Feature Story:
Finding Your Inner Tai Chi

Posture, Poles and PD

Summer Ice Cream Socials

Photo: Michael Harmon
Dear Friends of Hope Parkinson Program

Here in Southwest Florida our population may ebb and flow like the tide, but our sense of community always remains strong. Whether we live here for a month or year-round, we share a common bond. We enjoy and appreciate the incredible quality of life that Southwest Florida provides.

It’s no wonder everyone is happy here! We have incredible weather, sparkling ocean water, great shopping and dining. And Southwest Florida provides wonderful health care options, specialty medical services and – exceptional resources like our Hope Parkinson Program something special most of our participants don’t have at home.

One of our seasonal Parkinson Program participants recently shared with me that she delayed her trip back to her northern home by a month because she wanted to complete her tai chi workshop. Another participant expressed how much she would miss her support group while she was away for the summer months. And one gentleman requested “homework” from his movement class coach so he wouldn’t fall behind while he was away.

To our seasonal participants, we are happy that you have a residence in Southwest Florida, but we’re happier still that you call our program home. Hurry back!

To those of you who will be with us all summer long, we are not slowing down. We have many activities planned including a new pole walking class and a photography contest! Just choose something you like and join us!

Warm regards,

Samira K. Beckwith
President and CEO
Hope HealthCare Services

Dear Friends of Hope Parkinson Program

Parkinson’s disease and Dystonia:
Dr. Amanda Avila

As we age, aches and pains can become a familiar part of everyday living. However, Parkinson’s disease patients can experience pain beyond normal aging. Many times, the pain is related to dystonia.

Dystonia is a painful, cramping or twisting movement involving one or more parts of the body. It can be both an early manifestation of PD, or it can arrive later after the disease has progressed. Common places for dystonia include the head and neck (more frequently called cervical dystonia), hands (writer’s cramp) and feet (toe curling). Early onset Parkinson’s disease patients frequently experience a painful, inward deviation of one foot when walking as one of the first symptoms of their disease.

Dystonia’s exact cause is unknown, but we believe that it develops when incorrect signals are sent from a part of the brain called the basal ganglia. This area is abnormal in Parkinson’s disease and Parkinsonism as well.

Research has suggested that up to 40% of people with PD will experience dystonia. In patients who have atypical Parkinsonisms like PSP, CBD or MSA, rates can be even higher.

There are many effective treatments for dystonia, including some Parkinson’s disease medications like levodopa or trihexyphenidyl. Since PD patients frequently experience dystonia when their medications are wearing off and their dopamine levels are low, many times the most effective treatment is to re-dose in the usual manner. Some patients need to dose more frequently during the day because their dystonia will reoccur. For dystonias involving the legs or neck, botulinum toxin injections can help ease muscle cramping and provide pain relief when medications are ineffective. Finally, deep brain stimulation is effective at suppressing dystonia and does not require taking any additional medication.

Amanda Avila, MD
Hope Parkinson Program Medical Director
Movement Disorder Specialist, Florida Neurology Group
Ask a PD Expert: Kathrynne Holden, MS, RD

How important is keeping hydrated if you have Parkinson’s Disease?

If I had to pick just one nutrition-related topic of greatest importance for those with PD, what would it be? Protein and levodopa? Constipation? Timing medications and meals? No – none of these. The topic would be water. Plain water.

Dehydration is unfortunately all too common in PD. Lack of thirst, fear of not making it to the bathroom in time, and taking medications with just a sip of water instead of a glassful can all contribute to dehydration. Even a slight imbalance in hydration can make all the difference to your health.

Dehydration can cause confusion, mental changes, balance problems and falling. In more extreme cases, dehydration can cause urinary tract and bladder infections, kidney failure and heat stroke. Because some of the symptoms of dehydration mimic PD symptoms, caregivers often assume PD is advancing and assume there is nothing that can be done. The situation often goes untended until the person is hospitalized and given IV solutions, antibiotics or other treatment.

