**With your help we have hope**

**THE NEWSLETTER OF ALSTRÖM SYNDROME UK Winter 2015 Issue No.16**

**Alström NEWS**

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

Our thoughts and prayers go out to all the victims and their families of the recent horrific

attacks in Paris. We must not allow these events to destroy our love, respect and friendship for

one another. We must remain focused on the future which involves supporting and spreading the

shared love for our families and friends who are affected by Alström Syndrome around the world.

Alström Syndrome UK will always remain a diverse and multi-cultural group; no matter what

background, religion, race, class or culture you may be from. We are in this together and should

always remain united as one.

FIRST CLINICAL TRIAL FOR AS IN THE UK!

ASUK have been working alongside

the specialist team at Queen Elizabeth

Hospital, Birmingham and the Canadian

Pharmaceutical Company ProMetic to

prepare for the first clinical trial for patients

affected by Alström Syndrome in the UK.

The clinical trial aims to halt the progression

and possibly reverse some of the effects

of fibrosis (scarring) in the organs, which

is one of the main problems associated

with this ultra-rare condition. It may also

have the potential to improve sugar and fat

levels within the body, improving diabetes

and obesity and reducing insulin resistance.

We have now gained ethics approval for

the study and the study site at Queen

Elizabeth Hospital, Birmingham is open for

recruitment. We are aiming to enrol the first

patients in January 2016.

The trial will only be available for people

who are over the age of 16 and who meet

the eligibility criteria. Dr. Tarek Hiwot is the

Chief investigator and he will discuss this

fully with potential participants. All safety

measures are in place and patients will be

closely monitored throughout. ASUK will

be available to offer support, as well as

booking accommodation, travel and any

assistance which may be needed.

Patient information sheets will be

distributed to patients at the end of

December. These will contain a great deal

of information and we would urge you to

please make a note of anything you are

not sure of and we can discuss this further

with you.

On the 12th January 2016 a Clinical Trial

Information Day will be held at the new

Rare Disease Centre at the Queen Elizabeth

Hospital in Birmingham. This will be an

opportunity to answer all of your questions

and lunch will be provided. ASUK will

provide travel and any accommodation

which is required to attend this event.

There will also be tours of the clinical trial

centre so participants can view where they

will be cared for and monitored. Please do

not worry if you are not able to attend, we

will find an alternative date to answer any

questions you may have.

Please understand that you should not

agree to enter this clinical trial in the hope

or expectation that your own condition will

be improved. By volunteering for the trial

you are making a positive step to improve

our understanding of the condition and get

more information on potential treatments.

Siblings Matter Too Siblings Matter Too

Kerry attended the launch of a new report from the charity Family Fund and the University of Portsmouth that addresses these concerns –

‘Do Siblings Matter Too?’ – A summary of a research project investigating what it is like to be a sibling of a disabled child.

The event offered a chance to hear the authors present the research and what the implications are for policy and practice with siblings,

along with contributions from some of the siblings interviewed for the report themselves.

This report highlights a number of key themes for siblings, ranging from elements of a typical sibling relationship to issues of lack of time,

experience of aggression, violence and emotional upset.

Data taken from over 2,000 Family Fund assessments contributed to the

report, in which the key findings show:

• Siblings are often overlooked and their needs often ignored by policy makers

and service providers.

• Siblings are not identified by local authorities and schools.

• Few siblings are being supported by agencies such as Child and Adolescent

Mental Health Service (CAMHS) or Young Carer groups and it would be of

benefit if access to these and similar services, could be made more widely

available.

Sibs, a national charity for siblings of adults and children with a disability, have

identified a number of difficulties for siblings and state: “There is a need for

further research on the needs of young siblings who currently have a disabled

brother or sister...From our experience it would seem that being a sibling

today is harder now than it was 20 or even 10 years ago due to the increased

numbers of disabled children with complex medical needs, the diminished

availability of extended family for support, the inadequacy of services for

families of disabled children, and the fact that the majority of siblings are the

only sibling in the family.”

