Assert

Newsletter 52 Spring 2013

Angelman Syndrome Support Education and Research Trust

Meet our new trustees

Splash Landings

AS Clinic

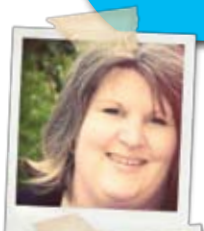
Boy Bites Horse

It's not Angelman Syndrome…

Standing up for Adi

Registered Charity 1021882

Your Assert Trustees



Rachel Martin
Chair, Online Support, North West and Welsh Region

Rich Williams
Vice Chair and Welsh Region

Lisa Court
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Russell Andrews
Sibling Support and Central Region

Sue Williams
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Pretentious arty-farty type Media & South East Region

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Research and South West Region

Linda Holmes
Regional Meeting Coordinator and North East Region

Sian Cartwright
Professional Advisor and North East Region

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

Useful Stuff

OUR FREEPOST ADDRESS

ASSERT
Freepost
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:
www.angelmanuk.org/spreadshirt

FRONT COVER

Photograph courtesy of Robert Chadwick. We'd like to use one of the great photos taken at our 2012 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 Chair

All change at Assert

Many of you will by now be aware that many changes are afoot at ASSERT HQ! First of all we had a facelift - our new logo, updated website, newsletter presentation and colour scheme have all been a huge success I'm sure you'll all agree.

Secondly, ASSERT would like to let you all know that Jeremy Webb recently stepped down from the position of Chair of ASSERT in order to spend more quality time with Claire and his family and to concentrate on other priorities. Jeremy has been a trustee and chair of ASSERT for 7 years. He oversaw the facelift and also the transition from holding our conference at Loughborough University to the hugely popular and far better equipped Hilton Hotel. We would like to say a very big thank you to Jeremy and to Claire for all the work that they put into ASSERT over the last few years - and to Chris Martin and Amy Francis who have also decided to step down this year. Rachel Martin and Rich Williams have jointly taken the reins and will be acting as Chair and Vice Chair respectively. Despite the difference in titles there will be no distinction in responsibilities and both are available via email should you wish to discuss anything.

The current team of trustees is very strong and we aim to take ASSERT onwards and upwards. We have big plans for the future with the very first UK AS Clinic (see page 14) being held in the near future and the concentration on both national and international research - more on that inside!

We would also like to welcome our new trustees Linda Holmes, Sian Cartwright and Katie Cunnea. All have children of varying ages with Angelman Syndrome and their experience is invaluable - you can learn more about them on page 12. We hope that you enjoy this edition of the ASSERT newsletter and that you will continue to support ASSERT in our mission to support families and educate the professionals that work with us.

Special mention has to go to our London Marathon Golden Bond runners Hollie Christiansen, Ed Winter, Ben Stagg, Ed Gillham and Graeme Dunn. By the time you read this, deadlines being what they are, they will all be nursing sore limbs and great memories, having completed the course. But we'll get more details from them for the next newsletter. On behalf of all of our members, thank you. And good luck also to the runners in the forthcoming BUPA Great Runs.

Rachel & Rich

Collection boxes

In this edition of the newsletter you'll find one of our new ASSERT collection boxes. If you have an event at which you'd like to collect money for us just use the box, then when it's full you can count the change and make an equivalent, secure on-line payment by clicking the red 'Donate Now' button on the ASSERT website. Just go to: www.angelmanuk.org

Alternatively you can complete the details on the back of the collection box, flatten it and send it along with a cheque made payable to 'ASSERT' and post it to: ASSERT, Freepost, PO Box 4962, Nuneaton CV11 9FD

Siblings Just for Us!

Young Sibs

Russell Andrews and his sister Melinda

What do you get when you cross a snowman with a vampire?

Frostbite!

What did the water say to the boat?

Nothing, it just waved.

What did Geronimo shout when he jumped out of the airplane?

Me!!!

If you can do better than this then send your jokes in and there will be a small prize for the best.

We also want to see some photos of you with you Angel brother or sister. Here's a couple of great photos of Max with his sister Holly.

Assert Sibling Group

www.angelmanuk.org/siblings

It's growing all the time. So if you're old enough to be on Facebook, join us and let's hear from you.

Older Sibs (...and parents)

I've mentioned here few times recently the research into how growing up with a brother or sister with a profound disability can affect the siblings(s). There isn't yet any direct research into how AS siblings are affected that I am aware of but there are some interesting and potentially helpful trends that researchers have identified across similar groups, particularly within syndromes such as Downs and among families where a child has epilepsy. I'm usually very careful to say that everyone is different and there's no doubt from the research that there are a number of factors that can affect siblings including their gender, position in the family, the size of the family and so on. However it is always very interesting that whenever I speak with other adult siblings they readily nod when I mention some of the feelings and experiences below. What is very clear is that impact of growing up with a brother or sister who has a profound disability can have an impact well into adult life and often beyond the experience of parents.

Research in America suggests some noticeable trends depending on your gender - very often older girls will take on personal care tasks for their brother or sister while older boys will often take on more household tasks. Some researchers have speculated that this can have an impact upon the type of career choices siblings make, with some older girls often choosing the caring professions and boys choosing practical careers.

There is quite a bit of evidence that suggests that siblings feel the pressure to be super-achievers in order to make up for the things that their brother or sister cannot do and they also tend to naturally take control of situations when they outside of the home because they are used to getting on and helping sort things out at home. This can sometimes be compounded by the desire of siblings not to be an additional burden to their parents so they can often have the tendency to be quite independent and self-reliant.

Of course, these aren't necessarily negative characteristics and adult siblings often speak with pride about how growing up with a brother or sister with a disability has meant they are resilient and able to deal with most things that life throws at them. And a very strong trend in the research is that siblings tend to grow up to be very tolerant. So, overall we are not a bad bunch!

Next time I'll say a bit more about the wider challenges that siblings face and look at some strategies that families can adopt to make sure that siblings are receiving the care that they need.

Russell Andrews

Alton Towers Splash Landings Weekend

Families from the North, South, East and West, converged on Alton Towers, **Splash Landings** hotel for a weekend to remember!

We all met up for a weekend away in the Caribbean themed, Splash Landings hotel, almost taking over the ground floor. By the end of the weekend the staff certainly knew about Angelman syndrome and certainly Angelman syndrome Mums!

Our trip to the resort was a real success, we had lots of fun, with 13 angels, and their families.

The first night was a meet and greet, where we all arrived and checked in to the brightly design themed reception. Travelling down to our Caribbean / beach hut-style rooms via the bright and musical lifts, which had all our angels laughing and dancing in delight. (Even on your own, you had to jig to the *Captain Pugwash* theme tune!)

The angels were a joy to be around all weekend, although Lucy did upset one woman in the pool by splashing her. She splashed Lucy back, objecting to her behaviour in the pool. Lucy laughed at the splashing and swept even more water onto her! Little did she know that Lucy's army of Angel friends were on their way to the hotel!

Leigh Howard took to the stage to perform an angel Dad rendition of *"Angels"* followed up by "The Angel Mummies" singing *"Moving On Up"* and really letting their hair down. These normally stay-at-home / never-go-out mums had suddenly remembered how to party - while all the dads sat at the side, rocking the wheelchairs to the rhythm!

Saturday was filled with swimming, visiting the sea life centre and catching up with each other in the bar.

After dinner at Flambo's restaurant we all took things a stage further by meeting in the bar in our Caribbean costumes! Congratulations are

due here to Wayne and Dean, who excelled themselves with their pirate costumes! Julie Morgan made sure all the mums wore grass skirts and if you weren't prepared to wear one she hit you with one!

