

SEPTEMBER 2013

IN THIS ISSUE

Kerr/Thorp Challenge	2
HAPS Heroes	2
Article: My Friend, Sasha	3
Article: Alcohol Consumption Is Not Associated with Parkinson's Disease Risk	4
HAPS Exercise & Support Group Schedule	Insert
Cupic Custom Homes Event	5
Parkinson's Enrichment Program	5
How's HAPS Doing?	5
Upcoming Events	6
Contributions and Tributes	7
Mark Ohls' Tribute	7

SEE INSERT FOR CHANGES TO EXISTING GROUP TIMES AND THE ADDITION OF A NEW HAPS GROUP BEGINNING THIS MONTH.



This publication is not intended to provide diagnosis or treatment. Always seek the advice of your physician or pharmacist with questions regarding medical conditions or drug interactions.

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Speech and Parkinson's

Linda Ronstadt recently revealed in an interview with AARP that although her official Parkinson's diagnosis came just eight months ago, she knew something was wrong long before that as she as she struggled with her singing voice over the past six years. Now, she says she "can't sing a note." This announcement has left many people wondering exactly how and why speech is affected for those with Parkinson's.

It is estimated that 60-90% of people with Parkinson's disease will experience some changes in speech and voice throughout the course of their disease. Speech is a multifaceted process that involves many nerves and muscles of the face, lips, tongue, larynx, throat and chest. With Parkinson's, problems with speech can arise as the disease process affects cells in the part of the brain that involves regulation of muscle tone and movement in the face, mouth region and throughout the body.

Hypokinetic dysarthria is the name for the type of Parkinson's related speech problems that occur with impaired muscular control of speech production. Most commonly, people with Parkinson's may notice one or more of these problems: an overall loss of volume; difficulty in shifting vocal volume; trouble with pitch leading to a monotone sound; hoarse, breathy or gravelly voice quality; poor articulation or "mumbling"; or speech that is either too slow or too fast.

So, what can be done? A growing body of evidence suggests that speech therapy, singing and other vocal exercises can enhance voice volume and clarity; diaphragm and chest extension; and improved facial and throat mobility, leading to a better ability to communicate. And participation in these activities may also improve mood and overall sense of well-being. HAPS currently offers a variety of programs like singing, speech and music therapy classes which address these changes.

The *ParkinSING* class, led by a professional vocal coach and pianist, uses singing as a fun and practical method of expanding participants breathing, maintaining and increasing their voice projection and working their lips, tongues, jaws and soft palates as they sing Broadway, folk and popular music to live piano accompaniment.

Speech therapy groups facilitated by licensed speech therapists are designed to help individuals with PD increase self-awareness about how their speech and voice sound through feedback from the therapist and other group members. The therapist provides ongoing education about the effects of PD on speech and teaches compensatory strategies to enable the person with Parkinson's and their care providers to maximize communication effectiveness. Voice and speech treatment techniques for improving breath support, articulation and voice quality are also taught.

Licensed music therapists lead the HAPS music therapy sessions by incorporating singing and vocal expressions along with live music which is created by participants—all based on the Neurologic Music Therapy (NMT) protocol. Vocal Intonation Therapy (VIT), Oral-Motor Respiratory Exercises (OMREX), Rhythmic Speech Cueing (RSC) and Therapeutic Singing (TS) are all used to challenge the range of the voice; exercise the mouth, tongue, jaw and respiratory system; improve intelligibility; and control the rate of speech.

The message is loud and clear—just as taking medications and exercise is important in managing Parkinson's so is maintaining your voice. There are many fun and effective options that can help you be heard in the fight against Parkinson's.

2013 Kerr/Thorp Challenge Raised Over \$38,000—We Met the Challenge Boldly!

With the outstanding generosity of HAPS constituents, clients and community shareholders who joined the Kerr/Thorp Challenge and contributed valuable funding over the past three months, we met the original \$12,500 challenge by the end of July and blew past the increased grant goal of \$15,000 by raising a total of \$23,134 by the end of August! Add \$15,000 that is matched and you contributed an incredible \$38,134 to support the organization's programs. We are immensely grateful to all who helped us meet the challenge, and especially, to Rob Kerr/Kerrco Inc. and Jim Thorp/Thorp Petroleum for their extraordinary commitment to HAPS by matching contributions and allowing your gift to have twice its impact.

