



# THE NASHVILLE DBS NEWSLETTER

## EDITORIAL LETTER

### PATIENT INTERVIEWS

Interviews with DBS patients,  
Doris and Ruth.

### WHAT IS "ADEQUATE"?

By Dr. John Fang

### FREQUENTLY ASKED QUESTIONS

Compiled by Dr. John Fang.

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As we pass the one year anniversary of this newsletter, we plan to build upon last year's issues and to focus on some of the new developments related to DBS for this year.

As mentioned in the prior newsletter, ANS, a St. Jude Company, has begun testing a new type of DBS stimulator for essential tremor. This device has a different system for the delivery of electrical current which may offer some benefits over existing devices. More importantly, this device offers an option for patients with ET over what is currently available.

Medtronic, currently the only DBS supplier in the USA, is also planning the release of new models this year. These new devices include a rechargeable battery and a smaller size model. Of course, a charger is required for this device to work, and persons electing to have this model will require additional training on its proper use. A major benefit of a rechargeable device is the longer service life, lengthening the time until surgical replacement.

In this issue's interviews, Doris, who has PD, points out that speech and balance often do not improve with DBS. We wish to reiterate that speech and balance problems should never be the primary symptoms prompting DBS for PD.

Please also welcome Jessica Stroh, LPN, to the DBS Newsletter team. Nurse Stroh has been working with the Vanderbilt Neurology DBS clinic since 2007, and will be contributing a nursing perspective to this publication.

Please continue to send in questions and comments. We enjoy both positive and constructive feedback. To provide an accurate and useful reference for learning about DBS remains our primary goal.

Sincerely,

John Y. Fang, M.D.  
on behalf of the editorial staff

Ms. Rosie Spain  
Dr. Joseph Neimat  
Dr. Fenna Phibbs  
Dr. Peter Hedera  
Ms. Rena' Carter  
Ms. Jessica Stroh

# Q&A

## with DBS Patients in the Community

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### Interview One : Doris

Why did you have DBS? (for PD)

I felt it would help me to improve my quality of life which would be helpful to me.

How long did you wait to have DBS?

After deciding to proceed and with having to undergo pre-operative examinations, I would say 3 months.

How long did it take for DBS to work?

It began working right away after initial programming.

What things did not go as expected?

My speech is not as good as it was before. My balance did not improve, and I was hoping it might but it has remained the same.

What symptoms have not responded to DBS?

[Same as above].

What expenses did your insurance not cover?

I don't know as of yet I have not received a bill.

How did you handle the changes after DBS?

I think I've handled it well, it has improved my tremor. I am also adjusting my medications to lower dosages and less frequently.

Would you do it again?

Yes.

What advice would you give to someone else considering DBS?

I would advise that they consider undergoing the procedure.

### Interview Two: Ruth

Why did you have DBS? (For tremor)

My neurologists recommended I have an evaluation with a movement disorders specialist. I had taken all medications that had been recommended, and there was no more medicine to be offered except to continue to increase dosages.

How long did you wait to have DBS?

I waited about six months.

How long did it take for DBS to work?

It began working immediately after it was programmed.

What things did not go as expected?

I cannot say anything did not go as expected because I did not know what to expect!

What symptoms have not responded to DBS?

I would have to say that I feel like I am having inward tremors but my family assures me they are not visible on the outside.

What expenses did your insurance not cover?

Insurance covered everything.

How did you handle the changes after DBS?

I handled it well, actually better than I thought I would. It gave me more confidence in myself. I had been afraid to go out in public because of my tremors and I did not like to initiate conversation with anyone.

Would you do it again?

Yes!

What advice would you give to someone else considering DBS?

I would advise someone to have it done immediately!

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# Medical Question: What is “Adequate” Regarding Medications?

## Background

DBS is being used for “medically refractory” essential tremor (ET), Parkinson’s disease (PD), and dystonia. What does the term “medically refractory” actually mean? Answering this question requires an extensive period of observation on medications that are typically used to treat each condition.

## Essential Tremor

For essential tremor the standard medications utilized in initial management include propranolol (Inderal) and primidone (Mysoline). Generally, the dose of propranolol necessary to produce symptomatic benefit in ET is up to 240 mg per day. However, this dose may not be achievable due to side effects or other contraindications such as asthma or certain types of heart conditions. Diabetes can also limit the use of propranolol. Primidone dosing typically is increased up to 250mg a day over a several week period. Side effects may increase the time needed to see a beneficial effect from primidone or may prevent achieving an effective dose.

