

hello

angelman^{uk}
support education research

Ch-ch-changes...
ASSERT is evolving!

Latest Angelman
award winners

IAD - International
Angelman Day

Latest AS therapies
and research

"Something to say..."
communication news

School & SLT support

#62
summer 2018



who

@angelman^{uk}



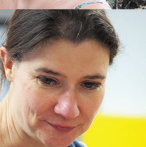
Rachel Martin
Chair and Welsh region
rachel.martin@angelmanuk.org



Lisa Court
Treasurer, Central region
lisa.@angelmanuk.org



Diane Fox-Jones
Website & Merchandise, SE region
diane.foxjones@angelmanuk.org



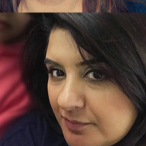
Andrea Baines
External fundraising, Central region
andrea.baines@angelmanuk.org



Jonathan Allen
Sibling support, SW region
jonathan.allen@angelmanuk.org



Tracey Campbell
Communication, Scottish region
tracey.campbell@angelmanuk.org



Nav Sanghera
Central region
nav.sanghera@angelmanuk.org



Louise Shaw
Central region
louise.shaw@angelmanuk.org



Mairi Leith-McGaw
Scottish region
mairi.mcgaaw@angelmanuk.org



(non-Trustee) **Dr Katie Cunnea**
Scientific advisor
katie.cunnea@angelmanuk.org



(non-Trustee) **Christyan Fox**
Media and merchandise
christyan@christyanfox.co.uk

hello

1993–2018. 25 years – what a huge milestone for ASSERT!

The last 25 years have seen many changes for ASSERT, Angelman Syndrome (AS) and genetics. What started off as a small group of parents supporting a few Angelman families in 1993 has grown into a team of trustees supporting over 800 registered members throughout the UK and overseas. We now offer a dedicated telephone support line, support through social media and emails, a family conference held every 2 years and a regular newsletter full of information, family stories and photographs of our loved ones with Angelman Syndrome. We have several films dedicated to educating about AS on our YouTube channel and we are committed to helping people with AS and complex communication needs access high level support and training to use Augmentative and Alternative Communication (AAC). We continue to work closely with professionals such as Jill Clayton-Smith, Chris Oliver, Bernard Dan, Erin Sheldon and we collaborate with many other expert parents and rare disease charities throughout the UK.

In 2013 ASSERT became a founder member of the Angelman Syndrome Alliance (ASA) – a group of organisations who agreed to work together to fund research into AS, primarily in Europe. Research has moved faster than anyone could have predicted and there is now the possibility of future treatments for aspects of AS that would have been unthinkable in the recent past. Who knows what new discoveries await us in the future?

As the current Chair of ASSERT, I am honoured to work alongside a team of wonderful trustees who all volunteer their time and their skills, sometimes at great personal cost to their family and social lives. The current and past trustees have all added tremendous value to the legacy left by the original founders and have taken us forwards, sometimes into unknown territory. As Bob Dylan said *"The times they are a changing..."* and now it is time to say goodbye to 3 of our longstanding trustees – Rich Williams and Sian Cartwright and Dr. Katie Cunnea, who have each resigned due to work and family commitments. We would like to thank them all for the time they and their families have given to ASSERT over the past decade and wish them well in the future. Dr. Katie Cunnea will continue to be involved as our scientific advisor. We are thrilled to welcome Nav Sanghera and Louise Shaw as our newest team members. Nav is mum to a 17 year-old daughter with AS and lives in Birmingham. She is excited to represent the Asian

community and is hoping to help families in minority communities with their AS diagnosis. Louise is mum to Holly and is known to many through her active support on Facebook. Louise has been a regular volunteer for ASSERT for many years. If you are interested in volunteering for us please see page 27.

And now – the future! The name ASSERT has served us well over the last 25 years and is recognisable to those who have been involved in the AS community, but unless you know what ASSERT stands for, it doesn't say who we are. In 25 years we have had 4 new logos but the name ASSERT has never changed. We believe that we are a progressive and forward thinking organisation and in a faster paced world we need to move with the times. Therefore, we are very excited to announce that after 25 years of being ASSERT our new name is AngelmanUK.

Today's social climate necessitates that information is accessed and processed quickly. AngelmanUK is instantly recognisable and it says who we are. Our mission is still, and always will be, to Educate, Support & Research all aspects of Angelman Syndrome and to continue the legacy left by the dedicated founders & trustees of ASSERT. It is thanks to their hard work that we are where we are today.

Thanks must go to Christyan Fox for his skill and hard work designing the new identity and to Diane for the time she spent coordinating the work done on the beautiful new website which is currently being made and will be available soon.

Don't forget about our family conference on August 10th-12th held at The Hilton Hotel, Coventry – details are on page 10. Conference is always a special time for families and is an opportunity to catch up with friends old and new. Saturday night is party night – dress up in your finest party wear and celebrate with us as a family (I have heard that there will be chocolate cake!).

We also have our fantastic adults only 25th Anniversary Celebratory Ball on November 10th, held at The Forest of Arden Hotel and Country Club! Celebrating 25 years is a once in a lifetime event and we hope you'll join us. This is a black-tie event at a prestigious country club and golf hotel. Why not book yourself in for a spa treatment or a round of golf or two whilst you recover from the night before? Details are on page 6-7.

Thank you to all our families and professionals for your support over the past 25 years. AngelmanUK looks forward to being with you for the next 25 years.

Rachel Martin, AngelmanUK

useful
information

Freepost address
AngelmanUK, Freepost
PO Box 4962, Nuneaton
CV11 9FD

Helpline 0300 999 0102
Email support@angelmanuk.org
Website www.angelmanuk.org
Shop angelmanuk.org/spreadshirt

Cover photo by Rob Chadwick
Please note that all opinions and views expressed by contributors are personal and not necessarily those of AngelmanUK.



1965
Angelman Syndrome discovered by Dr Harry Angelman, who called it 'Happy puppet syndrome, later renamed Angelman Syndrome by Dr Charles Williams.



1992
ASSERT set up as a parent support group.

1993

ASSERT incorporated as a charitable trust and registered officially as a charity.

1994
Grant of £10000 obtained from Oracle, £8000 donation from the band 'Madness'

2000

First ever ASSERT conference at Loughborough University, attended by approx 80 people.



2002
ASSERT launches a new logo.

2004
ASSERT launches its first website.

2010
ASSERT launches new logo and website.



2012

First ASSERT conference of The Hilton Hotel, Coventry attended by 417 people.

2013
First International Angelman day to raise awareness of AS across the globe. ASSERT becomes a founder member of the Angelman Syndrome Alliance, funding research in Europe.

2014

Gareth Edwards becomes the first ever patron of ASSERT.

2015
50th anniversary of Angelman Syndrome being recognised and Harry Angelman's 100th birthday. First ASSERT scientific conference and gala.

2016

First ASSERT communication conference and publication of 'I have something to say' booklet.

2017
First educational video of a series of 10 published on YouTube - 'Angelman Syndrome - what is it?'



2018
Grant of £25000 obtained from The One Family Foundation enabling ASSERT to provide training for families and communication systems for over 100 people with Angelman Syndrome.

ASSERT relaunches as AngelmanUK with a new website and logo.

what's in a name

Don't look now, we're changing. Christyan Fox takes you through some of the thinking behind the charity's new name and branding.

angelman ^{uk}
support education research

Pop quiz. You're probably all familiar with BT, NASA, BA, AUDI, IBM, BL, AA, BMW, DHL, IKEA, RAC, KFC, BMC, RNLI, ESSO, UNICEF, HTC, YKK, 3M...

But – without the help of Google – how many of those acronyms can you decipher?

For a large company or institution with lots of publicity, an acronym-based name can still work well. But for those with smaller budgets and a more modest profile, they can be a barrier. How many times have you found yourself having to explain what 'ASSERT' means, or more likely, just refer to us as 'the main Angelman UK charity'?

Having an acronym that cleverly forms a word also poses questions: the dictionary definition of 'assert' is 'confident or forceful'. That might describe a lot of AS individuals, but they're far from being the only characteristics.

None of these questions are intended to undermine the fantastic achievements of the founding members of the charity. Starting in 1993, ASSERT has made admirable progress in its relatively short history; from its origins as a family-run support group to becoming a much larger charity, now supporting over 800 registered members – and we hope you'll

be joining us at the Ball in November to celebrate their legacy – but while all other aspects of the charity have progressed its name has stayed the same.

Of course, changing the name is not a new idea. It was thoroughly discussed at the introduction of the last rebranding back in 2010 – when we had half the membership compared with today – but felt to be a step that might mislead people into believing the original ASSERT had failed and that this was a completely different charity. With a few more years' experience behind us we know that people are more aware of who we are and how we started and that a name change will be a relatively minor issue: in fact, our web and email addresses have been 'angelmanUK' for more than 10 years and it now seems a natural step to refer to the overall charity in the same way.

Rest assured, we're still the same charity, representing the same values and with the same parent-led, family-centric philosophy that the original founders intended.

I know the face



"Great Scott, Marty! Let's take the DeLorean back to 2010"

That's when the charity last changed its identity. It doesn't seem like very long ago, but that was back before the world made the leap into selfie-taking, swiping-left (or is it right?), Instagram, SnapChat, Spotify, Uber and asking Alexa to feed the dog via an app. There were no iPads and even the iPhone had only recently been launched. Happy days.

But the old logo was struggling to keep up. What had originally been designed to work on a letterhead – or maybe something as wildly futuristic as a website masthead – has been stretched and pulled in more directions than anyone could have imagined.

The charity's name change provided a perfect opportunity to redesign the entire identity from scratch. What was needed was more than a single icon that could be printed on an object, but an overall look and feel... a 'voice', that would be instantly recognisable. This takes a little time, and you have the first steps towards that goal in your hands now in the form of this newsletter. The conference will go further still and we hope our new website will be on-line before the end of the year. But an instantly recognised symbol was still required as a

starting point. Something that would work anywhere in the world. No small task.

Especially when you ignore all the usual tropes of wings, trumpets, clouds and flying babies (all clichés which undermine the name and work of Harry Angelman and have no association with his work). If you also dismiss those hackneyed 'social care' images of joined hands and genetic spiral ladders, you're left with very little to draw on: what 'one image would sum up the broad concept Angelman syndrome?

One of the most commonly defined characteristics of AS is the happy demeanour... but they're also individuals who can turn your world upside down... ah, now we're getting somewhere...

