

Alexander's Story

"C" is for Courage

One of the things that inspires us as volunteers for the TSFC is the courage and dignity displayed by the people we meet who have TS and their personal stories of triumph. One such story follows, written by one such person, a grade five student named Alexander. One of our in-service presenters went to Alexander's school last year to tell his classmates about Tourette Syndrome. In preparation for Peter's presentation, Alexander wrote a personal letter to be distributed to his peers. This was for them to take home for their parents to read and because of Alexander's willingness to tell his story, 90 people learned about TS and tolerance instead of 30. Alexander's letter is reprinted with his permission.

Dear Parent:

I am Alexander and I'm ten. My birthday is March 7. I have dark hair and hazel eyes and live in Saanich. I live with my family in three homes - mom's, dad's and Bub's - and with my dog Jake and two cats. My homes are fun and cool. My hobbies are skate-boarding and biking. My special talents include courage to do daring stuff. My favourite subjects in school are P.E. and art. The subject I am best at is spellin. A famous person I'd like to learn more about is Tony Hawk. A place I would like to learn more about is the far side of the moon. Sport team I am part of is soccer. The most interesting thing I did last summer was I went to a cabin in Parksville at a really fun beach with our friends. Three things I bet you don't know about me are that my dad is a pilot, my mom is a flight attendant and my grandma (Bub) is an author.

By the time you read this letter you probably know that this morning we had a classroom presentation on Tourette Syndrome, given by a volunteer from the Tourette Syndrome Foundation of Canada.

The reason we had this presentation is because of me. I've been diagnosed with Tourette Syndrome. This is in addition to a diagnosis made three years ago of ADHD. These are big labels for a ten year old. ADHD is well known - I think my dog has it too. But Tourette's is not well understood. My family and teachers wanted all of us to learn about this condition.

FAMOUS PEOPLE with Tourette Syndrome include Mozart and Robin Williams, who, according to Oliver Sacks, the famous neurologist and author, seems to have some kind of *voluntary- Tourette's*. Perhaps he meant that Robin has learned how to channel his tics into brilliant comedy. This is good news for me because I love music and comedy.

MY TICS Some of mine include eating stuff not meant to be eaten, which drives my family crazy, biting my lip, making funny facial expressions, blinking and experimenting with different sounds. I will write and erase over and over making holes in the paper; I need to have things done a certain way. My sense of smell, taste, hearing and sight are very sharp.

I cannot control my tics and sensitivities but for the longest time I have worked very hard to suppress and hide them, which has taken a lot of energy. Now that I understand I have Tourette's, I am relieved. If I can help others understand a bit about Tourette's, maybe I can relax when my tics and obsessions are present, and let them come out, without worrying that I will get into trouble or be ostracised or teased.

Maybe you know someone who has Tourette's. If not, maybe now you will recognize it when you see it and be relieved that you read this story.

Thank you for reading my letter.

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President's Message

In our last letter I talked about people with TS who are not interested in a cure. I don't know if this represents a majority or a minority of those with TS. I don't have data to support either side. What I do have are interesting stories from each side.

There appears to be two groups of people in this category - those who are severely affected but have found the necessary means to deal with their TS and those who are less affected and have found their tics to be just something they live with day to day.

In the first group we have people who have made the TS news - familiar names like Dr. Mort Doran, Jim Eisenreich, Mamoud Abdul-Rauf and Dr. Duncan McKinlay. These are people who have "beaten the demon" and did not let TS keep them from achieving their goals. There are countless others in this group - brick-layers, retail sales-people, artists, social workers, teachers, postal workers, private entrepreneurs - people we may meet on a daily basis but we don't see their TS.

In the second group are those with a less severe form of TS. Once again these are people from all walks of life. They may experience only a few tics during the day or may experience a great number of less bothersome tics.

Both groups are primarily made up of adults. For children, coping with tics can be hard enough, but having to deal with the ever changing variety and severity of tics just adds to the problem. For these kids their number 1 wish often is, "I just wish it would go away."

For the majority of adults, changes of tics and changes in severity of tics happen less frequently than with kids. They have learned coping skills and are less affected by any teasing they may be subjected to by their peers.

One young adult reported on a conversation that two of her friends had had after she left to attend university in another part of the country. We all know our friends talk about us when we aren't around but we seldom get to hear about it. One of the friends had commented "I miss her twitches."

