regularly. I recall holding my father's hand as we went to appointments, where I was given eye patches to treat what was thought to be a lazy eye. Despite these visits, my vision problems persisted, and no clear diagnosis was made.

It wasn't until I was 15, when a teacher advocating for me noticed my challenges, that I was referred for more thorough testing. This led to an appointment at a specialist eye hospital, where extensive examinations were performed, including an electrophysiological test. At the age of 20, I was finally diagnosed with cone-rod dystrophy, a condition that affects both the retina's ability to detect light and colour and its capacity to adapt to different levels of brightness. Later, it was confirmed that this visual impairment was due to having BBS.

The Impact on Education

My undiagnosed visual impairment made it incredibly difficult to learn in school. I couldn't see the whiteboard or read textbooks clearly, so I spent most of my time copying notes from classmates instead of engaging in lessons. Teachers misinterpreted my struggles which had a significant emotional impact, making me feel isolated and unsupported.

Things began to improve when a Special Educational Needs (SEN) teacher advocated for me, helping me receive extra support for my GCSE exams. Despite these efforts, the lack of suitable modifications, such as adapting exam papers to my visual needs, meant that I failed some of my exams. With determination, I retook some of those GCSEs, achieved high grades and later graduated with an upper second-class honours degree.

The Power of Support and Perseverance

My successes were only possible because of the encouragement and support I received from my family and dedicated professionals, as well as my determination to overcome barriers.

One of the most challenging moments in my journey was being told I would never be able to drive. For me, driving symbolised independence, and hearing this news was devastating. However, I've since realised that independence takes many forms and that, with the right support and resources, I can still lead a fulfilling and rewarding life.

Cultural and language barriers

Cultural and language barriers also played a significant role in the delay of my diagnosis and access to support. My parents, who were not fluent in English, struggled to navigate the complex systems needed to secure services for me, such as funding for Special Educational Needs transport.

Cultural beliefs also influenced the situation, as the idea that my condition could stem from a genetic disorder wasn't something my family could easily accept. The concept of genetic inheritance, especially in relation to conditions linked to cousin marriages, is a particularly sensitive topic in many Asian cultures, including my own. There is often limited awareness about how genetic conditions are passed down through families. This lack of understanding can delay diagnoses, prevent families from seeking genetic counselling, and hinder efforts to reduce stigma around rare genetic disorders.

Despite my younger brother exhibiting some characteristics of BBS, the connection was not recognised by medical professionals or within our family. Had this correlation been identified earlier, it's possible my brother's diagnosis could have been made sooner, and it might have encouraged my other siblings to pursue genetic testing to better understand their own risks.

Understanding Bardet-Biedl Syndrome

Receiving a formal diagnosis of BBS provided answers to many questions I'd had for years. The diagnosis brought clarity, but it also highlighted the importance of early identification and intervention. Earlier support could have eased many of the difficulties I faced in accessing healthcare, education, and employment.

Raising Awareness and Looking Ahead

Today, I advocate for greater awareness of BBS to ensure that others with the condition can receive timely support and care. The challenges I have faced have impacted on my well-being and quality of life, but they have also fuelled my determination to make a difference.

Navigating healthcare systems can still be frustrating, especially when professionals are unfamiliar with the complexities of rare conditions like BBS. Coordination between services remains a challenge, but I am proactive in seeking solutions and advocating for myself.

A Message of Resilience and Hope

Living with BBS has been a journey of ups and downs, but it has taught me valuable lessons about resilience, determination, and self-advocacy. While the condition has brought challenges, it has also shaped me into the person I am today. From achieving strong academic results to securing meaningful work in education and social care, I have proven that my disability is not a limitation, it's a source of strength.

Through sharing my story, I hope to inspire others to see their own strengths and potential, regardless of the obstacles they face. Raising awareness of conditions like BBS isn't just about improving services, it's about empowering individuals and families to live their lives to the fullest. Together, we can create a more inclusive and supportive world for everyone affected by rare conditions.

Running Through Life with BBS

By Ross Gallagher

I first got into running in 2004, when I attended a sports event for blind and visually impaired people in Dublin, organised by Vision Sports Ireland. That weekend changed everything for me.

The event brought together athletes from Ireland, the UK, Scotland, and Spain, including some top-level competitors. I took part in several track events over the Saturday, and I loved it. From that point on, sport, and especially running, became a big part of my life.

Since then, I have competed in nine May Games and three Metro Games in London, all for vision-impaired athletes, taking part in both track and field events. I have now been running for 22 years. I am 38 years old, and I'm still going strong.

Over the years, I have completed 377 road races and won 371 medals. I have also done 217 Park-runs over the past nine years, which is something I am really proud of. So far, I have run two marathons, including the Dublin City Marathon, as well as 132 five-kilometre races and 139 ten-kilometre races.

Running makes me feel good, physically, and mentally. I have BBS which affects me every day, but being active helps me manage my health. I also have visual impairment and compete in the V1 classification, which is the highest level for visually impaired athletes.

Staying active helps me manage my weight and overall health. I try to eat a healthy diet and keep moving through walking, gym sessions, and running. I know that for many people with BBS, managing food and feeling hungry all the time can be very difficult, and it is something many of us struggle with.

Running isn't the only thing in my life, though. I enjoy going to gigs, travelling, the cinema, and listening to music - and I love food too! Life is about balance.