I believe that staying hydrated is the single most important thing people with PD can do to maintain good health. Particularly in the hot weather of summer, when we lose more fluids through perspiration, it is even more important to stay well hydrated. To include more fluids in your day:

1. Drink a full 8-ounce glass of water each time you take medications, plus enough extra glasses between meals for a total of 6 to 8 glasses daily.

2. Make fruit-flavored water. Slice strawberries, kiwi, oranges or other fruit and place it in a two-quart pitcher of water overnight. In the morning, squeeze the fruits, letting the juices return to the pitcher. The fruit will flavor the water naturally, making it more interesting and acceptable, while also adding vitamins and minerals. No sweetener is needed! You can also add mint leaves for extra flavor.

3. Include juicy fruits with high water content, such as melons, tomatoes and oranges, in your daily diet.

4. Consider some of the chilled soups, such as gazpacho, since they also contribute fluid.

Finally, for those who have had urinary tract infections, drink a large glass (8-10 ounces) of cranberry juice daily or eat ½ cup blueberries to prevent further infections. Cranberry extract pills are also helpful.

Kathrynne Holden, MS, Moderator of the National Parkinson Foundation Forum
“Ask About Nutrition,” and author of “Eat Well, Stay Well with Parkinson's Disease,” and “Cook Well, Stay Well with Parkinson’s Disease.”
ON THE MOVE

New Workshop!
3-P: Posture, Poles & PD
July 27 – Aug. 31

Pole walking turns a regular walk into a whole body workout. Using special rubber-tipped poles outfitted with wrist straps, you will exercise your arms, shoulders, chest and back muscles as you walk.

This six-week workshop with instructor Lindy Smith will incorporate a gentle warm-up with special attention to posture, seated exercises for flexibility, standing challenges and breathing awareness. The ultimate goal after six classes is for those living with PD to be more confident and aware of how moving with a purpose can enhance life.

Pole walking has many benefits, including
- Whole-body large amplitude muscle activation to overcome bradykinesia
- Longer stride length and faster walking speed
- Better coordination through improved gait symmetry
- Provides tools for stretching
- Reduces fear of falling and pain especially for people with knee, hip or back pain
- Increases muscle strength and tone and feeling of control
- Improves balance and helps in overcoming gait problems
- Improves mood / decreases depression
- Social and recreational opportunity
- Sense of accomplishment

Due to limited class size, participants are limited to those with PD or Parkinsonism diagnosis only. One care partner per participant may attend for support. No special equipment needed. Loaner poles will be provided courtesy of LEKI.

The program is $20 per person, and registration is required by July 20. Please call 239-985-7727 or email Michelle.Martin@HopeHCS.org.

Hope Cape Community Room
2430 Diplomat Pkwy. E, Cape Coral
Mondays • 1 p.m.

Lindy is an AFAA Certified Group Exercise Instructor with continuing education credits in PD and AFAA Golden Hearts Senior Fitness. Prior to starting her own business, for 8 years she was the marketing manager for the pole company, LEKI USA, and received training from expert European Nordic Walking coaches.
Tai Chi Open Practice Classes Resume

A graceful form of exercise, tai chi is an ancient Chinese tradition that uses a series of simple, continuous, rhythmic and functional movements performed in a slow, focused manner accompanied by deep breathing.

Have you been interested but never tried tai chi before? Did you attend the popular 12-week “Tai Chi For Better Balance” workshop this past spring? Open practice classes are great for anyone who would like to improve balance and gait through regular tai chi practice.

