

Our Actions—Their Futures

Revolutionary Common Sense by Kathie Snow

The nation's unemployment rate remains very low (4.6 percent as of May 2006). Immigrants (legal or not) who choose to come here can easily find work. The government says our economy is doing great. And the estimated unemployment rate of people with disabilities remains shamelessly high at 70-75 percent!

Adding insult to injury, consider the birth-to-death services for individuals with disabilities: early intervention for babies, special ed for children, vocational services for adults, and therapies and interventions for all ages. Billions of dollars are spent on these services and we end up with what? A 70-75 percent "failure rate"!

What we're doing is not working! We continue to focus on helping people acquire "developmentally appropriate functional skills" (the able-bodied standard), based on the mistaken notion that unless and until a person with a disability can "do" this-or-that, he won't be able to be in regular ed classes, be included in the community, go to college, get a job, and on and on. We keep focusing on what we think their bodies or minds can or should *do*, instead of helping a person *be and become* who she wants to be!

For example, a teacher in a life-skills class is still trying to teach her sixth- and seventh-graders to tie their shoes! *Who cares if they can tie their shoes, and how will this help them get jobs in the future?* They can wear slip-ons, pull-on boots, or shoes with Velcro, or they can walk around with their laces untied like other middle-schoolers! While the teacher spends time on this functional skill, students are not learning the academics they really need. This dismal situation is repeated in the lives of millions of others, when the focus is on skills of dubious value at the expense of what's really important.

Targeting short-term goals, like functional skills, represents a dangerous level of short-sightedness, and the system encourages this bad habit. Early intervention focuses on birth-to-three, and seldom looks beyond. Special ed preschools serve three- and four-year-olds, and they seldom look beyond—ditto special ed in elementary, middle, and high schools. There's little or no continuity as children are moved up the ladder of services—few of us see the "whole person" across the lifespan. Within the different levels of services, we focus on functional skills—*for the sake of achieving those skills*—with little thought of whether these skills are really important for the child's long-term success.

Oh, we *think* we're thinking about the future, when we believe a child must learn to walk or talk or have "appropriate behavior" in order to be successful. I did, at one time. But when I met adults with disabilities whose power wheelchairs, service dogs, communication devices, and other supports helped them lead successful lives, I realized my then five-year-old son did *not* need to walk to have a good life! What he needed was a good academic education, and he also needed to learn how to live in the real world. Being

Continued on page 5

In This Issue

Our Actions - Their Futures	1
President's Message	2
Book Review - Natural Treatments	3
Dear Doctor - Deep Brain Stimulation	4
TSFC Conference - Niagara falls in 2007	4
What's new in Research - Habit Reversal Training	9
A new school for kids with TS	11
TS in the News - Briton's Idol	12

How to Reach Us

London Chapter
Box 28084
London, Ontario, N6H 5E1
519 457-4586
rayrobertson@hotmail.com
www.tourette-london.ca

National Office
194 Jarvis Street
Toronto, Ontario, M5B 2B7
416 861-8398
1 800 361-3120
tsfc@tourette.ca
www.tourette.ca

TSFC London Chapter Administrative Committee

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

TSFC London Chapter Advisory Committee

Dr. Duncan McKinlay
Dr. Mary Jenkin

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.

Contributing Authors

Brigitte Heddle
Dr. Mary Jenkins
Gerard Johnson
Dr. Duncan McKinlay
Jennifer Robertson

President's Message

Our front page story once again comes from Kathie Snow's Disability is Natural Free Press. The article is written in the United States and statistical quotes are for that country, however, the story is appropriate in any country.

The Book Review on page 3 is on a book by Sheila J. Rogers titled Tics and Tourette's – Breakthrough Discoveries in Natural Treatments. Ms. Rogers was a speaker at the TSFC 2005 Conference in Montreal and we picked up a copy of her book there. Her talk led to some interesting discussions about the use of alternative practices. If the review leaves you wanting more information, the book can be borrowed from our library.

At the conference in Edmonton I met and talked with Dr. Norm Forman, author of the book, "Exceptional Children – Ordinary Schools", that we featured in the book review in our August newsletter. Dr. Forman partnered with Bob Clements, Program Director of the Ontario Association of Education Advocates to present "Welcome to the World of School Advocacy." These two individuals have a wealth of experience in dealing with school systems.

Dr. Mary Jenkins' article is about Deep Brain Stimulation. This procedure is still experimental in its use for treating TS with less than a dozen cases worldwide. This is the first time we have addressed DBS in our newsletters and I hope you find it informative.

