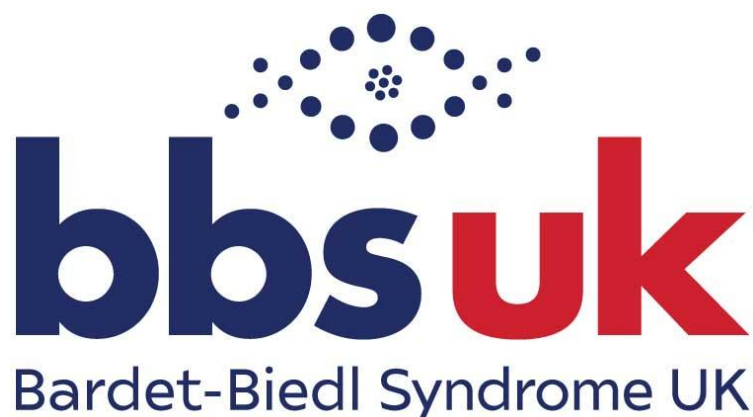




Conference 2026

25th – 27th September

Hilton Hotel, Northampton

Information Pack



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Welcome

Emma Hughes, Chair of BBS UK



Welcome everyone to the 33rd BBS UK Annual Conference. I look forward to connecting with our incredible community once again. Whether you're attending in person or joining us via Zoom, I hope you find the event both informative and uplifting.

BBS UK is dedicated to supporting individuals and families affected by BBS; our mission is to provide guidance, foster research, and enhance the wellbeing and quality of life for those living with this rare condition. Our conference brings together people living with BBS, families, carers, clinicians, researchers and partner organisations.

The theme for this year is Living Well with BBS, and we want the community to leave with this message: living well with BBS is possible when scientific progress, clinical expertise, practical support and lived experience come together.

During the conference, we aim to:

- ✓ Showcase progress in BBS research, diagnosis and treatment.
- ✓ Highlight practical strategies that improve health, wellbeing and independence.
- ✓ Share expertise from clinicians, researchers and people with lived experience.
- ✓ Strengthen connections between families, professionals and the wider BBS community.
- ✓ Inspire confidence, hope and action for the future.

To ensure you don't miss any of the sessions and activities, please take a moment to review the Weekend Programme included in this pack. Inside, you'll find:

- A full schedule with presentation timings
- Speaker profiles
- Useful information about the charity, event and venue

The hotel lobby will be the hub for the weekend, with easy access to the Business Corridor (where meeting rooms are located), the restaurant, bar, and bedrooms. If you have any questions throughout the weekend, our team members in BBS UK T-shirts are here to help. Each year, we welcome new delegates alongside returning attendees, so please introduce yourself, ask questions, and make the most of being part of the BBS support network.

A link to a short feedback form is included on the back page of this booklet and will be sent via email after the conference. We encourage you to share your thoughts to help us improve future events.

If you would like to support BBS UK, information on making a one-time donation or becoming a Friend of BBS UK with a regular contribution is also included in this pack. As a charity, we rely on donations to continue providing essential support services, including this conference, which are more vital than ever.

A special thank you to our incredible speakers for their expertise and dedication. We are also extremely grateful to our sponsors, whose generous support helps make this conference possible and enables us to bring the BBS community together. Their contributions are essential in advancing our collective understanding of BBS and ensuring continued support for those affected.

We look forward to a weekend of learning, sharing, and, most importantly, connecting.

Enjoy the conference!

Emma

Sponsors

Rhythm Pharmaceuticals and Axovia Therapeutics have generously supported the BBS UK conference through unrestricted educational grants. They have had no influence over the creation, development or content of the meeting.

Our heartfelt thanks go to Rhythm Pharmaceuticals and Axovia Therapeutics for their support.



