

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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Focus on Mental Health

Have you heard about the flight safety instructions that are given before a flight takes off? It goes something like this: "In case of an emergency if a child is seated beside you, put on your own air mask before helping to put an air mask on the child." The CF Foundation says parents of a child with cystic fibrosis can focus so much on caring for their child that they do not notice when they are beginning to have problems themselves. The build-up of stress and anxiety can be gradual and, if you're not paying attention, can cause larger problems before you realize it. Taking steps to take care of yourself can help you, your child, and the rest of your family. The CF Foundation gives some of the following tips that can help you avoid becoming overwhelmed:

- Respond to bills, medication instructions, and insurance forms as they arrive.
- Learn as much as you can about CF if you haven't already. Connect with other parents of children with CF for general support and advice on how they handle their responsibilities.
- Make time for yourself and others who are important to you, such as your spouse or partner, friends, and family. Do something you like together with your spouse or significant other (do anything not CF-related together, such as watching a movie).
- Eat a healthy diet.
- Practice good sleep habits. Do your best to get enough sleep. Go to bed and wake up on a consistent schedule. Avoid staying in bed when you are not sleeping.
- Get outside or in nature each day. Try taking a walk.
- Find one person you feel comfortable confiding in who will let you vent without being judgemental.
- Do something you like on your own (start small).



As parents it is difficult to make time for ourselves but it is important for our children to see us taking care of ourselves as an example to them. You sacrifice so much and take such great care of your kiddos. You deserve a huge pat on the back and permission to put yourself first every now and then!

Maintaining Your Nebulizer

Owning a nebulizer means that you'll need to perform some basic cleaning and maintenance to keep it in working order. Compressor filters eventually become dirty and channels get clogged. Also, the tubing, masks, and mouthpieces will degrade over time. It's essential to clean your nebulizer, replace parts, and check for dysfunctional components to make the most of your nebulizer treatments. Here are some of the basics:

Always follow manufacturer's instructions for cleaning your nebulizer, parts, and accessories.

Do not use nebulizer masks longer than recommended, even if they seem fine. Some accessories, like disposable masks, are meant to be thrown away after 5 to 7 uses, while regular child and adult nebulizer masks are meant to be used for up to 6 months. Plastics degrade over time and your treatment benefits may decrease with a mask used longer than directed. Upon replacement, make sure to purchase one that's compatible with your nebulizer.

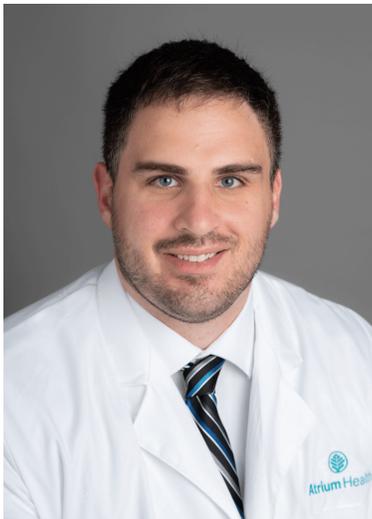
Change the nebulizer filter as recommended in your owner's manual, or when it appears grey or dirty. Failure to change the filter will make your compressor unit work harder than it should and will eventually cause the unit to fail.



Reminders

- Clean the outside of the tubing and replace it when recommended.
- Replace any part or accessory that appears cracked or worn.
- Keep extra tubing, mouthpieces, and masks on-hand in case they become damaged or worn.

CF Care Team Spotlight



Meet Dr. Zack Held!

Dr. Held joined Levine Children's Specialty Clinic in September 2019, where he will be splitting his time between Cystic Fibrosis and Nephrology. He will be available for consults in clinic as well as outpatient therapy sessions in his office.

Before coming to Charlotte, Dr. Held studied at Suffolk University (Mass.) where he was also an adjunct professor. He has previously worked at the Bradley Children's Hospital in Rhode Island and UMASS Memorial Medical Center in Worcester, MA. We are very excited to welcome Dr. Held to our Levine Family!

The Importance of Sleep

With the beginning of a new year, it is a great time to establish a bedtime routine and make sure your kids are getting enough sleep. It is important for their mental and physical health, safety, and quality of life. Adequate sleep duration and quality help your kids concentrate, learn, react quickly, make decisions, create memories, and function optimally. Children with CF are at greater risk for sleep disruptions due to coughing, medication side effects, illness, infection, shortness of breath, and pain (to name just a few). For these reasons, it is vitally important to discuss sleep with your CF care team. According to the National Sleep Foundation, sleep needs are highly individual. Babies needs as many as 16 hours of sleep a day, children ranging from 10-12 hours of sleep per night, while teenagers - 8-10 hours. It is important to pay attention to your child's needs by assessing how they feel on different amounts of sleep.

Tips from the experts for better sleep

- Find your child's ideal bedtime and allow them the full amount of sleep needed.
- Make bedtime a special time. Read and interact with your child.
- Establish a simple routine. It should not last too long and should take place primarily in the room where the child will sleep. It may include a few simple, quiet activities such as a light snack, bath, cuddling, saying goodnight and a story or lullaby. The kinds of activities in the routine will depend on the child's age. Children like to know what to expect.
- Put them to bed at the same time every day. It is best to keep the same waking times, meal times and nap times daily.
- Create a quiet, dark, relaxing, and cool environment in their bedroom. Sound machines and nightlights can be helpful.
- Avoid electronics or TV as it will over stimulate the brain and make the transition to sleep more difficult.
- Avoid caffeine in the afternoon and evening hours.



