



Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK (ASUK) is a 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. Our mission is to raise awareness, conduct pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics. Further information about our work can be found at www.alstrom.org.uk

Welcome to the Summer 2022 ASUK Newsletter

Hello Everyone,

I hope you, your family and friends are all keeping safe and well and that you have all enjoyed a lovely summer. It has been great to see updates and photos of many of you out and about and having fun. I love to hear and read about your adventures and see some of the new experiences and activities you are taking part in.



There have been many things to celebrate such as Lexi and Adam's wedding (pictured left) – HUGE congratulations to you both!

There have been lots of achievements too such as Hassan's 140 mile tandem ride across Europe – see page 3 for more details, young people passing exams and being accepted into university, success at

Judo competitions and many of you developing skills and confidence to try new things. My son Kion has bought himself a Honda Goldwing motorbike and is enjoying getting out on the open road with his stepdad and grandad (although it gives me nightmares!). He has also been following his beloved Rotherham United Football Club around the Country.

Sadly, we have had to say goodbye to some members of our community this year. Our thoughts are with Rob, Stephen and Connor's family and we send them our love and best wishes.

A warm welcome to ASUK

We have had quite a few changes at ASUK. We welcomed our new Chair (Sharon) and Vice-Chair (Kez) along with new members Carol, Haris, Mokey and Jane to the Board of Trustees. Trevor and Alex have stepped down from the Board but we are really pleased they have agreed to continue to volunteer with the ASUK team.

Jane Biglin our Senior Family Support Worker retired in April but Jane will remain part of the team as she joins our Board.

Sarah Oliver and Toni Smith joined us as our new Alström Syndrome Care Coordinators earlier this year and they have fitted into the ASUK team perfectly. Toni has been helping to coordinate clinics and Sarah has been supporting people with benefits, education and social care assessments. Together, Toni and Sarah have been supporting people to apply for grants. You can find out more about their roles on the next page.

New families have joined ASUK and I am sure you will join me in giving a huge warm welcome! We will be providing opportunities to bring our community together in the very near future and we hope you will all join us to meet up with old friends and new.

Challenging times ahead

As we approach winter, please remember that our AS doctors recommend that everyone eligible should have the flu, pneumonia and covid vaccinations and boosters.

The cost-of-living crisis is likely to hit our community hard so please get in touch with us if you need any support. We have provided further information and guidance on our website <http://www.alstrom.org.uk/family-support/> You can also find out if you are eligible for emergency funding on page 7.

The ASUK Board of Trustees have set aside additional funds to support our community. Please remember that you can apply to us for a health and wellbeing grant and adults over 18 can apply for a Big Activity Challenge grant.

It has been great to see so many of you taking advantage of these grants. Please speak to Toni and Sarah for more information.



Thank you

As always, a big thank you to all our families, friends and supporters and to the medical teams in Birmingham. The pandemic still hangs over us and we have some challenging times ahead but we will continue to be there for one another.

We are stronger together so let's stay in touch. Stay safe and look after yourself and your loved ones.

We are here for you.

Kerry and the ASUK team

Meet our New Alström Syndrome Care Coordinators!!

Hello, I'm **Sarah Oliver** and I am delighted to have become one of the newest members of the ASUK team. I'm joining the team as your Care Coordinator and will be working four days a week usually on a Monday to Thursday.

My new role will be a national one supporting people across the UK. I have supported people with sensory loss / deafblindness for most of my working life.

I trained as a secondary school teacher and worked as a special needs assistant in a secondary school for a short time, before I started working for the charity Sense in 1998. During my time with Sense, I've had several roles including 7 years working as an Assessment and Advice Officer, this is very similar to my new role as Care Coordinator at ASUK. I also spent 3 years as a Care Act Assessor completing Specialist Deafblind Guidance Assessments, these were commissioned by Local Authorities across England. I spent two years studying part-time whilst working to complete the Deafblind Studies Diploma. This developed my understanding of living with sensory loss and qualified me to be able to carry out specialist assessments. Almost two years ago, at the start of the pandemic, I was made redundant from my role at Sense. Since then, I have been a support worker for a young person who has complex needs following an accident.

Whilst working for Sense, I have had the pleasure of meeting some of you and been trusted by you to complete your Specialist Care Act Assessments. This enabled me to develop a knowledge and understanding of Alström Syndrome. Jane Biglin and I also both worked for Sense at the same time, occasionally working together providing assessments, advice, and support to people with Usher Syndrome.

I live with my family in North Yorkshire and have two teenage sons. One who has just left school, the other who has just started his GCSE's. Apart from spending time with my family and working, I'm also a governor at the local primary school where my children used to attend.

I look forward to meeting you all, hopefully in person at some point over the coming months. As well as catching up with those of you who I've not seen for a while.

Please contact me directly if you would like any information, advice, or support.

