



Alström Syndrome UK

Strength for today, hope for the future

News, Views and Useful Links!

ASUK Family Grants



Simmie is thrilled with her new talking combination microwave oven that she has bought with a grant from ASUK. Take a look at the first batch of muffins she made – mmm delicious!



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!

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



*Photo above provided by SeeAbility

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.”



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EID Mubarak!

ASUK would like to wish all those who celebrated the end of Ramadan on 14th June a very happy 'Eid Mubarak'.

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 a good 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>

Welcome Asya!

Please join us in welcoming Asya Choudry 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>





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The Big Activity Challenge

The Adventure starts here!



What is the Big Activity Challenge?

ASUK are offering adults (18's and over) with Alström Syndrome, the chance to try out a new activity. You can apply for between £50-£500 to pay for the activity, all we ask you to do is

provide some photographs and write an article for publication in the ASUK newsletter (within a month of the activity) telling us about your experience, how accessible it was, what you achieved, if you're going to take it up as a new hobby etc. 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!

Please complete the application form on our website <http://www.alstrom.org.uk/asuk-big-activity-challenge/> and send it to Liz at liz.loughery@alstrom.org.uk or if you would like any further information or support completing the form you can contact her on 07517 278 946. We will be in touch 10 days following receipt of your application with a decision and next steps.



A HUGE THANK YOU to everyone who continues to support ASUK through donations and fantastic fundraising activities. We are very grateful for your efforts and kindness, it really is making a difference to people's lives.

Fantastic Fundraising



Our very own Hassan along with a team of disabled cyclists will cycle 130 miles to raise money for good causes one of which is Alström Syndrome UK. The riders will make their way from Morecambe finishing in Saltburn-by-the-Sea.

The event has been organised by Choices 4 All, supported by www.bradforddisabilitysports.co.uk and <http://www.capitalofcycling.org>

Hassan has a visual impairment

and he will be riding on a tandem with Tim Curtis, who is the GB National Squad



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Special Olympics Cycling Coach. There will also be three hand cyclists, George Herd, Alana Walker, and Danny Flynn, riding on hand cycles with power assist. This allows them to cycle at equivalent levels to non-disabled cyclists and it allows friends to cycle together at the same pace, regardless of disability. We would like to say a huge thank you to Hassan and wish him the very best of luck! Watch this space for news of how he got on!



Apply for Apple iPad Air 2 through RNIB & VICTA

VICTA support children and young people who are blind or partially sighted by providing equipment to aid their visual impairment. VICTA is currently working in partnership with RNIB on a product grant programme focussed on supporting independent study using technology. If you are registered blind or partially sighted and a UK resident aged between 11 and 25 you could be eligible for an Apple iPad Air 2 (32 GB) with case. Click here for more details: <https://www.victa.org.uk/grants/>

Next month's e-news – we'd love to hear from you!

ASUK would love to hear from you, send us your news, articles or any links that you think others would find useful. Get in touch by email liz.loughery@alstrom.org.uk or feel free to call Liz on 07517 278 946.

Useful links and information – July's round-up!

<https://www.guidedogs.org.uk/services-we-provide/>

<https://deafblind.org.uk/what-we-do/>

<https://www.sense.org.uk>

For anyone attending clinic at the QE a new centre has opened:

<https://www.touchbasepears.org.uk/activities/>

<https://specialneedsjungle.com>

Seeability

<https://www.seeability.org>

Council for Disabled Children

<https://councilfordisabledchildren.org.uk>

Thank you for your continued support <https://www.justgiving.com/alstromsyndromeuk>

Further information can be found at www.alstrom.org.uk