



Newsletter 56 Spring 2015

Angelman Syndrome
Support, Education & Research Trust

Liverpool 2015

Practical advice
on adaptations

Boy Bites Horse

Samuel's
helicopter
adventure

AAC and guilt

IAD Meetings 2015

A Tale of 2
Doctors
and a
child



Your Assert Trustees

Rachel Martin

Chair, Online Support, North
West and Welsh Region
rachel.martin@angelmanuk.org



Rich Williams

Vice Chair and Welsh Region
rich.williams@angelmanuk.org



Lisa Court

Treasurer, Merchandising
and Central Region
lisa.court@angelmanuk.org



Sue Williams

Secretary and Welsh Region
sue.williams@angelmanuk.org

Katie Cunnea

Research and South West Region
katie.cunnea@angelmanuk.org



Diane Fox-Jones

South East Region
diane.foxjones@angelmanuk.org



Linda Holmes

Regional Meeting Coordinator
and North East Region
linda.holmes@angelmanuk.org



Sian Cartwright

Professional Advisor and North East Region
sian.cartwright@angelmanuk.org

Jonathan Allen

Sibling Support and South West Region
jonathan.allen@angelmanuk.org



Catrina Fraser

Scottish Region
catrina.fraser@angelmanuk.org



Mairi Leith-McGaw

Scottish Region
mairi.mcgaw@angelmanuk.org



(non-Trustees) Rosemary Teggin

N. Ireland & Eire representative
rosemary.teggin@angelmanuk.org



Louise Shaw

Central representative
louise.shaw@angelmanuk.org



Useful Stuff

OUR FREEPOST ADDRESS

**ASSERT, Freepost, PO Box 4962
Nuneaton, CV11 9FD**

OUR WEBSITE

www.angelmanuk.org

EMAIL ASSERT

assert@angelmanuk.org

HELPLINE

0300 999 0102

ASSERT Families - New Diagnosis Advice
Contacts - Support

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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

Spring is well and truly in the air, at least it is here in Wales! The daffodils are in bloom and the lambs are in the fields. It also isn't quite as wet and grey as we are used to!

Along with the renewed enthusiasm for spring cleaning and life in general, many Angelman Families are turning their attention to helping their children communicate more effectively. The lack of effective communication is probably one of the hardest things for our families to cope with, along with seizures, which affect many of our children of course.

Approximately 100 parents, carers and professionals attended the ASSERT organised Proloquo2Go training session at the Hilton Hotel in Coventry in early February. Feedback has been extremely positive and the information presented by David Niemeijer, Jennifer Marden and Erin Sheldon has spurred many in to buying the app and experimenting with it at home. We also have many families who are using PODD successfully and who are either hosting or attending training sessions throughout the country. ASSERT feels strongly that effective communication should be at the centre of what we hope to achieve in supporting our families. Communication is a basic human need and whilst some may not benefit immediately from this new approach, the long term impact and change in standard assumptions will be to everyone's benefit in the long run. How often have you had to argue with professionals that those we care for do not have opinions of their own, or that they cannot inform you that they are in pain or are incapable of choosing their favourite meal for example?

We have a few projects in mind which we hope to see come to fruition in the coming year, so watch this space!

Lots of you volunteered to host Mary Louise Bertram when she visited the UK this year. Unfortunately, her visit has had to be postponed but it will be taking place towards the end of the year. We will be in touch with those who kindly offered to accommodate her.

February also saw us mark International Angelman Day with 13 regional meetings on Saturday 14th or Sunday 15th February. All the meetings were well attended by families from around the country and everyone had a great time. Please see page 10, 11 and 12 for photographs and accounts of the day.

As we head through the Easter period, thoughts must also turn to our many fundraisers who have spent the long winter months clocking up those training miles; ahead of the many sporting events that will shortly be upon us. From all of us, thank you. Without your efforts, none of this would be possible.

Beyond that, the warmer days and holidays will soon be upon us. Don't forget to send us all of your holiday snaps and stories. They make us all laugh, cry and determined to do something adventurous ourselves.

Looking further ahead, you may also remember that 2015 is a momentous year for the Angelman Syndrome community. It is 50 years since Angelman Syndrome was first reported by Dr Harry Angelman and it would have been his 100th birthday. There are a number of global celebrations and ASSERT is honoured to be hosting the 4th International Angelman Syndrome Scientific Conference in Liverpool, in October. We are currently chasing suitable grants to help us mark the date in style - a perfect opportunity to recognise the important work that Dr Angelman conducted all those years ago in Merseyside. We hope that members of the Angelman family will be attending as our guests and invitations to all International Angelman Organisations have been sent out. Please see page 4 for further info.

On a more sombre note, we were saddened to learn recently of the death of former trustee Neil Buchan. Facing up to a battle against cancer, Neil stepped down from the team in 2013 after 5 years of committed service to ASSERT. Those south of the border will know him from past conferences, especially on the excursions and in the bar afterwards. I hope you'll all join us in raising a glass to Neil and echo our condolences to his loving family. They have lost a husband and dad. We have lost a friend.

Rachel & Rich

An update on Our Patron Gareth Edwards...

Gareth is currently back and forth between Los Angeles and London working very hard on his latest film, the first Star Wars spin off. The name was announced recently and it is to be called "Rogue One" and filming will start in the summer in the UK. Its going to be an busy year for him but he is hopeful to be coming along to Liverpool in October. Please keep a regular check on our website and Facebook page for any exciting announcements relating to Gareth in the coming months.



Gareth & his niece Ella

4TH INTERNATIONAL ANGELMAN SYNDROME SCIENTIFIC CONFERENCE



1915 - 1965 - 2015
LIVERPOOL



2015 is a momentous year for the Angelman Syndrome community. It is 50 years since Dr Harry Angelman first discovered Angelman syndrome, at the time calling it 'Happy Puppet' Syndrome. A Dr who trained at Liverpool Children's Hospital and worked in the local community; it would have been his 100th birthday this year. Therefore, this year's International Angelman Syndrome Scientific Conference is being hosted by ASSERT.

The meeting will be held at the brand new Children's Research and Education Centre, Alder Hey in the Park, Liverpool on Friday 2nd October 2015. It will be attended by leading scientists and educators from institutions in Europe and further afield. It will also be attended by local professionals and researchers and representatives of Angelman Syndrome Organisations from around the world.

This will be followed on Saturday 3rd October by a Scientific Symposium for Parents and carers of those with AS and our international visitors, and then the **ASSERT Golden Gala and Fundraiser.**

The Scientific Symposium and Golden Gala will be held at the Marriott Hotel, Liverpool.



All funds raised on the evening will be going to further European Research into Angelman Syndrome.

Accommodation for Friday and Saturday night at The Marriott is at a significantly reduced rate for those attending, this is available at a rate of £119 for a single room and £129 for a double or a twin room. You are free to book accommodation for either one or two nights, whichever makes it easy for you to attend the event.

