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Manitoba Families for Effective Autism Treatment

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MFEATnews

President's Report

It is with a certain amount of anguish that I write what will likely be my final president report for the MFEAT organization. After being involved with the MFEAT since it's inception in 1997, I have decided to not seek re-election in the role of President for the upcoming term. I do plan to stay on the executive board for one more year in a supportive role to assist the incoming president in a smooth transition. While I'm still very interested in the pursuit of effective treatment for ASD children in Manitoba, it seems like the appropriate time to step aside and transition to new leadership. While this may be a time of reflection and remorse for myself, it is anything but that for the organization. MFEAT is in the process of developing a roadmap for a new strategic plan, which will guide the organization in the direction we need to take in order to meet our future goals and objectives. This will include some changes to the board structure and create many new opportunities for increased input and involvement from our membership.

(continued on page 2)

MFEAT Annual General Meeting

MFEAT's Annual General Meeting will be held on Saturday, June 21, 2008 from 10:00 am until noon in the West Dining Room at St. Amant Centre, 440 River

Road, Wpg, MB. We will be discussing many urgent items, including the road map for our strategic plan. Agenda for this meeting

is on page three. Plan to attend!



Calendar

- MFEAT AGM.....June 21, 2008
- St. Amant 15th Annual Conference.....Oct 9 & 10, 2008
- MFEAT Annual Conference.....Nov 6th & 7th, 2008
- Gym Night beginning.....Sept 26, 2008

The end result will create a stronger organization that is structured to meet the needs of families and children in Manitoba seeking effective autism treatment. It will also strengthen our public image and position us to be able to respond to developments in the autism community in a timely manner. I am personally very excited about this initiative, and know it will prove to be a tremendous success.

Advocacy Update:

Unfortunately there has not been any progress on the school age ABA proposal we submitted to government in November of last year. As an organization we are very disappointed in the delayed response in regard to this submission, but anticipate an announcement on school age services is pending. We will continue our dialogue with the necessary stakeholders in order to expedite an announcement in the shortest possible timeframe. We hope to have additional information in time to share it with you at the Annual General Meeting in June.

MFEAT Conference:

This year's event is scheduled for Nov 6 and 7th at the Canad Inn at Polo Park. Once again the conference committee has put together an excellent slate of presenters for this years event. Additional information will be available at the AGM and on our website at www.mfeat.ca

MFEAT Annual General Meeting-

Our annual general meeting is set for June 21st at 10:00 AM. We are providing food for the event and will be discussing many urgent items including the road map for our strategic plan. There is an agenda included in the newsletter. We are also seeking at least two new executive board members (including a secretary) and are looking for someone to publish our newsletter in the upcoming year. We also anticipate several opportunities to volunteer as a sub-committee member once our restructuring process has taken place. It is extremely important that we have your input at this meeting and hope many of you will plan to attend.

MFEAT Gym Night- We are in the process of developing a family gym night and support group which will commence in September. Further information will also be available at the AGM in June.

I think that brings you up to date on some of the more important events and issues we are currently working on. When I reflect upon the accomplishments of the MFEAT organization over the past 12 years I can honestly say I'm amazed at what we have achieved. Through the years of early advocacy, to the ABA pilot project ,the permanent preschool program at St Amant and development of school age services, we have given hundreds of

Manitoba families new hope for a brighter future for their children with ASD. We have also developed many strong partnerships and recruited valuable allies through our advocacy efforts. I think we are viewed in the community as an organization who operates on values such as trust, respect, honesty and integrity. I feel very honored and privileged to have been part of such a dedicated and committed organization. I have gained a great deal of knowledge, met some very good people, developed many friendships and have memories which will last a lifetime. While there are far too many names of individuals to acknowledge I'd simply like to thank everyone for the support, cooperation, patience and understanding that they have given me over the past few years as MFEAT president. In closing I would like to remind the membership that although we have accomplished much as an organization, there remains much to do. While we have sustained funding for preschool services and are working on resources for school age ABA, there will likely always be a need for continued advocacy to ensure services remain in place for children to access effective treatment in our province. We need a strong collective voice to get our message through to those that need to hear it. Please consider joining us for the AGM on June 21^s .

