



**Alström Syndrome UK**  
Strength for today, hope for the future

Alström Syndrome UK (ASUK) is an award winning charity who provide information, support and advice for individuals affected, their families and carers and professionals. Alström Syndrome is a very rare genetic condition which can cause progressive blindness, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very 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](http://www.alstrom.org.uk)



# A huge thank you

to our friends and supporters

## Welcome to the 19th edition of the summer newsletter.

Firstly, a huge thank you to all of those that have raised money and awareness of our charity this year, your support is greatly appreciated. Our theme over the last 6 months has been awareness raising and developing resources. I'm delighted that the animation 'Living with a rare disease' has received over 1300 views in 3 months, as well as the launch of the new website, providing links to new resources and links from partner organisations.

The website has been viewed in 74 different countries, with the most international visitors from the USA, Canada and Pakistan. This helps to strengthen our links with families and professionals, learning from each other and driving forward research initiatives. We will be asking you about your views and what you think our research priorities should be over the next 3 years.

### Family Support

I have great pleasure, in welcoming our new family support worker, Carrol Birchall to the ASUK team. Carrol has personal experience and a deep knowledge of AS, as well as being a trained advocate. She is out and about meeting families (mainly in the midlands and the north) she introduces herself on page 3.

### Conference 2017

Preparations for our 'Health, Happiness and Wellbeing' conference are well under way and I'm pleased to say that families have booked from across Europe, as well as families throughout the UK. Professor Pietro Maffei from AS Italy will be presenting his latest research and clinical developments, there will be updates on the clinical trial and the chance to get involved in the 'Fitbits' good health project with some personal stories about successful weight loss and improved fitness levels. I look forward to seeing you all there!

Meanwhile enjoy this summer update with a large glass of something cold and refreshing or in my case a cup of tea!



**Ann Chivers,**  
Chief Executive at ASUK

## Launch of animation

### - diagnosis doesn't have to be rare

Our animation was launched on the 12th May to raise awareness, aid diagnosis and show a positive and enlightening image of the condition and our work. The response we have had, has been fantastic, *'This animation is a work of brilliance! So enlightening, helpful, positive, educational. ... Congratulations! My early life on an animated screen! Thank you!'*

If you haven't had chance to view this yet, take a look, we would love to hear what you think <http://www.alstrom.org.uk/awareness-animation-is-launched/>



**Alström Syndrome UK**



## Have you seen our updated website?

We hope our new website will bring the Alström community and professionals together. Our aim is to make it accessible, useful and informative. You will find a wealth of information to learn more about this complex condition. We will be keeping it up to date with evidence based research and practice to improve the lives of those with Alström Syndrome and those who care for them.

Have a look at the Family Support pages, where you can find useful resources to guide you through the maze of benefits and support services. As well as not forgetting about the fun things you enjoy and highlighting organisations that provide accessible activities and breaks in the UK. Please get in touch if you have suggestions of organisations that you have found helpful and we can add to these resources.

Please tell us about your experiences and any topics you would like to see on the website. Feedback is always welcomed.

## Going, Going, GONE!

### Be quick to secure early bird rate at our unique event 'Health, Happiness and Wellbeing' Conference

We warmly invite you to our 'Health, Happiness and Wellbeing' conference taking place on the 6th and 7th October 2017 at the Aston Conference Centre in Birmingham.



Teams from Birmingham Children's Hospital and the Queen Elizabeth Hospital will be presenting clinical developments and research and clinical trial findings. Saturday includes practical workshops on the law and benefits, fitness and health, technology, Independent living and much more.

If you need accommodation; we have negotiated an early bird rate at the Holiday Inn, Snow Hill (near Birmingham Children's Hospital) in Birmingham at £59.00 per room, per night (rooms sleep two adults and two children) but these rooms are limited so please contact the hotel directly on 0121 647 3999 quoting A1C Group Name: Alström Catherine Lewis by the 31st July 2017 so you can ensure you get this special rate.



The conference will begin with a scientific symposium from 2:00 pm on Friday 6th October and will conclude after an evening of entertainment and celebrations on Saturday 7th October 2017.

