



Newsletter 60 Spring 2017

Angelman Syndrome Support, Education & Research Trust

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to Florida

IAD





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Useful Stuff

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HELPLINE
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ASSERT Families - New Diagnosis Advice
Contacts - Support

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

FRONT COVER
Photograph courtesy of Robert Chadwick.
We'd like to use one of the great photos taken
at our conferences on each of our future
covers. If your AS family member was one of
those photographed and you do not want their
images used on ASSERT material please let us
know at the above address as soon as possible.

CONTENTS OF THE NEWSLETTER

You will notice that the pieces in this newsletter
are drawn from a wide variety of sources.
While we are keen to promote discussion
and to pass on any views and experiences, it is
also important to appreciate that the opinions
and views expressed by contributors to this
newsletter are personal and not necessarily
those of ASSERT.

Letter from the Chair

With the weather improving every week as we head towards the return of summer, many of us are planning memorable family days out again. But when you add in the additional challenges which conditions such as Angelman Syndrome pose, details around such days are even more important. Facilities, attractions, accessibility, weather suitability, age appropriateness, distance, as well as cost, all play a key part in the planning process. Who needs spontaneity anyway?

As parents we have often (as I'm sure you have) been frustrated by a lack of awareness when enjoying family days out, with a person who has profound needs. For example paying full entry rate to facilities that can only be partly accessed still annoys, but over time and thanks to the pressure of social media, things are slowly improving.

The more of us that comment, the faster the pace of change will be. If you enjoy a great day out, please contact the operator and celebrate it with them, commenting on both our Facebook and Twitter channels too. Likewise if the experience was less than favourable, tell them and us. A single whisper will get lost, but we've developed quite a loud voice of late. Let's use it!

What a momentous year 2016 was for ASSERT-culminating in the support for our cause by LucasFilm (thanks to Gareth). (In case you want to see it again, the film can be found on our website/YouTube channel). To see our small charity sitting alongside the likes of Unicef and Great Ormond Street on the Force For Change website was truly inspiring. With such a bench mark to follow, 2017 is looking to be equally strong.

We now have a new member of the trustee team, Tracey Campbell. After writing last year's AAC guide, Tracey has been "rewarded" with more work and key role in our first AAC conference weekend. (Welcome Tracey, and thank you).

Whilst the communication conference had an obvious Angelman Syndrome bias, the event also appealed to those dealing with other conditions- and perhaps even more importantly, professionals. The word around AAC is growing, but until we can get the professional bodies to fully embrace it at school then those we care for will be left unsupported away from the home, regardless of what we - as parents, carers and those with Angelman Syndrome - achieve.

Gareth must have inspired us, as ASSERT recently launched the second and third of our new short films. The first was a general introduction; the second covers behaviour; the third covers communication. All can be found on our YouTube channel. The stars of the films are undoubtedly the siblings and there are more films in the pipeline that will explore the topics in a little more detail. Thank you to all of those who took part and to Molly, Lottie and Diane for their patience and creativity.

We are one with the force. The force is with us!

Rachel & Rich



Gareth & his niece Ella

An update on Our Patron Gareth Edwards...

Gareth is currently having a well deserved break after the huge success of Rogue One. Well when I say break, he has gone away but he is in the throes of writing his own film which may or may not make it onto the big screen. He may or may not get an offer he can't refuse to make another blockbuster. At the moment, we don't know what is next on Gareth's agenda and I can assure you he never tells his family anything, so I don't have any inside information! One thing I did manage to get him to do before he headed off was to sign a few Rogue One DVDs which we are offering in our prize draw. If you want more details please turn to page 13.

International Angelman Syndrome Day - 15th Feb

INTERNATIONAL
ANGELMAN
DAY FEB 15



International Angelman Day is held on February 15th. This was the 5th year of IAD and in the tradition that we have now set, ASSERT arranged a number of meetings across the UK. IAD fell on a Wednesday this year and so some meetings were the weekend before and some were the weekend after. Here are some stories of a few of our meetings.

South Central

We had a lovely sunny day in Feb for the South Central IAD meet up in Thames Valley Adventure Park, Maidenhead. The Park is specially designed for families like ours, so everyone attending had a great time in the sensory room, soft play area and fantastic outdoor space and the staff were brilliant. There were 12 families over the course of the day with 21 AS individuals and siblings and 22 adults. It was lovely to see some familiar faces and meet some new ones. Huge thanks to Sarah Brown for all her help with the organising.

- Andrea Baines

London

We held the South East region's IAD at Burview Hall, Mencap Centre in Walton on Thames. The event was very well attended with about 16 families using the wonderful venue with a large hall, kitchen, games room and sensory room. The weather was lovely, so many families used the secure outdoor area with its playground and wheelchair accessible swing. Others followed the woodland path leading from the garden to a lovely shaded secure woodland area. However our own son was far more interested in the biscuits and cakes laid out for everyone to enjoy, we eventually had to remove the food and close the hatch asking people to come into the kitchen if they wanted any more food. Perhaps next time we'll manage to persuade him to venture outside.

- Diane Fox-Jones

Yorkshire

A lovely IAD event at Mencap in Leeds. Great facilities, lots of space, a sensory room, soft play area, music, far too much food, lots of laughs and great to catch up with all the families that came. A big thank you to Becky for bringing her guitar and singing for us. Let's do it all again next year.

- Sian Cartwright

North West

The northwest families had a lovely day at The Children's Adventure Farm Trust <http://www.caft.co.uk>. Lots of new friendships were made and some old ones rekindled. CAFT provided a wonderful buffet and even threw in some Llamas and some ducks for us to feed. All agreed it was a wonderful day and I'd like to thank all who attended and supported this year's North West & Wales ASSERT IAD event.

- Rachel Martin

South Wales

Great time at the IAD get together in SNAC and some new faces too.

- Donna O'Driscoll

Central

We had a great afternoon enjoying a splash in the pool followed by a bouncy castle and trampolines and anything else we could find in the sports hall! It was lovely to see familiar faces and its always lovely to see new faces. A wonderful few hours chatting and watching the kids have a fabulous time.

- Lisa Court

Photos left to right: South Central, London, Yorkshire, North West, South Wales, Central



SCOTTISH CONFERENCE

Unfortunately the Scottish Conference which was scheduled for August 2017 has had to be cancelled. We understand that some of you may be disappointed but we did not receive sufficient interest to make it financially viable. We will be organising a future event for Scotland on a smaller scale. Also, we will be having our usual biennial conference in Coventry in August 2018 and as always, everyone is welcome to attend the Coventry conference.