Luke's Favorite Home-Made Hot Chocolate

DIRECTIONS

Makes 1-2 Servings

1. Mix and heat your half & half and vanilla to your desired temperature.
2. Then, add in your cocoa powder and sugar, whisk or stir vigorously.
3. Place your preferred amount of mini marshmallows inside your favorite mug.
4. Then carefully pour your hot chocolate into the mug over the marshmallows.
5. Gently sprinkle a small amount of salt on top of your marshmallows for a sweet and salty treat.

Don't be afraid to add any of your other favorite mix-ins! Caramel, chocolate shavings, or sprinkles are fantastic additions.

INGREDIENTS

- 2 Cups of Half & Half
(or your preferred dairy,
the more calories the better!)
- 1 teaspoons of vanilla
- 2 tablespoons of cocoa powder
- 2-3 tablespoons of sugar
- Sea salt (to your preferred taste)
- Mini marshmallows and/or caramel,
chocolate shavings, sprinkles

Do you know??

- 1) Which member of your CF Team helps you to find new ways to gain wait?
A. Nutritionist
B. Physical Therapist
C. Doctor
D. Nurse
- 2) Which member of your CF Team teaches you how to do airway clearance?
A. Social Worker
B. Doctor
C. Resident
D. Respiratory Therapist
- 3) Which member of your CF Team prescribes medicine to keep you healthy?
A. Doctor
B. Nurse
C. Nutritionist
D. Radiologist
- 4) Which member of your CF Team can help you cope with having CF?
A. Nurse
B. Physical Therapist
C. Social Worker
D. Pharmacist
- 5) Body systems affected by cystic fibrosis include:
A. Sweat glands
B. Pancreas
C. All of these
D. Lungs
- 6) The recommended diet for someone with cystic fibrosis is:
A. Low fat diet
B. High calorie and high fat diet
C. High fat diet
D. High calorie diet
- 7) Approximately how many people in the United States have CF:
A. About 5,000
B. About 30,000
C. About 50,000
D. About 100,000
- 8) What is the most prevalent gene mutation in CF?
A. F508del
B. G551D
C. R117H
D. R553X
- 9) Which is true about most people who have CF?
A. Lung infections are common
B. Thick, sticky mucus helps germs grow in the lungs
C. Lung infections can cause damage to the lungs over time
D. All of the above
- 10) True or False? Exercise can help improve your lungs.

Answers: 1) A 2) D 3) A 4) C 5) C 6) B 7) B 8) A 9) D 10) T



Upcoming Events

FEB 01 GALA Fashion Breathes Life

6:00 PM, February 1, 2020 Bryon's SouthEnd Carolinas - Charlotte
Welcome to Fashion Breathes Life - a charity gala benefiting the Cystic Fibrosis Foundation. This year's event promises to be one you won't soon forget, filled with fashion, food and fun.

FEB 22 CHEF'S DINNER An Evening with Master Chefs

5:30 PM, February 22, 2020 Quail Hollow Club Carolinas - Charlotte
Master Chefs is an elegant evening of dining, aromatic wine and charitable giving where top chefs from throughout the Southeast gather in one kitchen to prepare seven seated courses of culinary delights. This event has raised more than \$5 million helping to find a cure for cystic fibrosis (CF), a rare, genetic, life-shortening disease.

MAR 07 FINEST Guys and Dolls Charlotte 2020

6:30 PM, March 7, 2020 Hilton Charlotte Center City Carolinas - Charlott
The Guys & Dolls Auction Gala is Charlotte's premier event for young professionals. Coming up on its 20th year, the event features fabulous Live Auction Packages put together by dedicated "Guys" and "Dolls" up for auction to the highest bidder. Packages include fantastic trips, shopping sprees and many more surprises, all auctioned in spectacular fashion at the black-tie gala in Uptown Charlotte.

APR 25 HIKE Charlotte Spring Xtreme Hike 2020

April 25, 2020 Appalachian Trail: 19 East to Iron Gap Carolinas - Charlotte
The Charlotte Chapter of the Cystic Fibrosis Foundation is proud to present the 2020 XTREME HIKE to Cure Cystic Fibrosis. In just one day, a dedicated team of Xtreme Hikers will hike the 30.1 mile stretch of the famed Appalachian Trail in an effort to raise funds and awareness for the CF Foundation's mission to find a cure for cystic fibrosis.

APR 25 GREAT STRIDES Monroe 2020 Great Strides

9:00 AM, April 25, 2020 TBD Carolinas - Charlotte
For 30 years, Great Strides - the Cystic Fibrosis Foundation's largest national fundraising event - has supported the Foundation's mission to cure cystic fibrosis and raise awareness for this rare, genetic, life-shortening disease that makes it difficult to breathe and shortens lives. Great Strides provides a fantastic opportunity for family, friends, students, and colleagues to come together and make a difference in the lives of people with CF.

