



# RHUBARB

*The ISADD Newsletter*  
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## EDITORIAL



### *The Season's Greetings to all our readers.*

With the festive season once again rushing at us, let me wish all Rhubarb readers the compliments of the season, and may you have a prosperous and peaceful 2007.

The year has, once again, seemingly flown by and I am left wondering where it went.

For our parents with younger children especially, perhaps the year has not seemed so short, as they struggled to learn all that's needed to know about ABA/DTT, and working with their child.

For some of our overseas personnel, the year may have seemed interminably long. In Dubai, we have been working for over six months to try to establish a branch office there (at time of writing still nothing has been finalised), and in Ireland, the government is reviewing its funding for parents with a pre-school child with autism – and ISADD's viability there will depend largely on the outcome of this review. Waiting for the government's decision (at time of writing there is no news) to be announced is something akin to watching a pot come to the boil!

On looking back over the year, it has been a busy one, with its usual ups and downs. One stand-out "up" however, was the great feedback we received from our survey of WA client families – published in the previous

edition of Rhubarb. As I've said before – and often – it is knowing that we are making a real difference to the lives of children with autism that makes this job worth doing.

Daryl Cooper.  
Executive Coordinator, Editor.

## ANOTHER OCCUPATIONAL TRAINEE COMMENCES TRAINING

After a year's effort to obtain the appropriate visa, we welcome Lina Skaisgiryte who has arrived in Perth to commence a year's training with ISADD. Lina is a psychology graduate from Lithuania, and plans to make a career in the field of autism. At completion of training, she will return to work with ISADD Europe (see announcement later in this edition). We would like to thank our federal Member of Parliament, Don Randall JP, for his assistance with obtaining Lina's visa: - it is amazing how the bureaucracy speeds up when an MP gets involved!

## NEXT CASE MANAGER TRAINING

The next Case Manager Training Course commences March 11, 2007. As with previous courses, this is already shaping up as a very multicultural event, with participants expected from Dubai, Lithuania, Ireland, New Zealand.

If previous courses are any guide, participants can expect an intensive – and exhausting two weeks of training covering a huge range of topics, but also an exciting time during which some lasting new friendships will be made. Participants will leave with not only new and enhanced skills, but also with closer ties to their colleagues in different parts of the world.

## **MEDICAL MYTHS ABOUT AUTISM DEBUNKED.**

At a recent seminar organised through the WA Autism Diagnosticians Forum, Dr. Michael Msall, a paediatrician from the University of Chicago, presented the topic “Assessing Controversies in Autism”.

Dr. Msall covered a number of popular fads, including secretin, chelation therapy, megavitamins and special diets, presenting research evidence indicating that none produced any measurable benefit. He reported an interesting study in which both experts and parents were asked to estimate any positive effects of a treatment on a child: while the experts could discern no noticeable difference, most parents reported positive gains. This result was interpreted as indicative of the parents, having spent large sums of money on the treatment, grasping at any positive change in the child and ascribing it to treatment, rather than to normal developmental change which would have occurred in any event. (This also explains why ineffective treatments manage to survive for so long after they are scientifically discredited).

As well as research, Dr. Msall reported several case studies, the most frightening of which was a pre-schooler kept on a special restricted diet for two years. When the family finally sought medical help, the child was suffering from severe malnutrition requiring 90 days of inpatient treatment, with the total cost to attain full appropriate oral nutrition being in excess of US\$300,000!

He pointed out that while the only treatments demonstrated to be effective were the Behavioural ones, this did not mean that paediatricians did not have a role to play in the management of the child with autism. Many children with autism do have co-existing medical conditions, and all children can benefit from medical monitoring of their growth and development.

*Coincidentally, I found a review of this article shortly after attending the seminar above:*

## **STUDY FAILS TO FIND BENEFIT IN GLUTEN-FREE, CASEIN-FREE DIET**

In a double-blind clinical trial, the researchers randomly assigned 15 children with an ASD to either an experimental group who received the Gluten-Free, Casein-Free (GFCF) diet, or to a control group who received a similar diet (specially prepared meals) which were not gluten or casein-free. Participants and investigators were both blind as to who was receiving which diet.

The researchers found no significant differences on the range of measures used (including the CARS, the Ecological Communication Orientation (ECO) Language Sampling Survey, and in-home observations).

