

### President's Message

In this issue we welcome a new writer to our newsletter.

Brigitte Heddle is a new member of the TSFC and a new volunteer for the London Chapter. As the mother of a boy with TS and OCD, she has spent many hours researching TS and has always had a keen interest in science. She has experience as a research associate for a cancer researcher and is joining us to help put research study reports into language we can better understand. Welcome, Brigitte.

In our February 2006 edition we had two new names that didn't get an introduction.

Gerard Johnson is Vice-president of our chapter, helps with the production of our newsletter and has been active on committees at the National level. During the day Gerard drives a bus for the London Transit Commission and at home he is the father of a 15 year old boy who has TS and OCD. Last issue Gerard wrote the first article in a series talking about his life before he heard the words "Tourette Syndrome."

Jennifer Robertson is a young woman who has lived with TS for the past 18 years. Jennifer is a graduate of NSCAD University in Halifax where she received a Bachelor of Fine Arts degree in 2005. She works part time in London as a gallery assistant and part time as a practicing artist. Jennifer's second book review appears in this edition. Welcome, Jennifer.

Appearing in this edition is a special article introducing the TSFC's Bulletin Board. Please have a look at this new TS "talk" forum and give our National office feedback.

I hope you enjoy the variety of topics represented in the articles by our 5 contributing authors and that you will find value in the content. Let us know what you think of our newsletter, or volunteer to help make it even better.

Thank you to everyone who has contributed.

*Ray*

### TSFC Bulletin Board

The TSFC offers one of the best means of communication for people with or affected by Tourette Syndrome, it's known as the TSFC Bulletin Board.

One of the most valuable benefits of this Board is that it allows people affected by Tourette Syndrome to exchange information no matter where they are located. This interactive site is moderated and controlled using TSFC's standards and guidelines.

Discussions on the Board are fully monitored for content and propriety. You do not have to know anything about how to navigate a forum to participate. This Board is not a chat room and those with limited keyboarding skills are very welcome.

Our intentions are to offer a free and safe environment to those looking for help and support. It may take some trial and error but there is no fear of making a mistake and there is also no need to be shy about making a faux pas in the way you express yourself. Our policy is to extend a warm welcome to all. To ensure your success, the moderators are there to help and online instructions are provided.

The benefits to TSFC members and volunteers who participate in this forum are endless. It can be a venue to congregate, share information about experiences, promote upcoming activities as well as develop social contact. Of course you can also ask questions about any aspect of Tourette Syndrome. Our participants interact

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## How to Reach Us

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### TSFC London Chapter Administrative Committee

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Dr. Duncan McKinlay  
Dr. Mary Jenkin

### 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.

### Contributing Authors

Brigitte Heddle  
Dr. Mary Jenkins  
Gerard Johnson  
Dr. Duncan McKinlay  
Jennifer Robertson

and provide support to people from all over the world. You can even hone your own support skills as you learn more about the disorder.

Many of the TSFC members who have visited the Bulletin Board have not visited in a long time and have been missing out on all the new features and benefits that have been added to this Forum. We encourage you to join and if you haven't visited for a while, to come back and take advantage of the new features that have been added since your last visit.

If you did not know this resource existed then you need to visit and read through the messages posted by our registered forum members. As a forum guest you cannot post a message or vote in the forum so you are encouraged to register and meet all the great people who actively participate. Once you fill in the required information and provide a valid email address, you will receive your login information by return e-mail. This will be the only e-mail you will receive from the forum. You will not be added to any e-mail list nor will your information be used in any way except to validate your registration.

There is nothing to lose and lots to gain by visiting and or participating in this phenomenal resource. You are encouraged to publicize the forum at your meetings, on your website and in your literature such as brochures and posters. The TSFC has some of the best resources on Tourette Syndrome in you, the volunteers and members. Your participation on the Bulletin Board makes it the "world class forum" it is fast becoming.

### Tic Together



The TSFC's wrist bands are green to match our logo and are marked with the words "Tic Together." These wrist bands are available at our monthly support meetings and cost only \$3.00. Proceeds help support the TSFC at the National level – keeping our 1-800 help-line open, producing the National quarterly newsletter and making available materials such as our six handbooks and videos.

If you are interested in wrist bands contact our chapter treasurer, Linda Johnson at 519 649-5092 or lindajathome@sympatico.ca.

**Front of the Class: How Tourette Syndrome Made me the Teacher I Never Had**

By Brad Cohen, with Lisa Wysocky

The author of this book is a wonderfully contagious optimist. If you are upset or depressed or worried about Tourette Syndrome in your life, I highly recommend reading *Front of the Class*. It is entertaining, moving, very readable, and most of all inspiring. A lot of books are intended to be inspiring and don't live up to that claim, but *Front of the Class* is a truly uplifting book. (Not only that but a good read - I read it in 2 sittings of several hours each, and couldn't stop turning the page - a noticeable difference from the last book I reviewed, which had its dry bits and I have to admit I didn't actually finish.)

