



Transitioning to Adulthood: Independent Living

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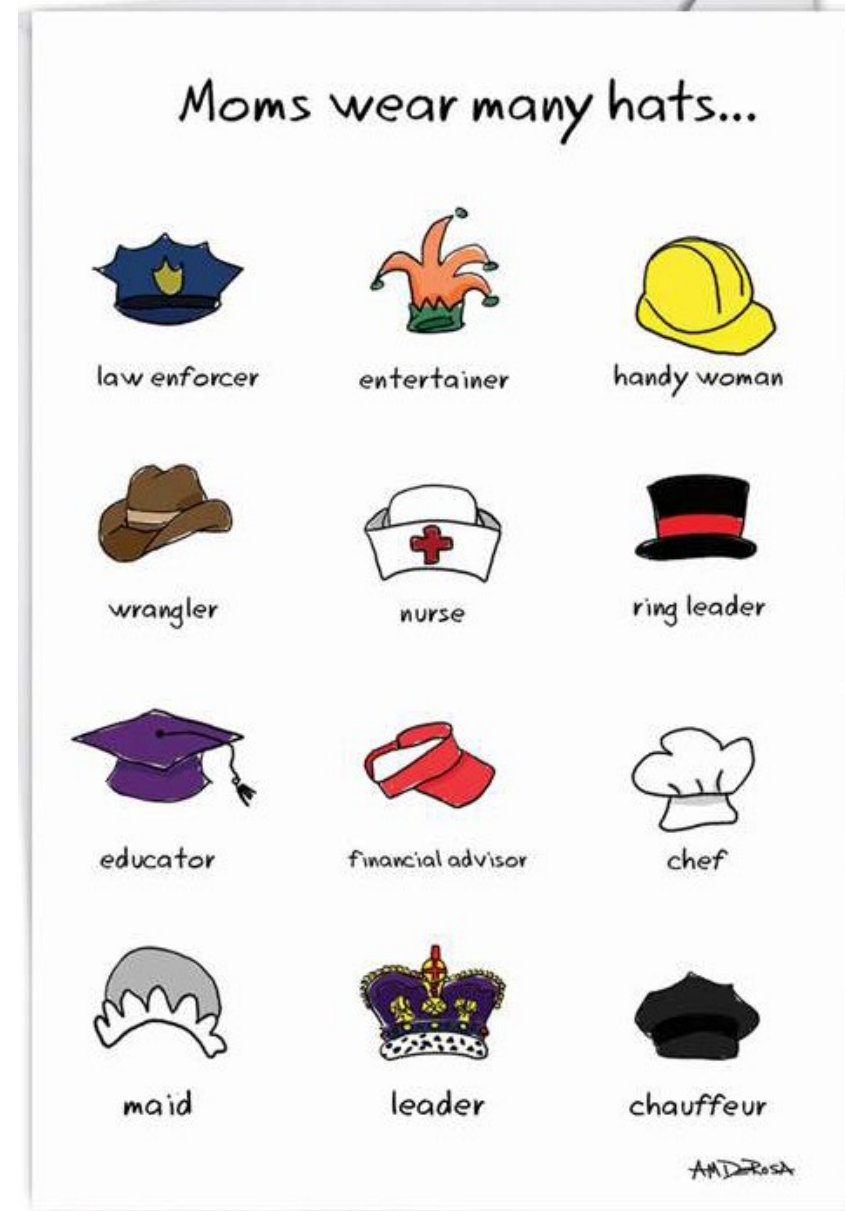
Overview

- Meet Kerry & Kion
- Introduction to ASUK
- A parent perspective on independence
- Introduction to T-KASH
- Meet Melissa
- An adult perspective on independence
- Mental Health & Rare Conditions
- ASUK Wellbeing Project
- AS Global
- AS Patient Registry
- Final Thoughts...



Hello!

- Mum
- ASUK and BDB
Chief Executive
- Rare Disease Patient
Representative/Advocate
- Patient Representative on
the England Rare Diseases
Framework Delivery Group



How it all began...