The event aims to bring together families, individuals and professionals to learn more about this ultra-rare condition. This is a unique opportunity to hear about pioneering research and clinical developments, take part in interactive workshops and learn from each other's experiences; as well as meeting up with other families and friends. Join us for either or both days.

We're delighted that Dr Pietro Maffei from AS Italy and Professor Colin Johnson from the Institute of Molecular Medicine at St James's University Hospital, have agreed to speak about their current research and clinical developments.

Conference booking forms can be found on our website <http://www.alstrom.org.uk/asuk-conference-book-today/> If you are having any difficulties completing the booking form or if you would like the information in an alternative format such as Braille, please call or email me.



## We look forward to seeing you all there!



## Breaking down Barriers, logo is unveiled!

The Breaking down Barriers project focuses on developing supportive and inclusive services for individuals and families affected by genetic conditions. Providing opportunities for people to learn and talk about genetics to enable them to make informed choices about their future. The advisory board are pleased to launch their new logo and feel it reflects the meaning of this diverse project. You can find out more about this project via their website [www.breaking-down-barriers.org.uk](http://www.breaking-down-barriers.org.uk)

*Understanding genetics together in our diverse Britain*

## ASUK is delighted to welcome Carrol to our team!

Carrol Birchall, who many of you may already know has joined us as a Family Support Worker. With Carrol's experience and knowledge of Alström Syndrome, advocacy work and supporting families, we know she will be a real asset to our team.

"I am delighted to join the team at ASUK to support families. I am the mother of a young man who has Alström Syndrome and have supported him through sight and hearing loss, diabetes and various other issues that come along with Alström Syndrome. I have previously worked for Herefordshire Peoples Advocacy

in the Crisis team, Dudley Citizens Advice Bureau as an Outreach Caseworker and Preston Advocacy as an advocate. I also have the privilege of being a volunteer Family Outreach Coordinator for Alström Syndrome International and have participated in many international conferences and adult team activities over the years.

I have experience of empowering individuals and supporting adults with complex needs. In my free time, I sing in a local community choir and love to go for long walks with our Springer Spaniel, Angus." **Carrol**



## ASUK joins UK Rare Disease Policy Board – Improving services for all

ASUK is delighted to announce we are now on the UK Rare Disease Policy Board.

ASUK is involved to help improve services for people with Alström Syndrome and others affected by rare conditions in the UK. The All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions published a report calling on the Department of Health to implement the Strategy for Rare Diseases and improve services for people affected by rare conditions.

The work of the UK Rare Disease Policy Board will include the continuing development of the Strategy for Rare Diseases, ensuring the 51 commitments from the strategy are being met. The UK Strategy for Rare Diseases highlights the way we can improve the lives of all those with rare diseases in the UK by 2020. It details 51 commitments and each part of the UK will take action and develop plans to implement the strategy, working together to pool resources, knowledge and experience where possible.

You can read the full report and find out about the 51 commitments from the Rare Disease Strategy via the Rare Disease UK website:

<https://www.raredisease.org.uk/uk-strategy-for-rare-diseases>

### Contact a Family, introduce their birth to five parenting workshops

Contact a Family offer useful resources and information for families including information about benefits, welfare rights, local services and support, activities and education. They have also received funding to provide workshops about early years entitlements, visit their website to find out more

<https://www.cafamily.org.uk/news-and-media/introducing-our-birth-to-five-parenting-workshops/>

The Contact a Family Freephone helpline for parents and families is 0808 808 3555.

### New funding rules for children with SEND

Special Needs Jungle provides useful information about special educational needs and disability issues faced by children and their parents. They have produced an article about the new funding rules for Children with Special Educational Needs to try and help families navigate all these changes, which can be viewed on their website

<https://www.specialneedsjungle.com/explaining-new-funding-rules-for-early-years-children-with-send/>

If you would like individual help with entitlements relating to education contact

ASUK National Transition Coordinator, Marie McGee. You can get in touch with Marie by email [marie.mcgee@alstrom.org.uk](mailto:marie.mcgee@alstrom.org.uk) she would love to hear from you.



(Front cover of the report, picture kindly provided by Rare Disease UK/Josh Tucker.)



