



**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. 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](http://www.alstrom.org.uk)



Welcome to the

# Summer 2019

ASUK Newsletter

Issue 22 – Summer 2019

Welcome to the 22nd edition of the ASUK Newsletter

*An update from Ann Chivers, Chief Executive*

At last summer is here, although you wouldn't know it this week! It seems to have been raining cats and dogs everywhere from Lands' End to John O' Groats. So some lovely sunny stories in this update, Curtis and Taylor jetted off to Barbados, and Hannah flew a single engine plane. They were some of the first to apply for the Big Activity Challenge, if you're inspired follow in their footsteps, go to the website and apply today!

<http://www.alstrom.org.uk/travelling-blind-where-will-your-adventure-take-you/>

Talking of travelling, Alex and I were delighted to be invited to speak at the Alström Syndrome International conference in Galveston Texas. An inspiring conference and a brilliant opportunity to meet families and professionals from all over the world. Some of our take away thoughts, were about the how and when children, young people and adults get a first diagnosis of Alström. It differs significantly all over the world, and we hear wildly different stories just in the UK. We need to find ways to improve this and ensure that in future individuals get an earlier diagnosis. This is the focus of this year's family gathering on Saturday 19th October in Birmingham. Please come along and tell us about your diagnostic journey, was it a bumpy or smooth road?

I hope the sun has come out by the time you are reading about what everyone has been up to! Please let me know if you would like to contribute any articles to the next newsletter, how about volunteering at the family gathering or have any feedback on any of ASUKs services. As ever thank you for your continued support. I look forward to seeing you in October.

Best for now

**Ann Chivers**, Chief Executive at ASUK

*PS Thank you to everyone who has returned the 'Early years questionnaire', and there's still time if you haven't had chance yet, get yours in by the 26th July 2019 to share your story. We will give an update on the results at the family event October.*



**Ann Chivers**,  
Chief Executive at ASUK

## SAVE THE DATE! - ASUK Family Gathering

**Saturday 19th October 2019 in Birmingham**

You will all be pleased to hear, ASUK are beginning to plan a family gathering to bring us all together for a day where we hear about your experiences, your stories and what is important to you.

They'll be plenty of time to reconnect with old friends and have fun making new ones. This is sure to be a time of many laughs, catching up, reminiscing, and memory making.

**Planning for the big event - please tell us your ideas and views.**

Whilst we get stuck into planning the event, we'd love for you to share your thoughts with us about what you would like to see or do.

What would be your favourite activity; would it be holding

an exotic animal, zorbing or something more chilled out like a yoga or mindfulness session?

We all know how quickly technology moves on, wouldn't it be great to have technology organisations coming along to demonstrate their accessible products including computer and phone products.

Which organisations would be top of your list? Would it be Orcam with their wearable technology that can read text, identify products and recognise faces! Or maybe something for your computer such as accessible products like the latest screen readers.

**We would love to hear from you and join us in making this event extra special...**



Please get in touch, Catherine is looking forward to hearing from you! Her email address is [Catherine.lewis@alstrom.org.uk](mailto:Catherine.lewis@alstrom.org.uk), please ensure all your ideas and suggestions are sent in by the 2nd August 2019 so we have plenty of time to plan.

## Around the World with Alström

ASUK Trustee, Alex Griffiths-Rayson and our Chief Executive, Ann Chivers set-off on the 30th April 2019 to attend the Alström Syndrome International Conference in Texas, USA. The event was spread over 5 days from the 2nd – 6th May 2019 and included family and professional seminars, workshops, and a chance to network with families and professionals.

It was an opportunity for people affected by AS from all over the world to come together and share their experiences and meet other people affected by this ultra-rare condition.

We were very excited to be taking part as well as presenting. Ann talked about the journey of ASUK and how working together on a global scale can vastly improve awareness and research worldwide.



Ann and Alex enjoyed catching up with families, friends and professionals – they all had one thing in mind; improving the lives of people affected by Alström Syndrome.

**A huge thank you to ASI for inviting Alex and Ann to present.**



## European voice is going strong!

Congratulations to Genetic Alliance UK, Chief Executive Jayne Spink who has been elected to the Eurordis Board of Directors.

