



# Tourette Syndrome Foundation of Canada

## London Chapter

Newsletter

May 2007

### Presidents Message

Our lead article, "Barking but not mad" was given to us in mid 2006 by a member of our Chapter Advisory Committee with the intent that we use it in whatever way we could. Included here is the first of 3 segments of "Barking but not mad."

In Dr. Mary Jenkins' column she talks about movements we may have seen in our children during the very early years that may or may not have been associated with Tourette Syndrome.

Brigitte Heddle looks at recent studies that shed light on the ever present question "Is what I see part of my child's TS?"

I found both articles interesting in that they help us understand that while our kids may be diagnosed with TS, all of their behaviours may not be a result of their TS.

Jennifer took home the book "*Just Checking: Scenes from the Life of an Obsessive-Compulsive*" and found that checking for germs can be addictive, or is that compulsive or maybe it's just obsessive.

Make sure you have September 27, 28 & 29 marked on your calendar for our annual conference in Niagara Falls.

*Ray*

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### Barking but not mad.

*"Barking but not mad" was written by Alex Gunz, who has a Ph.D. in social psychology and is doing post-doctoral research at a university in Missouri. He has an interest in writing popular psychology articles and this is one of his first, written in early 2006. The article has been divided into 3 segments and included here is part 1. Parts 2 and 3 will follow in later newsletters.*

I have a friend who pokes himself in the eye, whips his head sideways, and occasionally screeches. He has a friend who frequently blurts "I am the cookie monster, yes I am." No, they don't belong to a fraternity.

What they have in common is a condition first described in 1885 by a Frenchman with far too many middle names: Georges Albert Édouard Brutus Gilles de la Tourette. He wrote about nine people whose behaviour was invaded by bouts of semi-voluntary "tics" - short movements and verbal expressions they had difficulty suppressing. At about 1% of the population, Tourette's Syndrome is surprisingly common. A smallish town could easily fill a gym with 'Touretters'. It took a long time for even the experts to realize it was so commonplace, which, as it turns out, is a testament to the incredible lengths people will go not to tic in public. Unfortunately, this suppression comes at a cost, paid for with hemorrhaging concentration, and, often, self-blame.

Tics come in endless variety. Head tossing, whistling, wall slapping, each "Touretter" has their own unique mix. My personal favourite is "giggle" (not giggling, just saying the word). Interestingly, tics change and evolve over time, and are even somewhat contagious. A roomful of open Touretters will pick up versions of each other's tics like

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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 Jenkins

### **Our Mission**

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

### **Our Vision**

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

### **Regular Contributing Authors**

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

*Barking but not mad – continued from page 1*

administrators swapping new uses for the word "synergy". Somewhere, a Touretter has read this paragraph, and is now saying "giggle."

Modern research has shown that Tourette's is based on a complex set of genetic predispositions, and starts young. It usually kicks in around age 6 or 7 with some blinking, facial gestures, sniffs, and throat clears. It tends to get worse for a year or two, peaking in severity around age 10, and then easing off during adolescence. Symptoms rarely disappear entirely (10% of the time), but they fade so much that almost half the adults with Tourettes don't even realize they still have tics. That said, tics can start as late as 18, and can remain severe one's whole life - often a long one, as the condition per se isn't at all dangerous.

The most famous attribute of Tourette's Syndrome is a compulsion to swear called 'coprolalia'. It is actually pretty rare. Less than 10% have it, and those are mostly the oldest and most severe cases, often with other "comorbid" conditions. It is not, however, barred from the deaf - they just sprinkle rude gestures into their signing.

### WHAT'S GOING ON?

But how does this mysterious syndrome work, you ask, and what does it feel like to have it? Read and understand this following few paragraphs without at any point blinking your eyes.

Here's an analogy: Presidents and generals have different jobs. Presidents are supposed to communicate with other nations and make broad decisions about the direction of the country ("we're building a wall / remaining neutral / invading France"). Generals work out how to actually DO all those things, and fuss about getting them done. Because there's only one president, s/he can't micromanage much, so the generals end up running a lot on their own.

No blinking now, don't be weak. Now your brain works the same way, except for 'President' substitute 'cortex' (the top layer), for 'General' substitute 'basal ganglia' (a collection of bits in your mid-brain), and

*Continued on page 4*

# Dear doctor

By Dr. Mary Jenkins

**Question:** From time-to-time we hear a mother of a child with diagnosed Tourette Syndrome (TS) talk about knowing from the time the child was 4-12 months of age that her child was “different.” It is reported that “*ritualistic behavior or habit patterns occur in up to 10% to 20% of normal infants and young children*” which means that these conditions are far more prevalent than TS. Does the 1-2% that develops TS come from this group?