One thing I would really like to say to anyone living with BBS is: if you've ever thought about trying sport, give it a go. You don't have to be fast. You can walk, jog, or run, it all counts. Parkrun, in particular, is a great thing to try. It's very social, welcoming, and full of kind, friendly people. I've set myself goals along the way, like reaching 250 Park-runs and working towards 400 road races. Achievements like that keep me motivated.

Running has given me confidence, structure, friendships, and a sense of purpose. Living with BBS hasn't stopped me from doing what I love, and I hope my story might encourage someone else to take that first step too.

My Art and Me

17-year-old Radvile Stasiunaite was diagnosed at a young age, and her experience of growing up with BBS has had a significant impact on her communication and education.

For much of her childhood, Radvile was largely non-verbal and found it difficult to process and communicate information in the same way as other children. This continued during her time in mainstream school, where her vision loss and limited support made learning and exams extremely challenging. These experiences had a significant impact on her confidence and mental health.

In 2019, Radvile moved to a special educational needs (SEN) school, and this marked a turning point. With the right environment and tailored support, she began to gain confidence, which had a positive effect on her communication. Over time, her speech improved, and she became more comfortable interacting with others. Being in a setting that understood her needs allowed her abilities to develop in ways that hadn't been possible before.

Art has been a constant presence throughout Radvile's life. As a child, she often doodled while sitting in hospital, using drawing to pass the time and express herself, when words weren't available. During lockdown, she began drawing more regularly, finding it helped her manage stress and express emotions.

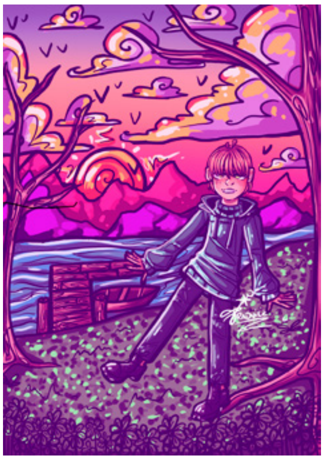
In 2022, Radvile started creating digital art after getting an iPad and using Procreate, a digital art programme. While she enjoys experimenting with different forms, including painting and clay work, digital art became her preferred medium. She enjoys working in a range of styles, particularly anime and watercolour, and is inspired by Starry Night by Vincent van Gogh.

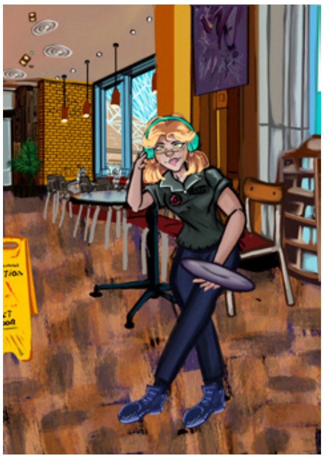
One of the pieces Radvile is most proud of is a competition entry featuring a realistic background and an original character she created herself. She also created a backstory for the character, which continues to inspire her artwork. Art plays an important role in how Radvile communicates and expresses herself. When anxiety makes it hard for her to speak, drawing allows her to share thoughts and emotions in another way. Creating art has also helped build her confidence and connect with others, particularly when people respond positively to her work.

Radvile has put her creativity to brilliant use at school. She has produced drawings and posters for school events such as music festivals, designing tickets and promotional materials, and has built a strong portfolio as part of her photography and ICT course.

When asked what she would say to others living with BBS, Radvile's message is simple: with the right support, you can overcome challenges and find your own way to follow your passions. She encourages others not to give up, even when obstacles feel overwhelming. If she had stopped trying, she says, she would not have the artwork she is proud to share today.

Printed here are some examples of Radvile's digital artwork.





A Mother’s Words

When Catherine Anderton recently rediscovered a poem she wrote soon after her son Patrick was diagnosed with BBS, she reflected on how much had changed for their family.

“I wrote them not long after Patrick was diagnosed and as a family we were struggling. I’d forgotten all about them until I was sorting out some papers. They made me realise what a dark place we were in as a family but also how far we have come, especially Patrick. He is our gentle giant and a very happy young [man].”

Her poem *A Perfect Child* captures emotions that many parents will recognise; the uncertainty of those early days, the deep love that carries families through, and the slow but steady movement toward hope. Writing can be a powerful and cathartic way to make sense of those experiences.

BBS UK have been privileged to support Patrick and his family through our BBS clinic service. Now 28 years old, it is wonderful to see how far Patrick has come. Catherine’s words speak not only to their own journey, but to the shared resilience and connection within our BBS community.

My Perfect Child by Catherine Anderton

They said to just get on with it and see what you would do
The truth was the experts didn’t really have a clue
They said the future would be bleak and difficult to take
They said they didn’t know what progress you would make
They said to take it one day at a time and not to expect too much
Little did the experts know how many
lives you’d touch

The experts gave you little hope of leading a normal life
They said that you would be hard work and bring us lots of strife
They said that many milestones would pass you right on by
The future seemed so very bleak, but we knew we had to try
They gave us lots of leaflets and many books to read
And told us to get on with it and see where your life would lead

No leaflet could prepare us for what the future held
At times the things you do have us overwhelmed
And yes you do reach milestones only at a different rate
And every milestone you pass, opens up another gate
You make life very interesting, no day is quite the same
But I think with time you are winning in this game

A smile never goes unnoticed nor a step unseen
The many things you do were once a distant dream
And every new sound you make is stored deep inside my soul
The experts never told how wonderful was this parent role
Every little bit of progress proves the experts wrong
Your achievements are endless and go on and on and on
And now we look forward to all the years yet to come

We know there will be ups and downs, some sadness, but also lots of fun
So we will just get on with and be amazed by each new thing you do
We will look forward to the future and continue to find the real you
We will help the experts; show them the things that you have done
Because you have just got on with it and we know there is so much more to come.