Eurordis is an alliance of patient organisations across Europe, ensuring their voice is heard at a European level. They represent 862 rare disease patient organisations in 70 countries and the voice of 30 million people affected by rare diseases throughout Europe.

Collaborating on a European and International level is vital in the management of rare diseases and learning further insights from around the world.

One area that has been key in this development and sharing of expertise is through the European Reference Networks (ERN's). Where healthcare professionals can share information and expertise on specific symptoms, across borders.

We can't shy away from the fact that Brexit could impact our European work and developments, including across ERN's but we are maintaining strong links with Europe to ensure the voice of rare diseases in the UK are heard. You can go onto the Genetic Alliance website and show your support for ERN's by signing your name <https://protect-erns.eu/>

We are delighted that Jayne has been elected to maintain and develop further strong links with the European sector and ensure the UK stands strong together with our European friends and families. You can find more information about the work of Eurordis on their website <https://www.eurordis.org>



## Roaring good time on Rare Disease Day 2019!

Rare Disease Day took place on the 28th February and this year the theme was 'Bridging the gap between health and social care'.



Both the children's and adult clinics coincided with Rare Disease Day so it was a great opportunity for ASUK to raise awareness about the condition and how the specialised clinics make a difference. Families had a great time; creating posters, sharing their thoughts and having fun with face paint and nail polish!



## Honoured to speak at the House of Lords

On the 11th March 2019 the Conservative Muslim Forum (CMF) brought together expert speakers at the House of Lords to discuss the issues affecting Britain's Muslim communities and to also share the experiences of Britain's Jewish communities.

We would like to extend our thanks to the CMF for inviting us to speak and for giving us the opportunity to share information about the important work of **Breaking Down Barriers (BDB) Project**.

It was a fabulous evening with very interesting presentations from the CMF and from Jnetics who are one of the member charities of BDB. We discussed the role of BDB in supporting patient organisations, support groups and community networks to develop supportive and inclusive services and to work in collaboration to share examples of good practice and to develop accessible resources so that families understand genetic risk and can make informed choices.

Jnetics spoke about their GENEius Project and their plans to provide an education programme and carrier screening to people within their communities. CMF Chair, Mohammed Amin discussed genetic risk and the importance of genetic testing.

The evening concluded with a question and answer session. Representatives from different communities joined together to share their knowledge and experiences. We would like to say a big thank you to CMF for welcoming us to the forum, we look forward to future collaborations.



### Top left to right

CMF Secretary – Faruk Miah, Imam Shakeel Kunwar, Lord Sheikh, ASUK National Development Manager and BDB Project Lead, Kerry Leeson-Beevers, CMF Chair – Mohammed Amin, Executive Director, Jnetics - Katrina Sarig

### Bottom left to right

CMF Executive Member – Suzy Webb, Sylvia Adams Charitable Trust Director – Jane Young, BDB Community Engagement Manager - Asya Choudry

## Luton Health Awareness and Genetics Event

As part of the Breaking Down Barriers project, ASUK was delighted to host the Health Awareness and Genetics Event in Luton, alongside Flying Start Luton and Public Health Luton for families and professionals.

The event was a great opportunity to link services together and explore areas for development, especially in terms of referrals to genetic services.

For more information about the Breaking Down Barriers project go to: <http://breaking-down-barriers.org.uk/>



## Calling for Government Action!

ASUK joined over 125 patient organisations who have signed the Rare Disease UK's open letter, asking the Government to review and refresh the UK Strategy for Rare Diseases. This coincided with Rare Disease Day and has now been sent to Baroness Nicola Blackwood, the Minister in charge of rare diseases.

Baroness Blackwood presented at the Rare Disease UK, Westminster Reception for Rare Disease Day. She discussed her own diagnostic journey of having a rare, undiagnosed condition, for 30 years and the challenges it caused.

At the reception, she announced the new [National Genomic Healthcare Strategy](#) to ensure the UK can offer a predictive, preventative and personalised health and care service for people who are affected by rare diseases.