HAPS strives to remain relevant, vital and connected to the community it serves by presenting programs that fill gaps in care for all who are living with a diagnosis of Parkinson's disease—including patients, spouses, family members and caregivers. We try hard to offer client-centered, innovative programs that address the intricacies of navigating life with this movement disorder. HAPS is committed to being an advocate and voice for Parkinson's, responding to current trends and disseminating knowledge about the disease.

On behalf of the Board of Directors and the entire organization, we thank you. As we provide essential services for families affected by Parkinson's in greater Houston, we are here to do the work—but we can't do it without continued financial contributions and friendship. We sincerely appreciate this tremendous show of support from the many friends who believe in the organization's mission and make our efforts possible.



Thank You!

Many thanks to Eugene Lai, MD, PhD who led the presentation of the August HAPS Summer Lecture Series, *What's New in Parkinson's Research*, on Friday, August 9th. We appreciate your time and expertise.

HAPS Heroes Return as Marathon Co-chairs

HAPS Marathon co-chairs Debby Hurlbert and Kathy Smith are back for one more season leading our Superhero Squad in the 2014 Chevron Houston Marathon on January 18-19. Last year, Debby and Kathy were among top fundraisers who helped HAPS raise a record-breaking \$79,500! And both participated in the ABB 5K Fun Run/Walk alongside our biggest turnout of walkers. **Debby and Kathy want you to join them this year and show our community that it is possible for people with Parkinson's disease to complete this race!**



Debby, who has participated in the 5K since 2010, is amazed by the support she receives from family and friends during this event. Debby says, "A lot of people with PD think that they can't walk that far, but they can. There are crowds of people cheering you on along the way and it's fun." Last year, Debby used a wheelchair for the race and her team took turns pushing her towards the finish line. For Debby, it doesn't matter if she is walking or wheeling, she always feels like she is accomplishing something meaningful.



Kathy will be walking in her fourth consecutive 5K. For her, this event is something she can enjoy with her family. This past year, Kathy's brother Dave flew in from Philadelphia and surprised her at the starting line the morning of the race to walk with her. Kathy uses the Marathon as a chance to raise awareness for the disease and give back to HAPS. She describes crossing the finish line as an emotional feat and says, "Each year when they put that medal around my neck, it validates that I am still here, still fighting this disease and I can still do this."

To join Debby and Kathy's Superhero Squad in the 2014 Chevron Houston Marathon, please contact Kelly Nicholls at 713-313-1621 or nicholls@hapsonline.org.

Photos by Michael McKann

My Friend, Sasha

BY BETSY ARBELOVSKY

Early in Parkinson's, I developed Freezing of Gait (FOG) and started falling. I just celebrated one year, five months without a fall! The previous year and a half I fell abruptly 19 times, with seven serious injuries. Sasha, my Medical Mobility and Alert Service Dog anticipates episodes of FOG, and alerts me so I sit instead of falling.

Service Dogs are routinely trained to pick up dropped items, open doors, pull off socks, retrieve a phone or provide stability. Sasha has close to 100 commands.

I've been told about 50% of these specially trained dogs can also alert. The dog "invents" their alert. Shortly after Sasha and I were partnered, our favorite time of day was a walk on the beach by my home. So, I was shocked one day, 20 yards into a walk, when Sasha blocked me like a gate and whined like crazy. I said, "bad boy" and tried to go around him, but he blocked me, so I pushed past him. I got 10 feet farther and he blocked me again, whining and wouldn't let me get around him to the right or to the left. Knowing he wanted to go to the beach more than I did, I realized something must be wrong and I sat on the ground. He lay in front of me for a few minutes and then jumped up like nothing was wrong and we went to the beach. Sasha has done this 44 times. Physicians who have seen us theorize Sasha sees and or hears a change in my gait that is imperceptible to us.

I am always being watched by Sasha, if I roll over in bed, he gets up and walks over to check on me. When I exercise in a pool, he lies by the side of the pool and never takes his eyes or ears off me. I've had four falls in his presence; twice I ignored his alert—a mistake I have sworn not to repeat!

