



Tourette Syndrome Foundation of Canada

London Chapter

Newsletter

Fall 2004

Message From The Chapter President

The Chapter executive is excited about the children's TS clinic being set up at CPRI. Dr. Duncan McKinlay has joined the staff at CPRI and has been given the task of establishing this, "first in London," centre for treating children with TS. London becomes the third centre in Canada to have a clinic specifically for the treatment of TS.

Three people from our Chapter attended the recent TSFC "Conference 2004" hosted by Vancouver chapter. The quality of the conference program and the organization of the entire weekend were excellent - as we have come to expect from our conferences. Thanks goes out to our Executive Director, Rosie Wartecker, for her exceptional talent in putting together our conferences.

Nadyne Gooding and I attended as Directors of the Foundation and Gerard Johnson attended as the London Chapter's official representative. Gerard's report of the conference is included in this newsletter and he reported in more depth at our September meeting.

We continue to have good attendance at our Chapter support meetings and I look forward to seeing everyone again in November.

Ray Robertson
Chapter President

TSFC's Latest Production

On Monday, October 25, 2004 the Tourette Syndrome Foundation of Canada took over the Film Board of Canada's theatre facilities to launch a much awaited new video.

The video, titled "Circle of Support" is the TSFC's first major video production. The original concept was to create a video for use by educators in areas of Canada where volunteer, TSFC sanctioned, In-service providers were not available or couldn't be expect to travel to.

The end result is something greater: a package, -- the video, a copy of TSFC's Educator's Guide and a workbook -- that can be used in any school in Canada. Parents will also find this video useful as they prepare to advocate for their child.

The launch was attended by members of the TSFC board of directors, donors who funded the project, some of the production crew, a few of the actors and a number of volunteers who couldn't wait for their copy to be mailed.

The package will be available for purchase within the next couple of weeks. For a limited time, those who already have the Educator's Guide will be able to purchase the video alone.

Everyone involved in the project is bursting with pride over this accomplishment!



Support Meeting

Our local support meetings are starting again after the summer break. If you want to talk to other parents of children with TS then come out to the meetings. With about 15 people each month these meetings have been well attended. There has been much informative and thought provoking dialogue exchanged. As always, we have our resource library of literature and videos available to our members at the meetings.

Support meetings are held on the 2nd Thursday of each month, except July and August at the following location:

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

**Note: If you borrowed any books or videos please remember to return them so others can enjoy their benefits. If you are having trouble getting to the monthly meeting but have borrowed material please drop the material off at Madam Vanier Children's Services and have it labeled for the Tourette Syndrome Foundation of Canada.*

Newsletter Update

It has been my responsibility to put this newsletter out for our members on a quarterly basis. I apologize for not keeping up to the task and for the tardiness of this latest (no pun intended) newsletter. I will endeavor to be timelier in the delivery of your newsletter and I hope that this has not caused anyone any problems.

Sincerely,
Gerard Johnson

TSFC Conference 2004 Report

The TSFC National Conference for 2004 was held on June 10 – June 12 in Vancouver, B.C. The theme for this years' conference was "Moving Mountains, Overcoming Obstacles" and boy, did this conference achieve that goal! To begin with there was a required Herculean effort by Rosie Wartecker and everyone involved with setting up the conference when all the materials that were supposed to be air delivered (as per the *confirmed* booking arrangements) ended up being *ground* shipped instead and were on route somewhere in between Toronto and Vancouver on the first day of the conference! Needless to say, we saw people overcoming obstacles and seemingly, moving mountains, getting things to run as smoothly as possible! Congratulations to everyone and especially the young people that were involved and helped out so much.

On Wednesday evening the Vancouver Chapter of the TSFC hosted a "Meet and Greet" for the Board of Directors and all the volunteers who had arrived for the Thursday morning workshops. Our chapter was well represented by Ray Robertson and Nadyne Gooding, who are Directors of the Foundation, and I, the London Chapters official representative. The time spent renewing acquaintances with other members of the TSFC and meeting more new contacts was an experience that will continue to be of benefit as the flow of new information and resources from national contacts continues to bring our Foundation unity from coast to coast.

