



The Disability Hierarchy

The Disability Hierarchy

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Notice to Members

The Tourette Foundation of Canada – London Chapter will hold an annual members meeting on January 12, 2006. Nominations will be accepted for officer positions or director-at-large prior to and at the meeting.

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.

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to the person and the family, too. Not only did I feel my son wasn't as "bad off" as children who had a "worse" disability, I also felt our *family* was "better" than families where a "worse" disability was present.

In society, this stratification may reinforce pity, and the *level* of pity is equivalent to where a particular disability sits on the Hierarchy. In the disability arena, it can result in physical segregation, social isolation, and other negative outcomes for people with disabilities. And the "severity" of these outcomes also corresponds to where a person's diagnosis sits on the Hierarchy---and a variety of different Hierarchies exist!

I was fortunate, however. Within a few months, I rejected many societal and professional notions that reflect the Disability Hierarchy. This transition was enhanced by my participation in the Partners in Policymaking leadership development program (www.partnersinpolicymaking.com) when my son was three. The wisdom I gained from the training and my classmates (including adults with developmental disabilities) helped me adopt new ways of thinking.

I learned that a disability is a disability is a disability---one is not better or worse than another---and the greatest barrier facing individuals with disabilities is not the disability itself, but *attitudes* about disability and the resulting *social policies* that dictate the treatment of people with disabilities. Now, let's move on to some other examples.

During one of my presentations about attitudes, "Sabrina" shared the following about her twin sister, "Kristina," who uses a wheelchair: "People talk about Kris like she's not even there," she exclaimed. "I mean, she's not *retarded*---she just uses a chair!" The unspoken message seemed to indicate it would be acceptable for Kristina to be presumed incompetent if she *did* have a cognitive disability, but it was *not okay* since her sister had a physical disability. Was Sabrina aware she was promoting the Disability Hierarchy? Her next comment was even more disturbing: "My sister moved into her own apartment for the first time, and it's really scary for my mom and me---I mean, *Krissy is our baby!*" I was stunned! These 20-something young women are twin sisters, yet Sabrina sees her sister as "our baby." Would this occur if Kristina did *not* have a disability? Again, it seemed Sabrina was unaware that she held the patronizing attitude which she so resented in others. How could others see Kristina as a competent adult if her own same-aged sister and her parents didn't?

At another conference, a group of adults (who happened to have cognitive disabilities) said they liked the stories I shared about my son, Benjamin. But I was surprised when one of the leaders sympathetically said, "Benjamin

sounds like a neat kid, but it's really too bad he can't walk." For years, I had heard similar comments from people who knew nothing about disabilities, who felt this was the "right" response. This same sentiment was now being uttered by a leader of a self-advocacy group! He evidently embraced a Hierarchy in which physical disabilities are "worse" than cognitive disabilities---which is the opposite version Sabrina embraced.

"Suzanne," the leader of a parent organization, told me about helping "Marcia" with special ed issues. Marcia's child had a part of his brain removed to control seizures. Suzanne said, "When I think of Marcia's son, I realized how blessed I am---my son *just* has autism, and he's very *high-functioning*." Shocked that a "leader" held such an attitude, I asked, "If you're *blessed*, what does that make Marcia? *Cursed*?" She sputtered that she didn't "mean anything by it." Then why did she say it to me, and would she have shared this opinion with Marcia?

We also promote the Hierarchy when we make a diagnosis the defining characteristic of a person and/or the family member! This occurs during an introduction like, "I'm the parent of a 'Down syndrome child';" with an Email address such as "c5para@xyz.com;" or an Email signature like "Mary Lou, mother of Stephen, severe MR and uncontrolled seizures." In an Email to me, Mary Lou complained that no one could see past Stephen's disabilities. *Duh*---how can they when her signature makes his diagnoses the most important things about him? And how does Stephen feel about this? The *intent* of this practice is to "share information," but few consider what unintended negative outcomes may occur.

At a meeting of parents of children with disabilities, a "contest" erupted. Adoptive parents introduced themselves by sharing their children's labels and "problems." Some of the birth parents "gave the prize" to the adoptive parents, saying: "Wow---you've got us beat! You *chose* to adopt kids with all these problems!" The adoptive parents upped the ante with, "Yeah, we *knew* about *our* kids' problems, *but you didn't*, and you still kept your children, *so you're more special*." Gag! This patronizing "special, heroic parent" myth will never die as long as we continue to feed it.

It seems no population in the disability arena is exempt from the stratification of the Disability Hierarchy. A friend who was a Voc-Rehab counselor said his coworkers often ridiculed people with developmental disabilities who had come to them for employment help. They spoke freely in front of my friend who has an acquired disability. He resigned his position in disgust.

