Benefits of Exercise for People with Parkinson’s Disease

Terry Ellis, PT, PhD & Tami Rork DeAngelis, PT, MSPT, GCS
Boston University Sargent College of Health and Rehabilitation Sciences
Center for Neurorehabilitation

Given the advances in the medical and surgical management of Parkinson’s disease, people with Parkinson’s disease can live a long and productive life. Participation in an exercise program should be an integral part of the management of Parkinson’s disease to optimize quality of life and day to day function. The research demonstrates that people with Parkinson’s disease can improve strength, flexibility, cardiovascular fitness, walking speed and endurance, activities of daily living and health related quality of life. Important components of an exercise program include the practice of strategies to improve day to day function (e.g., moving in bed and rising from a chair), walking with external cueing—such as music—to help regulate the pace and speed of walking, strength training, exercises to increase flexibility and joint motion, and cardiovascular fitness training. Animal studies and epidemiological studies suggest a potential neuroprotective effect of exercise; however, the effect on humans has yet to be appreciated.

The key to exercise is to make exercise a part of your life. Although short-term exercise can be beneficial, long term participation in exercise is important to reap prolonged benefits. People with Parkinson’s disease should consult with a physical therapist with expertise in Parkinson’s disease who can develop an individualized exercise program targeting the specific issues of each person. Physical therapists can design an exercise program that can be done at home or in a gym in a way that will optimize people’s ability to integrate it into their everyday lives. Some people do best exercising as part of a group exercise class. At the Center for Neurorehabilitation at Boston University, we developed Community Wellness Programs for people with Parkinson’s disease. These group exercise programs are based on the results of a study we conducted demonstrating improved quality of life, day to day function, and walking speed in people with Parkinson’s disease who participated compared to those who did not. The Community Wellness Programs consist of exercises to im-

(Continued on page 7)
Dear Friend,

I am pleased to introduce myself as the President of the APDA Massachusetts Chapter, elected in April, 2009. I have been a member of the Board for 9 years, and have lived with PD for even longer. It is a privilege to represent the APDA Massachusetts community, and I look forward to meeting with you and hearing how we can improve our services and support.

I believe that the APDA Massachusetts Chapter is already one of the strongest in the country. I am indebted to Past President Keith Ciccone, who has ably led the Chapter over the past 5 years, and to the Information and Referral Center (I&R Center) staffed by Cathi Thomas, RN, MS, Debora Case, and Medical Director Dr. Marie Saint-Hilaire. I am pleased that our Board membership has grown, and we are seeing more volunteers. I am confident that we have a sound foundation for the organization’s future growth.

The 23rd annual APDA Massachusetts Chapter Parkinson's Walkathon was a resounding success, raising over $100,000 for Parkinson's research. The weather was perfect, and the Walk was attended by more than 1,500 people. A large number of volunteers, led by Keith Ciccone and Kim Creem, did a great job of managing the effort. Significant fundraising events for 2010 are in the planning stages.

In an effort to provide you with the services you most need, APDA Massachusetts recently conducted 3 focus groups in the PD community. APDA Massachusetts is expanding partnerships with other organizations in a "virtual support network", leveraging each organization's strengths to increase the services available to you. For example, we have partnered with Boston University Sargent College to establish the Community Wellness Programs, Combined Health Charities to increase donation opportunities, and other organizations to bring you services to improve quality of life.

Initiatives supported by the APDA MA include:
* 46 support groups across the state. In 2008 the Massachusetts Chapter provided financial support for 80 Parkinson Support Group leaders from throughout New England to attend an all-day facilitator training program.

* An informative website with up-to-date content that is visited on average 780 times a month by 460 unique visitors.

* 10 Grants in 2009 to support programs in Massachusetts providing a direct service to individuals and families living with Parkinson's.

These grants funded 6 wellness programs, an adult children's support program, and support to the Spirited Movement foundation who held a retreat for individuals and families coping with PD.

* Numerous educational programs held regularly throughout the state. Highlights include the Biannual Sturbridge Conference attended by 500 individuals, family members, and vendors; scholarships for health care professionals to attend the annual Boston University PD Health Care training program; and support for our APDA Nurse Coordinator to provide education to healthcare providers in rehabilitation, assisted living, and long term care centers.

I am hopeful that a cure for PD is getting closer, with increased drug and stem cell research activity. The Chapter is committed to supporting research, but we also are very committed to helping you with your everyday needs.

