

Assert

Angelman Syndrome Support Education & Research Trust

Useful Stuff

Freepost Address

ASSERT
PO Box 4962
Nuneaton
CV11 9FD

Assert Conference

3-5th September 2010
Loughborough University
Epinal Way Loughborough
LE11 3TU

Website

www.angelmanuk.org

Email

assert@angelmanuk.org

Helpline Number

Assert Families - New Diagnosis
Advice - Contacts - Support

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Contents of the Newsletter

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

Letter from the Trustees

Welcome to the latest ASSERT newsletter which we trust you will find helpful, informative, and will keep you in touch with the AS world.

The trustees are running fast now with the plans for the conference which we hope will build on previous successes. Certainly we have an exciting range of topics being covered as well as the usual chance to meet old friends and enjoy time chatting with others who can totally sympathise with the daily challenges we all face. I do hope that many of you will be able to join us, and to encourage you we have kept the cost the same as last time. We fully know the importance of this time to many so wanted to ensure that as many could come as possible. Once again we are looking to encourage more families with older AS individuals to come to the conference, looking at topics specifically relevant to this age range, as well as encouraging more professionals to come and benefit from the conference. If you have professionals that you deal with, do let them know about the conference as you, and they, could well benefit from their attendance.

Often it is this time of year, once the weather is improving, that we are looking for things that we can take the kids to, especially places which are AS friendly. For those of you in the London area, I would like to draw your attention to the London Zoo Special Children's Day on Saturday 12th June. This is a day they have every year where they give special concessions to families with a child with special needs. The tickets are significantly reduced from normal prices. For more details please contact Steve Marriott on 0207 449 6551 or steve.marriott@zsl.org. All tickets for this day must be purchased before 4th June.

I would also like to take this opportunity to apologise for the lack of ASSERT presence over the last few months. I am sure that we are all aware of the challenges that life brings to any family, and that is without adding the AS factor. As the majority of the trustees are parents or carers of an AS child themselves this means that they are far from immune from these life distractions which unfortunately will at times affect our ASSERT work. As trustees we endeavour to keep this disruptions to a minimum but ask you to bear with us when they do happen. In the meantime, I would like to thank all of those who contributed to this newsletter; to Rachel and Christyan for the many hours spent in compiling and formatting it, and would like to make a little nudge to those who maybe could contribute to future newsletters. Despite how small or insignificant you feel your contribution could be, I am sure that the ASSERT audience would be very appreciative of your thoughts.

Looking forward to seeing you at the conference in September.

jeremy well

Useful Websites

- ☀ Challenging Behaviour Foundation
www.thecbf.org.uk
- ☀ KidsOut
www.kidsout.org.uk
- ☀ Orthotic Products
www.gilbert-melish.co.uk
- ☀ Special Educational Needs
www.senmagazine.co.uk
- ☀ MumsNet Special Needs
www.mumsnet.com/Talk/special_needs
- ☀ Talking Point (speech & language)
www.talkingpoint.org.uk
- ☀ Harnesses
www.childharness.ca/index.html
- ☀ Safespace Beds
www.safespaces.co.uk
- ☀ Intensive Interaction (communication)
www.intensiveinteraction.co.uk/
- ☀ Baby Monitors
www.babymonitorsdirect.co.uk
- ☀ Makaton
www.makaton.org
- ☀ Family Fund
www.familyfund.org.uk
- ☀ Contact a Family
www.caffamily.org.uk
- ☀ Toys for Disabled Children
www.tfh.com



www.everyclick.com

is a search engine that allows you to raise funds for charities for free through searches, online shopping and donations.

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Central Region

Rosemary Teggin
(non-trustee)
N Ireland & Eire Representative

If you have any experiences,
good or bad, or details of
any fantastic places to take
our A/S kids to then please
write or email the details to us.

Assert Conference

3rd-5th September 2010

Loughborough University Epinal Way, Loughborough LE11 3TU

The conference is an ideal opportunity to make new friends, meet the professionals and maybe learn something new.

LOOK

The programme consists of keynote presentations, 1:1 with professionals, workshops and Regional Breaks - opportunities to meet with others who may live in your region.

There will be trips out each day for children accompanied by a carer - but children other than nursing infants will not be allowed into the conference.

In the evening you are free to join everyone in the bar area for a well deserved drink and for the ASSERT raffle.

The ASSERT Trustees would like to congratulate fellow trustees Rich and Sue on their recent marriage and also on the safe arrival of Baby Max!



