



## **2006 National Parkinson Foundation 4<sup>th</sup> Annual Young-Onset Conference**

By Todd Bischoff

Being a newly diagnosed Parkinson Disease patient, I was apprehensive about attending the National Parkinson Foundation's 4<sup>th</sup> Annual Young-Onset Conference in Washington, DC July 6-8, 2006. Not only was it clear across the country (I live near Los Angeles), but also I was afraid of what I might see and hear. But off I went, not having any idea of how my life was about to dramatically change.

My personal PD story is unique, full of weird circumstances and irony. (But then again, whose PD story isn't?) I was officially diagnosed on April 4, 2006 (4/4/06) at the age of 46. I found the "numerical coincidence" to be a little disconcerting. (As an ex-semi pro ice hockey player, we all tend to be a little on the superstitious side.) It was also National Parkinson's Awareness month, and believe me I was aware! Like most PD patients, as I looked back at the years prior to my diagnosis, I realized my symptoms started years before I knew that my brain was being invaded by an unwanted and uninvited visitor.

Even stranger is my personal contact with the two most famous faces of PD, Michael J. Fox and Muhammad Ali. Around 1997, I was back east in New York, running an ice hockey camp. A father of a child I was working with asked if I wanted to play some hockey with the guys later that night. I went and Michael J. Fox was there. It was a pretty uneventful evening on the ice but I recall thinking that Mike was one twitchy guy. I don't mean that in a disrespectful way. I just thought he was full of nervous energy. A year later, he announced to the world he had PD. It was an "ah-ha" moment.

A couple of years later in 2000, I ended up in Los Angeles and was taking an acting class. There I met May May Ali, one of Muhammad Ali's daughters. Instantly we became fast friends. One day May May called and asked if I'd like to come meet her father. Of course I said yes, as I'd been a fan since childhood. We met at a hotel in Beverly Hills and I was able to spend a great deal of time with Muhammad. He was as kind and gracious as you could ask for, especially for someone of his celebrity and stature, and certainly in spite of his disease. Little did I know at the time, but my own personal PD symptoms were already well underway.

Even after meeting both Michael and Muhammad (and following their now very much public stories), I still had no clue that PD had set its sights on me. The signs were all there, glowing like a brightly lit neon sign tattooed right across my forehead. I just didn't see it. And really, why would I? I was relatively young and in great shape physically, so there was certainly no reason to think I had something like PD. After all, it's an old person's disease, right? Wrong.

I ended up going to the doctor after years of stiffness (rigidity), slower walking (bradykinesia), problems with my writing (micrographia), lack of arm swing on my right

side when walking, and problems with my fine motor skills. I was having problems holding pens and gripping my silverware when eating. Simply trying to get 3 crackers out of the box was becoming a huge ordeal. I even had some typical non-motor symptoms common to PD patients, like loss of smell, depression, and sleep disturbances.

But it was the slight resting tremor in my dominant right hand that finally sent me to the doctor. It would move ever so slightly, which wasn't bad. But the troubling thing was, I couldn't get it to stop. I'd move my hand to different positions, all with the same result. My hand would just sort of vibrate and there was nothing I could do to stop it. I was convinced I had a brain tumor. What else could it be?

After blood tests to rule out other possibilities, two neurologists, one PD specialist, a trip to the Muhammad Ali Parkinson Research Center in Phoenix, Arizona, and a trial dose of Sinemet, the diagnosis was confirmed. Four times, At least my doctor was polite when saying those four dreaded words, "You have Parkinson's Disease" by adding, "I'm sorry." Stunned doesn't even begin to describe how I felt.

So, fresh from my diagnosis, I decided to head to Washington, DC for the NPF Young-Onset conference. I wanted to connect with people around my age who had PD, and learn from their personal experiences and stories. I wanted to be inspired by what they had accomplished, and I wanted to see that having PD was "no big deal." I thought that seeing people with PD who were doing "fine" would allow me to further accept my diagnosis and help me move forward with my life.

But I was also scared of what I might see and hear. We've all seen Michael and Muhammad on TV, but they're celebrities and this was so much more real. I was going to be surrounded by literally hundreds of fellow young-onset PD patients. What if I saw a bunch of people who weren't doing well? What if they were in bad shape, depressed, miserable, and hating life? Was that really worth traveling clear across the country for? So it was with much trepidation that I boarded my plane, bound for an experience that was going to change my life forever.

I had the "travel day from hell" (that started at 5:30 AM Pacific time), in which I encountered plane mechanical issues, missed flights, and missed shuttles. I arrived at my hotel in Washington, DC at 10:45 PM Eastern time. My superstitious nature was telling me this was all a very bad sign. (Even my luggage arrived on carousel 13!) Since I was still on California time, I decided to head to the hotel bar for a beer. I'm not a big drinker by any stretch of the imagination, but I decided I deserved a drink after the day I'd had. And it was there I met my first two fellow young-onset PD'rs. My "luck" was about to change in ways I could never imagine.

