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 Summer 2025 ASUK Newsletter

Hello Everyone,

I hope you are all well and enjoying the summer with family and friends. Our summer newsletter is packed full of information and top tips. I hope you enjoy catching up with everything that has been happening within the Alström community.

I love hearing all about your adventures and achievements. I would like to personally thank those of you that have taken on challenges to raise money for ASUK. We really do appreciate all your efforts and will make sure that every penny you raise is well spent.

It has been a busy and exciting year so far at ASUK, with different research projects now underway. We have been developing the T-KASH resources and lots of new areas have been popping up on the website including podcasts, wellbeing resources and we are now even on TikTok!

We want to make sure that ASUK continues to grow and develop and provides the services and support that you want. The ASUK Team and Board of Trustees met earlier this year to discuss our charitable objectives and our vision, mission and values.

Following further discussions with the AS community, these have all now been updated. We have developed a new business plan and identified priorities for the next 3 years that includes the broad and extensive work that we do.

Our Charitable Objectives — (what we aim to do)

- To promote the health and wellbeing of people with Alström Syndrome – particularly (but not exclusively) through the provision of awareness raising, support, advice and information for people living with Alström Syndrome, their families, carers and those working with them.
- To promote research into Alström Syndrome and related conditions in the UK and abroad and disseminate the results to the public.

Our Vision

A world where people living with Alström Syndrome receive a timely diagnosis, access to specialist care, treatment and support and feel empowered to live the life they choose.

Our Mission

To provide information and person-centred support for people living with Alström Syndrome, their families, carers and the service providers involved in their care. To raise awareness, facilitate research and advocate for specialist services and support. To create opportunities for peer-to-peer support and provide fun and engaging activities.

We have also used the letters of the word 'Alström' to create our values.

Our Values

Alström Syndrome UK
Strength for today, hope for the future

Always Welcome
Our diverse community is at the heart of everything we do, where everyone is respected, valued and supported to feel empowered.

Learning and Listening
Your lived experience matters, we learn from you and adapt our services to meet your needs.

Supportive
We offer person-centred support for you and your family throughout your journey with AS and at the highly specialised clinics. We support the ASUK community and each other.

Togetherness
We are stronger together and when we collaborate with like-minded people in the genetic and rare condition community.

Researching
We drive forward research and clinical developments to help improve how AS affects your life now and in the future.

Öpenness
We are open, honest and transparent in our work and offer outreach support and education through raising awareness and addressing health inequalities.

Motivated
We are a highly motivated team, we may be small, but we are mighty, trusted and our voice is loud.

Take care and have a lovely summer everyone.
We are here for you
Kerry and the ASUK Team

Save the Date
Monday 15th September 2025
7:00—8:00 pm (UK, BST)
AS Global Webinar
Mounjaro in Focus: Expert Insights
for the AS Community
Prof Tarek Hiwot and Sadaf Ali will be sharing their clinical insights and answering your questions.
Scan the QR code with your mobile phone to register.

Breaking Down Barrers Across the UK

Sophie, our Lived Experience Coordinator shares with us how she has been raising awareness and collaborating over the past few months.

With the arrival of summer, it's a great opportunity to reflect on some of the work I've been involved in at Alström Syndrome UK and Breaking Down Barriers.

The new year started with the Festival of Genomics and Biodata in London. This annual event brings together businesses, charities/Non-Governmental Organisations (NGOs), researchers, students and patient advocates from across the genomics community. We collaborated with The GRACE project at The Open University, which was started to raise awareness of genetic testing among underrepresented groups and to get better representation of our diverse society in genomics research.

We enjoyed talking with the public about their views on genomics research, some sharing personal stories. It was energising to meet so many students passionate about health equality and keen to pursue careers in patient advocacy and community engagement in science. The event was also an invaluable opportunity to network with a range of organisations and to talk about the importance of equity in genomics and rare disease research. I left feeling even more hopeful for the future.

In March, I attended the Living Well Symposium in Stoke-on-Trent hosted by Metabolic Support UK. This event focused on what it means to live well with a rare condition and the support needed for this, which ranged from day-to-day adjustments to legislative protection through the Equality Act. The programme included children sharing their school day experiences to an employment lawyer talking about his role as both an advocate and legal representative. It was a moving and thought-provoking day and a powerful reminder of the importance of advocacy and empathy as well as protection through policy and law.

