



Newsletter 49 Autumn 2011

Angelman Syndrome Support Education & Research Trust

**Latest news on
FAST research**

Oliver's Bed

**New Young Sibs
Club!**

**London Marathon
2011 report**

**Assert launches
its new website**

Your Assert Trustees



Jeremy Webb, Chair and East Region



Lisa Court, Treasurer and Central Region



Rich Williams, Merchandising and Welsh Region



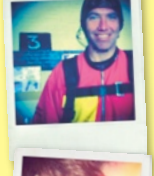
Sue Williams, Secretary and Welsh Region



Christyan Fox, Media and South East Region



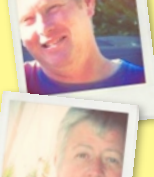
Russell Andrews, Sibling Support and Central Region



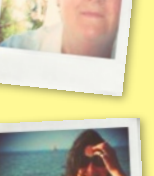
Neil Buchan, Fundraising and Scottish Region



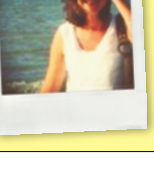
Rachel Martin, On-line Support and Welsh Region



Chris Martin, Welsh Region



Rosemary Tegg (non-Trustee)
N. Ireland & Eire representative



Finn Emmerson has recently resigned as a trustee. We'd like to take this opportunity to thank her for all her hard work for Assert over the years, we'll miss you Finn.

Useful Stuff

Our Freepost Address

ASSERT
PO Box 4962
Nuneaton
CV11 9FD

Our Website

www.angelmanuk.org

Email Assert

assert@angelmanuk.org

Helpline

0300 999 0102

Assert Families - New Diagnosis
Advice - Contacts - Support

Assert Shop

Wear your charity with pride! T-shirts, polo shirts, bags, hats and lots more from Spreadshirt, our on-line retailer:
<http://458768.spreadshirt.co.uk>

Front cover

Photograph courtesy of Robert Chadwick. We'd like to use one of the great photos taken at our 2010 conference on each of our future covers. If your AS family member was one of those photographed and you do not want their images used on Assert material please let us know at the above address as soon as possible.

Contents of the Newsletter

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

Letter from the Trustees

All go in Assert world

You will hopefully have noticed that the Assert trustees have been busy making progress on a few things here. Firstly, our new all singing, all dancing web site, www.angelmanuk.org, which hopefully you will not only find more attractive to look at but also will contain a wealth of useful information. All of the trustees have been tasked with helping to provide information for the site, so hopefully we will be able to regularly update it with more useful things for you. So do check back often.

We have also announced our conference dates and venue for 2012, 31st August to 2nd September at the Hilton Hotel, Coventry. Whilst we have enjoyed a good few very successful conferences at Loughborough, we felt it was time for a change, both to keep our sanity, but also as sometimes the student accommodation was basic to say the least; maybe this is just a sign of me getting older. So the Hilton, Coventry it is, which I am sure will be relative luxury. The staff have assured us they will remove anything breakable. My thanks go to Christyan Fox-Jones who offered to lend them the irrepressible Harvey to AS-test their rooms. Strangely enough they did not take him up on this kind offer. The venue will be much better, being nicely contained, and we will pretty much have the run of the whole hotel. I think the rest of estate have probably, and wisely, fled for the weekend. In terms of programme, we are still working on it, however rest assured it will contain a good mix of old and new. Particular aims this year are more on supporting siblings, which we started at the last conference, and then more on older AS individuals, post-education, leaving home etc. So please do come and join us for what I am sure promises to be a great time, meeting old friends and making some new ones. From personal experience, I can guarantee it will be a very valuable time and money well spent.

For many, the conference is a great time to be able to share experiences with each other, as let's face it we are the real experts, but with the conference only running every other year, this leaves a gulf of time in between. If you are into Facebook I would encourage you to join our Facebook group, *Angelman UK*, where you can continue conversations started at the conference, or start new ones, asking questions to see if others have had a similar experience. There is always a good amount of healthy discussion going on. For siblings we also have our sibling group: *My Brother/Sister has Angelman Syndrome*, where you can chat about your experiences. We encourage you to make use of these groups.

Jeremy Webb

PS We've had a number of enquiries asking why we don't produce the newsletter more regularly than twice a year. The reason is that as well as being Assert trustees we're all busy parents just like you, many of us with a day job too, so time is short. The current 24-page format is quite lengthy, so we've decided to try to produce a shorter newsletter of 12 pages, initially three times per year. Look out for the first of the new format in Spring 2012.



Siblings – Just for us!

A few years ago I made the rather dim mistake of asking two identical girls I was teaching what it was like to be twins. They gave me identical withering looks and said in unison “er... normal”. Occasionally I get asked what it is like to be the brother of someone with AS and I feel like giving the same response. If you can't remember life without your AS brother or sister then having them around is 'normal'. This is one of the significant ways that siblings are different to their parents and can account for why many parents are surprised that their children can apparently take disability in their stride.

Of course you do know there are differences and they become more obvious as you grow up and spend time in homes without Angelman's. Being in a house that is quiet, where food can be left out on table tops, where everyone sleeps through the night definitely doesn't seem normal! Going out as a family without having your brother or sister make you the centre of attention might be fairly unusual too.

I've been spending some time recently looking at the research into children who grow-up with a profoundly disabled brother or sister and the good news is that actually most of us grow-up to be just like everyone else, perhaps a bit cranky at times but not much more or less than anyone else. There are some interesting differences between ages and girls and boys but different studies say different things and sometimes contradict each other.

I may say more about this next time but in the meantime thought I'd leave you with more comments from our Sibs group at the ASSERT conference 2010 (and get in a shameless plug for Conference 2012 where we will have more activities for siblings).

Things that make me sad about having a brother/sister with AS

When people make fun of him
when people stare

Not knowing about the future

When she gets in the way or doesn't understand

When she hits me and pulls my hair

I feel sorry for her when she can't do something

When he pinches and nips me

Things that make me happy about having a brother/sister with AS

When he smiles and gives everyone hugs

He is always happy

When we get the arm-bands for queue-jumping at theme parks

Everyone is friendly to us

My sister has a fantastic character

She makes me more friendly

He makes me feel confident

Finally, don't forget the Facebook page:

My brother/sister has Angelman Syndrome

We have 68 members now and it's growing all the time so, if you are old enough to be on Facebook, join us and let's hear from you.

Russell Andrews



New Young Sibs Club!

Everyone gets
a T-shirt!