Siblings Matter Too is a discretionary grant fund administered by Family

Fund, introduced in 2011. Family Fund wanted to do more to address and

acknowledge the unique role siblings play, and to provide opportunities

which they could not otherwise enjoy. As such, the Fund has been able to

secure £100,000 of funding (less costs) to recognise the contribution of

siblings to family life. The contribution made by siblings had been reported

as crucial to helping a family manage, and this fund was aimed at helping

siblings who provided exceptional levels of help and support.

ASUK believe that the family as a whole is important and disability can affect everyone including siblings, this report highlights their needs

and how every part of their lives can be impacted (photos above show siblings having fun at the ASUK conferences). Please get in touch

with the ASUK team if you need any support or to take part in fun activities, as we are here to assist families including siblings.

You can find read the full report via the Family Fund website

www.familyfund.org.uk/News/new-siblings-report

 Dates for your Diaries

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

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

1st February 2016

6th June 2016

5th September 2016

7th November 2016

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

13th/14th January 2016

13th/14th April 2016

13th/14th July 2016

4th, 5th and 6th October 2016 - Young Adult Clinic

12th/13th October 2016

Dates for your Diaries

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

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

1st February 2016

6th June 2016

5th September 2016

7th November 2016

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

13th/14th January 2016

13th/14th April 2016

13th/14th July 2016

4th, 5th and 6th October 2016 - Young Adult Clinic

12th/13th October 2016

Exciting New

Communities Project

The Sylvia Adams Charitable Trust who

funded our successful Asian Mentoring

Scheme would like to develop a further

project to expand and develop this area

further with ASUK. The new project is

aimed at facilitating patient organisations

to join together and share examples of

best practice and develop new guidelines

on effective ways to support families

who experience barriers when accessing

mainstream services. We will not only

focus on Asian families, although the

information we gathered throughout the

Asian Mentoring Scheme may be useful

to other organisations and will aid our

understanding as we begin to work within

different communities. ASUK National

Development Manager, Kerry Leeson-

Beevers will be leading on this exciting

project in the New Year.

Living Painting

Book Launch

Fabulous Millie is one of the very first children

in the UK to receive the Living Paintings book

‘The Bear Who Went Boo!’ by David Walliams.

The story is about a cheeky polar bear cub

who loves startling other animals... it has been

launched in Braille.

Living Paintings are now reaching 10,000

blind and partially sighted people across the

UK with their FREE postal library.

They publish unique Touch to See books

with raised pictures accompanied by audio

descriptions.

You can find out more about Living Painting

via their website:

www.livingpaintings.org

Activities

Following our successful BBC Children in

Need funding, ASUK National Transition

Coordinator Marie McGee has been

organising fantastic healthy eating

workshops such as ‘Foodie Fun Friends’

to coincide with the Children’s multidisciplinary

clinics at the Birmingham

Children’s Hospital. These have been very

well received by families, who have enjoyed

the sessions, particularly the new healthy

foods to try. It has also been a great chance

for families to come together to get to

know one another and have some fun! One

parent gave their thoughts “Loved it! Herbal

tea would be a great option. I loved seeing

the kids having so much fun.”

As one of the children has limited function

in one of her upper limbs she adapted the

activity by using her chin instead of her

hand. This was something that she worked

out for herself and went onto join in with

the activity as an equal to her peers. She

even coined the phrase ‘Chin Power’ which

we all quoted at some time during the

activity. She reminded us all where there is

a will, there is a way!

Marie also organised for the Midlands

Police Force to drop by, for one little boy

who is fascinated with the Police Force.

They even let him take home some life size

police pictures and memorabilia for his

room, he was over the moon!

Marie is organising a residential activity weekend

at Whitemoor Lakes for young people

affected by Alström Syndrome and their

families from the 18th – 20th March. We are

also planning a horse riding residential break

and sailing activity day, so please get in touch

if you would like further information.

