

PARKINSON'S NEWS

May-June 2009

PARKINSON'S SUPPORT GROUP OF TARRANT COUNTY

Editor: Ann Milam



Word from the President

by Helen Robertson

It was so good to see the turnout for the Caregivers Luncheon and to be able to show them how much they are appreciated. It's incredible the love and caring shown by our caregivers to their Parkys. And a big thanks to each of you for your continued support to the group. Thank you, Doug Day, for your inspiring and encouraging words to us all.

We will be electing new members to the Board at the May annual meeting. The nominating committee members are: Loretta Belisle, Debbie Benner, Ned Baker, Elsie Wilson and Helen Robertson.

Meetings Scheduled

Broadway Baptist Church—305 W. Broadway, RM 302—Fort Worth, TX 76104

May 18, 2009—1:30 p.m.

Our speaker will be **Cindy Nolan, PT.** Cindy, and her associates; Cindy Betsill, OT, Andrew Martinez, PT, Gratia Childers, SLP of Baylor-All Saints Rehab Unit will bring us a program on “**Exercise Training “BIG” and Therapy Updates**” for Parkinson's Disease. LSVT “BIG” is a new therapy protocol done by certified PT's and OT's based on the Lee Silverman Voice Treatment (LSVT) model. We all know how important it is to exercise our bodies and voices to keep both working as well as possible. Let's all come and give this group the opportunity to keep us updated on all that is new and is helping with Parkinson's.

June 22, 2009 - 11:30 a.m.

Patriotic Luncheon

Sandwiches will be provided. PSG members are to bring picnic type foods: chips, vegetables, salad, or desserts. Our program speaker will be **Dan Bruce** of Cardiovascular Home Health speaking on “**Safe Choices**”

A brief Board Meeting will be held AFTER the luncheon to elect officers for the coming year.

Notice: We do not have meetings or newsletters in the months of July and August. We hope to see you all again in September. Have a safe and fun summer.



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



Member News

Charles Johnson is now under hospice care at Odyssey Hospice and is not expected to live very long. He has been in and out of the hospital for the past year battling one thing after another. Please keep Dora and Charles in your prayers.

Announcement

We are currently collecting e-mail addresses from members for our directory. We hope to be able to put our newsletter "online" for those with internet capabilities, thus reducing the cost of printing and mailing newsletters. (We will still mail newsletters to those who prefer it that way.) **When you pay your 2009 dues please send the coupon on the back of this newsletter, with e-mail address filled out so we can record your e-mail address in our records.**

Equipment Available

Elsie Wilson has a 2001 Silver Chrysler Town & Country Ramp Van. Can be used with manual or electric wheel chair or scooter in driver's or passenger's side. Less than 38K, in good condition. You can call Elsie at (817) 275-1909 for more information.

Mark your Calendars: May 7, Michael J. Fox will be appearing in a segment on ABC called: "Always Looking Up Adventures of an Incurable Optimist"

Annual Dues

The Dues structure was changed by a majority of vote at the March meeting. Dues are now as follows:

- A. Individual and Family (patient and partner) annual Dues.....\$20.00
- B. Professional Member annual Dues \$30.00
- C. Life Member one time Dues \$200.00

Your Dues Provide:

- Building usage-Annual donation to Broadway Baptist Church
- Parkinson Phone Help Line
- Equipment for Exercise Classes
- Hospitality - Refreshment Supplies and Caregivers Luncheon
- Newsletter printing and postage
- Publicity - Brochure Cost
- Sunshine Fund for Cards, plaques and postage
- Research-Annual donation to National Parkinson Alliance Research Fund
- Entertainment
- Development of Website

If your dues are due, please pay them so we can do more. Thanks to all who have already paid.

Tulip Pin



If you signed up at the March meeting for a Tulip pin, and did not pick it up at the April meeting, be sure and see Jack King at the May or June meeting to receive the pins you ordered. They are \$3.00 a piece.

