

Empowering People with Parkinson's

FALL EDITION 2015

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APDA Medical Director

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Raised over \$11,000 with
your support!

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SAVE THE DATE!

APDA Open House
Tuesday, October 27, 2015
(5:30-7:30pm)
700 West Hillsboro Blvd, Building 3,
Suite #110
Deerfield Beach, Florida 33441

**APDA Physicians and Parkinson's
Patients Workshop**
Saturday November 21, 2015
8:00am-3:00pm
Holy Cross, Dorothy Mangurian
Women's Center,
1000 N.E. 56th Street
Fort Lauderdale, Florida 33334

Call 800-825-2732 for RSVP,
Tickets, and Information

Parkinson's Disease (PD) highlights from the American Academy of Neurology meeting (AAN) 2015.

There were a number of presentations at the 2015 AAN meeting regarding genetics and PD. There is still no genetic test that will predict reliably who will get Parkinson's disease, and it is not a strongly genetic disease so one does not have to worry about passing it onto the children. However, there have been a number of genes identified that predispose to getting PD, and these genes may be triggered by certain environmental agents. Since there is better understanding of the proteins that these genes are producing, there is hope that manipulating the generic mechanisms, or altering these proteins will lead to novel pharmacologic therapies.

A group at the University California San Diego, and from Yale University, presented interesting data on stem cell research in PD. They have been using parthenogenetic neural stem cells (NSC) that are derived from unfertilized human oocytes (human eggs). These cells are chemically directed to differentiate into human NSC, and this group has succeeded in reliably reproducing the cells in large numbers and they can be cryopreserved (frozen) and transported to distal sites where they are used. They have transplanted these NSC into both rodent PD models, and into primate (monkey) PD models. In both models they have shown the cells survive, and make dopaminergic connections with tissue in the substantia nigra, and striatum where they have been implanted. The animals have shown improvements in parkinsonian features. The group has demonstrated safety in these tests. Blood tests in the animals are normal, and none of the animals have developed dyskinesia or dystonia (a major problem in the human fetal cell transplant trials). When these test animals were subsequently sacrificed, necropsy did not show any abnormality. Specifically there was no evidence for tumor development, or distal spread of stem cellular tissue into other organs. This group does plan on moving into phase I, and phase 2 trials in humans to assess safety, and dose (number of cells needed). This will require injection of cells into brain tissue. This is an exciting move forward in this field.

There were several interesting presentations at the AAN related to neuroimaging and PD. One presentation was using DAT scanning (dopamine transporter imaging with SPECT), and following patients from baseline over the first 2 years of the disease using this imaging modality. This did show a decline in DAT activity which progressed in a predictable fashion over that first two-year period. This may prove to be a tool that can be used in research, to assess medication and other interventions insofar as slowing disease progression. Another study looked at brain structure in the striatum, and substantia nigra in PD using advanced techniques utilizing 3T MRI. In this study, they evaluated the effects of aerobic exercise on these brain structures. Using diffusion tensor imaging (DTI), they accessed fractional anisotropy (FA) and mean diffusivity (MD), in those brain regions. The FA normally decreases, and the MD normally increases in brain structures with normal aging, and it does so more dramatically in PD. The study observed a number of patients with PD (age 50-80), who had not been involved in a regular exercise regimen, and examined their brain at baseline, and then again 6 months after a regular exercise regimen of brisk walking 15 minutes, 3 times a week. The patients showed clinical improvements in aerobic function, PD motor function scores, and sense of well-being after the exercise regimen. However, in addition, the advanced brain imaging demonstrated improved brain structure (increased FA, and decreased MD) in the substantia nigra and striatum. This was a first time that an anatomical study in humans has shown reversal or modification of neurodegeneration through aerobic exercise. The effects of increased cerebral blood flow, and increase in trophic factors which support cells and cell growth, seemed to be provoking neurogenesis (new cell growth).

The moral seems to be that exercise is still an excellent strategy in PD.