Fundraising Roundup

We would like to say a heartfelt thank you to everyone who has supported BBS UK through fundraising this year. From endurance challenges and workplace initiatives to community events and family-led fundraisers, the creativity and commitment shown by our supporters has been truly inspiring. Every fundraiser, big or small, plays a vital role in helping us continue our work supporting individuals and families affected by BBS. Here are just a few highlights and upcoming fundraisers that reflect the incredible variety of ways you have supported us this year.

London 10K: Running Together for BBS UK

We were delighted to have four fantastic runners take part in last year's Vitality London 10K, raising awareness for BBS UK, and an incredible £2,100.

Our very own Tonia Hymers tackled the race with a huge smile, while experienced runners Octavia and Luke made the challenge look effortless. A special mention also goes to Bilaal Ali, BBS UK trustee, and service user, who proudly completed his first-ever 10k and came away with a well-earned medal, already asking, "What can I do next?"

Reflecting on the experience, Bilaal shared:

> "Running the London 10K is deeply personal for me. Living with BBS means I face challenges every day, and raising funds for BBS UK feels like turning those challenges into purpose."

London Marathon

Michael O'Sullivan will be taking on the London Marathon in April, running in recognition of his sister, Mary, who lives with BBS. For Michael and his family, BBS UK has provided guidance and support over many years. As Michael explains:

> "BBS UK has been a constant support to our family through the years. Raising funds for this charity is my way of giving back to the organisation that has done so much for us and countless others."

Michael has set himself a fundraising target of £10,000 and has already raised just over £7000!

Brighton Marathon

James Anstee is taking on the Brighton Marathon, also in April, running in support of his younger sister, Emmy, who was diagnosed with BBS in 2008. James also volunteers with BBS UK in a digital marketing role.

This will be James's first marathon, and he has set himself a fundraising target of £5,000. Thanks to the incredible generosity of his supporters, he is already close to reaching this goal, including an amazing £4,000 donation from British Friendly Society Ltd, a client James has worked with, who chose to support BBS UK through their staff away day fundraiser.

Royal Parks Half Marathon

Keely Weatherall and Emma Twomey will be running the Royal Parks Half Marathon in October to raise funds and awareness for BBS UK. Keely shared that her family is currently awaiting genetic testing for her son, following the identification of several markers associated with BBS. During this time, she has immersed herself in learning about the condition and connecting with the BBS community. Regardless of the outcome, Keely and her family are determined to support the rare genetic condition that has opened their eyes, with even her son, Theo, organising his own fundraiser to support BBS UK.

A Workplace Lunch Fundraiser

After attending our annual conference, Funda Guzel organised a homemade lunch at work to raise funds. Funda's brother lives with BBS, so the cause is especially close to her heart.

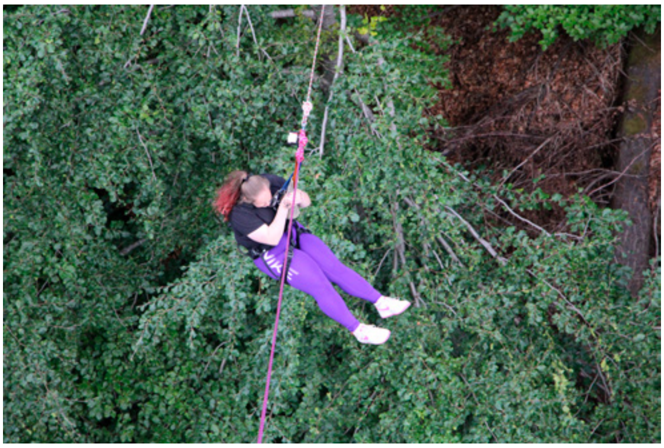
Alongside delicious food, Funda shared BBS UK publications with her colleagues to help raise awareness of the syndrome. Thanks to generous donations from her colleagues and a kind contribution from her employer, Hiremech Ltd, the event raised an incredible £1,500.

A Birthday to Remember

Our very own Amy Clapp and her family took on a high-adrenaline challenge to celebrate her daughter Sienna's 12th birthday, travelling to Scotland for the adventure. Sienna, her sister Abi, who lives with BBS, and friend Beth braved the dramatic Highland Swing, while Amy and her son Josh courageously faced a 40-metre bungee jump over the River Garry.

The day was filled with courage, laughter, and unforgettable memories. Although Amy admitted afterwards that she would not be rushing to do it again, the photos and videos show just how exhilarating the experience truly was.

We are incredibly proud of the Clapp family for their fearless spirit and for raising an amazing £658 in support of BBS UK.



Fundraise with us

Feeling inspired? There are lots of ways to get involved and you do not need to be a marathon runner to make a difference. You might choose to take on a personal challenge, organise a social or workplace fundraiser, or turn something you already enjoy into a way of raising funds. Big or small, every fundraiser helps.

