

MAGNIFYING IMPACT





2021 ANNUAL REPORT

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.

How Love and Parkinson's Research Inspires Mimi Winter

Nearly 40 years after George G. Kaufman left Germany in 1936 with his parents, he found happiness in Chicago, IL, where he met his future wife, Mimi Winter. He eventually retired as Loyola University Chicago's John F. Smith chair professor of economics and finance after serving Presidents Gerald Ford and Jimmy Carter. Wherever George and Mimi lived or visited on their international travels when George was invited to speak about economics, he loved walking everywhere.

One day in New Zealand, George fell during a walk. "The following year he continued to have falls and the doctor diagnosed him with Parkinson's," Mimi said. "Of course, he was a researcher by profession, and therefore researched until he found that the Parkinson's Foundation was very involved with Parkinson's research and helping people with Parkinson's."

Mimi and George were excited to learn that the Foundation funds unique research studies. "Outside-the-box research areas are often where the gold is," said Mimi, who is also a member of Leaders in Research, which brings together donors with a passion for advancing the Foundation's research agenda.

After 18 years together, Mimi lost George to Parkinson's complications in 2020. In memory of George, she advanced their collective passion to end Parkinson's through a \$1 million donation to the Parkinson's Foundation.

The Parkinson's Foundation George G. Kaufman Impact Awards funds six innovative researchers — those established and those new to the Parkinson's field who explore the disease through an atypical lens. "When living through Parkinson's, it was always helpful to know that progress was being made through research," Mimi said. "I am very excited to be able to contribute."

We are here for you.

Call our Helpline at **1-800-4PD-INFO** (473-4636) or visit **Parkinson.org.**

UPDATE

From Our CEO



2021 was another challenging year as we continued to experience the wide-spread ramifications of the COVID-19 pandemic. And yet, despite unprecedented global disruptions, the donors and volunteers at the Parkinson's Foundation stood with us and helped ensure that the Foundation had its best year ever.

Throughout this report, we share how we are "Magnifying Impact" to make life better for people with Parkinson's disease (PD) now and in the future.

This year, we raised more money and achieved our highest mission ratio ever, with 87% of revenue dedicated to our critical research, care and education initiatives. With greater resources, we were able to fund programs that kept our community connected in this potentially-isolating time, like the **PD Health @ Home** virtual education series. We were also able to expand our healthcare professional training, Parkinson's Foundation Team Training, to a virtual platform to make it more accessible to the global health professional community.

We also invested even more resources in cutting-edge scientific initiatives like **PD GENEration: Mapping the Future of Parkinson's Disease,** a global study that provides genetic testing and counseling at no cost to people with Parkinson's. Our outreach efforts focus on Spanish-speaking communities and Caribbean nations to ensure greater variation in our data, a critical consideration to understanding the causes of Parkinson's disease. Our ultimate goal is to enroll up to 15,000 individuals in the next four years to accelerate clinical studies aimed at identifying new therapies.

Furthermore, we invested \$2 million in community grants, more than ever before. This funding will address unmet needs in the Parkinson's community, like Parkinson's-related mental health, wellness, exercise and education programs, across 42 states.

We know how critical it is to accelerate progress on Parkinson's research and care, so we launched a multi-year fundraising campaign called **Reach Further.** We will raise an additional \$30 million in the next four years to bolster our investments in core mission programs.

Finally, we magnified our commitment to meeting the present needs of the Parkinson's community in our new 2022 strategic plan. We have set ambitious goals for advancing research, expanding our global clinical care network and furthering education in previously unreached communities.

Our objective is clear — that all people affected by Parkinson's are engaged and empowered to live better lives. Thank you for helping us Reach Further, together.

Sincerely,

John L. Lehr

President and Chief Executive Officer



mechanisms of the brain to arm us with the knowledge necessary to fight diseases like Parkinson's. Organizations like the Parkinson's Foundation really make a difference in helping to support the researchers trying to do this work. My hope is that through this award we can generate enough research to garner federal funding that will sustain Parkinson's research in my lab for many years."



Taraz Lee, PhD University of Michigan 2021 Parkinson's Foundation Stanley Fahn Junior Faculty Grantee

customize

treatments.



