Parkinson's Foundation

# WOMEN AND PARKINSON'S: CLOSING THE GENDER GAP IN RESEARCH AND CARE

A patient-centered agenda for change

# FOREWORD

A diagnosis of Parkinson's disease (PD) impacts women and men differently. Women with PD experience different symptoms, medical side effects, challenges with access to healthcare delivery and a lack of social support compared to men with PD. Despite these differences, there has not been a concerted national effort to more fully understand how sex and gender impact treatment, care and most importantly, quality of life.

Recognizing the need for action, the Parkinson's Foundation launched the "Women and PD Teams to Advance Learning and Knowledge" or "Women and PD TALK" project as a pivotal component of our Women and PD Initiative. Women and PD TALK is the first national effort to address the long-standing gender disparities in Parkinson's research and care. Since its inception, Women and PD TALK has hosted several educational events and 10 regional forums, giving women with PD, research and healthcare leaders a platform to share concerns, findings and input derived from their respective fields and real-world experiences.

As the project lead for Women and PD TALK, it is with great pride that I present Women and Parkinson's: Closing the Gender Gap in Research and Care. This landmark report, developed in collaboration with a national network of researchers, clinicians and women with PD, represents an expanded understanding of the roles sex and gender play in care, treatment options and quality of life for women with PD. These comprehensive, patient-centered recommendations provide an unparalleled opportunity to change how Parkinson's is studied and treated in women.

Women and Parkinson's: Closing the Gender Gap in Research and Care is central to the Foundation's mission of making life better for people with Parkinson's disease by improving care and advancing research toward a cure. It is a demonstration of our commitment to community collaboration and developing groundbreaking approaches to advance treatment and care for underserved communities. Our hope is for this agenda to serve as a catalyst for inquiry, empowerment and change among researchers, clinicians, women with PD and their families.

Thank you for your interest in joining us as we create solutions that lead to better lives for all women living with Parkinson's disease.

**Veronica "Ronnie" Todaro, MPH**
Executive Vice President, Chief Operating Officer
Parkinson's Foundation

**The Women and PD Teams to Advance Learning and Knowledge (Women and PD TALK) project was made possible through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (3998-PDF).**

# TABLE OF CONTENTS

> *At the heart of the Women and PD TALK Project is acknowledgment that Parkinson's is not just a movement disorder, but a complex bundle of medical symptoms and consequences complicated further by the impact of gender. Gender accountability in medical research and care, that women experience Parkinson's disease differently from men, is patient-centered outcomes research at its best. We need updated and comprehensive information pointedly looking at how women are impacted by Parkinson's disease so that choices, decisions and outcomes are efficacious and accurate from the source.*

**Ann Boylan, MA,** Women and Parkinson's Advocate

# EXECUTIVE SUMMARY

Parkinson's disease (PD) affects approximately one million men and women in the United States, and more than 10 million people worldwide.[1] Women have been shown to have a lower risk of developing PD,[2] and research suggests that there are differences in the way that men and women experience Parkinson's. Studies indicate that women diagnosed with PD report different symptoms, more often report side effects and changes in their symptoms throughout the day and receive lower-quality healthcare than men.[3,4] This publication aims to highlight the historically unmet research and care needs of women with Parkinson's disease, and elicit action in addressing these needs in future research and care.

The Parkinson's Foundation has created the first national research and care agenda specific to women with PD to address the disparities that they experience. This agenda was derived from 10 regional forums, as well as a national forum, hosted across the United States, to understand the experiences of women with PD. This research and care agenda reflects the priorities identified by women with PD, medical professionals and care teams at these forums. The purpose of this agenda is to promote research and care practices that enable women with Parkinson's disease to maximize their quality of life.

This agenda is focused on three topics:

**Research**

1. Understanding PD in women through research.

**Care**

2. Ensuring better care for women with PD.

**Education & Empowerment**

3. Educating and empowering women with PD.

For each topic area, goals and priorities have been identified for researchers, medical professionals, women with Parkinson's and care teams for women with PD.

**Topic One: Research**

**Goal: To increase and improve research (basic, translational and clinical) to better understand Parkinson's disease in women.**

### *Priority: **Inclusiveness***

- √ Women need to be included in PD research.
- √ Increased focus on recruiting female participants, who reflect a representative sample of women in relation to demographic factors, stage and onset of PD, is critical.

### *Priority: **Relevance***

- √ Research must be relevant to women with PD and should be designed around the unique needs of women.
- √ PD research must include topics examining the effect of biological sex, including sex hormones, on PD risk, progression and response to treatments.
- √ Additional research is needed to better understand the differences between aging, PD and menopause.
- √ Research must address the qualitative impacts of Parkinson's disease on women.

### *Priority: **Quality***

- √ Further PD research study findings should be required to be analyzed in consideration of sex/gender.
- √ Existing data should be pooled and analyzed for information about women with PD.

**Topic Two: Care**

**Goal: To improve healthcare access and delivery for women with Parkinson's disease.**

### *Priority: **Accessibility***

- √ PD care must be more accessible to women.
- √ Medical professionals should adopt practices that promote women's utilization of services.

### *Priority: **Personalization***

- √ PD care should be personalized to women and should reflect that women may require different services than men or may require that similar services be administered differently.

### *Priority: **Communication***

- √ Medical professionals and women with PD need to work together to minimize miscommunication.
- √ Medical professionals and women with PD should work together to identify goals for treatment to improve shared decision-making practices.
- √ Medical professionals should improve communication within the medical community to appropriately connect women with PD to available comprehensive services.

**Topic Three: Education and Empowerment**

**Goal: To empower women with Parkinson's disease and their care teams to advocate for optimal Parkinson's care focused on women's unique experiences.**

Priority: ***Self-management***

- √ Women need to be provided additional tools and resources for the self-management of PD.
- √ To promote positive behavior change and shared decision-making, tools need to be provided to women early in their diagnosis.
- √ Tools should be made available to women to assist them with maintaining their personal and professional relationships while managing their PD.

Priority: ***Shared Responsibility***

- √ Women with PD need to have access to women's-only peer-to-peer services.
- √ Care teams should work to better understand the needs and priorities of women with PD.
- √ A positive PD experience requires the participation of an involved and knowledgeable care team.
- √ In addition to resources to promote care team involvement, there is also a need for resources to support care team members.

Priority: ***Advocacy***

- √ Additional education efforts are needed to increase public awareness about PD.
- √ Advocacy is needed to minimize the disparities women with PD experience.
- √ Additional attention to resources for women with PD should be a public policy issue.

> *Most women find it difficult to reverse their role from caregiver to care-receiver. My daughters asked if anyone went to the doctor with me. ‘Why not?’ they asked when I said ‘No.’ Because I never thought to ask anyone to go with me.*
>
> **Sharon Krischer, MA,** Women and Parkinson’s Advocate

## IMPACT/AIMS

Women have not been adequately represented throughout the course of Parkinson's disease research.[5] Biological and socio-cultural sex and gender differences are often not considered when determining research and care priorities for PD. The limited research that has been done shows that women with PD have different experiences than men with PD as they relate to risk, symptoms, treatment and care. Without attention to and consideration of differences between men and women with Parkinson's, women may not be fully receiving the benefits of Parkinson's treatment and care options. This publication aims to highlight the historically unmet research and care needs of women with PD and elicit action to address these needs in future research and care.

### INTENDED AUDIENCE

This publication is intended for use by Parkinson's disease researchers, medical professionals, funding agencies, women with PD and their care teams. Researchers and medical professionals are encouraged to use this as a guide for potential research studies and care practices. Women with PD and their care teams are encouraged to utilize this agenda as a tool for community advocacy and self-empowerment. Research funders are encouraged to consult this agenda in consideration of allocations for PD research and community programs.

> The purpose of this agenda is to promote research and care practices that enable women with Parkinson's disease to maximize their quality of life.

### PURPOSE

The purpose of this agenda is to promote research and care practices that enable women with Parkinson's disease to maximize their quality of life.

The expected long-term outcomes of the research and care agenda are to: (1) increase the number of research studies conducted that address the needs and priorities of women with PD, and (2) increase knowledge among women with PD and the medical professionals who care for them to facilitate better-informed healthcare decisions.

### PROCESS FOR SETTING A PRIORITIZED RESEARCH AND CARE AGENDA

The Women and PD Teams to Advance Learning and Knowledge (Women and PD TALK) project was made possible through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (3998-PDF).

On Jan. 1, 2017, the Parkinson's Foundation initiated the Women and PD TALK project to create the first national, prioritized Women and Parkinson's research and care agenda.

The Parkinson's Foundation and project key personnel identified female community stakeholders to serve on the Women and PD TALK national team to assist with the creation and dissemination of project deliverables. This team of experts collaborated with the Foundation throughout the duration of the project to ensure that all activities aligned with community needs. National team members consisted of women with Parkinson's disease, representatives from major medical universities, representatives from national Parkinson's organizations and a representative from the National Institute of Health (see Appendix A: Women and PD TALK Leadership).

Project key personnel and the national team hosted 10 Women and PD TALK regional forums across the U.S. to discover unmet needs and research priorities for women with PD. Each site was led by an all-female team of one or two women with PD, a physician/clinician/researcher and an allied health professional (see Appendix A: Women and PD TALK Leadership). Each regional team organized and hosted a one-day forum with guidance from and materials provided by the Foundation. Regional forum sites included:

- San Francisco, California
- Chapel Hill, North Carolina
- Los Angeles, California
- Rochester, New York
- Sioux Falls, South Dakota
- Portland, Oregon
- Philadelphia, Pennsylvania
- Minneapolis, Minnesota
- Chicago, Illinois
- Birmingham, Alabama

Forum participants consisted of women with PD, care partners, health professionals, government representatives and individuals working directly with women with PD. Regional team leaders recruited a range of 25 to 53 registered participants at each forum. Each regional forum consisted of morning educational presentations and afternoon breakout sessions. Participants received breakout session questions in advance of

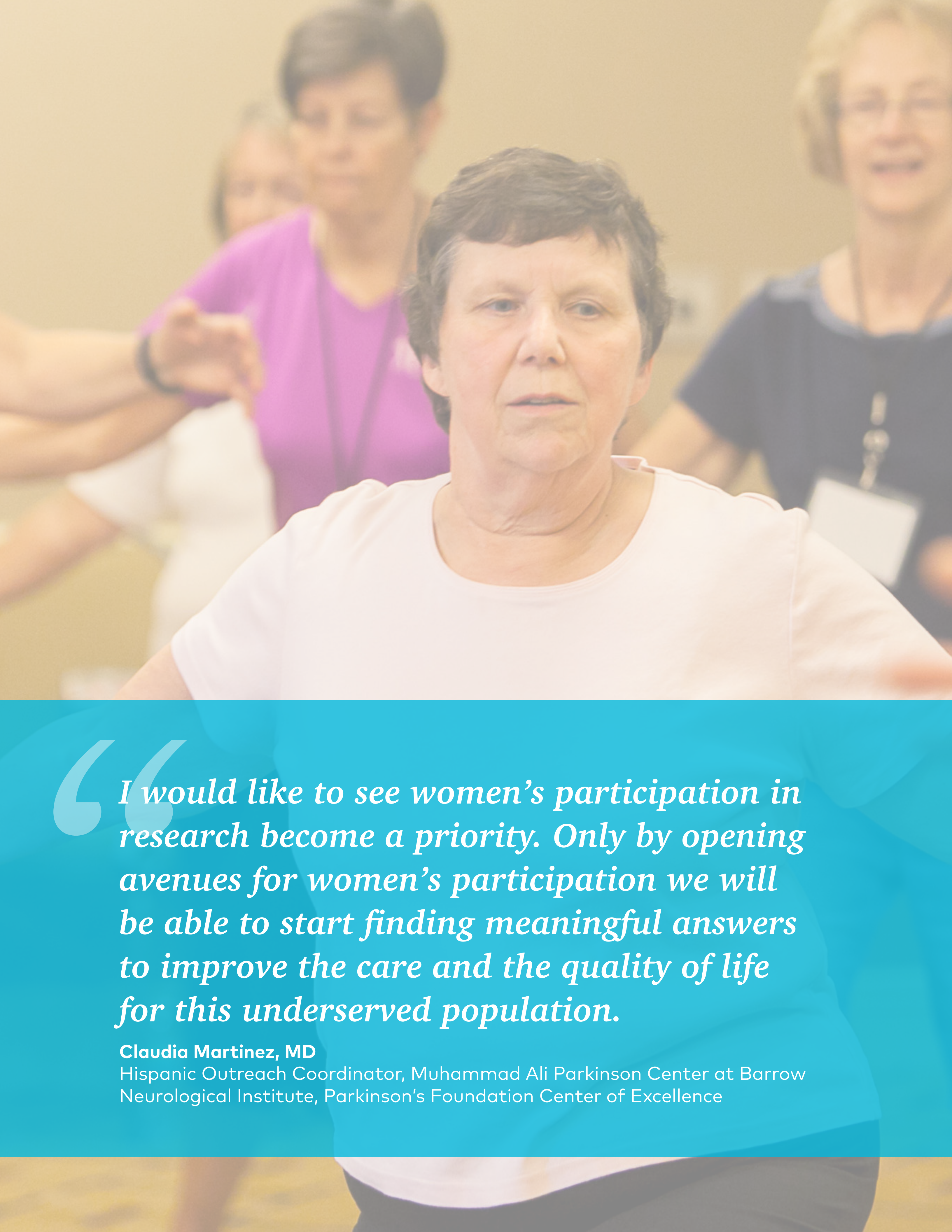
the forum and were split into two groups for the breakout sessions: (1) women with PD and (2) care partners, health professionals and individuals working directly with women with PD (referred to from hereon as stakeholders).

