



Newsletter 55 Autumn 2014

Angelman Syndrome
Support, Education & Research Trust

**ASSERT National
Conference 2014**

**2015 – The big
announcement...**

Joshua's new home

**International
Angelman Day**

**Ice Bucket Challenge
for AS**

Regional Meeting round-up

**Fundraising
reports**



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Useful Stuff

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HELPLINE
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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

2014 saw our 8th biennial family conference. Over 400 people attended the Hilton Hotel in Coventry. I am sure that you will join us in saying that it was the best conference so far. Speakers shared expert knowledge in the fields of communication, science and research, the new SEN guidelines, behaviour, genetics and neurology. International speakers Erin Sheldon, mum to Maggie (AS) and Mary-Louise Bertram, a Speech and Language therapist from Australia brought the communication revolution to us here in the UK and inspired many of us. ASSERT will do all we can to support you and your new communicators on their communication journey. To start you on your way we have arranged a training day with Proloquo2go which is being held in February 2015 in Coventry. Please see page 20 for more details. Also, we are hoping to see both Erin and Mary-Louise again next year for a series of parent and professional workshops. More on that at as and when the details are confirmed.

Once again we owe our photographer Rob Chadwick a huge amount of gratitude for donating his time to photographing our children at the conference. Many of you now have some beautiful photographs of your children and we have a stunning portfolio to use in future ASSERT publications. If you have not yet requested your conference photos, please turn to page 20 for more information.

ASSERT would also like to say thank you to the staff at the Hilton Hotel who again went above and beyond to make the weekend run as smoothly as it did. And we can't forget to thank the trustees who repeatedly dedicate a large portion of their free time to organising the conference often sacrificing time with their own families so that you, our ASSERT families, can experience the camaraderie and friendship to be found when we get together. You will be happy to know that we have already booked the venue for 2016 and are currently working on who to invite to present and exhibit... all suggestions are welcome at this stage.

By the time you are reading this, Dr Katie Cunnea, Christyan Fox and myself will have been to the 3rd European Angelman Syndrome Alliance meeting in Paris where we will also have attended the AFSA French family conference. Meeting the international scientists who are researching AS allows ASSERT to bring you up to date information and strengthens international relations. The world is a smaller place thanks to social media but meeting our international family is far better in person. Please see page 21 for details of the programme.

Next year, 2015, is very significant in the world that is Angelman Syndrome. Not only would it have been Harry Angelman's 100th birthday, it will also be the 50th anniversary of Angelman Syndrome first being reported by Dr Angelman. With that in mind, we have a very exciting announcement to make. Please see page 21 for more details.

The ASSERT trustees hope that you have an uneventful and healthy time over the upcoming holidays and we look forward to 2015 with excitement and anticipation.

Rachel Martin

And a word from our Patron Gareth Edwards...

It's a real privilege to be the Uncle to Ella, my niece who has Angelman Syndrome, and even more of an honour to be the Patron for ASSERT.

I'm really sorry I couldn't be there for the conference this year but I heard it was a huge success. I will be over in the UK with Star Wars next year, so hopefully I will get to meet you all at the Gala in 2015... until then, may the force be with you!



Siblings Just for Us!

Jonathan Allen

Firstly, I must say how fantastic the conference was and what a positive experience I had throughout the weekend. I was proud to be the sibling representative and to be the sibling voice to parents in my workshops, but also felt proud by the way siblings interact with their AS brothers and sisters.



When I was growing up I became increasingly aware that sometimes my friends didn't understand the condition that my older sister, Eloise, had. This was my first national conference and to see all of the siblings interacting with one another, making new friends and seeing old friends from past conferences was

something I'd never comprehended before. It only serves to show how beneficial the conference is not only to parents but to all family members.

Additionally, the trips to Drayton Manor and Twin Lakes were so enjoyable for a lot of the siblings, although a lot of the AS individuals seemed to be a lot more fearless than I about going on the rides!

What struck me most was just how good all the siblings were with their brothers and sisters. Their importance in the lives of those with Angelman Syndrome was obvious and the sibling's conduct was a testament to their families.

All of our experiences as siblings, whilst similar in some areas, are wholly unique to us and some of us face different scenarios to others. In my workshops I tried to focus on four key areas that most affect the lives of siblings: a lack of attention, schooling, understanding and transition. I feel that these were key issues and judging from the high level of interaction from parents it would appear this is true. This interaction also enabled parents to share positive experiences with one another of things they do to counteract some issues presented to siblings and the family environment.

It was my aim that both parents and siblings could leave the workshops in the knowledge that important issues had been raised that otherwise may have been overlooked in a family environment. I also hope that it leads to closer family relationships that can easily become fraught when one member has special needs.

I appreciate these issues are by no means exhaustive, and problems can also be unique to some families; in which case please feel free to contact me if you wish – my email is below. Additionally, many families were unable to attend so if you want more information on the workshop I presented please do get in contact.

As fantastic as the 2014 conference was, I want to hear your views on what could be made better for siblings in the future, whether at conferences or otherwise.

Please contact me at: jonathan.allen@angelmanuk.org with your suggestions!

Reece Jones

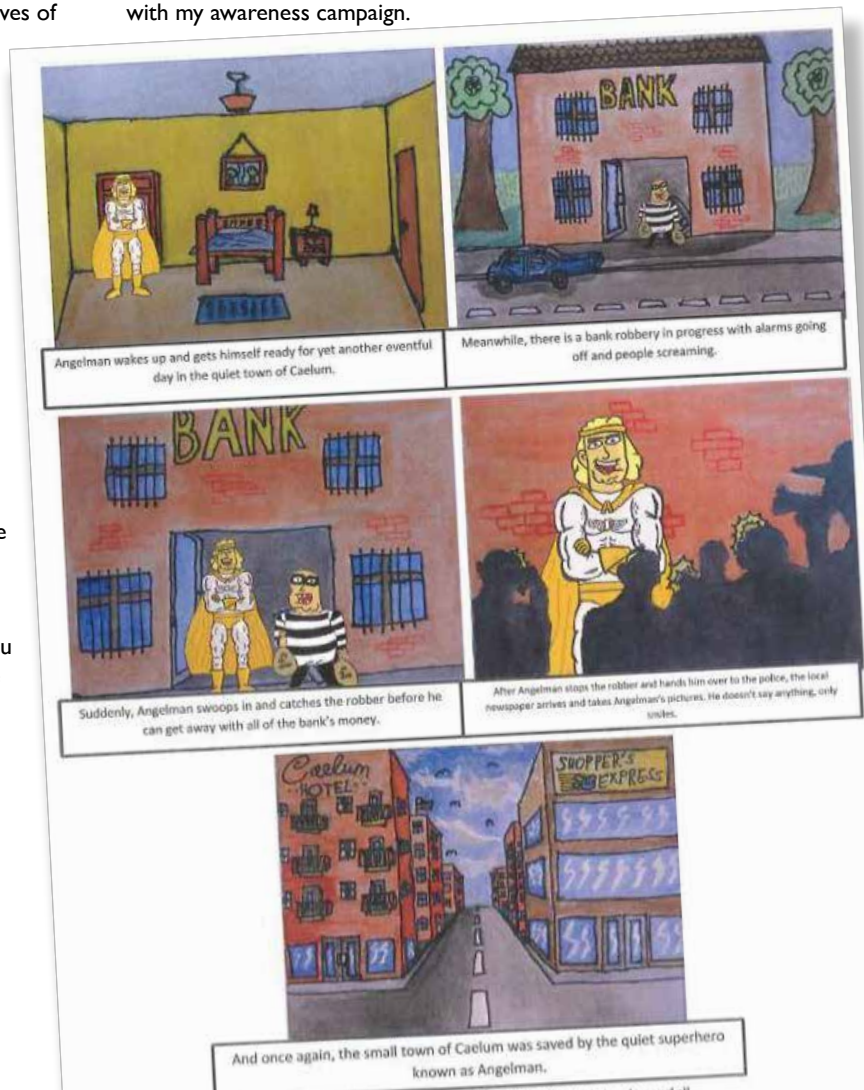
Just before Christmas 2013, my twin brother, Theo, was finally - after nearly 18 years - diagnosed with Angelman Syndrome, after being told he had Cerebral Palsy when he was younger.

This was purely by chance, as Theo was struggling with his legs and his walking. We saw a specialist to find out why and were told more than we bargained for. The specialist ran some DNA tests and the results came back 'Positive' that he had Angelman Syndrome. She also did some tests on my mum and it turns out that it was just a one-off, and will not affect any of my cousin's children or my children.

It was after this that I decided to dedicate an A-Level art project to Angelman Syndrome. Because of the name being 'Angelman', I decided to turn Angelman into a superhero and make a comic strip to outline some of the symptoms. I also made a leaflet to explain what the condition was and what ALL the symptoms are. This was all done on Photoshop.

After I completed the project, I decided to take it further and create an awareness campaign. My goal is to make it as well known as Cancer, Down Syndrome and Autism.

I have created a Facebook and Twitter page, and have had an article featured on the front and back page of my local newspaper. I have also been on the North West news. I am hoping to continue with my awareness campaign.



We are always really keen to receive your pictures, photos, letters whatever you would like to send so that we can print these in future newsletters.

Here's a photo of James Windridge and his letter about his brother Toby.



Toby is my super hero because
he's my brother. Do you
think I care, That's what you
angelman syndrome?
I don't care I just love him.
he's fantastic and always
happy

by James W age 6



Assert Sibling Group

www.angelmanuk.org/siblings

It's growing all the time. So if you're old enough to be on Facebook, join us and let's hear from you.

