

Angelman Syndrome
Support, Education & Research Trust

Conference 2016

Transition

Working Groups

MG Trophy Championship

Scottish Conference 2017

The Communication Revolution


International Angelman Day 2016

Your Assert



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Useful Stuff

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OUR WEBSITE
www.angelmanuk.org

EMAIL ASSERT
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HELPLINE
0300 999 0102

ASSERT Families - New Diagnosis Advice
Contacts - Support

ASSERT SHOP
Wear your charity with pride! T-shirts,
polo shirts, bags, hats and lots more from
Spreadshirt, our on-line retailer:
www.angelmanuk.org/spreadshirt

FRONT COVER
Photograph courtesy of Robert Chadwick.
We'd like to use one of the great photos taken
at our conferences on each of our future
covers. If your AS family member was one of
those photographed and you do not want their
images used on ASSERT material please let us
know at the above address as soon as possible.

CONTENTS OF THE NEWSLETTER

You will notice that the pieces in this newsletter
are drawn from a wide variety of sources.
While we are keen to promote discussion
and to pass on any views and experiences, it is
also important to appreciate that the opinions
and views expressed by contributors to this
newsletter are personal and not necessarily
those of ASSERT.

Letter from the Chair

If you've spent any time on-line since Christmas, you can't fail to have noticed the growing visibility of International Angelman Day on February 15th. In just a few years, this internationally co-ordinated event has gone from strength to strength with newsfeeds and timelines now full of group photographs, family snaps and personal messages from all around the world. For those hearing about Angelman Syndrome for the first time, whether because of diagnosis or personal interest, this annual tsunami of human positivity cannot be anything other than inspirational. This outlook on life was one of the founding aims of ASSERT and it's fantastic to see it spread around the world. For those of you who attended, helped, shared, supported, organised and championed the day- thank you.

Another topic that you can't fail to have missed is the communication revolution that is spreading like wildfire through not just our global community but others who are also caring for loved ones with complex needs. It is something that ASSERT has championed from the beginning and it is something that we will continue to do. It featured heavily at our last conference in 2014, in Liverpool last year and will feature at our conference later this year. In addition, we have set up a working group to develop our expertise within the UK, rather than relying totally on our globetrotting 'stars' (see elsewhere in this edition). Tracey Campbell, ASSERT member, experienced AAC user and mum to Leia, is leading this project. Welcome to the team- and thank you.

We will have additional information and advice available for distribution soon. Something that we know we have had a number of requests for over recent months.

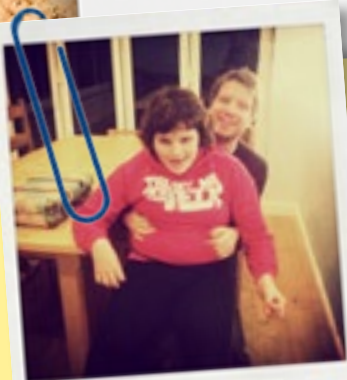
The focus on alternative communication represents something bigger than giving people a clearer voice however. And that's why it's important to continue with, regardless of whether your loved one can or can't use an iPad. It's something quite subtle that will take a while to filter through to all corners of society. It's a change in mind set. It's presuming that those we love and care for can, rather than cannot. It's presuming competence until proven otherwise. Something that the rest of us take for granted.

Letters have gone out to all registered members for Conference 2016. As ever, the demand for places will be high, so please send in your forms if you wish to join us; and then enjoy the return of the longer days as we count down to September!

Lastly, Linda Holmes informed the team recently that she has decided to step down as a trustee. On behalf of everyone in ASSERT, we'd like to thank Linda (along with Rick, Becky and Lucy) for the support and input over the last few years and wish them all the best of luck for the future.

Enjoy the sunshine!

Rachel & Rich



Gareth & his niece Ella

An update on Our Patron Gareth Edwards...

Gareth has had a very busy start the year. Filming finished early 2016.

He is now busy editing the film ready for the December 2016 release.

Currently he is in the UK but will shortly be heading over to San Francisco to finish editing. Hopefully you have all seen the trailer for Rogue One which was released early April. The hype has now well and truly begun and this will only escalate over the coming months. We hope to have some exciting announcements later in the year

Meet Our Communication Advisor

Hi, I am Tracey and I am delighted to say that I am the new ASSERT Advisor on Communication for families. I live in Glasgow with my husband Gordon and our 3 children Abbie, 12; Leia 9 (AS); and Finn 4. ASSERT was one of my first ports of call after Leia was diagnosed with Angelman Syndrome and from that first moment on the Association has enhanced our life by giving us access to information and experts, to say nothing of the new friends we have made.



Tracey Campbell Family

INTERNATIONAL
ANGELMAN
DAY FEB 15



International Angelman Day

15th February 2016

International Angelman Day is held on February 15th. This was the 4th year of IAD and ASSERT's second year of arranging meetings across the UK to celebrate this special date. Last year was a great success with 13 meetings. We managed a few more this year! There were 16 meetings around the UK with a good mix of local halls and trips out for all of our families to attend. Here's a selection of some of our meetings.

North West

The North West and Wales regional event for International Angelman day 2016 was held at Chester Zoo. We had a record number of families who braved the cold and had a walk around the zoo. We all met up at lunch time and took over the cafeteria and it was an amazing opportunity for many families, some of which had never met another AS family, to make new friends and to hear about and make plans to attend future events and the conference. Despite the cold everyone had a lovely time and it was lovely to meet old friends and new.

Central

We had a wonderful afternoon enjoying the very large sports hall of a local school. It was great to see so many families come along and as always it was a good mix of new and familiar faces. The children really enjoyed the magician, the bouncy castle and slide and I think the most successful part of the day was the dance class. It was great to see our AS individuals, siblings and parents all joining in the dance moves!



Yorkshire

In Yorkshire we celebrated IAD at Sensory World in Dewsbury. None of us had been to the venue before but we were made to feel very welcome by the staff. It was lovely to catch up with some familiar faces as well as meet new families who had not been to other Assert events. In the sensory room the ball pool was very popular and there was lots of chatting, information sharing and laughter in the café. My son ate his body weight in pizza (sorry if anyone missed out as a result!).

East Anglia

A lovely fun day out was had by all at the Sealife Centre Great Yarmouth. It was lovely to meet old and new friends.





Essex

We all met at Cromwell Manor, and what a wonderful afternoon it was. Families were able to meet up with each other, some for the first time, some for a reunion. Our angels ranged from under 2 years old, to over 30. We danced under the lights, we played in the ball pool and mini soft play, enjoyed lots of bubbles & we had a wonderful spread laid on. It was an absolute pleasure to host this event and to meet all the wonderful families who came along. So many smiles were captured on camera, the biggest was when we brought out the chocolate cake!

London

We had a fabulous turn out for at the Royal Botanical Gardens Kew, with 14 families coming together to commemorate IAD. Conditions were arctic but the mood was warm; our Angels delight in meeting old friends and making new ones kept spirits high. Fuelled with sandwiches and cake, we were guided round the gardens and the Princess of Wales Conservatory for a vibrant carnival themed display of Brazilian plants and orchids. Huge thanks to all the families that came, to the Royal Botanical Gardens for free entry and 4 wonderful volunteer guides from the Discovery programme and Madiha from White Peaks Cafe for her help in organising the food and room.

Photos: 3 photos uploaded titled



South Coast & Hampshire

The South Coast IAD event was held at Eastleigh. Approx 10 families enjoyed 3 hours of fun including a disco, sensory room, inflatable games and a fantastic buffet, followed by cake! The children all enjoyed seeing each other and the families got a chance to compare stories and experiences with others who understand!



South Central

Thanks to all the families who came to the South Central IAD in Abingdon - I talked myself hoarse and ate far too much cake, so a good afternoon all round! 26 people (7 families) attended, long term friends and some new families who were meeting other AS individuals and their families for the first time. Entertainment was provided by Georgina and her "Little Dudes Disco". As George is herself an SN mum who gets it, all the equipment she brought was chewable and she let the kids dictate the pace, playing games (including wrapping us all in loo roll!) when they were interested and just helping out when they weren't, letting everyone have a chance to catch up. The venue, run by another charity, was given free of charge for the event and was a great space to hang out in. And Louise came alone to help out and learned a valuable new skill!! Can't wait for next year!

