



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 24 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.



It's that time of year where I look back and reflect on everything that has happened throughout the year, and I have mixed feelings about 2024. I feel inspired by the many things people within our community have achieved. I feel hopeful for the future with the support we are receiving from our scientists and healthcare professionals. We have new medications to help manage weight, diabetes and heart related conditions and we have plans to develop new research initiatives that will hopefully increase our understanding of Alström Syndrome and lead to even better treatments in the future.

However, I also know how difficult living with Alström Syndrome can be. Two much-loved members of our community, Amber and Kathryn, sadly passed away recently and our thoughts are with their family and friends at this incredibly difficult time. I also know that many are experiencing challenging times whether it be through our battles with health, education, social care or dealing with the current financial crisis. Please remember we are here for you. We may not always be able to fix things, but we can certainly walk beside you and want to support you in any way we can.

The cold weather has certainly arrived and along with it comes illnesses. Please remember to keep your vaccinations up to date and seek medical advice if needed. Further information can be found on page 10.

For me, one of the highlights of 2024 was the ASUK 'Together Again' conference in October. It was fabulous to see everyone again, catching up with old friends and getting the chance to get to know some of our newer families. What really inspired me was the resilience within our community and it was clear just how much we all got out of coming together - we really are stronger together. A huge thank you to everyone who took part in the conference. If you couldn't make it, we missed you and we hope to see you at the next one.

We have had a couple of changes within the team. Cathy Chadwick-Rayner, our Networks & Outreach Coordinator will be leaving at the end of the year. Cathy has done an excellent job developing the Breaking Down Barriers (BDB) Community Outreach Project and on behalf of the team, I want to say a huge thanks to Cathy and wish her all the best.

We are very pleased to welcome Sophie-Mira Roberts to our team as our new Lived Experience Coordinator. Sophie will be working with people living with Alström Syndrome and other rare conditions throughout different areas of our work. This includes our BDB Experts by Experience Advisory Group and the different Lived Experience and young person's advisory groups we support for various research projects.

In 2025, the ASUK Board of Trustees will be developing our new strategy and we need your help. We want to make sure that we prioritise what is important to you so we would appreciate you sharing your thoughts and ideas with us. We will be sending out a survey but also welcome your thoughts via telephone call, message, email, voice note etc, whatever works best for you. We will share our findings and plans with you and would appreciate any feedback.

I would like to say a big thank you to the ASUK team and the Board of Trustees for all their hard work and support throughout the year. I also want to thank our scientists and clinicians for their care and support and for the efforts they are making to push forward with research to search for the very best treatments for people living with Alström Syndrome.

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. We really appreciate all that you do and promise to make sure we make every penny count!

We hope you all enjoy the festive period and wish you health and happiness for 2025!

Take care everyone.

We are here for you
Kerry and the ASUK team

Together Again!



This year's conference brought families and professionals together for the first time since 2019, when Covid hampered our efforts to be together in person. This was a great opportunity to explore the latest research and clinical developments and share our lived experiences and top tips.

Medical and Scientific Meeting

On Friday 11th October 2024, ASUK representatives, scientists and healthcare professionals with a passion for Alstrom Syndrome, came together to discuss research developments and to identify priorities for the future.

This was an opportunity to identify areas of expertise, learn more about the research priorities within the AS community and to explore gaps, next steps and funding opportunities.

Saturday 12th October 2024 ASUK Conference

While family members and carers were busy engaging in conversations, listening to talks and interacting during the workshops, children and young people had a fun-filled day out at Drayton Manor theme park. This was made possible with the support of our fabulous volunteers Nichola and Chris who supported families throughout the trip and everyone had a great time!

Kerry Leeson-Beevers, ASUK Chief Executive, opened the conference with a warm welcome to everyone who had travelled far and wide to attend. Kerry gave an insight into why it is so important to bring families and professionals together to share experiences and to learn from one another. Being surrounded by people who understand and having the opportunity for peer-to-peer support is incredibly valued by the ASUK community.

Chase Palmer, President of Alström Syndrome International from America and Jack Chu, from AS China alongside Ann Chivers, AS Global Adviser gave an overview of the work taking place across the world and the difference people can make by completing the Global Patient Registry.

