



Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK (ASUK) is a charity who provide information, support and advice for individuals affected, their families and carers and professionals. Alström Syndrome is a very rare genetic condition which can cause progressive blindness, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very difficult. Our mission is to raise awareness, conduct pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics. Further information about our work can be found at www.alstrom.org.uk



Welcome to the Summer 2021 ASUK Newsletter

An update from Ann Chivers, Chief Executive

Well at last summer is finally here!

Time for picnicking in gardens and parks. The team here at ASUK got a little overexcited and have sent out picnic bags, activity packs and vouchers to families to enjoy in gardens and parks. The lovely Macy (pictured bottom of page) couldn't wait to unwrap their picnic pack, and had their first picnic adventure of the season indoors!



Ann Chivers, Chief Executive



Henry (pictured left) and his family were over the moon to receive their parcel...

“Thank you so much for the picnic pack, it felt like Christmas morning when all the parcels arrived! Henry and his brother had enormous fun opening everything and setting up a temporary camp in the living room!! This half term we went away in our caravan and took Henry's new supplies with us, he had so much fun eating his breakfast in his very own tent, and we took the picnic rucksack down to a nearby reservoir to enjoy some lunch by the water. Thank you also for the Asda voucher which I will use to get some healthy food for our next adventure.”

Talking of adventures, as you turn the page you will read about an inspirational young man who has conquered a mountain having just completed a walk-up Ben Nevis – what an achievement!!

We hope you enjoyed the AS Global conference in December last year as much as we did, bringing people from 23 countries together was incredible and we hope to do it again the same time this year, so we hope you can join us for this special event on **Saturday 4th December 2021**.

As lockdown restrictions ease, many of us are still feeling anxious, and will remain cautious. There are some top tips from the charity Rareminds on how to manage anxiety on page 9.

Welcome on board!

I am delighted to welcome Vanessa, Cathy and Derek to the team at ASUK. Under Kerry's leadership they will be driving forward the Breaking Down Barriers project. They bring a wealth of knowledge and experience, you can read more about them on page 10.

We say a fond farewell to Liz Wadsworth who has been part of the AS Clinics for many years as our clinic coordinator, we wish her well in her new adventures as she retires. Also fond farewells, to our Psychology team at both the Queen Elizabeth and Birmingham Women and Children's Hospital. We wish you the best and would like to say a huge thank you from all at ASUK!

We would like to welcome on-board Kelly Watkins who will be the new clinic coordinator for the adult service. We also welcome back Lindsay Wilson as the clinic coordinator for the children and young people's service and say another huge thank you to Conor McElroy for stepping into Lindsay's shoes to cover maternity leave. We look forward to working with you and hopefully getting our face to face clinics back up and running again.

Thank you

Thank you to all those through lock-down who have kindly taken the time to complete the patient registry. The aim is to build a bank of knowledge and information about Alström Syndrome, that we hope will benefit people with Alström now and in the future. If you haven't completed yours yet, then please take this time to complete your information.

As always, a big thank you to all our families, friends, and supporters for giving their time, contributing towards fundraising campaigns and sharing their own personal stories.



Best for now
Ann
Ann Chivers
Chief Executive

Aiming High!!

Hassan has recently graduated from Henshaws College in Harrogate.

Hassan is always looking for his next adventure and over 2 years ago, when he heard about an expedition to the top of Ben Nevis from Bradford Students Central, he accepted the challenge without a second thought.

“I knew it would be a tough one and I would need to be in peak fitness to achieve this difficult challenge.”

Even though Hassan was studying at Henshaws, with support from his personal assistant, he embarked upon a daily regime of exercising at the gym, cycling and walking to build up his fitness levels.

Hassan embarked on 3 gruelling hikes in preparation. The first hike was to walk up the Stepping Stones in Settle where Hassan injured his leg. On this occasion, he ended up receiving treatment at the A & E department, but this did not deter Hassan. The next hike was for Hassan to climb Skiddaw in the Lake District and lastly, a climb up Ingleborough Falls. This alone is a fantastic achievement for any adult to attempt however, Hassan was determined to get to the top of Ben Nevis.