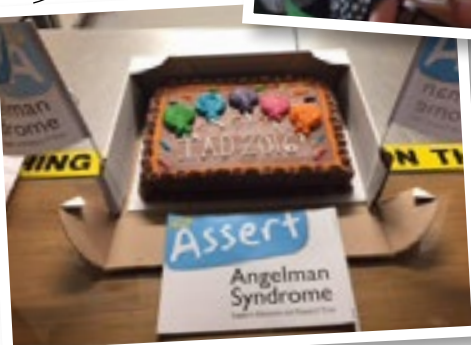


South West

The Eden Project was the venue for our South West IAD meeting this year and we had a lovely mix of families from Devon and Cornwall. All the families enjoyed some time together, exploring the Biomes and Ice Skating rink, we even got a glimpse of the Stick Man!



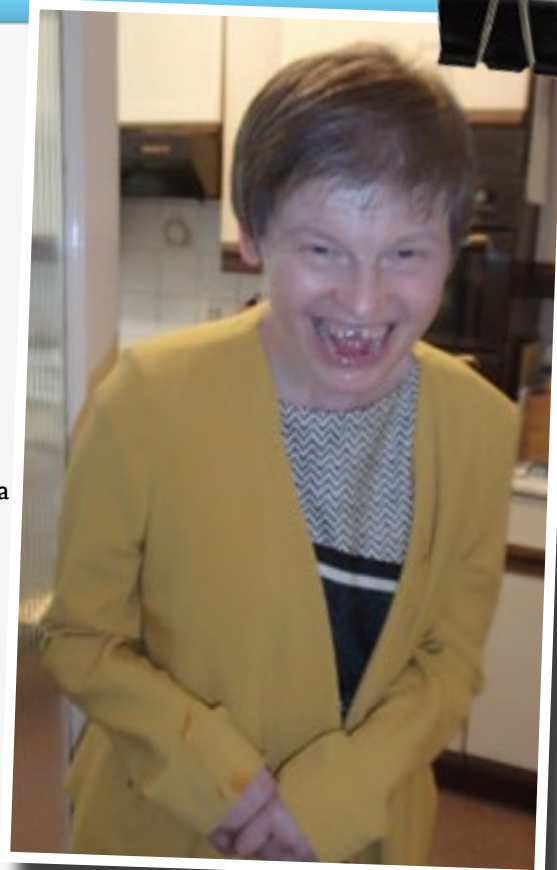
During our visit we had time to catch up with familiar faces and meet some new families, one of which was recently diagnosed, so sharing stories and providing advice between us was invaluable – we all continue to learn from each other which is the wonderful network we have, even this far down the Island! Our Angels and Siblings were amazing and enjoyed a lovely day out.



Sandy

“What does the future hold?” is a question that figures prominently in the minds of parents of those with Angelman Syndrome and other learning disabilities. It is especially significant when considering the issue of living away from home.

Our daughter, Sandy, is now 55 years old. She has successfully lived away from home since late in 1986 and is very happy and leads a full life. She lives with five other people in a purpose built home with 24-hour person-centred care provided by an enlightened organisation with a totally committed staff team. We have always felt strongly the importance of establishing a full and satisfying life for Sandy that will stand her in good stead for the future. When we see the variety and extent of her activities, the breadth of her social circle and the satisfaction that she clearly gets from life, we realise that living away from home has broadened her horizons and increased her self confidence in ways that we would not have dreamt possible. Yes, she is always pleased to see us but when the time comes, she is eager to get back to her own life in her own home. Despite her complete lack of verbal communication, her actions leave us very reassured.



Sandy's energy and love of food have not diminished with age. She remains fit whilst remaining quite slim. However, since reaching “middle age” she has experienced some ‘absences’, but these are now controlled with medication and as a result she has not had any for some time.

Sandy thoroughly enjoys her visits to the cinema, has no problem sitting through a whole programme; and is off as soon as the final credits role. With no speech, the extent of her apparent understanding in such situations never ceases to amaze us. We suspect that much of her activity derives from her curiosity and her love of watching people. This is particularly noticeable in situations where there are large numbers of people and a lot is happening. A full programme of activities is always arranged during her annual holiday. This summer she spent a few days in Looe in Cornwall with two of her carers.

She apparently now sleeps much better and the night staff do not see as much of her as when she was younger. Equally, some of the more disconcerting characteristics such as hair pulling are much less.

Sandy's self confidence is further enhanced by her weekly visit to the local club for adults with special needs which will be celebrating its 50th anniversary this year. There are weekly meetings and numerous outings. A highlight of the year for Sandy and a group of her contemporaries (about 12 in number) is a weekend away at a seaside hotel. Each has their own volunteer to support them. She attends the local day centre four days a week while staff at her home keep her busy with a series of activities and outings tailored to her interests and designed to develop her potential.

A full and satisfying life, that is fashioned around Sandy's interests, involves a wide circle of friends. We are reassured that this can continue without interruption when we can no longer be involved.

Joan & Ian Lockhart

Siblings

Dear Jon



Problems can be written anonymously to jonathan.allen@angelmanuk.org or to Jonathan Allen via a message on Facebook.

Dear Jon is an anonymous problem help page for siblings. It gives siblings the opportunity to seek advice on issues that they face in dealing with their brothers and sisters who have Angelman Syndrome. Hopefully by providing advice it can deal with these concerns that siblings have and also help others who may be reading and going through similar issues.

Dear Jon,

I feel like my teenage son is being left out as my Angelman child demands so much attention at the minute. He hasn't complained at all but I am worried that he will end up feeling pushed out.

Jon's Answer: Being a teenager is often a time for people to develop identities of their own and I don't think it is a massive concern if your son is doing this. However, I do understand that family is important and that you don't want him unhappy with his home situation. A good idea is often making specific time at the end of the day to focus on him if you can, when your Angelman child is in bed. Additionally, if you can then make your son aware that you are always there for him if he needs you. It may be that there are some activities your children can do together which will help them remain close.

Dear Jon,

I have a sibling who bites me a lot recently and I am not really sure as a sister how to deal with this.

Jon's Answer: This is something that my Angelman sibling used to do to me and it is not uncommon behaviour. It may be difficult but the best thing I found in my experience was to completely ignore her. If I do not give her any attention then there is no reward for her for doing it. This meant that she soon stopped biting me and instead other behaviours were improved when I gave her attention for them.

Dear Jon,

I am worried about the future care of my sibling. It is not a consideration at the minute and my parents have said that they will ensure that I am never forced to care for him. However, I feel guilty about moving on with my own life and not being there for him.

Jon's Answer: Feelings like this are completely natural. If possible then I encourage parents to at least make future plans where possible and not rely on siblings for this. However, every situation is unique to each family. Feelings of guilt and resentment are common and are nothing to be ashamed about. The fact that you have these feelings clearly shows that you care about your sibling. However, it is important to develop as your own person at the same time. Ultimately you should make the decision that you are most comfortable with.

Literacy & Communication

A message from Tracey:

As a family, communication is one of our main focuses. Leia uses a PODD book and has the Compass app on her two dedicated iPad talkers. Leia was first given a PODD in 2013 but I had no training on the system or how to implement a communication system. As such, it wasn't used very much until I heard Mary-Louise Bertram and Erin Sheldon at the ASSERT Conference 2014. Our communication journey from then has come a long way, thanks to information from the Conference and contacts we have made since, especially via Facebook groups and the ASF Communication Series. Like all families, we still have our good days and bad days but we are trying really hard and I cannot begin to describe the joy each and every time Leia uses her talker in a real and genuine manner.

I am currently in discussion with the Speech and Language Therapists in my local NHS about the local guidelines which are still very prohibitive for some children. I am also about to start running a communication club at Leia's school and look forward to sharing some of the ideas with you all. Whilst my own experience is in PODD, the implementation of any communication system is similar and through the communication club at school I will be getting exposure to more systems which should allow me to advise regardless of the system used already. I genuinely believe that, with the right implementation, all individuals with Angelman Syndrome can improve their communication and I am excited to help with that as much as I can.

