

ASSERT

Angelman Syndrome Support Education & Research Trust



ISSUE THIRTY FOUR OCTOBER 2002

REPORT

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Letter from the Trustees

There's a lot to read about in this issue and we hope it is up to the usual standard! You will read on page 2 that the Conference at Loughborough back in September was a resounding success. We were very encouraged by the positive comments we received both from the presenters and participants. Many thanks to all who came and made it the success that it was. A reminder to all participants – if you haven't already done so, please complete and return the Conference Evaluation Sheets to the PO Box address – if you don't return them, we assume everything was wonderful and you have no comments to make for improvements next time!!

ASSERT 2000 club – there has been confusion in the past few issues with this in that each time we have said that we have included a form to join and each time there has been no form!! This time we would assure you that if you wish to join, all you have to do is send a in a cheque for £12.00 or multiples with your name and address on the back of the cheque, we will do the rest!

As we have indicated in previous newsletters, Jim will be leaving us next year and we are looking for a replacement or replacements. Some people at the conference indicated that they might be interested and we would be pleased if they could contact Sally Walburn on 01268 415940 to discuss this further. We are very mindful that we have been trustees for a while now and need some new blood and ideas. We are keen to recruit more of you to bolster up the good work we are doing and develop ASSERT further. The conference was extremely successful as we have said, but in order to promise

another in two years time we need support and energy to do this. So please do get in touch.

There is also more information in this Report about the joint ASF/ IASO Conference which is to be held in Washington DC next July, if anyone is interested in going or would like to know more about it, please contact Sally Walburn.

Enclosed with the newsletter is a survey, which is being carried out by The Royal Free and University College Medical School. ASSERT has agreed to mail these to you on their behalf, and would appreciate it if you are able to complete the forms and return them to the Department of Child Health in the prepaid envelopes provided, PLEASE DO NOT RETURN THEM TO ASSERT. Although they are studying children conceived through IVF treatment, they need to balance their results against the general population and therefore this is where your input is vital. Thanks for your co-operation.

We would draw your attention to the next Report, please send in articles by the deadline of 30th December, these can be on any subject you like although this time we will be particularly interested in holidays (people will be booking up early in the year), and any other information you feel would be useful for other families. Looking forward, Lucy Bennett, one of the conference speakers, has sent an article she wrote about dealing with challenging behaviour, so we will be printing this in the next issue/s.

For now, that's it. As always we hope you have a good read and look forward to receiving your articles.

The Trustees of ASSERT

Attention!!

We are currently updating our records and preparing the Contact Register, please check your details on the enclosed forms and either a) if the details are correct initial the form and return it or b) if the details are wrong or have changed make any amendments necessary, initial the form and return it to us.

IN ANY EVENT PLEASE RETURN THE FORM TO ASSERT

These periodic updates help us keep our records current and stay within the laws concerning the keeping of address

lists. All our records are kept confidential and, except where an individual has agreed to their name being printed in the Contact Register, addresses are not given to any third party

You can return the form either by post to ASSERT, Freepost SEA 7078, PO Box 505 Sittingbourne ME10 1BR (you don't need a stamp but if you put a stamp on it keeps our costs down) or by Fax to 01795 429061 or email to jim@angelmanuk.org.

2nd National Conference Report



Sunday morning break

The Trustees of ASSERT are pleased to report that our second national conference was a resounding success!! There will be a video available in due course for those unable to attend or who missed sessions, we anticipate that it will cost £15 inclusive of post packing and VAT. As soon as we have more information on this we will let you know.

There were 145 conference participants, which included 48 families. It was tantamount to the success of our last conference that 19 families came again and we had double the number of the first conference held back in September 2000.

Friday 6th September

A bad traffic day! Like all days in this Country, however, unlike the rain, this didn't dampen the spirits of the families who arrived from about 3.00 p.m. onwards – there was a six Junction tailback on the M1 due to accidents and unfortunately quite a few were caught up in this. We carried on and began with a First Timers Talk. This talk was meant to address the emotional side of the conference since for many it was their first time at a conference and for some the first time they had met and seen other AS children and adults. Rooms were allocated and we hope that everyone was happy with the accommodation – they were basic University Undergraduate rooms, but they did have ensuite bathrooms, and there were no precious objects to worry about with the children.

Dinner was served between 6 and 7 p.m. and was up to the standard of 2 years ago – plenty of variety and plenty of it!! We certainly didn't starve over the weekend. There was a Welcome Address in the bar at 8.00 p.m. and the inevitable raffle which raised £120 for ASSERT funds, thanks to all who bought tickets. Most people trickled off to bed afterwards although I do believe the Aberdeen contingent once again availed themselves of the alcohol which was on offer and trundled in, in the early hours having corrupted one of the trustees who shall remain nameless but we know who he is – he had a rather sore head the next day!!

Saturday 7th September

The main conference day – we began early with breakfast between 7.30 and 8.30 a.m. – most were in early and enjoyed the full English breakfast, cereal, toast etc that was on offer – certainly this fortified us for the day. The children and adults and their carers set off for Conkers, which was an outdoor activity place. Unfortunately it was not suitable for everyone and some came back early but the little train proved a big hit with some of the older young men who apparently spent most of the day on it going backwards and forwards!! Many thanks to Nick Bartholomew, the trustee who co-ordinated the event.

As far as the main conference went, we had a very busy day ahead. There were displays in the main foyer area and the table, which was heaving with the Fledglings Toys and products for people with disabilities proved extremely successful. Bob Griffin came in the afternoon so that people had an opportunity to look at his carer-controlled trike, which we had previously seen two years ago. Many parents then had purchased a trike and we wanted to give new families an opportunity to try it too. There were a couple of researchers who wanted help from Angelman Families and they provided a different dimension to the conference. Many thanks to the families who supported them in this, both Professor Peter Hammond and Professor Chris Oliver were extremely appreciative of our support and co-operation.

We had a main session in the morning on Behaviour, Epilepsy and Communication and we also heard from Tina Lockett about the Son Rise Programme, which she used with her daughter Abbie. The Programme was developed in America and has been used with people with Autism. Tina feels that it has made a difference to their lives and has prepared Abbie for school and for life. It was an alternative view that we thought should be shared with other parents in case they might like to try some of what Tina did. In the afternoon the conference was split between those who were taking part in Communication workshops and watching the Angelman Project videos. The main auditorium continued with Sleep problems and Transition, followed by an overview of what both the researchers were doing. The presentation on the Facial Morphology was extremely interesting and one wonders how much further our technology can possibly go – if you see the video you will know what I mean!

