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Manitoba Families for Effective Autism Treatment

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MFEATnew

School Age ABA Informational Session

Manitoba Families for Effective Autism Treatment (MFEAT) and The St. Amant ABA Program invite you to attend a School Age ABA Interim Funding informational session for families. The focus will be on identifying issues, answering questions and providing support to families and schools as they begin to deliver services in the school setting. Discussions will include:

- Criteria for Interim Funding & Letter of Intent
- Status of permanent school age ABA programming & advocacy tips for families.

This session is critical for families of children who are currently receiving or interested in accessing ABA school age interim funding. Please join us in the Ambassador A room from 1 – 3 pm on Saturday, **February 25th** at the Canad Inn Fort Gary, 1824 Pembina Highway.

Mark your calendar and plan to attend!

President's Report

Once again the New Year is upon us and MFEAT continues to be extremely busy with several activities. Some of the major issues we are working on are listed below:

Advocacy Update

School Age ABA Interim Funding:

This issue remains front and centre for MFEAT as it has certainly required a significant amount of effort to address issues and concerns raised by families, schools and school divisions. MFEAT continues to meet with government representatives to develop strategies to address various implementation issues. St. Amant Centre has also invested a great deal of time and energy in meeting with families and school divisions in trying to facilitate ABA services for families that have applied for the funding.

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Calendar

School age ABA Informational Session.....Feb 25, 2006

Bill 13 – Forum on the Regulations.....Feb 15, 2006

RDI workshop.....Mar 23-24th, 2006

ASM workshop.....April 21, 2006

Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors

Glen O. Sallows and Tamlynn D. Graupner - Wisconsin Early Autism Project (Madison)

Twenty-four children with autism were randomly assigned to a clinic-directed group, replicating the parameters of the early intensive behavioral treatment developed at UCLA, or to a parent-directed group that received intensive hours but less supervision by equally well-trained supervisors. Outcome after 4 years of treatment, including cognitive, language, adaptive, social, and academic measures, was similar for both groups. After combining groups, we found that 48% of all children showed rapid learning, achieved average post-treatment scores, and at age 7, were succeeding in regular education classrooms. Treatment outcome was best predicted by pre-treatment imitation, language, and social responsiveness. These results are consistent with those reported by Lovaas and colleagues (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). To read about this study, visit

<http://depts.washington.edu/pdacent/archive/checkitout7.pdf>

Asperger Manitoba Inc.

Asperger's Syndrome (AS) is a neurodevelopmental disorder of the "mild" end of the autism spectrum, which affects language and social functioning, often with accompanying perceptual, emotional and behavioral symptoms and sometimes motor problems. Autistic -like behaviours and language patterns are frequently evident. Because these are very serious chronic disorders, affected individuals need special education and often medical and psychological support. Parents and caregivers need accurate information and encouragement. These needs often compound as individuals with AS enter adulthood presenting a vast array of stressful challenges to establishing independence and entering the work force. Once they leave the school system, many young adults with Asperger's are left in a kind of limbo, without the supports they need to survive the long term. They remain emotionally and financially dependent on their families, and caregivers.

Asperger's Syndrome has been recognized in North America as a distinct diagnosis since 1994. Therefore many children went undiagnosed or collected various medical labels which dealt with symptoms without adequately looking at the individual as a whole.

Asperger Manitoba Inc. is incorporated as a not-for-profit corporation in the Province of Manitoba, Canada that grew out of a parent support group for parents of adults with Asperger's Syndrome. AMI developed out of need and frustration - the need for understanding and ongoing support for Asperger adults to live and work within society. The frustration arises from the fact that this kind of support for individuals living with Asperger's and their families is not presently a reality. In 2004 a number of members of the support group, along with some professional caregivers, formed Asperger Manitoba Inc. in an effort to increase public awareness of Asperger's Syndrome and to work toward improving the quality and level of services available to persons with AS.

