

# hello

angelman   
support education research

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Communication  
and Literacy  
Conference 2019

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IAD - International  
Angelman Day 2019

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Young Carers  
Awareness Day

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The Angelman Rally

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Carers Week

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Fundraising report

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**#64**  
spring 2019





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Welcome to the first newsletter of 2019. It's been a year of changes at AngelmanUK, and along with our new name and rebranding we have a brand-new website which should be live by the time you receive this newsletter. It will still be accessed at [www.angelmanuk.org](http://www.angelmanuk.org)

The trustees, Diane in particular, have put a tremendous amount of work into the website and we hope you find it informative and enjoyable to look at. Please get back to us with any feedback, good or bad. We want to make using it a pleasurable experience for parents and professionals and we are happy to listen to what our families say.

Our second Communication & Literacy conference is being held this year at The Hilton Hotel, Coventry. Friday 11th October is purely for professionals to attend so please do invite your teachers, Speech and Language Therapists and anyone else on your child's team. There is a higher charge for professionals, however we are offering 3 places for the price of 2, which makes it a bargain! Families and people with AS are welcome to attend on Saturday 12th and Sunday 13th October. A Zoo trip is planned for Saturday and we have family workshops arranged for Sunday. This was a hugely successful last time even if it was a little chaotic at times! Please see page 5 for details on how to book.

There are 6.5 million carers in the UK and every single one of our Angelman Families consists of family carers and sibling carers. It's a hard job as we all know; but it can be tremendously rewarding. Carers week this year is 12-16th June and has the theme 'Getting Carers Connected'. This could be connecting to other carers, to support groups, to services or even to technology. See pages 14-15 for some ideas and if you would like to organise a regional event for carers in your area please do get in touch with us before 27th May. This will give us time to circulate information to our members. AngelmanUK is keen to support this initiative and a small budget can be allocated to help with expenses if necessary.

Finally, we sadly say thank you and goodbye to our sibling trustee Jonathan Allen. Jonathan's parents were part of the original group of families who formed ASSERT many years ago and it's been a pleasure to have maintained that family involvement. The wheel keeps turning however, and Jonathan is leaving us as we head into the future as AngelmanUK to concentrate on his family and his career. In his place we would like to welcome Sian Allen (no relation despite the same surname!). Sian is 24 and has a brother with AS, Gareth. She is very keen to work with us on new projects and is already active in the sibling Facebook group. We look forward to working with her on exciting future projects.

**Rachel Martin, AngelmanUK**

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. See pg5 for booking details.

## family conference

**28-30 august 2020**  
**Hilton Hotel, Coventry**

You can read all about last year's family conference on pages 4-5 of our previous newsletter (issue no.63). If you missed it in 2018, you'll definitely want to make a note in your diary for the next one in 2020.



## angelman<sup>uk</sup> awards

Huge congratulations to film makers Molly Brown and Lottie Fox-Jones (who is an AS sibling) for winning TWICE this year

for films submitted to The National Charity Film Awards 2019. Our film 'What does AngelmanUK mean to you?' won the silver prize and a film made for Woodlands School in Surrey (attended by many of our children with AS) 'Welcome to Woodlands School' won the bronze prize. Molly and Lottie are both very talented ladies and AngelmanUK is very proud to work alongside them.





# what is communication?



So often in the world of Angelman Syndrome we talk about alternative communication and how we can improve that for our loved ones. But how often do we stop and think about what communication is? When we consider communication, how can we then help those with Complex Communication Needs replicate it? Communication can be complex or simple. It may be a legal contract with very sophisticated terms and jargon or it can be a smile. A worthwhile exercise is to think about your own communication over the last week.

- Who did you communicate with?
- What methods of communication did you use?
- Why did you communicate?
- How do you change your communication depending on the person, place and tools available to you?
- What opportunities did you get to communicate?

Put simply we communicate for connection. When we think about this it is easy to see that the majority of people with Angelman Syndrome are very good at connection and therefore communicating. So let's know think about the same set of questions for the people with Angelman Syndrome that we know?

- Who do they communicate with?
- What methods do they use?
- Why are they communicating?
- Can they change their communication depending on circumstances?
- What opportunities did they get to communicate?

In considering these differences we can think about what ways can we help people with Angelman Syndrome communicate? How can we help their communication be understood? One

way we have been working on recently is the use of video. Leia has quite a few different signs and gestures, some of which are much more obvious than others. I have compiled a list of all her different signs and we are currently trying to capture them all on video so we can share with the new people who come into her life. We have also added some communications that could be considered challenging but have tried to do this in as sensitive a way as possible by keeping the clips very short.

The first step in a communication journey can simply be recognising the communication that the person already has. What are all the different ways that your person with Angelman Syndrome communicates?

Tracey Campbell

# communication and literacy conference 2019

angelman<sup>uk</sup>



## who Speakers

**Jane Farrall**  
Speech & Language  
Pathologist & literacy expert

**Tabi Jones-Wohleber**  
Speech & Language  
Pathologist and Assistive  
Technology team member  
for Frederick County public  
schools, Maryland, USA

**Erin Sheldon**  
Literacy & Language  
development specialist for  
Assistiveware and mother  
of a teenage daughter  
diagnosed with AS

**Chris Oliver**  
Prof. of Neurodevelopmental  
Disorders, Director of  
the Cerebra Centre for  
Neurodevelopmental  
Disorders

**Rosie Clark**  
Head Teacher, Woodlands  
School and PODD trainer

**Livvy Hepburn**  
Teacher at Manor Mead  
School and PODD trainer

**Carly Hynes**  
Senior leadership team  
Sandfield School

**Tracey Campbell**  
Communication Support  
Trustee for AngelmanUK

## when

**Professionals**  
Friday 11 October

**Families**  
Saturday 12 and  
Sunday 13 October

## where

The DoubleTree Hilton Hotel, Paradise Way  
Walsgrave, Coventry, CV2 2ST

## info

**Friday 11 October**  
(registration 8.15am) 8.45am - 4.30pm  
Professionals £150 (3 for 2) including lunch and  
refreshments. CPD available.

**BOOK ONLINE**  
[www.regonline.com/angelmanukpcc2019](http://www.regonline.com/angelmanukpcc2019)  
• Please book accommodation directly with the hotel.

**Saturday 12 October**  
(registration 8.00am) 8.45am - 4.30pm

**Sunday 13 October 9.00am - 3.30pm**  
Two days, one night. AS free Adult £150 Carers £50  
Child (4+) £50 (Non-AngelmanUK family adults £200)  
Including meals, refreshments and accommodation.

Parents' conference includes Saturday Zoo trip and  
Sunday hands-on family workshops.

**BOOK ONLINE:**  
[www.regonline.com/angelmanukfcc2019](http://www.regonline.com/angelmanukfcc2019)



**WEAR JEANS  
CHANGE LIVES**  
Mon 16 to Fri 20 Sept 2019

Jeans for Genes Day is the annual fundraising campaign for Genetic Disorders UK, the national charity that supports individuals and families affected by a genetic disorder.

Monies raised fund the work of the charity and provide grants to organisations for projects that aim to transform the lives of children with genetic disorders. Genetic Disorders UK is the national charity working to improve the lives of individuals and families living with a genetic disorder. They do this by providing resources and support directly to those affected, and to the charities and patient groups dedicated

to a single genetic disorder or related group of genetic disorders. We are thrilled that AngelmanUK has been the recipient of a grant from GDUK in recent years: we received £10.5K for our 2016 family conference and £5k for our 2018 communication project.

It is their mission to raise the profile and promote understanding of genetic disorders among the general public, which they do through their one-day fundraising event, Jeans for Genes Day. You can raise awareness and funds by getting your colleagues or school friends to donate money in order to wear denim clothing or jeans to work or school and this year you can choose which day or days is best for you! Remember to use the hashtag #jeansforgenes when you post selfies rocking the double denim look!

