

## Medicaid Act Expanded to Include Sickle Cell Disease

In October 2004, the Sickle Cell Treatment Act (S. 874/HR 1736) was enacted as part of the JOBS Act. The Sickle Cell Treatment Act was sponsored by Senators Chuck Schumer (NY) and Jim Talent (R-MO) and carried wide bi-partisan support in the Senate. The legislation adds treatment for Sickle Cell Disease an optional Medicaid service.

According to the legislation, covered strategies and treatments include chronic blood transfusions to prevent stroke, genetic counseling and testing, and other treatment and services to prevent stroke. Notably, nothing in the new legislation “shall be construed as implying that a State Medicaid program ... could not have treated, prior to the date of enactment of this Act, any of the primary and secondary medical strategies and treatment and services” described in the legislation under its Medicaid program, including as Early and Periodic Screening, Diagnostic and Treatment services. The legislation also provides an enhanced 50 percent federal matching rate for services to identify and educate individuals who are likely to be eligible for Medicaid and who have Sickle Cell Disease or are carriers and for education regarding the risks and prevention of stroke and other complications.

Additionally, the legislation creates 40 Sickle Cell Disease Treatment centers across the country. A National Coordinating Center will coordinate the research conducted by health professional and universities and distribute model protocols and educational materials. An annual appropriation for fiscal years 2005 through 2009 is included to carry out these activities.

Sickle cell disease primarily affects African-Americans. It is an inherited defect in blood that causes normally round blood cells to take on a sickle shape. These sickle-shaped cells clog the blood stream, creating obstructions that result in severe medical complications. The disease affects approximately 70,000 Americans; more than 2.5 million Americans, mostly African-Americans, carry the sickle cell trait. According to Senator Schumer, “While we have known about the dangers of Sickle Cell Disease among African Americans for a long time; new immigration trends in New York—including new immigrants from West Africa—appear to be driving a sharp increase in Sickle Cell Disease in Harlem and other communities in New York.”