More recently in June, we joined forces again with The Open University for the Glasgow Science Festival. We led a public engagement activity called the 'Tree of Life' exploring 3 inherited genetic traits: earlobe attachment, thumb dominance when clasping hands and the ability to taste bitter. Based on results, people placed a different coloured leaf on our Tree of Life. The activity offered a creative way to view how different, yet similar, we all are, and how much more there is to discover about what makes us human. The event also opened the opportunity for people to share personal health stories and for us to remind them of the importance of recognising the differences between us in genomics research.

Alongside these events, a key part of my work is to coordinate our lived experience groups. I've had the privilege of supporting the Diversity in Diabetes Young Persons Advisory Group, a group of young people living with type 1 diabetes who are helping shape the future of healthcare for young people from diverse backgrounds. We are currently making a video aimed at clinicians, to improve patient-clinician relationships, by fostering greater empathy and understanding of social and cultural differences and how these affect a person's lived experience with type 1 diabetes.

Our Experts by Experience Advisory Group, which represent a range of rare conditions, have remained a vital source of insight across a number of projects. Their contributions have been particularly valuable in shaping discussions around the NHS 10-Year Health Plan. It is important that the needs and voices of people with rare conditions are embedded in the future of NHS services. The group shared their thoughts on 3 key areas: the switch from analogue to digital systems, move from hospital to community care and a shift in focus from treatment to prevention.

We are also currently recruiting young people from underrepresented backgrounds with type 1 diabetes for our IMPACT1D advisory group. This group will support researchers at Birmingham Women's and Children's NHS Foundation Trust to shape research design so it is more inclusive and relevant to the communities they serve. We look forward to our first meeting with our new members.

Whether it's through community events or our lived experience groups, it's been an incredibly rewarding time filled with collaboration, learning and meaningful connection. I'm incredibly grateful to everyone who has shared their time and been a part of this.

I look forward to what the next season brings.
Sophie (pictured below) Sophie-Mira Roberts
Tel: 07469012944
Email**:** **sophie-mira.roberts@alstrom.org.uk**

The difference ASUK Grants make

Here is Ella in her new sandals! Celebrating her Birthday today! She loves them. It's so nice for me as well, that I can dress her up in a pretty dress and sandals. I think it's such a huge responsibility as a parent to dress your child who isn't able to choose and see for themselves, isn't it? Thank you to everyone who made it possible for Ella to have these.

Love Catrin and Ella x

ASUK Culture Family Forum - Together we are stronger, and our voices are getting even louder!

The Culture Family Forum (CFF) Members have had a very busy year including presenting at the ASUK conference, inviting several guest speakers to their meetings and reviewing products.
Marie gives her thoughts; In October, Aisha and Eddie presented at the Alström Syndrome (AS) Conference about the CFF meetings and their participation. Eddie and Aisha spoke very confidently answering many questions from the audience. The session finished with Aisha singing, All I want for Christmas, by Mariah Carey, which got everyone joining in, singing and dancing!

Alisha, a member of the CFF, and Professor Barrett could not attend the conference in person. Instead, Alisha conducted an online interview with Professor Barrett, and the recording was played at the conference. The interview addressed topics such as repurposed medication, cataracts, and future research. Professor Barrett was impressed with the thoroughness of Alisha's questions.

One of the objectives of the CFF meetings is to enhance members' confidence in listening, speaking, and presenting. Katie recently led a book review on "Silverborn: The Mystery of Morrigan Crow, Book 4." As joint facilitators, Melissa and I observed that she spoke with notable confidence and assurance. She has been able to develop these skills at her own pace, within this supportive and safe environment. The CFF members also reviewed Ramble Tags, these are lightweight harnesses, designed to be worn on the upper arm, or wrist of a guide, for assisted walking or running. Ibrahim commented, 'I thought it was good. I held onto it while my dad wore it.'

Other notable topics of discussion has been Adam's mobility training, Eddie, Hannah and Katie's work experience, Ibrahim's Duke of Edinburgh Award, (DofE) challenges, Aisha's curling and Prom night, Anna's interest in other cultures, and general discussions about holidays, birthdays and coping with first adult clinic appointments.

