

# hello

angelman   
support education research

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AngelmanUK Family  
Conference 2018

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AngelmanUK 25th  
Anniversary Ball

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*"Model AAC with me!"*  
Another way to talk  
while you play

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Sensory Detective

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Days Out and  
Holiday Top Tips

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Great North Run  
report

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**#63**  
autumn 2018

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# hello

They say time flies when you're having fun...and haven't we had a fun year! Christmas is already here and the new year is fast approaching. Kicking off our anniversary year we had our regional events to mark International Angelman Day (IAD) 2018 and the trustees are busy planning our 2019 events. We hope that as many of you can join us as possible. IAD is an initiative started by the international organisations to raise awareness of Angelman Syndrome across the globe. It is an opportunity for people to meet other local families, socialise and raise local awareness through newspaper articles or radio interviews. The dates and venues for IAD 2019 will be posted on our social media accounts and sent out by letter to all our members.

Our family conference in the summer was a huge success as always. We had some amazing speakers, some of whom were new to us such as Becky Lyddon from Sensory Spectacle as well as welcoming old friends like Professor Bernard Dan back once again. On the Saturday night we had a fabulous party with dancing, balloons and mocktails for the children! (I'm sure the grown-ups enjoyed a few glasses of prosecco instead!) It was lovely to see our children and loved ones with AS dressed up to the nines to party the night away and a huge amount of fun was had by everyone (see p4-5 for our full conference report). The 2020 conference has been booked for Friday 28th-Sunday 30th August 2020, so you have plenty of time to make arrangements if you plan to attend. We can't recommend it highly enough – it's an amazing weekend.

25 years is a huge milestone for any organisation, especially one dedicated to raising awareness of a newly recognised rare disorder. We celebrated in style this year with our 25th Anniversary black tie Ball on November 10th at The Forest of Arden Country House Hotel. Live music was provided by *The Sunshine Soul Revue*, we had a silent auction and a fun casino! Special guests this year included Mr Samuel and Mr & Mrs Jones, relatives of Dr Harry Angelman. Coincidentally, a member of their extended family has recently received a diagnosis of Angelman Syndrome. What a small world! See pages 8-9 for photographs of the evening.

A huge thank you must go to our fabulous fundraisers – we couldn't do what we do without your help and support. If you are hosting an event or fundraiser please contact us to see what newly designed merchandise we have – balloons, hand clappers, wristbands, car stickers and collection boxes or even running vests if you're feeling brave – we have lots of things to help you raise money AND awareness.

We would also like to welcome our newest trustees on board – Jenn Smith and Emma Goodson are known to many and will be finding their feet in the coming months. To round up our momentous year we will soon be having a super-duper website to match our fantastic rebranding. Keep an eye out for the release date - we hope you like it!

**Rachel Martin, AngelmanUK**

# save the dates

The dates for two great AngelmanUK events have now been arranged. Members will be receiving a written invitation and booking information for all our events, but until then please make a note of the dates in your diary so that you can plan around them. You won't want to miss them!

## communication conference

11-13 october 2019  
Hilton Hotel, Coventry

Communication at all levels is one of the biggest issues for our families.

Our first Communication Conference in 2017 was such a great success that we're making it a regular event.

## family conference

28-30 august 2020  
Hilton Hotel, Coventry

You can read all about this year's family conference on pages 4-5. If you missed it this time round, you'll want to make a note in your diary.

**useful**  
information

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PO Box 4962, Nuneaton  
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**Helpline** 0300 999 0102  
**Email** support@angelmanuk.org  
**Website** www.angelmanuk.org  
**Shop** angelmanuk.org/spreadshirt

**Cover photo** by Rob Chadwick  
Please note that all opinions and views expressed by contributors are personal and not necessarily those of AngelmanUK.

*Dear Jon is an anonymous problem page for siblings, giving them the opportunity to seek advice on issues they face in dealing with their brothers and sisters who have Angelman Syndrome. Your questions could also help other people who might be going through similar issues.*

Jonathan Allen  
Sibling support



## Dear Jon

*I sometimes find it tricky when I am at home as the activities that we do depend on what my sister with Angelman Syndrome wants to do, even with watching TV shows.*

## Jon says

I would suggest that you think about the activities that you both enjoy as a good basis to go from. That way, when deciding what to do you can suggest something that you know you will want to do. This is even relevant to TV shows as hopefully there will be some overlap in shows that you like to watch.

If it is a situation where your sister is doing something you don't necessarily enjoy, then if possible, perhaps just do a different activity for a while and try and do something you both enjoy later on. Hopefully you can find some common ground in the activities you both like and it means you can bond further as siblings.



## Dear Jon

*I am frustrated that often I feel I need to be at home for my brother, who has Angelman Syndrome, but I sometimes feel very frustrated by how much work it takes to look after him. I also feel bad about this.*

## Jon says

First of all, you should never feel guilty about your emotions. Living with someone who has a disability is difficult and there is no shame in admitting that it is frustrating. A good solution I have always found is to take say an hour or even half an hour at the end of a day just to do something you want to do on your own. Whether it be watching a few TV episodes or reading a book. This helps to unwind and you are just taking time for yourself.

Alternatively, you may find getting out of the house is also a good solution. Going for a long walk or visiting a friend in the evening can also be a good way to relax away from the environment which you can find frustrating at times. It is very important that you always look after yourself as well as caring for a sibling with Angelman Syndrome. It is easy to forget to look after yourself but it really should be a priority otherwise you do end up with more feelings of frustration that will only manifest.



## Dear Jon

*I am worried about the future care of my brother. As I am getting older, it seems as though my parents feel I will either have to care for my brother or at least be seeing him all the time. I do get on well with my brother most of the time but don't want to care for him and want to have my own family.*

## Jon says

Feelings like this are completely natural. If possible then I encourage parents to at least make plans and not rely on siblings for future care. However, every situation is unique to each family. Ultimately you should make the decision that you are most comfortable with.

I cannot stress enough the importance of having an open conversation with your parents about this and if they have not properly discussed it with you, then I suggest you bring it up with them. This will allow you to unwind and talk to people who really understand your circumstances.







# family conference

## Coventry, 10-12 August 2018

As well as 2018 being our 25th anniversary, it was also family conference year! Everyone looks forward to our family conference including the trustees, all of whom work extra hard to make the weekend a success. This year the conference was held once again at The Hilton Hotel, Coventry. We have an excellent relationship with the hotel staff and they tell us that they look forward to us coming every time!

We listened to feedback from our families and changed the date slightly this time from the last weekend of the English summer holidays to a date part way through. We appreciate that this date didn't work for some but we had to try. It would be nice if we could accommodate everyone's arrangements but this simply isn't possible. The Saturday trip this year was a visit to the thrilling theme park - Drayton Manor with a more sedate day planned for Sunday – a trip to Twycross Zoo. Everyone enjoyed their days out, no one was left behind and thankfully the weather was kinder to us this year!

We had speakers from all over the UK covering topics as diverse as Science and Research, EHCPs, Sensory Processing Disorder, Transition to adult services, Wills and Trusts and many more. It was a pleasure to welcome back old friends such as Bernard Dan and to welcome our new speakers. If you have a suggestion for a talk or speaker for our conference in 2020 please let us know – we are always looking for new and interesting subjects to cover.

This year we had a slight change in the

programme and we asked families to split up according to age/need. We had talks for younger families and newly diagnosed running concurrently with talks for families with older children or adults. This seemed to work well and is something we hope to continue in future conference programmes.

