



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

Welcome to the

21st Edition

of the ASUK Newsletter

Issue 21 – Winter 2018

Welcome to the 21st edition of the ASUK Newsletter

I would like to take this opportunity to say a personal thank you to all our families, friends and supporters for their time, donations and inspiration shown throughout 2018. I would also like to extend our gratitude to the dedicated medical professionals, particularly those at the Queen Elizabeth Hospital and Birmingham Children's Hospital. The teams work tirelessly to provide support to individuals and families and to find ways to further improve treatment and minimise the impact Alström Syndrome has on people's lives.

This year we have strived to bring greater independence and empowerment to our families, more so than ever before. Through our family grants and 'Big Activity Challenge' we have helped people to have 'once in a lifetime' experiences that are often considered unachievable; such as flying a plane, abseiling and taking up piano lessons to name a few!



Ann Chivers,
Chief Executive at ASUK

2019
Happy
New
Year

The Family Gathering – Identifying the Diagnostic Journey

We are in the process of finalising a date for a family gathering in 2019 where we will focus on the 'Diagnostic Journey'. The day will be action packed and have lots of opportunities for discussion around your AS journey and how it was initially recognised; – with your help we aim to improve the rate of diagnosis.

Meanwhile, enjoy this winter update on what families have been doing over recent months and the work of the ASUK team.

On behalf of us all at ASUK I would like to wish you a very happy and healthy New Year! We look forward to seeing you all soon. Happy reading!



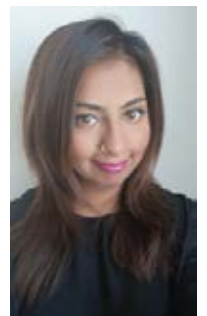
Welcome Asya and Parminder!

Please join us in welcoming Asya Choudry (pictured right) and Parminder Singh Jutla to the ASUK team.

Asya will fulfil the role of Community Engagement Manager for the Breaking down Barriers project managed by ASUK. This project involves supporting organisations to develop their capacity and outreach work within the rare disease communities. You can find out more about the project here: <http://www.alstrom.org.uk/breaking-down-barriers>

Parminder Jutla is joining the ASUK Board of Trustees. He brings extensive experience and knowledge of community development and fundraising and will be a welcome addition to the board.

Parminder pictured left in the Tough 10, 2018 Cannock Chase run in aid of Cancer Research UK.



Awareness Raising

Cardiomyopathy is one of the conditions that affects people with Alström Syndrome. National Development Manager, Kerry Leeson Beevers attended the Cardiomyopathy UK Information day to understand more about dilated and restrictive cardiomyopathy, as well as learning about new developments in research, medication and support.

The Cardiomyopathy UK charity provides lots of useful information, including fact sheets on the different types of cardiomyopathy, medication, travel and life insurance, alert cards and many other issues. For more information and guidance on living with cardiomyopathy, you can download or order their fact sheets and publications from their website:

<https://www.cardiomyopathy.org/cardiomyopathy-information/cardiomyopathy-information>.

You will also find details of other information days throughout the country that both individuals and families are welcome to attend.



The ASUK team attended the QAC Sight Village event in Birmingham in July. This was a very worthwhile and informative event for people who are visually impaired, for professionals and for organisations wishing to improve their services for the visually impaired.

More information on the QAC upcoming events can be found on their website: <http://www.qac.ac.uk/exhibitions.htm>.

A special thanks to Chris Lyon (pictured right with Carrol and Liz from ASUK) who many of you will know. Chris gave an excellent presentation about Alström Syndrome at Sight Village, talking about his lifestyle and his experience of specialist care assessments and how they can help. Chris was filmed being interviewed about Alström Syndrome – you can view this insightful short film by going to <https://vimeo.com/283655026>



Global Genes Summit 2018

ASUK along with 800 other rare disease organisations, patients and advocates attended the Global Genes Summit held in California in September 2018.

Global Genes was founded in 2008, with the goal of helping families affected by rare disease, developing resources, and much needed support, helping eliminate the challenges of rare disease. The summit took place over 2 days and provided a fantastic opportunity to collaborate with peers and mentors, and to learn from an amazing selection of inspirational speakers.

