

APRIL 2009

Dance for Parkinson's

Recent studies have shown that music and dance have a rehabilitative effect on movement and balance and help improve the quality of life for people with Parkinson's. In a study published in the *Journal of Neurologic Physical Therapy*, M.E. Hackney, S. Kantorovich, R. Levin, and G.M. Earhart found that Argentine tango dancing was a reasonable activity for people with Parkinson's disease and required participants to multitask activities such as balance, turns, movement initiation, changing speeds and backward movement. Hackney, et al. found that tango participants showed improvements in balance and mobility. They suggest that tango should be considered as a complementary therapy similar to tai chi, which requires balance and attention to movement control when addressing Parkinson's related movement problems. Furthermore, "social dance in a group setting can enhance motivation" for movement.

Although tango in particular has shown promising effects on Parkinson's disease, regular dancing may also provide help with symptoms. Concetta Tomaino D.A., MT-BC, LCAT of Beth Abraham Family of Health Services states, "One of the tricks of Parkinson's is that the person has to feel the beat and the anticipation of the beat," noting that "the rhythm and pattern of music synchronizes our internal rhythm and provides a cue for the body to move even when the body cannot provide that cue for itself." This understanding of movement indicates people are unique and have individual ways of experiencing and responding to music. They may need to listen to various types of music to find a beat they are able to follow since each type of music has a different cadence and tempo that determines a specific form of dancing.

In response to current research on this subject, **Houston Ballet Foundation and Houston Area Parkinson Society are pleased to announce their partnership** in an innovative, collaborative dance program for people with Parkinson's in the Houston community. This new program, modeled after the pioneering program that the Brooklyn Parkinson Group and the Mark Morris Dance Group developed, will be launched this spring. This initiative allows HAPS to expand its exercise program, adding a new type of dance group to its existing tango dance class. Like the tango group, it promises to be a fun and exciting environment for people to tap into their creativity and apply some of the ground-breaking approaches that are proving to benefit those with Parkinson's. The expanded dance program will incorporate various types of music and will encourage participants to dance independently and find their own beat.

If you are interested in participating in the HAPS dance program, or any of the HAPS programs, please contact the HAPS office 713-626-7114. Beginners are welcome, no partners required—just a willingness to have fun!

PAN Forum 2009 Wrap-up

Kathleen Crist, LMSW



In March I made my third trip to Washington, DC to participate in the 15th Annual Parkinson's Action Network (PAN) Research and Public Policy Forum. Almost 300 people in person and 800 via live webcast attended this year's event. It was wonderful to see so many familiar faces



and to see so many new and enthusiastic individuals attending the PAN Forum for the first time. The atmosphere was filled with excitement and renewed energy due to the recent Executive Order reversing barriers to responsible scientific research involving human stem cells just the week before. Even those participants who didn't support stem cell research could celebrate the new administration's clear commitment to health care reform and its significant investment in medical research of all kinds at the National Institutes of Health.



The first two days were filled by immersing ourselves in the latest science and policy issues related to Parkinson's disease. By the third day we were ready to head to the Hill to meet with our Congressional representatives. As in the past, we had three legislative requests. Each "ask" or request was made of members of the Senate and the House for their



support. The first "ask" was to sign onto the Dear Colleague letter requesting \$55 million for the Department of Defense Neurotoxin Exposure Treatment Parkinson's Research (NETPR) program. The second request was to ask our Representatives to co-sponsor the National MS and Parkinson's Disease Registries Act and to ask our Senators to support the Senate bill which was expected to be introduced in the coming weeks. Finally, the third "ask" was a request for them to join the 14 other Senators and 153 other Representatives already on the Bicameral Congressional Caucus on Parkinson's disease.

This year's forum proved to be very successful. There were over 280 scheduled visits with various Congressional members, many "drop in" meetings and numerous contacts made by those participating via webcast. It was great to see so many people from all over the country come together again for this event. Everyone's story is different, but the mission is all the same; to bring attention to this disease and to advocate for more research that will bring us closer to new treatments and closer to a cure. If you would like more information, are interested in getting involved, or want to see the webcast of the forum, go to www.parkinsonsaction.org.

