



# RARE BLACK LIVES MATTER TOO

Authors: [Nadia Bodkin](#), [Ashanthi De Silva](#), [Kay-Diene Robinson](#)

The socioeconomic fallout from the COVID-19 pandemic has hit America hard, particularly people of color disproportionately. Because people of color tend to make less than their White counterparts, they are less likely to have the financial resources to outlast the recession brought on by the pandemic and have systematic barriers to health care, as a direct result of deep rooted institutionalized oppression.

America's racially biased systems have generated a snowball effect of oppressive barriers towards generations of Black people, that was ultimately exposed to the world by the COVID-19 pandemic. Black people are more likely to forgo necessary medical care as layoffs continue and essential workers are forced to risk their lives without being provided the appropriate Personal Protective Equipment (PPE). Historically, Black people are at greater risk of losing their homes to foreclosure and eviction; and as a result of poverty, a large proportion of Black Americans use their local emergency room for medical care. Preventative health care is a luxury and privilege that most Black Americans do not have access to, resulting in extensive pre-existing conditions. It's not surprising that, [nationwide data collected](#) shows that deaths from COVID-19 in the Black community are two times greater than the percentage of the population they make up; in some states, this rate is even higher.



GEORGE FLOYD:  
*i can't breathe.*

EVERY SICKLE CELL PATIENT:  
*help me, i'm in pain.*

**same fight, different place**

For those Black Americans born with a rare condition or have a child with a rare condition, the obstacles are even greater. Most rare diseases Black Americans suffer several years undiagnosed, especially when there are no known familial genetic disorders that have been previously identified. For those with known familial genetic disorders like Sickle Cell Disease and Alpha and Beta Thalassemia, obtaining the treatment needed to treat debilitating symptoms, like chronic pain, is a well known obstacle amongst the rare disease patient advocacy community. Several Black rare disease people have a learned distrust for the healthcare and pharmaceutical industries, as a direct result of several historical injustices committed by researchers, like the [Tuskegee Syphilis trial](#), often resulting in lowered participation in clinical trials and studies. Because most natural history studies and clinical trials do

not include people of color, the Black community often lacks access to genetic information, directly impacting the ability to develop targeted treatment options.

For the stakeholders in the rare disease space, especially those in leadership positions, this moment in time is calling for thoughtful pause and self-reflection. Most people that enter the rare disease space professionally are well intentioned, seeking to improve and extend the lives of those suffering from chronic conditions. Despite these good intentions, many, particularly those who are White, have unintentionally perpetuated the racist structures that make the U.S. inequitable.

The Rare Advocacy Movement (RAM) is currently asking the adult rare disease community for feedback regarding the experience of living with a rare disease in America. We look forward to the truths that the results will unveil in order to better help guide the development of future programs aimed at improving the lives of all rare disease people. We encourage all rare disease people of color, 18 years of age and older, to participate and make their voices heard. To access the Adults Living Rare survey, visit [RareAdvocacyMovement.com/AdultsLivingRare](https://RareAdvocacyMovement.com/AdultsLivingRare). The results of the Adults Living Rare survey will be shared publicly to help inform the development of much needed programs.

Several American industries require incorporating an [equity lens](#) into its corporate structure in order to truly combat hidden racial and gender biases. Racial and gender biases can be found at the core of almost every American industry, disproportionately impacting the Black community, resulting in America's most vulnerable group being people of color. Despite being approximately [13%](#) of the U.S. population, Blacks constitute only [5%](#) of all doctors and [10%](#) of nurses. Within the American rare disease landscape, Black patients frequently report experiencing neglect and blatant disrespect from White emergency room doctors, often resulting in an exacerbation of the patient's medical condition and overall decrease in quality of life.

America is a multiracial society in desperate need of initiatives and programs that allow for more racial and gender inclusion — especially given [data](#) indicating Black patients' health outcomes improve when matched with a same-race provider. The Black rare disease community is in desperate need of practitioners that take their medical claims seriously, despite the color of their skin. For this reason, people of color have such a difficult time acquiring an accurate diagnosis for a chronic health condition.

Unfortunately, the American healthcare industry is not the only industry in need of restructuring. Housing assistance, education, food and judicial industries all have work to do in order to break down the racial barriers that have caused the American society to violate the basic standards that all of its residents have agreed to follow and abide by.

[“Black American people have watched time and time again how the contract that they have signed with society is not being honored by the society that has forced them to sign it with them.”](#) - Trevor Noah

In accordance to the principles of the U.S., as declared by the Declaration of Independence, “[all men are created equal](#)”. Unfortunately, members of the Black community have not been treated equally in accordance with the principles of the American society, all because of the color of one’s skin. This is a humanity issue that can no longer be ignored.

