Making Life Better Matters to the Sorensen Family

Super Bowl Champion Daniel Sorensen and his family noticed gradual physical changes in his dad, Kory. Soon after, Kory was diagnosed with Parkinson's disease. They looked for help.

"My mom called the Parkinson's Foundation Helpline, where she found kind words, vital resources and much-needed reassurance that helped us prepare for this disease," the Kansas City Chiefs player said.

The Sorensens battled Parkinson's as a family. "In a way, this time in our lives was a gift," Daniel said. "When we otherwise may have gone about our busy lives, instead we came together every chance we could. I called him every day on my drive home from my Chiefs practices. Dad always wanted to hear how my game went." In Kory's case, symptoms quickly progressed. A few years later, the “heart and soul of the family" passed away.

The mission of the Parkinson's Foundation remains personal to Daniel. "Those living with Parkinson's and the loved ones caring for them need all the help we can get in navigating daily life with this disease. My family and I are committed to the Parkinson's Foundation and ultimately finding a cure."

“We are fortunate enough to donate to support the Foundation's work. It means so much to honor my father’s legacy, and I’m proud to have a role in raising awareness and funds for this disease. After all, Parkinson’s does not stop. And as a supporter of the Parkinson's Foundation, neither will I."

Our Mission

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson’s community.

We are here for you.
Call our Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.
I am pleased to report that the Parkinson’s Foundation had its best year yet, committing more resources to mission programs than ever before. Most importantly, we were able to reach more people with Parkinson’s disease and have a greater impact in the Parkinson’s community.

Like so many other organizations, we had to pivot in the spring to make our mission programs and fundraising activities accessible during a time of social distancing. The 2020 Annual Report is dedicated to volunteers and staff who helped ensure that we continued “Connecting Communities” and highlights our efforts to develop and deliver at-home programming to the Parkinson’s community.

In the spring, the Parkinson’s Foundation launched PD Health @ Home, a brand-new online program focusing on wellness, exercise and mental health. Since its inception, PD Health @ Home has connected with tens of thousands of participants across the country. In similar fashion, we transitioned our signature fundraising event, Moving Day, A Walk for Parkinson’s, to a virtual walk, Moving Day USA. Thousands of volunteers and advocates tuned in to exercise from home, fundraise for Parkinson’s programs and unite around our shared mission. Thanks to their efforts, we had a record-breaking year in fundraising, allowing us to dedicate more funds to our clinical, research and education programs.

In research, we expanded our genetics initiative: PD GENERation: Mapping the Future of Parkinson’s Disease. Researchers are already utilizing results from the study’s successful pilot phase, and our new at-home genetic tests are now available to anyone with a Parkinson’s diagnosis.

In 2020, the Foundation continued to forge new partnerships with leading organizations serving the Parkinson’s community, notably the U.S. Department of Veterans Affairs and AARP, along with our valued corporate partners. These partnerships allow us to reach even more people with Parkinson’s, and ensure that we connect with the more than 60,000 individuals who are newly diagnosed each year in the U.S., providing the resources they need to live well with the disease.

I am delighted to note that we were recognized as one of the “Best Non-Profits to Work For” by the Non-Profit Times in 2020. This honor is a testament to the dedication of our entire staff and their commitment to the Parkinson’s community, especially during these difficult times.

The Parkinson’s Foundation team is optimistic about the future for the Parkinson’s community. We remain here for you and are fighting Parkinson’s disease on all fronts. Thank you for helping us build better lives, together.

Sincerely,

[Signature]

John L. Lehr
President and Chief Executive Officer
Connecting the Care Community

106,114
life-saving Aware in Care hospital kits distributed to help people advocate for quality care when hospitalized.
At the Foundation, we know that receiving expert Parkinson’s care translates to better symptom management, less anxiety and, ultimately, a better quality of life. Equally important to receiving expert care is working to make it accessible for **everyone** in the Parkinson’s community.

We make expert care accessible through our 47 international medical centers designated as Centers of Excellence. Every center houses a specialized team that practices the latest in Parkinson’s treatments and therapies. New this year, we awarded Community Outreach Resource Education grants to 19 Centers of Excellence to support the creation of innovative therapies and programs to help underserved populations, and further professional training in three countries and various U.S. cities, including: New York, Massachusetts, Ohio, Indiana, Minnesota, among others.

We are here to support you and your family from the beginning of the Parkinson’s journey. One year since launching the Newly Diagnosed: Building a Better Life with Parkinson’s Disease campaign, we **engaged with and reached more than 10,000 newly diagnosed people.** We connect them with resources and advice through our free newly diagnosed kit, plus webinars and podcasts.

