



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

Postal Address

PO Box 1552
Launceston
Tasmania 7250
Australia

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NEWS AND VIEWS

From the President

By the time you receive this newsletter you will have already had a look at the conference details for next year. The organising committee is very excited at being able to secure such high profile speakers as Dr Christopher Gilberg and Ms Carol Gray, both of whom are very excited about coming to Tasmania. You will also note that three prominent practitioners in the field of Autism Spectrum Disorders in Australia are also presenting and we welcome them, they are: Ms Vicki Bitsika, Dr Laurie Bartak and Dr Tony Attwood.

Ms Wendy Lawson, who visited the state in November to launch her new book "Life Behind Glass" in Tasmania and present workshops and address parent groups, will be returning in the week after Easter - approx April 12th. Keep the week free if you want to attend one of her workshops. More details will be sent out closer to the date.

As Christmas approaches many of us look forward to the long Christmas break with some trepidation, especially as many of our children don't cope very well with the change in routine. I know many people find it easier to deal with problems as they arise if they can talk to someone - "a problem shared can be a problem halved". Committee members, a friend, anyone who is a

good listener can really help us when we need a chat.

Many thanks go to the committee of Autism Tasmania for their hard and dedicated work throughout the year.

I'd like to wish all our members a happy, safe and relaxing festive season and look forward to seeing you all in the new year
Rose Clark

From the new Editor

Welcome to the final issue of Autism News for this year from your new editor. I had the opportunity to assist Rachel with the last edition just before she left the state and I hope that I can do you - the readers; and the newsletter justice.

I also hope you will find these articles interesting and that you may be inspired to put pen to paper as Lisa Minchin did - thank you Lisa! There is no one definitive experience of Autism and it is always interesting and enlightening to read other people's stories.

So - read on and enjoy

Cheryl Scott

Autism Tasmania Library

Members are able to to borrow books from any of our three libraries free of charge. The only cost incurred would be postage; if there is no other means of delivery. Please ring any of the numbers below to access the library in your area.

NW	Michelle Williamson	6442 4079
North	Tricia Bourke	6334 2843
South	Roseanne Lay	6244 2540

Secretary

Rachel Hodge, a new committee member and founding member of the Northern Asperger Support Group is now our new secretary. Rachel is doing an excellent job and is being helped in her position by Sue Thorogood.

Goodbye AGAIN to Rachel Evans

Once again we say farewell to Rachel Evans, who has left Tasmania to take up a position with the Autistic Association of New South Wales.

On her return to the committee during the year, Rachel took up where she left off working extremely enthusiastically with all tasks that came her way.

We are all disappointed to let Rachel go (again) but wish her all the very best in her new position.

NEWS AND VIEWS

Young Autism Support Tasmania

(Supporting Families Teaching Applied Behavioural Analysis)

Our first AGM took place on the 16th of September, after having been incorporated for 7 months and yet we have been meeting as a support group for 2 years now.

One result of the last few committee meetings has been the compiling of an Autism and ABA information sheet comprising of frequently asked questions and information. A popular question at the moment being "What is Applied Behavioural Analysis" or "Discrete Trial Training" as it is often referred to. The answer to this being that Applied Behavioural Analysis or ABA is a teaching method founded on scientific principles of learning. ABA employs the basic strategies of behaviour modification, rewarding desired behaviours to build socially useful skills and improve academic performances.

ABA employs the following methods:

- Breaks tasks down into simple, more achievable steps.
- Teaching is on a one to one basis to begin with then progresses to generalising information to various settings and situations.
- Each response receives immediate feed back.
- Children experience a high success rate which maintains motivation and enhances learning.
- A high priority goal is to make learning fun for the child.

What is most important about all this is that, as so many families such as mine have found, it is a very successful method of teaching in any situation.

A speaker from the Epilepsy Association was invited to our October meeting and this proved to be very popular. Jura Tender (Clinical Psychologist from

Perth) also returned for a short while to Hobart in November and is due back in March 1999.

