**BBS UK Conference 2025**

Livestream Programme of Events: Saturday 26th April 2025

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

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| **Time** | **Activity** |
| 9:00am | **Livestream starts** |
| 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 |
| 10:50am | **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 |
| 1:0ppm | **Break** (1 hour) |

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

**People living with BBS** will only need to register for the one Zoom link, and they can stay on that link for their afternoon sessions.

**Parents/carers** of children with BBS will need to register for an additional link to join their afternoon sessions.

# **People Living with BBS:**

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| **Time** | **Activity** |
| 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** Chetan Meshram, Vice-Chair, BBS UK  |

# **Parents of Children & Young People Living with BBS:**

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| **Time** | **Activity** |
| 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** Emma Hughes, Chair, BBS UK  |

Thank you for tuning in to the BBS UK Annual Conference livestream! Recording will be available on our [YouTube channel](https://www.youtube.com/%40bardet-biedlsyndromeuk2209/playlists), where you can also watch our past conferences.