MFEAT President - Eldon Strachan

Manitoba Families for Effective Autism Treatment

**Annual General Meeting Agenda
Saturday, June 21, 2008 - 10:00 a.m.**

**Location:
West Dining Room
St Amant Centre
440 River Road**

Welcoming and Introductions

5 mins

IntroductionsEldon

MFEAT Business

90 mins

- 1. Adoption of Agenda..... Eldon
- 2. Approval of Minutes of 2007 AGM All
- 3. President's Report Eldon
- 4. Treasurer's Report/ Approval of Audited Financial Statement.....Stephen
- 5. MFEAT Long Range Planning Roadmap.....Lori
- 6. Election of Directors All
- 7. Appointment of Auditor.....Stephen
- 8. New Business..... Eldon
 - a. School Age ABA Funding / Advocacy update.....Eldon
 - b. Parent Support Group / Gym Night.....Martine
 - c. MFEAT Conference.....Teresa
 - d. MFEAT Secretary / Newsletter Editor Eldon
 - e. Other New Business Items..... All
 - f. Next Meeting All

Families of autistic kids demanding Ont. eliminate wait list for treatment

(May 13, 2008 Canadian Press)



TORONTO — The father of an autistic teenager who has camped out at the Ontario legislature for more than a week is vowing not to eat until the province agrees to eliminate the backlog of children waiting for a crucial but costly therapy.

Stefan Marinoiu, 49, who has been drinking nothing but water for eight days, is trying to put pressure on the province to deliver the treatment more quickly to autistic kids, including his 15-year-old son Simon. "He can hurt all of us when he has those violent tantrums which, of course, come out of his frustrations not being able to communicate with us," said Marinoiu, who had to quit his job a few years ago to help care for his son. "It's a pretty bad situation. I'm getting weaker, I'm getting older, and I cannot hold on (to) him anymore."

Marinoiu will be joined by other parents Tuesday to put pressure on the province to eliminate by November the wait list of 1,148 eligible autistic children who are still waiting to receive intensive behavioural intervention

therapy, or IBI. The group will also be asking the government to provide IBI treatment in schools no later than September 2009, as well as obtain guidelines and financial assistance from Ottawa for autism services.

But Education Minister Kathleen Wynne said she can't make those promises, although the province is working to make schools more accessible to autistic children. "My heart goes out to people who have these very special and severe needs," she said. "We will continue to work with the family to provide the resources in the school that this student needs." Thousands of teachers and support workers are currently being trained to provide another kind of therapy, called applied behavioural analysis, in schools, Wynne added. Some schools already have therapists to provide the more intensive IBI therapy, but not in regular classrooms because the one-on-one treatment works better in a separate space, she said.

The province has also boosted funding and almost tripled the number of children receiving IBI treatment to more than 1,400 as of March 31, said Children and Youth Services Minister Deb Matthews. The list of children waiting to be assessed to see if they are eligible to receive IBI has also dropped to 363 from 1,027 four years ago.

Marinoiu said he's been unable to obtain services to help care for his son, who was dropped from the wait list after he surpassed the cut-off age of six. The Liberals eliminated that cut-off threshold in 2005, but say a dramatic increase in the number of children with autism has put additional pressure on the system, causing wait lists to grow.

The number of children waiting for IBI has jumped to 1,148 at the end of March from 89 in early 2004. Critics point to the rising numbers as proof the province isn't serious about giving autistic children the help they need. Marinoiu's hunger strike is just one indication of the distress parents are feeling, said Conservative critic Elizabeth Witmer. "It's another broken promise," she said. "The premier promised one thing. It's simply not happening."