Our last support meeting for 1998 will be held at Marti Zucco's Italian Restaurant in North Hobart on the 16th of December at 7:30pm. Everyone is most welcome and it should be a great opportunity to relax and enjoy a meal in good company.

For information regarding any of the above please contact me on 62 297 818

Grace Talbot (President Y.A.S.T.)

Giant Steps Update

With Christmas fast approaching, it is go, go, go at Giant Steps. Plans for the next school year are being made as some children prepare to leave and new students are getting ready to start here in 1999. For staff at the centre, the summer will be spent recruiting staff and developing an extended service.

Negotiations have been finalised with the State for Government for another 3 year contract.

Our recent information evenings held around the state have met with an enthusiastic response. We are looking at ways of better serving the Autism community. Please keep in mind that, although these information evenings are finished for now, we are always interested to hear your feedback or any ideas you may have about our service, whether you are a parent or a professional. We can be reached on 6362 2522.

The launch of our Christmas Catalogue has met with a phenomenal response - with orders flooding in from around the state. The recent Baby Show/raffle raised in excess of \$20,000, which was a fantastic effort. It's encouraging to know that there is such strong support in Tasmania for our centre.

GST would like to wish everyone involved with Autism Tasmania a happy Christmas and a safe New Year. We look forward to your continued support in what look likes being a very exciting 1999.

Brett Hosking



FEATURE ARTICLES

THE AUTISM-SECRETIN CONNECTION

by Bernard Rimland-Ph.D.

*reprinted from Autism Research Review International
Vol 12 No 3 1998*

Parker Beck is a friendly and happy five-year-old a delight to be with. Two years ago he was a miserably unhappy, non-verbal, very troubled child with chronic diarrhoea, whose parents, Victoria and Gary, had literally tried every treatment and every test they could find, including MRIs, EEGs SPECT scans, allergy evaluations, and many, many others. In desperation, they took Parker to yet another major medical centre for yet another test. The Becks wanted an endoscopy, an examination of Parker's GI tract. Victoria, who had studied the subject extensively, insisted that the test include an infusion (slow injection) of secretin.

Secretin is given scant attention in medical dictionaries and textbooks. It is a natural substance, a hormone (the first hormone identified), and is used to diagnose -not treat- digestive problems.

The physician resisted. Secretin was not part of his normal procedure for endoscopy. However Victoria's reading and her observation of Parker's food preferences convinced her that pancreatic enzyme deficiency and acidity were issues in his case. She managed to convince the physician that since secretin was safe, he should humour this determined mother.

Parker's immediate response to the secretin was surprising. His pancreas reacted very strongly to the infusion. Parker's longer term response was even more surprising; he began to improve in every area! Within three weeks, he had progressed from a two-word vocabulary to hundreds of words including short sentences ("I want juice"). He initiated eye contact- and began to attend to people, to videos, and to music. He was suddenly potty trained and soon began to respond to requests. He started to draw and to name items drawn. At five weeks however improvement began to wear off. Parker needed more secretin, but the physician was still sceptical.

It was then, July 1996, that Victoria Beck phoned me. I was fascinated. "No," I told her, "I had never heard of this before." I offered some suggestions that proved helpful

and encouraged her to prepare written documentation of her discovery, so that it might be better shared with others.

A repeat SPECT scan and blood tests done at the Becks' request at other laboratories confirmed Parker's improvement. At the Becks' insistence, the physician finally did repeat the infusion nine months later, and again three months after that, each infusion bringing about more improvements. Responding to the challenge of proving the value of the infusions, the Becks compiled convincing before-and-after -and-videotapes of Parker, along with before-and-after lab test data.

Victoria became the hub of a small network of keenly interested parents. She referred other parents to the physician. She informed other parents and other physicians about her discovery in an effort to learn if Parker's case was only one of a kind.