We finished with a question panel, and then a new venture for us, Mums and Dads workshop. These workshops proved for some, to be the highlight of the conference. The Dads workshop discussed some powerful, pertinent but taboo issues, and apparently could have gone on for much longer – I must say that seeing the fathers coming out, they looked absolutely drained! We Mums finished on time and had we known they were going to take longer, we too would have continued. It felt comfortable to be together with others, many of whom had experienced the same feelings and frustrations – there was lots of emotion in both workshops – this shows that meeting together with others who know how you feel is so important. This was also something that many commented about on their Evaluation Forms – meeting other parents.

Dinner was the usual far too much food and choice! We all met in the bar and at 8.30 onwards were entertained by a magician, come party man, come Disco. The children and the young adults certainly had a great time – particularly one young AS man who was quite miserable when he came in that evening (having ridden on the train all day!) – he was the star of the show and ended up in fits of laughter. The highlight was when a real rabbit was pulled out of the hat, which sent everyone aaaahhhhhing! Karen Robertson celebrated her 31st Birthday at the conference and we did not let this pass without humiliation – our entertainer dragged her onto the stage, made her stand with her thumb on her head and a thumb in her mouth whilst she turned around and we all sang Happy Birthday, she left with a balloon crown and a very red face!

Sunday 8th September

The last day of the conference or rather morning. Everyone was looking very tired including the trustees! Unfortunately one family had to leave us as their child was unwell, but with our children that seems to be the way things go at times!

We began with an overview on Angelman Syndrome from Dr Jill Clayton Smith who was with us for the whole morning. There were concurrent workshops on Communication, Resuscitation, and the Angelman Project videos. Jill also did a smaller workshop session where parents were in a smaller group and could ask more questions, particularly for the few there who had children who were undiagnosed. We finished with a Question and Answer/General discussion session but unfortunately some were not able to attend due to workshops running on and also children coming back in from swimming. However, we have included the closing remarks in this newsletter which were going to be delivered at the conference to bring it to an end.

Families trickled away and us as trustees finally got away at about 1.30 p.m. but one young man really didn't want to go home – Ben – he had thoroughly enjoyed himself and wanted to make sure we were all going as well before he got into the car. I must not let this report pass without mentioning how much all the AS children and adults enjoyed seeing each other again – I was privileged to witness Ben arriving and seeing his friend Calum (Gerry Egan's son) for the first time in about two or three years, it was a wonderful reunion for both of them, they were clearly pleased to see each other again. This shows how important it is for our young people to develop friendships with their peers and demonstrates that we as parents are not always the people they want to be with – just like any other teenagers.

Phew! It was all over and after the high of the weekend we all now feel a little deflated – however, it will hopefully be happening all over again in two years time and for those who didn't make it this time – we look forward to sharing our next conference with all of you too!

Here are the Closing Remarks from the Conference, which due to time restraints we didn't get to say, we feel that these are important to share with you all particularly with regard to thanking all those who took part and emphasising the need for you to support ASSERT in the future.

Closing Remarks

Well, this has been a very special event and I sincerely hope you will all go home today much wiser than you were when you came. I also feel there will be a sense of deflation and sadness that it's all over, however over the weeks and months to come I know you will look back and think upon the happy times that we have all spent together.

Before I launch into the thank yous etc I would like to remind you all to complete your evaluation forms, these are a vital way of us getting feedback, good or bad, on how you felt the conference went. You can either leave them at the Registration desk or post them, however, I would urge you to do this ASAP whilst it is all fresh in your mind.

Such an event as the conference has been planned over the last two years. Many thanks to Jim and Dick who visited Loughborough on a few occasions in order to check out the facilities and activities, plus finalise and agree the accommodation, venue, food etc with Nick Hunt and his team who once again have come up trumps and made us all feel welcome, thanks go to them too.

I would especially like to thank Jim for all the help and support he has given me, including the enviable task of compiling the conference packs (I shouldn't think he wants to see a photocopier in a hurry), sending out all the bills and dealing with the room allocations and much more besides.

I must also thank my fellow trustees who have supported and coordinated the event this weekend, it has not been easy fitting everything in around family and AS life, but we have all done it. Sadly David and Margaret Kinnear had to leave early and Jackie and Bernie Silver were unable to attend as it has been the Jewish New Year this weekend, but I would assure you that they have been in our thoughts and I dare say we in theirs!! What a conference they missed?!

Thanks to all our speakers who have given of their time and expertise and I hope you have enjoyed listening and partaking in the sessions and workshops. I would particularly like to thank Finn Emmerson with whom I have spent a lot of time planning and talking about her workshops and also sharing lots of ideas for the conference.

We are coming towards the end now and before we all go, I would bring to all your attention, as I have in past newsletters, the fact that if it wasn't for us as trustees, conferences and ASSERT would not happen. This year we have said goodbye to Elaine and Steve Sears who have for the last 10 years supported many of you and given time to ASSERT, especially Elaine who was our treasurer. Fortunately for us Nick Bartholomew was so smitten by us at the last conference he has stepped into Elaine's shoes and has taken up the mantle of treasurer.

Jim Brennan one of our longest serving trustees; has made a tremendous contribution to ASSERT, but, he too will be standing down next year and this will leave a huge gap which we need to fill either with one or several people. For those of you who don't know, Jim's house hosts the ASSERT office, he deals

If you enjoy these articles please think about writing one about your family, we really find this the most interesting part of the report. The address to write to on this or any other subject is: ASSERT, P0 Box 505, Sittingbourne, Kent ME10 1NE



with all the correspondence, much of the banking and sees to the post office box, as well as a numerous amount of other tasks which I won't list but are all vital to keep ASSERT ticking over. Unless we have someone or some bodies to replace Jim the future of the work we do is uncertain. All of us are very busy people and we can only dedicate so much time to ASSERT, as you all know everything we do is voluntary.

