

The Charlotte CF Family Advisory Board (FAB) is a group of Cystic Fibrosis parents and caregivers who provide feedback and partner with the Atrium Health CF Care Team to improve patients' and families' experiences and care during office visits and at the hospital. The FAB is committed to enhancing medical care and quality of life for children and adults with Cystic Fibrosis and their families.

Welcome to the first edition of our CF Seasonal Newsletter—a tool for you to know what's happening at your CF center and hospital, and to discover upcoming educational and connection opportunities.

Atrium Health Receives Accreditation by the Cystic Fibrosis Foundation

ARTICLE FROM ATRIUM HEALTH NEWS | LEVINE CHILDREN'S • April 3, 2019

Charlotte, NC is now home to an officially accredited Cystic Fibrosis Center for children and adults, as recognized by the Cystic Fibrosis Foundation (CFF). An accreditation is recognition of a center that is proven to maintain the strict quality guidelines as identified by the CFF and dedicated to improving the lives of cystic fibrosis patients and families in the community it serves. Among the many criteria to receive this accreditation is a commitment by the care team to continuously strive to improve the care of a patient by giving them better physical, mental, and family health.



“To say accreditation has been a goal of mine would be an understatement,” said Ashley Chadha, MD, specialty medical director, pediatric pulmonary and sleep medicine at Levine Children’s. “It is why I came to Charlotte. Atrium Health needed a Cystic Fibrosis Center and the patients and families deserved it. I could not be prouder of the hard work and commitment of so many within our team and community to make this happen.”

The impact for Levine Children’s patients will be immediate and long-lasting as Dr. Chadha and his multidisciplinary team—which includes a respiratory therapist, registered nurse, dietitian and social work support, along with Dennis Schellhase, MD, center director of the Atrium Health Cystic Fibrosis Program—build world class clinical care, education and research to support patients with cystic

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Atrium Health Receives Accreditation by the Cystic Fibrosis Foundation (cont.)

fibrosis. Under the leadership of Daniel Howard, MD, and Ken Coggins, MD, adults with CF will also continue to receive this high level of care as guaranteed by the accreditation.

This nationwide network of more than 130 centers has dedicated healthcare professionals who partner with people living with cystic fibrosis and their families to provide expert cystic fibrosis care and specialized disease management so that people living with the disease can live longer, healthier, more productive lives.

The Cystic Fibrosis Foundation funds and accredits care centers located at teaching and community hospitals across the country. Care centers also participate in clinical research. To maintain this accreditation, each center undergoes a review every year and periodic re-accreditation peer site visits to make sure each care center provides a consistently high standard of care.

With the boost of this accreditation comes an even greater desire for Dr. Chadha to do all he can to help his patients at Levine Children's— learning from them along the way.

"Cystic fibrosis patients teach us about resilience, dedication, commitment and fight," said Dr. Chadha. "Taking care of them reminds us all that our work is never done and our commitment has to be equally firm and strong to support and see our patients through this battle. I can only hope caring for them makes me a better doctor and person."

SAVE THE DATE

CF Education Night

Wednesday, May 22 • 6:30-8:00pm
Gorelick Auditorium • Levine Children's Hospital

We are launching quarterly CF Education Nights as an opportunity for caregivers in our local CF community to connect with each other while expanding their knowledge on various aspects of CF care. Guest speakers may include physicians or other members of our multidisciplinary care team, or experts on each quarterly topic.

Our first CF Education Night on Wednesday, May 22 will focus on the new CFF Accreditation. Learn what accreditation means for families and patients when they attend CF clinic, and discover what to expect in the upcoming months with the increased funding from the CFF. The evening will wrap up with Q&A.

Virtual Option available.

LEARN MORE & RSVP ONLINE:
charlotteCFfamilies.org/education-nights

FUN EASY RECIPE

Easy Peanut Butter Balls

Makes 12 Balls

INGREDIENTS

- 1/2 cup peanut or nut butter
- 1/2 cup oats
- 1/2 cup dry whole milk powder
- 1/4 cup honey (not for children less than 2 years of age)
- 1/4 cup chocolate chips or raisins/craisins

DIRECTIONS

- (1) Combine all ingredients together in a medium bowl.
- (2) Roll into golf-ball size balls.
- (3) Store in an airtight container in the refrigerator.

NUTRITION

- 1 ball with chocolate chips = 150 calories
- 1 ball with dried fruit = 130 calories

You can get almost 300 calories with 2 peanut butter balls versus 80 calories for a small granola bar!

May is CF Awareness Month

ARTICLE FROM CYSTIC FIBROSIS FOUNDATION • May 1, 2015

May is national Cystic Fibrosis Awareness Month. Across the country, thousands of volunteers will come together to raise awareness and tell our story of hope and progress. You can join them.