Please also get in touch with your ideas for

future activities and we will try and organise

these for you. Events will be funded by ASUK,

to secure your place, please contact:

Marie McGee on Tel 07812 173953 or

email marie.mcgee@alstrom.org.uk

ASUK Family

Wishes Do Come True! Wishes Do Come True!

Millie absolutely loves Frozen and has

always dreamed of playing in the snow

with her favourite character – Olaf! Thanks

to the Make a Wish Charity, Millie’s dream

became a reality.

In November, the family arrived at the

Snowdome in a limo, where Olaf was

waiting in reception, Millie’s face lit up

when she saw Olaf waiting for her! She

ran straight towards him and gave him a

massive hug. Hand in hand they went to the

party room where Olaf danced and danced

with Millie!

Next it was time to play in the snow! Olaf,

Millie and her family threw snowballs at

each other, whizzed down the snow slide

on sledges and rolled in the snow. Olaf gave

Millie some presents which she absolutely

loved! He even wrote her a special message

on her new game: ‘Thank you for being my

best friend, lots of love Olaf.’ After lots of

cuddles, laughter, dancing and games – it

was finally time to say goodbye. Later that

evening the family went to watch Disney on

Ice and Olaf skated over to Millie’s front row

seat and waved at her. “She was so

excited, to her it’s the world,” Mum Michelle

remembers. “That’s something she’s going

to treasure for a long, long time.”

There are many charities that create special

memories by providing special activities,

holidays or even equipment such as a

sensory room in your home.

Most grant providers, personalise the

wish to exactly what you would like so

it is a truly magical and unforgettable

experience. Many families who are affected

by Alström Syndrome have had amazing

wishes granted such as a dream holiday

to Disneyland Florida and a Formula One

Race Day. Please get in touch with the ASUK

team if you would like to apply to a dream

making charity and we will try and help

make your dreams a reality.

The Seeing Ear Poetry Competition

You may remember in our summer newsletter we published your poems from the Seeing Ear Poetry Competition. Many of you

entered and your poems are going to be published in the anthology, well done!

You can see all the winners at the following link: http://www.seeingear.org/home/the-seeing-ear-poetry-competition/

Twins Katie and Hannah Beck (pictured

above) are also having their poems about

‘winter’ published:

Winter

White, frosty snowmen

Fried onions on steaming hotdogs

Gliding reindeers pulling Santa’s sleigh

Jack Frost making nose’s cold

Bobble hats and warm woolly socks

Winter is here

By Hannah Beck, aged 8 years old

Winter

Icy white frost on the grass

Silver cobwebs shining in the morning sun

Hot chocolate with fluffy white cream

Robins tweeting, looking for food

Tinkling bells on Santa’s sleigh

Winter’s on its way

By Katie Beck, aged 8 years old

 One of our members, Debbie Lewis has

also composed a very moving poem about

her experience prior to her son being

diagnosed:

When Adam was first shown to me

A beautiful baby was what I could see

Ten perfect fingers, ten perfect toes

Two lovely brown eyes and a small button nose

A sleeping baby, so content

We knew he had been heaven sent

We loved him more each passing day

“He’s a gorgeous baby” people would say

We never dreamed there was something wrong

He ate well, slept well, grew big, grew strong

Eight months later problems showed

Doctors said “development slow”

Late to sit, to crawl, to walk

We waited four years to hear him talk

“Please God No” I silently plead

But our darling Son has special needs

People tell us we’ve been blessed

God’s special children go to the best

But I get so angry deep inside

I just wish someone could tell us why

Eight years later we still don’t know

Adam remains undiagnosed

But we know we are lucky

He’s well and he’s strong

When he plays and he laughs

You would think nothing is wrong

What does it matter if his development is slow

We both love him dearly

That much we know

 Awareness Raising Awareness Raising

We are seeking to improve awareness of the

charity, and network with our current and

potential partners in a number of ways in

order to help all our families and members.