Well, not **everyone** gets a tee shirt – only special people. If you are under 13 we want to encourage you to send in a piece of art-work or writing (a story, poem, that sort of thing) that we can publish in the newsletter in the Siblings section – it can be about what it's like to be a brother or sister of someone with AS or it can be about something that matters to YOU.

And for everyone that has something published we will send back an "I'm no Angel!" siblings tee-shirt.

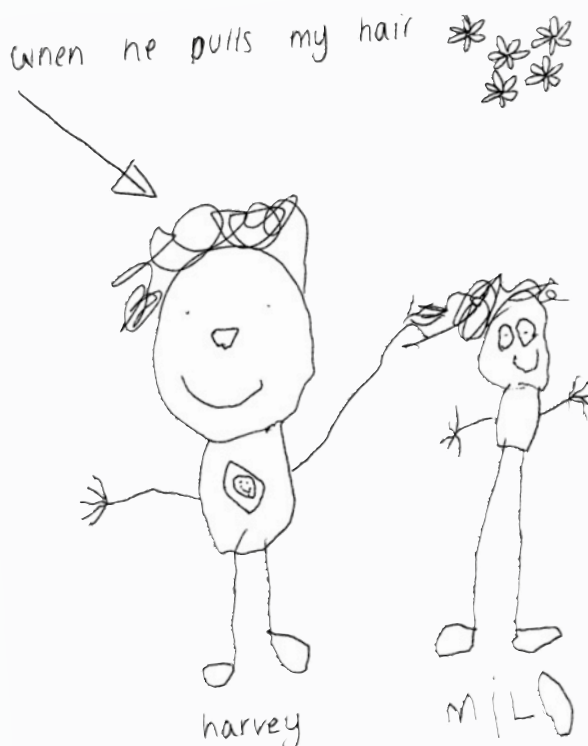
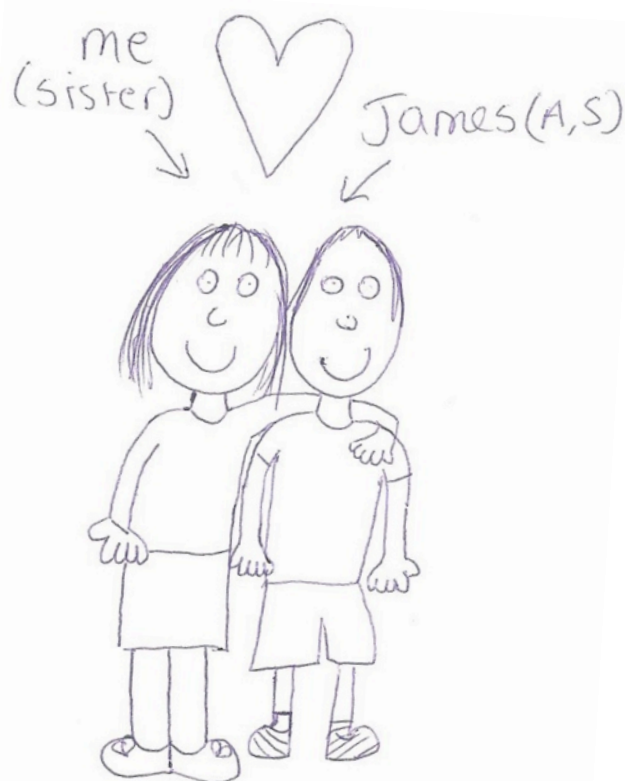
So what have you got to lose?

Send your entries to Russell Andrews either via email: Russell.Andrews@angelmanuk.org or by post to

ASSERT
PO Box 4962
Nuneaton
CV11 9FD

...and don't forget to tell us your tee-shirt size!

Alex Edgar with her brother James



i would like to go to milo land...

Milo Fox-Jones, aged 5 and his brother Harvey
(plus a little help from Lottie with the writing and flowers)

Assert's new website is here!

After many long delays and a lot of teething troubles Assert finally launched its new website in August. Hopefully most of you will have already seen it, but for those who haven't we've kept the usual address of:

www.angelmanuk.org

On the right you can see a few of the new pages and the improved layout should make it much easier and more enjoyable to navigate.

However, we don't want to stop there - some of the areas are still growing. We're intending to add more articles and newsletters to download, a history of Assert, an on-line shopping feature for merchandise purchases outside of the Spreadshirt items, and lots more.

Having lived with the new site for a couple of months we've already responded to some of your comments, so we're expanding the News section on the front page to include regional meetings and adding a 'Donate Now' button to the page header to make it easier for everyone.

We value your feedback, after all, you're the people who are going to use the site. If you see areas where we might improve, things we've left out or areas we need to make clearer, just let us know via the usual contact details at the front of the newsletter.

Oh, and if you like the new site, don't forget to let us know!



Friends of Assert

As trustees we have been considering how we can draw more people in to help with the organising of the activities of the Trust on a voluntary basis and we are particularly keen to move beyond parents and carers as we know these people already have significant pressures on their time.

Assert membership has always stretched beyond parents and carers and we wouldn't wish to change this however we are considering establishing a 'Friends of Assert' group which would be mainly people who aren't parents/carers who may have more time to give to support events we run.

This may be members of the extended family, friends or people with an interest in AS without the direct care responsibility. If you are interested in supporting this group or know of people who might wish to be part of it please let me know, you can contact me via the Assert website, or email me directly at: Russell.Andrews@angelmanuk.org

Thanks,

Russell Andrews

Ella's Sponsored Travel

Ella, 4, was diagnosed with AS when she was just 2. She has a sporadic mosaic imprinting centre defect.

She attends a mainstream pre-school close to the home called 'The Cherry Playgroup'. The staff here have been amazing with Ella and she has progressed enormously over the past year.

When a sponsored 'travel' was suggested at the playgroup to raise money for upkeep, it was thought that half of the money raised should perhaps go to Assert. The aim was not only to raise funds for the charity but also to raise awareness in the community.

The sponsored travel was a roaring success and £375 was raised, £187.90 was given to Assert. Ella herself completed an amazing 82 laps of the course! Ella and her playgroup were then featured in the 'Cambridge News'.

Antonia Burton, Ella's mum



Is there a “cure” for Angelman Syndrome?

We wanted to make comment about the very high profile research that is taking place in the U.S. under the banner of the FAST organisation. Part of the reason we want to comment is that we are concerned about the amount of hype that is surrounding this research, much of which is not actually information which has been published by the FAST organisation itself, but we suspect is more the result of rumours growing bigger with each telling.

The position in which we find ourselves at Assert is a hard one, in that unfortunately we are having to bring an amount of realism to a very emotive subject, however we feel that we have little choice. We as much as anyone else are desperate to see steps forward in the treatment and therapy provision for our children which improves their quality of life.

