

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. Our CF Seasonal Newsletter is a tool for you to know what's happening at your CF center and hospital, and to discover upcoming educational and connection opportunities.



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5 Ways to Partner With Your Care Team

FOR FAMILIES MANAGING CYSTIC FIBROSIS...

Managing cystic fibrosis (CF) may feel like a balancing act where the demands of CF are just one part of a busy day. By sharing what matters most to your family, you can partner with your care team to help find balance. Consider using these tips to help you prepare for your clinic visits.

1 Ask for Help With Your Family's Care Plan

Share openly and honestly about your loved one's needs so your team can work with you.

- You are experts in what does and doesn't work in your loved one's life.
- If something's not working, share that with your team so you can come up with solutions together. Your team is there to help you.

2 Share What's Going on in Your Life

When life changes, your family's care plan may need to change too.

- Life can sometimes get in the way of doing daily CF care — and vice versa.
- Your team knows that things come up that impact how you are able to manage CF. Share what else is going on at home so your team can help you make positive changes.

3 Communicate Outside of Clinic

Your family manages CF every day, so why wait until clinic to ask questions?

- CF care happens in real time, so think about how you can reach out to your care team with new ideas or questions when something comes up.
- If something urgent is going on, connect with your team for advice and next steps.

4 Invite Other People Into Your Family's Care Planning

Managing CF doesn't have to be a solo activity.

- Managing CF can often be a family affair, so think about a team approach to care.
- Think about who else in your life can join the journey of managing CF and invite them to participate in care discussions at clinic.

5 Approach Difficult Conversations with Respect

You and your team are motivated by a shared goal: improving your loved one's health.

- Your team is there to help you manage CF, but it's not always easy to work together.
- Even when it might be difficult, think about how you all can work with your team to find a plan that works for your loved one's life and that will help them meet their medical goals.



33rd Annual NACFC this Fall

BY: REBECCA PRESLAR, CF MOM & FAMILY ADVISORY BOARD MEMBER



October 31st - November 2nd is the 33rd annual North American Cystic Fibrosis Conference in Nashville, TN. It is at this event every year where our CF care team learns the latest research and therapies, while connecting with other physicians & care team members across the world—all so they can come back to Charlotte and provide Atrium Health CF patients with the best care possible.

Did you know as parents you are able to participate in the conference? The CF Foundation provides virtual options for the plenary sessions (where the huge updates are announced) and select workshops throughout the conference. You can watch from the comfort of your own home and still benefit from the brains presenting live at the conference. Registration for virtual sessions will be announced closer to the conference, but you can learn more at www.nacfconference.org.

Our Care Team selects one member from the CF Family Advisory Board each year to attend the conference. Last year, I was privileged to experience NACFC! This Fall, FAB member, Kristy, will be attending the conference. You can hear her first-hand experience during our November 16th CF Caregivers Education Day. Check out the flyer on the back page & RSVP online at charlotteCFfamilies.org/caregiver-education-day.

CF Care Team Spotlight KENDRA BLEVINS



Hi, I am Kendra Blevins the new Cystic Fibrosis Nurse Navigator. Some of you may recognize me from the 10th Floor of Levine Children's Hospital. I grew up in the mountains of North Carolina in a small-town Lansing in Ashe County. I have been a nurse for about 5 years. I moved to Charlotte around 2 and a half years ago when I accepted the position on LCH 10. This is where I fell in love with the CF population and found my passion in nursing. I look forward to meeting all your amazing kiddos in clinic. Most recently, I graduated from Appalachian State University, in December of 2018, with my Master of Science in Nursing with a focus in Nursing Education. I love football season and cheering loudly for the Carolina Panthers.

You Know You're a CF Parent When...

By Lisa C. Greene

ARTICLE FROM HAPPYHEARTFAMILIES.COM

- You clean out your purse and the bottom is full of enzymes along with loose change and gum wrappers.
- You look at nutritional labels to find items with the most calories and fat instead of the other way around!
- Instead of hearing, "The dog ate my homework!" you hear, "The dog ate my nebulizer!"
- Your friends call you when their kid is sick instead of their pediatrician.
- You snitch salt packets and stash them in your purse, car and diaper bag.
- You want your kids to eat all of their dessert instead of all of their vegetables.
- The older your child gets, the heavier you get!
- You are a mobile germ control unit.
- Your refrigerator and kitchen counters look like a pharmacy.
- You call hamburgers, french fries and milk shakes "health food."
- Your highly-trained ears can hear another person coughing from a mile away.
- You know more about the medical system than the clerk on the other end of the phone.
- You ask for a DNA test on your child's first date.
- When the cashier looks at your grocery cart filled with high calorie, high fat food and says, "Umm... there's a good class on nutrition next week..."
- People think you're nuts when you say "Wow! That was a good cough!"
- You find yourself discussing private bodily functions over the family dinner table.
- As a short order cook and gourmet chef, you know the secret to tasty food: FAT!
- You know more medical terminology than some professionals.
- When you go out to dinner on a date night, you still get out the enzymes!
- You can flush a pic line faster than a nurse.
- You are a walking fat and calorie counter.
- You are a doctor, nurse, lawyer, pharmacist, accountant and child psychiatrist all in the same body!
- You make nebulizer soup in a large pot every night.
- You can care for your special child better than anyone else in the universe.