### The Promises are:

- Every person with a rare disease will have a dedicated person responsible for coordinating their care
- Every patient with a rare disease will be given an 'alert card', including information about their condition, treatment regime and contact details for the individual expert involved in their care
- Every child with a rare condition will be transferred to appropriate adult services when they reach the age of 18, even if that adult service is not the commissioning responsibility of NHS England

The full information about this Genomic Strategy can be found on the Gov.UK website:

<https://www.gov.uk/government/news/health-minister-nhs-must-lead-the-world-in-genomic-healthcare>

Some of this is in place for people who are affected by Alström Syndrome but we must make more improvements to ensure everyone who is affected by Alström Syndrome is supported now and in the future.

## Biggest overhaul to the Blue Badge Scheme

Did you know that the Blue Badge scheme is to undergo the biggest changes since the 1970s? From April 2019, the scheme will be expanded to include people with what is often described as 'hidden disabilities', such as mental health issues or autism.

Automatic entitlement to the Blue Badge will be extended to those in England who score 10 points under their Personal Independence Payment (PIP) mobility test of being "unable to undertake any journey because it would cause overwhelming psychological distress to the claimant".

Those who get PIP mobility for other reasons will not qualify for a Blue Badge automatically, but they may still be able to qualify for a Blue Badge if they fall into one of three groups:

1. 'They have an enduring and substantial disability, the effect of which is that the person is unable to walk or undertake a journey without it causing very considerable difficulty when walking.'
2. 'They have an enduring and substantial disability, the effect of which is that the person is unable to undertake a journey without there being a reasonably foreseeable risk of serious harm to the health and safety of that person or any other person.'
3. 'They have an enduring and substantial disability, the effect of which is that the person is unable to undertake a journey without it causing very considerable psychological distress to that person.'

People in England who fall into one of these three groups will qualify for a Blue Badge (regardless of whether they get PIP or not). However, to qualify they will need to be assessed by their local authority. There are many disability rights campaigners championing these changes, but many people who currently have a Blue Badge, also feel there aren't enough disabled parking spaces available.

The charity Disability Rights UK has further information on their website :

<https://www.disabilityrightsuk.org/news/2019/january/we-welcome-extension-blue-badge-scheme-those-hidden-disabilities>



## 'My Guide Dog and Me'

Have you ever wondered what having a guide dog is really like, how are you assessed and what training is involved?

Meet Kion and Curtis, they have both passed their guide dog assessment and are now on the waiting list to have their first guide dog. . .

Following their assessment, they were both invited to Shireview Guide Dog centre in Leeds (photo right) to get used to walking the dogs. They began learning how to look after a guide dog and their essential needs such as grooming. They were given lots of time throughout the visit to ask questions in preparation for the arrival of their guide dog.



### 'The start of my Guide Dog journey'

Catherine Lewis had the pleasure of interviewing Curtis about his dream to have a guide dog and the difference this could make to him.

### Can you remember what first attracted you to wanting a Guide Dog?

My first thoughts were enabling me to be more independent and giving me the confidence to get out and about.

### How long have you wanted a Guide Dog for?

I have wanted a guide dog for a while, but I didn't really look into it for a long time. I didn't start the process until about a year ago (April 2018).

### What was the assessment process like?

(please explain for people who don't know anything about the assessment process, what you had to do and did you encounter any challenges and what were your highlights.)

The main part of the assessment process was checking how my mobility is at the moment, so how confident I am already to get out and about using my cane. They assessed my mobility on routes that I currently use with my cane and also future routes that I would like to do with the guide dog. At the time of my assessment no guide dog was available so we used a demonstration harness to assess how I would manage with a dog.

They really want to get a good indication of what your life is like. Where you live, where the dog will be able to go to the toilet, how tidy you are. . . so they can check that a guide dog would fit into your life.

### Did Guide Dogs for the Blind explain what their criteria is?

Not really, they just assessed my capabilities currently to get out and about, as well as the difference a guide dog would make to my life.

### Did they explain what makes a good Guide Dog partnership?

They try to match a dog to you; so they asked how active I am and what I like doing. They also looked at how quickly I walk so they can match a dog to a similar pace to me.

### Tell us an interesting fact about Guide Dogs that we may not know?

Guide dogs for the blind supply all food, and vet checks are paid for too so I don't have to worry about this. There is just a minimal payment I need to make, it wasn't very much and this may have changed since I applied.

It is important that the dog always looks their best, so they need to be groomed every day so they always look presentable when out and about, especially if I get a long haired breed.