Gala tickets can be purchased for £75 each and include entrance to the Scientific Symposium during the day on Saturday 3rd and then the evening Gala reception. If required, tickets can be purchased for the evening Gala reception only. An invitation will be sent out to all ASSERT members during the Summer 2015. This will contain details of the Scientific Symposium and how to purchase your tickets and book the accommodation.

We look forward to welcoming you to this once in a lifetime international event!

Please note that children are not invited to either the Scientific symposium or to the evening Gala. The Gala is limited to adults 18yrs and over due to space available and the nature of the event.



Meet the team

ASSERT are very pleased to introduce a few new members to the team. We are sure you will join us in welcoming them on board. Look out for future events where you will hopefully be able to "hi" in person.

Diane Fox-Jones

Hello, I'm Diane, ASSERT's new trustee. I'm married to Christyan, who is a former trustee and author of the blog boybiteshorse.co.uk, (there's only room in our family for one trustee at a time.) We live in Thames Ditton, near Kingston upon Thames and we have 3 children, Lottie, aged 19 and currently studying Illustration and Animation at Kingston University, Harvey aged 17, AS deletion and extremely lively and Milo aged 9 and football mad even though we know nothing about football.

Christyan and I work together at home designing, writing and illustrating children's books. Working from home means that we're both available to care for Harvey, I don't know how we'd manage otherwise.

Harvey is extremely excitable and so full of energy that it's hard to keep up with him. He can now run faster than either of us and is much stronger than me. Harvey is fast approaching adulthood and we are finding the transition from fairly helpful children's services, to what appears to be non-existent adult services, very daunting. In a few years time I hope to be able to tell the ASSERT community that transition isn't as bad as it appears.



Mairi Leith-McGaw

Hi, I am Mairi the crazy horsey one, I am a proud mum to 3 lovely kiddies Jon (AS) 7, Ritchie 4, and Molly 1, and married to my wonderful husband Richard. We live in the north east of Scotland with a selection of horses dogs cats chickens and rabbits. Because life isn't crazy enough I am really excited about moving on from a Scottish representative and taking up my new role as a trustee with ASSERT and looking forward to being part of all the up and coming events.

Louise Shaw

Hi, my name's Louise, I'm married to John and together we have a beautiful little girl Holly who's 6. Holly was diagnosed with Angelman Syndrome when she was 2 and a half, although we knew from much earlier on that she was experiencing significant delays especially with her speech. Yet 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?'

Having Holly has changed my life for the better in so many ways, and although there are always difficult days, she has taught me empathy, acceptance, and love on a completely different scale. Joining ASSERT when Holly was diagnosed was the best thing we could have done. We have received so much support, made lots of friends with other Angelman families and learnt a huge amount from all the parent experts!!! Joining ASSERT as a representative is an extremely exciting step for me and I thoroughly enjoyed organising an IAD meeting in February as my first assignment! I look forward to getting to know more of you all at upcoming events!



Heather Dobbs Adaptations



We're the Dobbs family from Southampton. Nicole is 7 and has AS deletion. Her brother Connor is 6 and they love each other dearly! He sometimes has a difficult time (like most AS siblings I imagine) negotiating Nicole's tendency to take whatever toy he's playing with and then proceed to sit/squash/lean on him so he can't move!! Just another normal day in our household!

Since Nicole was diagnosed just before her 2nd birthday, she has developed Epilepsy, learnt to walk, settled into a sleep routine and gained some independence. Throughout this time as a family we've been accepting what future Nicole will have and how our lives will always be different now. This has involved making lots of changes to our house and finding the right tools to help Nicole in her life.

We thought we'd share some of what we've found in the hope it helps others and maybe encourage others to share what they've found so we can learn from them!

Here's some of the things we use to help with and have adapted for Nicole;

Wood burner stove and Bespoke Wrought Iron fireguard. We replaced our open fire and toddler fireguard with these last year as we could never leave Nic in the room with the open fire lit for a split second as she'd have the remotes, her socks and your phone thrown over the fireguard and getting nice and toasty by the fire! Not to mention her favourite sport being kick the fireguard as hard as you can or hold onto it and jump as fast as possible! Now we have no open flames and the fireguard doesn't budge! We had to get it specially made but it's well worth it.

Pocket system Eclisse sliding doors. We had standard double opening doors previously which Nicole used to bang large objects into and really test the hinges by opening and shutting the doors very hard! We've recently had these doors installed and they just slide back into the frames leaving a lovely open space with nothing for her to bang into or damage!



TV Anti Glare screen protector. Nicole used to like banging her head on the tv or her hand just like the interactive whiteboard at school! Since using these protector's the TV is safe and she's really not that bothered about doing her previous antics (and of course if she does we can just ignore it).

Skirting board radiators. Nicole has a tendency to bang her head on hard sharp objects to communicate (generally to show frustration) and would often use the edge of the radiator to do this. We replaced the living room heating with skirting board radiators which meant we could remove the extrusion of the old radiators. We can push all the furniture right back to the walls now and no worries about bits sticking out for her to bang on.

Egg Chair from IKEA. A lot of AS families have these and they're great. Nic likes to sit in it with her iPad, hood down, with her brother spinning her! Great fun

Story Sequencer. We bought these from Amazon and have printed some Boardmaker symbols for it and have recorded the word. Nicole presses the button for what she wants and it talks! It's great to get our attention and Nicole loves that she can communicate. Hungry is getting very worn out already though!



Heather has very kindly offered a brand new Ultimate Anti Glare TV Screen Protector for a 38-40" flatscreen TV worth £77. If you would like to be put in the draw for this please email assert@angelmanuk.org by 31st May 2015.



Stable door. This is the door from our play room/living room into the kitchen. It's been fantastic to keep Nic away from the gas hob and hot oven and let things cook in the microwave without her constantly opening the door! It's strong enough to withstand her holding onto it and jumping but also to keep her safely out of the kitchen! We've put door knobs on the other doors as she's not yet worked out how to open them!

Feeding time! Nic uses her Rifton Activity chair at meal times. It has thigh straps which secure her should she have a drop seizure and chest harness which we only use if her epilepsy is particularly bad. Her feet rest on the footplate and all 4 wheels have brakes. She uses a plate guard and deep rimmed plate with a right angled feeding spoon. Food is a big motivator for Nicole and she's perfected her feeding with her spoon and rarely spills these days! She still uses her Tommee Tippee beaker for her milk or water as she refuses to put an open topped mug to her mouth!

We have just ordered her next bed of the Safe and Sound Mini Low from Creative Care and the travel pod from them. We're expecting delivery any day!



Walk in Shower. Luckily Nicole can stand in the shower and hold onto the rails but if she did need a chair she could use this also. Installed through the DFG as well, her shower has been a lifesaver for those messy mornings and nights when her nappy doesn't do its job! She has her aided language displays laminated in the bathroom which we use each time she's in there.

