



One Medical Center Drive
P.O. Box 9214
Morgantown, WV 26506
Phone: 304-293-1201
Fax: 304-293-1216

Clinic Location:

2nd Floor
Physician Office Center
Ruby Memorial Hospital

Your CF Care Center

Kathryn Moffett, MD, Center Director

Cassandra Arevalo-Marcano, MD, Assoc Peds Director

Ameesha Fogle, RN-Nurse Coordinator

Kristen Myers, MSW,LGSW-Social Worker

Ryan Juel, MS,RD,LD - Dietitian

Brittany Sines, RRT-Respiratory Therapist

Melissa Knopp-Pharmacist

Janelle Mentrikoski, PhD-Psychologist

Tammy Clark, RN-Research Coordinator

Dave Felton, PT,DPT -Physical Therapist

Mountain State CF 411

Office Hours 8:00am-4:30pm Monday-Friday 304-293-1201

On Call- 24 hours Monday-Sunday 1-800-982-8242

Your phone calls are **very important** to us. If your child is sick, please call as soon as possible so we are able to contact a physician and schedule an appointment. If it is after hours and you are unable to wait until morning please call the 1-800 number or go to your nearest emergency room.

Your CF Physicians



Dr. Casandra Arevalo- Marcano
Center Director
Pediatric Program Director
Pediatric Pulmonary



Dr. Kathryn Moffett
Associate Pediatric Program Director
Pediatric Infectious Diseases

Your CF Care Team



Ameesha Fogle, RN
Nurse Coordinator



Kristen Myers, MSW, LGSW
Social Worker



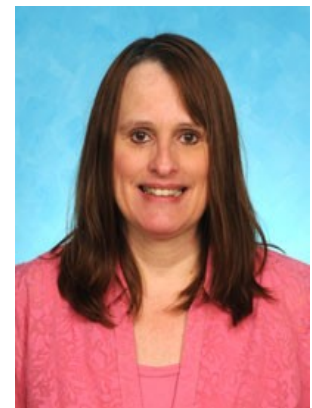
Brittany Sines, RRT
Respiratory Therapist



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Dietitian



Dave Felton, PT, DPT
Physical Therapist



Tammy Clark, RN
Research Coordinator



Janelle Mentrikoski, PhD
Psychologist



Melissa Knopp,
PharmD
Pharmacist

Important Numbers

Ameesha Fogle **Pediatric Nurse Coordinator**
304-581-1659

Ryan Juel **Dietitian**
304-581-1956

Kristen Myers **Social Worker**
304-293-1208

Brittany Sines **Respiratory Therapist**
304-293-4011

Tammy Clark **Research & Clinical Trials**
304-293-5264

Dave Felton, **Physical Therapist**
304-598-4118

WVUH Specialty Pharmacy (Allied)
304-285-7216

Phone Calls

When to call:

1. If your child is sick with cold symptoms, increased cough, congestion, stomachaches, chest pain, cramps or issues using the bathroom, please call your CF center.

Things to Mention When Calling:

Symptoms– How long has this been going on?

What have you done for this previously?

Any Allergies?

Your Pharmacy Contact Information

2. Prescription Refills:

Before each and every clinic visit, please check and see if you there are any medications you may need filled in the next few weeks and ask for these at your visit.

We do not want you to run out of your medications and often prior authorizations for certain medications can take 48-72 hours.

We would like to know as soon as possible that you are needing refills. Waiting until last minute often results in missing medication for days at a time.

Please allow 48-72 hours for prescription refills requests. These can be made in clinic or over the phone by calling 304-293-1227.

3. **Paperwork, Letters & Forms:** If you need school forms, FMLA paper work, or other letters/documentation, please call us in advance and let us know. We are able to have this letter prepared for you at your next clinic visit.

You can request this by calling Kristen at 304-293-1208.

What to expect at your clinic appointment



The Routine Follow Up Visit– these are scheduled every 2-3 months and more often if you are sick. At this visit, we will check your weight, height, nutritional status, examine you, and collect a throat or sputum culture. Beginning at 4-5 years old, you will perform a breathing test called PFTs to assess your lung functioning. Besides seeing your physician, you will also see a dietitian, social worker, respiratory therapist, mental health specialist and nurse. Bring medications that your child is taking with you or a list you may have. Sometimes we may ask you to bring the device you are using for chest physical therapist, for example your vest.

The Annual Visit– Once a year, your child will have an annual visit which can often be a little bit longer. We will monitor you for every aspect of your CF. During this visit blood work will be ordered and any shots needed will be given. If you'd like to save time and get your blood work done before your clinic appointment please contact Erin to make sure your orders are placed and you can get your blood work done before your appointment.

Annual Blood Work:

Complete Blood Count (CBC) to check for anemia and the bodies response to infection, and Prothrombin Time (PT) to check for clotting function.

Liver & Chemistry to check liver health, nutrition, and early diabetes.

Vitamin levels to check for inadequate absorption of fat soluble vitamins that can lead to complications.

Other Tests to Expect Every Year:

Chest X-Ray

At 10 years old: Oral Glucose Tolerance Test (GTT)

Research

Potential new drugs are being tested at care centers across the United States by people with CF of all ages. Your care center is a great source for news about current CF research.

