Black Clergy Health Brief: A Resource for Pastors

Provided by Health Committee of The Black Clergy of Philadelphia and Vicinity
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"MAY IS CYSTIC FIBROSIS AWARENESS MONTH"
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DID YOU KNOW

- Cystic fibrosis (usually called CF) is a progressive, genetic disease that affects the lungs, pancreas, and other organs.
- CF is an inherited disease. It causes certain glands in the body to make mucus that is too thick and sticky. This mucus plugs ducts and other passageways. Mucous plugs are most often in the lungs and intestines and can cause problems with breathing and digestion.
- There are close to 40,000 children and adults living with cystic fibrosis in the United States (and an estimated 105,000 people have been diagnosed with CF across 94 countries)
- CF can affect people of every racial and ethnic group.
- Tremendous advancements in specialized CF care have added years and improve the quality of the lives of people with cystic fibrosis. During the 1950s, a child with CF rarely lived long enough to attend elementary school. Today, many adults with CF are living well and achieving their dreams.

How is CF recognized?

People with CF can have a variety of symptoms, including:

- Very salty tasting skin
- Persistent coughing, at times with phlegm
- Frequent lung infections including pneumonia or bronchitis
- Wheezing or shortness of breath
- Low growth/weight gain despite a good appetite
- Frequent greasy, bulky stools or difficulty with bowel movements
- Nasal polyps
- Chronic sinus infections
- Clubbing or enlargement of fingertips and toes
- Rectal prolapse
- Male infertility

What CF is NOT:

- CF is not contagious. It cannot be caught from a person with CF in spite of their persistent cough. CF is caused by a genetic mutation.
- CF is not caused by anything the mother or father did, or did not do, before or during pregnancy.
- CF does not affect the brain, nervous system, or the capacity to learn.

Diagnosing CF

- Diagnosing cystic fibrosis is a multistep process, and should include a newborn screening, an analysis of perspiration called a "sweat test", a genetic or carrier test, and a clinical evaluation.
- Newborn screening panels are less likely to include rarer mutations, which are more common in people of color with cystic fibrosis. As a result, infants of color with CF are disproportionately diagnosed later than non-Hispanic white infants.

Addressing Inequities in the CF Community

- *CF is growing in the US among people of color*. People of color are 15% of the people with CF in the U.S.
- Research shows that people of color with CF, particularly people who are Black and Hispanic, experience unique challenges and often have negative experiences that can lead to poorer outcomes.

- The Cystic Fibrosis Foundation is working on many efforts to support improvements in care and care delivery to help achieve equitable outcomes for Black people with CF, including:
    - Convening a cohort of staff members and external advisors from the broader CF community to serve as the External Racial Justice Working Group (ERJWG). Half of the group's members are Black people with CF or a family member or caregiver, and half are researchers and care team members from multidisciplinary backgrounds with experience in diversity, equity, and inclusion (DEI) and health equity.
    - Funding genetic therapy programs that have the potential to treat all people with CF, including those with rare and nonsense mutations.
    - Reducing barriers to enrollment in clinical trials
    - Establishing a nationwide initiative focused on improving equity, sensitivity, and timeliness in diagnosing people of color with CF.

"When our daughter was a baby, we noticed that she wasn't growing as well as she should and would have frequent respiratory infections. It wasn't until she was three that she was diagnosed with CF. She was not diagnosed as early as other kids because CF was thought to be extremely rare among African Americans. Like many people of color, her genetic mutation is so rare that a therapy has not yet been found to address it. More funding and research is needed to address the way that CF affects people of color." – Pastor Jay Broadnax

Living Well with CF

Each day, people with CF complete a combination of the following therapies:

- Airway clearance to help loosen and get rid of the thick mucus that can build up in the lungs.
- Inhaled medicines to open the airways or thin the mucus. These are liquid medicines that are made into a mist or aerosol and then inhaled through a nebulizer and include antibiotics to fight lung infections and therapies to help keep the airways clear.
- Pancreatic enzyme supplement capsules to improve the absorption of vital nutrients. These supplements are taken with every meal and most snacks. People with CF also usually take multivitamins.
- An individualized fitness plan to help improve energy, lung function, and overall health.
- Medicines that reverse the effects of the genetic mutations that prevent enough water and chlorides being absorbed by cells. These medicines only work for people with specific genetic mutations.

How Churches can Foster Cystic Fibrosis Awareness

- Start a community event in conjunction with a local Cystic Fibrosis Foundation Chapter such as the Philadelphia chapter found at www.cff.org/Philadelphia
- Participate in, or sponsor a participant in a CF research fundraiser event such as a "Cycle For Life" bicycle ride, a "Great Strides" walk, or "Paddle to a Cure" boat rowing event
- Become a CF advocate to advance CF research and promote access to care at www.cff.org/advocate or by texting FIGHTCF to 96387
- Learn more about the lived experience of people with CF through *Community Voice*. CV a forum for people 13 plus affected by CF to share their experiences, perspectives, priorities, and knowledge to impact CF research, care, and programs at www.cff.org/communityvoice

To learn more, visit www.cff.org or call the Cystic Fibrosis Foundation, Delaware Valley Chapter at 610-325-6001. For additional information, contact Geoffrey Harden, Senior Development Director at gharden@cff.org

Sources:

- Cystic Fibrosis Foundation cff.org
- Introduction to Cystic Fibrosis for Patients and Their Families, Sixth Edition, James C. Cunningham, M.D. Lynn M. Taussig, M.D.
- Addressing Health Inequities in the Cystic Fibrosis: cff.org/about-us/addressing-health-inequities-cystic-fibrosis-community