**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

## **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 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**, RNC (Royal National College for the Blind)

## **12:35pm – Update from BBS UK**

**Tonia Hymers**, Operations Manager, BBS UK

## **1:00pm – Break for 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**

## **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, Dr Viola Kretschmer**

## **4pm – Personal Perspective**

**Emily Bartell**, USA

## **4:20pm – Closing Remarks**

Chetan Meshram, Vice-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**

**Emma Hughes**, Chair, BBS UK