Linda Hopkinson

I am sure that many of you remember Linda Hopkinson who used to attend our conference along with her carers. Linda sadly passed away in 2012 and I think it's true to say that her presence at the conference is missed by all who met her. Mark Rushmere was Linda's carer and friend and recently took the time to write to ASSERT about what Linda meant to him. Finding a good friend and carer for our loved ones with AS is high on most parent's agenda, and I'm sure that Linda and her family were very grateful for Mark's friendship. ASSERT would like to thank Mark for taking the time to learn about Linda and how Angelman Syndrome made her who she was.

My Friend Linda

Today is International Angelman day, I've been to Linda's grave (her Mother Vera and Father Alan are buried there too) it was freezing cold with a low grey sky and the wind had blown numerous flowers and keepsakes over. Somehow I managed to jam the pink roses (Linda loved pink) into that colander bit in front of the headstone where they stayed up right despite nature's best efforts, I tucked a little note to Lin under the elastic band holding the flowers in place and sat on a nearby bench. Grey skies and cold winds really don't seem appropriate for Angelman Day and certainly not for reminiscing about Linda. Even on the day Linda past away the sun shone into her bedroom if nowhere else in the world.

Looking back on the years spent with Lin it's difficult to pick out specific moments most of it is one big blur of hysterical laughter, teddy bears, giggling fits, rubber ducks, hysterical laughter, ripped up magazines, dribble, spilt drinks, broken toilet seats, hysterical laughter, giggling fits, more dribble, rubber cows, Chitty Chitty Bang Bang, laughter-induced flatulence and more giggling fits.

Our bond was by no means instant; I can remember when I first started working with Linda, she would sit at one end of the sofa and I'd be at the other. Over time Linda gradually moved further down the sofa to the point where she virtually sat on me, I'd be there doing the paperwork as Linda would bobble around strangling her teddy or chuckling at people getting hurt on Casualty (I remember one episode where a little boy fell out of a tree and landed on his head, Linda found that particularly amusing). My handwriting was appalling enough in the first place without the aid of Linda's excitable elbows. Every time she jogged me I'd complain loudly much to her amusement.

Linda liked it when I was noisy (and a little bit naughty), when no one else was at home I'd empty her entire toy box all over the floor, crank up her Keisha CD and blast the football around the

living room whilst shouting "Rooney!" Again much to her entertainment, Linda's laugh was extraordinary, a highly contagious mix of Popeye and Sid James, filthy but completely endearing. These days if no one else is at home I occasionally shout "Hopkinsonnn!" and I can still hear that smile inducing chuckle echoing down the hall way.

Having put this off for so long due to not knowing what to write I've now realised that I could write endlessly about the time we spent together.

For the most part our relationship was based on trust and a whole lot of mucking about and I mean that in a positive way, fun was Linda's main motivation in life (apart from maybe cake and custard) so by making everything we did together fun things kinda' worked and if that meant both feet going into the same trouser leg now and again then so be it. Getting Linda ready for bed often resembled that Laurel and Hardy film, the one where with they move a piano upstairs. Once she was in her pyjama's I'd shout "last one in is a rotten egg" and we'd both race to her bed, I generally let Linda win these races but occasionally I'd jump in too, again much laughter ensued.

I often find that working with individuals with severe learning difficulties who are non-verbal (I really don't like that term doesn't seem particularly accurate when I consider the amount of noise some of the tenants make) the most meaningful moments are the tiniest, a shared smile or look a held hand, I can't quite put that in to words but I'm sure those of you reading this will understand.

As much fun as it was working with Linda, being part of her world was so much more than that, working with adults with learning disabilities is a privilege and gaining their trust and friendship despite the obstacles faced is truly a wonderful experience and in all honesty being a part of Linda's life is still the best thing that I've done with mine.

I recently came across a quote that for me sums up working with adults with learning disabilities perfectly:
"Don't walk behind me; I may not lead. Don't walk in front of me; I may not follow. Just walk beside me and be my friend."

Albert Camus

Mark Rushmere





Conference Review 2014

Over 20 years ago now my parents were two of the founders of ASSERT and they ran it for about 8 years. The charity has had a significant impact not only on my life growing up, but on us all as a family.

When the charity first started it was literally ran out of our home lobby. The charity phone line was there and our house was always busy. The first meeting was only a very small number of families and my parents never imagined the charity could grow to the level it is at now. For over 400 people to attend the weekend is not only incredible but also very moving for my parents who came on the Sunday.

I have been very fortunate in that in March I was able to join the board of trustees to represent sibling's views and provide support for them. This August was the first time that I have been able to attend an ASSERT national conference and I loved every minute of it.

Seeing all of the families and angels arrive on Friday was great for me as I had never been in such a natural environment where I didn't have to explain the ins and outs of the condition that my older sister, Eloise, has but instead everyone understood immediately.

The trips over the weekend were also received well. Many of the siblings and angels alike loved the big rides; although I must admit that I backed out of a few and certainly screamed on the ones I went on!

I think I speak on behalf of everyone who attended when I say what a high standard of speakers we had at the conference this year (excluding myself at the risk of sounding arrogant!). I certainly learnt that I underestimate Eloise's potential capability and her level of understanding.

I was delighted to be asked to give a workshop myself on issues facing siblings. Expanding this area of focus, which has only become more prominent in recent years, serves to show how forward thinking ASSERT is still and that we as trustees and families are developing.

ASSERT has been through two generations of my family now; going full circle. The way that the charity has evolved could not have been done without the support of so many families, donations and those who have guided it over the years.

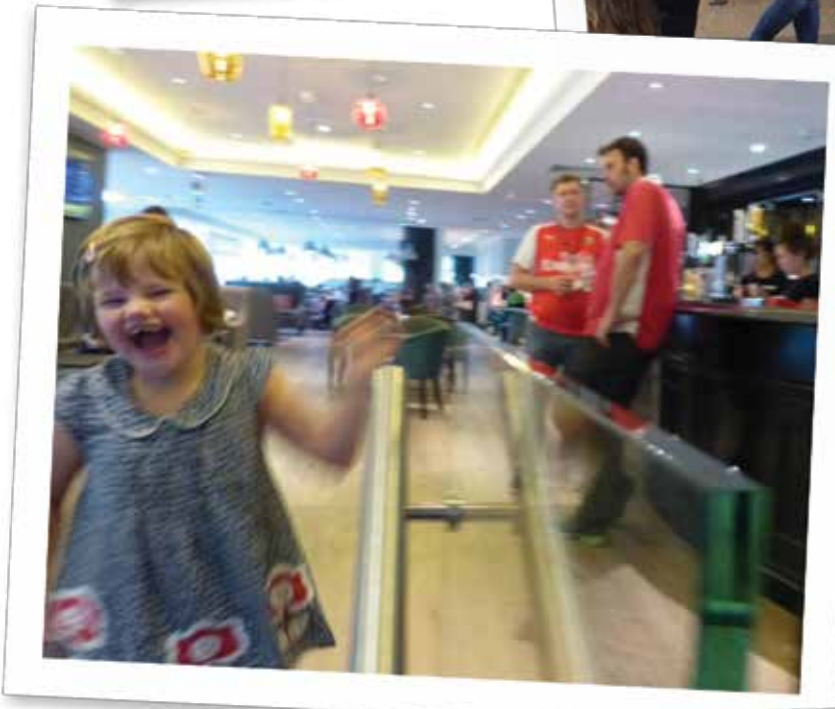
I would like to take this chance to say thank you to you all that make it such a fantastic charity for me to be a part of (and also to the staff at the Hilton Hotel who were fantastic all weekend!). If nothing else, the angels certainly left their mark(s) on the automatic doors of the hotel with literally thousands of finger prints!

Jonathan Allen



Conference 2016

Can you believe that Lisa Court (or 'The Mistress of Efficiency' as we like to call her) has already organised the dates of the next conference in two year's time? Please put the dates of Friday 2nd September – Sunday 4th September 2016 in your diary to ensure you keep the weekend free. The conference letters and application forms will be sent out early 2016.



2014 London Marathon

ASSERT have 5 golden bonds each year. Unfortunately 2 of our golden bond runners had to defer their places until next year due to injury, so we had 3 golden bond runners for 2014 and 2 runners who very kindly ran on our behalf with their ballot place:

| | |
|-----------------|--------------|
| Gemma Ellis | Golden bond |
| Michael Fisher | Golden bond |
| Karl Scally | Ballot place |
| Iain Lovett | Golden bond |
| Matthew Vaughan | Ballot place |

We've received the massive total of just under £8,200 between our 5 runners. Another fantastic effort from all those involved! We are truly grateful for your efforts, its no easy task running 26 miles.

ASSERT have 5 golden bonds for the London Marathon 2015. If you would like to be considered for one of these bonds then please email lisa.court@angelmanuk.org by 30th November 2014. The minimum sponsorship is £1,500.

Gemma Ellis & Michael Fisher The London Marathon 2014 was a day we will never forget. When we began our training regime it was hard to vision being able to run 26 miles when we struggled to run two! But little by little together we found it easier and easier and were running further and further.

The training regime was hard, especially in the cold winter months! But at all times we had ASSERT in mind and the fabulous work they do and how much the money we would raise would affect children's lives. We were honoured to be running for such a great cause as it is also one close to our hearts knowing a little boy that is living with this syndrome. His family praised Assert for everything they have done for them and told us how much the money we raised would directly affect him. My boyfriend and I were shocked with the generosity when it came to fundraising and couldn't believe that we not only reached our target but raised more than we ever could have imagined. When the money had been raised the reality of what we were going to do really sunk in and the few weeks leading up to the marathon we were feeling very nervous. Nothing could have prepared us for the ups and downs we felt on the day. The last 6 miles were the toughest but the crowds support and motivation meant we never gave up. The atmosphere was truly amazing. When we crossed the finish line together we can honestly say there was never a prouder moment for both of us. We will never forget that amazing feeling knowing we had not only achieved something personally so amazing but also we had done it for such a great cause made it all worthwhile!

