



Tourette Syndrome Foundation of Canada

London Chapter

Newsletter

February 2007

Try to include me: I've got TS

I'm a Tourette I've got lots of talents
I do many things; believe that I can
because of my ticks I am different
watch: I'll soon become a successful man

Encourage dialogue, I always do
and nurture togetherness everyday
I need to be seen and heard just like you
appreciate me and I'll learn your way

If I feel safe and you make me belong
then I can build my castle in the air
success breeds success so I won't go wrong
I will do my best, so will you be fair

And yes, I've copro, so sadly I swear
so when I say the 'f' word; please don't hear

Mary Robertson (15/09/06)

When Dr. Mary Robertson said that she would like to do more for people with Tourettes in Canada, I asked her to write a poem for the children with TS in London, Ontario.

This was on Thursday, the day before she was to make the keynote address that would open our annual conference in Edmonton on September 15, 2006.

Her presentation on Friday morning was the highlight of the conference, updating us on old topics and new developments. Her talks are always entertaining and she covered a wide range of subjects and packed a lot into a short time.

Dr. Robertson concluded her presentation with this poem that she had written overnight, for the children of our London.

Ray

Dr. Mary Robertson is currently Emeritus Professor of Neuropsychiatry at the University College London (England) and Visiting Professor and Honorary Consultant to the Tourette Clinic at St George's Hospital and Medical School, London. She is the author of 258 publications, has written 3 books on Tourette Syndrome and has had 81 poems published. She is also a member of the Professional Advisory Board for the Tourette Syndrome Foundation of Canada.

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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

Brigitte Heddle
Dr. Mary Jenkins
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Dr. Duncan McKinlay
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President's Message

Thanks go out to Dr. Mary Robertson for our front page feature. Feel free to copy this poem and use it where you can, perhaps taking it to school and sharing it with teachers and fellow students or showing it to grandparents, aunts, uncles and cousins.

Jennifer gives us an honest assessment of the book she reviewed – **"After Disability: A Guide to Getting on with Life,"** demonstrating that not every book with an interesting title should be read by everyone. This is why we review books. As she states in her review, this book would benefit those whose lives are "significantly limited by" TS.

Coincidentally, Mitch, a close friend of Jennifer's, was the victim of an auto-bike encounter, in late 2006 that left him with no ability to consciously control movement below his neck. His condition has improved and continues to improve, but still leaves him only able to move one finger centimeters in any single direction. Jennifer asked if she could keep this book to share with Mitch before returning it to our library and of course she can. Mitch, we're hoping for the best for you.

Please don't "drink and drive" and please "bike responsibly."

Dear Doctor takes a look at 5 commonly asked questions regarding TS medications. Dr. Mary Jenkins talks about a variety of medications, when to use them and their affects.

In "What's new in Research" Brigitte Heddle looks at a recent paper that asks is OCD really an anxiety disorder? The process the authors used to arrive at their conclusions and some of the intermediate results are very interesting.

We have included a school speech written by 10 year old Brock Mazzocato that has been published in The Winston Gazette, a publication of Camp Winston. In discussion with Peter Copp, Assistant Camp Director at Camp Winston, he informed us that their waitlist has over 400 children and the wait is at least a couple of years. So, if you are interested in Camp Winston's program for kids with TS, contact them early.

The Brake Shop team at CPRI was somewhat surprised at our printing of the article "Discipline Made Easy" in our August 2006 newsletter. In a collaborative effort they have responded to the "1,2,3 Magic" approach to children's behaviour issues. Their response is included on page 4.

One of the programs the CPRI Brake Shop has made available for families with TS is called "Give Me a Brake." We have heard many good things about this program, so, when Lisa Jacobs, a member of our chapter, added her kudos about the program, we asked her to "put it in writing." She did and we have her story in this newsletter. Thanks, Lisa.

Once again we have included our schedule of upcoming Bingo events. If you ever wanted to help people with TS without a lot of training or specialized knowledge this is a great opportunity.