Lived Experience



**Complex,
ultra-rare &
progressive condition**

Patient Organisation



**Began in 1998
National organisation
Supporting 92 patients**

Community Network



**Began in 2016
Network of over 70
rare/genetic organisations**

Global Connections



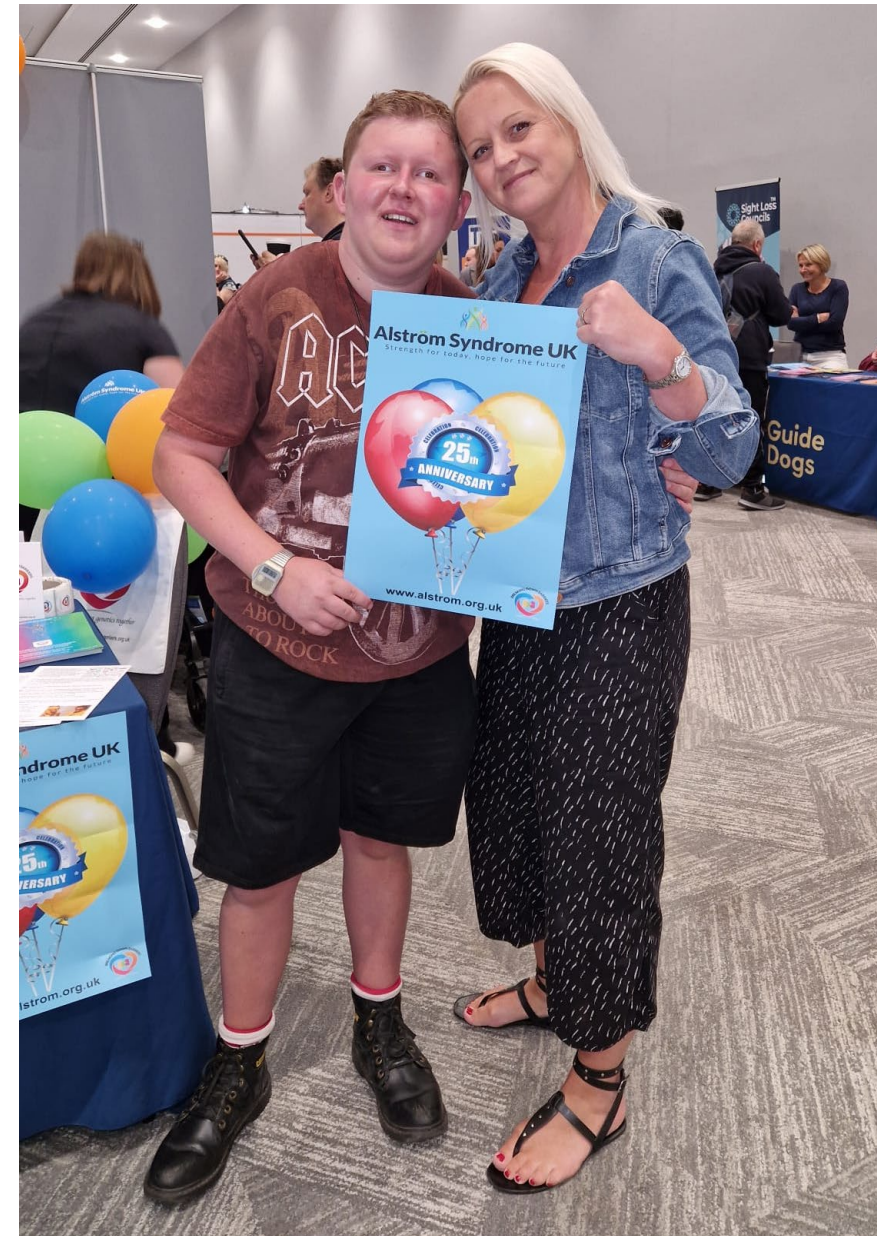
**Began in 2022
Connect virtually to
the global
community, to
collaborate, connect
and learn together**