Sadly, I cannot guarantee a conference in two years time, simply because we may not have the manpower. We would therefore, appeal to you, if you can help ASSERT in any way please let us know. You do not have to be anyone special to be a trustee nor have any qualifications, if you would like to know more about it, please chat with us afterwards or have a think

and pick up the 'phone in a little while. You all know the old saying 'many hands make light work'!

Seriously think about how ASSERT as helped you, wouldn't it be a shame for those parents following in your footsteps if there wasn't anything like ASSERT for them? ASSERT is not about to die, I would assure of that, but we wouldn't be asking for help if we didn't need it.

Finally and I mean finally! It's time to go, many thanks for coming and all your contributions over the weekend, we hope you all have safe journeys home and as a way of thanks to everyone, please give us all a round of applause!

Sally Walburn

THE CONFERENCE 2002 – GRANDPARENTS' PERSPECTIVE

We attended our first National Conference this year. We attended a West country Regional Conference last year, which was excellent. However the scope of the National Conference was obviously greater and manifestly much more could be covered in 1½ days than in a full afternoon. The first thing, which struck us, was the efficiency of everything. The organisation was superb and long experience has taught us that such things do not just "happen". They are the result of sheer hard work by a number of people and a great deal of foresight. This gives confidence to attendees who can relax and get the best out of everything. It is, we feel, the essential foundation of any successful conference and this one was markedly successful.

Our wonderful little granddaughter, Isabelle, was diagnosed with AS in October 2000. We started, and anyone reading this will understand what we mean, a very steep learning curve about a condition about which none of our family (and no local doctor) had ever heard. In the learning process, therefore, Isabelle provided the parameters for our developing knowledge. We tried very hard to avoid stereotyping but without comparators it is difficult indeed to establish a norm as-to behaviour and development. We made early contact with ASSERT and the courtesy and patience of Jim Brennan in steering us in the right directions was nothing short of remarkable. We met others through the Helpline and that was extremely helpful. Slowly our extended family felt its way towards a better understanding of AS. But still to all intents and purposes Isabelle was AS. She was our total knowledge. This leads on to the second major discovery, which came from the Conference. Suddenly, the perspective of AS widened. There, around us, were children of all ages and abilities and parents and grandparents who had been there before, who had had the same questions to ask as we had. There, were older children walking normally (Isabelle has taken some steps but has yet to take that final confidence step) and there were children communicating. A great surge of better understanding

enveloped us. And indeed we were able to contribute; even to boast, as all grandparents tend to do! Isabelle sleeps through the night and she will eat with relish pretty well anything offered to her – and with a spoon, which she has done from about the age of 18 months. Equally suddenly Isabelle was Isabelle – as she has always been but now in a much wider context, just as Ben is Ben, Lauren is Lauren, Calum is Calum and so on. Of course we do not have the responsibility for bringing up Isabelle; that falls to our lovely daughter and her husband and their other children. But we do need to know things and perhaps a more general knowledge is important for grandparents.

Finally, there is the quality of the presentations. There, available to all, were medics and others willing to discuss and to give of their knowledge and experience. From beginnings after Isabelle's diagnosis where we were feeling around in the dark and AS invariably spelled "mystery", we were in a sea of knowledge and normality at Loughborough. We are very grateful for the opportunity to give back something to ASSERT by becoming Trustees. But there is no way that we could have made the transition from novices to feeling part of almost the "world" of AS without attending the Conference 2002. We now know people, we know wonderful children (and look forward to seeing them grow up) and we have shared experiences and have learned much. To those (and there were many) who listened to us with great patience and who answered all our questions with equal patience, we are most grateful. It helped us enormously. To anyone who was unable to attend the Conference this year, we would say; "as soon as you know the date of the next one, write it in your diary in bold letters". It will be a very rewarding experience; a crucial part of the business of having a child with AS in the family and immensely reassuring. As for us, we are already looking forward to Conference 2004.

David and Margaret Kinnear.

The Conference – A Very Positive Experience!

The following is from Michelle Turner and I was extremely touched by how much both she and Alistair had gained from the weekend – this is a success for everyone concerned and highlights how valuable such an experience is. Sally Walburn

Firstly I should introduce us all, my name is Michelle and I am married to Alistair. We have three lovely (most of the time!) children, Caitlin age 6, Holly age 9 and Stephen who is 12 and has AS. There have been many times when I've been tempted to write something for the newsletter but, either I've decided it's not something anyone would be interested in, or just that life with Stephen takes over and the moment passes!

This time the moment isn't about to pass because our lives have changed for the better and it has a lot to do with this years ASSERT conference in Loughborough. That statement might sound a bit over the top but, before we went to the conference we had got to the point where we just couldn't cope with Steve. He had become a set of problems that seemed to be getting greater as the weeks went by. Alistair is in the army and frequently away for anything up to six months at a time. The girls seemed to be suffering and I was getting increasingly depressed.

All the professionals involved with Steve were saying that he was hard work and his teacher told me that Stephen was "one of the most difficult children I've ever worked with" ! People started to talk about residential school and it seemed the only way forward at the time. No-one once said that maybe the school weren't doing their jobs and maybe the other professionals involved should be making sure Steve was accessing everything he should be, to enable him to progress. In hindsight it should have been us that noticed the lack of support for Steve but because we were so tired and stressed we listened to the professionals (normally a mistake I know!).

We realised at Stephen's annual review that his statement was seriously outdated as it was written when he was 2 1/2 so we requested a statement review with the highlight on his current school not meeting his needs and with an intention of finding a residential school placement. Everyone supported us (to our faces anyway!) and everyone involved started to make their reports. The reports have highlighted that there is no communication programme in place at school, Steve was having to wear nappies at school, even though he didn't at home or respite, because he couldn't 'tell' them he needed the toilet! He was being strapped into a chair for a large part of the day! And he was also having a lot of 'accidents' on the playground and around school, which were causing a great deal of physical damage.

The statement was due to come back on the 5th September but because our social worker got his report in six days late it was delayed. So when we arrived at the conference we were just waiting to find out if Steve would be able to go to a residential school.

On the journey Stephen stayed totally dry even though we were stuck on the infamous M25 for two hours! He was very calm and quiet through the whole journey and impeccably behaved (not normal behaviour for Steve I should add!)

