

ASSERT

Angelman Syndrome Support Education & Research Trust



ISSUE FORTY NOVEMBER 2005

REPORT

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REGISTERED CHARITY NO. 1021882

Letter from the Chair

"Time flies when you are having fun!" Well that is how the saying goes, although personally I think it seems to fly most of the time, but may be that is just me getting older. The ASSERT trustees have been keeping themselves busy with a number of projects that I wanted to share with you so that you know what we are doing.

One of our main projects at the moment is we are producing a DVD on AS. The aim is that this will be a short documentary, about 30 minutes, which will be informative, giving a realistic view of AS, but also positive in terms of showing from personal experience that there is life after an AS diagnosis. We feel that this will be an invaluable resource both for new families and also anyone wanting to know more about AS. Our aim is that this should be released in time for the conference in 2006.

Talking of the conference, we are in the early stages of planning our 2006 conference. More details will follow shortly, however we hope that this will yet again be a valuable source of information and support. We are aiming that not only will the program provide useful sessions on topics relevant to you, but also plenty of time to chat and with others.

Many of the leaflets that we have sent out in the past, and the tri-fold leaflets that we make available for you, have reached the point of needing updating, so that is another major task that we are undertaking. Obviously these things do not happen overnight, but we are hoping that the new versions will be even more helpful, as well as having more up to date information.

We are also hoping to do some of our own research. This research will be looking partly at incident rates of AS, so that we can update our information, but also looking at more of the specifics in terms of how AS individuals are affected in many different areas. This is something that we will need your support in so watch this space.

Thank you to everyone who took the time to complete the questionnaires. This is an invaluable source of feedback which not only tells us when we are getting things right, which is always nice to know, but also helps us to realign our sights when we could do better. It also has given us some very important indicators as to the areas that we need to concentrate in the future so that we are able to provide you with even better ongoing support. As trustees we will be discussing the issues raised and hopefully you should see some more action as a result in the near future.

I want to highlight an interesting point that came out of the questionnaires. In answer to what people would like to see more of in the ASSERT report, 31% of you answered you would like to see more family reports. Then, in response to, "Could you write an article?" 52% said yes! I know there are times when we struggle to find useful and relevant content for the newsletter. So guys, you have said you want it, and you have said you can do it, so please send us in your articles/stories. They don't necessarily have to be great epics, often it is just nice to find out how other members of the ASSERT family are getting on.

Without you ASSERT would not exist. After all, ASSERT is an organisation that exists primarily for its members. So I would encourage you that if you have any comments, or want to get more involved, then please contact us. There are many ways, large and small, that you can help. If you have any special skills that you think would be useful to ASSERT then please make yourself known to us.

Just to show that I am occasionally ahead of the game, although I am not sure my wife would always agree, I would like to take this opportunity on behalf of all the trustees to wish you a Happy Christmas and a Happy New Year and we look forward to meeting many of you at our 2006 conference.

Jeremy Webb



HELPLINE

ASSERT Families/New Diagnosis/Support Line

01268 415940

Christmas Gift Ideas

We are approaching the time of year that all our children love, and AS children/young people are no exception – how will we protect the Christmas tree this year? Yet if you are anything like us it is also a time which can produce much heart ache as we try and work out what to buy. Do we get something which they will enjoy and is safe, or do we buy something that is age appropriate. And what suggestions do we make to relatives who want advice as well so that they do not buy totally inappropriate gifts. In previous years we have made visits to large toy stores to get ideas for all the kids, only to come out feeling depressed that the only appropriate toys seemed to be baby toys. The other side is that you go to providers of specialist toys and equipment, but then you pay for that privilege, often excessively. So what is the answer? Well we thought we would give some ideas of this that we have found that have worked us. Ruth is 8, and our suggestions are things that we have bought, that she loves, that are safe, and that have survived her attentions.

1. **V-Tech Discovery Tree** – Available at most large toy stores, retail price £24.99, although you can get it cheaper than this. Five balls that are posted into the top of the tree, whirl round the trunk, setting off lights and sound, especially at the keyboard bit at the end. Plenty of buttons to push and flashing lights! Ruth even managed to play with this one with her arm in plaster.
2. **Bubble Tube** – Argos call it a “Bubble Fish Lamp”. Whilst available from specialist retailers at expensive prices, you can get this for £24.99. Would require some additional securing, but we found that a couple of Velcro straps secured high up on the wall sufficed.
3. **Disco Ball** – Many varieties are available. “Trendy” gadget type shops are good as they are often selling them cheap. You can get space type ones which have extra fibre-optics at the top which are even more visually pleasing. Not a hands-on toy.
4. **Buckaroo or Ali Baba Bucking Camel** – or other varieties. Great for anticipation type games. Whilst Ruth is not good at putting things on, she almost bursts with excitement the longer it goes on. Good for encouraging turn taking as well. Prices are about £9.99.
5. **Trampoline** – Vast range of shapes and sizes which seem to range from one for under 8’s (£15 ish) to adult type (£80 ish). Might need additional safety net and to secure into ground. Ruth loves sitting on it whilst someone else does the bouncing but is also fairly adept at bouncing herself in a sitting position.
6. **Bath ducks** – Many varieties, but we have found that the glow-in-the-dark or colour changing ones are particular popular. Also very chewable.
7. **UV Light** – Originally we almost discounted this idea as specialist shops were so expensive, but then we found that Maplin sold one for £14.99, which was significantly cheaper. Anything white glows amazingly, brought new