Who can forget the party on Saturday night? What an amazing night for adults and children alike. It was such a wonderful sight seeing our AS loved ones in their finest party wear coming through the balloons and down the red carpet! The excitement was palpable and everyone did so well to wait patiently until the doors were opened. All were rewarded with a glass or two of prosecco or a sparkly 'mocktail' followed by an excellent disco. Here's to the next 25 years!

### Now for some facts and figures!

We had over 300 families in attendance this year along with 17 speakers and 22 exhibitors, plus trustees and their families; 400 people in total.

The total amount paid by you – our families – was £22,972.64. The conference is always heavily subsidised by AngelmanUK as we feel that it is the most important event in our AS calendar. AngelmanUK met the shortfall of £60,570.88. This money is raised for us thanks to your generous donations and fundraising events and we are very grateful for the time and effort that you, our families put in to raising much needed funds for us.

The total cost of the conference was £83,543.52. This includes all accommodation, meals, entry fees transport for the trips and expenses for our speakers who very generously donate their time.

Every year we hear some amazing comments from our families about the high quality of the accommodation and the excellence of the speakers and this is always fed back to the AngelmanUK team, the hotel and to our guest speakers. However it does need pointing out that we also receive some negative feedback as well. Whilst constructive criticism is encouraged, and we do listen and make changes based on your recommendations, please bear in mind that the trustees spend many sleepless nights in the run up to conference trying to make it the best it can be, and we rarely get any of the benefit. Please be kind with your criticism - the AngelmanUK team are volunteers who feel strongly that they want to help and support others in their 'spare' time and it isn't appropriate to be overly negative about the venue or the work we do to support you – our families. If you feel that you would like to volunteer to help at future events please email [Louise.shaw@angelmanuk.org](mailto:Louise.shaw@angelmanuk.org) We look forward to seeing you there!

The *angelman*<sup>uk</sup> Trustees







# angelman days out

*It can seem daunting going out with a Special Needs child, making a day's outing feel more like an expedition to Outer Mongolia. There is so much more to consider, and it can sometimes feel as though you should be going away for a week because of the 'extras' you need to take with you. The key is "planning" - I know, I know. To my husband that's a dirty word, but it really does make all the difference. Fortunately, there are lots of places across the UK that are much more switched on to various disabilities and making concessions to help accommodate them. Don't get me wrong, there's always room for improvement, particularly with the disabled toilet, but things are heading in the right direction. Lots of attractions and venues offer help with free carer tickets, quiet times when there are less people around or the ability to jump queues. I've compiled a list of different attractions or days out that are available across the UK, that are disabled friendly. The list is by no means exhaustive... there are plenty more out there, but I've tried to include a good spread of popular activities.*

**Kathryn Wrigley**

**A Radar Key** is an essential bit of kit for the discerning disabled parent. It is a key which allows you to unlock disabled toilets across the UK. It is provided under the National Key Scheme, and a key can be purchased for £4.50. More details are available online. Lots of attractions and venues use the radar key system to stop their disabled toilets being occupied by someone able to use a standard toilet.

**Cinema Exhibitors Association (CEA) Card** this scheme allows a free carer ticket with a disabled person. It's accepted by 90% of UK cinemas and costs £6. The card is issued to the disabled person and displays their photo, meaning that any companion can claim the free carer ticket. The card is valid for a year and can be renewed by supplying documentary evidence such as DLA/PIP award. More details can be obtained online or through your local participating cinema.

**National Trust** - they have lots of houses and parks across the country. They have a scheme where you can apply for an "Access for All Admit One Card". It needs to be applied for in advance of your visit, and can be used by any accompanying carer. Check with the venue for suitable accessibility, as some may not be suitable for particular needs.

**The Eden Project** - all the site including the bio-domes are wheelchair friendly with wide, solid pathways. You can explore different ecosystems, and there are usually activities laid on for younger children.

**Theme Parks** - most will give a free carer ticket to accompany a disabled patron. It is worth calling or checking their website before you go to find out what paperwork they require sight of. Some also operate a queue-jumping system, recognising that not everyone is able to stand peacefully in long queues! Alton Towers use this system, as does Legoland. It is worth noting that if you accompany a wheelchair user, Legoland is fully accessible, BUT it is situated amongst hills, so there are lots of fairly steep inclines to push the wheelchair up! Some theme parks may refuse access to specific rides because of the lack of mobility of your child so it's worth checking ahead. This is due to health and safety concerns about how they would evacuate your child in an emergency situation.

**Sea Life Centres** - there are five across the UK, and it's free for a carer and for the under threes. They have good wheelchair access, with lots of low-level tanks so vision is not restricted.

**Music festivals** - many will provide a free carer ticket and it's worth getting in touch before your visit so you can access the accessible viewing area, camping and toilets.



**Football matches** - lots of clubs offer discounted match tickets for disabled supporters, or have schemes where a carer can get in free. To find out what your team offers, and what disabled facilities they have, Google 'disabled supporters [your team]'

**Theatres** - many offer concessions on tickets for the disabled and some offer a free carer ticket. Some, including West End productions, have special 'autism friendly' performances which are for people who might struggle to stay seated throughout a performance or make impromptu noises! Check your local theatre to find out more.

**Museums** - lots are doing more to be more accessible to disabled children and young people with autism. For example, The Victoria and Albert Museum in London provide sensory packs, and early bird and night owl events are available at the Science Museum. The Science Museum has lots of



interactive exhibits, where the visitor can get 'hands on'. They have a bubble making workshop, water play and distorted mirrors; plenty to occupy the whole family. They have medical rooms which they are happy to be used as a changing room, although it obviously has no hoist facilities.

**Scenic walks** - walks that are accessible to wheelchairs can be found by visiting [WalkswithWheelchairs.com](http://WalkswithWheelchairs.com). They have a wide range of suitable walks.

**Hydrotherapy** - lots of special needs schools have out of hours sessions that aren't publicised. The water is warmer than in regular pools and the changing facilities will be better than the local swimming pool. To find out if there are any near you, search 'hydrotherapy pools for disabled children in [your area]'.

**Feel the Force Day** - this is a one-day event that has been going for a handful of years and is open to all with a disability. It has all kinds of science fiction/superhero/fantasy items made available to be touched or handled, making it a much more interactive experience. It features items and clothing from films such as Star Wars, and Doctor Who. For more information, Google "Feel the Force Day" to get regular updates.

**Trampolining & soft play centres** - it's always worth asking, as these venues will often open one night a month specifically for

disabled children and their families. It'll be quieter and less busy than when open to the general public, and is a great opportunity for siblings to be able to play in the same forum together.

**Motability** have compiled a really handy free guide, split into different areas of the UK, so you can find out what is going on in your local area. It's also available online, and contains reviews of 180+ accessible days out. It's called "Rough guide to Accessible Britain" and can be found at [accessibleguide@motabilityoperations.co.uk](mailto:accessibleguide@motabilityoperations.co.uk)

**Places like Groupon** sometimes do reduced-price tickets to attractions, so it is worth taking a look online to see if you can access any discount codes, or offers.

**The Max card** is a discount card that enables families of disabled children to save money on popular attractions and days out, including Madame Tussaud's and Harry Potter Studios Tour and many more. To get the card and view a list of participating attractions, contact your participating local authority or charity.

