Assert

Newsletter 61 Autumn 2017

Angelman Syndrome
Support, Education & Research Trust

Registered Charity 1021882

Your Assert

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Useful Stuff

OUR FREEPOST ADDRESS
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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

We started off our ASSERT year in February with a series of regional events celebrating International Angelman Day. Over 300 people attended events all over the country. Many friendships were made or renewed and we are already busy planning events for IAD 2018.

We then had our amazing Communication Conference. This was attended by 57 professionals on the Friday and by over 230 people on the Saturday and Sunday, including 49 people with Angelman Syndrome. I have to admit that the prospect of holding interactive communication workshops with multiple people with Angelman Syndrome in one room was a little daunting for all concerned, however it was a resounding success! Many walked away from the conference full of hope and a renewed vigour to help our loved ones find an effective way to communicate. It can sometimes feel like a long, uphill journey, but when your child or adult with AS uses a form of Alternative or Augmentative Communication (AAC) for the first time, whether its by using a PODD book or an app on a device it makes all the hard work worth it.

We would like to thank Jane Farrall, Mary-Louise Bertram, Erin Sheldon, Rosie Clark, Livvy Hepburn, Jennifer Marden, Callie Ward, Emily Webb, Jules Whicher and our communication trustee Tracey Campbell for speaking or presenting a workshop over the weekend. Tobii-Dynavox and the guys from Smartbox also attended and exhibited some of their amazing equipment. The weekend wouldn't have been such a success without you all.

We are very sorry that the Scottish conference had to be cancelled, however please see below for an exciting update!

ASSERT had 8 runners in the London marathon who raised a staggering £23,122 between them - see page 27 for personal write-ups and photographs. ASSERT is incredibly grateful to the dedicated people who sacrifice their time, blood, sweat and tears to raise money for us. Running marathons or mega marathons, baking cakes, climbing mountains etc etc. It's all very much appreciated and every penny counts.

A huge thank you goes to all our members, your friends and families who voted for us in the OneFamily Grant application. WE WON!!! How amazing is that? The ASSERT trustee's are busy making plans on how to use this money in the best possible way for our families. Keep an eye out for exciting details!

ASSERT has an exciting programme of events being planned for 2018. IAD 2018 will see a series of regional events for families where you can meet old friends and make new ones. Invitation letters will be sent to all registered members early in the new year. For Scotland this year, ASSERT will host a one day IAD conference covering topics such as epilepsy, sleep, co-ordinated support plans and other information relevant to our Scottish families. A day trip for children and carers will also be arranged. The programme is still being finalised and will be confirmed soon.

ASSERT is 25 years old in 2018!!! This calls for something special - see page 13 for further details.

Of course 2018 is our family conference year. It goes without saying that this is an amazing opportunity for families and professionals to gather together, learn from each other and have a wonderful time. Be sure to get your deposits paid nice and early - we don't want anyone to miss out!

And finally we said goodbye to Catrina Fraser who stepped down as trustee so that she could concentrate on her son's health issues. Thank you for your hard work.

The ASSERT trustees hope you have a wonderful holiday season.

Rachel & Rich

An update on Our Patron Gareth Edwards...

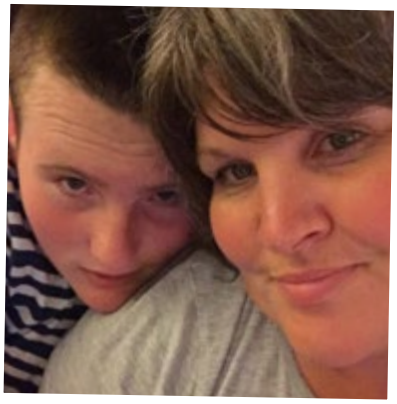
Gareth & his niece Ella

Gareth has had a very quiet 2017 compared to the excitement of 2016. He was still doing some promotion for the film (Rogue One – A Star Wars Story) in early 2017 but then he finally broke free and was able to catch his breath before starting to plan his next busy project. There have been lots of meetings and work behind the scenes but as yet we are none the wiser as to what his next film will be. It's a case of waiting to see what happens in 2018. Hopefully the force is with him!

Meet the Trustees

We would like to introduce the trustees of ASSERT. For those of you who have been members for a few years and attended various events, you will know us well. Others who are new to ASSERT won't be so familiar with our faces. However, even those that have been around for a few years will probably learn a thing or two about us in the article below! So here we are, your trustees. First and foremost, we are all volunteers. We work tirelessly to ensure we do the best we can on your behalf. All of us have a close personal relationship with someone who has Angelman Syndrome. We are able to share a multitude of experience to help support all those in the AS community. We work well together and have a bold vision for the future of ASSERT which we hope will increase our ability to support our families and professionals.

Rachel Martin



Hi, my name is Rachel and I have been a trustee of ASSERT since 2006. I have been chair of ASSERT since 2012.
I am a single parent and I live in Bangor, North Wales with 3 of my children, James aged 16 (AS Del+), Isaac, known as Zac who is 11 and Elizabeth who is 10. We have lived in Wales since leaving Bolton in 2009, and even though my knowledge of the Welsh language is limited, my children are fluent Welsh speakers. James loves meeting and greeting people and is the worlds best hugger. His most favourite thing is his iPad – life wouldn't be the same without YouTube! He's also learning to use a communication app called Proloquo2go. His favourite request is for chocolate or swimming!

Unfortunately, living in a rural area means that services for people with disabilities are sadly lacking, and as James is the only child with an Angelman diagnosis in Gwynedd, the largest county in Wales, it can feel a bit lonely sometimes. Thanks to James, many doctors, teachers and professionals have increased their knowledge of Angelman Syndrome and all that it entails - although this has been challenging at times as you can imagine.

Rich Williams

Hi, my name is Rich, I'm originally from Sheffield, I now live in Swansea with my wife Sue, and son Max (born 2010). Aged 40 something (I stopped counting a few years ago).
I'm also dad to Holly (born 2002 del+) who lives in Wiltshire with her mum. I work for the National Trust and I've been a trustee of ASSERT since late 2004. I like music, politics and generally refusing to grow up gracefully. As a dad, I've worked hard to make sure that my two children grow up with a great relationship despite the distance between them- and the fact that we have managed to make it work (so far) is one of the things that I am most proud of. As an extended non nuclear family, we have had many challenges over the years including significant health scares for Holly but we're still going. Still smiling. My favourite aspect of working for ASSERT is seeing everybody arriving at the start of conference.
My best memory so far is opening the Liverpool Celebratory Gala dinner, as a warm up act to Gareth Edwards, with more bad Star Wars jokes than I thought I would get away with.

Katie Cunnea

Hi, my name is Katie, ASSERT's Science and Research trustee (since 2014). I am a biochemist with a PhD in structural biology/electron microscopy and I work for the Medical Research Council near Didcot. I live in Eastleigh, Hampshire with my husband David and our three children, Ruby (10) Finley (8) and Amber (1). Ruby has Angelman Syndrome. She loves swimming and watching YouTube on her iPad!

Lisa Court

Hi, my name is Lisa and I am the treasurer of ASSERT. I've been involved since 2005. It was after attending our first conference in 2004 and seeing what an amazing job the charity were doing that I wanted to become involved.

I live in the Midlands with my husband Craig and our 3 children – Ella who is 15 and has AS, Jacob who is 12 and Thomas who is 9. Myself and Craig both work full time so it's a busy house juggling work and school and kids and everything that AS brings with it. But we are still smiling!

Time for hobbies is scarce but I have recently joined a gym and try and go several times a week… well you never know when the next premiere will be! (Lisa is sister to ASSERT's Patron, Gareth Edwards.)

Andrea Baines

Hi, I'm Andrea and our son, Woody, was diagnosed with Angelman Syndrome in 2010 at 18 months old. The support we were given from ASSERT at that time (and since) was exactly what we needed, when we needed it. In 2015, I was asked to help with the ASSERT sponsored ASA Scientific meeting in Liverpool. During this time, I was invited to be a trustee and got the chance to give something back.

Ben and I met in Manchester and married in 2002. We moved to Oxfordshire shortly after, and now live in a 'project' house, which we really hope we will finish…one day... We have three amazing and energetic sons, Will, Woody and Jamie. In the last year, I have taken up running (badly) to keep up with them. In any spare five minutes, you'll usually find me sewing, which I love because it's quiet and I can sit down to do it!

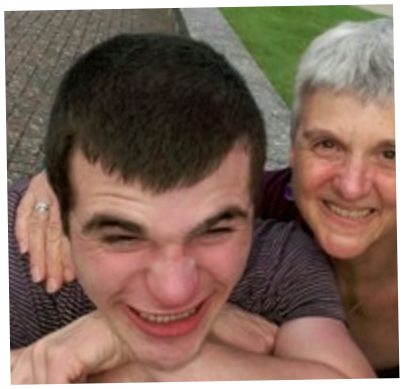
Diane Fox-Jones

Hi, my name is Diane and my middle child, Harvey, aged 19, has Angelman Syndrome, we also have Lottie, aged 22, whom Harvey adores. Milo, aged 12, is our third child.

