



Parkinson's Disease and Movement Disorders Research Database Fall 2016 Newsletter

The Parkinson's Disease and Movement Disorders division has been collecting data from our patients with different neurologic conditions for nearly 14 years. The data collected which is about our patients' quality of life, symptoms and level of disability is used for clinical care. Many of you (or your family members) have signed research consent forms allowing us to use the information you and your physician fill out at each visit for research purposes in addition to your clinical care. Those patients who have agreed for their information to be used are a part of the Research Database Study. Using the data we have collected from these consented participants, we are able to:

- Learn how our patients are doing day to day
- Look at changes in symptoms over time
- Investigate disease progression in relation to any available and applicable treatments
- Guide future research

Turning over a new leaf

In the recent months, we have been trying out new procedures and forms to improve the level of clinical care our neurologists provide and to improve the data we collect from our consented participants, how we collect that data and how we enter it into the Research Database. Some of those changes are...

- There are no additional forms to complete once a year for participating patients.
- There are new forms you complete with better questions replacing some of our older and longer forms
- You now receive your paperwork by mail a few days prior to your appointment to complete prior to coming in.
- We are researching ways to complete your paperwork electronically. Stay tuned for more updates!!

If you would like more information about the Research Database study or to confirm your participation in the study, please contact Latasha Shoffner at lshoffner@som.umaryland.edu.

If you would like help filling out your paperwork, please let a research staff member know!

The Genetics Study



Since 2012, we have been working on a genetics study for Parkinson's disease and related disorders as a sub-study of the Research Database study. We are collecting genetic samples from over 2,000 patients with Parkinson's who have agreed to participate in the Database over the last 14 years, as well as non-Parkinson's controls (such as spouses, children and other relatives). Many of you have been asked to give a blood or saliva sample, which is linked anonymously to information that is currently stored in our database. As Dr. Shulman, one of the Principal Investigators on this study, states: "We saw this tremendous opportunity to collect genetic samples on patients we already have years of data on. Even though some of the data was collected years ago, the genetic samples can be collected at any point." She goes on to say that, "...In this early work we're doing now, we're actually going to examine certain Parkinson's disease subtypes- in particular, patients with relatively rapid versus slower progression and patients with more tremor versus those with less tremor." This information may help predict how the disease may develop and point the way toward more effective treatment.

Number of Participants enrolled in the Parkinson's Disease and Movement Disorders Database...

3500+

Number of posters, projects and papers published...

150+

Number of future research projects to learn more about these disorders...

Endless!

Now that's "PRICELESS"!!

What's new and upcoming...



The Dynaport Study

We started our first study involving an activity monitor and currently are asking patients to wear a small biosensor device while completing a few walking tasks in the clinic. We are using the information obtained by the device and combining it with questionnaires filled out by physicians and patients during the current visit. This information is tied to information previously collected through the database and genetics studies as well. It is predicted that the biosensor can provide additional information on gait and balance impairment in PD with minimal additional effort compared to the standard clinical assessment. This study currently uses the Dynaport MT biosensor device from a company in the Netherlands. Please let us know if you are interested in participating or hearing more about future studies involving activity monitors.

Within Our Reach returns better than ever!

“Within Our Reach (WoR), The University of Maryland Annual Parkinson’s Disease Symposium” is an annual PD/Parkinsonism patient and caregiver educational symposium. This unique patient educational program recognizes the importance of engaging patients and family members in an active process to learn the new skills necessary to manage their Parkinson’s or Parkinsonism disease. The conference educates patients and care partners to be proactive self-managers and healthcare consumers. Breakout sessions are used to bring together attendees with similar challenges and interests in order to promote group problem-solving and networking and the Movement Health Fair features the latest exercise and movement techniques intended to physically engage our participants. The next symposium will be held on Friday, May 5, 2017. Contact Michelle Cines by email at mcines@som.umaryland.edu for additional information.



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We thank you for your continued participation!

If you have any questions regarding the Database study or any of our other research opportunities, please ask for one of our research staff members listed above.