



# *AUTISM NEWS*

Newsletter of Autism Tasmania Inc.

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### *From the President*

Welcome to our first newsletter for 1998. As I write, Dr Tony Attwood's visit is quickly approaching. Registrations are coming in steadily and we look forward to two informative days. Tony is an interesting and entertaining presenter; his seminars have been very popular with both parents and professionals. Dr Attwood has a new book on the shelves, *Asperger's Syndrome - A Guide for Parents and Professionals*. We will review this book at a later date.

Recently the National Association for Autism (Australia) had a teleconference with representatives from each State. On the agenda was the imminent incorporation of this body. Once this occurs, we will have a national voice through membership of the National Caucus of Disability Consumer Organisations. Autism Spectrum Disorders will be brought to notice as a specific disability at Federal Government Level.

The new Disability Allowance Guidelines were also discussed. These have been causing some heartache for many families, especially those with a member with Asperger's Syndrome and PDD(NOS). We have received regular telephone calls regarding the new forms parents have been asked to complete.

In this newsletter you will find details regarding National Autism Awareness Week in May. There will be a wide range of events, including presentations by Ms Louise Ulliana. Having recently attended a day where Louise presented three very informative and inventive workshops, I look forward to her return. The parents day Ms Ulliana will be presenting is also a Commonwealth

Respite for Carers funded occasion, where families can take advantage of care for their child in their own home or at the venue.

For those parents who have a child with Autism Spectrum Disorder in a government school, you will most likely be aware that DECCD has an Autism Consultant who covers the whole State. Mrs Jenny Vince, who was the consultant for the initial two years, has taken up a new role as principal of Maydena Primary School. She has been replaced by an equally friendly face - Mrs Kathy Gill, who visits schools throughout Tasmania from her base at Letitia House in Mount Nelson.

In finishing, as part of National Autism Awareness Week, we need people to sell buttons on Friday 22nd May. If you or your friends can give up an hour or two, it will be greatly appreciated.

### *About This Newsletter*

In this edition you will find a wide range of articles that we hope you find interesting and informative. We aim for a mix of information that will interest our wide readership including families, carers and professionals in the health and education fields. Thanks to those who have submitted articles.

### *The Next Newsletter*

Our next newsletter is due out in mid-June. Articles and items of interest can be mailed to P. O. Box 1552, Launceston by the last week in April. It takes at least six weeks to sort through articles, type them, layout the issue and distribute it to you, bearing in mind that our newsletter is produced on a voluntary basis.

## *Fundraising - Tulips, Tulips, Tulips!!!!*

For all the keen gardeners out there, we have included a Van Dieman Quality Bulbs Catalogue. Inside there is a wondrous array of bulbs in full colour. The good news is that every order placed will help raise money for Autism Tasmania.

### **What Do You Have To Do?**

If you want to order any bulbs, just complete your order form and mail it directly (and post-free) to Van Dieman Quality Bulbs. They will mail your order to you. Every order form has an Autism Tasmania stamp on it, so that when the orders are processed, a percentage will automatically be credited to us. PS - These bulbs look wonderful and make beautiful gifts grown in pots. I've previously ordered from these catalogues and am always thrilled with my purchases.

## *Asperger Syndrome and Autism Seminar with Dr Tony Attwood*

Dr Attwood is a Clinical Psychologist well respected in the field of autism, having worked in England alongside Dr Lorna Wing. Dr Attwood was last in Tasmania in 1993 and 1994 when he provided many parents and professionals with an outstanding introduction to autism and Asperger Syndrome. Registrations for both days are currently being received. Please contact Mark Ward 6343 2308 for further information.

## *Asperger Syndrome and Autism* with Dr Tony Attwood

TO BE HELD AT

**THE UNIVERSITY OF TASMANIA  
LAUNCESTON CAMPUS  
SIR RAYMOND FERRALL CENTRE**

Professionals - Friday 27th March 1998  
Parents - Saturday 28th March 1998

## *National Autism Awareness Week*

National Autism Awareness Week 1998 will be happening from 17th - 24th May. We have organised a range of activities; some aimed at raising the profile of Autism Spectrum Disorder, others providing an occasion for parents and their children to participate as families in outings.

### **Sunday 17th May**

Families are invited to Falls Park at Evandale for train rides on the Evandale Light Railway's miniature trains and a picnic lunch or barbecue. Come along for a great day!

### **Friday 22nd May**

This is our statewide button day and we need many members, families and friends to help sell buttons. This is a great chance to raise the profile of Autism Spectrum Disorder.

### **Friday 22nd & Saturday 23rd May**

Seminars will be held on both these days in Launceston, again for professionals on the Friday and for parents on the Saturday (A Commonwealth Respite for Carers Function). Ms. Louise Ulliana will present a continuation of the workshops held earlier this month through Giant Steps Tasmania. Ms Ulliana is a speech pathologist and principal of Wetherill Park School, run by the Autism Association of NSW. She has extensive experience in schools, tertiary institutions, support accommodation schemes and post-school options programs, especially in the field of visual communication for people with communication difficulties. Registration and further details will be posted at a later date.

### **Sunday 24th May**

There will be an outing for Southern families at Wentworth Park, starting at midday. Please bring your own picnic or barbecue, as facilities are available.

## *1996/97 Annual Report*

Included with this mailing is a copy of our 1996/97 Annual Report. We apologise for the delay in making it available to you. Should you have any questions about the report or the management of the organisation please feel free to contact a member of the committee.

## FEATURE ARTICLES

### *Autism and Fragile X Syndrome - What is the Connection?*

by Dr Jonathan Cohen

*Dr Jonathan Cohen is the appointed liaison person in Australia for the International Fragile X Alliance and is a Senior Lecturer, Department of Community Medicine and General Practice, Monash University, Victoria. The following article is reprinted from Autism News, December 1996, published by Autism Victoria.*

#### **Introduction**

Fragile X Syndrome (FXS) is now recognised as the most common inherited (or familial) cause of developmental disabilities (1). Affected individuals present with a wide range of physical, developmental and behavioural characteristics with autism-like features being common. The prevalence of the condition is similar to that of autism and is estimated at between 1/1000 and 1/4000 individuals in the general population (1). The carrier rate however has been estimated at up to 1/300 females (1). A specific DNA blood test for FXS is now available and reliably detects both affected individuals as well as carriers. Diagnosis is vital in order for individuals and their extended families to implement optimal treatment and interventional strategies and allow informed decisions to be made regarding family planning.