It is possible to apply for 'Merlin's Magic Wand' to gain free access to a Merlin attraction for a disabled child and immediate family only. They can also help with a limited amount of travel costs, but not accommodation. Merlin venues include attractions such as the Sea life centres,

Alton Towers, Thorpe Park, Chessington and Legoland. For full details of availability and how to apply, visit the website.

And [skybadger.co.uk](http://skybadger.co.uk) is a charity that helps find adventure for disabled children and their families. Their website is full of all sorts of ideas for interesting days out.

To make sure your day goes as smoothly as possible, some simple checks will iron out any last-minute panics:

**CHECK YOUR JOURNEY** - particularly if you are travelling on public transport. If you are taking the train, you may need to book assistance getting on and off 24 hours ahead.

**CONTACT THE VENUE** - ask what mobility aids and facilities are available, and check what documents you need to take to access any concession or skip queues

**PREVIEW THE DAY** - show your child a video of where you are going using Google Images or the attractions own website. This will help your child prepare for what they will see and do.

**STAND OUT** - make sure everyone in your party is wearing easily identifiable clothing, so it won't be so easy to get lost in a crowd. Write a contact number on the back of your child's hand in case you become separated.

And finally... **DONT FORGET** spare clothes, pads, drinks, medications, wipes, coat, the kitchen sink and a cuddly toy! Now you can go and have fun!



# we had a Ball

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## AngelmanUK 25th Anniversary Ball

10 November 2018

My experience of Angelman meet-ups usually involves snatching a couple of sentences with another parent or carer in passing, before having to dash off and rescue Woody from whatever chaos he is currently causing. This usually happens whilst I am covered in his dribble, the remains of his last meal and sporting a hairstyle that can only be achieved by having your hair grabbed and stuffed in his mouth while he has you in a full headlock. So it was lovely to see so many familiar and new (to me, at any rate) faces at the AngelmanUK 25th Anniversary Ball all scrubbed and polished in black tie attire and actually have a chance at some real conversation!

Guests, including members of AngelmanUK, their friends and families, professionals who have worked with us over the years, and a couple of adult individuals with Angelman themselves, were greeted with a drinks reception followed by a three course meal.

Speeches were started by Jonathan Allen, the current (but sadly departing) trustee for sibling support, followed by Sally Walburn, former Chair of AngelmanUK (ASSERT as it was then). The concluding speaker was the founder of the charity, Richard Allen, bringing us full circle as he is Jonathan's father.

Following their storming performance at the Liverpool gala three years ago, the brilliant *Sunshine Soul Revue* (now officially self-styled as the Angelman band (Charles Villiers the keyboard player, has a son with AS) provided the music for dancing again. Jonathan and I competed for being the first on the dance floor, but were beaten to it by Laura.

The casino tables saw some intense action and the competition for the ultimate prize of a bottle of champagne was fierce. With prizes including a beautiful quilt hand-made by the niece of Harry Angelman (Yvonne Jones), dinner for two at the Shard, a week's caravan holiday, tickets for *Phantom of the Opera*, a signed Liverpool football shirt, a rugby shirt signed by the entire 2015 Welsh Rugby world cup team and many others, the silent auction also attracted some hot bidding right to the end of the evening.

In all, a really brilliant night and I can't wait for the next one.

**Andrea Baines**







# becoming a sensory detective

*Becky Lyddon guides us through ways in which you can understand your child's Sensory Processing Difficulties.*

Over the past 7 years I have regularly been asked by parents and professionals what certain characteristics mean relating to their child's sensory needs. Being able to detect and work out why someone may do something will give us huge clues as to how they respond to their environment.

For people with Sensory Processing Difficulties (SPD) this is the best way in which we can help to personalise the way they are supported in their day to day lives.

My definition of SPD is when "the brain finds it difficult to do its most important job. This job is organising and responding to the sensory messages it receives." SPD will affect everyone differently and so in order for us to truly understand our child or the students we support we must step into the shoes of being a Sensory Detective.

Sensory characteristics like chewing on things, rocking, hugging tightly can all be ways we can understand SPD (watch a video I made on Sensory Spectacle's YouTube channel explaining some of these characteristics and what they mean). I refer to these as characteristics and not behaviours as they are things that person's body requires. They need that particular proprioceptive, or vestibular input in order to 'feel ok' in that moment and to focus on what is happening around them.

Recently at the Angelman Syndrome conference I introduced our 8 sensory systems which we need to be familiar with. These consist of our 5 external senses that we are probably familiar with from school – smell, taste, touch, sight & hearing. In addition to these we have 3 internal senses which are hugely important to our development – Proprioception (our body awareness), Vestibular (sense of movement) and Interoception (our internal feelings of hunger, tiredness and when we need the toilet). You can learn more about these in detail on any of our workshops, see our website for more information.

All our senses have to work together for us to be able to learn certain skills in life. If someone has SPD it can mean that they find it hard to do this, therefore activities like brushing their teeth or getting their haircut can be overwhelming depending on their SPD.

Most often for people with SPD we initially notice characteristics which are seeking or avoiding sensations. Seeking characteristics may be loving reflections in water, licking things, hugging tightly, chewing things and constantly moving. Avoiding characteristics may be covering ears, refusing to wear new clothes, difficulty with buttons and gagging easily in response to smells. I explain these in more detail in my videos on YouTube.

When understanding your child's sensory needs we cannot just observe one characteristic, like squinting their eyes and presume it is because they are avoiding light – it might be because they processing too much vestibular input. As a Sensory Detective we need to gather as much information as possible and map it out specifically to your child's needs before we begin to implement support for their sensory lifestyle.

*I (Becky Lyddon) am Founder of Sensory Spectacle. I work internationally with people with Sensory Processing Difficulties (SPD) to create immersive learning tools to help create a better awareness and understanding of SPD. You can learn more about SPD with any of our guide books, free downloads, workshops & events. Head to our website or contact us for more information [www.sensoryspectacle.co.uk](http://www.sensoryspectacle.co.uk)*





# summer holiday survival

*The summer holidays are long behind us, so now's the time to start preparing yourself for the next one...*

The summer holidays might seem a distant memory now, but every year as the time comes round again, a familiar panicky feeling starts to emerge and I remember disastrous summers gone past and how I've struggled to cope. So I thought maybe I should organise myself properly and get sorted for each of the holidays so I didn't find myself crying into a vat of coffee on day 1!

**So here it is...**

## **my holiday survival check list!**

I start by printing off a week by week calendar so I can plan the holidays. For me, this is the equivalent of having a big to do list - I can cross each day off and then when the week is finished, I can throw that sheet away/ tear into tiny pieces/ burn it (delete as appropriate!!). This activity is purely psychological but it helps and even if it feels like I'm walking through treacle, I can see I'm actually getting somewhere!

day! You need days of doing nothing.... sometimes that's all you need to do. Dealing with the outside world on top of your children can wait! If you book too much in, you'll end up in a frazzled heap! On these lazy days I make good use of iPads etc, and yes, YouTube is a godsend! No one says you have to be perfect! Obviously if staying at home doesn't work for you, then get out every day!! Do what works but don't feel guilty!!!

Last year, I bought a weekly calendar with Pecs symbols (these are equally very easy to make but I just couldn't be bothered!!) so Holly could see what she was doing each day. She also helped choose some of the activities she did this year which she loved... luckily it was the park, friends and play doh... which I could manage fairly easily!!! This year I did make a calendar for the 6 weeks holiday and a whole heap of 'no school' symbols. Although Holly wasn't in the least bit interested, I removed a symbol every day and showed her so she could see the days counting down. This was particularly helpful in the last week as Holly suffers with anxiety and in particular separation anxiety from me.