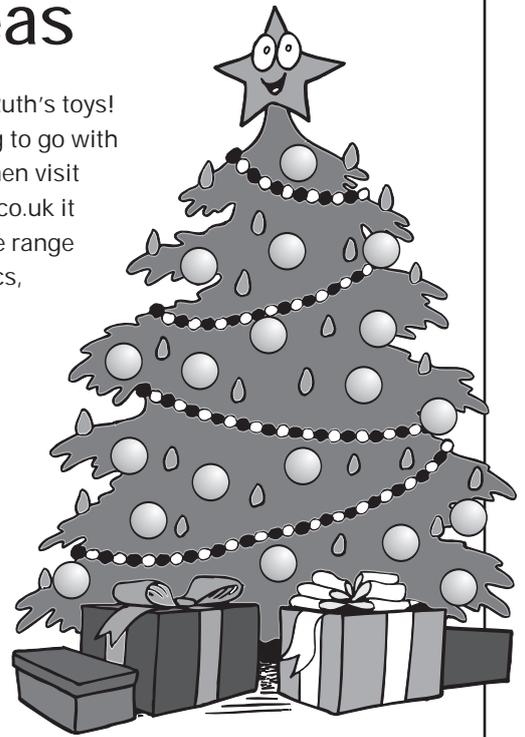
- life to some of Ruth’s toys!
8. Want something to go with your UV Light then visit www.glowshop.co.uk it has an extensive range of paints, plastics, objects, etc. all which response fantastically to UV lights. We bought a number of plastic strands of different colours and suspended them from some net

curtain wire to allow some pulling. With the UV light they look excellent. Also bought some paints, so if you have an artistic member of the family...

9. **Tonka range of trucks, emergency vehicles and diggers.** OK, don’t tell Ruth as she will probably be getting something from this range for Christmas. Yet our kids, especially Ruth, spent ages on Saturday in the shop playing with these. Lots of buttons to push, lights to watch, noises to hear and wheels to spin. Range from about £8 upwards. We were amazed at how cheap they were, expected Tonka to be more expensive, and at how much they did. OK, so they are now plastic rather than the metal ones we remember, but that will probably save a few teeth.
10. **Musical instruments** – Several of the toy shops do a wide range of instruments, including shakers, drums, tambourines, jingle bells and cymbals. Whilst excessively annoying at times, especially as you child becomes more adept at playing them, we have been surprised at the punishment these can take and still survive.

Well we hope that you find this useful. It is just a matter of looking around, I know, not something you really want to do at Christmas. We are slowly learning to keep our eyes open throughout the year. You may find it helpful to chat to your child’s therapists or school to get an idea of skills they are working to encourage. That is why we got the Buckaroo and Posting toys. For sensory equipment such as lights etc, try some of the cheap electrical stores such as Maplin or Tandy, you will be amazed what you can pick up. If you have any successes in this area, please write in and let us know. We hope that you have a Happy and Noise filled Christmas!

Claire and Jeremy Webb



Great Stocking fillers!

ASSERT Wristbands

Now you too can support ASSERT and wear a fashionable wristband in the process! They are available in blue and bear the wording Angelman Syndrome Support Education and Research Trust – we hope to raise awareness and need you to support us by selling to family and friends – and any other interested parties – for bulk orders please contact Rich Williams, for individual orders please send £2.00 plus 35p p & p per band to: ASSERT Freepost PO Box 13694 Musselburgh Scotland EH21 6XZ

God's Special Child

I'm sending you a special child to cherish in my name,
For you to love with all your hearts, and teach her just the same,
For she is not like other babes, nor she will ever be,
But can you love her just the same, and take good care of her for me.

She may not see, or hear, or run, or learn as others do,
But she'll be yours and she will take her guidance from all of you.
The road is hard, she'll break your heart, you'll cry a million tears,
But I promise when she smiles at you the pain soon disappears.

I know you'll cry, 'why her? Why us?' but I needed teachers true,
And that is why with care and trust, I've selected you.
So please don't turn your back on her, although she may be slow.
If you'll accept her as she is, then together you will grow.

She needs to learn the skills of life, for that I've chosen you.
And with your love to guide her, I know you'll see her through.

Don't try to see the future, I promise that to none.
Just live each day for all it's worth, and enjoy my special one.

CASS Conference

End of July 2006 London Ontario –
for more details contact CASS
www.angelmancanada.org

ASA Australia Conference

This was held from 30/09 – 02/10/05
and we hope to bring you some
information about the conference next
ASSERT Report

Christmas Cards

It was very disappointing not to receive any entries to the Christmas Card Competition – hence no Christmas Cards for sale this year – however, whilst you are all in the Christmas mood, please get your children to draw a picture for NEXT year – Christmas 2006 – the age categories are: 3-5 years, 6-8 years, 9-12 years and 12-15 years with no limits for AS Please send in artwork on a plain sheet of A4; entries will be judged by the trustees and the winning designs will be displayed at the conference, where the cards will be for sale – closing date will be 31st March 2006

Please note that
the deadline for
the next edition
of the
ASSERT Report
is 00 month 2006.



Udaw – supporting working carers –
produces a useful leaflet about working
and juggling caring – leaflet no 343
'phone 0845 6060640 email:
parentsandcarers@usdaw.org.uk

Disabled Toilets

ASSERT has heard from Diane Brown via email – she asks:
I don't know how many other parents have the same problem as me about changing their child when out in public. The problem being the substandard facilities within disabled toilets. I was advised to write to the following people: Part M Building Regulations Division Office of the Deputy Prime Minister 26 Whitehall London SW1A 2WH.
I have had no reply and also The Chairman British Standard Committee B/209/9 British Standards Institute 389 Chiswick Road London W4 4AL. We need to explain our situations fully and ask if it can be included in their next review. Perhaps if enough people write we can achieve a result.

London Marathon



For all you fitness fanatics don't forget that ASSERT has 5 Golden Bond Places for the London Marathon in April 2006 – if you have applied for a place and been unsuccessful and you would like to enter and raise some money on behalf of ASSERT, please let us know. The cost of places is £1000 – usually covered by your sponsorship – phone Sally Walburn for details 01268 415940 It is open to anyone family or friends who can help – training usually begins Dec/Jan.

