



Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK (ASUK) is a charity providing information, support and advice for individuals affected, their families, carers and professionals. Alström Syndrome (AS) 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 www.alstrom.org.uk

Welcome to the Winter 2023 ASUK Newsletter

Hello Everyone,

I hope you are well and looking forward to the festive period.

Our winter newsletter is packed full of information and top tips, so I hope you enjoy catching up on everything that has been going on within the Alström Syndrome (AS) community.

We have some very exciting news to share with you all. We are planning two conferences next year, the first will be the AS Global conference on zoom on the **27th January 2024** and drum roll please... our second one will be a face to face conference on the **11-13th October 2024**. We are so looking forward to everyone being together again so we really hope you can join us! We want to make sure that we offer something for everyone so please share your thoughts and ideas with us. The conference will be in the Midlands, and we are researching venues. Please save the date and we will be in touch with more details in the new year.

In October, ASUK Trustee, Melissa (pictured below, exploring America) and I had the privilege of presenting at the Alström Syndrome International (ASI) Conference in Baltimore, USA. We spoke about independence, the work of ASUK and AS Global. We were joined by clinicians and researchers from Birmingham and others from around the world. It was great to hear about the developments in the understanding, management, and treatment of AS. Around 40 families attended the conference and it was lovely to meet up with old friends and to make new ones. We had a wonderful time and I want to take this opportunity to thank Melissa for being such a fabulous ambassador for ASUK.

As I reflect on 2023, I have mixed feelings as usual. It has been a challenging year with some of our community experiencing issues with health and wellbeing and the cost-of-living crisis is having a big impact on many. I also see so many positives too.



Families have been meeting up together, I have seen new friendships form and existing friendships strengthen. People within the AS community are challenging themselves and achieving great things. We had our first residential weekend since the pandemic, and we are forming new collaborations around the world. This year ASUK celebrated our 25th anniversary and I feel very proud looking back on how far we have all come together. A very big thank you to the ASUK team and to every one of you for your part in making ASUK what it is today.

We have so much to be thankful for and I end the year with a sense of hope. The AS multi-disciplinary specialist clinics are seen as the gold standard of care and the medical and scientific community within the UK and beyond are really starting to work together and push forward with research. I know these things take time and as a Mum, I share your frustrations about the fact that we do not yet have a specific treatment for Alström Syndrome. I do believe that there is hope and by working together, we will continue to improve our knowledge of the condition which in time, will lead to better and more effective treatments. On behalf of the team at ASUK, I would like to say a huge thank you to all the clinicians, researchers, and scientists, we are very grateful for everything you do.

I would also like to say a very big thank you to all our friends, families and supporters who have given so generously to ASUK throughout the year. Check out page 4 where you can find ways to get involved in fundraising activities.

We hope you all enjoy the festive period and we wish you health and happiness for 2024!

Take care everyone.

We are here for you
Kerry and the ASUK team



Jai's Dream Took Flight at Birmingham Airport!

Work experience gives young people the opportunity to have a short-term placement with an employer, to work alongside people as they go about their daily tasks. It supports the development of young people's skills, introduces them to new people and they can learn more about the world of work.

Jai has always wanted to have a chance to work at Birmingham Airport and find out more about the types of jobs that people do there. With the help of his mum and the ASUK National Transition Coordinator, Marie McGee he was able to secure a day's work experience in different departments of the airport. His day started with a 'meet and greet' with the customer experience staff, who welcomed him into their airport team. He was given a customer experience uniform and a security pass, as for part of the day he would be going 'airside'; this is the technical term for going beyond custom control and security. Jess Sage, from the internal communications team and Alison Hill, Birmingham Airport Compliance Coordinator accompanied Jai throughout the day, with Jess recording a film of his experience.

Jai was then whisked off by Sargent Bell one of the airport police, who showed him around the police station. Jai went into the control room; he met a group of officers who were being trained in security management and spent some time in a police cell. Jai commented, *"The cell is horrible, I'm not staying here!"*

Once back in the airport's main terminal, Jai was guided by Shafique, one of the customer experience team who took him down to the departures lounge. Shafique helped to orientate Jai, whose next job was to direct passengers to the check-in desks or answer any of their queries. Jai told Shafique. *'I liked helping the lost passengers.'*

From there, Jai moved onto the check-in area used by Emirates Airlines, where the staff explained why boarding cards are so important and how everyone needs one to travel. Although it was lunchtime now, Jai wanted to keep going, so he made his way up to security where he gave out clear bags for passengers who were travelling with liquids. He was kept very busy with a steady stream of people, with one gentleman commenting on how efficient Jai was!

