



Mini-lesson

Sickle cell disease and genetic engineering

Sickle cell disease (SCD) is a common genetic condition affecting people around the globe, primarily those with West or Central African ancestry (including many African-Americans and Latinos), as well as people of Middle Eastern, South Asian and Mediterranean descent. Many students of biology learn about SCD, and many students know of it from personal and family experience.

This mini-lesson asks students to consider the plans for genetic engineering as a treatment for SCD, and to think about the dimensions of race, trust and informed consent as they relate to clinical trials. Students read a brief overview of SCD, and then read a longer article about the latest vision for a treatment, described in *MIT Technology Review's* article, "[Sickle-Cell Patients See Hope in CRISPR](#)," by Emily Mullin, August 23, 2017. A short video in the article explains how CRISPR works, and should be shown in class.

Students can respond to the questions below in writing or in a classroom discussion. Finally, students are invited to take a short online quiz developed by pgEd and "pin" their awareness of SCD on our world map.

Student readings and questions

Sickle cell disease (SCD) is a common genetic condition affecting people around the globe, primary those with West or Central African ancestry (including many African-Americans and Latinos), as well as people of Middle Eastern, South Asian and Mediterranean descent. Many biology students learn about SCD in class, and many of you may know about it from personal and family experience. You will be asked to read, watch a short video, and consider the plans for genetic engineering as a potential treatment for SCD. You will also think about issues of race, trust and history as they relate to developing new treatments for disease.

Sickle cell disease is caused by a version of one of the hemoglobin genes, which encode for the hemoglobin proteins that carry oxygen in red blood cells. Typically, each person

has two copies of this gene, one copy that is inherited from each biological parent. Most people have two copies of the gene variant that produces a form of the protein called hemoglobin A. People with SCD have inherited two copies of the gene variant that produces a form of the protein called hemoglobin S. Hemoglobin S proteins cause the person's red blood cells to adopt a sickle (curved) shape, leading to chronic, incredibly painful symptoms.

Please read the following news article:

["Sickle-Cell Patients See Hope in CRISPR,"](#) by Emily Mullin, August 23, 2017. Technology Review.

The plans described in the article are to use CRISPR, a genome editing technique, to make genetic changes that will allow red blood cells to produce functional hemoglobin proteins. This genetic change could then result in the person's body being able to make red blood cells that do not become sickle-shaped. This would hopefully reduce the SCD patients' symptoms, such as severe pain.

Discussion questions (also on worksheet below):

1. The article says: "Despite the lingering safety concerns about using CRISPR in people, some sickle-cell patients and their doctors are already embracing it." Hertz Nazaire, the artist interviewed in the article, says, "I would be one of the first people to volunteer and say, 'I want to take part in a study.'" Would you volunteer to be one of the first people to try this treatment? Why? What are three questions that you want answered before you make a final decision?
2. From the *Technology Review* article: "But [sickle cell physician Dr.] Andemariam says there can also be trust issues between sickle-cell patients and their healthcare providers. Black patients may be suspicious of signing up for clinical trials, particularly given historical examples of medical experimentation on African-Americans without their consent. The infamous Tuskegee study, for example, left African-American men with syphilis deliberately untreated in an experiment that ran from 1932 to 1972."

Finally, take a short quiz developed by pgEd, working your way through 5 questions, and "pin" your awareness of SCD on our world map. <http://map-ed.org/maped/?q=10>

What to learn more? Check out pgEd's lesson "[Protecting athletes with genetic conditions: Sickle cell trait.](#)" Also, for more about genetic engineering, see "[Genome editing and CRISPR.](#)"

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STUDENT HANDOUT

Name: _____ Date: _____

1. The article says: "Despite safety concerns about using CRISPR in people, some sickle-cell patients and their doctors are already embracing it." Hertz Nazaire, the artist interviewed in the article, says, "I would be one of the first people to volunteer and say, 'I want to take part in a study.'"

A.) Would you volunteer to be one of the first people to try this treatment? Why or why not?

B) What are three questions that you want answered before you make a final decision?

1.

2.

3.

2. From the article: "But [sickle-cell disease physician Dr.] Andemariam says there can be trust issues between sickle-cell patients and their healthcare providers. Black patients may be suspicious of signing up for clinical trials, particularly given historical examples of medical experimentation on African-Americans without their consent. The infamous Tuskegee study, for example, left African-American men with syphilis deliberately untreated in an experiment that ran from 1932 to 1972."

A.) How can a lack of trust between some groups of people and doctors/healthcare providers impact peoples' health and the care they receive?

B.) How can doctors and medical researchers work to build trust with patients from communities that may not trust them? Is this important? Why or why not?