



**Dr. B. Duncan McKinlay**  
Psychologist

London, ON, Canada  
url. [www.lifesatwitch.com](http://www.lifesatwitch.com)

**Website:**

Tourette Syndrome • OCD • ADHD  
Sensory • ODD • IED/‘Rage’

**Publishing:**

*Nix Your Tics! Eliminate Unwanted Tic Symptoms:  
A How-To Guide for Young People*

### **What is “Deep Brain Stimulation”?**

This is a procedure approved for use in Parkinson’s Disease, essential tremor, and dystonia. It has also been used at times for Multiple Sclerosis. In essence, Deep Brain Stimulation ‘turns off’ overactive brain regions without destroying them. Other neurosurgical techniques (like a pallidotomy or thalamotomy) actually cut these brain regions. The difference with Deep Brain Stimulation, then, is that the change is reversible, whereas cuts in the brain (called lesions) are permanent. Tremor symptoms are monitored over months and years, and in most cases gradually decrease.

Deep Brain Stimulation is a very invasive procedure, involving 2 operations. The first step is to implant a lead with electrodes around the selected area of the brain. These electrodes run to an external battery pack for an initial test to see how well the patient responds to the stimulation. Assuming the response is positive, a few days later surgeons will implant insulated cables under the scalp, neck, and upper chest that run from the electrodes to a spot just under the clavicle (collarbone), where a pulse generator is implanted. This pulse generator delivers high-frequency stimulation designed to block brain function, and can have its ‘volume’ turned up and down to control the amount of brain affected by the stimulation. Depending on what side of the body your involuntary movements are on; implants may be on your right, left, or bilaterally.

Besides the risk of site infection, there are few reported side effects to Deep Brain Stimulation. Batteries in the pulse generator require replacement every one-and-a-half to five years.

### **Why The Hype?**

April 1<sup>st</sup>, 2004 was the first time in North America that Deep Brain Stimulation was attempted in the treatment of Tourette Syndrome. Jeff Matovic was the patient, and surgeons at University Hospitals of Cleveland Movement Disorders Center performed the operation. Bilateral implantations were made in an area of the brain known as the thalamus. The thalamus is like a switchboard for sensory information in the brain, and is involved in the brain pathway believed to be disrupted in Tourette Syndrome. While a number of brain areas have been selected for Deep Brain Stimulation in the past, the thalamus has been the area of choice when the goal is to rid the patient of ‘extra’ movements (for example, tremors).

Mr. Matovic’s case of Tourette Syndrome was reportedly quite severe, yet surgeons reported that his symptoms had all but disappeared within hours after the stimulation was turned on. This procedure is not purported to have ‘cured’ Mr. Matovic’s Tourette Syndrome. To liken Tourette Syndrome to ‘leaky brakes’ over movements and sounds, the brake pedal is still soft when pumped. Deep Brain Stimulation is akin to taking your foot and jamming it against the tire instead; you haven’t fixed the brakes, but you have still stopped the car.

### **Is This A Break-Through Cure Then?**

My thoughts are similar to those of the TSA (<http://www.tsa-usa.org>) and TSFC (<http://www.tourette.ca>) who have both released official statements on their websites. While this is a



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very promising and exciting step, it is necessary to see more successful cases, and to watch how they each do over time, before recommending Deep Brain Stimulation as a viable treatment option for Tourette Syndrome.

Why is it necessary to do MORE research? Sometimes new treatments cause initial improvement just because they ARE new and exciting – this can be described as the **Hawthorne effect**. Other times, new treatments work at first because the person believes so passionately that they WILL work. This is called a **placebo effect**. In both of these situations it is not the TREATMENT that is working, but the person's REACTION TO the treatment that causes improvement.

Brains are also very good at reversing changes made to them – they don't like to be altered from how they intend themselves to be. This is called **homeostasis**, and is why sometimes a treatment that works at first tends to 'wear off'. In the case of Deep Brain Stimulation, if Mr. Matovic's brain finds a way to compensate for this additional outside stimulation, the tics may yet return.

Finally, Mr. Matovic's case is unusual given that his reported severity was quite high, his tics worsened in adulthood, and his symptoms were reportedly resistant to many medications that are used for Tourette Syndrome. It is possible that his brain is not a 'typical' Tourette Syndrome brain, and that Deep Brain Stimulation will not be as effective for other individuals with Tourette Syndrome.

Now, so far the effects of Deep Brain Stimulation seem to be quite long-lasting (it has been over a year now since Mr. Matovic's miraculous transformation, and some individuals in the Netherlands continue to see benefits many years following surgery). Unfortunately this doesn't mean that everyone should therefore undergo this treatment. The procedure involves many risks, and indications so far are that once Deep Brain Stimulation is turned on, patients cannot tolerate having it turned off. Professionals performing Deep Brain Stimulation have made clear that they will not consider any patients who do not have very severe symptoms, and whose very severe symptoms have endured for at least 5 years despite all other treatments available having been tried.

Plus, many people with Tourette Syndrome adapt to this brain overactivity and even value it in their daily lives. Removing this overactivity, then, becomes irrelevant given that they are successful and happy BECAUSE of their difference, not in SPITE of it. Even the neurosurgeons involved in this landmark procedure caution that not everyone with Tourette Syndrome requires treatment.

For more information log onto the hospital website at <http://www.uhhs.com/dbs>

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