



# Tourette Syndrome Foundation of Canada

## London Chapter

Newsletter

Fall 2003

### Welcome To Fall - 2003

It has been a while since our last Newsletter and there have been many events of note that have occurred during this very busy time. We will endeavor to update and inform our local membership through this newsletter and to keep it published on a regular basis.

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### Conference 2003

Our London Chapter of the TSFC hosted Canada's national conference on Tourette Syndrome May 9 - 10, 2003. The conference was a great success with people in attendance from across Canada and the USA. Our Conference theme was "Growing Awareness of Tourette Syndrome" and as anyone in attendance can tell you, we achieved that objective!

The Educator's Workshop, part of the Professionals stream of the conference, was well attended. The information provided during these sessions will do much to further advance an understanding of Tourette Syndrome and its associated disorders among those attending. Providing professional people with positive methods of dealing with persons with TS, within an educational environment, will help all our kids to have a more productive and positive experience during these important developmental years.

An important part of our National Conference is raising funds to help pay some of the cost for running such an event. We had a successful raffle and silent auction with numerous items donated locally and also from the National Office. Thank you goes to Denise and Wayne Miller as well as

Shannon and Bob Stoyles for all the items they made or got donated for the raffle and silent auction, including a team autographed hockey stick from the Toronto Maple Leafs, many beautiful, hand crafted, wood items and more. We are grateful to Linda Johnson for canvassing dozens of businesses and companies successfully for many conference donations. Special thanks to everyone else who helped with donations running the raffle and silent auction. This events' success is your success!

The New PL provided TV advertising for and media coverage during, the conference. Carrie Kelly made the contacts and arrangements for all the television, news & radio. She also designed the conference logo. Thanks Carrie!

The Children's Program was a success with acknowledgement going to Nadyne Gooding for organizing and running it. Although there were challenges with so many diverse personalities mixing together, it was a wonderful 2 days for the youngsters to play and interact with each other. There were a number of workshops and activities scheduled over the two days. These ranged from self advocacy to learning to play in an air band. I especially enjoyed the "Air Band" that performed during the Saturday night banquet. They made the cardboard instruments too! It was organized by Dr. Duncan McKinlay during a workshop and the kids put on a magnificent show!

Thanks go to Ray Robertson for his efforts in getting everyone together and coordinating the work between the many different committees and volunteers involved. All the hard work that Rosie Wartecker and the staff from the National Office in Toronto did ensured our 2003 conference ran smoothly. Thanks to Rosie and her staff.

There were so many positives during this conference that I just don't have the space to recount them all. It was my first TS conference, but I'm sure it will not be my last!

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## To The Conference Volunteers

The Tourette Syndrome conference was a great success which would not have been possible without those men and women who volunteered their time, effort, and talent. To the many dedicated individuals that worked so hard on the conference goes the gratitude of the London Chapter of the TSFC. Thank you is not enough for all your work and effort. Your dedication is what made this one of the best conferences ever!

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### Disinhibited Thoughts #5

B. Duncan McKinlay, Ph.D., C.Psych.  
(Supervised Practice)

*"Don't use the disorder as an excuse"! "Take responsibility for your actions"! "Saying that you have Tourette Syndrome is just a convenience".*

These are phrases that I'll wager we've all heard more than once. As we should. These are important principles to abide by -- ones on which it is easy to slip, I can well attest. It is tempting to assume that, because we can now actually point to the things that are not working properly in the TS brain, this means that the person with TS is powerless to effect change and is thus not responsible for his/her actions. For example, how many times have YOU caught yourself beginning an evaluation of yourself or something you've done with, "Considering that I have Tourette Syndrome....."?

My topic this time around IS about responsibility for your actions. However it is not actually directed at Touretters. It is directed at everyone else.

We Touretters are very visible in our numerous demons, and our requirement to be responsible for

them all is obvious. Perhaps because we project the need to be responsible so blatantly, some feel free to drape all of their own ownership in a situation onto us as well. And perhaps because we are so used to hearing that we must take responsibility, we are also quick to accept all ownership. In that way, people with TS can sometimes become very convenient "coat-hangers" onto which others shrug their accountability. After all, Touretters can always be relied on to amplify a reaction. In doing so we conveniently provide the means for others to move the focus of the situation off of themselves and onto the overreaction.

