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 Spring 2026 ASUK Newsletter

Hi everyone, and welcome to our spring newsletter. I hope you are all keeping well and starting to enjoy the warmer weather. Scott and I are looking forward to getting out in our campervan a bit more although the cold weather didn't stop us! It feels like it has been a long winter, but we made the most of it. Kion and I have continued to support our local football team Rotherham United and have attended all home and away matches. It's not looking too good for us this season, but we always enjoy our football days no matter what, spending quality time together and with our family and friends. Cole has been busy working, and he passed his driving test last year. He has a new car and loves it although he has now decided he also wants a motorbike like his brother – my young men are determined to give me sleepless nights!

I have really enjoyed following all your adventures on social media and have loved catching up with people over the phone and in person at a few of the clinics recently. I hope to catch up with more of you this year and I am really looking forward to seeing everyone at our first family festival in July. This promises to be a truly special day where people can come together to connect, learn and most importantly, have fun. Whether you're trying your hand at a new sport, reconnecting with friends, or simply enjoying the atmosphere, there will be something for everyone. We are passionate about creating opportunities that build confidence and celebrate what each person can achieve, and this event has been designed with that in mind. Alongside the activities, we will be sharing some new and exciting research developments that are an important step forward in improving understanding, treatment and care for people living with Alström Syndrome. We are also hoping to arrange an adult social the night before so please let us know if you fancy meeting up.

Over the past few months, we have seen so many inspiring moments across the Alström community - from powerful personal stories to important national conversations around equity and rare conditions. It has been a time of reflection, progress, and connection.

In this edition, you can read about Hannah's incredible sailing adventure and read Melissa's beautiful poetry. You can also find out about the time when a pop star and Leicester City football team had the privilege of meeting AJ and Teddy! These are just a few examples of the confidence, resilience and determination that we continue to see shining through our wonderful Alström community.

We are proud to share updates from Rare Disease Day 2026, where the theme of 'Equity' has encouraged important discussions about fairness in healthcare, education and everyday life. Listening to people with lived experiences guides everything we do at ASUK, and we will continue to amplify your voices as we work towards a more inclusive future.

We are also introducing some new opportunities to get involved, including our new book club and upcoming 'Beyond Sight' series sharing experiences of life after sight loss. These initiatives are all about connection and creating spaces where people feel heard, supported and inspired.

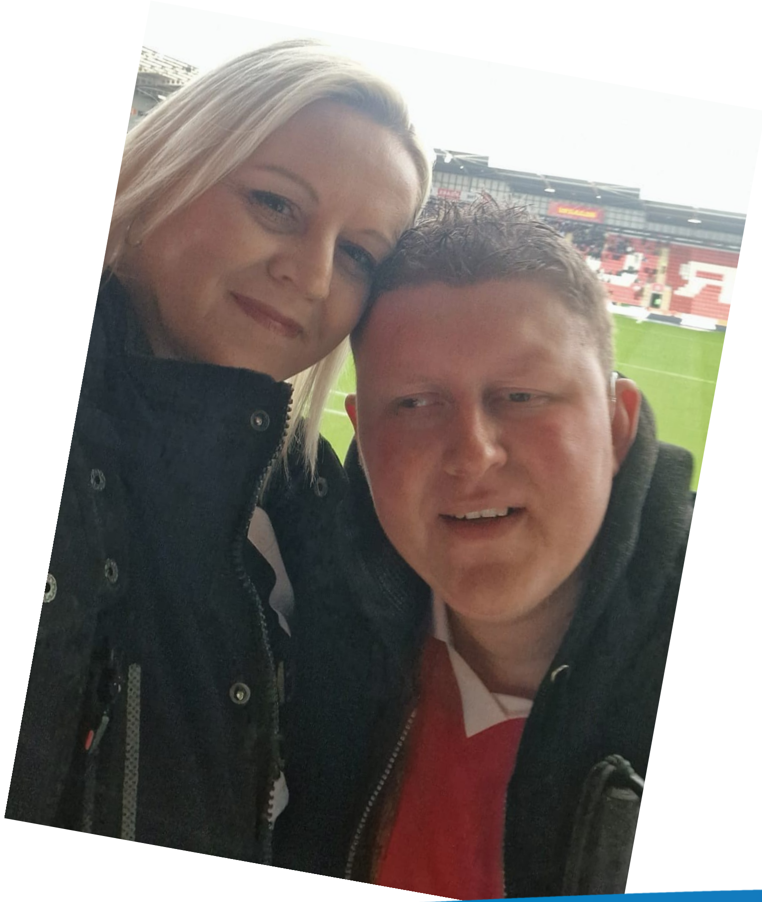
I want to take this opportunity to thank the ASUK team for all their hard work. I feel privileged to work with such incredible people who go over and above to support our community and each other.

Finally, a huge thank you to every one of you - our families, supporters, researchers, healthcare professionals and partners. Your strength, openness, support and commitment continue to shape everything we do.

Together, we are building a community that not only supports one another but also drives meaningful change.

Take care everyone –
I hope to see you soon!

We are here for you
Kerry** **and the ASUK Team



New Adventure on the High Seas!