Breakout sessions were facilitated at each forum using scripted questions (see Appendix B: Regional Forum Breakout Questions). In total, 242 women with Parkinson's and 178 stakeholders shared their insights. Breakout sessions were audio recorded and analyzed through thematic analysis to capture the women and PD experience, unmet research needs and future research priorities.

In each of the 10 regional forums, participants reported on women's experiences with Parkinson's disease as they related to PD risk, symptoms, treatment and care in response to the scripted breakout questions. Participants were encouraged to share when they felt that gender differences were present in these areas, but informed that the overall purpose of the breakout sessions was to better understand their personal experiences, whether as a woman with PD, or as a person working directly with women with PD.

Once compiled, regional forum summary reports were shared with regional forum participants and team leaders for comment. Project key personnel, national and regional team leaders then identified community stakeholders with whom to share these findings and strategize agenda priorities at a national forum. The national forum brought together 15 regional team leaders and an additional 36 community stakeholders to collaboratively develop a patient-centered research agenda (see Appendix A: Women and PD TALK Leadership). The resulting agenda, presented here, reflects the priorities and strategies generated at the regional and national forums.

> “*When I first experienced PD symptoms, they were explained away as the stress of a working mom. I was prescribed medication for anxiety and the eventual diagnosis of Parkinson's was not made for another two years.*
>
> **Carol Clupny, MS,** Women and Parkinson's Advocate



> *I would like to see women's participation in research become a priority. Only by opening avenues for women's participation we will be able to start finding meaningful answers to improve the care and the quality of life for this underserved population.*

**Claudia Martinez, MD**
Hispanic Outreach Coordinator, Muhammad Ali Parkinson Center at Barrow Neurological Institute, Parkinson's Foundation Center of Excellence

Women and men differ in terms of underlying biology, development and environmental exposures.[6] Women and men also face different social roles.[7] These sex differences can drastically impact one's health and are important to consider across all diseases, including Parkinson's disease.

## RISK

Diagnosing PD is challenging; on average, such diagnoses are accurate in 80.6% of cases.[8] Research studies use multiple strategies – self-report, administrative data sources, active case finding, etc. – to define and find Parkinson's cases.[9–11] Regardless of data source, studies consistently find men at higher risk of developing Parkinson's disease.[2,12–17] PD risk increases with age,[15,16] and male risk preponderance may be more pronounced in older age.[14,15]

The reduced risk of PD among women is not completely understood. Evidence suggests differences in underlying biology, environmental exposures and behaviors may be important. Likely, the etiology behind sex difference in risk is multifactorial.[18] Hormones, namely estrogen, may also reduce PD risk in women, but the relationship between estrogen and PD is complicated. The effect of estrogen may differ by type (endogenous versus exogenous), timing and exposure duration.[19–21]

Non-genetic factors, like environment and behavior, may play a large role in PD development, particularly for non-early onset PD.[22] Smoking, coffee intake, physical activity and non-steroidal anti-inflammatory drug (NSAID) use may reduce the risk of PD.[11,23,24] However, other factors like dairy consumption, head trauma and herbicide exposure may increase the risk of PD.[11,25,26] The likelihood of exposure to these risk factors differs by sex,[25] and various exposures may act as risk factors in one sex but not the other, or have opposite effects in each sex.[18]

## SYMPTOMS

There is a lack of consensus on whether men and women have different and/or worse motor symptoms. If women have less severe motor symptoms, it could make diagnosis in women more challenging. Women may experience more non-motor symptoms than men (e.g., cognitive, autonomic, psychological, sleep-related).[27,28] Psychologically, women have more depression,[29–31] sadness[27,32] and anxiety or nervousness.[29,31–33] These non-motor symptoms can negatively impact patient quality of life, particularly for women.[29,34] Although only relevant to those with PD onset prior to menopause, PD symptoms are impacted by both menstruation and pregnancy.[35,36]

Comorbidities are common but different among men and women with PD.[37] Women have more osteoporosis, hip fractures, rheumatoid arthritis and osteoarthritis.[37] Meanwhile, men are more likely to have atrial fibrillation, acute myocardial infarction, colorectal cancer and chronic obstructive pulmonary disease.[37] Although these comorbidities and their corresponding symptoms are separate from PD, they complicate disease management.

## TREATMENT

Men and women take similar dopaminergic medications and combinations of dopaminergic medications to combat PD;[27,38,39] however, women are more likely to experience medication-related dyskinesias.[3,27,38,40,41] Women also have more motor fluctuations and wearing off.[27,42,43] For psychological non-motor symptoms, women are more likely to be prescribed antidepressants[27,31,44] and benzodiazepines.[27] Pain management is similar for men and women.[45]

While the risk of developing PD is reduced in women, those diagnosed with the disease can encounter greater hurdles in obtaining an accurate diagnosis, experience more non-motor symptoms, face greater treatment-related dyskinesias and may be less likely to see medical specialists than men with PD.

Deep brain stimulation (DBS) is a beneficial PD treatment, particularly for people with motor complications and poor symptom control with medication.[46] Comparing outcomes after DBS, men and women have similar improvements in motor symptoms after DBS; however, women have greater improvement in health-related quality of life (HRQoL)[47] and disability.[48] Women are less likely to receive DBS.[49] This sex disparity could stem from fewer referrals for women,[3] women having more benign symptoms and not needing DBS[3] or higher refusal of DBS by women.

Evidence suggests that many behavioral interventions and modifications may improve PD motor and non-motor symptoms. Exercise,[50–52] protein restricted diets[53] and voice and speech therapy[54] are all potentially beneficial. However, few studies examine whether the benefit or patient adoption of these interventions differs by sex.

## CARE

Women are more likely to be unhappy with the process of obtaining a PD diagnosis.[55] However, some evidence suggests that women experience a longer time from onset of symptoms to diagnosis, onset of symptoms to when they first visit a movement disorders specialist and diagnosis to when they first visit a movement disorders specialist.[56]

Women with PD are more likely to be single or widowed,[57] and men with PD are more likely to have a spouse as their primary caregiver.[44]

Specialist care is associated with a reduced risk of hip fracture,[4] hospitalizations for PD-related illness,[58] repeat hospitalizations[58] and skilled nursing facility admission,[4] but women are less likely to see a specialist for their PD.[4] Mortality[4] and healthcare costs[58] are also lower in those seen by a neurologist and people who see a neurologist are more likely to use hospice care.[59] Women are just as likely as men to utilize physical or occupational therapy, but less likely to utilize speech therapy.[60,61]

While the risk of developing PD is reduced in women, those diagnosed with the disease can encounter greater hurdles in obtaining an accurate diagnosis, experience more non-motor symptoms, face greater treatment-related dyskinesias and may be less likely to see medical specialists than men with PD. Addressing these disparities and other gender-specific needs among the population of women with PD can improve quality of life.

> *Before I go in for an appointment with my care team, I monitor and record my symptoms, medication schedule, activities, sleep and diet for the week before. I want to present an overview of how I'm doing, not just a snapshot of how I look during a 20-minute visit. I bring in a typed-up summary and my questions. This way, I get to "speak" about what's on my mind and I get my questions answered. It makes my appointments productive and keeps me on track.*
>
> **Elizabeth Ogren, MA**
> Women and Parkinson's Advocate

> *My team--neurologist, family doctor, physical therapist, support group, family and friends--are the travel guides on my Parkinson's journey.  They give me hope, strength and motivation to keep fighting, to live well with PD.*
>
> **Mary Tidwell,** Women and Parkinson's Advocate

## WOMEN AND PD PRIORITIES

The regional and national forums identified several unmet needs for women with PD. The conversations held at these forums highlighted that women's health outcomes are not solely dependent on medical care, genetics or biology. Societal norms, health behaviors, place of residence, support structures and other factors interact to influence the experiences of women with Parkinson's disease.

An agenda that does not address the influence of all of these factors could be less effective in improving the health of the population of women living with PD.

This agenda attempts to capture the issues that are most pressing and will have the greatest potential impact on the women and PD community, while simultaneously accounting for the multiple factors that influence women's health outcomes. Addressing these needs can improve the lives of women living with Parkinson's disease, enabling more personalized PD guidelines to allow providers to tailor treatment to individuals.

The goal of this agenda is to improve quality of life for women with PD by raising awareness around the barriers that prevent optimal research and care. Some of the identified barriers were not gender specific, but were included given their reported influence on women's health outcomes.

Although the recommended priorities were identified and developed for women with Parkinson's disease, developing solutions for some of the non-gender-specific priorities could benefit all individuals with PD.

> Societal norms, health behaviors, place of residence, support structures and other factors interact to influence the experiences of women with Parkinson's disease.

This agenda is focused on three topics:

1. Understanding Parkinson's disease in women through research.
2. Ensuring better care for women with PD.
3. Educating and empowering women with PD.

For each topic area, goals and priorities have been identified for researchers, medical professionals, women with PD and care teams of women with PD.

## TOPIC ONE: RESEARCH

***Regional Forum Identified Unmet Research Needs***

Regional forum participants emphasized the importance of designing research around the unique needs and experiences of women with PD.

When discussing risk factors related to Parkinson's disease, participants questioned the lack of research on sex hormones. They questioned the role of hormones in the development and progression of PD, and participants that were premenopausal at diagnosis discussed fluctuations in symptoms throughout the month. Participants also discussed the lack of clarity between symptoms of PD, aging and menopause and several felt that this may have contributed to a delay in diagnosis. Of 148 participating women with PD surveyed, 31% waited more than a year from when they first brought up their symptoms with their provider to when they received a Parkinson's disease diagnosis. Participants also speculated upon possible onset triggers for PD, and whether PD was accelerated by certain factors (stress or other health conditions).

> **Studies should engage women with PD in the design, implementation and analysis of research to more effectively identify best practices for study inclusion and retention.**

Of 156 participating women with PD surveyed, the most frequently reported impactful motor and non-motor symptoms included bradykinesia (69%), rigidity (53%), fatigue (67%) and sleep disorders (54%). Participants reported observational differences in symptom presentation and severity between men and women with PD. They questioned whether these observational differences were a result of flaws in the capture of symptoms (bias, reporting, etc.) or whether significant symptom differences existed between men and women with PD. These discussions further led to conversations about the lack of qualitative research in PD. Participants shared a variety of motor and non-motor symptoms that they felt were negatively impactful to their quality of life, but were often not captured in appointments or questionnaires. They discussed how symptoms impacted identity, activities and relationships. Many participants reported withdrawing from activities due to the perceived inability to keep up with others (physically and cognitively) or feeling that they were drawing unwanted attention to themselves.

Participants also discussed challenges with being more involved in PD research and care. Several forum participants shared that they were the main caretakers in their family, and time taken from that role, given the already decreased productivity with PD, would be a huge cost.

Participants' opinions aligned with the Foundation's findings after conducting a review of the existing literature on women and Parkinson's disease. Studies suggest that there are differences between men and women with PD, however, the explanations for these differences remain largely unknown. For this reason, this agenda prioritizes action in three areas of research to understand PD in women; these include research inclusiveness, relevance and quality.

## STRATEGIC RESPONSE GOAL AND RESEARCH PRIORITIES

**Goal: To increase and improve research (basic, translational and clinical) to better understand Parkinson's disease in women.**

### *Priority: Inclusiveness*

Before any changes can be implemented to benefit women, women must be included in PD research. Without increased representation of women in Parkinson's disease research, the mechanisms, progression of and treatment response to PD cannot be fully understood. Work to improve representation should include increasing research of relevance to women (see Priority: Relevance) and designing research studies to accommodate for the barriers that prevent women from participating in research. Studies should engage women with PD in the design, implementation and analysis of research to more effectively identify best practices for study inclusion and retention.