KIDZ TO ADULTZ

The Kidz to Adultz exhibitions are a great source of information if you are looking for equipment or services. There are currently 5 around the UK each year – North, South, Middle, Scotland and Wales. There are 2 remaining exhibitions in 2017, Kidz to Adultz North and Kidz to Adultz Scotland. The exhibitions are free to attend so if there is something you are looking for and it was convenient to attend then we would strongly recommend you go along and spend a few hours seeing what is available. Further information can be obtained from <http://www.disabledliving.co.uk/kidz-to-adultz/>



SCOTLAND:

14th September at
Royal Highland Centre,
Edinburgh.



NORTH:

16th November at
EventCity, Barton Dock
Road, Manchester.



Siblings

Dear Jon



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

Problems can be written anonymously to jonathan.allen@angelmanuk.org or to Jonathan Allen via a message on Facebook.

Dear Jon,

My older sibling has Angelman Syndrome and requires a lot of care, for which I have helped out a lot over the years. I am at an age where I need to start thinking about making decisions about a potential future career. I am torn as to whether or not I should do something supporting special needs as I feel that this is where a lot of my life experience is.

Jon's Answer:

It is natural that a lot of your experiences in life will be focused around disability and special needs, as Angelman Syndrome can be intense and can dominate certain aspects of family life. However, I would be keen to point out that you should never feel obliged to carry out a career in relation to special needs just because of your sibling. At the same time, whilst you are young you have a lot of options open to you and I wouldn't necessarily rule anything out. There is a lot to be said for care work and working around disability and special needs but ultimately it comes down to what you are passionate about; you will be doing that career every day and you should ensure it is one you find makes you happy and rewarded.

Dear Jon,

I sometimes find it difficult when I am with my Angelman Syndrome brother a lot of the time as the activities that we do depend on what he wants to do. It's particularly hard as he and I have quite different interests.

Jon's Answer:

First of all, this is not an uncommon problem and one that I have had raised with me many times. It's often my advice to try and focus more on the activities and interests that you do share with each other to have quality time. However, this can be difficult particularly for siblings of different ages, genders and with different interests. There is nothing wrong with having time to yourself or with others to do what you want to do. However, if you want better quality time. However, if you are often better quality time with your brother then even simple things like going for a walk, which is a fairly neutral activity, can be rewarding and help strengthen the bond and understanding between the two of you.

Dear Jon,

I have a younger sister with Angelman Syndrome who is always full of energy but never sleeps! Whilst most of the time I love her energy, at times it can be a real pain, particularly if I'm tired after a long day or need to sleep before an early start.

Jon's Answer:

It seems as though you have a good relationship with your sister which is always a good start. However, it is important that you look after yourself as well as her. If you don't look after yourself then you may end up taking out your frustration on her. It may be a good idea to talk to your parents or whoever your sister's care givers are to sort out how best to manage your time and when you are and aren't able to help. There is no shame in saying that you need to sleep and look after yourself too. I hope that a clear discussion helps to sort this out for you.

Looking Up

Whenever I tell people about my older sister, Eloise, they usually do not know what Angelman Syndrome is. Once I have explained my older sister's capabilities and limits, it is always nearly met with the same reaction of "poor her". This has always confused me, just because she isn't "normal" doesn't mean that she has any less quality of life.

In actual fact, Eloise is very fortunate. She goes swimming every week, goes to college, has atmospheric classes, has a constantly stimulating home life and always people around her to give her plenty of attention! The list doesn't end there either with the interspersed of theatre trips, monster truck shows and persistent meals out. I always struggle to see how this is "poor her" at all.

Moving on, when I am talking to people the other thing that seems to commonly be said to me is that despite the fact she is older, I'm really her big brother because of her disability and the looking after that she needs. Again, this something that really confuses me.

If people could only see the hundreds of ways that Eloise is and always will be my big sister. Eloise is a master of doing all the "usual" sister things of being a pain and doing things to annoy me, as all siblings do! However, she has also provided me with a very unique way of looking at life.

Having Eloise in my life has always meant that my perspective on life has been a lot more family oriented than most other people, especially people my age. This appreciation for people close to you and that life isn't all about money or careers means that I have gained a key insight into life at a much younger age than other people, if they ever gain that insight at all. You know what? I'm a lot happier for it. Life isn't measured by a trivial notion of personal success but by the happiness caused by the people around you and I am always grateful to my sister for providing me with this outlook.

Finally, and most importantly, Eloise has taught me that life is short and not to worry so much about things! As I have grown up and become a young professional(ish) adult, the stresses of modern life creep in, such as paying bills, performance at work etc. However, Eloise has always been a beacon of happiness and doesn't worry about anything like this at all. She isn't aware of these stresses and horrible things that take place in modern world or even aware of the EU referendum! Eloise just gets on with life with a big smile and very loud giggle. Everyday I look up to Eloise. Everyday I try to be more like Eloise.

Jonathan



Sibling Fundraiser

University of Sheffield History Society Fundraiser

Shortly before Christmas, The University of Sheffield History Society held their annual charity fundraiser and this year ASSERT was very fortunate to be nominated as one of the two charities for the proceeds to be donated to.

The fundraising took the form of an auction and there were many great prizes on offer ranging from football tickets to see Chelsea to bacon sandwich vouchers for the local campus hangover destination – it was unclear which the students attending the event held in higher regard!

The event was organised and run by David Boorer and Alice Clemens who are the social secretaries for the society. David has a sister with Angelman Syndrome and like many siblings has grown up around the condition. ASSERT is therefore a charity that is particularly close to him and which he was keen to raise money for. We are grateful for both the efforts of David and Alice in running this event.

Jonathan Allen attended the event on behalf of ASSERT and confirmed it was a huge success, raising a whopping total of £474.83 for ASSERT.

It has to be said that the total was aided by the very enthusiastic auctioneer, James Hines, whose full on approach to the role ensured that people did not shy away from bidding!

A big thanks again to David and Alice!



My baby sister

My daughter Ruby was diagnosed at 13 months old, when I was 8 months pregnant with her brother Finley. I have to admit it was an incredibly difficult time, especially because at that time we didn't know if Finley was also at risk of having AS. Once I knew Ruby had a deletion and there was no increased risk of having another child with AS I started considering whether we should have a third child. It always felt like an incredibly difficult decision to take, and I wanted to know I was doing it for the right reasons. I didn't want to feel like I was trying to replace Ruby, I didn't want to make our already very difficult lives any more difficult. But mostly I was terrified of being hurt again.

Fast forward 8 years and I finally plucked up the courage to try for another baby. We were a little hesitant, although our lives have got easier because Ruby has calmed down... ok discovered how to use an ipad, and her sleep is much better. However, Ruby is now quite big and physically stronger. She is generally quite a calm relaxed child, but she can be jealous. If Finley has a cuddle with Daddy, Ruby gets right in there, trying to push him out of the way so she can have a cuddle. We were worried she would be jealous of a baby. Anyway, once pregnant I broke the news to my husband first, and then knowing she couldn't tell anyone... Ruby second. A wry little smile crept over her face as she looked at my tummy... then back to the ipad (did she understand? who knows, but I like to think she did).

