



**BIG EASY FLEUR DE LIS PARKINSON'S SUPPORT GROUP
Meeting Minutes 5-21-18**

TANDEM Physical Therapy – coming to your neighborhood June 2018 !

1. Opening prayer: Dr. Ferd Becker Remembering our friend, Fritz Grannan....
2. New Members: Welcome Bags – may need to wait 'til next month?
3. Old Business:
 - *MARIE McCLELAND – doing well post-op and grateful for all the food and well wishes sent from Group !!
4. New Business:
 - **Fund Raiser ideas: “Cocktails at Sunset” <SYC>; “Be A Kid Again” in City Park { Too hot?}; Partner with Inspired Living Kenner (?)
 - { Need an events chairman }**
 - ** “OPEN OFFICE” is a free WORD program. < Openoffice.org >

Speakers today

Dr. Gerald Calegan – NeuroMedical Center Baton Rouge, and

Graham Martin –(for Mary Brocato) Acadia Pharm Rep. Introducing **Nuplazid**

Objectives

- Introduce common non-motor symptoms of PD: hallucinations and delusions
- Describe those symptoms
- Explore how your health care provider can assist

Parkinson’s Disease is more than Motor Symptoms

- Most familiar symptoms of PD are motor symptoms (TRAP)
 - T – Tremor, specifically resting tremor
 - R – Rigidity, difficulty moving and stiff arms and limbs
 - A – Akinesia, no or slow movements
 - P – Postural instability, posture problems.

- Cognitive symptoms (particularly hallucinations and delusions) are under-diagnosed and under-treated.
 - These are common and experienced by majority of people with PD (estimated at 50% of population.)
 - The non-motor symptoms are more bothersome and affect quality of life.
 - These include memory problems, slow processing speed, sleep problems, anxiety and depression.

Hallucinations and Delusions are perceptions or beliefs that are not real, which makes them distinct from other conditions.

- Hallucinations – seeing, hearing or otherwise perceiving things that are not there.
- Delusions – fixed belief or unusual thoughts, beliefs or worries that aren't based on reality.
- These are NOT dementia or vivid dreams or problems with sleep.
- Most PD patients will have vivid dreams at some point, or REM sleep disorder (moving around while sleeping, “acting out” the dream.).

Causes

- Internal Causes
 - Progression of PD
 - Dehydration
 - Change in vision
 - Other medical conditions
 - Infection (Urinary Tract Infection (UTI) or pneumonia)
- External Causes
 - Some PD or other medications. All PD medications can cause hallucinations for some people
 - Alcohol or other recreational drugs
 - Dim lighting or time of day -- Sensory deprivation

- Early symptoms
 - Illusion – perceiving something which is there but looks like something else. An example is mistaking a sock for a rat.
- Who is at risk and why
- Dopamine deficiency is believed to play a major role in motor symptoms. Too much can cause hallucinations.
- Serotonin is thought to play a major role in hallucinations and delusions
- Other risk factors
 - Older age
 - PD duration
 - PD severity
 - PD medications
- Symptoms may change over time
 - Early symptoms
 - Insight is retained (the person knows that what they see is not real.
 - Passage or prescience (the person thinks they see something moving or feel that someone is in the room.)
 - Illusions
 - Feelings of passage or presence
 - Hallucinations
- Symptoms Progress – In one study, symptom progression was shown to occur over a 3 year time period, but this can vary for individuals.
 - Later Symptoms
 - Insight is lost (Person does not know what is real. This can be scary.)
 - Complex hallucinations and delusions
 - Hallucinations: Experiencing things that are not real

- Seeing things
- Feeling
- Tasting things
- Hearing things
- Smelling things
- Body sensations
- Delusions: what people with PD may believe
 - Persecutory delusions – someone is trying to harm, steal from, or deceive you
 - Jealousy – partner is cheating on them
 - Reference Delusions – like the TV is talking to them.
- Why treat these problems?
 - Hallucinations and Delusions were responsible for nearly 25% of hospitalizations of people with PD
 - Hallucinations and Delusions in PD are associated with an increased burden on caregivers

How do you treat this?