The long waits have forced many parents to drain their savings and go into debt to pay for the therapy, said NDP critic Andrea Horwath. "Here we are, years down the road, and we still have the same situation," she said. "Parents are still going bankrupt. Parents are still extremely frustrated with the lack of available services. Parents still are fearful of trying to transition their kids into school, knowing darn well that the services aren't available in the school either."

Without help, Mariniou said his family may be forced to put his son in an institution - something he refuses to do. "I don't have a life anymore and I've got nothing to lose," he said. "So I'm going to stay here until the government is going to get it."

A number of families of autistic children are still waiting to see if they will be able sue the Ontario government and seven school boards for damages over funding for specialized treatment. The group argues the province discriminates against autistic children because they can't always get both their therapy and education within the public school setting. The Ontario Court of Appeal, which heard the case in February, is expected to release its decision this summer. An estimated 50,000 children and 150,000 adults in Canada have autism.

Report on the National Autism Research Symposium

Toronto, Ontario
November 8 & 9, 2007



Introduction

The National Autism Research Symposium was held on November 8 and 9, 2007 at the Four Points Sheraton Hotel, Toronto. Part of a series of initiatives on autism announced by the federal Minister of Health, Tony Clement, in November 2006, the symposium brought together researchers, health professionals, educators, service providers, family members and persons with autism, as well as community organizations and government representatives. Held under the auspices of the Canadian Institutes of Health Research (CIHR), Health Canada and the Public Health Agency of Canada, its purpose was to inform participants about the current state of knowledge on autism, to further the dissemination of ideas and to assist the research community in planning research. In accordance with the symposium's goal of information sharing, the event provided an opportunity for a variety of individuals to convey their knowledge and

views on a diverse set of issues related to autism. The opening evening, for instance, featured a group of speakers who shared their insights and knowledge on living with the condition - a young man with autism, the parent of a child with autism, and a prominent researcher in the field. The second day of the event offered an opportunity for participants to learn about the state of the science on autism, with presentations by twelve leading Canadian researchers. The symposium also featured break-out discussion sessions, through which all participants were invited to share their thoughts on many different aspects of the condition. This report provides an account of these informative presentations, and discussions.

Conclusion

At the end of the day, participants were invited to communicate any parting thoughts. At this time, many interesting views were shared. With respect to research, one participant commented on the need to better fund knowledge translation. Another stressed the need for parents and researchers to work together more closely. The value of good experimental design was also underscored, with one participant commenting, "in the autism intervention research... we are accepting much lower standards for the autistic population than we would for any other population." The need for

Have you considered becoming an MFEAT Board Member?
If you are interested in becoming an MFEAT board member as we continue to advocate for effective autism treatment, please come the AGM on June 21st. We are looking to recruit new board members and the positions of Secretary and Newsletter editor are available.

Parental Information on the Hiring of Tutors Advertising Opportunities

a) Local Newspapers

- Manitoba Community Newspapers Association (Choices of 45 local papers across Manitoba)
Call 947-1691

- La Liberte (French)
Call 237-4823 or 1-800-523-3355

- The Manitoban (U of M)
Call 474-6535

- The Uniter (U of W)
Call 786-9790

b) St. Amant

St. Amant may have staff who want after school hours.

c) Tutor Registry

Contact:
jakobson@mts.umanitoba.ca

d) Word of Mouth

Talk to people within your community. They may be interested or know of others:

- Educational:
 - Assistants / Teachers
 - Assistants/School Staff
- Your former Preschool:
 - Tutors/Senior Tutors
 - /Consultants
- University Students
- College Students
- Postsecondary Students:
 - Faculty of Education / Speech Therapy / Occupational Therapy / Medicine / Early Childhood Education / Behavioral Psychology / Educational Assistant Courses
- or persons who are interested in entering these courses.
 - Daycare or nursery school workers / respite workers
 - Your local community groups or churches

reliable information was also emphasized, especially in the area of treatment options, the goals of specific treatments, and evidence for their effectiveness.

