



BBS UK Conference 2025

Livestream Programme of Events: Saturday 26th April 2025

**Please note that timings are subject to change*

9am – Livestream starts

Conference opens

9:15am - Welcome

Emma Hughes, Chair, BBS UK

9:20am – Update on Gene Therapy

Prof Beales, Axovia Therapeutics

9:50am - Therapeutic Approaches for Retinal Dystrophies

Robert Henderson, Consultant Ophthalmologist & Vitreoretinal Surgeon, GOSH & Moorfields Eye Hospital

10:20am - Setmelanotide Clinics Update

Dr Elizabeth Forsythe

10:45am – Break for 20 mins

11:05am – Wills, Trusts and Decision Making

Philip Warford, Renaissance Legal

11:30am – Personal Perspective

Stefan Crocker

11:50pm – Staying Safe Online

Sophie Corness, RNC (Royal National College for the Blind)

12:20pm – Update from BBS UK

Tonia Hymers, Operations Manager, BBS UK

12:45pm – Break for 1 hour 15 mins

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

2pm – Thinking About Food

Kenneth Michie and Dr Emma McGibbon

2:50pm – The Power of Peer Support

Denise Rawden, Retina UK

3:15pm – Comfort Break for 15 mins

3:30pm – Communication at a Cellular Level: An accessible update

Dr Emilia Kieckhöfer, Julia Günzler, Jannis von Spreckelsen, Viola Kretschmer

4pm – Personal Perspective

Emily Bartell, USA

4:20pm – Closing Remarks

Emma Hughes, Chair, BBS UK

Parents/carers of children with BBS

2pm - 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 – Break for 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