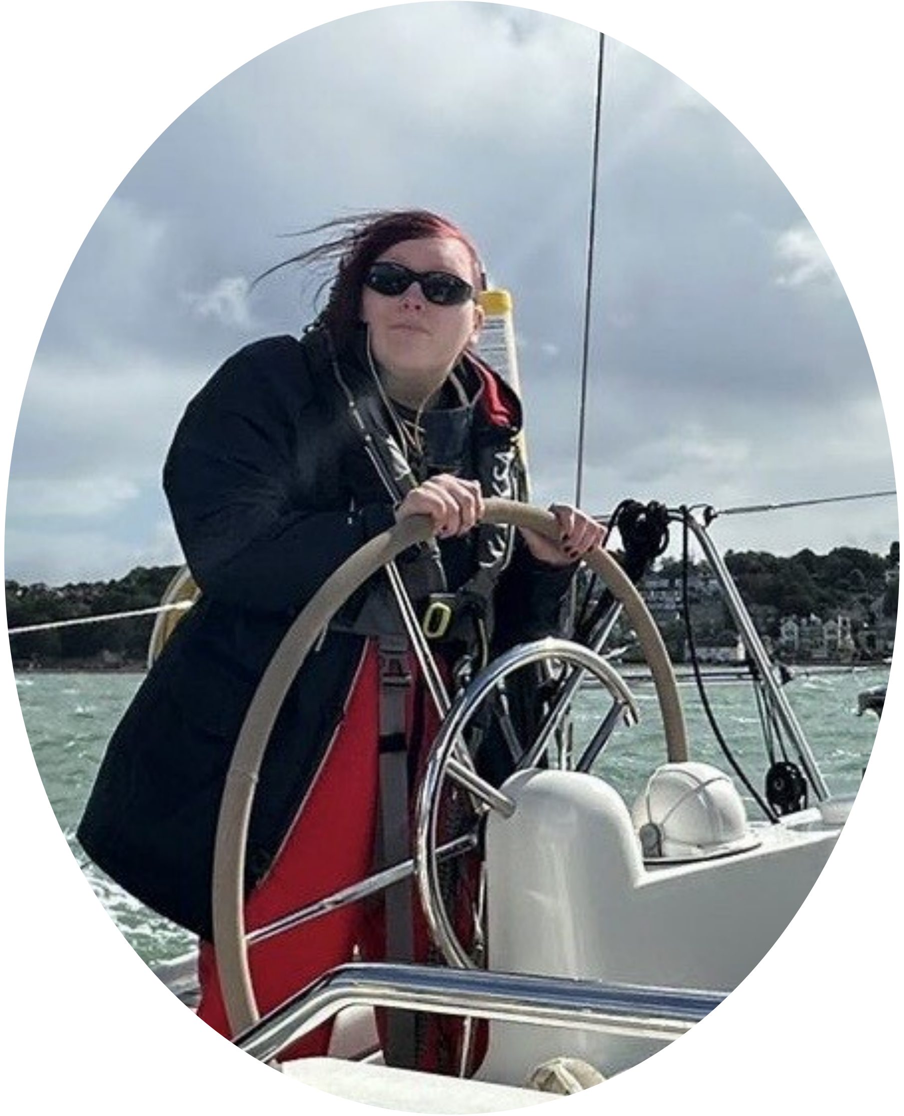
Sailing by Hannah Bromley-Challenor

I have loved sailing since I was a child when I first tried dinghy sailing as part of a school trip. Since then, I have been on all sorts of boats, but my favourite type is staying on motor cruisers, or narrow boats. I have been boating with my parents in Wales, Scotland and the Norfolk Broads. The motor cruisers are very compact so you can orientate yourself very quickly and feel very safe onboard, although depending on which type of boat you get, there can be lots of stairs to negotiate, and some are very steep, almost vertical. I find the rocking of the boat really relaxing and I probably sleep better on a boat than at home. One of my favourite things to do is helming or steering using the wheel, especially when there is a bit of a breeze as it feels so liberating. You also get to meet a lot of nice people from fellow sailors, lockkeepers, if there are any locks, and local taxi drivers. There are usually plenty of nice places to eat and drink along the way so you still can enjoy things like takeaways or fish and chips.

This summer I got to try a new exciting sailing experience. I had the opportunity to go sailing around the Solent and the Isle of Wight on a sailing yacht. This was slightly different to what I am used to because I have never been on a sailboat, apart from the dinghy sailing I had tried before, but this boat was much bigger, and so were the sails. I was really excited to give it a go, and my parents were also supportive as they have done a lot of sailing in the past, so they were able to make sure I had all the right equipment and clothing, like wet weather gear. The skipper and sighted volunteers were helpful with answering any questions and reassured me about all the important information, like safety on board, and how to get around. I was sent a check list of things to bring, but I was really lucky because my mum’s sailing gear fitted me, so I had most of it, but there was the opportunity to hire the wet weather gear if I didn’t have it, and they even sent me a survey of what food I would like to eat on board. Before I even met anyone, we had a Zoom call so I could meet the crew I was going to be with. For my trip there were two other visually impaired people, sighted volunteers and the skipper. They also set up a WhatsApp group to stay in touch before we all met up on the boat.

When the day of the trip came, we had an orientation of the boat, a safety talk, and we sorted out life jackets. We went round the table introducing ourselves and explaining how much eyesight we have and how much previous experience we've had sailing. They were reassuring and told us we could be as involved as we like. They also emphasized that if we wanted to do anything specifically, we could just let them know. I've always wanted to improve on ropes and knots, so they taught me how to use the winches, which are used to control the sails, and I also helped tie up the fenders at the end of the day’s sail. Fenders are air filled rubber cylinders which are used to protect the side of the boat when it is moored. They also showed me how to handle the ropes and lines properly because it is important that they do not get knotted. This is because they run through the winches which control the sails.

Another thing I enjoyed doing was helming, both upwind which is a bit rougher because it is sailing against the wind, but also more fun, and downwind which is sailing with the wind, which is smoother and faster. To help me position the wheel, there was a tape or a small knot of rope on the top centre of the wheel, so I knew when to go back to the middle to keep the boat going straight but I also had the skipper next to me, who was overseeing all the crew and giving us directions. My experience of helming really helped me, and my parents noticed this when I went cruising with them after my trip. They noticed that I was much better at judging how much I had to move the wheel to slightly change direction.



We had a lot of fun on the boat even when we were not sailing, like playing music with the Bluetooth speakers in the saloon, helping with cooking, going for a drink when we moored on the Isle of Wight, and having ice cream. In the evening when we were back on the boat, we played a game called The After Eight challenge, where I had to put an After Eight on my forehead and move it into my mouth without using my hands. Silly, but very funny. I also made some new friends who I'm still in contact with.

I really enjoyed sailing and found it has helped with my confidence, I have gained new skills and met new people. I would recommend it to anyone who wants to try something new. I am happy to answer any questions about my article if anyone is interested, and if you see me at one of the clinics, I would be happy to talk to you about it. I am also on social media if you would like to get in touch.

Hannah

Exciting News: A Celebration of Possibilities, Connections and Unforgettable Moments

Our First Family Festival - Have a Go Sports Event

Everyone Welcome

Alström Syndrome UK
Strength for today, hope for the future

THE ALSTROM COMMUNITY FESTIVAL

Join us for a day of FREE activities designed for all ages.
A celebration of possibilities, connections,
and unforgettable moments.

- Try sports and activities you never thought possible
- Meet friends old and new
- Discover what you can achieve in a welcoming, supportive space
- Enjoy a fun, relaxed atmosphere for the whole family

Come for the fun, stay for the friendships!

Contact Catherine to reserve your FREE place today
Catherine.lewis@alstrom.org.uk

When
11th July
2026

Where
New College
Worcester

We are absolutely delighted to share some exciting news for the summer ahead!
Date: Saturday 11th July 2026
Venue: New College Worcester
ASUK is thrilled to invite you to our very first Family Festival, a unique day designed to bring our community together to connect, learn and most importantly, have fun.
We will start by giving an update on what has been happening in the Alström community and will be sharing some exciting new research developments with you. Members of the clinical team will be available throughout the day to answer your questions and join in the fun!
Then it’s time to dive into an exciting range of inclusive activities!
From axe throwing and archery to tennis and judo; from mini-golf, pony rides, swimming and inflatable obstacle courses and even go-karts, there is something for everyone. You can even explore weight and gym training sessions, all fully accessible and designed to be inclusive for all ages and abilities.
This is a chance to try something new, build confidence, celebrate what you can achieve and spend time with people who truly understand your journey. Reconnect with old friends, make new ones, and create lasting memories in a welcoming and supportive space.

Whether you come for the updates, the activities, or simply the joy of being together, we would love to see you there.
Thanks to the generosity of our supporters and a grant from Sport England, this event, including all activities, food and refreshments is **completely free of charge.**
New College Worcester is easy to access, with excellent road links just off the motorway and convenient train connections. If you would like to make a weekend of it, there are a range of hotels nearby and plenty of local attractions to enjoy, including the West Midlands Safari Park.

We don’t want distance to be a barrier to attending this special event, so if travel costs are a concern, please do get in touch with Sarah, our ASUK Care Coordinator, to discuss possible grant support, you can email her at sarah.oliver@alstrom.org.uk or by giving her a call on 07917 958502.
Please scan the QR code to complete your booking form.

Please email **Catherine** if you have any questions about the event,
catherine.lewis@alstrom.org.uk

We look forward to seeing you all there!

Beyond the Pages: Get Lost in the Story and Start your Book Group Adventure With Us

Reading is a window into worlds both familiar and unknown, allowing us to explore new ideas, cultures, and perspectives. People often find joy in how books spark curiosity, foster empathy, and inspire personal growth.

The brilliance of reading books lies in their ability to transport us, challenge our thinking, and connect us with others across time and space. Whether it's a favourite story, a new insight, or the simple pleasure of a quiet moment, reading can be a truly enriching experience.

Does any of the above resonate with you? If you’re the kind of person who likes to melt into the story and disappear for hours into the undiscovered pages then our new Book Group may be for you.

Join Alström Syndrome UK's book group, meeting every six weeks, wihere members choose the books and come together to share perspectives and insights in a supportive community. The time and meeting platform will be decided by the group as a whole as it is extremely important that this is an accessible experience for all those involved.