To make things even easier, we have teamed up with Run for Charity, giving access to a wide range of challenge events across the UK. From 5Ks and marathons to Tough Mudders, bungee jumps, and inflatable fun runs, you can choose an event and location that suits you and start fundraising straight away.

We are here to support you with ideas, resources, and encouragement along the way. If you cannot see the event you are looking for on our website or would like to talk through an idea, please email fundraising@bbsuk.org.uk.

Find out more and get started:
www.bbsuk.org.uk/support-us

Legacy Donations

During times of loss and sadness, we are sometimes contacted by family members and friends who choose to remember a loved one by supporting BBS UK, either through a gift in their will or by holding a collection at a funeral or wake.

We are deeply grateful to be thought of in this way and would like to sincerely thank all the families and friends who have chosen to honour their loved ones through supporting our work. Your generosity is both moving and invaluable.

A Heartfelt Thank you!

From barn parties and birthday celebrations to workplace events and physical milestones, our supporters continue to find creative ways to get involved. Thank you, from the bottom of our hearts to everyone who has fundraised, donated, volunteered, or cheered someone on. Your generosity makes a real and lasting difference.

Friends of BBS UK

Friends of BBS UK are our wonderful regular donors. By giving a monthly donation, our Friends help BBS UK plan ahead and continue providing trusted support, advocacy, and information for people living with BBS and their families.

Every regular gift, no matter the size, helps create stability and allows us to grow and improve our services over time. It's a simple way to stand alongside the BBS community and make a lasting difference.

Would you like to become a Friend of BBS UK?

- Scan the QR code or visit our website
- Complete the 'Become a Friend of BBS UK' form
- Set up a monthly standing order with your bank (using your name as a reference)

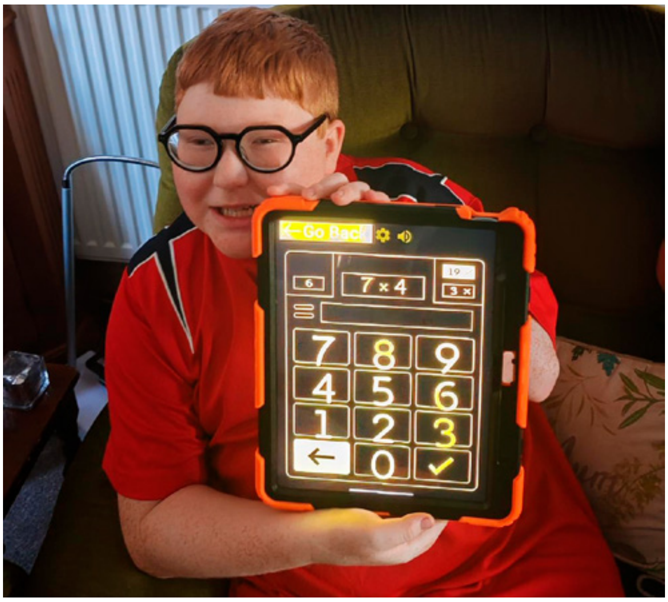
A heartfelt thank you to all our Friends for your kindness, generosity, and ongoing support.

IT Equipment Funding Scheme

BBS UK recognises that in today's fast-paced digital world, access to up-to-date IT equipment is more important than ever.

BBS UK offers an IT Equipment Fund, designed to support our members in upgrading or acquiring essential digital technology to enhance their daily lives.

Through this scheme, we aim to help individuals access education, healthcare, training, and support services that are increasingly delivered online, as well as maintain social connections and manage day-to-day living more independently.



Who Can Apply?

- Anyone with BBS, from primary school age upwards.
- Applications may be submitted by parents, carers, or healthcare professionals.
- Applications are limited to once every 5 years.

How to Apply

- Contact Advice Service Manager, Rebecca Perfect at rebecca.perfect@bbsuk.org.uk
- You will be contacted by the Advice Team within two weeks, to discuss your application.
- Please note that funds are limited and devices will be provided on a first-come first-served basis.

BBS UK is delighted to have received a grant from The Powell Family Foundation to support our Advice Service and IT Equipment Fund for young people up to the age of 25. This generous funding will help ensure that young people have access to vital support and resources, and we are truly grateful for their support.

THE POWELL FAMILY
FOUNDATION

Ireland Regional Group

The BBS UK Ireland Regional Group continues to grow, creating opportunities for families and individuals affected by BBS to connect, learn, and shape the future of services in Ireland.

Ireland Information Day

A major highlight of the year was the Ireland Information Day, held in Dublin on Saturday 11th October, which brought together families, professionals, volunteers, and the BBS UK team for a day of learning, community, and shared purpose. The Information Day welcomed 65 attendees, and for many this was their first opportunity to meet others affected by BBS in person, helping to reduce isolation and build meaningful connections within the community.

The programme included a diverse range of speakers, covering research, healthcare developments, lived experience, and practical support. A key focus of the day was to further our ambition for multi-disciplinary BBS clinics to be set up in Ireland, and it was gratifying to hear of progress made towards this goal from Jackie Turner, Genetic Counsellor, who we are working with to drive this project forward.

During the afternoon round-table sessions, attendees had the opportunity to ask questions, share experiences, and explore topics most relevant to their own circumstances.

