American Parkinson Disease Association South Florida

The Parkinson's Source

Summer 2013 Issue 46

AMERICAN PARKINSON DISEASE ASSOCIATION • 800-825-2732

Some Recent Studies and Therapeutic Strategies — Procedures, Medication and Exercise

Thomas C. Hammond, MD

The cardinal motor symptoms of Parkinson's disease (PD) are well known: resting tremor, muscular rigidity referred to as cogwheeling, and significant slowing of movement referred to as akinesia. Some postural unsteadiness, with a forward stooped posture, and some risk of falls occurs as the disease progresses.

Pathologically, we know that there is a loss of pigmented cells in the upper brainstem nucleus referred to as the substantia nigra (SN), that the SN cells produce dopamine, a neuro transmitter that interacts with higher brain nuclei refer to as the striatum, that the resulting dopamine deficiency state has been the target for most of our current PD medications, and that the surviving cells in the SN have small inclusion bodies, called Lewy bodies.

Since the discovery in 1997 that Lewy bodies contain large quantities of alpha-synuclein there has been quite of bit of PD research directed at this protein. The National Institute of Neurologic Disorders and Stroke (NINDS) has funded the Parkinson's Progression Markers Initiative, and many major research institutions are investigating methods for determining progression of Parkinson's disease based on blood tests, tissue biopsies and other methods. If identified, a biomarker may help detect the disease earlier in its course and help determine if treatment strategies are effective, or are delaying disease progression.

Alpha-synucein

One recent study of alpha-synuclein (ASN) blood levels and spinal fluid levels have not proven useful as a test for determining PD, or for evaluating the progression of PD. However, another study using skin biopsies in patients with newly diagnosed PD, showed over 55-60% of sweat glands cells stained for ASN, as compared to none of the healthy control patients.

In patients with atypical Parkinson's, such as multiple system atrophy, a very small percentage of cells, 3% or less, will show the ASN protein in skin biopsy. Since alpha-synuclein protein has also been identified in colonic biopsy tissue from a large percentage of PD patients, further research on this finding can be expected.

Gene Therapy

Gene therapy in PD particularly utilizing glial derived neurotropic factor (GDNF) has been a hot topic. This molecule is one of a family of substances that nurture, repair, and stimulate growth of normal dopamine cells. The goal would be to Introduce it into the brain tissue of PD patients to improve dopaminergic function and symptoms. Over the years, past trials which used a sister molecule to GDNF, to deliver neurturin into the brain tissue of PD patients, failed to show benefit.

Continues on page 9

Maintaining Hope in the Midst of Struggle

By Linda O'Connor, LCSW
Reprinted from the APDA Los Angeles Chapter's website

In my work as Coordinator for the APDA Information and Referral Center I have the opportunity to talk with people diagnosed with PD and their family members every day, and one of the most significant aspects of our contact often centers on the subject of hope. Sometimes it is spoken and often unspoken, but the question of hope is always present in some way.

Living with Parkinson's disease is challenging both physically and emotionally, for the person who has the diagnosis as well as family members. And in difficult times it becomes vital to have something to hold on to, and in my opinion one of the best things is hope. Because being hopeful can be such a powerful tool in coping emotionally, it is certainly worth further exploration and understanding.

Continues on page 7

The Parkinson's Source

Published two to three times a year by:

American Parkinson Disease Association
South Florida Chapter
201 East Sample Road
Deerfield Beach, FL 33064
Phone: 954-786-2305
Toll-Free: 800-825-2732
Fax: 954-786-7349

Email: apdasflorida@netzero.net
Web: www.apdaflorida.org

Coordinator and Editor
Gigi Gilcrease, RN, MBA

Medical Director
Thomas C. Hammond, MD

South Florida Chapter Board of Directors
President – Linda Gilchrist
Vice President – Abbi Bentz, RN
Exec. Dir. – Gigi Gilcrease, RN, MBA

Advisory Board Members
Faye Kern • Claire McCarty
Rhoda and Seymour Olchak
Janice Leonard • Gail Baldwin
Sheila Finkelstein

APDA National Office
135 Parkinson Avenue
Staten Island, NY 10305-1425
800-223-2732 • 718-981-8001
info@apdaparkinson.org
www.apdaparkinson.org

APDA National Young Onset PD
www.youngparkinsons.org

APDA National Rehab Center
888-606-1688

APDA Dedicated PD Veteran Center
888-838-6256, ext. 1715

Congratulations Faye!

In June, Faye Kern, APDA Coordinator West Coast Florida, retired. For eighteen years, Faye maintained the Information and Referral Call Center, provided education, symposia, developed and assisted support groups, and worked with other PD organizations along the West Coast, Panhandle, Central and northern areas of Florida. Faye always went the extra mile through her total dedication and commitment to the Parkinson community. Although she has retired, Faye will continue to help with support groups and events. Much gratitude goes to Faye for being the "bright star" that patients, caregivers, family and professionals could count on for resources and counseling. We wish her much happiness!

PARKINSON'S – INFORMATION & REFERRAL

The American Parkinson Disease Association funds Information & Referral (I & R) Centers. Call to get answers to your questions about Parkinson's disease and related issues. The Centers provide counseling and advocacy for patients and family members, education materials, newsletters, support group networks, referrals to community resources, symposia, workshops, community awareness initiatives and fundraisers.

