ARDA
TO EASE THE BURDEN TO FIND THE CURE
American Parkinson Disease Association

The Parkinson's Source

Issue 38 Winter 2010

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

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/l-dopa 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

Continued on page 4

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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

Outside Florida

April 24, 2010 (Saturday)
Parkinson's Unity Walk – Central Park, New York
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

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.

APDA Walk-A-Thon
Ease the Burden. Find the Cure.

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 committment 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.

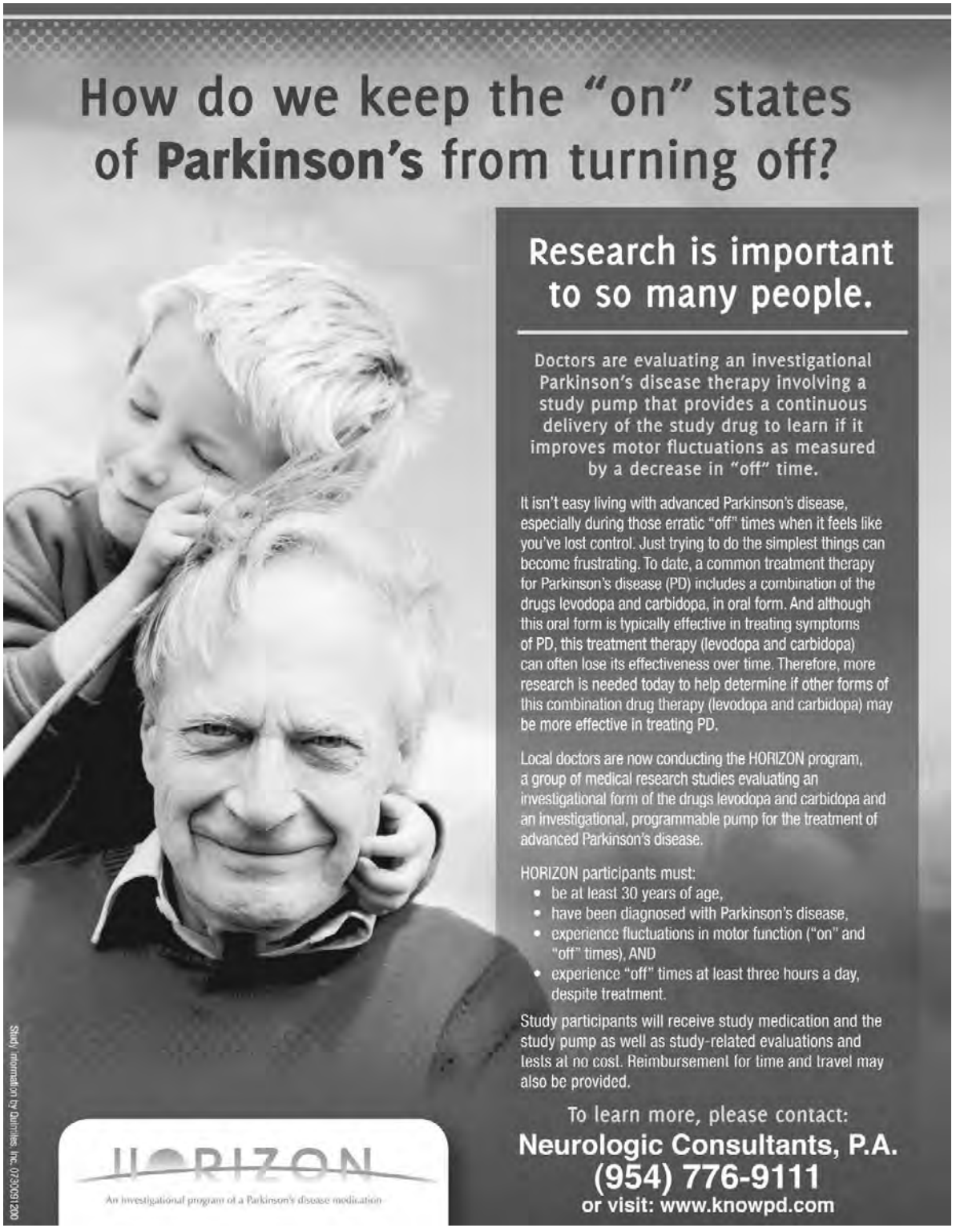
A New Formulation of Levodopa/Carbidopa

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 levadopa/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 urrently underway in South Florida through March 31, 2010, see accompanying flyer or for more information contact 954-776-9111.



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

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.

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
Jacksonville
Jacksonville – Young Onset
Orange City
St. Augustine

WEST COAST FLORIDA

For information on the groups in cities listed below, contact: APDA Coordinator Faye Kern 727-328-6246

Avon Park
Barrington
Bradenton
Clearwater
Englewood
Fort Walton
Inverness
Lady Lake
Lakeland
Leesburg
North Port
Ocala
Orlando
Palms of Largo
Pensacola
Springhill
St. Petersburg
Sun City Center
Tampa
West Pasco
Young Onset
Tampa Bay

THE Parkinson's Source

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

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Permit #: 2438

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.

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_____

Inside Issue No. 38, Winter 2010