The trek was postponed during the pandemic and although this was disappointing for all at Bradford Student Central, Hassan decided that he would continue training. During this time, Hassan took up the ‘50 stairs challenge’ and every day he climbed 50 flights of his stairs, all whilst continuing to raise funds for our NHS.

“When the day finally arrived, I was so excited. Having travelled to Scotland the day before, I set off with my student group. The journey began at 6.30 in the morning, the air was still and cool. It was a long hard climb and after a touch of cramp, I reached the top of Ben Nevis at 3.05 in the afternoon. I was only one of three severely sight-impaired adults that had reached the top. I was overjoyed, it was the best feeling in the world. After a short rest, we made the long trek back down the mountain where I reached the bottom at 11pm.”

Hassan has raised £1,000 for the NHS.

Hassan said he felt a few aches the following day but was soon up and about and heading back to the gym.

With restrictions lifting, the student group were able to celebrate their achievements together with a picnic in Bingley followed by a night of dancing in a Bradford night club!

Hassan aspires to own his own gym and is currently starting work placement in a gym to achieve this aim.

Hassan enjoys an active life and next he is off to Carfest for another adventure.

Well done Hassan. You are a truly remarkable young man!!



Adversity reigns!! By Lexi

Well, what a year 2020 was, a worldwide pandemic, shielding, panic buying, face masks, vaccinations and craziness. A year where I postponed my wedding, not once but twice, stayed inside my house for over a year – other than the occasional walk at 6am in the woods, where I could guarantee no other humans – was matched to a new guide dog, had riding competitions cancelled and oh yes, caught Covid-19.

After a year of shielding from this wretched virus I became infected and tested positive just after Christmas 2020. On 31st December, I was admitted to hospital for the duration of one month, where I received care and treatment for my Covid-19 symptoms. Upon returning home, I was extremely weak, mobility was difficult and slow, and it took all my energy just to do normal tasks that I would have done with ease before. Slowly I'm recovering, however it is taking a very long time to regain strength and energy.

Before the pandemic, I received funding from the Adult Empowerment Grant, provided for adult AS patients to organise and participate in an activity that challenged them in some way. I have always been passionate about horse riding, however I wanted to challenge myself by entering a dressage competition. I have always thought as a blind rider that dressage would be impossible to achieve as all the movements you perform with your horse, have to be accurate, precise and at specific points within the arena. I believed this was something I'd never achieve and have been told as much by others in the past. In September 2019, I started riding at a new Riding centre and after a series of conversations my instructor said she believed I could become a dressage rider.

The lessons were quite expensive, so I applied to ASUK under their Empowerment Grant scheme and received £500 to achieve my goal.

I started training as a dressage rider from December 2019. I had to work on my accuracy within the arena, my straight lines, and circles as these were all things that I would have to perform precisely for the test. I was fortunate enough to ride an experienced dressage horse, who was extremely helpful and boosted my confidence.

The plan was, that in May 2020 I would enter the Riding for the Disabled Association (RDA) Regional Qualifiers 2020. The RDA run groups for children and adults who have any disability, the opportunity to ride horses and build skills, confidence and relationships with others. They hold competitions for all different disciplines within riding, such as dressage and show jumping as well as carriage driving and vaulting. The dressage competition was to be held at Hicksted. If I did well and scored highly I would then progress onto the National championships. However, the pandemic threw a huge spanner in the works, by March 2020 all competitions were cancelled. I was disappointed but took this as an opportunity to practise and train more. I couldn't ride whilst the country was in lockdown and this made me extremely sad and depressed. I use my riding not only as physical exercise, but also for my mental wellbeing. The longer I couldn't interact with horses the worse my mental health became.

Thankfully in September 2020, the stables opened again, and I was able to ride. The elation I felt was euphoric and I was eager to progress with my challenge. However, with all competitions cancelled, I didn't think I would achieve this. I continued my riding and was just hoping that competitions would happen in 2021.

