

OUR COMMITMENT

RECOMMENDATIONS FOR

Equity, Racial Justice,
Diversity, & Inclusion



The Barrow Family, JARROD (far left) and JAHSIR (youngest, middle), HAVE CF



Cystic fibrosis is a disease that can affect people of **every racial and ethnic group**. Many in the CF community, particularly Black, Hispanic, and other communities of color, have experienced **health disparities influenced by systemic barriers** that have long gone unaddressed.

To achieve our mission of finding a cure and providing all people with CF the opportunity to lead long, fulfilling lives, the Cystic Fibrosis Foundation is **committed to using equity, racial justice, diversity, and inclusion** as key principles to guide our work.

As part of this commitment, the Foundation convened 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.

This group has engaged in deep listening efforts, collaborating to **better understand the unique barriers and challenges** that Black people with CF face. Anticipating that many of the resulting learnings may be applicable to people with CF from other communities of color, the group recognizes that recommendations may be expanded for broader reach.



The ERJWG identified **three key areas***, with recommendations of how the Foundation can improve its programs, processes, and policies to advance more equitable and just outcomes.

This is a long-term, sustained effort, and an implementation roadmap is being developed detailing the scope and pacing of the Foundation's activity, with many efforts already underway.

*Health Equity & Outcomes | Diverse Workforce Development | Community

NICK, HAS CF

OVERARCHING RECOMMENDATIONS


The following are recommendations to be applied across the Foundation's ERJDI-related efforts.

- Acknowledge "misses" in the past and how we are going to change moving forward
- Ensure balanced representation of Black people with CF in efforts to learn from the community
- Establish and maintain CF Foundation leadership alignment around internal and external focus to drive ERJDI progress
- Keep Black people, including CF Foundation staff and community members, engaged and central through partnership or transparent communication
- Conduct coordinated community listening to improve CF Foundation outreach and apply findings to enable the organization to become a more trusted resource for Black people living with and impacted by CF

KEY AREA 1

HEALTH EQUITY & ● OUTCOMES

Support improvements in care and care delivery to help achieve equitable outcomes for Black people with CF



Many people of color with CF, including Black individuals, **disproportionately experience health disparities** which have been influenced and exacerbated by systemic barriers that have long gone unaddressed. The Cystic Fibrosis Foundation is committed to supporting programs that address these barriers and is working to ensure all individuals have the opportunity to achieve optimal health outcomes. As part of this work, the Foundation is focused on supporting improvements in care and care delivery to help achieve equitable outcomes for Black individuals with CF.

The following is an overview of the Foundation's approach to improve health equity and outcomes. This work will **help advance our mission to find a cure** and help all people with CF live long, fulfilling lives.

INITIAL DIAGNOSIS

- Support research to better understand CF-causing mutations, including those more common in Black people with CF
- Increase representation in Foundation materials and leverage influence beyond Foundation channels to correct the misconception that Black people cannot have CF
- Advocate for and educate on best practices for newborn screening and diagnosis
- Provide information and tools for Black people struggling to get a CF diagnosis or access to care



EARL, HAS CF
Diagnosed at age 20

CARE AND MANAGEMENT

- Provide resources and training for care teams to better understand disparities and their impact on health outcomes, and to build trust with patients
- Promote high-quality care practices that increase health equity and are personalized to the unique experiences of Black people with CF
- Encourage universal screening for social risk factors
- Better understand the impact of race and ancestry on clinical measures and monitoring