If you or a loved one is interested then please contact Melissa.
We can’t wait for you to get lost in the pages and your Book Group adventure to begin.

Beyond Sight: New Perspectives on Life After Sight Loss

Share Your Story: Life After Sight Loss - Recorded Series

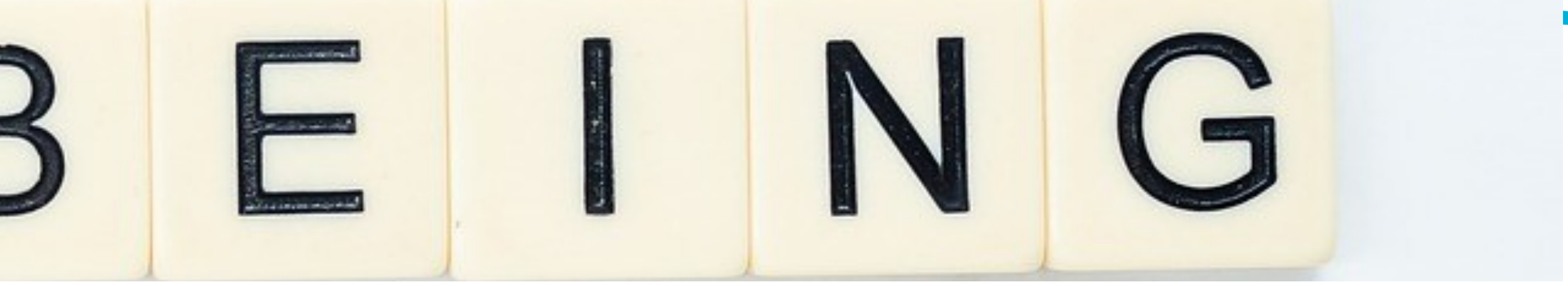
We're inviting individuals who have experienced sight loss to share their stories, insights, and perspectives for an upcoming recorded series.

Your contributions will help create a powerful and inspiring collection of stories that showcase the resilience and adaptability of individuals who have navigated life after sight loss. Some of the topics the series will cover include: navigating education, work, the kitchen, independent living, mental health, fashion and recreation.

By sharing your experiences, you'll help break down stigmas and raise awareness about the challenges and opportunities that come with vision loss. Your voice and story can inspire and empower others who are navigating similar journeys.

We welcome contributions from anyone who has experienced sight loss, whether it's a personal story, a message of hope, or a reflection on the impact of vision loss on daily life. Your participation will help create a recorded series that celebrates the complexities and richness of life after sight loss.
Please get in touch with Melissa, our Wellbeing Coordinator, if you would like to be involved, she can also support you on your journey.

Melissa, Wellbeing Coordinator
Melissa Crowland
Email: **Melissa.crowland@alstrom.org.uk**, Tel: 07301 078059.
Melissa works part-time on a Wednesday and Friday



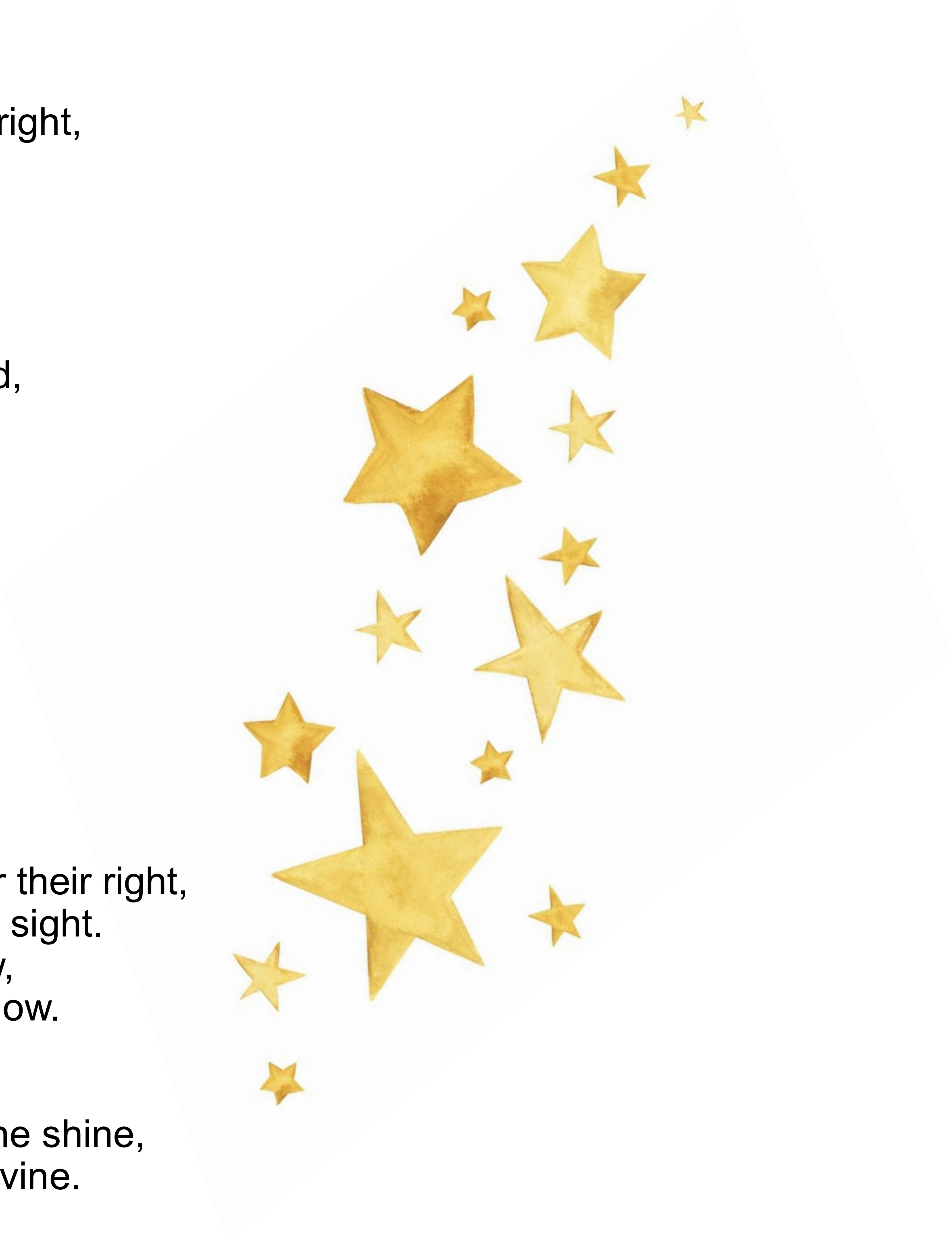
For our Rare Disease Day campaign, Melissa not only shared her lived experience in a podcast but also shared her thoughts as beautiful poems.

