

NOVEMBER 2014

IN THIS ISSUE

5 th Annual Caregiver Conference	2
Article: Women & Parkinson's Disease: Understanding this Specific Journey	4
HAPS Exercise & Support Group Schedule	Insert
PDF Expert Briefing	6
HAPS Holiday Sing-Along	6
Welcome Angelica	6
Contributions and Tributes	7
Grocery Store Rewards Programs	7

Changing the Face of Parkinson's: Forty and Forward!

This November, we not only celebrate National Family Caregivers Month and Thanksgiving—Houston Area Parkinson Society also celebrates forty years of serving the Houston community. HAPS was established in 1974 by a small group of families who were determined to fill a critical need for support. They united to discuss that need because they knew what was required to care for a loved one with Parkinson's, and they laid the foundation with ardent grassroots efforts that set the stage for HAPS to become the organization it is today.

In this historic year, we recognize the extraordinary vision of our founders and the enduring contributions and vigilance of the caretakers who have nurtured the organization, furthered its mission and allowed HAPS to become a national model for Parkinson's patient support organizations. And so we take great pride in acknowledging HAPS Past Presidents and showing our gratitude for their invaluable gifts of time, talent and support, having led the organization with passion and commitment through the years. Their noble efforts have contributed to building, sustaining and fortifying our organization, enabling our accomplishments.

We are amazed at the outstanding generosity of our supporters—foundations, corporations, organizations, people with Parkinson's, caregivers, family members and friends—who have collectively made it possible for HAPS to reach this 40th anniversary milestone. It is remarkable to think about how far we have come since those first few years, looking back from then to now...

4 exercise & discussion groups each month to 170 exercise & support groups each month
18 clients attending programs monthly to 800 clients attending programs monthly
288 households receiving our newsletter to 3,500 households receiving our newsletter
\$3,400 HAPS Annual Budget to \$814,000 HAPS Annual Budget

HAPS depends on all the stakeholders who are impacted by the work we do to help us achieve our mission—one that calls for innovative programs and comprehensive services that include **education, advocacy, therapeutic exercise, enrichment programs, support groups, transportation, information and referral, case management, subsidized respite care and emergency financial aid.** All which are free of charge but not without cost.

While we reflect on our beginnings, we look ahead to the future with the promise and continuing commitment to providing crucial programs and essential services that allow those with Parkinson's to have the best quality of life possible—until a cure is found. Together, we can build on this strong foundation and, with your help, carry the mission forward into the next forty years. **Help HAPS continue to make a difference by making your contribution today!**

HAPS groups will be closed Tuesday, November 11th in observance of Veteran's Day and also the week of Thanksgiving!



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.

To request permission to reprint content published in this newsletter, please contact the HAPS office at 713-626-7114 or info@hapsonline.org.



5th Annual Parkinson's Caregiver Conference: What now? What next?

Saturday, December 6, 2014

8:30 am–2:30 pm

United Way
50 Waugh Drive
Houston, TX 77007

CONFERENCE AGENDA

- 8:30 Check-in and Continental Breakfast**
- 8:50 Welcome**
- 9:00 Defining Dementia**
- 9:50 Break**
- 10:00 Medication Management**
- 11:00 Lunch**
- 11:30 Break**
- 11:40 Breakout Session I**
1. Bed Mobility
 2. Understanding Speech & Swallowing
 3. What You Need to Know about DBS
 4. Coping While Caring
- 12:30 Break**
- 12:40 Breakout Session II**
1. Understanding Speech & Swallowing
 2. Get Up and Go
 3. Legal Planning
 4. Nutrition and Parkinson's Disease
- 1:30 Break**
- 1:40 Breakout Session III**
1. Get Up and Go
 2. Legal Planning
 3. Coping While Caring
 4. Nutrition and Parkinson's Disease
- 2:30 Adjourn**

"Sometimes those who work the hardest and give the most are the quietest about what they do...they inspire the rest of us."

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.

This event is a free conference for caregivers only. Breakfast, lunch and educational materials are included.

Registration is required by Wednesday, December 3, 2014 by phone at 713-313-1704 or email at crist@hapsonline.org.