I can be contacted by email, sarah.oliver@alstrom.org.uk or by phone or text **07917 958502**.



Hello, I'm **Toni Smith** and I joined the ASUK team as your Care Coordinator alongside Sarah Oliver.

My usual working days will be Tuesday to Thursday. My role will be to help coordinate and support the Alström Syndrome multi-disciplinary clinics in Birmingham and the outreach clinic in Leeds.

I started my early career in an Early Years education setting and then moved into Family Support Services. I have experience working within social care fostering and adoption teams as well as supporting Looked After Children.

Throughout the last 10 years I have worked as a Family Support Worker in a Special Needs School for children who were aged between 2 to 19 years old. Their needs varied and many had complex health care needs. My passion is to ensure everyone's voice is heard, supporting the equality in services and information offered.

I live with my family in South Yorkshire and have three sons and two grandchildren. We enjoy sports so I'm usually spectating at some sort of football or cricket match. I also like crafting. I look forward to meeting you all, hopefully in person at some point over the year at one of the multi-disciplinary clinics.

Please contact me directly if you would like any information, advice, or support.

I can be contacted by email at toni.smith@alstrom.org.uk, or by phone or text on **07825 384362**.



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

Where will your adventure take you!

We have also been able to provide equipment for individuals and families and grants towards the **Big Activity Challenge!**

Feeling inspired to have your own adventure - Why not start planning your Adventure today?

If you are over the age of 18 and are affected by Alström, you can apply to ASUK for a small grant of up to £500 towards an adventure or activity. All we ask, is afterwards you provide some photographs and write an article for the newsletter, telling us all about your experience—such as how accessible it was, what you achieved, or even if you're going to take it up as a new hobby. If you would rather talk to us about your experience, we can help you produce a podcast for the ASUK website.

Once you've chosen your destination, or activity have a hunt around for the best prices and plan exactly what you would like to do.

How you can apply!

Get in touch with Sarah or Toni who will send you the application form.

Hassan, (pictured right) took on his challenge, by cycling on his tandem for 140 miles across Europe!

Hassan's journey has been captured on film, as soon as it is ready we will share with you!

He is also raising funds for those affected by AS at the same time, you can show your support by visiting his JustGiving fundraising page

<https://www.justgiving.com/fundraising/hassanseurotrip>



Could you benefit from a Fitbit?

Many of you may remember the fitness initiative we started in 2016 following a consultation with families. ASUK provided Fitbit watches to help people focus on exercise, in particular helping to measure distance and the number of steps walked every day – thinking through what did it mean in everyday activities to achieve 10,000 steps? Fitbits also helped people to monitor things like heart rate and sleep patterns.

We would like to hear from any of you who would be happy to share your experience of using a Fitbit.

- ♥ Did you find it helpful?
- ♥ Did you use the device to monitor activity?
- ♥ Did it encourage you to maintain a particular level of exercise?
- ♥ Did it encourage you to go out walking?
- ♥ Do you still use a Fitbit?

If you are happy to share your experiences, we would love to hear from you!

Trevor and Kathryn took part in the fitness initiative and Dr Richard Paisey has been keeping a record of their activity levels over a number of years.



Kathryn shares her thoughts:

“Firstly, depending upon which type you choose depends on how accessible it is. Most of the later and more up to date versions have touch screens. Also, consider what you want a Fitbit to do for you. I have a charge 5 which is great. The app can be a little fiddly at times. Some sighted assistance may be needed for setting up or detaching devices from the app. I really like the heart monitor and high and low notifications on

mine. They come in all colours and two sizes of bands. I started with a Charge HR and worked my way up to a Charge 5. Some count climbing floors and others do not. Fitbits are generally great but can have issues syncing and you need to check computer, tablet and phone requirements to check that they are compatible. If not, you will end up with a device you cannot use. On mine there are steps, distance, calories burnt, steps taken in one hour if below 250 steps, heart rate, heart zones, high and low heart rate notifications, mindfulness, nutrition, sleep hours, water drunk when logged, food eaten when logged, blood glucose level when logged and an ECG checker. Thanks! Kathryn”

Trevor shares his thoughts:

“I love my Fitbit! It helps me to set personal goals and I have been much more active since I started wearing it. It has been instrumental in keeping me stable over the last few years.”

If you are interested in receiving a Fitbit or another type of exercise equipment or monitoring device, please let us know.

ASUK grants are available and we are keen to provide support to people with Alström Syndrome to help you become more active and to support your health and wellbeing.

Please contact Catherine Lewis for more information

Welcome our new Trustees

You may have noticed there has also been some changes on the ASUK Board of Trustees.

Due to their length of service on the Board, our Chair, **Trevor Parkin** and our Vice Chair, **Alex Griffiths-Rayson** had to step down, but they aren't going far!