For more information on I & R Centers in your area visit www.APDAparkinson.org

SOUTH FLORIDA

APDA I&R Center –DEERFIELD BEACH & South Florida Chapter
(Hosted by Broward Health North)
201 East Sample Road, Deerfield Beach, FL 33064, (800) 825-2732
Gigi Gilcrease, RN, MBA, Program Coordinator
ggilcrease@browardhealth.org

Caregiver Respite Program

A Parkinson's caregiver respite program is available in Broward and Palm Beach Counties. Respite care can be defined as a short-term option to provide periodic time off for the full-time family caregiver (care partner) to rest and renew him/her from providing continuous assistance to a family member with a diagnosis of Parkinson's disease. Eligible care partners may apply for respite care either through an in-home program or at an adult day care center.

Since 1961 —The mission of
the American Parkinson Disease Association (APDA)
is to

Ease the Burden, to Find the Cure!

Boca Ballet Theatre PD Dance

PD dance incorporates many beneficial approaches and therapies for PD including:

- Mind/Body relationship
- Use of senses- visual, auditory, tactile
- Exaggeration of movement
- Music therapies
- Rhythmic movement and cadence
- Guided Imagery
- Creativity in PD
- Stress management
- Therapeutic value of laughter
- Posture and balance
- Positive Attitude
- Sense of well being and accomplishment
- Socialization

The American Parkinson Disease Association South Florida was pleased to fund Boca Ballet Theatre's BBT4PD, six-week PD Dance Pilot Program which started April 22. Class space filled quickly and there is now a waiting list for the next session. Cindy Surman and Natalie Parker, teachers at the Ballet, recently received training from the Mark Morris Dance Group in Dance for PD.

Gigi Gilcrease, RN, MBA, Executive Director APDA South Florida, "Because of the overwhelming interest in the PD Dance, APDA South Florida will be sponsoring the program beginning this September."

For more information contact Boca Ballet at 561-995-0709.

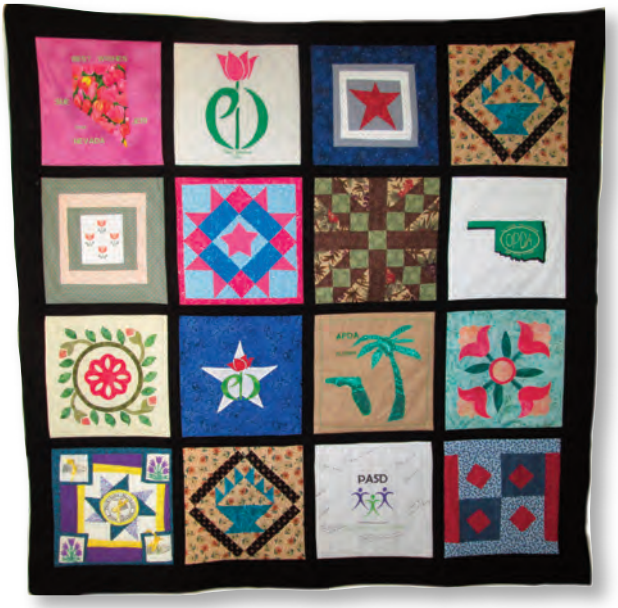
New Exercise Class in Fort Lauderdale

This 45-minute class meets every Tuesday and Thursday at 2:00 pm beginning September 3rd. Class size is limited to 10 participants. Exercises can be performed seated, standing, in a wheelchair or with a walker.

The class uses functional training and Tai Chi with a focus on balance exercises to improve posture and stability, and stretching to increase flexibility. A variety of equipment such as weighted bars, free weights, medicine balls, resistance bands, and body weight will be used.

Located at
Mind & Mobility
2655 East Oakland Park Blvd, #5
Fort Lauderdale, FL.
Contact Mateo Martinez at 954-630-3131.

Parkinson's Quilt for Joel Gerstel



Shortly after Joel Gerstel, APDA national President and CEO, announced his retirement last summer, Susan Dietrich, RN, Coordinator of the APDA Information & Referral Center at the University of Virginia called upon her APDA colleagues to help craft a Parkinson's quilt for Joel. Graciously, Janice Leonard, APDA South Florida member, volunteer, talented quilter and jewelry crafter, designed the Florida section of the quilt. The beautiful finished quilt, displayed above was presented to Joel at his retirement luncheon this past last Winter.

Spring Events

West Coast Florida

Parkinson's Symposium – Celebration

On March 9th, Faye Kern, APDA West Coast hosted J. Eric Ahlskog, MD, PhD , Mayo Clinic Rochester, MN who presented 'Parkinson's Disease' The Big Picture,' and held a Question & Answer Session.

The event was held at the Town Hall in Celebration, Florida. Over 100 persons attended the event.

Sweets for Parkinson's

Members of the Tampa support group raised over $2,800 for PD Research selling homemade fudge and toffee. Faye Kern states, "Many thanks to all who made donations. Special thank you to Tom and Judy Shaw and Dick Snyder. "

The text at the right was excerpted from a letter to Judy Shaw from Charlene Allo, Director of Chapter Relations/Special Events at the headquarters of the American Parkinson Disease Association, Staten Island, NY.