In addition to identifying strategies that improve the representation of women in research studies, attention should also focus on recruiting female participants that reflect a representative sample of women in relation to demographic factors, stage and onset of PD. For research to accurately capture the entire population of women with PD, recruiting a representative sample of women should be  a priority.

### *Priority: Relevance*

Research must be relevant to women with PD. There are biological differences between men and women, and additional research should be conducted to understand how these differences manifest in PD. Parkinson's research must include topics examining the effect of biological sex, including sex hormones, on PD risk, progression and response to treatments. Studies assessing whether hormonal differences, age at menopause, use of hormone therapy and hysterectomy influence onset, rate of progression, or treatment response in women could benefit researchers and practitioners when designing treatment protocols for women with PD.

Research must aim to better understand the differences between aging, PD and menopause. This type of research should involve an analysis of women with and without PD. Several aging, PD and menopause symptoms overlap, and it is important that research offer clarity to women with PD and the medical community about the differences between the three to prevent misdiagnosis. If women with early signs of PD are reporting symptoms that are being incorrectly associated with menopause or aging, this diagnosis delay could prevent them from benefiting from early treatment.

> Decreased social engagements, changes in roles or identities, decreased productivity, decreased intimacy and changes in personality are often not measured, discussed or taken into consideration when identifying the best personalized treatment approach for PD.

Research should also be culturally relevant to women. PD metrics and scales used to capture PD presentation and reported experiences should be investigated to confirm cultural relevance to women (e.g., quality of life, outcome metrics). Parkinson's disease assessments can trace the progression of PD through objective measures, however, they may miss important socio-cultural changes. Decreased social engagements, changes in roles or identities, decreased productivity, decreased intimacy and changes in personality are often not measured, discussed or taken into consideration when identifying the best personalized treatment approach for PD. Without addressing qualitative changes not traditionally captured in PD assessments, women's needs cannot properly be addressed.

*Priority: Quality*

To reduce gender disparities in Parkinson's disease research, research quality should more thoroughly encompass women with PD. Further PD research study findings should be required to be analyzed in consideration of sex/gender. Simply put, sex and gender influence behavior and health outcomes.[62] Without this analysis, women's experiences with PD may not be understood. In analyzing research by sex/gender, treatment programs can be more personalized and impactful to the person treated.

Research analyzing sex/gender can be expensive. To improve our understanding of Parkinson's disease in women, existing data should be pooled and analyzed for information about women with PD. This time and cost-efficient analysis can answer questions in a robust manner and can be the foundation for proposing new research questions. By improving the quality of analysis and data, women's experiences can be more accurately captured and represented in research.

## TOPIC TWO: CARE

PD care programs should help women feel comfortable and included.

***Regional Forum Identified Unmet Care Needs***

Regional forum participants emphasized the complexity of women's PD care and discussed several factors that influence their treatment and care considerations.

Participants discussed the importance of creating a treatment and care plan that optimizes quality of life and maintains independent function. Women discussed wanting to contribute to the development of their treatment plans with their provider. However, several women reported not feeling heard or feeling like their priorities were not taken into consideration. Several women shared how a lack of shared decision making negatively impacted their adherence to treatments.

Regional forum participants emphasized the importance of positive care experiences.

Although some regional forum participants were able to share care best practices, many shared medical care team interactions that they felt negatively impacted their care access and utilization. Several women with Parkinson's disease shared experiences of poor communication or miscommunication with their provider, including long wait times to an accurate PD diagnosis, provider dismissiveness or a lack of transparency. Several participants shared how negative care experiences impacted symptom reporting, with underreporting being discussed as a major concern. Women were not consistently sharing their concerns or symptoms with their providers, particularly around mental health and other sensitive topics (e.g., pelvic floor problems), and were consequentially not treated for these issues. Participants felt that they were suffering in silence and did not feel comfortable sharing these issues with their provider or did not know about the availability of programs and resources to treat their symptoms.

Several stakeholders discussed the importance of a comprehensive and coordinated care approach, but shared that women were not proactively (and in some instances reactively) referred to allied health and mental health services. Stakeholders questioned the lack of current standards for referrals to services but were optimistic that increased referrals would lead to increased utilization.

Participants discussed factors that influenced their treatment decisions, which included personal preference, treatment efficacy and side effects. Of 155 participating women with PD surveyed, the most utilized treatments for PD included medications (95%) and exercise (92%), followed by physical therapy (50%) and diet (43%). Participants shared a wide range of other preferred treatment alternatives, either in addition to or in place of medication or surgical treatment therapies. These alternative treatment options included physical, occupational and/or speech therapy, diet, exercise, acupuncture, cannabidiols and more. Exercise was identified as a critical component of symptom management for Parkinson's disease. Participants felt that in addition to the positive benefits of symptom reduction, group exercise classes offered a camaraderie and accountability that they had not received from other therapies.

Participants reported several complications with fine-tuning medication and surgical treatment options to treat symptoms. Several participants reported inconsistent efficacy, unwanted side effects and inconsistent treatment adherence for medications and questioned the variance in dosage recommendations among medical providers.

> **Care designed to be personalized and culturally relevant could better inform policy and research moving forward.**

Aside from medically related considerations, participants also recounted several experiences in which culture or gender norms limited their ability to care for themselves. Many participants shared how family, spousal, employment or parental responsibilities got in the way of accessing or advocating for better care.

To enable women and their medical care teams to maximize the effectiveness of PD care, this agenda prioritizes action in three areas of care improvement, including care accessibility, personalization and communication.

## STRATEGIC RESPONSE GOAL AND CARE PRIORITIES

**Goal: To improve healthcare access and delivery for women with Parkinson's disease.**

> Medical professionals and women with PD should work together to identify goals for treatment.

### *Priority: Accessibility*

Parkinson's disease care must be more accessible to women. Improvement of accessibility includes ease of access, availability and appeal to women. Programs should target health, wellness and management of PD, and should be designed to be more welcoming to women. PD care programs should help women feel comfortable and included.

Medical professionals can strive to make earlier referrals and encourage utilization of Parkinson's disease-related healthcare services. Medical professionals should adopt practices that promote women's early utilization of services. By proactively referring the several services that women will need throughout the course of their care, medical professionals can help women better establish and navigate their own medical care teams.

### *Priority: Personalization*

Parkinson's disease care should be personalized to women. Both biological and gender/cultural differences influence PD health outcomes, and programs should be designed to address these differences. Medical professionals should investigate the effectiveness of standard Parkinson's disease treatment options and programs on women with PD. Women may require different services than men or may require that similar services be administered differently. Women may be more vulnerable to particular symptoms or experiences, and it is important that medical professionals identify treatment options that can address women's issues and concerns. Several quality of life and independent function activities women are engaged in center around traditional female roles. Care designed to be personalized and culturally relevant could better inform policy and research moving forward.

### *Priority: Communication*

Medical professionals and women with PD need to work together to minimize miscommunication. Transparency, shared decision-making and empathy can all further positive communication experiences between medical professionals and women with PD. Medical professionals and women with PD should work together to identify goals for treatment. By each setting appointment and care expectations, women and medical professionals can work together to provide and receive more positive care. In setting expectations, it is important that women with PD and medical professionals work to be more transparent with one another about symptom reporting, treatment recommendations and treatment adherence. Symptom checklists can encourage discussion about sensitive issues, like mental health and intimacy. Medical professionals should also work to improve communication of empathy when diagnosing or working with women with Parkinson's disease. Medical professionals should actively work to build long-term relationships with women, accounting for women's personal and medical goals. In instances where women are treated like patients, and not people, they may be less likely to utilize, or adhere to treatment recommendations.

Due to the complexity of Parkinson's disease treatment and care, medical professionals should improve communication within the medical community to appropriately connect women with PD to available comprehensive services. Women with PD cannot be expected to manage and coordinate their care alone. Women require several types of treatment over the course of their care, and it is important that medical professionals communicate with allied health professionals and non-PD specialists (e.g., cardiologists). In better coordinating care within the medical community, fewer women's issues should go undetected.

> Identifying strategies and tools to enable women to reach out to others for support could benefit women who are at risk of isolation.

## TOPIC THREE: EDUCATION AND EMPOWERMENT

***Regional Forum Identified Unmet Education and Empowerment Needs***

Regional forum participants emphasized the importance of peer-to-peer and educational resources, involved care teams and community advocacy for women with Parkinson's disease.

Participants shared the positive impact of and need for women's peer-to-peer services. Several women shared that they felt completely alone until meeting other women with PD. In several instances, participants shared that peer-to-peer services inspired them to advocate for better care and adhere to their PD treatment plan.

Women with PD are more likely than men with the disease to live and attend medical appointments alone.[44] Several participants discussed the burden of disease management, and how not having an involved care team (spouse/partner, family member, friend, etc.) or attending appointments alone negatively impacted care utilization and access. Women wanted to know what to expect, when to access specific services and to feel empowered enough to talk to their providers about their PD needs. Participants also identified several gaps in Parkinson's disease education and advocacy literature pertinent to these issues. Women overwhelmingly shared that they wanted tools and resources to maintain independence while managing their PD.

> **To ensure that women's needs are prioritized in Parkinson's disease research and care models, additional advocacy is needed at local, state and federal levels.**

Several participants shared that a positive experience with Parkinson's disease requires the participation of an involved care team (spouse/partner, family member, friend, etc.) Participants expressed that when a care team was involved and knowledgeable, they had a more positive PD experience. Some participants described the initial shock of their partner stepping into a caregiving role. They shared that although care partners were often well-intentioned, they didn't take proactive steps to maintain their own health, and at times were burned out and frustrated. Women also expressed the importance of remaining a "spouse" and continuing a relationship outside of caregiving and PD. Several women also expressed their desire to communicate their needs and priorities to their family, friends, church members and employers about their PD, but were fearful of the potential repercussions. Some women discussed not wanting to involve a care team in their care. Women wanted to remain independent and were not always open to the idea of asking for assistance.

Over the course of their journey, several participants discussed how they have developed positive advocacy skills and were able to build impactful Parkinson's disease programs for women in their communities. However, they also shared several barriers to expanding these programs, including a lack of funding, resources and general awareness of the disease.

Recognizing the many people involved in a single PD journey, this agenda prioritizes three areas of action to empower women with PD; these include education about self-management, shared responsibility and advocacy.

## STRATEGIC RESPONSE GOAL AND EDUCATION AND EMPOWERMENT PRIORITIES

**Goal: To empower women with Parkinson's disease and their care teams to advocate for optimal Parkinson's care focused on women's unique experiences.**

***Priority: Self-management***

Women need to be provided additional tools and resources for the self-management of PD. Tools need to be provided to women early in their diagnosis to promote positive behavior change and shared decision-making.

Resources that encourage women to reach out for assistance are also needed. Women should not hesitate to involve others in their care. Identifying strategies and tools to enable women to reach out to others for support could benefit women who are at risk of isolation.

Women also need to be provided tools and resources for the management of relationships. Parkinson's disease directly impacts women's relationships, and it is important that tools are made available to women to assist them in maintaining their relationships while consecutively managing their PD. Resources are also needed to help women better communicate with non-medical professionals.

### *Priority: Shared Responsibility*

Women with PD need to have access to women's-only peer-to-peer services. Women with Parkinson's disease need an environment in which they feel comfortable sharing their experiences, asking questions and learning different management strategies.

Care teams should better understand the needs and priorities of women with PD. Due to the complex nature of Parkinson's disease, women living with the diagnosis must utilize several medical services throughout the course of the disease. Although some women manage this journey alone, care teams should be more involved in this journey to offer assistance when possible. Women with PD should not be the only members of their care team knowledgeable about their diagnosis. Care teams have a shared responsibility to ensure that women are receiving positive and comprehensive PD care. An involved and knowledgeable care team can lead to more positive health outcomes for women.

In addition to resources to promote care team involvement, there is also a need for resources to support care team members. It is important to provide support resources to care partners, as well.

### *Priority: Advocacy*

Additional advocacy is needed to minimize the disparities women with Parkinson's disease experience, in comparison to their male counterparts. Advocacy is a major component in promoting PD research and receiving optimal PD care. To ensure that women's needs are prioritized in Parkinson's disease research and care models, additional advocacy is needed at local, state and federal levels.