Weekly hour-long afternoon classes will be offered on

- **Mondays at 3 p.m.**
  Hope Cape Community Room
- **Wednesdays at 2:30 p.m.**
  Hope HealthPark

*Everyone is welcome!*

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**Q: What is neuropsychology?**

**A:** Neuropsychology measures the output of the brain, which is a particular set of brain behaviors (or symptoms) to determine the current level of function (or dysfunction) and the strength and weaknesses of various regions and networks in the brain. During the past decades, neuropsychological testing has become a very sophisticated science. The United States Congress declared the 1990s the “decade of the brain.” This explosion of brain science and government support has resulted in tests that are highly accurate, standardized instruments with predictive accuracy in the 80-95% range. These tests have been validated through clinical trials that adhere to stringent, objective standards. Neuropsychological tests provide quantifiable results that indicate the amount of deviation from baseline norms. The latest (5th) edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) recognizes the valuable role of neuropsychology in the assessment of cognitive disorder. The DSM-5 cites neuropsychological assessment as an objective manner in which to assess dementia.

**Dr. Mabel Lopez**  
Neuropsychologist, Licensed Psychologist, PY 7375  
Mind and Brain Care: [www.MaBC.com](http://www.MaBC.com)  
239-768-6500
Michael and Carolyn Harmon happily retired from Kentucky to Lehigh Acres in 2010, eager to begin enjoying a Southwest Florida lifestyle. Retirement agreed with them; the couple spent their days relaxing and reveling in the balmy weather. Things changed when only two years later, Michael was diagnosed with Parkinson’s disease.

Determined to find help for her husband, Carolyn set out to learn everything she could about the movement disorder. Since they were still new to the area, the Harmons were unfamiliar with programs available to help individuals with Parkinson’s disease and their care partners.

In 2013, just as the couple was getting accustomed to the changes related to the disorder, an aneurysm, surgery and stroke left Michael, who is 75, unable to walk. He had to be lifted by others to get out of bed or to rise from a chair. Enjoying his favorite hobbies, such as photography and cooking, became an impossibility.

“I was almost useless!” he said.

“I was reaching out for information on how to help Michael,” Carolyn said. “I found the Hope Parkinson Program, and it quickly became our main source of information about how to cope with PD.”

Through Hope’s educational events and by interacting with health care professionals, therapists and individuals living well with Parkinson’s disease – the Harmons learned about improved therapies, and efforts to find a cure for the disorder.

They were impressed with Hope’s ability to provide speakers from groups such as The Michael J. Fox Foundation for Parkinson’s Research and the University of Florida Movement Disorders Center. This is how they accepted the invitation to participate in PD research trials.

Carolyn also discovered an important way to be involved in the lives of others who have Parkinson’s disease: She now teaches the twice-a-week “Tai Chi for Better Balance” classes at the Hope HealthPark Campus. In addition to calming the mind, improving fluidity of motion and being fun, the class helps individuals reduce their risk of falls.

“If you have Parkinson’s, I think that one of the main things you can do to help yourself is to keep moving, learn what you can about fall prevention, and maintain your flexibility,” Carolyn said.

The opportunity for Carolyn to volunteer teach the tai chi classes presented itself after the couple took the class together and saw a boost in Michael’s balance.

When Carolyn learned about a workshop for potential instructors in fall 2014, she was concerned about leaving Michael home alone, since he was still unstable on his feet.

“Michael and I talked it over, and he really encouraged me,” Carolyn said. “He told me, ‘You like this! Go for it!’”

Carolyn’s classes, provided free of charge, have had as many as 20 participants. Her volunteer activity has caused the couple to practice tai chi more often – up to five days a week.

“Often, when people come into a class, their body is changing and they’re fearful of losing balance and falling,” Carolyn said. “‘They sort of withdraw and slink away. To me, the whole thing is about understanding your illness and gaining confidence, being able to live in society and not being afraid to get out and do things.”

Through the movements of tai chi, Michael has reduced his shuffling and improved his finger flexibility, a development praised by his movement disorder
specialist, Dr. Amanda Avila. His stamina and balance have been boosted, as well. Michael, who previously ran a deli, has even returned to the kitchen, where he enjoys baking cakes and making dishes such as chili and spaghetti.

“It's just been a gradual process of getting better,” he said. “I would lose my balance in the kitchen, but now it's not a problem. I still have so many things that I like to do. I'm just getting better at it!”

