

COMMUNITY, SUPPORT & BOXING:

One couple's recipe for PD success

After experiencing rigidity and fatigue, Lynda was diagnosed with Parkinson's disease (PD) at the age of 54. Like many people in her position, she was in denial at first. Fortunately, her husband of 22 years, Michael, was not only there to be her solid support system — but her care partner as well.

The two began their PD journey together and set out to learn as much as they could about the disease. After a movement specialist told Lynda that she could fight PD with exercise, she and Michael became coaches at Rock Steady Boxing — an exercise program designed specifically for people with PD that can help manage symptoms.

Lynda and Michael also became APDA PRESS™ facilitators in their community. PRESS, short for Parkinson's Roadmap for Education and Support Services, is an American Parkinson Disease Association (APDA) signature program that covers a set curriculum each week to set members up for a successful PD journey. The couple is passionate about helping others and enjoy expanding their knowledge about PD at the same time.



Lynda and Michael explore Bryce Canyon.

“PRESS helps us stay up to date on all the new developments regarding PD. Everyone shares what they know and we all learn something. Giving back to the PD community is very fulfilling,” says Lynda.

On top of making a difference in their community, Lynda and Michael have been given a new perspective on life. They remain positive and find strength in each other, all while cherishing every moment they spend together.

With Michael by her side, Lynda knows she never has to face challenges alone. The healthy communication between them helps Michael understand that Lynda will need his help at times, but maintaining Lynda's independence is important as well.

Being a care partner for a loved one with PD can be challenging at times. Michael shares that he finds motivation in Lynda's commitment to keeping her PD symptoms at bay. “Her regimen of exercises and other Parkinson's related activities is pretty amazing,” Michael explains. Despite Michael being Lynda's care partner, their marriage always comes first.

“She's my life partner, my wife, my best friend, and I happen to be her care partner.” — Michael

After living with PD for more than 10 years, Lynda knows just how many misconceptions there are about the disease. She wants more people to know that PD is more than just tremors, and oftentimes the invisible symptoms are



Lynda finds Rock Steady Boxing to be an electrifying workout.

just as significant. She also wishes more people were educated on the many ways to fight the progression of PD.

Lynda and Michael are grateful for the work APDA is doing for the PD community. “APDA has been there with trusted information,” the couple explains. “The education and programming provided by APDA can make the difference between continuing to be able to move or not.”

Whether providing groups like PRESS, hosting in-person and virtual exercise classes, or simply being a source of support and information, APDA is proud to be there for people like Lynda and Michael.

A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

As a fresh new season of spring is upon us, I want to tell you just how thankful I am for your support. I also want to share my excitement as I imagine the new possibilities of growth that lie ahead for the Parkinson's disease (PD) community.



There are so many inspiring examples of those who face PD head-on — like Lynda and Michael, whose story is featured in this issue of *Insights*. Their optimism is contagious and thanks to the generosity of people like you, we can help people like Lynda and Michael live their lives to the fullest every day.

You'll also learn more about what research says about the effects of probiotics on PD, as well as how sleep and PD are related. Every new detail we learn about PD paves the way towards treatments and a cure — and for that, I am so grateful.

With Parkinson's Disease Awareness Month upon us, I hope we can continue to count on you as we drive even more progress for our family members, friends, and neighbors who have been touched by PD. With you on our side, there's no limit to what we can do.

Warm regards,

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

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

APRIL IS PARKINSON'S DISEASE AWARENESS MONTH

PD Awareness Month is the perfect time to show your support for the PD community. Let's come together and raise awareness for this disease as we continue to share hope and strength with everyone living with PD and their loved ones.



Read our tips below on how you can get involved and support the PD community

Get connected

Make this the month you try a new fitness class, get back to your support group, or volunteer for an upcoming event. Find more information at apdaparkinson.org/events.

Be a listening ear

If you know someone with PD, make plans to spend some quality time together, lend an ear or hand, or offer words of support.

Take time for yourself

Take time to recommit to yourself and focus on your needs. When you do, you'll have more energy to educate and inspire others!

When you're part of the PD community, every month of the year is PD Awareness Month— but this April, let's go even further to share hope and strength with everyone affected by PD!



LEARNING MORE ABOUT HOW LIFESTYLE AFFECTS PD

Are you or a loved one living with PD? Are you curious to know how lifestyle habits can impact your journey with the disease? Below, we share insight into two health-related topics — sleep and probiotics — and how they interact with PD.

Sleep & PD: How Are They Related?

During a recent episode of APDA's *Dr. Gilbert Hosts*, we featured special guest Dr. Maria Ospina — a movement disorders specialist. Together, they answered questions regarding sleep issues and PD, a very common symptom for people living with PD.

Q *I'm very tired by lunch and fall asleep in the afternoon. Is this normal?*

A: People with PD may have fatigue at particular times during the day, occurring after a dose of medication. This can be very common. Sometimes the best solution is to take a short nap to regain energy for the rest of the day.