AN APOLOGY FROM ASSERT

We have had a number of comments following an article in the last newsletter regarding the rebranding of ASSERT and particularly in relation to changing the logo. As a response to these comments I would like to offer some clarification. Firstly, I would like to apologise for any offence which was taken from the article, this was definitely not our intention. We want to acknowledge the invaluable contribution of a number of people, without whom the charity would not be in the healthy position that it now enjoys. These people include the previous trustees, whose tireless efforts built the charity from nothing into a support group which for many, including the current trustees, we have been able to rely on in times of desperation when many others just would not listen or could not understand what we and our families were going through. We fully acknowledge this contribution and want to place on record our heartfelt thanks to all those concerned. We would also like to also emphasise that whilst as trustees we felt that it was time to change the logo to a newer more contemporary design, we do not want to belittle the benefits provided by the previous logo during its lifetime. Again, we want to thank those involved, in particular Aleks and Jackie Klimanska, who gave vast amounts of time and effort, not to mention their extreme generosity often doing printing on behalf of ASSERT without any cost to the charity. Again, an invaluable contribution which helped to set the charity on its feet.

I doubt in this age of multi-media frenzy, when so many organisations are vying for attention in an overcrowded market, that there are many organisations that have not gone through some rebranding in the last 10 years. In fact only the other day I was listening to a radio programme which was talking about this very subject with a large national charity who because of their name meant that in the programme's survey that very few people interviewed actually knew what the charity did. The programme expert was saying that it was vital for charities to look at their image and how people viewed them, even in just the short time it takes to look at a logo, if they were going to stand any chance of survival. As a very small national charity, this is something that as trustees we have a duty to take very seriously.

In conclusion, I would like to reiterate our apology to anyone who took offence at the article, and we would like you to rest assured that we are not changing the charity beyond recognition, and the charity's core values remain the same; to provide support, to facilitate education, and to enable research in this rare syndrome.

Jeremy Webb, ASSERT

SIBLINGS - JUST FOR US

Hello and welcome to *Just for Us* - ASSERT'S all new siblings page, dedicated to siblings of any age of children with Angelman Syndrome.

Let me introduce myself. My name is Alexandria Edgar (Alex). I am 11 years old and I have a 6 year-old brother called James who has Angelman Syndrome.

I also have another brother called Zac, a sister called Beth and 3 other step brothers and sisters. I live with my family in Bolton, Lancashire. I will be writing something about my life with my brother for each newsletter.



This year we went to Euro Disney, Paris-it was awesome!! We flew from Manchester really early in the morning-it was the first time we had taken James in an aeroplane and he loved it!! He got so excited when we were taking off and landing-he wasn't bothered by the bit in between! He behaved well most of the time but he did get a bit bored and started shouting and kicking the poor people sat in front of him! Because we had James we were given a pass which meant we could go to the front of the queue. We got a few dirty looks off some of the people who had been standing in line for ages but that didn't matter! My favourite ride was Space Mountain-we went on it about 10 times!

We stayed at the Sequoia Lodge Hotel - it was lovely. The food was fantastic, there was a swimming pool and the rooms were really nice, although James did manage to escape and wander down the corridor at 3am trying all the doors!

If you have anything to say about your life as an A/S sibling or you think that someone deserves a special mention, just write or email to the addresses above and we will include it in the next newsletter.

Or if you would like to write a story, a poem, tell jokes or draw a picture to do with your siblings with Angelman Syndrome then please email me at assert@angelmanuk.org or write to ASSERT at: PO Box 4962 NUNEATON, CV11 9FD.

We need your articles and pictures for our very own page!



The **Canadian Angelman Syndrome Society** would like to invite you to the 10th CASS International Conference being held on July 21st until July 24th, 2010 in Montreal, Quebec, Canada .

We will be joined by such internationally renowned researchers such as Drs. Charles Williams, Chris Oliver, Stephen Calculator, Edwin Weeber, Jane Summers, Ben Philpot, Susan Yuan and Asuri Prasad.

For more details and a full programme please visit:
<http://www.angelmancanada.org/>

Romeo and Juliet - William Shakespeare...

Yes that's right.

I am writing to tell you how proud Paul, my husband, and I are of our beautiful Angel, Kate. Kate is now 26 years old and for the last two years has been involved with a local drama group. Kaleidoscope, for adults with Special Needs. How she's blossomed since then!

We would never in our wildest dreams have thought that Kate would be involved in something like this. In her first performance, two years ago, at the Daneside Theatre in Conleton she played the role of Juliet in Shakespeare's *Romeo and Juliet*. She did so well and looked so beautiful. She kept pointing to the flowers in her hair and clapped herself at the end of the performance. It brought tears to our eyes. What a drama queen. Kate needed some support whilst on stage from one of her carers but she did really well.