Baby Amber is now 4 months old, and Ruby has surprised and touched all our hearts (yet again). She absolutely adores baby Amber. She kisses her (I had never seen her kiss before). Plays with her and tries to help change her nappy and dress her. Ok so she is much better at removing socks and hats, and when I say "pass me a nappy Ruby" I tend to get 6 nappies rather than 1. But the effort is there. We do have to be extremely vigilant not to leave them alone together because Ruby can be a bit over enthusiastic playing with her. She has learnt to touch her gently, and that she isn't allowed to try and pick her up. She also wants to push the pram which has to be monitored very carefully. But overall the love that Ruby shows to her baby sister makes any difficulties all worthwhile.

Katie Cunnea



Meet the Experts Q&A

- Jane Farrall

We would like to introduce you to one of our experts – Jane Farrall.

How did you end up working with individuals with ASN?

I started working for the Education Department in my state and pretty quickly figured out that that was my area of interest! AAC became my passion so quickly. Everyone needs a voice!

What is the best thing about your job?

Everything! (Except my boss.)

What is the worst?

Working for myself means I have to do all the admin as well as the exciting stuff.

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

That's a tricky question! Individual clients would be in the 100s. However, these days I work with whole schools and many of the schools have adopted a whole school approach of a robust AAC system within the school as a result of my consultancy.

What is your best/favourite communication story/journey?

There are so many! Some of my favourite ones relate to strategic competence – which

is when an individual makes the best use of the vocabulary they have to get their message across. I love the student who went to food and chose “lemon” and then to verbs and chose “ate” to tell his mum to “laminare” something. Others relate to communication autonomy – such as the student who told us “dad girlfriend fight dad sleep couch”. His Dad was most annoyed he'd told us.

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

Yes. Unfortunately sometimes people want the tool but don't get that they HAVE to model it for it to be successful.

Where can people turn to for advice on starting an Augmentative Alternative Communication system if they can't get on a course or access to a consultant such as yourself?

The Angelman Communication Training series is awesome as you know! That would be my first suggestion – and is a great option for many people supporting individuals with complex communication needs, whether they have Angelman Syndrome or another diagnosis.

What experience do you have with Angelman Syndrome?

I have worked with individuals with Angelman Syndrome at different times over the last 26 years. People with Angelman Syndrome generally have a great sense of humour.



What is your funniest story?

I was working really hard to get a student with Angelman Syndrome to pay more attention to books – but whatever book I tried he just wanted to watch me reading the book rather than looking at the book. After a while I made an electronic version of a book with a recording of me reading it and some small animations to see if I could get him to pay more attention to the book that way. We read it together the first time and then using his AAC system (Proloquo2Go) he told me I could go – and then proceeded to listen to the book over and over again! If he caught sight of me watching he would pause the book and tell me to leave again!

Have you any new projects you are currently working on?

I'm just about to start using eye gaze to look at where emergent students with CCN are looking on a page during shared reading. I'm excited to get started.

You have one hour to spend with anyone you like. Who do you choose? What do you talk about?

This is such a tricky question! But probably Karen Erickson – and we'd talk about AAC and Literacy of course. Everytime I talk to Karen I learn so much. Mind you, Oscar Wilde and Stephen Hawking also spring to mind.

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

Reading

What is your motto for life?

No-one is "too" anything.

What do you always keep in your handbag?

USB memory sticks

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

Assume competence and attribute meaning.

What is your number one tip for a parent?

Assume competence and attribute meaning!

Communication Club

Last year I decided to start a communication club at my daughter's school. After playing around a bit with different formats I have found a format that works really well for me and the kids that come along. (Well I say found, I stole it from Kate Ahern after watching her give a talk about it on YouTube). Each one tries to follow a theme, it's easier for planning and the idea being that we model as much as possible, that is the goal throughout all the different activities. It's still early days but each club improves a little on the last one.

Here is the format –

Hello song

Each person gets to choose a style in which we sing the song

Hello to (name), hello to you, hello to (name) hello

This is always interesting; we have had some tricky ones including library (we sang very quietly) and Cara who is non-verbal so we signed. Without a doubt the most disgusting was my own charming daughter who requested we sing it like we had runny noses, gross but fun.

Story

We then have a book, this is not a guided or shared activity as sadly we don't have

enough time to do that in the session. But we do model “turn the page” and obviously modelling of opinions and things by the parents as we go along is encouraged. A prop can be helpful to maintain focus on the book (although not a multitude of props as it is not a puppet show).

Game or Activity

The book is followed by a game or activity (for example craft); participants chose the corresponding letter to indicate their preference. They have always chosen the game so far but I have both prepared anyway. I follow Kate's rules of not too much mess on the craft.

Music break

After this it's time for a sensory music break. Initially we tried to stick to the theme for the music but as we get to know the children we just play music that they like. Next time I plan to introduce choices using letters.

Literacy Activity

A literacy activity is next and it is usually a predictable chart writing based on the theme. Predictable chart writing has a repeated sentence that everyone gets to fill in with their word.

Goodbye song

Lastly we finish off with the school goodbye song.

If you have the motivation to do something similar I can highly recommend it, it is seriously good fun!

Tracy



Rogue One: A Star Wars Story



Well, what can I say? The last couple of months of 2016 building up to the release of Rogue One were phenomenal. The hype for the film was huge and ASSERT were able to jump on the band wagon and get a huge amount of exposure with the release of our "ASSERT Meets Rogue One" awareness film. If for whatever reason you have not watched this yet then please do search on YouTube and watch this amazing film. It still gives me goosebumps watching it, and I've seen it quite a few times now! It has now had over 26,000 views. Never ever before have we had such an audience where we have been able to teach them about Angelman Syndrome and ASSERT.

As for the main film, this was a huge success. I'm sure a lot of you went to see the film and hopefully you will agree that Gareth did a grand job. I was very lucky to be able to go to LA with my mum for the world premiere and then back to England for the UK premiere. It was a whirlwind few days and something I doubt I'll ever do again. It was an experience I will never forget.

To celebrate the success of the film Gareth kindly "volunteered" (with a bit of persuasion from his sister!) to sign 20 copies of the film which we are going to give away. If you would like to be put in the draw for one of these DVDs please either email lisa.court@angelmanuk.org or send your name and address to our freepost address which is

ASSERT, Freepost, PO Box 4962, Nuneaton, CV11 9FD.

The closing date is Friday 21st July. All names will be put into a hat and the first 20 will each receive a DVD.

Lisa Court



Trivia fact 1:

For the die hard Star Wars fans out there, you have probably wondered where the planet name "Scarif" came from. Well I can explain. Gareth is a big fan of a certain coffee house. One day he was getting his usual drink and they asked his name to write on his cup. His response was "It's Gareth". The person translated that as "Scarif" and that's what they wrote on his cup. Gareth read the name and thought "that's a great name for a planet". So there you go, that's where that came from.

