

July 2020

Volume 2 Issue 3

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Corona Virus (COVID-19) Update from the CFF

The Cystic Fibrosis Foundation (CFF) continues to closely monitor the spread of the coronavirus (COVID-19) throughout the United States and around the world. They are actively evaluating the potential implications for people with cystic fibrosis, as they are aware that the coronavirus outbreak is causing significant concern to those within the cystic fibrosis community. We encourage you to refer to the **Centers for Disease Control and Prevention (CDC)** for the most up-to-date information at www.cdc.gov/coronavirus.

The CDC has issued guidelines for people who are at higher risk:

- Stay at home as much as possible to further reduce your risk of being exposed
- Wash Your Hands
- Take everyday precautions to keep space between yourself and others
- When you go out in public, keep away from others who are sick and limit close contact
- Avoid crowds
- Clean & disinfect often
- Avoid cruise travel and non-essential air travel

Great Strides Update

The Bismarck chapter's Great Strides event has changed its date! Instead of happening in June, the event has been rescheduled to take place September 12, 2020 at Pioneer Park in Bismarck, ND. You can find more information and register to walk 2 miles or run a 5K (new this year!) online at <https://www.cff.org/Minnesota>.

Great Strides is the Cystic Fibrosis Foundation's largest national fundraising event. Registration is free, but walkers are encouraged to raise funds. Your support will help the CF Foundation pursue new therapies and provide vital support to meet the needs of the CF community.

Cystic Fibrosis Clinic Updates

We are changing our CF clinic dates! Starting in May 2020, CF clinic will be held every 3rd Thursday of the month instead of every 3rd Tuesday. Please make sure to mark the changes on your calendar. If you are unable to attend your CF clinic appointment in person, the CHI St. Alexius Heart & Lung clinic has video-telephone & online chat services available via Zoom. Just let your health care provider know if you wish to use this service.

Dr. Carla Zacher, our longtime CF clinic pediatrician, has taken another position and her last day with us was in May. We thank her for her time, care, and contributions to our CF team over the years - she will be missed!! Dr. Jane Grorud will be taking over as our new CF clinic pediatrician and CF program director. Welcome Dr. Grorud!

CF Patient Advocacy Group Update

Good news! **The Patient Advocacy Council will begin on July 9, 2020 at 6:00pm.** We will be mailing out information with instructions on how to participate. Meetings will be done via Zoom, with the meeting number & access code available to those who wish to participate. All Zoom meetings will be recorded & saved, and can be viewed at any time by those who cannot attend. If you wish to participate, please contact Christina, LMSW at cbond@primecare.org.

Summertime Hydration

With summer and higher temperatures upon us, it is important for people with CF to stay hydrated and stay safe in the sun. People with CF are at higher risk for dehydration and salt depletion through sweating— which can make it harder for the body to properly function. Issues that can arise are hyponatremia (low salt levels), bowel obstruction, heat stroke, and thicker secretions which in turn can make it harder to breathe & increase risk for infections.

What Can I Do?

- People with CF who exercise -- particularly in the summer heat -- should take sodium tablets or other forms of salt supplements to prevent hyponatremia. You can also enjoy salty snacks.
- Don't wait until you feel thirsty. Make it a goal to drink at least 64 ounces throughout the day. Caffeinated drinks don't count. An easy way to check if you are drinking enough is to check the color of your urine. If it is dark yellow, then you need to drink more fluids.
- Drink before, during, and after you exercise. If you are exercising in the warm weather, you will need to drink even more fluid than usual. When exercising, it is recommended that you drink 6-12 ounces every 20-30 minutes.
- Babies need extra fluids, too. Infants can get dehydrated more quickly than young children, so make sure to keep them hydrated and dressed in clothing that will keep them cool. Ask your care team if supplements are needed for your infant during the summer months.
- Wear sunscreen.
- Breathe easy. Make sure you are equipped with your inhalers and nebulizers so that you can keep the mucus loose and easier to shift in the heat. Don't forget about anti-inflammatories. It's a good idea to have these handy, as allergies can play havoc with your chest.

Get to Know Your Cystic Fibrosis Team!

Team Member: Heidi Shannon, FNPC:

I am a mom, horse owner and nurse practitioner. I enjoy learning new things and having new experiences.

1. Who would you want to play you in a movie of your life? Sandra Bullock
2. If you could choose to do anything for a day, what would it be? I would like to ride horse with friends in the Badlands.
3. Who would you want to be stranded with on a deserted island? My family and my horses.

Important Dates:

Cystic Fibrosis Clinic Dates

July 16, 2020

August 20, 2020

September 17, 2020

October 15, 2020

Patient Advocacy Council Dates: July 9th, 2020

Great Strides 2 Mile Walk & 5k Run:

September 12th, 2020 at Pioneer Park, Bismarck, ND

More information is available at

<https://www.cff.org/Minnesota>

Your CF Team Members:

Dr. Monica Paulo

Dr. Jane Grorud

Dr. Parveen Wahab

Deb Fueller FNPC

Heidi Shannon FNPC

Deb McPherson PharmD

Stephanie Friedt RRT.RPFT

Carrie Thom, RN

Samantha Risan RDN, LRD

Christina Bond, LMSW

34th North American Cystic Fibrosis Conference

October 22nd-24th, 2020: **This is now going to be held as a virtual-only event this year.**

More information is available at <https://www.nacconference.org/Home/>