Because we arrived late we went straight to the bar where he saw his Uncle Jim and then dragged him off to meet everyone else! The first thing Alistair noticed was a young boy who was the spitting image of Steve when he was 7/8. We didn't pay too much attention to this until much later. That night Steve took ten minutes to fall asleep and then slept through until six the next morning, which is totally unheard of! On the Saturday he behaved brilliantly at breakfast and then went off on his trip. He was exhausted when he came back that evening. While waiting for dinner we had a lie down and Stephen had his head on my shoulder. After a little while he lifted his head looked me right in the eye, stroked my face gently and said, "ah mum mum" Believe me there were tears! He has said mum before but more as a sound and it's been almost a year since he's even done that.

Saturday night he put on his smart shirt and looked very handsome (okay I'm biased but he did!) The first thing he did was drag Uncle Jim to the dance floor! Then he came back and sat quietly watching everyone and drinking his bitter shandy which he thought was great! Next came a game of pass the parcel where he managed to dent Liam's balloon sword a few times, even though Nick and I did our best to stop him!

That night he slept through the night again and was eager for his morning of swimming. All in all he had a fantastic time and we have some lovely photo's to show him when we talk about it.

While Steve was having such a good time, Alistair and I were meeting the other families and attending the workshops etc. For the first time since we've had Steve, people were coming up to us and saying "wow how did you get Steve dry all day?" and "Wasn't Stephen well behaved at the bar" The parents of the child we thought looked like Steve at an earlier age were experiencing all the same problems we encountered with Steve. The funny thing was we hadn't really noticed how well he was behaving!! We had got so used to all the bad bits that when the good happened we were just so grateful for a break from the 'behaviours' that we didn't pay too much attention! After that first day though, we paid attention and were amazed at what our son was capable of. Also we found out how much input other children were receiving and how well they were doing. It made us aware of how let down we are by our professionals.

We came back from the conference determined that Stephen was going to get the help he needs and reach his full potential, we have no expectations, we are going to let Steve show us what he can do. We have decided that we don't want our son to go to residential school yet but that we want the best school for him. We have also stopped looking at the negative side and started to look at Steve properly. We have arranged a meeting for all involved with Steve to make sure that we are all doing our best for him and helping him reach his full potential.

Since coming back from the conference we have been a different family and more importantly we have our son back! He will never again just be a set of problems because we now don't feel so alone. The conference did all of this for us and if you didn't go this year take my advice and try and make the next one. We are still fighting the school and the statement so I'll write an update on that one later. In the meantime we just want to say thank you to ASSERT and to all the families at the conference.

Update on Lyndsey Marsh

Dear All,

I read Gail's (Gail Hanrahan Barnes Article March 2002) letter with interest as we had a similar situation but with different results. Lyndsey had a new consultant a few years ago and he stated that he would like to try and get her off the medication. Lyndsey was taking 25mls of Epilim twice a day and 2 tablets of Lamotrigine twice a day. He started with the Epilim and reduced it by 5mls in the morning for a month and then 5mls at night for another month – this continued until she was having 5mls in the morning and 10mls at night. It was at this point that Lyndsey starting fitting again and she was immediately put back onto 10mls in the morning and the fits stopped. Apart from when she had her back operation Lyndsey has only had a few drop fits and is still only taking the 10ml doses.

Unfortunately it hasn't made any improvements with her general behaviour and her concentration etc, nor has it resulted in any weight loss!!! Having said that Lyndsey has vastly improved in general behaviour and understanding as she has got older (she is 26 this year) but her concentration is no different to when she was a child. I am also wondering if any other parents have children who when they reach a certain point in learning things suddenly forget the earlier parts. For example Lyndsey was learning Makaton signs and

had learnt about 10 and was using them really well when all of a sudden she learnt the toilet sign and forgot all the others and even now several years later only uses three signs. This has happened several times with different things and I am almost sure she has forgotten them but it could be laziness.

On a different note, in spite of all I said. (Editors Note: You may remember Eileen writing about their trip to New Zealand in Oct 2000 and Jan 2001 Reports, on their previous trip in 1999). We returned to New Zealand last year and took Lyndsey with us. We spent several days with Anne and Kirstie Fulcher and what a marvellous time we had. Lyndsey and Kirstie remembered each other and fell into each other arms and became inseparable. Amongst many things that we did was a trip into town. Kirstie walked really nicely and helped push Lyndsey's chair, but all the time she was shouting "hello" to everyone, and when she paused for breath Lyndsey took over shouting "hello" and I have to say that very few people could resist their beaming faces and spoke back to them. There was only one occasion that Lyndsey wouldn't copy Kirstie and that was on a picnic that we had gone on. Kirstie decided to roll down a grassy bank with great hilarity but Lyndsey refused to copy her, apart from this they did everything together. If only the distance was not so far and they could meet more often.

Eileen Marsh

ASSERT 2000 Club

Apologies for not including this in the last newsletter!

Winners for April were:

1st Mrs V Hocking – Dorchester

2nd Miss AD Turner – St Neots

3rd Mrs A Carter – Somerset

4th Mrs S Warner – Leicestershire

Draw took place on 19 April 2002

Drawn by Mrs L Jobson – Manager
Home-Start Sittingbourne & Sheppey
Witness Mrs P Wilkins – Secretary
Home-Start Sittingbourne & Sheppey
Congratulations to all!

Computers for the Disabled

New and 2nd hand PCs and parts supplied to the disabled home user, disabled centres and organisations by a non profit making charity PCs and parts purchased, but donations always welcome – contact Mr Paul Harris
Tel: 01268 284834 Fax: 01268 479028
E-mail: bigpaul@blueyonder.co.uk
Website: www.cftd.co.uk

Kindersafe Bed

We heard about this from Zoe Rose at the recent ASSERT Conference, she has one for her son who is three. The bed surround is a series of waterproofed wedges, which connect together to provide a safe surround. It would not be suitable for more active children. For more information and a leaflet contact Kinderley Trinity Hall, Llangollen Road, Acrefair, North Wales LL14 3SF
www.playservices.co.uk
Tel: 01978 810777 Fax: 01978 823660

Telephone Preference Service

If you are tired of answering the telephone only to find it is someone doing a survey or trying to sell you something, then consider registering with the Telephone Preference Service (TPS).

This service is free of charge, and when you register your telephone number is added to the TPS list so licensed companies involved in telephone selling will know you do not wish to be contacted. Your details are kept in confidence by TPS.

