



Newsletter 59 Autumn 2016

Angelman Syndrome

Support, Education & Research Trust

Conference 2016

Communication,
Communication,
Communication.

Scottish Conference
2017

EHCPs

Communication
Conference 2017

ASSERT Meets Star Wars

More Fabulous Fundraising

Registered Charity 1021882





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



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



Diane Fox-Jones
South East Region
diane.foxjones@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



Andrea Baines
External Fundraising and Central Region
andrea.baines@angelmanuk.org



(non-Trustees)
Rosemary Tegg
N. Ireland & Eire representative
rosemary.teggin@angelmanuk.org



Louise Shaw
Central representative
louise.shaw@angelmanuk.org



Tracey Campbell
ASSERT Advisor for Communication
tracey.campbell@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

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

As the year draws to a close, I think that we can say, without doubt, that 2016 has been a momentous year both for ASSERT and our wider Angelman Syndrome community.

The year started with a bang thanks to a very successful series of International Angelman Day events across the UK and an external grant award from Genetics Disorders UK (Jeans for Genes).

The global phenomena of AAC within an AS context has gathered pace significantly, and our home grown expertise continues to gather knowledge and support.

The 2016 conference was also a highlight, despite the weather doing its best to intervene. Widely regarded as our best yet, it really was a great weekend and one that was charged with a positivity that we are working hard to carry into future events.

Our fabulous army of fundraisers surpassed themselves this year. From the intrepid long distance runners, the walkers, the swimmers, the cyclists, the musicians, the bakers, the writers, the knitters, and the artists right through to the Sci-Fi enthusiasts, thank you.

On an international level, the Angelman Syndrome Alliance continues to grow, and the second wave of project funding is now under way. That coupled with research elsewhere means that there is now more global scientific interest in Angelman Syndrome than ever before.

The year is finishing on a high thanks to the support of Lucasfilm and our patron Gareth Edwards. The short film donated by Lucasfilm has now had well over 21k views on YouTube. Many of those are from outside of the AS community therefore helping raise awareness of the condition to a whole new level. Having witnessed Gareth's entertaining speeches both at Coventry this year and in Liverpool in 2015, we're all looking forward to that Oscars acceptance speech in due course. In all sincerity ASSERT would like to wish Gareth the best of luck with the film. Through the obvious family connections, we are aware of just how much of his life he has had to put on hold for the last couple of years- and yet he has still found time for us and our cause.

Within ASSERT there have been changes. Both Linda Holmes and Sue Williams have stepped down as trustees this year. Many of you will know Linda from the days out that she used to organise in the Yorkshire region- and it something that she continues to do away from ASSERT. Sue, a trustee and ASSERT's secretary for over 8 years will continue to be a welcoming face at conference. We would like to publicly thank them both for their hard work and dedication during their tenures.

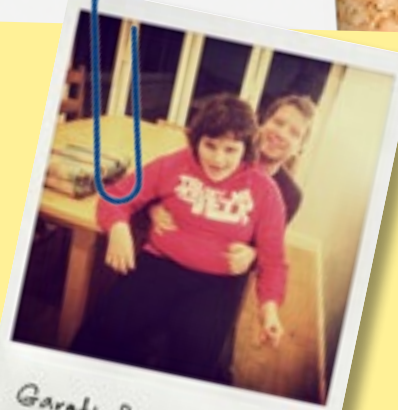
2016 has also seen its fair share of sad news. Not least the loss of one of our own, James Myers. Our thoughts are with his mum Andrea and their family across this particularly difficult period. They are also with anyone else within the AS community for whom 2016 has brought sorrow.

From all of the ASSERT team, we wish you all a peaceful Christmas.

Rachel & Rich

An update on Our Patron Gareth Edwards...

Unless you have been locked away in a darkened room for the last few months, you will definitely know about the very exciting release of *Rogue One: A Star Wars Story* which will hit the cinemas on 16th December. The build up for this has been huge, there is a lot of excitement amongst true *Star Wars* fans about what they can expect. Hopefully a lot of you will be going along to see the film. We hope you enjoy it! A lot of you may also know about the fantastic awareness film that was released towards the end of November. To date, this has had over 21k views which is just phenomenal, it has been so well received by everyone. The exposure has been far and wide. Please see page 24 for more details on this film.



Gareth & his niece Ella



Summary of the Conference 2016

Everyone I have spoken to had a great time at the 2016 Conference; even the rain didn't spoil anyone's fun too much! Inspiring and entertaining speakers, lively workshops, energetic dancing, fun trips and of course, the opportunity to catch up with old friends and make new ones. As my AS son reached out one morning at breakfast and grabbed one lady's pristine white shirt with his jammy fingers, my horrified apology died on my lips as she turned to him with a beaming smile and went in for a big hug; jam, crumbs, dribble and all. Acceptance, no judgement and the chance to experience 'normal' for a weekend - what could be better?

Andrea Baines

Here are some more detailed experiences from the weekend:-

First Conference – Sophie Edeson

For a long time, I'd been putting off going to conference. I was nervous. We went for the first time this September, a couple of months after William's eighth birthday. I was glad that we'd waited, but equally glad that we went.

Typically, we were late, but we were greeted by the smiling face of an ASSERT trustee and given all the information we needed, free drinks tokens included! The atmosphere was amazing: warm, relaxed, slightly crazy, but all good. It felt great to be there.

Throughout the whole weekend we were really impressed by the level of thought, care and attention that had gone into every aspect of the conference. The calibre of the speakers, the opportunity to go to smaller workshops, the trips, the food, the evening entertainment were all just right. I'm in awe of the work that the trustees must have done putting the whole thing together.

There were some real delights on the weekend; seeing hosts of laughing thrill-seekers having the time of their lives on the rollercoasters at Drayton Manor; getting random cuddles from smiling Angels on the dance floor and not having to cook or wash up for a whole weekend! On a more serious note, the conference gave us the timely nudge we needed to do some of the things that we had let slide. When we got home we felt inspired to dust off William's iPad and check out the research

going on at Cerebra. We're finally doing something constructive with Proloquo2go and have signed up for a communication study, too.

All in all, it was a great experience. Happy, fun, useful, inspirational. We will definitely go again.

Day Trips – Catrina Fraser

Time rolled around again for the ASSERT biannual conference and this time the trips were to Drayton Manor and Twycross Zoo.

Saturday, and the weather wasn't looking too good, but we set off on the buses to Drayton Manor. By the time we got there, the heavens had opened, but nothing was going to stop us all from enjoying ourselves. Tickets in hand and hoods up, we entered the park ready for a fun filled day!!! We had queue jump passes for the rides which were a Godsend, as the rain was so heavy we really didn't want to be standing about. My 11 year old thought it would be funny to take me on this round thing on a stick that threw us in the air!!! Joke was on him as I loved it and he came off near tears!!! I wasn't so brave in the cable car ride though; if you have an over excited AS child who loves to bounce then I would say this ride isn't for you!!

The day was cut short due to the weather but it didn't ruin it for everyone, some wanted to stay and play in the rain!

Once back at the hotel and dried off, we were greeted with hot drinks and biscuits - cloud and silver lining come to mind! I heard from a few people that regardless of the weather, they had a great day with their kids at Drayton Manor.





Sunday took us to Twycross Zoo. I had to individually count in all of our party and with my thick Scottish accent and the fact I had somehow caught mild tonsillitis, no-one could understand what I was saying!! But thanks to Craig (Lisa's husband) translating, we finally got in. First stop the monkeys and I have to say they are the cutest animals I have ever seen. Looking around at all the families enjoying themselves made me very happy and proud to be a Trustee for ASSERT. We all stood looking in at the monkeys in awe. I'm sure the monkeys were looking back and thinking 'wow look at all those kids banging on the glass and laughing their heads off at us swinging around!' Some kids got to get up close with the monkeys when the show offs were right on the glass and banging back at the kids! It was wonderful to see the kids' faces light up! In the rest of the park we saw butterflies, zebras, and Meer cats and we also got to pat and play with goats, rabbits and guinea pigs. We left with a list of animals we need to buy for our house!! Safe to say that won't be happening anytime soon, or the next trip could be to the Fraser's Home Zoo!!