At Christmas, I have a calendar which includes symbols for Christmas Eve, Christmas Day, Boxing Day etc so Holly has a visual representation of when things are happening.

I also wrote her a social story using the Pictello app about returning to school which included photos of her school friends and new class (pinched this idea from Erin Sheldon). Again, her interest was fleeting, but when tackling difficult situations such as a return to school, I find having as many resources as possible to hand helps because you just never know what will work! Even if something hasn't worked previously, it's always worth revisiting!

However, my "pièce de résistance" is... help in the form of another child (another fab Erin Sheldon idea). Please note, this is not a sibling, which although are great and clearly have their uses, they also have to help a lot of the time and the holidays are their down time too. If you can borrow a friend's child, or

someone else's special need sibling (those at conference will have seen this in action with Holly and her friend Mason), it works brilliantly because they get to hang out with another family who although might be annoying, they're never quite as annoying as their own family, they get everything paid for them including sweets as incentives, they are always really well behaved for you as you are not their parent, and most kids just love being helpful and getting praise for it! Now I do have to point out, this is not child labour, and these children are in no way responsible for the child they're playing with. They are just there to be a friend.... and do you know what, aside from the extra little treats and little bit of pocket money every now and then, most kids will absolutely love spending time with our children because they can choose to, it's not expected of them and they will form a bond with your child despite the hair pulling, dribbling etc. Ultimately this also means a potential real friendship and although it means another child to take with you everywhere, they are there to help you so no bickering with siblings or you. This is my absolute life saver!!! If you take one thing away from this.... this is it!

Resources can be bought from ASD Bright Ideas (<https://asdbrightideas.co.uk/asd/>) They have a huge range of fantastic resources which are very reasonably priced.

**Louise Shaw**



The next thing I do is get dates booked in for respite (clearly the absolutely most important thing!!), dates with friends (including your friends!) dates with family (only if they are helpful and nice, otherwise don't plan to see them in the holidays!!), holiday activities/ clubs/etc.

Dates with other special needs families are also incredibly useful - days where you don't have to explain your child, deal with staring eyes while your child has the most epic meltdown known to man.... this is self-preservation! We all need it if we are to survive!

However, (and this is really important for me!) do NOT book something in every



# holidays

*We've received lots of your holiday stories and pictures over the last few months, here are a few to ease you through the winter months.*

This summer we braved the journey to France (taking all my family with us for support and baby sitting duties!) Sam loved the beach, having his own pool, and generally having lots of attention and cuddles!

We've also spent a week in the Lake District, been to forest school with another lovely Angelman family and we have prepared for the start of big school!

We've had a brilliant summer with our beautiful, amazing little boy, but have had the usual issues with sleep and anxiety and I feel very tired as Sam is constantly on the move and is into everything!! (I'm quite looking forward to him starting school so I can sit down for a minute!)

**Jess Porter**



This year's summer holiday was the first time both our kids were off together, as Bertie started full time school after Easter, and he was at previously at full time nursery over the holidays. Bobbi-May is 6 and Bertie is 4 and both have UBE3A mutation. I was feeling very nervous and anxious knowing it was going to be full on from when they got up until bedtime and as Dad/my partner works 6/7 days a week supporting us since I gave up work 3 years ago.

However school came up trumps this time giving them both 8 days of holiday club spread over two weeks, which was brilliant and meant they would be able to go out on trips together plus it would be cheaper than paying for a carer to help me get out! Unfortunately though, just before the holidays, Bertie started having absence seizures once every other day. Although he'd had drop falls in the past nearly a year ago, this was new to him which meant everyday he was more tired and started having daytime naps. He then started on another new medication and the absences stopped.

Another surprise from school was a TA who offered to help me whenever I wanted it! This was a God send - someone had finally offered their free time and someone that I could trust and loved my kids. So I had help a few days a week when we were able to go out. I also had help from my amazing mum on other days, although this is getting harder for her now as she's no spring chicken (despite her looking younger) and now has early onset Parkinson's. She does find it challenging but will never say no to helping me as she is incredible but I do have to let her rest more and use outside help!

We had days out at Aldenham Country park in Borehamwood, Herts as they have an adventure playground and it caters for SEN including pony rides. Bobbi-May was very upset getting on the pony, as I knew she would be as she didn't like it when school took her! She was so scared, she clung onto my neck until I had to let go and with that she just got on with it, she really enjoyed herself and wanted another go straight after!! Which she did! Bertie was bored straight away and just wanted to slip off the pony resulting to me having to carry him back half way as he wouldn't walk, he's one heavy little boy!

Most of our sunny days we played in our garden splashing in the hot tub, playing on the swings, slide, trampoline, squirting water guns at each other and riding Bobbi's Tomcat bike having lots of fun! We had a fun day at Guilliver's Land, Bobbi-May went on all the rides, even the Tea Cups. That was one for her aunty as I'd have been sick! Bertie still wasn't felling himself but managed to go on most rides. We ate out lots at the local Harvester as they love the salad cart especially the raisins and I'd rather give a tip for cleaning up our mess than me having to do it at home haha!

At the end of the holidays we managed to meet other fellow AS friends who are local to us. We went and stayed over at Tracey and Steven Blohm's in Southampton, which was lovely seeing their little Katie, who's the same age as Bobbi-May and has the same mutation. In fact, they could be sisters if Bobbi-May wasn't so tall! And to end the holidays we went to Thomley Hall with the local Buckinghamshire mums and their children. Although I think I only managed a quick hi and how are you as mum and I had to follow after the kids, as there was too much fun to be had!!

I survived which was the main thing and we did lots along the way when possible but I'm so glad school has started as that was the longest 6 weeks of my life! Roll on our family holiday at Christmas to Thailand as we so need a break and a cocktail!

**Carolyn Doherty**







There is no denying that the summer holidays are hard, very hard, but this year I think we managed to get through it relatively unscathed and had lots of fun along the way. There were days when I was on my own with the girls 24:7, which limited what we could do and where we could go, but on the days that there was help available, we made the most of it. This summer we went searching for *The Gruffalo*, played in

the sand and visited a variety of beaches, playgrounds and country parks across Essex and Kent. We visited the Aquarium on Clacton Pier and threw sand at the terrapins (oops), and fed the goats and stroked a snake at Colchester Zoo.

This summer was also full of firsts, we played with slime baff (OMG the mess!), danced at a silent disco, went on our first fairground ride at a family music festival and

subsequently went to our first amusement park at Pleasurewood Hills, Jessica absolutely loved the log flume and refused to get off. Apart from all of the ice cream that she consumed, I think one of Jessica's favourite moments of this summer was visiting her dad whilst he was fishing and managing to catch her first fish, she was so pleased with herself.

**Gemma Jay**

The prospect of a heatwave with an Angel meant summer looked like it was going to be long and difficult. Luckily for us the three times we were brave enough to go away for long weekends, were the only times it was cold and wet all summer. Hooray! (says

Max, AS del+ aged 6). His siblings, Holly and Ted, were also quite happy in wellies and waterproofs. So, some beach time in Wales, a log cabin in the Peak District and a very wet festival (turns out Max LOVES hip hop) made for some fun times after all.

A summer made all the more memorable by Max walking independently for the first time at the end of the holidays. Sorry we missed the conference though!