Karl Scally London Marathon 2014 was an automatic placement as I'd deferred my previous year after breaking my leg on a training run. Training started in October 2013 and I ran in all weathers over winter determined I was going to get a new personal best.

On the day the journey across London's underground starts quietly with a few runners on the trains, gradually stop by stop more and more runners with the red Virgin London plastic bags get on until the train is packed. Half a mile walk to the start from the train give you time to calm down and take a few moments to get your head clear. I like to arrive early to wander around, relax, spot the celebrities, see all the

different fancy dresses and to soak up the atmosphere.

I'm lucky with my start position

as my finish time allows me to be towards the front of the starting areas. Even in my position near the front it's a mass of arms and legs for the first mile all running fast. Slowly the crowds open so you can start finding your own pace. The first 10 miles pass quickly with a party atmosphere all around you, music playing through speakers, live bands and masses of supporters.

Approaching mile 12 at Tower Bridge the crowds get louder, you turn right onto the bridge to be met by a wall of sound, this is the loudest area of the course and you can't hear yourself think. Off the bridge turning right towards the city you're now hitting half way and might see the leaders coming down the other way in the next couple of miles, this year I didn't see any. Into the Isle of Dogs and the City at mile 15, my wife and daughter are waiting to wave at mile 19 so this gives me a boost to know they're not that far away. Crowds are definitely quieter and more sparse for the next few miles. Quick wave for a photo moment at 19 then it's a race to the finish. Mile 20 this year I knocked out my fastest mile, going through it at 6min30 pace, seeing my daughter and wife at 19 giving me a bit of a boost.

Down out of the city to go past the end of Tower Bridge, I'm at mile 22 at this point seeing the thousands still going the opposite way at mile 12 still making their way up to the city. It's now a straight run down the Thames to Big Ben.

Right turn and down to Bird Cage walk. This is the worst part of the run for me, you know at this point it's about a mile to go and now all you want to do is finish. You're so close and yet it seems so far. There are signs every 400metres counting down from the mile marker, each one feels a little further way from the last and you feel like you're never going to get through the last mile. Eventually a 200metre sign appears but you still can't see the end, last right hand turn into the Mall to see the finish line, you muster whatever you have left to sprint to the end.

Your medal is given to you as you cross the line, goodie bag and then the next 20 minutes you're being photographed, finding your bag and trying to get through the crowds and out to meet your family and friends. In all this your legs are seizing up or cramping and you're struggling to walk. Over the next few days you're in pain every time you move your legs and you swear you'll never do it again but the moment that ballot opens you're back online to register. You've to work hard, endure so much during training and on the day but there is no words to describe the elation of crossing that line.

Iain Lovett Even after suffering a tear to his Calf Muscle a short while before, Iain Lovett was determined to take his place in the London Marathon for ASSERT. Iain is a brilliant supporter of ASSERT because of the support it provides to all the families, including ours.

Despite several tears in his calf muscle in the last 40 minutes he kept going and did 4hr 33 which was 32 mins off his last marathon time so he was very pleased, especially as he had trained in the cold and on the day it was much warmer! Iain was the only runner to go back on himself at one point, he missed his family at one marker and then at another, so he went back to see them which gave him a massive boost.

Iain is so pleased to support ASSERT, he recently spent a couple of hours with me at our house with Sophie and his Labrador, I think he was exhausted when he left! Iain is so pleased to have been able to support ASSERT, he feels we are worth every penny. **Tracy Dunne**



2014 Bupa Great Runs

We're very grateful to everyone who has taken part in the various Bupa Great Runs this year and raised much needed funds for our charity. Well done to every one of you who ran for ASSERT, your efforts are much appreciated. ASSERT have applied for a number of places for the Bupa events for 2015: Great Edinburgh Run, Great North Run, Great Manchester Run, Great Birmingham Run and Great South Run. The minimum sponsorship is £250. If you would like to put your name forward for one of these runs please contact: lisa.court@angelmanuk.org

Chris Stratford After running two London Marathons raising money for ASSERT I was delighted to only have to go half the distance this time and run the Great North Run. It was a wonderful day which started with a knock at the door at 4.30am from fellow ASSERT runner Nigel Flook and we headed up to the blue skies of Newcastle. The occasion couldn't have been better, sunshine all day and an incredibly supportive local community out en masse to line the 13.1m route.

I had set myself a target of 1:35 which would have been a personal best and I beat that by a minute, finishing in 1:34:10. Thanks to everyone who sponsored me once again with all the monies going to ASSERT.

David Collis-Smith Sat 7 September I was in the blazing sunshine at the start of The Bupa Great North Run - right at the front with about 200 'elite' runners and recalling my little white lie on the application form about my expected finishing time; I'd never believed it would make a difference to where I started, but on this occasion it did. I was mingling with my fellow runners and warming up with 90's icon Mr Motivator. Another runner engaged me in general running chit chat - what marathons I'd run before, personal best times etc. I knew I was in for a tough time when he told me he was running to the end then turning around to run all the way back in about 3 hours!

A 10.30 start - well, kind of a shuffle until you cross the actual start 20 metres further up - those at the back take up to 40 mins to cross the line. Crowds three or four deep for the first mile or so. I normally run 8.30 minute-miles in training, but at this point I was having to run a 6.30 minute mile just to hold the swarm of runners overtaking me! I couldn't look like Mr Slow so I went for it, concentrating so much I hardly noticed crossing the impressive Tyne Bridge.

After 3 miles the crowds thinned so I took the opportunity to slow to a more modest pace - just as the first brutal uphill arrived, actually lasting for 3 miles! The sun was blazing and I was leaking gallons, only thinking about how long I'd have to go until the downhill and finish - not good when you're less than a third of the way round. The downhill section finally arrived and I started to relax and regain some confidence - and for the first time started to smile as I enjoyed the surroundings.

The crowds were giving out sweets - even some beer - but at 11 miles the 'wall' thing hit me. A slow mile followed but suddenly we saw the sea and boy I could smell those chips! All the boost I needed to give me a push to the finish - an awesome sight with thousands of spectators to shout and encourage the runners. It kind of became a sprint passing the 800m then 400m - I have never been so pleased to cross a finish line!

I started the race with about 200 runners in front of me; I came in at number 10,060 so was overtaken by a few! But in the context



David Collis-Smith



Poppy Cartwright



Catrina Fraser

of over 50,000 runners behind me and I finished in a respectable 1h 56 mins which I was extremely pleased with. Can't wait till next year!

Poppy Cartwright As if getting up at 8am wasn't difficult enough for a slightly lazy 20 year old, I then remembered I had a half marathon to run - a daunting prospect as I had only managed about half that in 'training'. Countless nervous wees and a 30 minute walk from our starting positions (way back with the pantomime cow and someone pushing a wheelchair) to the start line, the whole event began to feel like a 13.1 mile run to the toilet. I hadn't given much thought to running that sort of distance but was hoping the huge bowl of pasta I'd eaten the night before would just somehow carry me to the end, and all of a sudden we were off.

I was shocked by the amount of people on the streets to watch the Great North Run and support everyone, but was glad to have my mum running along with me, for most of the way at least (something started to ache at around 11 miles and - caring daughter that I am - left her behind). The water points didn't help my need to use the toilet. At one point I considered stopping to use a portaloos, but feared if I sat down I may never get up again. Aside from needing the toilet before even crossing the start line I was concerned about going 3 hours without being fed, so you can imagine my joy when members of the public were handing out biscuits and slices of orange along the way. At one point my mum and I even shared an ice lolly which I was later informed Mo Farah had done in the morning race, maybe I was doing it right after all.

I crossed the line at 2 and a half hours, aching in places I didn't know existed and couldn't quite believe I had run that far. I peeled my sock away from my gammy toe and wondered what had kept me going the whole time; the enormous bowl of pasta the night before, the ice lolly, the fear of 'jelly legs' if I stopped, or maybe just my happy, smiley brother whose photo I had pinned to my 'ASSERT' vest and who I knew would have been cheering me on the whole way.

Catrina Fraser Sun 27 April I took part in the Bupa Great Edinburgh 10m Run with my 2 friends Angela Carmichael and Allison Donnelly and fellow Angelman mum Mairi Leith-McGaw. We slightly underestimated what we were putting ourselves through; we did some light training - by light I mean none! We started off strong, powering through the first 4-5 miles then dragged ourselves through the remaining miles. Well all but Mairi, she's super fit. We had a great time running, laughing, crying, walking and limping our way to the finish line.

As we neared the finish line I was getting emotional thinking of my angel and the others that I was doing this for - then I saw Angel Jon and that's when the tears came. I suppose it's not about your fitness level but more about willpower and our love for helping raise awareness and funds for ASSERT. Once over the finish line we received our medals and also a wee cuddle from Jon; that made all the tears and sore feet worth it. I was quite literally dying as were my 2 friends; Mairi on the other hand looked like she was ready to start a race not just finished one, I said I would never do another 10 mile run but I know come next year I will have my name on that list and be unprepared again, but I love doing it for our Angelman kids, and I'm no gonna lie, the KFC and the box of 24 Krispy Kreme donuts helped on the journey back to Clydebank!

More fabulous fundraising...



Syndrome and we appreciate everything you guys try to do. We look forward to working with you again soon.

Zoe Gilbert & Faye Hennessey

Team Ally

Both Leila and Jed Ally finally had their lovely long hair cut earlier last month. The evening was covered by the local newspaper, which made the hair cut a truly special event for all. The children enjoyed every minute of it, even though mummy was extremely apprehensive!