After breakfast on Thursday we got right down to business as we split up to go to the Volunteer's workshop. Two workshops ran simultaneously, one focusing on the school In-Service program, while the other workshop dealt with facilitating a self help meeting and staying on track effectively while handling some of the challenging situations that may, from time to time arise. Both workshops were well attended and had good reviews from the participants who will be taking back some of the skills they acquired to their respective local

chapters. Later on Thursday evening, the keynote speaker was Mike Kwiatkowski, a Canadian Olympic athlete, who has overcome unbelievable physical injuries that were supposed to have ended his career, to become a member of the Canadian National Olympic snowboard team. His talk was aptly called, "If Kids Can, We Can!" After his talk a lucky youth member of the audience received an autographed Official Canadian Team's Olympic Snowboard. That was one happy kid.

We next had a number of small workshops which were a mix of information and lively discussion on issues that are very common to everyone dealing with TS in their families.

On Friday the day got off to great start beginning with breakfast and an enthusiastic talk given by Stuart Ellis-Myers, a motivational speaker who helped everyone get acquainted with one another through various techniques including wearing big red clown noses! It was a lot of fun and quite an ice breaker for everyone there.

The first session of the day was Margaret Weiss, M.D., Ph.D., FRCP, who gave a talk about ADHD and the associated behavioral issues. One point stood out in her talk about the social impact of ADHD. Untreated ADHD has DOUBLE the incidence (40%) of substance abuse to the non-ADHD population. Treated ADHD lowers the level of substance abuse to normal levels – 20%. This is definitely something to think about when dealing with our kids with ADHD.

After this I attended the Adults Issues Forum, facilitated by Kitchener, Ontario's Gord Brown. We had a lively discussion about some important problems facing the TS community and came away with a lot of food for thought. Hopefully it was a beginning to things that need to be looked at and not just a passing commentary.

Later there was an Awards Luncheon and many deserving individuals were recognized for their various contributions to the TSFC.

Next on the agenda came a presentation by B. Duncan McKinlay, Ph.D., C. Psych., called

"From Victim to Victory: A Personal Recipe for Success" which was well presented and well received by the many people in attendance. I have always enjoyed any workshop I have attended that Dr. McKinlay has given. As always, it was a session full of information delivered in an effective and insightful way that incorporated the communication skills and humour of our inspired presenter.

Later in the evening there was an outing to Granville for dinner. It was another chance to network with and meet new people from across Canada and North America. Many of the people I communicate with as a member of the Communications and Marketing committee now have a face to put with the voice or email. The food was good too!

Saturday started with breakfast and was followed by the Annual General Meeting of Members. After this Anton Scamvougeras, M.B. ChB., FRCP presented, "Optimizing the Treatment of Tourette Syndrome and Associated Disorders" with many practical treatment plans to deal with TS Plus.

Robert Araujo, Ph.D., delivered an informative and thought provoking presentation, "Standing with the Disordered Child: A New Approach to Behaviour Management".

The final presenter was Ross Greene, Ph.D., who delivered his presentation titled, "Understanding 'difficult behaviour': Children do well if they can... if they can't we adults need to figure out why so we can help" The premise is that children want to behave, do well and please their parents. If they cannot do so we, as adults, must figure out why and come up with effective ways to help these kids do well. It gave me a whole new perspective for looking at how I might help when behaviour problems arise when dealing with my TS child's challenges.

Later Saturday night was the banquet, with some very emotional award presentations, followed by a robust and entertaining Karaoke night and the conclusion of the silent auction.

Sunday was a travel day back to Ontario so I could get back to work on Monday. The entire weekend was a wonderful experience that I hope I can incorporate into my volunteer work at the local level. If anyone has any questions please contact me at: (519) 649-5092 or by email at: gerard.johnson@sympatico.ca

Disinhibited Thoughts #8

B. Duncan McKinlay, Ph.D., C.Psych.

TS in the Workplace II

Last time, I talked about how if a TS'er wants the luxury of not telling people about his/her TS in the workplace, then there are natural consequences to that. The realization that the hole one finds oneself in is self-dug might hopefully prompt him/her to think more about disclosing to others.