**Answer:** In my clinical experience and from speaking to other health care professionals, many parents will report that their child displayed motor behaviours in early childhood that were “different” from other children. There is likely more than one explanation for this reporting. I will review three possible explanations to explain these phenomena.

## 1. Rarely tics may begin at an early age:

The typical or average age for onset of symptoms of Tourette Syndrome (TS) is 6 to 7 years of age, although there is a wider age range of symptom onset. Not infrequently, parents will describe behaviours that are similar to tics at a very early age, sometimes under 2 years. This includes eye blinking, shoulder shrugging, and arm movements. These occur in irregular bouts, similar to tics, and are often suppressed when the child is focusing. It may well be that these are in fact tics, that have started at a very early age.

## 2. The motor behaviours associated with ADHD may begin in early life:

In TS, approximately 50% of children have symptoms of attention-deficit/ hyperactivity disorder (ADHD). Typically the symptoms of ADHD begin before the onset of the tics. ADHD is usually not diagnosed until children reach school age, but in early childhood some children with ADHD may exhibit hyperactivity and impulsivity. They often begin to walk earlier than peers and are described as being “on the go” and much more active than their peers even before one year of age. It is possible that these behaviours of early ADHD behaviours are the “different” behaviours that parent of children with TS are referring to.

## 3. Stereotypies, “ritualistic or habit behaviours”, develop before 2 years of age:

Lastly, there are “ritualistic or habit behaviours” that have many similarities and some differences to tics. These have been termed **Stereotypies** and are repetitive movements that begin in very early childhood and persist as the child ages. The exact occurrence of stereotypies is not known, but they are felt to be common. Stereotypies occur in normally developing children in addition to children with developmental issues. Stereotypies most commonly occur before 2 years of age.

Typically, stereotypies are repetitive hand flapping, arm shaking, and hand clenching postures. Unlike tics they usually occur only in times of excitement, anxiety, or boredom. Often they appear when a child is watching a favourite TV program or listening to a favourite story. The pattern of movement is a constant, fixed pattern that is continuous, prolonged, and not associated with premonitory urges. Unlike tics, the movements do not change over time. Stereotypies are benign patterns of movement and usually do not bother the child. The child is often not even aware of these movements. The movements do not interfere with activity and the child stops the movements easily when distracted with another task. Unlike tics, stereotypy movements are stopped easily, without conscious effort, and there is no underlying urge to continue the movement.

Children with stereotypies have a greater chance of developing motor and vocal tics later in childhood. In one study of children with stereotypies, approximately 20% went on to develop a tic disorder. In the general population, only 1-2% of children develop Tourette syndrome. This means that children with stereotypies are more likely to develop tics and Tourette syndrome than children without stereotypies. However, it must be remembered that most children with stereotypies (80%) do not go on to develop tics or Tourette syndrome.

*Dr. Mary Jenkins is a Neurologist and Movement Disorders Specialist with the Department of Clinical Neurological Sciences at the LHSC University Hospital in London, Ontario.*

for 'France' substitute, lets say, the boy/girl/b-list-celebrity of your dreams. Your cortex does the thinking and planning, while your mid-brain figures out how to blink, smile and mumble "how'r you".

And yes, while we're at it, our cortexes often ARE absentee managers, leaving the running of large swathes of the show to the mid-brain. This is why we have so many conversations that start with everybody saying "how'r you?" and nobody remembering to say "fine." It is also how we can leave our houses intending to visit Grandma, and end up driving half way to work instead.

Still not blinking? Good. Now the cortex has a telephone of sorts for talking to the mid-brain. It's called the striatum, and comes with a "stop" and a "go" circuit. One of these initiates activities, and the other quashes them (I won't tell you which is which). Right now your cortex (president), having picked up strange ideas about not blinking, is imperiously telling your striatum's "stop" circuit to squirt your basal ganglia (generals) with inhibitory neurotransmitters (strongly worded memoranda). It probably has a bit of a war on its hands, though, because mid-brain's like to blink. A lot.

Unfortunately, wars are distracting for the executive branches of brains and governments alike - which is tragic when they have important psychology articles to read so you better go ahead and blink. I need you to pay attention to this next part.