Welcome to my Home... I think....

This piece was written by Sharon Burleson Clarksburg WV USA and was given to me some years ago. I have adapted it slightly – we can all relate to this scenario!

Hello! Welcome to my home. I think, I mean, maybe you are welcome...I am not sure yet. When I get to know you, I'll know for sure.

My child is disabled, and I need help to do all the things he needs done. So I need you. He needs you too, because he gets worn out and bored by me and sometimes dislikes me about as much as sometimes I dislike him (please don't start making judgements about me – we have just started. It's just that I'm honest, and as much as he is the sole reason for my existence, there are times when both of us wear thin).

Your service sent you here. I called for help, but I don't get a choice of who comes into my home and my life. You come at your convenience, usually between 9.00 a.m. and 3.00 p.m. Monday to Friday. I'm on my own evenings and weekends, when my other children tug at me and want and feel slighted and offended and I feel stretched to the limit. You 'phone me and tell me you are coming on Tuesday morning so I put the stack of unanswered mail and the unpaid bills in the cupboard with the cereal bowls, race dirty and clean clothes up and down the stairs, shove toys and odd shoes in cupboards and under beds, and run the gauntlet with household sprays to get fingerprints off everything, and then you call and tell me you have to cancel because of a meeting. Of course I understand, yes, that's fine, Friday afternoon? Well, I was going to try and get to the library and maybe take a nap...what? Oh. That's the only time you have? Well, OK I know it's important that you come. And we really need the help. Fine. Friday at 1:30. We'll be here.

My husband resents people coming in and out of our home. He says he feels as though he is living in a goldfish bowl. He says getting help means sacrificing our privacy and spontaneity. He can't scratch his stomach as he walks down the hall in his shorts anymore. Now he has to have clothes on, suck in his gut and put on company manners. And he really hates it after you leave, because sometimes I cry because I feel inadequate and stupid and foolish. Sometimes it's nothing you say or do, it's just your perfectness unsettles my motherhood. Sometimes when you are great I feel threatened and because of others who came before you, I feel judged and talked about, and as though you have met with others and have developed a plan to implement on me.

I can't always tell when you are real. But my son can. So watch him. If he responds and welcomes you, then I set aside my needs and cares and let you have everything I have, including my son. I have to trust you because he trusts you and looks forward to your knock at the door.

What? Oh, good grief! I forgot your paperwork again! Wait, I know it's here somewhere. I was working on it last week just after the hot water heater burst and right before my husband came home laid off. Wait...I think I wrote on the back when the bank called about the deposit to cover the overdraft. Yes! I found them! Right behind the peanut butter...wait, I'll just wipe them off a bit.

You know, I used to be normal. I used to have control of my life, my time, my home. Having a disabled child turned my life upside down. My priorities changed. What I would settle for changed. What I would ask for changed. Who I would accept changed. All that changed because my child needs things and people and ideas and funding. So my life consists of meetings, regulations, documentation and paperwork, social workers and agency people, policies and procedures manuals and administrative decisions, delays and rumours of delays in money, people turning up when arranged, people leaving, and people turning up when not needed.

Please don't judge me. And I'll try not to judge you. You see, in the long run, if I don't measure up I am still his mother. So we are all stuck with each other, and I'm willing to try and make the best of it. Help me grow, help me to become better. Accept me as a person, not some perfect saint. I really do know my child better than anyone else, so help me express that and put it to best use. Walk alongside me, not to judge me, but to understand my role within the heart of my family. Give me tools and words and people that, like pieces in a jigsaw, interlock to allow for my strengths and compensate for my shortcomings.

Please don't push me to the limit, because if you do, you'll see me at my worst: short tempered, impatient, inflexible, and emotional. I'm no good to my son either. Each one of us has that fine line. I try to recognise when I am approaching that line, and usually that's when I am at my most irritable and complaining to you. Please realise that one facet of me is the tired miserable mother, just as real and acceptable as the superwoman who overcomes unbelievable obstacles. There are sunny days and then there are thunderstorms, all part of a temperate climate.

Well...anyway, hello. Welcome to my home...I think.

Where to park in London?

Blue badge parking is a great idea as long as you know where to find it. Transport for London has published the London Blue Badge Guide. This 96 page book features a fully indexed street map of central London, on which are marked the locations of all Blue Badge parking bays. Additional information includes an accessible London Underground map, parking at all London Airports, Congestion Charge and much more. The guide is available from The Blue Badge Network Tel: 01384 257001 priced at £4.50.

ASSERT Website

www.angelmanuk.org

ASSERT Email

assert@angelmanuk.org

Seen In

- Feeding aprons and dribble bibs, collars and kerchiefs ideal for use in SLD schools and the home.
- Designed by a parent
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Watchdog Warns Over Medication Name Confusion

The US Food and Drug Administration (FDA) and the pharmaceutical company AstraZeneca have sent letters to health care professionals in the United States reporting dispensing and prescribing errors connected with the anti-epileptic drugs Topamax and Tegretol. The FDA reports medication errors due to the similarity of the names of Topamax, Tegretol and Toprol-XL, a drug licensed for the treatment of hypertension and angina. These reports include instances where Toprol-XL was incorrectly given to patients instead of Topamax, Tegretol, or Tegretol-XR, and vice versa, some of them leading to serious side effects. In a letter to professionals, AstraZeneca has asked doctors to take extra care when prescribing medication, suggesting that prescriptions should be legible and use both the brand name of the drug and its generic name. They have also asked pharmacists to take extra care when dispensing medication.

Information from Epilepsy Action News:

Vagus Nerve Stimulation "Effective" In Treating Childhood Epilepsy

New research suggests that vagus nerve stimulation (VNS) is effective in treating children with epilepsy whose seizures have been difficult to control by using medication.