Ring 0845 070 0707 for more information.

Stay warm and Save Money

If you receive any one of several benefits such as Income Support or Disability Living Allowance, are over 65 or have a child under 16, you could be entitled to a 'Warm Front' grant of up to £1000 (£2000 for the over 60's). The 'Warm Front' grant is available for such measures as loft insulation, draught proofing or even a new heating system, tailored to your needs. The 'Warm Front' grant is available to both owner-occupied and private sector tenants. To find out if you are eligible for a grant call the free phone help line on 0800 952 1555 Mondays to Fridays 8am to 6pm.

Afasic News on Speech & Language Therapists

Speech and Language Therapy has been designated a 'shortage profession' by the Government. That means employers in the UK will now find it easier to obtain work permits for therapists from outside the UK. Meanwhile the Royal College of Speech & Language Therapists warned the Government that plans to increase the number of speech and language therapists will not produce benefits until 2004.

Information from Contact a Family

Leisure and the Law

Mark Robertson, Manager of the Contact a Family Helpline, writes:

Most readers will know how difficult it can be for a disabled child to enjoy ordinary leisure facilities in the same way as other children. This article takes a brief look at what the Disability Discrimination Act says and what you can do if you believe your child has been discriminated against because he or she is disabled.

Since the Act became law in 1996, it has been illegal to discriminate against disabled people in the provision of goods, facilities and services, which includes leisure facilities. But what does this mean?

In effect, the law says that leisure facilities available to children without a disability should be available to children with disabilities to the same standard and on the same terms. Your child should not be treated less favourably than other children, so if, for instance, the local cinema refuses entry to your child, or a waiter in a restaurant refuses to serve your child when other children are allowed to eat there, they may be breaking the law. Similarly, if you are asked to pay more for your disabled child's holiday than for your other children for the same holiday, that too could be illegal.

It does not matter if it is a leisure facility you pay for, such as a trip to a local swimming pool, or something which is free to everyone such as a local park. For instance, it could be illegal if a child who uses a wheelchair is refused entry to a local park.

However, the Act says that in some circumstances it would be justified to treat your child less favourably. This means that in some cases it would not be illegal. Not surprisingly, if your child has been refused entry to the local swimming pool because of good health and safety reasons, this would not be illegal. Also, it is unlikely to be illegal for a cinema to refuse entry to a child with severe behavioural problems if they are likely to be very noisy or boisterous because other people's enjoyment of the film could be spoiled.

In addition, it would be illegal to refuse to make reasonable changes to procedures or policies if these changes would allow your child to make use of a facility. For example, the children's section of the local library may be downstairs and a child in a wheelchair may find it very difficult to access. Although at the moment there is little legal pressure to make physical changes to the premises there may be something reasonable the staff could do to help your child use the library. One reasonable step might be to allow your child use a staff lift or for staff to fetch books for your child. If the staff refuses, this may be a case of discrimination. Refusal does need to be justified.

At the moment, many of your rights are about the way in which services are provided. However, from October 2004 the law will be extended and from that date 'reasonable adjustments' to actual premises of leisure facilities may be legally required in certain circumstances. This will be where there is a physical barrier which stops, or makes it unreasonably difficult, for your child to access a leisure facility. The term "premises" does not just mean buildings; it includes kerbs and paving, parking areas, gates, public facilities such as telephones and service desks, lighting, seating in the street or a pub garden, fixed signs, paths in a country park, and many

more physical features.

In the meantime, if you think your child has been discriminated against, the Disability Rights Commission may help. You can contact them on 08457 622 633 (text phone 08457 622 644) or e-mail: enquiry@drc-gb.org. Similarly a local disability project may be able to help with any legal action or complaint. Call the Contact a Family Helpline for details of disability advice projects in your area.

Access to Leisure

This article previously appeared in Update, the newsletter of Action for Leisure. It is reprinted here with the kind permission of the author.

Inclusion is very firmly on the Government's agenda. Many new initiatives are starting to ask how services are provided for disabled children, young people and adults, and how they might be provided to be more effective. We are also seeing more consultation work taking place with disabled children and young people. This consultation is starting to reach children with more complex and profound disabilities, a group that has been excluded for some time. Pippa Murray is working on one of these projects and funded by the Joseph Rowntree Foundation, Pippa has been consulting disabled young people, their families and non-disabled people about their leisure time and activities, and how inclusive services are. As this research project draws to a close, Pippa highlights some of the main findings and issues raised by the young people:

A recent research project, looking at the experience disabled teenagers have of inclusive leisure, found that talking with young disabled people about what they liked to do in their time out of school or college, quickly led to conversations about all sorts of things – family, friends, school, exams, music, future prospects, sexual relationships, going out and so on.

Young disabled people did not see leisure in isolation from the rest of their lives, making particularly strong connections between their opportunities for leisure and their educational experience. For most young people, schools are where friendships are made and developed; friends are the people we choose to spend our leisure time with. However, they told how both mainstream and special schools contribute to the difficulties they commonly have in forming relationships.

Having placed leisure firmly in the context of relationship, young disabled people showed how their interests were the same as all young people – music, bowling, clubbing, going to the pictures, the pub, going out for meals, going on holiday – with family or friends. Unfortunately, they could not take access to such activities for granted as they frequently faced barriers in the forms of lack of physical access or lack of respect and common courtesy.

The full report "Hello! Are you listening?" – Disabled teenagers' access to inclusive leisure by Pippa Murray, was published in July and is available from York Publishing Services, 64 Hallfield Road, York YO31 7M Tel. (0 1904) 430033. Price on application.

For more information about the research please contact Pippa Murray, 14 Jarrow Road, Sheffield S11 8YB e-mail: pippa@pippamurray.fsnet.co.uk

Moving Out

Thanks to Carol Eve who wrote the following about the difficult decision that the family had to make with regard to her daughter moving away from home.

Some of you may have met my family before, but some of you haven't (Carol and the family came to the Eastern Regional Meeting at Elmbrook School last May). So for you families who are new to the group, our names are Carol and Charlie Eve and we have two daughters, Michelle 24 and Tammy 18 who some ten years ago were diagnosed with Angelman Syndrome but over recent years professionals have changed their minds and now they are unknown. We have two other daughters, Tina 20, Emily 17 and one son, Mark 23.