To promote advocacy for women, additional education efforts are needed to increase public awareness about PD. Increasing awareness about PD can encourage greater community engagement and advocacy.

Increased attention to resources for women with PD should be a public policy issue. Women, their care teams and medical professionals need to advocate for research and care that is designed around women's unique needs.

> “*Becoming my own advocate and taking charge of my health care has really helped me to live a better life with Parkinson's disease. I have sought out doctors that are right for me and have learned to ask the hard questions. I hope to help others do the same through my work with the Parkinson's Foundation and the Women and PD Initiative.*
>
> **Kelly Weinschreider**
> Women and Parkinson's Advocate

> *I had difficulty relating to others in my support group, not realizing that the major problem was that they were all males. As such, they did not have to deal with the clash between their overt Parkinson's behaviors such as slurred speech and ungainly dyskinesia and society's pressures to maintain a "feminine" appearance (thin body, graceful movements, hair and make-up well done, hiding signs of aging and keeping up with the household chores such as dinner).*

**Sue Kuveke,** Women and Parkinson's Advocate

# OUR COMMITMENT TO IMPROVING HEALTH OUTCOMES FOR WOMEN WITH PD

The Parkinson's Foundation is fully invested in improving health outcomes for women with PD, and the development of this agenda has been a critical first step in promoting research and care practices that enable women with Parkinson's disease to maximize their quality of life. Over the next several years, the Foundation will take action on the nine strategic priorities outlined within this agenda in collaboration with key stakeholders invested in improving research and care for women with Parkinson's disease.

The Foundation will first focus its resources and attention to driving change in the four strategic priority areas of research relevance, care communication and shared responsibility and self-management for education and empowerment.

## RESEARCH RELEVANCE

The Foundation will host a convening of experts to identify critical research questions examining why women are at a reduced risk of developing PD. This convening will focus on topics such as sex hormones, stress and environmental exposures, which were identified in the literature and at the regional forums. In addition, the Foundation will conduct and support research utilizing data obtained through the Parkinson's Outcomes Project to identify gender differences in clinical care, disseminate initial findings and target areas for further research identified to be most impactful for women and PD community.

## CARE COMMUNICATION

The Foundation will partner with its Centers of Excellence to improve care communication between women with Parkinson's and medical professionals. The Foundation will provide funding to select centers to create, assess and disseminate shared decision-making tools designed to promote effective conversations between women with PD and their providers, taking into consideration the unique concerns that may influence women's health outcomes. Once tested, these tools will be made available for use to all centers and the broader Parkinson's community.

## SHARED RESPONSIBILITY

The Foundation will continue its targeted efforts to educate and empower women with PD and their care teams. In addition to the educational programs that will continue to be offered around the country, the Foundation will sponsor an education symposium specifically focused on the mental health and well-being of male and female care partners to women with PD. This symposium will also emphasize that through shared responsibility, care teams and women with PD can work together to manage the progression of PD in a manner that supports all involved.

## SELF-MANAGEMENT

The Foundation will invest in developing resources that target women newly diagnosed with PD. This project has identified the need for tools to help women navigate their journey from the beginning of a diagnosis. If women are experiencing a longer time between onset of symptoms and a diagnosis than men, it is particularly important that women are engaged early on in their progression. Tools and resources to help women feel prepared and knowledgeable about what to expect can improve their mindset and promote proactive behaviors that maintain their desired quality of life.

*Gender is one of the lenses through which we view and experience the world, including when it comes to health issues and access to treatment options and resources. As a clinical social worker, I would like to see an increased awareness of and sensitivity to the unique needs of women with Parkinson's among care providers and researchers; to improve the standard of care and resources across genders, we must continue to understand the differences between men and women with Parkinson's – this ultimately enhances quality of life.*

**Jessica Shurer, MSW, LCSW,** Center Coordinator & Clinical Social Worker, Parkinson's Foundation Center of Excellence at UNC Chapel Hill

# APPENDIX A:
# WOMEN AND PD TALK LEADERSHIP

## PROJECT KEY PERSONNEL

Project Lead: **Veronica Todaro**, MPH
Executive Vice President, Chief Operating Officer
Parkinson's Foundation
New York, New York

**Megan Feeney**, MPH
Senior Manager, Community Engagement
Parkinson's Foundation
New York, New York

**Allison W. Willis**, MD, MS
Assistant Professor of Neurology and of Epidemiology
University of Pennsylvania School of Medicine
Philadelphia, Pennsylvania

**Sharon Krischer**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Los Angeles, California

## WOMEN AND PD TALK NATIONAL TEAM LEADERS

**Ann Boylan**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Union City, California

**Beth-Anne Sieber**, PhD
Federal Liaison, National Institute of Neurological Disorders and Stroke
National Institutes of Health
Bethesda, Maryland

**Clarissa Martinez-Rubio**, PhD
Senior Director, Clinical Affairs
Parkinson's Foundation
Miami, Florida

**Joan Hlas**, LISW
Clinical Social Worker
Struthers Parkinson's Center, Parkinson's Foundation Center of Excellence
Golden Valley, Minnesota

**Karen Smith**
Women and Parkinson's Advocate
Parkinson's Foundation
Evansville, Indiana

**Leslie A. Chambers**, MSPH
President & CEO
American Parkinson Disease Association
Staten Island, New York

**Lisa M. Shulman**, MD
Professor of Neurology
Director, University of Maryland Parkinson's and Movement Disorders Center
University of Maryland School of Medicine
Baltimore, Maryland

**Ruth Hagestuen**, RN, MA
Struthers Parkinson's Center, Parkinson's Foundation Center of Excellence
Minnetonka, Minnesota

## WOMEN AND PD TALK REGIONAL TEAM LEADERS

**Adrienne Keener**, MD
Assistant Clinical Professor
University of California, Los Angeles
Los Angeles, California

**Allison W. Willis**, MD, MS
Assistant Professor of Neurology and of Epidemiology
University of Pennsylvania School of Medicine
Philadelphia, Pennsylvania

**Alyssa Elder**, PT, DPT
Assistant Clinical Professor
University of Southern California
[re+active] physical therapy and wellness
Los Angeles, California

**Amie Hiller**, MD
Assistant Professor
Oregon Health & Science University Parkinson Center
Veterans Affairs, Parkinson's Disease Research, Education, and Clinical Center
Portland, Oregon

**Amy M. Chesire**, LCSW-R, MSG
Center Coordinator
University of Rochester, Parkinson's Foundation Center of Excellence
Rochester, New York

**Amy W. Amara**, MD, PhD
Division of Movement Disorders, Department of Neurology
The University of Alabama at Birmingham
Birmingham, Alabama

**Ann Boylan**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Union City, California

**Carol Clupny**, MS
Women and Parkinson's Advocate
Parkinson's Foundation
Hermiston, Oregon

**Caroline M. Tanner**, MD, PhD
Director
San Francisco Veterans Affairs, Parkinson's Disease Research, Education, and Clinical Center
Professor, Department of Neurology
University of California, San Francisco
San Francisco, California

**Christina M. Christie**, PT, CCE, FAFS, FMR, 3DMAPS
Women's and Men's Health Program Manager
Athletico Physical Therapy
Park Ridge, Illinois

**Elizabeth Ogren**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Edina, Minnesota

**Jennifer G. Goldman**, MD, MS
Section Chief
Parkinson's Disease and Movement Disorders at the Shirley Ryan AbilityLab
Professor
Department of Physical Medicine and Rehabilitation and Neurology
Northwestern University Feinberg School of Medicine
Chicago, Illinois

**Jessica Shurer**, MSW, LCSW
Center Coordinator & Clinical Social Worker
Parkinson's Foundation Center of Excellence at UNC Chapel Hill
Chapel Hill, North Carolina

**Joan Hlas**, LISW
Clinical Social Worker
Struthers Parkinson's Center, Parkinson's Foundation Center of Excellence
Golden Valley, Minnesota

**Karen Virciglio**
Facilitator, Birmingham Parkinson's Support Group
Women and Parkinson's Advocate
Parkinson's Foundation
Birmingham, Alabama

**Kelly Weinschreider**
Women and Parkinson's Advocate
Parkinson's Foundation
Chicago, Illinois

**Kris Gjerde**, PT, MPH
Women and Parkinson's Advocate
Parkinson's Foundation
St. Paul, Minnesota

# APPENDIX A: WOMEN AND PD TALK LEADERSHIP

**Laura Lieb**, CRNP, MPH
Nurse Practitioner
Department of Neurology, Division of Movement Disorders
American Parkinson Disease Association
Information & Referral Center
The University of Alabama at Birmingham
Birmingham, Alabama

**Lisa Mann**, RN, BSN, MA
Team Care Coordinator and Education Director
Oregon Health & Science University Parkinson Center
Portland, Oregon

**Martha A. Nance**, MD
Medical Director
Struthers Parkinson's Center, Parkinson's Foundation
Center of Excellence
Golden Valley, Minnesota

**Mary Jones,** PT, MBA
Director Avera Brain & Spine, Inpatient Therapy,
Wound Services & Diabetes
Avera McKennan Hospital
Sioux Falls, South Dakota

**Mary Tidwell**
Women and Parkinson's Advocate
Parkinson's Foundation
Sioux Falls, South Dakota

**Mary Tranberg**
Women and Parkinson's Advocate
Parkinson's Foundation
Sioux Falls, South Dakota

**Nina M. Browner**, MD
Director
Parkinson's Foundation Center of Excellence at UNC
Chapel Hill
Chapel Hill, North Carolina

**Ruth Schneider**, MD
Assistant Professor of Neurology
University of Rochester, Parkinson's
Foundation Center of Excellence
Rochester, New York

**Sharon Krischer**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Los Angeles, California

**Stephanie Myers**, PT, DPT, GCS, NCS
Avera Therapy
Harrisburg, South Dakota

**Susan Heath**, MSN, RN
Movement Disorders Nurse Clinician
Department of Neurosurgery
Evergreen Health
Kirkland, Washington

**Susan Kuveke**
Women and Parkinson's Advocate
Parkinson's Foundation
Burlington, North Carolina

**Yvonne Hylton**
Women and Parkinson's Advocate
Parkinson's Foundation
Rochester, New York

## WOMEN AND PD TALK NATIONAL FORUM PARTICIPANTS

**Adrienne Keener**, MD
Assistant Clinical Professor
University of California, Los Angeles
Los Angeles, California

**Allison W. Willis**, MD, MS
Assistant Professor of Neurology and of Epidemiology
University of Pennsylvania School of Medicine
Philadelphia, Pennsylvania

**Alyssa Elder**, PT, DPT
Assistant Clinical Professor
University of Southern California
[re+active] physical therapy and wellness
Los Angeles, California

**Ann Boylan**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Union City, California

**Anna Grill**
Women and Parkinson's Advocate
Moving Day DC Chair
Aware in Care Ambassador
Parkinson's Foundation
Washington, District of Columbia

**Annie Li Wong**, MSN, RN, GNP-BC
Movement Disorders Nurse Practitioner
San Francisco Veterans Affairs, Parkinson's Disease
Research, Education, and Clinical Center
San Francisco, California

**Carol Clupny**, MS
Women and Parkinson's Advocate
Parkinson's Foundation
Hermiston, Oregon

**Caroline M. Tanner**, MD, PhD
Director
San Francisco Veterans Affairs, Parkinson's Disease
Research, Education, and Clinical Center
Professor, Department of Neurology
University of California, San Francisco
San Francisco, California

**Cheryl Pierce**, OT
Occupational Therapist
Encompass Health Lakeshore Rehabilitation Hospital
Birmingham, Alabama

**Chizoba Umeh**, MD
Associate Neurologist
Brigham and Women's Hospital
Boston, Massachusetts

**Christine Hunter**, RN, BSN
Director, Clinical Research
Baylor College of Medicine
Houston, Texas

**Claudia Martinez**, MD
Hispanic Outreach Coordinator
Muhammad Ali Parkinson Center at Barrow
Neurological Institute, Parkinson's Foundation Center
of Excellence
Phoenix, Arizona

**Danielle Abraham**, PhD, MPH
Postdoctoral Researcher
University of Pennsylvania School of Medicine
Philadelphia, Pennsylvania

**Danielle Agpalo**
Intern, Community Engagement
Parkinson's Foundation
New York, New York

**Elizabeth Ogren**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Edina, Minnesota

# APPENDIX A: WOMEN AND PD TALK LEADERSHIP

**Elizabeth Stemporzewski**
Associate Director, R&D Patient Advocacy
Biogen
Cambridge, Massachusetts

**Gregory Pontone**, MD, MHS
Director, Parkinson's Neuropsychiatry
Clinical Programs
Johns Hopkins University
Baltimore, Maryland