A diagnosis of Angelman Syndrome comes along with the sad knowledge that your child or loved one will have very limited speech. When accepting the diagnosis you learn to accept that you will not be able to have a conversation with your child or loved one. This certainly used to be the case but there is a communication revolution happening, and it is being led by the Angelman Community. How did it start and what does it mean for individuals with Angelman Syndrome?

Traditional guidelines for access to speech and language interventions such as a language system require the individual to show certain skills under a test situation. Typical skills include

- i. Follow directions
- ii. Make choices
- iii. Listen and attend
- iv. Make eye contact
- v. Take turns
- vi. Show joint attention
- vii. Understand cause and effect

Each of these can present problems for someone with Angelman Syndrome.

When someone is being asked to specifically follow instructions, particularly in a testing environment as much Speech and Language Therapy is, the level of anxiety experienced can very often lead to apraxia. This means that however much the person understands and wants

to comply with the instruction, they simply cannot do it. This failure leads to more anxiety and adds to the problem. This can also make turn taking very difficult.

Choices are by their nature limiting. For people who are notorious for wanting to follow their own agenda the chance of failure is high with a limited range of choices. When someone does not choose it does not necessarily mean that they do not understand. All that can be inferred is that the person did not choose.

Angelman Syndrome comes by definition with difficulties processing sensory information. This can make both eye contact and listening and attending virtually impossible for individuals who can only process information from either their eyes or their ears at one time.

Sitting still and concentrating is very difficult for those with proprioceptor problems as the brain has to work very hard to keep remembering where the body is; this leaves little room for concentrating on tasks that are not highly stimulating and makes joint attention difficult to prove.

Cause and effect is often described as the foundation for communicating intentionally. Often activities to teach cause and effect are unrelated to communication and can have no purposeful meaning. This means compliance may not be

high. However, challenging behaviour, although not altogether desirable, is a form of communication full of intent.

Until recently the widely shared belief was that people with Angelman Syndrome were unable to communicate and therefore unsuitable for AAC, despite parents knowing that their children were very often meeting criteria in other ways. Enter into the scene Mary-Louise Bertram, an early-years teacher from Australia. In 2009 Mary-Louise became a teacher in a class with four individuals with Angelman Syndrome. She believed that using an AAC system would help to teach the pre requisites of language and recognised that we start to teach babies the language that they will eventually communicate in before they are even born. These theories were not new but sadly they were definitely not common practice. All the children in Mary-Louise's class were given access to a full communication system, PODD.

In 2010 on an Angelman Syndrome forum, a parent came on asking for help as her school wanted to use a PODD communication book and she was looking for evidence that it wouldn't work. Mary-Louise posted saying that actually PODD could work for someone with Angelman Syndrome. She was met with so much criticism that the moderator jumped in to her defence. She too thought Mary-Louise was crazy but felt that people should at least be polite. That moderator was Erin Sheldon, mum of a child with Angelman Syndrome who was, at that time, studying for a Masters in Education in inclusive teaching practices. Mary-Louise felt she had found a kindred spirit and, through some very persistent messaging and sharing of literacy information, she got Erin to believe her. They have been communicating ever since and the Angelman community and others have benefitted hugely.

In 2011 Mary-Louise started working with individuals across the USA and Canada as well as Australia. In 2013 she was granted money by the Angelman Syndrome Association of Western Australia and the state government to conduct a state-wide communication project. Each person with Angelman Syndrome in Western Australia was given access to a communication system and parents and key communication partners were taught how to model the system, as is the evidence based best practice. The communication gains were studied over a year. Every single participant aged between 2 and 45 improved in their communication skills. Interestingly, the oldest participants made the most significant gains proving that no one is too old to start learning a language. In 2014

ASSERT managed to get both Erin and Mary-Louise to attend the biennial conference and so the UK was added to the list of countries with a growing interest in communication and literacy for those with Angelman Syndrome.

The communication revolution has also been greatly enhanced by the internet and Facebook. Many professionals are still bound by, or believe in, the outdated guidelines and therefore do not give individuals access to language systems. This has resulted in parents introducing a language by themselves. Teaching someone to use a new language system is not easy; putting this together, with the difficulties many face trying to persuade other family members or professionals to buy into the idea, is not a task that many could tackle on their own. However, with the Facebook groups, help is only a post away - it is astonishing how many people are always willing to lend some advice or be a sounding board for ideas.

The most useful tool that has been released for communication and Angelman Syndrome is a series of webinars that has been commissioned by the Angelman Syndrome Foundation (ASF) in America. The ASF Communication series is a (school) year-long project with webinars every week on how to best introduce communication to someone with Angelman Syndrome. It also includes a very necessary element of literacy as this is required if a person is to grasp the whole concept of language and communication. Each week a dedicated team of professionals spend an hour sharing their best practice with the world. It is meant for anyone who requires AAC at whatever stage they are at in their language development. The webinars are also available on YouTube and will remain there indefinitely for anyone to start at any time or to revisit.

Given that the revolution only began 6 years ago, it has come a long way. So, whilst individuals with Angelman Syndrome will have very limited speech, their communication can be so much more.

It takes a lot of time and effort to introduce a communication system and there may be an element of cost if self-funding. But if you choose to make the leap of faith, none of you will be disappointed.

Tired yes, disappointed no.

Tracey Campbell

Literacy & Communication Q&A

My child is deletion positive, is there any point in trying to introduce a complicated communication system?

In a word yes! Some of the best communicators with Angelman Syndrome are deletion positive. There is an element of problem solving that goes into introducing a new system but with that in place and the right implementation of the system, every single person with Angelman Syndrome can improve their communication. If you need any advice about the best way to introduce a system please get in touch.

My child is generally happy and I always know what they want, so can AAC actually make a difference to us?

Most people with AS are skilled in non-verbal communication and as a result can often get their needs and wants met. However, communication is so much more than that. When we communicate with others, only a tiny proportion of that is about requesting. A full communication system allows individuals the opportunity to communicate to the best of their ability. It allows them to be more in charge of their environment. Also, it is very hard to contribute to society without a reliable method of communication. For these reasons and more, a comprehensive AAC system can revolutionise life for the individual and the whole family.

I have been told my child is not yet ready for AAC, at what age will she be ready?

There is no age that children or adults become ready for AAC; the age they are at right now is the best age to start. The guidelines in the UK are still based on an outdated approach and require that people have a certain skill set before they can get access to a communication system. This may mean that your Speech and Language Therapist is restricted in what they can offer. However, all current research shows this is not the case. When you introduce the system, the focus is all on the communication partners using the system to show how it is done. This then means that the person for whom the system is for doesn't need any skills before they get a system.

Which communication system should I choose?

As long as the communication system you choose has enough words in it to say what whatever you want to say when you want to say it, then it is a full system and is therefore ok. There is some new research that shows that the actual communication system is much less important in the ongoing success of the system than the implementation and training of it. It may be worth researching to see if people in your local area, schools or groups use to a particular system and if they would be able to offer you training or help implement the system. If there is no specific system that people can help you with, you can contact ASSERT, watch webinars 2 and 3 from the ASF communication series and or post in any of the Facebook groups to get further advice.

My child has left school and we have no access to services. How can I get the help I need?

ASSERT and other Angelman Syndrome charities across the world are aware that there is a large gap currently for adults with AS in terms of access to communication. Until very recently, the people with Angelman Syndrome were considered unsuitable for AAC which has meant that many adults have left the education system before getting a communication system. The good news is that there is no upper age limit to learning to use AAC and, in fact, it has been found in Australia that adults often acquire the language faster than their younger counterparts. However, the truth is that it also puts a greater emphasis on the family to be the driving force behind getting and implementing the system. It may be expensive as funding choices are more limited. Most adult services for AAC are for those with an acquired communication need and specifically preclude those with learning difficulties. The challenges of getting everyone involved in using the communication system, which is crucial for successful implementation, may also be greater. Please contact ASSERT if you are in this situation as we are very keen to help those facing the above difficulties.