We Get Letters – This is exciting! We received a letter to the editor from a reader with comments about our November 2006 feature article "Our Actions—Their Futures." The writer suggested that some areas of the article were meant more for people with physical handicaps and didn't necessarily apply to kids with TS. We'll include the letter in our next edition.

If you would like to tell us what you think about an article in one of our newsletters, our newsletter in general or even just about TS, put it in writing and send it to us. You may get published.

Along with some other shorter stories and a couple of advertisements, that's our February 2007 newsletter. Thanks to all who have contributed.

Ray

Book Review

After Disability: A Guide to Getting on with Life

*Lisa Bendall, forward by David Onley
Toronto: Key Porter Books Ltd, 2006*

After Disability is a practical hand book aimed at Canadians who are new to a life with disability. It offers guidance on the type of everyday matters which are simple for non-disabled people to navigate, but which demand much more thought and effort for those afflicted with life-altering conditions.

The author, Lisa Bendall, has decades of experience in the area of disability advocacy, primarily from working as the editor of Abilities Magazine. She has written this book to provide a basic information package to answer all the questions she regularly fielded while at the magazine.

Statistics Canada defines disability as a condition where "everyday activities are limited because of a health-related condition or problem." The book is not specifically written for people with TS, but those with strong symptoms of TS, OCD, ADHD or other associated disorders may well fall into this designation. Most of the information provided is, however, aimed at mobility impairments such as Spinal Cord Injury, Multiple Sclerosis, Arthritis or Fibromyalgia.

The book provides invaluable information on setting up your life to achieve the most you can under your particular limitations. It discusses topics such as assistive devices and technology for mobility impairments; practical renovations for your home to provide easier access; financial considerations such as tax exemptions, workers compensation and benefits; equal opportunities for employment and education; how to navigate the systems of accessible transportation; interpersonal issues such as dating and parenting with a disability; and how to carry on your leisure interests despite impairments.

One of the most helpful elements in the book is the contact information section at the end of each chapter. Public and private associations and businesses that provide services and information are listed by province and nationwide, such as the

Accessible Housing Society in Calgary, the Parenting With a Disability Network and the Centre for Independent living in Toronto.

Books are also listed, as well as informative websites such as NEADS, an online job registry for people with disabilities, and the Online Occupational Therapist Finder.

After Disability is highly recommended for those sufferers of TS whose lives are significantly limited by the disorder, or for others who suffer from mobility impairments.

Reviewed by: Jennifer Robertson

Bingo Fundraising to help others

Our Chapter has raised over ten thousand dollars to help families with TS since we began running bingos in September of 2005.

Bingos provide a way for people who want to be volunteers and help others with TS but only have a few hours each month to contribute. It doesn't require hours of preparation or hours spent doing reports after the event. Just set aside 3 - 4 hours each month and if it can fit into your schedule, call us and then put it on your calendar.

Upcoming bingo events are:

Friday, February 23, 2007
Saturday, March 25, 2007
Monday, April 2, 2007
Saturday, May 26, 2007
Saturday, June 30, 2007
Friday, July 20, 2007
Wednesday, August 15, 2007
Tuesday, September 4, 2007

Our TSFC Bingos are at Lucky Days Bingo,
539 First St., London, Ontario,
We can use your help from 5:45pm to 9:30pm.

If you are interested in helping other families with TS by working at a Bingo event contact us at:

519 457-4586, or
rayrobertson@hotmail.com, or
lindajathome@sympatico.ca

CPRI's Brake Shop Team Responds to our article "1-2-3 Magic"

This letter is in response to the "1-2-3 Magic" book summary which appeared in a previous instalment of your wonderful newsletter.

While our team very much applauds the efforts of TSFC London in disseminating a wide variety of approaches to parenting and treatments for TS and its associated disorders, we feel compelled to caution your readers against accepting any and all of these practices as gospel without a healthy dose of scrutiny. This holds true for approaches also read in Today's Parent, heard on Oprah...or taught in our clinic for that matter, which is why our Self-Management Group includes an adult-only session where parents and teachers alike can debate the relative merits (or potential liabilities) of the practices we endorse.

