

**Aspergers Syndrome Support Group
for Families in Macarthur**

July 2008 News Sheet

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Support Meetings

Our support meetings continue to be a valuable time for parents to meet with other people in a similar situation and share experiences and ideas. Whilst our numbers remain low the people who do come along all contribute to the often wide ranging discussions that take place.

We are always welcoming new members with nearly 130 people on the support group's mailing list. Some people come along without a formal diagnosis for their child or family member, others bring along grandparents and other family members to increase their awareness of Aspergers.

A couple of members have been encouraging their local school to start up a support group for parents, which is a great idea. If your child has aspergers there will be certainly other children at the same school who have aspergers or not yet diagnosed or are facing the same issues as your child. Getting together can be of benefit to all concerned and is welcome by schools.

August Meetings

- **Second Wednesday's of the month** 13th August 10 am at The Coffee Club Café at Macarthur Square, next to Border Books, downs stairs and outside where all the new coffee shops etc are.

This month we will again have a representative along from **Autism Spectrum Australia (Aspect)**, who is the peak organisation in NSW for Autism Spectrum Disorders. Lija Simpson will join us to discuss what Aspect are currently doing and have planned for the future. I met her at a workshop recently and found her very knowledgeable and enthusiastic to assist families.

Lija's six month project called Aspect Linx (with funding provided by FaHCSIA) to connect with groups around NSW that provide support to families with aspergers or autism spectrum disorder. The aim of this project is to:

- Provide information to support groups about resources for parents and carers and Autism Spectrum Australia resources
- Provide the Aspect Autism Information Line with updated information about ASD support groups and support services that families are finding useful

Our Support Group is well connected with a number of other groups in Sydney and with Aspect and shows by working co-operatively we can share information and ideas to benefit all parents and people on the autism spectrum.

- **Second Thursday of the month** 14th August 7pm at the Harrington Park Community Centre Fairwater Dr next to the shopping centre. Opportunity for those who work or are busy during the day to meet other families and share their experiences and ideas.

Resource Library

Got a book and want to return it? Our library is somewhat depleted at present with a number of books out on loan. I do encourage people who have borrowed a book to contact me so I can arrange to get it back on our shelves so others can benefit from reading them. Happy to collect it off you – no questions asked.

Kites for Kids Day

23rd August 11 am to 2 pm in Koshigaya Park, Campbelltown – opposite the Library and Catholic Club

This community event is always well attended by families from our support group, and across the community. Come and decorate your own family kite and see how well you can fly it. Last year we have over 150 kites painted out by families with most reaching the skies over Campbelltown – as well as a few in the kite eating trees.

There is plenty of room to spread out the picnic blanket and watch the entertainment being organised. Lions Club of Campbelltown will be along to feed you if you forget your picnic lunch, with Streets providing that all important favourite – Paddle Pops. Face painter, clowns and other activities can be enjoyed and you can pick up your free information bag including C91.3 giveaways.

Kites for Kids is a celebration of National Early Childhood Intervention Week and is organised by services from across Macarthur including the Families in Partnership Co-operative.

Livewire

Livewire is a free online social networking website for young people 10-18 years with a chronic illness or disability, living in Australia. Members can make new friends, catch the chat events and guests in the chat room, have their say in the forums and check out all the latest music, movies, TV and sport news and goss, plus hot interviews and games!

The website is a closed community with chat hosts available from 12noon to 8pm daily. The hosts are there to oversee the proceedings, support newcomers, and ensure a fun and safe environment. Members are divided by age into different sites (10-12, 13-15, 16-18), with age-appropriate content in each. Every application is authorised with written parental consent and proof of identity.

Livewire is run by the Starlight Foundation. Find it at www.livewire.org.au

Gluten/Casein Connection

Extract from Behaviour, Learning & Health - The Feingold Assn USA

A baby nurses, and usually falls asleep when full. This is due partly to endorphins made by the baby when tasting milk, and partly to the milk protein itself which enters the baby's blood in a morphine-like form. This "leaky" gut is normal in babies, and is one reason that babies may develop allergies if given solid foods too early – because when other partially digested proteins get through the gut wall and into the blood, where they don't belong, they may be treated as invaders by the infant's developing immune system.

Toward the end of his first year, the baby's intestinal wall becomes less permeable, allowing tolerance for new foods. However, if anything has happened to prevent this, damaging the delicate intestinal system, the growing child may experience symptoms of digestive distress, allergies, or cognitive problems. It has long been known that incompletely digested proteins can cause allergies. Less well known is that the incompletely digested casein protein (casomorphin) and gluten protein (gluteomorphin or gliadorphin) both act as morphine's, possibly causing symptoms of autism, ADHD, or even schizophrenia.

