S.C.A.R.E.

talks

about

SICKLE CELL ANEMIA

Why get the facts about a blood disease like sickle cell anemia? The number of reasons for getting these facts totals about 2½ million.

That's the number of black Americans who either have sickle cell anemia or have the capacity to pass it on to their children . . . and their children's children.

Somewhat even more startling is that an estimated one-half of these 2½ million people know little or nothing about a disease that brings pain, crippling, and early death to the lives of its victims.

To help make this a thing of the past is one purpose of this booklet. It tells what the disease is . . . how you get it . . . how you know you have it . . . and what to do about it.

This is where testing comes in. Helping to make testing a thing of the present is still another reason for this booklet.

Quick and simple testing is now possible for everyone. To locate the special testing centers, call the nearest number listed on the last page of this booklet.

A visit to one of them might show the need for counseling and/or treatment should the test results show that the individual has sickle cell trait or the more severe form known as sickle cell anemia. The trait is likely to be found in 1 out of every 10 black Americans tested... sickle cell anemia, in 1 out of every 400.

On the other hand, no trace of either the trait or anemia is likely to be found in at least 9 out of every 10 individuals tested. That's another way of saying that a visit to a sickle cell clinic for 9 out of every 10 black Americans will lead only to peace of mind. And a few minutes of time is certainly a small price to pay for that!

Why not think all of this over as you read through the pages that follow? Then you can decide for yourself!

WHAT IT IS

Q. Why is blood so important to the body?
A. Blood is the life stream of the human body that carries food and oxygen to all of its parts. It also fights germs and helps rid the body of wastes.

Q. What are red blood cells?
A. One of the four main parts of blood. They move continually throughout the body leaving oxygen at places along their route and picking up carbon dioxide —a waste product of the body.

Q. What are healthy red cells like?
A. Healthy red cells have a round shape something like a doughnut. Their round shape makes it easy for them to float in the blood stream and move around the body.

Q. What is meant by hemoglobin?
A. Hemoglobin gives red cells their color. Without it, oxygen could not be carried throughout the body.

Q. What does hemoglobin have to do with anemia?
A. Too little hemoglobin in the red cells or too few red cells causes the condition known as anemia. It means that the body cannot get as much oxygen as it needs to be healthy.

Q. What is meant by sickle cell anemia?
A. There are many different kinds of anemia. One of them is known as sickle cell anemia. It is called "sickle cell" because the red cells actually take on the shape of a sickle when the oxygen in them gets too low.

Q. What is the danger of having red cells shaped like sickles?
A. To begin with, the amount of oxygen in these cells is low. In addition, their sickled shape makes it hard for them to float in the blood stream with ease. Not only do they clog up at certain passageways—they break apart. They break so easily that the body is not able to make new cells fast enough to take their place.

Q. Do people with sickle cell trait have red blood cells that are shaped like sickles?
A. No, people with sickle cell trait do not have red blood cells shaped like sickles. That is why this form of the disease is not usually active, and treatment is necessary only in extreme situations that will be described later.

Q. Do the red blood cells of people with sickle cell trait differ in any way from normal cells?
A. Yes, in people with sickle cell trait some of the hemoglobin is abnormal, but not as much as in people with sickle cell anemia.

HOW YOU GET IT

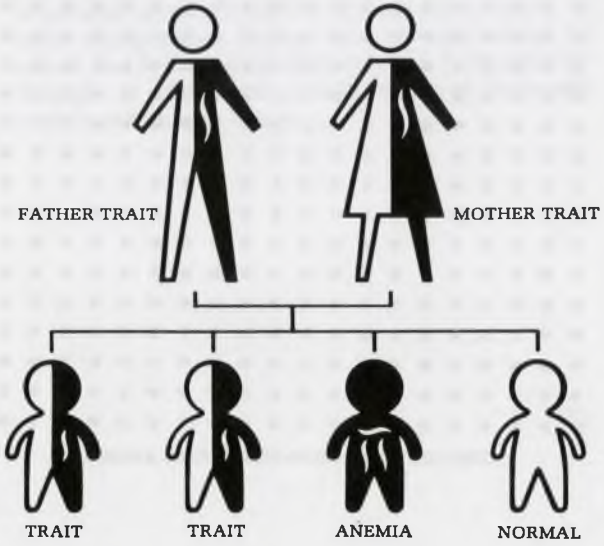
Q. Is it possible for the trait to turn into the serious form known as sickle cell anemia?