Useful Information

Wi-fi

The hotel offers free unlimited Wi-Fi for all guests. The code is: NORTHAMPTONQ3

Social media

We welcome you to post about the conference on social media. Please use the hashtag #BBSConf26 and remember to tag us on any of the platforms listed below:

- **Facebook:** www.facebook.com/bardetbiedlsyndromeuk
- **Instagram:** [bardetbiedlsyndromeuk](https://www.instagram.com/bardetbiedlsyndromeuk)
- **LinkedIn:** www.linkedin.com/company/bardet-biedl-syndrome-uk

Urgent enquiries

At the hotel

Tonia Hymers: 07591 206680
Natalie Elsayy: 07785 922654
Amy Clapp: 07591 206787
Angela Scudder: 07591 206788

Children and Young Person's Trip

Laura Davis: 07512 198484
Vicky Harman: 07860 650352

All emergencies must go through Hotel Reception

Looking After Your Wellbeing

Whether this is your first conference or you have attended before, we understand that in-person events can sometimes feel overwhelming. We have put together some information to help you look after your wellbeing and enjoy the conference.

Many people have their own ways of coping when they start to feel anxious, tired or overwhelmed. Here are some ideas that might help:

- Find a quiet place to rest and recharge. This could be the Quiet Room, your hotel room, outside in the gardens, or another quieter public area of the hotel.
- Join in as much as you feel comfortable with. We encourage everyone to get involved, but if you need to step away from an activity or session, that's absolutely fine. You will be welcomed back whenever you are ready.
- Look after yourself. Remember to drink water, eat regularly, use the breaks to visit the bathroom, and get some fresh air if you need it.

- Look out for each other. If you are concerned about someone, please speak to a member of the BBS UK team.
- Take a break from difficult topics. Some of the subjects discussed during the conference may be difficult or upsetting. You are welcome to leave a session, take some time in a quiet space, or join a different activity.

Need some support?

If at any point during the conference you feel worried, overwhelmed or need some support, please speak to a member of the BBS UK team. We are here to support you.

Safeguarding

BBS UK staff and volunteers will be on site throughout the conference.

BBS UK staff and volunteers have completed safeguarding training and know how to respond if a concern is raised. Any safeguarding concerns will be passed to the appropriate member of the BBS UK senior team and managed in line with our safeguarding procedures.

If you have a safeguarding concern during the conference, please speak to a member of the BBS UK team.

Illness and Infection

Some people attending the conference may be particularly vulnerable to infections. If you have symptoms of COVID-19 or another contagious illness, please do not attend the conference in person, we are livestreaming the event, so please join online instead. Follow current NHS guidance and, if you are unsure whether it is appropriate to attend, seek advice from your GP or another healthcare professional.

Thank you for helping us make this conference as safe and accessible as possible for everyone.

Photography and video during the weekend

Please be aware that photos and video will be taken during the weekend for use in our publications, on our website and on social media. If you do not wish to appear in any photos or videos, please request an opt-out form from the BBS UK reception desk.

Weekend programme of events

Friday

Time	Activity	Location
From 3pm	Registration and check-in to hotel.	Hotel lobby
6pm to 7:30pm	Evening meal (rolling service)	Restaurant
7pm to 8pm	Children & Young People's Group	Spencer
7pm to 8pm	Looking After You! Caring now and into the future	Collingtree 1
7:30pm to 8pm	New Attendees Group: Adults living with BBS	Collingtree 2
8pm to 9pm	Relaxation and Mindfulness: for parents and carers	Collingtree 1
8pm to 9.30pm	Social Group for adults living with BBS	Collingtree 2
8pm to 9pm	New Families Group: Parents	Isham Room

Quiet Room: A quiet room is available for individual prayer and reflection.

Advice Service Appointments Available

Our Advice Service Social Workers Shirin Memi and Beatrice Adeogun will be available for pre-arranged appointments across the weekend. To reserve a space, please contact them directly by emailing Shirin.memi@bbsuk.org.uk.

Invitation for adults living with BBS

Would you like to meet, chat and have fun with other adults living with BBS?

Friday 25th September @ 8:00pm in Collingtree 2

Join us for a relaxed and informal get-together, a chance to meet other adults with BBS, share experiences, make new connections and enjoy some fun games together.

We'd love to meet you there!