Further information and how you can get involved is available on their website <https://globalgenes.org/>



Alström Syndrome multi-disciplinary clinics - Dates for clinics in 2019

Adult clinics at the Queen Elizabeth Hospital, Birmingham

9th and 10th January 2019
27th and 28th February 2019
10th and 11th April 2019
12th and 13th June 2019
9th and 10th October 2019
13th and 14th November 2019

Children's clinics at Birmingham Children's Hospital

18th February 2019
13th May 2019
5th August 2019
11th November 2019

Outreach Clinic in Leeds

November 2019 – Exact date to be confirmed

There are details about what happens at the clinic and what to expect in the AS clinic information leaflet. You can download or read this online at: www.alstrom.org.uk/nhs-clinics/

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.

If for any reason you cannot attend please let us know as soon as possible.

If dates need to be changed we will let you know as soon as possible.

ASSAI Family Day Padua, Italy October 2018

ASUK were kindly invited by Pietro Maffei, the President of ASSAI (Association of Alström Italy) to their family day on 13th October 2018. This was a wonderful event that we feel very grateful to have been part of. It was an excellent opportunity to share some of the knowledge we have developed in the UK and provide information about our multi-disciplinary clinics. It was also helpful to meet some of the Italian AS patients and their families, and learn about their experience and how they manage day-to-day.



We listened to stories about how, despite the challenges they face, they have achieved amazing successes both from a personal and academic perspective – truly remarkable and without doubt an inspiration for us all! ASUK will keep in touch with ASSAI and continue to share information and work together to improve our knowledge and understanding of AS.



Understanding genetics together

Breaking Down Barriers Workshop September 2018

Under the leadership of Kerry Leeson-Beevers we recently met up with representatives from other member organisations, the Trustees of the Sylvia Adams Charitable Trust, clinicians, community development workers and academic researchers who all have an interest in developing supportive and inclusive services for people from ethnic minority communities.

Over the course of 2 days we explored how we can support inclusive services for all those affected by genetic conditions. This workshop is one of the many activities we have designed to share knowledge about the inequalities experienced by families in accessing mainstream services and to jointly develop strategies to address the difficulties and issues faced.



The workshop proved to be a great success and a good opportunity for us to listen and share thoughts with the people who are working so hard to make lives of others better.

Jnetics Screening Day

Asya Choudry, Breaking Down Barriers Community Engagement Manager has joined Jnetics for their screening event at Jewish Community Secondary School. This event is taking place as part of the GENeius programme, a comprehensive education and screening initiative targeting young Jewish adults which was launched by Jnetics in 2017.

GENeius aims to make Genetic Disorders education and screening standard practice in the UK in an effort to encourage people within the Jewish community to consider screening before starting a family.

Jnetics are currently working with Year 12 students in Jewish schools, Jewish University students and with couples taking part in a synagogue pre-marriage process.

We are delighted to have Jnetics as a member organisation of Breaking Down Barriers. We are very impressed with the success they have had so far and with the passion and dedication they have demonstrated in their efforts to help make a difference. You can find further information on their website www.jnetics.org/geneius/

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



Celebration Residential Weekend

Earlier in 2018, families enjoyed a weekend at the Pioneer Centre in Kidderminster funded by Children in Need. Families had the chance to catch up with old friends, meet someone new, try something new and last, but not least, relax and have fun!

Families tried abseiling, zip wiring, archery, bouncy castles, arts and crafts and high ropes. Spurred on by each other lots of Mums and Dads tried something new too!

The rain on the first morning didn't dampen spirits and the families and youngsters got stuck into fun games whilst they waited for the sun to come out! Everyone loved the outdoor activities and those that were a little apprehensive to start with soon changed their minds once they'd given it a try! As the sun went down we gathered around a campfire, ate marshmallows and sang ridiculous songs. Lots of laughter and fun was had!



This is what some of the parents and young people said:

"An opportunity to meet families in a relaxed environment, spending time with them all. The Pioneer staff were fantastic, had patience and time for the young people, gave encouragement and support but also stood back to allow for independence" (Parent)

"I enjoyed the banana song at the campfire and the banana eating competition!" (Young person)

(I enjoyed) "all of it, superb fun, enjoyed every bit!" (Parent)

The Big Activity Challenge

The Adventure starts here!

