

Dear Patients & Families,

On behalf of the URM Pediatric CF Care Center, we wanted to reach out and offer connection and support to our community. In light of COVID-19, these are challenging and anxious times. We encourage all of you to take time to care for yourself.

The messaging and information is changing quickly around COVID-19. As we figure out how impacted our CF community will be, please know that we share your concern and we are working diligently to determine the best approach to continue to care for our patients.

Your safety and well-being is our highest priority.

Steps to Stay Healthy

- Clean hands frequently with soap and water (wash for at least 20 seconds) or with alcohol-based hand sanitizer
- Avoid touching your eyes, nose, and mouth
- Stay hydrated and get plenty of rest
- Avoid close contact with people
- Work remotely whenever possible
- If you are sick, stay home
- Cover your cough or sneeze with a tissue, then throw the tissue in the trash
- Clean and disinfect frequently touched objects and surfaces
- Get your flu vaccine. It's not too late!

The best option for patients with cystic fibrosis is to practice social distancing to avoid contracting coronavirus even from people who show no signs as this could lead to significant health problems for CF patients. This means limiting play dates and interactions. We recognize you do this routinely with your CF care, but this needs to be even stricter than before. Send others to the store, not your child with CF.

In order to best serve the cystic fibrosis patients, we have made important and drastic changes to the care plan. Please keep in mind that we have the safety of your child at the heart of what we are currently doing. We will be limiting the patients coming to clinic. We are now offering TeleHome visits. These are phone call only visits. These calls will let us go over much of the information we review in a clinic visit, but we will not have the ability to check lung function or perform a physical exam. If you elect to participate in a TeleHome call, it will be processed through insurance. We do not have the ability right now to perform a telemedicine visit as an alternative to in-clinic visits. In addition, it may be from a different provider depending upon who is completing the appointments that day. If your visit is not for an urgent need, we can cancel and reschedule your appointment at a later date when hopefully the risk to our community has declined to a level that is safer for non-urgent visits. Marcy, Elle, and Kim are still here and are available by phone or MyChart.

If you do not already have MyChart, please consider signing up for access immediately; that is one of the ways for us to maintain communication with you.

IF YOU ARE HAVING SYMPTOMS SUCH AS RUNNY NOSE, SORE THROAT, COUGH, FEVER, OR DIFFICULTY BREATHING, BEFORE COMING TO YOUR APPOINTMENT, PLEASE CALL OUR OFFICE AT 275-2464 AND ASK TO SPEAK WITH A NURSE.

If you think you may be infected?

Call the UR Medicine COVID-19 support line at 1-888-928-0011 or your health care provider BEFORE visiting your provider's office, Urgent Care, or the Emergency Room.

The CF community is one focused on sharing, support and kindness. Please do reach out if you are struggling in any way. Many resources have already been identified and we are here for your support.

As we are all learning our new normal, you may have questions and maybe fears about what is happening. Here are some resources you may find helpful:

Great article for adults to help with talking to kids about coronavirus

<https://childmind.org/article/talking-to-kids-about-the-coronavirus/>

Article on managing anxiety/mental health

<https://store.samhsa.gov/product/Taking-Care-of-Your-Behavioral-Health-During-an-Infectious-Disease-Outbreak/sma14-4894>

Videos, audio, and show segments from Daniel Tiger to Sesame Street helping with way to keep kids safe and healthy

<https://www.pbs.org/parents/thrive/how-to-talk-to-your-kids-about-coronavirus>

<https://www.npr.org/sections/goatsandsoda/2020/02/28/809580453/just-for-kids-a-comic-exploring-the-new-coronavirus>

<https://www.brainpop.com/health/diseasesinjuriesandconditions/coronavirus/>

Free, printable social story about the Coronavirus

https://theautismeducator.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-.pdf?fbclid=IwAR1ulf42_sHE6gejRqSA3l-1z6FFpRvVpliZXzggPDDGiKpN5LJgK0oWIXM

Video/Self-help for anxiety resulting from Coronavirus

<https://vimeo.com/398138843/b4dc58fcf5>

Since we do not know when the infectious period for coronavirus will truly end, this may result in multiple rescheduled appointments or TeleHome check-ups. We understand that this is an incredibly stressful time for the CF community and the entire world. We are here to support you!

If you have concerns about any symptoms your child is having or regarding this letter, please contact the center (585-275-2464) so we can address these concerns. Please check our website to keep updated with further changes as they come.

Our thoughts are with you...

Sincerely,

Your Care Team