

PSGTC NEWSLETTER

May & June 2010

Editor: Ann Milam

Message from the President



What a great turnout we had for the March Caregiver's Luncheon! Dr. David Capper's presentation was such an inspiration to all caregivers and we were especially appreciative of his recounting his recent work in Haiti along with other doctors after the devastating earth quake that hit that country. We are fortunate to have such a caring person supporting our group.

At the May meeting, you will be asked to choose three members to serve on the Board of Directors over the three-year period, beginning June 28, 2010. I urge each of you to be present for this important election.

Dues were due April 1, 2010

Your dues must be paid no later than **June 15** to remain on the active member list.

Dues are as follows:

Individual & Family (patient and partner annual Dues.....\$20.00

Professional Member annual dues.... \$30.00

Life members One time fee.....\$200.00

Please mail your dues along with a membership application form, so the dues will be credited to the correct person/family. (Form is on last page of this Newsletter)

Your prompt attention to this is greatly appreciated, and keeps our Support Group going.



Our meetings are held on the 3rd floor of:

Broadway Baptist Church

305 W. Broadway, RM 302

Fort Worth, TX 76104

May 24th meeting:

The meeting will be held at 1:30pm with Reflections Choir entertaining us with a wonderful concert from these amazing young people.

Refreshments will also be served at this meeting.

* * *

June 28th meeting:

This is our annual Patriotic Covered Dish Luncheon, and will be held at 11:30am. Bring a covered dish to be shared with others.

To recognize members who have served in the armed forces, please bring a framed picture of yourself to be displayed on the welcome table.

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BOD MEETING will be held at 10:00 am ~June 28, 2010



For Support Group information call our Help Line at (817) 275-1909

Exercise Class by Bob Belisle

With summer upon us, I want to wish everyone a very safe summer holiday season. As many may be traveling, we hope you will be safe on your travels and return soon to exercise with us. Please watch your calendar to make sure when we are exercising. As a general rule, we continue with our regular schedule of "MONDAY, WEDNESDAY AND FRIDAY AT 10:30am" We will have a holiday Monday, May 31 for Memorial Day. The church will be closed and we will return on schedule on Wednesday, June 2, 2010. The church will also be closed Monday, July 5, in observance of Independence Day.

We have had several new faces in our exercise class recently. We hope they learned a little about us and what we are accomplishing with the exercises we do, and that they will come back and join our group.



Splish ~ Splash

Many of you know our member Cindy Nolan. She is a Physical Therapist at Baylor All Saints, Fort Worth. She is specialized in treatments for Parkinson's Patients. Cindy has been working on getting a "POOL" class together at Baylor All Saints for the Parkinson's Patients in our area. She doesn't have a definite start date yet, so come to the regular Support Group meetings for the latest information on this new exciting form of exercise.

This water exercise will be funded by N. Texas Chapter of the APDA and will be held once a week at Baylor All Saints Medical Center Carter Rehabilitation and Fitness Center. (This is the same location as the Movement Disorder clinic with Dr. Madhavi Thomas.) The tentative plan is to have the classes on Tuesdays at 2:00pm. The class will be 45 minutes and will be designed to apply water exercise principles to the special exercise needs of persons living with Parkinson's Disease and other related illnesses.

Caregivers Corner

Loretta Belisle

The caregivers meet on the 2nd and 4th Friday of each month. We meet at 10:30, the same time as the Parkinsonians are exercising in the adjoining room. It is an excellent time to gather with other caregivers and share experiences and helpful tips. We welcome all caregivers to join us, whether your patient is able to exercise with the group or not. **Our regular schedule will continue throughout the summer months.**

Newsletter & Meetings

There will be no Newsletter published, or General Meetings held in the summer months. After this issue, the next issue will be Sept/Oct, 2010.

PDF WEBCASTS

Jack King has found that at the website pdf.org you may view PDF Briefings. Surf around this site for lots of interesting possibilities too numerous to name in this article. Beginning May 3, you can register for the next briefing which is about Fatigue, Sleeplessness, etc. Additional instructions will be given when you register. Note that you can access the WEBCAST by telephone or PC. As you scroll down into the website, you will see a number of links, such as Past Online Educational Events, etc that are of interest.

We have a member who lives in the area near Loop 820 and I-20 just west of Lake Arlington. He would like to contact someone who could give him a ride to the meetings, and or the exercise classes. If you are able to help, please contact Helen Robertson for more information.

Blessed are the cracked for it is they who let in the light!!



SHOP KROGER TO HELP PSGTC

Take the barcode below with you to Kroger, And have the cashier scan it before your Kroger card is scanned. Whenever you shop Kroger, a percentage of what you pay will go to PSGTC!

PARKINSON SUPPORT GROUP OF TARRANT COUNTY



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PARKINSON SUPPORT GROUP ACTIVITY MAY 2010

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3 Exercise 10:30am	4	5 Exercise 10:30am	6	7 Exercise 10:30am	8
9	10 Exercise 10:30am	11	12 Exercise 10:30am	13	14 Exercise 10:30am Caregivers Meeting	15
16	17 Exercise 10:30am	18	19 Exercise 10:30am	20	21 Exercise 10:30am	22
23	24 Exercise 10:30am <i><u>PSGIC Meeting 1:30</u></i>	25	26 Exercise 10:30am	27	28 Exercise 10:30am Caregivers Meeting	29
30						