The Raffle went down well and while Alton Towers didn't want us to actively sell tickets to general guests, many bought them. We raised £200 for ASSERT. Thank you to everyone who bought tickets and generously donated prizes.

It has to be said at this time, although we had a great weekend, and the hotel is fantastic, there were a few hiccups and lack of communication / organisation between the managers of the hotel, although this did not spoil our overall enjoyment of the weekend. When asked if they wanted to do it again, all said they would.

Linda Holmes & Diane Box

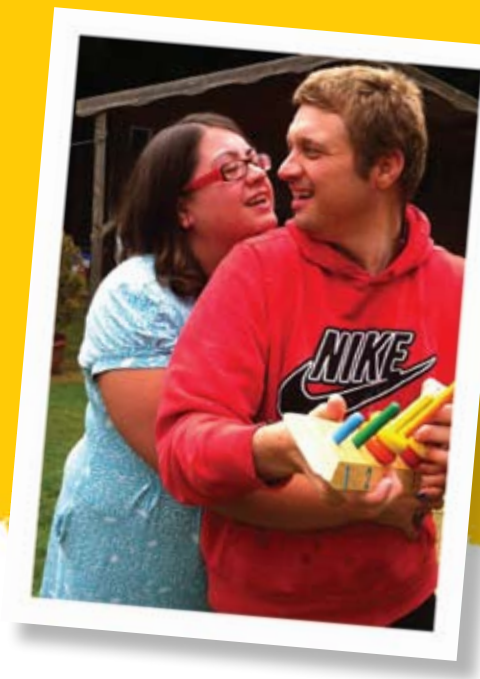
Roll on our NEXT weekend away...

Friday 14th June – Monday 17th June
Haven Thorpe Park Holiday Centre,
Cleethorpes Lincolnshire DN35 0PW
Static caravan hire/Tourers/Tents

EVERYBODY WELCOME

Contact Diane Box 07833 372828
or Linda Holmes 07739 363456

Standing up for Adi



After her mother died unexpectedly at the age of just 57, **Helen Porter-Hughes** became the primary carer of her disabled older brother Adi. Here, she describes how she has come to terms with such an immense responsibility.

Interview by Clare Goldwin

Unlike most new parents, I didn't choose to start a family. I didn't have nine months to get used to the idea and I certainly didn't come home from hospital cradling a tiny baby. Because in my case my 'child' is my older brother Adrian - or Adi, as we've always called him. Adi has a rare genetic disorder called Angelman syndrome. While he's 36 and 6ft tall, he isn't steady on his feet, can't speak, has the cognitive abilities of a two year old and displays severely autistic behaviour. Those with Angelman are known for their happy personalities – Adi gives the best bear hugs – but he can also lash out, biting and hitting. Recently, my sister was holding his hand and he dug his fingernails into her arm so hard that it bled. He just doesn't understand what he's doing. Our mother, Julie, was always his chief carer, but when she died from cancer two years ago, I became parent to a 36-yearoldtoddler overnight. While Adi lives in residential care just a few miles from my home, he still needs someone to give him the voice he will never have. Whether it's a stressful fight to stop him being evicted from his home because they say they can no longer cope, applying for funding or accessing technology that might help him communicate, battling for Adi is a huge job. And, I'll admit, one I have mixed feelings about. As a result of growing up with a disabled sibling, I never wanted to be a mother.

Of course I love my brother dearly and can't imagine life without him, but I have always been adamant that I didn't want to have children of my own. I grew up watching my mother struggle with a very challenging child and, while most children become less of a responsibility over the years, I know all too well that there are some who never develop. Adi still enjoys the things toddlers do – children's TV programmes and Lego. He has a five-minute attention span and will never have any notion of danger; if he's not watched, he'll put his hand on the hob or run into a road.

Living with Adi, who is nine years older than me, shaped my life from an early age. I've always been very sensitive towards those who are more vulnerable, and for as long as I can remember, he was someone I instinctively knew I had to protect. Mum would tell a story about how we were in a supermarket when I was about four years old and a group of teenage boys were teasing him. Apparently, I marched right up to them fearlessly and said: 'He is different, but it's not his fault!' I was always standing up for my big brother. From the age of 11, Adi went to a special boarding school because his needs were too great to be met properly at home, but he still came home during the holidays. He wasn't potty trained, but also wouldn't keep his nappy on at night. He slept very little, would destroy anything in his room and had to be locked in overnight for his own safety. It was tough for my mum – she would be the one up at 5am every day washing him and cleaning up the mess. Unless you were to cry or shout at him, he wouldn't know anything was amiss because he has no understanding of right and wrong – and he hasn't the capacity to grasp the concept of being sorry, let alone say it. Beyond a few unintelligible words, he can't speak, and he simply does these things because he's bored or frustrated.

I think I grew up faster and became more self-sufficient than most children. If I ever had an argument with my sister Katie, who is three years younger than me, we'd try to sort it out between us and not bother our parents. We had to get used to hiding anything precious because Adi is so destructive. And we had to get used to him biting and hitting us; it was difficult, but we knew he never meant it because he's not a monster. There's actually a lot of joy

around him. He adores theme parks and also loves the beach, especially the sensation of walking barefoot in the sand, and naughty food, such as chocolate and crisps. The fact it might be on someone else's plate doesn't stop him from helping himself. I've always been very responsible, too.

When growing up, I never had the desire to rebel. Although I was never embarrassed or ashamed of Adi, I do remember in my early teens feeling resentful of our situation, particularly as it was harder to have friends over to visit. But those feelings passed; I realised they were just pointless. As well as witnessing the exhaustion Mum suffered, I also saw the guilt she carried. Doctors had previously assumed Adi's disability was caused by oxygen starvation at birth – it wasn't until blood tests were done six years ago that we discovered he had Angelman. So Mum not only felt guilty that she wasn't doing enough for him, but she also thought she was responsible for his disabilities in some way. Katie and I were both born by Caesarean section to avoid similar complications, and so we always had a sense that because Adi had suffered, we didn't have to. I think I've always felt some guilt, too, because I wasn't disabled. When we were very young, we'd write to Father Christmas and at the top of the list would always be: 'Please make Adi better'.

I met my husband Jon at university and I was very clear with him from a few months into our relationship that I didn't want children; thankfully, he has never wanted them either. We've been married for four years and even now I'm adamant that I won't change my mind. It's not that I don't love children – I do. I volunteer as a leader at a local Brownie pack, which I really enjoy. But I don't want to be responsible for another human being 24 hours a day, 365 days a year.
Given how I feel about children, the irony of the situation in which I now find myself isn't lost on me. While Adi will always live in residential care, making sure his needs are being properly met is almost a full-time job. And like any parent, I find myself fretting about him when I'm not with him: is he happy, eating enough and being properly looked after? Mum never discussed what was to happen to Adi after her death. She just said, 'Look after him'. Perhaps she thought it wouldn't happen for years – she was only 57 when she died – or maybe she wanted us to enjoy our lives without having any future responsibilities hanging over us. When she got ill with a rare and aggressive cancer, it was never the right time to talk about it, and she died within three months of being diagnosed. We were very close and it was devastating to lose her so quickly. I was particularly upset that having worked so hard all her life, she never got to realise her dream of going on a cruise. It was a couple of months before we felt able to think about who should take responsibility for Adi.

