

Big Easy Fleur de Lis Parkinson's Support Group

Meeting Minutes 6/25/18

- Meeting led by Tina Gundalo.
- Prayer by Dr. Ferd Becker.
- Reminder re upcoming seminars:
 - LVST Seminar on June 30, noon-2pm, East Jeff Hospital, Esplanade 1.
 - Parkinson's Conference, July 14, Baton Rouge, Pennington Center
More info: chseproed.com/LAParkinsonsConference2018
 - Luke LeJeune lleje11@lsu.edu or 225-578-8763.
 - Those who attend seminars are asked to bring back information/report to group
- Website not working so Tina will demonstrate it at another meeting. Tina suggested that individuals sign up with national Parkinson's organizations to receive information and announcements directly (to relieve Bonnie of responsibility of emailing all the announcements to members). Offered to help anyone who needs assistance signing up for informational emails.
- Warren Flint had knee replacement surgery and Nancy Flint reported that he is having difficulty bouncing back from anesthesia, so both were unable to attend today.
- If you go to Copeland's in Kenner, please thank them for donations of bowtie pasta each month; if you go to Sam's in Kenner, thank Cassandra for donation of sheet cake.
- Tina reminded members about Caregiver's Support Group
 - First Wednesday, 3421 Causeway Blvd #502, 504-828-0900
 - Members who have attended the group reported positive experiences, helpful information.
 - Tina reminded caregivers to ask for help, and friends to be assertive in providing respite time and support.

SPEAKER: Lori Boudet, Adamas Pharmaceuticals

Gocovri: first and only drug approved by FDA for dyskinesia in Parkinson's patients.

Dyskinesia:

- Uncontrolled, jerking, writhing or twisting movements caused by Levodopa.
- Can be in face, neck head, trunk, legs or whole body
- Dyskinesia is different from tremors (*shaking* of hands, legs). Ask your physician if what you are experiencing is dyskinesia.
- Can make it difficult to eat or cook because can't hold utensils, difficult to drive or manage dressing self.
- Possibly an aspect of Parkinson's progression, but generally considered a side effect of Levodopa

Levodopa is "gold standard of Parkinson's treatment...."

- Over time, increasing doses of Levodopa are needed to control Parkinson's symptoms.
- Increasing dosages of Levodopa increase likelihood of experiencing dyskinesia.
- 90% of Parkinson's patients will develop some form of dyskinesia.
- Balancing act of increasing Levodopa to control Parkinson's symptoms (stiffness/rigidity) vs side effects like dyskinesia.
- Dosage of Levodopa that brings on dyskinesia is different for everyone.

Gocovri

- Decreases dyskinesia 40%
- Can increase “On Time” up to 4 hours, and decrease “Off Time” by one hour each day.
 - *On Time: the period when Levodopa is working (and when dyskinesia occurs).*
 - *Off Time: when Levodopa isn’t working (stiffness/rigidity increases).*
- Extended release Amantadine
- Is taken at night, slowly releases throughout day to increase functional time.
- May allow an increase in dosage of Levodopa while maintaining functionality (though clinical trials did not test increasing dosages of Levodopa)
- Side effects: Gocovri may not be suitable for you. Talk with your physician.

Insurance Coverage/Cost:

- Most insurance will cover. (Only FDA approved med for dyskinesia in Parkinson’s.)
- You can call your insurance company to see if they cover.
- Ask your pharmacist what the cash price is.

Assistance Program: Gocovri Onboard

- Can help with co-insurance, co-pays
- Provide two weeks of meds free
- Will help you work toward getting the assistance you need to pay for Gocovri

www.Gocovri.com

- Resources
- Information about dyskinesia
- Safety and side effects
- Caregiver information
- Info on **Gocovri Onboard** program

Conclusion:

- You do not have to live with dyskinesia.
- Gocovri is another tool for managing Parkinson’s

Adamas will be starting Patient Programs: physician and patient taking Gocovri will come to speak to small groups at a restaurant about Gocovri, resources available. Lori will keep group informed.



Tina reminded group that LSU will be looking for “Health Partners” for the fall: Parkinson’s volunteers to help LSU students learn. She will be back to discuss the program at another meeting.