



Newsletter 53 Autumn 2013

Angelman Syndrome
Support Education & Research Trust

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report 2013**

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Fundraising**

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Summer Photos

AS Clinic



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ASSERT SHOP

Wear your charity with pride! T-shirts,
 polo shirts, bags, hats and lots more from
 Spreadshirt, our on-line retailer:
www.angelmanuk.org/spreadshirt

FRONT COVER

Photograph courtesy of Robert Chadwick.
 We'd like to use one of the great photos
 taken at our 2012 conference 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

Well, here we are again. Our Autumn newsletter (or as one member recently referred to it at a regional meeting in South Wales, 'My magazine'). We hope that the beautiful summer we have just enjoyed allowed you to spend many hours in the sun with your families. Please see pages 26 & 27 for all the holiday photographs that you kindly sent in.

Autumn also means something else. As well as crunchy leaves and the beautiful colours on the trees, frosty mornings and fresh air, it means that we are less than 1 year away from our next ASSERT conference! The conference is once again due to be held at The Hilton Hotel in Coventry on 29th, 30th and 31st August 2014. The next conference promises to be a unique and extremely informative event. Places are allocated on a first come first served basis so keep an eye out for information and invitations in the New Year.

ASSERT would like to welcome Mairi Leith-McGaw and Catrina Fraser on board as regional representatives for Scotland. They will be responsible for organising regional meetings and events in Scotland and will also be points of contact for newly diagnosed families in Scotland. Their email addresses can be found inside on page 2.

On that note we also have to inform you that Russell Andrews, trustee for the Central region and responsible for sibling support, and also Neil Buchan, trustee for Scotland have both resigned due to work commitments and family responsibilities. ASSERT would like to thank both Russell and Neil for their contribution to the smooth running of ASSERT and we wish them nothing but the best for the future. If you feel that you have relevant skills and enthusiasm to offer ASSERT and you would like to be involved then please feel free to contact the current trustees with a brief introduction at assert@angelmanuk.org. It would be great to have input from those grandparents amongst you who perhaps have a slightly different perspective and experience - along with anyone who has a relevant professional background.

We have had some wonderful regional meetings recently, with many more due to be held. If you have a suggestion for a venue for a regional meeting or if you would like to arrange a meeting or event for ASSERT then please get in touch with Linda (details on page 2). We have 2 full pages inside with photographs and reviews of our recent regional meetings.

And finally... fundraising! We have had a fantastic year for fundraising. The London Marathon alone raised almost £19,500. Then there has been all the other fundraisers taking part in numerous events around the country. You can read all about these on pages XX - XX. Keep up the brilliant work!

Rachel & Rich



Siblings

Just for Us!

Young Sibs

Wellchild Awards 2013 – Sam Dee

On Wednesday 11th September, Sam attended the Wellchild Awards 2013 to receive his award for Most Caring Child 2013. I nominated Sam, as a way to show my appreciation for all the help he gives me looking after Hannah (Del+). The awards were held at The Dorchester Hotel in London, we had an amazing time from check-in on Wednesday until check-out on Thursday lunch time. Sam was so excited to have CBBC presenters Dick and Dom on our table at dinner. We met so many people from Prince Harry to Duncan Bannatyne. Both Nick and myself are so proud of what Sam, as a sibling has to go through and sacrifice. We hope this goes a little way to show him how much it all means to us.

Beckie Dee



“My brother Sean” by Sami Tunbridge age 11

Sam entered a story competition and was awarded 2nd place. Well done Sami!

On the 24th December 1998, a beautiful baby boy was born. His name was Sean Tunbridge he had blue eyes and light coloured hair. He had his first Christmas the day after he was born, but he was able to get out of the hospital for New Years Eve. By the age of fourteen months, my mum & dad realised that Sean could not walk or talk, and tests showed that he has Angelman Syndrome.

If you see the world through Sean eyes everything is perfect. You see, Sean is special. He is 14 years old, and he is my brother. Angelman Syndrome is a deletion on chromosome 15. People with Angelman are very happy and they love water. Sean can be very sociable. He still can't walk or talk, but he knows what he wants.

He is a big part of our family life and we try to include Sean in everything. Sometimes it can be very hard, as he screams and people stare at him. I hate it when people stare. Everything we do is an adventure for him, and when he's not with us I miss him.

My friends all like Sean they have grown up seeing him so they understand him, Sean loves musical toys, balloons and bubbles.

I have realised that although he doesn't play with anyone and doesn't communicate he knows a lot of people.

Any little milestone that he reaches is a huge achievement for all of us. I feel very happy for Sean because he is a really good brother. I always have lots of fun with him when I play with him. We play wrestling a lot, he loves it because he is ticklish.

One day Sean will be able to walk, he can do it but he is very unstable. He has to do exercise and we go swimming as a family and this is his favourite.

I have learnt to be caring to others who have disabilities. I dream that one day Sean can walk and communicate with us more. We also help with fundraising for his school and I enjoy taking part.

Unrelated to the article above, Sheri-Lee Taylor sent in this great photo of Rhys and his 'big' sister Nevaeh.



'Big' little sister!
Nevaeh and Rhys

Older Sibs (...and parents)

In the last newsletter I covered some of the findings from research among families where a child has a profound disability and its impact upon siblings. These included how siblings often tend to be caring/practical depending on their gender, and how siblings can be resilient people and often tend to be (or feel the pressure to be) over-achievers compared to their peers. This time I'd like to get into some of the more challenging and particularly difficult issues that siblings can often face. Of course, it's important to keep restating that every family and every sibling is different and so it might well be that experiences in your family are or were different. However I think there is some benefit in covering these issues and as trustees we would be very interested in hearing back from siblings or parents on your experiences and strategies.

One very common trend among siblings is that growing up they often felt frustrated that it was difficult to get the full attention of their parents and that sometimes they felt interest in their own thoughts, ideas and aspirations were sacrificed for their brother or sister's needs. This trend is more common in families where the sibling is the only other child and can be increased further if they are the older child. There is some evidence to suggest that siblings tend to 'submerge' these feelings as they grow-up for the greater good of the family but that they can often come to the fore after the sibling has left the family home and has some time to stop and reflect back on their experience. Adult siblings sometimes report that it was only when they started to bring up their own children that they realised just how much their own needs had been second to their brother or sister as they had grown up.

Younger siblings often talk about the embarrassment their brother or sister's behaviour causes when their friends are around. Some also talk about the fear as a young child that they might have caused their brother/sister's disability or that they themselves might be able to 'catch' it.

For siblings whose brother or sister is reaching an advanced age the challenge of who will be responsible for their brother or sister's care once the parents have died becomes an increasingly important issue and one that can weigh heavy on an older sibling's mind.

None of these issues are insurmountable providing that there is an awareness and a will to address them. And of course, the

key to all these situations is communication. Here are some strategies that families report have been successful for them.

For younger siblings:

- Set aside specific 'special' time to be spend with them
- Talk about what the disability is and that it is not 'catchable'
- Allow them to share their feelings of frustration/anger
- Encourage them to have their friends round to the house
- Celebrate their individuality
- Encourage them to have their own interests outside of the home

For older siblings:

- Talk about the future for their brother/sister, care expectations etc
- Accept that siblings are not parents
- Agree care and involvement boundaries

This is not meant to be an exhaustive list and I'm very aware from my own engagement with siblings and with parents that many families have their own successful strategies so I encourage you to write in and share them (we can make them anonymous if you'd prefer) so that we can share them with others. Bye for now.

Russell Andrews



Assert Sibling Group

www.angelmanuk.org/siblings

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

Regional Meeting Roundup

ASSERT have been busy over the last few months organising a number of regional meetings. We are continuing to organise more meetings across the country and so if you have not had a meeting in your area lately then please be patient, we hope to cover most areas in the coming months. Please check the website or look out for a letter in the post informing you of what has been organised.

So in no particular order, here are some details on the recent meetings:

North West – 2nd March

The North West regional meeting was held once again at Greenfold School, Bolton on Saturday 2nd March. It was attended by several families from Bolton and the surrounding areas. Both Jill Clayton Smith and Dr Dan Hindley put in an appearance and chatted with parents. The children enjoyed a bouncy castle and the parents enjoyed socialising and chatting over a buffet lunch. Thanks to all those that attended.

