

My Grandmother

By Alexandra Marsek

Hardworking, stubborn, caring and beautiful are the words that come to mind when I think about my grandmother, Alice Weiner.

Grandma was a strong, independent woman who graduated from NYU and worked in the field of cancer research. At the age of twenty-nine, she was married and had two children. About forty years later, she and my grandfather moved to Florida. In 2004, my grandfather passed away and my grandmother was diagnosed with Parkinson's disease. I was only five years old at that time, so I do not have much memory of her before her diagnosis, but I do remember that for a few years after being diagnosed, she continued traveling, swimming, playing tennis and driving.

We would visit Grandma in Florida two to three times a year. Eventually, she started losing her motor skills and was no longer able to pursue the activities she loved. When we went to visit her in 2008, I could tell

that her Parkinson's was getting worse. She was no longer able to get up as easily and she had trouble balancing. Seeing her like this made me scared. Later that year, she had her first fall. My mother and aunt made her get Lifeline Alert and a home aide for a few hours a day. She refused at first, but she eventually agreed.

"As the disease progressed, her voice diminished – but not her determination."

As her Parkinson's progressed, she became less social and less active. She started to show increasing signs of the disease and took a bad fall in 2010. My mom flew down to Florida and gave her the option of hiring a full-time aide or moving in with us. I was very upset when I heard the news that she was coming to live with us. I did not want an aide living at our house or my social life to be ruined, but it was not. I ended up enjoying having Grandma there, and I'm pretty sure she enjoyed living with us.

We settled into a routine, which consisted of helping Grandma with her exercises and speech therapy



Alexandra Marsek and her grandmother, Alice Weiner

a few times a week, and I even got her playing Wii Fit. During my soccer games, Grandma would walk around the track with my mom and she also enjoyed watching me swim. Most days after school, I would come home and watch TV with her. Some days we played cards.

At first, she thought she was a burden. My grandmother did not like being helped out all the time and would try to do things for herself, which caused a few minor falls. One day I came home and there was an ambulance in our driveway. I immediately asked my father if he thought she would be okay. All he told me was that it was a bad fall. That happened on March 29, 2011. Two days later, Grandma died peacefully at the age of eighty-four. I am very grateful that I had the

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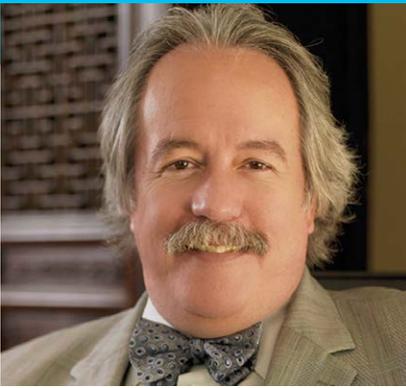
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Message from the Chairman



I am proud to be the new Chairman of the NPF Board of Directors and look forward to building on the great work of Dr. Bernie Fogel, Past Chairman, and Paul Oreffice, Chairman Emeritus.

I am touched in a very personal way by Parkinson's. Both my parents have Parkinson's disease (PD), so I have an intense interest in NPF's mission to improve the quality of care for people with PD through research, education and outreach. As a close family member of loved ones living with Parkinson's, I am deeply aware that PD impacts not only the one million people who have been formally diagnosed, but their extended families and caregivers. I am proud that NPF is very concerned about their well-being, too.

NPF helped me find an amazing movement disorder neurologist for my mother 12 years ago, and while I saw with my own eyes the difference this made in mom's quality of life, I now appreciate

even more fully its positive impact on my mother, thanks to our Parkinson's Outcome Project, which is proving that treatment by a trained neurologist can make a huge difference in a person's ability to live well with PD. Of course, I am aware that many people living with PD are not as lucky as my mother. But while it saddens me to know that there are hundreds of thousands of people in this country with Parkinson's who do not have access to the best medical care, I am heartened by the fact that NPF is taking the lead in training more than a thousand medical and health care professionals in "best practices" for Parkinson's patient care. However, much more needs to be done.