Conference 2016

I recently helped give a presentation in London on the topic of the ASSERT biennial conferences. The audience listened intently to Andrea Baines and I enthuse about the event and it was clear that our passion for the weekend was about more than just a couple of nights in Coventry.

So why is conference held in such high regard by other Angelman Syndrome society figures, other Angelman Syndrome groups and other UK charities?

The answer, I think, is that it is special.

It's special because of the sheer volume of attendees. For those feeling a sense of isolation, coming together and enjoying a sense of collective normality is magical. Seeing 5 or 6 buses of happy faces leaving on the excursions is something that only conference can deliver. And it changes perceptions.

It's special because of the quality and variety of information available. All too often, much of our research is spent online at midnight. At conference we have the chance to meet and question the authors of our late night entertainment. For hours.

It's special because Angelman Syndrome is what we all have in common. Conversation is easy and relaxed. Glasses are raised in unison at the approach of an arm. The eyes in the back of the head work overtime. Not just for yours, but everyone else's too. It's a place where friendships are made, re-enforced and reacquainted. For all ages.

It's special because the whole family experience the weekend together. The sibling bonding is as important as the keynote speech.

And it's special because it sums up what ASSERT does best. It is organised by a small team of trustees, but couldn't happen without you. Your fundraising ensures that we can keep costs to a minimum. Your experiences allow collective learning. And your determination to get the whole family to Coventry inspires all that come into contact with us.

Did you know that after the first year in Coventry (2012), the hotel actively asked us to return as the staff had been so taken with us?



Trustee Mairi Leith-McGaw

As always, the conference will be fully booked. Because of the nature of the event, we try not to turn any late applicants away- even if they end up in a

different hotel. But as the community continues to grow, that may happen soon. To confirm your place, please return your booking form as soon as possible. If you haven't received it, please contact assert@angelmanuk.org and a replacement can be sent out.

See you in September!

Rich Williams



Our leaving gift to the Hilton in 2014, a covering of hand prints!

Scottish Conference 2017

SCOTTISH CONFERENCE

Many of our families in Scotland struggle to attend the conference in Coventry due to a clash with school holidays and the long distances involved. We listened to your feedback and decided that we would offer our Scottish families their very own conference.

Therefore, ASSERT is very pleased to announce the first ever Scottish Conference to be held **Friday 11th - Sunday 13th August 2017**

The Golden Jubilee Conference Hotel, Beardmore Street, Glasgow, G81 4SA

The conference is open to all ASSERT families anywhere in the UK but priority will be given to those who live in Scotland as the information will be relevant to Scottish law and the Scottish education system. Obviously families in Scotland are still able to attend the regular ASSERT conference held in Coventry, but we hope that those who are not able to attend Coventry are at least able to attend a conference that is closer to them.

The conference will follow the same format as our regular family conference and letters will be sent to families in Scotland closer to the time. Details will also be on our website.

If you have any questions or suggestions please contact Catrina.fraser@angelmanuk.org or Mairi.mcGaw@angelmanuk.org who are the trustee's for Scotland.

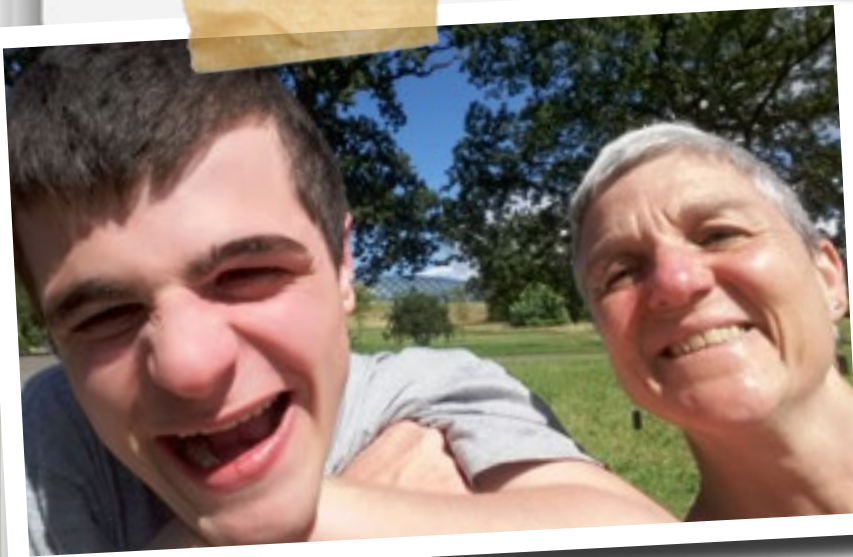
General enquiries can also be sent to ASSERT@angelmanuk.org



Scottish Conference



Golden Jubilee Hotel



Transitions Moving to Adult

Do you give your friends a hug when you meet up with them? In Adult Social Care this is apparently a bit of an awkward issue if you have a learning disability. Some services just don't consider this as normal behaviour and once the dreaded word 'safeguarding' is mentioned, the conversation is apparently over. End of. At a meeting last year Peter and I struggled to stay straight-faced as a well-meaning manager explained her plan for care workers to hold a giant cuddly toy between themselves and Euan, to permit hugs without, you know, actual bodily contact. However we have manoeuvred around that obstacle with at least some of our son's current support, but whether or not it's appropriate for Euan, who's almost 21, to hug support workers (in his mind, his mates) has taken up far too much of my time in the last three years since Euan moved to adult services.

For the time being at least Peter and I want Euan to continue living with us. He attends a local college 3 days a week and we have a small team of support workers who look after him before and after college and on the other weekdays. Peter and I both work so this support is vital to allow us to continue in our jobs. The doorbell rings at 8am each weekday as a support worker takes over and I am running to the station by 8.15am, Peter has a long commute and has often already left. On a non-college day a second support worker turns up at 10am so that they can all go out. (Because of behavioural issues adult social care insist on a ratio of 2:1 when staff go out with Euan). We are fortunate to have such reliable support workers from an organisation with a Transitions Team, so they are all in their 20s and 30s and have very much become Euan's friends. Euan has a personal budget and the agency have been very good at working with us to provide additional support during college holidays. Having support workers in and out of our house every day is not without its challenges – we

are forgiving people but the overflowing ashtray outside the front door and the regular, muddy footprints in the hallway have, we admit, tested us a little. On the whole, however, the benefits have outweighed the disadvantages.

For Euan the hardest part of the transition process was undoubtedly the move from school to college. He missed the familiarity of staff and peers who had known him since he was 3 years old. From September to Christmas 2014 he was a very, very unhappy young man and his behaviour was the most challenging it has ever been. Months of hard work and input from umpteen health and social care professionals mean that Euan is now much more settled and college is a more pleasant experience for Euan and for the staff who work with him. He has benefitted enormously from an Intensive Interaction approach and is now more fully involved in a range of college activities.

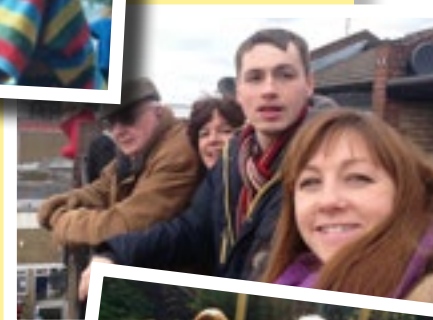
Respite came to a halt when Euan was 18 and finding appropriate adult respite has proved a hard nut to crack and we're not there yet. It has been a stressful process managing without regular respite for so long. Our local authority deemed Euan's behaviour as too challenging for their services and yet he was assessed as not challenging enough for NHS respite. (Hey, care innovators! Anyone fancy setting up some provision for semi-challenging young adults?) After complaints to both our local authority and the NHS we are now allowed to pursue possible respite care out of area. Our fingers are very tightly crossed that the provision we are now considering will work out for us all. In the interim Euan's support workers have occasionally stayed overnight in our house with Euan while we have been away for the night. But a weekend at home on our own is still something we're dreaming of.