Saturday

8:45am	Registration and refreshments for day delegates in hotel lobby
8:45am	Whipsnade Zoo trip for children and young people: Assemble outside for group photo and prompt 9am departure
9:15am	Conference Room Opens Collingtree Suite at end of Business Corridor
9:30am	Welcome Emma Hughes
9:40am	Scientific Progress and the Future of Living Well with BBS Professor Phil Beales
10:20am	Targeting Metabolic Health in BBS: from mechanisms to practical interventions Professor Jeremy Tomlinson & Dr Melanie Kershaw
11:00am	Break (20 mins)
11:20am	Optimising Vision & Adaptive Strategies Dr Helen Palmer & Dr Rupal Morjaria
12:00pm	Small Steps, Big Difference Lived Experience Panel
12:30pm	Safe, Confident & Connected in a Digital World The 2 Johns
1:00pm	Lunch in Seasons Restaurant and Lobby
2:00pm	Practical Workshops & Exhibitors: see separate programme
3:50pm	Return to Collingtree
4:00pm	BBS Beyond Borders: Small Steps Together for Big Differences Tim Ogden
4:15pm	Living Well with BBS: Where we go from here Tonia Hymers
4:30pm	BBS UK Conference 2026 Closes Please join us for refreshments in the lobby

Workshops & Exhibitors: 2pm-3.45pm

Exhibitors will be available throughout the day. Workshops will take place after lunch, from 2pm to 3.45pm. You will have booked or been allocated your workshop places in advance. If you're not sure which workshops you're attending, please visit the BBS UK Reception Desk during lunchtime, where a member of the team will be happy to help.

Room	Session 1: 2pm	Session 2: 3pm
Collingtree 1	Ask the Experts Q&A: Expert panel, hosted by Professor Phil Beales.	Ask the Experts Q&A: Expert panel, hosted by Professor Phil Beales
Collingtree 2	Real Talk on Sight Loss: Tech, Independence, and Living Well: Paula Thomas, ECLO, GOSH Zoe Bates, ECLO, RNIB & Vicky Johnson, ECLO, RNIB	Explore Meta Glasses Tommy Dean, Guide Dogs
Brudenell	Advice Service: By Appointment Shirin Memi Beatrice Adeogun	Advice Service: By Appointment Shirin Memi Beatrice Adeogun
Watson	Healthy Living: Small Changes, Easy Wins Sarah Flack (Principal Dietitian) & Emma McGibbon (Clinical Psychologist):	Navigating Support and Services for Adults with BBS (16+) Rebecca Perfect and Amy Clapp
Isham	Parent Advocacy Toolkit: Navigating SEND with Confidence Ghazala Anwer, supported by Rebecca Perfect	Developing Skills for Adulthood Suzie McDonald and Terri-Ann Bent Rehabilitation officers, Habilitation VI UK (up to 25 years old)
Spencer	Online Safety and Device Security for Adults with BBS The 2 Johns	Supporting Children and Young People to Stay Safe Online The 2 Johns

3:50pm: Return to Collingtree after the workshops for final sessions.

Saturday evening

Time	Activity	Location
6:30pm-8pm	Evening meal (rolling service)	Seasons Restaurant
7:30pm	Pop-Up 'Cinema' showing Children's Movies (Unsupervised)	Lowther Room
8:30pm-10:30pm	Family Quiz, raffle and karaoke	Collingtree Suite

Sunday morning

Breakfast, Catch-ups & Goodbyes

Sunday morning is informal, giving everyone time to enjoy breakfast, catch up with friends and say goodbye before travelling home.

Our Patient Liaison Officers and Advice Team will be available during the morning if you have any questions, worries or concerns you would like to talk through before you leave. Private rooms will be available if you would prefer to speak to someone confidentially.

11:00am – Hotel Check-out

Publications

We have a range of publications available from our reception desk, including:

- Introducing Bardet-Biedl Syndrome
- Medical Information Booklet
- My Life, My Future: Young Person's Handbook

Copies can be downloaded via www.bbsuk.org.uk or accessed via

the QR code above, right. Or you can email admin@bbsuk.org.uk for a copy by post.



Become a member of BBS UK

Take a moment to ensure you are a member of BBS UK!

You are a member if you have completed an application form or given consent when asked by our team. If you have received AGM voting information in the past, you are already registered. If you're unsure, contact us at admin@bbsuk.org.uk, and we'll check for you. BBS UK's members are at the heart of everything we do. By joining, you become part of a supportive community that helps shape the charity's direction and impact. Membership ensures transparency, credibility, and strengthens our ability to support individuals and families.

Membership is free! Join today at www.bbsuk.org.uk and click 'Become a member'.