Let me start by saying that much of the research that is being done is very exciting, and a lot of very positive progress has certainly been made by the researchers. This is something we welcome, and we do look forward to seeing positive results from their research. It would seem that they have made significant progress in their research and that some form of treatment which may help in the management and relieving of symptoms does seem to be a distinct possibility. However, and this is the hard bit, we must express our concerns when claims of a “cure” are being highly emphasised. The trustees of Assert cannot claim to understand all the ins and outs of the research which is why we took advice from Jill Clayton-Smith and Professor Bernard Dan, two professionals who are noted worldwide for their knowledge and experience with Angelman Syndrome. So our opinion is not just one that has been formed by our fairly minimal knowledge but has come after seeking the expressed opinion of people who, in our opinion, know what they are talking about.

A couple of years ago Bernard wrote a very comprehensive response to the claims that were being made and we are including that again. here. Apologies for this, but we felt that in the light of the heightened profile of FAST since gaining significant new funding for their research and clinical trials, that it was important that we reiterated our position.

Jeremy Webb

Professor Bernard Dan has very kindly prepared a brief overview of the research being carried out and also the implications of that research.

There is no cure for Angelman Syndrome - but management needs to be improved.

I was asked to answer the question: “Can Angelman syndrome be cured?” I would love to say yes. I would love to say soon. But I can’t. To give a short answer: there is no cure for Angelman syndrome but management needs to be improved. And I can say that we (and many others) are working hard on it.

The cause of Angelman syndrome can be determined in about 80% of individuals that show the characteristic features of the condition: reduced expression of a gene called UBE3A. Various genetic abnormalities can lead to this impairment (deletion, imprinting defect, mutation, etc.). The UBE3A gene was known before its involvement in Angelman syndrome was suspected. Some of its functions have been described, but it is likely that there is lot more to discover in this field. A number of teams of

researchers (including ours) across the world (not enough, though!) are busy studying these issues further. Thanks to advances in genetic engineering, they (we) can use mice in which that gene has been knocked out to study certain aspects of functioning, hoping that this relates to Angelman syndrome as seen in humans. Clearly, mice tolerate the genetic problem better than people, and it is not easy (if possible at all) to distinguish between normal mice and those with the genetic abnormality with the naked eye. Special tests are required to demonstrate learning, movement and of course EEG abnormalities. We can even check if the abnormalities we find can be reversed once the gene has been restored.

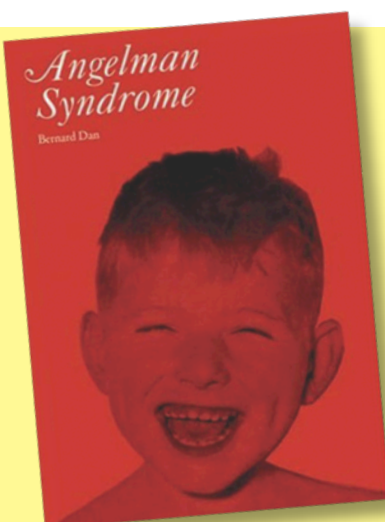
This research is very important to gain a better understanding of the mechanisms that lead to Angelman syndrome. Some definite abnormalities have already been demonstrated in some parts of the brain of the genetically modified mice. But the full picture is extremely complex, and none of the involved researchers can claim their findings actually explain how the cause (reduced UBE3A expression) produces all the effects, that is the developmental, motor, intellectual, speech, behavioural and epileptic problems that characterise Angelman syndrome, let alone cure the syndrome. In fact, it is not possible to cure a brain developmental disorder unless one can modify brain function at a very early stage – long before birth. Brain development heavily relies on orderly processes that start in the embryo, drawing developmental trajectories. In Angelman syndrome, the diagnosis always occurs relatively late in the brain developmental history: late infancy at best, later childhood in most cases. Current research does not aim at discovering a cure but rather at improving management in order to optimise development, ameliorate symptoms and improve the quality of life of children and adults with Angelman syndrome. Great progress has been made in recent years and a lot more still can be expected.

But the use of the word ‘cure’, implying recovery from an illness, is deceptive in this context. This issue of curing Angelman syndrome is central to the FAST (Foundation for Angelman Syndrome Therapeutics) website. This website provides useful information about several aspects of Angelman syndrome, but some statements (probably used for the sake of simplicity) are just incorrect.

I can’t agree with the claim that “current research suggests that neuronal development occurs correctly in the brain in AS, but neuronal functioning is impaired.” Current research has poorly addressed neuronal development in Angelman syndrome, and the impairment in neuronal functioning documented patients with Angelman syndrome and animal models is sure to interfere their neuronal development. There is an urgent need for further high quality research in Angelman syndrome. The objectives must be clear. Both basic and clinical research must be encouraged, bearing in mind that management issues must be tailored individually, based on the specific needs of patients.

Professor Bernard Dan

Dept. of Neurology, Hôpital Universitaire des Enfants Reine Fabiola, Université Libre de Bruxelles.



Angelman Syndrome

by Bernard Dan

As one of the only books available on the subject this comprehensive guide to the clinical management and basic science of Angelman Syndrome will be of value to clinicians and researchers as well as parents and relatives.

As it's printed in such small numbers the price is usually very high at £71.25 but we've made an arrangement with the publisher to make the book available to ASSERT members for the special price of only £37.50. Contact Assert for a copy of the publisher's pdf file for mailing details.

Paperback: ISBN 978-1-898683-55-1

London Marathon Report 2011

We had a fantastic turnout at this year's London marathon with 8 golden bond runners and 2 additional runners who ran on their ballot place for ASSERT. Between the 10 of them, they raised the huge sum of just under £13,400. What a magnificent effort! Our runners were:

Karl Scally, Mark Lillicrapp, Haidee Kerr, Tim Higgins, Dan Gritton, Stephen Brooks, Chris Stratford, Dan Masser, David Collis-Smith and Helen Tweed

Helen Tweed



In amazement from the sheer amount of people I nervously joined in at the red start Pen 5 ready and waited to tackle the distance ahead. Training had gone well and my target was set at under 4 hours. It was massively hotter than any other weather I had trained in but I had fluid on my belt and lots of water stops were planned so I wasn't too worried.

The Gun went and it took just over 4 mins to reach the start line, and then we were off, at exactly the same pace we had been going for the last 4 mins due to crowds! It was difficult to maintain a steady pace for any time during the Marathon due to the people in front of you slowing or having to speed up to overtake and my GPS watch informed me that I had done an extra 1/2 mile by the finish! As if 26.2 wasn't enough!

