



A patient-centric approach to Parkinson's research

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Cristina stresses how important this funding is. "It's critical since the National Institutes of Health is cutting money. A lot of people like me are surviving with money from private foundations," she says.

It's only through the generous support of donors like you that Cristina is able to carry out her important research. She is thankful for your support. "Thank you very much for your help. It's very useful for me to start a new career. I'm extremely honored to try and find a cure for Parkinson's disease."

It's motivating for me to know that I'm working for something that in the future is going to help somebody."

— Cristina Guardia-Laguarta

What's Happening at APDA

Parkinson's Awareness Month is less than 30 days away! This April, join APDA in raising awareness for people with Parkinson's disease and their families. Whether you spread the word via social media, or participate in one of our Optimism events – your support means the world to people living with Parkinson's disease.

Sign up for the 22nd Annual Parkinson's Unity Walk and help APDA walk to raise awareness!

The walk takes place on Saturday April 23, 2016 at Central Park in New York City. Visit www.unitywalk.org for more information.

APDA recently joined the Unified Partner Program and also participated in the Parkinson's Action Network (PAN) Forum that took place from February 29 to March 2, 2016.

At the 2016 PAN Forum, leading researchers, scientists and clinicians shared discoveries, emerging treatments and options that may improve the lives of people with Parkinson's disease and their families.

Shawn Thornton of the Boston Bruins generously donated \$100,000 to APDA Massachusetts. The Shawn Thornton Foundation is a charity dedicated to improving the lives of those affected by cancer and Parkinson's disease. We are so thankful for this support.

Working together to "move the needle"



Clinical trials are an important step in discovering the causes, treatments and ultimately a cure for Parkinson's disease. Before drugs can be approved to be used in a patient population they are rigorously reviewed through the mechanism of a clinical trial.

APDA recently offered a webinar called *Spotlight on Clinical Trials – What You Need to Know*. This program was generously supported by Acorda and Lundbeck Pharmaceuticals. It's designed to help people with Parkinson's disease, family members and care partners.

The 60-minute webinar, now on APDA's website at www.apdaparkinson.org/webinars, features two expert speakers – Marie Saint-Hilaire, MD, FRCPC and Ray James, BS, RN. In the webinar, they discuss:

- The role of clinical trials in Parkinson's disease
- Phases of a clinical trial, from idea to approval
- Participation in a clinical trial: consent, eligibility, schedule of activities
- How to find ongoing clinical trials



Dr. Saint-Hilaire is one of the expert speakers for the *Spotlight on Clinical Trials* webinar

Participation is key to clinical trial success

Clinical trials are critical in accelerating the Parkinson's drug development process. Unfortunately, 85% of trials face delays and 30% never even get off the ground because of a lack of volunteers, resulting in a dramatic slowdown in progress toward a cure.

It's very important for people with Parkinson's disease as well as control participants to get involved.

"There has been tremendous progress in how we treat Parkinson's disease since I started working in the field," says Dr. Saint-Hilaire. "This is thanks to thousands of great people who participated in the studies to get new medical and surgical treatments approved by the FDA, or who helped us show the benefit of exercise, or the role of genetics in PD. The Parkinson's community is very grateful to them but we are not done yet. We continue to need the participation of everybody to beat this disease."

To learn more, visit www.apdaparkinson.org/parkinsons-disease/clinical-trials. Or if you're interested in watching the Clinical Trials webinar, please visit www.apdaparkinson.org/webinars.



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A patient-centric approach to Parkinson's research

Every year, APDA awards research grants to junior investigators performing research at an academic institution to pursue research in Parkinson's disease.

One of these promising young scientists is Cristina Guardia-Laguarta.

Currently, Cristina is conducting research at the New York Presbyterian-Columbia Medical Center. She is studying the mitochondria, which is the energy engine of the cell. Her goal is to see if the mitochondria is affected when mice and cells are expressing a mutation of Parkinson's disease.

"The idea is to find the biological pathway that is affected in Parkinson's disease, so that other groups who are working more with patients and pharmacological treatments can apply drugs in this pathway," says Cristina.