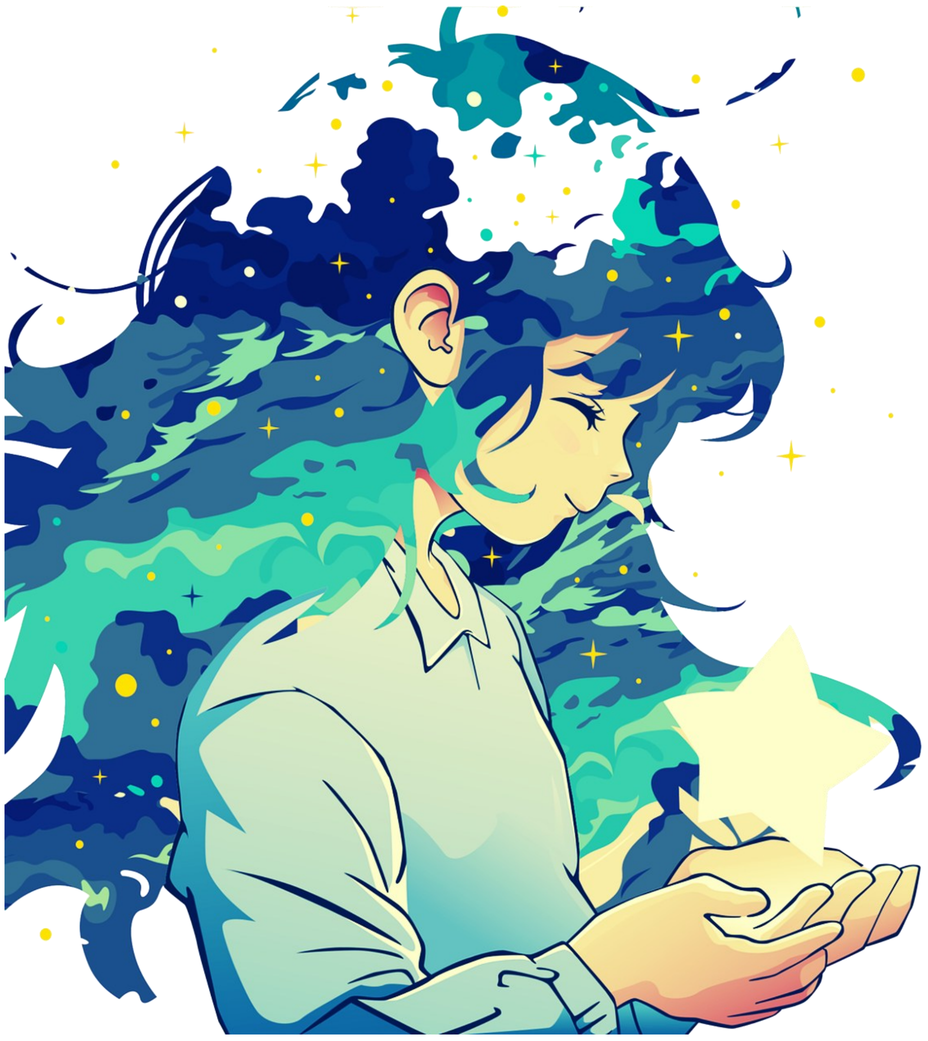
Equity

In Alström Syndromes shadow, equity shines bright,
A beacon of hope, for the long and the fight.
Equal access, to care and to might,
A fundamental right, day and night.
With every step, a voice is gained,
Awareness rises, and hope is maintained.
Research advances, and treatments are gained,
A brighter future, for all is obtained.
In unity and strength, our community stands,
Together facing, Alström Syndromes demands.
Equity's power, brings light to the land,
A world of fairness, at hand.

What is Equity?

Equity's voice cries out to be heard,
For all to have a chance, to be undeterred.
In education, employment, and play,
Equity's goal is to level the way.
For those with Alström Syndrome, it's a fight for their right,
To access quality care, and a life worth living in sight.
With equal opportunities, they'll thrive and grow,
And their unique contributions, the world will know.
Equity's role, to bridge the gap and bring,
A fair and just society, where all can sing.
It's time to break down barriers, and let everyone shine,
And equity in Alström Syndrome, will be truly divine.





Hope

In the darkness of a rare condition's hold,
A glimmer of hope, a light to behold.
A beacon in the night, a guiding star,
Illuminates the path, near and far.
With every step, a new dawn breaks,
And though the journey's long, hope's heart it makes.
In the face of uncertainty, it stands tall,
A resilient spirit, that refuses to fall.
Through trials and tribulations, it finds its way,
And in the silence, a voice begins to say,
"I am strong, I am brave, I will endure",
And with each breath, a new story will ensure.
Hope's flame flickers, but never goes out,
A burning fire, that guides through life's devout.
With every setback, a lesson's learned,
And in the heart, a newfound hope is earned.

Rare Disease Day 2026—All About Equity

What an incredible Rare Disease Day!
From powerful conversations, podcasts and presentations in Westminster to advocates, families and organisations coming together to raise awareness.

Rare Disease Day is observed every year on the 28th February (or on the 29th if it falls on a leap year), the rarest day of the year!

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse, but united in purpose. Rare Disease Day was set up and is coordinated by EURORDIS (Rare Diseases Europe) and 65+ national alliance patient organisation partners. Here in the UK, Genetic Alliance UK coordinates many of the events and awareness raising in the UK throughout Rare Disease Day.

This year's theme is Equity.
Through our Breaking Down Barriers Network we have been focusing on what equity means to you. We have been listening to people with lived experience of rare and/or genetic conditions, to capture what equity means in real life, from healthcare, education provision and our identity. With one very important question at the heart; **What needs to change in the UK to make life fairer?**

We have created **All About Equity podcasts** where you will hear from people talking about what matters most to them. Including giving their top tips and ways we can all make a difference to make lives fairer and more equitable in the future.

Pop along to the Breaking Down Barriers website to see these wonderful insights from the community.
https://breaking-down-barriers.org.uk/rare-disease-day-2026/

Rare Disease Reports have been Launched

Kerry and Sophie attended the Westminster Rare Disease Day reception at the House of Commons.
It was clear from listening to the excellent speakers Alison and Sophie, (Breaking Down Barriers Lived Experience Coordinator) that much more needs to be done to make things more equitable for people living with rare conditions. A huge thank you to Genetic Alliance UK for organising such a fabulous event and for highlighting lived experiences in their Rare Disease Day 2026 report.
'Equity for rare: Delivering fairer healthcare systems for people with rare conditions' https://geneticalliance.org.uk/wp-content/uploads/2026/02/Equity-for-Rare-RDD-2026-report.pdf

Minister Ashley Dalton announced the publication of the 2026 England Rare Disease Action Plan that has now been published and can be found here **England Rare Diseases Action Plan 2026 – GOV.UK https://www.gov.uk/government/publications/england-rare-diseases-action-plan-2026**

Sue Farrington also shared information about the development of The NICE Quality Standards for Rare Conditions. A very big thank you to Sue and members of the wider rare disease community for their excellent leadership on this great work.
NICE Quality Standard for Rare Diseases https://www.nice.org.uk/guidance/qs214

Showing Your Stripes
The ASUK and Bardet Biedl Syndrome UK teams joined up with the Centre for Rare Diseases at Queen Elizabeth Hospital Birmingham who were 'showing their stripes' in the main atrium to celebrate Rare Disease Day.
Information stands were set up to raise awareness of rare conditions, alongside the Advanced Therapy Treatment Centre (ATTC) network, who shared information about advanced treatments in rare disease care.

