



Tourette Syndrome Foundation of Canada

London Chapter

Newsletter

November 2007

Finding Friends

Half of all ADD kids have trouble making and keeping friends. But having childhood friends is a better predictor of adult happiness than is I.Q. or academic achievement.

by Gay Edelman

Eight-year-old Josh stands alone at the edge of the playground, watching the other kids play. He'd like to join them but has no idea how.

Eleven-year-old Tina sits on the porch steps in tears. From the next block, she can hear the sounds of a birthday party to which she wasn't invited - even though she thought the birthday girl was her good friend.

Fourteen-year-old Torn spends all his free time alone, on his computer. No one calls him, and he calls no one.

Is anything sadder - or more frightening to parents - than a friend-less child? "Parents fall apart crying about their child's situation," says Richard Lavoie, a special-education consultant in Barnstable, Massachusetts, and the author of *It's So Much Work to Be Your Friend*. "And it's never about academics. It's always about the pain of social isolation their child is facing."

It's hard to overstate the importance of friendships. Mary Fowler, the Fair Haven, New Jersey-based

author of *Maybe You Know My Teen* and the mother of an ADD son, says that having close childhood friends can make "the difference between things going well, or becoming a hard-to-manage teen, dropping out, abusing substances, and being in trouble with the law." Experts say that having positive social relations in childhood is a better predictor of adult happiness than is I.Q. or academic achievement. "Friendships are not a luxury," says Lavoie. "They're a necessity."

Missing cues, lacking skills

All parents worry about their children's friendships. But for parents of ADD children, the concerns are especially pressing. Making friends requires hundreds of skills - talking, listening, sharing, and so on. These skills do not come naturally to children with ADD.

"They miss social cues that other kids learn by osmosis," says Carol Brady, Ph.D., a clinical psychologist in Houston. "Having ADD is like trying to watch six TVs at once. While you're deciding which one to pay attention to, some subtle information passes you by."

ADD kids have friendship trouble for all sorts of reasons. Some aren't good listeners. Some yammer on and on about a specific interest -- oblivious to the fact that other children might not share the interest. Others drive away potential friends by impulsively blurting out unkind comments. One mother in Hawaii says her "mother hen" daughter alienates peers by trying to micromanage their lives.

Continued on page 3

In this Issue

Finding Friends	1
Dear Doctor	5
Soft Sound Sensitivity Syndrome	6
What's New in Research	7
TS in the News	8
Conference 2007	9
Advocating for Your child	10

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Our Mission

The Tourette Syndrome Foundation of Canada is a national voluntary organization dedicated to improving the quality of life for those with or affected by Tourette Syndrome through programs of: education, advocacy, self-help and the promotion of research.

Our Vision

All People who have Tourette Syndrome will lead quality lives as accepted and valued members of an informed, tolerant society.

Regular Contributing Authors

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President's Message.

Our lead article "Finding Friends" was originally printed in ADDitude magazine in January of 2006. Friends are necessary for all kids, but are especially important for those who have difficulties with social skills. The author, Gay Edelman, provides some excellent tips for helping our children develop friendships.

Dr. Mary Jenkins' article provides us with information to help understand the differences between TS and other tic disorders and to separate tic disorders from other movement disorders.

Our research article reports on a British study involving artificial food colours and food preservatives and "hyperactivity." We don't have a lot of detail about this topic, only what our source article provided. We may be able to find more on this topic later.

We have two reports from "Conference 2007" in Niagara Falls. Nineteen people attended from the London Chapter area and all reports, so far, are that this was a great conference.

Brigitte Heddle has put together an interesting article on advocating for your child. Brigitte and her son, MacKinley, attended Conference 2007 in Niagara Falls where one of the presentations involved advocating. Her article combines information from the conference presentation and her own experiences advocating for her son.

Also included is an interesting article on Soft Sound Sensitivity Syndrome. It's amazing how researchers keep finding new parts of the larger picture.

In my last "message" I said that Book Review and Putting the Brakes On would return next time. That didn't happen, and I can only say that these columns will return as time and space permits.

I hope you enjoy our November 2007 newsletter.

Ray

Finding Friends continued

In some cases it's unclear what the precise problem is. "I just think some kids have an air around them that other kids pick up on as a target," says one mother, worn out from years of worrying about her ADD child's awkwardness and social isolation.

Big kids have bigger problems

For young children, a lack of social skills may not be a serious problem. If a six-year-old says or does something untoward, for example, other children may ask why, but are unlikely to take offense. What's more, young kids typically have a hands-on "social director" - a parent or caregiver who solicits play dates and stays on hand to make sure they go smoothly.

