

Cystic Fibrosis



A NEW WAY TO SUPPORT FAMILIES

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview of a specific disability, special health care need, or other major topic**
- **Current practices**
- **Personal Stories**
- **Family support, advocacy and services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.



Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.

Overview: Cystic Fibrosis

Cystic Fibrosis (CF) is a disease passed down through families. It is part of everyday life for over 30,000 people in the United States¹, and about 1,000 new cases are found every year.² CF changes the way a person's lungs and digestive system work, making the body produce thick, sticky mucus. When this mucus is in the body, it is harder to break down food. The nutrients in food, like fats, proteins, and vitamins, leave the person's body without being used. CF also clogs the lungs and puts those with the disease at risk for getting serious lung infections.

People with CF can have different symptoms, such as:

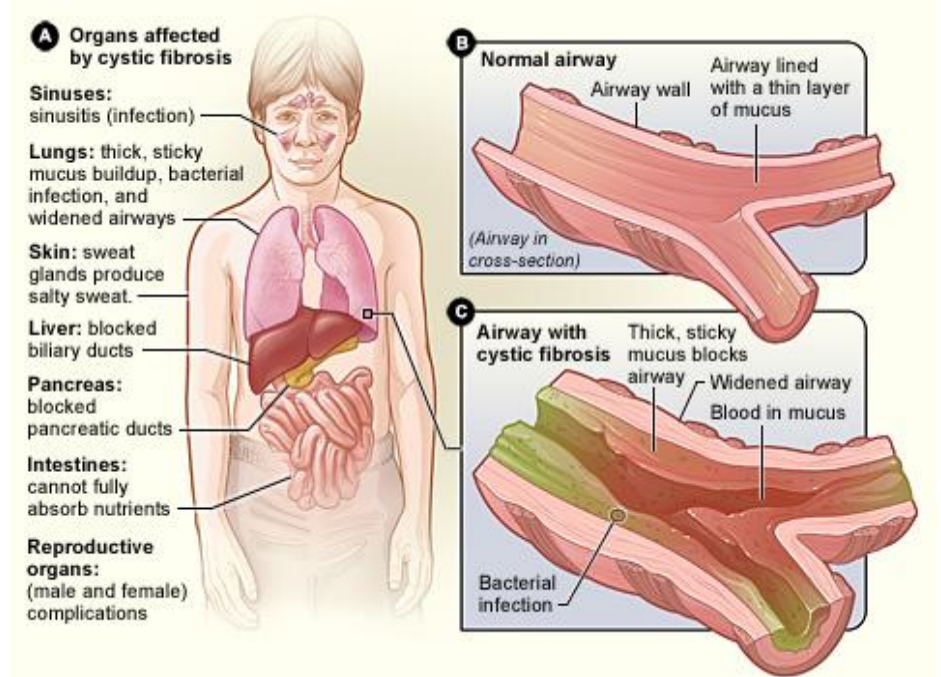
- coughing that does not go away, often with mucus that comes up from the lungs;
- lung infections that come back again and again;
- very salty-tasting skin/sweat;
- shortness of breath;
- wheezing;
- poor growth/weight gain, even when the person has desire for food and healthy eating habits;
- large, greasy stools or trouble having bowel movements.

Over the past 50 years, the amount of time a person with CF was expected to live increased from only 10 years to 37 years of age. This great progress came about because parents of children with CF, researchers, doctors, and people

with CF worked together to find better ways to treat Cystic Fibrosis.

The first big step forward in uncovering the cause of CF was made in 1989, when doctors found a gene linked to the disease. Since then, many improvements have been made in finding and treating CF. There is still no cure, but special medical care, doctor-prescribed drugs, therapies, and CF diet can help make life longer and better for those with Cystic Fibrosis. (See Current Practices section for more information on this topic.)

A child can only get CF when both of his or her parents carry a special CF gene in their bodies. Over 10 million Americans (about 1 in every 31 people) carry this gene. Many do not even know it. Each child born to a mother and father who both carry the CF gene has a 1-in-4 chance of getting Cystic Fibrosis and a 3-in-4 chance of carrying the gene in their own body, which they may pass to their children.



