

APRIL 2011

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Marathon Update

HAPS will be recognized with the 2nd place award for top fundraising charity without a team-in-training program at the annual Marathon awards luncheon!

April is Parkinson's Awareness Month

Born on April 11, 1755, Dr. James Parkinson, a British physician, first described Parkinson's disease in a detailed medical publication called "An Essay on the Shaking Palsy" in 1817. The essay was based on six cases he observed in his medical practice and on walks through his neighborhood. Sixty years later, French neurologist Jean Martin Charcot was the first to truly recognize the importance of Parkinson's work and named the disease after him.

Today, nearly 200 years after Parkinson's disease was first identified, there are over one million Americans living with the disease. While much has been discovered about the disease, much remains a mystery such as what exactly causes it; and despite the best efforts of science, there is still no known cure.

Together, with millions around the world we recognize April as Parkinson's Awareness Month. You can get involved too! Help spread the word by educating yourself and others about Parkinson's disease and the services HAPS offers the community. End Parkinson's Awareness Month on a good note by attending the HAPS Annual Educational Symposium on Saturday, April 30th. At this event, you can learn about advances in research and treatment, get helpful information about managing Parkinson's and you can support the global effort to fight PD by signing the Global Parkinson's Pledge.

2011 Annual Educational Symposium

MOVING FORWARD WITH PARKINSON'S

LIVING UNTIL A CURE IS FOUND

Saturday, April 30, 2011

8:30 am—3:30 pm

United Way

50 Waugh Drive ~ Houston, TX 77007

See insert for program and registration details

Registration April 1st—25th



The printing and distribution of this newsletter was partially supported by a grant from



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

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An Astronaut's Journey with Parkinson Disease

By Rich Clifford

It was just past midnight on March 14, 1996. I began the day strapped into the crew compartment of a space shuttle headed for orbit. I was minutes away from the launch of shuttle mission STS-76, and I could hear the voice of launch control counting off the seconds until finally I heard, "3, 2, 1 and *liftoff* of the shuttle *Atlantis* on a mission to the Russian MIR space station." That pre-dawn launch was my third space shuttle mission as a United States Astronaut. It was, however, my first mission to space after being diagnosed with early Parkinson disease (PD).

It seems improbable if not impossible: an astronaut with PD had not only been certified for space flight, but had also been certified to perform a planned space walk on the MIR space station. That morning, as I began the ascent into orbit to rendezvous with the MIR, I thought about my own personal journey leading up to that moment. It was as hard as any I'd ever faced, but one that I had never given up on. A journey that had begun almost two years earlier.

My second mission had been STS-59 in April 1994 and it was very successful. I felt completely fit during and after the flight. About six months later I went in for my annual flight physical. Everything, including my standard neurological exam, was satisfactory. Just as a favor, I asked the flight surgeon after the exam if I could have an orthopedic surgeon look at my right shoulder (I played competitive racquetball and thought I might have recently injured it during a game). He asked me where it hurt and I told him it didn't hurt at all. Rather, my right arm just seemed to hang without moving when I walked. I could tell I must have touched a nerve (no pun intended) because he immediately called for the Chief Flight Surgeon. The Chief asked me to walk with him down the hall. Little did I know how that walk would change my life. The next thing I knew, the Chief informed me that he was taking me into Houston the next day to see an expert at the Medical Center. I was surprised at the sudden and ominous turn of events, as I had assumed my visit would have yielded a quick fix and allowed me to resume my competitive racquetball. That's when the Chief informed me I was going to see a neurologist, a man by the name of Dr. Joseph Jankovic. I assumed this was part of the normal sequence to get my arm fixed.

I was surprised by the urgency of the visit, and more than a little confused when, after taking a careful history and examining me, Dr. Jankovic informed me that I had PD. I had never heard of this disease and as someone who considered himself to be in excellent physical condition, I naturally assumed it was something I could conquer. In fact, my response was something like, "OK, fix it so I can get back to my racquetball!" Then, reality hit me. Hard! The doctors explained I had several tests ahead of me. PD was a clinical diagnosis and confirmed only by eliminating - through tests - all other neurological disorders. Needless to say, racquetball was no longer on my list of priorities.

The test results came back negative. The doctors were right: I had PD. But my only symptom was that my right arm didn't move when I walked. It seemed impossible. I didn't want to believe it, and for a while I refused to believe it.

So many things went through my head when I began to learn more about my condition, but I was resolute and determined not to let it affect my outlook. The medical community respected my privacy and only those senior NASA managers with a need to know were informed. They asked me what I wanted to do, and my response was quick: I wanted to remain on flight status and remain in the cue for a future space flight. *I wanted to remain an astronaut.*

According to researchers, PD is a progressive degenerative disease that occurs over time. That meant it was very likely that I had PD prior to my first shuttle flight STS-53 in December 1992. I saw no limitations to what I could do just because I had PD, and I used all of the available research to build a case for why I should continue to fly. Thankfully, the NASA flight surgeons, senior NASA management, and my family supported me, and I was granted return-to-flight status under the condition that I would be watched closely by the flight surgeons. I also knew that I could not disclose my condition publicly.

