

ASPERGER SYNDROME PARTNER INFORMATION  
AUSTRALIA INCORPORATED

**ASPIA**

(Formerly **GRASP** Partner/Spouse Support Group)

*“Mutual acknowledgement and understanding  
of the Asperger marriage experience”*

**NEWSLETTER – NOVEMBER/DECEMBER 2005**

*This Newsletter is the largest we have ever produced. In the last 5 months, ASPIA has made so many monumental steps forward that it is hard not to feel overwhelmed by what ASPIA seems to be accomplishing, the approval and interest that ASPIA is receiving, and the encouragement to continue being what we are – a support group, connecting point and information source for partners (& ex-partners) of adults with Asperger's Syndrome.*

**Website**

*For those who receive this Newsletter by post, we are very excited to announce the recent establishment of our own website at [www.aspia.org.au](http://www.aspia.org.au). If you are able to access the internet, please have a look. The website has given us a new platform for providing a point of contact and expanding our advocacy and support work. We are finding it quite powerful to be able to refer people to the site for information and contacts and it is receiving a great deal of positive feedback. I want to acknowledge Nola for building such a professional-looking & user-friendly website, of which we can be extremely proud.*

**November meeting**

*At our last support group meeting on November 5 about 30 people attended and we had a wonderfully constructive discussion about Aspia's purpose and what to do about the range of other support needs that keep being presented to us, such as groups for Asperger adults, teens, parents of adults, parents of teens, children of Asperger parents, etc. We are also receiving an increasing number of requests for people to be connected with others who live locally to them. We want to thank Jeroen Decates & Eleanor Gittins, key psychologists in our support network, for their attendance and support at this meeting, and for helping to guide the discussions.*

*It was declared at this meeting, that Aspia cannot assume responsibility for starting and running other focus groups, such as for adults with AS, or parents, but that we are prepared to be like a clearinghouse and collect details of people's interest, contact details and location and pass these on to others also interested and from a similar location. For those who use the internet, and are interested in an alternative focus/interest group, or a desire to be connected with others who live near you, please visit the page at [www.aspia.org.au/groups.html](http://www.aspia.org.au/groups.html) and register your interest, along with your preferred (safe) contact details and your location. Please understand that by doing so, you are giving us permission to pass on your contact details to others with the same focus/interest and that live in your area.*

*For those who receive this by post, please write to Aspia or phone Carol on 0408 817 828 to register your interest/focus area, your contact details and your location.*

*You may also register if you are a partner and would like to meet other partners in your area. Already we have a growing number of partners in the Illawarra area, the Central Coast and the Eastern suburbs of Sydney, so "chapters" or satellite groups of Aspia are a definite possibility.*

***A strong collective statement** was made at this meeting, that Aspia support group meetings need to continue as they are, as a place for partners to talk about partner issues. For most, this safe & supportive environment is the only place where partners are believed and understood and are free to "de-brief" about their issues, discuss with others ways of addressing and managing home life, or just find closure. We believe that this environment needs to be protected and preserved for these essential needs. From time to time we will help organize workshops for a wider range of needs.*

**Numbers growing**

*You may be interested to know that our contact list has grown to above 200 now, and new enquiries continue to come in each week. Thank you for being part of this wonderful movement of support for partners/ex-partners of adults with Asperger's Syndrome, and we would encourage you to keep in touch and continue adding your contribution, either by attending meetings, being willing to connect with others locally, advocating & spreading awareness, passing on relevant information to us or by sending much needed donations to cover the costs involved in keeping us going.*

**Radio exposure**

*As part of the advertising for our conference, members of our group suggested we contact Alan Jones at Radio 2GB. I followed through and wrote to him and received an email in reply suggesting I phone the open line one morning and tell people about our conference. In much fear & trepidation I did this, and found Alan very warm and interested. He asked questions and allowed me to answer and give details of our group, our website, our conference and a little bit of general information about Asperger's Syndrome. I received about 30 enquiries in the following days as a direct result of these few minutes on 2GB, which shows how great the need is for us to be a "voice".*

