

NET-PD Newsletter



This newsletter is especially for NET-PD LS1 participants and their families

NET-PD...Exploring Options to Slow the Progression of Parkinson disease.

Hello to our Study Participants

Welcome back! Another year has flown by and it is time again for another Participant Newsletter.

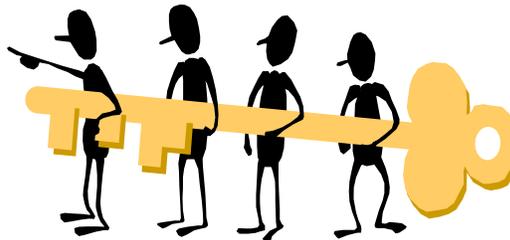
We thought that you may be interested in knowing a little more about this group you are a member of, so here are some general characteristics.

1741— The total number of people who enrolled in the study. Almost 90% continue in the study which is key to our success

1123— The number of men enrolled.

618—The number of women enrolled.

64— The average age of people



Study Participation is key to the success of NET-PD LS1

enrolled in the study.

2.5— Average number of years people have participated in this study.

We hope that these numbers help illustrate that you are part of something BIG. Your continued participation is much appreciated and the basis for the success in this trial.

Study Update— Where do we go from here?

The first person to enroll in NET-PD LS1 began the study on March 13, 2007 and the last subject was enrolled May 28, 2010. We hope you will continue with us until the last enrolled subject reaches the 5 year mark! We expect most people to complete their last in-person visit between

May 2014 and May 2015. Of course, you can always change your mind at any time. You might wonder why we would like you to continue longer than five years. This is an important study and marks the largest group of PD patients being followed for the longest time. Our

ultimate goal and hope is to improve the quality of life of PD patients and their families through your contribution. Continuing beyond five years will only strengthen the information that we obtain from you and others like you.

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Special points of interest:

- *Just Between Us— One person's story about life and participating in the NET-PD LS1 Trial*
- *Contact Information*
- *Meet the Investigators*
- *Travel Tips*

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Meet the Investigators: Brad Racette, MD

Brad A. Racette, M.D. is a Professor and Vice Chairman of Neurology at Washington University in St. Louis, Missouri. He completed his undergraduate work at Princeton University and attended medical school at Northwestern University in Chicago before relocating to St. Louis and completing his residency and fellowship training. He and his family have lived in St. Louis for 18 years. His primary research interest is in the environmental epidemiology (health event

patterns the public) of PD. His Musculoskeletal Epidemiology NIH funded laboratory conducts occupational epidemiologic studies into the causes of PD as well as geographic information systems research investigating community level risk factors for PD. He serves on numerous medical advisory boards, is a member of the Neurologic, Aging, and



Brad Racette, MD

Study Section for NIH, and recently joined the NET PD steering committee. Dr. Racette is an avid cyclist and rides with his wife and friends in Europe each spring. He has two daughters, Sophia and Isabella, who are both accomplished scholar athletes.

Meet the Investigators: Debra Babcock, MD, PhD

Debra Babcock is the Program Director for the Behavioral and Cognitive Neuroscience Program at the National Institute for Neurological Disease and Stroke (NINDS) which is part of the National Institutes for Health. NET-PD is funded by the NINDS, and Dr. Babcock serves as the NINDS representative to the NET-PD LS1 Steering Committee. Besides running her program, Dr. Babcock also spends one day per week

caring for patients with neurological disorders at the National Naval Medical Center in Bethesda.

Prior to working for the NIH, Dr. Babcock was a neurologist and researcher at Washington University in St. Louis, Missouri. While there, she saw patients with movement disorders such as Parkinson and Huntington's Disease, and conducted basic neuroscience research on factors influencing brain cell survival. Her

education includes a MD from the University of Illinois, a PhD in Psychology from Rush University, and a BA from the University of Chicago (where she also did her residency in Neurology).

In her leisure time, Dr. Babcock spends her time gardening, painting, and annoying her neighbors with her violin playing. She is also a runner (distance dependent on how annoyed the neighbors are).