"Things of little worth can be found easily. The surface of the world is covered in dirt and stones. But to find diamonds, one has to dig deep, to break through layer upon layer of the hardest rock, to get to its core. We are no different. The things that come easily to us are usually worth very little. The things we treasure are precisely those things that we worked so hard for." ... Anonymous



April is Parkinson's Awareness Month



ASK THE ADVOCATE

Dear Advocate,

Q. "What is Grassroots Advocacy?"

Dear Reader,

A. *Grassroots advocacy involves actions taken by concerned citizens to demonstrate their support of an issue. These citizens are everyday people like you and me motivated by an interest in public issues and a desire to make a difference. Grassroots advocacy starts at home, on a local level where individuals and groups take active support of an idea or a cause. These causes may be related to research, social service programs, public policy or personal interests. You may not know it, but when you are talking to your doctor about medication changes due to undesirable side effects, making sure hospital staff understand the importance of medication timing, talking to others about Parkinson's or discussing the needs of an individual with PD when looking at Assisted Living facilities, you are an advocate! When people decide they are going to be part of a solution, there is no limit to what they can accomplish.*

Nina Brown Receives "Women of Courage" Award

by
Anne Thobae

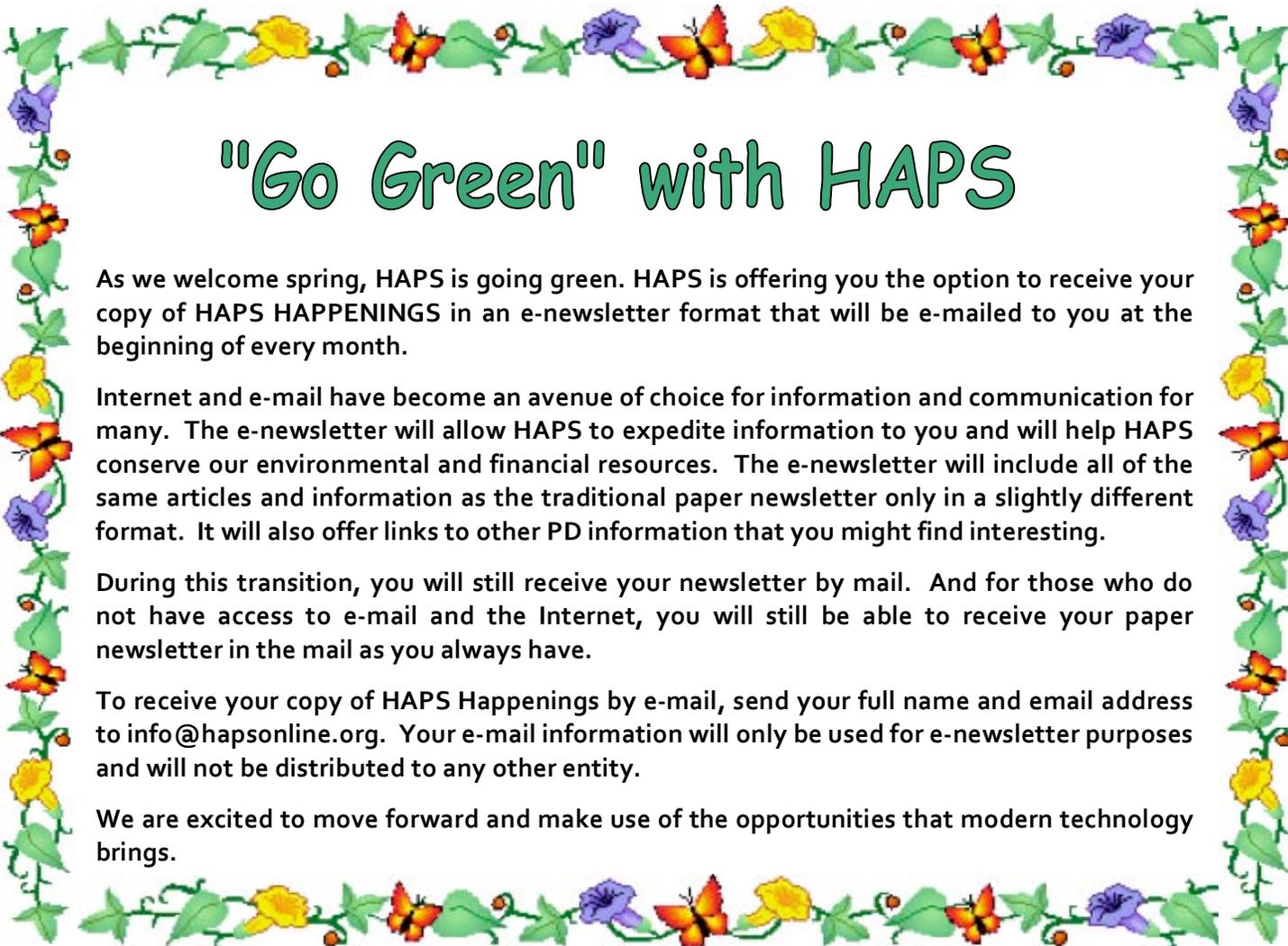


Nina Brown accepting award from Lynn Goldberg, Women of Courage co-chair

On March 8, at a luncheon attended by more than 450 people, Nina Brown received the Houston Chapter of Hadassah's highest honor – The Women of Courage Award – for local and national advocacy work for those who can't always speak up for themselves. Created in 2004, the award acknowledges female contributions to health care/health education and/or recognizes women who have lead inspirational lives.

When Brown was diagnosed with Parkinson's disease in 1985, she realized that while circumstances may have determined her life, she could shape her life by what she made of the circumstances. Fighting for a cure as an advocate for stem cell research and helping others live full lives with the myriad of symptoms that accompany an incurable, progressive, neurological disease became her passion.

Brown never anticipated that having a debilitating disease would be a stepping-stone on the path to the life she leads today. As a full time volunteer, she works with HAPS at the local level, is a state coordinator for PAN, and has co-founded two organizations that advocate and educate legislators and the public regarding regenerative medicine. "Since I'm not a scientist or politician, advocacy is the one thing I can do to give myself and others hope. As the theme of the luncheon, 'Building a Better World' suggests, it's up to all of us to advocate for the freedom to receive the best medical care possible," said Brown.