Guest speakers always bring another dimension to the group with the intention of inspiring and motivating the young people. Speakers have included Charlie Softley, PhD, Keele University, Lecturer in Pharmacology. She gave a wonderful talk about her research into AS, using frogs and tadpoles. Professor Barrett provided an overview of his career as a medical doctor and his passion for rock music. In the most recent meeting on the 24th June, Sean Carolan discussed his experiences working for British Airways as a flight attendant. He informed the members about his travels to over 200 cities globally. He also mentioned his longest flight, which is 15.5 hours from Japan to Heathrow, London, and disclosed the location of the secret door used by the crew to access their sleeping quarters. The guest speakers' diverse perspectives and experiences help to broaden the young people's view of the world.

It's been a real pleasure for Melissa and I, to see the group develop over this time. At first everyone was shy of each other, but over time it's turned into a really supportive community. It is lovely to see our young people forming friendships and swapping tips and tricks on how to navigate the world with AS. Everyone who attends the meetings is always engaged, we not only talk about important topics but have time to laugh together, share news and updates and it's great to see everyone in the group striving and thriving to live their best lives. All CFF members are involved in decision-making, ensuring that each member's input is considered. The group follows established guidelines for online behaviour, including respect, taking turns, and maintaining confidentiality. Members participated in creating these rules to promote a sense of ownership and mutual understanding.

On a personal note, Melissa and I learnt so much from listening to our young people, whether it's how to navigate a new medication or ways to make life more accessible. It is a true pleasure being facilitators for this group and we look forward to many more lively, engaging conversations!

Marie McGee, National Transition Coordinator and Melissa Crowland, Wellbeing Coordinator.

Welcome to Wellbeing

Melissa, our Wellbeing Coordinator gives us a wonderful update on the Wellbeing project.

Well, it has been a busy time in the world of wellbeing. We have been updating the new dedicated wellbeing section of the ASUK website and getting the webinar series under way.

If you pop along to the website, you'll be able to find recordings of all the webinars we've done so far. You will also be able to read through and listen to fact sheets, top tips and practical solutions to help you look after your wellbeing.

There are also recordings of past discussions from conferences about techniques and courageous conversations. If you were unable to attend the event at the time, it is a great way to learn some more information and add to your toolbox of coping strategies.

We try really hard at ASUK to make our information and the website accessible to as many people as we can. You will be able to find both written content and recordings of all the techniques and strategies that are discussed. You will also be able to find image descriptions of all the images we use, making sure that everyone can access all areas of the wellbeing section of the website.

We are midway through the 'Welcome to Wellbeing' series. These are interactive sessions held on 'Microsoft Teams' at 7pm (UK time) on the last Thursday of the month.

Thank you to everyone who has attended so far. Listening to techniques and strategies from others has been really helpful. We are stronger together.

So far, we have hosted sessions on:

- What is meant by Wellbeing?
- Managing and Understanding Anxiety & Depression.
- Surviving the Summer.
- Being a parent of a person with Alström.

We also have some exciting future discussions planned.

With topics including:
- Compassion.
- Fatigue and Burn Out.
- Sleep.
- Creating Healthy Boundaries.

Please don't worry if you've been unable to get to a session due to your other commitments. They are all recorded and top tips are added to the wellbeing section of ASUK's website. This means that you can interact with our content any time, any place - in a way that suits you.

We are always looking to promote topics and discussions that are important to our community. So, if there's something you would like to discuss please do get in touch.

ASUK are keen to develop peer-to peer support, and we'd like you to get involved.
Peer-to-peer support is when people who share similar lived experiences come together to support each other by discussing their lived experience. So, whether you're a person with Alström, a parent, a sibling, a grandparent or support someone in another way, ASUK wants to hear from you.

Would you like to join a friendly, open group with others who share your lived experiences to discuss life and coping strategies. Listening to others who share your experience can be extremely validating. It's important for you to feel like you're not alone and speak to those who share your experience. If you, or someone you support with Alström Syndrome, would be interested please contact Catherine Lewis or myself so we can put these groups together.

