

# BBS UK Conference 2025

## Weekend Programme of Events

*\*Please note that timings are subject to change*

### Friday

<b>Time</b>	<b>Activity</b>	<b>Location</b>
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 25<sup>th</sup> 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	<b>Drayton Manor trip for children and young people:</b> Assemble outside for group photo and prompt 9am departure
9:00am	<b>Conference opens in Collingtree Suite</b> at end of Business Corridor
9:15am	<b>Welcome</b> Emma Hughes, Chair, BBS UK
9:20am	<b>Update on Gene Therapy</b> Prof Beales, Axovia Therapeutics
9:50am	<b>Therapeutic Approaches for Retinal Dystrophies</b> Robert Henderson, Consultant Ophthalmologist & Vitreoretinal Surgeon, GOSH & Moorfields Eye Hospital
10:20am	<b>Setmelanotide Clinics Update</b> Dr Elizabeth Forsythe
10:45am	<b>Break</b> (20 mins)
11:05am	<b>Planning for the Future – Wills, Trusts and Decision Making</b> Philip Warford, Renaissance Legal
11:30am	<b>Personal Perspective</b> Stefan Crocker
11:50am	<b>Staying Safe Online</b> Sophie Corness, Royal National College for the Blind (RNC)
12:20pm	<b>Update from BBS UK</b> Tonia Hymers, Operations Manager, BBS UK
12:45pm	<b>Lunch</b> (1 hour 15 mins) 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 2: People Living with BBS

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

## Collingtree 1: Parents of Children/Young People

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

## 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 <b>GoalBall UK</b>		
9am – 10am	<b>Children and Young People</b>	Collingtree Suite
10am – 11am	<b>Adults Living with BBS</b>	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.