Last June she was in a production entitled 'Don't look Back' based on Greek mythology. She was much more confident, needing far less support and was just as delighted with her performance. She also really enjoyed the after show party with her family at the pub later that evening. Next summer's performance is still a secret but we're all looking forward to it so much.

I hope this story will give encouragement to other parents and help them appreciate that some of our Angel children have special talents as well as 'special needs'. With the difficulties that Kate has she has continued to surpass any expectations we might have had for her when she was younger.

Best wishes, Jenny and Paul Reid

SWINE FLU

Following the hard winter and the increasing numbers of queries through the helpline and on-line regarding Swine Flu, vaccinations and our AS children, Dr Jill Clayton-Smith very kindly prepared this statement for us.

There is a lot of general information on the NHS website but of course they can't mention every syndrome individually. The important thing to remember is that swine flu is behaving just like any other seasonal flu and the death rates are similar. There is no evidence to suggest people with AS are more susceptible to swine flu, they don't have problems with their immune system, for example, but children under five are at higher risk of getting more severe symptoms if they do get it and there is one study from the U.S. which suggests that children with long term conditions including epilepsy, cerebral palsy and developmental delay are also at higher risk of getting complications like pneumonia with swine flu. This information was on the Medline Plus site in the U.S. which is affiliated to the U.S. National Institute of Health on September 3rd 2009. I would think that individuals with AS come into this category of patient. The advice for this group is to seek medical attention sooner rather than later if a child develops fever or flu-like symptoms, and that they should be in the priority group for immunization when this becomes available. It's important to realise, however, that many of the disabled children who had complications probably did so because they were immobile or had some chest problems already. Most Angelman children don't have these problems, though seizures may well increase the risk for complications. Finally, swine flu numbers have fallen dramatically in the UK over the last two months which is reassuring. The most important thing for families to do is to keep washing their hands frequently, discard any used tissues quickly and observe the other hygiene rules on the Swine Flu website.

Jill Clayton-Smith

★ Angels Without Voices ★

Thursday 27th August 2009 saw the inaugural event for Angels without Voices, a fundraising project in aid of ASSERT. The Red Carpet event saw 150 guests don their Glad rags and descend on Glasgow's Premier Private Members Club 29 for a mix of live music, Dancing Girls and Silent Auction.

★ Guests were welcomed with a Champagne reception followed by a choice of sumptuous cocktails. With photographers on hand to take everyone's picture on arrival in front of a specially commissioned Oscar Backdrop. ★

The silent auction featured some fantastic and exclusive items including signed footballs from Rangers FC, Celtic FC and Manchester United FC, Signed Gold Discs of Casino, Top Gun & Grease and an Exquisite Vera Wang Niki Bag donated by Kate Moss.

★ All the generous donations raised a great deal of interest and went a long way in the success of the event and the £6500. The raffle included items such as an Xbox 360, Limited Edition BAFTA Placemats, Glengoyne Distillery Master Blending Session and a Cut and Colour at Saks St Vincent Street raised £1200 alone! ★

The night was kicked off with a short video presentation highlighting the amazing work and support ASSERT offer and featured the real stars of the night – the Angels:

★ Graced by the presence of Cara Kennedy, Fashion Writer for Scotland's Premier Glossy "No! Magazine" Cara kindly judged and presented prizes for Best Dressed, Male, Female and Couple with prizes donated by Bedlam Paintball, Hilton Glasgow Grosvenor, Guys Restaurant, Kroma Hair, Rainbow Room Stirling & Jemma Kidd Make-up School. ★

★ ★ ★ ★ ★ ★

Best Dressed Male: Neil Miller

Best Dressed Female: Hanna McMillan

Best Dressed Couple: Alice Saula & David Baird

★ ★ ★ ★ ★ ★

The event featured in the No! Magazine's 25th Sept – 15th Oct issue and further pictures of the event online at www.no!magazine.co.uk

★ The Live entertainment began with an astounding performance from the dance troupe Filthy Gorgeous with their own Cell Block Tango from the Musical Chicago and throughout the night guests were treated to the vocal styling's of Sam Simmons, Scott Cameron and Marty-Joe Rogan who are all featured on the Music from the Movies CD all finished off by another outstanding Hip Hop performance from Filthy Gorgeous. ★

Angels without Voices have created a children's book called *Just Like You*, written, illustrated and printed all free of charge to help in the fundraising for ASSERT

LOOK!