**One of our key priorities is to make virtual professional training available and accessible to the global health community.** We developed innovative ways to connect with essential workers who treat people with Parkinson’s. For the first time we hosted Care Team Training (formally ATTP) online, and launched a revamped 15-hour online accredited course for physical therapists taught by researchers and clinicians. Since 2002, **more than 2,300 healthcare professionals have completed vital team-based approach training.**

We hosted the Parkinson’s Foundation Exercise Convening to create the first-ever Competencies for Exercise Professionals Working with People with Parkinson’s. Our goal is to ensure that people with Parkinson’s and healthcare professionals follow standards of care and create safe and disease-specific programs that help people live with and slow down the symptoms of Parkinson’s.

**Find out how we connect care and Parkinson’s communities at Parkinson.org/ExpertCare.**

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“Receiving a Parkinson diagnosis can be overwhelming. I reached out to the Parkinson’s Foundation for resources to accelerate our learning curve and to develop realistic expectations. What I found was hope. The Foundation has a wealth of information and resources for the newly diagnosed to help understand and deal with Parkinson’s, and to shift your focus to improving your quality of life.”

Denise Coley, Living with Parkinson’s
Parkinson’s Foundation People with Parkinson’s Council Member
Connecting the Research Community

3,000 people with Parkinson’s will be enrolled in PD GENERation by December 2021, immediately utilizing their test results to better manage their Parkinson’s and enroll in more clinical studies.
We continue to embark on innovative and engaging ways to connect the research and Parkinson’s communities. The launch of the first-of-its-kind national genetics initiative, **PD GENEration: Mapping the Future of Parkinson’s Disease**, in 2019 has expanded to allow more people to participate, no matter where they live.

PD GENEration offers bilingual genetic testing and genetic counseling at no cost for people with Parkinson’s. Last year, we tailored the study, launching the most comprehensive Parkinson’s genetics test available as an at-home testing kit.

The number of people with a genetic tie to Parkinson’s may increase as PD GENEration continues to gather data. PD GENEration researchers have also newly identified extremely rare genetic mutations linked to Parkinson’s. The National Institutes of Health recognizes the significant impact PD GENEration has already made in the genetics field through appointing us as founding chairs of the first Parkinson’s disease expert panel in genetics. Under the Foundation’s leadership, the panel analyzes PD GENEration data with more than 40 of the world’s leading Parkinson’s researchers.

The goal of PD GENEration is to leverage genetics as a powerful tool to help us uncover what is responsible for slowing or stopping the progression of Parkinson’s. This knowledge will propel us toward optimizing Parkinson’s treatments and **advance how we design clinical trials**. As for participants, they can immediately utilize their genetic results, discussing them with their doctor to help manage their Parkinson’s.

We fund a diverse portfolio of research because we know that any scientist at any moment can get us closer to a cure. In the last 10 years we have supported **584 researchers through Parkinson’s Foundation research grants**.

The goal of Parkinson’s Foundation research grants is two-fold: fund cutting-edge research that can lead to better treatments, care and ultimately, a cure, and back the sharpest minds in the Parkinson’s field. **We funded $4.2 million to advance promising research through 46 grants around the world in 2020**.

Find out how we connect with the research community at [Parkinson.org/Research](http://Parkinson.org/Research).

“With COVID-19 halting basic science research and clinical trials, PD GENEration is one study that continues to accelerate scientific progress forward for Parkinson’s disease by offering genetic testing and counseling remotely. This study is changing the paradigm of how we conduct clinical research by paving the way for other studies to be conducted virtually.”

Anne-Marie Wills, MD
Massachusetts General Hospital, a Parkinson’s Foundation Center of Excellence, PD GENEration Study Site Investigator
154,300 people joined us for Facebook Live events held over 10 weeks as part of PD Health @ Home, a program designed to meet community needs arising from the pandemic. Neurologists from our Centers of Excellence led multiple events.
In 2020, we launched new programs that provided immediate access to the impactful educational, health and wellness resources people with Parkinson’s and care partners could participate in safely from home.

To ease the challenges of physical distancing, we launched PD Health @ Home – an interactive series of virtual events designed for the Parkinson’s community. To date, more than 230,800 participants across 22 countries participated in PD Health virtual programming. PD Health currently hosts innovative weekly expert-led educational webinars, guided mindfulness sessions and tailored fitness videos.

Care partners are essential. Last year we hosted the virtual and free 2020 Care Partner Summit, addressing critical care partner topics, from mental health to life planning that reached 1,700 participants across 49 states.

