



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

Winter 2019

ASUK Newsletter

Issue 23 – Winter 2019

Welcome to the 23rd edition of the ASUK Newsletter

An update from Ann Chivers, Chief Executive

With the new John Lewis Christmas advert on telly it is officially the start of our Christmas preparations! I usually cook on Christmas day but this year I don't want to spend all my time in the kitchen, time with our ever-growing family is more important. We have lots of stodgy Christmas family recipes, but this year we are trying to be as healthy and active as possible, easier said than done at Christmas! If you have some healthy recipes or tasty meals or snacks with zero sugar, please send to us to share with other families on the ASUK website.

The theme of healthy and active was threaded into this year's Family Conference. Hassan led a busy workshop telling us all about his health and fitness achievements through joining his local cycling club. I won't embarrass him by saying how much weight he has lost, but I know folk came out of his workshop inspired and determined to look at their own lifestyle and how they can exercise more and eat a healthier diet.

Alex and Haris presented their views on top gadgets, more on that on page 2, families shared their stories about their own diagnostic journey and Dr Tarek Hiwot gave an update on management and treatment. Catherine will send you the conference report, including Doctor Hiwot's slides and post onto the website along with some great photos of that graphic illustration! Meanwhile a big thank you to everyone who came and contributed to the conference and for the great feedback!

'Thank you so much for the warm welcome and wonderful information provided. Exceeded our expectations!' (Mary Ahern, family member)

Staying on the subject of healthy and active, find out what people have been up to as part of the Big Activity Challenge, from a Game of Thrones adventure in Ireland to relaxing in the Highlands. If you haven't yet applied for the activity grant talk to Carrol, Jane, Kerry, Catherine or Liz. It's quick and simple to apply and plan your 2020 adventure!

Welcome on board!

I am delighted to welcome Melissa, Sharon, Elena and Tim to the Board of ASUK. They bring with them a wealth of experience, knowledge and understanding, read more about their specialist skills and interests on page 11.

Thank you

As always a big thank you to all our families, friends and supporters for giving their time, contributing towards our fundraising campaigns and sharing their information openly in our quest to improve diagnosis.

On behalf of the team at ASUK I would also like to thank the dedicated medical and research teams; particularly those at the Birmingham Children's Hospital and the Queen Elizabeth Hospital who work tirelessly to find further treatments and minimise the impact of Alström on individuals and their loved ones.

Finally, our thoughts are with all who are coping with difficult times. Please remember that you are not alone, we are here for you. Wishing you and yours a lovely Christmas and a healthy, happy and peaceful New Year.

Best for now

Ann and the ASUK team.



Ann Chivers,
Chief Executive at ASUK

Past, Present and Future Conference 2019

Thank you to everyone who joined the Alström Community on the 19th October 2019 for the Alström Syndrome UK Past, Present and Future conference in Birmingham. Whilst the families and professionals gathered at the conference, the youngsters had a fun-filled day at Drayton Manor Theme Park.

The conference brought families together to map their diagnostic journey, with the aim to learn how they were diagnosed so we can target our future awareness campaigns to ensure families affected are diagnosed quicker. Families got together to map the diagnostic journey with the aim of learning more about the challenges and how we can improve the rate and speed of diagnosis for future generations of families. Individuals and loved ones told their stories, exchanging ideas on what helps and what hinders!

Liz Loughery, ASUK Project Manager updated families and clinicians about progress on the Alström Patient Registry. She thanked those who had contributed questions for the registry and asked for more volunteers to review the working model as soon as it's available. The hope is that by creating a registry, scientists can easily develop research projects and individuals and families can, by updating their own information annually, gain a deeper insight into Alström Syndrome. Further information about the registry can be found on our website www.alstrom.org.uk



The highlight of the day was dancing to a newly created exercise routine called 'the Stroove' this was great fun and it was fantastic to see families, the ASUK team as well as some of the Clinicians taking part and dancing along to the music!



The day included interactive workshops, we heard from:

- **Guide Dogs**
- **ASUK Members, Alex and Haris who shared their insights into some of the useful technologies and gadgets that help them in their everyday lives**
- **Hassan and Kez gave an account of their healthy lifestyle and how they keep themselves motivated**
- **Gayle from Birmingham Children's Hospital lead a yoga workshop**
- **And Kerry led an Alström workshop for new families, answering questions and introducing ASUK and how we can provide support**



Dr Tarek Hiwot presented his latest research and clinical updates and discussed future treatments, developments and the challenges faced.