#### **Characteristics of FXS - physical, developmental and behavioural**

It is important to realise that the characteristic features of FXS may not always be present. The spectrum of involvement in FXS is broad and the classical features of an intellectually disabled male with prominent ears, long narrow face and large testes may be seen in only about 60% of adult males. Prior to puberty, children may not demonstrate these features and males may not be intellectually disabled (IQ<70). These features may delay diagnosis.

*Associated medical conditions* include epilepsy, recurrent ear infections, mitral valve prolapse and

connective tissue laxity with resultant flat feet and loose joints.

Global *developmental delay* is seen and includes, fine and gross motor delays and co-ordination difficulties. The majority of males exhibit intellectual impairment, speech delay, abnormal speech patterns and learning difficulties. Females tend to be less affected because this is an X-linked condition but up to two thirds will demonstrate intellectual deficits and tend to present with shyness, social anxiety and learning disabilities especially in maths.

*Behavioural features* include attention deficit in most individuals (with or without hyperactivity), autistic features (impaired social interaction and communication, hand flapping and biting, gaze aversion, pre-occupation with objects, difficulty adjusting to change, speech perseveration) sensory defensiveness and anxiety.

#### **FXS and autism - how commonly do they occur together?**

The association between autism and FXS has been frequently addressed in the literature for well over a decade yet remains somewhat controversial (2) with many authors differing widely in their views. This is a result of inadequate sample size as well as different behavioural and diagnostic testing criteria. Studies looking for FXS in autistic populations have shown rates varying between 0% and 20% (3) however summing up of all large studies gives us a figure of 4-5% (1). *This mandates both cytogenetic and DNA testing for all individuals with autism spectrum and related diagnoses as per current internationally accepted guideline (4).* Conversely, studies looking at the diagnosis of autism in FXS populations show up to 16% fulfilling the DSM-IV criteria (1) with many more having autistic features (1,5,6,7).

#### **Similarities between the two.**

There are a number of features common to both autism and FXS. These include gaze aversion

aberrant language production, deficits in social behaviour, motoric stereotypes, inattentiveness, aggression and self abuse and sensory integration problems (5). Children tend to present with speech or other delays, attention problems and unusual or odd behaviour patterns that are often described as "autistic-like". Because these behavioural features are generally the most obvious, paediatricians not requesting DNA testing for FXS will miss this diagnosis and if these children present to a speech pathologist, child psychologist or psychiatrist they will tend to be diagnosed with "mild" or "atypical" autism, Asperger syndrome, Pervasive Developmental Disorder or developmental disability of unknown cause.

### Differences between the two

#### 1. Biological

Aside from the physical and developmental characteristics, it is worthwhile noting that here is a genetic cause of autism as a result of the absent FMR-1 protein known to result in the syndrome we recognise as FXS. This protein is found bound to ribosomes in the cytoplasm and has recently been associated with two other proteins, FXR-1 and FXR-2 which themselves are autosome-derived (8). Little is known about the function of these proteins however it is clear that the genetic basis of autism per se is not X-linked as is FXS.

Nonetheless, at the recent International Fragile X Conference in Portland, Oregon, a number of speakers presented case studies of autism in FXS carriers and their siblings which were thought to be genetically determined (8). Biological similarities exist as shown in the few MRI studies that have been done to date yet clinical correlations have not been demonstrated. Much work remains to be done in this area.

#### 2. Behavioural

The core features of autism of qualitative impairments in social interaction, communication and restricted stereotyped behaviour patterns is where the controversy begins. An increasing number of professionals working with large numbers of families with FXS note that although there is certainly an increased rate of behaviours associated with autism, these are qualitatively

different in FXS. These differences revolve around social interaction, social anxiety, theory of mind, sense of humour, perseverative and tangential language, sensory defensiveness and anxiety.

Whereas those with autism don't read emotional signals, don't recognise and don't communicate feelings, in contrast, those with FXS do. They are socially aware but actively avoid social interactions. They demonstrate a higher level of arousal (which leads to social anxiety) and it is this anxiety which may lead to either shyness or inappropriate behaviour. Furthermore, once aroused, FXS tend to stay that way for much longer than their age- and IQ-matched cohorts. Simply put, they want to socially interact and attempt to do so but then become anxious and actively withdraw. This approach-withdrawal phenomenon is very much a feature of FXS. In contrast, those with autism tend to be socially oblivious and it is this lack of social comprehension that leads to inappropriate behaviour. *Individuals with FXS thus tend to exhibit more social anxiety rather than social indifference as compared to their non-FXS autistic cohort.*

*Gaze aversion* is a prominent feature and if you look at an individual with FXS and ask a question, they will typically avert their gaze, their head and often their whole upper body away while answering. This is thought to be part of the widespread sensory defensiveness seen prominently in FXS. The FXS cohort tend to be even less tolerant of all sensory stimuli than their non-FXS autistic counterparts. This leads to more disturbances of mood and arousal but interestingly less behaviour problems overall (5,6).

*Sensory defensiveness* is notably more prominent in FXS than in their autistic cohorts. In the same way that gaze aversion is thought to be a response to avoid visual hyperarousal, many individuals react to harsh bright lights (such as classroom fluorescent lighting), extraneous sounds (such as a plane passing overhead or a motor mower outside), strong smells and itchy clothing. There are a wide range of strategies that can be implemented to effectively help the individual cope and perform with these issues.