Our family currently has no legal right to act for him – he doesn't have the mental capacity to give power of attorney and legally is in the care of the local Community Learning Disability Team – but he still needs people to fight his corner. And that job fell to me. Our fathers aren't in a position to take on such a big commitment (we're actually half-brother and sister – Adi's father was my mother's first husband). Katie works long hours, whereas my job supporting students who face a range of disabilities is part time and gives me long academic holidays.

Of course, I always want to do my best for my big brother, but because everything happened so quickly two years ago, I never got to question whether it was something that I wanted. Fortunately, my family is behind me and I've also had lots of support from the Angelman charity Assert (angelmanuk.org). And if I ever doubt I've done the right thing, a hug or a smile from Adi reminds me what's most important.

Helen Porter-Hughes

This article first appeared in the January 2013 issue of Psychologies magazine: www.psychologies.co.uk

Improving the lives of carers and the people they care for

10 -16 June 2013

When people need help with their day-to-day living they often turn to their family and friends. Looking after each other is something that we do.

Up and down the UK there are six million people caring unpaid for an ill, frail or disabled family member or friend. These people are called carers but they would probably say "I'm just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a good neighbour."

Carers help with personal things like getting someone dressed, turning them in their sleep, helping them to the loo, helping them move about or administering their medication. Carers also help with things like shopping, laundry, cleaning, cooking, filling in forms or managing money.

The reasons people might need help can vary. Maybe they were born with a disability or had an accident that left them disabled. Or they have an illness or disease. Their problems may be physical or mental. They might need help because they are getting older and frail. But what doesn't vary is that they need help, and if you look after someone - for whatever reason - caring is part of life.

For many people caring comes briefly, maybe helping someone who has come out of hospital to get back on their feet - a few intense months that turn your life upside down and then it's over. For others it may be a regular obligation of a few hours a week helping out. For those with disabled children it can be a lifelong commitment. Some people are caring round the clock, 24 hours a day. How caring affects you depends on how much you are doing, what else is going on in your life and to some extent what kind of a person you are. Caring can be a rich source of satisfaction in people's lives. It can be life-affirming. It can help deepen and strengthen relationships. It can teach you a multitude of skills and help you realise potential you never thought you had.

But without the right support caring can have a devastating impact. Evidence shows that caring can cause ill health, poverty and social isolation. When caring is intensive and unsupported you can struggle to hold down a job, get a night's sleep, stay healthy and maintain your relationships with friends and family.

One in every eight adults in the UK is a carer. It's something that will happen to most people at some point in their lives – in fact every year, over two million people become carers for the first time. At the start caring can be bewildering, confusing and demanding. All carers need some support and back-up. Caring without support from others can present serious risks to your health and well-being.

Most people need some sort of practical support to help with caring for a relative, partner or friend. This could be equipment to help you lift the person you care for, an alarm system for peace of mind, someone to look after the person you care for while you go out, or the opportunity to have a more substantial break where the person you care for goes into residential care or someone steps in to care for them for. By having a carer's assessment you can work out with your local council what support you and the person you care for will need.

Carer's assessments are a way of identifying your needs as a carer. They look at your role as a carer: how being a carer affects you, how much caring you can realistically do (while still allowing you to be involved in other activities outside caring), and any help you need. Find out about this from your local council or carer organisation.

There is no doubt that without the right support caring can all too easily damage your health. You'll need to find the balance between caring and looking after your own health needs. It is not an easy balance to find, but remember – the better your physical and emotional well-being, the better you will be able to cope with the demands of caring.

- Juggling the demands of caring with the responsibilities of a paid job is a tough call. People often feel pulled in two directions and as many as one in five people with significant caring responsibilities end up giving up work.

- Those who fall out of work pay a heavy price – facing financial hardship and missing out on their own pension. So it pays to think carefully before giving up your job and explore all the options for support.

- Telling work about your caring role is not always an easy step and you might feel it depends on whether your employer is likely to be supportive. Find out by asking your colleagues, personnel officer or union representative. There may be existing support that you are not aware of, or you may find that your employer is open to exploring ways to support you.

For most people, caring hits your finances. Your income can take a dramatic drop through giving up work or reducing your working hours; you may face extra costs, such as heating, petrol and laundry, because you are looking after someone.

As a carer you should take the opportunity to have a benefits check to make sure you are claiming everything that you are entitled to. This will help you understand what benefits you or the person you care for might be able to claim and how to do so. This is particularly important if the person you care for is going to need care for a while.

What you or the person you care for may be entitled to:

- Benefits for the person you care for, like Disability Living Allowance for people under the age of 65 or Attendance Allowance for those over 65.

- Carers' benefits such as Carer's Allowance if you are providing care, unpaid, for 35 hours or more for someone who receives the right level of disability benefit.

- Council Tax discounts

- Discounts on fuel bills if you receive certain benefits.

- Protection for your State pension.

- Extra Tax Credits if you need childcare for your disabled child and you work.

Carers Week is the ideal time to find out what support is available to carers in your local area and help you prepare to care. For information or to find out what is happening in your area during Carers Week go to www.carersweek.org For information about how to get involved contact Carers Week Manager **Helen Clarke** or 020 7378 4955.

Assert's New Trustees

Katie Cunnea

Hi, I am ASSERT's new Research Trustee. I am married to David and we have two children, Ruby who is 5 and has AS and Finley who is 4. We live just outside the New Forest in Wiltshire. I originally trained as a biochemist and have a PhD in protein structural studies. I worked for a short while at Southampton University in one of their research labs before starting a career in Educational publishing. I will be helping ASSERT members make sense of scientific research and build ASSERT's contacts in the scientific community worldwide.

I will have a regular spot in ASSERT newsletters so watch this space for reviews of the research going on around the world. If anyone has any particular research paper or science query they want explained please let me know.

Why should we be interested in AS research?

In the past few years there have been a number of research groups (all outside the UK) focusing on the molecular mechanisms that result in Angelman syndrome. (Molecular mechanisms are the interactions that occur between different molecules inside our cells). Some progress has been made in our understanding of what the AS gene does, how it works, and why the symptoms of AS develop if it is missing. A few groups have used this new knowledge to hypothesise, and begin to research, different ways that we might, one day, reverse or treat AS symptoms. This is a big challenge and will take considerable time and effort. The effect the AS gene has on the body and the way it is controlled is very complex and there is still much to learn. While scientists have connected some pieces of the puzzle, no one knows what the full picture looks like yet. We don't fully understand the mechanism that leads to the differences in the cells and tissues of people with Angelman syndrome. Additionally no one knows yet whether any of these differences can be corrected. There has been some debate about whether AS symptoms are reversible recently, but ultimately no one knows yet.

This situation is true for other genetic conditions too. As scientists continue to try and find potential treatments for other genetic conditions, their findings and the methods they use might be transferable to Angelman syndrome research. However, we do need scientists specifically looking at Angelman Syndrome to make this possible. This is where I hope to make a difference, promoting and encouraging more scientists to consider looking into AS, especially as there is very little research of this kind going on in the UK currently.

A final note from me: as a scientist Angelman syndrome fascinates me and being in an era of rapidly increasing understanding of genetic conditions, it is an exciting time ahead. At the same time as a parent I would say it is important to accept your child for who they are right now and celebrate the effort of their achievements.

Assert Conference 2014

ASSERT are thrilled to announce the 2014 conference will be at the Hilton Coventry (Junction 2 M6) on Friday 29th August – Sunday 31st August 2014. The 2012 conference was so successful at the new venue that it was a unanimous decision amongst the trustees to return there next year.

Booking forms and letters will be sent out during early 2014, but please put the dates in your diary now so that you keep the weekend free.

