



# Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK (ASUK) is a charity who provide information, support and advice for individuals affected, their families, carers and professionals. Alström Syndrome (AS) is an ultra-rare genetic condition which can cause progressive sight loss, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very difficult. Our mission is to raise awareness, conduct pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics. Further information about our work can be found at [www.alstrom.org.uk](http://www.alstrom.org.uk)

## Annual Review • Impact Report 2020-21

Advancing Diagnosis, Care, Treatment and Support  
for those living with Alström Syndrome in the UK

ASUK is an ambitious and highly focused charity, determined to improve the lives of those affected through personalised family support, research initiatives and raising awareness.

**84** people (known to us) in the UK have Alström Syndrome (AS).

We have supported **82** families throughout this year.



Most professionals will never meet a person with this ultra-rare condition.  
It is likely that there are more individuals with AS, who remain undiagnosed — we are working hard to change this!



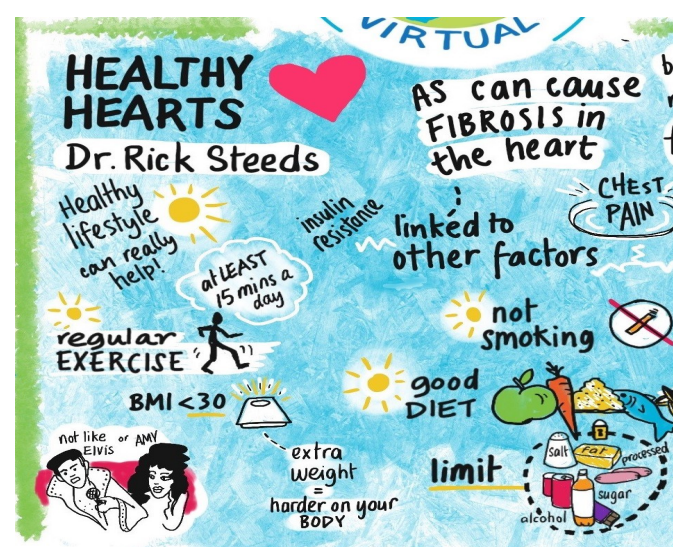
## Bringing the Global community together

Due to Covid-19, ASUK had to act quickly to ensure families had the support they needed throughout the pandemic. With no face to face visits, home, school or clinics taking place, we worked with the AS specialist teams in Birmingham to ensure everyone could be seen in a virtual telemedicine clinic to check on their health and wellbeing.

The need for our support services and factual information about Covid-19 increased substantially. We ensured that families received our continued dedicated support by offering personalised online support, webinars and telephone calls throughout the pandemic. We worked closely with the clinical teams in Birmingham to support the introduction of telemedicine clinics and the distribution of home health monitoring equipment. We also worked with local services to ensure families could access appointments where needed.

As shielding continued we gathered the Alström Global community together, organising the first ever virtual conference. Our aim was not only to bring the community together but provide a global insight from researchers, clinicians, and families from around the world.

- **183** attendees from across **23** Countries
- **15** presenters & **4** Interactive workshops
- **7** Family 'experts by experience' speakers
- **13** Hours of collaborating knowledge and experience
- **100%** Would attend another AS Global conference
- **9/10** Average score for how much attendees enjoyed the conference



## ASUK strive to empower those with AS to reach their potential and dream big! The year in numbers!

- **64** children and adults attended **8** Alström Syndrome (AS) specialised tele-medicine clinics, enabling them to get individual, medical expertise.
- **4** newly diagnosed individuals and their families contacted us, to learn more about Alström Syndrome, how it may affect their lives and seeking our support.
- **7** Team Around the Family meetings attended, leading to robust Education, Health and Care plans and further support for young people.
- The ASUK Family Support team provided **11** virtual home and **7** school sessions to ensure families had the right support and are receiving everything they are entitled to.
- **45** individuals completed the AS Patient Registry which we hope will lead to learning more about this rare condition.
- **100%** of families who completed evaluation forms told us they were 'happy' or 'very happy' with the AS clinics

## We organised virtual activities and information sessions

- **19** children built a bear character and joined the Teddy Bears virtual picnic.
- **Sparkle Sisters Culture Club** Time to Talk sessions were developed for young people.
- **14** Webinars, providing Covid-19 guidance, information, and ways to stay safe and entertained.
- **13** Time to Talk sessions for over 18's.
- Gave **17** small grants for items such as, craft sets, Tonies books, gym balls, talking watch, playhouses, trampolines...
- **11** Members of the AS community took part in the 'Staying in, working out' video.



### Developed with families and clinicians 'Stay Fit, Stay Healthy, Stay Happy' wellbeing packs.

These were distributed to **every** family and included favourite family recipes, top tips to stay active and technology which helps independence. We also developed 'Bodkin' our exercise and posture mascot!





## Developing Independence

Despite the challenges our community has faced, it has also been a time for some to flourish and thrive.

Several young people were transferring to adult services during this time, and at such a pivotal time in a young person's life, we didn't want the lack of face to face support to impact their experience of moving to adult services.