Twycross Zoo was a great trip; someone told me that their AS child threw his glasses into the turtle enclosure!!! This made my day, only a group of AS kids could go to the zoo and entertain the monkeys and share our glasses with the animals!!

We all had a wonderful time on both trips. Now to plan for 2018 and hope and pray the weather is better.

Siblings at Conference – Jonathan Allen

Being a sibling to someone with Angelman Syndrome is at times difficult (to say the least!). I'd grown up having a close relationship with Eloise, my older sister, but I think I was always aware of how it was perhaps a different relationship compared to my friends and their siblings. The conference provided a fantastic environment for all the siblings to meet and talk to one another, sharing experiences with people who know exactly how they feel.

One thing that really struck me this year at the conference was the willingness and maturity of siblings to look after, engage with and support their AS siblings. This is especially true of the younger ones who you would perhaps not expect to behave in such a way. Whilst there are some inevitable downsides to having a disabled sibling, I have always said that it has shaped my perspective in life in such a positive way. It was really moving for me to see the positive effects in other siblings of all ages.

I would also like to thank all of the people who took the time to come and see my sibling's workshop and I hope that you took something away from it. It is not always easy being a sibling (and even harder being a parent!) but seeing so many of you take the time to come to my talk really shows that there is a conscious effort from parents to make the best possible environment for all the family.

Finally, I would just like to say a massive thank you to all of the siblings who helped me out over the conference weekend whether it be running the merchandise stall or beating me on the Playstation! I look forward to seeing you all in the future.



Conference 2018

The trustees have listened to your feedback and have now moved the conference dates to be in the summer holidays. We appreciate how difficult it can be to take your children out of school. So please put your dates in the diary for 2018. We hope that having the dates now allows you to plan your summer holidays in 2018 around the conference and therefore ensuring you are able to attend the weekend. So make a note:

Friday 10th August – Sunday 12th August 2018

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 sometimes feel like I don't understand my brother, who has Angelman Syndrome, properly. We often get on well but if I don't understand what he means then it might lead to him being upset about something and I don't want this to be my fault.

Jon's Answer: The first thing to remember it is isn't ever your fault if you cannot understand him. Angelman Syndrome presents a wide range of communication difficulties and it is one of the biggest challenges. If your brother is upset due to something he couldn't communicate properly then this isn't down to you but rather is just a part of everyday life with Angelman.

If you do want to improve communication with him then it takes time and there are a number of different ways you can do this. It might be that he has an iPad which he uses to communicate and you could help him learn further with that. Alternatively he might have a system you can use. Ultimately though, over time we learn what different things mean with those with Angelman Syndrome and they learn what we mean also. It is also important to remember that every person with AS is different and what works for one person may not work for another.



Betsy and Rufus Hasler

BETSY (randomly):

"Everyone with Angelman Syndrome is like sunshines aren't they?" About her brother Rufus.

Dear Jon,

I have recently moved out of the family home and I am actually concerned about how my parents are going to cope without me. As my AS sister has got older, she has become much bigger and stronger and so when I was at home I was doing a lot of the physical side of things with her. I am worried about how my parents are going to cope with this and whether or not I should have moved out.

Jon's Answer: The lines between sibling and carer often become blurred but it is key that you take on board the fact that you have your own life to lead as well. There does come a point where you have to make your own way in life and it is important that you do not feel guilty or regret about this; it is a completely normal thing to do.

If you are concerned about your parents then it may be that talking to them helps alleviate concerns. It may be that you have discussions with them about alternative arrangements, perhaps whether or not home help is appropriate for some hours of the week where a carer comes in to help with your sibling.

Dear Jon,

Sometimes I feel that having an AS sibling is just too much as they are so demanding. I feel guilty for saying that but sometimes I just find it too difficult to give them constant attention and play with them.

Jon's Answer: Any person who deals with someone with Angelman Syndrome needs time to themselves as well. You cannot be an effective person to deal with AS unless you have some time to look after yourself as well. I suggest talking to your parents about your role and if possible you could perhaps just take some time for yourself to relax. Further, you could always go and see friends as this gives you time to hangout and relax too.

Alternatively, there are also fantastic young carers groups about the country and this will give you a chance to let off steam with other people who understand exactly what your situation is like.



Communication Conference 2017

As mentioned in the last newsletter, ASSERT are proud to be hosting the first mini conference dedicated to Communication and Literacy. The conference will be held at The Hilton Hotel in 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 to all of our members. Please note that the conference is open to both parents/carers and professionals. The schedule is still being confirmed but rest assured it will be a very exciting line up with as many speakers as we can fit in! Please put the dates in your diary. Letters will be sent out early 2017 with the details.

I Have Something to Say

ASSERT are delighted to include 2 copies of the 2nd edition of the booklet 'I have something to say...' Those of you who attended the 2016 ASSERT family conference may already have a copy of the 1st edition. The 2nd edition contains some important additions so please feel free to pass this on to your professionals.

'I have something to say...' is a collation of widely available information taken from various sources such as online blogs by renowned Speech, Language & Communication specialists, Facebook groups, expert parents, educators and published papers. It contains information and tips on how to access Augmentative & Alternative Communication, (AAC), different types of AAC and how to model language. It explains why current guidelines do not reflect the evidence base for best practice and importantly it signposts readers to further information.



We hope that the booklet will help parents and professionals work together to enhance the communication skills of our children and adults with Angelman Syndrome. Obviously the information contained in the booklet is relevant to many others so we hope that teachers, Speech & Language Therapists and other professionals will appreciate and use the booklet with all for whom it is beneficial.

ASSERT would like to thank Tracey Campbell for taking the time to find and collate the information on behalf of ASSERT and for writing it in an easy to understand format. Tracey is mum to Leia (AS UPD). She became involved with communication after the 2014 ASSERT conference and has successfully implemented PODD for her daughter. She has worked with local schools and helped other children in the area of E. Renfrewshire, Glasgow, to access and implement full language systems. We would also like to thank Rosie Clark and Livvy Hepburn for editing the 2nd edition, Dan Hasler for his help with the graphics and all the professionals and parents out there who share their knowledge and expertise so freely.

Extra copies of the booklet can be requested by emailing assert@angelmanuk.org.

Communication and Angelman syndrome

My AAC Journey by Tracey Campbell

This was a Facebook post I made in response to many people commenting on our AAC journey at the ASSERT conference.

Over the weekend many people have said "Wow, I love what you are doing", "That's amazing" and asked "How have you made it work for you?" So here is the truth behind our AAC life.

2 years ago ASSERT, Mary-Louise Bertram and Erin Sheldon changed our world. They spoke and I listened. I made it my number 1 mission to help Leia to communicate. This was to the detriment of other things at times. But, I firmly believe that participating in life as fully as possible requires language. I believe Leia has a lot that she can contribute and that she deserves to be given as good a chance as possible to achieve this. We can catch up with the other stuff.



- I joined as many groups as I could on Facebook and people helped me anytime I asked.
- I learned to use the book.
- I started taking the book everywhere.
- I started using the book.
- I gradually built in times when I would use it and built it up.
- I set targets that were small and realistic.
- Leia has 2 siblings, 1 older 1 younger. They make fantastic communication partners and it means generally there is someone else to model to when Leia appears to/doesn't pay attention.
- We have good support for Leia from grandparents and carers.
- We have good support for us from friends that believe in us, Leia and communication.
- Leia has great friends in school and outside who use her communication system with her.
- Leia got it quickly, that helps to keep us going and with buy in from others.
- Leia had no major visual or motor skills to overcome.
- I am really determined.

Here are the things that made it easier for me:

- I already had a book.
- My husband and family believed me and in Leia.
- Leia now has a fantastic school team who don't question me, they listen and are willing to try things I suggest.

We are not magical, it has taken two years of hard work and determination to get to this point and we still need to keep going.

To begin with we sometimes forgot to take the talkers with us.

Some days go by and I have not modelled a single thing.

I still have ALD's on my laptop (now broken, eek!) that I haven't printed.