We awarded more than $1.5 million in local community grants across 38 states – from dance, music and choir therapy groups to fitness classes and wellness events. This funding helped many grantees host their program online, allowing for participants to have new opportunities to socially engage and check in with each other.

Hispanic and Latino populations remain one of the most underserved populations in the Parkinson’s community. We launched a new Spanish podcast series, Spanish blog and bilingual video series specifically for the Spanish-speaking community.

Empowering our community through resources and information is vital to our mission. PD Conversations is an online community that offers a network of support across eight discussion groups created for care partners, those newly diagnosed or living with Young Onset Parkinson’s and more. People can connect with others who share the same challenges and hopes, while finding answers to their questions from trained Helpline specialists. Last year 20,028 people received vital counseling and support from our Helpline specialists.

Help us continue to connect the Parkinson’s community to empowering resources at Parkinson.org/GetInvolved.

“The Parkinson’s Foundation maintains active engagement with the Parkinson’s community during the COVID-19 pandemic using multiple novel ways of interaction. Specifically, it is at the forefront of virtual programs for people with Parkinson’s. PD Health @ Home provides the Parkinson’s community with essential health and wellness tools to help them stay safe and healthy while socially distancing.”

Tanya Simuni, MD
Northwestern University, a Parkinson’s Foundation Center of Excellence
$368 million invested in Parkinson’s research and clinical care since 1957.

106,114 free, life-saving Aware in Care kits distributed to help people get better care in a hospital since 2011.

7,400 health professionals have completed Parkinson’s-tailored professional education courses online and in person.

4.7 million people visited Parkinson.org, the go-to online Parkinson’s resource, in 2020.

20,100 people around the world joined an Expert Briefings educational webinar in the 2019-20 series.

2020 in Numbers
91,000 podcast episodes downloaded in 2020.

3,000 people with Parkinson’s will be enrolled in PD GENERation by December 2021, receiving free genetic tests and counseling sessions.

20,030 Helpline calls and emails answered in 2020.

237,030 people received vital counseling from specialists on our toll-free Helpline, 1-800-4PD-INFO, since 1998.

200 Parkinson’s Foundation online events hosted in 2020.

193,500 people with Parkinson’s treated in Centers of Excellence — the largest global network of Parkinson’s clinics.

$1.5 million awarded to 117 community grants across 38 states and for the first time, in 3 countries (U.S., Germany, Canada).

584+ scientists received Parkinson’s Foundation funding since 2010.

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The Parkinson’s Foundation gratefully acknowledges all our supporters who donated $2,500 or more between July 1, 2019 and June 30, 2020.

Our generous donors allow us to further our mission to make lives better for people with Parkinson’s and advance research toward a cure. We thank them for their dedicated support.

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Participants stretch during a Parkinson’s Movement Initiative (PMI) Pilates for Parkinson’s class in Durham, NC. The Parkinson’s Foundation community grantee offers weekly, free movement classes to the local PD community and their care partners that focus on mind-body connection through exercise. In 2020, PMI launched online classes.

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In 2020, we established impactful partnerships with care partners and their loved ones.
WE CARE. WE FIGHT. WE MOVE.

Moving Day, A Walk for Parkinson’s, is an event that brings the community together to raise awareness and funds to fight Parkinson’s. In 2020, our 45 Moving Day events across the country went virtual to celebrate movement — proven to help manage Parkinson’s symptoms — and deliver inspiration.

We hosted our first-ever Moving Day USA, a nation-wide virtual event that connected communities around a common goal — to beat Parkinson’s. From the safety of home, participants joined workout sessions led by local fitness instructors and heard powerful stories told by people in the Parkinson’s community. Thanks to our sponsors, donors, participants and volunteers, we had a record-breaking year in fundraising that will support our mission.

Move with us! Sign up for a Moving Day 2021 event at MovingDayWalk.org.
How Nancy Went from Care Partner to Community Walk Super Star

“I want those with Parkinson’s and their families to know that they are not alone, ever, but they need to reach out, stay connected and keep moving — mentally and physically,” Nancy Redkey said.

In 2001, Nancy and her husband, Ed, discovered the power of exercise after Ed was diagnosed with Parkinson’s. They also found much-needed help and resources through the Parkinson’s Foundation. Nancy felt so grateful for the help she received that she sought to help others in her Poughkeepsie, NY, community navigate their own fight against Parkinson’s. She brought resources to her community through hosting an annual Community Walk, “Walk Over Water.” Nancy has raised more than $150,000 to help us make life better for people with Parkinson’s.

At Moving Day Community Walks across the country, we fight Parkinson’s. Community Walks give volunteers, like Nancy, an opportunity to organize a walk in their own community that does not have a Moving Day event.