FXS individuals tend to present with a characteristic

*jocular litanic pattern of speech* and exhibit *perseveration* especially when aroused. Language is tangential in content and this is different to the tangential thought seen in schizophrenia. Those familiar with the individual and their recent experience will have no trouble perceiving the associations in their conversation. Results comparing FXS with autism show more impaired adaptive skills functioning, with age, comparatively poorer functioning in communication, daily living skills, socialisation and motor skills and more behavioural problems than their FXS cohorts without autism (6).

### 3. Educational

Overall, individuals with FXS showed greater arousal (sweating measured by skin conductance), gaze aversion, language disturbance and aberrant motor behaviour when looked at by strangers than did non autistic matched controls in a study reported by Sudhalter et al (5). Clearly, this will impact negatively in educational settings particularly when the individual is asked to respond or perform a task or when IQ is being tested. The FXS individual's performance in IQ testing will be maximal in situations where attention has been paid to a quiet and relaxed environment (extraneous sounds and external stimuli reduced) where they are prepared and familiar with the process and assessor. Testing is best done over a few short sessions in order to minimise the prevalent attention deficits.

Children with FXS tend to demonstrate a socially engaging nature, strong imitative skills, a well timed sense of humour and intense interests. Drama can be a very effective teaching tool especially in modelling appropriate social and life skills. Abstract concepts such as maths is a relative weakness, but this can be circumvented utilising calculators or life skills such as shopping. They are strong visual learners and so gain most from pictures, video and readily available computerised technology. They understand concepts in a 'gestalt' manner rather than for example phonics. Adaption of teaching strategies to take advantage of these strengths result in vastly improved outcomes both behaviourally and educationally with consequent reduction in stress for teaching staff, the individual and their family. Because of their imitative skills, providing these strategies are implemented and

sufficient support services are available, most students will perform better in an inclusive school setting although they will still require a lot of one-to-one and small group teaching.

### Summary

Autism Spectrum Disorders are described on the basis of observed behaviour and diagnosis is thus subject to variation. FXS is a genetic condition which is diagnosed following a blood test and is a cause of autism spectrum disorders in a substantial minority of cases. FXS demonstrates typical physical, developmental and behavioural features that present in a unique pattern. A wide range of treatment and intervention strategies are now available and are specific to the condition. Autism spectrum disorders and autistic features are seen in increased frequency in FXS and may require different management strategies to those used in "pure" autism. DNA testing for FXS should be considered if not done already or if testing was performed prior to 1992 in any individual with autism spectrum features, if other clinical features of FXS are present or if there is a family history of similar conditions. Professionals and families need to be aware of the specific strengths and weaknesses associated with FXS in order to enhance management and improve outcomes for affected individuals and their families (10).

*A wide range of educational resources for professionals and families and further information regarding FXS is available from the International Fragile X Alliance (Australia): 263 Glen Eira Rd, North Caulfield Vic. 3161. Tel: (03) 9528 1910 Fax: (03) 9532 9555 email: jcohen@netspace.net.au*

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*and Carrier Testing*

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American Academy of Paediatrics, Health Supervision for Children with Fragile X Syndrome Paediatrics Vol 98 No 2 August 1996

## **Teaching Motor Skills Graduated Physical Guidance**

*The following article has been prepared by Dr Sue Bettison a clinical psychologist from Sydney. In the article Sue highlights the gross motor or movement difficulty experienced by many people with an autism spectrum disorder and offers a strategy for providing graduated physical guidance to assist in the teaching of motor skills. Reprinted from Autism News, December 1997, published by Autism Victoria Inc.*

Many people with developmental disabilities do not know how to move to achieve a given result. They do not explore and try things voluntarily and so do not build up a range of skills that they can adapt to new tasks. Graduated physical guidance allows us to move a learner through the performance so that he or she is practising the movement, even though the individual may not be able to initiate the movements spontaneously. It also ensures that the child who habitually resists doing things when asked, gradually relaxes and accepts the task as something that is part of daily life.

Graduated physical guidance enables us to ensure that the individual does what is needed without feeling frustrated or angry. It also helps us to observe the learner closely. In this way we gain

the detailed understanding of the person that is crucial in making the teaching of movements a real teaching and learning experience for both.

If the individual does not immediately start the correct movement after a prompt or instruction is given, or stops part way through, give gentle, physical guidance. With your hands, move the appropriate parts of the learner's body through the required motions. Your aim is always to give as little guidance as possible in order to allow every opportunity for the person to make the movements spontaneously. Therefore, you should be ready to release control the instant the individual begins to make the correct movement. You can only sense the initiative on the learner's part if your touch of grasp is light, slow and gentle. However, when you withdraw your control, your hands should be kept close to the learner, shadowing his or her movements in order to give immediate physical guidance should the movements stop or go in the wrong direction.

If the learner begins to move in the wrong directions or pull away, you should block the movement. Do not force the individual to move in the correct direction. Block the incorrect movement until the learner is still, and relaxed, then you can continue physical guidance of the correct movements without resistance.

Your aim is also to reduce your physical guidance until it is no longer needed. You may begin with a gentle grasp and physical guidance for the total movement. You should reduce this as quickly as possible over trials to a gentle push and then just a touch. Watch and feel the learner's movements carefully, so that you can reduce or take away physical guidance the instant he or she takes the initiative. As the learner moves more confidently, you should keep your hands close by. Once you feel sure that the correct movements will always be carried out, you can relax and merely observe. However, as learning occurs, always be prepared to give the amount of guidance needed at the time.

Graduated physical guidance is crucial to the success of teaching any motor skill to people who have difficulty understanding and organising their own learning or following a model of instructions.



It allows you to show the learner what to do without force. It reduces the likelihood of resistance or fear. It enables the learner to develop confidence. It prevents us from confusing the learner with constant talking and it enables both the teacher and learner to concentrate solely on the task at hand.

Adapted from:

Bettison, S. (1982). *Toilet Training to Independence for the Handicapped*. Charles C Thomas: Springfield, Illinois, pp27-28.