Is it a smiley face? Is it a frown? Is it a cheeky individual playing a game? Who knows?

But the frowny-smiley is only a small part: just like an AS individual he pops in and out and always adds a sense of fun, but just like an AS individual you can't always take them to every occasion. Harry Angelman was a real person, so the main logotype was designed to represent a signature.

An occasional splash of pink to our core colours of yellow and blue adds a new twist on an old theme. Supplementing the logotype by highlighting some key words in

a clear friendly font can help us with almost any message we need to convey. Stir it all together with a quirky sense of fun, and we now have a fab and flexible system - constantly changing but always recognisable - that should see us well into the future.

Or at least until the next technological leap.

"One of the most commonly defined characteristics of AS is the happy demeanour... but they're also individuals who can turn your world upside-down..."



angelman awards

2018 Charity Film Awards

The Charity Film Awards were created to celebrate the success and increase exposure of film in fundraising, and to encourage donations for good causes.

The charities that entered created videos that have the power to move, to warm hearts, to inspire, to engage... to change the world. To do good.

Almost 400 charities entered in 2018 and 60,000 members of the public voted. Nearly 10% of those who voted also made a donation.

For the charities involved there have been millions of shares on social media. More importantly, it is estimated the campaign created an additional quarter-million extra views of the videos, dozens of press stories and in excess of 2 million page impressions related to the awards on the internet.

After the public vote, our film *'Angelman Syndrome - What is it?'* was shortlisted. The judges made us finalists, then the winners of the 2018 Charity Film Awards were announced at the ceremony held at Central Hall Westminster, London on 11 May.

We were extremely delighted to win the Bronze Award, a huge achievement considering that the film that won our category had been narrated by Sir David Attenborough!

Film makers Lottie Fox-Jones and Molly Brown collected the award on behalf of the charity. Perhaps they were so successful because they both have a close family

member with AS. Well done to Lottie and Molly! **Diane Fox-Jones**

2018 Epilepsy Action Awards

Dr Dan Hindley works at Royal Bolton Hospital as a consultant paediatrician and specialises in epilepsy and neuro-disability. Most of us know Dr Hindley from the ASSERT conferences and for attending the Angelman clinic in Manchester with Helen Jameson, Specialist epilepsy nurse. He's also warmly regarded as being one of the nicest consultants in Bolton and currently cares for several AS families in the area. Dr Hindley was recently awarded the Epilepsy Health

Hero award at a ceremony held at the Leeds Civic Hall, earlier this year.

The Epilepsy Action Awards recognise and celebrate the efforts made to improve the lives of people with epilepsy. Twelve awards were presented, honouring the work and commitment of volunteers, fundraisers, schools, employers & healthcare professionals. AngelmanUK would like to pass on our warmest congratulations to Dr Hindley on winning this award and we look forward to continuing our working relationship with him and Helen for many years to come.

Rachel Martin



what

Come and join us in celebrating 25 years of supporting the Angelman community.

You will soon be receiving a formal invitation to our 25th Anniversary Ball, along with the menu and booking details, but while you're waiting, make a note of the new date.

where

Forest of Arden Hotel & Country Club
Meriden, Birmingham, CV7 7HR

when

The date has now been rearranged to
Saturday 10th November 2018

Thanks to a generous donation we are excited to be able to offer our registered families a reserved place at the Ball for the incredible price of £60 pp for members, including dinner and B+B.

If you are a business that would like to support us please email Lisa.court@angelmanuk.org for details of how to book a place or to buy a table.

Black Tie / Formal Wear. Drinks reception 7.00pm.
3-course dinner 8pm. Silent Auction 9pm.

This truly is an amazing achievement for all involved with the charity.

We started in 1993 thanks to a small group of parents.

As a result of their dedication and time we now support over 500 families in the UK and overseas. We work closely with eminent professionals such as Jill Clayton-Smith and Chris Oliver and we fund and support research both in the UK and in Europe. We have supported many families through the initial diagnosis right up to their children becoming adults and moving on, and in recent years we have made a concerted effort to help families and people with Angelman Syndrome and complex communication needs in their quest to have their voices heard by providing education, training and practical solutions.

We could not do this without YOUR support and we would love you to come along and join us on 10th November to celebrate this incredible achievement.

Having a Ball

angelman 
syndrome support education research

Building sibling relationships through communication

It's no secret that when someone in the family has Angelman Syndrome (AS) it can take a toll on family relationships – particularly with those who are siblings. AS typically requires round the clock care and siblings can lose out, not only in terms of attention from their parents growing up, but also part of the 'usual' sibling experiences and bond.

Whether you are part of a family with a new diagnosis or with a diagnosis from decades ago, it is difficult to hide from the recent technological advances that have assisted with communication. With the use of iPads and PODD books becoming more prevalent in the Angelman community, in turn there are many more families trying to model with communication aids for individuals with AS.

This has had some fantastic results for some families who now have individuals who can communicate some of their needs and feelings – which usually turn out to be hunger!

However, at the same time, this means that a condition that already requires round the clock care becomes even more demanding. With modelling, the ideal scenario is to demonstrate to individuals as much as possible how to use their communication system, e.g. PODD book or iPad (other electronic devices are available!) to communicate. This means that there is often little time to be given and shared with a sibling. This is an issue for siblings and parents alike, the latter of whom no doubt want to do the best for all of their children.

Whilst it could mean that a sibling feels pushed out and also has less time with their brother or sister, communication modelling can be implemented to include them.

A fantastic solution is to get all the family modelling. Where siblings are able to help with modelling, it means that all of the family is involved in the same activity. This can help stop the feeling of being pushed or that attention is being focused on one individual – it can seem like a game at times.

This supports positive relationship between siblings regardless of age. With younger siblings it can be seen as something fun to do, particularly as they may not be able to have access to an iPad all of the time, or at all. It is of course hoped that with time that the individual learns to communicate with the iPad themselves (not that the modelling would stop). When that begins to happen, siblings can feel closer to their brother or sister. They can feel a sense of pride and reward that they helped the process and effectively helped teach their sibling to talk!

"This has had some fantastic results for some families who now have individuals who can communicate some of their needs and feelings – which usually turn out to be hunger!"

Additionally, older siblings have grown up with a sibling with whom they usually develop their own little communication methods. However, with the addition of technology this can develop further and the already established relationship can take on a new form. It will enable personalities to shine more in the sibling relationship and they too can feel a sense of reward from knowing they helped in their AS sibling learning to communicate.

It is important to remember that often siblings (particularly those who have hit the teenage years!) may well not want to help with this process all of the time, want their own space and not feel obliged to assist with modelling. That of course needs to be respected to. However, I do feel that where possible and the sibling is willing, this kind of activity should be encouraged.



Dear Jon is an anonymous problem page for siblings, giving them the opportunity to seek advice on issues they face in dealing with their brothers and sisters who have Angelman Syndrome. Your questions could also help other people who might be going through similar issues.



Jonathan Allen
Sibling support

Dear Jon

My brother recently got an iPad to help him communicate but now he gets even more attention whilst my parents try to teach him how to use it.

Jon says

This is not uncommon and there has been a massive increase in those with AS being able to communicate with technology such as iPads. In actual fact teaching them to use them can be a lot of fun and very rewarding! You should try to get involved in modelling language to them on the iPad.

When your brother begins to get the hang of it, it can make for some very funny results and will also help your relationship with him.

You should also talk to your parents about maybe having some special time set aside for you also, perhaps when your brother is in bed. That way you know that you are equally important to your parents.



Dear Jon

My sibling has Angelman Syndrome and never sleeps. She always has bags of energy a lot of the time. Though I love her, I find it exhausting to always be around her.

Jon says

Self-care is incredibly important when regularly dealing with someone with such demanding needs. If you can, then you should try to take some time for yourself so that when you are around your sibling you aren't feeling so overwhelmed. If possible then setting aside regular you-time each week, even if just for an hour may emotionally recharge you.

Additionally, if you find that she is being quite full on, it may be a case of trying to do calmer activities if possible, such as painting or quiet times whilst watching a DVD. The more regular these activities become, hopefully the more he will calm down when they occur.



Dear Jon

My brother and I are both now teenagers but sometimes I feel trapped in my life and having to be around to help look after him sometimes.

Jon says

It is certainly not easy to be a sibling to someone with Angelman Syndrome, however it is also important to make sure that life isn't getting on top of you. Something I know has helped many siblings has been young carer groups. If you are able to find one in your local area then it is an hour or two a week with other people who are in similar situations. I really think this allows for you to unwind and talk to people who really understand your circumstances.

Further, often talking to friends can help a lot too. Whilst they may not fully understand the situation you are in, they may be able to offer some support and give you a chance to talk about your frustrations.





are you
excited?

angelman ^{uk}

national conference

10, 11, 12th August 2018

**Double Tree Hilton,
Coventry**

Not long now... are you counting down the weeks like us?

The programme for the AngelmanUK 2018 family conference is printed here. We've worked very hard to bring you a variety of exciting, informative talks and workshops. As usual the programme is subject to last-minute changes but I'm sure you'll agree that it looks like an amazing weekend.

Saturday night is party night so dig out your dancing shoes and finest party wear and join us in celebrating our 25th anniversary – an amazing achievement for a small, parent-run support group.

Trips this year are to Drayton Manor on Saturday and a relaxed visit to Twycross Zoo on Sunday. Please note we don't provide carers, and children remain your responsibility at all times. If you need more information please email info@angelmanuk.org.

