



Newsletter 57 Autumn 2015

**Angelman Syndrome**  
Support, Education & Research Trust

**Liverpool 2015**

**Communication  
Matters**

**Boy Bites Horse**


**Angelman Syndrome  
Alliance**

**Fabulous Fundraising  
Roundup**

**A Plea for a Voice**

**New ASSERT  
Merchandise**





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## Useful Stuff

OUR FREEPOST ADDRESS  
**ASSERT, Freepost, PO Box 4962**  
Nuneaton, CV11 9FD

OUR WEBSITE  
[www.angelmanuk.org](http://www.angelmanuk.org)

EMAIL ASSERT  
[assert@angelmanuk.org](mailto: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](http://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

2015 has been a fantastic year for ASSERT and one in which our 'small' charity grew up.

We have always been blessed with an army of fantastic fundraisers for which we are all eternally thankful- and you have gone from strength to strength this year. But historically, as a charity, we operated in a two year cycle where much of our income was then spent on our flagship conference. All of the funding was down to the ASSERT community.

Hidden away at the bottom of the Liverpool promotional material was a beautiful logo that really opens up the possibilities for the future. It simply said "funded by the National Lottery". In a society with many charities all clamouring for attention, being recognised as a worthy recipient of a grant is priceless. And it is something that will open doors for us elsewhere as we get better at filling in the forms that make the DLA application look simple.

Our commitment to the Angelman Syndrome Alliance is already evidence of this brighter future. As is our ongoing desire to champion the issue of communication at the highest level. It's clear that, along with the much needed support aspect, both of these topics are at the top of the list for our members and we are now putting a lot of effort into these areas. We are at the start of the journey, but we have taken that important first step.

And dreams are no longer limited by practical finance.

But as important as the future is, we are still totally reliant up our intrepid fundraisers for the present. From all of us thank you. If the article in this edition inspires you to join them, then please get in touch.

Without those sore body parts, it wouldn't make any difference how many forms we fill out.

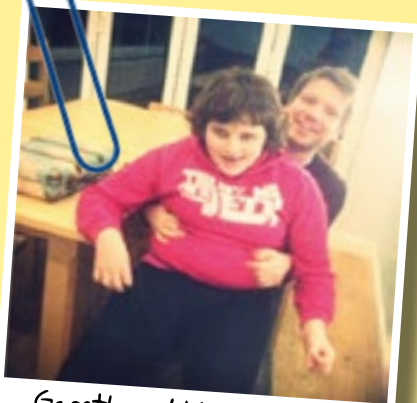
International Angelman Day this year was also notable in that many of the events taking place around the UK were organised by you. 2016 is already starting to mobilise, so if there were no events in your area on or around February 15th, and you'd like to put that right, please do so.

Rachel & Rich

## An update on Our Patron Gareth Edwards...

It was so great coming to Liverpool and meeting everyone. I'm back in London filming for a while. We should hopefully be done early next year. Then

its onto editing ready for release in December 2016. We have a busy 12 months ahead! I will hopefully see you all again soon, maybe at the conference next year depending on my schedule and I also hope to be able to give you some exciting news in 2016!



Gareth and his niece Ella

## Meet Our New Trustee

Hi, my name is Andrea and I am very excited to be a new ASSERT trustee! I am married to Ben and we have three beautiful, lively boys, Will (9), Woody (short for Edward - AS del +ve, 7) and Jamie (4). We live in Abingdon, in Oxfordshire. My mother in law first contacted ASSERT for us when Woody was diagnosed with AS in April 2010. He was then 18 months old and the information and support we were given was a lifeline. The support has continued over the years, with regional meet-ups, conferences and contacts with Angelman families far and wide.

As Ben ran the London marathon in 2013 for ASSERT, I know first hand how much time and effort people put into fundraising. I can't run to catch a bus, but after many years working in science research (both behind the lab bench and in admin roles I am hoping to be able to help raise extra money for ASSERT by applying for grants to support existing projects and to fund new ones too. The Liverpool ASA/ASSERT scientific conference was my baptism of fire and I was so proud to have been part of the team for that.



Andrea and her family

# 4TH INTERNATIONAL ANGELMAN SYNDROME SCIENTIFIC CONFERENCE



1915 - 1965 - 2015  
LIVERPOOL



I'm not sure what I expected to happen at Liverpool Scientific Gala weekend. As a veteran of helping deliver many conferences, some of the aspects of the weekend were very familiar. The last minute juggling, the multitasking, meeting friends old and new and of course, burning the candle at both ends.

However, I wasn't really prepared for what actually happened and the lasting memories created.

The scientific debate, I'm ashamed to say, went well over my head. It's probably true to say that I was as confused as the scientists and our guests were when our coach driver decided that he wanted to drive round Alder Hey hospital twice. Given the importance of the NHS in Liverpool in the Angelman story, I'm sure they didn't mind too much.

But that didn't stop intense debate and scrutiny and the few bits I did understand left me wanting to understand more.

Saturday began well, with many familiar faces arriving and the parent conference getting into full swing. Some of the speakers were those that had attended the scientists' day. Others were regular favourites with updated data and information. Again, much to take on board for us all- and Katie will pick up elsewhere.



On behalf of ASSERT, I'd like to apologise to our foreign delegates for the Liverpoolian coffee. I'm told that one of the highlights on the city tour we organised for them Saturday morning was for a Starbucks seen near a famous Beatles landmark.

During the afternoon, I had the privilege of sitting in with the ASA meeting and listening to the passion, the determination to overcome barriers both cultural,

financial and national was inspiring. I'm also very proud that ASSERT is laying a part in this multinational development- and this was celebrated at the end of the afternoon with two new member groups joining the Angelman Syndrome Alliance. Don't tell anyone, but the paper they signed was blank on the day- with the formal agreement being drafted over the next few months.





# 4TH INTERNATIONAL ANGELMAN SYNDROME SCIENTIFIC CONFERENCE



1915 - 1965 - 2015  
LIVERPOOL



Which leads us on to the Gala dinner.

The room looked stunning. Our attendees even more so. A delicious meal quickly led to the speeches of which mine was first.

The bad jokes aside, it was an honour to be the support act for both Gareth Edwards and Liz Huglin, Harry Angelman's niece. As I said at the beginning of my bit- it was great to see so many experts on AS in one place. And a few scientists. It's a strength of ASSERT that we are often our own support. It cannot be underestimated how important it is to us and it is something that is greatly admired from afar.

Gareth then gave a heart-warming and poignant account of his relationship with his niece, Ella and of a recent set visit to his current Star Wars project. It was a pleasure to listen to him speak and that Oscar speech can't be far away. He really is proving to be a great ambassador for both ASSERT and our members- and we hope to capitalise on this much more over the next year or so.



Liz Huglin. What can I say? Aside from welcome to our community. A community you knew nothing about and one that holds so much gratitude to your family. The room listened intently as she recounted her memories of her uncle, the origins of the family name and the profound effect the days experience was having on her. Her speech finished with the presentation of a letter from Bill Clinton to Dr Harry Angelman thanking him for his services to medicine. It was and is a great honour.

After a rousing cheer, the night descended into a party- with fantastic music provided by one of our very own Charles Villiers and his band- the Sunshine Soul Revue.

The past met the present and talked about the future at this unique event- and it is one that will stay with me for a long time. Thank you to everyone who helped organise, deliver and shape it. It was a celebration to remember for many reasons.

Happy birthday Harry Angelman.

Rich



# 4TH INTERNATIONAL ANGELMAN SYNDROME SCIENTIFIC CONFERENCE



1915 - 1965 - 2015  
LIVERPOOL



In 2012 I had the privilege of representing ASSERT at the first European Angelman Syndrome Alliance (ESA) conference hosted by the NINA Foundation, held in Rotterdam, The Netherlands. That conference was the catalyst for many changes, several of which directly affected the direction in which ASSERT was heading. At that meeting, the Angelman Syndrome Alliance was proposed as a formal collaboration of AS groups from across Europe who would work together to fund research into AS in Europe. The ESA was formalised the following year (2013) in Rome where ASSERT and other organisations signed an agreement where we promised to work together and to donate funds to international scientific research projects.

When in Rome it was suggested that as 2015 was such an important year for the AS community, and that as Dr Harry Angelman was originally from Liverpool, it would be appropriate for ASSERT to host the next conference in Liverpool itself. What an honour that would be.....and here we are. Lots of hard work, many late nights and early mornings, hundreds of emails, and now its all over!

But what a success it was! The conference was the culmination of a great deal of hard work and dedication from all the trustees, with most of the work done in the early hours of the mornings!

This conference was also the first time that ASSERT has applied for and managed to secure funding from outside agencies and we were very lucky to be awarded a grant from The National Lottery Fund which meant that we had enough money to offer the conference at the gala free to our members and their guests!

The Friday conference for professionals and representatives of the ESA was held at the old Alder Hey Education and Research Centre, which was fitting as Dr Harry Angelman completed some of his training at Alder Hey and even practiced there for a short time.

On Friday we heard from noted scientists such as Ype Elgersma, Ugo Mayor and Qing-Jun Meng who baffled everyone except other scientists, Jill Clayton-Smith spoke about the increasing number of AS like conditions whilst Matthew During spoke about the upcoming trial of OVI01/ Gaboxadol.

Saturday passed in a blur of talks from the same scientists who adapted their presentations for parents and carers to understand.





# 4TH INTERNATIONAL ANGELMAN SYNDROME SCIENTIFIC CONFERENCE



1915 - 1965 - 2015  
LIVERPOOL



One of the highlights of the day was hearing Dr Becky Burdine explain the science of AS in layman's terms which made it easier for all to understand. Prof David Clayton spoke about birdsong, communication and learning, and whilst his interest has not previously been in AS, he went away from the conference with the spark lit for possible future collaborations with AS researchers.

As always, Mary-Louise Bertram stole the show. Parents throughout the world are benefiting from hearing her inspirational talks about how our individuals with AS are capable of far more than they have been given credit for. So many families are now putting what they have heard into practice and are actively working with schools and professionals to give our children a voice through the use of AAC.

The weekend finished off with the Gala dinner celebrating 50 years of AS and recognising the centenary year of Dr Harry Angelman. We were honoured to have Liz Huglin, niece of Harry Angelman attend the Gala on behalf of the Angelman family who spoke passionately about the family name, her uncle and his work. It was a very emotional speech and I think everyone was moved by what she said.



