



CF Foundation Seeks Input from Communities of Color

Hearing from diverse voices is critical as we continue our journey to listen, learn, and take action against racism and discrimination.

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Cystic fibrosis affects people of many different racial and ethnic backgrounds; however, for many years there has not been adequate recognition or representation of Black individuals and other people of color within the CF community.

As part of its early work to address racism and discrimination, the CF Foundation is working to deepen its understanding of this issue by listening to Black members of the CF community, other people of color with CF, and leading researchers who are focused on health disparities. In those conversations, sobering evidence affirms that race impacts every aspect of an individual's experience with CF:

- **Diagnosis:** Infants of color with CF carry mutations that are less likely to be evaluated and identified on prenatal and newborn screens, are older than their white counterparts at the time of diagnosis and first clinic evaluation, and are two and one-half times more likely than white infants to have failure to thrive.
- **Representation in clinical research:** In 29 studies that reported race and ethnicity over a period of nearly 15 years, Hispanic and Black people with CF made up only 2 percent and 1 percent of participants, respectively, despite making up approximately 7 percent of people with CF.
- **Access to therapies to treat the underlying cause of CF:** Black and Hispanic people with CF account for nearly 40% of individuals with rare mutations that are not candidates for CFTR modulators.
- **Outcomes:** Black and Hispanic people with CF have a nearly two-fold higher risk of death before the age of 18 compared with white people with CF. Unadjusted mortality (31%-61% increased risk) and access to lung transplants is worse in Black, Hispanic, and Asian candidates with CF.

Throughout our discussions, Black members of the CF community have shared a need to build trust with both the Foundation and other members of the CF community. They have expressed concern about the lack of representation across a range of settings, and report upsetting experiences in healthcare settings about the ways their race impacts their care.

As we begin to take action guided by these findings, it is critical that we hear from diverse voices to better understand the unique needs and perspectives of people of color within the CF community.

If you are interested in helping to shape the Foundation's efforts to create an equitable and inclusive community for all people with CF, we encourage you to complete this interest form. As part of this effort, the Foundation is also recruiting individuals to join a working group that will focus on understanding how racism affects the Black CF community, including its impacts on research and care.

We feel great urgency to confront the challenges facing people of color across the CF community; we are also committed to taking steps that will result in meaningful, lasting change.

If you are not a person of color but would like to be involved with this work and other Foundation initiatives, please join Community Voice. For other questions, please contact info@cff.org.

The Foundation is grateful to Terry and Michele Wright, founders of The National Organization of African Americans with Cystic Fibrosis, as well as Raeshaun Jones, founder of Inhale Melanin Exhale Power, for their input throughout our early listening efforts and guidance to ensure we take the right first steps.

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Cystic Fibrosis Foundation
4550 Montgomery Ave.
Suite 1100 N
Bethesda, MD 20814

301-951-4422
800-344-4823 (toll free)