**With your help we have hope**

**THE NEWSLETTER OF ALSTRÖM SYNDROME UK Winter 2014 Issue No.15**

**Alström NEWS**

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AlströmNEWS

Alström Syndrome UK provide information, support and advice for individuals affected, their families, carers and professionals

working with them. Alström Syndrome is a very rare genetic condition which can lead to progressive blindness and deafness and

can also lead to heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different

stages making diagnosis 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

Registered Charity no: 1071196 Registered Company Limited by Guarantee 3557191

The Alström Syndrome UK Team would like to wish you all a

Merry Christmas and a Happy and Healthy New Year

CHILDREN IN NEED FUNDING SECURED!

ASUK Office Manager, Catherine Lewis and

ASUK National Development Manager,

Kerry Leeson-Beevers have developed a

transition project to ensure young people

and their families who are affected by

Alström Syndrome receive the support they

need alongside establishing fun activities

throughout their journey into adult services.

We are delighted to announce that the

Children in Need application to run this

three year transition project has been

successful.

The project will work with young people

and their families affected by Alström

Syndrome. By providing fun activities and

one to one support with transition, ensuring

that young people who are affected are

less isolated, healthier and able to better

manage change.

Curtis Vasey and Kerry Leeson-Beevers are

already busy planning support activities

for the Transition Project. Our first regional

support group is likely to take place in

Scarborough as we do have a number of

families within easy reach of this location.

This will be a weekend break where we

run workshops for young people, parents

and siblings. We are also looking to plan

an activity such as bowling and the Vasey's

will help us to run a goalball session on the

Sunday morning. We will be planning similar

events at different locations throughout the

UK.

ASUK is delighted to be awarded this grant

and we look forward to starting this exciting

project in the New Year.

If you have any ideas for this project we

would love to hear them. Please contact

Curtis and Kerry on 01709 210151 or email

curtis.vasey@alstrom.org.uk and kerry.

leeson@alstrom.org.uk

Curtis Vasey who has been an ASUK Trustee

has decided to step down from his role but

he would still like to remain involved in

the work of ASUK. Especially in developing

transition services and activities for young

people affected. Curtis has been a dedicated

Trustee who has always had the needs of

our families at the heart of everything he

has done. ASUK would like to sincerely

thank him for his commitment and support

over the years.

It showcases your truly special photographs.

Please contact Catherine Lewis if you would

like to order a calendar, they are priced at

£10 each and 100% of the money raised will

support families with Alström Syndrome.

Tel: 01803 613117 or email Catherine.lewis@

alstrom.org.uk

Cheques can be made payable to ‘Alström

Syndrome UK’ and sent to 31 Shearwater

Drive, Torquay, Devon TQ2 7TL

Alternatively please make your payment

through our Just Giving page

https://www.justgiving.com/

alstromsyndromeuk/

Thank you to our calendar Sponsors:

ASUK National Development Manager,

Kerry Leeson-Beevers had the privilege of

speaking at the prestigious World Orphan

Drugs Congress in Brussels from the 12th –

14th November 2014. Kerry's presentation

was about living with a rare disease and

this journey. This was a great chance to

network and learn from one another

to develop solutions in the rare disease

sector. Kerry is pictured far left with BBC

Health Correspondent Fergus Walsh and

Campaigner Alan Thomas at the event. You

can learn more at http://www.terrapinn.

com/conference/world-orphan-drugcongress/

index.stm

Kerry has also attended the Acquired

Deafblindness Conference in Belfast, where

we had an information stand and ran a

workshop to raise awareness of Alström

Syndrome. 14 different countries were

represented and many delegates were from

specialised Deafblind Centres. There was a

great deal of interest in the condition and

many useful contacts have now been made.

On the 16th November 2014, ASUK Founder,

Kay Parkinson gave a talk on the patient

experience to SOBI Pharmaceutical's top

60 Executives at their strategy meeting

held in Cap Ferrat France. She received

a standing ovation for her talk and was

presented with a book illustrating other

patients’ experiences and many of those

present were moved to tears on hearing

what her children had experienced. SOBI are

a Swedish Pharmaceutical firm specialising

in Rare Diseases and they would now like

her to give the talk to their Board of

Directors. Kay was also invited into

their CEO's strategy round up which

was a great experience and learning

opportunity.