Fundraising

Throughout this weekend, we'll be exploring the many things that can help people live well with BBS, from advances in research and healthcare to practical support, greater independence, shared experience and connection.

Often, it is the small steps that make a big difference. The same is true of supporting BBS UK. A monthly donation, signing up for a fundraising challenge, organising an event or supporting someone else's efforts may feel like a small action, but together they enable us to continue providing the support, information and advocacy our community relies on.

Become a Friend of BBS UK – and receive a free gift!

One small way to make a lasting difference is to become a Friend of BBS UK by making a regular monthly donation.

Whatever the amount, regular donations give us a reliable income that helps us plan ahead and develop our support, advocacy and information services for people living with BBS and their families.

Becoming a Friend is easy:

Step 1: Scan the QR code and complete our online Friends form.

Step 2: Set up a standing order with your bank, using your name as the reference so we know who to thank.



Everyone who becomes a Friend during Conference Weekend will receive a free gift. If you are attending in person, visit the BBS UK reception table to collect yours.

To all our existing Friends, thank you. Your regular support makes a real difference.

Celebrating Our Amazing Fundraisers

Some small steps turn into rather big challenges!

This coming year is our biggest marathon year yet, with Team BBS UK represented at the Manchester, Edinburgh and London Marathons and the London Landmarks, Hackney and Royal Parks Half Marathons.

Our runners are giving their time, energy and a great many training miles to raise funds and awareness for BBS UK. We are enormously grateful to every one of them, and to everyone who sponsors, supports and cheers them on.

Scan the QR code to visit our JustGiving page and support Team BBS UK.



Could Your Next Step Be a Fundraising Challenge?

You don't need to run a marathon to make a difference.

You could take on a personal challenge, organise a social or workplace fundraiser, or turn something you already enjoy into a way of supporting BBS UK. Through 'Run for Charity', available via our website, you can also choose from events across the UK, from 5Ks and inflatable runs to marathons, Tough Mudders and bungee jumps.

Whatever you choose, we'll be here with ideas, resources and encouragement.

Small steps really can make a big difference. Every Friend, fundraiser and donation helps BBS UK continue our work so that people with BBS and their families have the support, information and opportunities they need to live well with BBS.

Scan the QR code, visit www.bbsuk.org.uk/support-us or email fundraising@bbsuk.org.uk to get involved.



Service User Advisory Group

The BBS UK Service User Advisory Group (SUAG) helps make sure that the experiences and views of our community are reflected in the work we do, and provides an important community voice within BBS UK. Members review our services, information and plans, and share their experiences, ideas and suggestions to help us understand what is working well and where we could do things differently or better.

SUAG feedback helps inform BBS UK's decision-making, service development and future strategy. The group meets approximately four times a year via Zoom. Over recent years, members have contributed to a wide range of BBS UK projects, including:

- our Annual Conference
- newsletters and publications
- the Medical Information Handbook
- BBS UK's strategy and service development.

We currently have three spaces available and would love to hear from service users who are interested in getting involved. We want the group to reflect the breadth of our community, so we are particularly keen to hear from people whose experiences or perspectives are currently less represented. At present, we would especially welcome interest from fathers of children with BBS.

If you are interested, please email Natalie Elsayy at admin@bbsuk.org.uk

Speaker Profiles



Emma Hughes

Emma lives in a village near Petersfield, Hampshire, with her husband Phillip, their two sons Charlie and Archie, dog Max and cat Zebe. Emma has worked at Thomas Pocklington Trust, a national sight loss charity, since 2008, where she is Director of Services. She has extensive experience in developing and delivering services for blind and partially sighted people and is passionate about ensuring that lived experience is at the heart of service development and decision-making.

Emma has been Chair of BBS UK for the past two years, working closely with fellow trustees, staff and volunteers to support the charity's development and ensure that the needs and experiences of people living with BBS and their families remain central to its work. She is proud to be

part of the BBS UK community and looks forward to continuing to support the charity as it develops its services, partnerships and ambitions for the future.



Professor Phil Beales

Professor Beales obtained his degrees in Genetics and Medicine from University College London. He undertook postgraduate training in both general medicine and paediatrics before specialising in Clinical Genetics

In 1999, he published the largest survey of BBS symptoms with the help of members of BBS UK (then LMBBS). This culminated in the identification of many new features not previously described in the medical literature and enabled Professor Beales to propose new diagnostic criteria, with the expressed purpose of enabling an earlier diagnosis for many more children.