But as children get older, social interactions become more complicated - and children with ADD fall behind. This was certainly true for Jay Edmond, a 15-year-old from Burlington, North Carolina. Jay's mother, Jodi, says that his odd comments and disruptive behavior became too much for his peers. "Kids he had been friends with started steering clear," she says. "By middle school, he was a marked kid. The more the kids pushed him away, the more outrageous his behavior got."

What about teenagers? "By high school, parents of all kids need to be backing off and letting them manage their own relationships," says Rick Zakreski, Ph.D., a clinical psychologist in Shrewsbury, New Jersey. "In high school, there usually are so many possible activities that they're likely to find a niche. Keep an open mind. Don't judge his group by appearances."

But don't back off *too* far: A recent study of nearly 12,000 seventh-through-twelfth-graders discovered that teens who have warm relationships with their parents - they talk often, share activities, and are affectionate with each other - also tend to have good friendships.

Parents must get involved

Parental involvement is essential if ADD kids are to make and keep friends. That can mean something as simple as helping your child initiate conversations and "supervising from the window," as one parent puts it. It can mean driving your child to another town to visit a potential friend. It can mean attending a parents' workshop given in conjunction with your child's friendship group, or talking to your child's therapist.

"Some of the hardest work I do is with the parents of ADD children," says Avie Lumpkin, an ADD coach in Alameda, California. "They are good parents, and they have worked hard, but they may be trying the traditional parenting things, which don't work."

ADD kids often have little sense of how they're perceived by their peers, and they commit social gaffes without realizing they've done so. Another kid will give them a shove, and they'll fail to realize that calling the kid a "jerk" a moment ago had anything to do with it. Or they'll have no idea that a game broke up because they kept ignoring the rules.

To help, Lavoie urges parents to conduct what he calls a "social autopsy": Parents and child discuss what went wrong, why it happened, and what the child could (not should) do differently next time. Be as sensitive and as tactful with your child as you would be with a close adult friend; too much negative feedback can damage your child's self-esteem. When your child has a successful interaction, congratulate him.

According to Michael Thompson, author of *Best Friends, Worst Enemies*, one of the most effective things parents can do is to set a good example. In addition to socializing frequently, that means making an effort to forge friendships with the parents of your child's peers. Thompson also recommends enlisting the support of your child's teachers, and staying connected to the community through clubs, religious organizations, and so on.

Medication's role

If impulsive behavior - dominating play, interrupting, jumping from one thing to the next - keeps other kids away, medication is probably necessary. In fact, your child may need to be "covered" by meds even after the school day ends. "Kids who are having trouble with social skills may need meds all day, every day," says Carole Watkins, M.D., a Baltimore psychiatrist.

Puberty may occasion a new look at medication or dose. Lumpkin says, "When hormones start changing, what's worked up until that point will probably need to be changed."

ADD medication alone may not be enough. One mom from Hartford, Wisconsin, found that temporarily adding the antipsychotic drug Risperdal on top of her son's usual ADD meds had a double payoff. "It calmed him down," she says. "He went up to A's and B's in school, and it allowed him to make a friend."

Groups and teams

Stephanie Bixler's son, Matthew, now nine, struggled with friendships for years. "He pushed away every kid who tried to be his friend," says Bixler, a resident of Lemoore, California. "His play was so chaotic that others had a hard time wanting to be around him. He was also greedy with his toys."

She credits team sports with much of Matthew's recent success. "He started to realize everything wasn't about him," she says. "As the team concept sank in, it overflowed into his play. After two seasons of baseball and two seasons of football, we are now seeing him develop healthy friendships."

But if your child expresses an interest in Little League or another structured athletic organization, proceed with caution. Call the coach before the first practice, and discuss whether your child would fit in. If you decide to take the plunge, accompany your child to meet the coach or another child who will be on the team *before* the first get-together. Remember, transitions are hard for ADDers.

For many ADD kids, getting involved with a "friendship group" may be a better option.

Patience and perspective

Most socially isolated children find their way - eventually. They get a better handle on their behavior, along with a broader perspective on the dynamics of friendship. And once kids hit adolescence, they tend to act on the powerful urge to "fit in." As Zakreski puts it, "By high school, the vast majority of kids with ADD do end up fitting in somewhere." Goth kids may look scary, but they may actually be less into drugs than the more clean-cut kids.

The same experts who urge parental involvement (and who urge counseling for kids who seem stuck in the "lone wolf" role) say it's important that parents not worry *too* much about a socially isolated child.