A. No, the trait cannot become sickle cell anemia . . . but occasionally can be just as serious. For example, the sickling of the red blood cells can be brought on by situations in which an extreme loss of blood or a severe loss of oxygen takes place. Situations like a sudden accident or a major surgical operation might bring about an extreme loss of blood. A severe loss of oxygen could result from riding in an unpressurized airplane or from climbing a very high mountain. Treatment becomes necessary for sickle cell trait only in these extreme situations or others like them.

Q. Why then is it so dangerous to have the trait?
A. It is dangerous to have the trait because the trait can be passed down to one's children when they are born just like the color of eyes and the size of body are passed down. In fact, if both parents have the trait, it is possible for their child to be born with the more serious form of the disease known as anemia.

Q. Is there more than one way of getting sickle cell trait or sickle cell anemia?
A. No, the only way to get either form of the disease is to be born with it. It cannot be spread from one person to another like a cold or like the measles.

Q. What are the chances that parents with sickle cell trait will pass it on to their children?
A. Every time a man and woman who both have the trait, have a baby, the chances are: (a) two in four that the child will have the trait just like its parents; (b) one in four that the child will have the serious form known as sickle cell anemia; and (c) one in four that the child will have no form of the disease at all.

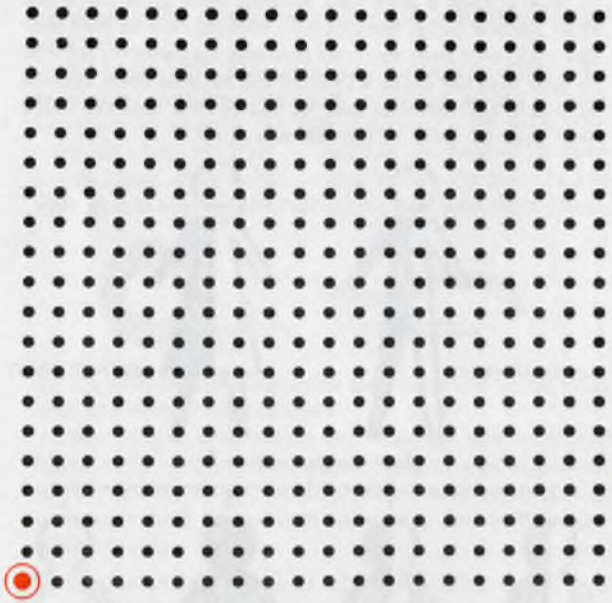


WHO CAN GET IT

Q. Are some races of people more likely than others to have this disease?
A. Yes, people whose ancestors came from Africa are more likely to have it. This means particularly black people, but Caucasians from the Mediterranean area, the Middle East, and parts of India may also have it.

Q. Just how many people have this disease?
A. One out of every ten black Americans have the trait; one out of every four hundred of them have sickle cell anemia. This means that well over two million people in this country have the trait; more than 50,000 have sickle cell anemia.

ONE OUT OF TEN HAVE THE TRAIT



ONE OUT OF 400 HAVE SICKLE CELL ANEMIA

HOW YOU KNOW YOU HAVE IT

Q. Is it possible to tell at birth whether a child has sickle cell anemia?
A. Yes, it is possible—but only by using special tests designed for this purpose. Other means are not possible because the disease does not usually show itself until the child gets to be at least 6 months old. This is when the symptoms of the disease can first appear.

Q. What is meant by symptoms?
A. Symptoms are ways of telling that a disease or condition is keeping the body from being healthy. For example, a sneeze is a symptom of a cold; a rash is a symptom of the measles.

Q. What then are the symptoms of sickle cell anemia?
A. There are many different symptoms of sickle cell anemia. Some people have all of them; others have some of them. People with it: (a) get pale, tired, and short of breath; (b) have pain in their arms, legs, back, and stomach; (c) lose their appetites; (d) have eyes that take on a yellow cast; (e) have joints that swell up; (f) have bodies that do not grow and develop as fast as they should; and (g) have low resistance to infections.

Q. When are the symptoms at their worst?
A. The symptoms are usually at their worst in the young child and during periods of time known as sickle cell crises. Symptoms often become milder as the child grows older.

