



Fabry Focus on Health

Discussions with experts on health issues that affect the Fabry Community

Sponsored by Chiesi Global Rare Diseases

ISSUE 2

“People living with Fabry should try to hold any meetings with their doctor or other healthcare worker via telemedicine whenever possible.”

The Impact of COVID-19 on Treatment in Fabry Disease



Dr. Eric Wallace is a nephrologist and Medical Director, Telehealth; Co-Director, Home Dialysis, Co-Director, UAB Home Dialysis at UAB Health.

He is a specialist in the treatment of Fabry including issues associated with the impact of Fabry on the kidneys. He is also a leading advocate for the effective application of telemedicine in healthcare.

Q: *Dr. Wallace, what do you feel are some important general guidelines that people living with Fabry should consider related to COVID-19?*

While we don't have a lot of data or information about the impact of COVID-19 among people living with Fabry, it is important for all of us to follow the guidelines from the CDC and others about social distancing, staying home, hand washing and other protective measures. In addition, people living with Fabry should try to hold meetings with their doctor or other healthcare worker via telemedicine whenever possible.

Q: *Can you provide some guidance on how people should use telemedicine?*

Most providers are now making it possible for patients to interact with their care providers using email, phone and video teleconferencing. All patients should ask if this is an option with their provider. For people who will use this option, especially the first few times, here are some important things to keep in mind:

- > Make sure you understand how the technology works – it is a good idea to practice making the connection in advance of your appointment.
- > For video conferencing, make sure that your internet, computer or mobile phone are working and confirm the contact information.
- > Prepare for your appointment! Make sure you have a list of topics, symptoms and questions prepared in advance.
- > If you are using email or phone, make sure to use very descriptive and precise terms to discuss your health. For example, if you are in pain try to use words that explain the level and duration of your pain accurately.

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Q: *Should Fabry disease patients continue their infusions?*

All patients should discuss issues about their infusions with their doctors. For many, it may be possible to schedule infusions at home. And we should consider that in general the risk of COVID-19 is worse than the risk associated with skipping or delaying one infusion.

For home infusions, you should make sure that no one in your family is showing any symptoms of COVID-19 and you should confirm with the infusion nurse that he or she also does not have symptoms before they enter your home. If you have any concerns, it may be better to reschedule the appointment. This step is also essential to protect infusion nurses.

Q: *What about any special considerations for patients treated with ACE or ARBs?*

Treatment with ACE and ARBs provides cumulative benefit over many months or years, and so it is unclear what risks most patients may face if they stop treatment short term. While most patients use these options to treat proteinuria, in some cases it is used to treat hypertension. For those patients, stopping treatment could present a risk of a hypertensive emergency. All patients should discuss any decisions related to skipping or stopping treatment with ACE or ARBs with their physician.

Q: *What special considerations are there for transplant patients?*

The key for transplant patients is to stay home. They should limit visitors, even with family members. If they must visit treatment centers for laboratory tests, they should take the highest possible precautions to protect themselves. And they should ask their provider if they can meet for routine checkups and other visits using telemedicine.

Q: *What about for patients who are also diabetic?*

These same precautions would apply. Anyone who has another health issue in addition to Fabry should take extra steps to protect themselves including quarantine, no or limited visitors and only leaving the home when essential and while taking precautions.

Q: *What should patients do if they think they have symptoms of COVID-19.*

For all people who are symptomatic, they should NOT just go to the hospital. You should call the hospital first to confirm your symptoms and alert them that you are coming in. You should confirm the precise process the hospital uses for admitting COVID-19 patients and follow that process exactly. Make sure to let the hospital know that you have symptoms and that you are also living with Fabry disease. Let them know about any other health issues you are experiencing.

Q: *Are there any other issues that people should keep in mind?*

The job loss associated with COVID-19 means that many people might lose their insurance. It is important to contact your insurer and watch for any information from companies that manufacture your therapies to find out about support programs for patients who cannot afford their medications.

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.