A child doesn't need to be in the "in" group or get invited to lots of parties. In fact, studies show that having even a single close friend is all it takes to develop social self-confidence. This friend doesn't even have to be a peer. "It can be a neighbor, a teacher, a grand-parent," says Lumpkin. "Once that connection is made, it can become the vehicle for kids to listen and make some changes in their lives."

GAY EDELMAN is a freelance journalist who lives in Red Bank, New Jersey. This article was first published in ADDitude, January 2006 and is re-printed here with permission.

Bully-proofing your child.

Teasing and playful banter are an inevitable part of childhood, but ADD kids often don't know how to respond. Parents should encourage their children to stand up to teasing without overreacting, which might escalate the problem.

- Alert your child's teachers and school principal about any bullying, and let the school take care of the situation.
- Suggest that the school establish anti-bullying rules, if it hasn't already done so.
- Encourage your child to stay calm in the face of the bullying. He might count to 10 or take a few deep breaths before responding. Help him brainstorm some good comebacks. He could agree with the bully: "I am overweight. Maybe I should go on a diet." Or he could pre-empt taunts by saying, "Hi, what are you going to tease me about today?" The key is to remain emotionally detached.
- Teach your child to yell, "Ouch! Stop that!" each time he's taunted. That will attract an adult's attention without his tattling.
- Encourage your child to stand up straight, make eye contact, and speak in a firm, authoritative tone. If the bullying seems to have a specific, petty target, like the type of cap your son wears on the bus, have him leave it home for a few days.
- Ask your child for a daily progress report, and offer abundant encouragement.

Friendship groups can help some children with ADD learn social skills. In general, kids should participate in a group before middle school, when social pressures really intensify. Fourth and fifth graders are especially likely to benefit.

Friendship groups are typically led by a psychologist or social worker. The group leader uses role-playing, games, and other techniques to teach empathy and social skills.

Experts caution parents not to try to run a group themselves; in addition to lacking counseling skills, parents tend to be too emotionally involved. But they may want to observe the group in action so they can help their child transfer the skills he learns to the other parts of his life.

If your child's school doesn't offer a weekly friendship or social skills group, suggest one. Or you may be able to find a nearby therapist who does.

Watch out: Private groups can be expensive. You may wish to incorporate some form of group participation into your child's IEP or 504 plan.

Non-tic Movement Disorders

By Dr. Mary Jenkins

Many children with tic disorders may be referred to a neurologist with concerns of other neurological problems. What are the other movement disorders that are not tics and what distinguishes these from tics?

Tics are movements or sounds that are preceded by a premonitory or “warning” urge. The movement or sound is made in response to this urge. The urge is like an itch that needs to be scratched, and performing the tic makes this urge go away. The tics can be suppressed or held in, but this makes the urge feeling worse, and eventually the tic occurs. The presence of an urge is one of the unique features of tics and does not occur with any other movement disorder. In addition, but not exclusively, tics tend to change over time. Someone may have a neck turning tic for 6 months and then they may develop an eye blinking tic. Other movement disorders may generalize or spread to other body parts, but the original movement always persists.

Stereotypies are a common movement disorder that is often mistaken for tics. Briefly this is a movement that usually begins in early childhood and persists with the same movement pattern throughout childhood. The movements, which are often hand-waving, arm flapping or hand clenching, occur at times of excitement, boredom or anxiety. They are not associated with an urge and they are easily suppressed. They never interfere with activities - the child does not drop things or stop an activity for the movement to occur; in fact, activity will suppress these movements. Stereotypies are a benign movement pattern that generally does not bother the child.

Another movement disorder that may be confused with tics is dystonia. Dystonia is a twisting or abnormal posture that may occur in any body part. Dystonia may occur at rest, but is always worsened with voluntary movement. Dystonia is not suppressible and is not associated with an urge. Unlike tics, dystonia usually interferes with activities such as walking or writing. This is a rare problem in children and may be due to a number of causes most of which are genetic. In adults, dystonia occurs more commonly and the cause is generally unknown (idiopathic). An example of dystonia is writer’s cramp.

Tremor is another common movement disorder that may occur in childhood. Tremor is a rhythmic, oscillatory, shaking movement

usually in the hands or head. This is also not associated with an urge and is not suppressible. The tremor often interferes with hand writing and other fine motor tasks. While there are many causes of tremor, the most common cause is genetic.

Chorea is a rare movement disorder that occurs in children and adults. This is a slow, writhing movement that may occur in the limbs, neck, or trunk. The word “chorea” means dance and the movements have a dance-like quality. Like the other movement disorders, chorea is not suppressible and has no associated urge. Chorea occasionally interferes with activity, but often these movements are mild and not bothersome. Chorea may be due to a number of causes, all of which are extremely rare, especially in childhood.