Kay then travelled to the Cilia

Conference in Paris from the 18th –

21st November 2014. This event was

attended by 390 delegates, which

brought together patients, patient

groups, clinicians and scientists.

ASUK Family Support Manager,

Iram Shah attended the Family

Fund Conference on Learning

Technology and Disability in Cardiff

on the 19th November 2014.

The Conference was looking at

how advances in technology are

enabling disabled children to make great

strides in their learning, communication and

social skills. Family Fund, Chief Executive

Cheryl Ward presented a short film of how

new technology has made a difference

to the development of two children. The

workshops centred around accessible

devices, physical and motor challenges and

accessible learning and literacy.

The ASUK 2015

calendar is now ready!

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ASUK RAISING AWARENESS THROUGHOUT THE WORLD

Alström Syndrome

Research Project –

Have your say!

Sense are funding a research project

which will be looking at the experiences of

people with Alström Syndrome (and other

rare syndromes) who attend specialist

clinics. If you (or a relative) attend the QE

in Birmingham or Birmingham's Children's

hospital and would like more information

about taking part in this research project

please contact Liz who is a researcher at the

University of Birmingham on l.ellis.2@bham.

ac.uk or 0121 414 4392 07745 244597

Dates for your Diaries

Please find below the dates for next year’s AS multi-disciplinary clinics.

The Children’s clinics will take place at Birmingham Children’s Hospital

16th February 2015

18th May 2015

21st September 2015

16th November 2015

19th November 2015 – Children’s Outreach Clinic in Leeds

The adult’s clinics will take place at the Queen Elizabeth Hospital,

Birmingham

7th/8th January 2015

20th/21st May 2015

23rd/24th September 2015

11th/12th November 2015

The UK is leading the way in the

development of Genomic Medicine

The aim of the 100,000 Genome Project is

to sequence 100,000 genomes by the year

2017. We all have around 20,000 genes

made from our DNA and these are what

make up our genome which is present in

almost every cell of the body. The DNA of

a person contains around 3 billion letters

and the technology used to sequence these

genes in recent years has been very slow

and expensive.

As technology advances, the cost of gene

sequencing has reduced and it now costs

around £1,000 to sequence a whole genome

and takes a matter of days to complete.

The purpose of this project is to develop an

understanding of the role of different genes

within the body and the impact they have.

The more samples collected, the greater

the knowledge scientists hope to develop,

hence the need for a sample size of 100,000.

It is also important to study the person and

their medical history alongside the samples

they collect. This will help to make links

between the science and the experiences

of individuals and how they are personally

affected by a particular disease. The hope is

that a greater understanding of genomics

will result in personalised medicine which

will enable medics to predict how a person

may respond to particular treatments. If this

is possible then genomic medicine may be

made available as part of the NHS care we

all receive in the UK.

Genomics England will initially focus on rare

diseases and cancers. Ciliopathies will be

covered under rare diseases and therefore

there is a strong possibility that this will

include Alström Syndrome, however, this

will depend on those who consent to taking

part. The samples collected will be from

patients and two close blood relatives.

Rare diseases collectively are not rare and

therefore genomics may have a major

impact on both of these groups of diseases.

A key message being relayed is that patients

are extremely important throughout this

whole process and that informed consent

is of prime importance. Genomics England

has an Independent Ethics Advisory

Committee to review all patient information

and consent forms. They are running a

series of patient engagement activities

and ASUK have already been consulted.

There is a possibility that when studying

a person’s genome, researchers may

discover ‘incidental findings’. Only specific

information will be fed back to the patient

and they will be given the opportunity to

opt in or out of receiving this information.

The information gathered from this project

will be stored securely and anonymously by

Genomics England. Medical professionals

and commercial companies will be required

to submit a research proposal and undergo

an ethical review if they wish to gain access

to this information.

