

# BBS UK Conference 2025

Livestream Programme of Events: Saturday 26<sup>th</sup> April 2025

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

Time	Activity
9:00am	<b>Livestream starts</b>
9:15am	<b>Welcome</b> Emma Hughes, Chair, BBS UK
9:20am	<b>Update on Gene Therapy</b> Prof Beales, Axovia Therapeutics
10:00am	<b>Therapeutic Approaches for Retinal Dystrophies</b> Robert Henderson, Consultant Ophthalmologist & Vitreoretinal Surgeon, GOSH & Moorfields Eye Hospital
10:50am	<b>Setmelanotide Clinics Update</b> Dr Elizabeth Forsythe
11:05am	<b>Break</b> (20 mins)
11:25am	<b>Planning for the Future – Wills, Trusts and Decision Making</b> Philip Warford, Renaissance Legal
11:50am	<b>Personal Perspective</b> Stefan Crocker
12:10pm	<b>Staying Safe Online</b> Sophie Corness, Royal National College for the Blind (RNC)
12:35pm	<b>Update from BBS UK</b> Tonia Hymers, Operations Manager, BBS UK
1:00pm	<b>Break</b> (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:

Time	Activity
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, Dr Viola Kretschmer, Mainz, Germany
4:00pm	<b>Personal Perspective</b> Emily Bartell, USA
4:20pm	<b>Closing Remarks</b> Chetan Meshram, Vice-Chair, BBS UK

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

Time	Activity
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> 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](#), where you can also watch our past conferences.