**Helena Malkin**





# communication barriers

angelman<sup>uk</sup>

Recently, whilst completing coursework for university, I was looking at the barriers Leia faces when it comes to communicating. I found this a really worthwhile exercise so I thought I would share my experience. Leia has the tools she needs for communication, although they continually need updating and getting time to do this is definitely a barrier. I have actually recently employed Leia's sister to help, although it's too early to say if it's working out, it also helps Abbie to develop a greater understanding of Leia's issues and the challenges she faces. Still, having the tools is a great start.

The next thing to think about is how to physically access the tools; we have straps and harnesses to physically carry devices, floats for swimming, ALDs for environments not suitable for PODD (such as bathroom, trampolining and a bedtime cushion) as well as extra devices for modelling. If your words aren't to hand, you can't use them and no one is modelling them to you. If your loved one doesn't have the ability to directly access AAC, then you might need to consider partner assisted scanning or eye-gaze as alternatives. A good rule of thumb is if they can access YouTube then they can access most AAC devices.

Anxiety is another big barrier for Leia; when she is anxious her ability to communicate decreases. We are currently

working on coping mechanisms including deep breathing, yoga, massage and listening to relaxing music to help Leia regulate her body. Leia has self-talk pages in both her book and her talker which contain relevant phrases to build internal dialogue. There are phrases for self-motivation such as "I can do this" and, for self-regulation, "I do not need to pull hair", along with solutions like "I need a hug". We are also about to introduce Zones of Regulation (ZoR) which are another self-regulation tool. See picture for an idea.

Leia has a real lack of communication partners who use her AAC with her, so to combat this we are providing training. This is not the ideal scenario but there is no alternative at the moment. First up I am going to visit Leia's Guides group and chat to them about what communication actually is as well as showing them PODD and letting them practice. We are hoping they can work towards the Communicator Badge as a troupe and that Guides will take turns in being "Modeler of the Week". I will visit a few times throughout the year to check everything is ok and provide further training as needed. This will need to be repeated for all the places Leia goes including school and home... I suspect Guides will be the easiest by far!

Leia also does not receive a balanced literacy education, a major barrier but

not one I have any solutions to yet, I will keep you posted if I do. The other barriers are in the same category and something many of you are experiencing too. Policies and procedures are out of date and too many people don't believe in the abilities of those with Complex Communication Needs. For now I keep chipping away but with little effect sadly.










Those barriers may sound familiar to you or you may have many different barriers. For example not everyone has a clear yes and no. This is a big barrier yet it can be overcome.

This is a link to a video by **We Speak PODD** on teaching the movements <https://youtu.be/EL93jAz8gOc>

**Kate Ahern** also has a great series on teaching yes and no <http://teachinglearnerswithmultipleneeds.blogspot.com/2012/11/>

So why not have a think about the barriers to communication that are faced by your loved one and concentrate on the ones that you can do something about. If you don't have any professional help and are looking for advice, then please contact Angelman UK or ask on the AngelmanUK communication and literacy group.

**Tracey Campbell**

Blue Zone Sad, Tired, Sick, Bored, Sleepy	Green Zone Happy, Calm, Excited, Relaxed, Comfortable	Yellow Zone Worried, Shy, Anxious, Scared	Red Zone Uncomfortable, Withdrawn, Extremely Anxious, Terrified
			
 			
When I'm in the blue zone I...	When I'm in the green zone I...	When I'm in the yellow zone I...	When I'm in the red zone I...
<ul style="list-style-type: none"> <li>Express my needs and wants to others using my PODD</li> <li>Hang out with Pippa</li> </ul>	<ul style="list-style-type: none"> <li>Explore new things</li> <li>Communicate with others and feel great!</li> <li>Play with Pippa</li> </ul>	<ul style="list-style-type: none"> <li>Take a few deep breaths</li> <li>Tell others how I'm feeling</li> <li>Ask for help and express my needs and wants using my PODD</li> <li>Pat Pippa</li> </ul>	<ul style="list-style-type: none"> <li>Use my breathing techniques</li> <li>Listen to my Silver Sky music</li> <li>Cuddle Pippa</li> </ul>





# communication matters



freely accessible to family members as well as professionals. For further details look at I-ASC website.

There were a few sessions involving training partners that were

This year's Communication Matters conference was held 9th to 11th September. The keynote speech was on an exciting new project based at Manchester Metropolitan University where we were advised that by December they should be releasing an online assessment tool, offering guidance and support on choosing an appropriate communication system. These tools will be

very interesting. One was carried out by KeyComm (Edinburgh and Borders) and it focused on training for parents of children with Complex Communication Needs. The year long project showed good results with all parents happier with their skills as communication partners and all children making communicative gains. Another was based at the SeaShell Trust; it was a 3 month project upskilling Pupil Support Assistants. Again the results were positive and all people felt happier with their skills after the training programme. Another interesting idea was the ACE Centre using video footage so that less familiar people could easily learn about the communication intention of different access, or to show people how to use or problem solve communication devices.

As well as the useful sessions, it was clear that there are professionals out there doing lots of good work promoting robust language for everyone. We just need to figure out how to spread the good work that they are doing.

**Tracey Campbell**

## angelman syndrome alliance

For those of you who are new to AngelmanUK the ASA is a collaborative project between international charities to fund scientific research into Angelman Syndrome.

### **We are currently funding two projects;**

Tiziana Borsello and Silvia Russo, Milano, Italy. Project title: *Potential therapeutic approach for synaptic deficit in Angelman syndrome: the JNK inhibitor peptide.*

Ben Philpot, UNC, USA. Project title: *Quantifying EEG abnormalities and identifying biomarkers in Angelman Syndrome.*

Both projects are nearing completion and the next grant call has just been announced.



The 6th International scientific conference was held in Germany on 12-13 October. There was an exciting list of speakers, M. Scheffner, H. Sitte, Y. Elgersma, S. Chamberlain, B. Distel, S. Russo, B. Philpot, K. Egawa, C. KannegieBer-Leitner, B. Horsthemke, Ed Weeber & J.Daily Agilis Biotherapeutics, E.Schneider IONIS Parmaceutical, Inc. and E.McNeil, Biogen and OVID Gaboxadol trial.

We also held our annual board/members meeting. Myself and Rachel Martin represented Angelman UK. I also sit on the board. Look out for much more information in our next newsletter!

**Katie Cunnea**

# model aac with me

*Some of you may have seen **Jodi Melendez** at our recent family conference. Here she offers a guide to her own experiences of modelling AAC with her own AS daughter.*

My daughter, Sirlei, was three at the time. I remember her first introduction to symbols and 'communication' involved bubbles. During therapy, we would blow bubbles and she would have to point to the symbol for 'more' in order for us to blow more bubbles. I didn't necessarily dread this



time spent in therapy but it did feel very much forced, very much 'do this', and very adult driven and controlled. Teaching my daughter to communicate became just another therapy. Something to hurry and get over so we could do the 'fun' stuff. That is not how I wanted to feel, nor should I have felt, about teaching my daughter to communicate. I began to learn different ways, new strategies, to teach my daughter to communicate and reinforce what communication is really about. I began to enjoy and look forward to teaching my daughter about communication. Teaching Sirlei to communicate, and the interactions

that followed, became rewarding for their own sake. It no longer felt like "work." One of Sirlei's very first words, using symbolic communication, was 'beautiful.' We were playing and blowing bubbles together on the grass. She reached out and touched the icon for 'beautiful.' It was her very first opinion she shared with me using her communication book. One of the first times she told me something that I didn't already know. All the time that was spent making her say 'more' for bubbles could have been spent playing, having fun and getting to know her more intimately. Showing her that communication is powerful for her. That she could use her communication book to tell us what she thought, not just what we wanted her to say. I share this experience because it was so powerful for me and so pivotal in the way I began to support Sirlei and continue to support Sirlei in her communication journey.