Most CF care centers have research team in charge of clinical trials. The research doctors (usually called "investigators") and research coordinators can provide you with information about current clinical trials and answer all of your questions. The research team enrolls people with CF in clinical trials and works closely with volunteers throughout the clinical process.

There are always new opportunities to participate in clinical trials. Be sure to ask your or your child's CF doctor or nurse or a research coordinator to keep you informed.

More information is available on the CF Foundation website, www.cff.org. Here, you can find the CF clinical trials in your area via an online search tool. The tool allows you to narrow your search- for example, by age, lung function, or type of therapy- and provide you information on clinical trials that you can then discuss with your CF care team.

You can also sign up to receive clinical trial email alerts, which keep you informed of new clinical trials and trial results.

To find a clinical trial:

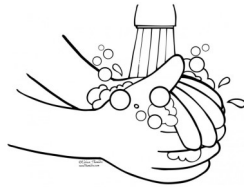
Visit www.cff.org/Find or clinicaltrials.gov

**Call the CF Foundation Toll Free Clinical Trial Hotline
at 1-800-FIGHT-CF**

Call Tammy Clark at— 304- 293-5264

Infection Control

In Clinic: When you arrive, be sure to **use a mask** when in the waiting room or walking the halls of the Physician Office Center (POC). **Handwashing** is the best way to prevent the spreading of germs. You are able to use hand sanitizer in the waiting room. There will also be a sink and soap where you can wash your hands once you enter your exam room. You will be placed into **contact isolation** (all caregivers wear gowns & gloves (& masks)).



In The Hospital: Regular **handwashing** is the best way to stop the spread of germs. Always wash hands after guests/staff are in your room. Be sure to make sure staff is also washing their hands. You are to **wear a mask** anytime you leave your room.. All CF patients are on **contact isolation** once hospitalized. Ask your nurse about these precautions.

And **REMEMBER:** CF patients are NOT to be together indoors (a waiting room, on elevators, or any gathering place). Stay 6 feet apart at all times from other CF patients outside.

Hospital Stay: What you need to know



Before You Go:

1. **Be honest** with your child— your child needs to trust you and be prepared. There may be some things that are uncomfortable or hurt. It is best to prepare them for this. Reassure them that this is okay and it is okay for them to be upset.

2. **Explain Why**— It is important for your child to understand why they are coming into the hospital and what may be needed while they are in the hospital. Give them the opportunity to ask questions. It is okay to say I don't know and contact someone who may be able to give them a better answer. The hospital stay is just temporary and is what is best for them. It is important to let them know the hospital is a place to help you from a young age. Children often gauge their reactions based on their parents. If they notice you are upset, they may often become scared. It is best to have open conversations about their CF care and possible CF hospitalizations from a young age.

3. **Make Arrangements**— Notify their school (collect school work), notify and make arrangements with your employer (if you need FMLA— find out about that before entering the hospital, sometimes it's good to know your works policy before ever needing to go into the hospital), and arrange for care for other children/family members.

4. **Pack Bags**— Often children are most comfortable when they bring things that are important to them. For example, a favorite blanket, a movie, an iPod or a game they enjoy to play.

Be Prepared:

- Child Life will be a very important part of your stay. Ask for them to come to your child's room. They will help with distraction during procedures, and bring games & books to your room.
- We are a teaching hospital. The Pediatric Hospitalist team will care for your child on 6SE and the pediatric Intensive care Unit. The CF team will be consultants and see your child every day. We work jointly and we value that communication is vital for the hospital stay to be successful.
- **PICC Lines**— During a hospitalization your child may require a PICC line (a peripherally inserted central catheter.) **Why are PICC Lines Used:** They are used to give you IV medications or fluids. Because the tube is so small and flexible, the line can last several weeks to months, which means fewer needle pokes and less pain for your child.

Communication tips while in the hospital:

A hospital stay can be stressful, especially if it's your child's first time. Good communication can help you feel more comfortable and confident in your child's care. Here are a few tips:

- You may not always see your child's primary Cystic Fibrosis physician at the hospital. Rest assured that the doctor who treats your child will work with your CF doctor to agree on a treatment plan
- Doctors and nurses will "round" in your child's room each morning to discuss the plan for the day. It's always okay to ask questions if you don't understand something or if the plan has changed
- If you can't be at the hospital during the morning "round" ask for a phone update
- WVU Medicine is a teaching hospital. You may see medical students and residents, along with the staff physician. Sometimes it may feel like you are answering the same questions several times. Try to be patient, as this is part of the process. The team is working together to deliver the best care possible for your child.
- All doctors and nurses will wash their hands when they enter your child's room. It's always okay to ask them to wash again.