In the United States VNS is currently only licensed for use in people over the age of 12, however, a study by researchers at Columbus Children's Hospital has demonstrated that the system can be effective in reducing seizures in younger children.

The study followed more than 75 children with epilepsy between the ages of one and 17 who had surgery to implant a vagus nerve stimulator. The results showed that 59 per cent of the children did not have any further partial seizures and that hospital visits relating to the child's epilepsy were reduced by 41 per cent. Only five per cent of the child had side effects severe enough that they had to be withdrawn from the study. Dr Juliann Paolicchi, director of the hospital's Comprehensive Epilepsy Centre, commented that the reduction in the amount of time spent in hospital was of major benefit both socially and financially to the children and their parents. As part of the next phase of her study, Dr Paolicchi will look at the data for patterns in children with one type of epilepsy versus another and whether the outcomes differ by age.

European Approval Given For Keppra Use in Children with Epilepsy

The European Commission has approved the use of the anti-epileptic drug Keppra (levetiracetam) in the European Union. Its licence will allow it to be used as an add-on therapy in the treatment of partial-onset seizures in children from four to sixteen years of age. Approval was based on a clinical trial, the results of which were most recently reported at the European Paediatric Neurology Society Congress in Gothenburg. The clinical trial was of 198 children with partial-onset seizures whose epilepsy was not controlled by other anti-epileptic drugs. The results showed that 45 per cent of those who received levetiracetam for 14 weeks had at least a 50 per cent reduction in seizure frequency, and seven per cent became seizure free. Dr Tracy Glauser, director of the Comprehensive Epilepsy Program at Cincinnati Children's Hospital and principal investigator of the study, commented: "More than 25 per cent of children with epilepsy experience treatment resistant seizures or intolerable side effects from medication. Keppra was effective and well-tolerated by children in the study, many of whom had tried multiple anti-epileptic drugs prior to trying Keppra."

Behaviour Strategies

Strategies that have worked with some of the children with AS that I have taught:

1. Change behaviours with reinforcement, as much as humanly possible remove all attention away from undesirable behaviours
2. Behaviour is a form of communication, find out what purpose it serves and replace with a different behaviour that serves that purpose.
3. Teach what is functional and makes sense
4. Use the child's natural interests to teach new skills
5. Repetition
6. Your student will already have a method of communication, use it and expand it
7. Make sure your student knows how much you like and respect him/her
8. Enjoy

Lisa Gleeson (from the Angelman Listserve)

BDF Newlife

I have some information that may be of interest for your next newsletter, it's a charity that I have found that has funded some accessories for our daughter Ella who has AS. Ella will be 3 in September, and last month we were awarded a Maclarens buggy as she was too big for her previous pushchair. When we collected the buggy we were told that although this was provided for free of charge by our health authority, no accessories would be provided.

My mum saw an article in our local paper about a charity called 'BDF Newlife' which amongst other things, offers grants for basically anything you want, the only stipulation being that you cannot get funding elsewhere.

I called them and asked if they would be prepared to fund the accessories to the buggy, they agreed, so I completed a very simple application form, my health visitor signed it and they phoned within a couple of days to say that the application was approved and now the goods are on order. I have asked for the sun shade, rain cover, shopping basket and carry case (total value approx £100).

In their literature they sent me, there are examples of other funding that has been provided, for children with all sorts of conditions. The smallest amount was for a 4 year old girl whose nappy would leak each night, so they provided extra bedding and pyjamas at a cost of £150. The largest amount was for a 6 year old boy who needed a specialist cot bed and mattress at a cost of £4415.

They also have a helpline for support (for parents and professionals) and a web site offering information. I have not used any of their other services, purely the grant service, so I cannot comment on these services.

But I would highly recommend this charity to any other AS family as they were extremely friendly and helpful, the application form was very straightforward and it was approved as soon as they received the details. Telephone number is: 01543 468888 Website is: www.bdfnewlife.co.uk Helpline number is: 08700 70 70 20 Address BDF Newlife, BDF Centre, Hemlock Way, Cannock, Staffordshire, WS11 7GF (UK Charity No 1001817)

English Health Service Users Sought for Survey

People in England are being invited to tell the National Health Service what they want in the future from health and community services. It is hoped by the Department of Health that the consultation exercise, 'Your Health, Your Care, Your Say', will allow thousands of people and hundreds of organisations to take part. Participants will be asked a number of questions about what they want from community health and social care services in their everyday lives. The three questions that the public will be asked during the consultation are:

1. How can people look after themselves and how can we help you take care of yourself and support you and your family in your daily lives?
2. When you and your family need help and support, how, when, where and from whom do you want to get it?
3. How can we help you get the right services, when you need them, and ensure your care and support is properly coordinated?

Participants will also be asked to debate other topics and ideas including how to help older people remain independent, how to tackle root causes of ill-health and whether people should be allowed to register with a family doctor near their workplace. Marking the start of the consultation, Patricia Hewitt, secretary of state for health, said: "This exercise is a chance for us to see democracy in action and really listen to what people want and what they don't want. More than five million people in England live more than 10 miles from a hospital and around 90 per cent of all the contact that people have with the NHS and care services takes place in the community. It therefore makes sense for us to focus our attention on these services and ask the public for ideas on what they should look like in the future."

The survey can be completed online at www.nhs.uk/yoursay.

Information from Challenging Behaviour Foundation

Problems with sleep?

Many families do not report their disturbed nights to professionals because they do not imagine they would be able to help. True or False?

Many professionals do not include sleep issues in their assessment of needs. True or False?

The Handsel Trust is collecting information and raising awareness about sleep issues for families with a child with special needs. If you are a parent/carer or professional who has experience of sleep issues, contact Peter Limbrick, Tel. 01905 23255 or Email p.limbrick@virgin.net.