This is not to say that some approaches are "right" and "effective", and others are "wrong" and "useless". What we ARE saying is that different children exhibit 'bad' behaviour for different reasons (e.g. poor behaviour versus a skill deficit), and different approaches are optimally suited for each of these reasons.

"1-2-3 Magic" is without doubt an excellent approach for some children, parents, and issues. It is not, in our estimation, a helpful tool for dealing with "leaky brakes" though (chronic deficits in ability to self-regulate movements, noises, attention, impulses, thoughts, emotions, etc.). This opinion is in part created from our clinical experience – innumerable families that have come to our service citing "1-2-3 Magic" as a shining example of what HASN'T worked for their family. It is also in part created from our basic theoretical model of the "Brake Shop". For example, an approach that assumes opening a dialogue with your 'irrational' child is counterproductive, assumes a child who is incapable of insight into his/her skill deficits and is not in need of empathy for his/her situation. An approach that assumes a child WILL stop themselves at the count of "2", assumes a child who is even CAPABLE of stopping him/herself in the moment. An approach that hangs the stress of an impending consequence

over the child's head at the moment of defiance assumes two things: it assumes a child whose skill deficits will not worsen with stress and it assumes that the child isn't already motivated to stop this behaviour. Finally, an approach that instructs a parent to be more calm and deliberative in his/her parenting approach assumes a parent who does not have the same genetic predisposition towards "leaky brakes" as his/her child.

Of course, ultimately we recommend that you consult with your own mental health professional before choosing ANY approach – your own team will know your family's individual factors and needs best. It is for this reason that our Family Resource Centre offers a disclaimer on all of its literature and videos which echoes this sentiment.

Dr. B. Duncan McKinlay, Psychologist
In collaboration with the CPRI Brake Shop team

The Tourette Syndrome Foundation of Canada

London Chapter

Notice to Members of Annual Meeting

The London Chapter of the Tourette Syndrome Foundation of Canada will hold an annual members meeting on April 12, 2007 to review financial reports for the year 2006 and to elect officers for the following year.

Members in good standing may make nominations for the positions of President, Vice-president, Secretary, Treasurer and/or director-at-large. Nominations must be made at least 10 days prior to the meeting.

Tourettes Plus Syndrome

By Brock Mazzocato

Maybe you noticed, stared, giggled, questioned or wondered "Brock, why do you blink so much?" Funny, because I asked myself the same question before my doctor talked to me and my family. My mom thought my eye lashes were too long and asked the eye doctor if she could cut them. Silly her!

Good morning judges, teachers, Mme Gamble and fellow students. Today I would like to talk to you about Tourettes Plus Syndrome. I chose this topic because I was just diagnosed in the summer of 2004 with my mom who also has it. When the doctor told us we had this mom and I had no clue what they were talking about as do many of you probably. I think it is important for me to tell others about it so they can understand me and not feel like they have to stare and giggle or wonder – "what is that guy doing?"

A lot of times I do things that I cannot control... yup... like blinking my eyes, or shrugging my shoulders. Some people swear or make silly sounds. Maybe even twitch their head. Not only do I do some of these things but it makes my brain play tricks on me, and I cry for no reason or even get angry. A lot of times I get upset because I don't want to feel this way and I don't know why I do but I am learning to deal with it. My medicine helps me lots.

"I get upset a lot because I don't want to feel this way and I don't know why I do, but I am learning to deal with it."

It was really strange how it all happened to me. One day I got really, really, really angry and can't remember what happened. Mom and dad told me that I got really upset and started to do things that I never did before like punching, kicking, screaming and I even picked Mom up and pushed her off of me. When we saw the doctor, mommy, daddy and grandma talked and talked and talked to the doctor. I swear I did not think we were ever going to leave that place. He told them that I had Tourettes Plus and that when I forgot what happened that is when I had a "rage" attack which made me get very angry. Finally we were sent home to research this disorder and these are some things we started to learn:

Tourettes Syndrome is a nerve disorder. It means that when I was born some of my nerves in my brain were criss-crossed and so it sends messages to some parts of my body to do certain things which are called "tics". The Plus meant that I also have other disorders which are all a part of it, like Obsessive Compulsive [Disorder] which means that I do certain things over and over again like when I go to bed my bed has to be in a certain way before I can be comfortable or even lining up all my toys in a certain way before I can play with them. The other is

Attention Deficit [Disorder] which means that I can only concentrate on things for a little bit and then I need to take a break because my brain gets tired so usually when I do my homework it takes me 3 or 4 times longer than everyone else because I can only do it for a little while at a time. This happens a lot at school when I am in class because if someone does something even as little as taps their foot I lose track of where I am and focus on that.