Brad Cohen is a teacher with Tourette Syndrome living in Atlanta Georgia; *Front of the Class* is his memoir of growing up with TS, focusing on how TS has affected his ability to attain his goals in life.

Cohen tells his life story beginning before the onset of TS, throughout his elementary and high school years, through to a college degree, and into the workforce. He describes his life with humorous anecdotes and relates stories of significant events with such emotion that the reader feels the highs and lows along with him. He focuses the book on the obstacles that TS caused in his life and how he overcame them. The emphasis is overwhelmingly on the achievement of attaining his life's goals despite TS, and he describes these achievements so clearly that they effectively serve as a road map for anyone navigating adolescence with TS, or any similar disorder.

He takes us through his diagnosis due to his mother's diligent research, his crusade to spread understanding and acceptance of TS, his social development from an outcast who made funny noises to a young man with many meaningful friendships and involvements, his leadership roles with various school and religious organizations, and most significantly, his quest to become a teacher in order to be the role model and helping hand that he lacked while growing up. Cohen's Tourette Syndrome is the reason he wants to be a teacher (in order to help children who need it), the obstacle that holds him back from it (principal after principal turns him away from teaching jobs because of his unsettling and distracting tics) and the reason he is so good at teaching when he is finally in front of the class (a national-level Teacher of the Year Award and countless stories of happy and healthy students prove it).

This book is a story of triumph with Tourette Syndrome as well as a guidebook to living happily alongside the disorder. It is not just a book for teachers; I recommend it for anyone looking for ways to deal with their or a family member's TS. I think it would be particularly appropriate for teenaged boys with TS.

Reviewed by Jennifer Robertson

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A mother tells a story about her 7 year old daughter:

The girl just couldn't get dressed in the morning - didn't know what to wear, - socks didn't feel right, - snow pants made all the other clothes feel bunched up, - missed the bus. Mom had to drive her to school again. Mom eventually ran out of patience, picked up the girl, socks, boots, snow suit, mitts, school satchel and lunch box, met the bus at the road and dumped all into the first available seat on the bus.

The next morning there were no problems getting ready for school and catching the school bus. Her behaviour pattern had been changed.

A father tells about his 22 year old son:

The boy had been diagnosed with severe TS, had prescription medication which he took sporadically and spent his days sitting on the floor in front of the TV, rocking forward and backward. Three younger siblings couldn't have friends over and were spending more and more time away from home.

With few options left available the father took the boy to University Hospital and had him committed for a period of 2 days. At the end of the 2 days, the boy had a friend sign him out.

When the boy arrived at home, the father met him at the door, gave him 2 dollars for bus fare and told him he couldn't live here anymore.

The boy survived, got his own apartment with the help of social assistance, eventually got a job and took responsibility for his own life.

These stories show a person in a pattern of Tourette Syndrome and/or Obsessive Compulsive Behaviour that was altered "over night" by an outside influence.

How do traumatic events like these alter the behaviour pattern of a neuro-chemical disorder?

Could parents prepare a planned treatment "sequence of events" that would "cure" a child of certain behaviours?

## Reply

*Certain stories show a pattern of Tourette Syndrome and/or Obsessive Compulsive Behaviour that was altered "over night" by an outside influence. How do traumatic events like these alter the behaviour pattern of a neuro-chemical disorder?*

Obsessive Compulsive Behaviours occur commonly in children and adults with Tourette Syndrome. The Obsessive

Compulsive Behaviours may be quite mild and have little impact on the person's day-to-day life; however, in other cases the symptoms may be more severe and have a much greater impact. When the symptoms are more severe, it is called Obsessive Compulsive Disorder (OCD). OCD is characterized by the recurrent obsessive thoughts, images or impulses that invoke anxiety and the compulsive behaviours or ritualistic acts which aim to decrease this anxiety. OCD can be extremely distressing to the person dealing with the disorder and very frustrating to those around them.

An example of OCD is the young girl who has an unrealistic fear of leaving her mother to get on the bus to go to school. In order to decrease this fear or anxiety, she has a ritual of having to dress only in certain clothes and to put them on in a certain order. If she is allowed to carry out this dressing ritual her anxiety may decrease, and she may be able to get on the bus; however, her dressing ritual takes an hour every day and she is consistently late for the bus. This is very frustrating for her mother who is also late for work because of this behaviour.

Treatment of OCD has been extensively studied in both children and adults. While mental health practitioners of course could not and would not ethically condone the use of "traumatic events" to treat ANY disorder, a highly effective treatment for obsessions and compulsions does exist that involves using "outside events" to "alter behavioural patterns". This technique is called Exposure and Response Prevention or "ERP", and it works by helping an individual to confront his or her anxieties. Because this could easily be misunderstood as using trauma for treatment, further explanation is important!

