

OCTOBER 2016

“I’m Not Alone Anymore.” Moving Day® is Five Years Old and Changing More Lives!

“Moving Day® changed my life.”

“I was alone, and now I’m not alone anymore.”

“I had no idea this many other people in my community are dealing with Parkinson’s.”

These are the comments Kayln Henkel, National Parkinson Foundation (NPF) Senior Director of Signature Events, hears again and again from people who participate in Moving Day® events throughout the U.S.

Launched in 2011, Moving Day® has grown from three markets to 20, impacting and inspiring more people than ever before. Moving Day Miami, to be held on November 13th, will be the 100th event. “We can’t wait to see what’s in store for this amazing program and look forward to adding more events each year,” says Kayln. “It’s incredibly humbling when people email us asking for a Moving Day in their community. They see the positive impact it can have and want that for their friends and neighbors.”

In addition to focusing on movement and exercise, Moving Day® has a

strong educational component that empowers people. “In that one day, people’s lives can be changed through education and the focus on the importance of exercise,” says Kayln.

The impact of Moving Day® goes far beyond the event day itself. Funds raised by walk teams and generous sponsors further NPF’s national mission and fund local programs through community grants. “Through our work in the community,” says Kayln, “we hear what the community needs and try to address those needs. Boxing has become a popular exercise program, giving people a chance to fight for a better quality of life. These are the types of programs we love to support!”

While the funds and awareness are extremely important, people are the heart and soul of this event. Carolyn Gloudemans’ life was at a dead end. A cancer survivor and RN, she persevered through her Parkinson’s symptoms, which included difficulty walking, falling and tremors in her left arm. But eventually, Carolyn had to leave her beloved work with newborn babies in the NICU. “I pretty



much threw in the towel,” she says. “I wanted to give up.”

When Carolyn read about Moving Day® in her local California paper, it was exactly what she needed. Starting to train for the walk, Carolyn could barely walk a quarter of a mile. But that didn’t stop her. She walked three days a week, made changes to her medication and followed her doctor’s advice on improving her stride. “It was my dream to be able to accomplish this walk and to not give up on the possibilities of what I can achieve,” she says. Moving Day changed Carolyn’s attitude about everything. “You can’t let Parkinson’s give you a reason to not do things. You just do it *your* way. If I leave a Moving Day walk knowing I impacted one person, that gives me a reason to keep moving on and to never give up!”

Then there are the people in the Dance for Parkinson’s class in Florida, funded through a Moving Day® community grant.

(continued pg 6)

He Has Parkinson’s.
But Parkinson’s Doesn’t
Have Him. 2

It Takes a Network...
to Improve Care 3

It’s All in the Family 4

How a Granddaughter’s
Love and Many Donuts
Support Change 5

Upcoming Team Hope™
Endurance Events 5

Passionate About Wine
and Helping NPF 6



He Has Parkinson's. But Parkinson's Doesn't Have Him.

By Larry G. Zeiler

I was diagnosed with Parkinson's disease (PD) in March of 2004. The last 12 years have been challenging, to say the least. In the beginning, not knowing which symptoms would worsen or which new ones would appear made it difficult to devise a treatment plan. My neurologist could only look at my present symptoms and use her experience to decide which medications to prescribe.

I not only deal with my PD symptoms, but also with side effects of the five medications I take daily. These side effects include freezing, difficulty walking when meds are wearing off, dry mouth, impaired enunciation of speech, loss of smell and taste, difficulty swallowing, and sleeping problems. Anxiety is, at times, overwhelming. But at least I don't experience each symptom every day. I can go a week and not have gait or freezing issues; then again, I can have two days when my symptoms are relentless.

Family, carpentry, gardening, photography and working at my church were my passions before diagnosis, and I wanted to continue them all. In order to do so, I realized that I needed a strategy for living with and combating Parkinson's. I made the decision that I was not

going to allow this illness to alter my lifestyle.

