



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 and carers and professionals. Alström Syndrome is a very rare genetic condition which can cause progressive blindness, 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

Welcome to the Winter 2021 ASUK Newsletter

Hello Everyone,

Firstly, I hope you, your family and friends are all keeping safe and well.

This is my first update as your new Chief Executive after taking over the role from Ann Chivers in November 2021. Ann has been supporting me in my new role throughout our handover period, and in January 2022, Ann becomes our Executive Director. Her work will focus primarily on developing our international work as part of Alström Global. This will enable us all to learn worldwide perspectives about Alström Syndrome, make connections, extend our community, and build on our knowledge and expertise.

I am absolutely thrilled to be starting in my new role as CEO. Working with individuals and families affected by Alström Syndrome has always been the one thing I have valued most throughout my time at ASUK. Family support and our highly specialised clinics will continue to be a priority moving forward. I look forward to continuing to work in collaboration with individuals, and organisations to address health inequalities and striving for equitable access to services and support for people affected by rare and genetic conditions.

I feel privileged to work with such an exceptional community, staff team and trustee board and together we will continue to drive the charity forward. I would like to take this opportunity to reassure families that my priority will always be maintaining our high standards of family support and ensuring you get the support and assistance you are entitled to. I will continue to be a hands-on member of the team and will always, only be a phone call or email away.

Due to the pandemic, we are still mainly working virtually. We are missing meeting up with you all in person, but we are so pleased with the ways we have all managed to keep in touch by phone and virtual get togethers. Following strict Covid-19 restrictions, we have managed to restart some face to face clinics. We know that some of you still feel anxious about travelling to Birmingham during this time so the teams in Birmingham are being flexible and continuing to offer virtual appointments where possible.

Global Communities

It was great to see so many of you on the 3rd and 4th December 2021 at the virtual global conference. Like many of you, we look forward to the day when we can all meet face to face again. This virtual world has enabled events for people from all over the world to join together. I watched in amazement as we had speakers from Italy, America, China, the UK and from the Palestinian Territories, all bringing their insights and stories to the AS community.

As the mother of an adult son with Alström Syndrome, I felt a real sense of hope and belonging. However, I also felt sadness when listening to parents at the start of their journey in countries where there is very little support or knowledge of the condition. This just highlights the importance of our global work as nobody should be left feeling they are alone on their journey. Thank you to everyone who attended and got involved by asking questions and sharing personal experiences. Thank you to all the speakers who gave their time to bring their knowledge, expertise, and their communities to all of us. We are so grateful to you all.

We are hoping in the new year to bring the global community together more frequently on a range of topics in interactive sessions, we hope you will join us for these too.

The Breaking Down Barriers project is going from strength to strength with over 50 organisations now part of the network. On the 25th January 2022, we will be providing a webinar to showcase our 'New Year, New Offer' providing a glimpse into what the Breaking Down Barriers team can offer the network through support, guidance, training and more. You are all more than welcome to join us. Details will be published shortly.

As we reflect on a year full of ups, downs, challenges, and opportunities, let's make the new year a time to connect together. Why not reach out to those you may not have connected with for some time and check they are OK. Many people say having an ultra-rare condition like Alström Syndrome is very isolating - in the new year, why not join one of our community webinars and meet old friends and new from around the world. Joining together, we can support one another and learn from each other's experiences.

Thank you

As always, a BIG thank you to all our families, friends, and supporters as well as the healthcare professionals in Birmingham. The pandemic has been an incredibly challenging time and we are so thankful for the way they have continued to provide support, guidance, and reassurance.

Who knows what the future holds and how long coronavirus will shape our lives? We are stronger together so let's stay in touch. Stay safe and look after yourself and your loved ones.

Remember that you are not alone, we are here for you. Wishing you all a healthy and happy Christmas and New Year!

Kerry and the ASUK team



Alström Global Conference

Be Inspired. Be You. Be Together

Quick snapshot—full report will be published in the new year.

In true virtual style, we brought together families and professionals from **21 Countries** from around the world to learn from one another and share their stories at the AS Global conference.

On Friday 3rd December 2021, we had cosy fireside interactive chats with families coming together for a pre-conference gathering to share stories and experiences.

Saturday brought presenters from China, the UK, America, Italy and the Palestinian Territories. Our aim was not only to bring the community together but provide a global insight through presentations from families, researchers and clinicians from around the world.

