



## Medical Director's Update:

**PRIONS IN PARKINSON'S DISEASE**

**NEW TARGETS FOR DEEP BRAIN STIMULATION**

**BENEFITS OF EXERCISE**

*Thomas C. Hammond, MD*

The World Congress on Parkinson's Disease and Related Disorders held its semiannual meeting in Miami Beach, Florida December 13-16, 2009. A number of hot topics on Parkinson's disease (PD) arose during this four day meeting. One of the keynote speakers was Dr. Stanley Prusiner, who received the Nobel Prize in Medicine and Physiology in 1997 for his work on prions and prion-related diseases. Prions are a new class of self reproducing pathogens composed of protein with no DNA or RNA. It has been shown that prions are the infectious agents causing several neurologic diseases such as Creutzfeldt-Jakob Disease in humans and bovine spongiform encephalopathy (mad cow disease) in cattle. In these diseases, accumulation of misfolded proteins in cells cause cell death and result in a rapidly progressive dementia. Additionally, misfolded proteins play a major role in causing cell death in Alzheimer's disease.

In Parkinson's disease there is a loss of cells in the midbrain nucleus of pigmented neurons called the substantia nigra (SN) leading to a deficiency of dopamine, a nerve transmitter, which these cells produce. This dopamine deficiency results in resting tremor, stiffness or rigidity of muscles, severe slowing of movements (akinesia), and balance problems which are the cardinal motor features of PD. Replacing dopamine through oral administration of levodopa in the form of carbidopa/levodopa will reverse the motor symptoms in PD. What causes the SN cells to die in PD has been an ongoing discussion among specialists in this field. If we understood the cause for cell death, more appropriate and specific PD therapies could be developed.

Dr. Prusiner's lecture focused on the Lewy body (LB) in PD. Lewy bodies are small rounded inclusions found pathologically in the cells that are dying in the SN in PD patients. LB are also found in other motor regions within PD brain and furthermore, these inclusions are

also found in other cell groups related to the autonomic nervous system (bladder, bowel, blood pressure symptoms), in olfactory nerve cells (loss of smell), and in cerebral cortex neurons (cognitive decline). An abnormal misfolded protein called alphasynuclein (ASN) is an important part of the LB inclusions in these dying cells. In some families a gene has been identified that miscodes production of alphasynuclein and this miscoded gene leads to abnormal production of ASN which in turn causes the early onset of Parkinson's disease in these family members.

It has been shown in recent years that misfolded ASN can be transmitted from one neuron to another neuron in cell cultures of dopamine cells. Brain tissue obtained from autopsy of patients who had undergone fetal cell transplant 12 to 16 years ago have been closely examined in the past year. In those cases, the fetal cell transplants are readily identified as surviving tissue within the host brain. Alarmingly though, a number of the fetal cell transplants had developed Lewy Body inclusions. This finding suggests that the ASN protein in fact infected the transplanted cells. In this way, ASN is behaving like a protein infectious agent (prion). This was in fact the theme of Dr. Prusiner's keynote speech. This theory: that ASN may behave like a prion and infect cells in a similar fashion as other prions in mad cow disease and Creutzfeldt-Jakob disease, would help explain the progressive cell loss in PD. If, indeed, ASN is behaving this way, it may offer new targets for treatment, specifically medications that alter the misfolding of these proteins. Further research on this topic should be fairly easily assessed in laboratory models.

The pedunculo-pontine nucleus (PPN) as a target for deep brain stimulation (DBS) was discussed at this meeting as well. The PPN is a deep cluster of cells in the upper brainstem, a little bit further into the brain



## 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](http://www.youngparkinsons.org)



## Upcoming Events

**March 1, 2010 (Monday)**

ANNUAL PARKINSON'S SYMPOSIUM  
11:00am - 2:30pm  
Marriott Boca Center – Boca Raton  
Register on or before February 22nd  
800-825-2732

**April 10, 2009 (Saturday)**

ANNUAL "FUN" WALK AND PICNIC  
FOR PARKINSON'S RESEARCH  
10:00am – 1:30pm  
Lake Ida Park – Heron Pavilion – Delray Beach  
800-825-2732