It is only too effortless to obscure your own behaviour behind ours. We are easy to blame, and of course we have our share of blames to shoulder. But remember that even OVERreactions are still VALID reactions. We are still reacting TO something. It is simple to remember the Tourettic response. It is a little bit more difficult to remember that there was a REASON for that response, no matter how disproportional the cause was to the effect.

In any situation, both people involved are responsible for their own part in it. Sometimes, however, the person who is made to be wholly responsible for the situation is merely the person who was second-fastest in recognizing the OTHER person's responsibilities....

Don't assume that OUR need to take responsibility for our own actions somehow supercedes your own. You'll be surprised how quickly a Tser's escalation can end when you admit your own faults in a situation. To those with TS, I also suggest that self-esteem and respect from others can begin with the decision to carry your own weights, but not those of others.

Until next time, my friends!!

Duncan McKinlay, Ph.D., C.Psych. (Supervised Practice)

## 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.

*\*Note: If you borrowed any books or videos please remember to return them so others can enjoy their benefits.*

Support meetings are held on the 2nd Thursday of each month, except July and August.

We also have a room in which our children with TS can meet with their TS peers giving them a chance to interact in a safe environment of mutual respect and understanding. This is a supervised room with rules that are encouraged and followed by those in attendance.

### Upcoming Support Meetings:

September 11, 2003 - regular support meeting  
October 9, 2003 - regular support meeting  
November 13, 2003 - regular support meeting

All meetings are held at Madame Vanier Children's Services, 871 Trafalgar Street, London, Ontario.

The evening begins with coffee at 7:00 pm and the support meeting begins at 7:30. Parents, caregivers and other adults interested in Tourette Syndrome are welcome to attend.

Meetings are a great source of information!

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## Children's Mini Golf Tournament

On Thursday, July 10, 2003 our Chapter held its 7<sup>th</sup> Annual Mini Golf event. This was an evening for TS children to meet other TS children. We met

at 7:00 pm on the course at the corner of Adelaide St. N. and Windermere Rd. in London.

Despite the inclement weather the event proved successful with everyone enjoying themselves, playing miniature golf and eating ice cream.

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## National Board of Directors Elections 2003

The TSFC had its Annual General Meeting at the conference in May. Elections to fill the vacant positions on its Board of Directors were held. The people filling the positions were announced during the banquet Saturday evening. The London Chapter is well represented with Ray Robertson being elected to the position of Executive Vice President, as well as adding the responsibilities of Chair of the Long Range Planning Committee. Nadyne Gooding has been elected to the Board of Directors and has also added the responsibilities of Chair of the Communications Committee.

Ray and Nadyne have been involved with the London Chapter of the TSFC for many years now and we all applaud their success and wish them well as they take on these important positions in the TSFC. I know they can count on us for any assistance and support they require.

CONGRATULATIONS!

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## Newsletter News

Gerard Johnson has accepted the task of putting our chapter newsletter together. If you are moving please send us an updated mailing address to:

[london.newsletter@sympatico.ca](mailto:london.newsletter@sympatico.ca)

or

P.O. Box 28084  
London, Ont.  
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## Local Contact Information

To get in touch with the London Chapter, Executive, call Ray Robertson at (519) 457-4586 to leave a voice mail message or we can be reached by e-mail at: rayrobertson@hotmail.com.

Our mailing address is:  
P.O. Box 28084  
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We would like to hear from you about how the Chapter could better serve you. Watch our Internet site at [www.tourette.ca](http://www.tourette.ca) for details of upcoming events.

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## Parting Thoughts

I have been coming out to the London support meetings for a few years now. I am encouraged by the example of others who have come and shared what life with a TS child is like for them. People have offered much more than mere words of encouragement. I have met people who have gone through many experiences dealing with difficult situations and stubborn bureaucracy. Some had to break down barriers of misinformation and misunderstanding to get the help their children needed. I have seen and heard examples of what a benefit it can be, getting the information about what Tourette syndrome is, into the hands of people who need to know. Information is the most potent antidote we have available for ignorance and misunderstanding. It makes such a difference in easing the situation of a child with TS when people are informed. I want to extend my personal thanks to all those who have come out to our support meetings and shared their experiences with TS. I have also found the resource materials invaluable as I start to understand this baffling disorder that has touched my own family.

Sincerely,  
Gerard Johnson

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

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or

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*"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."*