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American Parkinson
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Information & Referral
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This newsletter is in-
tended solely to provide
you with information on
Parkinson's disease. You
should not make any
changes to treatment
without first discussing
them with your healthcare
provider.

Coordinator's Notes

Cathi A. Thomas RN, MS

Summer has arrived, and not only is this an ideal time to begin planning for the fall, it is an opportunity to take a breath and reflect on all that we have accomplished during this past year.

This spring we held the second annual Healthcare Professional Training Program for physical therapists, occupational therapists, nurses, and speech and language pathologists who provide care to individuals with Parkinson's disease and their families. This 2.5 day program was developed by Terry Ellis, PhD, PT and Tammy Rork, MS, PT of the Center of Neurorehabilitation; Marie Saint-Hilaire, MD, and myself from the Boston University Parkinson's Disease and Movement Disorder Center; and Donna Diaz RN, MS, APDA Connecticut Coordinator. Seventy-five participants received information on the most current, evidence-based, innovative rehabilitation treatments available. Additional faculty included Samuel Frank, MD, Anna Hohler, MD, Leslie Fawcett Vickers, RN, MS, Elizabeth Hoover, CCC-SLP, Sue Berger, MS, OTR/L, Nancy Broderick, MS, OTR/L and Stacey Zawacki, MS, RD. Additional presentations were provided by a panel of individuals with PD and family members who graciously shared their personal experiences of living with PD. This program would not have happened without the extraordinary planning of Tami Rork and BU students in the Physical Therapy program.



May 1st visit to MA State House.

I would like to personally thank the American Parkinson Disease Association and Teva Neuroscience for their generous support of this conference. In addition, five participants received scholarships from a gift provided by Dr Ernest and Rae Selig to support the education of individuals caring for patients and families. Specialized training was also made available on how to conduct PD Community Wellness Programs. These Wellness Programs evolved from research which has supported the benefit of exercise and self-management

Letter from the Chapter President

Keith J. Ciccone

Dear Friend,

As your Chapter President, I am honored to share the progress we have made in 2008. This past spring was especially busy, including opportunities to raise awareness and fundraisers to support research and programs throughout Massachusetts. I would like to take this time to express my sincere appreciation to our wonderful Chapter Board members. These individuals volunteer tirelessly throughout the year to provide ongoing support to the Parkinson community in Massachusetts.

This spring the Chapter joined Valeant Pharmaceuticals and Boston University Sargent College in welcoming Loni Ali and Kapil Sethi, MD, FRCP for a presentation entitled "The Role of the Care Partner in the Successful Treatment of Parkinson's Disease." Loni Ali is the wife and primary care partner to Muhammad Ali and Dr. Sethi is a Professor of Neurology and the Director of the Movement Disorders Program at the Medical College of Georgia. Dr. Sethi provided an informative presentation on the latest information in PD and Mrs. Ali inspired us with her personal experience of caring for a family member with Parkinson's. To watch a video of this presentation, visit www.bu.edu/today/buniverse.

On April 6, 2008, the MA Chapter held the 2nd annual fundraiser at the Coriander Bistro in Sharon, MA. Award-winning chef/owner Kevin Crawley demonstrated his culinary skills in his interpretation of modern French cuisine and a delicious dinner was served. A silent auction was enjoyed by all. A special thanks to Jill Crawley and all who participated in this event.

As always, there are countless individuals, organizations, and communities that donate their time and funds to the MA Chapter. Some individuals have organized their own fundraisers in support of the Chapter, including parties, marathons, and golf tournaments. For example, thanks to the organization and support of Meg McAuliffe, the 9th Annual South Boston Pub Crawl took place this past fall. This event continues to demonstrate what can happen when people get together and decide to work towards a common goal of helping others. This

fundraiser alone was a stupendous success raising over \$2,370! If you are interested in becoming involved with the MA Chapter of the APDA, please contact me at (617) 638-8466 or email information@apdama.org. The board meets every other month, and there are several committees that need your help.



Keith Ciccone joins Senator Cynthia Stone Creem, board member Kim Creem, and Carole Slabin, recognizing April as Parkinson's Disease Awareness Month. Keith received a proclamation signed by Governor Deval Patrick.



Left: Loni Ali joins APDA I & R Center and MA Chapter staff along with faculty from Boston University Sargent College.