Gareth Edwards - Patron of ASSERT gave a humorous and heartfelt speech, most notably about how he didn't recommend having boys based on his experiences of looking after his nephews! He finished by congratulating the ASA on what had been achieved so far and referred to a little known film about intergalactic relations by quoting 'the force is strong with this one'.....I have no idea what he meant!

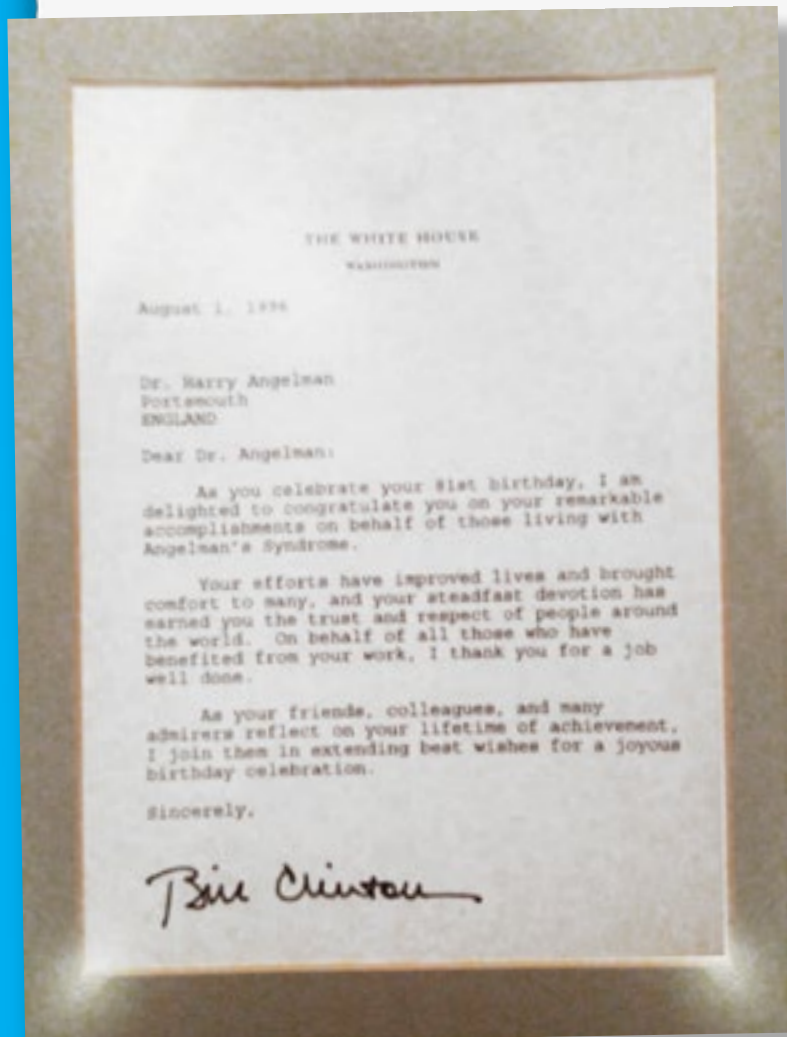
The idea of a scientific conference was uncharted territory for ASSERT and was met with a certain degree of trepidation and scepticism by some. However, our raison d'être is to support and to educate families and professionals about AS. Times ARE changing, science is moving forwards, possible new therapies and treatments are on the horizon however far away that may be and ASSERT has shown that we can move with the times whilst remaining true to our roots.

The ASSERT trustees hope that all who attended the conference had a brilliant weekend and enjoyed it as much as we did. Maybe one day we will do it all again once Lisa has recovered!

Rachel



# A letter from Bill Clinton

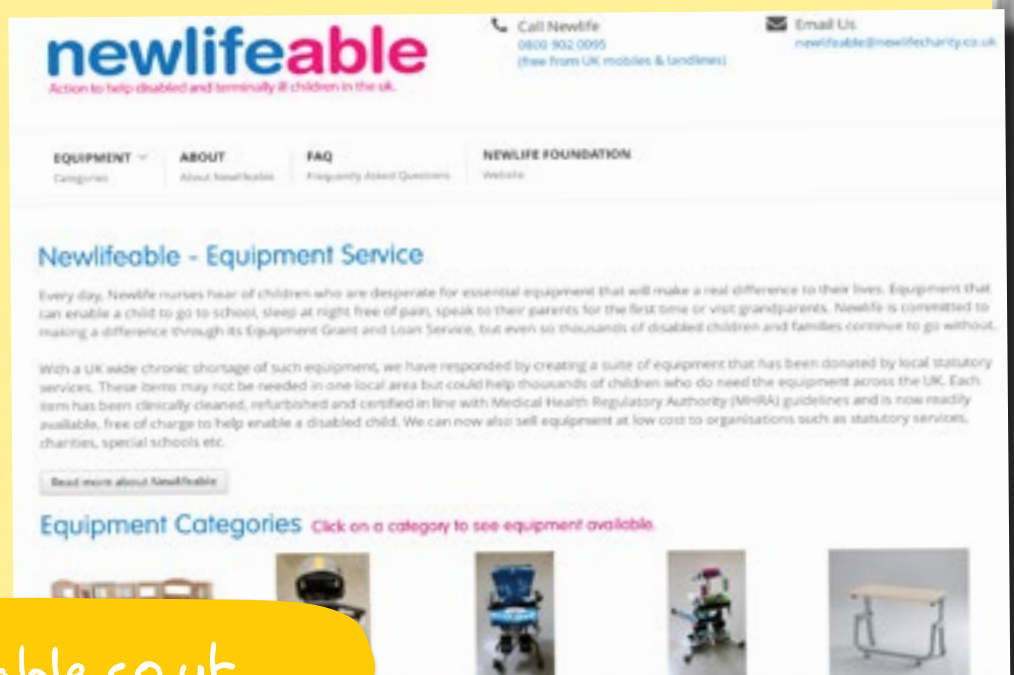


Bill Clinton

As mentioned on the previous page, Liz Huglin thrilled us all by reading out a letter from Bill Clinton to Dr Harry Angelman, thanking him for his services. We were not aware of this letter prior to the evening, so it was a wonderful surprise. Liz then donated the letter to ASSERT which was very generous of her. Here is the letter for you all to see. Its not every day you get a thank you letter from the President of the United States!

## Newlife

Newlife are an excellent charity who have helped a number of our families over the years by funding equipment that can't be sourced elsewhere. They now offer reconditioned equipment free of charge. Please take a look at their website to see if there is anything that may be suitable for you.



[www.newlifeable.co.uk](http://www.newlifeable.co.uk)



# Siblings

## Dear Jon



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

Problems can be written anonymously to [jonathan.allen@angelmanuk.org](mailto:jonathan.allen@angelmanuk.org) or to Jonathan Allen via a message on Facebook.

Dear Jon,

When I left for university everything with my brother, who has Angelman Syndrome, was good. However, when I came back he didn't take it so well and he became quite aggressive and upset with me. This has really got to me and I'm worried that every time I go away for a period of time, when I come back things are going to be bad again. Is there anything I can do to make this easier for my brother so he doesn't react like this?

There are a few things I would recommend with this situation:-

Something I do, although I don't necessarily recommend, is I often get my sister gifts when I turn up after not seeing her for a while. They aren't often expensive and often just bubbles which she really loves. But using the gift with her straight away seems to take her focus, relax her and make it a positive experience straight away.

My sister lives in a residential care home and something they do offer is a Skype chat. I don't know whether this would be possible for your sister (and obviously those with AS never stay still for long) but a 5 minutes face to face on Skype may keep things familiar and you may find she actually really enjoys it as it is not only something new but actually like an interactive photo to her (which is how my sister would see it).

Something that I haven't tried but apparently works really well in your kind of situation is scent. If you have a blanket or hoody or something that smells like you then give that to your brother for when you are not there then it can keep that familiarity going. Even a blanket with your perfume on or something can apparently make a difference. That way when you turn up it more relaxing and normal for her.

Dear Jon,

I am 14 and I love my younger sister but sometimes I feel a bit trapped in my life and having to be around to help look after her sometimes.

It is certainly not easy to be a sibling to someone with Angelmans, however it is also important to make sure that life isn't getting on top of you. Something I know has helped many siblings has been young carer groups. If you are able to find one in your local area then it is an hour or two a week with other people who are in similar situations. I really think this allows for you to unwind and talk to people who really understand your circumstances.

Dear Jon,

My younger brother has Angelman Syndrome and has loads of energy a lot of the time. However, sometimes because he is so full on, he can be too strong with me and sometimes scratches me too.

You should never take it personally if he scratches or pulls you hair, my sister, Eloise, is forever doing that and it usually just means that she wants attention or wants to do something else. Additionally, if you find that he is being quite full on, it may be a case of trying to do calmer activities if possible, such as painting or quite times whilst watching a DVD. The more regular these activities become, hopefully the more he will calm down when they occur.



Holly and Max - "who says having a sister in a wheelchair can't be fun. Not me!"

# Communication Matters

The Communication Matters National AAC Conference is the UK's leading annual AAC event. This conference was held in Leeds in September. It provides a unique forum to meet and exchange information with representatives from all disciplines associated with AAC, including parents, carers, professionals and suppliers of AAC. Jonathan Allen and Mary-Louise Bertram attended on behalf of ASSERT. Tracey Campbell also attended as a parent representative. Jonathan and Tracey have given their experiences of the weekend. Mary-Louise will be giving her experiences and views in the next newsletter.

## Communication Matters – A Trustee and sibling's perspective

In September this year I was fortunate enough to be able to attend the Communication Matters conference in Leeds. Communication Matters, for those who don't know, is a charity who support people of all ages who find communication difficult because they have little or no clear speech.

The conference this year had a large focus on AAC (augmentative and alternative communication). My older sister, Eloise, is 26 and has never had proper verbal communication skills (at most she sometimes says "Hiya" to get your attention). To see the range of options that may be available to her moving forwards was fascinating for me at the conference.

Most notably, there was the PODD communication method and Proloque2go. It was just incredible to see how individuals can go 20 years with no communication and then a year later have the vocabulary to communicate their needs and even have basic conversations.