There is also a CD of Music from the Movies which features *Sam's Song*, a very moving song written for ASSERT and all the Angels in the UK.

Both the book and the CD are available to purchase online at www.angelswithoutvoice.co.uk at a cost of £5 each + P&P

1. Sam's Song - Marty Joe
2. Nothing Compares to You - Sam Simmons
3. Is This Love - Jono
4. Black Velvet - Gail Diment
5. Mack the Knife - Scott Cameron
6. Iris - Gerry Rogan
7. First Cut is the Deepest - Sam Simmons
8. Nobody Does It Better - Gail Diment
9. Sweet Caroline - Scott Cameron
10. What a Wonderful World - Wendy King

with special thanks to
www.discwizards.com
Marty Joe Rogan, Neil McNeil
and mckaysee



Presents
Music from the Movies

If you are a Blue Badge holder you can now get the Blue Badge map sent direct to your mobile phone. It covers the whole of the UK and shows parking bays, accessible toilets, petrol stations and local council parking rules.

You need a phone that can connect to the internet.

Text Blue to 83377 (standard rates apply)



The Family Fund helps families with disabled children and young people aged 17 and under to have choices and the opportunity to enjoy ordinary life.

We give grants for things that make life easier and more enjoyable for the disabled child, young person and their family, such as washing machines, driving lessons, computers and holidays.

The Fund is a registered charity, helping around 53,000 families on the lowest of incomes across the UK. We provide grants to families totalling £31 million pounds a year.

New Criteria

From 1 April 2010, the Family Fund has changed the way we look at income to help families on the lowest of incomes. We will consider a grant application where a family's total income from all sources, including net income and benefits, is below £25,000 in England and £27,000 in Northern Ireland, Scotland and Wales.

If you live in England, you can apply if you can say Yes to all of the following:

- You live in England
- You are the parent or carer of a severely disabled child aged 17 or under who lives at home. (The Fund has its own definition of severely disabled please click here to read our definition).
- Money coming into your household is less than £25,000. This is the money you receive from benefits and tax credits. If you are working we also count your net income (this is the money you take home after you have paid tax and national insurance). We do not count Disability Living Allowance or Child benefit.
- You have permanent legal residency in the UK and have lived in the UK for six months

If you live in Northern Ireland, Scotland or Wales you can apply if you can say Yes to all of the following:

- You live in one of the above countries
- You are the parent or carer of a severely disabled child aged 17 or under who lives at home. (The Fund has its own definition of severely disabled please click here to read our definition)
- Money coming into your household is less than £27,000. This is the money you receive from benefits and tax credits. If you are working we also count your net income (this is the money you take home after you have paid tax and national insurance). We do not count Disability Living Allowance or Child benefit.
- You have permanent legal residency in the UK and have lived in the UK for six months

We are not able to help children and young people in local authority care, including those living with relatives or foster carers or where a statutory agency has a responsibility to pay for the items.

Family Fund definition of severe disability

As the Family Fund has limited funding, and is unable to help all families caring for a disabled child or young person it has its own definition of severe disability. To meet the Family Fund definition of severe disability, children and young people must have additional complex needs, or have a serious or life threatening illness.

AND

There must be evidence that the child's additional needs impact on family's choices and their opportunity to enjoy ordinary life; and the degree of planning and support required to meet their needs is much greater than that usually required to meet the needs of children and young people.

AND

They must require a high level of support in three or more of the following areas:

- The physical environment
- Education
- Communication
- Access to social activities
- Personal care, supervision and vigilance
- Specialist resources, including Information and Communications Technology, required
- Medical or therapeutic treatment and condition management

AND

The child's condition must be long term or life limiting. By long term we mean lasting or likely to last 12 months or more.

If you are in doubt as to whether your child or young person would meet the Fund's

Contact us

Family Fund
4 Alpha Court
Monks Cross Drive
York
YO32 9WN
Tel 0845 130 4542 or 01904 621115

Textphone 01904 658085

Fax 01904 652625

Website: www.familyfund.org.uk

Email: info@familyfund.org.uk

If you need an interpreter, we will use Language Line. Please contact us, telling us the language you use

Just a thought...

"I can assure you that there is no more powerful advocate for children than a parent armed with information and options"

Rod Paige - former U.S. Secretary of Education

Raffle Prizes

121
K77P CW5B

We are appealing for raffle prizes for the conference. If you are in a position to approach your employers, local shops and businesses, or if you have unwanted gifts or left-over prizes from your own raffle that you would like to donate to ASSERT, please contact us as soon as possible.

Thank you.