In previous weeks Leila and Jed with the help of school friends and mums held awareness assemblies to promote their sister Eurielle's (Belle's) condition. Further to this we held two events at the school; A 'Bits and Bobs for Belle' and 'A Badge and Bracelet for Belle' stall.

TEAM BELLE raised a staggering £832.42. After a few extra donations from friends and family, including our family Ice Bucket Challenge the total is £1000. This will be split equally between ASSERT and Eurielle's sensory room fund.

We're so proud of what the kids have done - not only managing to raise a huge amount of money but also generate awareness for ASSERT and Angelman Syndrome.

Laurence Ally

Sponsored Walk

Our Company - Alun Griffiths (Contractors) Ltd - hold an annual charity walk to raise money for good causes, usually for a charity that is close to one of our walkers or their family personally. A friend of ours, Kerianne Price, has a gorgeous little boy called Zac who has Angelman Syndrome. He is 3 years old and lives in Talywain along with his brother Theo who is 6. So this year we chose to raise money for ASSERT.

We walked from Monmouth to Symonds Yat along a multi-use path so that Kerianne and

Zac could join us. We had lots of families with kids and toddlers and they all made it the 4 miles there, lunch break at a local pub, and then 4 miles back to the cars.

I am pleased to say we raised the total sum of £1,121.41 on behalf of our Company. This amount is made up from sponsorship and donations.

Cathy Greenow

Zoe and Faye's fundraising

We are pleased to tell you that myself and Faye Hennessy have raised in total £2,853 for ASSERT.

We had so much support in doing this. Our first event was a charity football match which was on the 27th June at our local football pitch in Barnstaple. We had a number of players who generously gave up their time in order to play. They each had their own sponsor forms and raised an amazing amount of £700. On the day we also did a raffle and sold some food and drinks and raised a further £300. As a thank you the local pub - The Wrey Arms - donated food for the players and a local DJ came over to play some tunes while the teams celebrated.

Our second event was on the 19th of August and we did an auction which consisted of over 30 prizes the top prizes were, a sea lion swim for two people worth £200 a lion feed worth £100 given to us by the Combe Martin Wildlife and Dinosaur park, along with £100 of vouchers from Lilicos wine and tapas bar where we held the event.

The Breaks Collective, a local hip hop band, also came and supported and played for the occasion. We managed to raise £950. We also have had donations via the Just Giving page which made up our total.

We both enjoyed every bit of this and in the New Year we hope to tackle the Three Peaks challenge to raise more money for ASSERT.

ASSERT has done a lot for my family as my sister Jade has Angelman



Bungee Jump

Becky Holmes completed her bungee jump in Crete. She raised approx £120.00. Becky jumped 214 feet over the sea shore at new world bungee, star beach, Heraklion, Crete. She was really nervous, though not as nervous as mum and dad (and grandparents back home!) but wanted to do it again after!

Linda Holmes



Wirral Walk

I wanted to do something positive following Jack's diagnosis and decided to do the 15 mile Wirral coastal walk. My brother was swiftly roped in to be my buddy on the walk as Jack was being looked after by his dad. It was a tough slog as it was very windy but we were so proud to finish all for our Jack and the other Angelman families out there. I managed to raise £1277 and I am so pleased with the support and kindness shown by family, friends and even strangers! (we wore our vests with pride).

Jack received his diagnosis at the end of January 2014 when he was 2 years 2 months. I had an idea quite early on that he had Angelman Syndrome (thanks to the lovely Colin Farrell) but we went through genetic testing and that took some time as

our GP did not think he had AS. Initially we were devastated and thought about how life would be very different for our family but we pulled together and tackled it head on. I really wanted to do something for ASSERT to raise awareness and funds for the families and children affected by AS and I have been so amazed by the support I have received on twitter and Facebook. Getting the message out is my goal now and I will continue to do anything I can to support the charity.

Jack amazes and surprises us every day, he takes very small steps of progress and for that we are so grateful. There is always a loud cheer in our house if he does something slightly different! He is our world and we are lucky to have him. The laughter fun and good times we have (camping especially) are priceless. The one thing so concerning is that few people have heard about Angelman Syndrome including many health professionals and I hope we can change that.

Cheryl Gerrard



Lanhydrock Wheelers Club Charity Ride

Lanhydrock Wheelers is a Cornish Cycling Club set up by Sophie Dunne's Uncle, Gary Clements - Gary decided to organise a charity bike ride for ASSERT on 1 June 2014. What was supposed to have been a leisurely charity ride soon became a fast paced race amongst the keen riders of the club!

Three routes were planned, 30, 60 and 111 mile routes! Over the hills and far away the club clocked up over 4,000 miles between them and raised £912. Sophie Dunne and Mawgan Hook and their families attended the start of the ride to show their support, we had to be there for 7.30am on a Sunday - that's dedication from everyone!

Tracy Dunne



Research Report ASO's. Antisense... whats?

You might have heard about ASOs in relation to Angelman syndrome recently. Katie Cunnea (ASSERT's Science & Research Trustee) asks what all the fuss is about.



I first heard of antisense oligonucleotides (ASO's) in June and I have to say it is the most exciting scientific proposal I have heard with regards to a potential treatment for AS.

Why? Because the theory is simple and grounded in understanding. Also the research proposes to lead to a drug that would be specifically designed for AS. (If you want a more detailed description than the one I give here please go to <http://www.angelman.org/understanding-as/educational-webinars/>)

So far we have heard about minocycline from Edwin Weeber's lab, a drug typically used as an antibiotic to treat severe skin infections. We have also heard about topoisomerases from Ben Philpotts lab, a group of drugs including potent chemotherapy drugs. The concern I have at the moment with minocycline is that no one has yet determined why it might affect individuals with AS. With regards to topoisomerases there is understanding about why it can switch on the paternal AS gene, but the drugs are not designed for AS, aren't specific and so could interfere with other processes, potentially leading to nasty side effects. Neither of these issues are insurmountable and we must wait and watch to see the outcome from ongoing research.

So why am I excited about ASO's?

Firstly Art Beaudet is clearly a brilliant scientist, who has vast experience working on imprinted genes. He was one of the scientists that identified UPD in AS. A quick google search revealed several prominent awards such as the 2002 Colonel Harland Sanders Award for lifetime achievement in genetic research and education & The Allan Award "to recognize substantial and far-reaching scientific contributions to human genetics, carried out over a sustained period of scientific inquiry



Art Beaudet

and productivity".

His theory goes that RNA from the paternal chromosome is copied by polymerase molecules in both the sense (forward) and antisense (reverse) direction (the little trains in the diagram represent the polymerase molecules). When polymerase molecules try to copy in both directions the polymerase molecules collide and can't finish copying to the end. This means the gene cannot be fully copied to create protein (the square blocks).

An ASO can be made which interferes with the antisense & enables the gene to be copied and functional protein to be produced. ASO's are very specific, and so would only affect the genes involved in AS, without impacting others such as those involved in Prada Willi syndrome. It is a nicely described & evidenced theory. It is still a theory though and we don't know if it will progress to a treatment, but I think it is very exciting.

An issue that has been of some concern recently to parents on Facebook is whether there is a window of opportunity to stop irreversible damage with regards to AS. So even if we could turn the AS gene(s) back on would it be too late? This is a very valid question, and is important for us to understand. Art Beaudet addresses this in the webinar and states initial results in mice indicate that there is a window of opportunity.

Thinking about basic child development common sense suggests to me that the earlier a treatment the more effective it would be. However, just as Ype Elgersman told us in his talk at the ASSERT conference, it is important to realise these experiments were carried out in mice, and to compare a human's ability to learn & adapt, to a mouse's, does not give us conclusive evidence. More research is needed before we have answers.

For more detailed information please watch online <http://www.angelman.org/understanding-as/educational-webinars/>
Katie Cunnea

The ASSERT Clinic

The clinic takes place at the Royal Manchester Children's Hospital four times a year and is led by medical geneticist Professor Jill Clayton-Smith - familiar to many of you from the Assert conferences. A number of other professionals attend, including Dr Dan Hindley (Consultant Paediatrician who has a particular interest in epilepsy and neurodisability), Eric Taylor (Educational Psychologist), an epilepsy nurse, a physiotherapist and often a medical student. An Assert trustee also attends to give a parent perspective, information about Assert and support for families.

Whilst it may seem daunting for some families to find a room full of professionals, the clinic provides an opportunity to discuss any issues affecting someone with Angelman Syndrome. Common issues raised by families include development and prognosis for the recently diagnosed, epilepsy control and medications, behavioural issues, mobility, scoliosis and the difficulty in diagnosing physical illness in those with a severe learning disability i.e. the difficulty in recognising pain in those with a learning disability where this may

be manifested by challenging behaviours or withdrawal.

There are usually three appointments available at each clinic; each lasting about an hour, providing plenty of time for a holistic assessment of physical and mental wellbeing. Where appropriate Jill and the team will liaise with GPs and other clinicians when they feel further investigations or changes to medication are advisable for the person with AS.

Although the clinic is held in a children's hospital the team are happy to see AS adults - many of those seen have been known to Jill since they were diagnosed as children and the clinic provides a valuable learning opportunity for professionals to track development, adding to their knowledge and expertise about the condition.

Referral to the clinic is via the GP of the person with AS as funding needs to be agreed before an appointment can be offered.

