

Heart & Lung Clinic

Cystic Fibrosis

CF Connection



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Care Center Data 2019

Each year every Cystic Fibrosis accredited care center is evaluated by reviewing certain criteria. The data is collected over a one year period, and is then compared to a national average and a national goal. This allows us to see where our center excels and where we may need improvement. The criterion reviewed includes:

- Evaluation of lung function of our CF patients through the FEV1

- Evaluation of nutritional status by measuring body mass index (BMI)
- Screening for diabetes and depression
- Meeting care guidelines require at least four clinic visits per year, two lung function tests and a throat or sputum culture on each patient

Our care center data from 2019 showed:

- The median FEV1 for our CF patients who are 18 years & older was 64%, while the National average was 68.5%. There is no 2019 data available on median FEV1 for our CF patients ages 6-12 years due to the limited number of patients at our CF clinic.
- 55.6% of our CF patients had quarterly clinic visits, while the national average was 62.8%. We encourage quarterly visits to help monitor and catch infections early which in turn can help prevent loss of lung function (which is measured via FEV1)
- 23.1% of our adult female CF patients had a BMI less than 22, while 24.5% of our adult male CF patients had a BMI less than 23. Having a BMI ≥ 22 for females and ≥ 23 for males has been correlated with better FEV1 and better health outcomes. Our clinic was below the national average, meaning many of our CF patients are at or above the ideal BMI. Successful implementation of nutritional therapy combined with advances in respiratory care, has led to increased life expectancy and improved quality of life
- 100% of our CF patients (12 years & older) performed a depression screen, compared to the National Average of 81.9%.
- 94.4% of our CF patients (12 years & older) performed an anxiety screen (GAD-7), compared to the National Average of 81.7%.

Our CF Clinic Bacterial Infection Rates:

The faulty gene that causes CF makes the body produce thick, sticky mucus due to salt imbalances. This mucus builds up in the lungs and can allow germs to thrive and multiply, which can lead to infection. Despite significant progress treating cystic fibrosis, infections remain a serious problem and can lead to worsening lung disease or death. Complication rate from infections for our CF patients has been low.

- 18.8% of our CF patients had *S. Maltophilia*
- 50% of our CF patients had *S. Aureus*
- 0% of our CF patients had *B. Cepacia Complex*
- 75% of our CF patients had *P. Aeruginosa*

More care center data can be found at cff.org

COVID-19 Vaccines

What vaccines have been approved for COVID-19?

- Two vaccines have so far been authorized by the U.S. Food and Drug Administration (FDA). The first, from Pfizer, was authorized on Dec. 11th. The second, from Moderna, was authorized on Dec. 18th. Submissions for additional vaccines are anticipated in early 2021.

Can I choose which vaccine to get?

- Initially, there will be a limited supply of authorized vaccines. When a vaccine becomes available, you will likely have only one option. That option, along with all other vaccines, must meet the same, strict criteria for safety and efficacy before it can be authorized by the FDA and offered to the public.

When can I get vaccinated?

- When authorized, the limited supply of vaccines will be distributed in phases. First in line will be people who are at greatest risk for exposure to the virus, including those working in health care settings or people living in congregate settings, like long-term care facilities. Next will be those considered frontline essential workers and people age 75 and older. This group will be followed by people age 65 and older and those with certain medical conditions that put them at high risk of developing severe COVID-19 illness.
- People with CF (age 16 and older), should consult their doctor to determine if they meet the criteria for this high-risk group as defined by their state authorities. Vaccine distribution is determined by the Centers for Disease Control and Prevention (CDC) as well as stated and local authorities.

Do I need both shots to be vaccinated?

- Currently, the authorized vaccine and those expected to be reviewed by the FDA, require two shots. Timing between the shots does vary and should be reviewed with your doctor. It is important that you receive both shots of the same vaccine to fully benefit from the protection that the vaccine provides.

What are the side effects?

- Although side effects from the different vaccines may vary, those that have been commonly reported in clinical trials include pain where the shot is injected, fatigue, muscle aches, chills, and fever. These side effects usually go away within a few days and are a sign that your immune system is working. Talk to your doctor about what you can expect, when to seek medical attention should you experience a bad reaction, and if you have had an allergic reaction to vaccinations or injectable therapy in the past.

More information about the vaccines can be found at cff.org, fda.gov, and cdc.gov

Get to Know Your Cystic Fibrosis Team!

Team Member: Dr. Monica Paulo, MD: I enjoy quilting and traveling to visit family.

- What is your dream car? Ford Thunderbird
- What is your favorite genre of books? Golden Age Mystery (1910-1950)
- If you could be on any TV game show, which one would it be? Password

Important Dates:

Cystic Fibrosis Clinic Dates

February 18, 2021
 March 18, 2021
 April 15, 2021
 May 20, 2021

Patient Advocacy Group Dates

Jan 14th, 2021
 March 11th, 2021
 May 13th, 2021
 July 15th, 2021

Your CF Team Members:

Dr. Monica Paulo
 Dr. Jane Gorud
 Dr. Parveen Wahab
 Deb Fueller FNPC
 Heidi Shannon FNPC
 Deb McPherson PharmD
 Stephanie Friedt RRT.RPFT
 Amber Burck, LPN
 Samantha Snow, RDN, LRD
 Christina Bond, LMSW

35th North American Cystic Fibrosis Conference

September 30th – October 2nd, 2021 in San Antonio, TX

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