I felt great for the first 16 miles. Pace was good, time was set and the target seemed a mere jog away, but then at about 16.5 miles, the heat started to zap my energy and I picked up my fridge and started to slow. From then until about 24 miles, it was a hard slog, of shouting within to keep going, maintain the pace, do it

for Ella! I found myself pouring water all over myself at one mile then by the next I was dry again and in desperate need of more! People were flaking all around me, the poor St Johns Ambulance were running about like headless chickens trying to attend to all the victims of Heat!

At mile 24 I knew I had only 2.2 miles to go. Was on about 3 hours 40 mins so knew sub 4 hours was within my reach if I could just make myself run and a lot faster than I was going! I managed it though and staggered over the line in 3 hours 58 mins and 7 secs! I was overjoyed. Had a little moment and a little cry to myself. Thank god it was over! It was a real achievement and I would definitely do it again, but I will never say it was easy because it was so far from that! It was all helped though by the amazing support from the crowds. It was unbelievable the lengths people went to show their support!

Karl Scally

Coming out of Christmas knowing I'd eaten and drank too much and also knowing in 15 weeks I'd be running the marathon I used every opportunity to run, averaging 50 to 60 miles per week.

The night before the marathon I woke and checked my watch what seemed like every hour until the point I knew I had to get up and travel across London. I think I was more nervous about missing the start, once at the start my nerves settled.

The start happened fast, the crowd moved suddenly forward then we were off. The first few miles were hard to run due to the amount of runners around but soon opened up. The 14 mile point you start into Isle of Dogs, the 7 miles around the Isle of Dogs were draining and a hard slog in the heat. I saw my daughter holding up a good luck sign as I ran past 18 miles which helped kept me going but around 21 miles I got cramp in my right calf, this was the first time I'd stopped running. From this point I struggled, slowing down and having to stop to stretch my leg every mile. As I ran back down towards the last 4 miles the welcome site of Big Ben appears, the crowd swells again and the noise rises.

At mile 26 a "365 yards to go" sign, even at this point you can't see the finish. I'm not sure who measured the last 365 yards but it felt like I'd run an extra couple of miles in that last stretch.

Crossing the line (even in pain) was emotional....bring on next year's.





Stephen Brooks

I ran the London Marathon for my daughter Lacey Brooks who has Angelman Syndrome. It took a lot of motivation, training and hard work as I am getting no younger and seem to be always getting injured. It was a great privilege to run for Assert, on the race day the atmosphere was electric and spurred me on. It seemed as if all of London came out to support all of the runners. I hope this inspires other people affected by Angelman syndrome to run for this charity. I had a lot of support from my family and friends prior to the race I would like to thank them all for their support and sponsors.

Chris Stratford

Only people who have run marathons know what "the wall" is. For me, this was at mile 18 where my legs and head decided they had had enough and wanted to go to the nearest pub. At this point though, you have to question why you are doing it and what the consequences are of deciding to collapse over a barrier and pretend you only intended to be a spectator anyway.

When running for a charity, this is the incentive. I was delighted to run, together with Karl Scally (who finished a million miles ahead of me) for Assert and this got me from mile 18 to 26. I was very lucky to have some very generous people sponsor me and when, at your lowest, you remember this, not finishing simply wasn't an option.

The whole experience was fantastic, I enjoyed the training (most of it) and the day itself is a wonderful experience where you meet a whole host of characters along the route who you share your highs and your lows with. It is definitely something that everybody should aim to do in their lifetime. I was delighted to raise money for Assert as part of the experience.



Tim Higgins

Well, the London Marathon is over and what a hot one it was. My shoulders were bright red from the sunburn! It was not the most successful of days. I had planned to do the marathon in under 4 hours and was running on target to do 3 hours and 50 minutes until the 16th mile. Then my back went – it felt as though someone had kicked me in my kidneys, this meant I ended up walking on and off for the remainder of the race. I finished in 4 hours 23 minutes which to be honest I was disappointed with but I was still in the top 40% of people to finish. I went to the St John's Ambulance afterwards to get my back looked at and was even more disappointed when I remembered that I had been carrying ibuprofen around with me and I should have taken some during the race! Straight after the race I was saying that London would be my FIRST and LAST marathon, however a niggling voice in my head is saying 'Do it again, you know you can beat that time!'. Looking back, running London was a great experience and I would recommend it to anyone.



Haidee Kerr

Like many people, I had never heard of Angelman Syndrome or Assert. That was until 3 years ago, when a workmate's baby son was diagnosed. The lovely smiley William is now 3 years old, working closely with his Dad, I know the countless times he has been admitted to hospital, often in an emergency situation, has undergone major surgery and will need constant and specialised care his whole life.

I heard all about Assert and what a great help the support network and in particular attending the annual conference has been to William's parents.

What really struck me is that Assert is such a tiny charity run purely by volunteers and relies solely on fundraising/donations. I wanted to do something to help and the London Marathon it was!

I'm not a natural athlete and found the training really hard, horrendous in fact! The day was (as you'd expect) tough and I managed to miss my family and friends at 5 different checkpoints only seeing them at mile 23!

I didn't quite manage my target time of under 5 hours but 5.07 wasn't TOO far away!

I rewarded myself with a well earned beer at the end, purely for re-hydration of course!

I'm proud to support Assert, I hope the money and awareness raised have helped, what a fantastic job it continues to do.



The Great North Run



Are you interested in running for Assert but don't think you can manage a whole Marathon?

Or perhaps you applied for the Marathon and didn't get a place?

Assert have applied for a number of places for the Great North Run next year. The event takes place on Sunday 16th September 2012 in Newcastle.

The Great North Run is the world's largest half-marathon and is televised live on the BBC. There are approximately 54,000 runners – and we do hope a few of these runners will be wearing our Assert vest!

We are hopeful we will secure some places, which we will then offer to anyone who would like to run and raise money on behalf of Assert. We have set the minimum sponsorship at £650.

If you would be interested in running for Assert at this fabulous event then please send an email to lisa.court@angelmanuk.org. Once we have been allocated our places and we know what numbers we have, we will be in touch to all those who have emailed in.

Angelman Syndrome Links

Information



Angelman Syndrome Foundation The web site of the American Angelman syndrome group. This is an excellent site with much good information.