We live in a busy chaotic life and it can be hard, it's not all the rosy Facebook life that people see.

Whatever I do isn't enough, I can never hope to achieve the same amount of Language Input that I have given my other children.

I have stopped letting the guilt from these things become apathy, any modelled word is better than no word.

That's it, simply we do. I am not perfect but I do because as Yoda said there is no try.

So if you are on an AAC journey at whatever that stage, do something today. It is hard but it is worth it.

Communication Matters

Tracey Campbell attended the Communication Matters conference on behalf of ASSERT.

Here is Tracey's summary of the event:

Dr Angharad Beckett, Associate Professor of Political Sociology and Deputy Director of the Centre for Disability Studies in Leeds started formal proceedings with the Monday morning plenary. She gave an overview of Disability Rights and the changes in the past 30 years. It was an interesting talk with a real insight into just how far we have come and yet we still have a way to go. Something we can all relate to. The best way to help:

Education is the most powerful weapon we can use to change the world. Nelson Mandela

Woodlands school in Leatherhead has introduced literacy across the board for all children. One of their most successful strategies is the introduction of a reading circle where the older students read to the younger pupils. This has resulted in increased interest and ability for all involved.

Jennifer Marden introduced Core Word Classroom a free new resource from Assistiveware, the makers of Proloquo2Go. The resource teaches how to use P2Go but it would work for any core word system easily and can be adapted for PODD, in easy to manage chunks. The free downloads include planners, modelling guides, displays and a guide to 5 minute fillers, easy tasks that can be done easily and quickly to maximise time using the communication system.

www.assistiveware.com/assistiveware-core-word-classroom

Did you know that you can download a free copy of compass editing software with PODD page sets. The software works in the same way as the app but has no voice output. It is useful for editing more easily and without needing access to the Speech Generating Device and it can be used with smartboards!

www.tobiidynavox.com/support/compass/

The very best thing that happened at CM was that not only did I get to meet and have dinner with Gayle Porter, the creator of PODD, she gave me her commemorative coaster and signed it for me. I was very fortunate as she can't sign things in Australia anymore as she gets mobbed!

The Tuesday afternoon plenary session was by Martin Pistorious, the author of Ghost Boy. Martin is an AAC user and Ghost Boy his autobiography. It's a heart wrenching but worthwhile read. A very befitting ending to the conference to remind us all just how important it is that everyone be given access to a robust

communication system.

Gayle gave a talk entitled "Engaging Parents to Interact Using AAC" here are some good tips from that talk. Nobody taught you how to communicate; you learned it through natural experience.

Try not to think of communication as a way of learning everything the user knows and feels, it is impossible to know everything that someone knows. When was the last time your mother knew all the thoughts in your head?

Remember that we all use lots of different ways and tools to communicate; communication books, speech generating devices and aided language displays are part of that.

If too little language is given it leads to frustration, too much and it can be overwhelming. It is much more beneficial to introduce a new language at pace that suits the people who are modelling the system, along with strategies to find more when ready.

For AAC implementation to be successful it needs to be all about the interaction. If you are thinking about the AAC user and their interests then the experience is likely to be more fun, and it is more likely to be learned from and repeated.

Using AAC is different not difficult, you can do it!



Meet the Experts Q&A

- Livvy Hepburn

We would like to introduce you to one of our experts – Livvy Hepburn. Livvy teaches at a special school in Surrey and is currently training to be a PODD trainer. Some of you will have met Livvy at our conference or maybe on a PODD course. We have put a variety of questions to Livvy and we hope you enjoy reading her answers.

How did you end up working with individuals with AS?

I have worked with several children with AS as a teaching assistant and subsequently as a teacher in 2 schools for children with SLD, however through my role supporting PODD training in the UK with Rosie Clark, I have met many families of children with AS and have had the pleasure of working directly with many of the families and their children.

What is the best thing about your job?

The incredible kids and families I get to spend time with and have the opportunity to meet. It's hard to pinpoint the best thing about my job - I fully believe that I have the best job in the world. It's hard at times but I cannot see myself doing anything different.

What is the worst?

I wish I had more hours in the day and always think there is more that I could do!

How did you first find out about PODD?

I found out about PODD when I was working as a teaching assistant.

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

Not a clue!!!!!!

What is your best/favourite communication story/journey?

A girl in my class has AS, she had been using PODD for around a year and had recently received an iPad with the compass app on. It was all fairly new but she wowed me one day whilst I was reading a story to the class. She turned up her iPad to 'yell volume' before saying 'Boring. I want a rest'. I could have been deeply offended that my story was boring (maybe I was a little!) but really I was just so excited to see that we had given her the words to complain. How powerful it is for a child with complex communication needs to be able to interrupt their teacher and say it's boring! I wonder how many of the other children in my class wanted to say that too! I haven't read that story again!

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

Success with PODD takes many forms. I have worked with children who have not yet used PODD expressively but I still have open expectations that they may do some day and I feel that the child will have gained benefits from the aided language input in terms of supporting their understanding of what is going on and the world around them, often reducing anxiety levels. What I do know is that if you don't try then you never know what somebody is capable of.

Where can people turn to for advice on starting an Augmentative Alternative Communication system if they can't get on a PODD course?

Facebook is an invaluable resource with so many wonderful parents, family members, AAC users and professionals who have a lot of advice to give!



People with Angelman Syndrome generally have a great sense of humour. What is your funniest story?

Probably when I was chatting with my class using PODD, I commented that one of my support assistants had had her hair cut and used a child's book to model 'opinions - I think it's lovely' With a very knowing and cheeky glint she pointed to 'ugly'. Unsure if it was a symbol she knew, recognised and had selected on purpose I told her what the symbol said and gave her the opportunity to say another word but she was 100% certain that this was the word she wanted to say.

What did you think of your first ASSERT conference?

What a conference! The second I walked into the hotel I could sense that I had walked into a positive, buzzing atmosphere. It was wonderful to be surrounded by all those families and experts - I would definitely be keen to come along again. You can see just how much hard work and thought has gone into organising such a well-attended and successful conference!

Did you take anything away from it?

The quality of talks that had been organised were fantastic and I learnt a lot.

Have you any new projects you are currently working on?

I have almost finished my work towards becoming a certified PODD trainer so that is exciting! I am also working on implementing balanced literacy instruction and the four blocks approach with my class after attending the fabulous five day literacy intensive course with Jane Farrall and Sally Clendon in April. It's an

exciting learning curve for me and it's been great to see many successes with my pupils even so early on in the process.

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

As strange as it seems, my work feels like a hobby and a lifestyle to me rather than a job. Alongside that I love travelling, being by the sea, going out to eat more often than I should and catching up on sleep whenever the opportunity arises!

What is your motto for life?

My favourite quote that sums up my view of life would be 'life isn't about waiting for the storm to pass, it's about learning to dance in the rain'

What do you always keep in your handbag?

My handbag seems to be constantly full of empty food wrappers and old receipts. It's no wonder I can never find what I am looking for.

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

So many children I have worked with have exceeded my expectations - it's so important to have open expectations, don't set limits and recognise that we never know just how much a child is able to understand.

What is your number one tip for a parent?

Don't be too hard on yourselves!!

Leia Campbell's Stories

Here is a selection of stories that Leia has written using her PODD book. She has done some at school and some at home, the ideas and words are all her own with a few conjunctions added in by me or her teacher. She has written some of them spontaneously and some after being given a particular topic.

It has taken us a long time to get to this point both modelling consistently and by making up story books for her to share using mainly the app Pictello. Her first story was written on her birthday earlier this year and came as a big surprise to us all!

Parent's night

Gran and Grandpa go to Abbie's parent's night. Abbie has been sneaking second lunches and going home for extra chips. Gran and Grandpa are not happy.

Story and Title by Leia

A really exciting day

Archie and Laurie are going to make a movie. In the movie they jump and bend. Then they go for a swim and a float in the swimming pool. Last they go to the amusement park. Pippa accidentally smacks Finn. Stop.

Dolphin Tale

Once upon a time there was a dolphin. Abbie met the dolphin at the swimming pool. Cara was there too. They played games together. They were happy and laughing.

