



Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK Conference: Together Again!

08:45 - 09:00 Wave the children & young people off for their big day out at Drayton Manor theme park

08:45 – 09:15 **Registration**
Grab your information bag, network over coffee and choose your workshops

09:15 – 09:30 **Welcome** - Introduction to ASUK and plans for the day
Kerry Leeson-Beevers, Chief Executive
Alström Syndrome UK

Welcome – Summary of Medical and Scientific Developments
Prof. Tim Barrett
Honorary Consultant Paediatric Endocrinology and Diabetes
University Hospitals Birmingham NHS Foundation Trust

09:30 – 09:45 **Welcome our friends from around the world**
Chase Palmer, President, Alström Syndrome International
Bernd Rosenbichler, Founder, Alström Syndrome Initiative Germany

09:45 – 10:45 **Alström Syndrome – Clinic and Treatment updates**
Quiz the Clinicians – each clinician will be interviewed by a young, person, adult or family member with lived experience.

Panel

Prof. Tarek Hiwot
Endocrinology - Consultant in Inherited Metabolic Disorders
University Hospitals Birmingham NHS Foundation Trust

Dr Melanie Kershaw
Consultant Paediatric Endocrinologist
Clinical Lead Rare Diabetes Services
Birmingham Women's and Children's NHS Foundation Trust

Antonio Ochoa-Ferraro
Specialist Pharmacist
University Hospitals Birmingham NHS Foundation Trust

- 10:45 – 11:15 Refreshment Break**
- 11:15 – 12:15 Alstrom Syndrome – Research update**
- Quiz the Researchers** – each clinician will be interviewed by a young, person, adult or family member with lived experience.
- Panel**
- Prof. Tim Barrett**
Honorary Consultant Paediatric Endocrinology and Diabetes
University Hospitals Birmingham NHS Foundation Trust
- Sadaf Ali**
Clinical Fellow - Metabolic Medicine
- 12:15 – 12:35 Genetics 101**
Dr Denise Williams and Dr Hannah Titheradge
Consultants in Clinical Genetics
Birmingham Women's and Children's NHS Foundation Trust
- 12:35 – 12:50 Joining the AS Community**
Annalise & Brendan Bailey
Family Members and Experts by Experience
- 12:50 – 13:05 Culture Family Forum**
Marie McGee
ASUK National Transition Coordinator
- 13:05 – 14:00 Lunch and Networking**
An informal chance to network, explore the information stands and get involved in the Patient Registry
- 14:00 – 14:45 Workshops**
- Workshop 1 Practical Tips to support with Challenging Behaviour**
Speaker TBC
- Workshop 2 Research Developments and time to tell us your Research Priorities**
Prof. Tim Barrett, Dr Tarek Hiwot and Sadaf Ali
- Workshop 3 Education, Life at University and what happens next?**
Haris Hamid & Jane Biglin
- Workshop 4 Gadgets, Equipment, Daily Living and Having Fun!**
Carol Prescott & Simmie Gould

- 14:45 – 15:00** **Grab a drink and head to your next workshop**
- 15:00 – 15:45** **Workshops**
- Workshop 1** **Practical Tips to support with Challenging Behaviour**
Speaker TBC
- Workshop 2** **Research Developments and time to tell us your Research Priorities**
Prof. Tim Barrett, Dr Tarek Hiwot and Sadaf Ali
- Workshop 3** **Education, Life at University and what happens next?**
Haris Hamid & Jane Biglin
- Workshop 4** **Gadgets, Equipment, Daily Living and Having Fun!**
Carol Prescott & Simmie Gould

Not joining a workshop? Relax and catch up with friends in the chill-out area

- 15:45 – 16:00** **Grab a refreshment on the way back to the main conference room**
- 16:00 – 16:20** **Getting a Good Night's Sleep – Sleep Strategies**
Dr. Shyam Madathil (+ insomnia CBT practitioner, TBC)
Consultant Physician- Respiratory Medicine; Somnologist
- 16:20 – 16:40** **Courageous Conversations**
ASUK Wellbeing Service – looking after your mental health
Melissa Crowland
ASUK Wellbeing Coordinator
- 16:40 - 17:00** **Feedback and takeaways from the day**
- 17:00** **Children arrive back from their outing**
- 17:00** **Adults only zone – early bird drinks for the over 18's**
- 18:00** **Celebrations! 26 years of ASUK**
- 18:30** **Evening meal** served at 6:30 pm
Followed by entertainment, games and activities in the evening.
There will also be quiet areas to chat and catch up with friends.

The ASUK Team and Trustees will be available throughout the conference.

- The **ASUK Family Support Team**; Sarah, Clair and Marie will be available throughout the day to offer guidance, information and support and Melissa will be on hand to offer guidance on mental wellbeing and the technology and gadgets that she wouldn't be without.
- Breaking Down Barriers, Networks and Outreach Coordinator Cathy will be providing the **Tree of Traits activity** – where you can discover your family features!
- **Health professionals, researchers and clinicians** will be available throughout the day during breaks and over lunch to offer any personalised guidance or support.

Time to find out more...

- **Guide Dogs for the Blind** will be showcasing their services and will be on hand to answer any questions.
- **Technology stands** - demonstrating useful gadgets and equipment.

A prayer room/quiet area will be available throughout the week-end in the Hawthorn Room

Please note this agenda may be subject to change due to circumstances outside of our control.