



Big Easy Fleur De Lis Support Group



Meeting Minutes

April 30, 2018

- * Warren and Nancy Flint {new members} announced they are trying to start a Pinochle group, for anyone interested. They will be assisting new members with Welcome Bags, follow up calls and Support with PD questions and issues. They ask that all new members please fill out the “Member Profile”, to ensure you are on the mailing list.
- * Big Easy PD is the final name for LLC.
- * Marie McClelland – Surgery on May 7th went well !
- * End of Life and Hospice Legal issues: Louisiana Directives – Advanced Directives (not the same). Most doctors will have the LA Directive. Check People’s Health – Google It. Also the “Five Wishes”, any hospital has it.
- * Bonnie met the author of the book *Chicken Scratch* – available on Amazon. Quick Read, She has had early onset PD for many years- and writes about her experience with DBS as well.
- * Neurology Now – free magazine. Now called Brain and Life. Has terrific articles. Can get it online or delivered free. < Brainandlife.org >
- * Considering a fundraiser with Fox organization, and /or Inspired Living Kenner.
Need a Chairperson for activities and Fun Raiser.
- * REMEMBER: The next meeting is May 21st , a change in schedule due to Memorial Day.
- * RxGreenhouse – medical marijuana source, reported to open in Jefferson Parish in September.
- * List of drugs in the Symposium program on DRUGS THAT PD PATIENTS SHOULD NOT TAKE.
copy attached to the agenda.
- * Wellness center offering Spring classes – Line dancing, Ballroom Dancing, Tai Chi, others
- * Caregivers’ Support Group – Held 1st Wed. of month (next meeting-June 6th) 504-828-0900
- * May Brooks is the PD contact at NIH (National Institutes of Health). They follow a Parkinson’s Patient and do some genetic research. They take three at each visit. They pay for travel expenses.
800-362-3479 BrooksM@ninds.nih.gov

At this point during the meeting, we were treated to the delightful, soothing melodies of our two favorite professionals wearing many hats...**Dr. Sarah Perez**, Tulane Center for Clinical Neurosciences, Division of Movement Disorders, on Clarinet and **Jan Grimes**, Professional-in-Residence Collaborative Piano, on Piano ! As if this was not enough to gladden our hearts, Jan shared her famous “HACKS for Life with PD” ! Here are a few we remember.....

Life Hacks:

*Tremor

- Spill-Proof cups
- Weighted gloves
- Heavy Weight Utensils for eating

*Walking and Freezing

- Mats which look like stairs, assist with freezing
- Cueing gadgets – laser shoes, laser pointers
- Canes which sense when you stop and rattle a little to give a tactile cue
- One PD patient used a jar of candy to motivate him to cross his home threshold

Jan's freezing hacks:

- * When she is freezing, her husband puts his foot in front of hers so she can step over his foot.
- * Imagine footprint cut outs on the floor and aim for them. This is easier on a tiled floor or a patterned carpet.
- * Aiming for visual points on the pattern of the floor.
- * Print out of stairs on the floor.
- * Counting aloud, in sets, like 1, 2, 3, 4, 1, 2, 3, 4
- * Trouble going through doorways – tries walking sideways, possible backwards.
- * Tries to take BIG steps
- * Alternating walker with the cane. Sometimes sit in Rollator and roll around.
- * Giving motivational verbal cues
- * Stop, stand up straight, take a deep breath and reset.

* * *

When nothing works....

Take the opportunity to accept help.

Take a moment to educate and encourage others and visit with people SO IMPORTANT-especially newly diagnosed !

***Ultimate mobility hack is exercise – biking, dancing, tango, rock steady, etc.

Around the House Hacks – Dr. Sarah Perez – Simple

- * Making the most of trips from room to room:
 - Use devices which free up the hands {apron with pockets; fanny pack}
 - Strategic placement of handles and door stops
- * Rowena the Rollator, used to:
 - Get the coffee maker to the sink in the rollator
 - Move laundry
 - Moves things from the freezer
- * Old fashion TV tray on rollers

No-Trip tips: from Jan-

- Ramp from den to garage
- In sewing room, put orange tape on the edge of the rugs
- Non-slip surface for chairs, for sewing (square of non-skid silicone)
- Fashioned a holder for the sewing machine pedal
- In bathroom, cut up a bathmat and toss the pieces around the shower. Non-skid pad on seat in shower.
- Handles on the tub and the side of the toilet
- Pill organizer
- Fingernail trimmer – hands slipped on the handle, so she wrapped it with medical tape so that it is non-slip
- Hair dryer holder – gooseneck device for hands-free hair drying (?)
- In the garden – four wheel cart with big tires !
- Clever in the closet
 - Strap on the cell phone to keep it with you. (?)
 - Gardening apron with pockets to carry cell phone, etc.
 - Buttonless bags, zippers, closures, etc. She started making Japanese knot bags, which have no closure. She has the pattern and will share.
 - Napkin clips – like a small clothespin (used in sewing) to attach a napkin to her clothing to keep the napkin on her lap
 - Button puller, long handled shoe horn – available on amazon
 - Sock assist – Walgreen's
 - Satin Sleepwear helps you slide in and out of bed, or satin sheets. Boxers are available on the internet – {mansilk pajamas}
 - Magna ready shirts – has magnetic closures instead of buttons. Looks like a regular dress shirt
- Attitude
 - Avoid bad situations and people
 - Break the downward spiral by changing setting /activities
 - Expect the best and do not worry about what-if moments
 - Being flexible in your schedule: accommodating for motor symptoms and fluctuations
 - Being forgiving in your expectations for the day.
- Perspective
 - Finding opportunities to bless others and pour into relationships
 - Savor the moments of normalcy
 - Not taking life for granted, being grateful
 - PD is a Humbling condition
 - Finding less value in what I do, and more value in what I am !

There is a silver lining in having Parkinson's. You have to rejoice in the moments you can help or inspire someone.

Irma Bombeck: *When I stand before God at the end of my life, I would hope that I would not have a single bit of talent left, and could say, 'I used everything you gave me'*