### West Central Florida

**March 3, 2010 (Wednesday)**

PARKINSON'S SYMPOSIUM - CLEARWATER, FLORIDA  
1:30pm - 4:00pm  
*Presentations by:*  
Dr. Ahlskog – Dementia and Lewy bodies  
David Weismantel MPT – Balancing Parkinson Everyday  
RSVP by Feb 27 to Faye 727-328-6246 or email  
[afkapda@aol.com](mailto:afkapda@aol.com)

### Outside Florida

**April 24, 2010 (Saturday)**

Parkinson's Unity Walk – Central Park, New York  
[www.unitywalk.org](http://www.unitywalk.org)

The beautiful tulip quilt crafted by Janice Leonard, diagnosed five years ago with PD, is being raffled in April during Parkinson's Disease Awareness Month. 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. You need not be present to win.

**MARCH 1, 2010 (MONDAY)**  
**ANNUAL PARKINSON'S SYMPOSIUM**

Marriott Boca Center • 5150 Town Center Circle, Boca Raton

*Featured Presenters:*

Eric A Ahlskog, MD, PhD – Neurologist, Movement Disorder Chair – Mayo Clinic, Rochester, MN

Joyce Saltman, EdD – Professor Education, Public Speaker and Author – New Haven, CT

Thomas C. Hammond, MD – Neurologist, Associate Professor Nova Southeastern – Fort Lauderdale, FL

Registration Begins at 10:30 a.m.

11:00 a.m. - 2:30 p.m.

*Lunch • Valet Parking Available*

\$15.00 per person

Reserve your seat — Registration and payment must be received by February 22, 2010

For information call 1-800-825-2732

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## April is Parkinson's Disease Awareness Month



World Parkinson disease Awareness Day is April 11th. This day commemorates the birthday of Dr. James Parkinson, the English doctor who first described the condition in 1817.

The tulip is the symbol of hope for Parkinson's.



**Saturday, April 10th**

**Lake Ida Park – Delray Beach**  
**Annual Parkinson's Fun Walk and Picnic**  
**Fundraiser for Parkinson's Research**

Your \$25 Registration Fee gives you  
1 food ticket, 1 t-shirt, 1 raffle ticket

Raise \$200 or more and you will also receive  
a \$25 restaurant certificate

**A**ttend the festivities and enjoy a  
leisurely day in the Park!

**P**romote Parkinson Disease Awareness  
to ease the burden!

**D**ine on BBQ with friends, listen to  
music, exercise, laugh, walk, win raffles

**A**Cure! That's what we are hoping for –  
please give generously!

*Continued from page 1*

### **Medical Director's Update:**

tissue than the routine targets of DBS in PD which are the subthalamic nucleus (STN) or globus pallidus interna (GPI). According to information presented at this meeting there was a dramatic improvement in a number of patients who had severe impairment of balance and gait or freezing attacks as symptoms of their PD. Standard PD DBS usually does not help gait imbalance and falls. DBS of the PPN in some patients will eliminate these troublesome complications of the disease. DBS of the PPN also seems to help regulate sleep and wakefulness in PD. This nucleus is very close to a regulatory center in the brainstem for sleep. The patients with DBS of the PPN seemed to have improved quality of sleep and improved daytime vigilance (less daytime drowsiness).

Joseph Jankovic, MD from the Baylor College of Medicine in Houston, Texas did discuss their experience with PPN DBS in patients who were "pure freezers." These patients had little other stigmata from PD but had severe problems with freezing spells and falls. He commented that these patients did seem to benefit from PPN DBS but the benefit was short-lived and seemed to wane by the end of the year. However, as opposed to DBS of the STN in which there is immediate response of PD symptoms, the patients who undergo DBS of the PPN did not derive any immediate benefit but rather the benefit accrued slowly over weeks and even some months.

In that same session, some discussion took place regarding spinal cord stimulation for PD. There is a model for PD in mice in which electrical stimulation of the dorsal columns of the spinal cord had dramatic benefit in reversing the parkinsonism. This benefit is felt to be occurring from the spinal cord tracts stimulating the PPN. This may offer a method for stimulating the PPN with a significantly less invasive procedure. So far the spinal cord stimulation work has only been performed in the mouse model of PD. In these mice, PD symptoms were improved or entirely

reversed with stimulating the spinal cord. I look forward to further information regarding these new targets for stimulating neural tissue to help PD patients clinically.

