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MFEATnews

MFEAT Hosting Wine & Cheese

Manitoba Families for Effective Autism Treatment invites you to attend a Social Evening, Wine and Cheese.

This is a great opportunity to socialize and network.

Please join us at Ecole Lacerte, 1101 Autumnwood, Winnipeg, MB. (corner of Autumnwood & Cottonwood) on **Feb 23rd, 2008.**

Hope to see you all there!

See page two for more information.



President's Report

Advocacy Update

There is some good news on the advocacy front as we were able to attain the resources we needed to address some of the issues we were experiencing in the school age ABA funding structure last fall. We also developed a

definition of school age ABA services document, along with a proposed model structure which we shared with the government representatives at our November meeting.

We are waiting on feedback from these

documents when we next meet before we finalize them.

(continued on page 3)

Manitoba Families for Effective Autism Treatment

162-2025 Corydon Ave
Suite 129
Winnipeg, MB
R3P 0N5
www.mfeat.ca info@mfeat.ca

Our Mission Statement:

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

Calendar

MFEAT Wine & Cheese
Social Evening.....February 23, 2008

Community Living "Come
Together 2008".....February 13, 2008

*1st MFEAT Annual
Wine and cheese*

Date: Saturday February 23rd 2008

Price: free!!!

Time: 1:00 p.m. to 4:00 p.m.



*Where : at École Lacerte , 1101 Autumnwood
(At the corner of Cottonwood and Autumnwood)*

*Please join us for a status update from the MFEAT
committee, followed by a wine and cheese.*

*This is a great opportunity to come and socialize, network
and meet parents, grandparents from the pre-school and
school age programs. It is an opportunity to share ideas,
successes and struggles with our children.*

Please reserve / RSVP by February 15th.

Call Martine at 254-8477 or by e-mail at: mlaczko@mts.net

We look forward to seeing you there!

President's Report – continued from page one.)

We are also planning on possibly meeting with other bodies in Manitoba Education such as SSAMM, MASS and MAST to possibly seek input as well. Once these documents are complete we will be sharing them with schools and school divisions involved with ABA programming.

MFEAT Conference: This year's event was once again a tremendous success. I would like to thank the conference committee for all the hard work in putting together another great conference.



MFEAT Wine and Cheese:
The next general meeting will be held on Saturday Feb 23th in the form of a wine and cheese. The event will serve as an opportunity to briefly review MFEAT business with a quick information exchange, but more importantly is meant to be a social gathering where parents can share information and get to know one another better. There is further

information on the event in the newsletter. Please note that we require RSVP in order to properly prepare food and beverages.

Family Services Facilitated Session on ASD Services:

MFEAT was invited to participate in a session for ASD services stakeholders. The purpose of the event was to gather information in hopes of identifying a clear vision and action plan to enhance services for ASD individuals in Manitoba. There was a lot of good discussion and information exchange and the group was able to identify a few key areas to work on both in the short and long term picture. Further information will be available once the final report is circulated. It is anticipated that there would be future meetings of a cross section of the various stakeholders in the form of a working group or committee. MFEAT has volunteered to be part of that group if it becomes a reality.

Other Initiatives:

National Autism Symposium:

MFEAT sent a letter to the Federal Health Minister in regard to the Autism symposium which was held in early November. We were disappointed with several aspects of the event including short notification, limited participation and narrow focus among others. It is our hope that a future event with a much broader focus will be scheduled in order to address the recommendations made by the Senate Committee on Social Affairs, Science and Technology in their March 2007 report titled "PAY NOW OR PAY LATER: Autism Families in Crisis"? We will keep the membership posted on developments in regard to this issue.

New Brochure: Our new brochure is complete and we are very excited at the final product which looks great. I'd like to thank board member Heather Milne and all the other volunteers who worked on putting the brochure together. If you would like a copy please contact the MFEAT office at 487-1685.