For more information, a community toolkit or a donation pack please contact Jeans for Genes on their hotline number 0800 980 4800 or check out their website:

[www.jeansforgenesday.org](http://www.jeansforgenesday.org)

## what

**Topics to be covered include**

- Communication and Angelman Syndrome
- Teaching Literacy to people with Complex Communication Needs
- Model as a MASTERPAL
- All things AAC
- PODD, Proloquo2Go and more...
- Your children and your school CAN!
- Maintaining Motivation and much more...



# IAD international angelman day

15 February 2019



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## A round-up of some of the events across the UK

The purpose of this day is to:

- Raise awareness of the condition worldwide.
- Mobilise people to action and encourage fundraising for the individual organisation in their country.
- Promote research and educational resources in the organisation's own country.
- Remember those people with Angelman Syndrome who are no longer with us.

AngelmanUK families met at various locations over the UK to celebrate and commemorate this special day.

**South Central: Andrea Baines**  
**Thames Valley Adventure Park**  
We had a lovely day at the South Central IAD meet up, at Thames Valley

Adventure Park. 12 families attended, approx. 25 people for a double celebration – not only was it IAD but it was also Bobbi-May's 7th birthday. Thank you to Carolyn (Bobbi's mum) for the snacks and everyone enjoyed the birthday cake and singing Happy Birthday. It was great to meet a couple of new (to me) families too, especially the Dhanjal family who were part of the original Angelman Syndrome Support Group (ASSG).

**Scotland: Tracey Campbell**  
**Glasgow Science Centre**

The Scottish International Angelman Day was held in the Glasgow Science Centre on Saturday 16th February. We had 6 individuals with AS ranging in age from 2 to 42, with their families a total of 26 people.

The Science Centre was a bold choice and I did have visions that we may never see one another once we had entered the Science Mall - there are 3 floors of exciting and interactive exhibitions, all cleverly designed to engage everyone regardless of their scientific background



– it was so engaging and overwhelming we could have had 26 people running around over 3 floors for several hours! However, the worries were unfounded. Everyone had a lovely time, with enough time to chat, play and join in the science shows too.

The Science Centre staff were very accommodating and helpful from booking right through until we left (and afterwards when I had to phone and ask if they had my bank card, which they did!). They also gave us access to a large room where we could have coffee

and relax in the afternoon. Well that was the plan, the reality turned out to be a game of tag for the best part of an hour. Exhausted and happy, all that remained was to thank the staff for a lovely and enjoyable day. Great to catch up with old friends and make new ones. Looking forward to the next one.

**East Anglia: Gemma Dineen**  
**Banham Zoo, Norfolk**

The Large and Dineen families enjoyed a day out at Banham Zoo to celebrate IAD.

**N.Wales & N.West: Rachel Martin**  
**Warrington Sensory Play Centre**

This year the North West region once again went to the Warrington Sensory Play centre. We had approximately 100 people who all brought food to share and it was a real party atmosphere. As usual we met up with familiar faces and made plenty of new friends. The staff at the Sensory Centre are always helpful and we've been going for so long now they know most of our families well. The centre is designed to be suitable for all

ages and is built with adults and carers in mind. The younger ones enjoyed the ball pit and the sensory room, and the siblings hid themselves away in the dark room or took advantage of having a slide big enough for them to run up and slide down unencumbered.

**Central: Lisa Court**  
**Nuneaton Sports Centre**

We had a lovely few hours in Nuneaton to celebrate IAD. As in previous years, we had a good mix of new and familiar faces. The kids had a blast on the bouncy castle and soft play and there was some very competitive football being played by the siblings! We celebrated Bobbi's birthday with song and a cake. There was an abundance of cakes and some delicious samosas to share. All in all it was a very successful afternoon enjoyed by adults and children alike.

**Yorkshire: Jenn Smith**  
**The Eureka Museum**

It was great to meet so many new families at the Yorkshire meet up at Eureka.

The museum provided fun for all ages and I think our party covered them all! While everyone explored the 2 floors independently, the joy when you turned a corner to find another family already exploring an exhibit meant you just had to join in!

**Surrey: Diane Fox-Jones**  
**Burview Hall, Walton-on-Thames**

For the third year running the South East regional IAD was held at Burview Hall Mencap Centre in Walton-on-Thames. Luckily it was another beautifully sunny day so we were able to make full use of the specially designed venue which includes a fantastic outdoor play area and even a small woodland. The venue also has a large sensory room and hall. This year the games room was used for filming but we managed to move the table tennis table and football table into the hallway so that no-one missed out on the fun. The event was very well attended and we had chance to meet quite a few new parents as well as time to catch up with old friends over tea and biscuits.



# your new **angelman**<sup>uk</sup> website

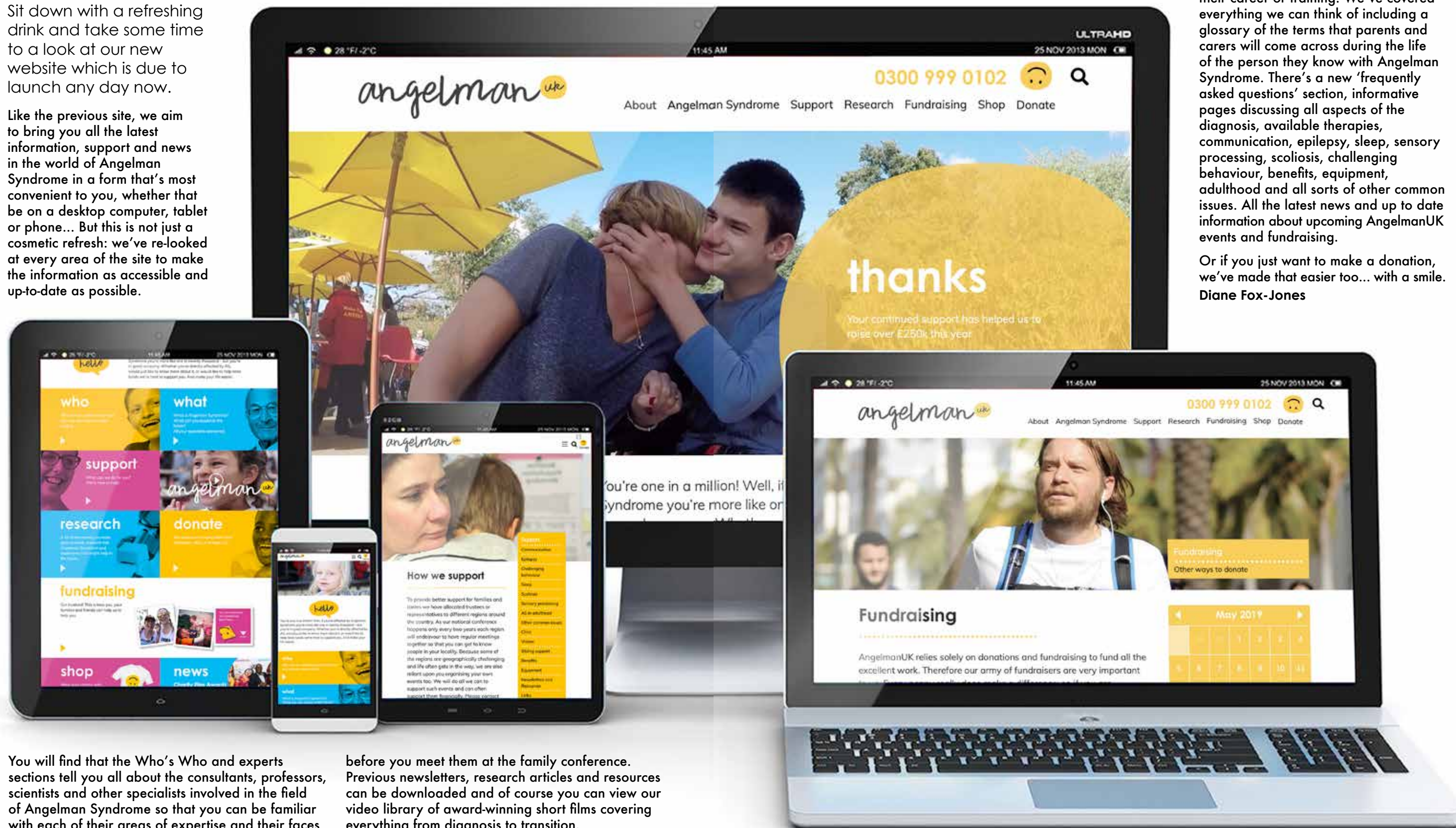
Sit down with a refreshing drink and take some time to a look at our new website which is due to launch any day now.