They have both kindly agreed to continue supporting the charity as volunteers. Trevor will work alongside the ASUK Financial Services Committee and Alex will work alongside Ann and AS Global.



Our new Chair, is **Sharon Bates** who has been an ASUK Trustee for 3 years.

Sharon is delighted to tell us a little bit about herself:

"I have worked within the NHS for many years, and now work as a Practice Manager at a medical centre in Devon. This involves the day to day running of our practice to provide patient care and planning future service developments.

I hope to bring my knowledge of healthcare, NHS systems and my drive to support charities to my role as an ASUK Trustee.

I continue to work in a variety of voluntary roles for local charities; volunteer dog walker for the Cinnamon Trust (for 20 years) and I volunteer at a local North Devon animal charity (for 5 years) where I help to care for stray, ill or unwanted pets prior to rehoming. I am also the Chair of the Board of Trustees for the North Devon Hospice (having been a Trustee for 3 years).

I enjoy travelling and have been fortunate enough to travel the world over the last 30 years – and I continue to do so. You will often find me walking the great outdoors as I am lucky enough to live close to moors and coastal paths.



Kez Hayat who has been on the Board of Trustee for 9 years is now our interim Vice-Chair. Kez has extensive knowledge and experience of Alström Syndrome, through his own lived experience as a parent of a Son living with AS.

Kez is also Head of Diversity and Inclusion at Bradford Teaching Hospitals NHS Foundation Trust, which has proven invaluable as we utilise his knowledge on the Breaking Down Barriers project Advisory Board.

We also have four new Trustees joining the Board, Haris Hamid, Carol Prescott, Jane Biglin and Mokey Yates.

Haris is part of the Alström Syndrome community and is very enthusiastic to bring his knowledge and lived experience to support the Board of Trustees.

"I would like to be part of the board because I have Alström so I can use my experience to help families understand what Alström is about. I'm keen to learn and will be able to help and participate in any new research and development taking place. I have studied level 3 Business which involved a lot of financial elements so my knowledge can be helpful when coming to the board."

Carol, is a Habilitation Specialist as part of the Sensory Needs Team in Bury. Carol has worked with many of our young people and families over the years and brings a wealth of knowledge and experience of the care and support system.

"I have worked for many years in various local government Sensory needs teams. After re training to be a Habilitation specialist over 14 years ago I have had the pleasure of taking a journey with so many babies, children/ young people and families teaching strategies to develop independence.

The role introduced me to Kerry over 10 years ago and many wonderful/dedicated staff within ASUK along the way. Together we have shared the values that we all hold, and I was honoured to be accepted on the Board of trustees at the beginning of this year. I will strive to work hard to ensure that all decisions are in the very best interest of the Alström community. Out of work I am very blessed that I can take breath-taking walks on the Cumbrian fells/ mountains with family and friends. I look forward to working closely together with you all and continue to drive the charity forward."





Jane, will already be very familiar to most of you as she has recently retired from her role as Senior Family Support Worker with ASUK.

“I joined the ASUK team in August 2016. I thoroughly enjoy meeting and supporting people affected by Alström and truly feeling part of a wonderful family. My early career was in travel – first as part of a very small charity which gave information on holidays for people with disabilities and then taking this knowledge to customer services within large UK tour operators. I then moved into universities and colleges to support sensory impaired students and then qualified as a Post 16 Teacher of the Deaf and worked with people with Usher Syndrome through Sense. It is always my aim to listen to what people say to enable me to guide them towards achieving their aims.

I retired from my family support role in 2022, but I am now an ASUK volunteer and looking forward to joining the board, helping and supporting where I can.”

Mokey, recently retired from her job at Ernst & Young (EY) Global. A Chartered Accountant based in London, her role involved developing policies and methodologies that are used by EY’s audit teams around the world.

Mokey grew up in South Africa, where she met Marina Valenti, from AS Italy at school. They are lifelong friends, despite now living in different countries – Marina in Italy and Mokey in England. Marina, whose daughter has AS, introduced Mokey to Ann Chivers, and, as a result, Mokey is now looking forward to joining the Board of Trustees, and hopes she can help to further the aims of ASUK. Mokey has also assisted with the ASEU accounts, her financial experience and knowledge will be invaluable in supporting the Board.



Mokey is married to Roger, and they have two children and two grandchildren. Besides babysitting her grandchildren as often as possible, Mokey loves walking in the countryside, dancing (ballroom, Latin and ballet), building dolls houses and reading. She moved to rural Northamptonshire in 2018, where she enjoys the wonderful birds and abundant wildlife of the Nene Valley, as well as the flowers, fruit and vegetables that Roger grows in their garden.

We know you will join us in welcoming them all to the Board.

Why not meet everyone (virtually) at the ASUK Annual General Meeting on the 23rd November 2022 from 7-8pm (UK time). Get in touch to register.

We thank all Trustees past and present for all the dedication and support they provide to ASUK.