¹ (Cystic Fibrosis Foundation, 2010)

² (National Heart Lung and Blood Institute, 2010)

Cystic Fibrosis is more common in Caucasian families (of northern European descent) than Hispanic/Latino and African American families. It is least common in Asian American families.³ The number of boys and girls born with Cystic Fibrosis is about equal.

The Centers for Disease Control (CDC) suggests that all newborn babies be tested for CF. Because of this, most people with the disease (around 70%) are diagnosed by age two. Finding the disease early can add years to a child's life by helping doctors know how to take care of growth and lung problems. Treating CF from a young age also helps to cut down on the number of serious lung infections and hospital stays.

Learning about Cystic Fibrosis can be confusing. Don't be afraid to ask questions of your doctors, other families who have gone through it too, and our staff here at the Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center. We're here to help.

Works Cited

American Lung Association. (2010). *American Lung Association: State of Lung Disease in Diverse Communities 2010*. Retrieved November 12, 2010, from <http://www.lungusa.org/assets/documents/publications/solddc-chapters/cf.pdf>

Cystic Fibrosis Foundation. (2010). *About CF: Cystic Fibrosis Foundation*. Retrieved November 12, 2010, from Cystic Fibrosis Foundation Web Site: <http://www.cff.org/AboutCF>

National Heart Lung and Blood Institute. (2010). *Lung Diseases: Cystic Fibrosis: National Heart Lung and Blood Institute*. Retrieved November 12, 2010, from http://www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_summary

³ (American Lung Association, 2010)





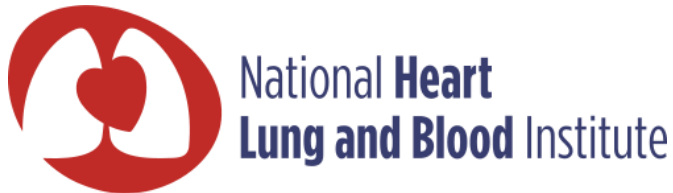
Current Practices

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.

On the following pages, you will find more information on Cystic Fibrosis from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



How Is Cystic Fibrosis Treated?

Cystic fibrosis (CF) has no cure. However, treatments have greatly improved in recent years. The goals of CF treatment are to:

- Prevent and control lung infections
- Loosen and remove thick, sticky mucus from the lungs
- Prevent or treat blockages in the intestines
- Provide enough nutrition
- Prevent dehydration (a condition in which the body doesn't have enough fluids)

Depending on how severe the disease is, you or your child may be treated in a hospital.

Specialists Involved

If you or your child has CF, you may be treated by a CF specialist. This is a doctor who is familiar with the complex nature of CF.

Often, a CF specialist works with a medical team of nurses, physical therapists, dietitians, and social workers. CF specialists often are located at major medical centers.

Treatment for Lung Problems

The main treatments for lung problems in people who have CF are chest physical therapy (CPT), exercise, and medicines.

Chest Physical Therapy

CPT also is called chest clapping or percussion. It involves pounding your chest and back over and over with your hands or a device to loosen the mucus from your lungs so that you can cough it up.

You might sit down or lie on your stomach with your head down while you do CPT. Gravity and force help drain the mucus from your lungs.

Some people find CPT hard or uncomfortable to do. Several devices have been developed that may help with CPT, such as:

- An electric chest clapper, known as a mechanical percussor.
- An inflatable therapy vest that uses high-frequency airwaves to force the mucus that's deep in your lungs toward your upper airways so you can cough it up.
- A small handheld device that you breathe out through. It causes vibrations that dislodge the mucus.
- A mask that creates vibrations that help break the mucus loose from your airway walls.

Breathing techniques also may help dislodge mucus so you can cough it up. These techniques include forcing out a couple of short breaths or deeper breaths and then doing relaxed breathing.

This may help loosen the mucus in your lungs and open your airways.

Exercise

Aerobic exercise that makes you breathe harder helps loosen the mucus in your airways so you can cough it up. Exercise also helps improve your overall physical condition.