Consider These Facts:

- Approximately 30,000 children and adults in the United States have CF.
- More than 10 million Americans are symptomless carriers of the defective CF gene.
- CF used to be considered exclusively a childhood disease. Thanks to advancements in CF research and care, people with the disease are living into their 30s, 40s and beyond.
- The life expectancy for someone with CF has doubled in the last 30 years, but people still lose their lives to this devastating disease every day.
- The CF Foundation will not rest until they find a cure for all people with cystic fibrosis.

Take some time this month to educate someone about CF or encourage people in your community to get involved. It only takes a few minutes to make a difference.



The Cystic Fibrosis Foundation is a non profit donor-supported organization, with a mission to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatments, and ensuring access to high quality, specialized care.

The Carolinas Chapter - Charlotte Office of the Cystic Fibrosis Foundation has many opportunities for you to get involved. Your participation in any way will help the CFF achieve their mission – finding a cure for all people with CF.

For complete list of fundraising events & volunteer opportunities: charlotte.cff.org



Great Strides provides a fantastic opportunity for family, friends, students, and colleagues to come together and make a difference. There are many local walks coming up this month, and it's not too late to sign up! **Find a walk near you: cff.org/greatstrides**

ROCK HILL, SC
Friday, May 3rd
5:30pm

FRANKLIN, NC
Friday, May 3rd
5:30pm

BREVARD, NC
Saturday, May 4th
9:00am

ASHEVILLE, NC
Saturday, May 4th
3:30pm

MONROE, NC
Saturday, May 4th
10:30am

CHARLOTTE, NC
Saturday, May 18th
9:30am



Community Voice provides opportunities for people with cystic fibrosis and their family members to actively shape research and programs that affect the CF community. Because each person's experience is unique, it's critical for the CFF to hear from as many people as possible. Whether filling out a survey or participating in a focus group or committee, Community Voice members are helping to shape efforts for the entire CF community. The best part? It's a no-pressure way to get involved. You choose how much, or how little, you want to be involved and which topics are of the most interest to you.

Register today: cff.org/communityvoice

Teaching Your Child to Swallow Pills

By Jennifer Butcher, PhD, Pediatric CF Center Psychologist

ARTICLE FROM MICHIGAN MEDICINE CF CENTER NEWS & NOTES • Spring 2018

Learning to swallow pills can increase your child's independence, reduce the unpleasant taste of medicine, and save time. Many older children can learn to swallow several pills at once. Here are some tips to help your child learn this important skill.

What age? That depends. Some preschoolers can swallow pills and some teenagers struggle. One study showed that 91 percent of 6 to 11 year olds easily learned to swallow a small pill, but 9 percent needed more practice.



When to start? Start when your child shows interest or when taking liquid medications or opening enzyme capsules become a hassle. The summer before your child enters kindergarten is a good time to start. If they are not able to swallow at this age, take a break and try again in a couple of months. It is also a good idea to teach pill swallowing before there is pressure to succeed. A bad time to start would be right after your child is prescribed a medicine that is only available in pill form.

How do I teach my child?

1. Tell your child what you are doing and explain that the food that he/she swallows is bigger than pills.
2. Practice "chugging" water (drinking about two ounces of water in one breath).
3. Once your child can chug water, practice with candy. Start with very small candy, like cake sprinkles. Place the sprinkle on the back of your child's tongue. Tell him/her to take a drink while holding the head level.
 - If successful, move up slowly to bigger sized candies (mini M&Ms, Tic Tac).
 - If not successful, have him/her swallow a smaller size again, and then stop.
4. Practice over several days.
5. Praise your child and give small rewards that are tradable for a small prize (for example, five stickers = 15 minutes of tablet time).
6. When your child is ready to start with medicine, start with a small, chewable tablet first.

Can I try anything else?

- A pill swallowing cup: The pill is placed in the cup spout. When the child takes a drink, the pill slips out with the water.
- A Flavored drink: This may help to hide an unpleasant taste.
- A flavored throat spray: This product is similar to a flavored drink and may help the pill "slide" down the throat.

What if these techniques do not work? Most children can learn to swallow pills with parental support, but some need more help. Warning signs include children who are developmentally delayed, have chewing/swallowing difficulty, or experience high anxiety or a negative attitude about pill swallowing. If your child is still having trouble learning to swallow pills or if you have questions, please ask for help in the clinic. Nursing or psychology can help. One study showed that 95 percent of children who could not swallow pills learned to do so with behavioral support.

CONNECT WITH CHARLOTTE CF FAMILIES

Be the first to know about upcoming Charlotte CF Families events and Atrium Health CF Program announcements.
Join our email list at: charlotteCFfamilies.org/stay-connected



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