## SCULPTURE WORKSHOPS FOR VISUALLY IMPAIRED CHILDREN

**EUREKA!** the national children's museum in Halifax is looking for families of visually impaired children aged 5- 15 years to get involved with a brand new arts project starting in September. The project includes a free visit to the Yorkshire Sculpture Park as well as free entry to Eureka! on the day of each sculpture workshop.

Sessions will be led by Lynn Cox, an interdisciplinary artist and recipient of the Winston Churchill Memorial Fellowship. Under Lynn's guidance, the children will learn about sculptural forms at the Yorkshire Sculpture Park, experiment with different materials throughout the sessions and create a piece of sculpture which will go on display at Eureka! And Eureka! enablers will be on hand to make sure that everyone has fun.

**PLACES ARE LIMITED so you must be able to attend sessions on the following dates:**

- **30th September** - at the Yorkshire Sculpture Park
- **7 October, 11, 18, 25 November and 2 December** - at Eureka! the national children's museum, Halifax

EUREKA! May be able to offer assistance with transport to the Yorkshire Sculpture Park but you will need to travel to Eureka! independently. Eureka! is right by the train station, and a member of the Eureka! team can meet you there if you wish.

To find out more and register your interest, please contact Trizia Wells by emailing [trizia.wells@eureka.org.uk](mailto:trizia.wells@eureka.org.uk) and put **SCULPTURE SESSIONS** in the subject heading.

**Or you can phone Trizia on 01422 398474. PLEASE RESPOND BY FRIDAY 28 JULY**

## ASUK Raises Awareness on Rare Disease Day

Rare Disease Day is held every year on the last day of February, to raise awareness of rare conditions, how they can affect patients' lives and looking at ways to improve treatments and research. This year's theme was research, and the slogan, 'With research, the possibilities are limitless'.

ASUK Chief Executive, Ann Chivers and ASUK National Development Manager, Kerry Leeson-Beevers attended the British Paediatric Surveillance Unit event: 'From bench to bedside' at Birmingham Children's Hospital on the 27th February 2017 to mark Rare Disease Day.

The event focused on the development of new treatments for babies and children. Presentations considered the challenges of developing new treatments for rare diseases and the hurdles that exist in delivering new treatments to those who most need them. You can find out more about Rare Disease day via the Rare Disease Day website <http://www.rarediseaseday.org/>

**A big thank you to the lovely twins and their family, for allowing us to use their pictures on the new leaflets. We hope you all like our updated logo and colours as much as we do!**





## Enjoying a cup of tea at the Rare Disease Day Tea Party!

ASUK attended the Rare Disease Day, Tea Party on the 30th March 2017 in London. This was an opportunity to raise awareness through our new resources and network with organisations from the 'rare disease community'. ASUK National Development Manager, Kerry Leeson-Beevers is pictured left with Richard Lynn, Scientific Coordinator from British Paediatric Surveillance Unit (BPSU) enjoying a cuppa!

Kerry was also pleased to represent ASUK at the FP7 clinical trials and research workshop, at the European Medicines Agency on the 29th March 2017 in London. The workshop brought together Patient Organisations, Regulators, Researchers and Industry to develop further understanding about small population clinical trials and drug development for rare diseases.

## Let's connect

### Have you heard about Disease Maps?

These maps connect people with the same condition around the world. Alström Syndrome UK have added their details and wouldn't it be fantastic if we all added our information so we can see everyone around the globe. Have a look on the website to find out more

<https://www.diseasemaps.org/alstrom-syndrome/map/>

## Inspirational family – what an achievement!

In Maariyah's memory, her family and friends decided to raise awareness of Alström Syndrome by running in the Great Birmingham 10K run. The run took place on Sunday 30th April 2017 and they all finished the race, what an achievement!

**A HUGE THANK YOU** to the family for supporting Alström Syndrome UK. You can still show your support and visit their Just Giving fundraising page

<http://www.justgiving.com/princessmaariyah>

**The family have currently raised over £1,500!**



Thank you also to David Lunt who again ran in the Virgin London Marathon in aid of charities which are close to his heart, including ASUK.



## 'Let's Get Moving'

The Let's Get Moving project is now in full swing. We have sent out the welcome packs including a FitBit fitness tracker to gather information about exercise habits.