Myoclonus, unlike chorea, is a very bothersome involuntary movement disorder. This is a jerking, very rapid, shock-like movement. Myoclonus may occur in any body part and greatly interferes with activity. For instance, if a child were trying to hold a pen, the myoclonus movement may cause the pen to fly out the child’s hand. It is not suppressible and there is no urge or warning. This is a very rare condition and has many causes.

Finally, in all cases of movement disorders, one must consider a seizure disorder as this can also cause involuntary movements such as rapid eye blinking or arm movements. In cases of seizures, children may lose consciousness or awareness briefly. None of the other movement disorders affect awareness or consciousness and this is a key distinguishing feature. In the case of a seizure, an EEG (electroencephalogram) is essential for diagnosis.

In approaching movement problems in children, the history of the pattern of onset and features around the movement are important for diagnosis. In addition, seeing the movement is essential for diagnosis. With the exception of seizures, medical tests do not distinguish the type of movement disorders, but may be useful to determine the underlying cause.

Parent's Self-help Meetings

The London Chapter of the TSFC hosts monthly parent Self-help meetings from 7pm to 9pm on the second Thursday of each month, except July and August. Meetings are held at:

Madame Vanier
Children's Services,
871 Trafalgar Street,
London, Ontario

Directions: Go south on Rectory Street to the end of Rectory. Turn left. You are now on Trafalgar Street. Madame Vanier is approximately 100-200 meters on the right.

Our Resource Library is available during meetings and books and videos can be taken out on loan.

The Kids Klub meets at the same time as the Parents Meeting. (*Please see our website www.tourette-london.ca for a list of rules for Kids Klub*)

Our next 4 meeting dates are:

December 13, 2007
January 10, 2008
February 14, 2008
March 13, 2008

All parents of children with TS are welcome to attend. Members and non-members are equally welcome.

Self-Help

The need to talk, hear other's stories and to learn from others the facts, ideas and feelings.

Soft Sound Sensitivity Syndrome

An article in the London Free Press on July 28, 2007 by Ian Gillespie titled "It's official, (slurp, chomp, smack) he's nuts" drew my attention to the Oregon Tinnitus and Hyperacusis Treatment Centre and an article by Martha Johnson, M.S., CCC-A titled "Soft Sound Sensitivity Syndrome."

In his article, Gillespie says "for years, I've been driven to heights of annoyance by the sounds of someone – usually a beloved family member – emitting loud noises from their mouth while eating." Gillespie's article doesn't mention Tourette Syndrome or Obsessive Compulsive Disorder but goes on to say "for years I've gone nuts whenever I hear mouth noises."

Johnson says that a number of cases of what she calls "unusual cases of hyperacusis" have come to her attention at her clinic. These cases have involved a strong negative reaction to sounds of eating, breathing, speaking or lip smacking.

This type of hyperacusis often begins in childhood, as early as 6 years and as late as 20 years. Seventy percent of cases are girls.

Johnson states "there are often a few other concerns about the patients, occasional ADD/HD or mild obsessive compulsive disorder, however, as a group they are high functioning, capable individuals. No remarkable medical history presents itself in the reporting of the patients as a whole group. As a matter of fact, they tend to do well in school as a general rule, academically, enjoy social outings and friends, and participate in many different activities."

Johnson has evaluated 90 such cases and consulted on another 215 cases. She admits that this is a small subset of hyperacusis but that it is an important one.

Most of the reported cases were brought to the attention of physicians. Occasionally hearing tests have been conducted but these people "exhibit perfectly normal hearing." Johnson states "most patients have seen psychiatrists who attempt to diagnose an emotional disorder and most of the patients are then prescribed various chemicals such as anti-obsessive drugs, anti depressants, anti anxiety drugs, or other types of psychotropic medications."

Sounds that top the list are generally mouth or nose sounds and include biting, chewing, forks clicking on plates or teeth, tongues licking lips, lips smacking

when opening or shutting, sssss sounds or other high frequency sounds, fingernail biting and breathing.

Reactions to these sounds range from mild – including removing oneself from the room, a child may take their plate from the dinner table and go into another room to eat their meal – to the extreme - crying, yelling, striking out, and verbally abusing the person making the sounds. Johnson states “just seeing another person 'prepare' to lift the fork to the mouth can set off a severe reaction.”

Johnson calls this condition “Soft Sound Sensitivity Syndrome.” The condition can develop rapidly, within days, and even something as simple as looking at the family dinner table can cause emotional distress. In some cases a particular person will be associated with the sounds and that person will be avoided.