Fundraising

In memory of David Williams, Gregory Cane's grandfather

Gregory's family and friends made donations to ASSERT in memory of his grandfather, David Williams, who died in September 2015. Gregory was diagnosed with Angelman Syndrome on 11th April 1988 when he was 2 ½ years old. It was a diagnosis that deeply moved his grandfather and influenced where he bought a holiday home a few years later. He chose a safe place where Gregory could explore, have some fun and his parents some respite. Gregory's grandfather was a constant presence in his life for 30 years. They shared a sense of humour and a love of trains. In the first photo Gregory, aged 5, is enjoying a walk in his Grandfather's arms along the Thames. In the second photo, 23 years later, they are watching the Boat Race in Hammersmith with Gregory's older sister Natalie and his Mum. Gregory's passion for cake is unrivalled we believe and in the last photo they are joined by his younger sister Francesca and Grandma to enjoy a fabulous 29th birthday cake!

Moira Cane



In memory of Tracey Lancaster

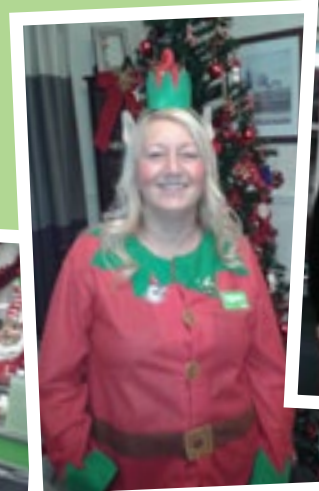
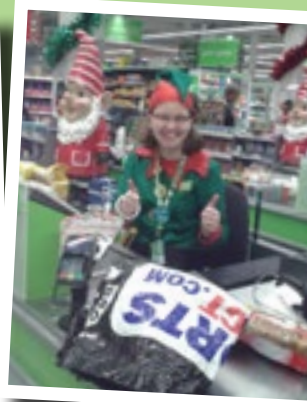
On December 12th 2014 my sister Tracey went to be an angel in heaven, there's not a day that goes by when I don't think about her. I miss her so much and want her memory to live on so in May 2015 on what should have been her birthday I held a fun day at Asda Middleton where I work. All staff wore blue t-shirts and donated a pound we had a cake stall and tombola someone dressed as Elsa from Frozen and we did bag packing. Sian, Boni, Alex and Patsi came along to help. My daughter Claire and grandson Riley worked hard selling the tombola tickets. We raised £680.88 we had a brilliant day for a brilliant charity.

Karen Lancaster

Christmas Day

On Christmas Eve we did a dress down day at Asda Middleton where I work and collected £100 for Assert. Sian Cartwright came to collect the money on behalf of Assert.

Karen Lancaster



100,000 GENOME PROJECT

Genome Project

The 100,000 genome project is a research project looking at rare diseases and cancer. Over 135 rare diseases are currently included in the Project, including neurodevelopmental disorders and various epilepsy syndromes. This list is regularly updated as new diseases are added. People invited to take part will be thought to have one of these conditions. Patients who are invited to take part may have been given a provisional or clinical diagnosis but not yet have had a molecular diagnosis. A molecular diagnosis is based on a genetic test result rather than on other signs or symptoms.

If you think you may be eligible, you can ask your doctor to refer you to your nearest NHS Genomic Medicine Centre.

When a patient with a rare disease is invited to take part, two of their close relatives are asked as well. This will help doctors analyse the genome. Relatives cannot volunteer for the Project themselves.

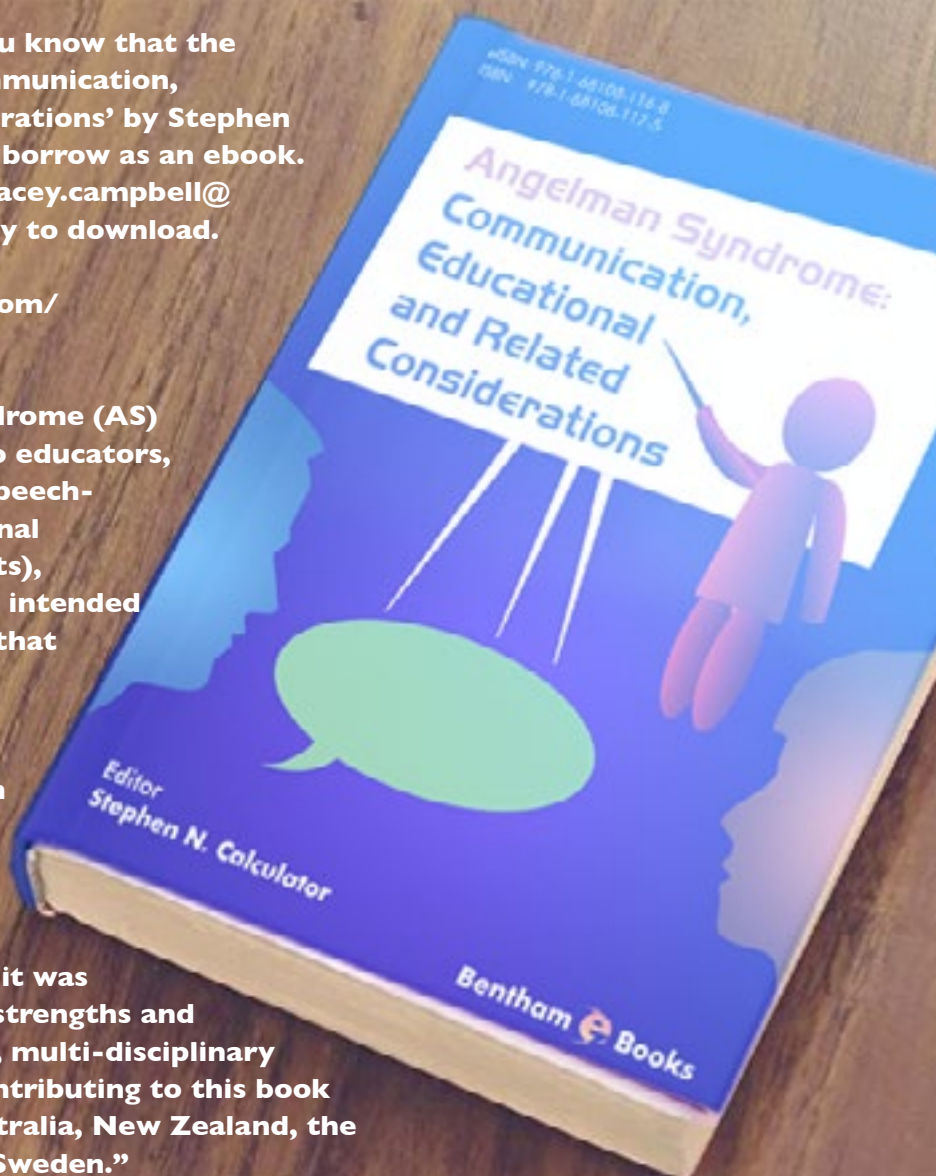
Some people taking part in this Project will get a diagnosis for their disease for the first time, but many will not. For some patients, a particular treatment may be suggested based on their results. In most cases this won't happen. The main benefits are likely to be for other patients in the future.

Unfortunately, this project is not open to applicants from Scotland.

ASSERT is very pleased to let you know that the book 'Angelman Syndrome: Communication, Educational and Related Considerations' by Stephen N. Calculator is now available to borrow as an ebook. Please email Tracey Campbell tracey.campbell@angelmanuk.org to request a copy to download.

<http://ebooks.benthamscience.com/book/9781681081168/>

"Individuals with Angelman Syndrome (AS) present a variety of challenges to educators, allied health professionals (e.g. speech-language pathologists, occupational therapists, and physical therapists), parents, and others. This book is intended to be a comprehensive resource that integrates theory with practical strategies aimed at optimizing individuals' acquisition of the types of functional skills that can contribute to positive changes in their overall quality of life. Given the complex nature of AS, it was determined that in order to properly meet this goal it was essential to address individuals' strengths and challenges from an international, multi-disciplinary perspective. As such, authors contributing to this book represent the USA, Canada, Australia, New Zealand, the Netherlands, Italy, Austria, and Sweden."



BOY BITES HORSE

NOTES FROM AN ALTERNATIVE CHILDHOOD

An entertaining blog that reports the like of a (so-called) Special Needs child. Read more at www.boybiteshorse.co.uk

“Transition”.