One day at a craft show, I came across an inspirational saying in carved wood that read, "THE ONLY DISABILITY IN LIFE IS A BAD ATTITUDE." This simple saying became my driving force. I realized that my attitude was the key factor in accepting that I had PD and that I had to meet what challenges lie ahead. I had to learn to move past the "what ifs" and the uncertainties.

I became militant about my medication regimen, taking exact dosages at scheduled times. A continuing presence of each drug in my system was vital to controlling my symptoms.

I also began living with some daily concrete principles:

1. I had to **stop worrying about the progression of my present symptoms** and if new ones would develop. Worrying gives you something to do, but doesn't get you anywhere. I don't believe in the saying, "We write our life story," as I didn't choose my eye color, or to be exposed to Agent Orange, and I definitely did not choose PD. However, I can



Larry Zeiler and his family

choose to control what is within my power.

2. I believe **constant movement** is of prime importance in the fight against PD. A body in motion tends to stay in motion. So no matter how you feel **GET UP, DRESS UP, SHOW UP AND NEVER GIVE UP.**
3. **I begin each day at 6:00 a.m.** I set goals and I know what I want to accomplish whether it be at church, in my garden, or working on a piece of furniture. If you believe you can, you're halfway there. My attitude demands that I accept nothing less than 100 percent effort of myself.
4. I strive every day to **walk 10,000 steps.** I use a Fit Bit to track my steps. I now average 12,368 steps per day (about

(continued pg 4)

PARKINSON'S FOUNDATION BOARD OF DIRECTORS

John W. Kozyak, Esq.
Chair

Howard Morgan
Vice Chair

Gregory Romero
Secretary

Marshall R. Burack, Esq.
Assistant Secretary

Alberto Dosal
Treasurer

Stephen Ackerman
Assistant Treasurer

Andrew B. Albert
Constance W. Atwell, Ph.D.

J. Gordon Beckham, Jr.
Karen Elizabeth Burke, M.D., Ph.D.

Alessandro Di Rocco, M.D.
G. Pennington Egbert III

Stanley Fahn, M.D.
Richard Field

Guido Goldman, Ph.D.
Stephanie Goldman

Arlene Levine
Mindy McIlroy

Robert M. Melzer
Gail Milhous

Michael S. Okun, M.D.
Timothy A. Pedley, M.D.

Paul R. Blom,
Interim Chief Executive Officer



It Takes a Network...to Improve Care

By Peter Schmidt, Ph.D., Senior V.P., Chief Mission Officer

Recently, we received a call on our Helpline. The Helpline is staffed by experienced clinical professionals who always stand ready to counsel people calling for information, support, or recommendations about Parkinson's. But this call was a difficult one: A mother needed advice regarding her 10-year-old son. After undergoing successful treatment for leukemia, the child had developed Parkinson's.

What could we do to help? The Helpline agent contacted me and asked for a recommendation for this special case. I told her that this is why we have a Centers of Excellence program.

People call Parkinson's a "snowflake" disease because no two patients are alike. However, for the most part, patients receive similar treatments. Doctors and scientists have developed the concept of evidence-based medicine, where we review research findings to make sure that the care patients receive represents the best treatment available. For most patients, we can rely on a similar person having been involved in studies, and your doctor can learn from the experience of their care.

But for some patients, there is no evidence. No one has run a randomized trial of Parkinson's treatment for 10-year-old leukemia survivors, for example. When there is no science — no evidence — we have to rely on the wisdom of experts. For Parkinson's, these experts are at centers of excellence, where neurologists, nurses, physical therapists, occupational therapists,

speech therapists, social workers, neurosurgeons, and other clinicians have all worked with Parkinson's so extensively that they can make the right decisions for even the most uncommon cases.

I called a friend at a leading Parkinson's center and we sent the boy there.

