

National Minority Health Month
WEEKLY OPED BY EXPLORERS HS INTERNS
THE GENERATIONAL SCAR
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Black women are three times more likely to die from a pregnancy-related cause than White women. Many may believe this is due to healthcare quality and racism, but this is right. The disparities throughout history that black people have faced within the science/medical community have broken their trust. As shown to this day, many People of Color do not rely on the help of healthcare due to the lack of quality care. But continuing from the past has allowed the science/medical community to slowly heal the generational scar left and patch it up with a new form of trust.

One of the significant science experiments widely known in the black community and other minority communities is the Tuskegee study. Beginning in 1932, the study was conducted in order to find a cure for syphilis, which was incurable at the time. If they joined the experiment, they lured low-income black men by offering free healthcare, food, and burial stipends. Six hundred black men over the age of 25 enrolled. Eventually, in 1947, penicillin became available as a treatment for syphilis, but it was never offered to men at any point during the remaining 25 years of the study. The men were treated terribly, like lab rats; their sole purpose was to find the long-term effects of this disease. In the mid-1960s, the unethical study was uncovered by a USPHS whistleblower named Peter Buxtun, who made complaints to the government, which were ignored. Buxtun leaked the experiment in 1972, and it went public. A lawsuit was later filed on behalf of the men and their families, resulting in a \$10 million settlement. One hundred study participants died of late-stage "tertiary" syphilis, with others passing away from other conditions in which the infection was one of the factors. After the disclosure of the study, many black people were traumatized by the medical industry and felt the need to stay away from any medical care. The community understood their worth when the experiment treated them like humans. As the decades went on, medical mistrust increased.

In the past couple of years, scientists have developed another treatment that helps many cancer patients in need and sickle cell patients. This discovery has built a new connection and is a step closer to getting a glimpse of trust within the black/African American community. Sickle cell anemia is a genetic disorder affecting hemoglobin, the oxygen-transporting molecule in red blood cells. Sickle cell disease causes the body to produce hemoglobin S, an abnormal form of the molecule that distorts the shape of red blood cells (resembling a sickle), disrupting their function. Sickle cell anemia is caused by the mutation of a single base in the DNA sequence of the β -globin gene (HBB). In healthy people, glutamic acid (GAG) is the resulting amino sequence. However, this is substituted for valine (GTG) in sickle cell anemia patients. This mutation causes the formation of hemoglobin S, the protein's disease-associated form. A blood test usually diagnoses sickle cell disease. However, CRISPR-Cas9 systems have been altered to have a more rapid diagnostic for the genetic mutation that causes the disease. The only cure for sickle cell disease is a bone marrow transplant from a healthy donor. This transplant approach is challenging since there needs to be a suitable donor, immune rejection of the transplant, and graft-versus-host disease (GVHD). The second approach to CRISPR sickle cell gene therapy involves a gene knockout, switching off the gene that suppresses fetal hemoglobin. This method causes fetal hemoglobin (hemoglobin F) to be expressed, replacing the mutated adult hemoglobin. By mutating (knocking out) the BCL11A gene, the expression of hemoglobin F is indirectly promoted. This approach was developed after it was found that sickle cell patients with a natural mutation in their BCL11A gene were resistant to disease symptoms. The researchers predict that editing efficiencies of 20% should be enough to result in significant clinical benefits to sickle cell patients.

To account for the diverse lived experiences and exposures of various populations, clinical research should be appropriately inclusive of racial and ethnic minority groups and other populations experiencing health disparities, including sexual and gender minority or socioeconomically disadvantaged populations. When conducting clinical trials and methods that help the black/African American community, the community must be involved in all aspects of the process.

Question: Why was House Bill 1036 covering 3-D mammograms imperative to the African American/Black community? Please respond to Community of Employees for Racial Equity care@fredhutch.org

EVENTS THIS WEEK

Speaker Danisha Jefferson-Abye from Tubman Health Center:

**THE RESPONSIBILITY OF
REIMAGINATION**

Wednesdays
12:00PM

Brave Space Discussions: continuation of speaker's themes

Thursdays
12:00PM

Prize from Emails

Announced every Friday