ERP is a technique in which people are guided through a hierarchy of anxiety-provoking situations and learn to overcome the fear associated with these events. During "Exposure" the person is placed in contact with the feared object or situation in order to bring out the anxiety and distress. Then during "Response Prevention" the person is not allowed to carry out any rituals or other anxiety reducing behaviours in response to the exposure. Under the guidance of a trained psychologist, the person is taught to confront their anxiety about the particular situation, rather than either avoiding it or allowing the unhealthy compulsive behaviour to continue. With each new ERP "assignment" (mutually agreed upon by therapist and client), the anxiety and unwanted behaviours gradually decrease as the person learns to deal with the situation in a new way. The therapeutic environment creates a safe and controlled place to deal with these fears and ultimately, to conquer them.

These therapies are very complex and require specialized training. The techniques must be offered in a safe and validating way. Parents or family members should not attempt these strategies on their own, but instead require the guidance and supervision of a qualified psychologist. If the exposure is not done properly, it may severely traumatize the child and make the situation worse. For example, in the case of the girl with separation anxiety, if she learns to gradually

separate from her mother, the intervention is a success; however, if the mother suddenly sneaks away, the girl can become more anxious and as a result, the separation anxiety becomes more of a problem.

The psychologist's role is not only to guide the person through managing the anxiety, but also to help the person deal with family and interpersonal issues that have arisen as a result of these behaviours.

The underlying cause of OCD is not completely understood; however, research has shown that both genetics and the environment likely contribute to the development of the behaviour. The part of the brain involved is the deep frontal brain structures and there are chemical changes which alter the way the brain processes information in these areas. Certain medications can be helpful in changing the brain chemistry to allow the brain to function without the associated anxiety. Research has shown time and again that psychological interventions for anxiety, such as ERP for OCD, are very effective. Research has also demonstrated that ERP treatment affects the brain in the same way that medications do. In other words, either medication or ERP will work to make certain changes to an individual's brain chemistry. Which treatment you choose depends on personal factors and personal choice.

Dr. B. Duncan McKinlay, PhD, C.Psych - Psychologist  
Dr. Mary Jenkins, MD, FRCPC - Neurologist

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## Support Meetings

The London Chapter of the TSFC hosts monthly support meetings from 7pm to 9pm on the second Thursday of each month, except for July and August, at:

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

### *Our next 3 meetings will be:*

June 8  
September 14  
October 12

On July 13 we expect to gather for mini-golf, chats and ice-cream at Windermere Golf North London at the north east corner of Windermere Road and Adelaide Street at 7pm. If weather permits we'll golf, if not we'll chat.

## What's new in Research

By  
Brigitte Heddle

From - Archives of Pediatrics & Adolescent Medicine 2006

Title - Adulthood Outcome of Tic and Obsessive Compulsive Symptom Severity in Children With Tourette Syndrome

By - Michael H. Bloch, Bradley S. Peterson et al.

The Authors conducted a study which included 46 children with Tourette Syndrome, which I will for ease of writing shorten to TS. These children had all received a structured clinical evaluation before the age of 14. This I interpret as they had been diagnosed by health care professionals with TS before the age of 14. The study took place at the Yale Child Study Center Tic and OCD Outpatient Specialty Clinic.

The purpose of the study was to clarify how tic and Obsessive Compulsive Disorder (which I will shorten to OCD) symptoms progress throughout childhood and whether it can be predicted earlier on in childhood how severe the symptoms will be in the teen years and early adulthood.

The basis for this study is current knowledge that TS starts in early childhood and that half to two thirds of children with TS experience a reduction or complete disappearance of tic symptoms during their teen years and that at least one third of adults with TS have OCD as well.

The initial interviews with these 46 children were followed up on 3.8 – 7.6 years later. There is no explanation why the follow up interviews took place after a different number of years for each child. My guess is that the children were not all the same age when the study started and the authors wanted to conduct the follow up interview when they all were the same age. However, there is no mention of how old the children were when the study started, and how old they were when the study ended.

From the follow up interviews the authors learned that 85 % of the children reported a reduction in tic symptoms during their teen years. The average age with the worst tic symptoms was 10.6 years. 41% reported at one time experiencing OCD symptoms and that the worst OCD symptoms occurred approx. 2 years later than the worst tic symptoms. The authors also found that if the tics got worse during childhood the tics would get worse at the time of the follow up interview age. They also found that if a child's intelligence increased during childhood it seemed to be followed by an increase in OCD symptoms at the follow up. Unfortunately the article does not explain how the authors defined and measured an increase in intelligence.

Based on the findings of their study the authors concluded that OCD symptoms in children who have TS became more severe at a later age and were more likely to persist than tic symptoms.