Whilst the conference was in progress, the children and young people enjoyed a fabulous day out at Dublin Zoo. Organiser, Erica McVeigh told us:

> The excitement was building on the bus drive to the zoo, the weather was kind to us too, with no rain clouds in sight. The first part of the trip was a guided tour, the guide was fantastic with the children, she checked what animals they wanted to see and planned the route to get as much in as possible in our time with her. Everything was done at the children’s pace, we saw chimpanzees, lions, giraffes, and hippos just to name a few; we even managed to see a couple of dinosaurs! Everyone was able to ask questions and the guide shared interesting facts about the animals and their native habitats. It was a great day with a fabulous group of BBS children, their siblings, and adults full of excitement, laughter, and plenty of steps!

Feedback collected after the event highlighted how valuable the day was for those who attended.

- **100%** rated the event as Excellent or Very good
- Confidence in managing BBS and accessing support increased
- Attendees particularly valued meeting other families, hearing directly from expert speakers, and reported feeling less alone.

Many comments reflected the importance of connection and reassurance:

> “Irish families struggle so much… the support from BBS UK and the knowledge shared with us means so much.”

> "As a grandparent attending my first BBS conference, I was overwhelmed by the care each BBS family had for one another. The information was clear and effective, and the professionalism of the medical teams was outstanding."

Thank you to everyone who completed the form. This feedback will directly inform the planning of future Ireland Regional Group events.

Community Fundraising in Ireland

It has been another fantastic year of fundraising in Ireland. From the Belfast Marathon to the Royal Canal Extreme, and from tea parties to a Clubbercise event, our Irish fundraisers have really gone all out to show their support for the charity.

Fundraising doesn't always involve running shoes! In September, over 30 clubbers gathered at Ballyclare Golf Club for a vibrant Clubbercise fundraiser, organised by Lindsay McKnight, Co-ordinator for the BBS UK Ireland Regional Group.

The hall was transformed into a 90s disco, complete with neon lights, glow sticks, fancy dress, and silent disco headphones, and the group danced, laughed, and raised an amazing £1,243.

Huge thanks to event host, Christine, Ballyclare Golf Club, everyone who donated prizes and supported the event.

We are incredibly grateful to the pupils and staff of Scoil Náisiúnta an Choimín in Donegal, who chose BBS UK as one of the beneficiaries of their Christmas 'Mummers' fundraiser. The school raised an amazing €710, with the donation accepted by Pauric Moy and his dad, Ciaran, on behalf of the Charity. Thank you to everyone involved for their generosity and support.

Getting Involved with the Ireland Regional Group

The success of the Ireland Information Day reinforced the importance of regional events in building connection, sharing knowledge, and driving change. The Ireland Regional Group welcomes involvement in many forms, from attending events and joining online meetings, to sharing experiences, fundraising, or volunteering.

If you would like to get involved or find out more, please contact Lindsay.McKnight@bbsuk.org.uk

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Newsletter Volunteers Needed

Do you have strong proofreading skills or professional experience reviewing written content?

We are looking for volunteers with a keen eye for detail and experience in editing, communications, publishing, or a related field, to help proofread and sense-check newsletter articles and reports before publication. Your input will help ensure our content is clear, accurate, consistent, and accessible for our community.

If you have relevant experience and would like to support BBS UK in this way, please contact admin@bbsuk.org.uk.

Service User Advisory Group

The BBS UK Service User Advisory Group (SUAG) brings together people with lived experience of BBS, including adults with BBS and parents/carers, to help shape and inform the Charity's work. The group meets regularly online and ensures that service user voices are central to BBS UK's decision-making.

What we've been working on

Over the past year, SUAG's work has included:

- Reflecting on the experience of attending the BBS UK Annual Conference in April 2025 and making suggestions for topics and speakers for the upcoming conference in September.
- Helping to ensure that the Annual Conference Report is clear, accessible, and useful for the wider community.
- Ongoing review of BBS UK services and resources, including how information is shared with families and individuals.
- Contributing to discussions that inform future planning and priorities for the charity.

SUAG offers a space to connect, share lived experience and influence the direction of BBS UK. Members say it feels meaningful to know their voices help shape the Charity's work across the UK and Ireland.

Thank you to our members Adrienne, Ashley, Daniel, Dianne Hand (BBS UK Trustee), Ehtessam, Emma, Graeme, Ikra, and Sue, and to our Chair and BBS UK Trustee Rachael Zimbler.

Would you like to join?

To ensure SUAG continues to represent a broad range of voices, we are currently particularly keen to hear from parents and guardians of children living with BBS.

If you are interested in joining us, please email Natalie at admin@bbsuk.org.uk to find out more.

Seeing Us:

a BBS Documentary

We are proud to support those who use creativity to shine a light on BBS. That's why we were thrilled when Milly Springle, a university student whose brother has BBS, chose to focus her documentary project on the Syndrome. While this documentary was independently produced by Milly as part of her university work, we were glad to help her connect with members of the BBS community.

We are incredibly grateful to Milly for choosing BBS as her subject, and for the care and sensitivity she brought to the project. Our sincere thanks also go to the three individuals who took part. Your honesty and openness make this film powerful, real, and deeply meaningful.

Please note: some parts of the documentary may be emotionally challenging. If you feel you need support after watching, we are here for you. Don't hesitate to reach out.

You can scan the QR code here to watch on YouTube.