There was a whole host of presentations from quizzing the Clinicians and Researchers to Dr Denise Williams and Dr Hannah Titheradge giving us a crash course in Genetics 101. Interactive workshops provided an opportunity to discuss education, accessible sports, gadgets and technology.

A highlight of the day was Aisha from the Culture Family Forum getting us in the Christmas spirit by singing Mariah Carey's, All I want for Christmas!

We all gathered for a wonderful evening of fabulous food and time to catch up with old friends as well as having fun making new ones. Children and young people (and parents and carers too!) had great fun trying on the fancy dress outfits and playing games, before everyone said their farewells.

From emotional presentations to joyful singing, the conference had it all! Above all it was a chance for families to be together, to share stories and make friends.

Thank you to Guide Dogs for the Blind for offering support throughout the event as well as Focus 4 Vision who provided information about empowerment through sport and activities. The ASUK team were also on hand to offer demonstrations of products that can help make life easier and offered personalised support and guidance to families.

The one thing that people always say they enjoy most about ASUK events is the opportunity to meet other families and socialise together. Well, this conference certainly did just that!

The day had a relaxed feel to it, with plenty of time to chat and share experiences.

"Really lovely to be together in person. It's a great opportunity to spend time with parents and professionals. There was a good balance of lived experience and scientific content."



Thank you

A HUGE THANK YOU to families, carers, scientists, healthcare professionals and volunteers who travelled from around the UK and across the world to attend the conference, supporting youngsters, sharing knowledge and lived experiences of Alström, offering insights and understanding.!

“The ASUK staff are some of the nicest people I've met, you all care so much about the families. I could see how much hard work it must take to organise this event. You had thought of everything.”

A full conference report will be circulated shortly.

Winter Wellbeing

Last year, ASUK did a piece of research to look at whether there was a need to provide a Wellbeing Service for people living with Alström Syndrome.

Many of you kindly took the time to participate in our survey and shared your thoughts with us. This provided us with vital insights into what you wanted from a Wellbeing Service.

The findings demonstrated that there was a need for this support. You felt that you would benefit from having both one-to-one discussions and small group sessions focussing on thoughts, feelings and emotions, as well as daily living skills and coping strategies.



Melissa gives her thoughts:

It has been an incredible nine months working as ASUK's first Wellbeing Coordinator and I feel privileged to speak to and support so many fabulous people.

Apart from having many interesting conversations, some of the other projects I've been working on have been providing:

- A guide for technology and equipment to support people living with a visual impairment in their daily lives and when accessing education.
- A global webinar focusing on helpful technology and Apps.
- A 'Welcome to Wellbeing' webinar series, with the first online introductory session starting on the 28th November 2024.
- A presentation at the exciting ASUK conference in October, where it was so lovely to meet some of our amazing families and make new friendships.

My presentation shared strategies and ways to empower you and your loved ones to maintain positive emotional wellbeing. The session finished with a group meditation which hopefully allowed people to leave the session feeling relaxed.

Since April 2024, I have been able to support over 21 individuals whose lives have been impacted by Alstrom Syndrome both in the UK and overseas. It has been a

ASUK is grateful for all the support and help in delivering the conference and raising awareness of Alström Syndrome. Thank you to the presenters and exhibitors for taking part and making this conference a truly memorable event.

See you at the next one!



privilege getting to know all our families and support them with navigating some of the challenges of the Syndrome.

“I like that you are there when I am feeling emotional because of Alström Syndrome, you understand the needs about the condition, and you are good at understanding me. You give me time and space to talk about my feelings.”

So, what's coming up in the future for the Wellbeing Service?

Of course, lots of conversations with you and others who are impacted by the condition.

I'm also working on a guide focusing on how to build resilience when facing uncertainty and how to keep yourself positive. Being positive isn't about being happy every moment of every day, it includes acknowledging some of your less pleasant emotions and navigating through them.

The 'Welcome to Wellbeing' series is continuing, and the sessions are being held on the last Thursday of every month. These are online from 7pm, it would be wonderful if you could come and join me and the AS Community, everyone is welcome. Shortly after each session, the recording and top tips will follow on the website, for you to look at in your own time.

I'm always wanting to talk about the topics and issues that are important to you. So, if you'd like a webinar on a specific topic please get in touch and I'll do my best to make it happen.

