

ASSERT

Angelman Syndrome Support Education & Research Trust



ISSUE THIRTY TWO MARCH 2002

REPORT

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REGISTERED CHARITY NO. 1021882

Letter from the Trustees

Welcome to this first edition of the ASSERT Report 2002. As you all know this will be a busy year with the conference scheduled for September 6 – 8 at Loughborough University, Loughborough, Leicestershire. Details about the costs and how to register are on page 10. For anyone who has not attended a conference or regional meeting this is a great opportunity to meet, find support, friendship, and information from other families and from the 'experts' (although I know we would all agree that when it comes to Angelman Syndrome we are all experts!!). Some of us have been fortunate to attend several conferences worldwide and every time we have walked away feeling uplifted, supported and most importantly, that there are lots of people just like us coping with the same, similar and different problems, but all with the common bond of Angelman Syndrome. We cannot recommend strongly enough the positive experience that it is. We hope to see as many of you there as can make it – it is worth bearing in mind too, that our conference allows carers' and AS persons to be there free of charge – we don't think that there is any other organisation that does this for families, this is all due to fundraising. We thank those who have generously donated to ASSERT in order for us to be able to offer this to you all.

As hinted in the last Report, we have a new logo – we hope you agree that it is more modern in design and will herald a new beginning. The website has been updated and in keeping with some of the other Angelman Syndrome groups the address is now www.angelmanuk.org (ASF (USA) is www.angelman.org and CASS (Canada) is www.angelmancanada.org) – we wonder if others will follow suit! If anyone else can help with the website, please let us know.

Please note that the Support Line number has changed to 01268 415940 – there is now only one number for all support calls, it also accept faxes.

We are pleased that a couple of people have come forward as new trustees. Many thanks to Nick Bartholomew who is joining us as a new trustee and more importantly offering to take on the role of Treasurer (you can read a short report from him on page 11). Later this year after giving 10 years of support to families as trustees, Steve and Elaine Sears will be resigning. Both Steve and Elaine have contributed in many ways to the development of ASSERT and were, along with Richard and Alison Allen, founder members of the group. Steve was treasurer in the early days and Elaine is the current treasurer, she has been doing this for 9 years. Many of you will have spoken to Elaine on the Support line, as she

has been 'on-call' during the day and also some evenings during the week. We know how much you have valued the time she has spent talking and supporting many of you, especially at the time of diagnosis. We also know that there are many who keep in touch with Elaine, as it is important to talk to a friendly voice and a person you don't have to explain yourself to each time. Steve has videoed meetings in the past and provided a back up to Elaine, as well as participating in regional and trustees meetings. We are sure you would all like to thank them for their invaluable voluntary contribution to the work of ASSERT, and we wish them well in the future.

Jim Brennan will also be moving on next year (2003) and we will need a secretary/administrator. He has been active in ASSERT for the last eight years and has been a backbone in the organisation, opening post, distributing information, keeping information updated and photocopied, typing the minutes, keeping the family files up dated, organising the conferences, supporting the regional meeting organisers, manning the professional support line, and much more besides including keeping the other trustees on their toes! We have some time to find a replacement for Jim whether it is one person or several people. **We would ask all of you now, that if you or someone you know could help with this or just one of the tasks, let us know.** We are sure that you must realise that this role is extremely important to the functioning of ASSERT, if there is no-one to take on this role (or some of it), there will have to be a considerable down sizing of the work that we do, that may mean no more conferences, less meetings, less newsletters and less time for support. At this stage it is important that every member realises that an organisation such as ASSERT does not work unless there is goodwill and voluntary contributions from the trustees – **that** is why we have been appealing in the last few Reports for new trustees. If you can help, please get in touch – trustees do not have to be parents.

Apologies for there being so few family stories in this edition of ASSERT Report – unfortunately we haven't received any since the last newsletter. The update on Guy Hanarahan Barnes was received just before the last one went to print and so that's all we have this time.

We hope you will take seriously our appeal for support and we look forward to hearing from you – this includes help at the conference – no one has come forward to offer help even if it is just for half an hour this would be a great support to the trustees – especially if the conference is to be the success we hope it will be. Please help us!!

The Trustees of ASSERT

Family Stories

Guy's Progress

I thought I would write with an update about Guy. I have written articles for newsletters in the past and thought it was time to let you know what was happening with the Hanrahan-Barnes family.

As I think I wrote in my last contact we were in the process of taking Guy off his medication. Guy has been fit free since he was 3 and a half years old. His convulsions were usually febrile and occurred through episodes of illness or quite often when something had hurt him (pain related). Guy was first prescribed Tegretol and after constant increases ended up being overdosed on this drug and fitting more frequently (my diagnosis, not the paediatrician's, he told me that the medication would not cause seizures). Eventually he was put on Epilim, which seemed to control his seizures and after some years fit free and without having to increase his medication (even though he had grown considerably) I finally persuaded my Paediatrician to help me reduce his medication, somewhat reluctantly he agreed, although with a "on your head be it" and "if it ain't broke don't fix it", type of attitude. (As you can probably gather from my comments I do not hold my particular Paediatrician in high esteem).

Guy improved so much after the initial reduction, his concentration, sleeping and general behaviour was much improved, we were delighted and determined that one day he would be off his drugs completely.

That day finally came in May this year, after reducing his dosage by half a ml every 2 weeks for quite some time Guy was finally off his medication. Its now October (nearly November) and to date Guy has had no adverse affects from this action, in fact I would go as far as saying he has again improved his concentration skills, understanding and general behaviour considerably.