Presentations were given at this meeting regarding PD and exercise. The University of Pittsburgh Group presented further studies on mice, rats, and monkeys showing that exercise seems to produce some neuroprotective benefit in these animals in experimental models of PD. In these models the exercised animals are less likely to develop Parkinson's disease if exposed to toxins which normally provoke parkinsonism. In each of these experiments, animals were divided into groups, those of exercise animals and those which did not exercise (mice and rats used a running wheel, monkeys used a treadmill!). In each of the experiments, the exercised animals do not develop Parkinson's symptoms when exposed to toxins that produce PD in the nonexercised group.

Strategies to treat Parkinson's disease with exercise were also discussed by Dr. Giladi from Tel Aviv University in Israel. Dr. Giladi presented data suggesting that more vigorous exercise programs that increase the heart rate and respirations (more vigorous aerobic exercise) seemed to have some benefit in improving Parkinson's rating scales in PD patients compared with less vigorous exercise programs. This is an ongoing area of exciting research.

In this issue, we reviewed the possibility that Lewy bodies contain a protein, which is in fact a prion that may be the reason for gradual progression in this disease. This understanding may lead to new targets for treatment in PD. Secondly, new targets for neural stimulation were discussed and lastly exercise again appears to produce some neuroprotection and will likely slow progression in this disease.

So get out and exercise and build up a little sweat!

*THOMAS C. HAMMOND, M.D.*

*APDA I&R Medical Director*

### **Michael Hirsh, spearheaded the garage sale to raise funds in support of the American Parkinson Disease Association.**

As Michael Hirsh was preparing for his Bar Mitzvah, he decided that he wanted to honor his grandfather and aunt who suffer from Parkinson's disease. So, he asked his family and friends to donate items for a garage sale which he held prior to his event. Michael raised over \$600 for PD research. Many thanks to Michael for his creativity and commitment to making a difference.



## Parkinson's Disease Update & Recognition Luncheon

The Parkinson's Disease Update and Recognition Luncheon held on December 7, 2009 in Deerfield Beach, is an annual event celebrating the individual volunteerism of persons with PD, caregivers and corporate sponsors with special recognition to persons who have made a notable impact on the Parkinson's Community of South Florida.

Thomas C. Hammond, MD, APDA Medical Director (APDA Information & Referral Center) provided a PD update followed by a question and answer session. In keeping with a celebration theme and holiday cheer, the audience played Parkinson's Jeopardy. The competition was "fierce" for the coveted prize of lotto tickets provided by Brie Parks of Lojack Safety Net. Four tables won the first, second and third prizes

(tie). A good time was had by all with many people commenting that they had learned something new. Hmmm. Is that why that pesky I&R Coordinator recommends attending educational programs?

This year's event honored Cmdr M Philip & Joan Lorber who generously donate funds in support of many programs offered by the South Florida Chapter. Sadly, Joan lost her courageous battle against PD last summer.

We extend much gratitude to the Lorber Foundation for many years of dedication and support. Many thanks also to Teva Neuroscience, Broward Health and Lojack for their contributions.



*Back row (far left) APDA Director/Coordinator Gigi Gilcrease, RN, MBA and (far right) APDA Chapter President Linda Gilchrist and Medical Director, Thomas C. Hammond, MD with honorees Sheila Finkelstein, Gail Baldwin, Marilyn Morganstern and Seymour Olchak. In the front row (left to right) Patricia Miller, Hazel Haas, Agnes Porzio, Rhoda Olchak and Helene Dieter. Not in attendance was Alan Perry and Cmdr Philip Lorber. These dedicated volunteers are but some of the many persons who are instrumental in support groups, educational programs and fundraising events.*