The project may directly benefit some

of those taking part by receiving new or

improved treatments. However, the majority

may not benefit directly but it is expected

that their information will be used to

develop knowledge and understanding

There is a great video ‘understanding

genomics’ which you can view via the

Genomics England website.

and help to create additional research and

development. There is still so much to learn

about genomics but it is believed that this

project is a major step in the right direction.

ASUK will continue to follow this project

closely and will update you regularly with

any new developments. If you require

any further information, please contact

Kerry Leeson-Beevers, ASUK National

Development Manager at Kerry.leeson@

alstrom.org.uk

Further information can be found at

Genomics England, The 100,000 Genomes

co.uk/the-100000-genomes-project,

Project, 2014 http://www.genomicsengland.

(accessed 8 December 2014)

!

Let’s think of those New Year’s resolutions

and get active and moving!

Exercise has many benefits - it can ease

muscle aches and pains, reduce stiffness,

and increase flexibility, balance, strength

and mobility. It can also help you get fitter,

have more energy, lose weight, lift your

mood and most importantly, it can be fun.

Alström syndrome makes it especially

difficult for you to maintain a healthy weight

so regular exercise is really important for

you. Exercise programs work best when

tailor-made for an individual, taking into

consideration specific needs, abilities, and

difficulties.

For further information you can

get in touch with Nicky Cartwright

(Physiotherapist at Queen Elizabeth

Hospital Birmingham)

nicola.cartwright@uhb.nhs.uk

Your doctor can be a useful resource in

accessing community ‘health and fitness’

initiatives at your local leisure centres

through an ‘exercise referral’. This can

provide the one to one support you may

need to ‘get going’ or to try new ways of

exercising.

You will need to visit your GP to speak

further with them about their ‘exercise

referral schemes’. I will be really pleased to

hear about how you get on and what you’ve

found out that is available to you. If who

would like support accessing local health

and fitness initiatives in your own area

please contact me. Good exercising!

Have a Go Sports Day!

Action for Blind People and British Blind

Sport would like to invite children and

young people aged 8 to 17 with sight loss

to a FREE have a go day to try out different

sports. This day is taking place on the 10th

February 2015 at the Doug Ellis Sports

Centre, 150 Wellhead Lane, Birmingham,

B42 2SY. As this event is during school

time please ensure that you get

permission from your school to attend.

They will also need a parent to stay for

the duration of the day. Various sporting

activities will be on offer for the young

people to try, with exit routes for these

sports for them if they really enjoy them

and want to continue them at a club.

Please contact Liz Williams for details

on 0121 665 4200 or email elizabeth.

williams@actionforblindpeople.org.uk

A HUGE THANK YOU to everyone who continues to support our great cause!

Thank you to Les Wilkins and the Lewis

family who organised a quiz night in their

local pub, this raised a fantastic £300 – well

done!

Sue Vasey asked for donations to go towards

ASUK rather than receive Birthday presents

which raised a fabulous £250 – well done

and Happy Birthday!

The St. Agnes art group held an art and

craft exhibition in St. Agnes, Cornwall and

raised £235

Kayleigh Lewis (pictured here) has been

very busy making crafts and candles and

selling them at craft fayres to raise funds for

ASUK, thank you Kayleigh.

Please support Melanie Davison and her

Brother Fabian who are bravely doing the

Bath Half Marathon on the 1st March 2015

in aid of ASUK. Please show your support via

her Just Giving page http://www.justgiving.

com/Melanie-and-Iwe

A HUGE THANK YOU to everyone who

continues to support our great cause! 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; we also have spaces

available in the Silverstone Half Marathon

and the Bupa 10K Marathon. These funds

raised really do make a huge difference and

ensure we can support families throughout

the year.

Kayleigh Lewis

Ice Bucket Challenge

Get involved in the fundraising craze

which has gripped the world and is

sweeping across social media – The Ice

Bucket Challenge!

It’s simple, just challenge a friend to

have a bucket of ice-cold water poured

over their head in exchange for a dona

tion to ASUK, then they will nominate

someone else to do the challenge.