"Thank you so much for your continued efforts on behalf of our organization and the PD Community. I have been receiving donations from the Tampa Bay PDSG Annual Fundraiser and wanted to reach out to you and acknowledge all your hard work and dedication."

South Florida

Parkinson's Symposium–Boca Raton

On March 11th, APDA South Florida held their Annual Parkinson's Symposium at the Marriott Boca Center. Presentations included: Becky Farley, PhD, MPT "Train Your Brain, Train Your Body,' Keynote Speaker J. Eric Ahlskog, MD, PhD 'Parkinson's Disease' The Big Picture,' and Jonathan R. Jagid, MD, 'Deep Brain Stimulation Treatment Update.' Thomas C. Hammond, MD introduced the physicians and participated in the 'Neurology & Neurosurgery' Q&A Session. There were over 250 attendees.

Becky Farley, PhD, MPT

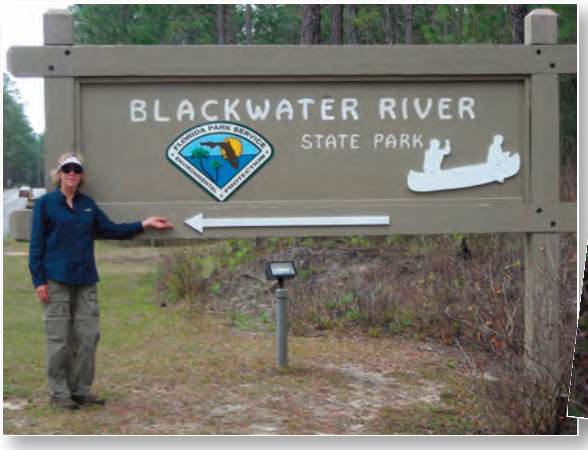
Thomas C. Hammond, MD, Jonathan R. Jagid, MD and J. Eric Ahlskog, MD, PhD

Gail Baldwin's Florida Panhandle Hike

From March 29th – April 6th, Gail Baldwin hiked over 100 miles from the Alabama border to Ft. Pickens, Florida. This is the second hike she has made in honor of her brother, Steven, who passed away in 2011. To date, she has raised $2700.

Gail works tirelessly to increase awareness, raise funds for programs, and also volunteers at support groups and events. Much appreciation, Gail for your help and generosity.

If you would like to support Gail, and honor Steven's memory, you may send a donation to APDA SFL, 201 East Sample Rd, Deerfield Beach FL 33064. Please note "Hike" on your donation.



April - Parkinson's Awareness Month

South Florida

April 14th Delray Beach FL – Optimism Event

South Florida's annual Parkinson's Fun Walk and Picnic was held on April 14 at Lake Ida Park in Delray Beach. The program included entertainment by Mel Matthews, BBQ from Lucille's Bad to the Bone, veggie stand provided by Thomas' Produce, one mile fun walk by the lake, games and prizes, silent auction and many wonderful raffle gift donations.

Barbara, Michael, Vincent and Stephanie Borello hosted "Fact or Fiction" and Trivia games, providing prizes to the top winners. Rhoda Olchak's wonderful team of volunteers manned the registration booth, veggie stand and sold raffle tickets. Generous Silent Auction donations were received from The Marriott Boca Center, Broadway Across America, Sailfish Marina, Eye Center Pembroke Pines and a private donation of an elegant shower fixture.

Over 150 persons attended the event receiving towels, water bottles, tote bags, fans, key chains and travel pill containers complements of Chase Bank and APDA national headquarters. This annual signature event reflects the American Parkinson Disease Association's Optimism Campaign and our mission of providing events and services to help ***ease the burden*** for persons and loved ones challenged by the effects of PD, while raising funds for Research to help ***find the cure***.

Walk Chair and Co Chairs, Rhoda Olchak (center) and Barbara Borello (right) discuss games with Gigi Gilcrease, RN -APDA South Florida Executive Director.

Many thanks to all who participated and donated to the Walk!

Marathon Donors (individuals raising more than $200)

Rhoda Olchak
Seymour Olchak
Ann Kirschner
William Kirschner
Helene Dieter
Barbara Borello
Michael Borello
Vincent Borello
Stephanie Borello
Eileen Samuels
Morty Samuels
Carla Blunck
Bernard & Eunice Kleinman
Adele & Dolph Bodlander

Maintaining Hope in the Midst of Struggle

Continued from page 1

Defining Hope

According to the dictionary hope is: "A desire accompanied by expectation of or belief in fulfillment; also expectation of fulfillment or success." Richard Lazarus a psychologist who has done a great deal of study and writing on hope defines it this way:

"To hope is to believe that something positive, which does not presently apply to one's life, could still materialize, and so we yearn for it. Although desire is an essential feature, hope is much more than this because it requires the belief in the possibility of a favorable outcome."

The fact that having the diagnosis of PD brings with it so much uncertainty, and because you don't know absolutely for sure what will happen next, this creates the possibility that something good may happen, and that possibility makes room for hope to enter.

No one's future is absolutely foretold, so while there may be reason to fear, there is also great reason to hope.