PODD book. Nicole has this near her wherever she is and has only been using it for just over 6 months. She confidently asks us for her iPad with it and more recently told us that "I don't like this". Then went on to say "too noisy" when her brother had his friend and 3 siblings around late one evening! As soon as she had told us how she felt and we repeated this to her, she waved at them all to go home! She'd obviously had enough!

These are a few of the bits that make our lives a little bit easier and allow Nicole to have experiences like any other child. It'd be great if you could share what your solutions are for your life in the next newsletter too!



Wessex through floor lift. This goes up into Nics bedroom (we stuck some stickers on it to make it less boring) and was installed and funded through the Council Disabled facilities grant.

Nickel Bed Tent by My Ready, Set, Bloom. Nicole has slept in this for over 3 years and we have a spare one we take on holiday and another at respite. She loves it and it's allowed us to go on cruises out of Southampton and stay in hotels throughout the UK. A normal UK single mattress sits inside it to give the tent its shape and the zips are all on the outside. We tie them together with a key ring as she's worked out how to undo them! The whole tent packs away so small for travel, it's very practical. It's not the most hardwearing, but it's done us for quite some time now! She wears large size Sleep bag/grobag type things over her pyjamas at night as she refuses to keep her duvet on!



Siblings

Dear Jon



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.

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

Dear Jon

I am having some personal problems at school but I don't feel I can talk to my parents about it as they have so much going on with my sister who has AS. I don't want to stress them out further.

I am sure that your parents would take the matter seriously and even though they may already be stressed and have a lot going on, they will care about the issues you are having. Even if it means that they are slightly more stressed, your parents will care more about your well-being than anything else.

Alternatively, you may have some close friends who you are able to talk to and who will lend support. Depending on the issues involved, often just having someone to talk to can be enough to make you feel a whole lot better about things.

Finally, depending how serious the problems are, it may well be worth talking to a teacher or school counsellor if there is one. It may seem more daunting but they are professional people trained in dealing with issues that students have.

Not talking about the issue means that you are bottling it up and the emotions you feel can build up. Siblings to those with AS have a lot going on in their lives anyway so it is important to have an outlet where possible.

Dear Jon

My friends don't really understand what Angelman Syndrome is so I find it difficult to have them over or even talk about my brother at times.

The best thing to do in this situation is not to blame your friends for not understanding the situation. They don't live with anyone with Angelman Syndrome so it is difficult to expect them to understand fully.

I have found that taking the time to explain about the condition in more detail and also the effects it can have on you personally, enables people to understand more fully the circumstances of your life.

People have different perceptions and levels of understanding

and if a friend doesn't understand still then it is important to respect that they are not doing it on purpose.

Dear Jon

I love my brother, who has Angelman Syndrome, very much but he is younger than me and I sometimes feel very frustrated by how much work it takes to look after him. Further, when I feel frustrated with him it makes me feel guilty too.

First of all, you should never feel guilty about your emotions. Living with someone who has a disability is difficult and there is no shame in admitting that it is frustrating.

A good solution I have always found is to take say an hour or even half an hour at the end of a day just to do something you want to do on your own. Whether it be watching a few TV episodes or reading a book. This helps to unwind and you are just taking time for yourself.

Alternatively, you may find getting out of the house is also a good solution. Going for a long walk or visiting a friend in the evening can also be a good way to relax away from the environment which you can find frustrating at times.

It is very important that you always look after yourself as well as caring for a sibling with Angelman Syndrome. It is easy to forget to look after yourself but it really should be a priority otherwise you do end up with more feelings of frustration that will only manifest.

Dear Jon

I sometimes find it tricky when I am at home as the activities that we do depend on what my sister with Angelman Syndrome wants to do, even with watching TV shows.

I would suggest that you think about the activities that you both enjoy as a good basis to go from. That way, when deciding what to do you can suggest something that you know you will want to do. This is even relevant to TV shows as hopefully there will be some overlap in shows that you like to watch.

If it is a situation where your sister is doing something you don't necessarily enjoy, then if possible, perhaps just do a different activity for a while and try and do something you both enjoy later on.

Hopefully you can find some common ground in the activities you both like and it means you can bond further as siblings.

.....

Thanks for your photos and drawings, we do enjoy receiving your correspondence. Please keep it coming!

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Here is a photo of Ella (age 12), Jacob (age 9) and Thomas (age 7) enjoying their holiday in Somerset last year.

We went to Somerset for a week with my mum, dad, Ella and Thomas and my nan was upset because she couldn't go.

Jacob

We were in the sea swimming like fish splashing and jumping in Somerset. I went with my sister Ella and my brother Jacob. I went for a week. My mum and dad were watching me.

Thomas

Here is a drawing from Max who is 5 years old, it is a picture of himself and his sister Holly.



Me and My Sister Indy

My name is Tao Harvey and my little sister Indy has Angelman Syndrome. I am twelve years old and Indy is seven. We live in Wellington, Somerset with our mum Katy, our dog Tilly, our cats Mellow and Peaches and a Gecko called Gizmo.

The picture is from our holiday in Woolacombe. It is my favourite picture of them all. It can be hard having a sister with Angelman Syndrome but I wouldn't change her. I think the hardest part is when she gets poorly and starts to fit. It's horrible. The things I love most about her are her smile, her laugh, the fact she wants to always play with me and she cheers me up when I'm sad.





International Angelman Day

15 February 2015

ASSERT arranged 13 meetings around the UK to celebrate International Angelman Day. As well as February 15th being a special date, 2015 is also a special year. It is the 50th anniversary of the discovery of Angelman Syndrome and it would also have been the 100th birthday of Dr Harry Angelman. We were thrilled to see lots of families coming along and spending a few hours enjoying the company of other families, watching the children playing and having a chat and a catch up.

Bury St Edmonds

What a great way to celebrate Angelman Syndrome Awareness Day!

We all met up at a local church in Bury St Edmonds that was ready to celebrate with a bouncy castle, bubbles, and loads of food! We spent the afternoon chatting and letting children run wild. We had some fabulous "Angel's" who wanted to chat from the pulpit, some who couldn't get enough bubbles to pop, and some who sampled a bite of everything on the table!

However I think the most laughter we had was during clean up, when a clever adult started popping balloons by sitting on them; some willing participants also had a go! The laughter was contagious and left a smile on my face the rest of the weekend! We hope everyone enjoyed the afternoon and appreciated each and every one of you who came from near and far!

Hollie Christiansen

Bexhill

A great day had by all at the South East regional meet up. I hope to do the same next year.

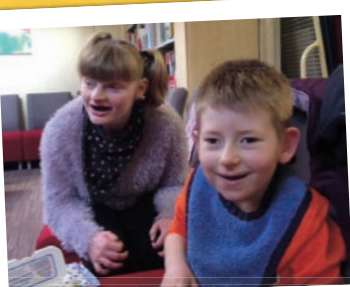
Tammy Munro



High Wycombe

Lots of cake, plenty of smiles and a bubble party The perfect recipe for a group of Angelman families to meet up in High Wycombe to celebrate International Angelman Day. With Ben at the door on official welcoming duties, Natasha dancing in the bubbles, Cody and Woody getting stuck into the tasty bubble mixture, Natalie and Sydney overseeing events, Holly and Jacob winding each other up, Jack and William thoroughly enjoying popping the bubbles and the families having an opportunity to chat and feel 'normal' for a few hours....I think it's fair to say a good time was had by all! Thank you ASSERT!