## **Conference Report**

Our first conference on October 23 & 24 is now over and on the whole we are very happy with how it went, with about 55 attending on the Sunday and 70 on the Monday. There are always anxieties when organizing events like this, particularly when it's the first we've done, and there were some elements of concern on the Monday, but overall many ongoing benefits have been achieved and many new contacts made and people helped. Chris & Gisela were delightful and we appreciate so much the way they are willing to open up their own marriage in order to help other couples to understand and learn ways to manage better. Roger was charming and provided a great deal of information about Asperger-appropriate services which we hope can become a reality for Australia in the future.

West's Leagues Club at Ashfield was the perfect venue and everyone was expressing how comfortable they felt and how much they also enjoyed the beautifully presented food. The bookstall by Book In Hand was fabulous.

DVD's of the sessions are being prepared, but this is a fairly time consuming task. We will let you know when they are ready for order.

Unfortunately, we were unable to cover the conference costs entirely, and it is only through one very generous donation from within our group that we have been able to finalise all the accounts. We would be very grateful for further donations from those who have the means, to enable us to be in a safer place financially. Thanking you.

## **Farewell and Acknowledgement**

With sadness, we wish to announce the retirement of Psychologist LYDIA FEGAN who has become very dear to many of us within ASPIA. We have written the following on our website:

"ASPIA would like to acknowledge Lydia's profound contribution to ASPIA from its very beginnings. Lydia took the initiative to connect the founding members of ASPIA with each other and was the first inspiration for the dream of a support group for partners. She is known for her warmth and faith in her clients as she provided much-needed validation at the most crucial point in our journeys when we finally discovered Asperger's Syndrome and found someone who believed us."

Lydia, we want to wish you all the very best in your retirement, and no doubt new ventures, and promise you that our thoughts and gratitude will be with you forever. You're leaving a huge hole in our support network, which we can only pray will be filled by someone as caring, knowledgeable and inspirational as you. Thank you Lydia.

## **Our Stories**

Unfortunately, the writing of our stories has become overshadowed by all the other "happenings" within ASPIA of recent months, and perhaps it's time to focus on this again. From discussions in our meetings, we discovered that it is helpful to know who our target audience is in order to know how and what to write, and we feel it is most strategic to target professionals such as psychologists, counsellors, doctors, etc. What do you want them to know? One of our members has proposed a template to help with structuring our stories. I will attach or enclose this with this newsletter. Please forward them through to us when you are ready. Anonymous is fine.

## **Research projects**

From time to time we become aware of professionals or organizations carrying out research to do with Asperger's Syndrome. Most of these are in relation to children or teens, but the more research is done in general, the more awareness and experience will be developing among professionals, so if we can we really should try to support them. If you have a child or teen in the target age group, you may find it very interesting and worthwhile to become involved. There are two projects I'm aware of at the moment.

**One is on "Friendship and Loneliness in Individuals with Asperger's Syndrome"** and the target group is high school aged children, with a hope of expanding the research to adults. Andrew Whitehouse of the University of Western Australia is conducting this research, although he is presently undertaking a Fellowship in London. You can look at the information on Aspect's website [www.aspect.org.au/research/wa.asp](http://www.aspect.org.au/research/wa.asp) and request an information pack.

**The second research project requires boys aged 8 – 12 yrs who have a formal diagnosis**, and the researcher is Dr Jeff Bailey of Edgecliff, Sydney. Find out about his services at [www.drjeff.com.au](http://www.drjeff.com.au) or 0415 555 786. The study is exploring the ways boys with AS view group work in a primary science lesson, how they respond to two problem scenarios and what this means in terms of their ability to take the perspective of others. The second half is an investigation of an area of cognitive problem solving called executive function. The researcher is trying to find out how boys with AS solve a range of problem solving tasks. These studies are important because little has been done to explore these areas. **What's involved?** The boys, along with at least one parent, will need to attend Dr Bailey's rooms at Edgecliff (right next to train station) for about 3 hours. They will be involved in a brief task that explores how they control their distractibility and then the science problem solving tasks, then finally an intelligence test that has the subtests needed to explore executive function. **The benefits for parents** include a thorough, free comprehensive analysis of the boys' intelligence, a summary report outlining results and a chance to chat with Dr Bailey about your child. The boys will receive a \$50 gift certificate for educational toys/activities from a store of Dr Bailey's choosing, and they'll gain information that will be very important for their lives.