"Go Green" with HAPS

As we welcome spring, HAPS is going green. HAPS is offering you the option to receive your copy of HAPS HAPPENINGS in an e-newsletter format that will be e-mailed to you at the beginning of every month.

Internet and e-mail have become an avenue of choice for information and communication for many. The e-newsletter will allow HAPS to expedite information to you and will help HAPS conserve our environmental and financial resources. The e-newsletter will include all of the same articles and information as the traditional paper newsletter only in a slightly different format. It will also offer links to other PD information that you might find interesting.

During this transition, you will still receive your newsletter by mail. And for those who do not have access to e-mail and the Internet, you will still be able to receive your paper newsletter in the mail as you always have.

To receive your copy of HAPS Happenings by e-mail, send your full name and email address to info@hapsonline.org. Your e-mail information will only be used for e-newsletter purposes and will not be distributed to any other entity.

We are excited to move forward and make use of the opportunities that modern technology brings.

Orthopedic problems with Parkinson's

A new study found that Parkinson's not only leads to shaking and coordination problems, but secondary orthopedic conditions, as well.

People with Parkinson's often move and walk less, and generally stay indoors. Decreased movement may lead to bone loss, and reduced exposure to sunlight from staying indoors can decrease a person's vitamin D levels, which are necessary to keep bones strong. The combination of decreased bone density and instability from tremors and rigidity can greatly increase a person's risk of falling, breaking bones and developing osteoporosis.

What to do?

Author of the study, Dr. Lee Zuckerman, chief resident of orthopedic surgery at State University of New York's Downstate Medical Center, recommended patients check their bone mineral density and get treatment to reduce the risk of fracture.

He also recommended physical therapy, vitamin therapy and medication to increase bone density, and therapies to optimize gait and rigidity.

CONTRIBUTIONS

Your donation is much appreciated. Your thoughtfulness helps HAPS continue to provide much needed services to people with Parkinson's and their families.

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HAPS does not provide diagnosis or treatment. Always seek the advice of your physician or pharmacist with any questions you may have regarding a medical condition or drug interactions.