ISSUE FORTY-FIVE SPRING 2009 REPORT

Website www.angelmanuk.org **Email** assert@angelmanuk.org **Telephone** 0300 999 0102

Assert

Angelman Syndrome Support Education & Research Trust

Our New Freepost Address

Assert
PO Box 4962
Nuneaton
CV11 9FD

Useful Websites

http://www.thecbf.org.uk/

http://www.kidsout.org.uk/v2/who/children/

http://www.gilbert-mellish.co.uk/index.php

http://www.senmagazine.co.uk/

http://www.mumsnet.com/Talk/special_needs

http://www.idic15.org/c15d_overview.php

http://www.childharness.ca/index.html

http://www.intensiveinteraction.co.uk/

http://www.babymonitorsdirect.co.uk/index.html

http://www.makaton.org/

Contents of the Newsletter

You will notice that the pieces in this newsletter are drawn from a wide source of places. 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 ones and not necessarily those of ASSERT.

Letter from the Chair

This time of year always fills me with a sense of awe and relief. Having watched the London Marathon from the comfort of my living room I see the thousands of people running most to raise lots of money for charity. My thoughts towards them alternate between sheer admiration for their efforts of bravery to total disbelief that anyone would be foolish enough to even consider putting their body through such torture. So I respect them with awe, and sit in the relief that I did not cede to my previous foolish thoughts of actually joining them. Indeed, at one point I even thought of taking Ruth with me, something which I am sure that she would have loved especially with so many people close at hand to grab and smile at. In all seriousness though, I would like on behalf of ASSERT to thank all those who took part in the marathon this year, raising such wonderful amounts for ASSERT which will definitely help us with our work in the future. I would also like to thank the two runners who unfortunately we injured in the weeks before the marathon so were unable to take part. Many will not have seen the fruit of your months of training, but we are still very grateful for your commitment.

Later in this newsletter you will find an article from Bernard Dan providing his take on the latest research that is taking place in relation to Angelman Syndrome. We welcome this clarification from him, even if some of the terminology does escape me, as it provides a very useful perspective on the research. I would also like to clarify that ASSERT is excited by the research that is being done however the reason we felt it necessary to ask Bernard to write this article was due to our concern in the way that the word "cure" is being used in relation to this research. We do see that the research may well provide very positive benefits to those affected by Angelman Syndrome, in helping manage the condition, but do not see that this would lead to a cure in the same way that one might take aspirin to cure a headache. I do hope that you find Bernard's article helpful. If you have any more questions or concerns on this area, please do not hesitate to contact us.

We are now starting planning for our next conference which will be held in September 2010. Comments from the last conference were very encouraging so I know that we are all looking forward to this again, albeit with some trepidation as it means a lot of work for the trustees. I know for the trustees one of the highlights of the last conference was the inclusion of more older AS individuals, an area we strive to improve our support. We are always looking for new speakers and organisations to present at the conference to further enrich the offering of information that is available. If there is anyone you think would be good to present at the conference, whether it be for a keynote talk, workshop session or to have a stand in the exhibition area, please do not hesitate to let us know. Similarly, if there are things you think we could do better, then please do tell us.

I hope you enjoy reading this newsletter, and once again my thanks go to Rachel for the hours that she has spent compiling it. Having produced a few newsletters myself, I know the hard work that is involved in sourcing the information and bringing it all together. Thank you also for those who have contributed to this edition, and a little nudge to those of you who haven't; please do send us your stories etc so we can enjoy reading about more members of the ASSERT family. This is your newsletter for your support group.

Jeremy Webb

Assert is changing!

As you can see from the new, all-singing-and-dancing logo at the top of the newsletter, ASSERT is changing. Although ASSERT's previous identity had served it well for many years it was in many ways a product of its time - but times change and to reflect the new mood of the charity and the fresh blood and enthusiasm of the new trustees, a new look has been taken with the fundamental ways in which ASSERT presents itself.

We've been lucky enough to persuade some of the country's leading design firms to donate their time and expertise in re-assessing where ASSERT stands today and how it should be presenting itself to a modern world. Through contemporary eyes the previous logo might be viewed as somewhat authoritative, confused, not particularly attractive, un-parent and un-child friendly; more like something you might associate with a petrol station, security company or logistics firm (not to mention some of the less charitable suggestions!), saying little about ASSERT, its aims, or most importantly the people it represents. When compared with identities for some of the other main charities and syndromes, ASSERT's was noticeably lacking.

As the logo is often the first point of contact for new families (via website or newsletter) these were obviously undesirable characteristics. ASSERT's identity should be, above all, friendly and welcoming, contemporary, and have associations with Angelman Syndrome itself. The new logo is primarily designed to be friendly: the font is more natural and loses those aggressive capitals. The full version of the logo is at the top of the newsletter: first letter has a halo above, transforming it into a walking figure.

But is it a halo? Some might see a face or a sun, it could signify happiness or distress… all characteristics of the syndrome itself. The "Halo-A" part of the design can also be singled-out for solo applications, such as on signage or merchandising. Although you can't see it here, the colour version of the logo maintains a link with the past by retaining variations of the previous blue/turquoise colours supplemented with a yellow for the halo, suggestive of other Angelman associations with water and sun.

To save costs to ASSERT and its members the new identity is being introduced gradually, first on the newsletter and in a new and exciting range of merchandising, ultimately replacing the previous logo in all applications as stocks of existing items are used up. The website will initially incorporate the new logo into its existing design, but this will eventually be superceded by a comprehensive re-design.

The new merchandising is an experiment in itself in that ASSERT now has the opportunity to create a more flexible range without having to invest in large stocks of items which can be slow to sell. The new range will be available through the ASSERT website via a link to a third-party site where you'll be able to buy pre-existing designs or custom-design your own variations. All details will be on the website soon. The new range will be limited to T-shirts at first but it's hoped that other items will soon be introduced.

If anyone has any questions about the new identity or would like a more comprehensive overview on why and how it came about and who was involved, they can contact me via the trustee's email address.

Christyan Fox

Samuel's Ball Pit

Our eldest son, Samuel, is 6 years old and AS Deletion. He absolutely loves ball pits and always makes a beeline for them in any soft play area. They are great for his physical and sensory development. However, he is far too big and strong for the small ones available in the shops. Last year we came upon the idea of having one specially made for him that was "Samuel size" and "Samuel-proof"! We did research on the internet and approached a company in Bristol that made soft play equipment and they said they could make one to suit his needs. The only problem was that it would cost just under £2,000! We decided to approach some charities and we were very lucky to get it entirely funded. Earlybirds, a local charity in Weymouth, promised £500 and Cerebra promised the rest. We were very excited and ordered the ball pit straight away. It is bright red and yellow, has an MDF frame, measures 1.5m x 1.8m and has 1600 balls! We have put it in Samuel's room. Samuel and his younger brother Willoughby absolutely love it, as you can see from the photo, and we've even got used to picking up the balls from all around the house.