AMI's purpose:

- 1) To provide support for those affected by Asperger's Syndrome by offering education and counselling.
- 2) To educate the public about Asperger's Syndrome and the needs of persons affected by Asperger's Syndrome by collecting and disseminating information on the topic.
- 3) To undertake activities which are ancillary and incidental to these objects.

For more information on Asperger Manitoba Inc. please visit

www.asperger-manitoba.ca

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While there have been some instances where services have successfully been implemented and the children are doing well there are also many challenges.

It is extremely important to note that the interim funding granted by the government was to help offset the financial cost for families who are implementing, or demonstrated an interest in implementing ABA programming in school. **MFEAT & St. Amant have identified to government representatives that the current level of interim support is not be sufficient to successfully deliver programming in Manitoba.**

MFEAT is continuing to work on our goal of transitioning to optimal, permanent school age ABA programming.

For this reason, we are focusing on re-defining criteria for current interim funding eligibility. Information will be forthcoming. Families should also be aware that a waitlist for school age services currently exists, and because of the higher than anticipated interest in this service, it is feasible that some families may be affected. MFEAT is currently discussing this issue, and will work with the government and St. Amant to make recommendations on this issue. If you are interested in applying for the funding and meet the funding criteria, it is

in your benefit to submit your application as soon as possible.

****An information session on school age ABA services will be held at Canad Inn -Fort Gary on Feb 25th from 1:00 – 3:00 p.m. It is critical that all families who are interested in extending ABA services for their child into the school setting attend. All families who are currently receiving services through St. Amant and/or are MFEAT members will receive a mail out with further information.***

School Age ABA Advisory Committee:

The committee has not met since the last report . The next meeting is scheduled for March 22nd, during which some of the issues above will be reviewed.

ABA Preschool Program: The Pre-school program currently operating at St. Amant Centre continues to deliver excellent results and is operating at maximum capacity. MFEAT provides ongoing input with representation the ABA pre-school Program Executive Committee. We are extremely pleased with the partnership we have developed with St.

Amant and are very appreciative of the tremendous support, enthusiasm and professionalism they have demonstrated in the delivery of the program. Those interested can refer to St. Amant’s ABA Program Bulletin (February Issue) for more information. Call 256-4301 ext. 3442 to be sent a copy, or access archived copies on the program’s website at www.stamant.mb.ca

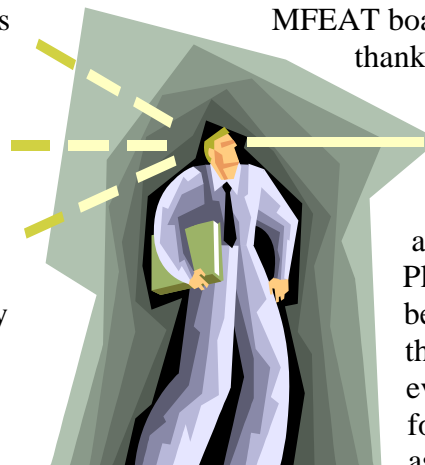
Additional Initiatives

MFEAT Conference:

Once again this year’s conference was very successful with a full schedule of excellent presenters. The feedback received from conference participants was very positive. On behalf of the MFEAT board, I would like to

thank the Conference Committee for all their hard work and dedication in delivering such an excellent event. Plans are already being discussed for the 2006 conference event and we will forward information as it becomes

available. That covers most of the critical business currently in progress within the organization. Our primary focus continues to be around the implementation of the interim school age funding and the development of



Jason Drysdale – School Principal

Jason is a principal in the River East Transcona School Division. He has administrative and teaching experience from Kindergarten to Senior 4. Jason has worked on various school and divisional level committees in various areas including the areas of curriculum planning and implementation, differentiation, and school planning.

During the presentation, Jason will share his experiences on helping school staff as they begin to work with the requirements of the Appropriate Education Act.

Annette Lyss – Manitoba Association of Parent Councils

A parent, in the Seine River School Division, will provide a parent's perspective on what the regulations mean or don't mean in providing an appropriate education for their children.

