



The Parkinson News

July 2016

NO MEETING IN AUGUST.

SEPTEMBER MEETING

Wednesday, September 28, 2016

2:00 - 3:30 pm

Daytona Beach Regional Library

We look forward to welcoming back *Dr. Jay Van Gerpen* from the *Mayo Clinic in Jacksonville*. This time his topic will be *"Update on Neuroprotective Therapy"*.

Donations

Thank you! We received the following donations in the month of June:

\$5000 from Anonymous

\$25 from Ronald Pagano in memory of Frances Pagano

\$293.62 from Community Health Charities

Golf Tournament

The Paul Anthony Cancer Champion Initiative Inaugural Celebrity Golf Tournament will be held at the Daytona Beach Golf Course on Saturday, August 27, 2016. Although it is primarily to benefit the Paul Anthony Cancer Foundation a portion of the proceeds will be given to our association (PAGDB).

For more information contact Deborah Barrs-Paul at 386.569.0508 or Jolette Ponds at 352.586.7457.

SAVE THE DATE!

The *9th Annual "Sole Support for Parkinson's" FUN WALK* will be held on *Saturday, November 12, 2016* from 10 am to 2 pm at the *Port Orange Civic Center Amphitheatre*.

Registration forms will be available at the next meeting and will be included in the next newsletter. You can also register on-line at our website www.ParkinsonDaytona.org

We are still in need of sponsorships, door prizes and in-kind donations so if you know someone that may be able to help please have them contact Vince Kinsler at 386.676.6375

JULY MEETING

Wednesday, July 27, 2016

2:00 - 3:30pm

Daytona Beach Regional Library

City Island - Daytona Beach • 105 E. Magnolia Avenue

Our speaker will be *Registered Dietician Stacey Scrabis* with *Halifax Health*. She will discuss the important role nutrition plays in Parkinson's disease.

Stacey Scrabis received a four-year athletic scholarship from Florida State University where she graduated with a double major in Dietetics and Nutrition & Fitness. Her twenty year career as a Registered Dietitian has been spent specializing in oncology and intensive care, a nutrition educator for the WIC program, an out patient dietitian specializing in weight management and oncology for Halifax Health, and working with individual and teams as a Sports Dietitian. In addition, her growing business, Nutrition Connection, keeps her busy developing and teaching nutrition classes and conducting health seminars. Stacey currently works part time as the Sports Dietitian for Embry-Riddle Aeronautical University athletic department. She has been a guest speaker on various radio and television broadcasts.

Seating is limited. Reservations are required.

Call Affordable Home Care at 386.676.6375 no later than 12 noon on Monday, July 25th. Refreshments will be served. We look forward to seeing you there!

Recap June Meeting

Dr. Carolyn Geis, Medical Director of Brooks Rehab and Director of Neuroscience for Halifax Health presented "Keeping your Stride with Parkinson's". It was well-received and it was great to have her return yet again. We are appreciative of her time, interest, and ongoing support.





DANCE FOR PD NEWS ~ DELAND PROGRAM ON HOLD

The Dance for PD program is currently on hold for the DeLand YMCA only. The anticipated re-start date is Wednesday, August 31st.

**NEW EXERCISE PROGRAM AT DELAND YMCA
(Time Limited)**

This program is temporarily in place of the *DeLand Dance for PD* program (which remains on hold). This has been changed to Wednesdays only from 12:30 pm to 1:30 pm

Moving For Better Balance (Thai Chi)

Wednesday – 12:30pm-1:30pm

**DeLand YMCA
761 E. International Speedway Blvd**

**This program is free and runs through August 25th and everyone in our association is welcome to attend.

For more information, contact the DeLand YMCA at **386.736.3000**.

NEW EXERCISES CLASS IN DELAND (Ongoing)

This ongoing exercise program started June 21st and is up and running. It is offered by Florida Hospital and is free to PWP's.

Note: The time has been changed too since it was first announced.

**Florida Hospital DeLand
701 W. Plymouth Avenue**

**1st and 3rd Tuesday each month
10:30 am to 11:30 am**

Anyone interested in attending this program is encouraged to call Nicky Miller at Florida Hospital **386.943.4707**.

**Is Parkinson's Disease
on the Rise?**

A new study finds that the number of new cases per year of Parkinson's disease (PD), and related diseases known as parkinsonisms, may have increased over a 30-year period. A possible explanation lies in the dramatic decline in cigarette smoking in recent decades.

Smoking reached its peak in the 1940s and 1950s in the United States. Between then and 2009, the smoking rate among American men went down from 67 percent to 23.5 percent. An earlier study suggested that smokers may have a reduced risk of PD, and speculated that the decrease in smoking could lead to a higher incidence of PD decades later.