One of our members who is taking part explains *'I have now had the Fitbit for a month and love it. I discover more about the app every week. I'm still getting to the gym weekly despite not having a guide dog at present. Also, starting using the treadmill again twice a week and walk daily.'*

Dr. Richard Paisey will be gathering the data from the FitBits and information packs to analyse how a healthy diet and exercise may affect people with AS. Send your information to Dr. Paisey at [Richard.paisey@alstrom.org.uk](mailto:Richard.paisey@alstrom.org.uk) or if you would like to speak to him about the project you can call him on **01626 354758**. Please get in touch if you would like to find out more or be involved.

### Would you like to get out and about, running or walking?

British Blind Sport have launched a 'Find me a Guide Database' where anyone over the age of 18 who is affected by a visual impairment can search for a guide in their area to support them with running or walking. All guides are fully trained and DBS checked. You can find more about the work of British Blind Sport via their website <http://www.britishblindsport.org.uk/>

Just like ASUK, there are many organisations who promote the importance of a healthy lifestyle which includes fitness and exercise.

The deafblind charity, Sense are prioritising sport and physical activity as they believe it can play a key role in improving lives and keeping people fit and healthy. Not only the health benefits, social benefits, increased confidence as well as the potential to make new friends.

Sense Active was launched as a new function within Sense in 2014, following the award of £250,000 from Sport England to deliver an exciting project called Deafblind Active.

The project enables Sense to organise sports sessions including football, swimming, rowing, yoga, cycling and gymnastics. All sessions are free to attend! Parents and carers are welcome to come along and join in too.

Here are some of the sessions which are currently being run, you can also find out more by visiting the Sense website:

<https://www.sense.org.uk/content/about-sense-active>

### Birmingham - Sensory Sports Club

Friendly multi-sports sessions for young people aged 14-25. The range of fun activities including hockey, tennis, football, cricket and basketball! Family and carers are welcome to come along and join in too.

**Dates:** Every Thursday, starting 12 January 2017

**Time:** 6pm – 7.30pm

**Venue:** Queen Alexandra College, Court Oak Road, Harborne, Birmingham. B17 9TG

**How to book:** Places are limited – to book a place or for more information, please contact Callan Barber at [callan.barber@sense.org.uk](mailto:callan.barber@sense.org.uk) or on 07813 825 571.

### Peterborough - Yoga

Gentle, friendly yoga sessions for adults. Family, friends, carers and assistance dogs are welcome to attend too.

**Date:** Every 2nd Monday in 2017

**Time:** 2.00 – 3.00pm

**Venue:** St Peter and All Souls, Fitzwilliam Street, Peterborough, PE1 2RS

**How to book:** Places are limited – to book a place or for more information, please contact Callan Barber at [callan.barber@sense.org.uk](mailto:callan.barber@sense.org.uk) or on 07813 825 571.



### West Midlands - Adapted Cycling

Friendly adapted cycling sessions for people aged 14+. Come along and try a range of different bikes including tandems, trikes, hand-pedalled bikes and wheelchair-friendly bikes. Family and carers are welcome to come along and join in too.

**Date:** Every Wednesday starting 1 March 2017

**Time:** 11am -1pm

**Venue:** Tudor Grange Leisure Centre, Blossomfield Road, Solihull. B91 1NB

**How to book:** Places are limited – to book a place or for more information, please contact Callan Barber at [callan.barber@sense.org.uk](mailto:callan.barber@sense.org.uk) or on 07813 825 571.

### London - Ice Skating

These sessions are for people aged 14 years or over with a sensory impairment or complex needs. Parents, carers and support workers are very welcome to come along and join in.

**Date:** Starting 19 April, every Wednesday until 12 July. (No session 1 June)

**Time:** 12.15pm-1.15pm

**Venue:** The Sobell Centre, Hornsey Road, London. N7 7NY

**How to book:** Places are limited – to book a place on the sessions, or for more information, please contact Taylor Huxster at [taylor.huxster@sense.org.uk](mailto:taylor.huxster@sense.org.uk) or on 020 7014 9365 (available Tues, Wed and Thurs)

### London - Yoga

These sessions are for people aged 14 years or over with a sensory impairment or complex need. Parents, carers and support workers are very welcome to come along and join in.

