



Alström Syndrome UK
Strength for today, hope for the future

Alström Syndrome UK (ASUK) is an award winning charity who provide information, support and advice for individuals affected, their families and carers and professionals. Alström Syndrome is a very rare genetic condition which can cause progressive blindness, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very difficult. We endeavour 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 20th edition of our newsletter

A huge thank you!

Firstly, I wanted to say a very personal thank you for all the support ASUK has received over the past year. We are always grateful to those who so generously give their time, donations and energy to improve the knowledge and understanding of Alström Syndrome. Together we can make a difference to people's lives.

Conference 2017

It is fair to conclude that the ASUK Scientific Symposium and Family Conference 2017 was a huge success! So many people contributed to ensure that everything ran smoothly and participants had lots of time to network, catch up with old friends and find out about research as well as new project initiatives, especially the 'Get fit' challenge. The Conference Report and a link to the films of the conference including Dr Rick Steeds thoughtful summary of the Scientific Symposium can be viewed on our website. Please feel free to share these with your own networks.

<http://www.alstrom.org.uk/ASUK-conference/>

Next steps

We will be sending out a survey to individuals and families who couldn't attend this time around, to find out about their top ten priorities. For those of you who have already taken part thank you for your thoughtful responses. We aim to publish the results of the survey in the New Year which will help shape the strategic direction of ASUK in the coming years.

I hope you found the conference as informative and inspiring as I did. See you at the next one! Meanwhile, enjoy this winter update over something hot and comforting! From all of us at ASUK, to you and yours, wishing you a happy and healthy Christmas and New Year!



Ann Chivers,
Chief Executive at ASUK

ASUK Family and Professional Conference 2017

The ASUK 'Health, Happiness and Wellbeing' conference took place in Birmingham on the 6th and 7th October 2017. It was fantastic to see so many families and professionals from across the UK and throughout Europe, coming together, to hear clinicians and researchers presenting the latest developments and future initiatives.



It was also a time to bring families together to make new friends and meet up with old ones, particularly during the Saturday evening when the Alström family came together to natter and dance the night away. . .

You can read the full conference report and see videos from the event, including a film of the conference on our website:

<http://www.alstrom.org.uk/ASUK-conference/>



Working with international partners

Collaborating with families and professionals internationally will help us to expand our knowledge and understanding, so we have been discussing joint projects and presenting at International conferences.



Ann and Kerry were delighted to meet-up with our American colleagues from Alström Syndrome International (Clair Francomano, Robin Marshall and Heather Cox, pictured left). The conference was a great opportunity to consider future developments.

We joined the World Orphan Drugs Congress in Barcelona in November, which highlighted the importance of orphan drug and clinical development for all rare diseases. Patients organisations reiterated the importance of involving patients in all stages of development. This conference offered an ideal opportunity to learn more about patient registries highlighted as a key priority for ASUK members. For more information follow the link below.

<http://www.terrapinn.com/conference/world-orphan-drug-congress/index.stm>

ASUK Chief Executive, Ann Chivers and National Development Manager, Kerry Leeson-Beevers presented 'The Voice of Patient's Associations' at the 'Rare Diabetes and Obesity Syndromes' in Padua, Italy in September. ASUK's key message is to ensure the patients' voice is always heard and patient organisations are included at all stages of development.

Raising awareness in UK & Europe

Kerry Leeson-Beevers gave a 5 minute lightning talk at the 'Findacure Rare Disease Showcase' in October in Newcastle.

Kerry also highlighted the Breaking down Barriers project during the Genetic Alliance UK 'Upskilling Our Members' conference in London in September.

ASUK attended the Cardiomyopathy UK National Clinical Conference 'Hidden in Heart Failure' in London to learn more about the clinical developments in cardiomyopathy and the research currently being developed.

We were pleased to present at the *Asterix symposium in September in the Netherlands, giving an insight into patient engagement in clinical research and why it is vital to include patients at all stages in developing research initiatives.