Healthy Hampers

We know what a tricky time the last few years have been with the uncertainty around Covid-19 and the challenges this has brought, so we wanted to send you a little something to brighten your day!

We were delighted to secure funding to send New Year healthy treats to adults affected by Alström Syndrome. You should have all received a fabulous fruit and vegetable hamper.

We would love for you to share any photos of the hampers and your cooking creations.

Don’t forget you can always pop along to the ASUK website to find lots of tasty and healthy recipes to try.

<https://www.alstrom.org.uk/stay-fit-stay-healthy-stay-happy/>



Fun for All!

It has been a busy Summer and we know that families have been out and about enjoying the glorious weather. ASUK has been busy supporting children and young people to take part in activities and opportunities which have been funded through a BBC Children in Need grant.



Lock me up!!

On the 3rd July 2022, a group of young people and their families had a great day out at the West Midlands Police Museum. Marie, Toni and Sarah supported families throughout as they meandered through the cells, forensic areas and viewed the police bikes, model horses and big blue telephone boxes! Not to mention the trying on of the police cloaks!

ASUK Culture Sparkle Sisters (CSS) will reach a global audience!

The Culture Sparkle Sisters continue to meet on a monthly basis, Their discussions have covered a number of topics including, money management and working with their Habilitation Workers. The CSS have agreed to speak at one of the ASUK Global webinars to talk about growing up with Alström Syndrome and offer advice to parents/carers around the world. At the webinars, parents and carers from different countries will have the chance to ask questions about how to support their own children or young people. ASUK CSS are keen to share their lived experience and provide lots of top tips to help with many areas of life living skills, what a personal assistant does or how to cope in school/college.

"I would love to speak to people around the world who want to know how to live with AS. I live with it every day; I know I can offer advice to other people!"

"Oh yes it is, ohhhhh no its not!"

ASUK has organised a number of theatre trips which have taken place across the country. This has included Goldilocks and the Three Bears Pantomime in Birmingham, Hex in London, Rock and Roll Beauty and the Beast in Leeds and Snow White in Blackburn. Where possible ASUK arranges for families to attend audio described theatre performances, where hearing aids can be linked to the radio aid system. All the families have fed back that they have had a wonderful time and really enjoyed the laughter and fun!

Laughing out loud... "Thank you so much for booking these tickets. The show was amazing and so much fun. My brother was very loud in the audience, shouting out with everyone and laughing out loud!"



“I want to do it for myself!”- Building independence skills and having fun!

ASUK continues to work with children and young people on an individual basis, to support the development of their skills and knowledge with their healthcare and everyday life. Being independent is an important part of life, at any stage. From toddlers playing by themselves to young people learning to cook or manage their laundry, learning how to do things for themselves is very important for all our children and young people. Through various grants we have been able to provide equipment, resources, or opportunities, that aid independent development. This can include one cup kettles, where a hot drink can be made safely to bean bag chairs that support posture. ASUK also supports young people who want to push their boundaries and learn new skills. Recently a young person was funded to attend a residential trip without being accompanied by parents/carers. This is a huge step towards independence, building confidence in their own ability and learning how to cope with change!



“I use the one-cup boiler, it's better than the one at school. I use it to make drinks independently.”

Over the summer young people have also had an opportunity to drive an adapted fire engine. One family member fed back 'My brother was super excited! It's such a fab activity, he's been talking about it non-stop!

Moving and Stretching

ASUK are always looking for opportunities to encourage children and young people to maintain a healthy lifestyle. This is underpinned by the physiotherapist at Birmingham Women's and Children's Foundation Trust who give out a range of exercises and stretches which can be used on a daily basis. Bodkin is the character that ASUK uses to depict all the exercises/stretchers that can be found in the Wellbeing Packs. Don't forget to use Bodkin's stretches every day!

BBC Children in Need are also keen to fund a number of health and wellbeing opportunities. In the past year ASUK has used the funding to support a number of initiatives including bike ability lessons (learning to be safe when cycling) and a young person has benefited from a gym pass where he is building up his muscle strength, posture, and endurance.

‘The new exercises are good for me, and I am learning more about looking after my body.’



New opportunities - Let your creativity Shine!

ASUK have recently launched our Summer Creative Festival-Let your Creativity Shine! It is for anyone aged 18 or under to take part in a creative writing/drawing/making project. We want to use all the artwork, creative pieces, stories and pictures on our website, in newsletters, and social media, to let the world know how wonderful and creative our children and young people are!

The closing date for this has now been extended to 31st October 2022.

Whitemoor Lakes Residential – Getting to Know You Weekend, April 28th-30th 2023

At long last ASUK are happy to announce that we have booked a family residential weekend at Whitemoor Lakes, Staffordshire, April 28th-30th 2023. There will be opportunities to take part in all sorts of activities such as abseiling, canoeing, arts, crafts, and a campfire sing song! The activities are aimed at children and young people from age 8 upwards. In the first instance places will be offered to those who have not been on an ASUK residential before. Applications for the residential will be emailed in the New Year.