Glowing reports from other parents and physicians made it clear that Parker's response to secretin was not unique. To the best of our knowledge about 120 autistic aid autistic-like children have received secretin infusions to date, given by about 20 physicians throughout the U.S. All were inspired by what happened to Parker Beck. The numbers are growing each day, and in the near future, after Victoria gives her first public lecture at our Defeat Autism Now !(DAN!) Conference in New Jersey October 3-4 and after NBC Dateline breaks the story at about the same time, the numbers will really grow. I have urged Ferring Laboratories, currently the sole producer of secretin, to consider markedly increasing their output.

The best guess of the physicians with the most experience is that about 60% of autistic and autistic-like children (and possibly adults) respond positively to secretin. The results are sometimes remarkable

One mother of a 13-year-old daughter told me that within days there was eye contact. The girl began to speak coherently, and soon rejected the heavy duty ear protectors she had always insisted on wearing because of hyper-acute hearing.

The parents of a four-year-old boy reported (this will probably be reported on Dateline) that the boy's IQ rose from the 60s to the 120s within a few months.

A high-functioning autistic adult wrote to a friend that he "became much better oriented in space," and that "for the first time colours were remarkably pure and clear and

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there was no distortion. Deepest colours were stunning to me because I had never seen them that way before.

In addition to such behavioural, cognitive and sensory improvements there are multiple reports of important and quite unexpected changes in physiological functions following secretin. For example:

- The rubella and/or mumps antibody levels in at least four children (including Parker Beck) have gone from extremely high to normal levels.
- Significantly improved blood flow was seen in several children in repeat SPECT scans
- Several children have shown a significant drop in blood ammonia levels
- Secretin has normalised the bowel function of numerous children who had diarrhoea or constipation.

How could secretin a lowly digestive hormone, do all these things? Well, it turns out that, in addition to its role in digestion, secretin is intimately involved in many activities of the brain, including stimulating the production and utilisation of the neuro-transmitter serotonin. There are secretin receptors in many places in the central nervous system, including the eyes.

Secretin undoubtedly plays a role in the gastrointestinal problems common in autistic children [See ARRI reports on vaccine damage (eg. ARRI 12/1))and gluten/casein intolerance (eg ARRI 11/3).]

While we believe that the hormone secretin is very safe and very helpful in many cases of autism, there is much more that we *don't* know. Everyone is in a learning mode. We do not have the answers to important questions that are commonly asked, such as:

- Which children (or adults) are the most suitable candidates?
- What is the appropriate dosage?
- How often should secretin be administered, for optimal effectiveness?
- How effective are other routes of administering secretin, such as by a patch, lozenge, spray, or salve?
- Since secretin is a digestive hormone, are children with digestive problems most likely to benefit?

As a prescription drug, secretin must be administered by a physician. FDA regulations permit the physician to use prescription drugs as he or she wishes, so even though

secretin is labelled for use diagnostically, it may legally be used "off label" for other purposes, such as treating autism.

The Autism Research Institute is working closely with Victoria and Gary Beck to learn as much as possible about this phenomenon, and we are in touch with the doctors and families involved. We are systematically collecting data to help us learn all we can for the benefit of our readers.

If you have or know of an autistic child or adult treated with secretin, please write or fax ARI (fax 619-563-6840) for a copy of our one-page secretin data collection report form, or copy it from our website at www.autism.com/ari or www.secretin.com.

Victoria and Gary Beck have compiled a booklet of useful information, titled "Unlocking the Potential of Secretin". It will be available from ARI in late October. Cost \$15 including priority mail postage (in California, \$16.16, including tax) Mail Orders only: Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116.

"GUT REACTION" - does diet hold a clue to autism?

The New Scientist magazine (9 June, 1998) recently published an item by John McCrone with the above title. The Autism Victoria office received a number of calls about the article. We have also had queries about; a recent article in the Herald Sun about a new treatment for autism - a hormone called secretin. This commentary has been prepared for your information based on the material that we have been able to locate about autism and intestinal conditions-

The *New Scientist* article focused on a controversial theory that in some cases autism may be the indirect result of an intestinal complaint. The culprit is thought to be cow's milk, or rather, the proteins in cow's milk such as casein and gluten. In some individuals, these proteins are unable to be broken down into amino acids, and become peptides instead. Through a complex process, these peptides may be causing damage the membrane protecting the brain, and thus impact on the brain's development.