Harvey left school this summer which was a very daunting prospect, but after a lot of research and a very lengthy battle with the Local Education Authority, we managed to secure a place for him at an extremely well-respected college. Hopefully our decision to send Harvey to college daily rather than residential will turn out to be the right one, but he appears to love being at home and we didn't feel that he was ready to live away just yet. Also, I don't feel ready to let him go. His cheeky smile and that special look in his eyes makes up for all the difficulties we face, well most of the time anyway.

We both work from home which helps our caring roles, but we do definitely rely on domiciliary carers after college each weekday and a combination of day care and respite most weekends. Managing Harvey's diary is a full time job in itself as there are constantly carers cancelling, appointments to organise, respite dates to be booked and transport to organise, not forgetting all that washing to be done.

But then there's that smile again.



Sian Cartwright

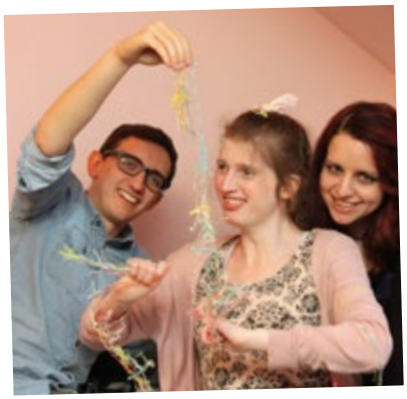
Hi, my name is Siân. I live in Leeds with my partner Peter and our son Euan who is 22 (AS del). Our daughter Poppy now lives and works in Newcastle. I have a background in health and social care and for the last five years I have been the Health Development Manager with Carers Leeds, a carer support and information service in the city. I am the ASSERT representative at the quarterly AS clinic in Manchester and will have met some of you there over the last few years. Since leaving full-time education Euan has had a small team of support workers and accesses two excellent local initiatives for young adults with learning disabilities during the week. However since leaving Children's Services we have had major difficulties in finding suitable respite provision…the search continues.

Having dabbled in upholstery and screen-printing I would love to have more time to do creative things but I do make a lot of cakes and also belong to a local rock choir which guarantees that I come home singing every Thursday.

Tracey Campbell

Hi, my name is Tracey. I live in Glasgow with my husband Gordon, our 3 children Abbie, 13; Leia 11 (AS); and Finn 6 and a labrador named Pippa who is 2. I became a trustee earlier this year. I am a Biomedical Scientist and work as a Training Manager in the Microbiology laboratory at Glasgow Royal Infirmary. When I am not at work, ferrying children around and doing the many tasks involved in a busy household with 3 children I am found watching webinars, reading information and generally devouring all information about AAC and literacy for people with Complex Communication Needs. I run a Communication Club at my daughter's school. I also spend a surprising amount of time writing emails asking for services to be improved, sadly with varying degrees of success.

As a family we enjoy spending time at our caravan where we just love being on the beach. Watching movies at the weekend is a must. We (or I) like the idea of the family walks with the dog but they often don't turn out as well as we would hope!



Jonathan Allen

Hi, my name is Jonathon and I am the sibling support trustee at ASSERT and have been a trustee since March 2014. With an older sister and younger sibling, Eloise (AS del+ born 1989) and Elion respectively, I am the awkward middle child! I live in the South East of England and practice law, though I have lived across the country. Despite this, I still see my family regularly, including Eloise, who continues to be a big influence in my daily life. My parents were actually two of the founders of ASSERT back in 1993 before standing down just before the turn of the millennium. I am fortunate enough that those who progressed and developed the charity beyond anything my parents could ever envisage, invited me to the board of trustees also.

As the sibling support trustee, I provide regular support to those who are siblings and parents alike. Having grown up with an Angelman sister and now gone through the transition of Eloise living in a home for life, I hope that I can use my experience to support others.

Mairi Leith-McGaw

Hi, my name is Mairi the crazy horsey one. I live in South Aberdeenshire in the north east of Scotland with my husband Richard and our three children, Jon (AS) age 10, Ritchie (middle child syndrome) age 7 and Molly (little princess syndrome) age 4. We live in a mad house with our 2 dogs Harris and Drake, 3 cats Pops, Rose and Simon, and 5 horses Logie, Min, Poppy, Meisha and Hamish. We all enjoy the out doors and especially horse riding as a family.

Communication Conference

ASSERT were delighted to host their first Communication Conference in May this year. Whilst the hotel and hosting a conference were familiar to most of the trustees, the format and content were very different.

Friday was a day for professionals to attend, this was attended by a total of 57 from all over the country. There were 6 different talks during the day followed by 2 workshops so it was a full schedule. We were delighted to host Jane Farrall and Mary-Louise Bertram from Australia, Erin Sheldon from Canada, Jennifer Marden from The Netherlands, and Callie Ward and Emily Webb from a bit closer to home, England. The feedback we got from the professionals who attended was very positive and the ability to take three members of a team was equally well received. The ongoing feedback being that this helps to engineer change when they go back to school as the information is coming from more than one source.

Over the weekend we hosted 230 attendees, 49 of whom have Angelman Syndrome (AS). The Saturday was a day for parents and carers although we also had a few dedicated professionals who came as they hadn't been able to take the time off work on the Friday. The format and most of the content was the same as the previous day, although we were delighted that Rosie Clark and Livvy Hepburn could join us for the weekend.

Sunday was the real experiment as, for the first time ever, we hosted workshops for individuals with AS as well as parents and carers. With 49 individuals with AS at the conference it took a bit to organise and was a rather daunting prospect for those of us running the workshops. Despite the trepidation, everyone ended up having lots of fun although it is fair to say that I personally have been cleaner on an aeroplane than I was that day when I returned to Glasgow covered in a lovely custard and chocolate sauce combination!

ASSERT Scottish Conference

Saturday 17th February 2018

As you already know ASSERT is hosting a one day Scottish conference for International Angelman Day 2018. For those who haven't attended a conference or event they are memorable experiences. For many, conference is a chance to meet old friends, relax with other AS families and is a chance for families to learn from each other.

The conference has something to offer everyone including professionals with an interest in Angelman Syndrome. They are invited to come along to meet our families and to further their knowledge of this rare condition.

The programme is still being finalised, but it will as always, be fascinating, supportive, insightful, challenging and thought provoking in equal measure. Confirmed subjects to be covered include neurology & epilepsy, the ketogenic diet, communication, early support, transition to adult services and much more.

The Stirling Court Hotel is located within the very picturesque grounds of Stirling University and is fully accessible. It has leisure facilities including a gym, swimming pool and a cinema for those who want to stay longer and make a weekend of it. ASSERT has negotiated a discounted B&B rate for the weekend.

As the conference is for adults only we have organised a trip to Dynamic Earth. The principal focus of Dynamic Earth is to facilitate a better public understanding of the processes that have shaped the Earth. This includes the Big Bang, the beginning of life, plate tectonics and glaciers. As it is highly interactive, this trip will be suitable for AS individuals of all ages and their carers along with siblings. There is also a soft play and a café. For more details check out the website www.dynamicearth.co.uk . Whilst ASSERT is unable to provide carers or childcare you are welcome to have additional family members or carers to attend the day trip to allow both parents to attend the conference.

Families from all over the UK are welcome and all ASSERT are asking for is a non-returnable confirmation payment of £10 per family by the 15th December to confirm your booking.

Letters and booking forms have been sent to all members registered in Scotland. Families outside of Scotland are more than welcome to attend. Please email assert@angelmanuk.org or telephone our support line (0300 999 0102) for an application form.

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 about to move away from the family home to go to university. Unfortunately this is quite a way from my parents home where my brother, who has Angelman still lives. He is only slightly younger than me and whilst I worry, that he may miss me, I know he will be fine. I am more concerned that for the first time he will not really be a big part of my life and I am worried I won't be able to cope at university without seeing him at the end of each day.

Jon's Answer:
It is completely natural to be nervous about many aspects of university and missing family is always a big one, even if they don't have AS. Given that your brother has AS which can be so demanding and intense, it is understandable that you are concerned such a big part of your life will be there less regularly.

Something that I know can help is videochats, whilst he may not understand entirely, I'm sure he will find it funny to see you on a screen and at the same time you will hopefully maintain a sense of closeness with him. You could also have photos of him and your other family in your room.

It is important to remember that whilst you are moving away, it is likely that you will still have large parts of the year at home from university, especially when you have no student loan left! You will of course be able to spend a lot of time with him then.

I also think it is important to focus on yourself at times too. University can be a fantastic experience that you should embrace as much as possible. Whilst it may be weird, it is now that you will in part develop more of your own identity which is less defined by your family environment.

