



# AlströmNEWS

*With your help we have hope*

THE NEWSLETTER OF ALSTRÖM SYNDROME UK

Summer 2013 Issue No. 12

## A time for celebration and for great sadness

*It has been a story of both triumph and tribulation - a time for celebration and great sadness for ASUK.*

*While the charity continues to make extraordinary strides across the UK and Europe we always remember how vulnerable and precious our Alstrom*

*family is. It is easy to forget the adversities and daily struggles faced by those who have achieved so much in so short a time. Since our last newsletter Kevin Goodwin, Sean Waiting and others have passed on to a more peaceful place. We will never forget them or those that*

*have gone before them for their fortitude and immense contribution to the success of the charity and support it gives to so many others.*

*Inside, we pay tribute to the key roles Kevin and Sean played in creating greater awareness of Alström Syndrome.*

## The fun of the fair..



**Well  
done  
Iram,  
BA  
Hons**

**Congratulations to Iram Shah who has been awarded a Bachelor of Arts with Honours in Special needs and Inclusion Studies.**

Iram is a true inspiration to all; she has managed to study for her degree at the University of Wolverhampton whilst supporting her two children Rida and Shamas who are both affected by complex conditions, including Alström Syndrome.

Iram gives her thoughts: "I would like to take this opportunity to thank Kay and Kerry for their tremendous support, Kay has been a perfect role model for me and Kerry has been a strength to me when times got difficult with Rida and Shamas. I can't thank them both enough and I am now excited to continue my role (Family Support Worker) with the charity on a full-time basis."



*Above: Enjoyment on the children's outing at the Annual Conference. Special report - turn to the Centre Pages*

## Kay to forge further links with Europe

ASUK Founder and Director, Kay Parkinson has worked tirelessly for families affected by Alström Syndrome and this is going to continue with Kay now forming exciting links in Europe to cope with the increased workload. Kerry Leeson-Beevers was appointed ASUK Acting Chief Executive Officer

from 11th February. This will enable Kay to provide more support to the new Board and take up many of the exciting UK and EU possibilities.

"I have every faith that Kerry will prove a dynamic and innovative acting CEO and continue to progress the charity. She will be able to keep a firm eye on patients' needs and

aspirations and develop new and interesting ideas together with our new Chair, Michelle," says Kay.

• **Alström Syndrome Italy** is now up and running. You can keep up to date with Associazione Alström Syndrome Italia [www.facebook.com/AASItalia](http://www.facebook.com/AASItalia) Please look at their Facebook page to show your support...

## 'Family visits are important to me'

I am very pleased to have been promoted to Acting Chief Executive Officer of ASUK. Any of you who know me well, know how passionate I am about this charity and about ensuring that all of the needs of our families and individuals affected by Alström Syndrome are met.

Kay has done a wonderful job in establishing this charity and has achieved so much over the years. She has also been a great support to me professionally and personally and I look forward to us working together in our new roles.

I first became involved with the charity around nine years ago following the diagnosis of my son Kion. After attending our first conference and clinic I soon joined the Board of Trustees and later became chair.

I then resigned from the board and successfully applied for the positions of Child Development Officer and Asian Family Support Worker. I was later promoted to Development Manager and gained more responsibility, including the management of the Asian Mentoring Scheme which has considerably increased our numbers.

Undoubtedly, the best part of my



**Kerry Leeson-Beevers: 'We have an excellent team at ASUK'**

work has always been the direct involvement with children, young people, adults and their families.

While my new role has meant that I have had to reduce the amount of visits I am able to make to families, it is very important to me that I am still able to do this to a certain degree.

I need families to know that they can always contact me with any issues they may be facing and I will do my very best to support them in resolving any issues. Iram Shah is doing a wonderful job in her role as Family Support

Worker and has taken over much of my previous role. It is as important to me as it always has been to Kay that ASUK remains a user-led service and that we consult with our members, including children and young people on a regular basis to ensure we are meeting their needs.