Coordinator's notes continued:

strategies in individuals with PD. To date, thirty Community Wellness Programs have been implemented in the New England area. The next course is scheduled for March of 2009. If you are interested in participating, please let us know.

On May 1, 2008 board members of the APDA MA Chapter and staff of the APDA Information & Referral Center at Boston University Medical Center joined the National Multiple Sclerosis Society and Adult Onset Disability Alliance for an Action Day at the Massachusetts State House. This day long event provided an opportunity to meet with state legislators and share the issues and concerns experienced by the many Massachusetts residents affected by Parkinson's disease. We also had an opportunity to meet with members of other statewide organizations. A great deal can be accomplished in greater numbers.



2008 Winchester Symposium program committee

Our Annual Winchester Symposium was held on Thursday, June 5th at the Jenks Senior Center. Over 100 individuals and families gathered to ask Parkinson Specialists Dr Anna Hohler, Terry Ellis, PhD, PT, and Elizabeth Hoover CCC-SLP questions about the latest advances in treatment. We were especially pleased with the opportunity to see Alan Tarin, founder of the Winchester Support Group. Alan traveled from New York to attend the symposium and meet with friends.

Please take time to review this newsletter so that you know what support is available to you. I invite each of you to contribute news, ideas, and suggestions for future reports as well as our website, www.apdama.org. Have a great summer!



Healthcare professionals participate in the second annual PD Training Program held at Boston University.

A Medication Update

US FDA approves Requip® XL™, the first and only oral once-daily non-ergot dopamine agonist for Parkinson's disease. The product will be available mid-July, 2008. For additional information, visit GlaxoSmith-Kline's website at www.gsk.com.

APDA Massachusetts Chapter 22nd Annual Walk-A-Thon



Sunday, June 8, 2008 was hot and humid, but this stopped no one. Over 1,000 individuals participated in this year's Massachusetts Chapter APDA Walk-A-Thon. The walk was held at the beautiful facility of

Reebok International Headquarters in Canton, Massachusetts. Chapter President Keith Ciccone served as this year's walk chairperson. Special thanks to Keith for an outstanding job. This year's event included over 65 teams, many vendors with information and goodies, and Matt Siegel, the number one DJ from Kiss 108, as our Master of Ceremonies.

We had the opportunity to honor two very special people in the Parkinson Community. Mr. Howard Porter of Stoneham received the APDA Massachusetts Volunteer of the Year Award. Leslie Fawcett Vickers, RN, MS of Hingham received the APDA Massachusetts Healthcare Professional 2008 recognition of service to the Parkinson Community. Leslie is the Director of Bayada Home Care Nursing. She has worked closely with individuals and families affected by Parkinson's for most of her professional career and has been instrumental in developing Parkinson's disease home care programs. Congratulations and thank you to Howard and Leslie.

The final numbers are not in, but to date the Massachusetts Chapter has collected over 100,000 dollars. This money will be used for research projects that have been submitted to the American Parkinson Disease Association and carefully reviewed by the APDA Scientific Medical Advisory Board.

A walk of this magnitude could not be accomplished without the dedication and commitment of many individuals from our Parkinson community. This all volunteer group portrays the extraordinary human spirit of caring that exists throughout our state. Our walk committee has worked non-stop for the past eleven months. As we close this year's event we are already looking forward to next June and look forward to seeing you there.

Special thanks to our walk committee, volunteers, team captains, team participants, walkers, sponsors, vendors, and gifts in kind from our community!

Walk Committee

Keith Ciccone	Wendy Green
Laura Bridges	Anne Marie Gregg
Debbie Case	Beth Hagan
Kimberly Creem	Steve Hart
Melissa Diggin	Lauren James
Wendy Green	Ray James
Rosalyn Nascimento	Marie Knasis
Kristen Stapleton	Volodymyr Lyczmanenko
Cathi Thomas	Kevin Maguire
Denyse Turpin	Jean Mathis
	Cheri Milano
	Rick Mirkin