Our Transition Coordinator Marie McGee worked with the young people to explain about the transfer to adult services and discussed with them the telemedicine clinics and how they can have their voice heard. Marie supported the young people to think through the sort of questions they would like to ask and helped them to build their confidence to own their consultations and appointments.

This support was clearly demonstrated in their telemedicine clinics as the youngsters took full charge of their consultations, asking and answering questions with confidence and maturity.

### Speak up and be heard!

*"I liked the clinic online because I could speak up for myself. My teacher helped me, but I did all of the talking. It's good for all the Alström children to speak up because it's important for people to listen to them and hear about their body and their feelings."*

## If you go down to the woods today...



ASUK have had to be creative in finding ways to keep our youngest members engaged and entertained throughout the pandemic. One of our highlights was the Teddy Bears Picnic. In preparation for the picnic, we sent families a party bag with lots of goodies; a party crown, musical instruments, foam animal face masks and colouring sheets. They also received their very own build a bear or character which they could choose and personalise on the Build a Bear website. Every bear was invited to the picnic! Lots of siblings, parents and carers came too and had organised party food!

*We all just wanted to say thank you for arranging the party this morning. He was engaged the whole way through - we had to keep him on mute most of the time because he talked to you none stop! He had a really lovely time, and it was so good to see you all.'* ASUK Family Member.

## Small things that can make a big difference

### 'My Google Assistant is like a friend to me!'

Ruby and her older sister Khaynaat share their thoughts about their new Google Assist, which ASUK was pleased to fund with a small grant.



My Google Assistant (GA) is my friend, I speak to it and it gives me lots of answers. I ask it questions like what is the weather like today or what has happened in the news, it always gives me the answers. I also ask GA to play music things like Little Mix songs which is one of my favourites. I had to teach it to find Bollywood music for me, now it can find radio stations and all sorts of different Bollywood style music. If you use your GA a lot, it starts to know what you like, and it can find things easily for you.

I have lots of fun with my GA, I ask it to tell me jokes and I like to ask GA what type of music it likes! My GA makes me laugh because it sometimes gives funny answers! The GA keeps me entertained when I am doing things in my room. It has helped me to find lots of things - it has helped me to stop being bored and find things out for myself.

Khaynaat, Ruby's older sister commented; *'My family and I have been really surprised how Ruby is using her GA. I thought she would never use it, as she found the voice over on the iPad annoying and frustrating to use. Before Ruby had a GA she would listen to music on her radio, I would have to help her find radio stations. Now I've noticed that she is a lot more independent, searching on her GA for music or asking questions about things she wants to know. Using Ruby's GA has improved her overall confidence to ask questions. I've heard her chat more to family members and **she informs us** as to what is happening in the local area as she listens to the news. Ruby also gives us her opinion as to what has happened, which is great as we end up chatting much more about things.'*

Ruby sums up;

*'I would tell other people to use their Google Assistants, because it is fun to listen to music, find out what the date is or what the weather is going to be like. Using your GA will stop you from struggling to find out things. Instead of asking other people questions, now I can ask my GA questions, which makes me more **independent**, and I can do it by **myself!**'*



## Breaking Down Barriers project:

- Worked with **37** patient organisations, support groups and community networks to develop resources to improve engagement with people from diverse communities, as well as sharing good practices to ensure everyone can access healthcare services.
- Worked with training providers to deliver **11** group training sessions with **112** attendees from within the BDB Network.
- BDB organisations took part in a Rare Disease Day film, **'Share your Colours, Share your Culture'** to celebrate everything rare and what culture means to you.



**Share your Colours...**  
**Share your Culture...**

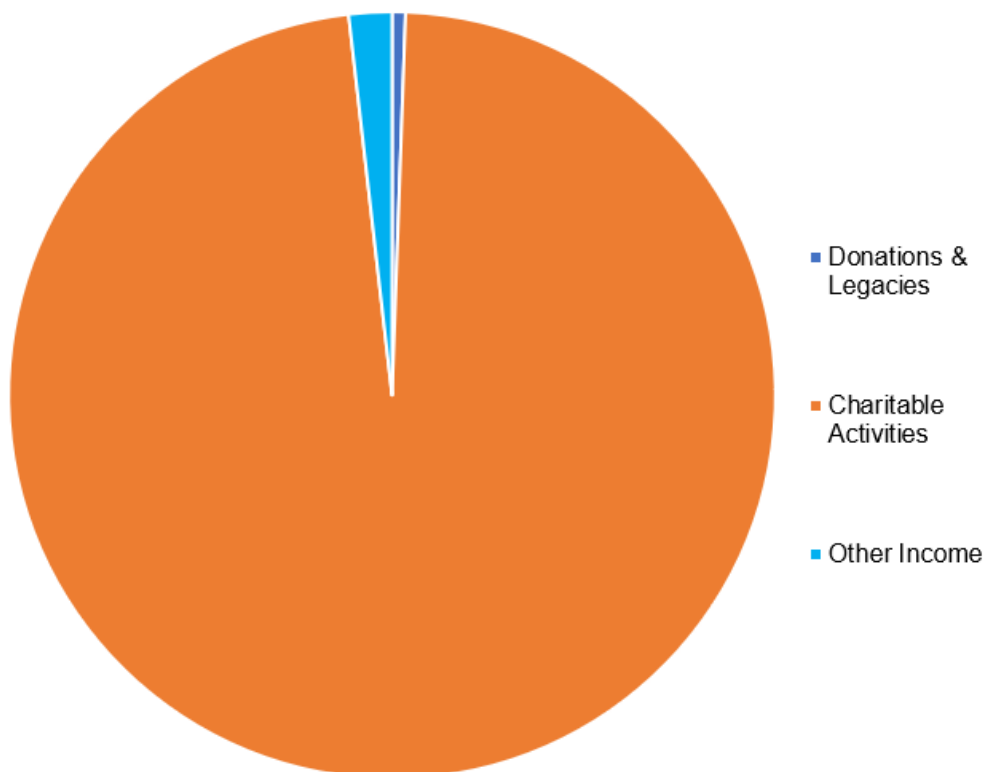
**RARE DISEASE DAY 2021**  
**28 FEBRUARY**



