

### President's Message

In May 2005's newsletter I posed two questions to two adults with TS. The second question I asked was:

"If you could personally direct TS research into an area that would help others, what would that research be?"

The adult who replied regarding social skills problems said "I would probably try to direct the work into identifying the source and exact cause of our behaviours, tics, rages and all" and find a way of "obliterating" them once and for all.

When I began writing about what we would do with a cure if we had it, I talked about some people who wouldn't accept the cure, but I also mentioned that there were others who would be quite happy to "obliterate" their TS. As an adult with TS this person said he would like to see the cure applied at the first sign of TS "but given a choice "FROM DAY ONE", I believe many people would opt out."

Applying a cure at the first sign of TS would negate the need to look for the "positives that come with TS" in the child and would get around the problem of parents wishing for a cure when that wish would imply that they are not content with their child's imperfections.

I recognize that there are long lists of ways that kids with TS are better than others. Are these statements that TS kids are kinder, more creative, more sensitive, etc just put together to make us all feel better? Couldn't our children have these same gifts if they didn't have TS?

As parents of children with TS what could we wish for in the way of research. Could we wish for something that would eliminate the bad side - the suffering - and still keep what we see as the good parts of our child's TS? How do we turn our child's experiences into a wish for other children? Could it be that no child ever again will have TS? The common bond of Tourette Syndrome has been the source of many friendships and these types of bonds would never be formed again. But maybe friendships made on soccer fields would take their place. I'm not sure I buy that.

What do you think about the direction of TS research? If we, in Canada, had money available for research how should it be used?

*Ray*

### Asperger Syndrome And Tourette Syndrome

For more than 2 decades, researchers have commented on the co-occurrence of Tourette Syndrome (TS) and autistic spectrum disorders (e.g., autism). The results of many studies conducted in the 1980's and 1990's suggested that the rate of TS in autistic children was higher than the rate of TS in the general population. In 1994, a new diagnosis was added to the group of autistic spectrum disorders, called Asperger Syndrome (AS). Although AS was first described by Dr. Hans Asperger in 1944, it has gained more widespread recognition in recent years. Children with AS are often characterized as being at the "high end" of the autistic spectrum, since they are higher functioning in many ways compared to children with autism. Although individuals with AS and autism share core diagnostic features, such as social communication difficulties, children with AS tend to have higher intelligence, better language skills and stronger daily living skills than children with autism.

Since 1994, there have been only a few studies looking at the co-occurrence of TS and AS specifically. Some researchers believe that there may be a higher rate of AS in children with TS. In the Tourette Syndrome Neurodevelopmental Clinic in Toronto, we began to wonder about this overlap several years ago, when we observed a number of children who met the criteria

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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.

## Aspergers Syndrome continued from page 1

for both TS and AS in our clinic. This led us to conduct our own study of TS and AS with a grant from the University Health Network Allied Health Research fund. The results of that study are now available and we hope to publish the findings in a scientific journal shortly. Overall, we did find a higher rate of AS in our clinic population. In fact, it was quite a bit higher. One of the reasons for this may be that the children who come to our clinic are quite complex, and may not be representative of all children with TS who are in the general community. Still, there is good reason to do more research to help us understand why these two disorders may occur together at a higher rate.

In our study it was very interesting to note how many symptoms of TS and AS overlap. For example, children with TS and children with AS (even without TS) both frequently report heightened sensory sensitivity, difficulty paying attention, different types of repetitive movements, obsessions and compulsions, and some learning difficulties. However, most children with TS do not report difficulties with social communication (e.g., making and keeping friends, interacting appropriately). This is an important area of skill deficit, which helps us to distinguish between TS and AS when we are making diagnoses. The results of our study suggest that making the diagnosis of TS and AS can be tricky because of the similarities in certain symptoms. It is important for clinicians to understand that some symptoms (such as those described above) are not unique to TS or AS, but can occur in both. Parents who feel that their child is struggling significantly in the social domain (e.g., having trouble understanding how to behave in social situations) should be aware of the overlap between TS and AS, and are encouraged to consult their child's physician regarding any concerns.