**Gretchen Rosswurm**
Women and Parkinson's Advocate and People with
Parkinson's Advisory Council
Parkinson's Foundation
Dallas, Texas

**Hilary Hansen**
Executive Director, US Patient Advocacy and Strategic
Alliances
Merck
Washington, District of Columbia

**Jaclyn Carson**, PT, DPT
Clinical Faculty
Physical Therapy Faculty Scholar at Parkinson's
Foundation
LSVT BIG Certified
University of Montana Physical Therapy Clinic
Missoula, Montana

**Jennifer G. Goldman**, MD, MS
Section Chief
Parkinson's Disease and Movement Disorders at the
Shirley Ryan AbilityLab
Professor
Department of Physical Medicine and Rehabilitation
and Neurology
Northwestern University Feinberg School of Medicine
Chicago, Illinois

**Jennifer Hale**, PT, DPT
Clinical Assistant Professor
Department of Physical Therapy
Texas State University
Round Rock, Texas

**Jessica Shurer**, MSW, LCSW
Center Coordinator & Clinical Social Worker
Parkinson's Foundation Center of Excellence at UNC
Chapel Hill
Chapel Hill, North Carolina

**Joan Hlas**, LISW
Clinical Social Worker
Struthers Parkinson's Center, Parkinson's Foundation
Center of Excellence
Golden Valley, Minnesota

**Joohi Jimenez-Shahed,** MD
Associate Professor of Neurology
Baylor College of Medicine
Houston, Texas

**Kathleen Crist**, LMSW
Executive Director
Houston Area Parkinson Society
Houston, Texas

**Kelly E. Lyons**, PhD
Research Professor of Neurology
University of Kansas Medical Center
Kansas City, Kansas

**Kelly Weinschreider**
Women and Parkinson's Advocate
Parkinson's Foundation
Chicago, Illinois

**Kevin Hylton**
President-elect, Co-Chair, Mission Delivery
Parkinson's Foundation Greater Rochester
Rochester, New York

**Kim Nitz**, MSW
Community Program Manager
Parkinson's Foundation Heartland
Leawood, Kansas

**Kristy Pomes**
Senior Manager, Communications and Marketing
Parkinson's Foundation
Miami, Florida

**Leslie A. Chambers**, MSPH
President and CEO
American Parkinson Disease Association
Staten Island, New York

**Lia Hotchkiss**, MPH
Director, Eugene Washington PCORI Engagement
Awards Program
Patient-Centered Outcomes Research Institute
Washington, District of Columbia

**Lisa Cone**
Women and Parkinson's Advocate and Parkinson's
Advocates in Research
Parkinson's Foundation
Wheat Ridge, Colorado

**Lisa Hoffman**, MA
Associate Director, Professional Education
Parkinson's Foundation
New York, New York

**Lou Eisenbrandt**, RN
Women and Parkinson's Advocate
Parkinson's Foundation
Overland Park, Kansas

**Martha A. Nance**, MD
Medical Director
Struthers Parkinson's Center, Parkinson's Foundation
Center of Excellence
Golden Valley, Minnesota

**Meg Poe**, MA, NBC-HWC
President and Owner
Poe Wellness Solutions
Durham, North Carolina

**Megan Feeney**, MPH
Senior Manager, Community Engagement
Parkinson's Foundation
New York, New York

**Michele York**, PhD, ABPP-CN
Associate Professor, Neurology
Head, Section of Neuropsychology
Baylor College of Medicine
Houston, Texas

**Miriam Weber**, PhD
Associate Professor
University of Rochester
Rochester, New York

**Monica Goodman**
Women and Parkinson's Advocate and Parkinson's
Advocates in Research
Parkinson's Foundation
Atlanta, Georgia

**Nancy Ennis**
Women and Parkinson's Advocate
Parkinson's Foundation
Houston, Texas

**Polly Dawkins**
Executive Director
Davis Phinney Foundation
Boulder, Colorado

**Rebecca Erikson**
Women and Parkinson's Advocate
Parkinson's Foundation
Mont Belvieu, Texas

# APPENDIX A: WOMEN AND PD TALK LEADERSHIP

**Ruth Schneider**, MD
Assistant Professor of Neurology
University of Rochester, Parkinson's Foundation Center
of Excellence
Rochester, New York

**Sharon Krischer**, MA
Women and Parkinson's Advocate
Parkinson's Foundation
Los Angeles, California

**Shirley Triche**, FNP
Nurse Practitioner
Emory University Brain Health Center
Atlanta, Georgia

**Vanessa K. Hinson**, MD, PhD
Director
Medical University of South Carolina, Parkinson's
Foundation Center of Excellence
Charleston, South Carolina

**Veronica Todaro**, MPH
Executive Vice President, Chief Operating Officer
Parkinson's Foundation
New York, New York

**Yvonne Hylton**
Women and Parkinson's Advocate
Parkinson's Foundation
Rochester, New York

> *Most of the women living with PD that I have met are either single or the family caregiver/partner. I found myself in the same situation and sought information and relationships that helped me cope, creatively manage and be proactive in managing my condition. Being with other women provides the opportunity to share feelings, information and approaches to make my life better. Just listening to the stories told the first time I met with a group of women living with PD encouraged me to take more positive steps to care for myself.*

**Kris Gjerde, PT, MPH,** Women and Parkinson's Advocate

# APPENDIX B: REGIONAL FORUM BREAKOUT QUESTIONS

**For Women with Parkinson's**

*Women and PD Teams to Advance Learning and Knowledge (TALK) Regional Forum*
*Focus Area Discussion Questions*

## RISK

1. Is there a specific risk factor (genetic, biological or environmental) that comes to mind with your Parkinson's diagnosis?
2. Do you think that this risk factor (genetic, biological or environmental) was specific to your sex or gender roles (occupation, timing [e.g., pre- or post-menopause], etc.)?

## SYMPTOMS

1. What Parkinson's-related symptoms (motor and non-motor) most impact you? Do you feel that any of these are different (more severe or present) because of your sex?
2. What Parkinson's-related symptoms (motor and non-motor) most impact your sense of self? If those symptoms were addressed, would that improvement greatly impact you? Please explain.
3. What Parkinson's related symptoms (motor and non-motor) do you most frequently report to your physician?

## TREATMENT

1. Think about your current Parkinson's treatment (medications, deep brain stimulation (DBS), exercise, etc.) What factors did you and your physician consider when deciding on your current treatment for Parkinson's (alleviation of specific symptoms, side effects from previous treatments, other co-morbidities or limitations)?
2. How have you responded to your Parkinson's treatment (negative and/or positive)?
3. How has your Parkinson's treatment impacted you? What has it allowed for and/or what has it taken away?

## CARE

1. Have you experienced barriers to accessing medical care throughout your Parkinson's progression? Do you think that some barriers are unique to you being a woman? Please explain.
2. Who is a part of your care team? How have they impacted (positive and/or negative) your Parkinson's experience?
3. In what way could your Parkinson's care be most improved?

**For Stakeholders**

*Women and PD Teams to Advance Learning and Knowledge (TALK) Regional Forum*
*Focus Area Discussion Questions*

## RISK

1. Is there a specific risk factor (genetic, biological or environmental) that comes to mind with your female Parkinson's patients (or constituents or the women that you care for)?
2. Do you think that this risk factor (genetic, biological or environmental) was related to their sex or gender roles (occupation, timing [e.g., pre- or post-menopause], etc.)?

## SYMPTOMS

1. What Parkinson's-related symptoms (motor and non-motor) most impact your female patients (or constituents or the women that you care for)? Do you feel that any of these are different (more severe or present) because of their sex?
2. What Parkinson's-related symptoms (motor and non-motor) most impact your female patients' (or constituents or the women that you care for) sense of self? If those symptoms were addressed, would that improvement greatly impact them? Please explain.
3. What Parkinson's-related symptoms (motor and non-motor) do your female patients (or constituents or the woman who you care for) most frequently report to you?

## TREATMENT

1. Think about Parkinson's treatment options (medications, DBS, exercise, etc.) What factors do you and your female patients (or constituents or the women that you care for) consider when deciding on a treatment for Parkinson's (alleviation of specific symptoms, side effects from previous treatments, other co-morbidities or limitations)?
2. How have your female patients (or constituents or the women that you care for) responded to Parkinson's treatments (negative and/or positive)?
3. How have Parkinson's treatments impacted your female patients (or constituents or the women that you care for)? What has it allowed for and/or what has it taken away?

## CARE

1. Have your female patients (or constituents or the woman that you care for) experienced barriers to accessing medical care throughout their Parkinson's progression? Have some of these barriers been unique to women? Please explain.
2. What do the care teams of your female patients look like? Who is part of their care team? How have they impacted (positive and/or negative) your female patients' Parkinson's experiences?
3. In what way could Parkinson's care for women be most improved?

# APPENDIX C: A BACKGROUND REVIEW OF THE SEX-RELATED DIFFERENCES IN PARKINSON'S DISEASE

## INTRODUCTION

Women and men differ in terms of underlying biology, development, environmental exposures and social roles.[6,7] These sex differences can impact one's health and are important to consider in Parkinson's disease (PD). Several literature reviews examine sex (or gender) differences in PD and cover a wide breadth of topics.[3,19,25,35,63–72] The aim of this review is to synthesize and expand on these reviews, emphasizing topic areas discussed as part of the Parkinson's Foundation Women and PD Teams to Advance Learning and Knowledge (Women and PD TALK) project.[73]

## INCIDENCE AND PREVALENCE

Diagnosing PD is challenging,[8] and research studies use multiple strategies to define and find PD cases.[9–11] Regardless of definition or data source, studies consistently find that men have a higher risk of developing PD. Studies suggest that the incidence rate of PD in men is 1.5 to 2.1 times higher than in women.[2,12–17] The risk of PD increases with age,[15,16] and this male risk preponderance may be more pronounced in older age.[14,15] For both sexes, Hispanics and Whites have a higher risk than Blacks or Asians.[15,16]

## SEX DIFFERENCES IN PARKINSON'S DISEASE

### *Sex Differences in Disease Risk*

The reduced risk of PD among women is not completely understood. However, differences in underlying biology, environmental exposures and behaviors may be important. Likely, the etiology behind the sex difference in risk is multifactorial.[18]

PD stems from depleted dopamine due to damage to the nigrostriatal dopaminergic (NSDA) system in the brain.[74] Evidence suggests that there are sex differences in the brain and NSDA system that make men more likely to develop PD.[25,65,75–77]

Hormones, namely estrogen, may also reduce the risk of PD in women. Basic science research suggests that estrogen has protective effects in the brain, including the NSDA system.[19,65,66,78] However, findings are mixed on whether estrogen, both endogenous (produced by the body) and exogenous (taken as a medication), reduces PD risk.[20,65] The type, timing and duration of exposure may all be important.[19–21]

Reproductive health characteristics (e.g., parity, age at menopause, menopause type) can influence levels of endogenous estrogen. When pooling data from multiple studies together, a study found no significant association between reproductive health characteristics and risk of PD.[79] However, some studies have found significant associations. For example, multiple studies find that surgical menopause (i.e., oophorectomy) is associated with an increased risk of PD.[80,81] However, this link may be due to detection bias – women who undergo surgical menopause may be more closely followed by medical providers for PD symptoms.[21] Cases of PD have been reported in the postpartum period. These cases may be the result of drastic declines in estrogen after delivery.[82] However, other postpartum factors, such as anemia and inflammatory processes, may be to blame.[82]

Exogenous estrogen findings are similarly unclear. A meta-analysis found no association between oral contraceptives and PD risk.[79] However, a U.S. study found long-term oral contraceptives decreased the risk of PD.[83] Findings on hormone replacement therapy (HRT) are inconsistent,[20,81,83–85] and the effect of HRT may differ by menopause type.[21]

Non-genetic factors, like environmental exposures and behavior, may play a large role in PD development, particularly for non-early onset PD.[22] Smoking, coffee intake, physical activity and non-steroidal anti-inflammatory drug (NSAID) use may reduce the risk of PD.[11,23,24] However, other factors like dairy consumption, head trauma and herbicide exposure may increase the risk of PD.[11,25,26] Men may have a higher likelihood of exposure to these risk factors, which in turn may increase their risk of PD.[25]

Additionally, various exposures may act as risk factors or protective factors in one sex but not the other, or have opposite effects in each sex.[18,24,86–89] For example, NSAIDs reduce the risk of PD for men but increase the risk, albeit non-significantly, for women.[90] There may be an interaction between estrogen and risk factors in women.[91]

