



Alström Syndrome UK

Strength for today, hope for the future

News, Views and Useful Links!

Celebration Residential Weekend



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

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

The rain on the first morning didn't dampen spirits and the families and youngsters got stuck into fun games whilst they waited for the

sun to come out! Everyone loved the

outdoor activities and those that were a little apprehensive to start with soon changed their minds once they'd given it a try! As the sun went down we gathered around a campfire, ate marshmallows and sang ridiculous songs. Lots of laughter and fun was had!

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

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



Some of the highlights from our fantastic weekend at the Pioneer Centre

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

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

Harrogate Horse riding

A couple of weeks ago the ASUK Children in Need Project organised a fantastic horse riding event! The young people enjoyed petting the horses and walking and trotting inside and outside in the paddock. They also had a chance to ride a mechanical horse which gave them the experience of walking, trotting and galloping! This was followed up with rosettes to celebrate achievements! Thank you to all at the Follifoot Riding Centre – we had a wonderful time!



Marie, our young people and their families at the Follifoot Riding Centre

ASUK would also like to say a big thank you for the Children in Need funding that has helped create some wonderful activities and opportunities for our young people and their families. Over the last 3 years we have organised numerous events that have:

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

Thank you Children in Need!

Farewell and Greetings!

For those of you that attend the adult Alström clinic you will be familiar with Jayne Hodgekiss, the Alström Diabetes Clinical Nurse Specialist. Jayne has recently stepped down from her role supporting ASUK. She is being replaced by Liz Chandler who also has vast experience in Diabetes. Below is a special message from Jayne which she has asked us to share with all those who attend the adult clinics:

*"Dear All, it's with a heavy heart that I wanted to let you know that I'm needing to pass over the role of Diabetes Clinical Nurse Specialist in The Alström Service to my colleague Liz Chandler. Unfortunately, I have taken the decision to take on some extra teaching commitments and while I'm not leaving the Queen Elizabeth Hospital I'm unable to continue with my current level of commitment to the service. Getting to know you and support you over recent years has been very special and rewarding. It only goes to say that I wish you all the very best in the future, I know Liz will keep me in touch with news from you all.
Best wishes to you all, Jayne"*

ASUK would like to say a huge thank you to Jayne for all the hard work, support and dedication she has provided to our adult patients over the years. We would like to wish Jayne all the very best in the future, we will miss her!

Jayne's replacement Liz Chandler can be contacted on Liz.Chandler@uhb.nhs.uk. We look forward to working with Liz and getting to know her over the coming months!

New technology to help the visually impaired

Some of us were lucky enough to meet representatives from OrCam earlier this month. We were shown a new device called OrCam MyEye, the device has been designed to help the lives of people with a visual impairment through the use of artificial vision. It



Two people with Alström Syndrome receiving a demo from an OrCam representative.

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

information on this technology, please contact us or click [here](#) for quick access to the OrCam website.

NIHR Think Research Rare Diseases Patient Day - 21st March 2018

Kerry attended the National Institute for Health and Research (NIHR) Think Research Rare Diseases Patient Day on 21 March 2018. This event was aimed at rare disease patients, carers and people who work for a rare disease group. The day included presentations and workshops on topics in social media, working with industry, genomics, data and research and was also a good opportunity to meet others from the rare disease community.



One of the presentations given at the NIHR Rare Disease Patient Day

Click [here](#) for useful resources from the day kindly provided by NIHR.

Thank you to our Fantastic Fundraisers!

A HUGE THANK YOU to everyone who continues to support ASUK. The numbers of people being diagnosed with Alström Syndrome is increasing so please get in touch if you would like help to arrange a fundraising event! The funds raised make a huge difference and ensure families are helped and supported throughout the year.



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



And well done to our fantastic runner **David Lunt** who took part in the Virgin London Marathon on Sunday 22nd April to help raise funds for ASUK. David had an amazing run and despite the hot weather completed in 5 hours and 8 mins. Fantastic, thank you David!

Easy Fundraising

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



Every time you shop online via 'easyfundraising' at one of the 3,300 retailers including John Lewis, Aviva, Sainsbury's and Booking.com, a donation will be made to Alström

Syndrome UK, and it won't cost you an extra penny. Have a look at our website for more details and get shopping today! <http://www.alstrom.org.uk/easy-fundraising-while-you-shop/>

Take a peek at past copies of our Newsletter

To catch up with any past copies you have missed – they are worth a peek! <http://www.alstrom.org.uk/newsletters/>

You can also watch these inspirational videos - Kez and his son Hassan give a truly insightful interview in the film "Diagnosed at 17" and "We are an Alström family".

Thoughtful interviews with clinicians and professionals which were filmed during last year's conference. ASUK Trustee, Alex gives a truly inspirational interview about not allowing your disability to define you in 'You are not your disability'

<http://www.alstrom.org.uk/alstrom-inspiration/#1512555267228-c65ee93d-ba42>

From us all at ASUK

Thank you for your support

<https://www.justgiving.com/alstromsyndromeuk>

www.alstrom.org.uk