CYSTIC FIBROSIS

Among the South Asian Community

What is cystic fibrosis? Cystic fibrosis (CF) is a genetic disease that is most known for causing progressive lung disease, but which impacts every organ system.

CF impacts people of **all** races and ethnicities, including people of South Asian origin. While more common among people of European descent, it is estimated that 1 in 10,000 people of Indian origin have CF, while exponentially more people are carriers of the gene that causes cystic fibrosis. If two carriers 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 a variety of factors. 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*

Cystic fibrosis is 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 in these systems, leading to chronic infections, malnutrition and progressive lung damage.

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.

Sadly, due to the misperception that CF is rare among the South Asian community, many physicians may miss the signs and fail to order testing for children who have CF. If you believe your child has symptoms, do not hesitate to ask for testing, which may include a sweat test to measure salt levels, and/or a genetic test, in which the blood is analyzed for a broader range of mutations.

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

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CFRI Cystic Fibrosis Research Institute

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