Rachel Martin

Central – 20th April

A get together was held at a local special school for families in the Central region. There was the usual mix of familiar and new faces. The Family Information Service came along and gave a talk on what services they offer. Wizardy Woo and his white rabbit came along to entertain the children. There were a few heart-stopping moments when Wizardy Woo decided to let the children touch the real life rabbit – I am very pleased to say the rabbit left with all his ears, tail and nose intact! It was nice to chat over lunch and as usual the kids made good use of the soft play and sensory room.

Lisa Court



South West Thames Valley Adventure Playground 24th August

Families from the South West region joined together in Maidenhead, Berkshire at the Thames Valley Adventure Playground (TVAP) for a picnic. A number of families attended with AS children aged from 19 months to 15 years.

TVAP is a purpose built playground for disabled children, which provided an ideal environment for the children to play safely whilst giving parents the opportunity to chat and discuss the general difficulties that we all face with Angelman children.

The sun wasn't shining and we had drizzly rain on and off all day but this didn't spoil the fun. The children made the most of all the facilities that the playground had to offer. Which included playing in the paddling pool with water guns, the sensory room, soft play area, trikes and running around the large garden. Although all the parents were pulled in different directions by the children, we did get the chance to sit down to eat our picnic under cover and have a really good chat.



At the end of the day all the children and most of the parents were extremely tired, but had had a really enjoyable day, which I hope we can all do again very, very soon!

Sarah Brown



Scotland - 3rd August

A meeting was held in Bathgate, East Lothian on 3rd August. We had a great afternoon with quite a few new faces which is always great to see. It started with a buffet lunch and a chance for families to meet. Then we had a session with Joanne Goodall who works for Jo Jingles Glasgow - we had a one hour session with song and dance and musical instruments. It went down very well and had everyone involved so a great success. We are at present arranging a Christmas party for December, details to follow.

Neil Buchan



Regional Meeting Roundup

continued...

London - 19th May

Sunday May 19th saw several families from the Hertfordshire and surrounding area meeting in Watford for a social lunch provided by ASSERT. There were some familiar faces there — Sally and Matthew Walburn, Jeremy Webb and family — along with a recently diagnosed young man and his mum and dad. So a range of experiences were shared.

A Reiki drummer and therapy practitioner was present which provided an alternative experience for some of the attendees. Deborah Gundle who set up Netbuddy was there promoting the website – and the new, that week, car sticker alerting emergency services that someone with a disability is likely to be in the car should they be called to an accident..... see www.netbuddy.org.uk

There was lots of noise and cake and the time went all too fast..... hope we can do it again sometime.

Pam Robertson



North East - 31st May

The siblings' view

On Friday, Mummy, Hannah, Rhiannon, Daddy and Daniel went to a donkey sanctuary. We went on a donkey ride, Rhiannon and I rode on a donkey round a field. Daniel went on a cart in his wheel chair. We loved going on the ride the best. Daniel giggled lots once it got going!

I saw 3 guinea pigs. Rhiannon liked the ginger one the best. I liked the ginger and white one too. It had sticking up fur down his back!

We played outside with the cars and trikes. Daniel went in the back of my car and Rhiannon chased us. We made a new friend called Penelope. She was nice and very friendly. Next we had lunch. It was tasty. We sat near Corey and his brother Oliver. Oliver loved to pinch my cake. It was funny. He loved chocolate cake! We saw a Great Dane outside he was huge like a horse. There was also a puppy which looked like a Dalmatian. We bought some donkey key rings.

After that we moved to the farm next door. We went for a walk in the woods and played hide and seek. Next we had a drink and helped the lady set up a shop to sell things to people. We sold Euan's Daddy a pencil and bought lots ourselves.

Then we walked over to the climbing wall and had a go. I felt a bit scared but managed to climb half a wall. Rhiannon was really good and climbed like a monkey all the way to the top! We watched lots of children climb up a ladder. They did really well to get to the top and let go but they didn't fall because they had a harness on them. Kerry gave us some sweets afterwards. They were yummy. We had a lovely day meeting lots of new people.

Hannah and Rhiannon Hewitt

The parents' view

It was rather daunting receiving the invitation to a regional meeting, but at the same time, we really wanted to go. When we arrived we were met by lots of friendly faces. It was scary walking in on a group, who obviously knew each other, but people came and introduced themselves to us and it was made a lot easier. Daniel is nearly 3 years old and we have had his diagnosis for nearly 2 years. To see what the future may hold by meeting all the other children was both eye opening and informative, confirming the possibilities whilst realising the limitations of the syndrome. Previously we have just gone from facts from the consultant; 'Daniel won't be able to do this, he can't do that, everything is in place now, nothing more can be done, but let time take its course.' It was lovely to see children and young people walking around, engaging with their family and friends they were seeing again.

Lunch time was a great treat, to see who could match Daniel for appetite. Many could! Amidst the pockets of activities; donkey riding, climbing, exploring the farms, there was plenty of space and time to chat to other parents. Nothing felt rushed, and everything natural, you didn't have to apologise for any behaviours shown, which didn't meet social etiquette of day to day life. Getting an insight into our current predicaments of sleeping, and what may happen in the next few years, to considering about the future, and chatting about the impact on siblings was good. This was matched with the peace of walking through the woods contemplating and processing the day's events. Thank you Linda for arranging such a wonderful day; it was a perfect balance of activities for all, fabulous food and hosting and new friends.

Caroline and Mark Hewitt



London Marathon

REPORT
2013

ASSERT are thrilled to be able to say that between our 6 marathon runners (5 Golden Bond runners and 1 running on their ballot place) they have raised the astounding sum of almost £19,500. Absolutely fantastic! We are extremely grateful to all of our runners who have worked so hard to raise a huge amount of money for ASSERT.

If anyone would like to put their name forward for the chance of a Golden Bond place in the London Marathon 2014, please email Lisa.Court@angelmanuk.org by 1st December 2013. The minimum sponsorship is £1,500.

Hollie Christiansen

I was beyond thrilled to be given the chance to run the 2013 London Marathon for ASSERT. As we won't live in the UK forever I can say this will be hard to beat as one of the greatest memories during our time here for me.

Training was a challenge most of the time, and then I injured my back and thought I would have to pull out as I couldn't even walk a quarter of a mile. However, I thought of all our Angel's, thought of their day to day trials, and knew that if they could do it so could I. The atmosphere during the race was amazing; the spectators' cheering the whole way through drove me to the finish. I remember telling my husband that the weather forecast for the day of the race was bound to be sunny and maybe a little on the hot side, and it didn't disappoint. The weather was gorgeous, which made every long hard run in the wind, rain, and snow during training lose themselves in comparison to the pleasure the sun brought that day.

The course itself was beautiful, the people of London generous, kind, and motivating. I do have to thank a random stranger at mile 18 that held out a banana just when my prayers for extra energy had finished, she yelled, "someone needs this!" That banana was my saving grace for the rest of the course! Training was hard as I worked back from my injury and though I had to give up hope on my desired race time, the finish was still

glorious at 5:29:09! I did think of all our children during this run, and what beautiful children they are. It was such an honour to represent ASSERT in London. The donations, love, and support from friends and family were unreal, and I wouldn't think twice about doing it again if ever given the chance.

Ben Stagg

Taking part in the London 2013 Marathon to raise funds for Assert has been a massive privilege and a hugely uplifting experience. I would absolutely recommend it to anyone who might be interested in taking part, and I'd love to do it again in a few years.

I decided to apply for a place for a few reasons: Firstly, my son Woody was diagnosed with Angelman Syndrome in 2010. Coming to terms with the diagnosis and working out what our new normal is has not been easy. Assert have been one of the very few sources of support for us as a family during this time, so I was keen to do something to support them. There were also a few other reasons - I had been consistently running a few times a week during 2012, I've always said I would complete a marathon at some point, I'm getting closer to 40, and of course enthusiasm borne out of the London 2012 Olympics.

The training was serious work. I followed a 16 week training plan from Runner's World which required 4 runs a week. It was tough keeping up, but through most of the plan, each week saw me able to run a mile or two further which was hugely gratifying. It was also hard for my family as they had to give me the time to do this, and then put up with me talking incessantly about running, carbs, my feet...

The day itself was an unforgettable experience. After all the training and preparation, actually taking part was very fulfilling. The excitement of being part of a vast running tide of humanity, all with one shared goal was also pretty special. Unfortunately I had picked up a bit of an injury a couple of weeks before the big day so I did not get round as quickly as I would have liked, but I gritted my teeth and I did get through it and I can also honestly say that on that day I could not have covered the distance any faster.