**CONTACT DETAILS for Dr Sue Bettison**

32A Castle Howard Road, Cheltenham, NSW, 2119, Tel (02) 9869 4019 or fax (02) 9868 2539 or email <bpaddick@fl.asn.au>

## **GENETICS, AUTISM AND PRIORITIES**

*Reprinted from Autism Research Review International Volume 11, No.2 1997, Editors Notebook/Bernard Rimland Phd.*

Few, if any researchers have argued as long, as consistently, and as ardently as I have that genetics play an important role in the causation of autism.

In the late 1950's, when I started my study of autism I was virtually alone in arguing not only that autism was biological disorder, not caused by covert maternal rejections, but also that there was a strong genetic component in its causation.

In my 1964 book *Infantile Autism: the Syndrome and Its Implication for a Neural Theory of Behaviour*, I protested: When dark-haired and dark-eyed parents produce a dark complexioned child, we are all quick to agree: "Mendel was right!" But when introverted parents produce a child who similarly shows little interest in socialisation, the refrain inexplicably changes to "Aha, Freud was right!" (p64)

Long before computerised literature searches made the task easy, I arduously ferreted out every twin set that had been mentioned, even in passing, by reading virtually every autism article in the world of literature. Of the 14 sets I found, 11 were identical, and in all of the identical sets, both twins

were autistic (pp54-58). The dearth of fraternal and discordant twin pairs has since been confirmed in many studies.

Similarly, my 1964 assertion that where mental illness has occurred in the families of autistic children, it tends strongly to be an affective disorder, and not schizophrenia, has been repeatedly supported by later research (pp.76, 159-163,171).

I started autism/genetic research at Stanford and UCLA. In 1964 I collaborated with Luigi Luzzatti at Stanford by providing carefully diagnosed cases of autism for chromosomal analysis, and a few years later did the same with Arnold Mandell and Lewis Judd, then of UCLA.

In 1976, I co-authored a paper with Mary Coleman in which we proposed an autosomal recessive model for autism-a proposal repeated 10 years later by Edward Ritvo. In the 1980's and 90's, I continued to provide genetic research groups at Stanford and UCLA with cases of multiple child families from our large database.

Yes, I have worked long and hard to encourage genetic studies of autism.

Despite these efforts by myself and a few others, the genetics of autism was largely neglected. No more. Within the last few years, the genetics of autism has suddenly become a growth industry. Earlier this year there were active genetics-of-autism research programs in at least seven U.S. universities - but that's not all. On May 30th, the National Institutes of Health announced the start of a five year, 27 million dollar international collaborative network of research centres on autism. Research will involve 24 universities in 13 states and four foreign countries. While the research is by no means limited to genetics, genetics are heavily emphasised.

Am I happy that genetics research is at last being given the attention it deserves? Yes, I certainly am.

Am I disappointed that so much money and resources are being spent on the genetics of autism, at the expense of other projects which might have surer, faster and better payoff? Yes, I certainly am.



There is an old Chinese adage to the effect, 'be careful of what you wish for - your wish may be granted.'

Why am I now concerned that genetic research is over-supported? For several reasons. Without question, there are many causes of autism, only some of which may be expected to be largely caused by genetic abnormalities. In this regard, autism is vastly different from Huntington's disease, cystic fibrosis, phenylketonuria, Tay-Sachs disease, and many other conditions where single genes play powerful roles. Even in those gene-dominated disorders, genetic research has thus far resulted in very few, if any, effective approaches to treatments. An all-out race at this point to find the far more elusive and diverse autism genes seems a bit premature.

Edwin Cook and associates have found the first gene associated with autism. This is a very important development, and Dr Cook and his colleagues are to be commended. The gene relates to the processing of serotonin in the brain. What are the implications of this finding for the near term prevention and treatment of autism? In a comprehensive review of the neurochemistry of autism published in 1990, Dr Cook wrote, "The most consistent finding has been that over 25% of autistic children and adolescents are hyperserotonemic. However, after 29 years of investigation, the mechanism of hyperserotonemia has not been determined." I am concerned that another 29 years may pass before such genetic research bears fruit, in terms of prevention and treatment.

As our readers know all too well, there are many, many autistic children with us here, today. And many more are being born every day. Shouldn't at least one million of those 27 million dollars be used to investigate, and make more effective, treatments that are here now, and are known to provide major benefit to some autistic children?

A prime candidate for such research funding is vitamin B6. This vitamin, along with the mineral magnesium, is used in the production of serotonin. Since 1965, 18 research reports have been published by scientists in six countries showing that about

half of all autistic children and adults improve significantly when given large amounts of B6. Unlike drugs, B6 is a safe, natural substance the brain requires. Why do some autistic people need extra B6? No one knows. What other nutrients, vitamins, minerals, lipids, amino acids - might be given with the B6 and magnesium to enhance their effectiveness? No one knows. Research to compare blood levels of various enzymes and neurotransmitters, before and after treatment with B6, comparing B6 responders with non-responders, might produce very informative results that could help autistic persons we live with every day. Such research cries out to be done. It is not being done. No money.

Another area in which a small expenditure of money could make a big difference relates to the use of diets in which certain substances are avoided. Karl Reichelt of Oslo has pioneered in this area for decades, showing the highly significant effects of removing gluten, gliadin and casein from the diets of autistic children. There are now about forty research studies in Norway, the UK, Italy, and the U.S. supporting this finding. Special diets are hard to implement. The problem might be solved by giving the children special digestive enzymes that would break down the peptide from these foods and permit their assimilation. Like B6 research, that would help thousands of living, breathing autistic children who are here now. No money for such work, but millions of dollars for the more glamorous search for genes.

### *Autism Gene Discovery: A False Lead?*

*Reprinted from Autism Research Review International Vol. 11, No4, 1997*

Earlier this year (ARRI 11/2), Edwin Cook, Jr., and colleagues reported preliminary evidence of the first specific gene linked to autism. Cook et al. found that a shortened form of the serotonin transporter gene, which codes for a protein that reabsorbs the brain chemical serotonin into neurons after it is released, tended to be inherited by autistic children.

A new study by S.M. Klauck et al., however, casts doubt on Cook et al.'s findings. Klauck and co-workers actually found that the long, not the short,

version of the gene tended to be inherited by autistic children.