Louise Shaw





Honiton

Although there were only two families, the Hooks and the Francis', at the South West IAD ASSERT meet we still had a great time! The local leisure centre provided a great soft play area with a huge bouncy castle and go carts which we all (yes adults too) thoroughly enjoyed. Tea and plenty of cake finished off the afternoon. Hopefully a few more families can join us for the next event!

Amy Francis

Marlborough

Thank you to all of the families and friends who came to the South West meeting in Marlborough. We had a fantastic time with a bouncy castle that I must say I really enjoyed! There was a lot of laughter and I hope everyone enjoyed themselves as much as I did. I look forward to seeing you all again soon in a similarly lively and interactive environment.

Jonathan Allen

Walsall

It was a great to see new and old families. Our children had a lot of fun playing on the bouncy castles and ball pit. Look forward to doing it all again next year!

Nav Sanghera



Warrington

On Sunday February 15th over 70 people from across the North West and North Wales met up at Warrington Sensory Centre. <http://www.warringtonsensorycentre.org/> The centre is designed to provide a fully inclusive soft play and activity centre for all ages – from babies up to adults and their carer's. It has a stimulating activity area, ball pool, sensory room and dark dens. For some it was their very first experience of meeting other families who care for someone with Angelman Syndrome, and for others, it was a chance to meet up with old friends and to make new ones. Whilst the 'first time' is always daunting, the newer families gained so much simply by seeing and meeting some of our older children.

"Been an eye opening day as we've met Angels of various ages and abilities. Feeling like we're at the start of a long road but inspiring to see carers, parents and siblings doing a fantastic job."

– Newly diagnosed parent.

We had a fantastic buffet provided by our parents, the staff at the centre couldn't have been more helpful and everyone had a brilliant time. I have a feeling that it may become a regular haunt for our NW regional events.

Rachel Martin





Clydebank

On Sunday 15th February we held our International Angelman Syndrome Day in Scotland it was a great day and we had a wonderful turnout, our day was held in a local hall. We had a Fayre with Home Baking, Tea & Coffee, Tombolas, guess the monkeys date of birth, Bouncy Castles, Face Painting and much much more. We also had some local ladies who sell jewellery and crafts comes along and have a table top sale, these lovely ladies donated half their sales to ASSERT. I also got a special surprise visit from my fellow Scottish Trustee Mairi Leith-McGaw which made my day even more special, it was a great day and fun was had by all we raised a massive £478 with one of my wonderful friends Angela donating the rest to make it up to £500. Thank you to all who attended and donated you made our Scottish IAD a great and successful event.

Catrina Fraser

Basildon

We celebrated International Angelman Day Eastern Region at Pioneer School in Basildon. 13 families attended the day and we had a lovely buffet lunch, and enjoyed use of the facilities of the swimming pool and soft play. It was a very useful informal day and a chance for local families to meet up and discuss issues and chat about schools and services and share experiences.

Hopefully we will all meet again at the conference in 2016!

Sally Walburn



As well as the meetings arranged by ASSERT, there were also some other awareness and fundraising events to celebrate IAD around the UK:



Montessori Childrens House

We are a nursery school in Wimbledon and we raised £300 for ASSERT. All the children dressed as angels and we had a cake sale.

Montessori Children's House

Northern Ireland

A number of families met up at Castle Espie to celebrate IAD by wearing blue in honour of the rare syndrome. Families came from Ballywalter, carrickfergus, belfast, Strangford and Downings in Donegal. We enjoy meeting up and really are like a large extended family. It is precious time spent together. The children in the group affected with the syndrome include Aimee, aged 6 from Carrickfergus, Logan McKechnie, aged 8 from Ballywalter, Jack Gregory, aged 4 from Belfast, Sam Stockdale, aged 3 from Strangford, Aoife Gribbin, aged 8 from Belfast, Identical twin's Zach and Luke Cullen, aged 7 from Downings, Donegal.

Emma Stockdale

Deighton Court

IAD 2015 fundraiser at Deighton court Walsall
by Myah Sanghera & Family



ACC & Guilt



Guilt may or may not be something you struggle with. If it is then this is for you.

Many messages have hit my inbox in the last few months whilst I've been off. The overwhelming feeling in each message is guilt. Guilt that 'I didn't know all this stuff', that 'as a parent I should have done this sooner', guilt that 'I should have pushed for more earlier', 'I shouldn't have trusted the Speech and Language Therapist', and guilt that 'I'm not doing enough'.

Here's my thinking....

A) "I should have known all this stuff"

Hmm. No. You shouldn't have. Your child didn't come with a manual. Tell yourself it's absolutely perfectly AOK that you didn't know about PODD or AAC or Proloquo2Go or Aided Language Input. You'd actually be kind of weird (or a therapist or a random googler) if you did know about this stuff before you landed in The Land of Complex Communication Needs.

Repeat after me:

"We do the best we can with what we know".

B) "I should have done this sooner"

Hmm. No. Trust in the timing. For many families the focus is on day to day survival for a while. That's life and it's ok. If you are ready now then we are here for you. If you don't feel ready yet then just stalk us. But remember you may never feel 'ready' and if we wait for the 'perfect time' it may never happen. Sometimes we just have to take the leap of faith and start. But it's also perfectly AOK to tell yourself "life is a bucket of poo right now and I am juggling a bazillion plates in the air and if I add anything new then we are going to have a bazillion smashed plates in a bucket of poo and I can't handle that". Take a deep breath. Think about it again tomorrow.

C) "I shouldn't have trusted the SaLT"

Yes. You should have. You have landed in this new place and the expert guide, your SaLT, was meant to guide you well. You were right to expect to be shown the best way forward and you were right to

trust him or her. If the SaLT didn't guide you well then that's not your fault. Shake that guilt off.

Something must have happened in your mind, in your gut instincts, in your experience to make you think 'there must be a better/other way'. You trusted YOUR gut. You trusted YOURSELF. Woot! No guilt to be had over that. You explored other options. You landed here.

D) 'I have so much to do/catch up on/learn'

Hmm. Yes. It is a steep learning curve but you do not need to know, nor are you expected to know, absolutely everything about AAC and Aided language Stimulation (ALgS) by the end of a weekend. Baby steps, my friend, baby steps.

E) 'I'm too late, I missed the window'.

Pfft. The window never closes fully. Sometimes it gets a bit jammed and we have to recruit a team to try to coax it to open wider but it never closes super mega tightly shut. A bit of elbow grease and a glass of wine helps too.

The bottom line is that the day your child was born you got injected with a dose of Grade A Parent Guilt. Know that the communication and literacy journey you and your child are on will have hills, valleys, ebbs, flows, forks in the road, potholes, beauty, laughter, and tears.