I grew up listening to my mother whistling – around the house and also as our special signal for me to come home. As her PD progressed, she became unable to whistle, that is, until she received free voice therapy lessons through an NPF chapter. I will never forget my mom calling me on the phone and whistling again. Now, a whistle may seem like a small thing to people who don't understand that we need to do whatever it takes to stop Parkinson's disease from prematurely taking away the important things in people's lives. So much of NPF's work concerns

improving people's quality of life. And regular exercise can make a huge difference. That's why I'm such a strong supporter of Moving Day®, A Walk for Parkinson's. Last year, I teamed up with my friend and former Attorney General Janet Reno and raised \$36,632. We were the top team! It was great to see Janet smiling and the joy on the faces of her many admirers. They were thrilled that we were making a difference by increasing awareness, raising money and honoring someone we love so much. Janet Reno was one of the first people I talked to when my mother was diagnosed and I will never forget her kindness.

NPF has so many fantastic programs and the Helpline is one of my favorites. I would love to raise enough money to extend this service, so we can provide even more coverage in the evenings and on weekends. I'm busy working with NPF's board and senior staff to try to raise funds to continue and expand our research and support services. I promise to work hard for the next two years to do *Whatever it Takes to Beat Parkinson's*®. I welcome your ideas and I need your support.


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Chairman, Board of Directors

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Make Every Step Count @ the Parkinson's Unity Walk

By Carol Walton, Chief Executive Officer,
The Parkinson Alliance

Imagine a beautiful spring day in New York City's Central Park. Over 10,000 people unified around a common goal – to raise funds for Parkinson's research that will move us closer to a cure and develop therapies to improve the quality of life of those living with Parkinson's disease. The 20th annual Parkinson's Unity Walk was held on Saturday, April 26, during which participants walked a gentle 1.4 miles in Central Park.

Twenty years ago, a very courageous woman set out on a mission. Margot Zobel, a person with PD (PWP), single-handedly rallied a small group of supporters to create the first Parkinson's Unity Walk in 1994, an event that has grown from 200 participants raising \$16,000 in its first year to 10,000 participants raising over \$1.7M for research in 2013.

Margot was determined to fight Parkinson's disease and she united the entire Parkinson's community with her positive spirit. Her vision included bringing the major Parkinson's foundations together to provide a day of community and education, and ensuring that **100 percent of donations support research**. Although Margot passed away in 2010, her spirit is still with us.

The Unity Walk is the largest grassroots event for Parkinson's disease in the U.S., raising awareness and funds for research, and supported by seven major Parkinson's foundations.

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chance to know my grandmother better during the last eight months of her life. It's a time I will never forget.

My grandmother's example of working hard to achieve what you want definitely struck a chord with me. As the disease progressed, her voice diminished – but not her determination. Now I can speak for her and others who have this debilitating disease. The day after she passed, I created a Team Hope fundraising website on Parkinson.org to raise money and awareness for the



The NPF team at Unity Walk, from left to right: Nerissa Balland, Kama Sanguinetti, Cathy Whitlock, Rob Shaw, Joyce Oberdorf, Karen Hamilton, Candace Leeds, Sara Teeter and Darcy Taylor.

On that day, people living with Parkinson's disease, and their families, have the opportunity to meet with representatives from the Walk's sponsors and the many Parkinson's foundations to learn about available resources and therapies, clinical trials and advocacy. At the Ask the Healthcare Experts booth, they might speak with a movement disorder specialist, neurosurgeon, physical therapist, or other healthcare professional.

Says Jenny Erasmus, "Through the people my mother met at the Walk, she has joined support groups, learned of new medications, and was referred to the movement disorder specialist she now sees on a regular basis. Without this event, we would be utterly lost.... My family owes a great deal to the Unity Walk. Simply put, it's a lifesaver."

While the Unity Walk promotes community and education, its primary goal is to raise funds for research. There is strength in numbers.

Visit www.unitywalk.org for information on next year's event.

National Parkinson Foundation. Each year since, I have hosted a jewelry party, with proceeds going to Team Hope for Parkinson's. This is my way of honoring my grandmother's life.