Thank you to Liminal BioSciences and Rhythm Pharmaceuticals for sponsoring the event and for the kind donations from companies for our charity raffle including:

- Experience Days, who donated a £50 voucher www.experiencedays.co.uk
- West Midlands Safari Park who donated 2 tickets to their attraction
- B&Q who donated a £30 gift voucher
- The Glee Comedy Club for 2 tickets to one of their live shows

The evening entertainment saw families taking to the dancefloor to show us their moves and Mary's shock at winning the large fluffy white tiger was priceless!

Thank you to everyone who gave generously in the evening, we raised £200
We look forward to welcoming you all again, same time next year!
The full conference report can be viewed on our website.



Big Activity Challenge

You may remember in the Summer Newsletter, Curtis and Taylor were bowled over by their bowling adventure to Barbados. Now we are delighted to report on adventures in Ireland, relaxation in Scotland, feeding tigers in Kent and a fun-filled trip to watch Aladdin in London. All made possible by the Big Activity Challenge grants that ASUK give to adults with Alström.

Dreams do come true...

Kayleigh's Mum, Debbie gives a personal account of this special trip.

"It was a brilliant day for us all at the Big Cat Sanctuary. We were made very welcome by our guide Maddie, who explained everything so well and clearly to Kayleigh. Kayleigh and I both fed a male leopard called Yarko whilst his family including his 5 month old cubs looked on.

Kayleigh fed Neron a black jaguar and I fed Imara, a white lioness and Allen fed Puna, a Sumatran tiger.

We all felt nervous and excited at the same time, it was amazing to be so close and feed these amazing animals.

We had a two-hour tour and enjoyed every minute. Kayleigh has always had a love of animals' especially big cats so this really was a dream come true for her.

Many thanks to Alström Syndrome UK for making this special day possible"



A visit to Games of Thrones in Ireland – A trip of a lifetime!

A personal account from Amy



"I was full of excitement as we set off from my house on Friday 5th July for what was going to be a trip of a lifetime. The date by design being my 35th birthday. We reached the airport some time before we were due to fly. This plan was a good one as we had some fun when going through customs and then our plane was delayed twice so we arrived in Belfast later than planned. We took a taxi to

our hotel complex, unpacked and as the weather was so warm decided to take a walk through Belfast centre.

The hotel we stayed in was perfectly located right in the heart of Belfast. I was eager to explore the place I had come to as a baby but being too young could not remember. We walked through streets going all the way down to the botanical gardens which were beautiful in the warm evening sunlight. We sat by a fountain in the grounds as birds in the trees all around us sung, as the sun fell down on the 18th century glass work of the tropical plant house standing nearby.

After walking through the gardens we went all the way up to where the Ulster museum was located so that we knew where we needed to go when we would return the next day. By this time, it was getting late so we walked back through town and found a little Thai restaurant for our meal before returning to our room. I knew I would have to be up early so quickly settled down to sleep but I was too excited for the next day so it took me a long time to fall asleep.

Saturday 6th July

Originally I decided that we should use public transport to get from the hotel to the Game of Thrones site to save money but found that for an extra payment we could arrange for a door to door service on Game of Thrones transport driven by an extra from the series who would act as our guide for the entire day. I would encourage anyone coming to the tour to do this if they can, as it was an incredible edition to my journey.

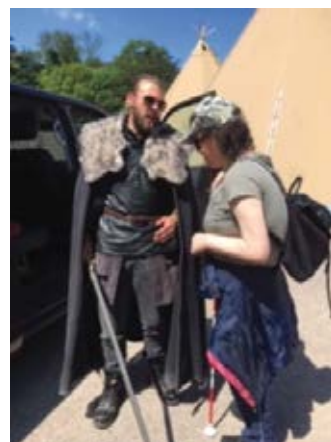
We weren't due to be picked up until 1pm so we got ready and set off to have breakfast in the nearby pub. Choosing to sample a local delicacy, I tried Irish breads and really enjoyed them.

We then had a couple of hours free so we decided to explore another section of Belfast town, that we had not had time to explore the night before.

We walked through the town and came down to a square where they had a series of street performances which they were calling a Busk-a-thon. As we were walking down Sherieda (my PA) said she could hear them playing the tune from Game of Thrones. I unfortunately could not hear this but as we entered the square I could hear them playing Christmas songs. We listened for a while before heading for more of the city. We stopped in a shopping centre where we came across a monument with tropical plants and ferns that for some absurd reason had golden sheep in the middle. We sat on the bench and stared at the flock statues in complete and utter puzzlement. We then left the area and returned to the hotel positively bursting with excitement.

When the car pulled up our guide Jamie stepped out of the car dressed all in costume despite the extreme heat of the day! He was dressed in a gambeson and leather over tunic with full trousers that he wore whilst he was an extra in the series. I am so glad I chose to have them pick us up because on the way he told us all about the places we passed on the way and lots of anecdotes about being on set.