However, CF causes your sweat to become very salty. As a result, your body loses large amounts of salt when you sweat. Thus, your doctor may recommend a high-salt diet or salt supplements to maintain the balance of minerals in your blood.

If you exercise regularly, you may be able to cut back on your CPT. However, you should check with your doctor before doing this.

Medicines

If you have CF, your doctor may prescribe antibiotics, anti-inflammatory medicines, bronchodilators, or mucus-thinning medicines. These medicines help treat or prevent lung infections, reduce swelling, open up the airways, and thin mucus.

Antibiotics are the main treatment to prevent or treat lung infections. Your doctor may prescribe oral, inhaled, or intravenous (IV) antibiotics.

Oral antibiotics often are used to treat mild lung infections. Inhaled antibiotics may be used to prevent or control infections caused by the bacteria mucoid *Pseudomonas*. For severe or hard-to-treat infections, you may be given antibiotics through a tube inserted into a vein. This type of treatment may require you to stay in the hospital.

Anti-inflammatory medicines can help reduce swelling in your airways that's caused by ongoing infections. These medicines may be inhaled or oral.

Bronchodilator medicines help open the airways by relaxing the muscles around them. These medicines are inhaled and often are taken just before CPT to help clear out mucus. You also may

take bronchodilators before inhaling other medicines into your lungs.

Your doctor may prescribe mucus thinners to reduce the stickiness of your mucus and to loosen it up. These medicines can help clear out mucus, improve lung function, and prevent worsening lung symptoms.

Treatments for Advanced Lung Disease

If you have advanced lung disease and the level of oxygen in your blood is low, you may need oxygen therapy. Oxygen usually is given through nasal prongs or a mask.

If other treatments haven't worked, lung transplant may be an option if you have severe lung disease. A lung transplant is surgery to remove a person's diseased lung and replace it with a healthy lung from a deceased donor.



Treatment for Digestive Problems

CF can cause a number of digestive problems, including poor growth and development, bulky stools, intestinal gas, a swollen belly, severe constipation, and pain or discomfort.

Nutritional therapy can improve your strength and ability to stay active. It also can improve growth and development in children. Nutritional therapy also may make you strong enough to resist some lung infections. A nutritionist can help you create a nutritional plan that meets your needs.

In addition to having a well-balanced diet that's rich in calories, fat, and protein, your nutritional therapy may include:

- Oral pancreatic enzymes to help you digest fats and proteins and absorb more vitamins.
 - Supplements of vitamins A, D, E, and K to replace the fat-soluble vitamins that your intestines can't absorb.
 - High-calorie shakes to provide you with additional nutrients.
 - A high-salt diet or salt supplements that you take before doing vigorous exercise.
 - A feeding tube to give you more calories at night while you're sleeping.
- The tube may be threaded through

your nose and throat and into your stomach. Or, it may be placed directly into your stomach through a surgically made hole. Before you go to bed each night, you will attach a bag with a nutritional solution to the entrance of the tube. It will feed you while you sleep.

Other treatments for digestive problems may include enemas and mucus-thinning medicines to treat intestinal blockages. Sometimes surgery is needed to remove an intestinal blockage.

Your doctor also may prescribe medicines to reduce your stomach acid and help oral pancreatic enzymes work better.

Treatments for Cystic Fibrosis: Complications

A common complication of CF is diabetes. The type of diabetes that people who have CF develop often requires different treatment than other types of diabetes.

Another common complication is the bone-thinning disorder osteoporosis. Your doctor may prescribe medicines that prevent your bones from losing their density.

This information is provided courtesy of the National Heart Lung and Blood Institute, a member of the National Institutes of Health. Original article: www.nhlbi.nih.gov/health/dci/Diseases/cf/cf_treatments.html



Cystic Fibrosis: Diet and Nutrition

At lunch, Lindsay often gets bored with having the same old conversation with her friends:

"You're so lucky!"

"Yeah, I'd give anything to be able to eat as much as you do and be so skinny!"

"Cheeseburgers or mac and cheese every day - that would be great."