If you or someone you care for, or support is finding things difficult to manage please do not hesitate to get in touch with me. We can arrange a call, or speak through text, email or voice note.

You can email me on:

melissa.crowland@alstrom.org.uk

Call, text or What's App me on: 07301078059

My working days are Wednesday and Friday.

I can't wait to hear from you in the future. Remember you are Braver than you believe, Smarter than you think and Stronger than you seem.

**The warmest of regards Melissa
(your Wellbeing Coordinator)**

Hann has Graduated!

My Graduation by Hannah Bromley-Challenor

Having written two previous articles about my four years at the University of Winchester, I thought I would update you on how all my studies finally culminated in receiving my degree at my graduation ceremony. This took place in Winchester Cathedral on the 24th of October.

It was an amazing day with such a great atmosphere throughout. It seemed like the whole city loves graduation week, as there were so many people out, mingling with all the students dressed in their gowns, and their families. Mum said everyone was smiling at us.

First, we went to Winchester Guildhall, where I was fitted with my black and purple gown, and fringed waterboard hat. After this we gradually made our way to the cathedral, taking in the atmosphere around the town. When we arrived at the magnificent cathedral, there was a growing queue of guests outside lining the block and a separate one for students. Mum, who was acting as my guide, and I had to go through a separate side door of the cathedral because of my accessibility requirements. I was shown to a seat in the front row near to one of the ramps attached to the stage. A member of staff then showed me where to enter and leave the stage and they let me practice the doffing of the hat and the handshake with the Chancellor, which I was a little nervous about. I was so happy to find out that I was surrounded by friends who had also been on the same course. We were able to chat and find out what everyone has been doing since we were last together.

Prior to the ceremony, when everyone was gathering and being seated in the right places, we were entertained by a choir from a local school, who sang beautifully. Then, the graduation ceremony began. It started with an announcement telling us how long it would last, which I think was an hour and a half give or take a couple of minutes, and what would happen if an alarm went off – which fortunately, didn't happen.

We got to watch a short video that included encouraging messages from our lecturers and the Chancellor. Our new Chancellor, Hugh Dennis, who has only started this year, made a good speech before the presentations started. I studied medieval history, but all the humanities courses were included in the day's events. These included some interesting subjects such as animal welfare, all the genres of history, sociology, and joint honours.

It felt like such a supportive atmosphere, as you just wanted to clap and cheer for everyone as you were so happy for everyone to get their degrees. When it was my turn, I lined up with my group and waited for my name to be called. I felt both nervous and excited to shake hands with Hugh Dennis, but glad I did it. When I got back to my seat my graduation certificate in its presentation folder was handed to me by a staff



member of the graduation team. At the end of the ceremony, all the graduates were in a procession out of the cathedral led by the Chancellor and other staff, to a cheering audience, which felt amazing. Mum spotted Dad on the way up the aisle, and we briefly stopped for a photograph, which nobody seemed to mind. We then saw Delfi, my notetaker at university, who was sitting a little way up on the other side of the aisle, which made me happy too. It was so nice to meet up with lecturers outside the cathedral, although I was a little sad that my dissertation supervisor could not make the ceremony, but he has contacted me since.

Following the graduation ceremony, everyone walked back to the Guildhall where a reception was laid on. Here I got the opportunity to speak to my friends, have photographs done, or buy merchandise – I got a personalized graduation bear. I returned my gown and hat, and we continued the celebrations in town.

Appropriately, we kept the day medieval-themed. We first celebrated at the Royal Oak, a pub on the high street that is thought to be the oldest pub in England. It was given as a gift in 1002 from Emma of Normandy, twice Queen Consort of England, first as the wife of Aethelred the Unready, and then later married to Cnut the Great – all of whom I have studied extensively in my time at university. We then had dinner at Ask Italian which is housed in a building that has been there since 1052, which would have been during the reign of Emma's son, Edward the Confessor. I would recommend both places if you are in Winchester.