Christmas 2020 came, and the country went back into lockdown. I went into hospital and when I came home, I could barely walk, let alone ride a horse. It wasn't until March 2021 that I felt strong enough to attempt getting back on my horse. I had built up a strong bond with my 15.2HH black and white cob horse called Bomber and whilst I was eager to get back on, I wasn't sure I'd physically be able to. My physical and mental health were both at an all-time low and I felt that I needed to push myself to continue to get better. I felt that if I could get on my horse again, everything would eventually be ok.

The short story is that I did it. I got on, walked around for a bit and then had a little trot on both reins. I was amazed that I could still ride and actually I could ride better than I could walk at this time. I felt whole again and was able, over the coming weeks and months, to use riding as a benchmark to the progress I was making.

During one riding session my coach announced she had some exciting news. The RDA weren't going to open for normal competitions, but they were going to try something new and put all the competitions online. We had to film my tests at the stables and then send it off to be judged. I was extremely excited about this, however the filming needed to take place in June and we were already in April. I didn't feel I had very long to get ready, however my coach believed I could do it.

After weeks of practising for weeks and weeks, competition day arrived. I'd spent £400 on my training but had kept £100 spare to buy a show jacket and white jodhpurs which I had to wear for the competition. I arrived at the stables early and got my horse Bomber competition ready. With the help of some of the staff, we platted Bomber's mane and tail, gave him a bath and brushed him all over. He looked very handsome once complete; it was time to ride. Feeling mostly excited but a little nervous too, I mounted and rode into the arena. We warmed up and then we were ready to film. I rode the test twice, so I had two videos to choose between. After I'd finished, I felt elated and extremely pleased with Bomber. I felt that we had ridden the test better in a few training sessions, but everyone was very pleased with us both and said we rode a very accurate test. Then the torture began, as we had to select the film, send it off and wait for the results.

Almost a month went past but, on the 12th July, I received my results. I'd scored a lot higher than I ever expected. I scored 71.76%, I won my class and I had been selected to progress on to compete in the National Championships, which are to be held virtually in September 2021.

So, my challenge was a huge success!! I have achieved more than I ever thought I would. All I wanted was to enter a competition and have the experience of doing so. I never thought I'd be any good and I never thought I'd win. It has shown me that with hard work, even in adversity of illness, world pandemics and disability, if you want something bad enough, with a little hard work and support from others, **we can achieve anything!**



Let's Bring the Global Community Together

This year's conference was somewhat different to the usual face to face gathering and networking, that the Alström Community enjoy so much. Due to the pandemic, this year the Alström community joined together at the first virtual global conference.

Our aim was not only to bring the community together but provide a global insight through presentations from researchers, clinicians, and families from all over the world.



183 attendees

From **23** Countries



15 Presenters

7 Family 'experts by experience' speakers



4 Interactive workshops

13 Hours of collaborating knowledge & experience

100%

Would attend another AS Global Conference



9/10

Average score for how much you enjoyed the conference

Global Science and Research Day 1

The Scientific Symposium began with a look at research and clinical insights from **Qianwen Zhang and Dr Xiumin Wang**, Chief of Department of Endocrinology, Genetics and Metabolism at the Shanghai Children's Medical Centre in **China**. Qianwen explained about their work and how they have found 57 patients in China, mostly under 18's.

This presentation was followed by **Dr Vincent Marion**, Team Leader at National Institute for Health and Medical Research Hôpitaux Universitaires de Strasbourg, **France** who talked about current research developments. Dr Marion gave an insight into their current academic research looking at the gene identifications and clinical studies. Explaining the pathological make-up and the importance of gene coding. This coding can mean symptoms can be targeted and managed through specific treatments.

Dr Rob Semple, Chair of Translational Molecular Medicine Centre for Cardiovascular Science from the University of **Edinburgh**, gave an insight into the research study he is starting which is beginning to look at the role unhealthy fat tissue plays in diabetes, heart, and liver problems, seen in AS patients.