We already run a successful parent support group where likeminded parents get together and can discuss any issues they may be having. Attending one of these groups showed me how much parents want to learn from one another and support each other. With the expertise from other parents and the highly knowledgeable Family Support team, I felt that parents went away with an increased sense of wellbeing.

We want to create micro-communities within ASUK, so regardless of who you are, and how you're impacted by Alström Syndrome you feel supported and empowered to have your voice heard.

It is a motto of ASUK's that 'we are stronger together'. Get in touch so that ASUK can champion what is important to YOU.

It's your agenda that's important to us. We want to promote: your topics, your time, your talk. Play a key role in the development of our support services and get in touch with us.

Creative Ways to Positive Wellbeing—Activity to try

There are many creative ways that can promote your wellbeing and these can be done anywhere and don't cost a penny.

Enforcing positive mental health should be affordable and accessible for everyone, which is something that ASUK always champions.

Metawriting

A way of focusing on your thoughts, feelings and emotions that can truly work for you.

Metawriting is described as writing, either creatively or in an autobiographical way to help the writer navigate thoughts, feelings and emotions which may be difficult to verbalise.

Sometimes negative thoughts can become overwhelming, as the thought gets louder and louder, and bigger and bigger in our head, becoming all consuming.

A way of taking back control of our thinking, is writing and journaling. It can be a great way to work through any feelings you may be having before you talk to someone about it.

Using writing for therapy is also useful, as it gives you the space to decide what you talk about and process your thoughts, feelings and emotions about any given event. It's up to you whether you write non-fiction or a poem or story that documents how you are feeling.

People who are already receiving therapy can use journaling to record how they feel after their session has ended. This allows them to develop insights into themselves and can help them reflect on the work they have done so far.

However you choose to offload, metawriting can be a real way of getting your thoughts, feelings and emotions, down in a way that echoes your innermost narrative. Whether you're young, old or in between you can adapt exercises to work for yourself or your child.

Below is a poem I wrote when I was struggling with negative emotions.

I wanted to write a note to myself to remind me it was okay not to feel okay.

It's ok not to be okay

I know today's been hard
And your inner light is dim
And your heart lies in broken pieces
Trapped deep beneath your skin.
I know your roads been tough
But you've walked it straight and true
Think of all the lights that shine,
And switch their brightness onto you.
Right now your blue skies turned grey
You're scared you're hurt you're angry
But tomorrow is a new day
You're safe with me my friend
Just remember in the end
It's okay not to be okay.
I know that life has been unfair
What it's done to you' s not nice
But if you turn your face to the wall
What was the point of that sacrifice?
I know you want to cry
To throw things, scream and shout
But I'm your friend, I'm here for you
Let all your feelings out.
Right now your blue skies turned grey
You're scared you're hurt you're angry
But tomorrow is a new day
I am here for you my friend
But remember in the end
It's okay not to be okay.

If you would like to learn more about how creative writing or journaling can work for you or a loved one, please get in touch with Melissa, our Wellbeing Coordinator, so she can support you on your journey.

Melissa

Melissa Crowland
Wellbeing Coordinator
Tel: 07301 078059.
Email: **Melissa.crowland@alstrom.org.uk**

Meet some of our incredible fundraisers – our everyday heroes!

24 hour fitness challenge!

Millie and her supporter Pete, accomplished an incredible 24 hour fitness challenge in June and the donations will be split between ASUK and the residential school New College Worcester: **www.justgiving.com/campaign/24hourchallenge**

10K in 10 days!

In February 2025, Aidan did the impressive challenge of 10K a day for 10 days!

"We would like to do this on behalf of our daughter Sheila as thank you to Alström UK for the support provided to us since her diagnosis in 2021. They provide a multi-disciplinary clinic annually for us. They organise accommodation and provide us with meals. The charity is amazing, and the team provide support to us whenever we need it. Sheila is an amazing little girl, who has been through so much for someone so little, both of our families are very proud of her. We are determined that this illness will not define her. Any donation would be greatly appreciated, I'm running 10k a day for 10 days, starting 21st Feb for 10 days. I'm ready to hit the roads…lets go"

26 mile Challenge

On the 7th June 2025, Sara took on the challenge of walking 26 miles in the pilgrims marathon, Nant Gwrtheyrn to Aberdaron. "I am doing this challenge to raise awareness of this ultra-rare disease that affects my 8 year old niece Ella."