Full Session Overview

Defining Dementia

Michele York, PhD

This topic will explore the differences between normal aging, mild cognitive impairment and dementia in Parkinson's disease. Practical ways to help compensate for these changes in daily life, which include communication strategies and environmental modifications, will be discussed.

Medication Management

Aliya Sarwar, MD

This presentation will review medications commonly used to treat Parkinson's disease as well as standard strategies for improving patient function and mobility through appropriate medication management.

Breakout Session Overview

Understanding Speech and Swallowing

Sunita Kavrie, PhD

The changing dynamics of the effects of PD create an increasing challenge for caregivers to understand the range of possible changes in the language, speech, cognitive and swallowing abilities of individuals with PD. This session will review how caregivers can assist with compensatory strategies to maintain maximal functional independence in each of these areas.

Bed Mobility: Assisting with Movement in Bed

Betty MacNeill, PT, PhD

Participants will learn techniques for helping an individual with Parkinson's get into and out of bed, roll in bed and move from a lying down to an upright position. Opportunities for demonstration and practice will be available.

What You Need to Know about DBS

Aliya Sarwar, MD

Learn about Deep Brain Stimulation as a surgical treatment for PD including information about the surgical procedure; how DBS works; who is a good candidate; which Parkinson's symptoms benefit most and for how long; what to expect before and after surgery; and what defines DBS success.

Coping While Caring

Kathleen Crist, LMSW

Finding healthy ways to cope with the daily changes and challenges associated with caring for a person with Parkinson's is key to longevity as a caregiver. This topic will focus on tips for successful caregiving including the importance of self-care; connecting with others and available resources; and ideas for helping patients maintain their independence.

Get Up and Go!

Betty MacNeill, PT, PhD

This session will show caregivers how to assist the person with Parkinson's to move from a seated to a standing position and begin walking. In addition, discussion about basic conditions associated with good balance and fall prevention will be included. Opportunities for demonstration and practice will be available.

Legal Planning—Preparing for the Future

William R. Hayes

This session will address legal issues and terms that caregivers need to understand as well as discussion of estate planning, who pays for long term care and the differences in important documents needed for illness/incapacity and medical decision making.

Nutrition and Parkinson's Disease

Karen Stonecypher, PhD, RN

Food, dehydration, constipation and managing Parkinson's disease are a balancing act that many caregivers face every day. This session will offer a few tips to make this balancing act a little easier.

Women & Parkinson's Disease: Understanding this Specific Journey

By Robin Morgan



Astonishing characteristic, human adaptability. Four years into the diagnosis, my living with Parkinson's disease (PD) feels normalized. Yet as a writer and activist in social justice issues, especially the global Women's Movement, I've found myself asking questions not only about

my own diagnosis, but also the particular impact of this disease on women in general. In asking these questions — of scientists, doctors, people with PD and care partners — it's become clear that we need to better understand and address the realities of women with Parkinson's disease.

Why? Because with Parkinson's, women and men have different needs and experiences. We can see this in the growth of same-gender support groups, in which a person may feel more comfortable discussing intimate details than in a mixed female-male group. We can see it in facts coming to light about differences in women's symptoms, side effects, care and participation in research.

We are beginning to glimpse that understanding how PD affects women differently from men is critical to better meeting the specific needs of women — and of men.

The PD Experience(s)

We all know that Parkinson's disease can be very different from one person to the next. But did you know that some of these differences may be due to gender? For instance, current numbers indicate that women are slightly less likely to get the disease (though it's conceivable that limited access to specialist care may partly explain lower reported rates among all women; this needs study).

When it comes to the disease presentation, women seem to show delayed onset of motor symptoms. And there's some evidence that women are more prone to depression and medication-associated dyskinesia. Women with PD tend to have more difficulty than men with daily activities, like walking and getting dressed, but show less cognitive impairment and are less likely to show behavioral problems (e.g., wandering, physical and verbal abuse). There is also initial evidence that men and women have different responses to medications — but whether estrogen, as evidence seems to show, or other factors are responsible is still a question.