AS clinical expert's **Dr Tarek Hiwot** and **Prof. Tim Barrett** from the UK and **Prof. Pietro Maffei** from **Italy**, gave their overview of the recently updated clinical guidelines and their use in the treatment and management of Alström.

Marina Valenti, AS Italian Association and European Reference Network Patient Representative, **Italy**. Marina joined us from the AS Italian Association in Italy, to update us about the European Reference Networks. Marina gave an overview of why ERN's are important as no Country alone has the knowledge and expertise to treat rare and complex conditions. Working together in this way, ensures patients have access to the best expertise available. ASSAI and ASUK were pleased to have worked together on the Early Years research project.

Kerry Leeson-Beevers, National Development Manager from ASUK provided an insight into the AS multi-disciplinary specialised clinics in the **UK**. Explaining how throughout the pandemic clinics have continued as tele-medicine clinics, enabling patients and families to meet with the AS Clinicians virtually, maintaining regular health checks.

AS Global Conference, Living Well—Day 2

The second day began with **Robin Marshall**, Alström Syndrome International's Executive Director, who reflected on the journey of Alström over the years. The collaboration between organisations and research initiatives which were developed by his late wife, Jan Marshall whose passion to help and support the AS community has driven this research forward.

We all took a moment to reflect and remember all those we have loved and lost along the way.

Ann Chivers, ASUK Chief Executive chaired the conference and began by giving a brief update about the Scientific Symposium from the day before. Ann highlighted the focus of day 2, which was on health and wellbeing and emphasised the need for the Alström community to work together to learn from each other and share knowledge and experience. Ann encouraged everyone to complete the **AS patient registry** to help inform researchers of the global picture of Alström Syndrome.

The scientific presentations can be found on the ASUK website <http://www.alstrom.org.uk/ASUK-conference/>

The first sessions of day two centred around Covid-19. **Dr Tarek Hiwot** and **Prof. Tim Barrett**, AS Clinical Leads from Birmingham NHS Trusts, joined us to give their observations of Covid-19 from their experience and what they have encountered in their clinical practice. Dr Hiwot, reminded us that we are all new to this virus but the scientific community and Clinicians are learning about the virus at an accelerated rate. The main risk factor in adults is age but also obesity, heart disease, diabetes and people who have serious underlying health conditions, this makes adults with AS clinically extremely vulnerable.



Prof. Barrett explained that the main risk factors for children are those, who have received a solid organ transplant and taking immunosuppressant medication, children undergoing cancer treatment, those affected by severe asthma or chest infections and those with severe disease such as severe kidney disease. For children in the UK, the current information is more reassuring, even with underlying health conditions, children have recovered well from Covid-19. The benefit of attending school outweighs the risk of getting Covid-19.

Both clinicians said how reassuring it is that vaccines are now available, and AS patients in the UK should be in one of the priority groups, but we need to be led by the UK Government on this.

Dr Rick Steeds, AS Adult Cardiac Consultant, from University Hospital Birmingham, highlighted how you can keep your heart healthy; how following a healthy balanced diet and taking regular exercise, can help.

AS is linked to fibrosis in the heart, which can also be attributed to other lifestyle factors such as smoking and following an unhealthy diet with no exercise.

Dr Steeds emphasised that just 15 minutes of regular exercise a day, alongside a healthy diet can help keep you and your heart healthy.

Sarah Turner, Assistant Psychologist, from Birmingham Women's and Children's NHS Foundation Trust, spoke about how to keep our minds healthy; setting ourselves achievable goals and a schedule of the things we like to do, against those we must do. Reminding us to keep an eye on our mood and try to be kind to ourselves through these very difficult times.

Staying on the healthy theme, **Catarina Leal**, Paediatric Diabetes Dietitian from Birmingham Women's and Children's NHS Foundation Trust, presented **'Live Life on the Veg!'** explaining how important a healthy balanced diet is to our overall health, including controlling our weight, diabetes and blood pressure. Catarina told us about healthy snacks and ways to exercise to support our overall wellbeing.