Wearing headphones at meals, turning the TV too loud or unexpected leaving of the room can be indications that someone is suffering from this syndrome.

Johnson writes:

“It is suspected that the loss of inhibitory functions of the efferent system of the auditory pathways (from brain to ear) plays a role in hyperacusis. Changes have been noted in areas from the outer ear to the brain stem areas, and possibly higher, to support this idea, over the past ten years. And it is fairly well known that most people with hyperacusis will often develop secondary psychological overlay conditions such as hysteria, anxiety, panic disorder, paranoia, and depression. Personally I have observed these symptoms in patients and found most of them to be rational solutions to an irrational condition. The withdrawal from society, the use of earplugs to try to prevent

exposure, the isolation from the annoying trigger sounds, and the use of sound as a masking attempt, are signs of an intelligent sentient being attempting to structure their universe.”

Johnson goes on to say:

“this syndrome clearly takes its toll on the well being of the person, the family, the scholastic life, and limits future opportunities. The sufferers will clearly express an understanding of what it was like 'before.' They are acutely aware of their problem and often try to hide it from others outside the family unit, and will go to great lengths to 'cover up' their concerns. They are often labeled with misdiagnosed syndromes, I believe. “

In a conversation with Dr. Mort Doran in 1998 he talked about living with undiagnosed TS as a child in Toronto. Eating supper with his parents could be stressful and he would often take his plate into another room to avoid the sounds of his father eating.

Other similar stories have surfaced over the years of people with TS having obsessions with the sounds of others eating and there appears to be a prevalence of this disorder associated with TS. One person talked about being really annoyed that the TV news anchor always made a smacking or kissing noise between stories.

Johnson reports that treatment is possible – habituation therapy and broad band sound generators have been helpful. She invites those interested to contact her.

Ian Gillespie is a columnist with Sun Media and his “the flip side” articles appear in The London Free Press on Saturdays.

What's New in Research?

by Brigitte Heddle

On September 9th I read an interesting article on BBC's (British Broadcasting Corporation) International News Website hyperactivity and food additives.

This article quotes a study that linked food additives with hyperactivity.

The study was carried out for the British Food Standards Agency (FSA) by researchers at Southampton University and published in The Lancet (British Scientific Journal). They conducted a study of 300 randomly chosen children aged 3, 8 and 9. The article states that not all the children had behavioural issues (it is not clear from the article how behavioural issues should be understood.) The study

found that “(children) behaved impulsively and lost concentration after a drink containing additives.” The article then goes on to quote Dr. Andrew Wadge, the FSA’s chief scientist as saying: “We have revised our advice to consumers, if a child shows signs of hyperactivity or ADHD then eliminating the colours used in the ...study from their diet might have some beneficial effects.” The lead researcher Professor Jim Stevenson said “the study,..., showed that certain mixtures of artificial food colours alongside sodium benzoate, a preservative used in ice cream and confectionary, were linked to increases in

hyperactivity.” As a word of caution he adds: “However, parents should not think that simply taking these additives out of food will prevent hyperactive disorders. We know that many other influences are at work, but this at least is one a child can avoid.”

So it is perhaps worthwhile for families, with children who have ADHD, to look into if their child’s diet includes food items with additives that could be eliminated and see if it helps lessen the symptoms.

Leaky Brakes 101

Spring 2008

The CPRI’s spring 2008 “Leaky Brakes” 101 series will begin on April 2. If you are interested in attending this 6 week series, contact CPRI at (519) 858-2774 ext 2025.

TS in the News

A report in Newsweek on September 3, 2007 titled “**Taking on Tourette’s – a new approach to stopping tics before they happen offers hope to thousands who live with the disorder**” provides some conflicting information regarding habit-reversal training (HRT).

The article provides a brief description of HRT and talks about the experiences of nine-year-old Marg MacKrell and nine- year-old Rick Shocket. (Shocket’s story was reported in our August 2007 newsletter and in our November 2006 newsletter, Brigitte Heddle wrote about HRT.) Both children benefited from their exposure to HRT.

However, many doctors are of the opinion that tics can’t be suppressed or that “suppressing them only aggravates them” and then there are studies that oppose this view.

Dr. Roger Kurlan, a neurologist at the University of Rochester, states that “we don’t see a particularly important role for the behavioral therapy.” The

article states that Kurlan “usually uses medication when his TS patients need treatment” and isn’t sure that HRT has any effect on the underlying condition.

The article states “critics also complain that depicting tics as “habits” that can be reversed ignores the underlying biology of Tourette’s.”

Leonard Misner, 39, who has Tourettes, opposes HRT on the basis that “we in the tourette community have fought hard to get insurance companies to understand that this is a genetic neurological disorder.”