ASUK will continue to work with the medical teams in Birmingham to develop and support the clinics and ensure that the Alström Service remains patient-led.

Recent and future changes in legislation and the re-structure of health, education and social services is causing concern for many of our families at present. We will continue to link with relevant organisations to ensure we are aware of any new developments and how these may impact on our families and will find effective ways to support you through this time and keep you fully informed.

We have an excellent team at ASUK and a strong and supportive board of Trustees and I would just like to take this opportunity to thank everyone for the support they have given me. I look forward to us all continuing to work together to drive the charity forward.

## Study on genetic conditions in the family

The Medical Research Council is running a small project on pre-implantation genetic diagnosis (PGD).

The aim is to put more detailed information about PGD into the public domain, and ensure that the patient voice is central to this information.

PGD is a technique that enables couples with a particular inherited condition in their family to avoid passing it on to their children. PGD is used when one or both parents has a known genetic abnormality and diagnostic testing is performed on an embryo to determine if it has also inherited the abnormality.

One of the regular tasks at Genetic

Alliance UK is to monitor the list of conditions that are awaiting a licensing decision at the Human Fertilisation and Embryology Authority and ensure that there is a statement from the perspective of patients submitted in time for the licence committee meeting. The committee must decide if the condition proposed for PGD is sufficiently serious to warrant a licence.

The aim of the statements is to describe the effect of the genetic condition under consideration on the family as a whole, including the inheritance pattern. Genetic Alliance UK have made more than 100 statements in support of PGD

for individual conditions. The statements would be useful evidence in making the case for innovative therapies such as PGD, and the emerging technology of mitochondrial replacement, to continue to be supported. The Genetic Alliance will help bring forward statements of the highest standard.

For more about inheritance patterns here: [www.geneticalliance.org.uk/education2.htm](http://www.geneticalliance.org.uk/education2.htm)

You can make contact about this new project with Nick Meade, Policy Analyst on [nick@geneticalliance.org.uk](mailto:nick@geneticalliance.org.uk) or call 020 7704 3141

## Another top award for Liam

**Talented Alström teenager Liam Mackin has won another prestigious award - this time for his outstanding work with The Children's Society in transforming the lives of disadvantaged children.**

Liam, an 18-year-old, from Shipley, proudly received his award at the fifth annual *Over the Rainbow Awards*, held in Gaydon, Warwickshire.

The event was organised by The Children's Society and formally recognises the outstanding work by children and young people who are involved with the charity.

Using money from The Children's Society's Pot of Gold scheme - where young people manage and allocate funding to other children and young people - Liam worked with The Children's Society's LEAP project in Leeds to raise awareness about disability.

He has also been running life skill workshops to help people who are visually-impaired and has set up his own company offering training to parents, carers and others who help the blind or partially-sighted.

Speaking after the ceremony Liam said: "Working with The Children's Society has been an amazing experience and one which has allowed me to give something back to the people who have made such a difference to my life."

Last year he was presented with an award for Best Positive Role Model for Disabilities at the National Diversity Awards 2012.



Above left: Acting CEO Kerry announcing Liam's other award at the conference and top right John Parkinson and Kerry present a special award to Maariyah Iqbal

## Special recognition

During the ASUK conference three special recognition awards were given for particular achievements during 2012.

- Maariyah Iqbal received inspirational young person of the year award
- Ayisha Iqbal received supportive sibling of the year award
- Liam Mackin received special achievement award

All cyclists received medals for taking part in the 2012 sponsored cycle ride which was from Torbay Hospital to the Queen Elizabeth Hospital in Birmingham. Well done to everyone who continues to smile through adversity and thank you to everyone who continues to support ASUK.

**Handbook may be useful**

Alström Syndrome International have produced an Alström Syndrome handbook which contains some very useful articles, although this isn't endorsed by ASUK. Copies can be obtained from Jan Marshall at [jan.marshall@jax.org](mailto:jan.marshall@jax.org)

## When Tenacious Amy took over the helm

**Amy Stannard Tilley, supported by ASUK Family Liaison Officer John Parkinson, flew to Malta for a tall ship adventure.**

There they boarded Tenacious, operated and owned by the Jubilee Sailing Trust, a registered charity who enable people of all physical abilities to sail side-by-side as equals.