## Disinhibited Thoughts #14

Today is October 20, 2001. On this day my status as a doctor will be officially conferred. Right now I sit with another 14 about-to-be-Ph.D's in the 2<sup>nd</sup> row of the tightly packed gymnasium at the University of Waterloo and listen to our convocation address. It is entitled "Making A Difference". Ever since my first year of undergraduate studies at McMaster University, after having just carefully (and illicitly) printed "*Ph.D. Countdown: Z Minus 9 Years*" in black magic marker on the corkboard above my cot in room 505 of Woodstock Hall Residence, I have wondered what this day would look like. It dawned as a day of deep reflection. The time spent. The MONEY spent! The people, and the experiences. The changes in what I know and, consequently, in whom I am. The personal sacrifices. I found myself thinking about my grandfather: gone now for over 3 years, I wonder if perhaps the only essential difference between us was a fortuitous Ann Landers article at the age of 18. I was, by dumb luck, granted freedom from MY life of symptom internalization and confusion, misperception, and depression. What inconceivable strength to live such a full 87 years bereft of explanations or help. What a brave man.

At one time in my life I declared with wry pessimism that, should I actually make it to my doctoral convocation, a piano would likely fall on me as I cross the platform to at long last claim my prize. As the day loomed close, however, my thoughts instead strayed to something decidedly less ominous – whether or not I would suppress my tics as I accepted the degree. 'Understandable reactions' be damned – I didn't want to get laughed at. Not today. Not when my family sits in the audience and shares in the experience with me. Not when I've worked so hard for so long – shouldn't there be some kind of atonement? A collective unspoken attempt at reparation (partial as it may be) offered by attendees who recognize my right to dignity in this hour? My grandfather cried when he saw my first tentative public tics. At the time (so long ago now), lost in my own turmoil, I assumed the reaction to be borne of dismay and embarrassment of me. Now I understand he may have felt consumed with undeserved guilt.

Then I remembered one of the reasons why I tic so openly now on a daily basis. To make people think. To challenge preconceptions. To educate others in TS and, in so doing, ensure that they spend their knee-jerk, often unflattering (to all concerned) reactions on me instead of on another. To ease the lives of others as a result. To Make A Difference.

I felt chagrin for faltering enough to spend any time dwelling on this decision. When my name was called I strode across the stage in the same way that I live my life, and as the same person who achieved this distinction. Disinhibited. I vocally ticced as the doctoral hood was positioned on my shoulders. I stuck my tongue out at the Chancellor, who stood to meet me and shake my hand. My newly donned cap and tassel wobbled precariously on my jerking head. And everyone applauded. Tears stung my eyes, but not in embarrassment or dismay. In pride. The woman sitting next to me

throughout the ceremony made obvious efforts to avert her eyes from me, and turned her back to me during the ritual shaking of hands and sharing of congratulations among graduands. I didn't care. Today is for you, grandpa.

**Until next time, my friends!!**

**B. Duncan McKinlay, Ph.D.**

**Visit "Life's A Twitch!" at <http://www.lifesatwitch.com>**

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**October 2001**

*Note: in this installment of Disinhibited Thoughts I make reference to an Ann Landers article featuring Tourette Syndrome. I had not read this column in years, and only recently dug it out of storage during the filming of a documentary on my life and work in order to see it through changed eyes. To my utter astonishment and delight I found that a member of the Tourette Syndrome Foundation of Canada (a parent of a child with TS) wrote the letter that prompted and largely comprised the article. The article appeared in the London Free Press in approximately April of 1992. I hope the author of that letter is reading this, and will contact me. I owe this individual tremendously.*

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## Fund Raising - Bingo

At our last bingo event, on May 16<sup>th</sup>, we had 15 volunteers. Eight of the 15 were Chapter volunteers. On April 28<sup>th</sup> there were 19 volunteers and 13 were from our Chapter. The remainder of the group is made up of friends of the volunteers who just want to help. Each bingo requires at least 13 people, but we look for a few more in case some can't make it at the last minute.

If you are interested in helping please contact Linda Johnson at 649-5092. Our next 4 bingo events are scheduled for:

June 16  
July 8  
August 31, and  
September 23

To date we have raised over \$5,000 to help with the work of our Chapter. The Chapter executive is currently planning how best to use these funds.

Some of the ideas on the table are: (putting education packages in schools, (promoting TS within the medical community including UWO, (research, (etc.

We would like to hear from you with your ideas.

**May 2006**

## Advocacy Training Program

The Ontario Association of Education Advocates ([www.oaea.ca](http://www.oaea.ca)), in partnership with The Learning Disabilities Association of Ontario ([www.ldao.ca](http://www.ldao.ca)), is pleased to offer a comprehensive and innovative course in advocating for children with special needs. The course will be presented on LDAO's state-of-the-art web-based distance learning platform.