If your child or young person wants to visit the theatre, take part in day trips, try driving a car or a fire engine, build on their health and fitness, is looking for personalised resources, or to take part in other activities please contact Marie McGee, ASUK National Transition Coordinator by email;

marie.mcgee@alstrom.org.uk



A BIG THANK YOU to all our funders who make this work possible

Emergency Funding

BBC Children in Need Emergency Essentials Programme supports children and young people who are facing exceptionally difficult circumstances and is delivered by Family Fund Business Services. The programme provides items that meet a child's most basic needs such as a bed to sleep in, a cooker to provide a hot meal and other items or services critical to a child's wellbeing. If you have a child up to and including the age of 17 and you are experiencing a crisis or emergency and live in the UK, then please get in touch with your Care Coordinator, Toni Smith. Toni is now registered as a Family Fund Referrer, so please get in touch with her if you need this emergency support and to discuss if you are eligible.

One question we are often asked is ‘how many people in the world have Alström Syndrome?’

The simple answer is we don’t know! We could have a wild stab in the dark; but working globally really is helping our understanding of the condition as well as trying to answer this fundamental question.

ASUK have been reaching out to families and professionals from around the world, so that we can learn from one another and really start to grasp how many people in the world are affected.

Alström Global Community Wellness Club

Usually on the last Thursday of the month the AS Global community have been coming together virtually to discuss a range of useful topics.

February 2022 – How I manage my diabetes

March 2022 – How I manage my information

April 2022 – Food, Fitness and Healthy Habits

May 2022 – The benefits of a Mediterranean diet

June 2022 – Hearing Health

July and August – postponed for the Summer holidays

September 2022 – Hearing Health with Dr Lucy Dalton

October 2022 – Hear from the Culture Sparkle Sisters

November 2022 - Preparation for the Conference!

3rd December 2022 – AS Global Conference

Don’t worry if you have missed any of the sessions, you can view the recording and top tips from the session on the ASUK website <http://www.alstrom.org.uk/as-global/>

Top Tips for enjoying a Healthy Lifestyle

This webinar brought together, Dr Richard Paisey, Alström Syndrome clinical expert and Marina Valenti, Mom, and expert by experience from AS Italy Association, (pictured below) who gave their views about leading a healthy lifestyle.



Q1. Can you prevent diabetes with a healthy diet and exercise?

Dr Richard Paisey: Published studies over a 10-year period, from Finland, USA, UK, and China have found that a healthy lifestyle can reduce by half the chance of developing diabetes in adults at risk from being overweight and borderline high blood glucose levels (pre-diabetes).

In Alström Syndrome the diabetes is linked with the genetic change causing extreme resistance to insulin. Lifestyle has just as important a part to play, as exercise and healthy eating can delay the onset of diabetes. Two studies comparing Canadian and Italian people with Alström syndrome from their early years up to reaching their twenties, looking at their lifestyle, culture, and diet, found that Canadians were very overweight by their mid-teens and had diabetes. Whereas the Italians who were studied had significantly less individuals who went on to develop diabetes, they were slimmer, and no insulin was needed.

Q2. What are the advantages and disadvantages of medicines which control appetite?

Dr Richard Paisey: There are three types of medicines which control appetite:

Medicines that mimic the bodies appetite control

Medicines that don’t allow the absorption of fat

Medicines that affect the brain and hormones to make people feel full.

Over the years, some of these drugs have had unacceptable side effects and have been withdrawn.

One drug which has been established and is now used is Semaglutide. It works to mimic a hormone from the bowel which sends a message to the brain to say you are full. This hormone is reduced in type 2 diabetes, including those with Alström syndrome.

Some people with AS have started on this drug and once the initial three months of side effects subsides, the results appear to have been positive.

“It is the first time in my life I have ever felt full”, experience of adult with AS who is taking the drug Semaglutide.

Note: This drug is not yet licensed for people under 18

Q3. Is metformin a good drug to take for diabetes for a person with Alström?

Dr Richard Paisey: Yes, it has been recognised to help people control their sugars for over 50 years.

It stops the liver producing too much sugar, so that diabetes improves. It won’t stop the diabetes or cause weight loss.

Note: If you are very unwell, metformin must be stopped as in this circumstance it can cause too much acid in the blood.

Please get advice from your healthcare provider.

Check with your healthcare provider before changing any medication, or starting any new exercise or health regime.

Q4. Is a keto diet recommended if you have diabetes and Alström?

Dr Richard Paisey: The ketogenic diet is a very low carbohydrate, high fat diet that shares many similarities with the Atkins and low carb diets.