Annual General Meeting 2025

We held our Annual General Meeting online on Saturday 8th November 2025, and we would like to thank all the members, trustees, staff, and volunteers who joined us. Members approved the Annual Report and Accounts and heard updates on the Charity's progress over the past year.

We said goodbye to Tazeem Abbas, who stepped down as Treasurer and Trustee after two years of dedicated service. We are very grateful to Tazeem for her excellent financial stewardship and are pleased that she will remain involved in an advisory capacity during the transition. Trustees Gareth Owens and Dianne Hand were re-elected, and the existing Honorary Officers were confirmed.

The full AGM minutes are available to read on our website by scanning the QR code.

Are you a Member of BBS UK?

BBS UK's members are at the heart of our work. Become a member and you will join a growing group of people who play a part in everything we do. Having dedicated members enables us to meet our aims and objectives more fully. Engaged and involved members ensures transparency, credibility, and expands our impact through increased volunteering and community engagement. The collective strength of our membership not only benefits individual members, but the BBS community as a whole.

Members also have:

- The opportunity to participate in decision-making and shape the direction of the Charity
- The chance to vote to elect BBS UK trustees and to become a trustee
- Access to BBS UK projects including the IT Equipment Fund and Chris Humphreys Memorial Fund

In addition to becoming a member, you can support BBS UK's work in all sorts of ways. There is no pressure to do anything, but if you are keen to take action, we will support you every step of the way.

Options include:

- Taking part in surveys, focus groups and government consultations
- Sharing personal experiences
- Fundraising to support BBS UK's work

Membership is entirely **free** to ensure that everyone who needs our support can access it. To become a member, visit our website or scan the QR code:

How will I know if I am already a member?

To become a member, you will have either completed an application form or consented to becoming a member when asked by one of our team. If you have been sent AGM voting information in the past, you are already a member. If you are not sure, contact us at admin@bbsuk.org.uk and we will check for you.

Kidney Function in BBS

The following information has been taken from the BBS UK Medical Information Booklet and has been approved by Dr Asheeta Gupta, Consultant Paediatric Nephrologist at GOSH.

BBS can affect the kidneys in a number of ways. However, kidney problems that progress to kidney failure requiring dialysis or transplantation occur in only a small minority of patients. Regular monitoring is important so that any issues can be identified and managed at an early stage.

More than half of people with BBS have kidneys that are slightly abnormal in shape or size. Some may have cysts (fluid-filled sacs) within the kidneys. These changes are usually detected on ultrasound scans and rarely cause problems with kidney function.

Your kidney specialist will use scan results to determine how frequently monitoring is needed and what form this should take.

Early signs of kidney problems include protein in the urine and high blood pressure. For these reasons, blood and urine tests, as well as ultrasound scanning of the kidneys should be a routine part of monitoring in BBS.

Chronic Kidney Disease (CKD) is divided into five stages. CKD stage 1 is the mildest, with kidneys showing abnormal shape/structure, but normal function. CKD stage 5 is the final stage and may require dialysis or kidney transplant.

Only a minority of patients with BBS develop significant kidney impairment. A review of 219 BBS patients attending specialised BBS clinics in the UK found that only 12 (6%) developed kidney failure requiring dialysis or transplantation. The encouraging news from this review is that patients who do not have any evidence of kidney abnormalities in early childhood are very unlikely to develop severe kidney problems later in life.

As people age, however, other health factors may contribute to declining kidney function, including:

- Obesity
- Diabetes
- High blood pressure
- Hardening of the arteries

The good news is that individuals who do develop kidney failure generally respond well to dialysis and kidney transplantation.

Some individuals with BBS may have difficulty concentrating urine, leading to:

- Passing larger volumes of urine
- Increased thirst

Urinary tract infections (UTIs) and bladder infections (cystitis) can also occur but are treated in the usual way. Staying well hydrated, avoiding constipation, and emptying the bladder regularly can help reduce infection risk.

Clinicians have also observed that some individuals may hold onto urine and pass large amounts only a few times a day, while others may wake frequently during the night to urinate. Holding urine for long periods can stretch the bladder and potentially cause problems later in life.

Patients can avoid this by ensuring they empty their bladder frequently, for example, when they wake, after mealtimes, and before bed, whether they feel the urge to go or not.

High blood pressure can occur in any type of kidney disease and should be monitored and treated where necessary. It places additional strain on the kidneys, making management especially important in BBS.

Obesity can also increase strain on the kidneys and worsen high blood pressure. Maintaining a healthy weight is therefore important not only for overall health in BBS but also for protecting kidney function. If you are concerned about your kidney function or have any questions about kidney health, please contact your renal specialist. Further information can be found in the BBS UK Medical Information Booklet or via the organisations listed below:

Signpost

National Kidney Federation
www.kidney.org.uk
0800 169 09 36

Kidney Care UK
www.kidneycareuk.org
0808 801 00 00

PKD Charity
www.pkdcharity.org.uk
0300 111 1234

Dietary Support for Families

At our Annual Conference in April 2025, Specialist Dietitian Sarah Flack delivered a thoughtful and practical session on one of the most challenging aspects of living with BBS: managing hunger, food, and weight. Sarah has worked within the specialist BBS clinics since they began and understands both the medical complexity of the condition and the daily pressures families face. Her session explored not only the biology behind hunger in BBS, but also realistic strategies that can help in everyday life.