**Date:** Starting 20 April, every Thursday until 29 June.

**Time:** 2.15pm-3.45pm

**Venue:** Pancras Square Leisure, 5 Pancras Square, London. N1C 4AG

**How to book:** Places are limited – to book a place on the sessions, or for more information, please contact Taylor Huxster at [taylor.huxster@sense.org.uk](mailto:taylor.huxster@sense.org.uk) or on 020 7014 9365 (available Tues, Wed and Thurs)

### Get Yourself Active research project

Get Yourself Active and the University of Birmingham want to find out what you think about how information about physical activity and sport is presented to disabled people.

You can do this in your home. It would take in total about 15 minutes of your time.

#### Who should take part in the research?

- If you are disabled and affected by one or more of the following impairments: amputation, spinal cord injury, restricted growth, Cerebral Palsy, visual impairment, hearing impairment
- If you have been unable to take part regularly in physical activity or sport for a while
- If you are over the age of 18

### How to get involved

Get in touch with Eva Jaarsma, if you are interested in taking part in this research and give your name and the best way for the researcher to contact you. They will then arrange a time for you to take part in the research from your own home. Once your bit is done you will receive your £15 Amazon voucher. You may also randomly be selected to receive £100 Amazon Voucher!

#### Who to contact

Eva Jaarsma – Research Fellow at University of Birmingham

**Email:** [E.Jaarsma@bham.ac.uk](mailto:E.Jaarsma@bham.ac.uk)

You can find out more on the following website

<http://www.getyourselfactive.org/2017/04/25/take-part-in-our-research-and-receive-a-15-amazon-voucher/>

### Summer holiday fun!

With the summer holidays upon us, looking for accessible activities to keep your children and young people entertained, can at times be tricky. Victa is a charity who provide a range of fun activities throughout the year for children and young people who are visually impaired. These include fun day trips as well as activity week-ends and even International trips. Places are limited so please go to their website to find out more

<http://www.victa.org.uk/2017-victa-activities/>



## Heatwave strikes – key points to remember

The NHS have brought together key points to stay safe and well during the hot summer weather, particularly when heatwaves strike. Further advice can be sought via their website <http://www.nhs.uk>

### Main risks:

The main risks posed by a heatwave are:

- dehydration (not having enough water)
- overheating, which can make symptoms worse for people who already have problems with their heart or breathing
- heat exhaustion and heatstroke

### Who is at risk?

A heatwave can affect anyone, but the most vulnerable people are:

- older people, especially those over 75
- babies and young children
- people with a serious chronic condition, especially heart or breathing problems
- people with mobility problems – for example, people with Parkinson's disease or who have had a stroke
- people with serious mental health problems
- people on certain medications, including those that affect sweating and temperature control
- people who misuse alcohol or drugs
- people who are physically active – for example, labourers or those doing sports

### 1 Level one alert: be prepared

The Meteorological Office has a warning system that issues alerts if a heatwave is likely. Level one is the minimum alert and is in place from June 1 until September 15 (which is the period that heatwave alerts are likely to be raised).

Although you don't have to do anything during a level one alert, it is advisable to be aware of what to do if the alert level is raised. Knowing how to keep cool during long periods of hot weather can help save lives.



### 2 Level two alert: heatwave is forecast

The Met Office raises an alert if there is a high chance that an average temperature of 30C by day and 15C overnight will occur over the next two to three days. These temperatures can have a significant effect on people's health if they last for at least two days and the night in between.

Although you don't need to take any immediate action, follow these steps in preparation:

- Stay tuned to the weather forecast on the radio, TV or social media or the Met Office
- If you're planning to travel, check the forecast at your destination.
- Keep cool and hydrated

### 3 Level three alert: when a heatwave is happening

This alert is triggered when the Met Office confirms there will be heatwave temperatures in one or more regions.

Follow the instructions for a level two alert. The following tips apply to everybody when it comes to keeping cool and comfortable, and reducing health risks.