As we came up to the castle and its grounds he also enthralled us both with tales of behind the scenes and the crew while they had been filming the series. Jamie's tales were both illuminating and truly fascinating. Once we reached our destination we rolled through the grand gates into the castle as Jamie told us of how they had changed the landscape and the troubles it had caused for him and all those on set to maintain as the series was filmed. We got out in the courtyard and this is where our actual trip began and what an experience it was!



A tour of many parts, the first was looking round the courtyard as Jamie told us about the real history of the main castle that had been used as Winterfell for the first three series. As we went around he had brought pictures of how it had looked in the series and as we moved around the buildings he explained what they had changed and why. He also explained where the green screens

had been located in order to create the special effects used in the show. Sherieda described in detail what the buildings looked like now as well as what is in the images that he was showing us.

We then moved to the next part of the tour down at another castle that was used to create the twins and the land around that was used repeatedly as several different sets throughout the many series. On the way, we passed the river which fell down to a massive salt water lock as Jamie told us how it was used in the Game of Thrones and having learned that I was also interested in ancient history told me about the many islands in the lock and the ancient history of the area which was on both counts truly illuminating.

As we arrived at the second part of the tour we walked up through a small wood in to large fields surrounding the area that was used as Robert's and Tyren's war camps in the series. Jamie explained the tricks they used to make it appear that there were hundreds of tents in the scene. For me, this was where the magic happened... I had been explaining to Jamie how things were audio described in the series and what they had chosen to and not to audio describe and he started to describe both the pictures he had brought with him and what we were looking at in contrast with deep detail. He had been listening to Sherieda describe things to me as we were going round and he naturally picked up what she was doing. Without being asked he started describing all that was around us. This just made things even more extraordinary and magical and meant that it was even more accessible for me than I could have ever imagined.

We finished this part on top of the castle that and been used to create The Twins in the series before returning back to the main castle. The next and final part of the experience which I did not think was part of our particular tour was that we got to dress up in replicas of the real costumes worn on set and then shoot on the archery range. These had been used by actors playing characters such as John Snow while actually filming the show. Despite how much audio description you get on TV it is something else entirely to actually wear clothing made using old techniques and fabrics. To actually wear them and feel what the garments feel like is a dream come true for someone like me who is a fabric crafter. As well as shooting arrows while still dressed in traditional clothes was a true experience. Our guide, Jamie aided me to fire the bow and although I was the first blind archer he had had, he was brilliant in describing what it was he was asking me to do and I had a great time on the range.

All too soon our time at Winterfell was up and because we had run well over time we did not have time to visit the souvenir shop to get mementos of our time there, this was the only disappointing part of the whole trip. I really did not want to take off the costumes or leave the place!

As we had been walking around I had been talking with our guide and found out that we had much in common as both of us had a love of all things mythological and ancient and medieval history. We were his last tour for the day and he offered to take us the long way back to the hotel so that we could drive by a large prehistoric henge that was nearby. I thought we would just drive by but instead he got me out and guided me to it and showed me a Dolmen which is an ancient structure found across Ireland. A final experience in a day that was full of unbelievable experiences. It was a day I will never forget.

Jamie dropped us back at our hotel over an hour and a half later than he should have finished work and we reluctantly said our goodbyes to the most amazing guide I've ever met. That night we went out for tea to an Indian restaurant before returning back to our room as again we would be up early the next day.

Sunday 7th July

We were up early on what was to be our last full day in Belfast. I would've loved to stay longer but as that was not possible, we woke early and set off after breakfast.

We visited the Ulster museum and the Game of Thrones tapestry which we had planned to see as part of our trip. On the way, we stopped off at the tropical plant house that was part of the Botanical gardens. Despite the heat inside being almost unbearable it was a fascinating place with a couple of tactile displays that were truly informative. A tactile display of the building that we were standing in was extremely interesting but what was very informative was a series of diagrams showing the life cycle of a fern leaf, something I had not even considered before.



Walking through the entrance way of the museum we were greeted by a magnificent recreation in willow of the throne itself with a trio of dragons created by the same craftsman hanging from the ceiling several feet above. Unfortunately, I wasn't able to get close or touch the throne as it was behind ropes. We took some time to go through the galleries dedicated to early Irish history that held several scenes of prehistoric history that was full of things I had never known and had a couple of interactive displays. I was so happy that I managed to identify the examples of fur and skin that were in one display. We progressed through the history of very early Ireland and as we moved through the displays found information about Dolmen's that we had seen the day before.

