Background Reading for Debate

Ms. Kahn is teaching her science class about genetic testing. Her students have a range of opinions about whether or not genetic screening should be regulated by the government.

“I don't think that pregnant women should have genetic tests for their babies,” says Shana. “It's wrong to make choices about a baby's future based on genes.”

"I agree with you, Shana,” Colleen replies. “But some people might want to be tested even before they decide to have a child. Some genetic tests can tell adults if they are *carriers* for a fatal genetic disease. If both parents carry the gene, their child might have the disease when it is born. The parents might choose to adopt instead.”

Shana asks, “What does it mean to be a ‘carrier’ of the gene?”

“That has to do with what we were learning before about dominant and recessive alleles,” Dylan says. “If you have one dominant and one recessive allele for a trait, you’re a carrier for the recessive trait. The dominant trait is what you see. But if your child inherits your recessive allele and gets a same recessive allele from the other parent, then the child will have the trait. It works the same way whether you’re talking about blue eyes or a genetic disease.”

“People don’t usually talk about being a carrier for blue eyes, though!” says Colleen. “Usually they use the word ‘carrier’ when they’re talking about a disease, like sickle cell anemia.”

“Sicka what?” says Shana.

“Sickle cell,” says Colleen. “I think it makes your blood cells a funny shape, and then they don’t work right.”

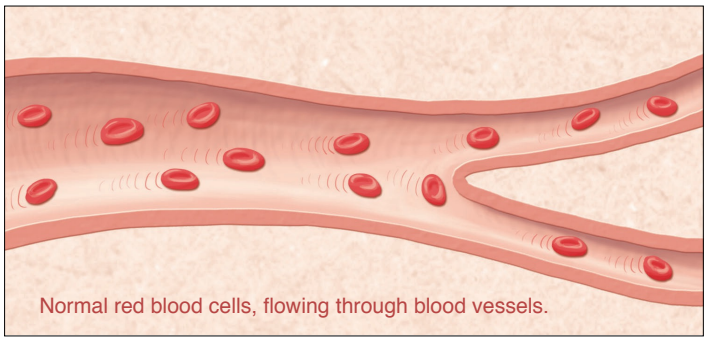
“That’s right,” says Ms. Kahn. “Normally, red blood cells have a circular shape. They have something called hemoglobin that carries oxygen to where it’s needed throughout the body. But when someone has two recessive sickle-cell-causing alleles, their body makes a slightly different form of hemoglobin. This form of hemoglobin causes the blood cells to have a sickle shape, kind of like a crescent moon. And the sickle cells don’t carry oxygen as well. Between the poor oxygen carrying capacity of the sickle cells and their tendency to catch on each other and block normal blood flow, sickle cell anemia is a serious health hazard. It can shorten life expectancy by a lot, although treatments have gotten better in recent years.”

“How do you catch it?” asks Andrew.

“You don’t catch it, you have to inherit it,” says Dylan. “That’s why it’s called a genetic disease.”

“I heard,” says Colleen, “that sickle cell anemia is more common among people who are from certain tropical places, or who are descended from those people. Why is that?”

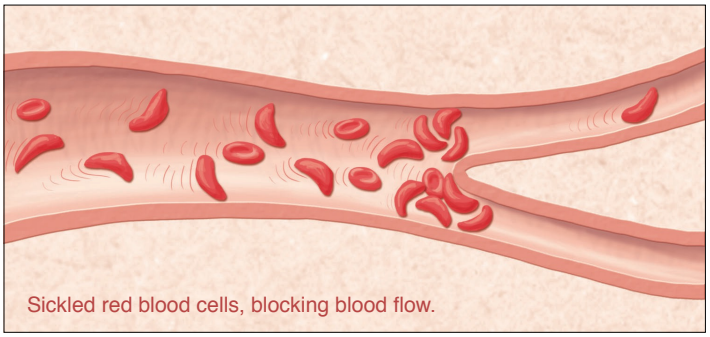
“Well,” says Ms. Kahn, “It turns out that although having the two recessive alleles that cause sickle cell anemia is bad for you, having just one of those recessive alleles can be an advantage in certain situations. The dominant allele in sickle cell carriers causes them to make enough normal hemoglobin that they generally don’t have the problems associated with sickle cell anemia. But the recessive allele is what’s called *incompletely recessive*: it does cause the body to make some sickle shaped blood cells with abnormal hemoglobin. And it turns out that this blood condition creates a harsh environment for a microscopic parasite that can get into the human bloodstream and cause malaria.”



Normal red blood cells, flowing through blood vessels.

Ms. Kahn continues, “Malaria is a disease that kills hundreds of thousands of people each year, and the parasite that causes it lives for part of its life cycle in humans, and the other part of its life cycle in mosquitoes that thrive in tropical areas. So malaria is much more common in the tropics, where so many of the mosquitoes are. People who are sickle cell carriers can still get malaria in the tropics, but they generally have less severe symptoms of the illness and have a lower risk of dying.”

“That’s kind of cool,” says Dylan. “The costs and benefits of having certain genes can vary depending on what you’re up against in your environment.”



Sickled red blood cells, blocking blood flow.

“Right,” says Colleen. “But here in North America, being a sickle cell carrier is pretty much all bad, because you probably won’t get malaria here, so all it means is that you might pass a dangerous allele on to your kids. I for one think the responsible thing to do would be to get a genetic test to find out whether or not I’m a sickle cell carrier before I decide whether or not to have a baby.”