We're here for you. Please also remember that this AAC, Literacy, and Angelman is still in its infancy. There is so much we are learning. We all have guilt about not doing enough, not being enough. Sometimes we just have to squash that guilt down into our left gumboot and just keep hobbling on.

Little and often. Model, model, model. Ask questions, try different things, and reach out when everything and everyone is in a funk. The sun will still rise tomorrow so set little goals like modelling something at bedtime or saying one thing about your day using the AAC at mealtimes.

Mary-Louise Bertram

A brief guide to deprivation of liberty and the Deprivation of Liberty Safeguards

What is it all about?

The Human Rights Act 1998 states that nobody is allowed by law to be deprived of their liberty by the State without a good reason. One of those reasons is if a person is of "unsound mind." If a person lacks capacity to make a decision about something, they will usually be deemed to be of "unsound mind." Therefore people who lack capacity to make particular decisions may be deprived of their liberty lawfully. In this country the Mental Capacity Act 2005 (as amended) ("MCA") gives the circumstances in which this can lawfully happen.

When can someone be deprived of their liberty?

If your family member is assessed as lacking capacity to make a decision about where they live and how they are cared for, a best interests decision will usually be made for them. They may be placed in a care home or supported living, or receive support in their own home.

The law says that if a person is being

- a) confined in a particular place for any real period of time
- b) they are not free to leave that place; and
- c) they are under continuous supervision and control; and
- d) those living arrangements are the responsibility of the local authority or NHS

then that person is likely to be deprived of their liberty.

What happens when someone is being deprived of their liberty?

The law states that if someone is deprived of their liberty, it needs authorising and regularly reviewing to make sure it is in their best interests, because they can not make the decision themselves.

If your family member is deprived of their liberty in a hospital or a care home, and over 18, they will be made subject to what is called a standard authorisation under the Deprivation of Liberty Safeguards, or DOLS. This will be arranged between the placement and the local authority. The DOLS sets out in the MCA the procedure that must be followed. Family members and carers should usually be consulted and may even be appointed as a representative for the individual.

The authorisation will state how often it will be reviewed. The review is the most important part of the authorisation as it is a safeguard to ensure that the person being deprived of their liberty is receiving appropriate care in the right place, in their best interests.

If your family member is living at home, or in supported living, over 16, and they are being deprived of their liberty, the local authority or the NHS (depending on who is funding the care arrangements) will have to apply to the Court of Protection for the deprivation of liberty to be authorised. The process is very similar to that under DOLS.

It all sounds very serious

Being deprived of your liberty is a serious issue as it is a restriction on your human rights. However, in this context, having a deprivation of liberty authorised whether by the Court of Protection or under DOLS is a positive thing because it gives your family member protection. It means that the care regime they are being provided with must be the least restrictive of their liberties, and any restrictions that are in place must be proportionate to the risks posed to the individual's welfare. It means that family and other interested parties will have their views taken about what is in the individual's best interests. It means that your family member will have their voice heard about what they would like in terms of where their care is provided and what care they receive.

What if I disagree with the authorisation?

If you think your family member's care arrangements are not in their best interests, you may be able to challenge the authorisation if it has been made under DOLS. If the Court of Protection has authorised the deprivation of liberty, you can apply to the court to have the authorisation reviewed. The person subject to the authorisation can appeal against it also, if they disagree with their care arrangements, and they will receive support to do so.

I want to find out more

It is widely acknowledged that anything concerning deprivation of liberty can be very complicated. If you want to find out more about this then please contact ASSERT on 0300 999 0102 or assert@angelmanuk.org and your details will be passed on to Anthony Collins Solicitors who kindly provided this information.



Neil Buchan.

ASSERT trustee for Scotland 2008 - 2013

It is with sadness that we announce that Neil Buchan, former ASSERT trustee for Scotland, died on 2nd April 2015 whilst surrounded by his family.

Neil was passionate about raising awareness of Angelman Syndrome in Scotland and was very proud of the role he played. He was a familiar figure to many at both regional events in Scotland and at the ASSERT conference, and was liked by all who met him.

It was clear for all to see how much he loved and admired his wife and children, talking about them with obvious pride at trustee meetings and regional events, and our heartfelt sympathy goes out to Linda, Kerri-Marie, Sammi, Kieran and Rhys.

"A tall man with great big smile and a heart of Gold....." - Mairi Leith-Mcgaw

He will be missed.

In memory of Neil, the photo on the front cover of this issue is his son Kieran. This photo was taken at our 2012 conference which was the last conference attended by Neil and his family.



Member Update

As you will be aware from our previous newsletter, we have requested that all members return their 'Member Details' form included with the last newsletter. We need to update our database to ensure we have everyone's details up to date and also to enable us to provide a contact register. The response hasn't been that good so far, and so as it stands at the moment we are unable to issue a contact register. Please could anyone who has not sent in their form return it asap. If you have misplaced the form, please email assert@angelmanuk.org with your address to request another copy. As stated in the previous newsletter, not only do we need to ensure your details are up to date but also that we have your permission to print your details if you wish to be included in the contact register. If you have registered with ASSERT in the last 6 months you do not need to complete this form. Thank you for your co-operation.

Jute Bags

ASSERT jute bags are still available.

They have proved very popular so far, and I'm sure everyone who has one of these bags will confirm how useful they are. They are a great way of raising awareness of ASSERT.

The bags are £3.50 each.

The postage costs on top are then:

1 – 4 bags £2.80 postage

5 – 9 bags £3.80 postage

10 bags or more – please email for a price.

Please send a cheque made payable to ASSERT to our Freepost address or you can pay by bank transfer. For more details please contact Lisa.Court@angelmanuk.org



Antonia Burton

Ella was approaching her third birthday and after a summer spent having regular Portage sessions, I felt it was the right time to think about starting her at some kind of nursery or playgroup. Up until now, Ella had always stayed by my side. We had been to a number of different 'stay and play' groups together and Ella had showed that she was a highly sociable little girl. I therefore assumed she would be ready to enjoy a more regular group by herself.

I made some enquiries into our local village playgroup but sadly they were full, as too was their long waiting list. I wasn't sure where else to look as we had only been living in this particular part of Cambridge for less than a year. I had been occasionally visiting the local children's centre so I decided to ask them for advice. I'm so glad I did as unbeknown to me there was a playgroup operating right next door to the centre. Within minutes of finding this out, both the playgroup manager and SENCO came out to speak to me, meet Ella and tell me about their setting, The Cherry Playgroup. They were so friendly and easy going and Dawn, the SENCO, immediately hit it off with Ella. I knew instantly that I wanted her to attend. We did have to wait a couple of weeks to secure a place but really, it all happened pretty quickly and by her third birthday, Ella was enrolled.