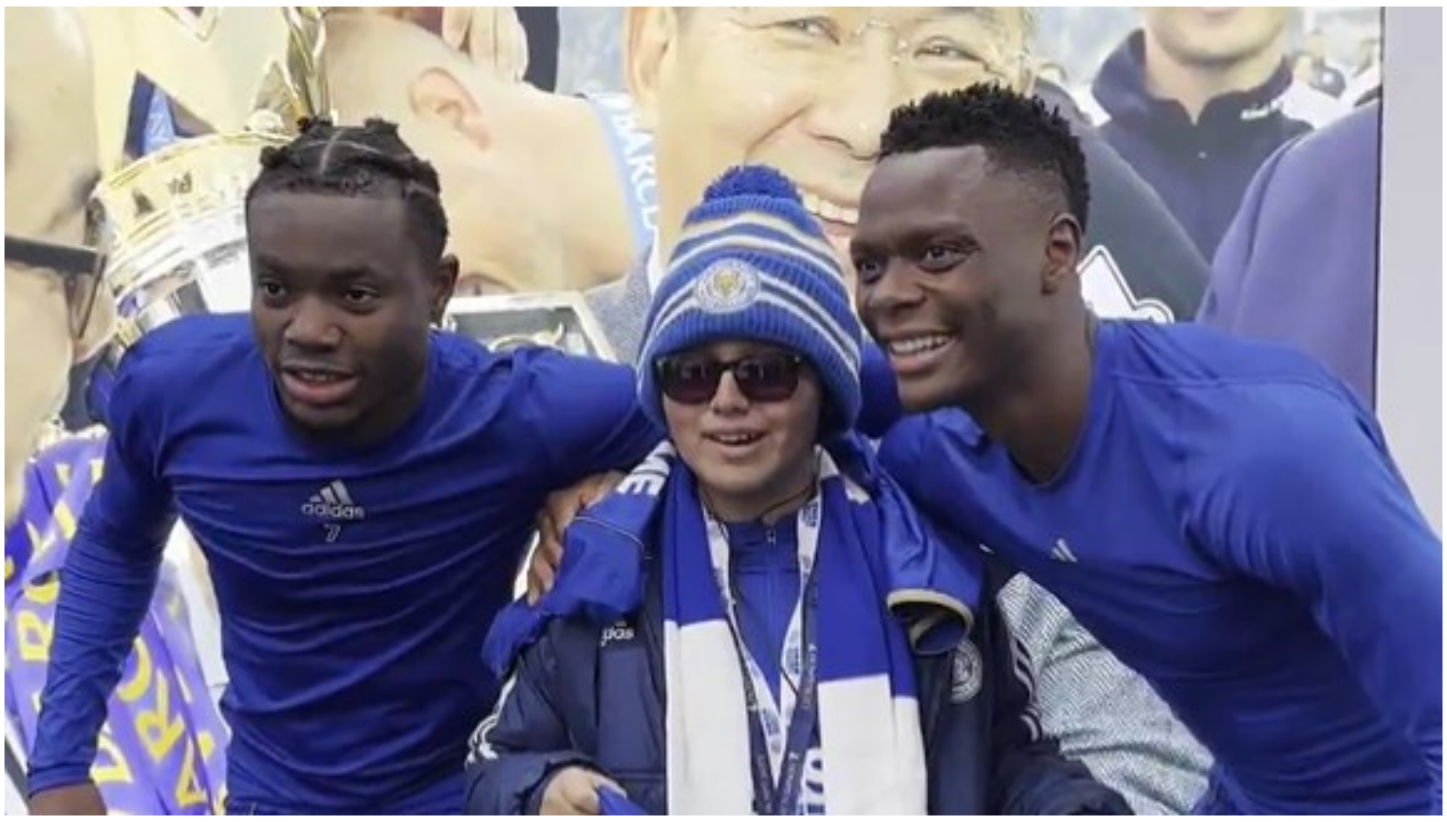
Thank you
Thank you to everyone who shared their experiences and insights as part of this campaign.
If you'd like to share your experiences in a safe and supportive space — either through a future podcast or in one of our Focus Groups — we'd really welcome you. Please feel free to reach out to Catherine by email **Catherine.lewis@alstrom.org.uk**

Dreams Come True for Teddy and AJ!

Teddy and his Dad were invited to test out Leicester City Football club’s audio descriptive commentary service, as well as getting the chance to watch his favourite team play against Stoke City.

Before the match Teddy was given a tour of the dressing room and took his chance to give his favourite player a bit of extra luck by kissing his right football boot… and can you believe it actually worked!

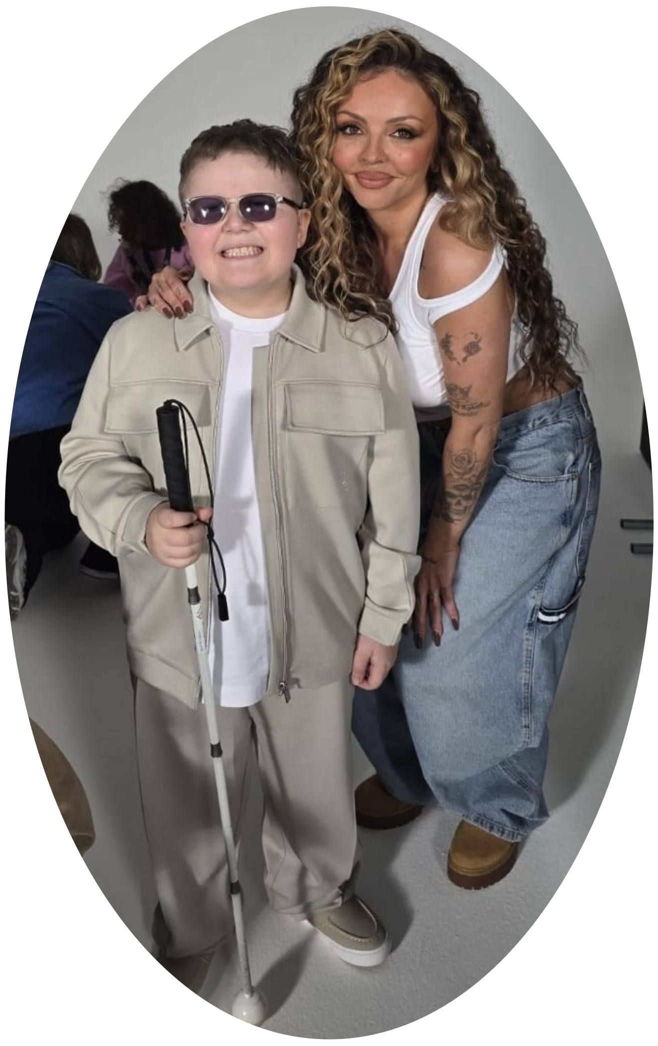
Leicester City's Patson Daka scored his first goal of the season. Teddy's dad, Phil, said watching his son meet the players was a "special moment". "I couldn't believe it when the goal went in, it was unbelievable," he said. "He was the lucky charm, Teddy said it was the best day of his life. To share it with him and to see his face - you can't put a price on that."



Honouring Incredible Women and Their Amazing Families

Jesy Nelson, from the girl band Little Mix whose twin daughters have been diagnosed with Spinal Muscle Atrophy brought together families for a special Mothers Day photo shoot. This was an amazing campaign to hear their incredible stories and raise awareness of their children’s rare conditions.

Annalise and her son, AJ who is living with Alström Syndrome were part of the special campaign, Annalise shares her thoughts; “words can’t describe how much of a caring, kind person Jesy is and how much AJ and I enjoyed being part of this special campaign.”



Research, Clinical and Intern News

Join Together on World Alström Day - 3rd May 2026

Carl Henry Alström was a Swedish psychiatrist who first identified and described Alström Syndrome in 1959. His work brought attention to this rare genetic condition, helping to improve understanding, diagnosis, and care for those affected. Today, his legacy lives on through continued research, clinical care, and the global community working to support individuals and families living with Alström Syndrome. On World Alström Day, celebrated on the 3rd May Carl Henry Alström's birthday, we recognise his contribution and raise awareness of this rare condition.

How you can get involved

This year, we are inviting our community to come together and raise awareness across the world.

