



WU Wolfram
Research Clinic

Washington University School of Medicine

Wolfram Research Clinic Newsletter

November, 2018 Vol.13

WU 2019 WOLFRAM RESEARCH CLINIC

Wait no more - the 2019 WU Wolfram Research Clinic planning is underway! We're sure many of you have lots of questions and hopefully some of them will be answered here. If not, you can always contact Samantha directly. Her contact information is below.

Due to the number of participants enrolled in the clinic and an effort to make the clinic days more manageable, we will be dividing the clinic into two sessions. The official dates for the clinic are as follows:

Group 1

Arrival: Tuesday, 7/9/19

Clinic: Wednesday, 7/10/19 – Friday, 7/12/19

Group 2

Arrival: Sunday, 7/14/19

Clinic: Monday, 7/15/19 – Wednesday, 7/17/19

Scientific Session (TBD)

Saturday, 7/13/19

Family Dinner

TBD

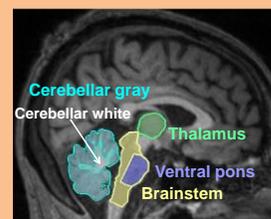
We are still working out the details of the Scientific Session and the Family Dinner(s) and we will share that information with you as soon as it is finalized. Until then, these are the clinic dates. It is important at this time that you let Samantha know if you have a preference to attend as part of **Group 1** or **Group 2**. Please keep in mind that another person or family cannot communicate your preference for you. Samantha must hear from you directly as to which session you'd like to attend. If you do not have a preference, that works too. You will then be assigned to a group once all preferences are in. The deadline for reserving your slot in a particular group is Jan. 31, 2019. That being said, it is important to get your preference in as soon as possible as we are trying to split the groups evenly which means that your preferred group could reach capacity prior to you stating your preference.

RESEARCH UPDATE

Dear Wolfram Community,

Since the last newsletter, we have been very busy, both looking backwards to data from previous research clinics and looking forward to our 2019 research clinic.

Looking backwards, we submitted two papers for review based on previous research clinic data. One paper is on sleep disturbances in Wolfram syndrome, where we show that there is a high rate of sleep apnea based on the sleep monitoring we did during the 2015 and 2016 clinics. The second paper is based on our longitudinal neuroimaging data, and suggests that Wolfram syndrome affects the development of specific regions and tissue types in the brain, and ultimately degenerates others. From these data, we recommend the best measures for tracking neurodegeneration over time in clinical trials. We hope that these findings will help with clinical trial planning, with the development of more brain-targeted interventions, and will inspire other groups to investigate specific hypotheses about the mechanisms underlying these changes.



Looking forward, planning for next summer's research clinic is underway! Samantha has been reserving rooms, Heather has reserved the MRI scanner and collaborators are blocking off their calendars. We are also testing our new MRI sequences to better measure changes in the optic nerve and in white matter across the brain.

Finally, the Snow Foundation is leading an effort, with which we are helping with, to obtain grant funding from the NIH to support a research and clinical symposium for

RESEARCH UPDATE cont...

families during the clinic. Stay tuned for details! Time will pass quickly, and before we know it, we will be greeting some of you in summery St. Louis!

Sincerely,

Tamara Hershey, PhD

Professor

Scientific Director and Principal Investigator

WU Wolfram Research Clinic

tammy@wustl.edu; 314-362-5593



WU 2019 WOLFRAM RESEARCH CLINIC cont...

For the 2019 WFS Research Clinic we are exploring the possibility of adding small groups or roundtable discussions sessions to the Saturday session. In order to explore this further, we'd like to get some feedback from the families about what sort of topics that they would like to discuss, learn more about, or share. As a participant or family member, you could have the option of presenting or leading one of the small groups too. Of course this would be completely voluntary.

If you have ideas about what topics you'd be interested in exploring further, please contact Samantha as she will be compiling a list of suggested topics to be considered.

Some topics that have been suggested thus far are:

Going off to College with Wolfram Syndrome

Neurogenic Bladder and Treatment Options

Sleep Hygiene

Speech & Swallowing

What would you like to know more about???



CLINICAL CARE UPDATE

Dear Wolfram families,

We're so excited that we will be seeing so many of you this summer! Since it's been two years or more for many. In order to help us better prepare for your child's visit, it would be incredibly helpful if you would request records from your doctors at home and have them sent to Samantha (address below). We are very interested in changes in current conditions, anything new going on and/or any recent lab tests. Any information that you are willing to share will be valuable in helping us to keep up-to-date on what is happening with your child. Please send medical records to:

Washington University School of Medicine
c/o Samantha Ranck, MSW
660 S. Euclid Ave
Campus Box 8134
St. Louis, MO 63110

You may also contact Samantha to request a medical release form to complete and copy to send to various physicians allowing them to send records to us. As always, I'm happy to write anyone letters for insurance appeals, notes to miss work for the clinic, etc.

All the best to everyone,

Bess Marshall, MD (Marshall@kids.wustl.edu)

Pediatric Endocrinologist

Medical Director, WU Wolfram Syndrome Research Clinic



Follow the link below to read a recent article discussing Wolfram Syndrome and featuring our very own WFS Clinic Scientific Director & PI, Tamara Hershey, PhD:

<https://medicine.wustl.edu/news/3-million-to-help-expand-wolfram-syndrome-research/>

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