Your neurologist may recommend other medications for ET in addition to propranolol or primidone in some situations.

## Parkinson’s Disease

In Parkinson’s disease, the standard medications for symptom management include combinations of levodopa and carbidopa (eg. Sinemet and Parcopa) and dopamine agonists such as bromocriptine (Parlodel), pergolide (Permax), pramipexole (Mirapex), ropinirole (Requip), and rotigotine (Neupro). Other medications that may be useful in certain situations include amantadine (Symmetrel), tolcapone (Tasmar), entacapone (Comtan), selegiline (Eldepryl, Deprenyl, Zelapar), and rasagiline (Azilect). A combination of carbidopa, levodopa, and entacapone (Stalevo) may also be prescribed in specific situations.

In order to determine whether an adequate period of medication usage has occurred, your movement disorders neurologist will review your prior use of these medications as a group. Since most persons with PD will require combinations of medications in order to control symptoms, candidates for DBS will have generally tried not only individual medications, but also at least two or three taken at the same time. Your response to each medication and to the various combinations or cocktails will be used to determine suitability for DBS.

## Dystonia

Dystonia is probably the most challenging of the three movement disorders regarding medical management.

Botulinum toxin (Botox or Myobloc) has been FDA (Food and Drug Administration) approved for some types of dystonia, such as cervical dystonia or spasmodic torticollis. For these specific disorders, a trial of botulinum toxin is appropriate prior to further consideration of DBS.

Other medications that are often prescribed to treat dystonia include baclofen (Lioresal) and drugs that block acetylcholine such as trihexyphenidyl (Artane) or benzotropine (Cogentin). Several other options exist, and most movement disorder specialists will prescribe at least three medications before referral to DBS.

## Conclusion

Determining what is an adequate trial of medications for DBS candidacy is a very complex process with many options. A movement disorders specialist with many years of training in the medical management of ET, PD, and dystonia should help to decide what is an adequate trial of medications.

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## Frequently Asked Questions

### **Can I stop my medications after I get DBS?**

Most people are able to reduce some of their medications after surgery. However, whether this can be done depends upon a number of factors including how well your medications were tolerated prior to surgery.

We advise PD patients not to stop all of their medications after surgery in order to avoid substantial downtime. Some PD patients may actually need to increase the use of medications after DBS. Often this is because of side effects from medications prior to surgery.

### **What happens if I get anxious during surgery?**

Your surgical team has many options if you become anxious during surgery. Since sedation can affect the clinical examination, your doctors will avoid anti-anxiety medications if possible. However, if your safety is threatened by your anxiety, you could be administered sedatives on a short-term basis. Other modalities such as massage or a brief break during the surgery can be utilized in some situations. If you know of other things that you typically do to treat your anxiety, please notify your surgical team prior to surgery.

### **How long does it last?**

DBS batteries are designed to last about five years. The actual battery life can vary considerably (eg. plus or minus over 3 years) depending upon the settings that have been programmed by your doctor.

As long as the batteries are replaced on schedule, the long-term effect of DBS can last well over ten years. More precise information about the longevity of DBS will become available as more people who were implanted in the past report on the duration of response.

### **Why are some symptoms resistant to DBS?**

The fact that DBS works at all is still somewhat of a medical mystery. It appears that certain pathways in the brain become overactive in dystonia, PD, and ET. DBS helps to regulate the electrical activity in these pathways. However, not all symptoms always come from the same pathway, and the entire pathway cannot be controlled with DBS. In addition, there may be critically important neighboring pathways close to the abnormal pathways that can be affected by DBS when the output from the generator (battery pack) is turned up. Effects on these other pathways limit the maximum allowable current flow through the DBS electrode.

In PD patients, gait and balance are often relatively resistant to DBS. In ET patients, speech problems may not respond well to DBS either.

Some patients with the Kinetra device may choose to have one program to control tremor best and another program to minimize speech problems. In this situation, the Access programmer is used to switch back and forth. This option is not available with the Soletra system.

### **What is the cost of replacing the Patient Access programmer?**

Currently, the cost of a Soletra controller is approximately \$595.00, and the cost of a Kinetra controller is approximately \$695.00.

Personal health insurance may or may not cover replacement so inquiring with your insurance company beforehand is recommended.

Additionally, patients may want to consider adding their personal programmers to their homeowners (or personal property) insurance if allowable. Your insurance agent should be able to answer this question.