With colleagues at Baylor College of Medicine in Houston, Professor Beales discovered the first gene to cause BBS in 2000. Since then, at least 26 genes have been linked to the syndrome, and his research group has made major advances in our understanding of its underlying causes.

Professor Beales has been medical advisor to Bardet-Biedl Syndrome UK since 1996, was made President of the Charity in 2005 and is a founder member of the BBS UK Scientific Advisory Board. In 2010, he established, with the support of BBS UK, National Multi-disciplinary Clinics, a comprehensive genetic testing platform for all persons with BBS in the UK. In recent years, he cofounded Axovia Therapeutics to deliver the first gene therapy trial for BBS.



Professor Jeremy Tomlinson

Jeremy Tomlinson is a Professor of Metabolic Endocrinology and Consultant Endocrinologist at the University of Oxford's Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM). After studying at the Universities of Cambridge and Oxford, he completed a PhD investigating steroid metabolism and obesity before undertaking further research fellowships in obesity and insulin resistance. His research spans a range of metabolic disorders, including the specific metabolic changes associated with BBS, while his clinical practice supports patients with a broad range of endocrine and metabolic conditions.

Jeremy has been providing metabolic and endocrine expertise to the adult BBS clinic at the Queen Elizabeth Hospital Birmingham since its establishment more than 15 years ago. In this session, Jeremy will explore the metabolic health of people living with BBS, including the underlying

mechanisms, associated health risks, recent research developments and emerging treatment approaches.



Dr Melanie Kershaw

Dr Melanie Kershaw is a recently retired Paediatric Endocrinologist with a special interest in rare Diabetes syndromes. She delivered the Birmingham clinics in the NHSE Rare Diabetes Services for Children with BBS and Alstrom Syndrome for 15 years until the end of May 2026. She was also the Clinical Lead for the BBS and the National Children's Alstrom syndrome service at Birmingham Children's Hospital for the last 5 years.

Dr Kershaw set up and delivered the Children's Setmelanotide service for children with BBS attending the Birmingham Clinics, enabling eligible children to have the opportunity to benefit from this medication. Dr Kershaw continues to support the BBS and Alstrom clinical services in BCH in an advisory role. Her presentation will cover the pathways involved in controlling hunger and how we burn off energy in the body, and how BBS and specific medications can affect these pathways. She will also talk about the experiences and outcomes seen in children who have received specific treatment with Setmelanotide in the Birmingham clinic.



Dr Helen Palmer

Helen Palmer has been a Consultant Ophthalmologist at the Queen Elizabeth Hospital Birmingham since 2003 and she joined the Adult Bardet-Biedl Service there 10 years ago. She specialises in Medical Retinal conditions, such as those associated with diabetes. She has seen at first hand the challenges that are faced by people with BBS, as well as by their families, particularly with regards to their sight loss.



Dr Rupal Morjaria

Dr Rupal Morjaria is a Consultant Ophthalmologist specialising in macular degeneration, diabetic eye disease, central serous retinopathy, retinal vein occlusions and inherited retinal disease such as retinitis pigmentosa. She is the retinal genetics lead within her department and works as part of the specialist BBS clinic at Queen Elizabeth Hospital Birmingham.



Graeme Roache

Graeme Roache is 39 years old and lives in Dumbarton Scotland with his parents. He has a beautiful black guide dog called Gibson who has been with him for over 2 years. He was diagnosed with BBS at age 9 and has limited central vision, no peripheral vision and night blindness.

He has been attending the annual conference for a number of years and supports BBS UK by organising various fundraising events. He is also a member of the Service User Advisory Group, helping to provide feedback on the charity's projects and services.

Graeme's interests include tandem cycling, VI tennis, going to the gym, watching sports, listening to music, audiobooks and podcasts.

Emmy Anstee

Emmy Anstee is 24 years old and was diagnosed with BBS at the age of nine. She regularly shares her experiences of living with BBS, including through appearances on podcasts such as RNIB Connect, where she talks about the adaptations and support that have helped make everyday life easier.

Emmy is also a keen volunteer and currently volunteers with a theatre company. Through her own experiences, she has learned how small changes, practical adaptations and the right support can make a real difference to confidence and independence.

