

hello

angelman ^{uk}
support education research

Communication
and Literacy
Conference 2019

Christmas Gift Ideas

Making and Maintaining
Special Friendships

The Angelman Rally
update

Exploring Anxiety

Fundraising report

#65
autumn 2019



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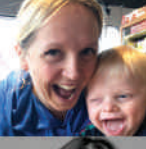
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The latter half of the year is upon us, the clocks will have changed before this newsletter arrives and thoughts are turning to the age-old questions of 'What do I buy my loved one with Angelman Syndrome for Christmas when they just prefer to play with the box?' and 'Where can I buy reasonably priced sensory toys?' Questions we've all asked many times over the years! Many families find answers on our Facebook pages and through face-to-face conversations with other AS families at conferences and regional events. If you're still searching for gift ideas, we've provided a list of interesting items and where to find them on pages 6-8. For other questions, why don't you join our Social Media community – simply search for AngelmanUK and request to join the groups. You'll find hundreds of new friends who will have the answers to many of your questions and AS-related conundrums!

If you prefer the face-to-face approach and love meeting up with other families then I'm sure you would have enjoyed our recent Communication and Literacy Conference, held once again at The Doubletree Hilton in Coventry. The Friday programme was aimed specifically at school staff and Speech & Language Therapists. It was attended by over 90 enthusiastic professionals and it was amazing to see some of the teams planning on putting what they had learned into practice as soon as the conference ended! One group held a team meeting right there in the hotel and many teaching staff have returned to school with renewed determination to help our children communicate better. Our family weekend was attended by over 180 people: those with AS, siblings, aunts, uncles and grandparents. It's heart-warming to hear that, thanks to the conference and the highly experienced presenters, people with AS are making a start with AAC (Augmentative and Alternative Communication), using their devices or communication books more, or even starting to write! Presuming potential is the mantra of the AAC community and AngelmanUK recognises that ALL people with learning disabilities should be given the opportunity to communicate effectively with peers regardless of presumed ability. If you don't try, you'll never know! For a round-up of the weekend see Tracey's article on page 16. And be sure to fill-in the survey – we need your feedback to improve our services to you.

Our general survey (available on our FB page and website) revealed that our families want more regional events. We try to make our main conferences accessible to people throughout the UK but this invariably means that some have to travel further than others. Unfortunately we can't realistically hold multiple conferences, but we have listened and hope to be holding more regional events next year, starting with Christmas parties in some areas and our usual International Angelman Day events on Feb 15th. But we need YOUR help! There are areas in the UK with no local trustee, or where the local trustee is also a parent who works full time. If you have suggestions or better still, can give some of your time as a regional volunteer, please email louise.shaw@angelmanuk.org. We can only offer more regional events with your help and support. Don't forget that all at AngelmanUK are volunteers we have no paid staff. Why don't you join the team?

Keep an eye on social media and the website for details of all regional events. Registered members also receive invitations through the post so please make sure you keep us informed of any changes to your postal address.

Our pop-up shop should be open on the website by the time you read this – details and link on page 5. It will only be available for a short time so make sure you order your Christmas presents and IAD merchandise in plenty of time!

Finally, the AngelmanUK trustees would like to wish you all a Merry Christmas and a Happy New Year.

Rachel Martin, AngelmanUK

The dates for two great AngelmanUK events have now been arranged.

Members will receive 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!

IAD International Angelman Day

15 February 2020

Regional meetings will be taking place all over the country. Registered families will receive information via post, and keep an eye on Social Media for dates and locations.

family conference

28-30 August 2020
Hilton Hotel, Coventry

You might have read all about last year's family conference in 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.

Booking information will be sent out in the new year.



Where to start? I am hoping I can add a bit of a view from a Dad's perspective, we often hear stories of how hard it is for Dads and that men don't open up enough. Well, they are probably right, but that doesn't mean I can't try and help a bit, right?

It is certainly not easy, we have spent so much time fighting for everything, from suitable seating in classroom to support from the local authority. I have noticed that a lot of mums do the talking, on Social Media, at conferences, generally day to day. They often carry the challenge of being the advocate, so what am I supposed to do when Jenn is doing such a good job? I support her. I am the hand on her shoulder telling her I've got your back, keep going. I find I make a lot of telephone calls, the chasing things up, the bits that, whilst only taking a couple of minutes during a break at work, can take a lot of stress from someone at home dealing with the day to day care role. Jennifer sorts out all the appointments, therapies, school visits, PAs etc as I am out of the house over 12 hours each day, whilst she works from home. It would be easy to say that I only help out a bit, but I don't. I do my fair share and pick up the slack when I need to. We all have bad days and it is important to recognise this and not beat yourself – or each other – up (literally or figuratively). We're a team. The three of us against anyone who tries to stop us. Team Myth. Working 12 hour days means it would be so easy to miss out on the important things, Christmas plays, sports days, surgeries, EHCP meetings but I am really lucky. My work have an excellent Flexible Working Policy that means I do get time to be able to go to some appointments and work from home (which is handy as I work over an hour away in another city). I know that not everyone is this fortunate,

after all, not all jobs can be done from home. Don't let that stop you! Have a chat with your HR team about it, you might be surprised at how much they can do to support you. When starting at a new company or in a new role I make the point of taking my line manager to one side and explaining everything about Alastair, how it affects me and my family, how it might affect work and what support I might need. It shows that you are a human and that you may need help, it doesn't then come as a shock to them when you are asking for some flexibility to be there for your child. I have a great example of how Flexible Working saved our summer! Jennifer decided to dislocate her elbow and sprain her ankle playing Frisbee, I didn't work a full week in the office for 3 months. My Line Manager was fine, my team knew where I was and everything continued. But I was at home to get Alastair off to school and back again at the end of the day. I kept on top of all the things Jennifer would normally do and I worked a full working week. Yes, I was shattered by the end of it, but it's what we do. I know Jennifer would have done the exact same thing if the roles were reversed (although I am now banned from anything unsafe...).

For now, I will leave it here, we can revisit this in later articles if you would like me to expand or talk more. It would be great to have a regular 'Dad's Corner' in the newsletter, to open up some conversations, so if you would like to talk about your experiences, please get in touch with Jenn (jenn.smith@angelmanUK) or look me up on social media if you prefer.