Not all adults are happy with the status quo. There are those who wish for changes in their own TS and there are those who wish for changes that would keep another child from experiencing what they went through. More about these wishes next time.

Ray Robertson
President, London Chapter

Miniature Golf - Family Fun Night - 2005 Update

TSFC Annual Mini-golf Tournament

Thursday, July 14, 2005 saw another of London's famous Annual Mini-golf Tournaments. Fifteen competitors took part in the fierce play which resulted in at least 3 holes-in-one. The boys rallied early to gain the lead however at the end the girls had the highest average score and won the grand prize.

But, the boys challenged the judging and tried to get the grand prize for themselves, saying the lowest average score should win. The judges were confused and eventually declared both girls and boys winners.

Those who came for the ice-cream were sorely disappointed. Even now, weeks later, its hard to believe that on one of the hottest days of the summer, ice-cream wasn't being served because it was too cold - frozen too solid was the story. However, the one single adult who was most in need of ice-cream was able to whine, cajole and beg, and 1 - just one - cone's worth of maple walnut ice-cream was carved out of the frigid tubs using specially heated scoops. Thanks to these servers for their heroism, otherwise the evening would have been a total disaster.

Also on the plus side, the course management gave each player a complimentary second 18 holes. I think this must have been where the scoring got confused.

Both adults and kids enjoyed the conversation after the golf. Older kids and younger kids paired off and talked about motor bikes, horses and paint ball while the adults swapped tales and talked about report cards and medications.

All-in-all, we can mark up another successful mini-golf tournament in London, Ontario.



TSFC London Chapter Administrative Committee

President Ray Robertson
Vice-president Gerard Johnson
Treasurer Linda Johnson
Director at Large Nadyne Gooding

Disinhibited Thoughts #11

I used to think that learning to accept myself was to be the final step in my personal climb to wellness. At first it seemed this intuition was correct -- benefits both expected and unforeseen materialized as belief in my own self-worth bloomed. However, with it came cynicism and disappointment in the world as I conceived it. I also detected an alarming fury mounting within me – fury at a planet that had for so many years wronged me incessantly and, I now believed, undeservedly. I felt myself hardening and, in so doing, jeopardized a very special relationship I was in. With the possibility of this loss came incredible clarity: a realization that if I'd almost driven away this angel I must be doing something very wrong. Maybe self-acceptance was only a way station – a plateau on which to rest before embarking on new and succeeding ascents. I had learned to accept myself. But now I had to learn to again accept everyone ELSE.

Yes there has been plenty of hurt. It IS justified anger. There WERE tough times in the past and they DID ache. It is not somehow small, weak, inferior or stupid to feel bitterness: there are totally valid reasons for this. But I must move on regardless. I cannot allow past interactions, or the assumptions they produce, to tarnish or squander new opportunities.

I have done so in the past: it was a protective function, and an understandable one. For a very long time this was an adaptive way to be – odds favoured that my actions or words WOULD be misinterpreted or reacted to in the most negative of ways, and I was scared to hurt anymore. It was safer to pre-emptively anticipate and react in order to dull the subsequent blow and avoid a rage borne of surprise.

I realize now that I'm reading from an old book though – ironically I was starting to put my walls back up just as others were ready to finally take theirs down. I have been diagnosed. People around me are now educated, aware of why I am the way I am, and ready to apply this new information. TS in general is so much better known and recognized today. I, through education and experience, have become a considerably different person who now elicits very different reactions than in the past. Now it is "safe" to be the loving person I've always wanted to be.

If I continue to assume the worst of new people and situations then it is MY behaviour that is now in question - now it is I who is not being fair to the WORLD. It's time for me to catch up to the circumstances and show forgiveness. In my heart and not just my head. If I damage my own future by not doing so this allows past

unfair acts to continue to win. They don't deserve to have this power over me.

I will not replace old assumptions with blind optimism: this only puts a new face on the same mistake. I will instead do my best to treat new situations with a clean slate. And if I do happen to be treated unjustly my newfound self-assuredness will lead me to DO something about it rather than endure it passively or fester over it heatedly.

It seemed appropriate that, having experienced this catharsis, I should send out a "Hello I'm back" correspondence to the many friends and family members I had feigned impenetrability to. It also seemed appropriate to take a chance on some new people I had summarily dismissed. I received in reply such openness, kindness and generosity I was ashamed to see how many people had been willing and waiting to show me affection if I'd only let them.

