

Fabry Focus on Health

Discussions with experts on health issues that affect the Fabry Community

Sponsored by Chiesi Global Rare Diseases

ISSUE 1

Understanding the Impact of COVID-19 in the Fabry Community



Maryam Banikazemi, MD, is Clinical & Biochemical Geneticist; Director, Fabry Disease Program; Co-Director, Lysosomal Storage Disorders Center at Boston Children's Health Physicians – New York Medical College in Valhalla, NY.

She answered these questions for us from her home, where she is advising many patients with Fabry on their risks and how to help stay safe during this time.

Q: What should patients with Fabry know about COVID-19? Is the Fabry community at an increased risk?

I have gotten this question a lot recently! According to the CDC, older adults and people of any age who have serious underlying medical conditions might be at higher risk for severe illness from COVID-19. This includes people who are 65 years and older, people of all ages with underlying medical conditions, particularly if not well controlled, including chronic lung disease or asthma, people who have heart conditions or who are immunocompromised. The CDC also states that people with chronic kidney disease and those who are on dialysis may be at increased risk as well, and I encourage those patients to connect with their treating physician.

Like all of us, I encourage the Fabry community to adhere to the guidelines set forth from the CDC regarding social distancing and handwashing, and, if you or a loved one believes they are having COVID-19 symptoms, isolate from others and connect with your doctor immediately.

Q: What about children diagnosed with Fabry?

While I have not seen data specific to Fabry, remember that even if you are young or otherwise healthy, you are at risk for COVID-19, and you can put others at risk as well if you do test positive. It's important that we all do our part to slow the spread of this virus including following the directions of local and state authorities.

Q: Should I continue receiving treatment for Fabry?

If you are receiving your infusions at home, my advice is to continue as long as you are feeling well and not experiencing symptoms of COVID-19. If you are, please check with your infusion nurse first before a home visit. If you receive treatment in a

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hospital, that's a different story. Depending on your other risk factors like age or other co-morbitities, it might be better to skip an infusion or ask if home infusion would be available to you. I recommend you consult with your treating physician, and together you can decide what is best for you.

Q: If I am on dialysis, should I continue to go to infusion centers?

It is important to continue receiving dialysis. Please contact your treating physician and transplant team to determine the best way to continue care.

Q: What about caregivers?

Just like patients with Fabry, caregivers should be following social distancing and other current guidelines. It is also important to take time for self-care, and to take time for things they enjoy – reading a book, cooking a special meal, taking a walk outside for fresh air and a change of scenery!

Q: What else can I be doing?

I know this is a hard time for all of us, and living with a disease like Fabry may cause additional anxiety. But there are things you can do to stay your personal best mentally and physically. I encourage you to make smart choices – do your best to stop smoking if you do, maintain a healthy diet, stay hydrated and remain active to the best of your ability. Take walks in your backyard and get fresh air. You can also consider taking zinc supplements. Zinc has been demonstrated to support the immune system and help control infection. It may also provide "add-on" benefit in rehabilitation of various pulmonary diseases including COPD and asthma.

Stay connected to the Fabry community and to other friends and family for sources of support. You are not alone, and I am hopeful that brighter, healthier days are ahead of us.

Chiesi Global Rare Disease is committed to connecting patients with information from experts and healthcare professionals. This information is intended for patient education and should not replace or modify the information provided by your treating physician.

