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Opinion

Debunking the Myths Around Sickle Cell Disease

In the United States, sickle cell disease (SCD) is considered rare, because it affects only about 100,000 people nationwide. As such, not many people in the U.S. are aware of what SCD is, or if they are aware, they have limited experience with the disease.

As with any disease, low awareness can spur myths and misperceptions and make it more difficult for those affected to obtain the care and support they need. Throughout my career, I've been asked a number of questions about SCD — many of which are common myths.

In this article, I will share some of the more common myths, in an effort to separate out the facts from fiction.

Sickle cell disease is a "Black" disease.

Myth! It's true that in the U.S. more than 90 percent of people living with SCD are of African descent. SCD occurs in one out of every 365 African American births. However, it's not exclusive to this patient population. SCD is also found in people of Indian, Middle Eastern, Hispanic, and Mediterranean ethnicities.

Sickle cell disease is contagious.

Myth! You cannot "catch" SCD — it is a genetically inher-



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ited condition (passed down from parent to child). For a child to inherit SCD, both parents must carry the sickle cell trait (or have the disease) and each must pass the sickle cell gene to the child.

“SCD occurs in one out of every 365 African American births

A person with the sickle cell trait will automatically develop sickle cell disease.

Myth! Sickle cell trait is different from SCD. Just because a person carries the sickle cell trait does not mean they will have the disease. What's the difference? When a person has only one copy of the sickle cell gene, he or she will have sickle cell trait. Someone with SCD will have two copies of the sickle cell gene.

A person with sickle cell trait can, however, pass the disease on to his or her child,

if the other parent also has trait. That's why testing for sickle cell trait or disease is incredibly important. Sickle cell disease (and sickle cell trait) can be diagnosed through a simple blood test. In developed countries, like the U.S., babies are now routinely screened at birth to determine if they carry the trait or have the disease.

People with sickle cell disease abuse pain medication.

Myth! Studies have shown that there is no increased substance abuse in patients with SCD. The most common symptom of SCD is excruciating, debilitating pain that often does not respond to over-the-counter medications and needs opioids to provide relief. Over time, the body becomes used to the opioids—ultimately leading to high doses being required to manage SCD pain. This need for high doses of opioids (which may not even provide complete relief from the pain), has unfortunately led to the perception that these patients are “drug-seeking.”

A baby born with SCD will die before reaching adulthood.

Myth! Until the 1990s, SCD was considered a life-threatening condition as many children born with the disease

did not live to adulthood. In developed countries, like the U.S., this is no longer true, with the majority of children living to adulthood, thanks to advances in SCD care.

However, the life expectancy of someone with SCD in the US is only between 40 and 60 years, compared to average U.S. life expectancy of 78.74 years. There is still much more work to do to improve the outcomes of people with SCD in the US and worldwide, particularly in underdeveloped countries. Although the disease was identified more than 100 years ago, there are still very few medicines available to help patients or address SCD symptoms. While there has been recent progress in this area, more still needs to be done. At Pfizer Rare Disease, we are working tirelessly to bring safe, effective treatment options to those in need.

One way to help address this is to encourage participation in clinical trials. To date, there have been several challenges in securing adequate participation of African Americans in clinical trials, which has been one of the key barriers to the development of new SCD medications.

Read the rest of this commentary at TheSkanner.com

Don't Let '45' Take Credit for President Obama's Economy

The income, poverty and health insurance data released by the Census Bureau on September 13 confirms what many of us already knew. President Obama's last year was one of economic improvement for many individuals. The median income rose from \$57,230 in 2015 to \$59,039 in 2016, an increase of 3.2 percent. Black income rose 5.4 percent, from \$37,364 in 2015 to \$39,400 in 2016, while White income rose from \$63,745 to \$65,041, an increase of two percent. The income gap narrowed very slightly, with African Americans making 58 percent of White earnings in 2015 and 60 percent of White earnings in 2016. This income ratio typically hovers around 60 percent, and this situation has not improved, since 1967. Despite an absolute improvement in incomes, the racial income disparity remains.

Fewer than 1 in 10 whites earned less than \$15,000 per year, compared to 20 percent of African Americans at that low earning level. While 18 percent of Whites earned less than \$25,000 a year, fully one-third of African Americans earned so little. At the same time, while 7.4 percent of Whites earned more than \$200,000 a year, only 2.8 percent of African Americans



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had similarly high earnings. At the top, there was significant improvement for African Americans—we didn't cross the 1 percent line on high earning until 1997, and

“This gap will not be closed unless there is some intervention, some form of reparations, or some special program that will empower African Americans

now our percentage has more than doubled. Still, it would take hundreds of years, at the rate we are going, to close the gap with Whites.

With incomes as low as they are, it is unsurprising to find African Americans more heavily represented among the poor than Whites, but again, President Obama's last year in office saw a real drop in the poverty level. The poverty rate dropped from 13.5 percent in 2015 to 12.7 percent in 2016, and the Black poverty rate dropped from 24.1 percent to 22.0 percent. There

were 800,000 fewer African Americans in poverty in 2016 than in 2015. That's good news. Child poverty was also overwhelming. With 15.1 percent of White children living in poverty there were nearly twice as many Black children living in poverty at 29.5 percent. Among elders, 8 percent of White seniors were poor, compared to 18.5 percent of African American seniors. And when Black women headed households, 34.2 percent

intervention, some form of reparations, or some special program that will empower African Americans. If that didn't happen in the Obama administration, it is unlikely to happen in during the current one.

President Obama's singular success, of course, was health care. More than 93 percent of Whites, 92 percent of Asian Americans, 89.5 percent of African Americans and 84 percent of Hispanics had health care in 2016, continuing an upward trend that began in 2011 with the introduction of the Affordable Care Act (ACA). Of course, Republicans have promised to “repeal and replace” Obamacare. They have been unsuccessful, because so many Americans like the program and use it, even though it has flaws. The program should be tweaked, but not replaced, but we'll see what happens in coming months.

Despite improvements in income data, too many Americans aren't feeling the improvements. That's how “45” was able to manipulate people into believing that they were worse off than they had ever been, and that he was going to improve their quality of life.

Read the rest of this commentary at TheSkanner.com