Q. In spite of this, do people with sickle cell anemia die at an early age?
A. Yes, many people do, but only recently doctors have begun to realize that certain patients with sickle cell anemia can live well beyond the age of 40. New and improved methods of treating infections and other conditions arising from this disease have helped to make this possible. Today, there is every reason to expect that in the not too distant future, further breakthroughs in science will permit victims of sickle cell anemia to live even longer.

WHAT TO DO ABOUT IT

Q. Is there a cure for sickle cell anemia or sickle cell trait?
A. No, there is no cure for sickle cell anemia or the trait. However, a lot of research is going on to find new ways of treating the disease. Infections that frequently go along with the disease can be helped through the use of special drugs known as antibiotics.

Q. Why then is it important for people to know whether they have the trait–since there is no cure for it?
A. There are at least two good reasons why it is important for people to know whether they have the trait.

(1) To take care of their own health. Doctors should be told when this disease is present even if a patient is being treated for some other ailment or condition as in pneumonia, pregnancy, or major surgery. Otherwise, trouble could develop. Other situations might also arise in which special treatment would be required. They are likely to result either from an extreme loss of blood or a severe loss of oxygen. A showing of blood in the urine is one symptom that calls attention to the need for treatment.

(2) To plan for the health of future children. People should know whether they have the trait before marriage. This permits a couple to get advice from a doctor on the risk of having a child with sickle cell anemia–especially if both of them carry the trait. Also, families in which the trait is present should be prepared to teach their children what the disease is and how it can affect their lives. One of the best times to teach this to children is during their high school years when they have some understanding of the biology of the human body and the role of genes in its growth.

Q. Since there are usually no outward symptoms of sickle cell trait and the symptoms of sickle cell anemia are sometimes mistaken for other ailments, how can someone find out whether they have this condition?
A. Only a special blood test can tell for certain whether a person has sickle cell trait or the anemia. ORDINARY BLOOD TESTS DO NOT REVEAL THE TRAIT. ORDINARY BLOOD TESTS CAN ONLY SUGGEST THAT SICKLE CELL ANEMIA MIGHT BE PRESENT.

Q. What is the test for "sickle cell" like?
A. The test is quick and easy, taking only a few minutes of your time. There are two main parts to it: (1) a doctor or technician pricks your finger to get a small drop of blood; and (2) a special test is done on that blood sample. The results tell whether or not the red blood cells contain some of that particular kind of abnormal hemoglobin known as sickle hemoglobin.

Q. What happens when the test shows that the red blood cells contain some sickle hemoglobin?
A. This first simple test is really known as screening. If the test shows signs of sickle hemoglobin, you would be asked to return for a different kind of blood test that is longer than the first. This second test tells for sure whether you have sickle cell trait, anemia, or possibly another form of the sickle cell disease.

Q. After this second test has been completed, what would be the next step?
A. The results of this test will permit a doctor at the clinic to give medical advice that is right for you. Should the test show that you have sickle cell trait–you would receive counseling. If you have sickle cell anemia–you would be given further tests as well as special medical treatment and counseling.

Q. Are relatives of a person with sickle cell anemia apt to have it too?
A. Yes, it is likely that relatives of someone with sickle cell anemia would have either that or the trait. Therefore, it is even more important for them to be tested.

Q. Where can someone go to be tested?
A. A list of all the clinics where you can be tested for "sickle cell" is given on the last page of this booklet.

A visit to one of them might show the need for counseling and/or treatment–should the tests show that the individual has sickle cell anemia or carries the sickle cell trait. But remember, chances are at least 9 out of 10 that your test will show neither the trait nor the anemia. In other words, a visit to the clinic for 9 out of 10 black Americans will lead only to peace of mind.

ALL MEMBERS OF THE BLACK COMMUNITY SHOULD BE TESTED FOR "SICKLE CELL."

CALL FOR INFORMATION:

S.C.A.R.E.

Sickle Cell Anemia
Research & Education, Inc.

1930 Sutter Street
San Francisco, CA 94115

(415) 563-6040
(24 hours)

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1115 Broadway
Oakland, California 94618
(415) 452-4014

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or consult your
local chapter

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SCARE (Sickle Cell Anemia Research and Education, Inc.) provides free testing, community education, genetic counseling, and medical care services to the at-risk population through its network of chapters, and sponsors research projects all across the country to provide the best methods of treatment to victims of Sickle Cell Anemia and related blood diseases.

If you need more information, or would like to join this vital effort, just write or send your contributions to:

S.C.A.R.E.
P.O. Box 40118
San Francisco 94140

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