From the perspective of individuals with autism, some participants commented importance of autistic individuals being heard, being able to advocate for themselves and being in charge of a system that affects their lives. One individual noted the difficulties that both autistics and non-autistics may have in understanding one-another - stating that the problem rests "somewhere in the middle".

Many participants expressed their appreciation for the event, for the opportunity to learn about autism related research from across the country, and for the chance to engage in dialogue on autism related issues.

Closing Remarks

In her concluding remarks, Barbara Beckett expressed her hope that the symposium had provided everyone with "a much better concept of what we know and what we don't know through research. Researchers, people with autism and their families, paediatricians, psychologists, social workers, occupational therapists, educators, and hopefully all of those groups whose work impacts on the lives of people and families with autism will have heard some messages that will be

helpful in their professional lives. And hopefully people from the autism community will have received as well some information from research that gives them some perspective for their own lives."

She noted that the goals of the symposium were to inform stakeholders about the current state of knowledge on autism and to assist the research community in planning for the research. "From the perspective of researchers, I would like to think that you have heard today some ideas from the various other sectors that have given you new perspectives or perhaps given you some new ideas for areas that might be researchable within your own means and current set ups and infrastructure. And perhaps it will enable you to do a little bit better research on what you are already studying or perhaps redirect a little bit into areas that you see may be of more direct interest to other stakeholders."

To view the entire report, please visit: <http://www.cihirisc.gc.ca/e/36237.html>



The Lovaas Institute has launched a blog! Please visit www.lovaas.com/blog to read articles, post comments, ask questions and join the discussion about the latest in Autism research and the Lovaas Model of Applied Behavior Analysis.

-High School Students
Talk to teachers who work with them. Some schools have courses in child development or related subjects so talk to those teachers. The resource teacher/guidance counselor or another person in the school may know of responsible students wanting to do something like this.

-You may have the opportunity to dyad with another family to advertise and share tutors.

-Anyone. "Word of Mouth" can really help.

e) Flyers/Posters

Flyers and posters can be good advertising. Examples of places to post:

- Community Bulletin Boards
- Church Bulletins
- Universities /Colleges /Postsecondary Schools
- High Schools
- Daycares/Nursery Schools

f) Student Employment Centers

Universities/Colleges have Student Employment Centers where employers in the community can place postings that require university students/graduates. The following are some contacts:

-University of Manitoba
Website: umanitoba.ca/student/employment
Email: student.employment@umanitoba.ca
Phone 474-9456

-College Universitaire de Saint-Boniface. Phone Lorraine Roch @ 235-4401

- University of Winnipeg
Website: ccs.uwinnipeg.ca/employers
Email: ccs@uwinnipeg.ca
Phone 786-9231

- Red River College
Phone 632-2128
Email: ljamieson@rrc.mb.ca

g) Craig's list

Adds can be posted at: <https://post.craigslis.org/win>
Qualifications you may want to consider in a tutor:

- 1) Hours they can commit, are they compatible with your hours, can your child work productively during these hours, and is the person flexible with hours. You may have to be flexible yourself in order to keep good staff. You may need to alter hours around exam schedules/ school / other jobs. You need to plan a schedule with them.
- 2) Experience/knowledge of working with children
- 3) Might have experience/knowledge working with special needs
- 4) Might have experience/knowledge of ABA
- 5) Leadership experience, volunteer experience
- 6) May want someone who is self assured, sense of humor, patient, enthusiastic, fun spirited, able to relate to kids or able to relate to the age of the student with autism, willing to learn and apply what they learn.
- 7) What are their future plans/how long can they commit to work for you?
- 8) Are they prepared in your interview?
- 9) Discuss with your consultant and team what the

goals/focus are for your school age program i.e. academics, social skills, life skills etc. so you can hire a person who would be most appropriate for these needs.

The main point to hit home: know what kind of person you are looking for at the outset and then know how to draw out that person in an interview.