MFEAT Sub-Committees:

The MFEAT organization continues to grow and as we do there seems to be additional work required in order to meet the needs of families in Manitoba. The executive board will be holding a visioning event in order to review our mandate and develop a clear path for the future. We envision that we will need to formalize a sub-committee structure in order to accomplish our long term goals and objectives, once this process is complete. We may be looking for volunteers from the general membership who can assist by possibly sitting on one of these sub-committees. If you are interested please contact the MFEAT office, any board member, or send us an e-mail at info@mfeat.ca

MFEAT Confidential

Information Policy: We have developed a policy in regard to how we use confidential information collected from families who are members of MFEAT. As you know there are new privacy laws which limit how personal information is collected, stored and used by organizations. The new

policy should be available on our website in the very near future. If you have any questions or concerns about this policy or our procedures of handling confidential information, please don't hesitate to contact an MFEAT board member.

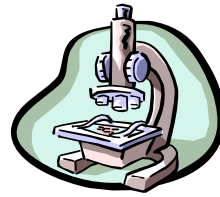
MFEAT Member Contact Information Form: You will probably have noticed the contact information form which was enclosed with your newsletter. I would encourage you to complete the form and return it to us so that our contact information is current. There is also an opportunity for you to become more involved with MFEAT by volunteering to assist us in various roles.

In closing I hope you will consider joining us for the wine and cheese on Feb 23rd. I think it is extremely beneficial for families to remain connected to the organization and to one another. We want to hear your feedback in regard to the issues that are important to you and your child. We also have families who have a strong desire to network with others and this forum will serve that purpose very well. Once again mark your calendars and don't forget to RSVP in advance. In the meantime please feel free to call me with any concerns or questions you may have in regard to the MFEAT organization.

Eldon Strachan
MFEAT President

Opportunity to Participate in a Study?

*An invitation from:
Ansley Verbeke, M.A.
Ph.D Candidate
Department of Psychology
University of Manitoba*



Dear Parent(s),
I am a PhD student at the University of Manitoba and I am currently conducting, as part of my PhD Degree, a research study that examines language skills. We are currently recruiting children who are just learning to talk and are able to echo some words.

The following is a brief description of the study: When assessing the types of tasks that a child can readily learn to perform, it is important to know his or her ability to make certain types of discriminations. One particular type of discrimination involves the ability to correctly state the name of an object. For example, the ability to say "cat" when asked "what it is" and seeing a picture of a cat requires both visual and auditory discriminations in that the individual must be able to identify the picture as a cat and then produce the correct word. In this study we will assess and attempt to teach a variety of tasks of this nature.



In this study we will:

- 1) Assess your child's visual and auditory discriminations on the Assessment of Basic Learning Abilities (ABLA) Test to determine what types of tasks he or she can readily learn.
- 2) Determine your child's ability to repeat words, name objects and ask for desired items.
- 3) Attempt to teach your child to correctly state the names of six objects for which your child currently does not know their names.

Participation in this study is voluntary, and will include one to two, 30-minute sessions per week. Sessions will be scheduled at your child's convenience. If you are interested in more details, please contact me at 256-4301 ext 5444.

This research is supervised by Dr. Garry Martin, Distinguished Professor of Psychology, University of Manitoba, and Dr. Dickie Yu, Director of Research, St. Amant. Thank you for your consideration.

*Aynsley Verbeke, M.A.
Ph.D Candidate
Department of Psychology
University of Manitoba*

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Does MFEAT have your current contact information?



We are updating our records!

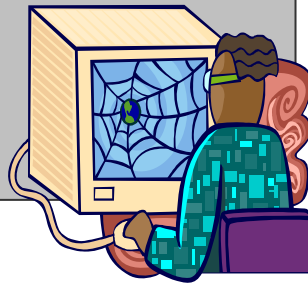
We want to be sure we have your current contact information. Enclosed with this issue of MFEAT news you will find a contact form along with a postage paid return envelope for your convenience. Please take a few moments to fill it out your name, mailing address, phone number and email address and return it to us!