In recent months this has been happening

both in the UK and in Europe.

Within the UK

On the 14th July 2015 Kerry (pictured

below) attended the Genetic Alliance

Conference: celebrating 25 years of

supporting, campaigning and uniting.

Kerry had the honour of presenting at this

prestigious conference and informing the

delegates about our great work, raising

awareness and uniting together to support

genetic conditions throughout the UK.

Ensuring patients voices are always heard!

On the 14th September Kerry attended

the Cambridge Rare Disease Network’s

first annual conference. The Cambridge

Rare Disease Summit took place at the

Cambridge Judge Business School. Bringing

together 150 key stakeholders to debate

how to best address the huge social and

therapeutic unmet needs around rare

diseases. A range of topics were discussed

including Alternative Funding Strategies,

New Rare Disease Initiatives on the Horizon,

the Potential of the Cambridge Cluster and

Engaging with Pharma.

You can find out more via their website:

www.camraredisease.org

On the 19th October 2015 Kerry also

attended the Ciliopathy Alliance 5th

Anniversary Members meeting in London.

This was a great opportunity to present

our research updates at the meeting and

network with other similar organisations.

More information about the work of the

Ciliopathy Alliance can be found via their

website:

www.ciliopathyalliance.org/events/futureevents.

html

MSc Genomic Medicine

On Friday 2nd October 2015, Iram Shah was

a speaker on “Living with a rare disease”

part of the MSc Genomic Medicine at the

University of Birmingham. The purpose

of the talk was to share her journey of

living with a rare disease and also to stress

the importance of holistic integration of

genomic technology into patient care

within the National Health Service,

including via the ambitious Genomics

England Ltd (GeL) 100,000 Genomes

Project.

Iram (pictured below) also attended the

mySense conference on Saturday 7th

November in Birmingham. This was a

very informative conference, offering

information stalls and workshops

throughout the day. Iram attended many

benefit changes and exploring the world

through play workshops and networked

with other attendees to share ideas and

experiences.

Throughout Europe

Kerry headed across to Barcelona to

attend the innovative Asterix Meetings.

Kerry represented ASUK and Patient Think

Tank to ensure patients voices are heard

at every stage. Patient Organisations and

Statisticians joined together to explore

clinical trial designs in small patient

populations and discussed the challenges

this presents and possible solutions. You

can find out more about the work of Asterix

via their website http://www.asterix-fp7.eu/

Kerry (pictured below) has also just

returned from the World Orphan Drugs

Congress, in Geneva, where she engaged

the delegates in our journey and current

developments. This was a great opportunity

to raise awareness and seek insights into

research projects and developing future

collaborations with patient organisations,

academics, medical professionals and

pharmaceutical companies.

Information and Campaigning Information and Campaigning

LSE Published on

Orphanet

Orphanet Journal of Rare Diseases has

published the work we initiated with the

London School of Economics in 2014

about High quality, patient centred and

coordinated care for Alstrom Syndrome:

a model of care for an ultra-rare disease.

It focused on researching the cost

effectiveness of the service we provide and

the additional costs which families face.

Orphanet Journal of Rare Diseases is

an open access, online journal that

encompasses all aspects of rare diseases

and orphan drugs. The journal publishes

high-quality reviews on specific rare

diseases, aiding further awareness raising

for AS and ASUK.

The conclusion of the study has shown

that organised, multidisciplinary “one stop”

clinics are patient centred and individually

tailored to the patients needs with a better

outcome and comparable cost compared

with the current standard of care for rare

disease. Our proposed care model can be

adapted to several other rare and ultra-rare

diseases.

Further information and the research article

can be found via the link below:

www.ojrd.com/content/10/1/149

Nystagmus The Way

We See It

Please go to the on-line link below to

watch this amazing video featuring TV

presenter Richard Osman and produced

by Nystagmus Network. It is an insight

into having the condition and not letting

anything hold you back!