### **Editor's ramble ...**

On the subject of writing, there are opportunities opening up for Aspia to make contributions to other newsletters, etc. For quite some time I personally have wanted to try and write some articles based on partner experiences, including my own, that we can use in our awareness & advocacy work. I am finding this particularly difficult and have realized that this will involve me revisiting places in my own experience that are quite traumatic. I know your thoughts are with me, and I want to convey to every other partner, and interested professional receiving this newsletter, just how much I appreciate the input, friendship & support that you provide for me in my role as co-ordinator, and in my own journey of recovery. We are all contributing to each other's journeys, and this is so important, as I'm sure you'll all agree.

**Relief/Grief** - When speaking to new contacts, I'm often reminded of that time in our journeys, just following discovery or diagnosis, when we enter a completely overwhelming place where our heads and hearts feel so overloaded with new information and answers, where we experience a startling sense of relief, but a crushing sense of grief as well. I've been searching for words to describe this, but apart from a "roller-coaster ride in the dark" or being "steam-rolled" or like being in a "dark pit with nothing to grasp hold of", I'm not managing to be very imaginative. Anyone have any suggestions? We need to invent a term of our own. I believe this time is particularly difficult, dangerous and black and I would encourage anyone at this stage of your journey to spend some sessions with a counsellor, looking particularly at issues of loss and grief. Some speak of almost becoming non-functional at this time. We do come through this period, but it takes all the courage and external support we can take hold of.

**Eyes** - One of my favourite places to read is in the Book of Proverbs in the Bible, especially in the old English wording. This week I read in Proverbs 15 & verse 30 "The light of the eyes rejoices the heart ... " and I immediately thought of the importance and value we place on good eye contact and how much we refer to another person's eyes to gauge where we're at with them, and how much joy and warmth we can receive this way. How we look for and long for that "light" of acknowledgement, of reassurance, of love, of understanding, of trust, of care, of respect, and of an open soul in our partner's eyes, and in so many instances, this "light" is not there or our gaze is avoided. We are left wondering, confused, hurt, feeling ignored and unvalued, etc. Eye contact and expression is an issue with Asperger's Syndrome, and we must accept this, but I just felt I would like to make acknowledgement of this need in a non-AS person and encourage you to nurture other trusting and warm relationships that are available to you, particularly your children, who need this eye contact in a double dose from you, and your heart needs to experience the joy and reassurance that this can bring to you too.

### **Our next ASPIA support group meeting is SATURDAY 3 DECEMBER, 2pm – 5pm**

**Parramatta RSL Club, Lachlan Room (or Lennox Lounge if available)**

**Cnr Macquarie & O'Connell Streets**

**Free parking station opposite Club's front doors in Macquarie Street**

We will be enjoying a visit from two psychologists at this meeting. One of these professionals has a particular interest in Asperger teens/young adults & Sexuality which could open up some interesting discussion for us too.

This meeting was planned as a time for general discussion and consolidation, particularly following our November meeting. A topic that was suggested for discussion was "**Communication**" so please come along with your input and suggestions, particularly strategies and methods that have worked for you and your partner.

**\$5.00 donation at the door**

**Please bring some Christmas nibbles or goodies to share for afternoon tea.**

Please remember that there will be **NO JANUARY MEETING**. Our first meeting for 2006 will be Saturday February 4. We have many speakers lining up for 2006 and these will be announced as dates are confirmed.

My best wishes to everyone for a very safe and enjoyable Christmas & New Year season, and I look forward to meeting more members at future meetings as you are able to attend. God be with you all. Sincerely, Carol.

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