Once, early in Sasha's training, I threw a ball, yelled fetch and only then realized I had his leash looped around my wrist. Quickly implementing an ultimately flawed plan, I tried to run to keep up with Sasha. If anyone had filmed it, the video would have gone viral! There were arms and legs going in all directions.

Sasha helps me up and down stairs, pausing on each stair, with his paws even so I can steady myself without injuring him. If I'm standing, he is gently leaned against me, monitoring me. He walks me slowly and safely across ice and through narrow spaces. I can confidently walk through a crowd with Sasha; because people automatically give me a bit of space, I'm not shoved. He has lain unnoticed under airline seats, in restaurants, yoga classes, theaters and at medical appointments. Sasha significantly reduces stress. Now my husband doesn't panic if I'm too slow to answer his call. Before partnering with Sasha, at least once a week, someone would ask me if I'd had too much to drink. Not one person has mistaken me for drunk with Sasha at my side!

All this comes with a price. When we get off a long flight, we make a bee line for the Service Dog Relief Area, NOT the Ladies Room. I always have lamb, liver snacks, a collapsible water dish, plastic bags (don't ask) and a clothing roller with me. Did I mention shedding? Service Dogs are groomed daily, but they still shed. Expensive food and veterinary care are only partially offset at tax time, as expenses for a Service Dog are treated just like other medical expenses.

Just like any other medical strategy, Sasha has side effects. Worry over loose, aggressive dogs is my greatest concern. Sasha is effective because he pays 100% attention to me. Many Service Dogs cannot work after being attacked by another dog.

I cherish lively discussions on a range of topics; now almost everyone talks to me about dogs. Almost everyone is wonderfully supportive and knowledgeable about Service Dog laws and etiquette, but the occasional hassles are exhausting and sometimes deeply painful.

Much less often, but more traumatic is when someone challenges your right to be in public. Federal Law is crystal clear, a person with a disability assisted by a Service Dog can go EVERYWHERE any other member of the public is allowed. There is no legally required or recognized "certification for Service Dogs," and it is a violation of a person's Civil Rights to demand any paperwork before granting access.

It is perfectly legal to ask a person two questions: Does the dog serve a person with a disability (yes or no), and what type of service does the dog provide (mobility, alert, sight, hearing)?

After a few sessions with a dog trainer, the family pooch may be able to help out, or at least not harm those who don't need a fully trained Service Dog. Dogs need to be walked and they naturally encourage longer strides; both bonuses for those dealing with Parkinson's. Visual stimulation can reduce the risk of Freezing of Gait, so any obedience trained dog continually swinging their

nose in front of your knee might prevent a fall. Any dog can be easily trained to pick up what you've dropped. Most importantly, teaching the family pooch to not pull or trip could prevent a catastrophic fall whether a person is dealing with a neurological challenge or not, and after all, we are all opposed to falling!

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Alcohol Consumption Is Not Associated with Parkinson's Disease Risk



Drinking alcoholic beverages is not associated with Parkinson's disease (PD) risk, according to a new study published in the June issue of *PLOS ONE*. However, in additional analyses the study did find that among those who drink only beer, greater consumption was associated with lower risk for PD and among those who consumed only liquor, greater consumption was associated with higher risk for PD. No association was found between wine and PD risk.

While previous studies have found that cigarette smoking and coffee consumption are associated with a lower risk of Parkinson's disease, research on alcohol consumption and PD risk has shown conflicting data. The researchers, led by Rui Lui, Ph.D., of the National Institute of Environmental Health Sciences in Research Triangle Park, NC, were interested in learning more about alcohol's effects on Parkinson's disease risk and how specific types of alcoholic beverages might influence that risk.

The study looked at 306,895 people (ages 50 to 71 at the time) who participated in the 1995-1996 NIH-AARP Diet and Health Study, which collected detailed lifestyle and dietary information from participants. Researchers followed up with study participants and compared the alcohol consumption of the 1,094 people who were diagnosed with PD between 2000 and 2006 to those who did not develop the disease.