Linda Holmes

Hello, I live in Leeds and am one of the new trustees for the Yorkshire and Northeast region. I'm married to Rick, we have two daughters, Lucy 17 and Becky 10 going on 20! Our nephew Chris 23 also lives with us.

Lucy was one of the first 25 in the UK to be diagnosed with 'ube3a mutation'. I have always wanted to find the other 24 so I started up my own Facebook group 'ube3a mutation link group'. This really took off, along with my other group 'Halo Happy Campers'..... Another aim in life is getting as many Angel family campers/caravaners together as possible to take part in some fab 'Angelman getaways'.

I am very much a people person and ran my own business with Rick for 16 years, but nowadays I have left him to it.... as I am 'nearly' addicted to Facebook! Seriously though, the support that can be found in the ASSERT group 'Angelman syndrome UK' and 'UK Angel mums' is so very beneficial. I have met some lovely families along the way that are now considered an extension to ours. I am also an admin of the 'Adult Angels' group and 'Angelmans post 16 UK'.

My role within ASSERT is 'meet up co-ordinator', I'm keen to get everyone together and join hands across the country! Hmmm - possibly a fund raising event? Let me know if anybody wants to go for it!

Sian Cartwright

Hi, I also live in Leeds with my partner Peter and our two children Poppy, who is 19 and currently at university in Newcastle and Euan (AS deletion) who is just 18. This means we are now entering the realms of adult social care and we are currently trying to find appropriate respite provision for Euan as, locally at least, everything we did have access to disappeared on Euan's eighteenth birthday.

I originally trained as a social worker and for many years I have worked in health and social care for local authorities, the voluntary sector and most recently for the NHS. I have a particular interest in ensuring that carers have access to support and information and in addition to my role with ASSERT I am Chair of Trustees at Carers Leeds (part of the Carers Trust).

Useful Websites & Interesting Blogs

Support

- www.cafamily.org.uk
- www.mencap.org.uk
- www.autism.org.uk
- (Princess Royal Trust for Carers) www.carers.org
- (Transition) www.transitioninfonetwork.org.uk
- www.challengingbehaviour.org.uk
- www.learningdisabilities.org.uk

For iPad/apps

- www.autismpluggedin.com
- www.atmac.org
- www.blog.friendshipcircle.org/2011/02/02/the-special-needs-ipad-app-series
- www.lilliespad.com/special-needs-ipad-blog/tag/special-needs-apps
- www.techlearning.com/Blogs/37722
- www.momswithapps.com/apps-for-special-needs
- www.gadgetsdna.com/10-revolutionary-ipad-apps-to-help-autistic-children/5522
- www.oneplaceforspecialneeds.com/main/library_pick_great_apps.html
- www.ikidapps.com/2010/10/apps-for-children-with-special-needs.html

Blogs

- www.boybiteshorse.co.uk

Pre-loved equipment

- www.disabreg.pwp.blueyonder.co.uk
- www.askdes.org.uk
- www.disabledliving.co.uk

Clothing and swimwear

- www.incywincy.net
- www.disabled-clothing.co.uk
- www.togs4specialsprogs.com

Legal

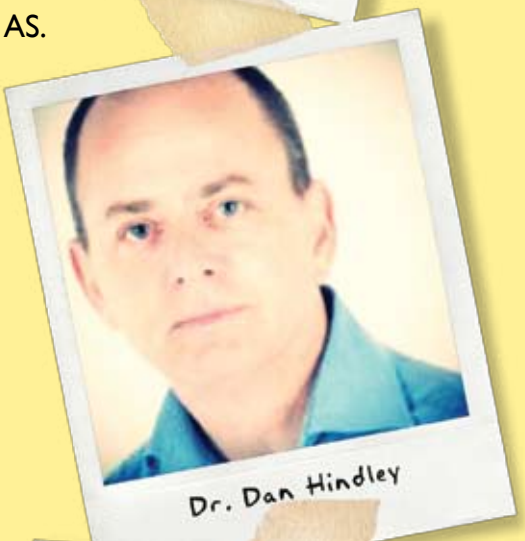
- www.ipsea.org.uk
- www.scope.org.uk
- www.mencap.org.uk
- www.challengingbehaviour.org.uk

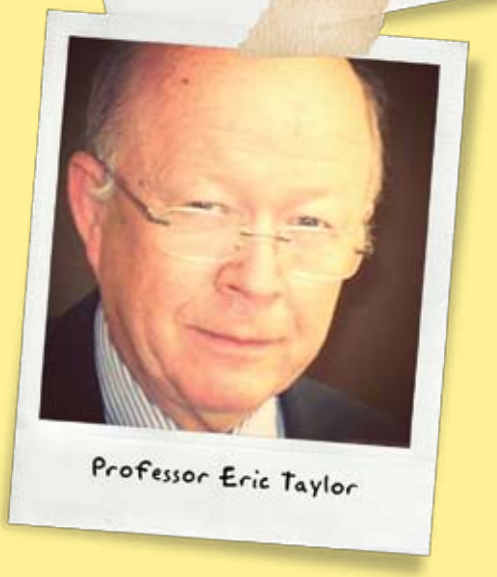
This website offers very useful tips and advice and is run by an AS mum

- www.netbuddy.org.uk/newsletter/netbuddy-tools

Angelman Syndrome Clinic


Professor Jill Clayton-Smith


Dr. Dan Hindley


Professor Eric Taylor

Angelman Syndrome was first reported and given the name Happy Puppet Syndrome by Dr Harry Angelman in 1965. Harry Angelman was a paediatrician based in Warrington in the North of England. In recent years the focus on AS has switched to the US where they have many professionals interested in AS. Despite this, the US still looks to the professionals that we have at our fingertips here in the UK such as Jill Clayton Smith, Chris Oliver and others. Many of you are familiar with these exceptional professionals and several of you have met them in person, however, there are many families who haven't yet had the privilege of speaking with doctors and professionals who are world experts in AS.

Therefore, ASSERT is very proud and extremely excited to announce that we are supporting the very first Angelman Syndrome clinic to be held in the UK.

We have a provisional clinic date of 1st August 2013 and the clinic is to be held in Manchester. We are hoping to hold 3 or 4 clinics each year for both adults and children with AS. The clinics are being held for those who have a clinical need to meet with the professionals.

We plan to see 3 or 4 families at each clinic, with each family having an hour for a full consultation with a clinical geneticist, **Jill Clayton-Smith**, a Paediatrician, **Dr Dan Hindley,** a Psychologist, **Eric Taylor,** a Physiotherapist will also be available and we are hoping to have a Speech Therapist, Dietician and other professionals present on the day. A representative from ASSERT will also be attending for the day to discuss ways in which we can support families.

Every patient is to be referred by their GP or other doctor sending a written referral to:
Dr Jill Clayton-Smith, Genetic Medicine, 6th Floor St Mary's Hospital, Oxford Rd, Manchester M13 9WL.

If you know that one of your professionals who has an expert interest in AS would like to attend the clinics in a professional capacity then please contact ASSERT with their details.

Adaptive Skiing

When Ruby was diagnosed with Angelman Syndrome I didn't think it was ever going to be possible for her to join in with some of the adventurous activities that my husband and I enjoy. Seeing as we were told she would never have good enough balance to walk properly, skiing seemed completely out of the question. But our physiotherapist told me about adaptive skiing, and after a couple of years I started to look into it. Three years on and I am a qualified adaptive ski instructor and Ruby has learnt to stand-up ski down a little slope.