*Asterix is an EU funded research project with the overall aim to achieve more reliable and cost efficient clinical development of treatments for rare diseases and to stimulate the search for treatments for these devastating and largely ignored diseases. ASUK has been involved in this project to ensure patients voices are heard at all stages of clinical research design and development.



Partner Projects

The Breaking down Barriers project which has kindly been funded by the Sylvia Adams Charitable Trust, continues to gather momentum. Workshops are bringing together patient organisations to discuss, share and develop supportive and inclusive services for all in our diverse communities who are affected by genetic conditions. The workshops explored the challenges and achievements that charities have experienced. You can read more about this exciting project on the website:

<http://breaking-down-barriers.org.uk/>

'I was in charge of the car!'

Up and down the country, our young members have been taking part in specialised driving sessions funded by Children in Need. Southampton, Rotherham, London and Birmingham have played host to excited young people who have had chance to take control of a brand new Vauxhall Corsa. Under the care of their driving instructors, the young people were taken through a number of skills including reversing, bay parking, navigating roundabouts and an emergency stop.



Family members looked on in amazement at the skills and confidence demonstrated by the young people. One young person said; *"Awesome!! Loved going fast! I want another go! It made me feel really excited. I didn't think my brother could do it, but he has!"*

One Parent commented *"This is a dream come true for my son! Our family can't believe he has the chance to be in charge of a car, driving by himself. This will be a memory for us all to cherish!"*

Since taking part in the activity, Alisha (pictured left) who took part in the activity has Brailled (accompanied by a written translation) a piece about her driving experience, which will be available for everyone to read at the yearly AS children's clinics held at the Birmingham Children's Hospital. She has shared the following extract: *"When it was my turn I learnt about the steering wheel, pedals, the gear stick and the handbrake. Then it was my turn*

to drive, I actually drove round corners and a roundabout. My driving instructor was called Sheryl. I had a fantastic time!"

After the driving session the young people and their families had time to enjoy a meal, socialise with each other and share the thrills of the day.

Thank you to Children in Need for funding this activity as part of our Transition project. Enabling young people to not only have a go at activities that they never thought possible but also to make new friends and have lots of fun! Please visit the ASUK website to see a short film of the driving experience in action <http://www.alstom.org.uk/having-fun/#1512468726161-b772e63f-29eb>

Further information about specialised driving session can be found at: www.youngdriver.eu



Climbing the walls!

Chris, who has Alström Syndrome, with limited sight and hearing loss, shares his thoughts on wall climbing.

“On Friday 25th August, I went along, with a local group of 9 people, all visually impaired, to Westview Leisure Centre in Preston to have a go at indoor rock climbing. I was a bit hesitant as I wasn’t sure what was going to happen. The instructor told us all about the climbing wall. You basically get into a harness that you wear around your thighs and waist and it’s attached to a big rope, like a tow-rope.”

Before they let me near the harness, I had to do some exercises to warm up my muscles. The harness was quite comfortable and felt like I was sitting in a seat. Once the rope was attached I started to climb the wall. I had to feel for grooves and holes in the boulders on the climbing wall. The holes were all different sizes and different heights. I had to pull my body up by using my hands and feet.

At the first attempt, I couldn’t reach the top. My hands and legs turned to jelly and I came back down to floor level. It was quite a strenuous exercise. At the second attempt, I got over my fears and just kept reaching for the next hole to place my hand in then reached for the next hole for my foot to fit in. I reached the top in about 15 minutes. When I got to the top the instructor was there with me and we abseiled down to the ground together. This meant descending to the ground backwards by pushing my feet against the wall, holding the rope and sliding down to the ground with the rope between my legs. It was very exciting and I am doing it all again next month!”



If you are interested in finding out more about this sport have a look at The British Mountaineering Council the ‘Disability Needn’t Stop You Climbing’ article shows what is possible and where to find further information:

<https://www.thebmc.co.uk/disability-neednt-stop-you-climbing>

ASUK would like to say a HUGE THANK YOU to Chris, who has been raising funds and awareness of Alström through selling his own pottery creations at a local Craft Fair in Freckleton.