Some parents, however, said they had noted an improvement in their child, and opted to continue the diet after the study concluded.

While one small study is not conclusive, this study presents more evidence that dietary interventions appear to have little or no benefit in treating the symptoms of autism.

Reference:

Elder J H, Shankar M, Shuster J, Theriaque D, Burns S, and Sherrill L. (2006) *The Gluten-Free, Casein-Free Diet in Autism: Results of a preliminary double blind clinical trial*. Journal of Autism and Developmental Disorders 36 (3) 413-420

## **ISADD WORLD REVIEW**

### **NEW ZEALAND**

Palmerston North Case Manager, Fiona Sutherland, has recently spent two weeks in Perth, updating her skills, and finding out how things are done here. She reports that the time was well spent, and has returned to New Zealand with renewed enthusiasm and confidence. This is the second instance of a Kiwi making a return to Perth (the other being

Julia Challenor), and it is great that these personnel show so much dedication and commitment to their vocation.

### **ISADD SINGAPORE**

Demand for services in Singapore continues to grow, and our dedicated and enthusiastic team there is struggling to keep up.

Jura has just completed a visit, during which parents attended an evening where they watched a video of Lovaas' work and its effects, followed by a discussion on future options. One option is the possibility of ISADD supporting home schooling to meet the gap so many children experience.

### **ISADD EUROPE**

ISADD Europe is now a Limited Company, based in Cork, Ireland. As in other areas where we have established a local organisation, ISADD Europe will enable us to operate more efficiently in that region, thus providing a better service to our clients there – currently Ireland and Lithuania, and possibly, in the future, areas of the UK.

In another testimony to the effectiveness of ABA/DTT, while in Ireland, Jura contacted a former West Australian client family now living there. The mother reported they had settled in well, but that no-one would believe her child had had a diagnosis of autism!

### **ABA IN LITHUANIA**

As reported last edition, the families to whom Jura introduced ABA/DTT have formed an association. This is known as Kitoks Vaikis, which means "Different Child" We have entered into a Memorandum of Understanding with them to provide services and look forward to a long and successful collaboration.

### **THE EDITOR'S BEGGING PRODUCES A RESULT.....**

Thank you to Christine Vaccai for submitting the following:

**Free Materials!**

Website: [www.dozlearn.com](http://www.dozlearn.com)

This is a fantastic must-see website. It has a lot of useful ideas and materials. The website has free safety compics with two great social stories. One is about fire safety and street safety. The street safety social story is a sing-along animation about how to cross the road when at traffic lights, crossing a crosswalk, crossing at the driveway. It tackles all different scenario/situations. You could also copy and paste the street safety pictures into a powerpoint and enjoy the show at home. The website also has emotions game and various word games like "what is different" that your child may enjoy. To find the social stories, simply click on the songs and games (orange) link. Then click on songs and a sublink will appear. Pick the story you are interested in. It takes about three minutes to load, so be patient because it's worth it. Have fun!

Christine Vaccai.

### **Wedding Bells**

On Sunday November 19<sup>th</sup> on the river shore at East Fremantle Yacht Club, the marriage of Tanya Williams to Brian Brennan took place. The Bride was radiant, and the setting ideal. Several ISADD staff were lucky enough to take part in Tanya's special day. Best Wishes to the happy couple.

### **ANOTHER REMINDER!**

**ABA INTERNATIONAL CONFERENCE IN SYDNEY**

August 12 – 14 2007 at the Hilton in Sydney. Registrations are open on line at [www.abainternational.org](http://www.abainternational.org)

And don't forget! **Gina Green** will also be visiting Australia around that time.

## HOW MANY HOURS OF THERAPY?

*A parent in Victoria posed this question in the ABIA newsletter: in turn the newsletter invited responses from readers. This is the response I submitted (D. Cooper)*

The question of “how many hours of therapy does my child need?” is a perplexing one for most parents. The answer, based on the current state of our scientific knowledge, is simple: “We do not know”. To elaborate: We know from controlled group experiments that, with between 30 and 40 hours of therapy per week that nearly 50% of children will be symptom-free after two years. BUT we cannot predict which individual children will be in that 50%. NOR do we know if the others could attain symptom-free status with more hours per week, or with more years of therapy. Yet again, we do not know if the 50% who are symptom free after two years would still have been symptom-free if they had had only twenty, or fifteen, or ten hours a week.