Ms. Lyss has served on the Board of the Manitoba Association of Parent Councils (MAPC) for the past six years and is currently the Co-President. She has served as a MAPC representative on the Department of Education's Special Education Inclusion Committee for the past few years.

Ms. Lyss has always had an interest in the topic of Inclusive Education, having attended school with exceptional children in junior and senior high, and currently as a parent, and as support worker of exceptional children.

For further information please contact Jim Hoddinott at 222-9577 or by email:

<mailto:jhoddinott@retsd.ca>

Bill 13



Bill 13 – What Are Your Afraid of

**Manitoba Council for Exceptional Children invites you to attend:
A Forum on the Regulations and What They Mean To You**

Date: February 15, 2006
Place: Fairmont Hotel
2 Lombard Place
Winnipeg, MB
Time: 7:00 – 9:00 pm
Cost: Free
Refreshments Provided

Yvonne Peters - lawyer
A human rights lawyer will provide a legal perspective on Bill 13 and the Regulations. What do they mean? Do the regulations match the intent of Bill 13?

Ms. Peters practices as a lawyer in Winnipeg specializing in equality rights and human rights law. Her practice offers a blend of legal advice and social policy development.

In addition to her work as a lawyer, public speaker, educator, law reform consultant and board member, Yvonne Peters is a prolific volunteer. She has worked with numerous organizations, including the Canadian Disability Rights Council, Women's Health Clinic and the National Association of Women and the law.

optimal school age programming in our province. We remain committed to helping families and working with schools and school divisions to establish ABA services in these settings.

The February meeting of the general MFEAT membership has been replaced by the school age information session on February 25th. Once again, I urge all families with a stake in this to attend. Progress cannot happen without the voices of the families being heard. Our next regular membership meeting will likely be the Annual General Meeting in June. In the meantime please don't hesitate to contact me or any other board member with any questions, comments or concerns you have about our organization.

*MFEAT President
Eldon Strachan*

Mission Statement:
Our mission is to ensure Manitoba children with Autism Spectrum Disorder have access to effective treatment.

ASD-CARC Autism Research

Parent Advisory Group Questionnaire – Providing ASD-CARC researchers with new directions for research

*A message from Dr. Jeanette Holden
– January 20, 2006*

Listening to family members:

Many years ago, my Mother said to me that she just wished that people who worked with my brother Jim would simply explain things to Jim before they made changes to his seating arrangements at his sheltered workshop, or to his schedule. Despite the fact that Jim did not have much language, he did understand much of what people were saying, however, if they don't speak clearly and simply, he only comprehends every few words, and he can misinterpret what they are saying and become very upset because he thinks he is being punished when they make changes, and he doesn't know what he has done wrong. For example, one day he came home very very upset, and when my Mother called to find out what happened, they told her that they felt a lady who Jim liked to bring coffee and tea and her coat to, because she has a walker and cannot do it easily herself, was taking advantage of Jim and becoming lazy. To "correct" this, they separated Jim and his friend, moving Jim to sit with other people while

he worked. Jim felt he was being punished – wouldn't you feel the same if no-one explained the situation? This taught me a very special and important lesson: that no matter how much training and education "professionals" have, they are not the experts about the children of others. Families have so much to offer professionals, if they would only listen.

Our ASD-CARC is blessed with the good fortune of having a very active and knowledgeable Parent Advisory Group – PAG for short. This terrific group of parents had many discussions, and decided that there were so many questions that they each had, that they would develop a questionnaire based on these questions and their own observations: the PAG Questionnaire. They had so many questions, that it has been broken down into small sections, that will be released every approximately 2 weeks. We hope you will help us develop new areas of research by completing each section, which will take only a few minutes of your time every 2 weeks. PAG - Section 1 and PAG - Section 2 are now available. Please log in to complete these at www.asdcard.com Please feel free to provide feedback and suggestions at any time, <mailto:autism@post.queensu.ca>

Relationship Development Intervention – RDI Workshop

*Going to the Heart of Autism –
Relationship Development
Intervention.
Asperger's Syndrome &
Pervasive Developmental
Disorder*

Relationship Connections is hosting a 2 day RDI workshop on March 23 – 24th, 2006 featuring speaker Steven Gutstein.