This training is essential for anyone involved in the exceptionalities field such as:

- Parents/Guardians
- School Professionals
- Special Education Program Staff
- Residential and Treatment Centre Personnel
- Others who Relate to Children with Exceptionalities in the Schools

Beginning June, 2006, we will be launching our Advocacy Training Certificate Program. Participants will receive a Certificate of Completion from OAEA for our Parent Consultant in Education Advocacy course.

Following the course there will be opportunities for practicum work for those who want to increase their skills and perhaps work as parent advocates. Those who complete this phase of the training will receive a Certificate as an Education Advocate and will be listed on the OAEA Directory.

For early registration, savings and additional information contact LDAO. The cost of the Advocacy Training Program will be \$350 with a \$50 savings for early registration received by May 26, 2006. You may:

- Register online with Visa via the LDAO website <http://www.ldao.ca/courses/oaea> by following the instructions provided. Note: This option will be available by May 1<sup>st</sup>
- Call LDAO to register by phone with a Visa 416-929-4311 ext. O
- Send a cheque made payable to LDAO along with a registration form.

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## CPRI Brake Shop:

### Putting The Brakes On Rage

It is important to understand where rage (or intermittent explosive disorder) comes from. It is not the result of bad parenting or the child not trying hard enough. It is also not an example of the child being manipulative, calculating, or choosing to behave badly. Rage is the natural reaction that all people have when they are overloaded beyond their capacity to cope. Most people rarely, if ever, reach that point though. These children, because of the disorders they have, are frequently enduring more 'brain overload' than people

typically have to put up with. They do not have “low frustration tolerance” – they have more frustrations TO tolerate!

This doesn't mean those rage behaviours are 'ok' or should be accepted: the child who rages must be made accountable for his or her actions. There is no need to ask the question, “was that behaviour caused by the disorder, or was that the child”, because it is always both. It is always the child who is doing or saying these things that are unacceptable in the ‘real world’, but it is always the disorder that is making it so difficult for this child to cope with life's bumps without reacting in very negative ways.

Because of this, it is important to help these children decrease their ‘overload’, so that they can be the people they want to be, and react the way they would react if they weren't so overloaded. To expect a child to behave the way other children do when they are drowning in brain overload isn't fair; it is a set-up for the child AND for you.

**So let's give 'em a brake!**



**Find out what overloads the child, and find ways to avoid these things:**

-ensure a consistent sleep schedule; everyone is more overloaded when they are tired and these children will show it more because of the overload they are already trying to manage. Sleep clinics can offer strategies and/or medications. For the child who's “head won't stop”, a TV in the room (set by a timer to turn off on its own) can be a very helpful distracter from his/her thoughts so (s)he can fall asleep

-reduce the effects of any painful symptoms (e.g. massage or chiropractic manipulation) if tic movements are creating muscle strain

-explicit, consistent, and predictable structure helps these children feel more control in a life where they have little internal control. Implement routines that become habits and so therefore rely less on memory. Use pictures or other visual ‘cues’ so that the child can always see what the day is going to look like. Avoid surprises – even ones intended to be positive can quickly overload an unsuspecting child!

-everything in life can't be predictable; if something unexpected comes up, use ‘soft’ transitions. This means that you give warning time to the child that a bump in the road is coming. A helpful technique is the ‘good news/bad news’ strategy: say, “the BAD news is that we are going to have to stop doing this soon. The GOOD news is that you are the FIRST ONE to know about it, and so we have a chance to get ready for it”.

-use the method of ‘collaborative problem-solving’ to compromise on decisions that would lead to

overload. This is a method developed by Dr. Ross Greene and is described in his book, “The Explosive Child”.

-if a brother or sister and this child are like gasoline and fire, plan to keep them as separate as possible. Individual trips, rearranging car seating plans so these children aren't sitting beside each other, or not having bedrooms next to one another are a few ideas that other parents have used.



**Learn the signs that the child is getting overloaded, and teach those signs to him/her:**

- common ones are:
  - getting very quiet
  - breaking eye contact
  - retreat; attempting to leave the situation
  - biting nails; agitated
  - pulling into/chewing on clothes
  - monosyllabic responses
  - speaking in monotone
  - less patient
  - increase in symptoms (i.e. MORE sensitive to touch/movement, MORE hyperactive/impulsive, MORE obsessive/anxious)

-keep track of rage episodes: do they always happen on a certain day? Or at a certain time? With certain people? When the child is doing a certain activity? If you find a pattern, you and the child can play scientist together to figure out what is different about THAT situation versus situations where they DON'T get overloaded. **An excellent predictor of rage episodes is when the child is required to “change gears” or shift into another activity.**



**Don't accidentally become part of the problem!**

-beware the ‘set-up’: consider sensory sensitivities, obsessions, tics, and other symptoms when planning to take a child to a particular environment. If the environment will be incompatible with the symptoms, this doesn't mean the child can't go but it might mean that some accommodations will be necessary. For example, plan to go for a shorter period of time, or bring ear-plugs, or ‘case the joint’ for available escapes/places to take a quiet break.

