

Parkinson's Warriors

John Cernosek
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The Johns Hopkins Parkinson's Disease and Movement Disorder Center is unique in that it (in subspecialty) is 1 of only 16 Ataxia Centers in the United States. The Ataxia Center, directed by Dr. Liana Rosenthal, offers a multidisciplinary approach to the identification and treatment of cerebellar ataxia.

Ataxia is defined as the presence of abnormal, uncoordinated movements. This term is often used to describe a neurological symptom caused by the cerebellum, which is located in the back part of the brain. The cerebellum is responsible for many motor functions, including the coordination of voluntary movements, balance and posture. Those with cerebellar ataxia often have an "ataxic" gait, which is walking that appears unsteady and uncoordinated. Writing, reading, picking up objects, speaking clearly and swallowing may also be abnormal. Symptoms and progression vary depending on the cause of the ataxia and are specific to each person.

Please find below an article from Ataxia Warrior, John Cernosek, who describes a day in the life of a person living with cerebellar ataxia. Please join and support Team Ataxia as they raise awareness, engage the community and fundraise with Pacing for Parkinson's!



John Cernosek

It all begins the night before, when I'm relaxing at my desk with a beer and a cheese plate. I make a to-do list for tomorrow on a dry-erase board. I plan too many activities, so I'm not aimlessly sitting around at any point. There are about eight things I could be doing with my day; each either a purposeful counter to ataxia, or a personal interest. I ponder the list, do some writing, watch a little Netflix, head to bed.

I live with my girlfriend, Yiomarie, in downtown Silver Spring, Maryland. She wakes up before me—I don't know what time—and brews coffee. She puts it in my thermos with a little milk, and on my desk. I start stirring around 10 o'clock. I ask Alexa what's in the news and she gives me the briefing.

I use a rollator in the apartment and have handles strategically placed on the walls in the hallway and bathroom for faster and easier navigation. I amble one room over into the office and spend the next three hours or so reading books, training my brain with Lumosity games, sending emails, procrastinating.

I go swimming usually four times a week. This involves eating a decent breakfast—not too heavy, but something; otherwise I think about food the entire swim. A bowl of Cheerios with blueberries, almonds, a banana, and a glass of V8 fuels me. I wear my swimsuit under gym clothes, pack my bag with goggles, a shammy, and a pull buoy. I hop on my Travelscoot and go. This sounds like a simple enough process; but leaving the apartment in a timely and organized manner is one of the most difficult things I do.

A 15-minute ride across town and I'm at the gym. There are six steps down to the locker room, so I take the elevator. I choose the locker at the end of the row because it is the least in the way for my slow

undressing. Once I'm ready, I fight through a heavy glass door. It's a rule that you shower before swimming. I pull up to the accessible stall, grab the grab bar with my left hand, and stand. I turn on the water with my right hand, step in, get wet, step out and back onto the scoot. Half the time the next heavy glass door into the pool is open, half the time I have to wrestle with it. I scoot across the deck and park next to the railing. Gripping the railing, I stand, pivot, and sidestep into the water. I take a lane and swim, swim, swim; then exit the same way I entered.

When I leave, the lifeguard opens the heavy glass door for me. I rinse the chlorine off in the shower, wait for someone to open the other heavy glass door for me, because my wet bare feet slip on the tile if I try. I dress at my locker, elevator to the lobby, and a 15-minute scoot home. It's a lot of work, going for a swim; but I love it, and I know—I often have to remind myself—that every effort is helping me.

At home, I eat dinner, watch Orioles baseball, exercise my posture. I stand between my walker and the couch, and move as much as I can without holding onto anything. Or I veg on the couch the whole game. Then I shower, come into the office for a snack, to record my day's activities, and make my list for tomorrow. I do some writing, watch a little Netflix, and head to bed. If I don't swim, I have a host of other things I do to keep my spirits and physicality high, including riding the stationary bike, yoga, playing the piano, and more. It's a grind; I wouldn't have it any other way.