Canada Autism.com

Canadaautism.com endorses the [Autism Spectrum Disorder \(ASD\)](#) Petition to Canadian Parliament (House of Commons). The website provides updates and information about the petition for people with ASD to be able to access health care. For more information, please visit <http://canadaautism.com/>

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Autism Asperger Publishing Company

(AAPC) is an independent publisher specializing in books on autism spectrum disorders based on the latest research on autism, Asperger syndrome and other pervasive developmental disorders. They have recently expanded their titles of books and resources on social skills and sensory integration dysfunction.

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Genetic flaw appears to increase risk of autism 09/01/2008



Researchers have made an important discovery in the search for answers in the mystery of autism. They've identified a genetic flaw that appears to increase one's susceptibility to the condition.

The researchers found that a segment of chromosome 16 is either missing or duplicated in about one per cent of individuals with autism or related disorders. That may not sound like much, but the study's senior author, Dr. Mark Daly, of the Massachusetts General Hospital Center for Human Genetic Research, tells CTV News that those people who have this chromosomal abnormality have "a very, very high risk of autism." In fact, kids with the chromosomal abnormality have a 100-fold increased chance of developing autism than kids without it. What's more, the researchers found that the gene flaw does not appear to be inherited. In the autistic kids the

researchers identified who had the flaw, none of their parents had it as well. "This tells us this is a spontaneously rising mutation," says Daly.

Dr. Steven Scherer, a senior scientist in Genetics & Genome Biology at Toronto's Hospital for Sick Children says that will come as good news to many parents of autistic children.

"We can actually tell the families - it's not your fault. It's just something that happens randomly, a genetic roll of the dice," he says.

That's reassuring news for parents like Usha Uthayan. Her twin boys, Nakulan and Sadhu, both have autism.

"When parents realize there is something spontaneous and not necessarily something the parent did, it goes a long way to reducing their guilt," she tells CTV News. "Because, naturally, when any parent discovers any sort of disability, the first thing you look at is: is it something I did? Is it a part of me that has been passed on to my child?" Daly says while science is still a long way from understanding how this chromosomal deletion or duplication increases the risk for autism, the discovery is an important clue.

"This is one piece of a very complex puzzle, as we try to determine the biological roots of autism," he told CTV News. "But genetics offers hope. In the case of autism, it is the only path of hope in understanding the biomechanical causes of the disease."

Studies suggest that up to 90 per cent of cases of autism spectrum disorders have some genetic component, but only 10 per cent of cases can be attributed to known genetic and chromosomal syndromes.

Daly's team decided to conduct a complete genome scan of samples from the Autism Genome Research Exchange, which contains DNA from families in which at least one child has autism or a related disorder.

The scan of more than 1,400 autistic children and a similar number of their unaffected parents revealed that an identical region of chromosome 16 was deleted in five of the kids with an autism spectrum disorder.

They then looked at clinical testing data from almost 1,000 patients from Children's Hospital Boston - about half of whom had been diagnosed with autism or a related developmental delay.

Among those with a developmental disorder, five children had the same deletion, and four more had a duplicated chromosome segment. No abnormalities were seen in DNA from children without autism or developmental delay.

"These large, non-inherited chromosomal deletions are extremely rare," says Daly, "so finding precisely the same deletion in such a significant proportion of patients suggests that it is a very strong risk factor for autism."

Daly says his team is now pursuing more detailed genetic

studies to see if other genetic flaws can be found.

The findings could have important significance for improving diagnostic methods. At the moment, autism is diagnosed by observing a child's behaviour and looking for the classic signs of the disorder, such as a lack of eye contact. But since autism is a spectrum disorder, there are wide ranges of autistic behaviour.

By identifying gene abnormalities, doctors could soon have the first clinical diagnostic tool for autism. That's exactly what Dr. Scherer is hoping for. He has been conducting similar research into the genetics of autism and says he also some exciting research that will be published later this month on other chromosomal abnormalities of autistic children.

He says a test for the chromosome 16 abnormalities is not far off. And when it comes, it will be the first test specific to autism.

"We can perform a very simple DNA-based test that's quite simple, inexpensive and rapid," he says, noting that other hospitals will also likely look to include the test in families with increased rates of autism.

Early detection is key, he says, since it could mean that crucial intervention, such as behavioral and educational therapy, could be started earlier.

