

# BBB AUTISM SUPPORT NETWORK/AUTISM SOCIETY ONTARIO (YORK REGION CHAPTER)

# PRESENT

### THE E-NEWS

http://www.bbbautism.com/about\_bbb.htm

Volume 7, Issue 4 December 18, 2002

Hello Everyone!

I am writing the intro to this issue of the E-NEWS because as many know Liz has had a very challenging time lately.

For those that may not know, Liz's father died recently following a long illness. I would like to extend my condolences to Liz and her family from all of us at BBB who cherish our leader. She continues to inspire many with her tireless efforts to put out the e-news, manage the website, support us at the message board, give individual support via email AND she now has a very important paying job that takes up 30 hours a week of her time.

When she is not doing that, she is parenting her own children, one who has autism and another with ADD. How does one woman do all that? For the last 8 months she has been making treks on the weekend to care for her father and support her mother. It really is mind boggling that one woman can do all that, but it gives us all hope and inspiration that when it gets tough, we can rise to the challenges we all face.

Unfortunately autism doesn't live in a vacuum. We all have many other facets of our lives that we deal with as we maneuver the maze of ASD. So this issue of the E-news consists of a holiday message which is very appropriate for this time of year. My message to Liz..Enjoy the break hon! you deserve it.

Love, Diana



"Dear Family and Friends:

" Was written for the purpose of it being sent to relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism.



Dear Family & Friends:

I understand that we will be visiting each other for the holidays this year! Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful.

As you probably know, I am challenged by a hidden disability called autism or what some people refer to as a pervasive developmental disorder (PDD). Autism/PDD is a neuro-developmental disorder, which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see but which make it difficult for me to adapt to my surroundings.

Sometimes I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: some may not speak, some write beautiful poetry, others are whizzes in math (Albert Einstein was thought to be autistic), or have difficulty making friends. We are all different and need various degrees of support.

Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time, like you would if you landed on an alien planet and didn't understand how the inhabitants communicated.



This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by ok. But if something, anything changes, and then I have to relearn the situation all over again! It is very hard.

When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time. You might think I am ignoring you--I am not. Rather, I am hearing everything and not knowing what is most important to respond to.

Holidays are exceptionally hard because there are so many different people, places and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, it's very hard work and can be extremely stressful. I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat. If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting in one place for even 5 minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me and my parent's will handle the situation the best way they know.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, its no wonder eating is a problem! Think of all the senses involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky-I literally cannot eat certain foods as my sensory system and/or oral motor coordination are impaired.

Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable! Temple Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed with sandpaper. I often feel the same way in dressy clothes.

When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!)



Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things--just please be patient with me and understanding of how I have to cope...mom and dad have no control over how my autism makes me feel inside.

People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "self regulation," or "stimming'. I might rock, hum, flick my fingers in my face; flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to your world. Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kinda like self-regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable, and I don't want to come out of that comfortable place and join your hard-to-figure-out-world. Perseverative behaviours are good to a certain degree because they help me calm down.

Please be respectful to my mom and dad if they let me "stim" for a while, as they know me best and what helps to calm me.

Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you Neurotypical folk!) It hurts my parents' feelings to be criticized for being over protective or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, Sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow tippy rules.

I am a unique person--an interesting person. I will find my place at this celebration that is comfortable for us all as long as you'll try to view the world through my eyes!

Article reprinted with permission of editor/author, Viki Gayhardt.



#### FUNDRAISER ALERT!!

Please Help our good friend Diana! She needs to raise funds to train a service dog for her son.

30% of Sales at Shopaholic Heaven between now and March 31 will go to assist her. Shopaholic Heaven is located at <a href="http://ww.shopaholicheaven.com">http://ww.shopaholicheaven.com</a>

I also have an Ebay auction going as **Autism Friends** Donation to Diana..The Sale of the Dinnerware Set at Ebay will be added to the fundraiser funds. You can bid here : http://cgi.ebay.ca/ws/eBayISAPI.dll?ViewItem&item=2077225505&rd=1

Also on the shopaholic Site is a paypal donation button just in case you don't see anything you like to buy to support you can still make a contribution to Diana.

Catalogues can be snail mailed to anyone that is interested and we accept checks or money orders as payment. Email me at <u>shopaholicheaven@sympatico.ca</u> to request a catalogue be mailed to you.

