**BBS UK Conference 2025**

Weekend Programme of Events

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

# **Friday**

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| **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**

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| 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

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| **Collingtree 1:** People Living with BBS |
| 2:00pm | **Thinking About Food** Kenneth Michie, Dietitian, GSTTDr 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, GermanyJannis 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 |

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| **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 |

# **Saturday evening**

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| **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**

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| **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.