Walk Volunteers

Marc Beneck	Kathy Mulhall
Julia Beneck	Judith Murray
Laura Bridges	Rosalyn Nascimento
Joel Brown	Laurie Pant
Janet Brown	Elaine Proulx
Kurt Brown	Paul Proulx
Boston University Physical Therapy Students	Tami Rork
Norma Butter & Family	Mary-Elizabeth Russell
Debbie Case	The Shore Family
Keith Ciccone	Gerald Slabin
Mike Cleary	Andrew Slabin
The Corduck Family	Alex Stapleton
Elise Cohen	Billy Stapleton
Laurel Cohen	Kristen Stapleton
Mark Cohen	Taylor Stapleton
Gary Creem	Cathi, Erin, & Liz Thomas
Kimberly Creem	Mike Travis
Melissa Diggin	Tan Truong
Diane Durkee	Laurie Jo Tullis
Sid Durkee	Colleen Turpin
Terry Ellis	Danielle Turpin
Tim Ferry	Denyse Turpin
Nancy Fine	Julianne Turpin
Abbey Green	Jeanne Vatour
Michael Green	Ryan Vickers
Robbie Green	Molly Velazquez-Brown
	Alex Yen

Again, another very special thank you to #1 DJ Matt Siegel from KISS 108 for his continued support each year!



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Greater Medford VNA
Honest Tea
New England Sinai Hospital
Novartis Pharmaceuticals
Porter Art Group Stoneham
Teva Neuroscience
Valeant Pharmaceuticals
Vernalis

Teams

Arnie's Family
BU Neurology
Butch's Brigade
Canton Lion's Club
Carole's Crusaders
Charlie's Crew
DCMARCH
DOPA SCHMOPA
Ed's Striders
Fletcher Family & Friends
Grammies Hope
Granddad's Girls
Grandpa's Gang
Hamel Ten Pins
Hank and Erin
Jack's Pack

Jiggs' Team
Jim Cronin Team
MAB Community Services
Marti's Marchers
Team Mooradian
NSCC Nursing
Papa Flash
Papa's Posse
Papa's Progeny
Patsy's Posse
PD Young Onset Support Group
PJ's Pacers
Polonia Fights Parkinson's
Rich's Team
Robbins Team
Sheldon's Squad
Sheri's Angels
Silver Streaks
Skip the Walk... Grab a Beer!
Team Bob
Team Guzikowski
Team Herb
Team Jeff
Team Jerry
Team Morris
Team Pelletier
Team Sinai
Team Spirit
Team Stoller
Team Timilty
Team Traweek
The Bankuti Bunch & Friends
The Lennon Sisters
The Simpsons

The Two Steps
Vinny's Voyagers
Weiss Walkers

Gifts In Kind

Alfredo Aiello's Italian Foods
All A Girl Needs 2
Bernie & Phyl's Furniture
BJ's Wholesale Club
of Danvers & Natick
Boston Beer Company
Classic Faces
Cathi Thomas, Keith Ciccone, & Deyse Turpin
Kevin Egan
Museum of Fine Arts, Boston
National Amusement/ Showcase
Cinemas
Papa Gino's
The Playwrite Restaurant & Bar
Roger's Jewellery Store
Salem Wholesalers
Shiseido
The 99 Restaurant
Treasures 4 U
Zoo New England

Please let us know if we did not include your name or organization. Thank you.



Update on Research

Marie Saint-Hilaire, MD, FRCPC

Associate Professor of Neurology, Boston University Medical Center
Medical Director of the Parkinson's Disease and Movement Disorders Center and
the APDA Center for Advanced Research at Boston University Medical Center



Early Detection in Parkinson's Disease

We still do not know what causes Parkinson's Disease (PD) other than rare forms of genetic PD. However, studies have shown that first degree relatives (parents, siblings, children) have a slight increase in their risk of developing PD. First degree relatives may share many of the same genes and risk factors for PD as the patient. By studying relatives of PD patients, we will have a greater chance of identifying these risk factors.

The PARS study ongoing at Boston University Medical Center seeks to determine if specific tests are available to predict who is at risk for developing PD. The ultimate goal of the study is to develop effective screening measures for PD to allow for earlier intervention and management. Many PD patients experience loss of their sense of smell, sometimes years before the onset of the classic motor symptoms. By using smell testing, in combination with other tests, the PARS Study hopes to develop a system to detect PD before it progresses to motor impairment.

This study was developed by researchers at the Institute of Neurodegenerative Disorders in New Haven, CT. As of March, 2008, sixteen centers from around the country are participating in this innovative study. Dr Danna Jennings of IND is the Principal Investigator and Dr. Samuel Frank is the Site Principal Investigator at Boston University Medical Center.

