

## My Road to Deep Brain Stimulation

By Nina P. Brown



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I know Parkinson's effects everyone differently, but after 25 years of a relatively slow progression, I wasn't prepared for what happened. The handful of expensive medications I used to take on a precise 3-hour schedule had increased to every hour or hour and a half.

They no longer overcame the dystonia or cramping in my toes that made it difficult to walk. I had such unbearable sweating episodes that I constantly carried around battery operated fans. My coordination was poor, I was weak, and although I had been fortunate not to have previously had much of a tremor, I developed one before the surgery.

Prolonged use of the same medication that allowed me to move at all caused severe dyskinesias - wiggly, tiring, unsightly, uncomfortable and uncontrollable movements. I fluctuated between dyskinesias and being totally "frozen" ----so rigid that I was actually reduced to being bedridden. There was the constant threat of losing my balance, falling and breaking bones. The emergency room knew my name, if not for cracked ribs, then for aspirating pills. My future looked pretty bleak. I was on a fast-track to total disability.

For years, different doctors told me that I was a perfect candidate for Deep Brain Stimulation, but I wasn't ready. I had been following a Parkinson's Internet discussion group. Reading everything that was written about DBS, I felt as if I would be trading in one set of problems for another, but the problems that accompany DBS are minor compared to what I was living with. It wasn't a question of life or death, it was the quality of life. And since I had waited until I basically had no quality of life; when I was ready, I was more than ready.

I had DBS surgery December 3, 2009. I am doing well. Recovery has been slow due to muscles that atrophied from many months without physical activity, but I am finding that physical therapy helps. I am better than I was before the surgery - I have "on" times again, I can move and I am not taking medications every hour. Frustration and patience are two of my biggest challenges, but I am determined to overcome them. I have learned to celebrate all the improvements big or small and look forward to what is to come, accepting that it may come slowly. With my eyes on the road a head of me—I haven't given up hope!

### MARK YOUR CALENDARS

2<sup>nd</sup> World Parkinson Congress  
Sept 28– Oct 1, 2010  
Glasgow, Scotland

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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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# Marathon Mania!

The 2010 Chevron Houston Marathon was an enormous success—our final Marathon fundraising total was an unprecedented \$56,150! HAPS owes this year's achievement to so many people for all they did to help the organization reach its goal. We couldn't have doubled the amount raised in 2009 without the determination and guidance of our Marathon Chair, Fred Stephens. HAPS was honored to receive support from our Sidewalk Squad Sponsor, Wartsila; T-shirt Sponsor, Sterling McCall Acura; 53 walkers and runners; and over 500 people whose contributions helped further the mission of HAPS.

## HAPS TOP 5 FUNDRAISERS!

**Fred Stephens** \$8,185 • **Killian Gilbert-Smith** \$3,740 • **Gabe Zamora** \$2,989 • **George Puig** \$2,775 • **Claire Calvin** \$2,524

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# HAPS PD EXERCISE AND SUPPORT GROUPS

ALL GROUPS ARE FREE OF CHARGE—PLEASE CALL TO CONFIRM GROUP TIMES AND LOCATIONS

## CENTRAL

<b>PD &amp; DEMENTIA/ LEWY BODY DEMENTIA CAREGIVER SUPPORT GROUP</b>	4th Monday of month 10:30 am—12:15 pm	Support group specifically for caregivers of persons with Parkinson's and dementia	For more information and to see if this group is appropriate for you Kathleen Crist, LMSW 713-626-7114
<b>WATER EXERCISE</b>	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
<b>EXERCISE</b>	Tuesdays 3:30—4:30 pm	TIRR 2455 S. Braeswood Houston, TX 77030	For more information Alfonso Hernandez 713-520-8670
<b>SPEECH &amp; EXERCISE</b>	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
<b>YOUNG ONSET SUPPORT GROUP</b>	2nd Wednesday of month 7:00—9:00 pm	For those younger than 55 with Parkinson's disease	For more information Celeste Harris, LMSW 713-313-1621
<b>TAI CHI</b>	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
<b>TANGO</b>	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
<b>DANCE</b>	Mondays 12:45—2:00 pm	Houston Ballet Academy 1921 West Bell Street Houston, TX 77019	For more information Kathleen Crist, LMSW 713-626-7114
<b>EXERCISE</b>	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
<b>POST DBS SUPPORT GROUP</b>	4th Tuesdays of every other month 6:00—7:30pm	For those who have completed Deep Brain Stimulation Surgery	For more information Celeste Harris, LMSW 713-313-1621
<b>TAI CHI</b>	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

<b>EXERCISE &amp; SPEECH</b>	Mondays Exercise 9:00—9:45 am Speech 9:45– 10:30 am	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
<b>WATER EXERCISE</b>	Thursdays 12:00—1:00 pm	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Alfonso Hernandez 713-520-8670
<b>CAREGIVER SUPPORT GROUP</b>	3rd Monday of month	Clear Lake Rehab Hospital 655 E. Medical Center Blvd. Webster, TX 77598	For more information Celeste Harris, LMSW 713-313-1621
<b>EXERCISE</b>	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

<b>WATER EXERCISE</b>	Tuesdays Thursdays 2:00—3:00 pm	Bay Area Rehabilitation 7 Swalm Center Drive Baytown, TX 77520	For more information Alfonso Hernandez 713-520-8670
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# HAPS PD EXERCISE AND SUPPORT GROUPS