Children and adults with BBS usually have lower energy needs yet often experience stronger and more persistent hunger signals. This mismatch makes weight management especially difficult. Hyperphagia, or excessive hunger, may present as frequent requests for food, including during the night, seeking out additional or hidden food, or becoming distressed around food; it is important to note that these behaviours are biologically driven. There is no single diet that works for everyone with BBS, and support must always be tailored to the individual.

Around 70 percent of children with BBS experience obesity from a young age, and between 72 and 86 percent of adults are affected. While these figures are significant, there is encouraging news. Data from Great Ormond Street Hospital shows that around 60 percent of children reduced their BMI between clinic appointments, and a further 9 to 10 percent maintained a healthy BMI. With consistent specialist input and steady, manageable changes, progress is possible.

Families are navigating these challenges within a modern food environment where food is widely available in shops, schools, workplaces and through delivery services, and where celebrations and social events often centre around eating. For those living with BBS, managing food can feel like a full-time responsibility, requiring planning, supervision, and emotional resilience. Research led by Dr Elizabeth Forsythe has shown the wider impact hyperphagia can have on family life, including disrupted sleep, increased household stress, avoidance of social situations and feeling judged by others who may not understand the biological drivers behind eating behaviours. In response to feedback from families, hyperphagia questionnaires have been developed for parents and carers, and for young people aged 11 and over where appropriate. These are now used in specialist clinics to help teams better understand hunger behaviours and tailor support accordingly.

Sarah shared practical strategies that many families already use. When children start nursery or school, it can be helpful to inform staff early about BBS and hyperphagia, explain that food-seeking behaviour is biologically driven, and prepare children in advance for food-related events such as parties or celebrations. Clear communication can reduce misunderstanding and protect children from unfair judgement.

Portion guidance can support balance without strict restriction. Using smaller plates can help meals remain visually satisfying, offering water instead of fruit juice can reduce excess sugar intake, and the hand can be used as a simple guide for portions: a palm-sized portion of protein, a fist-sized portion of carbohydrates and a cupped hand of vegetables. The goal is steady balance rather than rigid control.

Sleep also plays an important role, as poor sleep can increase cravings for high-energy foods in both children and adults. Supporting consistent sleep routines may therefore help with appetite regulation. Physical activity does not need to involve formal exercise; building around 20 minutes of movement into daily routines, whether through walking, active play or dancing, can bring meaningful benefits. NHS resources such as the 10 Minute Shake Up games and your local authority’s Local Offer pages may help families identify accessible activities.

Sarah encouraged families to make the most of clinic appointments by completing food or behaviour diaries where possible, bringing questions and openly sharing what is and is not working. At Great Ormond Street Hospital, families can use MyGOSH to stay in contact between visits or request local dietetic support.

Managing hunger and weight in BBS is complex and ongoing. The key message from Sarah's session was clear: these challenges are rooted in biology, not willpower, and specialist, compassionate support makes a difference. If you would like to discuss dietary support, please contact your Patient Liaison Officer.

Scan the QR code for the NHS 10 Minute Shake Up games.

BBS UK Out and About

Team BBS UK has been out and about educating people about Bardet-Biedl syndrome, making important professional connections, and learning about technology and support services that might benefit our community.

Parliamentary Round Table on Genetic Obesity

Team BBS UK had the privilege of joining a Parliamentary Round Table on genetic obesity, with the aim of starting a conversation that will ultimately lead to earlier diagnosis and equity of care and access to treatments.

Guests included patients, parents, clinicians, and patient organisations. Discussions were led by the expert panel: Professor Paul Dimitri, Dr Tony Goldstone, Dr Elizabeth Forsythe, and our very own Angela Scudder, with Professor Sadaf Farooqi chairing the discussion. It was humbling to see so much passion and patient advocacy from everyone present.

A heartfelt thank you to Antonia Bance MP, for hosting and summing up so beautifully, how critical it is that rare disease obesity patients and their families receive timely, holistic, patient-centred care and support.

Retina UK Professionals Conference

The Advice Team attended the Retina UK Professionals conference in September, meeting and educating medical and sight loss professionals about Bardet-Biedl syndrome and helping them to better understand the condition and support those affected.

BBS Global Day 2025

Back in October, BBS UK joined many international BBS organisations and supporters to celebrate BBS Global Day. The aim of the yearly event is to raise awareness, raise funds and support research into BBS.

In the lead up to the day, a video was created featuring people from around the world sharing their stories and saying how proud they are to be part of the BBS Global community. Watching it again brought up many good emotions for us. It was moving to see and hear from so many community members in different languages, and you might even spot a few familiar faces. The video shows just how far our community reaches and how connected we can still be, even from a distance. We loved it, and we hope you do too.

Scan the QR code to access the video on Facebook:

Sight Villages

Team BBS UK supported groups of service users to attend both the Birmingham and London Sight Villages last year. Sight Village is a brilliant opportunity for people with visual impairment to try out accessible technology and services first-hand. From audio and Braille equipment to magnifiers, computers, daily living aids, and support services, it is all about helping people find what works for them. For many of our service users living with BBS, events like this are a chance to explore new ways to live more independently and confidently.

Microsoft Accessibility workshop

As a Microsoft employee and father to a daughter with BBS, David Prince is passionate about accessible technology and empowering people with disabilities to make technology work for them.