Keeping this secret between myself and those closest to me, I was subsequently assigned to STS-76. I was to be a member of the crew, but was told I would not be assigned to perform the planned space walk (extra-vehicular activity, or EVA, in NASA speak). I, along with another astronaut named to the STS-76 crew, had performed the majority of the development testing of hardware and operational procedures for the experiment packages to be deployed during the planned space walk. In other words, knowing as much as we did about the subject, our expectations were that we would be assigned to perform the EVA. I informed management that I wanted to do the EVA and that I didn't know there were limitations imposed on my capabilities. I think they were actually surprised by my desire to perform the space walk, despite my condition.

Before long, they reassigned me the EVA. The mission was highly successful, including the six-hour long EVA during which my crewmate and I attached four MIR Environmental Effects Payload experiments to the station's docking module to better understand the environment around MIR over an 18-month period.

Looking back, I recognize the difficult decision NASA senior management made in assigning me to STS-76. I am thankful to have had the full support of the Flight Surgeons, Dr. Joseph Jankovic, and Johnson Space Center management. They presented my capabilities to the NASA Headquarters Space Flight Medical Review board and I know it was not an easy decision for the board and senior management to clear me for flight. I am grateful for their support in realizing the risk they took with me when there were dozens of other qualified astronauts who could have performed this mission. It is a testimony to their certification processes that they were assured I could perform the mission.

And although no one ever restricted me from going public with my PD, I knew it was best to remain quiet at the time. Too many questions of the managers and medical review board by an inquiring press would have proven to be embarrassing for all of us. I could imagine the focus of the typical question, "How could you let someone with Parkinson disease fly in space?" I am forever appreciative for the opportunity these people afforded me. They took the high road instead of making the easy decision, which would have been to ground me permanently.

With this article I have now gone public. Following my third and final space shuttle mission, I left NASA in January 1997 and joined the Boeing Company as Space Station Flight Operations Manager. In 2007, I became the Deputy Program Manager of Boeing's Space Shuttle Program, a position to which I am committed until the Space Shuttle fleet's retirement in 2011. In writing this article, I hope to inspire others with PD by showing them that Parkinson is not the end of your life. I believe that mental limitations are defined by what you make of your situation. In the famous words of former NASA Flight Director Gene Kranz, "Failure is not an option." I am continually reminded of this by my best support group: my wife Nancy and my sons Richard and Brandon. Without their encouragement I probably would have followed a different path.

It has been 17 years since I received my initial diagnosis. I left the Astronaut ranks in 1997 for reasons not associated with PD. The disease has progressed as you would expect, but its acceleration is following a very low ramp, thanks to the help of my doctors and continued advances in PD research. I am still active in the workforce and play golf as often as I can. All in all, I am far from giving in to the limitations of PD, but rather I'm planning to - as the late Paul Harvey said at the start of each of his radio shows - "stand by for the rest of the story."

Rich Clifford is a member of the HAPS Board of Advisors.

His story will appear in the Spring 2011 issue of the National Parkinson Foundation's newsletter, *Parkinson Report*.

HAPS PD EXERCISE AND SUPPORT GROUPS

CENTRAL

PD & DEMENTIA/ LEWY BODY DEMENTIA CAREGIVER SUPPORT GROUP	4th Monday of month 10:30 am—12:15 pm	Support group for caregivers of persons with Parkinson's and dementia or Lewy Body Dementia	For more information Kathleen Crist, LMSW 713-626-7114
WATER EXERCISE	Mondays 2:00—3:00 pm Thursdays 11:00 am—12:00 noon	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information and to request participant paperwork Alfonso Hernandez 713-520-8670
EXERCISE	Tuesdays 3:30—4:30 pm	TIRR 2455 S. Braeswood Houston, TX 77030	For more information Alfonso Hernandez 713-520-8670
SPEECH & EXERCISE	Wednesdays 2:30—4:00 pm	Memorial Dr. Presbyterian Church 11612 Memorial Dr. Room 102 Houston, TX 77024	For more information Alfonso Hernandez 713-520-8670
YOUNG ONSET SUPPORT GROUP	2nd Wednesday of month 7:00—9:00 pm	For those younger than 55 with Parkinson's disease	For more information Kathleen Crist, LMSW 713-626-7114
TAI CHI	Tuesdays 10:30—11:30 am	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
TANGO	Wednesdays 1:00—2:15 pm	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information Kathleen Crist, LMSW 713-626-7114
DANCE	Mondays 12:45—2:00 pm	Ballet Academy 610 Preston Houston, TX 77002	For more information Kathleen Crist, LMSW 713-626-7114
SINGING	2nd Monday of month 12:00—12:30 pm	Ballet Academy 610 Preston Houston, TX 77002	For more information Kathleen Crist, LMSW 713-626-7114
EXERCISE	Thursdays 9:30—10:30 am	W. Gray Adaptive Recreation Center 1475 West Gray Houston, TX 77019	For more information Alfonso Hernandez 713-520-8670
POST DBS SUPPORT GROUP	4th Tuesdays of every other month 6:00—7:30pm	For those who have completed Deep Brain Stimulation Surgery	For more information Kathleen Crist, LMSW 713-626-7114
 NEW PD SUPPORT GROUP	3rd Tuesday of month 10:00—11:30 am	American Red Cross 2700 SW Freeway Houston, TX 77098	For more information Kathleen Crist, LMSW 713-626-7114
TAI CHI	Fridays 11:00 am—12:00 noon	Memorial Dr. Presbyterian Church 11612 Memorial Dr. Room 102 Houston, TX 77024	For more information Alfonso Hernandez 713-520-8670

