

Research, Care, and Education

An Interview with John L. Lehr, President and Chief Executive Officer, Parkinson's Foundation

EDITORS' NOTE John Lehr leads the Parkinson's Foundation as President and Chief Executive Officer. He has nearly three decades of nonprofit fundraising and management experience, with a strong focus in the voluntary healthcare and medical research sectors. Lehr played a key role in merging two legacy Parkinson's organizations into the Parkinson's Foundation in 2017. Since joining the Foundation, fundraising revenue has grown each year by



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double digits, allowing the Foundation to greatly expand its mission programs. Lehr led the efforts to open 17 regional chapters to better serve local Parkinson's communities. These developments and other initiatives have allowed the Foundation to earn a 4-star rating from Charity Navigator, a Platinum Seal of Transparency from GuideStar, and to be named to the 2020 list of Best Places to Work by The NonProfit Times. Lehr earned his BA and MA in history from Villanova University. From 1990-1991, he served as a Peace Corps volunteer in Sri Lanka.

FOUNDATION BRIEF The Parkinson's Foundation (parkinson.org) makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything it does, the Foundation builds on the energy, experience, and passion of its global Parkinson's community. Since 1957, the Parkinson's Foundation has invested more than \$400 million in Parkinson's research and clinical care.

Will you highlight the history of the Parkinson's Foundation and how the Foundation has evolved?

The Parkinson's Foundation is the result of a 2016 merger of two national Parkinson's organizations – Parkinson's Disease Foundation based in New York and National Parkinson Foundation based in Miami. The goals of the merger were to create one larger national organization that builds on the best mission programs of each legacy organization; that achieves greater efficiencies; and that dramatically increases revenue for investment in existing and new programs benefitting people living with and affected by Parkinson's disease (PD).

The Parkinson's Foundation is focused on three mission pillars: research, care, and education. Six years into the merger, the Foundation has committed nearly \$170 million to mission programs, achieved a mission ratio in the mid- to upper-80s range annually, and attained the highest ratings by independent nonprofit rating agencies. The Foundation has extended its reach considerably through the expansion of our research initiatives, both basic and clinical; the expansion of our Global Care Network,

which today includes 51 Centers of Excellence, six Comprehensive Care Centers, and one Network of Excellence in Italy; the expansion of our online educational and resource offerings; the launching and expansion of our genetics initiative, PD GENERation: Mapping the Future of Parkinson's Disease, which has registered more than 5,000 participants in its clinical trial; and the expansion of our Community Grants Program, which is now providing \$2 million of annual funding to local organizations in nearly 40 U.S. states.

What do you feel are the most important things for people to know about Parkinson's disease?

Parkinson's disease is a degenerative neurological disorder that affects one million people in the U.S. and 10 million individuals worldwide. For most people, the diagnosis of PD occurs later in life, although about 5 percent of people with Parkinson's are diagnosed with Young Onset Parkinson's disease (YOPD) before the age of 50. No two people with PD have the same course of disease. Some may have mild motor symptoms and no cognitive deficits. Others may have rapid onset of motor and/or cognitive

symptoms, including loss of executive function or dementia. For most people, the cause of PD is unknown, but likely includes a combination of genetic, environmental, and natural aging factors. Between 10 percent and 15 percent of people with PD have a direct genetic form of the disease confirmed through genetic testing. In PD, alpha synuclein, a protein that occurs throughout the body but is concentrated in the substantia nigra of the brain, destroys dopamine neurons, leading to an array of motor, cognitive, emotional, and sensory issues. The most obvious are motor symptoms, including resting tremor, unstable gait, rigidity, and slowness of movement. Dopamine replacement therapy is the main treatment for PD, although it provides only temporary relief and must be taken continuously. It also has challenging side effects like dyskinesia, or involuntary movements. In addition to dopamine replacement therapy, exercise is one of the most effective ways of mitigating the symptoms of PD. With a combination of good medical care and exercise, people with PD can live for many years with a high quality of life.

Will you discuss how the Parkinson's Foundation works and provide an overview of its initiatives?

The Parkinson's Foundation is a national organization with 17 chapters across five regions. As mentioned earlier, it has three areas of focus or mission pillars: research, care, and education (for patients/care partners and professionals). The Foundation's vision is a world without PD. As such, it is committed to finding a cure for PD. It is also committed to ensuring that people living with the disease have access to high-quality healthcare and to information and resources they need to make the best care decisions. The Foundation raises funds through

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charitable donations from individuals, foundations, and corporations and uses those funds to support its three mission programs and operations.

In research, we fund investigator- and center-led basic research looking into the underlying causes and basic biology of PD. We fund research on patient outcomes to see which interventions are having the greatest impact. We operate one of the world's largest genetic testing studies to identify those with genetic mutations so they can participate in upcoming clinical trials.

In care, we fund a Global Care Network of Centers of Excellence and Comprehensive Care Centers that are providing care to hundreds of thousands of individuals with PD. Many of these Centers also serve as collaborators on research studies focusing on various issues such as hospitalization with PD and palliative care delivery.