What is the Big Activity Challenge?

Are you an adult with Alström Syndrome? Do you want to try a new activity? You can apply for between £50-£500 to pay for an activity, all we ask you to do is provide some photographs and write an article for publication in the ASUK newsletter, or, if you would rather tell us about your experience, we can help you produce a podcast for the ASUK website. Who knows, you may inspire others to try out new activities too!

How you can apply!

You can find the application form on our website:

<http://www.alstrom.org.uk/asuk-big-activity-challenge/>

and send it to Catherine at Catherine.lewis@alstrom.org.uk or if you would like any further information or support completing the form you can contact her on 07970 071675.

Go on... Care to Share? - Make a Difference Today

Have you shared the Alström Syndrome awareness video? Developed by families and clinicians, it's definitely worth a share on Facebook. We can all raise awareness of this ultra-rare condition and make a difference today

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



Harrogate Horse riding

The ASUK Children in Need Project also organised a fantastic horse riding event! The young people enjoyed petting the horses and walking and trotting inside and outside in the paddock. They also had a chance to ride a mechanical horse which gave them the experience of walking, trotting and galloping!

This was followed up with rosettes to celebrate achievements! Thank you to all at the Follifoot Riding Centre – we had a wonderful time!



ASUK would also like to say a big thank you for the Children in Need funding that has helped create some wonderful activities and opportunities for young people and their families.

Over the last 3 years we have organised numerous events that have:

- Helped and encouraged youngsters to eat more healthily
- Educated young people to help them to manage the syndrome more independently which has given them much more confidence and control over their lives!
- Encouraged youngsters to make new friends helping youngsters to feel less isolated and lonely



Shop till you drop!

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 an extra penny. Have a look at our website for more details and get shopping today! <http://www.alstrom.org.uk/easy-fundraising-whilst-you-shop/>



Great News!

ASUK are very happy to announce that we have been awarded 3 more years funding from Children in Need. This is an excellent opportunity to continue to deliver fun and exciting activities for children and young people. To make best use of the funding ASUK is organising activities across three regions North, Midlands and South.

ASUK will also continue to deliver the Foodie Active Friends (FAF) Club, getting families together prior to attending the children's clinic in Birmingham.

FAF Club is a place to; socialise, develop friendships and learn more about healthy living, in a fun way. The focus of the club has changed slightly to include education and activities that concentrate on an all-round healthy lifestyle, along with developing social skills and confidence.

In September 2018, we welcomed new and current ASUK family members to the FAF Club. We were overrun with delicious 'Healthy Hedgehogs', made by young people, with help from their parents/carers and ASUK staff members. Anne Cheesbrough from SENSE, who is a wonderful friend to all the ASUK families, supported alongside John Pemberton, BCH Dietician. John also led an education session around adding as much colourful food as possible to all our meals. He also ensured we were stress free with a relaxation session that concentrated on breathing techniques.

We celebrated two birthdays: Jessica Rowlinson who is now officially a teenager and Carrol Birchall- ASUK Family Support Worker, who is just past her teenage years!



**'I was very proud of my hedgehog,
it was good to make it!'**
(young person aged 11)

**'I really like the cooking and
doing things together',**
(young person aged 13)

**'It was great fun, it really was,
I felt so comfortable with everyone -
let's do lots more things together' (Mum)**



Family Grants

'Go, go, go Adam!'

In early September ASUK gave Adam a grant to fund a very special red go cart for him to use at school where he has a large hall to peddle around in and of course outdoors, weather permitting! The go-cart has been a huge hit with Adam and it has helped him to become more mobile and active!



Simmie

Simmie is thrilled with her new talking combination microwave oven that. Take a look at the first batch of muffins she made – mmmm delicious!



Rebecca

Rebecca has also been in touch to thank us for her new Tablet computer, she is absolutely delighted with it and takes it with her everywhere!



'If I can fly a plane what else can I do?'

