

# BBS UK Conference 2025

## Weekend Programme of Events

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

### Friday

**From 3pm** Registration and check-in

**6pm to 7:30pm** Evening meal, in Seasons Restaurant off Hotel Lobby

**7pm to 8pm** Children & Young People, in Watson Room

**7:30pm to 8pm** New Attendee Meeting for Adults with BBS, in Isham Room

**8pm to 9:30pm** New Attendee Meeting for Parents, in Isham Room

**8pm to 9:30pm** Social meet-up for adults living with BBS, in Collingtree 2

### Saturday

**8:30am** Registration and refreshments for day delegates in hotel lobby

**8:45am** Drayton Manor Trip, assemble outside for group photo

**9am** **Conference opens** Collingtree Suite, end of Business Corridor

**9:15am** Welcome, Emma Hughes

**9:20am** Update on Gene Therapy, Professor Phil Beales

**10:00am** Therapeutic Approaches for Retinal Dystrophies, Robert Henderson

**10:40am** Setmelanotide Clinics Update, Dr Elizabeth Forsythe

**11:05am** **Refreshment Break for 20 mins**

**11:25am** Wills, Trusts and Decision Making, Philip Warford, Renaissance Legal

**11:50am** Personal Perspective, Stefan Crocker

**12:10pm** Staying Safe Online, Sophie Corness

**12:35pm** Update from BBS UK, Tonia Hymers

**1:00pm** Lunch, 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 1: Adults with BBS**

**2pm** Thinking About Food, Kenneth Michie and Dr Emma McGibbon

**2:50pm** The Power of Peer Support, Denise Rawden

**3:15pm Comfort Break**

**3:30pm** Communication at a Cellular Level (Title TBC)

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

**4pm** Personal Perspective, Emily Bartell, USA

**4:20pm** Closing Remarks, Emma Hughes

**4:25pm** Refreshments and Networking in lobby area

### **Collingtree 2: Parents of Children & Young People**

**2pm** Supporting Transition to Adulthood, Marie McGee and Anna Smith

**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**

**3:30pm** Habilitation: What to Expect in Your Child's Mobility & Independence Programme, Suzy McDonald

**3:50pm** Dietary Support, Sarah Flack

**4:20pm** Closing Remarks, Chetan Meshram

**4:25pm** Refreshments and Networking in lobby area

### **Saturday evening**

**6:30pm to 8:00pm** Evening Meal in Seasons Restaurant and Lobby

**7:30pm** Pop-Up Children's Cinema in Lowther Room (unsupervised)

**8:30pm to 10:30pm** Family Quiz and Raffle, in Collingtree Suite

## Sunday morning

Goalball with Kathryn Fielding of GoalBall UK in Collingtree Suite

**9am-10am** Children and young people

**10am-11am** Adults with BBS

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.