Dear Jon,
My younger sibling, with Angelman Syndrome, is getting more and more active which I find difficult as they take my things and invade my room. Sometimes it is funny and I don't mind but other times it can be really annoying!

Jon's Answer:
This is definitely a common problem, as we all know that respecting personal space is not something those with Angelman Syndrome like to do! It may be best to discuss this issue with your parents who may be willing to provide you with a lock to your room. Alternatively, they may try to make sure that your sibling is distracted when you want to do something important on your own. The important thing to remember is they aren't (usually) doing it on purpose to be annoying, they just want to hang out with their sibling!

OneFamily Foundation Grant

If you were using social media platforms over the late summer, then you hopefully saw the OneFamily Foundation bid ASSERT entered, voted for it and shared it with friends and family.

The OneFamily Foundation bid was a competitive grant, where you invited members of the public to vote for your proposal. There were four categories and three funding levels within each category. ASSERT's proposal was called "I have something to say: AAC use in Angelman Syndrome". It was entered into the "Health and Disability" category, in the "up to £25,000" funding stream (the maximum allowed).

It has three aims
• Provision of AAC systems - ASSERT will provide up to 50 families with an AAC system (either a PODD book or a copy of the ProLoQuo2Go app (NB funding is for the app only – we will not be funding iPads).
• Provision of training. There is little UK expertise in using AAC systems with AS individuals. ASSERT will provide training days to teach parents/carers/therapists/teachers how to effectively use the systems at home and in school/care placement settings.
• Increase the use of AAC for AS individuals and ultimately for AAC systems to be offered to all individuals in the UK with complex communication needs.

Thank you so much for all the votes, shares and cajoling! It was an extremely close competition. Although we were in second place when the voting period ended, during the vote verification stage we gained enough votes to put us back into the winning spot! The money awarded will help ASSERT towards achieving our communication aims. The campaign has also raised awareness of AS, the need to presume competence for AAC systems and the need for better training in AAC system use required in the UK.

We are working for the next few weeks with the OneFamily Foundation over the administrative details of the award and the project timelines. Once these have been finalised, we will be contacting all registered members of ASSERT with full details of how to apply.

Family Conference 2018

Save the Date...

The family conference for 2018 has been booked:

Friday 10th August - Sunday 12th August 2018

As announced in the previous newsletter, for the first time in the conference history we have moved the dates to be in August. This is in response to the feedback we had to say that some of you could not attend due to some schools having already returned before the first weekend in September. Some found it stressful to return on the Sunday evening and be ready for the first day of school on Monday. These August dates mean that all areas of the UK will still be on their school holidays and therefore there isn't the issue of a long drive home and school the next day. We are reminding you of these dates so that if you do want to book a summer holiday as well in 2018 you can ensure it does not clash with the conference.

Archie Walker

This is Archie-Jay Walker who is 8 years old and from Middlesbrough. Archie is a big Middlesbrough football club fan and season ticket holder. Recently for his 8th birthday he got the new training tracksuit. I posted a picture of him on FaceBook. A few days later I got an email from Middlesbrough football club who had fallen in love with Archie's infectious smile and asked if he would like to be a model for the MFC clothing range. He was invited to attend the club training ground for the photo shoot where he was joined by the players. Archie really enjoyed his time in the limelight and we can't wait to see him in the MFC club shop window, online and in the magazine.

Mark Walker

Pitt Hopkins

Pitt-Hopkins Syndrome (PTHS), like Angelman Syndrome (AS), is a rare neuro-developmental syndrome. It has many similarities to AS such as developmental delay, motor delay, hypotonia, frequent lack of speech and usually a very happy demeanour. Both PTHS and AS present with ataxia, leading to an unusual gait when affected individuals learn to walk. Many with PTHS also have epilepsy but do not show the distinctive EEG pattern of individuals with AS. Characteristic facial features of PTHS include a cupid-bow upper lip, full bottom lip and wide mouth. Hyperventilation, daytime apnoea and prominent foetal pads on fingers and toes can be further indicators towards a PTHS diagnosis.

PTHS is known as a differential diagnosis for AS, as many children eventually shown to have PTHS have initially been tested for AS: some have even been given a clinical diagnosis of AS when it was Pitt-Hopkins all along! A poll of the Pitt Hopkins UK group showed that out of 41 families replying, only 9 had not been tested for AS before receiving their PTHS diagnosis.

Between 1995 and 2003, our son Christopher was tested several times for Angelman Syndrome and male Rett Syndrome. As these tests were inconclusive, he was entered into a research project and received a molecular diagnosis of PTHS in October 2007, a few weeks after the test was developed. We were in the right place at the right time!

We got in touch with Contact a Family and were told that PTHS was so rare there was no support group and we should start one. Over the next few months, via CaF and the Inspire site in the

United States, we found a few other parents whose children also had PTHS. We started an online international Google support group together in April 2008.

Although we didn't originally call ourselves Pitt Hopkins UK, our group began in summer 2008 when we had our first UK meet up. We have continued to meet at least once a year since then. A couple of years later it was suggested that I should look into starting a charity in the UK but I was reticent as I felt we shouldn't divide ourselves off from the international community. We were also very involved in setting up the Dutch charity. I contacted the Charity Commission for advice and a basic constitution was produced. Then my mother became terminally ill and all ideas of starting a charity were shelved.

In 2015 the idea of becoming a charity was raised again. I was invited by Rachel Martin to attend the 50th anniversary celebration of Dr Angelman's first description of AS. I had a wonderful time, some great pep talks with some of the ASSERT trustees and left recharged and ready to find some other parents interested in becoming trustees of a charity for Pitt Hopkins UK.

My husband and I approached 3 parents whose children were newly diagnosed with PTHS and one mother who had been interested from the beginning.

We worked again on a constitution and discovered how to navigate the "user friendly" Charity Commission website and forms. Eventually in May 2016 we achieved our registered charity status.

Our aims are; to raise awareness of PTHS, particularly among health professionals; to support and advocate for families living with PTHS; to deliver the latest information about PTHS. Pitt Hopkins UK also hopes to fund future research in key areas which impact quality of life, such as breathing anomalies and constipation exhibited by many children and adults with PTHS.

We are now 16 months into the life of the charity and it has been a steep learning curve! There are many challenges ahead but we are confident that Pitt Hopkins UK will provide support to affected families and raise the profile of the syndrome with medical professionals.

Sue Routledge

Assert SILVER Assert SPRING FLING

Saturday 19th May 2018

In 2018 we will be celebrating 25 years of ASSERT!!!

To acknowledge this milestone we would like you to join us for a night of friendship, fun and fundraising.
To be held at the beautiful
Forest of Arden Hotel & Country Club.

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

Price per person £135 (includes B&B and Evening Meal)

(Strictly 18+)

Dress code - Black tie / formal.

3 Course dinner
Fun Casino.
Silent Auction
Live music provided by 'Sunshine Soul Review',
the amazing band who performed at Liverpool.

Why not extend your stay to include a spa treatment or two or a round of golf? (Please book direct with the hotel)

Letters and booking details will be sent out January 2018.

1993 - 2018 Assert

Divorce

Divorce is a topic that is rarely mentioned in the newsletter - despite the fact that there is strong evidence to suggest that those households dealing with disability (and especially young/newly diagnosed children) are more likely to end up facing it.

I've never seen any concrete evidence to explain as to why this might be other than the obvious strain and fatigue. But I did read something online recently which made me stop and think. One of the reasons may be simply down to the love of that we have for our children. Additional needs can mean additional fights, stress and worry. With all of the emotional expenditure and tunnel vision that goes with this, it is often that we forget to make time for our relationships. Over time, this could make small cracks that all relationships face even larger. So, please remember yourselves amidst the chaos. It can only ever be a good move.

Some evidence shows that once the relationship has survived 6-8 years of the additional strain, rates fall back to normal background levels, so there might be something in this.

As someone whose life changed significantly 12 years ago when Holly's mum and I parted, I've been giving some thought to how life has delivered upon its promises and perhaps offer some hope to those struggling themselves.

When I was initially no longer dealing with Angelman Syndrome on a daily basis, I was perhaps more confused than I had been at diagnosis. Daily routines had gone, and the need for a clear head on the practicalities of setting up elsewhere whilst still carving out a Holly sized space was key. For those no longer in the 'family' home (and that's usually but not always, Dads like me), there can also be a degree of social stigma and prejudice to overcome too - even when there are no grounds for it.

Break ups are hard at the best of times. Harder when children are involved and can be even more difficult if those children have additional needs.

Thankfully, for me at least, the split wasn't acrimonious - but I have utmost respect for those going through the process and having to deal with that as well. If that's you then please remember that you have at least one thing that you both agree on amidst the emotions. The pain will fade, but your love for your children won't.