When we came into the medieval section we found information about historical characters who I had been chatting with Jamie about the day before. When we finished learning about history of the area we moved to the exhibition we had really come to see. We entered the gallery where the tapestry, a massively long piece of embroidery, had been hung. We were not allowed to take pictures in the gallery, which was a bit of a shame but understandable due to what it has been made of.

When we walked in, Sherieda scanned a barcode on her phone which meant as we walked round she was given a record of what each of the images was depicting with its place in the series along with detail of the episode and some behind the scenes information as they were filming on set. It was worth its weight in gold as Sherieda, who has not seen all the series right up to its final end in series 8 which meant she could describe what the image was depicting with greater detail and accuracy. It allowed her to tell me what was going on in each image itself in contrast with the episode that it was representing and great detail of its colour and style as we moved from image to image. The interactive addition was a brilliant idea and it not only aided Sherieda but enhanced my enjoyment of the entire tapestry. For someone who is a lover of fabrics, especially tapestries, being able to see in the flesh an example of medieval style and technique it was truly an incredible part of my trip.

When we left the museum we walked back through Belfast to shop for gifts to take back home for friends and family before returning back to our hotel, very exhausted but very satisfied. Later that evening we had tea at a very fine Japanese restaurant before coming back to our room as we had to be up at a crazy time the next day.

Monday 8th July

We left for the airport at a ridiculous hour! I was sad to be leaving Belfast, I would have loved to stay longer. When we reached the airport, our assistance on the Belfast side was far superior to Leeds Bradford, as they stayed with us the entire way until we got on the plane. This was in complete contrast to the haphazard assistance we had had through Leeds Bradford airport.

We arrived back in Leeds around midday and made our way home. We arrived to find Mum had put up a welcome home banner as she had been tracking us on the internet and knew when we would arrive.

Wow, what a trip!"



Relaxation in the Highlands

A personal account from Stephen



Majella Williams who is my Sighted Guide and myself, Stephen, kindly thank ASUK for allowing us to go to The Crieff Hydro Hotel and Spa in Crieff about 30 mins taxi ride from Perth.

The day started dramatically as my taxi broke down as I was meeting Majella in London but we just arrived at Kings Cross bang on time! We both had a wonderful time and Majella has already booked to go again with her husband Thabo - for me I can only return when I have the money, but it is hoped that will be soon.

Majella had two massages, I had four: a men's facial and head massage together on the Saturday and an all-in-one Aromatherapy and a foot massage on the Sunday.

We used the Spa pool, Jacuzzi and Sauna and the food was excellent, but I preferred The Brasserie to The Mickle Restaurant. Somehow I think both Massage and Hydrotherapy are very important to All Alström patients and am exceedingly keen to find a place where I can have a "Full body massage" once a week as it has benefited the stiffness in my body, especially my neck which has not moved properly since my neck and back surgery in 2010.



However, I may not be able to afford such massages so help from ASUK may be needed.

Also, after the facial and head massage I noticed my hearing in my right ear improve and my left eye stopped weeping. Plus, Majella said she could see my eyes for the first time as they were relaxed. She also noticed how the muscles in my legs were relaxed after a full body massage and were almost straight which I haven't been able to do for a long time. The combination of relaxation, therapies, spa, walk in the fresh Scottish countryside and lovely food and nightly entertainment made for a truly wonderful trip that I will always remember and would highly recommend for others.



Behind the scenes at Aladdin –

and sponge cakes, literally made of sponges!

John, Adam's support gives a personal account of this special trip

We became aware of the opportunity of a big activity trip and we knew it would be a chance to give Adam the experience of a lifetime.

Adam loves music, he has an incredibly eclectic taste ranging from classical to pop to fifties and sixties but one thing he does love is show tunes. He has many CD's and DVD's from both West End and Broadway shows and can often be heard singing along.



After much discussion with Adam, he decided that he wanted to see Aladdin as it has the 'vocal eyes audio description and backstage touch tour. He got very involved in planning how to get to London and the big activity funding allowed him to do everything he wanted to do. Adam asked if John and Penny could go with him on the day and as the 13th drew closer he got more and more excited.

The journey begins

We left just after 10am, driving up the M2 to Bexleyheath. Adam wanted to have an early lunch at my house so we went to the local bakers and Adam chose what he wanted for lunch. Adam loved the journey, both Penny and I provided the best audio description we could of the sites along the Thames, highlights were Tower Bridge and HMS Belfast.

Following a wander around Trafalgar Square we made our way over towards the Prince Edward Theatre in Old Compton Street. Adam was beginning to feel peckish so with a huge range of restaurants to choose from he decided on Italian.