Sincerely,

Volodymyr Lyczmanenko

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has."

- Margaret Mead
How Can You Help?

The APDA MA Chapter needs your help…

Make a donation:
Funding is crucial for research and program support. Consider making a tax-deductible donation in honor or memory of a family member or friend. This can be done by writing a check payable to APDA MA Chapter, by phone at (617) 638-8466, or online at www.apdama.org.

Become a member:
Individual or family membership supports our organization in many ways. Consider joining by completing the application below.

Volunteer your time:
Our volunteer Chapter Board recognizes the benefits of individuals who donate time to help “To ease the burden, to find the cure.” Board members look forward to matching your strengths and interests to volunteer opportunities. Please call (617) 638-8466 or email president@apdama.org.

COMMUNITY HEALTH CHARITIES

The APDA MA Chapter is pleased to announce its affiliation, as an associate member, with Community Health Charities of New England.

The mission of Community Health Charities of New England is to raise funds for, and increase awareness of, its member charities through workplace giving campaigns. These member charities, all of which are nationally recognized health agencies, offer vital resources and services including education, treatment, outreach, and research in communities throughout New England. If your workplace participates in the Community Health Charities giving campaign, you can designate the APDA MA Chapter as recipient of your donation. Visit www.chcofne.org.

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, 72 East Concord St, C3, 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.
More than 1,500 people attended this year's Parkinson Walkathon which took place at the beautiful Reebok International Headquarters in Canton, MA on Sunday June 7, 2009. It was a glorious day full of sunshine, love, caring, and of course a lot of fun. Matt Siegal of Kiss 108 emceed, and the fabulous Corduck family (Bean team) scooped ice cream for hours on end. There was pizza, beverages, and tasty snacks. In addition, participants received useful information from many participating vendors and entered a raffle for the chance to win some fabulous prizes.

This year’s Walk Coordinator, Keith Ciccone brought together one of the finest groups of volunteers, including our very active board members. Over 50 volunteers worked behind the scenes for several weeks and continued throughout event day. As in years past, three volunteers were recognized for their support of the MA Chapter of the APDA. Chapter President Vlad Lyczmanenko presented awards to Paul and Elaine Proulx and Past President Keith Ciccone.

Net proceeds from the Walkathon reached $105,253! A check totaling this amount was sent to APDA National to support research. Research projects are reviewed annually by their distinguished Scientific Advisory Board: www.apdaparkinson.org.
Board member Kim Creem joins her team, Carole’s Crusaders at this year’s Walkathon. Kim coordinates volunteers for the APDA MA Chapter.

Start Planning Your Walkathon Team Today!

67 teams participated in this year’s Walkathon. Thank you for your great efforts.

- Barbie's Dolls • Bean's Team • Bob's Bunch • Braintree Rehab • BU Neurology • Burt's Bombers • Butch's Brigade • Canton Lions Club • Carole's Crusaders • Charlie's Crew • Climbers for a Cure • Dopa Schmopa • Ed's Striders • Frank Family • Fredtastic! • Grammy's Team • Grampy's Group • Grandpa's Gang • Hamel Ten Pins • Jack's Pack • Jed's Warriors • Jerry's Team • Jiggs' Team • Jim Cronin's Crew • Jimmy's Family & Friends • Ma's Bit-O-Honeys • Marti's Marchers • MOFOCA • Papa Flash • Papa's Angels • Papa's Posse • Papa's Progeny • Patsy's Posse • Quags • Remembering Gram and Memere • Rich's Team • Robbins' Raiders • Rota Rooters • Sheldon's Squad • Sheri's Angels • Sinai Sashayres • Struble Striders • Team Bob • Team Donald Bush • Team Farina • Team Florio • Team Herb • Team Jemiola • Team Jerry Silver • Team Matt • Team McAuliffe • Team Morris • Team Proteus • Team Silverman • Team Stoller • Team Taylor • Team Timilty • Team Traweek • Team Whitmore • The Crosby Crusher's • The Friends & Family of Manny • The Walk-Ons • Together We Can • Vinny's Voyagers • Wasner •

The 24th Annual Walkathon will take place on
Sunday, June 6, 2010

Reebok International Headquarters - Canton, MA
Registration starts at 11:15am and the Walkathon begins at 12noon.
Let Your Voice Be Heard!