Growing up without such technology as iPads and other tablets, I never really thought Eloise would have the ability to communicate in any real terms. We are perhaps all guilty of having a busy routine with our Angels and not challenging their abilities further. However, with new technologies available there are so many new options. Yes, it certainly takes a great deal of effort and patience using these new forms of communication, but the rewards are so worth it.

Both PODD and Proloque2Go are symbol/image based forms of communication; one being in the form of a book and the other an interactive app for iPads/tablets. At the conference though, what became really clear is that just like a baby learning to talk, this is completely new language for the user. Therefore, it can take 6 – 12 months of persistently showing the user how to engage with the communication device before they begin to grasp it. However, when they do the results are unbelievable and do seem to make it worth it.

I think the conference for me can be summarised by the fact that I have certainly underestimated the potential and my sister has, but also that we will be trying out some of these methods in the future. For anyone who has the opportunity to go in the future, I highly recommend it.

Jonathan Allen





# Communication Matters – A Parent's Perspective

I went along to the Communication Matters conference in Leeds September 2015. Communication Matters is the UK branch of ISAAC and they help promote the best possible communication for people with complex communication needs. Fellow Angelman mum and PODD user Jules Whicher had recommended it to me as she felt she had gained lots of knowledge the previous year from going. I was unsure what to expect but I was pleased to be meeting up with Jules and knew that Rosie Clark, Livvy Hepburn and Mary-Louise Bertram were all going so I was in safe hands.

The first night's entertainment was some pretty impressive signing with Sign Out Loud. The speakers for the first morning's keynote came from Scope Australia, it was very awe-inspiring. Scope has been working towards making the region of Victoria in Australia "Communication Accessible". They offer training and advice to businesses who are interested in the scheme and then they go through a formal assessment process by an AAC user. If they pass they are granted a certificate and a plaque which they are allowed to display in or outside their premises which lets customers know that they are an AAC friendly business. Hopefully this is a practice that could be adopted here in the UK.

I went to a variety of sessions throughout the day mainly focussing on the Scottish based ones. From this I mainly realised that there is a lot of good knowledge out there and that a lot of people who believe in AAC users, but the knowledge is not necessarily being passed on to parents and educators. I also realised that there is a big difference depending on where you are in the country. Sadly for me Glasgow does not have any kind of support network for those using AAC, although I was already aware of this. There has been a Scottish government funded project recently called "The Right to Speak". Whilst the funding has ended the main people involved are keen to keep working together and hope that they can still strive for access to services for all. Let's hope that happens.

Other sessions I attended that day were, "Developing a Communication Accessible School" by Rosie Clark and "Do More with Core" by Jennifer Marsden. Rosie's talk explained how the school that she works in started off small and has ended up with communication rights across the board for all pupils. The school has recently won the Shining the Light Award for best practice in Alternative and Augmentative Communication. Do More with Core was a useful insight into the main words that we should be modelling to our children. Namely, focus on more functional language and less on nouns. There has been a similar webinar included within the ASF Communication Series and for anyone who hasn't seen it yet, I would seriously recommend checking it out.

After a busy day it was on to the most important part of the conference - the Sunshine Ball! It was a good evening and the theme of sunshine really helped brighten up a fairly chilly September evening.

The following day I attended more Scottish sessions. The final session that I attended was "Lights, Camera, Action" which was about how music in school can really make a difference. The pupils of Ash Field Academy, along with the help of two local musicians, had been making videos of songs that the musicians had written. The pupils decided to get more political and made a video campaigning for better public toilet facilities. They helped write the song as well as sing in it. The result was brilliant, you can find it on YouTube if you Google "Ash Field Academy you've got to go".

Both this session and the Sign Out Loud from the first evening have really inspired me to try out different methods to help Leia to sing. She loves music and I am sure she will respond really well to this.

Overall the conference was a worthwhile experience and it is fantastic to know that there are so many people passionate about AAC in the UK. Now just the small task of filtering that enthusiasm to all the educators and SLT's across the country!

Tracey Campbell



Mary-Louise, Tracey and Jules

# Our Fabulous Fundraisers!

It has been yet another fantastic year on the fundraising front. We have had a great mix of 'volunteers' to take the places in a number of events that we have purchased, along with family and friends choosing their own way of fundraising. Thank you so much to everyone who has raised funds for us. Every single donation, no matter how large or small, really does make a difference. All money raised goes directly into allowing ASSERT to continue supporting you. So please keep up the great work!

If you are thinking perhaps you would like to do something to raise funds for ASSERT in 2016, but are not sure what to do, then how about applying for one, two or all of the following events:

Event	Distance	No. Places	Event Date	Deadline to apply
London Marathon	26.2 miles	5	24th April	30th November 2015
London 10k	10km	24	30th May	31st December 2015
London to Surrey cycle ride	100 miles	6	31st July	31st December 2015
Great North Run	13.1 miles	5	11th September	31st December 2015
Great South Run	10 miles	5	23rd October	31st December 2015
Great Manchester Run	10 km	5	22nd May	31st December 2015
Great Birmingham Run	10 km	5	9th October	31st December 2015
Great Edinburgh Run	10 miles	5	17th April	31st December 2015

If you would like to apply for one of these places or would like more information please email [assert@angelmanuk.org](mailto:assert@angelmanuk.org).

## London Marathon 2015

This year we had 9 runners – 6 golden bond runners (as one place was carried over from last year) and 3 runners who very kindly ran for us on their ballot place. Between them, they raised over £15,200. What an unbelievable amount of money. The London Marathon is our biggest source of income for a single event and each year our dedicated runners put their all into training for the event and raising funds for our charity. It is a huge commitment and it is a decision that is not taken lightly. ASSERT would like to say a huge thank you to all of you for your brilliant efforts.

### Golden Bond Runners

Will Aldridge  
Clare Mann  
Emily Iredale  
Thomas Burke  
Jenna McKenna  
Sharon Hurcombe

### Ballot Place Runners

Karl Scally  
Steven Coates  
Jay Edmonds



## Will Aldridge



I decided to apply for the Virgin Money London Marathon 2015 after I turned 18. I have always been into sport and keeping fit so I decided to put my fitness to the test. I chose ASSERT as my chosen charity as my little cousin, Evie, was diagnosed with the syndrome at birth, and suffers badly, not being able to walk or talk at the age of 9. I can see what Evie's

parents go through to look after her, but don't have a clue what it would be like to be in their shoes, and I know there are hundreds of other parents or relatives in the same position.

From the off I was keen to get people behind me in following my journey with the four months of training I was doing. I started training in January, and trained all the way up to the day before the marathon, training 6 days a week. It was a real challenge training during winter and after work but knowing it was for such a good cause helped my motivation massively. I set myself the target of 4 hours and was doing everything I could to make sure I achieved this, including monitoring my running speed and time in training.

As I got closer to the big day my training was obviously longer but the warmer weather and lighter evenings helped me out massively. The training seemed like a huge part of my life but before I knew it, it was time to collect my running number and get my ASSERT vest ready for the day.

The marathon day itself was fantastic, the weather was perfect being not too warm but not at all cold, and the atmosphere was unforgettable. The other runners are great, everyone is one big team out there and the fans are amazing too. Everyone cheering just jeers you on throughout the 26.2 mile run. I even managed to see my mum, dad and other family at one point and also my girlfriend and her friends at another. Huge motivation seeing people who have helped you during the training and preparation for this day. I managed to complete the marathon in 3 hours and 41 minutes, which beat my target!!!! I was over the moon with that time and always will be. All the hard work paid off and it topped off the amazing experience! I would advise anyone who thinks they would like to do the marathon to do it because it is an unforgettable experience and massive achievement.

Not only did I beat my time target I beat my fundraising target too! My target was £1500 and I managed to beat that by a couple of hundred pounds and still counting! Big thank you to all the people who donated, friends, family and colleagues.

I would also like to thank the hard work ASSERT put it to make it happen for me, helping me fundraise and be prepared for the big day. Lisa helped me massively sending me a lot of helpful information about the charity and all the things I needed, my vest and also my marathon photo. Thanks again!

## Clare Mann

'Whilst training for a 10 mile run, my friend Kelly Martin talked me into entering the London Marathon to raise money for ASSERT, agreeing that we would only do this if we both received a place. Just before Christmas, I was offered a place but Kelly wasn't.

We decided that I should run anyway and that Kelly would help with my training and fund raising. It's a cause close to our hearts as Kelly's son William lives with Angelman Syndrome.

The initial training was not too bad but as the distances increased it became more and more physically and mentally challenging.

Whilst doing the training, Kelly and I, along with help from family and friends, arranged a disco, which raised over £1100. The support was amazing from friends, family, local businesses etc.

My mum also held a coffee morning raising £200 and a friend organised a cake sale for me raising £85.

On the day of the marathon, the weather was ideal for a

marathon runner, but horrible my family who had come to support me.

As I crossed the start line, my nerves filtered away and I started to run... and run... and run some more and eventually, 5 hours and 40 minutes later I crossed the finish line. It was an amazing feeling to know that the hard work had finally paid off and I'd completed what I'd set out to do... run the London marathon and raise over £3000 for an amazing charity.



# Sharon Hurcombe

When Lisa got in touch with me in December 2014 to tell me I had been successful in securing a charity place at the London Marathon 2015, I thought to myself 'what the hell have I done?'

I had only been running since January 2014 and that was only a sofa to 5k course, the farthest I had run was 13 miles, so I was no hardened runner. I have to admit I nearly chickened out. But, I gave myself a good talking to and told myself it was something I had always wanted to do and to stop being a wuss.

So I started training and fund raising in earnest, to be fair the fundraising concerned me more than the training, but I baked cakes, collected stuff from friends and family for a car boot, I sold stuff on eBay and on Facebook pages, I knitted and crocheted things, you name it, I did it.

I trained with a friend and increased my mileage by a mile a week up to a distance of 20 miles, we decided at this stage that if we could run 20 miles, we could wing the last 6.2 miles with the help of the support and atmosphere of the occasion.

It was an amazing day with so much support and comradeship along the way, and we did indeed need that support the last 6.2 miles but we did it.

At the end I broke down in tears in my husbands arms, not just gentle silent tears, but great big racking sobs! The relief of finishing, the sense of pride and achievement and the thought of the fact that I had done something for my grandson Ollie.

