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 Acadia 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, FRCP 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.

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. Sant’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, 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 fight 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 apdaparkinson.org/webinars.

For more information, visit our website at www.apdaparkinson.org, or call (800) 223-2732. To make a donation online, visit www.apdaparkinson.org/Winter/Insights.
Looking forward to the future, the researchers who are working tirelessly to discover the support of generous donors like you.

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 with 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

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.

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When you first speak to Ken Carter, 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.

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.

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“Music takes you out of the darkness.”

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 Trombone Clefs. It’s a great way to focus and a great emotional release.”

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