While Dr. Jenkins was putting together her article, the London Free Press headlined a story on the front page of the Business section of October 7, 2006 titled "Invention rewires brain." The sub-title reads "The award-winning technology may relieve neurological disorders such as Parkinson's" and later in the article includes Tourette's syndrome as one of the conditions that may be helped. The company is Medtronic, based in London, and the story says that "the technology was created by Mandar Jog, a neurology professor and director of the movement disorder program at the London Health Sciences Centre." It will be interesting to see how this technology differs from the DBS technology that Dr. Jenkins talks about in her article.

Brigitte Heddle takes a look at Habit Reversal Training (HTR.) Her article is based on 3 sources which are identified by an editor's note at the end of the article. Many years ago our family was told that there were alternatives to medication. Those alternatives were always elusive. Perhaps HRT is what we have been waiting for.

The article on Shannon's school is a copy of a news release promoting the Distinctive Learning Centre. I first met Shannon in March of 2002 after her son had been diagnosed with TS and have been aware of some

of the struggles the family has gone through dealing with the education system. Interesting concept – when the school system fails you, create your own school.

We also have TS in the News, an interesting article by Steve Mooney of Capabilities Plus about being a teacher's aide and a number of other interesting pieces. I hope you enjoy our November newsletter.

Ray

Book Review

Tics and Tourette's – Breakthrough Discoveries in Natural Treatments

by Sheila J. Rogers

Royal Palm Beach: Association for Comprehensive NeuroTherapy, 2005

This is an amazing book. I admit, I am probably biased in favour of it because I have a strong personal belief in alternative lifestyle choices, but it's hard to imagine anyone not being intrigued by the possibility of tics and OCD being completely eradicated without the use of medications.

This book is for anyone who has ever experienced, or seen a loved one experience, the side-effects of conventionally prescribed medications. We all know the list: weight-gain, lethargy, drowsiness, a "zombie-like" state of reduced alertness and mental capacity, mood swings, anxiety and more. A series of trial and error attempts to find the right combination of medications and dosages. Sometimes we wonder if the side-effects are worse than the tics and compulsions, and wish there was an alternative treatment. This book tells us there is, and describes a variety ways to go about it.

The book is compiled by Sheila J. Rogers, Director of the Association for Comprehensive NeuroTherapy, an organization founded by parents and concerned others to investigate a comprehensive approach to diagnosing and treating TS and associated disorders. ACN focuses on examining environmental, mental, and nutritional causes for tics and controlling and adapting these factors to reduce symptoms. They publish an online journal called Latitudes which reports on these issues and which is the basis for this book. Because many of these approaches have not been studied scientifically, most of the information

documented comes from anecdotal reports from parents and sufferers world-wide who have themselves, or with the help of alternative medical specialists, tested out these alternatives.

ACN investigates the relation between environmental factors such as household chemicals, scented products, pesticides and fertilizers, dust, mould and pollen, and noticeable increases in tics, OCD, ADHD and rage. It also has chapters dedicated to nutritional factors such as artificial food additives, sugar, caffeine, and food allergies to wheat, dairy, citrus etc. I found particularly interesting the research contributed by specialists on the correlation between flickering lights from television and computer screens, radiation from cell phones, high noise levels, and chemicals and heavy metals in some foods and vaccines.

I was really excited by this book and as I was reading it resolved (as I often do) to re-evaluate my diet and lifestyle choices in an effort to improve my health and possibly reduce my tics. As the book cautions, adjusting lifestyle factors is not guaranteed to eliminate tics completely, but it's hard to ignore the common sense that the food we eat and the environment we surround ourselves with affect our health profoundly. I highly recommend this book.

Reviewed by Jennifer Robertson

What is the role of brain surgery in the treatment of Tourette Syndrome?

By Dr. Mary Jenkins

Brain surgery, in the form of Deep Brain Stimulation surgery, has been proven useful to treat other movement problems such as Parkinson's disease and tremor. This is not a cure; the purpose of the surgery is to treat the symptoms of the disease. In Parkinson's and tremor, the optimal location target in the brain for surgery has been determined after years of carefully studied research. Following surgery, patients with Parkinson's and tremor can often reduce their medication dose but in almost all cases, they still require a low dose of medication.