It involves drastically reducing carbohydrate intake and replacing it with fat. This reduction in carbs puts your body into a metabolic state called ketosis.

Ketosis is a metabolic state in which your body breaks down fat to ketones which can fuel the brain, heart and muscles instead of sugar. Following a ketogenic diet is the most effective way to enter ketosis. Generally, this involves limiting carb consumption and filling up on fats and protein, such as meat, fish, eggs, nuts, and healthy oils.

It is a way to lose weight quickly, and can control type 2 diabetes. The longest studies have lasted up to 5 years, and more studies are needed.

Yo-yo diets aren't healthy and instead consider leading a healthy diet, reducing the size of your meals, avoiding junk food, and eating wholemeal, bread, pasta, and rice may be a more sustainable way to eat healthily. Leading a healthy lifestyle is a long-term plan, developing healthy habits works better than a short-term fix.

Q5. Is high intensity training recommended if you have Alström?

Dr Richard Paisey: High-intensity interval training (HIIT) is a type of workout that combines short bursts of intense exercise with periods of rest or lower intensity exercise.

Alongside a healthy diet, cross fit training and HIT training can be a good way to feel well. It is also as good as other exercise such as walking.

It can be a good method as you don't need expensive equipment or need to go to the gym-try press ups, sit ups and running on the spot or a static bicycle in your own home!!

Q6. How common is extreme insulin resistance in people with Alström?

Dr Richard Paisey: It is a key marker for diagnosing Alström. It shows the genetic effect of the syndrome which slows the flow of glucose into cells.

Q7. What is the impact of cholesterol?

Dr Richard Paisey: Cholesterol is very important to consider.

Many people affected by Alström Syndrome have high blood cholesterol and triglyceride levels. In combination with diabetes and kidney disturbance this has been shown to cause hardening of the arteries, even heart attacks in those who are 30 to 40 years old. Nowadays with good treatment/prevention of these conditions from an early age this can be prevented.

We are now diagnosing Alström earlier, so we can treat with statins and adopt a healthy lifestyle to try to prevent hardening of the arteries.

Q8. What are your top tips for a healthy lifestyle?

Bite size Top Tips:

- ♥ Keep active
- ♥ Keep your weight down
- ♥ Avoid fatty foods, such as junk food
- ♥ Don't drink sugary drinks

Marina shared her top tips for encouraging healthy eating for toddlers

- ♥ Try to make sure the food is as interesting as possible
- ♥ Keep to strict rules as a healthy diet is so important
- ♥ Ensure the people around your child also know why this is important
- ♥ Get them involved in the preparation and cooking, handling different textures, and trying new tastes
- ♥ Use high quality dark chocolate to dip fruit into
- ♥ Wrap the fruit in brightly coloured paper to unwrap, especially at parties so the children don't feel left out and take alternatives that they will like instead of the sugary sweets and cakes.



Top Tips for healthy eating

- ♥ Reduce carbohydrates and replace with wholemeal options such as pasta, bread and rice.
- ♥ Nuts are good – but avoid salted, roasted nuts or additives such as extras like Cajun as these come with extra fats and salts.
- ♥ Cut down on processed food and junk food.
- ♥ Fruit and vegetables are mostly slow release and un-processed, they contribute to a healthy balanced diet, increase vitamin intake and feeling of fullness, and increases fibre intake.
- ♥ Sugar, including sugary breakfast cereals and sugary drinks are not recommended. These should be avoided and can give an excessive insulin release.
- ♥ Use natural sweeteners, like honey and try cake recipes using root vegetables like beetroot, carrot or parsnip.



ASUK provides a Foodie Active Friends Clubs, where children and young people prepare and cook together. It is a great way to try new foods and handle different textures and tastes.

Further Information

There are more top tips, healthy recipes, and exercises on the ASUK Wellbeing Club area of the website:

<http://www.alstrom.org.uk/stay-fit-stay-healthy-stay-happy/>

Published research papers and references can all be found on the ASUK website:

<http://www.alstrom.org.uk/research-papers/>

Thank you

Thank you to everyone who joined the session and particularly to Dr Richard Paisey, Marina and Valentina who shared a short video of her extraordinary roller blading and other activities showing how she stays healthy.

We're always pleased to share quotes from attendees:

"Dr Paisey explanations were extremely interesting and puts lots of the pieces of the puzzle together, because his explanations are very simple"

"Thank you for the opportunity to all get together, it has been so interesting"

See you at the next global session!!

Alström Global Virtual Conference

SAVE THE DATE!



Saturday 3rd December 2022 2:00 – 7:30 pm (UK, GMT)

REGISTRATION WILL OPEN SOON!!



Alström Syndrome UK
Strength for today, hope for the future

AS Global Patient Registry

Be part of history—let's find all those pieces!

The ASUK Patient Registry enables you to provide your health information in an easy and straightforward format by completing questionnaires about your health in a safe and secure way.