Lindsay is one of about 30,000 people living with cystic fibrosis (CF) in the United States, and she has to eat high-fat, high-calorie foods just to stay healthy. A lot of the time she just doesn't feel well enough to eat the foods most teens crave. And sometimes, when her schedule's really hectic, she'd love to just skip a meal like her friends do.

CF is a genetic disease that affects the body's epithelial cells, which are found in many places, including the sweat glands, the lungs, and the pancreas. An error in these cells causes problems with the balance of salt and water in the body. The body responds by making thick mucus, which blocks the lungs and sometimes other ducts and passageways, causing infections and breathing problems.

This mucus can also keep the intestines from absorbing important nutrients like fat and vitamins from food, which means that teens with CF may be short and underweight for their age, and they may get sick a lot because their bodies can't fight infections well. People with CF need extra calories and nutrients to help them fight infection and keep their lungs strong, particularly if they get sick with colds or the flu.

With the right balance of nutrition, extra fat and calories, and prescribed supplements, though, teens with CF can keep themselves healthy.

Nutrient Know How

Like everyone else, guys and girls who have CF should eat a balanced diet that includes plenty of fruits and veggies, grains and breads, dairy products, and protein. In addition, people with CF have some specific nutritional needs to help them stay healthy. Here are some of the nutrients they need to get more of:

Protein. About 15% to 20% of the calories a teen with CF eats should come from foods rich in protein, like meat, eggs, soy foods, fish, nuts, or beans.

Iron. Iron is important to help fight infection. It also helps to carry oxygen in your blood from your lungs to every cell in your body. Fortified cereal, meats, dried fruits, and dark green vegetables are good sources of iron.

Salt. Teens with CF lose a lot of salt in their sweat, especially during hot weather and when they exercise. A good way to replace this salt is by adding salt to food and eating salty snacks. A CF dietitian (a specially trained food and nutrition expert) may recommend sports drinks for after sports practice or gym class, especially during hot weather.

Zinc. Zinc is important for growth, healing, and fighting infection. Good sources include meats, liver, eggs, and seafood.

Calcium. People with CF are especially at risk for osteoporosis, a condition where the bones

become weakened. Dairy products are good sources of calcium - and full-fat dairy products like whole milk are good sources of fat and calories as well. Many fruit juices now include calcium as well.

Fast Facts on Calories

In general, teens with CF may need more calories a day than others in their age group - that's about 2,900 to 4,500 calories daily, depending on the individual. What are all those calories for? Like every other teenager, girls and guys with CF need calories to fuel their growth during puberty. They just need more of them.

Every person with CF has different nutritional needs. Teens with CF and their parents can work with a CF dietitian to figure out exactly how many calories they need each day. The dietitian looks at growth and weight gain over time and comes up with a nutrition plan.

Some people with CF like to keep close tabs on the number of calories they eat in a day. Others find that counting calories is stressful and find it easier to focus on adding calorie boosters with fat in them to the foods they normally eat.

So how can people with CF add calories to meals? In general, they should avoid all diet foods. Whether eating at home or away, here are some simple tips:

- Drink whole milk and milk shakes.
- Add extra butter or margarine to foods like potatoes or pasta.
- Use regular (not diet) dressings on salads or vegetables.
- Eat burgers with bacon and cheese.
- Eat pizza with extra cheese.
- Add cheese to sandwiches.
- At breakfast, eat omelets with extra cheese and ham or bacon.
- Top salads and sandwiches with avocados or guacamole.
- Eat calorie-rich desserts such as ice cream, pudding, and cheesecake.

- Top hot chocolate, pudding, and other desserts with whipped cream.

Besides eating high-calorie meals, it's a good idea for guys and girls with CF to carry some high-energy snacks with them. Suggestions include trail mix, nuts, packets of cheese crackers or peanut butter crackers, and veggies like carrots or celery with small containers of dressing that don't need to be refrigerated.