Trivia fact 2:

Did you know that Gareth has a small acting role in his film? It is towards the end of the film and he is only in the shot for a few seconds – but he is most definitely there. If you haven't spotted him then look out when Darth Vader comes to try and retrieve the Death Star plans. One of the rebel soldiers might look familiar! Gareth didn't get a credit for his acting, and his character didn't have a name so Gareth named him "Lever-puller".



Lisa & Gareth at the LA Premiere

Florida



“You’ll NEVER get me on a nine hour flight with Harvey,” were the words my husband used when friends said that the Starlight Children’s Foundation was going to send their family, including their severely disabled daughter, to swim with dolphins. We didn’t imagine that it would ever be possible to fly to Florida with our own 18 year old, extremely mobile, challenging and hyperactive son, Harvey. It took a few years for our friends to persuade us to attempt such a holiday, but eventually we plucked up courage to apply to Starlight. To our amazement our request for a family holiday was approved, even including two absolutely essential carers to accompany us. Before we had time to think about what we’d got ourselves into, the flights were booked.

Starlight were sending us to Give Kids the World, a wonderful, specially built, quite surreal, 79 acre, non profit, resort in Kissimmee, Florida. After a lot of debate we decided to travel in June despite the fact that it may be very hot and humid.

Starlight also gave us tickets for all the theme parks and for Discovery Bay where we were to swim with dolphins. It was going to be a trip of a lifetime for the family, especially for the children, but our main concern was how we would survive two nine-hour flights. Harvey has arms like an octopus and doesn’t sleep well at the best of times, but his consultant couldn’t have been more helpful; she approved our application by telling Starlight that our family were ideal candidates and she couldn’t have done more to help us prepare for the flight. This even involved weekly visits to our house on Saturday mornings to drop off various different concoctions of medications for us to try in order to calm Harvey enough for such a long flight. Unfortunately, even after weeks of trying, none of the new medicines had the calming effect we were looking for and I was beginning to panic. The consultant said that the drugs we had tried would normally knock out a large man, but they did nothing to Harvey. In the end the consultant temporarily increased Harvey’s normal medication, Clonidine, combined with Melatonin, at carefully worked-out times during the flight and we kept moving seats, taking turns to eat, sleep or entertain Harvey. Despite our worries the flights were manageable.



The trip was a massive success, despite sleepless nights. Harvey thought that all his Christmases had come at once. All the food and ice cream he could eat, a different theme park each day, swimming and water play late into the balmy evenings, even an air boat ride looking for alligators. A highlight of the trip was Discovery Cove where we swam with dolphins, but unfortunately Harvey didn't understand that he needed to stand still waiting for the dolphin to swim past. We couldn't stop him splashing and drinking the salty water while trying to poke the dolphin's blowhole, but a very helpful and extremely strong life guard was on hand to help with the difficulties and helped us hold Harvey. We at least managed to stop him kicking the dolphin, but Harvey really preferred floating in the warm current around the winding river which was absolutely beautiful.

June turned out to be an ideal time to go. It was hot in the middle of the day, but not too hot and we could swim at 9.30 in the evening, which was an ideal way to entertain Harvey. We had a few very heavy rain showers, particularly one afternoon, but it rained less than I thought it might.

Our only problem was the nights; Starlight had arranged for us to have locks on the bedroom and ensuite doors, but Harvey soon figured out how to open them and on the first night I woke to find him trying to get out of the front door at 3am, luckily I'd put the chain on the door, otherwise we may have found him in the lake opposite our villa. Even with someone sleeping in the same room, Harvey would get up in the night and quickly get into danger in the open-plan kitchen and front door area without waking anyone. So my husband put a mattress on the floor blocking the bedroom door and tried to sleep, but he was woken many times each night with Harvey trying to escape.

For Harvey the best thing about the trip was that the whole family were together. Harvey even had his two favourite carers, Nicki and Louise, taking turns with us to help him during each day - we certainly couldn't have coped without them. We had a fabulous time and want to thank Starlight and Give Kids the World for an amazing experience.

Anyone can refer a child to Starlight for a wish: parents, grandparents, medical professionals, friends, social workers... simply complete the Starlight wish referral form. <http://www.starlight.org.uk/> (Note that during the application process you'll need a letter from your consultant to prove eligibility).

If your application is approved, the Starlight Foundation ask the child and their family for three wishes, one of which will be chosen, however only one of the wishes can involve a trip abroad.

Starlight aim to create a truly magical experience for the child and his or her family, exceeding all expectations and creating precious, unforgettable memories to share, laugh and smile about. They deal with every organisational detail and ensure that no additional burden is placed on parents.

There are also other similar wish foundations including Make a Wish Foundation.
<https://www.make-a-wish.org.uk/>



Diane Fox-Jones

Buying/Funding for Equipment

Tips for funding or purchasing specialist equipment

There's no doubt that most individuals with Angelman syndrome will need some degree of specialist equipment. Some will need lots of it. Only time will tell what, if anything, your child will need and adopting a wait and see attitude, rather than trying to plan immediately after diagnosis for every future possibility for your child, will save you a lot of time, worry and expense.

If and when you decide the time has come to furnish your child with additional equipment, there are a vast array of products available to help you and your Angelman individual.

From the basics of specially designed forks that can be held by the shakiest hand and unspillable* plates and cups, to high tech wheelchairs (my sister showed me a wheelchair recently that could go up steps. Backwards. By itself. I never thought I'd hear myself say I 'wanted' a wheelchair for my son, but if you have to have one, that one was pretty awesome), hoists and safe, secure beds for all that sleep they don't have. Monitors to measure oxygen levels, observe seizure activity and just how exactly they are making that weird banging noise in the middle of the night. Communication aids, special toothbrushes, personal care equipment. Modifications to your home, such as ramp access to the front door, wider doorways for wheelchair accessibility, a driveway for safe access to the monster size car you now find yourself needing. Double bannisters on the stairs, or a through-floor lift or an extension to house a downstairs bedroom and/or a wetroom. The list goes on and new products and technologies to enable and assist people with disabilities of all kinds are arriving on the marketplace faster than ever.

***Note:** Angelman children are notoriously curious, and determined. I believe several have been testing the unspillable plates and found them to be perfectly spillable. Much to their delight.

In an ideal world, all of this would be free, but sadly, we don't live in that world. Adding the terms "special needs", or "disability aids" is tantamount to adding several ££££s to the price, often out of the price range of most of us. Most of us won't win the lottery, find a hitherto unknown rich relative or carry out a bank robbery. But there are some options around to ease the burden.

1. Don't be afraid to ask

Gifts for our AS individuals can be difficult. I can't tell you how many shape sorting toys which flash lights and play tunes we've been bought for our son over the years, or how much I've cried over each one, because my son couldn't even pick up the shape, let alone sort it and post it correctly. Ask instead for monetary donations towards a specific item, or even, if it's not too much and you're comfortable with it, for the item itself.