Are there other differences we haven't yet identified?

Care and Caregiving

When it comes to medical care, women are 22 percent less likely than men with PD to see a neurologist. Studies show that seeing a neurologist can significantly improve care, so women may well suffer as a result.

What about caregiving? We know that with a diagnosis of PD, the entire family is affected. In all societies, women are often the “tent poles” of the family. If a family member falls ill, a woman is likely to become the primary caregiver. Caregivers in the US — of the young, the sick, the elderly, and the dying — are overwhelmingly women. In light of limited government support, how are we helping women whose relatives live with PD?

And what if a woman herself gets sick? Many women with PD have supportive partners. But studies across other disease areas indicate that women who become ill may be at risk of finding themselves without a partner. A recent study done by Amelia Karraker, Ph.D., and Kenzie Latham, Ph.D., found divorce among older couples rises when the wife — but not the husband — becomes ill. Another by Michael Glantz, M.D., focusing on cancer and multiple sclerosis, found a six-fold increase in risk for divorce or separation when the affected spouse was the woman.

Does every woman with PD need to worry about divorce? No. And it's important to note that the studies don't tell us why couples separate or who initiates the separation. But the research points to patterns that must be explored in PD so we can support affected families.

Research and New Treatments

Historically, women have been underrepresented in clinical trials. One example is heart attack research. Early studies of heart attacks used only male participants, operating under the assumption that women rarely had heart disease. Heart attack symptoms are notoriously vague, and assuming women do not get them made it even harder for women to get diagnosed. Because the Women's Movement protested, women were finally factored into the research. When they were, assumptions were proved false — today, we know that the leading cause of death for US women is heart disease, as it is for men.

The presence of women in research has improved since the National Institutes of Health (NIH) policy in 1986 that supposedly would correct any imbalances — but not enough. And this imbalance may well be having an impact on the development of new PD treatments for everyone.

Previous to the 80s, participants in nearly all research studies had been male, it being assumed that women were simply “small men,” who would react in similar ways to experimental medications (a dangerous assumption, as we’ve learned). Rationales for the inequality included the perceived complexity of recruitment and inclusion of women in studies; the necessity to protect a woman and her potential fetus from harm from experimental treatments (and thus avoid liability); and the difficulty of studying treatments in light of women’s hormonal changes.

Fortunately, further research, including that done by the Society for Women’s Health Research, blew holes through these excuses, pointing out that including women in clinical trials improves the studies. The presence of women helps scientists develop more targeted treatments. We also learned over time — the hard way — that leaving women out of research has serious consequences.

Without women in clinical studies, scientists have no idea how we might react differently to medications. The FDA recently instructed women to cut doses of the sleeping pill Ambien in half, because new research shows women metabolize the active ingredient more slowly than men. A recent PD study called SURE-PD shows the implications for both genders — women benefitted from an experimental treatment, urate, but men did not.

Last, there’s the [il]logic that excluding women from research into experimental treatments protects us from potentially dangerous consequences to the self or a potential fetus, which might be a concern, in the case of PD, for women with early onset disease (two to five percent of people with PD). But this excuse simply delays our risk until a drug is already on the market. It’s simply vital to include women in studies, so we can understand how a woman’s physiology determines her treatment.

A Time for Change

Until quite recently, the particular needs of women — half the human species and 51 percent of the US population — whether as people with PD or care partners, has not been fully understood. This is not an abstract issue, or political rhetoric. We have only begun to do the serious, gender-inclusive research necessary to understand differences between men and women in disease and treatment, which ultimately can benefit both.

There are heartening signs of change, though. Many studies now analyze their data for different responses between women and men. The NIH recently mandated that in the earliest stages of research (before clinical trials) scientists must test theories on female as well as male lab animals and cells. And women now comprise half the participants in clinical research funded by the NIH.

But we still have work to do — the NIH studies represent only 23 percent of research. Women are still underrepresented in the other 77 percent of research, that’s done by drug companies and medical-device manufacturers. And while some studies are looking at gender differences, they often leave this analysis out of their published papers.