Location: Canad Inns Polo Park, 1405 St. Matthews Ave, Winnipeg, MB

For more information visit <http://members.shaw.ca/vicstone/>

Autism Society of Manitoba (ASM) Workshop

*Navigating the Middle Years &
Beyond: Practical
Strategies for Home and School*

The Autism Society of Manitoba (ASM) is hosting a workshop on April 21, 2006 featuring speaker Brenda Myles .

Location: Canad Inns Polo Park, 1405 St. Matthews Ave, Winnipeg, MB.

Registration deadline: Feb 21
For more information visit www.autismmanitoba.com

** The publication of the above conference dates is an information source only and does not constitute endorsement, recommendation or support of the MFEAT organization for such events or treatment.

AGRE Researcher Identifies Genetic Association Between Autism and ENGRAILED2 (EN2)

AGRE Researcher James Millonig and colleagues have published a genetic association study focusing on a gene called ENGRAILED2 (EN2), which is involved in the formation of the brain during early stages of postnatal development.

Specifically, EN2 was shown in several studies, to be essential for the proper formation of specific types of cells called Purkinje cells in the cerebellum. Eliminating this gene in mice reduced the number of these types of cells in the cerebellum.

Remarkably, individuals with autism have reduced levels of these Purkinje cells in the cerebellum, a brain structure involved in activities such as learning and language acquisition. These activities are often a source of difficulty for individuals with autism.

Previous genetic evidence had shown that a gene in the vicinity of EN2, if not EN2 itself, had a statistical likelihood of being involved in autism. In 2001, scientists at Columbia University and UCLA, among others, carried out a genome scan on 110 families who participated in the AGRE program. In a genome scan, scientists look for excessive

sharing of genetic variants among affected individuals. These variants serve as markers of the genetic terrain. If a particular set of markers shows excessive sharing among individuals affected with autism, this implies that autism is linked to that part of the genetic map. EN2 has been genetically mapped to an area on the short arm of chromosome 7 (7q), which showed this type of linkage.

Dr. Millonig and his colleagues realized that all lines of evidence implicated the EN2 gene and chose to test its potential genetic association using the Transmission Disequilibrium Test (TDT), a fairly common and sensible method in genetic research. Their group used a public database of genetic variants or Single Nucleotide Polymorphisms (SNPs, pronounce as SNiPs) which are single chemical changes in the DNA code that vary among individuals at a particular location on the genetic map. Four of these SNPs were chosen and tested on 138 triads (2 parents and 1 affected child) in the AGRE collection.

The TDT test simply asks the question whether each parent was more or less likely to transmit form A versus form B of the variant to the autistic child. If the parents were statistically more likely to give A than B, then A is either the cause of the susceptibility to autism or, as is often the case, that A is a good

marker for that susceptibility. The research team chose two SNPs in areas that actually serve as the blueprint for the EN2 protein. Curiously, those two variants did not show any association with autism. However, the two variants that did show an association with autism are located in a region previously considered "junk" DNA. It is now known that these "junk" regions often contain sequences that serve as a signal for when genes get turned on, how often, and in response to which triggers turned on, how often, and in response to which triggers. Future work will probably include looking at a greater number of families in the AGRE collection in order to replicate these findings. In addition, the discovery and testing of

additional SNPs will help to better define the area that seems to be most associated with autism susceptibility. This work adds to the growing body of evidence that genes involved in brain development are important in autism susceptibility and highlights the potential role of the cerebellum in autism. Finally, this study provides one of the most promising candidate genes in autism susceptibility. Funding for this study was provided in part by NAAR and the March of Dimes.