By sharing her experiences on the panel, Emmy hopes to give an honest insight into life as a young adult with BBS and some of the things that have helped her along the way.



Alisha Saleem

Alisha Saleem is a second-year Social Work student from Luton, working towards a career supporting children with their mental health and wellbeing.

Alisha's younger sister lives with BBS and growing up alongside her has given Alisha a unique perspective on how BBS can shape family life. Attending BBS UK's annual conferences has also given her the opportunity to connect with other siblings and families who share similar experiences.

Outside of her studies, Alisha works as a carer for an elderly woman living with dementia. She is also a keen horse rider and enjoys caring for and competing with her two horses, as well as spending time with family and friends.



Samantha Newman

Samantha Newman is a nurse, and is mum to two daughters, Chloe, 16, who lives with BBS, and Makenna, 10.

As Chloe's mum, Sam has experienced first-hand the journey of seeking a diagnosis, accessing medical support and navigating ongoing care for a child with BBS. Being both a parent and a nurse has given her a unique perspective on healthcare. She understands how important it is for parents to feel listened to, supported and included in decisions about their child's care, while also recognising the pressures and challenges faced by healthcare professionals.

Sam hopes that by sharing her family's experiences, she can highlight the importance of listening to families, understanding their individual circumstances and ensuring that children and their families feel heard, valued and supported throughout their healthcare journey.

Jackie O'Brien

Jackie O'Brien is 48 years old and was diagnosed with BBS in 2015, at the age of 35. She enjoys meeting and talking to people, as well as music, dancing, theatre, concerts, cooking, baking and walking.

Jackie recognises the challenges that can come with living with BBS, but draws on her determination and willpower to help her overcome obstacles and continue doing the things she enjoys.

She is passionate about raising awareness of BBS and believes greater understanding and education is needed, particularly in schools and healthcare. By sharing her experiences on the panel, Jackie hopes to help others understand more about life with BBS and the difference that greater awareness and support can make



The Two Johns

John Woodley and John Staines, known as 'The 2 Johns', are former police detectives who spent their careers tackling online and offline child exploitation in a range of covert roles. Recognised experts in online safety, they have spent over a decade delivering engaging presentations to schools, parents, professionals and safeguarding organisations across the UK.

They are regular contributors to national media, including BBC Breakfast, BBC Radio 4 and Channel 4, and have helped thousands of children, families and professionals navigate the digital world safely.

Their session will cover practical ways to stay safe online, including using apps and online games safely, understanding privacy settings, and helping families navigate the digital world with confidence. They will also explore how the traditional 'stranger danger' message applies in today's online environment, providing practical advice for parents, carers and professionals.



Tim Ogden

Tim Ogden is executive director of the Bardet Biedl Syndrome Foundation (US), and father of a young man with BBS. He created the Foundation in 2014 after being elected president of the BBS Family Association in 2012. He has led the Foundation to more than \$2.5 Million of fundraising to improve treatment and care of people with BBS, including funding CRIBBS, one of the largest databases of people affected by BBS which has enabled the publication of more than a dozen research papers, and the initial work on BBS retinal gene therapy. The BBS Foundation recently held one of the largest BBS family gatherings with more than 250 delegates, including 80 BBS families, doctors and researchers in attendance. Tim is married to Dr. Erica Davis, a leading BBS research geneticist.



Tonia Hymers

Tonia lives on the Essex coast with her husband Rob and sons Daniel and Connor. Tonia's connection with BBS UK began in 1998 following Dan's diagnosis. Attending their first BBS UK conference that year and meeting young people and adults with BBS gave the family a positive outlook for the future and marked the beginning of Tonia's involvement with the charity.

After a 17-year career with Barclays, Tonia worked with BBS UK and Professor Philip Beales on the development of the specialist BBS clinics. She went on to hold a number of service and operational roles within the charity before becoming CEO. Alongside this, she studied to postgraduate level with the Open University.

Drawing on both personal and professional experience, Tonia is passionate about ensuring that people with BBS and their families are heard, supported and able to access the specialist services and information they need.