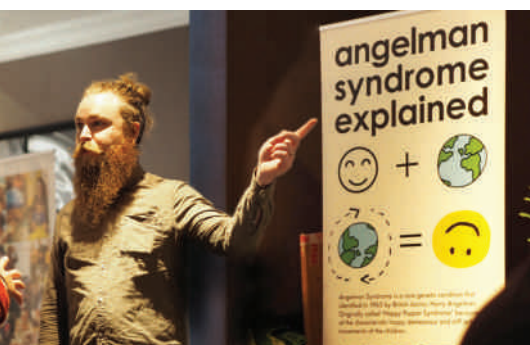
Smile, it confuses people.

Adam Smith



Photos by Jenn Smith and Christyan Fox

communication and literacy conference 2019



The communication conference was a great success once again. It was fabulous to see so many people using AAC systems. Seeing people with Angelman Syndrome communicating in such a natural way was also very inspiring for those who are new to their communication journey.

Friday – Professionals day

We were honoured that Jane Farrall returned for our second conference and she started off the professionals' day by giving a comprehensive overview of communication. Tabi Jones-Wohleber then discussed her 'Model as a MASTER PAL' training series. These free resources are available at: <http://bit.ly/ModelasAMASTERPALtrainingmodule> and discuss the different aspects of modelling. These are suitable for beginners and those looking to improve their practice. Sarah Rivard took the place of Erin Sheldon at the

last minute. Sarah is mum to Hannah who has Angelman Syndrome and is a teacher in Canada and as such has insight from both her professional and personal life to discuss building positive relationships. Rosie Clark, Livvy Hepburn and Carly Hynes then discussed how they influenced their schools to become communication positive environments.

After lunch we had Teach Us Too speaking for the first time. Jonathon Bryan is the teenager behind the Teach Us Too campaign, he attended the conference with his mum and his teacher, they discussed his journey both before and after he had access to his communication alphabet board. Jane's session in the afternoon was on Building Language Through Emergent Writing explaining why writing is crucial for everyone and how to make it accessible. The AAC showdown gave a quick overview of the most commonly used systems for people with Angelman Syndrome, namely, PODD, Proloquo2Go, SuperCore and Snap plus Core First. The last



session of the day was an update on research carried out by The University of Birmingham on communication and Angelman Syndrome.

The day was very positive with some teams even staying behind to start planning implementation for the following week. We have already had positive reports from some of our families saying that practice from their professionals has changed already.



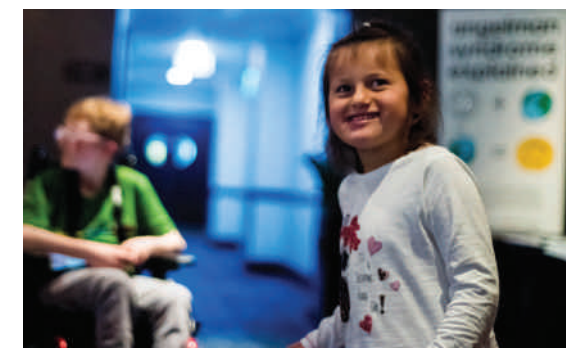
Saturday – family conference

Carly Hynes and Tracey Campbell started the day discussing Aided Language Input using Core Boards and Aided Language Displays followed by Jane who explained why these alone aren't enough. Tabi then repeated her talk on her 'Model as a MASTER PAL' series. This was followed by Jane and Tracey discussing common pitfalls and solutions when implementing communication systems at home. After lunch, Jane discussed literacy and communication and Rosie shared some hints for getting the team on board. The sessions then split into workshops for the remainder of the day.

Sunday workshops

The highlight of the weekend for everyone! Sessions involved a mix of games, literacy and communication. We had several comments on how the sessions had given everyone ideas on how to bring communication home and most importantly how to make it fun.

.....



"We have been modelling like crazy since the weekend (Woody actually got fed up with us this evening took his PODD book off me, closed it firmly and threw it on the floor – I picked it up and modelled, oh I think you are cross and tired and it's time to finish. He shot me a LOOK!) My husband got Woody's PODD book out and was modelling too! Our oldest son farted and B modelled 'gross' and 'stinky'. Most fun we've had at tea for a loooooong time." **Andrea Baines**

"Just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far-reaching effects." **Dalai Lama**

"Thanks to all who presented at the conference – the ripples spread far beyond our AS community. James' class friends & staff were given and are wearing their core word boards. This is a first for James' school (inspired by the conference) and it's nice to hear that his friends are using them to comment about his work. 'Good' 'more' 'I like it'." **Rachel Martin**



angelman^{uk} christmas gift guide

Christmas is very nearly upon us! While this is often a magical time filled with family, food and merriment it also comes with the question 'What do I buy my loved one with Angelman Syndrome for Christmas when they just prefer to play with the cardboard box?' or 'How do we keep gifts age-appropriate when an individual with AS grows older yet enjoys exploring toys aimed at pre-schoolers?' It is also hard to know which companies to trust and who are out to target vulnerable individuals.

We've compiled a list of suggestions - all of them endorsed by an AngelmanUK family or a friend of someone with Angelman Syndrome.

Inflatable Roller Wheel

Being inflatable means this can be stored easily and brought out in the summer in the garden or in the home for seating and rocking. We've seen them being used as ball pits.

"My son used to have something like this when he was younger, if you've got the space, he loved it."



Wooden Peg Sorter

"My son is over 40 and still loves Melissa & Doug wooden peg sorter toys."

Experience Gift Cards or Yearly Passes

Buying experiences are a great idea, they can be used over the long summer holidays when finances are often tight. Have a look at your local aquariums, museums, theme parks, cinemas too, they often offer a yearly pass allowing you to return time and time again, always check their companion/carer options too, most allow a free second ticket.

"My son adores trains and Swanage Steam Railway is near us so we get relatives to buy him a gift card for there so he can enjoy some journeys throughout the year."

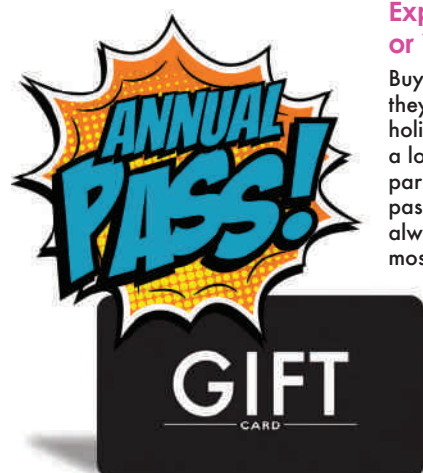


Photo Blanket

Being inflatable means this can be stored easily and Jessops, Tesco and Asda all offer these, simply upload your photographs and they do the rest.

"My brother (25) loves a blanket so I am having him a family photo blanket made with 40 images"



Vibrating Snake

Allows soothing vibrations to be trapped over the neck and back or to be explored using hands.

