

# NET PD NEWSLETTER

This Newsletter is especially for NET PD LS-1 participants and their families.

**Volume 2**

**Summer 2009**



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

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## Welcome New Patients!

Since the last newsletter in Spring 2008 we have had over 522 new patients join our study. Copies of our first newsletter can be obtained by asking your site’s coordinator. In the first issue we provided some background information regarding the purpose of the study and introduced the people at the top. For this newsletter and in the future we would like to focus on the people who really make it possible: the patients. If at any time you think of a topic you would like covered or have a submission for the newsletter contact your site and



have them forward the information. All submissions will be anonymous and your privacy will be protected.

### **Study Drug “Recipes” and Reminders**

Many subjects have voiced concern regarding weight gain. Please remember to mix the study drug with food you already eat, instead of introducing it as a whole new meal. Favorite “recipes” for mixing with study drug include yogurt, juice and pudding. Yogurt appeared to be a top choice since it is available in many flavors.



Participants also submitted helpful tips on how to start a routine to remember to take their study drug. One subject even submitted these clever dispensers.



While perhaps not every participant can design and craft a handy dispenser such as this, many participants found it helpful to place the study drug packets in the kitchen or some other place they were sure to see it. This served as a gentle reminder and made the dosing more convenient.

### **Participant Submission**

A letter from a fellow study participant:

*Several years ago I was introduced to clinical trials by answering a newspaper ad. The details of the study escape me at the present time, although I do recall the study had something to do with cholesterol and that*



*my level was high. I was fairly healthy and viewed my participation as an interesting activity.*

*Being diagnosed with Parkinson's in early 2004 changed my outlook on many things. Suddenly, I had an illness for which there was no cure. I will have Parkinson's for the rest of my life. I can't print or write legibly. I stumble and shuffle when I walk. My senses have diminished; I can't climb a ladder high than three steps, etc., etc., etc. These are all symptoms, but there are many I, fortunately, do not have, but may in the future. I have faith that through research a cure eventually will be found, but the cure will not come overnight. There will be no headlines in our morning newspaper. It will come in small steps like the creatine study.*

*Two 5-oz, packets of creatine (the study drug) mixed with applesauce, cottage cheese, pudding or yogurt is the daily dosage for 5 years. Of course, since this is a blind study, a placebo, an inert, harmless substance, is used. My favorite mixer is yogurt since it is available in many flavors and sizes. and can be eaten any time of the day. Other mixers used are milk and some juices.*

*To maintain study integrity a participant has to establish a procedure or routine for taking the study drug. Mine is to set two packets out in a conspicuous place the night before, ready for use the next day.*

*Participation in a clinical study is a way of keeping abreast of developments in the field of PD research and satisfaction in knowing that you may be giving back.*

### **Websites of Interest**

Last February, Frontline, originally aired on PBS, ran a documentary telling the story of one man and his life with PD. The show can be viewed online at:

<http://www.pbs.org/wgbh/pages/frontline/parkinsons/>

In addition to viewing the show in its entirety, there are many links and discussions that may be of interest.



The Weight-Control Information Network offers publications and resources on nutrition, physical activity and weight control. Handouts are available at the following website.

<http://win.niddk.nih.gov/publications/index.htm>

## **Meet the Researchers**

In our inaugural edition we featured Dr. Karl Kieburtz and Dr. Barbara Tilley. In this edition we will introduce you to Robert Hauser, MD and Sue Reichwein, CCRC.

**Robert A. Hauser, MD, MBA** is a Professor of Neurology, Director of Parkinson's Disease & Movement Disorders Center and Clinical Chair of Signature Interdisciplinary Program in Neuroscience at the University of Southern Florida in Tampa, FL. His clinical specialties include Parkinson's Disease as well as other movement disorders including Huntington's Disease, restless legs syndrome and tremor. In addition to clinical responsibilities Dr. Hauser remains active in Parkinson's research. He not only serves on the Steering Committee for NETPD but is also a site investigator. His research interests are focused on developing medications to slow or stop the progression of neurodegenerative disorders. Dr. Hauser has authored or co-authored more than 150 peer-reviewed publications and lectures frequently at scientific meetings around the world. He is a Past Chairman of the Interventional Neurology Section of the American Academy of Neurology, and has served on the executive committee of the Parkinson Study Group. As a clinician and researcher he is committed to furthering progress in clinical trial and design.



**Suzanne Reichwein, CCRC** was born and raised in Philadelphia. She earned a degree in Social Work from the University of Pittsburgh. Upon moving back to Philadelphia in 1996 she started at the Parkinson's Disease and Movement Disorders Center as an outreach and research coordinator. A year later the center became affiliated with the University of Pennsylvania Health System. Having only done social science research previously clinical work with patients was a new endeavor. Under the tutelage of great doctors and coordinators at the PD&MDC as well as coordinators with the Parkinson's Study Group she was able to learn the business and has been coordinating clinical trials ever since. In 2002, Suzanne assumed the role of

Program Coordinator and Social Worker for the Center but chose to continue working on clinical trials on a limited basis. “Spending so much time with research patients allows me to draw on my counseling and social work skills so it is a perfect blend of science and patient interaction.”

### **A Final Thought**

Henry Ford once said, “Coming together is a beginning, staying together is progress, and working together is success.” Please don’t underestimate your individual contribution to the success of this clinical study. Without participants like you, research is not possible. Thank you.