That's all I hear around here lately and I've no idea what it means. Apparently I have a birthday today and it's a 'big one'. Yeah, yeah, Happy Birthday to Me... if you've read my views about previous birthdays you'll already know what I think about that – so forgive me for yawning and bring on the cake.

But this Transition thing has been causing sleepless nights for Frowny for the last year. Ok, she's always been a bit of a worrier, but even by her standards this seems to be a bigger deal than usual. Even Smiley seems spooked, which is so unusual that it's starting to make me sit up and take notice.

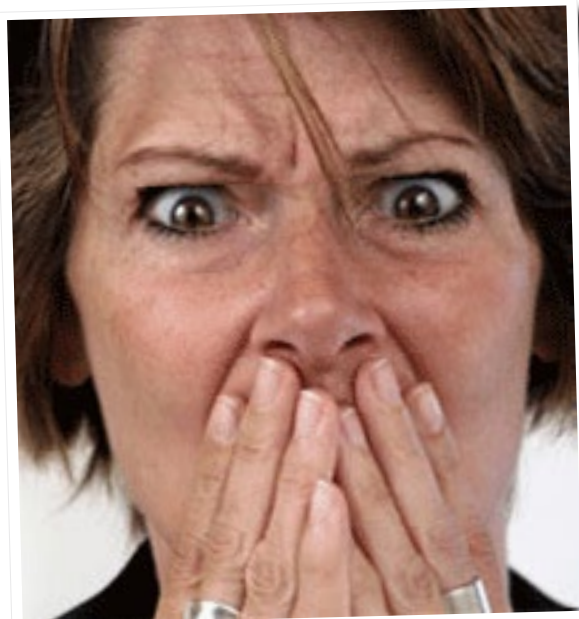
Apparently this one's a 'special' birthday; one where everything changes. I have no problem with that – people seem to spend a lot of their time worrying exactly how old they are instead of spending their time doing whatever they want.

For example, I still play with baby toys – and I'm not ashamed to admit it: they're brightly coloured, you can easily carry them around with you, give them the occasional rattle or suck and they don't get in the way of anything else I happen to be doing at the time. I've looked at other children playing with their PlayPodBoxes and as far as I can see it just involves making little men run around inside the television, and getting them do all the things you might be doing yourself if you weren't using a PlayPodBox. What's that all about?

But for some reason this big birthday is supposed to be different. For a start they say I won't be going to my usual Saturday clubs or respite centres, and that most of the people I've played with for the last ten years or more – and even the bus drivers – will all change. Well that's just silly; you can't make that many people just disappear, even if you're playing the world's most enormous blanket-game of peek-a-boo. Anyway, I'm good with change. I like new people and new places to explore.

And now there's talk about 'adult services' and something called 'adult-appropriate-activities' which sounds really impressive, but as far as I can make out these are just things like woodwork and cookery and gardening and art and basket-making. I've had a go at all this stuff before: the best bit about woodwork was waving a hammer around. Eating is absolutely, definitely better than cooking. Digging in the soil is far more fun than gardening. Spreading paint around with your hands onto your clothes, the walls and on other people is a lot more satisfying than using a brush on paper. As for basket-making, well, I've eaten several baskets and can't really see the point of pursuing that any further.

They're also talking about teaching me 'life skills', like emptying the washing machine, doing the shopping and dressing myself. Yeah, right, good luck with that... I've already put loads of effort into getting people to do all the dull stuff for me, so there's no way I'm giving that up in a hurry.



The bestest, funniest thing I heard was that these new places have lots of things called 'jigsaws' (I've never done one), fish tanks (...and the point is?), DVDs (lovely and shiny, but they don't seem to do anything, even when you bang them really hard) and all the chairs are arranged in a semi-circle around a big-screen TV (I never watch it). But no toys, no singing nursery rhymes, no soft play, no plastic ball pits, no swings, no slides, no sand pits, no roundabouts, no trampolines and no bouncy castles. Now I definitely, absolutely know that this must be the biggest, fattest fib ever because if you didn't have any of that stuff you'd just sit in a corner and dribble and be bored out of your skull every day for the rest of your life.

Well, I don't believe a word of it.

So I've decided I'll play along with them for a few days. I'll meet these new people and visit the new places and play their new games and if I don't like them I can just go back to the old places and be back with the friends I've got now.

Easy.

I don't know why people make such a fuss about 'Transition'.

Kidz To Adultz



Kidz to Adultz South
Thursday 9th June – Reading



Kidz to Adultz Scotland
Thursday 15th September - Edinburgh



Kidz to Adultz Wales
Thursday 7th July – Cardiff



Kidz to Adultz North
Thursday 17th November – Manchester

For more information please go to www.disabledliving.co.uk

Kate Pickering

www.lucidariley.com

It's not everyday that one of your oldest friends comes to lunch on a sunny summer Sunday and asks 'Would it be ok if I dedicate my next book to The Pickerings?'

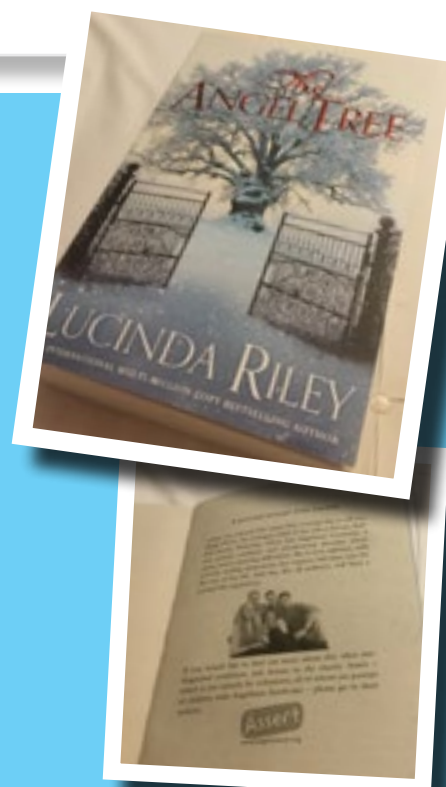
Being the very practical people that we are and not ones to make a fuss we were quite taken aback as our friend, Lucinda Riley (Edmonds), is a prolific authoress, has books translated into 28 languages and published in 38 countries.

Her aim - to raise awareness of Angelman Syndrome.

So here we have it:

The Angel Tree - in The Sunday Times Top 10 best seller list for December 2015 and dedicated to our family.

Lucinda has written a beautiful message at the end where she talks about us, Livvy, Angelman Syndrome & ASSERT.



The Communication Revolution

Over recent years ASSERT has been supporting parents on their mission to give children with Angelman Syndrome access to effective communication. We have worked with communication and literacy specialists within the community such as Erin Sheldon and Mary-Louise Bertram, bringing them over from Canada and Australia to help us start the Communication Revolution here in the UK. Both have presented at the conference and travelled around the country presenting workshops and working with schools and families on a personal level. Thanks to Erin and Mary-Louise, parents and professionals are realising that our children ARE capable of far more than ever given credit for. Schools and professionals are embarking on the communication journey with our families and the ripple effect is being felt beyond the small Angelman community. Thanks to 'Presuming Competence', children who were previously deemed to be too 'low functioning' are being given the opportunity to have their voices heard through various AAC systems. This is a huge accomplishment and an amazing legacy that the AS community can be very proud to have been involved in.

ASSERT is very keen to continue helping and supporting our families with communication. Please see below for current and future projects.

1. 4 BLOCKS LITERACY

We Sponsored Erin Sheldon, Effie Pearson and Tracey Campbell to attend the recent 4 Blocks literacy Course presented by Jane Farrall. This is a paradigm shifting course looks at giving all students, regardless of disability, the ability to use alternative methods of reading and writing. The course was attended by several mums from the international Angelman Community as well as UK

communication Specialists and teachers. The knowledge gained by everyone who attended will be filtered down to our parents through various workshops and facebook groups.

