



WU Wolfram  
Research Clinic

# Washington University School of Medicine

## Wolfram Research Clinic Newsletter

February, 2018 Vol.10

### WU 2018 Wolfram Research Clinic

Yes, we're still waiting! No word yet on the final determination of funding for the 2018 Wolfram Research Clinic. But, as we said, we are proceeding with the planning. We wanted to share with you the final dates of the clinic and a couple of changes from previous clinics. **The official clinic dates are Wed., 7/11/18 thru Wed., 7/18/18.** The way it will work is that we'll have two groups thus two clinics; Clinic 1 and Clinic 2. **Clinic 1 will be held Wed., 7/11/18 thru Sun., 7/15/18. Clinic 2 will be held Sat., 7/14/18 thru Wed., 7/18/18.** Testing will take place on week days and the Wolfram Group meeting (formerly known as the "Saturday Session") will be held on Saturday, 7/14/18.

The change most frequently requested by the families on the post-clinic evaluations is more time built in to the schedule for families to socialize. In an effort to meet this request, we are working on setting up family socials at least one night during each clinic and one after the Wolfram Group meeting on Saturday. It will take a bit to find a space that fits our group but we want you to know that we heard your request and we're working on it!

#### Dates to remember:

Clinic 1 – Wed., 7/11/18 – Sat., 7/14/18

Wolfram Group meeting & Family Social – Sat. 7/14

Clinic 2 – Sat., 7/14/18 – Wed., 7/18/18

If you have a preference of attending Clinic 1 or Clinic 2 please let Samantha know sooner rather than later!

**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](mailto:rancks@npg.wustl.edu)

### RESEARCH UPDATE

Dear Research Clinic Families:

2018 has brought another publication from the Wolfram Research Group! This article, titled "Understanding activity participation among individuals with Wolfram Syndrome", was recently accepted to the *British Journal of Occupational Therapy*.

We wanted to learn more about the use of Occupational Therapy (OT) services in people with Wolfram Syndrome (WFS), and how participation in daily activities could be affected due to WFS symptoms. Participation in daily activities means being able to do the things we want and need to do, which leads to more independence and improved quality of life. Knowing the activities that are most important to those with WFS can help us develop better and more patient-focused interventions and services.

We asked research clinic participants questions about 1) their use of OT services in the past and present, 2) which daily activities were most difficult for them to accomplish, how important these activities are to them and how satisfied they were with their performance and ability to do the activity, and 3) which WFS symptoms affected these daily activities.

Overall, we found that only 22% of participants have ever used OT services. These services were most often for fine motor coordination and low vision. In addition, we found that daily activities identified as important were self-care (personal care, mobility), productive (household management, going to school or work), and leisure (recreation and social) activities.

Overall, we found that people reported reduced participation in daily activities when compared to a non-WFS group. In addition, participation was more restricted

over time as WFS neurological symptoms progressed. Adults had more difficulty with activities that were related to social activities and getting out in the community and children/teenagers had more difficulty with activities related to playing and school. See list on the next column for details. Participation in daily activities was most restricted due to walking/balance problems and loss of vision.

These findings raise awareness of the impact of WFS symptoms on daily life and point to neurologic and vision symptoms as being the most limiting aspects of WFS. OT professionals can provide self-management techniques and strategies for low vision or balance issues. These approaches may be of help to those not already using OT services.

For more information, look for this publication in the near future: Bumpus E, Hershey T, Doty T, Ranck S, Gronski M, Urano F, & Foster E. Understanding activity participation among individuals with Wolfram Syndrome. *British Journal of Occupational Therapy*. (In Press).

Sincerely,

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Thanks to Tasha Doty, M.A. and Samantha Ranck, M.S.W. for summarizing this paper.

### **Top Identified Problematic Activities in WFS participants:**

#### Children (Under 18 years):

- ✓ Bicycling
- ✓ Skating
- ✓ Skateboarding
- ✓ Team Sports

#### Adults:

- ✓ Driving
- ✓ Being in long-term relationships
- ✓ Going on dates
- ✓ Meeting new people
- ✓ Indoor exercise/ fitness

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### **CLINICAL CARE UPDATE**

Dear Wolfram families,

The big health news right now in the U.S. is this really horrible influenza epidemic. I hope none of you have been affected. With all the Wolfram features, adding the flu will be all the harder. The flu vaccine doesn't quite match up with the Influenza A this year. But, those who had the vaccine should have a shorter and less severe illness. Still, our ICU, like many others, is overflowing and our ER is double staffed and expanded out into the cafeteria. Flu A is finally beginning to wane, but, bonus round, flu B is now spreading. If you haven't had the vaccine, you still may benefit – talk to your doctor! If you find that one minute you feel normal and a few hours later you feel awful with muscle aches, fatigue, fever, etc. – call your doctor right away. The good news is that Tamiflu is effective to fight this flu A, but you have to start taking it right away after you develop symptoms. Don't go to the ER or an urgent care unless advised to, so as not to spread the flu around. Wash your hands a lot and stay away from sick people as much as feasible. Spring will be here soon!

All the best,

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