Results

- Overall, total alcohol consumption was not associated with Parkinson's disease risk.
- People who drank beer only and consumed one or more beers per day had a 59 percent lower risk of PD than non-alcohol drinkers.
- People who drank liquor only and consumed one or more drinks per day had a more than two-fold higher risk of PD than non-alcohol drinkers.

What Does It Mean?

The major finding of this study is that there is no association between total consumption of alcoholic beverages and future risk of Parkinson's disease.

This is in contrast to caffeine consumption and smoking which are associated with lower risk for PD. Researchers have tried to explain the association between caffeine and smoking to PD in one of two ways - either that there is something protective in caffeine or in smoking which reduces the risk for PD, or, that people with PD are less predisposed to addiction, possibly because of reduced dopamine even before disease onset. The fact that alcohol consumption is not associated with reduced PD risk argues against the second hypothesis.

In additional analyses, the researchers found that among those who consume only beer, higher consumption was associated with a lower PD risk and among those who consume only liquor, higher consumption was associated with a higher PD risk. It is very difficult to interpret these findings because of the opposite effects of beer and liquor consumptions. Plus this study reports on an association between a substance (alcohol) and an outcome, but is not designed to prove definitive cause and effect.

The study did not investigate the reasons why beer and liquor affect Parkinson's disease risk. One proposed mechanism would be that beer consumption elevates plasma urate which is associated with lower PD risk. The higher risk of Parkinson's disease among liquor drinkers may be due to the detrimental effects of liquor's high ethanol content and its lack of vitamins and antioxidants.

Research on alcohol consumption and Parkinson's disease still shows conflicting data. People who do not drink alcohol should not start drinking beer to try to prevent PD.

Reference: Liu R, Guo X, Park Y, Wang J, Huang X, et al. (2013) Alcohol Consumption, Types of Alcohol, and Parkinson's Disease. PLoS ONE 8(6): e66452. DOI: 10.1371/journal.pone.0066452 <http://dx.doi.org/10.1371/journal.pone.0066452>

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Cupic custom homes opens their house to haps



Cupic Custom Homes recently hosted, *Come to our House*, an event that raised almost \$10,000 for HAPS programs and services. Inspired by family members with Parkinson's disease, Cupic Custom Homes owners Kristina and Shane Cupic organized this open house as a way to give back to the Parkinson's community while premiering their newest project, a fabulous multimillion dollar custom home in the Piney Point area. The evening was filled with live Latin jazz and refreshments along with Argentine Tango performances by members of HAPS' Tango class with *Bésame Mucho* sung by Raul Orlando Edwards.



HAPS sincerely thanks the Cupic family and Cupic Custom Homes for hosting such a wonderful event to benefit our organization and for providing a unique opportunity to raise awareness of Parkinson's. We also would like to thank all of the HAPS Tango group members who performed at the event.



Special thanks to all of the generous Underwriters who helped make this event possible: *Cactus Power & Light LLC, Law Office of Manuel Gonzalez, Pawan Grover M.D., P.A., Ken Kehoe & Company, Charlotte Leach and Martha Turner Properties, Brent and Dr. Mazie Leftwich, Law Office of Claudia Lozano, Memorial City Bank, Memorial MRI & Diagnostic, OrthoMed, Joyce P. Schechter and Ambassador Arthur Schechter, Spagnoletti & Co., Sprint Waste, Stewart Cadillac, Texas Orthopaedic & Aquatic Therapy Institute, and University General Hospital.*

Photos by Michael McKann

Parkinson's Enrichment Program pilot project update

HAPS continues to recruit participants for a pilot project for an extended enrichment program for people with Parkinson's disease. This four-hour program, beginning October 11, 2013, will meet once a week for six weeks at Memorial Drive Lutheran Church and is intended to function as a social, educational and entertainment opportunity for those who participate. Each weekly session will include speakers on various Parkinson's and non-Parkinson's related topics. The program will also include discussions, peer support and recreational activities such as Wii, card games, book club and more!

HAPS is looking for 15-20 people with mild to moderate Parkinson's disease who can function independently and can commit to the six-week pilot program. If you are interested in participating, contact the HAPS office at harris@hapsonline.org or 713-626-7114.

How's HAPS Doing?