In Tourette Syndrome the role of brain surgery is more complex. First, the exact location in the brain that causes Tourette Syndrome is not known and so the optimal location for surgery is also not certain. Second, unlike Parkinson's and tremor, which are present at all times, tics may wax and wane in severity over the day, from day to day, and from week to week. Finally, many children with tics may improve and have resolution of the tics in adulthood. Because of this variability of tics, the response to any treatment can be difficult to determine.

What does the surgery involve? This is a form of brain surgery where a stimulator is implanted targeting one discrete location or nucleus in the brain. There are 3 parts to the Deep Brain Stimulator system that are implanted. The first is an insulated wire with four electrodes called a lead. The lead is placed deep in the brain through a small opening made in the skull and the wire runs out to the scalp. This part of the surgery is done using local anesthetic, so the patient would remain awake during the placement of the lead. The placement of the lead is determined by the patient's responses during surgery, in addition to CT and MRI scans and electrical signals from the lead. Then under a general anesthetic, an extension wire is placed running from the lead at the scalp to the neurostimulator. The neurostimulator is like a pacemaker and is placed under the skin just below the collarbone. The neurostimulator is programmed by an external computer that will adjust the system to the optimal level. The surgery can last several hours. The surgery is quite safe with a very low rate (<1%) of complications such as bleeding, stroke or infections.

So far, there are 6 published cases of adults with Tourette Syndrome treated with Deep Brain Stimulation surgery. The improvements in tics ranged from a low of 20% improvement in one person to a high of 90% improvement in another person. The other 4 people had improvement in tics of 39%, 54%, 72% and 83% respectively. These reported improvements were not measured in a "blinded" assessment. This means that both the investigator and patient knew that the stimulator was "turned on" during the assessment. The effects on obsessive-compulsive disorder and attention-deficit hyperactivity disorder were

not consistently recorded and so it is not certain if these were better, worse or the same following surgery. In these surgeries, 3 different areas or nuclei in the brain were targeted to place the leads; of the three areas in the brain where the leads were placed, it is not known which one is the best one location.

The Tourette Syndrome Association (TSA), USA has recently commissioned a number of Tourette's experts and neurosurgeons to review the role of brain surgery in the treatment of Tourette Syndrome. Based on all of these facts listed above, a number of recommendations have been put forth from Tourette's specialists and from the TSA. They recommend that surgery be reserved for adults over 25 years of age with severe tics, which interfere significantly with the person's life. In addition, they should have been treated with at least 4 different medications and have shown a poor response to all medications. It is recommended that people who meet these criteria be sent to a centre that specializes in treatment of Tourette Syndrome. They should be evaluated by a neurologist, psychologist and neurosurgeon skilled in the use of Deep Brain Stimulation surgery. Associated disorders (obsessive-compulsive disorder and attention-deficit hyperactivity disorder) should be assessed. Following surgery, the assessments of improvement should be carried out in a "blinded" evaluation, where neither the patient nor investigator is aware if the stimulator is turned on or off. In addition, the results of the surgery including patient satisfaction should be recorded in a central registry that can be accessed by all health care workers involved in the treatment of Tourette Syndrome. It is also recommended that formal studies be done of this procedure. Finally, while they suggest that brain surgery has the potential to be an effective therapy in a selective group of adults with severe tics, there are many unknowns that require further study before definitely recommending the surgery.

Dr. Mary Jenkins column is a regular feature of our newsletter. If you have a question that you would like Dr. Jenkins to answer, e-mail us at rayrobertson@hotmail.com

TSFC Conference 2007

Niagara Falls, Ontario

September 27-29, 2007

Our Actions - Their Futures.. continued from page 1
pulled out of class for therapy and missing academics would *not* help him in the long run. But having power mobility so he could become more self-reliant and being able to play with other kids and make friends at recess made a difference in his life at the time *and* laid a strong foundation for his success as a young adult—he's now in college.

The artificial standards imposed by the service system (including special ed) may be important *within* that system, but they're relatively unimportant in the Big Picture of life. What *is* important? Believing in yourself; having what you need so you can do what's important to you (such as an education, as well as assistive technology, accommodations, etc.); and being around people who support your hopes and dreams. Think about your own life and what's helped you achieve success.

When will we reject the status quo—the conventional wisdom (which is not very wise) that ultimately leads to the incarceration of people with disabilities in the gulag of second-class citizenship, lost dreams, and hopelessness?

What if *our* work was focused on *their* work in the future? What if—starting with babies—*everything we did* was guided by the presumption that children with disabilities will grow into adults who can and should go to college and/or enter the workforce, and live the lives of their dreams? How would our actions be different?