I stayed with her for the first few mornings as she seemed unusually clingy. I just presumed she would in time become more relaxed with her new surroundings but oh, how wrong was I? It came as a massive shock to me to find that she didn't relax at all. In fact she became more and more anxious, realising that I was going to leave her. I hadn't thought for a second that Ella was going to find this hard and looking back, I feel very naive to have not even considered that leaving me was a totally new concept for her to take on.

The next six weeks were awful. My bubbly, sociable, smiley little girl was showing a side I had never seen before. She became quiet, clingy and very withdrawn. Everyone kept telling me that she would be fine in time but I really couldn't see that she would.



Each day, when I eventually managed to peel her off me and leave, she would apparently spend the entire morning 'patrolling' all the exits and windows hoping to see me returning for her. She had never really been a particularly loud, shouty baby but suddenly she had discovered this voice from out of nowhere. It honestly sounded like she was being murdered! The poor little thing was suffering with real separation anxiety and I felt terrible for her. At this stage, Ella still didn't have any words or signs so obviously she couldn't tell me how she was feeling. It seemed apparent though that she was really quite traumatised. When I would return at the end of every morning, she had worked herself up into such a state that she just didn't seem like my Ella at all. She was totally exhausted and sweaty from all the crying and clung on to me for dear life.

At the same time that Ella started playgroup, a referral also came through to begin one to one music therapy. We had been on a waiting list for a number of months for music therapy and surprise surprise, it just so happened that what were soon to become the two biggest and most positive interventions in Ella's life so far, would both start at the same time! As you can imagine, this was an surprise, it just so happened that what were soon to become the two biggest and most positive interventions in Ella's life so far, would both start at the same time! As you can imagine, this was an awful lot for Ella to take on so it didn't come as a shock that she found the early stages of music therapy also very difficult. I was able to attend music therapy with her but

obviously she assumed that I was going to leave her there like every morning at playgroup, so she again became a little leach that I couldn't pry off.

The first six weeks of playgroup felt like forever but of course things became easier for my little angel. Gradually she understood that I was coming back at the end of the morning and gradually she became more relaxed with the staff. As I write this article, Ella still attends The Cherry Playgroup. She has now been there for a year and a half and we have seen a number of different one to one members of staff come and go but I have to say, that every single teacher that has ever come into contact with Ella at that setting – whether it be management, one to one or any other general practitioner - they have been absolutely wonderful.

I never expected to find a setting as fantastic as this one. I had previously worried so much about Ella starting any kind of preschool, about finding the right environment for her and people that understood and accepted her. I have since met many parents that have had hugely negative experiences with different 'early years' settings and they have been left feeling like everything is a constant battle. I have been extremely lucky myself and so feel the need to let these, and other parents alike, know that there are places out there with truly amazing staff that do want what's best for our special kids and will do everything in their power to get it for them.

As a parent of a child with severe special needs, I honestly couldn't have asked for anymore than this playgroup has given us as a whole family. From the very beginning, not only has everyone involved there been utterly committed to Ella's happiness, welfare, learning and any other needs but they have been a constant support to me, having the time to discuss every days achievements and concerns and also to my son, Harry, who for the last six months has been attending regularly and has also had an enormous amount of support and is thriving.

Ella has, in no doubt, been at the best possible setting for the last year and a half and has achieved ridiculous amounts whilst being there. The staff have learnt alongside Ella as she has gone from being a shy little 3 year old with a relatively unknown syndrome, to a bright, energetic, babbling 4 ½ year old that is now beginning to use PECS and is signing and even saying a dozen or so words. Now, for anyone that is at all familiar with Angelman Syndrome - you know that that's pretty incredible!!

Antonia Burton

Useful Websites & Interesting Blogs

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

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

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

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

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

Ah, bathtime.

I can't believe it's taken me so long to get around to this subject as it's my favourite time of the day. You can keep your walk-in showers – as far as I'm concerned nothing beats wallowing in a nice warm tub of water.

So what exactly happens in my bath? Some people like to play with rubber ducks, or boats or submarines but they're not for me. Sometimes I like to chew on the tail of a large rubber dinosaur and just chill, but mostly I think it's much more fun to play with the taps: turning them on and off, on and off. Actually I don't usually have to turn them off because there's always someone there to do it for me. I've heard other people have their baths on their own, which must be terribly lonely for them. I've always had an audience for mine and, on the whole, I enjoy the company as long as they don't try to spoil the fun.

For some reason my turning on the taps seems to make people grumpy, so you'd think they'd cheer up when I switch my attention to pulling out the plug – but no, it just seems to make their mood worse. And then they turn on the taps even though they've just told me not to do it. Some people are never satisfied.

Then there's the question of bubbles. I used to have a lot of bubbly baths, which was brilliant if you wanted to put your head in the water and pretend to have a big white beard and bubbly hair (trust me, this joke never gets old). But then they said I was eating too many of the bubbles so they stopped putting it in.

Sometimes I'm in the mood for a good old splash and there are a lots of different methods I can recommend. At the bottom end of the scale there's the simple hand-slapping-the-water method. That's ok for starters, but it's tiring after a while and quite honestly there are more effective ways of redistributing water. To move the game on a bit you can reach over the side – causing quite a slosh in itself – and pull in a towel or two. Then you can throw the towels out again. This has the added benefit of keeping people busy for a few minutes so that you can go back to turning the taps on to keep the water level topped up. But if you're really going for the full 'Perfect Storm' effect you need to slide your body forwards and backwards along the bottom. If you get up enough speed you can cause a double Tsunami which will have people running in all directions. Ah, you should see the joyful expressions on their faces.

But some nights I just like to wallow. Wallowing in a nice warm bath at the end of a tiring day is as good as life gets as far as I'm concerned. I lie on one side with half my face in the water so that whenever I fancy a drink I just have a quick slurp. In fact the bath is where I do the majority of my day's drinking. I've never really mastered the art of the cup and having a syringe full of water squirted into your mouth isn't the most pleasant way to take a drink so a few gulps of warm, soapy water usually hits the spot quite nicely.

Of course all that drinking can bring on problems of its own; after all, any water that goes in has to come out at some point. But the way I look at it, you're sitting in water anyway so what difference does a little more make? Especially if I've been in there a while and it needs warming up. Ok, so it goes a little yellow and Curly Top has now refused to share my



water afterwards, but I think that's his loss. Smiley and co. used to try to catch my outpourings in a plastic cup but after a few futile attempts and some very wet hands they've given up. That reminds me, Flower Girl only recently found out what the plastic cup in the bathroom was for; turns out she'd been using it to drink from when she came in late.

I was going to tell you about hair washing... but quite frankly it's too distressing. I really must remember to speak to the social worker about this.

Anyway, all good things must come to an end and eventually they pull the plug on me. But I'm sure you didn't expect me to be beaten so easily; a quick press of the thigh and I can keep the water in for at least another ten minutes, and there's no way I'll ever get out of a perfectly good bath while there's even the tiniest drop of water left.