Samuel's Fireguard

We have a wood burning stove in the lounge and when Samuel was younger we got through several shop bought fire guards by shaking them to death and ripping them off the wall! We got so fed up that my husband, John, decided to design a "Samuel-proof" one. We got a local blacksmith to make a nice rounded one out of steel bar which is bolted to the wall. It has special spring/lift up locks so even adults get confused how to open it! It is so solid that even Samuel has no hope in dislodging it, but it also looks very attractive, unlike most "special needs" things we have to have in the home for Samuel. It cost just over £200, but in real terms, as it will have to be there forever, this works out quite reasonably spread over the years.

Amelia & John Coffen Dorset

Bits and Pieces

Louisa May Alcott once stated
"I am not afraid of storms for I am learning how to sail my ship."

"Over the last ten years, I have been learning how to sail my ship in rough waters from the Hurricane of Autism blowing into my home in 1998 with the diagnosis of my son, to literal hurricanes like Andrew, Katrina, Rita and now, Gustav. During the Weather Channel's updates as Gustav entered the Gulf of Mexico, they threw out a new term again and again and it dawned on me that I have spent most of my adulthood navigating waters in *The Cone of Uncertainty*. The swells from the winds and waves of each storm over the last decade have come frighteningly close to drowning me but what is evident each time is that as they move over warmer and warmer waters increasing in intensity, so does my own strength and resolve to find the best in every situation." **~ anon**

As I watch you sleeping!

As I watch you sleeping, I realize just how great your accomplishments are.
I know how much you struggle to have made it this far.
As I watch you sleeping, I can't imagine how my life would be without you.
Even through the hard times I'd be lost without you.
As I watch you sleeping, I see just how much you have brought into my life.
All the joys and happiness, all the wonder and excitement.
As I watch you sleeping, I am overcome with such love.
Your sweetness and happiness, are something I can't get enough of.
As I watch you sleeping, I think just how lucky I am.
To be the mother of such a beautiful little boy.
As I watch you sleeping, all of my worries seem to melt away.
I know that no matter what happens; together we can make it through another day.

~anon~

http://www.communitycare.co.uk/Articles/2004/10/28/46856/whats-in-a-word.html

An interesting article offering words of wisdom for those filling in the dreaded DLA forms!

ASSERT Website
www.angelmanuk.org

ASSERT Email
assert@angelmanuk.org

New Helpline Number

ASSERT Families - New Diagnosis Advice - Contacts - Support Line

0300 999 01 02

Regional Meetings

Could you host or help to organise a regional meeting in your area? It could be a coffee 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**.**

Regional Meetings 2009

CENTRAL REGION. 24 Jan 2009 Hinckley. Lisa Court

The first Central regional meeting (or the first that I've been aware of in the 5 years I've been involved with ASSERT) took place on Saturday 24th January 2009 at Dorothy Goodman School in Hinckley, Leicestershire. There were approximately 17 families in attendance. We had AS individuals of all ages, and an abundance of siblings as well!

Professor Chris Oliver and his team from Birmingham University came along to the day, and gave a presentation to parents whilst the children were entertained by a children's entertainer along with making full use of the facilities on offer – ball pool, light sensory room, outdoor play areas, balls / hoops / tunnels etc. It was a really lovely day and everyone seemed to enjoy themselves. Lunch was very kindly funded by Vision Express in Hinckley and Banbury (thanks to Nav and Jas Sanghera for co-ordinating this). It was an opportunity to catch up with familiar faces from the conference, and also to meet new faces. There was the usual swapping of stories between families and tips / advice being shared around. I hope this will now be a regular event going forward, and I'm hoping to arrange another regional meeting for August / September so please do come and join us!

Lisa Court

Review of Chris Oliver & Team Presentation

We were presented a summary of the research which was funded by the National Lottery and conducted by Clinical Psychology teams from the Universities of Birmingham, Bangor and London. The study has been assessing children with Cri de Chat Syndrome, Cornelia de Lange Syndrome and Angelman Syndrome, trying to establish behaviour profiles by looking at social interaction.

Chris and his team reported on their findings so far for AS. "What is challenging behaviour?" - this can be hair pulling, hitting out, dropping to the floor, plate / drink tipping, self harming etc. Why do AS individuals resort to this? Usually it is always attention seeking rather than malicious or wilful aggression. What does the individual want? What has happened to trigger the behaviour? How can parents / carers manage this behaviour? Tactics such as avoiding eye contact or removing the individual from the situation seems to work. A lovely video clip of an AS individual was played who clearly showed his preference as to which activity he wanted to do! The group were then divided into several smaller groups with a member of the research team. People were asked to discuss ideas of how the project information should be presented back to the general public / parents / etc…

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Review of Chris Oliver & Team Presentation continued…

Suggestions of a book with photos, a text based book, web site, information sheet, inclusion or exclusion of tables and graphs, CD ROM, video with audio descriptions were all suggested. Chris Oliver and his team took away all of the comments and suggestions from the session, and will be using this information when deciding on how to present their research. They were very grateful for all the input received, and were very glad they came along to hear what everyone had to say. It is hoped that a summarised version of the research will be published in the ASSERT newsletter as and when the research is complete.

Angels in the Park Picnic

Organised by Kathryn Adams, mum to Melissa
July 19th 2009 Fell Foot Park, Windermere, Cumbria
Please see Melissa's website for details**:** http://www.angeltales.co.uk/
http://www.nationaltrust.org.uk/main/w-fellfootpark
All Welcome!

Cerebra
Positively Different

More help for Children in 2009

Cerebra, the National Charity for children with neurological or brain-related conditions has announced a big increase in their funding in 2009. Cerebra's Parent Support Department provides a wide range of services: Our help-line and information service can look into any questions you may have related to the condition or care of your child. If we are not able to help with a question we will do our best to find others who can. By request we will endeavour to put you in touch with other parents who share some similar experiences. Our postal lending library holds many titles for lending and includes sensory toys. We publish resources including a guide to applying for Disability Living Allowance for children under 16 and a book: "Managing Stress for Carers". We have Sleep Counsellors who can advise on sleep-related problems and a growing team of Regional Officers who can offer face-to-face help with a wide range of issues. We have a holiday home in Pembrokeshire and can assist in the production of a Personal Portfolio for your child. **All our services to parents and carers are free.** Cerebra also commissions and funds research, and generates interaction between researchers, involved professionals and parents and carers. This includes our successful internet-based E-learning course which has helped many parents and carers improve their understanding and care for their children better. **From January 2009 we invite parents and carers of children aged 16 and under with brain-related conditions or injury to apply for one of three direct benefits:- The Cerebra Grants Scheme:** - offers grants for a wide range of items of direct benefit to the child. Past grants have included: tricycles, trampolines, specialised computing equipment, specialised car seats, buggies, sensory toys and certain therapies in mainland UK. **The Speech & language Therapy Voucher Scheme:-** offers a voucher for up to £500 of therapy for children who have not had access to one-to-one or group speech therapy for 6 months or more. **The Wills & Trusts scheme:-** Provides up to £350 towards the establishment of a will and/or discretionary trust by a qualified person.

