Fellows

Michele and Terry Wright

Cofounders, the National Organization of African Americans with Cystic Fibrosis, North Little Rock, Arkansas

by Beth Howard, AARP

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En español

We started the National Organization of African Americans with Cystic Fibrosis (NOAACF) in 2017 to raise awareness of cystic fibrosis in minority communities and to support patients and caregivers.

The problem we're trying to solve

Nearly 40,000 people of every racial and ethnic group in the U.S. have cystic fibrosis (CF), a genetic disorder that causes significant problems with breathing and digestion. But there's a misperception that it's a white person's disease, which can result in a later diagnosis in people of color. That was the case with Terry, who was only diagnosed when he was 54 even though he had been hospitalized, seen multiple health care practitioners and unknowingly dealt with the devastating consequences of the disease throughout his life. Advances in the diagnosis and treatment of CF have transformed the prognosis of this disease from a severely reduced lifespan to a chronic condition with a rapidly increasing life expectancy. However, minority populations continue to fall through the cracks. There are limited resources and educational materials that specifically address Black, Indigenous and people of color (BIPOC) with cystic fibrosis.

Our mission is to educate patients, families, caregivers and health care providers, and raise awareness that cystic fibrosis can impact anyone. Our work includes outreach to the nationwide network of more than 130 care centers for CF patients and their families. Through these efforts, our long-term goal is to reduce delays in diagnosis and improve outcomes for underrepresented communities.

The moment that sparked our passion

The closest Terry came to being diagnosed was in 2000, when a doctor told us, "If you were not Black, I would say you had cystic fibrosis." So it was missed. In 2017, we were desperate to find answers because we knew that the clock was ticking. Terry had had several surgeries, and was in and out of the hospital and getting worse. From Michele's previous work in health care, she knew that infectious disease doctors are often brought in to solve medical mysteries and we reached out to one in our community. After talking with him for 30 to 40 minutes, he said he thought that Terry had cystic fibrosis, which led to him finally getting tested, diagnosed and treated. After we solved the mystery of the illness that had been devastating Terry's life, it became important for us to do what we could for others with the same problem.

What we wish other people knew

There is power in embracing your faith and surrounding yourself with people who believe in you being a better you. Take whatever you are going through and let it be your testament to open eyes, help others and to show them a different way.

Advice to others who want to make a difference

Terry always says, "If I can make a difference and positively impact the life of just one cystic fibrosis patient, then my living, suffering, and CF journey would not be in vain." We all have a chance to create positive change. Just get moving and do something, because if everybody individually and separately can do a little, then together and synergistically we can impact the whole.

How our approach is unique

We recognized a need that no one else saw and stepped in to close that gap, establishing the first national organization specifically focused on cystic fibrosis in the African American community. When Terry was diagnosed, there was no brochure for African Americans. So we developed one. When we realized that there were probably many others falling through the gap, we developed — in coordination with Jennifer L. Taylor-Cousar, M.D., professor of medicine and pediatrics at National Jewish Health in Denver — the Wright Cystic Fibrosis Screening Tool, which has been endorsed by the Cystic Fibrosis Foundation and is now being used around the world. While this screening tool can't diagnose CF, it can help individuals and their medical providers to consider whether a person might have the disease, and depending on the results, to ask a doctor about specific tests for it.

We also put on an annual conference called BIOMERGD, which stands for Blacks, Indigenous, and Other Minority Ethnicities With Rare and Genetic Diseases, that raises awareness not only of cystic fibrosis but also other rare diseases in the BIPOC community. Through NOAACF, we want to bring inspiration, encouragement and a "breath of hope" to people from all walks of life.