For one thing, I have this phenomenal sister I never knew I had. I can't wait to get to know her better.

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

February 2001

| How to Reach Us | |
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TSFC Annual Conference 2005

This is our newsletters last opportunity to remind everyone that the next Annual National Conference for the TSFC will be at the Delta Centreville, Montreal, Quebec, on October 20 - 22, 2005. A Preliminary Program And Registration Information Will Be Posted on the TSFC's web site. You can expect the usual world class speakers, an educators day, and programs for children, youth and adults. Make your plans for that weekend now so you aren't disappointed later. See you in Montreal!

Volunteers Needed

Our chapter is in urgent need of someone to review new books and write a short synopsis that we can print in our newsletter.

It wasn't so long ago that there were only a couple of books available on the subject of TS. The names of these books or even the books themselves were passed on to new acquaintances and everyone was up-to-date. Today we have more than 50 books in our library and new books are coming faster than we can review them.

If you are interested in writing one or more reviews for other members to read please contact Ray Robertson at 519 457-4586 and leave a message or e-mail at rayrobertson@hotmail.com.

Your reviews will be printed in our newsletter, posted on our website and made available to other chapters for their newsletters. Your review could even be picked up and published in the Green Leaflet, our national newsletter. Your name will be at the bottom of each publication – you could become famous.

PS. and part of your review will need to be your opinion on whether this book is worth reading and if so who should read it.

Support Meeting Report

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 4 meetings are:

Sept. 8/05
Oct. 13/05
Nov. 10/05
Dec. 8/05





As we are all aware the beginning of a new school year can have many challenges, especially for those families with a child newly diagnosed with TS or TS+. Are there issues that need to be addressed or resolutions to a problem that you believe might help somebody else going through some similar problem? Come and share your experience with us! That's what these support meetings are all about.

Our Resource Library is available during our Support Meeting. The Kids Klub meets at the same location and time as the Parents Support Meeting. (*Please see our website www.tourette-london.ca for a list of rules for Kids Klub*)

CPRI Brake Shop: Putting The Brakes On Inattention

Everyone has a hard time paying attention once in a while. It can happen for many different reasons: being bored or tired, not understanding what is going on, feeling afraid, hiding a problem you are dealing with, or not liking yourself very much. When people have a much harder time paying attention than their classmates a lot of the time EVEN WHEN THEY WANT TO, though, and this causes problems at school and other places, it is given a name: Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type, or ADHD-PI. At least that's what it's called nowadays – in the past it has been called Attention Deficit Disorder (ADD), and even Minimal Brain Dysfunction (MBD)! Both of these terms are now obsolete though.

WHATEVER you call it, it can be a real pain:


-  You might be told that you 'aren't listening', which is true, but people seem to think you are doing that on purpose!
-  They also might say you make "careless" mistakes...but that doesn't seem right, because you DO care!
-  You mean to finish something, but then before you know it something ELSE side-tracked you and you forgot all about the FIRST thing!
-  You lose things because you are paying attention to something else when you put them down, and so you 'forget' where they are!


AARGH!! WHY IS THIS HAPPENING??!!

This is why: most people have brakes to help control where they focus their concentration (called "**selective attention**"), how many things they centre their concentration on (called "**attentional control**") and the energy to maintain that concentration (called "**sustained attention**"). If these brakes are leaky, different problems can result. For one, your attention may be in the **wrong place**. You may be focused all right...but on the wrong thing! Or your attention may be in **too many places at once**, which means that you've got little bits of focus all around the room and every time someone moves or talks it grabs a little bit more of your focus. Another thing that can happen is that you have a hard time **turning your energy on when you need it, and off when you don't** – you might be falling asleep in class during the day when you need that energy, but then are up and raring to go at 3 o'clock in the morning! Finally, you may be experiencing some of all three of these problems together! No WONDER everything seems so much harder for you to do!


So let's give 'em a brake!


It will be important for these children and youth, for those who work with them, and for those around them to understand that **their ability to concentrate and stay on task will fluctuate from day to day and from task to task.** Patterns may be discernible, predictable, and therefore worked around. Keeping a logbook of what time of day, what types of tasks, and in what sort or surroundings they are able to work optimally may help you to find common factors that help their performance.