Hope is considered by many of those who study it to be an emotion and as such is made up of two parts: cognitive (hopeful thoughts) and emotional (how hope feels). The cognitive part refers to the fact that when we hope we gather together information related to a desired future event. So when you hope for an amazing new treatment, or even a cure this requires you to generate a different vision of your condition in your mind.

But hope also has a feeling aspect, which refers to the fact that when you project in your mind a positive future most people experience a comforting, energizing, elevated feeling, an upward shift in mood. So we say we are "lifted up" by hope, or hope has "wings". It is this elevated feeling that can help fight despair and decrease stress which is always helpful in managing the PD symptoms.

"To hope is to believe that something positive, which does not presently apply to one's life, could still materialize, and so we yearn for it. Although desire is an essential feature, hope is much more than this because it requires the belief in the possibility of a favorable outcome."

Hope vs. Despair

I don't think any discussion of hope is would be complete without some acknowledgement of its relationship to despair. They are two sides of the same coin. The definition of despair is "utter loss of hope", the consequence of which is usually depression. Coincidentally one of the symptoms of a clinical depression is hopelessness. The conditions for us to either hope or despair are also the same: great stress, anxiety and struggle. So in a sense we are presented with a fork in the road, the choice to hope or despair.

Now that being said, it is important to note that feeling hopeful is not usually a constant feeling for most people. As human beings we have good days and bad days, and some people are more inclined by personality to be hopeful. Hope can also be a mixed bag, it can include doubts as well as positive expectations – that's normal. What we hope for may also change as circumstances change. But generally speaking staying on the hopeful side (or trying your best) is infinitely better than the alternative.

Hope as a Coping Process

Maintaining a hopeful attitude can be an extremely helpful coping strategy in two particular ways; first it produces action. Studies have shown that hope can galvanize efforts to seek improvement of an unfavorable situation. Without hope we are unlikely to act in our own behalf. Hope combines yearning for something better with the belief that our actions could help to bring about the outcome we want.

Hope is why people seek out information about Parkinson's disease and its treatment. Hope is why people become actively involved in getting the best treatment possible. Hope is why people exercise, concentrate on good nutrition and attend to their emotional well being. Hope is why people connect with each other for support. Hope is why people don't give up even in some of the most difficult situations. It keeps us engaged with life. The second way that hope aids coping is that it serves as a vital resource against despair. The best defense we have against despair and the depression that accompanies it is hope.

Cultivating Hope

Choose to be Hopeful

Because hope is partly a cognitive process involving thoughts, it is possible to make a very deliberate, conscious decision to be hopeful. Now this normally doesn't happen overnight, usually it's an evolving process, and it may not work every single day especially if you're having a particularly bad day, BUT…it's worth trying to focus on having a overall hopeful attitude as much as possible. Part of this is looking for reasons to hope: maybe it's a new piece of research, maybe it's a new medication, maybe it's experiencing the benefits of yoga or tai chi, maybe it's just seeing the smile on your spouse's face. Sometimes you have to look pretty hard to find reasons, and sometimes it may be very small things you find, but it can keep you going. Counting your blessings can also be a good way to keep things in perspective.

Live Today

A common, often causal thing you hear people say is "one day at a time"…but this really does hold some truth. One of my most common suggestions to people with PD and their family members that I talk to on a daily basis is to focus on taking things a step at a time. People naturally want to know what the future holds for them, but I have yet to meet anyone who has a crystal ball (including doctors). And the reality is that living too much in the future (or in the past) causes you to lose today and possibly overlook some reasons to hope.

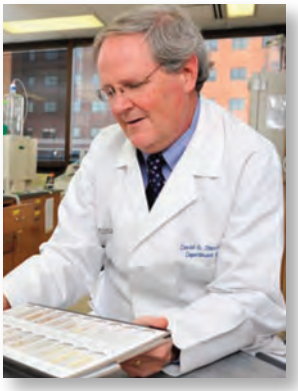
Treat Depression

Depression is commonly associated with PD, as a result of the disease process itself as well as in reaction to the loss and adjustment it brings. The good news is that depression is treatable. So I recommend monitoring your mood, be aware of the signs of a clinical depression and talk to your doctor. Both medication and counseling have been found to be very effective in treating depression. Living with PD is a difficult enough challenge without adding on depression.

Seek out Models of Hope

Look for inspirational people, written materials, support groups, online information and support, or anything that can be a source of hope to you. What's important is that you find what works for you personally and then seek it out whenever you need it.

David G. Standaert, MD, Phd To Chair APDA's Scientific Advisory Board



David G. Standaert, MD. PhD, the John N. Whitaker Professor and Chair of Neurology and head of the Division of Movement Disorders and Center for Neurodegeneration and Experimental Therapeutics, at the University of Alabama – Birmingham, has been named chairman of APDA's Scientific Advisory Board. Dr. Standaert who joined the board in 2002, succeeds G. Frederick Wooten, MD as the board's fourth chairman.

Dr. Standaert, graduated magna cum laude in biochemistry from Harvard University, earned a dual degrees (MD and PhD) from Washington University School of Medicine, St. Louis, MO. His post-graduate studies were completed at Jewish Hospital, St. Louis, the University of Pennsylvania and Harvard Medical School, Massachusetts General Hospital.