GROUP SCHEDULES CAN ALSO BE VIEWED ON THE WEBSITE AT [WWW.HAPSONLINE.ORG](http://WWW.HAPSONLINE.ORG)

## SOUTHEAST

<b>SPEECH &amp; EXERCISE</b>	Tuesdays Speech 1:30—2:00 pm Exercise 2:00—3:00 pm	Kindred Bay Area Hospital 1004 Seymour Street Pasadena, TX 77506	For more information Alfonso Hernandez 713-520-8670
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## SOUTHWEST

<b>EXERCISE</b>	Mondays 10:00 –11:00 a,	First United Methodist Church 1220 FM 1092 Missouri City, TX 77459	For more information Alfonso Hernandez 713-520-8670
<b>SPEECH &amp; EXERCISE</b>	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
<b>PROGRESSIVE SUPRANUCLEAR PALSY SUPPORT GROUP</b>	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

<b>SPEECH &amp; EXERCISE</b>	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
<b>CAREGIVER SUPPORT GROUP</b>	3rd Tuesday	1st United Methodist Church of Katy 5601 5th Street Room 107 Katy, TX 77493	For more information Celeste Harris, LMSW 713-313-1621

## NORTHEAST

<b>EXERCISE</b>	Wednesdays 10:00— 11:00 am	First United Methodist of Humble 800 East Main Humble, TX 77338	For more information Alfonso Hernandez 713-520-8670
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## NORTH

<b>WATER EXERCISE</b>	Mondays 12:00 noon—1:00 pm	HealthSouth 18550 IH 45 S Conroe, TX 77384	For more information Alfonso Hernandez 713-520-8670
<b>EXERCISE &amp; TAI CHI</b>	1st, 3rd, 5th Thursdays 1:30—2:30 pm 2nd, 4th Thursdays	Woodlands United Methodist Church 2200 Lake Woodlands Drive (Aldersgate Hall) The Woodlands, TX 77380	For more information Alfonso Hernandez 713-520-8670
<b>CAREGIVER SUPPORT GROUP</b>	1st Thursday of month	Woodlands United Methodist Church 2200 Lake Woodlands Drive (Aldersgate Hall) The Woodlands, TX 77380	For more information Kathleen Crist, LMSW 713-626-7114

## NORTHWEST

<b>EXERCISE</b>	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
<b>CAREGIVER SUPPORT GROUP</b>	Please call	Tomball United Methodist Church 1603 Baker Drive (Faith Building) Tomball, TX 77375	For more information Celeste Harris, LMSW 713-313-1621
<b>SPEECH</b>	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
<b>CROSSROADS GROUP</b>	2nd Wednesday of every other month 7:00—9:00 pm	For individuals with PD between age 55 and 70.	For more information Celeste Harris, LMSW 713-313-1621

# SAVE THE DATE



***Approaching  
Parkinson's  
Creatively:  
New Treatment for  
a New Decade***

**HAPS Annual Educational Symposium  
Saturday, April 24, 2010  
10:00 am—2:45 pm  
United Way  
50 Waugh Drive  
Houston, TX 77007**

Approaching Parkinson's Creatively:  
New Treatments for a New Decade

10:00	Check In
10:15	Introduction
10:20	Keynote Speaker
11:20	Lunch
12:00	Breakout Session I (45 minutes)
1:00	Breakout Session II (45 minutes)
2:00	Breakout Session III (45 minutes)
2:45	Adjourn

Breakout session workshops include:

**Art • Dance • Singing • Tango • Wii-habilitation**

## KEYNOTE SPEAKER

"Laughing" Laura Gentry

Certified Laughter Yoga Instructor

Laughter Yoga combines Yogic breathing with unconditional laughter. This technique is based on the scientific fact that the body cannot differentiate between fake and real laughter. The physiological and psychological benefits are the same: reduced stress, lowered blood pressure, strengthened immune system, decreased physical pain and boost of mood and happiness. Created by Dr. Madan Kataria, a family physician from Mumbai, India, Laughter Yoga has become a worldwide phenomenon with over 6000 laughter clubs in 60 countries.



**Join us for a day of fun,  
enjoyable exercise,  
creativity and socialization.  
The event includes lunch  
and is free of charge!**

Check out her website [www.laughinglaura.com](http://www.laughinglaura.com) for more information on Laughing Laura Gentry and Laughter Yoga!

# CONTRIBUTIONS

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## New Information from the FDA on Azilect

Based on the results of a study reviewed by the Food and Drug Administration (FDA), many of the food and medications restrictions associated with Azilect therapy have been removed or reduced.

**Food**—The dietary tyramine restriction is not ordinarily required when Azilect is taken at recommended dosages. Tyramine is found in certain foods and beverages such as tap beer and soybean products. You should still avoid foods with very large amounts of tyramine (like aged cheese) because of the potential for interaction with Azilect resulting in sudden, large increases in blood pressure.

**Medications**—Prescribing information no longer says to avoid common medications like decongestants and other cold products. While use is no longer restricted, you should use caution while taking these medications with Azilect due to the potential for elevated blood pressure. Azilect should still not be taken with other MAO inhibitors, certain pain medications, some cough medicines (containing dextromethorphan) and specific muscle relaxants.

Teva Neuroscience is in the process of informing patients, doctors and pharmacists about these changes. You may see or hear outdated information for awhile. If you have any questions during this time, talk to your doctor. You may also want to contact Teva Neuroscience at **1-877-4AZILECT** 8am-5pm CST.

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