 You may have heard of different medications that are used for ADHD – names like Ritalin, Dexedrine, and Concerta. **These medications tend to be more helpful for the OTHER type of ADHD** – that Predominantly Hyperactive-Impulsive Type (ADHD-PHI). Don't worry though! They can still be tried if you want. Plus there are still plenty of other things that can help, listed below:


 I mentioned difficulties with regulating energy levels: those with ADHD-PI cannot always be as alert as they want to be, and they cannot always shut off their energy when they want to. Strategies intended to help keep the person stimulated such as **in-class stand-and-stretch breaks** may help when the 'volume' is turned too low; squeezing a **stress ball, chewing gum, or doodling** may help burn off extra arousal so the person can better pay attention when the 'volume' is turned too high. Here's something you may not have known: lots of times that fidgeting child IS doing what you've asked him to do – paying attention! In fact, even though it sometimes makes them look as though they are not paying attention at ALL, fidgeting actually helps them to do it BETTER...


Motivation:


 A lack of motivation isn't the CAUSE of the problem (the 'leaky brake' is), but it can still help to minimize the problem. Picture the individual's wandering attention as being like a magnet looking for something to stick to. If we can't control where that "attention magnet" goes, but we still want it to stick to the right thing, then we'd better build that thing out of a magnetic metal. Increasing motivation for a task helps to make it "magnetic"!

 It is important to give the individual **choices** when working, so that (s)he has some control over the session (making up for the LACK of control over his/her focus). Whenever possible, **incorporate a topic or item that the student already very much enjoys and/or is successful at** into the assignment. This results in more personal investment in the task, and therefore increased intrinsic motivation to complete it.


 To maximize the individual's interest, **teach in short sessions** and **reward his/her effort** on a task, as well as the outcome. It may also be necessary to **use immediate and concrete rewards** (e.g., small candies, stickers, etc.) as well as social praise to increase his/her on-task time.


 **Clear, concise directions that include only one or two steps** at a time will help to make sure that ALL the directions are heard before that attention wanders off again! And to prevent forgetting, **write each step down or use a picture** as a reminder. It might be helpful to place a "white board" in a strategic place in the house or classroom, where instructions can be written and/or diagrammed to aid in remembering which tasks (s)he has done, and still needs to accomplish. A written instruction sheet with places to check off tasks might also be helpful. As each set task is completed, (s)he should "check in".


 Along the same lines, it is smart to **keep a backpack or DayTimer**, where a "to do" list and materials (e.g., homework assignments, appointments to keep) can be kept. (S)He can check and update this list on a regular basis, crossing off tasks when (s)he has completed them and adding new tasks as they come to mind. Structuring your day through the DayTimer takes the pressure off remembering everything yourself; the DayTimer remembers everything for you! **Only one thing has to be remembered now: check the DayTimer whenever you need to remember something!** For more tips on DayTimer use, go to <http://www.lifesatwitch.com/datafiles/daytimers.pdf>.


 Because most everyone's brain is trained to immediately pay attention when their name is said, **use the individual's name frequently** when speaking to him/her in the home and classroom. You could also ask the individual to **repeat, in his/her own words, what (s)he has been asked to do.**

Teacher-Specific:


 Using as many **visual materials** (pictures, models, etc.) as possible is generally beneficial for these students.


 A schedule that spreads out short periods of time for "boring", difficult, or taxing work, **alternating** with times for **"interesting" or active work** (e.g. role-playing, a "hands-on" activity, incorporating an existing interest or humour into the task), should help improve performance. People with ADHD-PI may need to take **breaks** from time to time during the school day.


 **Taxing work should be provided in small 'chunks'.** For example, a page of math problems could be administered one row at a time (perhaps by computer to reduce paper requirements) so (s)he does not become overwhelmed or distracted by the number of questions to complete.


 **Preferential seating** isn't a punishment – it is actually a smart strategy! Sitting near the front of the classroom means that there is less for you to see, and therefore less for you to get distracted by! It also


means that you are closer to the teacher so that you can ask more questions about what to do next and keep on-track.