Researchers led by Walter A. Rocca, M.D., M.P.H., analyzed medical records of people living in Olmsted County, MN, a set of data from detailed records between 1976 and 2005, the researchers identified 906 people with parkinsonisms (diseases such as Lewy body dementia and progressive supranuclear palsy) and 464 people with PD. They found:

- Incidence rates of parkinsonism in men increased from 38.9 per 100,000 person-years between 1976 and 1985 to 55.9 between 1996 and 2005.
- Rates of PD in men increased from

18.2 between 1976 and 1985 to 30.4 between 1996 and 2005. The increase was greater for men over age 70.

- No similar trends were seen for women.
- PD incidence was higher for people born between 1915 and 1925, suggesting that early-life exposure to influenza boosted PD risk.

The decline in smoking provides a possible explanation, although other lifestyle or environmental changes also could increase PD risk or provide protection from PD.

Projected into the future, the rate of increase found in this study points to a much larger number of people with PD in the coming decades than indicated by earlier estimates. If this is indeed the trend, then effective planning throughout the health care system will be needed – and the requirement for new therapies and a cure is more urgent.

Science News June 20, 2016

Condolences

Longtime member of our Association and our former Treasurer **Mark Lipp** died July 13, 2016. Our thoughts are with his wife Sherry and their circle of family and friends.

**Support Groups
at Bishop's Glen**

**People with Parkinsons
&
Parkinson's Caregivers
Meet in Separate Rooms**

1st Tuesday of Every Month

**Next meeting:
Tuesday, August 5, 2016 ~ 2:15 pm**

**Bishop's Glen Retirement Community
900 LPGA Blvd., Holly Hill, FL 32117**

Facilitators:
Karen Grant, L.C.S.W.
Julie Randolph, L.C.S.W.
Halifax Health Hospice of Volusia/Flagler

Complimentary refreshments will be served.

**RSVP to (386) 226-9110
or email: Helen.Kuhel@rhf.org**

DANCE *for* PD®

The cost of this program is fully subsidized by our Association (PAGDB).

Time and locations:

Monday 1:00pm ~ Port Orange Family YMCA

4701 City Center Dr., Port Orange, FL 32129 • (386) 760-9622

ON HOLD - Wednesday 12:30pm ~ DeLand Family YMCA

761 E. Int'l Speedway Blvd., DeLand, FL 32124 • (386) 736-3000

Wednesday 1:15pm ~ Southeast Volusia Family YMCA

148 W. Turgot Ave., Edgewater, FL 32132 • (386) 409-9622

Thursday 1:00pm ~ Ormond Beach Family YMCA

500 Sterthaus Ave. Ormond Beach, FL 32174 • (386) 673-9622

To register for the program, call the closest YMCA or Bev Johnson at 386-738-9622 ext. 313 or visit vfymca.org

Learn more about

*D*ance *for* PD @

by visiting

www.danceforpd.org



*So
get out
and
DANCE!*



Summary of "Debunking Ten Myths that May Sabotage Treatment of Parkinson's Disease"

Dr. Eric Ahlskog of Mayo Clinic in Rochester, Minnesota presented at our May meeting. It was very well attended and well-received. Here is a summary of the 'Ten Myths' taken from the handout of his Power Point presentation:

Ten Myths:

1. Levodopa stops working after a few years.
 - Never stops working (except in parkinsonism-plus disorders)
 - Over 10 to 20 years-responses not as dramatic as initially but remains beneficial, responses fluctuate and no longer smooth, after age 80 age-related factors superimpose
2. Almost everyone develops disabling dyskinesias on levodopa
 - Reflects an excessive levodopa dose, may never become problematic despite years on levodopa
3. Dyskinesias are worse than parkinsonism
 - Are not painful, always resolve with reduction of levodopa doses
4. Levodopa should be saved for later
 - No evidence that the best responses can be saved, indications for starting treatment are compromised activities and inability to remain physically active
5. The levodopa dose should be limited... but why?
 - Don't take more than you need but take what you need
6. Carbidopa/levodopa should be taken with meals
 - Consistent effect if taken 1 or more hour before meals or 2 or more hours after a meal
7. Controlled-release carbidopa/levodopa is preferred (Sinemet CR)
 - Effect only lasts about 1 hour longer than regular carbidopa/levodopa, slow to kick in and more erratic, expensive-not necessary for initial treatment
8. The dopamine agonist drugs are nearly as effective as levodopa
 - Not nearly as effective as levodopa, unique side effects
9. Levodopa disrupts sleep
 - Insomnia is common in PD, adequate levodopa is the best sleep aid for PD
10. We have drugs that may slow PD progression
 - 11 major drugs trials last quarter century-all negative

Simple Meds by Home Instead

Simple Meds is an easy to use pharmacy which sorts and organizes monthly prescriptions, over-the-counter medications, and even vitamins, into simple multi-dose packs. It is covered by most health plans. There is no additional cost, however, co-pays may apply.

Here's how it works:

Step 1: You call the toll free number and Simple meds will call your doctor, insurance plan provider and pharmacy.

