

THE Parkinson's Source



Issue 40

American Parkinson Disease Association • Deerfield Beach, Florida • 800-825-2732



THE Parkinson's Source

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Reminder:

All material related to Parkinson's disease contained in this newsletter is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the Editor, the I&R Center, the Medical Director of the Center or the APDA.

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National Young Onset PD

www.youngparkinsons.org



Thomas C. Hammond, MD

NEW DEVELOPMENTS: FALLS, DROOLING & EXERCISE IN PARKINSON'S DISEASE

Loss of dopamine producing cells in the substantia-nigra (SN), which is a pigmented area of tissue in the upper brainstem, has long been known to be the pathological hallmark for Parkinson Disease (PD). PD is clinically characterized by resting tremor of the limbs, rigidity of the muscles, slowing of movements (akinesia), and postural imbalance. The last of these features – postural imbalance – is the cause for falls and is perhaps the most disabling feature of this disease.

Falls result in substantial morbidity with fractures and concussions as well as loss of confidence. A recent study relating to predicting falls in PD found that over a six month period 48% of patients reported at least one fall; and half of them fell more than once. Falls in PD seem most often related to freezing of gait (FOG) and postural instability (tendency to fall backwards). Gait disturbance and falls in PD respond poorly to dopaminergic treatments such as l-dopa (Sinemet), pramipexole (Mirapex), or ropinirole (Requip). Furthermore, deep brain stimulation (DBS) does not seem to significantly improve balance or lessen falls in PD. These conventional treatments work best on tremor and slowness of movement or akinesia.

In the PD falls study, there was no difference in dopaminergic medication use or in "off-time" between those who were fallers and non-fallers. Other studies using PET scans have suggested PD fallers have no worse dopamine depletion than non-fallers. Other neural networks seem to

contribute to locomotion problems in PD patients. Tapping into these alternative pathways may lead to better treatments.

There is a fascinating phenomenon in Parkinson Disease referred to as "paradoxical kinesis". This phenomenon occurs when an alternate or supplementary pathway comes into play in PD patients and they can suddenly perform motor activity in a normal fashion such as running upstairs, or downstairs, or dodging an oncoming vehicle. An example of paradoxical kinesis is the famous story of the nursing home fire in which the medical staff were worried about the PD patients trapped on the third floor. While the staff members were reporting this dilemma to the firefighters, someone noticed that the wheelchair bound PD patients were all standing outside the building looking up at the fire! They had run down stairs and escaped the fire.

It has long been known that external cuing can circumvent motor dysfunction in PD. For example a PD patient who is frozen can break the freeze by stepping on a spot visualized on the floor. This is the principle used by therapists in treating PD and is the basis for specialized PD walkers with built-in laser lights that shine on the floor creating a spot for the patient to step toward. There are also specialized "PD canes" with a trigger activated colored whip that the patient can step toward. These visual cues allow PD patients to break freezing spells by using an alternative motor

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President's Message

Greetings!

I hope this newsletter finds all of you well and preparing for a wonderful Holiday.

My thoughts are with you and your families especially during the Holiday Season. I fully understand the challenges

you may be facing as a person with Parkinson's disease, care partner, family member or professional working with PD families.

As a caregiver myself, in addition to a full-time job, I know only too well the relief and hope I felt when I first contacted the APDA to learn more about PD and related issues. Because the disease is unique to each individual, no two persons are alike, being able to talk to, meet with or have access to a Parkinson's professional is essential as a complement to the medical treatment plan designed by your neurologist.

I was unable to attend the Annual APDA Chapter Presidents and Coordinators Conference last summer. However, Gigi Gilcrease, RN, MBA, Executive Director and Program Coordinator, attended and brought back some timely and up-to-date information on Parkinson's disease, as well as the current challenges that charities are facing in these uncertain and tough economic times.

If it is at all possible for you, I invite you to please consider giving an end-of-the-year donation to the APDA so that we can continue to meet your needs and provide assistance through our direct and indirect programs and services. I would like to share with you a sample of the past year's efforts that speak to the need for APDA's programs of education, literature, support, referrals and other information.

Our South Florida Center distributed over 15,000 pieces of literature which included booklets, newsletters, and other PD information; and over 8,000 persons received direct education through inquiries to the Center or attending symposia, support groups and other in-services. I have left much of the statistics out, such as physician and other healthcare referrals, but I think you can better tell what it takes to operate our Chapter and Center.

Thank you for your consideration.

Jim and I hope you have a very Happy Holiday and a Joyous New Year!