A novel way of raising funds for ASSERT

Is there a way in which you can raise money for charity whilst simultaneously engineer an excuse for boys road trip across Europe? Oh yes...

Giles and Paul are close friends of the Blackburns who are blessed with an angel called Callum. Whilst discussing ways in which they could provide some support for ASSERT and have some fun an idea began to take shape. Several pints and some internet research later the idea became fully formed and the Wacky Rally adventure had begun.

The mission – drive 1500 miles from Calais (France) to Split (Croatia), through 5 countries in four days in a car costing no more than £250, car decoration and ridiculous outfits compulsory.

Step 1 – buy car. Naturally this involved a few more pints and some heated discussion about the relative merits of reliability and coolness of car. Finally prudence beat vanity and a relative sensible K reg Saab 9000 with 186,000 miles on the clock was procured from an 'under the arches' dealer somewhere in the wrong end of Slough.

Step 2 – decorate car. More heated debate, there may have been a beer or two but its getting a bit hazy by now. We settled on turning the car in to a mobile golf course and of course the requisite full golfing regalia for the intrepid drivers. A full weekend work was required to bespoke tailor an Astroturf suit for the Saab. There was also several realisations that weekend. We had an oil leak (solved with gaffa tape), the air conditioning did not work (ideal for the 35 degree temperatures in southern Europe) and, to compound matters, the passenger heated seat was stuck on max

Step 3 – the drive..... The big day loomed. On the Eurostar crossing the Saab was ideally positioned in the performance car carriage of the train, sandwiched between a Lotus and a Ferrari. We arrived in France, met up with about 100 other Wacky Rally participants with a wondrous collection of outfits and decorated cars and then drove in convey for 8 hours until 600 miles later we arrived in Bern, Switzerland. The driving rain and the resultant soaked Astroturf had done wonders for the performance of

the car. Not. A quiet night in Bern retiring to our beds at 5am. The next day was the big one with a drive through Switzerland and the mountains and over the Stelvio Pass (one of Top Gear's ultimate driving roads). The sat nav shots show what a ridiculous road it really is – we had a few problems with the brakes which made the drive a little more... er... exciting I think is the word. The top of the pass also presented the best opportunity for some more driving – this time golf balls from the top of the mobile golf course...



Stelvio Pass

After another early night, we awoke to a dismal morning of weather and made the dreadful mistake of following the sat nav instructions which took us over a very narrow dirt track with sheer cliffs. There were some sweaty palms and this was not just because of the heated passenger seat. Eventually we made it back to some sensible roads and managed to get back to more than 15 miles per hour. We pointed the car at Ljubljana and a few hours later arrived at our accommodation for the evening. A rather fetching prison cell. Actually it was a former prison, now converted in to a hostel but complete with grills on the windows and doors. Now time for the big push through Slovenia and some more fantastic roads to Croatia. After a spot of trouble with border control whilst crossing in to Croatia (the car log book said the car was white – it was before the AstroTurf) we finally persuaded the border guards that it was all in the name of charity and we were on the last leg to Split.

After 1500 exhausting miles there was limited appetite for the drive home so we had to get rid of the car and ask Mr Ryan (Air) to complete the journey home for us. Fortunately a Croatian taxi driver thought that the car might make a good novelty taxi in Split. We happily handed over the keys and celebrated, yes you guessed it, with a couple of beers.

Giles Derry



Giles & Paul

Giles and Paul are more than just 'close friends' but the godfathers to our Angel, Callum and our daughter Keira.

They have both been a huge support for us throughout the years and we are so blessed to have them in our life. If Callum could talk he would tell them how wonderful they are and how lucky he is to have them in his life. A huge thank you to Giles and Paul for their incredible enthusiasm, remarkable generosity and for taking on this challenge to raise not only necessary funds but awareness for Angelman Syndrome.

With much appreciation,
Alistair and Heidi Blackburn

Gilfach Goch Community Association

On Friday November 27th 2009, the community of Gilfach Goch got together in support of a fund-raising event to help those with AS. 'Valley's Got Talent' was hosted and organised by the volunteers at Gilfach Goch Community Association. From the outset, the event promised to be a huge success with tickets selling out in advance – a first for any fundraising event at GGCA.

No less than twenty local acts contributed to the success of the evening. From the toddlers of Tumble Tots crèche, to the more experienced artistes, each performer did their upmost to prove that this valley certainly does have talent !!

Guest of honour was GGCA's very own angel – 7 year old Morgan Williams. Morgan is an active participant in a wide range of activities based at Gilfach Goch Community Association and is much loved by staff, volunteers and her fellow peers.