Another workplace question I've been asked is whether TS'ers have a better opportunity exploring occupations that lend themselves to self-employment. From watching those that I know, and from what I've heard reported by others, it would seem that we tend to go to one of two extremes. Some TS'ers start their own businesses and thrive in that independence. Others find themselves as teens drawn to Air Cadets and the Militia, and eventually surrender almost ALL independence by joining the service. Last week an adult TS'er who had served told me that only recently has anyone (a chaplain, actually) officially come "out of the closet" and openly admitted their TS.

I don't believe there is a "right" direction.....the path you take is guided by personal preference. However I DO believe both directions are in response to the poor control or regulation we have over ourselves (our poor inhibitory controls). Let's address self-employment first. Myself, I thrive for independence. I have come to realize that I can achieve any ENDS I desire so long as I have

flexibility in the MEANS for getting there. Hence the role of graduate student is a perfect one for me.....no one cares HOW or WHEN or for HOW LONG I work on WHAT, as long as I meet the requirements of the degree within the allotted time. No one looks over my shoulder and demands that I work at a particular time, or on only one thing at a time, or that I stay with one task until its complete, or that I shift to the next task at a particular time. Hence I ride my waves, I work in the way my brain was DESIGNED to work, and I excel. This has been made very clear to me at times when I have taken summer jobs where there was very little freedom or flexibility in the MEANS to accomplishing a task. Doctor-to-be or not, "grunt" job or not, each time I failed dismally.

On the other hand, joining the army gives you very little of this precious flexibility I speak of, yet many TS'ers thrive there as well. Why? It is a very controlling environment, and self-control (over movements, attention, thoughts, etc.) is the crucial element that we lack neurologically. Thus, in a very real sense the service allows us to compensate for what we weren't given genetically - it acts as a "surrogate frontal lobe" telling us exactly when to do what, how to do it and for how long. Left to your own devices you are unable to regulate yourself, and so you voluntarily adopt someone else's devices to get you blissfully on track.

Now that I think about it, this discussion mirrors the Expression or Suppression choice I speak of frequently in my presentations. If you want to express who you are, you must find an environment that will allow you to explore how you can best work. If you want to suppress the differences, you must find an environment that best substitutes that which you are lacking.

Until next time, my friends!

Duncan

Volunteer Evening

Our chapter will host its second Volunteer Focus meeting on November 18, 2004 at Madame Vanier Children's Services.

Volunteer Focus is an opportunity to learn more about the TSFC and in particular the London Chapter and find out what you can do to help people with TS.

We have a list of jobs that could be taken on by a volunteer (or shared between volunteers.) One position that is currently open is that of Agency Coordinator. This job is not time sensitive in that it can be done whenever the volunteers has a few spare hours.

If you would like to volunteer to help or just want to learn more about volunteering please join us on November 18.

"Leaky Brakes" 101

The CPRI Break Shop is pleased to offer a limited number of seats for our new course, offered to the general public for free and starting October 19, 2004.

The 2004/2005 course consists of six sessions in Zarfes Hall on CPRI campus from 7 p.m. to 9 p.m., on the following Tuesdays:

Session Outline:

Oct. 19/04	The ABC's of Leaky Brakes
Nov. 16/04	Sensory Processing Issues
Jan. 18/05	Home strategies
Feb. 15/05	Home strategies II
Mar. 22/05	Pharmaceutical Interventions
Apr. 19/05	Family Functioning

To Reserve a spot for the 2004/2005 programme, call (519) 858-2774 ext. 2171

Yard Sale

Saturday, June 4, 2005, has been set for our 3rd fund raising Yard Sale. Money raised from this event will go towards Chapter operating expenses.

Keep us in mind between now and June when you have something you want to throw away – it might have some value at our Yard Sale. We will begin collecting items in April.

If you can help out on the day of the sale, let us know. All hands will be welcome. We have a possible location (the home of one of our volunteers) but if you have a better one we would like to hear from you. Also, we could use some space to store items prior to the sale date and help with moving things from place to place.

Or just drop in on the day of the sale and spend some cash.

This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Gerard Johnson. Anyone wishing to make comments or wanting to contribute to the newsletter, please contact Gerard via email at: gerard.johnson@sympatico.ca

Visit your London Chapter Web Site at: 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."