HEALTH

HEALTHWIRE

TAKING ANOTHER LOOK AT SICKLE CELL DISEASE

PART II

Even with diminishing funds, medical professionals are hopeful concerning the development of treatments for SCD. Previously, the estimated median life span of SCD patients was only 20 years. Now, with advances in preventive treatment and updated guidelines for screening, doctors and scientists are predicting longer, healthier lives for infants diagnosed with SCD. "The outlook for sickle cell disease patients in the 90's is encouraging," according to Oswaldo Castro, director of Howard University's Comprehensive Sickle Cell Center.

That increase is attributed to the 1986 discovery that twice-daily doses of penicillin reduce the risk of infants developing the deadly infections that are more invasive when sickle cell is present. Now, infants diagnosed with the disease are immediately administered penicillin for at least the first five years of life.

Other treatments on the horizon are butyrate and hydroxyurea. Butyrate is a natural animal fatty acid that stimulates the production of fetal hemoglobin found in fetuses that could possibly reduce symptoms of sickle cell disease in adults and children.

"The more fetal hemoglobin you can get into the cell, the more nonpolymerizale (non-clotting) molecules you have," said Samuel Charache, professor of medicine at Johns Hopkins Hospital (Journal of the American Medical Assoc. Vol. 264, No. 4). With less clotting in the blood stream, sickle cell anemia patients have fewer of the painful episodes associated with the disease.

Hydroxyurea, like butyrate, also increases fetal hemoglobin but decreases bone marrow which could lead to brittle, easily broken bones. It also is most effective at dosage levels that are near toxic which can be dangerous. Neither butyrate or hydroxyurea are considered potential cures for SCD. Both treatments are still being tested and are not generally available to SCD patients. Bone marrow transplants and gene therapy come the closest to providing doctors with hope for a cure for SCD, according to Charles F. Whitten, director of Wayne State University's Comprehensive Sickle Cell Center.

The manufacturing of red blood cells occurs in the bone marrow. Therefore, by replacing the bone marrow of a sickle cell patient with that of a healthy patient, normal production of red blood cells is induced. Whitten cautions that the chances of the host rejecting the imported bone marrow are so high that transplants are not currently recommended. Bone marrow transplants are also restrictive, he says, because they require a full sibling donor.

Gene therapy replaces the gene for the sickle-causing hemoglobin with a gene of a normal hemoglobin. However, the technique is still in the early stages of development and has yet to be tested on humans.

Castro stresses the need for parents to take greater reproductive responsibility. "Unfortunately, even now there are still too many couples who are unaware of their risk and who will be surprised by the diagnosis of sickle cell disease in their newborn infants," he says. Adults can be screened to determine their likelihood of bearing a child with the genetic disorder or prenatal screening can be done as early as nine weeks after conception. A 1992 survey shows universal neonatal screening is already in place in all but seven states and only 13 states do not mandate testing.

Medical professionals do not want those diagnosed with SCD or with sickle cell trait to consider their futures bleak. For potential parents who both have the sickle cell trait and choose not to have children, adoption might be considered. In other circumstances, education and a strong family and medical support system can soften the impact of the disease and can improve the lives of those with SCD.

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WHAT PARENTS & COUPLES PLANNING TO BECOME PARENTS SHOULD KNOW ABOUT SICKLE CELL TRAIT

In the United States there are more people with sickle cell trait than sickle cell disease (SCD). Though carriers of sickle cell trait are often as healthy as non-carriers and have no chance of developing the disease themselves, there are some important facts that couples planning to have children should know about sickle cell trait.

How does one get Sickle Cell Trait? It is contagious. Sickle Cell Trait like hair color, eye color, and other physical characteristics is passed down from parent to child through the genes.

How is Sickle Cell different from Sickle Cell Disease? Unlike Sickle Cell Disease, Sickle Cell Trait does not cause any major health problems. The only time Sickle Cell Trait may cause illness is in situations where oxygen is low (such as at very high altitudes). People with Sickle Cell Trait may also need special attention if they have anesthesia for surgery.

If my child has Sickle Cell Trait should I be tested? Yes. If your child has Sickle Cell Trait it means that either you or your partner or both of you are carriers of the trait. If only one of you has the trait, you cannot have a child with Sickle Cell Disease. However, if both of you are carriers of the trait you can have a child with Sickle Cell Disease.

What are the chances of two partners with Sickle Cell Trait having a child with Sickle Cell Disease? There is a 25% chance with each pregnancy that the child will have Sickle Cell Disease. There is a 50% chance that the child will have Sickle Cell Trait and a 25% chance that they will neither carry the trait nor have the disease.

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AIDS COMMUNITIES TO FIGHT FOR 1994 CLINTON BUDGET

AIDS COMMUNITIES FACE A tough fight to increase federal funding for AIDS programs in 1994.

Despite a strong commitment from the White House, conservative anxiety about the federal deficit and partisan politics may make AIDS funding a victim of congressional budget slashing. Senate intentions on funding issues were signaled by the body's failure to pass President Bill Clinton's economic stimulus package, which included an additional $200 million in emergency money for the Ryan White CARE Act for this year.

"We're finally seeing leadership from the White House which we've never seen before," notes AIDS Action Council (AAC) legislative affairs director Karen Ringen. "This is a clear signal to the communitees that the president is serious."

The Clinton budget, released on April 8, contains over $500 million in increases for HIV-related research, prevention and health care services. Overall, the

(See AIDS, Page 21)

BELINDA ROCHELLE