For more details or to apply for any of our services please contact us on 0800 328 1159 Or email info@cerebra.org.uk or apply online via our website www.cerebra.org.uk

NORTH WEST REGION 15 March 2009, Bolton, Rachel Martin

We had a wonderful meeting at Greenfold School. It was lovely to meet up with old friends and also to meet new families from other regions who have recently had a diagnosis and were meeting AS families and their children for the first time. Catering was provided in the form of a Hog roast which everybody enjoyed, we had Bouncy castles and slides for the children (and adults!!) and we had a visit from The Elizabeth Svendson Trust for Donkeys and Disabled Children.

We had a presentation from Paul Birk from Cerebra on the use of Personal Passports or Profiles for our children. The passports can be used to communicate our children's needs and wants to caregivers, family members and friends, bus drivers, school personnel etc. They are in the form of a booklet that can be carried in their bags and shown to new acquaintances. Please see the Cerebra website for more details. www.cerebra.co.uk. The day was attended by about 15 families and included friends and medical professionals. We held a raffle to contribute to the cost of the day and the prizes were presented by Postman Pat who very kindly took the day off work to attend!

We have had requests for another ASSERT family day out in the NW-if you have any suggestions or would be interested in attending a day out with other ASSERT families please contact ASSERT – 0300 999 0102 www.angelmanuk.org

Leah Walters

Judy Birkhill

Jaimie & Lynne Scowcroft

A **BIG** thank you to Paul Birk, Racketies, Fancy That (Bolton), Postman Pat, Dr Hindley & Helen Jameson and to all the families who attended and also to all who donated cakes and raffle prizes.

[redacted]

Just for Us!

Hello and welcome to **Just for Us** - ASSERT'S 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 7year old brother called James who has Angelman Syndrome. I also have another brother called Zac and a sister called Beth and 3 other step brothers and sisters. I live with my family in Bolton, Lancashire. 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 into ASSERT at

P O Box 4962, NUNEATON, CV11 9FD

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

Hi Assert

I am writing about my little brother Sean and what I like about him and what I find annoying about him which isn't that much because I really like him. I like the way that if you are in a bad mood he can make you happy by smiling at you. And when you look at him he smiles and hugs you. I also love his laugh. There is lots of things I love about him but I have put my 3 best things.

There is only one thing I don't like about him and that is the way whenever I have something to eat like crisps I can never have them to myself.

From Nathan Walsh age 12 about my brother Sean Walsh age 10.

Hi, I'm Oli, I have a Angelman's brother named Josh I love him dearly even though he is different to me. I have a great family I have two brothers Josh,& Sam. I also have a great Mum & Dad called Andy & Fran. They love me and I love them. Since Christmas Josh can't stop signing about Santa or chocolate. He had a great Christmas. He loves to catch everyone's attention and show us what he has done. He absolutely adores food and he eats everything, except hot curry. He once tried my dad's curry and we know he didn't like it because he bit my dad after he ate it! This is not rare though as he does hit, pinch and pull our hair sometimes. Me & my family sometimes find it hard with Josh, but he goes away on respite so we get time on our own and do some of the things we can't do with him. I love Josh and I'm happy to call him my big brother. I would love to hear from other siblings. I am 8 years old

Thank you Nathan and Oli

This may of interest to parents of children with Angelman Syndrome as well other disabilities:

Happy Kids Holidays

I worked as a SEN teacher in Sheffield for 12 years (National Autistic Society, Bents Green Special School, LEA Autism Service) and I now live in France. In response to the requests of many families with children with Autistic Spectrum Disorders, I've established happykidsholidays, a registered non profit making association. We intend to:

· Link families with children with ASDs and other disabilities with property owners in France who are committed to providing a holiday in a safe, non-judgemental environment

· Support families in preparing for their holidays

· Provide support on holiday where necessary and possible

We are also able to provide fully or partially supported holidays for adults with Asperger Syndrome and other related disabilities: www.happykidsholidays.com

SPECIAL KIDS IN THE UK

Special Kids in the UK, the charity which provides support, information and contact between families of children and young people with special needs in the UK, is holding its annual family day on Saturday 15th August in South Derbyshire.

The day is free of charge to all members and their families who attend and consists of activities such as bouncy castle, quad biking, entertainment, arts and crafts, face painting and more. Members are able to camp at the site where it is held for the weekend, a few days before and/or after if they wish at a reduced cost negotiated by Special Kids.

Last year we had almost 50 families camping and over 200 attendees on the Saturday. For more details on the day and how to book your free place, Please note camping places are limited http://www.specialkidsintheuk.org/

The London Marathon 2009

Despite early weather reports of a rainy weekend, the morning of Sunday 26th April dawned with clear skies and warm sunshine in the capital. Perfect Marathon running weather then!

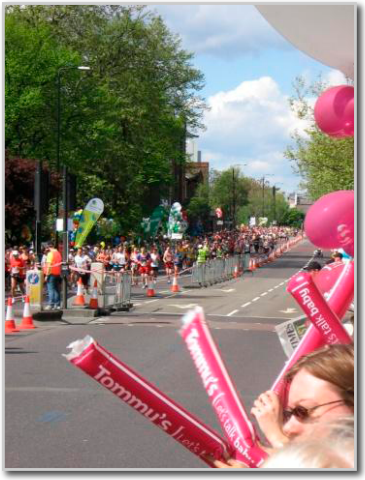
Our drive down from Swindon to the East end (very highly recommended disabled parking facilities and accessible viewing position) saw Sue, Holly and I set off through thick fog and then road closures. And a chance to really confuse our satnav!

And then out came the sun screen!

Shortly afterwards, the first of the wheelchairs came zooming past.

I'm just hoping that Holly doesn't get ideas now. These were followed by first, the leading female runners and then the men.

And then the 35,000 runners came…



Trying to pick out our ASSERT runners proved a difficult task but never the less it was a fantastic day out as a spectator.

And even more so, knowing that just by being there, we were helping support all of the people raising millions of pounds for good causes.

But back to our ASSERT runners. In the end we had seven - two having dropped out with injury in the last couple of weeks prior to the event.

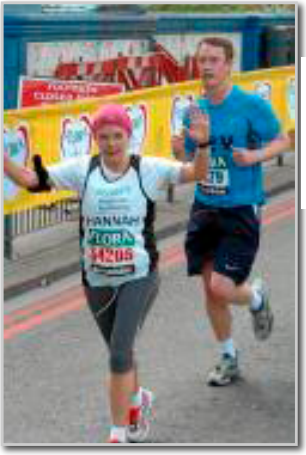
So thank you to Mike and Ryan for all of the hard work that you put in. Perhaps another year?