This adventure involved Amy in almost every activity on board. Regardless of physical disability and previous sailing knowledge you can take the helm, set the sails and get involved in all aspects of running the ship, including the cleaning!

They sailed the beautiful Sicilian coast and even saw Mount Etna erupting! Amy had a fabulous time and she can't wait to be involved in the next adventure...



**Do you fancy adventure?**

ASUK will be organising future sailing trips with the Jubilee Sailing Trust so please get in touch with John Parkinson if you are interested in joining the fun! You can email John on: [john.parkinson@alstrom.org.uk](mailto:john.parkinson@alstrom.org.uk) or call him on 01803 409952.

# Research spreads right across Europe



The various medical and research studies both here and in Europe were discussed at another successful Alström Syndrome family and professional conference in April.

The studies are aimed at providing further insights and treatments for those with rare diseases.

The conference, held at the Menzies Strathallan Hotel in Birmingham, was chaired by Alex Griffiths-Rayson. Alex, an ASUK Trustee and Patient representative, did an excellent job throughout the day.

Kerry Leeson-Beevers opened the conference by explaining her role as Acting CEO and her future vision for ASUK.

This was followed by presentations by Dr. Rob Semple Consultant Endocrinologist from Cambridge University, Professor Tim Barrett Professor of Paediatric Endocrinology from Birmingham Children's Hospital and Dr. Richard Paisey, Consultant Endocrinologist from Torbay Hospital. They discussed the findings from the Big Lottery Medical and Scientific Research Project.

Dr. Tarek Hiwot discussed his new adipose research study. The adipose tissue is the fat which is stored in our bodies; its main role is to store energy in the form of lipids, although it also cushions and insulates the body. In recent years it has also been recognized as a major endocrine organ as it produces many hormones.

This study will look at the adipose tissue in more depth as this tissue can affect other organ systems of the body and lead to disease.

Dr. Vincent Marion went on to explain about his research into Alström Syndrome, which is taking place in France. He is currently looking into the possibility of developing eye treatments for Alström patients.

AS patient representative Liam Mackin (also the winner of the National Diversity Award for 'Positive Role Model for Disability') gave a patient's perspective of living with



Alström Syndrome which inspired everyone.

Philip Watts from the Jubilee Sailing Trust discussed Sailing Holidays which are provided by the Jubilee Sailing Trust for everyone - no matter what their physical ability.

## WORKSHOPS

After lunch the afternoon sessions consisted of a choice of workshops:

1. **Transition** which was hosted by Marie McGee, Transition Coordinator from Birmingham Children's Hospital
2. **One year on**, Development of the Adult Services which was hosted by Dr. Tarek Hiwot, Consultant in Inherited Metabolic Disorders from the Queen Elizabeth Hospital, Birmingham
3. **Euro WABB and the Paediatric Clinics** which was hosted by Professor Tim Barrett from Birmingham Children's Hospital
4. Richard Copson from Pannone's Solicitors discussed **Disability Rights** with families
5. Gujit Kahlon from Action for the Blind discussed **Accessible Technology** with families

The AGM was chaired by ASUK Chair Michelle Hough and this was a great opportunity for families to meet the new Trustees and discuss the future progression of the charity.

"It was wonderful to see so many families at the AGM and to feedback the improvements that have been implemented as a result of the first family questionnaire by ASUK, BCH and QEH. Listening first-hand to comments and suggestions directly from the families is always a valuable part of the AGM and this interactive session was certainly no exception," says Michelle.

## POSITIVE FEEDBACK

During the Medical and Scientific Meeting many presentations discussed the current research projects which are taking place throughout Europe. This included interesting talks from Dr. Vincent Marion from Strasbourg into new insights and treatments for Alström Syndrome.

