



Cystic Fibrosis

What is it?

Cystic fibrosis, or CF, affects breathing and digestion (breaking down food). CF causes the body to make thick, sticky mucus that clogs the airways of the lungs and can prevent the pancreas from doing its job to help digest food. In people with CF, the sweat glands also make very salty sweat.

What causes it?

CF is inherited when both parents carry an abnormal CF gene and pass it to their child. A person who has one abnormal CF gene is called a carrier. Carriers do not usually have any health problems caused by CF. When two CF carriers have children together, each baby has a 25 percent chance of having CF. Most children with CF do not have a family history of the disease.

How is cystic fibrosis detected?

Newborn screening is done on tiny samples of blood taken from the infant's heel 24 to 48 hours after birth. A positive newborn screen does not mean that your baby has CF. If your baby has a positive newborn screen, special testing called a sweat test must be done to know for sure. Your baby's doctor will help arrange for sweat testing at a clinic specializing in CF. Most babies who need sweat testing do not have CF, but it is very important to rule it out.

What problems can it cause?

CF is different for each child. Symptoms may include:

- 1) Coughing or wheezing.
- 2) Lung infections.

- 3) Too much mucus.
- 4) Trouble gaining weight and growing.
- 5) Greasy stools.

It is very important to follow the doctor's instructions. Children with CF need to see the doctor more often than kids without CF.

How is it treated?

Although CF cannot be cured, many things can be done to treat the symptoms. People with CF must eat a healthy, high-calorie diet and take vitamins to help them grow. Some people must also take medications to get more nutrients from the food they eat. To breathe better, many people with CF need help clearing mucus from their lungs each day. Some medications also can prevent infections and help with breathing.

Cystic fibrosis in children

The child should see a regular primary care doctor and a doctor who specializes in CF. A team of health-care providers can give the child good medical care and teach the family about cystic fibrosis.

The child should have lifelong treatment that is followed closely.

Where can I find more information?

Cystic Fibrosis Foundation

www.cff.org

800.344.4823

March of Dimes

www.marchofdimes.com

Children Special Health Services (CSHS)

State Capitol Judicial Wing
600 E. Boulevard Ave., Department 301
Bismarck, ND 58505-0269
Toll Free: 800.755.2714
701.328.2436
Relay TDD: 701.328.3975
CSHS website: www.ndhealth.gov/CSHS
North Dakota Department of Health website:
www.ndhealth.gov

Family support resources available from CSHS:

- Guidelines of Care Info
- Family Support Packet
- Financial Help Packet
- Insurance Fact Sheet

Family Resources

Family to Family Network
Center for Rural Health
University of North Dakota
School of Medicine and Health Sciences
P.O. Box 9037
Grand Forks, ND 58202-9037
Toll Free: 888.434.7436
701.777.2359
Fax: 701.777.2353
E-mail: NDF2F@medicine.nodak.edu
www.medicine.nodak.edu/crh

Pathfinder Services of ND
Pathfinder Family Center
1600 2nd Ave. SW, Ste. 19
Minot, ND 58701
Toll Free: 800.245.5840
701.837.7500
Relay TDD: 701.837.7501
E-mail: ndpath01@ndak.net
www.pathfinder.minot.com

Family Voices of North Dakota, Inc.
P.O. Box 163
Edgeley, ND 58433
Toll Free: 888.522.9654
701.493.2634
Fax: 701.493.2635
www.geocities.com/ndfv

**This fact sheet has general information. Every child is different and some of these facts may not apply to your child specifically. Certain treatments may be recommended for some children but not others. All children should be followed by a metabolic doctor in addition to their primary-care provider.

Acknowledgement

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Disclaimer

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