Our seven runners who made it to the starting line all made it home again safely- something that I'm sure many of us can only admire. I struggle to run for a bus most days let alone 26 miles on a hot sunny day.

All of our runners were wearing our newly designed ASSERT running vests complete with the new look logo.

First home was Charlotte Dale, who Finished in very athletic 3 hours 16 Minutes and 39 seconds.

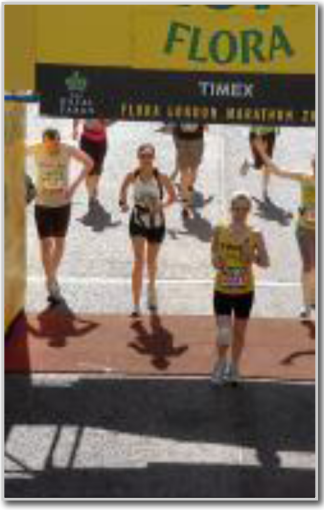
Then came John Wilson, who finished in 3 hours 40 minutes and 47 seconds. His fundraising included an employer contribution from the National Grid and represents the second long distance run for ASSERT.



Hannah Fatt was next across the line in 3 hours 47 minutes and 19 seconds. Her fundraising was also helped with an employer contribution from Marsh, the insurance broker and stands at over £1400 to date.

Next to finish was Tina Smith at 4 hours 48 minutes and 55 seconds, who still looked ready to run it again despite the heat!

Delphine Fawke, running for Samuel Coffen came next in a very respectable time of 5 hours 4 minutes and 31 seconds. Our biggest online fundraiser, Delphine raised over £3000 and appeared in her local newspaper with Samuel and Amelia Coffen just before the big day.



CARING FRIEND: Delphine Fawke, right, with Samuel Coffen, six, and his mother Amelia

Picture: Colin Hunter (D-9421[illegible])

Run of her life for Samuel

A SWANAGE mum is set to run the London first marathon in aid of a youngster who suffers from a rare condition.

Delphine Fawke, 35, is taking part in the London Marathon on behalf of Samuel Coffen, six, of Church Knowle, who has Angelman Syndrome.

The condition means the sufferer has delayed and learning disabilities, epilepsy, a sleep disorder and scoliosis – a curved spine.

The money Delphine raises will go to the Assert Angelman Syndrome Support Education and Research Trust (Assert), which is run by volunteers and has no paid employees.

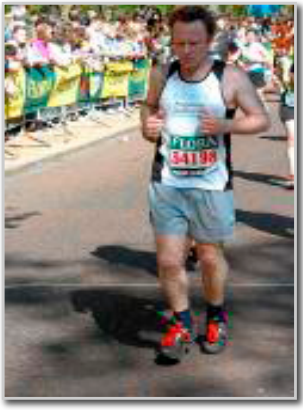
Mum-of-two Delphine said: "I've done the Swanage Half Marathon before and the Bournemouth Half, so it's a big jump. I'm a little bit nervous a bit, but it's great to do it for a cause like Assert, so I'll have that at the back of my mind and I'll do it no problem.

Delphine met Samuel's mum, Amelia, through a toddler group, as their children are similar ages, and has been out there cheering Delphine on from home on Sunday.

Amelia, said: "We are so grateful that Delphine is running the marathon for Samuel. Assert is an excellent support group with a network of people with hands-on experience and a wealth of knowledge on this rare condition.

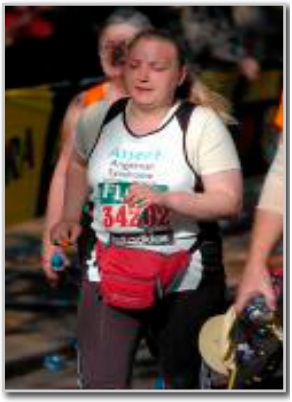
"We've turned to them on many occasions to get support and information. It is difficult to find charities. It's very hard work looking after him but he's a very gorgeous, smiley boy."

Sponsor Delphine at www.justgiving.com/phinfawke. Find out more about Assert at angelmansyndrome.org.



Jason Asbury, who had travelled down from the West Midlands was next to finish in 5 hours 23 minutes and 47 seconds. A keen sportsman, Jason was very excited by the prospect of running in the marathon when I emailed our runners to wish them good luck a couple of days before hand.

Our seventh runner was Nadine Vernon, who travelled down to London from Wales. A fantastic effort saw Nadine finish in 6 hours and 58 minutes. Of her experience, she said "..I look a mess in the photos and I didn't realise that I pulled so many stupid faces when I run. I'll have to work on my pose!" I was a bit disappointed with my time as I've previously completed the Snowdonia marathon twice with slightly better times but I think the heat got the better of me. Still, I can't complain as I had a fantastic time, the atmosphere was great and it was something I will never forget. It's all thanks to Assert as I would never have been there if it wasn't for you. I really appreciate you giving me a space and I wore my vest with pride! My leg is on the mend now, although I had about 10 miles still to go when it got painful. I only had a few days to rest as I had to go back to work."



Nadine, supported by her local community was running for Gareth Meadows, who has AS, and his parents Mike and Sheila. Nadine and Sheila are heading off to Peru in November to take trek the Inca trail for us.

London Marathon 2009

So a great day saw ASSERT take its place in the world's biggest fund raising extravaganza and much needed funds raised. Thank you Charlotte, John, Hannah, Tina, Delphine, Jason and Nadine. And also to Ryan and Mike. And to all of their sponsors.

John, Jason, Nadine and Delphine all had ***justgiving*** pages and these will still be live if you still wish to donate. Their pages, along with those of all our other fundraisers can be found at www.justgiving.com/angelman

Manchester to Blackpool Bike Ride
July 12th 2009

Paul Boon, parent trustee and dad to Sebastien, 3yo del+, is hoping to complete the above ride on July12th 2009. The ride is to raise awareness of AS and promote and raise funds for ASSERT. If you would like to donate please go to the following link:

http://www.facebook.com/l/;www.justgiving.com/angelman-syndrome
www.justgiving.com/angelman-syndrome

If you or someone you know wishes to ride as part of the team then please contact Paul directly through his facebook profile or email for details. "We will be meeting up at the finishing line (mirror ball) and once rested a few of us AS parents are planning to go down to the beach and build sandcastles and play in the puddles/sea (whichever is nearest)". "If you have any questions or queries then please do not hesitate to contact me."