The Nystagmus Network is the UK’s leading

charity for nystagmus. It provides support

and information as well as encouraging and

funding research and raising awareness of

the condition. You can find out more about

their work via their website:

www.nystagmusnet.org/https://m.youtube.

com/watch?v=Ey-UD5Vzu\_Q

Demand Change!

DEMAND CHANGE and join Neil Morrissey,

Ross Kemp, Barabara Windsor, Dame Shirley

Bassey and many more who #seetheneed

for a sight loss advisor in every eye

department by 2019. Currently only one in

three UK eye departments offers this vital

support.

Go to the RNIB website and add your name

now...

www.rnib.org.uk/see

Rare Disease Day 2016

Plans for this year’s Rare Disease Day

events are well underway. There will be

parliamentary receptions in all four of the

home countries – so make sure you take

note of the dates now:

• Welsh Reception, 23rd February, 6-8pm,

Senedd Cardiff.

• Northern Ireland Reception, Monday

29th February, Stormont, Belfast.

• Scottish Reception, Tuesday 1st March,

Holyrood, Edinburgh.

• Westminster Reception, Wednesday 2nd

March, Houses of Parliament, London.

In addition to these receptions Rare Disease

UK are hosting a number of events across

the country in collaboration with the

National Institute for Health Research’s

Rare Disease Translational Research

Collaboration (NIHR RD-TRC).

More information can be found via their

website:

www.raredisease.org.uk

You can also find more information at:

https://www.rareconnect.org/en/community/

alstrom-syndrome - connecting rare disease

patients globally

New Paediatric

Dietician Joins the AS

Team

My name is John Pemberton, I am the new

Paediatric Dietitian for the National Alström

Syndrome Clinic held at Birmingham

Children’s Hospital. I am following on from the

good work of Hazel Riggall who has retired.

I started in September and have enjoyed

meeting many families at the National

Conference and in the September and

November clinics.

I have worked as a Dietitian for ten years, six of

those in the NHS specialising in diabetes and

four years working for a private company that

manufactures medical devices for diabetes.

Having a mixture of experiences in both

public and private health care has fostered a

strong desire to achieve results for the people

I see. Alström Syndrome is very new to me

and I am looking forward to learning as much

from the families about Alström Syndrome as

hopefully they will from me about nutrition

and exercise.

My personal interests in nutrition and exercise

with specific reference to Alström Syndrome

are:

1. Insulin resistance is a known issue

with Alström Syndrome, therefore, what

is the carbohydrate tolerance for Alström

Syndrome? Does it vary from patient

to patient? What is the best advice for

carbohydrate amount?

2. High intensity Exercise (HITT) is the

best know type of activity to reduce insulin

resistance. I am interested to find out through

experience, if this is practical, possible and

desirable for people with Alström Syndrome.

Examples of HITT exercise protocols are

exercise (running/rowing/fast walking/

jumping jacks/air squats) fast pace for 20

seconds (out of breath), then 10-20 seconds

rest and then repeat eight times in total so the

whole session only takes 4-6 minutes. HITT

exercise has been shown to be more effective

than 30 minutes of continuous moderate

paced activity.

3. How can I make the education on

portion sizes as practical as possible given

that sight and hearing can be impaired

with Alström Syndrome. My initial thoughts

are using hands as the portion guides, as

everybody carries them around so you do

not need scales and booklets! For example,

at meal times it’s easy to assess if your sizes

are ok if you know one palm size of meat is

enough and one fist size potato is enough

with one thumb of butter but you can have

two or more palm sizes of vegetables. I like

the KISS approach (Keep It Simple Stupid) as I

often need things explained simply.

With Christmas coming up there are treats,

massive carbohydrate portions and parties

ahoy! First of all enjoy yourself its Christmas

but keep in mind Christmas is one day of

big eating not two whole weeks! One thing

I have invested in and to assist in keeping

me trim is a Spiralizer. Visit Mr. Google to see

this in action but it essentially a cheap tool

that allows you to make vegetables linguine

style and may help keep your carbohydrate

portions under control and who knows

vegetables may even become fun.