From there, Jai needed to get over to the duty-free department as staff were waiting for him to help them give out leaflets to passengers, so they could get a

discount on their purchases. To do this Jai needed to go through staff security, which is the same as passengers' security, but it's hidden away in series of corridors which run right around the airport. Jai was introduced to several duty-free staff who explained their roles and talked to him about the products they sold. He then took up position by the entrance to duty-free, where he declared to passengers that there was 10% off some in store products, while he thrust a leaflet towards them.



After a short and much needed break, Jai was then taken down to the Emirates boarding gate. He was met there by Amy, one of the Emirates ground staff. At this stage Jai did not know that a surprise lay in wait for him. Firstly, he was given a one-to-one tour of an A380 plane, which can hold up to over 800 passengers, Yikes! (This is one of the largest passenger planes in the world). He then had a chance to try out first and business class, by then he had one of the posh seats that changes into a bed...wouldn't we all like to travel like that?

Just when he thought his day couldn't get any better, Amy surprised him with a visit to the cockpit of the plane. This is where he met Captain Howard and his first Mate, who told Jai all about their jobs and how important safety was on the plane. Jai asked about the controls and how they navigate the plane. Jai was surprised to find out how small the cockpit was, and how unbelievably it could fit up to three pilots at a time. As Jai was leaving the aircraft, Amy took him outside so that he could get an idea of how big one of the engines was. To do this he felt the bottom of the engine's casing which gave him an idea of the circumference of the engine (we checked the engine was not on, so Jai was not blown away!).

Alison Hill, Birmingham Airport Compliance Coordinator commented:

'It was our pleasure for my team and I to plan this day for Jai and give him the opportunity to be part of the airport family. Throughout the day he has had a huge smile on his face, I can see how much he has enjoyed himself. We are delighted that we could support him not only with his work experience but help one of his dreams come true too.'

Jai was tired, but very happy about his day at Birmingham Airport, on his way home he stated to his mum:

'It would be great to work at the airport one day, although it's very tiring!'

Jai's mum Pam was very impressed with the team who supported her son:

'I was blown away by their thoughtful and patient approach to Jai. They took the time to understand his needs and adapt the day to suit him. I can't thank them enough.'



Did you know?

- ♦ An Emirates A380 is as long as 2 blue whales and as tall as 5 giraffes.
- ♦ The plane is made up of over 4 million parts.

Please get in touch with Marie if there are any work experience places you would like to try, and she will try and sprinkle her magic again!

Email marie on Marie.mcgee@alstrom.org.uk



Exciting News!! - Save the Dates!

Not one but two conference dates in 2024

**AS Global Conference—virtual
Saturday 27th January 2024**

**ASUK Family and Professional Conference—face to face
11th—13th October 2024**

**More details will follow shortly...
We can't wait to see you all in person again!!**

Hedgehog Rolls – Enjoying the art of bread making!

Hedgehogs are one of Britain's most recognisable and well-loved wild animals. They love living in our gardens where they eat beetles, caterpillars, and worms. Children and young people don't eat beetles or worms (I hope not!) but they do enjoy making all sorts of things and that includes hedgehog rolls! As part of the ASUK preclinic activities, which are generously funded by BBC Children in Need the children, young people and their families have been introduced to the art of breadmaking. To do this they have learnt how to create hedgehog rolls, by making their own dough, shaping them into hedgehog shapes, adding peppers for the spines and currants for the eyes. The activity introduces them to different textures, supports their fine motor skills and encourages them to try out new cooking techniques.

Carwyn aged 5, remarked
'I like rolling and pinching the dough.'

Everyone also had a chance to take part in some art activities including decorating canvas bags or painting owls and mugs with porcelain pens.

