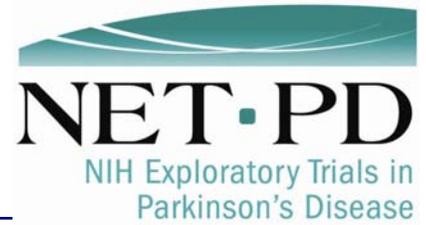


NET-PD Newsletter



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

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

Congratulations on a Study Milestone!

**Volume 5
Summer 2012**

In March 2012 the first person enrolled in the LS-1 study reached the 5 year, Month 60 mark, and we're still going strong thanks to you! The study staff continues to gather information on the majority (1415/1741) of enrolled participants. Participants are seen annually for in person visits and then have a phone visit 6 months later.

The study will continue until 2015....seems like a long way away but it will be done in the blink of an eye! Your contribution and dedication to research is remarkable, and we believe your efforts and information will provide a rich resource for researchers for years to come.



Special points of interest:

- *Poem: Spread Kindness, Joy and Hope*
- *Article: Our Traveling Companions*

When does the LS-1 study end and why is it so long?

We encourage all participants to continue in the LS-1 study until the study comes to its planned conclusion. So just when does it end? The end of the study is slated to occur with your last in-person visit between June 2014 and May 2015. The LS-1 study is a long study that will provide valuable information about the natural history of patients with Parkinson disease. By continuing to participate in the study you will provide important information about long term treatment effects,

disease progression, possible gender differences, cognitive changes, medication use, the incidence of depression, and many, many more valuable pieces of information. This information will be helpful to doctors who treat patients with Parkinson disease now and in the future. Results may help to guide their treatment options in the future or identify new targets of therapy. In the end the LS1 study will be the largest cohort

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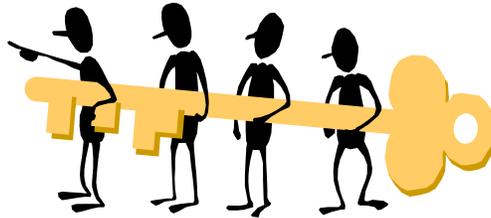
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followed for the longest time. Each individual helps make that happen. Whenever possible, we do want you to continue with your annual in-person visits to the study center. However, we do understand there may be times that this is not possible. Study staff will work with you to reschedule these visits, or to conduct a modified visit via phone. You are important to us and the future treatment of all people with

PD. We hope that you will continue to partner with us to improve the care and treatment of PD.

Even if you choose to end your participation, the information that you have already provided is extremely valuable for the very reasons listed above. We would continue to use the data that was provided to us along with other data from the remaining participants.



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

Study Conference Call

The first ever conference call with the study investigators was held September 29, 2011. During this hour long call the investigators provided an overview of the study and answered questions from study participants.

We hope to continue having calls with participants at least annually to provide you with study updates.

If you have ideas about these calls and what you might want included, please discuss with your site staff who will pass this information on to central staff.



Ideas for Taking Study Drug

Participants are always asking study staff about different ways to take the study drug.

Have you considered mixing study drug with:

- Applesauce (sweetened or unsweetened)
- Yogurt (regular or low fat/sugar free)
- Morning cereal (hot or cold)
 - Diet soft drinks, Gatorade, flavored waters
- Pudding (regular or low fat sugar free)
- Scrambled eggs (add after removal from heat)
 - Mashed potatoes
- Salsa used as dip or topping



Activity and Exercise are Important

Medical journals and the web are filled with information about the benefit of exercise for everyone. With Parkinson disease exercise is even more important to maintain strength, flexibility, posture and balance. The National Parkinson's Foundation offers information on exercises for people with Parkinson disease.

One booklet available on line through the National Parkinson's Foundation is "Fitness Counts". This booklet provides the reader with key points to starting a safe and effective exercise program. As always, consult your physician prior to starting any new exercise regimen.



Shared Sentiments

The NET PD study staff expresses thanks to the authors.
Your work is truly inspiring to others.

Spread Kindness, Joy and Hope

By S. L. Kelley

Be a kind encourager: deliver hope.
Give helpful suggestions so others can cope.

Treasure the beauty of the moon
along with each and every star.

Thank God for so many blessings
and be thankful for who you are.

Be like a torch; be positive, shine your own light.
Enlighten others; help them gain insight
And never give up the fight.