Feel better? Good. Tourette's Syndrome (TS) is a condition where the "stop it" loop of your striatum doesn't work as well as it should. Dr. B. Duncan McKinlay, of the Child and Parent Resource Institute (CPRI) in London, Canada, describes Tourette's as having "leaky brakes." Imagine a car where your foot works fine, and the brake pad works fine, but the tube connecting them leaks. Your foot issues a command that is the brake pedal equivalent of "STOOOP!!" which is duly delivered to the brake pads as "maybe slow down a bit, if it's convenient."

The brake pads in cars only do one thing, but mid-brains are like Generals - they orchestrate manifold behaviours. Mid-brains can get you shouting or blinking like nobody's business, but what they don't understand is that you aren't supposed to do these

on, say, a blind date, or when some article tells you not to. Social awareness is El Presidente Cortex's job. But when the only brake cortex has on the mid-brain leaks, it either has to put up with a lot of embarrassing twitching and talking, or has to scream red-faced into the striatum, trying to get the blankety-blank message through. You probably had a hard time not blinking for a few minutes. Imagine struggling like that all day. Every day.

The experience of having a tic feels a lot like that urge to blink your eyes. Your mid-brain generates a "premonitory urge", a feeling that is often experienced as a physical sensation in a part of your body that you have to do something to get rid of. A Touretter with a shrugging tic might feel like there was tension in his shoulders, which he needs to shrug to release. It's similar to the urge to scratch a mosquito bite. The longer you ignore it, the stronger it gets, the more of your attention it hijacks, and the more scratching you have to do to satisfy it when you finally give in.

Some Touretters will suppress tics all day in public, and then try to find a quiet place to let out the explosion of tics that have built up. When that quiet place is the car ride home from school, unsuspecting parents can be in for a shock.

*Look for part 2 of "barking but not mad" in our next issue.*

## **Children and Youth Crisis Intake Team**

If your child is in crisis or requires counseling, help is just a phone call away. Ages 0 to 18 and Parents.

### **Partner Organizations:**

Adult Crisis Services  
Craigwood Youth Services  
Madame Vanier Children's Services  
Western Area Youth Services

### **What do we offer?**

- 24 hour access to telephone crises intervention
- Prompt follow-up appointments
- Brief counseling
- Intake and referral to services for parents, children and youth
- Support while waiting for services

Call 519 433-0334

## CPRI Brake Shop: *Putting The Brakes On Tics*

There are many things said about Tourette Syndrome that just aren't true – I think I should mention some of these things in case you've heard them and believed them:

Tics **AREN'T** caused by a lack of discipline, and punishment for tics will **NOT** eliminate the symptoms (in fact, punishment may make them worse)!

Tics are **NOT** done on purpose, although some tics can look purposeful if you do not understand conditions like Tourette Syndrome.

**Very FEW** people with Tourette Syndrome swear, and when they do it is in a special way that doctors who work with Tourette Syndrome can recognize.

In fact, **MOST** people with Tourette Syndrome have **VERY MILD** symptoms that aren't very noticeable at all!

Finally, it **ISN'T JUST KIDS** who have Tourette Syndrome – most people have it their entire lives, and it doesn't stop them from doing what they want at all! Like me – I'm a doctor who helps people with problems they are having (called a Psychologist) and I have Tourette Syndrome too!

Whenever people do different movements, or make different sounds, it is up to their brains to learn those movements and sounds and store them away for later so we don't have to learn them all over again the next time. In a way, **the brains of people with Tourette Syndrome work TOO well** – they learn and connect TOO MANY movements and sounds; not everything needs to be remembered for later, but those eager Tourette Syndrome brains don't seem to realize that! Eventually those brains have stored up **SO MANY** movements and sounds in **SO MANY** places they seem to **ALWAYS** be telling us to move and make noises! When that happens, we say that a person 'tics' or 'twitches', and has Tourette Syndrome.

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

It will be important for all members of the family to work towards acceptance of the diagnosis. The more you accept the diagnosis, the less of a problem tics can be! This is for a few reasons. The less 'worked up' family members become over symptoms, the less they will occur. Also, the more family members are able to identify symptoms as certain skill deficits rather than purposeful behaviour, the less apt they are to get into a power struggle and the more everyone will be able to work together to problem-solve issues without being drained by

undue emotion. Finally, acceptance of the diagnoses made and recognition that many of these behaviours are borne of these diagnoses rather than from wilfulness will present many new opportunities for coping success. An example of this is finding ways to allow a disruptive tic to come out in a modified, acceptable way rather than simply punishing the child for "not stopping".

You might be wondering – can anything be a tic? Almost! Tics follow 2 major rules:

Tics are made from things we do or noises we make **A LOT** – they are **frequent** movements and sounds

Tics are made from things we do or noises we make **THE SAME WAY EVERY TIME** – they are **stereotypical** movements and sounds.