Kind Regards
Paul Boon (Assert Trustee & AS Parent)
Paul_Boon76@hotmail.com

Fundraisers

ASSERT relies totally on our very supportive fund raisers for everything. And for that we are all in your debt. Thank you. Those that put in the hard work training for physical events or spend the time planning events often go uncelebrated. But, I'd like to change that. So if you are raising money on our behalf, and would like to tell everyone about it, please email the details to me, along with a picture. Alternatively, you can always set up a fundraising page on www.justgiving.com as the people mentioned previously have done. These people have raised thousands of pounds for us- and their pages will continue to do so even after their events. Please support them if you are able. If you would like to receive our fundraising guide, preferably via email to keep our costs as low as possible, please also get in touch. **Rich Williams**

BOURNEMOUTH BAY RUN APRIL 20009

Kelly Manley with Donny

Mark Taylor and Donny

A well earned rest!
Donny, Mark, Kelly, Danni & Shane Paull.

Ebay for [redacted]

ASSERT is now a registered charity with *Missionfish*, the charities co-ordinator for ebay and we now appear within its ebay charity listings.

Raising money for us when selling goods on ebay, couldn't be simpler. Simply look for us in the charities section when listing your goods, and then select the percentage you wish to be donated. And not only that, the sale price donation is eligible for gift aid too!

When you're selling, the real beauty of eBay for Charity is that there's something for everyone - yourself included. You decide exactly what percentage of your final selling price you'd like to give to charity (that's good causes sorted), and what percentage you'd like for yourself (that's you sorted). You also get to choose which charity you'd like to support.

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That's not all. We'll give you a fee credit on your basic insertion and final value fees equal to the percentage you donate every time you list an item for charity.

It's seen by everyone

eBay for Charity listings are the same as any other eBay listing, except for the blue and yellow eBay for Charity ribbon in search results and your chosen charity's mission statement and logo in your listing. This means your listing can be seen by everyone who searches through eBay.co.uk. It'll also get extra visibility through the eBay for Charity pages. It's the perfect way to make a difference – while doing what you do every day on eBay, whether you're a fishing enthusiast selling angling gear or a big business trading electronics.

We have seen many articles recently relating to a "Cure" for Angelman Syndrome. Whilst ASSERT supports all research into Angelman Syndrome, we felt that clarification regarding claims of an imminent cure was necessary.

Prof. 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 characterize 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 aim at discovering a cure but rather at improving management in order to optimize development, ameliorate symptoms and improve of 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 issue 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. (*Italics-editor)

Latest 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

Mrs H M Tait
Jenny Gray
Adidas Womens 5k challenge
Thomas Pyne
Mrs Knapp (fundraising)
Mr & Mrs Simpson
SWCG
Vision Express Banbury & Hinckley (Central R/M)
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Please note the deadline for the next Assert report is 15th July 2009

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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 ASAP.

Thank vou

Ask a Professional - Q&A

We would like to invite questions for our panel of experts. If you have questions regarding any aspect of Angelman Syndrome, including Neurology, Genetics, Speech & Language/communication issues, Feeding problems, Physiotherapy or Behavioural
issues then please contact ASSERT.

Our experts are happy to answer any questions and ASSERT is here to help you as parents/carers or professionals.

We would like this to become a regular feature of our newsletter so we need your help. The answers to your questions will
also be of help to other parents who may be facing similar issues.

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

ASSERT Website
www.angelmanuk.org

ASSERT Email
assert@angelmanuk.org

New Helpline Number

ASSERT Families - New Diagnosis Advice - Contacts - Support Line

0300 999 01 02

Are you aware that if you have a child or vulnerable adult living with you that you may be eligible for **discounts on your Gas, Electricity, Water and Council Tax bills**? Ask your regional suppliers about specific schemes for capping or reducing your essential outgoings if you live with a disabled individual. Watersure is one run by most water companies for families who live with an incontinent child or with someone who has a need for more water! (made for Angelman families??) Each area supplier has their own guidelines and regulations. http://www.unitedutilities.com/watersure.htm

Step-parent to an Angel

So here I am, I'm 36 and in the last year I've been dunked in a ball pool, on a fairground ride which made me feel dizzy, rolled around on the floor (dignity in tatters), developed an ability to rearrange furniture and hide all manner of things - all because I fell in love with the father (Rich) of an angel (Holly). We're by no means the only partnership where one person has a child from a previous relationship, but add AS into the mix and it becomes a whole different ball game.

I thought it would be good to share the experience of equivalently being a part time step-parent, because at times that can feel like quite an isolating experience, and after talking to people at conference, I now know I'm not the only one out there.

Rich and I met when he came to work in my office and we developed a really good friendship. Although I knew he had a daughter, my knowledge of AS was completely non-existent. Holly and I met about 2 years ago when I visited Rich for a chat and a cup of tea. I'm not quite sure what I was expecting, but within minutes I'd been giggled at, clambered on, had my tea balancing skills severely tested. Soon I ended up on the floor, building structures out of stickle bricks for her to knock over - a sure sign of things to come.

Our relationship continued to develop and in July 2007, I moved in with Rich and Holly comes to stay every other weekend. However, it didn't take long before the reality dawned on me and I suddenly felt that 50% of all weekends now were Holly-based, but Rich (after being a full time parent) now had every other weekend free. Cue a lot of talking and understanding from all sides.

Holly's now 6 and a bundle of fun, with amazing energy and enviable destructive powers. She has the stubbornness of an ox, could teach Houdini a thing or 2 about escapology. However because we are not the primary carers as with so many aspects of our lives, we make it up and make do as we go along. Our 2 bed house is not entirely suitable for Holly (especially as she continues to grow and her reach expands) – so the weekends before she comes to stay are spent Holly-proofing (or as near as possible) by tidying things away, boxing ornaments and breakables up and tying the curtains back to prevent her world famous Tarzan impressions. We've now got it down to a fine art – or is she just being gentle on us?!

For the first time in my life, I am now responsible for someone else's safety and welfare. Every weekend presents us with new challenges, including watching the bath water pour down the lounge walls, and as soon as every challenge is solved she gives us a new one just to keep us on our toes!

However the ultimate responsibility for Holly doesn't lie with me, but with her biological parents. This has been challenging to deal with at times, because as a step-parent equivalent (even a part time one) I take on some of the hard work, care and emotional commitment, but have no part in the decision making

regarding her welfare. For instance, if Holly has doctor's appointments or needs her care levels adjusted, I have to stand back and let her parents deal with it and I've found this to be a hard thing to deal with at times.

And then there's the future. Rich and I have agreed we'd like to extend our family further, but this presents us with all sorts of issues. Accommodation, financial changes etc which all prospective parents face – but we also have to find somewhere which is suitable for Holly and her ever changing needs as well.

There's no denying that my life has changed completely since I met Holly and looking after her is harder work than I imagined, but I'm gaining and learning so much from her. She has a magical ability to charm others entirely on her own terms, but still being truly accepting of others – amazing. Her giggle is completely infectious and as I mentioned before, I've experienced so many new things with and because of her, and I'm now becoming an expert on *Fimbles*! No part of my life has now been left untouched by Holly and her AS, and quite often I have the bruises to prove it!