This was followed by Dr. Edward Callus, Clinical Psychologist from Italy who discussed enhancing the Physician and Patient communication around end of life care. The meeting also discussed the Big Lottery Research Project and ways to advance the research into Alström Syndrome.

We would also like to thank the exhibitors from Royal National College for the Blind in Hereford, Guide Dogs for the Blind, Hearfirst Training and the Jubilee Sailing Trust.

"Thank you to everyone who contributed to making this conference a success. We have received positive feedback from delegates and people particularly seemed to enjoy the different variety of presentations and the afternoon workshop sessions.

"Thank you to all of our speakers for taking the time to attend our conference, especially those who travelled long distances to be with us. Liam Mackin's presentation captured the hearts of everyone and was by far the highlight of the event!" added Kerry Leeson-Beevers, Acting CEO.

## Book for the Bank Holiday next year!

The 2014 Alström Syndrome UK Family and Professional conference will take place on the 24th May 2014 at the Hilton Hotel in Northampton.

The Hilton Northampton hotel is conveniently located for access to the M1, situated at Junction 15. The hotel is only 10 minutes' drive from Northampton town centre and 40 minutes from London Luton Airport (LTN).

You can keep fit in the fully equipped Livingwell Health Club or swim laps of the 18-metre indoor pool - the largest pool in Northamptonshire, which also includes a whirlpool, sauna and steam room.

All guest rooms at the Hilton Northampton are spacious, bright and airy, and feature WiFi.

The conference is being held on a bank holiday week-end so you won't need to dash back to school!

Please get in touch as soon as possible if you would like to attend as we will be applying for individual grants for families to reduce the cost of the weekend.

Please put this date in your diary as this will be a fun-filled weekend for everyone involved. We look forward to seeing you all there!



## The biggest, wettest, rides for children



Whilst their parents attended the ASUK Conference, 32 children embarked on an adventure to Drayton Manor Theme Park

Although it was very cold, we were very thankful that the weather stayed dry!

The children and volunteers were eager to get going as we left the hotel to make our way across Birmingham to the award-winning Drayton Manor Theme Park.

The children had a great time at Drayton Manor which is home to some of the biggest, wettest and scariest rides around with Shockwave, Europe's first stand up rollercoaster, Stormforce 10, with a backwards water drop and Apocalypse. voted the scariest ride in the UK by Channel 4's The Gadget Show.

There was also, for the first time in Europe Thomas Land where the younger children had great fun! There was time to stroll around the 15 acres of open plan zoo which is home to over one hundred species from all over the world.

The children really enjoyed the experience and were returned to their parents exhausted after their exciting day.

"A HUGE THANK YOU to all the volunteers who took part in the children's outing without their help the outing wouldn't have been able to take place," said Catherine Lewis, PA and Events Coordinator



## Super auction

On the Saturday evening before the conference we had an evening meal followed by the ever anticipated charity auction which this year also included tombola and a raffle. A HUGE THANK YOU to everyone who donated auction items and took part; ASUK raised £1,034.00 which is excellent. Pictured left: John Parkinson and Kion Leeson-Beevers with a giant teddy.



- Trevor Parkin and his family raised £800 through a school fete
- Rachel Martland ran the Liverpool Half Marathon and raised £488
- Lloyds TSB also contributed £550 towards the donation.
- Patrick Rooney raised £640 doing the Wild Warrior Challenge

## Fantastic - with over £33,000 raised

Last year, through the dedication of many families and individuals affected by Alström Syndrome over £33,000 was raised for ASUK.

ASUK would like to say a HUGE THANK YOU to everyone who showed their support in 2012. This year we have already raised over £1,000 from calendar sales and over £400 from the car draw raffle. Thank you to the RNIB Pears Centre, HearFirst

Training, New College Worcester, and Frankham Consultancy who sponsored the 2013 calendar.