SOUTH

EXERCISE & SPEECH	Mondays Speech 3:30—4:15 pm Exercise 4:15—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
WATER EXERCISE	Thursdays 4:00—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	3rd Monday of month 4:00—5:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Kathleen Crist, LMSW 713-626-7114
EXERCISE	Wednesdays 4:00—5:00 pm	St. Andrew's Episcopal Church 2535 E. Broadway, FM 518 Pearland, TX 77581	For more information Alfonso Hernandez 713-520-8670

EAST

WATER EXERCISE	Tuesdays Thursdays 2:00—3:00 pm	Bay Area Rehabilitation Center 3513 Decker Drive Baytown, TX 77520	For more information Alfonso Hernandez 713-520-8670
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**ALL GROUPS ARE FREE OF CHARGE—PLEASE VISIT THE WEBSITE AT WWW.HAPSONLINE.ORG OR
CALL TO CONFIRM GROUP TIMES AND LOCATIONS**

SOUTHEAST

SPEECH & EXERCISE	Tuesdays Speech 1:30—2:00 pm Exercise 2:00—3:00 pm	Kindred Hospital Bay Area 4801 E Sam Houston Parkway Pasadena, TX 77505	For more information Alfonso Hernandez 713-520-8670
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SOUTHWEST

EXERCISE	Mondays 10:00—11:00 am	First United Methodist Church 1220 FM 1092 Missouri City, TX 77459	For more information Alfonso Hernandez 713-520-8670
SPEECH & EXERCISE	Tuesdays Exercise 2:00—2:45 pm Speech 2:45—3:45 pm	St. Phillips Methodist Church 5501 Beechnut Room 104 Houston, TX 77096	For more information Alfonso Hernandez 713-520-8670
PROGRESSIVE SUPRANUCLEAR PALSY SUPPORT GROUP	3rd Saturday of month 1:00 pm	Memorial Hermann SW Houston Prof Building II - Learning Center B Hwy 59 at Beechnut Houston 77074	For more information Karen Kennemer 281-358-2282

WEST

SPEECH & EXERCISE	Tuesdays Speech 5:20—6:05 pm Exercise 6:05—6:50 pm	1st United Methodist Church of Katy 5601 5th Street Room 111 Katy, TX 77493	For more information Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	Please Call	1st United Methodist Church of Katy 5601 5th Street Room 107 Katy, TX 77493	For more information Kathleen Crist, LMSW 713-626-7114

NORTHEAST

EXERCISE	Wednesdays 12:00 noon—1:00 pm	HealthSouth Rehabilitation Hospital 19002 McKay Blvd. Humble, TX 77338	For more information Alfonso Hernandez 713-520-8670
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NORTH

WATER EXERCISE	Mondays 12:30—1:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	For more information Alfonso Hernandez 713-520-8670
SPEECH	Tuesdays 1:45—2:30 pm	Reliant Rehab Hospital N Houston 117 Vision Park Blvd. Shenandoah, TX 77384	For more information Alfonso Hernandez 713-520-8670
EXERCISE & TAI CHI	1st, 3rd, 5th Thursdays 1:30—2:30 pm 2nd, 4th Thursdays	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670
CAREGIVER SUPPORT GROUP	1st Thursday of month 1:30—2:30 pm	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Kathleen Crist, LMSW 713-626-7114
DANCE & SINGING	2nd Friday of Month 12:00—2:00 pm	Woodlands United Methodist Church 2200 Lake Woodlands Drive The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670

