

MARIJUANA & PD

While the medications that doctors prescribe for Parkinson's disease (PD) can be helpful, there remain gaps in what the medications can treat. Some people with PD are eager to find alternative methods to help their symptoms and look into whether other therapies, such as medical marijuana, also known as medical cannabis, can be useful.

The two primary chemicals that are isolated from the cannabis plant are Delta-9-tetrahydrocannabinol (THC) and Cannabidiol (CBD). THC exerts the mind-altering effects that recreational marijuana is known for, whereas CBD does not. For the most part, medical marijuana consists of purified combinations of these two chemicals in varying ratios. The combination can be dispensed as a liquid, pill or nasal spray.

Based on what is known about the biology of cannabis, one could hypothesize that THC and/or CBD *may* be helpful for aspects of PD such as tremor, stiffness, insomnia, dystonia, pain, dyskinesias or weight loss – but more research needs to be done to help us truly understand what symptoms THC and CBD can treat and what doses are needed. This is a challenge however because the federal government continues to consider marijuana an illegal substance and will not fund research involving marijuana. There are various efforts to try to change this, with the hope of opening up medical marijuana to further study.

Just like any medication, medical marijuana can interact with

other prescription medications and can also have side effects. Therefore, patients need to discuss all of the risks and benefits with their doctor.

In the United States, medical marijuana is available in some form in 46 states, as well as Guam, Puerto Rico and the District of Columbia. However, there are vast differences as to how it is regulated so be sure to research the specific laws in your state.



Medical Marijuana *Tips and take-aways*

- Talk to your physician about whether your symptoms may be amenable to treatment with medical marijuana, possible interaction with your other medications, and all potential side effects.
- If you try medical marijuana, be sure to assess the positive benefits and the side effects just like you would any new medication, and report back to your physician.
- Keep on the lookout for additional clinical trials to help assess whether medical marijuana is useful for specific PD symptoms.

For more information on this topic, visit: www.apdaparkinson.org/medical-marijuana

SPOTLIGHT ON DR. GIULIETTA RIBOLDI



Giulietta Riboldi, PhD, a post-doctoral fellow at the Marlene and Paolo Fresco Institute for Parkinson's Disease and Movement Disorders at NYU Langone Health, is the recipient of a 2018 APDA Post-Doctoral Fellowship for her work studying how mutations in a protein called glucocerebrosidase (GBA) lead to the development of PD.

GBA is an enzyme that breaks down a large molecule in nerve cells called glucocerebroside. When both copies of the GBA gene are mutated, glucocerebroside accumulates in cells, causing Gaucher's disease. Mutations in one (or both) copies of the GBA gene is also a genetic risk factor for the development of PD. However, only a small percentage of people with one GBA mutation develop the disease and it is not yet clear why some people with the mutation develop PD while others do not. This project investigates whether interactions with other genetic changes are responsible for why

Continues inside



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

There is so much to be hopeful and optimistic about as we embark on this new year with the strength of friends like you behind us! I am excited to bring you the latest updates from APDA and give you a glimpse of where 2019 will take us.

You are making a difference. With your help we are making so much progress in our efforts to understand, treat, and ultimately cure Parkinson's disease. In these pages you will read about some of the latest scientific advances that have us more energized than ever in our fight against PD.

You'll read about how medical marijuana treatments might help people with PD, and, as always, hear directly from Dr. Gilbert answering your most pressing questions!

And last but certainly not least you're going to get a closer look at Christine, an inspirational woman who is living with Parkinson's, but not defined by it. I know that her incredible strength and heart will lift your spirits as they do mine.

Thank you for all you do to help people with PD live life to the fullest.

Warm wishes for a happy, healthy new year,

Leslie A. Chambers
President & CEO

American Parkinson Disease Association

Spotlight on Dr. Giuletta Riboldi
Continued from cover

GBA mutations contribute to disease in some people and not others. We asked Dr. Riboldi questions about her research:

Q. Why is it important to distinguish between people who carry the GBA mutation who develop PD and those who do not?

A. When patients manifest the first symptoms of the disease it means that the degeneration of the dopaminergic neurons in the brain has been ongoing for some time. Unfortunately, when we are dealing with neuronal cells it is difficult to replace what has already been lost. Thankfully, we are now learning more and more about the specific molecular mechanisms that may go awry in PD, including those involving GBA mutations. So far we only know that mutations in the GBA gene increase the risk of developing PD. However, the ability to identify patients with genetic mutations that place them at a higher risk of developing PD may soon significantly affect early treatment options. It is exciting to think that a condition that is known to be a sign of increased risk may one day become a marker that helps us to choose treatment.