Please note: I am unable to ship items overseas so can only accept orders from US and Canadian Residents. Tina



AUTISM SOCIETY ONTARIO - YORK REGION CHAPTER SUMMARY OF MEETINGS AND WORKSHOPS FOR 2002 - 2003 \*\*\*\*\*

#### **MONTHLY CHAPTER AND PARENT SUPPORT GROUP MEETINGS**

All Parents, Friends and Professionals Welcome

7:30 p.m. ~ 2nd Floor Boardroom to December 2002, 11181 Yonge Street,

Richmond Hill 905-780-1590



Note that 2003 Chapter meetings will be held in B13 (unless otherwise noted)

Tuesday January 14th	Chapter & Parent Support Meeting
Monday February 17th Chapte	er & Parent Support Meeting & Guest Speaker;
Topic 'Asperger's Syndrome'	
Wednesday March 19th	Chapter & Parent Support Meeting (this meeting will
be in Rm B07)	
Tuesday April 8th	Chapter & Parent Support Meeting
Tuesday May 13th	Chapter & Parent Support Meeting
Tuesday June 10th	"Summer's Coming" Potluck/Mingle

## ~ PARENT EMPOWERMENT WORKSHOPS ~ FALL 2002 THROUGH SPRING 2003

Sponsored by Autism Society Ontario ~ York Region Chapter

Refreshments: 30 minutes before Presentation Start Time

Cost: Free to Member families, \$ 10.00 for Non-members. (Unless otherwise noted)

Memberships available at the door. \$ 30.00 annually

#### REGISTRATION REQUIRED:

by e-mail asoyork@axxent.ca by voice-mail: 905-780-1590

To avoid disappointment, please register so that we may ensure enough handouts, refreshments and seats. Those registered will be contacted should any workshop be cancelled due to low registration or poor weather.

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~ A NEW DIAGNOSIS - WHAT TO DO NOW? REGIONAL SUPPORT LEADER, AUTISM SOCIETY ONTARIO Starting March, 2003. Running monthly. Continuous Registration. Dates & Times will be



arranged as each group of 6 - 8 is registered. Review of the 'Beginner's Guide to Autism Spectrum Disorder - Preschool Edition'

~ LIVING WITH ASPERGER'S SYNDROME GARY WALESKI Monday February 17th 7:00 - 9:00, Meeting Room B13 A 'first hands accounts" presentation by an adult living successfully with Asperger's Syndrome

~ SILENT VOICES: GROWING UP AS A SIBLING OF A SPECIAL NEEDS CHILD VICTOR PRETO AND CHRISTINE WOODCOCK Tuesday March 25th 7:00 - 9:00, Meeting Room B13 Victor Preto is a social worker and a trained facilitator in Sibling Support groups for the past ten years. He is also a certified play therapist and crisis intervention worker. Christine Woodcock is a child and family resource consultant, a trained facilitator in Sibling Groups and a crisis intervention worker. Both with Thistletown Regional Centre's TRE-ADD program. The focus of this workshop will be to introduce participants to the array of issues and stressors that can affect siblings of special needs children. Additionally they will also talk about recent research findings in the area of sibling support as well as tips and strategies for overcoming family hurdles. They will give an overview of the groups they run for Siblings, promoting group cohesion, thought provoking discussions and problem solving skills training.

## ~ TRANSITIONS DURING THE SCHOOL YEARS LINDSAY MOIR, EDUCATIONAL CONSULTANT COMHNADH CONSULTING, LONDON, ONTARIO

Tuesday April 29th 7:00 - 9:00 pm, Meeting Room B13 An overview of the three transitions:

1) School Entry: attendance rights and responsibilities, the registration and initial IPRC processes, Special education programming in the primary grades, pertinent school board documents you should have, and a general overview of education legislation.

2) Transition to High school: deals with the changes between grades 7-8 and the high school system. Helpful hints on how to manage this transition are discussed.



SENSORY INTEGRATION - 'MAKE & TAKE' WORKSHOP INSTRUCTOR - SHIRLEY SUTTON, OCCUPATIONAL THERAPIST Saturday May 24th 9:00 a.m. to 4:00 p.m.

COST: To Be Advised

We have approached a corporation to sponsor this important workshop, as it is normally offered to professionals at a cost of \$125. Your Chapter WILL subsidize this fee, however, regardless of the level of corporate sponsorship attained. Our goal is to again offer this workshop at a cost that our families can afford. Your registration now will strengthen our proposal for corporate sponsorship. REGISTRATION REQUIRED - LIMITED SEATING COST WILL INCLUDE REFRESHMENTS & LUNCH

'Make & Take' is a series of 5 mini workshops dealing with sensory, oral and fine motor skills for children with special needs, with an emphasis on children with an Autism Spectrum Disorder. Many items and a 40+ page manual are included with the S.I. 'kits'.

Who Should Attend? Parents teachers, mediators, educational assistants and 'hands-on' therapists!

