



WFS WOLFRAM
RESEARCH CLINIC

Washington University School of Medicine Wolfram Research Clinic Newsletter November 6, 2015 Vol.1

WU Wolfram Research Clinic

Dear Patients and Families,

Due to the efforts of many people, the 2015 Wolfram Research Clinic was a huge success. This year we also had more people return completed surveys on time. Thank you! Occasionally we will send out a survey at various times throughout the year. Thank you for completing and returning those surveys. We know your time is valuable and we appreciate your continued efforts!

Samantha Ranck, MSW
Research Clinic Coordinator
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314-362-6514

ENROLLMENT

We are interested in enrolling new families with Wolfram Syndrome. INQUIRIES FROM NEW FAMILIES OR QUESTIONS FROM ENROLLED FAMILIES OR CAN BE DIRECTED TO SAMANTHA RANCK. She will help answer your questions or refer you to the appropriate person.

FEEDBACK

We are always re-evaluating our approach to the research clinic to see if there are ways that we can improve the experience for families. We value your feedback and comments. Please send any suggestions you may have to Samantha Ranck.

REMINDERS

Next year's clinic will be held from the evening of **Tuesday, 7/12/16 thru Saturday, 7/16/16.** We will let families know if there are opportunities to begin testing earlier in the week.



RESEARCH UPDATE

Believe it or not, our 5 year grant that funds the WU Wolfram Research Clinic (TRACKING NEURODEGENERATION IN EARLY WOLFRAM SYNDROME, National Institutes of Child Health and Development, HD41890; Principal Investigator: Tamara Hershey) will be ending in the spring of 2017!

We are working hard to renew this grant so that we can continue to advance our understanding of the natural history of neurological features of Wolfram Syndrome. We are also collaborating with Tim Barrett's group in the UK and others to analyze their patients' MRI scans and share some of our neurological tests.

Information gained from these studies will guide clinical trial design and measurement choices, and will generate new hypotheses about the important neurological problems in Wolfram Syndrome.

Your continued participation in these studies is absolutely critical in making progress towards effectively testing interventions.

Thank you!

Tamara Hershey, Ph.D.
Professor
Scientific Director of Research Clinic
&
Bess Marshall, M.D.
Professor
Medical Director of the Research Clinic



Tamara Hershey, PhD and Bess Marshall, MD

CLINICAL CARE UPDATE

Finding physicians that have expertise with, let alone knowledge of Wolfram Syndrome can be difficult. In my role as the Medical Director of the WU Wolfram Syndrome Research Clinic, I have had over 6 years of experience caring for children and adults with Wolfram Syndrome in our study and coordinating care with members of the WU and SLCH community in pediatric endocrinology, ophthalmology, neurology, audiology, urology, neuroimaging, physical and occupational therapy, psychiatry, and genetic counseling.

I am happy to provide clinical care to any patient with Wolfram Syndrome (regardless of their involvement in any study) and information to physicians and patients regarding Wolfram Syndrome clinical care. Clinical consultations can be arranged with me or any member of the Wolfram physician team by contacting me (Bess Marshall, M.D.; marshall@kids.wustl.edu or 314-454-6051) or Samantha Ranck.

Clinical feedback reports on each patient were sent out to families in October. If you did not receive your report please contact Samantha Ranck.

I reviewed the reports and contacted families if there were new findings that needed special attention. Please always feel free to call or email if you have any questions about your results. Also please call or advise your doctor to call if you have any questions about your child's or your own clinical care. We are always happy to consult or to provide letters to insurance companies, schools, disability boards, etc.

Best,
Bess Marshall, M.D.

NEW: The WU Wolfram Research Clinic Website

We are excited to announce the launching of the WU Wolfram Research Clinic Website! The website will contain relevant information about upcoming clinics, updates on 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 at:

hersheylab.wustl.edu/wolframresearchclinic.html

RESOURCES

- * Genetic and Rare Disease (GARD) Information Center – (888)205-2311 or <http://raredisease.info.nih.gov/GARD/>
- *National Association for Parents of Children with Visual Impairments (NAPVI) – (800)562-6265 or <http://www.napvi.org> E-mail: napvi@perkins.org
- *Additional information about the WU Wolfram Research Clinic study can be found at <http://ClinicalTrials.gov>;
*WU IRB approval #: 201301004

It takes an army of physicians, scientists, coordinators, technicians, nurses, translators and students to run the WU Wolfram Research Clinic.

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