INGREDIENTS

- 1 stick butter (8 Tbs.)
- 1 1/2 c. sugar
- 2 eggs
- 2 cups flour
- 1 tsp. salt
- 1/2 tsp. baking soda
- 2 medium bananas, mashed (about 1 c.)
- 1/2 tsp. vanilla
- 1/2 c. sour cream
- 2 c. chopped walnuts or pecans

SUPER Banana-Nut Muffins

These muffins are a great breakfast idea for busy school mornings. Whip up a batch on the weekend, and have a healthy, high-calorie breakfast in no time!

DIRECTIONS

1. Preheat oven to 400 degrees F.
2. Mix together the butter and sugar, then the eggs.
3. Mix together the dry ingredients first, then add to the butter/sugar/egg mixture.
4. Next add the banana, sour cream, and vanilla.
5. Last add the nuts.
6. Place the mixture into a non-stick pan that has 6 LARGE muffin tins.
7. Bake for 25- 30 minutes or until browned.

NUTRITION

Calories 835 • Fat 47gm • Carbohydrate 97gm • Protein 14gm

NOTE: If you're not the baking type, you can also buy pre-made and pre-wrapped muffins in many flavors from companies like Otis Spunkmeyer or Kirkland brand (Costco), which have 500-600 calories each. Also, muffins from fast-food restaurants such as Starbucks or Dunkin Donuts are good high-calorie choices, and usually have about 450-500 calories each. Yum!

Don't Forget Your Flu Shot!

ARTICLE FROM CFF.ORG

In people with CF, the flu can lead to a severe lung infection, like pneumonia. If you have the flu, you may feel worse than you do with a typical lung infection or pulmonary exacerbation. Contact your CF care center or doctor's office as soon as you feel flu-like symptoms. Antiviral medications used to treat people for the flu are most effective if taken within 24 hours of the start of symptoms. These drugs may help lessen your symptoms or how long you are ill.

Flu symptoms include:

- Body aches and headache
- Fatigue
- Fever and chills
- Increased cough
- Sore throat

HOW IT SPREADS

Like many germs, the flu virus can spread by direct and indirect contact and through the air. To reduce the risk of getting and spreading the flu, it is important for you and everyone around you to follow infection prevention and control practices like hand washing and getting vaccinated.

REDUCING THE RISK: THE FLU SHOT

The flu vaccine or "flu shot" can reduce the risk of getting the flu by helping the body fight off or increase its immunity to the flu virus. It is best to get the flu shot early since it can take around two weeks after vaccination for the body to build up its immunity to protect itself against the flu virus. The best time to get the flu shot is in September through October, but getting vaccinated in December or January is still helpful as flu season can last until spring.

CF Patient Spotlight LUKE NEWMAN



Luke Newman

- Age 5
- Favorite food: McDonald's cheeseburgers
- Favorite activity during nebs-PT: Watching anything with Transformers or American Ninja Warrior
- Favorite outdoor activity: Going to the park
- What I am really excited about: Going to big kids school(kindergarten)!
- What do I want to be when I grow up? An Astronaut
- Most recent accomplishment: Lost his first tooth
- CF mutation: deltaF508

" Luke is our first and only child and he is the light of our life! We learned about his CF diagnosis 2 weeks after his birth thanks to newborn screening. While it was a very difficult time, we are now so thankful he was diagnosed early. The team at Levine's has been great, and Luke loves going, except for labs....not a fan of needles. We try to keep our lives as "normal" as possible while staying engaged in lots of activities while maintaining our treatment routines. We are excited about the advancements in treatment therapies and the growth of our clinic. We hope to continue to share our journey and support fellow CF families."

— Brian & Leisa Newman

The Importance of Caring for the Caregiver

ARTICLE FROM CFF.ORG

Common Stressors:

- New CF diagnosis
- Time-consuming treatments
- Lung infections
- Lung function tests and results
- High calorie requirements for maintaining weight
- Sputum culture results
- Hospitalizations
- Doing home IV antibiotics
- New feeding tube
- CF-related diabetes diagnosis
- Managing insurance

Living with cystic fibrosis or caring for someone with CF is stressful. Symptoms, treatments, and associated costs can be a source of worry for people with CF and their caregivers. Caregivers may include biological, adoptive or foster parents, grandparents, partners or spouses, extended family members, or even close friends who participate in the regular day-to-day care of someone with CF.