Be careful then! Sometimes we might be doing or saying something over and over again, just joking around. If we aren't careful though, what we are doing or saying could become a tic!

Sometimes it seems like there is a devil in your head reading your thoughts and making the tics you hate the most the worst ones of all, and at the worst times! Don't worry though – that's not what is happening at all! It is **STRESS** that makes tics worse:

Things like being tired or hungry or hot are stressful.....and will make your tics worse.

Being in a room with a LOT of people or a LOT of stuff going on is stressful.....and will make your tics worse.

If you or other people pay a lot of attention to your tic or point it out all the time.....that is stressful and will make your tics worse.

If you really hate a tic, or are embarrassed by it, that is stressful too.....and will make your tics worse.

A strategy to try, then, is to pretend your tics are a pesky little brother or sister. Just as this little brother or sister will only bug you more if (s)he knows (s)he's getting under your skin, so will the tics. The best way to "get the tics back", or to "play a joke on those pesky tics" is to pretend that they don't bother you – laugh about them with others, or roll your eyes at that silly Tourettes.

Sometimes tics can make our bodies sore...and the more we are thinking about how sore our bodies are because of our tic, the more we end up doing that tic! Ways to help us not think so much about our bodies, then, is to take a hot bath or shower, to get a massage, to wear a hot towel, meditating, or to go to a chiropractor or acupuncturist. All of these things will help to get rid of any pain our tic caused us or help us to relax, so we aren't always concentrating on that tic.

Singing while listening to music, playing an instrument, or playing a hard video game keep you so busy your brain doesn't have a chance to tell you to do your tics!

Going for a long run, swimming, or riding a bike can 'use up' all that energy that normally goes into the tics – this means that you tic less! When you first start, the tics might still be there but eventually they run out of fuel and go away until after you are done exercising. These exercises can also help train you to be more aware of your body and to control it.

Having someone, alone or in partnership with you, talk to your classmates about what tics are (called a 'classroom in-service') can help a lot! Many times the problems that the tics cause have more to do with people's reactions to the tics than the tics themselves; people with tics are always surprised at how having tics just isn't "a big deal" to others once they understand what is happening. Creating an environment where you no longer have to feel embarrassed about ticcing, or feel the need to hold in your tics, can further decrease your stress and anxiety, helping you to concentrate more on school and tic even less!

On the next page is a technique called "Habit Reversal Training". It works very well for helping our brains to 'unlearn' some of this extra stuff it should have forgotten a long time ago. It can work even better than medications! It is much harder work than medications, though, and takes a while before it works really well. You need to be really patient and not give up if you are going to try "Habit Reversal Training", and you will only want to use it on those really pesky tics that hurt you, or make it hard for you to do schoolwork or the things you enjoy. The BEST TIME to start practicing your habit reversal is first thing in the morning, before you've even had your first tic!

Finally, it is not unusual for individuals with TS to be able to **suppress** ('hold in') their symptoms. Just as a person can (with limited success) fight off an ever-mounting urge to scratch an itch, people who feel a rising need to tic (called a "**Premonitory Urge**") can have a small amount of power over when and how they tic. Hence, it is neither surprising nor strange for teachers or friends to see a very

different 'you' than your parents do. In fact, suppression of symptoms in one environment tends to lead to making tics worse somewhere else (called a "**rebound effect**"). Therefore, the LESS tics one person sees, the MORE tics the next person will probably see!

Parents and teachers should know, though, that suppression is only a temporary solution; everyone eventually has to scratch their itch. Holding it in can increase symptoms of irritability, defiance, obsessiveness, and explosiveness while decreasing the ability to concentrate, meaning that suppression can cause more problems at school and with friends than the tics themselves would have! People with Tourette Syndrome sense that they must release these symptoms somewhere and somehow, and will do so where they feel most safe, secure, and cared for. Hence, rather than feeling like a "bad" parent or teacher if someone is ticcing in your presence, you can take pride in that fact. Because revealing tics is a measure of comfort with the situation and people around them, this is in many ways a compliment to you!

© 2004, Dr. B. Duncan McKinlay, Psychologist

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## Parent Self-help Meetings

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

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

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

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

Our next 4 meetings dates are:

June 14, 2007  
September 13, 2007  
October 11, 2007  
November 8, 2007

# What's New in Research

*By Brigitte Heddle*

In this issue I will take a look at an article that was presented at the Neurobiology of Disease in Children: Symposium on Tourette Syndrome in Los Angeles, California from September 28<sup>th</sup> to October 1<sup>st</sup>, 2005. The article is titled: Attention-Deficit Hyperactivity Disorder (ADHD) Comorbidity: A Case for “Pure” Tourette Syndrome? The author is Martha Bridge Denckla, MD from the Kennedy Krieger Institute in Baltimore, MD.