## 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.

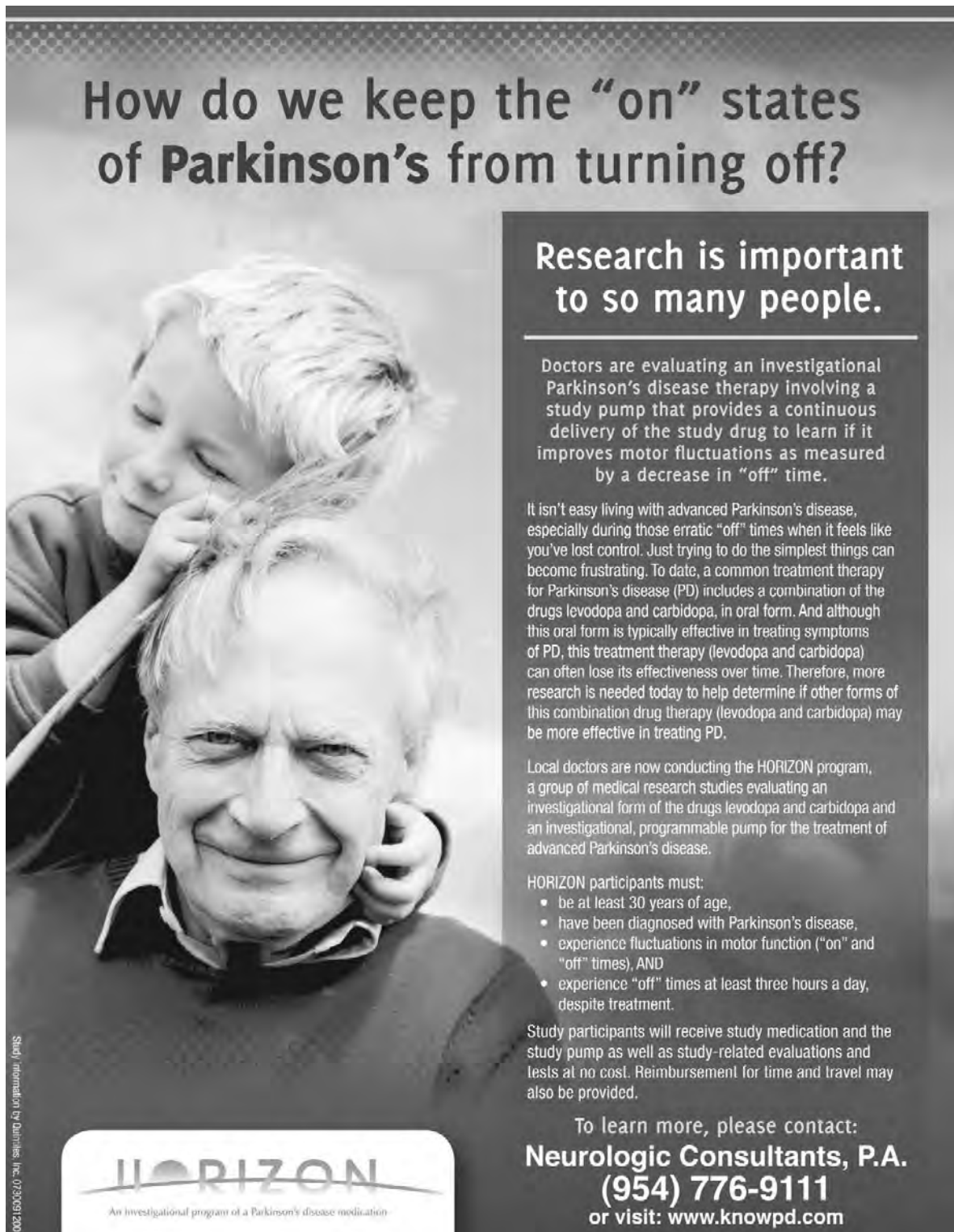
## A New Formulation of Levodopa/Carbidopa

Advanced Parkinson's disease patients must generally use complex regimens of medications, taking frequent doses throughout the day. In Europe, one strategy for managing symptoms is the use of levodopa/carbidopa intestinal gel. The medication is administered in much the same way as an insulin pump delivers a continuous dose of insulin to patients with advanced diabetes.

Levodopa/carbidopa intestinal gel is given as a continuous dose, to try to avoid wide swings in brain levels of dopamine. The patient wears a small pump, which delivers a steady supply of the medication through a tube placed into the small intestine. Medication is absorbed to provide a continuous supply of dopamine to the brain. The pump may be adjusted to increase or decrease the amount of levodopa/carbidopa intestinal gel for better symptom control.

Levodopa/carbidopa intestinal gel is currently not approved by the FDA for use in the United States. It is registered in the entire European Economic Area (EEA) under the trade name Duodopa™. Marketing authorizations outside the EEA have been granted in Australia, Canada, Croatia and Switzerland. Orphan drug status was obtained in the European Union in 2001 and in Australia in 2006.