Robin Watts, International Safeguarding Expert and Trainer, gave his overview of how we can keep ourselves safe online. Reminding us, that we should think before we share anything and be aware of how to keep our information safe, through strong, unique passwords and checking our privacy settings.

The rest of the afternoon had us all glued to our screens, with members of the AS community sharing their insights and experiences.

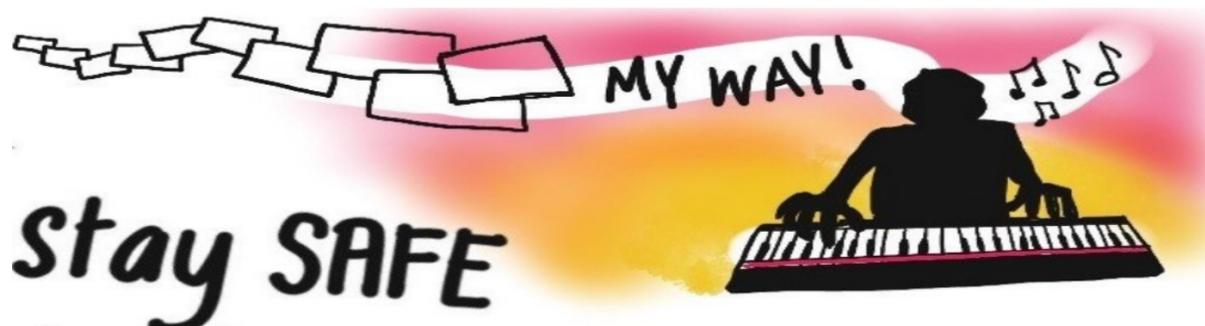
Lexi shared her insights into useful technologies and gadgets that support her to live independently. Lexi explained that above and beyond all the technology and gadgets in the world, her guide dog 'Uni' is her number 1 support, that she wouldn't be without.

Jamie, from America began by describing her personal perspective of her Journey to Independence.

Jamie reminded us to **"find something you love to do and do it. For me, it is playing something that has 88 keys some black and some white also known as the piano. For you, it could be reading, making pottery, playing an instrument, or watching college football. This Syndrome is rough, and we need something we can turn to when times get tough."**

Interactive Workshops

The conference concluded with attendees heading off into separate virtual rooms. ASUK Senior Family Support Worker Carrol and her son Chris, told us about useful kitchen gadgets, ASUK Trustees, Lexi and Melissa gave their insights into growing up with AS and answered parent's questions and ASUK National Development Manager, Kerry explored the support and information available for those families and individuals who have been recently diagnosed.



I did it my way!

The conference concluded with an emotional display of family photos from around the world, whilst Jamie played her piano rendition of 'My Way'.

Concluding points and next steps...

- ⇒ Stay in touch
- ⇒ Join the Patient Registry
- ⇒ Join the AS campaigns
- ⇒ Fundraise for ASUK so we can do this again!
- ⇒ Join us for the next Global Conference on **Saturday 4th December 2021**

Thank you

The board of Trustees and the team at ASUK, would like to say a HUGE THANK YOU to everyone who joined the conference. Thank you to those who shared their knowledge and their lived experience of Alström, offering insights and understanding to help us know more.

A big thank you to all the presenters; for giving their time so generously and making this a truly memorable event. See you at the next one!

Why not listen again? — you can find further information, including the conference recordings on the ASUK website: <http://www.alstrom.org.uk/ASUK-conference/>

"Thank you for all your hard work, not only to enable the conference, but to be a source of information and support for Alström families!!!"

We loved it all from listening to the Doctor's and Dietician to listening to Lexi and Jamie."



**Save
the
Date!**

**Join us for the next AS Global Virtual
Conference**

**Bringing families and professionals
from around the global together
for this special event!**

Saturday 4th December 2021

AS Global Conference



The time is now!

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

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

You have the potential to make a real difference to everyone living with Alström now and in the future.

How to join?

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

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

Don't delay, enrol TODAY!