2. RESEARCH PROJECT

Effie Pearson is a PHD student on Chris Oliver's team at The CEREBRA Centre for Neurodevelopmental Disabilities at Birmingham University. Effie is working on a project funded by ASSERT & CEREBRA looking at Presuming Competency and showing how people with Angelman Syndrome and Complex disabilities have the ability to use a robust communication system when given the appropriate opportunity. This will hopefully lead to a piece of published documentation which will help families access the Speech and language Therapy and AAC equipment that our children need, without having to prove competency through the use of single switches or objects of reference.

3. ASSERT ADVISOR FOR COMMUNICATION (AAC)

Tracey Campbell, mum to Leia (AS), embarked on her communication journey after hearing Mary-Louise speak at the conference. She and Leia are using PODD and Tracey is busy trying to change the world. At least in Scotland anyway! Tracey volunteered her services as a Communication Advisor to ASSERT and she will be the point of contact for questions about AAC, Communication and Literacy. If she or the team of trustees at ASSERT don't know the answer to a specific question she will primarily be the one who researches and find the answer for you. Tracey will be helping to organise some of the future projects that we have in mind. She can be contacted at communicate@angelmanuk.org or tracey.campbell@angelmanuk.org Twitter @trAACeyc

4. FUNDING AAC & TRAINING

ASSERT is now in talks with several UK communication charities looking at how we can help parents access external training in AAC and communication. We are also looking at how we can help those who struggle to fund equipment or expensive apps, through working with various charities who fund AAC equipment. ASSERT cannot directly fund grants for equipment but we are looking at ways in which we can help. Please be sure to check our website or Facebook pages for further information on this.

5. COMMUNICATION BOOKLET

We will soon be publishing a Communication booklet for parents to use in school, with their professionals or for personal reference. This booklet has been written by Tracey at the request of ASSERT and many people, including Erin Sheldon have had input. We are very excited about making this available to you and feel that it will be of tremendous help to everyone. Please expect the booklet to be available in the early summer. We will make sure that one is available for all who require a copy.

6. ASSERT COMMUNICATION CONFERENCE

We are very excited to be hosting the first mini conference dedicated to Communication and Literacy. The conference will be held at The Hilton Hotel, Coventry on 27th and 28th May 2017. This will not be a free event but ASSERT is keen to make it as financially accessible as possible. The conference is open to both parents and professionals. Further details will be given on our website and FB pages and letters will be sent out in good time with booking details and costs.

ASSERT COMMUNICATION WORKING GROUP

To help with the projects listed above we would like to have a dedicated communication team working alongside the board of trustees. The Literacy and communication team will liaise closely with the trustee's and Tracey. The purpose of the group will be to make sure that information is disseminated at regional meetings and that families who need help with communication are encouraged to meet and support each other. Jane Walker, mum to Daniel (AS upd) in Birmingham has offered to be a contact for those who have questions about or who use Makaton. Jules Whicher, (mum to Charlie, Clinical dx) is based in Nottingham and has tremendous knowledge of PODD and literacy. Emma Brooks who lives in North Wales and has experience of using both Proloquo2Go and PODD with her teenage son Dimitri (AS del+). We envisage meeting the communication team once a year to discuss goals and objectives. We hope to embark on a train the trainer scheme where those in the team will be offered support and education in order to pass on this knowledge to our parents through newsletter articles, our website, regional events and workshops. This is very much a work in progress. If you are successfully using an AAC system with your child or have knowledge and experience that you would be willing to share please email ASSERT@angelmanuk.org to discuss how you can help. Ideally we would like people from various regions within the UK to help facilitate meetings and support.

Easy fundraising

ASSERT are registered with EasyFundraising. This is a great way of purchasing items online and automatically making a donation to our charity. There is no extra cost for you here, and it does not take any more time.



So there is no reason not to do this! Please visit the website and register. Going forward, any eligible purchases can then be done through EasyFundraising and ASSERT will automatically receive the donation. This can be anything from a few pence to a few pounds depending on where the purchase is made and how much. With Christmas shopping on the horizon this is the perfect way to generate funds for ASSERT. This has to be the easiest way of donating to ASSERT without really doing anything!

For more details please visit the website: **www.easyfundraising.org.uk**

Useful Websites

Support

- www.angelman.ie
- www.disabledliving.co.uk/Kidz/North
- www.cafamily.org.uk
- www.mencap.org.uk
- www.autism.org.uk
- (Princess Royal Trust for Carers) www.carers.org
- (Transition) www.transitioninfonetwork.org.uk
- www.challengingbehaviour.org.uk
- www.learningdisabilities.org.uk

Blogs

- www.boybiteshorse.co.uk

Pre-loved equipment

- www.disabreg.pwp.blueyonder.co.uk
- www.askdes.org.uk
- www.disabledliving.co.uk

Clothing and other equipment

- www.fledglings.org.uk
- www.clothingsolutions.org.uk
- www.incywincy.net
- www.disabled-clothing.co.uk

For iPad/apps

- www.autismpluggedin.com
- www.atmac.org
- www.blog.friendshipcircle.org/2011/02/02/the-special-needs-ipad-app-series
- www.lilliespad.com/special-needs-ipad-blog/tag/special-needs-apps
- www.techlearning.com/Blogs/37722
- www.momswithapps.com/apps-for-special-needs
- www.gadgetsdna.com/10-revolutionary-ipad-apps-to-help-autistic-children/5522
- www.oneplaceforspecialneeds.com/main/library_pick_great_apps.html
- www.ikidapps.com/2010/10/apps-for-children-with-special-needs.html

Legal

- www.ipsea.org.uk
- www.scope.org.uk
- www.mencap.org.uk
- www.challengingbehaviour.org.uk

This website offers very useful tips and advice and is run by an AS mum

- www.netbuddy.org.uk/newsletter/netbuddy-tools

Same But Different

Photographer gives people with Rare Diseases a voice

Jake is a happy, sociable boy who loves meeting people. He loves his family and friends and thinks nothing of going up to strangers and hugging them. He loves music and his karaoke machine. Jake also has a fascination with water so swimming is a favourite activity. He dislikes face painting, masks, fancy dress and animated characters.

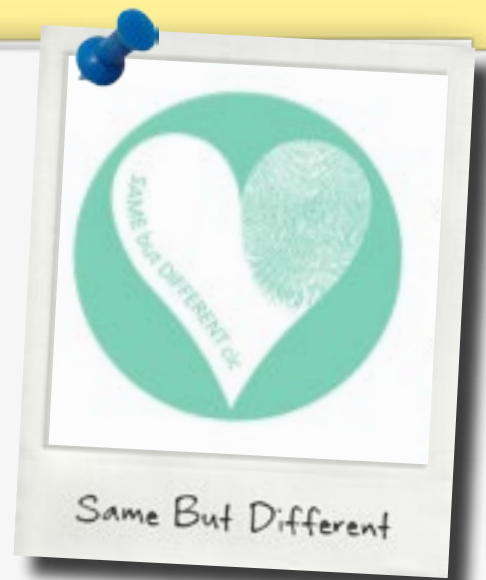
Not everyone takes the time to learn about Jake or to find out what he is like as a person. They see his unusual behavior or witness a temper tantrum and turn away. Sometimes the barrier to finding out more is simply because they do not know how to ask about his condition – Angelman syndrome.

Jake and his family are taking part in the 'Rare Project' which has been created by Ceridwen Hughes, director of not for profit organization Same but Different.

Through the 'Rare Project' Ceridwen is taking photographs of people with rare conditions and accompanying it with background information so people can learn not just about the condition but the person behind it too.

During each photo session, Ceridwen works hard to create an enjoyable experience and capture "the real person." She has studied Makaton and has a Level 1 British Sign Language qualification to help her overcome barriers when people are non-verbal.

"I want to try to break down some of the barriers that exist for those with disabilities and rare diseases in particular. Often the person taking part in the project has never had a portrait taken before because they may be nervous or have challenging behavior. It does not matter what condition each person has, they are ultimately still people with their own likes and dislikes and they deserve to have a voice," Her hope is that through the project people take the time to look at the images, read the story and if it just makes people stop and think, then she will be happy.