Meet the ASUK Team



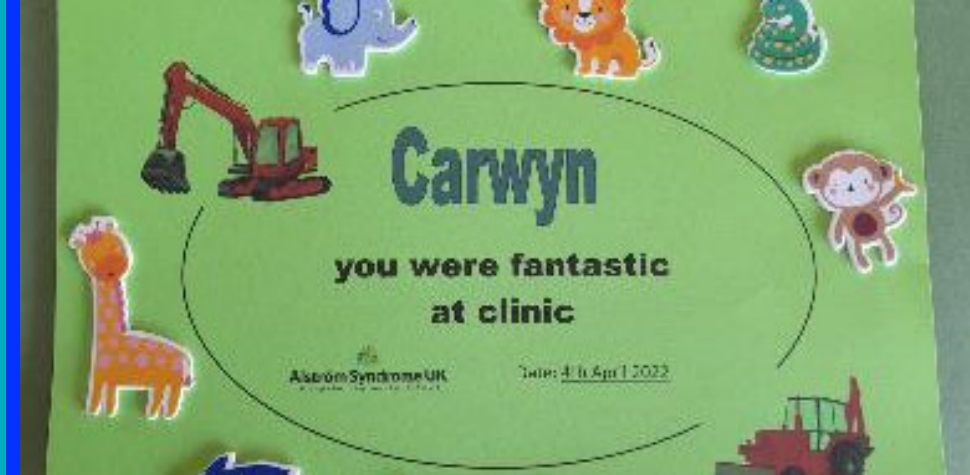
Alström Syndrome UK

- Clinics originally started with consultants/tests in a Torquay hotel with a few clinicians/volunteers from Torbay Hospital
- In 2006, ASUK joins forces with Birmingham Children's Hospital and Torbay Hospital to establish NHS highly specialised service (multi-disciplinary clinics)
- In 2012, the adult clinics moved from Torbay Hospital to Queen Elizabeth Hospital, Birmingham
- ASUK has a contract with NHS England
- Working in partnership with Birmingham Women's & Children's and Queen Elizabeth Hospital, Birmingham
- ASUK Care Coordinators offer Family Support and Clinic Coordination
- ASUK's relationship with families helps to support clinics and maintain 100% attendance



Care Coordination & Support

- Family Support Team - 2 Care Coordinators & a Transition Coordinator
- Liaising with professionals from health, education and social care
- Contribute to assessments
- Direct Payments
- Grant applications / exercise equipment
- Family breaks and activities - the big activity challenge!
- Person centred plans for all
- Transition tools and resources (T-KASH)



Map of UK Patients

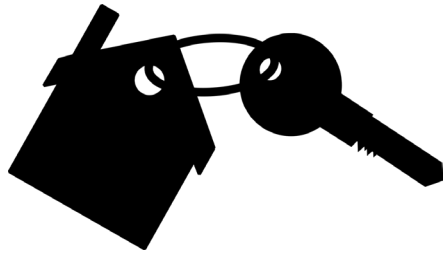
88 People
(31st March 2023)



K21
UTM

What does independence mean to Kion?

K10N XX



What Kion's independence means to me?



STRESS

The T-KASH logos



- Co-produced with young people/families and staff from ASUK
- Covers 12 key aspects of a young person's life
- Each logo represents topics to have developmentally appropriate conversations with young people
- Identifies and develops the young person's knowledge and skills to manage their healthcare
- Supports key change points in a young person's life including moving into adult services
- Conveys questions from the young person to the healthcare team/other providers
- Informs Education and Social Care Plans (EHCP) and Social Care / Care Act Deaf/Blind Plans – other assessments



Hello!

- ASUK Trustee
- Expert by Experience
- A qualified Therapeutic Humanistic Counsellor (therapist)
- A qualified Social Worker

What does independence mean to me?

- Work life
- Training
- Living with Alström Syndrome



Let's talk numbers!

- There are approximately 8000 rare conditions worldwide (National Institute of Health)
- There are approximately 300 million people living with a rare condition worldwide
- In the USA, there is approximately between 25 and 30 million people living with a rare condition, this is 1 in 10, or 1 person in each elevator, and 4 in every bus
- In the UK approximately 3.5 million people live with a rare condition



Mental Health...

What do individuals say?

Study conducted by Spenser Tansley Et Al 2022

- Questionnaire of over 1200 people living with a rare condition and over 560 carers
- Investigating how having a rare condition impacted on an individual's mental health
- **90%** stated that they felt; anxious, depressed, stressed or worried
- **36%** of individuals with the condition and **19%** of carers stated that they wanted to end their life
- **23%** of participants stated that the health care practitioners facilitated conversations about mental health including sign posting to services
- **1/2** of participants stated that mental health wasn't mentioned at all in their health care appointments
- **88%** stated that they had negatively been impacted by their interactions with health care professionals

Recommendations

- There is a need for more mental health interventions for those impacted by rare conditions and relevant signposting





Wellbeing Project

Consulting with the AS community to:

- Check what they know about mental health
- Find out how we can help
- Provide supportive sessions - talking about feelings & emotions, living skills and coping strategies for individuals, their families and/or care givers
- Provide signposting and further information