"My son loved playing with a vibrating snake in hospital so I have bought him one for Christmas."



Floor Piano

Perfect for those who roll, crawl or walk!

"My daughter loves the one in the film 'Big' and she loves music."



Smartmax

These are ideal for those who like to build but struggle with fine motor skills or those who like to keep their hands busy. While these are quite large, they are not recommended for young children or individuals who put things in their mouth.

"Smartmax are a great size especially for older children. They are very easy to play with as they are magnetic."



B. Magical Teepee

A cheap alternative to a sensory den, it already has a light show inside but why not add your own textures and sounds.

"My son loves his Teepee, it also has lights inside"



Remote Control Ocean Wave Projector Nightlight

Because who wouldn't love this?

"My son has to have some kind of noise in order to stay calm and sleep at night so this works well. Nice alternative to most other night lights which are usually aimed at young children and babies."



Shockproof and waterproof Bluetooth wireless speaker

Play music from your phone or tablet and don't worry if it gets thrown around the room.

"We bought one of these and it has lasted well for our daughter, it even goes in the shower and copes with chewing and dribble."

more over the page...

angelman^{uk} christmas stocking filler ideas...



Whirly Pop
Spins, bounces, lights
up and makes noise!
Perfect!



Chuckle Ball
They say that laughter is the best medicine!
Chase this around the room or feel
it shake in your hands.

Some of our
favourite
stores are...



Sensory Sparkle
Sensory Sparkle
(sensorysparkle.co.uk)
offer a selection of
handpicked goodies to
provide children and
adults of all abilities
with a spark of fun
to ignite emotional
satisfaction through
play and sensory
exploration. They are
very reasonably priced
and perfect for those
stocking fillers.



TFH
TFH (specialneedstoys.com)
manufacture toys designed to overcome obstacles to play.

Learning SPACE
Learning SPACE (learningspaceuk.co.uk) specialises in educational and sensory resources, providing a wide range of exciting toys, games, puppets, software and books. They offer gift cards too if you are unsure of the perfect gift.



Fledglings
Fledglings (fledglings.org.uk) aim to help make life a bit easier for a parent and more fulfilling for their child. They specialise in finding those unusual items, including many specially designed for disabled children with specific needs. From wheelchair covers to learning resources.



your new
angelman^{uk}
shop



Hooray! The AngelmanUK shop will be open in time for Christmas for you to buy gifts and clothing for loved ones. From AngelmanUK-branded water bottles to jute bags, T-shirts and hoodies... we will have something for you to purchase as a gift whilst supporting us financially at the same time.

Products will change depending on availability, so take a look at the website for ordering details and to see what's currently on offer or contact Lisa Court (lisa.court@angelmanuk.org)

The new shop will still be accessed at the previous address www.angelmanuk.org/shop

PLEASE PLEASE...

Avoid 'Cheap Disability Aids' and 'Sensory Education LTD'; we have heard from many families that their orders simply did not arrive. If you are buying from a new site for the first time always check for reviews online.

The above suggestions can be found on Amazon, and don't forget to use smile.amazon.co.uk and choose AngelmanUK as your charity. With no cost to yourself, Amazon will make a donation to AngelmanUK with every purchase.



angelman?
instagram!

Did you know we are on Instagram too?

Follow us @angelmanuk for some great AS-related pics and up-to-date information.

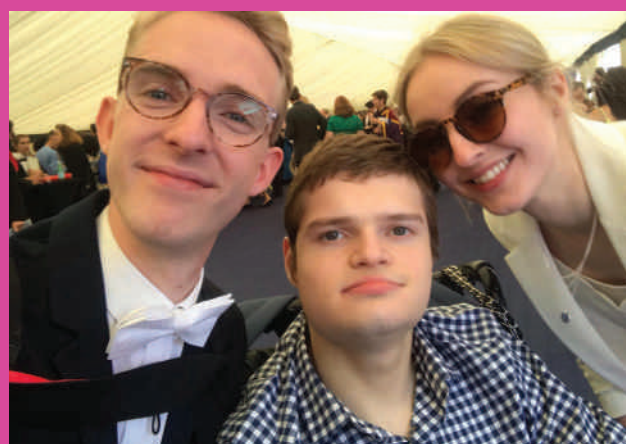
Siblings

During the communication conference it was great to see so many young people helping their brothers and sisters to have a voice. We had fantastic workshops where we got to hear about everyone's relationship with their sibling with Angelman Syndrome and learnt how we can use alternative communication methods to talk or even play games. Some people have shared stories below of what it's like to have a sibling with Angelman Syndrome, it's interesting to see how different we all are and so important that siblings are heard too!

I'm looking forward to hearing from and meeting more of you over the coming months, if there is anything you would like to share or read about in the next newsletter, please get in touch: sian.allen@angelmanuk.org

Alexandra, 23 I've never thought of my brother as having any disabilities he's always just been Robb to me. Robb and I are 2 of triplets and I've always felt close to him even though he has never had any speech, he has his own unique way of communicating and the best smile ever! Up until the last few years we lived together with my mum so I saw him every day and could help with his care and naturally spent a lot of time with him. Now he lives in his own house with personal assistants and the rest of us are at university. When I go back home to see him with my other brothers, he's always made a jump forward in a new skill. It reminds me that he is too is learning and growing as a person just like we are and it's important to spend time with him to catch up on his new tricks!

Ryan, 10 Being a sibling of an Angelman child is hard but (sometimes) enjoyable. It is hard because: - My brother might bite, scratch or even pull my hair - He sometimes breaks my things - He might embarrass me in front of my friends - He might stop our family from going to places. It is hard but they can also make you laugh and do funny stuff. I've made good friends who have an Angelman brother or sister. I do wish that my brother would be normal. He sometimes makes me feel annoyed, happy, sad and angry.



David, 24 My sister Hannah is 4 years older than me, she's now 28 and I always have to stop and think about that when people ask me how old she is. First, because in my eyes she's so old now I've lost count. Second, because despite everything, I have never seen her change massively in my eyes, despite the fact we're not children anymore. She is still the same loving, affectionate, cheeky, food devouring pain of a big sister I have always known her to be. To this day she still goes for breaking my neck every time she gives me a hug. But as time has passed this has changed the dynamic of our

relationship, as it does with all siblings as they grow older and embark on their own respective adult lives. Daily annoyance is no longer the norm, and I'm now a bit stronger to resist her attempts to snap my vertebrate when she goes for the bear hug. Home for us is London. But for the past 5 years I have been at University in Sheffield, whilst Hannah now lives away from home down in Hampshire. Although she comes home every other weekend, sadly I am not able to, and for years I'd always joke at the irony that every time I did come home would be the weekend that she didn't. This meant I would often go months without seeing Hannah.

