Alström NEWS

With your help we have hope

THE NEWSLETTER OF ALSTRÖM SYNDROME UK

Winter 2015 Issue No.16

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

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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

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

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 multi-disciplinary 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 week-end 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

Supported by
BBC Children in Need

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

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/future-events.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

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

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.

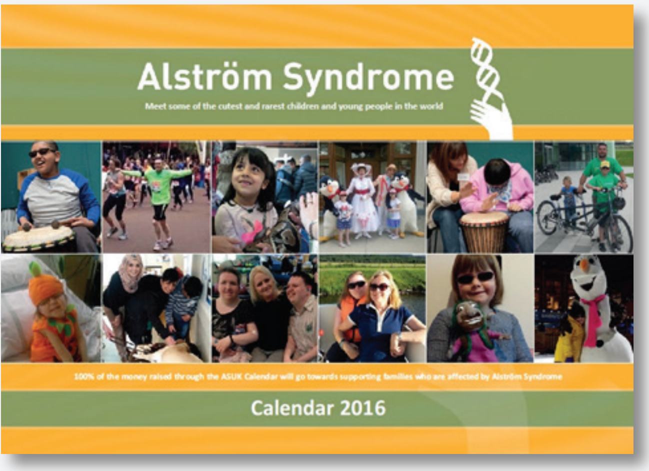
Fundraising

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/

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
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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.

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.

Health & care information you can trust
The Information Standard
Certified Member

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 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.