Exercise Class by Bob Belisle

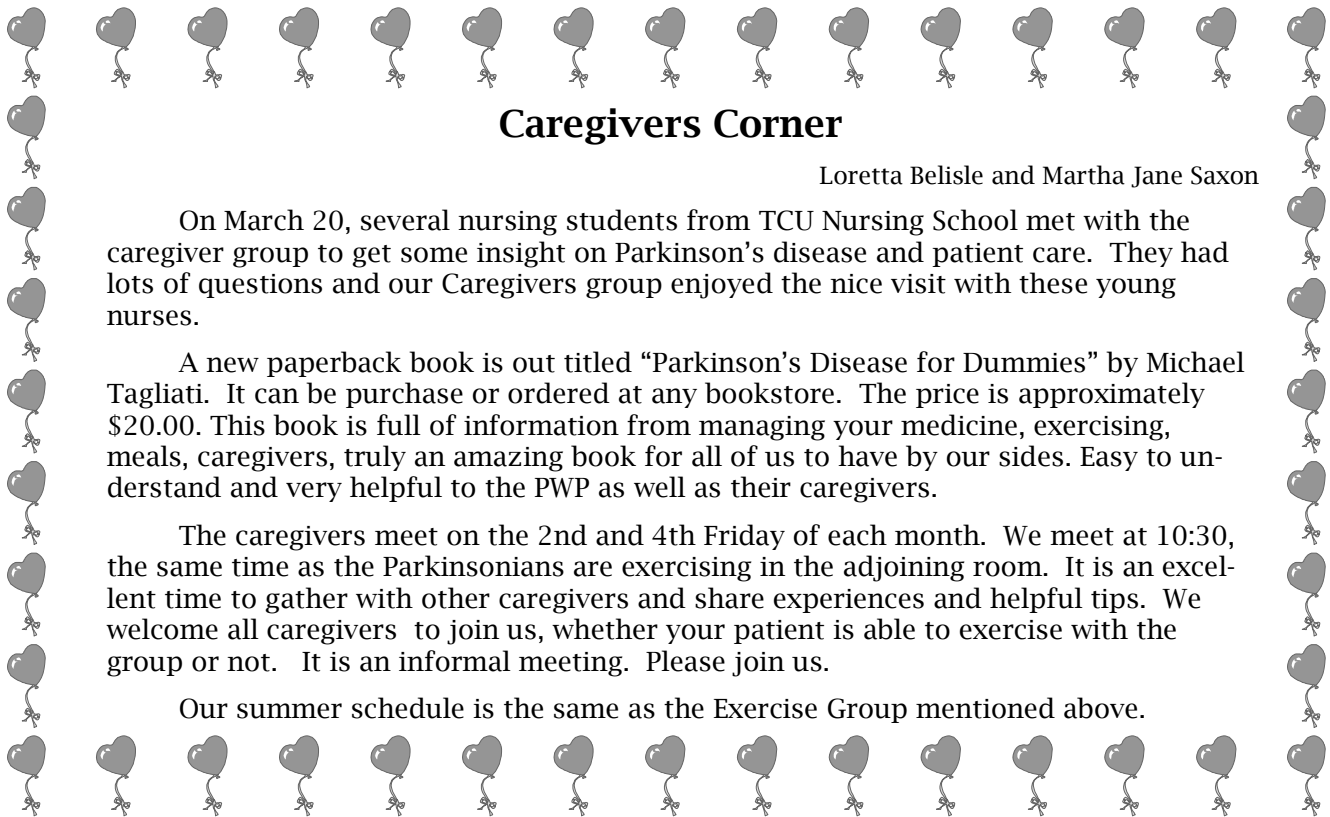
WOW! How exciting.....we have had several new visitors to our exercise class recently. We hope they learned a little about us and what we are accomplishing with the exercises we do, and that they will come back and join our group.

The exercise group meets Monday, Wednesday and Friday at 10:30am for an hour of good flex and strength training. It is so important for us folks with Parkinson's Disease to exercise to keep our joints flexible and our muscles strong. We meet on the 2nd floor of the Broadway Baptist Church. Please consider joining us for this time of fun and beneficial exercise.