ASSERT Website

www.angelmanuk.org

ASSERT Email

assert@angelmanuk.org

Sefton Carers Club

The Sefton Carers Saturday Club is a group of full time family carers of people with severe learning difficulties. For more information contact George Cureton, Telephone 0151 474 7725 or visit www.carersonsaturday.com

Contents of the Newsletter

You will notice that the pieces in this newsletter are drawn from a wide source of places. This is tremendous, and we hope you will agree that it makes interesting reading. However, while we are keen to promote discussion and to pass on many 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 the trustees of ASSERT.

Lisa Court

Thanks to Finn Emmerson for giving us this information from Mencap News.

New guidance strengthens carers' rights 31 August 2005

The Department of Health published new guidance in August 2005 to strengthen the rights of carers. This guidance accompanies the Carers (Equal Opportunities) Act 2004 and sets out the issues for local authorities under the Act, including the duty to inform a carer of their right to a Carer's Assessment as well as work and leisure opportunities. The 2004 Act made three main changes to the law on carer's rights, including requirements that:

- local authorities inform carers that they can have a Carer's Assessment
- Carer's Assessments must consider whether a carer wants to work or take part in any education, training or leisure activity
- When a local authority requests another public service provider – such as an education, housing or health body – to give assistance in planning services for a carer, that the public service must consider this request.

The new guidance also updates the Carers and People with parental responsibility for disabled children guidance which was published in March 2001 to accompany the Carers and Disabled Children Act 2000. Find out more Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 Combined Policy Guidance www.dh.gov.uk/assetRoot/04/11/78/66/04117866.pdf Carers (Equal Opportunities) Act 2004 www.opsi.gov.uk/acts/acts2004/20040015.htm

Contact Sheets

A big thank you to everyone who returned the contact sheets so we can update the records – it was a really useful exercise and it has allowed us to update phone numbers, addresses, names, partners, and diagnosis information. If you have any changes in your life that will affect ASSERT records, please let us know – we know it won't be the first thing you think of, but when the dust settles it is helpful for us to have this information. Please be assured that we handle everything with the strictest confidence and we do not pass on your details to any other person or organisation without your permission. If you haven't returned your form yet, we are still interested so please still send it in to us – there is no deadline but the sooner the better.

More new trustees!

It's great that we have another couple of trustees joining us – Wendy Paine who I am pleased to say along with Gerry is representing the north of the British Isles – it's good to have the northern perspective to keep us southerners in order! Lisa Court has agreed to take over the treasurer role and we would like to take this opportunity to thank Nick Bartholomew for his dedication to this task over the past few years – he stepped in to the breach when Elaine Sears resigned, volunteered at his first meeting and has been doing his bit for ASSERT ever since. It is with great relief we welcome Lisa and that we can finally let Nick off the hook! We wish Nick, Sharon and Liam well and hope to see them again in the future – perhaps at the conference – we will miss you Nick!

Lisa Court

My name is Lisa Court. I am 33 years old, married to Craig, we live in Warwickshire and we have two children: Ella who is 3 and has AS and Jacob who is 18 weeks.

Ella was diagnosed with AS at 15 months old. When we were given the diagnosis, we weren't given any information on the condition, or any pointers on where we could turn for help or advice, we were even told Ella had 'limited life' because of her condition (which is obviously not true). We were just left to get on with it. As soon as we found out about ASSERT, we immediately signed up and our first contact was the conference in September 2004. I have to say, it was a very emotional and difficult weekend, as it was the first time we had met any other families but it was just so nice to realize that we weren't alone, and that there are others out there going through exactly the same as what we are going through. So that's why I have agreed to become a trustee of ASSERT, to help continue the excellent work that has been done so far, and to try and ensure that everyone gets the help and support they need as I know that without it, we would all be a lot worse off.

Wendy Paine

I live in York with my husband Mike and our daughter Natasha, who is 3 and was diagnosed with AS (deletion) at 18 months. Mike has another daughter, Gemma, who is 9 and spends weekends and holidays with us. Before Natasha was born, I worked as a Business Implementation Consultant for a software company who produce HR and Payroll systems. Prior to that, I had almost twenty years experience working in various personnel and training roles.

When Natasha was 8 months old, she had her first (obvious) seizure. That, combined with the lack of sleep since she was born, made Mike and I decide that it was not practical for us both to work and I have been a full-time mum since.

The past three years have been a massive learning experience for Mike and I, as neither of us had any significant experience of disability. We have been extremely fortunate in our health professionals, including our GP, Paediatrician, Epilepsy Nurse and Neurologist, who are all incredibly supportive. Our experience with other agencies, in particular, Social Services, has been far less positive and we now realise how resilient and persistent we, as Natasha's parents, have to be.

It is this difficulty in accessing and sometimes even finding out about the range of services/support available, which made us realise how important an organisation like ASSERT can be. Whether it is for information, advice, or just to share some of the anger and frustration caused, not by Natasha, but by the system we have to work within, it's good to know there is somewhere to go. The conference last year was also hugely appreciated by us and was particularly positive for Gemma, who was able to see other people with AS and to make friends with children in similar circumstances.

In view of this, it felt important to become involved and I hope that I can help ensure ASSERT continues and develops its good work.

Family Stories



Come on in the water is lovely!

In the last ASSERT Report we gave you information about Hendra Holidays – one of our families visited the park in the summer and met up with Matt Way and his family who also are members of ASSERT, Rich Williams wrote:

Following the article on the Hendra Holiday Park in Newquay in the last issue of the newsletter, I thought you might be interested in the details of our recent stay with Matt and his team.

We booked the holiday at Hendra before Matt and his family joined ASSERT, so we were very much experiencing the small world syndrome again. Having bought a trailer tent at the beginning of the year, we set out on our first family holiday, not really sure what to expect of the park, or Holly's (our 3 year old angel) reaction to it. We needn't have worried, as the facilities were excellent, as was the service we received from Matt Way and the large team working there.

