

# PSGTC Newsletter

Sept. ~ Oct. 2012

Parkinson Support Group  
of Tarrant County



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## WORD FROM THE PRESIDENT ...

By Linda Tunnell

Fall? Rain? Where are you? We're so ready for cooler weather and rain!

We're looking forward to our new year of meetings; seeing old friends and new ones. Welcome to all of you.

Most of our officers will be familiar to you except for Secretary. **Janet Graves** instead of **KT Wolff** will be keeping us informed of the previous meetings. **Doug Day**, **Helen Robertson**, and I will still have our same office. I don't want to leave out **Cathy Collier**. Again, she is in charge of programs. We appreciate her hard work. We have hard working committees that help to keep us informed.

If you would like to volunteer, we would welcome you.

**Janet Edgar** and her mother, Gail, will continue to make centerpieces for our luncheons. We appreciate their work. Janet & Gail lost their father/husband in May, but will continue coming to meetings and contributing to our group. They brought a big bag of articles Joseph had not used. Be sure to look thru all of them. Anything you can use, take them including medications that others have brought that they no longer take. Take what you need.

We look forward to seeing you at our first meeting, a luncheon, on September 24th at 11:30. Until then, stay cool, stay safe, stay happy.

*Linda Tunnell, President PSGTC*

## Our Meetings are held at:

**Broadway Baptist Church / 305 W. Broadway, RM 302  
Fort Worth, Texas 76104**

### Monday, Sept. 24, 2012 - Luncheon

11:30 am-1 pm Broadway Baptist Church,  
Room 3rd floor meeting room. Board of Directors Meeting at 1 pm.

Luncheon sponsored by Brookdale Senior Living. Licensed physical therapist Donna McElroy will talk on "Fall Prevention."

*Our exercise group meets Monday, Wednesday and Friday of each week from 10:30-11:30 am at Broadway Baptist Church, Room 206 We have plenty of room for more and invite you to join us in the fight to keep mobility.*

*Caregivers meet on the 2nd and 4th Fridays in the room behind the exercise group to share ideas and give support. Come join us. Never feel alone on this journey.*

### Monday, Oct. 29, 2012 - PSGTC Meeting

1:00 pm, at Broadway Baptist Church, 3rd floor meeting room with snacks provided by Trail Lake Nursing and Rehab and a presentation on "Speech/Voice Therapy" by Beth Sharp Watson of Harris Methodist Hospital.

## Michael J. Fox Looks Past Stem Cells in Search For Parkinson's Cure

Michael J. Fox, whose turn from Parkinson's disease patient to scientific crusader made him one of the country's most visible advocates for stem cell research, now believes the controversial therapy may not ultimately yield a cure for his disease, he told ABC's Diane Sawyer in an exclusive interview.

There have been "problems along the way," Fox said of stem cell studies, for which he has long advocated. Instead, he said, new drug therapies are showing real promise and are "closer today" to providing a cure for Parkinson's disease.

"Stem cells are an avenue of research that we've pursued and continue to pursue but it's part of a broad portfolio of things that we look at," said Fox.

*MJFox on Stem Cells (Continued on page 4)*

During bad weather, exercise or other meetings may be cancelled. Call the help line (817/275-1909) if you are in question about a particular day's meeting. Be sure to check our Website at: [www.psgtc.org](http://www.psgtc.org).

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.

## Bill Geist

CBS “Sunday Morning” correspondent Bill Geist broke the news to viewers that he has Parkinson’s disease.

“Some of you had been speculating that I might have Parkinson’s,” he said in the taped announcement while seated on a park bench. “Well I do. I’ve had it for years. Told no one, not even my kids. Didn’t want them to worry, didn’t want to be seen as the sick guy.”

His son is Willie Geist, appearing as co-host of the Today show.

“Proud of my dad this morning,” Willie tweeted Sunday. “Not easy to go on TV and tell the world you have Parkinson’s. Let’s fight it.”

Bill Geist, 67, said “I’ve been in surgery, wheelchairs, taking equine-strength painkillers, doing physical therapy. I’ve had so many steroid shots Major League Baseball will probably ban me from watching games on TV.”

“I hope to see you again soon on ‘Sunday Morning,’” he said in the clip.



## Parkinson’s and good eating

The symptoms of Parkinson’s can present challenges for maintaining adequate food and fluid intake.

These can be accompanied by a loss of fine motor skills and the inability to handle small objects makes it more difficult to handle eating utensils and can extend the time required to eat.