 **External reminders** to keep on task will be of great assistance:

 one example is the **Tone-Tape**, which is a cassette that randomly emits tones while a student works. Each time a student is working appropriately when the tone emits, points are given – if he is off-task, points are deducted. At the end of each day points can be cashed in for tangible rewards. The **Attention Training System** is based on a similar premise but is more elaborate. A small battery-operated electronic counter is placed on the student's desk, which automatically awards the child a point every sixty seconds. If the student wanders off task, the teacher uses a remote control to deduct a point and activate a small warning light on the student's module. The ATS delivers unobtrusive but effective feedback, functions during regular classroom activities, circumvents the problem of treatment generalization, and has been shown to be as effective as stimulant medication in increasing attentiveness. Each teacher can control four student modules.

 another example is **The Invisible Clock**, a small personal timer which can be kept in the individual's pocket. It uses silent vibration signals or beep alerts at specified times to cue him/her for specific tasks. It can be used as a learning tool, or as a reminder to practice positive new behaviours and/or habits. The **WatchMinder™** is a specially designed shock-resistant sports wristwatch with large, easy-to-read display for time, date, training and reminder functions which also provide silent reminders (vibration) similar to a common pager. It is simple to operate, pre-programmed with over 60 visual reminder messages and 20 training/self-help messages that can be activated and displayed at pre-set times during the day. Multiple messages can be selected daily.

 These and other such items can be found online at the **ADD Warehouse** (<http://www.addwarehouse.com>).

 **"Teaching the Tiger"** by Marilyn Dornbush, Ph.D. and Sheryl Pruitt, M.Ed. is an excellent resource for finding classroom strategies to assist the teacher in educating, or a parent in parenting, a child with ADHD (both the Predominantly Inattentive Type, and also the Predominantly Hyperactive-Impulsive Type).

Finally, adults working with these children and youth sometimes indicate concerns about the seeming inability of individuals with ADHD-PI to learn from past experiences. Individuals with ADHD-PI often have **difficulty linking cause and effect simply because their roving attention visits many more places in between the 'action' and the 'consequence'** and so the connection between the two isn't as obvious. By explicitly linking these two events this can help them to understand WHY they are being rewarded or punished, to better carry those experiences with them, and to not feel as 'out to sea' as they sometimes might when consequences appear seemingly out of nowhere.

© 2004, Dr. B. Duncan McKinlay, Psychologist

TS In The News

The Toronto Star's July 7 sports section features a heading on page 3 that reads **"The toughest opponent"** and uses the entire page to report 3 stories about TS and sports in what may possibly be the "best ever" newspaper coverage of TS.

The page highlight is a 7 by 10 inch photo of 12 year old Dustin Doudelet holding a lacrosse racket and looking ready to play. The feature story is about Dustin, written by Lois Kalchman. A side bar by sports editor, Mary Ormsby titled "Don't be afraid of Tourette's" tells about how TS affects CBC sports broadcaster Elliotte Friedman. A box at the bottom right is titled "On the field with Tourette's" and identifies 3 sports professionals with TS.

The caption under Dustin's photo reads:

"When Dustin Doudelet plays lacrosse or hockey, he's not just facing the other team, he's also got to deal with coaches, teammates and players' parents who are uncomfortable with his often-misunderstood neurological disorder, Tourette's syndrome."

The Kalchman article tells about some of Dustin's challenges but deals more with how Jay Michaels coped with his son Dustin's TS. The article contains quotes from Rosie Wartecker, our TSFC executive director and Dr. Paul Sandor, head of the TS clinic at Toronto Western Hospital and Chair of the TSFC Advisory Committee. These quotes add credence and show that a good amount of research was put into the story.

Mary Ormsby's article is a well written and succinct report about how Elliotte Friedman copes with his TS. Friedman, 34 years old, is a CBC sports broadcaster who was first diagnosed while a student at the University of Western Ontario. According to the story, Friedman once had a heartfelt chat with retired major-league baseball player and Tourette's sufferer Jim Eisenreich.

The "On the field with Tourette's" box at the bottom right corner contains quotes from Tim Howard, Manchester United Goalie:

"They (opponents with the ball) could be out there by midfield somewhere and I may have a twitch, a tic of the eyes, of the head, of the arm. But when they get in there and it's time to go to work, it just doesn't happen."

and Jeremy (Twitch) Stenberg, freestyle motocross rider:

"I always got teased in school. But whenever I got teased, I'd always fight them. (Now) I forget I have it."

and Mamoud Abdul-Rauf, former NBA player:

"It only affects me on the free-throw line – I'll be there twitching, getting some of it out while someone is shooting. When I'm coming down the court, I might throw out my arm, but I'm still focused on what I'm doing. In fact, Tourette's has made me a better ballplayer because it created a compulsion for practice and routines and trying to get it right."