Although Cristina is in the very early stages of research, she has made some significant discoveries. Recently, she presented her findings to APDA's Scientific Advisory Board.

"We hypothesize that early events occurring in dopaminergic neurons at the level of the mitochondria-associated membranes could cause long-term disturbances that lead to PD," she says.

Patient experiences help drive important discoveries

To better understand the complexities of Parkinson's disease, Cristina believes that researchers must tap into real-world patient experiences.

"Every day, I'm very focused in the lab and sometimes you can lose sight of exactly how



Cristina Guardia-Laguarta is accelerating Parkinson's research thanks to an APDA grant.

important the research is that you're doing. That's why it's good for researchers like me to have relationships with patients. It's motivating for me to know that I'm working for something that in the future is going to help somebody," says Cristina.

Cristina also has a positive outlook on the future of Parkinson's disease research. She adds: "I think we are going to end up finding out that all neurodegenerative diseases are related. Alzheimer's, ALS, and Parkinson's disease all have a common background so perhaps we are going to find out they are not as far away as we think."

The importance of funding Parkinson's research

Receiving funding is often a major challenge for young researchers like Cristina. She is grateful for the APDA-funded research grant.

"APDA is a great organization because they focus on the patient. They use the money to help patients and also to help people who are working in research at both the basic and clinical levels. The money goes to the places where it's really needed," says Cristina.

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To learn about the many ways you can support APDA, please call (800) 223-2732 or visit www.apdaparkinson.org/ways-to-donate.

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



A message from
President and CEO,
Leslie A. Chambers

Dear Friends,

Have you ever heard the term “meaningful medicine”? Right now, we’re extremely encouraged to see a shift from the traditional medical model of treating Parkinson’s disease and symptoms to one focused on a patient-centered approach.

Patient-centric themes are becoming a reality in both healthcare and biomedical research. As one of the only Parkinson’s organizations that has a dual focus on patient support and research, we truly know how important this shift is for the Parkinson’s community.

People living with Parkinson’s disease are finding their voices in the long-term management of this chronic disease especially when it comes to assembling an entire healthcare team, tracking daily medications and responses to treatments, and also aggressively seeking out and participating in health and wellness programs.

Additionally, the tech explosion is impacting how Parkinson’s disease will be managed, treated and someday cured. We are continuing to explore the latest in wearable technologies, and analyzing data to help researchers streamline and speed up their endeavors in treating Parkinson’s disease.

Every day, we are making progress and moving the needle in the fight against Parkinson’s disease – but we can only make these important strides thanks to the support of generous donors like you.

You are driving meaningful changes that are impacting people with Parkinson’s disease as well as the researchers who are working tirelessly to discover a cure. I am confident we are getting closer each day.

Looking forward to the future,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

Promoting positivity with Young Onset Parkinson’s disease



Diagnosed at age 42, Ken’s mission is to empower others to live optimistically with Parkinson’s disease.

When you first speak to Ken Cater, his southern accent and positive attitude instantly puts you in a good mood. It’s that same optimism that he uses every day to carry out his mission in life: to empower other people with Parkinson’s disease to live a happy and full life.

About 12 years ago, Ken faced a very difficult diagnosis. The doctors said: Parkinson’s disease. He was only 42 years old at the time.

Looking back, Ken’s symptoms began to appear well before his diagnosis. It was actually his wife who first noticed something was wrong. They were sitting in the car and Ken’s hand started to shake. Ken brushed it off to work-related stress. He had also been having problems falling and staying asleep.

Right now, Ken says his physical symptoms aren’t too bad. *“My medications have been pretty good to me. They work and I’m still on low doses. Hopefully, I can continue to move forward like that.”*

However, one of Ken’s biggest challenges he faced when diagnosed with Parkinson’s disease was selling the engineering firm he owned, which employed 60 people in three different offices.

Ken copes with obstacles like this by turning to a support system, which consists of his wife Mary Virginia, their twin 11-year-old boys, and other close friends. As the President of the Parkinson’s Association of Alabama (PAA), Ken is actively involved in helping other people live optimistically with Parkinson’s disease.