HAPS engages in ongoing assessment of its programs by evaluating the level of interest and need reflected by participation and attendance, and through feedback from clients utilizing its services. In addition, HAPS maintains a dialogue with similar regional and national organizations to share perspectives regarding the value of programs and services that address chronic disease care management for the Parkinson community. HAPS meets formally with peer groups at the World Parkinson Congress and at regular meetings with a consortium of independent regional Parkinson's organizations from across the U.S.

Continuing communication with medical professionals and movement disorder specialists on the HAPS Medical Advisory Board also assists our organization in its efforts to improve the quality of life for the growing Parkinson's population in the Houston area. Together, we work in partnership to provide programs that foster prolonged mobility, functional independence, enrichment and opportunities for social connection.

We would like to hear from you to help us determine how we are doing in providing you with appropriate programs, groups and services. **Please complete the enclosed HAPS Program Evaluation and return by November 1, 2013.** Responses will remain anonymous and may be mailed in the enclosed envelope, scanned and emailed to info@hapsonline.org or sent by fax to 713-521-3964. If you have any questions, contact HAPS at 713-626-7114.



**4TH ANNUAL
PARKINSON'S CAREGIVER CONFERENCE:
dealing with the day-to-day**

**Saturday, September 7, 2013
8:30 am—2:00 pm**

United Way 50 Waugh Drive Houston, TX 77007

Houston Area Parkinson Society (HAPS) and Parkinson's Disease Research, Education & Clinical Center (PADRECC) invite you to attend this special, full-day educational event designed exclusively for caregivers of individuals with Parkinson's disease (PD). This program will offer participants helpful, practical information for managing the challenges of caring for someone with PD including sessions on medication management; communication and swallowing; independence and safety; nutrition; understanding cognitive changes and more!

This event is a free conference for caregivers only. Breakfast, lunch and educational materials are included. Registration is required by phone at 713-626-7114 or email at crist@hapsonline.org.



Research Roundtable Comes to Houston

The Michael J. Fox Foundation invites you to a private Research Roundtable to hear from leading scientists in the field about the status of research toward next-generation treatments for Parkinson's disease.

Dave Iverson, an award winning journalist and contributing editor for The Michael J. Fox Foundation, will lead a panel discussion on "Improving Symptomatic Treatments, Developing Disease-modifying Therapies and the Role of Biomarkers in Research." Audience Q&A will follow. Light refreshments will be provided.

WHEN: *Monday, September 9, 2013
6:00 – 8:00 PM
(6 – 6:30 Meet and Greet/Registration)*

WHERE: *Hyatt Regency Houston
1200 Louisiana Street
Houston, Texas*

Register by Wednesday, September 4th.
Registration is complimentary. Seating is limited.

Contact Hallie Nazar de Jaucourt, 212.509.0995 ext. 204
or hnazardejaucourt@michaeljfox.org

FEATURED PANELISTS:

Brian Fiske, PhD
*Vice President of Research Programs
The Michael J. Fox Foundation*

Joseph Jankovic, MD
*Professor of Neurology
Distinguished Chair in Movement Disorders
Director, Parkinson's Disease Center and Movement Disorders
Clinic Baylor College of Medicine - Department of Neurology*

NEWLY DIAGNOSED EDUCATION PROGRAM

For those who have been diagnosed with Parkinson's disease within the last three years.

Saturday, September 21st 8:30 am — 12:30 pm Presented by Dr. Mya Schiess

Contact the HAPS office for more information at 713-626-7114 or crist@hapsonline.org

CONTRIBUTIONS

We are extremely grateful to the following individuals for their generous support of HAPS. Without the continued support of our donors, none of our programs or services would be possible.

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While we make every effort to be accurate and thorough, it is possible to accidentally omit or misspell a name. Please contact the HAPS office with corrections.



Houston Area Parkinson Society mourns the loss of Board member Mark Ohls who died after a brief illness August 12th. Mark joined the HAPS Board of Directors in January of this year and contributed significantly to the organization in the time he served. Inspired by fellow Board members, the Mark Ohls Memorial Fund has been established as a lasting tribute to this valuable member of the HAPS family to support emergency respite care needs among HAPS clients. Mark will be remembered for his outstanding warmth, sincere enthusiasm and loyal commitment to community service.

Houston Area Parkinson society

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