In our experience often having an ultra-rare condition can be a lonely place, feeling that no one really knows what you are going through. Events such as the global conference are a great opportunity to bring everyone together to show the strength and resilience that is evident throughout the community and to reinforce that you are not alone.

The first sessions of the day, centred around research and discoveries. **Qianwen Zhang** and Dr. Xiumin Wang, Chief of Department of Endocrinology, from Shanghai Children Medical Centre, discussed the continuing research across China.

Exploring the onset of symptoms compared with the rest of the AS world wide population throughout Turkey, America and Poland. She also discussed her research into facial features and whether this could be a diagnostic tool going forward.

It was lovely to see the AS Greater China Association coming together and holding events throughout the year (photo below).

The first conference and party of ALMS patients in China!! 2021-07-30

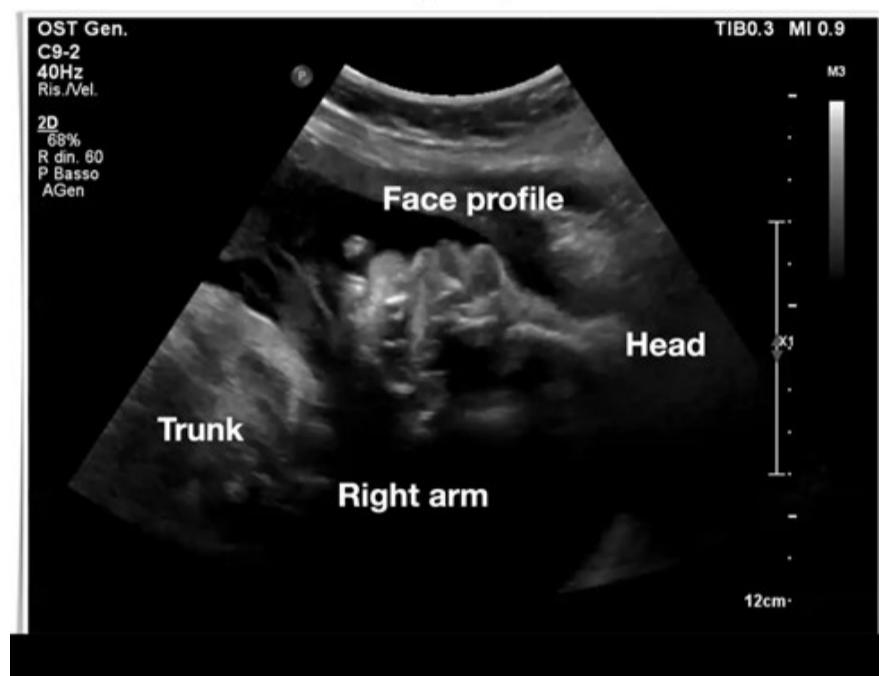


Dr Pietro Maffei Consultant Endocrinologist from Padua University in Italy, was up next with his eagerly anticipated presentation about the first baby born to a couple, where the Mother is affected by Alström Syndrome. It was fascinating to hear about the pregnancy. Although as he explained that often due to insulin resistance, and fibrosis in the body, it can make it a challenge to become pregnant. This Mother who had a mild phenotype, carried the baby until 35 weeks when health complications meant they needed to perform an emergency c-section. The baby was born on the 22nd February 2021. Both Mother and baby are doing well and were discharged from Hospital after 6 days.

The family would like to remain anonymous but we hope one day we may get to see a picture. The only one we have

currently is from the ultrasound (picture below) which shows the baby developing at the regular rate with no health complications.

January 12, 2021



Next we welcomed **Dr. Reham Khalaf-Nazzal, MD, PhD**, Physiology and Medical Genetics from the Faculty of Medicine from Arab American University/Jenin and **Dr. Emma Baple**, Clinical Senior Lecturer (Genomic Medicine), Consultant in Clinical Genetics from the Royal Devon and Exeter Hospital, England. They discussed the partnership between Exeter Hospital in England and the community work happening across the Palestinian Territories. They have found clusters of families affected by AS in a small village in the Palestinian Territories and they are using the facilities at Exeter Hospital, to implement diagnostic genetic testing.

This community work between the two organisations, doesn't stop here, they work together to educate people on the ground, in the communities and clinicians in the Hospitals. They would like to work with ASUK to promote the patient registry, translate the medical handbook and work with the clinicians in Birmingham to look at further testing, training for health care professional and looking at ways we can help these communities going forward.