Suggested items to bring

- Any medications that the hospital doesn't have (e.g. Orkambi, Kalydeco, Symdeko, Trikafta)
- A pillow and blanket to make your child's room feel more like home
- Cozy slippers so you and your child don't have to walk barefoot
- Favorite games, books, crafts, music, etc. for entertainment
- Sweat pants, T-shirts, extra clothing
- Personal toiletry items (toothbrush, toothpaste, hairbrush)

Your Child's Age Matters: When they are young they may not understand hospitalizations and it may not seem to mind hospitalizations. As they get older it is important to continue to have open communication regarding hospitalizations. Encourage them to ask questions. Adolescents need to be treated with respect and should be a part of the conversation when it comes to hospitalization. At some point they will be living on their own and will need to take initiative when it comes to their CF care. Encourage them to pay attention to how they are feeling and to be aware of their body and speak up when they are not feeling well. Encourage your teenager to stay connected to their friends/classmates through their cell phones and internet as that will make the process of going into and leaving the hospital the easiest on them. Discuss with them about having visitors and when is a good time.

Nutrition

Nutrition is very important for those with CF. There is a direct positive correlation between lung functioning and body weight. It is important to have a well balanced high calorie diet with fat, protein, and salt to give your body what it needs to grow. Normal weight gain helps build strong lungs and will preserve your lung function. Good nutrition also helps keep your immune system strong to fight off infections you may encounter. It is important to not only add calories to your diet but to add calories that are beneficial for you.

Pancreatic Enzymes: Enzymes last approximately 45-60 minutes and should be taken BEFORE eating. If you snack often, you may need to take more enzymes. Be sure to talk about this with your dietitian. Enzymes are not needed when you are eating/drinking things that do not have fat or protein in them. For example, drinking juice, sports drinks, flavored ice, hard candy, etc. You do need to be sure to take enzymes when drinking milk, protein shakes, or high calorie shakes. Enzymes should never be crushed. Be sure to keep enzymes at room temperature.

Vitamins and Minerals: You will be prescribed a special "CF" Vitamin. This has water soluble sources of fat soluble vitamins A, D, E & K. CF patients require this due to malabsorption as a result of pancreatic insufficiency despite enzyme replacement.

Tips For Adding Extra Calories: Eat small frequent meals with enzymes. Take advantage. Drink nutritious drinks with protein for example supplement shakes, milkshakes, and milk. Keep when you are feeling hungrier. For example if you are most hungry in the morning, have a larger meal at this. High calorie snacks handy so they are easy to grab on the go. Have your child help with food prep at a young age so they understand what they need to be eating. Praise your child for eating well, and do not force feed as that can create your child to resent food. Check out chef4CF.com for a high calories recipes!

Respiratory

1. **Bronchodilator & Hypertonic Saline**— Albuterol or Xopenex can be mixed with your hypertonic saline into the same neb cup. This should be the first treatment given. This allows your airways to dilate and the hypertonic saline to work on thinning out the mucus in your lungs.
2. **Pulmozyme** – This should be given next; in a separate neb cup. This medication needs to be kept in the refrigerator until time for use; and should never be mixed with any other medication.
3. **Airway Clearance** – Vest, CPT, Acapella, etc. This is done while you are doing your nebulizer treatments. Remember to do your Huff cough, too!
4. **Inhaled Antibiotics** – Tobi, Cayston, (aztreonnam), Colistin, Ari-kayce (amikacin). These are to be done in a separate neb cup and AFTER any and all airway clearance. You want these drugs to settle in your lungs and not be “shaken up” by your vest or any other mode of airway clearance.
5. **CLEAN & DISINFECT** your nebulizer supplies after every treatment! This is most important of all. Ask us how to best keep your

If you have any questions, please do not hesitate to call me!

Brittany Sines, RRT

Respiratory Therapist

304-293-4011

Respiratory Care

Vests

Hill-Rom – The Vest and The Monarch

Customer Service: (800) 426-4224

<https://respiratorycare.hill-rom.com/>

RespirTech – InCourage System

Customer Service: (800) 793-1261

<http://vest.respirtech.com/patients.php>

AffloVest

Customer Service: (888) 711-1145

www.afflovest.com

(typically serviced through Mountaineer Home Medical (304-225-6290))

Websites for purchasing nebulizer sets out of pocket:

www.justnebulizers.com

www.nebology.com

Both of these websites offer the PARI LC Plus neb sets at a low cost.

Nebulizer Care in the home

Caring for your nebulizer equipment is a crucial aspect of your respiratory care! Here is a remind of the correct way to clean and disinfect your equipment per the CFF guidelines.

Step 1: Clean!

Wash with warm soap and a mild detergent

Step 2: Disinfect!

Disinfection options:

- A. Boil method: place nebulizer cups and mouthpieces in boiling water for FIVE minutes
- B. Bottle Sterilizer: A baby bottle/breast pump sterilizer has become a popular method for disinfecting nebulizer equipment. There are many options you can use; pictures and information provided below.
- C. Dishwasher: Place neb cups and mouthpieces on top shelf and run the dishwasher on “sanitize” cycle. This is probably the least common method, simply because it takes longer and is not as efficient.

Step 3: Dry!

Allow all parts to air dry before storing



Philips Avent Microwave Steam Sterilizer
Approximately \$15 (Amazon.com)



Munchkin Latch Sterilizer Bags (180 uses)
Approximately \$7 (Amazon.com)

Notes