It was only a short walk across to the theatre. The touch tour started at 5.30pm and we arrived just in time. We were shown around by a member of staff who briefed us on the tour and how it would work.



The group consisting of about 20 people (including support) who were guided backstage, down and up a couple of winding staircases until we were on the stage itself. The stage was set up with various displays each accompanied by a member of the backstage staff who provided explanations of how things worked and how they were used in the show.

The touch tour staff were very knowledgeable and extremely helpful, showing Adam the many costumes and props, his favourite had to be the swords. We laughed at one of the props; the sponge cake, which was literally made of sponges!

The touch tour finished at around 6.30pm, giving us time to pop outside for some fresh air and a quick coffee at Costa. We were back to the theatre for 7.15pm ready for the show to start at 7.30pm.

Unfortunately, you are not allowed to take pictures during a show, so we haven't been able to capture just how much Adam enjoyed the show. He was singing along throughout and the audio description really helped him enjoy the experience.

The show finished at around 10:30pm and it was 10:45 before we got out of the theatre. The original plan has been to get a tube back to the O2 but Adam was very tired, and it was incredibly busy so we decided to get a cab back.

We were back to the O2 for around 11:30 before the 90-minute drive back home. Adam got into bed about 1:15am, he was exhausted but absolutely buzzing for what he said had been, "a great day".



What a day!

The ASUK big activity challenge wanted to provide a fun filled activity or adventure, well this day certainly delivered for Adam. He had the opportunity to experience things that under normal circumstances he never could. He travelled on a water taxi and in a cab. He visited a London theatre for the first time and got to spend time on the streets of London, experiencing all the different sounds, smells and hustle and bustle. More importantly, he was able to make his own choices on all aspects of his day, where we went, how we got there and where he went to eat.

Perhaps the best indicator of the impact that the experience had on Adam was the excitement with which he explains what he did to colleagues and family. 8 weeks later and he is still talks about the trip every day!

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

If you are, 18 years old or older and have Alström syndrome, you can apply to ASUK for a small grant. 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!

Yes... you can fly!

Check this out, iFLY's indoor skydiving, which is inclusive and has accessible flying indoors for all – how fantastic! One of our members shows us how it is done!

<https://www.iflyworld.co.uk/what-is-ifly/all-abilities/>



'My Guide Dog Journey'

Following on from our Summer newsletter where we interviewed Kion and Curtis who are currently on the waiting list for a Guide Dog. Catherine Lewis had the pleasure of interviewing Alex about the ups and downs of having a Guide Dog and the difference this has made to her life.

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

Ever since I was a little girl I had wanted a Guide Dog. I hated my cane and refused to use it but I saw a having a Guide Dog as something much more appealing. Plus I liked the idea of being able to take my furry friend with me wherever I went.

What was the assessment process like?

The assessment comprises of three parts:

1. A member of my local Guide Dog team came to visit me for a general information visit. This is where you get to ask all the questions you have about potentially having a Guide Dog. It's also an opportunity for the team to begin to get to know you and whether you would be suitable for a Guide Dog
2. Mobility assessment, this is where a Mobility instructor comes to assess the level of mobility you have and to look at your long cane skills and the types of routes that you may have and want to use with a Guide Dog. It's important that you have established cane skills as you may need to fall back on these if your dog is ill and cannot work. Also it is important that you have enough routes to give a dog enough work to do. If either of these areas are weak the Mobility Instructor can work to build these with you before you move on to the next stage of the assessment.
3. Guide Dog Assessment, this is carried out by a Guide Dog Mobility Instructor (GDMI) and is more focused around your requirements of a dog and your lifestyle, situation and circumstances. You do a short handled walk; where the GDMI pretends to be the dog, using a Guide Dog harness this is to assess your walking speed and tension you need through the handle to be able to follow a dog.
4. At the end of this visit the GDMI will give you some inclination of whether they believe you will be a good applicant for a Guide Dog. The GDMI then has to go away and have a meeting with the rest of the team before you get a call to say whether or not you've been accepted onto the waiting list.

Did they explain if you can choose your own dog and what makes a good Guide Dog partnership?

You cannot choose your own Guide Dog. This is not how the process works. The Guide Dog comes to their owners usually between 18 months old and 2 years and is trained in how to guide someone already. So, you would not be able to choose your own dog for this reason.



When you have your Guide Dog assessment you are asked dog specific questions about your preferences e.g. gender, coat colour, breed, you can have preferences and some Guide Dog Owners do. However, Guide Dogs already factor in many lifestyle and circumstantial criteria to match the dog as closely with the owners' lifestyle and work load, so by specifying these characteristics you are likely to often wait longer for a dog.