Requirements to hire:

Family Services and Housing require the tutor to have:

- 1) An up to date and original criminal record check, which they can access at their local RCMP or Municipal Police Department.
- 2) Character references: They should also have an up to date Child Abuse Registry which they can access at 102-114 Garry Street, in Winnipeg or they can download info at www.gov.mb.ca/fs/childfam/cchild_abuse_registry.html or phone 945-6967 or 1-800-282-8069.

Note: Remember to "Sell your Program!" You are investing a lot of time and energy into the person you will be hiring. You want someone who can focus on the benefit of your child and commit to stay with your program. You need to be up front with your needs and your child's needs. It is beneficial to bring a candidate you are interested in to meet your child and view an ABA session. The more informed the potential candidate is the more likely you will hire an employee who will commit to continue with your child.

What's Happening in the US

Arizona to Revise its Insurance Laws to Require Coverage of Evidence-Based, Medically Necessary Autism Therapies (March 21, 2008)



Autism Speaks today joined Arizona families and other autism advocacy organizations in applauding Governor Janet Napolitano and the state's legislators for enacting House Bill 2847, which will require insurance carriers to provide coverage of evidence-based, medically necessary autism therapies. In many states, insurers explicitly exclude coverage of these therapies from policies, which places a significant financial burden on families seeking to provide their children with necessary services. Autism Speaks has launched a multi-state initiative to address this discrimination. The new Arizona law requires insurers to cover up to \$50,000 a year for Applied Behavior Analysis therapy for children until age nine, and \$25,000 a year for children until age sixteen. It covers therapy for children whose diagnoses reflect the full range of the autism spectrum. Applied Behavior Analysis (ABA) is recognized by the American Academy of Pediatrics and the U.S. Surgeon General, among others, as an effective, evidence-based treatment for

children with autism. "Every state in the nation, and every Governor, is facing the same struggle to meet the treatment needs of this growing population," said Governor Napolitano. "In my view and in the view of the families who have struggled to pay for necessary treatments for their children with autism -- often resulting in bankruptcy or families joining the state welfare rolls -- HB 2847 is a necessary insurance update to cover essential treatments for these children." "With the enactment of this legislation, Arizona joins the ranks of states that have recognized the unfair & unreasonable burden being imposed on families of children with autism," said Elizabeth Emken, Autism Speaks Vice President for government relations. "These families are either going broke trying to provide services for their children or stitching together inadequate treatment plans because they simply cannot afford the help their children need and deserve. That is about to change." The passage of this legislation was the result of a grass-roots advocacy effort led by hundreds of committed families with the support of local and national advocacy organizations, including: the Autism Society of America, Greater Phoenix Chapter; ASA Pima County and Northern Arizona Chapter; Supporting Autism Now through Education; Asperger Parent Network; Arizona Autism Coalition; Arizona Autism

Support; Southwest Autism Research & Resource Center (SARRC), Recover our Kids (ROK), and the Center for Autism and Related Disorders (CARD), among others. "This new law is a great victory for Arizona families and those living with autism," said Lisa Glow, CEO of the Southwest Autism Research & Resource Center (SARRC). "We are especially pleased that the legislation includes coverage of therapies for individuals with Asperger's Syndrome and Pervasive Developmental Disorder (PDD), in addition to autistic disorder. All children on the spectrum can make improvements with treatment, so no category of children should be excluded or discriminated against." "The autism community came together in support of this legislation in a way that was unprecedented," said Gretchen Jacobs, a lobbyist -- and mother of a four year-old girl with autism -- who worked on the legislation. "Family members from around the state made phone calls, wrote letters and walked the districts of lawmakers. It was a coordinated campaign that brought out the best in our community." The legislative effort began as "Steven's Law", sponsored by Democratic Sen. Amanda Aguirre of Tucson (Senate Bill 1263), and named after the son of Char Ugol, the mother of a child with autism. The bill was then amended onto House Bill 2847 sponsored by Rep. Bill Konopnicki.

Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional Needs from School to Community:



Purpose

- directs provincial government departments to support cross-departmental policy development and coordinate administering bodies who work directly with students who have exceptional learning needs which include school divisions, institutional schools (including those in correctional and treatment facilities residential settings) regional health authorities, and child and family services authorities.
- outlines the interactive roles and responsibilities of transition planning partners and their timelines.
- provides guidelines and support materials for transition planning and implementation

This document replaces Manitoba Transition Planning Process Support Guidelines for Students with Special Needs Reaching Age 16 (1999). It is intended for transition planning partners, including Manitoba Family Services and Housing, designated agencies, Child and Family Services Authorities and Agencies, Manitoba Health and Healthy Living, regional health authorities and their programs and services, Manitoba Education, Citizenship and Youth and educators in Manitoba. As students enter the senior years, they must begin to plan for their options in life after High School. The goal is to help partners better support students with exceptional needs who require supports from the provincial government, its agencies and/or Regional Health Authorities after leaving school. This includes students with mental, learning, physical and psychiatric disabilities, persons with spinal cord injuries and persons with a visual disability or who are Deaf or hard of hearing. The transition planning process facilitates timely access to available adult supports. Supports may assist individuals to contribute to the economic, social and cultural life of Manitoba. To view this document please visit: http://www.edu.gov.mb.ca/k12/docs/policy/transition/bridging_to_adulthood.pdf

Motivating Sounds Music Therapy

Motivating Sounds offers:

-Summer Music Camps for all ages & abilities

-Programming provided in a small group setting (max 6) with opportunities for individual and smaller group experiences

-Music Celebration to be shared with family & friends at the end of camp.



- Looking for a few more school-age registrations in order to begin an after school group for this age group.

-Please contact Tanya Loewen, MTA for more information @ (204) 943-0848 ext. 1 or motivatingsounds@mts.net

Dates:

July 7-11 (AM): Pre-School
 July 21-25: School-Age
 August 11-15: Teen
 End of August TBA (AM):
 Pre-School

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St Amant Conference

When: Thursday and Friday, October 9th & 10th, 2008.

The St. Amant Conference returns with two days of informative programming and inspirational speakers. If you have a professional or personal interest in developmental disabilities or autism, then you won't want to miss the St. Amant Conference 2008.

For more information, visit www.stamant.mb.ca



Our Mission Statement:

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

“Gym Nights”

With the support of MFEAT, Michael & Martine Laczko will be hosting “gym night”. The first gym night will be on Friday, September 26th, 2008, from 6:00 -7:15 pm at Ecole Lacerte, 1101 Autumnwood, Wpg, MB. This is a perfect opportunity for your child to get some exercise and have fun doing it! At the same time, you have the opportunity to socialize and network with other parents!

Each family will be responsible for hiring a trained tutor / coach for their child. Please come with your child and their tutor / coach. The children and their coaches will be busy running through the stations in the big gym while parents can meet in the small gym to chat.

For more information, please come to the the AGM at St. Amant Centre on June 21st or contact Michael or Martine Laczko at mlaczko@mts.net



Goldeye Tickets for MFEAT members

Tickets are available to the Winnipeg Goldeyes game on Saturday, June 28, starting at 7:00 pm. The game day event is Post-Game Fireworks.

Tickets are free, and are available to MFEAT members and their immediate families on a first-come, first-served basis. Seats are in Section A, rows 4 and 5. Anyone interested should contact Stephen Sutherland at:

E-mail:

stephen.sutherland@merc.com

or Daytime Phone: 934-4843

or Mail: Stephen Sutherland, 211 Campbell St, Winnipeg, MB, R3N 1B4

Please let Stephen know:

1. How many tickets you need.
2. How you want to receive the tickets (pickup at the MFEAT AGM or delivered to you by mail).
- 3 Mailing address



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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