Guy is now 11 years old, he is still a happy, loveable boy, he still has Angelman Syndrome and everything associated with it (not that I expected any different, contrary to what my paediatrician feared, he thought I was hoping for a miracle cure and told me as much) but he is now not clouded by a drug I personally think he didn't need.

I personally believe that Guy had febrile convulsions, common in many children and who for those considered "normal," grow out of by the age of 6 years. Because Guy has

AS I think he was labelled with the epilepsy condition, and the doctors could not see beyond his syndrome. I may of course be wrong, hey I'm only a mother, but I firmly believe that I know my son better than anyone and stand by my own judgement on this. I didn't tell my paediatrician that I was taking him off his drugs, (I told my GP and the school doctor, for support) but let everyone dealing with him know what I was doing and how. To this day he still doesn't know and I have so little respect for the man I don't feel the need to tell him.

I would be interested to know if any other parent has had similar experiences as far as seizures are concerned, but would like to also state that every child is different (even those with AS), just because our children have the same syndrome they shouldn't all be grouped together as being exactly the same, and that I am not advocating that how we have treated Guy's seizures is how all children with AS should be treated, every case is different. I would like also to say that with all our children, we should trust our own instincts and not always think that everything the medical profession tells us is the gospel truth, no one has my son's best interest at heart more than myself and his dad, and no one knows him better than we do either. It was my instincts that took him to the doctor at 8 weeks old saying I thought something wasn't quite right, it was my instincts that persuaded the GP that he was not developing properly at 8 months and finally convinced her that I was not just a neurotic mother, and my pushing that finally got a diagnosis at 15 months when everyone else thought I was going mad. But if my instincts have failed me this time be rest assured that I will let you all know, after all I'm just a mother and not a paediatrician and I can admit to being wrong, here's hoping I'm not.

Many thanks to Gail for that update. We are sure that some of you will have also agonised over this situation but ASSERT would not advocate anyone taking their child off anti-convulsants without discussing it with your paediatrician. Gail took the decision she did and it could have backfired, she took a risk and so far, fingers crossed, it has paid off. Like all advice given ASSERT is not endorsing or promoting any action by parents, but rather giving you the information as it is, for you all to make your own judgements. It's just interesting to hear what you are all up to, and, hey if it works, then brilliant!!

Bernie's Channel Swim

I am pleased to inform you all that I have now completed the channel swim – 1600 lengths, 25 miles, in the fantastic time of 24 hours and 14 minutes. So far I have managed to raise £400 to help pay for carers to attend the conference in September. Remember, every £50 raised will pay for another family to attend, cutting their costs by 50%. Any cheques should be payable to ASSERT, and sent via the PO Box address.



ASSERT 2000 Club

We are first approaching the end of our first and very successful year of the 2000 club. We would like to thank all of you who have taken part and congratulate all the winners. It is now time to remind you that we need you to renew your membership and also invite any newcomers to take part. It costs £12 per year to join and 50% of the money taken is given back during 4 draws over the year – this is just 25p a week to help ASSERT to run. If you would like to join in or participate again, please complete the enclosed form and send it together with your cheque payable to ASSERT for £12 (or £24 and so on if you would like two or more chances!). Last year we raised £667.47 (Jim said that the odd figures is because we had to change some Irish punts!)

DON'T FORGET TO INCLUDE YOUR NAME AND ADDRESS ON THE FORM AND THE CHEQUE – JUST SO WE KNOW WHERE TO SEND YOUR WINNINGS!!

2000 Club Winners

Following the latest draw, congratulations go to

1st Jenny Reid,
2nd Mrs L Davies,
3rd Mrs I Parker,
4th Mrs N Jolleff.

Angelman Study Day

There is to be an Angelman Study day for professionals at the Wolfson Centre London on the 1st July 2002. If any professionals reading this would like to attend, please contact: The Conference Office at the Institute of Child Health and you can register by phone 0207829 8692 or email Courses@ich.ucl.ac.uk

Fledglings

Fledglings is an independent not for profit organisation founded in 1998, which is staffed entirely by volunteers. It was established to provide families caring for a child with special needs, and their related support workers, with information about and easy access to helpful products.

They produce a newsletter and the first edition came out in December of last year. They have ideas about all sorts of equipment, from nappies to books, to toys and buggies and clothing – if they don't supply it they will advise on available sources. If you want to know more, or would like a newsletter, please contact Fledglings: 6 Southfield, Ickleton, Saffron Walden, CB10 1TE, telephone: 0845 458 1124, Fax: 0845 458 1125 or email: enquiries@fledglings.org.uk

Don't EVER Forget

Your presence is a gift to the world,
You're unique and one of a kind.
Your life can be what you want it to be –
Take it one day at a time.

Count your blessings, not your troubles,
And you'll make it through what comes along.
Within you are so many answers,
Understand, have courage, be strong.

Don't put limits on yourself;
Your dreams are waiting to be realized.
Don't leave your important decisions to chance –
Reach for your peak, your goal, and your prize.

Nothing wastes more energy than worrying –
The longer a problem is carried, the heavier it gets.
Don't take things too seriously –
Live a life of serenity, not a life of regrets.

Remember that a little love goes a long way –
Remember that a lot goes forever.
Remember that friendship is a wise investment,
Life's treasures are people... together.

Have health and hope and happiness,
Take the time to wish on a star.
And don't ever forget for even a day...
How very special YOU are!

Important Events

National Carers Week –
10th – 16th June

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



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.