The reason I have decided to write this story in this issue is that it may affect others who have an older disabled adult who is getting ready to leave home. I wanted to share with you what it is like to be a parent going through the experience I have had and I hope it will help.

Over the past couple of years, our eldest daughter, Michelle has been displaying very challenging behaviour, throwing things, breaking things in the home, beating me up and others, mostly to do with frustration at not being able to express or tell us what she was feeling like and why. She was assessed and given drugs to calm the behaviour by the Adult Psychologist but they only made her unwell and worse, so we stopped. In time it got so severe, it was like waiting for a time bomb to go off and I was getting badly beaten. Still I carried on, as we love her, as you do, until it got so bad we had to ask Social Services to help. They came round to the house and after several meetings we decided that Michelle might like to try independent living in a place of her own. Her name had already been down for this for 18 months and as luck would have it a house owned by a housing association came up in February of this year. The house has three bedrooms and so Social Services had to find another disabled person who also wished to leave home and match

them with Michelle, leaving the third room for a carer to sleep in. A match was found and every week the girls met up. The other person is called Pauline and she has Down's Syndrome, they got on extremely well. A care agency was found and carers from there took them out every Monday and Wednesday so they could get to know each other.

The house was not ready until June, our whole family was becoming increasingly stressed and wondering what was going to happen. Michelle could not understand what was happening and we could not explain it to her. I cried a lot, as I felt guilty giving up the caring and her. It was like I was being defeated as I had planned to look after our girls till my last breath. But it was affecting the entire family unit and Michelle was obviously unhappy.

On June 17th Michelle moved into her house. She has not looked back. We visit as often as we want, she is very happy and relaxed, pleased to see us and not worried when we go home. She came for a visit in August with her carers and Pauline as it was her birthday and we gave her a party, when it was time to go, she just kissed everyone goodbye and was fine.

Obviously there's a lot to sort out, teething problems with staff coming and going as 7 workers is a lot on different shifts. You have to buy everything except large furniture items and electrical items e.g. washing machine, cooker etc as the housing association bought those.

I have stayed in control of her finances but keep a record of every penny spent and collected.

At home things have calmed down and Mark also moved out at the same time to his bungalow, which he is buying in the same road as us. So lots of changes. It has made us realise that we have done the right thing for Michelle and us and we will want the same for Tammy. I have asked to put her name down now, as I don't want to get in the same situation as we did with Michelle. As long as she remains happy and content, so do we.

Carol Eve

10 TIPS FOR CAREGIVERS

(From the US National Family Caregivers Association)

1. Choose to take charge of your life, and don't let your loved one's illness or disability always take centre stage.
2. Remember to be good to yourself Love, honour and value yourself you're doing a very hard job and you deserve some quality time, just for you.
3. Watch out for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
7. Trust your instincts. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Stand up for your rights as a caregiver and a citizen.
10. Seek support from other caregivers. There is great strength in knowing you are not alone.

ASSERT Adopted

Melissa Silver's aunt, Estelle Gudde has just become President of Barkingside Rotary Club. During her year in office, all the fundraising will be given to her chosen charities, one of which is ASSERT. ASSERT will be promoted by Barkingside Club, for the next year, and in November Sally Walburn will be talking at their meeting about ASSERT and giving them an insight into what we do and our aims for the future. Melissa attended the first fundraiser where £300 was raised on the raffle and lots of ASSERT trifold leaflets were given to fellow Rotarians. A further 'At Home' was held in August with about 80 people attending, all proceeds from the raffle were donated to ASSERT. Hopefully this year will be a good year for the Rotary and for ASSERT.

Bernie Silver

News from Abroad

Dear Families, Professionals & Researchers,

We are pleased to invite you to the joint ASF Eighth Biennial Conference and IASO Second World Conference to be held in Washington, D.C., July 2-5, 2003. ASF was founded by a group of parents in 1991 at a meeting in Orlando, Florida. The IASO was founded by national Angelman Syndrome associations in August, 1998 in Ottawa, Canada.

This unique ASF/IASO Conference aims to:

- inform and educate parents, professionals, and researchers about the origins, treatment, and management of Angelman Syndrome
- encourage members of national Angelman Syndrome associations to exchange and share their projects and experiences
- stimulate international scientific collaboration on Angelman Syndrome research
- encourage international communication among people involved with the care of persons with Angelman Syndrome

This ASF/IASO Conference will provide a special venue for everyone who loves, helps, or cares for people with Angelman Syndrome. Parents and professionals from all parts of the world will have a great opportunity to learn the latest scientific facts about this rare condition. They will also be able to interact with the scientists and among themselves. And researchers will have a unique opportunity to present the very latest findings of their work and compare notes with colleagues from around the globe. The Conference, in short, will be an event that lets us share what we know, and spread the word to those who have no help or are isolated locally, nationally, and internationally.

We are pleased to invite you to this Conference in Washington, D.C., the U.S.A.'s capital. Washington is a most interesting and beautiful city and is a particularly fun place to be during the 4th of July when this special event will take place. We look forward to seeing you in 2003.

Hal Lippman and Heikki Taimio
Conference Co-Chairs

Abstracts by scientists, professionals, and parents dealing with any aspects of Angelman Syndrome are encouraged.

The Conference agenda will include Plenary Sessions with keynote presentations and concurrent sessions/works hops organized from among the following general topics (see the abstract submission form for a more extensive list.): medical science, therapies, physiotherapy, education, social issues, adulthood, family issues, and advocacy,

Abstracts are due October 1, 2002 (however we have been assured that this date is flexible). Send your abstract and a completed Abstract Submission Form via e-mail to info@angelman.org. Or you can mail an IBM compatible diskette together with a paper copy of the abstract and an Abstract Submission Form to the Angelman Syndrome Foundation; 414 Plaza Drive, Suite 209; Westmont, IL 60559 USA. All files should be saved in Word format, text only. Please name the file after your last name and indicate the topic of your presentation. An abstract form is available on the Internet at <http://www.angelman.org/2003Conf/forms.htm>. Abstracts must be in English. All presentations of abstracts must also be in

English. National Angelman Syndrome support groups may assist in the translation and presentation of abstracts originally written in another language. Abstracts should not exceed 250 words, text only, inclusive of the title of the paper and the name(s) of the author(s).