Thank you to all our fundraisers, you are our true everyday hero's.

No challenge is too big or small.

From sponsored walks and fun runs to adrenaline-pumping skydives, this is your chance to do something amazing—for yourself and for others.
Together, we can raise funds and make a HUGE difference for our small but mighty community.
This summer, every step taken, cake baked, and challenge completed helps us support those diagnosed with Alström Syndrome. Challenge yourself because when a condition is ultra-rare, every voice, every penny, every event matters more than ever.
Join us this summer, let's have some fun, connect together, and support the Alström Syndrome Community.

How can we help?

- We can send you a fundraising pack, with lots of goodies.
- We can chat with you about ideas and how to make them a reality.
- We can support you to set-up a JustGiving page for your donations.
- We can help spread the word by sharing your fundraising activities on our social media channels.

Just Giving is a great place to start by creating your fundraising platform and share with your friends and families, so they can support you. You can also make **donations** quick and easily on here too **www.justgiving.com/alstromsyndromeuk**

Get in touch with Catherine who can support you throughout, email **catherine.lewis@alstrom.org.uk** or call on 07970 071675 she can't wait to hear from you!

Achievements Galore!

Thank you ASUK

"I want to say a huge thank you to each and every one of you for all the support you've given, not just to me, but to families and friends across the UK and around the world. From the bottom of my heart, thank you for helping me through the last three years of my university journey. Without your help, I wouldn't have made it to university, let alone graduated and move forward towards my goals.

There are so many of you I'd love to thank individually… but there are just too many of you!

I officially graduated on the 22nd July, and it was a truly special day, getting to celebrate with family and friends one last time before everyone went their separate ways. I had hoped to invite some of you to the ceremony, but unfortunately, all the seats were fully booked. Hopefully, you can come next year when I graduate from my MA!

I'm proud to share that I finished my degree with an overall grade of 71.18%, which is a ***First-Class Honours.*** *At the start of my third year, I was sitting at 64%, but I worked really hard and pushed myself and with your support, I improved my final result. I'm really proud of that achievement.*

Looking ahead, I'm planning to start an MA in Media Production next year, and my long-term goal is to eventually pursue a PhD in Media Production.

This past year has been amazing. I especially enjoyed working with you all on the radio project in January. The 6pm show was a highlight! Seeing Marie in the radio room for the first time was such a great experience; she was trying out something totally new, and it was fun catching up with her. The show reached around 311 listeners: 10% from the UK, 25% from Europe, 5% from the USA, and 60% from other countries! Hopefully, we can do another show next year, and I'd love to invite you to experience it again.

Take care of yourselves, stay safe, and stay out of the sun! (Unless you've got SPF 1000 on of course!)

Warm regards,
Abdullah"

Let's get research ready and connect communities together

In the UK we have a comprehensive database of people diagnosed with AS, but we know the numbers globally are very patchy. Researchers and drug developers look for this information when considering drug trials and research initiatives, so why not be part of the AS Global database and help us get research ready!

We have set-up a quick and easy contact form for people outside of the UK who have a confirmed diagnosis so that we can try and understand the global figures.

As always, the Alström community have rallied together and there has already been a fantastic response.

We have had **162** people complete the contact forms! **112** of these are from across China, Hong Kong and Malaysia.

We are also, working with Alström Associations in Spain, Italy and Germany to translate the contact form so they can complete their information easily in their preferred language.

If you live outside the UK and you or your family member is diagnosed with Alström Syndrome, you can complete your information too.

This is also a great way so we can see which families live near each other and connect communities together!.

https://forms.gle/4gDeVc3E5qE3yuMA8

11th ALSTRÖM SYNDROME INTERNATIONAL
FAMILY MEDICAL CONFERENCE &
SCIENTIFIC SYMPOSIUM
Fort Worth, Texas

JOIN US
DEEP IN THE
HEART OF TEXAS
TO ENJOY BBQ,
BOOTS AND A LOT OF
"YEEHAW!" WITH YOUR
ALSTRÖM FAMILY!