We would toss out developmental scales once and for all, and recognize the value of assistive technology, supports, and accommodations. We would provide children (even little ones) with power wheelchairs, communication devices, and other tools so they can get on with their lives instead of spending years in therapy! And therapists would move from being hands-on providers to consultants who could help parents, teachers, and others learn how to help a child be who he wants to be and do what's really important to him.

Educators and parents would realize that school-aged children with disabilities need a real academic education so they can move on to vocational school, college, and/or enter the workforce (including starting

their own businesses). They may learn differently than other students, but all children are natural born learners! We can modify the curriculum and/or provide the supports they need to ensure they'll receive the education they need for later success.

We will recognize the absolute necessity of children with disabilities being included in general ed classrooms and in the community so they can learn how to get along in the world. Being in segregated, self-contained classrooms or in “special” (segregated) activities is no preparation for life in the real world as an adult!

We won't worry so much about “appropriate social skills.” We'll realize, for example, that a child who prefers his own company can be a successful adult via self-employment or in a job where there's little interaction with others. There are people *without* disabilities who prefer their own company, and they choose jobs where they work more-or-less alone. This is more of a “personal preference” than a “disability issue”!

We'll expect children with disabilities to take responsibility for their lives and make decisions as early as possible. We can no longer afford to keep children in a perpetual state of infancy and, again, we'll give them the assistive technology, supports, and other tools they need to live self-determined lives.

Perhaps most importantly, we'll spend lots of time talking to our children about their lives as adults, just as parents do with their children who don't have disabilities. Sitting around the dinner table, moms and dads will say things like, “When you grow up and live on your own... [or go to college, get married, drive a car, or a myriad of other things],” so our children will know we have big dreams and high expectations for them. It doesn't matter whether we “know” these things will really happen—*our parents* didn't know what *we* would achieve as adults, but hopefully they dreamed for us so we could learn to dream for ourselves!

Our belief system—not a person's disability—is the most important predictor of a person's success. For if *we believe* she can and should enjoy successful employment as an adult, we'll do what it takes to make that dream a reality! On the flip side, if we *don't*

believe it can happen, it won't—not because of the person's diagnosis, but because of our actions or inactions! How can we live with ourselves—as parents, teachers, or professionals—knowing our work has contributed to preparing a child for nothing more than unemployment, helplessness, and dependence?

There are many more ways to do things differently, so put your thinking cap on! And it's never too late to make changes in how we work with *adults*. Again, we can move beyond the status quo, and focus on what the person really needs so he can get the job he wants, live in the home of his choice with the supports he wants, and more.

Parents of children with disabilities and adults with disabilities can and should take the lead in this action. We can check everything we do by asking, "Are my actions going to lead to employment, or are they focused on meeting the artificial goals of the service system and wasting time?" And we can hope professionals get on board. But if they don't, we need to move on, even if that means getting out of the system, and go our own way—on our own or with the support of family, friends, and people in our communities.

So far, the practices of the service system have not lived up to the promises, as evidenced by the 70-75 percent unemployment rate. How much longer will we keep going down the path to nowhere?

Pull quotes:

If you treat an individual as he is, he will stay as he is, but if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be. Goethe

Children who are treated as if they are uneducable almost invariably become uneducable.
Kenneth B. Clark

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Tourette Syndrome Foundation of Canada London Chapter Parent Self help Meetings

The London Chapter of the TSFC hosts monthly parent self-help meetings from 7pm to 9pm on the second Thursday of each month, except for July and August. Meetings are held at:

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

Directions: Go south on Rectory Street to the end of Rectory. Turn left. You are now on Trafalgar Street. Madame Vanier is approximately 100-200 meters on the right.

Our Resource Library is available during meetings and books can be taken out on loan.

The Kids Klub meets at the same time as the Parents meet. (*Please see our website www.tourette-london.ca for a list of rules for Kids Klub*)

Our next 4 meetings dates are:

December 14, 2006
January 11, 2007
February 8, 2007
March 8, 2007

Responsibilities and Expectations of an Aide

*"I am only one, but still I am one.
I cannot do everything, but still I can do something.
I will not refuse to do the something I can do."*
-Helen Keller

During my work and research with children with special needs I made a list of observations about what makes an effective aide to a child with special needs. I would like to share them with you now.