No exercise on Friday, May 22, and Monday, May 25, 2009 due to Church closure those days.

Summer Exercise Schedule

During the summer months, (July and August) we will maintain our regular schedule of exercise as mentioned above with the exception of the July 4th Holiday, which will be Friday, July 3. No exercise class will be held that day.



Caregivers Corner

Loretta Belisle and Martha Jane Saxon

On March 20, several nursing students from TCU Nursing School met with the caregiver group to get some insight on Parkinson's disease and patient care. They had lots of questions and our Caregivers group enjoyed the nice visit with these young nurses.

A new paperback book is out titled "Parkinson's Disease for Dummies" by Michael Tagliati. It can be purchase or ordered at any bookstore. The price is approximately \$20.00. This book is full of information from managing your medicine, exercising, meals, caregivers, truly an amazing book for all of us to have by our sides. Easy to understand and very helpful to the PWP as well as their caregivers.

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. It is an informal meeting. Please join us.

Our summer schedule is the same as the Exercise Group mentioned above.

All of his life Ole had heard storied of an amazing family tradition. It seems that his father, Grandfather, and great-grandfather had all been able to walk on water on their 21st birthday. On that day, they'd walked across the lake to the boat club for their first legal drink.

So, when Ole's 21st birthday came around, he and his pal Corky took a boat out to the middle of the lake. Ole stepped out of the boat and nearly drowned! Corky just managed to pull him to safety.

Furious and confused, Ole went to see his grandmother. "Grandma, it's my 21st birthday, so why can't I walk across the lake like my father, his father and his father before him?"

Granny looked into Ole' eyes and said, "Honey, let me explain something to you. Your father, grandfather and great grandfather were born in January. You were born in July." —from the Senior News





Library News

By Elsie Wilson

Helpful Steps to Improve Your Own Care

1. Be clear about your expectations for each clinic visit.

Bring a list of questions

List your goal (s) for each appointment. This helps focus the appointment on you, rather than your disease.

Talk about your goals. Ask if treatment exists and what steps you need to take to help you reach your goal,

Understand why certain treatments are recommended. For instance, ask why you are taking each medicine. If your therapist recommends certain exercises, ask what they are designed to help or prevent.

Be honest. Let your provider know if you do not think a treatment will work or if you do not think you can comply with a treatment.

Work with your provider to choose the best time to return for follow-up visits. For example, let them know if you need to be seen more frequently because of your concerns or fears.

2. Be an active participant in your visit.

Ask your clinician: "What information do you need from me to help us work as a team in my care?"

Organize a "Carebook" and bring it to each clinic visit including contact information for your doctors and pharmacy.

Keep a list of your current and past medicines, doses, and timing. If you stopped a medicine, be sure to keep track of both the dose and reason for stopping.

Take the time to accurately fill out any questionnaires your providers give you. This gives you and opportunity to write down information you feel is important for your provider to understand.

Be sure to leave with an understanding about your treatment. Ask for a written copy of each treatment commendation and why it is recommended.

Ask your doctor to write why you are taking a medicine on each prescription so that it is clearly stated on the bottle. (For example: Sertraline 100mg daily for *depression*.)

Consider including your family or friends in your health care visits.

3. Continue self care between appointments.

Keep a log or notebook of each treatment and its effectiveness.

Share your list of medicines and their side effects with your care partner.

Stay connected. Search for groups or activities to help you stay well.

Emotional health: support groups, meditation, guided imagery and counseling.

Physical health: exercise, yoga, tai chi and dance classes.

Cognitive health: creative activities such as art, music and crafts classes.

Stay safe and reduce medicine errors by updating your list of medicines between appointments.

Change your medicines only under the supervision of your clinician.

Tell your team if you are not taking medicines as prescribed, or if you are unable or unwilling to take your medicines.

If a walker is recommended for safe walking, give it a try!

Pay attention to your general health.

See your primary doctor for yearly check-ups and preventative care.

Ask your doctor about skin checks, bone health and nutrition.

Seek help for weight management, smoking and alcohol use if needed.