Like the previous site, we aim to bring you all the latest information, support and news in the world of Angelman Syndrome in a form that's most convenient to you, whether that be on a desktop computer, tablet or phone... But this is not just a cosmetic refresh: we've re-looked at every area of the site to make the information as accessible and up-to-date as possible.

We've spent the past year in making the new site as informative as possible for all those involved with Angelman Syndrome at any level. Parents and carers of newly diagnosed children can feel comfortable learning about the new experiences they are

encountering from their home environment. Our more experienced parents can visit the site and find information about the next stage in their child's life. And professionals and students can look at the AngelmanUK website in order to find out about the Syndrome, sometimes for the first time in their career or training. We've covered everything we can think of including a glossary of the terms that parents and carers will come across during the life of the person they know with Angelman Syndrome. There's a new 'frequently asked questions' section, informative pages discussing all aspects of the diagnosis, available therapies, communication, epilepsy, sleep, sensory processing, scoliosis, challenging behaviour, benefits, equipment, adulthood and all sorts of other common issues. All the latest news and up to date information about upcoming AngelmanUK events and fundraising.

Or if you just want to make a donation, we've made that easier too... with a smile.  
**Diane Fox-Jones**



You will find that the Who's Who and experts sections tell you all about the consultants, professors, scientists and other specialists involved in the field of Angelman Syndrome so that you can be familiar with each of their areas of expertise and their faces

before you meet them at the family conference. Previous newsletters, research articles and resources can be downloaded and of course you can view our video library of award-winning short films covering everything from diagnosis to transition.



January 31st was Young Carers Awareness Day! Here we celebrate some of our sibling's stories caring for a brother or sister with Angelman Syndrome.

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**Betsy** is 7 and is a young carer to Rufus who is 5. She takes it all in her stride most of the time but does worry when he's unwell. When he first started having seizures she was constantly on the lookout for one, quite anxious for a time, checking on him all the time and notifying me if he did anything unusual. Now they're under control she is more relaxed. She helps me when we're shopping and I push the trolley with the baby in while she pushes the wheelchair. She gives him toys in the car if he's getting impatient, shares snacks with him while I feed the baby, grabs a clean nappy and wipes if we're in the middle of a toileting predicament. She has eyes in the back of her head while we're out and about and grabs his arm if he's about to pull a stranger's hair or touch a random person's hand. She puts up with a lot of hair pulling, grabbing, being 'slobbered on' as she calls it, being woken in the night and having to watch his same favourite films over and over. She helps model his AAC and puts things on for him to watch/play on his iPad. She's a bit 'grossed out' by some of the things he does at the moment and is completely besotted with her baby sister so he doesn't get half the attention that he used to when she was younger. I'm hoping that's just a phase but equally, there's no pressure. She knows we have an expectation that everyone in the family helps each other out if they can so hopefully that attitude will become engrained. She's just started going to a Young Carer's club once a month and a siblings' club at Rufus's school every week so she gets her chill out time and also a chance to chat about feelings and what's been going on at home.

**Freddie** is the 'third parent' in our house! He is always on hand to help with Penny or Ollie whilst I'm dealing with the other! We wouldn't be able to do half of the activities we do if Fred wasn't as proactive and mature as he is. He is so thoughtful and kind which I'm sure is partly down to having a sibling with AS. His life certainly isn't as easy as his peers but it is so full of the love and fun that comes with Ollie!

**Miss Ruby** is a younger carer for Shay. She helps him walk, communicate and everything in between. She knows to lay Shay down and keep the area safe when he's having seizures she will talk to him and reassure him. Ruby also recently saved his life by alerting me to him choking when I wasn't in the room. She found my phone and called for the ambulance while I was saving Shay. She then went around and packed a bag ready for our hospital stay. Ruby is the most amazing, caring, thoughtful little girl at just 10 years old. Even though her life is harder than other children's she never complains. I couldn't be anymore proud of her.

**Harris** is still only 6 but a great modeller for Tilley. He knows her traits and what she is trying to communicate. Since her diagnosis he is so much more aware and caring to anyone else who needs any extra support. Im sure hes going to grow up with Tilley to be the best, most supportive big brother.

**Sam** (17) was just 3 when Hannah (14) was born so he can't remember life being any different. He has had to grow up much quicker than his peers. Over the years he's had to face many challenges that being a young carer brings with it ..... having his sister taken off to hospital during the night, having plans changed at the last minute to simply having to have her needs come before his. In 2013 Sam was awarded the Wellchild Most Caring Young Person award .... it was a fantastic moment to see him being recognised although he couldn't see what the fuss was all about.



**Becky** is 16 and young carer to Lucy 23. She's like many other young Carers in that she has never known life without her caring role. She takes it all within her stride. Becky has become a very strong person who has had to face various obstacles along the way, in particular her sister's extreme challenging behaviours. She was once a very shy person and when she was 11 with the help of Barnados Young Carers she was introduced to singing and learnt to play guitar. She has since won awards in national singing competitions for her singing and songwriting skills and performed for vast audiences such as the Leeds 02 academy and the Barnados AGM in London. She often mentions her sister and AS whilst on stage helping to raise awareness of the Syndrome. She has also bungee jumped over the sea to raise money and awareness. She makes us very proud of all she has achieved at such a young age.

**Stewart** - Scott's twin brother - did a large photo exhibition on Angelman Syndrome while he was at university, raising a lot of awareness with help from other Angelman families. He got married just over a year ago and made Scott the ring bearer. The ring was tied to a silk cushion so it could be carried from Scott's chair down the aisle with a one arm support from his dad, passing it to Stewart who unfastened the ring. Scott got a round of applause from the guests so was very proud of himself. His older brother has appeared in a few TV shows and mentions Angelman syndrome wherever he can. He's a regular on local radio and has raised a lot of awareness explaining in detail about Angelman Syndrome and his brother. Scott also has another brother, **Nathan**. He's very spoilt by both and could not ask for two better siblings. I am very proud of how they both overcame the often difficult times siblings face and giving up many things over the years to put Scott first and become the men they are today.

**Tao** will be 16 in 4 weeks' time and turning into the most gentle, thoughtful and caring young man I've ever met. I have been a single mum to Indy (11 with AS) and Tao (16) for the majority of their lives and couldn't have done it without my son's help. When big brother is around then no one else will do. Watching him care for his little sister makes me the proudest mum on Earth. Tao has had the weight of the world on his shoulders at times over the years, whenever Indy's been hospitalised you can see the fear on his face but he's stayed strong for me and Indy through every second. I honestly believe that having the love of an Angel in his life has helped him to become the best he can be.

**Ryan and George** are both young carers for their big brother Matthew in different ways. Ryan is 14 months younger than Matthew so even from toddler age he has helped with feeding, encouraging play, helping with portage too. Matthew used to hate the physio and OT programme we'd been set by Brainwave so Ryan used to do it all first, even at 2, and then help Matthew do it. He has been his voice for almost 8 years as well as standing up for him whenever he needs to, he's always been proud to say "That's Matthew, he's my brother and he just needs you to give him time and help him". Even last week he had to tell his friend to stop copying Matthew's noises or he wouldn't play with him, to me that shows great maturity, he could easily ignore it and become embarrassed. The little one - George - is already showing caring signs; he cleans Matthew up after dinner, helps bath him and blows bubbles for him. The days Matthew goes in his wheelchair he is straight in, lifting his feet up to put the foot rests down for him and wants to push him. Lots of tears and lots of giggles with the 3 of them, so proud of each of them individually and also suffer an enormous amount of guilt for how much harder their lives are from their friends.

