Special Topic

WOLFRAM RESEARCH CLINIC & COVID19

Dear Wolfram Friends,

As you are all entirely aware, the COVID19 pandemic is affecting all of us, directly or indirectly. We know that we will all be challenged, but we don't know how much and for how long. **For now, the Wolfram Clinic is planned for July (see last column for details).** With any luck, by that time we will be looking back on the pandemic with relief and will carry on the clinic as planned. However, we do not want to put you at even the slightest risk by traveling if the pandemic is not gone by July. So, **it remains possible that the clinic will need to be postponed and/or changed to a series of mini-clinics occurring throughout the year.** We will keep you all up to date on any decisions.

In the meantime, please take care of yourselves. The advice you are hearing from Dr. Fauci at the NIH is absolutely excellent advice: 1) stay away from crowds as much as possible, 2) wash your hands any time you touch any surface that someone else outside your immediate group might have touched, and 3) self-quarantine to minimize contact with other people as much as is feasible. You may also want to wear a mask in public if you must go out.

Everyone who lives with a person with Wolfram syndrome or is frequently in contact with a person with Wolfram syndrome must also follow all the same advice so that they don't inadvertently spread the virus to that person. We feel that Wolfram Syndrome symptoms could worsen the effects of COVID19 and vice versa, so **it is imperative that the entire family and close contacts follow precautions.**

Special Topic, cont...

Published reports about the range of symptoms in early COVID-19 infection help to self-monitor for symptoms of the disease. Consider taking these steps to monitor your health:

- Take your temperature with a thermometer twice a day—once in the morning and once in the evening—to monitor for low-grade temperature elevation (>99.9°F, >37.7°C). Note that the Centers for Disease Control and Prevention (CDC) continues to list a temperature of 100.4°F (38°C) as a criterion for suspected COVID-19 infection, but low-grade fevers are frequent in the early stages of illness.

- Watch for ANY of the following symptoms to increase detection of possible COVID-19 infection: cough, trouble breathing, fatigue or malaise, OR muscle aches (myalgia). If you have any of these symptoms, you should stay home and avoid interactions.

- The following symptoms DECREASE the likelihood you have a COVID-19 infection and are therefore reassuring: ear pain, sinus pain, and/or nasal congestion. If you have any questions or concerns about any symptoms, you should contact your healthcare provider.

For more information please see the CDC website at: [https://www.cdc.gov/coronavirus/2019-ncov/index.html](https://www.cdc.gov/coronavirus/2019-ncov/index.html)

If you have any questions about 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 during this worrisome time,

Dr. Bess Marshall: Marshall@kids.edu,
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WU Wolfram Syndrome Research Clinic
Use this practice to come back to the present moment – taking care of self and the needs of the moment, with loving attention.

- Consciously breath in/out – dropping the shoulders – sensing into the body,
- Calming the anxiety and fear,
- Letting go of tension in the body/mind,
- Trusting the precautions and advised modified working/relating methods,
- Patience with the uncertainty and the duration of this “time”,
- Accepting of the recommended changes (even if you don’t want them),
- Adding compassion for yourself and for others suffering from this pandemic, and
- Knowing this too shall pass.

At this “time”, we can realize how interconnected we all are; how the health and wellness of human beings everywhere impacts all of us and that we are all in this together.

What’s new from research clinic data...

Taste and smell function in Wolfram syndrome.

Developmental hypomyelination in Wolfram syndrome: new insights from neuroimaging and gene expression analyses.