Q *You suggest that to help keep a person awake during the day, his/her activities should be increased, but my husband's PD is very advanced, and he needs constant supervision to do anything. What are some good activities to consider?*

A: Listening to music, looking through family photos, looking through magazines, taking walks, going to the park, going grocery shopping, and participating in a seated exercise class are ways that someone with advanced PD can stay active.

This is just a small sample of what Dr. Gilbert and Dr. Ospina covered in their conversation. To learn more visit apdaparkinson.org/SleepQ&A.

What the Latest Science Tells Us About Probiotics & PD

Probiotics have gained popularity in recent years when it comes to easing symptoms of PD — but what exactly are they, and can they make a real difference for people with PD?

Probiotics refer to foods or nutritional supplements that contain micro-organisms (such as bacteria or yeast) meant to support health. Probiotics include certain yogurts as well as supplements in powder and pill form. Prebiotics are defined as foods that don't contain micro-organisms themselves, but rather promote the growth of good micro-organisms.

Research is underway to determine whether manipulating gut bacteria in those with PD using probiotics can be therapeutic. Clinical trials are open if you or someone you know would like to participate. So far, data from these trials suggests that certain probiotics may help symptoms of PD, particularly GI symptoms. However, prebiotics may be a more effective way of manipulating gut bacteria than probiotics.

If you're interested in incorporating probiotics or prebiotics into your diet, talk to your doctor about whether this is right for you.

To learn more about probiotics and PD, visit apdaparkinson.org/Probiotics.

TWO DAYS OF EDUCATION & INSPIRATION

With more than 3,000 registrants, 25+ speakers, and 20 different sessions, the two-day **APDA Virtual Parkinson's Conference** was an important opportunity to bring the PD community together.

Designed to educate, empower, and engage attendees, the conference offered an exciting line-up of healthcare experts, personal stories, and energizing activities. Highlights included helpful presentations focused on:

- Anxiety, gastrointestinal issues, and deep brain stimulation
- Stem cell research and new lab tests for PD
- The science behind singing, art, and movement for PD
- An honest and compassionate care partner panel conversation
- Helpful advice for those who are newly diagnosed
- And much more!

Participants from around the globe connected with the presenters and each other through lively Q&A sessions and community message boards.

Did you miss it? Don't worry! The recorded sessions are available on APDA's YouTube channel (look for the Virtual Conference playlist). We encourage you to watch as many sessions as you can! And keep a close eye on apdaparkinson.org/events so you don't miss future programs.



“ASK THE DOCTOR”

with Dr. Rebecca Gilbert



Q: My husband was just told that he may have PD – where do we go from here?

A: A diagnosis of PD can be overwhelming but with the right information and medical care, your husband will hopefully be able to continue living his best life! The first thing to do is to make an appointment with a movement disorders physician who has specialized training in PD. If you need help finding a doctor in your area, you can contact us at apda@apdaparkinson.org or call 800-223-2732. Next, read credible information about PD so that you are educated about the disease. APDA has a lot of great resources on our website. Our PD handbook provides a helpful overview and is a great place to start — you can find it at: apdaparkinson.org/handbook-download/ (also available in Spanish and Simplified Chinese)

Q: Do concussions cause PD?

A: Traumatic brain injury does increase the risk of PD by a small amount. However, increasing the risk of PD is not the same thing as directly causing PD. This risk adds to all the other risk factors that a person is subjected to including genetic risk, exposure to toxins in the environment, and other factors (some of which may not even have been identified) to determine whether or not a person eventually develops PD.

Q: Is there a definitive test for Parkinson’s disease?

A: Typically, people with PD demonstrate very characteristic findings

on clinical exam. Therefore, for most people, PD can be diagnosed relatively easily based on clinical exam alone. However, for those whom the diagnosis is more challenging there are several options available. There is an imaging test called a DaTscan. There is also a test of the cerebral spinal fluid (via a lumbar puncture) and one of the skin (via a skin biopsy), which can give more information on whether a person has the pathological features of PD. Please be aware that none of these three tests can distinguish between PD and similar neurodegenerative diseases, so the testing still has its limitations.

Dr. Rebecca Gilbert is the Chief Scientific 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.

HOW CAN SOCIAL WORKERS HELP?

Social Workers serve as advocates, navigators, counselors, advisors, facilitators, and champions, whose objective is to help improve the quality of life of every person they serve. They are highly-trained professionals with a Master of Social Work degree and required to be professionally licensed in the state where they work.

In the PD community, Social Workers fill a key role as a member of the multidisciplinary care team and help people with PD and their families to navigate the difficult transitions in their journey. They are the connectors to community resources and they have expertise in addressing the psychological, emotional and often spiritual impact a diagnosis of PD can have on family relationships.

Social Workers can help in many ways:

- Provide PD education, especially for someone newly diagnosed and who may be experiencing anxiety and uncertainty.
- Help you develop short and long-term plan of care to anticipate changing needs with a PD diagnosis.
- Connect you to vital support services during the continuum of care to avoid isolation and encourage connection to others with PD.

If you are interested, ask your physician for a referral. Many larger medical institutions have at least one social worker in the Neurology department.



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apda@apdaparkinson.org | apdaparkinson.org

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