Stories of Hope, Stories from Palestine



Prof. Tim Barrett, Professor of Paediatric Endocrinology, AS Paediatric Clinical Lead from Birmingham Women's and Children's NHS Foundation Trust, talk was titled 'Do you know your BP from your BMI?'

Prof. Barrett explained about how we can monitor our own health at home and what the readings mean for us. He gave some top tips throughout, about how we can lower our blood pressure, such as reducing our salt, eating lots of fruit and vegetables, avoiding saturated and trans fats and tobacco, reducing our alcohol intake and having regular exercise.

He also suggested taking your blood pressure first thing in the morning as this is when we are most relaxed, appose to when we have just finished a meal or taken part in exercise. Everyone has their own targets, so talk through specific readings with your local health care provider.

The next three talks were a real highlight, with families from our community sharing their stories. First up was **Marina** from Italy who shared her own family journey of acceptance and resilience. She gave her top tips and uplifting phrases she has picked up along the way.

Then we heard from **Jennifer** from America, about her three Amigos—sharing her family story of her three boys being affected by AS. Their fun loving, get up and go attitude, showed through; especially as Chad has recently faced one of the toughest years of his life. Chad went into heart failure and spent 111 days in cardiac ICU, but after rehab he is now doing well with a heart pump.



Jennifer's top tips are to embrace everyday, remember that you are the expert, your kids can accomplish anything they put their mind to and take advantage of all the resources and support available to you.

Lexi, our own ASUK Vice Chair was up next to showcase how she overcame Covid-19 and became a dressage champion. Lexi explained about her journey of riding and her love for

My Achievements

- 1st in 2020 virtual competition
- 1st at the RDA Virtual Regional Qualifiers 2021
- 2nd in a Virtual Dressage Test November 2021
- 3rd in the RDA Virtual National Championships 2021



horses and how with lots of practice, anything can be achieved. Lexi has recently come 1st, 2nd and 3rd place in Dressage Championships—showing us all how it is done. Her motto '**If I can do it, anyone can do it!**'

We were delighted to welcome **Archana Kulkarni**, Consultant Ophthalmologist, Paediatric Ophthalmology and Adult Strabismus from South Warwickshire NHS Trust, Warwick Hospital and Birmingham Women and Children's Hospital.

Archana discussed sight, support and beyond, looking at the different lenses, tints and support aids which can help people affected by vision loss.

Cathy Chadwick-Rayner from our Breaking Down Barriers project brought us a quick snapshot of scams and how to keep you and our loved ones safe. She highlighted the different forms of scams and top tips to keep safe. Reminding us all to take 5 before acting, take a moment to think, is this legit or could it be a scam.

I've won the lottery again!

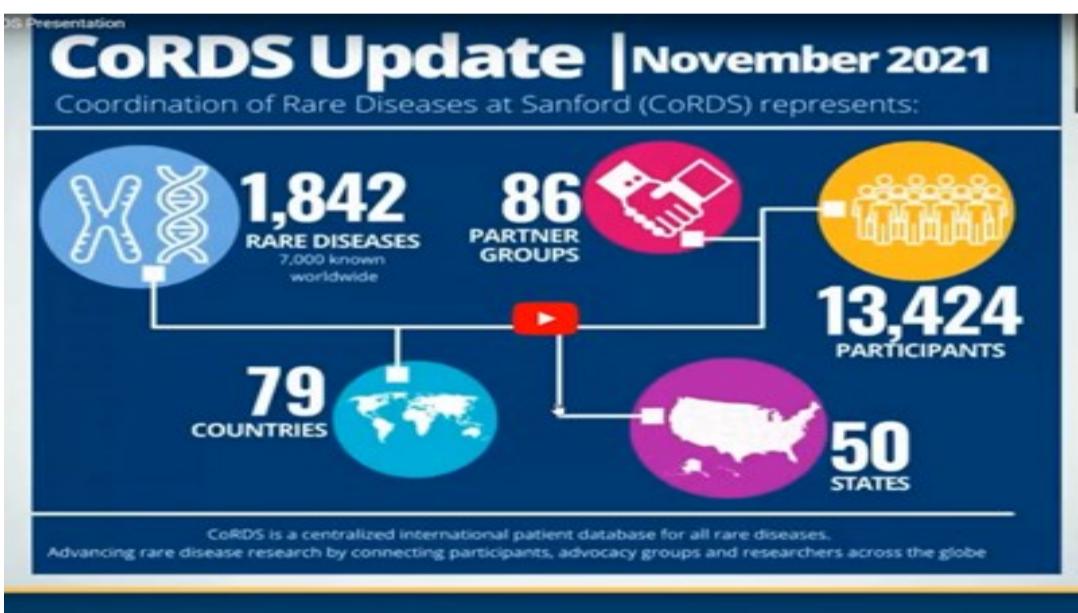


Scam Busting Session

Cathy Chadwick-Rayner
Breaking Down Barriers

AS Global Conference 2021

Alyssa Mendel, Research Project Manager, from Coordination for Rare Diseases at Sanford (CoRDS) gave us a whistle-stop tour of the Sanford Research Unit and explained all about the AS Patient Registry and why it is important for all to be involved.