-mistaking brain overload for a power struggle will lead to very ugly results! Don't force eye contact, raise your voice, or touch the child unexpectedly when you see the signs of brain overload!

-even giving a child a hug when they are overloaded is a bad idea: GOOD or WELL-INTENTIONED stimulation is still stimulation, and makes the overload worse. Talking 'too much, too soon' about the situation is also a bad idea for the same reason – this can draw out the overload longer. Also, the words will not have the impact you hope them to have during the overload, no matter HOW appropriate or well chosen those words are!

-If a child has reached overload, the only thing to do is to allow it to pass (restraining and/or removing the child to a safe location if necessary, and keeping words to a minimum). You'll know it's over with when the child chooses to approach you again, or leaves his/her haven (what a 'haven' is, is explained below). This is not fun for you OR the child; this is why doing everything possible to allow it to pass as quickly as possible is desirable. Of course, preventing an overload before it happens is always the BEST plan!

jostle, will spill that water and make a mess. This mess is the rage that you want to avoid. Each of these strategies lowers the water a teensy bit, but each extra demand on the child or each situation that increases a child's symptoms raises the water a teensy bit. The game is to always be taking more water out than you are putting in – if the water never reaches the top, then rages will no longer occur! Keep in mind that while a person with a full beaker SEEMS to be very angry with you, and this can make you very angry with them, don't be fooled! The REAL enemy is that full beaker – and as long as the two of you are duking it out, it wins. However, getting wise to the games the overload in this beaker is playing allows the two of you to stop fighting one another, team up, and beat the overload!

Once you begin to play this game, you start to pick your battles carefully – you realize that some things just aren't worth doing or getting excited about if it is going to take up a lot of space in that beaker. It can even become a way of making life choices – some people have chosen the community they are going to live in based on how much it fills their beaker. I did that – I have a pretty full beaker too! I've learned how to keep it from overflowing and making me rage, though, and so can your child.



#### **Learn ways to 'lessen the load' again:**

-adults give themselves quiet space all of the time; sports teams take time-outs to re-strategize in order to win the game. Teach the child to use time-outs like this: as a valuable tool rather than something that happens when you get in trouble. **Time-outs should NOT be used as a punishment!** Instead, model going to your room to deep breath or to distract yourself with something interesting. Afterwards, share how you feel and act and think differently when you are no longer overloaded. Help the child to learn how to recognize when (s)he is no longer overloaded too: everyone is a little bit different. Be flexible in the length of the time-out; it ends when the load is light enough to manage being around others again.

-having a haven is very important. This is a quiet space to 'recharge' that is entirely under the child's control. When (s)he is in there people leave him/her alone or ask permission to come in, and the child can keep this space however (s)he likes (messy OR very clean!). Again, given the lack of control that the child feels over him/herself this helps to compensate by giving more external control to the child. Everyone needs to feel a certain amount of control in their life to be happy, and avoid the depression and anxiety that leads to overload.

It is important to realize that none of these strategies, on its own, is the 'silver bullet'. These and many others all work together to decrease overload enough to avoid rage episodes. Think of it as a game; picture a beaker that is almost full of water – so full that any more water, or a little

© 2004, Dr. B. Duncan McKinlay, Psychologist  
Putting The Brakes On Organizational Difficulties

### **TS in the News**

On Sunday, February 12, 2006 The Burlington Post headlined a story as "Living with Tourettes – Two educational DVDs help promote understanding of complicated disorder." This 1000+ word article was written by Tim Whitnell, a staff writer for the Post.

The piece opens with

If Gord Brown merely sneezed a lot, most people would understand he has no control over it and (would) likely have some degree of sympathy, possibly offering a 'bless you'.

However, when Brown goes on a vocal odyssey alternately whispering, talking or shouting words and phrases – some of them seemingly odd or out of context, others extremely crude and shocking – he likely receives little understanding, a lot of stares and snickers and a wide berth in public from strangers who don't understand his situation."

In his private life, Gord is 45 years old, is not married, owns his own home and has worked for Canada Post for many years. Gord is a Director of the Tourette Syndrome Foundation of Canada and chairs the Adult Issues Committee. He is also President of the Kitchener-Waterloo Chapter of the TSFC. In his public life, where he spends



many hours leading self-help meetings, in-servicing schools and appearing in public as an advocate for people with TS, Gord has recently appeared in a number of news articles and is being featured in a couple of upcoming TV spots.

The occasion that precipitated this news article was the first meeting in more than a year of the Hamilton chapter being held at the Burlington Art Centre. Those present viewed the two latest video releases from the TSFC.