ASUK believes that despite the challenges that our children and young people face, given the right support they can have a go at anything they set their mind to. Flying an aeroplane is a dream that a lot of people have, being visually impaired and flying an aeroplane, well you might think that would never happen! In August 2018, funded through Children in Need, Hannah Bromley Challenor was chosen to be a pioneer for ASUK. Hannah met with the staff and pilots from Aerobility (a charity who gives disabled people an opportunity to fly an aeroplane) where she had the opportunity to try out a flight simulator, visit air traffic control and flew a four-seater Piper PA28 aeroplane. Accompanying her on the

flight was her mum Sue and the pilot Mike. Hannah took part in a 30-minute flight over the roof tops of London. It did not stop there, for several minutes Hannah also took full control of the aircraft while taking direction from Mike. Hannah is a great example of the true grit and determination that children and young people with AS display daily.

In Hannah's own words:

"Picture the scene you're going on a plane in Gatwick to your holiday destination. You are guided down the aisle to your seat and get told how to access the stuff you need in case of an accident as well as a nice staff member at the front telling you where the exits are. It's probably what most of us have at the forefront of our thoughts when you get asked about flying, or probably the second if we are reminiscing the times, we've lost our luggage. What if that stereotypical image in your head was different?

Sometimes I'm glad that I can't see, because if I could there would be times like being on top of a zip wire tower that I would freeze. You've either got the fear of everything or nothing, and if you have a moment of the later then you've got to take a leap at having a once in a life time opportunity that ASUK and Aerobility presented me to. I got the chance to fly a small aircraft, twice!

It's one of those places where everyone was so kind and made you so comfortable that even the shyest person feels like they can speak. We were shown around by Gail who introduced us to 2 guys who were actually making a small aircraft right in front of us. We also went to a separate room or small building where it was on display some names of people who fly there as well as an Olympic torch from the Paralympics. The first thing they showed us to us was a flight simulator which gives you a rough idea what you be doing in the air. I have to say even though apparently, they have good graphics this isn't helpful for someone with no sight but the real flight makes up for that, so you're not missing out on much.

Outside you can walk straight up to the plane you are flying and feel around it to get an idea of its shape. They let you walk around it until you find a part that feels like sand paper and with one foot on this surface and your hand on a small handle no bigger than one you might find on a small cupboard you have to lift yourself up onto it. You've then got to use your hands to feel the seat and once you find it you put yourself facing outwards so you can slide backwards so you can get into your seat on the far side. They will place a pair of overhead headphones on you which you can hear the radio and what other people are saying for directions. They turn a lot of corners before getting up in the air which you can definitely feel underfoot. And when you go up in the air it just feels like when you're in the car going over a hill but just a lot steeper. Once you are actually out in the open flying you feel like you are flowing with a



rocky motion. The gears you have to pull closer to you to go up and pull back to go down with going left and right, count to 3 out loud then back to the centre. It is such a smooth journey. When you do come down it is like going down invisible steps as they descend a little at a time. Would advise to eat afterwards, you don't go green but you do get headaches and stomach on the way down. The wheels hit the ground before you know it.

If I can do it again I would definitely do it and also advise others to try it. If you want to see pictures and videos of me flying you can go to my Facebook page if it helps you to decide".

ASUK is finding out more about funded flights for children and young people up to age 18. Anyone over 18 can contact Aerobility directly at www.aerobility.com, telephone 0303 303 1230. You can book flights in different parts of England. The cost varies from location to location, as each airfield charges different prices for use of the take-off/landing strip. (There is also a weight restriction, please check this when booking).

Kayleigh achieves her dream!

27-year-old Kayleigh has Alström Syndrome, she has overcome huge barriers to achieve her dream of being able to horse ride. With support from the horse riding instructors and SeeAbility Kayleigh has learned the skills necessary to overcome all the practical and safety issues to make riding accessible. Kayleigh told us about her experience:

"I really love going. I like saying hello and goodbye to my horse, Pumpkin and stroking her face and mane. I also enjoy the smells of Pumpkin, the paddock and the stables. Now I've done my level 1 & 2 rosettes, I like being able to move with the horse – I was a sack of spuds to begin with because I can't see her! Lisa is my teacher and she is very good. She has taught me all the parts of the horse and saddle I can reach and she has never taught a blind person before. Lisa talks to me constantly because I need her feedback to know I'm doing the right things. Deanne (senior in-house rehab worker) did a very good assessment and taught Lisa how to support me and help me mount and dismount. I've just bought myself a pink sparkly riding hat that fits me properly and Horseshoes Riding School put tinsel on their helmets. I'm working on my level 3 rosette now, which involves trotting and changing the reins at the same time. Pumpkin is very patient and Lisa has to trot with the horse on a lead rein."



