



Saturday 13th July 2024

- 7.30 am – Registration desk opens.
- 8.30 am Supervised activity area opens.

CONFERENCE STARTS 8:45am

08.45 Welcome

Wendy Hocking Chair of Kleefstra Syndrome UK

08.50 History of Kleefstra Syndrome UK

Chris Heslehurst, founder member of Kleefstrasynndrome.org

09.00 Journey of Kleefstra syndrome and EHMT1 gene

Professor Tjitske Kleefstra, known for her pioneering work on Kleefstra syndrome, the condition named after her.

09.30 Understanding and Reducing Sleep Problems

Professor Caroline Richards, Clinical Psychologist. University of Birmingham.

09.50 The Education Health and Care Plan Pathway

Courtney Helliwell, a Local Authority SEND Team Leader, Mummy of Florence age 1 with KS.

10.05 A sibling story -

Lucas Heslehurst, brother of Leah Heslehurst

10.15 Refreshment Break – *Children remain in the Supervised Activity Area.*

10.45 Research findings of the KS Speech and Language Study

Lottie Morison, paediatric speech pathologist, and
Professor Angela Morgan, Murdoch Children's Research Institute, Melbourne, Australia.

11.15 Developing Feeding and Speech using Oral Placement Therapy (OPT).

Amy Rush, Specialist Speech and Language Therapist

11.40 Wendy Hocking/ Lindsay Quigley – Communication Tools

11.45 Professionals Q & A panel.

Prof. Kleefstra, Courtney Helliwell, Amy Rush and Prof. Caroline Richards.

12.20 Lunch Break – *Children must be collected from the Supervised Activity Area*

13.35 Welcome back.

Wendy Hocking, Chair.

13.40 Sensory Processing Differences

Laura Graham. Specialist children and young person's Occupational Therapist in Sensory Integration.

14.00 Managing Behaviour and the Be Well Checklist

Dr Jane Waite, a Senior Lecturer in Psychology at the School of Health and Life Sciences at Aston University.

14.25 Kleefstra Clinical Guidelines

Professor Kleefstra.

14.45 A sibling story

Matthew Watts, Jamie's older brother.

14.55 Refreshment Break *children remain in the Supervised Activity Area*

15.25 KS Clinical Guidelines - Mental Health and Behaviour (TBC)

Dr Stacey Bissell, Assistant Professor at the University of Birmingham, School of Psychology.

15.45 Gastrointestinal issues in Kleefstra syndrome

Dr Peter Gillet Consultant Gastroenterologist at the Royal Hospital for Children and Young people, Edinburgh, Scotland.

16.20 Professionals Q & A panel.

Prof Kleefstra, Laura Graham, Dr Jane Waite, Dr Stacey Bissell, and Dr Peter Gillett.

16:50 Prize Draws

Wendy Hocking

17.00 Conference closure *children must be collected from the Supervised Activity Area*

17.20 Group photo

19.00 Children's and Family entertainment

Dave Benson Phillips, Silly Songs, and Makaton signs.

20:00 Social gathering in Bar Vista

