



Big Easy Fleur de Lis Parkinson's Support Group Meeting Minutes 7/30/18



- Big & Loud Hello – Stretch!
- Prayer led by Dr. Ferd Becker.
- Welcome: New Members – Welcome Bags
- Announcements: Bonnie Huddleston
 - Cupping Massage (good for circulation) Wellness Center-CASEY SMITH 504-503-6868
 - Twitchy Woman blog: sign up on her website: twitchywoman.com
 - Timer bottles for sale from **Big Easy** for \$5 (batteries are replaceable).
 - Book Lending Library: just write down your name to borrow a book.
 - Important Medication Reminder: Take levodopa meds one hour before or 1 hour after eating (protein competes with levodopa).
 - Important Reminder re your doctor: Not all neurologists are **Movement Disorder Specialists**. You should see a **MDS** at least once a year.
 - Dr. Jay Rao; Dr. Brian Copeland - LSU 504-412-1517;
 - Dr. David Houghton; Dr. Georgia Lea – Ochsner 504-842-3980;
 - Dr. Sarah Perez - Tulane 504-988-5561
 - Thickened water/liquids helpful for swallowing issues (donations available for you to try).
 - New members: please fill out member profiles and pick up welcome bag.
 - Marie is doing well; thanks to volunteers Jan & Ron Barone for arranging food while she recovers.
 - Dan Flynn: first donor to official **Big Easy** non-profit 501(c)(3).
 - Please refer to agenda for information re new drug trials for Neuraly.
 - Committee sign-up sheets being circulated for volunteers. **Big Easy** started in 2008 with eight members, now 233 on roster. It's a lot of work – we need help. Especially needed: Marketing/Communications: flyers, brochures, manning booths at various seminars; CD needs updating.
 - To participate or donate to the Walk: **Team Big Easy** at www.parkinsonswalk.org
 - National Mentors: volunteers willing to provide information to newly diagnosed PWP contact Bonnie if interested. BonHudd4417@gmail.com
 - The VA is very helpful for PWP. If you are a veteran, contact the VA.

SPEAKERS (Q & A Format): Dr. Jay Rao and Dr. Brian Copeland

Q. How important is it to see Movement Disorder Specialist?

A. It is critical that patients **start with an MDS when they are first diagnosed**. Treatment in the first three years is critical.

Q. Do you recommend participation in Neuraly Study?

A. Do not miss this chance. Get ahead of the game. Call and make sure that as many people from this group as possible will get on the study. You will get medicine for free for two years to determine its impact on the progress of the disease. You will then be eligible for the drug for three years until it's on the market. Ted Dawson is respected researcher.

But, you may not qualify for the study if you have DBS. The new drug will not help with day-to day treatment. It is for long-term.

The drug to be used is already used for diabetes. It will not stop or reverse the disease, but is hoped to slow it down. If you have diabetes, ask your doctor for the diabetic drug which works the same way as this one.

<https://parkinsonsnewstoday.com/2018/07/20/neuraly-raises-36-million-to-advance-nly01-potential-parkinsons-therapy-into-clinical-trial/>

- Info on study:
NLY01. Neuraly Inc. is developing the compound for clinical use. It is anticipated that Phase I clinical trials will begin in 2018 and Phase II clinical trials will begin 2019. Criteria for patient selection has not been determined for Phase II. Neuraly Inc is establishing a web page and an education page will be on their web site for interested patients. **Please follow Neuraly Inc for updates. No URL available at this time- stay tuned !**

- **Info on Ted Dawson**
Ted M. Dawson, M.D., Ph.D.
Director, Institute for Cell Engineering
Director, Morris K. Udall Parkinson's Disease Research Center
Interim Director of the Movement Disorder Division and
the Parkinson's Disease and Movement Disorder Center
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Q. What type of exercise do you recommend for a patient who has trouble standing or walking?