As with ageing, the senses are affected, with loss of smell and taste commonly occurring. As a result, loss of appetite can occur and lead to a lack of interest in food.

In addition, the automatic movements of the gastrointestinal system slow down which can result in dysphagia (difficulty swallowing); feeling full quickly and gastric reflux due to slow emptying of food and fluid from the stomach; and constipation. Slow movement of the gastrointestinal muscles can be exacerbated by a lack of physical activity.

Because of these symptoms and a potential decrease in food intake and unintentional weight loss, protein-energy malnutrition can occur. Medication containing levodopa should be taken on an empty stomach to ensure optimal effectiveness. This may cause nausea in some people, but this can be managed by taking it with a small snack that is easily digested.

Ensure that Parkinson’s disease medication is taken on time and, if possible, 30 minutes to one hour before a meal.

Provide adaptive eating utensils, plates and cups.

Provide assistance whenever required.

Provide a social, pleasant environment in which to eat.

Be alert to consistent coughing or choking while eating or drinking as this can indicate difficulties with swallowing. Ensure appropriate food textures and fluid thickness if dysphagia is an issue.

## Top Questions to Ask Your Doctor

### Q: Why is this medication being prescribed/What symptoms signal a problem, and how should I respond?

*You want to make sure you have a complete understanding of your medication regimen, including potential drug interactions and side effects.*

### Q: How will you monitor my Parkinson’s treatment/Who will coordinate my care?

*Find out who your main contact is, when you should return for your next visit, and how frequently your medication schedule will be evaluated and adjusted.*

### Q: What other professionals do you recommend I see?

*Ask for a referral to a physical therapist, speech-language pathologist, occupational therapist and social worker. Ideally, you’ll be assessed by these providers at least once.*

### Q: What types of exercise and wellness activities are most suitable for me?

*It’s a good idea to find out about local exercise classes and support groups geared toward people with movement disorders.*

### Q: What happens if I begin to feel depressed?

*People with chronic health problems are most at risk for depression. If you think you may be depressed, ask your doctor to screen you.*

### Q: Can you recommend a dermatologist?

*People with Parkinson’s have a higher risk of developing melanoma, a potentially lethal skin cancer, and should be screened once a year.*

### Q: What are the best ways to prevent or manage constipation?

*Ask your doctor about strategies to relieve symptoms such proper dietary fiber intake or changes in medication.*

### Q: What treatment options are available for sleep disturbances?

*More than three-fourths of people with Parkinson’s report sleep-related symptoms.*

### Q: What are the latest developments in Parkinson’s treatment/Is there a clinical trial appropriate for me?

*Clinical trials are research studies that give patients access to promising new medical treatments that aren’t available yet to the public.*

### Q: What hospital should I go to in an emergency?

*People living with Parkinson’s have higher hospitalization rates. Discuss the “what if” scenarios with your doctor. Tell your doctor about [Aware in Care](#).*

*Please contact the NPF Helpline, 1-800-4PD-INFO (1-800-473-4636), if you would like to discuss questions you should ask your doctor on your next visit.*



**Anyone interested in helping to make a quilt devoted to people with Parkinson's, their caregivers?**

The Parkinson Disease Foundation has a quilt project that raises awareness for Parkinson's disease when holding a Parkinson's educational event with your support group, or putting it on display in the community to show the impact of PD locally.

The Parkinson's Quilt Project is the first global quilt project to focus the world's attention on the nearly one million people in the US and seven to 10 million people worldwide living with Parkinson's. The project aims to raise awareness of the impact that the disease has on people living with Parkinson's – along with their families, caregivers and friends – and on our continued urgency to find a cure.

Over the past year, more than 600 people created quilt panels. Panels include photos, illustrations and items that express each quilter's experience with PD. Visit <http://www.pdf.org/en/quilt> for more information.

**Who's up to it?** Send an e-mail to Susan Williams ([susan-institches@att.net](mailto:susan-institches@att.net)). Just maybe, we can build a quilt together that will grace our speaker's podium.

### **Take away some of the worry about a hospital visit with Aware In Care **FREE** kit**

National Parkinson's Foundation (NPF) has an "AWARE IN CARE" kit filled with useful tools and information to help a person with Parkinson's during the next hospital visit.

It's a NPF a national program which aims to help people with Parkinson's disease get the best care possible during a hospital stay. According to a recent study, three out of four people with Parkinson's do not receive their medications on time when staying in the hospital.