A researcher of HRT at UT San Antonio suggests that TS can be both behavioral and biological.

This article, while being somewhat low key and not being in a recognized medical journal, demonstrates the controversy over how a neurological disorder can be treated psychologically.

Debate such as this can only benefit families with TS.

Report on TSFC Conference 2007 - Making Waves

By Gerard Johnson

The annual TSFC National Conference 2007, held September 27 – 29, at the Brock Plaza Hotel in Niagara Falls, Ontario is over. Kudos to all involved in the conference planning, session facilitating and arranging the various speakers. As always, the conference contained tons of great information, well presented, that is relevant to the TS community.

The conference started off (unofficially) on Wednesday evening with a “Meet and Greet” for all those volunteers who arrived early enough to renew old acquaintances and make new contacts with many individuals from across Canada and the U.S. This has always been a wonderful way to connect with the people that are the “grass roots” of our organization, the volunteers, and I am sorry I missed getting to it this year.

Thursday started off with breakfast followed by a full day of the 2 Volunteer Day workshop sessions. One session included the well attended “In-Service Presenter Training” for anyone interested in giving In-Service presentations. The other session, running at same time, was a “Give & Get” that provided information on many topics. These sessions were led by volunteer facilitators and were interactive sharing “think tanks” of ideas. Included were running a summer camp, running a Chapter help line, fund raising, putting out a chapter newsletter, getting speakers for your local chapter meetings and running an In-service Program. The sessions I attended were well presented, informative and interesting with a lot of “Giving and Getting” of ideas and information. Congratulations and thanks to the many facilitators for putting in so much effort to help all the volunteers in attendance gain so much information through the giving and sharing of their knowledge.

Later Thursday evening the General Registration opened. There was a formal welcome reception followed by an amazing opening address by a young boy, Dylan Peters, who wrote the book, **Tic Talk - Living with Tourette Syndrome**. It's his story, in his own words, about being a 9 year old with TS. Hearing his story and seeing the courage he had to step up and speak about his life was inspirational and a great way to “Officially” start the conference. We now have a signed copy of his book in our resource library (available during the monthly Parent Support Meeting). Later there were several sessions/workshops you could attend. These included the Mom's workshop, Dad's workshop, Adult and young adult meet and greet, Children meet

and greet, and a Youth meet and greet. Again I heard only good things from all those who attended the various sessions.

Friday started with a buffet style breakfast followed by the conference welcome and opening remarks. We then were treated to a session by Denise Rackett, a Certified Laughter Yoga Leader and Teacher, called “Learn to Laugh it Off”. This was an interesting way to get things started before heading off to the Educators Track, General Track or the Adult Track. I attended the Adult Track, the first session being Ryan Clarke's “Advocacy – Starting to Engage”, in which we received a wealth of information about getting through to the government when advocating for fairness and needed attention to the many issues that need addressing. It was a presentation that was more generic in how to gain the “ear” of government when trying to advocate for an issue rather than specifically advocating for TS.

Janet Rumsey and Cathy Wylie were the facilitators of the next session, “A Funny Thing Happened to Me on the Way to the Forum” about the TSFC Forum, “an online place to exchange ideas, information and support about issues related to Tourette Syndrome.” If you haven't visited the TSFC Forum you can access it through the national web site, www.tourette.ca and clicking on the link.

At the awards luncheon the many awards were presented to individuals that made a difference in the TS community at a National or local level. Our London Chapter's own volunteer, Linda Johnson, was recipient of the 2006 Community Service Award for her hard work in running the Bingo events our chapter hosts for fund raising. Congratulations Linda on being recognized for all your work and effort to help raise money for our London Chapter. Congratulations to all the other award winners as well. To see a complete list of award winners please visit the National web site.

After lunch Dick Averbs, MFA, presented “How Does TS Affect Career Choice”, a research project in the works, trying to determine if having TS can affect the type of career choice you follow. For instance, in a creative or scholastic environment where there is a prevalence toward acceptance and tolerance. It was a thought provoking session in an area that is new and unique in this form of TS research. We can all look forward to further developments of this project, provided funding is available to continue.

Dan Pruitt then gave a session on “Time Management from the Inside Out” about ways someone can help themselves or someone else with ADD/ADHD issues to learn to better utilize tools available for Time Management. (I’ll look into this when I get more time...) Thanks for sharing your great tips and strategies with us Dan. We next had a Male Roundtable, facilitated by Gary Marmer, Ph. D. running concurrent with a Female Roundtable, facilitated by Joanne Cohen, LCSW. These sessions dealt with issues relating to work, disclosure, and relationships. After the afternoon sessions we had a free night or an optional dinner at the Skylon Tower. Dinner was interesting as it involved a long elevator ride to a very high restaurant, with a view of the falls. Not for everyone!