We have no answers, but continue to talk and laugh about the situation together to try and find the best solution for our family. I think one of the main things I've learnt is that our lives no longer have a rule book to follow, so all we can do is try and muddle through the best for all of us, and if it works for us, then that's just fine.

So if you've found yourself suddenly thrust into the world of Angelman Syndrome, remember you're not alone and there are others out there, just like you. I'd love to hear from you and share our experiences.

Sue Martin, trustee.

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

The Night Is Darkest Just Before The Dawn

Having spent the last 21 years testing my parental skills bringing up my 3 daughter's and in particular our youngest, Katie (14, diagnosed with Angelman Syndrome), I was starting to feel independence was looming and dawn was breaking in our lives. How wrong was I!

Living with a child diagnosed with Angelman Syndrome (don't forget we all suffer from it!) presents many challenges and at times many rewards. However nothing was about to prepare us for the next instalments in our monumental chapter of life!

I was out walking the dogs one sunny afternoon and came across a lovely 3 bed bungalow for sale with wonderful views across Weymouth bay, whilst on the way home I decided that it may now be time to consider downsizing and this picturesque property fitted the bill perfectly.

My oldest daughter, Lucy had moved to Bournemouth with her work and rented a flat with her partner Chris. When I got home all excited to tell my wife about this property, she managed to get in first and tell me that Lucy and Chris had decided to move back home to save enough money for a deposit for a flat. Got rid of one and two come back!! Bother, bungalow thoughts out the window. Not that we did not want them home its lovely to have all the family together but its just the thought that again ones life is directed by our kids! How many of you can relate to that situation? Well saving money is certainly working for them living at home, so far they have managed to save enough money to buy a new VW Beetle and go on holiday!! Good old Mum and Dad!

Like her Mum Lucy has Endometriosis, a difficult condition to live with as not only does it leave you with severe pain, you have to combat severe fatigue. Both Lucy and her Mum have had surgery to alleviate the systems but Endometriosis is a very difficult condition to alleviate.

That in reality was a minor issue compared to what was about to hit us. In November 2007 my wife Deby, (aged 44 at the time, she will kill me for mentioning that!) was diagnosed with aggressive breast cancer. Words will never explain the turmoil of emotions that raced through our minds as we sat in the consulting room trying to inwardly digest information regarding the diagnosis.

My young wife (I have to say that now I have mentioned her age!) is the main carer for Katie, imagine the nonsensical feelings we were experiencing as we sat there with our world crashing around us. How would we cope? How would she understand why mummy is so ill? How will this affect her life? Why are we only thinking about Katie? Well with the passage of time the answer to all this is quite simple, as always we just have to cope!

Following the shock of the diagnosis we met with the cancer care nurse who sympathetically guided us through the road ahead. The road map was followed as planned albeit many diversions along the way!

As always our first priority was the care of Katie. We consider ourselves quite fortunate living in Dorset, the level of care and compassion within Social Services, Education and Health is quite amazing. As soon as we had the date for Deby's first treatment respite was arranged on our behalf, Katie's school notified and working with us to address her needs with the Health profession organising appointments around Deby's care. All this without a fight!

The first planned milestone for Deby was the chemotherapy, her main concern related to a decision on wearing the cold cap to prevent hair loss (sorry men not available to us in normal life!). She decided not to use the cap as it would have prolonged her stay in hospital with no guarantee of success. Deby's first major emotional heartache was the loss of her beautiful thick hair, it was not a rapid loss at first however it just all seemed to disappear after the fourth session of treatment. All was not lost, the NHS provide a grant for a wig however we decided to procure one privately to ensue we had a wider choice.

The only way I could cope as an individual was not to see this as the traumatic experience it obviously was but to try and look at it in a more light hearted way, its just my way of coping! The hair loss was my first opportunity to apply my coping strategies. As we had been married for 25 years this was first opportunity to go out with a blond!! It did not work as the wife decided on a colour similar to her natural look (and before you think it, she dyes her hair so she did not go for a grey wig!). My second opportunity came when we had a family gathering, its amazing how different men look wearing a female wig!

One positive point concerning the hair loss, because it was gradual Katie did not show any signs of concern; it was business as usual as far as she was concerned and great fun when she pulled it off!

Overall the Chemo went better than expected considering the aggressive nature of the drug. We only had a major blip when Deby went Neutropenic. Her immune system got so low with the treatment that she picked up an infection and had to spend a week in hospital in isolation. This caused another panic, Katie was due home from Respite the day Deby went into Hospital. On the phone to Social Services, School and the respite centre and all sorted, an extended stay for Katie! One consolation, the food in the canteen was very nice!

The chemo is a nasty drug and destroys cells without discrimination, after each session the immune system gets very low and then just as you are building up another session comes along. As each session passes its like a perpetual drain and the side effects seem to get worse each time. This made caring for Katie even harder as time went on, as for the school holidays during chemo, nightmare! Fortunately I work for Dorset Police and they have a very good support policy and I was able to take time off at very short notice, a bonus for Katie both parents at home to play with!

As we run our own business from home, Wessex Sleep Centre (www.wessexsleepcentre.co.uk bit of free advertising there!) it became more and more difficult to balance work commitments with home responsibilities. However with our ever increasing partnership with the infamous Bob Griffin from Tomcat and my good friend and business partner Dave, we were able to continue and maintain our business to the high standards and service level we previously enjoyed.

Following the six Chemo sessions Deby had a scan, this was our first bit of good news, the results showed that the tumour had disappeared. Our first thought was great no operation, however this was short lived and the surgeon informed us that a mastectomy was necessary to ensure all cancerous cells were removed. A major blow and the most traumatic news you could ever imagine, with the psychological effects beyond recognition. On a positive note plans were put into place for Katie to go into respite for three weeks to give Deby time to recover from the operation (and me as the new domestic god! Having said that I still cant work the controls on the washing machine, any one want a size 12 jumper that would fit a 2 year old?)

As well as the respite Katie receives, Social Services provide a carer in the home for 3 hours a day, this has been a tremendous help and the service is still provided to date (hope that does not put a jinx on the carer services now I have said that!)

Well the operation went to plan and Deby was soon out of hospital and taking charge of the washing machine! It was a slow recovery with the physiological effects of having a breast removed taking far longer to come to terms with compared to the physical recovery from the operation. Time is a healer, however Deby has never fully accepted her womanly loss. We accept that what was done was needed to survive but the mind has trouble understanding that!

The recovery has gone so well that Deby has now been referred for reconstructive surgery, big bonus here, they take the tissue from the tummy. Not only a breast reconstruction but a tummy tuck as well! Now never one to miss an opportunity I asked Deby if I could provide some pictures of some nice breasts from magazines for the surgeon to work too! Well why not?

Anyway now the black eye has disappeared, we have since found out that the surgeon also gives you a lift in the good breast. Thinking about that, if they did not do this then you would have the new one pointing up and the original pointing down! Think this is technically called gravity over time! Think I might get another clout for mentioning that!