**Spencer** is 14 and young carer to his sister, 9. Spencer was 5 when Sophie came along and he has always loved having a sibling - since diagnosis and epilepsy creeping into our 'normal' Spencer has just got on with life and is so incredibly understanding when plans change, we have to leave earlier than others and just understanding that we need time as a couple, so he is always happy to help out with Sophie when grandparents or assistants are with Sophie. Sophie adores her brother who really has grown up into a very caring, considerate and thoughtful young man - we are very proud of who he has become.

**Joel** age 12 does a lot of little jobs and will watch his brother if I need to do the simple things in life... like go for a pee!  
Dan loves his brother and regularly squashes him with proper Angel hugs.





# angelman rally



On the 16th of May, Henri's dad, Xavier, will be doing a sponsored motorcycle ride, with two friends, from Surrey to Mt. Etna in Sicily for AngelmanUK. They have a huge backing from the motorcycle industry and on their return on 2nd June the finishing line will be at Burview Hall, Walton-on-Thames, where Henri's mum Corinne Burns will be hosting a fundraising fun day for Angelman families to welcome home our riders. The event is called the Homecoming Fundraiser and all are welcome to join in the fun. We here at AngelmanUK want to give them all the support we can ahead of their ride, so we caught up with them before departure.

Preparations are well under way but let's start with their story. After 6 years of IVF, Henri was born in January 2017 to two delighted parents who had hoped and wished for their little miracle to arrive for a very long time. Being a nanny, Corinne quickly started to realise that Henri wasn't hitting certain milestones and went to the doctor to start investigating. Henri was diagnosed with Angelman Syndrome at 7 months old. Naturally, this was a bit of a bombshell; Corinne remembers the first few months: "We had fought for so long to be a family and were over the moon to feel like regular people and not 'the IVF couple'. We were so in love with our baby, but I knew early that something wasn't right. I approached doctors about Henri's development but was brushed off several times as an 'anxious new mum'. We fought on and eventually, we arranged an EEG scan."

Corinne's persistence paid off and the EEG revealed Henri was having multiple

seizures. What followed was over two months in hospital where Henri was tested for everything they could think of.

Xavier explains what happened next: "I remember being sick with worry, terrified that my little boy was ok. I had no idea what was wrong and I spent every minute I could by his bedside. Corinne was on maternity still, but I had to go back to the office and work. My boss was so supportive – not once complaining or even asking for an explanation. I remember getting the diagnosis. I didn't fall to my knees and cry out to the sky like in a movie – after all, I'd never heard of Angelman Syndrome! I listened and comforted



Corinne (who had heard of AS)."

Corinne: "After we came home from the hospital, nothing was the same again. The house looked grey and abandoned, and Xav and I mourned the future we thought we had finally achieved. We clung on to our home for a little while longer, but we used the last of our savings to do so. Everything looked a bit bleak, but then Xav arranged with his parents to move us all in with them in an attempt to save money and rebuild our lives. Between working full time and being a dad, it took him 3 months to empty the house, put things into storage and move us into his parents' house. Xav was always very good at organising things and making things happen. Losing our home was a sad time, of course, but it mostly felt like an active step forward; which helped everyone's mental state."

Xavier: "Since being with grandparents, Henri has had stability and we have had time to focus on his development. Henri is a very charming, cheeky little monkey! His smile is like a ray of sunshine and everyone who meets him immediately loves him. From the moment he wakes up to the moment he falls asleep, he is a delight – a bit grabby – but a delight. He also loves water so, as chief of bath time, we quickly discovered that he is having a small riot with his toys splashing about. I work from home now to help Corinne and Henri and I am so lucky to get so much time with my son. He and I have a great bond and when I walk into a room he explodes with excitement to see me."

Henri and his family face a lot of challenges in the years ahead and it all seemed very overwhelming to Corinne

and Xavier, but then something happened: the spark of an idea.

Xavier: "I wanted to do something positive to help my son. I didn't realise it at the time, but I think my brain was going into survival mode and activating its own therapy! After the 2018 AngelmanUK conference and meeting Rachel, Lisa and so many families, I was inspired to do something in support of AngelmanUK who do so much for us families. I needed to do something for my own mental health too so, one evening, over a few drinks with two of my childhood friends, Dan and Graham, I voiced an idea – to run a half marathon! Much laughter was had by them both so, realising my limits, we felt a charity motorcycle ride would be more appropriate. We'd ride to Mt. Etna in Sicily raising as much money and awareness as possible for Henri and the Angelman community."

Corinne: "AngelmanUK have been a great help to us. I made good contacts through their social media and learned a lot about our son's condition, meaning we

were better able to support him. The rally has been a lot of work over the past nine months. As Xavier's original idea started to gather momentum, it wasn't long before a local production company got involved, which changed everything! Suddenly, we had a brand: *The Angelman Rally*! And a website too! More local businesses got involved and, as each one did, the ideas grew bigger and bigger! Far more so than we could manage on our own."

Xavier: "With a production company behind us, we were suddenly able to make content for social media and this meant attracting sponsorship for the ride. Triumph where the first company we approached and they were really supportive – more so than we expected – and as things grew, they got more behind us. Eventually, big international brands were approaching us at bike shows and newspapers were writing about us! The motorcycle world has really got behind the rally and, with it, the level of awareness we were able to reach has multiplied many times over."

The route will see the riders leaving leafy Surrey on the 16th May for Dover, skirting around Lake Geneva, over the Alps, and into Aosta, Italy. From here they will ride to Verona, where the famed painting 'Boy with a Puppet' by Francesco Caroto resides. It was this painting that inspired British doctor, Dr Henry Angelman to recognise the symptoms of his patients, leading to his ground-breaking research into the condition and the subsequent renaming of the disorder from 'Happy Puppet Syndrome' to Angelman Syndrome. Eventually, reaching Sicily via Bologna, Rome and then approaching Mt Etna itself. The return leg sees the boys riding the Italian west coast via Piza, then Genoa, before crossing the French border and cutting through Monaco, Montpellier and the record-breaking Milau viaduct – the tallest road bridge in Europe, and one of the tallest bridge structures in the world. The final leg of the journey will pass through Paris, and finally home to a warm welcome.

At the Homecoming Fundraiser event, supporters can look forward to a family fun day, delicious stone-baked pizza from StokedEats, and several different fun activities, all hosted by Corinne and her sister-in-law, Elize. "We'll have guests from our business partners, local dignitaries and AngelmanUK itself – all captured on

film by *The Power Station*. Everyone is welcome and we hope to make it a great day for our Angelman families."

A major component of the endeavour is the production of a short film to bring awareness to a wider audience. Produced by *The Power Station*, the film will deal with themes including mental health and a father's perspective on family life as they face living with the condition and learning about AS from other families. The film will be released in December 2019

*The Power Station*: "We're delighted to be supporting The Angelman Rally and, having now met angels and the people who care for them, we are 100% invested in shining a light on this condition. We are keen to hear from people in the community who would like to be involved. (steve@power-station.com)"

For more information on the rally go to [www.theangelmanrally.org](http://www.theangelmanrally.org) where you can read more about Henri, the riders, make donations, buy T-shirts, express an interest in attending the Homecoming Fundraiser or simply wish them good luck. The website is full of photos and blog posts for you to follow. Make sure to follow them on social media and catch all their live updates during the trip. Contact Xavier directly at [xavier@theangelmanrally.org](mailto:xavier@theangelmanrally.org)



## save the date

A homecoming fundraiser will be held at Burview Hall Mencap Centre in Surrey on the 2nd June 10am–2pm. Don't miss it!