A good partnership comes from hard work between you and the dog to build a strong and solid bond, based on trust and understanding. A good partnership can take up to a year to become solid.

When did you first receive your new furry friend, was this a long wait?

I first met my new Guide Dog Unique (pictured below) on 31st October, after receiving a call a week before from a GDMI saying they may have a possible match for me. I got a little information on the phone about her name, age and breed but had to wait until Halloween to meet her and find out more.

My first Guide Dog Lilly had officially retired on 1st May 2019 and so I have spent 5 months without a dog, having to revert back to my long cane. Unique came to live with me and we began training together on 11th November 2019.

Could you tell us a bit about the training process with Lilly and how long did this take?

When you train with a Guide Dog, usually you will go 'on class' which involves staying at a hotel for 2 weeks with 3 to 4 other people who are also training with their new dogs. When it came to training with Lilly there wasn't anyone else training at this time, being just 18, it was decided that I would train at home. Lilly was brought to live with me and we started training on 6th April 2010. A GDMI came to our house for the next two weeks to teach me how to work Lilly and learn the guiding commands, how to put her harness and other equipment on, also how to look after her, feed her, groom her and take her for free runs; where she gets to play and run free. We learnt extremely quickly together and she had an incredible memory for routes. A Guide Dog has to be taught the routes their owner uses and how to keep them safe on these routes. When training it is the GDMI's job to keep the pair safe until the dog has remembered the route and give advice on the best places to cross road etc.

I qualified with Lilly in just under the two weeks and we became a partnership starting our journey which would span the next 9 years.



What has your journey with Lilly been like?

My journey with Lilly has been incredible, she gave me the freedom and independence I had craved for a long time. She enabled me to move around safely and to let my family and friends be just that, rather than having to guide me or keep me safe.



When we were paired I was in my last year at sixth form in a secondary school, afterwards we went on to spend a number of years at college where I had many academic successes, she has been my shadow through everything I've done in these past 9 years. We moved into our first independent home together in 2013, she has enabled me to go horse riding, cycling and walking; by giving me a means of safely getting places, but also giving me confidence to try new things. She has supported me through family passing away, new babies in the family, new jobs and new environments, none of which I could have done without her. She is not only my guide but she is my best friend, my emotional support and confidence giver.

Guide Dogs usually work for around 7 to 9 years. They are usually approaching 2 years old when they are matched with an owner and retired between the ages of 8 and 10 depending on health and ability to continue to work. I was very lucky that Lilly had been extremely healthy during her working life and still wanted to continue to work until she reached 11. On 1st May 2019, Lilly retired and hung up her harness for good.

Once Lilly had retired was she still able to live with you?

I'm extremely lucky that I'm in a supported position where I've been able to keep Lilly as my pet dog whilst waiting for and now training with a new Guide Dog. Lilly will continue to live out her retirement with us.

Sadly, not all Guide Dog Owners are in this position so some have to rehome their previous Guide Dog when their new one comes along. They can nominate a friend or family member to adopt their dog or they are often offered back to their puppy walkers; the individual family who raise the puppies for the first year of their life before they going into training at about 14 months old. If there is not anyone in a position to take the retired dog, there is a list that Guide Dogs hold which has people who would like a retired dog.

How long did you have to wait for a new Guide Dog once Lilly had retired?

I was extremely lucky and only had to wait 5 and a half months without a dog.

Tell us all about 'Unique'?

Unique or Uni as we call her for short is an 18-month-old Labrador cross golden retriever. She was puppy walked in Dartford in Kent and they trained in Maidstone Kent for 4 – 6 months before she came to me.

She is a lively puppy who loves to work, but is still a little head shy about putting her harness on. That's something we must work on, but once it's on she is loving working. She is coping well with a difficult working environment. Whitstable where we live has lots of narrow streets, people and a lot of pavement furniture as we call it; A Frame signs, table and chairs, and other things that clutter the pavement. She is learning quickly and I feel we'll be a very compatible partnership.

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

Guide Dogs are taught from a young age to go to toilet on command. There is a specific word you use and they know that's when they must go and do their business.

There are currently 5,000 Guide Dog partnerships in the UK.

Not all Guide Dogs are Labradors. 65% are Labrador cross Golden Retrievers, but there are also pure Labrador and pure Golden Retrievers used as well as some German Shepherds and German Shepard cross Golden Retrievers used too. There is also a ranger of colours used such as yellow, black and brown. There are only 9 chocolate Labrador Guide Dogs as these are often not suitable to become Guide Dogs.

What does having a Guide Dog mean to you?

