President’s Column

It is hard to believe that it has been three months since my last column. Time seems to fly as I mature in age!

Three noteworthy events happened during that time.

First, we had a very successful 16th Annual Symposium with 400+ attendees and over a dozen service providers showing what they had to offer PD patients and their caregivers. Sixty-five attendees took the time to give us feedback on how we might improve future symposiums by filling out the program evaluations. Thank you for your input. The Question and Answer session after lunch was rated the most informative session of the program. My thanks to all the volunteers, PFNWO Board and UTMC Staff who made this event successful through their many hours of hard work. Mark your calendars for The 17th Annual Symposium scheduled for April 5, 2014.

Second was the Grand Opening Celebration of the Gardner-McMaster Parkinson Center held on May 24. Over 300 people took advantage of this opportunity to tour the new center at UTMC. It was a very gratifying day for Dr. Elmer, his staff and his patients. The Center is a dream come true for all of us!

The third significant event was the National Hockey League Stanley Cup playoffs. Yes, the Stanley Cup playoffs! How do the playoffs relate to Parkinson’s you ask? During the finals between the Chicago Black Hawks and the Boston Bruins, all the games were very highly competitive and physical. Several games went into overtime. One game even went into triple overtime. By the sixth game, both teams were physically exhausted, but they didn’t quit. With about six minutes to go in that game, the Bruins broke the tie and took the lead. It seriously looked like the Bruins would win the game. There was no way the Black Hawks were going to score to tie the game in the remaining six minutes because they seemed to have nothing left to give. With less than two minutes left in the game, the Black Hawks spectacularly scored not one, but two goals in a 17 second span to win the game and the Stanley Cup.

That is the same kind of perseverance we need to show while fighting our common foe, Parkinson’s. Whether it is the monotonous task of taking our meds on time, or the struggle to follow our exercise routine, we must not give up. When all seemed for naught, the Black Hawks didn’t quit. We can also “win”, like them, by enjoying the positive effects meds and exercise provide us in diminishing our PD symptoms. All of our medical advisors remind us that exercise is extremely important in combatting PD. While we dislike doing exercises, they may be just what we need to help us “win” our championship!

(The fact that I won an exceptional bottle of wine from my son-in-law by virtue of the Black Hawks’ victory had nothing to do with me using this analogy.)

One last note, our thanks go out to the Hidden Hills Golf Club for choosing PFNWO as the designee for the proceeds of the women’s golf outing on July 17. We sincerely appreciate your support.

Until next time...
Dennis Ploszaj, President PFNWO
Happenings

**RESEARCH OPPORTUNITIES**

- Are you on Sinemet and are you experiencing “off” time where your medication is not working well and do you experience bloating, heartburn, nausea or vomiting after meals?
- Do you have Parkinson’s disease, are between 45-75 years old, not currently taking Azilect (rasagiline), and are experiencing difficulties with your memory or thinking?

If you answered “Yes” to either of these questions, you may qualify for one of the clinical research trials being conducted by Dr. Elmer/Dr. Menezes/Molly Scott and the research team in the Gardner-McMaster Parkinson’s Disease Center.

If you are interested in finding out more about the Parkinson’s disease research studies being conducted, please call Stephanie Wilson RN – 419-383-6721.

*Helpful Clinical Websites for Parkinson’s disease research*

**Save the Dates!**

7th Annual Parkinson’s Awareness Walk by the Lake
Saturday, September 7th along the Grand Lake St. Mary’s in Auglaize County.

4th Annual Romp to Stomp, Parkinson’s Awareness Walk & Kids Run
Saturday, September 14th
10:00 a.m. – NOON (Registration 9:00 a.m.)
Flower Hospital
5200 Harroun Rd, Sylvania, OH

5th Annual Parkinson Gala
Friday, October 18, 2013
The Pinnacle
6:00-10:00 p.m.