During the 1980's parents and doctors were noticing that a change in an autistic child's diet regime by cutting out gluten and casein, or adding enzymes, vitamins and minerals seemed to help both the incidence of stomach upsets and the child's mental state. Some observers

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believe autism to be an auto-immune disease, and that an allergic reaction might confuse the immune system into attacking the brain itself. A key researcher in this area is Dr Vijendra Singh of the University of Michigan.

The 'weak gut' theorists, including Paul Shattock in the UK and Dr Karl Reichelt of the Paediatric Research Institute, University of Oslo, Norway believe that diet-derived peptides could be to blame for causing autism. 90% of the autistic children they tested had abnormally high urine levels of certain peptides. The researchers believe that these peptides may somehow leak from the gut and find their way to the brain. Shattock has also observed higher levels of indoleacrylic acid in the urine of children with autism. Not much is known about this acid except that it is a "by product of the pathway that transforms the amino acid tryptophan into hormones and neurotransmitters like serotonin."

The sum total of these somewhat scattered research findings, as described in the *New Scientist* article is a whole lot of new questions to ask in the quest for an understanding of what causes Autism Spectrum Disorders. As one father said, "there are so many questions about this... but when it is your child, you have to do something." This father has removed casein and gluten products from his son's diet and has observed significant improvements in the five years since doing this. His son remains autistic, but much happier and more responsive to people and to learning new skills. A number of families has read the *New Scientist* article and contacted the Autism Victoria office for further information. Unfortunately we have very little information other than passing comments in some of the general references. However parents could talk to their doctor about diet issues and consult a dietitian or nutritionist. One of our members did locate a book entitled "*Biological Treatments for Autism and Pervasive Developmental Disorder: What's going on? What can you do about it?*" by Shaw, W., Rimland, B., Semon, B., & Lewis, L., (Great Plains Laboratory, January 1998), for those using the Internet you can locate supply of this book at <Amazon.com>.

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We're on the Net!

Our address is

www.autismtas.org.au

DON'T MOURN FOR US

by Jim Sinclair

[This article was published in the Autism Network International newsletter, Our Voice, Volume 1, Number 3, 1993. It is an outline of the presentation Jim gave at the 1993 International Conference on Autism in Toronto, and is addressed primarily to parents]

Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle.

But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person.

Some amount of grief is natural as parents adjust to the fact that an event and a relationship they've been looking forward to isn't going to materialise. But this grief over a fantasised normal child needs to be separated from the parents' perceptions of the child they *do* have: the autistic child who needs the support of adult caretakers and who can form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means.

I invite you to look at our autism, and look at your grief, from our perspective:

Autism is not an appendage

Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it:

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Autism is a way of being. It is not possible to separate the person from the autism.

Therefore, when parents say, "I wish my child did not have autism", what they're really saying is, "I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead."

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.

Autism is not an impenetrable wall.

You try to relate to your autistic child, and the child doesn't respond. He doesn't see you; you can't reach her; there's no getting through. That's the hardest thing to deal with, isn't it? The only thing is, it isn't true.

Look at it again: You try to relate as parent to child, using your own understanding of normal children, your own feelings about parenthood, your own experiences and intuitions about relationships. And the child doesn't respond in any way you can recognise as being part of that system.

That does not mean the child is incapable of relating *at all*. It only means you're assuming a shared system, a shared understanding of signals and meanings, that the child in fact does not share. It's as if you tried to have an intimate conversation with someone who has no comprehension of your language. Of course the person won't understand what you're talking about, won't respond in the way you expect, and may well find the whole interaction confusing and unpleasant.

It takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are "foreigners" in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world.