These articles, covering an entire page and all containing a positive spin, are the kind of stories that make good publicity. The awareness of TS provided by this publicity is something we could not afford to buy. If you see stories about TS in the news let us know so we can add them to our archives and share them with others.

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, Attention-Deficit/Hyperactivity Disorder, Obsessive-Compulsive Disorder, Sensory Processing Dysfunction, 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/social communications issues**
- **school interventions/non-pharmaceutical management**
 - **home support**
- **review, and panel of experts (professional, parent, child, supports)**

A different "CPRI Brake Shop" clinician will present each topic. Time for questions is allotted. Each spot is reserved for a particular attendee, and successive sessions assume past information. Hence, you are encouraged to attend all sessions.

Enrolment is without charge. To reserve a spot for the next available 6-week programme, call (519) 858-2774 ext 2171

For immediate release

July 8, 2005

Commission to investigate application of safe schools legislation and policies

Toronto – The Ontario Human Rights Commission (the "Commission") has initiated a complaint against the Ministry of Education (the "Ministry") and the Toronto District School Board (the "TDSB") alleging that the application of the *Safe Schools Act* and related school discipline policies is having a disproportional impact on racialized students and students with disabilities.

"We still hope to work with the Ministry and the TDSB on an effective process for addressing this important issue", commented Chief Commissioner Keith Norton. "However, with so little progress having been made since the Commission first raised concern in 2003, we felt it was necessary to take the next step of initiating these complaints before the next school year begins so that the Commission may use its legislated power to investigate and seek a systemic resolution of the issues more directly." If no resolution is reached, the complaints could be referred to the Human Rights Tribunal of Ontario. No such determination has been made at this point.

While the Commission certainly supports the objectives of ensuring schools are safe, disciplinary measures must be fair, effective and non-discriminatory.

A report released by the Commission in July 2004 identified that research from the United States, Great Britain, and Nova Scotia has demonstrated the discriminatory effects of school discipline policies, and recounted similar experiences of students, educators and front-line community workers in Ontario. In a public submission made to the TDSB in April 2004, the Commission called upon school boards and the Ministry of Education to acknowledge the situation, and take appropriate action, including collecting data on suspensions and expulsions in order to monitor and safeguard against discriminatory school discipline legislation and policies.

In accordance with the Commission's new *Policy and Guidelines on Racism and Racial Discrimination*, individuals, organizations, and institutions can be held liable for failing in their duties to take appropriate action to address human rights issues of which they are aware, or ought to be aware.

"We prefer a cooperative approach," added Norton. "One where all parties are open to examining the concerns raised in order to ensure racialized students and students with disabilities have equal access to education."

Copies of the Commission's policies, submissions, and reports are available online at www.ohrc.on.ca.

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| <p>Jeff Poirier Manager, Communications Policy and Education Branch (416) 314-4539</p> | <p>François Larsen Director Policy and Education Branch (416) 314-4532</p> |
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This information is provided as a public service by the Ontario Human Rights Commission. Although we endeavour to ensure that the information is as current and accurate as possible, errors do occasionally occur. Please verify information before acting on it.

Continuing Genetics Study

In a TSA report on Research Awards for 2004-2005, Dr. Peristera Paschou, Yale University School of Medicine, states that the current year study is a continuation of a project that was initiated last year with the support of a research grant from the TSA.

Dr. Paschou goes on to say "The genetic basis of TS remains elusive. Nevertheless several genomic regions have been implicated."

Efforts in the previous year had been focused on the evaluation of a specific DNA region as a candidate for susceptibility. The report says "Results so far are quite encouraging."

"In a study of four large multigenerational families with multiple individuals affected with TS we obtained positive association and linkage results with multiple genetic markers in this interval. Study of an independent sample of small nuclear families with one or two affected children (provided by the Toronto Western Research Institute) also produced positive findings."

The study continues this year with an attempt to reproduce previous results in three independent samples of families with one or two children with TS and their parents. Two of these samples will be made available through collaboration with the Toronto Western Research Institute and Semmelweis University in Hungary.

Research grants are awarded by the TSA from funds raised for research and from gifts made available by individuals and family foundations.

Taken from a report by the Tourette Syndrome Association, Inc of the USA titled "TSA Research Award Program 2004-2005."

This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Gerard Johnson. 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 via email at:

gerard.johnson@sympatico.ca

Visit your London Chapter Web Site at:

www.tourette-london.ca

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