Parkinson's Associated Risk Factor Study (PARS)

IRB # H-26493.

You may be eligible to join if

- * You have a first-degree relative (mother, father, sibling, or child) diagnosed with Parkinson's disease**
- * Your age is 50 years or older**
- * You have not been diagnosed with Parkinson's disease yourself**
- * You have no history of nasal trauma or surgery involving your nose or sinuses. If you are interested in participating, please contact us at**

Visual Difficulties in Parkinson's Disease

John W. Gittinger, Jr., M.D.

Patients with Parkinson's disease often complain of difficulties with vision. They may have blurred vision or double vision or may be affected by dry eyes. Many vision complaints are related to Parkinson's disease, although some may be related to problems with the eye itself.

Because Parkinson's disease decreases the frequency of blinking, eyes may dry out. Also, some of the medications used to treat Parkinson's disease also decrease tears and may therefore dry out the eyes. Drying of the eyes may cause the cornea to become irregular, which decreases vision and makes the eyes more sensitive to light. Ironically, a dry eye may cause an increase in tearing because the tear glands secrete in response to irritation.

Parkinson's patients may use artificial tears to allow the eye to heal and thus improve symptoms. Preservative-free artificial tears are ideal because they can be used more frequently.

Parkinson's patients may develop double vision because their ability to coordinate the movements of their eyes is impaired. The double images are often side-by-side. It happens more with reading or close vision. This can progress with time as it is related to decreasing dopamine levels in the brain. The first line of treatment is to optimize medical management. Some patients experience double vision at particular times of the day related to when they take their anti-Parkinson drugs. Increasing medications and adjusting medication times may improve this symptom. Closing one eye when double vision occurs may be the best way to manage infrequent double vision.

If the double vision is constant, then reading glasses incorporating prisms sometimes help. Prisms bend light and bring objects into focus on the same part of the retina in the two eyes. Plastic press-on prisms, called Fresnel prisms can be attached to glasses (like a

sticker) and easily changed or removed without having to make a whole new pair of glasses. Advanced cases may be improved with an eye patch or surgical repair.

Individuals with some forms of Parkinson's disease or a diagnosis of progressive supranuclear palsy may have difficulty accomplishing rapid eye movements for reading. A simple step that often improves the ability to read is to give up bifocals and have a separate pair of reading and distance glasses.

Parkinson's patients also develop other problems with their eyes related to the natural aging process. Glaucoma, cataract, and macular degeneration are three frequent problems. Parkinson's patients over the age of 50 should have a yearly eye examination.

Correcting vision problems can improve an individual's ability to participate in activities like reading or watching a show and may significantly improve a person's walking and balance abilities.

Dr Gittinger is a Professor of Ophthalmology at Boston University School of Medicine and a Neuro-ophthalmologist at Boston Medical Center.



Library of Congress-National Library Services "Talking Book Program"

This program administers services including the loan of audio equipment, books, and materials at no cost to individuals with visual disturbances.

Call 1-888-657-7323 or visit www.loc.gov/nls for additional information

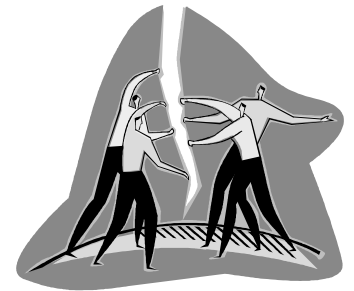
Information to Share from People Who Care...

This column includes information that has been shared by individuals with PD, family members, health care professionals, and/or interested members in the community.

Dance!!! The JF&CS Parkinson's Dance Program

Nancy Mazonson, M.S., OTR/L, Program Coordinator of the Jewish Family & Childrens Services Parkinson's Family Support Program describes an exciting new Dance program, the first of its kind in Massachusetts, for individuals with Parkinson's disease.