Some organizations tout "their" disability as "worse" or "more challenging" than others---using a variety of words and strategies, plus a dose of pity---hoping to reap more fundraising dollars. Some go beyond the Hierarchy---essentially placing death and disability in the same

category. One organization's brochure includes "Tips for Having a Healthy Baby" and also features this bold statement: "[We've] achieved a track record of advances that have saved millions of babies from death and disability." This reinforces the "disability as a fate worse than death" paradigm. And this is demonstrated by a commonly-heard exchange, when the question, "Do you want a boy or girl," is usually followed by, "It doesn't matter, as long as the baby is healthy." Translation: "As long as the baby doesn't have a disability." Babies with disabilities are considered unhealthy or different, so they're unwanted and have no value. If this horrific mentality---better to be dead than have a disability---is present within the disability arena, we shouldn't be surprised that it also exists in an Academy Award winning movie (*Million Dollar Baby*).

Finally, there are some people in specific "disability communities" who say "their" condition is "so different," or who state it isn't really a disability at all! They express vehement disdain if they (or their children) are said to be similar to others who are on the lower rungs of *their* version of the Disability Hierarchy.

Little progress in changing societal attitudes will be made if we endorse the Disability Hierarchy. And we shouldn't wait for consensus within the disability arena---that probably won't happen. But we can exert a positive influence, each in our own way, if we so choose.

Consider your own attitudes, words, and actions. Do they represent a hierarchical better/worse classification of developmental, acquired, cognitive, sensory, physical, mental health, and/or other types of disabilities? Do they indicate a medical diagnosis is the most important thing about a person? And do they reflect a belief that some people with disabilities and/or their family members are "so different" from you/your family?

The mantra, "If you're not part of the solution, you're part of the problem," certainly applies to this dilemma. Do your words and actions affirm *positive images* of people with all types of disabilities or do they perpetuate the Disability Hierarchy? It takes courage to look within; sometimes it's painful. But out of the self-examination can come positive, powerful change. Perhaps we would do well to follow Gandhi's sage wisdom: "Be the change you want to see in the world."

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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:

December 8, 2005
January 12, 2006
February 9, 2006
March 9, 2006

CPRI Brake Shop: **Putting The Brakes On Obsessions and** **Compulsions**

Obsessions are thoughts, ideas, or pictures that keep coming into your mind even though you do not want them to. They may be unpleasant, silly or embarrassing. Compulsions are things that you feel you have to do although you may know that they do not make sense. Sometimes you may try to stop from doing them but this might not be possible. You might feel worried or angry or frustrated until you have finished what you have to do (Taken from the Children's Yale-Brown Obsessive Compulsive Scale by Goodman, Price et al., 1991).

Compulsions are the rituals we often do to make the obsessions go away for awhile – those obsessive thoughts torment us very much, and make us feel very uneasy. When something we do makes the torment and unease stop, this feels really good! In fact, it feels so good that we learn to do that thing more and more to keep the torment and unease away; this is how those things become rituals. Common obsessions are about dirt and germs, that you've forgotten to do something, or that something doesn't look or feel or wasn't done "just right". Some obsessions are thoughts that make us feel ashamed, like thoughts about hurting someone you love. Common compulsions or rituals are cleaning, organizing things a certain way, checking something over and over, counting, or stockpiling unnecessary things.


The problem with rituals is that they might be taking up a lot of our time. They might be a little silly and they might embarrass us or cause problems with friends. Plus, we might not always have time to do our rituals, or people might not understand our rituals. And if we can't do them, or if someone takes them away, that brings all the


torment and unease back even stronger than before! We might blow up at someone, or in a situation, because we can't handle all those obsessions again!


All this doesn't mean we are weak, or lack moral fibre. What it DOES mean, though, is that most people have good enough brakes over their thoughts to stop them when they don't want to think those thoughts anymore. We don't. That traps us in the same thoughts over and over so we can't shift to new thoughts as easily as others can.

All this doesn't mean that we can't do anything about it, though! You CAN recover from the problems that Obsessive-Compulsive Disorder (OCD) creates, and you CAN get rid of all that torment and unease. You know what else? You deserve to!


So let's give 'em a brake!

 Of critical importance is to educate the person in what obsessions and compulsions are, and how to recognize when they are interfering with his true intentions. Many children and youth, when first diagnosed, are not aware that the impulses and thoughts they deal with are not common experiences for other children. Furthermore, they may have never known what it is like to NOT have these experiences. Hence, developing the insight to recognize the disorder's influence will take time and patience. It is, however, an integral step for learning to deal with the diagnosis. Doing so will help them to "distance" themselves and their thoughts from the anxiety and discomfort created by the obsessions. Once they are able to do that, they are better equipped to withstand things that do not go 'just right' without subsequent outbursts or turmoil.