He reports that his laboratory is interested in the pharmacology and neurochemistry of the basal ganglia and the mechanisms of Parkinson's disease, and other conditions which produce abnormalities of movement. Dr. Standaert says, "Our experimental approaches combine classic neuroanatomical methods with modern techniques of molecular and cell biology, using in situ hybridization, immunohistochemistry, laser capture microdissection, gene array profiling, animal models of disease, and in vitro systems."

VETERANS UPDATE:

VA Expands Dates of Agent Orange Exposure in Korea

Veterans who served along the demilitarized zone (DMZ) in Korea during the Vietnam War, now have an easier path to health care and benefits. The Department of Veterans Affairs (VA) has expanded the dates when illnesses associated with exposure to Agent Orange can be presumed related to their military service.

Previously, VA recognized exposure for service between April 1969 and July 1969. VA now presumes exposure for service between April 1, 1968 and August 31, 1971, if a Veteran served in a unit determined by VA and the Department of Defense to have operated in an area of the DMZ where Agent Orange or other herbicides were applied. (see www.publichealth.va.gov/exposures/agentorange/korea.asp)

This presumption simplifies and speeds the application process for Veterans of the Korean DMZ. VA says it encourages Veterans who believe they have health problems related to Agent Orange to submit their application for VA health care and disability compensation benefits.

To apply for health care benefits online go to www.1010ez.med.va.gov/sec/vha/1010ez, or contact the nearest VA health care facility at 877-222-VETS (8387). To file a claim for disability benefits, apply online at www.ebenefits.va.gov, or contact the nearest VA regional office at 800-827-1000.

Reprinted courtesy of Susan F. Gulas, RN, APDA's Dedicated Veteran PD Information & Referral Center, 888-838-6256, ext. 1715.

Much Appreciation to Our Corporate Memberships

Gold Members

Medtronic

LifeCare of Florida

Maxicare Select, Inc.

Silver Members

Alternative Home Health Care

Responsive Home Health
"Responding with Care Since 1994"

Village Home Care of the Palm Beaches, LLC.

Much Appreciation to Our Walk Corporate Sponsors

Marriott Boca Raton at Boca Center

Medtronic

Lucille's Bad to the Bone BBQ

Park Summit
A FiveStar Quality Care Community

Thomas Produce Co.
Growers, Packers, & Shippers of Florida's Finest Vegetables
Boca Raton, FL

Sailfish Marina Resort

Broadway Across America

Tributes & Donations

We greatly appreciate your tributes and donations. Tributes and are a wonderful way to acknowledge the memory of a beloved person or to honor someone who means so much to you. For over 20 years, your generous donations have helped to increase Parkinson's awareness, develop educational programs, provide free educational materials, distribute *The Parkinson's Source* newsletters, facilitate patient and caregiver support groups, provide current information to our mailing list, fund exercise and special programs, maintain the caregiver respite program, sustain the APDA Information & Referral Center helpline, maintain our website, www.apdaflorida.org, and fund research as determined by the APDA National Scientific Advisory Board. The donations listed below were received from to February 2013 – June 2013.

REMEMBERING

Humberto Bahr
Alfredo Manduley
Keki Bhote
Bob & Audrey Stern
Helena Millar Cleveland
Thomas & Janet Fahey
William & Judith Sherman
Christine Long
Chuck Craig
Elaine Aronson
Lawrence E. Crawford
Linda Hardenburgh
Flloyd Degroff
June Degroff
Donald Denny
Bill Roderick
Jerry Diamond
Judith Miller
Frances Doniger
Marjorie Fishman
The Ladies Club of Piper's Glen
Shirley & Perry Gold
Gerry & Diane Ringel
David & Iris Werber
Fred & Ruth Flanz
Joseph & Michie Flanz
Gladys Freedman Albert
Madeleine Devega
James Gilchrist
Nadine Comiter
Richard & Sarah Gilchrist
Georgia & William Gilcrease
Jeffrey & Lisa Horn
Cherry Laska
Rhoda & Seymour Olchak
Melody Walesby
Phillip Golbitz
Ruth Roddin
Paul Goldman
Marvin & Phyllis Goodman
Charles Haugh
Sarah Tuller Golub
William Kirschner
Robert & Anne Cohen
Paul & Gail Horowitz
Ann Kirschner
Dr Stuart & Cynthia Kleit
Ruth Newman
Ruth Rockoff
Gerald & Barbara Teplitz
Wycliffe Spirituality Club
Seymour Levine
Frank Raphael
Ben Porto
Renee Harris
Charles Rafshoon
Susan Weiss
Eli Reinstein
Reuben & Florence Freedman
Norman Schenker
Sandra Eisenstein
Edna Feingold
Doris Fox
James Ledley
Lester Sebold
Helaine & Marvin Gurgold
Jeffrey Stein
Susan Katzman
Bunny Tye
Leslie Tye
Selig Wiener
Marvin & Phyllis Goodman
Lawrence & Ethel Seidman

HONORING

Libby Bay's 80th Birthday
Harvey Rich
Dick Bonner's 80th Birthday
Willard & Naomi Frechtel
Stan & Karen Bartel
Maddy Frishman's 70th Birthday
Dawn & Marvin Mill
Evelyn Kohring
D. McPeake
Dr. Graham & Mrs. Martin
Jules & Bernice Cooper
Gordana Tesic
Jelena Mamic
The Birth of Julia Tobin
Beverly Tobin