Thomas C. Hammond, MD

Editor's Corner

Welcome to the first 2015 Edition of "*Empowering People with Parkinson's Newsletter*". In the featured story we continue to highlight pertinent studies and medical information from our Medical Director: Dr. Thomas Hammond.

We're aspiring to having a living, learning culture with a growth mindset that allows us to provide you with current updates surrounding medical research and services. We want you to know that "YOU" are our most important customer. We are steadfast in our evolution at the South Florida Chapter to improve our delivery systems, create industry partnerships which will enhance additional opportunities for training and education offerings. By developing strong collaborations and alliances this effort will increase our community awareness.

What's new in the Chapter?

Our first official announcement is the appointment of Dr. Arif Dalvi, as the Chairman of the Medical Research and Education Advisory Council. Dr. Dalvi will assemble a group of Medical Thought Leaders within the multidisciplinary Parkinson's world who will guide us in developing new support group guidelines, while keeping us abreast of new research. To that end, all of you will be the benefactors of this information helping you in your daily lives. In addition, Dr. Dalvi will also engage you in answering your questions on the APDA Website, under the caption "Ask the doctor". For those of you who gravitate to the internet; in the not too distant future we envision scheduling webinars, which will provide value based information to keep you abreast and informed.

In October, Rebecca Hahessy, has been hired as our new Program Director. Rebecca will work with all of our support groups and exercise programs working towards a new level of Excellence. We've already started to incorporate dynamic topics. We want all of you to feel that you have "ownership" in your groups. Keep those emails coming. We are all in this "together"!

In case you've not notice, The Chapter has a new office. We do hope that you will RSVP to attend the Open House, Thursday October 27 from 5:30-7:30pm. Please RSVP by October 19. To RSVP, please call (800) 825-2732. Our new office will give us the capabilities to run additional support groups, offer annual training for our support group facilitators, and we hope you will consider this a place where you'll join us for an event or stop by and review resource materials.

APDA is also happy to announce our re-commitment to the BBT4PD program at Boca Ballet for the 2015-2016 season. As Rabbi Singer said on more than one occasion. "When we are dancing, we don't have Parkinson's". Now that's medicine for the soul!

APDA will host our "first" Physicians & People with Parkinson's workshop. We are inviting Medical Practitioners from all disciplines, and medical students to discuss the latest medical research and techniques. Our Host Sponsor is: Holy Cross Hospital, Dorothy Mangurian Comprehensive Women's Center, Fort Lauderdale. Saturday, November 21, 2015, Registration opens at 7:15am. If you are interested in attending, you can go online to purchase your ticket at:

www.apdaflorida.org. For ticket information, email: apdaflorida@apdaparkinson.org, or call (800) 825-2732.

Lastly, and certainly not least, we want to thank you for your continual financial support. Your donations play a major role in our ability to drive our mission both locally as well as funding medical research. We are not supported by any government agency. It's your dollars which fuel the engine. Every day, you are front and center in our decision making. This organization provides the "boots on the ground" for those with Parkinson's and Care givers. We hope you enjoy this issue of Empowering People with Parkinson's Newsletter.



Denise Jordan
Executive Director

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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.

APDA SOUTH FLORIDA CHAPTER

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Rebecca Hahessy, Program Director

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www.apdaparkinson.org

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www.youngparkinsons.org

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888-838-6256, ext. 1715



From the President

Throughout my career as a pharmacist, I was taught to give back to our community to help our customers lead healthier lifestyles by providing talks to the community, taking back outdated medications or simply performing community service hours.

In my family, my brother who is a dentist, started a national program called “Give Kids A Smile. This program provides dental care for children in the St. Louis inner-city area who would normally not be able to afford to see a dentist. So when my sister, who is the Executive Director of the St. Louis APDA Chapter, called me to say she had given my name to Gigi Gilcrease, the previous Executive Director of South Florida’s APDA Chapter, I knew I had to get involved. After all, it was APDA which gave my parents a lot of support over the years when my Mother needed help with her Parkinson’s Disease. Now, almost two years later, I am giving back to the Parkinson’s community in South Florida, as I have recently been elected to serve as President of our Board of Directors.