Carolyn, 63, is encouraged by how the Hope Parkinson Program's movement classes, educational events, creative and social activities have motivated Michael and other individuals with the disorder.

“You can't let this disease take you down, and that's why the Hope Parkinson Program is there for you,” Carolyn said.

Resources for Parkinson's Disease
Contact the following organizations for more details and current programming schedules.

**Area Agency on Aging for Southwest Florida**
State-designated disability resource center
Medicare and Medicaid counseling, emergency electricity assistance, adult daycare, home delivered meals, homemaker assistance, legal assistance, and access to health and wellness programs. 866-413-5337
www.aaaswfl.org

**Bonita Springs YMCA's Pedaling for Parkinson's**
Marla Ramsey, 239-221-7560

**Charlotte Regional PD Exercise Classes**
733 East Olympia Ave.
Punta Gorda, FL 33950
Jim Norton, 941-637-2450

**Dubin Resource Center Dementia Safety Program**
Dementia caregiver education and support groups, 239-437-3007;
www.alzheimersswfl.org

**Laughter Yoga**
Fort Myers Beach
Meg, 614-216-9371;
coolabah123xyz@gmail.com

**Lee County Parks and Recreation Community Pools**
San Carlos, Lehigh Acres,
N. Ft. Myers,
Pine Island, 239-533-7275

**Lehigh Senior Citizens Center**
219 Plaza Dr., Lehigh Acres, FL
Weekly Tai Chi Balance Classes
239-369-5355
seniorcentermgr@comcast.net

**Lee Physician Group Memory Care**
"Powerful Tools for Caregivers" is an educational program designed to help family caregivers take care of themselves while caring for a friend or relative.
Allie Henderson, 239-343-9224

**LMHS Chronic Disease Self-Management Workshop**
"It's All About You," 239-424-3122

**LMHS PD Rehab Clinics & Balance Screening**
Lee Center for Rehabilitation and Wellness
2070 Carroll Rd., Suite A, Ft. Myers
Outpatient Rehab at City Center, Ft. Myers
Register with Nathalie Grondin, PT,
239-418-2023

**LMHS Share Club**
SHARE-Club@LeeMemorial.org
Senior health & wellness program serving residents of Southwest Florida age 50 and older; 239-424-3765

**Punta Gorda Monthly Support Groups**
Punta Gorda Isles Civic Association
Room #4
2001 Shreve Street, Punta Gorda, FL 33950
Usually meet on 4th Friday of the month
10:30 - 11:30 a.m.
Kelly Gaylord, 941-637-6418;
www.PDCareGiverSupport.org

**Whole Body View Movement and Balance Class**
Dan McGovern, 239-634-6656;
dan@wholebodyview.com

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**National Resources**

**NPF National Parkinson Foundation**
PD Help Line; Patient Education Booklets; Aware In Care Kits;
"Ask the Doctor Forum"
www.parkinson.org
800-473-4636

**MJ Fox Foundation**
PD Research Opportunities
www.michaeljfoxfoundation.org

**UF Center for Movement Disorders**
3450 Hull Rd., Gainesville,
32607
www.movementdisorders.uhealth.org
352-265-8408

**Davis Phinney Foundation**
www.davisphinneyfoundation.org

**PDF Parkinson Disease Foundation**
www.pdf.org
Hope Parkinson’s Program members kept busy this Spring at events and gatherings including the Community Education Event “Managing Speech and Swallowing Problems,” the Tai Chi for Better Balance Workshop, and the PD Ladies’ Support Group.
PD Expert Tips-Speech & Swallowing

Drooling and Parkinson's: Take Control

Patients often report sialorrhea, or drooling, as one of the most bothersome Parkinson's symptoms. Why does it happen, and what can we do about it?