One of the mums commented
'I enjoyed painting the ceramic owls, it was a bit of downtime, and it gave me a chance to talk to the other families.'

The preclinic activities are an important way for families to meet socially in an informal and relaxed environment. This can be especially useful for any new families who may be nervous about coming to their first clinic. Early this year a new family gave some great feedback which included:

'This is really good (pre clinic activities), I didn't know that we would meet so many families- this is a good idea' Dad.



Support the Winter Appeal and bring the joy of Christmas to families this year



We simply couldn't do what we do without the generosity of our supporters.

As living costs continue to squeeze every penny from our already stretched families, many are struggling and having to choose between eating and heating.

Alström Syndrome UK provides personalised support, including grants for essentials but as a charity, we rely on our generous supporters to continue providing our vital services.

Why not have some fun and help families this Winter?

Host a Christmas jumper party or arrange a Christmas quiz...

Get the family involved and do a Santa dash around your local park...

Challenge yourself with a daily task, anything from running 5K a day to no chocolate!

Join a fundraising event in your local area, such as a Santa run or even a Marathon!

**Please donate to our cause through our JustGiving page
www.justgiving.com/AlstromSyndromeUK**

Every penny really does makes a HUGE difference

All the way from Hong Kong...

My name is Jack, and I recently moved to the UK with my family. My younger daughter, Anna, who is now 12 years old, was diagnosed with Alström Syndrome when she was 7 years old. Prior to our relocation, I had the privilege of working with Alström Syndrome Greater China Association (ASGCA) in Hong Kong, through which I discovered ASUK, a remarkable patients' organisation dedicated to Alström Syndrome in the UK. It was through ASUK that I learned about the exceptional work being carried out at Birmingham Children's Hospital (BWCH), including the provision of multidisciplinary clinics, a service that was unavailable in our previous city.

Last month, we embarked on our journey, starting from Coventry and checking-in at the arranged welcoming Holiday Inn. Our first encounter with ASUK took place at Ronald McDonald's House, where an activity organised by ASUK awaited us. This gathering not only introduced us to the ASUK and BWCH team members, Sarah, Clair, and Marie, but also provided an opportunity to connect with other families affected by Alström Syndrome. Through ice-breaking activities, crafts, a delightful cooking session, and a shared dinner, we forged meaningful connections and I had the chance to share the situation of AS in Asia. The revelation that there are 140 Alström Syndrome patients on the other side of the world left everyone astonished. It was a truly enriching and joyous experience.

On the second day, ASUK meticulously organised a range of multidisciplinary clinics for Anna, covering areas such as cardiology, ophthalmology, endocrinology, psychology, dietetics, physiotherapy, genetics, and transition support. The thorough check-ups and consultations were seamlessly coordinated by ASUK and BWCH. As patients, all we had to do was relax, follow the instructions, and attentively listen to the advice provided by the compassionate and professional

healthcare experts. The friendly demeanour and patience exhibited by the staff created a comforting atmosphere, allowing Anna to feel at ease and not be overwhelmed by the unfamiliar environment. Given the absence of similar AS clinical services in China, I extended an invitation to a PhD student from Shanghai Children's Medical Centre, currently studying at Queen Elizabeth Hospital Birmingham, to observe and gain insights into the operations of these clinics. It is my hope that such a beneficial arrangement will offer support to the AS community in China, aiding their journey towards enhanced care and treatment.

In conclusion, my family and I would like to seize this opportunity to express our heartfelt gratitude for the unwavering support and meticulous arrangements provided by ASUK and BWCH, particularly during our initial steps in this new country. The assistance we received has undoubtedly facilitated our adaptation process, making us feel welcomed, secure, and embraced by the larger ASUK family. We eagerly look forward to actively contributing to the community of Alström Syndrome in the future.

Jack Chu



Picture of Jack, his family and the ASUK team

NHS Alström Syndrome Multi-Disciplinary Clinics 2024

Birmingham Women's and Children's Hospital clinic dates for 2024:

8th January
10th January (virtual)
15th April
10th July (virtual)
22nd July
14th October

Outreach Clinic in Leeds in November - date to be confirmed

Queen Elizabeth Hospital, Birmingham adult clinic dates for 2024:

17th and 18th January
20th and 21st March
15th and 16th May
19th and 20th June
18th and 19th September
20th and 21st November

If you have any queries about the clinics, please contact Care Coordinator Clair, by email

clair.pudaruth@alstrom.org.uk or call 07825 384362

Hann the Historian – back for part 2 Talking Medieval History, Goal Ball, Mobility and Friendships!



