



BIG EASY FLEUR DE LIS PARKINSON'S SUPPORT GROUP



Meeting Agenda

9-24-18

1. Opening prayer: Dr. Ferd Becker

New Members: Please complete "Member Profile" & pick up Welcome Bag

Thank You to Jan & Ron Barone for food set up every meeting !

Thank You to Jill Siemssen & US WorldMeds for our delicious sandwiches!

Thank You to Sonny & Nancy for delicious Cake & Pasta every meeting !

3. New Business:

A. Allan Murphey Financial report

** Visit to Steve Scalise

** Current \$ needs are: + Flash Drives to replace the Welcome Bag CD's;

+ "Big Easy" Lapel Pins; + Order 300 more Green PD Brochures

B. Save the Date :

** **Dec. 28th** 11:30 Holiday Luncheon– Augie's / Harahan

4. LA Walks for PD **Oct. 13th** – Team "Big Easy" < www.parkinsonswalk.org >

5. CARE GIVER SUPPORT GROUP – 1st Wed. 3421 Caus. Blvd. #502 504-828-09002. New Members:

6. TIPS 'N TRICKS:

1) **Time to get our Flu Shots! Will be given at November meeting by AmeraCare !**

2) Hearing Tests in your home offered by **Dr. Tripp Griffith - 738-4557**

3) Help Line - Parkinson's Foundation has extended their hours to answer all your questions –
800-473-4636 {9am – 8pm}

4) Deliver to your Docs our Green Brochures –sign-up sheet on table!

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7. Our presenters today: Jerry White - **Medtronic DBS {Deep Brain Stimulation}**, Dr. Sarah Perez, MDS,

Medtronic Neuromodulation:

What is Medtronic DBS Therapy? (deep brain stimulation)

The controller device is implanted in the chest with wires going in to the portion of the brain which controls motion.

Conditions for which this is indicated:

- Parkinson's Disease
- Essential Tremor
- Dystonia
- Obsessive Compulsive Disorders (OCD)
- Epilepsy

Cardinal symptoms of Parkinson's

- Tremor (Shaking)
- Rigidity (Stiffness)
- Akinesia /Bradykinesia – inability to move spontaneously / involuntary movements
- Postural instability (falling, stooped over posture)

DBS addresses the first of the three symptoms...

Window of Opportunity

- When the standard Parkinson's medication starts to not control symptoms.
- When the medications no longer control your symptoms, DBS will no longer be effective. Can wait too late.

Steps (Timeline)

- CT Scan or MRI
- Develop a surgery plan
- Assemble a full team – neurologist, neurophysiologist, surgeon and others
- Place the DBS leads
 - Target area is very small
 - Patient needs to be awake to test for results, side effects
- Place the neurostimulator
- Programming sessions will be necessary to adjust leads
- It is reversible, can be taken out.

Reasons for Medtronic

- It has FDA approval
- Over 200,000 patients implanted
- 3 different battery types, 3 different leads
- 4 different indications
- More implant and programming centers world wide
- MRI compatibility – check on yours before having an MRI
 - All DBS are not MRI compatible (e.g. older ones)
 - All of the current systems are full-body MRI compatible
- 25 years' experience
- Programming

Questions you should ask:

When is it time to take action?

What are the benefits and risks?

What can I expect from the surgical procedure and therapy adjustments?

Is DBS Therapy covered by Insurance?

- Covered by many insurance companies and Medicare
- Your Dr. will get prior approval for the procedure
- If you receive a denial and wish to appeal, work with your doctor.
- You may also contact Medtronic Coverage group

DBS will not reduce your future therapy options. This procedure can be reversed.

Question: How about flying?

Answer: No problems.

Question: At what stage of PD should this be done? What are the side effects?

Answer:

- Side effects are identified during the testing and programming. Reduced with adjustments.
- There is a little bump on the top of the skull after the surgery. May need a customized helmet for motorcycle riding. May feel some transient tingling or facial pulling, but can be resolved with adjustment.

Question: When to consider DBS.

Answer: Consider DBS if the main problem is tremor. If you are having ups and downs, dyskinesia, consider DBS.

Question: Do you have to continue medication after DBS?

Answer: If pills control your symptoms, you don't need surgery. When the medication becomes less effective, you should consider DBS. Also, you should need less medication and experience fewer highs and lows. Most people will require some medication. Most people do one side (of the brain) at a time and you might need meds for the other side, until you have it done, if you decide to.

Audience Comment: One person who has had it said she was amazed at how little pain there was. She had severe rigidity in her lower extremities, which the DBS relieved.

Question: Have they had patients where the DBS did not work?

Answer:

- This does not affect the progression of the disease.
- They want to be very specific on the symptom they are treating.
- This does not completely erase all the symptoms, but provides improvement

Question: What about freezing?

Answer:

- This is defined as the inability to move when walking or in enclosed spaces.
- This is an on/off phenomenon.
- Freezing is one of the hardest things to treat and they haven't found anything that works. (Yet)!

Question: Can this be done if you have a pacemaker? Answer: Yes

Dr. Sarah Perez, MDS Neurology, Tulane

There are only six MDS specialists in the city. Access is an issue. You need to maintain your neurologist appointments.

Question: Is there any relationship between uncontrolled diabetes and PD?

Answer: Diabetes medications are being looked at for treatment of PD. When you have any other medical problems, your PD symptoms will be worse, ie: anxiety, dehydration, salt concentration in the blood, UTI, other infections.

Question: Is being cold a symptom of PD.

Answer: PD patients seem to be more sensitive to cold. It worsens symptoms. Also heat can be a problem, causing excessive sweating.

***Oct. 29 MEDICARE INFORMATION FOR 2019**

Molly Prokop - SHIP Counselor; Maria Alvarez – Social Security Advisor

***Nov. 26 Rich Baudry- Baudry Therapy (PD centered therapy) Big & Loud demo**

Rock Steady Boxing Demo

Flu Shots given – AmeraCare Home Health {Cherie Pausina}

***Dec. 28 Holiday Luncheon @ Augie's our host– Jill Siemssen & US WorldMeds**

HUG SOMEONE EVERY DAY ! Visit our Web Site: BigEasyFleurDeLis.org