We have been busy bees up and down the country

ASUK attended the Queen Alexandra College, Sight Village events in Birmingham, London and Manchester. The events demonstrate the latest technology, equipment and support services available to people who are visually impaired or partially-sighted.

We had stands in Birmingham (ASUK Chief Executive, Ann Chivers and Family Support Worker, Carrol Birchall from ASUK pictured below at the Birmingham event) and Manchester, to raise awareness of Alström Syndrome. We met some interesting people and insects- including this buzzy bee who visited our stand!



ASUK Family Support Worker, Jane Biglin attended the London Sight Village event with several ASUK members, not only to gather useful information and resources about new technologies, equipment and support provision but also to bring families together to share experiences and make new friends.

Chris Evans talked about 'our Kion'

Kion inspired us all on Chris Evans morning show, promoting the BBC Children in Need appeal.

(BBC Radio 2 breakfast show Monday 13th November 2017)

Kion talks about his experience of Alström Syndrome.

Follow the link below to the recording on BBC iplayer. The feature is at 2 hours 1 min into the programme.

<http://www.bbc.co.uk/programmes/b09dxm9z#play>

More about Children in Need can be found at this link:

<https://www.bbcchildreninneed.co.uk/fundraisinghub>





Stay Well This Winter campaign

The NHS #StayWellThisWinter campaign aims to ensure everyone who is eligible receives their free flu vaccination.

Flu is a highly infectious disease and can lead to serious complications, particularly in these risk groups listed below:

- anyone aged 65 and over
- pregnant women
- children and adults with an underlying health condition (such as long-term heart or respiratory disease)
- children and adults with weakened immune systems

If you fall into one of the groups above you are eligible for the flu vaccine – it's free
Contact your GP or pharmacist.

Further information can be found via the NHS website:

<https://www.nhs.uk/Conditions/vaccinations/Pages/flu-influenza-vaccine.aspx?>



Alström Syndrome Multi-disciplinary Clinics 2018

Adult clinics at the Queen Elizabeth Hospital, Birmingham

- 24th and 25th January 2018
- 21st and 22nd March 2018
- 11th and 12th April 2018
- 27th and 28th June 2018
- 26th and 27th September 2018
- 7th and 8th November 2018

Please confirm attendance. ASUK will be in touch with individual families prior to each clinic they are due to attend.

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

Please get in touch if you would like further information.

Children's clinics at Birmingham Children's Hospital

- 29th January 2018
- 14th May 2018
- 17th September 2018
- 12th November 2018

Outreach Clinic in Leeds
15th November 2018

Important Information about Audiology Appointments at the QEH

When you attend the Queen Elizabeth Hospital Birmingham for your annual Alstrom clinic you may have the opportunity to see an Audiologist. In preparation for this visit, if you are prone to excess wax please make arrangements to see the nurse at your GP surgery or your ENT provider for wax removal. Unfortunately we cannot guarantee the availability of an ENT specialist to carry out this procedure when you attend clinic.

If you see an Audiologist during your time at the Queen Elizabeth Hospital they will examine your ears and offer advice as needed. They may test your hearing if appropriate and carry out basic hearing aid maintenance. However if you are a hearing aid user you should also be registered with a local provider. In order for you to be hearing at your best your hearing aids require regular maintenance throughout the year; this may include replacing tubes, filters, making new ear moulds and fine tuning your hearing aids. Ideally you should be seeing your local audiology provider at least every six months.

Information provided by Gemma Mason, Senior Audiologist from the QEH Audiology Department.

Thank you Rob!

During the AS multi-disciplinary clinic in October, a day of celebration and sadness began as we said a fond farewell to Dr Rob Cramb. Rob has been a dedicated and positive supporter of AS patients and ASUK.

Rob has been on the AS journey since the AS multi-disciplinary clinical service moved from Torbay Hospital to the Queen Elizabeth University Hospital in Birmingham.



We would like to take this opportunity to thank Rob and wish him well in his retirement.