We can't wait to see you all in Coventry!

workshop sessions

1 Genetics 101 - *Professor Rebecca Burdine*

2 Parent to Parent Q+A
Sally Walburn & Gerry Egan

3 Communication & Modelling
Jodi Melendez

4 Epilepsy & Neurology
Professor Bernard Dan

5 EHCPs - *Laxmi Patel (Boyes Turner)*

6 Siblings for parents - *Jonathan Allen*

7 DLA & PIP - *Contact*

8 Sleep & Behaviour Q+A
Dr. Mary Heald

9 Sensory Detective: What is SPD and what can you do to support your child?
Becky Lyddon (Sensory Spectacle)

10 Caring for Carers - *TBC*

11 Transition to adult services - *TBC*

Saturday Programme

8:45 - 9:00	ASSERT to AngelmanUK: 25 years and counting - <i>AngelmanUK</i>	
9:00 - 9:30	Angelman Syndrome: Onwards and upwards! - <i>Gerry Egan</i>	
9:30 - 10:00	Angelman syndrome: A brief introduction to different phenotypes - <i>Professor Rebecca Burdine</i>	
10:00 - 10:30	Sensory Detective: What are the characteristics of Sensory Processing Disorder and how can you support your child - <i>Becky Lyddon (Sensory Spectacle)</i>	
10:30 - 11:00	Coffee break	
11:00 - 12:30	Model AAC with Me: Another way to talk while you play - <i>Jodi Melendez</i>	
12:30 - 13:15	Lunch	
13:15 - 14:45	<p>14+ years</p> <ol style="list-style-type: none"> 1 Getting through the teenage years <i>Sally Walburn</i> 2 Joining the grown-up world A parent's perspective <i>Contact</i> 3 PIP & adult benefits <i>Gerry Egan</i> 	<p>0-14 years</p> <ol style="list-style-type: none"> 1 DLA and entitlements <i>Gerry Egan</i> 2 Getting the best EHCP for your child <i>Laxmi Patel</i> 3 Sleep & Behaviour: What works? <i>Professor Chris Oliver</i>
14:45 - 15:15	Coffee break	
15:15 - 16:00	Workshop 1	
16:00 - 16:45	Workshop 2	
16:45 - 17:30	Workshop 3	

Sunday Programme

8:45 - 8:50	Introduction - <i>AngelmanUK</i>	
8:50 - 9:40	International Research and Trials - <i>Professor Rebecca Burdine</i>	
9:40 - 9:50	How does the UK support and fund scientific research? - <i>Dr. Katie Cunnea</i>	
9:50 - 10:20	Update on University of Birmingham research: Sleep, communication and behaviour <i>Professor Chris Oliver and Effie Pearson</i>	
10:20 - 10:40	Coffee break	
10:40-11:10	A secure financial future: Wills and Trusts - <i>Donna Holmes</i>	
11:10 - 12:30	<ol style="list-style-type: none"> 1 Epilepsy, neurology and Angelman Syndrome - <i>Professor Bernard Dan</i> 2 The future: Potential treatments and possibilities - <i>Professor Bernard Dan</i> 	
12:30 - 13:00	AS Clinic update - <i>Professor Jill Clayton-Smith</i>	
13:00 - 13:45	Lunch	
13:45 - 15:15	(Live link) Angelman Syndrome: AAC, Apraxia and Anxiety: <i>presenter Kate Ahearn</i>	
15:15 - 15:30	AngelmanUK Conference Close and refreshments	

Please note that speakers and content are subject to change.

international angelman day

15 February 2018



A round-up of some of the events across the UK

In 2018 we continued our tradition of arranging a number of regional meetings around the UK to celebrate International Angelman Day. IAD is held on 15th February. This year that date fell on a Thursday, so various events were arranged around the UK the weekend before and the weekend after. Here are a selection of some of our meetings.

South Central: Andrea Baines 'Swings and Smiles', Thatcham

The south central IAD event took place on Saturday 17th Feb at Swings and Smiles in Thatcham. This is a former Children's Centre, now converted into a specialist play centre catering for all ages and needs.

Nine families attended, with AS individuals ranging in age from 4-26. Everyone loved

climbing into and out of the enormous ball pit and enjoyed the soft play area and general use play room. The weather was good enough to make use of the fantastic outdoor space too. The staff were awesome and wouldn't let us clean up! A lovely afternoon, catching up with friends old and new and definitely a venue worth returning to.

The phenomenally talented (yet touchingly humble) Christyan Fox managed to get in everyone's way while taking pictures, a few of which you can see here.

London: Diane Fox-Jones Burview Hall, Walton-on-Thames

For the second year running we held the South East region IAD at Burview Hall Mencap Centre in Walton-on-Thames, a specially designed venue for families like ours. It was an unusually lovely, warm and sunny day so we made full use of the fantastic outdoor space as well as the large sensory room, games room and hall. It was very well attended and we had chance to

meet quite a few new parents as well as time to catch up with old friends over tea and biscuits.

Christyan Fox and Lottie Fox-Jones took the happy-snaps while Lottie and Molly Brown did their best to capture as much footage as possible of fast-moving AS individuals... coming to a YouTube channel near you soon.

West Coast: Rich Williams Bristol Zoo

On the 18th February, families from all over the South West and South Wales descended on Bristol Zoo to celebrate International Angelman Day in style. Despite the cold, we had a good turnout with over 30 people present. A brief get together at the doors, followed by families touring the zoo at their own pace meant that familiar faces were regularly seen throughout the day. Despite the reputation of our group, all enclosures remained firmly locked for the duration of our visit.



South Coast: Katie Cunnea Paultons Park, Romsey

Lots of fun was had at Paultons Park for eight families celebrating national AS day. A highly-recommended day out for families with an AS individual. People in wheelchairs get free entrance, and you can buy an annual pass for a carer. Or if you have a diagnosis letter you qualify for a queue-jump-pass to get onto each ride once.

Peppa Pig World is great for younger children (but most rides are accessible for all ages), and there are now some faster rides in the rest of the park for older or braver siblings. It is quite flat (unlike LEGOLAND) and not as spread-out as Alton Towers so good for wheelchairs and pushchairs.

N West & N Wales: Rachel Martin 'Boomerang' – Bury

This year the North West families had a change of venue for their IAD meeting. We all went to Boomerang in Bury on Sunday

11th February. Everyone had a wonderful time playing in the sensory room and on the soft play equipment, we even lost one of the dads in the ball pool! We had cake (of course!) and it was lovely to catch up with some old familiar faces and to meet some of our newer families. Looking forwards to 2019 already!

South Wales: Tracey Brocklebank S.N.A.C – Port Talbot

What a wonderful afternoon we all had at the special needs activity centre in Port Talbot! Several families were able to attend with their amazing children. We had the privilege of meeting up with some old friends as well as meeting some new families.

We all brought food to share at lunch time where we were able to chat about the ups and downs of the last year with our special ones. The Centre provided a really good atmosphere for the children to play, with a soft play climbing frame and ball pit which were great hits with many of the children

and siblings – and what a great game it was playing with the musical instruments or just climbing in a box!

A great day was had by all – certainly by me and Blake (19yrs). All the young and old finished the day with plenty of smiles whilst sharing ideas, information and making future plans.

Thank you to everyone who attended the S.Wales meet up. Blake and I look forward to meeting up with you all again next year!

Central: Lisa Court Sports Centre – Nuneaton

Everyone had a wonderful afternoon enjoying the bouncy castle and soft play and other fun activities. It was great to see younger ones and older ones, familiar faces and new faces. We were all able to have a chat – in between chasing after our kids! It's always great to get together catching up on the news from the previous time we met, or introducing ourselves to new families.

scottish

conference day 2018

After a shaky start, when it looked like the Scottish conference couldn't go ahead due to a disappointing lack of interest, the day was a great success.

The day was held in the Stirling Court Hotel as a central Scotland location. Also, although Rachel didn't make it she was delighted that there was enough tartan around and shortbread was served with afternoon tea. I am not sure if any of our Scottish attendees even noticed but we like to keep Rachel happy. More importantly we received excellent service from the hotel staff who were both friendly and efficient.



We had a good balance of presentations on a wide range of subjects that were relevant to both newly diagnosed and those who have been around for a while as well as catering for all ages.

- Genetics
- Enquire
- Communication
- Ketogenic diet
- Enable
- Living independently

All the presentations were interesting and well received. Please see further information on some of the subjects covered below.

The evening meal was served in a private dining room and despite

the reservations that it hadn't been Angelman Syndrome proofed, it went very well with no breakages. It was actually very nice to be dining in such pleasant surroundings. The food was delicious and just what was needed for those making their long journeys home.

A very successful day which we can hopefully repeat in the not too distant future.

The conference day started off with an overview of the genetics of Angelman Syndrome, the presenter Dr. Eleanor Reavey is a clinical molecular geneticist and added a laboratory perspective to the presentation, which was well received.

Enquire are a Scottish organisation set up to help people understand the different aspects involved with additional supports for learning. This talk led to an interesting discussion on what can people do if they are unable to get access to communication systems. One of the most important lessons was that it is law in Scotland that every local authority must make adequate and efficient provision for additional support as it is required by that child or young person. No one can be educated to the best of their ability without a robust language system and therefore it seems that every local authority must provide one for every person with Complex Communication Needs. It is unknown if anyone has ever been given access to a communication system by using this law.

The last talk of the morning was Jude Philip an independent SLT specialising in AAC, her talk was an interesting reflection on what we all communicate about and why everyone needs access to a robust system to meet their communication needs. She asked some key questions:

- What communicative functions do people need to communicate effectively?
- What are the different ways we conceptualise language (this involved chocolate!)?
- Are we giving the right input to achieve desired output?
- Are we giving access to the right vocabulary?
- What do we know about language learning?

scottish

conference day 2018

There were three separate speakers representing *Matthew's Friends*; together they provided a highly informative and inspirational presentation, even for those lucky enough not to have to deal with seizures. The life-changing effects of the ketogenic diet for some are amazing - however, it is not to be undertaken lightly. Please contact the very approachable people at *Matthew's Friends* for further advice, they will be only too happy to assist (www.matthewsfriends.org).

Enable Scotland first demonstrated the difference they can make to the lives of the people they are lucky enough to be involved in. We then all participated in a group exercise to discuss challenging behaviours. It was a very interesting process as actually through each of the tables we each found something that we could advice another on. One of the aims of *AngelmanUK* is support and this exercise demonstrated how we can as parents and loved ones of someone with AS help one another.

The talks concluded with our very own Gerry Egan proudly talking of his son Callum and his independent life. It was a long time in the planning (10 years people!) but Callum really does have a wonderful life including many holidays home and abroad! It has been a rocky and painful road (not for Callum for his parents) but it seems worth



it. Gerry did say he was only too happy to help others thinking of living independently whether a private independent or otherwise. I am almost sure he agreed to me printing that in a newsletter too!

We rounded the day off with an informal discussion that was a worthwhile addition, we discussed diets, respite and communication. We could have gone on but sadly we were sprung by the people returning from the day trip!

Tracey Campbell

HKD solutions have very kindly offered us the use of a UrZone bed for the weekend of the conference. If you would like to apply to use this bed please contact lisa.court@angelmanuk

It was lovely seeing so many families at the Scottish Angelman Conference on the 17th February. We had the opportunity to demonstrate the UrZone to interested families and to showcase its many features and benefits. The UrZone is a low sensory safe environment for sleeping or calming down. The all-around mesh allows for air flow and visibility for the occupant to see out (whilst having diffuse light coming in which soothes the brain) and for carers to see in. A see-through panel for camera or personal observation can also be included. With the low sensory environment, your loved one will often go to sleep quicker and stay asleep for longer resulting in calmer, more rested individuals and their parents or carers.