I try to tell myself that, like any siblings our age, life happens, more responsibilities are taken on, and whilst it can be upsetting, I try to think that this would be the norm regardless of the lives we led. But what helps is knowing that, irrespective of our own lives and how they're led, Hannah is happy. She lives in a home where she is comfortable and surrounded by people that love her and care for as her own family would.

I'm now moving home after my time at university, and a benefit of that will be having more time with Hannah again. But as the years go on, regardless of where both of us are, it will always be the knowledge that she's content wherever she is; that will help the moments I miss her, and when we as a family return home for Christmas and so on, she'll be there.

angelman uk



Alexandria, 22 My relationship with James has changed since I moved out and found a house for myself and my partner. Despite being over 100 miles away, I try my best to stay in contact with James. Even though our relationship has changed, it hasn't changed for the worse - I'd actually like to think it's better. When we visit James in North Wales, he absolutely loves it. He can't contain the excitement when he sees us walk in the door. What I love the most is that fact he seems to enjoy seeing

Ryan (my partner) more than he does me. Just when I think he's making a beeline for me, he walks straight past me and hugs Ryan. When we're not able to visit we often FaceTime. James loves FaceTime, but he has a big habit of clicking that red button on the screen to end the call when he's had enough of seeing my face.

I believe the distance and time away from each other has helped me to appreciate our relationship a lot more.

Betsy, 7 Life with Rufus is tricky, happy, giggly, hard, frustrating and tiring. He makes me giggle when he does funny noises. Usually he does really funny trumps in the shower almost every night and it makes us all laugh. I can even hear them from my bedroom! When we go shopping sometimes he grabs strangers and it makes me feel a bit embarrassed. Sometimes when we are playing I hurt him by accident and it makes him really upset and he cries a lot. He pulls my hair and it makes me feel angry and frustrated. When I'm with him I usually feel happy when we're watching his iPad together because he's quiet and calm. Sometimes I feel worried that Rufus is going to have seizures and get constipated again because they are the two bad things that have happened to him and he had to go to hospital for both of them. Sometimes I have to get nappies for him, help with feeding him, push the wheelchair, help get him dressed, put something on the iPad for him, get him out of bed in the mornings and I have to make sure he doesn't grab my little sister. The thing I love most about Rufus is his sense of humour.



Sian, 24 Since I finished university and moved further away I don't necessarily think my relationship with Gareth (22) has changed but he has definitely become used to not seeing me on a regular basis. Now when I go home he always gets so excited to see me, is very affectionate and will often use his iPad to watch me through the camera, although he makes it very clear when I've overstayed my welcome - I've previously been handed my coat and shown to the front door! I love how well he gets on with my partner, they have a fantastic relationship and quite often I'm pushed aside when we visit together! I'd like to see him more regularly but I don't think the distance between us has affected our relationship too much.



angelman rally

angelman ^{uk} update

It's been a big year for The Angelman Rally (TAR). Following the success of the rally earlier in the year we catch up with TAR to hear about how they got on over the Alps, the Homecoming Fundraiser held on the riders' return, and why one of the bikes only just made it home a couple of months later!

Xav: I'm Xav, and I have a son, Henri, with Angelman Syndrome. The Angelman Rally was something I set up with friends and family to help me heal and learn what AS really is. TAR set off from Jack Lilley's Triumph main dealer in Ashford, on the 16th May. It travelled south through France, over the Alps, then west across Italy to Verona to find a very special painting before heading south to Sicily and climbing Mount Etna. All that before returning through Monaco and central France. On their return, Corinne (Xav's better half) had arranged the Homecoming Fundraiser in conjunction with Elmbridge Mencap.

Corinne: I can't ride, so I decided to get involved in other ways. I took care of the Social Media and organised the homecoming. The Social Media part was easy, as I have done it for several charities and performers over the years, but the homecoming was a little more daunting. Turns out I needn't have worried though, as I had a small army of people who were itching to get going! The first thing to arrange was a venue. The only choice for us was Burview Hall, run by Elmbridge Mencap. They were delighted with what we were doing and bent over backwards to help. Burview Hall has all the facilities to help people with additional needs and is well known to the south east AS community

as IAD events have been held there. Holding our event in familiar surroundings meant AS families would feel a little more comfortable.

AngelmanUK: We were there! It really was an amazing day! So, what happened in Monaco?

Xav: Oh, that was quite the day! We planned for a short 200-mile ride, with a photoshoot in Monaco. It all started so well. We came out of our last Italian tunnel and emerged in France in good time. We took our exit for Monaco: from childhood, I remembered the glamorous people and stunning cars and boats and I wondered if I was, myself, now one of the beautiful people. I was turning up, after all, with a film crew and on a flashy motorbike... I was dreaming about who might play me in a



film, when I was snapped out of this reverie by shouting over the intercom. Dan had slipped in oil, lost his front wheel, hit the deck and was now sliding down the road with his bike over-taking him! Things came whooshing back to reality and suddenly we were all hi-vis jackets, hazard lights, stopping traffic, and running over to Dan. He was super lucky – I don't think he had any injuries at all! His bike was not so fortunate though. Everyone was working hard to be calm and say sensible things but we were running out of light...

We befriended a mechanic who showed us to a hardware store. We came back with a few essentials, including chemical metal, and we repaired the engine in a carpark. A couple of hours later, we left in the dark for our destination, arriving at 2am! The bike held out but looked very sorry for itself and we never saw Monaco. Maybe next time.

Xav: The weather in France and northern Italy was horrendous and I had a run-in with the police; I lost my driving licence and bank cards while on the road! They blew out of a pocket that I failed to close properly following a toll. Our TAR convoy stopped as I went back on myself looking for my life. On my return, the police had pulled up to investigate the rest of the convoy. In mountain regions, Italian motorways are dual carriageways that wind through valleys and most of the time you are on either a bridge or in a tunnel.

So, they are looking to clear the motorway of broken-down vehicles and coordinate public services very quickly. Foolishly, I told them I had lost my licence and this meant they would not let me leave as I had no way of proving I was legally eligible to ride a motorcycle. After a lot of smiling and explaining via Google translate, I presented my international driving licence. Despite

looking like a wartime ration book, this was enough to satisfy both coppers to the extent that no further questions were asked. They were very nice and looked very smart in tight jodhpurs.

