

DEEP BRAIN STIMULATION FOR TS

Hope or Hype?

Two years ago, I wrote a short article for this newsletter about recent publicity regarding treatment of severe tics with deep brain stimulation (DBS). The publicity at that time involved a single patient in the U.S. with only three cases having been reported in a single medical journal article. At that time, I wrote that very little was known about the potential for DBS to reduce tics in TS.

So where do we stand two years later? We know that a few additional patients have had their stories told on U.S. television programs, and that four additional cases have been reported in medical journals. Thus, we do know a little bit more than we did two years ago, but more questions than answers still remain.

What is DBS?

DBS involves surgical implantation of electrodes into a deep part of the brain. Once the stimulators are implanted (often under the skin in the chest), they are turned on to deliver carefully controlled electrical stimulation to the targeted parts of the brain. DBS has been studied extensively in Parkinson disease and essential tremor, and most of what is known about DBS comes from experience with those disorders. Also, the procedure is being used increasingly in certain forms of dystonia, and is being investigated for possible use in depression and obsessive compulsive disorder (OCD). Its use in TS is still considered experimental by most experts.

TSA-supported Guidelines for Investigating DBS in TS

The TSA has worked actively to gather emerging information about DBS in TS and to provide leadership in this area. In 2004, the TSA arranged for a panel of experts from around the world to meet at the 4th International TS Scientific Symposium. The panel determined that there was a critical need for specific guidelines

for future investigations of DBS in TS. These guidelines have been written and are now published in *The Journal of Movement Disorders*. One goal of these guidelines is to assure that all potential DBS candidates are fully informed about the risks, benefits and alternative treatments available. A second goal is to make sure that DBS is truly an appropriate clinical treatment choice for each individual patient. Finally, we sought to assure that early clinical experience will be documented publicly to facilitate rational decision-making for both clinical care and future investigations. While TV news magazine stories may be interesting and entertaining, it is only through careful descriptions in high quality medical journals that we can really learn from the experiences to date.

TSA International DBS Workshop

The TSA sponsored an international DBS Workshop in September, 2006 in Stresa, Italy. Invitees included all known neurosurgeons and clinicians worldwide who had performed DBS in TS or were considering the operation in the near future. In addition, experts on DBS in other conditions as well as experts on TS were invited to provide their important perspective and back-

ground information. Forty-five surgeons, clinicians, and scientists attended this two-day workshop. By any measure, the meeting was a success. A cooperative spirit prevailed, and plans for future collaborative investigations were launched.

Next Steps

Several future goals were agreed upon including: 1) determining the characteristics of good candidates for DBS; 2) determining whether there is a “best” target in the brain; 3) determining whether associated symptoms such as those in OCD, ADHD and anxiety improve or worsen with DBS treatment for tics; and 4) establishing an international database to track results from each site performing the procedure. There are several clinical trials in progress or being planned to determine the safety and efficacy of DBS in TS. These trials will ultimately answer many of the critical questions. Until those answers are forthcoming, DBS must be viewed as an investigational, unproven, but potentially promising treatment for severe tics that do not respond to other treatments.

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TSA MAKES A DIFFERENCE

Historical Changes in Federal Legislation

In August the TSA family celebrated Tourette Syndrome's inclusion in the text of the reauthorized Individuals with Disabilities Education Act (IDEA). The changes in the 1,705 pages of regulations will have an impact on students with TS, their families and teachers. Reading it through, digesting the significant changes and determining what those changes mean to individuals is a huge task. TSA asked our two most experienced education experts, Sue Conners and Kathy Giordano, to share their insights after a close reading of the text.

Inside the center of this issue is a pull-out hands-on user's guide to the portions of the IDEA that are most important to our community. We hope it will answer your questions about the new regulations and serve as an informational tool to take with you when meeting with your child's school personnel.