1. Role model appropriate behaviours.
2. Provide proper support and encouragement to the child. (Physical, social, emotional, cognitive, occupational, spiritual.)

3. Provide opportunities for the child to be able to participate in activities as an individual or in a group. Opportunities that are both at the child's level and that challenge the child to grow.

4. Advocate on the child's behalf in the daycare and community through the development of workshops, seminars and staff meetings.

5. Attend workshops and seminars in order to gain new skills and knowledge as it relates to children and special needs.

Expectations of an Aide

1. Enjoy the child.
2. Child first. Disability second.
3. The child is an active member of the family, school, community and society.
4. The child will be treated with respect.
5. All children have needs and rights. Those needs and rights are to be met by everyone that comes in contact with the child.
6. Children should not be denied books, toys and activities just because the aide/teacher is not scheduled to be in.

Home, school, hospital, daycare, playground or whatever you want for your child.

The decision to begin this process is probably the most difficult but once you get started thinking about what's best for your child it becomes an exhilarating experience.

To begin, all you need is a pen, paper and a moment to be able to think. (This is the hard part that I mentioned earlier. It seems the higher number of children in the home or program is in direct correlation to ones inability to have free time to think.)

There are 4 simple rules when starting:

- Money is not an issue right now.
- Whether it exists or not, is not an issue right now.
- This can be done individually or as a group.
- It also should not land you in jail!

What these rules do is generate enthusiasm in yourself, or within the group if more than one person is

involved. Why is enthusiasm so important? Enthusiasm produces hope. Hope produces goals. Having goals produces action and that action gets you one step closer to reaching those items on your list.

I like to ask people "What's your perfect environment for your child?" The list of people I have asked includes Physical Therapists, Occupational Therapists, Educational Assistants, Early Interventionists and Teachers.

This is what they had to say:

- Everyone working with a child is working in co-operation with each other.
- Make sure the child is learning in the same environment as the other children.
- Physical goals are being met.
- Have many contacts.
- People have a sense of humour.
- People are knowledgeable about child development and special needs.

I know setting and reaching your goals can be very difficult sometimes but working daily at making your goals a reality even if it's only a little amount is still propelling you forward.

There are 3 ways to become more effective at setting and achieving goals. They are:

1. The goal must be specific. For an example let's take a look at the goal "Have many contacts." This goal can be changed to "Add 5 new contacts to my list by December 5, 2006." In making the goal more specific you're setting a clear idea for your mind to focus on. The other benefit is when faced with life challenges having a specific goal has more staying power, especially when it's attainable. Which leads us to step number 2.
2. Your goal must be attainable. Please don't mistake this for easy. An easy goal is a boring goal and when you hit it there is little if any gratification. Plus with an easy goal you won't build any momentum because your mind's thinking "This is easy I don't have to do anything today." So how do you know when your goal is attainable? You will feel a sense of urgency upon writing it down, you will be energized and want to work towards completing it.
3. Creating the action plan. How are you going to get your 5 new contacts by December 5, 2006? Where do

you need to go? Who can help you achieve this goal? Your action plan for day one will look something like this. "I am going to call X,Y,Z company and speak with Mr. Jones."

In closing, creating your perfect environment starts with you, a pen and piece of paper and can end with you and your child's perfect environment becoming a reality.

Oh, just in case I haven't asked you yet. "What is your perfect environment for your child?"

Steve Mooney

Benefits of Joining the TSFC

One of the benefits I have derived from attending the parent support meetings of the London Chapter of the TSFC is gaining an insight into understanding my fellows. By that I mean, with the knowledge I have learned about Tourette syndrome and the many facets of the oft-time accompanying disorders of ADHD, OCD, and LD etc. I have become more sensitive and tolerant to those many differences I encounter daily with other individuals for whom I had lacked understanding for, previous to my education into TS and TS+.

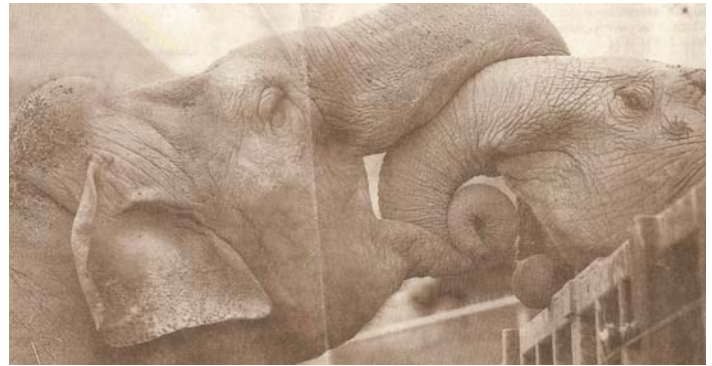
For me this demonstrates the effectiveness of the dissemination and distribution of knowledge and education about one disorder that benefits many others with similar and sometimes even unrelated disorders and challenges. What we do in the TSFC greatly benefits many more people than just those with TS and TS+.