Knowing how Angelman children like routine we was very conscious that we had to balance Deby's care with Katie's care. We have had difficult times as well as good, Katie enjoys the company of family and friends that have been here helping us however that down side is that when they go home she still insists on the same level of attention (by insist I mean moan!)

We have not had the best of years with Katie's health, she has been suffering terribly with mouth ulcers. Not a major problem but they make her irritable thus the pinching and hair pulling increases. We did get referred to the surgeon recently to review her Scoliosis (Curvature of the Spine), fortunately as she has lower lumber Scoliosis they decided that as she was not in pain they would just monitor the situation until it started to affected her mobility. The consultant was confident that she was not experiencing any pain or discomfort. Going by her hyperactivity levels we would have to agree with that diagnosis!

Amy, our middle daughter seems to be the only one in our family that has remained healthy. Recently she turned 18 and suddenly found the joys of Weymouth nightclubs! It still baffles me how long she can stay in bed for over the weekend, still as she says, I am an old fart now!

While I am testing my literacy skills informing you about my family's ladies problems I bet you are thinking what about poor old Paul? Well lets firstly set the scene, you are all aware that when a man is ill no one knows because us men don't like to mention it. When we have man flu (that's one up from bird flu, communally known by the female fraternity as a sniffle!) no one knows because we don't like to mention it!

Now Deby is on the road to recovery, Katie is Katie, and Lucy's Endometriosis stable; I have to go in for a major operation. It's a highly complicated operation involving many hours under the knife, some might even say "life threatening" However, I am a man and I don't like to mention it! Just to stop you wondering I am going to have an operation to rectify my Lateral Epicondylitis. There is a common name for this condition but I don't like to mention it as it lessens the effect of this highly complex condition. Some refer to its as Tennis Elbow but I don't like to mention it!

It's been a difficult 2 years with some very dark personal moments. Cancer is an awful word to hear let alone endure, the bad times are very bad and the good times hard to find. Its difficult to be positive but you just have to carry on and believe in life. With the loving support of family and friends Deby has managed to pull through and survive this terrible disease, it has made us stronger as a family and in some respects more appreciative of life (well, that's what Deby now says when she uses my credit card!)

Let's all hope and pray that the next chapter in our lives is less traumatic, we have been living for today and we are all now looking forward to living for the future.

Paul Chick
Loving husband to Deby, loving Dad and mobile bank to, Lucy, Amy and Katie
Tel: 01305 833741 Email: chickie@talk21.com

Exhibitions and Shows

Mobility Roadshow-4-6 June 2009, Kemble

Kidz down South – 18 June 2009, Rivermead Leisure complex, Reading

Disability North – 21-22 Oct 2009, Newcastle Metro Radio Arena, Newcastle

Kidz up North – 26 November 2009, Reebok Stadium, Horwich, Bolton

Kidz in the Middle – 11 March 2010, Ricoh Arena, Coventry.

http://www.kidzupnorth.co.uk/kidzinthemiddle.php

For Ever, For Everyone?

This phrase is something that the National Trust strives to live by. Yet how many of us have ever contemplated visiting an NT property as part of an family day out? The answer is probably not.

Is that because we know from previous visits that they are not suitable for families with disabled children? Perhaps it is the cost, or the accessibility? Perhaps the uncertainty?

The NT owns and protects over 350 historic houses, industrial monuments and mills. Along with forests, woods, fens, beaches, farmland, downs, moorland, islands, castles, nature reserves and villages.

Yes some will, by their very nature, not be the most AS appropriate sites to visit. However, as each is, by its own definition, unique, there will be just as many that are.

Before working for the NT, I was a member, and so far (fingers crossed) Holly and I have not broken anything of historical value, destroyed years of conservation, caused disruption to others or caused the extinction of anything. Even Avebury (right) is still standing.

What we have had, however, are many visits to interesting places, fresh air, freedom (and probably ice cream). So how can you find out more? The National Trust (www.nationaltrust.org.uk) has sites across England, Wales and Northern Ireland.

Details regarding access can be found on the website or by obtaining a free copy of the Access For All Guide. It details the practicalities of a visit with a wheelchair, disabled toilets etc. Chock full of the information that we all like to have in advance. Severely disabled children are admitted free of charge with a paying adult. Alternatively, an admit one card can be obtained, free of charge, that will allow a necessary companion free entry, whilst the disabled visitor pays normal entry costs. Valid for a calendar year, this card therefore entitles a parent and child entry for the cost of one child place. And not all sites charge an entry fee!

Many of the bigger more open sites only charge for entry into specific museums or galleries.

To obtain a free copy of Access For All or to request a free Admit One card, please contact the Access For All Office on 01793 817634 or e-mail accessforall@nationaltrust.org.uk

If you have a specific AS/NT related question, contact me at rich@angelmanuk.org, and I'll try and get an answer for you.

So go on, you might just enjoy it!

Rich Williams

An open letter to the nurses we have known

Firstly, and most importantly, thank you for looking after my child when she is unwell.

When my daughter is sick enough to be in hospital, she is usually very sick. The fact that she is always somewhat sick does not make it easier to bear the times when she is very sick. In many ways it makes it harder, since I know that not all children get better all the time. So if I tell you that my daughter is ill, or that I am worried, don't say "she looks alright to me". The signs that she is unwell can be extremely subtle; that's one of the reasons why I stay with her, to interpret for her and for you. Don't assume I ever get used to sitting by her bedside watching her fight for breath.

I do know my way around the hospital, this is true. Please don't assume this means I remember where your linen cupboard is, or that I know how to access the parents' rooms. It was only on the last day I spent on your ward that I realised there was a washing machine available to parents - this is the sort of information it would be useful to tell us when we first arrive. Or at least that second day. Especially if it's an emergency visit.

To the nurse who sat down and figured out a decent workable pain management plan and then made sure it was implemented, thank you. To the nurses working the shifts before this nurse came on board, please consider taking the time to do this yourselves. It only took her ten minutes, and it saved her a lot of time running about checking the charts for the rest of the night. And it kept my daughter out of pain.

I appreciate that there are other children on the ward, and I understand that some of them may be sicker than my daughter. For future reference though, the nurse who said "I'm very sorry but we are really busy at the moment; I should be able to be with you in twenty minutes" left me in a much better mood than the nurse who said "There are ten children here you know". I don't need to be made to feel bad for requesting help with my daughter.

Please don't be offended when I double check the drugs you are giving my daughter. I know you've read the chart; I know you've checked with the other nurse in the room. It is not that I don't trust you personally. It is simply that my daughter has, at times, received the wrong dose of medication. So if something looks different to what I'm used to, I will check that. The response "we use a higher strength solution so the volume is less" is more likely to fill me with confidence than "I've checked it, we don't make mistakes".