I presented at the 2018 Angelman UK Conference on the topic of making communication fun and powerful for our loved ones with Angelman Syndrome. As a parent of a child with Angelman Syndrome, as well as a Special Educator working with and supporting students and families on their communication journey, I understand the struggles and triumphs that come along with teaching someone to communicate using an Alternative and Augmentative Communication (AAC) system. As parents, I feel that many times professionals instruct us to model our children's communication systems and it feels like another chore that has been assigned that just piles on top of an already long list. Parents might worry they aren't doing it "right" and hesitate for fear of doing it "wrong." Others resist

their role as "therapist" and insist on their right to just be mom or dad. If parents perceive AAC modelling as the work of a therapist, some parents are less likely to participate and others can be intimidated. My presentation focused on lifting AAC support from the world of "work" and helping families see it as play. How AAC modelling was a way I got to know my child more deeply, interact more intimately and play with more fun and abandon.

I have learned that communication is not about just giving a right or wrong answer. Communication is not about giving the answer to a question that is already known. Communication is not about testing or proving competence. True, authentic communication is about so much more. It is about making a connection with your child. About getting to know your child more deeply. Communication is learning something about your child you didn't already know. The remainder of this article will focus on ideas and strategies I use at home to help maximize engagement in modelling and AAC, encourage interactions and conversations, model essential and important vocabulary and the importance of inviting others in.

I know that many of us deal with very serious circumstances on a daily basis. As parents we are responsible for so much when it comes to our children with Angelman Syndrome. We are responsible for their health, making sure their diet is just right, seizure control and juggling medications, all the appointments and therapies that need to be scheduled, advocacy on their behalf and more. Even with all of this in mind it is OK to take a break and just be mom or dad. To be silly and irreverent. To smile, laugh and just have fun with your son or daughter. Here is your permission!

One way I maximize engagement in modelling AAC is through fun and playful activities. It is helpful to use activities and toys that require a partner's role and have cause and effect properties.

Take slime, for example, instead of having the slime as the centre of the activity where perhaps all your communication revolves around asking for "more" slime, use the slime as a tool but strive for the







interaction between yourself and the AAC user to be the heart of the activity. I have done this by pretending to sneeze slime out of my nose and in the process model words such as "gross!" 'something's wrong, I have to sneeze!' 'yucky' 'I'm sick.' etc. My children, especially Sirlei, think this is hilarious and are therefore completely engaged in the activity and the subsequent modelling of the AAC. Lots of toys can be used in this manner. Just be mindful and strive for you, a sibling, a friend, the AAC user or somebody to be at the heart of the activity; not the stuff.

attention to the communication system is having an expectant pause and wondering aloud if the child might have something to say or wondering aloud what the AAC user might be thinking. For example, I might say "I wonder if you want to choose how I read the book next" then pause for 5-10 seconds, looking at the communication system, inviting her to participate. If she chooses not to that's ok! I would then say "hmmm I think I'll read it 'silly'" and model silly on the communication system and then read the book very silly. I might then wonder aloud again inviting her to choose but not demanding she does. By not being forced to use the communication system the AAC user can be more relaxed, less anxious, and hopefully more likely to enjoy, engage and participate in the activity.

As parents it is important that our children be able to communicate essential concepts such as their opinions, if something is wrong and being able to advocate for themselves. I use pretend play in order to provide more opportunities to model these important concepts. For example, dolls/action figures, stuffed animals, parents, siblings and friends giving

their opinion using AAC, pretending that they are sick and describing what it feels like with AAC using words such as tummy ache, lonely, scared, sad, hurt, nervous, etc., and pretending to self-advocate for themselves and others, i.e. stop it, don't touch me, leave me alone, I need help, you're hurting me, I mean it, etc. By using pretend play to practice and model when, where and how to communicate these concepts gives our kids lots of opportunities, in a controlled and safe environment, to practice using this type of vocabulary. Of course, it is also important to model these essential concepts in real life situations but, in order to get more opportunities to model, pretend play can be very beneficial.

Trust me when I say, even I run out of new, fun and engaging ideas to model AAC. Parents, we don't have to be the only the ones that come up with all the ideas. We can look at kids the same age or similar age and see what is engaging to them and adapt it for our kids. We can reach out to other parents, peers, friends, siblings, relatives, support workers and others close to your child for a new perspective of how

to provide more opportunities and invitations to connect and have fun with our sons or daughters through AAC. Also, invite others in. Allow and encourage others to connect with and model AAC with your child. This is not only powerful for the AAC user but also powerful in building understanding and helping to foster relationships between our sons and daughters and the community we are building around them. I have found others genuinely want to connect with our loved ones with AS but sometimes need an open invitation and a way to do so. Modelling AAC can be that invitation and opportunity they need.



Please remember that modelling your child's AAC is messy. Remember it's not about being perfect or doing it right or wrong. It's about connection, communication, making memories and having fun with your son or daughter! All of which are rarely perfect or go as planned. Think of modelling AAC as just another way you talk while you play. Just another way to get to know your child more deeply and play with more fun and abandon.

To see videos of me in action, modelling AAC, or using the ideas and strategies referenced above visit [www.aacconference.com](http://www.aacconference.com) and watch my presentation entitled *Jodi Melendez: Making Modelling Fun at Home*.

*Jodi Melendez, B. Ed, is an Elementary School Special Educator in Utah, United States. She is also a member of her region's Utah Assistive Technology Team. Her nine-year-old daughter has Angelman Syndrome.*



Another way to maximize engagement in modelling AAC is by giving the power to the AAC user. Our kids spend a lot of their life being told what to do, when to do it, or how to do it. It can be so powerful if we flip the script and give them some of that power back. Show them that they can effect change in their world by using AAC. Let the AAC user be the one to tell others what to do! Let them boss you around and tell you what action to do (i.e. bend, roll, jump, crawl) or how to read a book (i.e. silly, sad, like dad, excited) using their AAC. We want our children to see their communication system as powerful for them. Not another tool that we use to gain control and power over them. Doing activities like this is one way to show that using their AAC can give them power and effect change in their world and increase the likelihood they will want to use it in the future.

We want to encourage interactions and 'conversations' using AAC but we need to be very careful to not demand it. We instead want to invite participation and attention without any expectation that the AAC user must use the communication system. This





**James Johnson & Keeley Anderson**

*We had an amazing day being part of the Great North Run. Being able to raise as much money as we did for such a brilliant charity made all the pain worth it. It definitely won't be the last run.*

As usual we had a number of very dedicated runners and fundraisers who kindly put themselves forward to represent ASSERT/AngelmanUK at the Great North Run this year. We had 8 runners in total who between them raised nearly £5,000. What a massive amount of money, thank you very much! Our runners were:

- Derek Maytum
- Poppy Cartwright
- Gavin Smith
- Phil Thomas
- James Johnson
- Lucy Smith
- Caroline Bennett
- Keeley Anderson

## 2019 events

AngelmanUK have places available in the following events:

- **Great North Run**
- **Great South Run**
- **Great Edinburgh Run**
- **London Vitality 10,000** - Mon 27th May 2019 (Bank holiday)
- **London to Surrey 100 Cycle Ride** - Sun 4th Aug 2019

London Marathon places for 2019 have already been allocated, but if you have questions or would like to be considered for the London Marathon 2020 or any of these other places, contact: [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org)

## new trustees

Hi all, my name is Emma Goodson. I'm 37 and live in north Essex (I'm from south east Kent originally) with my husband Andrew and our 2 year old cheeky son William.

