



Tourette Syndrome Foundation of Canada

London Chapter

Newsletter

January 2004

What's New?

Welcome to the winter edition of the TSFC newsletter for the London Chapter. I hope you had an enjoyable Holiday Season. Our newsletter is intended to keep our local members informed about the latest happenings in and around the London area.

There is a lot that has been happening in London and area. We have the Annual General Meeting coming in March; there is a new citizen in our local community of particular interest and importance to the TS community in South-western Ontario; we have an additional format to our monthly support meetings. In addition we have more new resource material available at our monthly support meeting.

Come out and get informed!

London Chapter Annual General Meeting

The London Chapter will hold their 2004 Annual General Meeting on March 11, 2004 at Madame Vanier Children's Services, 871 Trafalgar Street, London, at 7:00 pm. At this meeting financial statements for 2003 will be presented to the members and elections will be held for all Executive positions.

Current terms of office for President, Vice-President, Secretary and Treasurer will expire at this time and new officers will be elected by the members.

If you are interested in running for an executive position or would like to nominate someone for a position contact Gerard Johnson, Secretary, London Chapter:

Phone: (519) 649-5092

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Welcome to London

We have a new resident in London. Say hello to Dr. B. Duncan McKinlay, Ph.D., C.Psych.

Dr. Duncan is a registered Psychologist with the College of Psychologists of Ontario, practicing with children and adolescents in the areas of clinical and school psychology. He has taken on a position with the Child and Family Resource Institute (CPRI) in London, Ont.

I know our local London TSFC chapter and the London TS community as a whole, joins me in wishing Dr. McKinlay a warm welcome to our community and much success in his new position.

Dr. McKinlay has requested that the following statement be included in our newsletter, as a point of clarification:

"Because Dr. McKinlay will soon be offering clinical and educational services to the TS+ community in London and South-western Ontario through his new position at CPRI, "Life's A Twitch!" will no longer be offering presentations within the Brant, Bruce, Elgin, Essex, Grey, Haldimand-Norfolk, Hamilton-Wentworth, Huron, Kent, Lambton, Middlesex, Niagara, Oxford, Perth, Waterloo, or Wellington counties. If you live in one of these listed areas, any requests for Dr. McKinlay's services must now be directed to the Child and Family Resource Institute (CPRI) at 519.858.2774."

To access Dr. McKinlay's website, "Life's a Twitch!" go to: www.lifesatwitch.com

New Support Meeting Agenda

In addition to the usual support meetings the London Chapter executive approached the group with the idea of having a guest speaker or information session every other month. With great enthusiasm those present forwarded suggestions of people and topics which might be of interest to the group. Mark your calendar now, so you don't miss any of our meetings.

February 12th - 7 p.m. Support Meeting

March 11th - 7 p.m. Annual General Meeting, Support Meeting and Special Talk about Special Education.

Nadyne Gooding, who represented TS on the Special Education Advisory Committee (SEAC) for the Thames Valley District School Board and prior to that the Elgin County Board of Education, will be our guest speaker. She will share with us her knowledge about special education, explain Individual Education Plans

(IEP's), and what it means to have your child identified.

April 8th - 7 p.m. Support Meeting

May 13th - 7 p.m. Support Meeting and Guest Speaker - TBA

June 10th - 7 p.m. Support Meeting

July 8th - 7 p.m. Mini-Golf London North Golf Center, Windermere Rd. (NE corner of Windermere and Adelaide St.) – Lots of fun for the whole family!

Disinhibited Thoughts #6

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

Does Tourette Syndrome really go away in adulthood? My own evidence in dispute of this "myth", while anecdotal, is considerable. As of late, "we" seem to be coming out of the woodwork with great speed; in fact, the parents of TS children in the Wellington-Waterloo chapter are in danger of being overrun!

Personal impressions aside, though, the research to support such a statement simply isn't there either. The few studies which have addressed the issue of outcome all agree that **TS for the vast majority of us is a life-long condition**; my own belief is that we are genetically predisposed to be disinhibited, and that quality of oneself will always remain within us in one form or another. While *some* individuals remit completely, the most the rest of us can expect is to see a reduction in our tics (which also is far from guaranteed). And, some research adds, the declining or vanishing tics may simply be "trading" with other forms of disinhibition regulation problems, such as OCD, in a seesaw kind of effect.