Sian Cartwright

Useful Websites & Interesting Blogs

ASSERT Jute Bags

The new must-have accessory of the year is the ASSERT jute bag! These are being modelled by my 2 boys and I'm sure you will agree the bags are something you can use for every occasion. They are very practical and a perfect size whilst at the same time raising awareness of our charity. The bags are £3.50 each. The postage costs on top are then:

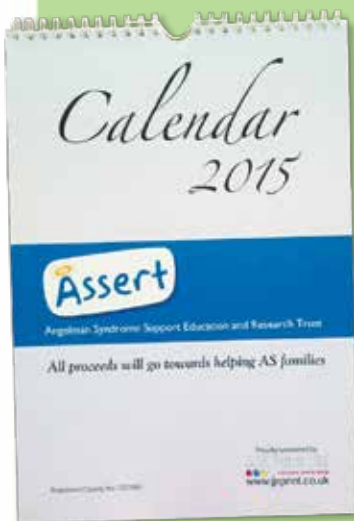
1 – 4 bags £2.80 postage
5 – 9 bags £3.80 postage
10 bags or more -
please email for a price.



ASSERT 2015 Calendars

Calendars are also now available and are full of lovely photos of our AS children. A perfect Christmas present for friends and family! The calendars are £5 each. The added postage costs on top are then:

1 or 2 calendars £1.50 postage
3 calendars £2.00 postage
4 or 5 calendars £2.80 postage
6 calendars or more - please email for a price.



If you would like to order some bags or calendars or both, please send a cheque made payable to ASSERT for the total amount to our Freepost address, along with your name and address. If you would like to pay by bank transfer, please put your surname as the reference and send an email to confirm the payment has been made and to provide your address.

If you would like to pay by bank transfer for either item but do not have the details, please email to request the information. The email address to be used for any of the above requests is:

lisa.court@angelmanuk.org



Stuck for Christmas present ideas?

You can also support ASSERT by buying from our range of 'I'm No Angel' and other T-shirts - alongside lots of other great gifts - through our website.

You can find our online shop through the link on our website or by going directly to:

www.angelmanuk.org/spreadshirt

Support

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

For iPad/apps

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

Blogs

- www.boybiteshorse.co.uk

Pre-loved equipment

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

Clothing and other equipment

- www.fledglings.org.uk
- www.clothingsolutions.org.uk
- www.incywincy.net
- www.disabled-clothing.co.uk
- www.togs4specialsprogs.com

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

Regional Meetings

ASSERT have arranged limited regional meetings in 2014 due to the focus on the biennial conference. We do plan to increase the number of meetings in 2015. If you would like to arrange a meeting locally for families in your area, please contact ASSERT who can send letters to local families, assist with booking the venue etc.

Please contact Linda Holmes for more information: Linda.Holmes@angelmanuk.org

Here are some details on meet ups in the previous months.

Snowdome, Tamworth - 15th March

We had a fantastic time at the Snowdome enjoying snow play. There were over 100 people in attendance which was lovely to see. The kids had a fabulous time rolling round in the snow and playing on the tubes and slide. We had a private room to sit and have a coffee and lunch and a chat, it was great to see new and familiar faces. A number of families booked additional activities such as tobogganing and the inflatables in the pool. We took our family into the pool afterwards along with a number of others. It was great fun! Ella splashed around in the water whilst the boys went on the inflatable assault course. It was a really enjoyable afternoon.

Lisa Court



Crealy Park, Exeter 27th April

Some 8 families met at Crealy Adventure Park in April, travelling from Dorset, Somerset, Cornwall and Wales. For some of us it was our first time meeting other families and everyone had a fab day - the weather held up for us, although we all got soaking on the water rides. The kids had a great time with the animals and all in all a good day was had by all.

Tracy Dunne

Deep Sea World, North Queensferry 13th September

On the 13th of September we had a Scottish regional meet at Deep Sea World in North Queensferry.

Thanks to everyone who came along it was great to see everyone old faces and new ones. It was with heavy hearts we said our farewells to Michele Catchpole and Koby who joined us for the last time before they move to Essex. We would like to wish them well in the move and we will all miss them dearly. Don't be strangers guys.

If anyone has any suggestions with regards to places we could go for days out, preferably with an indoor option due to our lovely weather please get in touch and we will try and sort out more up and coming dates.

Photo of Jon and Koby who couldn't quite contain their excitement at seeing each other again.

Mairi Leith-McGaw



Ice Bucket Challenge

After seeing friends and family post videos on Facebook of them doing the ALS Ice Bucket Challenge it gave me an idea on how we could help raise money for ASSERT, doing something mad and also the fact it involved water, which as you all know our AS children just love!

So I started the Angelman Syndrome Ice Bucket Challenge; I doused myself in freezing cold water then nominated 5 friends and texted my donation. My friends did it, then again nominated 5 more people - it was a hit! We had mums and dads, grannies and grandpas and also some AS children and sibs joining in! It was fantastic to see our community get in on the act and help raise money for such a fantastic charity as ASSERT.

At the time of going to print, the total amount raised from the Ice Bucket Challenge is the fabulous £1,49.36. A massive thank you to all of you who took part or donated.

This is my 8 year-old son and Angelman sib to Andrew 12 taking part in the challenge and also one of myself with help from my wonderful hubby!

Catrina Fraser



Darren Fraser



Sian Allen



Catrina Fraser



Mairi Leith-McGaw



Mark Neilson



Rich Williams & Jonathan Allen



Richard Leith-McGaw

Is a Welfare Deputyship the answer you need?

Donna Holmes from Anthony Collins Solicitors seeks to provide an overview of your rights and the law relating to your child's care and welfare decision making.



As parents of a child with Angelman Syndrome, meetings with care agencies, Doctors and Social Services will be common place and a regular part of life for you as you work with others to secure the best possible life for you and your family, particularly with your child with AS.

However, as your child moves towards adulthood (or what is often referred to as Transition), your role as the person with parental responsibility and therefore someone with a significant role in determining the best outcomes for your child may increasingly be challenged.

As a starting point, the law says that once a person turns 18 years of age, they are legally an adult. This means that the role of a parent has to change as the child becomes independent of you. A tough enough change when you have seen your child grow and develop over many years – but what about where your child remains reliant on you or others to meet all of their physical, emotional and social needs as is the case with your AS child?

Adult Social Services are trained and used to involving the 'service user' in the decision making and taking a person centred approach to the care and services they receive. This is great on paper but for parents endeavouring to look after their child, you may find your voice is no longer (or much less of) a deciding factor. You might even feel that your voice is not heard. If you are able to see that your child is well looked after and content, you may be able to accept this as a natural part of the growing process.

However, what happens if you have serious concerns about the care your child is receiving, their placement or services and are then faced with comments such as 'your AS child has chosen this', 'you aren't the decision maker' or 'your child is over 18 now so it's none of your business'. What then?

Whether your AS child is over or under the age of 18, they will always be your child and you will probably know them, their likes, dislikes and needs better than anyone else. But if you feel you are excluded for being able to input into the decision making – what can you do?

The Law

The starting point is to make sure that you and all the professionals involved with your child are on the same page and where possible you have a great working relationship with them – built on mutual trust and respect from both sides.

In practice however, this might be harder to achieve. A lack of invites to meetings, being told you can't have a say or that your child has decided otherwise might begin to erode your confidence in the team around your child. So why are they taking the approach they are?

The Mental Capacity Act 2005 (MCA) s.1(2) states that a

number of possible options they might like to do e.g. for a day trip or visit.

However, for the 'big ticket' decisions in life, decisions will need to be made on their behalf. And that's where the multi disciplinary approach to determine best interests will come in, and s.1(5) of the MCA requires this approach to be taken.

However, it might be of small comfort to know that a decision is a best interests decision for your child if you haven't been able to input into that decision.

Your role, as a parent for your child with AS and someone interested in them, their care and their future should be taken into account in determining what is in your child's best interests. This is set out in s.4(7) of the MCA which states:

- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- (b) anyone engaged in caring for the person or interested in his welfare,
- (c) anyone of a lasting power of attorney granted by the person, and
- (d) any deputy appointed for the person by the court, as to what would be in the person's best interests.....'

You will see from this wording it is clear that as a parent, and person caring for and/or interested in your child's welfare you should be consulted if practicable.

Therefore, you have a legal right to be consulted. If you feel you are not being involved appropriately, the starting point would be to remind the decision maker(s) – often the Social Worker, Care Home or Care Staff – that you have a legal right to be consulted. It might just be a genuine oversight or a lack of communication that is the issue. Hopefully an open, honest and friendly conversation can set the record straight.

You should also be aware that there might be decisions where, for a range of reasons, it is not practical for you to be consulted e.g. if there is an emergency or if you are away on holiday.

However, a systemic and continued failure to be consulted is very different. Whilst you should take every opportunity to simply remind decision makers of your legal right to be involved, it is easy to see that repeated failures can soon cause a lack of trust with the system and concern that your child is not being appropriately looked after. In such cases we are often approached to ask if parents can apply for a Welfare Deputyship.

What is a Welfare Deputyship?

A Welfare Deputyship is an order by the Court of Protection appointing a person or people who can make decisions for a person lacking capacity about matters relating to their welfare

- such as where they should live, with whom they should have contact and also medical treatment decisions.

Due to the impact and emotive nature of welfare decisions, the Court's favoured approach is to encourage the parties to talk and reach an amicable conclusion, and if that can't be done, for the Court to decide a particular issue, rather than appoint a Deputy.

However, there will be some cases where so many decisions need or will need to be made over a period of time that going to the Court for a decision about each one would be costly and ineffective (as well as taking a huge amount of time). For example, a series of serious medical treatment decisions. In those circumstances, the appointment of a Welfare Deputy might be considered to be appropriate.