I understand that things get very, very busy on the ward, and that certain things are beyond your control. I would therefore like to say a particular thank you to the nurse who let me know what time the ward was likely to be at its most quiet, and who suggested that I waited until then to go and find something to eat, because she would then be able to send in an HCA to sit with my daughter. I know things can change suddenly, but knowing that things were likely to be quiet meant that I could relax a little more whilst off the ward.

I did appreciate the short chats we had when things were quieter; thank you to those of you who came to see us and spent a bit of time just generally chatting and trying to bring my stress levels down. That was truly appreciated. However, to the nurse who spent ten

minutes ranting about the stupidity of nurses working 12 hour shifts, and how dangerous it was to be working for the final four hours, and how easy it was to make mistakes, I'd just like to ask did it not occur to you that my daughter was being nursed by many staff working 12 or 13 hour shifts? I didn't need to know the research showing how dangerous that was; I needed to be able to have confidence in the staff caring for my child.

To the nurses who allowed me into the recovery room as soon as my daughter was out of theatre, thank you. To the nurse who didn't let me know when my daughter was out of theatre until I asked, and who then did not come and find me when my daughter was ready to return to the ward, do you know how much that upset me? I appreciate that different hospitals have different policies on allowing parents into the recovery wards and that you are not responsible for those policies and can't change them. But you knew where I was, it would not have taken thirty seconds to keep me informed. To the nurses who put down what you were doing (when it was safe to do so) and came to watch my daughter having seizures, so that you would know what they looked like, thank you. To the nurses who insisted tonic clonic seizures were the only seizures which counted, I suggest you obtain some epilepsy training. Stat.

To the nurses who stayed on hours past the end of your shifts, in order to give full and proper handovers, in order to write notes, in order to change beds and adjust oxygen settings and give meds and speak to doctors, THANK YOU. You shouldn't have had to do that, and I know you do it day after day after day. Thank you.

To the nurses who took the time to get to know my daughter, thank you. To the nurses who spoke directly to my daughter, thank you. To the nurses who listened to me, who asked me to explain treatments to my daughter before carrying them out, and who gave me the time to do so, thank you. To the nurses who did not know how to speak to my daughter but who tried, thank you. I hope my suggestions were useful. To the nurses who marched in, spoke to neither of us, and injected my daughter or rolled her over like a slab of meat, I hope you understood that my anger was directed at your poor practice, and was not simply because I was stressed. I hope you listened to my explanations and realised that my daughter is a human being and needs to be treated with dignity. I suggest some training in learning disabilities. To the nurse who brought in stickers and feathers for my daughter, a very big thank you!

To the nurses who worked with us several days in a row, thank you. To the staff nurse who put different nurses with us every shift "because they all need to learn about complex needs", whilst I appreciate the fact that our experience will benefit other children, please think about the effect this had on us. We had to train new staff, every shift, and that is not a swift process. It meant that I was unable ever to relax knowing that my daughter was being cared for by someone who knew her. To the nurse who realised this was happening, and swapped with one of the new nurses for a few hours, thank you. Similarly, to the nurse who watched me count up all the student doctors, student nurses, student therapists all joining in on a wardround, and who rounded them all up and got them to leave us alone with the doctor for a while, thank you.

I know it isn't your job to keep music playing for my daughter when I am not with her. To the nurses who promised to keep an ear out and hit the play button when the CD finished, thank you. To the nurse who snapped that she didn't know how to use those

who refused to enter the room so I could show her which button to press; you left me with the choice of going without food or leaving my daughter unhappy. Why did you think that was acceptable?

To the nurse who broke all the rules and made me a cup of tea one night; I think you very possibly saved my life. To the night nurses who sat down and played a game of cards, loudly, at the nursing station - please don't do that again. I am sure a night shift when you only have three patients, when all three patients have parents with them, and when none of the patients is ill, must
be boring. But keeping the parents awake with the noise of your game, that doesn't go down too well. I appreciate there is only so much admin which can be done overnight, but perhaps I could recommend some reading for you. Epilepsy awareness perhaps? Or profound and multiple learning disability? Or visual impairment training. Failing that, may I recommend reading magazines and eating chocolates as a quieter occupation?

To the clinic nurses who insist on weighing my daughter before clinics, please request or fundraise for a set of hoist scales. When I state that I do not wish to stand on the scales myself, please respect that. You don't know what reason I may have for not wishing to know my own weight. And having you know my weight and not me, that isn't a solution either! Additionally, although I can at present hold my daughter safely whilst standing on a regular set of scales, the time will come when that is no longer a safe option. I refuse to believe my daughter is the only child you see who cannot sit on a pair of scales herself - please get the correct equipment.

To the clinic nurses who think my child will not need magic (numbing) cream because she doesn't understand what is happening, shame on you. To the nurses who allow me to hold my daughter's arm steady for you and believe me when I say I have done it before and will manage just fine, thank you.

To the clinic and community nurses who tirelessly chase up appointments and treatments, phone between clinics to check progress, spend hours sorting things out for us, cheer when things are going well, send my daughter birthday cards, thank you. You simplify our complex lives.

My daughter is always going to be disabled. I am familiar with her disabilities, and I am the expert in my child. Thank you to those of you who recognise my expertise. Thank you too those of you who realise that a new need, a new diagnosis, is going to upset me as much as it would upset the parent of any other child who hears bad news for the first time. Thank you to those of you who take the time to educate me about the new needs, new concerns, who enable me to remain the expert in my child. Thank you to those who help me to have confidence in my ability to carry out new treatments, live with new risks.

There may well be times when you can't do anything for us. "I'm sorry, there's nothing more I can do at the moment" is a better way of turning us down than "that's just the way it goes sometimes" or "you always knew this was a possibility". Tread softly.

A few tips. Please don't be offended if I forget your name. I'm operating on very little sleep and my daughter is my focus. If you are a student nurse, please tell me you are a student nurse. Unless there are 12 of you in the room all at the same time I'm not likely to object to your presence. And your somewhat naive and occasionally insulting questions will be answered with more sympathy and in a more educational manner if you are open with me about the fact that you are tying to learn things before you qualify. Listening to me explain a complex query about drug interactions and possible seizures and letting me ask it over the course of ten minutes before saying "oh I'm just the student; I'll get one of the nurses to come and see you" is not helpful.

Finally, thank you to those of you who realise that my daughter is my life, she is my daughter. Thank you to all those of you who realise that although my daughter is very profoundly disabled, she still has a good quality of life. That she does not have a DNR order, and that she does not at this point in time require one. That her doctors and I are in agreement that she is for full and active treatment. To those of you who disagree with this, the person to argue it with is the Dr, not with me, and definitely not in front of my daughter. To those of you who spent time trying to find her smile and watching her melt into a puddle of giggles, thank you.

Taken from 'Behind the child'

http://behindthechild.blogspot.com/

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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.