Trike

Miray Kester has contacted ASSERT, just after the last newsletter went to print – she has got a trike which she is happy to pass on to another family. Unfortunately we have no more details but if you are interested, give us a call on 01268 415940, and we will get in touch with her on your behalf.

HELPLINE
ASSERT Families/New
Diagnosis/Support Line

01268 415940



Important Research Information

Important Research Information from Heikki Taimio – Vice President of IASO

Many thanks to Heikki for passing this information to us.

The following very important scientific article is forthcoming in the Journal of Medical Genetics (published Dec 2001):

AC Lossie, MM Whitney, D Amidon, HJ Dong, P Chen, D Theriaque, A Hutson, RD Nicholls, RT Zori, CA Williams and DJ Driscoll:

Distinct Phenotypes Distinguish the Molecular Classes of Angelman Syndrome.

This research was conducted at the University of Florida, Gainesville, FL, except for Dr. Robert Nicholls who works at the University of Pennsylvania, Philadelphia, PA. I cannot forward the full text of the article to anyone, however with the permission by the main author, Dr. Daniel Driscoll, I will summarise the main results, starting with the Abstract:

Background – Angelman Syndrome (AS) is a severe neurobehavioral disorder caused by defects in the maternally derived imprinted domain located on 15q11-q13. Most individuals acquire AS by one of five mechanisms:

- I) A large interstitial deletion of 15q11-q13;
 - II) paternal uniparental disomy (UPD) of chromosome 15;
 - III) An imprinting defect (ID);
 - IV) A mutation in the E3 ubiquitin protein-ligase gene (UBE3A);
- Or V) unidentified mechanism(s). All classical patients from these classes exhibit four cardinal features:
- 1) Severe developmental delay and/or mental retardation;
 - 2) profound speech impairment;
 - 3) A movement and balance disorder
 - 4) An AS-specific behaviour, typified by an easily excitable personality with an inappropriately happy affect. In addition, patients can display other characteristics, including microcephaly, hypopigmentation and seizures.

Methods – We restricted the present study to 104 patients (93 families) with a classical AS phenotype. All of our patients were evaluated for 22 clinical variables including growth parameters, acquisition of motor skills, and history of seizures. In addition, molecular and cytogenetic analyses were used to assign a molecular class (I-V) to each patient for genotype/phenotype correlations.

Results – In our patient repository, 22 % of our families had normal DNA methylation analyses along 15q11-q13. Of these, 44 % of sporadic patients had mutations within UBE3A, the largest percentage found to date. Our data indicate that the five molecular classes can be divided into four phenotypic groups: deletions; UPD and ID patients; UBE3A mutation patients and individuals with unknown etiology. Deletion patients are the most severely affected, while UPD and ID patients are the least.

Differences in body mass index, head circumference and seizure activity are the most pronounced among the classes.

Conclusions – Clinically, we were unable to distinguish between UPD and ID patients, suggesting that 15q11-q13 contains the only maternally expressed imprinted genes on chromosome 15.

What follows is a list of my observations of some of the most interesting details from the article:

- 1) this is the first comprehensive analysis of genotype-phenotype correlations (i.e., matching of genetic classes with clinical features) among all five molecular classes of AS. It reveals significant differences among the five classes in growth parameters, achievement of developmental milestones, as well as severity, frequency and onset of seizures.
- 2) Of the 146 individuals from 134 Angelman families in the U. of Florida AS repository, this study was restricted to the 104 individuals from 93 families who had an AS clinical score of 1 or 2. A score of 1 shows an absolutely “classical” phenotype in every respect, whereas a score of 2 meant that the patient was fairly classical, but demonstrated one or two features (e.g., mild or absent seizures or obesity) that were atypical for AS. The latter patients were extremely likely to have AS, since they fulfilled all of the 4 main AS criteria. The remaining 42 patients, all of whom had normal laboratory testing, exhibited some but not all of the four cardinal features of AS.
- 3) Extensive laboratory testing showed that the patients/families fall into the five classes as follows: 64/63 large deletion (class I), 7/7 UPD (class II), 7/3 ID (class III), 15/10 UBE3A mutations (class IV) and 11/10 with no detectable chromosome 15 abnormalities (class V). In percentages, the distribution of patients was: 68 % deletion, 7 % UPD, 7 % ID, 14 % UBE3A and 11 % unknown.
- 4) Statistical analysis was performed on the clinical features of 61 U. of Florida patients (all class II-V patients plus randomly selected 21 patients from class I) as well as 77 additional patients gathered from the earlier scientific literature: The body mass index showed that patients in classes II-IV were taller and heavier than in classes I and V. More than 70 % of UPD and ID patients are above the 80th percentile for their age group. The relative lack of obesity in deletion patients could be caused by their severe underlying motor defects. Less than 15 % of individuals from classes II and III had microcephaly, whereas more than 55 % of patients from the other three classes had a head circumference less than the 3rd percentile. The deletion patients (class I) had the least developed motor skills. One of the most striking observations was that 50 %