Having a Guide Dog means that I can be free and independent. I don't have to rely on anyone else to keep me safe. I can go out by myself and not need anyone else to take me. I also get to take my best friend everywhere I go and this gives me comfort, security and emotional support too. I feel extremely vulnerable using a long cane and often endure a lot of abuse and nastiness from people, I encounter none of this with a Guide Dog. I feel whole when I have a Guide Dog by my side.

Further interviews and information can be found on the ASUK website.

#LoveMyCane campaign

Chris Styles, Mentor Project Officer from the 'Look' charity, is on a mission to get everyone to love their cane. In his blog he describes how he had to come to terms with using his cane and initially feeling embarrassed by it, but he overcame this to realise the difference it makes to his life. Rather than feeling ashamed he now feels empowered. He is on a mission to get everyone who uses a cane to upload their stories, their struggles and their cane journey in the hope it will inspire others.

On the Look website you can check out other people who have uploaded their stories, videos and information about how they love their cane and making it socially accepted

<https://www.look-uk.org/love-my-cane/>

Alström multi-disciplinary clinic dates in 2020

Children's clinics - at Birmingham Children's Hospital

- 20th January 2020
- 20th April 2020
- 20th July 2020
- 19th October 2020

Please get in touch if you would like further information.

Adult clinics - at the Queen Elizabeth Hospital, Birmingham

- 8th and 9th January 2020
- 26th and 27th February 2020
- 18th and 19th March 2020 (Transfer clinic)
- 15th and 16th April 2020
- 10th and 11th June 2020
- 14th and 15th October 2020
- 11th and 12th November 2020

The outreach clinic in Leeds is usually in November. We will let you know as soon as we have an exact date confirmed.

ASUK will be in touch with individual families prior to the clinic they are due to attend. Should dates need to be altered for any reason then we will inform you as soon as we can. If for any reason you cannot attend your allotted clinic then please let us know as soon as possible.

Travel News! Let's make everywhere accessible for all

Electric cars must make noise by 2021

New regulations mean all electric cars must produce an engine sound.

From 1 July 2019, all manufacturers must install a system in new types of quiet electric and hybrid electric vehicles. Sound generators will produce a specified level of noise when they are reversing or running below 20 km/h (about 12mph). The sound generated will be similar to that made by a conventional engine and can be temporarily deactivated by the driver if judged necessary. The new regulation to make acoustic systems within electric vehicles compulsory will allow those who are visually impaired to hear vehicles more easily.

Green transport is a step in the right direction for cleaner air and reducing pollution but the potential hazards posed by quiet electric vehicles, especially for people with visual impairment must be taken into account. The regulation will apply to all new types of 'quiet' electric and hybrid vehicles from 1 July 2019, and to all new quiet electric and hybrid vehicles registered from July 2021.

It would be better if it was sooner than 2021, but at least it is a step in the right direction. This is welcomed news especially for people affected by visual impairment and hearing impairment but for all road users it's good news, accessibility for all...

Pavement parking

We often hear how accessibility problems can hinder people with disabilities, whether this is not being allowed into a restaurant due to having a guide dog or not being able to get around freely, or feeling unsafe due to shared spaces or vehicles parked on pavements.

We were pleased to hear that the Transport Committee have just published a report which recommends that all pavement parking should be banned across England. As well as recommending an awareness campaign to highlight the negative impact pavement parking can have on our society. This can lead to isolation and dangerous situations where people who are affected by disabilities are having to navigate the road to go around these vehicles.

The problem of pavement parking concerns many disabled people as not being able to use pavements because of motorists parking on the kerb hinders people's mobility. Not only does pavement parking force wheelchair and scooter users onto the road, but it also causes problems

for blind and visually impaired people who don't expect a vehicle to be parked in their path. The problem of pavement parking is certainly not new and a campaign was launched in 1979 by the National Federation of the Blind called "Give Us Back Our Pavements". Despite this campaign the problem has not been resolved and many disability groups continue to raise awareness of this issue.

The Road Traffic Act 1988 states that In England and Wales it is illegal to drive on pavements and footpaths, and in London, parking partly or wholly on the footway is prohibited.

The Department for Transport is currently conducting research into pavement parking; looking at its impact, councils' existing powers, and potential solutions including a new law.

Hazardous shared spaces

Shared space, also known as shared surfaces, is a design approach used by local authorities which is intended to improve the urban environment for everyone. In these 'shared spaces' the physical divides between the footways and the roads are reduced or removed altogether, meaning pedestrians, cyclists and vehicles all have to share the space.