On the 3rd May 2026, you can take part by:

- Sharing a post on social media
- Using the hashtag #WorldAlstromDay
- Sharing your story, a message, or simply spreading awareness

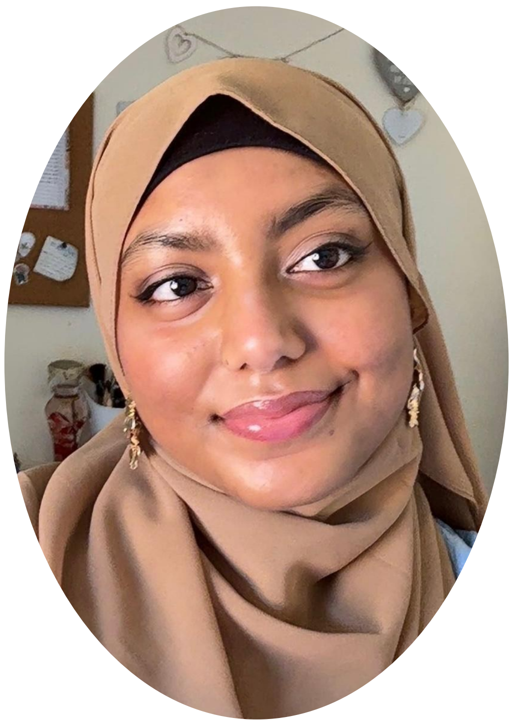
A social media pack will be available on the Alström Global area of the website, with ready-made graphics and messages for you to download and share.

www.alstrom.org.uk/as-global/

Together, we can make Alström Syndrome more visible and help ensure that no one feels alone.

A rare condition. A global community.

Elina joins the team



ASUK were delighted to welcome Elina to our team. Elina joined us from Keele University as an intern to learn more about our charities communication. Looking at what we are doing that is working well and areas we could improve. Elina tells us a bit about herself below:

"I am a second year Neuroscience BSc student, studying how the brain and nervous system work, and how it shapes our thoughts, emotions and behaviours. Neuroscience helps us understand everything from memory and movement to mental health and neurological disorders. I have a strong interest in genetic conditions and inclusive research.

I am currently an intern at Alström Syndrome UK, where I am supporting efforts to improve internal and external communication at the charity to help raise awareness for the Syndrome. My previous experience includes a placement with the National Institute for Health and Care Research, where I worked to enhance the accessibility of the Participation in Research Experience (PRES) survey for minority ethnic groups, and hand-on lab work at Regina Industries in an ISO-accreditation facility, where I packed products, filled blood collecting tubes, processed consumables and tested their products.

Outside of university and research, I work part-time as a waitress at a cosy little Italian restaurant. It's a fun way to stay connected to my roots, I get to speak Italian again from when I lived in Italy! I also love dancing and painting in my free time. I'm passionate about blending science with creativity, and one day I hope to work in biotech, helping develop new treatments that genuinely improve people's lives."

Alström Syndrome UK

Strength for today, hope for the future

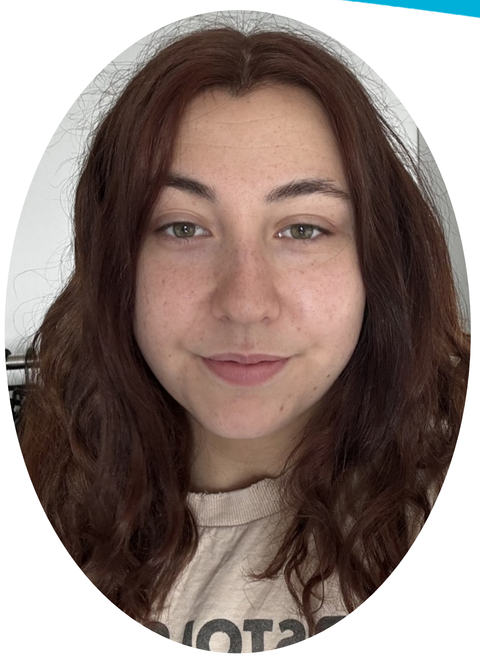
Melanie is Retiring

Melanie Kershaw, our AS Clinic Lead for the AS Children's Services, will be retiring this May. Melanie has been an integral part of the ASUK team, bringing dedication, compassion, and expertise to her role, and making a lasting difference to the children and families she has supported over the years.

"Melanie was always so thorough with my son, always taking the time to consider our needs and checking everything carefully. I will always be extremely grateful for the time and dedication that she gave to me and my family"
Feedback from Family Member

The team at ASUK would like to extend our heartfelt thanks to Melanie for her commitment and invaluable contribution. We wish her a very happy and well-deserved retirement, filled with new adventures and time to relax.

Meet our new researcher, Laylaa



Hello, my name is Laylaa, and I've recently begun a PhD dedicated to exploring premature cellular ageing in individuals living with Alström Syndrome. My academic journey began at the University of Liverpool, where I completed my degree in Pharmacology after discovering a deep interest in how science can help improve lives.

Alongside my studies, I worked in the university's Equality and Diversity sector, which fuelled my commitment to making research more inclusive and impactful. Over time, I developed a strong passion for Alström Syndrome and knew I wanted to contribute to better understanding and managing this complex condition.

I will be working with the teams in Birmingham and my current research focuses on how premature cellular ageing affects people with Alström Syndrome, and importantly, how we might be able to slow or treat this process. Because Alström Syndrome affects multiple organs, understanding cellular ageing could hold the key to improving outcomes across several body systems.

I'm incredibly proud to be working on something so important, and I hope my research can bring meaningful change to the Alström community.

Children's Clinics 2026

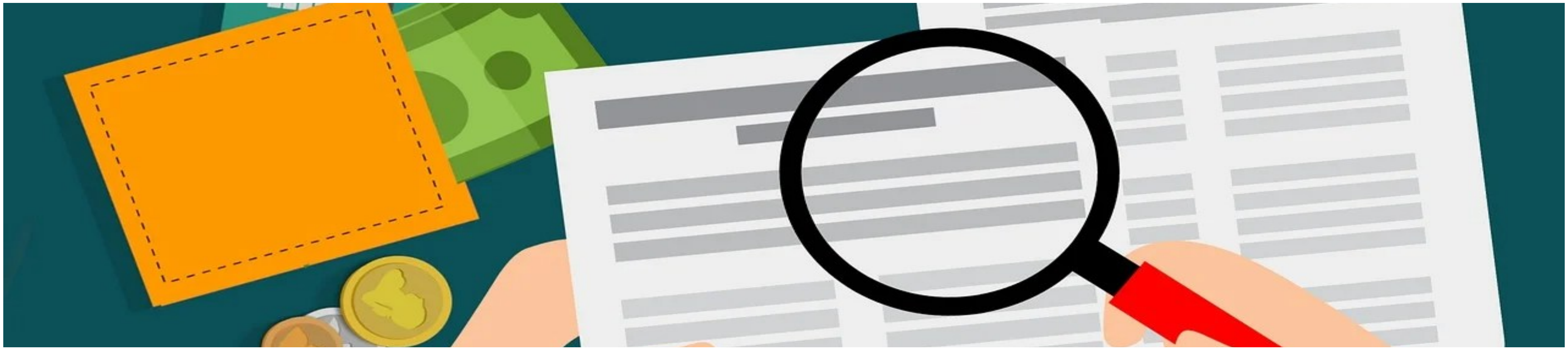
To be held at Birmingham Women and Children's Hospital.
26th January
28th January (virtual/telemedicine clinic)
27th April
20th July
22nd July (virtual/telemedicine clinic)
12th October
23rd November

Adult Clinics 2026

To be held at the Queen Elizabeth Hospital, Birmingham.
14th & 15th January
18th & 19th March
13th & 14th May (transfer clinic)
17th & 18th June
16th & 17th September
18th & 19th November

Should dates need to be altered for any reason then everyone shall be informed as soon as possible.

UK Benefits Changes – April 2026



From 6 April 2026, a number of important changes to benefits will come into effect. These mainly affect Universal Credit and benefit payment amounts.

Most benefits are increasing and will rise in line with inflation (around 3.8%).

This includes:
- Universal Credit
- Child Benefit
- Personal Independence Payment (PIP)
- Carer's Allowance
- State Pension

These increases are automatic – people do not need to reapply.