Robin Marshall (Alström Syndrome International) and **Ann Chivers (ASUK Executive)** also went on to explore this topic further. Robin explained '*I implore you, wherever you be in the world to take the time, find the person you need to help you translate it and help you fill-it out. Get it done soon, because the sooner you do, the sooner you greatly improve the chances that we will indeed find further treatments. There are lots of wonderful things happening in the world right now, because there are lots of Scientists jumping in.*'

The time is now!!



Patient Registry – don't delay, enrol today!

With the world suddenly finding themselves in lock-down, let's take this opportunity to break out of ground hog day and complete the ASUK Patient Registry. This is an ideal time to get all your medical information and medications all in one place.

We have two videos, featuring Ann and Kerry who answered your Patient Registry questions:

<https://www.youtube.com/watch?v=PhstDDBWtBQ&t>

Or you can check out their shorter version in this podcast:

<https://www.youtube.com/watch?v=9529wvuSQ3Q>

Knowledge is power!

The ASUK Patient Registry enables you to provide your health information in an easy and straightforward format by completing questionnaires about your health in a safe and secure way.

This information will be available (anonymised) for researchers and clinicians worldwide to learn more about Alström Syndrome and develop treatments into this rare condition. It is free to join for both you and professionals. This information will help build a worldwide picture of Alström Syndrome, improving knowledge and understanding of this rare and complex condition for everyone on the planet!

You have the potential to make a real difference to everyone living with Alström.

How to join?

Find the CoRDS Connect website and complete the CoRDS activation form, it is quick, secure and easy to do, just go to the website below:

<https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>

Don't delay, enrol TODAY!

A big thank you to those who have already completed the registry. Why not volunteer to help others? If you can offer any support to help others to complete the registry, please get in touch with Catherine. If you need any support to join the registry or if you would like any further information, please get in touch with ASUK Office Manager, Catherine Lewis on 07970 071675 or email catherine.lewis@alstrom.org.uk

Join our team!

We Need YOU!



Do you relish the challenge of making a positive impact on people's lives supporting individuals with a rare condition and those who love and care for them?

If you do, then come and join our award-winning charity, Alström Syndrome UK (ASUK) which provides information, support and advice for individuals, their families, carers and professionals.

Alström Syndrome (AS) is a very rare genetic condition which can cause progressive blindness and hearing loss. Most people with Alström Syndrome will have dual sensory loss. It can also lead to heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis and treatment difficult. ASUK raise awareness, support pioneering research, and enable better treatments and monitoring through multi-disciplinary NHS clinics.

We have one position available as part of our highly commended family support service. This role will be responsible for supporting the coordination of the Alström multi-disciplinary clinics in Birmingham and linking with local healthcare professionals. As well as offering dedicated personalised family support and developing and continually updating person centered plans.

Role 2-3 days per week (flexible)

Location Based at home

This role will require frequent travel in Birmingham and the Midlands

Salary £22,448-£25,448 (Full Time Equivalent)

Depending on experience and knowledge.

Closing date Monday 10th January 2022 by 9am

Interviews 18th/19th January 2022 (this may be a face to face or virtual interview, so please keep these dates free)

About you

You will have experience in a similar role where you will have learnt the importance of supporting individuals and families according to their needs, whether that is professionally, as a volunteer or as a relative with lived experience. Ideally you will have some experience of working with people with dual sensory loss and be confident in talking with individuals who may have a range of differing abilities. You will recognise the importance of good support and continually look for ways to improve this vital family support service. You will have brilliant people and administration skills.

It will be a distinct advantage if you have personal experience or a connection to a rare and/or complex condition.

If you like a challenge, want to make a difference to people's lives and feel passionate about the rights of families then we would be eager to hear from you.