17th Annual PD Symposium,
Saturday, April 5, 2014
at Parkway Place, Maumee, OH

**DTD Classes**

*Classes in Bowling Green, Findlay, Fremont, Sylvania and Toledo.*

**In Bowling Green contact:** Wood County Committee on Aging, Inc. at 419-353-5661 OR 1-800-367-4935 and ask for the Program Department or email programs@wccoa.net

**In Findlay contact:** Hancock County Agency on Aging – Fitness Center, at 419-423-8496, ext. 2004

**In Fremont contact:** Lesley King at 419-334-6630

**In Sylvania contact:** Ashley at 419-517-8282 or asautter@kingstonhealthcare.com

**In Toledo contact:** Michelle Masterson at 419-530-6671.

**What is your ROADMAP to living with Parkinson’s?**

**Clinical Trial for Parkinson’s Patients with Symptoms of GI Dysfunction.**

Gastrointestinal Dysfunction may cause a delay or decrease in the effect of your oral medications taken to treat Parkinson’s.

If you suffer from these symptoms, then you may be eligible to participate in a clinical trial testing the effectiveness of an investigational medication, in the form of a once-a-day patch, used to treat Parkinson’s patients with symptoms of GI Dysfunction.

**Gastrointestinal Dysfunction Symptoms:**
- Nausea or vomiting
- Constipation or excessive gas
- Feelings of fullness or bloating
- Abdominal pain
- Anorexia or weight loss

**Study participants must:**
- Be 30 years of age or older
- Have Parkinson’s disease for at least 3 years
- Have at least one symptom of Gastrointestinal Dysfunction

Study participants will receive study-related procedures, Gastrointestinal Dysfunction evaluations, and study medication, in the form of a once-a-day patch, at no charge. Compensation for time and travel may be provided.

If you or someone you know may have Parkinson’s disease and symptoms of Gastrointestinal Dysfunction, Call Today For More Information:

For more information, please call Stephanie Wilson RN – 419-383-6721.

**Parkinson Foundation of Northwest Ohio Gala**

Shake Rattle & Roll!

October 18, 2013
6:00 PM - 10:00 PM
The Pinnacle
Maumee, Ohio

Proceeds from the evening will be donated to the Parkinson Foundation of Northwest Ohio for Parkinson awareness, education and assistance programs.
Our New Home - Dreams Do Come True!

Visit us on Facebook!

The Movement Disorder Division of the Department of Neurology is now located in the

GARDNER McMASTER PARKINSON CENTER
3000 Arlington Avenue, MS 1083
Toledo, OH 43614
GMPC@utoledo.edu

CLINIC PHONE: 419.383.4405
CLINIC FAX: 419.383.3073

RENEW OR REGISTER NOW!

Kroger Community Rewards Program
PFNWO
Organization #:81482
Visit www.krogercommunityrewards.com and register today.
Any questions contact Program Coordinator: Barbara Harris at barbarah0913@gmail.com or 419.448.9333

PARKIE SEZ....

By mthompson

You take a warm shower, jump into bed and find a good position to get to sleep, and soon you're off in Zzzz-land. Waking up four hours later you try to get out of bed but it feels like you've been glued to the sheets. The dreaded "Velcro Syndrome!" Trying to slide across the bed to get out with cotton sheets is a real chore, especially on a hot and humid night. Solution! Buy a set of polyester sheets and pillow cases. Combine those with polyester pajamas, or silk if you can afford them and you'll be sliding all over the place. But now you have another problem. You can't get a grip on the sheets to pull yourself up. Purchase a pair of NFL receiver gloves made out of that sticky vinyl stuff. Cheap ones, right around $20, will do. Now you can slide and stop on a dime. Don't get too rambunctious or you'll find yourself on the floor looking like Parkie.

Don't throw those pillow cases away either. They work great on your fuzzy couch or recliner. Just lay one on your chair.

When your ready to get up, just slide to the front of the chair and stand up.

SLIP...SLIDING AWAY...WE'RE JUST SLIP, SLIDING AWAY!!

With apologies to Paul Simon

I THINK I'LL SLEEP ON THE COUCH

FLY YOUR FLAG!!

Frankly Speaking/August 2013 3
7th Annual Parkinson’s Awareness Walk by the Lake

Saturday, September 7th • 9:00-11:00 a.m.

Sponsored by the Parkinson’s Support Group of Auglaize County, Auglaize County Council on Aging, Grand Lake Health System, and area physical therapists.

Join us for this gentle walk along the shore of Grand Lake St. Marys. For each “benchmark” you make, there will be a surprise waiting for you. Refreshments and door prize drawings will be in the second shelter house midway through the walk.