Looking back at it now and remembering all those runners, all with different abilities, the fast, the slow, those that had to walk and indeed crawl, those in high heels, or a rhino suit, the fridge

carriers, the blind runners and those running as a three legged team, they all had their own obstacle to overcome to get to their goal of reaching the end of that long 26.2 miles and without their fellow runners, their families or the massive amount of support from the crowds, I doubt that as many would have reached their goal of completing the race.

The way I look at it is that our Angels are just like those marathon runners, they each have their own obstacles to overcome to reach their goals and without the support of their own families or the Angelman community and the Angelman Charity, they would be hard pushed to reach their goals, so I am proud to have played some part in contributing towards this support.

Would I do it again? Well immediately after the race, in between sobs, I vowed I would never do it EVER again, now it's 6 months later and I suppose the fact that I have asked Lisa to be added to the list of wannabes for the 2016 London marathon means that my answer is YES I would lol.

At the end of the day, I can get over the obstacles in my marathon of 26.2 miles and take between 4.5 and 5 hours to do it, whereby our Angels obstacles and personal marathons will last a little longer; therefore the lost weekends running, lost toenails and the fact that I had a job to walk for days is a small price to pay to raise funds and awareness for this great charity.



# Karl Scally

2016 will be my 5th London marathon and it never fails to be an epic day. It starts early with the nervous runners chatting to each other on the trains to Greenwich swapping training or past marathon stories. Marathon day is the only time complete strangers actually are allowed to talk, laugh and joke with each other on a London tube. This is only the build up to the apprehension on the line then in to the overwhelming support and noise from all the supporters and music on the route.

My 2015 London Marathon was a great run but still a personally disappointing run. I started well, by half way I was hitting every target I'd set and cruising around easily. 18 miles they'd altered the course a slight bit to include a fly over; at this point I knew I was going to struggle in the remaining 8 miles. Pushing through pains I was starting to get in my legs I got to 24 miles, looking at my watch I realised I was still ahead of schedule by 2 mins so decided to have a little walk to stretch my legs out and get my head together for the last 2 miles. Still over 90 seconds ahead I continued on determined to keep the pace going. Mile 25 I realised I'd overrun by 0.4 of a mile which then put my schedule calculations out. I was now behind my schedule, I tried to push hard in the last 1.2 miles counting it down one tenth of a mile at a time.

As I came around the corner to the final straight my hamstring cramped, I looked up at the clock over the finish line and realised I was going to miss my target. I sprinted the last few hundred yards with my hamstring still cramping and knowing I was going to miss the time I wanted. 3hrs00mins and 39 annoying seconds!!!

The walk at mile 24 and not taking the racing line cost me my sub 3hrs. It was a new personal best, it's a London Marathon good for age time so I'll have an allocated place for another 2 years but the disappointment of missing 3hrs by 39seconds will be the one thing that I will remember for 2015 and I'm aiming to rectify in 2016.

As I stood in the Horse Guards Parade with my wife in complete agony with cramp in my legs and feet I was muttering over and over the words "Never again!". My friend (who'd also run it) turned to me and said "Same again next year?" and without thinking I replied "Yeap, I'll be here." At the end of the day the pain is temporary but running the London Marathon will be with you forever.



## Great Runs

ASSERT have had a number of places for the various "Great" runs around the country for a few years now. These are also very popular events.

The total amount of fundraising received to date in 2015 from all of the "Great" Runs is the fabulous £4,400 and we still have more on its way.

Great efforts of all those involved, thank you very much.

### Great Manchester Run:

Roxanne Brooks  
Cally-Ann Brooks  
Stephen Brooks  
Nicola Holland  
Lee Atkinson

### Great South Run:

Michael Fisher  
Gemma Ellis  
Sukhninderjit Braitch

### Great North Run:

Sian Cartwright  
Poppy Cartwright  
Teresa Ellinor  
Simon Smith  
Clare Campbell  
Tina Ellinor  
Alan Tranter  
Simon Rose  
James Kurszewski  
Rebecca Castle  
Ally Streletska  
Joseph Hill  
Charlotte Corner  
Rachael Murdoch  
Stephanie Thandi

## Sian Cartwright

Between us we have endured 2 knee operations (both mine), 2 in-growing toenails (Poppy), groin strain (Poppy) and a pulled hamstring (me) but somehow a second Great North Run seemed like a good idea.

Up early, plenty of carbs for breakfast, a couple of nervous wees and we left the house at 8.30am. Poppy lives in Gateshead and we headed to the nearest metro station in good spirits. However all trains coming through the station were full to busting and, along with a crowd of other runners, a 3 mile walk was clearly the only realistic means of making the start line on time.

The sun shone, the spectators cheered, the Red Arrows flew overhead, musicians played and we soaked up the carnival atmosphere of the GNR. By about 9 miles Poppy and I were both finding it hard going on such a warm day and given the unanticipated 3 mile walk to the start I think my legs felt we should have been nearing the finish line. My friend Val was waiting for us at 11 miles

so after slowing to a waddle for a mile or so we picked up the pace to impress her as we saw her waving in the distance. We hauled ourselves the last couple of miles (brisk walk, waddle, jog, waddle, jog) and finally crossed the finish line together with big smiles. Could we make it three in a row next year? I'm trying to persuade my partner Peter that it's his turn.



Poppy and Sian Cartwright

## London to Surrey Cycle Ride

This was another first for ASSERT in that it was the first year we had purchased places for the London to Surrey Cycle Ride, and it was also our first non-running event. It takes quite a commitment to cycle 100 miles in one day but we were lucky to fill our 3 places. Our 3 cyclists raised over £4,300. What a fantastic effort!

Our 3 cyclists were:

Vel Petrovic  
Vlad Lazic  
Darko Petrovic

## Vel Petrovic

"We would be honoured!" was the reply when I asked the boys in March if they were interested in riding 100 miles for Ollie's charity Assert.

Our training began with many circuits around Richmond Park in the evenings after work and progressed to Box Hill and Leith Hill on the weekends.

The support during the ride was great and encouraging – "Well done Assert!" were the shouts from the spectators.

Ollie was supporting us as we rode through Kingston in the final stages and riding through Rayners Park we were greeted by my niece and nephew Zara and Charlie selling flapjacks on a stall for Assert. They were very excited and did a great job so a big thank you to them for their support.

A huge thank you to all the people that generously sponsored us, we managed to raise £4,367.78 for Asserts Angelman Syndrome.

Thank you to Darko Petrovic and Vladimir Lazic for riding, it was a fantastic day and can't wait to do it again next year.



## London 10k 2015

This was the first year that ASSERT purchased places for the London 10k. This looks like it is going to grow and grow in popularity in the coming years. It's a great event around the streets of London but just not quite as far as the usual marathon! Our 5 runners raised nearly £2,500 between them and there is still more money to come in. Well done guys!

Our 5 runners were:

Shelley Cachia  
Ed Winter  
Sarah Brown  
Jonathan Allen  
Karen Davies

This year I have taken part in 2 races for ASSERT The London Bupa 10k and Plusnet Yorkshire Marathon.

The Bupa 10k was on the 25th May (my birthday). I am not new to running I used to run long distance and Cross Country at school and restarted again in my late twenties. I



stopped again due to injury, then married life and children got in the way. When my youngest Grace started school 3 years ago which gave me the spare time to restarted running for general exercise. After entering a couple of races I realised that I still loved running especially races! I also discovered that it's my coping strategy for dealing with my Son Cody's Angelman syndrome.

## Sarah Brown

It gives me more strength and energy to deal with day today battles with an energetic Angel and it also helps me to stay mentally strong.

On the day of the race I felt so proud to be wearing the ASSERT vest. My parents came to watch and handed out ASSERT balloons and leaflets. I had such a brilliant day, I saw Jo Pavey, I got a personal best of 48 minutes and raised £399.80 for ASSERT.

York Marathon was on the 11th October, The hardest part of Marathon training was finding the time to fit all the runs in, especially the long runs which can take up to 4 hours. The week before was really hard because Cody was in hospital due to increased seizure activity. Luckily for me he was well enough for me to travel to York. The week after we ended up in hospital again and I can tell you sitting around in hospital after doing a marathon is painful. I was walking like I had gait legs! The race was amazing I had my name printed on my vest and all the lovely People of York shouted my name as I ran passed. My time was 3 hours 46 mins 55 sec, I am so happy after the week I had with Cody in hospital and myself suffering from Cold I was just so happy to be running. My sponsorship total is £245 and I am still collecting.



# Other Fundraising

There has been a great variety of fundraising completed through the year. Here is a selection of some of our wonderful fundraisers.

## Michelle Matthews -Farmageddon

Tom was diagnosed with Angelman Syndrome (UPD) in May 2014 when he was just 2 ½ years old. The day we got the diagnosis was obviously devastating and was full of the 'unknown', however we wanted to end the day on a positive. So we googled AS charities and ASSERT came up in the search engine. We emailed that night and straight away we got a reply from Lisa Court, which really did mean so much. We registered with the charity straight away and since then ASSERT have helped in so many ways, including introducing us to other AS families.

We want to raise as much money as we can for ASSERT and at the same time raise awareness for Angelman Syndrome. So on the 25th April we started our campaign and got a team of 17 Family & Friends, the 'Assert Angels' to enter the 'The Farmageddon Run'. A 5km run on a farm, tackling manmade and natural obstacles through woodlands, farm tracks and across grassland.

Our initial target was to raise £1000 between us which at the time seemed a tough challenge, but as soon as we set up the 'Just Giving' pages and sponsorship forms the support was incredible.

Quest Events the company that runs 'Farmageddon' had designed some tattoos to be sold on the day from an 'Assert Stand' and all the profits going to Assert. A few of the 'Assert Angels' work for Premier Inn (Whitbread PLC) including myself, who kindly donated £1500 with their 'Raise & Match Scheme'. Caterpillar UK another one of the employers of an 'Assert Angel' donated £250.

My niece Emily and her boyfriend 'Big Tom' organised an 'Assert Stand' at his school 'St Peters Independent School' over a weekend when they had an open day and raised £458. This truly was amazing, as they organised it all themselves and gave up their weekend to raise awareness. Overall our 'Assert Angels' did us proud and we cannot thank them enough. We all finished the 'Farmageddon Run' injury free and for most it was a real sense of achievement. The day was very emotional, with lots of support on the 'sidelines' from family & friends cheering us on, including Tom.