### Do you get to choose your dog and what breed would you ideally like?

You can specify a breed but it can take a lot longer to get a guide dog if you have a set breed in mind. There are lots of different breeds, many are cross-breeds Retrievers and Labradors mainly. My only preference was; they get on with children, other dogs and animals.

### Have they suggested how long it may take to get a Guide Dog?

The average wait can be around 2 years from the start of the application process. The longest person on their waiting list at the moment has been waiting around 18 months.

### Once you have your furry friend, how long does the training take?

I think about 4-5 weeks and this can take place at my home or at a hotel and my home, whichever I would prefer.

### You must be very excited about getting a Guide Dog, what will it mean to you?

I am looking forward to the extra independence and freedom to get out and about more. It will mean I can be less reliant on other people and the guide dog will be company for me, especially when I am feeling down, just having someone there will be really good for me.

Let's hope Curtis and Kion don't have to wait too long for their furry friends. . .

We are all excited to find out who their guide dog will be!

Follow their journey to discover the highlights and challenges along the way <http://www.alstrom.org.uk/my-guide-dog-and-me/>

**YOU have the Power to Make a Difference in just 15 minutes!**

**We Need YOU!**



YOU have the power to improve lives for the better by simply providing us with answers to some of the questions we have about infant health. ASUK have created an infant questionnaire and your response will greatly strengthen the quality of the data we keep and will form part of a broader project we are embarking on to use data to:

- Improve care
- Increase understanding of the condition
- Accelerate patient diagnosis.

In about 15 minutes YOU can make an incredibly valuable contribution to research, without ever leaving your home!

**YOUR data is critical in the fight to make a real difference to the lives of all those affected by Alström Syndrome**



## **Data collection – why is your participation important?**

### **Early diagnosis and better treatment**

Information about AS health in infants will help Clinicians and Researchers recognise patterns in the occurrence of symptoms in particular 'red flag' signs that could inform an early diagnosis.

### **What does this actually mean for patients?**

An early diagnosis of AS means patients can receive the right medication and treatment at the right time and share their experiences with others sooner. Diagnosis is complex, as very often infants do not present with the same set of symptoms - AS can affect babies in different ways.



## HOW YOU CAN HELP



### Information is KEY

We know that the more information we can gather about Alström the more we can learn about the condition and improve its' management and treatment.

You may be familiar with the little 'Red Book' that tracks your child's health and developmental milestones, using this information and what you remember about your babies early years ASUK would like to start to document your child's health information in a similar way, so that we can get a broad picture of how your baby progressed from birth through to their early years.

Working with Clinicians we have developed some questions that we hope will give Clinicians a greater understanding of infantile symptoms and when and how they appear.

If you're willing to share some of your child's early health information we would be very grateful if you could respond to the questionnaire that follows. It should only take around 15 minutes to fill in. We are happy to receive responses by post, email or over the telephone – whatever is easiest for you.

There are 16 questions in total, please complete each one as far as possible. Where there is a multiple-choice response please mark an 'X' in the box that is most applicable to your child.

You should receive an information pack in the post which contains your questionnaire. You can also complete the questionnaire on the website:

<http://www.alstrom.org.uk/you-have-the-power-to-make-a-difference-in-just-15-minutes/>

Please contact Liz if you need any assistance in completing this form on 07517 278946

Please email completed forms by the **26th July 2019** to [liz.loughery@alstrom.org.uk](mailto:liz.loughery@alstrom.org.uk)

or post to Alström Syndrome UK, 4 St Kitts Close, Torquay TQ2 7GD

Thank you for taking the time to complete this survey, you really are making a difference to families now and in the future.

### It's anyone's game!

Para sport Ambassador, Jonnie Peacock is inspiring others to have a go at sport, no matter what your ability  
<https://www.bbc.co.uk/sport/av/get-inspired/47629509>

This is based around para sports ambition to create a fun and vibrant community for players, parents and coaches to share their experiences of para sport, and find useful hints, tips and information on inclusive opportunities across the UK.

Go to the para sport website and enter your postcode to find inclusive sports in your area <https://parasport.org.uk/>



**Calling ALL Alström Champions!  
Support Alström Syndrome UK Today!**

We rely on your generosity to support our work in improving the lives of all those who are impacted by this ultra-rare condition. There are so many ways you can get involved, whether you fancy throwing yourself out of a plane, riding a 200 mile bike ride or whipping up some cakes to sell with friends, the money you raise for ASUK will make a real difference.