1. The title should be brief, clearly indicating the nature of the research or the case study and typed in all CAPITAL LETTERS.
2. State authors' names (family name, first name, no initials), relation to an individual with AS (if applicable), institutional affiliations (if applicable), full mailing address, phone and fax numbers, and email address.
3. The text of the abstract should include:
 - a) a statement of the purpose of the study, case, or project (preferably in one sentence)
 - b) a brief description of the methods used
 - c) a summary of the results obtained
 - d) a conclusion
 - e) reflections and concrete proposals for action stimulated by the research or case
4. Place an asterisk * sign after the name of the presenter.

If you are interested in presenting, please:

- send your abstract (maximum 250 words, text only)
- in English
- saved in Word-format
- name the file after your last name and indicate the topic of your presentation

If **submitting** via E-mail

- go to <http://www.angelman.org/2003Conf/forms.htm> to download and complete the Abstract Submission Form.
- Send your Abstract Form and Abstract to info@angelman.org

If submitting via Mail, be sure to include:

- a completed Abstract Submission Form.
- an IBM compatible diskette with your abstract
- a paper copy of your abstract.

Angelman Syndrome Foundation
414 Plaza Drive, Suite 209
Westmont, Illinois 60559-1266
U.S.A.

Questions can be directed to:

Phone: 1-800-432-6435
outside the U.S. 1-630-734-9267
Fax: 1-630-655-0391
E-mail: info@angelman.org

Review of scientific abstracts and selection of those for platform (oral) or poster presentation will be undertaken by the Scientific Committee. Abstracts submitted by other professionals and parents will be reviewed and selected by the Program Committee. Notification regarding the submission of your abstract will be sent by February 2003.

ASF reserves the right to accept/reject any abstract received for consideration in the program agenda.

Drooling problems?? Then read on....

Hi, I just thought that I would write and tell you all about our "Angel" – William.

William is just 13 years old and as typical of Angelman Syndrome as you can get! Full of mischief, fun and devilment. We are typical parents of an "Angel" exhausted, exasperated and stoical! William has a younger brother James, who is totally normal for a 12 year old (I leave that to your imagination!) However James is a lovely lad – all his friends mums love him anyway, and always willing to play games with William. He puts up with a lot for such a young chap, i.e., ALWAYS having to remember to shut his bedroom door and being unable to play with things like his Lego with Will around because Will takes it to pieces and then chews it up. No malice intended, he just likes to investigate everything thoroughly and still likes to mouth things constantly. He sucked one of those really large orange garden slugs once for ages, very gently – he didn't hurt it as it had shrunk into a sort of boiled sweet shape! Will found it really funny as I tried to get it off him, heaving whilst he chuckled at my discomfort and horror! Then made his YEUK! sound when we put it back in the garden.

Actually, it is Will's mouth that I want to talk to you about. If you are an Angels' parent, you will be very aware of all the best places to buy bibs, tissues flannels etc as drooling seems to be a very common problem. A few years ago, we decided that this was sort of OK for a child but wouldn't be so endearing in a teenager or adult, so we asked if Will could have an operation that we had heard of to help him.

The operation involves removing the child's tonsils and then reversing the salivary glands underneath the tongue and bringing them out where the tonsils used to be so that the saliva goes down the throat instead of everywhere else. It is not a pleasant op I have to say but Will's enthusiasm for food saw him through. Also we visited a homeopath and got him some heavy duty Arnica to take just before, and after the op which I am sure made a massive difference to the amount of facial swelling afterwards – which really was minimal, when we had expected him to look like he'd done 10 rounds with Frank Bruno!

Will only stayed in hospital long enough to wake up and have a wee as I felt that it would have been really hard to keep him

from "playing" with the other poorly children. The staff weren't keen at all to let him home the same day, as the site where tonsils have been removed can bleed very badly. I am a midwife and trained nurse, so I took the responsibility and

brought him home anyway. He settled right down as soon as he got into the car, and I felt was much less likely to have a problem as he was so much more relaxed. The rest of his recovery was uneventful and he was soon back at school. The op was a great success and Will only drools occasionally now if he is concentrating very hard on something that he is looking down on. So, if you are thinking of it, we can recommend it, go for it. It really makes a difference.

I would also just like to say a thank you to the folk who put the ASSERT newsletter together, and generally run the group for the benefit of all of us. It does make you feel like you have friends who understand out there and it's nice to read about other families, their children and their coping strategies. Yes, of course we all love our kids and their big grins but as we all know, they are flippin' hard work to keep up with, so every idea that works to make our lives easier is worth its' weight in gold.

Best wishes to all from Sue Hathaway, William's mum.



William and his new trike

Parental Leave Information

From Jan 2002 parents have a right to parental leave from work under the Maternity and Parental Leave Amendment Regulations 2001

There is a lot of info to be found on www.dti.gov.uk/er/parentresp.htm There is also a booklet Parental Leave a guide for employers and employees URN99/1193 The DTI Parental leave enquiry line 020 7215 6207 Mon-Fri 9.30 – 4.30pm

Essentially parents of children receiving DLA under 5yrs on 15th Dec 1999 are entitled to take agreed periods to a max 18 weeks of unpaid leave to look after a child or make arrangements for the child's welfare up until the child is 18 years old. There are various clauses that need to be read and understood but worth looking at.

It could and I think should be argued that good practise for employers would be for them to consider such action to support any child in such a way regardless of their age. Life work balance agreements are becoming more accepted by good employers and need to be highlighted to others!

Pam Robertson

Motability

You may have read in the last newsletter about the Walburn's who are opting out of the Motability scheme. In response to that article we received the following from Patsi Whelan Archer.

Hello everyone at ASSERT, Patsi Whelan-Archer (Bonnie's Mum) here, just to let you know that we also dropped out of the Motability scheme this year, we needed an adapted vehicle so that our son Alex (who has C.P. & is now 11yrs old and wheelchair user) can access it more easily.

We looked at the scheme & it would have cost us £7,000 in advance payment for a car that cost £13,000 !!!!! So we opted for buying from Gowrings Mobility after visiting the Naidex exhibition, the car is fully adapted so that Alex can be pushed in in his wheelchair or drive himself in his powered chair. There are four seats, sliding doors which make it easier access for Bonnie too, Gowrings were excellent, kept all their promises and also helped to sort out insurance, we have three years AA cover so we're very happy, and Alex's mobility money is paying for it so we're not any worse off financially either.