Glucose monitoring- Freestyle Libre device and sensors

About 12 months ago, ASUK realised that for patients who were taking part in the Prometic clinical trial, glucose monitoring was becoming an issue and even deterring some people from taking part in this research. Part of the monitoring needed to take part in the trial meant patients were having to check their sugar levels using the finger-prick method frequently throughout the day. Not only were patients finding this inconvenient but often painful.

ASUK looked into ways to overcome this issue and found the Freestyle Libre device. The device is a way of monitoring your glucose levels by attaching a small round shaped disc to your upper arm and this continually reads your glucose levels with a reader. The reading includes your current glucose, a glucose trend arrow indicating which way your glucose is going, and a graph of your current and stored glucose readings.

One of our members and ASUK Trustee, Alex Griffiths-Rayson shares her experiences of using the device and sensors:

“For the last 6 months, I’ve been monitoring my blood glucose with the Libre device. I wear a sensor on my arm which is about the size of a £2 coin and when I want to monitor my levels, instead of having to get my Glucose meter out, find a testing strip, figure out which way it goes in the machine, prick my finger, squeeze some blood out, find the right spot on the stick – without getting blood everywhere - and then finally wait for the machine to tell me what my levels are, with the Libre device all I do is turn the machine on and hold it near to the sensor and I get a glucose reading. Scanning makes my life so much easier.

Whilst making life easier and quicker to do the glucose readings, there are some other positives to wearing a sensor. Firstly, it doesn’t matter how I hold the device when I need to scan, it will scan through thick coats and jumpers and I haven’t found anything it won’t scan through.

When I scan I get a blood glucose reading, but there is also a black arrow next to the reading indicating in which direction my glucose is heading so I can manage my food, insulin and activity intake better which means less spikes in my sugar control. I also can see a graph at the bottom on the screen, the sensor can hold up to 8 hours’ worth of information, so in-between scans the sensor is storing information which I can then access when I take a glucose reading. I now know what my sugars levels are doing whilst I am asleep which again helps me to control my levels better.

All of the information that is stored on the device is transferable to a computer and I am also able to create reports that I can then send to my doctors for them to look at, which enables them to look for patterns and trends.

The sensors are really comfortable to wear, which to me is one of the most important things. I forget that I am wearing it most of the time and the adhesive that attaches it to your skin is very good and doesn’t come off in the shower or whilst swimming. The adhesive can become a little loose towards the end of the two weeks in which you wear the sensors for, however some tubular bandage helps to keep it projected and in place. This is only an issue for me if I am in extremely hot weather where I may sweat a lot. Sun cream and other body creams can also loosen the adhesive so I try to wear extra bandaging and don’t put creams on this area. The tubular bandages aren’t that pretty so I’ve used tattoo sleeves to make my protection prettier.

The sensors last for two weeks and I do need someone to support me in putting them on, as you have to line up two different parts of the sensor to ensure it works properly and you only get one chance for that to line up properly. Being blind, I occasionally walk into things – a hazard of life – and I’ve knocked one or two sensors off whilst doing this, hence why I started to wear the protection. Once you’ve knocked a sensor off it cannot be used again. This can be quite frustrating as I’ve knocked one off where I’ve only been wearing it for two days and it has to go in the bin. However, this doesn’t deter me from wearing them.

One negative about the Libre is that they aren't always 100% accurate. If your sugars are very high or very low I still need to do an actual glucose check with another machine as the levels can rapidly change during these times and it can take the Libre a little while to catch up. This is due to the blood it uses to get readings is the subcutaneous blood rather than capillary blood from the finger. Most of the time however it has a good level of accuracy and I am happy to rely on it giving me accurate readings.

The only other negative is that for someone who has no sight the Libre scanning device isn't particularly accessible, however if you have an android phone you can connect this to your Libre device and use the flash scanner in this and by using speech you can then make it more accessible.

Whilst the Libre may be expensive to buy and the sensors are £48 for one it is worth buying as it has revolutionised how I test my blood sugars and manage my diabetes. I am now able to do as many tests a day as I want and I'm also able to monitor my sugars through the night."