The Parkinson's Dance Program combines yoga dance movements from Kripalu Center for Yoga and Health in Western Massachusetts with the innovative and exciting work being done by the Mark Morris Dance Group in Brooklyn, NY with people with Parkinson's. Nancy Mazonson and dance instructor Naomi Goodman, MPH, went to Brooklyn to train with the Mark Morris dancers. This May they created the first six-week dance program. The class is designed for people with Parkinson's, as well as their spouses, friends and family. There is no difficult choreography to learn, but moving to the beat, stretching, and feeling the rhythm in their bodies had everyone in the class smiling and feeling invigorated. Said one participant, "I've been waiting for a class like this since I was diagnosed!" One week the group was privileged to have John Heginbotham, a Mark Morris dancer, lead the session. On June 25, WCVB filmed the program for their Health Beat segment. For more information on this wonderful program contact Nancy Mazonson, MS, OTR/L, Parkinson's Family Support Program coordinator at 781-693-5069 or nmazonson@jfcsboston.org.



Support Group News

Cathi A. Thomas, RN, MS

We are fortunate to have many support groups located throughout Massachusetts. A recent count identifies forty-one groups. Each group provides a service which is a tremendous help to individuals and families coping with Parkinson's disease. Participants attend meetings to learn information, share experiences, and exchange ideas. Consider attending a meeting- you will be happy you did.

New England APDA Coordinators and Chapter Presidents have planned a support group facilitator conference for November 13th in Sturbridge, MA. This meeting will take place one day before the bi-annual APDA Parkinson Disease Conference. Support group leaders will receive additional information soon.

A number of individuals have requested information on supporting the family caregiver. There are a few groups that meet specifically for caregivers. Other groups provide special opportunities for caregivers during a meeting, usually as a break out. I am in the process of forming a small group of individuals who will first assess the current support available to caregivers, but more importantly focus on what caregivers need. I am looking for volunteers. If you are a family caregiver and have time to meet in early September, please let me know. I can be reached at 617-638-8466 or information@apdama.org. For a complete list of all the support groups, visit www.apdama.org.

CHIPSpeaking: A Text to Speech Software

George M Higgins, ghiggins1@roadrunner.com



I was diagnosed with Parkinson's disease a little over three years ago. Prior to that, I was having trouble with my voice. It was getting softer and softer. Now, I cannot be heard. My speech therapist mentioned that there is Text to Speech software on the market. With that information, I searched the web looking for software that spoke when you hit the Enter key after you type your message.

What I found was what I was looking for and more, and it is FREE! The software is called *CHIPSpeaking: Conversational Help for Individuals with Problems Speaking*. John T. McF. Mood, S.F.O., developed the software at the request of his brother, "Chip", George McF. Mood, III, P.A., who had A.L.S. He wrote it because the 'name brand' programs ran \$800 and up for the software. Some of these programs require additional proprietary software to work. The cheapest he found was a total of almost \$2,000! CHIPSpeaking can be used with MS Windows98 and up including XP. Unfortunately Windows Vista and Mac OS are not currently supported.

CHIPSpeaking is fairly simple, and quite easily used. The buttons are easy and fairly large to accommodate persons with motor skill difficulties. CHIPSpeaking has an area to type what you want the computer to say. It also can let you paste text into the speech entry area. This allows you to read your email without looking at it, which will allow persons with difficulty seeing small text on the screen to hear their messages. CHIPSpeaking has 30 Macro keys that let you create your own standard text messages. It also has close to 50 built in phrases. If you need a Text to Speech program, I encourage you to go to the CHIPSpeaking website: www.chipspeaking.com or e-mail chipspeaking@aol.com. Of course, the best way to become familiar with it is to download a copy. If you have trouble running it, contact John Mood and be sure to provide him with the version of Windows you are using so he can make sure you have the right drivers. Remember, it is FREE!

New Support Groups in 2008:

UMass Memorial Worcester Parkinson Support Group

Monthly, 2nd Wednesday, 6:30-7:45pm

(no July or August meeting)

University of Massachusetts Memorial Medical Center

Contact: Elizabeth Austin, PsyD

(508) 856-2409 or austine@ummhc.org

Arlington

Monthly, 1st Wednesday 6:30-8:00pm

(no July or August meeting)

Sunrise Assisted Living Center of Arlington

1395 Mass Ave, Arlington, MA 02476

Contact: Debbie Case

(617) 638-7729 or dcase@bu.edu

Wakefield (formerly Stoneham)

Monthly, 1st Thursday, 10:00am

Wakefield Senior Center

30 Converse Ave

Wakefield, MA 01880

Contact: Howard Porter

(781) 438-0326 or porterart1611@yahoo.com

& Jane Lavender (781) 438-1157

Milton

Monthly, 2nd Thursday, 1-3:00pm

Milton Council on Aging

10 Walnut Street

Milton, MA 02186

Contact: Leslie Vickers RN, MS

(617) 472-1333 or LVickers@bayada.com

Calendar of Events - Save the Date

Friday, September 12, 2008

13th Annual Putt for Parkinson's Celebrity Golf Tournament

~ Sandy Burr Country Club, Wayland, MA
See back page for more information and visit www.puttforparkinsons.golfreg.com.