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

The new virtual world

ASUK have worked with NHS Trusts in Birmingham to ensure the AS experts can still monitor the health of patients remotely during the pandemic. This has included telemedicine clinics where professionals from the AS multi-disciplinary clinics are on hand to answer any queries and monitor patients' health virtually.



In December 2020, patients were sent home monitoring equipment, such as weighing scales, blood pressure monitors and a tape measure to help patients to keep track of their own health. The packs contained information on how to use the equipment and demonstration links.

Health Monitoring Equipment Instructions and monitoring sheets can be downloaded from the ASUK website. Alongside a video of how to use the equipment <http://www.alstrom.org.uk/nhs-clinics/#HomeMonitoring>

Going forward and with strict restrictions in place the AS multi-disciplinary clinics have started to resume face to face clinics.

One of the first clinics to resume was the transfer clinic, for those moving from Paediatric services across to the Adult services at the Queen Elizabeth Hospital. ASUK Transition Coordinator, Marie McGee, and ASUK Family Support worker Jane Biglin supported the young adults in this big step forward. Marie and Jane were delighted to give every young adult a pack of useful goodies. We are delighted to have received such positive feedback from those attending.

'I was so ready to transfer but Covid got in the way. It's a relief to speak to the adult team, I had lots of unanswered questions for them.'



Alström Syndrome UK
Strength for today, hope for the future

**Are YOU one in a million?
Help find out?
Don't Delay, Enrol Today
in the
AS Patient Registry**

Picnic party!

Children in Need have kindly funded ASUK to provide picnic packs and days out to encourage families to venture outdoors. We have distributed these to children and young people affected by Alström Syndrome. Through this funding we have also been able to provide days out for families and additional support.

We are delighted to announce that we have received funding to expand this project to adults, you will be contacted by your Family Support Worker shortly or if you are booking your holiday and want to take your picnic goodies please give us a call.

The feedback from families has been fantastic!!

“Thank you for the voucher.

We used the picnic blanket and tent already at the beach last Saturday, we loved Alton Towers together on Monday and we are planning another picnic with the rest of the gear and the voucher for early July.

He is certainly benefiting from the charitable support and I am making sure he makes the most of it.

Thanks again for all the items. I cant tell you how incredibly uplifting and motivating it is to have that kind of benevolent help, along with my efforts as well.”



Lockdown easing: managing anxiety

All in the same storm, but not all in the same boat

We have been developing some mental health resources alongside the charity Rareminds. These are centred around the lockdown easing and the uncertainty that this brings.

The full comprehensive leaflets will be uploaded shortly to the resources section on the ASUK website

<http://www.alstrom.org.uk/family-support/>

Until then, we have brought together some top tips and links to find further support.

Although we have all experienced the pandemic in our own unique and particular way, we have all shared an experience of enormous change and uncertainty as a result of Covid-19. This is on top of the uncertainty and challenge of living day-to-day with a rare condition. We know too that some groups have been particularly impacted by Covid-19 such as children, the elderly and those within diverse communities.

The phrase **‘all in the same storm, but not all in the same boat’** sums up the experience of the pandemic overall.



Whatever the circumstances, we have all had to manage a lot of sudden changes and find ways to adapt very quickly, both practically and emotionally. Even though easing of restrictions seems like a big step forward the virus looks likely to be with us for some time. We are all learning ways to cope that work for us.