Be a flame; spread kindness about.
Decrease worry; diminish doubt.

Share joys with others; tell a good joke
Support others graciously so they will have hope.



Our Traveling Companions

Of all the companions I might want to take along with me on a trip, traveling “with PD” is not one that I would choose. However, it goes with me, like it or not. Parkinson’s disease has been my constant companion for the last 3 years. During this time I have been on many trips that I might have otherwise put off. With a little effort, it has been possible to sometimes forget about this traveling partner!

I read in a book about Parkinson’s that if you like to travel, there is no reason to put it off (in other words, go while the going is good!). I took that advice to heart and spent weeks in libraries and book stores perusing the shelves. I then spent late evenings on the Internet where I consulted vacationstogo.com, tripadvisor.com, and many other websites that took me to some places I have been to and many that I have not.

My “travels” took me around New England, the US, and the world. I will never take most of these trips, but I sure enjoy planning them. I did not ever consider my health status because I can do anything when it is in my mind. I never had to limit my dreams.

As it turned out, I did have the opportunity to travel to the US state that is the farthest away from New England. Can you imagine a better place to be in January than Oahu and Hawaii?! My husband is an environmental scientist and was doing research at the military bases in Hawaii. I was able to accompany him.

Before leaving on any trip, there are many things to get done. With PD, careful preparation is key and all the pre-trip work pays off. There are many books about PD that give you lots of travel advice. I won’t repeat the advice here but I do have a few hints that may be helpful. The first involves medications. As you already know, determining a medication schedule is difficult on a trip but imagine when your airline travel is 14 hours long! Some meds make you tired, some keep you awake, some you have to take with food and others on an empty stomach. If you need anti-nausea medicine, be sure that it is compatible with your PD meds. Don’t forget to bring an empty bottle of water that you can fill once you have passed security.

My PD is often not noticeable by others. This is a good thing since I like to be as “normal” as possible, but it is also a bad thing since sometimes my behavior just isn’t normal and those around me don’t know why. I tend to trip when hiking on uneven terrain and I am very afraid of falling in a place where I can’t be easily helped. On my recent trip, I sometimes found that it was just too much effort to go sightseeing. I found myself saying “I am fine, just need a little time, you go ahead.” By staying behind, I saw and did things that I would otherwise have missed. For example, I took an Aqua Hula dancing class offered at the hotel where we stayed. Another day I spent the afternoon in the park watching Tai Chi classes.

My next travel tip may surprise you. To make your trip more comfortable and less stressful,

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invest in a fancy cell phone! You will be surprised at some of the features that it has. You can use it as a camera to take pictures, and you won't have to carry a large case around. You can then send that picture to your family back home (like a postcard). There are all kinds of apps for traveling including an app that you can use to get driving directions. You can make dinner reservations using the "Open Table" app. There are apps to guide you on walking tours. Your phone automatically gives you the correct time and weather for the place you are visiting. You can use the Internet to connect with your newspaper back home to see if you are missing anything (most likely you aren't). The app "Places" can help you locate such necessities as an ATM machine, a coffee shop, and the hours that a museum is open. And oh yes, you can use your phone to make calls as well, saving you time and effort. With a simple call, you can arrange a meeting place that will allow you a little time to rest. For me, a phone meant that I could locate my husband when we had a mix-up on where to meet! That cell phone may be your new best friend.



Another new "gadget" is a tablet/lpad, which can be a wonderful aid on a trip. I like the 7-

inch Kindle Fire because it fits in my purse. This means that I don't need to carry a suitcase of books to read and I can also listen to a book being read using headphones. I can get Wi-Fi in most hotel lobbies and other public places, and I can journal my trip if I want. During those long waits at airports, I can play my favorite word games to keep me occupied. And if anyone wants to see a picture of my grandchildren, I have one at my fingertips...



So, I encourage you to follow the advice given in every PD book. Research where you are going. Talk to others with PD and find out what works best for them. Learn ways to make the most of your trip, plan time for relaxation as well as touring, take lots of pictures, and store lots of memories. My husband and I will never forget our final evening in Hawaii when we ate outside on a lanai and watched the sun as it set over the Pacific Ocean.

A Final Thought:

"If you want others to be happy, practice compassion
If you want to be happy, practice compassion."

— The Dalai Lama