For this benefit, I am very thankful and I hope it makes life's challenges a little easier for individuals I encounter that struggle for understanding, tolerance and some sort of normalcy in living.

Empowerment through knowledge is fundamental in the pursuit of developing an attitude of tolerance and acceptance for all of us that deal with TS or any type of life challenging issues. Getting informed and spreading the knowledge of that information helps everyone.

Gerard Johnson

Interesting



Pack Their Trunks and Set Them Free

A "letter to the editor" in the Edmonton Journal on Sunday, September 17, 2006 responds to a previous article titled "Zoo criticism undeserved" in what appears to be an ongoing dispute regarding the welfare of elephants in zoos, specifically the Valley Zoo in Edmonton. The editor chose to title this letter "Pack their trunks and set them free."

As part of the lengthy letter, P.J. Armstrong writes "Elephants live in large social groups in the wild. The social group is at once teacher, nurturer and protector. In captivity, elephants live alone or with just one or two other elephants in an impoverished environment."

In the next paragraph, Armstrong states:

"These living conditions cause stereotypic behaviour (repeated motor movements) such as head bobbing, swaying from side to side, and trunk tossing, indicating that the elephant is stressed."

In humans, we would call this condition Tourette Syndrome, and suggest that stress was only a periphery contributing condition. Perhaps there is something here we should be looking at more closely.

Where does the Grand Old House hide its tics?

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What's New in Research

By Brigitte Heddle

In this article I will take a look at Habit Reversal Training (HRT), which is used to give people with tic disorders control over their tics and is used either as a compliment or in place of medication.

What is Habit Reversal Training then? It is a group of methods that people suffering from tic disorders can learn and apply every day, anywhere to give the person better control over their tics, improving self esteem and reducing physical and emotional discomfort caused by tics. The methods used are:

- Awareness Training
- Competitive Response Training (CR)
- Anxiety Management Techniques
- Operant Techniques
- Motivational and/or Ancillary Techniques (which lumps together several techniques such as Habit Inconvenience Review, Creation of a Tic Hierarchy, Social Support, Behavioural Reward System, and Cognitive Strategies

Awareness Training (AT):

AT is based on the idea that if a person increasingly becomes aware of his/her tic behaviours it will help improve self control. The person is asked to describe his/her tic occurrences in detail and to re-enact tic movements while looking in a mirror. The therapist will also immediately point out every time a tic occurs during a session. Furthermore, the patient will learn to become aware of early warning signals that a tic is about to happen and identify situations where tics are most likely to occur. When the person has demonstrated ability to detect tic urges the person will learn to use:

Competitive Response Training (CR)

The CR should be a behaviour opposite to the tic behaviour and should be maintained for several minutes, produce awareness of the tic and be compatible with normal activity and discreet in a social setting. It is important to note that CR is not a way to

suppress tics, which could cause great discomfort and anxiety/stress in the person with tic behaviour. It is a gradual process that gives the person more and more control over the tics and can be used to “disguise” tics, that the person would feel embarrassing, in a social setting without actually suppressing the urge to tic. An example of CR for vocal tics is slow rhythmic breathing through the nose until the tic urge has passed.

Anxiety Management Techniques:

These techniques are used based on the observation that increases in stress and anxiety lead to increases in tic frequency, intensity and duration. Most often deep breathing, progressive muscle relaxation, and imagery exercises are used to decrease stress/anxiety in people who have tic disorders. The rewards of these exercises can be short lived if only practiced in a therapy setting.

Operant Techniques:

Is described in rather vague terms, but is basically based on a system that rewards tic free intervals and tic behaviours are punished. How and exactly when is not elaborated on. It is also mentioned that it is unclear whether observed improvements are due to the person just suppressing the tics (which in my opinion cannot be ideal, because we all know that the tics will out eventually, if suppressed) or whether by releasing the tics in a controlled manner.

Motivational and/or Ancillary Techniques

The common denominator for these techniques is that they are easily learned and inexpensive to administer and may enhance the acceptability of Habit Reversal Training to children and their families, who are involved in this type of treatment.

