



WU Wolfram
Research Clinic

Washington University School of Medicine

Wolfram Research Clinic Newsletter

May, 2019 Vol.15

WU 2019 WOLFRAM RESEARCH CLINIC

Hello from St. Louis! This is the last WFS Newsletter that you'll receive before the clinic so please read the following information carefully as some things have changed. If you have not responded to the most recent request for information, please do so now. This information is important as it helps us in planning for everything from budgeting, to hotel rooms, to scheduling, to the Community Conference. Please be on the lookout for upcoming communications!

Due to the Community Conference and people extending their clinic visit to attend, we are very limited on hotel rooms this year for Friday and Saturday nights. We should have enough rooms at the Parkway but it is important to get your travel plans in right away to make sure you have a room reserved for your entire stay.

For those who are covering the cost of the extra nights at the hotel, this will be done exactly like it has in the past. We'll make the reservation in our block of rooms and will indicate that the family is paying for the designated night(s) and then you'll be able to pay the bill for those night(s) when you check out.

Travel Reimbursements

Please bring your travel receipts to the clinic orientation as Beth Beato will be there and will begin processing your reimbursements right away. If there are any questions we can get them answered prior to you leaving instead of trying to get them answered after the clinic. **PLEASE NOTE** that the clinic is only able to reimburse for the following:

Airfare, for those flying to St. Louis, **economy class airfare for the study participant and one proxy only will be reimbursed**. We are unable to reimburse for travel insurance, upgrades (e.g., early-bird check in, priority seating, upgrades in class) or transfer/change

RESEARCH UPDATE

Dear Wolfram Community,

As we prepare for the research clinic and the community conference with the Snow Foundation, a few other things have been going on that we want you to know about!

First, we have published a paper that describes how the size of brain regions change over time in Wolfram syndrome. This paper is based on the brain imaging that we have done over the last 8 years in the Wolfram research clinic. You can find the paper online here: [Evidence for altered neurodevelopment and neurodegeneration in Wolfram syndrome using longitudinal morphometry](#). The findings have important implications for current and future clinical trials for treating Wolfram syndrome neurodegeneration.

Second, we have continued to interact with other groups that are working on current and future clinical trials, both here in the US, the UK and Belgium.

Finally, we have been working with investigators in Estonia on their mouse model for Wolfram syndrome to determine whether they display similar changes in the brain to people with Wolfram syndrome. If this mouse model is similar in its brain features, we then would be able to do more specific brain studies that might suggest brain-specific treatments.

If you have any questions about any of these research projects, please let me know! I am always happy to talk to you.

Sincerely,

Tamara Hershey, PhD

Professor

Scientific Director and Principal Investigator

WU Wolfram Syndrome Research Clinic

tammy@wustl.edu; 314-362-5593

CLINICAL CARE UPDATE

Dear Wolfram families,

Greetings to all of you! We have had some questions recently and in the past about managing diabetes at the clinic. There are a few of the appointments that you may have that can be affected by your blood sugar. And, the Boost test affects your blood sugar itself, of course. Samantha has worked hard to not put a meal right before you will need to have a stable blood sugar, and we will have someone in the research unit and at the MRI unit to help you test or raise/lower your glucose if needed. When you check in at the welcome registration, one of us will point out the times when your blood sugar will be important.

If you use an insulin pump or other technology, you will have to take it off if you are having an MRI. So, be sure you have extra infusion sets or sensor sites with you – one for your MRI and at least one for unexpected emergencies. Unfortunately, the pump and sensor companies don't give us samples of sets and sites much anymore, so I will probably not have a spare handy. If there are supplies that you don't have that you think you will need while you are at the clinic, please let Samantha know right away so we can see if it is possible to get those. Any medications that you normally take, you will still keep taking for the clinic. You don't need to adjust your insulin doses or anything like that.

If you are flying here, you may want to ask for a travel letter from your doctor so that you can carry all your supplies on the plane. The TSA has not been too picky about that recently, but you never know.

I am so excited that so many of you will be in St. Louis soon!

All the best to everyone,
Bess Marshall, MD (Marshall@kids.wustl.edu)
Pediatric Endocrinologist
Medical Director, WU Wolfram Syndrome Research Clinic

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fees, regardless of the reason. Also, please do not use any airfare vouchers you may have as we are not able to reimburse for those. **For those flying internationally, please make sure you use a United States air carrier. If you are unsure if the airline you are considering is a US carrier, please contact me.**

For those who are driving their own car, **mileage will be reimbursed at the standard mileage rate of \$0.20 for travel between your home and Washington University.**

The study will calculate the mileage and reimburse based on that number.

For those driving a rental car to the clinic, **the cost of the rental will be covered.** However, we are unable to cover the cost of gasoline or insurance for a rental car. Also, we will only be able to reimburse for an economical car (not a van or an SUV).

The clinic is not able to reimburse for meals during this time. Breakfast is available at the hotel and lunch for clinic participants and their proxies is provided at the clinic. Families are on their own for the evening meals.

Any questions regarding reimbursements can be directed to Beth at (314) 362-5041 or beatob@wustl.edu.

If in doubt, please check with us first!

Any other questions regarding the clinic should be directed to Samantha Ranck at blankens@wustl.edu or (314) 362-6514.

We are so excited to see everyone in July!



For more information or questions about the Community Conference please follow this link on the Snow Foundation's website for more information:
<http://thesnowfoundation.org/first-annual-wolfram-syndrome-community-conference/>