

Heart & Lung Clinic

Cystic Fibrosis

CF Connection



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Care Center Data for 2021

Every year the H&L CF center collects and compiles data for the CFF foundation. This information is used to help us see how our clinic is doing compared to other CF centers around the nation. This allows us to see where our center excels and where we may need improvement.

A few of 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 2021 showed:

- The median FEV1 percent predicted for our CF patients who are 18 years & older was 81.5%, while the National average was 79.5%. Our median FEV1 percent predicted for our CF clinic was up almost 2% compared to last year.
- From data we collected, ~70% of our CF patients attended their quarterly clinic visits in 2021. 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)
- 37.5% 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 33.9%. 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 79.8%

More care center data can be found at cff.org

NACFC 2022

For the first time since the COVID-19 pandemic began, the 36th annual North American Cystic Fibrosis Conference (NACFC) was held in person in Philadelphia, PA. This event historically has drawn more than 5,000 researcher and clinicians from around the world. The conference provided numerous and exciting opportunities for attendees to listen and learn about developing treatments, as well as allowed them to share their thoughts, opinions, and discuss the various topics related to CF.

Several of the CF care staff at the Heart and Lung clinic at CHI St. Alexius Health had the opportunity to attend the conference this year. The team members who attended are excited to share with you what they learned!

Sam (Dietitian): I learned a great deal from the conference! I felt the classes I attended provided helpful information that will greatly benefit our CF patients. Some of the topics covered included the importance of reaching & maintaining good nutrition status, prevalence of malnutrition & how to diagnose, important vitamins and minerals to help support health & well-being (for instance, did you know that vitamin D plays an important role in bone health?), and using body composition as part of the nutrition assessment. They also discussed the ever-changing nutrition recommendations for those on CFTR modulators. If you have any questions pertaining to your nutrition you can always reach out to me via phone at 701-530-7877, email at samantha.snow@commonspirit.org or see me at your CF clinic visits ☺.

NACFC 2022 Continued

Leanne (Pharmacist): This was my first time attending NACFC in person and it did not disappoint! I cannot wait to share and implement the things I learned with our CF patients. The meetings I attended covered everything from pregnancy and lactation with modulator therapy, genetic counseling/fertility, antibiotics for multidrug-resistant organisms, vitamins/supplements, and much more. Did you know when shopping for vitamins/dietary supplements you should look for a USP Verified Mark on the label? It means that the dietary supplement contains the ingredients listed on the label, in the declared potency and amount. There was also a lot of great discussion regarding new research for patients who have rare CF mutations who currently don't qualify for modulator therapy. If you have any questions regarding medications/drug interactions/side effects please reach out to me via phone at 701-530-6929 or email me at leanne.saville@commonspirit.org. I look forward to seeing you all at your next CF clinic day visit!

Christina (Social Worker): I had a fantastic time attending my first NACFC. It is such an exciting time to be working with patients who have CF as well as the families who provide support. Through this event I expanded my knowledge of CFTR Modulators, was inspired by stories of hope and resilience, learned new techniques with Dialectical Behavior Therapy (DBT) and connected with social work professionals at clinics outside of North Dakota. I was able to learn about current studies that are taking place related to managing stress with a chronic illness, parenting while managing CF, the benefits of Physical Therapy related to female health with CF and the benefits of Palliative Care as part of the CF Clinic Team. I was able to learn about other CF Clinics that have active and progressive thinking Patient Advisory Councils. It is my desire to grow our support network for patients and families through this group as they begin to advocate for their medical care and needs within the clinic. Please reach out to me if there is anything I can do as your Social Worker. I can be reached at christina.bond506@commonspirit.org or by calling the Heart and Lung Clinic at 701-530-7542. As we head into the end of 2022 I look forward to making 2023 even better. I can't wait to see each one of you at your next clinic visit.

Deb (Nurse Practitioner): I have had the opportunity to attend the NACFC a few times in my career, and all I can say is the NACFC is always an incredible experience! It was great to be there in person again and see all of the amazing advances in research and treatments that has happened over the past couple of years, especially with the introduction of modulator therapy. The hot topics of the classes I attended included the significant decline in hospitalizations, increased life expectancy for those with CF, the significant(!) increase in pregnancies, the decreased number of lung transplants, and the overall less problems with low weight (body mass index) and poor nutrition. If you have any questions regarding your CF care, you can reach me via phone at 701-530-7542 or send a MyChart message.

You can also view the presentations and plenary sessions from the conference on the web! Please visit https://www.youtube.com/results?search_query=nacfc+2022

This is a small representation of what I took from the conference. There is so much to take in and remember, and so much excitement from the scientists as they reveal their breakthroughs!

And most importantly there is so much **HOPE** for the future!

Important Dates:

Cystic Fibrosis Clinic Dates

Jan 19, 2023
Feb 16, 2023
March 16, 2023
April 20, 2023

Patient Advocacy Council Dates

January 12, 2023 at 6:30 PM
March 9, 2023 at 6:30 PM
May 11, 2023 at 6:30 PM

Your CF Team Members:

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

37th North American Cystic Fibrosis Conference

November 2nd- November 4th, 2023 in Phoenix, AZ

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