With all good wishes,

Linda Gilchrist

Upcoming Events

South Florida

December 6, 2010
Parkinson's Update &
Volunteer Recognition

North Broward Medical Center
 Deerfield Beach, FL
 800-825-2732

[This program made possible by a grant from the Community Foundation of Broward]

January 26, 2011
Parkinson 101 Workshop For
Newly/Recently Diagnosed

North Broward Medical Center
 Deerfield Beach, FL
 800-825-2732

Spring Events

Information coming soon.

PD Quilt Raffle and Jewelry

The beautiful tulip quilt crafted by Janice Leonard, diagnosed seven years ago with PD, is being raffled. The quilt is beautifully complete with red tulips, the symbol for Parkinson's, on a white background, silver awareness ribbons and a yellow block in the center with the word HOPE embroidered. It is finished with red binding around the edge.

Tickets are \$5 each or five for \$20. To purchase raffle tickets call (800) 825-2732.

Janice also designs PD bracelets, book marks, cell phone jewelry, earrings and many other beautiful pieces. She donates a percent of her sales to the APDA.



Parkinson's quilt and jewelry.



As 2010 comes to an end, our dear friend, the talented Dr. Joyce Saltman, has offered these reflective and inspirational thoughts.

The Present

Imagine there is a bank that credits your account each morning with \$86,400.

It carries over no balance from day to day. Every evening it deletes whatever part of the balance you failed to use during the day. What would you do?








Draw out every cent, of course!

Each of us has such a bank. Its name is TIME. Every morning, it credits you with 86,400 seconds. Every night it writes off, as lost, whatever of this you have failed to invest to good purpose.

It carries over no balance. It allows no overdraft. Each day it opens a new account for you. Each night it burns the remains of the day.

If you fail to use the day's deposits, the loss is yours. There is no going back. There is no drawing against the "tomorrow".

You must live in the present on today's deposits. Invest it so as to get from it the utmost in health, happiness and success! The clock is running. Make the most of today.

-  To realize the value of ONE YEAR, ask a student who failed a grade.
-  To realize the value of ONE MONTH, ask a mother who gave birth to a pre-mature baby.
-  To realize the value of ONE WEEK, ask the editor of a weekly newspaper.
-  To realize the value of ONE DAY, ask a daily wage laborer with kids to feed.
-  To realize the value of ONE HOUR, ask the lovers who are waiting to meet.
-  To realize the value of ONE MINUTE, as a person who wrongfully ended their best relationship.
-  To realize the value of ONE MILLI-SECOND, ask the person who won a silver medal in the Olympics.

Treasure every moment that you have! And treasure it *more* because you shared it with someone special ...special enough to spend your time.

And remember that time waits for no one.

Yesterday is history. Tomorrow a mystery. Today is a gift.

That's why it's called the present!

Author Unknown.....

Parkinson's Caregiver Respite Program

In home and adult day care respite assistance is now available to Chapter members in Broward and Palm Beach Counties. To learn more about these programs contact the APDA Chapter at 800-825-2732.

New Support Group in Palm Beach Gardens

APDA is pleased to announce that the Palm Beach Gardens support group has found its permanent home. The group is meeting the 3rd Wednesday of each month from 2:00pm-3:30pm on the second floor of the Christ Fellowship Life Center 5343 Northlake Boulevard. The group was started by Alicia Roman, Carol Gallagher and Joann Lang who worked very hard to get the group up and running. For more information, call Alicia Roman at 561-626-5880 or APDA at 800-825-2732.



*Happy
Holidays*

***We wish
all of you
a safe and
wonderful
Holiday
Season.***

*South Florida Chapter
American Parkinson
Disease Association*

Jump for a Cause

American
Parkinson
Disease
Association



Hannah Bentz walking her horse, Crystal to the arena.



Winning Team, Buttonwood Street with trainer Bobbi Rottman.



Hannah Bentz presenting a commemorative plaque to Rabbi Singer.

On November 6th, Jump For A Cause, took place at the Jim Brandon Equestrian Center in West Palm Beach. It was the first Parkinson's equestrian fundraiser in South Florida designed by Hannah Rachel Bentz, a young equestrian. This creative and generous young woman designed the event as her mitzvah project in honor of Rabbi Merle Singer, the senior Rabbi at Temple Beth El who was diagnosed with Parkinson's disease shortly after retiring.

Approximately 200 people attended the amateur equestrian jumping event to see the team horse jump competitions and "horseless" jump competitions while enjoying Christafaro's gourmet dinner, musical entertainment, dancing and more. The Winning team was Buttonwood Street, team members Katie Jones, Shoshanna Gordon and Maggie Gampher. The fastest rider of the day was Jaime Gennari from team Equine Couture.

