

Campaign Raises Awareness of Latinos With Cystic Fibrosis

Latinos with cystic fibrosis are often underdiagnosed and are underrepresented in clinical trials.

January 27, 2023 By Laura Schmidt

The cystic fibrosis (CF) nonprofit The Bonnell Foundation, in collaboration with biotech corporation Genentech, has launched “We Are the Extended CF Familia (“Somos La Gran Familia FQ”), a Latino-centered awareness campaign to educate and empower Latinos living with CF, who are often underdiagnosed and face greater health disparities.

CF affects more than [3,000 Latinos](#) living in the United States, and, despite advances in treatment, Latino patients are 27% more likely to die of CF compared with non-Latino white patients, according to [The Bonnell Foundation](#).

A recent study from Genentech found that reasons Latino patients do not seek medical treatment include communication barriers and unfair treatment by the health care system. Yet Latinos with CF who do seek medical attention are often misdiagnosed or diagnosed later because they do not fit the typical characteristics of a CF patient, which many have considered a predominantly Caucasian disorder.

Latinos with CF are more likely to be excluded from clinical trials for CF medications; indeed, Latinos participated in only 7.5% of studies for CF drugs, according to a study published in [the Journal of Pediatric Pulmonology](#).

“Somos La Gran Familia FQ” hopes to fight these disparities by providing bilingual education and information about CF to patients, caregivers and physicians.

“The Bonnell Foundation takes pride in housing these educational resources to raise awareness among the CF community about the discrepancies in both diagnosis and care amongst people of color,” the [initiative’s home page reads](#). “We are fully committed to seeing that anyone with CF is correctly diagnosed either through mandated newborn screenings or by a pediatrician; we know that early intervention is the key to improving health outcomes among people of color.”

To learn more, click Tu Salud’s [Health Basics for Cystic Fibrosis](#). It reads in part:

What is cystic fibrosis?

Cystic fibrosis (CF) is a progressive genetic disease that severely affects the ability of the lungs, pancreas and other organs to function properly, according to the Cystic Fibrosis Foundation.

A defective gene causes thick, sticky mucus buildup. The mucus clogs the lungs' airways and traps bacteria, causing infections, extensive lung damage and respiratory failure. Because of the mucus, the pancreas is unable to release digestive enzymes that allow the body to break down food and absorb important nutrients.

More than 30,000 people are living with cystic fibrosis in the United States, and 1,000 new cases are diagnosed each year. In addition, more than 75% of people with CF are diagnosed by age 2, and more than half of the CF population is age 18 and older.

What are the signs and symptoms of cystic fibrosis?

Symptoms associated with CF, include:

- Very salty-tasting skin
- Persistent coughing, at times with phlegm
- Frequent lung infections, including pneumonia or bronchitis
- Wheezing or shortness of breath
- Poor growth or weight gain in spite of a good appetite
- Frequent greasy, bulky stools or difficulty with bowel movements
- Infertility in most males and reduced fertility in females.

CF can lead to complications in the respiratory, digestive and reproductive systems, such as damaged airways, respiratory failure, diabetes, nutritional deficiencies, infertility or being less fertile and much more.

How is cystic fibrosis diagnosed?

Every state in the United States routinely screens newborns for CF in an effort to treat it early if diagnosed.

These screenings include a test that assesses blood samples for high levels of immunoreactive trypsinogen (a chemical released by the pancreas), genetic exams to confirm diagnosis and to check for specific defects on the gene responsible for CF, and sweat tests to determine whether the skin is saltier than normal.

In addition, diagnostic exams are recommended for older children and adults who weren't screened at birth.

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<http://beta.docker.tusaludmag.com/article/campaign-raises-awareness-latinos-cystic-fibrosis>