At times, CF can make daily activities, like going to work or school, socializing with family and friends, and managing finances, more difficult for either the individual with CF or their caregivers. Over time, these stressors can have a negative impact on mental health and well-being for families affected by CF.

Practicing self-care, or activities intended to take care of our physical, emotional and spiritual health, build personal resilience and play an important role in managing CF care successfully. Effective self-care prevents stress from becoming overwhelming and may protect caregivers from developing more persistent symptoms of anxiety or depression.

Research shows that caregiver depression and anxiety can negatively affect CF patients' health outcomes, including lower body mass index (BMI), decreased lung function (FEV1), increased frequency of hospital admissions, increased child anxiety and depression, and decreased child quality of life.

When caregivers practice self-care, it sets a good example for their child or teenager with CF. This is one of the best ways caregivers can teach a child or teen with CF to value their health and wellness as they move into adulthood.

Taking time for self-care is not selfish; it is necessary to help and care for others well. When practicing self-care seems the most challenging, it is often when these activities are most needed. Receiving help and support is a healthy and necessary part of managing the complexities of CF.

SAVE THE DATE: Our next CF Education Night will feature a CF psychologist and focus on Mental Health.

Mark your calendar for Wednesday, February 26, 2020 at 6:30pm in Gorelick Auditorium (LCH).

Learn more and RSVP online: charlotteCFfamilies.org/education-nights

EXAMPLES OF SELF-CARE

PHYSICAL	EMOTIONAL	SPIRITUAL
<ul style="list-style-type: none"> • Eat a healthy, balanced diet • Get 7-8 hours of sleep each night • Exercise a few times a week (brisk walking, jogging, biking, etc.) • Limit screen time • Get outdoors a few minutes a day for fresh air and natural light • Focus on preventive medical care in addition to CF care 	<ul style="list-style-type: none"> • Stay connected to supportive people • Delegate tasks to others • Ask for help before feeling overwhelmed • Express emotions through healthy outlets • Learn to recognize and stop negative thinking patterns • Establish boundaries; say "no" • Schedule time for fun and use humor • Celebrate life milestones 	<ul style="list-style-type: none"> • Make time for quiet reflection • Practice gratitude • Keep a journal • Attend a worship service • Allow time for play and creativity

You're Invited

CF CAREGIVER EDUCATION DAY

SATURDAY, NOVEMBER 16, 2019

10:00am - 1:00pm • Gorelick Auditorium • Levine Children's Hospital

Agenda

- 9:30am Continental Breakfast & Vendors
- 10:00am Welcome*
- 10:15am NACFC Recap
- 10:45am Break & Vendors*
- 11:00am Medical Hot Topic – Triple Combination Modulators
- 11:30am Transitions & CF R.I.S.E.
- 12:00pm Lunch & Vendors*
- 12:15pm CF Panel Discussion

*Raffle Items During Breaks!

WHO SHOULD ATTEND?

CF Caregiver Education Day is for more than just parents! Anyone who cares for a Cystic Fibrosis patient will benefit from the education and vendors, including: grandparents, spouses, relatives and friends.

**Event is not designed for children, Also please note, due to risk of cross-infection, cystic fibrosis patients may not attend this event.*

VIRTUAL OPTION AVAILABLE

Event will be live streamed for caregivers unable to attend & for adults with CF to participate. RSVP as a "virtual guest" and login instructions will be emailed.

WHERE TO PARK?

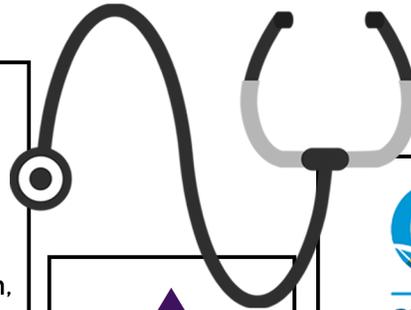
Please park in the visitor parking deck located near the main hospital entrance. Gorelick Auditorium is located in the LCH lobby. Parking will be validated at event.



Continental Breakfast & Boxed Lunch Provided!



Panel Discussion with CF Care Team, CF Parents & Adult CF Patient



Medical Updates



Hear the latest in CF research and developments announced at the 2019 NACFC, plus a first-hand account of a CF parent attending the conference!



Learn what's happening with Triple Combination therapies, including preliminary FDA results and eligibility.



Discover how children with CF can begin transitioning towards self-care with help from our new certified program.

Vendors



Hillrom™



... And More!



NEED MORE INFO?