The experience has been very positive overall, it's been great



Hollie Christiansen



Ben Stagg



Graeme Dunn

to give something back to Assert, to be able to cross something off my bucket list and also, most importantly it has helped me somehow to come to terms with Woody's diagnosis. Fantastic. Thank you Assert.

Graeme Dunn

Training for and completing the London Marathon was one of the biggest challenges of my life. My training didn't go well at all due to severe pain in my right knee (several major operations for Football injuries). I had big plans of pounding the roads evening after evening and getting plenty of miles in my legs to try and achieve a decent time and make the Marathon experience as pleasant as possible. My plans went out of the window and training was extremely stop start. The furthest I managed in training was one run of about 11 miles, not at all ideal. I had my family telling me to call it a day on several occasions as they could see how much pain I was in and they'd witnessed me hobbling around after training sessions. I could not quit, it is not in my nature. I kept thinking of Anna, other Angelman sufferers and all the people who had kindly sponsored me. There was no way I was going to let anyone down even if it meant I'd be crawling over the finish line on April 21st!

I made a (crazy) decision to wear a crocodile suit about a week before the race. I knew in my heart of hearts that I wasn't going to be able to run the whole way and wanted to make it more of a challenge! That it most certainly was with the temperature on race day in the early twenties!! What a donut I was thinking to myself as I started to put the suit on near the start line. I did feel a lot better however when I spotted several rhinos and sonic the hedgehog warming up next to me. Their outfits looked a lot heavier than mine so I drew some inspiration from that.

It took over half an hour to get through the start line but the atmosphere and occasion made the hairs on the crocodile suit stand on end. Here we go I thought, 26 miles and 385 yards to go. I managed to run the first 13 miles then the old knee started to play up. I had it in my head before the race to try and run 13 miles then walk as fast as my green legs would carry me. I kept trying to run a bit but the pain was too much, I thought to myself just walk as quick as you can and you've got more chance of finishing, keep running and there was a big chance that I might

not make it. I was in severe discomfort during the second half of the Marathon and kept thinking to myself that I can't stop, must keep going, don't want to let anyone down. The crowds support was absolutely unbelievable, this played a huge part in me making it to the finish line.

During the race I had some friends and family cheering me on at various points around the course, this was a big help. However I couldn't get my head around total strangers shouting encouragement and cheering me on for the entire course. "Go on Mr Crocodile", "Keep going Mr Alligator", "You can do it Mr Dinosaur" was ringing in my ears when I was starting to flag. The tremendous support of the crowd along with the feeling of being part of a large running family will live with me forever. Every runner has a story to tell, all shapes, sizes and outrageous fancy dress outfits all desperate to cross the finish line and achieve their goal. The last couple of miles were so emotional, I was fighting back the tears as feelings of relief, proudness and joy came over me. After crossing the line the adrenaline and buzz of the occasion numbed any pain I had in my legs, half an hour later I was sore, hobbling to the tube station with ice pack in hand. The organisation of the event from registration at London Excel to the after care in the meet and greet area was top class. The occasion made me proud to be British and all of the runners thoughts throughout the day were with the killed and wounded in Boston a week earlier.

It was a real pleasure to run for little Anna and ASSERT. I was playing with Anna at a barbecue recently and she is really making good progress, she was running around chasing her friend Donny who also has Angelman Syndrome. It's great to think that money raised could make a difference and I would recommend running for ASSERT to anybody as it's not as well known as some of the other larger charities yet it needs as much support as possible. I've been talked out of doing anymore Marathons for the time being by my family but who knows what the future may hold. Maybe a sponsored cycle ride would suit me better these days. Whilst I have my health I would definitely like to continue fundraising for others who do not enjoy this luxury that we take for granted at times.

Continued....



Ed Winter



Richard Brownlee



Ed Gillham

REPORT London Marathon 2013

Ed Winter

After last year I said to myself that I would never run the marathon again but, with memories of the day and support from everyone and the satisfaction that I had raised money with 7 other runners for ASSERT helped me to decide to run the 2013 London Marathon.

As soon as the training started I soon remembered how hard it was to prepare for a marathon and the time and hours through the run, snow and wind it took. I had great support from my family and the Walburn family. I had to keep reminding myself why I was running and how much the sponsorship money has and will help ASSERT.

On the day of the Marathon, was very different to any other that I and any would have experience, including the supporters. We all had our charities thoughts in our minds but also the tragic events at the Boston marathon. The minute silence prior to the start was extremely emotional, even with various runners having tears running down their cheeks.

When the run started the supported was overwhelming and bigger, louder than ever before.

I was determined to beat last years time of 5hours 5mins, which I'm happy to say I did and just under an hour (4 hours 7mins).

Once again, thank you to ASSERT for allowing me the great opportunity to run the marathon and help raise sponsorship for a fantastic charity.

My training started for earnest early in December and all was going to plan (well reasonably!) up until about a month before the race at which point I started to get quite a lot of knee pain in my left knee during my longer runs. Luckily some regular trips to the physio and some rest seemed to do the job and I managed to make it to the start line feeling reasonably confident I would be able to make it around.

I was running on my own (given my other friends had not managed to secure a place) so was looking forward to seeing my family and friends on the way around. Apparently I looked in good shape when I went past my support group after 12 miles but however, looked somewhat more pale each time when I saw them again at mile 19 and mile 23 :)

I must admit miles 20 through 26 are just as hard as everyone warns you! However, the support of everyone watching and cheering you on is amazing and for sure it is an experience I am very glad to have done (although not sure I will be running another one just yet..) and also would recommend to everyone else.

In the end I finished in 3 hours 22 mins and 52 seconds which was probably slightly better than I was hoping for. I met all my family friends afterwards and went for some much required food a a cold beer (after i had drunk a lot of water and a dioralyte to help re-hydrate!). All in all it was a very enjoyable and rewarding experience and am very grateful for everyone who sponsored and supported me and helped me raise money towards a very worthwhile and valuable cause that ASSERT supports.

Richard Brownlee

We discovered earlier in the year that my cousin's grandson Cameron had been diagnosed as having Angelman Syndrome. I had gained a ballot place for the London Marathon for 2013 and therefore thought this was a very worthy cause and also a very relevant one to our family to try and raise some money for.

Congratulation to all runners!

Connor Aldred

It is with great sadness that I am writing to you following the death of our grandson, Connor James Aldred on 10 June, aged 17 years. Connor was diagnosed with AS when he was just over a year old. Devastating as this news was, he gave us such joy over the coming years. Always smiling, I often said, he can't speak but he smiles for England. Connor was loved by everyone who met him. He will always be remembered for his smile. My sister Val, known to Connor as Auntie Val, wrote this poem for him, which touched all our hearts. We have asked for this poem to be published by ASSERT in memory of our grandson Connor.

John and Carole Aldred



For Connor

I'd like to own up and admit it,
There was once a time and I'm not proud,
That on meeting someone with disability,
I'd quickly melt into the crowd.

Or I'd cross the road to avoid them,
Or I'd walk the other way,
In an effort to make no eye contact,
That's thankfully different these days.

Because they are all just ordinary people,
But the process didn't quite go to plan.
So no need to feel uncomfortable or turn away.
And I learnt that from a special young man.

All Connor needed was to love and be loved,
He gave innocent trust and in turn,
Showed us how not to judge and to accept what's to be.
He taught us more than he'd ever learn.

But despite all this young man's problems,
With a glint in his eye all the while,
He was not without plenty of mischief,
Carried out with a big beaming smile!

He had arms like the span of an eagle,
If he saw something, it wouldn't be long.
He'd spin round, and shuffle towards it.
And in the wink of an eye it'd be gone!

He would give you the biggest hug possible,
And have a crafty pull of your hair.
Or he'd grab your arm and pull it towards him,
And pinch your skin, just under there!

All with the wickedest laughter,
To him it was such a game.
The more you begged him for mercy,
The harder he'd squeeze you again.

So now the Angel Man is with the Angels,
Leaving memories that we will hold dear.
A life worthwhile and I'm proud to say,
You made a difference to me while you were here.

Today is a celebration of your life.
A life all too short it seems.
Goodnight Connor, I'll never forget you,
Now you'll always be seventeen.