Saliva and Swallowing
Saliva is the necessary lubricant that holds our food together and helps to transport it efficiently without particles getting misdirected or sticking in our throat. Some of the early swallowing research reported that saliva is a weak stimulus, or messenger, for the sensory receptors that carry the message to the brain stem swallowing centers, and which in turn triggers the instruction to swallow. Hence, if the sensory-motor system that governs swallowing is beginning to work less efficiently, drooling and other swallowing issues might be one of the consequences. The problem may be not too much saliva, but reduced swallowing frequency. Swallowing can become another one of those automatic systems that is being affected by Parkinson's with a shift to “manual control.” Drooling, like falling, can be a symptom representing the advancement of Parkinson's, and may also be a predictor of more serious swallowing problems in the future.

Medical Treatments
There are a few medical treatments available to reduce profuse and embarrassing saliva production. Botox injections are recommended by some physicians, but it is important to remember that it will wear off in about 3-4 months. You will need to repeat the Botox injections throughout the year. Neurologists may suggest atropine drops. Atropine is from a category of drugs called “anticholinergics” that have a side effect of drying secretions. There are mixed reviews regarding the use of atropine drops for sialorrhea, and other side effects – including hallucinations – have been reported. While treatments like Botox and atropine might provide some cosmetic improvement, keep in mind that too little saliva can also create problems.

30-Day Drool Less Challenge
If you have become concerned about excess saliva, why not take a 30-day challenge and try some suggestions below? I recommend 30 days because a lesser commitment will simply not be long enough to judge the effect or create a better habit. If you belong to a support group, you might want to challenge other members to join you!

1. Remember that sitting or standing up straight and closing your lips is one of the first things you can do to manage your saliva.

2. Try chewing some gum for 15 minute sessions several times a day. I recommend bubble gum. (Bazooka is my favorite, but denture wearers can try Freedent gum.) Really work the gum in your mouth. Use your tongue to move it from side to side, up against the roof of your mouth, and push with your tongue against the resistance of the gum to blow bubbles.

3. Apply a flavored, sticky lip gloss regularly and use as a sensory cue to keep your lips closed. Press your lips together and feel the stickiness. Swallow your saliva and notice the improved pressure when lips are closed.

4. Tart and sour flavors are good messengers. Make your own mixture of concentrated lemon juice and water and put in a small spray bottle. Keep it with you in your pocket or purse and spritz frequently to activate a swallow of saliva.

5. Finally, using a rolled up, soggy handkerchief or tissue to wipe your saliva is a bit “yucky.” Instead, try a terry cloth wrist band like tennis players use. It’s a handy way to “mop up” drool and it can easily be thrown in the wash.

Mary Spremulli, MA, CCC-SLP
Blogger, owner Voice Aerobics
http://www.voiceaerobicsdvd.com
MEET HOPE: Hope PACE®

Southwest Florida’s older residents have access to services to help them stay healthy, active and socially connected – and remain in their own homes rather than requiring nursing home care – through Hope HealthCare Services Hope PACE program.

Designed to meet the needs of seniors while also helping their families and caregivers, PACE (Program of All-Inclusive Care for the Elderly) provides comprehensive, coordinated health care services, dental services, therapies, transportation and meals for those who would otherwise qualify for placement in a nursing home.

Through PACE, opportunities for socialization and care are available both at the PACE Care Centers and in the individual’s home. In addition to meeting health care needs, PACE offers help with personal care and light housekeeping.

For those 55 and older, the program provides participants with all health care services, including primary and specialized medical care, as well as:
• medications; medical supplies and equipment
• lab and diagnostic services
• occupational, speech and physical therapy
• all necessary prescription drugs
• home care and personal care aides
• hospitalization, skilled nursing facility care and end-of-life care

To qualify, participants must have a health care diagnosis that qualifies them for nursing home care, live in Lee, Collier or Charlotte counties, and agree to allow the professionals at Hope HealthCare Services to manage their medical care. There is no fee for those with Medicaid; those with Medicare or other insurance can request a cost estimate.