*Location subject to change due to Grand Lake St. Marys conditions.

For final location details or questions, call Michelle Evans with the Auglaize County Council on Aging at 419-394-8252

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FUNraiser Event

1 Mile Family Walk/1 Mile Kids’ FUN Run
Saturday, September 14

Flower Hospital Campus Flower Hospital
5200 Harroun Rd, Sylvania, OH
10:00 a.m. - 12:00 p.m.
(Pre-registration 9 a.m.)

Kids’ Run at 9:20 a.m. with Family Walk to Follow
Featuring: Live Music, Raffles, Snacks and Family Fun, Romp to Stomp T-Shirts available by preregistration.

For pre-registration information contact Mark Fischer at 419-787-7440 or 419-882-8341 or e-mail fischer0917@aol.com

Sponsored by the Parkinson Foundation of NW Ohio & Flower Hospital
Awareness Family Walk is Free
Donations to the Parkinson Foundation Accepted.

Kids’ Romp to Stomp Fun Run
$10 per Child
(includes FREE Water Bottle & T-Shirt)
Help us OUT FOX Parkinson’s Disease at the 8th Annual Team Fox Walk to benefit the Michael J Fox Foundation to be held at ProMedica Bay Park Hospital Campus on Saturday, October 5th.

This year we are adding a Kids’ “Fox Trot” race at 10:30 a.m. followed by the walk at 11:00 a.m. Registration begins at 9:30 a.m. in The Bay Café (follow signs posted at the main entrance).

The trail is a 1/2 mile loop around the inland pond and is wheelchair accessible. There is something for everyone: music, raffle, kids activities, and a chance to win prizes. Refreshments will be provided as well as “goody bags” for walkers.

Janet started this event in tribute to her father, Lester R. Cowell who had PD for 10 years. Lester was a lifelong Northwood resident, loving family man, and watercolor artist.

“Like Michael J Fox, my dad managed the disease with a sense of humor and optimism and that is why I was inspired to join Team Fox,” says Janet. “I met Tammy Rivera, a Physical Therapist at Bay Park’s Total Rehab several years ago when she came to the 6th Team Fox Walk. She works with PD patients on a regular basis. Tammy has helped get the word out about how exercising can delay the affects of Parkinson’s Disease. She has been instrumental in taking this event to the next level and getting the whole community involved.”

Team Fox is the grass roots arm of The Michael J Fox Foundation which is dedicated to finding a cure for Parkinson’s Disease. To make a donation visit www.teamfox.org and search for Participant Janet Clough under “Donate to a Fundraiser” or you can donate at the event (cash, check or credit card accepted).

Be part of the mission to speed a cure! The answer is in all of us. See you at the Walk!

Questions? call Janet at 419-376-4423.

Dexterity and Parkinson’s Disease

How can I minimize embarrassing dexterity problems?

Dexterity problems can include fumbling for bills, change, and credit cards at checkout counters. Staying at home is a great temptation when your symptoms are showing, but it only deprives you and your spouse or friends of the pleasure of each other’s company. And it isolates you. The truth is that few people will even notice your symptoms. A bad tremor while making change is taken for a momentary rattling. Knocking over a glass at dinner? Spilled soup? It happens to everyone.

Some Parkinson’s patients embark on an endless search for the perfect wallet, but the issue is not limited to money. Car keys, theater programs, church bulletins, a glass of wine, or a plate of food at a buffet — worse yet, both a glass and a plate. Everyone drops things. It just happens more frequently with Parkinson’s patients, who carry around this baggage of “disease” that seems to get a little heavier with each mishap.

Compensatory strategies can be helpful: A large wallet for easy access, counting change ahead of time, not using change, asking a friend to hold your drink while you steady a plate, etc. When you encounter a new problem, think about the best way to handle it the next time. And remember, dropping change is a symptom of your disease, not a reflection on your character. The more you are out and about, the more people will see you, and visibility means greater acceptance from others as well as increased confidence. Parkinson’s disease doesn’t have to be a prison.
Tell Us What You Smell

Reduced sense of smell is a common but little noticed symptom of Parkinson’s disease (PD) that may occur years before the onset of motor symptoms or a diagnosis. The Parkinson’s Progression Markers Initiative (PPMI) seeks 10,000 people over the age of 60 who do not have Parkinson’s to take a simple smell survey online.