Splash Landings Hotel

Alton Towers 16-18th February 2014

The 2013 event was so successful we've decided to do it all again in 2014! ASSERT have negotiated a 25% discount so two nights bed & breakfast (16-02-14 & 17-02-14) is just £322.50 per family room. There's no extra charge for the larger rooms for 6, although these rooms are limited.

The 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!

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





Parenting and the school holidays!

I'm whacked! Today has very nearly beaten me. Today, I have tried to be the best parent I can be ...in the middle of the school holidays with two young children, one of which has Angelman Syndrome.

The dreaded holidays usually turns me into some kind of hermit. I find it all too easy to hide from the world, even my friends, all because the thought of taking both kids out on my own is way too horrific!! I've come to the conclusion that the reason I find it so stressful out and about, is because people don't generally look at Ella and see 'special needs'. This is a good thing, I know but the fact of the matter is, she does have special needs, severe special needs and although she is highly mobile and looks pretty 'normal', other parents are not expecting her to whack their child in the face, bite them on the back or suddenly start shouting at the top of her voice for no apparent reason! Being the social bunny that she is, Ella gets so excited to be around new children, especially girls and it's really fantastic to see - that is, until she grabs hold of their hair and sends them flying. I'm a little ashamed to admit, that these days, I've started to find it easier to begin explaining A.S to other parents, even before Ella's done anything, almost like an apology for the behaviour that may come.

I'm currently attempting to work out what, if anything, triggers her outbursts because 60-70% of the time, she even takes ME (her mum) completely by surprise, let alone a stranger! Quite often, Ella will be walking along with me, happily holding hands and she'll make me feel so proud at how grown up and confident she's become. Then, totally out of the blue, she'll let out this ridiculously dramatic yell (you know the one, the 'someone's killing me' yell) and start running off in the complete opposite direction - and she's fast! It's sometimes a real job for me to catch and stop her before she gets to a road or river edge. Of course I know it's amazing that she is so fantastically able but being so able and active, whilst having zero safety awareness, can be a dangerous combination.

Then there's Harry. Harry is my gorgeous little fella who's your typical 'Is he just hyperactive or has he got ADHD?' 4 going on 14 year old. Both kids are amazing, really wonderful but the two together, coupled with the school holidays, is truly a recipe for insanity - my insanity!

Today however, we did venture out to spend a few hours with some friends. Now, you'd assume that being with friends would be easier but these friends are my friends, whose kids are Harry's friends i.e 4 year old lunatic, mental boys! As much as I love my friends and their kids, this has got to be an even more stressful scenario. I know what you're thinking, 'Chill out woman, they're your friends, they understand about Ella'. They do, yes but their children don't. All they see is a rough little girl who's different, who pushes, pulls and bites occasionally. They're unsure of her so their defences are up straight away and get in first with their pushes and taunting. Together with my friends help, I do what I can to teach the kids about Ella. I try to explain calmly how she just wants to be friends, how she can't communicate as easily as them and how they just need

to take her hand and include her but they just don't get it, they don't see that actually, she's scared of them. I personally, find it hard not to get upset when I hear things like 'Let's get Ella' or 'Don't go near Ella' and it takes a lot of energy to constantly have to intervene. I've tried to tell myself that the more time they spend together, the more they'll get used to her and begin to understand but today I found myself wondering, is it really worth the headache or poor Ella's anxiety, when she sees those crazy little boys coming at her with toy weapons? Possibly not!

Don't get me wrong, Harry is, on the whole, brilliant with his big sister. He loves her and he's used to her behaviour but he sometimes gets carried away with his friends and joins in with their taunts. I feel that he does need to spend time with his best buddies and have fun in the holidays but at the same time, I don't want to put too much pressure on him so young, to have to look after and stand up for his sister. Just the other day, I was explaining to him 'again' about Ella and telling him, that maybe, he could show his mates himself how to be more gentle with her. In response, he turned to me and he shouted "I don't want you to talk to me anymore!". He'd had enough of me going on about it and do you know something?, I don't blame him. He's a clever little boy but it's hard to really know what goes on inside such a little fella's head and I certainly don't want him to feel burdened by his sister.

So, I'm sitting here this evening, exhausted, reflecting on the day. I've been calm (as calm as I can be), I've not shouted at the kids (that much), I haven't let them spend hours on the iPad or watching tv (well, maybe 1 hour) and we've embraced the day by seeing friends and going out to the park. I feel like I've been teaching the world about my daughter and at the same time, desperately attempting to be a sane and happy mum. Hahaha! If I thought I could keep that up everyday of the school holidays, I might have to think again...

Antonia Burton



New study at the Cerebra Centre! Sleep in Angelman syndrome



Cerebra have funded research at the University of Birmingham to conduct a number of studies on sleep problems in children with Angelman syndrome over the next six years.

Why?

Although parents often report that their child experiences a range of sleep problems, there is limited research examining the precise nature of these difficulties in Angelman syndrome. The aims of this six year project are to describe the nature of sleep difficulties in children with Angelman syndrome, to examine how sleep difficulties relate to parental well-being, and to explore potential interventions.

What will happen if you/the person you care for decide to participate?

The first stage of the project will be a large scale questionnaire study examining sleep difficulties in children with Angelman syndrome, Smith-Magenis syndrome (in which sleep problems are also reported), and children with an intellectual disability.

This study would involve parents filling out an online (or postal) questionnaire about how long children take to get to sleep, and any problems with staying asleep at night. We are also interested in investigating the impact of sleep problems on the rest of the family.

How do I take part?

We will be inviting families to take part in this research towards the end of the year. We will be advertising the study on our Facebook page: www.tinyurl.com/cerebracentre-birmingham and sending out information to families on our database. If you would like more information or would like to be contact about this project in the future, please contact **Jayne Trickett** at: JXT292@bham.ac.uk or on: **0121 414 2855**



Parliamentary Magazine

Angelman Syndrome, ASSERT and the new multi-disciplinary clinic led by Dr Jill Clayton-Smith in Manchester were recently featured in *The House* (cover date June 14th 2013).

The parliamentary magazine is sent to all sitting MPs and Peers. We hope that the decision to take up this unexpected and prestigious offer will make seeking help from your local MP a little easier, should you find yourself in that position.

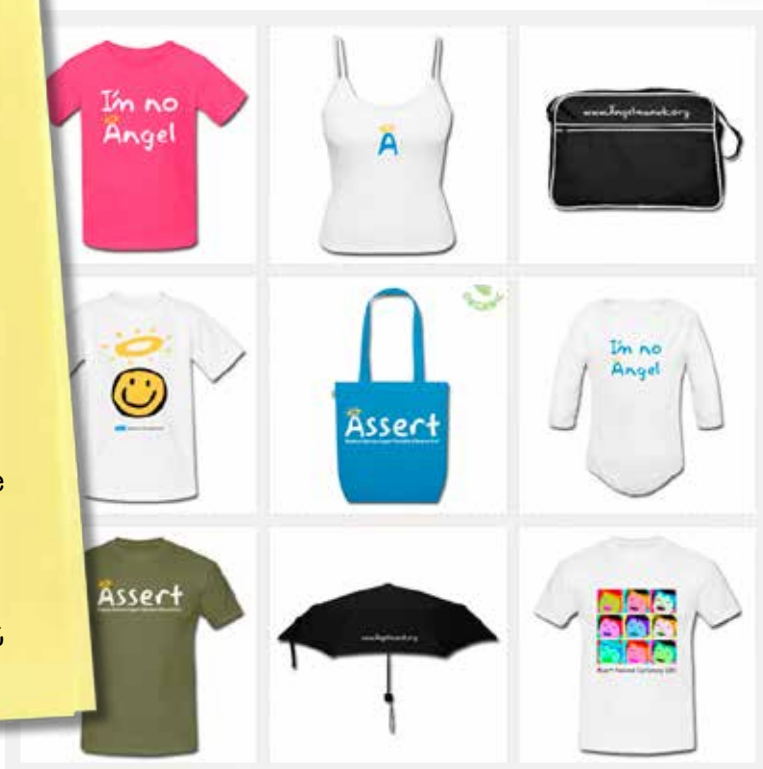


Don't Forget!

You can also support Assert by buying from our great range of T-shirts and other gifts.

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

www.angelmanuk.org/spreadshirt



First AS Clinic

ASSERT is very proud to inform you all that the very first UK Angelman clinic was held on 1 August 2013 Royal Manchester Children's Hospital. The Angelman clinic has been made possible thanks to a very generous donation to ASSERT from the estate of Vera Hopkinson, mother of the late Linda Hopkinson who I am sure many of you will remember from previous conferences.