I got through it. New routines were established, written, rewritten and then rewritten again as life moved on. But that's our lives in general, isn't it?

And now 12 years later, I look upon it as a positive for all of us. I've now been happily married to Sue (who many of you will know from her time as an ASSERT trustee too) for almost 8 years. Max, 7, adores his big sister. Holly aged 15, now living 100 miles away from us with 'Auntie Les', still has to put up with regular visits from both us and her 'new' extended family. With the exception of Max and I, all have voluntarily entered the crazy world of Angelman Syndrome!

A number of health scares over the years for Miss H have really helped cement those relationships and 'Team Holly' is now fully formed and ready to take on the future. I'm very proud of both my children. Max is very proud of his sister and like most AS siblings, doesn't bat an eyelid when confronted by 'different'.

Unless it's down to a nifty right hook followed by a giggle. But that's Holly just taking advantage of the circumstances isn't it?

Rich Williams

International Angelman Day 2018

ASSERT are busy planning a number of events around the country to celebrate International Angelman Day in 2018.

The actual date February 15th falls on a Thursday and so our events will either be the weekend before (Saturday 10th / Sunday 11th) or the weekend after (Saturday 17th / Sunday 18th).

Letters will be sent out early in the New Year detailing all the events. You are welcome to attend any event that we are hosting, it doesn't have to be your local meeting if you would prefer to attend one further afield.

Jeans for Genes

We are delighted to announce the ASSERT are now one of the partners for Genetic Disorders UK (http://www.geneticdisordersuk.org/), the charity behind the national Jeans for Genes day campaign.

This means that not only will we be able to apply for funding from the organisation again in future, but we will also earn money through their 50/50 partnership scheme. For every new organisation (school, workplace, etc) registering to hold a "Jeans for Genes" day event next year and choosing ASSERT as their affiliated charity, Genetic Disorders UK will donate 50% of the money raised from that organisation directly to ASSERT.

So if your school or workplace didn't hold a Jeans for Genes day event this year, register them over the next few months for next year's event and ask them to choose ASSERT as their affiliate charity.

Thank you!

Angelman Syndrome Research Update 2017

According to PubMed (the international database of research articles) so far in 2017 there have been about 40 research articles published with Angelman Syndrome appearing in the title or abstract (summary). I can not describe them all here, but I wanted to give you an idea of what scientists are looking at and highlight some papers that might be worth a more thorough read... (or you can email me to find out more).

First though just to mention there was a useful unbiased review published at the end of 2016 by paediatricians Wen-Hann Tan , & Lynne Bird from Boston & California (respectively) titled "Angelman syndrome: Current and emerging therapies in 2016" which looks at all the published clinical trial data relating to AS(1).

Arguably the most interesting papers this year have been published from Ben Philpot's laboratory. One study was developed from the observation that although studies have shown individuals with AS essentially have a 'normal' brain structure (in that all the structures are there) a symptom of AS is microcephaly. So the study wanted to look at how microcephaly might explain why the brain of new born babies with AS does not grow and function as it should. Their experiments were carried out on mice and they found that the volume of white matter in mice with AS is reduced and axons are abnormally small, this would result in slow nerve conduction and could explain reduced motor functions(2).

In another paper the Philpot lab looked at why reduced dendritic spine densities are common in Angelman syndrome. In the brain neuron's are the specialised cells that pass information around. Dendritic spines are little protrusions on the neurons that help them transmit information. So obviously with less spines you can imagine that the brains cells would struggle to send and receive information correctly. Before this current study, we knew that people with AS had less dendritic spines because of studies on postmortem tissue. What we didn't know was whether the spines were not forming in the first place, or whether something was causing them to decrease. In the study they tracked the spines in live mice with AS over multiple days using a special imaging technique. They found that spine formation is normal, but rather than being maintained when the mouse 'learned' the spines were lost. They discovered the process underlying the loss of dendritic spines, which in turn leads to the neurons not working properly. This is exciting because a potential treatment for AS would be to look for a way to correct spine maintenance(3).

There was also a collaboration of well respected USA scientists (Michael Sidorov, Gina Deck, Marjan Dolatshahi, Ronald Thibert, Lynne Bird, Catherine Chu, and Benjamin Philpot) who describe a way to measure abnormal EEG activity specific to Angelman Syndrome. This could be useful to doctors and also researchers (looking for ways to measure if treatments/drugs are effective)(4).

There have been a few interesting clinical papers published. Ron Thibert and colleagues published two papers on treatments for epilepsy. One focused on the low glycemic index diet(5). The other showed that "newer antiepileptic drugs such as levetiracetam, lamotrigine, and clobazam, and to a lesser extent topiramate, appeared to be as effective - if not more so - as valproic acid and clonazepam while offering more favorable side effect profiles. The low glycemic index treatment also provided effective seizure control with minimal side effects. The majority of subjects remained on combination therapy with levetiracetam, lamotrigine, and clobazam being the most commonly used medications, indicating a changing trend when compared with prior studies"(6). Another study from the Netherlands found that postural muscle tone loss and collapsing while laughing was only seen in individuals with a deletion(7).

Another clinical paper looked at whether menstruation in young women with AS had any associated problems. They found that less than half of individuals used hormones to manage menstruation (mostly to try and stop periods completely) and that although requiring full assistance to manage hygiene, menstruation is not associated with significant problems in

AS(8). Another paper from Germany and the Netherlands looked at continence in individuals with AS. They found incontinence was not associated with behavioural difficulties, but was correlated with the genetic form of AS a person had and how severe an individual's epilepsy was(9).

There were two interesting papers on communication; Stephen Calculator published a study of 18 families using a program for teaching enhanced natural gestures. Most families found the program helpful(10). Vanderbilt University and Oregon health and science university have explored expressive communication skills in a sample of 300 children and young adults with AS. They found use of picture symbols, object symbols and manual signs(11).

There have been a large number (14) of papers published on the genetic identification of Angelman Syndrome, mostly from China, (written in Chinese). Some looked at improving methods of identification of AS, others looked at unusual genetic cases of Angelman Syndrome that had been difficult to identify at first, and so are valuable for genetcists to be aware of. For example, one paper by Martin K et al. looked at the performance of a method to detect tiny genetic abnormalities that can detect Angelman syndrome and some other similar genetic conditions prenatally(12).

I could tell you about so many more findings, but there simply isn't the space. One thing is clear though, research into Angelman Syndrome continues to grow, and the effort of the global Angelman charities, parent support groups and AS community to raise funds, ask the important questions, take part in trials and complete questionnaires is having a significant impact on our scientific understanding of AS. Well done everyone and keep up the good work.

Katie Cunnea
Science & Research trustee

Refrences:

1. Am J Med Genet C Semin Med Genet. 2016 Dec;172(4):384-401. doi: 10.1002/ajmg.c.31536. Epub 2016 Nov 8. Angelman syndrome: Current and emerging therapies in 2016. Tan WH, Bird LM.

2. Decreased Axon Caliber Underlies Loss of Fiber Tract Integrity, Disproportional Reductions in White Matter Volume, and Microcephaly in Angelman Syndrome Model Mice. Judson MC, Burette AC, Thaxton CL, Pribisko AL, Shen MD, Rumple AM, Del Cid WA, Paniagua B, Styner M, Weinberg RJ, Philpot BD. J Neurosci. 2017 Aug 2;37(31):7347-7361. doi: 10.1523/JNEUROSCI.0037-17.2017. Epub 2017 Jun 29.

3. Maternal Loss of Ube3a Impairs Experience-Driven Dendritic Spine Maintenance in the Developing Visual Cortex. Kim H, Kunz PA, Mooney R, Philpot BD, Smith SL. J Neurosci. 2016 Apr 27;36(17):4888-94. doi: 10.1523/JNEUROSCI.4204-15.2016.

4.Delta rhythmicity is a reliable EEG biomarker in Angelman syndrome: a parallel mouse and human analysis. Sidorov MS, Deck GM, Dolatshahi M, Thibert RL, Bird LM, Chu CJ, Philpot BD. J Neurodev Disord. 2017 May 8;9:17. doi: 10.1186/s11689-017-9195-8. eCollection 2017. Erratum in: J Neurodev Disord. 2017 Jul 17;9:30.

5. Low glycemic index treatment for seizure control in Angelman syndrome: A case series from the Center for Dietary Therapy of Epilepsy at the Massachusetts General Hospital. Grocott OR, Herrington KS, Pfeifer HH, Thiele EA, Thibert RL. Epilepsy Behav. 2017 Mar;68:45-50. doi: 10.1016/j.yebeh.2016.12.018. Epub 2017 Jan 19.

6. Seizure treatment in Angelman syndrome: A case series from the Angelman Syndrome Clinic at Massachusetts General Hospital. Shaaya EA, Grocott OR, Laing O, Thibert RL. Epilepsy Behav. 2016 Jul;60:138-141. doi: 10.1016/j.yebeh.2016.04.030. Epub 2016 May 18.