And the outcome, if you succeed, still will not be a normal parent-child relationship. Your autistic child may learn to talk, may attend regular classes in school, may go

to college, drive a car, live independently, have a career--but will never relate to you as other children relate to their parents. Or your autistic child may never speak, may graduate from a self-contained special education classroom to a sheltered activity program or a residential facility, may need lifelong full-time care and supervision--but is not completely beyond your reach. The ways we relate are *different*. Push for the things your expectations tell you are normal, and you'll find frustration, disappointment, resentment, maybe even rage and hatred. Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined.

Yes, that takes more work than relating to a non-autistic person. But it *can* be done--unless non-autistic people are far more limited than we are in their capacity to relate. We spend our entire lives doing it. Each of us who does learn to talk to you, each of us who manages to function at all in your society, each of us who manages to reach out and make a connection with you, is operating in alien territory, making contact with alien beings. We spend our entire lives doing this. And then you tell us that we can't relate.

Autism is not death.

Granted, autism isn't what most parents expect or look forward to when they anticipate the arrival of a child. What they expect is a child who will be like them, who will share their world and relate to them without requiring intensive on-the-job training in alien contact. Even if their child has some disability other than autism, parents expect to be able to relate to that child on the terms that seem normal to them; and in most cases, even allowing for the limitations of various disabilities. It is possible to form the kind of bond the parents had been looking forward to.

But not when the child is autistic. Much of the grieving parents do is over the non-occurrence of the expected relationship with an expected normal child. This grief is very real, and it needs to be expected and worked through so people can get on with their lives--

but it has *nothing* to do with autism.

What it comes down to is that you expected something that was tremendously important to you, and you looked forward to it with great joy and excitement, and maybe for a while you thought you actually had it--and then, perhaps gradually, perhaps abruptly, you had to recognise that the thing you looked forward to hasn't happened. It isn't going to happen. No matter how many other, normal children you have, nothing will change the fact that this time, the child

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you waited and hoped and planned and dreamed for didn't arrive.

This is the same thing that parents experience when a child is stillborn, or when they have their baby to hold for a short time, only to have it die in infancy. It isn't about autism it's about shattered expectations. I suggest that the best place to address these issues is not in organisations devoted to autism, but in parental bereavement counselling and support groups. In those settings parents learn to come to terms with their loss—not to forget about it but to let it be in the past where it doesn't hit them in the face every walking moment of their lives. They learn to accept that their child is gone, forever, and won't be coming back. Most importantly, they learn *not to take out their grief for the lost child on their surviving children*. This is of critical importance when one of those surviving children arrived at the time the child being mourned for died.

You didn't lose a child to autism. You lost a child, because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for *us*. We are alive. We are real. And we're here waiting for you.

This is what I think autism societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it—and then *do* something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own parents are still grieving over having brought us into the world?


Take a look at your autistic child sometime, and take a moment to tell yourself who that child is not. Think to yourself: "This is not my child that I expected and planned for. This is not the child I waited for through all those months of pregnancy and all those hours of labour. This is not the child I made all those plans to share all those experiences with. That child never came. This is not that child." Then go do whatever grieving you have to do—*away* from the autistic child—and start learning to let go

After you've started that letting go, come back and look at your autistic child again. and say to yourself: "This is not my child that I expected and planned for. This is an alien child who landed in my life by accident. I don't know who this child is or what it will become. But I know it's a child, stranded in an alien world, without parents of its own kind to care for it. It needs someone to care for it, to teach it, to interpret and to advocate for it. And because this alien child happened to drop into my life, that job is mine if I want it."

If that prospect excites you, then come join us, in strength and determination, in hope and in joy. The adventure of a lifetime is ahead of you.

Jim Sinclair

Autism Spectrum Disorder is a life-long disability due to a form of brain disorder, the cause of which is unknown. An estimated 1 in 100 thousand people are affected. Autism Spectrum Disorder affects people from properly understanding the world around them to an otherwise sense : as well as affecting their ability to communicate, learn, interact with other people and to play normally.