 A good way to begin this education is to externalize the obsessions; create a name together for them (Mr. OCD, That Silly Brain Tic), and reframe problem situations as the Mr. OCD getting the person into trouble, rather than the person choosing to get into trouble him/herself. When the person is experiencing a moment of inflexibility, address the disorder rather than him/her. Finally, creating a code-phrase (e.g. "STUCK"! "BRAIN-LOCK!") to use when the person is lost in an obsession may be a way of breaking the hold and cueing everyone that the true enemy in a situation is that obsession, and not each other.


 When in the midst of discussing a "brain-lock", enquire as to what exactly the thought is the person is experiencing which is causing him such angst. Doing so can illuminate new potential avenues for problem solving

the situation (e.g. finding a way to satisfy the anxiety in a less obtrusive way). Knowing the anxiety-provoking thought can also allow others to help the person realistically appraise how “dangerous” the thought really is, thus further distancing himself from the anxiety (e.g., “what do you think might happen if you don’t _____? How likely do you really think it is that this would happen?).


 **Exposure and Response Prevention (ERP) therapy** is highly effective with OCD and could be explored as a treatment option. Here’s how it works: since the only reason we do the compulsions is because the thoughts bother us so much, we work to make the thoughts less bothersome. Those thoughts might still be there because our brakes are still leaky, but they don’t have the same power over us that they used to. This means we don’t need to do our compulsions and rituals anymore, because who cares now if those thoughts are in our heads or not! You might even learn to laugh at those silly thoughts trying to make you do things you don’t want to do!


People are sometimes concerned that spending a whole lot of time facing their obsessions will make their compulsions WORSE instead of better, but this isn’t true. Other people get scared that, by losing the fear around their obsessions, this means that they will actually start to do all the awful things they might be thinking about. That isn’t true either.


 It is difficult to fight every obsession at once; it is important to pick just the ones that are causing you the greatest difficulty and work on each of those one by one. As well, some obsessions if properly channelled and controlled can help you rather than hurt you (for example, thoughts around doing schoolwork really well might help your grades!). Therefore, some strategies below suggest how to ‘adapt’ to certain obsessions and compulsions or accommodate them into your life in ways that will not create problems.


 It is helpful for us and for those around us to recognize ‘triggers’ for certain obsessions, which then lead to the compulsions. Maybe whenever we go to a certain place, or do a particular thing, this makes those thoughts appear. Triggers could be certain toys, time of the day, amount of sleep the night before, amount of stimulation in the room (i.e. number of people or amount of noise), seeing a particular object out of place, or many other things. Some of those ‘triggers’ might be completely avoidable, so that we limit the times all of those thoughts will be popping up. This is a good plan at times when there just isn’t enough time to do the compulsion or to


‘shift gears’. On days when it can be predicted that it will be a “bad brain-lock” day, the day should be organized to anticipate difficulties – more transition time planned between activities, for example.

 For activities that you know ‘trigger’ the person’s obsessions, spend some time together deciding how long you will spend on that activity. Decide this before starting the activity though, otherwise you’ll already be ‘triggered’ and it will already be hard to think about it clearly! Create clear end-points to the activity and time them to occur at the start of something else equally interesting to you. Time Timers may be helpful visual reminders – available for sale at www.addwarehouse.com, these timers are set by moving a red disc counterclockwise to the desired time interval. The disc diminishes as time elapses until no red is visible on the timer face.


 Establishing many predictable routines will be important in decreasing the person’s anxiety, as they can rely upon the increased external structure. Routines will also make transitions between activities go more smoothly, as transitions can be made part OF the routine. It is even possible to plan for the unexpected by developing a routine to rely upon at these times – a routine for when you don’t know the routine!


 Using a computer for homework and also for as much schoolwork as possible (e.g. on a laptop, or using an Alphasmart) can be a really good idea for a number of reasons. Many times frustrations develop from obsessing on letters or page layouts that don’t look ‘perfect’ or ‘just right’. On a computer every letter is always precisely formed, lined up, or centred how you want it, and page layout can be changed in a snap! Also, these days the memory storage capacity of computers is enormous; any obsessions around keeping many useless things (called ‘hoarding’) can be easily accommodated on a computer.


 Sometimes it may seem like it is impossible to reason with the person experiencing obsessions and compulsions. This is because the person is ‘stuck’ – it doesn’t mean that what you are saying isn’t sensible and it doesn’t mean that the person with OCD wants to disobey you or pull you into a power struggle. They might want to shift away from whatever they are doing or saying just as much as you want them to! The more they try, though, and the more they think about it, the harder it gets to stop.

 For this reason, distraction can work really well with people who are obsessing. Using humour is an excellent distracter; it is a way to drive away anxiety


associated with the thought so that the person can shift more easily.