In this article Dr. Bridge Denckla is taking a look at a decade's worth of research that seems to indicate ADHD accompanying Tourette Syndrome has certain “unique and neurobehavioural differences and highlighted the importance of distinguishing children with this form from the 40% of children with Tourette Syndrome who do not have ADHD”. The author points out in her article that distinguishing between Tourette Syndrome alone and Tourette Syndrome with ADHD will prove useful for parents as well as the patients themselves in what she phrases “formulating expectations for short- and long-term prognoses”. I would have liked her to have been a little clearer here, but as she progresses through the article she does give several examples of what the differences seem to be between people with Tourette Syndrome only and those who have both Tourette Syndrome and ADHD and how that affects the children involved. Dr. Bridge Denckla also writes that it is important for researchers to make a distinction between the two conditions in their study methods or results will not be easily understood, perhaps even confusing.

With what the author calls volumetric magnetic image resonance imaging (MRI) it is shown that Tourette Syndrome without ADHD is anatomically different and less impairing from a Neurobehavioural point of view than Tourette Syndrome with ADHD.

For example, patients with pure Tourette Syndrome have enhanced motor speed (here I presume she is talking of motor skill meaning use of hands, fingers etc.), but patients with both Tourette and ADHD or only ADHD are slow on timed motor tasks. The author also mentions that children with only Tourette Syndrome seem to be spared of learning disabilities in written language only. Whereas written language is an area that Tourette Syndrome plus ADHD sufferers have problems with, those same patients do not have

problems with reading and math. She writes that children with only Tourette Syndrome show unexpectedly high IQ scores in relation to siblings without Tourette Syndrome. In her own research she has not encountered any children with only Tourette Syndrome who had any learning disabilities, but mentions in the same paragraph that 23% of children with Tourette Syndrome only have learning disabilities. The author explains that the neurological circuits in the brain that involve motor control, cognitive control (cognition being the ability to gain mental knowledge through the senses, experience and thought) and emotional control are different between people with Tourette Syndrome only and people with Tourette Syndrome and ADHD. She finds support for this claim in MRI scanning studies. It is interesting that only boys have been studied in the first study, but unfortunately she does not explain why. It is also a small study, which perhaps could mean that the results may be different if the study was repeated on a larger scale. She mentions later on another anatomical difference found in boys, but does not elaborate on possible gender differences. In another study the researchers found other differences in the brain anatomy between patients with Tourette Syndrome only and Tourette Syndrome with ADHD.

She moves on to discuss other testing that was done over a five year period in the 1990's. In this section she gets quite technical about how the studies were done, because the changes, to how the studies were done, seemed to affect the results somewhat. Of greatest interest is a finding on Executive Function (Executive Function meaning those abilities needed for problem solving, e.g. attention, planning, organization including ability to recognize and correct mistakes- this definition is from “Understanding Tourette Syndrome – A Handbook for Families’ published by the Tourette Foundation of Canada). In a group of children studied between 1990 and 1995 it was found that there was more executive dysfunction with children who had both Tourette Syndrome and ADHD than with children who had only Tourette Syndrome. In a study conducted between 1995 and 2000 more care was taken to screen out obsessive compulsive symptoms. In this study there was difficulty finding executive dysfunction. Although their findings were more subtle and even somewhat different than findings in older studies the findings

indicated that pure Tourette Syndrome patients had less executive function issues than the Tourette Syndrome plus ADHD and ADHD on its own. Since 2000 research has, according to the author focused more on ADHD.

Even the age of the study groups can affect results as one age group will be somewhat different than a slightly older age group

How a study is being conducted in all its details can make it very difficult to draw conclusions on the findings and it is therefore important that studies get repeated and analyzed to see if the method used is useful or confusing when it comes to interpreting the results. There are so many factors that can affect the outcome of a study for better or worse.

She admits that even after a decade of research there are still unanswered questions; one in particular is whether Tourette Syndrome plus ADHD is a distinct syndrome, even though it is very similar to ADHD without any other issues attached. The author writes that research since 2000 has mainly focused on ADHD and that this research is showing that children with ADHD have more learning problems and problems with recalling learned information.