You may have heard: Following successful recruitment of the original groups needed for PPMI, MJFF’s landmark biomarker study, the study has expanded to include a cohort that has risk factors for developing PD. By studying potential risk factors of PD in individuals who do not have the disease, this arm of PPMI could help researchers detect PD in patients before the onset of motor symptoms.

How can I help spread the word?
Ask your friends and family who are over 60 and have not been diagnosed with PD to visit http://www.michaeljfox.org/PPMI/smell for more information about this arm of the study and encourage them to take our smell survey at www.michaeljfox.org/takethesmellsurvey.

Ladies Day 2013

Thanks go out again this year to Hidden Hills Golf Club located in Woodville, Ohio. For the second year in a row, the proceeds from their annual Ladies Day Event will be donated to the Parkinson Foundation of Northwest Ohio.

Board Treasurer Stacey Dunbar and Board Member Nancy Temme joined the festivities as waitresses for the wonderful event. The July 17th activities included 18 holes with a cart, continental breakfast, dinner, door prizes, 50/50, gift bags, and many other prizes!

If you are a golfer and looking for a new course to play, give Hidden Hills a call or visit their website at: www.hiddenhillsgolf.net. They are located at 4900 County Road 16 Woodville, OH 43469. Phone: 419-849-3693 Fax: 419-849-3695. FORE!!!
Fifty Shades of Parkinson’s

(APDA website by Elaine Benton Author and blogger; battling two chronic diseases whilst maintaining a positive attitude and sense of humor)

If I could possibly color code all the symptoms and side effects of Parkinson’s, I think there would be far more than fifty shades! The symptoms are many; vary to such a degree, each patient is unique. Most diseases have a set of common indicators that a patient would normally experience, but not in the case of Parkinson’s. Having met and spoken with fellow sufferers, each one has a different story to tell, no two are alike, and this is probably what makes diagnosis and getting the right balance of medications so difficult. What works for one person, doesn’t necessarily work for another.

As there are so many shades to Parkinson’s, unless you are familiar with this particular disease, you may be wary, not knowing what to expect when hosting; feeling at a loss as to the needs or abilities of someone suffering from Parkinson’s. If you are a fellow sufferer, then you will understand and relate to what I am saying. If you are not, I hope to convey what is often misunderstood, yet plays a huge part in the life of a Parkinson’s sufferer, and that you’ll realize what goes through our minds when invited out.

Maintaining one’s social life is very important – both for sufferer and caregiver. However going out, whether to a restaurant or someone’s house can put considerable stress on a person with Parkinson’s. Just getting dressed and ready to go, is a major operation requiring help and extra time. Even though it may be a party to celebrate a happy occasion, the thought of meeting someone I don’t know, explaining for the 100th time I have Parkinson’s, or someone who I’ve not seen for some time, realizing they may be shocked at a decline in my condition, causes a certain amount of stress. Parkinson’s feeds upon anxiety and stress like a hungry scavenger, so whenever possible being in calm circumstances, is preferable. Obviously I can’t wrap myself up in a cotton wool cocoon and retire from the world, but where viable I avoid uneasy situations.

At a social event where there are multiple conversations going on, I find it very difficult to follow, and can only focus on one person at a time. Noisy environments are highly disturbing, and often at a dinner party I am the last one to finish eating. Trying to make conversation and eat at the same time, simple as this may sound, is quite difficult for a Parkinson’s patient. Loud music or even background music can also cause interference in a social setting, making it hard to talk, listen or focus. People feel confused by my lack of facial expression and may think I am disinterested in what they have to say. ‘Masking’ is one of the most unsociable symptoms, as the germless expression concealing all emotions makes those who don’t understand, wary of talking to me. An additional factor is most sufferers are at their best first thing in the morning, but as the day progresses, a slow decline sets in and by the evening, intense fatigue is a big problem. Even an afternoon rest is not a remedy, and late nights I was once able to keep, are no longer possible.