The professionals that attended were:

- Jill Clayton-Smith (Geneticist)
- Dan Hindley (Paediatrician)
- Helen Jameson (specialist epilepsy nurse)
- Eric Taylor (Psychologist)
- Tara Gunn (Physiotherapist)
- Rachel Martin representing ASSERT

3 families were seen: a 22 month old little girl diagnosed 1 month prior to the clinic brought in by her parents, a lady aged 42 who was diagnosed at 11 months old came with her mum and sister, and a 2 year little boy with complex care needs, diagnosed as a new baby, who was brought in by his parents.

All the patients were vastly different and presented with very different issues. All the families left happy with the advice and care plans that were put in place. Hopefully all will continue to benefit from the input of the professionals.

All the doctors and therapists were amazed at the knowledge of the parents and carer's and were pleasantly surprised to see such a wide variety of ages and abilities.

The next clinic is due to be held once again at the RMCH on Thursday 28 November 2013. If you would like to attend this or any future clinics please ask your doctor or paediatrician to refer you to Dr Jill Clayton Smith, Genetic Medicine, 6th floor St Mary's Hospital, Oxford Road, Manchester, M13 9WL.

Useful Websites & Interesting Blogs

Support

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

For iPad/apps

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

Blogs

- www.boybiteshorse.co.uk

Pre-loved equipment

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

Clothing and swimwear

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

Legal

- www.ipsea.org.uk
- www.scope.org.uk
- www.mencap.org.uk
- www.challengingbehaviour.org.uk

This website offers very useful tips and advice and is run by an AS mum

- www.netbuddy.org.uk/newsletter/netbuddy-tools

Vera and Linda Hopkinson

Many of you will remember Linda Hopkinson (the lovely older lady with Angelman Syndrome), who was a familiar, inspirational face at Loughborough, along with her fantastic carers. We learned last year that she had sadly passed away and whilst we will miss her, there is no doubt that she created a lasting memory for many of us, along with a hope for the future. Less than a month after Linda's death, her mum, Vera, also sadly died.

Vera's will left a substantial sum to the most suitable charity and the executors decided that ASSERT was just that. We have therefore recently received a sum that will make a huge difference to both ASSERT and UK families affected by AS over the coming years. Just like Linda did.

Thank you Vera.



Joe and his walking

It's lovely to be writing this! I wrote an article and organised a regional meeting years and years ago so it's great to do an update!

Let me tell you about my family. I've been married to Stuart for 20 years and we have 2 boys. Joe who is 18 and a half and has AS and Will who is 14 and has no problems apart from lurching into puberty (and what a joy THAT is!) We live just outside Wolverhampton and we both work. Stuart has just opened his own delicatessen and I work in a Special Needs school as a Home School Worker, supporting parents. We have 2 boxer dogs and are involved in our local church, Will is a chorister there. I'm sure everyone can identify with the headlong rush that is our life!

We had Joe diagnosed when he was 13 months old. The professor at BCH always thought there was something else going on with Joe as he has always been a placid, easy going child, his fits have always been very controlled and he has mostly slept and ate very well. The only thing he's never done was walk. I have to say at this point that he is possibly the laziest child ever! Stuart and I are real outdoors people but we have produced a couch potato supreme! When we ask him to stand up he sits on his hands...and he's supposed to have learning difficulties!

Joe has always been a bottom shuffler... I remember the long, long hours trying to get him to crawl but he never mastered it. When he actually did do as the physiotherapist wanted it was the slowest, most ungainly movement ever...and he kept forgetting what to do, bless him! He loved bum shuffling, he felt safe and he could move at the speed of light! His younger brother never had any of Joe's second hand trousers as there was always a huge hole in the seat!



Joe was also fairly happy toddling round on his walker, unless he was faced with a long walk and he couldn't see his wheelchair, when he would moan like a soul in torment, but last year something clicked with him and he started walking on his own! He just got more and more confident in doors and progressed from cruising round furniture, bent almost double as he is a tall boy, to taking solid, stumpy steps on his own. He can now get up out of any chair, walk anywhere in the house, stop, think where he wants to go and change direction, usually towards food or his Mr Tumble DVD. He is still hesitant about walking outdoors... and I tend to hover very close to him.

There are pros and cons to this wonderful walking. Of course its fab for Joe. He is more independent; it's much easier to dress and undress him and it's great for his bones and fitness. But it brings its own small troubles. We need eyes in the back of our heads....we call him our 10 stone toddler! If I leave him alone for a second he's in the kitchen

sampling the crisps and contents of the fridge. We've put a stair gate on his bedroom door, as it doesn't bear thinking about if he went wandering by the stairs in the middle of the night. The phrase "have you checked Joe's gate?" is heard nightly, usually when we've just turned the lights off and settled down! We are lucky to have a fairly large house so I'll hear Joe's special heavy footsteps and think blimey where is he now? The dogs are a bit of a hazard... or is Joe a hazard to the dogs?... it's a good job they adore him!

So that's Joe and his walking! There's so much more to tell of life with our dear Joe. He's an adult now... don't get me started on adult provision and residential colleges....

Su Turner

The Court of Protection and Deputyships: Secret Court or Necessary Lifeline?

*The Court of Protection has been in the news a lot recently, and faces widespread suspicion about being a 'secret court' that 'controls' billions of pounds of vulnerable people's money. So what's the truth behind these headline grabbing claims? **Donna Holmes, Senior Associate Solicitor at Anthony Collins Solicitors** sets the record straight.*

In the UK, a lot of people are unable to manage their finances. Children with Angelman's Syndrome are amongst those who likely to need to have their finances managed for them. As a child moves towards adulthood, access to finances on their behalf is likely to become increasingly difficult. The law recognises that as children reach 16, they generally start to manage their own finances and by the age of 18, a person is seen as an adult. This means that a parental signature on a bank account held in a child's name will no longer be accepted and access to funds will become fraught with difficulties, due to data protection legislation and the law's recognition that people over the age of 18 are legally adults. Banks will ask for a Power of Attorney for a third party such as a friend or sibling to be able to deal with a bank account for someone else.

Powers of Attorney are legal documents which enable a person who has capacity to appoint someone that they choose to help and support them in managing and dealing with their finances. A child with Angelman Syndrome is, however, unlikely to have capacity to understand what a Power of Attorney is. This means that they would not be able to make a Power of Attorney.

If finances still need to be managed, there are 2 options which offer an alternative. If the young adult with Angelman's receives only benefit income and doesn't have any savings, then a Benefits Appointee can be appointed. That Appointee can then receive, manage and make payments from benefits income and should be able to be appointed very simply in conjunction with the Department for Work and Pensions.

However, issues often arise if a child has an account in their name where savings have been made for their future benefit throughout their childhood – whether accumulation of benefits, gifts or inheritance. In those circumstances, on-going income might be able to be managed through an Appointeeship, but what about that savings account?

Through legally appointed and suitable people known as 'Deputies' the Court of Protection provides the legal ability for a 'Deputy' to access bank account(s) of a child with Angelman's Syndrome and the ability to use the funds for their benefit. The Court provides oversight of the financial affairs of a person who lacks capacity to manage their finances for themselves. Through the Office of the Public Guardian, the role that Deputies play is overseen – ensuring that Deputies are supported in their role and have somewhere to turn for

help and advice, to make sure that they are spending the money of the person who lacks capacity on meeting their needs and in their best interests and generally making sure that the person who lacks capacity to manage their own finances is not exploited.

Deputies are often family members or friends, and an application can be made for the appointment of a Deputy using a Solicitor or by filling forms in and making a personal application. A solicitor or other professional only needs to be used if there is no one else willing, able or suitable to act as Deputy. The Deputy can then access bank accounts, make investments, use funds for the benefit of the person who lacks capacity and ensure that their interests are protected. The Court has a role, with the Office of the Public Guardian, to oversee Deputies and the role that they play to try and stop financial exploitation arising and provide support where it is needed. But the Court does not manage the money itself. It is 'secret' in that hearings are generally not held in public – so as to preserve the privacy and confidentiality of those who lack capacity. Generally people want their finances kept private – how much you have in savings, receive in benefits or earn is not something you would want shared with the world. The Court of Protection recognises this sense and wish for confidentiality in such matters and therefore keeps the majority of cases private – but it can publish details (although generally not names) of cases if that is in the best interests of the person lacking capacity or the wider best interests of the public.