Regardless of ethnicity, skin color has been a strong determinant factor as to how an individual is treated in America. While the experience of having darker skin can only be truly understood by people of color, several White people have joined the efforts of the Black Lives Matter movement, in solidarity. However, in order for the day to come when the color of one’s skin no longer triggers others to behave in ways that result in shorter life-spans, unwarranted shattered dreams, premature deaths and unjustified murders, White people must join the movement in action.

As members of RAM, representatives of the rare disease advocacy community, and women of color, we, the authors of this publication, recognize the social, economic, and health inequities that people of color face, and stand in solidarity and action with efforts for justice and equity.

We commit to helping to dismantle racist systems by supporting diversity and inclusivity and addressing existing racial disparities in the rare community.

We call on the rare disease community, including but not limited to, individuals, rare disease organizations, government organizations, policy makers, and industry stakeholders to recognize these disparities and work together to better serve patients and families of diverse backgrounds equitably. . It is past time for each of us to use our individual power to stamp out racism and injustice.

From clinical studies that explore the holistic journey of rare disease patients also being designed to capture the impact of race and ethnicity on quality of care and life -- to industry conference organizers going above and beyond to ensure that the agenda and panels are diverse and include Black patients, families and advocacy experts -- we each hold the power to actively be drivers of progress towards the values and goals we espouse.

As we work together on the road to recovery from the disparate impacts of the COVID-19 pandemic, we must recognize that our efforts will be incomplete and insufficient without equal effort to dismantle racist systems. We must ensure that our work creates a more just future where freedom of mobility rings true for all.

We call on everyone to choose love while spreading awareness. To all Black advocates and leaders in the rare disease space, we hear you and want to discuss collaborations with you. To all others interested, you are encouraged to also reach out and get involved.

Resources:

1. [Diversity, Equity, and Inclusion \(DEI\)](#) - This site is designed to give you quick access to information, experts, training, and resources that can help you develop or conceptualize your DEI program.
2. [Moving Equity From Theory into Practice](#) - Working with an equity lens is an intentional decision and a difficult process for an organization to undergo. During this 2016 webinar, leaders from the Colorado Trust, Consumer Health Foundation, and Interact for Health highlight their major accomplishments, lessons learned, and challenges with putting equity into practice in collective impact. Each speaker represents an organization at a different stage in their equity journey.
3. [Integrating Racial Equity in Foundation Governance, Operations, and Program Strategy](#) - PDF
4. [The Health Care Institution, Population Health and Black Lives](#) - PDF

References:

1. <https://wjla.com/news/local/dc-leads-the-nation-in-covid-19-black-death-disparity>
2. <https://hbr.org/2020/05/the-disproportionate-impact-of-covid-19-on-black-health-care-workers-in-the-u-s>
3. <https://www.wired.com/story/covid-19-coronavirus-racial-disparities/>
4. <https://www.npr.org/sections/health-shots/2020/05/30/865413079/what-do-coronavirus-racial-disparities-look-like-state-by-state>

## About the Authors



Nadia Bodkin is a seasoned rare disease patient advocate, born with three main rare conditions herself. Immediately after graduation, Nadia went straight into advocacy through EDSers United, a foundation she founded as a student. Nadia has held leadership positions at several rare disease advocacy focused organizations assisting in everything between nonprofit management to event planning. She is currently the Chief Executive Officer for [Blaze Therapeutics](#) and is one of the founding members of New Love Ventures. Nadia also founded and currently facilitates the coordination of the Rare Advocacy Movement's activities along with her fellow RAM colleagues.



Ashanthi De Silva is a writer and the Rare Disease Editor for The Mighty, focusing on strengthening connections and building resources within the rare disease community. As a medical writer, she writes regularly about new developments in the field of endocrinology. Her passion for connecting others and raising awareness about issues facing patients today continues to drive her work, and she looks forward creating safe spaces and advocating for progressive policies that will facilitate change within her communities.



Kay-Diene Robinson, MPH, CHW is a proud sickle cell warrior. Upon completion of her undergraduate degree, she began her advocacy journey by volunteering with the Sickle Cell Association of New Jersey in July of 2013. It was through this organization she discovered the possibility of a cure through bone marrow transplantation. On September 11, 2015, Kay-Diene underwent an allogeneic stem cell (bone marrow) transplant in hopes of curing her disease. In December of 2015, Kay-Diene was miraculously cured of Sickle Cell Disease. In September of 2018, she accepted the role as a Board Member for The Pain

Community, a non-profit organization dedicated to educating and advocating on behalf of all individuals living with any condition, disorder, or disease that has a pain component. Her role as a Board Member, Secretary, and Social Media Director for The Pain Community has allowed her to facilitate and spearhead the official partnership between The Pain Community and the Sickle Cell Disease Association of America, as of July, 2019. Her work as a trained Community Health Worker has allowed her to educate hospital personnel, including physicians, nurses, and support staff within multiple hospital systems on Sickle Cell Disease, new emerging therapies related to sickle cell disease and other relevant topics of importance.