This very successful evening raised a total of £500 for ASSERT. Plans are already underway for a follow-up event in November 2010!



Exhibitions of Children's Equipment

KIDZ SOUTH
JUNE 24 2010
Rivermead Leisure Complex
Richfield Ave
Reading RG1 8EQ

KIDZ UP NORTH
NOVEMBER 25 2010
Reebok Stadium
Bolton
BL6 6JW J6 M61

NAIDEX
APRIL 20 2010
National Exhibition Centre
Birmingham



Angelman's Syndrome

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Please note the
deadline for the
next ASSERT
newsletter is
June 15th 2010

Peru and The Inca Trail

Gareth, now aged 30, moved into his own home almost exactly 3 years ago, this together with retiring has left me with time and energy I had not been used to. It has also given me friendship from an amazing group of people who care for Gareth and his two mates on a daily basis in a gentle, fun and truly caring fashion.

Nadine the house leader had a really good idea, she wanted to raise funds for ASSERT, she attended the 2008 conference with me and just like that ran the London Marathon, not content with that achievement she set her sights higher and persuaded me to join her on the 4 day trek to Machu Picchu. I was too easily persuaded and together with another friend Ann, who runs a Victorian Walled garden, where people with learning disabilities go to work, we signed up paid our money and began the training and fund raising.

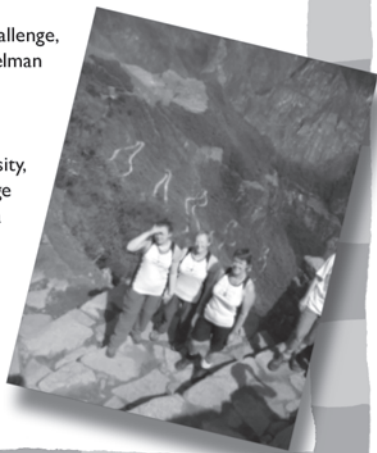
Wales is a good place to train there are literally loads of hills and it became really enjoyable walking further and further in the spring and summer evening sunshine. I put out begging letters and family and friends, knowing I am slightly mad, contributed generously.

It was not an auspicious day to begin such a challenge, Friday 13th November, but luck was on our side, Wrexham and Shropshire Railways gave us free first class tickets to London, with the most amazing breakfast and the flight via Madrid got us eventually to Peru some 18 hours later.

We had trained hard but none of us knew how we would cope with the altitude. After two days acclimatisation we were ready to begin the trek. We were lucky; none of us was badly affected just unable to walk up hills without puffing and panting. Monday, our first day on the trek was relatively straightforward, the second day saw perhaps the biggest challenge to cross Dead Woman's Pass, 4150 meters, and the third day, the most beautiful, we cross two passes through the cloud forest. After a final night camping we set off to reach Machu Picchu. It was a beautiful walk, we saw orchids and humming birds, we climbed the 'Oh My God' and then we were there, we had reached the 'Sun Gate'. I was given the honour of walking first through the gate, I think at 61, Wilo, our guide, didn't believe I would make it, believe me it is hard and you need to be fit to attempt it. He presented us all with a lovely Inca Cross we walked onto a ridge which looks over the most amazing valley which surrounds Mount Machu Picchu, it is breathtaking.

Gareth really does value his mobility and I felt this was a fitting challenge, we were experiencing some of what Gareth and others with Angelman Syndrome face on a daily basis as they struggle with balance and co-ordination to keep walking.

We are very grateful to all our friends and family for their generosity, Ann and I are so grateful to Nadine for her inspiration and courage taking us along. I am delighted that together we have raised such a large sum for ASSERT, but most of all the elation of achievement, the fellowship we experienced from the 15 group members, who all now know about Angelman Syndrome and Gareth. I feel so privileged to have been able to achieve something so wonderful at this stage of my life. Only two days home and I found myself having a sneaky look at the charity challenges magazine - where to next I wonder?



ASSERT families might be interested in the following article, reprinted with kind permission from the Epilepsy Research UK website: <http://www.epilepsyresearch.org.uk>

What's the best anti-epileptic drug for childhood absence epilepsy?

17 March 2010

Childhood absence epilepsy (CAE) is the most common epilepsy syndrome found in children, and it usually starts between the ages of four and nine years. During an absence seizure, the child will suddenly lose awareness, stop all activity and stare blankly into space. He / she will be unresponsive to voices and may show automatic, repetitive movements of the mouth or eyes. This is associated with a characteristic change in the electrical activity in the brain.