Alexandra is 15 years old and has raised over \$5,300 for Team Hope over the past three years. She hosts "Earthy Treasures" jewelry shows, a company that brings jewelry and gifts directly into people's homes. Proceeds go to the charity of their choice for hosting the party.

Staff Profile: A Day in the Life of Sara Teeter, Team Hope and Special Events Manager

Planning an event can feel like an avalanche of small details. But to Sara Teeter, NPF Special Events Manager, the details small and large are what keep her going! And she knows how important those details can be in ensuring a flawless event.

When you first meet Sara, you're greeted by a warm smile and a Southern accent. She hails from Charlotte, NC, which she misses, but she has quickly warmed up to the Miami coffee culture. "Un café con leche, por favor" is what you'll hear her say each afternoon at 2 pm. She needs the coffee as she rushes from meetings with the

CEO to her VP, bearing floor plans, guest lists, program scripts, table assignments, budget updates, and sponsor checks to make sure everyone's expectations are met for each event. Sara recently created an event in honor of our longtime chairman, Bernard J. Fogel, MD, at the Pérez Art Museum Miami. It was a spectacular occasion, all due to Sara's meticulous attention to detail and high expectations. It also helped that the event honored a very special man.

Another part of Sara's job is to run the community FUNdraising program known as Team Hope.



Sara Teeter with Bernard J. Fogel, MD

Team Hope lets you take the lead in planning your own event for NPF, and Sara is there to give you the guidance you need to pull it off. From endurance races to golf tournaments and benefit concerts, the possibilities are endless. If you have a good idea for raising funds and awareness to beat parkinson's, Sara is the one to call! Email her at: STeeter@parkinson.org

NPF Celebrates Long-Time Chairman of the Board, Dr. Bernard J. Fogel

On March 19, 2014, NPF hosted an exclusive event at the beautiful Pérez Art Museum Miami to honor our outgoing Chairman of the Board, Dr. Bernard J. Fogel. Dr. Fogel has been involved with NPF since 1968, and led the organization as Chairman of the Board from 2008-2014. He is best known for his dedication to helping others and for his exceptional history of giving back to the Parkinson's community. The New World School of the Arts High School Jazz Ensemble provided music during the event, and the evening concluded with a special performance by Nestor Torres, a world-renowned jazz flautist, with his momentous rendition of "Over the Rainbow."



Past Chairman Dr. Bernie Fogel and wife Judy

Share Your Story

Your stories of how you beat Parkinson's disease can help others. Please send yours to Jeff at jzeidman@parkinson.org and it may be published in an upcoming edition of Voice. We all have different experiences in life, and that is what makes the PD community so strong and diverse. NPF will edit your story for length and clarity, if needed.

(Please keep your story 500-600 words and send a high-resolution photo of yourself along with the article.)

Ask About Nutrition With Kathrynne Holden, RD

Q: What do you know about coconut oil for improving the mind? Do you think it's worth trying? I've read some popular posting by a woman who gave this to her husband with Alzheimer's and he was doing much better. Quite frankly, I'm more interested in natural foods for healing. What kind of coconut oil would one get? I thought coconut oil was a saturated fat and one to avoid. Also, what kind of store would carry this?

A: I'm extremely interested in this topic; I read and noted the same article, which has spurred some research on the use of coconut oil for cognition. However, the only human study so far was on college students; the rest are animal studies. It has been studied with regard to diabetes, heart disease and atherosclerosis, and it appears to improve health.

Whether it improves cognition, or is protective for those with PD, remains to be seen. However, I know of no reason to think moderate consumption of coconut oil would be harmful, and we may eventually learn that it is beneficial. We are not recommending coconut oil at this time as a treatment for Parkinson's disease but for those who decide to try it, it can be taken safely by starting with a teaspoon per day, and if it's accepted,

work up to one or two tablespoonfuls daily.

You want to look for 'virgin coconut oil.' Yes, it is a saturated fat; however: a) saturated fat has been under study lately and it has been determined not to be quite the bad guy that was previously thought; and b) it is composed of a different kind of saturated fat, called 'medium chain triglycerides' (MCTs). MCTs are digested quite differently, and can be beneficial – some tube feedings use MCTs, for example.