7. Res Dev Disabil. 2016 Sep;56:177-82. doi: 10.1016/j.ridd.2016.06.002. Epilepsy and cataplexy in Angelman syndrome. Genotype-phenotype correlations. Granild Bie Mertz L, Christensen R, Vogel I, Hertz JM, Østergaard JR.

8. J Pediatr Adolesc Gynecol. 2016 Aug;29(4):348-52. doi: 10.1016/j.jpag.2015.12.004. Epub 2015 Dec 21. The Effect of Menstrual Issues on Young Women with Angelman Syndrome. Kaskowitz AP, Dendrinos M, Murray PJ, Quint EH, Ernst S.

9. Incontinence in persons with Angelman syndrome. Wagner C, Niemczyk J, Equit M, Curfs L, von Gontard A. Eur J Pediatr. 2017 Feb;176(2):225-232. doi: 10.1007/s00431-016-2828-1. Epub 2016 Dec 20.

10. Description and Evaluation of a Home-Based, Parent-Administered Program for Teaching Enhanced Natural Gestures to Individuals With Angelman Syndrome. Calculator SN. Am J Speech Lang Pathol. 2016 Feb;25(1):1-13. doi: 10.1044/2015_AJSLP-15-0017.

11. Exploring Expressive Communication Skills in a Cross-Sectional Sample of Children and Young Adults With Angelman Syndrome. Quinn ED, Rowland C. Am J Speech Lang Pathol. 2017 May 17;26(2):369-382. doi: 10.1044/2016_AJSLP-15-0075.

12. Clinical Genetics, Martin K et al. "Clinical Experience with a Single-Nucleotide Polymorphism-Based Noninvasive Prenatal Test for Five Clinically Significant Microdeletions".

Kidz to Adultz Exhibitions

The Kidz to Adultz exhibitions are a great source of information if you are looking for equipment or services. There are currently 5 around the UK each year – North, South, Middle, Scotland and Wales. The exhibitions are free to attend so if there is something you are looking for and it is convenient to attend then we would strongly recommend you go along and spend a few hours seeing what is available. Further information can be obtained from http://www.disabledliving.co.uk/kidz-to-adultz/

Scotland
Friday 14th September, in Edinburgh

North
Thursday 15th November, in Manchester

Middle
Thursday 15th March, in Coventry

South
Thursday 17th May, in Farnborough

Wales
Thursday 5th July, in Bristol

Share your story in the Global Angelman Syndrome Registry

The Global Angelman Syndrome Registry is the first online Patient Driven registry for Angelman Syndrome; putting power in the hands of those who care for someone with the Syndrome.

Parents and caregivers are driving the collection of data by volunteering information about their child or adult with Angelman Syndrome that is rapidly becoming the largest collection of information on Angelman Syndrome to date.

The Registry will provide a tool for understanding developmental progress, medication and seizure management. More importantly, it will provide an invaluable resource to advance the search for therapeutics.

The timing is perfect; with pharmaceutical companies anticipating drug trials to treat the syndrome, the Registry provides the perfect mechanism to analyse, recruit and measure effectiveness of treatments.

Further information:
http://cureangelman.org.au/AngelmanRegistry/

Joining the registry:
https://angelmanregistry.info/

Contact the data curator:
curator@angelmanregistry.info

Visit us on Facebook:
https://www.facebook.com/angelmanregistry.

Four Blocks Literacy

I attended a 5 day intensive literacy course last year presented by Jane Farrall and Sally Clendon. During the course they taught us much about teaching literacy based on the four blocks system that was developed by Dr Patricia Cunningham and Dr Dorothy Hall. It was then adapted by David Koppenhaver and Karen Erickson for people with additional needs. Whilst the course was based on classroom ideas there are many that could be adapted and used at home. Jules Whicher mum to Charlie, clinical AS has being doing just that and presented a very inspiring talk on their experiences at Communication Matters Conference (see page 20 for more details on this conference) this year.

The four blocks programme is based on a balanced diet of literacy including;
• Reading to children – fiction and non-fiction.
• Reading with children – shared reading of predictable books.
• Providing opportunities for children to read by themselves.
• Writing for children – morning messages, journal entry, timetable.
• Writing with children – shared writing, cards, predictable charts, youtube search.
• Providing opportunities for children to write by themselves.
• Developing phonological awareness.
• Working with letters and sounds.

One of the most important ways to start is to build up a library of appealing books and other literature;

- Self authored books
- Remnant books
- Audio books
- Rhyming books
- Non Fiction
- Comics and magazines (laminated)
- Kindle
- iBooks
- Alphabet books
- Cbeebies – bedtime stories
- YouTube
- Tar Heel Reader (great resource for age appropriate books for emergent readers)
- Leaflets
- Pictello
- Subtitles on TV

Having the same text in many different formats is useful as they may like to flit between them. For example you could have a TV or animated adaptation (watched with the subtitles on), the physical book, a digital version and even your own written copy both digitally and printed. Charlie has a great version of Brown Bear, Brown Bear called Charlie Whicher, Charlie Whicher. What do you see?

When reading with children it is useful to already have the comments and questions you are going to ask written out on post it notes. For those not yet fluent in AAC writing down the pathways to navigate the pages of the system can be really helpful to keep the flow of the story going. Remember to leave a long enough response time before prompting AAC use.

People who have difficulties in the motor skills required for writing will need an alternative pencil in order to engage in writing tasks, that is choosing letters to get your message across. In order to do this they will need an alternative pencil, an alternative pencil is simply the 26 letters of the alphabet made available in an accessible way e.g a keyboard. Jane Farrall has an excellent blog on this found at http://www.janefarrall.com/lots-of-alternatives-pencils-for-everyone/ Just like with AAC this is a skill that is learned by watching other people doing it in the same way as is accessible to you. The writing for block addresses this need. It seems alien at first but there are many times throughout the day when we use alternative pencils, computers and phones being the most obvious.

Writing is hard for anyone to master and when you can't actually write the letters yourself it is even harder, this is why we need to write for real reasons:

- Shopping lists
- Youtube searches
- Sending cards
- Letters
- Birthday or Christmas wish lists
- Thank you cards or notes
- Typing out choices for songs, music or TV programmes, especially if they are not yet in the AAC system
- Write about something you have done to tell a story

There are loads of reasons why we write each day, choose the ones of interest and mix it up to keep engagement levels as high as possible. We keep a pile of pictures that we can choose from if we get stuck for a writing topic.
When working with letters and sounds there are many good videos you can watch. Sesame Street have a whole collection that different artists have sung on including 1D and JayZ! These help to make them more age appropriate.

Making alphabet books in things that are of interest are motivating, most people with AS start off with books about people and food. Tar Heel Reader have some really fun alphabet books for inspiration. We often go on a treasure hunt for things beginning with a particular letter then turn it into a Pictello book, although pictures stuck on paper would work just as well. When you are out and about you can collect things and make them into an alphabet book. Alphabet books can be either on a particular letter or a subject. It is not necessary to get every letter in your book, nor do you need to restrict to only one of each letter.

When it comes to whole words there are many apps, word wizard is one example. We have lots of alphabet resources that we use around the house for both letter and word recognition, including Velcro, magnetic, wooden, play dough cutters, suncatchers! There are a lot of alphabet resources out there!

The number one thing about literacy is to keep it fun. An equivalent literacy level of a typical 6 year old will allow a person to have the literacy skills they require to meet most daily needs. What a skill to teach someone. No matter what anyone tells you No Student is too anything to be able to Read or Write (David Yoder)

Tracey Campbell

Communication Matters Conference 2017

This year the conference started with a social media keynote. It was an interesting topic around what people who use AAC can access on social media, however perhaps not truly relevant to everyone and therefore an unusual choice for a keynote. That said, there is no doubt that it certainly may be a way to get people with Angelman Syndrome interested in literacy. We can now say a lot by the use of GIFs, stickers, emojis. Communication and literacy is changing for everyone and it does make it more accessible.

In the first morning session I attended a talk by I Voice, this is a charity for people who use AAC. They run a yearly weekend (attended by James and Rachel this year) and there are a few groups based at different spots round the UK. Whilst it seems like a lot of people who attend are people with cerebal palsy, they certainly seemed welcoming of all users of AAC whether you have a system in place yet or not. It is definitely worth registering and seeing if there is a group near you (www.Ivoice.info).

The last meeting of the morning was named "A Systemic Review of Family-led Interventions for Children with Communication Disabilities". However, despite the promising title, it was mainly about research methods. No one will be surprised to learn that more research is required although, reassuringly, the subjects that were exposed to Aided Language Simulation were the ones who made most progress with AAC.