Hope PACE Care Centers are located in Fort Myers, Lehigh Acres, Naples, Port Charlotte, and the newly opened Cape Coral location. For more information about the Hope PACE program visit www.hopepace.org or call 855-454-3102.

“The challenges of aging or coping with chronic illness can make it difficult to stay at home. PACE helps bring all health care services together to ensure individuals are getting the attention they need to remain healthy and independent. For working adults with parents who need care and attention, the PACE program provides peace of mind that their loved ones are being cared for in a safe and supportive environment that meets their physical, emotional and social needs.”

Samira K. Beckwith, president and CEO of Hope HealthCare Services and the founding president of the Florida PACE Association
Hope Parkinson’s Program Participants’
Summer Photo Contest

This summer, show us the world through your eyes as you travel to exciting new destinations, visit family and old friends back in your hometown, or explore all the beauty in your own backyard right here in Southwest Florida.

Take pictures of landscapes, animals, plants, people – anything that makes you feel happy or thankful – and share your very best image in the Hope Parkinson Program Summer Photo Contest. The winning photograph will be featured on the cover of the fall Hope Parkinson Program Newsletter.

Please keep the newsletter format in mind and take a vertical photo that has some empty space on the top to accommodate the newsletter title. Send your digital image to Michelle. Martin@HopeHCS.org with subject line “Photo Contest Submission” and include your name and phone number.

When sending your image, keep file size as large as possible and select “keep original size.” Submission deadline is Friday, August 14. One submission per Hope Parkinson Program participant, please.

Hope Parkinson Program Calendar Details

All events require pre-registration. Please call 239-985-7727 or email Michelle.Martin@hopehcs.org. The latest programming information can be found at Hopeparkinson.org

Event Locations:

CAPE CORAL
Cape Coral Wellness Center: 609 SE 13th Court, 33990
HOPE Cape Community Rm.: 2430 Diplomat Parkway E., 33909

FORT MYERS
Cypress Cove “Edison Room”: 10500 Cypress Cove Drive, 33908
Brookdale Cypress Lake: 7460 Lake Breeze Drive, 33907
FUMC-Faith United Methodist Church: 15690 McGregor Blvd., 33908
Hope HealthPark Community Rooms: 9470 HealthPark Circle, 33908
Shell Point Retirement Community Village Church: 15100 Shell Pt. Blvd., 33908

LEHIGH ACRES
Hope Lehigh: 1201 Wings Way, 33936

LABELLE
Hope Connections: 475 East Cowboy Way, 33935

NORTH FORT MYERS
Recreation Center: 2000 North Recreation Park Way, 33903
(Facility card required; $10 lifetime membership)

Schedules are subject to change.
Join the Hope Parkinson Program

There is no cost to register and becoming a participant is simple. Visit HopeParkinson.org/Join and follow the easy-to-understand instructions. Registration by phone is also available at 239-985-7727.

Ways to Give Back

SPREAD THE WORD: Share this newsletter with friends, relatives, coworkers and neighbors.

VISIT OUR RESALE STORES: Donate or shop at Hope Chest, North Fort Myers, 239-652-1114 and Hope Chest at the Crossings, Bonita Springs, 239-444-1100.

VOLUNTEER: Lead an exercise class or help with office work.

DONATE: Send a check to 9470 HealthPark Circle, Fort Myers, FL 33908 Or make a secure online donation at www.hopehcs.org
*Special Note: When donating online please indicate Parkinson Program in the comments field.

ORGANIZE: Design your own event to benefit our program. Call us at 239-985-7727 for details.

Sometimes love needs a helping hand.

They’re relying on you. And you may need some help. At Hope, we understand you have many roles in your family – and that few are as important as your role of caregiver. We can support all you do with our comforting care – coordinating medical needs, explaining options and providing emotional guidance for you and your loved ones. Together, we can make each day the best possible. Let Hope be there for you.

HopeParkinson.org

The Hope Parkinson Program is provided by Hope HealthCare Services, a not-for-profit, 501(c)(3)-status community-based agency.