Q. What if one of the readers of our newsletter wants to participate in your research, would they be able to?

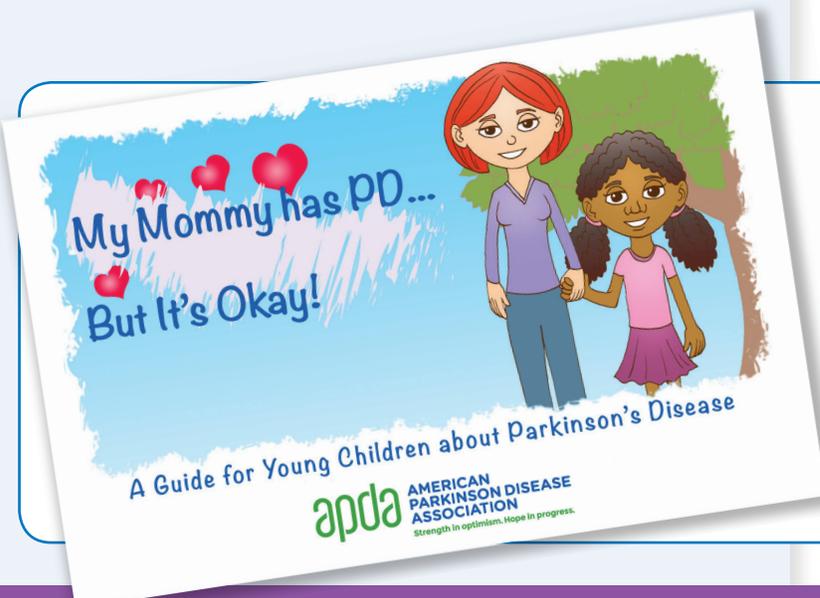
A. The Fresco Institute research staff is available to discuss the study with patients or healthy controls who are interested in contributing to our project. Please call **646-501-4367** to learn more.

Q. What fuels your passion for your research?

A. First is the curiosity to understand how diseases develop, how they manifest, and what may be done to provide treatment and care. I am driven by the knowledge that there are answers to these questions — they just need to be discovered. Secondly, the continuous support and encouragement that I receive from many of my patients reminds me why medical research is important and keeps me focused on doing my part in the care of these disorders.

To read more about Dr. Riboldi's APDA-funded research, please visit www.apdaparkinson.org/research-riboldi

To read more about genes and genetic testing, visit **A Closer Look** blog: www.apdaparkinson.org/doctorblogs/a-closer-look



When telling people about your PD diagnosis, each conversation can bring its own challenges. In particular, parents are often unsure of how to share the news with young children. *My Mommy has PD... But It's Okay!* is an easy-to-read illustrated booklet that can help parents navigate this tricky exchange and can help provide an opportunity for discussion. Recently revised and updated with colorful illustrations, it helps explain PD in ways that are easier for young ones to understand. The booklet can be downloaded for free from the APDA website and free hard copies can be ordered online as well.

www.apdaparkinson.org/resources-support/download-publications/

Look Closer

Meet Christine

What would inspire you to 'kick up' your fitness routine and lose 70 pounds? For Christine, it was hearing a diagnosis of Parkinson's disease at the age of 49. Fitness has always been a part of her life, but the news of her PD, in her words, "put a fuel under" her and caused her to take control of her lifestyle and eating.



"Fearless and determined"

Christine's determination and outgoing nature are obvious to everyone, and they make her a pillar of strength for her friends and for her family, including her five children. She also credits meditating, which she began doing after her diagnosis, with helping to reduce her stress level which in turn helps with her tremors.

"I also began moving quite a bit because the way I see it, moving water never freezes, so I continue to move as much as possible!" she says. She wants people to see that she is a "fearless, determined woman" who won't let anything slow her down, one who speaks up for herself and for others.

Christine is sharing her sense of optimism and determination with people across the country in big ways — as a cast member of APDA's *Look Closer* public service announcement and as a panelist at the recent APDA West Coast Parkinson's Education Forum. Christine also participated in APDA's PRESS™ program — a specialized eight-week support group for people diagnosed within the past five years. "Thanks to the PRESS program and APDA, I found the courage and confidence to stay strong and continue to push forward on bringing awareness to Parkinson's, not only this month but for the rest of my life."

"Just because you have it doesn't mean it has you"

Christine describes PD like this: "It is not a friendly disease and it does not discriminate. However just because you have it doesn't mean it has you... I didn't choose it, it chose me, but I'm still the same Christine. And although it might progress, I'm going to fight, and I'll never stop fighting. Thanks to APDA, my determination is unshakeable."