No rest even at lunchtime where there was a delegate meeting for those interested in AAC for those with learning difficulties. There is a real concern that many of these individuals are falling through the gaps with the current Hub set up along with the episodes of care for SaLT services. There has not yet been any follow up from this meeting but all information will be shared.

Next up was "A Hub's Experience of Developing AAC Expertise in Local Speech and Language Therapy Teams" which in my opinion, and that of many others, was mainly disappointing as it seems that there are real concerns about the expertise of the local therapists and by the attitude of some of the SLTs in the session, who very much bought into the theory that robust AAC was not for all.

The penultimate session was taken by developer Tobii Dynavox on "Core First, Pathways and Boardmaker Online" and this seemed to be the most relevant. Pathways is a free app that is really useful for helping explain AAC to other people and I would recommend that everyone downloads it.

"I Want More Language" was the final talk and it sounded more promising than it started off. There was mention of PECS and pre-requisites although, fortunately, it went on to say that PECS has significant limitations and the pre-requisites are not actually required. The most interesting part of the talk were the questions at the end. I ended up having to explain to all the SLT's in the room how you can teach the same

skills as you learn with PECS, along with all the other skills required for communication in a more natural way with a robust system, and that you can save the 9 months that Pyramid say that you need to learn PECS before moving on. My hope is that at least one person will learn from it and change practice.

The day still didn't finish there as there was a parents' meeting chaired by Jules where we had an opportunity to raise any issues we wanted to with CM. We will update on this as soon as we have more information once CM have had the opportunity to review matters and report to us. The main topics of conversation were about the pre-requisites and support for parents who are being told their children aren't ready, as well as mentoring programmes and support networks.

The second day of the conference was all individual workshops with no keynote. The first topic was on an award that several AAC users attained this year in mentoring. Whilst I think the Angelman Syndrome community are a while away from this yet, I hope that as we progress our communication journeys this would be something that would become applicable to some of our own AAC users. This scheme was a successful pilot and it is being progressed further by CM.

The second last talk of the day was "A Roadmap to Successful Communication Using AAC" by Amanda Hartmaan from Assistiveware. She, along with Jennifer Marden, has created the Core Word classroom resources. These are invaluable free resources that contain great ideas for home as well as school. There were some really good tips on activities during the talk including dress ups and selfies, along with high tech versions for those who don't like physically getting dressed up, screenshotting favourite YouTube videos, drawing emojis onto balls and firing them across the room, hide and seek with favourite items, puppets and jokes. The general idea is to have fun and model at the same time. She also had some good general tips. People should start their communication journey by thinking about where they want to end up. Take time to reflect on where you are and think about how to progress forward to the next step. Seek help and advice if needed. Try to identify the key people you need to help you, these can be friends as well as professionals. She also had some good tips for communicating using AAC and being a good communication partner. You need to create the opportunities for your loved one to want to communicate. Be mindful of the appropriate wait times required for responses, using expectant pause (look like you are waiting for a response) and appropriate prompting either verbal (it's a pink word or it's near the top of the page) or gestural (what about looking in this area) but not physical. Also remember that the response is just as important as the first thing you model, you can either repeat or use the response to expand.

The last talk of Communication Matters 2017 was the one that had most people in the room buzzing with excitement (that I attended) which was on "Building Blocks to Literacy at Home" by our very own Jules Whicher. I have written a separate article on this and it can be found on page 19.

Tracey Campbell

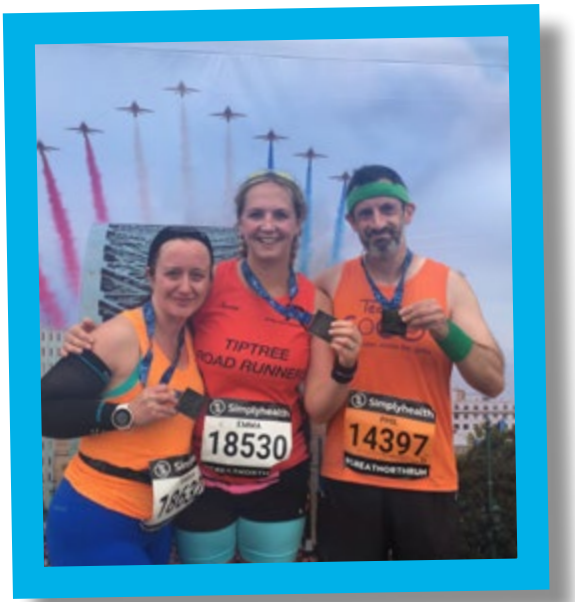
Fundraising

Tina Smith and Christine Maclachlan – Great North Run

This was my 3rd Great North Run and all have been memorable for different reasons. My first in 2013 was because I was 5 months pregnant with my little girl. My 2nd was 2015 we were a team of 5 all supporting each other so encouraging each other over the finish line was amazing, and this one was because I did it with my grandma. She turned 70 the week before and this was her 1st half marathon, her first Great North Run and her first run for ASSERT and she was beaming with pride as I was when I saw her come across that finish line, she wasn't going for time but she still did it in 3 hours 33 minutes which we are all as a family so proud of her. I've done 2 London marathons, a toughest challenge, London to Brighton (with our angel Flynn) and now 3 Great North Runs each for ASSERT, and each one makes me proud for different reasons, but the biggest reason we all do it for Flynn and other angels supported by ASSERT.

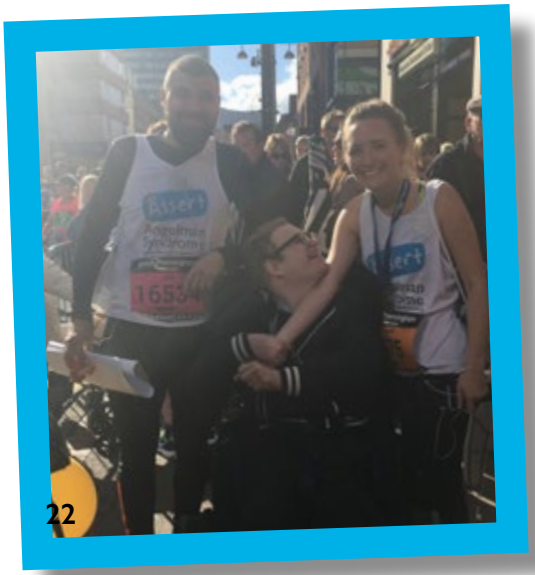
Mike Bennett – Great North Run

I was very happy to help out raising funds for Archie and everyone with Angelman Syndrome and being able to compete and finish the Great North Run Half Marathon was an amazing experience. I could feel the burn around 11 miles so I just thought of Archie & his wonderful smile.



Emma Goodson – Great North Run

OMG GREAT NORTH RUN! What a day! It was amazing. Not the best night's sleep but a very emotional day. Saw people running for charities all over that have helped William. Got interviewed by BBC and did a shout out for Colchester general hospital and ASSERT. My friend Nicola had an amazing day spectating. Managed 2 hours 27 minutes with two stops, one for a wee and one for a stretch. I did worry about William a lot and managed to send some texts during the run.



Lucy Mcgregor and Joe Jordan – Great Birmingham Run

Lucy and Joe ran the Great Birmingham run for ASSERT and raised £667.29

Vel Petrovic – London to Surrey Cycle Ride

Darko Petrovic and Vlad Lazic took part in the London to Surrey Cycle ride. Vel Petrovic was also due to take part, but unfortunately had to pull out due to injury. Between the 3 of them they raised £1,797 for ASSERT.

Tom Welland – London to Surrey Cycle Ride

Tom Welland, Thomas Long, Daniel Long and David Long took part in the London to Surrey Cycle Ride and raised £1,679 for ASSERT.

The MG Trophy Championship

ASSERT were nominated for a second year to be the charity of the year for The MG Trophy Championship. This is all because one of their drivers, Tim Martin, has a son who has AS and kindly put us forward. I was invited along to one of the race days to watch the cars speeding by and to also receive a cheque on behalf of ASSERT. The Silverstone event was great experience and the Court family all enjoyed watching Tim race and cheering him on. At the end of the day there was a presentation to all the drivers and it was then that I was invited to say a few words about ASSERT and to receive the cheque. I was presented with a cheque for £1,000. As it was such a ridiculously hot summer day one of the organisers had an inspirational idea to raise more money – she offered a "squirt for ASSERT" whereby she would spray you with cool water in exchange for a donation. This raised an extra £62. Brilliant idea! Thanks very much to Tim Martin and Pete Macwaters and everyone else involved in all the funds that have been raised for us.

Lisa Court

Michelle Vincent – Family Fun Day

I am very pleased to say that our family Fun Day raised £1,408 for ASSERT. The afternoon was amazing, I have been left with many memories to treasure. My daughter Klariece who is 12 years old had 14 inches of her hair cut at the event. This has been donated to the Little Princess Trust for a wig to be made for a child undergoing cancer treatment. Myself and some fantastic friends dressed up as well known characters for the kids. We had a bouncy castle, a photo booth, face painter, a man blowing up balloons, girls'/ boys' lucky dips, name the teddy, guess the sweets in the jar, cakes and sweets to sell. We also had a fantastic selection of raffle prizes. Ohhh and an ice cream van outside lol. It was fantastic to see some of our angel families there along with many people who had never heard of Angelman Syndrome.