MAY 21, 2026 6PM TO
MAY 25, 2026 10AM

REGISTRATION & BOOKING
DEADLINE: APRIL 29, 2026

LET'S COME TOGETHER FOR
CONNECTION, LEARNING & HOPE.

International Families Come Together in 2026 in Texas!

The online registration and hotel bookings are now open, pop along to the ASI website to find out more:

www.alstrom.org/the-11th-asi-family-medical-conference-scientific-symposium-registration-is-open/

Research News

In October 2024, the Alström Syndrome UK (ASUK) Medical and Scientific Advisory group (MSAG) met to discuss progress in Alström Syndrome (AS) research and to explore next steps. Members of the group also stayed on to join the Alström Syndrome Family Conference and listened to our community share their thoughts, experiences and hopes for the future.

Researchers and clinicians left the conference feeling inspired and have continued to meet regularly and drive forward with new research initiatives.

We are so pleased with the progress that has been made and wanted to share an update with you all on these new developments and the ways you can also get involved.

Alström Syndrome Workshop

We know from previous feedback that research into sight loss is one of the main priorities for people living with AS and this is one of the main messages the MSAG took away from the conference.

At the start of 2025, the MSAG applied to the University of Birmingham Institute of Advanced Studies to hold a workshop on AS with a specific focus on sensory loss. We are delighted to announce that the application was successful. This will be an opportunity to collaborate with different departments at the University of Birmingham including scientists and education specialists and our clinical teams at Birmingham Women's and Children's Hospital and the Queen Elizabeth Hospital, Birmingham.

We are also working with other sight loss specialists including experts from Moorfields Eye Hospital and hope to learn from developments in other conditions such as Usher Syndrome, Bardet Biedl Syndrome and Leber's Congenital Amaurosis (LCA).

You may have seen the recent news article about the successful gene therapy trials for LCA in the UK. We know that gene therapy would be challenging for a condition like AS due to the size of the AS gene (ALMS1). As technologies and techniques advance, we hope to be able to learn from gene therapy trials and other studies involving larger genes and ways that the AS community may benefit from these exciting developments.

The IAS Workshop: Finding Solutions for Sensory Impairment in Alström Syndrome, held at the University of Birmingham took place on the 30th June 2025.

Although places at the workshop were limited, the voice of our community was strongly represented. Kerry, Chief Executive of Alström Syndrome UK gave an overview of the condition, the activities that are currently taking place across the UK and globally for the management of Alström Syndrome, followed by lived experience perspectives from Tara (Mum to a child diagnosed with AS) and Melissa (person diagnosed with AS). It was very clear from their experiences that sight loss is one of the main research priorities for the AS community.

The workshop had a vast array of professionals, from education, medical, scientific and research institutions, with expertise in Alström, sight loss and other rare conditions. Many discussions focused around the current therapies, future work and next steps.

There will now be an opportunity to apply for additional funding from the University of Birmingham to take forward the ideas and research possibilities that were generated through the workshop discussions.

Rare Disease Day—Westminster was Calling!

This year, the Rare Disease Day reception at Westminster welcomed the rare disease community. People with lived experience, organisations at the heart of this work and policy makers discussed everything rare, the progress made to date and the areas which still need addressing.

Our Chief Executive, Kerry and Lived Experience Coordinator Sophie were delighted to be invited, and took the opportunity to raise awareness of Alström Syndrome and highlight the needs of the rare community.

Full information, including a link to Genetic Alliance UK **More than you can imagine: an anthology of rare experiences** which was launched at the event can be found on their website: **www.geneticalliance.org.uk/campaigns-and-research/rare-disease-day/anthology2025/**

Drug Screening Programme

Researchers in Birmingham have been developing cells with the support from the AS community who have kindly donated samples. Findings have shown that the cells in people with AS grow old more quickly. This premature ageing is called senescence.

At the end of 2024, the MSAG submitted an application to the LifeArc Centre for Acceleration of Rare Disease Trials (ARDT). The purpose of the LifeArc ARDT Centre is to improve the efficiency of rare disease trials and provide better opportunities for people to take part. This is a collaboration between Newcastle University, University of Birmingham and Queen's University, Belfast. As part of this new initiative, the University of Birmingham are funding 5 non-clinical PhD studentships to develop models that will allow treatments to be tested in rare disease clinical trials.