Dutch Angelman Association



The Angelman Project
www.angelmanproject.com/home.html



Special Educational Needs news
www.senmagazine.co.uk



Reading recommendations
www.scribd.com/doc/36260961/Angelman-Syndrome-From-A-to-Z

Sibling Support



Assert's Siblings page
www.facebook.com/group.php?gid=142621172447009

Therapies & Education



Talking Point (speech & language)
www.talkingpoint.org.uk



Intensive Interaction (communication)
www.intensiveinteraction.co.uk



Makaton Makaton is one of the recognised sign language systems used by AS people in communication.



Gina Davies: Attention therapy
www.attentionautism.com

Parental Support



Assert's Facebook page
www.facebook.com/group.php?gid=17790428608



Professionals Supporting Parents
www.right-support.org.uk



People with Profound & Multiple Learning Difficulties
www.pmlnetwork.org



National Family Carer Network
www.familycarers.org.uk



Challenging Behaviour Foundation
www.thecbf.org.uk



KidsOut
www.kidsout.org.uk



MumsNet Special Needs
www.mumsnet.com/Talk/special_needs



Family Fund
www.familyfund.org.uk



Contact a Family
<http://www.cafamily.org.uk>



Foundation for People with Learning Disabilities
www.learningdisabilities.org.uk



Foundation for People with Learning Disabilities
www.mychildandmemagazine.co.uk

Assert conference time again!

August 31st - September 2nd, Hilton Coventry

Just under a year might seem a long time for you, but for the trustees we are well into the swing of organising our next national conference for September 2012. For those of you who have never been to a conference before, let me start by giving you a bit of an insight as to what goes on which will hopefully encourage you that coming to the conference would be a good idea.

We all meet on Friday afternoon/evening, coming from all different parts of the UK, and some even from other parts of the world. Friday is always a very relaxed affair, with great food (I am sure it always tastes better when you don't have to cook it yourself), a couple of brief talks, and then off to the bar for time to relax, enjoy a couple of shandies, and meet people, who unlike the norm in our lives, have actually heard of Angelman Syndrome and totally appreciate the many challenges that we live with from day to day, which the majority are totally oblivious to.

Saturday morning starts of course with the most important part of the day, a full cooked breakfast; that's right there is no slumming it at Assert conferences! Then we head full swing into the main programme, whilst the kids and their carers head off to some local attraction. In previous years these have included Drayton Manor and Twin Lakes.

With the kids well catered for, hopefully now the remaining adults can enjoy a mix of talks and workshops given by professionals/experts on the many different sides to Angelman Syndrome. The range of these talks is very wide, some being on the medical aspects, some on the use of different therapies, some on managing our AS individuals behaviour and techniques to help this and some on other peoples experiences in a range of circumstances.

Whilst there are some keynote talks, which everyone attends, there are a good selection of workshops which you sign up for on Saturday morning. These again will range from more informational to very practical sessions. At the same time as this, because of the wealth of knowledgeable professionals around, who have actually heard of Angelman Syndrome and know lots about it (and we would hate for them to be bored), we also run one-to-one sessions, which you can sign up for. This gives you a chance to speak privately with one of the professionals about your specific circumstances to see if they can offer you any advice or pointers. Whilst, having never met your child, they might not be able to give specific assistance or diagnosis, we have found that these are invaluable sessions, and have proved to be very popular. The day continues in similar vein, obviously breaking for lunch and coffee breaks along the way.

Though the program has yet to be finalised, topics that we are highly likely to cover during the conference are:

- | | |
|-----------------------|-----------------------|
| •Communication | •Physiotherapy |
| •Eating and Drinking | •Mobility |
| •Behaviour | •Scoliosis |
| •Epilepsy | •Education |
| •Wills and Trusts | •Transition |
| •Benefits | •Leaving home |
| •Occupational Therapy | •AS and getting older |



Around 5pm the kids arrive back from the day trip and we move into our hands-on session. This is where you get a chance, with your AS individual, to try out whatever equipment is in the exhibition area. This in the past has included trikes, communications devices, beds, sensory equipment etc, etc. It is always great fun, and for many is a fantastic opportunity that they would not normally get. After that excitement, it is only right that we move onto the evening meal followed by entertainment and relaxing time in the bar. We try to provide a mix of entertainment, ranging from children's entertainers to a disco. One year we even had a magician going round who I know baffled most of us, especially burning £5 notes. It is always a great time to relax and chat some more.

Sunday is much of the same, another trip for the kids and carers, and more talks for the adults again with breaks for coffee and lunch. The conference finishes around 3pm (ish) with tea and cakes before we all head off for our different parts of the world, back to 'normal' life, whatever that may be.

It is often felt that the main part of the conference starts on the Saturday morning. Whilst in some respects this is true, as that is when the more formal part of the conference begins, for me it is the many opportunities to meet people who are in a similar boat to me that makes this conference such a rich and profitable time. Whilst we do appreciate that for some they are not able to commit to staying for the entire conference and so only come in for a day or two, I would like to encourage you that in doing this you are really missing a very big part of the conference. If like some, the thought of spending time trying to chat with people you do not know is a scary one or not your idea of fun, let me try and assure you that with AS kids around, adding to the provided entertainment in their own inimitable way, conversation comes easily. You do not have to explain your child or adults behaviour as everyone there is very used to it. Instead, you can share the joys and the trials with others who understand what it is like. Whilst it is not respite in our normal understanding, it is respite from having to explain and from being different. Instead, we are in the majority!



Hot off the press!

Hopefully this will all encourage you that coming to the conference is a good idea. If my ramblings have not done this, then hopefully this final bit of information will do so. Whilst we are not yet taking bookings for the conference - this will not be until the new year - the trustees have already agreed the costs for the conference and I am delighted to say that because of the valiant efforts of people fundraising on behalf of Assert, especially those running the London Marathon, **we are actually able to reduce the cost of the conference this time**, something I hope that in the current economic climate will come as a refreshing change. The costs will be:

Adults: £100 (reduced from £130)

Children: £50 (reduced from £75)

AS Individuals: Free

AS Carers: Free

Adult Day Only: £50

Child Day Only: £25

Please do have a good think about coming to the conference. I have attended all but one of the Assert conferences over the years, and I have never yet met someone who regretted coming, so come and join us for what I am sure will be a very enjoyable and rewarding time.

100km round the Isle of Wight... off-road... on a bike!

Back in June, 6 friends got together and entered the Isle of Wight 100km off-road bike ride to raise money for Assert. The motivation behind this was because of a 7 year old girl with AS called Niamh, the daughter of Martin & Marie Carty. In all they raised an amazing £7500 - Well done to all!