**Impact Report
The Knowledge Exchange
2022-2023**

AS Global

The Knowledge Exchange

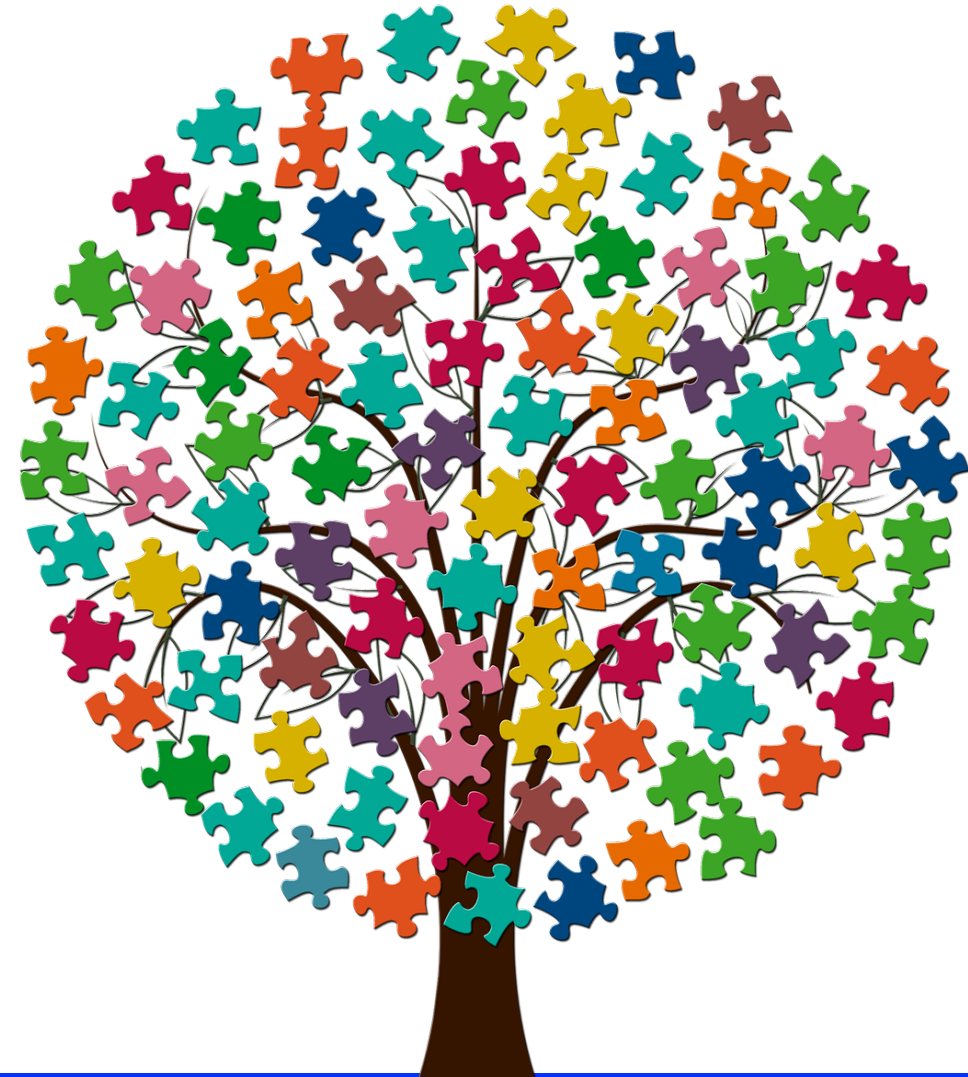
- To collaborate with families and professionals to continue improving our knowledge of Alström Syndrome and its' complexities, to develop better management and treatments.
- To support and/or help develop AS associations all over the world so that they in turn can support families, patients and improve knowledge in every country. Raise awareness.
- Learn together - every individual with AS to be on the CORDS supported patient registry which means that we are clinical trial ready anywhere in the world.
- Offer a virtual platform for all to be able to network, collaborate, share stories of hope and learn from each other.

How many people in the world have AS?

The purpose of the Registry is to:

- Develop and encourage more research into Alström Syndrome
- Collect relevant information for specific research projects
- Use the information provided to understand Alström better
- Establish a network between clinicians, other health professionals and researchers
- Provide better treatments and management for Alström Syndrome
- Improve knowledge and understanding globally
- Build a clearer global picture of Alström – including how many people are affected.

Researchers will be able to apply to have access to this information but won't be able to know who has provided it.



Baby Amelia is born!

- Baby Amelia was naturally conceived and born on 7th June 2023
- Weighing a tiny 2lb 3.5 oz
- After 54 days in neonatal intensive care, she was brought home by proud Mum, Lexi and Dad Adam
- Mum, Lexi has Alstrom Syndrome
- Family are doing really well



Final Thoughts...

- Learning from each other – we all have a part to play
- Sharing lived experiences and providing support services
- Impact of progressive health conditions and disabilities
- Understanding health inequalities
- No one size fits all
- Independence means different things to different people
- Mental health is as important as physical health
- Let's collaborate and connect
- Please complete the patient registry
- Thank you for all that you do!



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