The UrZone is very strong and durable (currently in use with several Angelman families), can be used on the floor, divan base, bed frame or profiling bed, it's easy to clean (washes and tumble dries) and fits into a suitcase for travel. It can be used as a daily home-use bed, for travel, respite or hospital use. Features include access holes for feeding or oxygen tubing, very strong material, frame design features (including gas struts) to increase strength and durability of the frame, LED lights and zipped-in bed sheets for 100% anti-entrapment during seizures or high night time mobility.

It can be assembled in 20-25 minutes with no tools but has been designed for quick partial assembly and disassembly in 2-3

minutes for emergencies or where full disassembly isn't required.

At HKD Solutions, we specialise in helping families obtain full funding where required. No-one who requires one should ever be without a safety bed and with the UrZone being the most versatile safety bed / low sensory safe environment on the market, it can give a family the freedom to feel better, safer and enjoy travel or respite with their loved one. Call us on 0131 450 7124 or email: info@hkdsolutions.com for information or assistance with funding.

Heather Ling, HKD Solutions
www.hkdsolutions.com/urzone.asp



UrZone bed



Gareth in the City of Angels

Our patron Gareth Edwards ran the LA Marathon earlier this year to raise funds for AngelmanUK.

Now as his sister I can vouch that this was a huge challenge for him. Gareth has never been 'sporty' and has never run before, yet he made the decision to run about 4 months before the race which meant a huge amount of training and focus during those months. He also pledged to match whatever was raised with a personal donation. He set his target at £5,000 which would mean £10,000 for the charity – fabulous! It was a busy few months for him leading up to the event with a combination of training and fundraising.

The big day arrived and Gareth completed his first ever marathon in 5 hours and 11 minutes. I was predicting his time to be in days rather than hours! His fundraising page went well over his target having had over £8,000 donated. Gareth gave his personal donation and rounded it up to a nice £10,000 giving a final total of £18,260. Wow!



365%

£18,260
raised of £5,000 target
by 144 supporters

Donate

Share on Facebook

Gareth's 'City of Angels' Marathon for ASSERT

Running the Los Angeles Marathon for Angelman Syndrome Support Education & Research Trust because as the patron, it's a cause close to my heart.



Angelman Syndrome Support Education & Research Trust
We help and support UK families to find the best in Angelman Syndrome.





Every year our London Marathon runners do an amazing job: firstly in completing the marathon and secondly raising a huge amount of money between them.

Our 5 golden bond runners and 1 ballot place runner all trained incredibly hard for the event, and also worked just as hard to maximise their fundraising. The actual race this year was exceptionally warm which made it very challenging for the runners.

I think across the board everyone ran a little slower than they perhaps would have, including the elite runners. Thankfully all of our runners finished in one piece.

Between them, our runners have raised the massive sum of £17,342. We are absolutely thrilled with this amount, it is a brilliant effort by everyone and we are extremely grateful to our runners for their dedication. Our 6 runners were:

- Michelle Walecki (golden bond)
- Emma Goodson (golden bond)
- Mike Bennett (ballot place)
- Joanne Benham (golden bond)
- Kyri Kyriacou (golden bond)
- Calum Barker (golden bond)



A big thank you to all of you for your efforts, and also to your family and friends for all the support you had whilst training and on the day.

We have five golden bond places every year. If you'd like to be considered for a 2019 place, email lisa.court@angelmanuk.org

more fabulous fundraisers...



You don't have to run a marathon to raise money, so here's a big thank you to a few of those lovely people who've found lots of other fun and clever ways of raising funds for

angelman^{uk}

Suki Haywood

In March, Suki hosted her own BakeOff, organising a cake sale and raising £500 for AngelmanUK. Yum Yum!



Emma Hallam

My son Alfie and his friend Thomas have decided to fundraise for AngelmanUK – his cousin Archie is a little angel. So far they have raised £38.01 with a sale of AngelmanUK-

themed cakes. They are also planning to sell cookies and do a sponsored walk – all their own ideas.

Thanks to AngelmanUK for all they do!

Elizabeth Dorte

Elizabeth wrote to tell us that a class from year 13 at the Sandon School in Essex planned and managed an event as part of their BTEC business course. They chose to arrange a fundraising event for AngelmanUK, organising a quiz night with different stalls and attractions for people to donate and also set up a table to educate those attending about AS and AngelmanUK. They raised a very impressive £405, which sounds like good business sense to us – well done to all and we wish you the best of luck on your course.



Pat Fox and Candice Thompson-Gardiner

Candice and Pat wanted to celebrate their special birthday year with a skydive! Their big leap raised around £2000 for AngelmanUK, and they had an incredible time doing it.

Amy and Grandad In Memory of Geoff Snow

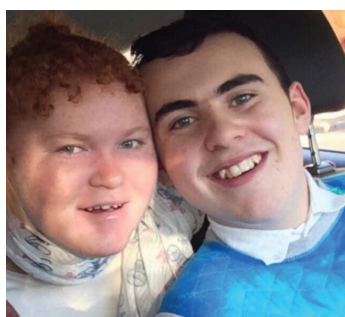
Amy was diagnosed with Angelman Syndrome in 1987, just before her second birthday. She was Grandad's first grandchild and she was always happy spending time with him; whether on his knee, on his quad bike or on holiday! Although they hadn't spent much time together in recent years, Grandad would have done anything for Amy. He sadly passed away in August 2017 and is greatly missed. Donations in his memory were made to AngelmanUK and the mental health charity, Mind. With thanks to all those who kindly donated, £912.48 was raised for AngelmanUK.

Keri Darrock (Amy's sister)



Vanessa Jones

We received this message from our son Danny's school today. This is a project entirely thought out by Danny without our knowledge. We shared this with you because we are so proud of our son and his kind and caring nature.



Hello,

I would just like to share with you Danny's excellent presentation today. We had the task of choosing a cause to raise money for before half term, and it was decided by vote that we would raise money for Assert, a charity that raises awareness for people with Angelman Syndrome, since it was something close to Danny.

Today we had the opportunity to decide on some fundraising ideas and ways to raise the level of awareness around the school, followed by a presentation. The presentation went very well indeed, from all of the students, but Danny in particular was exceptional. He led the planning for the presentation, helped others with their reading on stage and spoke about Angelman syndrome and what it is actually like to a room full of people. He should be incredibly proud of himself because he did it very eloquently, speaking from the heart and it really came across to everyone. I congratulated him afterwards, but I thought it best if I email you too to really show how incredibly proud he should be of such an excellent presentation.

Kindest regards

Mr R Allen
Intermediate Engagement Lead
Teacher of Science

Aurora Eccles School
Quidenham Norwich Norfolk NR16 2NZ



David Boorer and 6 of his friends ran the Sheffield Half Marathon – finishing in a very impressive 1h 47m while raising a hefty £1,346.76 for AngelmanUK. Well done David!



Nicholas Morris and friends displayed a fine spirit of entente cordiale by running the Paris Marathon to raise funds for AngelmanUK. Nicholas is a friend of Emma Goodson, whose son William has AS. They raised just over £426 for AngelmanUK. Bien joué (well done) Nicholas!

Andrea Baines has something to say about the recent series of communication courses AngelmanUK has been able to fund.

The *OneFamily* funded communication project “I have something to say: AAC use in Angelman Syndrome” is now almost finished. In total, we have been able to offer 10 training sessions (5 in PODD and 5 in Proloquo2go) across 5 different locations for 190 people.

There have been a few minor setbacks along the way – the application email address didn't work the day we went live; the PODD trainer was locked into, then out of her hotel room in Leeds (with all her training resources still inside obviously); in Chester, the projector didn't work and the loo roll ran out... even the weather had a go. It rarely snows in South East England, certainly not in March; the last thing I had been concerned about was snow! But The Beast from the East hit 24 hours before the Surrey PODD course was due to start. With the news and social media on Friday full of photos of overturned snow ploughs, chest high snow drifts, a weather forecast of more to come and plummeting temperatures, we were forced to take the decision to postpone the course at the last minute. With atrocious driving conditions on Friday evening and early Saturday morning, no food delivery and several peoples' respite/childcare being cancelled, it was the right decision at the time, but it was galling that by Saturday evening much of the snow had melted!

With Proloquo2Go, most of the issues we have had were to do with actually buying and distributing the apps. It seemed straightforward when we first came up with the idea, but in practice, not so much. After multiple emails, hours of phone calls and careful assembly of the jigsaw pieces of information, we got there in the end. Huge thanks to Annie and Donna who helped me with some troubleshooting at the last minute, but everyone who asked for the app has had it in time for the training. Apart from this, the courses have been well received and we've had some lovely feedback:

*"We are so excited now to get the app and get started!"
(Proloquo2Go, Thames Ditton).*

"...such an interesting and valuable couple of days – can't wait to start PODD!"
(PODD, Chester).

*"Now the hard work begins!"
(PODD, Chester).*

A close-up photograph of a hand holding a deck of playing cards. The cards are fanned out, showing various suits and characters, including a blue character on a card. Overlaid on the image is the text "I have something to say..." in a large, white, sans-serif font. The text is positioned in the upper left and center of the frame, with the ellipsis at the bottom right. The background is slightly blurred, focusing attention on the hand and the text.

I have something to say...

"It has given me the chance to sit and talk about nothing very much with H. The difference between using communication to teach her to ask for something and using communication to chat and spend time together is huge. It has been such a special time for us both and we have really forged a stronger connection. The fact that we can just chat in a normal and natural way rather than a staged communication exchange has been a revelation to both of us."

(PODD, Leeds)

"Thank you for such a fantastic day. I learnt so much as a clinician and will be adapting some of my practice as a result. The day delivered even more than I had hoped for."
(Proloquo2Go, Chester)

"It has opened my eyes to such a lot"
(PODD, Chester).

"Just wanted to let you know the training course held on Saturday by Jennifer was brilliant! I found it very informative and helpful and ideal for me just starting out using Proloquo2go."
(Proloquo2Go, Leatherhead).