To read more about Asperger Syndrome, parents might find the following websites to be helpful:

[www.udel.edu/bkirby/asperger/\\_for](http://www.udel.edu/bkirby/asperger/_for) the Online Asperger Syndrome Information and Support (OASIS)

[www.tonyattwood.com](http://www.tonyattwood.com)

Jennifer Saltzman-Benaiah, Ph.D., C.Psych. & Trina Epstein, Psy.D., C.Psych.  
Psychologists, TSN Clinic

## Book Review

Making Allowances – Personal Accounts of Tourette Syndrome

175 pages

Published by The Bluecoat Press, Liverpool (compiled by Chris Mansley)

Most of us know that living with Tourette Syndrome can be a very isolating experience. Especially when it first surfaces in ourselves or a family member, it can send us reeling with despair, suffering, resentment, and the feeling of being alone in a world that doesn't understand. But we aren't alone; there are many others who have had the same experiences with TS, and there are as many ways of coping and triumphing over it as there are diagnoses. Hearing these other stories can provide comfort and hope for those newly acquainted with TS, and confirmation for those already living with it.

Chris Mansley, the editor and author of the first account in this book, was in his thirties before he was properly diagnosed. Those misunderstood years prompted him to compile this book of first-hand accounts written by people with TS and their families.

The eighteen stories in *Making Allowances* represent a range of different people dealing with Tourette Syndrome. A refreshing perspective is gained by reading accounts from such diverse lives involved with TS. Several are written by parents of newly diagnosed children, and chronicle their panic as relatively normal childhoods slide into sequences of unexplainable new behaviour. Parents reading these stories will recognize the discouraging interactions with the medical, educational, and social support systems, and also the relief of finding someone who can offer valuable information. Some of the children have offered short descriptions of their own as well. Several accounts come from people like Chris Mansley, relating frustrating decades of winding their ways through psychiatric wards before knowledge of TS became more available and diagnoses and correct treatments were triumphantly found in mid-life. Perhaps the most interesting accounts were from men and women in their retirements, who had no access to that degree of medical attention when they were young and have lived whole lives accepting their tics as "habits" or idiosyncrasies.

The contributors also have varying degrees of severity of tics and associated disorders. ADHD, OCD, autism, depression, and eating disorders are all discussed, with some particularly insightful descriptions of lesser known mental forms of OCD, and the combination effects of these related disorders.

As first person accounts, most of the stories are written in a very conversational tone. This makes the book easy to read, as if you'd just opened a letter from an empathetic friend. However, it does mean that the contributors are not experienced writers, and some of the accounts can be hard to follow, sometimes monotonous, and in a few cases self-pitying. But they all express hope, optimism, determination, and a desire for their stories to reach others going through similar experiences.

Reviewed by Jennifer Robertson

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

### "Leaky Brakes" 101

For the family member (including the adolescent child), spouse, friend, neighbour, bus driver, crossing guard, babysitter...or anyone else invested in learning more about Tourette Syndrome, Obsessive-Compulsive Disorder, Sensory Processing Dysfunction, Attention-Deficit/Hyperactivity Disorder, and the disruptive behaviours associated with these conditions.

*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, call (519) 858-2774 ext. 2171.

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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 are:*

March 9  
April 13  
May 11

Dear Doctor:

Over the years that our chapter has been facilitating parent support meetings one concern has been persistent. The topic of headaches has come up time and time again. Parents have shared stories about headaches but no-one has been able to direct us to any medical information that would satisfy these questions.

Some of the cases parents have described are:

Case 1: A girl, 6 years old, experienced severe headaches over a period of 1-2 years. She was seen by the family doctor for this condition and referred to a pain specialist. Around this time she was diagnosed with TS and also around this time the headaches stopped.

Case 2: A boy, diagnosed with severe TS, was going through various medical appointments was asked by a specialist "what would be the most important thing we could help you with?" The answer was "make the headaches go away."

Case 3: A man who realized that he has TS after his son was diagnosed with TS remembers the headaches he had as a child and still experiences today.

What can you tell our readers about and connection between headaches and TS?

**Answer:**

There is a connection between headaches and Tourette Syndrome (TS). A number of studies have shown that migraine headaches occur approximately four times more often in children and adults with TS than in the general population. But why does this occur? Are there certain features associated with headaches that link it to TS?