However, being appointed or contemplating an application for appointment as a Deputy for your AS child is not an immediate answer - you will see from s.4(7)(d) above that a Deputy appointed by the court should be consulted. But a Deputy does not have the power to make a decision that your child would not otherwise have been able to make for themselves, for example, to force a medical professional to provide a particular treatment. In fact, if you read s.4(7), you will see that the appointment as a Deputy doesn't really have any greater status than being a person interested in your child's welfare - a role you already have.

The other thing to be aware of when contemplating applying for a Deputyship is - even if you were appointed as a Deputy - what do you do if a Decision Maker continues to disregard your views or fail to involve you in decision making? Your only option would be to discuss, complain and, if absolutely necessary, return matters to the Court of Protection for it to rule on.

Conclusion

In short, you do not need a Welfare Deputyship to be involved in the welfare decision making relating to your child. You already have those rights at law but sometimes, you might just need to remind others of those rights to make sure they are not forgotten.

There are cases where a Welfare Deputyship is both appropriate and needed but this is likely to be in rare in practice.. Ultimately, a Welfare Deputyship isn't the be all and end all - even if you have one in place, this doesn't necessarily mean that you will get to decide or influence a decision - and you may be left needing to return to the Court if your Deputyship were ignored.

The best advice is therefore to build the strongest possible relationship with those professionals and Decision Makers involved with your child, appreciate that they are human and will make mistakes, recognise that you will have a different role in your child's life which means that you won't always be at the forefront of decision making - but always fight for your right to be heard and make s.4(7) MCA 2005 a piece of legislation you commit to memory in case it is ever needed.

Donna Holmes, Senior Associate Solicitor,
Anthony Collins Solicitors LLP
0121 214 3671 donna.holmes@anthonycollins.com

Member Update

Included with this newsletter you will also find a separate, member update form which we would like you to complete and return to us at our Freepost address as soon as possible.

We would like to put together a Contact Register in the coming months which will be sent out to you, but in order to do this we need to ensure we firstly have the correct details and secondly your permission to print your details. We appreciate we already have permission from our newer members (as given on the registration form) but we need to be sure we have permission from our members who have been registered for a few years. ASSERT would like the Contact Register to be as complete as possible, including as many families who want to be included. That's why we need your help to complete and return this form as soon as possible.

Splash Landings

Alton Towers 15-16 February 2015

Due to the success of the previous 2 years, Linda Holmes is again arranging a trip to Splash Landings! Next February's trip is also due to coincide with International Angelman Day (15-02-15 & 16-02-15).

Two nights bed & breakfast is just £339 per family room for 4, and £389 per family room for 6. This price includes 2 days entry into the amazing pool and also 2 days entry into the Theme Park (please note the theme park will be only partially open, as it is the winter season/school holidays).

The whole complex is aimed at kids and families; the hotel rooms are decorated for kids and cartoon characters wander round the hotel. The lifts are like Captain Nemo's submarine, there's a huge pirate ship in the middle of the bar, a large flying machine in one foyer and a brightly painted car in the other. Not only that, there's all night children's entertainment too!

Contact: **Linda.Holmes@angelmanuk.org**
07739 363456 for further details and the discount code.



Transition Trials, Tribulations and Triumphs!

It was summer a couple of years ago and I was pushing my son Josh around an outdoor Shopping Village. It was more akin to running the gauntlet as he regarded any child with an ice cream or sweets as fair game. Avoiding a “diplomatic incident” took my full powers of concentration. Consequently, I missed the other frayed father wheeling his Angelman’s child in the opposite direction. My wife, Fran, spotted him, though, and set off in hot pursuit.

Within minutes Fran and I were chatting with the man like long lost friends. He was warm and engaging - but kept winking at Fran in a disconcerting fashion. Then he winked at me!

He apologised and explained that the strain of round the clock care for his child, sleepless nights, running a business, supporting his wife and raising another child had taken their toll and that he’d developed a twitch. Hearing another father’s account of the pressures of parenting a child with Angelman’s was somehow reassuring; I wasn’t the only one!

The man’s child was only a little older than Josh. Inevitably, the conversation turned to long term care and the dreaded subject of transition. I ventured the question, “Are you going to transition your child when they reach 18?” It may have been my imagination but I think he gave an involuntary shudder. The answer was a definite “no” – he and his wife would keep their child at home with them for as long as they could cope.

I can completely understand his decision. I have enormous respect for the sacrifice that so many parents make to keep their children at home, long term. I question, though, whether it is the best decision. I’m inclined to believe that it’s not although I think that there’s probably no definitive answer: each situation is different and each parent has to make their own choice.

Fran and I forced ourselves to confront the transition question a few years ago. We were given an excellent piece of advice – decide early on what you want to do in the long term and prepare accordingly. This was easier said than done. The temptation was to avoid thinking too far ahead; each day had enough challenges of its own without agonising over a future which often seemed unimaginable.

Nevertheless, we started to contemplate Josh’s long term care. We spoke to other parents, health care professionals and special needs teachers. We both served spells as governors at Josh’s school. We read books, attended Assert conferences and an excellent Mencap conference. We gleaned what information we could and we took inspiration where we could find it – and we reached some surprising conclusions.

Like many parents of children with Angelman syndrome, we’d always felt that our child’s needs would be best met by us. We had an intense commitment to his well-being and felt extremely protective. How could we ever entrust his care to anyone else?



However, we gradually reached the conclusion that it would be in his interests to transition away from home when he was eighteen or shortly thereafter. He would have to transition at some point, unless he predeceased us, and the trauma of him being moved into an alien environment aged 40, 50 or older didn’t bear contemplating. It was better, we reasoned, to move him at a younger, more adaptable age into an environment where he had as much freedom as possible, where he was able to develop friendships, interests and his own identity whilst still retaining close contact with the family.

We saw examples of where this had worked and we became convinced that this would be the best model for Josh. This raised other questions, though, such as “how do we best achieve this?” and “how do we prepare him for it?”

The question of preparation was easy in theory but tough in practice – respite! When Josh first went away for a respite weekend Fran was in tears for most of the time that he was gone. Josh, however, had a great time and it wasn’t long before we realised that respite could be beneficial for him just as much as it could be for us. It enabled us to spend quality time with our two younger sons and it gave Josh the opportunity to make friends and enjoy activities that he couldn’t have done if he had stayed at home. It also helped him adapt to time away from home. We started with infrequent, short respite stays before gradually increasing both the frequency and the duration. This was an approach that worked well.

The question of Josh’s housing and long term care seemed more challenging, though. Social Service process and procedure, budgetary considerations, conflicting advice and, dare I say, the occasional ill-informed professional seemingly thinking that they knew our son better than we did made the process more painful than it need have been.

In summary, though, we realised that there were really only two options open to us – a residential care home or supported living. We assumed to start with that the residential care home would best meet Josh’s needs given the profound nature of his disability. However, the more we explored the more we found our perceptions shifting.

To our surprise we concluded that Josh needed to have his own home with care delivered via a supported living package. This decision was based on the following:

- It would provide him with long term security and stability; it would always be his house and there would be no risk of him being moved somewhere else – even when Fran and I were no longer around.
- We would have control over the suppliers that delivered care to Josh in his home. If we were unhappy with the quality of the care we could change supplier. Josh is able to communicate his likes and dislikes to us and we would soon know if he was unhappy.
- Josh would have greater disposable income than he would enjoy in a care home
- We would be better able to ensure that his days were structured, varied and enjoyable
- We could ensure the quality of the home – easily accessible, quiet location, good ground floor access, etc.
- Josh could still benefit from communal living as we would ensure that his home could accommodate 3 or 4 others.
- We could choose the location of the property. We agreed with Josh's Head Teacher that if the property was near to his school, life skills lessons could be delivered within the home – something that his teachers felt would be of great benefit to him.

We concluded that for this plan to work we would ideally need to buy a house. This was a big financial challenge for us but planning several years in advance certainly helped. We made financial sacrifices, used all of our savings and all of the retained profits from my small business. My parents also contributed and scraping together all available funds enabled us to make an offer for a 4 bed bungalow.

However, it was at this point that our plans went awry as the purchase of the property stalled owing to problems with the sellers. This coincided with increasing levels of aggression from Josh towards his siblings. Consequently, we decided to proceed with transition anyway although into a care home as a temporary measure whilst we sorted out the problems with the house purchase. We ensured, though, that the care home was run by the same organisation that is going to deliver supported-living care to Josh in his own home; this has helped ensure a level of continuity in approach and, hopefully, in staffing.

At the time of writing, we have just exchanged on the property we're buying for Josh and we will complete in mid-October. There are still numerous challenges ahead including capacity and best interest assessments as well as a court of protection hearing.

Whilst the process has been daunting for us, Josh has been remarkably unfazed. We have been astonished at how quickly and how well he has adapted. He is enjoying his own space and not having to compete with two brothers for attention. One consequence of this has been that the times we spend with him tend to be more relaxed with hardly any sibling confrontation.

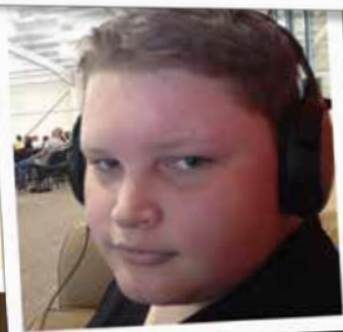
The impact on Josh's brothers has been considerable. Like the Angelman's father that we met at the shopping village, my youngest son had developed a very pronounced twitch: it has now disappeared. Both of our youngest boys are at key stages in their development and school lives. We no longer feel as if we're "short-changing" them as we have time for them and for each other. We are also rediscovering sleep!