 Routines should be established for and with the person experiencing obsessions and compulsions, and adhered to as much as is feasible. Doing so provides a constructive “channel” for some of the rigidity. Also, the resulting increased external predictability over his/her life will help to compensate for the loss of control felt over his/her thoughts and behaviours.

 Always check to make sure that the person who experiences obsessions and compulsions is very clear in what he is expected to do, and that he knows how to do it. These individuals are more likely than others their age to become “stuck” when feeling uncertain about how to proceed with a chore, a task, or a school assignment. These are also children and youth who may repeatedly ask the same questions over and over to cope with that anxiety.

 An appointment with a physician who specializes in mental health problems and who is familiar with psychotropic medications such as Selective Serotonin Reuptake Inhibitors (SSRI's) and tricyclic antidepressants (e.g. clomipramine) can be considered. This might be a psychiatrist, a pediatrician, or a neurologist. The therapy listed above may work better without any medications at all, though, unless the obsessions and compulsions are SO strong that it is impossible to even START therapy.


Finally, here's some handy “Don'ts” and “Do's” for family members and friends supporting those with OCD; I've taken some ideas from Dr. Fred Penzel, who helps people with obsessions and compulsions, and expanded on them:


 **DON'T force the person to get help.** You can't care more about treatment than they do, otherwise this simply becomes another area of power struggle.

 **.....but DON'T function for them, either!** If the person is getting his/her needs met anyway, why is it worth it to them to bother getting better? This might be hard for you to do – you might feel that you are being mean, purposely leaving the person with OCD in misery. Doing this has important implications for motivating him/her to want help though. If that person is unhappy enough, and the only way for change to happen is for him/her to participate in treatment, then (s)he will be motivated to work at making things better.


 **DON'T be responsible for the person following his/her treatment.** Otherwise, (s)he won't


learn anything from the exercises, or feel any personal accomplishment for accomplishing the homework.


 **DON'T try to 'catch' the person** in a compulsion, **show impatience** with slow progress, **or punish him/her for not getting help.** These things all add stress to the obsessions, which is the exact opposite of what we want to do. It will only make the obsessions and compulsions worse!


 **DON'T participate in the person's symptoms.** If you've already been doing this in the past, it is ok to either phase out your involvement OR go 'cold turkey'. Not 'playing along' may create a lot of anxiety in the person initially (particularly if you've participated in rituals in the past) and may cause some explosions (particularly if you stop 'cold turkey'), but this short-term frustration is much better than a long-term dependence on you. The more you take part in the compulsions, the more you are helping the person to avoid the anxiety the obsessions create. The more (s)he avoids the anxiety the less able (s)he is to tolerate that anxiety. What this all means is that the obsessions will become stronger and stronger, and that person will need you to engage in his/her rituals more and more often, and more and more quickly. Pretty soon the obsessions and compulsions have taken over everyone and everything!


 **DO** see the person behind the disorder.

 **DO** see the person's progress and acknowledge it, and be positive. If (s)he slips up, acknowledge the slip-up but still reinforce the EFFORT.

 **DO** obtain information about treatments, strategies and success stories from websites, books, media sources, and support groups. Plant these seeds in the person.

 **DO** offer to help with treatment

 **DO** support efforts to be independent (e.g. develop own homework). You will not be around forever, and this person must face their obsessions and compulsions for his/her whole life.

 **DO** concentrate on living your own life!

© 2004, Dr. B. Duncan McKinlay, Psychologist

Chapter Advisory Committee

We are pleased to announce that Dr. Mary Jenkins, Neurologist, has joined our Chapter Advisory Committee. Dr. Jenkins began practice in London in August of 2004 and is currently seeing TS patients at the Movement Disorder Clinic at LHSC (London Health Sciences Centre) and at the Pediatric Movement Disorder Clinic at CHWO (Children's Hospital of Western Ontario.) Before entering medical school at UWO, Dr. Jenkins was a special education teacher with the Thames Valley School Board.

Dr. Jenkins joins Dr. Duncan McKinlay on our Advisory Committee.

A MIND GAME for the Kids (or maybe even Mom and Dad)

- think of a number from 1 to 10
 - multiply that number by 9
 - if the number is a 2-digit number, add the digits together
 - now subtract 5
 - determine which letter in the alphabet corresponds to the number you ended up with (example: 1=a, 2=b, 3=c, etc.)
 - think of a country that starts with that letter
 - remember the last letter of the name of that country
 - think of the name of an animal that starts with that letter
 - remember the last letter in the name of that animal
 - think of the name of a fruit that starts with that letter
 - are you thinking of a Kangaroo in Denmark eating an Orange?
-

Study of Voluntary TicSuppressions

The TSA has chosen a study of the effects on TS patients of their voluntarily suppressing tics as one of the 2004-2005 funded projects. Included here is a description of the project proposal submitted by Dr Douglas Woods of the University of Wisconsin.