1. Habit Inconvenience Review:

Early on in the treatment phase the child and the therapist will make a list of all the negative aspects of the child's tics (i.e. embarrassing, painful, disruptive etc.). This list gets updated as the child's tics change/disappear. Creating this list helps the child overcome denial and accept his/her condition.

2. Creation of a tic hierarchy.

The child and the therapist use the complete list of that child's tics to rate how bothersome or distressing each tic is on a 1-10 scale. For younger

children and children ,who deny tic associated distress the tics are rated on how often they occur. This list gets reviewed each session. This list is used to choose the tics to work on for awareness training and competitive response training as well.

3. Social Support:

Family members, teachers and friends provide praise, encouragement, support, and guidance, helping the child with the treatment program.

4. Behavioural Reward System:

Most children benefit from a systematic rewards program to boost motivation and compliance with the Habit Reversal Program.

5. Cognitive Strategies:

Cognitive strategies are used to enhance the early recognition of tic urges and accurate labelling of these urges to facilitate greater control over tic behaviours. The child learns the difference between suppressing the urge to tic and expressing the tic in a controlled and less obvious manner.

Habit Reversal Training (HRT) was first described in 1973 and more studies have followed since then.

It has been noticed in studies that each child responds to a different treatment combination and that compliance tends to decrease as the demands of the treatment increase. Since the early days of HRT less emphasis is being placed on Competitive Response (CR) training and greater emphasis is placed on cognitive strategies designed to help the child learn early recognition of tic urges, labelling of those urges to improve control over tic behaviours and improve motivation for treatment.

In studies done to investigate the benefits of HRT it was found that although initially there is great improvement in the group of people with tic conditions these benefits don't seem to last on a long term basis, and it has been recommended that relapse prevention and booster sessions should be added to the treatment to help patients maintain the benefits of HRT.

It has also been recommended that HRT be used along with medication to optimize the benefits for the patients.

In conclusion, I think that HRT is very valuable, and people who have tic disorders should investigate what is available in their area. It is likely not a substitute for medication, but a valuable tool to use combined with medication. It makes the patient feel in charge and control of his condition as well as treatment; and boosted self esteem is a very positive benefit of the treatment.

Editor's note. The above information was based on the following 3 studies.

Habit Reversal Versus Supportive Psychotherapy for Tourette's Disorder: A Randomized Controlled Trial (Sabine Wilhelm, Ph.D., Thilo Deckersbach, Ph.D., Barbara J. Coffey, M.D., M.S., Antje Bohne, M.S., Alan L. Peterson, Ph.D., Lee Baer, Ph.D.) Reported in the American Journal of Psychiatry 160:6, June 2003.

Habit Reversal Training for Tic Disorders in Children and Adolescents. (John Piacentini, Susanna Chang, UCLA School of Medicine) Reported in Behavior Modification, Vol. 29 No. 6, November 2005 803-822

Curbing Tourette's Syndrome. An article about Doug Woods' program as reported by Kelly Kizer Whitt. In research Profile Spring/Summer 2004

Bingo

Fundraising to help others

London chapter volunteers are raising funds that are being used to provide information and support for families with TS.

Each bingo event takes about 4 hours and needs only 10 minutes before the bingo starts to learn the job.

Upcoming bingo events are:

November 29, 2006
December 21, 2006
January 20, 2007
February 23, 2007
March 25, 2007

If you are interested in helping other families with TS by working at a Bingo event contact us at:

519 457-4586, or
rayrobertson@hotmail.com, or
lindajathome@sympatico.ca

Local Mother to Open School for Children who Learn Differently

Shannon Stoyles plans to open a school in London, Ontario that will offer individualized programs for children experiencing barriers to learning.

Stoyles, the mother of a son with learning disabilities, calls the project the Distinctive Learning Centre, and while she feels the traditional education system does what it is designed to do fairly well, there are problems when it comes to children who are "wired" to learn differently from the majority.

"Children with autism, learning disabilities and other challenges really struggle in traditional private and public schools because of the standardized structure required to move a large volume of students through the system."

Stoyles's youngest son Paul, who has Tourette's Syndrome and other learning disabilities, went from being tested at a level two years behind in all subjects in the public system to one year ahead after enrolling at Galt House - an independent school in London that offered individualized programs. Galt House has since closed and Paul is now being home schooled.