The writer goes into a good amount of detail to describe the waxing and waning of tics, general statistics such as age of onset and male vs. female and gives a fair description of what it is like to have TS.

Also in attendance at the Burlington meeting was Jay Thomblinson, a 37 year old independent chartered accountant, who has a relatively mild form of TS. Jay talked about the newly released videos from the TSFC and was quoted as saying "Hopefully, it dispels the myth that we all swear." Jay and Gord are two of the people appearing in the video "A Journey of Discovery" which features adults talking to adults about TS.

Most of the video "A Journey of Discovery" was filmed in London when we hosted the annual TSFC conference in 2003.

Also mentioned in the article is another person who appeared in the video, Jill Solomon, of Montreal, who attended her first ever TSFC conference in London. In the video she admits to her peers that this (the London Conference) was the first time she had talked about her TS in any depth since her childhood diagnosis.

The last paragraph gives a promo to our most recent publication, a book titled "Understanding Tourette Syndrome: A Handbook for Families."

I rate this article an 8 out of 10. It loses 1 point for not being national and it loses another point for misspelling Jay Thomlinson's surname.

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## TSFC Annual General Meeting And National Conference

The TSFC Annual General Meeting (AGM) will be held in Edmonton, Alberta on Saturday, September 16, 2006. If you are a voting member you are entitled to vote on matters brought forward at the meeting. Prior to the September meeting you will receive an official notice of the meeting and a proxy form that you can use to allow your vote to be counted by someone else in your absence.

You can:

- attend the meeting and vote in person,
- assign your vote to the TSFC National Secretary who will vote in favour the Board of Directors' recommendations,
- assign your vote to the London Chapter's executive committee.

If you don't plan to attend this AGM in Edmonton, please do return your proxy as we need a certain number of votes to declare the meeting official.

The conference will open on the evening of Thursday, September 14 and run through the closing dinner and dance on Saturday evening.

Details of the conference aren't quite ready yet but we can tell you that this will be an International Symposium and not just our regular conference and that this event is in celebration of the Foundation's 30<sup>th</sup> anniversary. There will be a medical track, educator's track, general track, adult track, children's and youth programs and, Oh, of course options for activities at the famed West Edmonton Mall.

Formal programs will be mailed to members as well as being available on-line at [tourette.ca](http://tourette.ca).

*PS. If you wish your vote to be used by the London executive, send your proxy to:*

TSFC  
Box 28084  
London, Ontario  
N6H 5E1.

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## Volunteers Needed New TS Video

CPRI has contracted Andrew McKinlay, at AVC Consulting to produce a new "London, Ontario" video about TS. As of this writing there is a considerable amount of superb, clinical footage in the can and they are now looking to add some real life "flavour" - stories from families, individuals with TS, parents and others.

We have volunteered to help with this part of the video and currently have a mother/son team and two adults scheduled to appear.

This is a great opportunity to have our Chapter recognized and to gain some experience for the would-be actors, hams, producers or directors in your family.

If we have twiggged your interest in being part of this video, please contact me at [rayrobertson@hotmail.com](mailto:rayrobertson@hotmail.com) or leave a message at 519 457-4586.

An interview would take very little time and if you don't know what you would say, that isn't a problem. Andrew is good at

what he does and he will prompt you. Or if you have message you want to get out, well, you're the actor.

Ray

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## Interesting

From David Frum's Diary of July 1, 2004 is this paragraph, touching on - - - well you read it:

"In honor of Canada Day – Dominion Day as I still call it – one last go-round on Canadian subjects. Berkeley economics professor and blogger Brad DeLong objected to my observations about Canadian income levels. DeLong served in the Clinton administration, and is the author of an extremely interesting economic history that he posts by chapters on the Internet: all in all, a very smart guy, even if he has been driven into the intellectual's version of Tourette's syndrome by President Bush. At least he hates Noam Chomsky too. Anyway, DeLong disputes my claim that the cost of government has depressed Canadian living standards since 1993."

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## Membership Renewal

Your membership is important to us.

When you renew your membership, you are telling us that we are doing something right --- you are finding value in what we are doing.

If you haven't renewed for 2006, please do.

Send in the form that was sent to you. Include your payment.

If you don't remember if you have renewed, call 1 800 361-3120 and ask.

If you have lost or misplaced the form just send us your name and address and \$35.00 and we will renew for you.

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## Growing Up With Undiagnosed Tourette Syndrome: Part 2

By Gerard Johnson

As I stated in Part 1 of this article, it is my opinion that knowledge and education about Tourette syndrome (TS) and its' associated disorders is paramount in dealing with this often misunderstood neurological disorder. There are many books written about TS by experts far more learned than I will ever be. I am not an expert on TS and my article is based on my personal experience and understanding of TS. Please

seek professional opinion and help if you suspect Tourette syndrome may be a factor in your life or in your child's life. My search for knowledge about TS is incomplete and ongoing. Part 2 of this article is a continuation of a reflection from my adult perspective of growing up with undiagnosed Tourette syndrome.