You can read about Jake and other people taking part in the 'Rare Project' on their website www.samebutdifferentcic.org.uk or follow the work they are doing on their Facebook page at www.facebook.com/samebutdifferentcic

For further information, interviews and case studies please contact: Ceridwen Hughes on ceri@samebutdifferentcic.org.uk 07971 983028



MG Trophy Championship 2016



Prize Draw

MG Race

This year the MG Trophy Championship is proud to be able to choose ASSERT as its partner charity to raise money and awareness for, throughout the 2016 season. The MG Trophy Championship is one of the UK's best and most popular single make car championships and is one of the race series' that is operated under the MG Car Club Motorsport operation visiting the UK's top circuits.

One of our Angel's - William Martin's Dad races his MG ZR in the championship and William often attends the race weekends around the UK, cheering everyone up as he laughs hysterically at the noisy race exhausts and air tools around the pits. William is very popular amongst the MG Car Club family and this has been reflected in the Trophy drivers voting to support ASSERT making his family very proud.

The MG Trophy hope to help raise awareness of ASSERT by having all the MG ZR race cars show the ASSERT Charity sticker in their windscreens. Completing 14 races over 7 race weekends and often there are around 30 cars racing making it very exciting. Five of these rounds will be televised on the MotorsTV channel as part of the Final Lap series.

The Trophy Championship would love to see any Angelman families at any of the events, the details are below:

- Brands Hatch – April 30th/May 1st
- Silverstone – June 4th and 5th
- Mallory Park – July 3rd
- Knockhill - July 3 1st
- Oulton Park – September 3rd
- Snetterton – October 1st

For more information on purchasing tickets, ticket prices and information in general then please contact:

- Brands Hatch Tickets - www.brandshatch.co.uk/calendar/2016/may/bh-mgcc.aspx or call 0843 453 9000
- Silverstone Tickets - www.mgcc.co.uk/shop/category/mglive-2016/ or call 01235 555552
- Mallory Park - www.malloryparkcircuit.com/event/mgcc/ or call 01455 502214
- Knockhill - www.knockhill.com/index.php or call 01383 723337
- Oulton Park - www.oultontpark.co.uk/calendar/2016/september/op-mgcc.aspx or call 0843 453 9000
- Snetterton - www.snetterton.co.uk/calendar/2016/october/sn-mgcc.aspx or call 0843 453 9000

Prize Draw

ASSERT are very happy to be able to offer two sets of family tickets for the weekend race at Silverstone on June 4th and June 5th. All you need to do to apply is send a donation of £5 to ASSERT and in return you will receive one of the fabulous car stickers as sported by all of the MG ZR race cars, and your name will go into the hat to win the weekend tickets (the tickets would be valid for both days). The Silverstone meeting is one of the highlights on the calendar, it is much more than just a car race, they have lots of other exciting things to do and see.

You can send your donation in the following ways:

- By cheque to our freepost address
- By bank transfer to the ASSERT bank account
- By donating on our Just Giving or Virgin Giving page

If you transfer the money by bank transfer or on our donation page, please email assert@angelmanuk.org with your details for the car sticker and entry into the draw.

THE CLOSING DATE IS FRIDAY 13th MAY

We hope that lots of you will support ASSERT and The MG Trophy by entering the draw and also if there is a race near you then please do go along and show your support in person. It would be great to see a few of our families waving ASSERT flags along the route!



Assault

The issue of a child with Angelman Syndrome who has been involved in an assault is a live one. This can be a scary and worrying time for all involved. The main issue is ignorance of the condition.

Due to the symptoms, at times members of the public can end up being an intended victim. Assaults are unfortunately inevitable in every day life and can not be avoided or planned for.

It comes down to the victim understanding that the act was not done with intent.

The point to remember is that education is the key to understanding. It may seem obvious but unfortunately the public and the police do not always understand the situation.

If a member of the public is assaulted then hopefully any further action can be avoided with a full understanding of the situation and causes.

At times this may not be the case; sometimes the victim does not accept the explanation or it has been necessary to call the police due to a perceived 'imminent risk' that needs de-escalation.

This will mean that matters need to be discussed with the police who are unlikely to have any pre-existing knowledge of the condition.

Again understanding is key. Try to make them understand the situation, the causes, the lack of intent.

In an ideal world an explanation will suffice but that may not always be the case. If the matter does go further with the police/ Crown Prosecution Service (who decide whether someone should be charged or not) then make sure to identify the issues and seek legal advice. At these times it is sensible to seek legal advice to help advice and liaise with the police.

The key to all of this is again understanding. If there knowledge and explanation is shared then this should avoid further action or recriminations. Otherwise seek legal advice to assist with this.

.....

I want to find out more:

This information has been kindly provided by Anthony Collins Solicitors. If you would like to discuss further any issues relating to the above, then please contact ASSERT on 0300 999 0102 or email assert@angelmanuk.org and your details will be passed on.

Thank you to everyone who has donated to ASSERT. Your contributions - no matter how small - all make a difference. Without you there would be no ASSERT and we all know how important we are as a support to our families within the AS community.

Many thanks to...

Donations!

<u>Hazel Tait</u>	<u>Mr & Mrs Simpson</u>
<u>Ursula Hughes</u>	<u>Mrs Gillian Hill</u>
<u>Shona Gray (Craft It)</u>	<u>Bryony Strickland</u>
<u>The Phoenix International Charity</u>	<u>Bryan Blanthorn</u>
<u>Mrs Wallace</u>	<u>Mrs Julie Callaghan</u>
<u>Car & Marine Connection</u>	<u>Mr & Mrs Keating</u>
<u>Helen Edwards (in memory of Lola Owen)</u>	<u>Thelma Ray</u>
<u>Gloria Buckley</u>	<u>Mr & Mrs Webbing</u>
<u>James & Tony (Michelle Matthews)</u>	<u>Joanna Marcella - FDC Young Designers Award</u>
<u>Lad & Turner Opticians</u>	<u>Sukhninderjit Singh Braitch</u>
<u>Leila Ally</u>	<u>Leon Badger</u>
<u>Sean McFarlane</u>	<u>Mrs D Beesley</u>
<u>Rosemary & Nigel Teggin</u>	<u>Hansons Auctioneers and Valuers</u>
<u>Downley Pharmacy</u>	<u>In memory of Mrs Kathleen Ralph</u>
<u>Peter Mullen</u>	<u>LTSB Foundation</u>
<u>Noel Protheroe</u>	<u>Moira Cane (In memory of David Williams)</u>
<u>Ruth Curbishley</u>	<u>Heather Dobbs</u>
<u>Mary Stow</u>	<u>Avril Doherty</u>
<u>Alastair Ryan</u>	<u>Lynette Meek Griffiths</u>
<u>Stephen Roberts</u>	<u>Joan Broadhead</u>
<u>Robert Pavey</u>	<u>The Quality Property Company</u>
<u>Louise Graham</u>	<u>Julie Mawdsley</u>
<u>Winifred Neyland</u>	<u>Julien de Bournet</u>
<u>Leonie Raby</u>	<u>Carolyn Doherty</u>
<u>Samantha Wickens</u>	<u>Rima Hoque</u>
<u>Charlotte Oldroyd</u>	<u>Abersychan Dental Practice (Nigel Hooper)</u>
<u>Jennifer Mclarney</u>	<u>Lorna Ventham</u>
<u>Miles Cherry</u>	<u>Andrew Hayter</u>
<u>Search Laboratory</u>	<u>Anita Naylor</u>
<u>Mr Rodney Freeman</u>	<u>Patricia Ruiz de Carvalho</u>
<u>Karen Lacaster & Asda Middleton</u>	<u>ARMITTS Newsagents Matlock (Maria Allen)</u>
<u>Sutton Cricket Club</u>	<u>James Newman</u>
<u>Performers College</u>	<u>Natalie Giles</u>
<u>James Stott</u>	

Fundraisers!

Ed Winter - Bupa London 10k
Darren Keighley - Marathon
Amber Gunay - Firewalk
Laura Barrett - X Runner Wild Warrior
Nathan Proud - Leicester Marathon
In memory of Ken Goodwin
Suzanne Walker and Natalie Luke - Brighton Marathon
Gavin Punch-Smith - Leighton Buzzard 10k
ERG Fundraising Day

Thank You!



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