Dear Patients and Families,

Planning for the 2016 Wolfram Syndrome (WFS) Clinic has begun! Please be on the lookout for e-mail and/or snail mail communications from the clinic staff. Your prompt response to any requests for information helps us to plan more efficiently and ensure a smooth clinic experience. If you have changed your address, phone number or e-mail in the past year please contact Samantha Ranck and she’ll update your information thereby ensuring that you don’t miss any upcoming communications.

Samantha can be reached at:

Samantha Ranck, MSW
Research Clinic Coordinator
rancks@npg.wustl.edu
314-362-6514

**ENROLLMENT**

Enrollment for new patients with Wolfram Syndrome into the clinic is still open. We have enrolled 7 new patients with an additional 2 pending. Should you know of a patient or family who may be interested please direct them to the clinic Coordinator, Samantha Ranck. She will be able to answer their questions and get them started on the enrollment process.

**RESEARCH UPDATE**

We hope everyone had a relaxing and warm (at least in spirit) holiday season. We wanted to provide you with a few exciting updates on our research:

1) We are actively working with clinics in Birmingham (England), Lodz (Poland), Paris (France) and Montpellier (France) to collect similar data on Wolfram patients. Pooling data across centers will allow us to draw stronger conclusions and prepare for clinical trials faster. Indeed, this collaboration is an excellent platform for a multi-site clinical trial.

2) Important work from our Research Clinic was recently accepted for publication in *Scientific Reports*. This paper identifies a particular neuropathological finding in the brain that may help us track the progression of Wolfram Syndrome and lead to potential new targets for intervention. We will make this paper available to you once it is published.

**REMINdERS**

The 2016 clinic will be held from the evening of Tues., 7/12/16 thru Sat., 7/16/16. We will let participants know if there are opportunities to begin testing earlier in the week.
**CLINICAL CARE UPDATE**

Everyone is hard at work preparing for the clinic in July and we are delighted that so many of you will be able to attend. I’ve been working on the data from your favorite questionnaires – the two day and one week diaries! There is a lot of good information there that I will share once I get done sorting through it. If you have not filled out one of those diaries in the past couple of years, let us know if you’d be willing to send in one this winter.

As always, feel free to contact any of us should you need a letter to insurance or school or disability, etc., and I’m happy to write what you need. Likewise, feel free to call if you need a referral for a doctor near you or would like to see one of the doctors here for any aspect of your Wolfram.

Best,

Bess Marshall, M.D.
Professor & Medical Director of the Research Clinic

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**OT for Wolfram Syndrome cont.**

If you are interested in an OT consultation at Washington University, please let Dr. Marshall, Dr. Hershey or Samantha Ranck know and we will be glad to help you.

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**RESOURCES**

Have you visited the WU Wolfram Research Clinic Website?? The website contains relevant information about upcoming clinics, updates and links to publications relevant to our research, news related to recent progress in Wolfram Syndrome research and other information. Please be sure to check it out!!

[http://hersheylab.wustl.edu/wolframresearchclinic.html](http://hersheylab.wustl.edu/wolframresearchclinic.html)

*Additional information about the WU Wolfram Research Clinic study can be found at [http://ClinicalTrials.gov](http://ClinicalTrials.gov)*

*WU IRB approval #: 201301004*

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Below is a picture of Dr. Hershey, Dr. Marshall and members of the Hershey Lab who help guide this enormous effort!