Holidays abroad can be expensive, but there are UK ski centres that offer adaptive ski lessons that are a cheaper option. Disability Snow sport UK (DSUK) is the main UK charity but there are other independent charities that run at other dry slopes. DSUK arranges ski holidays abroad for disabled people and coordinates local groups in snow centres and dry slopes around the country. They also offer private lessons at certain slopes (mainly the snow domes). The local groups are more affordable and meet once a month. Mobility is not an issue, a ski instructor will assess a skier to determine if they can try stand-up skiing, or if they need to be in a bi-ski (see picture – a seat on skis). There are lots of different pieces of equipment to help those with less balance, less mobility or less obedience when it comes to stopping or turning!

Learning an adaptive sport like skiing takes the emphasis away from what a disabled person can't do and works out how to make the most of their abilities. It is about having fun and enjoying life. It can also be used as a motivation to learn other skills. I have been truly inspired by what is possible, and I would recommend to other families that they give it a go.

Katie Cunnea

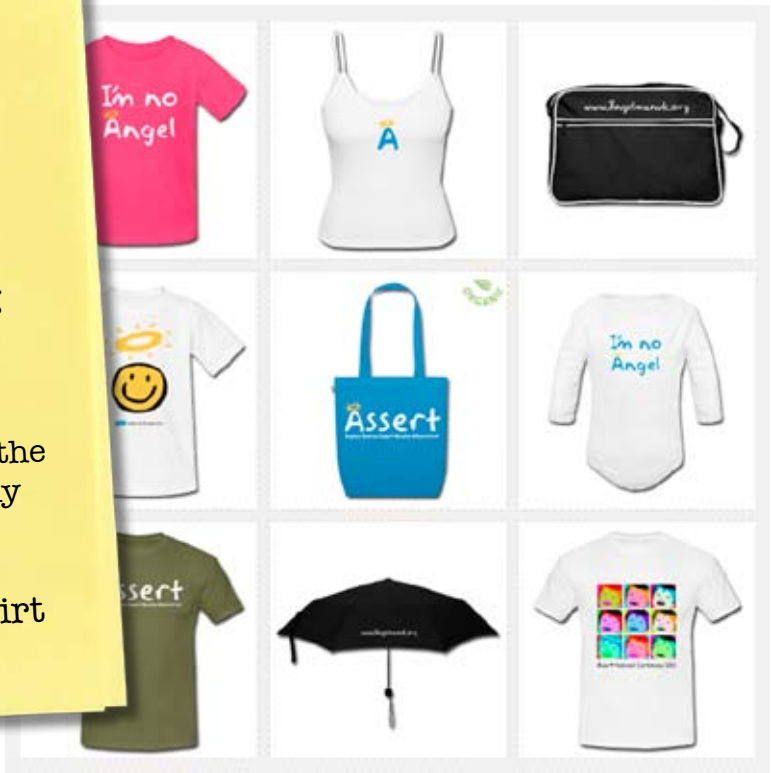
Assert

Don't Forget!

You can also support Assert by buying from our great range of T-shirts and other gifts.

You can find our online shop through the link on our website or by going directly to:

www.angelmanuk.org/spreadshirt



mencap

The voice of learning disability

We believe their financial care tomorrow is as crucial as it is today

Are you unsure about how best to leave your loved one with a learning disability money in your will? Planning ahead can make all the difference to those close to you, and provide you with peace of mind.

At Mencap, we understand that you are probably worried about how your loved one will manage their financial affairs when you are no longer around and concerned that a large amount of money may leave them in a vulnerable position. You may also be keen to ensure that they continue to receive their benefits but still enjoy their full inheritance.

The Wills and Trusts team provide parents, families and carers with free booklets about writing wills and setting up trusts for the benefit of a loved one with a learning disability.

We also organise free seminars around England, Wales and Northern Ireland. The free two-hour seminars offer vital, specialist legal advice and give families and carers a much needed opportunity to get answers to those difficult questions - that often make the process seem so daunting.

The next 'Planning for the Future' events in your area are:

North East –March 2013

East Midlands – April 2013

Wales – May 2013

Northern Ireland – May 2013 (TBC)

East – June 2013

London – June 2013

South East – July 2013

South Central – September 2013

South West – October 2013

West Midlands – October 2013

North West – November 2013

Visit www.mencap.org.uk/pffe to find specific dates and venues for your local events.

To find out more and to book a place, please contact **Gina Collins** on 0207 696 6925
email willsandtrusts@mencap.org.uk

Please note places at these seminars are always very popular so please book your place as early as possible to avoid disappointment.

If you cannot make get to the event but would like information about providing for someone with a learning disability in your will, contact the team:

Telephone 0207 696 6925
Visit www.mencap.org.uk/willsandtrusts
Email willsandtrusts@mencap.org.uk

Angels & Pimms Summer Fashion Show Extravaganza

in association with MOBU online boutique

The night includes: Welcome drink on arrival. Tapas courses served at your table.
Fashion stylists advising you on what clothes suit your shape! Fashion catwalk show.
Latest summer collection of clothes, bags and jewellery to view, try and buy.
Followed by staged appearance from *The Sounds of Buble*. DJ all evening.

A full night of fabulous fashion and fun with your friends!
13th July Starts 7pm until 11.30pm. Tickets £35 per person, can be booked as tables
if preferred via email: nessarogers@aol.com Telephone Vanessa 07854 015688
or Emily Turner 07817311012 (email farfields6@onetel.com)

The event is being held to raise awareness and funds for ASSERT and Angelman Syndrome.

Ramada Hotel, Penns Lane, Walmley Sutton Coldfield, Brimingham, B76 1LH

Regional Meetings and Notice Board

ASSERT are pleased to announce a number of regional meetings in the coming months.

Scotland

Saturday 27th July 2013 10.00am - 4.00pm
This is being held at Bathgate, High Church, West Lothian EH48 4HB
A buffet will be provided and there will be guests from 'Sense' Scotland and hopefully others who are yet to be confirmed. If you would like to attend please contact **Neil Buchan** 07513 056945

All ASSERT Regional meetings will give priority to families in their regions. However, if there are spaces available then you are more than welcome to come along, but please do contact the appropriate trustee prior to the meeting date.

There are other 'family weekend away/day trips' planned fairly regularly throughout the year that are not organised by ASSERT. The next one is at Thorpe Park, Haven site in June, details of which are given at the end of the **'Splashlandings'** write up. There may also be a weekend coming up in the Summer in Scotland - for those interested contact Linda Holmes. (The dates and location have yet to be confirmed).

Anybody interested in organising an event or wants help promoting it, don't hesitate to contact **Linda Holmes** 07739363456

Yorkshire

Friday 31st May 2013 10.00 - 2.00pm
This is being held at The Donkey Sanctuary Assisted Therapy Centre, Swan Lane, Off Blackhill Lane, Eccup, Leeds. LS16 8AZ
There is availability for 12 children/young adults to ride on the donkeys or in carts. (This includes siblings, however priority will be given to children and young adults with Angelman syndrome).
A Cold buffet will be provided. If you would like to attend, and if you would like to book a ride please contact **Linda Holmes** 07739 363456
(Closing date 24/05/13)

Administrative Assistant - Update

The role of an administrative assistant was advertised in a previous newsletter. Many thanks for those of you that applied for the role, we really do appreciate your support in wanting to work with ASSERT.

However, due to the number of changes currently taking place within ASSERT we have decided to put this on hold for the moment whilst our new trustees find their feet and our recent changes settle down - we will then review the situation.

South Wales

It is hoped there will be a day out sometime in July. Please check the website and Facebook page / group for details.