2. Ebay/second hand websites

There are many second hand buying/selling/swap websites and social media groups available. Your AS person won't care if the new equipment isn't brand new (although anything wrapped in cellophane is a big bonus in our house!) and second hand, or reconditioned equipment can be excellent quality, particularly for very expensive items such as iPads.

[NB Please make sure to use reputable web sites/sellers. There are some that are better than others and some that should be avoided at all costs. If something looks too good to be true, it probably is. Don't be afraid to ask for an opinion of a site in closed groups on social media.]

3. Council funding

Your local council may have an occupational therapist on its staff who will come and assess your home for any adaptations that may be necessary. These may be simple ones, like building a ramp to your front door, or large projects like money towards refurbishing a bathroom to a wetroom, etc. A disabled facilities grant will not be means tested if the disabled person it will benefit is under 18. Please see <https://www.gov.uk/disabled-facilities-grants/> for more information.

If you are funding your own building project to benefit your Angelman individual (for example, building an extension with level access rear doors so that they can access an enclosed back garden by themselves/provide a downstairs bedroom and/or wetroom), ask the council OT to write a letter to the planning office on your behalf to waive the planning fees: <http://www.legislation.gov.uk/uksi/2012/2920/regulation/4/made>

4. Applying for grants

There are lots of different types of grants out there that you can apply for, or your social worker can apply for on your behalf.

Some of the main ones are Newlife (<http://www.newlifecharity.co.uk/>), Family Fund (<https://www.familyfund.org.uk/>), Variety (<https://www.variety.org.uk/>), Roald Dahl Marvellous Charity (<http://www.roalddahl.com/charity/family-grants>), or the Caudwell Foundation (<http://www.caudwellchildren.com/>). A really useful website is: <http://www.disability-grants.org>. There are lots of different types of grants listed here, by region or grant type (eg adult or child, holiday, respite or home adaptations, etc).

Whether you are writing your own grant application, or asking someone to do it for you, there are a few things to bear in mind first. Although there are lots of grants available, there are many more people seeking funding than there is money to go around. Approximately 10% of all grant applications received are funded. It is therefore really important that you make a good application and it will require a bit of time to do it.

Here are some things to think about before applying:

- i. Check that it is the right grant for your needs and you meet the grant criteria. Is your AS individual the right age for the grant being offered, do you live in the correct area, does the funder provide money for the thing you want.
- ii. Make it clear why and when you need the money.
- iii. If you're not sure about whether the grant is right for you – just ring and ask. Don't guess and get it wrong.
- iv. Be brief, don't waffle.
- v. Ask someone to check through an application before you send it to check for spelling mistakes. Remember, a spell-checking tool on a computer isn't as good as a human eye – it can't tell the difference between "red" and "read", for example.
- vi. Read the whole application before you begin and make sure you clearly answer all the questions.
- vii. Allow plenty of time. It takes longer than you think to write the application and you need to allow 3-6 months for the application to be processed. It is almost impossible to get funding for something you have already finished, or already started.

Andrea Baines



When Andrew stopped eating....

Back in May 2016 we noticed a decline in Andrew's interest with food, he would turn his nose up at everything, gag and even make himself sick at the sight of food, now this is the same boy who would eat his own massive plate of dinner then seconds and then even some of mine, the boy loved his food, we also noticed he wasn't sleeping very well at night and would be awake more than usual for a child with Angelman Syndrome. We took Andrew to the GP where we were told he is ok and just being fussy and to persist with feeding. By the July 2016 Andrew was looking pale and very thin again we took him to the GP who weighed him and discovered he had lost 10lbs and it was then Andrew was sent to A&E for blood tests to see if we could figure out why he was refusing to eat and if it's something we could easily fix. Now we are at the end of Aug 2016 and by now our boy has had a handful of admissions to the Glasgow Children's Hospital and yet we are still no further forward other than Andrew's medical team wanting to put an Nasogastric Tube in, this is something as a family we were completely against as we knew they had no hope in getting that tube into Andrew and even if they did it would be out in twenty seconds flat, this is when Andrew was put on a build up milk Ensure, that he was to drink 3 times a day after 4 weeks he had gained an impressive 3lbs and all seemed to be on the up, sleeping was still an issue but as long as he was gaining weight we were happy.

As the months went on Andrew started to gain weight at a much slower pace, this was ok as he was at least gaining something our biggest concern now was that his immune system was becoming weaker and he was picking up every bug going around, from the common cold to hand foot and mouth then an ear nose and throat infection, plus his epilepsy and sleep was still causing an issue. On the 28th of December after months of no sleep we finally had a sleep clinic appointment.... or so we thought! 5 mins into the appointment the Doctor wasn't happy at all about Andrew's appearance as he looked painfully thin, we were lucky if he was taking one Ensure build up milk a day, a weight check later and Andrew is admitted onto a ward for emergency Peg surgery!! This was a shock for us we hadn't prepared ourselves for this. We came to the sleep clinic and now all of this was happening, we had no idea what a peg would mean for us as a family, what it would mean for Andrew and his future, and the thought of putting him to sleep for surgery made me sick to my stomach as he's not got the best track record with surgery and his epilepsy, usually comes round having had numerous seizures and will continue to do so for days. After a chat with Andrew's medical team the next day they decided they would need to get his weight up slightly for surgery so we would have a long stay in hospital. Bringing in the new year with my boy in hospital isn't exactly what I had planned but I knew from here on in 2017 would be Andrew's year to get healthy.

The 31st of January rolled round and it was surgery day for Andrew, he was in and out in under two hours with slight seizure activity that lasted a few days, 24 hours of no feeds then our boy was ready to get fed, Andrew took to the peg immediately he was showing signs of enjoyment of being full, he was happy and back to his usual smiling self he had clearly missed having a full tummy, myself and my husband Nicholas were trained on peg feeding and a week later Andrew was set to go home! We where so happy to have him home and try and get his feeding routine in place, Andrew requires 9 feeds a day a mix of Ensure and Water feeds, he has a safe swallow so can take orally if he wishes, which he did!! There was no stopping him he was eating away and enjoying food, his tummy was growing and he was feeding well via peg too, his medical team where amazed that he was eating orally for the time in about 6 months, he was starting to gain weight and sleep slightly better. We as a family got a massive shock as to what peg feeding was all about, timed feeds meaning we had to be home to feed every couple of hours as he can't feed sitting up and absolutely nowhere has facilities to lie him down and be fed, this for us was a big issue as we could no longer go out on family days and even now a few months later we are still to figure that out, we do have an appointment at the wheelchair clinic in a few weeks so hoping we can get his a chair with a slight tilt so we can feed out and about.