**Aware in Care** kits can be requested from your local NPF Chapter or NPF Center of Excellence. If you do not live in an area with an NPF Chapter or Center, you can order a kit online at [awareincare.org](http://awareincare.org)

Or contact the NPF Helpline at 1-800-473-4636.



Merry Ann

### **MEET AND GREET**

## **MERRY ANN BENCH**

### **HER MISSION:**

Usually the first smiling face we see at each PSGTC meeting is Merry Ann Bench and she is the first person to arrive at the caregivers' meetings. Merry Ann manages the support group's membership. She is one dedicated veteran of PSGTC and helped her husband, Floyd, battle Parkinson for 32 years. She offers humor and supportive help to all those she meets.

Merry Ann walks every morning, sometimes before the sun rises and insisted her husband Floyd join her. His reluctance spurred her to use the overhead fan and a well-aimed spray bottle of water on a couple of mornings to encourage his participation. When Floyd could no longer drive, Merry Ann gave him a set of "bogus" keys to carry. That set of keys bolstered his self-esteem during difficult times.

She has shared many caregiver tips including how to help a Parkie get out of a chair without stress on the caregiver's back and how to help them get up off the floor after a fall.

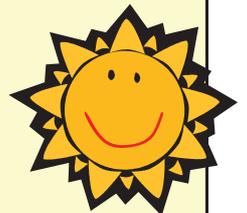
A drum major in high school and a Western-Union operator during WWII, Merry Ann still supports PSGTC with her tenacity, humor, and helpful tips even though her husband Floyd is gone.

**Wear your  
Parkinson pin  
with pride.**

### **Words of Sunshine:**

#### **Welcome New Members:**

**Dan\* Bowden**  
**Rusty and Trina Bowden**  
**John\* and Gloria Baggett**  
**Patricia Bane**  
**Earl\* and Ann Burrow**



#### **Prayers and Thoughts:**

**Ann and Bob Pace** are at Sunrise Assisted Living and can be reached by phone at the number listed in our current directory.

**Ruth Baker** is recovering after a fall and hopes to be up and using her walker soon.

**The family of Joseph Edgar** (1936-2012) honored his life with a celebration and remembrance.

**Carl Milam** had his DBS batteries replace in August as outpatient surgery and is doing great

**Rodney Wehrhan** has had his DBS unit removed because of some issues. When able he will return to rehab.

## Parkinson's Drug Errors Common in Small Study of Hospitalizations

**Family Practice News** - When Parkinson's disease patients are admitted to hospitals, they often end up on incorrect doses of levodopa during their stay – if it's prescribed at all – and sometimes inappropriately get metoclopramide or neuroleptics, dopamine-blocking agents that could make their disease worse, according to a study from the University of Calgary (Alta.).

That's what researchers from the university's Movement Disorders Clinic found when they compared what 44 of their Parkinson's patients took at home with what they were given after being admitted to Calgary hospitals.

Similar problems have been found at hospitals in the United States and Britain, perhaps because some hospital services are unfamiliar with PD treatment. "Widespread education of providers and safe-prescribing protocols are urgently needed to address these unsafe care issues," Dr. Katie Wiltshire said.

The National Parkinson Foundation is trying to address the problem with an Aware in Care campaign that helps patients and physicians overcome medication challenges during PD hospitalizations.

The team also hopes to give PD patients more control over when they get their medications, perhaps by keeping them on bedside tables, and involve pharmacy staff "right at admission, so that they can work to get the [medication] reconciliation done," she said.

*Excerpts from Northwest Parkinson Foundation news letter (nwpf.org). May 11, 2012*

## MJFox on Stem Cells

(Continued from page 1)

"It's not so much that [stem cell research has] diminished in its prospects for breakthroughs as much as it's the other avenues of research have grown and multiplied and become as much or more promising. So, an answer may come from stem cell research but it's more than likely to come from another area," he said.

To that end, his Michael J. Fox Foundation for Parkinson's Research, the largest private funder of Parkinson's disease research worldwide, has recently launched an online initiative to increase studies across the country by pairing patients with clinical trials in their areas.