Watch this inspirational video of ASUK Trustee, Alex being interviewed about not letting your disability define you.
<http://www.alstrom.org.uk/alstrom-inspiration/#1512555267228-c65ee93d-ba42>

Until recently, devices and sensors were only available to fund privately but from the 1st November 2017, the FreeStyle Libre sensor is available on prescription via the NHS, subject to suitability. If you are interested in trying these devices, speak to the Health Care Professional who normally treats your diabetes to discuss suitability for you and availability in your area. If you are given a prescription for the FreeStyle Libre sensor, supplies for these will be issued in the same way as usual prescriptions via a pharmacy. The FreeStyle Libre reader will be provided free of charge via a Health Care Professional from 1st November 2017.

You can find further information about the device and sensors via the Freestyle website <https://www.freestylelibre.co.uk>

Let us know if you experience any difficulties getting a Libre device or sensors as we may be able help.

Research - Clinical Trial into AS in the UK-Update

The first results of this trial have just been released and are showing some encouraging results. (September 2017) This is the first clinical trial in Alström Syndrome in the UK, please read further information below and follow the link to the Prometic website to read the full press release.

<http://prometic.com/prometic-reports-positive-clinical-data-from-ongoing-pbi-4050-study-in-alstrom-syndrome-patients/>

ASUK has been working in partnership with Prometic Life Sciences Inc. and the specialist clinical team at the Queen Elizabeth Hospital, Birmingham to support this first clinical trial for people affected by Alström Syndrome in the UK. The primary aim of the trial is to evaluate the safety and tolerability of PBI-4050 and its

effects on inflammatory, fibrosis, diabetes and obesity biomarkers in people affected by Alström Syndrome. It is early days and there are no guarantees that patients taking part in the trial will have any clinical benefit, but we hope this trial will enable further knowledge and understanding of this complex condition.

Further information about the clinical trial can be found via the website www.clinicaltrials.gov, using the trial reference number NCT02739217.

Have a look at these research highlights on our website via this link <http://www.alstrom.org.uk/research-highlights/>

European Medicines Agency is relocating

On the 20th November 2017, the 27 member states voted on where the European Medicines Agency (EMA) will relocate in the light of the UK leaving the EU.

The decision has been made to relocate to Amsterdam in the Netherlands by the 30th March 2019 at the latest.

ASUK hope the impact of the move will be minimal, to limit the disruption of the EMA's work and operations.

Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe, commented, "Patients are happy that the decision has now been taken, bringing to an end a long period of uncertainty and allowing the agency to plan for the future. We are pleased with the choice of Amsterdam, a city that meets the overall criteria recommended by patient and consumer groups in Europe. Amsterdam is accessible for visiting patient experts and we hope will encourage retention of current staff. This choice will support the continued presence of the patient voice at the agency and helps to preserve the value that the EMA brings to patients across the EU."

You can find out more about the work of the EMA and the full relocation news via their website:

http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2017/11/news_detail_002857.jsp&mid=WC0b01ac058004d5c1



Trustee Vacancy

Alström Syndrome is a rare genetic syndrome that affects less than 1 in 500,000. Alström Syndrome UK supports those living with the condition, their families and those working with them.

If you would like to use your skills and experience as a Trustee for Alstrom Syndrome UK we very much look forward to hearing from you.

Role Description

We are looking for 2 committed individuals to expand the range of skills within the current Trustee team. We are looking for dynamic and motivated people who can bring their strength, energy, insight and professional expertise alongside strategic vision, to fulfil this voluntary role. We want to have a wide range of people within the Trustees of the Charity and we seek to be representative of the diverse population we support. We welcome individuals with previous Trustee experience however we also welcome applications from those whose career path has provided the expertise we seek. We are particularly keen to hear from individuals with experience of the following areas fundraising, governance, Scientific/clinical, HR and financial.