As a global leader in Parkinson's clinical genetic research, the PD GENEration study offers genetic testing and genetic counseling at no cost for people with

Parkinson's. In 2021, we enrolled **2,400 participants** in the study

across all 50 U.S. states and Puerto Rico. To magnify the

PD GENEration

importance of diversity in Parkinson's research, we expanded the study to the Caribbean, doubled our efforts to reach underserved populations and now offer testing and counseling in English and Spanish.

Our research is bolstered by working alongside Parkinson's advocates. Generating and leveraging data from people living with Parkinson's and care partners helps us improve health outcomes and accelerate therapies. Parkinson's Foundation Surveys connect us to 4,000 people living with this disease. Publishing survey findings allows us to share essential information with the care and research community. In our COVID-19 and Parkinson's survey, we discovered that telehealth visits increased by 54% for people with Parkinson's during the pandemic.

Depression and anxiety are the top challenges impacting the overall health of people with Parkinson's. To magnify this issue, we started a new mental health study as part of our larger Parkinson's Outcomes Project — the largest clinical study of Parkinson's in the world. This study will help us determine the feasibility of incorporating depression screenings for people with Parkinson's in Centers of Excellence and other medical institutions.

Every year, we fund the most exciting and promising research ideas in the Parkinson's field. The next breakthrough can occur anywhere, which is why in 2021 we awarded **\$3.4 million across 34 research grants** currently underway in labs at medical centers, neurologist offices and universities.



esearchers funded through Parkinson's Foundation research grants since 2010.



conducted ranging on topics such as sleep, telehealth, medical cannabis and excercise.



research advocates and healthcare practitioners were trained through PCORI funding to run patient advisory boards that will advance patient-driven research at five Centers of Excellence.

Find out how we magnify research at Parkinson.org/Research.



"The Team Training program allowed me to understand my Parkinson's patients more holistically and be a better advocate for them to connect with the right professionals and get the care they deserve. This has also impacted me to be a better communicator and listener."



Jillian Klemm, CCC-SLP Speech Language Pathologist Parkinson's Foundation Team Training 2021 Graduate

better manage their

symptoms and

experience a

of life.

higher quality



More than **196,700 people receive expert care** at one of 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 research.

Research shows that receiving palliative care — additional support that helps ease the burden of symptoms — early in the disease results in better outcomes. To provide this extra level of care, we launched a program called, "Implementing Team-based Outpatient Palliative Care in Parkinson's Foundation Centers of Excellence." With an award from the Patient-Centered Outcomes Research Institute (PCORI), this multi-year project aims to integrate a palliative approach to care across our U.S. centers. More than 245 healthcare professionals have already started the virtual training.

In 2021, **247 healthcare professionals** completed our Team Training program to increase knowledge about Parkinson's and build comprehensive, interprofessional Parkinson's care. These professionals immediately implemented their care training and reported treating a combined 25,000 patients with Parkinson's. This training also benefits all their future patients as Team Training graduates now understand the fundamentals of Parkinson's, and the latest treatments.

Our programs aim to reduce barriers to care. For instance, Spanish-speakers are less likely to seek healthcare and participate in research. Our Promotores Project trains Hispanic and Latino community health workers to improve quality of life in their communities through health education. Alongside Promotores, we share critical Parkinson's information and show how care and education are linked to research participation within the Spanish-speaking community.



newly diagnosed people have found support and engaged with our Newly Diagnosed: Building a Better Life with Parkinson's Disease campaign.



120,000

people visited PD Conversations in 2021 — posting 330 questions to the online support community on Parkinson.org.