In conclusion, the author states that given the fewer anatomic abnormalities in the brains of children with Tourette Syndrome only, a group that consists of 40% of all children with Tourette Syndrome only, it is important to let parents know that their children will not face nearly as many challenges as opposed to children who also have ADHD. She also concludes that the programs and treatments proposed to children with both ADHD and Tourette Syndrome can be the very same as offered to children with only ADHD.

So what do we get out of reading this article? Well, we find out that as a parent it is very important to get a clear diagnosis of our children's condition. Do they have Tourette Syndrome only or is there more to it, such as ADHD? The answers help us choose the best possible treatment for our children.

Researchers (and parents too for that matter) would likely, after reading this article, wish to see more research done, such as repeating the studies done in this article to see if the same results are achieved. Researchers would perhaps wish to evaluate the methods used to find out why some studies done

slightly different came up with different conclusions. Perhaps, if the funding is there, to do larger study groups. It is also very important that the individuals participating in further studies have been identified as either having Tourette Syndrome only or Tourette Syndrome plus, or study results could be misleading.

The author seems to indicate a gender difference, because she mentions twice that studies were done on boys only. It would be interesting to find out if there is a gender difference.

It would also be interesting to compare Tourette Syndrome only to Tourette with OCD and OCD only and see if similar findings occur.

It is clear that there is still a lot to learn about Tourette Syndrome and its related conditions so much so that it is important to support research in this area, and what better way than to do so by supporting the Tourette Foundation, which encourages research and acts as a forum for all who have an interest in alleviating suffering in people who have Tourette Syndrome.

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## Responses:

*In response to the article "Our Actions—Their Futures, Revolutionary Common Sense by Kathie Snow" in our November 2006 newsletter, Dr. Duncan McKinlay writes:*

Good lead article. My only concern was that, because it was obviously written for more PHYSICAL disabilities, some of it didn't quite apply to our population. The main example I mean is where she indicates that pulling a child from school for therapy won't help him in the long run. That might be true for physical therapy (just give him the wheelchair), but I think it undersells some of the treatments for our kids. ERP is highly effective as a treatment for OCD and does make an immediate and substantial improvement in quality of life and success for those individuals, and it IS a therapy one might need to be pulled from school for. Ditto for HRT and collaborative problem-solving. Learning these skills gives these kids exactly what Kathie Snow claims is more important than anything else: being able to play with other kids (they won't if you always blow up or have to have YOUR way), believing in yourself, and having what you need so you can do what's important to you.

*Editor's note: ERP = Exposure Response Prevention. HRT = Habit Reversal Training.*

## BOOK REVIEW:

### *Just Checking: Scenes from the Life of an Obsessive-Compulsive*

By Emily Colas

New York: Simon and Schuster, 1998

This book should come with a warning: If you are obsessive compulsive and have a tendency to pick up compulsions from others, Do NOT read this book! I haven't had noticeable symptoms of OCD in over 5 years, but while reading this book, I found myself worrying about the germs I might pick up, and then worrying about the return of OCD! However, if you consider yourself relatively safe from contamination, or are the friend or loved one of someone with OCD, then you'll likely find this book interesting.

And maybe a little stressful. *Just Checking* is a memoir of a woman with extreme OCD centering on germs, blood, and any fathomable method of disease transmission. She describes a period of about 10 years of her life, through college, marriage and child rearing, through short humorous vignettes describing everyday episodes. Not one of these episodes is untouched by her irrational and obsessive fear of contracting an illness.

She describes scenes such as interrogating waiters in restaurants about the paper cuts on their hands and the healthiness of their blood; an elaborate ritual her husband was forced to perform in order to take out the trash without the slightest possibility of bringing contamination back into the house; and submitting new toothbrushes to a rigorous examination of the sealing of their packages. She is rendered virtually immobile by these compulsions, unable (or unwilling) to leave the house or interact with anyone outside the family. The author does a fantastic job of portraying how stressful it is to live under those mental constraints, and how they affected her relationships and quality of life.

Short, amusing and easy to read, this book was an entertaining way to pass a few hours and become acquainted with the extremes of OCD. Now, let's see if forgetting my new cleanliness compulsions is as easy!

*Review by Jennifer Robertson*

## Disinhibited Thoughts #15

### Met a New Girl

Met a new girl. The chemistry was palpable. With the giddy thrill that can only come from being consumed with attraction I cast a hook and waited for a call. When it came she confessed to having spent that entire day reading my website. Not knowing much at all about TS, she said, combined with the intense feelings she was experiencing towards me very much scared her. And so she had prepared some questions for me. Questions about disinhibition ("will I be able to have any secrets from you?"). About rage ("what do you do, and how should I react?"). About sensory sensitivity ("will there be times I will touch you and you will be repulsed by me?"). And she needed some real answers before we could go any further.