"Non-drug interventions for TS (e.g., habit reversal training; HRT) teach people techniques that may help to control (i.e., suppress) their tics. However, voluntary tic suppression may have unwanted behavioral side effects including a "rebound effect" in which tic frequency, after a period of voluntary

suppression, temporarily increases to levels greater than baseline. If this is true, it would suggest that we should be cautious in our approaches and use of non-drug therapies for TS.

"While many professionals assume that the rebound effect occurs, very little research has been done. It is unclear what enhances a person's ability to voluntarily suppress tics, and if a rebound effect occurs, the behavioral factors that create or prevent this effect are unknown.

"Our study will be coordinated by the University of Wisconsin-Milwaukee, and data will be collected at North Dakota State (Fargo, ND) and Western Michigan (Kalamazoo/Grand Rapids, MI) Universities.

"Our objectives are first to evaluate the effects of voluntary tic suppression on the frequency and severity of motor and vocal tics after three durations of tic suppression (5 min, 25 min, and 50 min). We hypothesize that tic suppression may lead to a temporary rebound effect that will increase as the duration of suppression lengthens. Second, we propose to identify variables that predict an individual's ability to suppress tics. It is expected that increased tic severity, decreased response inhibition, and deficits in working memory will reduce the ability to suppress symptoms.

"Our results will allow us to determine the presence or absence of a rebound effect, and whether it is more likely to occur as periods of suppression increase. Likewise, results may inform us on neuropsychological factors that would predict tic suppression or rebound effects. Our findings will be informative in the development and modification of non-pharmacological interventions for TS, and will aid in the understanding of tic suppression and its effects."

As parents of children with TS we believe we know the results of a study such as this, however, when the results are in, we may be surprised. Do tics lead to tic suppression or does tic suppression lead to increased tics? Or both? Or neither? Whatever the result, think about how much more effective we could be, attending a school meeting with scientifically proven facts?

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

Disinhibited Thoughts #12

Three instalments ago I told you how important it is to feel good about yourself. Then over the past two instalments I proceeded to make mention of the many unfortunate reactions you receive. I stated that you must show understanding and forgiveness in the face of these reactions. Finally I suggested that rather than hold the perpetrators responsible for their lack of knowledge about TS you must take the opportunity to educate; moreover you must be prepared to accept some blame for negative reactions aimed at you if you have not done so.

That's a tall order. I'll show you what I mean -- let's try a scenario: I've often experienced difficulties with the friends of girlfriends I've had. A person that has the capacity to understand me, patience to live with me, personality to enjoy me, strength to handle me and willingness to assume some public and familial awkwardness in being with me is a rare and special individual indeed. The odds that all of her friends will show the same combination of unique and coveted qualities are scant. Perhaps that is why I've often been plagued by the 'normie cheerleader squad': people that can so easily and quickly dismiss, judge or condemn me based on a very surface knowledge of who and what I am and rally to convince my partner to return to the fold of normalcy.

What is even more difficult, however, is that I cannot react to this behaviour. These people would be (and have been in the past) so quick to pull their friend away from what they perceive as an oddity, a danger.....yet when I manage to climb past my own defences I can appreciate their perspective as good friends watching out for someone they love (and what is more I'd better see this if I don't want to cause major rifts with my partner).

The final kicker is that after reaching deep into myself, after snuffing anger at rude and even malicious acts with the knowledge that I AM the disruption to the rule, I AM a discrepancy in expectations that I cannot blame people for not intuitively adjusting to, I walk spent and robbed down a hallway to find yet another person jumping, staring or snickering at my tics. My recent mental wranglings have not 'bought' me any right to retort to this salt in the wound. I must continue on. The obligations of living in disorder are relentless.

It may be true that for us to hold the knee-jerk reactions of others against them we ourselves are then small and in the wrong. People WON'T always understand, some people CAN'T understand, and we must leave it at that -- to do otherwise is being intolerant and unfair ourselves. However whether the reaction was necessarily purposely

malevolent or not, the end result is that we have been hurt and are left with little recourse to alleviate the pain.

That leaves us doing all the work. That means that others can react with impunity and we cannot. It's unfair. It's a difficult burden. And it's the way it is. While I'm not going to tell you that there is a fair solution to this quandary I, at the very least, thought you deserved some recognition, validation and commendation for living it day to day.

Until next time, my friends!!