**Get Involved and Make a Difference today...**

**Catherine is waiting to hear from you...**  
Call her on 01803 368871 or email [Catherine.lewis@alstrom.org.uk](mailto:Catherine.lewis@alstrom.org.uk) and see how you can make a difference and be a champion today!  
[www.alstrom.org.uk](http://www.alstrom.org.uk)

## Ello, Ello, Ello... Birmingham Bobbies make dreams come true!

On the 8th June, Birmingham police lock up played host to two very special young people and their families, where they enjoyed an afternoon of exciting activities. Jai and Zeeshan's family were welcomed by Inspector Steve Rice, who had kindly arranged a timetable of fun activities!

This included; dressing up in police uniforms, having their fingerprints taken, and spending time in the cells. He also added an extra sprinkle of excitement by inviting along local Police Officers and PCSOs to show the youngsters around their police van. Jai commented that 'other children should visit the lock up to learn about the police and find out they are nice people.'

This visit was followed by dinner where the families had chance to relax and get to know one another.

"PC's from Team 1 at Digbeth have met our friends Zeeshan, Jai and Marie from ASUK this afternoon, we had great fun showing them the police van and all of our equipment at the Police Station today"

Birmingham City Centre West Midlands Police Force.



We would all like to say a HUGE THANK YOU to the Police Constables and all the team at Digbeth Police Station for making a dream come true for these youngsters and their families.

ASUK are very grateful to BBC Children in Need which provides funding for opportunities that support ASUK children and young people to develop social skills, make new friends and try new challenges.

## Shopping has never felt so good!

### Did you know that you can support Alström Syndrome UK by shopping online?

Every time you shop online via easyfundraising at one of the 3,300 retailers including John Lewis, Aviva, Sainsbury's and Booking.com, a donation will be made to Alström Syndrome UK, and it won't cost you a penny. Have a look on our website for more details, and get shopping today!



<http://www.alstrom.org.uk/easy-fundraising-while-you-shop/>

## Bowled Over by the Adventure of a Lifetime

*A personal account from Curtis Vasey and Taylor Vasey*

"We have always wanted to watch cricket in a warmer climate and heard that England were playing Test Cricket in Barbados this year. We started planning how we would get there and how much it was going to cost. We successfully applied for the ASUK Big Challenge Grant to fund part of the trip, for this adventure of a lifetime. After much planning and excitement, the day arrived to start our journey to Barbados for 10 days of cricket and activities.

We caught the train to Gatwick Airport to board our flight to Barbados, leaving a cold, wet Scarborough behind us. Our brother, Rio and our Dad, Brian were part of our party of four. We had good seats on the plane and all sat together for the journey that lasted 8 and a half hours. The staff at Virgin Airlines were very helpful and the service was very accessible.

We landed in Barbados in the late afternoon and had pre-booked transport to take us from the airport to the hotel. The transfer took about an hour. The temperature was 29 to 30 degrees for the duration of the holiday.

The hotel staff were kind and helpful. Sadly, the hotel food wasn't the best. We had a walk to explore the local area, on the first day. The beach was sandy and we could hear birds singing. There were lots of uneven, narrow paths and these went up and down. Negotiating the paths, was a challenge!

The cricket matches were an hour away so there was 2 hours travelling each day. We travelled by bus in a group, from the hotel to the Kensington Oval at Bridgetown and we sat in a general seated stand. We could hear the people in the party stand and listened to the cricket radio commentary on our own headphones. We took our own radios with us. The atmosphere was good, and the weather was warm, although we were sat in a shaded area. Sadly, the England cricket team lost all their matches against the West Indies, on all 4 days.

We didn't have the opportunity to meet any current England test cricketers but did meet Darren Gough, a former England cricketer. Darren is involved in coaching from the side-lines, when not playing, and was helpful.

The all-inclusive trip on a Catamaran was the best event for us both. The trip lasted from 10am to 3pm. We set sail and the large boat headed out to sea. It was a very relaxing day trip. During the day, we enjoyed rum



*"We took lots of photographs and would like to share a selection of them with you from our Big Challenge."*

punch with fruit and fresh salmon. We were all able to enjoy the freedom of swimming in clear sea water with floats. It was great fun!"