"Overall," Klauck et al. report, "we were not able to replicate the findings of the first study.... and instead observed a tendency for the association of the opposite genetic variant of the gene with the disorder."

Researchers have suspected a link between serotonin and autism, because about one third of autistic individuals have high plasma levels of the neurotransmitter.

References available.

### *From our Readers.....*

*This section is an opportunity for you to share your experiences with others, have your say, comment, praise, whinge - whatever!!!. All articles will be published in good faith (the intent of your contribution will be honoured although some changes may occur). While we welcome your contributions the views expressed here are not necessarily those of Autism Tasmania.*

Julie Fyfe joined the committee of Autism Tasmania last year after arriving in Tasmania from South Australia. Julie has a young son, Cameron, who has autism..

It's funny how sometimes television seems so real. The very last scene of Nell, when Jodie Foster looks out along the dusky lake fighting back the tears for the memory of her little sister she once had, I did exactly the same today for the little boy I haven't got. Today I went to the Longford Harvest Festival with my son Cameron. I fought back the tears as I watched the children dance around laughing and giggling to the Irish Band, spontaneous, free and happy. Cameron sat next to me, with his head in my lap playing with the light and colours of his lego blocks, oblivious to how I was feeling, oblivious to the music, oblivious to the other children dancing around us. They were calling Cameron to join them with their eyes, which I could read, but Cameron could not. Cameron is 6 1/2 years old, and has severe autism.

Cameron and I arrived from Adelaide, just eight

months ago for the Giant Steps Program. I heard about Giant Steps on a morning program about three years ago and I came to Tasmania to investigate and left in tears because Adelaide had nothing like that to offer my little boy. Kindergarten is too busy, cluttered, noisy and unstructured with not enough 1:1 teacher time, the school system is even worse.

I decided well if they can do it (you Tasmanians) why can't we!! I then set about blowing my trumpet to the tune of Giant Steps. I joined the Board of the Autism Association of South Australia and I held a full day seminar about Giant Steps, which was attended by 150 parents and professionals. I was hoping to raise a collective group of parents that would help fight for more resources for our children with autism. A large enthusiastic parent group was formed called Positive Steps Forward, which I chaired. The group decided to work within the education system, to change policy, staff ratios and overall educate the bureaucracy about Autism Spectrum Disorder. Positive Steps Forward has made some huge political inroads, but as you know change is a slow and long process.

When Cameron was offered a position at Giant Steps in April last year we took the opportunity with both hands, Cameron's time was running out and the years were slipping by. The chance of successful change in behaviours decreases as age increases, the sooner the better and we had not a moment to lose. I was surprised that we were accepted, as I agree that local residents should get priority placements and to my knowledge they do. I will not hide behind the fact that interstates taking Tasmanian places is a contentious issue, because it is. It seems that the problem lies with the category 'A' funding policy where the child should have psychological reports suggesting severe autism to qualify. In all honesty no parent wants to hear such a diagnosis, but sometimes it is necessary to receive the desired outcome. The selection of category 'A' students is then decided by an independent panel based upon all the reports submitted by parents and other professionals, not by Giant Steps. Giant Steps Tasmania is one of only two schools like it, in the whole of Australia. It is unique, and highly specialised in meeting the

needs of children with autism.

I am saying all this because I feel very privileged to be given the opportunity to offer so much more to my son. Autism specific schools do not exist in Adelaide, and therapy based education is in its pilot stages, to begin later this year, as a direct result of pressure placed by Positive Steps Forward.

When we arrived Cameron was not toilet trained, he had a very limited diet, and was withdrawn from the world with temper tantrums due to the frustration of not being understood. He is now out of nappies, his ability to be able to eat different types of food has improved (not good but better), he looks up when you call his name. He understands simple commands like shut the door, or pick it up, sit down, we are going in the car, and do you need the toilet. He is calmer, more confident and willing to try new experiences, climbing on equipment for example. His world is beginning to open. Slowly day by day I see the window of opportunity open a little further. He has the most beautiful blue eyes, that can swallow me whole, we connect so often now, that I don't feel the need to cry when it happens anymore. I know as a parent I am not alone when we experience a lump in the throat, and the pounding of our hearts when our children are 'really with us.'

Giant Steps has done all this, the window is slowly opening. I am not expecting miracles, I am realistic in my expectations for Cameron. For myself, I no longer want to watch movies like Nell and feel sad for myself and my little boy. I am proud of how far he has come in a short time, I am proud of the strength he has given me, and I am thankful for the opportunity Giant Steps and Tasmania has given us.

Thanks - *Julie Fyfe.*

*The following contribution highlights the difficulties an adult with autism has at home and in the workplace on a daily basis and the coping mechanisms used by him and his parents.*

## MICKY

Twenty six year old Mickey who has autism lives in northern Tasmania. Although Mickey lives in a

quiet location his dream is to live on a 100 acre farm surrounded by bushland. Despite his need for solitude, Mickey says occasionally, 'It'd be nice to have a friend.'

Another predictable Sunday working in the garden to the accompaniment of racing cars and the synchronised voices of my son and the video commentary. He is word and accent perfect. Not for the first time do I permit myself the luxury of 'tuning out' allowing my mind to drift aimlessly. Tomorrow will come around all too quickly and with it the demands of a busy office and factory. Mickey will probably watch the same videos until lunch, I presume content with the familiar.

Someone walks up the lane and pauses at our gate to talk. Mickey, frowning, appears at the window. He's wondering what they want and even at this distance I can see the concern etched upon his face.

Weary from toiling in the garden I come inside to see whether my wife has prepared lunch. It is only now that I realise that the sounds of car racing have been replaced with Chopin and my spirits lift. Ah! If only ...

Mickey comes out of his room proudly carrying a beautiful pencil drawing of a tiger and yet I know that he will be overly self-critical and despite protestations from my wife and I will dismiss our praise.

It is 5.45am and Mickey comes down for breakfast, beginning his week with the usual routine. By 6.45am we are already in the car driving toward the city. He's recorded the sound-track of his favourite rally video so he can listen to the familiar commentary on the way to work. Mickey drives whilst I attempt to read a business journal. We don't speak.