***Sex Differences in Disease Symptoms***

Although not seen universally, studies find that women develop PD later than men.[17,92] This delayed onset in women could be biological in nature and related to estrogen exposure. Among women, higher parity,[39,92] later age at menopause[92] and longer duration of fertile life[39,92] are all associated with a later age at onset. Later onset could also be the result of women presenting with more subtle motor symptoms[27,92] or delaying care seeking.[56]

Many studies have examined sex differences in PD symptoms and severity including motor and non-motor symptoms, disability and

Table 1. Sex differences in disease symptoms or severity

| Symptom or Severity | Men Worse or Predominant | Women Worse or Predominant | No Sex Difference |
|---|---|---|---|
| Motor Symptoms | UPDRS Motor Score[29,39,57]<br>Rigidity[33,93]<br>Bradykinesia[33]<br>Upper body involvement[93] | Tremor at symptom onset[27,92]<br>Bradykinesia[93]<br>Posture problems[93]<br>Gait problems[93]<br>Freezing[70]<br>Falls[94] | UPDRS Motor Score[27,94]<br>Individual motor signs[97,27,38,92,95] |
| Non-Motor Symptoms | Behavior problems[31]<br>Orthostatic hypotension[93]<br>Urinary symptoms[29,30]<br>Sleep[27,29,32,33,93]<br>RBD[3,93]<br>Cognition[33,95,96]<br>Sexual dysfunction[27,29,32,97] | More symptoms[27,28]<br>Depression/sadness[27,29–31,27,32]<br>Anxiety/nervousness[29,31–33]<br>Gastrointestinal disturbance/constipation[30,32]<br>Urinary symptoms[29,30]<br>Sleep/fatigue[27,29,32]<br>Cognition[29]<br>Develop dementia[98]<br>Pain[32,93] | Hallucinations/delusions[31]<br>Sleep/fatigue[27,29,32,33,93]<br>Cognition[30] |
| Other Measures of Disease Severity | Disability[93]<br>HRQoL[57]<br>Shorter life expectancy[4,31,37,98,99] | Disability[19,100]<br>HRQoL[29,32,101] | Disability[95,102] |

UPDRS = Unified Parkinson Disease Rating Scale
RBD = Rapid eye movement sleep behavior disorder

health-related quality of life (HRQoL) (Table 1). The predominant sex differences are found in non-motor symptoms. Non-motor symptoms can negatively impact HRQoL, particularly for women.[29,34]

Sex differences in the progression of PD symptoms and severity over time have also been explored. Consistent with neuroimaging, many studies find no sex differences in PD motor symptom progression.[92,100,103,104] However, one study found that men have faster motor progression[105] and a second found that men have faster early progression but women have faster later progression.[106] For disability, studies find no sex differences[105,107] and faster disability progression in men.[103] When motor and disability severity were scored together, progression was slower for women.[108] Although only examined in one study, no sex differences in HRQoL progression have been found.[105]

Although comorbidities are separate from PD, they complicate disease management. Women have more osteoporosis, hip fractures, rheumatoid arthritis and osteoarthritis.[37] Meanwhile, men are more likely to have atrial fibrillation, acute myocardial infarction, colorectal cancer and chronic obstructive pulmonary disease.[37]

PD symptoms are impacted by both menstruation and pregnancy. PD symptoms may worsen during or prior to menstruation.[35,36] During pregnancy, women may experience improvement, no change or worsening of symptoms.[35,36] Given that estrogen is high during pregnancy, a worsening of symptoms is unexpected; however, this worsening may be related to inadequate PD treatment during pregnancy.[36]

### *Sex Differences in Disease Treatment*

Men and women take similar dopaminergic medications to combat their PD.[27,38,39] However, one study found that women are prescribed more dopamine agonists.[93] Adherence to dopaminergic medication is also similar between men and women.[109] Dopaminergic treatment for non-motor symptoms may be more beneficial to women.[110]

Levodopa is more bioavailable in women than men;[19,111] without proper dosing, women can be more susceptible to adverse effects of levodopa such as dyskinesias.[111,112] Dyskinesias tend to be more common in women.[3,27,40,41] Women also have more motor fluctuations and wearing off.[27,42,43] It is not entirely clear why women develop more dyskinesias,[64] but estrogen may be partially responsible by interacting with levodopa.[40] Several studies find that women are prescribed a lower levodopa equivalent daily dose[39,57,110] while others find no significant differences in dosage by sex.[30,38]

Examining other medications, women are more likely to be prescribed antidepressants[27,31,44] and benzodiazepines.[27] Men are more likely to receive medication for cognitive impairment or dementia.[44,113] Findings on antipsychotics suggest similar use;[44] however, men receive more antipsychotics in a nursing home setting.[31] Pain management is similar for men and women.[45] Women may be more likely to experience inappropriate co-prescribing of medications.[113]

Managing PD during pregnancy is challenging. Women with PD do not have worse fetal or maternal outcomes.[36] However, there is insufficient drug safety data for dopaminergic medication use during pregnancy.[36]

Sex hormones, including estrogen, could be therapeutically beneficial for PD patients.[19,71,78] Beneficial effects of sex hormones are demonstrated in animal models.[71] However, findings in humans are mixed.[114–116] Additional research is needed to determine if sex hormones can help treat PD, and, if so, the type, dosage, timing and duration of treatment that would be optimal.[19,71,114] Estrogen may also only be helpful to prevent PD and not helpful once PD has developed.[92]

Deep brain stimulation (DBS) is a beneficial treatment in PD, particularly for patients with poor symptom control with medication and motor complications[46], which are more common in women.[41] Men and women have similar improvements in motor symptoms after DBS; however, women have more improvement in HRQoL[47] and disability.[48] One study did find that men had a greater short-term motor symptom benefit from DBS.[117] Women and minorities are less likely to receive DBS.[49] This sex disparity could stem from fewer referrals for women,[3] women having more benign symptoms and not needing DBS[3] or higher refusal of DBS by women. One qualitative study suggests that there are no sex differences in patient thoughts about undergoing DBS.[118]

Evidence suggests that many behavioral interventions and modifications (e.g., exercise, certain diets, voice and speech therapy) may improve PD motor and non-motor symptoms.[50–54] Few studies examine whether the benefit or patient adoption of these interventions differs by sex. For example, women may not tolerate exercise as well as men,[70] and, early in the disease course, women are less physically active.[119] Additionally, certain disease symptoms may make physical activity challenging.[51]

### *Sex Differences in Disease Care and Care Utilization*

Although not universal,[93] evidence suggests that women with PD experience a longer time from onset of symptoms to diagnosis and onset of symptoms to first visit to a movement disorder specialist.[56] In the general population, women are more likely to seek medical care.[120] Consequently, such delays may be a function of delayed referrals.[56] PD patients have differing experiences with primary care – some providers miss the symptoms of PD while others refer quickly to a neurologist.[121] Women are also more likely to be unhappy with the process of obtaining a diagnosis of PD.[55]

Women, particularly Black women, are also less likely to see a specialist for their PD.[4] Women also receive less frequent neurologist care.[58] Specialist care is associated with a reduced risk of hip fracture,[4] hospitalizations for PD-related illness,[58] repeat hospitalizations[58] and skilled nursing facility admission[4]. Mortality[4] and healthcare costs[58] are also lower for those seen by a specialist. Use of occupational, physical and speech therapy and hospice care is more likely among those who see a neurologist.[59,60] Consequently, women are at greater risk for negative health outcomes.

With respect to provider preferences, some women in the general population would prefer to see a female neurologist.[122] For such women, there are fewer female neurologists overall and in academic centers.[123,124]

Women with PD have fewer provider visits than men.[37] However, women with PD, in general, are more likely to use allied healthcare.[60,61] Women are just as likely as men to utilize physical or occupational therapy, but less likely to utilize speech therapy.[60] Women with PD may be more likely to use home healthcare,[37] skilled nursing facility care,[37] hospice care[37] and nursing home care[59] than men with PD. These differences in sources of care suggest that women may have unique, unmet needs.

Women with PD are more likely to be single or widowed,[57] and men with PD are more likely to have a spouse as their primary caregiver.[44] More men need assistance from a caregiver, compared to women, particularly when PD symptoms are more advanced.[57] Additionally, men with PD are more likely to attend care visits with a caregiver.[44] Even after accounting for a variety of patient characteristics, women with PD are more likely to use a paid caregiver.[44]

Caring for a person with PD becomes more challenging with increases in comorbidities, disease stage and cognitive impairment.[44,125] Caregivers of PD patients are often inexperienced and have high amounts of anxiety and depression.[126] Anxiety and depression is higher for female caregivers.[126] Caregivers of men with PD have greater caregiver strain than those who care for women with PD.[44] Caregiving can be a barrier to caring for one's own health needs.[127,128] Women with PD may be caring for others and thus unable to adequately manage their own chronic condition.

## Discussion and Conclusions

Overall, women, especially minority women, are underrepresented in PD research, including clinical trials, and studies often do not explore whether findings differ by sex.[3,5,129] Studies that have explored sex differences suggest many differences between men and women with PD that span disease risk, symptoms, treatment and care. However, these studies often have contradictory findings. These discrepancies can stem from differences in study samples, methods and outcome measures. Patients from specialty care centers may differ greatly from those seen in other settings.[4] Methodologically, studies may fail to account for differences in characteristics between men and women during data analysis. Comparisons are also difficult when outcomes, such as disability, are assessed with different questionnaires across studies.[130]

There are several gaps in the PD literature. More research is needed on risk factors for PD in women, including the role of estrogen.[25] Although men and women experience different symptoms, it is unknown if women experience any unique symptoms or whether estrogen impacts disease symptoms.[19] It is also unclear if sex differences in depression and anxiety in PD stem from differences in underlying disease pathogenesis or sociocultural factors.[28] Questionnaires that assess symptoms and severity need to be validated to determine if they are appropriate to use in women.[131,132] Efforts are also needed to improve the diagnosis and management of PD for women.[3] Lastly, studies are required to determine care preferences and resource needs of women with PD.[72]

In conclusion, sex differences in PD risk, symptoms, treatment and care are pronounced; however, many gaps in knowledge remain. High-quality, longitudinal studies that include adequate numbers of women[72] as well as qualitative studies will be essential to address research gaps.

> “As a woman, Parkinson’s has distorted my identity, curbed spontaneity in group conversations, cut short my professional career, undermined both confidence and independence. I wish there were a way to better address the unspoken losses in PD.