As we know, children with Angelman's Syndrome are unlikely to be able to manage their own finances. So if you have savings for them, it might be sensible to look at spending those for their benefit before they reach 16 and access to accounts becomes difficult and then ensuring that Appointee arrangements are in place. Alternatively, having in mind the need for a Deputyship as they approach the age of 18 – and who will act in that role now and for the future – may help you to deal with those difficult conversations with the bank and understand why they are asking for paperwork to access an account.

Finally, ensuring that any money left for the benefit of a child with Angelman's is left in trust under appropriately drafted Wills may well avoid the need for a Deputy – and also ensures that you, as a parent, can choose who supports and assists your child's financial management if you aren't around to do so.

Donna Holmes is a Senior Associate Solicitor at Anthony Collins Solicitors LLP and specialises in advice to families where children lack capacity and need Court of Protection advice or specialist Wills to make provision for their children. Donna can be contacted on 0121 214 3671.

More fabulous fundraising...

ASSERT SUNDAY BRUNCH

Melissa our daughter has AS deletion she is 36 years old and lives in a residential home in Berkshire. As a former trustee of ASSERT it was decided in late June to raise funds for ASSERT by putting on a brunch.

Along with Martin & Estelle (brother & sister in law) who donated their house, the date was set for 28th July, a small charge per person was agreed.

We invited two local Rotary clubs: Barkingside who Jackie belongs to, Redbridge who Martin belongs to, with friends we had a great turn out over 70 people turned up. Martin and I were on egg duty, the other duties were carried out by the rest of both families. We offered eggs any way you like, pancakes, breakfast pastries, fruit, bagels, smoked salmon, cold drinks, hot drinks, so on and so on. We had an excellent array of good quality and diverse raffle prizes, which were donated. We were very lucky the sun came out to shine on us.

People started to arrive at 10.30 and the last left about 2pm a great time was had by all, most knew about ASSERT by the leaflets, newsletters and going on line

The money raised was (drum roll) £1250.00 including the raffle and lots of donations from people who could not make the brunch. Hard work but a great day; anyone want a big omelette? We have 5 dozen eggs left over.

Jackie & Bernie Silver



ANGLIAN WATER FAMILY FUN DAY

It was an event organised by Anglian Water and we had a variety of events on all raising money for local charities including Lincoln Cat Care, The Samaritans and Harry's Friends (a charity to raise money for the intensive care unit at Leicester Hospital as a colleague's little boy is seriously ill there so raising funds for intensive care equipment) and of course ASSERT.

We set up a fresh fruit stall and sold a variety of fruits kindly donated by Sainsbury's. We sold them and displayed them on skewers and they were a real hit with the kids. The weather wasn't kind to us but despite this it was a successful event. We had guys getting their legs waxed, pole fitness demonstrations, Zumba demonstrations, Netball shooting, bouncy castle, numerous stalls including ours, splat the rat game, 5 a side football match, dog show, BBQ and Tombola and Raffle.

We sold 64 skewers in total and raised £55 for Assert. If the weather had been hotter I think it would have brought more people out and we would have sold more as ours was the busiest stall there, got lots of compliments on what a great idea it was.

Tracey Shelbourn

GREAT MANCHESTER RUN

I just wanted to say a huge thank you for the opportunity to run on behalf of ASSERT in the Great Manchester Run.

The whole event was fantastic, I posted a better-than-expected time of 52min 24secs, spurred on by the incredible generosity of all those who sponsored me, and all our "Angels" everywhere. Current total (excl Gift Aid) stands at £1,157. An amazing day and very proud father of Joe.

Richard Barlow





GREAT MANCHESTER RUN

My reason for choosing this charity is unusual; I met Colin Farrell and when I contacted him, he kindly sent an inspirational message back to my children on a class photo. This meant a lot to the children, motivating them as well as allowing them to believe anything is possible. My awareness of AS came after the children researched him and asked me about Angelman Syndrome; reading about one of his sons having AS and not having any knowledge of this rare genetic condition made me feel a little ignorant, particularly working in my profession. I felt compelled to help raise awareness and in a small indirect way a thank you to Mr Farrell for making some children happy hearing from a Hollywood star.

Unable to organise a fundraising event at school, the class decided that I could do something but still involve the children in some way, so I decided to register with ASSERT and enter for the BUPA Great Manchester Run. I'd never taken part in any race previously but I was excited and nervous about the event and the challenge to run 10km to raise money for our chosen charity.

Unfortunately while training in February I trapped a nerve in my C5/C6 vertebrae which stopped further training for over 5 weeks. I was told not to train at all until after my discharge from physiotherapy and acupuncture. I felt completely devastated but was unwilling to give up doing the run or letting the charity down and so I decided that even if I had to walk the 10km I would.

On Sunday 26th May, I stood with over 40,000 people, waiting for the start. The anticipation, noise and excitement of the other runners was palpable - I half ran and walked the 10km course and my time was an amazing 1hr 24mins 56secs! I exceeded my fundraising target of £500, raising £905 but still hope to hit the £1000 mark. My only disappointment on the day was that I didn't see anyone else running for ASSERT; while I was raising the money it was evident that people in the UK were not aware of ASSERT or Angelmans, just like me, and without the children and their research, I would have remained clueless!

My last thought to you all is this... 'that if people are being asked what gift they would like for their birthday that everyone will - for one birthday - consider asking friends and family to make donation to ASSERT. Even if your birthday has passed for this year, I would urge you to pledge for next year. Together we can all make real difference to the lives of others.' Remember ASSERT is a voluntary organisation so anything you raise or donate will truly help - EVERY LITTLE COUNTS!

Kash Sandhu

PLYMOUTH HALF MARATHON

Gary Homer ran the Plymouth Half Marathon for ASSERT raising £610 (plus gift aid). The photo shows Gary with Tracey Dunne, her daughter Sophie and son Spencer.

Gary Homer



CHARITY CRICKET MATCH

We would like to thank Wedgwood club, for organising this annual charity event. We managed to raise a fabulous amount, double what we raised last year. Brilliant. We want to thank Jayton and the veteran teams that joined us this year, and of course our boys from the plume of feathers pub and Wedgwood cricket team who have been with us both years. Thank you boys. Thank you to John West, proprietor of the plume of feathers for donating the meat for the



BBQ, and to the girls on the tombola, and a special thank you to our good friend Paul Williams who gets the task of spokes man every time. We can't thank you all enough for the time and effort you put in for this day, it's for a great charity and we know you do it for our little angel, Hannah, who we know is very much loved. We couldn't ask for a better group of friends. Thank you for spending, and raising money for ASSERT.

Kerry Houghton

More fabulous fundraising...

TWO CASTLES RUN

On June 9th this year, I ran the Two Castles Run to raise money for ASSERT. The event is a ten kilometre run from Warwick Castle to Kenilworth Castle and something which I remembered from my days growing up in Warwickshire. In fact, I took part in the very first Two Castles.

That was a long time ago, 30 years ago, in fact – long before I discovered alcohol or McDonald's, and certainly long before I developed shin splints so bad that I had to give up running. In the past 30 years, I had done precisely three road races – and I ended up walking one of those because I broke one of my toes three weeks before!

Having entered the event on a whim (I thought it would be nice to do it again after three decades) I realised that I needed an incentive to make sure that I actually did it. I was conscious of not wasting the £18 entry fee, not to mention however much I needed to spend on running gear. That was when I decided that I should try and raise some sponsorship, because I knew that if nothing else I would then guilt myself into doing the run!

The next issue was choosing a charity. I was adamant that I didn't want to do anything for a big, national charity, let alone one of those who spend their income on television advertising. I wanted to know that the money I raised would really make a difference. I thought immediately of my friend John and his wife Louise, whose daughter Holly has Angelman's.

The first step was to ask John and Louise's permission to use Holly's photo on my JustGiving page. She's a beautiful girl with an amazing smile and I knew that she would bring in far more money than a photo of me would (by contrast, I've got the sort of face that looks like it has spent its life chasing parked cars). Fortunately, they agreed right away and event sent me some helpful links to ASSERT that I could put on the page.

The next thing, then, was to tell other people what I was up to. The first few – including Caro, my wife – responded with a certain amount of puzzlement. This was exactly the response I was looking for. I wanted people to go away and read up on Angelman's, just as I had had to do when I first heard about Holly's diagnosis.