Although children and adults can experience many types of headache, the most common are tension-type headache and migraine. Tension-type headaches are described as a dull, long-lasting, diffuse ache that may last for hours or days. In contrast, migraine headaches are described as a throbbing, localized pain lasting hours accompanied by light and sound sensitivity, nausea and occasionally vomiting. Like TS, migraine headaches have a hereditary component. Approximately half of children and adults with migraine have a family history of migraine headaches. In children, the average age of onset of migraine is 7 years of age, although it can occur at any age. In some children, headaches resolve as they approach adulthood and in others they persist. Many studies have examined the relationship between psychological factors and migraine, but these still remain unclear. Some children have higher rates of anxiety, depression or perfectionist tendencies, although this is not true for all children with migraines. Migraines

often interfere with daily activities, causing school or work absences and impacting social activities. Although the cause of migraine is not completely understood, the brain chemical serotonin is felt to play a significant role.

How does this relate to TS? As stated above, migraine headaches occur more frequently in children and adults with TS, approximately 25%, as compared to only 6% in the non-TS population. In addition, approximately half of people with TS have a family history of migraine. It was always assumed that people with migraine headaches and TS had higher rates of obsessive-compulsive behaviours and anxiety. Serotonin, the chemical in the brain which was felt to have a role in migraine, has also been thought to play a role in obsessive-compulsive behaviour and anxiety; however, a recent study of children and adults with TS and migraine, showed no increase in obsessive compulsive behaviours in this group. More studies are needed to better understand the causes of these two disorders.

What does this all mean? In conclusion, children and adults with TS do have a higher occurrence of migraine headache (four times higher). Both disorders have a hereditary component. Both disorders may be associated with obsessive compulsive/ perfectionistic behaviour in addition to anxiety although in many people these features do not exist. In terms of cause, there may be an association with one of the brain chemicals, in particular serotonin. Thus, although there is a link, there are many questions to be answered regarding the connection between migraine and TS.

Dr. Mary Jenkins

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## Membership Renewal

January is time to renew TSFC memberships. If you did not receive your renewal form in the mail, contact our National office at 1 800 361-3120 or by e-mail at [tsfc@tourette.ca](mailto:tsfc@tourette.ca)

New this year is a Family Membership at a cost of \$55.00. It provides all the benefits of a single membership for the whole family. Each family membership entitles the family to two votes at Annual General meetings.

Single memberships continue to be \$35.00.

As a bonus – limited time only – each family membership will receive a copy of the new Family Handbook.

## Disinhibited Thoughts #13

On optimism...

I write this on a bad day. I sit in my back garden alone, musing over a phone-call just received from a TS mom with whom I have not talked in years. As I listened to her repeatedly compliment me I felt a hollow fraud – unworthy of any of this flattery. The awkwardness this poor woman felt once she perceived the absence of my past signature enthusiasm was, to me, a poignant display of just how challenging the last two years have been for me.

I've worked long and hard to become an optimist, and prefer that way of being. Optimists are good, constructive, healthy people. Yet more often I find I am right in my scepticisms of people and situations than wrong. And I very much WANT to be wrong. I LOOK for opportunities to be ashamed of myself for underestimating others, yet can't deny that those throughout my life who swore they would be the ones I could trust, those in whose arms I then cried in unabashed relief, were the people who hurt me the most.

An established body of psychological research demonstrates that depressed people are MORE realistic than happy people – quite literally science has shown that it is the *well adjusted* who have a distorted view of the world! But is there some way to reconcile a realistic appraisal of one's experiences with an outlook other than depression? Perhaps in doing so one discovers what true optimism really is.

Maybe true optimism is the strength to weather difficulties. Maybe it is hope. True optimism just might be an almost religious faith in the inherent goodness of others despite the crush of daily reality. If this is true, then the Real McCoy is not to be found in an armchair – it is not a brittle bubble unable to withstand or tolerate any jostling from contradictory input. That would be optimism by default, neither forged nor tempered for strength. That is an optimism that lashes out painfully when it finds itself jeopardized.

I tend now to actively avoid that brand of optimism. Not because I see my perceptions as somehow superior to it, and not because I resent it either. It is more because I don't want to sully it – I feel it would be selfish of me to disturb what must be a very pleasant place to be. Perhaps I would have lived, blissfully delusional, in a similar bubble had I been born into a reality or set neurology where it was plausible to do so. Of course I would not have near the awareness and knowledge I now possess – the cornerstone of my identity, and something I would no longer trade for anything. Odd what a double-edged sword realism can be.

Perhaps for some of us optimism isn't ever going to BE about blind positivism – selectively filtering out, denying, minimizing or otherwise eliminating negativity from our

lives. We can't. Maybe for us optimism is about continuing to get up and brushing ourselves of potential cynicism. And maybe that's something to be really proud of.