Please find further information and details of how to apply on our website <https://www.alstrom.org.uk/join-our-team/>

Braille in Business, Insights from the Alström International Community from Jamie Seegar



For those who do not know me my name is Jamie Seeger. I am 43 years old and have Alström syndrome. I live about an hour outside of Philadelphia in Pennsylvania USA and I would like to tell you a bit about how my Braille skills have enabled me to work.

Let me back up a bit and say I went to college intending on becoming a history teacher in high school. The last semester of college I had to do a teaching practicum and things did not go well. I still graduated with a degree in political science with honors, but had to come up with another job strategy for my future. Luckily, a really good friend named Stewart Hughes came to the rescue. He already taught me how to use a windows computer using a screen reader and he followed my career at college. He was about to join an organisation called Virtual Vision Technologies and asked me if I wanted to join. In this job, I would be teaching other blind and visually impaired people how to use their computers. After doing a demonstration lesson and writing up a lesson plan I was hired. In this job, I took the train into the city of Philadelphia and then walked to the office. Actually I became friends with the first student I taught. I asked him if he knew anything about windows and he mentioned they were something we open and shut. I also traveled to some people's work locations to teach them the technology they needed so they could keep their jobs.

Unfortunately after about six months with this organization they decided to move. The commute would have been too long and into some very dangerous parts of Philadelphia. So I went looking for another place to work. Luckily this did not take long. A local non-profit, Montgomery County Association for the Blind (MCAB), had an opening for someone to teach computer skills to the blind. This commute would also not be easy. It required for me to take two trains and then walk about six blocks to get to the office. I did this in all kinds of weather. I went for the interview. Luckily I had a really good orientation and mobility instructor who taught me this route when I went for the interview. Again I got the job in June of 2002, that feels so long ago now. Yes at this organisation I did the same kind of work, but in a more expanded role. I taught anyone from kids up to senior citizens.

At some point MCAB wanted to expand its services and offer clients the chance to learn braille. That responsibility fell on my shoulders. You know that thing they say for jobs other duties as assigned, I guess this fell into this category. My smart brain figured out a way to do this even though I had no formal education in this area. In 2005, MCAB celebrated, its 60 years of being in existence. The MC for that event was the announcer for the Philadelphia 76ers which is our professional basketball team. He recognised me for all of my hard work and dedication.

Unfortunately in 2008, the economy in the US took a turn for the worse and I had to face the horrible reality of being downsized in 2012. The last few years at MCAB were not fun, seeing good people leave before I had to be cut. Now I am thinking what will be next for me in the working world. A good friend of mine recommended, that I become a braille proofreader. I thought I would give it a go and started on the process to become certified. In the US, we have a library for the blind and print disabled that is connected with the Library of Congress. They produce audio books and braille books for visually impaired and blind. So when I would get my certification, I could proofread books for this library. In order to get my certification, I had to complete a corresponded course that was offered through the National Federation for the Blind. I would receive everything I needed in the mail in braille and then I would mail back my completed lessons. This course took a year and a half to complete because of a slow mail system in the US. Because the material I was sending was in braille I could send it for free, but this would mean a camel was delivering and sending me the lessons. Well eventually I did receive my certification in English Braille American Edition or EBAE and then Unified English Braille (UEB).

In Philadelphia, there was an organisation that produced material in braille so I inquired about employment. They told me that they could use my skills. I just had to proofread a small sample of work for them to get hired. Since I started trying to do this while I was going through the certification process it took me three attempts to get hired. In January of 2016, I did get hired as an independent contractor for this organisation and in September was made a staff member. We proofread any kind of material. This would be books, magazines, stuff for Alcoholics Anonymous, Narcotics Anonymous, Social Security, US government, and tests. You never knew what you were going to read. Speaking of tests: We got the Advance Placement test for music the first year I was there. Advance placement was a way that high school students could get college credits before going to college. Since neither of my fellow proofreaders knew braille music and I did, this test fell in my lap. The agency really did not want to give the work back. Well ETS which oversees these type of tests, must have really liked what I did because I kept getting work from them to proofread. This was exhausting work. First I read the test myself to see if I could point out any errors and also to see if I had any questions about the braille music code. I usually would have some questions since I only knew braille music for the piano. These tests would have music scores for all instruments. Once I felt comfortable I then had to read the test over the phone to someone at ETS to verify that everything was done correctly. Yes, I did all the reading out loud. **Again exhausting work, but I did it!!**

In 2020 Covid hit the world. We were told to go home for a couple of weeks in the middle of March. This went into April. By May I finally got my braille display and the braille department figured out how we could continue to work from home. Things went on this way until August. At this point the CEO of the organisation decided to discontinue the whole braille production department. I guess she does not feel braille is important. 13 of us lost our jobs. Luckily one of the transcribers and my direct supervisor reached out to other agencies that did the same type of work. One organisation named National Braille Press said they would take myself along with two other proofreaders as independent contractors. So that is what I am currently doing. I get sent books to proofread along with audio files with someone reading the print to make sure things match. I send back the error reports. This totally works and I hope this lasts for a long time.

