



THE NASHVILLE DBS NEWSLETTER

EDITORIAL LETTER

PATIENT INTERVIEW

Interview with DBS patient:
Mary

FEATURE: Basics of the Activa Patient Programmer

By Dr. John Fang, Dr. Fenna
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information.

Over the past year, some patients have encountered various challenges related to the use of the new Activa RC and PC devices. These devices were designed to offer many more sophisticated electronic needs, and this has led to greater patient education requirements.

As noted in earlier issues of this Newsletter, we have been tracking the common difficulties with these new options so that we can help to troubleshoot them. This issue is dedicated to the use of the Activa patient programmer (APP), and the regular FREQUENTLY ASKED QUESTIONS section will be deferred for a future issue.

We had also planned to examine the use of the recharging function of the Activa RC in special detail. This device continues to be used sparingly, perhaps due to its greater maintenance requirements. We have been able to interview one patient with dystonia who has an Activa RC, and her interview is included on page 2.

In future issues we plan to include additional interviews from persons with the Activa RC. This will require a few months to complete. Persons who choose the Soletra and Kinetra devices will continue to be asked to provide their personal stories to share with our readers.

Clinical testing of the St. Jude Medical Eon device continues under the direction of Drs. Phibbs and Neimat for essential tremor. We anticipate that this device will become available in the not-too-distant future.

We continue to invite everyone interested in DBS 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
Dr. Joseph Neimat
Dr. Fenna Phibbs
Dr. Peter Hedera
Ms. Rena' Carter
Ms. Jessica Stroh

Q&A

with DBS Patients in the Community

Interview: Mary

Can you tell us which symptoms in particular prompted you to have DBS? (for dystonia)

My head turns to the right and just stays there with a lot of pain.

How long did you wait to have DBS after you decided to have it done?

A couple months

How long did it take for the DBS to work?

Same day.

Were there any complications during any of your DBS surgeries?

No.

Have you adjusted your typical daily activities as a result of DBS?

Somewhat. It takes up to thirty minutes every couple days to recharge the unit.

What symptoms have not responded to DBS?

I still have some head turning, but it is much better than before.

What expenses did your insurance not cover?

Insurance is still working on the bill. They initially denied the claim.

[Editorial note: If you have a problem with insurance for DBS, please contact your DBS coordinator for assistance.]

Have you noticed that you need less medication since surgery?

Yes. Less Botox now.

Would you do it again?

Yes.

In retrospect, would you have done anything differently in preparing for the surgery?

No.

What advice would you give to someone else considering DBS?

Go for it, and don't be scared.

Feature Presentation: Basics of the Activa Patient Programmer (APP)

Introduction

Although the concept of being able to recharge the DBS battery remains attractive, in practice, recharging can be difficult to accomplish at first. Furthermore, the Activa RC (Rechargeable Cell) does not last forever. From the factory, it has been programmed to turn off at nine years of use. Since non-rechargeable pulse generators such as the Soletra, Kinetra and Activa PC can sometimes last many years without all of the time and energy required for recharging, the main advantage of the RC device continues to be for patients who require very high electrical current usage or in situations where a patient's body habitus may not permit the use of a larger battery pack.

Both the Activa RC and its non-rechargeable sibling (i.e. Activa PC for Primary Cell) share greater options for the patient compared to the older IPGs. These additional options are accessed through the use of the Activa Patient Programmer (APP). This new programmer offers much more than just up and down control, and may require considerable practice to operate. The ability to select a menu of up to four groups was previously unavailable on the Soletra and Kinetra, and the four compass point navigation button requires more dexterity to operate.

In addition to instruction on recharging, we will also attempt to explain the most important aspects of how to use this patient programmer for the Activa RC and PC in this segment.

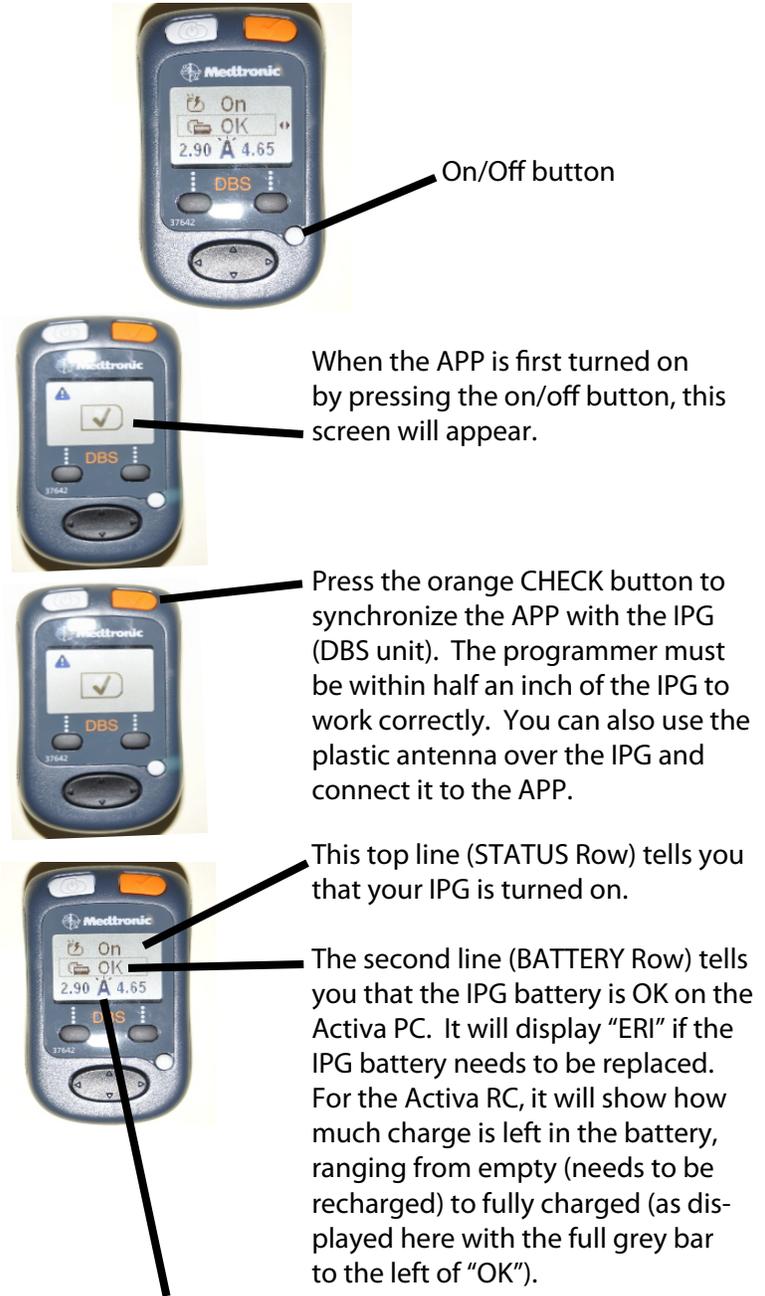
Keep in mind that not all options apply to all patients. In fact, many patients may never need to change their settings at all. However, being able to turn on and off the IPG (implantable pulse generator) and to check the battery life are important basic skills.