Shirley Sutton is an Occupational Therapist with over 20 years experience working with clients with special needs, from infants through teen years. Her specialty training areas include early intervention, developmental disorders and sensory integration. She brings extensive clinical experience from a wide variety



of settings, including consulting work with the Geneva Centre for Autism, two private therapy centres, several community living associations, and early intervention programs. Shirley co-authored the book 'Building Bridges Through Sensory Integration', 'Occupational Therapy for Children with Autism and other Pervasive Disorders' and the workbook 'Learn to Print and Draw: A Visual -Kinesthetic Approach'. Her private practice is located in Collingwood, Ontario (705-445-8069)

## **WORKSHOPS FROM OTHERS**

#### **SOCIAL SKILLS GROUPS**

Geneva Centre MAY expand their Social Skills Groups to York Region families who would be interested in participating in groups held in Barrie. Please call Geneva Centre at 416-322-7877

### NAVIGATING THE SPECIAL EDUCATION SYSTEM IN ONTARIO - A HANDBOOK FOR PARENTS OF STUDENTS WITH AUTISM SPECTRUM DISORDERS.

Autism Society Ontario is pleased to announce the release of its 2nd edition of Navigating the Special Education System in Ontario. A Handbook for Parents of Students with Autism Spectrum Disorders. This updated edition includes more first-hand accounts, more information on Asperger's Syndrome and information on various tools that was not included in the popular manual that was released a number of years ago. The hard-cover three-ring binder is approximately 200 pages long is available through ASO for \$25.00/copy plus postage. Funds raised will offset the cost of printing and distribution. Thanks go to ASO's Education Committee, led by Natalie Whatley, who completed their work as a volunteer committee on this excellent project this past summer. (- copies will be available chapter meetings. Save \$ 8.00 postage and handling charges! )



#### PRIVATE IBI / ABA THERAPIST AVAILABLE

Charlene C. Crane, Tottenham. 905-936-4119 Resume and references available at the Chapter office.

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MEDIATOR AVAILABLE Megan Nicholas, 905-830-1806 or 95-895-0038 - ASK Camp counselor, various therapy centres and group homes working with children with autism.

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#### ESTHETICIAN APPOINTMENTS

Melissa Shlanger at Wellsprings Natural Health & Beauty Spa, 905-780-6627 (Melissa is one of our teenaged Chapter members, who has graduated from high school and is now pursuing career training as an esthetician. Congratulations, Melissa! Living with ASD you have inspired us all to reach our goals.

LOCKS FOR LOCKERS, FOR SECONDARY SCHOOL AND JUNIOR HIGH STUDENTS WITH ASD

0, 1, 2 and 3 number Dudley combination locks can be purchased at: www.securityhouselock.com or call 905 669 5300. This means that you can buy a Dudley lock that has no combination (just pull), single number combo, only two numbers, or all three. I think you can even order a specific number. Best part is they look like every other Dudley lock the kids use. =====

#### ODSP WEBSITE AND NEW INFORMATION AVAILABLE

Ontario Disability Support Program (ODSP) is administered by the Ministry of Community and Social Services (MCSS). For over 18 years of age. Apply 6 months prior to 18th birthday.

New information is now available on their more user-friendly website:



An ODSP Handbook created to give potential clients, their family and friends, advocacy groups and community agencies a concise and easy to read guide on the application for ODSP and available benefits. The fact sheet of ODSP Employment Supports in plain language for those with lower literacy levels or learning disabilities - with more info on how to apply. The ODSP Employment Supports application package which can be filled out

online. A complete listing of all ODSP local offices.

www.gov.on.ca/CSS/page/services/ODSP/odsp.html

### **ENEWS BITES:**

1. "AUTISM FRIENDS: (www.autismfriends.com) Come check out our 800+ links, shopping section fundraisers for parent run sites coming soon!) Family pages and our Community section for chats 5 days a week! Coming soon to Autism Friends! Parent tips, ponderings and wisdom!

Autism Friends is a Member supported website run by a parent. We are always looking for parent contributions! Book recommendations, photos, best links, personal stories, poems & artwork by our creative geniuses. Contact Tina at: founder@autismfriends.com. Tina"

3. Autism Children's Intervention Services Inc. (http://www.aciscanada.com/) Grace Damouni, Director/Founder - 8171 Yonge Street, Suite 226, Thornhill ON, L3T 2C6, Tel 416. 219 2316, Fax 905. 832 3139 E-Mail: Grace@aciscanada.com

"Certified in PECS, Sensory Integration (went to Florida and took the course/lab with Pat Wilbarger), Greenspan's Early Infancy and Childhood course (Floortime/DIR), training in Lovaas, workshop in Handwriting Without Tears, degree in psychology and most importantly, many, (9) years of clinical work with children with PDD/Autism.

I work very closely with Dr. James Bebko of York University and Dr. Carolyn Lennox who are the consulting psychologists to ACIS.

