KENTUCKY NEWBORN SCREENING PROGRAM

PARENT TEACHING SHEET

Kentucky Newborn Screening Program, 275 East Main Street, Frankfort, KY 40621, Phone (502) 564-3756, Fax (502) 564-1510

Cystic Fibrosis (CF)

CAUSE

CF is an inherited disease that causes the exocrine glands to not work properly. The exocrine glands normally make thin, slippery secretions like sweat, mucus, tears, saliva, and digestive juices. In CF, the exocrine glands make thick, sticky mucus that may plug passageways (ducts) to the lungs, intestines, and other organs. Children with CF also have a high amount of salt and potassium in their sweat, which may cause problems during times of increased sweating. CF is not contagious and does not affect the brain. Most infants with CF are diagnosed within the first three years of life. As adults, the reproductive system will also be affected by CF. The thick mucus blocks the passageway for men to pass sperm and, in women with CF, blocks sperm from reaching the egg. Approximately 98 percent of men with CF are unable to father a child. Women with CF may have greater difficulty getting pregnant than women without CF.

IF NOT TREATED

The thick mucus caused by CF can clog the child's airway and make it difficult to breathe. It can also cause frequent lung infections. Because of the high amount of minerals lost during sweating, it is very easy for a child with CF to become dehydrated when they become overheated. The thick mucus caused by CF also keeps food from being properly digested, resulting in poor growth and malnutrition or a blockage in the intestine that requires medical treatment. Any of these events, in an untreated child with CF, are potentially life-threatening.

TREATMENT OPTIONS

Your child will need to be under the care of a cystic fibrosis specialist and a dietician. Treatment is required throughout life.

- The child with CF will need to take pancreatic enzymes to help with digestion. They may also have to take numerous other medications every day. These will be prescribed by their cystic fibrosis specialist.
- Daily lung percussion (clapping the hand on the child's chest and back) is often required for the CF child. This can be done in your home and usually lasts for 30 minutes each session, twice a day. The CF specialist will train you on the proper way to do this.
- Your child will also require daily respiratory medications that may be given in a pill, as a vapor (by being inhaled), or through the vein. This helps thin the mucus in the lungs and prevents lung infections from occurring.
- There should be absolutely no cigarette smoking around a child with CF!!!!!
- Contact your child's doctor immediately at the start of any illness. Children with CF may need to be treated in a hospital when ill to prevent serious health problems.

IF TREATED

With treatment, children with CF are seeing increased life expectancy into their 30's and even 40's and are living active lives.

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