Early on in the planning, I wanted to see the 'Boy with a Puppet' painting but later we heard rumours that it had been stolen, so we got in touch with the Castelvecchio Museum in Verona and they confirmed it was there. When we eventually saw the painting, the first thing that struck me was its size. It's tiny! I was expecting a huge thing – especially after seeing it on a banner outside – but no, it's a bit bigger than A4! The boy isn't named and doesn't look important, so how did he have his portrait painted and why is it important enough to be in this museum? But images on Google don't do it justice; the colours are stronger and the painting really projects out of the background in a way that is totally lost on the internet. On seeing it, I remember thinking about the boy in the painting and imagining his life. There are a lot of assumptions in this painting – I don't even know if it's a boy but, if he did have Angelman Syndrome, I wonder if he brought as much joy to his family as Henri does to ours. I turned from the painting to see a small crowd of people interested in why the three of us were being filmed. There's a photo of us somewhere looking a bit weirded-out because there were a whole bunch of tourists watching us reflect on this painting!

AngelmanUK: The rally is over. Did you achieve your goals?

Xav: 100% yes! I learned a lot about AS and myself. I learned what AS means and how to accept it. I gained confidence in how to best support and advocate for Henri. I



educated a lot of people on what AS is and now they can say, 'Actually, yeah, I've heard of AS and I know what it is'. TAR took a year of my life and in that time I went from self-destruction to a position of strength and purpose.

We do have another Rally in mind and we are looking for investors to take our secret concept forward. We know what we would like to do and it's very ambitious. We would love to make it really big but we can't do another self-funded event. So, investors, get in touch! xavier@theangelmanrally.org

AngelmanUK: Is there anything else you would like to say?

Xav: We were three friends who were already as close as brothers, who bit-off far more than we could chew. But, due to the challenges we faced, we came back all bonded and closer still. We remember this as an adventure. It's certainly given us all more confidence in various ways and we are all immensely proud of what we achieved. I am hugely grateful, not

only my riding companions, but to Stevie and Steph who came with us and to all our families for putting up with this and supporting us. Everyone played a huge part in the success of the trip and TAR family really is very big indeed! We hope the next one will be even bigger! I should also thank AngelmanUK for your support (specifically Lisa), Elmbridge Mencap, our sponsors (Triumph, Alpinestars, AGV, Sena, Continental to name a few) and our local businesses (Stoked, Nandos, NAL Properties, WPS Security Watchdog). Lastly, not least, my darling Corinne who has given me a son more perfect and beautiful than I could possibly have imagined and been a huge driving force behind the rally. And thank you to Henri for being my pride and joy and inspiration to so many people. I love you, you are my world.

AngelmanUK: A HUGE thank you to The Angelman Rally team, crew and supporters. The total raised currently sits around £3,800 and there is still chance to donate at: www.angelmanrally.org.



typical *angelman*^{uk} friendships

Alastair and Harry “Yes, Alastair’s genetic testing results are in, he has Angelman Syndrome, I’ll send you out an appointment to discuss it in the mail. Oh, and don’t Google it” *hangs up*. This was in 2005, there wasn’t an awful lot available to Google anyway, there wasn’t Facebook or the wonderful support that comes with it. So I was left to gather my own questions to ask when we were finally called back to speak to the geneticist. There is only one question I remember that I asked that day: “Will he be able to form and maintain a relationship?” The answer was “no”. Forever thriving off a challenge, I knew this wouldn’t be the case for Alastair. I have always strived for him to have typical relationships and his own friendship circle. In the early years this was pretty easy, he attended a mainstream child-minder until he was 5 years old. The children there grew up with Alastair, accepted him and never treated him differently to any of their other friends. When Alastair was 7, we moved house, away from the area his friends lived. Alastair was now at a SN school and there was a clear development gap between him and other children his age. But it didn’t take long before Alastair had a whole heap of new friends. We took Alastair to the local park one day and Harry, then aged 9 came over, sat on the floor with Alastair and kinda flapped along with him and talked to him about the rounders game him and a few others were playing. I answered all of his polite questions he had about Alastair before he returned to join his friends.

Harry: “There was something very distinctive about Alastair Smith. His blonde hair? His smile? The way he waved his arms in the air? His parents? The way he laughed? Quite frankly I can’t remember. If I were to take a guess, it would be everything I saw that day through those blue eyes of his. I don’t think I’d ever seen a boy smile so much, regardless of the boundaries Alastair had been faced with”.

The next day he was playing with our neighbour’s young girl. With permission from their parents I invited them over. I always had an activity planned, making pizza, sensory fun, something they could all enjoy together. They enjoyed hanging out. Many children would come over in the summer, drinking me out of cordial and throwing balls around the garden. Alastair has even been over to others

houses numerous times too! My favourite memory of this time was when they asked if Alastair could join them in a game of football on a field down our street. The children had become very independent and they had noticed Alastair hadn’t been given this same independence. I allowed them to take Alastair for an hour with strict instructions to come home at 7:30pm (the field is surrounded by houses and used by a lot of dog walkers). Anyway, 7:30pm came and went, as did 8pm. A little after 8 they all came back, they’d had Alastair out of his wheelchair sat on the touchline and took it in turns to keep him company as he watched on and had lost track of time. I obviously gave them a stern warning and explained why I had given the curfew but inside I was dancing! Alastair had gotten into trouble with his friends and I was so proud! The next time they didn’t want to take him in his wheelchair so they adapted a go-kart so they could pull Alastair on it, they had painted it and given him his own personal number plate.



Harry and Alastair grew inseparable. As they got older I would continue to look for mutual activities they could both enjoy. Live music, day trips, kayaking. We’ve even taken Harry on holiday with us, which was eventful but fun!

I asked Harry what his favourite memory of Alastair is...

“My greatest memory of Alastair was one I’ll clutch on to forever. It was on a mid-summer’s day on a beach near Scarborough, where Alastair was determined to get to the sea. With the sand being too wet for the chair to get him there, there was only one way of getting there. With the water being one of Al’s favourite things, getting to the sea was a necessity and the opportunity couldn’t be missed. With a slight push and a pull we got him on his feet. Alastair hesitated at first, but with patience and determination, he started walking to the sea. With the occasional pit stop for a break and a laugh Alastair soldiered on through and made it to the sea. He sat there content as could be, and believe it or not I think Alastair could have literally sat there on the edge of the tide line all day without breaking a sweat or turning his head to see what was happening around him.”

This day was a few days after Alastair took his first steps. Alastair was 11 and Harry 13. I had no idea that his favourite memory would be one of pride and admiration! Now the boys are much older they are pretty independent together. They are quite happy browsing the local shops together, running errands, grabbing a milkshake, watching movies or playing games. They attended a gig together just last week.