Jackie was a young mother of two from Canada, who had been diagnosed with PD for three years. Davis was an ex-professional cyclist from Colorado who was diagnosed six years ago (as athletes, we had an instant connection). We sat and talked for about two hours, excitedly sharing stories of our personal experiences and our reasons for coming to the conference. It was the first time for all three of us. (And for the next few days, we'd practically be inseparable.) Reluctantly, we headed off to bed, as we knew the next few days would be filled with sessions, new people to meet, and many more late-night conversations.

All the sessions were great and extremely informative. There were a number of doctors who shared information that cleared up many questions for me. They talked about fatigue; sleep

issues, depression, medications, exercise, stress, surgeries, complementary therapies, and so much more. After the sessions ended, they patiently met with people and answered everyone's questions.

I heard there were almost 400 people in attendance. About two-thirds were PD patients, the rest were caregivers. And yes, there were people who were more advanced in their disease than I was, and I won't lie to you. It was scary to see. But the important thing I learned, and I can't stress this enough, is that you can't compare yourself and your progression to someone else. PD is indeed a "designer" disease, in that it affects each one of us entirely differently.

For example, just because one person may be more dyskinetic, doesn't mean you will be too. Or if someone progresses quickly, that doesn't mean you will as well. And if you meet someone who didn't do well on a dopamine agonist, that doesn't mean it won't work wonders for you. We're all unique, and have our own personal versions of PD.

If I have any advice to offer, it would be this: don't compare yourself and your PD to someone else. You'll just be setting yourself up for disappointment, failure, and possible missed opportunities. The reality is, most young-onset patients with PD do very, very well for many, many years.

That being said, the best part of the conference (for me) was sharing stories with fellow young-onset PD patients. They came from all imaginable walks of life. Schoolteachers, principles, lawyers, mothers, ex-marines, athletes, scientists, artists, etc. PD knows no cultural, economic, spiritual, or gender boundaries. And that's what's so great about talking to them all. They all had different stories, different experiences, different viewpoints, and different hopes and dreams. The conversations would start early in the morning and always go deep into the night. Sleep was not high on the priority list.

It helps to hear that other people know what you're going through, despite their background or geographical location. They know the emotions you feel, the pain that you deal with every day, the frustrations you encounter on a regular basis, and the medication side effects. But more importantly, you're reminded of the successes that we all encounter on a daily basis, and yet sometimes take for granted. Those successes are right there in front of you, just waiting for you to recognize them. (Like getting those 3 crackers out of the box, or surviving a "travel day from hell!") And really, those moments are quite wonderful if you choose to see them.

I made some very deep, personal connections with people from all over the country. I've made friends for life, and that alone was worth the price of admission. In fact, as I was writing this, I received a call from Larry, an ex-marine from Virginia. He just wanted to say hello and talk a little about medications. And Randy, a minister from Minnesota, wrote to see if we could find some time for a phone conversation after he returns from a hiking and rafting trip in the Grand Canyon. (Believe it or not, life actually does go on after a PD diagnosis.) It's these types of relationships that, as the commercial says, are "priceless."

I walked away from my experience knowing that while I have PD and I hate it (which is okay and very normal), I now know that I'm part of a wonderful family that doesn't judge you for your faults, but instead accepts you in spite of them. Their arms were wide open and the embrace I felt was as warm and welcoming as you could hope for. The "travel day from hell" that I had just getting to Washington, DC? I'd do it over again in a heartbeat.

I'm more inspired than ever. I met people that lost careers and had to dramatically alter their lifestyles, and yet they found new joy and talents they never knew existed. It's as if they were butterflies just waiting to be released from their cocoons. From their experiences, I've gained a perspective on life that has forever altered how I look at myself, and the world around me.

I plan on public speaking at schools, colleges, and anywhere and everywhere people will listen about PD. I'm working on starting a young-onset group in my area. And I've started filming a documentary about young-onset PD. While PD may have taken away some parts of my life, but it's also given me a new purpose, and that's not a bad thing.

Next year the NPF Young-Onset Conference will be in Chicago, and I'll most definitely be there. I have family to reconnect with. I hope you'll overcome the fear like I did and come join us. We'll be waiting with open arms. And you'll be safe and at home. That's not a bad place to be. Not a bad place at all.

*-Todd Bischoff is a PD patient who lives in Ontario, California with his wife Joyce and their dog Kaylee. Todd is an ex-athlete, actor, radio personality, voice-over artist, and Child Life Specialist who now is a public speaker on behalf of PD, and is currently filming a documentary on young-onset PD. Todd can be reached at [brknbck89@verizon.net](mailto:brknbck89@verizon.net).*

**Todd will be leading a New Young Onset Parkinson Support Group in the Inland Empire, beginning in September 2006.**

**Date, time and location to be announced!**

**For more information call:**

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