"Just wanted to say how impressed we were with the training on Sunday, it was really, really good. [Jennifer] was first class, really knew her stuff." (Proloquo2Go, Leeds)

*"I've just arrived home and I am full of positive energy and looking forward to starting K in P2G. Jennifer was great and made the whole thing very clear."
(Proloquo2Go, Chester)*

*"The course was amazing, the PODD book is brilliant and I am beyond grateful."
(PODD Bristol)*



The attendees have been a good mix of parents and carers, Speech and Language therapists and teachers. It has been brilliant that some people are able to bring a whole 'team' of people with them to help support their AS individual. All age ranges of AS individuals have been represented as well, from tiny ones under 2, up to those in their 30s and 40s, proving that there is no 'too early' or 'too late' to start using AAC with your AS individual. The right time is right now!

We were able to rearrange the Surrey PODD course to Saturday 7th and Sunday 8th July. First refusal was given to those people who originally had places on the postponed course, with a few spare places which other people were able to take advantage of (see reports elsewhere in the newsletter).

We are currently working on plans for how to follow-up these courses, continue more next year and in what format so keep an eye out in future newsletters, the website and on the AngelmanUK Facebook pages for more information.

angelman 



communication

PODD + Proloquo2Go

Gemma Jay Proloquo2Go course

I would just like to say thank you to ASSERT (AngelmanUK) for organising the recent AAC courses. Like many families, I was having trouble with my daughter being able to access the full Proloquo2Go system at school, who had little confidence in my daughter's ability to use the app.

Following the Proloquo2Go course at the end of April, which both myself and my daughter's teacher attended, I requested a follow up meeting with her and the speech therapist to talk through setting targets and using approaches based on what we had learnt.

We agreed my daughter would have the full app available to her, with the same grid size as at home. She would have access to it at all times, they would model throughout the day and use more motivating activities when teaching new vocabulary. At the meeting, I showed video of how she's using the app at home and what she is capable of.

The next day the SaLT completed another assessment using the new Proloquo2Go



setup, during which my daughter was able to demonstrate more of the skills I'd said she was using at home. She was also able to navigate to the 'trip' button, and then rubbed her knee to tell them she had fallen over that morning, which she had.

I am so pleased that my daughter finally has the chance to show what she is capable of and that she now has access to all of her words. There are still things to iron out but we are finally moving in the right direction.

Unfortunately, there are still other Angelman families having problems with their children being able to access AAC at school, but hopefully we can work together to improve things for everyone.

Sian Cartwright - PODD training

The first PODD course was held in Leeds in February 2018 and was facilitated by Natalie Fitzpatrick. 13 people completed the intensive 2 day course, fuelled by much coffee and cake, and everyone left



enthusiastic to start having a go. Participants felt reassured that you can start small and that using PODD is a learning opportunity for parents, families and support workers as much as it is for someone with AS. It was helpful to have a couple of people at the workshops who had already started using PODD and their well-used books were a testament to how determined they are to incorporate PODD into their lives at every opportunity. Whilst starting young might be an advantage, it was also great to have families of adults involved in the training; it's never too late for any of us to learn new skills.

Katie Cunnea Proloquo2Go course

The Leatherhead Proloquo2Go course in April was well attended with 14 people being trained by Jennifer Marden. Feedback was very positive: everyone found the course useful, with most keen to learn more, especially practice modelling.

Diane Fox-Jones - PODD training

Another PODD course took place in Sutton on 7-8 July, facilitated by Rosie Clarke of Woodlands School, Leatherhead and Livvy Hepburn of Manor Mead School, Shepperton. Despite circumstances being against them (the heat in the room, too much light for the projector, the lax attitude of the venue staff, a children's birthday party next-door, band practice upstairs and Tesco mucking-up the lunch delivery), Rosie and Livvy battled-through to deliver a cracking course, explaining the principles of PODD and encouraging lots of hands-on practice, encouraging everyone with their own laminated-book-conversations. All came away thoroughly fired-up and enthusiastic to inflict their new-found knowledge on anyone prepared to listen – or in the case of individuals with Angelman syndrome, whether they're prepared to listen or not. Highly recommended.



communication School and SLT support

One thing that has been very apparent since ASSERT (AngelmanUK) received the communication grant is that many of you are still struggling to get the professionals on board with the idea of robust Augmentative and Alternative Communication (AAC) and Aided Language Simulation (ALS). Over the years, I've had varying success but I thought it was worthwhile trying to share some strategies. Please remember that you may be going against everything that the team have:

- a) Learned at university
- b) Practiced their whole career
- c) Been working within the local guidelines set by the NHS
- d) Professional pride

You are a parent with experience of one child, they are professionals with experience of hundreds of children. It doesn't mean you are wrong, but it helps plan your course of action if you understand the other point of view. After a full year of trying hard to get things implemented for Leia, this year finally at the last meeting I had some success.

What was different?

- I didn't directly ask for what I wanted. I stated what Leia would need to be successful in her future and then, when everyone agreed it would be important, I suggested ways we could make this work.
- In the past I have suggested that adults around the school should be able to use PODD. I have been told I cannot affect whole school change. This time I suggested that one of the things Leia finds very difficult due to her anxiety is using her AAC with people she doesn't know. Everyone agreed that this was the case and that for her future it would be hugely beneficial if she could communicate with unfamiliar people. We also agreed that school was a perfect

environment to start this off as it is a controlled environment. As a result, school suggested they get adults within her school wing to wear and be able to use PODD to converse with Leia.

Whilst it was a slightly different issue than for those who are fighting to get AAC introduced at all, the points from the change in tack are worth noting.

- Make it sound like you are asking for a small step rather than a huge change.
- Suggest that whilst you are not sure if your child is ready, you would like people to practice it for the future when he is ready. Because who knows how long it will take him or you. Be very sure to state that you do not want to take away the good practices that they already have in place.
- Mention consistency between school and home is important: that they have the AAC with them throughout the whole day. It is easier for a person with Additional Support Needs (ASN) to build habits if they are consistent and if they were ever to use AAC they would need to have it all day. You could also add in generalisation of skills here, you want your child to be able to use their skills in different settings.
- Admit that you do not know if this will work for your child but you feel like you need to at least try AAC and ALS to rule it out (there is no reason to think that it won't but it may help you to be seen as someone who is rational rather than demanding).
- Ask what they envisage for your child and how they see progression occurring. Try to think what they are envisaging for your child and see if you can dovetail them together. For example, the non-existent pre-requisites that your team may be insisting on can be taught using robust language.

Tried this and still no change?

Ask school to start on a smaller scale than you, by using Aided Language Displays or Core boards. The hope is that they could start to understand the process and realise they need more language. Examples can be found on the AngelmanUK Communication and Literacy Facebook page.

Video evidence is very powerful – if your son or daughter is at the stage of using their AAC, video it and share. I really do believe that keeping calm and maintaining a good relationship with professionals involved in your child's life is important but if you are having no success, challenging them may be necessary.

Ask for proof of the practice they are advocating, there is almost certainly none. Do your research before you go into any meeting, it is helpful if you can quote research or give them articles that they can look at. Project-core have just added an annotated bibliography to the website. It will help you locate and understand the most relevant research that can help you (www.project-core.com/annotated-bibliography).

Communication is a basic human right and denying someone the opportunity to learn to communicate to the best of their ability is unlawful. The problem is that your professionals will argue that they are giving access to communication in the best way they know. You need to change the way they think and that's not easy. If Speech and Language Therapy are affecting your relationship with school and you think you can manage on your own, with help from AngelmanUK and others, you can ask to be discharged. School is not so easy to be discharged from but they do have an obligation to provide an adequate education and it is impossible to do this without access to a wide range of vocabulary.

Good luck!

angelman^{uk} summer aac-tivity challenge



Tracey Campbell is challenging you to start putting your newly-acquired communication skills into practice.

Most people have already had their training for PODD or Proloquo2Go (or both, for those extra keen people) and received their books or apps. Now it's time to start using them! So, we're going to have a summer challenge leading right up to the conference, guiding you along the way with baby steps in case you have forgotten some of the knowledge imparted to you. And allowing everyone plenty of practice before meeting the experts again.

This is for all us old-timers as well as newbies, we all need some motivation to pick up the AACtion from time to time. For those who don't have a robust system yet, please join in by using the ALDs or core boards (or play around with both), copies can be found in the files of ASSERT Communication and Literacy Facebook Group or via email.

The challenges will be broken down weekly to help smooth you along your journey – I will be posting for PODD and Karen Gammack will help those with Proloquo2Go.

We will video or take pictures as appropriate. Please send videos ideally but pics or written explanations will help too. They will be really valuable to us and to you. Videoing helps improve techniques and can be shared with other people as demonstration of practice. You can share on Facebook or email.

Each person who completes all seven challenges will be entered into a prize draw to win either a copy of Pictello or a 6-month subscription to Boardmaker online.

Week 1 – Words available at all times.

Share pics of your solutions for ensuring that you always have your AAC with you. Please also share any problems you may be experiencing and we will help you troubleshoot them. This will also enable us to gather a large database of different ideas that we can share with everyone.

Week 2 – Chat words/Core words.

Practice using the common words of speech. Focus on I WANT MORE and LIKE until you feel comfortable but feel free to share practice of any core or chat words.

Week 3 – Starting conversation.

It's important to model to your loved ones that they can initiate communication. Please share videos of your chosen methods that you think will work for them.

Week 4 – Opinions and commenting.

Commenting and sharing opinions are fun ways to communicate. Let's use this week to demonstrate to our loved ones that their opinions matter too.

Week 5 – Partner Assisted Scanning.

PAS is where partners either point to and/or speak the names of the symbols and the communicator responds by indicating yes or no. Some people with AS will rely on partner assisted scanning as their primary method of communicating as they won't have the motor or visual skills to direct access with their hands or eyes. Others will only need to use it when they can't reach their AAC as they have climbed up to the top of the climbing frame and are now hanging upside down so they can reach the bit of chocolate they spotted

20 metres away, just an example! Regardless, it's a habit we should all practice to get good at. Videoing yourself doing this is a great reference for yourself as well as others. Please share – no-one is perfect at this!

Week 6 – Something's wrong.

we would all love it if our people with AS could tell them what's bothering them. Let's all share our woes this week and feel the wave of support.

Week 7 – Useful action feedback.

This helps people learn the best way to access communication. You can reference an action that the child is doing: *oh you turned your head to the side, I wonder if you are telling me no.* Or an action that you are doing that you would like them to learn: *I am putting my finger out, I am reaching across, I am pointing to the symbol for help because I need help.* Learning this technique will help you to teach the habits that people need to become more successful in their language journey.