J'MEIL, HAS CF

RESEARCH FOR NEW THERAPIES

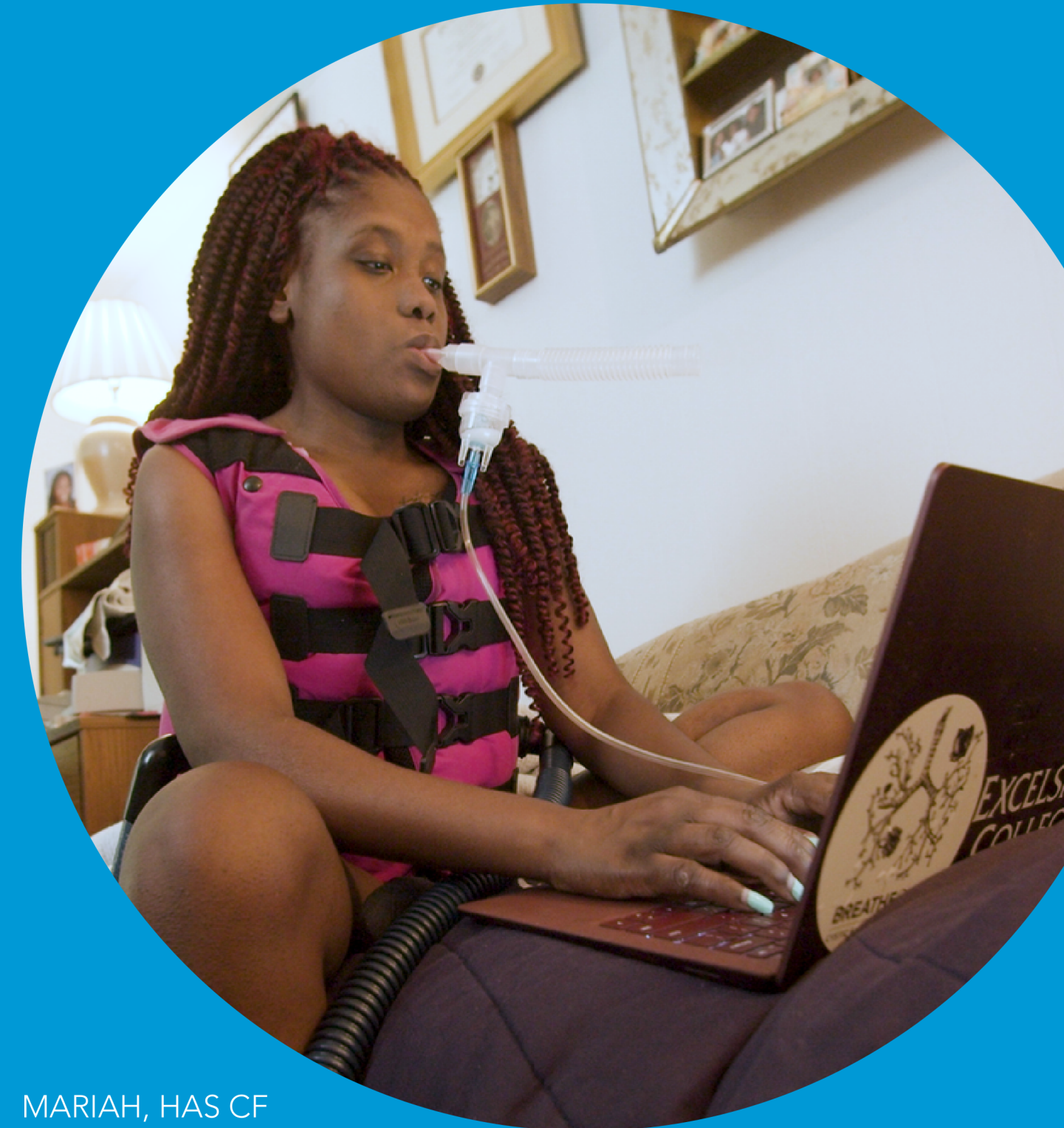
- Increase diversity in clinical trials, including those advancing new therapies needed for rare mutations, which are found more frequently in people of color with CF
 - Require diverse recruitment plans and more data reports
 - Develop toolkits for research and clinical teams
- Improve overall awareness of the research process and promote opportunities to participate
- Better understand key drivers that reduce diverse recruitment in CF clinical trials



ANGEL, HAS CF

UNDERSTANDING & AWARENESS OF INEQUITIES

- Fund research on the causes of, and how to reduce, health disparities for Black people with CF
- Provide transparent data on racial inequities Black people with CF experience
- Recognize and raise awareness that CF exists among Black individuals to normalize the diagnosis of CF in Black people



MARIAH, HAS CF

KEY AREA 2

DIVERSE WORKFORCE DEVELOPMENT

Advance a robust pipeline of diverse health care professionals and researchers from multidisciplinary backgrounds focused on CF who are equipped to address the changing health care needs of all people with CF

Evidence has shown that **diverse perspectives in research can generate greater innovation and productivity**, key components needed to accelerate efforts to achieve the Cystic Fibrosis Foundation's mission to find a cure for all people with CF. Increasing diverse representation in the care and research workforce, particularly among Black, Hispanic, and other people of color, in settings from care centers to clinical trials, can have a tremendous impact on mitigating the negative experiences people of color with CF have.

The following is an overview of the Foundation's approach to help advance a robust pipeline of diverse health care professionals and researchers from multidisciplinary backgrounds, throughout the spectrum from basic to clinical research, from populations underrepresented in medicine. This will help promote a diverse workforce that is focused on CF and equipped to **address the changing health care needs of all people with CF**.