Together we raised a whopping £5298.50.

Thank you 'Assert Angels'

Stuart, Kerry, Dawn, John, Nicola, Keira, Emily, Big Tom, Leann, Jamie, Vicky, Kate, Katie, Kelly, Ria & Dave



## Mairi Leith-McGaw

So it's the crazy horsey one doing more crazy horsey stuff!

There was an online campaign #willyouslowdownformenow in which other crazy horse people like myself took almost naked photos with their horse to raise awareness of horses on the roads. After weeks of badgering on Facebook with people asking when I was going to do it I gave in BUT the catch was that I would only post the photo to my profile if people sponsored me! And so they did so hear you go everyone me in all my glory with my horse Meisha who isn't looking to impressed at the whole situation...

## Nigel Fenning

Back in the winter of 2014, my work colleagues and I were sat comfortably in the pub on a Friday after work and decided that we needed to complete 'a challenge'. As the drinks flowed, so too did our confidence and belief in our levels of fitness. By the end of the evening we had settled on completing the national 3 Peaks (and many more challenges besides).

As sobriety hit, and a certain amount of research was conducted we decided against the national 3 Peaks (too much driving), and we settled instead on the Yorkshire 3 peaks. This is a more contained, but nonetheless challenging walk. For the uninitiated, the traditional Yorkshire 3 Peaks route starts in Horton on Ribblesdale and takes in Pen-y-gent, Wharfedale and Ingleborough. In all, a 12 hour challenge, approximately 25 miles with 1,600m of ascent and descent. That is a lot of steps. Trust me.

When it came to selecting a charity to support as part of this venture, I turned to my closest friends, Ben and Andrea and their family. My wife and I met Ben and Andrea the year after we left University and have remained in close contact ever since. Many years have since passed, and they now have 3 very energetic young boys. Their second eldest son, Woody, has Anglemans.

I know that Assert offer fantastic support and do great work in research and education. What I have also



Saqib, Faye, Ernest, Nigel and Julie

witnessed as an outsider is that they provide a much needed community for like-minded people to get together and share experiences. For that, I think it is worth a few lost toe nails and blisters.

Long story short – we completed the walk back in July in a respectable 11 hrs 20 minutes. 5 of us set out, only 4 returned (well, the other one 'retuned', but via 2 rather than 3 peaks). We lost 6 toe nails between us, and all now have a lot more respect for the hilly landscape of the Yorkshire Dales.

We were also able to raise nearly £500 in support of Assert.

I can't wait for the next challenge - we have a list, so watch this space.

## Tracey Campbell

Leia's Exciting International Angelman Day was held on 15th February 2015, International Angelman Day. I had been thinking about holding a PODD event and the idea kind of grew into a fundraiser to help people learn about what life is like living with communication and sensory processing difficulties.

I hired the local Scout Hall and dedicated half of the hall to tea, coffee and cake and the other half for activities.

For PODD activities I borrowed some books for people to look at and printed out the first two chat pages for people to see how many things they could say to one another. Sensory processing activities included Blindfolded obstacle course, Say the colour not the word, Pin the tail on the angel, Optical illusions and a What's in the bag.

All throughout the organising there had been an overwhelming amount of support from family, friends and the local community, including people whom I didn't even know very well. On the day it was no different; cakes appeared from all over; lots of people helped serve tea,

and coffee. Cakes were kept topped up, raffle tickets sold. Abbie's Guides helped by doing tattoos, nails, face-painting and even gave massages.

On the day to make money, the event was free but we asked people to make a donation or buy raffle tickets. My friend made a little Leia – an angel with a slightly fallen halo, people paid money to guess her birthday and win a chocolate hamper. There was also a special raffle for a bottle of 21 year old Royal Salute whisky. A cake stall, the Guides and one of Leia's old Rainbow helpers doing Shellac nails brought in the rest of the money. I had people who couldn't attend also donate online via JustGiving.

The day turned into a fabulous community event I couldn't have asked for it to be better. We raised almost £5,000 including a fabulous £3,102 for ASSERT. Not a bad day's work for an unassuming 8 year old girl.





## Search Laboratory

This year Search Laboratory have been working hard to raise money and awareness for ASSERT. We have tried to come up with some fun and interesting ways to achieve this. A large group of us walked the Yorkshire 3 Peaks on the August Bank Holiday Weekend taking pictures along the way and raising money even after the event had been and gone. We have organised a casino night, bake sales, Pancake Day at the office and Wear your PJ's to work day. We have also had great fun taking part in lots of organised races in and around Yorkshire including the Leeds 10K, the Yorkshire Marathon and the Great North Run. We are just preparing ourselves for the Abbey Dash 10k run in November where we will be donning our running shoes again!

It has been great over this past year getting to learn more about what ASSERT does and we have felt honoured to be a part of raising awareness of the charity and helping towards fundraising efforts too. We are looking forward to a visit in December where we hope to learn a little more about families who experience Angelman Syndrome and what the charity does to support and help these families.



## Amy Symmons

Jacobs daddy Andrew and his fellow colleagues at Nationwide did a sponsored walk of 14 miles round Swindon for 3 chosen charities of which Assert was one. They all completed it (with most toenails still on) and raised £377.00.

During the summer our village has a fun week of activities and fetes. They also run a competition of Scarecrow making. Our local pharmacy decided to support Assert (Jacob is a firm favourite of theirs) they built a fab Angel Scarecrow and raised an amazing £125 from customer donations. Even now they are still raising money as they have the Assert charity

## Nathan Walsh

For International Angelman Syndrome Day me and my friends, Matty Gardner, Alex Berry, Frances Rimmer and Scott Haydock held a cake sale in Runshaw College to raise money and awareness for Angelman syndrome. We sold cakes, wristbands and handed out leaflets. We raised a total of £38.10 and raised a lot of awareness around college with leaflets, posters and a radio announcement telling the college that it was International Angelman Syndrome Day within the next few days.

Doing this event and it having such an impact on the college meant a lot to me because my little brother, Sean who has Angelman Syndrome means the world to me and to see people in my college know and get a basic understanding of what Angelman Syndrome is makes the day worth while for me.



## Phil Adcroft

Three hardy northern blokes (Andy, Mick and Phil) left a sunny Preston in Lancashire on the afternoon of Monday 20th July heading to London town by train, ready for what they hoped would be a great adventure. Their plan was to cycle from London to Paris, arriving to coincide with Chris Froome's hopefully triumphant arrival the following Sunday in the Tour de France Yellow Jersey. Whilst all were keen cyclists, none had cycled this kind of distance before. Youth wasn't on their side (Andy was just 50, Phil nearly so and Mick had another 10 years on that) and at least one partner described them as 'old enough to know better'. However, with a strong camaraderie and shared fondness for beer, they were confident (well, fairly confident) they'd get there on Friday evening.

Tuesday morning brought a blue sky but more wind than you'd ideally want on what was the longest cycling day of the whole trip – 65 miles and 6 hours down to Newhaven.

An early start was called for. The Avenue Verte is a dedicated cycle route from one capital to the other, using the National Cycle Network and quiet country lanes. Or so it says. It might well be described as very poorly signposted and routed to make sure you get lost just about every 10 minutes. A 65 mile/6 hour day turned into 85 miles and nearer 12 hours in the saddle, finishing with an overnight stay in a poor hostel that could only be reached travelling cross country on paths that looked like roads on the planning map.

Wednesday saw us on the road for 6.30 (just over 4 hours after we got to bed) for a quick ten miles into Newhaven and the first thing in the morning ferry. It's a four hour crossing and thus allowed both sustenance and sleep to be caught up before emerging into a warm and windless Dieppe. Within 20 minutes it was clear that the French take the Avenue Verte much more seriously than the English. Superb signposting and dedicated cycle paths away from traffic are perfect for cyclists who don't really know where they're going.



Mick

Thursday brought more glorious weather and after a great breakfast and lots of coffee, we headed out on the road, stocking up at the local market with plenty of food to sustain us through the days 55 miles. It was obvious from the beginning that this was just the cycling we were looking for. Quiet country lanes with a car every hour, some decent climbs and long descents, tiny hamlets and hillside chateaux to keep the scenery interesting. So well did we cover the first 25 miles we rewarded ourselves with a small beer at Gournay. Refreshed and water bottles (or bidons if you prefer) replenished we headed out for the second half of the day's ride in fine spirits. There was the biggest hill of the entire journey coming soon, but we didn't care. We were cycling well and knew that once it was behind us, well, it was behind us. The joy of cycling the Avenue Verte in France is that you know that if you arrive at a junction without a sign, you shouldn't be at that junction. The first alarm bell of the day rang at the top of that 3 ½ mile hill. No sign and no apparent clue which way to go. No matter which way we turned the map, it was clear we were at the top of the wrong hill. At least it was a decent ride back down.

We'd missed a fairly large sign at the bottom, probably because it was put there in winter when the rather large tree it was behind wasn't in full summer bloom. Nothing for it but to ride up the right hill and congratulate ourselves on our King of the Mountains effort when we got to the top. The second alarm bell of the day had begun tinkling by this time. Whilst studying the map at the top of the wrong hill, Phil had begun to wonder about how



much mileage they actually had left for the day. The plan said just under 20. The itinerary so minutely detailed said that night's hotel was less than 20 miles away. The map said it was more than double that.

Something wasn't right and after a further hour's riding, Phil reckoned he'd better air this concern. After studying the route and the map it was clear that night's hotel was still about 40 miles away. All Phil's months of finely detailed planning was undone by the rather glaringly obvious fact that two pages in his guide book were stuck together and he'd missed out a huge chunk of map. Oh how we laughed.

After a hastily convened cycletrackside meeting, it was discovered that 4G, 3G or indeed any internet connection in the middle of French countryside wasn't to be relied on. Or even had. So backtracking to the last nearest town was the only option.

Friday was a scorcher with temperatures reaching the high 90s. Now this report may seem that this was a bit of a boys' adventure with some cycling thrown in between bouts of drinking beer, glorious French wine and eating delicious cheese. In a sense it was. But make no mistake, it takes a real effort to climb back on a bike in the morning with 50 or 60 miles in front of you when you've already got 3 times that behind you. But get on those bikes we did and off into The Vexin countryside we headed.