10th –16th June is Carers week. The theme this year is Getting Carers Connected.

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. It also helps people who don't think of themselves as having caring responsibilities to identify as carers and access much-needed support.

The campaign is brought to life by thousands of individuals and organisations who come together to organise activities and events throughout the UK, drawing attention to just how important caring is.

There are 6.5 million people in the UK who are carers. They will be looking after a family member or friend who has a disability, mental or physical illness or who needs extra help as they grow older. Yet many people don't identify themselves as carers, they simply see themselves as spouses, parents, sons, daughters, siblings or friends.

This means that many carers across the UK are not connected to vital information and support that can help them with caring.

#### What is a carer and how does caring affect you?

A carer is someone who provides unpaid care and support to a family member or friend who has a disability, mental or physical illness, substance misuse issue, or who needs extra help as they grow older.

Up and down the UK there are millions of people caring unpaid for an ill, frail or disabled family member or friend. These people

are called carers but they would probably say that they are just being a husband, a wife, a mum, a dad, a son, a daughter, a sibling, a friend or a good neighbour.

For some taking on a caring role can be sudden; someone in your family has an accident or your child is born with a disability as is the case for most Angelman families.

For others, caring responsibilities can grow gradually over time: your parents can't manage on their own any longer; your partner's or your child's mental or physical health gradually worsens. Some carers are classed as dual carers because not only do they care for their disabled child or sibling, they also care for elderly or aging parents.

Carers help with personal things like getting someone dressed, turning them in their sleep, helping them to the loo, helping them move about or administering their medication. Carers also help with things like shopping, laundry, cleaning, cooking, filling in forms or managing money. Caring for someone with a disability such as Angelman Syndrome or a similar condition involves helping with almost every aspect of the person's life, and most people with AS, regardless of their age or ability require full and constant supervision as well as full support. This can be incredibly tiring and emotionally draining for the carer. Not to mention the years of broken sleep which take their toll on our health and relationships. \*Please remember that if you provide care for over 35 hours a week, including night time care, and the person you care for is eligible for certain benefits, you are entitled to claim Carers Allowance. Information amount rates and criteria can be found at [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

Caring can be a rich source of satisfaction in people's lives. It can be life-affirming. It can help deepen and strengthen relationships. It can teach you a multitude of skills and help you realise potential you never thought you had. But without the right support caring can have a significant impact. Evidence shows that caring can cause ill health, poverty and social isolation. Carers often find it challenging to take care of their own wellbeing whilst caring. Its impact on all aspects of life from relationships and health to finances and work should not be underestimated. Caring without the right information and support can be tough.

This is why AngelmanUK is happy to support Carers Week by allocating small budgets to those who wish to organise a regional event which will facilitate carers getting together and connecting with other Angelman carers. This budget may not be enough to fully fund the event but it will help to subsidise the cost and will enable local carers to spend time with each other. If you would be happy to organise an event please contact us with your suggestion by May 27th at the latest. This will give us time to circulate the information to families in your area.

These events will be open to Angelman family carers only, they do not have to be child-friendly events and can be held on a weekday or evening.

The address to email is:

[support@angelmanuk.org](mailto:support@angelmanuk.org)

## Some suggestions are

- Coffee morning in a local café.
- Afternoon tea.
- Coffee, Cake + Chat in a family home.
- An information event – do you have a local Carers UK branch who could come to give a talk about local services or support groups? You could use a family home, café, village hall etc.
- A meal out for carers to meet up in a social setting.

These events will then be registered on the Carers Week website. If you wish to organise an awareness event at work or in your community about Angelman Syndrome and what being a carer means, AngelmanUK can supply printed media & merchandise and further resources about caring can be downloaded from the Carers Week website:

[www.carersweek.org](http://www.carersweek.org)

angelman<sup>uk</sup>





# guides

Girl Guides in Netherlee, Scotland have recently become involved in the Angelman community...

Leia is a 12-year-old girl with Angelman Syndrome who has been using PODD (both paper and app) for 4 years. She is very sociable and loves to join in but as she has grown older her anxiety and increased knowledge of her differences make this very difficult for her. She has been attending a local Girl Guides group for 2 years. Last year Leia went to Guides and enjoyed it – but she was more of an observer, never really joining in and very much keeping to herself.

I wanted to change that this year so I went into the Guide group not long after they returned from summer. I had prepared a handout for the girls. It contained a little bit of background about Leia, her likes and dislikes, explained a bit about why it is difficult for Leia to join in, her anxiety and why it is hard to be part of the group when you are the only one using a communication device. I then gave them some info about finding out more about how to use PODD. On the night I discussed communication, different means and reasons to communicate and that it is interaction, an exchange of information. We then did a bit of hands-on training

with the PODDs: first they said things that I asked them to and then asked them to use PODD to say what they had said today (this had been part of earlier discussion). They then went on with the rest of their night, using the talkers during activities. The girls picked it up very quickly, all with a preference for high-tech rather than the book. Leia absolutely hated me being there and talking about her but I put the night down as a success.

A few weeks after this and for a variety of reasons Leia's dad had to go and support her for one of the sessions, and he noticed a remarkable change; Leia seemed much more relaxed than previous times he had been there. During the evening, he could hear Leia's talkers being used in other groups. What a simple yet effective way to let Leia feel included. At one point in the evening they all came together to discuss communication, and a few of the girls were chatting over the leader. The leader decided to turn round, away from the circle until they stopped talking. Leia found this hilarious and as soon as the leader turned back round and started talking Leia turned around

in her chair. The girls were in stitches at her. Here was Leia not only present but participating and actually confident enough to be the star of the show!

A few weeks ago, it was International Angelman Day and the girls were doing a sponsored silence for AngelmanUK. During the hour the girls were allowed to use Leia's books and talkers (on silent). They did a fabulous job. Towards the end of the hour the girls had finished their activity and Leia decided to get mischievous. She started throwing bits of paper at one of the other girls and giggling, the other girl joined in. Fortunately, giggling was allowed! Other girls soon joined in and watched too. So lovely to witness not only Leia joining in, but her being the leader of this silent world and teaching the girls how to interact and have fun without the use of words.

Not every group will pick up the understanding and use of AAC so quickly but what a return for a couple of hours preparing and delivering training.

**Tracey Campbell**

## Leia's friend Megg

Hi I'm Megg, and I go to 1st Netherlee Guides. Recently we did a sponsored silence to raise money for AngelmanUK which is a charity that helps people who have Angelman Syndrome. The reason we are aware of this cause is that one of our fellow Guides, Leia, has this condition. Although we have noticed she acts differently to us, we all enjoy Guides and she is a really nice friend to us.

Unfortunately, Leia cannot speak so it makes it harder for us to know her better. Leia's mum helped us communicate with Leia and suggested we might like to try to live in her world

for a period of time. Doing our sponsored silence helped us understand what it might be like to be Leia. During the sponsored silence we found it hard to help other people with the activity or just communicate in general. Our leaders also found it difficult to explain how to do the activity without speaking aloud, which will help them to help Leia be part of Guiding.

The sponsored silence was a great opportunity for us to learn how to communicate in another way than talking. It also let us realize how often we chat about random things.

Through our sponsored silence we made over £400 – we are lucky to know some generous people.

# The Aunt's blog

I'm Bindu and live in Wellingborough, close to my brother Raj and his family. My niece, Nyra, was diagnosed with Angelman Syndrome (AS), aged 2.

Raj and his wife, Agna, had suspected something was wrong just before Nyra was one year old, as she wasn't doing the typical things someone her age would, and was missing milestones. After initially being advised Nyra is 'globally developmentally delayed', it took over a year for the medical professionals to diagnose the condition; they were finally told she had a genetic disorder, with the diagnosis of Angelman Syndrome (UPD) confirmed in August 2017.