Hyperactivity is another disorder that sometimes gets me in trouble because sometimes I get a little carried away and get really super silly and dad or mom say "Boo, time to slow down a bit" but sometimes that can spin the other way and I get really sad and cry and cry and cry for nothing at all... that part is not too nice. The last thing is anxiety which just means that I get panic attacks which mean sometimes my body freezes and I feel like I can't move or that someone is squeezing me really tight and won't let go. Have you ever felt like you have to sneeze and can't or you tried to hold in a cough but it drives you bananas and you do it. Well, that is what my tics feel like. Tourettes is something I was born with. I find it easy to talk to my mom about it because she knows what I am feeling and can help me out a bit. At first I felt sad, a little embarrassed and different from everyone and I did not want anyone to know because I did not want them to laugh at me. Now, because I belong to a group {where} everyone has it and I find out a lot of things, I kind of feel special having it... hey... who gets the chance to go out of town every three months to see their doctor and go shopping and miss school...I DO!!!!!! Really Mr. Brand I do miss it when I'm gone... honest...

Anyways, that's pretty much me. So now when you see me doing these things you will know why and probably won't even notice anymore because really it's not that bad. So if you have any questions come and ask me. Don't be afraid. I'm just like you. "I'm just a kid!!"

*A speech given to his school. Brock is 10 years old.
Reprinted with permission from "The Winston Gazette."*

Interesting

A recent publication, listing tics and compulsion, included "brushing against walls and doorways when passing by" - - a favourite of mine. As I looked around the house for evidence of this, I found dark areas in a number of places where oils from the back of my arms have marked the walls. At one location, I happened to glance down, and found the same evidence left on the wall by Montgomery, our 5 year old, 15 pound, grey, longhaired, house cat. Is this another area that should be researched?

Dear Doctor

Dr. Mary Jenkins answers some commonly asked questions about medication treatment for Tourette Syndrome

Consideration of medication treatment for a child or adult with Tourette Syndrome involves a detailed medical assessment and identification of the key problem areas. Medications may be used to treat tics, attention-deficit hyperactivity disorder, obsessive-compulsive disorder, anxiety, depression, and aggressive behaviours. In all cases, medication is only one part of the treatment plan. A number of medications have been well studied and much is known about their effectiveness, indications, and potential side effects.

When is medication treatment "recommended"?

The final decision to use medication follows a detailed discussion with the physician and patient. Many factors must be taken into account including 1) the severity of the problem, 2) the impact that the tics or behaviours may be having on the person's school, work, family, social life, and overall quality of life, 3) the interaction of medication with other medications, 4) the potential for the medication to control the symptoms, and 5) the potential side effects of the medication.

Medication is recommended for the treatment of tics if the tics are causing problems in any aspect of the person's life AND if he or she wishes to start treatment. For mild tics, often medication is not needed. For more moderate or severe tics, medication may be recommended depending on the degree of difficulty. If the tics are causing problems in the person's quality of life, we would recommend medication – if the tics were not causing problems, we may not recommend medication. Ultimately, the decision to start or not start medication is up to the individual with Tourette's.

What does the medication do?

Many times I am asked for a medication to make the tics "go away". Although we continue to search for the ideal medication to treat tics, the quest continues. None of the tic medications are a cure for the disorder. When tic medication works well, we expect

it will lessen the tics to the point that they are manageable or more tolerable, but it will not make the tics “go away”. Often on hearing this information, especially in cases of mild tics, patients may decide not to choose medication.

Which medication do you choose?