Universal Credit standard payments are going up.
The basic amount (standard allowance) will increase for all claimants
Example (monthly):
Single 25+: increasing to about £424.90/month
This means most people on Universal Credit will see slightly higher monthly payments.

Key Change: New Universal Credit claimants may receive less.
From 6 April 2026, there is a major change affecting people with health conditions or disabilities who claim Universal Credit.
Lower extra payments for **new** claimants.
People assessed as unable to work (LCWRA group) currently get about £423/month extra.
From April 2026:
New claimants will usually get around £217/month instead. That's a reduction of over £200 per month

Who is protected?

Existing claimants keep the higher amount
Some new claimants with:
Severe or terminal conditions may still receive the higher rate.

Why this is happening

The government is:
Increasing the basic Universal Credit amount but reducing extra health-related payments for new claimants. This is described as a "rebalancing" of support.

What this means for families

Some households will see higher standard payments. But others, especially those with health conditions — could be worse off overall if they apply after April 2026.

Child Benefit the two-child limit is being removed. Families with 3 or more children may receive additional support. This could significantly increase income for larger families.

Legacy benefits ending
Older benefits (like tax credits and income-based ESA) will fully end by March 2026.
Most people will need to move onto Universal Credit. It's important families respond to migration notices to avoid losing support.

Wage Increases

The National Living Wage will rise by 4.1%, from £12.21 to 12.71 per hour.
The National Minimum Wage for 18 to 20-year-olds will increase by 8.5%, from £10.00 to £10.85 per hour. For 16 to 17-year-olds and apprentices it will increase by 6% from £7.55 to £8.00 per hour.

Motability Scheme

Extra taxes will be added to cars leased through the Motability Scheme from 1st July 2026, along with restrictions on certain car brands. They will also be reducing the mileage allowance to 30,000 miles for a new three-year lease and 50,000 miles for a new Wheelchair Accessible Vehicle five-year lease. Excess mileage will be 25p per mile including standard rate VAT.

Further Information and Useful Links

Citizens Advice **https://www.citizensadvice.org.uk/**

Contact, for families with disabled children
https://contact.org.uk/

Benefit rates and increases 2026–2027 (GOV.UK)
https://www.gov.uk/government/publications/benefit-and-pension-rates-2026-to-2027/proposed-benefit-and-pension-rates-2026-to-2027

Benefit changes timeline (Turn2Us)
https://www.turn2us.org.uk/get-support/information-for-your-situation/benefit-changes-timetable/benefit-changes-timetable-2026

Motability Changes
https://www.motability.co.uk/changes

Get in touch

Please contact ASUK Care Coordinators, Sarah or Clair to discuss your own individual circumstances.
Clair.pudaruth@alstrom.org.uk / sarah.oliver@alstrom.org.uk

Jetting off – don’t forget to get covered!

We know at this time of year many of you will be longing for warmer climates and starting to book those holidays! It can often feel daunting thinking about how to get travel insurance when you live with a health condition, so we have brought together some helpful guides from trusted websites in the UK to support you in your search.

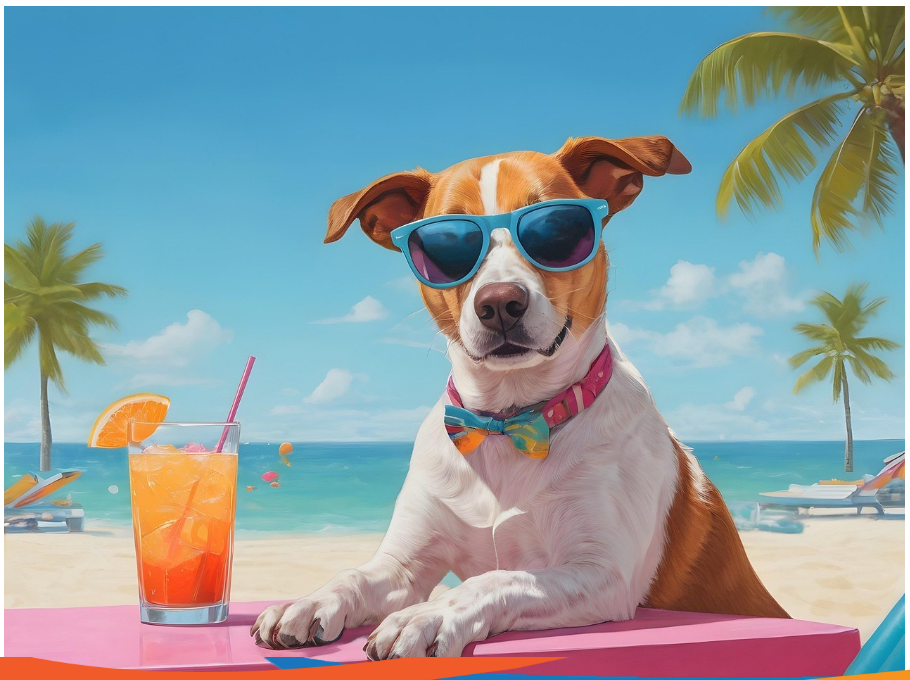
The links below offer travel insurance support and guidance for people who have medical conditions.

Money Saving Expert, gives a full guide about travel insurance and how to find cheaper cover.

The organisation Which? also has a full guide about the best travel insurance to have if you have a pre-existing medical condition, you can find more information on their websites.

https://www.moneysavingexpert.com/insurance/pre-existing-travel-insurance/

https://www.which.co.uk/money/insurance/travel-insurance/medical-conditions-travel-insurance-reviews-aACE34e8H6SN



Healthy Choices Quiz

We are supporting the Department of Health and Social Care and the NHS on a new campaign encouraging all adults to take the Healthy Choices Quiz.

This health and wellbeing quiz aims to empower adults to take control of their health by making small changes day to day.

Taking around 5 minutes to complete it asks questions about your lifestyle in the areas of eating, movement, alcohol consumption, smoking and vaping, mental health and sleep.

You’ll receive an overall score based on your answers. This score indicates how your lifestyle could be affecting your health and wellbeing.