When I went to the park

by Leia Campbell, UPD AS, Aged 10, using PODD

When I went to the park with Gran and Grandpa we saw:

- 1 Cara catching
 - 2 frogs hitting
 - 3 Paddington's pretending
 - 4 dad's thinking
 - 5 j's getting ready
 - 6 Emily's talking
 - 7 Rachel's loving
 - 8 Abbie's trying
 - 9 astronauts falling
 - 10 spiders standing still
- And some books.



Amelia (AS del+) looking at Leia's PODD book

Tips for approaching school & IAD

Tips for approaching school about communication by Tracey Campbell

When you and the professionals around you are not in agreement about the best way for communication it can be very difficult. The most important thing for everyone to remember is that it should be the interests of the individual that are the common goal.

It is more productive if you can maintain positive relationships, so it is helpful to begin with everyone stating the things they think are working well. Hopefully there should be some commonality here.

Once these have been looked at everyone can give their ideas of what is not working so well.

Next each person should think about where they want the communication journey to be going.

It would be helpful at this point to review all the ideas. If they are all very similar, great. If not some extra work will be required here before moving on to the next stage. If there can be a calm and sensible discussion where people are able to explain their ideas, this may be all that is needed. It is worth remembering that professionals do have experience with many children, sometimes over a long period of time. They do have expertise that you will require them to share with you so it is really worth staying positive and trying to work together. That said you can politely remind your professional that communication practices have been changing and that there is now a large evidence base to support full communication systems and aided language simulation. Parents are the expert on the person in question so that is worthwhile for everyone to remember.

Also please reassure everyone that the introduction of a full communication system is a long term strategy so it will not lead to the immediate abandonment of the good communication practice that is being used currently.

Likewise for the beginning of the journey it is all about the team learning the language - there is no expectations on the person themselves to use the language.

When your ideas and thoughts have come together you can then move on to discussing the strategy. How are you all going to take the best practices of the moment and get towards the future target?

This is where professional advice can be invaluable. They may even have had experience of introducing a full language system before. It is unlikely to be a smooth road even after you all decide that a full language system is the best idea.

This is where a team approach of sharing good practice tips between one another can really help. You are all learning a new language so it helps to do it together. Likewise the inevitable troubleshooting will be easier to do with more people involved.

Thanks to Erin Sheldon for sharing her ideas.

Not everyone is going to be able to change the minds of their teams, if this happens to you don't feel guilty about it. You are trying your best and that is what matters. As Erin says "What matters most is that our kids know we believe in them and that they see us keep doing our best."



International Angelman Day – Save The Date !!!!

As you probably all know by now, International Angelman Day is February 15th. In 2017, this falls on a Wednesday and so our usual get togethers will be organised either the weekend before or the weekend after. So at the moment, please keep both weekends free. A letter will be sent out early in the New Year with a list of all the events and you are welcome to choose whichever event you would like to attend.

If you have any suggestions for venues then please get in touch assert@angelmanuk.org

EHCPs – your questions

Our special educational needs (SEN) team at Boyes Turner solicitors were delighted to be invited to attend the biennial ASSERT conference on the weekend of 3-4 September this year. Our Head of Education, Laxmi Patel, gave a keynote speech on what the new SEN legal system means for children. Laxmi also ran workshops to help parents and carers understand what a good Education, Health and Care Plan (EHCP) should look like, how to avoid any problems with its drafting and how to successfully challenge the content of the EHCP once finalised.

Here are a few of the questions we were asked at the event.

Does my child need a Statement or EHCP?

There is a legal definition for special educational needs but, in essence, if your child finds it harder to learn than the majority of their peers and continues to struggle despite extra targeted support, then they are likely to have special educational needs (SEN). Parents may feel that their child's school is understanding and supportive – so why the need for a Statement or EHCP?

Both the Statement and EHCP are legally binding documents that enshrine a child or young person's right to support that is listed under the educational parts of the document. Both will detail your child's educational needs and the support that they need to meet those needs and both are circulated to everyone teaching your child so that they are all clear about what they need. As well as educational provision, Statements and EHCPs will also set out non-educational needs and provision. This includes health and social care needs and support.

The 'home' local authority has a duty to provide the support that is set out under the educational parts of the Statement or EHCP. For Statements, this is under Part 3. For EHCPs, this is under Section F. It is the local authority that the child lives in that has the responsibility, not the local authority that the school or college is in, if that is different to the 'home' local authority.

Sometimes local authorities will carry out an assessment of your child's needs and not issue an EHCP. Instead, they will issue another type of document that looks very much like an EHCP but is called something else, for example, we have come to know of documents called My Plan. Be very cautious about accepting this. My Plans are not enforceable and do not give any right to your child to support. Parents cannot challenge the content of other documents.

A Statement or EHCP can provide some confidence that your child will receive support at a time of squeezed local authority budgets.

How will my child's Statement be changed to an EHCP?

To transfer from a Statement to an EHCP, a transition process must be followed. Parents must be given at least two weeks advance notice of the start of the process.

As part of the transition process the local authority has to complete a new EHC needs assessment which must include information gathered from parents, the child/young person, the school/college, therapists, medical professionals and social care. This would be similar to the full assessment that was carried out when your child first

got a Statement. Statutory guidance states that the local authority does not have to seek any advice or arrange assessments where an assessment has been carried out recently and if you, the school and relevant experts all agree that the findings are sufficient for the purposes of an EHC needs assessment. Note that you all have to agree so parents can insist on the assessment.

The whole process from the start of the process to getting a final EHCP should take no more than 18 weeks. However, local authorities are struggling with adhering to the timetable. Often, this is because local authorities have only six weeks to obtain updated reports. Health and social care are often unable to respond within the timeframe. Our advice to parents is to keep an eye on the time. Find out what the delay is. Our advice is that it is often better to have a detailed EHCP rather than rushing the drafting of the EHCP with old information.

Until the assessment and new EHCP is finalised, the Statement of SEN remains in place and is enforceable.

How much funding do schools get for SEN support?

Mainstream schools

SEN funding consists of three elements:

1. The Age Weighted Pupil Unit (AWPU) –

this is the basic/core sum that all schools receive per child, regardless of their SEN. The total sum a school receives is dependent on the total number of students in the school. It is generally thought that the sum equates to between £2,000 to £4,000 per student, with primary schools receiving the lower end of funding. This is the core budget per student and is used to make general provision for all students in the school.

It is important to remember that special educational provision is any support that is additional to or different to provision that is provided for all students i.e. provision that is expected to be provided from the core AWPU.

2. Additional support funding (ASF) – schools are given an additional sum to meet the needs of children with SEN. ASF is based on a formula agreed between schools and the LA. The formula is based on various criteria including a social deprivation index which includes the allocation of more funding to, for example, schools with more children on free school meals. ASF comes from either the ‘designated schools grant’ or ‘schools block’ and forms part of the school’s ‘notional SEN budget’. All these terms could be used to describe this element of funding. Currently, the government suggests that schools use up to £6,000 for a pupil with SEN. Schools can choose to spend this money as they

think best to meet the needs of all their children with SEN. The LA can set out what it expects schools to provide from this funding but is unable to enforce it.

ASF is given to maintained schools by the LA and to academies and free schools by the Education Funding Agency (EFA).

3. Top-up funding – if a student with SEN requires funding over £6,000, then schools (maintained, academies and free schools) can request additional funding from the LA’s high needs block. If agreed, the school must use this funding for the individual student.

Special Schools

Special schools (maintained, academy and non-maintained but not independent schools) are provided with base SEN funding of £10,000 per student (the total sum based on an estimate of the predicted number of places in the next academic year). If required, schools can request top-up funding from the LA (if a maintained school) or the EFA (if an academy or free school).

Alternative provision

Pupil referral units are funded similarly to special schools, but with a base funding of £8,000 per place.

Post-16

SEN funding will include funding for the base programme/course according to the national 16-19 formula, with an additional £6,000 for each planned high needs place.

This information has been kindly provided by Boyes Turner Solicitors.

If you want to have an informal chat with one of Boyes Turner’s SEN solicitors, then please contact the team on 0118 952 7219 or advice@senexpertsolicitors.co.uk.