Whilst the transition process still has some way to run, we believe we have made the right decision for Josh and the rest

of our family. We've also learned a lot of lessons along the way. If you're starting to think about transition, here are six key things that we've learnt:

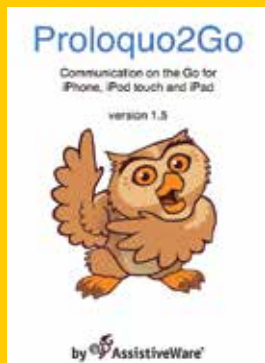
1. A good social worker is vital. We've experienced both good and bad social workers – engaged and proactive on one hand and uninformed and seemingly disinterested on the other. Forging a good working relationship with your social worker is vital. If the relationship isn't working then you have the right to ask for another worker to be assigned. We have experienced failure to take notes, to follow through on promised actions and a lack of knowledge of our son's diagnosis. This shouldn't be tolerated!
2. Think carefully about the long-term and plan for transition early if you decide it's the right route for you and your child. We live in Leicestershire where transition social workers aren't assigned until 6 months before transition. In our view this is far too late. We successfully pushed to have a transition worker assigned early. She's been invaluable.
3. Respite can benefit your child and you. It can be really tough to start with but can help to prepare your child for transition, paving the way for when the move away from home finally arrives.
4. Get support. There are local and national bodies out there that will be able to assist you. Find out as much as you can; don't be afraid to ask questions and don't be afraid to challenge the status quo. We have been told that certain things aren't possible only to find out shortly afterwards that they are!
5. We were able to buy a property – many are not. However, a long-term let is an option for supported living. Alternatively, you could approach specialist organisations for help. We would recommend Golden Lane Housing (www.glh.org.uk/). They were a fantastic source of help for us and do great work in helping tenants to own their homes.
6. Finally, no-one knows your child as well as you do. Be open to advice and input but be confident that you're best placed to make decisions about your child's future.

**Andy & Fran
Childerhouse**



Proloquo2go

Those who attended the conference in Coventry will be aware of the discussions that took place about enabling our children to communicate using a communication aid, specifically iPads. One of the apps that was discussed in detail over the weekend was Proloquo2go, created by Assistiveware. Due to the huge interest in this app, ASSERT



has arranged a one day workshop for anyone who would like to learn more about how to help their child to use P2Go. The workshop will be hosted by the CEO of Assistiveware and designer of P2Go, David Niemeijer and their SaLT Jennifer Marden, who will be coming over from Amsterdam. The cost is £40 for a parent/carer and £75 for professionals. The session will

be held at The Hilton in Coventry on Saturday 7th February 2015, from 10am til 5pm.

We would like to point out that this workshop is open to anyone, not just ASSERT members - so please encourage your child's teacher, SaLT or any other professional or friend who is involved to attend. It is also open to users who do not have AS. Full details will be sent out shortly.

..... Conference Photos

For those of you that came to the 2012 conference, you will remember the fantastic portrait photos taken by Rob Chadwick. We were very lucky that Rob kindly agreed to come again in 2014 and so we now have an abundance of new fabulous smiles and happy faces. If you would like a copy of your child's photos on a DVD then please send a donation to ASSERT to cover the costs of creating the DVD and postage and a little more if you can afford it. You can either send a cheque into ASSERT or you can pay directly into the ASSERT bank account. If you would like the bank account details or have any questions please email lisa.court@angelmanuk.org.



Letter from Pat Kemp

Pat very kindly sent this letter to ASSERT and asked that we share it with you.

My daughter Sarah is 47 and was only diagnosed with AS a couple of years ago. When she was 30 she went into residential care. A friend, whose daughter was in the home, told me of the vacancy. This coincided with us realising that Sarah was becoming increasingly bored at home unless we were actively occupying her (she is unable to do anything constructive herself). It was the hardest decision I have ever had to make but we decided to apply for the place. Sarah had always hated respite care, not eating or sleeping while she was there, and it was a terrible worry as to what would happen to her when I could no longer look after her.

It took a year to get the funding and during that time Sarah went to tea and on outings with the home. When the time came to move Sarah settled in straight away. It seemed like a miracle to us and still does!

Sarah comes home every weekend and I take her and some of the other residents to clubs two evenings a week, so I am still very involved in her life. We feel she has the best of both worlds. There have been problems over the years of course, and plenty more to come I know, but we have been around to sort them out and Sarah is very happy and well cared for at the home.

The relief knowing her future is settled is enormous and there is no longer the worry of coping if I was ill and we can now take holidays without the trauma of leaving her in respite care to pine.

I truly feel it is a good thing to do whilst one can choose a home and be around to help with the setline in process and explain all the little things that only we as parents know about our son or daughter.

Pat Kemp

FIND Launch Event

By the time you receive this newsletter, the new FIND website should be live. This is a new resources website that has been launched by The Cerebra Centre for Neurodevelopmental Disorders (University of Birmingham). Sally Waldron and Jane Walker (both are AS mums from the central region) very kindly attended the FIND Launch at Birmingham University on behalf of ASSERT at the end of September. Sally reported back to say "Both myself and Jane found the day to be very informative, in the morning session all of the syndromes - Angelman Syndrome, Cri du Chat, Cornelian de Lange, Fragile X, Smith-Magenis and Prader-Willi were briefly discussed by PhD students past and present.

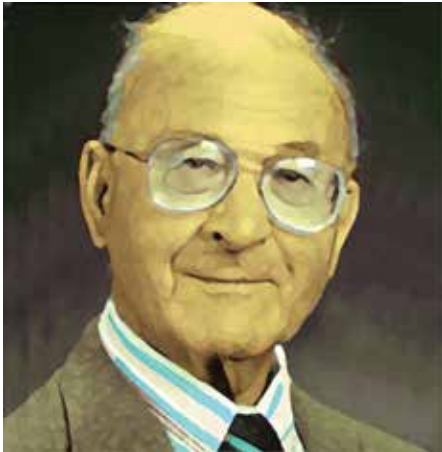
During the afternoon we were arranged into groups of parents and professionals to in order to discuss FIND to mention any glitches on the web page. Overall we were encouraged by the simplicity of the information put together on the site."

Please check out the new website:

www.findresources.co.uk



ASSERT Golden Gala and Scientific Symposium 2015 Bringing Angelman Syndrome Home



Dr Harry Angelman was born in 1915 in Birkenhead, Merseyside. He trained and worked as a doctor in Liverpool and Warrington. He first reported 3 cases of patients who exhibited similar symptoms to each other in 1965 and gave them the name 'puppet children'. This term was later revised

by Dr Charles Williams who reviewed the original report and in 1982 coined the name 'Angelman Syndrome' in recognition of Dr Angelman. Harry and Audrey Angelman were also instrumental in setting up the original (and now defunct) Angelman Syndrome Support Group called ASSG. ASSERT took over as the leading UK support group in the early 1990's when parents realised that what was needed was support and education about AS. ASSERT is now the largest parent-lead support group with over 770 members in many countries.

2015 would have been the 100th birthday of Dr Harry Angelman and is also the 50th anniversary of Angelman Syndrome being reported. Therefore ASSERT is both privileged and excited to announce that we will be hosting the 4th European Angelman Syndrome Alliance Scientific meeting in 2015.

The meeting will be held at the brand new Children's Research and Education Centre, Alder Hey in the Park, Liverpool on Friday 2nd

October 2015. It will be attended by leading scientists and educators from institutions in Europe and further afield. It will also be attended by local professionals and researchers and representatives of Angelman Syndrome Organisations from around the world.

The Scientific meeting on Friday will be followed on Saturday 3rd October by a Scientific Symposium for Parents and carer's of those with AS and our international visitors, to be followed in the evening by the ASSERT Golden Gala and Fundraiser to celebrate Harry Angelman's 100th birthday and 50 years of interest in Angelman Syndrome. This will be held at the Marriott Hotel, Liverpool. All funds raised on the evening will be going to further European Research into Angelman Syndrome.

Accommodation for Friday and Saturday night at The Marriott is at a significantly reduced rate for those attending, this is available at a rate of £119 for a single room and £129 for a double or a twin room. You are free to book accommodation for either one or two nights, whichever makes it easy for you to attend the event. We hope that a year's notice is adequate for those who need to arrange suitable childcare, as we appreciate it can be difficult for some.

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

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

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

3rd European Angelman Syndrome meeting Paris October 2014

On Friday 17 October Dr. Katie Cunnea, Christyan Fox and myself attended the 3rd European Angelman Syndrome meeting in Paris. We also attended the 3rd closed meeting of the Angelman Syndrome Alliance. You may remember that Katie and I attended the same meeting last year in Italy. Shortly after that meeting, ASSERT agreed to contribute £10,000 over 2 years to funding European research into Angelman Syndrome. Our contribution is combined with contributions from Ireland, France, Italy, Belgium and the Netherlands. A call for funding went out in summer 2014 and the first recipients of the grant, announced in Paris, were Dr. Ben Distel and Dr. Geeske Van Woerden.



Please check our website (www.angelmanuk.org) in the coming weeks for an update on all the applications for the European Grant. It is safe to say that the world of research into AS is moving forward at a rapid pace and ASSERT is proud to be part of that progress.

Rachel Martin



International Angelman Day

15 February 2014

Awareness & Fundraising at The Village School

As the second year of the Annual International Angelman Syndrome Day was approaching I thought it would be nice to raise awareness and fundraise to support ASSERT. After speaking to my sister Louisa and a friend Elizabeth we decided we could bake and sell.

Nathan's school has a shop, "The Village Shop," for the children, the ideal base for our cause, so I asked the Head, Kay Charles if we could use the shop for the day. Mrs Charles was delighted and gave the go ahead. I then realised "I don't know what I'm doing! I've never raised awareness for anything, and this is sooooo important for all of our Angels." I then contacted Rachel who gave me loads of suggestions and forwarded me onto Lisa, who sent me flyers, donation boxes, balloons, pens and current and previous ASSERT magazines.

