



**DYSTONIA
MEDICAL
RESEARCH
FOUNDATION**

servicing all dystonia-affected persons

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- ▶ **Dystonia is a movement disorder that causes the muscles to contract and spasm involuntarily.**
- ▶ **There are more than a dozen forms of dystonia, and many neurological and metabolic diseases include dystonia as a symptom.**
- ▶ **Deep brain stimulation (DBS) is a surgical procedure used to treat some forms of dystonia.**
- ▶ **DBS involves implanting electrodes into the brain. Powered by a stimulator, the electrodes deliver electrical signals into the brain to lessen dystonia symptoms.**

Deep Brain Stimulation Resources

The following resources are available to individuals and families who are considering deep brain stimulation (DBS) or who are in the process of undergoing DBS.

Medtronic

For more information on DBS for dystonia, visit Medtronic's website at www.newhopefordystonia.com. Medtronic is the manufacturer of the Activa brain stimulator device used in DBS. The site features a list of Frequently Asked Questions in addition to a list of neurosurgeons who perform the procedure. Medtronic also offers a booklet on DBS for dystonia.

Dystonia Medical Research Foundation

Visit www.dystonia-foundation.org. The "Treatment" section of the DMRF website features a section on brain surgery that includes information on DBS for dystonia.

The "Brochures and Materials" section of the website includes a booklet entitled *Surgical Interventions for Dystonia* which can be downloaded and features several pages on DBS.

Also in the Brochures and Materials section is a DVD entitled *Twisted*. This is an award-winning documentary by Laurel Chiten featuring people living with dystonia and the life choices they have had to make. Several of those profiled have undergone DBS. The DVD is 54 minutes in length and can be purchased from the DMRF for \$37.

Media stories featuring DBS may be accessed on the website under "News and Resources" and then under "Dystonia in the Media."

The DMRF can provide the names and contact information of DBS patients who are willing to share their experiences with DBS in addition to those who have experience with insurance companies and coverage for the procedure. The DMRF also produces a fact sheet that contains a basic description of DBS for dystonia. For more information, call 800-377-DYST (3978) or email dystonia@dystonia-foundation.org

Online Forum

An internet bulletin board created and maintained by Dee Linde, a DBS patient, is available for those considering DBS and those who have had the procedure and need additional support. The board can be accessed www.health.groups.yahoo.com/group/DBSforDystonia

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