

Health Insurance for Adults with Sickle Cell Disease

One of the most frustrating problems that adults with sickle cell disease face is health insurance coverage. Most individuals with sickle cell disease, upon turning the age of eighteen, must separate from their guardian's insurance coverage. Unless the adult with sickle cell disease finds group coverage at work, he or she faces an exhaustive search for adequate individual insurance coverage. For individuals and small groups, insurance providers use medical history, as well as individual risk factors such as sickle cell disease, to determine whether to provide coverage and under what terms. This is known as "underwriting". Insurers believe that affected individuals elect not to purchase insurance until they are already ill or anticipate a future need for health care. Therefore, insurers are given the right to underwrite any individual who does not seem to need major health care. This is the reason why adults with sickle cell disease find it hard to obtain individual health coverage. It is preferable to obtain a job which offers group insurance to all employees. Individual insurance can be obtained but it is very expensive.

As a whole, the sickle cell population needs to join together to change the negative assumptions perpetuated in the insurance industry and other communities. It is a fact that only a low percentage of affected persons have frequent hospitalizations. However, it is this percentage of individuals who are counted into primary statistics. More accurate studies cannot be initiated without the cooperation and unification of the less frequently ill sickle cell population.

According to researchers from the National Center for Human Genome and NIH-DOE Working Group, no federal laws are currently in place to prohibit health insurance discrimination based on genetics. However, Florida and Alabama laws prohibit insurers from denying coverage on the basis of the sickle cell trait. North Carolina prohibits insurers from denying coverage because the applicant has the hemoglobin C or sickle cell trait. Maryland prohibits discrimination in rates based on any genetic trait unless there is actuarial justification (insurance risk). California, Oregon, Colorado, Minnesota, Ohio, Georgia, New Hampshire, and Wisconsin prohibit insurers, to varying degrees, from requiring or requesting genetic tests or their results, from denying coverage on the basis of genetic tests, and from using tests to determine rates and benefits. California, Colorado, Oregon, and Wisconsin laws include provisions to protect the privacy of genetic information. However, none of these laws prohibit insurers from denying coverage based on prior insurance claims.

In 1996, Congress enacted a law, called The Health Insurance Portability and Accountability Act (HIPAA), which took a significant step toward expanding access to health insurance. HIPAA includes genetic information among the factors that may not be used to deny or limit insurance coverage for members of a group plan. Further, HIPAA explicitly excludes genetic information from being considered a preexisting condition in the absence of a diagnosis of the condition related to such information. HIPAA also prohibits insurers from charging one individual a higher premium than any other "similar situated" individual in the group. If an individual with sickle

cell disease leaves employment, he or she could carry the health insurance coverage individually. Information about HIPAA can be obtained from most health insurance companies. Deception in application for insurance results in denial of benefits in time of need.

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