Over the summer I kept busy, visiting museums, and watching a variety of films at the local cinema — Greatest Days was my favourite! Admittedly, this all had little to do with my dissertation, unless a play in the same period at the Great Hall in Winchester counts as light research.

One of the things I kept working on weekly throughout the summer was my mobility training around my home area. With my mobility officer, before starting a new route, we normally start by walking through the whole route sighted guided before we break it down to make it more manageable. I look at it as the first route from point A to B is one way and the reverse one is a second route to learn after. We break this down even further, into sections between landmarks, so I can learn it in stages by putting it all together later. This technique of breaking it down helps to focus on the stages that I find harder to remember when putting it all back together, so I can start at the previous section that I'm confident with and work on the section I need a little more time on practicing on in some sessions. It is important to me to know that I can do each section at my own pace so that I can do it safely and with growing confidence so that I can eventually do them independently. In the meantime, the lessons have helped with my confidence as I have improved on free walking, which is when you walk in the middle of a space without landmarks to hit against with your cane, as well as straightening up against bump-ons on crossings, at a deep curve or indenting with a parked car to cross roads. With these skills I have learnt the route from my home to the tube and back and have started learning the route to the local park. Also, when I update my friends on Facebook about my progress, the kind comments and reactions are a great motivation to improve on them. I hope one day to work towards getting a guide dog and I know that in future lessons I will be working on more travel skills so I can meet up with friends or travel for future work.

I had mixed emotions returning to Winchester in September for my final year, but I was looking forward to it especially to reunite with old friends as well as make new ones at the Fresher's Fair. Through the fair I met and joined the Access Network, the university's representational group for disabled students. I have made a lot of friends through the society, with one friend getting me back into goalball with Winchester

Goalball Club and another visited the City Museum with me, which was a lot of fun. My friends through Access have also helped me get more confident with my routes onto campus which I'm now doing a lot more, like one night I walked the route onto campus from my flat and my friends met me at different parts of it to make sure I stayed on track, it was the first time I had done the route in the evening and it was so reassuring to have their support. I cannot wait to do more sessions with them!

The way the weeks are arranged throughout the semester does feel a bit strange, I only have lectures on Mondays and Tuesdays, but they do this, so we have enough time to do research and write up our dissertations and work from our other modules. The two other modules I am studying alongside my dissertation are chivalry and the Second Viking Age, when they settled in Britain, which as my in-depth study I will be continuing over both semesters. I really enjoy the chivalry module as each topic within the modules, such as heraldry, Arthurian legends or where women fit into chivalry, are all really interesting and would quite easily want to investigate them in my own time outside the module. For the first assignment for this module is a presentation which I have chosen to do it on the 'History of William Marshal', which is an amazing biography from the twelfth century, and for this I got to visit his effigy at Temple Church with special permission to touch, it took my breath away!

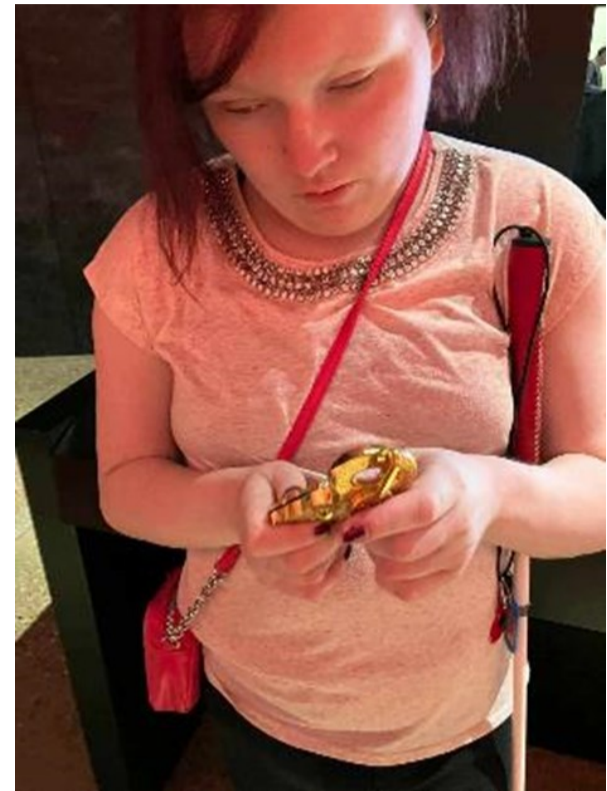
Another aspect of university that I would like to mention here is the Careers team who are really helpful and supportive. They have been helping me find volunteering with Hampshire History Trust which I will be working on the HistBites Podcast, writing up blogs to go with the episodes as well as work with object handling with Hampshire Cultural Trust and the immersive 878 AD experience, where Winchester goes back into Anglo-Saxon Wessex.