"But even if you found out you were a carrier," says Dylan, "that wouldn't mean that your baby would have a risk of having sickle cell anemia unless the father was also a carrier. If the father just had two dominant normal alleles for hemoglobin, there's no way your baby could be born with sickle cell anemia."

"Well then," says Colleen, "I would want to know whether my husband was a carrier before we decided to have kids."

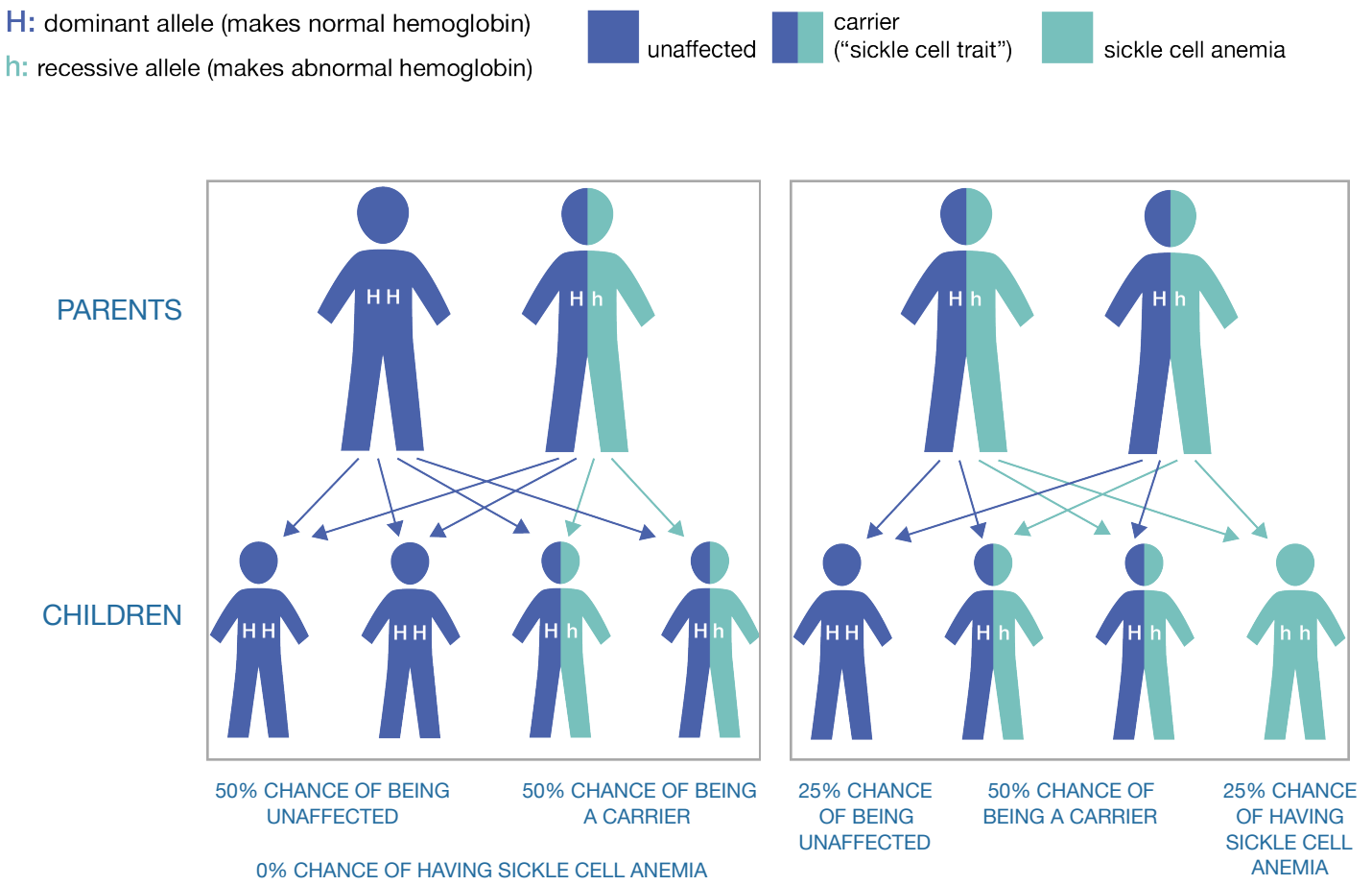
"You have a husband?" says Andrew. "But we're in middle school!"

"Ha ha, very funny. I mean if I were deciding whether or not to have children with somebody," says Colleen.

"Look, maybe you have a right to get a test if you want to, but I don't agree that you have a responsibility to get a test," says Shana. "And I'm very skeptical about the idea that anyone has a right to demand that somebody else get genetic testing. It's one thing if you want to test yourself. But everyone should have the right to keep their genetic information as private as they want, or even not get tested at all."

"I'm not so sure about that," says Colleen. "My husband's genes – uh, I mean my imaginary husband's genes – could have a big effect on me and my child. I'm responsible for that child, right? I think I would have a right to know about my husband's genetic information if I wanted to."

The class continues to debate who has a right to what genetic information.



Debate Success Tip:
Make sure you understand the difference between carrier ("sickle cell trait") and sickle cell anemia.