MEMBERSHIPS & DONATIONS

Dulsuma Andric
Barbara Barron
Andrew Bobkowicz
Beth Breus
Nicholas Bruno
Roger Bukszpan
Robin Caradonna
Sonia Carlile Weiss
Terry & Ruth Cusick
Evelyn & Richard Darmstadter
Don Ely
Melanie Ginsburg
Joseph & Wilma Goldstein
Carole Halper
Melvin Harbinger
Elizabeth Imhoff
Howard Isaacs
Fred & Linda Kohn
Paul & Francine Krenik
Susan Lincoln
Linda Littman
J. Robert Lowry
Cyrus & Evelyn Marder
Susan Marks
Victoria & Arthur Needleman
Phyllis & Peter Nichols
Coleman Pell
Matthew Pressman
Victoria Reynolds
Selma Roberts (United Way of Palm Beach)
Jennifer Schwartz
Ann Lou & John Scowcroft
Karen Sides
Donald Stange
Timothy Sweeney
Harvey & Florence Tabor
Donald Walsh
Donald & Patricia Widmayer
Richard & Nancy Wolter

THE ESTATE OF

Betty Jane Muzzey

SPECIAL EVENTS & PROGRAMS

Gail Baldwin's PANHANDLE HIKE
In Memory of Steven Baldwin
Timothy Chapman
Janet Davis
Allison & Todd Dietrick
Ellen & Jerry Dietrick (Edmond & Mary Shea Family Foundation)
Joan & William Dietrick
Helaine & Marvin Gurgold
Ruth Hazen
Howard Hoveman
Frances Katz
Howard & Claire Stern
Joyce & Ronnie Vaagenes
Myron Verch
Suki Vuori
Sheila Williams
Dance for PD
James Porter

FOUNDATIONS

The Ruth and Louis Gerstle Foundation

James and Sandra Porter Charitable Fund of the Community Foundation of Broward County

Recent Studies and Therapeutic Strategies

Continued from page 1

However, in the past 6 months a fascinating bit of research was presented in Science Translational Medicine, which showed that alpha-synuclein blocks the normal signaling pathway for GDNF, making it ineffective. Furthermore another molecule called Nurr 1, will restore the GDNF signaling effect, and protect the dopamine neurons against alpha-synuclein toxicity. The finding of Nurr 1, likely will lead to a new round of therapeutic strategies. This is exciting basic science that is translating itself into clinical research. New trials using these modifications in Gene therapy are already underway.

"Early Stim" – DBS Surgical Consideration

A study in the New England Journal of Medicine in February 2013, called "Early Stim" looked at the early use of DBS compared with standard medical care in treating PD. There were 251 patients in the trial with a mean age of 52 years old, who had Parkinson's on average 7-1/2 years. They were randomly assigned to Deep Brain Stimulation of the subthalamic nucleus STN, or standard medical therapy.

After being followed for 2 years there was a significant improvement in the DBS group as compared with the medical therapy group for quality of life, activities daily life, and mobility. Levodopa-induced motor problems such as dyskinesia were significantly less in the DBS group. Heretofore DBS has been delayed until later stages of PD when patients have more severe disability. This study clearly suggests that DBS should be considered earlier in the course of PD in suitable patients.

Transcranial Magnetic Stimulation

In April, The Journal of Neurology reported a small trial of transcranial magnetic stimulation (TMS) of the scalp in patients with PD. Based on research regarding DBS, it is apparent that the supplementary motor area (SMA, frontal brain cortex) exhibits a change in activity in patients with DBS of the STN.

In this study, researchers used superficial electrodes overlying the scalp in the SMA regions, applied magnetic stimulation using several different parameters, and compared the response to a control group (sham stimulation). The population included 106 PD patients; 36 received low frequency repetitive TMS, 34 received high frequency repetitive TMS, and 36 had a sham procedure.

After 20 weeks there was a significant improvement on a Parkinson's rating scale in those patients receiving low frequency repetitive TMS. These patients showed a moderate improvement in motor function, with improved gait, posture, and balance using this well-tolerated stimulation device. This is an exciting new development in PD and if confirmed with further studies, it should be safe to use in all stages of PD.

Medications Amantadine and Memantine

The standard current treatments for PD are directed at restoring dopamine deficiency that occurs as the SN cells are dying off. Levodopa generally given as the combination of carbidopa/levodopa (Sinemet) is still the most effective agent for treating the motor symptoms of PD. Dopamine deficiency leads to increased activity in other neural networks, such as the increased glutamate activity in the subthalamic nucleus (STN). This is the same area in which the mechanism of DBS suppresses over activity. Amantadine (Symmetrel) has been found to be a NMDA glutamate receptor antagonist, and works by suppressing this over activity, also felt to be the same mechanism of DBS in this area.

A recent study showed some benefit from another NMDA antagonist, memantine (Namenda) in terms of improved balance and posture in PD. The patients studied had severe gait disorder and abnormal, forward leaning stance. The memantine dose given was 20 mg daily and the patient's levodopa dose was left the same. There seemed to be some significant benefit in limiting the abnormal forward leaning posture in these patients. This was a small study of only 25 patients, but offers some promise for those patients with progressive forward stooped posture issues.