We share an office for some of the day. Before Mickey begins his regular tasks he reads the car advertisements in the local paper, often circling cars of interest or writing them down to be studied at some later time. Some of the tasks are complicated but Mickey has learned the procedures and can be relied upon totally to carry them out accurately. To the amazement of some staff and the amusement of

others, Mickey sticks rigidly to a time-table. The orders from our chief client are attended to at precisely 8.00am not a minute earlier or a minute later. He is totally responsible for incoming stock and it is very very rare that Mickey makes a mistake. The filing is done with accuracy unknown before Mickey had this responsibility.

The staff have had their morning coffee break. One half hour later Mickey takes his break, alone. He sits and draws. This time it is a picture of the Managing Director with a handful of hair (he's almost bald) jumping up and down, beads of sweat on his brow. Minutes earlier Mickey had heard his boss describe unrealistic customer deadlines. Mickey's pictures are pasted over the walls throughout the factory. They all tell a story. During the winter the factory is particularly cold. To inform the boss that working conditions were less than ideal, Mickey drew pictures of staff rugged up in heavy top-coats, mittens and scarves..their breath forming icicles, as they operated machines which discharged frost covered cartons. On the office door is a picture with the heading 'Welcome to Mawson's Hut.'

The staff all react differently to Mickey. Alan doesn't comment on the repetitive phrases he hears daily but admires Mickey's time-keeping. The mail is collected at 12 noon precisely! I cannot detect whether Ruth is irritated by his insistence that the goods for mailing be placed in the same place on the floor. If they are not in their place they are not collected...despite the rather obvious pile of out-going mail on her table! She recognises when he is moody and leaves him alone.

Mickey never initiates conversation but John knows how to get him chatting; he talks to him about cars. Mickey won't talk for long, in fact he gets annoyed when he sees others talking when they should, to his way of thinking, be working. All the staff are tolerant of Mickey's rather odd behaviours although some struggle for patience when his tuneless, often high-pitched whistle penetrates their selective deafness. Unable to shut out the noise and fearful of upsetting him, blood pressures rise.

Mickey has a sense of humour appreciated by some of the staff. The mundane routine can be lightened

by jokes or Mickey's mimicry of colleagues. For others the strange noises or repetitive phrases occasionally jar the nerves but furrowed brows are the only key to their disquiet.

This afternoon, Mickey is angry. Too many people have been asking him to do too many things. He's listed down their demands but he's confused. He doesn't know what has priority and at 2-30pm he should be.... There's a phone call from the major client requiring urgent delivery. The details have been scribbled down on a piece of paper..it's not in the usual format..Mickey checks and double checks, afraid of making a mistake. An unscheduled delivery arrives just as he is about to look at his list. He expertly manoeuvres the fork-lift and safely brings the incoming goods to a halt inside the factory. Today, the delivery note is different. The layout of the form has changed and so has the colour. The information is the same but it throws Mickey because it looks different. Later, I hear him muttering beneath his breath about others' lack of organisation.

I have just checked the accuracy of the Time Sheet Analysis against my figures in the computer. Mickey is spot on! I congratulate him but he is still wound-up and doesn't acknowledge me. I determine to see, once again, if I can prevent this upset to his routine.

For the moment the rush is over. Mickey has taken himself well away from everyone and has decided to do some packing, one of the filler jobs on his schedule. His routine visit to the post-office has been removed from his list of tasks because of his inability to cope with the hustle and bustle of the busy city and post-office. The people are never the same.

It is after five and Mickey is ahead of me as we walk towards the car. A passer-by momentarily looks at him and politely looks away but already Mickey has stepped off the kerb to avoid interaction. To alleviate the dark mood I begin to talk about a new car which has just passed in the other direction. These moods can result in talk of hopelessness and despair and I need to lift his spirits before we get home.



Dinner is almost ready. My wife looks relieved to see that Mickey's mood is not aggressive or greatly withdrawn. We eat together. My wife senses that questions are not appropriate and that Mickey needs time-out. His television is on. He is watching a comedy. In half an hour, with any luck, he'll be entertaining us with his mimicry of the comedians, recalling their punch-lines. My wife will be happy..and no doubt, I will, as usual fall asleep.  
R.B.

*The following article has been written at the request of the editorial committee. It contains some food for thought for parents of children with Asperger Syndrome.*

I write this with some reluctance, although the editors assure me that parents do want to read personal recounts. Ed. also asks that I be positive. I will try.

Our son is our first born. The first indications that he wasn't progressing within the normal continuum were evident when he only displayed single words at two and a half years of age. You will be familiar with the spectrum of health professionals within which we then found ourselves.

I'm not going to give a year by year account of his schooling. It is suffice to say that we reached crisis point in his Grade 3 year. The school setting had been fraught with difficulties, and became so unbearable he wanted to die. His life wasn't worth living..... no friends, hopeless at sport, crying constantly. His situation was compounded by the fact that he has what the professionals term "insight". He was, and remains so, very aware of his differences, and also able to articulate them. "The most popular children are those who are good at sport and also capable in the classroom." I offered him the option of home schooling. His reply: "I would like it, but you wouldn't be happy because you have things you want to do."

It was then that I took an extremely positive step and contacted Clare House (Child and Adolescent Services). We visited regularly for three years, and for much of this time had contact with the same psychologist. It was during this time, following attendance at Tony Attwood's seminar, that the

psychologist suggested that our son displayed many of the characteristics attributed to Asperger's disorder. While I recognise the difficulties associated with labelling, for us it would have been helpful to have been able to explain this to class teacher's rather than have him labelled as a difficult child in the classroom/school setting.

We are now well into high school. Certainly, there have been problems in settling in. However, we have been blessed with the most caring tutor, who has not written us off as paranoid parents. The school has been understanding of the situation. The high school setting has also meant that he is not the only child in his year group who is different, although they do seem to fall together. The future is unknown, but he has made great strides since those unhappy days of some years ago.  
Anon.