B. Duncan McKinlay, M.A.Sc., Ph.D. Candidate

Visit "Life's A Twitch!" at

<http://www.lifesatwitch.com>

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April 2001

ANNOUNCEMENT

Children and Adults with Tics and Tourette's Syndrome

Dr. Mary Jenkins is a neurologist in the Movement Disorders Program at London Health Sciences Centre with a particular interest in Tourette's syndrome. In addition to her neurology residency, she has fellowship training in both adult and pediatric movement disorders, including the management of Tourette's syndrome.

Your family doctor, pediatrician, or other specialist may send referrals for assessment of children and adults with tics and Tourette's syndrome to her office at University Hospital.

Referrals may be faxed to:

Dr. Mary Jenkins
fax: 519-663-3416

or Mailed to

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TS in the News

A story from Reuter's news service reported that researchers have found a gene that "appears to contribute to some cases of Tourette's." They report this information as coming from an article in the journal "Science" on Friday, October 14, 2005.

A TSA (Tourette Syndrome Association – USA) web site article leads with this paragraph:

"In what is being called a significant breakthrough in understanding the genetic underpinnings of Tourette Syndrome, researchers have identified a gene mutation that appears to lead to this neurological disorder in some individuals."

Dr. Matthew State of the Yale University School of Medicine was part of a study team that found a boy with TS and who had no other members of his family showing with TS. The gene involved is known as SLITRK1. The condition of the gene abnormality is called a "gene inversion."

The TSA web-site continues with:

"While not a cure, TSA's funding of this effort is not only a logical 'next small step,' but it is also potentially a 'giant leap' for the broader field of TS science, and especially for the long-standing efforts by scientists to identify the causes of, and improved treatments for this disorder," said Dr. Neal Swerdlow, Chair of TSA's Scientific Advisory Board and neuropsychiatrist at the University of California, San Diego, School of Medicine. "

Dr. State said that this find is not likely to be the answer to TS. He continued with "I think there is general consensus at this point that there are likely to be multiple genes, likely interacting, and probably different sets of genes in different people, that contribute to TS."

Dr. Yves Dion, a member of the TSFC's Professional Advisory Board, cautioned that this is a preliminary finding only. Dr. Dion added "It's too early to tell. The real clinical significance remains to be seen."

While the real value of this find doesn't appear as though it will have an affect on the daily life of those of us with TS in the next couple of years, it does sound like we aren't the left out group we were 20 years ago. Research is being effective, progress is being made.

Tourette Syndrome Foundation Of Canada – Conference 2005

Celebrating Hope, Change, Innovation

The TSFC conference of 2005 was held in Montreal, Quebec from October 20 – 22, 2005. It was an event that has become synonymous with excellence for providing updated news and information about TS and TS+, showcasing an incredible caliber of speakers and wonderful volunteer workshops.

My conference began Wednesday morning, Oct. 19, at 8:30 AM, with a road trip to Montreal accompanied by Ray Robertson, Nadyne Gooding and her daughter Charlotte, all traveling in Ray's van from London to Montreal. We had an instant route revision implemented as we came into Montreal, but we found our destination, the Delta Centre-Ville, around 5:30 PM without any real trouble. After the check-in we proceeded to have an evening meal then attended the "Greet and Meet" held in the hospitality suite. It was great to renew old acquaintances, chat with people that I haven't had a chance to meet before, and generally catch up with people from all across the country and the US.

The conference began in earnest with the Volunteer Leadership Development Workshops, Thursday morning from 7:30 AM to 5:30 PM. There were two workshops, as is usually the case. One was the "Fund Development Training Workshop" and the one I attended, "In-Service Presenters' Training Workshop", facilitated by Cathy Wylie.

The In-Service Presenters' Training Workshop is one of the necessary components to becoming a sanctioned TSFC In-Service presenter. There were a number of volunteers attending the In-Service workshop plus a representative from the Toronto police force, who trains other officers, who attended the conference for the entire weekend. It was fantastic to see there is interest in gaining information about TS so that police might more readily recognize some of the characteristics involved and perhaps alleviate some of the problematic issues that can arise when dealing with a person that has TS+. We were divided into groups and had to discuss and develop strategies for dealing with topics that would be a part of an In-Service presentation, and then we gave mini presentations on our groups' topic. My table had ADHD as a topic, and I learned from a 16 year old that was attending the workshop, that there is an aspect of ADHD he termed, "hyper-focused" which causes a person with ADHD to be unable to move off a task he is stuck on. For instance, a homework problem/question, and cannot

manage to skip and return to the problem later. He suggested that it might cause bigger problems to argue that the person who is experiencing this hyper-focus move on to a new problem. Instead it might be better to utilize a strategy of suggesting that it might be time for a short break from homework for a snack or something. He also gave the presentation for our table and was very articulate in delivering a fine mini-In-Service.