Meals and Munchies

People with CF may need to eat more regularly than some of their friends do, but that doesn't necessarily mean anything weird. Check out this sample meal plan that provides approximately 3,750 calories. (Find recipes for high-calorie foods that teens with CF can make at www.TeensHealth.org)

Breakfast - 3 frozen pancakes with 1 tablespoon butter and 3 tablespoons syrup; 1/2 cup of strawberries; Mighty Milk

Morning snack - 1 cup whole-milk yogurt; 1/2 cup granola; 1/2 banana; water

Lunch - Sandwich made with 4 ounces of turkey, 1 ounce of cheese, 1 tablespoon mayonnaise, 3 teaspoons mustard, lettuce, tomato, and/or onion; 10 baby carrots with 2 tablespoons ranch dressing; 1/2 cup apple juice; 14 pretzels; water

Afternoon snack - 1/2 cup trail mix and 1 cup Mighty Milk

Dinner - Creamy chicken fettuccine with broccoli; 1/2 cup juice; water

Exercise and CF

Regular exercise can help people with CF stay healthy by keeping lungs as free of mucus as possible and by building up muscles and bones. A person with CF can work with a medical team to develop an exercise plan that promotes physical and mental well-being.



More Than Just Food

Some teens with CF need to take vitamin supplements, especially for the fat-soluble vitamins (vitamins A, D, E, and K). These vitamins are important for growth and healing and they need fat to be absorbed. Because most teens with CF have trouble digesting fat, they often have low levels of these vitamins and may be prescribed supplements.

In some cases, teens with CF may have low energy or trouble gaining weight, even with good nutrition and supplements. For these teens, doctors may recommend they get extra nutrients through a tube that is inserted into the stomach (called tube feeding). Tube feedings, which most people choose to do overnight, provide about 1,000 to 2,000 calories. These overnight feedings leave teens with CF free to enjoy normal meals and activities during the day.

Tube feedings may sound gross, but they can be an excellent way to help teens who are having trouble gaining weight, especially when they are sick. Having a tube put in for the feedings is usually an uncomplicated procedure that doesn't require extensive surgery or a long hospital stay. In fact, most kids and teens who have feeding tubes inserted can go home the same day as they get the procedure done.

Enzyme Supplements

About 85% to 90% of CF patients have pancreatic insufficiency. This means that the body doesn't pass certain chemicals, called enzymes, from the pancreas into the intestines properly. These enzymes are necessary for a person to digest fat, starch, and protein. People with pancreatic insufficiency might have problems with growth and weight gain, and they might also have frequent and bad-smelling bowel movements.

People with pancreatic insufficiency need to take prescribed enzymes with meals and snacks to help them digest their food properly and get the nutrition they need to grow and develop. A CF doctor will work with a dietitian to prescribe enzymes based on weight, growth, and how much the person with CF eats at a time. Enzymes need to be taken with every meal and most snacks. They should not be chewed or crushed up, and the dose should only be adjusted by the dietitian or doctor.

Beating the Frustration

It can be difficult for teens with CF to eat enough in a day to meet their needs, especially when they aren't feeling well. Although lots of people think they would like to be able to eat whatever they want, many people with CF find it difficult to do so.

If you have CF, eating well and taking your enzymes and supplements will benefit you now and in the future. And if you have a friend with CF, be supportive. Remember Lindsay's friends? She'd probably appreciate it if they didn't bring up how much she eats every day!

In addition to the right diet, exercise can help give people with CF the energy and mental boost they may need. Talk to your doctor about the right kind of exercise for you, and pay careful attention to how you feel while exercising - and rest or stop if you get tired.

Like everyone else, people with CF need to take care of their bodies so they grow up healthy, strong, and full of energy.

Reviewed by: Allison Brinkley, RD, LD/N, CNSD
Date reviewed: February 2007



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Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.

Cystic Fibrosis: A Family Perspective

By Susan B., mother of two daughters with Cystic Fibrosis

I remember clearly the day when the diagnosis was given that my daughter had Cystic Fibrosis (CF). It was a Friday evening when the pediatrician called with the results of the sweat test. We had done the test earlier in the week to rule out CF as the cause of her failure to thrive. We heard the words, but couldn't really comprehend what it was going to mean to our family.

We had already lost a child to SIDS and to hear this news was devastating. This was in 1990, before the internet was available. We had no idea what the disease was or what to expect, and had purposely not done any research - we were sure this couldn't be our daughter's problem. We were hoping for a simple solution or quick fix. We wanted them to do the test again and find there was an error.