On November 11, Michael Perez, Director of the Spa at the Four Seasons in Palm Beach, held a silent auction in honor of Hannah Bentz benefitting Jump for A Cause. Guests were offered on the spot massages and other Spa mini treatments, dined on a variety of foods from the restaurants as well as delightful libations. Fashion models wearing some of the Fall runway collection items from Luca Luca's Worth Avenue boutique circulated the room. Kaufmann de Suisse Jeweler's also of Worth Avenue brought a beautiful collection of jewelry for the guests to try on and add to their Holiday wish list.

The APDA South Florida Chapter is honored and grateful to have been asked to partner with Hannah and her family on "Jump." We are equally honored and appreciative of Michael Perez and the Four Season Resort for hosting their magnificent event.

Four Seasons Silent Auction Benefitting Jump for a Cause

Precious Moments Photography.com Inc



Michael Perez & Hannah Bentz



The Bentz family: Abbi, Evan, Hannah & Steve



Kaufmann de Suisse Jewelers



Bob & Jessica Killgore, Susan Guinan & Greg Nelson were instrumental in the success of the events.



Luca Luca fashion show

Many Thanks to our generous sponsors.

FOUR SEASONS RESORT
Palm Beach



Innovative Hospice Care
VITAS
HELPING PEOPLE LIVE BETTER

spectrum Saddle Shop

TEMPLE BETH EL
OF BOCA RATON



**MULVEHILL
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SPAZIO SALON

MadBullGraPhics

Avenue Therapy
&
Wellness Inc.



Village Home Care
of the Palm Beaches, n.c.

Maxicare
Select, Inc.



The Bentz Family

Christafaro's
a fresh approach to caring



Gail & Steven Baldwin

Continued from page 1

pathway that uses vision to activate locomotion.

Interest in these non-dopaminergic pathways in PD locomotion has led to research regarding the pedunclopontine nucleus (PPN). This brainstem nucleus (group of cells) uses acetylcholine as its neurotransmitter rather than dopamine, which is the neurotransmitter in the SN that is degenerating in PD. Low frequency stimulation of the PPN with DBS seems to improve the movements and locomotion in animal models of PD. This has led to several small trials in humans with PD and has shown modest benefit in balance and lessening falls in these patients. The PPN as a target for DBS is still undergoing further research.

In a past issue of *The Parkinson's Source*, I reviewed a study in which a rodent model of PD was used to evaluate spinal cord stimulation to improve locomotion in PD. That research suggested that stimulating the upper cervical spinal cord would cause impulses to ascend into the brainstem affecting the PPN and thereby improving motor function. It clearly helped the PD rodents. A recent report in the journal *Neurology*, described two PD patients with moderate-to-severe motor impairment in whom cervical spinal cord stimulation was performed to test this therapy in humans. Despite this procedure being well tolerated and safe, there was no improvement in motor function or balance in these two patients despite various stimulation protocols. This was a disappointing result but will likely need further study.

Since the PPN is a cholinergic nucleus, it has been postulated that cholinergic therapy may help improve gait and balance in PD. A recent trial tested this hypothesis using donepezil (Aricept) compared to a placebo in 23 PD patients with frequent falls (greater than two times a week). Donepezil is a cholinesterase inhibitor (FDA approved for use in Alzheimer Disease) which increases acetylcholine in cholinergic brain nuclei. In the trial, each patient had a 6 week placebo period, a 3 week washout period,

and a 6 week drug period (donepezil). Thereby, each patient acted as his/her own control, this is referred to as a crossover design trial.

The results showed a significant decrease in falls in the patients when they were on donepezil compared with the placebo. The falls were about half as many. The patients with freezing of gait seemed to respond best. A second trial will need to replicate these results, but this study clearly suggests that a trial of donepezil (Aricept) is worthwhile in PD patients with frequent falls.

Drooling, which is referred to medically as sialorrhea, is a common problem affecting 75% of PD patients. A decreased rate of swallowing (an akinetic slowing feature) and decreased facial movements with some parting of the lips seems to underly drooling in most PD patients. Some drugs used in PD may increase saliva production such as donepezil (Aricept) and rivastigmine (Exelon).