of deletion patients were non-ambulatory, while over 95 % patients from the other classes had an ability to walk unassisted. Mean ages to walk were I: 4.6 years; II: 2.6; III: 2.4; IV: 2.8; V: 2.6. The deletion patients were also less likely to be able to follow simple commands, and they typically had a complete absence of speech. Almost half of UPD and ID patients have more than three words in their vocabulary. Seizures began very early in classes I (1.9 years on average) and V (1.4 years) compared to classes II (4.9 years), III (5.5 years) and IV (2.7 years). In the U. of Florida patient population, significant seizures (i.e., grande mal seizures requiring the use of at least one anticonvulsant) occurred in 19/21 deletion patients, but only in 1/7 UPD, 1/7 ID, 8/15 and 4/10 class V patients. 90 % of class I patients were hypopigmented compared to family members, but less than 25 % of classes II-IV and 44 % of class V showed evidence of hypopigmentation. Statistically, UBE3A patients are similar to UPD and ID patients in the development of motor skills, ability to follow simple commands, pigmentation, and they have a high incidence of early onset obesity. However, UBE3A patients differ from UPD and ID patients in that they were more likely to have a history of moderate to severe seizures and microcephaly. Class V patients are most similar to the deletion patients, but they differ in two important respects: class V patients walk about two years earlier, and they are less likely to have seizures compared to patients in class I.

- 5) Molecular analysis showed the highest UBE3A mutation frequency, 50 % in families not belonging to classes I-III, found to date in published studies. 7/16 of sporadic and 3/4 of familial cases had mutations within UBE3A, or 15/26 patients.
- 6) Five possible explanations for the 11 % of unknown cases are:
 - i) Many UBE3A mutations occur in non-coding regions which haven't been scrutinized yet
 - ii) UBE3A can be inactivated by other mechanisms
 - iii) Other genes, some of which may reside in the ubiquitin pathway (genome wide), can also cause AS. Any protein that regulates or interacts with UBE3A and all

proteins that UBE3A targets for degradation are candidates. So far, four proteins have been identified as substrates for UBE3A-mediated degradation: p53, HHR23A, the Src family kinase Blk and UBE3A itself.

- iv) AS-associated mutations can occur in other 15q11-q13 genes. The UBE3A antisense transcript is one candidate, and another one is the newly identified imprinted gene ATP10C. These genes warrant further investigation.
 - v) These patients do not have AS, but instead have disorders that mimic AS, such as Rett syndrome. However, this study made use of rigorous clinical criteria and extensive clinical expertise with AS, so that this last explanation is unlikely.
- 7) The study suggests that the degree of severity of AS classes could be ordered as: deletion – unknown – UBE3A – UPD/ID.
 - 8) It is clear that although mutations in UBE3A are sufficient to cause the four cardinal features of AS, as well as recurrent seizures and microcephaly, other 15q11-q13 genes must contribute to the development of motor skills, severity of seizures, cognition, growth and obesity found in the other classes of AS. Further studies should throw more light on the roles of other genes as well as delineate all the UBE3A target proteins which could promote the design of rational therapies for AS.

Last but not least, we should remind ourselves that all of the above results are based on scientific comparisons between groups of individuals, i.e. averages. As has been pointed out several times on the list serve (email list for Angelman Syndrome) in the past, there are significant differences between individuals in each genetic category, so that we should not 'doom' any of our children to follow the path of any averages in his/her genetic class. Furthermore, it is obvious that in some cases the 'order of severity' may be reversed between two individuals belonging to two different classes.

Heikki Taimio
Dad to Liisa (11, sporadic imprinting defect)
Finland, Vice-President, IASO

Appeal from Anna King – Contact a Family

Many families tell us wish they had heard of Contact a Family long before they did! Our aim is that every family caring for a child with a disability or special need knows about us, so we can make sure they have all the information and support they need. We are working on publicising our services and ensuring that parents and carers have a chance to have their voices heard. To achieve this we are often asked by the media for families who would be prepared to be featured in a newspaper, radio or television programme. Each article or programme helps Contact a Family to reach families who

were not aware that support was available. Contact a Family is looking for volunteers who would be prepared to be featured in media articles. Our staff would contact you and offer support and guidance before any interview went ahead. There would be no obligation to take part and you could change your mind about appearing in the media at any stage. If you are interested in volunteering or would like to talk about what might be involved, please contact Anna King at the UK Office or e-mail: anna@cafamilly.org.uk

Personal Passport by Paula Hills

We read this in the SNAP Newsletter (Brentwood, Essex) and thought this was a good idea: (unfortunately there wasn't room to print this in the last Report).

My son's classroom co-ordinator, Margaret, decided to develop the idea of a Personal Passport to help give information about the child (without talking over them or in front of them) after reading an article in Eye Contact. Oliver's passport takes the form of 5 pages laminated and joined together on a large ring, which hangs on his wheelchair. This means that it is always with him and on show. It is important that the passport is written in the first person.

CONTENTS

Front Cover: Has a lovely colour photograph of Oliver.

Page 1:

About Me – written from Oliver.

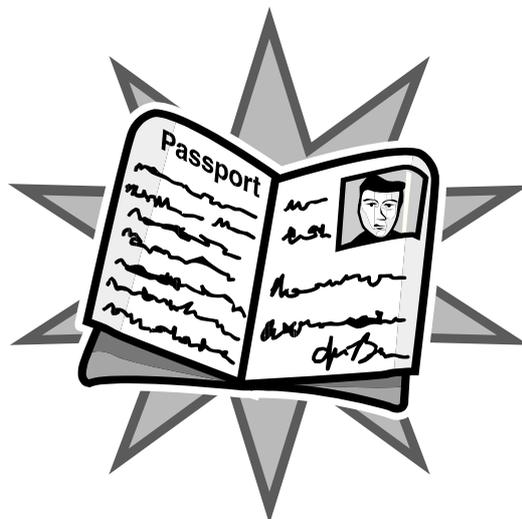
My name is ... I am years old, I was born on Diagnosis – I have ... I can ... I suffer from ... I need 2 people to lift me, I need time to respond etc.