William was diagnosed with Angelman Syndrome whilst on life support for his seizures in St Mary's PICU when he was 9.5 months old. The support and kindness received from Assert (as it was then) was invaluable, and has been ever since.

He's suffered from a lot of different poor health issues since birth and

seizures have been his biggest challenge. But as with most AS individuals he's got through every day with a naughty infectious giggle and the biggest grin on his face. He loves cuddles and kisses from everyone (whether they want to give them or not)!

Andrew and I both work full time in London. As such I spend quite a large chunk of my day commuting to and from home on the train. This gives me time to kill on social media, and it's perfect for me to be able to use that time to give something back to our wonderful community; so I am honoured to have been granted a position as trustee responsible for social media with Louise. I look forward to



being involved and meeting many of you over the coming years.



## Phil Thomas

*I was really proud and happy to support all the families of a child with Angelman Syndrome at the Great North Run.*

*One of my best memories from the day was the many people who came over to ask me about what Angelman syndrome was, including a young lady who knew someone with an Angelman baby but hadn't really spoken to the parents about it as she was afraid and didn't fully understand the condition.*

*I'm no expert but I hope I was able to educate a few people and raise awareness of Angelman Syndrome.*

*It was a fun idea to dress up too as this helped to stand out more but my advice to others considering something similar would be to apply some Vaseline to your neck if you want to run in a shirt and tie... hahahaha!*



Gavin and Lucy Smith



Derek Maytum



## Poppy Cartwright

*Hundreds of thousands of supporters; 43,000 runners; 1,700 calories burned; £1,552 raised (to date); 136 minutes of running; the 38th Great North Run (my 3rd); 18 degree heat; 13.1 miles; powered by 10 Jelly Babies and 2 ice lollies; 9 Red Arrows flying overhead; all for one amazing brother and a fantastic charity!*



## Caroline Bennett

*Oh my goodness it was definitely the toughest half I've done! It was hot and very hilly but the atmosphere was just amazing, the crowd was fabulous. I got given ice pops, sweets, oranges, ice lollies and even a cup of beer (which surprisingly went down rather well). The final mile was just fab with the support either side and managed to spot my family, including my 14 year old angel daughter, just before coming to the finish line! It was an amazing day and experience I won't forget although my time was much slower than I've done, I achieved my aim of completing it with a smile on my face and raised lots of money in the process!*

## new trustees

Hi, I'm Jenn Smith. Being a trustee of AngelmanUK is something I had wanted to do for a number of years. After recently completing a Masters degree in graphic design & art direction I can now give the role the attention and dedication it needs, complimenting this with part-time freelance work.

So a little about our family...

I live in Hull, East Yorkshire, with my husband Adam and our 14-year-old son Alastair (AS). As a family we love to be active, love to travel and love good food!

Adam works in Leeds as an Infrastructure Specialist, is charismatic and has a love for fixed gear cycling and fine beer.

Alastair attends school full time (for a rest we always say), is making strides with his AAC thanks to the wonderful support of AngelmanUK and is striving to be a typical teenager. His favourite hang outs are at live music events or kayaking in the sea.

As a trustee I hope to bring both positivity and empathy. I am a big believer that despite Alastair's disability we can do anything we put our minds to yet I know all too well the barriers



society, your postcode and professionals can put in the way.



# fundraising



## Ross Nightingale

What started off with me just wanting to complete a sponsored run and get a few friends and family to sponsor me, turned into a large-scale charity event that grew arms and legs. We have had an incredible few months and everyone's support and willingness to get involved has honestly been overwhelming. So many people have offered to help in any way they could. I have had emails and messages from near and far, of people offering their kind words and support or just wanting to donate. Considering I temporarily live in Beijing until next year and colleagues here don't overly know my son James or anything about Angelman Syndrome, everyone's efforts to raise the awareness and much-needed funds for people affected by this rare condition has been incredible.

So far, we have held:

- 1) A football tournament
- 2) A 24-hour cyclathon
- 3) Myself, my sister and a colleague have run 100km (10km everyday for 10 days)
- 4) Cake sales
- 5) Juicing sales
- 6) Video made for Angelman Syndrome with over 5000 likes & 100's of people sharing on Facebook
- 7) Charity event at the Embassy

We have currently raised over £7,000 but we are hoping for more!

You don't have to run a marathon to raise money, so here's a big thank you to a few of those lovely people who've found lots of other fun and clever ways of raising funds for

angelman<sup>uk</sup>

## Maria Alvarez

I got married last 15th September in Bilbao (Spain). All my loved ones were going to be there. It was the perfect occasion to bring awareness about Angelman Syndrome as well as the fantastic work AngelmanUK does to help families. For that, we gave our guests the beautiful AngelmanUK bracelets. We

didn't want to give it without explaining what Angelman is so we put the bracelets inside a bag with a paper inside explaining what's about.

Our lovely niece Martina, a true example of a fighter and the protagonist of this story - together with my other two nephews brought

us to the altar the rings and wedding tokens (wedding paraphernalia used in Christian wedding ceremonies in Spain). She was smiling the whole day and we are so grateful that her parents made the effort to come. We know how pain airports can be...

We love you!!





## Gemma & Julian Munsey

On Sunday 7th October, supported by family and friends, 4 year-old Ava Munsey completed a one mile sponsored cycle ride raising nearly £3,000 for AngelmanUK.

We are fortunate that many people take part in sponsored events to raise money for AngelmanUK. Normally it is the mums or dads, brother or sisters, other family members or friends of the family of our Angels. What makes this event a little different is that Ava has Angelman Syndrome.

During the Summer Ava received an early birthday present, a purple Tomcat trike. It quickly became apparent that going for a ride provided Ava with an enormous amount of enjoyment and independence - well, as much as you can have with dad chasing behind hanging on to the control stick!

It was whilst out for a ride a little boy who lives a few houses away asked if he could join Ava for the ride. He had plenty of questions about Ava, Angelman and her trike. The one he was most concerned about was 'how far can she go?' From this the idea was born.

The day itself went very smoothly. Bathed in glorious October sunshine, Ava, was joined by her friends, cousins and baby sister Anna for a ride along the Phoenix Trail just outside of Thame, Oxfordshire. We are pleased to report that Ava completed the mile with only one quick stop to take a photo and to allow everyone to get to the finish line to cheer her on.

Ava and her parents, Gemma and Julian, would like to take this opportunity to say a massive thank you to everyone who provided support and sponsorship.

When Ava is not on her trike, she also spends her time horse riding and swimming. Watch this space for an update on her next fundraising adventure in 2019...



## Miles Cave

We held a charity dance with raffles and tombola with prizes and hot food all donated by the organisers. It was a big night with lots of fun and dancing. Brody's nanna and grandad (Jane and Keith Barkley) go every week to the ballroom dance and George and Mary along with the group choose a charity every year for this special night. This is the second time they have held the event for Assert/ AngelmanUK. Brody was the star of the night and he loved being the centre of attention with everyone talking to him or giving cuddles. He loved sitting watching everyone dancing and getting involved with the waltz with Brody and I spinning around on the dance floor. He was a superstar. It was a fun night and everyone had lots of fun. When we left Brody and I walked round and said thank you to everyone. He enjoyed himself so much he was telling us all about the fun had on the way home and when we got home he was asleep in seconds.