The only accurate advice we can give parents is: the more hours of therapy you can provide, the better. So far, there is no hard evidence to support any maximum or minimum hours, but we do know that in published studies, there have been no cases of children attaining symptom-free status where less than twenty hours of therapy have been provided.

There are various bits of research investigating the possible predictors of successful outcome for individual children, but as yet, there are no conclusive answers. But from the trends shown by some of this research, and from experience as “real-world” providers, we can fairly safely say the following:

\*We have known of cases where intervention has commenced early (before Age 2) where 20 hours of intervention has resulted in symptom-free status after 12 months.

\*Generally, a minimum of fifteen hours per week is necessary if any permanent gains are to be made.

\*The following two factors seem to be at least equally important to successful outcome as the number of hours of therapy:

1. Quality of the Therapy provided, both in terms of program design and the delivery by therapists.
2. Parental involvement in the program. Where parents get good at therapy, and it becomes the normal way of interacting with their child, every waking hour can be “therapy” – then the number of hours of formal therapy become less important, and a child with “participating” parents will generally do much better on a given number of hours than a similar child where parents are “non-participants”.

Finally, parents should be aware that there appears to be a proportion (less than 25%) of children who seem to benefit very little, regardless of therapy hours. Again, we have as yet no way of identifying these children at the outset; and the fact remains that Early Intervention, using ABA, with as many hours as the family can manage, represents the child’s best chance of making permanent improvements in levels of functioning.

## “THERAPY FORUM” HIGHLIGHTS NEED FOR PARENT ACTIVISM

Recently I attended a “Therapy Forum” convened by People With Disabilities WA and gave a short presentation about ISADD.

The purpose of the forum, other than to inform consumers as to who was who and who does what, was to allow families to air their views on service provision. Predictably, the major issues that arose were the lack of adequate funding and waiting lists. In response to very heart-felt complaints on these issues by several families, I stated that the only way to get any change was for the families to get together as a group, and lobby the government. I was stunned when one father reacted saying, “we’re too busy looking after our kids to lobby

government, you people (providers) should be doing it for us!”

I didn't get a chance to respond to that comment at the meeting but will do so here. There are two points I would make. First, providers make an ineffective lobby. Our demands for more money will be seen as self-interest (we just want to make our organisation bigger – and more important), and we are not perceived (and perception is all-important in politics) as having any electoral impact. On the other hand, a group of well-organised parents are seen as working in the interests of the persons with disability, and as having an impact on the electorate (through even as simple a mechanism as saying loudly in public, “don't vote for that lot, they don't listen to, or do anything for us”).

Secondly, if you take the attitude that somebody else should be doing what you want done, you'll achieve very little in life, other than a sense of disappointment. If YOU have a passionate interest, then YOU need to pursue it, because even IF someone else will do it for you, they will not pursue it with the same amount of passion.

It is also somewhat ironic that this parent, who said he hasn't the time to get together with other parents, had time to attend the forum!

Having got that off my chest, I think the forum served some useful purposes: among them, providing consumers an opportunity to raise issues in a non-threatening environment, and it would be good to see some of the issues raised pursued further.

Daryl Cooper.

### **Eastern States Case Manager/Senior Therapist In-Service Week-End.**

5 case managers and 5 seniors attended a weekend in Adelaide.

We looked at various new drills and new ideas and especially worked on some ways to improve understanding of emotions in themselves and in others. Also we teased out a matrix which would help track language teaching. Above all we shared ideas reinvigorated our team spirit and decided that the next session should be in Tasmania.

Jura Tender

### **A Mother's Inspirational Story**

I am a mother of 2 beautiful boys Matthew 5 and Nathan 4 who both have Autism. I hope my story will inspire you not to give up with your child .

One day before Christmas I received the diagnosis my two sons had autism. I remember going home that night and saying a prayer to God as I watched my two boys sleeping. I couldn't stop the tears pouring down my face. I had great difficulty facing the massive responsibility and task ahead of me of raising my two boys with autism. I felt a deep sadness and hopelessness as I prayed I could hardly speak. I said, please God let my boys wake up tomorrow without autism and let their minds be normal. I thought if I wished hard enough it would go away or maybe it was a dream. Of course tomorrow came and they woke up the same. I felt numb and lifeless during that time and could not see any light at the end of the tunnel.