This information will be available (anonymised) for researchers and clinicians worldwide to learn more about Alström Syndrome and develop treatments into this rare condition. It is free to join for both you and professionals. This information will help build a worldwide picture of Alström Syndrome, improving knowledge and understanding of this rare and complex condition for everyone on the planet!

You have the potential to make a real difference to everyone living with Alström.

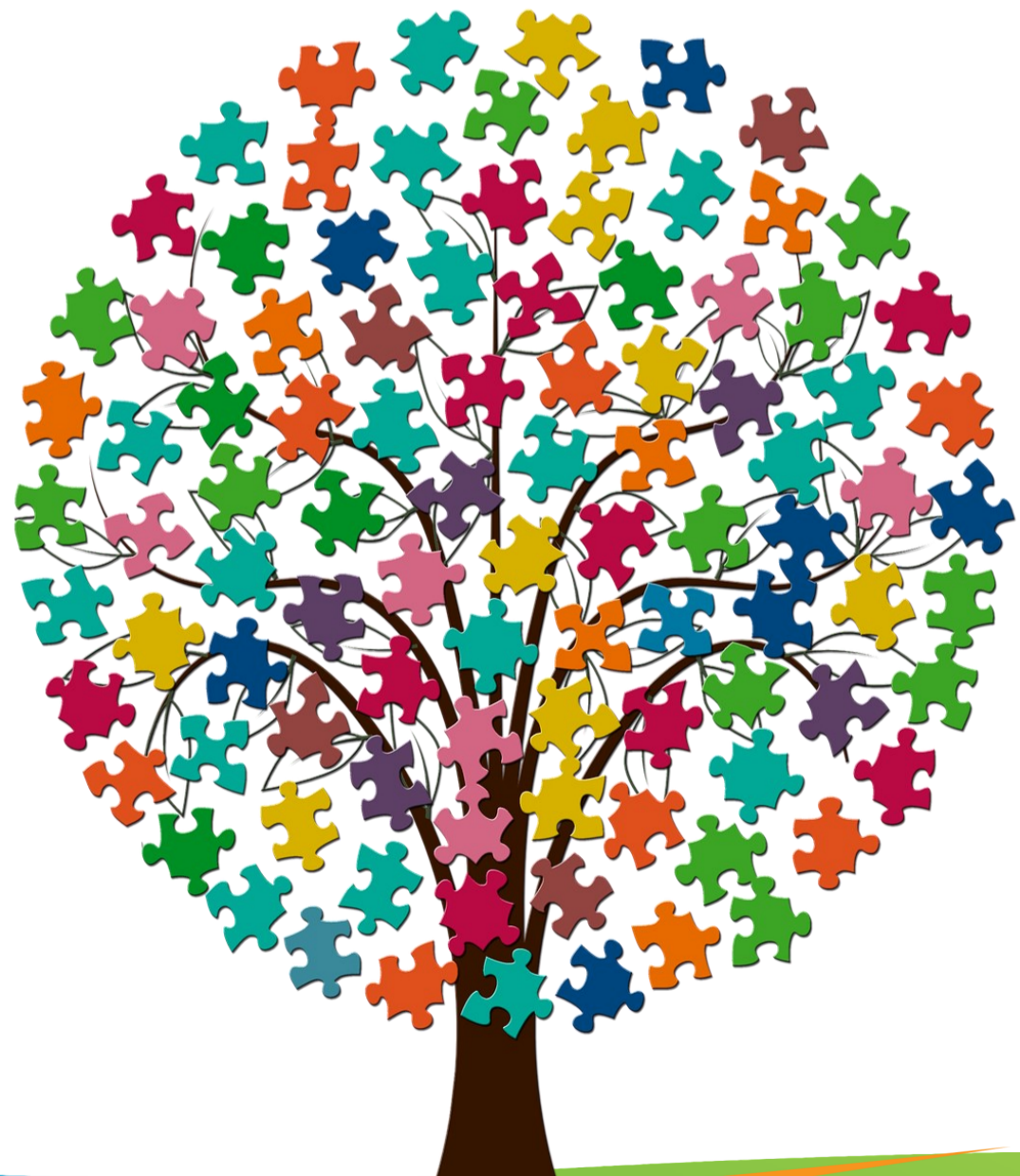
How to join?

Check out the CoRDS Connect website and complete the CoRDS activation form, it is quick, secure and easy to do, just go to the website below:

<https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>

Don't delay, enrol TODAY!

A big thank you to those who have already completed the registry. If you need any support to join the registry or if you would like any further information, please get in touch with ASUK Office Manager, Catherine Lewis on 07970 071675 or email catherine.lewis@alstrom.org.uk



Breaking Down Barriers Developments

ASUK founded Breaking Down Barriers in 2016, to facilitate a network of organisations working together to increase engagement and involvement with people from diverse and marginalised communities. Striving for equitable access to healthcare, services and support is at the heart of everything we do.