Saturday began with a buffet style breakfast followed by a “Town Hall Presentation” and then the TSFC’s Annual General Meeting. These helped to clarify some of the questions that were brought out in previous sessions, like the TSFC Forum, fundraising issues, an introduction to the Newfoundland and Labrador team for next years’ National Conference in St. John’s, themed, “Voyage Toward Our Vision”. Keep October 2 – 4, 2008 open for another fantastic TSFC Conference experience. After the refreshment break the Adult Track continued with the Couples Workshop. In this workshop we discussed some of the issues facing a couple in regards to OCD conflicts or compatibilities, finding someone and when to disclose about having TS, and dealing with expectations in a relationship. It was very well attended and should be on the agenda for future conferences as well.

After Lunch Roger Kurlan, MD, presented “What’s New in TS?” During this session we heard that HRT (Habit Reversal Training) is still controversial and new statistics about treating extreme movement tics disorders with DBS (Deep Brain Stimulation) show it is not a treatment that is ready for the mainstream. We had a refreshment break then back into the last session of the Adult Track, the Adult Issues Forum, moderated by Gord Brown. Gary Marmer and Joanne Cohen presented a review of their Roundtable sessions, and we continued to discuss issues such as disclosure to employers, interpersonal relationship, adult diagnoses of TS, and some of the experiences people have found when dealing with these issues.

Saturday night was the banquet followed by a dance and silent auction. The meal was quite good and the DJ, who has TS, was fantastic and had everyone up on the floor several times with the help of some enthusiastic kids! I think everyone had a good time and enjoyed seeing everyone else being so relaxed and happy.

My final impressions of the TSFC National Conference for 2007 – Way to Go Conference Committee! What a fantastic effort and success for EVERYONE involved! Thank you for helping me to learn more about TS so I can further educate others! It was a great experience reconnecting with people I know and meeting people I didn’t know. I sure hope I can join you in St. John’s, as we “Voyage Toward Our Vision” in 2008.

Advocating for your TS/TS+ Child

In this article I will take a look at advocacy and TS/TS+. The word advocacy comes from the Latin word *advocare*, meaning (according to the Compact Oxford English Dictionary): call (to one’s aid). This has, for example, in modern use come to mean a person who pleads a case on someone else’s behalf.

Advocacy, in many forms, is something we all do at some time or other throughout our lives, and I don’t know about you, but I think, when you have a child with TS/TS+, you seem to have to advocate quite often on your child’s behalf; at least that has been my experience.

I, therefore, thought it a good idea to share with you what I recently learned at the annual Tourette Syndrome Foundation of Canada conference on the subject of advocacy as well as my own experiences with advocating for my son who has TS and OCD.

At the conference, Ryan Clarke, the founder of Advocacy Solutions spoke on the subject of advocacy.

He pointed out that the reasons why advocacy is important to all of us is that decision makers (politicians on all levels, school principals, school

boards and school trustees as just some examples) react to those who can effectively bring the issues to their attention.

This is done, according to Ryan Clarke, with the help of a three step advocacy process:

Educate: Be able to describe who you are, who you represent and what your issues are to the decision maker.

Demonstrate: Be able to demonstrate why your issues matter to the decision-maker and why they should listen to you.

Advocate: Be able to articulate exactly what you need the decision-maker to do to further your issues.

Ryan Clarke also offered the following advocacy tips:

1. Know your message(s).
2. Keep your message(s) simple and grounded in facts. (Keep your communication clear, compelling and concise).
3. Deliver your message(s) over and over again, using all of your tools.
4. Ask for the one thing you really need, not a list of what you want.
5. Position your issues within the decision-maker's agenda.
6. Build impeccable relationships with the people who impact your issues.
7. Know the core facts about your issues.
8. Believe that you have the power to affect change.
9. Start today – you have the right to be heard now.
10. Don't ever give up – successful advocates are persistent in their efforts.

