

A4HNews...

www.aspergers4herts.org Issue 5



Website funding

As most of you will know by now, we have finished the main element of the web build with funds received from Grass Roots grants. We are pleased with the end result created by designer Russell Anderson and Web builder Gary McClumpha and

hope you will be too.

It was always anticipated that the website would be a portal for information to all, a resource that is easily assessable for each stage in life as well as a view to the work A4H are doing. We are now in the second stage of this

project, and are about to introduce a new member to the team in the position of liaison office. The liaison office will be responsible for gathering information that will support and update both the current web site and A4H News, along with member updates by email. All that remains is to launch the web portal via media channels, advertising materials and information cards within schools.



A photograph of two teenagers rock climbing on a large indoor climbing wall. The wall is grey with numerous colorful handholds and footholds. The climber on the left is wearing a blue shirt, dark pants, and a red helmet. The climber on the right is wearing a dark shirt, dark pants, and a red helmet. Both are secured by ropes. The background shows more of the climbing wall and some greenery.

Spidermen !!

It is with both sadness and triumph that we come to the end of the year long Teen Social Events course. When we received the grant funding for these events we were unsure of the exact direction the project would take and if the truth be told were a little anxious. But we can honestly say, judging from the parent's comments and what the young people who attended regularly have clearly gained, the course has been a huge success. Many of the participants were extremely worried at times, out of their routine and comfort zone for many of the events. But that's not surprising, looking at the schedule of events, we would have been too! Climbing up a 12 metre high wall, or for that matter throwing yourself down the snow dome on what were called sledges, but were no bigger than a dinner plate is little scary for anyone!

The 20 participants, who are all aged between 13 and 19 years, are a really captivating and varied group of young people with diverse and fascinating interests. Both Jean and France have really enjoyed getting to know all of them and their parents.

But it's not all about fun (although well disguised); at the end of the course regular attendance means each participant has gained:

1. Knowledge of activities that are available in the wider community
2. The experience of moving from a position of 'I don't want to do this' or 'I will not do this', to a positive position of, 'That was really good, I actually enjoyed it' and in many cases 'I want to do this activity again.' Some of the group now regularly do trampolining, rock climbing and Karting after their experience from the sessions.
3. A feeling of being at ease with other members on the course; there have been some friendships formed although interaction from parents are still often required to organise events.
4. The confidence to go on to join other Aspergers 4 Herts activities when they arise or adult groups, such as the one run by NAS.

Continued overleaf

End of Teen course

End of Teen course continued

These events have proved positive for parents too, having had each other to talk to and share views with, but also the pleasure of seeing their teenager get out there, have fun and socialize.

A huge thank you to Jean from all of us for the great work she has achieved in organising the events and working with the group.

I would like to share some of the many positive comments that have come out of these sessions from both the parents and the teen members themselves.



Jean and France receiving flowers from the members of the final teen event

“Thank you so much, I can’t believe how much he now looks forward to going to the activities and to think how I had to force him to go to the first taster sessions – I think the Karting was the turning point”

“He has really enjoyed the last set of activities and would love a place for the next session.”

“All the youngsters seemed to have had a great time. I thought you’d be interested to know that he has decided to try out the trampolining club and has got his first session this coming Friday with Alex the coach”

“I wanted to write to you to thank you so much for the lovely times you’ve given Campbell and I with the events you’ve organised. I have seen his confidence grow during the last year since he’s been attending your events. You and France have been true angels for us!”

Environment vs. genetics debate takes a turn

Environmental factors may play a greater role in autism than previously thought, tipping the scale away from a strict focus on genetics, two US studies released this month suggest.

In one, a team at Stanford University compared cases of autism in identical and fraternal twins and found that fraternal twins - who share only half of the same genes - have unusually high

rates of autism, suggesting that factors other than genetics may be triggering the disease.

In another, researchers at a health insurance company found mothers of children with autism were twice as likely to have been prescribed a common antidepressant during the year before their pregnancy as mothers of healthy children.

The findings suggest that something in the birth

environment, such as drugs, chemicals or infections, may be triggering autism in children who already have a genetic risk of developing the disease.

Clara Lajonchere, study co-author said that it has been well-established that genetic factors contribute to the risk for autism, but we now have strong evidence that, on top of a genetic link, the environment in which a baby grows in the womb may have a greater than previously realized role in the development of autism.