I have also enquired into volunteering with the National Trust's Sutton Hoo in Suffolk which will be seventh heaven to work at! The careers team have also helped me start writing up my CV and plan what I want to do after university when I graduate next year. Last week I got to talk to lecturers about a Masters either in History or Cultural Heritage and resources management (shortened to CHARM) which will let me work in a placement in a Winchester-based museum and will help get work in the heritage sector like Sutton Hoo, they both sound interesting, so I'm spoilt for choice if I continue to Masters. As an alternative I have also been looking into paid internships to either do over the summer or start next September, which I have applied for one, fingers crossed.

I hope my two articles on a myriad of elements of university life have shown life at university in a positive light, for other people living with Alström Syndrome. It has been a great experience over the last four years in Winchester and has brought me out of my shell and raised my horizons on possibilities beyond university. But I have to say apart from doing something I am

passionate about, the main and most important thing I have loved about university, is making new friends who, with luck, will be friends forever. If anyone reading this also follows me on social media, please continue to watch this space to get updates on next semester and beyond.



Hannah Bromley-Challenor
November 2023

Just can't wait

Do you find that there are times when you need the toilet urgently? This card can help. The Just Can't Wait card is recognised and supported by many retail and service organisations, giving you access to toilets not normally available to the general public. Just show your card. Although access is not guaranteed, the cards are widely accepted and acknowledged.

To find out more and to order your card, go to the Bladder and Bowel UK website www.bbuk.org.uk/just-cant-wait-cards/



'Every Body Moves'

The 'Every Body Moves' initiative which was developed in partnership by Paralympics GB and Toyota, sets out to connect disabled people with more opportunities to get active. It is part of the award winning Parasport platform, which is the nation's largest online platform that connects people with thousands of inclusive physical activities. Check out the 'Every Body Moves' website where you can search by your postcode and view a wide range of virtual workouts and top tips to get active <https://everybodymoves.org.uk/>

We need your help — Let's get to the Oscars!

The T-KASH (Transition—Knowledge And Skills in Healthcare) animation has been nominated for the Smiley Charity Film Awards... the Oscars of the charity film.

Just a few clicks and your vote will help us get to the next stage.

PLEASE SPREAD THE WORD AND VOTE NOW!

<https://smileycharityfilmawards.com/films/lets-get-it-right-for-young-people-t-kash-tools-transition-knowledge-and-skills-in-healthcare>



Protect yourself and stay well this winter

We hope you are well and coping with the continued financial and emotional strain that the cost-of-living crisis is having on the country right now.

We know that as we embark on winter, many of us will find these times even more challenging. Often the hardest thing to do is to put our hand up and say, 'yes I am struggling and need support'. During these unprecedented times, it is only by doing this that we can find ways to really help and support you. We have grants available so please get in touch with our Care Coordinator Sarah. Sarah works Monday to Thursday and would love to hear from you. You can contact her on sarah.oliver@alstrom.org.uk or give her a call or text on 07917 958502.

Also, if you need to review your benefits or just want someone to talk to, please get in touch. All information you provide will as always be kept in the strictest of confidence.

Keeping well this winter

There are some things you can do to help yourself stay well in winter. This includes getting your flu, COVID-19 and pneumonia vaccinations.

