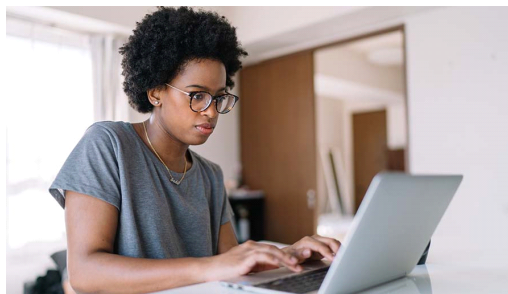


National Jewish Health Pulmonologist Guides Development of Innovative Tool to Help People of Color Screen Their Own Symptoms for Cystic Fibrosis

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DENVER — Cystic fibrosis (CF), a genetic lung disease affecting about 90,000 people worldwide, is most common within the white population, but it affects people of all races and ethnicities. People with CF often experience abdominal pain, diarrhea, difficulty gaining or maintaining weight, sinus congestion and productive cough. If not treated, a vicious cycle of inflammation, chronic infection and irreversible damage to the airways occurs early in life. The genetic disorder results in abnormal chloride (and water) transport, commonly leading to salty skin, and thick, sticky mucus in the intestines, sinuses and lungs. People with CF require lifelong treatment with multiple daily medications, so a misdiagnosis will ultimately be prematurely fatal.



“The recognition of CF in Black individuals and people of other racial and ethnic backgrounds has been markedly inadequate,” said [Jennifer Taylor-Cousar, MD](#), co-director for the adult CF program and the interim associate vice president of Diversity, Equity and Inclusion at National Jewish Health.

Following the virtual North American CF conference in the fall of 2020, Dr. Taylor-Cousar met Terry Wright, an Arkansas resident in his 50’s whose symptoms were misdiagnosed as asthma in combination with common gastrointestinal problems for decades. “In spite of having multiple symptoms consistent with CF, he and his wife Michele were once told by a physician that he couldn’t have CF--because he is Black, implying that CF is solely a ‘white people’s disease.’ Because of the misdiagnosis, he spent years undergoing surgeries that didn’t help, and spent countless days in the hospital throughout his life,” said Dr. Taylor-Cousar.

After Dr. Taylor-Cousar was introduced to the couple, they discussed the possibility of developing a free online tool that would be accessible for anyone to self-screen for symptoms of CF. She offered her medical expertise to create and refine the tool that could help reach the broader population. Then, Dr. Taylor-Cousar and the Wrights presented the tool to the Cystic Fibrosis Foundation’s (CFF) education committee, which found that it meets their guidelines and standards of an effective screening tool for public education about CF. Now known as the Wright Cystic Fibrosis Screening Tool[®], the tool is being shared with CF care teams through the CFF and with the general public on social media.

The new tool will help people self-identify symptoms that could be related to CF and aid medical providers in identification of potential individuals with CF, especially those who are Black, Indigenous, and People of Color (BIPOC). “The sooner we get the word out about this new tool the better – it could literally save, or change someone’s life,” said Dr. Taylor-Cousar. “Once they have a diagnosis, there are new disease-modifying therapies for CF for which people may be eligible.”

Once the screening is completed and the symptoms are consistent with CF, the individuals can take the information to

a doctor, who can refer them to get a test to confirm if they have CF. Individuals can undergo a short procedure called a sweat test, during which the sweat glands on their skin are stimulated with medicine and the amount of chloride they can reabsorb is measured.

The tool can be accessed by [this link](#), and is available in Spanish as well.

National Jewish Health is the leading respiratory hospital in the nation. Founded 124 years ago as a nonprofit hospital, National Jewish Health today is the only facility in the world dedicated exclusively to groundbreaking medical research and treatment of patients with respiratory, cardiac, immune and related disorders. Patients and families come to National Jewish Health from around the world to receive cutting-edge, comprehensive, coordinated care. To learn more, visit the [media resources page](#).

Media Contacts

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