It is now a different day. A better day – one in which I have finished my Ph.D., and one in which a wonderful new person in my life is coming to visit for the week. I have since called that very worried TS mom back to reassure her that the Duncan she knows is still there – she just caught him on a bad day. I ponder these issues again today with a fresh perspective. Am I an optimist? I think so. I just needed to get up again.

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

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

**Visit "Life's A Twitch!" at**

**<http://www.lifesatwitch.com>**

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*August 2001*

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### Our Donors are Important

Donations from our members and often from those who are not members help keep our chapter running. These funds are used for things like printing and mailing our newsletter, keeping our telephone voice-mail open and maintaining our web site. Each year we send a representative to the TSFC annual conference and volunteer training day to help keep our volunteers up-to-date on TS and the many tasks that are carried out.

In addition, we support the work being done at the National level, which includes the creating, editing, printing, handling and revising of our 4 current publications – Educator's Resource Kit, Understanding Tourette Syndrome - A Handbook for Educators, Guide to the Diagnosis and Treatment of Tourette Syndrome and A Handbook for Families.

The London Chapter of the Tourette Syndrome Foundation of Canada thanks each of you who helped make possible these activities and more.


## CPRI Brake Shop:


### Putting The Brakes On Organizational Difficulties

Many people with Attention-Deficit/Hyperactivity Disorder (ADHD) have organizational problems. This may be because **their attention was wandering during the instructions, and so they don't know how to start, or didn't hear all of the steps involved** (thanks to 'leaky brakes' over their attention; see "Putting The Brakes on Inattention"). It may also be because, in order to organize your thoughts, ideas, or steps you need to be able to 'put the brakes' on urges to jump into whatever step first comes to mind. Doing that isn't at all easy for some people with ADHD (see "Putting the Brakes on Impulsivity"). **Without brakes over your impulses, you can't pause long enough to decide what the best idea for your plan is, or what the best way is to pull off that plan.**

Neither of these 'leaky brakes' says anything bad about your intentions. Even still, though, these leaky brakes may cause you to start with a bad idea, or start with something that you later have to do over because other steps mess it up, or do it in an order that ends up taking you a lot longer than it should have. That's what happens when a person has missed steps, and/or immediately reacts to each step that occurs to him/her. It doesn't happen because you are stupid or don't care or didn't know better or can't learn. It happens because, without those brakes working properly, your brain is impatient to get it done NOW!


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


 ***It is not surprising that these individuals often lose or forget school items at home, or home items at school! It isn't an example of the child or youth trying to avoid certain work or passive-aggressiveness. It is simply a lack of organization! A strategy to minimize these organizational demands is to have "doubles" of such things as textbooks and pencil-cases. By having a school-set and a home-set this reduces time wasted looking for lost items, going back for forgotten items, or packing to go from one place to another.***


 **Settle on particular places for certain items to be put** (e.g. a set spot for backpacks). Visually label that spot, and create a routine around it (e.g. the backpack goes on the hook by the door as soon as you return home from school, and this picture of a child wearing his backpack is there to remind you of that. There is a cookie sitting on the shelf above the hook waiting for you each day after you have finished). It will likely take time for such routines to BECOME


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routine...but it will eventually happen if you remain consistent.


 Simplify lengthier or more complex new information, **and break new skills down into simpler component parts** (called task analysis) in which earlier steps are mastered prior to progressing to later steps.

 Present **clear simple verbal directions about the sequence of steps** in a task, using words like 'first', 'second', 'then', and 'after'; when necessary provide a written copy of instructions or a model for review as required and have the student verbally rehearse the steps.


 Recognize that **the individual may have difficulty generalizing learned skills to apparently similar or higher level items requiring the same concepts.** For example, being able to extract information from one graph or table does not necessarily mean that she will have the same success with another more complex item. Similarly, success with double digit multiplication or division does not imply similar success when multiplying or dividing with hundreds. Despite the concepts being the same, the latter places increased demands on organizational and memory skills.


 Develop activities in which the individual has to **arrange a series of statements on a topic into an appropriate order** so that they make sense in a paragraph. OR, cut up comic book strips into individual boxes and challenge him/her to figure out what order they go into to make the funny story.


 Have the individual keep a journal; **writing accounts of his/her day at school, the past weekend or other events create a primary focus on organization** (sequencing events, word order, etc.). Having her **write step-by-step directions** about a favourite activity (so that others may enjoy it too) also provides practice in sequencing and organizing events.