Hadas Golan, MS/CCC-SLP
Speech and language pathologist,
LSVT certified clinician,
Boston Medical Center,
Department of Otolaryngology
Voice and Swallowing Center

The following is an excerpt from two articles written by the creators of the LSVT LOUD voice treatment program:

“If you don’t talk loud enough - people stop listening.”
“If I have no voice, I have no life.”

These are direct quotes from two individuals who live with Parkinson disease (PD). They reflect the significant impact that a speech and voice disorder can inflict on the quality of a person’s life.

These two are not alone. Research shows that 89% of people with PD experience speech and voice disorders, including soft voice, monotone, breathiness, hoarse voice quality, and imprecise articulation. As a result, people with Parkinson’s report that they are less likely to participate in conversations, or to have confidence in social settings, than healthy individuals in their age group.

For years, speech and voice disorders in people with PD were resistant to treatment. The effects of conventional treatments - whether medical or surgical - were neither significant nor lasting. Speech therapy focusing on articulation and rate was not effective as well, resulting in reports that of the 89% of these people with voice and speech disorders only 3-4% receives speech treatment.

The recognition that speech therapy could be tailored to the specific problems of the Parkinson’s patient led to the development of a method aimed at improving vocal loudness: the Lee Silverman Voice Treatment (LSVT LOUD) method. This technique has helped many individuals with Parkinson’s and speech problems, giving them new hope for improved communication for work, family, and social activities.

Speech and Voice disorders in PD

There are several reasons why people with PD have reduced loudness and a monotone, hoarse, breathy voice. One is directly related to the motor difficulties in Parkinson’s, including rigidity, slowness of movement, and tremor. For example, the inadequate muscle activation that leads to bradykinesia (slow movement) and hypokinesia (decreased movements) in the limbs can also trigger a speech disorder. For speaking, the problem with muscle activation can result in reduced movements of the respiratory muscles (reduced breath support), larynx (reduced vocal loudness), and articulation (reduced clarity of speech).

Another cause of speech and voice impairment in PD is a deficit in the sensory processing that is related to speech. Clinical observations suggest that people with PD may simply not be aware that their speech is getting softer and more difficult to understand. When “soft speaking” people are told of this, they will often reply “No, my spouse needs a hearing aid!” Furthermore, if people in this situation are asked to bring their voice to normal loudness, they will complain that they feel as though they are shouting, even though they are perceived by listeners to be speaking normally.

Speech therapy: LSVT LOUD

Over the past 15 years, studies demonstrated that LSVT is an effective speech treatment for people with Parkinson’s. Those who have used it have improved their vocal loudness, intelligibility, facial expression, and ability to swallow, and maintained these improvements for up to 2 years after treatment. The program is administered intensively in 16 sessions over a single month. It improves respiratory, laryngeal, and articulatory function to maximize speech intelligibility. In addition, it incorporates sensory awareness training to help individuals with PD recognize that their voice is too soft, and convince them that the louder voice is within normal limits.

(Continued on next page)
**Coordinator’s Notes**

Dear Friend,

We are developing a comprehensive resource manual describing programs and services for patients, families, healthcare providers, and the community-at-large in Massachusetts. We need your help. Please share information that has made a difference to you or improved your quality of life. For example, have you participated in a special exercise class or worked with a rehabilitation specialist?

Please send us a note or give us a call at (617) 638-8466 or email information@apdama.org. We want to make this manual as comprehensive as possible.

Thank you for your assistance!

Debbie Case
Cathi Thomas, RN, MS

---

**How to get LSVT LOUD Therapy**

If you are experiencing a speech or voice problem or your spouse, family, or friends have brought it to your attention, be sure to tell your doctor. Ask for a referral and a prescription for a speech evaluation and treatment. The sooner you start speech therapy, the more likely you will be able to maintain communication skills as the disease progresses.

To learn more visit www.lsvt.org & www.LSVTGlobal.com.

**References:**

Ramig, Lorraine, Fox, Cynthia, Farley, Becky. The Science and Practice of “Speaking LOUD and “Moving BIG”


---

Elaine Proulx, Keith Ciccone, and Paul Proulx receive the APDA MA Chapter 2009 Volunteer Award.

(Benefits of Exercise for People with Parkinson’s Disease Continued from page 1)

prove flexibility, strength, and fitness level in addition to improving daily function with tasks such as walking, rising from a chair, moving in bed, and handwriting. The program also teaches participants strategies to manage their Parkinson’s disease effectively over the course of their lifetimes. These programs are available in specific locations in the New England area.