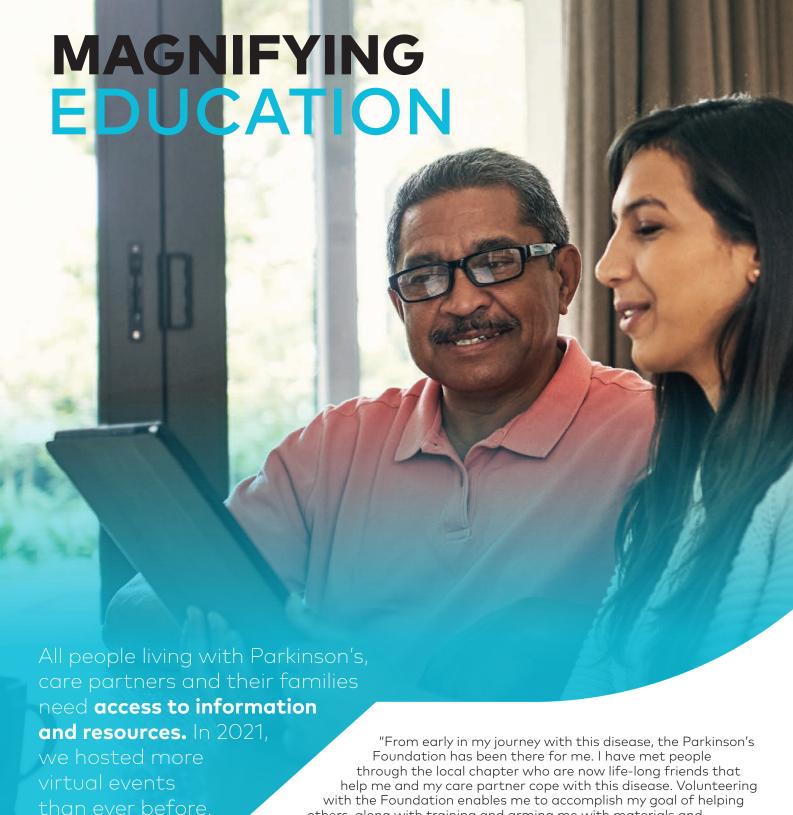
of Helpline callers reported finding answers to their PD questions that they were not able to find anywhere else.



115,900

Aware in Care hospital safety kits have been distributed to help people get better care in a hospital — of these, 3,615 kits were in Spanish.

Find out how we magnify care at Parkinson.org/ExpertCare.



with the Foundation enables me to accomplish my goal of helping others, along with training and arming me with materials and information that our community needs. It's tough living with Parkinson's, but it is reassuring to know that there is a solid organization where people come to work every day just to focus on my disease!"



Mel Mitchell People with Parkinson's Council Member Living with Parkinson's



PD Health @ Home — an interactive series of virtual events designed for the Parkinson's community — reached global heights in 2021. We hosted 143 online events and engaging with 93,562 participants across 60 countries.

Through community grants, we fund local programs that bring communities together and offer unique life-enhancing benefits — from dance therapy in California to young-onset boxing classes in Georgia. Last year, we funded \$2.2 million across 143 community grants. Within this funding, \$1.6 million was dedicated to programs that focus on diversity, equity and inclusion.

In order to address barriers to care and research, we continue to create tailored resources for Spanish-speakers. Our Spanish podcast episodes, blog articles and videos via a revamped español YouTube playlist that feature collaborations with Spanish-speaking Parkinson's experts, are among our most in-demand content.

Partnering with other organizations magnifies our impact, and helps Parkinson's populations access information, like veterans. Through our continued partnership with the U.S. Department of Veterans Affairs, our joint webinar engaged more than 1,000 participants. We also mailed 500 newly diagnosed kits to veteran clinics across the country, and launched dedicated webpages for veterans and their care partners.

Care partners need tailored resources, too, which is why we launched the Care Partner Program: Building a Care Partnership, an online course series care partners can complete on their own schedule. Additionally, our 2021 Care Partner Summit engaged 2,449 participants across eight virtual events that each emphasized mental health.



Parkinson's Foundation online events hosted in 2021.



community programs received a Community Grant across 42 states and 3 countries (Australia, U.S., Taiwan).



books were downloaded



"Alexa, what are Parkinson's symptoms?"

In 2021, we partnered with Amazon's Alexa to provide answers to Parkinson's questions based on information from Parkinson.org and other leading sources.

Find out how we magnify Parkinson's education at Parkinson.org/GetInvolved.

2021 by the Numbers



invested in Parkinson's research and clinical care since 1957.