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

In my hand I have something called... well, I don't exactly know what it's called.

It's a sort of magic, crinkly, looky, holdy, thing. But it's my absolute, all time, best-ever, favourite thing in the entire world (since Pink Ball). It's pink and it has crinkly-dangly bits and you can hold it in your hand and – sometimes – it makes music, but best of all it has a looky bit that shows you little pictures.

It's not a toy exactly, it's far more than that. It has magical powers. I don't mean the pointy hat, wavy-wandy stuff that Curly Top does with his cape and his playing cards – I'm talking about real, absolute power, full-on magic.

Do you ever have those days where there's just too much world?

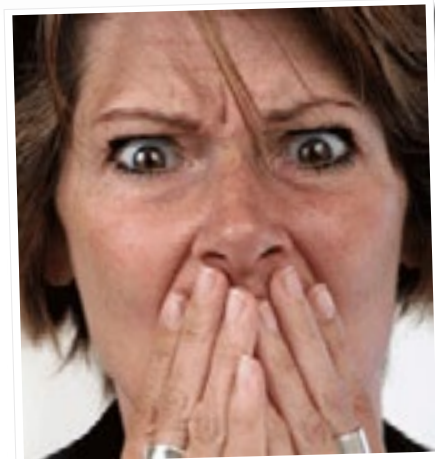
Well, what the magic, crinkly, looky, holdy, thing does is it takes the entire multi-coloured, loud, weird, flashing, confusing world of shouty, flashing, bright stuff and shows you only the teeny-tiny most important bits so that you can study them and see exactly what's going on without all the rest of the overwhelming too-much-stuff-ness of life. And if it isn't showing you a teeny-tiny bit you like, you just tip it slightly and it shows you a completely different teeny-tiny bit. How cool is that?

Sometimes I use it to look at Smiley and he looks back at me and we both do looking at each other for a while and we just know that we're two guys sharing a guy moment. Or sometimes I look at Frowny when she's busy doing all her busy stuff. Ok, she's usually far too busy to look back at me, but sometimes I do catch her looking very quickly. And even if she doesn't look my way I like to watch her because I know the world is really very alright indeed when I can see her doing all her busy things.

Sometimes I look at Curly Top and his friends, running around and being very shouty. He never, ever looks at me because he's too busy being really happy, but that's ok too.

The best place to do looking is while I'm sitting on the fourth stair up from the bottom. I've tried the one above and the one below but the fourth step is at the exactly-most-rightest height to give you the best view of everything that goes on in the house.

I've tried using the magic, crinkly, looky, holdy, thing in the car but the pictures move too fast. They're quite pretty and I sometimes look at it for a long time, but I can't really make any sense of it. I've never been allowed to take it to school but I don't think it would work very well there either; at school people are always trying to talk to you and make you do stuff. For the magic to work properly you need peace and quite and for people to leave you alone for a bit.



It used to make a noise – I think it was supposed to be music – it sounded really tinny but I quite liked it so I just kept my finger on the button. But, after about three or four days of me sucking on it, the music stopped for absolutely no reason and then it never made any more noise. I handed it to Smiley for some fixing and he tried the clever screwdriver thing but lots of sticky, wet, brown stuff came out of the back. So he gave it a wipe and a squirt of some smelly stuff, replaced the lid and gave it back to me. Then it didn't make any more music for ages, until one day it just started again, all by itself.

Actually, now I come to think about it, there's another weird thing: I've had the magic, crinkly, looky, holdy, thing for as long as I can remember, but sometimes I forget where I put it and it goes missing for a few days. But when it comes back it sometimes looks much shinier and smells funny and the crinkly bits are much crinklier and the tinny music noise works again. Maybe sometimes it just needs to have a rest for a while for the magic to come back.

Even weirder, I once saw another magic, crinkly, looky, holdy, thing at the bottom of my toy basket... but this one was all scratched and you couldn't see in the looky bit very well and the crinkly things had come off – so I knew it wasn't mine.

Spooky.

Are you IT?



As ASSERT continues to grow, and the IT projects are becoming more and more important to our work, we are looking to appoint a new trustee to meet the digital challenge. The trustees of ASSERT work as a team, but each have their own individual strengths to lead on. The role is obviously voluntary and would suit someone with good IT skills/knowledge/background. The position would be responsible for reviewing our current offer and service provision, data legalities, identifying possible improvements and helping to deliver the team performance in this social media driven digital age.

If you feel that you can spare a few hours per week to help us take ASSERT into the future, then please contact assert@angelmanuk.org with details of your interest/experience.



Request to all parents and carers from Dr Dan Hindley, Consultant Community Paediatrician

During discussions at the recent excellent, friendly conference in Coventry a number of parents and carers mentioned that the person they look after with Angelman syndrome will often collapse / head nod / have an 'absence' or 'seizure' in response to a specific stimulus such as eating, taking their top off, having their face wiped, getting dressed etc. There was also a recent paper which described people with Angelman syndrome collapsing during bouts of laughter.

Such episodes have not been widely acknowledged or characterised which has set me thinking!

So if you know of an individual who regularly responds to an environmental stimulus or an emotion (could be anything – music, having a shower, tooth brushing, loud noises, flashing lights, laughing, crying, excitement) with a 'funny do' which you do not think is behaviour perhaps you could drop me a line with a brief description and your contact details, and we could look into this in a bit more detail?

With many thanks
Dan

Dr Dan Hindley
Consultant Community Paediatrician,
Halliwell Children's Centre, Bolton, BL1 3SQ.
dan.hindley@boltonft.nhs.uk

VISION WITH ANGELMAN SYNDROME

Dr Gael Gordon

Senior Lecturer, Optometrist and Clinical Lead (Additional Support Needs Clinic), Glasgow Caledonian University

People with learning disability are ten times more likely to have problems with their eyes or their eyesight than the general population. The good news is that most of these problems can be managed. Unfortunately, however, people with learning disability are far less likely to be attending the optometrist regularly or to be provided with glasses. This may be because eye care is well down the list of priorities when managing the care of someone who has complex health and care needs. Families and carers may sometimes be unaware of the importance of regular examinations but they may also worry that an eye examination will be difficult to conduct on their child. There are of course challenges in examining the eyes of someone with Angelman syndrome but not being able to read or to talk should not be a barrier to good eye care; optometrists have a range of tests and techniques that they will use to assist them to test the eyes of your child.

People with Angelman syndrome are at risk for a number of vision and eye problems which their families and carers should be aware of.

Ocular hypopigmentation

Melanin is the pigment that gives our skin, hair and eyes their colour. The pigment in the eyes acts like a black-out curtain. Without sufficient pigment, light scatters in the eye. This is uncomfortable and can make it harder to see. Ocular hypopigmentation is the condition where there is insufficient pigment in the eye. It is a well-recognized and common feature of Angelman syndrome. The degree

of the hypopigmentation varies in Angelman, however, and some people will not experience any symptoms. If your child does experience difficulty with bright light, they should ideally wear sunglasses on bright days and possibly have tinted or photochromic (light-adaptive) spectacle lenses in their glasses if worn. If your optometrist considers that a tint is clinically necessary then the NHS will make a payment towards it (in many cases, the optometrist will ensure that this covers the full cost).

Myopia (Short-sightedness)

Myopia is a condition of the eye where there is a mismatch between the power of the optical components of the eye and the length of the eyeball. This results in unfocused light reaching the back of the eye (the retina) because the eyeball is too long. People who are only slightly short sighted can see quite well close up but need glasses for longer distances (such as watching the television or going to the cinema). People with Angelman who are only slightly short-sighted may not feel enough benefit from their glasses to want to keep them on. This is okay. The risks attached to not wearing glasses are very small and they may often find close tasks easier without them. There are reports, however, that high myopia (where very strong glasses would be needed) may be much more common in Angelman syndrome than in the general population. People who are very short-sighted need to wear glasses all the time and will not have clear vision at any distance. In our clinic, we find that people with learning disability who have very poor sight without glasses often tolerate their glasses very well because they benefit so much from them. A robust spectacle frame is to be recommended. Some of our patients wear frames that have been designed for sport. These are strong and flexible and may be worn with a head-band for extra security. For many patients, wearing glasses full-time straight away is not going to be an option. It is reasonable therefore to start building up the wearing time slowly. For some people only a few seconds will be tolerated at first. The aim is to try to increase the wearing time every day until the patient is comfortable wearing them for long enough to benefit from them.