Tai Chi

A study published in the New England Journal of Medicine presented data from a controlled trial which demonstrated that a tailored course of Tai Chi can improve postural stability and balance in patients with PD. In this study tai chi was compared to resistance training and stretching programs, and showed an objective improvement in postural stability (better balance) in the tai chi group. Furthermore, these improvements in postural stability led to fewer falls which is a common and difficult problem to treat in PD patients.

Treadmill and Resistance Exercises

Lisa M. Shulman, MD, Professor and Movement Disorder Specialist at the University of Maryland, studied three exercise regimens for PD patients. There was a high-intensity treadmill group (30 minute fast pace), a low intensity treadmill group (50 minutes easy pace), and a third group who performed stretching and resistance exercises with their legs, using exercise machines. The study showed there was benefit across all three exercise groups, and suggested that a combination of treadmill and resistance exercises may be the best combination.

In this newsletter, a number of new strategies being developed to treat PD were reviewed. It is particularly exciting to see that several of these strategies are leading to improved balance and decreasing falls. Again, a regular exercise routine, and perhaps becoming involved in a tai chi course, have been shown to help improve function in PD.

Be sure to tie your sneakers!

Sincerely,
Thomas C. Hammond, M.D., FAAN

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

South Florida

City	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Coral Gables	St. Matthews Church , 7410 Sunset Dr.	2nd Wednesday	11:00AM-12:30PM	Carol Goldman	305-476-8782
Coral Springs	Coral Springs Medical Office 3100 Coral Hills Dr. (next to hospital)	3rd Monday Support Group	2:00-3:30PM	APDA	800-825-2732
Davie	Nova Southeastern University NSU Ziff Health Care Bldg., 1st floor 3200 S University Dr.	1st & 3rd Wednesday 4th Wednesday **Caregiver Group** [PT Clinic]	10:45AM-12:00NOON 1:00-2:00PM	Dr. Blodgett	954-262-5611
Deerfield Beach	Broward Health North, 201 E. Sample Rd. Neuro Center (off lobby)	2nd Tuesday Support Group	1:00-3:00PM	APDA	800-825-2732
Delray Beach	South County Civic Center 16700 Jog Rd.	1st Wednesday Support Group & Exercise **Caregiver Group**	2:00-4:00PM 3:00-4:00PM	APDA	800-825-2732
Jupiter	Jupiter Town Complex Activities Building, 201 Military Trail	1st Friday (lunch) 3rd Friday (meeting)	1:00-3:00PM	Rose Kyle	561-744-7666
Miami	Baptist Hospital Professional Bldg. 8950 N Kedall Dr., Suite 105	2nd Friday 3rd Saturday	7:00-9:00PM (Eng) 12:00-2:00PM (Span)	Abe or Ivon Bertan	786-683-0240
Miami VAHCS *Veterans Only*	1201 NW 16th St., 7th Floor Pain Clinic Psych Office, Rm. D707	Every Thursday	10:45AM	Paul Hartman, PhD	305-575-3215
Palm Beach Gardens	Christ Fellowship Life Center Room 206, 5343 Northlake Blvd.	2nd Wednesday Support Group	2:00-3:30PM	APDA	800-825-2732
Port St Lucie	Harbor Place 3700 SE Jennings Rd.	3rd Tuesday Support Group	2:00-3:30PM	Cathy Laura	772-201-6007 561-209-6124
Royal Palm Beach	Royal Palm Beach Cultural Center 151 Civic Center Way	Monday & Wednesday Support Group & Exercise	10:00AM-12:00PM		
Stuart	Grace Place Community Church 1550 SE Salerno Rd.	2nd Monday Support Group	1:00-3:30PM	Aileen Stiehle	772-286-3268

Exercise Only – South Florida

Fort Lauderdale	Mind & Mobility 2655 East Oakland Park Blvd, #5	Every Tuesday & Thursday Functional Training & Tai Chi	2:00-2:45PM	Mateo Martinez	954-630-3131
Boca Raton	Sugar Sand Park Field House 300 S Military Trail First class is free, just stop by the park	Monday Wednesday	11:30AM-12:30PM 2:00-3:00PM	APDA	800-825-2732
Boca Raton	Boca Ballet Theatre	Two Days a Week PD Dance	Limited space must pre-register	Cindy Surman Natalie Parker	561-995-0709
Coral Gables	St. Matthews Church, 7410 Sunset Dr.	Dance, Yoga, Music		Carol Goldman	305-475-8782
Davie	Nova Southeastern University Sanford L. Ziff Health Center 3200 S University Dr.	Monday and Wednesday Physical Therapy PD Exercise Wednesday Speech Therapy PD Exercise	12:30PM 1:30-2:30PM	 Dr. DiCarlo	954-262-4149 954-262-7726
Greenacres	Temple Beth Tikvah 4550 S Jog Rd.	Tuesday Friday Tai Chi	10:00-11:00AM	Must pre-register Free to APDA SFL Chapter Members	800-825-2732
Palm Springs	St Luke's Catholic Church 2892 S Congress (school library)	Saturday Tai Chi	11:00AM-12:00PM	Must pre-register Free to APDA SFL Chapter Members	800-825-2432