Overall, the workshop was full of information on how to conduct an In-Service for various venues, such as younger aged school students, teachers, organizations and whole school auditorium presentations. We were provided with an easy to understand outline for using different aids, such as a power point slide projection, a flip chart, and overhead projector, or just an oral presentation depending on the location and the availability of materials to make a presentation. Attention to small details such as remembering to bring along magic markers AND white board markers, being sure not to mix the two together and maybe use the wrong one (magic marker) on a white board. Other areas covered included, but were not limited to, positioning of the flip charts and other presentation materials, positioning of the presenters themselves so as to give everyone attention and a feeling of inclusion. We had to sign our confidentiality agreements and the details of what this meant were explained. Cathy Wylie delivered a presentation that was informative, without becoming bogged down on small details, while still covering all the important issues and facts that are needed to put on a credible In-Service as representatives of the TSFC. Some of the small details included information about where the In-Service will be and how to get there, before we run into problems with logistics. Also, the logistics of the room in the building, such as does it have a working electrical outlet. Another was to be sure to get there early enough to set up the presentation so you're ready to go since most of the presentations are time limited and not being ready may use up what time there is. Attention to some of these small things can have a big impact on how the overall presentation is perceived. I believe Cathy Wylie deserves a BIG thank you for her efforts in giving all those present the tools we will need when representing the TSFC during any future In-Service presentations we conduct.

Thursday evening there were several "Getting to Know Us Better Workshops" that ran. Included in these were the Mom's, Dad's, Children's and Youth and Adults. Dan Pruitt facilitated the Dad's workshop. We quickly introduced ourselves and let the group know the general diagnoses and ages of our children. Then we discussed the successes and difficulties we faced having a child with TS or TS+. We touched on the areas of: dealing with guilt for the treatment of pre-diagnosed disciplines, trying to come to terms with the fact that we cannot "fix" this,

not imposing "blame" for the disorder, after all it takes the combined genes of both Mom and Dad for the child's' genetic makeup. It was a workshop that contained laughter and emotion from the Dad's who were fortunate enough to attend.

After the Dad's workshop was over I hurried to the Adult Issues Forum. I have an interest in both as I am a parent of a 14 year old son with TS+ and an adult with TS+. I got there just before it finished but enjoyed the 30 minutes that remained while I was there. It was great to see Dr. Yves Dion attending and he helped answer some of the questions about various issues from those present. Once the workshops were over it was time to socialize and get caught up with people I have come to know over the years. We had a laugh filled, joke fest till I finally headed to the room for some deserved sleep.

Next day, on Friday, began all the different tracks for the conference. These were the Educators Track, General Track and the Adult Track, that I attended. "So Now What? Going from Surviving to Thriving" was the first round table discussion, facilitated by Darin Bush. It was combined with Gord Brown's round table discussion, "An Intimate Look at Tourette Syndrome for Men Only" as there were logistics problems for holding both in a small area. It was an amazing hour and a half session that continued right through the break for another hour. We discussed problems related to medications, work relations, personal relations, social situations, self advocacy, legal issues, intimacy and some ethical issues. The topics discussed were addressed by different individuals who had already experienced similar situations and openly shared what was right about what they did and cautions about some of the issues involved. It was an informative and lively session with a serious tone tempered by the "TS sense of humour" that pervades throughout most of our lives.

I next had the good fortune to attend part of the session presented by Jonathan W. Mink, M.D., Ph.D., "Deep Brain Stimulation for Tourette Syndrome: Hope or Hype?" What a fountain of information on a very controversial subject. Dr. Mink presented the facts about DBS (Deep Brain Stimulation) for TS and the conclusions of what he has found to be true as pertains to DBS as a treatment for TS. At the time of his presentation there were only 5 published studies about DBS treatment for TS. This treatment, more common for treatment of Parkinson's disease, is the implantation of electrodes directly into the brain that send electrical pulses to stimulate areas of the brain that affect Tics, involuntary motor movements, that are a symptom of Tourette syndrome, and effect a cessation of these motor Tics. These electrodes are attached to wires that run under the skin, down the side of the neck to the chest area,

attaching to a battery that powers the electrodes. The procedure costs about \$30,000 (American currency) and the battery, when it needs replacing costs \$15,000. In addition to the monetary costs involved, there is the issue of numerous post-operative complications from bleeding 3 – 4%, erosion/infection 5 – 25%, seizures 1- 2%, post-operative mortality 0 – 1.8%, hardware failure 5 – 27%, battery failure and replacement at 6 – 9 months at high stimulation rates. Dr. Mink's conclusions were that DBS has exciting potential for TS, and should only be performed by a team with experience treating TS and experience with DBS. DBS is NOT a cure for TS and the risks are NOT trivial, DBS is probably appropriate for only a very small percentage of those with TS and that his conclusions would likely change with the accumulation of more experience with DBS. It was an eye opening session delivered by an expert in the field that gives us all plenty to ponder about this "breakthrough" procedure. Thank you Dr. Mink!