### Tips for coping in hot weather

- Shut windows and pull down the shades when it is hotter outside. You can open the windows for ventilation when it is cooler.
- Avoid the heat: stay out of the sun and don't go out between 11am and 3pm (the hottest part of the day) if you're vulnerable to the effects of heat.
- Keep rooms cool by using shades or reflective material outside the windows. If this isn't possible, use light-coloured curtains and keep them closed (metallic blinds and dark curtains can make the room hotter).
- Have cool baths or showers, and splash yourself with cool water.
- Drink cold drinks regularly, such as water and diluted fruit juice. Avoid excess alcohol, caffeine (tea, coffee and cola) or drinks high in sugar.
- Listen to alerts on the radio, TV and social media about keeping cool.
- Plan ahead to make sure you have enough supplies, such as food, water and any medications you need.
- Identify the coolest room in the house so you know where to go to keep cool.
- Wear loose, cool clothing, and a hat and sunglasses if you go outdoors.
- Check up on friends, relatives and neighbours who may be less able to look after themselves.



If you're worried about yourself or a vulnerable neighbour, friend or relative, you can contact the local environmental health office at your local authority.

Environmental health workers can visit a home to inspect it for hazards to health, including excess heat.



#### **Level four alert: severe heatwave**

This is the highest heatwave alert in Britain. It is raised when a heatwave is severe and/or prolonged, and is an emergency situation.

At level four, the health risks from a heatwave can affect fit and healthy people, and not just those in high-risk groups. These groups include the elderly, the very young and people with chronic medical conditions.

Follow the information given above for a level three alert. Check that anyone around you who is in a high-risk group is coping with the heat.

#### **How do I know if someone needs help?**

Seek help from a GP or contact NHS 111 if someone is feeling unwell and shows symptoms of:

- breathlessness
- chest pain
- confusion
- intense thirst
- weakness
- dizziness
- cramps which get worse or don't go away

**Get the person somewhere cool to rest and give them plenty of fluids to drink.**



Deafblind UK is a national charity supporting people with sight and hearing loss to live the lives they want. They offer a range of free services to help people build their confidence and independence; continuing their lives beyond sight and hearing loss.

These services include practical advice and information as well as emotional support for you and your family.

Their Information and Advice Line is free to call and is open from 9am to 5pm Monday – Thursday and 9am to 4pm on Friday, call 0800 132320 or text 07950008870. They can also provide support through home visits, befriending services, benefits advice, social activities and technology assistance. If you are in need of a holiday, they have two caravans in Wales and Norfolk which is available to members in need of some relaxation.

**For more information please visit their website [www.deafblind.org.uk](http://www.deafblind.org.uk)**

## **Ensuring voice of young people is heard**

Rare Disease UK has announced a new project that aims to find out more about children and young people's experiences of living with a rare, genetic or undiagnosed condition.

This will ensure that everyone affected by a rare, genetic or undiagnosed condition, no matter their age, has their voice heard. To find out how you or your child can get involved, and for more information about the project go to the Rare Disease UK website.

<http://www.raredisease.org.uk/news-events/news/rare-disease-uk-announces-new-project-about-children-and-young-people-s-experiences>

## ASUK Transfer week-end for young people

On the 1st July 2017, young people and their families embarked on a transfer week-end with a difference. In preparation for moving across to the adult clinics at the Queen Elizabeth Hospital in Birmingham, youngsters were welcomed to the Rare Disease Centre at the QEH to meet the team and familiarise themselves with the facilities. ASUK also supported families to get to know one another, sharing their own experiences and knowledge through a fun game of bowling and over dinner.

Families also had the opportunity to try out new technology during an Apple workshop looking at accessible technology. Transferring to adult services can be a daunting prospect for many youngsters, so we wanted this to be a positive experience not only through support and information, but to be fun and enjoyable for families.



## Queen Alexander College, Sight Village 2017

ASUK exhibited at Sight Village in Birmingham on the 18th and 19th July 2017. The event was free to attend and showcased the latest technology, products and services for people who are visually impaired. On the 19th July, Kerry and her son, Kion presented an interactive workshop about their experiences and top tips of living with sight loss.

ASUK will also be exhibiting at Sight Village Manchester on the 27th September 2017, if you are attending please come by the stand and say hello. You can find out more via the QAC website at <http://www.qac.ac.uk/exhibitions.htm>

## In need of a holiday!

The charity 'LOOK' has provided affordable holidays for the VI community for the last ten years in the north Yorkshire beach resort of Scarborough. Scarborough is a seaside resort with award winning sandy beaches, breath-taking coastline and many family attractions to discover. 'Look' provide a 5-bed holiday flat available to rent for adults, young people, children and their families who are affected by visual impairment. There is still some availability this summer so if you fancy a break to the seaside get in touch with 'Look' to find out more.

