Whew! Another successful clinic under our belts! It was wonderful to see everyone who came. This year we conducted 27 MRI scans and 458 assessments! No wonder we’re tired! Those numbers will increase as we will also be hosting a mini-clinic in the near future for those who could not attend the July clinic.

Mark Your Calendars!
The dates for the 2020 clinic have been set:

**Clinic 1**
Orientation – Tuesday, 7/7/20
Clinic - Wednesday, 7/8/20 thru Friday, 7/10/20

Wolfram Syndrome Community Conference – Saturday, 7/11/20

**Clinic 2**
Orientation – Sunday, 7/12/20
Clinic - Monday, 7/13/20 – Wednesday, 7/15/20

Moving Mountains:
Parents and Families Driving Research in Rare Disease
   Wednesday, August 28 @ 7:00 pm-8:30 pm
   T-Rex Room, 5050 Oakland Ave, St. Louis, MO 63110

FREE and OPEN to ALL. Junior Academy members, middle and high school students welcome and encouraged to attend. Registration not required.

Stephanie Snow Gebel is the founder of the Snow Foundation and a voice for rare disease that is working towards a cure for Wolfram Syndrome and developing novel therapies for diabetes, vision loss, hearing loss, and neurodegeneration. Hear one family’s story and join a discussion about how you can motivate and engage the research enterprise. Washington University researchers, Fumi Urano, M.D., Ph.D., and Tamara Hershey, Ph.D., who have collaborated closely with the Snow Foundation, will also be present for the discussion.

RESEARCH UPDATE
with Dr. Hershey

Dear Wolfram Community,
The 9th annual WU Wolfram Research Clinic is done! It was great to see everyone, and those who could not attend were missed.

In my one-on-one meetings with each family, I was privileged to hear stories of successes and struggles, which helped me gain more insight into the complex daily lives of families affected by Wolfram Syndrome. I hope each family also learned that WU scientists, clinicians and staff are working hard to make progress towards halting or preventing the symptoms of Wolfram Syndrome. Here are a few specific things that I discussed with families: 1) the research clinic is funded until 2023; 2) blood samples that we take from family members and patients will be used to test for a marker of neurodegeneration, which could be helpful in tracking the effectiveness of treatments; 3) the research clinic is designed to be able to complement and merge with any future clinical trial held at WU.

After the clinic was over, a nice article about Wolfram Syndrome came out on the front page of the St. Louis Post-Dispatch, St. Louis’ largest daily publication.


Finally, I want to personally thank all of you for coming to St. Louis and participating in this study. We look forward to seeing all of you in 2020 for the 10th Wolfram Syndrome Research Clinic!

Sincerely,
Tamara Hershey, PhD (tammy@wustl.edu)
Professor
Scientific Director and Principal Investigator
WU Wolfram Syndrome Research Clinic
Dear Wolfram families,

Thank you to everyone who was able to make the trip to St. Louis last month – it is always a joy to see you! We have learned a lot already. We have added a question regarding choking and learned that this contributes to the Wolfram burden for almost all of you. Also, we had not previously appreciated how common headaches of various types have been. We will compare notes with our friends in Europe on these symptoms to learn more.

As always, feel free to call if you need letters for things such as insurance, school, or disability. I am a little slow right now catching up on things, but I’ll get them to you shortly!

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

Feedback Reports

We are in the process of gathering the collected data needed to complete the feedback reports. Once that data is received, it has to be scored, analyzed and compiled in to report form. This process takes a bit of time. You can expect to receive the feedback reports no later than October 1, 2019.

Questions regarding the clinic or clinic results should be directed to Samantha Ranck, MSW at (314) 362-6514 or blankens@wustl.edu

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

For questions about the Community Conference please follow this link to the Snow Foundation’s website: http://thesnowfoundation.org/first-annual-wolfram-syndrome-community-conference/