Flu and COVID-19 vaccinations

It's important to get your seasonal flu and COVID-19 vaccinations if you're at higher risk of getting seriously ill from these illnesses.

Who should have the flu and COVID-19 vaccines

You may be able to get the free NHS flu and COVID-19 vaccines if you:

- are aged 65 or over (including those who will be 65 by 31 March 2024)
- have certain health conditions or a learning disability
- are pregnant
- live with someone who has a weakened immune system
- are a carer
- are a frontline health or social care worker
- live in a care home

Most children can get the children's flu nasal vaccine. This includes children who were aged 2 or 3 years on 31 August 2023, school-aged children (Reception to Year 11) and children with certain health conditions.

How to get the flu vaccine

If you're eligible for an NHS flu vaccine, you can:

- Contact your GP surgery to book an appointment
- Use the NHS online service to find a pharmacy that offers this service (if you're aged 18 or over)

www.nhs.uk/conditions/vaccinations/book-flu-vaccination/

Some people may be able to get vaccinated through their maternity service, care home or their employer if they are a frontline health or social care worker. You do not have to wait for an invitation before booking an appointment.

Covid booster programme

It is also important to protect yourself from Covid. If you are eligible for a seasonal COVID-19 vaccine, book your appointment online: www.nhs.uk/conditions/covid-19/covid-19-vaccination/getting-a-covid-19-vaccine/

Pneumococcal vaccine

If you're 65 or over or are at high risk then you're also eligible for the pneumococcal vaccine, which will help protect you from pneumonia. Ask your GP surgery for more information.

Who's most at risk from cold weather?

Some people are more vulnerable to the effects of cold weather.

This includes:

- People aged 65 and older
- Babies and children under the age of 5
- People on a low income (so cannot afford heating)
- People who have a long-term health condition
- People with a disability
- Pregnant women
- People who have a mental health condition

Get advice if you feel unwell

If you're 65 or over, or in one of the other at-risk groups, it's important to get medical help as soon as you feel unwell.

You can get help and advice from:

- A pharmacy – pharmacists can give treatment advice for a range of minor illnesses and can tell you if you need to see a doctor
- Your GP – you may be able to speak to a GP online or over the phone, or go in for an appointment if they think you need to
- NHS 111 – go to 111.nhs.uk or call 111 if you have an urgent medical problem and you are not sure what to do. The sooner you get advice, the sooner you're likely to get better.

In an emergency, go to A&E immediately or call 999.

Always remember we are only ever a phone call or email away!

Emergency – Text message

Did you know that people can text emergency services, but only if your phone is registered for the service in advance.

Don't wait until you need to call, it will be too late.

Do it now. How to register:

- ♦ Write an SMS text which just says "register" and send it to 999.
- ♦ They will reply with a message telling you more about the service.
- ♦ When you have read their message reply with "yes".
- ♦ Shortly afterwards you will get another reply message. This one will say you are now registered, or tell you there is a problem and how to solve it.

Information needed in a 999 text:

1. **Do you want fire, police or ambulance?**
2. **In just a few words, what is happening?**
3. **Where is help needed?**

Give the full address if you can, or a street name and landmark. Make it easy for the emergency services to find you.

When to use 999 text:

- Life is at risk
- Crime/trouble is happening now
- Someone is injured or threatened
- Person committing crime is near
- There is a fire or people trapped
- You need an ambulance urgently
- Someone is in trouble, or missing, at sea
- Someone is in trouble on the cliffs or on the shore

Nottinghamshire Police provide a video clip to help

www.youtube.com/watch?v=zRwYPGrtoo4

Keep warm and get help with heating

Keeping warm over the winter months can help to prevent colds, flu, and more serious health problems such as heart attacks, strokes, pneumonia, and depression.

Heat your home to a temperature that's comfortable for you. If you can, this should be at least 18°C in the rooms that you regularly use, such as your living room and bedroom. This is particularly important if you have a health condition. It's best to keep your bedroom windows closed at night.