Started a new internship. At long last the opportunity to "roll up the sleeves" and hone my clinical skills was mine to exploit. I couldn't wait to plunge headlong into the caseload. Within a couple of weeks I was notified that my three rotation supervisors wanted to meet with me, and that I "should bring some of my [TSFC] pamphlets". Evidently my tic symptoms had been less pronounced the day of my initial interview – my supervisors felt caught off-guard by my presentation now and had some reservations around my capabilities. How could I do a valid assessment given that my tics were so disruptive? How could I help others should my own neurology preoccupy clients?

In both situations above the questions were hard, fast, direct and pointed, and there were many of them. I did my best both times to respond in kind – without pulling any punches either. I told the girl that, yes, for better or worse I AM often disinhibited in voicing my perceptions of others, and so one requires a healthy ego and reasonable insight into oneself to handle that aspect of me. I told the supervisors that yes I don't often suppress my tics for a number of articulated reasons, I am quite comfortable with that choice, and by NOT constantly fighting my symptomatology it is considerably easier to effectively suppress in a circumstance where the tics would inappropriately interfere with the task at hand (such as an assessment).

What I felt begin to well up inside me in these situations was not resentment or anger or even a sense of discrimination. It was admiration of their honesty. Of their frankness in recognizing the important need to ask and learn about such things, and of the guts it took to follow through – people really make themselves quite vulnerable by exposing themselves in that way. I was grateful for the respect each showed me. It is easy

enough to dismiss a suitor or potential employee who has TS, based on what one thinks that diagnosis means. These people didn't allow their fears of the unknown, their assumptions of what TS is, or their shame that the disorder was influencing their choices stop them. They DID, however, afford me the honour of HAVING A SAY – they asked, listened, and thereby made informed decisions about me. And regardless of the outcome, you can't ask for any more than that.

Far from being brazen and explicit examples of the persecution and strife we must endure on a daily basis, and regardless of whether you despise, decry, ignore, lament or accept that the TS does raise issues that need addressing, people like those above are offering you dignity. Take it. Correct those perceptions that are

misguided and confirm those that are not. Assure and educate them. Get the girl. Get the job. If we ever want the general public to feel wholly comfortable with the differences of others we need to celebrate people like those above.

**Until next time, my friends!!**  
**B. Duncan McKinlay, Ph.D.**  
Visit "Life's A Twitch!" at  
<http://www.lifesatwitch.com>

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*January 2001*

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## Conference 2007

The Tourette Syndrome Foundation of Canada will hold their annual conference and general meeting of members in Niagara Falls, Ontario on September 27, 28 and 29 – Thursday to Saturday. This conference provides an excellent opportunity for families living in South-western Ontario to hear world class speakers talk about TS and associated disorders and to meet and talk with other families that share similar concerns of living with TS. You won't want to miss this opportunity as the next conference will be held on the east coast.

The conference will lead off on Thursday evening with registration, a reception and a choice of 5 workshops – mothers of kids with TS, fathers of kids with TS, adults with TS, teens with TS and their siblings and kids with TS and their siblings.

Friday will be a full day of information sessions with a variety of speakers beginning at 9:00 am and running till 4:30 pm. Friday evening can be spent on your own exploring the town or participating in one of the organized events. Because Friday evening events are optional, costs for these events are not included in the registration fees and must be paid separately.

On Friday, we will also host an Educator's day so be sure to inform your teachers so they may apply for funding.

Saturday morning will begin with the annual members meeting at 9:00 am. Information sessions will begin at 10:00 am and run till 4:30. The wrap up dinner banquet will get underway at 7:00 pm followed by some light entertainment and dancing. The banquet will be preceded by a social hour beginning at 6:00 pm.

The conference is being held at the Brock Plaza Hotel in downtown Niagara Falls. A block of rooms has been reserved for participants and will be available for booking at the special conference rate. Directions to the hotel will be available closer to conference time including parking arrangements. There will however be a fee for parking.

A teen' program and a children's program will run parallel to the adult programs on Thursday evening and during the Friday and Saturday daytime information sessions, but not on Friday or Saturday evening. Watch [www.tourette.ca](http://www.tourette.ca) for more details as they become available.