- Check for dehydration, infection or electrolyte imbalances
- Drug treatment
 - Adjusting certain anti-Parkinson's medication may help
 - Drugs are often added to treat these symptoms in PD, but prior to 2016, there were no FDA approved treatments (e.g. Seroquel, not FDA approved for this purpose). All anti-psychotics block hallucinations, but also block dopamine, which is a problem as it can make motor symptoms worse.
- Non-Drug Treatment Approaches
 - Self-managed coping strategies

- Cognitive techniques - education
- Interactive techniques – more stimulation tends to reduce hallucinations.
- Increase sensory input – engage socially, wear glasses and hearing aids.
- Visual techniques
- Psychotherapy
 - Cognitive – behavioral therapy
 - Supportive therapy (People who are more stimulated are less likely to have hallucinations. Sensory stimulation.)
 - Psycho-education
- Reporting symptoms is important
 - Only 10 to 20 % of people with PD will proactively mention their Hallucinations and Delusions to their health care providers. Some are embarrassed, not sure what to report.
 - If you sense or experience something unusual, ask your loved one if they perceived the same thing. Patients and caregivers should discuss the problem and describe what they perceive and discuss with the doctor.
 - Discussing your symptoms honestly and openly with your health care provider and how they impact your life is critical to developing a plan of action

Nuplazid

- First and only FDA approved medication for Parkinson’s psychosis.
- Affects activity of serotonin in the brain by binding to one specific serotonin receptor.
- Does not block dopamine.
- Shown to significantly reduce number and severity of hallucinations & delusions.

- May not completely solve hallucinations & delusions, but reduces and makes them less distressing.
- Takes a while to work – six to eight weeks to get full effect.
- Has no positive effect on motor symptoms, but no negative effect either, so you don't have to adjust other Parkinson's meds.
- Dose: 34 mg once daily (in form of two 17 mg tablets), no special instructions re taking with or without food, etc.
- Recommends trying Nuplazid even with mild hallucinations & delusions, because as Parkinson's progresses, you will need higher doses of Parkinson's drugs (which will increase number and severity of hallucinations & delusions).
- Side effects: nausea, peripheral edema, confusion, constipation – all experienced by less than 7% of patients taking Nuplazid.
- Does NOT cause depression.

You don't just pick up at pharmacy. Your MD enrolls you in the program, and the company sends the medication to you (after insurance approval). Financial assistance available (few people pay full price.)

SAFETY

- FDA has given Nuplazid a Black Box warning, "Increased risk of death in elderly patients with dementia-related psychosis" – BUT it should NOT be used for dementia-related psychosis (that's not what it's for).
- Can slightly prolong the QT interval on EKG (all anti-psychotic drugs do this). Be careful taking with other drugs that also prolong QT interval.

Q&A

- Any Diet & Nutrition advice for Parkinson's?

There is not a lot of study on this. But general recommendations: Try to avoid Sugar, High Glycemic Carbs, and, if sensitive or allergic -Dairy. Protein in small amounts, frequent small meals in concert with medication schedule, and thoroughly chewing food to avoid swallowing problems is recommended.

- If you are not currently having hallucinations, should you start Nuplazid?

You don't need Nuplazid unless you are having hallucinations & delusions.
If you are having vivid dreams, it may help, but probably you don't need it.
Clonazepam can help with "acting out" dreams.

OTHER BUSINESS

- T-SHIRTS: Will be ordering more t-shirts, same design on black, but lighter weight and ladies-style available. Order through sign-up sheet at meeting.
- Big Easy group is welcome to attend Wine Down on Wednesday at Deanie's on the Lakefront, Wednesday, June 20, 4:30 to 6:30 pm.

Next month, Tina Gundalo, our Web Master, will walk us through the Big Easy web site – **and answer questions you may have re: internet in general** 😊

Mae Brooks – Parkinson research NIH {National Institutes of Health Bethesda, MD looking for PD patients to be evaluated and followed by NIH

{Expenses paid by NIH } **301-496-4604**

CARE GIVER SUPPORT GROUP – 1st Wed. 3421 Caus. Blvd. #502 504-828-0900

- *June 25 Lori Boudet– Adamas Pharm- Gocovri (Amantadine) Dyskinesia
- *July 30 Drs. Jay Rao & Brian Copeland - LSU Medical Health Center
- *Aug. 27 Jill Siemssen-US WorldMeds - (Apokyn/Xadago)
- *Sept.27 Jerry White - Medtronic DBS {Deep Brain Stimulation}
- *Oct. 29 Roberta Powers-Lundbeck Pharm- (Northera) Orthostatic Hypotension
- *Nov. 26 Rich Baudry - Baudry Therapy (PD centered therapy)

SMILE – BE HAPPY – HUG SOMEONE EVERY DAY!

Visit our web site: BigEasyFleurDeLis.org

Join us on Face Book: *Parkinson's Support Group in the Big Easy*