A. This may be due to inadequate treatment. A physical therapy program is highly recommended.

- Two LSU Physical Therapy students were introduced. Sophie Eppling and Garrett Logan. They are starting a research program. Over the next year, they will be conducting a research program on exercise for PWP, particularly non-contact Boxing. Regular participation seems to improve the patients' ability to balance, gait, functioning and quality of life.

Rock Steady Boxing: fee to participate. If you qualify for the study, you don't have to pay.

Locations

- Krav Maga (<http://triumphkravmaga.com/>); Metairie
- or Fysical (<https://www.fyzical.com/new-orleans>)

Q. What would be a good program for PWP who have orthostatic hypotension and cannot stand very long?

A. It can be dangerous to do exercise with orthostatic hypotension. You need to work with your physician to find out what's causing it (medications, for example) and resolve the problem.

Until you are stable, you cannot safely participate in programs like Rock Steady. There are eated programs.

Q. When should PWP start treatment - early or late?

A. It depends: on your age and your role – are you still working? Or the primary breadwinner? Are you stiff, or are you shaking?

If it is not required, there are advantages to delaying medication as long as possible, to avoid side effects. You need to see a specialist who has seen multiple expressions of the disease.

Q. Are there differences between levodopa medications?

A. Rytary is probably the best levodopa medicine. Sinemet is fine, but only works for an hour to an hour and a half. Rytary is extended release and can work for four to eight hours.

Unfortunately, it has become increasingly difficult to get approvals because insurance companies do not like to pay for it. New drugs are in the market because they are better than the old. You have to fight your insurance company to try them.

Q. Pharmacists say that Carbidopa-Levodopa CR is continuous release.

A. Rytary is extended release. It last four to eight hours. You need to be a little careful with pharmacies. Be sure to check the tablets before you leave the counter to make sure you're getting exactly what you've been taking. Watch for switching to generics. Read the label – is it the correct dosage? If you are not getting what you need, change pharmacies.

Q. There seems to be more emphasis in the media on Parkinson's. Is there a higher incidence?

A. There may be some increase in incidence, possibly from environmental/workplace toxins like pesticides. But mostly you are seeing more advocacy. There are more advocacy groups who are getting the word out, asking for government funding of research.

Q. How are different drugs used for different symptoms? What is best for rigidity?

A. Different drugs work for different things. Sometimes Sinemet is not the best drug for tremors. That's another reason for a Movement Disorder Specialist.

Q. Is there a problem with taking Levodopa in combination with anti-anxiety medication?

A. There is no problem. Anxiety is a common problem with PWP. Some of it is life changes. Some of it is the disease process. It is recommended for PWP to avoid short-acting anti-anxiety medications (Xanax, Ativan, Valium) because they can increase the risk of falls.

Q. What do you think about using CBD for Parkinson's-related pain??

A. CBD is a derivative of the marijuana plant that does not contain the compounds that give you a high. It can't be recommended because it simply hasn't been researched. There have been no clinical trials for PWP. In general, it probably doesn't hurt, but the effect can't be predicted. It may help with pain, movement, dyskinesia – there are indications it helps with cancer pain - but no one knows for sure. It has effects in the Parkinson's area of the brain, but no one knows what it does there.

Q. What do you know about the NIH study?

A. They are looking for patients who have DBS (Deep Brain Stimulation). It is also a gene study – looking for genetic mutations.

Q. How common are hallucinations?

A. Hallucinations are very common in PWP, but they can be controlled reasonably well. Tell your doctor so they can be treated! Sometimes changing medications helps. Sleeping medications like Ambien can cause hallucinations. Low-dose Clonapin doesn't. Seroquel helps treat hallucinations. Bladder medications can also cause hallucinations, Oxybutin for example. Some of the newer ones have fewer issues but older ones do cause these problems. Myrbetriq is better. Prostate meds don't cause hallucinations.