The idea for the Distinctive Learning Centre grew out of the vacuum left by the closing of Galt House and a concern that all children can't be served by a one-size-fits-all approach to education. For Shannon, the school also needs to be a place where children with academic challenges can experience peer acceptance and social interaction.

"In Grade Two, the teasing got so bad, and Paul became so frustrated with trying to learn "the right way," that he ended up in the hospital, where it was discovered that he has learning disabilities.

Unlike children with intellectual disabilities, children with learning disabilities are required by the definition of that term to be assessed with average or above intelligence. Stoyles says that this intelligence, combined with difficulties processing certain types of information, leads to serious emotional and self-esteem issues.

"Often these children are very bright. In a system that doesn't present information in a way they can understand, they become frustrated and their self-esteem suffers terribly. They grow confused by the inconsistency between their assessment of their abilities and the rest of the world's. Their intelligence becomes a liability under the

circumstances." Shannon says a lot of people don't realize that these kids are often very smart and ambitious, and that with certain accommodations they can succeed.

As a refreshment attendant at a local golf course, Stoyles also wants the school to be accessible to parents regardless of income. "This should not be exclusive, she says. "I know how hard it is to come up with tuition money. We will have an income-based tuition system and we will work hard to find corporate sponsorship on a per family basis."

The disability services community in London is working with Shannon to make the Distinctive Learning Center a reality.

Vicki Mayer is the Executive Director of ATN for Persons with Disabilities. ATN offers various services, including providing diagnosis and accommodations for adults with learning disabilities.

"Shannon is absolutely right. The self-esteem and emotional issues that arise are a huge problem. The indirect cost to Canadians resulting from undiagnosed and untreated learning disabilities is enormous. Substance abuse, domestic violence, employment services, social assistance and corrections facilities are full of very smart people who may never know they have been struggling with a learning disability. I especially applaud the DLC's commitment to making the school financially accessible for parents."

The pieces are in place. Shannon has excited the disability services community in London about the Distinctive Learning Centre and she is ready to move forward. She feels she has achieved critical mass.

"We have staff. We have the supplies we need. We have strong support. A lot of teachers like the idea and Khalil Ramal, M.P.P. for London-Fanshawe, who has been a strong supporter of disability services, has offered to work with us. We do need to find a location and are looking for financial support from the business community. Other than that we are ready to go. I invite parents with children who would benefit from this idea to join us. And also organizations and businesses that see the value in what we are doing. We would like to be ready to open the doors in January 2007 and I know London can help me make it happen."

Tourette's in the News.

In America it's "American Idol", in Canada it's "Canadian Idol", in Australia it's "Australian Idol." However, in Britain, it's "Big Brother."

The most recent winner of "Big Brother" is Pete Bennett and Pete Bennett has Tourette Syndrome. For over 3 months, as he kept viewers glued to their television screens while he became a British Idol, he made sure everyone was aware that he had Tourette Syndrome.

Dr. Mary Robertson, who is perhaps the most acclaimed medical spokesperson for TS worldwide, well known in the TS community for her research, publishing and teaching, made a comparison between the number of people she had reached during her career and the number of people Pete Bennett has reached in his short (so far) public appearances.

Dr. Robertson estimates that the number of people she has reached during speaking engagements spanning

her career as a spokesperson for TS is 64,000. She estimates that Pete Bennett, over 3 months of television appearances, has reached 7 million people.

Dr. Robertson's audience has been primarily people who have heard about TS and have an interest in hearing more about the disorder. Pete Bennett's audience is made up of a cross section of the general public who, in general, know very little about TS.

Pete Bennett was featured recently in an interview with a popular British weekly, titled "The Interview They all Wanted" and managed to get Tourette Syndrome in front of millions more.

Also, Canadian Living's October 2006 edition devoted 5 pages to stories about Tourette's. Featured are Damian McDonald, Mandeep Sanghere, Duncan McKinlay, Janet Rumsey, Francois Parent, and Mort Doran with captions about the genetics of TS and Myths and Facts.

Excellent coverage.

The CPRI Brake Shop Leaky Brakes 101

New sessions begin April 4, 2007 and run for 6 weeks.
More information will be available in our next newsletter or call (519) 858-2774 ext. 2171 to reserve a spot.

This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Ray Robertson and Gerard Johnson. Anyone wishing to make suggestions or comments about the content or if you would like to contribute an article for inclusion in the newsletter, please contact Gerard Johnson via email at:

gerard.johnson@sympatico.ca

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