Following its success we are compiling a 2014 charity calendar. Sponsorship opportunities are now

available on a first-come, first-served basis. Sponsorship packages start from as little as £75. Please contact Catherine Lewis on 01803 613117 or email Catherine.lewis@alstrom.org.uk

Our fundraiser Julia Scott is doing an outstanding job applying to various charitable trusts to help raise money for ASUK. However, due to the current economic climate, donations to the charity have declined and it is more important than ever that we all work together to try and develop effective ways to raise money for our families. If you have any suggestions or feel you are able to support us in any way then please contact us. Thank you again.

## A big challenge - can you help?

Are you up for a rather big challenge and would you like the opportunity to have your say?

ASUK are launching a new project "Raise a Million for One in a Million" and are looking for people to be part of the team overseeing this exciting new project.

We will be aiming at corporate sponsors to initiate and support research in areas where we are unable to secure external funding.

As part of this project you will have a say as to how funds should be utilised. Some of you have some really great ideas.

For more about this exciting project please feel free to contact ASUK Chair, Michelle Hough on 01872 553067 or email michelle.hough@alstrom.org.uk

## Families total up £775

A fundraising event by the Vasey family (with the help of Verna Ellerby who offered up her garden) included music from three local bands and a fish and chip van. Liz Little sold charity cards and Curtis Vasey sold ASUK wristbands; many families took part and raised £775.00 Well done!!

## Luke's run raises £269

On the 27th May Luke Waiting, nephew of Sean, ran the BUPA 10K London Marathon in aid of ASUK and in memory of his uncle (see Page 7). Luke managed to raise £269.

## Time to turn out your old jewellery...?

Would you like to turn your unwanted items into a donation for ASUK? You can boost charity funds and benefit the environment by donating: Jewellery - unwanted gold, silver, costume jewellery and watches. Old and foreign banknotes

- in any currency, UK or foreign, and of any age or condition. So please have a look through old drawers, lofts, etc. to see if you can help. A recycling envelope is enclosed with this newsletter to make things easier.

## Great news as fresh awards are granted

Alström Syndrome UK (ASUK) has been successful in a funding bid for nearly £9,000 from Awards for All, for an exciting PossAbility project.

This funding will enable us to support individuals who have been diagnosed with Alström Syndrome to participate in voluntary activities in their local communities.

We will support organisations throughout the UK such as charities and local community groups to enable them to offer young people and adults with Alström Syndrome voluntary opportunities in their chosen area of interest. ASUK will support the young people and adults to discover their area of interest and

## Money for more short breaks

ASUK have just been awarded £4,875 from the Bradford Short Breaks Fund. This will enable both children and adults from Bradford to go to the Calvert Trust in the Lake District 25th-28th October.

Thank you to Liz Little who made us aware of the Bradford Fund. Please

through building relationships with community organisations and charities to support, both people affected and organisations involved to establish a volunteer programme.

**If you would like to be part of the PossAbility project, either as a volunteer or an organisation who has volunteering opportunities available, please contact Catherine Lewis who will be managing this project on 01803 613117 or email catherine.lewis@alstrom.org.uk**

"Our hope is that these opportunities will lead to future paid employment for our young people in a job where they can thrive and enjoy what they do," said Acting CEO Kerry Leeson-Beevers.

contact Catherine Lewis, on 01803 613117 or email Catherine.lewis@alstrom.org.uk for details of the Calvert Trust adventure!

Also, Jeans for Genes have awarded ASUK just over £12,000 to produce a DVD entitled 'Living with Alström Syndrome'. The DVD will be produced in a variety of different languages and will be a useful resource for all families, especially those who are newly diagnosed.

For more information about this project, contact Kerry on 01709 210151 or email Kerry.leeson@alstrom.org.uk

Thank You Jeans for Genes - <http://www.jeansforgenesday.org/>

## Success of Asian Mentoring Scheme

The Asian Mentoring Scheme is going from strength to strength, reports Acting Chief Executive Kerry Leeson-Beevers.