Q. After surgery, my spouse started having hallucinations, which he never had before. The doctor said the Parkinson's meds were fueling the hallucinations and cut back on his meds. Was this due to anesthesia?

A. First, do NOT cut out Parkinson's medications suddenly or completely, cold-turkey. This can be life-threatening. If you are hospitalized, **do not let them stop your Parkinson's medications.** Anesthesia can make Parkinson's worse or cause cognitive problems. Some people never quite get back to their pre-surgery status.

Q. What do you think about Nuplazid, the new medication to treat hallucinations?

A. It is helpful, does not work right away, can take several weeks. It is relatively safer than other anti-psychotic drugs, and doesn't seem to make movement problems worse. You may have heard it has been associated with an increased death rate, but that is a characteristic of that type of drug. It is not more dangerous than other medicines in this drug category used to treat hallucinations. For some people, the benefit is not worth the risk. For others, they are willing to assume that risk.

Q. Can you recommend any complementary or alternative therapies?

A. Nothing except exercise. In multiple clinical trials, no other "alternative therapy" has been shown to help. Exercise is the one exception. It improves symptoms. It may slow progression. One half hour of exercise every other day is the best therapy.

Q. I experience what I call inward tremors, like a cat purring inside me. Is that common?

A. **Xadago** can be helpful.

Q. There are so many drugs that interact with Parkinson's medications but, when you search on the internet, a lot of things pop up as contraindicated that really aren't. Is there a good resource to check for drug interactions?

A. The Parkinson's Foundation website. www.pdf.org
When you are prescribed a new medication, always look to see if it interacts with your Parkinson's medications. There should be checks in the system before you ever get that prescription (your doctor, the pharmacy) but it doesn't always happen.

Q. Do patients with Deep Brain Stimulators have to worry about coming into contact with magnetic fields?

A. The kind of magnetic fields you would typically encounter (microwave ovens, for example) are not a problem. Even if you were to encounter a very strong magnetic field (an electrician

working around a transformer, for example), the DBS would just turn itself off. There is no danger.

Q. Is there anything available now to slow the progression of Parkinson's?

A. Exercise.

Q. I have good days and bad days. Is that typical of Parkinson's?

A. Yes, just part of the disease. It's a good idea to keep a log of what you are experiencing. It can be helpful to share with your physician.

Q. I experience a sort of internal jump as I drift off to sleep. Is that due to Parkinson's?

A. Don't know.

Q. Do hallucinations have anything to do with dementia?

A. Yes, they can be connected in some people.

Q. Are there any drugs to help with memory loss?

A. Dementia drugs can sometimes be helpful, but not always much help.

Q. Are mood changes typical of Parkinson's?

A. That can be part of the disease. Anxiety or anger might happen as the PWP is getting close to needing their next dose of medication.

Q. Is there a connection between Parkinson's and gout?

A. Gout is caused by high levels of uric acid in the body. Some evidence suggests that higher levels of uric acid are somewhat protective against Parkinson's. Artificially increasing uric acid does not seem to give same benefit. That being said, if you have gout, you need to treat it, even though that would lower your uric acid level.

Q. Does Tylenol help pain associated with Parkinson's?

A. Some. Advanced cases not so much. Tylenol is recommended for Parkinson's pain.

Q. What do you think about a drug that increases circulation to the brain to treat Parkinson's?

A. Dubious that a pill can create angiogenesis, and question how it could be targeted.

Q. Any other research trials coming up?

A. LSU has **two trials** coming up.

One is an **observation trial** for PWP experiencing hallucinations.

The **Second** is correlating **eye movements with cognitive and movement functions**, not just for Parkinson's, includes Alzheimer's and other neurological diseases.

The LSU Physical Therapy Dept. is doing a **Study** mentioned earlier.

Dr. Copeland is sending the flyers with Trial & Study details to Bonnie to share with the Group.

Thank you to: Martha Good & Lista Hank for these excellent, detailed minutes !!

BH