Next, it was off to lunch and the Awards Ceremony. It was a wonderful opportunity to recognize many of the individuals and volunteers who have made a difference in the lives of people with TS. There should be pictures posted on the TSFC's National web site, www.tourette.ca later along with more information. Congratulations to all the recipients for their efforts and work.

After lunch, Yves Dion, M.D., gave a presentation on "Obsessive Compulsive Disorder and TS" sharing much of his knowledge and helping to educate us about OCD and the available treatments. I found Dr. Dion to be candid and caring as he answered questions and concerns from the audience. I'd like to express my thanks for his contribution and straightforwardness during all sessions he participated in during the conference.

The next session, facilitated by Daniel G. Pruitt was called, On Your Own: Organizing As A Path To Independence. This Adult Track session was geared to helping TS adults to stay organized and focused for success in society. Some of the issues addressed were planning, keeping a day timer, time management and other strategies. This session was well attended and a lot of information was given and discussed among the group. I have attended several of Dan's sessions over the years and once again, it was both a pleasure and a well of useful information.

After the session finished at 4:30 PM we had a break till 6:30 PM when we had a pizza and pasta dinner followed by an enthusiastic drumming session, facilitated by Matt Giordano, who has TS himself. It was amazing to see a room full of TS+ kids, adults, parents and siblings all creating havoc in an organized co-operative fashion.

Matt is a percussionist and led us in many rhythmic drumming sessions. We all had a laugh filled energetic time of it! Thanks for helping us "beat" the doldrums for a night, Matt!

Saturday started with breakfast at 7:30 AM followed by the TSFC Annual General Meeting. After we dealt with the "business" of the TSFC we got right back into more sessions. Next on the adult track was Cathy Wylie facilitating "Finding and Keeping a Job: Skills for Adults with TS/TS+" a session that was geared to helping individuals with TS/TS+ understand their rights and obligations when entering the work force, going to job interviews, seeking accommodations in the workplace and other issues relating to TS/TS+ and working. We discussed various strategies and solutions to problems encountered by participants of the session. Cathy has been involved with the Human Resources side of business for some time and imparted her knowledge freely and clearly, addressing many questions and concerns. Thanks for a great session Cathy.

After a refreshment break the adult track continued with the "Review of Medications for Adults" session, facilitated by Dr. Yves Dion. We were treated to a session full of information about the different medications available to adults with TS/TS+ and their different effects and side effects. Topics such as impotence, addiction and other side effects were addressed ably by Dr. Dion. I hope to see more of Dr. Dion at future conferences. Thanks for all you have helped throughout the conference.

Gary Altman, M.D., FRCPC, presented "Tourette Syndrome – Pharmacotherapy 101" after lunch. Using a PowerPoint slide show, Dr. Altman educated us on the various aspects of TS and its' various co-morbid disorders. He presented facts about the various treatments available and their effectiveness in treating the various TS+ disorders. One fact I found interesting was the answer to something I had wondered about. On the question of the different medications losing their effectiveness as a child grows, and the similar doses prescribed for both an adult and a child, Dr. Altman pointed out that the head grows very little between childhood and adulthood. So with TS being a disorder of the brain, the dose would be similar between adults and children with little decrease in effectiveness as the child grew. Makes sense to me! Another aspect of the presentation was the correlation between effective pharmacological treatments used for ADHD in conjunction with cognitive therapies. The effectiveness of each therapy on its own was far less effective than by using them together. There were questions from those attending and the answers were thorough and informative. Thanks for a wonderful presentation Dr. Altman.

The final session was by Shelia Rogers, MS, "Tourette Syndrome: Naturally!" and she presented us with many facts about natural remedies for treating TS/TS+. What a diverse session for treating the many aspects of TS+! Thanks Shelia, for your informative presentation and perspective on the alternative treatment of Tourette Syndrome through natural means. You gave us lots to think about!

We had a break until it was time for the banquet where we enjoyed a great meal and were introduced to the new executive board, including our new National President, Linda Newton. After the meal we were treated to a lively performance by Dr. Duncan McKinlay and the "Vocal Tics" air band! Rick Fowler and Friends helped to

rock and roll the night away! Their music was loud, raucous, rock and roll! What could be better? Rick, who also has TS, and his band played great music as time TIC(K)ed away!

Although I did not get to hear the speakers and presenters in the Educators Track or the General Track, I heard they were terrific, as were all the participants in all the sessions. The children's program, run by the Brake Shop team headed by Dr. Duncan McKinlay, was a huge success. Congratulations to all the organizers for all the hard work that went into this exciting and successful conference.

By Gerard Johnson

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

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