Ending sickle cell disease is a r of racial justice

BY BRETT P. GIROIR, OPINION CONTRIBUTOR — 06/15/21 11:31 AM EDT
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One hundred thousand Americans — the great majority of whom are Black — have sickle cell disease, an excruciatingly painful, terminal disease that on average leads to death before age 50, but for many much younger. But my review of Symphony Health Claims Data revealed only 30 percent of these one hundred thousand receive *any* form of medical treatment despite its widespread availability. Can you imagine the outcry if only 30 percent of Americans with cancer received treatment?

But at least we now clearly understand our national deficiencies. As reported by the Center for Medicare and Medicaid Service (CMS) for the nearly 42,000 people with sickle cell disease insured by Medicaid, only 16 percent of children and 10 percent of adults receive hydroxyurea, a daily pill that can reduce pain, prevent hospitalizations, improve function and save lives. Even more shocking, only one third of children receive a simple annual recommended ultrasound screening to determine their risk of strokes and help prevent them from occurring. And despite the FDA approval in 2019 of two new breakthrough therapies, access to these therapies is already being thwarted by a quagmire of medical indifference, bureaucracy and artificial barriers not supported by science.

Sickle cell disease is caused by a genetic mutation in one out of three billion DNA bases, no fault of its victims. This mutation arose 7,300 years ago, in a single child living in the Sahara region. One copy of this gene conferred resistance to malaria, a major killer in tropical areas; and thus, the mutation flourished, today present in 8 to 10 percent of African

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Americans, and an estimated 100 million people around the world. But when two individuals who carry a single copy of the mutation have children, on average one-in-four of their children have two copies of the mutation and thus sickle cell disease.

Now, because of advances in diagnostics combined with smart policies, all babies in the U.S. are now screened for sickle cell disease at birth, identified and given life-saving care by pediatric specialists. This has resulted in dramatic improvements in lifespan from the teens to mid-40s, with concomitant improvements in quality of life. However, most individuals with sickle cell disease still face overwhelming obstacles to health care as they become young adults, and thus their dreams of a normal life rapidly fade.

Our team at the U.S. Department of Health and Human Services (HHS) prioritized initiatives for people with sickle cell disease with the goal of normalizing their life-spans and quality of life. We created an interagency task force, educated providers and patients, enhanced awareness in Congress and the White House, improved data collection at Centers for Disease Control and Prevention and CMS, increased National Institute of Health sponsored research, incentivized appropriate prescribing, approved two novel medical therapies and developed a national blueprint for action through the National Academies of Science, Engineering, and Medicine (NASEM). And because of both public and private research, potential curative gene therapies are demonstrating dramatic successes in early clinical trials.

But more progress is needed. HHS should publish an annual sickle cell disease report card that assesses quality of care and progress on implementing the NASEM blueprint. Congress should fully fund the CDC Sickle Cell Data Collection Program, and mandate that CMS includes quality parameters for state Medicaid programs that incentivize stroke screening, vaccines, preventive health visits and appropriate use of medical therapies. The administration should increase budgets for sickle cell disease research at NIH and for education of health care professionals through the U.S. Health Resources and Services Administration. Congress should fund new grants for community health centers to implement multi-disciplinary care for sickle cell disease, including telemedicine linkages to medical specialists. The NIH should update its 2014 sickle cell disease treatment guidelines to provide specific recommendations for use of new therapies. It is also essential to establish a fair and equitable payment system, so that when expensive genetic cures become available, everyone in need can receive them.

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Finally, in Sub-Saharan Africa, where there is neither universal newborn screening nor basic sickle cell disease care, an estimated 50 to 90 percent of the 300,000 babies born with SCD annually will die before their fifth birthday. As such, the administration should support the newly formed Global Coalition to End Sickle Cell Disease, which HHS established in collaboration with the World Health Organization and the World Bank. By implementing inexpensive newborn screening for basic sickle cell disease, we can save the lives of an estimated 10 million children worldwide by 2050.

There is strong evidence to support that racism and discrimination underlie the historic inequities in sickle cell disease research, funding, health policies and national attention. With health equity being the mantra of the Biden administration, it is an ideal time to implement these additional policies. There would be no stronger affirmation of our national commitment to equity and racial justice than to prioritize assistance to those suffering from this disease.

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