Our Awareness Day was booked for Friday 14th February 2014, 10am-2pm, a letter went home with all the children informing parents of the Day and requesting donations. A donation box was given to the physiotherapy clinic and Nathan's primary school.

Thursday 13th February, Elizabeth came over. We got baking, made scones, carrot cake, Victoria sandwich (* and gluten free), jam tarts, shortbread, raspberry and coconut cake, my dearest sis baked all the cupcakes that evening after work, regular and gluten free.

On Friday I set up with Jadon (my eldest son), we had the informative Angelman DVD playing in the shop throughout the day. The shop was busy, children were coming, teachers and parents popped in enquiring about Angelman Syndrome, many flyers went out, everyone that came in bought at least two cakes, it was fantastic! Nathan came down with his class, he was really excited, he helped to sell cakes for a while and bought cakes for himself. The total donations collected was £104.20

Dinah Oti

Awareness at Riverside School, Orpington

For IAD, Siouxi's school talked about the condition at assembly and sent information home in schoolbags. Siouxi and the only other AS in the school, John, have been separated since P3 because they were always distracting everyone with their antics! So, they had



great fun working together to blow up balloons, make halos and have their very own little photo shoot. The cookery classes that morning made Angel cakes to send home and everybody got one!

Lindsay McKeown

Awareness and fundraising at Housing 21 Community Centre, Walsall

Myah is our eldest child and was diagnosed at the age of 4. Myah has a 4 year old bother Arjun and an 8 week old baby brother called Raajun. She loves all her family dearly. When IAD was formed I was over the moon that an international awareness day had been created for our children.

I'm very lucky to have an amazing family who wanted to celebrate IAD and raise awareness as well as fundraise for Assert. They all know how valuable Assert is to us and how it has helped us to interact with other families and most importantly in the first days of diagnoses helped us in what I can honestly say we're the darkest and scariest days of my life! We decided to hold a Tea party very last minute! The day turned out to be a great success.





We had lots of cakes and savoury snacks donated. We had a face painter and a crazy raffle too. Overall it was a lovely afternoon and we raised a fantastic £600. Myah had a great time, mainly because the cakes and crisps were on tap!

We're looking forward to the next IAD and if you're in the Midlands or don't mind travelling, you're more than welcome to join us.

A note from Harvin, Myah's aunty: We received the diagnosis for Myah when she was 4 years old and from then our lives changed altogether. It was our first real encounter with a disability. Myah amazes me every single day, she has 2 younger brothers who she cares for very much. She has a very big love for crisps and she is certainly the best person to cuddle up to and watch a comedy movie with. Myah also loves parties, she outdoes everyone on the dance floor! When Myah was first diagnosed it was the first time I had ever heard of Angelman Syndrome, therefore it is important to me to raise people's awareness so we held a tea and coffee morning in support of ASSERT. This proved to be a very successful event and Myah definitely enjoyed it, with all the cakes and chocolate.

Nav Sanghera

Awareness and fundraising at home in Nuneaton

What a wonderful morning was had by all. On 13th February I invited old friends and new neighbours to my "coffee and cake" morning to celebrate International Angelman Day.

I had a big sign hanging from my guttering to make as many people passing to look in, and a lot passed by and looked whilst on their school run. My friend kindly baked cakes for me and friends also brought their home made cakes.

I had 16 people turn up and apologies with donations from others. I gave a little talk to explain Angelman Syndrome and the wonderful work and camaraderie that ASSERT do for all of our children and families. There was certainly a buzz in the air, questions being asked and of course not many people knew Ella but her photos were all on show. I also handed out the old newsletters with photos and articles of other AS children and families. I did not ask for any money as my aim was to raise awareness of AS, but I did leave our beautiful ASSERT money boxes around in case anyone wanted to donate. I was absolutely delighted to find that they had donated the total of £371.80.

Yvonne Edwards

Awareness and fundraising at Gertrude Road Riding Stables

The fabulous girls and riders at Gertrude Road Riding Stables raised an amazing £85.70 for ASSERT on IAD by having a cake sale at the stables where Charlie rides every week. It was a great way to raise funds for ASSERT of course but it was also a fantastic platform to raise awareness in our community regarding Angelman Syndrome and how this affects Charlie. Another little boy with AS in the area came down to the event too after hearing about the fundraiser, so Charlie and his chum had a riding date the following week!

Jules Whicher

Celebration of IAD at The Donkey Sanctuary Assisted Therapy Centre

A small group of 6 families decided to celebrate International Angelman Day with a play date at The Donkey Sanctuary Assisted Therapy Centre. It was a great place for us to meet, where the kids could play and interact together, and all the children, siblings

included, got their turn riding a Donkey too. We all had a great day and made our presence known.

There was plenty of laughter around the room whilst the kids explored, climbed, demolished and caused mischief! The sensory room was a big hit with the kids, allowing them the freedom to be themselves. Dressing up and role play was popular with some of the siblings. The outdoor play area was great for everyone. It was a lovely time to get together, to offer support and friendship to each other, and celebrate unity.

Abby James



Thank you!

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

| | |
|-------------------|-----------------|
| Dinah Oti | Katie Cunnea |
| Claire Turlington | Amy Symmons |
| Louise Shaw | Sarah Brown |
| G Knight | Helen Neilson |
| Shelley Cachia | Katy Harvey |
| Megan Williams | Desiree Langan |
| Emma Shepherd | Samantha |
| Kathryn Wrigley | Wickens |
| Rachel Hulse | Sian Cartwright |
| Heather Dobbs | Charlotte |
| Michelle | Lambert |
| Matthews | Debby Chick |
| Tracey Fahey | Alison Dalton |
| Simone Burton | Jayne Roper |
| Audrey Sinclair | Veryan Hook |



Helpline 0300 999 0102
assert@angelmanuk.org

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

DONATIONS

| | |
|-------------------------------------|-----------------------------------|
| Mrs Hazel Tait | Angie Edmond |
| Crossfit Swansea | Megan Williams |
| (Melanie Thomas) | Sheila Thompson |
| Mr & Mrs Capen | Team 'Angelfish' (Sarah Brown) |
| Helen Edwards - New Years Eve Party | Freemasons Colne Lodge 2477 |
| In memory of Mrs Edna Pickering | (Mr Keith Holdaway) |
| Cyril and Val Turner | Julie Birks |
| Mr A J Taylor | Mrs Jean Cartwright |
| Tiny Toes Day Nursery | Ecole du Parc Parents Association |
| Yvonne Edwards - IAD Coffee & | CS Beauty Academy |
| Awareness morning | Wedgewood Cricket Club, Family & |
| Mr & Mrs Knapp | Friends (Kerry Houghton) |
| Matthew Vaughan - Christmas Cards | Arrow Taxis |
| Bidvest 3663 | Audrey Sinclair |
| Mrs Seel | Jonathan Brooks |
| Dawn Howden, Melanie Sedgwick & | Windham Nursery School |
| Christine Dear | Equiniti ICS |
| Jolly Chippy | Barclays Bank PLC |
| Gertrude Road Riding Stables - IAD | Team Ally - Leila & Jed Ally |
| (Jules Whicher) | St Nicolas Church Nuneaton |
| Mrs Walton - in memory of Abbie | Alun Griffiths (Contractors) Ltd |
| Lockett | Abergavenny |
| FDC Young Designer Awards | Emma Shepherd |
| (Joanna Marcella Reid) | Nav Sanghera - IAD |

SPONSORED EVENTS

| | |
|--|---|
| Val Birkett - Great Edinburgh Run 2013 | Sian Cartwright - Bupa Great North Run 2014 |
| Harry Kiely - Bupa Great North Run 2013 | Poppy Cartwright - Bupa Great North Run 2014 |
| Iain Lovett - London Marathon 2014 | David Cartwright - Bupa Great North Run 2014 |
| Karl Scally - London Marathon 2014 | Sharon Hurcombe - Bupa Great North Run 2014 |
| Patsi Whelan-Archer - Great Midland Run | Chris Stratford - Bupa Great North Run 2014 |
| Michael Fisher - London Marathon 2014 | Nigel Flook - Bupa Great North Run 2014 |
| Gemma Ellis - London Marathon 2014 | Emily Iredale - Sheffield Half Marathon 2014 |
| Sukhinderjit Braitch - Bupa Great Edinburgh Run 2014 | Fiona Matthews - No Mud Challenge 2014 |
| Matthew Vaughan - London Marathon 2014 | Jenna McKenna - No Mud Challenge 2014 |
| Catrina Fraser - Bupa Great Edinburgh Run 2014 | Harry Turner - Swim Walk 2014 |
| Mairi Leith-McGaw - Bupa Great Edinburgh Run 2014 | Cheryl Gerrard - Wirral Walk 2014 |
| Angela Carmichael - Bupa Great Edinburgh Run 2014 | Gary Clements - Lanhydrock Challenge 2014 |
| Allison Donnelly - Bupa Great Edinburgh Run 2014 | Andrew Woods - Liverpool Half Marathon 2014 |
| Simon Love - Bupa Great North Run 2014 | Rufus Johnson - GWR Towpath 2014 |
| David Collis-Smith - Bupa Great North Run 2014 | Clarissa Dunn - St Albans Half Marathon 2014 |
| Mark Darlow - Manchester Run 2014 | Georgina Bach - Ullswater Triathlon 2014 |
| Adam Long - Tough Mudder Challenge 2014 | Zoe Gilbert & Faye Hennessey - Various fundraising 2014 |
| David Johnston | Matt Way - Paddle for Life 2014 |
| Becky Holmes - Bungee Jump | |