Speech therapy focusing on oral exercises, increasing lip closure and swallowing efficiency have had disappointing benefits for most patients in terms of lessening drooling. Botulinum toxin injected into the salivary glands can decrease saliva production and lessen drooling. Botulinum toxin injections carry some risk of weakness in swallowing muscles and slightly increases the risk of aspiration pneumonia. It is also a costly solution for drooling. Anticholinergic agents have frequently been used to treat drooling. Atropine 1% ophthalmic solution, one to two drops two to three times daily in the mouth, can diminish oral secretions and decrease drooling. However, central nervous system side effects, particularly hallucinations, have significantly limited the usefulness of this treatment.

Recently, a trial in PD patients with drooling was successful using glycopyrrolate (Robinul) 1 mg three times daily. This is an anticholinergic agent that does not enter the central nervous system, so hallucinations were not a problem and no significant side effects were noted.

Therefore, a recent recommendation by the American Academy of Neurology is to use glycopyrrolate for drooling in PD. Another preliminary study showed that chewing gum will improve swallowing frequency and latency and thereby decrease drooling in PD patients.

Lastly, another study has demonstrated benefits related to **physical exercise** in Parkinson Disease. In this study researchers examined the risk for developing Parkinson's disease in the 213,701 participants in the NIH-AARP Diet and Health Study Cohort. This trial followed these individuals for many years and assessed diet, exercise, and other health-related behaviors as they relate to various medical conditions including PD. It concluded that moderate to vigorous exercise between the ages of 35 and 39, or in the past 10 years, lessened the subsequent risk of developing PD. If an individual was active physically in both periods they had a 40% reduction in the risk for developing PD.

Similar data sets suggest exercise is related to lowering risk of dementia and Alzheimer's disease. In animal models, forced exercise increases Glial Derived Nerve Growth Factor in animal's brains and this growth factor is associated with stimulating growth of dopaminergic neurons and protecting them from toxins. Furthermore, exercise has been shown to protect the nigrostriatal-dopaminergic system (the system that is dying off in PD). I therefore encourage PD patients and also their caregivers to exercise 30 minutes daily.

In summary, a preliminary study suggests the cholinergic drug donepezil (Aricept) may help balance and lessen falls in PD. Chewing gum and using glycopyrrolate will lessen drooling, and as always, daily exercise rules!!

*Thomas C. Hammond, M.D.
Medical Director – APDA I&R Center*

SUPPORT GROUP & EXERCISE CALENDAR • 1-800-825-2732

SOUTH FLORIDA

Deerfield Beach APDA I & R Center & South Florida Chapter

NORTH BROWARD MEDICAL CENTER
201 East Sample Road
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800-825-2732; 954-786-2305
FAX 954-786-7349
Gigi Smith Gilcrease, RN, MBA, Coordinator
E-Mail: ggilcrease@browardhealth.org
Web site: www.apdaflorida.org
Thomas C. Hammond, MD, Director.

MIAMI-DADE COUNTY

Coral Gables

TEMPLE JUDIAH, 5500 Granada Boulevard
2nd Thursday/month 11:00AM-12:30PM
Contact: Carol Goldman 305-476-8782

MIAMI VAHCS – Veterans Only

1201 NW 16th Street
7th Floor, Pain Clinic Psych Office, Rm. D707
Every Thursday 10:45AM
Contact: Paul Hartman, PhD 305-575-3215

BROWARD COUNTY

Coral Springs

CORAL SPRINGS MEDICAL OFFICE
3100 Coral Hills Drive (next to hospital)
Support Group and Exercise
3rd Monday/month 2:00-3:30PM
Contact: APDA 800-825-2732

Davie

NOVA SOUTHEASTERN UNIVERSITY
University Park Plaza – Rm 515
3530 S University Drive
1st Wednesday/month 10:45-12:00NOON
Contact: Dr. Blodgett 954-262-5611

Deerfield Beach

NORTH BROWARD MEDICAL CENTER
201 E. Sample Road, Neuro Center (off lobby)
Support Group and Exercise
2nd Tuesday/month 1:00-3:00PM
Contact: APDA 800-825-2732

Margate

NORTHWEST REGIONAL MEDICAL CENTER
2801 N. State Road 7
Support Group and Exercise
1st Friday 1:00-3:00PM
Contact: Agnes Porzio 954-972-2221

PALM BEACH COUNTY

Delray Beach

SOUTH COUNTY CIVIC CENTER
16700 Jog Road
Support Group and Exercise
1st Wednesday/month 2:00-4:00PM
Caregiver group – call for dates
Contact: APDA 800-825-2732

Palm Beach Gardens (NEW)

CHRIST FELLOWSHIP LIFE CENTER-RM 206
5343 Northlake Blvd
Support Group
2nd Wednesday/month 2:00-3:30PM
Contact: Alicia Roman 561-626-5880
or APDA at 800-825-2732