Getting a peg for Andrew has been the best thing we could have done, even though just now we are struggling and he's back to not taking anything orally and has lost all the weight he had gained we are sure he will continue to gain and feel positive that we have done the right thing for him, we are no further forward as to why he suddenly stopped eating and will probably never find out, his medical team think he just went off food and will more than likely be peg fed for the rest of his life. Andrew is now on the emergency list of an EEG as his medical team think he is in status and this could be the issue with his poor sleep. It's been a rough year for Andrew and looks like it won't get any easier anytime soon but he has coped so well as have my other two boys Darren and Jack, I don't think we could have done this without the help of our amazing friends and family. Our only wish is that we had got Andrew the peg sooner than later but we can't change that. We are just happy that we now know he's going to bed on a full tummy and for now we are doing all we can to make sure he's healthy as can be. Our boy has a long way to go but we know he will get there eventually.

Catrina Fraser

Mum to Andrew, 14



Angelman Syndrome and Vision

School bus – why a step back can be a step forward

Travelling to and from school on the bus has been a journey full of twists and turns in more ways than one. After beginning with some separation anxiety when first starting school, everything went well for quite a period. We used a Crelling Harness, due to travelling issues in the car before she started school when she just wouldn't keep her seatbelt on, and Leia went on to and got off from the bus without any fuss. After a while this broke down again, we got to the stage of having to physically man-handle Leia onto the school bus every day. This before then being transferred to the car.

Even when she was going to activities that she loved (horse riding) or visiting people that she loved (Gran) it was a struggle to get her into the car. It took me (us) a shamefully long time to realise that Leia was communicating with us very strongly that she didn't feel the need for the harness any more. This was in the days before we introduced modelling and full language systems so the only way she could communicate this was through her behaviour. She had been talking to me for months and I hadn't been listening. It took a little persuasion with the school that this was indeed what Leia was after. I understood their reluctance; it is much easier for me as a parent to say you can just try it than it is for a school bus to accept the responsibility of a pupil who may well not be safe if she won't be in a seatbelt. However, Leia responded very well, she had been right, she was ready to sit in her seat without a harness. This period of harmony was followed by the bus escort leaving, again some discontented behaviours followed on the bus - just getting to and from, not actually whilst on the bus. Then the wonder years, I do wonder if this was our very own Mary Poppins. Susan the most lovely of people was the escort on the bus. Leia was for the first time ever eager to go on the bus.

Sadly all good things must come to an end and Susan left. So we were back to the whirlwind of different escorts. Leia once again became unhappier on the bus, leading over time to Leia getting out of her seat whilst the bus was moving. This led to added angst between her and the bus escort, which led to Leia being less happy and her behaviour getting worse on the bus. She often wouldn't go to the bus in the morning and on a few occasions the bus couldn't wait any longer for her so we had to take her to school making us late for work.

After one such morning I phoned the school and asked for a meeting when I took Leia in, I wanted Leia to be present so see if she chose to help us understand the problem with the bus. Leia came to the meeting and we asked her if she liked the bus she said yes, she liked her friends. Was there anything she didn't like about the bus. No she said, then changed her mind. Yes waiting. The bus times had been highly erratic in the lead up to this event, including that morning when Leia had been waiting outside in the cold for 25 minutes for the bus. That along with some other parent's irate phone call led to the bus getting a regular driver and the bus times being more consistent. Again this worked for a while before the bus became a problem again.

We tried social stories and reward charts but they only had transient positive effects. Eventually the school phoned and said they were going to get a harness for Leia, she had become too unpredictable, unsafe and upsetting for some of the other students on the bus, leading to further behavioural disruptions. I expressed my concerns that a harness was not going to get Leia on to the bus any easier. However, the Health and Safety rules from the council stated that she must go back to the harness, so we had no further option.

However, Leia really took to the harness again and has been settled on the bus ever since. She can still sometimes be reluctant to get on the bus but in general it is a marked improvement. With hindsight I can look back and reflect on why the harness has this time been successful. I think the changes in the bus had made Leia get very anxious, the disruptive bus times were increasing this dramatically, the unpredictability meant that some days Leia had a long time in the morning to worry about going on the bus before it arrived. This led to heightened anxiety for Leia and the bus escort, they were then feeding off one another. Plus Leia knew that with her heightened state of anxiety her body couldn't cope and therefore no matter how much she wanted to stay in that seat she just couldn't. A very negative spiral of behaviour and anxiety feeding off one another. So what did the harness do? It meant that no matter what her anxiety levels she knew she would remain safe in her seat. This then led to a calmer bus environment which then further reduces anxiety.

Now we are not naïve enough to think that this will work forever but for now the bus journey is working again. Hopefully as we understand Leia's anxiety more and as her communication improves then we can resolve issues quicker in the future.

Tracey Campbell

Sian & Euan

New Shoes

Euan has never been keen on wearing shoes. If he can be persuaded to put them on they can be off again within minutes of going out in the car. He's so flexible that biting through tightly tied laces seems to be a minor inconvenience. Lots of time and effort has gone into making sure that Euan leaves home and college wearing shoes, even if they are off in between, and he rarely arrives home with them on. We've tried various styles and makes but the only footwear that Euan will tolerate are a good old pair of Pedro boots. You can keep your DMs, Timberland and Converse as far as he's concerned.

Because of Euan's preference to be barefoot his shoes last a long time but in January I realised they really were looking very battered and worn so I rang the podiatry department of our local NHS Trust, discovered that remarkably Euan was still on their books and made an appointment. On the day we (both) turned up wearing shoes –Hurrah! Shoes off to measure Euan's feet, new boots ordered with an estimated delivery of 3 weeks, and we left the clinic in a hailstorm with only one of us wearing footwear.

A few days later Euan had one night in respite. Our failure to find appropriate local respite since he moved to adult services 4 years ago had led to us trialling a facility out of area. We had already had a few issues with the service but the final straw was that he arrived home on this occasion with his shoes having been put in 'a gentle 30 degree (machine)



wash' and then left to dry on a hot radiator! We've always gone for a rub over with a damp cloth and a spot of polish every now and then but maybe that's old-fashioned. Needless to say the shoes were totally ruined and Euan was shoeless for two weeks in chilly February until the new pair arrived.

So, new shoes arrive and the battle to get Euan to wear them commences. After about a month things were just about back to normal. Phew! Until... Saturday morning we are getting ready to go out but can't find Euan's shoes. Eventually the only explanation seemed to be that after Euan had taken them off in a café when out with support workers the previous day they had been left behind. After making enquiries it was clear that the shoes had disappeared. We now have another 3 week wait for a replacement pair. Thank goodness for milder weather and the moral of the story is to order 2 pairs.

Conference 2018!!

Save the Date – the family conference for 2018 has been booked for Friday 10th to Sunday 12th August 2018.