The 6 team members were:

John Carty, Damian Coyle, Ian Rimmington, Craig Tait, Matt King and Peter Hodge

John Carty

I'd like to add that when the pain was at its worst the reason for doing it, Niamh, and the company of a great team got us to the end. I will never forget the feeling I had when we finished. A mixture of relief, total exhaustion and pride in the team which I felt honoured to be a member.



Damian Coyle

I've had my bike about 10 years and the brakes have never smoked before in response to those steep isle of white tracks. I have never consumed so much water, energy drinks, protein bars in such a concentrated period in my life. Despite the gruelling conditions, to put it very simply failure was not an option, so crossing the line together 11.5 hours later for such a fantastic cause was a brilliant feeling that will be etched in my memory for ever.

Ian Rimmington

A key moment that brought home the enormity of the task at hand was when I got to a down hill stretch and I had to peddle to get down due to the strength of the wind in my face. After 75k I think we were all dead on our feet but still we were motivated to continue. I believe through the support from each other and very importantly to deliver on the massive support we have received from our donors and friends and families.

Craig Tait

If there was something to say about the weekend was that the group was stronger than the individual. Because no one was willing to give in, the collective thought was to carry on and finish the 100k and that was exactly what we did. I have never undertaken such a physical and mentally demanding task but I am glad I was part of a team that did it.



Matt King

Pain is temporary but failure is forever, still in some pain but would like to thank my team mates for getting me through the last 30k.

Peter Hodge

It was a great pleasure to do something a little closer to home and actually see the joy it brings.

Botox and Bikes

This summer has been one of great activity for us. Ruth, now 14, has been having increasing difficulties with her mobility, and whilst she can still walk with assistance, she has slowly been bending her knees more as she walked. This has been caused by a combination of increased weight as she grows ever taller (much to Claire's despair) and tightening hamstrings. So this is the situation we found ourselves in, with Ruth's walking slowly getting worse and it being harder to manage her, especially things like getting her dressed as she was reluctant to straighten her legs.

Eventually we were referred to Great Ormond Street and it was decided to try giving Ruth some Botulinum toxin (Botox) injections in her legs, not to enhance her already very apparent beauty, but to relax the muscles in her legs, meaning she could not fight so much, and thus enabling us to more successfully carry out her stretching program. Now for many Botox injections can easily be carried out whilst awake and compliant to requests for keeping still, but this is Ruth with Angelman Syndrome we are talking about here, and keeping still is generally not something she likes to do. So it was decided, especially in the light of the fact that they also wanted to plaster cast her for knee and ankle orthosis to help with the stretching program, that the only option was for general anaesthetic.

So off we trekked, getting to Great Ormond Street for 7am, for Ruth to have her Botox injections and casting. For Ruth yet another great adventure, full of fun and new people to meet who have yet to experience her. For us, yet another new experience, wondering what would happen, and how on earth were we going to manage to carry out an "intensive" physiotherapy program just coming into the summer holidays. The day itself passed without incident, Ruth endearing herself to yet another set of people. The Great Ormond Street staff were refreshingly amazing, very able to cope with Ruth and all her game playing. So that was the easy bit, now for Ruth's physio program, which consisted of trying to straighten her legs a number of times a day, either using her gaiters, which prior to the operation had become impossible to put on, or putting her in her standing frame in conjunction with using her knee and ankle orthosis (KAFO's). The KAFO's are basically splints, with a part on the thigh and another part on the calf and foot which are joined by a metal bracket with a ratchet so that once you have achieved some degree of straightness, Ruth cannot then bend her knee back, holding her leg in a straight position and thus stretching the hamstrings.

We were amazed at how easy it had suddenly become to do Ruth's stretches, helped by the fact that Ruth actually seemed to enjoy all this attention, and generally was fairly cooperative, something which as she gets older and taller is more important. Slowly, over a number of weeks, the Botox wears off and the original strength returns to the muscles, but the theory is by this time the hamstrings will have been stretched. Initial signs are looking positive, Ruth is still happy to straighten her legs far more than she was before. Now it is just a matter of strengthening the muscles in her legs. This has been aided by regular hydrotherapy sessions at school, which Ruth loves, and then we have just been given a trike, funded by Cerebra, and provided by our friends at Tomcat. Ruth loves the bike, and is very happy to try and catch her brother cycling ahead, much to the despair of Claire and I who try and keep up behind. So all in all, a summer of a lot of hard work keeping up physio programs, but one which, from early signs, seems to have paid dividends with Ruth's mobility and her willingness to straighten her legs.

Jeremy & Claire Webb



Double-D Marathon Walk

We were five ordinary mums (really we are, honest!) looking to get fit have fun and put this all to good use by raising funds for some very deserving charities. We all have links with the charities through our families. When we were thinking of ideas of just what to do to raise money we came up with some fabulous but unfortunate ideas.....We don't like heights so sky diving is out of the question, swimming involves cold wet water so no cross channel attempt is possible, running makes your wobbly bits a bit too wobbly..... so..... walking seems ideal! Now what sort of distance was the next question.....

One of the bright sparks amongst us suggested a nice stroll along the seaside. After a few drinks one evening we had all agreed to a 26 mile walk from Dover to Dungeness! This has affectionately become known to us as the Double-D walk. (This also served another purpose of gaining us attention for reasons we won't go into but namely it being the average bra size!)

So on Sunday 14th August we walked from Dover harbour in Kent to the Lighthouse at Dungeness Lighthouse in the hope of raising some much needed funds for three worthy charities.



We managed to complete our marathon walk with not too much blood a lot of sweat and just a few tears!

Thank you so much to everyone for sponsoring us we managed to raise over an amazing £1500 just between us five ladies which has been split equally between the 3 charities! We even managed a photo and a mention in the local paper! There is more photographic evidence on Facebook!

We had an amazing time and loads of support on the day and would highly recommend fundraising to anyone.



Donna Brown, Tracey Etherington, Kate Hawkes, Debbie Chadwick & Claire Ottaway

Angelman Boy

Hi everyone

My husband & I live in Dorset, England with our 2 sons - Samuel, 9 AS del & Willoughby, 5. My Mum has written the poem below about Samuel. It was so lovely that I thought I ought to share it with you. Be warned - it made me cry! I'm sure you will relate to it and I hope you enjoy it.

