

Cystic Fibrosis Center Quarterly Newsletter

Family Education Night

November 20, 2019, was our annual Family Education Night. A big thanks to everyone who participated and helped make this year's event a success!

Our guest speaker was Cindy George from the Cystic Fibrosis Foundation (CFF). She discussed the CFF's commitment to finding a cure for Cystic Fibrosis (CF). Her presentation covered the drug pipeline and the progress over the last 30 years in treatment options. She also shared the CFF's commitment to pursuing new treatments such as gene therapy.

You can find information on the drug pipeline at:

www.cff.org/Trials/Pipeline.

Couldn't attend family night? If you are interested in viewing a recording of the presentations at Family Education Night, please visit:

<https://osfiol.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=5a4a2de6-e28a-4b17-bd2f-ab0b017138bf>.

Our Website had a Makeover!

The CF Center website has been updated! It has new pages and a new, improved look.

Check it out at

osfhealthcare.org/childrens/services/pulmonology/cystic-fibrosis/



North American Cystic Fibrosis Conference

The 33rd annual North American Cystic Fibrosis Conference (NACFC) was held in Nashville, Tennessee, from October 30-November 2. The team was able to attend this year. Various highlights from the conference include:

- * Approval of the new modulator medication Trikafta
- * Retirement of the CEO of Cystic Fibrosis Foundation, Preston Campbell
- * Potential of gene therapy to benefit those with CF
- * Commitment to focus on needs of individuals with CF who do not qualify for a modulator

You can watch recordings of the NACFC sessions about the above topics at

www.nacfconference.org/pages/templates/archives.aspx.



Lung Transplant LLC

Your CF team traveled to St. Louis in November for the Lung Transplant Quality Improvement project. We met with other transplant and CF centers for networking and education. Barnes Jewish Hospital hosted us for the two-day event.

We presented our progress in our quality improvement efforts and learned what other teams are doing to improve lung transplant outcomes.

Education was a theme that came up often during the center presentations. CF centers need education from transplant centers about referral requirements. And those with CF need early and consistent education about lung transplant to be able to make a decision regarding their care.

Thanks to those individuals who filled out surveys for us during your clinic visit. Your feedback has been very helpful and much appreciated.

Tips for Hospitalizations

Sometimes a stay in the hospital is needed to treat pulmonary exacerbations. The goal of hospitalizations is to provide a level of treatment that cannot be achieved at home. Here are some tips to help make a hospital stay effective:

- Bring specialty medications with you. The hospital does not carry some medications that people with CF take. You will need to bring the following medications with you:

-CF Modulators (Kalydeco, Trikafta, Symdeko, Orkambi)

-Pertzye brand enzymes

-Relizorb cartridges for tube feedings

-Cayston and nebulizer

-Amikacin and nebulizer

-Arikayce and nebulizer

- The hospital provides DEKA's Plus multivitamin, Ensure and Pediasure shakes. If you/your child prefer other multivitamins and high calorie shakes, please bring these with you from home.

- The hospital has therapy vest wraps and compressors. If you want your/your child's full vest you can bring your home therapy vest and compressor.

- You/your child will have an assigned respiratory therapist who will be available during the admission, so if you have any questions, they will be available to assist.

- You know your/your child's medications and therapies the best, so be an advocate for yourself/your child if something does not seem right. However, treatments will be increased to four times a day instead of the usual two times a day.

- The hospital has specific airway clearance devices: Acapella, PEP devices, therapy vest and IPV. If you/your child use another airway clearance device, you can bring it from home.

- Hospital nebulizer cups are single patient use (disposable); therefore, the cleaning method utilized may be different from what you do at home.

- Hospital staff utilize the aseptic technique when handling the nebulizer and dispensing medication.

- If you bring your/your child's own nebulizer unit to the hospital, you need to bring your home method of sanitization.

- Please avoid setting any equipment on the floor during admission.

- You are allowed to bring personal items from home (ex. pillow, blankets and stuffed animals).

Exercise –Tips for Staying Active in Cold Weather

Winter time can be a difficult time to stay aerobically active due to the cold weather and at times being stuck inside. However, here is an option:

HIGH INTENSITY INTERVAL TRAINING! (HIIT)

- Make a list of activities: Such as crab walk, bear walk, jumping, step-ups, sit-ups, push-ups, lunges, etc.
- Pick at least four of the options
- Use a timer to do one activity for 20 seconds at a high intensity, rest for 40 seconds. Pointer: you could use a Tabata app to help with timing!
- Go on to the next activity for 20 seconds followed by a 40 second rest.
- Continue this pattern for at least 8 minutes.
- Over time increase active time, but keep the rest time between each activity.

It is important to do a little warm up and cool down consisting of stretches and walking in place, or something of the like.

There are a variety of HIIT videos on the internet if you would be more interested in following a specific program rather than putting one together yourself.

Trikafta

We are excited about the new modulator that was recently approved. As with most new medications, insurance approval and coverage takes extra time and work on the back end.

We ask for your patience as we work to get this medication covered. In some cases, it can take up to a few months to get approval from your insurance. We will let you know as soon as we have approval.

A big THANK YOU to our nurses for the extra time and effort they have put into working with insurance companies to get Trikafta covered.



Family Advisory Board

The Cystic Fibrosis Family Advisory Board is made up of a core group of Family Advisors who work in partnership with CF staff members, physicians, and social worker to assess the implementation of Patient and Family Centered Care guidelines, develop quality improvement strategies, and support families of the newly diagnosed.

MISSION

The Cystic Fibrosis Family Advisory Board is dedicated to strengthening collaboration between patients and families and the Cystic Fibrosis Care Team so as to enhance the Center's ability to serve with the greatest care and love.

PURPOSE

The purpose of the Cystic Fibrosis Family Advisory Board is:

- Strengthen communication and collaboration among patients, families, caregivers and staff
- Bring the patient/family perspective to hospital operations
- Improve patient safety, quality and delivery of care
- Provide feedback about the needs and experiences of patients and families
- Serve as a resource on a wide variety of issues, services, and policies
- Promote CF education and awareness to students, hospital staff and members of the community
- Provide insight about how to personalize the CF experience
- Members will be able to share their unique experiences and help us make a difference in the lives of other patients and their families



Happy Holidays!

All of us at the OSF HealthCare Children's Hospital of Illinois Cystic Fibrosis Center would like to wish you and your families a wonderful and safe holiday season!