Raising Cystic Fibrosis Awareness in the Black Community

Arkansas native Terry Wright is making a difference nationwide

erry Wright of Little Rock was not diagnosed with cystic fibrosis until he was 54 years old – despite having frequent hospitalizations and living with the symptoms of the disease since birth. Cystic fibrosis is a rare, genetic disease that progressively limits the ability to breathe and ultimately causes premature death.





Terry remembers the pain and confusion of misdiagnosis all too well. He says, "Imagine if you continued to suffer, regardless of the countless hospital visits, up to and throughout grade school, with no changes as far as diagnosis or prognosis. I was repeatedly sent back to the hospital for the doctors to say, yet again, it was just a virus."

According to the CF Foundation Patient Registry, approximately 5% of people with CF identify as Black, which makes them more likely to have rare mutations that cannot be treated with current modulators.

In early 2017, CF became Terry's surprise diagnosis and his new reality. Nevertheless, it was a welcome answer to his distressing and uncertain health journey. The diagnosis allowed him to finally receive the correct treatment that he so desperately needed. It also opened doors for Terry to educate himself, and others, about

the rare disease so that he could begin improving his quality of life.

After his late diagnosis, Terry and his wife, Dr. Michele Wright, saw an opportunity to engage, educate and raise awareness of the disease in the Black community.

They created Raising Cystic Fibrosis Engagement in the African American Community, a program expansion from the National Organization of African Americans With Cystic Fibrosis, which aims to connect and engage people with CF through online workshops, a growing network of virtual support and other remote resources.

Staying six feet away from people is normal for those who live with CF, as they face a greater health risk from disease. With heightened infection risk due to COVID-19, building and maintaining online communities is more important now than ever.

To help make a difference and support Terry's work, the CF Foundation Arkansas **Chapter invites you to** attend its annual Golf with the Finest event on Friday, Sept. 11. Details and more can be found at https:// finest.cff.org/nwafinest20.

In recognition of his contributions, Terry received a 2020 Impact Grant from the CF Foundation. Terry is the first person from Arkansas to be honored in this way by the CF Foundation, which awards Impact Grants of up to \$10,000 per year to individuals or organizations who are leading unique projects and empowering the cystic fibrosis community.

"Living with CF is physically, emotionally and mentally challenging. No one understands this more than those living with the disease and their loved ones," says Sue Sullivan, head of community partnerships at the Cystic Fibrosis Foundation. "We continue to be inspired by the spirited individuals who have transformed their experiences into programs that continue to positively influence the lives of others living with CF. The Foundation is proud to support their efforts through our annual Impact Grants."

Terry continues to share his journey with others by bringing valuable resources, knowledge, empowerment and support to CF patients, families, healthcare professionals and the Black community. "If I can make a difference and positively impact the life of just one person living with cystic fibrosis," he says, "then my living, suffering and CF journey will not be in vain." ■