Make sure you film it and share it via

Facebook to raise awareness of this ul

tra rare condition and raise funds for

our great cause.

You can donate to Alström

Syndrome UK securely through

our Just Giving page:

www.justgiving.com/

alstromsyndromeuk/

or

Send cheques made payable to

Alström Syndrome UK to our

registered office 31 Shearwater

Drive, Torquay, Devon TQ2 7TL

You can see the brave souls who have

already taken on the challenge via our

facebook page www.facebook.com/

AlstromsyndromeUK -The videos are

hilarious!

You can Text ICED12 £10 to

70070 to donate to Alström

Syndrome UK and make a difference

today.

You can also donate via our

Just Giving page www.justgiving.

com/alstromsyndromeuk/

Goal Ball Success!

Curtis, Taylor and Rio Vasey have

been competing in a recent Goal Ball

Tournament and they came 2nd – Well

done lads!

You can learn more about Goal Ball and

how you can get involved at http://www.

goalballuk.com/

Taylor has not only been having fun doing

Goal Ball but bravely did a sky dive –

showing that anything is possible!

FAMILY ADVENTURES!

Stephen Thacker travelled to

Torquay to enjoy one of his passions;

to compete in a Chess Tournament,

Stephen gives his thoughts below:

I lost the fourth round game and drew

the remaining three to finish with

3.5 out of 7 which in a strong sighted

tournament is a creditable score for

me: chess is divided into three sections,

the opening which is played fairly fast,

the middle game where all the tactics

take place and is played at the slowest

speed, and the end game where time

is sparse and sometimes it's a race to

reach the time control as if you don't,

you've forfeited the game! There were

three time controls in this tournament:

40 moves in two hours for each player,

two moves in the next hour for each

player and finally, 30 minutes to finish

the game. In the sixth game especially

I blundered a piece in the opening only

to fight back and almost win the game!

I finished joint 15th but 21st on tie

break with 3.5 and there were 45 in the

tournament.

Judo

Achievements!

Many of our members are finding

that Judo can be fun and is a great

way to build confidence and self

esteem. Millie who is 7 years old

(pictured LEFT) has just received

her yellow belt in Judo and her

Mum Michelle has seen her

confidence and enthusiasm for

the sport grow. Also John James

(pictured RIGHT) who has just

turned 19 years old has been doing

Judo now for 4 years and he has

achieved his Orange belt in Judo –

well done to you both!

ASUK Bike Ride, Come and Join the Fun!

The planning for the Second Alström

Syndrome Bike ride has begun.

The first bike ride was a great

success and took place in 2012 from

Torbay Hospital, Devon to the Queen

Elizabeth Hospital, Birmingham –

a distance of over 200 miles – this

signified the move of the medical

team and sponsorship raised over

£16,000.

This time the bike ride is likely to

be a coast to coast route (TBC) and

we are hoping to cycle from the 1st

– 4th May 2015. We are aiming to

raise money and awareness as well

as socially interacting with each

other and having a great time!

Anyone can take part and whether

you have a bicycle, tandem, tricycle

or tagalong you will be able to do as

much or as little as you want. Any

support that can be given will be

greatly appreciated. Please get in

touch if you would like to take part

or if you would like to help by being

part of the medical/support team.

Please contact either Alex Griffiths-

Rayson or Curtis Vasey to register

your interest

Alex.rayson@alstrom.org.uk or

Curtis.vasey@alstrom.org.uk

Hands-up who wants a Tandem or trike?