*A study is currently underway in South Florida through March 31, 2010, see accompanying flyer or for more information contact 954-776-9111.*



**How do we keep the "on" states of Parkinson's from turning off?**

**Research is important to so many people.**

Doctors are evaluating an investigational Parkinson's disease therapy involving a study pump that provides a continuous delivery of the study drug to learn if it improves motor fluctuations as measured by a decrease in "off" time.

It isn't easy living with advanced Parkinson's disease, especially during those erratic "off" times when it feels like you've lost control. Just trying to do the simplest things can become frustrating. To date, a common treatment therapy for Parkinson's disease (PD) includes a combination of the drugs levodopa and carbidopa, in oral form. And although this oral form is typically effective in treating symptoms of PD, this treatment therapy (levodopa and carbidopa) can often lose its effectiveness over time. Therefore, more research is needed today to help determine if other forms of this combination drug therapy (levodopa and carbidopa) may be more effective in treating PD.

Local doctors are now conducting the HORIZON program, a group of medical research studies evaluating an investigational form of the drugs levodopa and carbidopa and an investigational, programmable pump for the treatment of advanced Parkinson's disease.

HORIZON participants must:

- be at least 30 years of age,
- have been diagnosed with Parkinson's disease,
- experience fluctuations in motor function ("on" and "off" times), AND
- experience "off" times at least three hours a day, despite treatment.

Study participants will receive study medication and the study pump as well as study-related evaluations and tests at no cost. Reimbursement for time and travel may also be provided.

To learn more, please contact:  
**Neurologic Consultants, P.A.**  
**(954) 776-9111**  
 or visit: [www.knowpd.com](http://www.knowpd.com)

**HORIZON**  
 An investigational program of a Parkinson's disease medication

Study information by Duinilis, Inc. 0730091200

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

## SOUTH FLORIDA

### 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

Room 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

Every Wednesday 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

#### Jupiter

JUPITER TOWN COMPLEX

Activities Building, 210 Military Trail

Every Friday 1:00-3:00PM

Contact: Lottie Redlin 772-283-5693

#### 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

#### Coral Springs

##### Coral Springs Education Center

3100 Coral Hills Drive

Wednesdays 2:00 -3:00pm

Contact Mary at 954-344-3344

#### 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

## CENTRAL FLORIDA

### 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

#### Holly Hill

BISHOP'S GLEN RETIREMENT CENTER

900 LPGA Boulevard

4th Wednesday/month 2:00-3:30PM

Contact: Bruce Kozak 386-226-9000

#### Kissimmee (New)

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: Lyndon Kirk 321-777-3590

#### 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

For information on the groups in cities listed below, call: APDA Coordinator

Audrey Strongosky 904-953-7030

Deland

Orange City

Jacksonville

St. Augustine

Jacksonville - Young Onset

## WEST COAST FLORIDA

For information on the groups in cities listed below, contact: APDA Coordinator

Faye Kern 727-328-6246

Avon Park

Ocala

Barrington

Orlando

Bradenton

Palms of Largo

Clearwater

Pensacola

Englewood

Springhill

Fort Walton

St. Petersburg

Inverness

Sun City Center

Lady Lake

Tampa

Lakeland

West Pasco

Leesburg

Young Onset

North Port

Tampa Bay

**NOTE:** Support Group day and time may change periodically. For current updates on South Florida Support Groups and Exercise call the APDA Information and Referral Center at 1-800-825-2732.

# THE Parkinson's Source

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

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## Help Ease the Burden, Find a Cure for Parkinson's Disease

Funding is crucial for Parkinson's research and local programs. Like most of you, economic times have greatly impacted charities. ***In order for us to be here for you tomorrow, we need your support today!***

Please make a tax deductible donation to the APDA South Florida Chapter by mailing the form below and including a check, money order, or credit card (Visa or MasterCard); or by calling (800) 825-2732; or going to our website at [www.apdaflorida.org](http://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

### Membership/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. VISA or MasterCard # \_\_\_\_\_ Exp. Date \_\_\_\_\_

### Tribute Information

In Memory of  In Honor of  \_\_\_\_\_ Send Acknowledgement to \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

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