Star Wars Day – The Crown, Sydenham

In celebration of 'Star Wars Day', May 4th 2017 saw The Crown Inn, Sydenham host a sold-out 'Star Wars' themed extravaganza, raising money for ASSERT. Bringing the region's biggest Star Wars fans together, guests had the opportunity to enjoy a feast of intergalactic treats, from vessels of 'Jawa juice' & platters of 'Jakku bread' to planet 'Endor' style suckling pig, pan fried bass fillet reminiscent of planet 'Scarif' or Yoda's favourite - 'Rootleaf Stew'. Dessert took the form of the much heralded 'Star Wars Chocolate Plate'... featuring moulded chocolate figures & ice cream planets, plated to resemble a live battle scene (lasers included), which had previously received much acclaim, appearing on BBC South.

A mind-bending Star Wars quiz weeded out the amateurs from the super fans, and the pub was decorated floor to ceiling with imagery from each of the Star Wars episodes, plus lightsabers, stormtrooper masks, and a life-size Darth Vader himself. With a meeting of minds, new fellowships were formed and alliances made - a fantastic time was had by all. With over £250 raised for ASSERT, the event was a great success, and plans have already begun for a repeat performance in 2018.

Pippa Simpson & Will Shaw

Ravi Jobanputra – London to Brighton Cycle Ride

Taking part in the London-Brighton Cycle Ride for ASSERT has been a massive privilege and a hugely uplifting experience. Whilst the training was challenging, the day itself was incredible. I managed to battle my way through stunning villages and country lanes as well as the dreaded Ditchling Beacon!! It was a great experience and I was met at the finish line by my nearest and dearest. I am so grateful to my friends and family for their support & generosity, which I know, will go a long way!

Suki Haywood

It has been a tough year for my family due to being in and out of hospital since Isla was 3 months old and not knowing what was wrong with Isla. After genetic testing we were told that Isla has Angelman Syndrome. I wanted to raise awareness for AS because none of our family and friends knew much about the condition but had been so supportive to us. So on Saturday 4th March 2017 myself and my mum Joan Brittain decided to raise money for ASSERT and so we held a tea & cakes day and we named it "Angelcakes Day". We baked and sold a number of home made yummy cakes, biscuits and goodies to sell to our family and friends to raise money for ASSERT and awareness of AS.

We had such an amazing and fun day, which also included a large raffle where we had so many lovely gifts for people to win. We got through nearly 3 whole books of raffle tickets so it was fantastic. My mum's house was packed with people and we didn't realise how busy it would be.

It was a chance not only to raise money for ASSERT but it was a chance to catch up with our family and friends and for them to come and have cuddles with Isla.
We were overwhelmed by the generosity of everyone who came along and the donations they made for the yummy cakes. After the event my husband Jamie took the unsold cakes to his work at NHS Protect (Elephant and Castle) where further donations were made.

Our initial fundraising raised £1,320 from 'Angelcakes Day' and £80 from NHS Protect giving the wonderful total of £1,400.

We have then had further donations from various other organisations. My sister in law Rebecca Brittain, Jenny Walker and I did a sponsored 10k walk which raised £2,111. The total amount we have raised is £4,178.

We would like to say a special thank you to:
Joan Brittain
The people who donated on Angelcakes Day
NHS Protect staff
Rebecca Brittain
Jenny Walker
Chigwell Nurseries
County Gate Lodge Freemasons
Slimming World – Ronnie and Sue Smith
CMS Cameron McKenna for donating £500 directly to ASSERT.

London Marathon

We had 8 runners taking part in the London Marathon 2017. 6 of these runners were registered against our Golden Bonds and 2 runners very kindly ran on their ballot place. (ASSERT have 5 Golden Bond places each year and we also had a place carried over from last year). Our runners were:

Golden Bond places

Sarah Brown
Gavin Smith
Clare Collins
Jane Tunbridge
Helen Bly
Scott Jones

Ballot places

Duncan Cottrill
Lisa Cutts

Our runners raised a massive £23,122.11

That is a phenomenal amount of money! We are absolutely thrilled to receive such a huge sum. As well as raising money our runners also raised awareness of Angelman Syndrome and raised the profile of ASSERT. Well done all of you, you have done an amazing job.

Clare Collins

13 years ago a little boy came into our lives, John Joseph Collins. Before he turned one, John was diagnosed with Angelman Syndrome. John is a beautiful, friendly, loving boy who is the centre of our family. Whilst as a family we understand John's needs, I hoped to make this relatively unknown syndrome known to more people so that ASSERT can progress with their great work.

It came to the big day. I had been training since the 26th December and logged over 300 miles but still I was incredibly nervous. I randomly met one other ASSERT runner at the Greenwich start line and we both hugged despite not even knowing each other's names!

After running past people dressed as rhinos and a man carrying a tumble dryer on his back, I luckily met my friend Grace, who had started at Blackheath and I at Greenwich, at 4 miles and together we ran the rest of the race. It was lovely to see so many of our friends and family along the way – especially as my family had a huge sign for me to spot!

Eventually we crossed the finish line in 5 hours 9 minutes.

My legs were exhausted and I was burnt red like a cherry but I am so incredibly proud of myself and the money everyone has helped me raise. I have raised £3,772.25 to go towards helping those like John.

Helen Bly

Another unsuccessful London Ballot in 2016 meant I could only run London if I secured a charity place. I had already eyed up a few marathons for the month of April and crossed my fingers that my nominated charity pulled my name out of the hat for their ballot. I was very lucky that it did and I received the news in December. This also meant the race was on to raise £1,500. Before the marathon even began I already went through months of organising events to raise the amount required to get me to the start line. A big relief when my target was reached before London and I could relax and enjoy the anticipation of running it for a second time. The first time I had run it in 2016 I was so nervous I made myself ill. This year I was just excited.

On the day of the race, we passed through the start line at 10.15 so 15 minutes behind the starting gun. I was running 9:15 pace, weaving around the myriads of people and Rachel was looking behind her for the pacers. The next minute she was gone. Well a solo marathon it was.

It was super congested, people running in huge blocks with hardly any gaps to get past. I ended up running on the pavements or up and over the centre of the road. Any way of getting around people to maintain my pace. 2.5 miles in I hear a shout from behind and Rachel has caught up to me. At 3 miles, the blue and red routes join together.

We ran together for a little while and I told her to be careful about not going off too fast as she will struggle in the later part in the race.

By 5 miles I decided I need to slow my pace as I knew I couldn't maintain my pace, and tried and drop to around 9:30 miling. I managed this for the next 3 miles but this pace started to slip away and I started to do 9:45 pacing. I was hot and my bag was chafing me. Mind over matter on this was getting me through and the thought of the feeling of Tower Bridge and seeing UKRunChat near 13 miles was getting me through. At around 6 miles, The Cutty Sark usually a great place for cheering was full of people this year, but all waiting for friends and family, there were no shouts or claps for the runners. Tower Bridge is a shining moment in the marathon. The noise is like nothing else. It felt amazing to be running over Tower Bridge again.

I knew from previous experience that it's a slog and a mental battle from 13 and my legs did not disappoint. They had already dropped to a tiring 10 minute mile at mile 13 and felt like I was starting to drag weights.

Going toward the Isle of Dogs, mile 16 my legs decided they were indeed made of lead and pacing dropped further but I knew that if I kept going I could still PB. Just keep going. Canary Wharf was coming up and both mile 18 and mile 21 were hell – both almost 11 minute miles and I never stopped running. My head never gave up yet every bit of my body was ready to. I was so tired. Every ounce of me wanted that London PB.

Just past mile 24 I saw Jen who called my name, I looked slightly deliriously at her as it took me a moment to realise who it was. It was great to see a familiar face. I waved briefly as I had passed and this spurred me on to Big Ben, mile 25 and almost there. Honestly you are almost there. I could taste that PB in my mouth. It felt great running down Birdcage Walk seeing 800m, 400m and turning the corner into The Mall. I was ready to finally get my sub 4:30. I had been dreaming of this since I ran my first marathon 2 years ago. I raised my arms and almost cried through the finish line, in relief, in happiness. It had been one of the toughest races I have done. Trying to get a PB, the amount of people, the heat, tired legs. Many reasons but tough all the same.

Jane Tunbridge

10 years ago I did the Great North Run, & as my son Sean turned 18 in December 2016 I wanted to do something big to mark this huge milestone, after considering different options, I said sod it I am gonna go for the big one & that was The London Marathon. So 10 years after doing a half marathon I was going to aim to do the full marathon.