I only realized over time the work and commitment needed in raising two boys with autism. I knew I would need a lot of strength but I had already been through a very stressful and frustrating time when the boys were babies before their diagnosis. I thought I was a bad mum and must be doing something wrong as my boys didn't develop normally but I didn't know why? I constantly blamed myself as they didn't coo or respond to my cuddles and didn't drink their bottle properly. They had strange behaviour like banging their heads on the wall, wouldn't look at me when I called their name or spoke to them and had great difficulty with eating any food. Mathew had to be hospitalised

twice because he wouldn't eat. I was so scared and I didn't know what to do. I felt helpless I knew something was wrong but health professionals didn't want to listen to my concerns I was angry and got depression. Why was this happening to me? Both my boys were not responding to anything I tried . I constantly felt so inadequate I wanted to do so much for them but what and how? I took my boys to professionals who specialised in young children and they diagnosed both my boys with autism. I felt relieved I am not to blame. I felt devastated though knowing that both my boys had autism. The following weeks I cried on and off all the time, what could I expect from myself and my children? would I be able to cope? Am I able to give my children the best chance?

Thank God those days are behind us. I got my boys into ISADD for early intervention and with their support and my hard work making up materials and doing lots and lots of generalising I have seen huge improvements. Today my boys speak fluently, eat almost everything, dress themselves attend school and have friends and are learning how to learn for themselves. It's a joy to see them play imaginary games together, play on the computer, talk to each other appropriately in conversation and express their feelings. They love to ride their bikes in the park and they are enjoying life to the full.

They are so special and I am too. They are thriving because I have put in the hard work. I have given them all I have, and my reward is seeing them talk to me and say, "I love you mummy". We are a loving family together. We have survived the diagnosis of autism, it is not a death sentence, and with hard work and sheer determination you can see results.

I think it's important and healthy for parents to acknowledge their feelings about raising a child with a disability and not just be told to get over it. We do get depressed and sometimes angry at the situation and sometimes feel that we can't make a difference but we can . Yes we can have those feelings but still keep on

giving our best to our children. We must keep trying, we have our children 24 hours a day 7 days a week and that's a hard ask for anyone even a parent without a child with a disability.

We mums and dads are special and so are our children, we have been given a gift. Our children are that gift and we have within us the love and patience to help our children reach there maximum potential. We must retrain ourselves to give love and nurture even if as a child we didn't receive it ourselves we can learn a new way of living. We have a life long commitment to helping our children find their place in life. We must do our best to help them get ahead and still love and look after ourselves.

The most important thing I must tell all parents is just one thing. "HOPE". I want you all to put this word hope in your hearts. It's so simple but its everything you need to be successful in helping your child grow. Hold onto hope that is to believe in yourself and your child. Hope that love can change you and your child . I call this word hope my rescue word that saved me from loosing everything. I kept believing despite the circumstances. Hope of knowing that things will change and my children can grow and learn. Hope in just knowing that my family and I can survive this life long journey and most of all that my children feel loved accepted and are able to love others.

My first experience of hope was wishing that one day my sons would say "I love you mummy". My time came when both my boys at different times said, "I love you mummy" and yes I could not stop my tears. Most parents write these words in a baby book as part of normal language but for me I didn't know if my sons would be able to speak. The words, "I love you mummy" I longed to hear; this hope kept me alive, fed my heart, renewed my hope in life and hope was engraved in my heart .

I want you all to know that this journey is a positive one, even though it is hard . Out of adversity can come hope and love and now I see my two precious sons playing, talking and

being loving to each other and I am filled with hope. Now as they grow my hope still remains for now I hope for their future, cars, jobs, homes and yes even wives. All things are possible if you have hope and love. Try and take each day as it comes and when you look back on your child's previous year, look through the eyes of hope and love you will see where your child was and where they are now. If its a small change its still a change and you've made the difference . Our children are

only as good as what we put into them, love acceptance, support and helping them reach there best is our gift to them . These are your children your dream your gift from God they are so special and our children will in time give back so much.

Sending you all my love and hope - *Kim*

## PHOTO CORNER



EASTERN STATES CASE MANAGERS/ SENIORS TRAINING



The Melbourne Team



More Case Manager/Seniors training