Amelia Coffen

*I sat in the bath and rang all concerned
Blonde hair and blue eyes, most beautiful boy
In the world.*

*Months passed, he delighted, smiles and laughter
Contentment too good to be true
And it was.*

*A rare type of syndrome, he'll never talk
And will walk with an awkward gait
And have fits!*

*Grief too deep for crying, my fists shook at God
Profanities uttered, my dear darling girl, so blameless
Why the hell her?*

*A wise woman said "be strong for your daughter"
Old treasures seemed trivial, I sold
My Just William collection.*

*Sorrow on sorrow, bruises and stumbles
Split head, drop fits and spoon fed, yet
So easily pleased.*

*Brave as a lion, no malice or envy
His love unconditional and deep
As the ocean.*

*He'll never ride bikes, play cricket or sing
Asks for so little but he shows us that
Not all angels have wings.*

Heather Murphy (Samuel Coffen's Grandma)

Support your charity!

Assert Merchandising

In association with Spreadshirt, our on-line merchandising shop is now open. Whether you just want to support your charity or are looking for that perfect gift for friends and family, you'll find something here to please everyone.

You can access the shop easily via our new website, or this link:

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

will take you straight to Assert's Spreadshirt page.

Select from mens, ladies and children's clothes, along with some great accessories - you name it we've probably got it, or there's a good chance it's coming soon.

And taking note of your conference feedback we've added some looser-fit shirts along with other great new products.

Shown here are just a few samples of what's on offer. Make sure you bookmark the Spreadshirt site and check back regularly for more great designs soon.

Assert
Angelman Syndrome Support Education & Research Trust


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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
incl. VAT EU
excl. delivery costs

Add to Basket

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
incl. VAT EU
excl. delivery costs

Add to Basket

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
incl. VAT EU
excl. delivery costs

Add to Basket

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
incl. VAT EU
excl. delivery costs

Add to Basket

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
incl. VAT EU
excl. delivery costs

Add to Basket

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

How far could you run in 24 hours?

24-hour Ultra-Run

A few months after starting a PhD working with children with Angelman syndrome, I decided to do some fundraising for Assert. As I have been running half-marathons and marathons for a while, I decided to challenge myself and enter a 24 hour race in the hope that the element of danger would increase sponsorship! I signed up for the Adidas Thunder run 24hr - a 10km cross-country circuit which you do as many times as you can in 24 hours.

I started training in the New Year, and quickly realised that I would have to be inventive to fit the 10-hour training runs in! The commute to work was done on foot rather than in the comfort of a car, and sleeping past 5am at the weekends began to be a thing of the past. Training for the race was definitely the hardest part, so by the time the race weekend came I was excited that my training was over and it was time to go out for my last long run.

As we lined up at the start, I placed myself at the back of the crowd of runners in order to avoid the stampede of the faster runners at the front. We were given the instructions for the race, and then we were off. The first few laps were quite straightforward – I kept to my plan to run as much as possible and walk up the hills. By the end of lap four (and after about 25 miles) my legs began to ache and I had the sinking realisation that I had only been running for about 5 hours and still had 19 hours to go. It was then when I began to doubt that I would ever be able to finish.

Things got much harder when darkness fell, and I found running almost impossible. I began to get very tired and had an overwhelming urge to sleep. By now I was mainly walking, with my legs too painful to even contemplate running.

With the arrival of dawn, a fried egg sandwich and a cup of tea, my enthusiasm was renewed – only six hours to go! I began to actually believe that I would be able to finish in one piece. Miraculously, I even found that I had the ability to run again and managed to hobble along for the rest of the race. I crossed the finish line after 24 hours and 82 miles with a very big smile on my face.

I am so pleased that over £1000 has been raised for Assert, as I know that it will be going to a really good cause. As for another race, I'll let you know when my legs have recovered!

Mary Heald



Only another 12 hours to go...



A well deserved 5-minute break!

ANDREW PICKS UP CHARITY CHEQUE



H.E. Photo

A Rothiemay youngster was the centre of attention when he called in to a Nisa store in Fife-Keith.

Andrew Spence was there to accept a cheque for £250 on behalf of two charities which support people like himself who have Angelman Syndrome.

Andrew, who starts Rothiemay School after the holidays, accepted the cheque from his godmother, Helen Andrews, who works at Nisa.

Andrew, who will celebrate his sixth birthday next month, was diagnosed with the AS in April 2008 and is deletion positive. Since the diagnosis his family have received a huge amount of support from the charities Brainwave and Assert (Angelman Syndrome Support, Education & Research Trust).

Mum Wendy, of Kimberley, Rothiemay, said, "Their support has been amazing and I do not know what we would have done without them. They really have been a great help to us and we would be lost without them.

"Some children only sleep for one or two hours a night but Andrew is quite good. He is not walking yet, but he is an absolute joy to behold. Epilepsy is by far the worst part of Andrew's condition," said his Mum. He goes to Perth once every six months for specialist clinics held by Brainwave.

Andrew has three sisters and two brothers, as well as two nieces, and his parents Wendy and Derek agree that the advice and support of both Brainwave and Assert have been a huge help to the whole family.

Chatrooms and social networking sites on the internet have provided the chance for them to be in contact with other families and speak to others in a similar situation.

Wendy is happy to share her experiences with others and to do so, visit their Facebook page at Angelman Spence.

Apparently this has been doing the rounds lately
Nadia Piper thought it might amuse

You know you've got a special needs child when...

- Your mobile phone contacts section is FULL of weird acronyms - SALT, ENT, PT...
- Your child's five-year-old brother uses words like 'interact', 'gluten-free' and 'sensory'.
- You are definite in the knowledge that if you had been given £1 every time a doctor has questioned you about your medical training (you have none!), you would be a helluva lot better off.
- You get stared at so often that you start to wonder if you have been featured on Crimewatch.
- You pack one case for yourselves, one for DS and another for his dietary needs before going anywhere for just one night.
- You start fancying Justin Fletcher, aka Mr Tumble.
- Your three-year-old is toilet trained, but your five-year-old is not.
- You can fill in a DLA form whilst watching EastEnders.
- All the windows in the house look like they've been invaded by slugs.
- The paediatrician tells you during a routine check-up that she thinks your child has ADHD on top of everything else, and you and your DH fall about laughing inappropriately.
- The school tell you that, 'we're afraid we will have to put your child on School Action Plus to get the educational psychologist in' and instead of shock, horror, amazement, you reply, 'Oh! Thank you soooooo much!' and all but hug the SENCO.
- Your child's eating/sleeping/toilet training habits would make them a prime candidate for *Super Nanny*.
- The doll is fed with a feeding tube, not a bottle.
- You just want to sigh at people when they whinge about the amount of parties their child has to go to this week.
- You realise your child has never been on a sleepover (unless you can call respite a sleepover).
- The SENCO knows where you're going to do your Christmas shopping and exactly how long you will be.
- You ask for a drink in a bar using Makaton, sign 'thank you' at shop assistants and ask waiters 'where the toilet is' signing the word toilet.
- You can park on a double yellow line and just bugger off for three hours.