Check your heating and cooking appliances are safe. Contact a Gas Safe registered engineer to make sure they're working properly. You can find an engineer from the Gas Safe register website

www.gassaferegister.co.uk/

Make sure your home is fire safe. For fire safety advice specific to you and your home, visit the online home fire safety check website to complete a safety check for your home www.safelincs.co.uk/hfsc/

Make sure you're getting all the help that you're entitled to. There are grants, benefits, and advice available to make your home more energy efficient, improve your heating or help with bills. Find out more about ways to save energy in your home on the Gov.uk website www.gov.uk/improve-energy-efficiency, or call the government helpline on 0800 444 202.

You can also find out more from Gov.uk about benefits and financial support if you are on a low income www.gov.uk/browse/benefits/low-income

Look in on vulnerable neighbours and relatives

Remember that other people, such as older neighbours, friends and family members, may need some extra help over the winter. There's a lot you can do to help people who need support. Icy pavements and roads can be very slippery, and cold weather can stop people from going out. Keep in touch with your friends, neighbours and family and ask if they need any practical help, or if they're feeling unwell.

Make sure they're stocked up with enough food supplies for a few days in case they cannot go out. If they do need to go out in the cold, encourage them to wear shoes with a good grip and a scarf around the mouth to protect them from cold air, and to reduce their risk of chest infections.

Make sure they get any prescription medicines before the holiday period starts and if bad weather is forecast. If they need help over the holiday period when the GP surgery or pharmacy is closed or they're not sure what to do, go to 111.nhs.uk or call 111.

If you're worried about a relative or elderly neighbour, contact your local council or call the Age UK helpline on [0800 678 1602](http://08006781602) (8am to 7pm every day). You can find your local council on GOV.UK.

A Christmas full of smiles

Over the festive period it can be hard to think of original gifts for our nearest and dearest. Let's take a look at some sensory items and experiences that should make everyone smile on Christmas day.

Sensory Bag

This bag can be as basic or extravagant as you fancy, but once you start adding to it, it can be tricky to stop! It is a great way to explore different textures, lights and sounds. It doesn't have to cost much, with many supermarkets selling cheap squidgy and fidget items.



Tactile and Braille books

RNIB sell a wide range of tactile and Braille books, which bring the joy of reading to all.

You could also sign up for a membership to Living Paintings, which would allow you to rent audiobooks, Braille or tactile books throughout the year. Some of these are even free!

Living Paintings

Their free postal library of Touch to See books provide access to the visual world for blind and partially sighted children and adults.

Ready for a journey through space and time?

For 60 years, the visual spectacle of Doctor Who has been captivating audiences around the world. Now, for the first time, the Whoniverse comes to life for blind and visually impaired people through touch and sound. The first Living Paintings, Touch to See Doctor Who experiences has landed, featuring a host of fan-favourites providing audio guides and exclusive commentary.

You can check out the full range on the Living Paintings website <https://livingpaintings.org/>

Experiences Days and Trips

Where is their favourite place to go?

Could you provide a membership or annual subscription.

What about a membership to the National Trust? It's a great way to get out in the fresh air and with over 500 places to visit, you will be spoilt for choice... also it is only £10 for a youngster to join the National Trust and if they have complex needs, two carers can be admitted free of charge.

www.nationaltrust.org.uk/membership

Musical instruments

This may sound like a parent's worst nightmare, but noisy musical instruments, provide great sensory enrichment for those with dual sensory loss – and they are great fun too! Why not get the whole family involved!

Light up

Sensory light up toys are very popular, due to their ability to create both a stimulating and a calming environment. There are many stores which provide items like these:

www.sensorytoywarehouse.com/

<https://specialneedstoys.com/uk/sensory-toys/sensory-lights>

Braille Gifts

Type into google 'Braille gifts' and you will find a plethora of items. The online shop Etsy has lots of personalised gifts, including Braille gift tags and cards.

One of our favourite finds, has to be the RNIB recycled silver heart necklace

which has 'love' Brailled on the front (pictured above).



Why not email us with your top gifts you have bought over the years – help others who may be stuck for ideas this year!

Santa is coming... by email

RNIB is helping to deliver the magic of Christmas by making sure all children with a vision impairment can receive a very special festive letter.

They have a team of elves that work closely with Santa to help him send letters in accessible reading formats – like Braille, audio and large print – bringing the joy of Christmas to those who may otherwise miss out.