These useful cards are available from Autism Tas. for \$1.00 for 20. Keep a few in your wallet to hand out at those times you need to explain your child's behaviour!

contact:
AUTISM TASMANIA Inc.
Autism Tasmania's phone number is in your white pages

PERSONAL STORY by Lisa Minchin

Lisa Minchin and husband David are the parents of two children Alice, aged seven and a half and James, aged four and a half. James was initially diagnosed with autism when he was two years and eight months old although we, his parents, had had concerns about him since he was only five weeks old when we were convinced that he was deaf. I am continually distressed when I hear other parents' diagnosis stories, the frustrations and the long waits and the reluctance of professionals to label, yet without a label how can therapy begin?

We commenced an intensive program of ABA under the guidance of clinical psychologist Jura Tender when James was three years and one month old and he made outstanding progress during the first ten months. With hindsight I think this rapid progress was really due to his

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being enabled to show what he already knew in the consistent and predictable discrete trial training format. Since then, his development has "plateaued" but continues steadily forward. He will attend the local kindergarten in 1999 with aide support.

I am a teacher by profession (as is my musician husband) but I have been on extended leave since James was born. Every year I have felt too concerned for James' development to be confident to return to work. I realise that many families with a child with autism do not have the luxury of this choice.

Last year, I joined the committee of Autism Tasmania because I wanted to have an idea of "the big picture" of autism statewide as well as being very concerned that we as an autism community throughout the state work together and pool our ideas and energies in order to best support all people on the autism spectrum here in Tasmania. I am also involved with the committee of YAST - Young Autism Support Tasmania - which supports families using ABA therapy and I hope that YAST will be able to successfully lobby for financial support for ABA therapy from the state government to the same extent that families using intensive behavioural interventions for their children in West Australia are supported by their government.

I want to emphasise that I am not against forms of therapy provision other than ABA and I support parents' rights to choose a therapy to suit their child and family situation. I just wish that all people with autism in Tasmania were far better assisted. I have seen several children make outstanding progress through ABA and so at the moment, ABA is our family's therapy of choice.

I feel that some of my professional abilities can be utilised through my committee work as well as serving as some sort of therapy for my own feelings of grief. I dearly wish that more people could come forward to share the load of committee work although know just how exhausting living with a child with autism can be. Committee involvement can provide companionship with those who understand as well as being a focus for one's energies. I am really looking forward to next year's conference as my coping method is to read everything that I can get my hands on as well as attending any seminar or conference I can.

My husband David and I organised the community service announcement for Autism Awareness Week through Southern Cross Television in May in which several children, including our son James, were featured.

It was a major psychological hurdle to surmount as James and David are frequently recognised when we are out and about. I guess it meant coming to terms with the fact that autism is nothing to be ashamed of and should not be hidden but nevertheless, it isn't easy having one's child recognised for that! I only hope that if there are any children who lose their diagnosis of autism through ABA or any other therapy in Tasmania, their parents are prepared to be open about their recovery and former developmental disorder.

I was inspired by Catherine Maurice's account of her children's autism and recovery in "Let Me Hear Your Voice" and reading her book gave me the impetus to embark on an intensive ABA therapy program for her little boy. My biggest criticism of her book is the fact that she has sought to conceal her children's real identities in order to avoid any stigma or discrimination being attached to them because they once had a diagnosis of autism. Surely such secrecy is an admission that she herself feels a sense of stigma? Wouldn't it have been wonderful if she could have proudly shown her recovered children to the world? Her book gave me much to think about. Catherine Maurice's children, unlike my James, were those with the late onset "regressive" type of autism. More precise information about the long-term prognosis for each of the autism subtypes is something I would like to obtain. All the parental accounts of recovery which appear in the back of the "Maurice Manual"- *Behavioural Intervention for Young Children with Autism* are about late onset children which seems to imply that if late-onset children are given intensive behavioural therapy early enough, the language and social skills that they have only recently lost are still salvageable.

I often feel stressed because I do not have the energy to accomplish all the things that I can see need to be done to help my son and other children like him but enjoy the companionship and common purpose shared by all of us on the committee working to help our loved ones (or those we have chosen to help professionally) on the autism spectrum. Fortunately we are living at a time when acceptance of difference and an understanding of people with additional needs are growing. I have my fingers crossed for a bright future for both my darling children.