Recharging

The basic procedure of recharging the Activa RC requires the user to position the recharging antenna over the area of the body where the Activa RC unit has been placed surgically. This disk-like antenna must be placed within a finger breadth of the Activa RC itself in order to activate charging.

Using the Programmer for the Activa PC / RC

Both Activa PC and RC IPGs share the same patient programmer, also known as the Medtronic 37642.



If your doctor has set more than one group (set of choices for your IPG), a letter other than "A" may appear in this window, along with the range of voltage (or other parameter that your doctor may have set for you). In this example the left body voltage is set to 2.90, and the right body is set to 4.65 volts.

Continued: Basics of the Activa Patient Programmer (APP)

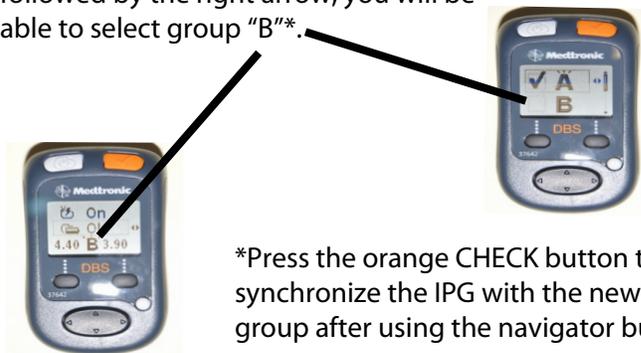
Turning off the IPG

To turn off your IPG, either to save battery life (eg. at night) or in the event of a malfunction, press this white button. The top line (STATUS Row) will change from "On" to "Off".



Changing the Group (continued)

In this example group "A" is initially selected. By pressing the down arrow on the navigator button, followed by the right arrow, you will be able to select group "B".

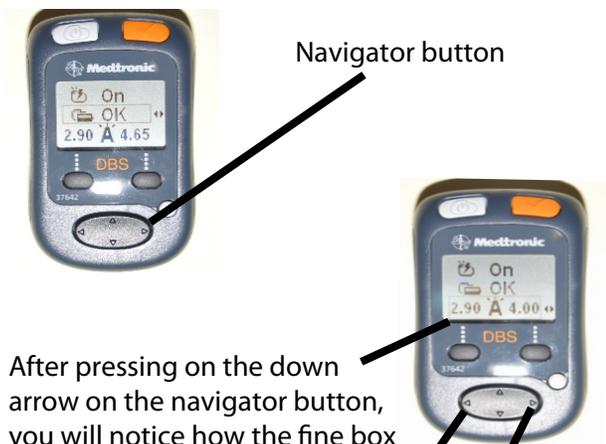


*Press the orange CHECK button to synchronize the IPG with the new group after using the navigator button.

Changing the Group

To change the Group on your IPG, your doctor must have given you the option to do so. Many patients do not need more than one group, in which case, it will not be possible to change the group.

If your doctor has given you the option, use the black Navigator button to move the cursor box to the third line (PARAMETER Row):



Navigator button

After pressing on the down arrow on the navigator button, you will notice how the fine box that was on the second line has moved to the third line.

Now you can press on the left or right arrows on the navigator button to change groups.

Changing the Voltage

Your doctor may have provided the option to change the voltage on your IPG without changing the group.

Use the left and right selection buttons located under the numbers to change the left body or right body.



This screen will appear after you select the left side of the body by pressing the left button. Press the left button (-) to lower the voltage, or press the right button (+) to increase.



You will see this symbol when you have reached the lowest possible voltage.



This symbol indicates that you have reached the highest voltage.



If your DBS is bilateral, each side of your body will be able to be set independently.

This symbol indicates that you are changing the settings for the right side of your body.



Finally, if you ever have questions about how to use your APP, do not hesitate to ask!