The site hosts both touring caravans and static caravans and has a large swimming complex with both indoor and heated outdoor pools. There are plenty of options for siblings with arcades, adventure playgrounds, soft play areas, trampolines, children's' activities and a full programme of family entertainment. The toilet/shower facilities were beyond our expectations, with disabled/family changing shower cubicles in both male and female blocks.

Most of the facilities are on one level, with the exception of the pool complex. This has a disabled lift. Even the bars are wheelchair accessible.

If this kind of holiday appeals, then I would seriously recommend Hendra. It lies about 2 miles from Newquay town centre and the beaches and is close to the A30 for exploring and visiting the rest of Cornwall if that's your thing. I don't think Holly wanted to come home. We're already considering returning next year.

Fundraising

Thanks to all of you who continue to support us – we are building funds now for the conference and the DVD film so this is where the main bulk of your donations will be going for the foreseeable future, unless of course you would prefer it to be used for another purpose.

Mrs H Amphlett-Carter
Mr A R Ayers
Mr & Mrs J A Bailie-Hamilton
Mr R J B Blake
Jim Brennan
Mrs Bruce – Wedding of Caroline & Gordon McMillan
Mrs L Buchan
Mr J G Capen – In memory of Mr R D Dyson
Sian Cartwright
Gwendoline M Cash
Charities Trust – Direct Payroll Giving
Dr W J Charles
Anthony Clements
Mr & Mrs Corbally Stourton

Steve Cupples – Wedding Of Caroline & Gordon McMillan
R Cutajar
"Dragons" Explorer Scout Unit
Sue Donnarumma
Mr Edward – Wedding Of Caroline & Gordon McMillan
Joanna Fern
Rev & Mrs T Girling
Gavin Graham
Mr & Mrs P Hawkins
Julia Hughes
Mr M Lewis
Dario Marchiano
Mrs Matthews
Mrs A Mc Bride – Wedding Of Caroline & Gordon McMillan
Michael & Nicola McIntock
Gordon & Caroline McMillan – in celebration of their wedding
Mr K I C McMillan – Wedding Of Caroline & Gordon McMillan
Millward Brown UK Ltd.
Mrs E H Murray
Mrs Susan Parr

Od – Quarto Design
Ranleigh Masonic Lodge
Thelma Ray
Royal Sussex Masonic Lodge No.342
S Holt Ladies Club
Sanderson Ltd
Mrs A Simpson
D M Skinner
Dan Spencer
Stuart Holmes Ltd
Mrs H M Tait
The Tuesday Afternoon Club – Mrs Webbing
Miss S Watchorn (London Marathon)
Mrs A E Webbing
Mr D M J White
Mr C R C Wild
Joanna Wild
Rich & Les Williams
Mr D White – Wedding Of Caroline & Gordon McMillan

How Bonni Spent her Summer!



No, I'm not getting out!

Hello friends thought that you might want to hear what Boni has been up to this summer, so I have written it as I think Boni would if she could!

Boni Archer age 35 summer 2005...

My summer was lots of fun, I went to Brean Sands in Somerset with Mum, Dad and brother Alex, we stayed at Pontins, we've never been to Pontins before, the pool was lovely and warm, the people were friendly and they had a big Jacuzzi too, so with the entertainment at night we really didn't have to worry about the weather, I loved all the shows and discos, it was a good holiday.

I went to a wedding and I enjoyed getting all dressed up for it, I even let Mum put dangly earrings in my ears and I even kept my bangles on and I didn't lift my dress or show my tummy so I was really good!

The very best thing that happened this summer was WE GOT A JACUZZI! I love it! As soon as Mum or Dad get me up wash and dress me the first thing that I do is reach for my arm bands and cozzie, I keep moaning and moaning until one of them puts me in it, Mum got some ballpool balls for it so I am in heaven! I heard Mum saying that she was going to put my bed into it, but I think she was joking really.

Guess what I did to Mum last week? We were coming out of the supermarket and it was very windy so Mums hair blew all over her eyes, I had a new leisure suit on that. had a tie waist, Mum didn't realise that my trousers had untied and had fell down to my knees pulling my pants with them! I was laughing and Mum thought that I was laughing because of the wind! Then someone shouted to Mum" excuse me, your friend has lost her pants!" Mum very quickly stopped, pulled my trousers and pants up and without looking up she quickly got us both into the car, her face was ever so red, I don't know why? I was laughing so much I had tears running down my face, I don't think that Mum was as tickled as me, maybe if she showed her bum to everyone she might see what fun it is! I think I'll try that trick again next time its a windy day.

This was a little bit of my summer, From Boni (still splashing) Archer.

Conference 2006 6 – 8 September Loughborough University Leicestershire

Many of you will be eagerly awaiting conference information – the details will be mailed out in January/February to every family, they will be sent at the same time so everyone has a fair chance to book. It is essential to book early. The programme will be along the lines of the last three conferences, but with a little more social time this time! The costs are to be decided, it may be a little more expensive than last time but we will endeavour to keep cost to a minimum. Places will be limited and allocated on a first come, first served basis. Last time we had to disappoint several families and some families had to stay off site. We appreciate that it is quite early to make a commitment but we will have a reserve list in case of cancellations! Prompt payment will also be required and we will have a strict policy on this as last time we received payments beyond the deadline.

Contact Register

We will be preparing the Contact Register from all the latest updated forms and previous information. Please remember that when you receive your copy, it is a resource for families only and to be used solely for the purposes of contact. If you need support or need to contact families for other reasons, please get in touch with us at ASSERT.

Can you Help? Are you a parent of an AS Adult or young person?