This will take us up to conference week when everyone can share their stories and get some help if need be! Grant application forms take upwards of 12 hours for Andrea to complete and the logistical organisation of this grant has also been very time-consuming. Of course, it is worthwhile when we see good results. All the evidence that we can gather from this challenge will help Andrea explain the benefits of the monies we receive and fill her weary heart to give her the rather large energy boost required to do it all again. There will be a prize-draw of some great prizes for those who participate too. Further details will be available soon. **Good luck!**



Gestures and non-verbal communication in children with Angelman syndrome

Researchers at the University of Birmingham Cerebra Centre for Neurodevelopmental Disorders are currently recruiting children with UPD or imprinting genetic subtypes for a study looking at gestures and non-verbal communication in Angelman syndrome. The assessment takes around 1 hour and can be done in the comfort of your own

home. Alternatively there's a telephone interview that takes between half - to 1 hour to complete. Children need to be between 2 and 16 years of age. For more information please contact Effie Pearson at exp137@bham.ac.uk or phone 0121 414 2855 Or see: <http://www.findresources.co.uk/gestures-in-angelman-syndrome>



Natalie Fitzpatrick is the newest PODD trainer in the UK and is based in the North East. Natalie recently provided some of the PODD training for AngelmanUK through the One Family Foundation grant. She is interviewed by our communication trustee Tracey Campbell.

How did you end up working with individuals with Additional Support Needs?

It was all the way back as a young teenager, doing work experience – I chose to shadow an Occupational Therapist working with adults with additional needs. This was my first taste of this type of work. I then went on to volunteer at a Scope centre for young adults with Cerebral Palsy. I knew I wanted to work in the disability sector from this point, but wasn't sure which direction to follow... Speech and Language Therapy, Social Work, Occupational Therapy or a special needs school teacher.

The Conductive Education course at Keele University was in its infancy when I was applying for university in 1996 – the information was not even printed in the prospectus – it was a loose sheet added to the envelope. When I read it, I knew this was what I wanted to do; it fit with all the areas of SEN that I was interested in. I visited a local CE provider and another on route to my interview to be selected for the course. I was hooked! The rest they say is history!

What is the best thing about your job?

I absolutely love to see the young individual's faces when they realise they 'can' do something, whether it is a physical skill, a cognitive skill or when they see someone understand their communication attempts – that is priceless!

What is the worst?

I still find it difficult to deal with professionals that do not have a 'belief' in the children, or clients with which they work. Unless we have an inherent belief in human potential, we should not be working in this sector.

How did you first find out about AAC?

Whilst at University we were taught a unit about assistive technology and how students with additional needs could access devices.

It wasn't until I was in my first job in a special school that employed Speech and Language Therapists that I saw this in real life terms, and also low-tech or paper based systems.

After working in the UK for 5 years I moved to Australia where I was introduced to PODD and it revolutionised my practice forever more. Throughout my 10 years in Australia I attended a number of workshops with Gayle Porter in the use of the direct access books, alternate access books, high tech considerations for PODD (before it was commercially available on Compass or the Grid), the 5 day advanced course and my accreditation to be a PODD presenter. I returned to the UK in 2016 and begun presenting and sharing my AAC knowledge here.

Can you give an estimation of how many people you have started AAC with directly?

Oh goodness this is a difficult one! I would say in excess of 80 students.

What is your best/favourite communication story/journey?

This is tricky too! There are so many! There have been a number of young (12-18mths old) students in 'Parent & Child' groups that have surprised their family with their ability to use a PODD communication book with very little receptive input. They observed us using them, initiated an interaction by vocalising and looking towards the book and then when I scanned the options, said something in context, and very relevant... the faces of their parent, and the facial expression of the little one was unforgettable. I also really loved it when a young girl (over-) heard a discussion between education assistants whilst assisting with her personal care. She then went home that night and told her mum, using her AAC. The next day the mum congratulated the assistant on her pregnancy – which was very new and secret!

Have you had any experiences when AAC didn't work?

I have and continue to see individual's being given AAC that does not meet their communication requirements. This is when I often see an initial success, when the individual is excited to use something (rather than nothing), but in a short space of time find that the lack of vocabulary restricts them and their interest fades. When I have introduced PODD to individuals I have not necessarily had experiences of it not working, more that alterations needed to be made to accommodate changes in presentation of the individual's physical or cognitive states.

Where can people turn to for advice on starting an Augmentative Alternative Communication system?

I would start with other people in the same position as you – find out what they have used or experienced and learn from their mistakes and success! Facebook groups are a great source of information and support. Seek provision from your Speech and Language Therapist (SaLT) and Occupational Therapist if access to a system requires it. If they do not have experience with AAC, ask to be referred to another SaLT that does.

People with Angelman Syndrome generally have a great sense of humour.

What is your funniest story?

A young man in Australia used his PODD to request pretend play and dressing up on a

regular basis. He would direct the staff to locate the feather boa – his favourite item of dress up! When it came to collating photographs for his end of year report he had so many feather boa shots! His family loved it!

Have you any new projects you are currently working on?

I am about to start work as a Teacher and Key Stage Leader in a new SEN school in September. They are interested in me introducing the school to PODD and have allowed me to continue my self-employed work as a PODD presenter and AAC consultant work, one day per week. I can't wait to be sharing the PODD and Aided Language Stimulation revolution!

You have one hour to spend with anyone you like. Who do you choose? What do you talk about?

I'd love to have an hour with Gayle Porter – she is so difficult to pin down! I'd ask about changing other professionals' beliefs.

What is your favourite thing to do when you are not working?

I love to go shopping or cooking – I find them both very relaxing.

What is your motto for life?

'I Can!'

What do you always keep in your handbag?

Little girls' hairbands and slides... I find them everywhere!

What is your number one tip for a teacher/professional?

We cannot truly show what we are affecting in the classroom, how we are supporting their learning, unless a child has a way of showing this. They need a form of AAC that allows them to show their personality and their learning. To do this, they need a robust form of AAC with a wide variety of vocabulary – this will then be more likely to include the words in which they are thinking. Adults need to teach / show individuals how to use AAC, when to use AAC and what they could say using AAC before expecting output. Assume competence at every turn in the communication journey!

What is your number one tip for a parent?

Take videos of your child communicating. Unfortunately, people will not always see what you do, and you know how the children do not 'perform' when the relevant professional is sat in front of them wanting to assess them! Believe in your child and believe in yourself!

Trial a safety sleeper bed for *angelman* ^{uk}



AngelmanUK are again thrilled to be able to offer two families the opportunity to trial the *Safety Sleeper* bed from Murray's medical: www.thesafetysleeper.co.uk

As before, all we ask in return is that you report back to us in time for the next newsletter along with a few photographs of the bed in use.

Please email lisa.court@angelmanuk.org with the age of your child, how long you require the bed and why you believe your child should be given the chance to trial the bed. Names will be drawn at random and will be passed on to Murray's Medical for them to arrange delivery. You will be responsible for returning the bed to AngelmanUK or to Murray's Medical at your own expense and will be asked to sign a disclaimer stating that you will be responsible for the full cost of the bed should it not be returned in 'as new' condition.

Gale Eland was lucky enough to trial a *Safety Sleeper* recently and shares her experience with us.

Elliot is 8 years old and currently has a *Safespace Voyager*. This travel system weighs 35kg and comes in two holdalls: cumbersome & extremely heavy to take around. The *Safety Sleeper* weighs just 9kg and comes in its own suitcase on wheels, making it super easy to travel with. It was easy & quick to put up and, with its own electric pump for the mattress, was effortless to inflate! It was as easy and quick to take down and pack away too. When Elliot first got into the sleeper, he was curious and a touch excited by it too, but he soon became tired and rested happily for quite some time.

I would highly recommend this *Safety Sleeper*, but like most things a trial night would be advantageous as every child is different. Luckily for us Elliot liked it!



IMAGINE ID

IMAGINE ID is collecting information about children with a genetic diagnosis related to learning problems.

The study hopes to recruit 5,000 families; the more families who are enrolled, the more useful the information will be, especially for families with very rare conditions.

What's involved? Parents complete an online questionnaire about their child and soon after receive a summary report.

This report has been welcomed by families:

"Until I sat down and answered all the questions, I hadn't really appreciated the number of peculiar little character traits that my son has."

"I'm going to take it into school so that they can put it in the file - any new professionals will be able to get a written summary and picture of the child."

Avery – We wanted to acknowledge the children's contribution to the project and the information gathered about them. We commissioned Marta Altes to write a book for children about rare disease and participating in research, *Avery*. The response to *Avery* has been overwhelmingly positive. Every family is sent a copy when they join the study; it is also available to purchase online (www.imagine-id.org)

"It's the most wonderful story ever. I can't describe how much it describes our family - my little girl is excited to show her teachers."

...and perhaps the most touching comment is from a brother:

"Mum, have you read this book? You've got to read it! It's just like me and Aiden. The little bird finds things difficult like Aiden does, but the brother bird is always with him, helping him, just like I help Aiden."

We need your help!

We have successfully recruited over 2000 participants but we urgently need more.



To be eligible, your child must be 4 years or older and have a genetic diagnosis with intellectual disability, learning difficulty or developmental delay. To find out more please visit: <http://imagine-id.org>

...or contact us:
imagine.id@nhs.net or 01223 254631

transition



Harvey's transition from school to college

We always knew that transition from school to college was going to be a difficult time and I felt very prepared for it. However, as the last school summer holidays approached and we still weren't sure which college Harvey was going to in September, I began to panic. Two colleges had offered places, but one was definitely preferable to the other.

Luckily, we'd been pre-warned, by speakers at various ASSERT conferences, that transition is a very long-winded process. We started our search for colleges and day centres more than two years before and had prepared ourselves, in advance, for a difficult journey. When we were offered a place at our first choice of college we thought we'd cracked the system.

It turns out that having a college place is only the start of the process, we still had to persuade the Local Authority to pay for it. This was not helped by the fact that Harvey didn't yet have an EHCP (Education, Health, Care Plan). He needed to change from a Statement of Special Educational Needs to an EHCP. In the Autumn, we had been told that transferring from a Statement to an EHCP would take 18 weeks - they lied.

At last, after months of preparing various consultants and other professionals' reports, numerous phone calls, emails, and meetings, the final EHCP arrived, but with the wrong college named on it! Parents have a right in law to express a preference for a school or college when a EHC plan is first made - they ignored this.

We then had to battle to get the college that had been named on the EHCP changed to the one we preferred. To do this we had to prove that the named college could not provide adequately for Harvey's needs. More phone calls, emails, and reports. We were considering whether we could handle another very long process, not to mention the expense of going to tribunal when, at the last moment, it was suggested that we should have a 'Way Forward' meeting. Armed with all the evidence we could gather, we turned up ready for a fight.