Being able to provide different resources and connect the dots for a people is gratifying for Ken. *“I talk to people who have been newly diagnosed almost every day...when their whole world is crashing down on them. That’s a very critical time for people. You can either be engaged and proactive or go into a dark spot,”* says Ken.

His advice for someone newly diagnosed?

“You need to be proactive with your healthcare. Don’t be afraid to ask questions. Exercise not only your body, but your brain. Stay engaged mentally and physically through activities. Don’t pull back, but also realize your limitations,” he says.

Ken is truly an inspiration to everyone he meets. *“I realized my mission in life. I want to help people live better and live well with Parkinson’s disease.”*

APDA is excited to collaborate with PAA for the *Spotlight on Treatment Advances* webinar. If you are interested in watching, please visit apdaparkinson.org/webinars.



P.M. Howard



Judy Roman

Music as medicine for the mind

Music is powerful. Would you agree? Whether it’s motivating you to push harder during a workout or relaxing your mind before bed at night, the act of listening to music can be comforting, therapeutic and simply uplifting!

For many years, music therapy has proven to be particularly effective for people with Parkinson’s disease.

“The therapeutic benefits of music extend to both the mind and the body – improving mood and reducing anxiety while providing a rhythm to facilitate more fluid and automatic movement. These effects can substantially improve overall well-being and quality of life,” says Dr. Terry Ellis, Director of the APDA National Rehabilitation Resource Center.

We had the pleasure of speaking with two very talented musicians who shared their stories with us.

“Music takes you out of the darkness.”

For Judy Roman, it all began with a misdiagnosis which sent her to the right doctor, and right hospital for the wrong reason. *“I ended up with a classically trained musician Dr. Frucht, who was the perfect neurologist for me,”* says Judy.

He immediately threw out the diagnosis of dystonia and replaced it with Parkinson’s disease. She was experiencing symptoms that prevented her from being able to play music. Judy has been playing saxophone her whole life, so this was her worst nightmare.

“My hands were bending backwards and I was playing on my second knuckles. I couldn’t even play my saxophone on the fingertips like you should,” says Judy.

In 2014, Judy underwent Deep Brain Stimulation (DBS) surgery. *“The difference [DBS surgery] made in my life is incredible...no more tremor. I was able to start playing music again.”*

Prior to her surgery, Judy performed two concerts which raised over \$2,600. She donated it all to APDA. One year after her last surgery, Judy performed a Celebration concert that raised more than \$1,100, which she also generously donated to APDA.

At the Celebration Concert, she ended by playing, *“You’ll Never Walk Alone.”* Judy adds: *“There were 70 people there and not a dry eye in the house!”*

Judy believes that music, dancing, theater and art are all so important to a person’s psychological well-being. *“Music takes you out of the darkness. It got me through more dark nights in the first year after being diagnosed. Just listening and playing it.”*

“Parkinson’s helped me appreciate being in the moment with music.”

Everyone remembers the first time they saw the Beatles. For P.M. Howard it was Sunday, February 9, 1964 on the Ed Sullivan Show. A couple of months later, on his 15th birthday, P.M. got his first guitar and was soon playing and singing in different bands.

About fifteen years later, P.M.’s teenage dream came true when he played the part of George in the original Broadway production of *Beatlemania*. Since then, P.M. has been involved in all different types of music: Big Band, One-man Band, Pop, Rock, Oldies Blues & Jazz, Musical Theatre and Opera, and Country.

Then in 2007, while attending a convention, he noticed that his knees were shaking slightly and he was stumbling and unsteady. His wife Jenny had been complaining recently that he was *“shuffling around, like an old man.”*

“A word began to creep up on me – and that word was ‘Parkinson’s,’ says P.M. *“When I got home, I went online and found a list of symptoms. I had almost every one of them. At first I tried dealing with it ‘naturally’ but that soon proved futile. It was only when I went to a movement disorder specialist and got on carbidopa-levodopa that I started feeling better.”*

P.M. continues to play music and says he’s singing better than ever. He encourages others with Parkinson’s to engage in music, whether by singing or playing an instrument. *“If you can sing, you can join the choir or the Tremble Clefs. It’s a great way to focus and a great emotional release.”*