Page 2:

My Family – names of grandparents, parents, brothers, sisters, friends, relations, information about pets, home, garden, nicknames.

Page 3:

Things about me – what I like about myself. What I like to do.



Page 4:

What I like to eat, medication, how I communicate, words I can say, what I like about school.

I was amazed how many people stop to read this passport, attracted by the photograph. It gives people the opportunity of talking to Oliver about things he enjoys with a deeper understanding of him. School uses these passports with visitors to the classroom. Avoiding the embarrassing, he's got, can't etc.

I have used the passport successfully when visiting hospitals and even out shopping with an inquisitive adult.

It's worth either encouraging your school to adopt a similar idea or do one yourself – believe me it can save the heartache when you are confronted by tactless people and questions that you don't want to answer.

Paula Hills SNAP

Contact a Family – Your help needed!

Contact a Family is a national organisation helping families who care for children with any disability or special needs. Many of the current articles we print are brought to you courtesy of their regular newsletter "Share an Idea". We received this letter from them in December 2001 and if you can help with this or other appeals please contact them on 020 7608 8700 or email: info@cafamily.org.uk ASSERT is affiliated to Contact a Family

The views and experiences of parent members of affiliated groups are essential to CaF and so I would like to take this opportunity to ask for your help with two important initiatives.

The first regards access to leisure. I am sure you will agree that it can be impossible for families of disabled children to make use of leisure facilities in their local communities for a variety of reasons. We are therefore running a leisure survey across the UK asking for parents about the barriers to using local services as well as for ideas on what helps. The survey is available on our website at www.cafamily.org.uk. If you have access to the Internet then do please go to our website and fill it in. It will only take a few moments of your time. The more voices

we have clamouring for inclusive leisure, the more impact we can make with policy makers. We will announce the results in Carers Week 2002 and use the results to press for equal choices for your children.

Secondly, you may be aware that the government has decided to develop a National Service Framework (NSF) for Children. I will be chairing the External Working Group on Disabled Children. This is a brilliant opportunity for Contact a Family to influence the development of the NSF – and to address all those issues that cause parents so many problems (such as services not talking to each other). I will be delighted to hear from any individual parents or groups who have burning issues about how services are delivered to their children.

I know how hard local and national groups work to support parents and I will work to ensure that government and policy makers hear your voices through CaF.

**Francine Bates
Chief Executive**

Publications

Remember it is always worth asking in your local library if they can obtain a copy of a book you would like to read but don't want to purchase.

Room to Move

by Alison Cowen Published for the Joseph Rowntree Foundation by Pavilion Publishing (Brighton) Ltd., The Ironworks, Cheapside, Brighton BN1 4GD Tel. (01273) 623222 e-mail: pavpub@pavilion.co.uk Web Site: www.pavpub.com ISBN 1 84196 009 8. Price £15.95 plus £3 p&p

Room to Move is written for parents of young people with learning disabilities and looks at the practical and emotional issues involved when those young people leave home to live independently. The author has drawn on the experiences of parents of seventeen "young" people (aged between nineteen years to mid-forties when they moved) as well as her own personal experience as a mother whose nineteen-year-old son has moved out. The book follows the process from the earliest thoughts that parents give to their child's future, through considering choices, taking decisions, planning and actioning the move. Finally the book looks at the issues of coping with change and adjusting to a different day to day life for both the young person and their families.

Each chapter includes many quotes from parents and young people to illustrate personal experiences and finishes with helpful "parent-to-parent tips" covering the main issues. There is a checklist of questions to ask housing authorities and care providers and a directory of terms and services covering subjects including advocacy, direct payments and tenancy agreements. The book concludes with a listing of useful organisations, books and videos.

Alison, the author, has been careful to stress the fact that each young person and family is unique, and each experience of leaving home is individual. Although the book is aimed at parents, the importance of keeping the young person at the centre of the decision-making and planning process is clearly emphasised. This book will also be of interest to professionals working with families and young people in transition to independent living. One parent-to-parent tip is: "It is never too early to start thinking about where your son or daughter might live in the future." This book is a useful guide in that process.

Sue Barnes

No Ordinary Life

The support needs of families caring for children and adults with profound and multiple learning disabilities

This is the title of a report recently launched by Mencap, which aims to highlight the massive caring tasks carried out by parents at home and their urgent need for practical hands on support. The findings highlight that parents spend on average 18 hours a day caring for their sons and daughters and are woken on average 3 times a night. It goes on to set out a range of recommendations aimed at improving the quantity and quality of services to families.

Individual copies of the report are available free from: Mencap, 123 Golden Lane, London EC 1 Y ORT Tel. (020) 7454 0454.

Code of Practice News

Ministers have announced that funding to help meet special needs would be £91 million in 2002-3. The government has withdrawn a draft Special Educational Needs Code of Practice in July after pressure from campaigners who were angry that it would not force education authorities to "quantify" in statements of special educational needs how much support, such as speech therapy, a child should be given. They feared it would be used as a loophole allowing authorities to make the bare minimum in provision. MPs approved an amended code in November, which says that support should normally be quantified. The new code comes into force in January 2002 along with the Special Educational Needs and Disability Act. IPSEA's John Wright, chief said, "They must now enforce this. If they cannot do that we will be back asking them to put it into law."