**Yvonne Hylton,** Women and Parkinson’s Advocate

# CITATIONS

1. Marras C, Beck JC, Bower JH, et al. Prevalence of Parkinson's disease across North America. NPJ Parkinson's Dis. 2018;4:21.
2. Baldereschi M, Di Carlo A, Rocca WA, et al. Parkinson's disease and parkinsonism in a longitudinal study: two-fold higher incidence in men. ILSA Working Group. Italian Longitudinal Study on Aging. Neurology. 2000;55:1358–1363.
3. Miller IN, Cronin-Golomb A. Gender differences in Parkinson's disease: clinical characteristics and cognition. Mov Disord. 2010;25:2695–2703.
4. Willis AW, Schootman M, Evanoff BA, Perlmutter JS, Racette BA. Neurologist care in Parkinson disease: a utilization, outcomes, and survival study. Neurology. 2011;77:851–857.
5. Tosserams A, Araujo R, Pringsheim T, et al. Underrepresentation of women in Parkinson's disease trials. Mov Disord. 2018;33:1825–1826.
6. Wizemann TM, Pardue M-L, editors. Exploring the Biological Contributions to Human Health: Does Sex Matter? Washington (DC): National Academies Press (US); 2001.
7. Eagly AH, Wood W. Social Role Theory of Sex Differences. The Wiley Blackwell Encyclopedia of Gender and Sexuality Studies [online]. American Cancer Society; 2016. p. 1–3. Accessed at: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118663219.wbegss183.
8. Rizzo G, Copetti M, Arcuti S, Martino D, Fontana A, Logroscino G. Accuracy of clinical diagnosis of Parkinson disease: A systematic review and meta-analysis. Neurology. 2016;86:566–576.
9. Harris MA, Koehoorn M, Teschke K. Ongoing challenges to finding people with Parkinson's disease for epidemiological studies: a comparison of population-level case ascertainment methods. Parkinsonism Relat Disord. 2011;17:464–469.
10. Wen C-J, Yen AM-F, Chiu SY-H, et al. Active and Passive Methods of Detecting Parkinson's Disease. J Am Geriatr Soc. 2015;63:1261–1263.
11. de Lau LML, Breteler MMB. Epidemiology of Parkinson's disease. Lancet Neurol. 2006;5:525–535.
12. Wooten GF, Currie LJ, Bovbjerg VE, Lee JK, Patrie J. Are men at greater risk for Parkinson's disease than women? J Neurol Neurosurg Psychiatry. 2004;75:637–639.
13. Caslake R, Taylor K, Scott N, et al. Age-, gender-, and socioeconomic status-specific incidence of Parkinson's disease and parkinsonism in northeast Scotland: the PINE study. Parkinsonism Relat Disord. 2013;19:515–521.
14. Moisan F, Kab S, Mohamed F, et al. Parkinson disease male-to-female ratios increase with age: French nationwide study and meta-analysis. J Neurol Neurosurg Psychiatry. 2016;87:952–957.
15. Van Den Eeden SK, Tanner CM, Bernstein AL, et al. Incidence of Parkinson's disease: variation by age, gender, and race/ethnicity. Am J Epidemiol. 2003;157:1015–1022.
16. Wright Willis A, Evanoff BA, Lian M, Criswell SR, Racette BA. Geographic and ethnic variation in Parkinson disease: a population-based study of US Medicare beneficiaries. Neuroepidemiology. 2010;34:143–151.
17. Alves G, Muller B, Herlofson K, et al. Incidence of Parkinson's disease in Norway: the Norwegian ParkWest study. J Neurol Neurosurg Psychiatry. 2009;80:851–857.
18. Savica R, Grossardt BR, Bower JH, Ahlskog JE, Rocca WA. Risk factors for Parkinson's disease may differ in men and women: an exploratory study. Horm Behav. 2013;63:308–314.
19. Shulman LM. Gender differences in Parkinson's disease. Gend Med. 2007;4:8–18.
20. Marras C, Saunders-Pullman R. The complexities of hormonal influences and risk of Parkinson's disease. Mov Disord. 2014;29:845–848.
21. Popat RA, Van Den Eeden SK, Tanner CM, et al. Effect of reproductive factors and postmenopausal hormone use on the risk of Parkinson disease. Neurology. 2005;65:383–390.
22. Tanner CM, Ottman R, Goldman SM, et al. Parkinson disease in twins: an etiologic study. JAMA. 1999;281:341–346.

23. Hernan MA, Takkouche B, Caamano-Isorna F, Gestal-Otero JJ. A meta-analysis of coffee drinking, cigarette smoking, and the risk of Parkinson's disease. Ann Neurol. 2002;52:276–284.
24. Fang X, Han D, Cheng Q, et al. Association of Levels of Physical Activity With Risk of Parkinson Disease: A Systematic Review and Meta-analysis. JAMA Netw Open. 2018;1:e182421.
25. Gillies GE, Pienaar IS, Vohra S, Qamhawi Z. Sex differences in Parkinson's disease. Front Neuroendocrinol. 2014;35:370–384.
26. Hughes KC, Gao X, Kim IY, et al. Intake of dairy foods and risk of Parkinson disease. Neurology. 2017;89:46–52.
27. Solla P, Cannas A, Ibba FC, et al. Gender differences in motor and non-motor symptoms among Sardinian patients with Parkinson's disease. J Neurol Sci. 2012;323:33–39.
28. Sauerbier A, Lenka A, Aris A, Pal PK. Non-motor Symptoms in Parkinson's Disease: Gender and Ethnic Differences. Int Rev Neurobiol. 2017;133:417–446.
29. Hu T, Ou R, Liu H, et al. Gender and onset age related-differences of non-motor symptoms and quality of life in drug-naive Parkinson's disease. Clin Neurol Neurosurg. 2018;175:124–129.
30. Nicoletti A, Vasta R, Mostile G, et al. Gender effect on non-motor symptoms in Parkinson's disease: are men more at risk? Parkinsonism Relat Disord. 2017;35:69–74.
31. Fernandez HH, Lapane KL, Ott BR, Friedman JH. Gender differences in the frequency and treatment of behavior problems in Parkinson's disease. Mov Disord. 2000;15:490–496.
32. Martinez-Martin P, Falup Pecurariu C, Odin P, et al. Gender-related differences in the burden of non-motor symptoms in Parkinson's disease. J Neurol. 2012;259:1639–1647.
33. Liu R, Umbach DM, Peddada SD, et al. Potential sex differences in non-motor symptoms in early drug-naive Parkinson disease. Neurology. 2015;84:2107–2115.
34. Yoon J-E, Kim JS, Jang W, et al. Gender Differences of Non-motor Symptoms Affecting Quality of Life in Parkinson Disease. Neurodegener Dis. 2017;17:276–280.
35. Rubin SM. Parkinson's disease in women. Dis Mon. 2007;53:206–213.
36. Seier M, Hiller A. Parkinson's disease and pregnancy: An updated review. Parkinsonism Relat Disord. 2017;40:11–17.
37. Fullard ME, Thibault DP, Todaro V, et al. Sex disparities in health and health care utilization after Parkinson diagnosis: Rethinking PD associated disability. Parkinsonism & Related Disorders. 2018;48:45–50.
38. Umeh CC, Perez A, Augustine EF, et al. No sex differences in use of dopaminergic medication in early Parkinson disease in the US and Canada - baseline findings of a multicenter trial. PLoS One. 2014;9:e112287.
39. Frentzel D, Judanin G, Borozdina O, Klucken J, Winkler J, Schlachetzki JCM. Increase of Reproductive Life Span Delays Age of Onset of Parkinson's Disease. Front Neurol. 2017;8:397.
40. Zappia M, Annesi G, Nicoletti G, et al. Sex differences in clinical and genetic determinants of levodopa peak-dose dyskinesias in Parkinson disease: an exploratory study. Arch Neurol. 2005;62:601–605.
41. Bjornestad A, Forsaa EB, Pedersen KF, Tysnes O-B, Larsen JP, Alves G. Risk and course of motor complications in a population-based incident Parkinson's disease cohort. Parkinsonism Relat Disord. 2016;22:48–53.
42. Stocchi F, Antonini A, Barone P, et al. Early DEtection of wEaring off in Parkinson disease: the DEEP study. Parkinsonism Relat Disord. 2014;20:204–211.
43. Colombo D, Abbruzzese G, Antonini A, et al. The "gender factor" in wearing-off among patients with Parkinson's disease: a post hoc analysis of DEEP study. ScientificWorldJournal. 2015;2015:787451.
44. Dahodwala N, Shah K, He Y, et al. Sex disparities in access to caregiving in Parkinson disease. Neurology. 2018;90:e48–e54.
45. Zella MAS, May C, Muller T, et al. Landscape of pain in Parkinson's disease: impact of gender differences. Neurol Res. Epub 2018 Oct 12.:1–11.
46. Weaver FM, Follett K, Stern M, et al. Bilateral deep brain stimulation vs best medical therapy for patients with advanced Parkinson disease: a randomized controlled trial. JAMA. 2009;301:63–73.
47. Hariz G-M, Limousin P, Zrinzo L, et al. Gender differences in quality of life following subthalamic stimulation for Parkinson's disease. Acta Neurol Scand. 2013;128:281–285.

48. Accolla E, Caputo E, Cogiamanian F, et al. Gender differences in patients with Parkinson's disease treated with subthalamic deep brain stimulation. Mov Disord. 2007;22:1150–1156.
49. Willis AW, Schootman M, Kung N, Wang X-Y, Perlmutter JS, Racette BA. Disparities in deep brain stimulation surgery among insured elders with Parkinson disease. Neurology. 2014;82:163–171.
50. Paillard T, Rolland Y, de Souto Barreto P. Protective Effects of Physical Exercise in Alzheimer's Disease and Parkinson's Disease: A Narrative Review. J Clin Neurol. 2015;11:212–219.
51. Amara AW, Memon AA. Effects of Exercise on Non-motor Symptoms in Parkinson's Disease. Clin Ther. 2018;40:8–15.
52. Dashtipour K, Johnson E, Kani C, et al. Effect of exercise on motor and non-motor symptoms of Parkinson's disease. Parkinson's Dis. 2015;2015:586378.
53. Wang L, Xiong N, Huang J, et al. Protein-Restricted Diets for Ameliorating Motor Fluctuations in Parkinson's Disease. Front Aging Neurosci. 2017;9:206.
54. Mahler LA, Ramig LO, Fox C. Evidence-based treatment of voice and speech disorders in Parkinson disease. Curr Opin Otolaryngol Head Neck Surg. 2015;23:209–215.
55. Plouvier AOA, Olde Hartman TC, de Bont OA, et al. The diagnostic pathway of Parkinson's disease: a cross-sectional survey study of factors influencing patient dissatisfaction. BMC Fam Pract. 2017;18:83.
56. Saunders-Pullman R, Wang C, Stanley K, Bressman SB. Diagnosis and referral delay in women with Parkinson's disease. Gend Med. 2011;8:209–217.
57. Lubomski M, Louise Rushworth R, Lee W, Bertram KL, Williams DR. Sex differences in Parkinson's disease. J Clin Neurosci. 2014;21:1503–1506.
58. Willis AW, Schootman M, Tran R, et al. Neurologist-associated reduction in PD-related hospitalizations and health care expenditures. Neurology. 2012;79:1774–1780.
59. Safarpour D, Thibault DP, DeSanto CL, et al. Nursing home and end-of-life care in Parkinson disease. Neurology. 2015;85:413–419.
60. Fullard ME, Thibault DP, Hill A, et al. Utilization of rehabilitation therapy services in Parkinson disease in the United States. Neurology. 2017;89:1162–1169.
61. Seo HG, Park SJ, Seo J, Byun SJ, Oh B-M. Rehabilitation Therapy Utilization in Patients with Parkinson's Disease in Korea. Parkinson's Dis. 2018;2018:9475415.
62. Johnson et al. JL. Facilitating the use of a sex and gender-based analysis in health research. International Journal for Equity in Health. 2009;8:14.
63. Shulman LM, Bhat V. Gender disparities in Parkinson's disease. Expert Rev Neurother. 2006;6:407–416.
64. Baker JM, Hung AY. Movement Disorders in Women. Semin Neurol. 2017;37:653–660.
65. Smith KM, Dahodwala N. Sex differences in Parkinson's disease and other movement disorders. Exp Neurol. 2014;259:44–56.
66. Bourque M, Dluzen DE, Di Paolo T. Neuroprotective actions of sex steroids in Parkinson's disease. Front Neuroendocrinol. 2009;30:142–157.
67. Pretzer-Aboff I, Bunting-Perry L, Spindler M. The Implications of Parkinson's Disease for Women's Health. J Obstet Gynecol Neonatal Nurs. 2016;45:723–736.
68. Georgiev D, Hamberg K, Hariz M, Forsgren L, Hariz G-M. Gender differences in Parkinson's disease: A clinical perspective. Acta Neurol Scand. 2017;136:570–584.
69. Picillo M, Nicoletti A, Fetoni V, Garavaglia B, Barone P, Pellecchia MT. The relevance of gender in Parkinson's disease: a review. J Neurol. 2017;264:1583–1607.
70. Roland KP, Jakobi JM, Powell C, Jones GR. Factors related to functional independence in females with Parkinson's disease: a systematic review. Maturitas. 2011;69:304–311.

71. Bourque M, Morissette M, Di Paolo T. Repurposing sex steroids and related drugs as potential treatment for Parkinson's disease. Neuropharmacology. Epub 2018 Apr 9.

72. Pavon JM, Whitson HE, Okun MS. Parkinson's disease in women: a call for improved clinical studies and for comparative effectiveness research. Maturitas. 2010;65:352–358.

73. Parkinson's Foundation. Women & PD TALK [online]. Accessed at: https://www.parkinson.org/expert-care/Expert-Care-Programs/Addressing-Womens-Needs/Women-and-PD-TALK.

74. Dauer W, Przedborski S. Parkinson's disease: mechanisms and models. Neuron. 2003;39:889–909.

75. Weiduschat N, Mao X, Beal MF, Nirenberg MJ, Shungu DC, Henchcliffe C. Sex differences in cerebral energy metabolism in Parkinson's disease: a phosphorus magnetic resonance spectroscopic imaging study. Parkinsonism Relat Disord. 2014;20:545–548.

76. Kotagal V, Albin RL, Muller MLTM, Koeppe RA, Frey KA, Bohnen NI. Gender differences in cholinergic and dopaminergic deficits in Parkinson disease. J Neural Transm (Vienna). 2013;120:1421–1424.

77. Gillies GE, McArthur S. Estrogen actions in the brain and the basis for differential action in men and women: a case for sex-specific medicines. Pharmacol Rev. 2010;62:155–198.