Host a community walk in your area! Learn more at MovingDayCommunityWalk.org.
The Movement Begins with You!

On February 8, 2020, we launched a new signature event, Parkinson’s Revolution. The in-person or virtual cycling experience generates awareness and raises funds that advance groundbreaking research, resources and better care for people with Parkinson’s. “The fight against Parkinson’s is personal for me. The Parkinson’s Revolution journey has led to many new friendships,” said Adam Mizock, who is living with Parkinson’s and raised $12,500.

Learn more at Parkinson.org/Revolution.

CHAMPIONS

Matthew Hakey
2019 Marine Corps Marathon
Maddie Hayes
2019 New York City Marathon
Laurie & Christopher Head
Tough Mudder Atlanta
Sophia Howard
2019 New York City Marathon
Bill Howell
2020 New York City Marathon
Megan Hudson
2020 Big Sur Marathon
Sarah Hurd
2019 New York City Marathon
Rachel Isenberg
Rachel’s Summer Challenge
Jennifer Jakoboski
2019 New York City Marathon
Jeff Kaminsky
2019 San Francisco Marathon
Andrew Leffler
2019 New York City Marathon
Erin Lenz
2019 Philadelphia Marathon
Zoe Lindemuth
2019 New York City Marathon
Etsuko Manogue
2019 New York City Marathon
Christopher Marciani
2019 New York City Marathon
Tony Mayes
2019 New York City Marathon
Jenna Palek
2019 Philadelphia Marathon
Robyn Pearson
8 for 80 Climb
Connor Pohl
2019 New York City Marathon
Chandra Ramamooorthy
2020 Big Sur Marathon
Jackie Reyneke
2019 New York City Marathon
Debra Jacobs Robinson
2020 New York City Marathon
Ally Rung
2019 New York City Marathon
Christopher Sampson
2019 New York City Marathon
Jacqueline & Jim Scott
2019 Philadelphia Marathon
Nicole Souza
2019 New York City Marathon
Ruth Stilwell
2019 Marine Corps Marathon
Eric Swanson & Team
2019 Philadelphia Marathon
Joyce Tracy
Zero Mile Fun Run
UGA Undergrad Neuroscience Org
Silent Auction for PD
Jacquelin Vargas
2020 New York City Marathon
Scott Whitworth
2019 New York City Marathon
Debra Willard-Parker
2019 Philadelphia Marathon
David Winter
2019 New York City Marathon
Amy Zahn
2019 New York City Marathon
Mark Zak & Brenna DeVincenitz
2019 Chicago Marathon
Paul Baio
Audecio Baio Memorial
Drew Gervino
Gabe Gervino Jr Memorial

REVOLUTION RIDERS

Katherine Burch, San Francisco
Adrienne Casano, Boston
Eleanor Cornell & Team Cornycle, Boston
Ann Heidger, Dallas
Ryan Johansen, Boston

John and Robin Katsaros, San Francisco
Debbie Lucchesi, San Francisco
Adam Mizock, San Francisco
Anne Reamer, New York
Stephanie Sadow & Team Jeff, Chicago
Jacquelyn Sieck, New York

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Virginia Shephard

Jamie Sieracki
Diane Troy

Become a Parkinson’s Champion at Parkinson.org/Champions.

As events shifted from in-person marathons to virtual fundraisers, our Parkinson’s Champions inspired us with their dedication. Champions have raised nearly $12 million to make life better for people with Parkinson’s.

We recognize and thank all the Parkinson’s Champions below who raised $2,000 or more between July 1, 2019 and June 30, 2020.

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Jamie Sieracki
Diane Troy

Become a Parkinson’s Champion at Parkinson.org/Champions.
Tom Manak’s Legacy to Help Those Fighting Parkinson’s in the Future

Tom and Rosemary (“Ro”) met as Marquette University chorus members. Forty-five years later, they still sing in a choir, and work together to navigate Parkinson’s.

Tom and Ro have gone from diagnosis to failed brain surgery, a stroke and now, advanced Parkinson’s. “As the disease progresses it gets more and more difficult,” Tom said. His color-coded calendar helps him keep track of Ro’s appointments, exercise classes and PD Health @ Home events — all of which they attend together. Tom also volunteers with the Parkinson’s Foundation on the People with Parkinson’s Council and the Care Partner Summit committee. “People need to know the Foundation is here for them,” Tom said.

“Leaving a planned gift is the right legacy for us to leave so we can help the people who will need it the most, whether they’re people with Parkinson’s, care partners, families, we know the Foundation will use the donation to advance its mission,” Tom said.