¹ Cost should not be considered a barrier to good sight either. All children and young people in full-time education in the UK are entitled to a free eye examination. Adults with Angelman will also be entitled to a free eye examination because of the benefits that they receive. Both children and adults in receipt of benefits are entitled to a voucher from the NHS that is to be used towards the cost of any spectacles that are required. Most practices have a range of frames that can be provided free with the voucher.

Hypermetropia (Long-sightedness)

Like myopia, hypermetropia is a condition of the eye where there is a mismatch between the power of the optical components of the eye and the length of the eyeball. In the case of hypermetropia, the eyeball is too short. A recent study of patients with Angelman found that 3 out of 4 were long-sighted. This is about 3 times more than you would expect in the general population. People who are longsighted may struggle to see close up and for those who need stronger glasses, they may also struggle at distance too. Young people with a small amount of hypermetropia may not need glasses because they are able to adjust the focus of their eyes. It is important to be aware, however, that a common side effect of anti-epileptic medications is a reduction in this ability to change focus. These children may need to wear glasses and especially for close up (for example when using their communication aid).

Strabismus (Squint)

The focusing system that allows the longsighted child to keep their vision clear and sharp is coupled to the system that allows us to converge (or cross) our eyes to read or look at things near at hand. For this reason, the extra effort that a longsighted child needs to keep things clear may also lead to a convergent squint (where the eyes turn in). Providing glasses that corrects the long-sightedness in these children should also correct the squint.

Divergent squints (where the eyes turn out) are also common in Angelman. Divergent squints are relatively rare in the general population but common in people with learning disability. Divergent squints are often more noticeable than convergent squints. It is possible to correct a squint surgically but, unfortunately, the eyes do tend to drift outwards again with time. Your child is unlikely to be disturbed by the squint – they will almost never experience double vision – and the ophthalmologist (eye doctor) may well advise against surgery.

How can I ensure that my child gets the best possible eye examination?

As with all things, your child will have the best experience when they and the optometrist are as prepared as possible beforehand. All

optometrists should be able to conduct an eye examination on your child but some will have more experience and some will have a special interest. Ask around for recommendations, phone the practice to check or search the SeeAbility website:

www.seeability.org/our-services/find-optometrist/

It is a good idea to bring your child into the practice to meet the staff on another day prior to the test. It can also be very helpful to practice shining a small torch in your child's eyes. Bright lights feature a lot in the eye examination and getting used to this sensation can reduce the anxiety that your child might feel around the eye test. SeeAbility also have a range of resources to help prepare your child for the eye test: www.seeability.org/sharing-knowledge/?book=having-an-eye-test. This includes a short easy read booklet explaining the eye examination to share regularly with your child in the lead up to the appointment. There is also a questionnaire that you should fill in to give the optometrist a good idea about your child and their vision before they start the examination.

Try to arrange the appointment at a time when the practice is quieter and when your child is likely to be at their best. If your child has visited the practice ahead of the appointment, make sure that they will be seen by the same members of staff on the day of the appointment.

Finally, even the most experienced optometrist may be unable to conduct a full eye examination in some patients with complex disabilities and/or very challenging behaviour. For these patients, occasionally, it is necessary to make a referral to the hospital for an eye examination under sedation. This is done only very rarely and where there are reasons to be very concerned about how well the patient sees. The best person to make this decision is the optometrist – it is never a wasted appointment. Over the years, moreover, and as we build up a relationship with them, we have found in our clinic, that in the most complex of our patients we will often manage to achieve a little more on every visit. So if this is the case, don't be discouraged please keep attending your optometrist.

Easy fundraising

With Christmas just around the corner 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 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

Let Your Voice Be Heard

The Cerebra 1,000 Families Study

What is the 1000 families study?

The 1000 families study is a large research project wishing to hear about the experiences of mothers, fathers and family members of children between the ages of 4 and 11 years with a learning disability and a range of other conditions including Angelman Syndrome.

Who are we?

We are a group of researchers from the Cerebra Family Research group based at the University of Warwick in Coventry. The study is funded and supported by the Charity Cerebra who support children with neurological disabilities.

Why is family research important?

Families of children with a disability face more stresses and difficulties than other families. There are a lot of things which families have to do on a day to day basis to support and care for their child with a disability. We need to understand the challenges that families face in order to support them, but also better understand what families' more positive experiences may be, and how different members of the family are coping. It is especially important to hear from families in order to inform future information, support and interventions for children but also parents and family members. Taking part in research can be a positive experience where your views can be expressed and valued. Please view our research video to learn more about why family research is important.

How can I take part?

The research involves taking a survey which takes about 20 minutes to complete. This can be completed online or you can request a paper copy to be sent to you by freepost. If you would like any more information please visit our website (details below) or email a member of the team at familyresearch@warwick.ac.uk. You can also follow us on Facebook or Twitter.

www2.warwick.ac.uk/fac/soc/cedar/cerebra1000families/surveyrequest

AS Clinic

The Angelman Syndrome clinic in Manchester now has a new member, Jenny Pemberton, who is a senior Speech and Language Therapist with direct experience of working with both children and adults with AS. It is great to have Jenny's input alongside the other professionals in the team.

There is a waiting list for clinic appointments so if you are discussing a possible referral with your GP or consultant please be clear about the specific issues you would want to discuss and most importantly please let the clinic administrator know if you decide you do not want to take up the appointment once it has been offered. Contact details will be on your appointment

letter. With only three appointments available at each clinic it is frustrating and costly when a patient doesn't attend. Even if you need to cancel at short notice it may be possible to offer the appointment to another family who would really benefit from attending.

If you would like to know more about the clinic or need support from ASSERT in the referral process please contact us via the telephone helpline 0300 999 0102 or email assert@angelmanuk.org. In some instances ASSERT may be able to help with the cost of attending the clinic for families who live some distance from Manchester.

Scottish Conference 2017

SCOTTISH CONFERENCE

As mentioned in the last newsletter, ASSERT have arranged the very first conference to be held in Scotland. The dates for your diary are as follows: Friday 11 – Sunday 13th August 2017. The venue is The Golden Jubilee Conference Hotel, Beardmore Street, Glasgow, G81 4SA.



Golden Jubilee Hotel



Scottish Conference

The conference is open to all and families from anywhere in the UK are welcome to attend, however 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. Letters will be sent to families in Scotland in 2017. For any families living outside of Scotland and who want to attend, please look out for the details on our website and Facebook page.

If you have any questions or suggestions please contact Catrina.fraser@angelmanuk.org or Mairi.mcgaw@angelmanuk.org who are the trustees for Scotland.

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

Family Fund Grants

Family Fund is the UK's largest charity providing grants for families raising disabled or seriously ill children and young people. Last year, we provided 89,423 grants or services worth over £36 million to families across the UK. We aim to give families raising disabled and seriously ill children and young people the same opportunities as others by providing grants for essential items such as washing machines, sensory toys, family breaks, bedding, clothing and computers.

We know that it can be a struggle financially, emotionally and physically for families raising a disabled or seriously ill child or young person, and these grants help break down many of the barriers families face and ease those additional daily pressures.



Here's what one parent had to say:

"We applied to Family Fund for a Lay-Z-Spa because it was something we could use together as a family at home. Bethany really benefits from using the hydrotherapy pool at her school, but she often can't take part as she gets a lot of infections, so we thought a having this kind of thing at home would be great for her."
"Bethany absolutely loves being in the Lay-Z-Spa! We're using it to do a lot of her therapies, it really helps her. We can't take her into a regular swimming pool because she has a heart condition, but because the spa is nice and warm we can get a lot of therapy done, and she just thinks it's brilliant."