Perhaps you think I would have to admit defeat when faced with an empty tub? Pah! Even without water I'd quite happily stay in the bath all night if they'd let me have a duvet. But no, the boring traditionalists insist on me getting out. Still, I don't see why I should make this easy for them so I don't give up until there are at least two people to haul me out and wrap me in a towel. Body drying I can just about tolerate but I firmly believe there are no circumstances under which you should ever let anyone rub your hair. And since the bath has finished I can't usually be bothered to stand up at this point but there are always some of my staff around to support my weight.

Dressing? Well personally I probably wouldn't bother but as I have lots of people to perform this service for me it would seem a pity to disappoint them.

And that's it. Nice and relaxed and settled for the evening so I go and lie on my bed where all my favourite toys have somehow magically scattered themselves within a convenient arm stretch.

But as soon as I'm on the bed I always have the terrible thought that I might be missing out on something that I'll need during the night, so I leap out and charge downstairs to check. It's always worth popping a head into the bathroom on the way as there's sometimes another bath running, and if there's no-one about I can jump in for another splash. Usually I bump into Smiley at this point. He likes to spend this part of his evening mucking about with armfuls of wet towels.

He does have some funny habits.

Angelman Syndrome Research

Questionnaire

Dear Parent/guardian/carer,

We are conducting a new study about Angelman Syndrome. In association with the University of Manchester and ASSERT, the study aims to identify in more detail, the specific medical problems associated with Angelman Syndrome and the quality of the medical care that people with Angelman Syndrome receive.

We need as many parents/guardians/carers as possible to fill out an online questionnaire, about the health of the person with Angelman Syndrome, and the support they receive. The more completed questionnaires we get the more relevant our findings will be.

This is a national study and all information collected will be anonymous and confidential.

Please complete the questionnaire by 1st June 2015.

Thank-you in advance and if you have any queries please contact: danhindley@nhs.net

Please follow the link below to access the questionnaire:

<https://www.surveymonkey.com/s/9LDFHWD> Password: 123ABC (capitals)

Dr Dan Hindley, Professor Jill Clayton-Smith, Rosie Conroy.

A Tale of Two Doctors and a Child

Two young male doctors walk into an isolation room on a children's neurology ward to place a new IV cannula in a ten year old girl. Her current IV has tissue and she needs another one urgently. They are met by two adult women and a sick child on her hospital bed. She is unwell, having multiple types of seizures, is in pain, and is dealing with constant choreo-athetoid movements that make her body writhe and wriggle. She does not speak but when she is well she is an excellent AAC user; and at all times she uses her whole body to communicate. She does not sit or walk independently but she is incredibly strategic in how she uses her body, and these two doctors don't know it but she can drive a power wheelchair with her Big Toe. She is a communicator, a thinker, a dog owner, a chocoholic, a fashionista, a reader, a writer, a lover of Frozen, a piano player, a daughter, a sister, a niece, a cousin, and a friend. She is known to, and respected by, AAC and Assistive Technology specialists around the world. Through her videos on YouTube she has inspired many families around the world to presume competence in their own child. For the next thirty minutes she is also the patient of these doctors. But, most importantly, she is a child. A whole child.

Doctor 1 gets right to business holding wriggly arms, looking for veins. The child's body writhes, her elbows hyper-extend inwards as he attempts to hold her arm out straight.

Doctor 2 talks to the child, and to her adults. He tells them why he is here, back in paediatrics. He addresses the child by her name.

Doctor 1 notices the adults are helping the child take her mind off of her pain and the need to be restrained by three people, by using her electric (vibrating) toothbrush to brush her teeth.

Doctor 2 comments the child must have beautiful teeth. Doctor 1 comments that it is the sensory feedback she is obviously seeking. He comments that "Children with a low mental age also enjoy Mozart".

Doctor 2 asks the child if she likes music, if she likes Les Misérables.

Doctor 1 taps veins, comments on the child's writhing and how it makes things difficult.

Doctor 2 chats with everyone about the child's love of Frozen. They talk about making snow out of conditioner and soda bicarb, about making snowmen. They talk about the child's love of Olaf.

Doctor 2 muses about what other things you could build with snow and suggests you could make a cat. He bursts into song "Do you wanna build a snow cat?"

Doctor 1 has his eyes on the prize, on getting the cannula in. The adults appreciate this but his manner and demeanour and his use of the term 'low mental age' have tainted him.



The site fails and they need to try another site, another arm.

The electric toothbrush runs out of charge.

The child cries and fights against this hell of restraint.

Doctor 1 asks the nurse to hold the child's arm more firmly.

Doctor 2 starts singing, in a loud, proud, fearless voice. 'I Dreamed a Dream' is sung with gusto.

The child turns to face him, she cannot take her eyes off of him. She vocalises her singing voice and sings along.

The line is in. The child indicated she has something to say. The adult asks the doctors to stay for a moment as the child has something to say and it may be to them.

Doctor 1 leaves.

Doctor 2 stays, watches, waits while the adult scans the child's PODD communication book.

The child has a seizure and cannot chat anymore. She is spent.

Doctor 2 thanks the child. Thanks the adults. He wishes her well. His name was Alastair.

I never bothered to ask the name of Doctor 1.

Mary-Louise Bertram

January 2015

Leia and her circle of friends



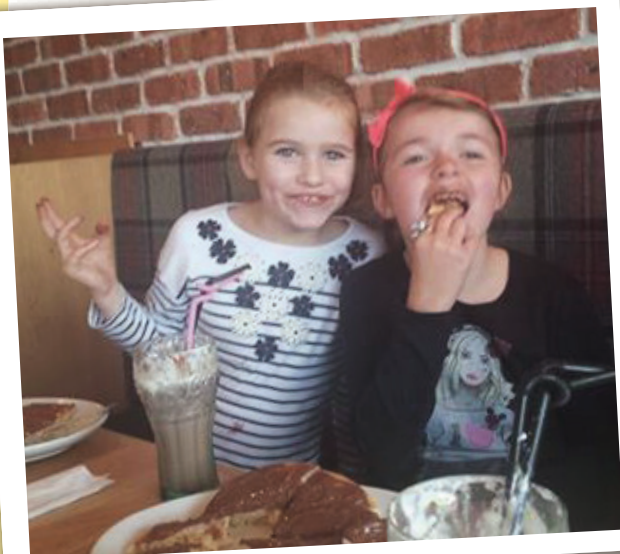
Leia is 8 years old, she has AS. She has a sister Abbie who is 11 and a 3 year old brother, Finn. At the ASSERT conference this year one of the keynote talks on the Sunday morning was about Maggie. Maggie has a fabulous life - she goes out with friends to the mall, has sleepovers, birthday parties, she has the life of an 11 year old girl. I realised that Leia could have more friends, we just hadn't given her the opportunity.