We know that most of our information in the ASSERT Report, relates to children and children's services and this has been highlighted in our recent survey. I do try and include generic information but as I do not have personal experience of adult services yet, it is not easy to find articles to fill this gap. To an extent I believe there are probably more services/grants etc for children than there are for adults. However, so that I can address this issue I need any information from you which you feel would be helpful to other families, then hopefully, I can re dress the balance. Please email articles or links to assert@angelmanuk.org If you have no access to the Internet, please send to the ASSERT Free post address.

Questionnaire Results

Claire Webb has painstakingly gone through all the forms returned noting your comments and scores. Thanks for all the supportive remarks about our service and Sally thanks you for all the positive feedback about the support she has given individuals over the years with ASSERT. It seems we are doing a good job – but as always there is room for development and improvement. It is very important that we have your feedback and Claire has prepared the following to report back to you.

We would however point out that some of your requests for information and meetings and extra support need to involve you! We cannot produce family stories out of a hat or organise regional meetings without your help! Likewise if you want more information for example on adults or schools – we need your feedback – we don't know what support is out there unless you tell us! We are a self help organisation and can learn from each others experiences, all trustees are parents of AS children and young people and do this on a voluntary basis. We would love to have paid staff but this involves extra resources and management from the trustees and at this moment in time is not an option for us. We have limited resources (particularly time!) and we are not trained or experts – everything we do is to support you and your families in a way that we would like to be supported. Perhaps if you have been helped by ASSERT it is time for you to thinkrather than what ASSERT can do for you.....what can you do for ASSERT?

Over to Claire.....

Thank you so much to all who replied to our recent questionnaire. This is an invaluable way for us to see how we have been doing, and to help us shape the work we do in the future. Whilst we will run questionnaires again, please do not wait until the next one before making any comments about the work we do or the support we provide. We are always looking for ways to provide better support and information. Anyway, here are the summarised results of the survey.

1. Initial Contact

1. How did you find out about ASSERT?

Hospital: 32%

ASSG: 13%

Internet: 10%

Other parent: 8%

Child Development Centre: 8%

Social Worker: 5%

Others: Contact a Family, Friend, Health Visitor, Other family member, GP, Physiotherapist, Geneticist

2. How helpful did you find ASSERT's information?

5: 72%

4: 22%

3: 6%

2: 0%

1: 0%

3. Would you have liked more information?

Yes: 24%

No: 76%

Topics:

Anything: 16%

Products – leisure, toys and equipment: 12%

Communication: 8%

Behaviour: 8%

Transition: 8%

Others: Scoliosis, Feeding problems, Sleep, Midazolam, Rectal Diazepam, Video/DVD, Professionals, Male adolescence, Relevant services to contact

Comments: 6 people commented fearful, too much information and would not have wanted to know any more. More information eventually, but not yet.

2. ASSERT Report

1. Do you receive the ASSERT Report?

Yes: 100%

No: 0%

2. Is the information informative and friendly?

Yes: 99%

No: 1%

3. What would you like to see more of, less of, or topics on, in the ASSERT report?

All responses were for more on:

Family stories: 31%

Choices for adult life – i.e. 24 hour provision: 6%

Agony aunt: 5%

Anything on older AS individuals: 5%

New member's information: 5%

Long for the news letter to arrive: 5%

Equipment: 3%

Holidays: 3%

More on 18-30 age group: 3%

Research projects: 3%

Sleep: 3%

Residential schools and colleges: 3%

Others: Funding and benefits, Therapies, International groups,

Adaptations, Events (such as London Zoo Disability Day),

Menstruation, Achievements my AS individuals, Will writing,

Statementing and statements, Parents notice/sale board,

Medication and drugs, Behaviour management, Independent

living, Nutrition, Transition (school to adult successes), Care in the community, Respite, Special Olympics, Future planning,

More colour and pictures, Services.

4. Could you write an article for the ASSERT report?

Yes: 52%

No: 48%

5. Have you any criticisms or compliments to make about the ASSERT report?

General praise: 46%

Too big and not often enough: 30%

Varied and factual: 5%

Others: It is free!, Good references to web sites, Well presented,

Add shading to break up boxes, Risks of epilepsy not covered,

Stories kept them going through the hard times, Received too late for next deadlines.

C. Trifold leaflet

1. Have you any criticisms or complements to make about the tri-fold leaflet?

What is the tri-fold leaflet: 59%

Useful to hand to professionals: 12%

Positive points: 9%

Needs updating in general: 6%

Others: Good basic information, Can you include comments from parents who have been helped by ASSERT, Stress the importance of contact with other families.

2. Is there anything else you would like included in the leaflet?

Only 1 response of no was given to this question, all others left it blank.

3. Would you like some leaflets to give out to others?

We have had requests to send out over 160 leaflets.

D. Web Site

1. Have you ever visited the ASSERT web site?

Yes: 39%

No: 45%

No, but intend to: 7%

No computer or not on internet: 9%

2. What did you like about the web site?

Information available: 36%

Easy to use: 9%

Honest information: 6%

General links: 6%

Helpful: 6%

Short and simple explanations with opportunities to ask for more: 6%

Not over powering: 6%

Others: A good start for further research, Not negative, Link to Makaton site, Bright and clear, Comprehensive, Personal, Clear and well set out, Information for new parents.

3. What did you not like about the web site?

No dislikes: 33%

Cannot view PDF files: 17%

Others: Limited information, A little technical at points,

Links suggest there are more info sheets yet these are not

available online, No pictures on home page – rather plain,

Impersonal, Lack of specific information – education laws and

appropriate links.

4. What information did you find helpful?

All and any: 33%

Parent stories: 13%

Photos: 13%

Others: Links, Communication articles, Genetics, Links to

overseas groups, Back issues of newsletters, Contact details –

ability to email – useful to give to professionals.

5. What information did you not find useful?

Some things become more relevant as time goes on –

1 response, no other responses.

