

## Care Center Data 2020

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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

Our care center data from 2020 showed:

- The median FEV1 percent predicted for our CF patients who are 18 years & older was 79.7%, while the National average was 77%.
- There was no data available on the percent of our CF patients who have quarterly clinic visits. 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)
- 23.5% of our CF patients had a BMI less than 22 for females or less than 23 for males 20 years & older, while the National average was 36.2%. Having a BMI  $\geq 22$  for females and  $\geq 23$  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
- 88.2% of our CF patients (12 years & older) performed a depression screen, compared to the National Average of 71.3%

More care center data can be found at [cff.org](http://cff.org)

## CF Advocacy Group Update

Great news! The cystic fibrosis advocacy group is now back up and running after some technical difficulties. We apologize for any inconvenience the delay may have caused. Everyone in the CF community is welcome to join and participate in the advocacy group meetings.

This group was created as a way to help make sure our CF program is meeting the needs, goals, and values of our patients and families. The group also provides an environment where we can talk about a variety of topics and issues, and it allows people in the CF community the opportunity to network and seek or provide support to each other. This is a place where you can share your ideas that can help us, as healthcare providers, better serve our clients & community. Past topics discussed have included: Coping with changes & stress during the COVID-19 pandemic, lung transplants, and mental health.

## CF Advocacy Group Update Continued

Please see the “Important Dates” section on the bottom of this page for future CF Advocacy Group meeting dates. If you wish to participate, please contact Christina, LMSW at [christina.bond506@commonspirit.org](mailto:christina.bond506@commonspirit.org).

## COVID -19 Vaccines & Boosters

The CF Foundation supports and encourages all people with CF and their families to get vaccinated. All three authorized vaccines have been shown to be safe and effective, and can help prevent hospitalizations and death. Side effects have been rare and minor for most people. The Pfizer-BioNTech vaccine (COMIRNATY®) was recently authorized for children ages 5 and older.

It is also recommended that those with CF consider receiving a booster shot. A vaccine booster dose is an additional dose of a vaccine that helps to “boost” the immune system’s ability to better fight the infection. The FDA and CDC have authorized booster doses for all three vaccines for individuals who meet certain requirements.

Please talk with your CF care team if you have questions or concerns about receiving a vaccine or booster shot. For more information, please visit [cff.org](http://cff.org) or [cdc.gov](http://cdc.gov).

## Cystic Fibrosis Clinical Trials

Clinical trials are research studies performed to evaluate the effectiveness and safety of a new treatment on people. All current FDA approved therapies and drugs used to treat cystic fibrosis have used clinical studies in their research. This is an exciting time for people with cystic fibrosis to help with the development of new treatments. Not only are there several clinical trials of therapies to treat the underlying cause of CF, but there are also many trials to treat key symptoms of CF and improve quality of life. These include studies of antibiotics and anti-inflammatories to treat lung infections and inflammation, as well as treatments to improve nutrition and digestion. There have never been more opportunities to help develop new drugs for cystic fibrosis than there are today, and numerous individuals with CF are needed to participate in clinical trials.

If you are considering whether you or your child should participate in a research study, please talk with your CF care team. They can help answer any questions you may have, including how your or your child's safety will be protected, why you might want to participate, how to find a clinical trial, or direct you to helpful resources. More information on clinical trials can be found at [cff.org](http://cff.org).

Remember to  
get a flu shot  
this year!

### Important Dates:

#### Cystic Fibrosis Clinic Dates

December 16<sup>st</sup>, 2021  
January 20<sup>th</sup>, 2022  
February 17<sup>th</sup>, 2022

#### Patient Advocacy Group Dates

January 13<sup>th</sup>, 2021

#### Your CF Team Members:

Dr. Monica Paulo  
Dr. Jane Grorud  
Dr. Parveen Wahab  
Deb Fueller FNPC  
Heidi Shannon FNPC  
Leanne Saville PharmD  
Stephanie Friedt RRT.RPFT  
Kim Chumley RN  
Amber Burck, LPN  
Samantha Snow, RDN, LRD  
Christina Bond, LMSW