The BDB project now has **over 60 member organisations** and the reach and creative ambitions from the team are going from strength to strength.



Derek, Vanessa and Cathy joined the team last year, and it has been great to see all the new developments and the benefits of this work.

Derek Sankar, BDB Community and Inclusion Coordinator has been supporting the BDB network and has been developing a range of webinars and in-person training.

"I have been offering a range of Equity, Diversity and Inclusion (EDI) webinars to help with further development of staff, Trustees, and volunteers across the network. Members can either book onto a planned session or request a session tailored to their organisations needs.

For National Hate Crime Awareness Week 8th - 15th October 2022 I will offer a webinar addressing how organisations and the Breaking Down Barriers network can respond to the hate crime those we support may face.

EDI and Community Collaboration Micro Sessions: I am developing short 5 min recorded Micro Learning Sessions on key topics to stimulate awareness, discussions, and action. They will build into a comprehensive resource bank on the BDB website.

I have been delighted to support individual members in community engagement and collaboration, implementing policy and good practice, building confidence and skills to work with new communities with staff and trustees, 1:1 consultation on fundraising, recruitment, community outreach and using translation and interpreting services. I have also been exploring opportunities for peer to peer support, sharing experiences and learning across the network.

I continue to engage with the network to understand more about how ASUK and BDB can help organisations to achieve their aspirations, with EDI at the core."

Cathy Chadwick-Rayner, BDB Networks and Outreach Coordinator has been delivering creative workshops within diverse communities in West Yorkshire.

This is a community outreach pilot project and the workshops include fun, interactive activities aimed at raising awareness about genes, genetic conditions, inheritance of genetic conditions and the support services and organisations available. The support, activities and crafts help to create a safe space, build trust, and aid the flow of conversations around barriers to good health. These workshops have been very well received and we plan to roll them out to other parts of the country in the future.



Cathy is a member of the NHS West Yorkshire Health Equity Fellowship. She is building connections with local service providers in the hope of bridging gaps between people, communities and healthcare professionals, to assist with positive change. She is also attending community events to raise awareness of ASUK and BDB.

We also welcome **Jas** (pictured right), who is supporting Cathy with the outreach pilot as our new BDB volunteer!



Vanessa Williams, BDB Patient & Public Involvement and Impact Coordinator.

"My Role is to create and support a diverse group of people with lived experience within BDB, to have a voice and be involved in creating the changes that we want to see in services everywhere. My current focus is to hold regular PPI groups with people from all over the UK from different backgrounds and ages with different lived experiences and health conditions. The group will help guide the work of ASUK and BDB, provide support and guidance to the BDB network and be involved in the different research projects we are part of.

You can find out more about the work of the BDB project team through the BDB website, including how to get in touch.

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;

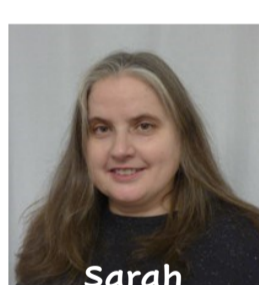
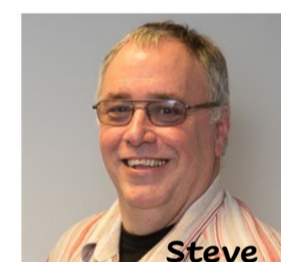
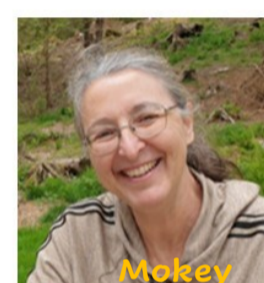
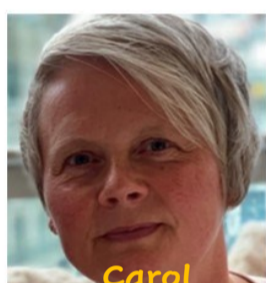
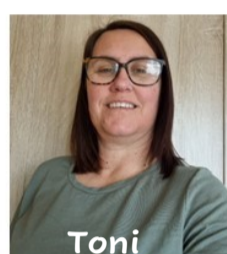
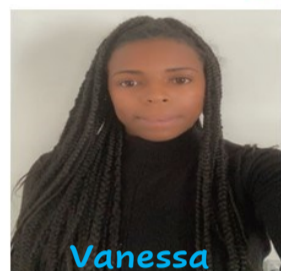
Please call **07970 071675 / 01709 210151**

Email: Catherine.lewis@alstrom.org.uk

Please get in touch if you have any articles or suggestions for our next edition, Catherine is looking forward to hearing from you!



Meet the ASUK Team



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Please visit our website www.alstrom.org.uk to keep up to date with our latest news.

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

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

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