Dr Emma McGibbon

Dr Emma McGibbon is a Clinical Psychologist within the BBS service at Guys and St Thomas' Hospital and previously worked in the paediatric BBS service at Great Ormond Street Hospital. Working across these services means that she has an understanding and expertise in how BBS can impact people across the whole lifespan.

Emma specialises in work with a range of rare genetic disorders and neurodevelopmental differences, including intellectual disability, sensory impairments, cerebral palsy, autism spectrum condition, ADHD and associated emotional wellbeing, behaviour and learning needs. She is keen to develop services for people with BBS and their families and works closely with colleagues at BBS UK to ensure that the right support is being provided.



Sarah Flack

Sarah Flack is Principal Dietitian and has worked at Great Ormond Street Hospital for over 20 years covering a wide variety of clinical areas during this time. Sarah previously specialised in looking after children with kidney problems and in this role first saw children with BBS.

Sarah has been an integral member of the BBS multi-disciplinary clinics team since it began in 2010 and has developed a deep understanding and clinical knowledge of dietary issues in BBS and its impact on those affected and their families. Sarah has worked closely with BBS UK over the years, providing chapters for information booklets, dietary articles for newsletters, giving presentations and running workshops at annual weekend conferences, further extending the dietary support and learning for BBS families.

Sarah will offer insights into what we have learned about hunger and food behaviour from children and adults attending our clinics. It will finish with some practical ideas to help.



Tommy Dean

Tommy Dean is a Technology Integration Partner at Guide Dogs. He evaluates accessible mainstream and assistive technologies and supports specialists across the organisation to develop the knowledge, skills and confidence to use and share them safely and effectively.

His work includes exploring accessible smartphones, wearables such as smart glasses and emerging electronic travel aids, developing practical guidance and training, and helping to embed appropriate technology within services for children, young people and adults with sight loss.



Amy Clapp

Amy is the dedicated BBS UK Patient Liaison Officer for the Birmingham Adult BBS Clinic at Queen Elizabeth Hospital. She supports patients and families throughout their journey by coordinating clinic appointments, helping them understand the information they receive, signposting them to relevant services and providing guidance on areas such as benefits, housing and social care.

Amy joined BBS UK as a volunteer after her daughter was diagnosed with BBS in 2012. Inspired to support other families, she became a Patient Liaison Officer with BBS UK in 2017. Alongside her role with BBS UK, Amy and her husband Gary are approved foster carers. She is passionate about supporting children, people with disabilities and families

Amy and her family have proudly supported BBS UK through fundraising challenges, including cutting off their long hair at a BBS UK Conference and taking on a family bungee jump and giant swing.



Rebecca Perfect

Until May 2026, Rebecca worked at BBS UK as Advice Service Manager, where she supported people living with BBS and their families to navigate a wide range of practical and social care issues. She has extensive experience in adult social care, including supporting people to access benefits, housing, healthcare and community services, and is passionate about empowering adults with disabilities to live as independently as possible. Through her current role at Electric Umbrella, Rebecca continues to champion inclusion, community engagement and opportunities for people with disabilities to thrive.



Suzy McDonald

Suzy McDonald is the Senior Habilitation Specialist for the Birmingham Education Habilitation Service, based at Priestley Smith Specialist School but working with vision impaired children and young people in a variety of mainstream and special schools across Birmingham.

The aim of the Habilitation Service is to develop each child's mobility and independence skills to the best of their potential. She joined the service in 2009 after 17 years at RNIB, including 9 years as RNIB's Curriculum Access Officer. Suzy is attending the conference representing Habilitation VI UK, the professional body for Habilitation Specialists.



Terri Ann-Bent

Terri-Ann Bent is part of Priestley Smith Habilitation Service, based at Priestley Smith Specialist School but working with vision impaired children and young people in a variety of mainstream and special schools across Birmingham. She joined the service in 2005 after working for Birmingham Focus on Blindness as part of their community Rehabilitation Service.

Terri and Suzy are offering a hands-on carousel style workshop offering ideas and proven solutions, using mainstream and specialist equipment, to maximise your child's independence. Aimed at parents of children in secondary and beyond, it will also offer the opportunity to try some of the activities under simulation spectacles or blindfold.



Ghazala Anwer

Ghazala is a parent carer with lived experience of navigating the SEND system for her son, who has BBS and complex health, sensory and educational needs.