I managed to function well in primary school, despite my many vocal and motor tics. I focused my attention on schoolwork and was an A+ student until grade 5. In grade 5 we had a change of teachers about 1/3<sup>rd</sup> of the way into the school year, and I found the new teacher difficult to understand. She seemed angry a lot of the time and no one liked her. Then, a couple of months later, we moved to a different area of the city and I was thrust into a foreign environment that was scary and unnerving for me. My grades had begun to suffer earlier that year and now they dropped even more, so I was only getting Cs and the odd B.

Printing had always been a challenge for me since I had poor small motor skills but once we began cursive hand writing my skills were really stretched to the limit. My hands and fingers often cramped as I held my pencil with a "death grip" that often caused the lead to break. I had to erase my spelling mistakes so there was no trace of the error, which led to my making a lot of holes in the paper as I erased over and over. Then I had to start over with a new page. This problem was only exacerbated once we started using fountain pens in grade 7. What a mess those things made! I spent many hours trying to get rid of unsightly ink blots! I made a lot more holes using those blue ink erasers. I didn't know the cause of my dilemma was Tourette syndrome and OCD related, I only knew my work was sloppy and messy looking so it had to be fixed.

One positive that came from my OCD was that my attention to detail was such that I always had great title pages for my projects. My stenciled letters were perfectly centered and all drawings and colouring were precise and accurate. The negative part of this is the time it consumed to do these "works of art" that could have been spent doing my other homework or playing. Also the tedious repetition of doing things "just right" was getting to the point that I hated school and I hated homework because it took me hours to finish things my friends did in less than an hour. I ended up with very low self esteem and little self confidence. I thought that I must be stupid because I was so painfully methodical that I was slower than other kids. It wasn't because of a lack of understanding it was a need to get it right that took me so long to complete even simple tasks.

Whenever I ventured into sports I was always the last player picked for the teams. I lacked the physical co-ordination and motor skills required for athletics. I grew to hate gym classes because it always revealed me at my most awkward, drawing unwanted attention to myself. I wanted to be invisible so people didn't look at me and see my strange movements and facial grimacing. Put all these things together and you get a messed up kid who is afraid to let anyone know what they think or feel out of fear and misunderstanding.

As an adult I now see where some of these things led me into the type of thinking that is not conducive to success in life. I had negative feelings about myself a lot of the time. I felt people were laughing at me, even if they weren't. I isolated myself from people and had a hard time developing relationships because of my fear of rejection. Growing up I had a really difficult time with second guessing myself all the time and was afraid to make a decision that might end up causing problems. I avoided responsibility because of my lack of confidence in making a decision about even insignificant issues. I contented myself with staying in the background, doing only enough to get by without drawing undue attention to myself. I was always self conscious, anxious, worried and afraid. These were some of the things that OCD managed to throw at me on a daily basis. When I was moody and sullen it was because I was worried about troubling thoughts that I couldn't get past. I never knew why I felt these things and couldn't give my parents any answer for my moods except, "I don't know!"

I doubt that any of this is really constructive in helping anyone with a child who is exhibiting things similar to what I was going through, but I do hope it can bring some small measure of understanding that the child going through these sorts of things is having severe difficulty adjusting to all the normal things that are going on in life while struggling to cope with their extra helping of issues. There is plenty of help available to those that want it. There are programs available through facilities such as CPRI and their "Leaky Brakes" program. There is the TSFC and their resources and materials to help educate and understand TS and its' related issues. Our local chapter's monthly parent support meeting is a place to meet other parents dealing with helping a child deal with TS and the problems it brings. I hope I have illuminated some of the mystery and welcome any comments or questions. Email me at: [gerard.johnson@sympatico.ca](mailto:gerard.johnson@sympatico.ca)

This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Ray Robertson. Anyone wishing to make any suggestions or comments about the content or if you would like to contribute an article for inclusion to the newsletter, please contact Gerard Johnson via email at:

[gerard.johnson@sympatico.ca](mailto:gerard.johnson@sympatico.ca)

Visit your London Chapter Web Site at:

[www.tourette-london.ca](http://www.tourette-london.ca)

*"The information provided on a particular medication and/or treatment is individual. Please consult your physician for the best treatment for you. Opinions expressed in the material printed in this publication represent the opinions of the author and are not necessarily endorsed by the Foundation, nor does acceptance of advertising for products or services in any way constitute endorsement by the Foundation. Every effort has been made to locate the copyright owners of the material quoted in the text. Omissions brought to our attention will be credited in a subsequent printing. Grateful acknowledgement is made to those publishers/authors who asked that their ownership be noted."*