Shared space aims to slow down traffic, reduce accidents and make an urban space more flexible and attractive for everyone. However, can you imagine if you can't see? The shared space design often means the removal of detectable kerbs, tactile pavement markings and signal-controlled crossings, which are really important for navigation, accessibility, inclusion and safety for people affected by disabilities, in particular visual impairment.

We're concerned that shared space schemes don't make streets safer and more accessible for blind and partially sighted people, they make it worse. The Government have decided to halt any further developments of shared schemes until these concerns have been addressed, but what about the existing schemes? All areas should be accessible for all and no one should feel isolated in their home due to their environment, whether this is obstacles posed by cars, hazardous schemes or quiet vehicles.

Take action – why not write to your local MP and local authority to see their approaches and actions on the shared schemes and pavement parking in your local area. ASUK are more than happy to support you with this if needed.

Sight Village - time to raise awareness

The Queen Elizabeth Sight Village Central event took place on the 9th and 10th July 2019. This free event provides lots of technology, equipment and support information for everyone affected by a visual impairment.

ASUK attended with an information stand and led a discussion on transition. Where people could talk about their experiences of what helps and what hinders?



Such as (above photos left to right) Sue and Mike from Guide Dogs, Traveleyes, Aneeba from Bardet Biedl Syndrome, Colin and Woody from the Macular Society, and Jody from Wolfram meeting up with Kerry and Liz.

Introducing some new faces

You may remember back in the spring we had a recruitment drive for new Trustees to join the Board of ASUK. We are very pleased to announce we have recruited not, one or two, but four new Trustees; Melissa Crowland, Dr Elena Riva, Sharon Bates and Professor Tim Barrett. They all bring a wealth of knowledge and experience to ASUK and they look forward to meeting you at our next event.

"I was diagnosed with Alström Syndrome when I was 26 years old, and it has been a really interesting time getting to know the ins and outs of the syndrome.



I have a bachelor's degree in applied social sciences and a Master's degree in social work. My passion is for raising awareness and promoting equality, this coupled with my studies and new diagnosis have made me extremely excited to join the Board of Trustees and further the cause of Alström Syndrome. In the future, I look forward to getting to know more families and raising awareness for both present and future generations." *Melissa*



"I am the Director of Studies at the University of Warwick Institute For Advanced Teaching and Learning. I have a background as medicinal chemist and chemical biologist. I have been successful in securing national funding to support my diverse research: from antibiotic research to students' wellbeing and global challenges such as the positioning of the 'genetic discourse'. Outputs of my projects have been disseminated widely, both via academic publications and public engagement events.

One of my great research passions is the social impact of Genetics technologies and discoveries. In this context, I teach the undergraduate module 'Genetics: Science and Society', where students from a variety of disciplinary backgrounds, familiarise themselves with the scientific, ethical, societal and legislative debates around genetics technologies, but also around the concepts of identity, disability, equality, and disabled rights.

My drive and passion is championing the rights of people with disabilities, I develop opportunities to create awareness of this amongst students and the general public. I am looking forward to contributing to the board of ASUK and working for and with people with Alström syndrome." *Elena*

"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." *Sharon*

Prof. Tim Barrett is the Paediatric Clinical Lead for the Alström Service at Birmingham Children's Hospital and a Professor of Paediatrics at the University of Birmingham, Honorary Consultant in Paediatric Endocrinology and Diabetes, and Programme Director for the Wellcome Trust Clinical Research Facility at the Birmingham Children's Hospital. Tim has been involved in delivering the AS clinical service for many years and has a wealth of knowledge, expertise and experience of this ultra-rare complex condition.



Ditch those Christmas cards and bring joyful tidings to ASUK

*From our house to yours we usually send cards.
Sending Seasons Greetings to those we hold dear.
But don't be offended when we say we're not sending cards this year.*

*See the cost of cards and the postage
for something that'll go in the trash.
We hope you'll support us when we say
that ASUK will instead get the cash.*



We would like to say a HUGE thank you to all our supporters who over the last few years have chosen not to send Christmas cards and donate to ASUK instead. These donations are very much appreciated and help to improve the lives of those affected by Alström Syndrome. If you would like to donate too it is an easy and safe process through our dedicated Just Giving website page; <https://www.justgiving.com/alstromsyndromeuk>

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/>

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

Please get in touch if you have any articles or suggestions for our next edition, Catherine is looking forward to hearing from you!
Her email address is Catherine.lewis@alstrom.org.uk, please ensure all your ideas and suggestions are sent in by the end of June 2020.

Meet the ASUK team



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Alström Syndrome UK
Strength for today, hope for the future

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](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!

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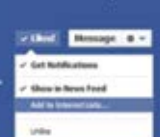
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Thanks!