

CYSTIC FIBROSIS

Among the East 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 East Asian origin. While more common among people of European descent, cystic fibrosis does occur in the East Asian community, and testing should not be ruled out should a person have symptoms of the disease.

Symptoms of cystic fibrosis can vary widely from person to person, based on factors such as age, genetic mutation, age of 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 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 of East Asian origin.

Sadly, due to the misperception that CF is rare among people of East Asian origin, many physicians may miss the signs and fail to order testing for children who have CF.

If you suspect your child has symptoms of CF, do not hesitate to ask for testing. If cystic fibrosis 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.

With early diagnosis, those with CF can receive proper care and achieve an improved quality of life.

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

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