Royal Palm Beach

CULTURAL CENTER
Royal Palm Beach Cultural Center
151 Civic Center Way
Support Group and Exercise
Monday and Wednesday 10:00AM-12:00PM
Contact: Mr./Mrs. Rodgers 561-791-9885

EXERCISE ONLY

Boca Raton

Sugar Sand Park Field House

300 S. Military Trail
Monday 11:30AM-12:30PM
Wednesday 2:00PM-3:00PM
First class is free, just stop by the park
Contact APDA: 800-825-2732

Davie

Nova Southeastern University

Physical Therapy PD Exercise
Sanford L. Ziff Health Center
3200 S University Drive
Monday and Wednesday 12:30PM
Call: 954-262-4149
Speech Therapy PD Exercise
Wednesday 1:30-2:30PM
Call: Dr. DiCarlo 954-262-7726

MARTIN COUNTY

Stuart

GRACE PLACE COMMUNITY CHURCH
1550 SE Salerno Road
Support Group
2nd Monday/month 1:00-3:30PM
Contact: Aileen Stiehle 772-286-3268

ST. LUCIE COUNTY

Port St Lucie

HARBOR PLACE, 3700 SE Jennings Road
3rd Tuesday/month 2:00-3:30PM
Contact: Cathy 772-201-6007 or
Laura 561-209-6124

CENTRAL FLORIDA

Holly Hill

BISHOP'S GLEN RETIREMENT CENTER
900 LPGA Boulevard
4th Wednesday/month 2:00-3:30PM
Contact: Bruce Kozak 386-226-9000

Kissimmee

Osceola County, Good Samaritan Village
Orange Blossom Trail
2nd & 4th Thursday -10:00AM – 11:00AM
Contact: 407-944-3362

Melbourne

SOUTH BREVARD PARKINSON'S
SUPPORT GROUP
Eau Galle Public Library
1521 Pineapple Avenue
4th Thursday/month 1:30PM
Contact: Deb Ridel 321-751-0444

Titusville

NORTH BREVARD PARKINSON'S
DISEASE AND CAREGIVERS
SUPPORT GROUP
c/o Parrish Medical Center
951 N. Washington Avenue
3rd Saturday/month 11:00AM
Contact: Mary McDowell 321-268-2363

NORTHEAST FLORIDA

Deland	Orange City
Jacksonville	St. Augustine
Jacksonville – Young Onset	

For information on the groups
in these cities contact either the South
or West Coast Florida Centers:

WEST COAST FLORIDA

Avon Park	Ocala
Bradenton	Orlando
Clermont	Palms of Largo
Dunedin (new)	Pensacola
Englewood	Springhill
Fort Walton	St. Petersburg
Lady Lake	Sun City Center
Leesburg	Tampa
North Port	West Pasco

For information on the groups
in these cities contact:

St. Petersburg APDA I & R Center

EDWARD WHITE MEDICAL ARTS BUILDING
2191 9th Avenue, North
St. Petersburg, FL 33713
Faye Kern, LPN, Coordinator
727-328-6246; Fax: 727-895-5213
E-Mail: afkapda@aol.com
Carol Pappas, MD, Director

NOTE: Support Group day
and time may change periodically.

For current updates on
Support Groups and Exercise
call the APDA Information
and Referral Centers.

THE Parkinson's Source

American Parkinson Disease Association
201 East Sample Road
Deerfield Beach, FL 33064
800-825-2732

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Do your friends and family tell you that they don't want you to buy them a gift for a special occasion?

Then don't.

Do they say that they have everything they need?

Then they probably do.

Who wants or needs more wallets, key chains, vases, statues, and so on?

Not many people.

And, maybe they don't need more money either. But they always like to receive a note or card to know you are thinking of them.

Let APDA send the card by making a tax deductible donation to the APDA South Florida Chapter by mailing the form below and including a check or money order or by calling (800) 825-2732; or going to our website at www.apdaflorida.org.

Please send your tax deductible donation payable to: **APDA South Florida Chapter, 201 East Sample Road, Deerfield Beach, FL 33064**

PLEASE PRINT CLEARLY

Contribution Information

Name _____ Phone _____

Address _____ City _____ State _____ Zip _____

Enclosed is my check for: \$1000 \$500 \$250 \$100 \$75 \$50 \$35 (membership) Other _____

Include membership with my donation of \$50 or more.

Tribute Information

In Memory of In Honor of _____ Send Acknowledgement to _____

Address _____ City _____ State _____ Zip _____

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