Experiences like this are why I find NPF's Centers of Excellence program so important. It is much more than a collection of great Parkinson's centers. NPF's staff scientists and clinicians work with our Centers of Excellence leaders to advance knowledge of Parkinson's care in keeping with our strategy of helping people who have Parkinson's today live better, richer, longer lives.

In the beginning, NPF's Centers of Excellence program was purely a scientific effort. NPF distributed funds to scientists to conduct research. However, as findings came in that supported the then-new idea that *team care* was the best way to address the complex, multi-faceted nature of Parkinson's, the Centers' function changed. We began to ask that NPF Centers take the lead in developing this better model of patient care, and to start to create the evidence that would compel others to adopt it. This effort was successful: NPF changed Parkinson's care.

This success inspired us and it inspired the Centers. Collective action was the key to an effective network. We took on important clinical topics, such as how to perform imaging in patients with

DBS. And in 2009, we launched the *Parkinson's Outcomes Project* to

create clinical evidence gathered at our Centers of Excellence that links expert treatments with outcomes. This project has let NPF share the approaches used by the very best Centers with doctors who are treating just a few Parkinson's patients in their communities.

Today, NPF's Centers of Excellence program is very different from the original, where we provided support to scientists to conduct work in their own labs. It is now a collaborative network where scientists at the Centers work with expert staff at NPF to improve the quality of Parkinson's care for everyone. To be accredited as an NPF Center of Excellence, a Parkinson's center can't merely deliver great care. NPF reviewers require that it help other providers deliver better care, too.

Powerful as it is, this program needs your support. The center where I sent the 10-year-old with Parkinson's was not an NPF Center of Excellence, as the nearest one was hours away. It is a great care-focused center conducting leading research — and an aspiring Center of Excellence. We need to grow the Center of Excellence program to make room for their participation. Please join with us and help us bring into our community of excellence leaders like this center and others who share our goal: better lives for everyone with Parkinson's.



Peter Schmidt, Ph.D.

It's All in the Family

By Alan M. Slewett, NPF Board Member Emeritus, Legacy Society member

My father, the legendary Nathan Slewett, served the National Parkinson Foundation (NPF) for 50 years as a member of the board, board president, board chairman and, finally, board chairman emeritus.



Alan M. Slewett

My father was a visionary who helped build NPF. During dad's long involvement with the foundation, NPF funded more than \$150 million in research and support services.

One principle that our mother and father passed down to us was the importance of helping people. That's why NPF's mission spoke to them – and to me. NPF's mission is a blend of patient care, patient outreach and research, with an emphasis on helping people live better with Parkinson's disease. I'm very

confident this foundation has helped tens of thousands of people.

NPF's call to help people living with Parkinson's resonated with many others in our family. My brother, Robert, an attorney, was extremely active in the organization, helping with legal work. My mother, Evelyn, was also very active. So was my sister-in-law, Sheila. I served as a board member for 14 years, focusing on the foundation's solicitations. For many years, my dad, my brother and I served on NPF's board together. Those were wonderful days. My children, Philip and Karen, supported NPF through participation in its sensational galas at which Bob Hope was frequently the star guest.

Fifteen years, ago, my sister-in-law, Sheila, and I made a legacy gift to NPF of an insurance policy. In addition, I plan to make a bequest in my will. A legacy gift is also a

gift to the donor. That's because anything I do for NPF makes me feel good. If you care about something or someone, it gives you pleasure to help them. NPF does a tremendous amount of good. Our family has always been proud to support this foundation.

The way you are thought of once you pass away should be important to people. For people of modest means, who don't have a large estate, even leaving a few thousand dollars to NPF is not only a wonderful thing for the foundation, but will cause others to remember you in a positive light.

My legacy gift is not about me. It's a family affair. It's about remembering and continuing what we *all* did for NPF.

To learn more about leaving a legacy, visit www.parkinson.org/plannedgiving

He Has Parkinson's. But Parkinson's Doesn't Have Him. cont. from pg 2

6.5 miles). My best day was 20,084 steps.