Saturday's ride into Paris wasn't without event. It was 20 miles further than the 10 they'd imagined for a start. It involved climbing fences with bikes to get round locked park gates, not falling off when Phil got his wheel stuck in a tram track and riding on Parisienne highways only marginally less terrifying than those in central London. Just after lunch, the three of us arrived at Gare du Nord, 257 miles further on from where we'd left on Tuesday. We were delighted with what we'd achieved and that delight was only improved when we could see the sponsorship money really starting to roll in now people actually believed these three 'old enough to know better' lads were better at this than probably even they thought. The absolute highlight of the weekend? Watching Chris Froome arrive into Paris on Sunday on his yellow bike, and, a couple of hours later touching that same

bike, having my photo taken with that same bike and meeting – wait for it – Dave Brailsford as he arrived back at the team hotel on a Team Sky bike. Dave thanked us for coming out and thought it 'an absolutely superb effort'. If you don't know who he is look him up. Then you'll know.

We only know Assert because Phil met Rich and Sue Williams at the Bearded Theory music festival about 8 years ago. We only see each other once, maybe twice a year. Phil and Andy have both supported a couple of young people with Angelmans but that wasn't really the connection. Phil has watched the passion Rich and Sue have for Assert through the window of social media and it's this passion that led to this fundraising. The more I read about Assert (and I do, a lot), the more crucial the work it does feels. It will seem fictionally sentimental, but three paragraphs ago the postman delivered the fundraising certificate and personal note of thanks. Personal note of thanks. Wow. Next year's trip is already in the planning stage with some added challenges to try and raise even more money. Assert is our charity of choice and, I imagine, always will be now. It feels special to be even slightly involved in the amazing work you do.



Andy and Phil

## The Blemain Group

The Blemain Group very kindly nominated ASSERT as their charity of the year for 2015 which meant that all funds raised during their Fun Day held on 25th May in Cheadle were given to ASSERT. Lisa Court and Rachel Martin attended on behalf of ASSERT along with a number of our families from the local area and further afield.

It was an amazing day. There was so much to keep the children and adults entertained for the day. There were fair ground rides, bouncy castles, other inflatables, trampolines, cakes, candy floss, sweets, ice cream, burgers .... Every child's dream! There was plenty for the adults as well with a Pimms bar and inflatable pub and hog roast.

Everyone who attended said how much they enjoyed the day and how welcoming everyone from The Blemain Group was towards our ASSERT families.

Thankfully the weather was very kind. The live band were very entertaining and sang a great mix of songs.

The final total for the day was a massive £6,557.98. A special thanks goes to Steve Dolmor who nominated ASSERT, as well as a huge thank you to all at The Blemain Group for raising such a fantastic amount and for being so hospitable.



## Easy fundraising

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



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

For more details please visit the website: [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk)



# A Voice Letter

## A Plea For A Voice

This letter was written by Tracey Campbell. Tracey has kindly given permission for any of our families to copy and use this letter.

To all the adults who make decisions for me.

I would like to take this opportunity to ask for a really small thing. Well, let me clarify that for you. It's a really small thing, but for me it's massive.

I would really like access to a voice – a full voice that lets me say what I want to say, when I want to say it.

Ok I hear you, you don't think I can manage and it's too much for me – I might get overwhelmed, but hear me out. I have been thinking about my baby cousin and how he got access to his voice. Here was me waiting for him to have to prove that he could use it. That's what the rest of us have to do, right?

Listen to this, they were crazy. They talked to him before he was even born, what's that about, that dude can't even breathe never mind point or nod.

Then I noticed that he didn't make a single sound for weeks, months even. But you know what, they kept talking to him using the same language. They didn't switch languages on him every few weeks.

It gets even stranger. He starts talking back to them in some weird sounding language, I have never heard anything like it, even the dog makes more sense. So here was me thinking; "that is it, he has blown his chances, new system here we come". But do you know what they did? They spoke back to him as if he was talking sense! Here is an example:

Cousin: "goo, blu, coo, coo"

Aunt: "Yes you have got the best mummy ever; I love you telling me all these stories"  
Really?

You know what else I noticed? If my cousin didn't answer in the way they wanted, no one ever gave 'The Look'; you know the one that says he is just never going to get this. I also noticed he didn't have to choose a lot between two random things on demand. All the stuff they talked about seemed more natural. Everyone believed in him no matter what rubbish they spoke. That side of the family have always been weird.

A much more normal approach is what my mum's friend has been doing. She is good at languages, teaches them and everything, so she decided that she would take up Mandarin. Off she goes to a class every week for an hour (I mean, it's a bit excessive but she's keen, I'll grant her that), apart from holidays and when life gets in the way she is there, primed up and ready to go. It's been about 1.5 years and she ain't exactly high functioning but hey, she can say hello and goodbye and who am I to judge.

Lately though I was wondering. Is it time to join the weird side of the family? What if I could get taught in the same way as my cousin, he has made much better progress than my mum's friend? I figure that if you just start teaching me the language, we can be working on a point or a yes or no at the same time. I mean, I know you think that I won't ever be able to do it but what if I can and you don't give me the chance? If you give me a full language, teach me how to use it, respond to my attempts in a positive way and give me time then who knows?

So I will do you a deal. If you give me this chance and you meet me in 20 years and I have a full life and a chance to contribute I will let you share in the glory. You can honestly say this started with your belief that this could work. (The rest of it is down to my hard work and everyone else's but you don't need to mention that). Hey, see even if I don't manage to get to that level, I do have a lot of good stuff going on in here, and you will be able to look me in the eye and say that you believe in me. That on its own means a lot to me.

Thanks for taking the time to listen.

Tracey Campbell,

On behalf of Leia

# BOY BITES HORSE

NOTES FROM AN ALTERNATIVE CHILDHOOD

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

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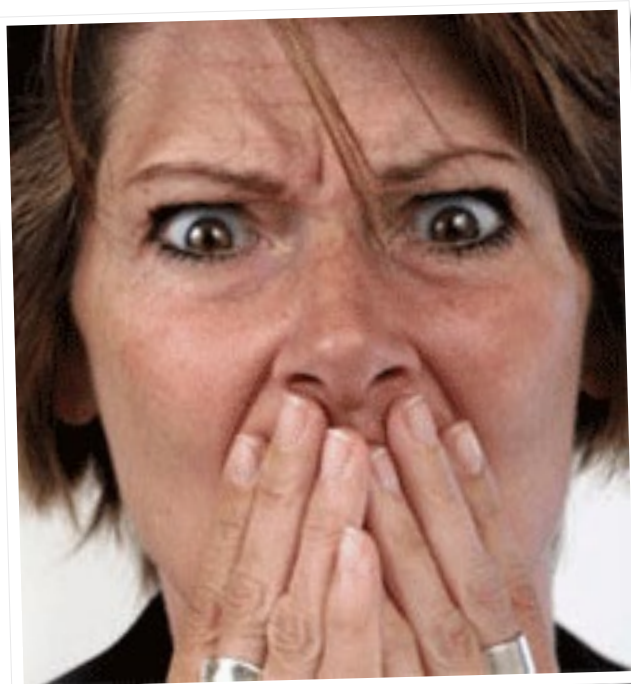
I'm not at all sure what the fuss is all about.

There I am, lying in the bath with my finger in my eye and Curly Top says "That's disgusting!" What's so disgusting about putting your finger in your eye? I'll bet you've all done it at some time. Of course if you're as talented as me you'll be able to hook the end of your index finger right round under the eyeball and make your left eye go in a different direction to your right. I do this quite a lot because I like the colours and funny patterns it makes. Smiley and Frowny have been told to stop me doing it... some nonsense about 'going blind' or something, I wasn't really listening. But honestly, how are they supposed to stop me? As soon as they turn their backs I'll just do it again.

While I'm on the subject, that's not all you can do with your finger. If I'm bored with sitting in my chair – usually either waiting for food to arrive or when I'm waiting for everyone else to finish eating – I sometimes stick one of my smaller fingers right up my nose as far as it will go and make a kind of clicking noise with the bendy boney bit inside. That one really freaks them out. I tried this once on Smiley's nose when he was carrying me out of the house to strap me into the car. I was a lot younger then; my fingers were very small and his nose looked very large so I thought I'd see how far up I could poke a finger. It turned out I could push it all the way up and hook it over the top into a kind of hole. I held on like that for a while but in the end it was too funny watching him hop around and I had to let go because I was laughing too much.

There seems to be a very fine line between what's funny or disgusting and I'm not sure I completely understand the rules. For instance, when I was very little one of my uncles discovered I'd never tried ice cream and decided to give me a bit of his on a spoon. He held it up for me to taste and I stuck out my tongue and then everyone laughed. Quite frankly I was a bit annoyed by this, not so much by the laughing as by the fact that I wasn't getting the ice cream. Apparently the thing that was amusing them so much was the fact that the end of my tongue was 'forked' when I stuck it out. They kept holding the spoon just that bit too far away for me to reach so that I was having to stick my tongue out as far as it would go. Frustrating. Eventually they got bored with this and just gave me the ice-cream so it turned out ok in the end and no-one mentioned the tongue thing again. Fickle lot.

I suppose the tongue isn't really what you'd call disgusting so much as fascinating. Now if you want disgusting you can't beat eating things. I've already told you about the various types of poo worth trying, but did you realise the sticky jelly stuff inside nappies is also good to eat? Leaves quite a dry taste in the mouth so you don't need too much of it, but you can always amuse yourself by spreading the remainder over the sheets and carpets.





Of course if you're thirsty then urine isn't a bad drink and it's always on hand. I usually refuse all drinks on principle – I can never remember what the principle is, but it's something I stick to – so I generally get very thirsty by bath time. I never understand why more people don't enjoy soapy water and it's even better once you've pee'd in it... slightly salty but well worth a try.

Anything else? Well you can't really count runny noses because everyone have those. And it's hardly my fault if they never give me a tissue to use. Like most boys what I usually do is rub my nose on my sleeve or trousers, but why stop there? Sometimes I'll wipe it across a wall, the sofa or the carpet – whatever's closest. In fact now I come to think of it one of the best places to rub it is in people's hair; Frowny's is especially good for this as she's got so much of it and it's always dangling in my face.