Central Florida

City	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Holly Hill (Ormond Beach/ Daytona Area)	Bishop's Glen Retirement Center 900 LPGA Blvd.	4th Wednesday/month	2:00-3:30PM	Vincent Kinsler	386-676-6375
Kissimmee	Friendship Room Kissimmee Village 4250 Village Drive	2nd & 4th Thursday	10:00 – 11:00AM	Craig Yohn	407-944-3362
Melbourne	South Brevard Parkinson's Support Group Eau Galle Public Library 1521 Pineapple Ave.	4th Thursday/month	1:30PM	Deb Ridel	321-751-0444
Titusville	North Brevard Parkinson's Disease and Caregivers Support Group Parrish Medical Center 951 N. Washington Ave.	3rd Saturday/month	11:00AM	Janet Rooks	321-268-6800
Orlando	Florida Hospital	4th Thursday/month	10:00AM-12:30PM		407-303-5295
Lady Lake	American Legion Building	2nd Wednesday/month (Sept-June)	2:00-3:00PM	Pat Pipa	pipipa1622@ emburgmail.com
Ocala	Lifetime Center, 941 SW Hwy, Suite 200		1:00PM	Lisa Walter	352-854-9498
Tallahassee	St Paul's Methodist Church	2nd Thursday/month	6:30PM		

West Coast - For updates for these classes, contact APDA South Florida at 800-825-2732 or National at 1-800-223-2732

City	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Bradenton	Summerfield Assisted Living 3409 26th Street West	3rd Monday Year Round	3:00-4:00PM	Rehab Staff	941-751-7200
Clermont	Cooper Memorial Library 2525 Oakley Seaver Drive	4th Tuesday	3:00-4:00PM	Deborah Snow	352-241-7476
Clearwater/Dunedin	William Hale Senior Center 330 Douglas Avenue	1st Friday (No meeting in August)	1:00-2:30PM	Faye Kern	afkapda@aol.com
Largo	Cypress Palms 400 Lake Ave, Cypress Bldg	3rd Tuesday	12:00PM (Lunch Served)		
Largo	Barrington ALF 901 Seminole Blvd.	Saturday Every Other Month **Caregiver Group**	10:30AM-12:00PM	Faye Kern	afkapda@aol.com
Leesburg	Lake Square Presbyterian Church 10200 Morningside Drive	2nd Tuesday	1:00-3:00PM	Pat	352-242-0376
St. Petersburg	St. Luke's United Methodist 4444 5th Ave. North St. Petersburg	2nd Monday (Sept-June) 4th Monday Year Round	1:00-3:00PM	Joan Xavier	jmdixon@gmail.com
Tampa	First Church of the Nazarene 5902 North Himes Avenue	3rd Wednesday Year Round	1:00-2:30PM	Jane Lowry	813-908-6685
New Port Richey	Elfers Senior Center, 4136 Burker Dr.	1st Thursday (Sept - May)	2:00-3:00PM	Susan Franchello	727-372-5410
Avon Park/Sebring	First Baptist Church of Sebring 200 East Center Avenue	2nd Monday (Sept - May)	10:30AM-12:00PM	Marvin Jones	
Englewood/North Port	Englewood Hospital 400 S. McCall Road	3rd Friday/month	10:00AM	Sue McNaire	947-270-2505
Sarasota	Freedom Village 6406 21st Avenue West			Sarasota Hospital	941-917-7048
Venice	Jacaranda Trace ALF	(Sept. - May)	10:00AM	Betsy Cundiff	941-408-3411
Pensacola	Wellness Center (hospital) 2120 E. Johnson Avenue	4th Tuesday/month	1:00PM		

Largo Caregivers Support Group

REMINDER

Meets on Saturday, every other month at The Barrington Senior Assisted Living Community. Please contact Faye Kern at afkapda@aol.com for information on date and time.

North Florida

Deland Orange City Jacksonville St. Augustine Jacksonville – Young Onset

For information on the groups in these cities contact the APDA South Florida, 800-825-2732.

Southwest Florida

Naples Bonita Springs

For information on support groups, exercise and services contact: Parkinson's Association of Southwest Florida 239-417-3465

THE Parkinson's Source

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

Non-Profit Org.
U.S. Postage
PAID
Ft. Lauderdale, FL
Permit #: 3973

Help support our mission — To Ease the Burden, To Find A Cure.

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

PLEASE PRINT CLEARLY

Donor Information

Name_____ Phone _____

Address_____ City _____State_____Zip _____

Tribute Information

In Memory of ☐ In Honor of ☐_____ Send Acknowledgement to _____

Address _____ City _____State_____Zip _____

Enclosed is my check for: ☐ $1000 ☐ $500 ☐ $250 ☐ $100 ☐ $75 ☐ $50 ☐ $25 (membership) ☐ $200 (Lifetime family membership)

☐ Include membership with my donation of $25 or more. ☐ Other _____

Your membership to the South Florida Chapter helps to support The Parkinson's Source newsletter printing and mailing 2 to 3 times/year (est. circa 3000), APDA exercise programs, caregiver respite assistance, invitation to end of the year PD Update, neurological nurse staff for Information & Referral Center, support group costs, PD 101 Workshops and educational events.

Inside Issue No. 46, Summer 2013