Through her family's journey, she has developed a strong understanding of EHCPs, annual reviews, multi-agency working, parent advocacy and the challenges families can face when trying to secure the right support for their child. She also supports other parents in her local area by sharing practical advice, guidance and encouragement based on my own lived experience.

She is passionate about helping parents feel more confident, organised and less alone when dealing with schools, local authorities and professionals.



Paula Thomas

Paula Thomas is an Eye Clinic Liaison Officer (ECLO) at Great Ormond Street Hospital, where she has spent the past 16 years supporting children and families across the hospital's eye clinics, including its dedicated monthly BBS clinic.

Living with a retinal condition herself gives Paula a personal understanding of the challenges families can face. Her non-medical role focuses on helping families navigate information, understand the support available to them, and make sense of what a diagnosis may mean for their child now and in the future.

Paula is passionate about making the eye clinic journey feel less overwhelming, providing practical and compassionate support tailored to each family's needs.



Zoe Bates

Zoe Bates is an Eye Care Liaison Officer (ECLO) at the Queen Elizabeth Hospital Birmingham, where she provides practical and emotional support to people living with sight loss and their families. Working closely with ophthalmology teams and external organisations, Zoe helps patients access the information, services, and resources they need to adapt to changes in their vision and maintain their independence.

Passionate about patient-centred care, Zoe is committed to ensuring that every individual receives compassionate guidance throughout their eye care journey. She works collaboratively with healthcare professionals, charities, and community services to connect patients with the right support at the right time, empowering them to make informed decisions and improve their quality of life.



Vicky Johnson

Vicky Johnson is an ECLO Service Manager for 16 years, supporting Eye Clinic Liaison Officers (ECLOs) across several hospital sites. Her role involves visiting eye departments and working together with hospital teams, community partners and colleagues to ensure people with sight loss receive the right support at the right time.

Vicky is passionate about improving access to timely, person-centred support for people affected by sight loss. She also works to develop inclusive services, support ECLOs to feel confident in their roles, and remove barriers for patients and their families.

Exhibitors



RNC provides further education and training for young people aged 16–25 with visual impairment. Alongside academic and vocational courses, students develop practical skills including mobility, assistive technology and independent living, helping to build confidence and independence for the future. www.rnc.ac.uk



Guide Dogs supports children and adults with sight loss, as well as their families. Their services include support with mobility and independence, technology, education and family life. At the conference, Guide Dogs will be showcasing their Habilitation Service, Technology and Learning Service, and Family Outreach Support Service. www.guidedogs.org.uk



VICTA supports children and young adults who are blind or partially sighted, and their families. They offer inclusive activities, family weekends, sports, residential opportunities and their Young Achievers Award, helping young people build confidence, independence and friendships. www.victa.org.uk



LOOK supports visually impaired children and young people, and their families, across the UK. They offer mentoring, events and activities, online communities and support for parents and carers. Their Mentor Project connects visually impaired young people with trained mentors who have lived experience of sight loss, helping them build confidence, connections and independence. www.look-uk.org



British Blind Sport aims to transform the lives of blind and partially sighted people through the power of sport and physical activity. British Blind Sport works to ensure accessible opportunities for individuals with visual impairments, from grassroots to elite levels, challenging and supporting the mainstream sport sector to be inclusive. www.britishblindsport.org.uk

Conference Feedback 2025

“Another very well organised conference, well done to the BBS UK team! This is a very important weekend for us and we hope it can continue for many years to come.”

“We really had a great time, we felt so welcomed by you all. With open arms and hearts, we were adopted by you all! ... Thank you all, you guys are awesome!”

“For my first time, I’ve left feeling very comforted and inspired. On the trains home I hit the ground running reaching out for various support and also fundraising ideas. Thank you!”

How did we do this year?

Your feedback really matters to us. Please take a few minutes to complete our conference evaluation by scanning the QR code.

Your thoughts help us understand what worked well, improve future conferences and demonstrate the impact of our work when applying for funding.



Thank you for being here and for sharing your thoughts with us, we truly appreciate it!

Thank you, and goodbye until next time!

Thank you for being part of the BBS UK Conference! We hope you’ve had a fantastic time, learning, connecting, and sharing experiences with others in our wonderful community. We wish you a safe journey home and look forward to connecting with you again soon.

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