I still remember the day Raj and Agna received the news and called me. I work in London and was just getting the train home when I took the call... and I cried all the way home. Part of me was in shock with the diagnosis, part of me felt helpless as I didn't know what to say or do – I'd never even heard of AS before. I used Google to learn more about the condition, wanting to find out more about the cure... quickly realising there was no cure.

We're a close family and myself, my parents and Agna's parents all spent a lot of time with Raj, Agna and their two other boys, Dhruv (7 at the time) and Sai (then 5). In the days and weeks following the news there were lots of tears all around. We simply did not know what to do to help take the pain of this news away.

For a while, I think Raj and Agna both ignored this was happening, maybe this was their way of dealing with the shock of it all. About 5 months after the diagnosis I was out of the country for a few months. I video-called the family regularly, and did not mention it, but deep down hoped they had starting facing the reality of the situation. When I returned home last summer I was overjoyed at the

transformation in them and their attitude to accept the condition for what it was. I was delighted they had started to find the help they needed to deal with the situation to ensure Nyra has the best future possible.

One of the biggest challenges we faced was how we could all communicate with Nyra, whether she understood what we were saying and how she would communicate with us. Raj and Agna researched extensively, trying baby sign language (and realising at this stage it will not work) but then found out about the communication system called PODD, based on the use of pictures to tell us what she wanted. PODD has become a daily communication tool, but we never really knew if Nyra understood the pictures – that was until we went on a family holiday to Cornwall in August 2018. Our lodge had a hot tub and we'd taken Nyra into it on the first night as she loves water, like most AS children. The next day after dinner we had the PODD open and asked Nyra where she wanted to go, she pointed to the garden picture followed by the swimming pool – she associated the hot tub with it being a 'swimming pool outside in the garden'. We were a little amazed and thought it was just coincidence. Anyway, the whole family went to the hot tub that evening to ensure we reinforced that we knew what she meant – and she loved it. The next few evenings, the same pattern happened, and we were overjoyed, especially the night when I asked her to go and get her swimming costume (drying by the door. She got off my lap, held onto the sofa and stumbled her way across the room to fetch it. We were all so happy that she understood and it gave us some hope for the future that maybe she understands more than we assume she does.



It has been a long year and a half since her diagnosis, but with a lot of support from Raj and Agna, and pushing from the rest of the family, Nyra has learnt to clap her hands and taken a few steps unaided – every little progress she makes amazes us, is a milestone to savour, and gives us the hope we all need for the future. Agna has given up work to become a full-time carer and spends a lot of time with Nyra each day helping her learn and develop.

Nyra's journey has only just begun, and the whole family have been amazed with the support of everyone we know – only time will tell what the future holds. But one thing is certain – we will never lose hope.

**Bindu Bakrania**



## new trustees

Hi, my name is Sian and I have a younger brother, Gareth who is 22 with Angelman Syndrome. I finished my degree in Product Design last year and have now moved to the South East of England with my boyfriend Jack, who Gareth absolutely loves! I still go home to visit my family as much as possible, but now Gareth is used to me not living

there and he usually just waves at me – his way of telling me to leave again! I work as a Nanny but try to use any spare time to work on my design

portfolio. Other than that I'm usually found socialising with friends.

I hope that my experience of growing up with Gareth and going through the transition into adulthood will help me to support others in my new role as the sibling support trustee and I look forward to getting to know everyone.

**Sian Allen**





# calum's story

*Calum was born in Inverness in January 1990. From his early days there were indications he was going to be different...*

Calum cried a lot, slept a little and missed a large number of the expected milestones.

Our doctor referred us to the Raeden centre in Aberdeen, a pretty unique place at that time and rather than try a number of different clinics we stayed in the centre for 5 days and the doctors and therapists came to us. We left after a week of pretty intense assessments and tests, not a lot wiser and with a diagnosis of 'global developmental delay'.

Calum was attending a special needs playgroup in Elgin. Ruth, a community physiotherapist, advised that Calum needed supportive footwear, cue the proverbial Pedro boots. Ruth really engaged with Calum and us, pushing hard on exercises, getting him up on his feet and walking a little. There's no doubt she was the reason he became mobile along with Joyce's determination to do the exercises and push equally hard. He often needed a wheelchair but he could manage around the house. Like all AS people Calum has a memory that would put an elephant to shame, he especially remembers people who buy him ice cream and people who do things to him he doesn't like, oh boy did he remember Ruth for the latter. He only had to see her walking through the town before yelling the place down. Ruth became adept at crossing the street and dodging into shops when she saw us coming.

When Calum was 4 we revisited Raeden and after another assessment and blood test, confirmed Angelman Syndrome deletion. We were given this news by a geneticist just prior to leaving the centre to drive home. This was 1994, there was no internet, and very little information except a leaflet from a Raeden doctor about ASSERT and the ASSG. We were fortunate in that ASSERT answered the phone first time and Richard Allen welcomed us into the ASSERT family and provided a load of information sheets.

In the '90s the 'system' sucked; health services knew little about AS and every

appointment started with Joyce and I delivering a teaching session. The Social Security system knew even less and didn't really want to learn about it. Without a diagnosis and an accepted keyword to 'pigeon hole' Calum into, everything was a fight or refused first time. We had a 2-year fight for DLA and ended up at a tribunal appeal, we still giggle when we recall the look of 'Oh, s\*\*t!' on the panel members faces when we pushed Calum and his chair through the door into the Hearing room, ensuring we bashed the door with the chair – Calum had the usual dribble-soaked bib and we were supported by a welfare rights specialist. It didn't take long for the Hearing and the decision was a full award of DLA, backdated for 2 years. We'll always be grateful to Albert from the Moray welfare rights group who supported us through that process.

Being Scottish and genetically frugal we knew we should be sensible with the back-payment and recognising our life was going to be different from most folks we considered long and hard how to best use it. Calum's older brothers had coped well with Calum but there's no doubt their lives were very different from their friends. Joyce and I elected not to be

sensible or Scottish and we took Calum and his brothers on a road trip to Lego Land in Denmark. We set off in our old Volvo estate, sailing on the ferry from Newcastle. Some 23 years later Calum will still use the Makaton sign for vomit and simulate puke when we mention a boat. I'm pretty sure DFDS must have the cabin clean by now. The holiday was great and something we never regretted. I think it also set in our minds that we could do normal things but just do them a bit differently with Calum.

Having an official diagnosis, a 'pigeon hole' word and a DLA award opened a whole range of things we could access to make life 'easier' according to the specialists. The tech was pretty low: the answer to the sleeping problem was to cut his bedroom door in half to create a stable door effect and safe environment. Calum loved this and became skilled in throwing anything moveable over the door – he was incredibly accurate with a dirty nappy. We had a wetroom that was essentially our bathroom converted with a drain in the floor and the bath replaced with a shower. We used a rucksack-type carrier to carry Calum about when the wheelchair wasn't suitable. My dad was a religious man and always told me I had a guardian angel on my shoulder looking after me – I'm sure it will ring true with many when I say I ended up with an angel on my shoulders dribbling on my head. We learned a lot of simple tricks to make life easier: child seat buckles turned to face inward stopped his escape antics in the car, a TripTrap Z chair was great for eating and playing on and kept him in place. Our Alvema buggy was a great piece of kit: comfortable, easy to use and it covered a great many miles.

Daily life with Calum became a series of objectives and assessments and it felt we were under scrutiny all the time, Joyce decided to list Calum's objectives in her own way...

## Calum can:

- Accurately ping a balloon from 10 paces into an open eye.
- Eat three yoghurts in total silence and leave no trace.
- Retrieve a toy from under a gas fire leaving only a small gas leak.
- Partially remove a carpet strip screw ensuring the position is correct to catch mum's foot when tip-toeing around the house at 3am.
- Stop a train by use of the communication cord whilst looking out of the window.
- When offered the keys to the front door of the house, post through letterbox at the speed of light.

