



PD Advocacy: The Difference it Makes

A few weeks ago I had the opportunity to speak to a high school science class on the subject of genetic diseases. Even though Parkinson's disease is rarely inherited, the opportunity was intriguing to me, and I jumped at the chance.

About midway through my presentation, one of the students asked me how I got involved with the local Parkinson's disease support group. It dawned on me that I had not yet told them that I had Parkinson's disease. So I took a deep breath, laid down my notes, took off my jacket and told them about my diagnosis. Although they knew of the well-publicized battles with Parkinson's of people like Michael J. Fox and Muhammad Ali, the illness did not seem real to them until I shared my story.

I gave them details about the symptoms and treatment options. I told them that a person does not die from Parkinson's disease and that the life expectancy is the same as that of anyone else. After answering several questions, I sat down to let the two students who had invited me finish presenting their project. I never expected what came next.

One of the students, a young man named Austin, stopped and said, "What Mr. Trussell failed to tell you during his presentation is that even though a person with Parkinson's disease has the same life expectancy as anyone else, the quality of their life is what really suffers. Imagine having to live your life around when you take medications and how long they will last, knowing that there is no cure." He continued, "Now we all know someone with Parkinson's disease and it is up to us to find the cure — we have to find a way to help!"

Needless to say my chin hit the floor. I looked at the teacher, and with tears in my eyes I said, "They really get it."

One hour out of my time. Thirty-two lives (counting mine) changed forever. I was reminded why I had gotten involved in Parkinson's advocacy in the first place.

Becoming an advocate can change your life forever. I never imagined that at 41 years of age, I would walk into a room full of people, whether they be students, local officials or business leaders, and say: "Good evening, I'm James Trussell and I have Parkinson's disease," much less, "We must find the cause and a

cure for this illness. I need your help and your money!" The "old me" would never have been that bold.

What changed?

There was a time when I did not want anyone to know that I had Parkinson's disease. I took small steps. My father tried to encourage me to talk about it, and in 2004, my friend Kristin Poulsen and I started the first Parkinson's support group in our area. Even then, I tried to hide my illness whenever I could.

Then, one evening, I was at a restaurant and overheard another guest ask the hostess not to seat her family next to my table. She did not want to expose her children to someone whom she thought was a drug addict. I realized then that I had to tell people I had Parkinson's disease! I walked over to her table, knelt down and said, "I'm sorry that you are upset by my shaking hands, but I have Parkinson's disease. I forgot to bring my medication and that is why I am having problems eating. Yes, I do have a drug problem, just not the kind you thought."

The look on her face was priceless. She apologized and asked me to explain what Parkinson's disease was and how someone so young could have it. I have not stopped talking since that day.

That was only the beginning!

I recently heard a preacher say: "Yesterday is history. Tomorrow is a mystery. Today is a present. Open the box and enjoy life!"

My take on advocacy is simple. Not everyone wants to be a "poster child" for PD.

Not everyone can stand in front of a crowd of people and talk about his or her disease. Not everyone is interested in politics or research or writing the next book on PD. But everyone can do something: even if it is simply raising awareness by wearing a Parkinson's t-shirt or putting a bumper sticker on your car.

James Trussell is Founder and Chief Volunteer Officer of the Northwest Georgia Parkinson Disease Association (a chapter of the National Parkinson Foundation). He is a Congressional Coordinator for the Parkinson's Action Network and was named to PDF's People with Parkinson's Advisory Council in 2006.

How to be an Advocate

- Keep yourself educated and informed about Parkinson's disease.
- Give a speech. It does not have to be fancy. Just tell your story!
- Organize a fundraiser. People like to help with worthy causes.
- Get involved with a support group.
- Start a Parkinson's support group if there is not one in your area.
- Learn more about being a political advocate for the Parkinson's Action Network at www.parkinsonsaction.org.
- Most importantly, do not hide — and never, ever be ashamed of your battle with Parkinson's disease.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice.

This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.