## NEWS AND VIEWS

### *Autism Consultant*

Jenny Vince has taken on a new role within DECCD and although we wish Jenny well, the knowledge and experience she has gained over the last two years will be sorely missed. Jenny continues to remain on the Autism Tasmania committee.

We welcome Kathy Gill from Hobart who has taken over from Jenny and invited Kathy to introduce herself to our membership.

*Kathy writes.....*

I completed my B.Ed in 1984 and taught in several Southern schools before beginning my Master of Education Degree in 1991, focusing on special education. I have worked in both regular classrooms and as a support teacher at Early Special Ed. in the south across the three districts of Bowen, Hartz and Derwent. During my time as a support teacher I worked with classroom teachers and others to ensure students with a range of disabilities were included into their local school communities. In 1997 I returned to classroom teaching and included three students with disabilities, two with Downs syndrome and one with Autism Spectrum Disorder. I was one of six teachers from around the state to be included in the book *Different Voices* which was

designed to identify and celebrate best practice in relation to students with high support needs. Late last year I was encouraged to apply for the position of Statewide Autism Consultant and was successful in my application.

As Autism Consultant I have a number of primary tasks to perform.

1. To provide assistance and advice to classroom teachers and other DECCD staff.
2. To support the development and implementation of appropriate Individual Education Plans for identified students in addition to general classroom activities.
3. To assist in the development and implementation of education policy and guidelines relevant to students with Autism Spectrum Disorder.
4. To develop and maintain knowledge relating to Autism Spectrum Disorder and disseminate current information.
5. To facilitate co-operative team management with parents and professional staff for identified students.
6. Plan and implement appropriate Professional development for all staff involved.
7. Maintain appropriate records and evaluate the effectiveness of educational services provided for identified students with Autism Spectrum Disorder.

My personal aims for my role as Autism Consultant are:

1. To attempt to evaluate the excellent work done by my predecessor, Jenny Vince.
2. To become familiar with all the stakeholders who are associated in any way with individuals with Autism Spectrum Disorder.
3. To increase awareness in the general community about Autism Spectrum Disorder and the numerous issues pertaining to the disorder.
4. To work in a collaborative way with the established groups already working with people with Autism Spectrum Disorder, For example Autism Tas., Giant Steps and Young Autism Support Tasmania.
5. To encourage greater acceptance in the community of people with disabilities, especially those with Autism Spectrum Disorder.

Please note that I have recently moved base from Timsbury Rd. School to Letitia House, Olinda

Grove, Mount Nelson. My new phone number is 6233 7175 and fax number is 6233 6980.

*Kathy Gill*

## *Giant Steps Tasmania*

Giant Steps has commenced 1998 on a positive note but with the same financial uncertainty. Several new staff have been appointed including Mick Clark as Program Manager, Rachel Evans to the role of play therapist and Sarah Koehne as ADL therapist. Giant Steps also welcomes Sue Nauman, Jessica Gugliotti and Mandy Atkins-Cock as therapy assistants, all of whom have varied experience in autism.

The refurbishment of "the house" donated to Giant Steps by Savage River Mines is nearing completion with the assistance of generous donations by The Lions Club of Tasmania, The Trust Bank Foundation and the Rotary Club of Deloraine. These donations are much appreciated and have enabled the conversion from a house which arrived in several pieces and in fairly poor condition to an additional building to house several therapy components. With the addition of the new building all aspects of the program will be housed on the one site and the staff will finally have a staff room. Several volunteers have generously given their time to work on the building to have it completed by the end of March.

The children have settled back into the routine with two new families taking the opportunity to attend the program. Several children are on inclusion programs and these are moving along steadily.

The nature of the program means that funding and fundraising will always be a priority for the centre. It is a paradox that although organisations are willing to fund the "bricks and mortar", it is considerably more difficult to access recurrent funding for staff.

A review of the program has been completed by Education Department Officers and forwarded to the Minister. Giant Steps representatives will be meeting with the Minister as this issue goes to print to discuss the future of the program especially as



the original contract with the Government is due for renewal in June.

At present Autism Tasmania is entitled to two nominees on the Board of Giant Steps. Tricia Bourke represents the interests of Autism Tasmania and the second position has been vacant since the resignation of Mick Clark. If you are interested in this voluntary but stimulating position, please contact Autism Tasmania.

### *Young Autism Support Tasmania*

(Supporting families teaching ABA)

We had our first meeting back for this year last month. There was lots of business to catch up with but also time to hear a number of positive reports from our parents on their children's progress. It seems that many of us have made the most of the extra time to do some additional ABA as well as some relaxing over the school break. Our membership has grown over the past few months which is another sign of the increasing interest in Applied Behavioural Analysis (ABA).

A family BBQ was held at Wentworth Park on the 4th of February to bring everyone together with siblings especially in mind. It was a very hot day but a good time was had by the many that attended. It was also an opportunity for some of our new members to meet everyone.

Clinical psychologist Jura Tender arrives from Perth on the 16th March for approximately a two week visit to Tasmania. As well as seeing our children on a home visit basis we are also planning two seminars.

1. A Language Development Seminar covering non-verbal language through to verbal language. This will be held at the Early Special Education Centre in Hobart on the 25th March at 7pm till 10pm. This is aimed at parents, therapists and teachers with knowledge on ABA.

2. A Successful Inclusion Into School of Children with an Autism Spectrum Disorder Seminar. This will be aimed at teachers and their support staff and will also be held at the Early Special Education Centre in Hobart on the 20th March from 9am till 1pm. For more information on these seminars or

Jura's visit please contact me on 6229 7818.

As always, our members and anyone interested in ABA meet at Albeura Street Primary School on the third Wednesday of every month at 7.30pm.

*Grace Talbot* - Y.A.S.T. Secretary

### **Autism**

*The International Journal of Research and Practice*

Published in Association with the National Autistic Society in London. The first issue was printed in July 1997. The launch of **Autism** reflects the recent worldwide growth in the research and understanding of autistic spectrum disorders, and the consequent impact on the provision of treatment and care. Articles will include substantive research reports as well as smaller scale action research and case studies. Critical reviews of recent theoretical and experimental work and its relevance to intervention and care provision will also be a core feature of the journal.