Unfortunately, many children with autism crave the casein and gluten that hurts them – like little drug addicts, they need their "fix." Parents of such children report that their child's whole diet consists of macaroni & cheese, cereal & milk, bread & butter, pizza, cheese puffs, cheese sandwiches, puddings, etc. Moreover, these children may have sensory problems related to diet – some tolerate only soft foods, while others cannot stand the feel of soft foods and require crunchiness. Removing casein and gluten quickly from such a child's diet may be a Mission Impossible task. We recommend a slower approach....

Remember that this is an addiction condition, and the child may have serious withdrawal symptoms, including behavioural deterioration, if changes are made too quickly.

Aspergers and Home Schooling

Dave Angel www.ParentingAspergers.com

Key things to think about if you are considering home schooling your child:

- Home schooling the child with Asperger's Syndrome can be beneficial because you know your child better than anyone else.
- In the home school environment, routine can be maintained because there is not the impact of the needs of other children or other interruptions. Further, you have the ability to teach to your child's strengths that may not be readily recognized by others within the school system.
- It may also help your child avoid the affects of bullying that is often associated with any child who is different.

However, the child with Asperger's lacks social skills and the ability to fit in with their peers, yet they usually crave this type of interaction. All children learn a great deal of their social skills in school.

At some point in his or her life, your child will need to develop skills that will help them interact in society. They will also need to develop the ability to make decisions in your absence.

It is not likely that they will have the opportunity to learn these skills in home school, unless you are very active with other social skills groups.

Source of last two articles NADA NSW Newsletter

Social Stories

Carol Gray developed the concept and specific structure of Social Stories™ for students with ASD. (For more information visit www.thegraycenter.org) Some people call them social scripts. The aim of Social Stories is to develop social understanding. It is important when introducing a Social Story that is introduced in a relaxed, positive environment where the student can "learn" the social situation and develop an understanding of the social context. They are a teaching tool!

1. Social Stories that explain "Other people's thoughts, expectations"

These Social Stories normally explain the impact of behaviour on other people. My favourite is "your friends are happy when you talk about dinosaurs three times a day" Below is an example by Annette Joosten, you can add photos, make into a little book etc.

Sitting Still

"Sometimes my teacher will say "Sit Still." Sitting still means: I will keep my legs still;

I will try to keep my hands on my lap; I will try not to touch other children.

The teacher is happy when I sit still"

More of Annette's Social Stories can be found in "Making it a Success" page 49 or her book "Book of Cool Strategies" available from booksellers.

2. Social Stories that explain "What to do in social situations"

These Social Stories explain the how, and what to do in social situations. I would encourage these to be on your coffee table, and used as bed time stories, constantly be reread to explain what to expect, particularly in school situations. For example: what to do if you lose, how to ignore other children. These are important skills students with ASD need throughout their education and work life. Below is an example

Asking for help

- Put your hand up to attract the teacher's attention
- Look towards the teacher
- Call out in a medium voice: "Excuse me, miss" or "Excuse me, sir"
- Wait for the teacher to say your name
- When the teacher has answered your question, say thank you

Excerpt from: *How to Stop Your Words from Bumping into Someone Else's* by Anna Tullemans and Rhonda Dixon

3. Social Stories that are "language/instructions"

Most students with ASD are very literal, and our language can confuse them because we assume they know what we want them to do. Telling children with ASD “what you want: not what you do not want” is a vital strategy.

Use positive clear instructions

- Child under table: DO NOT SAY “Get out” say “Sit on Chair”
- Child finish computer DO NOT SAY “ Stop computer” say “Finish computer, time for puzzle”
- Child about to hit you DO NOT SAY “NO HITTING” say “Hands down”
- Child about to run on road DO NOT SAY “ NO running on road” say “Hold my hand”

Source: www.suelarkey.com

Chess

When the 7.30 Report featured Gene Nakauchi on a programme early this year, their aim was to show a boy who had been severely autistic but whose condition had improved immensely once his passion for chess had been ignited.

Gene’s results to this point had been amazing for someone with such severe autism but it was felt that his inability to negotiate some of more collaborative areas of the game – such as when to offer, accept or claim a draw – would hold him back in his attempts to reach higher levels.

However in the past month, Gene, now 12, seems to have made another leap forward. He started July by winning the U/18 title and last weekend finished third at the Coffs Harbour Open: his 5/7 including a win over Australian Champion Stephen Soloman. The tournament winner Grandmaster Zhao Zong Yuan was moved to compare Gene with Australia’s best pre-teens of the past decade, Raymond Song and Moulthum Ly.

Chess is not the only sport where players conventionally regarded as disabled can compete and equal terms with ‘normal folk’ – a disabled South African sprinter will take part in the Beijing Olympic Games – but it is perhaps the only one where a disability can be forgotten. In Zhao’s eyes Gene is simply one of Australia’s best ever 12 year olds, period.

Source– The Sunday Herald 27th July 2008

Until next time **Bob Lester** 4648 1593 or 0400 481 520 or email coordinator@fip.org.au Check out www.fip.org.au for more information