

CYSTIC FIBROSIS

Cystic Fibrosis Impacts People of Every Race and Ethnicity

Cystic fibrosis impacts people of all races and ethnicities. While more common among people of European descent, cystic fibrosis is found in every community.

What is cystic fibrosis? Cystic fibrosis (CF) is a disease that is most known for causing progressive lung disease, but which impacts every organ system. CF is a genetic disease: if two carriers of the CF gene have a child, there is a one in four chance that their child will have CF.

Symptoms of cystic fibrosis can vary widely from person to person, based on many factors including age, genetic mutation, age at diagnosis, environmental exposures, and other health issues. Primary symptoms include:

- *salty tasting skin*
- *persistent cough*
- *frequent lung infections*
- *frequent sinus infections and/or nasal polyps*
- *poor growth and/or difficulty gaining weight*
- *frequent bowel movements with greasy or bulky stools*
- *wheezing or shortness of breath*
- *meconium ileus (intestinal blockage at birth)*
- *male infertility*

The basic issue with CF is a defective exchange of fluids across cells, caused by a mutation in the gene for the CFTR protein. While most people associate CF with lung disease, it can also impact the sinuses, liver, pancreas, and reproductive systems due to thick mucus that blocks small ducts, leading to chronic infections, malnutrition and progressive lung damage.

Due to the misperception that cystic fibrosis is rare among people of color, physicians may miss the signs and fail to order testing for children who have symptoms of CF. Due to lack of awareness of CF among the general population, those whose loved ones have symptoms of the disease may not know to insist on testing to rule out cystic fibrosis.

Early diagnosis is vital. CF is included on the newborn screening panel in every state, but these tests often fail to identify rare mutations more common in people who are not of European descent.

If you believe you or your child has symptoms of cystic fibrosis, do not hesitate to ask for testing. If CF is suspected, doctors usually recommend a sweat test to measure salt levels, and/or a genetic test, in which the blood is analyzed for a broader range of mutations.

There are therapies for cystic fibrosis. With a diagnosis, you or your loved one will have the opportunity to receive care so as to improve health and quality of life.

For more information, please visit www.cfri.org or email cfri@cfri.org.

Made possible through grants from Vertex Pharmaceuticals, Genentech, Gilead Sciences, and Chiesi USA.

CFRI Cystic Fibrosis
Research Institute

RESEARCH · EDUCATION · ADVOCACY · SUPPORT