In closing I want to say the road has not been easy, but one can still work having Alström Syndrome. Never give up!



A BIG THANK YOU to Jamie for sharing her personal journey with us.

Dates for your diaries

28th February 2022—Rare Disease Day

3rd May 2022—World Alström Syndrome Day!!

In 2022, we will not only be celebrating all things rare on rare disease day but also marking Carl-Henry Alström's Birthday on the 3rd May 2022 by creating World Alström Syndrome Day...

On these days we hope the AS global community to come together and complete the patient registry, more details will follow about these events and how we can all get involved.

Highlights from 2021

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 built their confidence to own their consultations and appointments.

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

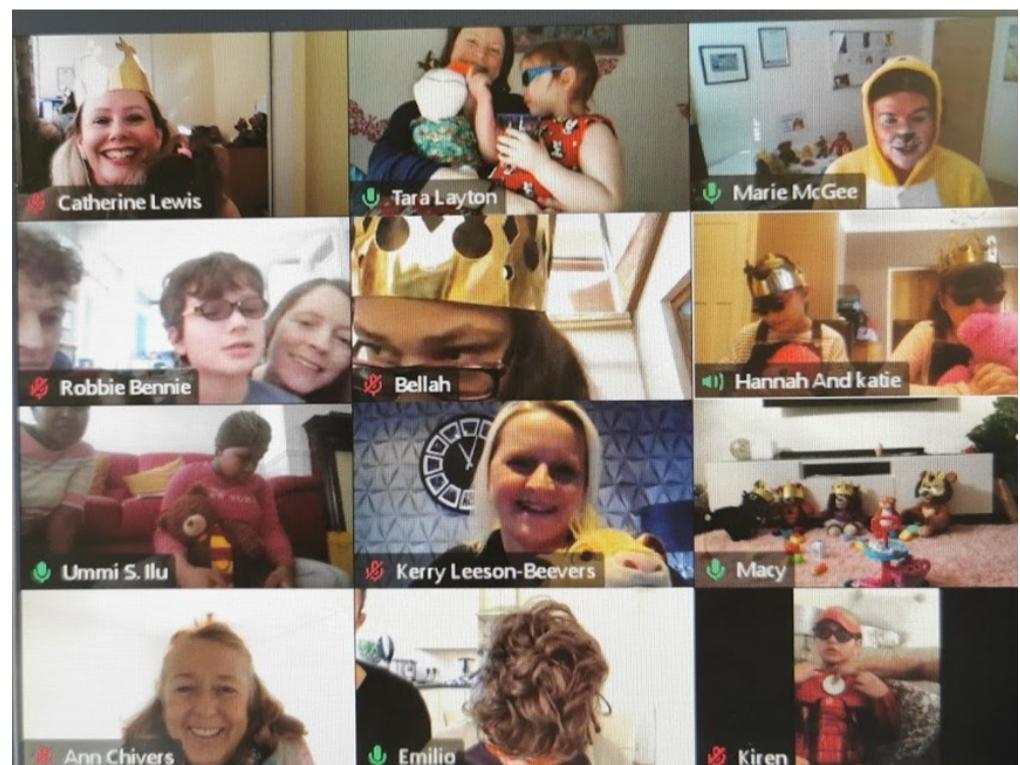
Speak up and be heard!

"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.



Introducing the Culture Sparkle Sisters, ASUK's newest online, advocacy group!

The ASUK Culture Sparkle Sisters (CSS) is a group of ASUK's young ladies aged between 13-16 years old, who meet monthly online to discuss a number of topics, and ideas chosen by them. The group is supported by Marie McGee, National Transition Co-ordinator, and Melissa Crowland one of ASUK's Trustees. Melissa's lived experience of living with AS is invaluable, as she uses her wisdom and experience to guide the CSS through a number of life skills.

