

# Fabry Focus on Health

Discussions with experts on health issues that affect the Fabry Community

Sponsored by Chiesi Global Rare Diseases

ISSUE 3

## Understanding COVID-19 Risks for People Living with Fabry Disease



**Raphael Schiffmann, MD, MHSc** is Medical Director of The Institute of Metabolic Disease at Baylor Research Institute.

Dr. Schiffmann has extensive experience in research related to the mechanism and treatment of neurometabolic genetic diseases such as lysosomal storage disorders, enzyme replacement therapy, and leukodystrophies.

**Q: What should Fabry patients understand about the risk of COVID-19 and their treatment?**

The guidance for all Fabry patients and for all people really is that you must take steps to minimize your risk. This includes following the latest guidance from the CDC and reputable health organizations about social distancing, hand washing, and staying at home. But for people who are being treated for Fabry, some additional precautions may be necessary. Whenever possible, infusions and other treatments should be transitioned to home. Patients should also consider using telemedicine options instead of in-person visits to connect with their care team. And if they need to visit a treatment center, they should take all necessary precautions to protect themselves.

**Q: What about patients who are participating in clinical trials?**

Every organization involved in clinical research will provide their own guidance to patients participating in their clinical trials. For example, our center stopped initiating new clinical trials, but we will consider adding patients to currently enrolling trials if it can be done with the appropriate levels of safety for the patient and our team. At this stage we should not be putting patients at risk for elective needs.

**Q: Are there special considerations for patients who are newly diagnosed with Fabry disease?**

Again, any decisions related to treatment should be made by the patient in consultation with his or her doctor. For some newly diagnosed patients, it may be relatively safe to initiate treatment as long as all necessary precautions are taken. And while we can't start treatment with infusions for new patients at home, it may be possible for some patients to continue treatment by switching to home infusions.

*continues on following page*

*"For people who are being treated for Fabry, some additional precautions may be necessary."*

*continued from previous page*

*“Any decisions related to the timing of treatment should be made with the treating physician.”*

**Q: *Should newly diagnosed patients delay initiation of treatment?***

Any decisions related to the timing of treatment should be made with the treating physician. With a chronic disease like Fabry, a delay of several weeks may not have a significant impact, but each patient is different. Any patients who do initiate treatment must be able to do so while taking all the recommended precautions to reduce their risk of infection with COVID-19.

**Q: *What about patients with neurological issues?***

This is a very important issue because it is possible that some drugs used to treat COVID-19 can interact with drugs used to treat Fabry disease. The medical team treating a Fabry patient for COVID must be aware of the risk of contraindication. When we talk about neurological issues in Fabry disease we generally mean either neuropathic pain/risk of a pain crisis or risk of stroke. The many challenges presented by COVID-19 can increase stress, which can put Fabry disease patients at increased risk of a neuropathic pain event. So stress reduction is a very important goal for patients. In addition, while there are no conclusive data, it is possible that some treatments for COVID-19 can increase the risk of cardiologic rhythm abnormalities and may present a risk of stroke in patients with Fabry disease who are already at higher risk.

**Q: *What should patients or a family member do if they are diagnosed with COVID-19?***

In addition to contacting your physician and following the course of treatment, the most important action is complete quarantine. If possible, anyone infected with COVID-19 in the home should be completely isolated from other family members – preferably on a separate floor or with as much distance as possible from other family members.

*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.*