What, then, can we do? As a woman with PD, I find myself adapting to personal changes — but as a writer and an activist, I can never adapt to inequalities, including those in research or care. Since such inequalities affect the basic ways we have regarded Parkinson’s disease — that’s a call to action.

Working with PDF’s Parkinson’s Advocates in Research program, I’ve met other people — folks living with PD, care partners, scientists doing research, clinicians — who are asking these same questions. Together, we’ve begun investigating ways to understand and end inequalities in research and treatment, and to better meet the needs of women. We’re just getting started, and we need and welcome your participation.

One place to begin would be taking PDF’s survey here, to help us understand the specific experiences of women with PD. Please contribute, whether you are male or female, person with PD or care partner, health professional or lay person. Another idea might be contacting PDF about its Women and PD Initiative, which we’re launching in spring 2015 (see box at top right) — a first step toward connecting the power of our vision, energy and resolve to change this situation.

We can educate ourselves on the subject and explore it with family and friends. We can discuss it with colleagues, form support groups, send letters to the editor, write drug companies urging gender-inclusive research, challenge medical professionals, and encourage women we know to get the specialist PD care they need. Each of us can help transform consciousness and make women visible in Parkinson’s disease.

One thing is certain: if we think we can solve half of a disease for half of the population, we all suffer.

Robin Morgan is the author of 22 books and host of “Women’s Media Center Live with Robin Morgan” (WMCLive.com and iTunes).

This article was originally published in the Fall 2014 edition of the Parkinson’s Disease Foundation (PDF) quarterly newsletter, News & Review. It is reprinted, in its entirety, with permission from PDF. For other publications, please visit www.pdf.org. To share your thoughts on the specific experience of women living with Parkinson’s disease, visit www.pdf.org/women14.

**Join PDF for PD Expert Briefing
Parkinson's and Parenting: The Impact on Children and Young Adults**

Parkinson's Disease Foundation hosts their latest PD Expert Briefing which you can join online or by phone.

Tuesday, November 18, 2014 12:00 - 1:00 PM CST

Elaine Book, M.S.W., R.S.W., Clinical Social Worker, Pacific Parkinson's Research Centre,
University of British Columbia, Canada

To register contact PDF at pdf.org or 1-800-457-6676

holiday sing-along

Presented by Houston Area Parkinson Society and Houston Ballet

Saturday, December 13, 2014
10:00 am - 12:00 pm



Celebrate the holidays with cookies and hot cocoa as we sing your favorite Christmas and Hanukkah songs to live piano music. Come dressed to win the best holiday sweater or vest contest!

Houston Ballet Center for Dance • 601 Preston Street • Houston, TX 77002
RSVP to info@hapsonline.org or 713-313-1704

Welcome Angelica!



Please join us in welcoming Angelica Rodriguez to the HAPS staff. You may remember Angelica from her undergraduate internship with HAPS this past year. Angelica graduated in May with her undergraduate degree in social work from the University of Houston Downtown and is currently attending the Graduate College of Social Work at the University of Houston. She previously worked 10 years in support services with AVANCE-Houston Head Start. Angelica joined HAPS in October as Coordinator of Therapeutic Programs—you will see her out and about at a group near you. Welcome aboard, Angelica!

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.

IN MEMORY

Joe Brown
Dana and Andrew Solomon

Howard W. Derrickson
Anonymous

Martin Kearney
Binky and John Strom
Hanna Reid

Leo A. Kissner
Bienvenu, Bonnezeze, Foco,
Viator & Holinga, APLLC

Nancy Cosine Martone
Celia Sparacio

Lillian Pettigrew
Sandra Pettigrew Reid

Arthur Evan Jones
Ann Wier Jones

Robert Schechter
Stephanie and Bubba Simon

Cynthia Pilkington
The Friendship Class

Gracie Frick
Marjorie Tucker

Mayor James "Blackie" Holmes III
Gail and Mike Hendryx

Bernard Mayes
Anonymous

IN HONOR

Nina Brown
Dana and Andrew Solomon

Dana and Chris Cahill
Carmen Carlson
Tanya Chi

Bob Casey, Jr.
The Brown Foundation, Inc.
Suzanne K. Morris

Ed Locheed
Suzanne Locheed

Margaret Romeo
Michael Romeo

Malcolm Pettigrew
Sandra Pettigrew Reid

Robert Davenport
Georgene and Thomas Brandon

GIFTS

Jonathan Shear
Cynthia Crellen
Albert Munn
Jo Rae Crofton

Margaret Condon
Jack V. Carper
Pat and Lew Levy
Michael L. Brown

Kathy Magnuson
Crews Sprovach
Margaret and Robert Merchant
Parkinson's Network North

