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## Care Center Data 2018

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

### Inside This Issue

- |     |                        |
|-----|------------------------|
| 1   | Care Center Data 2018  |
| 1&2 | Depression & Anxiety   |
| 2   | NACFC Update: Trikafta |
| 2   | H&L CF Team            |
| 2   | Important Dates        |

Our care center data from 2018 showed:

- The median FEV1 for our CF patients who are 18 years & older was 46.3%, while the National average was 69.4%. For our CF patients who are 6-12 years old, the median FEV1 was 92.2% compared to the National average of 96.8%
- 77.8% of our CF patients had quarterly clinic visits, while the national average was 61.3%. 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)
- 33.3% 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 45.8%. 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
- 100% of our CF patients (12 years & older) performed a depression screen, compared to the National Average of 81.9%

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

## Depression & Anxiety

The CFF (Cystic Fibrosis Foundation) has found individuals with cystic fibrosis and parents who take care of children with CF are 2-3 times more likely to experience depression, anxiety, or both compared to people in the general population. Research has shown people with depression and/or anxiety are less likely to perform their daily treatments, which can result in lower lung function, lower body mass index, or more frequent hospitalizations. Guidelines and screening tools have been developed to help CF care teams provide effective care for people with CF and their families with depression, anxiety, or both. The following are things you can do if you think you are depressed or have anxiety:

- Learn new coping skills – find effective ways to help manage stress
- Get Screened- If you have CF and are at least 12 years old or are caring for someone with CF who is age 17 years or younger, you can complete screening surveys including the PHQ-9
- Get Help- If the survey results suggest you are struggling with depression, anxiety or both, your CF team will recommend further evaluation and recommend treatments

## Depression & Anxiety Continued

What you can do to stay well and help improve your overall health and emotional wellness:

- Talk with somebody, preferably in person
- Spend time with people who lift your spirits
- Avoid alcohol and drugs
- Continue your CF treatment plan
- Practice good sleep habits
- Be physically active
- Join a support group – we at the Heart & Lung CF clinic are planning on starting a patient advocacy group, more information about it to be sent out soon!

## Important Update from the National Conference 2019: Trikafta

More than 5,000 cystic fibrosis researchers and clinicians from around the world gathered in Nashville, TN on Oct. 31 – Nov. 2 for the 33rd annual North American Cystic Fibrosis Conference (NACFC). One of the most exciting topics was the recent FDA approval of the triple-combination modulator, elexacaftor/tezacaftor/ivacaftor (Trikafta™) for people with CF ages 12 and older who have at least one F508del mutation. The approval of Trikafta means that more than 90 percent of people with CF could eventually have a highly effective treatment for the underlying cause of their disease. However, not all people with CF will receive the same benefit from this new therapy and other modulators, and some may experience side effects or drug-drug interactions.

People with two copies of the F508del mutation had a ten percent increase in lung function compared to treatment with the modulator tezacaftor/ivacaftor (Symdeko®), and people with one copy of F508del had more than a 14 percent increase in lung function compared to placebo. In people with one copy of the F508del mutation, Trikafta™ was also associated with significant improvements in sweat chloride, pulmonary exacerbations and quality of life. A study of Trikafta™ in children with CF ages 6-11 years old is currently underway.

To learn more about Trikafta or about the potential treatments the CF Foundation is exploring for people with nonsense and other rare mutations that do not respond to modulators, contact [cff.org](http://cff.org) or a member of your CF care team.

## Get to Know Your Cystic Fibrosis Team!

Team Member: Carrie Thom, RN:

I have been a nurse for six years. I love working with kids because they understand my sense of humor 😊. My fiancé and I just adopted a kitten named Geoffry.

1. What is your favorite movie? Dirty Dancing
2. Where is your dream vacation destination? London, England
3. What is your favorite food? Thanksgiving stuffing 😊

Remember to  
get a flu shot  
this year!

## Important Dates:

Cystic Fibrosis Clinic Dates

November 19, 2019

December 17, 2019

January 21, 2020

February 18, 2020

Patient Advocacy Council Dates TBA

34<sup>th</sup> North American Cystic Fibrosis Conference

October 22<sup>nd</sup>-24<sup>th</sup>, 2020 in Phoenix, AZ

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

Your CF Team Members:

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