With a report by CTV medical specialist Avis Favaro

Autistic mouse may offer clues about condition, treatments

CBC News- Monday, December 10, 2007

Scientists have created an "autistic mouse" after replacing a normal gene in its body with a mutated one.

They hope the mouse will yield clues about autism, a neuropsychiatric disorder in which those affected experience social, communication and sometimes cognitive deficits. Many perform repetitive motions, and some variants of the disorder are accompanied by a heightened spatial ability and high intellect.

"With this research, we can study changes in the brain that lead to autistic behaviours and symptoms, which may help us understand more about progression and treatment of the disorder," study author Craig Powell, assistant professor of neurology and psychiatry at the University of Texas Southwestern Medical Center in Dallas, said in a release.

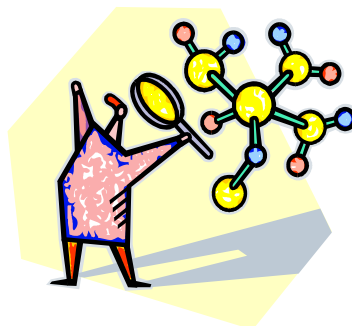
Researchers replaced a normal gene called neurologin-3 with mutated neurologin-3 gene, which is associated with autism.

The modified mouse showed autistic symptoms similar to those in people with the condition, according to the authors. It displayed decreased social interaction with other mice, anxiety, poorer co-ordination and pain sensitivity. It also showed advanced spatial learning abilities.

The scientists plan to test drug therapies on mouse models to improve social interaction deficits.

"For now, the mainstay of autism treatment is still behavioural therapy. The earlier we can get patients involved with behavioural interventions, the better off people with autism will be," said Powell.

The research was presented Saturday at the American College of Neuropsychopharmacology annual meeting in Boca Raton, Florida.



Community Living Manitoba presents: "Come Together 2008"

A unique dialogue between people with intellectual disabilities, their support networks, and Manitoba policing agencies.

People with intellectual disabilities are living, working and participating in their communities around the province. Sometimes they come in contact with the police either as victims, witnesses or offenders of crime.

In this unique one day session, participants will come together to examine the many issues that arise when people with intellectual disabilities come in contact with the policing agencies in Manitoba.

Specific issues will include: Informed consent, interviewing people that communicate and understand differently, implications of the Vulnerable Persons living with a Mental Disability Act, offender issues, prevention, relationship building, collaborating, coming together, the many ways people "tell the truth", and more.

**Date: Wednesday, Feb 13, 2008
Time: 8:30 am – 4:30 pm
Place: Greenwood Inn & Suite, Winnipeg, Manitoba**

For more information or to ensure you receive a full registration package, please contact:

cometogether2008@mts.net

Collective Voice of Autism Community in Canada Calls on Government to Take Steps to Establish National Autism Strategy

The following press release was in response to the federal government's response to the Standing Senate Committee recommendations on Autism tabled on Oct 17th, 2007. This response represents the first collaborative communication to our government from a new and growing ASD alliance. It calls on the Canadian government to embrace the recommendations of its Senate and to show leadership by committing to a comprehensive national ASD Strategy. In July of this year a small group of individuals representing a number of Canadian ASD organizations began preliminary meetings to discuss the possibility of developing a national alliance on issues of mutual importance to constituents. The broad goal of the partnership is to work together to promote responsive national policies and necessary programs in the areas of treatment and education, supports and accommodations, and research that will meet the diverse needs of the ASD community across the lifespan. It is hoped that a collective endorsement of a comprehensive National ASD strategy and better liason at the federal level will result in more action on the recommendations made by the Senate Committee this past spring.



OTTAWA - (Marketwire - Nov. 5, 2007)

The Conservative Government has provided its response to the Standing Senate Committee recommendations on Autism in its Response to the Report of the Standing Senate Committee on Social Affairs, Science and Technology, *Pay Now or Pay Later: Autism Families in Crisis*, tabled on October 17th, 2007.