Many medications are used to treat tics. The most commonly used medications include Clonidine (Catapres), Risperidone (Risperdal) and Pimozide (Orap). In addition, many other medications have been well studied and found to be effective including Metoclopramide (Maxeran), Olanzapine (Zyprexa), and Haloperidol (Haldol). Other medications such as Tetrabenazine (Nitoman) have been found to be useful, but have not been as well studied. The choice of medication is determined by the severity of the tics, the presence of other problems (such as inattention), and the potential side effects. In all cases the risks and benefits of medication must be reviewed. The medications with the fewest side effects are generally not as “strong” and so may be prescribed for milder tics. Some medications, such as Clonidine, have been found to be helpful in treating both the tics and inattention.

Will medication for Attention-Deficit Hyperactivity Disorder (ADHD) make tics worse?

The short answer is “No”. It was always thought the medication for ADHD; in particular, stimulant medication such as Ritalin, would cause tics or make tics worse. This question was examined in three well-designed, reliable studies in children with tics, started on stimulant medications. The studies concluded that stimulant medications do not cause tics. In most cases, tics were not increased by stimulant medication and in some instances; stimulant medication resulted in improved tics. This improvement was thought to be due to the improvement in ADHD symptoms. In a few cases, there was a brief, transient increase in tics, and then the tics returned to the baseline level.

Will the medication make me a “different person”?

The goal of starting medication in Tourette Syndrome is to improve the person’s quality of life. In many cases, the symptoms of Tourette Syndrome cause a

great deal of distress and pain for the person and the purpose of medication is to relieve some of this distress. If the medication is causing side effects that make someone feel “different”, then that is probably not the right medication.

In conclusion, careful evaluation and consideration must be taken before starting a medication to treat Tourette Syndrome. Although we have discussed medications, this is only one piece to the overall management of the disorder. Education, counseling, and behavioural strategies are all important components to the treatment plan.

Parent 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 for 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 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 meetings dates are:

March 8, 2007
April 12, 2007
May 10, 2007
June 14, 2007

What's New in Research

By Brigitte Heddle

In an article published in the Journal of Psychopharmacology in 2006 [20(6) (2006) 729-731] written by David Nutt and Andrea Malizia, the authors are taking a look at a debate in scientific circles regarding OCD. The authors of this article look at it from the perspective of what medicines are most beneficial to treat OCD.

The debate stems from some researchers who challenge OCD as an anxiety disorder. It has been suggested by some that OCD is an impulse control disorder or a habit disorder rather than an anxiety disorder.

Back in 1967 OCD was one of the first anxiety disorders to show response to antidepressants (shown in study by Fernandex and Lopez-Ibor). At the time it was thought that this meant OCD had an association with depression. Then other anxiety disorders also responded well to antidepressants including panic attacks. By 2003 in a study by Nutt and Ballenger it was mentioned that all anxiety disorders respond to antidepressants.

The authors write that OCD is different from other anxiety disorders both in some symptoms, such as ritualistic behaviour, as one example, and its association with tic disorders. Furthermore, OCD can be caused by immune related attacks. Brain imaging studies have also found over-activity in a part of the brain that is not over-active in other anxiety disorders. It is mentioned that effective drug treatment and psychotherapy and a particular kind of neurosurgery can have a positive impact on OCD. Yet, the same type of neurosurgery has been used in Sweden for panic disorder and with good results reported. These findings have caused a certain amount of interest in the possibility that OCD may be an impulse control disorder or a habit disorder rather than an anxiety disorder. The authors mention a study by Bartz and Hollander from 2006 as an example of researchers putting forth good arguments for OCD being an impulse disorder.

The authors, however, state that if OCD is eliminated from the group of anxiety disorders other issues arise. First of all it is a fact that many patients with OCD

experience anxiety to varying degrees. On this issue there is disagreement to what role anxiety plays in OCD. The authors go on to say that if various syndromes that have anxiety as part of its definition are analyzed it becomes difficult to separate them unless they are grouped into separate families. The authors warn that at this point not enough is known about the differences and similarities between various anxiety disorders and caution against splitting the anxiety disorders prematurely.

The point of this whole discussion of whether OCD is an anxiety disorder or not is to determine what medications are best to use.