10 Tips as lockdown eases

1. **Take your time** – If you are nervous or worried about re-engaging with others, take things slowly and build up your confidence gradually. It can help to break things down into different activities and build up gradually, allowing yourself to pause at the point you need to. Plan ahead. You might not feel comfortable meeting a large group of friends for example, but it might feel more doable to meet with one or two.
2. **Don't avoid things completely** - Although you may feel worried about engaging with people or taking part in some activities, it is also important not to avoid taking part completely. If certain activities feel too hard, try breaking them down into smaller more manageable steps for example going for a short period of time. You could also let someone you trust know, so that they can support you in dealing with any unhelpful comments or opinions if you need to.
3. **Stay connected** - Many patient organisations host online forums or groups, and being in contact with others going through similar experiences in managing lockdown easing can be very supportive. Connecting with nature, green spaces, and the natural world can also be very important for wellbeing. This might be as simple as enjoying a breeze from an open window, caring for a small plant, or taking a trip outside to a nearby park or garden. Use these to practice being 'in the world' again too, or for brief 'trial meet ups' with friends.
4. **Managing difficult thoughts and feelings** - Talking to someone you trust often helps difficult thoughts and feelings feel easier to manage. If you don't feel comfortable talking to someone you know, consider other supports such as your online rare condition community, local community, religious group, or a professional counsellor. It's important to know you are not alone, and we have made some suggestions for support services at the end of this article.
5. **Coping with loss or bereavement** – As it becomes more possible to meet up with wider family and friends, you may feel upset again - or for the first time - about those who you have lost during this time. Talk to your local religious or community leaders about alternative ways of remembering them, or undertaking certain rituals that may not have been possible at the time. If you did not have an opportunity to say goodbye, it may be that you could think of other ways to do so now. 'At a Loss' provide details of bereavement services in your local area and 'Cruse' provide lots of advice in coping with grief.
6. **Talk to your employer** if you need to, as many places are now offering more flexible working. If you would like to go into your workplace less (or more) or change your role, let them know what might help you and see what might be possible. Even if you haven't disclosed before about either your own health or caring responsibilities, this could be a good time to explore a working pattern that would better suit you or your family.
7. **Look after yourself** – Practicing self-care is not selfish, it is an important part of looking after yourself. Going through lockdown was emotionally demanding in different ways for everyone and you may have been in 'survival mode' for some time. Start trying to build back in activities and time for your own emotional wellbeing. If your healthcare needs have slipped down the agenda because you have been caring for someone else, take some time to think what might be important for your emotional and physical health at this point.
8. **Moderate your time on news and social media** as there is a lot of evidence that too much exposure to both can impact negatively on your emotional health. Social media can be an important source of support and connection, but if it starts to leave you feeling anxious or angry it might be time to take a break.
9. **Congratulate yourself for coping well**, or making positive changes as we are often quick to notice what we are not doing, or 'could do better.' Try to counteract every self-critical comment or thought with one (or two!) positive comments about what you have – or are - managing.
10. **Be kind to Yourself.** Coping with the pandemic, and adapting to so much change so quickly has been emotionally exhausting in its own right. If you were a key worker, parent/ carer or juggling different responsibilities and demands at home, there will have been additional pressures on you. Try to be kind to yourself – and others – as we enter this new phase.

Useful Resources

The **NHS Volunteer Responders** programme is still available to help support those who need it. Volunteers can collect and deliver shopping, medication, and other essential supplies. Call 0808 196 3646 between 8am and 8pm, 7 days a week to self-refer or visit <https://nhsvolunteerresponders.org.uk/services>

The Government's "Covid-19: guidance for the public on mental health and wellbeing" provides advice and information in several languages:

<https://www.gov.uk/government/publications/covid-19-guidance-for-the-public-on-mental-health-and-wellbeing>

Every Mind Matters is the NHS website for mental health with a section on coronavirus and wellbeing:

<https://www.nhs.uk/every-mind-matters/>

The Mental Health Foundation has provided guidance in several languages to look after your mental health during the coronavirus outbreak - <https://www.mentalhealth.org.uk/coronavirus>

Hub of Hope provides a searchable directory of mental health services in your local area- <https://hubofhope.co.uk/>

Carers UK has lots of useful advice for Carers - <https://www.carersuk.org/help-and-advice/coronavirus-covid-19>

Relate is an organisation that offers support, advice and counselling for relationships, including on the impact of the pandemic <https://www.relate.org.uk/relationship-help/covid-19-advice-and-information>

Rareminds can help you find specialist counsellor if you are impacted by a rare disease www.rareminds.org

Breaking Down Barriers project updates

Breaking Down Barriers is a network of patient organisations, support groups and community networks working together to develop supportive and inclusive services for individuals and families affected by genetic conditions.