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

If you are an over the age of 18 years old and are affected by Alström, you can apply to ASUK for a small grant of between £50 - £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 tell 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 need. You can then complete the application form which is available to download on our website. Please get in touch if you would like any assistance completing the form  
<http://www.alstrom.org.uk/travelling-blind-where-will-your-adventure-take-you/>

Who knows, you may inspire others to try out new activities too!

## Searching for 'rare' Trustees

We currently have vacancies for 3 Trustees to join the Board. ASUK is moving into its next phase of development reaching out to all families. The board are keen to recruit new Trustees to help fulfil ambitious plans and to support the overall mission and strategy.



### Personal message from ASUK Chair, Trevor Parkin

Welcome to Alström Syndrome UK (ASUK), a small national charity who support families affected by this extremely rare condition, Alström Syndrome.

The ASUK team provide a world class service which includes supporting people affected and their families. I am most proud of the charities approaches in developing the world's first; multi-disciplinary NHS clinics, clinical trials, research and the only medical handbook in the UK dedicated to the management of Alström Syndrome.

We have grand plans going forward and we would like further expertise on the Board of Trustees, whether this is through your financial management experience, knowledge of the social care system for people affected by complex conditions or your own personal experiences of caring for someone and knowing the challenges this can bring. We would like to hear from you and find out the ways you can help us to continue to drive the charity forward. I am proud to be part of the charity's innovative work in searching for answers into one of the rarest conditions and working hard to support individuals with Alström, their families and loved ones.

If you would like an informal discussion about the Trustee role please email Catherine on [catherine.lewis@alstrom.org.uk](mailto:catherine.lewis@alstrom.org.uk) or call her on 01803 368871 in the first instance, and she will help to organise a call between us.

I look forward to speaking with you.

Kindest Regards  
Trevor

**Trevor Parkin**, Chair of the Board at Alström Syndrome UK (ASUK)

### Role Description

We are looking for three people to compliment and expand the range of skills within the current Trustee team. We are looking for committed and motivated Trustees who can bring their strength, energy, insight and expertise alongside strategic vision, to fulfil this voluntary role. We would like a wide range of people to fulfil these roles and we seek to be representative of the diverse population we support.

We welcome individuals with previous Trustee experience however we also welcome those whose career path or caring responsibilities have provided the expertise we seek. We are particularly keen to hear from individuals with experience in the following areas; social work with particular interest in children or adults with complex needs, scientific/clinical expertise or financial management.

### What can you expect?

- A unique opportunity to use your experience to champion one of the rarest syndromes in the world and expand our reach
- A professional and supportive team, whose common goal is to further the insights into this condition and improve the lives of those affected
- To attend 3 face to face Board meetings a year (currently at the weekend in Birmingham)
- Contribute advice and support at quarterly board meetings. These are usually held by telephone in the evening.
- Attend the Alström Syndrome UK conference (held once a year).
- This is a voluntary position although expenses are paid (in line with our expenses policy).

### How to apply

We would love to hear from you; tell us about yourself, the experience you can bring and more importantly why you would like to be involved in this unique opportunity.

Please get in touch with Catherine Lewis and send your information alongside your CV via email to [catherine.lewis@alstrom.org.uk](mailto:catherine.lewis@alstrom.org.uk)

We would also greatly appreciate if you could complete the Equality and Diversity form which can be downloaded from our website <http://www.alstrom.org.uk/searching-for-a-rare-trustee/>

This role will require a Disclosure and Barring Service (DBS) check to be undertaken.

**Closing date – Friday 27th September 2019 at 5pm**

If you would like to know more about our work, please take a look around our website [www.alstrom.org.uk](http://www.alstrom.org.uk)

## Thank you!

After many years on the Board of Trustees, and 7 years as the Chair of ASUK, Michelle Hough has decided to step-down from her role. Michelle has led many changes throughout her time on the Board and helped to raise further awareness of Alström Syndrome and campaigned for the rights of many people with disabilities.