"The scheme was established in the hope that we would identify additional families affected by Alström Syndrome and ensure that our charity was accessible to everyone.

"We would then provide access to medical care at our specialised multi-disciplinary clinics in Birmingham," says Kerry.

"We would also work with the whole family to ensure everyone was

aware of the risks of having further children with this condition, support families to make informed choices about future pregnancies and to provide workshops where parents were able to learn more about Alström Syndrome to enable them to effectively manage the condition.

"We are extremely proud of our achievements. We feel we are meeting the aims and objectives of the project and are improving outcomes for families."

We have also seen an increase in the number of Asian families attending the Annual Family

Conference and taking part in activity events.

"I would personally like to thank our families for embracing our charity and for working with us to allow this project to be a success," added Kerry.

"Thanks to our fundraiser Julia Scott, the project has attracted just over £60,000.00. I would like to say a huge thank you to all of our funders, particularly NHS England, for funding my role and The Sylvia Adams Trust who fund Iram Shah as Family Support Worker."

## Vaccination: Look at more protection

The pneumococcal vaccination (pneumo jab) protects against pneumococcal infections - like pneumonia, septicaemia (blood poisoning) and meningitis.

Those who need the pneumococcal vaccination because they are higher risk include:

- All children under the age of two
- Adults aged 65 or over
- Children and adults with certain long-term health conditions, such as a serious heart or kidney condition

There are two different types of pneumococcal vaccine: one for children under two as part of the NHS childhood vaccination programme and one for people aged 65 and over, and people at high risk due to long term health conditions

**If you or your child have a suppressed immune system - you may need to have extra doses of the pneumococcal vaccination. This is because you may not produce enough antibodies to provide immunity after the standard dose of the vaccine. Ask your GP or your consultant at the AS multi-disciplinary clinics for more information.**

Also visit our website [www.alstrom.org.uk](http://www.alstrom.org.uk)

## Why 5 A Day is so important for your health

Fruit and vegetables are part of a balanced diet and can help us stay healthy. That's why it so important that we get enough of them.

The 5 A DAY campaign highlights the health benefits of getting five 80g portions in all of fruit and vegetables every day.

Fruit and veg contribute to a healthy and balanced diet and are:

- A good source of vitamins and minerals.
  - An excellent source of dietary fibre, which helps maintain a healthy gut and prevent constipation and other digestion problems. A diet high in fibre can also reduce your risk of bowel cancer.
  - Can help reduce the risk of heart disease, stroke and some cancers.
- Fruit and vegetables are also usually

low in fat and calories (provided you don't fry them or roast them in lots of oil). That's why eating them can help you maintain a healthy weight and keep your heart healthy. Fruit and vegetables can be taken fresh, frozen, chilled, canned or in dried form. Choose vegetables canned in water and fruit canned in natural juice, not syrup. For more information, visit our website [www.alstrom.org.uk](http://www.alstrom.org.uk)

## Sean and Kevin, just so inspirational...

Two very inspirational members of the ASUK family - Sean Waiting and Kevin Goodwin - lost their battles against the condition earlier this year. They will be very much missed.

In January, Sean sadly lost his fight for life with parents Terry and Jean by his bedside.

His mother, Jean, expressed her admiration for the way he dealt with the disorder. "He lived everything to the full and he was just a fighter. No matter what his disability was, he never complained and never asked why has this happened to me?"

As well as enjoying his horse-riding, going to the gym and supporting Manchester United, Sean also took every opportunity to promote the interests of disabled people. He had a great sense of humour and was a true inspiration to all. In previous years he was an ASUK Director and Editor of the ASUK newsletter.

Kevin sadly passed away in March. He had been seriously ill for a number

of weeks after being admitted to hospital with pneumonia and he did not recover. Kevin has been a huge part of ASUK, an advocate for people with disabilities and an ASUK Trustee. His determination and resilience was a true inspiration to all.