 Have the student **read written work aloud** to help identify problems with organization, and positively reinforce editing for improved 'flow'. Reward completed work that shows good organization **by clearly pointing out what she has done well.**

 **Teacher-Specific:**

 **'Preparation to Learn'** – ensure that the student is ready to learn by telling him/her in advance what will be taught, or how new information will be related to previously learned skills (this provides meaning or context to new information).

 **Use models, templates, key questions, opening sentences and/or vocabulary lists to enhance organization of written work.** Ensure (s)he knows that paragraphs, essays, or reports need an introduction, a middle where information is contained and a conclusion or ending. Using multiple modalities to demonstrate the organizations of things is valuable; for example, colour coding for various essay components, or an exercise where students who represent different components of an essay (held on cue cards) figure out amongst themselves in what order they should stand.

 As the volume and complexity of information to be organized and remembered continues to increase, **key points can then be highlighted in one colour and secondary points with another colour** – a skill that can take some time to master. This highlighting could be done on computer: certain text-to-speech programs, such as **Kurzweil** (<http://www.kurzweiledu.com>) will allow a user to transform these within-text highlights into an organized, point-form outline with the touch of a button.

 Another software program, called **Inspiration** ([www.inspiration.com](http://www.inspiration.com)), can be used to visually plan, organize, and sequence. It can be helpful for solving certain types of math problems by visually mapping solutions in a diagram format, and then printing off this “recipe” to use when appropriate. It can also be helpful for outlining essays as described above. Using a mouse the student can create visual ‘bubbles’ in a brainstorming format, then link and arrange these bubbles. Finally, (s)he can add his/her own text, voice notes, or links to files or websites making this a powerful study tool. This assistive software package is available for under \$100.

© 2004, Dr. B. Duncan McKinlay, Psychologist

## Fund Raising - Bingo -

### Volunteers Needed

Our chapter has recently contracted with a local bingo hall to sponsor bingo nights as a means of raising funds. We have some exciting ideas about how we will use the money we get to help promote and raise awareness of TS.

Our first 2 bingos were held on November 1st and December 13th and although we don't have exact figures yet it looks like we raised about \$1000 at each of these events. With one bingo each month, bringing in over ten thousand dollars per year, we can make a significant difference in the awareness of TS in the London community.

Each event requires between 12 and 18 people for about 4 hours in an evening. For our first 2 events we had 7 volunteers from 3 TS families. The remainder of the crew was made up of friends. Our goal is to have these bingo events staffed one hundred percent by volunteers from families with TS.

Volunteers are needed. No experience is needed. Training takes about 10 minutes.

This project provides an excellent opportunity to give back to a cause that has helped your family in the past and to help other families that are in need today.

Our next seven bingo events are scheduled for:

March 5 - Sunday

April 28 - Friday

May 16 - Tuesday

June 16 - Friday

July 8 - Saturday

August 31 - Thursday

Help us show the community that we care  
about people with TS.

Contact Linda Johnson at 649-5092 or  
[lindajathome@sympatico.ca](mailto:lindajathome@sympatico.ca)





## TSFC's new video features "kids for kids"

"Tourette is Powerful" is a ten minute video portraying kids with TS intended to help other kids understand what it is like to have TS.

*A tic is a muscle movement or a sound  
(words or noises) you can't control*

The video takes the form of an interview with long-time TSFC friend and associate Kelly Haines and her puppets. The 5 kids shown in the video are kids who attended the TSFC conference in Vancouver in 2004. Many hours of footage were eventually distilled down to 10 minutes of what is some of the best portrayal of kids with TS.

*"I can do everything other people can do, just differently."*

This is a video that can:

- help newly diagnosed parents understand what their child may be experiencing,
- help grand-parents, uncles and aunts understand TS,
- help neighbours (children and adults) understand your child's TS,
- help your children's peers and others in the community and at school understand why your children do the things they do.

*Tourette Syndrome is an energetic burst of tics and twitches.*

Watch as Devon, Jessica, Jeremy, Thomas and Jacob share their experiences with Tourette Syndrome. Learn from the real experts. Hear a sibling describe his brother's disorder. Understand the unique qualities all these children possess.

*Tourette is Powerful*

To get your copy phone 1-800-361-3120 or access [TOURETTE.CA](http://TOURETTE.CA)

DVD copies are available for \$24 (member price is \$19)  
VHS copies are available for \$16.45 (member price is \$13.45)

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Next time (May 2006)

News about another exciting new video -- "A Journey of Discovery" features adults talking to adults about TS.