Continued overleaf

Environment vs. genetics continued

Shared environment

The Stanford study involved 54 pairs of identical twins, who share 100 % of the same genes, and 138 pairs of fraternal twins, who share half of the same genes. In each pair, at least one of the twins had been diagnosed with autism.

The researchers found the chances of both children having autistic spectrum disorder were higher among identical twins than among fraternal twins. But fraternal twins were much more likely to develop autism than studies of children in families where a non-twin sibling has autism.

According to the study,

environmental factors common to twins explain about 55% of the cases of autism, and while genetic factors still play a role, it is much lower than previously reported.

Could it be antidepressants?

A separate study published at the same time looked to see whether antidepressants known as selective serotonin reuptake inhibitors (SSRIs) taken by mothers contribute to autism risk.

The team studied nearly 300 children with autism and 1,500 randomly selected children, and checked their mothers' medical records.

They found mothers of the children with autism were twice as likely to have taken an antidepressant in the year before delivery as children in the

control group. And the effect was strongest, three times higher, when the drugs were taken in the first trimester of pregnancy.

The author concluded that the results suggest a possible, albeit small, risk to the unborn child associated with in-utero exposure to SSRIs, but went on to say that this risk must be balanced with the risk to the mother of having untreated depression.

The team cautioned that the SSRI study was preliminary and said much more work was needed to understand the link between antidepressants and autism.

Reuters, 4th July 2011.

Available at

<http://www.reuters.com/article/2011/07/04/us-autism-environment-idUSTRE7634Y220110704>

The British 10k

Get inspired to take part in 2012

When in the past I have thought of people that run, whether as a one-off or on a regular basis, I have always come back to the same conclusion, "I couldn't do that, I can't run, not even a slow jog for that matter!"

But then I read an article about a local running club, it was free to join and on closer inspection of their web site I noticed comments other people had made. These people, like me, had never been runners before but there were accounts on the site of how they had started very nervously but managed to walk the 5k distance along with the other members. I noted they had, after a few weeks managed to run a continual 1k. A feeling of inspiration crept in as I read on, and after phoning for further reassurance I started

at the club the following week. Slowly 1k turns to 3, 5 and then 8k and enough confidence to enter for a place in the British 10k.

I am so very pleased I did it; what a fantastic feeling it has been to be part of such a renowned event and to have completed this run. The excitement of the journey up to London early in the morning with a mass of others all plastered with their running numbers just like me, to arriving at the start and looking back at what can only be described as a sea of thousands and thousands of runners all waiting to step over the line. The finish felt like a huge accomplishment for me personally, and the feeling of exhilaration after, when meeting the rest of the group, family and friends in Hyde Park was one not

to be forgotten.

Today is the day after the British 10k and I ache all over but I would do it again next year; it is a fantastic event that leaves you with a huge sense of achievement, community and being part of something... I can run, albeit slowly!!

Those taking part this year for Aspergers 4 Herts: Jem Tilson, Holly Butterfield, Cheryl Arthur, Eugene Meenan, Steve Mew, Lee Butterfield, Kevin Wallis and myself. A great effort by all raising over £2200 for the charity.

We now have places available for the 2012 British 10k, which incidentally takes part only a few days before the opening ceremony of the Olympics. Places are limited so please let us know as soon as possible if you would like to take part and raise some much needed funds for Aspergers4Herts.

Thanks to everyone involved, France.



NAS – Great Expectations campaign

Hello

My son Alex and I have experienced the best and worst of our education system. Some of Alex's teachers refused to acknowledge that he needed extra support. He became physically and mentally unwell because he didn't receive the help he needed. He was excluded twice because his schools didn't know how to cope.

Tragically, our story is not uncommon. The National Autistic Society's Great Expectations campaign has found that 1 in 5 families have taken legal action to get the right support for their child's education.

But, we know that we can get it right. After years of fighting, Alex and I are now being listened to and he has teachers who understand him and his autism. It's such a relief to finally see Alex thriving both academically and socially like we always knew he could.

The Government is planning to reform the education system because the battle needs to end. Their changes will shape the future of a generation of children like Alex. It's time MPs fought for us now, so families won't have to fight the system in the future. It's so easy to get your MP to speak up for you. Simply type your postcode into this online form and send the message from the NAS has already written.

Thank you
Angel

“Half of all children with autism wait over a year for appropriate educational support, and over a quarter have waited more than two years,” finds a new report by The National Autistic Society, published on 1st July.