I would also like to add that it is important to educate oneself about the hierarchy of the decision makers one wishes to influence, because it is important to start with the immediate decision maker, if your advocacy is successful at this level and your issue is resolved that is great. However, it isn't always that easy and in order to be taken seriously one must arm oneself with lots of patience and tenacity and move it up one level at a time until one is successful and the issue is resolved. This can take time, but there is no

point in going straight to the top. By taking it one level at a time, one is seen as someone who is cooperative and playing by the rules and likely will get listened to in the end! If there is no one who will listen to you within the organization where you are trying to affect change, then it is important to find out what impartial authorities can be found in the Canadian society either on a municipal, provincial, or federal level, who can help you affect the changes from without the organization where you are trying to advocate for, say, your child or yourself (or even a group of people). There are professional organizations, who can discipline their members (e.g. College of Physicians, Ontario College of Teachers), The Human Rights Tribunal (Ontario), School Trustees, School Boards, The Ombudsman (Ontario), Your local MPP or MP, just to mention a few. It is important to find just the right place to go and it can involve a few phone calls and internet research.

It is also important to document all conversations, emails, letters and phone calls and keep hard copies in a file in case it will be needed and to help your memory; and it is very important to try to keep your temper in check no matter how frustrating the situation can get; it impresses decision-makers if you stick to the facts and keep your emotions out of the situation!

Last but not least, make sure you have lots of support from family, friends and support groups such as the Tourette Syndrome Foundation of Canada; it can be very stressful advocating and running into resistance over and over, and it is nice to have support groups for networking and finding contacts and information required to be successful in advocating for one's issue(s).

On a personal level, I can share my own and current advocacy on my son's behalf. As mentioned earlier he has TS and OCD and therefore has fine motor skill issues. While he was in elementary level he had an Individual Education Plan (IEP) which gave him accommodations to help him be successful at school. A teacher refused to consult his IEP and called him lazy. Well, the first step was to try to create communication with the teacher and resolve the issue that way. The teacher refused to respond to our written communication, nor would he meet with us, so the issue was escalated to the principal who also

refused to help. The next step up was the superintendent, who not only refused to help, but appeared to try to brow beat us into letting go of this problem and a couple of other important issues as well. We then went the next step up, which was to contact the school trustees. They seemed unable to get anywhere with the superintendent. At this point we were at somewhat of a loss for where to go next. We then started talking to friends and acquaintances and did some internet research, made some phone calls and came up with the Ontario College of Teachers and the Ontario Human Rights Tribunal. We put all the written documentation together in chronological order and a memo with an outline of what the issues were, who the parties involved were and our suggestions for resolution to the issues and sent it to Ontario College of Teachers and the Ontario Human Rights Tribunal. This is where the matter is at present and we must now be patient and see what happens next.

Updates from Conference 2007.

By Ray Robertson

Dr. Roger Kurlan provided an update on PANDAS – (Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections). At our 1994 conference in Vancouver, a presentation was made based on information from a Boston University study that suggested there was a connection between the onset of TS and the occurrence of “strep throat.” Since that time, there has been a flurry of studies and 13 years later Dr. Kurlan reports that PANDAS are real and that they

“represent a subgroup of TS/OCD patients who are susceptible to GABHS (Group A Beta-Hemolytic Streptococci) infection as precipitant of their symptoms. It is not the only or even the most common precipitant for these patients.”

Webster’s dictionary defines precipitant as “one that causes the formation of a precipitate.”

Dr. Kurlan continued with

“it is likely that there are other subgroups with other preferred precipitants” and “ it is unknown whether

separating out subgroups based on clinical precipitants has clinical or scientific merit.”

Another speaker, talking about the criteria for TS, quoted the DSM-IV’s first requirement (a) which states “both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently.” This, in effect, means that the individual must have displayed at least 2 motor tics and at least 1 vocal tic prior to diagnosis. The speaker acknowledged that some experts have, for some time, accepted tics that produce sounds from the mouth and/or nose area but not originating from the vocal cords, such as sniffing or tongue clicking as fulfilling the requirement of a “vocal tic.” The speaker went on to say that any tic producing sound, whether from the vocal cords or not, can only be produced by muscle movement and therefore, motor and vocal tics are not that different since both are the result of a signal to a muscle. We look forward to a change in the DSM criteria.

Sheryl and Dan Pruitt gave a presentation on preparing our TS+ child to leave home - whether it be forced on us by university or college timetables or whether it’s just time for a move. Helping our children prepare to look after themselves on their own, requires some understanding on our part, and the Pruitts described ways that parents can influence the outcome.

Dr. Roger Kurlan provided an update on DBS (deep brain surgery) as a treatment for TS. He reported that 50 cases have been recognized world wide; 30 of these in Italy. Some side affects reported include fatigue, decreased concentration and altered sexual drive. In one case infection occurred in the incision and the leads were removed. Another case reported self-induced damage to the stimulator and the equipment was removed. Kurlan reported that, generally, there seems to be reduced benefit from DBS over time. He also stated that there are significant challenges and opportunities ahead with DBS.

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