I am proud to say our IBI program is very comprehensive as it includes collaboration with SLPs and OTs as well as the educational team. We help develop IEPs and provide trained shadows for classroom integration.

We do travel outside of the immediate catchments region (once every month or two depending on the time of year) to administer staff training, consultations, assessments and program development. We will travel to Guelph, Hamilton, Cambridge (for example) but only



during certain times of the year. However, we do not provide ITs (mediators) to service this region although we can train staff that the family has already recruited. For parents who are not interested in hiring a "team" we can set up the programs/binder.

BBB AUTTSM

We do however, provide "teams" and oversee the program for our catchment region, which is Markham, Pickering, Aurora, Richmond Hill, Thornhill, North York, Maple, and Woodbridge. If families live within this region we can offer a "team" with full services (assessments, programs, supervision etc) and this ranges in price from \$20,000 and up depending on the treatment plan the family has in mind (we offer different plans). In this regard we are very flexible which I believe makes us unique-we customize plans so that we are able to take into consideration the families needs/expectations. Grace Damouni, Director/Founder"

Leaps and Bounds offers Psychological assessments, we will have an assessment clinic in Richmond Hill starting in January 2003. We also offer home based I.B.I. programs as well as a centre based day program in Richmond Hill. We also offer Behaviour Management, educational services and Respite. For Information about Our Services contact: Deanna Pietramala, Director of the Specialized Programming Service Telephone 905-953-0569 email deanna@leapsandboundsservices.com web: http://www.leapsandboundsservices.com/index.htm

ACIS Canada: Social and communication skills summer camp-June 30-August 16 (back by popular demand). If you know of any families who may be interested please spread the word! We will send out an info package on the camp We have SLP, OT and a Special needs resource Iteacher who has specialized in autism who are involved in the camp. Focus is communication and social skills. Location: Maple we are taking registration end of December! CONTACT: Grace Damouni, Director/Founder, 8171 Yonge street, Suite 226, Thornhill ON, L3T 2C6, Tel 416. 219 2316

ACIS Canada: Currently has 3 wonderful therapists who specialize in working with children between the ages of 2-4. If you know of any families who are seeking IBI services for their children within this age range please feel free to refer us! ACIS services children between the ages of 15 months -10 yrs.

CONTACT: Grace Damouni, Director/Founder, 8171 Yonge street, Suite 226, Thornhill ON, L3T 2C6, Tel 416. 219 2316

FIDGITKITZ now available! Contact Joyce Lang at islang@sympatico.ca. Terrific sensory tool designed by the sister of a boy on the spectrum. Contents shown here:





Do you have an event, announcement, information or a request? Email us 50 words or less at liz@deaknet.com and we'll put it in an upcoming E-News issue. Email early to avoid disappointment! BBB Autism is not responsible for misrepresentations of persons or agencies utilizing this service. Don't forget to include an email address if needed.

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#### Past Issues

Archived issues (too many to list here) are available by link in HTML, plain text and PDF on our website at www.bbbautism.com/news\_arch.htm

#### **BBB PARENT GUIDES**

**CONTAIN PRACTICAL INFORMATION BY PARENTS FOR PARENTS Available on request, e**mail liz@deaknet.com and ask for: (also available in PDF format) NOW AVAILABLE ONLINE: OUR BBB GUIDES IN A PLAIN TEXT FORMAT SUITABLE FOR PRINTING. FIND THEM HERE: http://www.bbbautism.com/bbb\_guides\_contents.htm

- 1. Halloween
- 2. Epsom Salts (Calcium too) expanded version
- 3. Epsom Salts condensed version
- 4. Pros and Cons of telling your ASD child his/her diagnosis
- 5. How we advocate for our children
- 6. Guide to holidays and large family gatherings
- 7. Vaccine Concerns in Ontario

A notice to our readers...

The editor of this newsletter and founder of the BBB Autism support club is not a physician.

This newsletter may reference books and other web sites that may be of interest to the reader. The editor/founder makes no presentation or warranty with respect to the accuracy or completeness of the information contained on any of these web sites or in the books, and specifically disclaims any liability for any information contained on, or omissions from, these books or web sites. Reference to these web sites or books herein shall not be construed to be an endorsement of these web sites or books or of the information contained thereon, by the editor/founder.

The editor/founder reserves the right to make decisions as to whether contributions are appropriate with respect to content, length, etc. We will not publish offensive material using foul language, or contributions that are inflammatory or disrespectful to decisions by or beliefs of other parents (i.e. therapies). We do not **generally** accept contributions if they are ads for private service agencies/clinics. We are also unable to accept contributions after an issue has been completed. We reserve the right to edit content, but will inform you in advance if we are going to do this. ③

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