PD GENEration

MAPPING THE FUTURE OF PARKINSON'S DISEASE



of our goal accomplished to reach 15,000 PD GENEration participants — administering a genetic test and counseling session.

Participants enrolled from all

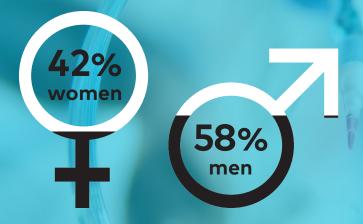
50 states

plus Puerto Rico and the Dominican Republic.

359

of participants have a genetic form of Parkinson's based on our genetic test results.

PD GENEration participants:





115,900

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



(196,700

people treated at Centers of Excellence — the largest global network of medical centers that specialize in Parkinson's care.



613 scientists

received Parkinson's Foundation funding since 2010.



\$2.2 million

awarded to 143 community grants across 42 states and 3 countries (U.S., Australia, Taiwan).



milllion

people visited our webpage in 2021. Read it now at Parkinson.org/10Signs.



257,300

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



91,850 podcast episodes downloaded in 2021.



5.9 million

people visited Parkinson.org, the go-to online Parkinson's resource, in 2021.

Honor Roll

The Parkinson's Foundation gratefully acknowledges all our supporters who donated \$2,500 or more between July 1, 2020 and June 30, 2021.

Our generous donors allow us to further our mission to make lives better for people with Parkinson's and advance research toward a cure. Thank you for your dedicated support.

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We thank our Leaders in Research members who are alongside us on the forefront of the Foundation's research efforts. Their generous gifts allow us to improve life for people with Parkinson's and bring us closer to a cure.

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Hiking for Parkinson's Awareness





Dan Schoenthal always wanted to hike the Appalachian Trail. He did not let a young-onset Parkinson's diagnosis or pandemic deter him. As a Parkinson's Champion, Dan meticulously planned his hikes. In 2021, he completed massive sections of the trail, garnering Parkinson's awareness on a global scale through Today and CNN interviews, while also raising funds for the Parkinson's Foundation

\$2,500-\$9,999

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Contemporary Dance that Doubles as **Complementary Therapy**





Research shows that dance can help manage Parkinson's symptoms. "The Ririe-Woodbury Dance Company, with the support of a Parkinson's Foundation community grant, will collaborate with choreographers to tell the stories of people living with Parkinson's," said Drew Jaussaud of the Ririe-Woodbury Dance Company. "Our goal is for Dance Uninhibited participants to experience long-term mental health benefits and produce original choreographic material, while increasing understanding of Parkinson's for our instructors.

Practical Workshops that Drive Change





The Grady Movement Disorders Clinic in Atlanta, GA, will host eight practical learning workshops for African American patients with Parkinson's. The Parkinson's Foundation grantee, Participants United Through Retention and Education PD Program, will cover critical Parkinson's topics such as mental health, exercise, diet and nutrition. "Grady is so grateful for support from the Parkinson's Foundation," said Chantale Branson, MD, from Grady Health System. "Our ultimate goal is to improve the well-being and quality of life of diverse patients living with PD."

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In Memoriam of Richard Alhadeff



We honor the legacy of emeritus board member, E. Richard Alhadeff. Shortly after his Parkinson's diagnosis, Richard served on our board from 2000 to the organization and his contributions to make life better for people with Parkinson's and their families.

2016. He served as vice chair and later provided invaluable legal guidance on the emeritus board. We are grateful for Richard's longtime commitment to

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Donors Invest in Parkinson's Research

Generous donations allow the Parkinson's Foundation to make life better for everyone impacted by Parkinson's. Thank you to the following charitable donors:

Wesley McCain, PhD

Entrepreneur, professor and philanthropist, Dr. McCain has been instrumental in helping the Parkinson's Foundation expand research toward a cure. Dr. McCain, who lives with Parkinson's, was one of the first participants and supporters of PDGENEration: Mapping the Future of Parkinson's Disease. His contributions led to the study's expansion to the Caribbean, allowing for greater diversity and more accurate data. "What inspired me was the data discovered in the course of research would eventually be available to all scientists," said Dr. McCain. "My view is that the more open the data is to researchers the higher the probability of an out of the box discovery."