Now, I am getting used to being at home again and looking into social groups to join in the local community. Recently, I went to my first Sight Village which was so exciting to meet people and see so many services and VI tech people. I signed up to several charities such as Eye Matters, Vocal Eyes for going to the theatre and Goalball, which has a group based in London which I might join. I am also continuing with mobility sessions and am currently learning a route around the block that involves only two road crossings. This is so I can gain more confidence in travelling on my own. I also recently went to a job fair that also included opportunities to chat about Master's degrees, which I might consider in the future. There were many interesting courses on offer, including history, writing, and one in theatre studies where I could use my research skills to adapt history into plays. Whatever the future holds, I will always look back at my time in Winchester, with joy.

Hannah Bromley-Challenor—November 2024

Everyone at ASUK would like to congratulate Hannah on graduating from Winchester University – it sounds like you had a fantastic time. We can't wait to hear what you get up to next...



During the ASUK conference, Aisha from the Culture Family Forum got us in the Christmas spirit by singing Mariah Carey's, All I want for Christmas!

...and here it is for you to watch too <https://shorturl.at/PF4Xv>

Please support us throughout the festive period



Every penny really does make a difference

Getting creative

Katie and Hannah have been taking part in work experience with a local creative company.

Katie made the purple hedgehog out of book pages which she folded and coloured purple. She also made glasses, a cane and added a bow. It's so impressive!

Hannah made the green gonk, Katie the purple one using materials that are very sensory. They look like they could be in Lord of the Rings.



What are Gonks?

Did you know that Gonks stem from Nordic and Scandinavian mythology. They are meant to be something like a mix of a gnome and a hobgoblin. In the original folklore, these curious little creatures were said to take a liking to barns or houses in the colder seasons. If families treated them well, they were said to protect the family and give them good luck. If the family did not respect the gonk, then they were said to play tricks on the family!

Community outreach updates

Breaking Down Barriers (BDB) now has **over 70 member organisations** and the reach and creative ambitions from the team are going from strength to strength.



BDB Networks and Outreach Coordinator, Cathy gives us her last updates as she is leaving for pastures new...

Along with the onset of the festive season, sunny, crisp blue skies, and crunchy lawns, it is also time for me to move on. I have learned so much in my role

as Networks and Outreach Coordinator on the Breaking Down Barriers (BDB) project and with Alström Syndrome UK, what a wonderful team you are!

I'd like to share with you some highlights...

Community outreach began with research for learning resources around the basics of genes and genetic inheritance, and finding and adapting some of these activities really helped with the journey: **Traits Activities**.

From here co-production began with the warm and welcoming Sanskat group in Leeds, testing and offering suggestions to improve the activities to become more accessible and inclusive, and hence our very own reusable, multisensory, Tree of Traits was born (pictured below).



This, along with other interactive activities, culminated into a series of workshops that I took to other groups – I am particularly proud of the 'Chat with our Ancestors' activity where I combined arts, crafts and history to create ancient symbol plaques. This creative activity has been enjoyed by many and has helped improve mental health and self-esteem (even if for a few hours), as well as cultivating a safe space in which to share experiences and barriers to health and health services. Plus, participants got to take home their creations and share with family and friends – extending the conversations and learning from community settings to homes.

There are so many highlights to think of, but taking the Tree of Traits to events across West Yorkshire is right up there: the fun, engagement, and interest has been outstanding. Included in these were community health events organised by a Junior Doctor in Bradford, an Eye Health Roadshow with the Association of Blind Asians in Leeds, International Women's Day at the Diamond Wood Academy in Kirklees, and a Hydration event with Roma CIC.

I also became a Health Equity Fellow with the NHS West Yorkshire Health and Care Partnership, building on my knowledge of the inequalities within our society and current health service strategies. Successfully signposting individuals for support has always been important to me, so many heartfelt conversations have taken place. It's not easy to measure outcomes from conversations with people you are unlikely to see again, but I was encouraged to learn from one particular lady that she had made a GP appointment for testing after visiting our Tree of Traits stall – I had provided her with some information from Hemochromatosis UK as she had heard members of her estranged family had been diagnosed with the condition.

Harnessing and sharing the learning from engaging with communities is vitally important to improve trust, reach, inclusion, accessibility, mental health, and to break down the barriers of stigma, blame and shame. Another highlight for me was running the workshop with many of you from the BDB Network at our London event – 'Leaving No-one Behind'. Your enthusiasm to the cause of sharing successful ways of engaging with communities was brilliant and great to witness. I have pulled together what you kindly shared for us all to learn from and I am also feeding what I have learned from my outreach in West Yorkshire into the West Yorkshire Integrated Care Board, via West Yorkshire Voice.