## PSGTC Meeting provides a place where Parkinson's voices can be heard



Photos by Bruce Dougherty

After our delicious catered meal, Cathy Collier (above right) spoke to us about what it means to have men and women to serve in the Armed Forces and protect our country. She said we should think about the military person and their families and what they are giving up for our freedom. Cathy is our Program Chairperson and always does a remarkable job speaking as well as arranging for others to speak/entertain at our meetings. After her talk, Cathy played the piano and led patriotic songs for all to sing and enjoy. 10 door prizes given at the drawing at the end of the our meeting (one exuberant winner shows off his prize above left).

After lunch and speaker, breakout meetings for PWP and caregivers discuss problems, suggest solutions and share experiences. We are all in the same boat and it helps to hear what someone else is doing regarding a particular problem.

### PSGTC is LOOKING FOR HELP!

PSGTC has supplies and equipment for use by our members, but we need a place to store and inventory these items. If anyone can volunteer, please contact Linda Tunnel at [lbtunnel@att.net](mailto:lbtunnel@att.net).



Be sure to introduce yourself to someone new at the next meeting. We want all our visitors to feel welcome. And we want those who can't make it to each meeting, to know that we miss them when they are not with us. We all have busy schedules and appreciate those who volunteer their time to make this group a success. From the Board of Directors, and the Committee members to all those who come to learn about Parkinson's Disease, thank you for making the effort to assist in making this Caregivers Group such a friendly and informative group.

# September 2012

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3 <b>Labor Day Holiday</b>	4	5 ▼	6	7 ▼	8
9 	10 ▼	11	12 ▼	13	14 ▼ ●	15
16	17 ▼ 	18	19 ▼	20	21 ▼	22 
23 30	24 ▼ <b>PSG Luncheon</b>	25	26 ▼ 	27	28 ▼ ●	29

# October 2012

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1 ▼	2	3 ▼	4	5 ▼	6
7	8 ▼ 	9	10 ▼	11	12 ▼ ●	13
14	15 ▼	16	17 ▼	18	19 ▼	20
21	22 ▼	23	24 ▼	25	26 ▼ ●	27
28	29 ▼ <b>PSG Meeting</b>	30	31 ▼ 			

## September Schedule of Events

- ▼ Monday, Wednesday and Friday Exercise at 10:30, Room 206 of Broadway Baptist Church.
- Second and Fourth Friday– Caregivers Meeting at 10:30 in the room adjoining Room 206.

**September 3-LABOR DAY HOLIDAY**  
*No exercise. Church closed.*

**September 9-Grandparents Day**

**September 17-Rosh Hashanah**

**September 22-Autumn Begins**

**September 26-Yom Kippur**

### Sept. 24—PSGTC Luncheon

11:30 am-1 pm, at Broadway Baptist Church, 3rd floor meeting room. Board of Directors Meeting at 1 pm

#### CAREGIVER MEETINGS

Meetings are held next to the exercise room on the 2nd and 4th Friday of the month. At 10:30 am. You will get great Caregiver support at these meetings. We welcome your participation in this group.

## October Schedule of Events

- ▼ Every Monday, Wednesday and Friday Exercise at 10:30, Room 206 of Broadway Baptist Church
- Second and Fourth Friday–Caregivers Meeting at 10:30 in the room adjoining Room 206.

**October 8-Columbus Day**

**October 31-Halloween**

### Oct. 29—PSGTC Meeting

1 pm, at Broadway Baptist Church, 3rd floor meeting room with snacks provided by Trail Lake Nursing and Rehab and a presentation on “Speech/Voice Therapy” by Beth Sharp Watson of Harris Methodist Hospital.

#### Have some Parkinson equipment you want to share?

If you have some equipment you want to sell, share, or donate to another PSGTC member, just let us know and we'll place a notice in the next newsletter, website, and on our Facebook page at Parkinson Support Group of Tarrant County



PARKINSON SUPPORT GROUP OF TARRANT COUNTY

Take this Barcode to Kroger's grocery store and have them scan it to your Rewards Card. Kroger's will donate a percent of everything you spend to our Parkinson Support Group. Ask your friends to participate too.

### Kroger Supports PSGTC

Meetings are held at:  
Broadway Baptist Church  
305 W. Broadway, Room 302  
Fort Worth, TX 76104  
For info about our group call:  
Help Line (817) 275-1909  
Website: www.psgtc.org

PARKINSON'S SUPPORT GROUP  
OF TARRANT COUNTY  
P. O. Box 939  
HURST, TX 76053

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

Date \_\_\_\_\_

Name of Parkinson Patient \_\_\_\_\_

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

Web Address: [www.psgtc.org](http://www.psgtc.org)

We're now on Facebook