Absence seizures typically last between five and 20 seconds, and they end as suddenly as they begin. Children with CAE usually develop normally, but because they may experience hundreds of seizures per day, if their seizures remain untreated, they risk falling behind at school (as their concentration and memory become more and more affected). Fortunately, the majority of children with this form of epilepsy become seizure-free when they reach puberty.

Approximately 70% of people with CAE have their seizures completely controlled with one or more anti-epileptic drugs (AEDs). The three AEDs that usually used to treat CAE are ethosuximide, valproic acid and lamotrigine; however, until now, no comparison between the three in terms of efficacy had been made.

Researchers in America, led by a team in Cincinnati, have now completed the first ever double-blind, randomized, controlled, clinical trial of these AEDs, in the treatment of CAE. They specifically looked at three aspects of the drugs - their efficacy, their tolerability and their neurological/psychological side-effects.

453 children who had been newly diagnosed with CAE were enrolled in the study over three years (beginning in 2004). Each child was randomly assigned treatment with either ethosuximide (total: 156 children), valproic acid (total: 148 children) or lamotrigine (total: 149 children). For each participant, the dosage of their allocated drug was increased until he/she was seizure-free, or until the maximum dose allowed or tolerated was reached.

Using the results obtained, the researchers established freedom-from-failure values for each of the AEDs. Freedom-from-failure refers to the percentage of cases in which a drug allows individuals to be seizure-free after 16 weeks of treatment, without causing intolerable side effects.

Finally, the group measured the impact of the three drugs on the children's ability to remain focused on every-day tasks.

The results showed that the freedom-from-failure values for ethosuximide and valproic acid were very similar (53% and 58% respectively), and approximately double that for lamotrigine (29%). However the older drug, ethosuximide, was considerably less likely than valproic acid to disrupt children's attention/concentration (33% and 49% respectively). There were no significant differences among the three AEDs with regards to how well they were tolerated/the percentage of cases in which they had to be discontinued due to side-effects.

These findings suggest that ethosuximide and valproic acid are more effective than lamotrigine in the treatment of childhood epilepsy, and that ethosuximide causes the least disruption in learning/attention.

Although further research is needed to confirm these results, this study is very helpful, because it will enable doctors and parents to make more informed treatment decisions for children with newly diagnosed CAE.

ASSERT Bank Account

Please be aware that we now only have our current account. All other accounts are closed. There have been some receipts paid into the other accounts which at the moment the bank are automatically transferring to our current account but I am sure there will come a time when they will not do this. So please do not pay any donations, collection tins etc into these other accounts. If you would like our current account details, please contact the support line.

Lisa Court, treasurer

Please feel free to pass this newsletter to all who wish to read it or who may benefit from its contents.
Thanks to all contributors.

REGIONAL MEETINGS

Could you host or help to organise a regional meeting in your area? It could be a coffee morning or a full on fun day. Recent meetings have been held in Special Schools and have proved very successful. Most schools are well equipped for our children with changing facilities, play areas and separate dining areas. Other ideas include local Soft play centres i.e. Wacky Warehouse or community rooms. If you feel that you would like to help families in your area meet up and build relationships then please contact ASSERT and we will help in whatever way we can. Moderate expenses can be covered if necessary.

C L A S S I F I E D S

If you would like to advertise to the ASSERT community send your adverts to us and we will endeavour to publish them in the next newsletter.

One of our ASSERT families has a wooden holiday chalet in North Wales that they have made suitable for their AS child. They would like to offer other ASSERT families the opportunity for week/weekend holidays. Situated on the banks of the River Seiont in Glan Gwna Country Park near Caernarfon.

High sided, electric rise and fall bed with external lock
Video monitor
Safety gates
Safe Kitchen- portable induction hobs (don't get hot)

Sleeps 8 (inc sofa bed)
TV and DVD
Large Decked area
Heated open air swimming pool
Restaurant, bar, gym and beauty salon on site

Contact Rachel & Chris Martin 07880863355 or 07879028071
for information and availability

Brand New!

Assert

Merchandising

Those creative pixies at ASSERT have been beaver away. In association with Spreadshirt, our on-line merchandising shop is now open for business.

Whether you just want to support your charity or if you're looking for that perfect gift for friends and family, you'll find something here to please everyone.

The **link at the bottom of the page** will take you straight to ASSERT's home page where you can select from mens, ladies and childrens clothes, along with some great accessories such as bags, badges, mugs, hats, aprons, umbrellas - you name it we've probably got it, and if we haven't there's a good chance it's coming soon.