And that's it. Nothing really out of the ordinary.

Well, unless you count the nail biting. Of course, lots of people do that but I notice they don't really put as much effort into it as I do... most of them seem to stop about a third of the way down the nail but with a bit of perseverance you can go a lot further. Ok there's usually a bit of blood to deal with but I've never been the squeamish type. And why stop with your fingernails? Obviously you're not all going to be as flexible as me but I find while I'm waiting for my fingernails to grow back a toenail makes an equally good snack between meals. Often better in fact because they smell so good at the end of the day. You have to be a bit more careful with toes because if you go too far the toe goes bright red and swells up for a few days and then you have to see the doctor for more medicine. But on the bright side it gets me out of having to walk for a while.

So what's all the fuss about? It's not as if I'd eat a croissant or anything like that. Now that really *would* be disgusting.

## AS Clinic

Assert supports the UK's only specialist Angelman Syndrome clinic which is held at Royal Manchester Children's Hospital every three months. The clinic is led by Professor Jill Clayton-Smith who has a long established interest in AS and will be known to many families who have attended Assert conferences. Dr Dan Hindley (Consultant Paediatrician) is another member of the clinic team and has a particular interest in childhood epilepsy. Other regular team members include an Educational Psychologist, a specialist epilepsy nurse, a physiotherapist and one of the Assert trustees. In due course we also hope to have input from a speech and language therapist.

In order to attend the clinic the person with AS must be referred by a GP or other clinician. There are three appointments available at each clinic, each lasting up to an hour, enabling a thorough discussion of whatever issues families wish to discuss. Commonly topics include the management of epilepsy, behavioural issues, mobility, communication strategies and prognosis. Although the clinics are held at a children's hospital the team also welcomes referrals from adults with AS and it is always interesting for Jill to meet up again with adults that she first met as children. Indeed tracking the development of people with AS over time provides a vital body of potential research material.

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

# Angelman Syndrome Alliance

## Why the Angelman Syndrome Alliance?

**“Because together we are stronger, have a louder voice and deeper pockets”**

Driving and funding scientific research into rare diseases is pretty challenging. ‘Rare’ of course means there are only a relatively small number of people affected. Funding organisations generally want to fund high impact projects, to ensure charitable money is well spent, or if they are commercial in nature, need to know there are enough people to buy the end product of whatever they invest in. ‘Rare’ also means there not so many people asking for research, or prepared to spend many hours working to raise awareness. So as a community this is what the Angelman community is faced with.

Few people realise exactly how much money it takes to fund scientific research - this is explained further in Andrea Baines’ article on page 27.

For a long while it was felt funding science was an impossible task for ASSERT. But in the past two years all that has changed, because of the Angelman syndrome communities superb ability to work together and support each other.

In 2012 Rachel Martin was invited along by the NINA Foundation to attend the very first European conference in Rotterdam. This spurred quite a considerable change within ASSERT and attitudes towards scientific research began to change. In 2013 ASSERT’s first science and research trustee was appointed (Katie Cunnea) and later that year Rachel and Katie attended the second European conference in Rome. Attending the meeting, was it has to be said, pretty ‘interesting’. Everyone there wanted desperately to make something work ... but language and cultural difficulties made it quite hard for everyone to be understood. Generally there were at least 3 people trying to talk at the same time, (in different languages). On top of that most people struggled to understand the process of becoming a funding body and how do you decide who to fund? It was a little tough, but by the end it was realised that everyone was pretty much trying to say the same thing. That year we established a scientific board (to advise us), signed an international agreement to work together and 5 countries agreed to put money into the first grant round (which would last 2 years).

In 2014 we met in Paris. This meeting went quite well, we ironed out some of the teething problems, planned out what else we needed to do, and generally strengthened our links with each other.

By Liverpool 2015 we had funded our first two scientists, Ben Distel and Geeske van Woerden. Having managed to raise almost £400,000 we were able to fund not just one project but two. What really blew me away in Liverpool was how far we had come since Rome, and how well we had gelled as a team. There was no talking over each other, there was real understanding between each other, and two more countries agreed to join the alliance, in part I suspect because we had tried, succeeded and proved we could work together to make it work. There are still a lot of challenges to face. Advertising and raising awareness is still high on our agenda. So please everyone spread the word.

Please visit the website for more information:  
[www.angelmanalliance.org](http://www.angelmanalliance.org)

Katie Cunnea





## Research costs

As well as support for families affected by Angelman Syndrome (AS) and public education about the syndrome, ASSERT also supports research into AS. After the International Angelman Syndrome Alliance (ASA) Scientific Conference in Liverpool earlier this autumn, it's clear that the term research now stretches well beyond laboratory based research projects. Many research groups focus on improving the lives of those affected by AS, whether that is by researching and informing families on new communication methods (augmentative and alternative communication (AAC), for example), or how following specific types of diet (eg ketogenic) can help to reduce the number and severity of seizures and the mechanisms by how these diets work or research into behavioural patterns, the reasons for these and suggestions as to how they might be improved. This type of research brings direct results relatively quickly to families and ASSERT is able to help out with research of this kind by putting AS families in touch with researchers for information and AS individuals to work with. This type of research, generally involving one junior scientist (PhD student or new Post-Doctoral scientist) and working with an individual often in their own home or school setting is relatively cheap in research terms, costing around £40,000-£50,000 per year (1).

More "molecular" projects into the causes and effects of AS with the aim of producing eventual therapeutics are a different story. Understanding the mechanisms of AS is a long term goal. From Harry Angelman's first diagnosis 50 years ago, scientists are only just beginning to understand what the function of UBE3A is and why the disruptions to this gene which causes AS are so far reaching for affected individuals. There have been great leaps forward in recent

years, but there is still a long way to go. The journey to bring a single therapeutic drug or treatment to market for any disease or disorder is expensive and long. For every 10,000 potential compounds proposed as potential therapeutic agents, only two or three will make it as far as clinical trial stage and from here, only one may make its way onto the pharmacy shelf. The whole process takes, on average, around 10-15 years and can cost as much as £450m per eventual drug produced (2). When the causes are complex and the condition is rare, as is the case for AS, the process can be even longer and costlier.

It is clearly impossible for a small charity like ASSERT to be able to fund a major lab-based scientific research project of this type alone. Due to the rarity of AS, government funding into AS research worldwide is very limited. In order to address this, the ASA was formed in 2012. Further details on the ASA is given by Katie Cunnea on page 26.

(1) Average UK Research Council salary plus on-costs.

Snape and Astles, 2010: The process of drug development from the laboratory bench to the market. *The Pharmaceutical Journal*, 285, p272 | URI: 11024236

Andrea Baines

## Contact Register

A contact register is enclosed with your newsletter. We hope you find this useful – it has been a long time in the making! This lists all families who have given permission for their contact details to be passed on. This information has been collated over the last 12 months and is based on the "Member Update Form" which was sent out, along with any new families who have registered recently. We do have a lot more families registered with ASSERT than is on this contact register but we cannot give out details without prior permission. If you find there are not any families in your area then please get in touch with ASSERT and we can check the database. We are then able to contact individual families to ask if their details can be passed on.

If you have any queries about the contact register then please contact ASSERT either by calling our support line (**0300 999 0102**) or emailing [assert@angelmanuk.org](mailto:assert@angelmanuk.org).

# Lyndsey Marsh

Lyndsey Marsh sadly passed away in 2010. Lyndsey's sister Kelly has written this letter below in memory of her sister.

Lyndsey started her journey at Barrett Maternity home in Northampton on the 3rd October 1976 to the parents of Mick and Eileen Marsh. She was born with Angelman Syndrome, though this was not actually diagnosed until some years later she soon developed the same characteristics associated with AS, but to anyone who knew her they were just typical of Lyndsey – smiling, laughing, compassionate, lovable and huggable. Saying this, Lyndsey also had a mischievous side. We as her sisters knew this only too well along with her niece and nephews.



Lyndsey's life was certainly full of adventures. She spent her first chapter in life at Whiston Road school before moving on to Greenfields special school in 1984 where she made many friends and was also a favourite amongst the teachers. One of my favourite memories in school was sports day, she loved it, all the parents and people watching, the only trouble was she was so interested in them and when it was her turn to race she was so busy waving to everybody that she forgot to run, and when she did it was pot luck whether it was in the right direction.

Lyndsey wasn't just busy at school as in 1990 she took off on her first foreign holiday, jetting off to Yugoslavia, this was quickly followed by Malta, New England and Disneyland in Florida!

In 1995 and at the ripe old age of 19 she left school, entered adulthood and moved to Shire Lodge. Here she quickly settled in, gained new friends and soon made a name for herself!

Even though Lyndsey was continually happy she did suffer some health problems, mainly caused by scoliosis. In 1998 she had rods inserted to assist straightening her body. Lyndsey true to form bounced back from surgery and a few months on you'd never have known as she tested out the rides back in Disneyland and dined with her favourite Disney characters.

In 2003 Lyndsey moved to her new accommodation with 6 friends. Lyndsey settled well into her new home, a beautiful purpose built bungalow and where the boys outnumbered the girls! Oh yes, how can we not forget she was such a flirt, Lyndsey was never happy with just one man, oh no, Lyndsey would always have at least 3+ in tow!

Lyndsey spent 7 happy years before venturing in her final adventure and maybe one that had the biggest impact in her life. The NHS withdrew their services for people with learning disabilities which enabled people along with Lyndsey for the first time to live independently with the assistance of their own support staff.

To everyone who knew Lyndsey, there are no words to summarise how we are feeling today or how we will feel tomorrow, all we do know is that she has left a huge void in our hearts that I will fill with the many great memories that she has left me. She will always live on as someone who is such an inspiration to us all, took life by the horns and filled it to capacity. As a family I think I speak from us all that we thank all those who have been involved and supported her which enabled her to do this.

**In memory of Lyndsey Alexandra Marsh 1976 – 2010**



# Merchandise

We have now expanded our ASSERT merchandise. As well as the usual wrist bands, car stickers, jute bags and 2 colour pin badges, we now have water bottles, gold pin badges, insulated mugs, key rings and trolley coins.

If you would like to order any of the smaller items (key rings, trolley coins, pin badges, wristbands, lanyards or car stickers) then you can order any number and quantity of these and whatever the total is, please add £1.50 for postage.

