

CHAMPIONING HEALTH EQUITY: RESEARCHER'S QUEST TO EXPAND ADVANCE CARE PLANNING IN HISPANIC PD COMMUNITIES

As part of our 2024-2025 research funding, the American Parkinson Disease Association (APDA) was proud to award Danielle Shpiner, MD, an APDA Diversity in Parkinson's Disease Research Grant, which is given to investigators exploring health inequities and/or differences among under-studied Parkinson's disease (PD) communities.



Dr. Shpiner serves in many capacities at the University of Miami Miller School of Medicine, including as an Assistant Professor of Clinical Neurology within the Department of Neurology's Movement Disorders Division. Her clinical and research interests include novel and advanced therapies for PD, health disparities, and medical education.

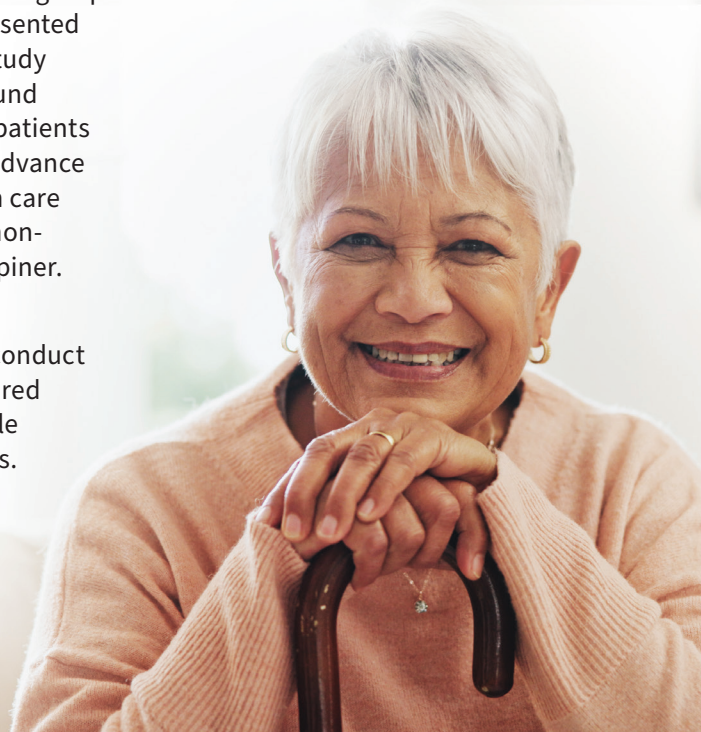
Dr. Shpiner's APDA-funded project — Improving access to advance care planning for Hispanic people with Parkinson's disease — is investigating barriers to advance care planning (ACP) among the Hispanic, Miami-based Parkinson's population.

ACP is the process through which patients determine and express their future healthcare preferences in case they become unable to do so. This may involve writing their preference down using legal tools called advance directives. While studies have shown that ACP is important to most patients with serious illnesses, access to these discussions is not equal, likely due to a combination of factors such as physician bias, health literacy disparities, and cultural preferences.

"At the University of Miami, we treat a diverse patient population, about half of whom identify as Hispanic — a group that is historically under-represented in PD research. In a previous study conducted by our team, we found that our Hispanic Parkinson's patients reported less engagement in advance care planning with their health care providers when compared to non-Hispanic patients," said Dr. Shpiner.

To investigate these barriers, Dr. Shpiner and her team will conduct focus groups and semi-structured interviews with Hispanic people with PD and their care partners. They will explore the reasons why this population has often been unable to access ACP discussions and potential strategies for improvement.

When asked what fuels her passion for research, Dr. Shpiner said, "I love having the opportunity to contribute to science that will help us **develop better ways of caring for Parkinson's patients and eventually find a cure!**"



HAND IN HAND: THE ESSENTIAL SUPPORT OF PARKINSON'S CARE PARTNERS



Care partners are the heart of support for people living with Parkinson's — providing love, companionship, and a steady hand through every twist and turn of the journey. They bring a sense of safety, trust, and connection, enriching the lives of their loved ones. Whether spouses, family members, close friends, or neighbors, care partners form a powerful bond, helping navigate challenges while fostering hope and resilience.

The role of a care partner adapts to the changing needs of their loved ones, and their support often includes:

- ▶ **Emotional Support:** Sharing moments of laughter, listening with compassion, and being a constant presence.
- ▶ **Physical Assistance:** Helping with mobility, medication, or daily tasks when needed.
- ▶ **Advocacy:** Ensuring that their loved one's voice is heard and respected in the healthcare system.
- ▶ **Coordination of Care:** Managing appointments and keeping communication open with healthcare providers.
- ▶ **Monitoring Health:** Observing changes and adjusting care as necessary.

Although November was National Family Caregivers Month, here at APDA we believe in honoring care partners *all year round*. Care partners, through their love and dedication, make life a little brighter and the journey easier for those with Parkinson's. We celebrate these incredible individuals whose dedication offers strength, joy, and comfort.

Here's a glimpse of how people with Parkinson's feel about their care partners:

"My wife is my eyes, ears, drill sergeant, and coach. She's always with me at doctors' visits, offering critical input when I can't see my own challenges clearly. She's my sixth sense, and I love and appreciate all she does for me." — Bob

"Bless my husband and sister who always try to meet my needs and wants. Which are many — especially when I am demanding. I love them for everything they do. My appreciation to all the aides, nurses, and doctors who help me every day." — Gail

For more resources, visit
APDA's care partner page at
apdaparkinson.org/carepartner.