RNIB Letter from Santa request service for a large print, braille or audio letter is now closed for another year. However, you can still ask Santa to send out a letter by email (the letter attachment will be in 16pt unless requested otherwise).

Please email Santa at santa@rnib.org.uk.

The closing date for email requests is Tuesday, 19 December 2023.

RNIB Accessible Cards: Better Connected

Buying and reading greetings cards can be a real challenge for blind and partially sighted people. That's why Hallmark are proud of their partnership with RNIB (Royal National Institute of Blind People) and of their latest collaboration: The Better Connected card collection.

Check out their Christmas cards in their online shop www.hallmark.co.uk/collections/rnib-accessible-cards



Breaking Down Barriers (BDB) Network Together again...

The BDB network now has **over 70 member organisations** and the reach and creative ambitions from the team are going from strength to strength.

On the 26th September 2023 we brought the BDB network together for the first time since lockdown, for the 'Leaving No One Behind' event in London. This was a great opportunity to collaborate, learn together and network once again.

We had a fantastic array of speakers from our membership discussing how they are embedding Equity, Diversity, and Inclusion in all they do, including Genomics England, Cystic Fibrosis Trust, Hemochromatosis UK, Rare Youth Revolution and Genetic Alliance UK. Our team also provided workshops throughout the day about engaging excluded communities and Patient and Public Involvement and learning from people with lived experience.

It was also great to hear from organisations about what challenges they have been facing and what matters to them now and in their future work. Our team member, Cathy Chadwick-Rayner, BDB Networks and Outreach Coordinator gives her thoughts:

'It was such a pleasure to meet members of the BDB network for the first-time face-face at our 'London BDB event – Leaving No One Behind', and even more fantastic was the enthusiasm in the room in the endeavour to connect with communities. Successful

engagement strategies were shared by many during the morning presentations and afternoon workshops – 'Engaging Excluded Communities.' I will be circulating the shared learning from the afternoon workshops, and some of my own outreach journey here in West Yorkshire, in the hope we can build a bank of positive strategies and ways to extend our connections, service reach, and engagement. I am also here for a chat if you wish to discuss your outreach engagement strategy, and if I may share a Hopi proverb...

'One finger can't lift a pebble.'

You can get in touch with Cathy by email

catherine.chadwick-rayner@alstrom.org.uk



The BDB website has had a makeover, check it out at www.breaking-down-barriers.org.uk

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 team;

Please call 07970 071675 / 07716 135940

Email: Catherine.lewis@alstrom.org.uk

Over Christmas and New Year the office will be closed from 21st December 23—3rd January 24



Meet the ASUK Team



Jas



Sharon



Carol



Lexi



Kerry



Catherine



Kez



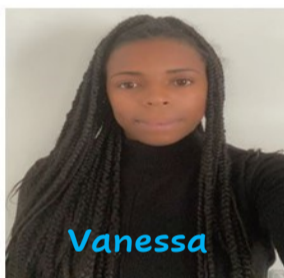
Trevor



Melissa



Haris



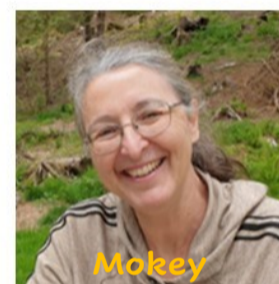
Vanessa



Clair



Ann



Mokey



Jane



Tim



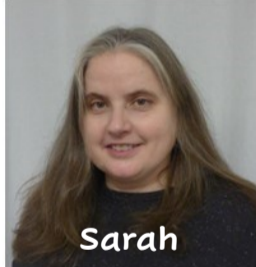
Steve



Marie



Derek



Sarah



Tarek



Cathy



Richard

Registered Office address: 4 St Kitts Close, Torquay, Devon TQ2 7GD

For all enquiries please get in touch on 07970 071675 / 01709 210151

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>

Please keep up to date with Alström Syndrome UK via twitter [@AS_UK](https://twitter.com/AS_UK) and also via our dedicated Facebook page www.facebook.com/alstromsyndromeuk please click 'like' to show your support and spread the word!

You can donate securely online, visit our Just Giving page to make a difference today, <https://www.justgiving.com/alstromsyndromeuk>