Lisa Minchin



NEWS AND VIEWS

Grantseekers Work Report

Trusts and foundations are established for the sole purpose of funding needs within the community. There are many charitable trusts and foundations located within Australia and overseas. Philanthropy Australia is a national membership organisation which represents private, family and corporate grant-making trusts and foundations. Its goal is to promote and protect the interests of both private and corporate giving in Australia.

On Monday 19th October, Philanthropy Australia presented a workshop for grant seekers at the University of Tasmania-Launceston campus. The workshop set out to explain how trusts function and how to go about seeking a grant from those under their umbrella organisation. The day was presented by Esther Lethlean from Philanthropy Australia and Helen Morris from the Sydney Myer Fund.

Trusts like the ones represented by Philanthropy Australia tend to grant money to areas of education, arts, welfare, health, the environment and medical research. Whilst some trusts only provide funds to specific areas, many of them are happy to receive applications from any of the above areas.

As trusts are governed by legal "wills", or sets of rules which determine the way in which funds can be distributed, it is important to ensure that applications are tailored to meet these requirements. The first step in establishing the requirements or rules of a particular fund is to contact a representative of the fund. In many cases, the contact person will also be able to help frame the application to meet their Trust's needs and rules.

Philanthropy Australia has published an inexpensive directory to help organisations like ours by listing details of each fund including: their rules, when funds are issued, in what amounts etc. For a fee of \$500, Philanthropy Australia also offers membership to its Resource Centre to grant seekers., which entitles member organisations, among other things, to receive regular publications, access to their research staff and to consult with Philanthropy Australia staff when making applications.

Trust funds are there to be used and our cause is just as worthy as any other, so I recommend that Autism Tasmania at least buy the directory and use it as a guide for future applications.

Brett Hosking

Epilink

Epilink is a program that has been developed to enable people to make telephone contact with others who have epilepsy and would like to share experiences of living with it.

The Epilepsy Foundation of Victoria aims enhance the quality of life of people with epilepsy, has been developed to help overcome the isolation that people often experience.

Personal contact with others who share the same sorts of experiences can be invaluable. The Foundation hopes to assist people with similar conditions and life situations to contact each other over the telephone.

How it works

Initially, when people express an interest in Epilink, they will be interviewed over the telephone by trained volunteers, and sufficient information will be collected from which to suggest a link. This process will provide an opportunity for the person concerned to outline their special needs or interests. They may seek contact with someone who has a similar type of epilepsy for example, another parent of a child who has recently been diagnosed, or they may wish to converse in a language other than English.

A computerised data base will be kept, including only data that the people interviewed say is appropriate to record. The Epilink Coordinator will then be able to access the data and suggest possible links. While it is anticipated that some links will result in brief informative once-off contacts, others may develop into lasting friendships.

This service is available to members of the Epilepsy Foundation of Victoria.

If you would like to become a member or would like more information contact Louise Pearson at the Epilepsy Foundation of Victoria telephone 03 9813 2866 toll free 1800 134087





NEWS AND VIEWS

"Mercury Rising" (Video release)

Kel Beckett, from the Autism Association of NSW advises us that the film, "Mercury Rising" has been released on video. Many of you will recall that this film is about an Autistic savant child who breaks a top-secret military code and becomes a target from the developers of the code. The film stars Bruce Willis as an FBI agent trying to protect the child.

A special arrangement has been made with the video distributor, where \$1.00 will be donated to the National Autism Association for every video sold. This could represent an industry donation of \$40,000! Kel urges us to encourage our friends and family to buy the video. He also pointed out that there is a consumer promotion where, through hiring the video and completing a word search, you have the chance to win a trip for two to Universal Studios.

At the end of the film there is a community service announcement which reads as follows.

In Mercury Rising the character of Simon is portrayed as an Autistic Savant. Savants are individuals who possess extraordinary abilities known as splinter skills. Savants make up less than 10% of the Autistic population.