We have listened to the feedback given and we have moved the date of the conference to be in the summer holidays so that you do not have the issue of travelling back on the Sunday and back to school on the Monday for those families in the UK, and already being back at school for those families in Scotland. The August dates mean that all areas of the UK will still be on their school holidays and therefore there isn't the issue of a long drive home and school the next day. These dates are being announced now so that if you do want to book a summer holiday as well in 2018 you can ensure it does not clash with the conference.

BOY BITES HORSE

NOTES FROM AN ALTERNATIVE CHILDHOOD

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

Overcome with Emulsion

So there I was in this enormous warehouse place, more brightly lit than the sun and stuffed from floor to ceiling with, well, stuff.

It's one of the most brilliant places in the world! Tons of space to run around, loads of places to hide, bright lights, lots of people, noise, and stuff of every size, shape and colour: sharp stuff, spiky stuff, sloppy stuff and sticky stuff – more interesting and fun than I could possibly imagine in my wildest dreams.

And I was strapped into a chair.

What's that all about? One minute I'm at home, politely asking – slapping your hand on the front door's glass works well – if we might go out for a bit of a run around. So me, Frowny and Giant Lady (I'm not kidding, she must be at least 9-foot-tall) all piled into the car, drove straight past the park, past the swings, past the swimming pool and ended up here.

I'm not absolutely sure where 'here' is. Frowny said something to Giant Lady about mixing paint but I don't see why she'd need to drive all the way over here for that; we've got loads of tins at home and I would have been happy to mix them all up for her.

I was soon starting to get a bit annoyed. It was obvious that they'd completely forgotten to undo the straps so that I could have a run around and a bit of an explore, and now they were just ignoring me, which was just plain rude.

I tried to get their attention with a few loud noises and a bit of shouting, but all I got in return were a couple of nice smiles and some soothing noises. Honestly, sometimes Frowny's communication skills are seriously lacking.

Lots of wriggling sometimes gets the message across but it's a bit

hit-and-miss: if you get it wrong you can easily end up sprawled across a shopping aisle with a strap around your chin and your arms tied above your head. Not a good look.

So when all else fails I resort to bouncing the whole chair. I don't usually have a very good memory but one thing I do remember is that pushchairs used to be enormous and I was really small, so trying to bounce them was almost impossible. But fashions must have changed because now I'm really big and most of the pushchairs are tiny, so these days I can bounce them around like a space hopper.

The aisles in this place were really wide and I was in the middle, just out of arm's reach of anything to fiddle with. So while Frowny and Giant Lady chatted to each other about paint (get a life), I had a bounce around to see if I could reach anything interesting.

I was tempted by a rack of brightly coloured squeeze tubes, but ultimately I always think size matters. So I headed straight for the towers of giant plastic tubs. A few bounces was all it took to be within toe-reach of the tubs, then I stretched my leg out as far as I could and managed to hook a shoe under the wire handle of one of the really big ones with '10L' written on the side. I was just pulling it towards me for a closer look when, for absolutely no reason whatsoever, the tub thing decides to crash to the floor and burst open.

Whoa ...

I've never seen so much blue paint in my life! In fact, I'm pretty sure I've been in swimming pools that had less liquid. It was all over the floor, on the shelves, on my shoes, up my legs and on the chair.

This was a lot more fun than I'd bargained for but hey, never look a gift horse in the mouth (I have absolutely

no idea what that means). So, still strapped in the chair, I stretched out both legs, leaned both arms over the side and got stuck in. Literally. It was sticky and creamy and slimy and smelt very, very, blue.

As if this wasn't enough fun for one day, Frowny and Giant Lady both started furiously rummaging in their bags and pockets, producing nothing other than a tiny little tissue, then decided to join in as well – taking the game up a notch by adding in some very impressive dance moves. At first Frowny started rubbing the tissue all over my fingers which seemed a bit silly when there was so much paint on offer elsewhere. But maybe she didn't really like the splashy-painty-game because she soon ran off for a game of hunt-the-tissue while Giant Lady decided to stay and hold my hands above my head.

Of course, Frowny's a world-class champion at hunt-the-tissue and she soon came dashing back trailing a long blue piece and got straight back into the rubbing. Loads of people had walked past by this time and I couldn't believe none of them wanted to join in. But of course today's grownups have a really short attention span so they soon tired of the game and decided it might be more fun to paint blue lines on the floor with the wheels of the chair.

Then a quick trip to the toilets (and a lot more furious rubbing. What is it with Frowny and all the rubbing?), back into the car and home in time for tea. An afternoon well spent I reckon.

P.S. We brought lots of the blue paint home with us to show Smiley (on the chair, the car, the shoes, and lots of the clothes). And then he spent his whole evening in the downstairs bathroom, scrubbing away at something or other and practicing all the rude words he knew. Weirido.

ASSERT are registered with EasyFundraising. This is a great way of purchasing items online and automatically making a donation to our charity. There is no extra cost for you here, and it does not take any more time. So there is no reason not to do this! Please visit the website and register. Going forward, any eligible purchases can then be done through EasyFundraising and ASSERT will automatically receive the donation. This has to be the easiest way of donating to ASSERT without really doing anything!

For more details please visit the website:
www.easyfundraising.org.uk



Useful Websites

Support

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

Blogs

- www.boybiteshorse.co.uk

Pre-loved equipment

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

Clothing and other equipment

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

For iPad/apps

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

Legal

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

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

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

STARS a Clinical Trial in Angelman Syndrome – Ovid Therapeutics

Those of you who attended our Scientific conference in Liverpool might remember Matthew During's presentation on gaboxadol and his hopes for a clinical trial to look at its effectiveness in Angelman Syndrome. Ovid therapeutics is now enrolling participants in the USA for this clinical trial. The trial, called STARS, aims to look at the safety and effectiveness of gaboxadol (now called OVI01) on various symptoms of Angelman Syndrome, such as motor function, behaviour, seizures and sleep issues.



Gaboxadol was first considered as a therapeutic in the early 1980s. It was studied as a painkiller and for treatment of anxiety, but also as a treatment for tardive dyskinesia, Huntington's disease, Alzheimer's, Huntington's and spasticity. Due to reports of its sedative effect, in 1996 pharmaceutical companies Lundbeck and Merck started a series of clinical trials to test gaboxadol as a treatment for insomnia. Despite progressing to phase III clinical trials the drug was dropped by the companies and in 2015, Lundbeck sold its rights to the molecule to Ovid Therapeutics, whose plan is to develop it for fragile X syndrome and Angelman Syndrome.

The drug, OVI01 is thought to help the brain decipher information it receives from a person's senses. We live in world that constantly bombards our bodies with sensory information. People with Angelman Syndrome struggle to isolate important information in the world around them, and instead their brain becomes overwhelmed with information (I know I don't need to tell you how poorly people with Angelman Syndrome cope in an overly stimulating environment). OVI01 is thought to work by reducing the over stimulation of the brains' cells.