Step 2: The team of knowledgeable pharmacists and pharmacy technicians will work with you to understand the prescribed drug regimen and will ensure all of your medications are accurate and reviewed for safety.

Step 3: Simple Meds pharmacy will dispense prescription and over-the-counter medications in conveniently marked 30-day compliance packaging indicating the date and time of day to take each packet.

Step 4: One month's worth of your medications

are delivered directly to your doorstep.

Step 5: Simple Meds will contact you about 10 days before the start of your next delivery to discuss.

Printed on each packet is the time of day, day of the week, date, patient name, prescription name(s), quantity and description, doctor name and expiration date.

For more information contact **Nicolle Cella**, Community Service Representative/Client Care Coordinator at Home Instead Senior Care at cell# **386.864.5918** or direct office# **386.366.9262**.

Editor's note: Nicolle facilitates the DeLand Area Parkinson Support Group

You can also call 1.844.ASK.MEDS or visit www.SimpleMedsRx.com

A Note from the Editor

I would like to remind everyone that we invite you to send us any feedback, comments, information, items of interest, or even a simple helpful hint. This is your newsletter and your participation is encouraged.

I also wanted to mention that I had the pleasure of facilitating our local Support Group at Bishop's Glen this month. I was with the "PWP's". The caregivers/carepartners meet separately in a different room across the hall. It was good to be back at Bishop's Glen, who hosted our group in its entirety for over 20 years until we outgrew the venue. We appreciate Bishop's Glen for continuing to support Parkinson's by hosting these groups.

Our monthly meetings that can be quite large in attendance enable us to present formal programs and attract some great speakers. But it is groups such as the ones at Bishop's Glen that are the true version of a 'support group', in that they are small enough to provide the time and privacy to openly share thoughts, feelings and ideas. And meeting separately gives you a chance 'to say what you may not be able to say in front of your loved one' and receive support from others who can empathize. So you may want to check it out.

Lastly, if you no longer wish to receive this newsletter or have a change of address please let us know. Our contact info is on the last page- feel free to either e-mail or call.

Your Editor Nancy Dawson

Exercise Group You Are Invited

Our weekly exercise group is open to those in our community living with Parkinson's. Walkers and wheelchairs are OK and caregivers are encouraged to attend.

WHEN: Tuesdays from 10:00am to 11:00am

WHERE: Seventh Day Adventist Church

Please call before attending your first session.

401 N. Williamson Blvd.

(North of International Speedway Blvd.)

For More Information: Call 386-231-6039.

Note: This program is provided free of charge.

IMPORTANT

Check with your physician before starting any exercise program.

This group is facilitated by therapists from Florida Hospital





"PD Tulip"
The unifying symbol
for Parkinson's awareness.

PARKINSON ASSOCIATION
OF GREATER DAYTONA BEACH
P.O. BOX 4193
ORMOND BEACH, FL 32175



Postage Courtesy of Halifax Health

Parkinson Association of Greater Daytona Beach

P.O. Box 4193 • Ormond Beach, FL 32175

386-252-8959 (Leave Message)

www.ParkinsonDaytona.org

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**DELAND AREA
PARKINSON'S SUPPORT GROUP**

The group will meet the 2nd and 4th Thursday of each month. The 4th Thursday is a chair exercise group. The meetings will be at the Cloister's in DeLand, 400 E. Howry Avenue, at 2:30pm.

The DeLand Group is facilitated by *Nicolle Cella of Home Instead Senior Care*. For more information contact her at 386.864.5918 or e-mail her at nicolle.cella@homeinstead.com

**FLAGLER AREA
PARKINSON'S SUPPORT GROUP**

Wednesday, August 10, 2016 - 1-3 pm

United Methodist Church

1520 Daytona Avenue - Flagler Beach

This meeting is facilitated by *Marianne Chapin and Karen Grant of Halifax Health - Hospice*. It meets the second Wednesday of each month from 1 - 3 pm.

At the August 10th meeting *Ed Pruitt of Edward Jones Financial* will share a personal experience with Parkinson's.

Dr. Desiree Challice P.T., D.P.T. of PEAK Fitness leads a 20 minute exercise program at the start of each meeting.

For more information contact Marianne at 386.872.1851 or e-mail her at mariannechapin@halifax.org or call Karen at 386.258.5100 or e-mail her at Karen.grant@halifax.org

**PARKINSON'S
RESOURCE
LIBRARY**

Located at

Attorney Randy

Schecter's office 1870

West Granada Boulevard

in Ormond Beach.

Just West of I-95.

HOURS:

Monday – Thursday

9am — 4pm,

Friday

9am — 3pm.

Please remember to return books to the library or bring to one of our meetings so others can benefit.

Thank you.

NOTE: The information in this newsletter and the information provided by our speakers is not intended as medical advice. Please consult your physician before trying anything new or different.