Central

It is hoped there will be a day out sometime in August or September. Please check the website and Facebook page / group for details.

Why not support ASSERT when you buy your next Greetings & Christmas cards?

Phoenix Trading have a great range of cards for all occasions and if you buy via **www.traceyscardsonline.co.uk** Assert can claim back 10% of the purchase price as a donation to their funds. When you place an order and go to the basket, just add the reference "**Angelman**" in the box at the bottom to enable Assert to claim their rebate.

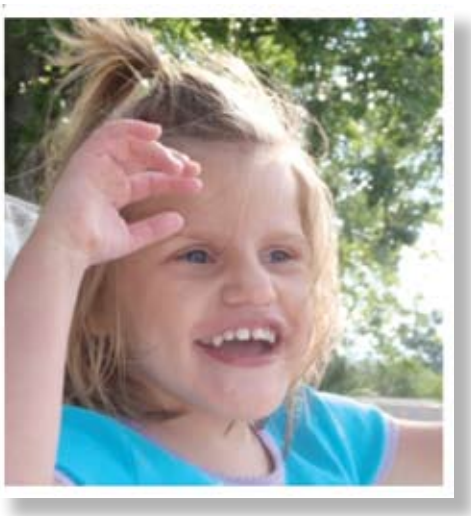
Not Angelman Syndrome... so what else could it be?

For many years after the original report of Angelman Syndrome by Harry Angelman in 1965, the cause of the condition was unknown, and the diagnosis was made clinically, i.e. based on the medical and developmental history of the child, the signs on examination and of course, the unique behaviour. From 1987, diagnostic tests became available but for many years these still weren't able to diagnose every child , and clinical diagnosis remained important. Nowadays, the situation has changed; Diagnostic testing is reliable and we can detect deletions, imprinting problems and UBE3A mutations using standard techniques. If an individual with suspected AS tests negative for all of these, then in all probability the child has another Angelman-like disorder. As time has gone on, a number of such disorders have been recognized and are summarized here by **Dr Jill Clayton-Smith**

Mowat-Wilson Syndrome

The condition is extremely Angelman-like in its presentation. The main features are microcephaly, seizures and characteristic face with deep set eyes and a prominent chin. Speech is usually absent, as in AS.
The main features which distinguish MWS from AS are physical ones. In MWS there are often some congenital malformations such as heart defects and agenesis of the corpus callosum, the midline structure of the brain. Another feature in some children is the presence of Hirschsprung's disease where the nerve supply to the bowel does not develop properly and severe constipation results. MWS is associated with a particular ear-shape, where the lobes are upturned or forward-facing. The eyes may be widely spaced and the eyebrows disorganized and growing in all directions. The nasal tip appears depressed, so that the area between the nose and the upper lip (the philtrum) is characteristically short. MWS is due to deletion or mutation of a gene called ZEB2 on chromosome 2.

Mowat-Wilson Syndrome; Google Images. Note the prominent ear lobes.



Pitt Hopkins Syndrome; Google Image. Note deep set eyes and prominent lips

Pitt Hopkins Syndrome

Pitt-Hopkins Syndrome was first described many years ago but until the Pitt Hopkins Syndrome gene, called TCF4 was identified recently very few patients were described. As in AS it may be associated with ataxia, seizures and intellectual disability with absent speech. Features characteristic of PHS are changes in the facial features over time, with the mouth and lips appearing more prominent and the development in mid-childhood of episodes of deep –breathing and breath holding, similar to that seen in Rett syndrome. There may be agenesis of the corpus callosum on the brain scan, the feet are often very slender and the fingers and toes often have little pads of tissue on the tips. PHS is associated with characteristic movements which include shaking the head in a figure of eight pattern and some hand wringing movements similar to Rett syndrome.

Christianson Syndrome; SLC9A6 mutation

This conditions is sometimes referred to as "X-linked Angelman Syndrome", but in fact it is a completely different disorder. Because the SLC9A6 gene is carried on the X chromosome, the condition affects only boys, though some milder symptoms may occasionally be seen in girls. Though children with Christianson syndrome look very much like AS children when they are younger when they present with an unsteady gait, seizures and often sociable behaviour, the picture changes as they grow older. Older boys usually have a very

thin build and have some unusual writhing or stiffening (dystonic) movements. Overall the picture is one of a slowly progressive disorder. MRI scans in this condition may show that the cerebellum at the back part of the brain is smaller. Another distinctive feature of the condition is unusual eye movements, with limitation of eye movements in certain directions. Diagnosis is made by testing the SLC9A6 gene.

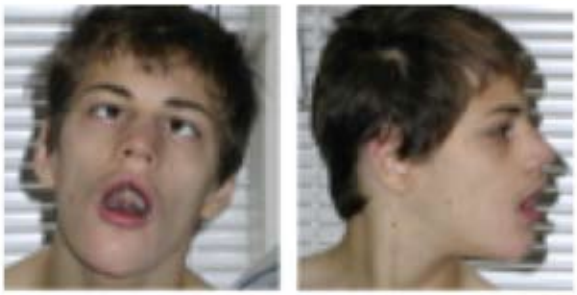


Photo from article by Mignot et al. Brain and Development 2013: 35(2) 172-176 Note the unusual eye movements

Rett Syndrome

Rett syndrome is a disorder which usually only affects girls. Though girls with Rett syndrome may have jerky movements, seizures, ataxia, and be very smiley when they are young, the symptom and signs change over time and become very different. One way in which Rett syndrome can be distinguished from AS is that in Rett syndrome there is often a normal period of development for the first 6-18 months of life before development comes to a standstill and then girls start to lose skills (regression). Characteristic behaviours then develop. These include repetitive hand movements, often with characteristic hand-wringing, episodes of overbreathing and breath holding, air swallowing with bloating of the tummy and periods of unexplained distress or anxiety. In Rett syndrome there is often loss of hand use. Smiling is not as frequent as in AS, though there may be episodes of laughing at night. Over time curvature of the spine and stiffness of the joints develop. The condition is caused by an abnormality of the MECP2 gene on the X chromosome. A further variant associated with the early onset of seizures is caused by changes in a gene called CDKL5. A further condition, where symptoms of Rett syndrome are present right from birth is caused by changes in a gene called FOXG1.

Google image from curerett.org.uk
Note typical hand-wringing movements.

MEF2C gene deletions/mutations

Several individuals with abnormalities of chromosome 5 involving a gene called MEF2C have been described. Many of these have symptoms suggestive of Angelman or Rett syndrome. Seizures include tremor, seizures, low muscle tone and autistic features. Some children have had birth marks in the form of prominent blood vessels on the skin, and others have had spells of overbreathing and agenesis of the corpus callosum. A characteristic face has been described with a "tented" upper lip. Most children have a deletion of chromosome 5 which involves the MEF2C gene so that the MEF2C gene is completely missing. A few children may have a single spelling mistake within the MEF2C gene.

Photo of child with MEF2C deletion from Zweier and Rauch. Molecular syndromology April 2012.
Note the little birthmarks on the side of the face.

STXBP1 mutation – Ohtahara Syndrome

In this disorder children characteristically present very early in life with a severe seizure disorder, including a type of seizure called infantile spasms, which may initially be very difficult to control. The clue to this disorder is often in the EEG which usually shows a characteristic pattern called "burst suppression". Often, the seizure control improves over time and children start to make some developmental progress. In several children with this condition the movements are jerky and balance may be poor. The condition is not usually associated with any specific characteristic facial characteristics.