Shown here are just a few samples of what's on offer. Make sure you bookmark the Spreadshirt site and keep checking back regularly as it will be updated with more great designs soon.

[Hello, you're not logged in. Login now!](#)
[Shopping Basket: \(0 articles\) \(£ 0.00\)](#)

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Assert

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Page 1 of 2 1 2 Products 1 to 10 of 15



Front & Back designs
 Men's Classic T-Shirt
 Classic-cut t-shirt for men, 100% cotton, Brand: B&C


Colour ☐ ☒ ☐

Select your Size

Quantity

Production time: within 1-2 Working days
Product number: 10163059

Price £ 11.90



Men's Classic T-Shirt
 Classic-cut t-shirt for men, 100% cotton, Brand: B&C


Colour ☐ ☒ ☐

Select your Size

Quantity

Production time: within 1-2 Working days
Product number: 10160666

Price £ 11.60



Women's Spaghetti Top
 Form-fitting shirt with spaghetti straps for women, 100% cotton, Brand: Spreadshirt


Colour ☐ ☒ ☐

Select your Size

Quantity

Production time: within 1-2 Working days
Product number: 10163119

Price £ 11.60



Women's Spaghetti Top
 Form-fitting shirt with spaghetti straps for women, 100% cotton, Brand: Spreadshirt


Colour ☐ ☒ ☐

Select your Size

Quantity

Production time: within 1-2 Working days
Product number: 9694890

Price £ 11.60



Umbrella
 Classic pocket umbrella with protective cover, Brand: Gremo

Colour ☐ ☒ ☐

Size One size

Quantity

Production time: within 1-2 Working days
Product number: 9713822

Price £ 10.60

<http://458768.spreadshirt.co.uk/>



Mug
Mug, ceramic, Brand: Printequipment

Colour

Size

Quantity

Production time:

Product number

One size

1

within 1-2 Working days

101655

Details



Retro Bag
Retro Bag, 100% polyester, Brand: Bag Base

Colour

Size

Quantity

Production time:

Product number

One size

1

within 1-2 Working days

9722983

Details



Men's Raglan Long Sleeve
Classic-cut long sleeve shirt for men, 100% cotton, Brand: Promodoro

Colour

Select your Size

Quantity

Production time:

Product number



within 1-2 Working days

9722941

£ 18.60

Add to Basket

Details

Size chart



Front & Back designs
Kid's Classic T-shirt

T-shirt for kids, 100% cotton, Brand: Anvil

Colour

Select your Size

Quantity

Production time:

Product number



within 1-2 Working days

10161483

Details

Size chart

Price

incl. VAT EU
excl. delivery costs

£ 15.30

Add to Basket

<http://458768.spreadshirt.co.uk/>

DONATIONS

Thank you to everyone who has donated to ASSERT.

Your contributions - no matter how small - all make a difference. Without you there would be no ASSERT and we know how important we are as a support to our families within the A/S community. Many thanks to:

The Royal Sussex Lodge No. 342

Mrs Tait

SWCG

David Muller

**Donations in memory of
Mr James Whiddington**

Mr & Mrs Rostron

Marie Green (donations from
collection box)

Kevin & Deborah Gundle

18th Edmonton Scout Group

Marsh Magic Employee Matching
(Hannah Fatt - London Marathon)

National Grid Employee Matching
(John Wilson - London Marathon)

**30th Signal Regiment, Gamecock
Barracks, Nuneaton**

Jenny Gray

Tina Smith (London Marathon 2009)

Simon Howton (London to Brighton
Cycle Ride)

Sukhraj & Pete Dhaliwal

Glencore International AG

Lottie Fox-Jones (Hinchley Wood School)

Charlie & Alfi Weekes

Crawford & Company

Paul Crabtree

Giles Derry

Russell McKay (Glasgow 1/2 Marathon)

Mr MacMillan

Mr & Mrs Knapp

Neil Buchan (sponsored Sky Dive)

Ruddington Ladies Probus

Mr & Mrs Simpson

Mr & Mrs Webbing

Shella Meadows & Ann Morton &

Nadine Vernon (sponsored trek to Machu
Picchu in Peru)

United Brothers Lodge 1069

Old Portmuthian Chapter 8285

Catrina McMartin (Glasgow 10k Run)

Melanie Booth (Bupa Great Manchester Run)

Mandy Bennett (Bupa Great Manchester Run)

Rachael Banks (Freckleton Half Marathon)

Paul Boon (Manchester to Blackpool Cycle)

The Two Matts (Canoe Challenge)

Ann Martin (Angels Without Voices)

Rich & Sue Williams (Wedding Donations)