"Without the grant from Family Fund, we wouldn't have been able to afford this kind of thing. She misses out on using the pool at school because of infection, so it's really great that we have a space at home now which we can use for her hydrotherapy. The help that Family Fund has given us has just been amazing."

Find out more

Visit www.familyfund.org.uk to apply for a grant, or why not join us on social media at:
Facebook (facebook.com/familyfund)
Twitter (@familyfund)
Instagram (www.instagram.com/family_fund)

Conference Photos 2016

For those of you who are regulars at our conference, you will be well aware of our fabulous photographer Rob Chadwick who comes along to take the most amazing photos of our children. For those of you who came for the first time in 2016, Rob Chadwick is just the most wonderful photographer who captures our children perfectly. He has photographed celebrities, politicians, even Royalty ... then he comes along to Coventry every 2 years! Rob gives ASSERT and our families full rights to the photos so you can print as many copies as you like. If you would like a copy of your child's photos then please send a small donation to ASSERT. You can either send a cheque into ASSERT or you can pay directly into the ASSERT bank account. The photos can be uploaded to Dropbox, or can be sent on a DVD. If you would like your child's photos then please contact lisa.court@angelmanuk.org.



ASSERT Meets Star Wars

Gareth was well aware of the potential massive exposure that could be given to ASSERT if he could link it into Star Wars. Gareth approached Lucasfilm and asked if they would produce an awareness video and thankfully Lucasfilm kindly agreed to help. We were invited to the set of Star Wars so that they could film Gareth and Ella together. We had a fantastic day on site watching the scenes being filmed and meeting the stars. As you can imagine, it was quite a challenge keeping Ella quiet to allow certain shots to be filmed – that's where the unlimited supply of sweets, biscuits and chocolate came in handy from the catering tent !!



This film has been produced at no cost to ASSERT. Lucasfilm have very kindly provided all of their services for free – from the cameramen who filmed us on set to the actors who stayed late to allow Gareth to be filmed with Ella and the editors who put the film together.

This is an amazing short film and although I am very biased I am absolutely thrilled with the end result. This has been available for a couple of weeks now and the response we have received has been absolutely huge. It has had a big impact on so many people. I have been told so many times how watching the film made them cry!

If you haven't had chance to watch the film, please do so. If you go to You Tube and search for "ASSERT Rogue One" you will find it. Enjoy!

Lisa Court

Darth Elvis and the Imperials



Following on from the success of the awareness film, ASSERT were contacted by a band called Darth Elvis and the Imperials – a Star Wars themed Elvis tribute! The band have written a Rogue One themed Christmas Song to be released on 16th December to coincide with the release of the film. They are very kindly giving all proceeds from the single sales to ASSERT. So please look out for this song. If your music genre combines Star Wars and Elvis then you couldn't ask for more! We would like to say a huge thank you to the band for contacting us and wanting to help raise awareness and funds.

Fundraising

As usual, our fundraisers have done a brilliant job raising lots of money for ASSERT. We are so grateful to everyone who raises money for our charity, however big or small the amount. Every penny really does make a difference.

Our London Marathon Runners this year have raised the amazing total of just over £13,000. That is such a massive amount of money. Thank you! Our runners were:

Ben French | Alex Moon | Craig Turlington | Fearghal Gallagher | Nick Plank

Paul Winter was also due to run the Marathon for ASSERT but had to pull out during training due to injury however Paul had raised funds for ASSERT prior to his injury.

The London Marathon places for 2017 have already been allocated. However, we have purchased a selection of the 'Great' races which are around the country and through the year. We also have places in the London to Surrey 100 mile cycle ride. Please ask your family, friends, colleagues if they would like to take part in one of these events and raise funds for ASSERT. For more details on any of the events or to put your name forward please contact lisa.court@angelmanuk.org.

Great North Run	10th September	13 miles	10 places
Great South Run	22nd October	10 miles	5 places
Great Birmingham Run	15th October	13 miles	5 places
Great Manchester Run	28th May	10 km	5 places
Great Yorkshire Harrogate Run	July (date TBC)	10 km	5 places
London to Surrey 100	30th July	100 miles	6 places



Craig and his inspiration, his nephew



Craig and his medal



Tim Durkowski & friends – South Downs 100 mile walk

Tim and his friends (Matt, Gareth, Mike and Mark) walked a whopping 100 miles across the South Downs and they completed this in a very impressive 38 hours. Between them they raised a staggering £7,193.40.



Ian Vasey – Great South Run

Ian ran the Great South Run for ASSERT raising the excellent sum of just over £623.



Abigail Povey – London 10k

Last year I lost someone close to me, a little boy who I'd practically grown up with. Jamie was the life and soul of every room and his smile was completely infectious. I knew I wanted to do something in his memory. This year I ran my first ever 10km for ASSERT. I can't say it was easy, but the motivation was all I needed to get me round. It was so lovely to see my mum and Jamie's mum Linda at the finish line (ready with macarons and some prosecco of course)! I'm so happy to say that thanks to the support of my family, friends, neighbours (and anyone Linda could catch) we raised such a big amount for ASSERT which I hope will contribute to the amazing work they do.

Abigail



Vel Petrovic & friends – London to Surrey 100 mile Cycle Ride

Vel and his friends (Darko, Vlad and Richard) took part in the London to Surrey 100 mile cycle ride. Between them they raised a massive £4,080.93.



Fundraising



Sarah Pope – Fundraising event at Aplomb Day Nursery, Enfield

The activities that we took part in through the week were lucky dip, decorating cakes, guess how many sweets are in the jar, find the sweet in the ball pool, dressing up and a cake sale. The children and staff had so much fun. The parents were very generous with their donations and we owe a big thank you to everyone who took part. We raised £137.90.

Sarah

Christina Munsey Syresham's Annual Scarecrow Festival

Grace Wyness has recently raised £260 for ASSERT on her stall at Syresham's annual Scarecrow Festival. She had a tombola and sold bric-a-brac and gave out ASSERT leaflets. Grace has a charity stall every year and this year decided to support ASSERT in honour of Ava Munsey who has strong links with Syresham and earlier this year was diagnosed with Angelman Syndrome.



Christina

Natalie Luke and Suzanne Walker – Brighton Marathon

Natalie and Suzanne fundraised and were both due to run the Brighton Marathon for ASSERT. Unfortunately Suzanne was injured before the event and was unable to take part, so it was just Natalie who took part on the day. Between them they raised the fabulous amount of £1,090.12



Mark Duckworth – Norwich 100 Cycle Ride

Mark took part in the Norwich 100 and raised the excellent sum of £762.50

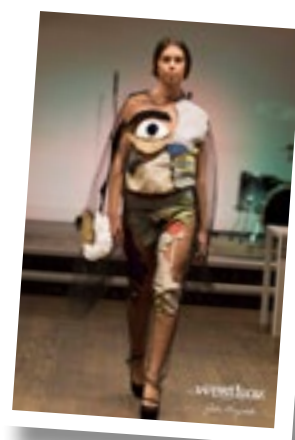


MG Trophy Championship 2016

As mentioned in the last newsletter, ASSERT were selected as the MG Trophy Championship charity for 2016. We were presented with a cheque at the Silverstone meet. One of our ASSERT mums Jenny Gray won the draw for the tickets and went along with her family to enjoy the day. We were presented with a very generous cheque for £700.

Joanna Marcella – FDC Young Designer Awards

Joanna has been supporting ASSERT for several years now – each year the proceeds of the FDC Young Designers Award are given to ASSERT. For 2016 we were given the excellent sum of £235.25.



Athena Wu - Fundraise 40

Athena Wu decided to mark her milestone birthday with raising funds for 3 charities, one of those charities being ASSERT. Athena plays in an Orchestra with Antonia Burton, and Antonia's daughter Ella has AS which is why we were one of the selected charities.

The event was a combination of a dance and an auction. By all accounts it was a very successful evening. Our third that we have received is the fabulous sum of £2,550.34.



Fundraising



Vicki Walker & brother Richard

Vicki Walker Enterprise Holdings Foundation

Vicki applied to her employers for a donation as her brother Richard has Angelman Syndrome.