The authors conclude by saying that it can still be argued that there are considerable similarities between the anxiety in OCD and other anxiety disorders and the reasons for OCD. The authors feel that OCD may be a complex mixture of anxiety mixed with behaviours and habits, but definitely that “the anxiety itself is similar to that seen in the other anxiety disorders and responds to the same treatments.” The authors go on to predict that a certain type of medication group called benzodiazepines may be more helpful in the early stages of what they call danger-related OCD, “when the rituals are less established and anxiety is more GAD-like (I am not sure what GAD-like refers to), benzodiazepines might be more helpful than they would be later in the illness when anxiety relates to prevention of rituals. It might also predict that benzodiazepines would be more useful in danger-than desire-related anxiety generally.” The authors admit that the data on use of benzodiazepines is old and goes back to 1991 and 1993 and are asking readers of this article if they are aware of newer data to forward this to the authors.

Now, you ask why write an article about whether OCD is an anxiety disorder or not? Why is that relevant for us, who either have OCD or have a loved one who has OCD? Isn't it only relevant for the doctors who prescribe the medications? My answer to those questions is that it is definitely relevant for both the patient and his/her families, because we are working together with the doctors on finding the right

treatment for the patient. This gives us the obligation to educate ourselves as much as possible about the illness and its current treatments.

My son has OCD and Tourette's and had for a few years done well with the medicines prescribed for him. All of a sudden these medications seemed to stop working and our son fell apart and could especially not cope with school. We had to re-evaluate the treatment for our son together with his specialist. In the end we opted for trying out a

medication that was geared towards impulse control and not usually used for OCD, as far as I know. But those were the issues we were dealing with: a boy who suddenly seemed to give into any impulse that entered his head. Well, it seems to work. So if we all, not just the doctors, educate ourselves on various medications and what symptoms they have treated successfully and where science is heading we stand in a much better position of helping the patient choosing the right treatment whether it be in the form of medication, therapy or other treatments.

The CPRI Brake Shop service for Tourette Syndrome & Associated Disorders presents

"Leaky Brakes" 101

For the family member (including the adolescent child), educator, spouse, friend, neighbour, bus driver, babysitter...or anyone else invested in learning more about Tourette Syndrome and its associated conditions (Obsessive-Compulsive Disorder, Sensory Processing Dysfunction, Attention-Deficit/Hyperactivity Disorder, oppositional-defiance, and "rage").

Each week is devoted to a different topic:

"leaky brake" disorders and their misperceptions

pharmaceutical management

sensory issues/cognitive-behavioural management

school interventions

home support

review, and panel of experts (professional, parent, child, supports)

Various "CPRI Brake Shop" team members will present these topics. Time for questions and networking is allotted. Each spot is reserved for a particular attendee, and successive sessions assume past information. Hence, you are encouraged to attend all sessions.

Annual fall and spring courses offered. Enrolment is without charge. To reserve a spot for the next available 6-week programme beginning April 4, 2007, call

(519) 858-2774 ext. 2025.

A Glowing Report

By Lisa Jakob

Our son Matthew was diagnosed with Tourette's Syndrome 3 years ago at the age of 9 and a half. He also has ADHD. Matthew's tics are not too severe and have been managed with medication since his diagnosis. Over the past year or so, however, we have experienced increased rage and frustration attacks. We were having problems dealing with these attacks and trying to diffuse them before they occurred. Matthew was also having problems dealing with these explosions. That's when CPRI came to the rescue.

We found out at our monthly Tourette meeting about a program at CPRI called 'give me a break'. It is a self management group for children with Tourettes and their parents to attend. The course runs over 9 weeks, with week 5 being an adult only session. We were unsure about the course at first, because of the school Matthew would miss (the class runs on Tuesday from 9:30 to 10:30 am), plus he is not always a willing participant in discussions.

The program was wonderful. Dr. Duncan and the staff put us right at ease and made everyone feel welcome and included. The group is small, only 6 children. They all had Tourette's and other associated disorders, so could relate to each other. The premise of the program was simple and easy to relate to. They use the 'beaker' analogy to identify the level of frustration the child is experiencing. The 3 main topics were

- 1: What fills my beaker?
- 2: How do I know that my beaker is filling?
- 3: How do I empty my beaker?