**Wednesdays, October
15, 22, & 29, 2008
6-8:00pm**

A Good Start Program

This three part educational series is designed for individuals recently diagnosed with Parkinson's disease and their families. This program will provide an overview of PD and treatment options, including medication and rehabilitation. The sessions will be led by a neurologist, nurse, physical therapist, occupational therapist, speech and language pathologist, nutritionist, and APDA staff. There is no cost to participate. The meetings will take place at Boston University Sargent College, 635 Commonwealth Ave. from 6-8pm. For additional information, call 617-638-8466.

Thursday, November 13, 2008

Support Group Leaders' Conference

~ Sturbridge Host Hotel, Sturbridge, MA
This all day conference will provide facilitators of Parkinson's disease and related groups current information and strategies to enhance support group dynamics.

Friday, November 14, 2008

New England Regional Bi-annual APDA Conference

~ Sturbridge Host Hotel, Sturbridge, MA
This day long event will include information on the latest advances in treatment and supportive services.
* Special overnight rates will be available at the hotel.

To learn more about these events please visit our website at www.apdama.org

Wellness Programs will startup again this fall. For information on individual programs, please contact the I & R Center at (617) 638-8466. In the meantime, continue to exercise and stay active!

The APDA has produced a new exercise booklet, *Be Active*, to assist you at home. This comprehensive educational booklet was written by Terry Ellis, PT, PhD, NCS, Tami Rork, PT, MSPT, and Diane Dalton, PT, DPT, OCS of the Center for Neurorehabilitation, Sargent College, Boston University.



Above: Board members Melissa Diggin and Keith Ciccone present Leslie Vickers, RN, MS of Hingham with the MA Chapter 2008 Healthcare Professional Award.



Above: Howard Porter of Stoneham receives this year's MA Chapter Volunteer of the Year Award.



Above: Volunteers Janet and Joel Brown tend the t-shirt table at this year's Walk.

Right: The Cookbook Committee, chaired by Elaine Proulx, works hard all year long.



Become a member of the Massachusetts Chapter of the American Parkinson Disease Association

Fill out the registration form and mail it to
APDA MA Chapter, 715 Albany St, Suite C329, Boston, MA 02118

Name _____ Date _____

Address _____

City _____ State _____ Zip _____

Email _____ Telephone _____

Membership Fee: \$10 per individual, \$15 per family
Make checks payable to: APDA MA Chapter.

APDA Putt for Parkinson's Annual Celebrity Golf Tournament

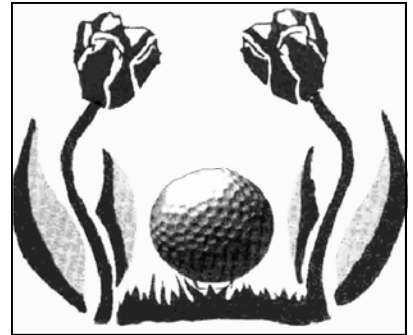
Friday, September 12, 2008

Come and join us for the 13th Annual Putt for Parkinson's Celebrity Golf Tournament presented by the Massachusetts Chapter of the American Parkinson Disease Association. The APDA will be hosting this event on Friday, September 12th, 2008 at the Sandy Burr Country Club in Wayland, MA. You can count on a fun-filled day of golf, barbeque, raffles, live and silent auctions, and a delicious lobster and clam bake. Over the past twelve years, The Putt for Parkinson's

event has raised over \$375,000 with a goal to continue efforts to "Ease the Burden - Find a Cure."

So come and help support the fight against Parkinson's disease by participating through playing golf, sponsoring a golfer, or taking part in the raffle and auctions. Don't Golf? No Problem, you can still register as a fundraiser through donations to the event or in support of a participant.

Further information, including registration, for this event can be found online at www.puttforparkinsons.golfreg.com.



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