Have a Merry Christmas

John Pemberton RD

Paediatric Diabetes Dietitian

Birmingham Childrens Hospital

ASUK Family and Professional Information and Activity Day 2015 ASUK Family and Professional Information and Activity Day 2015

On the 19th September 2015, our Information

and Activity Day was held at New College

Worcester. It was great to see so many families

enjoying themselves throughout the afternoon

with fun filled activities and informative

workshops. The day was chaired by ASUK Trustee

Kez Hayat and the morning sessions featured

our future pioneering research projects, clinical

updates and information sessions.

In the morning, we had clinical presentations

from our AS medical teams, Dr. Tarek Hiwot,

Professor Barrett and Dr. Rob Cramb and Dr. Rick

Steeds presented his cardiomyopathy study

findings and updates.

Families then had the chance to listen to Aline

Hagerimana, Director of Clinical Affairs, from

Prometics who had travelled from Canada to

give families an overview of the fibrosis clinical

trial. This was followed by a presentation from

Dr. Richard Paisey about the proposed ‘lifestyle

study’ researching the effects of a healthy

lifestyle and how this can help patients manage

their condition more effectively.

Jane Lodwig, Rare Disease Project Manager at

University Hospital, Birmingham showcased the

new Rare Disease Centre and explained how

these plans were coming together. Before lunch,

Sue Bushell, Community Engagement Officer

from Guide Dogs for the Blind gave an overview

of the work of Guide Dogs for the Blind and

provided useful information for families.

Families embraced the opportunity to chat with

the professionals and medical experts attending

the conference and the chance during the panel

discussions to ask any questions in a relaxed and

informal manner.

At the event, the ASUK Team were on hand to

support families to ensure they enjoyed a range

of activities including circus skills, drumming,

horse-riding, go-karts, zorbing, swimming,

bouncy castle, mini-zoo and archery. Workshops

were held in the afternoon and these included

healthy eating and cooking workshops and

technology demonstrations.

Hands on activities such as the mini-zoo

were great ways that members affected by

sensory impairments could have a memorable

experience. The zoo proved very popular for

families to be able to hold and feel exotic animals

such as ‘Alex’ the meerkat (pictured below) who

proved a real hit!

In the afternoon we held a number of

information and support sessions including

a Mums/Female Carers Workshop which was

facilitated by Iram and Dads/Male Carers support

session which was facilitated by ASUK Trustee

Kez Hayat. The running theme of the workshop

was around the child with Alström and their

journeys in living with this complex condition.

The sessions provided mutual support and

enabling each other to feel safe enough to share

their own experiences and learn from each other.

These sessions went really well and the overall

consensus was that participants really value

coming together to talk about their experiences

and to learn and network from each other, which

they feel is very powerful.

The healthy eating workshop provided a chance

for families to create some quick and easy

healthy meals with Natalie Bufton (New College

Worcester, ILS Teacher), Marie McGee (ASUK

Transition Coordinator) and Sarah Boocock

(Dietician at UHB).

Families also had the opportunity to have a go at

Goal Ball with one of our members, Liam Mackin

and gain further information from Guide Dogs

for the Blind and Dolphin Computers as well as

technology demonstrations.

A huge thank you to New College Worcester, their

support and facilities were excellent to provide

both activities and conference presentations.

Tours of the college were available throughout

the afternoon to enable families to ask any

questions about the specialist school.

It was great to see so many families enjoying

the activities in the afternoon, every activity was

accessible and provided fantastic opportunities

for everyone to have a go no matter what their

disability – proving it is what you can do that is

so important.

During the Annual General Meeting which

was Chaired by Michelle High, families and

professionals came together to learn more

about the charities work over the past year and

our priorities moving forward. Before leaving

everyone had the opportunity to socialise

together as they enjoyed a delicious two course

meal, followed by a fun raffle before travelling

home.