The program also uses Dr. Ross Green's approach called Collaborative Problem Solving.

Each week there was a review of the previous week and then we built from there. Session 3 involved identifying what fills my beaker and that's when the boys came alive. They got to draw all the things they feel before, during and after an explosion. It was the best session I think. Week 5 was the adult session only and we were fortunate to have Matthew's teacher attend also. She also found the program very informative and easy to understand.

I think Matthew got quite a bit out of the program, more than anything we have tried so far. It was also an eye opener for me. I was able to personally relate to much of the topics being covered. We all have a 'beaker' and different things cause it to fill and overflow. Learning techniques to empty the beaker and reduce the overflows has made a noticeable difference in our family. We have been trying to continue with all the good stuff that we learned. Things are definitely better around our house and I would recommend the program to any other families experiencing rage/anger related to Tourettes or other behaviours. It is well worth the missing of school (and work)

CPRI Brake Shop:

Putting The Brakes On Sleep Difficulties

Because we can accidentally 'train' our bodies to have problems falling asleep, it is very important to practice good sleep hygiene to prevent this unintentional 'bad' learning from occurring. Children with 'leaky brakes' may have bodies that are more susceptible to this kind of learning. Good sleep hygiene can also make it easier for children who are biologically predisposed to sleep difficulties to adapt to regular sleep schedules. Below are

a number of ways to improve sleep hygiene. At the end of this handout is a checklist with further ideas to assist you.

So let's give 'em a brake!

- **Keep a regular sleep schedule.** Don't vary bedtime/wake-up times by more than 1 hour even on weekends, and stick to a set routine. Do the same things in the same order every time – you might even want to

create a 'script' together so the words you share when your child is in bed are the same each night. Structure, as a general rule, is always very helpful for children with 'leaky brakes' – it fosters a predictability in their lives (and therefore a feeling of control) that can be otherwise lacking given their poor control over their own bodies, attention, emotions, and thoughts. This schedule should have a child in bed before 11 p.m. and up before 8 a.m.

- **No naps during the daytime.** Instead, wear them out during the day. Exercise is good, but not right before bedtime because exercise arouses the body and raises your temperature. To fall asleep you need your body temperature to lower instead. One thing we know about the body is that it automatically lowers its temperature (making you feel drowsy) 4-6 hours after you exercise. Therefore, by getting the blood pumping through some sort of activity 4-6 hours before bedtime, we can get our bodies to naturally prepare us for sleep right when we want them to!

- **Beds are for SLEEPING in!** The bed should be used for sleeping **only** – this will actually teach the child's body to prepare for sleep as soon as you are lying in this place and at this time. Lying in bed for hours reading or eating confuses your child's body, because now a variety of activities (some involving powering the body up, some involving powering the body down) are now linked to the bed. If the child frequently plays in his/her bed, this can even train the child's body to link activity with beds, meaning that (s)he will become stimulated rather than relaxed when (s)he lies down!

- **Stimulation is bad!** In order to allow the body to shut down, sources of stimulation need to be avoided in preparation for bedtime. Avoid fights shortly before lights out. Caffeine is a stimulant, and so no colas, Mountain Dew, teas, coffee, or chocolate in the late afternoon or evening should be permitted. As a rule of thumb; eliminate these items from the child's diet 6 hours before bedtime. Finally, is the room too loud or too bright for the child to fall asleep? Remember that your child may have 'leaky brakes' over his/her senses, and so sounds and/or light in the room that wouldn't bother you will prevent your child from falling asleep!

- **'Graduated Extinction'.** Decide how long you are going to wait before you check in on your crying child, and stick to it. Don't pick your child up or otherwise reward your child for those behaviours – just go 'in and out' long enough to ensure everything is all right. Increase this amount of time each night over many nights. Because this plan means that NO ONE sleeps well for a few nights, you might choose a weekend/holiday to start using 'graduated extinction'.