For whatever reason (I still say it was Holly and her smile) my plan worked. I'd tried to strike a balance between setting a target too low and one that was too high, but I was past the one I did set in less than a week. I was amazed by how generous people were prepared to be, even though it was years since I had asked for sponsorship for anything.

I have to admit that training for the race did not go that well. You might remember that April was a bit on the cold side and the start of May a bit wet, neither of which were great incentives to going for a run. And then, of course, the day of the run itself was a hot one, and all of my running gear was bought for much cooler weather, being full length and black. On the plus side, though, I was the only runner who looked like a giant stick of liquorice and therefore very easy to spot. I did have fun on the way around, although I did take it very easy to make sure that I finished and could claim all of that lovely money for ASSERT.

The best thing, though, was receiving a lovely letter from ASSERT a couple of weeks after the event, thanking me for raising the money. So many charities simply don't bother and it was a very welcome touch. Which reminds me, I've collected another £25 since then that I really ought to send in!

Richard O'Hagan

LONDON TO SURREY BIKE RIDE

Pete Munro raised a total of £1074 with half going to the British Heart Foundation and half going to ASSERT.



BATH HALF MARATHON

Christopher Bird raised a total of £282





FDC YOUNG DESIGNERS AWARDS

A fashion show was organised by Joanna Marcella Reid. Joanna's grandson has AS. The event was held in Mayfair, London on 11th July. One of our mums, Lindsay McKeown very kindly attended on behalf of ASSERT and gave a small speech on Angelman Syndrome and ASSERT. As you can see from the photos, it was a fabulous night and everyone had a wonderful time.

Lisa Court



SWIMARATHON

The Swimarathon is organized by Maidenhead lions club. It is held every year and I am hoping to persuade my friends to swim again next year.

The challenge wasn't easy especially as it was just after Christmas and New Year. We had to swim as many laps (1 lap = 2 lengths) as a relay team within 60 mins. Our team 'Angelfish' managed 67 laps.

Sarah Brown

'HALO HAPPY CAMPERS' WENT CAMPING!

A few families from the Facebook group, 'Halo Happy Campers' met up for their first official meet, August bank holiday weekend. Whilst there, three young siblings decided to spend most of one evening in silence! They all said they wanted to experience what it must be like for their brothers and sisters...

What made the challenge more difficult was the fact these three friends live hundreds of miles apart and don't see each other that often, having only these short breaks to catch up and talk. There was camping games and barbecues throughout their silence and they had to make themselves understood in ways they see their siblings try.

The three musketeers, Becky Holmes, Corey Howard and Stevie Comery worked really hard being sponsored to sit in absolute silence. They managed 3 hours and 5 minutes and only gave in as it was getting close to bed time.... Each were desperate to speak by the end! They were remarkable and raised £125.

A few more camping weekends are scheduled for 2014, anybody wanting to join us please contact Linda Holmes (either on Facebook or by email)

Linda Holmes



BOY BITES HORSE

NOTES FROM THE FRONTLINE OF AN ALTERNATIVE CHILDHOOD



Some of you might already be familiar with Boy Bites Horse, an entertaining blog that reports the life of a (so-called) Special Needs child. For those that aren't, sit back, buckle-up and enjoy the ride. More at: www.boybiteshorse.co.uk

The boy who ate all his clothes

Lately I've taken to eating my clothes.

Well, not all my clothes, mostly just my shirts, so the title of this piece is a gross injustice. Ok, I'll admit that I do occasionally have a mouthful of trousers but I wouldn't say it was every day. Socks don't even count as clothes so I'll chew on those whenever I get the chance.

Actually now I come to think of it I also eat fleeces, vests, pyjamas, hats, scarves, gloves and shoes. But that's it. Definitely nothing else.

Unless you count nappies. I don't even like nappies, all that urine-soaked silica gel stuff tastes bleeaaahhh!.. and it's terribly difficult to get out of your mouth once it's in there, but I just can't resist the texture when you yank on a good handful and the thing explodes in a fountain of sticky gel crystals. Wonderful stuff. And surprisingly difficult to get off a wooden floor.

Anyway, the clothes thing is relatively new, at least on this scale. I've always been partial to a bit of nibbling but recently I've realised just how insubstantial a lot of modern clothing is (no doubt attributable to economies of scale and the exploitation of the Asian workforce, but as people keep reminding me I'm 'special needs', so wouldn't know anything about that) and I can quite easily rip a shirt completely in half. Trousers are certainly more difficult but with a bit of effort you can usually get them to tear all the way up the seam of one leg. Sometimes they'll put a hoody on me in the belief that I won't be able to tear through something that thick. BIG mistake. I just regard it as a challenge and it makes their clothing bill much more expensive.

I do feel a little guilty about this: clothes aren't cheap, Frowny and Smiley aren't exactly rolling in cash and having to replace an average of a whole outfit each day must add up. Especially when they've taken the time to choose clothes for me. They quite like all this matchy-matchy stuff and I suppose I really should be taking more pride in my appearance at my age, but quite honestly I don't care what I'm wearing as long as I'm warm enough.

And tearing up my clothes is just too much fun to resist; if you've never tried it you should... the sense of freedom and liberation is joyous.

In truth I don't eat much of it: I usually start with my teeth before getting both hands involved and giving whatever it is a good old rip. Sometimes a large piece of the material comes away in my mouth and I'll have a munch on that. Thin stuff like T-shirts and pyjamas are actually pretty good. Socks aren't bad either, and the stringy stuff that comes off a one-piece bib is absolutely lovely, though it does get stuck in the teeth. But when it comes to the thicker stuff like denim or fleece material it's usually too difficult to swallow so I'll spit it out.

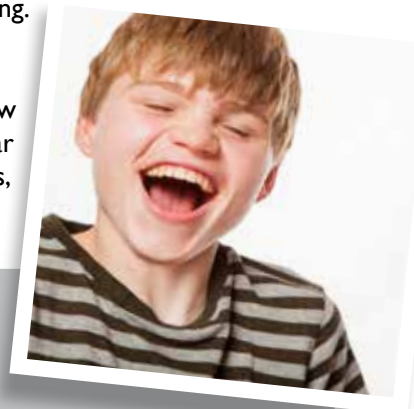
I originally started eating my clothes when I was bored but once I realised people had started taking notice I've found it equally effective when I'm hungry or when I feel I'm not getting the 100% attention I deserve. I also do it when I am getting attention, just to confuse people. I've had a clinical psychologist 'observing' me recently and this clothes-ripping behaviour is driving her nuts: just when she thinks she's pinned it down to one cause and effect I'll mix it up a little and do it for no reason whatsoever.



Frowny thought she could outsmart me by dressing me in 'sacrificial' clothes when she thinks I'm in a particularly destructive mood (things I've already partially torn, but also presents from relatives), so another good trick is to leave these totally intact and wait until she puts the good stuff on me.

Now I wouldn't want you to go away with the idea that my tastes are exclusively in clothing. That would be ridiculous and hardly a balanced diet for a growing boy.

I also eat curtains, furniture coverings, cushions, duvet covers, duvets, pillow cases, pillow stuffing, towels, bean bags, plastic mattress covers, change mats, lamp shades, tablecloths, car seats, shoes, shoelaces, rucksacks, handbags, tissues, paper, plastic, leather, rubber, toenails, excrement...



About The Boy Who Bit The Horse

I am a fifteen year old boy with so-called special needs. Primarily those are: I need to eat (a lot), I like plenty of exercise or I get really bored, I grunt instead of talking, I'm not much of a reader, I'm not too big on personal hygiene, I don't like being too hot or too cold and I like playing with my... well... y'know... so I'm pretty much like every other fourteen year old boy.

I live with a dysfunctional little group I'd hesitate to describe in terms as grand as a 'family'. There's Smiley, Frowny, Flower Girl and Curly Top – thoughts of them sounding like rejected cast-members from Snow White and the Seven Dwarfs are not so far from the truth.

There's also a whole troupe of 'companions' (I'm not sure if we're still allowed to use the word 'carers' and anyway this makes me sound more like Dr. Who) who are apparently there to entertain me and be at my constant beck and call. I hear not everyone has this courtesy, but I can highly recommend it.