GROWING THE DIVERSE CF WORKFORCE

Foster opportunities that support inclusion, recruitment, retention, and career advancement across cultural backgrounds. **Examples include:**

- Collect and evaluate demographics to know where we stand regarding diversity of CF care and research teams
- Support the development of programs, networking, and community-building events to expose and engage people from diverse backgrounds to research and care opportunities in CF
- Ensure grant programs are equitable and designed to support and appeal to a diverse applicant base
- Seek opportunities to increase awareness of CF research needs and funding opportunities in venues likely to reach individuals underrepresented in CF care and research
- Identify and advertise areas of specific interest to researchers from diverse backgrounds

SUPPORTING THE DIVERSE CF WORKFORCE


Support, engage, and ultimately retain diverse representation within the CF workforce so there is a network, from research teams to care teams, that is capable of effectively supporting the needs of people with CF. **Examples include:**

- Support and expand mentorship opportunities for members of the workforce from diverse backgrounds
- Make intentional and transparent efforts to ensure diverse representation at Foundation events, on committees, and in working groups
- Facilitate networking opportunities and support the development of peer groups for care and research team members from underrepresented groups
- Provide equitable and accessible career advancement resources and programs, which support critical career transition points for the CF workforce
- Foster an environment that promotes the recruitment of a diverse pipeline of physicians and researchers

KEY AREA 3

COMMUNITY

Enhance and create spaces, activities, programs, and resources for Black people living with and impacted by CF, where they feel included and are provided the opportunities to have their individual needs and preferences met



Cystic fibrosis is a disease that affects **people of every racial and ethnic group**. Historically, not enough has been done to celebrate the diversity of the CF community or to recognize that some experiences, particularly for underrepresented groups, have been more challenging than others.

Black people living with and impacted by CF have shared negative experiences ranging from **not having access to resources** relevant to their lived experiences to **gaps in representation and trusted relationships**.

The following are recommendations for how the Foundation will approach **fostering a more inclusive community** and creating an environment where Black people living with and impacted by CF are **welcome, represented, and valued**.

REPRESENTATION, EQUITY, & INCLUSION

- Create and/or tailor CF Foundation offerings to support inclusion and culture building through best practices to avoid tokenism
- Include Black people living with or impacted by CF in positions that enable them to use their voices and experiences to create change within the larger CF community
- Increase awareness that CF is not a white disease by collaborating with CF-focused organizations and others that more broadly support Black health
- Increase representation of Black professionals at all organizational levels of the CF Foundation
- Focus our approach for community and volunteer engagement with Black people living with or impacted by CF on partnership and establishing trust

REPRESENTATION, EQUITY, & INCLUSION (CONTINUED)

- Develop equitable and transparent guidelines that are consistently utilized so that community members are provided:
 - Honoraria for expertise as part of a working group or committee
 - Reasonable up-front expense coverage for presenting at an event
 - Consideration for non-monetary options when the individual is unable to accept monetary honoraria

“ Having someone I can visually identify with says a lot – that there’s efforts being made, that we’re talking and you actually hear us. And then, there’s also the connection and the trust building... it makes us feel like we have a seat at the table, we’re being heard through them (and) culturally, our interests are being taken into account.

Annette, ERJWG member
and person with CF



EDUCATION, RESOURCES, & SUPPORT PROGRAMS

- Leverage, develop, and identify ways for Black people living with or impacted by CF to connect, find support, and get involved (distinct from fundraising)
- Increase awareness of existing local and national support programs (and evaluate the need for additional ones) to address practical real-life challenges for Black people living with or impacted by CF
- Create, promote, and distribute resources specific to the experiences of Black people living with and impacted by CF

“

When we signed up for (resources), it was all displayed from a Caucasian person's experience, which makes living with CF even harder because you have to learn on your own... And you have to go and seek things that fit being Black and connect them with living with CF.

Rena, ERJWG member and Community co-lead, parent of two children with CF

”



TRAINING

- Establish a robust education strategy for CF Foundation staff that applies different learning modalities and factors in varying levels of DEI maturity
- Look for opportunities to encourage ongoing education for care team members, including cultural sensitivity and awareness trainings, and recognize care centers who have demonstrated that DEI is a priority

“

Blacks with CF are not only fighting for health equity in terms of CF, but also face other fights for equity inside and outside of the medical community due to being Black... they are real and we are fighting for our lives constantly.

Chandra, ERJWG member
and Community co-lead,
CF care center social worker

”



COMMUNICATIONS

- Leverage CF Foundation communications channels to build trust through conveying timely, accurate, and transparent messages about actions taken to meet our commitment to equity, racial justice, diversity, and inclusion
- Diversify CF Foundation communications channels to reach Black people living with or impacted by CF in the places where they prefer to receive information
- Develop guidelines for CF Foundation staff to create and disseminate audience-appropriate information informed by Black people living with or impacted by CF

“Some people get overwhelmed, they get inundated with a lot... there's a whole audience that you're missing because they didn't opt in to receive text messages or emails... We have to come up with (a better strategy) for increasing awareness.”

Lathronia, ERJWG member
and parent of a child with
CF





OUR VISION IS A CURE FOR
EVERY PERSON
WITH CF

JAHSIR, HAS CF



THANK YOU

FOR MORE INFORMATION, VISIT
cff.org/OurCommitment