



WU Wolfram
Research Clinic

Washington University School of Medicine

Wolfram Research Clinic Newsletter

October, 2020 Vol.19

Special Topic

WOLFRAM RESEARCH CLINIC & COVID19

Dear Wolfram Friends,

We miss you so much and look forward to seeing you, even if only by Zoom. Samantha and all the team are geared up to collect as much data as possible this year. Thank you so much for being flexible!

Dr. Marshall, the clinic medical director, couldn't let the opportunity pass to remind everyone not to let down your guard on this coronavirus. Like a lot of your own states, Missouri is in the midst of a terrible rise in hospitalized cases of Covid19. The consortium of hospitals that serve the greater St. Louis area are now at 90% of capacity. All of the hospitals and everyone who works at them are worried about what comes next week. As our nurses and doctors are also falling ill, our capacity can fall even without more cases - even if there is a room with a bed, no patient can be in that bed without a nurse and doctor to take care of them. St. Louis' hospitals, even our children's hospitals, are close to being overwhelmed. Right now, hospitals are doing a great job of keeping people with COVID alive, but if too many people show up for care, that may change. As this is happening in so many states, there are not extra traveling doctors and nurses to fly in and save the day like there were when the areas around and in New York City were getting swamped. Who is here is all there is.

So, why tell you this bad news? First, to thank you all for everything you are doing to keep yourselves from catching this virus! Face masks definitely help and definitely do not hurt you. They protect both you and others near you. There is absolutely no question about the truth of either of those things. Staying away from other people also helps (at least 6 feet if you both have on a mask, more if not).

Special Topic, cont...

Second, a lot of our cases are coming from families or friends who don't live together but who are getting together for meals. Why? At least partly because you can't keep a mask on and eat. So, when those holidays or birthdays, or whatever celebration comes up, please consider a get together without eating or drinking, so masks can stay on. Or, even better, celebrate virtually.

High-risk groups for COVID-19 are:

- people aged 60 years and older;
- those living in long-term care facilities; and
- people with underlying health conditions, such as obesity, hypertension, diabetes, cardiovascular disease, chronic respiratory disease and weakened immune systems.

Please keep yourself healthy and help keep your hospital from getting overwhelmed! And let's hope this gets under control soon so we can all go back about our usual business!

This is one of our favorite explanations of why masks and social distancing work (in these simulations, you can substitute masking for social distancing and it works the same.)

<https://www.washingtonpost.com/graphics/2020/world/corona-simulator/>

If you have any questions about WU Wolfram Syndrome Research Clinic or Wolfram and the coronavirus, please call or send an email or Facebook message to Dr. Marshall, Dr. Hershey, Dr. Urano or Samantha Ranck. We are thinking of all of you every day,

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Wolfram Syndrome Research Clinic Update

Over the last few months we've presented you with a modified version of the Annual Wolfram Clinic. This revision saw a significant shift from primarily in-person interactions to electronic and virtual ones and it looks as if this is how we'll be collecting data through the end of the year. Based on the increase in the number of COVID cases in the St. Louis and surrounding areas, we are suspending the mini-clinics at this time. Instead, we will focus on collecting as much data as we can via questionnaires, sent to your home, REDCap surveys, and virtual visits.

At this time, the majority of you have completed the Consent and Pre-Clinic REDCap surveys and are now beginning to receive the REDCap Data Collection Survey as well as receiving communications about scheduling the virtual visits for cognitive, endocrinology, genetics, neurology, and psychiatry testing. Our goal for the six virtual sessions, if possible, is to schedule them all within the same week. So please take a look at your calendar and be on the lookout for us to contact you to set up these virtual appointments.



Of interest...



Wolfram syndrome 1 in the Italian population: genotype-phenotype correlations.

Rigoli L, Aloï C, Salina A, Di Bella C, Salzano, G, Caruso R, Mazzon E, Maghnie M, Patti G, D'Annunzio G, Lombardo F.

Pediatric Research. (2020) 87:456-462.

[www.https://doi.org/10.1038/s41390-019-0187-4](https://doi.org/10.1038/s41390-019-0187-4)

Family reflections: Wolfram syndrome - Lauren's story.

Gibilisco, P.

Pediatric Research. (2020) 87:609-610.

[www.https://doi.org/10.1038/s41390-019-0679-y](https://doi.org/10.1038/s41390-019-0679-y)

Feeling Anxious During this Uncertain Time?

Try these when you're feeling anxious or stressed:

- Take a time-out. Practice yoga, listen to music, meditate, get a massage, or learn relaxation techniques. Stepping back from the problem helps clear your head.
- Eat well-balanced meals. Do not skip any meals. Do keep healthful, energy-boosting snacks on hand.
- Limit alcohol and caffeine, which can aggravate anxiety and trigger panic attacks.
- Get enough sleep. When stressed, your body needs additional sleep and rest.
- Exercise daily to help you feel good and maintain your health.
- Take deep breaths. Inhale and exhale slowly.
- Count to 10 slowly. Repeat, and count to 20 if necessary.
- Do your best. Instead of aiming for perfection, which isn't possible, be proud of however close you get.
- Accept that you cannot control everything.
- Welcome humor. A good laugh goes a long way.
- Maintain a positive attitude. Make an effort to replace negative thoughts with positive ones.
- Learn what triggers your anxiety. Is it work, family, school, or something else you can identify? Write in a journal when you're feeling stressed or anxious, and look for a pattern.

And last but not least, talk to someone. Tell friends and family you're feeling overwhelmed, and let them know how they can help you. Talk to a physician or therapist for professional help.



For questions directly related to the Wolfram Syndrome Research Clinic, surveys, or virtual visits, please contact:

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