One family gave their thoughts “Everything was

good, the kids loved all the activities, especially

the horse riding. We had a very memorable,

amazing time here”

ASUK will shortly be circulating a conference

report and questionnaire so we can ensure our

next conference in 2016 is bigger and better and

encompasses all your needs and aspirations.

Fundraising

THANK YOU to Our Fantastic Fundraisers! 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 London Bupa 10,000 run. These funds raised

really do make a huge difference and ensure we can support families throughout the year.

ASUK 2016 Calendar, Order Yours Today!

Thank you too to all the families who sent in their most precious family photos for the ASUK

2016 calendar. A HUGE THANK YOU to our sponsors New College Worcester, Retro Box Gifts,

RKD Films, HearFirst Training and Custard Moon Entertainments

We ask for donations of £10 for each calendar so please get in touch to order yours today – they will make great Christmas presents!

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 safe and secure Just Giving page https://www.justgiving.com/alstromsyndromeuk/

Did you know?

Information Standard

Certification

ASUK Office Manager Catherine Lewis has

been working hard to develop and uphold the

Information Standards kite marker.

We are delighted to announce that we have

maintained the Information Standards

Certification for another year, meaning you can

be assured that ASUK has undergone a rigorous

assessment and that the information we produce

is clear, accurate, impartial, evidence-based and

up-to-date.

ASUK is committed to producing trustworthy

health and care information of a high quality for

families and professionals. Always look out

for The Information Standard quality mark.

Welcome Steve

to Our Team

We are delighted to welcome Steve Scoffield

as our Finance Manager. Steve is a Chartered

Accountant with sixteen years experience

working in the charity sector, including eleven

years as Director of Finance at Lee Abbey in

Lynton and four years as Bursar at Broomhayes

the National Autistic Society School in Bideford.

Since leaving Broomhayes, Steve has worked

with a number of small charities and social

enterprises. Steve has also held a number of

charity trustee positions including nine years as

treasurer at North Devon Hospice.

Steve lives in Barnstaple with his wife Cathy.

They have two daughters and a three year old

granddaughter and are excitedly awaiting the

arrival of their second grandchild expected in the

New Year.

In his spare time Steve is a keen rugby and cricket

supporter his teams are Gloucester Rugby and

Worcestershire County Cricket Club. During his

time at Lee Abbey he found out he could sing

ASUK OFFER A 24 HOUR

HELP-LINE, COVERED BY

OUR VERY EXPERIENCED

TEAM:

Kerry Leeson-Beevers

Tel: 01709 210151 / 07716135940

Email: Kerry.leeson@alstrom.org.uk

Catherine Lewis

Tel: 01803 613117 / 07970071675

Email: Catherine.lewis@alstrom.org.uk

Iram Shah

Iram works part time and is fluent in

Urdu and Punjabi

Tel: 07988237664

Email: iram.shah@alstrom.org.uk

Marie McGee

Marie works part-time,

offering transition support to young

people and their families

Tel: 07812 173953

Email: marie.mcgee@alstrom.org.uk

Please feel free to contact any

member of the team.

and became known as “Pavarotti”, since moving

to Barnstaple he has been a member of a number

of local choirs.

We are delighted to welcome Steve who will be a

great asset to our team.

Registered Office

Our address is 31 Shearwater Drive, Torquay, Devon

TQ2 7TL

T shirts

ASUK T-shirts are available in sizes small, medium,

large, Extra Large and 2 XL. Families affected by

AS may have a free t-shirt per person affected.

Additional t-shirts are priced at £10 each.

You Tube, Twitter and Facebook

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 and also via our dedicated facebook

page www.facebook.com/alstromsyndromeuk , please

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

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

our latest news.

This newsletter has kindly been funded

by the Ulverscroft Foundation, serving

the needs of the visually impaired.

Tel: 01803 613117 or email Catherine.lewis@alstrom.org.uk

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.

With your help, we have hope