For more information on getting started with exercise or if you have specific questions about your exercise program, you can call the “Exercise Hotline” at the Center for Neurorehabilitation at 617-358-5066 where experts in rehabilitation will address your questions.
Supporting Patients & Families

The American Parkinson Disease Association (APDA) has as its mission: “To Ease The Burden, To Find The Cure” for this neurological disorder affecting over one million Americans.

APDA, headquartered in New York, focuses its energies on patient and family services, education, community awareness, and research. To accomplish this, APDA sponsors a comprehensive Information and Referral Center located at the Boston University Medical Center.

TURN TO US…

For help answering questions and working through challenges. We offer:

- A telephone helpline
- Counseling and advocacy
- Referrals to community resources
- Collaboration with volunteers from the APDA MA Chapter and the statewide support group network

ASK US…

For FREE, reliable information. This includes:

- Handbooks about the disease and daily living
- Newsletters and website announcements
- A library of books, DVD’s, and other resources
- Lectures and community programs
- Education for healthcare and community providers

COUNT ON US…

For friendly and professional assistance you can trust. The Center is:

- Staffed by a Nurse Coordinator and a Medical Director who is a Movement Disorder Specialist

CONTACT US...

APDA
Information & Referral Center
72 East Concord St., C 3
Boston, MA 02118
617.638.8466
Toll free: 1.800.651.8466
www.apdama.org

Need help with your prescriptions?

The Massachusetts College of Pharmacy and Health Sciences, under contract with the Massachusetts Executive Office of Elder Affairs, operates the MassMedLine pharmacy outreach program, a free, confidential service available to all Massachusetts residents. By calling a toll-free help line, patients can receive general information about their medications and side effects, in addition to personal assistance with accessing affordable prescription drug programs.
Supporting Patients & Families

There are 46 support groups for individuals with Parkinson's disease, family members and friends throughout Massachusetts. All groups welcome new members. Each group is unique, based on many factors, including group leadership, location, and longevity. Some groups serve special populations, such as the "Young Onset PD group" and the "Deep Brain Stimulation Group."

In addition, there are groups for individuals who are diagnosed with conditions that share some similarities to parkinsonism or Parkinson's Disease. These include Progressive Supranuclear Palsy (PSP), Multi Systems Atrophy (MSA) and Diffuse Lewy Body Dementia (DLB).

Contact the APDA Information & Referral Center to learn about a group near you. An updated support group list and calendar are available on the MA Chapter website: www.apdama.org.

The Young Onset Parkinson Support Group welcomes Allyson Litos Gormley, a Licensed Clinical Social Worker as group facilitator. Allyson has worked closely with the Parkinson Community in Massachusetts including roles in research as well as past project coordinator with the APDA Information and Referral Center at Boston University Medical Center. Allyson also served as Secretary of the APDA MA Chapter from 2002-2005. She played a key role in the successful coordination of the walkathon and Putt for Parkinson during this time.

Allyson received a Bachelors degree in Human Science and Service from the University of Rhode Island and a Masters degree in Social Work from Boston University. Allyson is experienced in group work and looks forward to working closely with support group leader Cindy Bittker and members of the Massachusetts Young Onset PD Group.

The group meets monthly on the second Sunday from 2-4 pm at the Jewish Community Center, Room 205, 333 Nahanton Road, in Newton, MA.

For more information please call the APDA Information and Referral Center at 617-638-8466.

Yoga Teacher Training Program
Saturday November 7, 2009
Yoga Center of Newburyport

Yoga teachers are invited to participate in a day long seminar presenting yoga strategies and safety tips that can be used to guide students with limitations associated with movement disorders. Registration is required. Please call (617) 638-8466 for more information.
The 3rd Annual BU Parkinson’s Disease Seminar for Healthcare Professionals was held on March 26-28, 2009. This program is a collaboration between Boston University Sargent College, Boston University Department of Neurology, and the American Parkinson Disease Association. More than 75 healthcare professionals participated in a 2.5 day training program to improve their knowledge in interdisciplinary treatment of Parkinson’s disease. Terry Ellis, PhD, PT, Cathi Thomas, RN, MS, Tami Rork DeAngelis, MS, PT, Donna Diaz, RN, MS, and Marie Saint-Hilaire, MD serve as course directors. A distinguished faculty provides cutting edge information on various topics including the effectiveness of rehabilitation, pharmacological management of motor and non-motor symptoms, nutrition, communication, and social interaction. To learn more about future programs, call (617)353-7525.