Websites

www.disabilitybenefits.co.uk
www.holidays4disabled.com
www.mobilitydatabase.com
www.disabilitynow.org.uk
www.youareable.com
www.eurobility.com
www.abilitynet.co.uk
www.cafamily.org.uk
www.aacproducts.org
www.widgit.com

Articles for the ASSERT Report

As hinted at the beginning of the Report we are very short on Family Stories – which everyone enjoys reading more than anything else. If you have a story that could be shared, or information you have found to be useful please write something for the Report. It does not have to be written on a computer, nor do you have to be the next Joanna Trollope, we can edit if needs be, the most important thing is to share your experience with others. You can write to us either via the post box address or email, or send a disc with the complete article; photos are also appreciated and will be returned.

HELPLINE
ASSERT Families/New
Diagnosis/Support Line
01268 415940



SpEARHead

SpEARHead (Special Education at Home) is a newly formed independent non-profit making advice organisation. Our service is free to all parents regardless of income, ethnic background, religion or personal philosophies. We are totally independent of government, local authorities and other organisations, and are able to offer our service to parents in England and Wales only.

SpEARHead was established to respond to the growing number of requests from parents of children with special educational needs, for accurate information and advice about their legal right to home educate their children. SpEARHead has also established that there are a growing number of parents who, for many and varying reasons, remove their children from school until such time as they are able to secure provision which they feel is suitable to meet their child's special educational needs. SpEARHead therefore offers advice on parental and LEA rights and duties in respect of both elective home education and on seeking suitable provision to be made by the local education authority either at home or otherwise. This includes advice on statutory assessment, statements, reviews and all other situations relating to children with special educational needs.

At present SpEARHead is run by a small team of volunteers who are legally trained and have a wealth of experience in advising, supporting and representing parents of children with special educational needs, and of home education issues. Through personal experience, our volunteers are fully aware of, and empathetic to, the fears and difficulties that may be faced by parents and children in a school based environment.

It is our policy to advise parents of all options available to them when considering which course of action to take in relation to their child's education. Further, we support parents whatever their choice, regardless of any personal opinions as to appropriateness the adviser may have. All advice is free, although parents may be asked to cover expenses incurred relating to an adviser offering support and/or representation at meetings. Our advisers are covered by Professional Indemnity and Public Liability Insurance. At present we mainly offer advice via telephone and e-mail. A web site is being created and advice and information sheets are being put together.

Contact: Ann McLean, SpEARHead, 6 Waverley Road, Worsley, Manchester M28 7UW Tel. (0161) 799 7244 e-mail: advice.spearhead@lineone.net
Web Site: www.advice-spearhead.org.uk

Donations

Thank you, to everyone who has donated to ASSERT since the last Report back in December, 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:

Laureen Anderson

In memory of Mrs A Brennan

Mr & Mrs G Burke

Mr P Eaton

Dawn Frazcek

Mrs J C Girling

David Hemsley

Mr P Jeffrey

Mrs C Joyce

Brig & Mrs Kinnear

Midland Centre Caravan Club

Royal Bank of Scotland

Mr & Mrs RT Simpson

Stockwood Medical Centre

In memory of Dawn Surman, Nanny

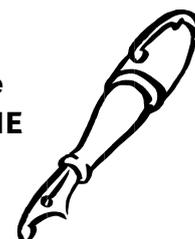
of Ben Luke and Ross Yates

Widgit Software

I have recently written to Widgit Software to enquire about their Bursary scheme for parents. Many of you will have seen the Rebus symbols used in some schools: these are helpful in developing a communication system for your child/adult. I hope that you have read in previous newsletters, the stories from Ben Robertson written in symbols and also the information on Communication prepared by Finn Emmerson, this should give you some ideas. If you are interested in symbols and laminating these for your child or using them in other ways it may be useful to know that Widgit run a Bursary scheme to assist parents with the purchase of the software – it usually costs £160. If you write to Widgit and explain why you should be considered for a bursary and how you are going to use the software they will let you know whether you can buy the software at a reduced price. It takes about four weeks for approval but it is worthwhile pursuing this. The website is www.widgit.com and the address is
Widgit Development Office,
26 Queen Street,
Cublington,
Leamington Spa,
Warwickshire CV23 7NA

Sally Walburn

**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**



Sleeping Sheet

The following information is from Karen Jones; Karen lives in Switzerland and has kindly sent one of these sheets to ASSERT for you to try (suitable for up to age 4), her son Tiger has Angelman Syndrome.



Bed time!

Tiger, like all AS children had a natural difficulty with getting to sleep, and staying asleep. For many years getting Tiger to sleep was a long and arduous process, which meant we had to sit with him, and hold his hand for up to 3 hours. If he woke and found you had left the room he would call for you to come back. The other problem was keeping Tiger covered and in his bed. He would spontaneously get up in the middle of the night and start to play with his toys. Tiger never had a problem with the dark and seems to see perfectly in the dark!

A couple of events helped immensely with his sleeping. One was when he learnt to walk. Once he was more mobile, and active he got more tired. The other was the introduction of the sleeping sheet. The sheet is essentially a bodice sewn into a fitted sheet. He can move freely around the bed, from side to side and up and down, but he cannot get out of the bed or uncover himself. When bedtime comes, He is zipped into his sheet. I then bend over to kiss him good night and he greets this with a hand in my face and pushes me away! He wont let me stay in the room. Once Tiger is in his bed, he will

not tolerate anyone in his room! As he goes to school now, and cannot sleep at lunchtime he is very tired at bedtime.

He now sleeps from 7pm to 7am, and I can make as much noise as I like, he never wakes up! No more sneaking around the house at night.