Eating and drinking in a social setting can be enough to deter me from participating, and I am likely to refuse a drink or food if offered. At a cocktail party for instance, standing holding a glass in one hand whilst eating delicate canapés is simply out of the question. Even if seated at a table, dropping food, especially on my clothes is a major worry. Any food that requires dexterity such as dissecting meat from a bone, or peas that have a way of falling off your fork and conspicuously rolling onto the floor, I avoid at all costs. Spilling a drink or knocking over a glass at the table is yet another scenario that goes through my mind.

All these seemingly small things may sound insignificant to you, but trust me, they are HUGE to a Parkinson’s patient, and can often prevent one from going places. Many patients are reticent about venturing out socially, yet however difficult socializing becomes, it’s important to maintain a social life, and essential to one’s emotional welfare and that of the family.

If you know someone with Parkinson’s, I hope you’ll now understand a little better and as a host be able to make your guests feel comfortable, and please remember to never serve peas!
Ashland County
2nd Tuesday 2:00 p.m.
Belmont Tower
2140 Center Street
Ashland, OH
Traci Malaska or Connie Butler 419-207-3003

Auglaize County
3rd Monday 2:00-3:00 p.m.
Joint Township District Memorial Hospital, 200 St. Clair Street, St. Mary's, OH 45885
419-394-3335
Michelle Evans Auglaize County Council on Aging 419-394-8252
1-866-244-6401
Linda Dicke 419-394-3335
Joint Township District Memorial Hospital

Defiance Area
3rd Monday 2:00 p.m.
The Second Baptist Church, 1945 E. Second St., Defiance, OH 43512
Nancy Temme 419-262-2950

Fremont Memorial Hospital PD Support Group
2nd Tuesday 2:00 p.m.
EVERY OTHER MONTH:
(Meets in Jan, Mar, May, Jul, Sept & Nov)
Fremont Moose Lodge, 2507 Hayes Ave., Fremont, OH 43420
Lesley King 419-334-6630

Hancock County
3rd Monday 12:30 p.m.
St. Michael's Catholic Church
750 Bright Road,
Findlay, OH 45840
Dennis Ploszaj 419-425-8506

Lima Area Parkinson's Support Group
1st Thursday of each month, 2:00-3:00 p.m.
NO meetings in December, January and February
St. Rita's Outpatient Rehab, 830 W. High St., Lima, Ohio 45801
Beth Hartoon 419-523-5391

Lucas County
2nd Thursday 1:30 p.m.
*Meetings do not occur January, February & March
Boulevard Church of Christ,
7041 W. Sylvania Ave,
Sylvania, OH 43560
Carrie Boze 419-841-3070

Mansfield Area/Richland County
3rd Wednesday 2:00 p.m.
People's Community Center,
597 Park Ave. East,
Mansfield, OH 44905
419-774-5200
End Reis 419-756-3703

Perrysburg Parkinson Disease Support Group
1st Thursday 2:30 p.m.
Zoar Lutheran Church,
314 E. Indiana Ave.,
Perrysburg, OH 43551

Putnam County Parkinson's Support Group
4th Wednesday 11:15 a.m.-12:45 p.m.
NO meetings in December, January and February
Henry's Restaurant, 810 N. Locust St., Ottawa OH 45875
Beth Hartoon 419-523-5391

Western Ohio
3rd Thursday 2:00 p.m.
New location:
Briarwood Village,
100 Don Desch Dr.,
Coldwater OH 45828
Paul Honigford 419-678-2851

Williams County
3rd Monday 12:30 p.m.
*Excluding County Holidays
Bryan Senior Center,
1201 South Portland,
Bryan, OH 43506-2079
419-636-4047
Laura Rohlfs 419-924-2927

Wood County PD Support Group
2nd Monday 1:30-230 p.m.
Bowling Green Senior Center,
305 N. Main St., Bowling Green, OH 43402
419-352-7558
David Buenting, Facilitator

CAREGIVER SUPPORT GROUPS
Toledo Caregivers (C.A.R.E.S.) Support Group
1st Monday 6:30 p.m. (except Holidays)
Lutheran Village at Wolf Creek Assisted Living
2001 Perrysburg-Holland Rd. Holland, OH 43528
Kristen Schuchmann 419-383-6737
Lisa Keaton 419-383-6770

Findlay Caregivers Support Group
1st Monday 2:00 p.m.
Bob Evans, 2400 Tiffin Ave., Findlay, OH 45840
Carol Hassan 419-423-1486