This year I had the pleasure of collaborating with the GRACE project, Open University of Milton Keynes, at the British Science Festival – we adapted the Tree of Traits and 'Chat with our Ancestors' activity to align with the event. I am sure that connections made on the day will help continue the work of BDB.



Many, many highlights, and much of it due to working with an inspirational team. The ASUK Conference in Birmingham confirmed how hardworking and dedicated this team is, and experiences shared by attendees and speakers taught me lots - all of which I intend to build on in my new position with an inclusive cycling project in the New Year. I am hoping my path will cross with many of yours going forwards, and I wish you all the best for the New Year.

Find out more about this work on the BDB website: www.breaking-down-barriers.org.uk/genes-family-history-and-your-health/
Please check out these websites for further information:
Traits activities to try at home: <https://learn.genetics.utah.edu/content/basics/activities/>



ASUK would like to thank Cathy for her positive contributions to ASUK and BDB during her time with us and we wish Cathy all the best for the future.

Warm welcome to Sophie...



As they say... as one door closes, another one opens! ASUK would like to warmly welcome Sophie to the ASUK team. Sophie will be joining us as our new Lived Experience Coordinator and will work across ASUK and BDB.

Sophie tells us a little bit about herself below...

I'm delighted to have joined the ASUK team as Lived Experience Coordinator. I am passionate about health advocacy and science engagement, particularly with underrepresented groups. I believe that science and health should be accessible and inclusive.

My interest in genetics stems from my own experience of having both autoimmune conditions and a rare condition. I understand first-hand the hurdles rare disease patients go through, from delayed diagnosis to continuity of care. This inspired me to study biology through the Open University in order to better understand my condition and help others. I then worked in public engagement in genetics research with the GRACE project. Alongside, I also interned with The Economist's Science section, reporting on Women in Science Day and the UK Biobank's whole genome sequencing project. I am also a Patient Ambassador for Medics for Rare Diseases. I look forward to contributing to the vital work that ASUK does to support those with lived experience and overcoming health inequities.

If you would like to get involved in one of our lived experience groups where you can share your knowledge and experience, then please get in touch with Sophie

Sophie-mira.roberts@alstrom.org.uk

NHS Alström Syndrome Multi-Disciplinary Clinics 2025

Birmingham Women's and Children's Hospital clinic dates for 2025:

6th January
8th January – virtual
7th April
7th July
9th July – virtual
27th October
8th December
Outreach Clinic in Leeds - date to be confirmed

Queen Elizabeth Hospital, Birmingham adult clinic dates for 2025:

15th & 16th January
19th & 20th March
14th & 15th May
18th & 19th June
17th & 18th September
12th & 13th November

Research News

Research: leaping forward with frogs!



Hi! I'm Dr Charlie Softley and I am a scientist based at the University of Keele. I recently set up my research group after moving back over from Germany.

My group is focussed on rare ciliopathies, particularly Alström Syndrome.

Ciliopathies are conditions where cilia (tiny hair-like structures throughout our body) are altered due to a genetic difference. I use and test new animal models for Alström Syndrome, including the African clawed frog (*Xenopus laevis*) and small aquatic flatworms (*Schmidtea mediterranea*).

Animal models are species that allow us to produce an animal version of a genetic condition so that we don't have to test drugs and gene therapies in humans straight away – we test them in the animal models first.

The tadpoles of the African clawed frog have cilia on their skin, similar to those found in our lungs. The cilia, along with the mucous that is produced, allow the skin to stay clean and free of dust and bacteria. By looking under the microscope, we can analyse the development of the cilia over time. The African clawed frog can easily be genetically manipulated. This means that we can give frogs Alström Syndrome, allowing us to study the differences in development and function of different cilia in this model.

Types of cilia and how to imagine them

There are three main types of cilia, along with other specialised types. To imagine these types of cilia, you can use your forearm and hand.

The first type is sensory cilia.

These are present in almost all types of cells in your body, and so are found in every organ. Put your elbow on a table or surface with your hand pointing towards the ceiling. Blow onto your hand. This represents the sensory effect of these particular cilia, the primary cilia or sensory cilia. In your body, they sense chemical signals such as hormones, which allow different parts of the body to communicate.