Most conditions are rare with groups of around 70 people, to organisations that represent more common conditions with around 13,000 members. We also work with a number of over-arching and umbrella organisations in the rare disease community. Collectively, BDB is communicated to over 360,000 members, plus families, carers and healthcare professionals.



BDB - Diverse Discoveries and Inclusive Insights Conference What a day!

For those who joined us on the 30th June 2021, it was an insightful and informative day.

We heard from organisations who are leading the way in engaging with our diverse and multi-cultural society, exploring the importance of the language and communication we use, learning about the developments in genetics and how health inequalities can have a devastating impact on the lives of families affected by genetic conditions.

One of the most rewarding times is getting feedback from attendees

"One of the most important meetings that has happened in the rare conditions sphere this year. Thank you for all the work you do"

"The whole conference was very well thought out. The quality of the speakers and delivery was excellent. The animation at the beginning totally captured what BDB stands for and how they want to work with partners. Very impressive!"

A HUGE THANK YOU to everyone who was involved; those who presented, interacted, and attended, roll on the next one!!

Welcome to our new team!

We have some exciting announcements to make as the BDB project goes from strength to strength, with now over 45 organisations becoming members – this can only increase our reach and knowledge within our network.

We are delighted to announce that we are expanding the BDB project and will be doing more outreach work, helping to link more of the BDB network with communities, services and families affected by genetic conditions.

As part of the project, we will have, not 1, not 2, but 3 new people joining our team!!



Cathy Chadwick-Rayner
Networks and Outreach Coordinator



Vanessa Williams
Patient and Public Engagement &
Impact Coordinator



Derek Sankar
Community Engagement Coordinator

They all bring a wide range of experience and knowledge to BDB and they will be a great asset to our network. I am sure you will join us in giving them a HUGE welcome.



Farewells...

Our BDB Community Engagement Manager, Asya Choudry has left ASUK to start a new role in Patient and Public Involvement.

We would like to say a huge thank you to her and wish her well in her new job.

Good Luck Asya!

Would you exclude me?

We are delighted to launch our 'would you exclude me?' animation, it was premiered at the conference on the 30th June 2021 and we are over the moon with the positive feedback.

After many months of creative exploration, we held our breath as it was released, wondering how it would be received and if the messages we intended came across in the right way.

Well the feedback has been fantastic, not least from Genomics England:

"I have been really impressed with the new animation you have launched. I can't tell you how much of that chimed with what I have been hearing and discovering over the last year."

Many organisations both inside and outside Breaking Down Barriers have been sending us their thoughts:

"We are absolutely LOVING the new creative and reflective animation from @BarriersDown which takes you on a journey of why the BDB project exists and why this collaborative work is vitally important."

If you haven't had chance to watch it yet, then please head across to our You Tube channel and feel free to share with your own networks <https://www.youtube.com/watch?v=E772s0iwzRQIf>



If you are interested in joining the network, please contact Catherine Lewis at catherine.lewis@alstrom.org.uk

Free iPads or iPhones for children with a vision impairment aged 3-18

Guide Dogs have launched a new service, Tech for All, to help children with a vision impairment access their own devices at home – to support learning, or simply to have fun and explore the interests and activities they enjoy.

Tech for All will provide iPads to visually impaired children aged 3-18 across the UK, while secondary school-age children (age 11-18) may choose an iPhone instead.

The devices have excellent accessibility features built-in, and online guides and tutorials will be provided to help them get started and to ensure that they know how to stay safe online.

The devices will be completely free of charge, with the only requirement being proof of vision impairment.

More information can be found at www.guidedogs.org.uk/techforall and applications are scheduled to open on Thursday 22nd July 2021.

Please contact your Family Support Worker if you need any support or assistance.

Unlock possibilities
with Tech for All

 Guide
Dogs

Free iPads and iPhones



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 07970 071675 / 077161 35940

Meet the ASUK team

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



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

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

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

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