To find out about LOOK's other services for young people and their families or to book or check availability,

call 07766220933/ 01432 376314 or email [admin@look-uk.org](mailto:admin@look-uk.org)



## EURORDIS: access to medicines for all

EURORDIS has published their position on early access to medicines in Europe; arguing for compassionate use to become a reality so patients in urgent need get the help and treatments needed. Currently many medicines take far too long to develop, which for many rare and complex conditions, these medical interventions are urgently needed.

A 'compassionate use programme' is sometimes used when all other options have been exhausted and patients are willing to take the higher risk of using a non-tested products which may offer help.

Depending on where you live, really does depend on if you can benefit from the 'compassionate use programme' and EURORDIS aim to help patient organisations, industry, member states and European authorities to recommend policy ideas to help. Further information and the Position Paper can be found on the EURORDIS website:

<http://www.eurordis.org/publication/early-access-medicines-europe-compassionate-use-become-reality>



## 27th June National Sunglasses Day



The 27th June 2017 marked National Sunglasses Day. ASUK got involved posting themselves in their shades to highlight how important this is, and even the office pets got involved!

Sunglasses protect your eyes, so remember to wear them 😊

## National Deaf Children's Society

National Deaf Children's Society are launching their new strategy and constitution this summer. It will renew their direction for the next few years and updating their constitution will help deliver the strategy. There will be an opportunity for their members to vote on these changes during their AGM in November. Please go to their website to find full details

[http://www.ndcs.org.uk/about\\_us/constitution/index.html](http://www.ndcs.org.uk/about_us/constitution/index.html)



Find out more via the RNIB website  
<http://www.rnib.org.uk>

ASUK offer a help-line during office hours and an answer phone service at all other times where calls are promptly returned by our experienced Family Support team;  
**Please call 07970 071675 / 01709 210151**

Please feel free to contact any member of the team



**Kerry Leeson-Beevers**  
Tel: 01709 210151 / 07716135940  
Email: Kerry.leeson@alstrom.org.uk



**Marie McGee**  
Marie works part-time, normally on a Friday offering transition support to young people and their families  
Tel: 07812 173953  
Email: marie.mcgee@alstrom.org.uk



**Catherine Lewis**  
Tel: 07970071675  
Email: Catherine.lewis@alstrom.org.uk



**Jane Biglin**  
Jane works part-time, normally on a Tuesday and Wednesday offering family support to families in the South  
Tel: 07714 798413  
Email: jane.biglin@alstrom.org.uk



**Carrol Birchall**  
Family Support Worker (covering Midlands and North England)  
Carrol works part-time usually on a Tuesday, Wednesday and Thursday  
Tel: 07847 760467  
Email: carrol.birchall@alstrom.org.uk



## Alström Syndrome UK

Strength for today, hope for the future

**PLEASE BE AWARE OUR ADDRESS HAS CHANGED:**

**Registered Office address:** 4 St Kitts Close, Torquay, Devon TQ2 7GD  
Please visit our website [www.alstrom.org.uk](http://www.alstrom.org.uk) to keep up to date with our latest news.

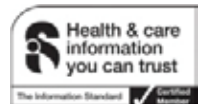


ASUK now have a dedicated You Tube page  
<http://www.youtube.com/alstromsyndromeuk>

Please keep up to date with Alström Syndrome UK via twitter @AS\_UK and also via our dedicated facebook page: [www.facebook.com/alstromsyndromeuk](http://www.facebook.com/alstromsyndromeuk), please click 'like' to show your support and spread the word!

### Information you can trust

ASUK is committed to providing information you can rely on as being accurate and trustworthy.



ASUK has been assessed as meeting the standards of The Information Standard and continues to be a certified member.

### Don't Miss Our facebook Posts!

Facebook's "EdgeRank" Algorithm is hiding posts for those who aren't willing to pay for sponsored placements!

Please visit our page follow these steps...

- Step 1: click "Liked"
- Step 2: check "Get Notifications"
- Step 3: check "Show in News Feed"
- Step 4: check "Add to Interest Lists..."



Thanks!