Under the direction of our new Executive Director, Denise Jordan, our South Florida Chapter will continue to provide the various support and exercise groups that Parkinson’s patients and their caregivers have expected us to provide. The Board of Directors will strive to provide a “home” for all Parkinson’s patients and a physician’s referral service. In addition, we are striving this year to expand our services into Miami-Dade and Broward Counties, as we already have a strong presence in Palm Beach County.

Our Board of Directors are here to serve the needs of our community in South Florida. If you have any ideas or suggestions as to what else we can do for our Parkinson’s patients in South Florida, please call Denise Jordan at 800-825-2732 and tell her what you would like us to accomplish.

I look forward to giving back to the community in memory of my Mother, Lillian Dalin.

Gary Dalin, M.S. R.Ph.

APDA Names Dr. Arif Dalvi, Chairman of Medical Research and Education Advisory Council, APDA South Florida Chapter.

Announcement of Dr. Arif Dalvi, "These are exciting times for APDA South Florida Chapter, We are extremely fortunate to welcome aboard Dr. Arif Dalvi, MD, MBA, Director of Comprehensive Movement Disorders Program at Palm Beach Neuroscience Institute. Dr. Dalvi is an innovator; and trained in the most current cutting edge and comprehensive procedures in treating Parkinson's in the 21st century. We look forward to his "Ask the Doctor" section which can be viewed on the www.apdaflorida.org website.

"The treatment of Parkinson's disease is ever changing. The introduction of levodopa as a treatment for PD was a revolution in medicine. However, many challenges remain including motor fluctuations, dyskinesias and cognitive symptoms. We aim to meet these challenges with new medications, new ways to deliver medications, and surgical treatments including deep brain stimulation. While the choice of treatment options has grown, making the right choice involves a shared decision making process between patient and their treating physician. I look forward to helping patients understand these choices and keeping them informed of new research developments in my role as Chairman of Medical Research and Education Advisory Council of the APDA South Florida Chapter".



Dr. Arif Dalvi, MD



Stress Relief For Caregivers

At some point, most of us will be concerned about caring for aging loved ones. Caregiving is stressful! Studies indicate that caregivers have trouble finding time for themselves, managing stress, and balancing work and family responsibilities. In addition, caregivers need help in keeping their loved one safe, talking with doctors and making end-of-life decisions.

The stress of caregiving has a physical effect, as well, in that caregivers have chronic conditions at nearly twice the rate of non-caregivers.

Caregiver Tip 1:

- Take care of yourself!
- Get a yearly checkup and alert your doctor that you are a caregiver.
- Tell your doctor if you feel depressed or nervous — don't dismiss your feelings as "just stress."
- Stay current on your immunizations — a dose of flu vaccine to the caregiver is also a layer of protection for the person receiving care.
- And it may sound like a cliché, but it's most important to eat healthy, exercise regularly, and get enough rest.
- Allow yourself "me" time – make time to do things you enjoy.

This is the first in series of caregiver tips from MorseLife Health System, a center of excellence in senior care in Palm Beach County. For more information about caregiving, call (561) 209-6174.

Are there benefits to physical and occupational therapy in the home for patients with Parkinson's disease? You bet!

Research has shown that although there is no cure for Parkinson's disease, there are ways the progression of the disease can be slowed and the physical impact of the disease managed more effectively through participation in regular exercise programs. For the patient diagnosed with Parkinson's disease, the overall goal of a regular exercise program is to improve your independence and quality of life through enhanced movement and function, as well as relieving any associated pain. In addition, an exercise program developed in collaboration with a physical therapist and occupational therapist is not only customized to your individual condition and needs, but in many cases can be covered under your Medicare benefit or other insurance carrier.