Luther Tweeten

Luther believes in leaving a legacy to help further Parkinson's Foundation research. After losing his father to Parkinson's complications and being diagnosed himself, Luther decided to support the Foundation through a generous gift now, and a Legacy Society pledge for the future. "My doctor at Mayo Clinic received a research grant from the Parkinson's Foundation and said it was a great place to support research towards a cure," said Luther. As an avid runner, Luther moves to keep his symptoms in check and often utilizes Foundation resources. "I am impressed with how the Foundation actively improves the lives of people with Parkinson's," said Luther.



Simone Charitable Foundation

The Simone Charitable Foundation believes investing in research is the key to improving care for people with Parkinson's. With a generous grant of \$500,000, the Simone Charitable Foundation supports PD GENEration, which provides genetic testing and counseling at no cost to people diagnosed with Parkinson's. PD GENEration screens for seven genetic mutations linked to PD and empowers participants to enroll in promising clinical trials that may lead to breakthrough treatments.



Gordon Beckham

Two years before Gordon's father passed away from Parkinson's-related complications in 2013, he joined the Parkinson's Foundation board. Since then, he is often reminded why he has continued to serve, host fundraising events and attend Moving Day Atlanta. "There have been several people, often close friends, who tell me they or their spouse were diagnosed, and it reinvigorates my commitment to the Foundation," said Gordon, Gordon finds his decade-long commitment to the Foundation rewarding. "Staff and board members do everything within our power to connect individuals, to personalize every interaction and show that we truly care. We invest in people, in one-on-one relationships and we want to help."





WE CARE. WE FIGHT. WE MOVE. \$35.1M

Raised since 2011



257 Moving Day **Events**



161,600 **Participants**



26 States



Moving Day, A Walk for Parkinson's takes place in 46 cities across the U.S. and brings local Parkinson's communities together to unite in the fight against PD.

In 2021, we hosted a combination of virtual and physically-distanced in-person events. With the launch of our new virtual walk, Moving Day @ Home, participants from around the country were able to join live Moving Day events from home. Thank you to our sponsors, participants and volunteers who inspire and allow us to advance Parkinson's research, deliver quality care and provide critical Parkinson's resources.

Top 10 Moving Day Teams

Amount Raised in 2021 Season

\$65,905

Edward Jones Heartland Kansas City

\$44,284

23andMe San Francisco \$42,150

Team Albert Chicago

\$41,452

Team Zuckerman Chicago

\$37,795

The Friedland Parkinson's Fighters Palm Beach

\$37,460

Berkowitz Pollack Brant/Provenance Wealth Advisors Miami

\$32,995

Larry's Lemons Twin Cities

Team Howard Twin Cities

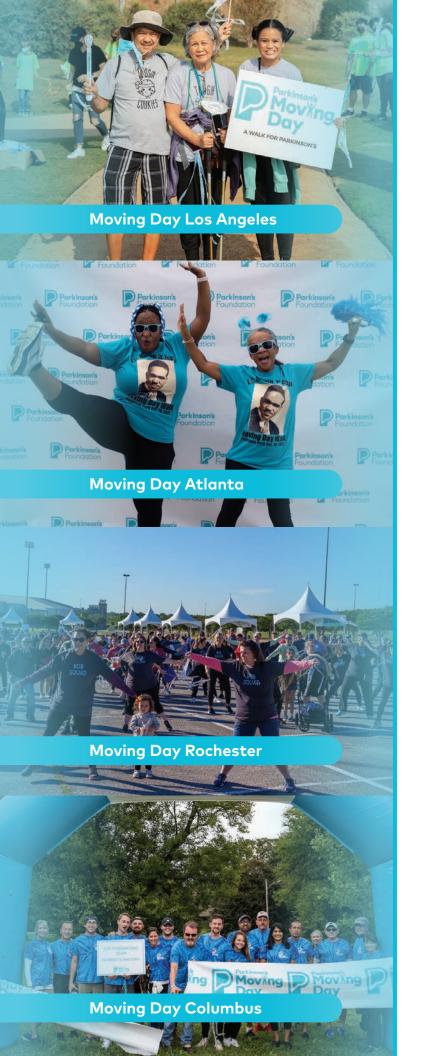
\$30,913

N. Scottsdale Movers and Shakers Phoenix

\$27,655

The Atlanta Movers and Shakers Atlanta

Move with us! Register for a Moving Day 2022 event at MovingDayWalk.org



MAGNIFYING

Parkinson's Awareness

Every year we magnify Parkinson's awareness through a high-impact, national campaign. For Awareness Month in April 2021, we launched the #KnowMorePD campaign.