The second type of cilia is motile multi-ciliated cells.

This is a bit of a mouthful, but it just means there are lots of cilia on the surface of each cell and they are motile: they move. To visualise these cilia, again put your elbow on a surface again. Move your arm backwards and forwards so that your hand traces a line across the ceiling. If you want to, allow your wrist to flop at each end. This demonstrates how these cilia push things along – they waft them. This is showing the cilia for example in your lungs that waft liquids around. It is also found in other areas of your body, such as the fallopian tubes which eggs travel along to get from the ovaries to the womb.

The third main type is motile mono-ciliated cells.

This means they move but have only one cilium per cell. To imagine this type of cilium, put your elbow on a table and move your arm to draw a circle on the ceiling with your hand. This is an asymmetric movement. These cilia are only present when we are very small and not yet born. The asymmetric cilia movement is what makes your body asymmetric, for example having your heart on the left-hand side.

Interesting facts about the African clawed frog!



The females are much larger than the males - 10-15cm for females and 4-10cm for males



The males "sing" underwater, especially in the evening



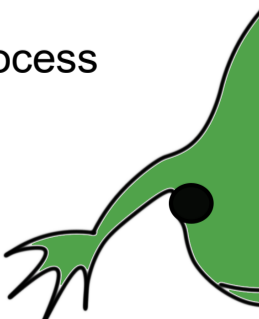
The males have sticky pads on their arms for hugging the females as part of their mating process



The females can lay thousands of eggs in a day



They originally were used in pharmacies as a pregnancy test!
Inject 3 frogs with a woman's urine. If they lay eggs the next day, the woman is pregnant!
Now of course we use non-animal tests for this!





Alström Syndrome UK

Strength for today, hope for the future

The Research

The frogs I work with have all three types of cilia, as well as lots of the specialised cilia seen in humans. This allows us to study a huge variety of different cilia - related symptoms. So far, we have only studied these frogs when they're very young and still tadpoles. Already at this stage, we see differences in heart and kidney function in the AS frogs compared to the healthy "wild type" frogs. This leads to a buildup of fluid on the belly. We also see differences in spine development and can see changes in the frogs' eye development, but we are so far unsure whether this is just slower development or a difference in their structure.

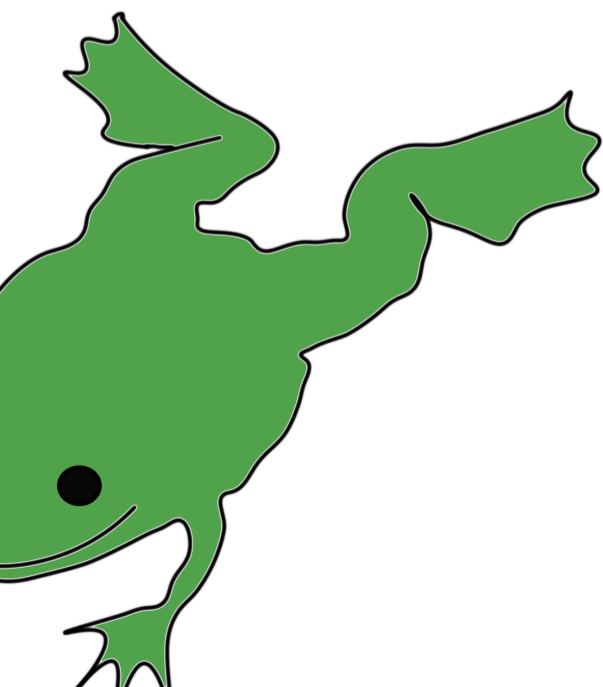
Over the next few years, we aim to study Alström Syndrome in the maturing frogs, allowing us to study the variety of symptoms that are seen in the frog at older ages. Specific symptoms that we are looking for include non-alcoholic fatty liver disease, reduction in kidney and heart function, and developing blindness or alterations in the senses.

This work with the frogs, as well as with the worms which is only just starting, will hopefully help us understand the biology behind Alström Syndrome. In the future, it may also be a tool for developing new therapies and testing new ideas.