APDA Coordinators Donna Diaz, RN, MS (left) and Cathi Thomas, RN, MS (right) join National Board Member Elizabeth Braun, RN, MS at the 3rd Annual Parkinson’s Disease Seminar for Healthcare Professionals at Boston University.

Tami Rork DeAngelis, MSPT, Senior Physical Therapist, Boston University Sargent College Center of Neurorehabilitation describes how to develop a Parkinson’s disease wellness program.
Research Opportunities

The APDA Massachusetts Chapter and Information and Referral Center is pleased to provide you with basic information on research studies on-going at various movement disorder centers. Although the APDA has not individually reviewed or specifically endorsed each study posted here, each has been reviewed and approved by the Institutional Review Board at its respective medical center. For further information on any study posted here, please utilize the specific contact information provided with the description of the actual study in which you are interested. As always, consult your physician to discuss the individual benefits and risks of each study prior to participating. To increase your awareness of ongoing research and clinical trials visit www.pdtrials.org, www.clinicaltrials.gov, or www.pdpipeline.org.

A Study Evaluating New Levodopa-Carbidopa Delivery System in Advanced Parkinson’s Disease

This study will evaluate a new method of delivering the medications levodopa and carbidopa. These medications will be administered continuously (16 hours per day) as an intestinal gel with a portable pump through a PEG-J tube. You may be eligible for this study if you have advanced Parkinson’s disease, and you experience “on” and “off” periods despite optimal treatment with available medications. For more information contact Peggy Rose at Beth Israel Deaconess Medical Center Parkinson’s Disease Research Center: 617-667-9885 or prose1@bidmc.harvard.edu.

Participants Needed for Study on the Health of Caregivers to Relatives with Parkinson’s Disease

If you are providing care for a relative with Parkinson’s Disease, and you are 60 years or older, you may be eligible to participate in a study on how caregiving affects your health.

This study will involve 4 yearly face-to-face interviews, conducted by trained interviewers at the General Clinical Research Center at BUMC in Boston’s South End. You will be asked questions about your physical and emotional health, and about the person for whom you provide care. In addition, you will be asked to give blood and urine samples. This study is funded by the National Institute of Health.

The first interview is expected to take 2 hours. It will take place in the early morning.

You will be reimbursed up to $40 for your time, and your parking costs will be paid. You can bring your care recipient to the interview where someone will stay with him or her during your interview.

If you are interested in participating in this study, please call Denyse Turpin, RN, MPH at (617) 638-7736.

Inosine Research Study in Parkinson's Disease

You may qualify for this PD drug study if you:

- Were diagnosed with PD within the last 3 years or if you are experiencing some of the above symptoms
- Are not currently taking medication for your PD
- Do not have a history of gout or kidney stones

Eligible participants will receive study-related evaluations, laboratory tests, and the investigational drug at no cost. For more information about this study, please contact Ray James, BS, RN at (617) 638-7745.

Visit www.apdama.org for an expanded list of studies in Massachusetts.
A Good Start Program - Wednesday, October 7, 14, & 21, 2009 - 6:00 - 8:00pm
A 3 part series for individuals recently diagnosed with Parkinson’s disease and their families.
Samuel Frank, MD, Anna Hohler, MD, Terry Ellis, PhD, PT, Tami DeAngelis, PT, MS,
Melissa Diggin, NP, Elizabeth Hoover, CCC-SLP, & Cathi Thomas, RN, MS
Boston University Sargent College
635 Commonwealth Avenue
Boston, MA 02215

Parkinson Education Programs Sponsored by TEVA Neuroscience & APDA MA Chapter
~ Holyoke, MA - Wednesday, October 14th, 2009 - 4:30PM - 6:30PM
Jagadeesan Udayarani, MD & David Rintell, Ed.D
The Delaney House
3 Country Club Road (Route 5)
Holyoke, MA 01040

~ Hyannis, MA - Monday, October 26, 2009 - 12:00 – 2:00pm
James McCarthy, MD & Joseph Friedman, MD
The Cape Codder (upstairs)
1225 Iyannough Road - Route 132 & Bearse's Way
Hyannis, MA 02601

RSVP is required for all of these programs. Please call (617) 638-8466.