### If You Go

**Date:** Thursday, September 27, 2007 to Saturday, September 29, 2007

**Location:** Brock Plaza Hotel, 5685 Falls Ave., Niagara Falls, Ontario

**Cost – Full Conference including Banquet:**

Member Regular Rate - \$325.00  
Member Early Bird - \$300.00  
Member Late Rate - \$375.00  
Non-member Regular Rate - \$395.00  
Non-member Early Bird - \$370.00  
Non-member Late Rate - \$415.00  
Teen and Children's program - \$75.00 per day

\* Late rate applies after September 10<sup>th</sup>

\* Teen and Children's banquet costs are extra.

## Tourette in the News.

Media coverage of Tourette Syndrome seems to be somewhat inadequate when compared to coverage of conditions such as cancer and heart disease. A recent in-depth article on schizophrenia in a Toronto Sunday paper begs an answer to "why is this condition getting this coverage and we aren't?"

But looking at "TS in the News" from a different perspective, a recently completed update of our print media archives shows:

- there are 168 articles making up 350 pages of material
- stories come from newspapers and magazines across the country –St. John's to Victoria. A few stories of special interest are from US publications.
- the earliest article is dated February 1979
- included are: 1 article from 1979, 3 articles from 1992, 8 articles from 1993. The numbers climb from there.
- 17 articles are from the London Free Press

The first London Free Press story is from June 4, 1992. Debora Van Brenk, a London Free Press reporter, interviewed Dr. John Dubois and Dr. Tom Preston and met with a family from Chatham where she talked to a teenaged boy with TS. The article, complete with a picture of the young man from Chatham and side bars telling about the TSFC, appeared in the London Free Press on the morning of our first London Chapter Tourette Syndrome support group meeting.

The stories aren't always about TS, sometimes they are about another event that is newsworthy, but involves people with TS. For example, the closing of a Salvation Army group home that left the parents of a child with TS wondering what to do next.

The majority of the articles come from cities or towns that have TSFC chapters. Volunteers from chapters are able to get TS noticed by their local newspaper either by ingenuity or because a TSFC

event is happening. Most TSFC conferences have had a mention in the local paper.

Occasionally a story appears where someone is using TS as a defense for inappropriate behaviour. An article appeared in June 2004 about a male doctor who was defending his inappropriate behaviour towards both female nurses and female patients as being a result of his TS. A number of articles follow up this story.

TS has been cited as a defense for more serious crimes in both New Brunswick and British Columbia. Our archives have minimized these stories.

Most stories are of a human interest nature and many show the surprise of the writer that they have just now learned that such a condition exists. There are stories about celebrities – movie stars, baseball players, basketball players, soccer players, surgeons and psychologists – some who have succeeded in spite of their TS and some who have succeeded because of their TS. The Canada Post internal newsletter has recognized two employees who succeed in their jobs while coping with TS.

An archive is generally thought of as a dusty old space where crumbling pieces of paper are kept and no one is allowed to touch in case they should fall apart. Even if you get permission to use an archive, you must travel to where it is located.

Our archive is different. All of our stories have been catalogued, reproduced and made available to our chapter libraries across the country. The London Chapter has a bound copy of the archived material that can be borrowed from our library.

We must, however, include a disclaimer that any and all information included in our archives is the opinion of the writer and/or publisher of the individual articles and not that of the TSFC. For accurate information regarding Tourette Syndrome, consult your physician.

## Interesting

### The Cheese Popcorn Ritual

My 18 year old son Jamie has TS and OCD. Through the years he has developed many interesting habits. However the most unique of these creations has to be his Cheese Popcorn Ritual. Jamie has done this almost every night for as long as I can remember.

The ritual begins with Jamie pouring a cereal bowl full of Chester's Cheese Popcorn (it's got to be Chester's). He sits in the living room with a small table in front of him. Jamie takes a piece of popcorn and nibbles off the pieces that stick out, until he's left with a little ball. He places this ball on the table and grabs another piece of popcorn and trims it. Jamie continues to do this,

placing the little popcorn balls in groups of ten until he's reached 100. Jamie counts the popcorn balls and adds them to a running total he has in his head, writing the number in the air beside him. (He used to do groups of nine, but the numbers got so high, that he decided tens would be easier for him to keep track of). The current total is 97,800. Jamie then eats the popcorn balls starting with the smallest and working his way up to the largest.

Always find the humour in the unique children we have.

Carrie Kelly

### London Ontario Mini-golf Tournament

July 12, 2007 will see our chapter's 11<sup>th</sup> annual Mini-golf Tournament and Ice-cream Extravaganza. Come out to Windermere Golf Centre at 7:00 pm (or around that time.)

Tee-off times are informal as are the rules. Adults can play a round or two with the kids or just sit and chat.

Only the ice-cream is mandatory.

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

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