So: “Will he be able to form and maintain a relationship?” The answer has actually been “yes”.

Jenn Smith & Harry Beaumont

typical *angelman*^{uk} friendships...

Rhys and Harry One of the many questions that we always have struggled with following Rhys’ diagnosis was his likelihood of real friendships - it’s always been heart-breaking seeing other kids being invited to endless birthday parties and never having that same “privilege” for Rhys.

As the years have gone on our ache for that only ever deepened and as his mom I’ve spent many a time crying about the “if onlys” as I usually only ever saw a connection with Rhys and adults. Then one amazing day this all changed for us! We met a beautiful family through the Church that we go to and our families instantly clicked. Suddenly for the first time I saw Rhys happily and excitedly interacting with Harry who is just one year older than him. Our excitement and appreciation has only grown as we’ve seen this friendship so naturally unfold. We spend many weekends some way or another hanging out together and the connection that they share is truly beautiful. There’s nothing forced about this friendship - we have never urged Harry to push him around; or take him for a walk; or sit and play together - it has always been prompted by this incredibly kind and so naturally loving-hearted boy, Harry.

We recently attended a Christian festival and after a day or two Harry again off his own back decided he wanted to do a presentation to all his fellow peers (over 100 kids!!!) at their youth group to introduce “one of his best friends” Rhys to everyone. I literally wept listening to him stand up there and share with so many people all about my son! He explained to them about Angelman Syndrome but then more importantly he explained to them about who Rhys was - the things he loved to do and even went on to say that he thought Rhys was really cool and was one of his best friends! In the days that followed Harry’s talk it was amazing to see just how many other kids Rhys’ age started coming up to him to say hi and give him a high 5!

It’s such a comfort knowing that as Rhys approaches his teens that he will have a buddy to look out for him; who is always looking for ways to include Rhys! I so very often when seeing them together can literally feel my heart bursting with joy! This friendship has brought so much to Rhys’ life but equally has meant more to us as Rhys’ parents than Harry will ever know. He’s been a Godsend to us and one we will never take for granted!

Sheri-lee Taylor



exploring anxiety

Tracey Campbell explores the effects anxiety can have when combined with Angelman Syndrome and some coping techniques you can try...



Leia has probably always suffered from anxiety, but over the past two years it has been very negatively affecting her life. Her gregarious AS personality has not been able to come to the fore when in company. She hasn't been able to eat when we have been in unfamiliar surroundings or even in familiar restaurants. Her empathy levels make it very difficult for her to be near anyone who is slightly ill or older people with mobility issues.

We have been working with CAMHS to help both Leia and ourselves understand her anxiety. One useful tool we have used is The Disability Distress Assessment Tool (DISDAT). To begin with, questions are filled out to describe how the person looks, behaves and communicates both when relaxed and anxious or distressed. When filling out the questionnaire, it actually helps make you think about the effects anxiety can have on a person which is a useful exercise in itself. When the document is pulled together, it can be shared with anyone who is likely to come into contact with the individual.

We have also recently completed an adapted version of the "Glasgow Anxiety Scale" for Leia. This was a very interesting exercise, particularly as Leia completed it by herself. The Scale uses 0 for "never", 1 for "sometimes" and 2 for "always". However, we changed it to be just a yes or no question to keep it simple. For each of the questions we had a pre-prepared printed boardmaker symbol. Based on previous observations of Leia's learning and completion of tasks, I knew that answering a question as a straight "Does this make you worried, yes or no?" wouldn't have worked.

So, instead, we used a double-sided page with one representing worried and the other for relaxed. We asked Leia in turn if each of the things made her relaxed or worried and she chose which side of the page to put them on. Then before she stuck them down, we went back over each one and asked Leia if she was happy to stick them in the place. For example, she changed her mind about being in busy places and, to be honest, I can see why this was difficult for her to choose as some aspects of being in busy places she does mind and others she doesn't. This will be the next step for us, looking at each of

the things that causes her worry and trying to break it down further. Hopefully then we can build some really directed strategies to help her cope with her anxiety. Some of the questions also related to how Leia actually physically feels when she is anxious. We repeated the same process as before.

With hindsight there were some extra questions that we should have asked related to particular symptoms that we see. It appears sometimes that Leia could be having headaches for example but as that wasn't part of the official questions we didn't ask that. We will come back to the ones we didn't ask at a different time.

I am aware that not everyone may be as able as Leia to complete this task independently for a variety of reasons, however the process of thinking about what is causing anxiety and thinking about the strategies that may help overcome them could be done by family members. For example, if the person with AS drops to the floor when they are asked to change task, what has caused the problem? Has anyone told them what they will be doing next? Were they given warning that they would be changing activities?

Throughout our whole journey with anxiety, I have come to realise that a lot of Leia's anxiety is because we haven't communicated the same information to Leia as we would have to her siblings in the same situation. And she can't ask the questions they would to gather the information they need to understand enough to feel comfortable with

different situations. Living in a world where you struggle to ask questions, you need more information but often get less. It is no wonder that anxiety is prevalent.

Tracey Campbell



angelmanUK survey

Help us to help you!

Have you completed our survey? What can we do better next time? How effective do you think we are and what can we do in the future to help your family? All our surveys are totally anonymous and take less than a couple of minutes to fill in! Links below...

Conference feedback Survey for families:

www.surveymonkey.com/r/M266LGV

Conference feedback for professionals day (please forward on to your schools etc if they sent professionals at your suggestion):

www.surveymonkey.com/r/VVYFZ2G



General feedback on effectiveness of AngelmanUK as a charity-survey open to all whether registered with us or not:

www.surveymonkey.com/r/GP6PWY5

Is there something you would like to see covered in our newsletter?

Or do you have an idea or completed article?

Email jenn.smith@angelmanuk.org with your ideas and suggestions.

Christmas 2020!

We know, we know... Christmas 2019 isn't yet in full swing but here at AngelmanUK we are thinking ahead. Next year we would like to offer AngelmanUK Christmas cards both in paper and a digital format for you to send to friends and family while supporting the charity and raising awareness. And this is where you come in! Whilst engrossed in festive and creative activities this winter we would like you to send us your Christmas creations for the chance to be on one of our cards next year! We are asking individuals with AS, their siblings and family (adults, parents and carers included) who like to be creative to come up with our new designs. We love colour, a vivid imagination and above all originality. This can be as abstract or as traditional as you like, there are no rules!