WHAT'S HAPPENING AT APDA

Registration is open!



The third annual **APDA Virtual Parkinson's Conference** will take place February 19-20, and registration is now open! Reserve your spot today and get ready for two days of the very latest PD info, hot topics, inspiration, community, and more! Expert speakers, fun breakout sessions, panel discussions — there's something for everyone! Visit apdaparkinson.org/Engage2025 to register and learn more.

Tell us your story.



We believe strongly in the power of personal stories, so whether you're living with PD or care for someone who is, please add your voice to the growing community of people living with hope and optimism in our Story Gallery! Your story may inspire others, and our expanding collection of stories can help people feel less alone in their PD journey. Visit apdaparkinson.org/stories to share your story today.

A MESSAGE FROM OUR PRESIDENT & CEO



Dear Friend,

As we begin a new year, I want to take a moment to express my heartfelt gratitude for your continued support. Your unwavering commitment has enabled us to provide hope, care, and strength to individuals and families affected by PD.

In this issue of *Insights*, we talk about new PD research, the importance of care partners in a PD journey, and more. I think you'll be especially interested to learn about unique studies such as Dr. Danielle Shpiner's research into ways to improve care options in the Hispanic PD population.

I'm incredibly proud of the life-changing work we're doing together as we uplift the PD community, and I'm excited to carry this momentum into the year ahead. Your generosity makes all of this possible — and for that, I am deeply grateful.

Wishing you a joyful and healthy year ahead,

A handwritten signature in black ink that reads "Leslie A. Chambers".

Leslie A. Chambers
President & CEO

American Parkinson Disease Association



RECONNECT FOR VALENTINE'S DAY WITH APDA'S PARKINSEX



Romance, intimacy, and special connection can often take a backseat to Parkinson's disease. Life with PD can be challenging, and it can feel busy and overwhelming, especially as symptoms change or increase. For those who have a significant other, you might be missing the tender touches, spicy moments, and the specialness of being a loving couple. Valentine's Day can serve as a good motivator to take some action.

APDA created ParkinSex to help people with PD and their partners deepen their connections and improve sexual wellness, which has been linked to overall health and well-being.

This innovative, experiential guide to intimacy and corresponding kit with items to encourage touch and connection were designed to help people with PD rekindle that special connection and find ways to revive intimacy in new ways that feel right for them.

"Discussing sexual health with patients often takes a back seat when dealing with other medical concerns that can accompany Parkinson's disease, but that doesn't mean that sexual health isn't vital to a person's wellbeing," says Dr. Rebecca Gilbert, APDA's Chief Mission Officer. "When prompted, regardless of reluctance, many people with PD admit that they miss the intimate connection they used to have with their partner or explain how their PD has put a damper on their sex life. The ParkinSex Booklet & Kit allows people to explore the topic in the comfort of their own home, on their own time, and get some practical ideas that will hopefully increase their quality of life."

You can request your own
ParkinSex kit today by visiting
apdaparkinson.org/parkinsex.



We hope that some of the easy and approachable suggestions help you rekindle a bit of that special connection — on Valentine's Day, or any day!



“ASK THE DOCTOR”

with Dr. Rebecca Gilbert

Q: I was recently told that carbidopa/levodopa doesn't help tremor. Is that true?

No. Carbidopa/levodopa often helps tremor. However, in a certain percentage of people, tremors don't respond well as other symptoms of PD such as slowness and stiffness. Movement disorder physicians measure whether medication doses are successful by monitoring slowness and stiffness of movement, symptoms of PD which are quite responsive to medication, as opposed to tremor, because that is less predictable.

Q: Does Parkinson's disease cause foot and calf cramps?

PD can cause dystonia, which is an involuntary twisting movement of a part of the body. It can often include the foot and leg and can be painful. It is also possible that dystonia is a feature of a dose of PD medication wearing off. Changing doses or timing of Parkinson's

medications may be helpful. Sometimes, botulinum toxin injections may be warranted to help dystonia.

Q: If my husband is due for a dose when he is not fully awake, I am afraid that he won't be able to swallow the medication properly. What do I do in this situation?

I would talk with your husband's doctor about this problem. In general, I would not give a person medication when it doesn't look like he or she will be able to swallow it. However, the best approach would be to try to figure out why he is often lethargic. Could his nighttime sleep be improved? Is he on a medication that is making him sleepy? If that is corrected, then he may be able to take his medication on time more often.

Dr. Rebecca Gilbert is the Chief Mission Officer at APDA. She oversees APDA's research portfolio in conjunction with APDA's Scientific Advisory Board. She also provides medical and clinical expertise to support APDA programming as well as print and web content.

LEAVE A LEGACY OF HOPE

Create a lasting legacy and enjoy tax benefits while supporting the Parkinson's community with a planned gift. Planning ahead can also give you peace of mind knowing that you've done your best to provide for your loved ones and the causes you've cared about during your lifetime. Learn more about the ways you can leave a lasting impact at

apdaparkinson.org/legacy or contact our Planned Giving office at

jcolasuonno@apdaparkinson.org

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

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apda@apdaparkinson.org | apdaparkinson.org

For more information, or to learn about the many ways you can support APDA, visit our website at apdaparkinson.org/Insights25 or call (800) 223-2732.