**Autism** is edited by Patricia Howlin and Rita Jordan (UK) and amongst its Editorial Board and Associate Editors the following names are featured, Simon Baron-Cohen (UK), Christopher Gillberg (Sweden), Margot Prior (Australia), Lorna Wing (UK), Lawrence Bartak (Australia), Gary Mesibov (USA), Michael Rutter (UK), and Digby Tantum (UK).

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For further information contact Autism Tasmania.

### *Questionnaire*

Also included in this mailing is a questionnaire for parents from Dr Robyn Young, Lecturer in the School of Psychology at Flinders University, South Australia. Dr Young would appreciate any responses to assist with her research on the early signs, or 'primary deficits', of Autism or other Pervasive Developmental Disorders and the characteristics exhibited that lead to a diagnosis of Autism (or other Pervasive Developmental

Disorder).

Please take the time to complete the enclosed questionnaire and return using the self-addressed pre-paid envelope provided. The anonymous questionnaire asks for a brief history of the autistic child's development, examining the range and duration of behaviours that the child may have exhibited at specific times of his/her development.

For more information please read the accompanying letter from Dr Young.

### *Letter to the Editor*

Dear Editor

There has been some discussion in the media recently regarding the use of Naltrexone as a drug therapy in the treatment of opiate abuse. As an opiate receptor antagonist, Naltrexone blocks the euphoric effects of such drugs as heroin. I was interested therefore to read, whilst surfing the internet, that Dr Jaak Panksepp of Bowling Green University, OH has been investigating the effects of Naltrexone as a treatment for some of the symptoms of autism.

Dr Panksepp, according to Stephen M Edelson Phd at the Centre for Study of Autism, Salem, Oregon, believes some individuals with autism may benefit from the drug. The literature seems to indicate that there has been improvement noticed in "...socialisation, eye contact, general happiness; normalised pain sensitivity; and a reduction in self injury and stereotypic (self-stimulatory) behavio(u)rs.." in those people with autism taking this drug.

Naltrexone as a treatment for some symptoms of autism is relatively new and long term side-effects, as I understand it, would be difficult to assess. From my limited reading, the most common side-effect, would appear to be gastrointestinal disturbance and according to Dr Edelson et al caution should be exercised when considering treatment of those who may also have Schizophrenia.

I would appreciate any further information from

readers particularly those who may have a background in medicine or clinical psychology. I am also interested in anecdotal information from readers regarding the drug Prozac as a treatment for Depression given to those with an autism spectrum disorder and from informed sources regarding long term side-effects, in particular, Tardive Dyskinesia.

Keep up the good work, Autism Tasmania!

*Paula Barnes.*

*The following article is reprinted from Autism News September 1997, published by Autism Victoria Inc.. We thought it may be of interest to families in Tasmania.*

### *Introducing Sam*

by Julie Ljiljak

*Julie decided to introduce her son Sam to the families of his kindergarten by writing a little about him. It is a strategy adopted by other parents and is well worthwhile. This is the text of Julie's letter to the other kinder families sent out during Autism Awareness Week last year. Reprinted from Autism News, September 1997, Published by Autism Victoria Inc.*

"My son Sam has Autism. Sam is very high functioning and copes well for a child with autism, but he still has problems which interfere with his development and interaction with the world. He loves other children and tries to play their way, but it's hard to join in a game of pirates when you think the game is firemen, and no one can explain your mistake.

His understanding of everyday things is mixed he can understand tangible things that are visible or easily demonstrated, but doesn't understand concepts like time, social behaviour and emotions. He has learned that the correct way to ask is to say "please may I have some?", but follows it up with "Now give it to me!". He has a repertoire of learned responses with no real understanding of the meaning behind them.

Sam has difficulty explaining himself and often gives long speeches about a favourite topic (outer

space or the body). He recites facts and figures he has learned from the television or computer, particularly when he feels anxious. These speeches must be word perfect and he will restart the speech if he mixes it up. He is unable to stop until he has finished giving all the information he can remember on the topic. Attempts to interrupt him are met with cries of "No, I'm not finished. Don't say that!" and often tears and distress.

Sam had to be taught to sleep at night, at the age of 4 1/4, as he did not understand the concept of sleeping all at once, but napped all day, and woke ALL NIGHT! He needed a flow chart to understand about using the toilet, and we now know that he is a very visual learner as well as extremely logical. Not much good in our society!

We have a very positive attitude to his future development. Sam's every achievement is cause for celebration and delight at his triumph over the confused messages in his head. We have learned that there is a positive aspect to living with a child with special needs, and that it is best not to look at the problem in isolation, but to balance the view by recognising his achievements and the joy of watching him grow and learn.

If you say "Hello!" to Sam someday and he responds by shouting at you to "go away" or "be quiet!", please don't think badly of him. He is confused by his own feelings and has no time to think of yours."

### THE KEY

*If you could see the world through my eyes you  
may understand  
Why I can't bear to look at you or feel you touch  
my hand  
The messages inside my head are painful and  
confused  
So can you see why my behaviour is so  
misconstrued?*

*If you could feel the isolation in this world of mine  
You may begin to understand why I can't toe the  
line  
Your rituals are strange to me and I don't  
comprehend  
The rules of your society and what you call a  
"friend".*

*If you could feel as alien in your world as I do  
You may begin to understand why I am not like  
you  
The things you live with every day can cause me  
such distress  
And every day I struggle just to make some sense  
of this.*

*If you would realise how understanding is the key  
To learning how to live with this and one day set  
me free  
Then I may begin to understand the meaning of a  
friend  
The road is long, please walk with me until we  
reach the end.*

### Reminder

## MS LOUISE ULLIANA

Speech Pathologist and Principal of Wetherill Park  
School, NSW

will return to Tasmania on the 22nd and 23rd May

as part of Autism Awareness Week Activities

Louise will discuss Visual Representation as a means of  
Communication for people with Autism Spectrum Disorder.