PARKINSON SUPPORT GROUP ACTIVITY JUNE 2010

Sun	Mon	Tue	Wed	Thu	Fri	Sat
		1	2 Exercise 10:30am	3	4 Exercise 10:30am	5
6	7 Exercise 10:30am	8	9 Exercise 10:30am	10	11 Exercise 10:30am Caregivers Meeting 10:30	12
13	14 Exercise 10:30am	15	16 Exercise 10:30am	17	18 Exercise 10:30am	19
20	21 Exercise 10:30am	22	23 Exercise 10:30am	24	25 Exercise 10:30am Caregivers Meeting 10:30	26
27	28 Exercise 10:30am <u>PSGTC Luncheon</u> <u>11:30am</u> <u>BOD 10:00</u>	29	30 Exercise 10:30am			

Clinical clues suggestive of Parkinson-plus syndromes include the following:

- Lack of response to levodopa/carbidopa (Sinemet) or dopamine agonists in the early stages of the disease
- Early onset of dementia
- Early onset of postural instability
- Early onset of hallucinations or psychosis with low doses of levodopa/carbidopa or dopamine agonists
- Ocular signs, such as impaired vertical gaze, blinking on saccade, square-wave jerks, nystagmus, blepharospasm, and apraxia of eyelid opening or closure
- Pyramidal tract signs not explained by previous stroke or spinal cord lesions
- Autonomic symptoms such as postural hypotension and incontinence early in the course of the disease
- Prominent motor apraxia
- Alien-limb phenomenon
- Marked symmetry of signs in early stages of the disease
- Truncal symptoms more prominent than appendicular symptoms
- Absence of structural etiology such as a normal-pressure hydrocephalus (NPH)

Multiple System Atrophy

The clinical definition of MSA is a progressive, idiopathic, degenerative process beginning in adulthood. Patients present with various degrees of parkinsonism, autonomic failure, cerebellar dysfunction, and, pyramidal signs that are poorly responsive to levodopa or dopamine agonists. Glial cytoplasmic inclusions (GCI) and a neuronal multisystem degeneration are the pathologic hallmarks of this clinically variable disorder.

Progressive Supranuclear Palsy

Progressive supranuclear palsy (PSP) is a neurodegenerative disease that affects cognition, eye movements, and posture. Characteristics include supranuclear, primarily vertical, gaze dysfunction accompanied by extrapyramidal symptoms and cognitive dysfunction. The disease usually develops after the sixth decade of life, and the diagnosis is purely clinical. Currently, no therapy is proven to be effective.

Parkinsonism–Dementia–Amyotrophic Lateral Sclerosis Complex

PDALS is a condition well described on the island of Guam and locally known there as Lytico-Bodig disease. The latter term is derived from the local Guamanian dialect, with *lytico* referring to the paralysis caused by the amyotrophic lateral sclerosis (ALS) component and with *bodig* referring to the "laziness" that describes the parkinsonian component.

Corticobasal ganglionic Degeneration

CBGD is characterized by frontoparietal cortical atrophy in addition to degeneration within the extrapyramidal system. The rigidity, bradykinesia, and tremor sometimes can benefit from levodopa therapy. However, the marked disability from the limb apraxia is progressive and generally remains unresponsive to rehabilitation efforts. Injections of botulinum toxin often relieve dystonia. In particular, the dystonic clenched fist may respond to injections of botulinum toxin, which helps relieve the pain and prevent skin breakdown.

Diffuse Lewy Body Disease

DLBD is a progressive neurodegenerative disorder characterized by the presence of parkinsonian symptoms and neuropsychiatric disturbances commonly accompanied by dementia. Progressive dementia is often the first and predominant symptom. Hallucinations and confusion are limiting factors.

Practical Management of Parkinson-Plus Syndromes—Comprehensive face-to-face counseling is indicated with the patient and caregivers involved. Give attention to emphasizing positive supportive measures. These include safety measures, such as use of appropriate walkers, occupational therapy, assessment of the home environment, physical therapy, and exercise. Specifically ask questions about swallowing mechanisms, and, obtain a modified barium swallow study. When difficulties with aspiration are detected, consider a change in diet and, placement of a percutaneous endoscopic gastrostomy tube to maintain nutritional status. Patients may exhibit an interest in surgical techniques such as deep brain stimulation, pallidotomy, or transplantation, but these are not indicated for Parkinson-plus syndromes.

Cognitive aspects—Hallucinations can be alleviated to some extent with quetiapine or clozapine. Dementia is the most difficult symptom to treat in this setting. A comprehensive neuropsychological evaluation repeated at intervals of 1 year can help in assessing the progression of cognitive symptoms in a quantitative way and can suggest coping methods

Eye signs—Some patients with PSP may benefit from prismatic lenses that compensate to some extent for the vertical gaze problems. Blepharospasm, facial dystonia, and apraxia of eyelid opening can respond to botulinum-toxin injections.

Help Line (817) 275-1909

For info about our group call our

Fort. Worth, TX 76104

305 W. Broadway, Room 302
Broadway Baptist Church

Meetings are held at:

HURST, TX 76053

P. O. Box 939

OF TARRANT COUNTY

PARKINSON'S SUPPORT GROUP



PARKINSON'S SUPPORT GROUP OF TARRANT COUNTY MEMBERSHIP APPLICATION AND RENEWAL FORM

Date _____

Name _____

Name of Spouse/Family Member/Other _____

Address _____

Home Phone _____ Cell Phone _____

e-mail _____

Preferred Type of Membership: _____ Family (patient and partner (\$20.00 per year)

_____ Professional (\$30.00 per year)

_____ Lifetime(\$200.00)

Make check payable to PARKINSON'S SUPPORT GROUP OF TARRANT COUNTY (or PSGTC)

Mail to: Merry Ann Bench, P. O. Box 939, Hurst, TX 76053

The contents or opinions expressed in this Newsletter are those of individual writers and do not constitute an endorsement or approval by Parkinson's Support Group of Tarrant County.