But as soon as the meeting started it became obvious that they had made a mistake regarding the costs (they had priced our preferred college as residential, the other for a day student). We only ever wanted Harvey to be a day student. We had never been shown the costings and it's surprising that

no-one had questioned the huge difference in costs months before. To our huge relief, they immediately agreed to swap to our preferred choice.

Harvey has now been at the college for two terms and after the initial settling-in process, which turned out to be much more of a problem for the college than for Harvey, everyone's very happy.

But our problems haven't ended there... we have just had the first EHCP review meeting in which we have had to prove that Harvey has improved and gained from being at the college, before the Local Authority would agree to paying for another year. Harvey's improvements are only ever going to be extremely small and difficult to prove so I really wondered whether they would agree to continue the funding, - but they have!

Will we get a third year? Probably not, but watch this space.

Diane Fox-Jones

trustee

news

In 2004, when my world was turned upside down with Holly's diagnosis, the geneticist handed us a scrap of paper that contained ASSERT's contact details: it was a lifeline. It was (pre-Facebook) a door to a world of support. And as it turned out, it was life changing for me personally in ways that I couldn't have imagined.

I attended my first ASSERT conference in 2004, and I still fondly remember the welcome, the bar without drinks, the second raffle because of a reasonable raffle prize and a bus full of kids all being given an inflatable squeaky hammer on the way back from the theme park. (Yes, it was as manic as you can imagine).

At the time, Sally was heroically keeping ASSERT going, alongside a small team of trustees and I duly stepped forward to be part of the team after a conference appeal. The support and conference were key moments in my life, and I wanted others to experience it too.

With 14 years of experience as an ASSERT trustee (and latterly vice chair too), I can now look back proudly on the contributions I've made; to the development of the charity, and the difference to peoples' lives I've seen as a result. Indeed, as I write this, I'm recently back from a fantastic PODD course – just one of many AAC courses that ASSERT has been able to deliver this year. And just as it was back in 2004, it's all still heroically held together by volunteers juggling their lives and the AS world.

But as ASSERT enters its new incarnation as



a rich experience

AngelmanUK – one fit for this media-driven age, I'm also acutely aware that for me, now is the right time to move forward. Holly is swiftly approaching adulthood and Max is now half way to driving, and I need to enjoy that prospect a little more before it's too late.

My last duty for AngelmanUK will be at Conference 2018 which is the perfect end to what has been a fantastic experience. I'm already looking forwards to 2020 when I will be able to attend as an attendee, rather than one of the co-ordinators.

The team is always a small one and the need for new volunteers is always real. If you've got skills to offer and time to spare, then please do get in touch. There are lots of ways of helping and all come with the guarantee of a sense of contribution and friendship.

I'd like to thank all of the fantastic people that I've worked with over the years for their support and friendship and I especially fondly remember those generous people who are no longer with us, and who would've loved to see what AngelmanUK has become. And finally, a huge thanks to the amazing AS individuals and their families whom I've met, laughed with, cried with and hugged.

And with that, I hold out my baton. If you think that you have pertinent skills to offer, passion for the cause and a desire to see the charity flourish, then get in touch. My circumstances allowed me to continue for nearly 14 years, yours may not. Honestly, it will be the best decision you've ever made. See you in Coventry!

Rich Williams (Ex)Trustee/vice Chair

new trustees

Hi my name is **Nav Sanghera** and I live in the West Midlands with my husband Jas and our 3 children, Myah who is 17 and has Angelman Syndrome, Arjun 7 and Raajun 3.

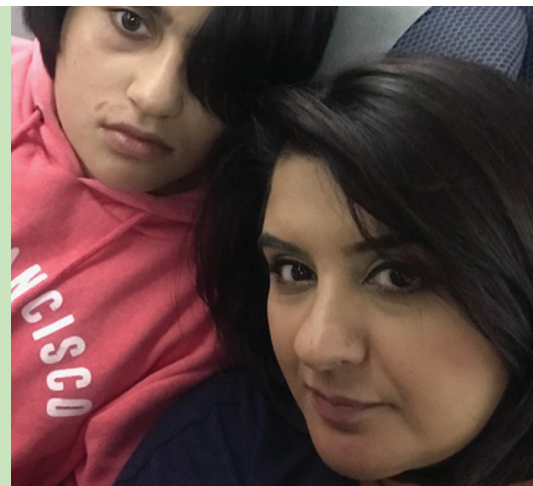
We have been a part of what we like to call the AngelmanUK family since we attended our first conference in 2006. The support we received from there on has been amazing for us as a family.

Over the years we have attended almost everything AngelmanUK has hosted! It's a chance for us all to make new friends and learn from each other. We have organised a few afternoon tea parties to raise money

for AngelmanUK and had the pleasure of organising an IAD event for our region which we all thoroughly enjoyed! My husband and I both work in the world of optics.

I recently left work after 10 years to spend more time with our children and start preparation for Myah's transition into adulthood. There is little on offer for Myah where we live so I know I'm going to have to fight hard to find something suitable.

I have a background in social care and I like to help support families who are in similar situations to us and also those families who come across



language barriers. We are a Punjabi-speaking family and I hope to be able offer support to any families having difficulties that can be associated with having a special needs child.

trustee appeal

AngelmanUK is moving forwards and we're looking for new people to join us. Our trustees are hard-working and proactive, working as a team to oversee the running of AngelmanUK and to ensure that we do the best for the Trust and for our families. We're looking for likeminded people of all ages who feel they can add value to the current board. We have an exciting future and we'd like you to be part of it.

We're looking for people with the following skills and interests: Fundraising, Accountancy, PR, IT, Social Media (across a wide range), Project Management, Legal and Governance, Social care and disability, Social policy, Communication and AAC, Graphic Design, Management. If you have a skill or interest which isn't listed please apply anyway – we may need what you can offer!

Applicants should be enthusiastic, committed team players who are happy to speak up and take an active part in running a national support organisation. There will be opportunities to represent AngelmanUK at conferences and events throughout the UK so the ability to travel on a weekday would be ideal but not essential.

The level of commitment for this role is ad hoc depending upon the volunteer's strengths. There will be busier periods of time when more commitment is required from all team members e.g. conferences or projects.



Practical Considerations

- Availability to attend 4 meetings a year in person or via Skype.
- Ability to take the lead or to help in organising at least one regional event per year in your locality.

- Ability to check and respond to emails on a daily basis if necessary.
- Volunteers are entitled to claim petrol allowance and expenses should they choose to do so.

Contact us: info@angelmanuk.org

new trustees

Hi, my name is **Louise Shaw**. I'm married to John and we live in High Wycombe, Bucks, with our beautiful, funny, cheeky daughter Holly, aged 9, who has Angelman Syndrome (ICD). Holly was diagnosed when she was 2 and a half, although we knew from early on that she was experiencing significant delays especially with her speech.

However, Holly always won everyone over with her mega watt smile and I'll never forget a nursery report saying 'happy happy Holly, is she ever anything else?' Joining AngelmanUK when Holly was

diagnosed was the best thing we could have done.

We received so much support, made lots of new friends and suddenly had access to a large number of parent experts!!!

Stepping up from being an AngelmanUK representative to a trustee is an exciting move and I'm looking forward to meeting lots of you at the conference in a few weeks!





Photo courtesy of www.timeshighereducation.com

Working towards treatments for angelman syndrome

Dr. Katie Cunnea guides us through some of the latest therapies and research.

If you are interested in Scientific Research into Angelman syndrome (AS) I am sure you will have heard about several different groups of people looking to launch clinical trials to treat Angelman Syndrome. The most recent group to announce its intention to move towards clinical trials, uses a technique to manipulate DNA called CRISPR-Cas9 (see reference 5 below for a nice video explanation). But what is it and does it hold the key to a therapeutic for AS?

There are three main avenues for treating AS that are being explored. Use of repurposed drugs to treat symptoms of AS, gene therapy and gene activation.

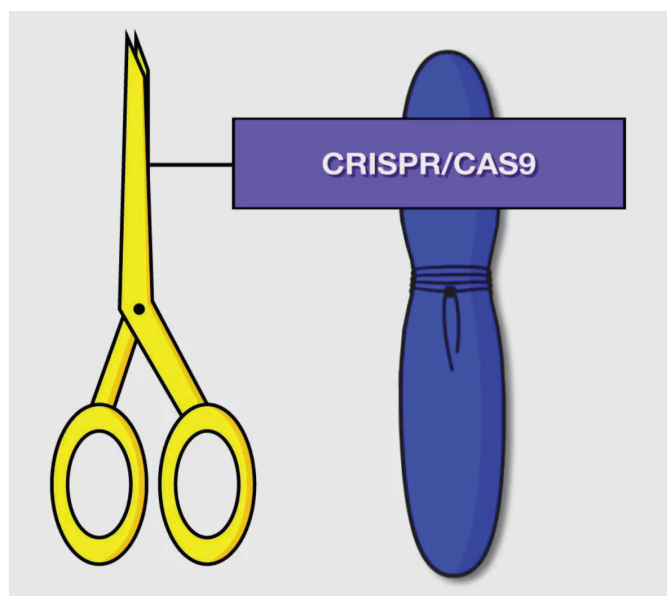
Targeting molecules involved in the chain of events that UBE3A controls (rather than UBE3A itself), with existing but repurposed drugs could be a fast way to get a drug out there to treat symptoms of AS. However, it has proven difficult to identify drugs that can help. Minocycline for example, unfortunately did not work out as hoped. Ovid pharmaceuticals OV101 might prove more beneficial¹.

Another approach is to try to un-silence the father's copy of UBE3A using anti-sense oligonucleotides (ASO's)^{2 & 3}. Use of ASO's would be reversible: stop taking the drug, and it will leave your system and in theory, unwanted side effects would disappear. However, the downside is that you have to keep taking the drug, and worse it is very difficult to get the drug to the right place. It would likely involve injections into the spinal cord or brain (which is perhaps not practical).

In May 2016, Agilis announced that it was working towards clinical trials in Europe for a gene therapy treatment for Angelman Syndrome⁴. It now it looks like research by Mark Zylka using CRISPR-Cas9 technology is also hoping to move towards clinical trials⁵. But are we close to a treatment or not?