In October, David hosted a free online workshop for adults living with BBS, sharing practical tips on how to get the most out of built-in accessibility features. These included text-to-speech, screen magnification, Microsoft's AI helper, Copilot, and other tools designed to support independence and confidence when using technology.

Attendees told us the workshop:

- Was easy to understand
- Taught them something new
- Helped them learn how to access further support from Microsoft

One particularly important takeaway from the session was that Microsoft offers free, dedicated support for people with disabilities through its Disability Answer Desk. This service provides help with Microsoft Office, Windows, and Xbox, and can also support users with third-party apps and technology.

The Disability Answer Desk can be contacted via:

- The Be My Eyes app
- Online chat
- Telephone support

Scan the QR code below to visit the Disability Answer Desk website:

A huge thank you to David for giving his time and expertise to share such valuable and practical information with the BBS community!

Stay Up to Date with BBS UK

Did you know you can stay connected with BBS UK throughout the week, not just at our annual conference or in our newsletters?

We share weekly posts packed with:

- Practical resources for living with BBS
- Links to surveys and research that help shape services
- News about upcoming events and workshops
- Community updates from across the UK and Ireland

Whether you are on social media or not, we have made it easy to stay up to date with resources, events, and ways to connect with others living with BBS.

Follow Us on Social Media

We are on Facebook, Instagram, LinkedIn, and X.

Private Facebook Groups: a safe space to connect

Want to talk with others who understand life with BBS? Join one of our private Facebook groups, open to people living with BBS and their families.

- BBS UK Group: for those living with BBS and their families. Must be over 18; those who are 16 and over may join with parental approval.
- BBS UK Adult Social Group: for those living with BBS, aged 18 and over, to enable them to make friends, share experiences and arrange social events.
- Ireland Regional Group: for the BBS UK community living in Ireland (Northern and Southern) and who have Bardet-Biedl syndrome (BBS) or have a close family member with BBS.

These groups are private and supportive spaces where you can ask questions, share experiences, and offer encouragement. Please note that these groups are for UK and Ireland residents only.

Scan the QR code for links to our social media pages and private Facebook groups. We are most active on Facebook.

Email admin@bbsuk.org.uk if you would like to join.

No Social Media? No Problem.

- You can still catch everything we post on Facebook, without having a social media account. Just visit our website's News and Events page to read the latest updates and find helpful resources.

Subscribe to Our Mailing List

- Want to receive updates straight to your inbox? Fill in our simple online form to subscribe. Scan the QR code to get started.

Conference Report 2025

- Our 2025 Conference Report was shared digitally and is fully accessible via the BBS UK website. We know that digital formats don't work for everyone, so if you would like to request a paper copy, please email admin@bbsuk.org.uk.

Scan the QR code to access now.

New and Updated Publications

We are very pleased to publish our new booklet, How Can We Help?

This short guide outlines the range of support BBS UK offers to individuals and families affected by BBS, including our support services, information resources, events, and community support. It has been created to raise awareness of our services and ensure that everyone in our community knows how and where to access support when they need it.

Our Medical Information Booklet has undergone an extensive review to ensure it reflects the most accurate and up-to-date information available. Our heartfelt thanks go to the BBS Clinics Teams for their continued support and expertise. The booklet is informed by published research and clinical evidence and has been produced in line with the PIF TICK quality framework.

Alongside these new and updated resources, we have a wide range of publications available, including:

- Introducing Bardet-Biedl Syndrome
- Booklet for Schools and Colleges
- My Life, My Future! Transition Handbook for Young People
- How We Look After and Safeguard Information About You

All publications are available in multiple formats on our website. Scan the QR code to access our publications.

Update Your Contact Preferences

It is important to us that you receive information in the way that suits you best.

Our newsletter is currently available as:

- A printed copy sent by post
- A digital version (Word or PDF) sent by email and available on our website
- An audio transcription video available on our website and YouTube channel

If you would like to update your preferences or change how you receive the newsletter, please contact us at admin@bbsuk.org.uk or complete the Mailing List sign-up form on our website by scanning the QR code.

Contact Details

General Contact/Enquiry

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Operations Officer
07784 922654
natalie.elsawy@bbsuk.org.uk
Mon–Fri 10:30am – 4:30pm

Fundraising

fundraising@bbsuk.org.uk

Chief Executive Officer

Tonia Hymers
07591 206680
tonia.hymers@bbsuk.org.uk
Mon/Tues/Wed/Fri 9am-4pm

Advice Service Manager / Social Worker

Rebecca Perfect
07421 455649
rebecca.perfect@bbsuk.org.uk
Mon-Thurs: 09:30am-3:30pm

Patient Liaison Officer: QEH

Amy Clapp
07591 206787
amy.clapp@bbsuk.org.uk
Mon-Thurs: 9:00am-3:30pm

Patient Liaison Officer: BCH

Laura Davis
07512 198484
laura.davis@bbsuk.org.uk
Mon-Thurs: 9:30am-2:30pm

Patient Liaison Officer: GSTT

Angela Scudder
07591 206788
angela.scudder@bbsuk.org.uk
Mon-Fri: 9:00am-3:00pm

Patient Liaison Officer: GOSH

Vicky Harman (from May 2026)
07860 650352
vicky.harman@bbsuk.org.uk
Mon/Wed/Thurs: 9am-3pm

Social Worker: Advice Service

Shirin Memi
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