New technology to help the visually impaired

Some of us were lucky enough to meet representatives from OrCam earlier this year. We were shown a new device called OrCam MyEye, the device has been designed to help the lives of people with a visual impairment using artificial vision. It uses a tiny camera that fits onto one arm of a pair of glasses.

Opposite the camera, a tiny speaker is positioned towards the ear and a voice speaks to the user about visual information detected by the camera. When the camera is directed at a page in a book or an email on a screen, the camera instantly "reads" the text, by converting visual information into the spoken word. Many of the visually impaired people told us how impressed they were with the technology and that they enjoyed been given the opportunity to give the device a try!

If you'd like more information on this technology, please contact us or visit the OrCam website www.orcam.com/en/



Have you seen our Family Support and Useful Resources page?

It is full of useful information, tips and useful links. We would love to hear from you if there is a topic you would like to know more about, or are an organisation with relevant information that we could link to, if you are - get in touch today!
www.alstrom.org.uk/family-support/

Educational Health Care Plan (EHCP)

What should a good EHCP contain? Does it reflect the individual? Has it achieved its purpose?

The link below is an example of what an EHCP could include - a useful resource for parents, children and young people and those supporting them.

<https://councilfordisabledchildren.org.uk/help-resources/resources/education-health-and-care-plans-examples-good-practice>



THANK YOU to Our Fantastic Fundraisers!

A HUGE THANK YOU to everyone who continued to support ASUK in 2018. The numbers of people being diagnosed with Alström Syndrome is increasing so please get in touch if you would like to arrange a fundraising event. Your kindness and fantastic fundraising efforts, really do make a huge difference to people's lives.



Well done to David Lunt (pictured left) who takes part in the Virgin London Marathon every year to raise money for a number of charities, including ASUK.

On Sunday 22nd April, David had an amazing run and despite the hot weather completed the course in 5 hours and 8 mins. Fantastic, thank you David!

A special mention goes to the Lewis family who once again have very kindly donated £65 from all the 5p's and 10p's they have saved over the last few months. This is very thoughtful of the Lewis's to consider ASUK and we are very grateful, thank you!

Bowled over by this donation!

Alström Syndrome UK would like to extend our thanks to Wickersley Cricket Club! Yet again members of the club have very kindly donated £1,916.66 to Alström Syndrome UK following a successful fundraising event. 17 year old Kion (pictured right), who is affected by Alström Syndrome accepted the donation and we are all very appreciative and grateful, THANK YOU.



130 miles to raise money for Alström Syndrome UK

Special thanks go to Hassan Hayat who is affected by Alström Syndrome. Hassan recently cycled 130 miles on a tandem from Morecambe finishing in Saltburn-by-the-Sea with Tim Curtis (who is in the GB National Squad), raising money for good causes including ASUK.

Read Hassan's personal account:

"I'm a young student from Henshaw's College in Bradford and along with a very enthusiastic sports guy called Adam Tasker I recently participated in a coast to coast bike ride. The bike ride was primarily to raise money for the AS charity, which supports people with a condition called Alström Syndrome.

I was very excited about this opportunity and I had worked with Adam Tasker in the past, so I registered immediately with little persuasion needed!



There was a fee to pay for this bike ride though, a sum of £250.00. I decided to pay this fee which covered staying at four different hotels, food, travel and petrol costs etc.

I used my own bike during this extensive bike ride and I bought my own cycling gear, I bought a t-shirt, cycling gloves and a rucksack. I already owned a helmet, so I was fine to buy the rest myself.

The night before, I packed some spare clothes for his exciting experience. I was proper excited! After finishing my studies on the 5th of June 2018 at Henshaw's College in Bradford, I then went for a hair-cut, which included a beard trim. After my hair-cut, I decided to go and see a friend and we enjoyed a tasty chicken donner meal together. Around 10:30 pm I remembered that I still had packing to do, which I got on with!