The focus of any home exercise program is to reduce stiffness and improve mobility, posture, balance and gait. Aerobic exercise increases oxygen delivery to key organs and body systems such as the heart, lungs and nervous system. Strength training exercises can improve walking, balance, coordination, and fatigue. Of course, as with any exercise program, maintenance of physical activity is critical to the ongoing benefits of the program itself. This may require lifestyle modification for many patients with Parkinson's disease, but the results will be worth it.

Working with your doctor, the physical and occupational therapist can also develop an at-home exercise program that works with your existing medical regimen. Understanding that many of the medications used to treat Parkinson's disease have certain limitations, including "on" and "off" times, as well as decreased effectiveness with long-term, chronic use, the physical and occupational therapist will work with you in order to focus on your "peak" productivity times, helping to reach the maximum benefit from your exercise regimen.

Although research continues, the benefits of exercises that challenge you to change the tempo, activity or direction of the movement "patterns" seem to be the most effective in helping to reduce symptoms. In addition, varying the actual exercises and including activities that promote attention and learning appear to promote the best outcomes. Types of exercises that do this are:

- Walking outside or in a mall
- Dancing
- Yoga
- Tai Chi
- Stepping over obstacles

- Marching to music with big arm swings
- Sports (ping pong, golf, tennis, volleyball)
- Aerobic/ Jazzercise classes

Some exercises have not been proven to challenge the decreasing communication between the nervous system and muscles. These exercises include:

- Riding a stationary bike
- Weight lifting
- Treadmill walking at slow speeds
- Lap swimming



Even if you have had physical or occupational therapy in the home setting in the past, a re-evaluation is helpful to ensure you're achieving the maximum benefit. As your disease progresses, there may be changes in your ability to walk, get in and out of bed, or manage your pain. In addition to potentially modifying your existing program to improve posture, balance, flexibility and strength, the physical and

occupational therapist can evaluate fall risk and address issues that may limit your mobility and confidence when out in the community.

As cost may be an issue for many patient's, it's important to know that physical and occupational therapy may be covered under both your Medicare Part A and Medicare Part B insurance as part of your home healthcare benefits. In addition, you can also utilize your Medicare Part B benefit for outpatient physical therapy and occupational therapy if you do not meet the criteria for home health care services. Finally, you may also be eligible through any number of commercial insurance plans for both in-home and outpatient therapy visits.

In the end, continued focus on maintaining your maximum mobility, both in strength and agility, will not only benefit your physical health but emotional health as well. For additional information regarding the benefits of home physical and occupational therapy, don't hesitate to contact the American Parkinson's Disease Association at 800- 825-2732 or Michelle Spencer of Caring People Home Healthcare Agency at 561-632-3852.

Matthew McDermott, MS RN

Caring People Home Healthcare Agency

Optimism Walk



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Support Group & Exercise Calendar

SOUTH FLORIDA

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Coral Gables	St. Matthews Church, 7410 Sunset Drive	2nd Wednesday	11:00am -12:30pm		
Coral Springs	Coral Springs Medical Office 3100 Coral Hills Drive (Next to hospital)	3rd Monday	2:00pm - 3:30pm	APDA	800-825-2732
Davie	Nova Southeast University Nsu Ziff Health Care Bldg,1st Floor 3200 S. University Dr.	1st and 3rd Wednesday 4th Wednesday Caregiver Group PT Clinic	10:45am - 12noon 1:00pm - 2:00pm	Dr. Blodgett	954-262-5611
Deerfield Beach	Broward Health North 201 E. Sample Road, Neuro Center (Off Lobby)	On Hold		APDA	305-970-0805
Delray Beach	South County Civic Center 16700 Jog Road	1st Wednesday	2:00pm - 4:00pm	APDA	800-825-2732
Jupiter	Jupiter Town Complex Activities Building 201 Military Trail	1st Friday (lunch) 3rd Friday (meeting)	1:00pm - 3:00pm	Rose Kyle	561-744-7666
Miami	Baptist Hospital Professional Bldg. 8950 N Kendall Dr. Suite 105	2nd Friday 3rd Friday	7:00pm - 9:00pm (Eng) 12:00pm - 2:00pm (Span)	Abe or Ivon Bertan	786-683-0240