Spotlight on:

MAYO CLINIC, JACKSONVILLE, FLORIDA

Your support helps APDA fund eight Centers for Advanced Research across the United States, where some of the best scientists in the field are conducting cutting-edge investigations that are helping us understand what causes PD and how best to treat it, and ultimately getting us closer to a cure.

One of these centers is at the Mayo Clinic in Jacksonville, Florida, where Dr. Dennis Dickson, MD, directs a busy center. Thanks to you, they are able to:

- Identify novel gene mutations that contribute to Parkinsonism
- Conduct a range of clinical trials looking at everything from gait in advanced PD to Lewy bodies of the gut
- Maintain a very active Deep Brain Stimulus (DBS) program with 75-100 procedures performed per year
- See approximately 1,500 patients each year



DEEP BRAIN STIMULATION MAY SLOW THE PROGRESSION OF TREMOR IF PERFORMED IN EARLY PD



Recent results published in *Neurology* suggest that deep brain stimulation (DBS) may slow the progression of tremor if performed early on in the Parkinson's disease (PD) course. This data, funded in part by APDA, implies that DBS may not just treat the symptoms of PD, but act to alter the course of the disease by slowing down the progression of tremor. The results are part of a study of 30 early-PD patients at Vanderbilt University Medical Center in Nashville, TN, who received either DBS plus optimal medical therapy, or optimal medical therapy alone, and have now been followed for about ten years.

An intriguing result that has emerged from this analysis is that rest tremor while off of all treatment was improved in the group that received DBS as compared to the group that did not. In addition, patients who had DBS were much less likely to have tremor move to previously unaffected limbs than patients who did not have DBS.

This Vanderbilt University group is collaborating with other DBS researchers to design a larger trial, of which APDA has been a proud sponsor and participant. For more details: www.apdaparkinson.org/dbs-article



Ask the

DOCTOR

Q&A

with
Dr. Rebecca Gilbert

Q. What is the maximum dose of Carbidopa/Levodopa that can be used for PD?

A. Carbidopa/levodopa doses vary significantly. The range can be from 300 mg/day to up to as much as 3,000 mg/day. To determine the right dose for you, you and your physician should discuss:

- What (if any) positive effects that Carbidopa/Levodopa has on your symptoms
- How long a dose takes to work
- How long the effects of a dose lasts
- The side effects of the medication (which could include low blood pressure, hallucinations, fatigue, Sinemet-induced dyskinesias, among others)

Your dose can be determined (and adjusted) based on your answers to these questions. Visit www.apdaparkinson.org for more information on PD meds.

Q. When undergoing anesthesia for a procedure such as a colonoscopy, do I take my meds as usual or not take them that day?

A. Different medications have different issues. For Carbidopa/Levodopa, ask your neurologist and gastroenterologist (GI) when you should take your last dose prior to the procedure. You'll likely be instructed not to take anything by mouth after a certain point prior to the procedure, but your GI may allow you to take a dose of Sinemet with a sip of water closer to the procedure, especially if you are dependent on the medication to move. Monoamine oxidase inhibitors (MAOIs) such as rasagiline (Azilect), safinamide (Xadago), or selegiline on the other hand, have a number of drug interactions, so some doctors advise patients to stop taking Azilect up to 1-2 weeks prior to any procedure and to restart it 1 week afterwards. It is important to check with your doctors on their specific policy.

For more information, visit our website at www.apdaparkinson.org, or call **(800) 223-2732**. To make a donation online, visit www.apdaparkinson.org/Renew.

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What's happening at APDA



What a Weekend! APDA West Coast Forum

The 2nd Annual APDA West Coast Parkinson's Educational Forum took place in October in Irvine, CA. It was a special weekend of education and inspiration. People living with PD and their care partners came together to hear the latest information from PD experts, try some new movement classes (dance, yoga, tai chi), and relax and enjoy themselves. For those who missed it, links to several of the educational sessions are now available online at www.apdaparkinson.org/videos.

Supporting a Broader PD Community in GA

Aiming to expand their reach and bring free education meetings to areas around Atlanta and the state, the APDA Atlanta Chapter hosted their first educational event in Marietta, GA this past October. Attendees enjoyed fun and fellowship while hearing the latest in PD research and treatment from Dr. Jorge Juncos, Medical Director of the APDA Information & Referral Center at Emory Brain Health Center and APDA Georgia Chapter board member. Like all APDA Chapters around the country, the Georgia Chapter is working hard to help more and more people impacted by PD live life to the fullest.

Joining Forces

The APDA Massachusetts, Connecticut, Rhode Island and Vermont Chapters once again joined forces for the biennial APDA New England Regional Conference this past October where 800 attendees participated in a two day program featuring educational PD information, 26 exhibitors and a fun evening of dinner and dancing.

