



Capital Area Parkinson's Society

January 2016 Newsletter

P.O. Box 27565, Austin, Texas 78755-2565

www.capitalareaparkinsons.org

Unconventional Wisdom: A Patient Organization Challenges Long-held Assumptions about Women and Parkinson's Disease

Neurology Now, December 2015/January 2016 issue

Bolster, Mary

It all started with an innocent question, insists Robin Morgan, a volunteer with the Parkinson's Disease Foundation (PDF). She was attending one of the foundation's Parkinson's Advocates in Research (PAIRS) training sessions when she asked, "How do we know that Parkinson's is primarily a men's disease?"

"Some of the doctors said, 'Tsk, tsk, we just know,'" says Morgan. "But others said, 'Interesting question. We don't know.'"

That question and the divergent answers inspired Morgan and several other women at the session, including Ronnie Todaro, MPH, vice president for national programs for PDF, to launch the first-ever Women and PD Initiative (<http://www.pdf.org/womenpd>). Their goal? To recognize the unique needs of women with Parkinson's disease, advocate for more research on the different ways the disease manifests in men and women, and put out a call to women to join clinical trials.

A MOVEMENT IS BORN

The three-day conference in Florham Park, NJ, in mid-September focused on the question of what makes women different from men in terms of Parkinson's. To sow the seeds of a grassroots movement, the PDF raised money to bring a group of 25 women with Parkinson's disease from around the country to the event to hear about their experiences.

After attending sessions led by female clinicians on everything from drugs in the pipeline to women's role in the family, the 25 guests were encouraged to take what they learned and replicate it or adapt it to their own communities. "The aim is for them to talk about Parkinson's in general, and women and PD specifically," says Morgan, who was diagnosed almost six years ago. "We want to inspire activism. Get people in their community to write to their members of Congress and newspapers for more research support, educate the public, and encourage more women to participate in clinical trials so we have a patient population to study."

DIFFICULTIES UNIQUE TO WOMEN

"Women are 22 percent less likely than men to be seen by a neurologist," says Morgan, referring to a 2011 study in *Neurology* about neurologist care in Parkinson's disease. Morgan herself was misdiagnosed for almost two years. "I was tested for absolutely everything—brain tumor, multiple sclerosis, Huntington's—even though I kept saying, 'I think I have Parkinson's,' because my mother had Parkinson's." It wasn't until Morgan went to a movement disorders specialist that she was finally diagnosed.

Women are also more prone to depression and dyskinesia (involuntary movements or tics), says Morgan, citing several recent studies in *Neurology* about sex differences in Parkinson's disease.

SEX-SPECIFIC RESEARCH

Morgan sees hope on the horizon, thanks to a recent mandate from the National Institutes of Health (NIH) for sex-specific research. "They mandated it right down to the cellular level," she says. Still, there's work to be done. The NIH studies "represent only 27 percent [of all studies]. We've got to impact Big Pharma to factor the other half of the population into research. Women are not just small men with different reproductive systems."

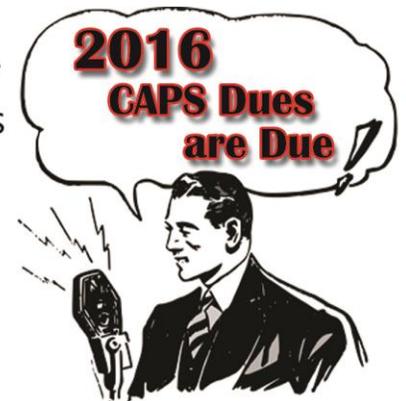
LOOKING AHEAD

The first meeting was a "rousing success," says Morgan. The women are back in their communities, spreading the word and communicating relevant details about the various sessions. "Their feedback will dictate where the initiative goes next: a bigger conference, no conference, mini-conferences, public service announcements, pamphlets, booklets."

There's no turning back, says Morgan. "I hope it makes general neurologists think about sex-specific medicine or listen to their female patients and maybe recommend a movement disorders specialist, because women with PD present differently than men. I hope it makes clinical researchers seriously recruit women."

With her simple question four years ago, Morgan helped set in motion an initiative she's confident will deepen and expand. "Once you factor in half the population previously ignored, things change." ■

Thanks to our members, CAPS is able to offer support and assistance to so many individuals. We appreciate your support! For those members who pay their dues in January each year, it is once again time to submit your payment. For those who paid later in the year, the annual dues aren't due again until one year from that date.



Area Outreach Support Groups

Deep Brain Stimulation (DBS) – 3rd Friday @ 2pm

Neurology Solutions Office
12201 Renfert Way, Suite 360
Austin, TX 78758

Lakeway – 1st Tuesday @ 2pm

Vibra Rehabilitation Hospital of Lake Travis
2000 Medical Drive, Lakeway, TX 78734

Marble Falls – 2nd Wednesday @ 2pm

Seton Marble Falls Healthcare Center
700 U.S. 281, Marble Falls, TX 78654

Northeast Austin – 3rd Tuesday Bimonthly @ 4pm

(Feb, Apr, Jun, Aug, Oct, Dec)
Legend Oaks of North Austin
Healthcare & Rehabilitation
11020 Dessau Road, Austin, TX 78754

Participant Organized Parkinson's Singing Group – Wednesdays 12:30-1:30pm

Unity Church of the Hills, Unity Oaks Bldg.
9905 Anderson Mill Road, Austin, TX 78750

Round Rock – 4th Tuesday @ 3pm

Note: No meeting in December due to holidays
Wyoming Springs Assisted Living
7230 Wyoming Springs Drive
Round Rock, TX 78681

Simultaneous Care Partner and Patient – 2nd Tuesday @ 10:15am

Covenant Presbyterian Church
3003 Northland Drive, Austin TX 78757

Young Onset Parkinson's Disease (under 55)

Contact: Bob Sahm at 512-914-2132

or rsahm99@gmail.com

Alex Andron at 610-389-4316

or alexander_andron@yahoo.com

For more information, visit www.capitalareaparkinsons.org.

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January Membership Meeting

Saturday, January 16 ■ 2:00 p.m.
Medical Office Building, St. David's Medical Center
5th Floor Conference Room, 3000 N. IH-35



Dr. Iris Wingrove will be our speaker for the January meeting. She is a board certified neurologist who graduated from the University of Texas Medical Branch at Galveston, and completed her residency at the Mayo Clinic. She is in private practice in Austin at Optimize Neurology, where she treats patients with a wide range of neurological conditions, including Parkinson's disease. She was awarded the John Calverly Excellence in Neurology Award in 2006.

There will be a potluck following the meeting.