STARS, the current clinical trial will enrol approximately 75 adults with Angelman Syndrome. Some of the people taking part will receive OVI01 and some will receive a placebo (fake treatment). No one, including the study team, caregivers or participants will know who is receiving the medicine and who is receiving the placebo.

If results are promising Ovid plans to test the drug on younger patients, and eventually in other countries. It will be interesting to see how this progresses, and we will of course keep you updated.

For more information go to <http://www.angelmanstudy.com/>

Katie Cunnea

Science and Research Trustee

Katie and Grandad – In memory of Frank Dale

Katie was diagnosed with Angelman Syndrome when she was 2 years old. She went to a brilliant school in Chinley, Derbyshire, until she was 19. Katie is now 23 and lives in a transitional home, not far from where we live. She returns home every week for an overnight stay but is always ready to go back as it is far too boring at home as there is not enough happening!

Katie is full of fun and mischief and is very sociable, she enjoys being in the hubub of things. She had a special bond with her Grandad and spent a lot of time with him when she was younger. Grandad loved nothing more than coming to our house and having a good chat with Katie. She would also often visit Grandad's house, which was only next door.

She particularly loved riding on his lawnmower and was always laughing and giggling as she travelled around the garden. Grandad would drive her anywhere, she really enjoyed going out and about in his car. He would often be seen going to the village shop to get toffes or sweeties for Katie. They both enjoyed these, like Katie, Grandad also had a very sweet tooth. Grandad was a very important part of Katie's life and he will be sadly missed.

Caren Dale



MG Trophy Championship

ASSERT were nominated as the charity of the year for The MG Trophy Championship. One of their drivers Tim Martin is a member of ASSERT, his son William has AS. Tim put our charity forward. Andrea kindly went along to collect a cheque for £300 from Pete Macwaters. The MG Trophy Championship have selected ASSERT again this year, and we will have more donations which will be listed in our Autumn newsletter.



Dear ASSERT

On Thursday 20th April 217 at our house we held a fundraiser raising money for ASSERT and Newlife Charities. ASSERT is the Angelman Syndrome charity which Daniel has, and Newlife is a charity which helps families in need. They helped us by buying Daniel a new bed which cost £7,800.

We had lots of stalls, including ASSERT merchandise, tombola (we donated most of our Easter Eggs to this) bran tub (we handmade cones of sweets and chocolate) book stall, raffle, teas, coffees, and lots of cakes which we baked the day before.

We worked really hard and had great fun. We had 46 people and 1 dog come to our house!

Here are some photos of our day.

We made an amazing £205.82 for you!

Yours Sincerley
Hannah and Rhiannon Hewitt



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...

Fundraising:

| | |
|------------------|---------------------------|
| Jack Winder | - J Skydive |
| Julian Munsey | - Syresham Fundraising |
| Scott Jones | - London Marathon |
| Gavin Smith | - London Marathon |
| Clare Collins | - London Marathon |
| Sarah Brown | - London Marathon |
| Duncan Cottrill | - London Marathon |
| Helen Bly | - London Marathon |
| Jane Tunbridge | - London Marathon |
| Lisa Cutts | - London Marathon |
| Carl Derbyshire | - Spring Wolf Run |
| Caroline Bennett | - Brighton Marathon |
| Andrew Woods | - Liverpool Half Marathon |

Donations!

| | |
|---|----------------------------|
| Hazel Tait | Gavin Henderson |
| Yvonne and Wendy (Helen Edwards) | Christine Manley |
| Aplomb Day Nursery | Ryan Donahue |
| FDC Emerging and Radical Designer Awards (Joanna Marcella Reid) | Stephen Roberts |
| Stu-Nique | Gordon Ward |
| In memory of Mrs Biggs | Angus Watt |
| Hansons Auctioneers | Greig Robertson |
| Great Doddington Primary School | Alex Damon |
| In memory of Mr Hedley Dowdle | Marian McCullough |
| In memory of Mr Frank Dale | Jamie Rose |
| David Morrison @ The Tuckshop | Deborah Welland |
| Hansons Auctioneers | Humber Learning Consortium |
| In memory of Mr George Robins | Emma Waite |
| The House Communion Fellowship | Rosemary Meadows |
| Neal Turk LLP | Lisa Lea |
| Mr & Mrs Pickering | Christina Cook |
| Kilbowie Primary School | Kjell Melmer |
| In memory of James Myers | Jennifer Crossley |
| Mr & Mrs Simpson | Julie Atkins |
| KBC NV London | Robert Brashier |
| Jane Baker | Amelia Coffen |
| Graeme Patterson | Celia Partridge |
| CCVTM / OVG | Paul Copner |
| Audrey Sinclair - London IAD Donations | Adam McDonaugh |
| Donna O'Driscoll - South Wales IAD Donations | Bert van den Bedem |
| The MG Trophy Championship | Paul Hughes |
| Kelly Kembery | Elizabeth Ford |
| Sarah Duffy | Claire Pine |
| Ruth Curbishley | Marilla Hills |
| In memory of Mrs Avis Simpson | Noel Protheroe |
| Jesters Scooter Club | Ross Warren |
| Jolly Chippy | Pete & Mary Williams |
| Brownhill Insurance Group | Peter Mullen |
| Coastline Harmony Chorus | Stephen Roberts |
| In memory of Bo Godfrey | Alexandra Caven |
| In memory of Gil Fieldhouse | Charles Eickenhorst |
| Friends and family of Molly Duffy | Ben Dalton |
| Morgan Ceramics | Jan Campbell |
| EDF Energy Scottish Staff Charities Scheme | Robert Brashier |
| Yara Pocklington | Navjeet Dhariwal |
| Gillian Murray | Ellen Walker |
| Roger and Madeline Ashton | Alex Clapton |
| Mr & Mrs Turner | Heather Dobbs |
| Coastline Harmony Chorus | Dominic Munsey |
| CMS Cameron McKenna Foundation | Zoe Alexander |
| Warwick Preparatory School | Alison Clarke |
| In memory of Mr Albert Godfrey | Joy Davidian |
| Charlotte Hamilton | Susan Laybourn-Morris |
| Helena Bannister | Lisa Mcdermott |
| Dukinfield Golf Club | Michelle Howarth |
| Benevity | James Dickens |
| Mr & Mrs Barratt | Andre Hoehl |
| Hook Heath Artisans Golf Club | Sophie Edeson |
| Wayne Chretien | Andrew Brown |
| SIG Trading Ltd (Carl Derbyshire Employee matching) | Maame Djan |
| In memory of Mr Thomas Pyne | James Laybourn-Morris |
| Hannah & Rhiannon Hewitt | Andrew Marshall |
| | Karen Cutler |
| | Daljit Sahota |
| | Hannah Heerey |
| | Stefano Liotta |



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Thank You!