Children with Autism have difficulty in making sense of the world in which they live. They may appear not to hear, or be over sensitive to and frightened of some sounds. Not playing with and interacting with other children is common, and often they don't speak, or use language in a non-communicative way.

They can retreat into repetitive behaviour, become withdrawn and have difficulty in understanding and empathising with the thoughts and feelings of others.

Autism is four times more prevalent in boys than it is in girls. and approximately one in 200 children born will have some form of Autism.

For more information on how you can help children and adults with Autism to find out more about the disability itself contact the Autism Association in your state.

Life Behind Glass by Wendy Lawson (Press Release)

136 pages A5 paperback \$19.95

For Wendy Lawson the world is indeed a strange place. It is noisy, confusing and full of contradictions. The people in it are distant and make no sense: why do they laugh and cry? Why don't they say what they mean? Wendy lived with feelings of disconnection, anxiety and confusion for over 40 years before being correctly diagnosed with autism, or more specifically, Asperger's Syndrome.

Recent studies indicate that 9 in 1000 children will be born autistic. Autism impacts on individuals in various ways but is always affects the way in which individuals understand the world around them.

Wendy describes living her life as if "behind glass", watching the happenings around her, but unable to touch them. As a result, she has often been treated as if she is either deaf or stupid, when in fact she is neither. This book is about her determination to come to terms with the constraints of her condition. It is a remarkable and unique personal account of growing up "different" and provides an understanding of the contributions that autistic people can make to society.

Despite the deficits in communication and social understanding that are part of her condition, has successfully completed degrees in social science and social work.

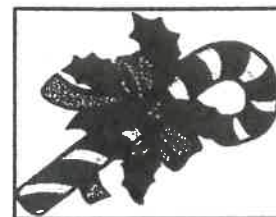
This book will be valuable to health care professionals, carers of autistic children, teachers, and families of autistic people.

To order send credit card details or payment to Southern Cross University Press PO Box 157, Lismore NSW 2480. Australia.

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email: scupress@scu.edu.au

Postage \$6.50





NEWS AND VIEWS

ASPERGERS GROUPS

Asperger's Northern Support Group

Our last meeting, held in late November, focussed on language development and difficulties. Our next meeting will be held on **Saturday January 23rd** at Walker House, Newnham.

It will be an ideal time to come along and share a chat and a cup of coffee. Children are welcome, as there is an enclosed outdoor area as well as indoor facilities.

For further information, please contact Rachel Hodge on 6393 37183.

Asperger's North Western Support Group

Our last meeting was held on Sat 28th November, where we discussed issues we would like to discuss at the special statewide meeting for all groups of Autism Tasmania that will be held at Ross soon. Our next meeting will be held on **15th Jan.** Contact Eileen Prunster for more information on 6445 7696.

Asperger's Southern Support Group

Thurs January 28th at Irene James' home 1/6 Argent Crt. West Moonah ph 6272 5509 from 7:30pm to watch a video of Temple Grandin's presentation at the NZ Autism Conference.

Thurs February 25th at Jan Mahoney's home 4 Norman Circle Glenorchy ph 6272 1049 at 7:30pm.

Thurs March 25th Movie Night
Contact Roseanne Lay for details ph 6244 2540.



COMING EVENTS

There is plenty happening over the next few months, so add the following dates to your calendar!

- **Southern Aspergers Support Group Picnic**
Join the Southern Group for a picnic at the Botanical Garden (at the bottom lawn, near the gazebo) on Sunday December 13th from 12 noon. BYO picnic.
- **Asperger's Syndrome Support Groups**
Contact the following people to find out about meetings in your area:

North:	Rachel Hodge (6393 7183)
North West :	Eileen Prunster (6445 1696)
South :	Roseanne Lay (6244 2540)
- **Young Autism Support Tasmania (YAST)**
(Supporting Families Teaching Applied Behavioural Analysis)
YAST meets on the 3rd Wednesday of each month at Albeura Street Primary School, Hobart at 7pm.
Contact Grace Talbot on 6229 7818.

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