78. Dluzen DE, McDermott JL. Gender differences in neurotoxicity of the nigrostriatal dopaminergic system: implications for Parkinson's disease. J Gend Specif Med. 2000;3:36–42.

79. Lv M, Zhang Y, Chen G-C, et al. Reproductive factors and risk of Parkinson's disease in women: A meta-analysis of observational studies. Behav Brain Res. 2017;335:103–110.

80. Ragonese P, D'Amelio M, Salemi G, et al. Risk of Parkinson disease in women: effect of reproductive characteristics. Neurology. 2004;62:2010–2014.

81. Benedetti MD, Maraganore DM, Bower JH, et al. Hysterectomy, menopause, and estrogen use preceding Parkinson's disease: an exploratory case-control study. Mov Disord. 2001;16:830–837.

82. Maltete D, Grangeon L, Le Goff F, et al. Four Cases of Parkinson Disease Diagnosed During the Postpartum Period. Obstet Gynecol. 2017;130:203–206.

83. Liu R, Baird D, Park Y, et al. Female reproductive factors, menopausal hormone use, and Parkinson's disease. Mov Disord. 2014;29:889–896.

84. Rugbjerg K, Christensen J, Tjonneland A, Olsen JH. Exposure to estrogen and women's risk for Parkinson's disease: a prospective cohort study in Denmark. Parkinsonism Relat Disord. 2013;19:457–460.

85. Currie LJ, Harrison MB, Trugman JM, Bennett JP, Wooten GF. Postmenopausal estrogen use affects risk for Parkinson disease. Arch Neurol. 2004;61:886–888.

86. Chen H, O'Reilly E, McCullough ML, et al. Consumption of dairy products and risk of Parkinson's disease. Am J Epidemiol. 2007;165:998–1006.

87. Cortese M, Riise T, Engeland A, Ascherio A, Bjornevik K. Urate and the risk of Parkinson's disease in men and women. Parkinsonism Relat Disord. 2018;52:76–82.

88. Ascherio A, Zhang SM, Hernan MA, et al. Prospective study of caffeine consumption and risk of Parkinson's disease in men and women. Ann Neurol. 2001;50:56–63.

89. Chen H, Zhang SM, Schwarzschild MA, Hernan MA, Ascherio A. Physical activity and the risk of Parkinson disease. Neurology. 2005;64:664–669.

90. Hernan MA, Logroscino G, Garcia Rodriguez LA. Non-steroidal anti-inflammatory drugs and the incidence of Parkinson disease. Neurology. 2006;66:1097–1099.

91. Ascherio A, Chen H, Schwarzschild MA, Zhang SM, Colditz GA, Speizer FE. Caffeine, postmenopausal estrogen, and risk of Parkinson's disease. Neurology. 2003;60:790–795.

92. Haaxma CA, Bloem BR, Borm GF, et al. Gender differences in Parkinson's disease. J Neurol Neurosurg Psychiatry. 2007;78:819–824.

93. Szewczyk-Krolikowski K, Tomlinson P, Nithi K, et al. The influence of age and gender on motor and non-motor features of early Parkinson's disease: initial findings from the Oxford Parkinson Disease Center (OPDC) discovery cohort. Parkinsonism Relat Disord. 2014;20:99–105.

94. Tassorelli C, Berlangieri M, Buscone S, et al. Falls, fractures and bone density in Parkinson's disease - a cross-sectional study. Int J Neurosci. 2017;127:299–304.
95. Augustine EF, Perez A, Dhall R, et al. Sex Differences in Clinical Features of Early, Treated Parkinson's Disease. PLoS One. 2015;10:e0133002.
96. Curtis AF, Masellis M, Camicioli R, Davidson H, Tierney MC. Cognitive profile of non-demented Parkinson's disease: Meta-analysis of domain and sex-specific deficits. Parkinsonism Relat Disord. Epub 2018 Oct 14.
97. Buhmann C, Dogac S, Vettorazzi E, Hidding U, Gerloff C, Jurgens TP. The impact of Parkinson disease on patients' sexuality and relationship. J Neural Transm (Vienna). 2017;124:983–996.
98. Willis AW, Schootman M, Kung N, Evanoff BA, Perlmutter JS, Racette BA. Predictors of survival in patients with Parkinson disease. Arch Neurol. 2012;69:601–607.
99. Ascherio A, Weisskopf MG, O'Reilly EJ, et al. Coffee consumption, gender, and Parkinson's disease mortality in the cancer prevention study II cohort: the modifying effects of estrogen. Am J Epidemiol. 2004;160:977–984.
100. Baba Y, Putzke JD, Whaley NR, Wszolek ZK, Uitti RJ. Gender and the Parkinson's disease phenotype. J Neurol. 2005;252:1201–1205.
101. Dahodwala N, Pei Q, Schmidt P. Sex Differences in the Clinical Progression of Parkinson's Disease. J Obstet Gynecol Neonatal Nurs. 2016;45:749–756.
102. Diamond SG, Markham CH, Hoehn MM, McDowell FH, Muenter MD. An examination of male-female differences in progression and mortality of Parkinson's disease. Neurology. 1990;40:763–766.
103. Jankovic J, Kapadia AS. Functional decline in Parkinson disease. Arch Neurol. 2001;58:1611–1615.
104. Louis ED, Tang MX, Cote L, Alfaro B, Mejia H, Marder K. Progression of parkinsonian signs in Parkinson disease. Arch Neurol. 1999;56:334–337.
105. Velseboer DC, Broeders M, Post B, et al. Prognostic factors of motor impairment, disability, and quality of life in newly diagnosed PD. Neurology. 2013;80:627–633.
106. Reinoso G, Allen JCJ, Au W-L, Seah S-H, Tay K-Y, Tan LCS. Clinical evolution of Parkinson's disease and prognostic factors affecting motor progression: 9-year follow-up study. Eur J Neurol. 2015;22:457–463.
107. Hely MA, Morris JG, Traficante R, Reid WG, O'Sullivan DJ, Williamson PM. The sydney multicentre study of Parkinson's disease: progression and mortality at 10 years. J Neurol Neurosurg Psychiatry. 1999;67:300–307.
108. Latourelle JC, Beste MT, Hadzi TC, et al. Large-scale identification of clinical and genetic predictors of motor progression in patients with newly diagnosed Parkinson's disease: a longitudinal cohort study and validation. Lancet Neurol. 2017;16:908–916.
109. Wei Y-J, Palumbo FB, Simoni-Wastila L, et al. Anti-Parkinson drug use and adherence in medicare part D beneficiaries with Parkinson's disease. Clin Ther. 2013;35:1513-1525.e1.
110. Picillo M, Erro R, Amboni M, et al. Gender differences in non-motor symptoms in early Parkinson's disease: a 2-years follow-up study on previously untreated patients. Parkinsonism Relat Disord. 2014;20:850–854.
111. Kumagai T, Nagayama H, Ota T, Nishiyama Y, Mishina M, Ueda M. Sex differences in the pharmacokinetics of levodopa in elderly patients with Parkinson disease. Clin Neuropharmacol. 2014;37:173–176.
112. Fahn S, Oakes D, Shoulson I, et al. Levodopa and the progression of Parkinson's disease. N Engl J Med. 2004;351:2498–2508.
113. Mantri S, Fullard M, Gray SL, et al. Patterns of Dementia Treatment and Frank Prescribing Errors in Older Adults With Parkinson Disease. JAMA Neurol. Epub 2018 Oct 1.
114. Saunders-Pullman R, Gordon-Elliott J, Parides M, Fahn S, Saunders HR, Bressman S. The effect of estrogen replacement on early Parkinson's disease. Neurology. 1999;52:1417–1421.
115. Parkinson Study Group POETRY Investigators. A randomized pilot trial of estrogen replacement therapy in post-menopausal women with Parkinson's disease. Parkinsonism Relat Disord. 2011;17:757–760.

116. Strijks E, Kremer JA, Horstink MW. Effects of female sex steroids on Parkinson’s disease in postmenopausal women. Clin Neuropharmacol. 1999;22:93–97.
117. Romito LM, Contarino FM, Albanese A. Transient gender-related effects in Parkinson’s disease patients with subthalamic stimulation. J Neurol. 2010;257:603–608.
118. Sperens M, Hamberg K, Hariz G-M. Are Patients Ready for “EARLYSTIM”? Attitudes towards Deep Brain Stimulation among Female and Male Patients with Moderately Advanced Parkinson’s Disease. Parkinson’s Dis. 2017;2017:1939831.
119. Mantri S, Fullard ME, Duda JE, Morley JF. Physical Activity in Early Parkinson Disease. J Parkinson’s Dis. 2018;8:107–111.
120. Thompson AE, Anisimowicz Y, Miedema B, Hogg W, Wodchis WP, Aubrey-Bassler K. The influence of gender and other patient characteristics on health care-seeking behaviour: a QUALICOPC study. BMC Fam Pract. 2016;17:38.
121. Plouvier AOA, Olde Hartman TC, Boots LPW, Bloem BR, van Weel C, Lagro-Janssen ALM. Time intervals in diagnosing Parkinson’s disease: The patients’ views. Patient Educ Couns. 2015;98:777–782.
122. Kerssens JJ, Bensing JM, Andela MG. Patient preference for genders of health professionals. Soc Sci Med. 1997;44:1531–1540.
123. McDermott M, Gelb DJ, Wilson K, et al. Sex Differences in Academic Rank and Publication Rate at Top-Ranked US Neurology Programs. JAMA Neurology. 2018;75:956–961.
124. Association of American Medical Colleges. 2018 Physician specialty data book [online]. Accessed at: https://www.aamc.org/download/493090/data/2018-aamc-physician-specialty-data-report.pdf. Accessed February 12, 2019.
125. Vatter S, McDonald KR, Stanmore E, Clare L, McCormick SA, Leroi I. A qualitative study of female caregiving spouses’ experiences of intimate relationships as cognition declines in Parkinson’s disease. Age Ageing. Epub 2018 Apr 3.
126. Gultekin M, Ekinci A, Erturk G, Mirza M. Female Parkinson’s disease caregivers have much anxiety and depressive symptom. Brain Behav. 2017;7:e00787.
127. Donelan K, Falik M, DesRoches CM. Caregiving: challenges and implications for women’s health. Womens Health Issues. 2001;11:185–200.
128. DiGiacomo M, Lewis J, Nolan MT, Phillips J, Davidson PM. Transitioning from caregiving to widowhood. J Pain Symptom Manage. 2013;46:817–825.
129. Sex-Specific Reporting of Scientific Research: A Workshop Summary. Washington (DC): National Academies Press (US); 2012.
130. Shulman LM, Armstrong M, Ellis T, et al. Disability Rating Scales in Parkinson’s Disease: Critique and Recommendations. Mov Disord. 2016;31:1455–1465.
131. Hambleton RK. Good practices for identifying differential item functioning. Med Care. 2006;44:S182-188.
132. Goetz CG, Liu Y, Stebbins GT, et al. Gender-, age-, and race/ethnicity-based differential item functioning analysis of the movement disorder society-sponsored revision of the Unified Parkinson’s disease rating scale. Mov Disord. 2016;31:1865–1873.

## Acknowledgements

This agenda was written and reviewed by:

Megan Feeney, MPH
Veronica Todaro, MPH
Christiana Evers, MPA
Parkinson's Foundation

Caroline M. Tanner, MD, PhD
University of California, San Francisco

Allison W. Willis, MD, MS
Danielle Abraham, PhD, MPH
University of Pennsylvania School of Medicine

Design by Ora Presby Gewirtz and Gretchen Heim

The Parkinson's Foundation wishes to acknowledge the contributions of the national team, regional team leaders and the many medical professionals, advocacy representatives and members of the Parkinson's community who participated in the regional and national forums. A note of thanks also goes to project key personnel, Allison Willis, MD, MS and Sharon Krischer, MA and Women and PD TALK intern, Danielle Agpalo. A special thanks to Lia Hotchkiss, MPH, of the Patient-Centered Outcomes Research Institute (PCORI) for funding and providing guidance throughout the course of this project.

/ParkinsonDotOrg

@ParkinsonDotOrg

/ParkinsonDotOrg

@ParkinsonDotOrg

/ParkinsonDotOrg

HELPLINE: ENGLISH/ESPAÑOL

1-800-4PD-INFO (473-4636)

Miami: 200 SE 1st Street, Suite 800, Miami, FL 33131
NY: 1359 Broadway, Suite 1509, New York, NY 10018

**PARKINSON.ORG**