I was so nervous I thought it could be great for Leia if it worked but I would be really disappointed if it didn't. Now I am not sure why, the situation would have remained as it was and we could have tried again in the future. I invited a family friend Katie, who is the same age as Leia, round to play. Katie has always gone out of her way to speak to Leia and has never seemed scared of her inability to speak. It felt like a date! What on earth will I do with them, what do normal 8 year old girls do I asked my friend, who laughed and gently reminded me that I had had an 8 year girl more recently than her. I decided on Arts and Crafts; Leia had a ceramic pony to paint and this was the time to bring it out. They both loved it, working on a side each, Finn occasionally helping. When Abbie her friend Anna came in they wanted to join in too. They then started painting silly faces on the pictures of the newspaper I had put down to save my table. Leia thought this was hysterical. When Katie's mum came to pick her up she really did not want to leave. I perceived this to be a success.

Since then we have had lots of friends to play. It has always gone well, they are keen to help Leia use her communication aid and never mind if Leia takes herself out for 5 minutes. One of the best nights was when I accidentally ended up with 8 kids in the house at the one time and

I was the only adult. I did, fortunately, have a local teenager in whom I pay to come and play with Leia on a Friday after school. They all played with play-doh, used Leia's PODD to model to her, she directed them all to take part in a mass dance session using her GoTalk app to show them dance moves from her Brownie songs, they all complied and had fun. It was great. Leia's confidence has markedly improved since the first play date and it has transferred over to group scenarios. Thank you Maggie for the inspiration.

Tracey Campbell



Samuel's Helicopter Adventure!

Earlier this year Samuel, 12 (AS Del) was lucky enough to have the opportunity to go for a flight in a helicopter! It really was an incredible day. He, his Daddy & brother, Willoughby, 9, went for a flight from Bournemouth Airport in an EC 120 Colibri Eurocopter (for helicopter buffs!) over the Purbecks in Dorset, including Corfe Castle, Swanage & even our home in Church Knowle.

We had been anxious about how Samuel would react and behave and had had visions of him grabbing the joystick in mid flight and causing total chaos! However, thankfully, our fears were totally unfounded as both boys were really well behaved and very laid back and relaxed throughout. Samuel was enthralled with the whole experience and loved looking down on the view of the places he knows and loves. The only thing he wasn't too keen on was the ear protectors, so they only stayed on for 5 seconds, but apart from that they all loved it. Even the weather was perfect - crisp clear and sunny.

It was all due to the kindness and generosity of a Helicopter Captain who is friends with someone we know. It was really lovely to meet such a genuinely caring and generous person who made us all feel extremely welcome and who thoroughly enjoyed the experience as much as we did. He had even prepared some special flight certificates and presented them afterwards along with a framed aerial photo taken from the helicopter for Samuel and a 'Super Boy' badge as well. We will never ever forget this special day and are thrilled for both Samuel and Willoughby – 2 very lucky boys indeed!

Amelia & John Coffen, Dorset



Fundraising

In readiness for IAD 2015, one of our parents, Dan Hasler, dad to Rufus, designed a limited edition IAD t shirt, in a collaboration with Andy J Miller who has worked for Nickelodeon. Sales of this very popular design raised over £435 for ASSERT.



Search Laboratory



We first came across ASSERT when we were looking for our Charity of the Year 2015. One of our staff members, Danielle, nominated the charity as she has known someone for a long time with Angelman's Syndrome and felt very passionate about raising the awareness of the charity and its aims. After a very moving presentation from Danielle, Search Laboratory decided that ASSERT was the right charity for us to support throughout 2015.

Our main aims are to raise the online profile of the ASSERT website to encourage more visitors to the site as well as playing our part in fundraising efforts. We have a number of events planned throughout the year including bake sales and Wear Your PJ's to Work Day; the main event being the Yorkshire 3 peaks Challenge on Saturday 27th June.

Everyone is really excited to work with the charity and we are looking forward to a visit this week from a representative of the charity to chat to us some more about the great things that ASSERT is doing!

Alison Mann



Thank you!

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

many thanks to...

CONFERENCE PORTRAIT DONATIONS

Nikki Gadd	Sandrine Marshall
Linda Holmes	Maureen Millward
Kelly Martin	Breeda Howard
Caroline Mason	Tracey Smith
Helen Edwards	Mrs Moran
Melanie Thomas	Maria Allen
Donna Waterhouse	

DONATIONS

<u>Hazel Tait</u>	<u>Mr & Mrs Webbing</u>
<u>Megan Williams</u>	<u>Thelma Ray</u>
<u>The Codfather</u>	<u>Mr & Mrs Simpson</u>
<u>Christine Reader</u>	<u>Jane Clark</u>
<u>Amy Lister</u>	<u>Marie-Louise Johnson</u>
<u>The Merriman Partnership</u>	<u>Tina Wright</u>
<u>Lesley Keeves</u>	<u>The Jolly Chippy</u>
<u>Joanna Reid (FDC Young Designers)</u>	<u>Helen Edwards</u>
<u>The Anchor Bar (Mairi Leith-McGaw)</u>	<u>Michelle & Stuart Matthews</u>
<u>W R Freeman</u>	<u>Mr & Mrs Knapp</u>
<u>Abby James</u>	<u>1st Johnstown Beavers (Mrs Wynne)</u>
<u>Graeme Paterson</u>	<u>Pete & Mary Williams</u>
<u>S Gray</u>	<u>Mr & Mrs West</u>
<u>Lindsey & Martin Pamham</u>	<u>Mrs Stella Turlington</u>
<u>The Play Station Rockingham, Rotherham</u>	<u>(in memory of Mr Leonard Buxton)</u>
<u>Blemain Finance Ltd</u>	<u>Mr & Mrs Patel</u>
<u>Mr & Mrs Barratt</u>	<u>Lisa Howton</u>
<u>Dinah Oti</u>	<u>Executive Resource Group Ltd</u>
<u>(IAD Awareness & Fundraising)</u>	<u>(Rebecca Perks)</u>
<u>Mr Ronald Boyes</u>	<u>Montessori Nursery, Wimbledon</u>
<u>Cirencester Community Church</u>	<u>Tammy Munro - IAD Meeting</u>
	<u>Cynthia Knowles</u>

SPONSORED EVENTS

<u>Becky Holmes - Bungee Jump</u>
<u>Sharon Hurcombe - Great North Run 2014</u>
<u>Sukhninderjit Singh Braitch - Great North Run 2014</u>
<u>Kevin Poynter - Bupa Great South Run 2014</u>
<u>Tom Callaghan - Bupa Great Birmingham Run 2014</u>
<u>Denny Luke - Bupa Great Birmingham Run 2014</u>
<u>Cristina Balekjian - Bupa Great South Run 2014</u>
<u>Alan Bradburn - Everest Base Camp Challenge</u>
<u>Martin Hiley - Bournemouth Marathon</u>
<u>Barbara Lemmon - Barbara's Birthday Bash</u>
<u>Blackbird GB - Snowdon Hike</u>
<u>Alex Moon - Portsmouth Marathon</u>
<u>Matt Woodley & Rebecca Melvin - Great Eastern Run</u>



Helpline 0300 999 0102
assert@angelmanuk.org

Angelman Syndrome Support
Education and Research Trust
Freepost, PO Box 4962
Nuneaton CV11 9FD