



WU Wolfram
Research Clinic

Washington University School of Medicine

Wolfram Research Clinic Newsletter

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WU 2017 Wolfram Research Clinic

The 2017 Wolfram Research Clinic has come to an end and we have another successful clinic on the books!

Thank you so much to both our new and returning families for their contributions and to the many testers and examiners who donated their time to this very worthy cause! Without you, the clinic would not be possible!

What's Next

As you recover from the clinic and settle back into your routines, we will begin the process of collecting the assessments, summarizing the results, and compiling the feedback reports that will then be sent to you this fall. The feedback reports will contain information on the following evaluations: audiology (for new patients only), neuroimaging and neuropsychology, neurology, ophthalmology, psychiatry, and sleep. If, after receiving your feedback report, you have questions or need additional information please contact us. We are also happy to speak with any physicians who view the feedback and would like additional information.

Kind Words

The clinic staff always welcome comments and/or suggestions from our families regarding the clinic.

We value your feedback and carefully consider it when planning the next year's clinic. We appreciate you taking the time to send us your comments. That being said, it's a special day when we receive such a kind message from a parent. Thank you!

"I just wanted to send a quick email and say thank you again to you and everyone for everything. Everyone was so amazing! I understand the disease a little more now after meeting with everyone. Seeing all of you working so hard together to better understand this disease and what makes it tick, well, I'm beyond grateful for all of you! For the first time since the diagnoses, I have some hope! See you all next year!"

RESEARCH UPDATE

Dear Research Clinic Families:

Our relatively small, focused research clinic went very smoothly this year, despite the record-setting heat in St. Louis. Thank you all for your efforts on this 8th annual WU Wolfram Research Clinic!

At the research clinic, we announced that **very good news** that the grant that funds our natural history study received an excellent score, making it **highly likely** to be funded. We find out for sure this fall. The grant represents 3.7 million dollars over 5 years and will focus on understanding individual differences in the neurologic phenotype of Wolfram Syndrome, and on testing hypotheses about myelination (the white matter) in the brain and how it changes over time and relates to symptoms. The bottom line is that we will be able to ramp back up next summer!

We are also committed, along with Dr. Urano and Dr. Barrett, to make any ongoing clinical trials fit with the natural history study so that we make the very best use of your time and the data collected. In doing so, we will make more rapid progress towards our goal of understanding and treating Wolfram Syndrome!

Samantha, Dr. Marshall and I will start planning the next clinic in the coming months. Stay tuned for updates on the grant and plans for next summer.

Best wishes to you all for a happy rest of summer and good luck to all students returning to school!

Sincerely,

Tamara Hershey, PhD (tammy@wustl.edu; 314-362-5593)
Scientific Director and Principal Investigator
WU Wolfram Syndrome Research Clinic
Suite 2203, East Bldg, 4525 Scott Avenue. St. Louis MO



CLINICAL CARE UPDATE

Hello to everyone from St. Louis,

Thank you to everyone who came to the Wolfram Syndrome Research Clinic in July. The clinic was a great success, though we missed the many familiar faces and all the hubbub of the usual big clinic!

Please know that, even if you did not come to the Wolfram Research Clinic this year, you are still welcome to request assistance with letters for school, disability, insurance, etc., at any time. You and your doctors are also welcome to call or email any time with concerns and we are happy to help wherever we can. Should you require any of these things please contact Samantha Ranck, the WFS clinic coordinator, and she will put you in touch with the right person.

To all of you who are participating in Dr. Urano's dantrolene sodium safety study, we have also been very pleased to see you when you come for your study visits. We are all waiting to see how the data from that study turns out. Take care and stay in touch!

All the best,
Bess Marshall, MD (Marshall@kids.wustl.edu)
Pediatric Endocrinologist & Research Clinic Medical Director



2017 Wolfram Syndrome Research Clinic -
Smiling faces all around!

Good Times!

Thank you once again to the Snow Foundation for hosting the family dinner night on the second night of the clinic. This is such a special time for families to be able to relax a bit and get to know each other. The family dinner is a highlight of the clinic each year and something that families very much look forward to.



Patiently Waiting



Dr. Hershey and clinic volunteers Olga Neyman, Marisol Ponton, Sharrada Srivatsa and Rachel Marshall waiting for the next testing session to begin.

Need Help? For questions or requests regarding the Wolfram Syndrome Research Clinic please contact the WFS Research Clinic Coord., Samantha Ranck, MSW at 314.362.6514 or rancks@npg.wustl.edu

RESOURCES

*For more information about Wolfram Syndrome and the WU Wolfram Research Clinic go to: hersheylab.wustl.edu

*One way to interact with other Wolfram patients and their families, to learn more about fundraising activities and scientific developments in the US and UK as well as, links to helpful resources is to follow the "Wolfram Syndrome" page on Facebook (www.facebook.com)