Send your entries to jenn.smith@angelmanuk.org

We can't wait to see what you produce!

Christmas Party Regional Events

AngelmanUK are organising a number of Christmas-themed regional events around the country.

At the time of writing the details are still being arranged, but a letter will be sent when the various events are confirmed.

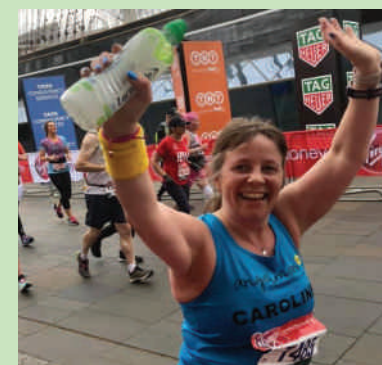
You can also check the website for the latest details of an event in your area, or email us: support@angelmanUK.org



sorry!

Due to technical difficulties we are unable to print the stories from our awesome fundraisers! We will rectify the problem and you can look forward to reading them in our next issue out in the new year!

If you'd like to be considered for a place in the 2020 London Marathon please email: lisa.court@angelmanuk.org



SEND law training

angelman^{uk}

Three AngelmanUK trustees recently attended the IPSEA level 1 training for the EHCP process in England (don't worry we are looking for equivalent training for Scotland, NI and Wales too).

IPSEA are a charity set up to give advice on the process and anything to do with appeals and education issues:

www.ipsea.org.uk

If you are starting the process and you want to ask for an EHC needs assessment, a useful link to follow is:

www.ipsea.org.uk/asking-for-an-ehc-needs-assessment

They even have a template letter you can use to request an assessment further down on this page.

If you want help during the EHCP process, or for appeals, you can make appointments on the website under:

How We Help > Our Services

We obviously cannot write up a whole day's course here but there were some interesting points:

In the EHCP, Sections B and F are the ones to concentrate on for accuracy. It's important that one contains the needs and one contains the provision. If you need to go to appeal you don't want to wait ages only for it to be thrown out because the sections contain a description that should be elsewhere on the form. There is a guidance document of what should go in each section, and specifically for sections B and F under:

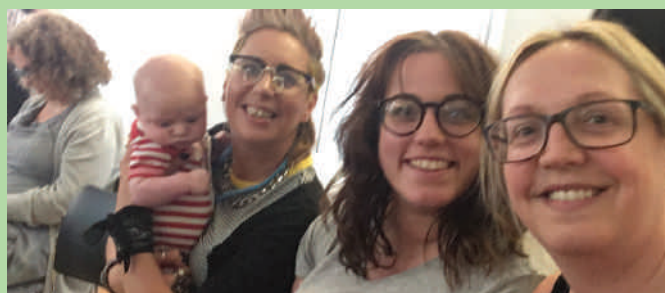
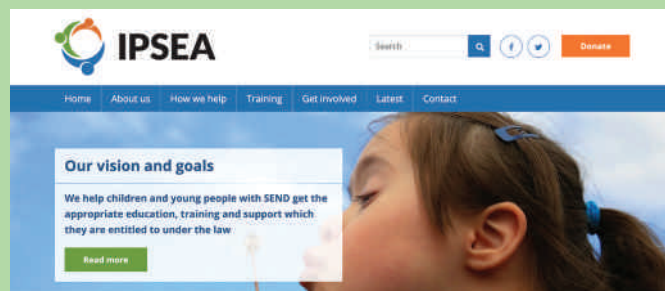
How we help > Get support > Education, Health and Care plans > What an EHC plan contains

If you do need to go to appeal, it's advisable to contact IPSEA for support as they are specialists in this area.

The course was very definite in suggesting that you ensure that the provision is as descriptive as possible. For example: x child will receive a provision of x sessions of x hours of x type therapy a week, rather than as some local authorities say 'the child would benefit from x type therapy'. If the school cannot provide that therapy, the onus is on the local authority to source the provision.

If a child changes provision (schools or from nursery to school or transitions from youth to adult services) then providing their needs haven't changed, that provision should go with them e.g. 1-2-1. The onus is on the provider to explain if 1-2-1 is not necessary anymore and simply saying cost or policy is not a reason.

Transitions were also discussed and where that is relevant is the capacity issue. You cannot get a power of attorney for youths with Angelman Syndrome as they have to have had the capacity in the first place to sign away their legal rights. So if there are issues with the gap of 16-18, or indeed with over 18s, then as a guardian you should still hold that right to make decisions on the EHCP process but you may need to get evidence that your youth with AS does not have that capacity such as a supporting letter or an assessment. You can of course apply for guardianship in court but that is usually for over 18s, leaving a gap for the 16-18 year-olds. An EHCP is valid until the person is 25. So even if the adult individual stops education for a while but wishes to return to education, you do not need to get a new EHCP, you just need to request a review of the existing one to validate or update any needs.



Although much more information on the appeals process and possible discrimination was given, the two big takeaway items here were: 1) it's really hard to prove a case of indirect discrimination and if you need to go down that route then the relationship between you and the provider is likely irrevocable so always try to use the review (re-assessment of needs) and appeals process first and contact IPSEA. 2) there is a shortage of judges and places for appeals to be held and a huge backlog of appeals to be heard. As such, many are being cancelled with no new date being initially set. If you can get a good quality EHCP up and running, or a review with re-assessment of needs first, this may give you the result you need.

For info on the appeals process navigate the website like this: **How we help > Get support Education, Health and Care plans > Appealing to the SEND Tribunal > General advice for all appeals**

This section covers the submission and content of an appeal: **Appeals about the contents of an EHC plan**

If your local authority is refusing to carry out an EHC needs assessment, IPSEA have given some supporting info and created a pack under: Refusal to assess appeals.

We hope this is a useful guide for everyone to whom it is applicable. Please email: support@angelmanuk.org if you cannot find the information you seek and we will try to point you in the relevant direction, or you can contact IPSEA directly.

Remember the above is only for those in England and is a brief takeaway of our interpretation of the key points you may benefit from. For proper legal advice you must contact IPSEA directly. We take no responsibility for the provision of advice from IPSEA as shared above as we are not legally trained in this matter.

Emma Goodson



ASA ANGELMAN
SYNDROME
ALLIANCE

research

The Angelman Syndrome Alliance (ASA) is a partnership of small organisations and parent support groups from around the world who are focused on supporting people with Angelman Syndrome, their loved ones, carers and clinicians. By combining resources, knowledge and a relentless dedication to initiate change, the ASA is uniquely positioned to drive advances in scientific knowledge about Angelman Syndrome. As a rare disease, major funding for scientific research is limited. The ASA is breaking new ground, utilising limited resources from around the globe in a smarter manner. By combining financial resources, we can fund research that individually our smaller organisations could not.