Life carried on for a number of years and we moved away from the Highlands back to our home in Musselburgh. Calum attended a "Special Needs School" in Dalkeith, we had the usual regular reviews and all seemed to be as well as expected.

The review just prior to Calum's 16th Birthday gave us an unwelcome surprise. We expected the usual routine review and plan for the next year. We were told his time at the school was finished, there was nothing more they could do to develop him and there was not a place for him after the Easter term. No build



up, no finesse or empathy or preparation just time to go. We had always been led to believe he would be in the education system until he was 18. Joyce and I learned a lot about 'the system' that day and 12 years later we both still feel the Scottish Education system failed Calum and our family horrendously at this stage of his life.

Transition to adulthood was a bit of a whirlwind; we had to visit day services and choose a care provider. We engaged with social workers for adult services and had to make decisions on how Calum's future was planned. We had to apply for guardianship powers as Calum became an adult – being his parents was no longer deemed to be enough under the law. It really was a difficult time and something the education and social care systems did little to prepare and support us through.

Thinking back, our family resilience was the thing that got us through the weeks and months of transition. One of the abiding memories was being asked to meet with the learning disability team. We headed to the meeting expecting

the usual two or three people, we walked into a room of 13 specialists all intent on meeting the objectives of their particular part of the system. It really was intimidating and verging on disturbing having your life and the care you have given to your child flayed open and discussed in such a forum. We gave feedback to the team on how it felt being thrown in like that with no warning or preparation and I'm pleased to say they did take it on board. Having said that, they were all good people and helped a lot in getting Calum into adult life. Daycare services, transport picking him up, carers coming to the house, arranging days out and other activities, our life changed again. We worked closely with the Action Group who provided his support and Calum sailed through the lot with only a tantrum or two.

Reflecting back, life was really hard on Calum's brothers; they both coped with Calum being centre of attention and both grew up into fine people with nice families; I think we really do need to recognise the impact on siblings. Calum now lives in a nice home with two friends and I'll share that story next time. He comes home on Sundays to spend the day with us and he will sign to us he wants to go home to his house, that to us indicates he's happy and contented.

In closing, ASSERT – AngelmanUK – was and is a large part of our life. We love the new name and hope sharing Calum's story has been interesting.

It has been for us.

**Gerry Egan**

## Charlotte Smith

My beautiful sister Charlotte passed away in November having lived with terminal cancer for the last few years. Not only did she live with it, she REALLY lived with it and showed everyone she met how to do so. She went on so many adventures with friends and family, finding something to smile and laugh about every single day.

Charlotte showed more strength and bravery than anyone I have ever known and has passed that on with abundance to her daughters Jude & Issy. She made great provisions for their future with Jude currently studying Forensic Psychology at Manchester University and Issy settling in well at Pegasus School in Derbyshire. Charlotte was always a positive and wonderfully supportive member of the Angelman community and talked so fondly of the many amazing families she had met. I am so very proud to have had the opportunity to run the London Marathon raising money for AngelmanUK, as one of Charlotte's wishes was to see her brother do so and that memory of seeing her at the finish will fondly live on, just like my big sister will do in the hearts of everyone who was lucky enough to meet her.

**Gavin Smith**





# fundraising



Run, cycle, swim, walk, climb, parachute, dance, bake... the imaginative ways you raise money for us are amazing! So here's a big thank you to a few of those fabulous fundraisers.

*angelman* <sup>uk</sup>

## Tom Moore

Tom and friends completed a bike ride from Cheltenham to Barry. They raised the massive total of **£4729.68**



## Dhruv and Nyra

In the lead up to International Angelman Day on 15 February, Dhruv, Nyra's older brother (now aged 9), proactively asked his headteacher if he could give a talk in assembly. He gave a talk to over 300 pupils at the school to raise awareness of Angelman Syndrome, followed by a question and answer session. Nyra made a guest appearance too (gate-crashing Dhruv's talk by walking over to him as she didn't understand why he was over there!) – the feedback received was excellent. Dhruv also organised a cake sale at his school on the 15th to raise money for AngelmanUK, raising over £500.

Nyra's nursery held a coffee morning and a raffle to raise awareness and funds

for AngelmanUK too, raising nearly £250.

Raj and Agna also led an awareness campaign for AS in our local region, resulting in an article in the local paper, a live interview for local radio and a 2.5 minute television clip shown on BBC local news for our region. In addition, we set up a JustGiving fundraising page to share our AS story and help raise funds for AngelmanUK. Total funds raised so far, including the nursery coffee morning and school cake sale, have exceeded **£2,500**. We have been overwhelmed with everyone's help and support, and cannot thank everyone enough for their generosity.

# fundraising

## Poppy Cartwright

Having done the Great North Run twice, I wanted something bigger and better for my third round of fundraising. Something different, fun, and obviously challenging, so 'Poppy's ASSERT Challenge' was born. Six challenges over one year, each representing the letters making up 'ASSERT'.

First up was the 'A' for abseil – a trip along the A19 to the North East's biggest bridge - the Tees Transporter Bridge. Two hours waiting 164ft up in the air on a cold, windy Sunday afternoon in Teesside wasn't the exciting vision I'd had of my challenges, but my turn soon came and I was back on safe ground within two minutes. (Well, relatively safe; I was still in Middlesbrough...). I'd been talking with a woman at the top of the bridge about my fundraising and my younger brother Euan (AS del+). She'd never heard of Angelman Syndrome and was intrigued to learn more, and I found her waiting at the bottom with a £5 note to kickstart my fundraising – a generous offering from a complete stranger and I felt really chuffed to already be spreading awareness of this diverse condition and amazing charity.

The next challenge was going to be tougher than just sitting back and being hoisted around: a 2.5km 'S' for swim. I've never been a good swimmer, so I knew this was going to take some motivation. On my first training session I found myself being snuck into the sauna and steam room at Gateshead Leisure Centre by a Greek man, and suddenly thought this could be a sport I was keen on. The rest of my training didn't follow the same path but it did become something I looked forward to and I somehow managed to splash out 2.5km in 1 hour 9 minutes – I'd never swam that distance or for that length of time so this felt like a real achievement!

Next up was another 'S' for skydive... something I'd thought about for a number of years but never got around to organising – my challenge gave me the push I needed! My skydive was postponed three times before I actually got the go ahead: 11,000ft above Shotton Colliery and what an amazing experience! The best thing I've ever done – I wanted to go straight back up again. Maybe I'll be able to rope in some friends and family next time...

The person all these challenges were ultimately about was my younger brother Euan and so it only seemed right to involve him with an 'E' for Evan challenge. The happiest, cheeriest, most smiley and loving person I know – but even he was fed-up halfway round a cold, wet Parkrun. I pushed Euan 5km around a park in Leeds one Saturday morning; more than my own bodyweight in a not very sturdy wheelchair, but we only bumped down one pothole. (I think this might have been the turning point for Euan.) I didn't get much support from my brother for dragging him out of bed on a gloomy weekend but the donations were coming in and I felt good!!

Then came the 'R' for run. The Great North Run, no less! A real hubbub of excitement here in the North East and I knew a number of people taking part. There's a suggestion that Geordies are some of the friendliest people on the planet and this is so prevalent on GNR day – you can't run more than 100m without being offered slices of orange, Haribos, jelly



babies, ice lollies, even beer and sausage rolls! (This is the land of Greggs, you know.) I'd trained hard and felt so pleased to cross the line in 2 hours 16 minutes: a GNR PB and a definite reason for pizza and pints.

The conclusion of my challenges was a big one – the 'T' for Three Peaks; Ben Nevis, Scafell Pike and Snowdon. My parents accompanied me for this one, as did Storm Ali. It was wet, windy, cold, snowy, rainy and hail-y and very hard work!! Fuelled mainly by cheese and salad sandwiches we completed the peaks across two days, and what a sense of achievement. We were the highest people in Scotland (and Britain!) one afternoon; the highest in England the following morning; and the highest in Wales just as the sun set that evening.