Many large grocery stores now carry virgin coconut oil; so do most health food stores.

Kathrynne is a registered dietician who specializes in nutrition, dietary needs and complementary treatments for Parkinson's disease. Post your questions to Kathrynne about dietary matters and Parkinson's disease at www.parkinson.org/nutrition.



Kathrynne Holden, RD

Shake it Off

By Sheldon Reynolds, Former Guitarist, Earth Wind and Fire

At the age of 51, Parkinson's started to affect me. I first noticed my left hand shaking and sometimes my balance was unsteady. It became frustrating for me. The body didn't want to respond to the signals I was sending it. It was like a delayed reaction from brain to body. For my family, it's been a real test of patience. They see a guy go from someone dancing all over the Internet to someone stumbling and struggling to keep his balance. They see two different people. My family was definitely aware of Parkinson's, yet the funny thing is there is no history of the disease in my family. I'm the reluctant pioneer selected who wanted to do something extraordinary in my life. And I did.

I mean music and not Parkinson's. My wife, Marilyn, does a great job taking care of me and I'm grateful for

her understanding. For sure, you need to pray for patience, patience and more patience! Something to always keep in mind: your loved ones are living with this 24 hours and seven days a week, too. My prayer is that someday there is a cure, so no one else has to live feeling disoriented like those of us living with and caring for those with PD. If you care about people, you want to help them.

I came to the conclusion that Parkinson's is like a one-way mirror: you can see others, but they can't see what you're dealing with inside. It takes time for the body to

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Sheldon Reynolds

Out of the Park for Parkinson's

By Gordon Beckham, Second Baseman,
Chicago White Sox

A couple of years ago, I launched **Out of the Park for Parkinson's** to help beat Parkinson's. This disease affects me and my family personally. My granddaddy was diagnosed with Parkinson's nearly a decade ago and passed away last June.

"Since we started *Out of the Park for Parkinson's* in 2010, I'm proud to say that friends and local partners have helped me raise \$173,000 in donations to support the National Parkinson Foundation."

The diagnosis hit hard, because my granddaddy has always been a big influence in my life. He even gave me my first baseball when I was a kid. He was always such an intelligent, energetic man. It was tough for me to see how complications from the disease keep him from talking and getting around like he used to.

My granddaddy's struggle with Parkinson's has given me an up-close look at the suffering it causes.



And I'm determined to help beat this disease. Since we started **Out of the Park for Parkinson's** in 2010, I'm proud to say that friends and local partners have helped me raise \$173,000 in donations to support the National Parkinson Foundation.

I want to keep raising awareness and funds to help beat this disease so future generations do not have to go through what our family and countless others have



Gordon Beckham with Joyce Oberdorf

been through with Parkinson's. My grandfather always made my life better. Now I want to honor him by hitting Parkinson's out of the park.

For more information go to www.OutofthePark.org

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catch up to what the brain has instructed it to do.

Although I have Parkinson's, the dreams and creative juices are still flowing. I continue to produce music, sing and perform. I have written a book called *A Voice from Heaven*. I have a radio show called *Sheldon Reynolds and Friends*, which I hope to continue doing as long as I can. I love to do interviews and speaking engagements, and am seeking opportunities to help others. My team is developing a reality music show for songwriters and a music talk show for artists and musicians. In the course of my world travels with Earth, Wind and Fire, I've taken many pictures of places all over the world. I would like to share them in a future exhibition. I also check on my longtime friend, Maurice

White. Every day I'm grateful to get up in the morning, take a walk in the park, and do what I enjoy doing using my God-given talents. I won't let Parkinson's stop me – and don't let it stop you! Join me and let's shake it off!

Sheldon Reynolds is widely known as former lead guitarist and vocalist for the legendary group Earth, Wind and Fire (1987-2002). During that era, Reynolds recorded with the group Chicago. Before joining Earth, Wind and Fire, Reynolds toured with blues performer Millie Jackson. He later played and produced music for Capital recording artist, Sun, and joined The Commodores in 1983. His current band's name is Elements of Fire, an Earth Wind and Fire tribute band.