NORTHWEST

TAI CHI	Fridays 11:00—12:00 noon	Tomball United Methodist Church 1603 Baker Drive (Faith Building) Tomball, TX 77375	For more information Alfonso Hernandez 713-520-8670
TAI CHI	Wednesdays 10:00—11:00 am	John Wesley United Methodist Church 5830 Bermuda Dunes (Boy Scout Building) Houston, TX 77069	For more information Alfonso Hernandez 713-520-8670
SPEECH	Thursdays 10:00—11:00 am	Foundry—A United Methodist Congregation 8350 Jones Road (Scout Building) Houston, TX 77065	For more information Alfonso Hernandez 713-520-8670
CROSSROADS GROUP	2nd Wednesday of every other month 7:00—9:00 pm	For individuals with PD between age 55 and 70.	For more information Kathleen Crist, LMSW 713-626-7114

A Note of Thanks...

We would like to recognize and offer very special thanks to those members of the HAPS family who have contributed so much over the past year by organizing creative fundraising enterprises that help make our efforts possible and help raise awareness the of Parkinson's disease all year long:

Dominique & Taka Furuta – *A Grand Night for Dreaming*, a musical event that brought local talent together with aspiring singers and musicians who have Parkinson's

David LeMaster & Jerry Ivins – *Shaken*, a play written by actor, director, English professor, playwright and person with Young Onset Parkinson's about his journey with PD

Angy & Jim Newell – Participation in the Janus Charity Challenge for the Ford Ironman in Florida

Jody Wheelless & Dr. Richard Simpson – Holiday Fundraiser at The Village Firefly

Pamela & Rod Skaufel – Running the Washington D.C. Half Marathon raising funds for both HAPS and the Parkinson's Association/ Mid West Branch in Ireland

Doug Benzuly & Michael Young – *Playing for Parkinson's*, a music fundraising event

Janet & George Hill – *For the Sake of the Shot*, Randy Rogers Band Golf Tournament



Dick Westney & HAPS President
Frank Donnelly

Special thanks to Dick Westney of Westney Consulting Group who has provided pro bono consultation to HAPS over the past year. This valuable contribution was made possible through an initiative with the United Way's Management Assistance Organizational Assessment Program in collaboration with the Harvard Business School Alumni Association.

Thank You! Thank You!

Many thanks to Dr. Mya Schiess, HAPS Medical Advisory Board member, who led the presentation of the Newly Diagnosed Education Program, Saturday, February 19th, 2011. We appreciate your time and expertise.

On Sunday, March 20th, nearly 200 people came out to hear *great* music and to support a *great* cause at The Big Easy. *Playing for Parkinson's* featured six top-name bands from the area performing the blues, rock n' roll and masterful music renditions throughout the afternoon. Originated and organized by Doug Benzuly and Michael Young, this live music event raised an amazing \$12,000 in contributions to help fund HAPS services and programs. HAPS would like to recognize and applaud Doug and Michael for their outstanding efforts, and thank all of the individuals who supported this event so generously – making it possible for HAPS to fulfill its mission to improve the quality of life for those affected by PD.



Anne Thobae, Ellen & Frank Donnelly, Doug & Cindy Benzuly, Michael Young & Susan Otte and Alfonso Hernandez at The Big Easy



Playing for Parkinson's organizer Doug Benzuly on stage at The Big Easy

CONTRIBUTIONS

We are extremely grateful to the following individuals for their generous support of HAPS.

GIFTS

Sadie Mae Hunt
Ellin and Robert Grossman
Doris and Ken Gainer
Khalid Halabi
Mary Margaret and Russ Schulze
Margaret and Robert Merchant
Mae Holm

IN MEMORY

Steven Kanaly
Patsy and Richard Sutton

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Elaine Greenberg
Esther and Glenn Bermann

Pamela and Rod Skaufel's
Washington DC Half Marathon Run

Daryl Warren
Hillary Wiese
Kurt Welborn
Chantay Canty
Leslie White
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Charles Pena
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Robin Hill
Michael Faust
Lisa Schultz
Shailesh Mayekar
Eddy Kruijs

Live Music and Parkinson's...

The Fort Wayne Philharmonic, Indiana University-Purdue University Fort Wayne and Physician's Health Plan conducted a study that looked at how watching a live concert would affect people with Parkinson's. The results, although subjective and based on each participating person's self evaluation, showed that tremors, stiffness, handwriting, swallowing and energy levels all improved during the music. While the results are exciting, this study will likely lead to more studies that look at objective findings, and the eventual results could possibly be life-changing for people living with Parkinson's.

Save the Date

Join us as we kick off our Summer Lecture Series

More details to follow in the May newsletter

Wednesday, May 25, 2011

6:00 – 7:30 pm

American Red Cross Building
2700 SW Freeway ~ Houston, TX 77098

Houston Area Parkinson society

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