The great thing about gene therapy is that patients would only have to endure one treatment for life. One massive risk of this however is that the process is irreversible so if something goes

wrong, or there are unforeseen side effects, there is nothing anyone could do. It is also essential to control how much of the gene is produced and where. The Angelman Syndrome Foundation recently announced it was funding Dr Mark Zylka to work on a treatment using CRISPR-Cas9 technology to stop the process that turns off the paternal copy of UBE3A. Deleting DNA that turns UBE3A off in the father's gene might be a better way to control the amount of UBE3A



Picture shows Angelman Syndrome Foundation funded research by Dr Zylka⁵. The scissors represent CRISPR cutting out the DNA (antisense transcript) that stops the father's copy of UBE3A working.

produced rather than adding UBE3A DNA to the maternal copy. But it is going to be important to test this.

The question about how close we are to treating human disease with gene therapy approaches is a question not just relevant for AS, but many human diseases. As a technique, CRISPR-Cas9 technology is still in early stages, and there are many ethical and safety concerns to test yet. Although some clinical trials involving the use of CRISPR-Cas9 have started in China, this is mainly due to lack of safety and ethical regulations. Other nations are being far more cautious. For example, evidence emerged in June that cells changed via the CRISPR-Cas9 method could become more susceptible to becoming cancerous⁶. There are also wider ethical concerns of playing 'God': should we be tampering with the human genome and/or what might we accidentally change? For the AS community there is also the question of whether replacing UBE3A after brain development has completed would do anything. It is certainly very exciting and there are many scientists excited about gene editing techniques and particularly CRISPR-Cas9 technology, but we should perhaps be cautiously optimistic and also realise things are not likely to happen too quickly^{7 & 8}.



Illustration by Sébastien Thibault from ref. 7. CRISPR, the disruptor, a powerful gene-editing technology is the biggest game changer to hit biology since PCR. But with its huge potential come pressing concerns.

References

1. <http://www.ovidrx.com/ovid-therapeutics-announces-first-patient-randomized-in-the-phase-2-stars-clinical-trial-in-adults-with-angelman-syndrome/>
2. <https://www.nature.com/articles/nature13975>: Meng, L. et al. (19 Feb 2015) Towards a therapy for Angelman syndrome by targeting a long non-coding RNA, *Nature*, 518, pages 409–412
3. CVM Professor's Antisense Program Being Investigated as Possible Angelman Syndrome Treatment. <http://vetmed.tamu.edu/news/press-releases/cvm-professor-s-antisense-program-being-investigated-as-possible-angelman-syndrome-treatment>
4. Agilis Biotherapeutics Announces Orphan Designation Approval in Europe for the Treatment of Angelman Syndrome: <http://www.agilisbio.com/wp-content/uploads/2016/05/Angelman-EMA-ODD-Press-Release-5-4-2016-Final-1.pdf>
5. https://www.youtube.com/watch?v=DIOd4xxPkog&feature=youtu.be&utm_source=ASF+General+Mailing+List&utm_campaign=5eeec6598d-EMAIL_CAMPAIGN_2018_07_02_03_44&utm_medium=email&utm_term=0_897f97cc10-5eeec6598d-46244829
6. Haapaniemi, E et al. (11 June 2018) CRISPR–Cas9 genome editing induces a p53-mediated DNA damage response. *Nature Medicine*. <https://www.nature.com/articles/s41591-018-0049-z>
7. Ledford, H., (3 June 2015). CRISPR, the disruptor. *Nature News Feature*, vol. 522, Issue 7554. <https://www.nature.com/news/crispr-the-disruptor-1.17673>
8. MRC policies and guidance for researchers, Genome editing in human cells: <https://mrc.ukri.org/research/policies-and-guidance-for-researchers/genome-editing-in-human-cells/>

happy about GDPR

As you may be aware, the new General Data Protection Regulation (GDPR) came into force on 25th May 2018 and has been introduced to help give individuals more control over what happens with their data. AngelmanUK only collects and stores data provided by you on your application form, for the purpose of sending communications relating to Angelman Syndrome.

To manage our compliance, we have engaged the services of gdprhappy.com who have been registered with the Information



Commissioners Office (ICO) as our Data Protection Officer (DPO). Any queries relating to your data and your rights under GDPR will be handled by our DPO who can be contacted at: dpo@gdprhappy.com

help us to help you keep

smiling

donations

Without your contributions there would be no angelmanUK to offer support for your family. Whether big or small, every penny really does make a difference. A very big thank you to...

<u>Mrs Hazel Tait</u>	<u>Suki Haywood</u>
<u>Pip Sinclair</u>	<u>Michael Heller</u>
<u>Neale Turk LLP</u>	<u>Mr & Mrs Webbing</u>
<u>Stu-Nique</u>	<u>Mr & Mrs Capen</u>
<u>The Ukes of Old FQM Ltd</u>	<u>The Sandon School</u>
<u>Les Petites Etoiles</u>	<u>Leicestershire Bobbin</u>
<u>Jonny & Mel's wedding</u>	<u>Lace Guild</u>
<u>Pete's Plaiice</u>	<u>Jeffery's Corner Nursery</u>
<u>In memory of</u> <u>Mr Geoffrey Snow</u>	<u>Emms Gilmore</u>
<u>Sarah & Carl Valentine</u>	<u>Liberson Solicitors</u>
<u>Lisa Howton</u>	<u>Charlotte Wilkinson & Severn</u>
<u>In memory of</u> <u>Mrs Rosemary Cunnea</u>	<u>Trent Water Ltd</u>
<u>Harriet Ellis Training &</u> <u>Recruitment Group</u>	<u>Seraosha</u>
<u>Old Portmuthian Chapter 8285</u>	<u>Pam Wild</u>
<u>Carol, Chris & Joshua Lee</u>	<u>Stephen Roberts</u>
<u>Shipdham Quizzers</u>	<u>Charlotte Walker</u>
<u>Jane Clarke</u>	<u>Peter Kandunias</u>
<u>Cynthia Knowles</u>	<u>Nicholas Han</u>
<u>Mr & Mrs Waters</u>	<u>Daniel Scott</u>
<u>In memory of Mr John Dufield</u>	<u>John Vincent</u>
<u>Jane Baker</u>	<u>Christine Manley</u>
<u>Dancers of Tadley and</u> <u>Basingstoke U3A</u>	<u>Natasha Lord</u>
<u>Dukinfield Golf Club</u>	<u>Nathon Spong</u>
<u>Mr & Mrs Taylor</u>	<u>Tim Yates</u>
<u>Sarah Duffy</u>	<u>Sue Vasey</u>
<u>Hedge End Medical Centre</u>	<u>Sarah Laforet</u>
<u>St Thomas Church</u>	<u>Natasha Rawe & Boots Beflast</u>
<u>Tiptree Road Runners</u>	<u>Beauty Matters</u>
<u>Thelma Ray</u>	<u>The Recruiting Sergeant</u>
<u>Cheshire Freemasons, Eaton</u> <u>Lodge 533</u>	<u>Pub & Restaurant</u>
<u>Coastline Harmony Chorus</u>	<u>Mrs KJ McArdle & Mrs DA</u> <u>Welland (in memory of their father)</u>
<u>Mr & Mrs Knapp</u>	<u>Emms Gilmore</u>
<u>Neale Turk LLP Solicitors</u>	<u>Liberson Solicitors</u>
<u>Mrs Greenaway</u>	<u>Forest Quilters</u>
<u>Emily Bagwell</u>	<u>Mrs Jan Moir</u>
<u>Mr & Mrs Gundle</u>	<u>Caldy Valley</u> <u>Neighbourhood Church</u>
<u>All Arms Junior</u> <u>Leaders Regiment</u>	<u>Dr W J Charles</u>
<u>Kids Planet Dukinfield</u>	<u>In memory of Keiran Bridges</u>

<u>Judy Macer</u>	<u>Catherine Murphy</u>
<u>Ian Blackham</u>	<u>Elen McGuinness</u>
<u>Jill Walsh</u>	<u>Damian Reynolds</u>
<u>Anthony Senior</u>	<u>Wendy Holt</u>
<u>Russell Hoyle</u>	<u>Jamie Faithful</u>
<u>Robert Brashier</u>	<u>Michelle Roberts</u>
<u>Marina Cook</u>	<u>Tom Williams</u>
<u>Amelia Coffen</u>	<u>Carol Cooper</u>
<u>Anne Chester</u>	<u>Shirley Ambrose</u>
<u>Andrew Smith</u>	<u>Prashna Haridas</u>
<u>Lucia Da Cunha</u>	

fundraisers

You've read about the efforts of our fabulous fundraisers elsewhere in this issue. Why not get involved yourself and organise an event to raise money for us. Contact lisa.court@angelmanuk.org and she'll send you a fabulous fundraising pack with all the details of how you can get involved.

<u>Kyri Kyriacou</u>	<u>London Marathon</u>
<u>Emma Goodson</u>	<u>London Marathon</u>
<u>Calum Barker</u>	<u>London Marathon</u>
<u>Michelle Walecki</u>	<u>London Marathon</u>
<u>Jo Benham</u>	<u>London Marathon</u>
<u>Michael Bennett</u>	<u>London Marathon</u>
<u>Dai & Catherine Jones</u>	<u>Golden Wedding Anniversary</u>
<u>Gareth Edwards</u>	<u>LA Marathon</u>
<u>Katy Jonas</u>	<u>Great North Swim</u>
<u>Paul Ford</u>	<u>Great North Swim</u>
<u>Jessica Porter</u>	<u>Great North Swim</u>
<u>Stephen Lees</u>	<u>Great North Swim</u>
<u>Steven Watt</u>	<u>Edinburgh Marathon</u>
<u>Ivy Liu</u>	<u>Edinburgh Marathon</u>
<u>Richard Stebbing</u>	<u>Brighton Marathon</u>
<u>Joanna Thompson</u>	<u>Kingston Half Marathon</u>
<u>Nicholas Morris</u>	<u>Paris Marathon</u>
<u>Angelman & Gracie's Angels</u>	<u>Belfast Marathon</u>
<u>David Boorer & friends</u>	<u>Sheffield Half Marathon</u>
<u>Sarah Brown</u>	<u>Manchester Marathon</u>
<u>Mark Duckworth</u>	<u>Coast2Coast</u>
<u>Kelly Fount</u>	<u>Race to the King</u>
<u>Candice Thompson-Gardiner</u>	<u>Skydive</u>
<u>Pat Fox</u>	<u>Skydive</u>
<u>Jade Bates</u>	<u>Recruiting Sergeant</u>
	<u>Music Festival</u>