## Sue Cherrington

I was pleased to have been presented a cheque from the Circle of Friendship lodge in Harrow for £1000 for AngelmanUK. The photo shows myself and Jack accepting the cheque from the Chairman, Mr Vic Webber.





# fundraising

## Sheila Meadows

We did it, God it was tough! Whether because of the heat and the terrain or whether because of our age, I was over 25 years older than anyone else, but the feel of sheer exhilaration to have achieved, we walked every step of the 45 miles, slept with the sand in our tent, enjoyed the company, they were a wonderful team. The Sahara is just so amazing hard to describe the sheer size of nothing but sand, it looks like what I imagine the surface of Mars would be like, the light, the way our Berber leader knew where we were and how to get to the lunch time tree!! It was out of this world. I feel proud and privileged and thinking of Gareth and how hard he has fought to walk and keep walking gave me the strength to keep going.



## Felicity Moy

Over 100 people came to our local park on 20th October 2018 to walk with Ruby to celebrate her taking her first steps a few months before. After a lot of training Ruby managed the walk very well (with a few 'Ruby Rests' along the way). It was very emotional for us seeing how many people came to show their support and love for Ruby. Thanks to everyone who walked on the day and donated on Justgiving we raised an amazing £5,500. We cannot think of a better charity for this money to be going to. Thank you AngelmanUK; we wouldn't be where we are without you!!



**Morgan Baker** took part in the Velothon Wales and raised over £290 for AngelmanUK.

## Lisa Court

Fantha Tracks raised £445 for us by selling signed photos, books and posters of our patron Gareth Edwards over two weekends at Star Wars Fandom Zone at London Film and Comic Con and Fantha Day 3. We are very pleased to say that Fantha Tracks will be raising more funds for us over the coming months with more signed items from Gareth. A big thanks to Mark Newbold who has co-ordinated all of this fundraising for our charity. Mark kindly came along to our conference in August with his wife Ruth to present us with the cheque.

**Andy Coe** Mel and I have been fostering for many years and have

looked after a lot of children. Emileigh came to us as a very young baby, five weeks I think, and it was obvious from the start she was different. She was diagnosed with AS some time later. As time went on we realised that she was part of the family and decided to adopt. This was finalised at the end of August and we had a celebration of this with family and friends. We asked for donations rather than gifts and so far we raised £70.







# fundraising rugby

AngelmanUK Charity Rugby Event on Wed 21 Nov

Hi I am Andy Stephenson and I am the father of a 12-year-old daughter, Hannah, who's recently been diagnosed with Angelman Syndrome (AS). From a young age we realised Hannah had some form of special educational needs. After countless hospital, consultant and specialist appointments, we finally received a diagnosis just over 6 months ago, through genetic testing carried out by the Centre for Life, a science centre in Newcastle-upon-Tyne. What a shock!

Approximately 4 months ago, I was racking my brains as to how I can raise awareness and assist AngelmanUK. As a passionate father and rugby player, I decided I would reach out to my immediate and rugby family, to plan a charity rugby fixture and evening. Amazingly, once I got to work with this idea everyone around me rallied around and chipped in with the organisation. We sent letters, emails, knocked on doors and spoke often about Angelman Syndrome and the effects to

Hannah and the family, all extremely useful as we planned the event!

Via a few close contacts and loads of bags of cheekiness I managed to source referees, pitch side first aiders, a live band, one of the best rugby stadiums in the English premiership, over

50 rugby players, over 60 raffle prizes and an Ex England and British & Irish Lions VIP guest. Not bad from an idea 4 months ago!

The two teams to play the fixture were my works team Royal Army Physical Training Corps (Apostles RUFC) and Durham City Clems Pirates! The game and event took place on Wed 21 Nov under the floodlights of Kingston Park, both teams warmed up in the AngelmanUK/Assert blue T-shirts. Within the stands family friends and spectators held Angelman flags, balloons and banners. For me the highlight was running out through the extremely well received guard of honour (tunnel) onto the pitch with Hannah and the rest of my family cheering and thanking all the players. The game was well-balanced and evenly contested in true rugby fashion as the Pirates won the game beating the Apostles 26 – 19. Pirates team

manger Andrew Oxhamsham picked up the Angelman Trophy from Mr Tim Payne (England and British & Irish Lions, European Cup Winner) now part of Newcastle Falcons conditioning team, we thank him for his support and time.

Following the game we had food and drinks in the 1877 stadium room, with amazing live music from the Tailgate band. After the match we then completed the auction and raffle (organised by my wife Nicola, sister Racheal and cousins Danielle and Hayley) to the happiness of the winners! Whilst struggling to hold my emotions together I thanked everyone for their support and we closed the event down with more live music... just a shame it was a school night!

We will look to replay the fixture at Durham City Rugby Club next year.

**Andy Stephenson**



help us to help you keep

# smiling



## donations

Without your contributions there would be no AngelmanUK to offer support for your family. Whether big or small, every penny really does make a difference. A very big thank you to...

Mrs Hazel Tait

David Roberts

Ed Duffy

Rockwool Ltd

The Recruiting Sergeant Pub & Restaurant

Roseacre Social Fund

Mrs K J McArdle & Mrs D A Welland (in memory of their father)

Mrs Jan Moir

Forest Quilters

Caldy Valley Neighbourhood Church

In memory of Keiran Bridges

Mr & Mrs Knapp

Alfie Hallam & Thomas Burkett

Wedgwood Cricket Club

Sarah Cokerton & Lexis Ball

Loughton All Saints C of E Primary School, Sheffield

Hannah & Rhiannon Hewitt

Forest Quilters

Mrs D Welland

Kendal South Westmorland Rotary Club

In memory of Deborah Tampsett

Fantha Tracks

Christyan Fox's Children's Book Students

Circle of Friendship Lodge Harrow

Mrs Fox & Mrs Stratton

In memory of Mr Robert Francis

Corporate Travel Management

Gwen Elliott

Charlotte Walker

Seraosha

Stephen Roberts

Robert Brashier

Anna Duenbier

Janet Cockbill

Appealing Properties, York

## fundraisers

You've read about the efforts of our fabulous fundraisers elsewhere in this issue. Why not get involved yourself and organise an event to raise money for us. Contact [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org) and she'll send you a fabulous fundraising pack with all the details of how you can get involved.

Caroline Bennett	Great North Run
Poppy Cartwright	Great North Run
Derek Maytum	Great North Run
James Johnson	Great North Run
Keeley Anderson	Great North Run
Phil Thomas	Great North Run
Gavin Smith	Great North Run
Lucy Smith	Great North Run

Neil Winkworth	Summer of Endurance
Morgan Baker	Summer of Endurance

Tom Moore	Cycle Ride
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Ross Nightingale	10k for 10 days
Ross Nightingale	Great Scottish Run

Slorach Wood Architects	Slorach Wood Charity Walk
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Lucas Thom	Skydive
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Sheila Meadows	Sahara Desert Trek
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Rich Williams	Swansea Bay 10k
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Helen Mepham	Thames Path Challenge
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Felicity & Dean Moy	Walk for Ruby
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Gemma & Julian Munsey	Ava's Bike Ride
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Patricia Bothwell	Patricia's Walk
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