

BBS UK Conference 2025

Weekend Programme of Events

**Please note that timings are subject to change*

Friday

Time	Activity	Location
From 3pm	Registration and check-in to hotel.	Hotel lobby
6pm to 7:30pm	Evening meal (rolling service)	Seasons Restaurant off hotel lobby
7pm to 8pm	Children & Young People's Group	Watson Room
7:30pm to 8pm	New Attendee Meeting: Adults living with BBS	Isham Room
8pm to 9.30pm	Social meet-up for adults living with BBS	Collingtree 2
8pm to 9pm	New Families Meeting: Parents	Isham Room

Prayer Room: A quiet room is available during conference weekend for individual prayer and reflection.

Invitation for adults living with BBS: Would you like to meet and chat to other people who are also living with BBS? Come and join us on Friday 25th April from 8pm to 9:30pm in Collingtree 2. We will be playing some fun games, chatting and sharing experiences.

Saturday

8:30am	Registration and refreshments for day delegates in hotel lobby
8:45am	Drayton Manor trip for children and young people: Assemble outside for group photo and prompt 9am departure
9:00am	Conference opens in Collingtree Suite at end of Business Corridor
9:15am	Welcome Emma Hughes, Chair, BBS UK
9:20am	Update on Gene Therapy Prof Beales, Axovia Therapeutics
10:00am	Therapeutic Approaches for Retinal Dystrophies Robert Henderson, Consultant Ophthalmologist & Vitreoretinal Surgeon, GOSH & Moorfields Eye Hospital
10:40am	Setmelanotide Clinics Update Dr Elizabeth Forsythe
11:05am	Break (20 mins)
11:25am	Planning for the Future – Wills, Trusts and Decision Making Philip Warford, Renaissance Legal
11:50am	Personal Perspective Stefan Crocker
12:10pm	Staying Safe Online Sophie Corness, Royal National College for the Blind (RNC)
12:35pm	Update from BBS UK Tonia Hymers, Operations Manager, BBS UK
1:00pm	Lunch (1 hour) in Seasons Restaurant and Lobby

After lunch we will split into two groups for more focused sessions:

Collingtree 2: People Living with BBS

Collingtree 1: Parents of Children & Young People Living with BBS

Collingtree 1: People Living with BBS

2:00pm	Thinking About Food Kenneth Michie, Dietitian, GSTT Dr Emma McGibbon, Clinical Psychologist, GSTT
2:50pm	The Power of Peer Support Denise Rawden, Retina UK
3:15pm	Comfort break (15 mins)
3:30pm	Communication at a cellular level: An accessible update Dr Emilia Kieckhöfer, Julia Günzler, Cologne, Germany Jannis von Spreckelsen, Dr Viola Kretschmer, Mainz, Germany
4:00pm	Personal Perspective Emily Bartell, USA
4:20pm	Closing Remarks: Emma Hughes, Chair, BBS UK
4:25pm	Refreshments and Networking: Lobby

Collingtree 2: Parents of Children/Young People

2:00pm	Supporting Transition to Adulthood Marie McGee, Transition Co-ordinator, Birmingham Children's Hospital and Anna Smith, Rareminds
2:50pm	Cognitive, Behavioural and Social Presentations in Children and Young People with BBS Dr Gabrielle Blumer and Dr Emma McGibbon
3:20pm	Comfort break (10 mins)
3:30pm	Habilitation: What to Expect in Your Child's Mobility & Independence Programme Suzy McDonald, Habilitation VI UK
3:50pm	Dietary Support Sarah Flack, Principal Dietitian, Great Ormond Street Hospital
4:20pm	Closing Remarks: Chetan Meshram, Vice-Chair, BBS UK
4:25pm	Refreshments and Networking: Lobby

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Saturday evening

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

Sunday morning

Time	Activity	Location
Goalball with Kathryn Fielding of GoalBall UK		
9am – 10am	Children and Young People	Collingtree Suite
10am – 11am	Adults Living with BBS	Collingtree Suite

We hope you have enjoyed this year's BBS UK Conference, please take a moment to complete an evaluation form before you leave. These are invaluable to the BBS UK Board of Trustees and form the basis of future conference planning.

The feedback form can be accessed via the **BBS UK website** or via the **QR code** below:



We wish you a safe journey home and look forward to seeing you again next year.