The purpose of the meetings is to engage the CSS in discussions that are fun, informative, and lively, that aim to build self-esteem and confidence while providing opportunities for self-advocacy. The group has been running since January 2021 where the CSS have discussed topics such as cane training, cooking tips, authors, and their favourite books. Guest speakers have delivered useful and practical advice. Alex, a ASUK Trustee talked about her life with her guide dog and gave lots of top tips of how to prepare for a guide dog assessment and how to use a guide dog to support everyday life. The CSS plan to interview Kerry Leeson Beevers, ASUK, CEO in the New Year, to find out more about her new role.

The CSS also review products looking at their accessibility, design, and suitability for other ASUK children and young people. So far, they have reviewed a clay art kit and beauty items such as face packs, shower gel and body lotion. The CSS are becoming more community and culturally aware, while beginning to demonstrate decision making and leadership skills. Marie and Melissa aim to provide a platform that supports the CSS to make choices and decisions while developing their self-assured, positive thinking.

'Being part of the CSS is good fun. I like meeting online and talking about different topics.' F, 16

The CSS is one of the many activities funded through BBC Children in Need, who have awarded ASUK funding for another three years. The funding is used to support Children and young people up to the age of 18 and provides a number of resources and activities. This includes pre-clinic workshops/meet ups, accessible equipment and picnic packs, which were delivered to all families during this years hot summer months.

Spotlight on our CSS supporter, Melissa

'I've been diagnosed with AS since 2018, so am relatively new to the Alström journey. However, I have always believed in raising awareness, and helping individuals with disabilities self-advocate. I am a qualified Social Worker and now training to become a counsellor. I have really enjoyed the work I do with the CSS as I enjoy working with the girls, who are all extremely eager to learn. I have also been able to gain tips and tricks from them too. It has been lovely to see them grow in confidence and the group develop. I am a passionate advocate for promoting good mental health and wellbeing and feel that the CSS is a great environment for its' members to grow organically. I can't wait to see how the group will continue to develop, and I'm sure that there will be many interesting and fruitful discussions to be had in the future.' Melissa Crowland, ASUK Trustee



Picture above, one of our sparkle sisters reviewing her clay kit.

I've won the lottery again!!

Top tips to keep you and your loved ones safe from scammers

Always stop and think...

Take 5 before doing anything and never feel rushed into a decision!



IT PAYS TO STOP AND THINK

- 1 Never disclose security details
- 2 Don't assume an email, text or phone call is genuine
- 3 Don't be rushed
- 4 Listen to your instincts
- 5 Stay in control



Tops Tips Nuisance telephone calls and text messages

- Contact your Telecoms provider – ask for Call Filtering or Call Blocking Services, they could be free!
- Don't recognise the number? Let it go to voicemail / Google the number to see who it is.
- Pause, let the caller speak first, if it remains silent just end the call.
- Block and Report suspicious callers.
- Consider purchasing a Call Blocker (pictured below) if receiving nuisance calls to your landline phone.
- NEVER give Remote Access of your devices to people you do not know.
- Don't click links in or call telephone numbers given to you in suspicious texts.
- In the UK, forward Scam Texts to 7726.

REMEMBER SCAMMERS PLAY ON HOPES AND FEARS . DON'T BE RUSHED – TAKE 5!