Also To come

TSFC's new Family Handbook



## TS in the News

On Tuesday, January 17, 2006 the "Dr. Phil" TV show did a segment on Extreme Disorders featuring a mother and father whose son was diagnosed with Aspergers at age 3 and Craig and Amy who talked about Craig's TS.

Dr. Greg Hipskind from Brain Matters Inc. appeared on the show and talked with Dr. Phil about Tourette's syndrome and his work in the area.

Dr. Hipskind displayed two brain images that showed blood flow from a normal brain and from the brain of a patient with TS. He then explained that the increased red areas on the image of the TS patient represented increased blood flow.

Dr Hipskind explained why these images were of value in his research:

"Well, the first thing that can be done in all of the cases that we're talking today is to get information about how the patients' brains are working. We look at these behaviors not as mental disorders - although they're listed in the book, the *DSM4*, which is the Bible of mental disorders - they're listed as mental disorders. We take a different view. We believe that all mental disorders eventually will be found to have a basis in the way the brain is working. So we look at the brain. We don't try to label them; we just look at different areas of the brain and we focus our treatments. Once we know the areas that are working or not working, we can focus our therapies to those specific areas of the brain."

He went on to say that we are not at the point where we can use imaging for diagnosis but that we are heading in that direction.

The bible of mental disorders that Dr. Hipskind referred to is the "Diagnostic and Statistical Manual of Mental Disorders, fourth edition" which reads:

### DSM4 Diagnostic Criteria:

A. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently. (A tic is a sudden, rapid, recurrent, nonrhythmic, stereotyped motor movement or vocalization.)

B. The tics occur many times a day (usually in bouts) nearly every day or intermittently throughout a period of more than 1 year, and during this period there was never a tic-free period of more than 3 consecutive months.

C. The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning.

D. The onset is before age 18 years.

E. The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington's disease or postviral encephalitis).

Dr. Hipskind's premise that "all mental disorders eventually will be found to have a basis in the way the brain is working" will be interesting to follow.

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## Interesting

The Exceptional Parent's 2006 Annual Resource Guide lists 273 syndromes

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## TSFC Annual Conference

September 15 and 16 in Edmonton, Alberta

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## Growing Up With Undiagnosed Tourette Syndrome: Part 1

By Gerard Johnson

Before I begin this article I need to say that 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.

This is a reflection from my adult perspective of growing up with undiagnosed Tourette syndrome. As I grew older and my symptoms became more pronounced, I tried to rationalize my actions and explain them without the benefit of knowing what was really "wrong" with me.

I suppose I first realized there was something different about me when I was age 7. I was in grade 2 and having trouble writing a test. My thoughts were racing and I couldn't focus on any individual question long enough to print my answers. When I read a question I read ahead and was actually thinking of the answers to 4 or 5 questions simultaneously, while being unable to focus on any individual answer. Although I tried to quiet my racing thoughts I was not able to and I started crying. My teacher came over and asked me what was wrong, but being only 7 I didn't have the vocabulary to express what was happening so I said there was a voice in my head that wouldn't let me write the answers to the test. Although my teacher recovered quickly from her initial reaction I remember the look of shock and surprise on her face. She told me to lay my head down and rest, that I didn't have to finish the test. That reaction frightened me and I learned that I should keep these things secret from other people, because they wouldn't be able to understand. I was certain that I must be crazy.

As I grew older I found I was doing some odd things. I was walking on the sidewalk but making sure I took two strides per sidewalk pad. Sometimes as I walked along a picket fence I would touch each separate picket, and if I missed one, I had to go back and start over. I thought it was silly and it sometimes was annoying but it didn't seem like a big deal. What bothered me more were the clicking sounds I made with my tongue and the roof of my mouth. They were often loud and the downward motion of producing the click hurt my tongue when it scraped against my lower teeth. I also sniffed constantly and made snorting sounds in the back of my throat. These things were the most bothersome to those near me and I was often told to stop making "those noises" even when I tried really hard to make them quietly so no one would hear. My parents and teachers were always telling me to blow my nose, which proved ineffective in stopping the sniffing. I didn't know these were vocal tics and my finger tapping, and facial grimaces were motor tics. One particular complex motor tic I had involved a facial grimace. I would open my mouth as wide as I could while twisting my head and neck down, then sideways to the right, then up as I rolled my eyes up. I did this to relieve the feeling of stickiness in my eyes, with an accompanying slight itchy, burning irritation. Although this worked each time I did the tic, I found I had to do it 2 or 3 times every minute each hour throughout the day. This is a tic I had for many years and sometimes my jaw would lock