Anyone who knew Kevin, knew he had the biggest heart, the greatest sense of humour and lived life to the full. In his memory the cycle ride will now become an annual event in his name. *The Goodwin Cycle Ride*, dates for the 2014 sponsored cycle ride will be published soon.

Nina Griffiths (Alex Griffiths Rayson's Nan) also sadly passed away after losing her battle to cancer. Nina was a great help on our recent sponsored cycle ride and she also will be sadly missed by everyone.

• Thank you for all the donations we have received in memory of Sean and Kevin. Also a huge thank you to Saffa Manzoor's parents who donated £1,000 in memory of Saffa who sadly passed away recently 'Truly an angel.'

# It's a 'great honour'

**Alström Syndrome UK has celebrated another accolade to mark its pioneering work in Europe.**

Founder and Director Kay Parkinson was presented with the EURORDIS Patient Organisation Award 2013 at a special Gala Dinner in Brussels in February.

This was two days before Rare Disease Day on the 28th which aimed to raise awareness with policy-makers and the public of rare diseases and of their impact on the lives of patients.

"This is a great honour - and underlines all the achievements made by the whole Alström family - patients, families, staff and directors.

"It also strengthens our resolve to keep on fighting to gain more recognition for rare diseases in Europe and around the world," says Kay, who lost her two children to Alström Syndrome.

EURORDIS, the European Organisation for Rare Diseases, recognised the "extraordinary work and commitment to patient support and advocacy for people with Alström Syndrome, which serve to improve living conditions and inspire others working in the field of rare diseases."



*ASUK Founder and Director Kay Parkinson and Acting Chief Executive Kerry Leeson-Beevers travelled to Brussels to attend the EURORDIS Black Pearl Gala Dinner. In our picture, Kay is seen receiving the prestige award from Avril Daly, EURORDIS Vice Chair*

## Publicity keeps us in the public eye

ASUK secured half a page in the Independent supplement which went out on Rare Disease Day 28th February 2013 co-inciding with the official announcement of the EURORDIS award. In the allocated 600 words we were able to raise awareness of the Big Lottery grant that has helped AS UK gain experience of research and produced a database and tissue resource.

ASUK were also delighted to appear in the RNIB Insight magazine - seen as a great resource for teachers, parents and professionals supporting children with visual impairments. The magazine article can be viewed on <http://www.rnib.org.uk/professionals/education/insightmagazine/exclusivecontent/Pages/Alstrom-Syndrome-young-people.aspx>

*The first Ciliopathy Alliance Family Conference 2013 held in Northampton provided a great opportunity for families to learn from each other's experiences of living with or caring for children affected by ciliopathies. Speakers included ASUK Acting Chief Executive Officer Kerry Leeson-*

*Beevers who gave two presentations, about current clinic experiences and life beyond the clinic - school, family and friends. A 'CiliopathyCafe' enabled conversations and discussions about the morning talks; these were then fed back to the group. The children had a fun-filled afternoon playing*

*ten-pin bowling and for babies there was a special crèche. The Ciliopathy Alliance would like to thank Jeans for Genes who provided a grant to enable the conference to go ahead and also everyone who helped in the planning and running of the conference.*

## Join us for the summer of fun

**ASUK are planning a week of fun from the 19th August 2013 in Torbay and we would like as many families as possible to join in, so please get in contact for further details.**

**Be sure to let your ASUK family support workers know what your wishes are....so they can help you plan exciting adventures.**

## Kez adds his skills to the Board

**ASUK have tried for many years to be truly representative of our families and our Trustees have been seeking Asian representatives on the Board.**

Now Khazar Hayat, the father of our most recently-diagnosed member, has joined and is making a marvellous impact on the Board. Khazar, who prefers to be called Kez, works in the Equality and Diversity Unit at Bradford University and the skills he has developed in this role combined with being a parent of a child with Alström Syndrome and his understanding of Asian culture makes

him a very effective Trustee. Please get in touch if you are interested in joining the Board of Trustees.

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Find more details at  
[www.alstrom.org.uk](http://www.alstrom.org.uk)