- **Bedtime Fading.** Put some reverse psychology to use. "You wanna stay up? Fine – stay up **reeeally** late"! Keep the activities boring ("this is what adults do when they stay up late") and keep the child awake until they've gone through the bedtime routine and been put into bed at a time that is 30 minutes past when they would naturally fall asleep. The child is tired enough that putting him to bed is not a battle – and no fights equal no extra stimulation! Over time, this 're-trains' your child's body that bedtime is a time of relaxation and the bed is a source of relief for their exhaustion. Once this occurs, the bedtime can be inched back slowly (15 minutes at a time) and eventually to the desired time (or at least a time where the child still seems well-rested in the morning). It is worth emphasizing that this is not intended to 'trick' the child, but his/her body instead!

- **More reverse psychology.** Oftentimes it is the stress around WANTING to fall asleep that ironically causes people to have problems falling asleep. They are trying too hard! One way to take the stress out of the equation is to emphasize staying awake instead. Have the child prepare for bed and get settled in, and then tell them how important it is for them to NOT fall asleep. It removes the pressure, and sometimes this is enough!

- **What if my child has Tourette Syndrome?** If your child experiences painful tics, a massage or warm bath/shower may help to relax his/her body. If muscles are chronically tight due to long-standing tics, chiropractic care may be necessary to correct any subluxations and allow the body to be 're-trained' how to relax.

- **What if my child is Obsessive-Compulsive?** Does your child complain that his/her head won't stop long enough for him/her to get to sleep? One technique to experiment with is the use of a TV in the bedroom. Sometimes a television program can serve as a distracter long enough for the child's body to relax and drift off. For this strategy to work, certain components are very important:

- - Use a television equipped with a timer that can be set to turn off after a specified time period (e.g. an hour). That way the child is not awakened later in the night by the noise. If this technique works for your child, the amount of time the TV is left on can be reduced.

- - Choice of show is crucial: it should be a low-stimulation show (i.e. without lots of explosions and excitement). It should also be very predictable, either because the structure of the show is always the same (like the way Law & Order always follows the same formula), or the content is familiar (a show or episode watched repeatedly). Knowing what's coming next in

the show is, in itself, comforting, and contributes to relaxing the child.

- What if my child has Attention-Deficit Hyperactivity Disorder? Allow the need for longer-than-usual routines. Given the problems children with ADHD can have around regulating their energy levels, it is more important to ride their 'waves' (when their energy is low and they are nodding off, DON'T re-arouse them by running them through a routine). If your child is on a stimulant medication, be aware that certain dosages at later points in the day can interfere with sleep. Be sure to speak to your physician and/or pharmacist about the appropriate administration of this drug.

- Added bonuses – better brakes, fewer headaches! One way to avoid power struggles around the use of these techniques is to let children know "what's in it for them". Arguments around lights out can easily look to children like just another way an adult is telling them what to do. Assure them that this isn't the case – not only will their brakes work better the next day the longer they sleep (like a battery being recharged), but recent research suggests that using good sleep hygiene can reduce the frequency and duration of migraine headache episodes (Bruni, Galli, & Guidetti, 1999).

A final point: for the child who is genetically predisposed to sleep difficulties, these techniques do not "cure" the problem. Rather, they create an environment that allows the child to sleep in a regular schedule despite their natural tendencies. Light bulbs will shine brightly until they burn out, as that is how they are designed to be – only by attaching them to a timer will they follow the schedule we set without need for intervention. For this reason, you should not be surprised if problems re-occur after some sort of disruption in the schedule (due, for example, to an illness or a vacation). Think of that disruption as being like a power outage on the timer – just as the light bulb would revert back to its natural tendencies, so do these children. We must simply reset the timer before we can expect the light bulb (or the child!) to again follow the schedule we desire.

If you'd like more detail than what is provided here, a good book to read is Sleep Better! A Guide to Improving Sleep for Children with Special Needs, by Dr. V. Mark Durand, Psychologist.

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Speaking on:
Children Do Well If They Can
Collaborative Problem Solving:
Overview of General Model

Tourette Syndrome Foundation of Canada
Conference and Annual Members Meeting
Niagara Falls, Ontario
September 27-29, 2007

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