Our #KnowMorePD 10-question quiz touched on the topics that matter most to our community — from early symptoms to hospitalizations and resources. As people took the quiz, responses showed the correct



answer and links to helpful tools. The goal was to educate audiences — because if we all #KnowMorePD, we can live in a world where there is **no** more Parkinson's.

Supporters around the world were able to visit Parkinson.org/Awareness, equipped with links to essential resources, social media tools and a partner toolkit. We also magnified the campaign's reach through dedicated emails, media and articles.

Campaign Highlights

8,200 people took the quiz

\$339,178 raised through campaign

14,000 visits to Parkinson.org/ Awareness

675 times

the #KnowMorePD hashtag was used on Instagrom

15 proclamations

signed by cities and states including Maryland, Massachusetts, Texas and Georgia

Help us magnify Parkinson's awareness in 2022 and beyond when you give to our Reach Further campaign at Parkinson.org/Reach.



Justin walked 50 miles in 17 hours and raised \$10,500 in honor of his dad.

Aditya rode 15 miles for his 15th of his grandpa living with PD.



The Swanson family became Champs@ Home, finishing a



Our Parkinson's Champions are energized to help us beat Parkinson's. Champions have raised nearly \$15 million to make life better for people with Parkinson's. We thank all Parkinson's Champions and recognize those below who raised \$2,500 or more between July 1, 2020 and June 30, 2021.

Bill Bucklew

Uncorking a Cure

Curbell Medical Products, Inc.

Jeans Day

Justin Cyrus

50 For Park - \$10,000 for Parkinson's Research

Mike DeBartolo

Playing for Parkinson's Tennis Marathon 2021, Par for Parkinson's Golf Tournament 2020

Traci Derlein

lovetracii: 12 hour charity stream for Parkinson's

Addy Fritzhand

Facebook Fundraiser

Manny Garcia

Facebook Fundraiser

Sibyl Goldman Facebook Fundraiser

David Gottlieb

Facebook Fundraiser

Travis S. Howe

Champs@Home

Hailey Hurteau

Parkinson's Fun Run 5K Linda Langsdorf

Facebook Fundraiser

Donna Leipzig

Facebook Fundraiser

Lisa MacGregor

Barefoot Open Golf Tournament

Lindsay Massau Champs@Home

Andy Mathis

Bunker Hill Golf Outing

Gehad Mohamed

First National Bank of Long Island Yoga and Meditation Night

Lindsay Northen-Bradshaw

Concert for Parkinson's & Lewis **Body Dementia**

Pledgeling Foundation

Pura Vida Bracelets

Pura Vida Bracelet Sales

Dan Schoenthal

Appalachian Trail Hike

Joyce Tracy Zero Mile Fun Run

Brent Troyan

Facebook Fundraiser

Villlage Supermarkets

Donation Drive

Jonah, Fran and Justin Vorbach

Jonah, Fran and Justin's Ride for Joe





of Appalachian



of elevation

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

Parkinson's Revolution

Debbie and her team rode silentdisco-style at Revolution San Francisco.



Mehtab rode for her father and arandfather at Revolution Boston.



Parkinson's Revolution is an indoor cycling, fundraiser that combines passion, determination and community to advance our mission toward a cure. In 2021, the event took place in 42 states and raised \$435,000. We thank all riders and recognize the below who raised more than \$2,500.

