

My Iron Man Has A Meaning: To Beat Parkinson's Disease

By Cristina Ramirez, Miami, Florida

Growing up people always told me "you look just like your dad." This used to offend me tremendously because I was a girl and he was a boy, so in my mind they were telling me: "you look like a boy." Little did I know that I not only got my looks from him, but I also inherited a big part of his personality and in particular his stubbornness.

It's been over 10 years since his diagnosis and as with any Parkinson's patient, the disease has taken its toll. Yet my father is a very private man and won't appreciate my sharing details of his illness with you. I'll just share this: he broke his back the other day, in typical stubborn dad fashion. Instead of sitting down while waiting for

someone, he said he could do it standing up and then fell.

I say my father is stubborn because he insists on doing things he no longer can. If I need to carry something, he volunteers to carry it for me. If someone needs help, he says he will do it. He will not go through the door if I open it for him; I must go first. He is a stubborn gentleman after all.

"To keep me going, I decided to race in my father's honor, and have been fundraising for the National Parkinson Foundation's Team Hope ever since."

In one single breath my father's stubbornness is both exasperating and inspiring. Why couldn't he wait sitting down? He ended up spending four days in the hospital and will need to wear a brace for the foreseeable future. Was it worth it?

He wants to carry that suitcase for me, but he can't. He has Parkinson's and fully knows what that means because his father had it also.

On the other hand, inside my father's ailing body is the man he once was. The man who was strong enough to make his own decisions, who could



Cristina Ramirez, Team Hope Member

certainly decide if he wanted to wait sitting down or standing up. He doesn't want to give up on that man.

So as frustrated as I get, I also find myself empathizing. And it's such a complex and difficult situation for him, for my mom who cares for him, for his doctors and for the community around him that I feel powerless. I submit to the decisions they make.

What I can do is use him as my inspiration. I have two young boys and three years ago I decided to get off the couch and get healthy. I have

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Message from the CEO



When I was a little girl, they didn't call it Parkinson's. Instead, my grandmother (Mem-Mem,

we called her) had "the shakes." She held her arm, shaking with a mind of its own, on her lap most days. She had other things too. Diabetes swelled her feet and made her even more unsteady in her walk. So when she fell, and broke her hip (misjudging how to open the bathroom door in the middle of the night), it wasn't too long before she passed away. That was before there were any drugs to treat PD.

Parkinson's runs in my family, they say. My Dad was always proud of his handwriting. As a leftie engineer, he prided himself on being precise. But it grew small and shaky before he died—so much so his crossword puzzles looked like they were filled in on a moving train, instead of in the den.

What I do know, from looking at the disease from an early age, and later as an adult, is that Parkinson's affects everyone in the family. I understand firsthand what it feels like to see someone you love lose their powers, sometimes slowly, sometimes pretty dramatically.

That's why I am proud to now lead the National Parkinson Foundation. We make an impact on people. We help them get better care, education and support. And we study what treatments have the most impact in real clinics – on everyone with Parkinson's – not just a handpicked group.

Because Parkinson's is a marathon disease steadily taking its toll, it is time we all join together and act now to defeat it.

Thank you for all that you do.

Congratulations to Lou Tinelli and Robert Hughes on their recent wedding!

Lou and Robert were married on October 13, 2013 aboard the Hybrid Yacht which sailed around lower Manhattan and the Statue of Liberty. They have been donating to NPF for several years. Robert was diagnosed with Parkinson's disease four years ago. In honor of their wedding the couple asked that gifts be made to NPF and they raised over \$5,000! Thank you again for all that you do for NPF! We greatly appreciate Mr. Tinelli and Mr. Hughes for including NPF in their very special day.



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www.parkinson.org/parkinsonscentral

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Paul Kelly with wife, Annie, at Moving Day Miami 2013.

I Continue to Fight

By Paul Kelly, Boca Raton, Florida

During every emergency call I responded to as a 34-year veteran firefighter paramedic, I was constantly challenged to overcome danger, adversity and to help people in distress. How did I do it? Through constant training and having the 'I can do this' mindset.

Eight years ago, on April 16th, the biggest challenge of my life was presented to me. From the doctor's lips to my ears, I heard the words "You have Parkinson's disease." At first, I felt feelings of shock, dismay and helplessness. Then reality set in and I realized I have to fight this!