Tom wants to keep helping the Foundation in the future. “For me, leaving a planned gift looks at the Foundation’s vision as a whole,” Tom said. “It’s not just research, education or community involvement. They have so many ways to help the Parkinson’s community and that will spread this donation a long way.” As Parkinson’s Foundation Legacy Society members, Tom and Ro’s dedication to the Parkinson’s community will never be forgotten.

Learn more about the Legacy Society and planned giving options at Parkinson.org/PlannedGiving.
John Lehr (Parkinson’s Foundation president and CEO) lower right and Leilani Pearl (Parkinson’s Foundation chief communications officer) lower left visit the Kingdor National Parkinson's Foundation, led by Mavis Darling, on March 4, 2020 in Nassau, Bahamas, at the House of Parliament.

Josh and Laura Kantor at the Parkinson’s Foundation Heartland Prohibition fundraiser on October 25, 2019 in Kansas City, MO.

Beyond the Diagnosis attendees during a physical therapy exercise in Orange County, CA, on January 2020.

Attendees warmly greet each other at the Better Lives, Together: Fresno Parkinson’s Summit on February 22, 2020 in Fresno, CA. The event had a record-breaking 350 attendees.

Andrew Jung and Linda Won attended the Aware in Care Ambassador Training in San Diego, CA, on September 26, 2019.

The Parkinson’s Foundation gratefully acknowledges those national corporate sponsors who actively support our mission critical programs and research initiatives.

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Kyowa Kirin
Medtronic
Right At Home
Supernus (formerly US WorldMeds)
Sharron and Joseph Ashby Hubert Fund of the Community Foundation of Broward

The generous $1 million grant from the Sharron and Joseph Ashby Hubert Fund of the Community Foundation of Broward made it possible to add the University of Miami Miller School of Medicine as a PD GENERation in-person testing site. The grant will also provide more genetic testing opportunities and counseling online for people with Parkinson’s in Florida’s Broward County. “With such a high concentration of people with Parkinson’s in South Florida, we are proud to fuel this vital and necessary research with this landmark grant,” said Amanda Kah, Charitable Funds Services Manager at the Community Foundation of Broward.

Kay and Gary Smith

“Kay and I were pleased to support the PD GENERation study to help further Parkinson’s research,” Gary Smith said. “As someone who lives with Parkinson’s, the potential of PD GENERation resonated with me on a personal level, but Kay and I also saw the larger impact this study would have on the entire Parkinson’s community. We want to do our part to ensure the study’s success.” Since attending their first Chapter research dinner in 2019, the couple stays engaged through events and as members of Leaders in Research.

Patt and Leon Westbrock

The Westbrocks know that Parkinson’s impacts the entire family. “Our family is proud to support the Foundation,” said Patt Westbrock, who is living with Parkinson’s. “The Foundation provides critical support and resources to everyone in the Parkinson’s community, while also advancing research that will lead us to a cure.” The couple actively works alongside the Foundation’s Minnesota and Dakotas Chapter and are Parkinson’s Foundation Leaders in Research members. They captain a Moving Day team and their daughter, Julie, serves on the Minnesota and Dakotas Chapter Advisory Board.

Neilia LaValle

“Supporting the Parkinson’s Foundation and the fight against Parkinson’s disease means a lot to me,” said Neilia LaValle, whose sister Cecelia lived with Parkinson’s. “I want to do everything I can to ensure others don’t experience what my sister did. Parkinson’s stole my beautiful, amazing, talented sister away from the world far too soon.” After making a generous memorial gift for Cecelia, Neilia began attending research events, eventually joining the Parkinson’s Foundation Leaders in Research. Cecelia’s memory inspires Neilia, as she features her sister’s artwork into fundraising for Parkinson’s research.
As illustrated below, the Parkinson’s Foundation directed 85% of its 2019-2020 spending on mission-related activities and 15% on fundraising and management combined.*

**Total Operating Expenses**
- 100% | $38,983,746

**Subtotal Mission-Related**
- 85% | $32,995,922

**Fundraising**
- 10% | $4,152,205

**General & Administration**
- 5% | $1,875,619

**Total Revenue**
- $40,962,620

**Total Year-End Assets**
- $45,116,415

**Net Assets as of Year End**
- $25,963,429

*Reflects Parkinson’s Foundation Audited Financial Statement for the fiscal year 2019-20.*
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The Parkinson's Foundation is privileged to have an outstanding and dedicated group of volunteers who generously donate their time and talents by serving on the Board of Directors. Without their selfless efforts, the work of the Foundation would not be possible.

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The Parkinson’s Foundation makes life better for people with Parkinson’s disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson’s community.