Sharing my research

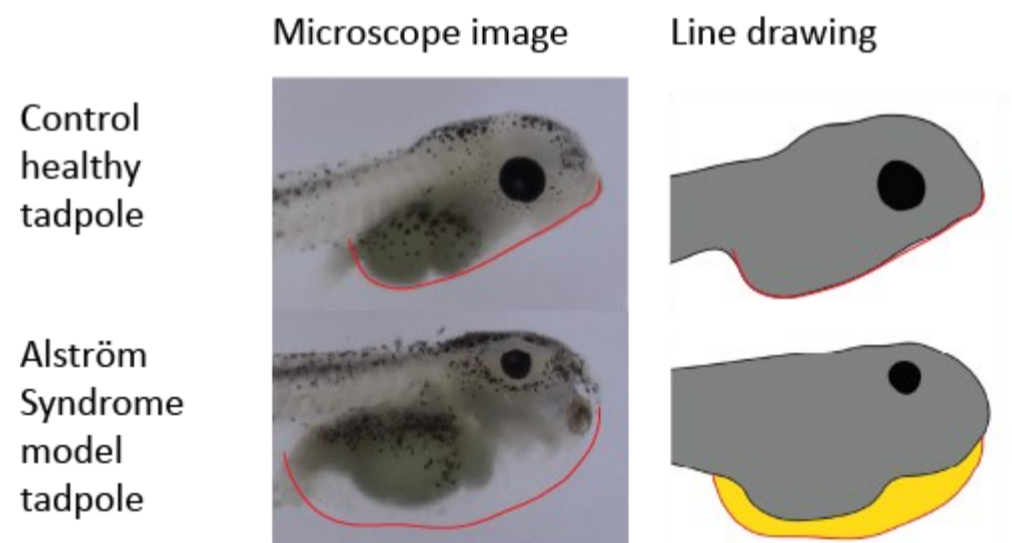
I regularly take my research to conferences, including the Cilia 2024 conference in Dublin, which Kerry Leeson-Beevers from ASUK also attended. Here I presented two posters, one for scientists and one for non-scientists.

I also make crocheted models of scientific objects (pictured right): kidneys, lungs, DNA, different types of cilia and of course frogs! This allows me to share my passion with people more accessibly and get them excited about science. It also means that children and adults can interact and engage with these models regardless of their level of sight.



I also was lucky enough to be invited to the ASUK Culture Family Forum online meeting this month. I was able to share with them lots of facts about my frogs and my work, and I also got to meet lots of new people in the community, which was fantastic. They each shared their successes from the last couple of months – every one of them should be really proud. I'd like to thank them for inviting me!

Charlies images below from the research show some of the differences in the AS tadpole.



Top row: tadpole with no manipulation
Bottom row: tadpoles with genetic manipulation of *Alms1* have large bloating forming a bubble around their organs (yellow in line drawing). This indicates an issue with heart or kidney function. They also have smaller eyes.



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. Families around the Country are having to make difficult decisions like 'heating or eating' and this just isn't right. Please don't suffer in silence, please get in touch.

We have a grant fund, to help people who may be struggling financially or need essential equipment such as a cooker or washing machine.

Our Care Coordinator, 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.

Our family support team are only a phone call, text or email away. 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.

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

Let's Stay Well

There are some things you can do to help yourself stay well in winter.

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 NHS flu and COVID-19 vaccines if you:

- ♥ are aged 65 or over
- ♥ 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.

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)
- ♥ Book a flu vaccination appointment online (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 or by calling NHS 119.

Check out the NHS website to find further information and book your appointment:

<https://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



Keeping Warm this Winter — Top Tips from the Red Cross

1. Keep your body warm

Extremely cold weather can have a negative impact on our health. People with respiratory problems such as asthma, or heart conditions are at particular risk during the winter months. Our bodies need to be kept at a core body temperature of 37C to stay

healthy, which means rooms should be heated to a minimum of 18C.

There are many ways you can maintain your core body temperature and stay warm in winter, without turning the central heating on.

Try these tips

- ♥ Layer up your warmest indoor clothing
- ♥ Eating healthily and drinking plenty of hot drinks throughout the day
- ♥ Get moving, this will help boost your circulation and keep you warm.

2. Keep your feet and hands warm

They might not be the first thing you think of, but if you want to stay nice and toasty this winter, it's important you know how to keep your feet and hands warm.