Anthony Apruzzese, Hoboken Heath Babb, Beaufort Scott Balke, Twin Cities Lexie Buchwald, Miami Rick Carey, USA

Adrienne Casano, Albany Lisa Cone, Denver

Sarah Freyman, Kansas City Melanie Hannon, Chicago

John Harthoorn, USA Lauren Hayes, Albany Laurie Kaman, Los Angeles

Matt Kolodny, Chicago

Roxanna Mehryari, Dallas Jesse Meshkov, Salt Lake City Amanda Meyers, Buffalo Bob Moses, Buffalo Julie Patterson, Beaufort Jennyfer Pedersen, Kansas City Isa Pressman, Chicago Scott Rider, Beaufort Stephanie Sadoff, Chicago Suzanne Tam, Chicago Webb Travis, Orange County

Debbie Lucchesi, San Francisco

Learn more at Parkinson.org/Revolution.



Parkinson's Foundation

Legacy Society

The Parkinson's Foundation recognizes and honors all Legacy Society members who support the Foundation in their wills, trusts, life income gifts, retirement plans and other planned gifts. Legacy Society members leave meaningful, lasting legacies for future generations.

E. Richard Alhadeff, Esq. Steven R. Ames Leo M. Amoroso Helen C. Avchin Christopher T. Baker A. Jeffrey Barash, Esq. Dorothy Beatrice Barbara Ellen Becker Connie Bierlein

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John Kozyak's Commitment to Leave a Legacy Motivated from the Heart

"I never thought of Parkinson's until my mother was diagnosed," John Kozyak said. "Since then, it has forever remained an intrinsic part of my life."

Eventually, John helped both of his parents navigate life with the disease, leading him to become invested in finding ways to make life better for people with Parkinson's and their families. "Witnessing the benefits of excellent care led me to the Foundation." John served on the Foundation's Board of Directors for 15 years, and as chairman of the board. He now serves on the Emeritus board.

In addition to hosting numerous, noteworthy wine fundraisers and Moving Day Miami teams, John is also a member of the Foundation's Legacy Society. "In my estate plan, I have a provision for a gift for the Foundation. I know the large-scale impact planned giving has on the growth of the Foundation — and their ability to jumpstart special, high-impact projects that help so many people."

John knows his future gift will continue to make a difference. "The Legacy Society is a heartfelt way to remember people and to be remembered. This is a great opportunity and responsibility of mine to share my luck in life. This disease has been around for more than 200 years, and we haven't found a cure yet. I want to continue helping the Parkinson's Foundation mission after I'm gone."



John W. Kozyak with his wife, Barbara Silverman.

Learn more about the Legacy Society and planned giving options at Parkinson.org/PlannedGiving.

2020-2021

Audited Financial Highlights

As illustrated below, the Parkinson's Foundation directed 87% of its 2020-2021 spending on mission-related activities and 13% on fundraising and management combined.*

Expenses by Category

Total Operating Expenses

100% | \$47,136,777

Subtotal Mission-Related

87% I \$41,168,791

Fundraising

9% 1 \$4,160,359

General & Administration

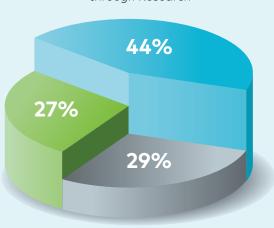
4% | \$1,807,627

\$10,889,511

Ensuring Better Outcomes through Improved Care

\$18,202,054

Understanding Parkinson's through Research



\$12,077,226

Educating and Empowering People with and Affected by Parkinson's

Revenues by Category

Total Revenue

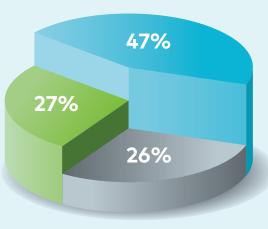
\$50,413,900

Total Year-End Assets

\$57,866,566

\$13,378,216 Institutional Givina: Corporate & Foundation

\$23,958,173 Individual Giving: Private & Bequests



\$13,077,511 All Other

^{*}Reflects Parkinson's Foundation Audited Financial Statement for the fiscal year 2020-21.

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Parkinson's Foundation Board of Directors are dedicated volunteers who guide us through their skilled leadership — invaluably setting the course towards an impact-driven mission.

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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.



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