It’s not too late to get in now fund tandems and trikes and

touch, so we can help you support you through ensuring the

source and fund a tandem support is in place for you to get out

or trike for you and your and about safely. Please get in touch if

family to get out and about. you would like to know more by calling

Catherine Lewis on 01803 613117 or

Following funding from email catherine.lewis@alstrom.org.uk

Sport England we can

Fun-Filled Residential

Trips on Offer

Young People aged between 18 to 25

years with a visual impairment from

across England can attend this exciting

Action for Blind activity trip which is taking

place from Tuesday 24th to Friday

27th March 2015 at the Windermere

Manor Hotel, Lake District, Cumbria. The

cost is £50.00

The Cost Includes: 3 nights accommodation

on a full board basis, travel costs

via train using a disabled railcard and

all planned activities. You will also have

the opportunity to use the hotel’s lei

sure facilities such as the heated indoor

swimming pool and sauna, plus make

new found friends. All participants must

be willing and able to take part in Workshop

based sessions, around Education

& Employment, Assistive Technology and

Confidence Building including planned

Social & Leisure Activities. To express an

interest please email: philip.wagstaff@

actionforblindpeople.org.uk or call 0161

787 9252

Victa is now open for applications for

their February youth weekend for people

aged 18 to 29 years old. After the success

of their November weekend they will be

returning to the Thorpe Woodlands Ad

venture Centre in Thetford Forest. On

offer will be a range of thrill-seeking activities

such as advanced high ropes, kayaking,

raft building and caving. It will take

place from the 6th – 9th February 2015

and will cost £35.00 The VICTA youth

weekends are a great chance to meet

new people from a similar age group and

to gain new experiences.

If you would like to take part

please apply or for more

information please call Victa

on:01908 240831 or email

admin@victa.org.uk

Gap Year Adventure!

Liam Mackin decided to take a gap year, look at his options before going to University and fulfil his

dream of travelling – and boy he did it in a big way! Liam shares his gap year adventure…

In August 2013, I received my A-level

grades and, unfortunately, they were not

high enough for me to attend my first

choice university. I spoke to Kay who

advised me that, rather than accepting

my second choice, it would be better for

me to have a gap year which would give

me time to consider my options. So I did.

What did I do in my gap year then?

Well, firstly I made sure to get a good

look around at good, red-

With all these on a regular basis I then

looked for something else to fill my time

with.

I asked ASUK Support Officer Catherine

to ask around at a few schools as part of

the PossAbility project to see if I could get

a placement. She found me one, Dixon's

City Academy, which were willing to

accept me as a language assistant for a

few hours per week. I work helping out

Democratic Republic of the Congo (a

French-speaking country!) who wanted

help with conversational English. When

I initially met her, her sister asked if she

could also join us and they now both take

part in the weekly sessions where we

practice conversational English and I also

learn and practice my French!

On top of all this I have managed to factor

in some travelling, something I have

always wanted to do.

brick universities so I had

In January I went to India for

a much better idea when it

twelve days with a company

came to applying. Secondly,

called Traveleyes, who organise

I picked up some leaflets

holidays for blind and partially

and prospectuses from local

sighted people.

colleges to see if there were

We flew to Delhi where we

any courses which would be

visited India's largest mosque

suitable for me.

and temple, rode through the

At Shipley college I enrolled

old town on rickshaws and saw

on advanced French and

Mahatma Gandhi's house and

German courses which I

other historical and religious

hoped would help me to

sites.

keep up on my level of

We then travelled to Agra

French and German (the

where we visited the amazing

subjects I will study for my

Taj Mahal and were able to

degree). These courses have

have our photographs taken

been really helpful, not only

on the bench where Princess

in maintaining my language

skills but in improving them as we have

general conversations about a range of

different topics. It's also not a bad thing

that the German class always ends up in

the pub!

At Bradford college I found a community

interpreting course. I enrolled and had to

take an entrance exam. I was told that I

would have to take the level 2, rather than

the level 3 course. I wasn't happy with

this because the level 3 course gives you

the possibility of getting the necessary

qualifications to become an interpreter,

whereas level 2 doesn't. With help from

my family, we contested it with the course

tutors and their manager. After a lot of

arguing and some help from the visual

impairment team, they relented and

allowed me to take the entrance exam

again which I passed and I was finally

accepted onto the level 3 course. I have

a support worker and have also been lent

a laptop and a voice recorder to help me

with the course and I am delighted that in

May this year I qualified as an Interpreter.

with conversational classes for year 8's

and 9's who are new to German and also

with a 6th form student, giving him extra

help to prepare for his oral exams. I'm

really enjoying this and it is a valuable

experience for me as teaching is the

career I want to pursue after university.