We are really pleased that our application has been successful, and a PhD student has been recruited to start work on AS. This is a 4-year programme where the PhD student will work with scientists and clinicians in Birmingham, and with ASUK and Newcastle University. The aim is to find drugs to target premature ageing (senescence) and improve health outcomes for people with AS. Our hope is that this could lead to a clinical trial and an effective treatment.

Neuropathy Study

A new study is being led by Professor Tarek Hiwot from Queen Elizabeth Hospital Birmingham and Professor Mitra Tavakoli from the University of Exeter. This study aims to better understand and assess pain and neuropathy in people with AS. The team will do this by exploring new ways to measure how the condition is progressing (biomarkers) in the eye (ocular) and the nervous system (neuropathy).

Pain and nerve damage (neuropathy) can significantly impact the quality of life for people with AS and other related conditions. Clinicians are not sure what causes this. This study will develop new ways to diagnose and assess nerve damage. The hope is that this will help improve diagnosis and future treatments.

Adults attending the AS multi-disciplinary clinics in Birmingham are being invited to take part. An information sheet is available with further details on the ASUK website:
www.alstrom.org.uk/research-highlights/#neuropathy-ophthalmic-biomarkers-in-AS

The future of the NHS - Back in patients' hands
Breaking Down Barriers Contributes to NHS 10-Year Health Plan

The Breaking Down Barriers, Experts by Experience Advisory Group were pleased to take part in the consultation for the development of the NHS 10-Year Health Plan.

The group shared views on three key shifts:

- Analogue to digital
- Hospital to community
- Treatment to prevention

At 168 pages, the plan is certainly ambitious and outlines a vision for a future-fit NHS. While the intentions are positive, it's important that no one is left behind—particularly those with complex needs or limited digital access. A one-size-fits-all approach won't work; care must remain flexible and person-centred.

The big question is around implementation—how will this vision be delivered in practice, and where will the funding come from? It's vital that the plan doesn't widen existing inequalities but instead supports underserved communities.

UK Government
NHS
FIT FOR THE FUTURE
10 Year Health Plan for England
July 2025

One encouraging step is the renewed focus on patient voice and experience. Plans include personalised care plans, expanded personal health budgets, and linking patient feedback to provider payments—key moves toward empowering people in their own care.

On 9th July 2025, the Government began rolling out neighbourhood health services in the most deprived areas, aiming to provide more joined-up, accessible care. Read more on the Government website, link below
gov.uk/government/news/government-takes-action-to-deliver-neighbourhood-health-services

We're now developing a report summarising the views of our advisory group and our reflections on the 'Fit for the Future' plan. We look forward to sharing this with you soon.

BEAT THE HEAT!

The UK is experiencing hot weather, and with heatwaves seeming to be occurring more frequently, we've pulled together some top tips to help keep you and your loved ones safe, cool, and well.

Look After Each Other

- A heatwave can affect anyone, but some people can be affected by the heat more than others, including:
- Older people (especially those aged over 75).
- Babies and young children.
- People with long-term or serious health conditions.
- Those taking multiple medications.
- People who live alone or in care homes.
- People who spend long hours outdoors or live in hot buildings (e.g. top-floor flats).

Check in on neighbours, friends, and family — especially those who may need extra help.

Keep Hydrated

- Drink plenty of fluids – even if you don't feel thirsty.
- Avoid alcohol, caffeine, and very sugary drinks – these can dehydrate you.
- Offer water regularly to children, older adults, and those who rely on carers.

Keep Cool Indoors

- Close curtains or blinds on windows that face the sun.
- Open windows when it's cooler outside (early morning, late evening) to let fresh air circulate.
- Use electric fans if temperatures are below 35°C – above that, they can make things worse.
- Take cool showers or baths, or use a damp cloth on your skin and pulse points.
- If safe, spend time in a cooler building like a library, supermarket, or community centre.

Stay Safe Outdoors

- Avoid going out in the hottest part of the day (usually 11am–3pm).
- If you must go out:
- Stick to the shade.
- Wear loose, light-coloured clothing.
- Use a wide-brimmed hat and sunglasses.
- Apply sunscreen (SPF 30 or higher) and reapply often.