Trustees are expected to:

- Attend 3 face to face Board meetings a year (currently at the weekend in Birmingham)
- Contribute advice and support at our regular evening telephone conferences (minimum quarterly)
- Attend Alström Syndrome UK conferences

This is a voluntary position; expenses will be paid in line with our expenses policy.

How to apply: If you would like to express your interest in this position, please send a covering letter along with your CV. Your CV will be considered by the Board and a response will be sent to you in writing. Please send via email to catherine.lewis@alstrom.org.uk

Closing date: Completed applications should be returned to us before 5pm on 12th January 2018. Applications received after that time may be considered if we have any further places available.

This role will require a DBS check to be undertaken.

Have you seen our animation?

Developed by families and clinicians, it's definitely worth a peek, ensuring we all raise awareness of this ultra-rare condition is vital.

We can all make a difference today... please share this video far and wide.

<http://www.alstrom.org.uk/awareness-animation-is-launched/>



Getting Messy at the Foodie Fun Friends Clubs

Since 2015, ASUK have continued to develop the Foodie Fun Friends Clubs through funding kindly provided by Children in Need.

These clubs are where families come together prior to attending the children's clinic in Birmingham to; socialise with one another, develop friendships and learn more about healthy eating in a fun way.



These clubs focus on three key areas:

Improved Relationship with Food

Children and young people who are affected by Alström Syndrome often find it difficult to maintain a healthy weight. Maintaining a healthy lifestyle is vitally important as this may delay the onset of type 2 diabetes and reduce pressure on vital organs.

During these clubs families have the opportunity to learn about healthy food in a fun and interactive way. The sessions are very hands-on and messy, so that the children can get involved no matter what their ability.

Improved Confidence

Improving young people's confidence to communicate and be assertive about the decisions in the life, is vitally important to ensure their voice is heard. Transition occurs throughout different stages in life and this is the time when our young people often need support the most. Developing the knowledge and skills to manage the syndrome is vital to enable the young people to develop control and confidence in their lives.

Improving Social Skills

Our aim is to facilitate age related support groups where friendships can develop and support systems can begin to help children, their parents and siblings feel less isolated. These clubs coincide with the children's clinic and provide learning and enjoyment before the clinic. Many of our children find it difficult to make friends with their peers due to their dual sensory loss and complex health needs. Through these clubs the children have become more confident in socialising and developing friendships.

During these sessions Paediatric Dietitian, John Pemberton from Birmingham Children's Hospital supports families by providing useful tips on how we can manage a healthy lifestyle. One way he does this is by showing families' portion sizes in easy to remember ways, such as a fist size or a palm size so preparing foods and eating the correct amount can be visualised.

One of the Mums who recently attended a Foodie Fun Friends Club said; *"It was lovely watching young people grow in confidence over a task, sharing independence and enjoying making the food together with other families."*

We have developed a range of videos including one of the 'Foodie Fun Friends Clubs'. Keep an eye on our website and social media channels to be the first to see these.



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

Please call 01803 368871 / 01709 210151

Christmas holiday

The charity office will close at 5pm on Friday 22nd December 2017.

If you need to get in touch urgently over the festive period, please call 01803 368871 and leave a message with full details including your name and telephone number. We will endeavour to return your call within 2 days. All other enquiries will be responded to on our return on Tuesday 2nd January 2018.

From all the team at ASUK we would like to wish you all a Merry Christmas and a very happy and healthy New Year!

Please feel free to contact any member of the team



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Family Support
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Alström Syndrome UK

Strength for today, hope for the future

PLEASE BE AWARE OUR ADDRESS HAS CHANGED:

Registered Office address: 4 St Kitts Close, Torquay, Devon TQ2 7GD
Please visit our website www.alstrom.org.uk to keep up to date with our latest news.



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

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

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Information you can trust

ASUK is committed to providing information you can rely on as being accurate and trustworthy.



ASUK has been assessed as meeting the standards of The Information Standard and continues to be a certified member.

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- Step 3: check "Show in News Feed"
- Step 4: check "Add to Interest Lists..."



Thanks!