Frances and Paul Terry, Jr.
Betty Ann Walston
Patricia A. Bahr
Janet and Donald Beckmann

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.

KROGER COMMUNITY REWARDS PROGRAM

1% of your grocery purchases can be donated to HAPS every time you shop. Even if you were formerly registered, each year you must go online to register for the program at www.krogercommunityrewards.com and follow these instructions:

- Click on "Create an Account "
- Create a screen name and password
- Enter your Kroger Plus Card number
- Use the non-profit number 80301 to donate to HAPS

If you have a Kroger card and would like to register, but do not have access to the Internet, HAPS will help you register online. Call Kelly Nicholls at 713-313-1621 for assistance.

RANDALLS GOOD NEIGHBOR PROGRAM

Randalls will donate 1% of your grocery purchases to HAPS every time you shop. Take this card along with your Remarkable Card to the customer service desk at Randalls. They will link your card to the HAPS Good Neighbor number—it's that easy!



HOUSTON AREA PARKINSON SOCIETY

Board of Directors

Mike Hendryx - President
Frank Donnelly, Jr. - Chair
Gabriel Zamora - Vice President/Treasurer
Leslye Weaver - Vice President/Secretary

Chris Brewster
Joan Cupic
Jo Furr
Joyce Gilbreath
Tom Ganucheau
Joshua Huss
Rob Kerr
John McClymonds
Jim Nicklos
Gerald Rideaux
Erick Sandlin
Terry K. Satterwhite, MD
Richard K. Simpson, Jr., MD
Pamela Skaufel
Randi Smith
Jim Thorp
Michael Young
Courtney Zavala

Staff

Anne Thobae - Executive Director
Kathleen Crist, LMSW - Director of Social Services & Program Development
Midge Claiborne - Director of Development
Kelly Nicholls - Coordinator of Marketing & Communications

Board of Advisors

Chris Bell
Ron Bernell
Nina Brown
Aubrey Calvin
Joiner Cartwright, Jr.
Bob Casey
Rich Clifford
Robert Cruikshank
Meredith Cullen

Matthew Easterly
Ellin Grossman, EdD
John E. Hankey
Harriet Hart
Kamden Kanaly
Liz Lary
Harriet Latimer
Dan Lauck
Anne Martin

Robert A. Martone
Marti McWhirter
Quin McWhirter
W.O. Neuhaus III
Malcolm Pettigrew
George Puig
Jeff Rosenberg
Arthur Schechter
Joyce Proler Schechter
Binky Stephenson Strom
John Strom

Medical Advisory Board

Richard K. Simpson, Jr., MD, PhD - Chair

Madhureeta Achari, MD	Cindy Ivanhoe, MD	William Ondo, MD
Leanne Burnett, MD	Joseph Jankovic, MD	Terry K. Satterwhite, MD
Steve Croft, MD	Jooji Jimenez-Shahed, MD	Mya Schiess, MD
Albert Fenoy, MD	Eugene C. Lai, MD, PhD	Desiree B. Thomas, MD
Stanley Fisher, MD	Laura Marsh, MD	Gage Van Horn III, MD
Erin Furr-Stimming, MD	Greg McLaughlin, MD	Ashwin Viswanathan, MD
Robert G. Grossman, MD	Kimberly Monday, MD	Michele York, PhD

Leann Randolph, LMSW - Social Worker & Advocacy Outreach Coordinator
Celeste Harris, LMSW - Social Worker & Coordinator of Special Programs
Angelica Rodriguez - Coordinator of Therapeutic Programs