Trevor Parkin, the Chair of ASUK thanked Michelle on behalf of the board: *'We would all like to say a huge thank you to Michelle for the commitment and passion she has contributed, helping ASUK to grow and develop into a robust and stronger organisation. ASUK will always be grateful for your focus and creativity.'*

We know this isn't goodbye, as Michelle will still be campaigning and championing the cause of Alström Syndrome.

## Don't Suffer in Silence

Mental Health Awareness Week took place from 13th - 19 May 2019. The theme this year was 'Body Image' and how we think and feel about our bodies.

Body image issues and mental health issues can affect all of us at any age and at any time of our lives. During the week, the Mental Health Foundation published new research as part of their campaign for change.

Their research says that 'over a third of UK adults have experienced anxiety or depression due to concerns about their body image. With social media attributing to 1 in 5 UK adults experiencing worry and concern about their body image following images posted on social media. It is easy to see how our body image can affect us daily and affect our mental health'.

Campaigners are highlighting the need for everyone to Be Body Kind and using effective regulation on how body image is portrayed. We all have a role to play in this to make change now and in the future.

**You don't need to suffer in silence, help is out there:**

- The charity Mind provide information and support to empower anyone experiencing a mental health problem. They also offer top tips on how to support someone who is affected and they offer a help-line and legal-line to offer advice.
- The Samaritans offer a free 24-hour helpline dial 116 123, where calls are taken in confidence.
- Rethink Mental Illness offer advice, information and support in your local area.
- A new service has just been launched; 'Shout for support in crisis'. This is the UK's free 24/7 text service for anyone who is in crisis at any time.

Go to the ASUK website to find full information including links and helpline numbers:

<http://www.alstrom.org.uk/mental-health-awareness-week-2019/>



## Rare Disease UK Report on Mental Health Impact

With many rare diseases being chronic, complex and often taking many years to diagnose, the effect on mental health can't be underestimated. Living with a rare condition can have a huge impact on our lives, including anxiety, stress, low mood, emotional exhaustion and suicidal thoughts, for both the patient and the carer.



Our mental wellbeing is just as important as our physical health and Rare Disease UK set-out in 2018 to explore this further.

In 2018, Rare Disease UK published a report on the mental health impact of living with a rare disease. It sets out its findings and recommendations.

You can read the full report on the Rare Disease UK website: [https://www.raredisease.org.uk/wp-content/uploads/sites/7/2018/07/living-with-a-rare-condition-the-effect-on-mental-health-pdf.pdf?utm\\_source=hootsuite](https://www.raredisease.org.uk/wp-content/uploads/sites/7/2018/07/living-with-a-rare-condition-the-effect-on-mental-health-pdf.pdf?utm_source=hootsuite)

## Accessible Travel Lounge Opens!

Rail passengers using Birmingham New Street Station can now use a new assisted travel lounge which opened on the 10th June 2019.

The lounge was provided by Network Rail as part of their 'Railway Upgrade Plan' and was designed with the guidance of Birmingham New Street's accessibility forum, which includes people with disabilities, their carers and advocates, to ensure the space meets the needs of all.



The space is intended to be welcoming and includes 24 seats at different heights, a water bowl for service dogs and a team on hand to assist (Thank you to Network Rail for providing the main photos).

**The reception will be manned during opening hours, which are:**

|                   |                    |
|-------------------|--------------------|
| <b>Sunday:</b>    | <b>0900 - 1900</b> |
| <b>Monday:</b>    | <b>0700 - 2100</b> |
| <b>Tuesday:</b>   | <b>0700 - 2100</b> |
| <b>Wednesday:</b> | <b>0700 - 2100</b> |
| <b>Thursday:</b>  | <b>0700 - 2100</b> |
| <b>Friday:</b>    | <b>0700 - 2100</b> |
| <b>Saturday:</b>  | <b>0700 - 2100</b> |



**Our very own Family Support Worker, Jane Biglin takes a peek!**

We would love to hear from you if you have used the lounge and what your experience was.

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

## Meet the ASUK team



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## Alström Syndrome UK

Strength for today, hope for the future

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Please visit our website [www.alstrom.org.uk](http://www.alstrom.org.uk) to keep up to date with our latest news.



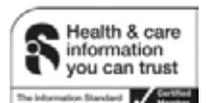
ASUK now have a dedicated You Tube page  
<http://www.youtube.com/alstromsyndromeuk>

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

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

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Thanks!