Top Tips Bank Scams

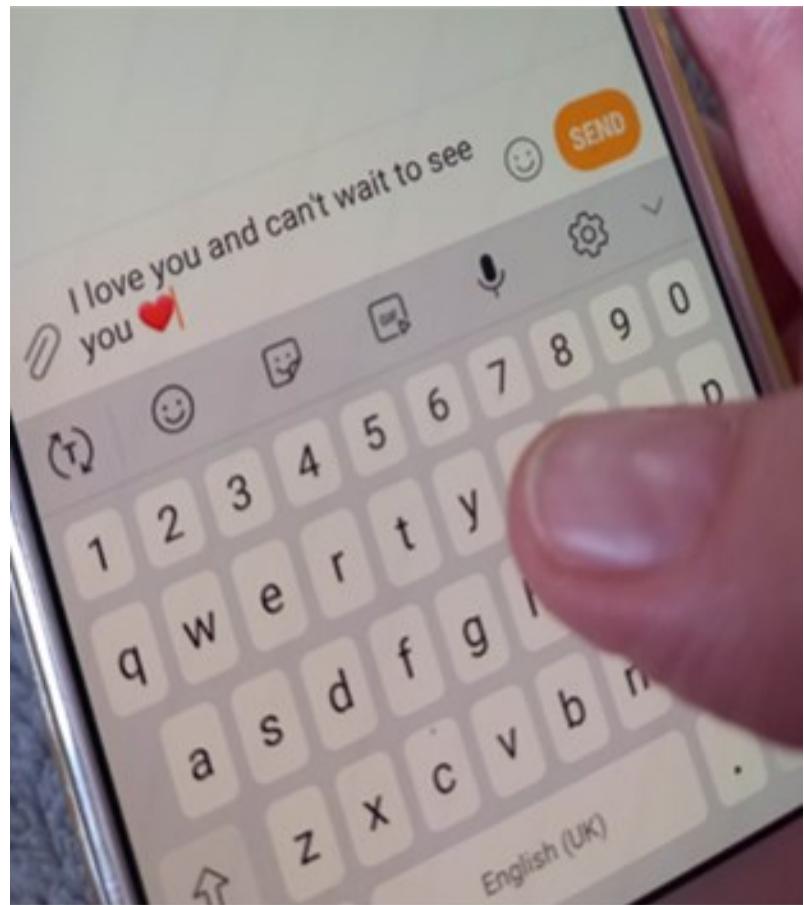


- Your bank will **NEVER** ask for your PIN and they will **NEVER** ask you to transfer your money to another account.
- Your bank will **NEVER** send a courier to collect your card.
- At Cash Points / ATMs beware of people standing too close behind you, shield your hand when entering the PIN.
- If in doubt about a call, email or text from your bank – notify your bank by calling the number on the back of your bank card or statement.
- Don't use public wi-fi to access any sensitive information such as your bank details.
- If you notice unusual activity on your bank accounts. Speak to your bank **ASAP**.

Top Tips

Staying safe online

- Keep antivirus software up-to-date.
- Don't click links or call numbers given in emails! Links can lead to viruses or send you to fake websites.
- If you think it is a suspicious email. Block the sender and delete the email. ('Right Click' on the mouse whilst hovering over the email)
- If your passwords have been breached by a data leak, change these straight away.
- 2 or 3 words + numbers and special character = A STRONG PASSWORD! (Something not easily guessed by scammers, therefore no pets' names, relatives names, dates of birth etc).
- Consider covering your webcam when not in use.
- Look for the LOCKED PADLOCK and https when shopping online (pictured below).



Top Tips Social Media

- Profile pictures – consider using one with your family and friends.
- Check your privacy settings – can scammers see your photos, posts, telephone number, email address
- Pause and think before posting messages and photos.
- If using Dating Sites communicate on the site and don't be lured away to unsafe sites that reveal your telephone number and/or email address.
- Beware of Romance Scams – if they start asking for money THINK SCAM!
- Check if your profile and image are being used without you knowing – Google yourself and 'Reverse Image Search' your social media image!
- Beware 'Earn quick cash' adverts – it could be Money Muling (Money Laundering).

Top Tips I've won the lottery? Fake prize draws and catalogues

- If you have to pay a transfer / admin fee to claim your prize THINK SCAM!
- Don't order goods from catalogues just to remain in a prize draw!
- Beware of signing up for goods on a monthly basis – is it a CPA, Continuous Payment Authority? This is not a Direct Debit and harder to stop once agreed!
- Beware of 'FREE TRIALS' – do you have to pay package and postage? Think about who you are giving your bank details to?
- Remember – 'If it sounds too good to be true, it probably is!'



ASUK offer a help-line during office hours and an answer phone service at all other times where calls are promptly returned by our experienced Family Support team;

Please call 07970 071675 / 01709 210151

Email: Catherine.lewis@alstrom.org.uk

Over Christmas and New Year the office will be closed from 23rd December 21—4th January 22

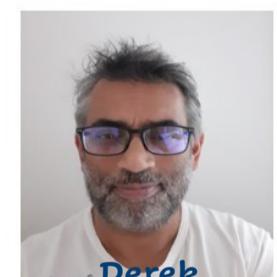
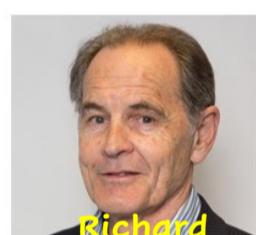


Please get in touch if you have any articles or suggestions for our next edition, Catherine is looking forward to hearing from you!

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Meet the ASUK team



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Please visit our website www.alstrom.org.uk to keep up to date with our latest news.



ASUK has a dedicated You Tube page <http://www.youtube.com/alstromsyndromeuk>

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