In fact, as I look around me I see there are lots of ways in which I can help people with the benefit of my autobiographical anecdotes. On the whole I think everyone works too hard and worries too much; in my experience of putting in as little effort as possible I still find that people bring me food at regular intervals, provide all the clothes I need, take me wherever I need to go and generally go out of their way to indulge me.

So I dedicate this blog to all those of you who are trying too hard in life.

Slow down. Sit Back. Relax.

Smile with me!

I would like to invite families to a new monthly group called 'smile with me'.

This is something I am testing to see if it is worth suggesting to other families to try in their local area. I live in Downton, Salisbury and would like to meet other families with children with Angelman Syndrome. Please note this is NOT an ASSERT regional meeting, but a regular play date (if you like), for families who live close to me in Wiltshire, Hampshire and Dorset. I am suggesting meeting for a couple of hours once a month. Probably in the afternoon on the last Sunday of the month. I will let you know where we are meeting via facebook, email and phone (if you don't have internet access). Please get in touch if you are interested. katiereader@aol.com, 07884 231259

Katie Cunnea

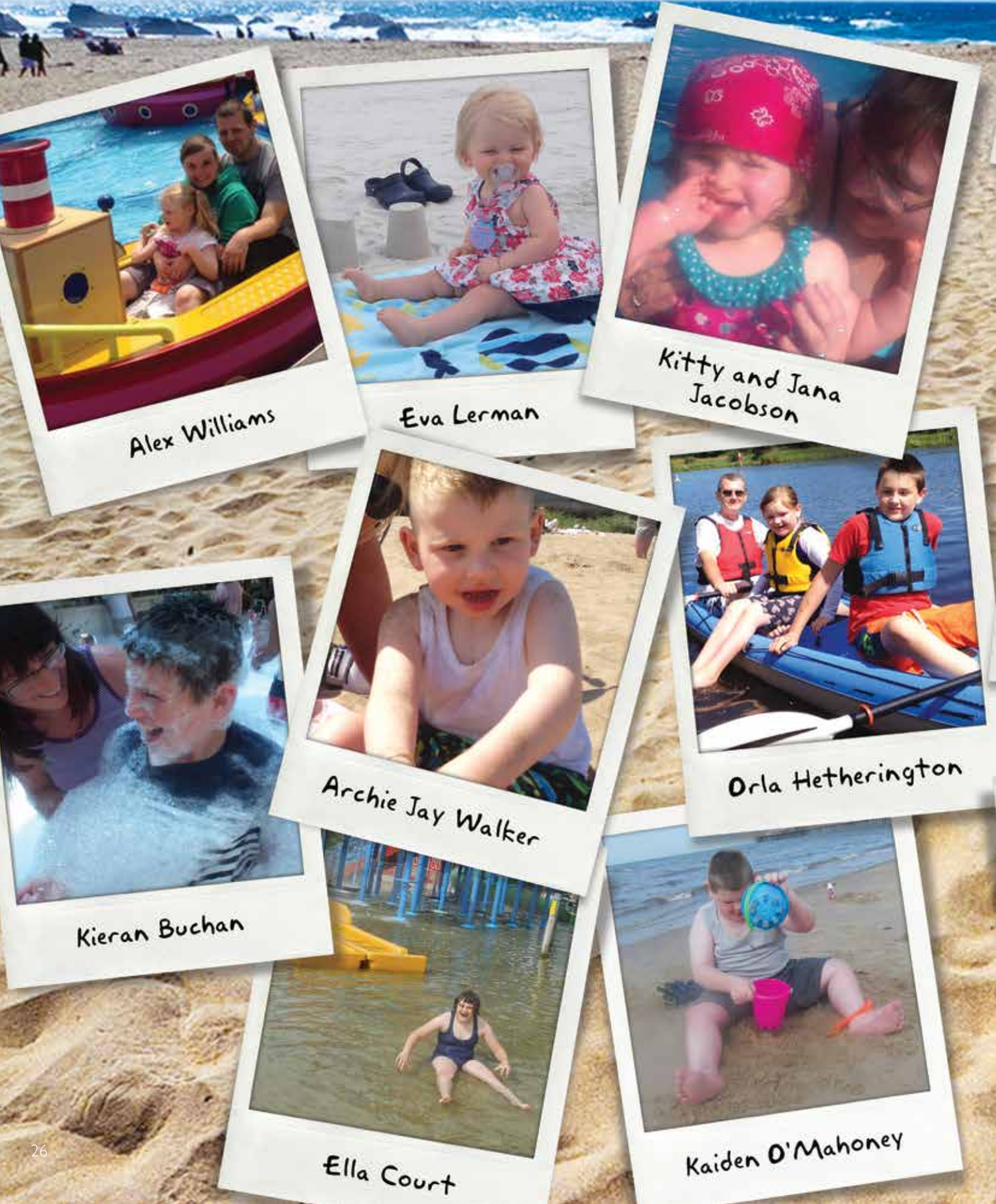
Research Update

As Katie Cunnea is ASSERT's Research Trustee, she and Rachel Martin recently attended the Italian Angelman Syndrome conference on October 11th / 12th. Numerous experts attended to talk about the current research that is happening around the world. Katie will be giving a review of the conference in the next newsletter.



Summer Photos

ASSERT asked you to send in the photos from your summer holidays in 2013. As it turned out, we've had some fantastic weather this summer which hopefully meant you had the opportunity at some point to get out and about and enjoy the lovely sunshine. Here's what some of you have been up to...



Alex Williams



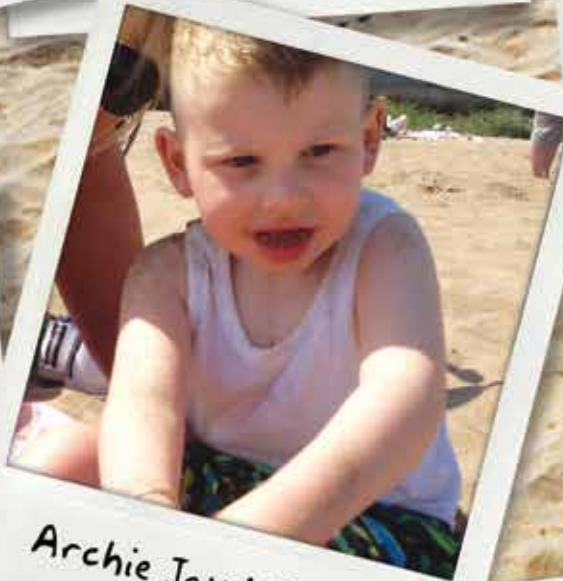
Eva Lerman



Kitty and Jana Jacobson



Kieran Buchan



Archie Jay Walker



Orla Hetherington



Ella Court



Kaiden O'Mahoney



Alex Williams



Ben Robertson & Zoe



Harry & Ella Burton



Samuel Coffen
and Willoughby



Eva Lerman



Max Bannister-Malkin



Kieran Buchan



Kaiden O'Mahoney



Orla Hetherington

Thank you!

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

many thanks to...

BUPA Great Runs

ASSERT have places available in a number of the Bupa 'Great' Runs for 2014. If you would like to be considered for a place, please email lisa.court@angelmanuk.org.

The minimum sponsorship is £500 for the Great North Run and £250 for the other events.

The races we have places for are:

- Great North Run
- Great South Run
- Great Edinburgh Run
- Great Manchester Run
- Great Birmingham Run



Helpline 0300 999 0102
assert@angelmanuk.org

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

DONATIONS

In memory of George Assinder

Mrs Tait

Joy Skeates (Conference Portraits)

Munia Lodge (L4096)

The QBE Foundation (Rachel Winter)

Rebecca, Sophie and Lewis Johnstone

Peter Bevan

Ixworth Middle School & Carter Christiansen

Tamin Rezek

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Half Ironman Distance Triathlon

St Davids Day 10k Run

London to Paris

Paris Marathon

Plymouth Half Marathon

Free Radio Walk for Kids

Two Castles Run

Bupa Great Manchester Run

Bupa Great Manchester Run

Bupa Great Manchester Run

Bupa Great Manchester Run

Bupa Great Manchester Run

Bupa Great Manchester Run

Bupa Great Edinburgh Run

Bupa Great Edinburgh Run

London to Paris Bike Ride

Bournemouth Bay Run

Sheffield Half Marathon

London to Surrey Cycle Ride

Swimarathon

Bath Half Marathon

Potters Half Marathon

Charity Fashion Show

Anglia Water Family Day

Fundraising Sunday Brunch