Finally, in February, came my most recent

piece of work. I have worked with the

Children's Society's disability department

on a regular basis for three or four years,

so when I was approached by a member

of the refugees and asylum seekers team,

informing me of a scheme which they

were running I was interested to find out

more.

The scheme was based around young

refugees, each of whom would receive

one to one mentoring on subjects

which they felt they need to improve.

We had three training days to learn the

difficulties faced by refugees and ways of

overcoming communication difficulties

as well as safeguarding.

I was matched with a girl from the

Diana sat, as well as to enter

the building. We also visited the fort of

Agra and the Marble Art Palace where

artifacts are made from the same marble

of which the Taj Mahal was constructed.

Our final journey took us to Jaipur, India's

cultural capital, where we rode on camels

and elephants, visited the Amber Palace,

fought our way through a typical Indian

market and saw how paper is made from

cotton in the village of Sanganir. It was a

truly amazing experience and one which I

will never forget.

I also visited Dublin on St.Patrick's day

and stayed for four days which was a

great experience. We lined the streets

for the St.Patrick's Day parade, visited

Trinity College and Dublin Castle and, of

course, sampled some Guinness.

In June I decided that I wanted to try and

fulfil an ambition I had had for a long time

and apply for a TV quiz show. I went onto

the BBC website and found a new show

which they were recruiting for called

Two Tribes. I filled in my application and

thought nothing of it. A couple of weeks

later I had a phone call from one of the

producers, they wanted me to take a

short test over the phone to see if I was

suitable for the show. I was asked 10

general knowledge questions and was

told I might hear back from them if I was

successful.

A little while later I was asked to go to

Manchester for an audition. We had to

answer a series of written questions, role

play the show and do a short piece to

camera. A week later I heard that I was

wanted on a recording of the show. I had

to go down to London and take part in

the recording.

The game show was aired on TV on the

28th August 2014 and you can see how I

did via the You Tube video:

http://youtu.be/U9MGl88HikY

I thought that that was the end of my gap

year but in August I was selected from

a list of applicants to travel to Latvia to

take part in the International Computer

Camp. A group of 6 people from the UK

joined up with representatives from

over 15 different countries to create

an international network of young

blind people. We took part in several

workshops including woodwork, judo and

cookery and visited some of the tourist

attractions. It was a wonderful 12 days

where I got to meet lots of new friends,

so now when I want to go travelling I’ve

always got somewhere to stay.

I still have some more travelling planned

with trips to Malta, Italy and China before

I begin at Nottingham University, where

I have been offered an unconditional

place.

On top of all of this I have also found time

to improve my mobility skills by doing

lots of train travel around the country,

met lots of new people and won another

gold medal for goalball. I don't regret my

decision to take a gap year, in fact I think

it's one of the best choices I have made

and I wouldn't have done it without Kay's

advice!

Until next time!

Merry Christmas and a Happy New Year

Did you know?

The Charities Registered Office address has changed to:

31 Shearwater Drive, Torquay, Devon TQ2 7TL

Tel: 01803 613117

Email: info@alstrom.org.uk

ASUK T-shirts are available in sizes small, medium, large, Extra Large and 2 XL.

Families affected by AS may have a complimentary t-shirt per person affected.

Additional t-shirts are priced at £10 each.

ASUK now have a dedicated You Tube page - www.youtube.com/alstromsyndromeuk

Please keep up to date with Alström Syndrome UK via twitter @AS\_UK

We also have a dedicated Facebook page - www.facebook.com/alstromsyndromeuk

Please click ‘like’ to show your support and spread the word!

You can also find more information at:

 https://www.rareconnect.org/en/community/alstrom-syndrome

Connecting rare disease patients globally.

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

Please show your support or get involved in one of our fundraising challenges.

Every penny which is donated supports children and adults with Alström Syndrome.

You can donate via our Just Giving page

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

With your help, we have hope

Alström Syndrome UK is a registered charity, number 1071196.

Registered Company Number 3557191