Others

This list is not exhaustive; there are several other conditions which are Angelman-like. These include some metabolic disorders such as MTHFR deficiency and other chromosomal disorders.

BOY BITES HORSE

NOTES FROM THE FRONTLINE OF AN ALTERNATIVE CHILDHOOD

Some of you might already be familiar with Boy Bites Horse, *an entertaining blog that reports the life of a (so-caled) Special Needs child. For those that aren't, sit back, buckle-up and enjoy the ride. More at: www.boybiteshorse.co.uk*

So there I was, sitting on a horse.

Why was I sitting on a horse?

I don't particularly like horses. I don't think horses particularly like me. I can't remember ever having expressed an interest in horses, looking at a horsey picture or playing with a horse toy. It's safe to say that horses aren't really my thing.

And yet there I was… around 7 years old and at something called Riding for the Disabled – a pejorative term if ever I heard one – but to be fair they seemed like really nice, friendly, if delusional, people. Their poster said they aimed to provide therapy, achievement and enjoyment to people with disabilities across the UK. And presumably to encourage a closer relationship with a large, furry animal. I just wish they'd done it with someone else.

I mean puh-lease… are we still living in the dark ages? Did the industrial revolution and the invention of the internal combustion engine completely pass these people by? Horses these days are purely a recreational activity and I can think of lots of things I'd rather be doing with my recreation time.

They're all very well when you see them in fields or in cowboy films but the whole horse thing just isn't for me; Smiley and Frowny had tried taking me once before and I was so bored I decided to have a lie down in the saddle halfway through the session. Everyone got very excited by that, but I just didn't see the point of making me trot around on an enormous beast – it's not as if they were going to let me keep it and I wasn't going anywhere fast with two people holding the reins. I'm pretty sure the horse didn't want to be there either – it looked perfectly capable of making its way round without any help from me and quite frankly I thought it had viewed me with a certain amount of disdain. Just like this one.

So: very uncomfortable saddle, very stupid hat (I was having that off at the first opportunity) and two very enthusiastic young girls to trot along with the reins… hello, they seemed to have added a third girl since the lying-down incident. And Smiley and Frowny weren't there to rescue me this time, this was a school trip. Bummer.

I was hungry too, but then I'm always hungry. To make matters worse I could see a toddler in a buggy on the other side of the barn, eating what looked like either a digestive or a raisin cookie… it was too difficult to tell from that distance, but I knew she'd be easy prey if I could only get off the horse.

I was just working out an exit strategy involving a clever deception with the hat when one of the enthusiastic girls made an impressive clicking noise with her mouth and the horse set off at a gentle, strolling pace. Actually this wasn't so bad. Ok, walking round a big barn in circles is a bit of a pointless way to spend the day but I've had worse experiences and the two girls holding the reins seemed to be enjoying it enormously. Where had the third one disappeared to?

Then one of them made another clicking noise and it all went pear-shaped as the horse broke into a trot. To say I wasn't very keen on this would have been putting it mildly… it was g-g-getting a b-b-bit b-b-bouncy! The hard seat was banging me in the booty and the ridiculous hat was slipping down over my eyes so that I couldn't keep my eye on the biscuit. I tried making a noise that I thought was a pretty good approximation of "Excuse me, but I really don't care for horse riding" but one of the dim-witted girls made an incorrect translation and replied "Ah, listen, he really likes it!"

Time to bale out. I decided that stretching my arms out like last time and laying down backwards should do the trick. Hang on, what was this hand behind me? Ah, that's where the third girl had got to; she was there to disarm the ejector seat.

Lying down wasn't going to get me out of this one. I always find that a quick tug on someone's hair gets their attention straight away – although this has stopped working on Smiley because he doesn't have much hair left. I couldn't reach any of the girls so I'll thought I'd try giving the horse's hair a good yank.

Nothing. Well, some ear flicking, but otherwise we were still trotting and now I was starting to feel quite nauseous. This was serious; I was running out of ideas.

Ah well, sorry horse… but emergency measures were called for. When all else fails I can think of only one more thing to do to get someone's attention. A little nip with the teeth is all it takes. And I know this doesn't really hurt because Frowny always makes an appealing yelping noise and does a little dance whenever I do it to her.

So I leant forward and sank my teeth deep into the horse's neck. The horse gave a loud splutter and all the smiles on the young girls faces vanished simultaneously as if someone had turned off a switch.

Anyway they seemed to know exactly what I wanted because they immediately turned the horse around, lead him back to the little set of steps, someone helped me climb down and they removed the silly hat. Result.

My chair was brought – ah, the relief after that saddle! – and someone guided me back to the office. And while my school teacher had a good old ding-dong with the now somewhat less enthusiastic girls, I was close enough to the toddler to offer my help with the uneaten biscuit. Chocolate chip. Bonus.

As I munched I heard the oldest of the girls patiently explaining to my teacher that it wasn't a case of my being 'not quite ready' for horse riding, but that there were never going to be any circumstances under which they'd ever let me near one of their horses again.

The horse looked as relieved as I was.

About The Boy Who Bit The Horse

I am a fourteen year old boy with so-called special needs. Primarily those are: I need to eat (a lot), I like plenty of exercise or I get really bored, I grunt instead of talking, I'm not much of a reader, I'm not too big on personal hygiene, I don't like being too hot or too cold and I like playing with my… well… y'know… so I'm pretty much like every other fourteen year old boy.

I live with a dysfunctional little group I'd hesitate to describe in terms as grand as a 'family'. There's Smiley, Frowny, Flower Girl and Curly Top – thoughts of them sounding like rejected cast-members from *Snow White and the Seven Dwarfs* are not so far from the truth.

There's also a whole troupe of 'companions' (I'm not sure if we're still allowed to use the word 'carers' and anyway this makes me sound more like *Dr. Who*) who are apparently there to entertain me and be at my constant beck and call. I hear not everyone has this courtesy, but I can highly recommend it.

In fact, as I look around me I see there are lots of ways in which I can help people with the benefit of my autobiographical anecdotes. On the whole I think everyone works too hard and worries too much; in my experience of putting in as little effort as possible I still find that people bring me food at regular intervals, provide all the clothes I need, take me wherever I need to go and generally go out of their way to indulge me.

So I dedicate this blog to all those of you who are trying too hard in life.

Slow down. Sit Back. Relax.

All Change to Benefits

As many of you will already know, and may in fact have already experienced, the Welfare Reform Act is introducing substantial changes to the present benefits system. **Donna Holmes** explains.

The changes are due to come into force from October 2013, overhauling the present benefits system and replacing the present variety of means tested benefits such as Income Support and Housing Benefit with one 'Universal Credit' ("UC"). The amount of UC will vary depending on the recipient's personal circumstances, including financial eligibility.

Those in receipt of current means-tested benefits will be transferred to UC on a phased basis between October 2013-2017 (based on current estimates), with new means-tested benefits claimants being awarded UC from October 2013. The aim of UC is to simplify the benefits system and to be fairer across the board. It will also seek to place a benefits cap on household's benefit income at the average earnings or working households in Great Britain. However, this limit will not apply if someone in the benefit recipient's household is in receipt of Disability Living Allowance (DLA) or constant Attendance Allowance. Some other entitlements will also be removed from the cap which could prove important for you and your family.

Personal Independence Payment to Replace Disability Living Allowance

As part of its overhaul of the present benefits system, the Government is to replace Disability Living Allowance (DLA) with a new benefit, which will be known as a Personal Independent Payment (PIP). For present recipients of DLA, there will be no immediate change as they will continue to receive DLA, subject to qualifying criteria, until the Department for Work and Pensions move the payments to PIP – at present there is no definite timescale for this transfer.