Good news in the federal response is the announcement of a new Autism Research Chair at Simon Fraser University focusing on the study of treatments and interventions. Autism organizations are encouraged to see more focus on applied research and best practices. In addition the government has promised further funding for ASD research in general, has committed to hosting a fall research symposium and is promising more investigation into the potential for developing national surveillance on ASD.

The response states that “...the Government of Canada acknowledges the complexity of the challenges related to ASD and agrees with the Committee that there is much work to be done to enhance collaboration and evidence on this issue...” Autism advocates across Canada had

hoped that the federal government would take a stronger position in response to the report, which provides unmistakably clear direction. A number of key organizations are coming together to urge our federal government to take a clear leadership role in confronting what truly is a national problem. Last December, the Standing Senate Committee investigating Funding for the Treatment of Autism heard from hundreds of families, adults with Autism Spectrum Disorders (ASD), experts in treatment and service delivery, researchers and Autism advocacy organizations across Canada – representing the over 200,000 children, youth and adults affected by ASD in this country. These figures, which are sobering enough, do not represent the true number of Canadians affected by the lack of adequate action and services for ASD. Parents, other family members and caregivers are also deeply affected, emotionally, socially and financially. In its ground breaking report entitled, *PAY NOW OR PAY LATER: Autism Families in Crisis (March 2007)* the bi-partisan Senate Committee recommended some urgent initiatives that the federal government could implement over the next two years in response to the crisis situation faced by many individuals with ASD and their families.

Most importantly, both Conservative and Liberal Members of this Senate Committee called on our government to develop a comprehensive National Autism Strategy to address the complex needs and glaring inequalities in public funding and access to targeted services and treatment across the country. ASD typically presents lifelong challenges to those individuals diagnosed as well as to their family members and to society as a whole – a comprehensive national plan is vital. The government declined to take up the Senate's recommendation to lead the way forward in committing to a National ASD Strategy. In spite of receiving hundreds of hours of testimony from all concerned; well-vetted and honed down by a dedicated committee of Senators, it seems that: "... governments do not yet know enough about ASD and its treatments to implement effective and well-informed strategies that would lead to meaningful outcomes,...". The 12-page response is very focused on knowledge gaps and provides a great deal of information about current special needs programming – little of which is Autism-specific. Our government's Senate Committee also supported fully the recommendation of a federal/provincial/territorial ministerial conference to look at innovative funding

arrangements for the purpose of financing Autism therapies, defining essential services and looking at new family support measures but the government has also declined to take up this recommendation. With the exception of First Nations and Inuit communities, the response is in keeping with federal practice and places all responsibility for health and educational funding decisions on transfer payments and service delivery squarely on the provinces and territories. This is in striking contrast to the U.S. policy dealing with the same funding crisis: the United States' Combating Autism Act of 2006 authorized the federal government to spend \$US 945 million over five years for Autism research, screening, intervention and education. Last week the joint U.S. House and Senate conference committee approved \$37 million for this year's spending on autism services and treatment programs alone. While progress has been made, it is clear that Autism Spectrum Disorders have not yet found their rightful place in the health, education and social service sectors at any level of our governments. Working in the Autism field, we hear daily the stories of the mental and financial hardship that parents,



family members and many adults with ASD experience. We are deeply concerned about the shortage of services; we recognize from first-hand, on-the-ground experience, the urgent need for qualified professionals to work with individuals with ASD. Immediate action is needed to address these glaring gaps. Now that this response has clearly acknowledged the seriousness of the pressures facing families and individuals with Autism - we hope the next step will be for our federal government, in cooperation with all of the provinces and territories, to take a leadership role with respect to Autism. Our growing stakeholder Alliance of ASD advocates and professionals working in the field provides an excellent and willing collaborative resource to assist this government in taking up the Senate's call to develop a comprehensive National ASD Strategy to address the lifespan issues of individuals with Autism Spectrum Disorders. If our government is seeking input in developing such a strategy, the expertise is certainly available. We call on the Canadian government to embrace the recommendations of its Senate and to show the leadership we so badly need to address this crisis as other countries have done. We all feel strongly that a National Autism Strategy must be formulated very soon and that developing this strategy should be vigorously pursued.