We would recommend this way of mobility as when we need to change this car, we will have the car as part exchange instead of having to find money. That to our way of thinking is dead money on advance payments as you don't get it back at the end of the lease.

Bonnie is well and continues to do well on the new drug Kepra, as is a lot of other people I know who's children are on it, I think this is the new ' Epilim ' a real breakthrough for Epilepsy in my opinion. Bonnie is really enjoying being an aunty to Flynn who is very close to her and nearly walking at 11mths, which Bonnie finds extremely funny, especially when he falls over of course!

Patsi

Please note that the deadline for the next edition of the ASSERT Report is 30 December 2002.



More news on Motability

Ford Customers Beware!! The Walburns have just handed back their Ford Galaxy definitely for the last time on Motability. Having spent one and a half hours at the dealership – Allen Ford in Romford, Essex, it seems that despite all the checks on the vehicle, including having it MOT'd and inspected, 'phonecalls to Motability, assuring them that no work prior to hand back needed to be done, a scratch (which will cost less than the insurance excess to repair) and a windscreen, now all of a sudden must be put right. Be warned – take your car to the Motability specialist for a pre hand back check, don't rely on Motability or the workshop or the MOT to alert you to repairs which might need doing to the vehicle. It will save any embarrassment and time consuming 'phone calls and then coming home and writing letters if you let them decide what is acceptable. It appears that the car must be immaculate before it goes back to the dealer. Hence why we are not using Motability anymore (although one wonders that if we were then maybe they may have had more customer care!).

Sally Walburn

Websites

Melatonin

Here is a website telling a few things about melatonin – and the effects on people with neuroproblems and delays.

http://www.keepkidshealthy.com/medicine_cabinet/melatonin_sleep_problems.html

<http://chem-faculty.ucsd.edu/harvey/wagstaffsleep/>

Feeding

The Sammons Preston website <http://www.sammonspreston.com>.

Hints and Ideas for Angelman Proofing your home!

<http://www.bethsturr.com>

Augmentative Communication

www.aac institute.org

<http://www.frame-tech.com/products.html>

www.aacproducts.org

Communication

www.hanen.org

<http://www.speakingofspeech.com>

www.enkidu.net

Angelman Syndrome Tests

<http://www.geneclinics.org/profiles/angelman/>

Clothing

www.discoverytrekking.ca/

Scoliosis

ConneXions

Connexions offers a range of guidance and support for 13 to 19 year olds to help make the transition to adult life a smooth one – for all youngsters not just those with disabilities. The information for young people with special needs is on the website

<http://www.connexions.gov.uk/document/s/lddinfopacksept2002.doc>

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.

Fundraising

Dear ASSERT

We are writing once again to say how well our daughter, Sophie is doing. Sophie was 22 months old when we last wrote to ASSERT, she will be 3 this October. We still take Sophie to all her therapy sessions, which she is responding to really well. We can't thank the physiotherapists enough as Sophie is now cruising round the furniture holding on tightly but getting from A to B, this is such a wonderful thing to see. Hopefully Sophie will soon reach the goal of being able to walk freely, but always remembering to take each day as it comes!

We would like to take this opportunity to enclose a cheque for £100, this was raised by Sophie's Great Auntie Sue who ran the London Marathon earlier this year, also a big thank you to Auntie Sue who also raised enough money for us to be able to buy Sophie her very own physio equipment to have at home.

This is a great help especially the landing mat as we can do all of Sophie's therapy on a daily basis, exactly how the physio's recommend. It's all hard work but great fun! We enclose a picture of Sophie with her Great Auntie Sue. We would just like to say, it's all worth it in the end.

The Munro's



Sophie and Great Auntie Sue

Donations

Thank you, to everyone who has donated to ASSERT since the last Report back in July, your contributions no matter how small all make a difference, without you, there would be no ASSERT and we know what a lifeline we are at times. We also collect foil, cans and stamps; stamps must be trimmed as close to the perforations as possible (don't trim those or the stamps will be no use). Please send stamps to Jim and contact Bernie Silver concerning the details for our account with Alcan and recycling aluminium.

Many thanks to:

Chickies Karting Team

Mrs J E Childerhouse

In memory of Sidney Firth

Genesis Housing Group

In memory of Mrs Gwen Goad

Sophie Munro's Great Auntie

Mrs Elsbeth Goth

Mrs Manouch

A S McGinley

Mrs Smeeton

Brenda Turnell

Mrs Wrigley

Telephone Support Line

For the moment we have streamlined the support line into one new number, which is 01268 415940. This will also accept faxes. Please do not use the old numbers.

We are still providing the 'On-call' service, which is not limited at the moment. You can still contact ASSERT at any time. Instead of trustees on call at different times we are currently monitoring the volume of calls and you will get through to Sally Walburn. Of course if you wish to speak to a particular trustee, Sally will pass the call on and get them to phone back you as soon as they can. You will at times get the answer machine, please be patient and leave a message. It is vitally important to leave your details clearly and also a time which is best for you to be contacted. As before we are here to share your frustrations and at times, your despair, but also the good news too! ASSERT is not able to 'fight your battles' for you but we can offer support, a listening ear and we will endeavour to point you in the direction of further assistance.

You can contact any of the trustees by letter or E-mail: assert@angelmanuk.org.

Mathew Dickinson Productions

In association with Manor Drive Methodist Church

A group of amateur players got together to raise money for the son of two of their number, Ben, who unfortunately suffers quite severely from 'Angelman's Syndrome'. The show was a great success and as a result of the income and generous donations received we are now delighted to send you a cheque for £1000.00 for your charity in the hope that this will help you advise families and assist young Ben and others like him throughout their lives.

Some of the money raised is to be used directly to help Ben and his parents Stephen and Debra and the remainder will be put into a trust fund for him for the future.

Most people who either bought tickets or made donations. We are enclosing a photo of Ben who has already had a very arduous existence, in and out of hospital, but hopefully the future for him and the family will be brighter.

With best wishes from everyone associated with our production 'Thank your Lucky Stars'.



Ben

HELPLINE
ASSERT Families/New
Diagnosis/Support Line
01268 415940