5. I play **Nintendo Wii video games** to help maintain my balance and strength. It's fun and helps improve movement and coordination. It challenges you to improve because you want to reach higher levels of difficulty.
6. **Photography** not only helps me forget about my PD, but it also gives me quality time with my younger daughter, since she enjoys it too. We are most fascinated by taking pictures of nature in all its glory. We frame and display our favorite photos throughout our homes.

7. **Gardening** is self-fulfilling. It helps me get my mind off those aches and pains. I take a lot of pride in the flowers that grow all around our home — from roses to day lilies to tropical canna. I get to spend time with my older daughter, who helps me.
8. Playing **brain games** on the computer helps maintain and improve knowledge. I challenge myself to learn new things. I've been told that learning something new helps the brain produce new cells. I hope that regenerating new cells can help slow memory loss.

9. I make **oak furniture**. I have made more than 100 pieces of furniture while living with PD.

As you can see, I stay busy doing the things I enjoy. At the end of each day, I have a sense of pride and accomplishment. *My days belong to me and not to PD.*

There is no medicine like hope. Hope will lead you to a positive attitude, which makes you believe there is nothing you can't do, even with PD. Your life doesn't have to end just because you have a movement disorder. Challenge yourself, have a positive attitude and have faith in God.

How a Granddaughter's Love and Many Donuts Support Change

By Hannah DeVries

Born on a dairy farm in southeastern Illinois, my grandfather felt the call of the city as a young man. He worked with his dad for one year after high school graduation, married his high school sweetheart, and headed off to make a different life. By the time he became my Pampa, he had earned a Ph.D. in Biblical Archeology, was a full (and beloved) professor at a university, had published multiple articles, dictionary entries and a textbook, and led annual excavations with students to archeological digs in Palestine. The man I first knew was an avid gardener, a great storyteller, and a fearless adventurer. During career week, he brought his leather knapsack and excavation tools to my third grade class. He was everyone's favorite – not a teacher or a nurse or policeman – he was a real live Indiana Jones! He was strong and brave, brilliant and exciting.

Although he was diagnosed with Parkinson's before I was born, I would have never known about his diagnosis through much of my early life. I am forever grateful to the doctors and researchers who allowed him to live nearly ten years with minimal symptoms. He continued to teach, engage with students, research, and write. As our family celebrated his fiftieth

wedding anniversary on a Caribbean cruise, he was able to manage his symptoms. Pampa even had great success with Deep Brain Stimulation surgical implants.

Today, after back surgery five years ago, my grandfather's symptoms have become more challenging. However, while these obstacles have slowed him down a bit, he has not given up. Though Pampa now uses a wheelchair, he remains mobile and participates in daily life activities. Through speech therapy, he has learned to keep his voice strong.

My grandfather's courage, as well as the work of countless researchers, doctors, and support groups, inspired my family and me to take action on behalf of those affected by Parkinson's. We know that a cure won't come simply through science, but from loving and dedicated people.

As a collegiate runner and aspiring physician, I wanted to combine my love of running with medical research for Parkinson's. This year, our family hosted our second annual "PD Donut Dash," a Team Hope™ for Parkinson's event, to raise funds for the National Parkinson Foundation (NPF). The "PD" stands not only for the disease we hope to destroy, but



Hannah DeVries with her grandparents also the man behind the inspiration, Pampa DeVries.

Each year, I love preparing for this event because it exemplifies how a community can come together to make a difference. A local donut shop, Donut King, has donated thousands of donuts. Local businesses and families have made extremely generous donations of time and money to help it come together. Each year, more than 200 runners and 50 volunteers have joined forces to fight Parkinson's disease together. We make a point of educating the participants about Parkinson's, and have even had a few people share their story through our Facebook page.

Not only has the "PD Donut Dash" raised money for NPF, it also gives those affected by Parkinson's a glimpse of everyone who is on their side.