So how did the communication of this malicious tidbit of hogwash somehow become common practice among well intentioned diagnosing doctors (both M.D. and Psychologist alike)?

Perhaps because of generational differences: TS simply didn't exist as a diagnosis before the Shapiros' labelled the disorder in 1978. Before that time, while these adults may have indeed been categorized, the labels were less than accurate ("nerves", "weird", "possessed", and the like). Because of this, there are (at least at this time in history) many children diagnosed with TS, but few adults. Hence, without an historical perspective to train the eye, it "looks" like TS must go away in adulthood.

Perhaps another reason that few adults come to the attention of clinicians is because by the time you are an adult, by necessity you have found some way to adapt, to cope in an often-unforgiving world. Since many adults were never diagnosed during the formidable years of their development, they never had the opportunity to explain away their difficulties, nor even always fully appreciate how much harder they were working than others to accomplish the same amount of work. In the absence of excuses they were forced to "Find A Way" to accomplish their goals. Hence, most of the TS adults I know are exceptional strategizers, and have a good sense of personal accountability.

Over time the person may well have succeeded in removing him/herself from the category of a "disordered individual", but (s)he did so not by re-wiring their heads; rather (s)he developed a better "fit" with their surroundings. Creativity, discipline, a re-channelling of Tourettic energies, and considerable and effortful compromise of what they are so that they may be what our world expects them to be was what solved their problems.

To then say that the neurology has simply "gone away" in these people is insulting. It does not give due credit to their phenomenal accomplishment. It minimizes the battles these individuals still face, whether with different manifestations of disinhibition or the uniquely adult challenges TS can bring. It also robs us of two tremendously positive opportunities. The first is the opportunity for TS children, lost and confused, to benefit from the wisdom of those who have "been there". The

second is the opportunity for TS adults to, through working with TS children, to become aware of their own gains and abilities. Together as mentor and student, TS adults and children can both develop pride, empowerment, and well-earned self-esteem.

I can envision a world where TS is no longer perceived simply as a catastrophic growth phase in a select population of abysmally unfortunate children. Instead, it will be seen as one of life's curves designed to test your mettle and to forever strengthen your character, a life-long potential to be harnessed with the help of the right tutelage and eventually even celebrated. Please dream with me.

Until next time, my friends,

Duncan
January 2000

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Tourette Syndrome and Migraine May Go Hand-In-Hand

A Review of an article by: Gerard Johnson
Source: Archives of Neurology, November 2003

I read an article recently about the incidence of migraine headache in individuals with Tourette Syndrome. Researchers have shown that patients with TS have a four-fold higher incidence of migraine headache than the general population.

The research, by Dr. Jankovic at Baylor College of Medicine in Houston, assessed the family history of migraine in 100 patients with Tourette Syndrome. Twenty-five patients reported having migraine headaches. Migraines were observed in 16 percent and 39 percent of pediatric and adult patients with Tourette syndrome, respectively, significantly greater than the corresponding rate of 6 percent and 11 percent reported in the general pediatric and adult populations. Twenty-four of

the twenty-five patients with migraine also had obsessive-compulsive traits. The article states that there is no significant difference in the presence of obsessive-compulsive traits and attention deficit in the TS patients with or without migraine. It does state that there was an incidence of migraine in family members of 56% of patients with Tourette Syndrome regardless of whether those patients had migraine.

Based on these findings, the researchers suggest that "migraine headache, if present also in family members with Tourette syndrome, may be used as a clinical marker for this complex genetic disorder."

Source: *Archives of Neurology*, November 2003

Is it possible that they are onto something here?
By Gerard Johnson

Local Contact Information

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

Our mailing address is:
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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 for details of upcoming events.

Notice

Please remember to bring back any borrowed resource materials from our resource library so others can benefit from their usage.

Thanks!



"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."