At the time, when I told everyone, they thought I was mad & even I thought it was crazy, but with the logo #teamsean & my best friend Lisa Cutts running with me I knew I could do it. Sean faces a lot of challenges, & he's always smiling so this pushed me even more.

It was hard as I'm not a runner, & I live in Gibraltar & Lisa lives in Broadstairs, but we both got a running app, & managed to synchronize our runs. With the help of a personal trainer he kept me on track, & I started to really enjoy my runs. I felt really good & had more energy for Sean.

Everyone in Gibraltar knows Sean so the fund raising was the easy part. I targeted big companies, & did a bake sale, a Body Combat workout & the Yoga centre donated funds from their Flag day which I took part in too. The donations just kept rolling in! Everyone was very generous & I managed to raise £7,157.41 for ASSERT & £7,211.41 for the Gibraltar Disability Society. Lisa ran for Whizz-kidz but also raised £ 3,543.46 for ASSERT, so that kept us focused to continue.

On the day I felt very proud in my ASSERT vest, we knew that we wanted to enjoy the race, we paced ourselves & took in the atmosphere, & it was such a buzz. I always knew we would finish it, & we never doubted it. What an amazing day, I couldn't move the next day, but felt exhilarated. I still can't believe I completed it. Sean was at the airport with his friends & team waiting to surprise me.

Events for 2018

ASSERT have a number of events available for 2018. Unfortunately the Golden Bond places for the London Marathon 2018 have been assigned. If you would like to put your name forward for 2019 please email assert@angelmanuk.org. The events currently available for 2018 are given below. For the first time we have purchased some places for the Great North Swim. We are hoping this will be just as successful as the runs. Please do ask family, friends, neighbours, colleagues, in fact anyone you know if they would like to take part in one of these events and raise funds (and also awareness) for ASSERT. The places will be allocated on a first come first served basis. Please email assert@angelmanuk.org to request a place. Please also use this email address for any queries.

Great North Run – 9th September 2018

Great South Run – 21st October 2018

Great North Swim – 8th – 10th June 2018

London to Surrey Cycle Ride – 29th July 2018

London 10k – 28th May 2018

Thank you!

Safety Sleeper

ASSERT is thrilled to be able to offer two families the opportunity to trial the Safety Sleeper bed from Murray's medical.
www.thesafetysleeper.co.uk/index.html

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

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

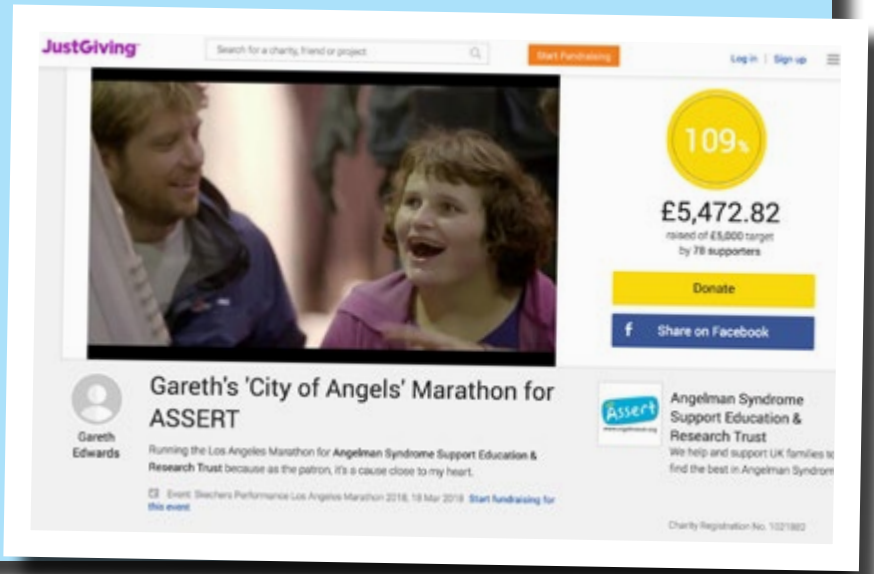
".....We strive for The Safety Sleeper™ to become every customer's choice in their pursuit of creating a secure and safe environment for their loved one, every night, at home or wherever they may travel."

The Safety Sleeper
A Fully Enclosed Bed System for Special Needs Families

Gareth Edwards and the 'City of Angels' Marathon

Gareth has rather foolishly decided to run a marathon! I didnt believe he meant it until he set up his donation page but it would appear he is serious. He has to be the most unsporty person there is. So that in itself should be enough to pledge a few pounds, just because he is putting himself through 26.2 miles in LA to raise funds for ASSERT. But to make this even sweeter, he has promised to match all the donations with a personal donation so ASSERT will receive twice as much money. Therefore if you have a few pounds spare please take a look at his page and make a donation. Every pound you donate will mean £2 for ASSERT. This could be quite costly for him both physically and financially! The link to his donation page is below. He hit his target of £5,000 within a few days of setting the page up but that doesn't mean the donations need to stop. Feel free to share this with anyone and everyone you know.
I want to maximise the money that we will receive.

www.justgiving.com/fundraising/gareth-edwards-la-marathon



Lisa Court

Easy Fundraising

ASSERT are registered with EasyFundraising. This is a great way of purchasing items online and automatically making a donation to our charity. There is no extra cost for you here, and it does not take any more time. So there is no reason not to do this! Please visit the website and register. Going forward, any eligible purchases can then be done through EasyFundraising and ASSERT will automatically receive the donation. This 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
- www.transitioninfonetwork.org.uk
(Transition)
- www.challengingbehaviour.org.uk
- www.learningdisabilities.org.uk
- www.carers.org
(Now Carers Trust, no longer Princess Royal Trust)
- www.carersuk.org
- www.mentalhealth.org.uk
- www.bild.org.uk
(British Institute of Learning Disabilities)
- www.rcslt.org
(Royal College of Speech & Language Therapists)
- www.talkingpoint.org.uk
(Information on children's communication)
- www.ican.org.uk
(The Children's Communication Charity)

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

Fundraising:

London Marathon:
Jane Tunbridge
Gavin Smith
Clare Collins
Helen Bly
Sarah Brown
Scott Jones
Duncan Cottrill
Lisa Cutts

London 10k:
Dave Windridge
Julian Munsey
Lisa Howton
Anna Knight

Great South Run:
Michelle Walecki
Sarah Brown

Great North Run:
Mike Bennett
Bethany Pye
Alice Pye
Pam McCullagh
Alex Fensome
Tina Smith
Christine Maclachlan
Emma Goodson

London to Brighton Bike Ride:
Teresa Ellinor
Tina Smith
Lee Ellinor
Simon Smith
Louise Dorian
Flynn Ellinor
Ravi Jobanputra

London to Surrey Cycle Ride:
Vel Petrovic
Darko Petrovic
Vlad Lazic
Tom Welland
Daniel Long
David Long
Thomas Long

Tough Mudder Challenge:
Marie Harnett
Tom McGregor

Just Walk:
Rebecca Brittain
Suki Haywood
Jenny Walker

Rachel Abraham	-	Manchester Marathon
Gill Jordan	-	3 Half Marathons
Kay McKenny	-	Coffee Morning
Kelly Fount	-	Hampshire Hoppit Trail
Colin Pery	-	Shrewsbury Half Marathon
Mike Kilgannon	-	Dublin Marathon
Eve & Ollie Tuson	-	Bike Ride
Chris Baxter	-	Great West Run
Stuart Matthews	-	Leicester Half Marathon
Charlotte Dunne	-	Oxford Half Marathon

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

Many thanks to...

Donations!

Mrs Hazel Tait
Audrey Sinclair
The Old Portmuthian Chapter 8285
Corfe Castle CE Primary School
In memory of Mrs Lily Tompson
Pete's Plaice
Beverly Burrows
The MG Trophy Championship
In memory of Mrs Mary Biggs
In memory of Mrs Lynne Booth
The Phoenix International Charity
Mrs Elizabeth Gunn
Masonic Charitable Foundation - Munia Lodge L4096
Elham Taherkhani
K Newbould
Paddle for Life 2017
Prue Purser
David Roberts
Monica & Claudia White - Bridgnorth Walk
Ravenhurst Primary School
Hillgate Travel
Mr & Mrs Boyes
Mrs B Fox
Kingswood Primary School
FQM Ltd
History Society of Sheffield University Students Union
In memory of Mr Stuart Robison
Peter Vardy Foundation
Sheffield University History Society
Warwick Preparatory School
Ajax Sea Scouts
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Mrs Kathleen Webber
Seraosha
Stephen Roberts
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Gina McDonald
Suzanne Morris
Tim Yates
David Tucker
Christine Searle
Stephen Lees
Sarah Cockerton
Louise Shaw
Peter Mullen
Noel Protheroe

Thank You!

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