The report carried out by NAS launches their Great Expectations campaign on Special Education Needs (SEN), which aims to inform and influence the Government's proposed overhaul of the SEN system.

The research, which involved over 1,000 parents of children

with autism and young people with autism themselves, found that far too many children with autism are not getting the education they need and deserve. The research found that only just over half of parents (52%) feel their child is making good

educational progress while 43% of young people feel teachers don't know enough about autism.

Parents should expect an education system that works with, not against, them, but too many parents have to fight the system to make it work. Forty-eight percent of parents say they have waited over a year to get the right support for their child, and 27% have waited more than two years. Most shockingly, 18% of parents have had to take legal action to get the right support for their children, and have been to tribunal an average of 3.5 times each.

Waiting for the right educational support can have an impact not only on the child's educational progress, but also on their mental health, behaviour and self-esteem.

Mark Lever, NAS Chief Executive, says: “Our report sets out the practical, often simple, steps that the Government can take to create a system that works for everyone. The proposed ‘biggest SEN reform in 30 years’, will shape the future of a generation of children with autism. Let's get it right.”

NAS website, accessed 6th July 2011. Available here <http://www.autism.org.uk/news-and-events/news-from-the-nas/children-with-autism-wait-too-long-for-educational-support.aspx>

We've got GREAT EXPECTATIONS



Donations from...

Waitrose

Shoppers at both Waitrose Stevenage and Hitchin granted Aspergers 4 Herts the highest level of tokens in their vote for your chosen charity token scheme. We were really pleased to receive the donation of £367 from Stevenage and £389 from Hitchin.

A4H Book Review

All cats have Asperger syndrome Kathy Hoopmann



I'm a trustee of Aspergers4Herts, and have a 10 year old son Harvey who was diagnosed with Asperger Syndrome (AS) in 2005, since which time we have drawn on all manner of support and advice. In many ways I have found people's personal accounts of AS particularly useful and have learned much from them.

Books have also been a great resource for us over the last six years. In particular *All cats have Asperger Syndrome* by Kathy Hoopmann has on numerous occasions provided a tangible link between me and Harvey, prompting open and honest discussion between us; it's even solved debates too!

This award-winning book was first published in 2006 and we first came across it at Angels, a local support group in Hitchin. It immediately struck a chord with me. Straight away I could see aspects of Harvey and some of his then 5-year-old AS ways depicted so concisely within.

The book is aimed at both children and adults alike and provides a helpful introduction to people who know nothing of Asperger Syndrome. It sets out to provide a high-level understanding of the syndrome itself and some of the feelings and experiences of those within its spectrum.

Harvey quite obviously felt a sense of pride that he had traits comparable to cats; they're animals he has a clear bond with both in home and everyday life. Reading this book together has certainly helped us in understanding each other and the polar opposite reactions we can have to the same experience.

All cats have Asperger Syndrome introduces AS with subtle humour, using language and feline photography that appeals to all, and it gradually builds a picture of AS from start to end. Harvey and I found it was a great way to establish some middle ground in discussing Asperger Syndrome, including what it can mean to newly diagnosed children, and to people who find themselves interacting with those children.

Children with traits of Asperger Syndrome and cats can be very similar in their characteristics and habits. We found there were many times while reading the book together that we looked at each other acknowledging the truth of what it was saying. We recognised the similarities between Harvey and cats and connected with the book's accurate assessments of situations he is regularly exposed to. For example, I am forever

fretting about Harvey going out on cold autumnal days in a flimsy T-shirt and telling him to wrap up; but he really doesn't sense cold in the same way and this is captured in one lovely photograph of a white cat sat in deep snow declaring: "I'm not cold." We also laughed at another illustration, as we recognise our own mealtime scenario of food having to be presented in the same way every time.

All cats have Asperger Syndrome builds on the dignity, individuality and potential of those with AS, really highlighting the positive aspects. This makes an extremely refreshing change from the numerous texts on Asperger Syndrome that focus on the perceived limitations and boundaries it inflicts, which have, on occasions, left me feeling pretty flat.

So if you want to feel uplifted and celebrate the positive side of AS, then you should read this book. Having read it many, many times, with Harvey and on my own, I always finish feeling a heightened understanding of, and pride in, my wonderful son and his unique approach to life.

Lee Butterfield