If you would like to order some water bottles and / or insulated mugs then up to 3 of these (any combination) plus any number of smaller items can be purchased, and please

then add £3.50 postage.

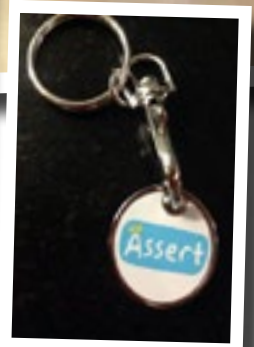
If you would like to order the jute bags plus any number of smaller items, then the postage for up to 4 jute bags is £2.80 and for 5 – 9 jute bags is £3.80.

For any other combinations please email [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org) for a price on the postage.

You can pay for the items by either sending a cheque made payable to ASSERT to our freepost address, or by paying the money directly into the ASSERT bank account. If you would like to pay directly into the account, please email [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org) for the bank details.

## ASSERT MERCHANDISE PRICE LIST

Insulated Mugs	£3.50
Water Bottles	£3.50
Keyrings	£2.50
Trolley Coins	£1.00
Gold 'A' Badges	£1.50
Two colour 'A' Badges	£1.50
Wristbands	£1.50
Jute Bags	£3.50
Lanyards	£2.00
Car Stickers	£1.50



## Alton Towers

14th-16th February 2016



In addition to her ASSERT work, Linda also organises the ever popular Splash Landings at Alton Towers. The prices for 2016 are the same as last year. 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 huge flying machine in one foyer and a brightly painted car in the other. Not only that, there's all night Children's entertainment too!

For further details & the discount code, contact: [lindaholmes65@hotmail.co.uk](mailto:lindaholmes65@hotmail.co.uk) 07739 363456

# Useful Websites



## Airport guide for those needing special assistance

This website provides all of the information you will need if you are flying into or out of Heathrow airport and need special assistance.

**[www.heathrow-airport-guide.co.uk/disabled-facilities.html](http://www.heathrow-airport-guide.co.uk/disabled-facilities.html)**



## Accessible Toilets

This website enables you to search for accessible toilets in any town / postcode within the UK. Please take a look at the website for more details.

**<http://www.changing-places.org/>**



## Epilepsy Pillows

ESUK are a charity that provide anti-suffocation pillows to all members at no cost. They have provided 1,480 pillows to date.

Epilepsy Sucks UK's purpose is to safeguard life: children, adults, vulnerable people, the elderly; anyone who is diagnosed with epilepsy. They work to restore the confidence of people with epilepsy including parent/carers of people with epilepsy -- and to defend quality of life.

If you would like to apply for a free pillow then please go to the website and join the group. Once registered you can then apply for the pillow and you will join the pillow list. All pillows are sent out in strict order of application and naturally, funds permitting.

**[www.esuk.uk.com](http://www.esuk.uk.com)**

## Support

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

## Blogs

- [www.boybiteshorse.co.uk](http://www.boybiteshorse.co.uk)

## For iPad/apps

- [www.autismpluggedin.com](http://www.autismpluggedin.com)
- [www.atmac.org](http://www.atmac.org)
- [www.blog.friendshipcircle.org/2011/02/02/the-special-needs-ipad-app-series](http://www.blog.friendshipcircle.org/2011/02/02/the-special-needs-ipad-app-series)
- [www.lilliespad.com/special-needs-ipad-blog/tag/special-needs-apps](http://www.lilliespad.com/special-needs-ipad-blog/tag/special-needs-apps)
- [www.techlearning.com/Blogs/37722](http://www.techlearning.com/Blogs/37722)
- [www.momswithapps.com/apps-for-special-needs](http://www.momswithapps.com/apps-for-special-needs)
- [www.gadgetsDNA.com/10-revolutionary-ipad-apps-to-help-autistic-children/5522](http://www.gadgetsDNA.com/10-revolutionary-ipad-apps-to-help-autistic-children/5522)
- [www.oneplaceforspecialneeds.com/main/library\\_pick\\_great\\_apps.html](http://www.oneplaceforspecialneeds.com/main/library_pick_great_apps.html)
- [www.ikidapps.com/2010/10/apps-for-children-with-special-needs.html](http://www.ikidapps.com/2010/10/apps-for-children-with-special-needs.html)



## Pre-loved equipment

- [www.disabreg.pwp.blueyonder.co.uk](http://www.disabreg.pwp.blueyonder.co.uk)
- [www.askdes.org.uk](http://www.askdes.org.uk)
- [www.disabledliving.co.uk](http://www.disabledliving.co.uk)

## Clothing and other equipment

- [www.fledglings.org.uk](http://www.fledglings.org.uk)
- [www.clothingsolutions.org.uk](http://www.clothingsolutions.org.uk)
- [www.incywincy.net](http://www.incywincy.net)
- [www.disabled-clothing.co.uk](http://www.disabled-clothing.co.uk)

## Legal

- [www.ipsea.org.uk](http://www.ipsea.org.uk)
- [www.scope.org.uk](http://www.scope.org.uk)
- [www.mencap.org.uk](http://www.mencap.org.uk)
- [www.challengingbehaviour.org.uk](http://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](http://www.netbuddy.org.uk/newsletter/netbuddy-tools)

# Thank you!

# Fundraisers!

[Thomas Burke - London Marathon](#)  
[Will Aldridge - London Marathon](#)  
[Emily Iredale - London Marathon](#)  
[Sharon Hurcombe - London Marathon](#)  
[Karl Scally - London Marathon](#)  
[Jay Edmonds - London Marathon](#)  
[Stephen Coates - London Marathon](#)  
[Clare Mann - London Marathon](#)  
[Jenna McKenna - London Marathon](#)  
[Stephen Brooks - Great Manchester Run](#)  
[Roxanne Brooks - Great Manchester Run](#)  
[Cally-Ann Brooks - Great Manchester Run](#)  
[Nicola Holland - Great Manchester Run](#)  
[Lee Atkinson - Great Manchester Run](#)  
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[Rebecca Castle - Great North Run](#)  
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[Rachael Murdoch - Great North Run](#)  
[Stephanie Thandi - Great North Run](#)  
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[Karen Davies - London 10k](#)  
[Andrew Woods - Liverpool Half Marathon](#)

[Alexandra Crisp - Half Marathon](#)  
[Michelle Matthews - Farmageddon](#)  
[Leann Squires - Farmageddon](#)  
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[Victoria Martin - Belfast Marathon](#)  
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[Lynn Connolly - Colour Me Rad](#)  
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[Kirsty Bell - Colour Me Rad](#)  
[Robbi Docherty - Colour Me Rad](#)  
[Paul Giles - London to Brighton Bike Ride](#)  
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[Search Laboratory - 3 Peaks Challenge](#)  
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[Vel Petrovic - London to Surrey Bike Ride](#)  
[Darko Petrovic - London to Surrey Bike Ride](#)  
[Vlad Lazic - London to Surrey Bike Ride](#)  
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[Josep Alvarez-Perez - JP Morgan Chase Challenge](#)  
[Paul Moran - Highland Perthshire Challenge](#)  
[Phil Adcroft - London to Paris Cycle Ride](#)  
[Charlotte Pyatt - Run or Dye 5k](#)  
[Luke Stevens - Bangor 10k Run](#)  
[Joanne Taylor - Runamuck Event](#)  
[Jenny Dolan - Peddle for Scotland](#)  
[Mairi Leith McGaw - wearing a dress & getting \(almost\) naked](#)  
[James Lovell - Walk round Swindon](#)  
[Charla Pointon - Haircut](#)  
[Nigel Fenning - Three Peaks Challenge](#)  
[Sarah Brown - Yorkshire Marathon](#)  
[Tracy Campbell - LEIA Day](#)  
[The Blemain Group - Charity Fun Day](#)  
[Nathan Walsh - IAD](#)  
[Paddle For Life 2015](#)

# Donations!

Karen Gammack  
Tracy Smart  
Maria Proctor, Sheila Caruso and Lillian Hale  
Marie's Café (Claire Turlington)  
Mrs Tait  
Dan Hasler  
Megan Williams  
Audrey Sinclair (IAD)  
Mr Stephen Dudman (in memory of Hilda May Dudman)  
Marie Brown (Charity Dance at Skelton Civic Hall)  
A Wardle  
Mark Wilson  
C342 Royal Sussex Chapter  
Jacky Lewis  
All Saints Church Pocklington  
Mrs J Cartwright  
Mrs D Moran  
Lafarge Tarmac Mountsorrel Quarry  
Rothschild  
In memory of Mrs Agnes Walburn  
Nuneaton O50 Friendship Centre  
Phil Riches-Weedon  
Catrina Fraser (IAD)  
Nav Sanghera (IAD)  
Maria Allen (Conference Portraits)  
Gilbert Knight (In memory of his father)  
Mrs Christine Parker (In memory of Alan Parker)  
David Cartwright  
Louise Shaw (IAD)  
Sarah Newall  
Honiton & District Darts League  
Mitchells & Butlers (Harvester Restaurants)  
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Gloria Buckley  
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The Jolly Chippy  
Tom Collier & St Peter's Independent School  
Northampton  
Links Park Community Trust  
Giles Derry  
In memory of Margaret Elsie Gadd

Sutton Cricket & Tennis Club  
Michael and Carol Challen  
Arrow Taxis Nuneaton  
Linda Dabbs (In memory of Jamie Dabbs)  
The Freemasons Grand Charity  
Mrs J Girling  
Anne Beaton (Womens 10k)  
The Royal Fund Raising Committee  
Isobel Mair School & Family Centre, Glasgow  
Scottish Friendly Assurance  
Mr A J Taylor  
Old Portmuthian Chapter 8285  
Mr & Mrs Taylor  
Duchess of Sutherland  
Liz Huglin  
The Cod Father  
Mrs Pauline Turner (Talking Spirit)  
Lorraine Blackburn  
Madeleine Dain  
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Mandy King  
Mark Wainwright  
Adam Hudson  
Linda Donnelly  
Angela Griffiss-Williams  
Stephen Roberts  
Lynn Sharp  
Matt Gray  
Caroline Meredith  
Poly Yip



Helpline 0300 999 0102  
[assert@angelmanuk.org](mailto:assert@angelmanuk.org)

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

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...