Oliver's Bed

How do you solve a problem like Oliver and where he sleeps, was beginning to feel like something out of a soap opera. Well all good stories start at the beginning.



Right from when Oliver could move around, if he wanted something, he banged toys, bottles and beds. Kicking endlessly in the night and morning to get your attention. So we moved him out of his cot-bed and into a large travel cot and again we got some sleep, because we had been blessed with an angel who liked his sleep but didn't sleep if he could make a noise.

So we approached our OT who informed us at first that they had a cage. I thought Oliver had Angelman Syndrome but apparently he had Animalman Syndrome or Monkeyman Syndrome. We had a meeting with the authorities and we got another OT.

So start again. Can you supply a bed? We have wooden ones, perspex ones, but Oliver doesn't sleep if he can make a noise... HELP, somebody listen to me!!!!!!

So there I embarked on my long arduous journey to get Oliver a bed, it was very long and very arduous. But sitting at my computer one day having googled a thousand different combinations of special needs bed, quiet bed, any type of bed etc, I found it: the Courtney Bed, manufactured by a parent of a young lady in America. Great, just what he needed, an oversized travel cot.

Ha-ha! You think my journey has ended you cry... Oh no it hasn't.

Approached OT again. No, it's not English and it isn't CE registered. Approached the charities, same answer, knocking my head against a brick wall would have been a lot less painful.

Approached Courtney Bed direct, bed no mattress, shipping, taxes etc would come to approximately £5000, out of our budget. So you hail, what do we do now? We then have a lightbulb moment; sitting down with Oliver's Dad Jon, we studied and studied the pictures of the Courtney bed and we decided as Oliver's daddy is a very talented cabinet maker, he would build his bed himself. He would know that it was completely safe, would last him the rest of his life and that it had been made with all the love and compassion for a very special little boy.

Oliver's godfather is a draughtsman and he drew up the drawings, we approached a yachting and marine company for the padding and sides and sent drawings. Jon built all the sides out of solid oak, bought a mattress and started to assemble.

So it was done and in place in his bedroom, we put Oliver in and zipped the side, said Goodnight and waited and after 30 seconds, Oliver rolled over and went to sleep, and that is the end of my story. Well, not quite.

Please doctors, physiotherapists, Occupational Therapists, Charities, Authorities - all our children even in the same syndrome do not require the same equipment, maybe it is time for you to look at the individual and not the syndrome.

Jon & Tracey Fahey - Parent to Oliver 4½ years

Assert Southern Regional Meeting - Saturday 26th November

PAULTONS PARK WINTER WONDERLAND

ASSERT would like to invite you to meet up with other families and visit Father Christmas at Paultons Park.



Entrance to **Santa's Christmas Wonderland** includes...

- The Santa's Christmas Wonderland experience
- Entrance to the amazing new Peppa Pig World featuring 7 fun rides and large indoor soft play area at George's Spaceship Playzone
- A great selection of the Park's rides & attractions including, The Stinger, Jumping Bean, Kontiki, Pirate Ship, Wave Runner, Birds and Animals, Gardens, The Magic Forest, Adventure Playgrounds and the Rio Grande Train.
- Super gift for the children and hot fruit punch and mince pie for adults



Assert is subsidising this event to the following prices:

- Adults and children 3 years and over: £10 per person (normal price £18.25)
- Children 12 -35 months: £6 (normal price £14)
- Infants under 12 months receiving a gift: Free (normal price £5.50)

We're afraid the usual concession to wheelchair users doesn't apply to the Christmas Wonderland.

If you haven't been there Paultons Park is targeted towards younger children about 2-13 years. However, I think if you are young at heart you will love it (I do!). It is very flat and wheelchair friendly, although you will have to carry out transfers onto rides.

If you want to come please send a cheque to our freepost address below with a note of your name and numbers attending, address, phone number, and email. We have to book in advance so please don't leave it until the last minute.

ASSERT, FREEPOST, PO Box 4962, NUNEATON, CV11 9FD

For further information please contact Katie Cunnea directly at katiereader@aol.com Or phone 07884 231259

An Introduction to Angelman Syndrome

Angelman Syndrome is a chromosome disorder that causes severe learning difficulties and affects around 1 in 20,000 people



This DVD offers accessible, practical information for parents and useful guidance for medical professionals.
www.angelmanuk.org

Assert has produced a DVD to offer accessible, practical information for parents and useful guidance for professionals. It includes interviews with parents and prominent Angelman Syndrome experts including:

- Bernard Dan, Head of Neurology at the University Children's Hospital in Brussels
- Dr Jill Clayton-Smith, Consultant Clinical Geneticist
- Professor Chris Oliver, School of Psychology, University of Birmingham
- Finn Emmerson, Clinical Specialist Speech and Language Therapist

It is divided into chapters; topics covered include:

Characteristics, Development, Perception, Behaviour, Feeding, Sleep problems
Seizures, Communication, Genetic diagnosis

Cost is just £2 + postage and packing (UK: £1, Europe: £2, Other: £3)

We see this as an invaluable aid to help families who have just received a diagnosis of Angelman Syndrome, as well as then to educate and inform the professionals that we all meet on our AS journey. We would encourage you to purchase a number of copies to pass onto these professionals; this is why we have priced the DVD at only £2, well below the cost price.

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:

General Donations

Mrs H M Tait

Mrs Jane Evans (in memory of Mr Stuart Evans)

Mrs Joan Capen

Mr & Mrs Smith

Wincanton Group Ltd

Hinckley Ladies Circle

Yorkshire Building Society Charitable Foundation

H.M.S. Solebay Association

St Nicolas Parish Church, Nuneaton

Dr W A Charles

Clydebank Benefit Delivery Centre

Mischon de Reya

Lloyds of London (Haidee Kerr London Marathon)

Capper & Co Ltd (Isle of Wight Bike Ride)

Vodafone (Isle of Wight Bike Ride)

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Chris Stratford

Mark Lillicrapp

Dan Masser

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Haidee Kerr

Tim Higgins

Dan Gritton

Stephen Brooks

Sponsored Events

Nicola Moore - Reading Half Marathon

Jeremy Mycock - Mont Blanc Mountain Marathon

Mary Heald - Thunder Run 24 hour

Physio Dream Team - Isle of Wight off-road bike ride

Claire Ottaway - Double-D Marathon Walk

Antonia Burton - Sponsored 'travel'