Calum Barker & Angel2Angel Team – Cycle Ride

Calum Barker (whose daughter has recently been diagnosed with AS) took on the daunting challenge of cycling 250 miles from The Angel Inn just outside Peterborough to The Angel of the North in Newcastle. 35 other cyclists joined Calum for the gruelling ride. The total amount raised was split between 3 charities, ASSERT being one of the charities. ASSERT have received the fantastic sum of just under £10,000 and there may be some more still to come.



ACME Archives – Star Wars Celebration Europe Poster Signing by Gareth Edwards

ACME Archives and our patron Gareth Edwards joined forces at the Star Wars Celebration Europe in the summer to raise a phenomenal amount for ASSERT. 250 limited edition prints were produced for "Rogue One: A Star Wars Story" and these were sold at £100. The posters were signed by Gareth and all proceeds were donated to ASSERT. After tax, ASSERT have received the fabulous sum of just under £19,000.



Sponsored Events:

Craig Turlington	London Marathon
Fearghal Gallagher	London Marathon
Alex Moon	London Marathon
Ben French	London Marathon
Nick Plank	London Marathon
Paul Winter (withdrawn - injury)	London Marathon
Abbi Povey	London 10k
Shelley Cachia	London 10k
Leah Westpfel	London 10k
Julien de Bournet	London 10k
Mandy Mattison	Great Manchester Run
Pamela McCullagh	Great Manchester Run
Darren Keighley	Great North Run
Sarah Brown	Great North Run
Martin Shaw	Great North Run
Ian Vasey	Great South Run
Heather Dobbs	Great South Run
Dan Heerey	Great South Run
Jackie Shread	Great Birmingham Run
Melissa Mcgrail	Great Birmingham Run
Joe Jordan	Great Birmingham Run
Lucy McGregor	Great Birmingham Run
Linda James	3 Forts Challenge Marathon
Simon Starmer	1000 km Cycle Ride
Emily Turner	Wolf Spring Run
Teresa Ellinor	TOUGHEST Challenge
Tom Cope	Barcelona Marathon
Alex Morgan	Dom's Leaving
Clare Jonas	Couch to 5k
Lee Buckley	Superhero Run
Tom Woolley	Windermere Marathon
Paul Moran	Edinburgh Marathon
Ewan Bennie	Half Ironman
Mark Duckworth	Norwich 100
Tim Durkowski	South Downs 100 mile walk
Matt Goldsack	South Downs 100 mile walk
Gareth Traves	South Downs 100 mile walk
Michael Grier	South Downs 100 mile walk
Mark Bell	South Downs 100 mile walk
Vel Petrovic	London to Surrey 100m Cycle Ride
Darko Petrovic	London to Surrey 100m Cycle Ride
Vlad Lazic	London to Surrey 100m Cycle Ride
Richard Kinglsey Smith	London to Surrey 100m Cycle Ride
Andy Knight	London to Surrey 100m Cycle Ride
Josep Alvarez-Perez	JP Morgan Challenge
Jack Donaldson	Yorkshire 3 Peak Challenge
Matt Way	Paddle for Life 2016
Lynette Thomas	Maidenhead Half Marathon
Everis	Tough Mudder Challenge
Athena Wu	Fundraise 40
Sarah Heather-Holt	Vitality Half Marathon
Christina Munsey	Syresham Festival
Jody Jones	Jody's Big Swim
Simon Copping	Silverstone Half Marathon
Andrew Lamare	Lands End-John O'Groats Ride
Angel2Angel Team	250 Mile Cycle Ride

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...

Conference Portrait Donations:

<u>Simone Burton</u>	<u>Shelley Cachia</u>
<u>Karen Gammack</u>	<u>Vernan Hook</u>
<u>Melanie Thomas</u>	<u>Linda Holmes</u>
<u>Kathryn Wrigley</u>	<u>Tracey Fahey</u>
<u>Amanda Johnstone</u>	<u>Gemma Vicary</u>
<u>Pamela McCullagh</u>	<u>Caroline Hewitt</u>
<u>Amy Symmons</u>	<u>Sue Cherrington</u>
<u>Michelle Matthews</u>	<u>Jane Gyekye-Mensah</u>
<u>Samantha Wickens</u>	<u>Helena Bannister</u>
<u>Anna Knight</u>	<u>Katy Harvey</u>
<u>Emma Shepherd</u>	<u>Ben Dalton</u>
<u>Audrey Sinclair</u>	<u>Nicola Moore</u>
<u>Laura Henderson</u>	<u>Jessica Jones</u>
<u>Sarah Brown</u>	<u>Claire McPherson</u>
<u>Caroline Mason</u>	<u>Claire Bartlett</u>
<u>Jayne Roper</u>	

Donations!

<u>Mrs Hazel Tait</u>	<u>The Disney Store, Southampton</u>
<u>Lee Parkin</u>	<u>Giles Derry</u>
<u>Catherine Seel</u>	<u>Scottish Friendly</u>
<u>Gloria Buckley</u>	<u>Mrs B Page</u>
<u>Hansons Auctioneers and Valuers</u>	<u>Stu-Nique Fitness</u>
<u>Royal Sussex Chapter No 342</u>	<u>Mr R Fox</u>
<u>Directline Group (Katie Dineen)</u>	<u>Mary Boyle & Beedy's Bar</u>
<u>Moiria Cane (In memory of David Williams)</u>	<u>Rodney Freeman</u>
<u>Kate Pickering</u>	<u>Mr T Harrell</u>
<u>Neale Turk LLP Solicitors</u>	<u>Alun Griffiths (Contractors) Ltd</u>
<u>Karen Lancaster</u>	<u>Pete's Plaice</u>
<u>Mrs Bradshaw</u>	<u>Jolly Chippy</u>
<u>Mr and Mrs Gray</u>	<u>Aplomb Day Nursery</u>
<u>Royal Sussex Lodge No. 342</u>	<u>Riversley Road Surgery, Nuneaton</u>
<u>St Martins Primary School, Scarborough</u>	<u>FDC Young Designer Awards 2016</u>
<u>In memory of Glynis Brockman</u>	<u>Noel Protheroe</u>
<u>Emily Matthews & Robert Smyth</u>	<u>Peter Mullen</u>
<u>Academy</u>	<u>Lindsey Nicholson</u>
<u>P F Cusack Ltd</u>	<u>Lani Martin</u>
<u>Dr John Ackroyd Trust</u>	<u>Lydia Barnes</u>
<u>In memory of John Brignome</u>	<u>Gareth Edwards</u>
<u>Martin Peat</u>	<u>Alex Hutchinson</u>
<u>Nav Sanghera (IAD 2016)</u>	<u>Mundeep Lotay</u>
<u>In memory of Mr Thomas Ryne</u>	<u>Rebecca Li</u>
<u>Stephen Mort</u>	<u>James Mason</u>
<u>Taylor Wrigley, Ruby Scott & Lucy Boulton</u>	<u>Stephen Roberts</u>
<u>In memory of John Brignone</u>	<u>Sara Vening</u>
<u>Derek & Helen Cross</u>	<u>Laura Bromilow</u>
<u>Pete's Plaice</u>	<u>Clare Carter</u>
<u>The Jolly Chippy</u>	<u>Jonatahn Billing</u>
<u>Mrs Linda Walsh</u>	<u>Stephen Larard</u>
<u>The MG Car Club Ltd</u>	<u>Hannah Heerey</u>
<u>In memory of Glynis Brockman</u>	<u>Ms E Bird</u>
<u>Gadbrook World Class Charity (Barclays)</u>	<u>Margaret James</u>
<u>Mr & Mrs Knapp</u>	<u>Anna Taylor</u>
<u>Enterprise Holdings Foundation</u>	<u>Huw May</u>
<u>Helen Edwards</u>	<u>John Stow</u>
<u>ACME Archives</u>	<u>David Thomas</u>
<u>Mandy Mattison</u>	<u>Sarah Davies</u>
<u>Jim Mowat - Hermes Lodge No. 5532</u>	<u>Natasha Stride</u>
	<u>Nicola Clinch</u>
	<u>Sian Renwick</u>



Helpline 0300 999 0102
assert@angelmanuk.org

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

Thank You!