Just Between Us— an original piece written by a fellow research participant

I have been a research chemist for many years. I now have Parkinson's disease. The diagnosis of Parkinson's is a devastating event in anyone's life. I was no different. I went through the usual stages of anger, denial and gradual acceptance of a new reality. One delusional idea that was seriously challenged by my diagnosis was that, despite all evidence to the contrary, I was somehow immortal. The preciousness of my own life and time became crystal clear. By the time I was diagnosed, my ability to work as a chemist had already been compromised. I began to see what this disease would cost me. When I was told there was no cure, I had the typical reaction of anger, frustration, and a sense of helplessness. Even though participating in a clinical study does not necessarily help me directly, it allows me to do something, to lessen that sense of helplessness.

The day I joined the NET PD creatine study group as a Parkinson's patient, I became a participant in research from a very different perspective for the very first time in my life.

Instead of being a research investigator, I was now a part of the research itself. I would be the investigated. This gave me something new to think about.

What does it mean to me to be a clinical study subject? I understand the nature of research. It requires much careful work and a lot of experimental control before anything definitive can be found. It is challenging and difficult and I have always enjoyed it. In my opinion, participation in discovery work is a good thing from any perspective. When I think about a clinical study which involves human subjects, this work seems substantially more complex and difficult to control than the typical experiments I have run. Therefore, subjects for these studies are carefully selected and screened. To be able to see any significant trends many research subjects are needed. Then there is the variability of human behavior, an aspect of these studies

which is very difficult to control. These differences made me think carefully about the kind of clinical research subject I would like to be, as a scientist, and as a person with Parkinson's disease.



There were other aspects of being a clinical study participant that required some different thinking. First, I would not know the results of the study for a long time, and would never know the specific impact of my participation on the results. Throughout the study, I would not know whether I had the study drug or the placebo. I could not go forward expecting to gain personal benefit from my participation. The broader reasons for participation in such a study had to be sufficiently motivating to me. Reasons for participating in a clinical study are many. The most important reason for me is the benefit to others who come after me with Parkinson's disease.

I must admit that even as I



Just Between Us, continued from page 3

went through the emotional adjustment to the idea of having Parkinson's disease, the scientist in me and my own curiosity about this illness were also at work. However, my main motivation for my participation is on lives other than my own. It is for those who follow me in this illness that I chose to be involved. In this way I become a small part of something much larger than myself. The effects of the study may extend well beyond my own lifetime. A part of me, therefore, goes forward, and in a strange way this is immortal, or as close as I will get to it.

What does it take to be a good clinical study participant?

Experimental control is essential to get good and believable study results. The quality of the study drugs and placebos must be carefully controlled. Probably the biggest factor however, is the variability in the behavior of the study participants themselves. To most carefully control the human factor, compliance of the study participants, which includes me, to the specific study guidelines is critical. As I go forward as a volunteer in the study, there is no one watching me to make sure I do the right thing. Therefore, my compliance and thus my contribution to the quality of the study are completely up to me.

I take the responsibility seriously. I keep the study drug (or placebo) where I can see it everyday. I try to be as consistent as possible in my participation. I plan to stick it out until the end. I realize I was selected based on specific criteria and cannot easily be replaced. I plan to do the very best that I can. For every bit that we learn in every study that is run we are one step closer to being able to say to the new person who walks into his neurologist's office with Parkinson's symptoms," We have a cure for this." That thought makes it all worthwhile.

Web Resources

The previous issue of the Participant Newsletter featured links to organizations and foundations related to PD. In this issue we would like to feature online communities— Sites that allow you to connect with others and sites that empower the person.

Remember, you are never alone. Patients Like Me, website that allows you to search for others based on condition, age, gender or a combination of factors. www.patientslikeme.com Parkinson Disease Blog contains links to many PD related web

blogs. www.parkinsonsblognetwork.com If there is a resource you would like to see listed in newsletter please let us know.

Travel Tips

As time goes on it may be harder to travel to the site for your study visit. Please let the site staff know if you are having problems. They may be able to

reimburse for costs or help arrange an alternate means of travel. We're here to make things easier for you so let us know how we can help.



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A Final Thought:

Individual commitment to a group effort - that is what makes a team work, a company work, a society work, a civilization work.

~Vince Lombardi



Contact Information