Upcoming Team Hope™ Endurance Events

OCTOBER 2016

30 Marine Corps Marathon

NOVEMBER 2016

6 TCS New York City Marathon

FEBRUARY 2017

5 Humana Rock 'n' Roll New Orleans Marathon

APRIL 2017

30 Big Sur International Marathon

For more information, visit www.parkinson.org/endurance for the list of events and details on each.

Passionate About Wine and Helping NPF

By Alberto Dosal, NPF Board Member, Co-Founder and Chair of *Wines on the Bay*

John Kozyak, Chairman of the Board of NPF, and I, were looking for ways to raise awareness and money for NPF. We both love wine, and one evening in early 2015, after attending a charity wine reception, it hit us. *Wines on the Bay* was born!

I am recently retired after a long career in technology services, and our family still owns three businesses managed by our sons, Eric and Brian. Two years ago, my wife, Lourdes, was diagnosed with Parkinson's disease. I've been an NPF board member since then.

As a wine aficionado, I own a small collection, belong to several wine groups and enjoy visiting California, France and other wine-growing areas. It's wonderful to put my



From left to right, John W. Kozyak, Esq., Chairman of NPF and *Wines on the Bay* Vice Chairman; Marcia Mondavi Borger, *Wines on the Bay* Honorary Chair; and Alberto Dosal, NPF Board Member and *Wines on the Bay* Chairman.

passion for wine into action for NPF, and to see the great response.

Our first *Wines on the Bay* took place at Miami's beautiful Coral Reef Yacht Club in November of 2015. Guests enjoyed wine tastings and the auction. The auction, alone, raised \$47,500. In all, we donated \$87,500 to NPF. We're projecting a donation of \$150,000 for this year's event, partly because we're

now offering the exciting capability of remote bidding and our auction items have increased greatly.

The venue holds 150 people, and we quickly sell out. Thanks to our remote bidding software, we expect more than 300 bidders nationwide to participate. Board members and donors who can't be in Miami for the event, can bid from anywhere by using a smartphone or laptop.

NPF's mission is to help every person diagnosed with Parkinson's live their best possible life now. *Wines on the Bay* funds better research and treatment that makes that a reality. This is very personal to me!

For more details, please visit our website www.winesonthebay.org.

"I'm Not Alone Anymore." cont. from pg 1

Dreema Stokes, NPF Community Development Director, South Florida, has observed the class over time. "At first, many people were in chairs," Dreema says. "Now most are standing up!"

Moving Day® brings people with Parkinson's, and caregivers, out of isolation. Sara O'Hare, NPF Community Development

Manager in Chicago, saw the power of connection at a recent event. "I introduced a team captain very newly diagnosed with Young Onset Parkinson's to another Young Onset

person. Both were still in careers, providing for families, one had a new baby. It was like gaining a support system. You could feel the relief – theirs and their wives'. Three years later, they're still in contact."

"Moving Day® is something special," says Scott Rider, Honorary Chair of Moving Day

Ohio 2016, and a team captain. He was diagnosed with Parkinson's at age 47. "There's tremendous camaraderie because we're fighting the same battle. People ask each

other, 'What medication are you on? What's your biggest annoyance? Who's your neurologist? How long since you came out of the closet about Parkinson's?' Moving Day is like a giant support group."

For Lisa Bateson, a team captain in Columbus, Ohio, who has participated in Moving Day® for five years, the event is "a celebration." Lisa was diagnosed at age 41. "The event gives family and friends a way to support me," says Lisa. "And it lets me show them that I'm doing okay."

"Our goal is to continue making a difference and connecting with people across the U.S.," says Kayln. "We need your support, and encourage everyone to get involved in this powerful movement. Come join us!" www.npfmovingday.org

"Moving Day® events are so vitally important. They not only contribute the funds needed for continuing research and care, but of equal importance, they inspire and bring together families and communities in the fight against Parkinson's disease. For me personally, that creates an empowering nationwide network of love and support."

— Robert Baittie, diagnosed with Parkinson's in 2012