SOUTH FLORIDA, CON'T

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Miami VAHCS Veterans Only	1201 NW 16th St 7th Fl Pain Clinic Psych Ofc Rm D707	Every Thursday	10:45am	Paul Hartman, PhD	305-575-3215
Palm Beach Gardens	Mandel Jewish Community Center in Partnership with Jupiter Hospital 5221 Hood Road Palm Beach Gardens Florida, 33418	2nd Wednesday	2:00pm - 3:30pm	APDA & Tiffany Jones, Jupiter Medical	800-825-2732
Palm Springs	St Luke's Catholic Church 2892 S. Congress	Saturdays Tai Chi Exercise	11:00am - 12:00pm	Lois M. Guionnaud, LMT	800-825-2732
Port St. Lucie	Harbor Place 3700 S.E. Jennings Road	3rd Tuesday	2:00pm - 3:30pm	Laura	561-209-6124
Royal Palm Beach	Royal Palm Beach Cultural Center 151 Civic Center Way	Monday & Wednesday Support Group & Exercise	10:00am -12:00pm	Bernice Weber	561-798-7798
Stuart	Grace Place Community Church 1550 S.E. Salerno Rd	2nd Monday Support Group & Exercise	1:00pm - 3:30pm	Aileen Stiehle	772-286-3268

EXERCISE ONLY - SOUTH FLORIDA

Boca Raton	Boca Ballet Dance For Pd (Bbt4pd)	Movement Exercise Offered On Two Days	Limited Space Must Register	Cindy Surman Natalie Parker	561-995-0709
Boca Raton	Sugar Sand Field House 300 S. Military Trail	Monday Wednesday	11:30am - 12:30pm 2:00pm - 3:00pm	APDA	800-825-2732
Coral Gables	St. Matthews Church 7410 Sunset Drive	Dance, Yoga, Music		Carol Goldman	305-476-8782
Fort Lauderdale	Mind & Mobility 2655 E Oakland Park Blvd, #5	Tuesday and Thursday Functional Training & Tai Chi	2:00pm	Mateo Martinez	954-630-3131
Greenacres	Temple Beth Tikvah 4500 S. Jog Road	Tuesday & Friday	2:00pm - 3:00pm 10:00am - 11:00am	Must pre-register	800-825-2732
Miami	UHealth Fitness & Wellness Center- University of Miami 1120 NW 14 Street, 9th Floor, Miami, FL 33136	Monday, Tuesday, Wednesday UM Cycling for PD			305-243-7802
Palm Springs	St Luke's Catholic Church 2892 S. Congress (School Library)	Saturday	11:00am - 12:00pm	Must pre-register	800-825-2732

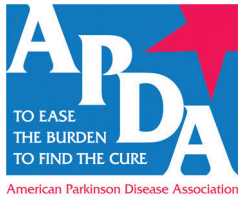
NORTHWEST FLORIDA,

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Tallahassee	St Paul's Methodist Church	4th Saturday / month	10:00am -12:00pm	Janice or Joan	850-364-0230
Pensacola	Community Room, W Fla Rehab Institute 8391 N Davis Highway	2nd Friday / Month	1:00 pm	Kathy Taylor	850-494-3212

NORTH FLORIDA,

CITY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Jacksonville	Shands/Jax 580 W 8 Street, Tower 1, 2nd Floor	2nd Wednesday / month	11:30am - 1:30pm	Karen Perin	904-244-9719

Deland • Orange City • St. Augustine • Jacksonville - Young Onset
For information on the groups in these cities contact APDA South Florida, 800-825-2732



American Parkinson Disease Association

700 West Hillsboro Blvd, Building 3,
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Deerfield Beach, Florida 33441

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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.