Email elizabeth.jorgensen@atriumhealth.org



RSVP BY NOVEMBER 8, 2019

charlottecffamilies.org/caregiver-education-day

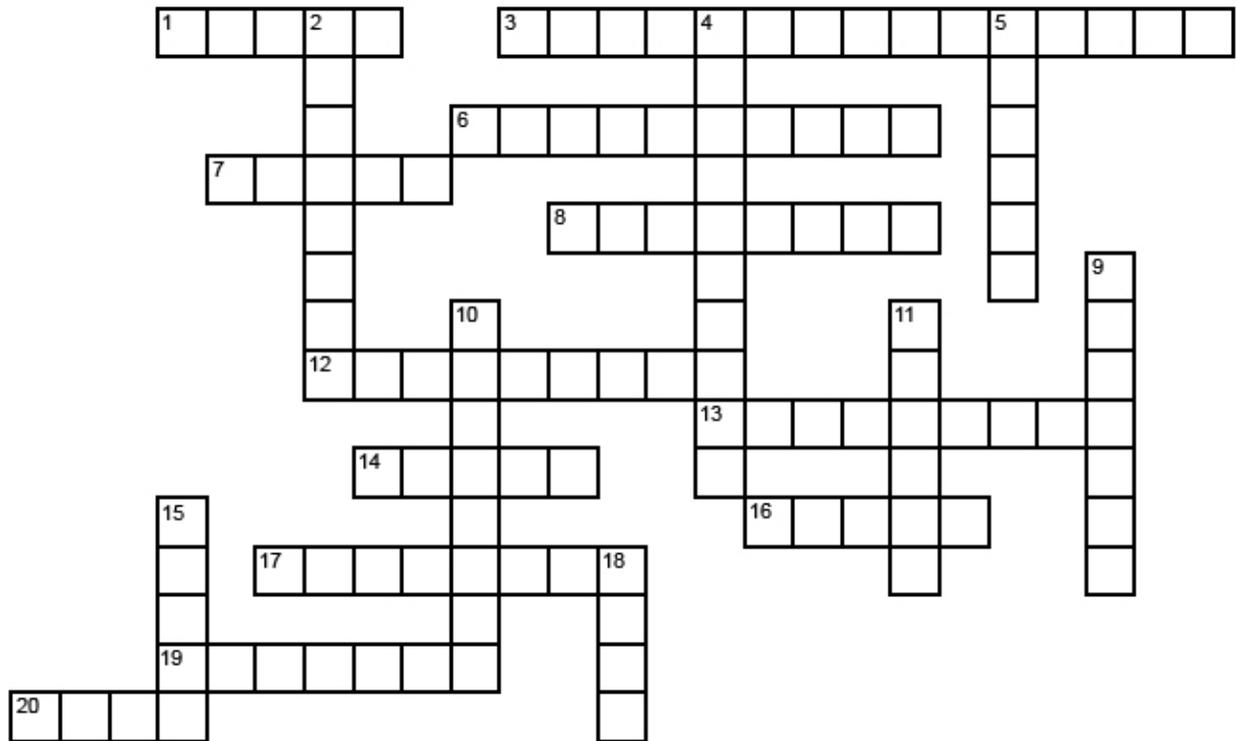


ATTEND VIRTUALLY?

Please RSVP & Login Instructions will be Sent by Email

CFunky Crossword

TAKE THE CHALLENGE



ACROSS

- 1 A small tube inserted through the abdominal wall directly into the stomach, which can be used to give extra nutrition.
- 2 A large airway within the lung, which branches from the trachea.
- 3 The process of dislodging mucus so that it can be more easily coughed out of the lungs.
- 4 A medication that treats an infection.
- 5 The backward flow of the stomach contents up into the esophagus, which can cause heartburn or respiratory symptoms.
- 6 The term for coughing up of blood.
- 7 Major organ affected by CF.
- 8 A disorder that results when the pancreas produces decreased amounts of insulin, resulting in high blood sugar levels.
- 9 A substance that is essential in small quantities to our nutrition
- 10 Organ that aids in the digestion of food and regulation of blood sugar levels.
- 11 Mucus which is coughed out of the lungs
- 12 The standard test for determining if someone has CF.
- 13 A viral illness that occurs in the winter and causes fever, body aches, and respiratory symptoms.
- 14 A sticky, slippery substance that is produced by the lining of the nose and airway, which it moistens and protects.
- 15 A large organ in the abdomen, which filters blood and produces bile.
- 16 A hollow area in the skull connected to the respiratory tract, which can become infected.
- 17 A single-celled organism that can cause lung disease when it enters through the mouth or nose.
- 18 This allergy to the mold *Aspergillus fumigatus* can cause respiratory problems for people with CF.
- 19 Substances produced in the pancreas, which are needed for properly digesting food nutrients.
- 20 Mutations in this gene lead to CF.

DOWN

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