

## **Genetic Screening & Discrimination - Relevance of historical experience**

### **Background:**

Sickle cell anemia is an autosomal recessive blood disease – a person has to have two copies of the sickle cell version of the beta-hemoglobin gene (HbS) to develop the disease. People who have inherited only one copy of the “sickle” variant do not suffer from the disease. However, they can pass the variant on to their children; they are referred to as carrying the sickle cell “trait.” Sickle cell anemia affects people of all races but it affects people of African-American descent with the greatest frequency. During the 1970s, sickle cell screening programs were developed to identify individuals with the sickle cell trait in an effort to reduce the incidence of sickle cell disease. Due to inadequate education and counseling, however, there was confusion about the differences between sickle cell trait and sickle cell disease. This often resulted in stigmatization and unfair discrimination.

### **Vignette:**

James Sr. was the class valedictorian at Central High School in 1975 and earned an aerospace degree from Georgia Institute of Technology. He became an accomplished pilot for Skyway Airlines, but his dream of flying ended when his employer restricted him from being a pilot even though he had outstanding scores on all his physical tests, because a blood test revealed the sickle cell trait.

James Jr. has his father’s ambition to become a pilot. He has just graduated from college with an aerospace engineering degree and was looking for a job as a pilot. His father has read recent newspaper stories about how most employees are not protected from genetic discrimination in the workplace. He is very worried that his son might also have sickle cell trait and be denied a job. James Jr. thinks his dad is overreacting and does not want to discuss these issues with his dad. He dismisses his father’s concerns and is ready to interview with a number of airlines and willing to give a blood sample if necessary.

### **Discussion points:**

Are James, Sr.’s concerns justified?

What lessons can be learned from the sickle cell screening programs of the 1970’s?

Is it reasonable for any employer to collect a blood sample from prospective employees and screen them for genetic variations?

What additional concerns are there when a genetic test is available for diseases with a higher prevalence in minority populations?

**Additional resources:**

Executive Order signed by President Clinton on 8 Feb 2000

To Prohibit Discrimination In Federal Employment Based On Genetic Information

[http://www.nhgri.nih.gov/NEWS/Executive\\_order/index.html](http://www.nhgri.nih.gov/NEWS/Executive_order/index.html)