My thoughts are that the sheet is a sign to him that it is time to sleep. Once he is zipped in, he understands very well it is the end of the day. At first we left the security guard on the side of the bed, as he would occasionally try to get out of bed and end up caught like a fish in a net. But he understands now he needs to be unzipped and calls in the morning for me to do this.

Tiger sleeps in a perfectly normal adult bed, which is quite near to the floor. We no longer use the security guard. The big advantage of the sheet is that I can travel quite freely as the sheet fits on any standard adult bed. I recommended the sheet to another AS mother, who also reports that her daughter's sleeping is much improved with the sheet.

I am happy to say there is nothing quite as glorious as a sleeping AS child!

Karen Jones



Morning!

For more information contact Sally Walburn.

HELPLINE
ASSERT Families/New Diagnosis/Support Line

01268 415940



ASSERT Family Conference – Loughborough 2002

By now you will have all received details of the conference in September. If you haven't for any reason and would like more information, please contact Jim Brennan on 01795 429061. It is most important that if you would like to come to the conference you return the application form together with your deposit as soon as possible. Places will be on a first come first served basis. The details are as follows:

Assert Family Weekend Conference

Our second national conference is scheduled for the weekend of 6/7/8 September 2002 at the University of Loughborough in Leicestershire.

Accommodation

Butler Court – This block has 201 twin bedded rooms, over 4 floors, each with en suite shower, basin and toilet. The block is sectioned so that there are 3 rooms and a kitchen in each section. (Access to the kitchen is by special arrangement).

Situation

Loughborough University is situated $\frac{3}{4}$ of a mile from the town centre and covers a large compact area.

Access

By Road Main entrance 1.5 miles from Jnct 23 of M1
By Rail 1.5 hours from St Pancras on the Sheffield line, bus service/taxi to campus
By Air East Midlands airport is about 8 miles North

Parking

Ample: close to all halls to be used.

Medical Facilities

There is a sickbay during normal working hours and a Doctor on 24 hr call. The nearest A&E is at Leicester about 10 miles away.

Recreational Facilities

Conference delegates are allowed to use all the facilities. Being a sports University these are very good.

Cost

As last time we have endeavoured to keep the costs to a minimum. Please bear in mind that most other conferences charge a registration fee; accommodation is extra and then on top of that you are expected to pay for your own food. Our price includes everything; the only additional extras would be drinks at the bar. For this fixed price you have accommodation, breakfast (full English), lunch (two courses), evening meal (three courses) and tea/coffee during conference breaks, [special diets can be catered for, as long as we know well in advance], use of all the University sports facilities including the swimming pool. ASSERT is subsidising some of the cost. Professionals will be charged at a different rate, please contact us for details.

Adults £50.00 per person per night

Children £25.00 per person per night

AS Children/Adults FREE

Parent carer/ carers FREE

Children's Activities

These are to be arranged, and dependent on the age group we have. If anyone has knowledge of the area and suggestions, So far we haven't heard from you, it will assist us greatly in the planning so PLEASE get in touch.

Carers

Due to strict guidelines within the Children's Act and acting in accordance with those of the Local Authority we are unable to provide carers. So, if you require a carer, they will need to come along with you. It is essential that if you are bringing children you have a full time carer, we feel that it is most important that there are NO children in the formal discussions and talks at the conference, it is distracting to both the speakers and those attending. We want everyone to get as much as they can out of the conference, there will be plenty of time for socialising during the course of the weekend, and this will be the time when we can all relax and enjoy our children being together. As this is an extra expense, ASSERT is fully subsidising the accommodation and food costs of all carers to enable families to bring a carer free of charge. However, we are unable to meet the employment costs of carers. This is thanks to the monies raised by Ken Walburn from the London Marathon last April, Bernie's Channel swim and the Junior members of the Caravan Club.

Remember that parents are carers and therefore one parent, providing they are caring at the conference (even if you swap around) will qualify as a free carer. For example, Mum may go on Saturday to the conference whilst Dad goes with the AS child/adult/children on the outing, then on Sunday it might be that Mum goes swimming with the child/adult/children and Dad goes to the Sunday session.

Exhibition Space

We will be selling exhibition space, so if you have used or developed a product or a service/alternative therapy, which could be of interest to other families, get in touch with Jim Brennan or Dick Barton and we will contact the companies concerned.

Posters

It would be nice to have a display of posters – so if you have anything you wish to share with other families and could make a poster display then please let Jim Brennan know. This can be on anything from Alternative Therapies to Equipment to Hints and Ideas, to Research both from parents as well as professionals. We have a large foyer area to use so this is a great opportunity to share your information with others during coffee breaks/lunch time/after sessions.

We very much look forward to seeing as many of you as possible in Loughborough!

Nick Bartholomew

As mentioned at the beginning of this Report we are pleased to welcome Nick as a new trustee and not only that, as our new treasurer too, the following is written by Nick as a way of introducing himself to you all.

I have been married to Sharon for nearly 12 years now and our son Liam who is nearly eight was diagnosed with AS at a year old, following a febrile convulsion. Liam is our only child although Sharon has a different view on that! We live in Thatcham, Berkshire, having moved here from Bristol in 1998 to be nearer my family as we were feeling very isolated in Bristol.