I wanted something fun and different and that's exactly what I got; my fundraising pushed me to do things I might not otherwise have given a second thought. Over **£1850** and loads of awareness about AS raised, it's safe to say I'm pretty pleased with how my challenges went, but I am glad I got this idea out of the way before the name change to A-N-G-E-L-M-A-N-U-K !

If you'd like to be considered for the London Marathon in 2020 please email [Lisa.Court@angelmanuk.org](mailto:Lisa.Court@angelmanuk.org)





# angelman<sup>uk</sup> fundraising

## Noah Beckwith

After learning about charity at school one day Noah came home and asked to raise some money, he chose AngelmanUK as the charity he'd like to support (AngelmanUK is supporting Ruby, a friend of Noah's nursery buddy) and he set up some challenges for the month of December, coming up with the ideas all by himself. Noah ran his first 2k race and cycled a mile in the December rain, baked and sold 50 mince pies, washed cars and tidied his room! We originally set his target at £100, he smashed it and raised **£1088**, all of this was his own idea and we are incredibly proud of him and his kindness.

## Annie Petherick (Freddie's mum)

As a family we have received so much support from AngelmanUK since just before our son's diagnosis in 2012. They have most recently funded a communication app and provided training for us to learn how to use it. They were vital in giving evidence to professionals when we were forming a case for Ollie to have an enclosed bed to keep him safe overnight and to try and manage his sleep disturbances.

Ollie's 'Grinny' Sharon Hurcombe has previously raised money for AngelmanUK by running the London Marathon. Ollie's brother Freddie wanted to do some fundraising and decided on a 24-hour silence. His original goal was to raise £50 but he exceeded his target by miles! I asked him to write a paragraph on how he

found it: "Being silent was a tough time but also a very good experience. It has made me understand Ollie's frustrations and will help me to be more patient with him. It has made me think that speaking is very valuable. Although it was very frustrating it has helped me learn. Thank you everyone that donated and thank you everyone at AngelmanUK for all of your help with our family."

We are so proud of Freddie who is an amazing big brother to both of his younger siblings and one of Ollie's biggest advocates. Our family are looking forward to raising more money for AngelmanUK in the future. Thank you to all of the trustees at AngelmanUK, your continued support is invaluable.



## Raj & Tanu (Annika Banga's parents)

We held a birthday party for Annika on Saturday 2nd February, with her friends and instead of presents we requested parents give donations towards our chosen charity, AngelmanUK.

We were a bit nervous to be honest, as this is the first party we've done for Annika at her new school. So I was unsure how parents would react to the little note in the corner of the invite, 'asking' for donations instead of gifts. What an amazing response we had !!! The messages from parents replying, saying what a lovely idea it was to raise money. With Gift Aid we donated almost **£800**.

We are so proud of how Annika understood why she didn't have a HEAP of presents from her friends. And instead has raised money to help families and carers of those who are supporting children with Angelman Syndrome.

We have said to Annika that she should feel VERY proud of herself for what's she's achieved. Yes, we instigated this idea to her, but this 6 year old went along with it.



## Ed Duffy

Ed has raised funds on several occasions for AngelmanUK. Ed's sister Molly has AS. This time round Ed has raised £45 for our charity. Here is a photo of Ed presenting the winning prize to Reg.



## Kate and Jason Langford

Kate and Jason were married on 8th December 2018 and instead of giving wedding favours they kindly gave a donation to AngelmanUK.



Kate and Jason also asked their wedding guests to donate any spare change in the collection boxes that were on display at the reception. They raised the fabulous total of **£330**. Kate's niece Amber has Angelman Syndrome.

# annie's story

My name's Annie, I'm wife to Iain and mum to Freddie age 8, Ollie age 7 (who was diagnosed with Angelman Syndrome in 2012) and Penny age 2. I'm sure if you're reading this newsletter that you are familiar with the trials and tribulations that come with living with Angelman Syndrome. I use humour as a coping mechanism and found writing about our family life in blog form helps me find the humour in situations that would typically be very stressful!

Recently we stayed at CenterParcs for a 'relaxing' weekend. I started to realise it may not be as relaxing as we'd hoped when I got to play a real-life game of Tetris as I crammed what felt like all of our worldly belongings in the car whilst leaving enough room for the children and wine (my other coping mechanism!).

I really recommend the facilities, our lodge had a huge wet room, and plenty of space to set up the tent that Ollie sleeps in when we are away. The only downside was that the living space was open plan which wasn't ideal with our little bin raider!

This may not come as a surprise to you that Ollie loves swimming. So off we set ready for a whole afternoon at the pool. Everything was going fab, Iain and Fred had gone off to check out the different rides whilst Penny, Ollie and I explored the toddler pool. The smell hit me first,

then as I stood Ollie up, his shorts shifted and I noticed some sweetcorn stuck to his back. I had a 'code brown' situation, a strong-willed 2-year-old who didn't want to leave the pool and no locker key. I will never be more thankful for the power of bribery in the form of going to look for sweets for the 2-year-old and for CenterParcs' amazing disabled changing facilities which include a bed and separate shower from the communal ones.

There is something about swimming that gets Ollie's bowels going so I have become particularly adept at cleaning him, his shorts and the wetroom with soggy paper towels and minimum fuss. It's always a bit of a heart stopping moment when the river of brown water starts running towards the edge of the cubicle and I have to act fast and use any body part available to divert the water back to the drain. I have considered packing a squeegee with our swimming kit to make this process more efficient!

By now Iain had located us, brought our clothes in and we managed to make it back to the lodge, via the sweet shop, relatively unscathed.

Now I was tasked with getting Ollie's swimming shorts clean to swim the next day. Due to a lack of washing machine it was a hands-on job. In case you are wondering, lather with shampoo and rinse x2. Lather with shower gel and rinse, then lather with antibacterial had wash and a very thorough, hot rinse and you're good to go!

I think Iain and I lost count of times we just gave each other the 'why do we try and leave the house' look over the weekend. Giving Ollie a golf club of his own for crazy golf is definitely a

memory that won't be soon forgotten (the bruises sustained will make sure of that.) Now we are home and the mountain of washing has reduced to its usual 5000m above sea level we are already looking to our next break away. There's no rest for the weary is our go to motto at this point!



## Logan's walk

A fundraising walk with the Bothwell, Whiteway and McLaughlin families. The total raised was **£137.44**.





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...

Corporate Travel  
Management

Mr Rodney Freeman

Mrs Hazel Tait

Marie & George Brown

Andy & Mel Coe

Nathan Strong &  
ROCKWOOL Ltd

Shelley Cachia

Stu-Nique

Patricia Matthews

Joan Butterworth

Old Portmuthian  
Chapter 8285

Jill Haston

Jesters Scooter Club

In memory of Anne Haycock

Kate & Jason Langford

In memory of Alan Smith

Basingstoke & Tadley U3As  
Circle & Folk Dancers

The Greyhound Pub, Coventry

The Nuance Group

Debbie Horsburgh

St Paul's Church, Chichester

Jane Clark

The Lilley Benevolent Trust

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In memory of  
Mrs Dorrie Paine

Continental Tyre Group Ltd

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Redwell Primary School

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Ed Duffy

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Charlotte Walker

Karen Kemp

Robert Brashier

Maria Moralee

Matthew Gregory

Josep Alvarez

Heena Shah

Shona Lamont

David Foster

Lee Solomon

Lesley Barbosa

## 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.

Noah Beckwith

Noah's Challenge

Poppy Cartwright

ASSERT Challenge

Andrew Stephenson

Rugby Match

Rich Williams

Bath Half Marathon

Freddie Petherick

Freddie's Challenge

Annika Bangu

Annika's birthday

Richard Gibbard

Greater Manchester Run

Neville McCrindle

Neville's birthday