open on me for 10 to 15 seconds causing excruciating pain. It also caused many stiff necks, pulled muscles and headaches. At night as I went to bed my facial muscles were usually very sore and tired. One vocal tic I had was I used to hum. While working on homework I hummed. While walking or playing I hummed. While washing dishes I hummed. In school other kids told me to stop. At home my Mom would ask me what song I was humming, and I learned to camouflage my simple hum with a tuneful one. Then I learned to whistle. It was about 7 years after I could whistle that I learned that other people whistled by exhaling while I whistled by inhaling. After I asked 10 or 15 people to whistle for me I couldn't believe I'd never noticed that I was whistling wrong! Now I whistle by exhaling and it is much easier! All of these things combined to make me feel weird and different from other people. I was shy and kept mostly to myself.

Imagine feeling forces that are beyond your control, controlling some of your actions. You hear a noise and look to see the cause of it. It happens that the noise originated to the left of you, so you turn to the left and look. Now you have an overwhelming urge to turn to the right, to even things up! There was no noise coming from the right, but that doesn't matter. What matters is relieving the mounting anxiety that is building because you HAVE to look to the right. Now imagine you need to do the same thing but you have to turn most of the way behind you to see where the noise is coming from. Now you need to turn the other direction to "even" it up. Or you get the strange feeling you must spin on one foot in a circle. After you do, you need to spin on one foot the other way, to "even" it up. Then imagine you are 12 and there are 2 or 3 friends with you and you need to do these things, while walking 2 paces to a sidewalk pad, sniffing and snorting and spitting, then add in the odd facial grimace as well.

I went through this sort of thing often without the benefit of knowing there was a cause for it other than that I perceived myself to be some kind of freak and probably nuts! What a relief it would have been to know there was a name for these things and it wasn't my fault. I could have explained to the people around me that I had Tourette syndrome and it caused vocal and motor tics. I could tell them I didn't do these things on purpose to bother them. Even if they didn't understand at least I wouldn't have felt as badly as I did for doing the "tics" I now know I was doing. Instead I expended a lot of energy trying to suppress these things while in

class. At recess I was able to get rid of the pent up things by running and playing tag and laughing and yelling a lot. Outside I could sniff and snort to my hearts content and no one was bothered, no one that is but me.

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## 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 our 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 649-5092 or [lindajathome@stmpatico.ca](mailto:lindajathome@stmpatico.ca).

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## Research/Studies

In the previous 3 issues we chose to report on research projects that we thought would be of interest to you. Another criteria was that we could understand the technical language used to describe the project.

- We chose to report on Dr. Rob Nicolson's project because it was a home-town study. That is something we should be proud of and should recognize and thank Dr Nicolson for. This was the only grant made outside the USA in the 2004-2005 year. We tried to describe the study in terms that had meaning for the average TS family.

- In the article on Genetic Research we omitted a lot of detail that involved "DNA regions" and "chromosome 17 (17q25)" but attempted to demonstrate that research into the genetics of TS was progressing. This study also contained a Canadian element.

- "Tic Suppression" is something we all understand and that was the reason for including an article about this project.

Of the fourteen projects sponsored by the TSA in 2004-2005 we were only able to report on 3. That 14 studies were associated with and promoted by the TSA is an indication of the activity that is taking place world-wide. Some of the research projects that we weren't able to report on include:

- Identification of Proteins Involved in Tourette Syndrome – Year 2
- A Genetic Study of Tourette Syndrome in a Founder Population
- Precise Tracing and Manipulation of Striosomal Circuits
- A Double Blind, Placebo Controlled Study of Omega-3 Fatty Acids in children and Adolescents with Tourette Syndrome – year 2

It is no longer true that "no one cares about people with TS."

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## A Que ST ion

What made the grand old house tic?

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Tourette Syndrome Association  
National Conference  
April 7-9, 2006 in Alexandria, Virginia, USA

- international Meet & Greet reception
- many new topics and speakers
- special newly diagnosed Seminar on April 6
- youth program
- teen program,

Visit [www.tsa-usa.org](http://www.tsa-usa.org) for more information/

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."*