Successful new claims for support are likely to be allocated PIP rather than DLA from April 2013 onwards (date subject to change). The main change is that a PIP will be awarded to those people aged between 16 – state pension age and, for the time being DLA will remain in place for those under 16.

PIP will be available at two rates, a Standard Rate and an Enhanced Rate

To qualify for PIP, a claimant will need to satisfy 'disability conditions' – for Standard Rate awards, this will mean that a claimant's ability to undertake 'daily living activities' is limited as a result of their physical or mental condition for the enhanced rate, that participating in those activities is severely limited or the claimant has a terminal illness.

The idea of 'daily living activities' for assessing qualification will be defined by regulations but will include assessments of a claimant's ability to prepare food and drink, address personal care matters, communicate and make financial decisions.

There will also be a mobility component to the PIP award for eligible cases which will be assessed according to whether a claimant is limited or severely limited in undertaking 'mobility activities' for the required period. Again, regulations will confirm the definition of 'mobility activities' but these will include moving around and planning a journey. However, if a claimant is classed as 'unable to benefit from enhanced mobility' no mobility element will be awarded.

The qualification criteria for benefit will be assessed through the provision of appropriate information and participation in a consultation with an approved assessor who will determine whether the threshold for PIP at either rate has been satisfied. A claimant will also need to have satisfied the qualification criteria for at least 3 months before the claim is submitted and be expected to meet them for at least 9 months afterwards unless the PIP is claimed on the basis of a terminal illness, in which case no time periods are required.

It is likely that payments of PIP will only continue for a maximum of 28 days after a hospital admission and PIP will not be payable to those living in care funded by the state.

This overhaul to the well known system of DLA is likely to be challenging for recipients but entitlement to this benefit and related entitlement such as a 'blue badge' can prove invaluable in improving quality of life for recipients.

DYSCERNE Management Guidelines

Dyscerne is a European Commission funded project which aims to improve the diagnosis, clinical management and information dissemination for rare dysmorphic diseases.

These aims will be achieved by:

- The creation of a European network of existing centres of expertise in dysmorphology.
- Development of a web-based dysmorphology diagnostic system (DDS)
- Development and wide dissemination of clinical management guidelines for selected dysmorphic conditions.

The project is a partnership between six existing centres of expertise in dysmorphology from; Belgium, France, Italy, Netherlands, Poland and the UK. The University of Manchester is the coordinating partner for the project. The UK team is lead by Professor Jill Clayton-Smith from the Manchester Regional Genetic Service, and the project support team is based at Nowgen - A Centre for Genetics in Healthcare.

WHICH CONDITIONS HAVE GUIDELINES BEEN DEVELOPED FOR?

One of the aims of the DYSCERNE project was to develop clinical management guidelines for four dysmorphic conditions. These are:

- Angelman Syndrome
- Kabuki Syndrome
- Noonan Syndrome
- Williams Syndrome

WHO ARE THE GUIDELINES FOR?

- Dysmorphologists and clinical geneticists
- Healthcare Professionals managing the day to day care of patients with these rare conditions
- Patient support group coordinators
- Patients, families, carers, teachers

GUIDELINE DEVELOPMENT METHODOLOGY

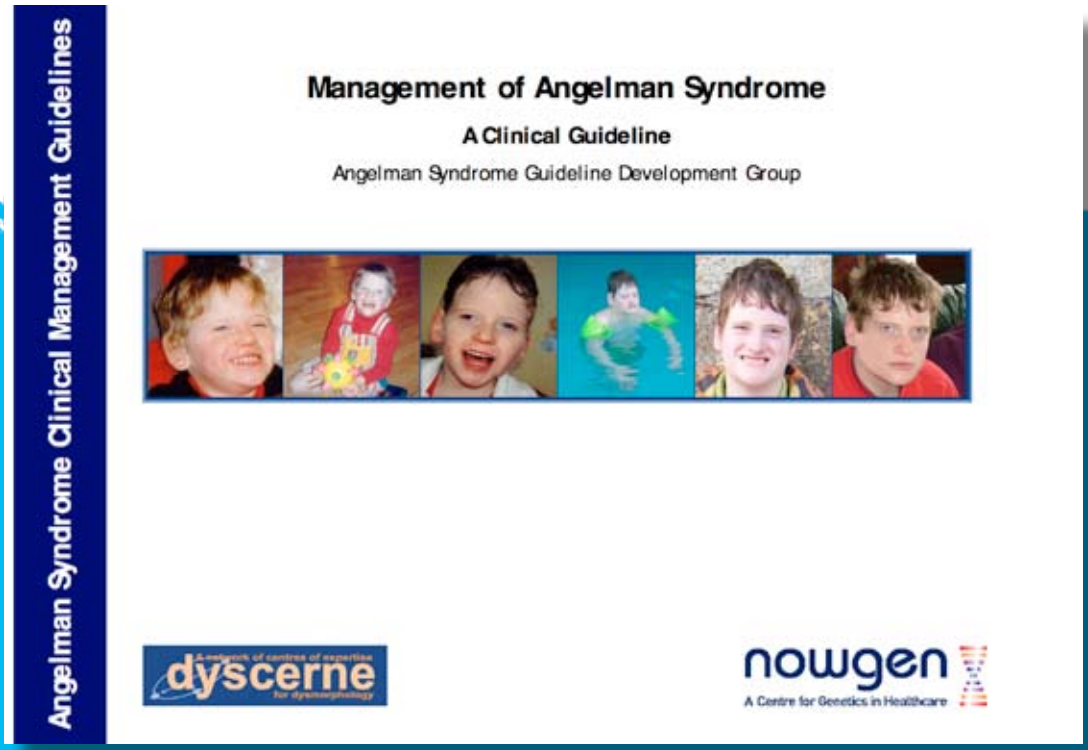
The DYSCERNE guidelines have been developed using a modified Scottish Intercollegiate Guidelines Network (SIGN) approach.

This method uses multidisciplinary groups of practising clinicians to both carry out a systematic review of the evidence, and to reach expert consensus on the optimum management of a specific condition, in order to make clinical management recommendations and produce validated guidelines.

The SIGN approach has been used to develop guidelines for a wide range of conditions including some cancers with strong genetic components (e.g. bowel and breast cancers), but for rare dysmorphic syndromes, there isn't such a rich evidence base, so our guideline development process has placed more emphasis on expert opinion and consensus, whilst still completing thorough reviews of the current literature.

The clinical guidelines for the management of Angelman Syndrome can be found here: www.dyscerne.org/dysc/digitalAssets/0/263_Angelman_Guidelines.pdf

Please feel free to print out the pdf file and share with your team of professionals.



Thank you!

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 all know how important we are as a support to our families within the AS community.

many thanks to...

BUPA Runs

Bupa Great Runs – ASSERT are very pleased to have finally been able to secure 5 places in a number of Bupa 'Great' Runs. The events are:

- **Bupa Great North Run**
- **Bupa Great South Run**
- **Bupa Great Edinburgh Run**
- **Bupa Great Manchester Run**
- **Bupa Great Birmingham Run**

We have one place left for both the Edinburgh and Manchester run in 2013. The minimum sponsorship is £250. If you would like to take either of these places please contact lisa.court@angelmanuk.org

If anyone would like to put their name down for any of these races for 2014 please email lisa.court@angelmanuk.org

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Mrs MacIvor

Assert

Helpline 0300 999 0102
assert@angelmanuk.org

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Nuneaton CV11 9FD