Our mission is to grow and support scientific knowledge about AS that can create fundamental and lasting changes in therapy for people with AS; so that parents, therapists and clinicians can improve the quality of life of those with AS.

Together we identify research that challenges our knowledge of AS today, to enable us to develop solutions for future therapies. The alliance focuses its investments on innovative science, with our ultimate goal to find therapies for patients with AS.

AngelmanUK is proud to be a founder member of the ASA and to date has donated approximately £35,600. We

also had the privilege of hosting the 4th International Scientific Conference in Liverpool in 2015.

The 7th International Scientific conference is being hosted by the Austrian Angelman Organisation on the 24-26th of September 2020 in Vienna, Austria.

If you would like to know more about the work of the ASA or the involvement of AngelmanUK please see...

www.angelman-alliance.org

...or contact:

rachel.martin@angelmanuk.org

Press Release September 2019

The Angelman Syndrome Alliance (ASA - a global initiative of Angelman Syndrome parent support organisations) announces 2019 Research Grant winners.

The ASA proudly announces three successful grant recipients in 2019: Dr. Ype Elgersma (Netherlands), Dr. Ugo Mayor (Spain) and Dr. Ben Philpot (USA). Dr. Ype Elgersma, Professor of Molecular Neuroscience, Erasmus Centre, Rotterdam, postulates that UBE3A plays a major role in the regulation of gene expression and sets out to identify respective genes. Dr. Ugo Mayor, Ikerbasque Research Professor, Bilbao, has a daring and novel approach to identify and validate the substrates and cofactors (including DUB enzymes) of UBE3A and to test the viability of targeting DUB enzymes as a therapeutic strategy for AS.

Dr. Ben Philpot, Associate Professor, University of North Carolina, fine-tunes his latest discovery by looking at quantifying sleep spindles from overnight EEGs as an Angelman Syndrome biomarker.

Speaking on behalf of the Scientific Advisory Board, Dr. Harald Sitte said:

"The result of the 2018 call for research proposals has yielded a good combination of different approaches which we hope will lead research on Angelman Syndrome into a bright future. We congratulate the three awardees and look forward to following their scientific work."

The previous winners of ASA Grants in 2014 and 2016 were Dr. Geeske van Woerden, Dr. Ben Distel, Dr. Silvia Russo and Dr. Ben Philpot.

One AS parent support organisation from any country can participate in the ASA. Our Scientific Advisory Board lends support and guidance to the members of the ASA.

ASA ANGELMAN
SYNDROME
ALLIANCE

Contact us if you wish to join, or if you are interested in learning more about Angelman Syndrome, the ASA or the scientific challenges:

www.angelman-alliance.org

For further information go to:

www.angelman-alliance.org

Communication: Betty Willemssen
betty.willemssen@ninafoundation.eu

Scientific Board: Harald Sitte
harald.sitte@meduniwien.ac.at

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

CTM

Mrs Julie Lawton

Pocklington Town
Football Club

In memory of
Mr Nelson Edwards

Ysgol Dyffryn Ogwen

The Knights of St Columba

Gail Whisker

John & Sarah Brookshaw

Scottish Friendly

Holy Trinity Church of
England Primary
School, Burnley

Earl Shilton Building
Society

Leicestershire Bobbin
Lace Guild

Westwards Nursery

J A Barrell

HMP Cookham Wood &
Oak Athletic FC

The Rotary Club of
Southampton Magna

In memory of
Mrs Carol Fowler

Mr & Mrs Willis

Mr R Fox

Mrs Sheila Thompson

Patricia Bothwell &
Logan's Walk

1st Netherlee Guides

Mr Fox

In memory of
Mr Brian Swan

Sally & Paul Waldron

The Cameron McKenna
Foundation

Mrs Beryl Walsh

Noel Protheroe

Rachel Haston

Nationwide Building
Society Chippenham

Dontaur Engineering

Stephen Roberts

Elize Lomas

Robert Brashier

Maria Moralee

Branka Torbica-Brocilo

Anna Marshall

Gwen Elliott

Charlotte Walker

Carmen Billingham

Alan Whitehead

Michael Eyre

Martin Peacock

Derek Pickering

Elaine Gooch

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 and she'll send you a fabulous fundraising pack with all the details of how you can get involved.

<u>Jessica Hall</u>	<u>London Marathon</u>
<u>Mathew Hendery</u>	<u>London Marathon</u>
<u>Hannah Mensah</u>	<u>London Marathon</u>
<u>Sharon Speers</u>	<u>London Marathon</u>
<u>Gareth Edwards</u>	<u>London Marathon</u>
<u>Paolo Noto</u>	<u>London Marathon</u>
<u>Danni McCormack</u>	<u>London Marathon</u>
<u>Victoria Moralee</u>	<u>Great North Run</u>
<u>Phil Thomas</u>	<u>Great North Run</u>
<u>Andrew Stephenson</u>	<u>Great North Run</u>
<u>Katy Jonas</u>	<u>Great North Swim</u>
<u>Xavier Lomas</u>	<u>The Angelman Rally</u>
<u>Bindu Bakrania</u>	<u>Nyra's Journey</u>
<u>Euan Miller</u>	<u>100m Ultra Marathon</u>
<u>Tracey Shelbourn</u>	<u>Lincoln 10k</u>
<u>Jonathan Allen</u>	<u>Lawnet Challenge</u>
<u>Gerard Black</u>	<u>Leeds Half Marathon</u>
<u>Will Hodgett</u>	<u>Leeds Half Marathon</u>
<u>Angela Linehan</u>	<u>Glow in the Park</u>
<u>Mark Hughes</u>	<u>Manchester 10k</u>
<u>Kathy Woolley</u>	<u>100km Peak District</u>
<u>Asha Odedra</u>	<u>Abseil</u>
<u>Mandy Humphries</u>	<u>Colour Rush Liverpool</u>
<u>Nicola Moore</u>	<u>Hell Fire Half Marathon</u>
<u>Gemma Boshier</u>	<u>Couch to 5k</u>
<u>Louis Brittain</u>	<u>Buzz Cut</u>
<u>Neville McCrindle</u>	<u>Bunty's birthday</u>
<u>Sarah Brown</u>	<u>Boulters to Bray Swim</u>
<u>Liz Godbolt</u>	<u>Boulters to Bray Swim</u>
<u>Clare Mann</u>	<u>Inflatable 5k</u>