Through my training as a firefighter/

paramedic, with the help of my wife, Annie, and my two children, Laurel and Paul, and with the guidance from Ed Gray with Geiger MD, I have pushed myself to new limits.

I ride my bike 2-4 miles several times a week and I work out at Geiger MD three times a week doing a variety of exercises such as boxing, sit-ups, pushups, planks and working with TRX straps.

I'm involved with NPF's Moving Day® walk for Parkinson's and a Young-onset Parkinson's support group. I will never say – "I give up." Life is too precious so I continue to fight!

Shopping Online this Holiday Season?

Get your holiday shopping done at iGive AND support the National Parkinson Foundation. iGive has partnered with more than 900 brand name stores to allow you to make a difference while buying all your gifts this holiday season. Participating iGive stores include: Macy's, Overstock.com, Nordstrom, Kmart.com, JCPenny, eBay and many more. You will have the convenience of shopping online while helping the National Parkinson Foundation at no extra cost to you. Register today at www.iGive.com and choose National Parkinson Foundation as your personal cause.



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been racing triathlons ever since and I write about it on my blog. This November, I will compete in my first Iron Man race (2.4 mile swim, 112 mile bike and 26.2 mile run) and I am afraid. I don't want to quit. Both amateur and professional triathletes who have raced the distance tell me there will come a point when I will doubt my capacity and will want to stop. To keep me going, I decided to race in my father's honor, and have been fundraising for the National Parkinson Foundation's Team Hope ever since.

I am counting on my dad's stubbornness to push me to the finish line. I'm counting on being just like him to stay standing when my body wants to sit down. It is true that many people tell my seven year old son that he looks just like me. He is a boy, and doesn't like being told he looks like a girl. So before the conversation goes any further I interject and say, "Well actually, he's just like his grandfather," and I am hoping the similarity doesn't stop there.

Cristina Ramirez is a parenting and fitness blogger who shares her path to health at www.TriathlonMami.com. You can also follow her on Facebook and Twitter @triathlonmami.

Staff Profile:

A Day in the Life of Mercedes Oliva, Director of Donor Services

It's Tuesday morning and Mercedes is adjusting her headpiece and settling into taking calls from donors. Her first call is a tough one, but one she hears often, a young man just lost his father to an 18 year battle with Parkinson's disease and he would like to set up a memorial gift. She listens to Michael as he praises his father's battle and talks about how his dad was strong and faced PD with a brave face. These stories renew her faith in family. Knowing that you have a strong family unit to help you get through a challenging disease makes the journey less fearful. Michael finishes by saying he is proud to name NPF as charity of choice because he knows his donation is going to a cause he believes in.

Her next call is a donation from Sam who has been donating to NPF since 2002. He always calls to renew his membership and take the opportunity to share with Mercedes that he is looking forward to receiving his *Parkinson Report!* Sam reads the newsletter cover to cover and appreciates the information. Mercedes then mentions we are going to roll out a new newsletter called *Voice*, which will feature great stories from donors like himself.

In between calls for the rest of the day, Mercedes enters generous donation information into the database. Mercedes is also in charge of making sure this information is entered in a timely fashion and properly executed



Mercedes Oliva

according to the donor wishes. After a great day, she goes home to her six year old son, and her two adopted dogs, Cookie and Rascal! Every day Mercedes speaks with donors and hears their stories; having this connection reinforces why she is proud to work for NPF.

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IRA Charitable Rollover

Are you age 70½? Do you have a Traditional or Roth IRA? If so, you can make a gift of up to \$100,000 per taxpayer directly from your IRA to the National Parkinson Foundation. In addition to supporting our research on meeting the needs in the care and treatment of people with Parkinson's disease, your gift:

- Counts toward your minimum required distribution.
- Avoids income tax on the distribution.

This opportunity is available only through Dec. 31, 2013. To make a gift from your IRA to the National Parkinson Foundation, you must instruct your IRA custodian to transfer a tax-efficient gift to us. Contact Darcy Taylor at (800) 473-4636 or dtaylor@parkinson.org for additional information.

Please check with your legal, tax or other professional for advice. We encourage you to work with counsel to determine the impact of this legislation on your particular situation.