When we could get to the library the next day, there was only outdated information on the disease. The stated life expectancy was 18 years old. It was an incurable genetic disease that we handed to our daughter through our genes. We felt like we had failed as parents.

After the diagnosis, we started our numerous trips to Children's Mercy Hospital and the Cystic Fibrosis clinic. We found many things we could do to help keep our child with CF healthy. We were referred to a support group, and met with other parents with children that had CF. We got involved in helping to raise money to find a cure through the Cystic Fibrosis Foundation.

We were advised by the doctors and nurses at Children's Mercy to have our daughter apply to the Children's Wish Foundation. She was granted her wish, and we had a once in a lifetime family vacation granted by this wonderful organization.

Knowing CF is a genetic disease, we weren't sure about having more children. But both coming

from large families, we knew our family wasn't complete. We have four children - two have CF and two do not. Our youngest daughter, who has CF, is at home and in elementary school. Our oldest daughter with CF is now in college and living independently. My greatest fear now is, "what will she do when she is no longer covered by our health care plan?"

The biggest challenge for our family is getting all the medications and treatments done each day. Most of the medications and breathing treatments are given twice a day. Enzymes are needed every time they eat anything. That means a trip to the nurse at school at lunch and snack. When you have a full day at school and an event in the evening, it makes it hard to get everything in. It takes several hours of time each day, and to be honest, it doesn't get done every day.

If medications are not done regularly, their breathing and pulmonary function deteriorates. Then a hospital stay is usually going to happen sooner rather than later. Even the common cold can become a major problem if not followed through with medicines and a doctor visit. Another challenge is making sure the medications don't run out and knowing what to order when. It's important to do the daily things to keep them as healthy as possible. My daughters have been very active in sports, and it's great for them to run until they cough!

Educating others (family, friends, school and church) and communicating about the disease is important as well. They need to be kept away from those with respiratory illnesses, and we let others know. At the same time, we have to educate others that their cough is not contagious. With the recent outbreak of H1N1, everyone is more aware of coughs. My youngest daughter's feelings were hurt one day when a classmate said "you are sick," thinking she was contagious. My



oldest daughter had some students in her lecture get up and move away from her because of her cough. It's hard when others don't understand.

We have come a long way since 1990 towards better treatment and finding a cure for CF. It is very promising that there are now "Adult CF" centers. Persons with CF are living longer with a better quality of life. It gives me hope that they will now outlive me.

The Children's Mercy CF clinic and the CF Foundation have been the best source of support and information for us over the past 20 years. I would highly recommend for any family with a child with a diagnosis of CF to seek out the best CF care center in their area, and to use the support services that the CF foundation has to offer.





Family Support Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.



Support for Families

Sharing Our Strengths (SOS) Peer Support Network

215 W. Pershing Road, 6th floor

Kansas City, MO 64108

Toll free: 800-444-0821

Web: <http://www.sharingourstrengths.com>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special health care needs, and professionals who are matched with peer mentors to share experiences, offer emotional support and network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

Cystic Fibrosis Foundation – Local Chapters:

Gateway Chapter:

St. Ann, MO

Phone: (314) 733-1241

Toll free: (800) 727-1464

Email: gateway@cff.org

Contact: Ms. Tracy Davis, Executive Director

Heart of America Chapter: (serving the Greater Kansas City Area)

Mission, KS

Phone: (913) 384-8997

Email: hoa@cff.org

Contact: Ms. Dana Wilson, Special Event Director

Cystic Fibrosis Foundation – National Headquarters:

6931 Arlington Road

Bethesda, Maryland 20814

Local: (301) 951-4422

Toll free: (800) FIGHT CF (344-4823)

Email: info@cff.org

Web: <http://www.cff.org>

Online Support Community and Social Networking:

www.HealingWell.com/cysticfibrosis





Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.