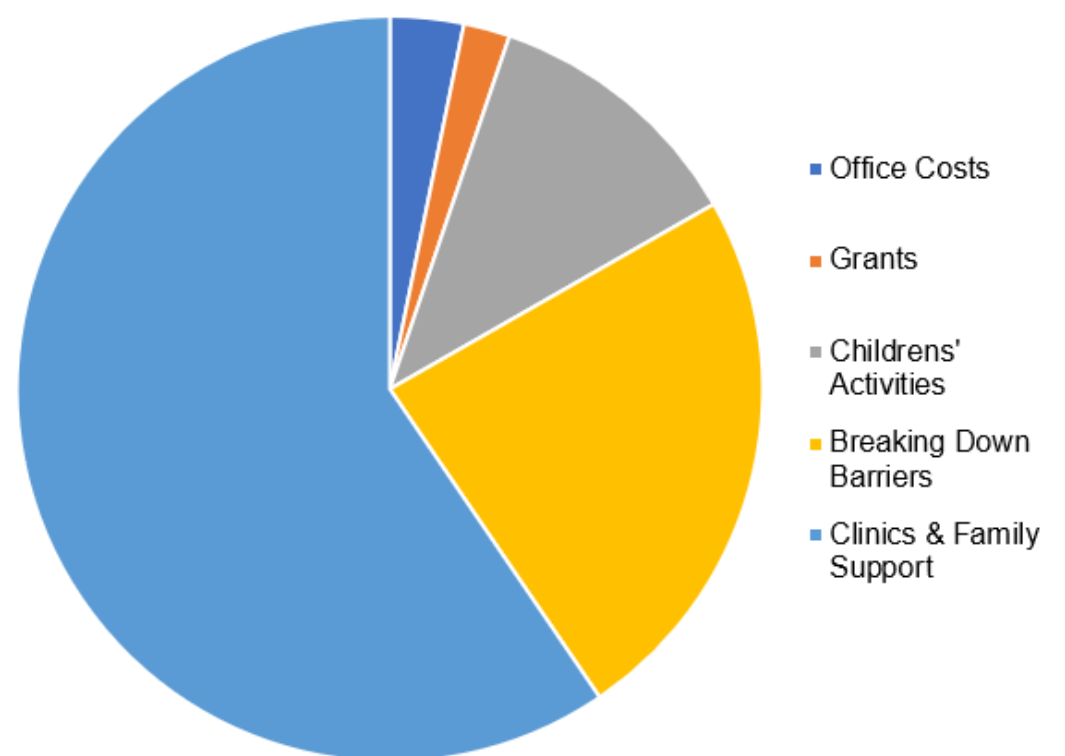
## Behind the scenes

- There were **8** Trustees on the ASUK Board
- 8** people work for ASUK, supporting families, promoting research and raising awareness
- ⇒ Our website reached **45,000** views from **175** countries
- ⇒ Our **'Living with a Rare Disease'** animation helped to raise awareness of AS reaching an incredible **891** views, **5808** since it was created in 2017.

**Alström Syndrome UK  
Income  
2020/2021**



**Alström Syndrome UK  
Expenditure  
2020/2021**



*All information is provided from the financial period 31st March 2020—1st April 2021.  
The full annual report and accounts can be found on the ASUK website [www.alstrom.org.uk](http://www.alstrom.org.uk)*

# Thank you!

We are always immensely grateful to everyone who continues to support ASUK each and every year, whether it's through donating, holding a charity event, or giving generously from a Trust Fund. We make every penny count to ensure that we learn more about Alström Syndrome, that families and individuals get help when needed and have the opportunity to share stories and experiences.

On behalf of families and those affected by AS and at ASUK we would like to say a huge thank you to all of the medical professionals at the Queen Elizabeth Hospital and Birmingham Children's Hospital, the NHS and local services who have worked with such energy and compassion throughout the pandemic. We are deeply grateful to you all.

Finally our thoughts are with families that have suffered loss and bereavement, we are here if you need us.

