

## Pioneering exercise trial



A growing number of PD clinical trials are focused on the disease modifying potential of various forms of physical activity. Unlike other types of trials, these offer benefits with no risks.

I participated in an early exercise trial that measured my ability to flex and hold my arm muscles prior to beginning and after adhering to a weekly program of aerobic, progressive strengthening and balance training with a personal trainer. The testing involved grasping and moving a lever as instructed while sophisticated instruments attached to adhesive skin electrodes recorded the signals my brain was sending to my muscles.

Trial results suggested that exercise improves certain signals sent by the brain to muscles of people with PD, and may eventually help determine which types of exercise at what frequency and intensity are most beneficial.

*Sheryl*

[http://journals.lww.com/jnpt/Fulltext/2006/12000/Case\\_Study\\_\\_Exercise\\_Can\\_Improve\\_Muscle\\_Activation.59.aspx](http://journals.lww.com/jnpt/Fulltext/2006/12000/Case_Study__Exercise_Can_Improve_Muscle_Activation.59.aspx)

This brochure is part of the Parkinson Support Center of Kentuckiana's (PCKY) 2010 "Living Well with Parkinson's Disease" program. PCKY's mission is to provide services that improve the quality of life for the Parkinson's community; to promote public awareness; to contribute to the local and national efforts to raise funds for support; and to accelerate the research for a cure.

[www.psky.org](http://www.psky.org)



## You're in control

Don't let fear of the unknown keep you from enrolling in a clinical trial. Every trial participant has the right to leave the trial at any time, for any reason. Halfway through one trial, I seriously considered doing just that because of a personality conflict with the study doctor.

After giving the situation much thought, I requested a transfer to a different trial site. I was told I could quit altogether or stay where I was. Neither option was acceptable to me. I wanted to switch study centers.

I documented the reasons for my request and passed it on to leaders in the PD community. They went to bat for me, sharing my written statement with the trial sponsors. A few weeks later I received approval to complete the clinical trial at a different facility. My persistence paid off.



*Jean*

Long distance girlfriends Jean Burns and Sheryl Jedlinski co-founded [pdplan4life.com](http://pdplan4life.com) in June 2007 to "give back" to the Parkinson's community. Through their web site and presentations at conferences nationwide, the two share their personal challenges and triumphs to inspire and empower others to "live well with Parkinson's."

[www.pdplan4life.com](http://www.pdplan4life.com)

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# Clinical Trials

[www.pdplan4life.com](http://www.pdplan4life.com)



 PDPlan4Life

## Your participation in clinical trials is critical to finding the cure

More than 10 years after I joined a small phase II trial studying several dosage levels of CoQ10, the jury is still out as to whether high doses of this dietary supplement can slow decline in people with early, untreated Parkinson's.

Trial participants who received the highest daily dose of CoQ10 "experienced 44% less decline in mental and motor disability," and improvement in all subscores of the Unified Parkinson's Disease Rating Scale. Despite these very promising results, it wasn't until January, 2009 that a large "QE3" trial was begun to determine whether CoQ10 has long-term protective or disease-modifying effects. The study is ongoing.

### Why do clinical trials take so long?

Each new treatment is tested in several different studies to ensure safety and efficacy. On average, it takes eight years from the time a drug enters clinical trials until it is approved. Determining if a drug slows disease progression or is neuroprotective can take even longer.

The biggest obstacle to the timely completion of clinical trials is that fewer than 1% of people with PD enroll -- far short of the number needed. Increasing clinical trial participation by only two or three percent could significantly reduce the time required to finish a study, making more effective treatments and a cure available sooner.

Knowing that time is not on my side, and having completed the 16-month CoQ10 trial with no adverse effects and still no need to start on



PD medications, I opted not to wait for the trial results to be published. With my neurologist's okay, I started taking the highest total daily dose of CoQ10 tested and have stayed the course. Time will tell if I made the right decision.

If we are to find new and improved methods of treating and even curing PD, we need many more clinical trial participants. Don't wait for someone to knock on your door and hand you a cure. No one else can do this for us.

If you were diagnosed within the last five years and take no PD medications, you are likely eligible for more trials than you ever will be again. Many test treatments that could potentially slow disease progression or prove neuroprotective because it is easiest to follow disease progression in patients before they are on the standard medications for PD. Don't let this opportunity get away.

*Sheryl*