In education, we have a vast array of print and digital materials that cover topics of primary concern to people living with and affected by PD, such as mobility, mood disorders, and mindfulness. Our main portal for these materials is our newly refreshed website, Parkinson.org, which received more than seven million visits last year, a new record. We also have the toll-free Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636), which is staffed by Helpline specialists during business hours in the U.S. and serves to answer questions in English or Spanish and make referrals.

How did the Parkinson's Foundation adapt the way it works to address the challenges caused by the pandemic?

When the pandemic struck in early 2020, it was just before our Spring Moving Day walk season. Moving Day is our signature special event for the Foundation, hosted in nearly 50 communities across the country. It serves both as a fundraising and educational opportunity, where tens of thousands of individuals participate annually. In Spring 2020, we moved to an all-virtual event which proved to be successful given the circumstances. This gave us confidence to host more virtual events, so we also launched PD Health @ Home to provide online programming five days a week to our community. We featured mindfulness, wellness, and fitness programming. This has proved to be so successful, with hundreds of thousands participating, that we continue it to this day. Like so many other nonprofit organizations, we thought

our fundraising revenue would be adversely affected by the pandemic and economic downturn, but as it turns out, our donors remained committed and we had record-breaking fundraising years in 2020, 2021, and 2022. This has allowed us to maintain our great staff and to initiate new programs that benefit people living with PD.

How critical are metrics to measure the impact of the Foundation's work?

Metrics are critical to everything we do at the Foundation. We have a dashboard that we update quarterly on programmatic, fundraising, operational, and financial objectives. Our most important metric is our mission ratio, which demonstrates that we are deploying funds for our mission and are providing meaningful programs to people living with PD. All our mission programs have primary and secondary goals, whether it is participant enrollment in a clinical trial or achievement of a research aim. Of course, fundraising drives our mission, so we are aggressive in goal setting. We are continually seeking to raise more revenue to invest in programs that advance our mission. Staff retention is another key metric. We believe strongly that staff continuity is critical to delivering mission, and work to ensure that our staff know they are appreciated for their contributions. In sum, we are pleased that staff retention is well-above normative ranges for the nonprofit sector.

Do you feel that there has been effective progress made in the treatment of Parkinson's disease and what are the treatment options?

Parkinson's disease is a very complex neurological disorder, not fully understood by the medical and scientific community. That said, there has been enormous progress made in understanding the basic biology, circuitry, and symptoms of the disease over the years. People diagnosed with PD in 2022 are likely to have better health and quality of life than those diagnosed a decade ago. Today, there are more tools to treat PD than before, including better dopamine replacement therapy; surgical procedures like deep brain stimulation, which helps restore motor function; and a far better understanding of the role that diet and exercise play in maintaining health and wellness. There are also many avenues of potential discovery, including drugs targeted at specific genetic mutations. That explains in part the Foundation's focus on

genetic testing and counseling. While there is no cure on the horizon today, there are many researchers working to find breakthroughs that will prevent or halt the progression of PD, while we search for the ultimate solution – a cure.

Did you always know you had a passion for nonprofit work and what makes the work so special for you?

I have worked nearly my entire career in the nonprofit sector, first in academic medicine (University of Pennsylvania and Children's Hospital of Philadelphia) and then primarily in disease-specific, voluntary health (Cystic Fibrosis Foundation, CureSearch for Children's Cancer, Parkinson's Foundation). I have had the great fortune of working with some of the best minds in medicine and science and have seen firsthand what can be accomplished when you bring great people together from many sectors and focus on a common goal. My nearly six years at the Cystic Fibrosis Foundation (CFF) taught me that the seemingly impossible can become reality when you have a great and dedicated team, maintain focus, invest wisely, and persevere in the face of adversity. The story of CFF is well known and is still remarkable because the Foundation transformed an ultimately fatal pediatric disease into a disease where people can expect to live through adulthood. CFF's approach was first to understand the disease as best as possible and then to invest in promising therapies that either controlled the symptoms or addressed the underlying defect. I believe a similar approach is possible in PD, and that we can transform PD from a debilitating, life-shortening disease to one that can be prevented or medically managed without symptoms. Throughout my career I have seen over and over how innovation can come from the nonprofit world. The mission motive is just as strong as the profit motive and can drive innovation forward.

What are your priorities for the Parkinson's Foundation as you look to the future?

The priorities of the Parkinson's Foundation over the next few years are focused on our three mission pillars. In research, we are looking for discoveries that prevent, control, and ultimately cure the disease. In care, we want to ensure that all people with Parkinson's disease have access to equitable and quality care. In education, we want to ensure that all people affected by Parkinson's have the information and resources they need to make the best decisions and have the best health and highest quality of life possible. We will accomplish those priorities by staying focused on people living with this disease and their needs; by collaborating with other organizations and stakeholders in academia, government, industry, and philanthropy to leverage resources for the greater good; by focusing on evidence-based and evidence-generating initiatives; and by ensuring that all our activities have maximum impact and reach. All of this will take greater awareness and resources, so we will continue to expand our messaging and fundraising efforts to meet our goals. ●