The next morning, I woke up, showered and then changed. I also woke up my dad, so that he could drive me to the centre where Adam Tasker would be waiting for me.

After loading the van with all the gear along with all the other cyclists I sat down in a hired mini-bus, setting off to Morecambe.

Two hours later, every-one made a rush for the toilets once in there. Then, we all cycled from Morecambe to Kirkby-Lonsdale. From there, we stopped for lunch, before carrying on to Kendall. On the first day there we cycled for 35 miles, a lengthy but hugely enjoyable bike ride. The plan was to stay in Kendall after the ride.

The next morning, I woke up and the van was reloaded with the bikes and equipment etc. The idea was to go on the next challenge, a bike ride from Kendall to Northumberland, which was 30 miles away. We set off at 11am and arrived around 4pm. I was quite tired, and a little peckish. We stayed over then in Northumberland, for only 1

night and had our evening meal there. We ate tons, chicken wings as a starter, and the main was fish and chips with garden peas. It was better than what we had the night before, as Adam Tasker got us all a pizza that was so horrible!

After eating, we settled down and watched a football match between England and Costa Rica, where England won, 2-0. I had a couple of J20's to celebrate England winning and Adam celebrated with a couple of beers.

The next morning, the cycling continued with extreme vigour and enthusiasm. With the vans loaded, the plans was to cycle to the Yorkshire Dales and have an overnight stay there. We had a next level pizza from an Asian takeaway and ordered from Just Eat. The other boys indulged and ordered extra chillies on theirs. After this, we all chilled out, chatting and having lots of fun on our last night.

In the morning, preparations were made for us to cycle to Saltburn, which was a 31-mile trip. We set off at 10am in the morning and got to Saltburn by 3:45 p.m. My bum was aching, my legs and back were also hurting, but it was so worth it! Great time, we hammered down on the gears all the way, every day. Just me and Tom Curtis, I was pedalling right at the front, ahead of the others. We had a lovely dinner then near a Seaside Resort, which was very tasty.

After the enjoyable meal, I felt a bit upset as I knew we were heading back to Bradford. From salty, salty Saltburn, back to miserable and cold Bradford. Everything was returned back to the shop, the Capital of Cycling and then we all returned home, after saying our long good-bye's."

The event was organised by Choices 4 All, supported by www.bradforddisabilitysports.co.uk and www.capitalofcycling.org. Thank you, Hassan!

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



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Further information about our work can be found at www.alstrom.org.uk

Meet the ASUK team



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Welcome back Catherine!

Congratulations to Catherine on the birth of her beautiful daughter Harper Grace, now 9 months old. Catherine has just returned to work and is delighted to be back! To start

with her working days will be limited to Tuesdays and Wednesdays and will be full-time from the 4th February 2019.

Catherine would like to say a HUGE THANK YOU for the kind gifts, cards and all the warm wishes she has received and is looking forward to seeing everyone in 2019!

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.



Don't Miss Our facebook Posts!

Facebook's 'EdgeRank' Algorithm is hiding posts for those who aren't willing to pay for sponsored placements!

Please visit our page follow these steps...

Step 1: click "Liked"

Step 2: click "Get Notifications"

Step 3: check "Show in News Feed"

Step 4: check "Add to Interest Lists..."

Thanks!



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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Ann Chivers,
Chief Executive at ASUK



The Family Gathering – Identifying the Diagnostic Journey

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Meanwhile, enjoy this winter update on what families have been doing over recent months and the work of the ASUK team.

On behalf of us all at ASUK I would like to wish you a very happy and healthy New Year! We look forward to seeing you all soon. Happy reading!

Welcome Asya and Parminder!

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Asya will fulfil the role of Community Engagement Manager for the Breaking down Barriers project managed by ASUK. This project involves supporting organisations to develop their capacity and outreach work within the rare disease communities. You can find out more about the project here:
<http://www.alstrom.org.uk/breaking-down-barriers>

Parminder Jutla is joining the ASUK Board of Trustees. He brings extensive experience and knowledge of community development and fundraising and will be a welcome addition to the board.

Parminder pictured left in the Tough 10, 2018 Cannock Chase run in aid of Cancer Research UK.