In July last year I changed career from engineering to managing a work skills project for adults with learning disabilities, which is hard work but much more rewarding. I'm an avid sports fan especially motor sport (*Chairperson's note – someone else other than Ken Walburn, moaning if a trustees meeting is the same time as a Grand Prix meeting tttt...*). I really prefer to take part in sport rather than watch and still haven't accepted that my football career is over. Occasionally I have a run out with a local veterans team but regret it for a week afterwards.

I have been a Leeds supporter (*groannn not another Leeds supporter, that makes two with Ken – I think there's a*

conspiracy going on to wear me down....chairperson again!!) since the late 60's and also keep an eye on local team Reading to see how they are doing – not too bad at the moment! I like good food (well any food really) and enjoy a pint when I get the chance. I am also a parent governor at Liam's school just so I can keep an eye on things.

I wanted to become a trustee because, as a family, we have benefited tremendously from the support we have received from ASSERT over the last seven years. Most significantly by meeting with and talking to other families at regional meetings, and the conference held at Loughborough 2000. These events are always inspiring and we come away feeling motivated and re-charged ready to take on the next series of inevitable challenges.

I would like to take this opportunity to thank all the trustees, past and present for all the tremendous work they have done and hope that I can live up to the high standard that has been set.

I am looking forward to getting more involved with ASSERT and look forward to getting to know more of you (even Paul Chick!!)

See you at Loughborough

Nick

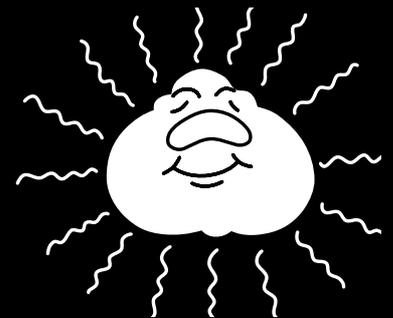
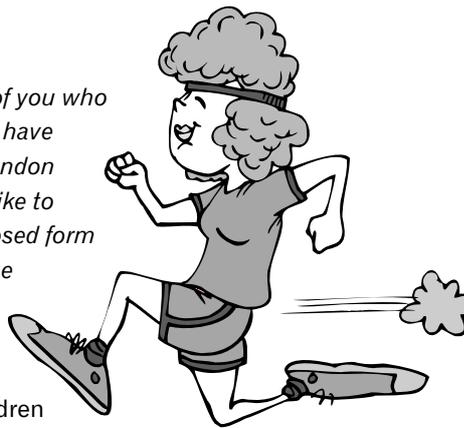
London Marathon

As always we would thank the many of you who have been fundraising for ASSERT. We have three runners this year running the London Marathon on 14th April, if you would like to sponsor them, please fill out the enclosed form and return it together with your cheque payable to ASSERT. This is a piece from one of the runners – Nic Barrass

I'm Nic, and I intend to run the marathon to raise money to help children like Millie to achieve the highest quality of life that is possible with their profound disabilities. Millie or Amelia Barrass is my much-loved niece, who was unfortunate to be born with Angelman Syndrome. For Millie this is not unfortunate as she has no idea what she might be missing out on, she just thoroughly enjoys her life. Her mother Elaine and father Alan ensure that she receives the best attention from the two of them and all those who can offer her the help she needs on a daily basis. She is a very lucky girl who can rely on the support and devotion of her parents, although at times the attention she demands can be very tiring for those who provide it.

I'm running the London Marathon on behalf of ASSERT so that I can offer support too and do my little bit for a beautiful little girl and all the other Angelman children. I know from Elaine that the support she receives from ASSERT, in a multitude of ways, is invaluable and can make the difference between a good day and a very bad day.

Nic Barrass (Amelia's aunty)



Holidays

It would be very helpful if you have any articles, information, or practical experience on holidays that you have loathed or enjoyed to share with our readers. It is always a challenge to find a holiday suited to all the members of the family. Please send your ideas and info to Sally Walburn who will be compiling a file on holidays which we can all use as a resource base for future reference.

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.

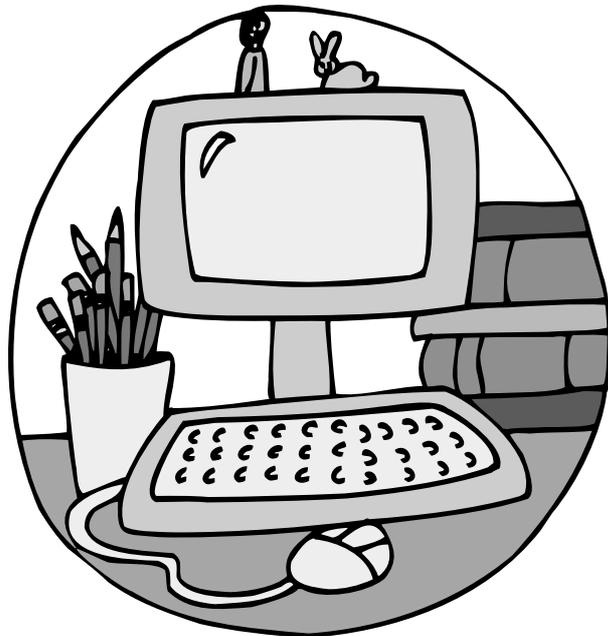
We are still providing the 'On-call' service, which is not limited at the moment. You can still contact ASSERT at any time. Instead of trustees on call at different times we are currently monitoring the volume of calls and you will get through to Sally Walburn. Of course if you wish to speak to a particular 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.

HELPLINE
ASSERT Families/New Diagnosis/Support Line

01268 415940



ASSERT Website

www.angelmanuk.org

ASSERT Email

assert@angelmanuk.org