



Alström Syndrome UK

Strength for today, hope for the future

Alström Global Virtual Conference Be Inspired. Be You. Be Together

Friday 3rd December 2021 6:30pm – 8:30 pm (UK, GMT)

Join us for cosy fireside chats...in this virtual preconference get together.

Fireside sessions

- 6:30 – 7:00pm **Welcome**
Ann Chivers
Alström Global, Executive Director
- 7:00 – 8:00pm *When you register you can choose which cosy chat you fancy*
- Session 1. **Growing old disgracefully**
Growing up with AS, empowering independence
Melissa Crowland
- Session 2. **Yes, you can!**
Lexi discusses sports and reaching your dreams
Lexi Griffiths-Rayson
- Session 3. **Braille in Business**
How Jamie made a business from her Braille skills
Jamie Seegar
- Session 4. **New to Alström**
Have your questions answered with Kerry
Kerry Leeson-Beevers
- 8:00 – 8:30pm **Final natter together before tomorrow's conference**
Ann Chivers

Saturday 4th December 2:00 – 7:30 pm (UK, GMT)

2:00 pm – 2:20 pm **Welcome from Ann Chivers**
Community Focus: World Impact

Around the world with Research, Science and Home Health

2:20 – 2:40 pm **Welcome to the world new bambino!**
The world's first baby born to a couple where mum is affected by AS.
Prof. Pietro Maffei
Consultant Endocrinologist
Padua University, Italy

2:40 – 3:00 pm **Q&A** session

3:00 – 3:20 pm **Welcome back our colleagues and communities in China**
Research updates
Qianwen Zhang,
Dr. Xiumin Wang, Chief of Department of Endocrinology, Genetics
and Metabolism.
Shanghai Children Medical Center

3:20 – 3:40 pm **'40 Families affected by AS discovered in small village in Palestine'**
Jara village in Palestine has 40 individuals affected by Alström.
Reham Khalaf-Nazzal
Local leader of "Stories of Hope, Stories from Palestine"
Genomic Research project, North of Bank, Palestine
Dr. Emma Baple
Clinical Senior Lecturer (Genomic Medicine)
Consultant in Clinical Genetics Royal Devon and Exeter Hospital,
England.

3:40 – 4:00 pm **Q&A** session

4:00 – 4:20 pm **Do you know your BP from your BMI?**
Blood Pressure and Body Mass Index are often measured by Clinicians, this is a why and how to session on the importance of doing this and how you can monitor this at home.
Prof. Tim Barrett
Professor of Paediatric Endocrinology, AS Paediatric Clinical Lead
Birmingham Women's and Children's NHS Foundation Trust

4:20 – 4:30 pm **Q&A** session

4:30 – 4:40 pm **Quick Break**

Active around the world

4:40 – 5:00 pm **Accepting and Connecting**
Marina from Italy talks about her own family journey of acceptance and resilience.
Marina Valenti, Italy

5:00 – 5:20 pm **The Three Amigos!**
Our journey with three boys affected by AS.
Jennifer Potter, America

5:20 – 5:40 pm **Horsing around**
How to be a dressage champion whilst recovering from COVID-19
Lexi, ASUK Vice Chair

Around the world staying safe and well

5:40 – 6:00 pm **Quick Break**

6:00 – 6:30 pm **I've won the lottery again!**
Spotting fraud and scams to keep you and your loved ones safe
Cathy Chadwick-Rayner
Networks and Outreach Coordinator for Breaking Down Barriers

6:30 – 6:50 pm **Do you know how many people in the world have AS?**
Be a piece of the puzzle, with the AS Patient Registry
Robin Marshall, Alström Syndrome International
Ann Chivers, Alström Syndrome Global
Catherine Lewis, Alström Syndrome UK

6:50 – 7:10 pm **Final Questions**

7:10 – 7:30 pm **Future hope, discoveries and working together**
Round-up with Ann Chivers

A HUGE THANK YOU to our generous sponsors AS Canada