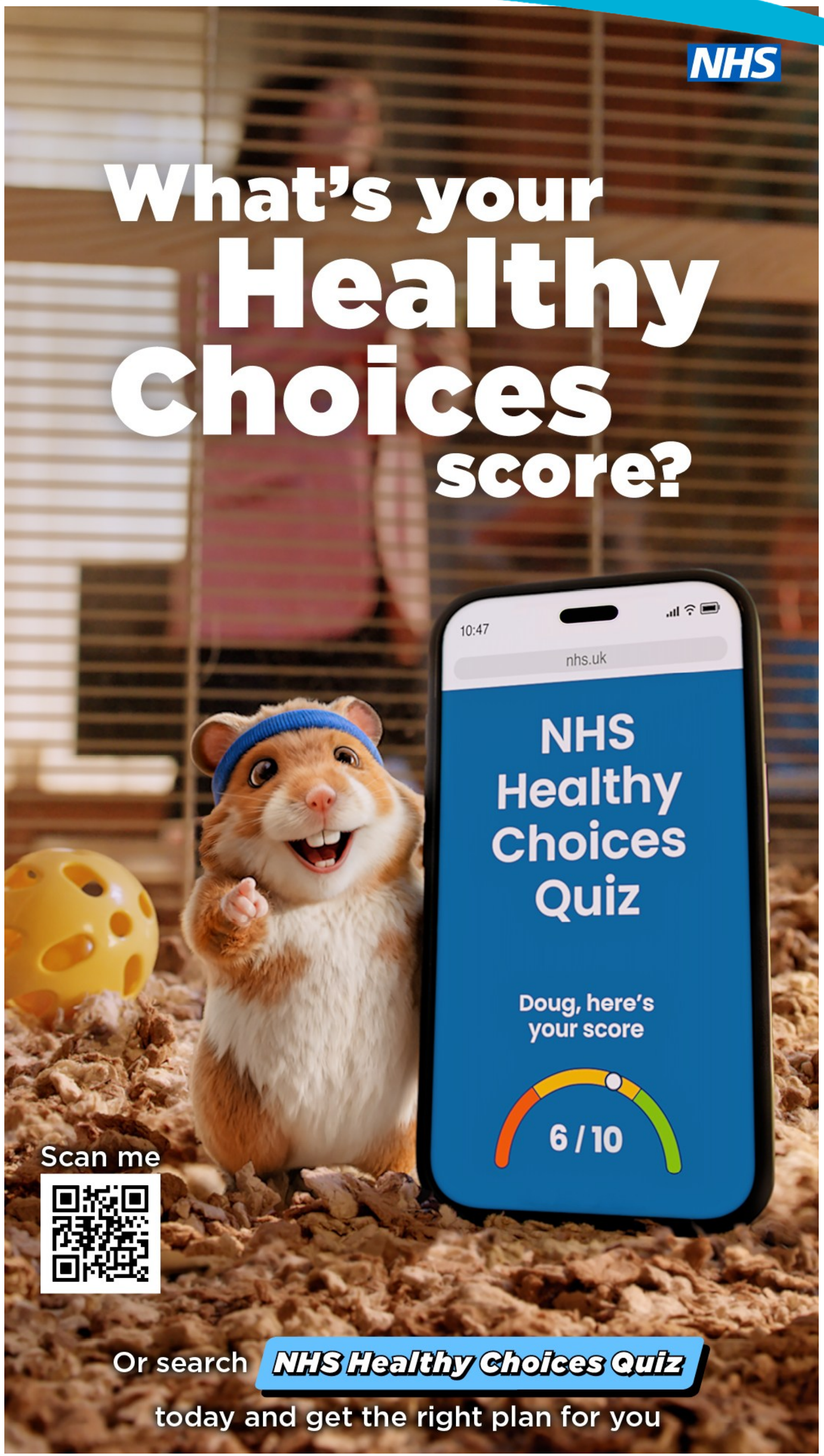
You’ll also be directed to guidance and advice for areas you could improve including a range of free NHS apps and tools.

From a 9-week running programme for absolute beginners, to an anxiety reducing email programme, the NHS has a range of support on offer.

Whether you want to eat better, move more or sleep deeper, the Healthy Choices Quiz can be your first step towards a healthier you.

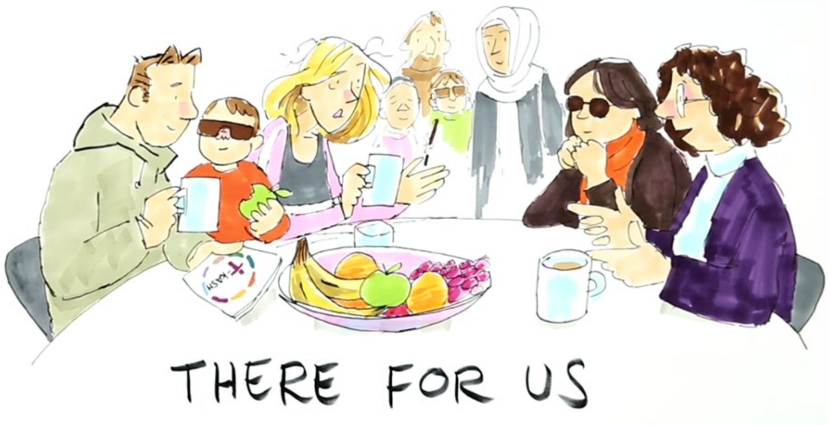
Take the free NHS Healthy Choices Quiz today:

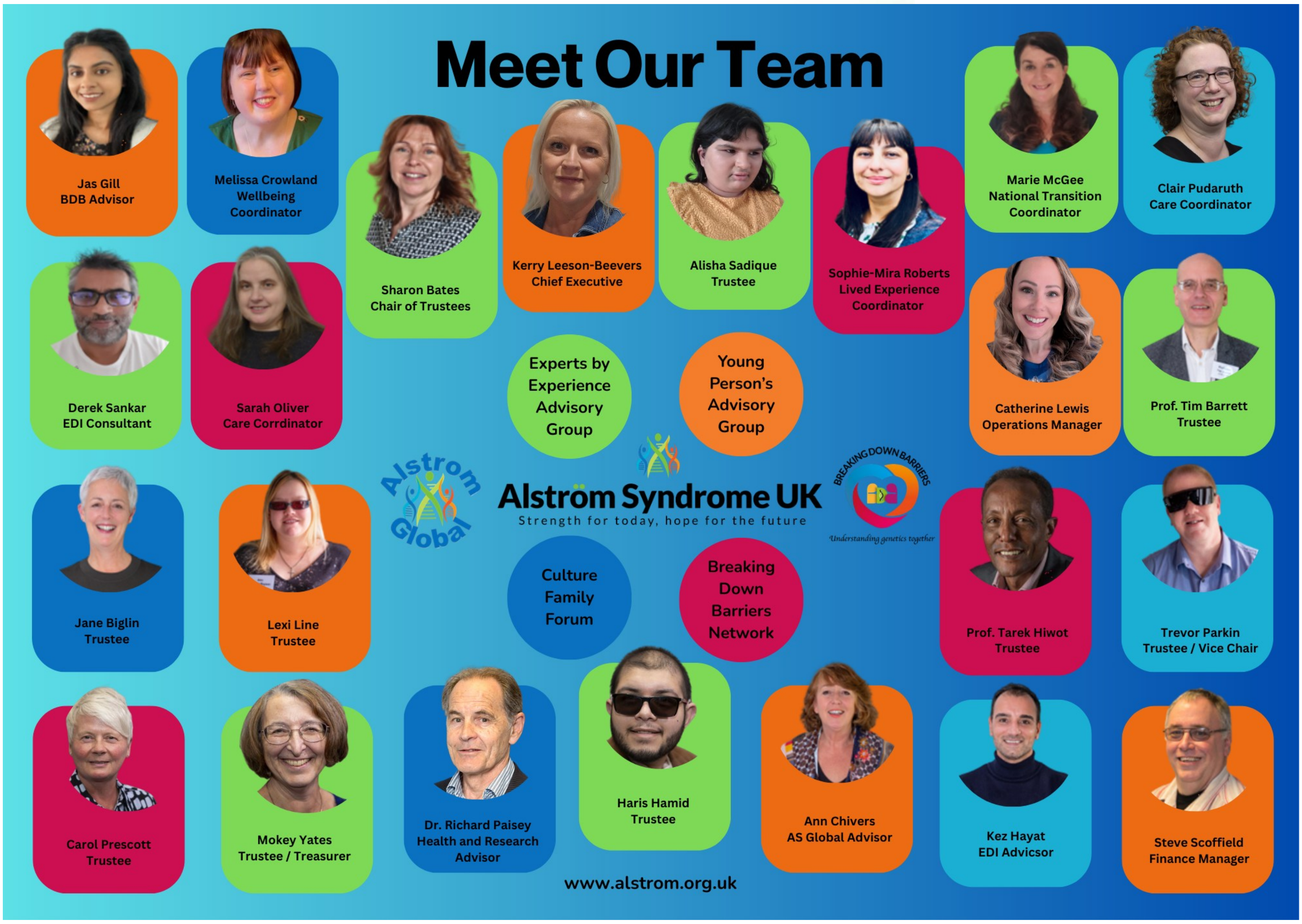
https://www.nhs.uk/hcquiz



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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BDB Advisor

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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 X **@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**

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