When it gets cold, your body works harder to keep blood flowing to your core and vital organs to keep them warm. This can change the blood flow to your hands and feet, meaning they may get cold. Keeping your fingers and toes snug can help regulate your body temperature, so make sure not to ignore them.

3. Keep your house warm

Heating one room during the day is a cost-effective way to keep your house warm and your energy bill down. Here are a few ways to keep a room warm without using central heating.

- ♥ Curtains—open your curtains during the day - the sun still provides warmth, even in the winter months but close them as soon as the sun sets to keep the warm air in. Investing in thicker curtains, or thermal curtain liners, will help keep the cold air out and prevent heat loss.
- ♥ Use a draught excluder
- ♥ Move furniture away from external walls
- ♥ Insulate your floor with rugs
- ♥ Avoid condensation on windows

4. Staying warm at night

Temperatures plummet when it gets dark, so in winter it's important to know how to keep your bedroom as warm as possible at night.

- ♥ **Bedding:** Staying warm in bed is vital for us all in winter. Use extra blankets or buy flannel or fleece bedding if you can. These materials are the warmest bedding options, as they trap body heat and are better insulators than cotton. Using thicker tog duvets will also provide additional warmth.
- ♥ **Electric or weighted blankets:** An electric blanket is a lot cheaper to run than a heater and provides a constant source of heat throughout the night. Weighted blankets are also very comforting and

help you stay warm as they don't let chilly air into the bed.

- ♥ **Toasty pyjamas:** Wearing warm clothes in winter isn't just for daytime. At night, wearing fleece or flannel pyjamas will go a long way to keeping you warm as they trap the heat. Don't forget your feet either. Bed socks will keep your feet warm and help you sleep.
- ♥ **Hot water bottle:** Cost effective and long lasting, a hot water bottle will provide a safe source of warmth throughout the night.

Don't forget to keep yourself safe with a hot water bottle:

The flower symbol on a hot water bottle indicates the date it was made (image below):

- ♥ **Number in the middle:** The year of manufacture
- ♥ **Flower segments:** The 12 months of the year
- ♥ **Dots inside segments:** The number of weeks

It's recommended to replace hot water bottles after two years because the rubber deteriorates over time and can cause burns. You should also check for signs of wear and tear.

When shopping for a hot water bottle, look for the British Standard Mark, which should be clearly marked on the body of the bottle. The current standard is 1970:2012



5. Find a warm space

As temperatures plummet, many organisations across the country are creating warm hubs. These spaces offer warm food and drink, heating and a place to meet others. Warm Welcome has 3,000 registered hubs across the UK, offering welcoming spaces to the public, find your nearest on the Warm Welcome website

<https://www.warmwelcome.uk/>

Many local organisations such as churches, town halls, shops, pubs and cafes are also offering warm hubs. Check with your local council www.gov.uk/find-local-council to find a space near you.

6. Get help with your energy bill

If you're claiming benefits such as Pension Credit, Disability Allowance, Income Support, Income-based Job Seekers' Allowance, Income-related Employment and Support Allowance, Universal Credit or Support for Mortgage Interest, you may be able to get help with paying for energy including your electric bill.

Check out the Government website for more information: www.gov.uk/browse/benefits/low-income or contact your energy supply who will be able to discuss your individual circumstances and explore what support they can offer.

<https://www.redcross.org.uk/stories/health-and-social-care/health/tips-on-keeping-warm-this-winter>

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

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Over Christmas and New Year the office will be closed from 23rd December 2024 — 6th January 2025



THERE FOR US

Meet the ASUK Team



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Melissa



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Mokey



Jane



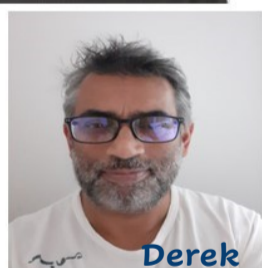
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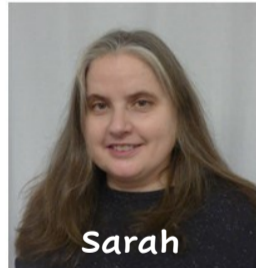
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ASUK has a dedicated You Tube page <http://www.youtube.com/alstromsyndromeuk>

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