Eat Light

- Eat smaller meals more often.
- Choose foods with a high-water content like fruits and salads.
- Avoid hot and heavy meals when possible.

Summer – healthy snacks

Pop along to the British Heart Foundation website where you can find lots of healthy recipes, including healthy snack ideas…

www.bhf.org.uk/informationsupport/heart-matters-magazine/nutrition/healthy-snack-ideas

Sleeping Tips During a Heatwave

- Use lightweight bedding and keep the bedroom as cool as possible.
- Sleep in the coolest room in your home if you can.
- A cool flannel or chilled water bottle (wrapped) at your feet can help lower body temperature.

Know the Signs of Heat Exhaustion

Be alert for:

- Headache.
- Dizziness or confusion.
- Excessive sweating.
- Pale, clammy skin.
- Nausea or muscle cramps.

Take action immediately: Move to a cool place, drink fluids, lie down, and cool the skin.

If symptoms don't improve within 30 minutes, call 111 or 999 and seek medical help.

Things to consider

- Ensure cooling aids like fans or cooling vests are easily accessible.
- Plan any essential travel or appointments for the cooler parts of the day.
- Monitor for signs of overheating or dehydration.
- Work with carers or support staff to make sure personalised care plans include heatwave strategies.

ASUK Care Coordinators are here to support you, so please get in touch if we can help go through any of the tips in more detail or if you need any further guidance.

Melissa our Wellbeing Coordinator gives us her top tips. *“You can get special sun cream for your lips. I’m noticing my lips are very dry and chapped because of the heat. I use lip balm daily, but you can get special sun-cream for them.*
Your blood pressure can also increase in hotter weather so when I am sitting, I elevate my legs to try and keep my blood pressure as low as possible.
I also make healthy versions of lollies which I eat more of in the heat.”

Keep cool with these **ice lollies,** you can make at home! Go onto the BBC Good Food Website, link below to find lots of Ice Lolly recipes, not only yummy to eat but fun to make too…

www.bbcgoodfood.com/recipes/collection/kids-ice-lolly-recipes

Don’t Forget about your Pets too!

Guide Dogs for the Blind have some top tips to keep your dog’s safe during the hot weather.
www.guidedogs.org.uk/getting-support/information-and-advice/dog-care-and-welfare/hot-weather/

The Met Office also have an area which has top tips to keep you and your pets safe, check it out

https://weather.metoffice.gov.uk/warnings-and-advice/seasonal-advice/health-wellbeing/tips-for-keeping-older-people-cool

Further Information

Please find below links to organisations who have further information on how to enjoy the hot weather safely:

NHS
www.nhs.uk/live-well/seasonal-health/heatwave-how-to-cope-in-hot-weather/

Age UK
www.ageuk.org.uk/information-advice/health-wellbeing/mind-body/staying-cool-in-a-heatwave/

Off the Record

Have you always wanted to know the ASUK team**,** the AS community, researchers and clinicians a little better… maybe some of their secrets or what goes on behind the scenes, well now you can in this ‘off the record’ podcast. Check out the new Podcast area of the ASUK website to find out who is related to a famous footballer and who loves pigs, who has a naked cat and much more besides!

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
Kerry.leeson@alstrom.org.uk

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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 **www.youtube.com/alstromsyndromeuk**

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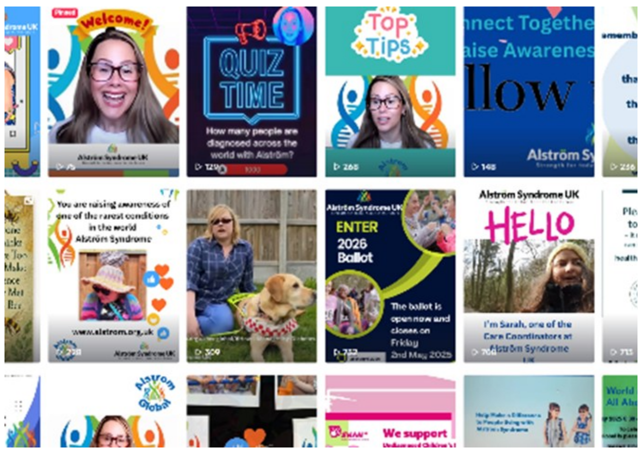

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