Ask about Nutrition With Kathrynne Holden, R.D.

Q: I was adding barley to my morning breakfast to zing up the fried rice I was making, along with some extra tofu (instead of eggs) and the Dr. Oz turmeric/garlic/pepper/salt seasoning shaker. I've been overweight all my life so I try to be conscientious about eating healthy, if nothing else. The last few days I noticed a rather drastic drop in my weight, several pounds in two weeks, and I'm not very hungry during the day, that's a change. I started researching barley and found the most amazing studies; it's like this wonder food that keeps your hunger pangs away for hours, kills off tumor cells (shiitake mushrooms used for cancer treatments in Japan), lowers serum cholesterol (as in heart disease conditions), help alleviate blood sugar levels (as in diabetes) and of course is extremely high in fiber so it improves your colon function. There's more but these are just some of the high lights. I can attest to not being hungry for hours. That is amazing because it's a first for me. There's also some interesting literature that it is effective to help alleviate infections and citations about how it's used in some hospital settings to help lower the infection rate among patients. Am I off track or is there real validity to these citations? Thanks! Christy

A: Christy, you continue to inspire and surprise me with your diligent research. And I'm delighted to be able to say that yes, your information is correct – barley is very high in both soluble and insoluble fiber, helps control blood glucose, is rich in lignin which help protect against some cancers, and helps reduce blood glucose spikes, among many other benefits. I recommend choosing hulled barley, rather than pearled barley, because the pearled form has had nutrients stripped away. The hulled takes longer to cook but is far more nutritious. A couple of good articles:

WebMD: Barley —

<http://www.webmd.com/vitamins-and-supplements/barley-health-benefits>

World's Healthiest Foods: Barley —

http://www.whfoods.com/genpage.php?tname=food_spice&dbid=127

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



Kathrynne Holden, R.D.

Parkinson's Pointers: Daily Tasks Made Easier

Parkinson's disease rigidity and tremor may make it difficult to handle toothbrushes, razors and hairdryers. Here are a few tips that may help:

- Sit down to brush your teeth, shave, or dry your hair as it prevents you from falling and helps you conserve energy.
- If your shoulders get tired, prop your elbows on the vanity or sink when you shave, comb your hair or use a hairdryer.
- Use an electric razor.
- Use an electric toothbrush.
- Use a hands-free hairdryer that can be mounted on a vanity.

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.)

Get Moving

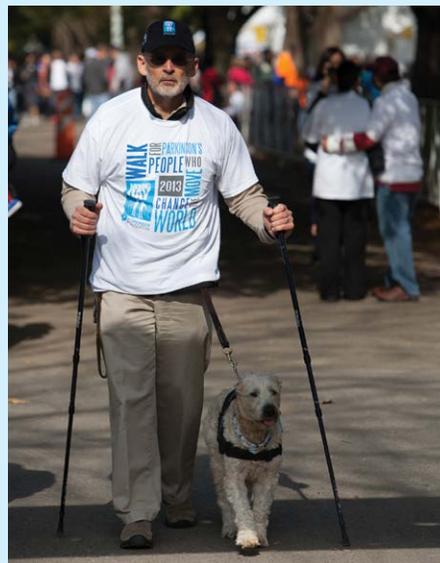
We have had another banner year with our Moving Day® events raising over \$1.5 million! The money raised through Moving Day® will go towards improving the lives of people living with Parkinson's through wellness programs, research aimed at treatment and care of the disease and the advancement of clinical care. This year we

“My most memorable experience from Moving Day® was being able to speak with other people who have PD. It really helped me understand they are going through the same problems that I experience. It was the first time I ever opened up to anyone other than my family - extremely helpful!” –Gordon

added 6 new events with a total of 20 events throughout the year! Moving Day® is more than a walk, it is a celebration and coming together of the Parkinson's community. We hear quotes every day, stressing how important the work we do with Moving Day® is to our NPF family.

Our Moving Day® walks continue to grow and expand

and we will be adding NEW walks in 2014. Please be sure to visit www.npfmovingday.org for more information about a walk in your area and learn about how you can get involved!



Choose the National Parkinson Foundation #11098 during the Combined Federal Campaign Sept. 1 through Dec. 15, 2013