6. What other information would you like to see on the web site?

Family stories: 19%

Research update: 13%

Behaviour: 13%

Others: History of ASSERT, Different situations, Message board, Regional meetings/local groups, Frequently asked questions, Education, Adult AS stories – i.e. oldest living, where they live etc, Relevant links.

E. ASSERT Conferences and Regional Meetings

1. Have you attended a conference or regional meeting?

Yes: 68%

No: 32%

2. Could you help organise a conference or regional meeting?

Yes: 28%

No: 66%

Not at present: 5%

3. Have you any comments to make about ASSERT conferences or regional meeting?

Excellent: 22%

Good to meet others: 15%

Useful: 11%

Friendly: 9%

Informative: 7%

More regional events: 4%

Well organised: 4%

Good to meet professionals: 4%

Good time: 4%

Others: Not enough time to talk, No carer for AS person, Bad time of the year, Good to keep up to date with other developments, Didn't like all the talks, A little repetitive after 3 conferences, Reassuring to experience help and support at such meetings as opposed to knowing it is available, Regional – Edgehill area Liverpool good, Indispensable source of information.

F. ASSERT in general

1. Have you any criticisms or compliments to make about ASSERT?

Great work: 20%

Thank you: 15%

Friendly and helpful: 15%

Reassuring: 8%

Always there: 8%

Report is professional: 8%

Others: It would be nice to hear about research we are involved in, Newsletter is mainly about younger children, Conference – like it to be nearer Welwyn Garden City, Not really much conversation about how AS affects parents, Pleased it is still going, Fantastic, good to see new trustees stepping forward, Breadth of news in reports, Always someone at the end of the phone in crisis, Listening ear, Non-critical.

2. What would you like to see ASSERT doing in the future?

Raise general awareness: 21%

Research and development: 6%

Promote funding: 6%
 More regional meetings: 6%
 More of the same: 4%
 Promote awareness with health professionals: 4%
 Group for undiagnosed: 4%
 Others: Merchandise, Being available at diagnosis, Being available for advice as children get older, Being available when facing various medical traumas, More research into why it happens/prevention, More meetings, More regular newsletters, Setting up AS homes, What it is doing now!, ASSERT envelop sticker, Continue conferences, Supporting older AS individuals, Behaviour, Eating disorders in AS, Respite views, Charities who help adults, Colleges for AS individuals siblings and families, Stem cell research, TV program on ASSERT, Non-conference years get together socially, Following up on older AS adults, Canvassing for more support for families (e.g. respite)

3. Any other comments?

Compliments directed to Sally: 32%
 Helpful, supportive, informative, reassuring, incredible, motivating, great person to talk to, fantastic source of information
 Very appreciative: 19%
 Nice to know you are there: 13%
 Keep up the good work: 6%
 Thanks: 6%
 Others: We bought our sons trike after seeing it in the newsletter, Don't feel that we belong to ASSERT – no diagnosis, Reassuring to know ASSERT all have first hand knowledge
 A film would be great

Press release from Mencap News

Families of disabled children celebrate with tears of joy as means test is finally abolished by Government 27 October 2005

Mencap, the UK's leading learning disability charity, welcomes today's announcement that the means test for the Disabled Facilities Grant has finally been abolished in England. Families of disabled children were delighted at the news that they will no longer have to struggle financially, building up huge debts and re-mortgaging their houses, in order to look after their children safely within the family home. The Disabled Facilities Grant is designed to help families of disabled children pay for vital adaptations to their homes such as a downstairs bedroom, bathroom or a vertical lift. The means test failed to recognise real expenditure, including mortgage repayments. This meant that very few families, including those on low incomes, were able to receive such support. This means test has already been abolished in Northern Ireland (December 2003) and Wales (April 2005) but until today, families in England were means tested, resulting in many facing staggering bills for vital building work. The Parkers were one such family. Under the means test system, parents Andi and Lucy were told they had to pay £16,000 – over half of their annual income – to make the vital changes to their home for son Ben, 7, who has a condition called global developmental delay* and autism. Andi Parker, 37, said: "Under the means test we were totally helpless. We are a family of six who live in three bedroom house. Having been assessed and deemed to be in 'crisis', it was decided we needed a downstairs bedroom for Ben. His condition means he can be aggressive and disruptive and so sharing space is not practical. However, we were expected to find £16,000 for the building work. This work is vital to the well being of my son, to give him a basic standard of living. I cried with happiness when I found out the means test had been abolished. At last we can begin to put our son's needs first." Jo Williams, Mencap's chief executive said: "This is

just fantastic news. No longer will parents have to struggle caring for their disabled children. Can you imagine having to carry your eight-year-old child up and down the stairs five or six times a day? That's 40 times a week or 1,200 times a month. Today's decision will make a huge difference to the lives of families with disabled children across England."

The Government's decision follows extensive campaigning work by a coalition of the UK's leading housing, disability and children's charities including Mencap. This decision puts into place recommendations made by an OPDM commissioned review (June 2005) to abolish the means test.

- A coalition of 14 of the UK's leading children's, housing and disability charities, including Mencap, NCH, the children's charity, Muscular Dystrophy Campaign, Scope, Shelter, Barnardo's and Contact a Family, campaigned to reform the grant for families with disabled children.
 * Global developmental delay may affect a child's speech and language, fine and gross motor skills, or personal and social skills.

For further information visit

www.odpm.gov.uk/pns/displaypn.cgi?pn_id=2005_0215

- Mencap works with people with a learning disability and their families and carers, fighting to end discrimination and prejudice, and providing a wide range of quality services. There are around 1.5 million people with a learning disability in the UK.
- Learning disabilities have many different causes but are always lifelong. A learning disability can affect someone's life in many ways, causing difficulties in learning, communicating or doing everyday things. A learning disability does not prevent someone from learning and achieving a lot in life, if given the right support.
- For information about learning disability issues please call the Learning Disability Helpline (England) on 0808 808 1111 or visit www.askmencap.info