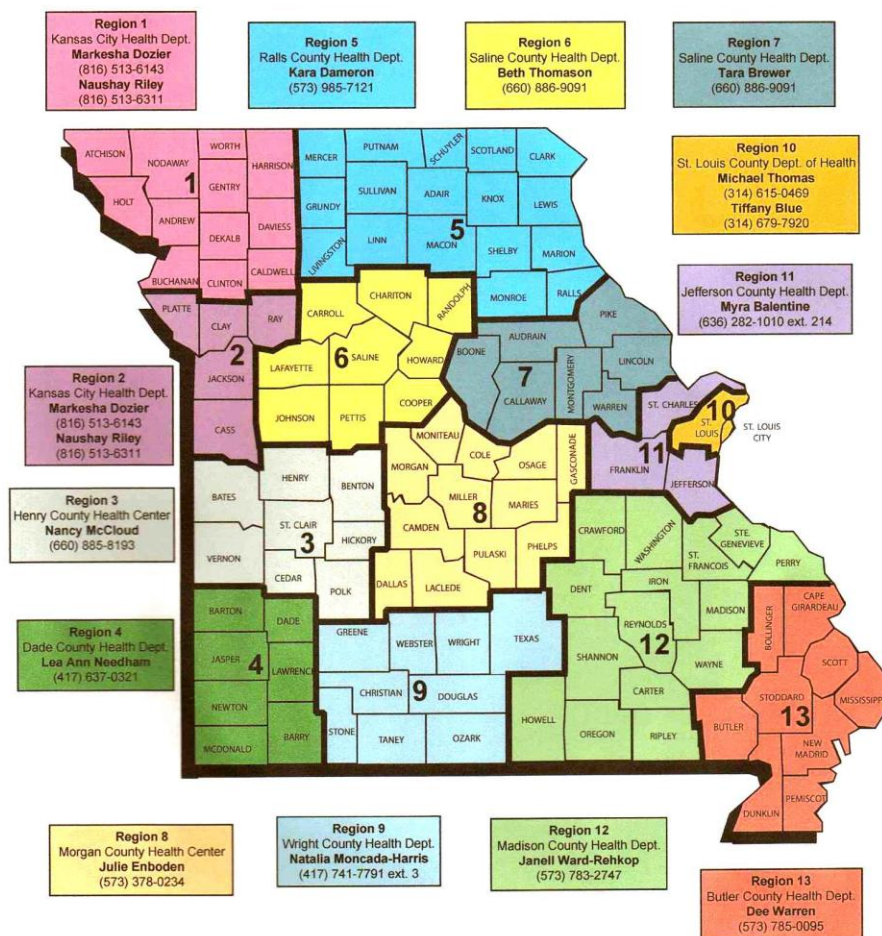
Missouri Service System Contacts

Children with Special Health Care Needs (CSHCN) Program

Missouri resident children (age 0-21) with Cystic Fibrosis who also meet financial guidelines may be eligible for the Missouri Children and Youth with Special Health Care Needs (CYSHCN) Program. This program covers outpatient tests and evaluations, and possibly inpatient care, surgery, physical therapy, occupational therapy, speech and language therapy, prescriptions, equipment and supplies.

If you feel that you or a member of your family may qualify for a Special Health Care Need Program, please use the map below and call the regional office that serves the county in which you reside.

**Missouri Department of Health and Senior Services
Bureau of Special Health Care Needs
Children and Youth with Special Health Care Needs (CYSHCN) Program
Service Coordinator Contact Information**



7/22/10

Missouri Service System Contacts, Continued

Cystic Fibrosis Medical Treatment Centers for Missouri residents:

Saint Louis University
Adult Cystic Fibrosis Program
3660 Vista, Suite 204
St. Louis, MO 63110
(314) 577-6190

The University of Kansas Hospital
(serving the Greater Kansas City Area)
3901 Rainbow Blvd
Kansas City, KS 66103-2937
(913) 588-6044

Washington Univ. Medical Center
At Barnes – Jewish Hospital
1 Barnes – Jewish Plaza
St. Louis, MO 63110
(314) 454-8640

Cystic Fibrosis Clinic
Children’s Mercy Hospital
2401 Gillham Road
Kansas City, MO 64108
(816) 234-3066

University of MO Health Care
One Hospital Drive
Columbia, MO 65212
(573) 882-6993

