STATEMENT

ALLIANCE OF GENETIC SUPPORT GROUPS
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

Genetic Discrimination and Privacy of Medical Records

MAY 21, 1998

Since 1986 the Alliance of Genetic Support Groups has worked to promote the interests of children, adults and families living with genetic conditions. As a coalition of consumers and genetics professionals, the Alliance has an umbrella membership reach of more than a million individual and genetic support group members. The Alliance toll-free helpline serves as a direct link to consumer concerns about the privacy of personal genetic information and genetic discrimination. We work to educate professionals and the public about the issues that touch the lives of these individuals. By supporting policies that normalize the life experiences of children and families, the Alliance works to foster personal, economic and social competence and autonomy.

The Alliance views the following principles as central to public dialogue about genetic discrimination and privacy of medical records.

- Genetic conditions are universal. Every man, woman and child has some genetic predisposition, condition or disease resulting from inherited or acquired genetic changes.
- Genetic information is inherently personal and must be treated as confidential and proprietary.
- Access to health care, education and employment is essential to all individuals, regardless of genetic inheritance.

There are children, adults and families across these United States whose lives are touched in profound ways by the promise of biotechnology and genetics medicine. There are also hundreds who already experience narrow windows of opportunity for employment, health care services and education because of identification with a genetic condition.

We know that history repeats what is not remembered. In the early seventies, the promising discoveries about sickle cell anemia resulted in gross violation of medical and genetic privacy, misuse of genetic test information and tragic injustice for productive individuals who lost jobs, health care and homes -- the very fabric that holds life together. Private and public employers arbitrarily discriminated against carriers of sickle cell trait as well as affected individuals without regard for performance track records, without assessing long-term productivity and health care risks and, in some cases, without accurate understanding of the implications of carrier status. Sadly many victims were healthy "carriers" of sickle cell trait or simply presumed to be affected because they were in a high risk racial group.
Now in 1998 the real life stories of Alliance helpline callers indicate that advances in genetic identification technologies pose increasing risks to health care and employment for growing numbers of the American public. Our toll-free helpline serves as a direct link to consumer concerns about privacy of personal genetic information and protecting access to jobs and health care.

Without doubt, the impact of genetic discrimination can be catastrophic for the individuals and families involved. However the impact of genetic discrimination must be measured in terms of broad and long range societal impact on public health and well-being and the future of medical research. Individuals tell us that they weigh the risks of genetic testing against the knowledge that test results could guide their medical and reproductive decisions. These same worries have led many to decline participation in clinical research studies that hold the most potential benefit for their future generations. If consumer confidence in the privacy of medical and genetics information is not restored, researchers won't be able to find the participants necessary to complete clinical research studies and deliver on the promises of genetic discoveries.

We know from daily calls to the Alliance helpline that the public is concerned about the privacy of personal genetic information and medical records. Without the assurance of federal protections of personal genetic information, public fears about genetic discrimination already threaten the pace of genetic research. Moreover, the Alliance is concerned that employers and insurance underwriters will target individuals identified with genetic conditions and restrict their opportunities to create productive and autonomous lives. Genetic discrimination threatens to create an underclass of citizens who are uninsurable and unemployable, at enormous public, financial and moral cost.

Nearly 30 years have passed since the sickle cell anemia tragedies, but we have not yet succeeded in making the public fully aware of the critical issues, as well as great promise, we face. This is a problem that will continue to grow with the rapid pace of genetic research and technology. We can now test for about four hundred genes but that small number will grow to the thousands, giving us the ability to identify predisposition and susceptibility to much more common health problems. Some day, fast and complete DNA analysis will be available. Since each of us is likely to carry five to seven mutated genes, we are all at increased risk for genetic discrimination as the detection sensitivity and cost effectiveness of genetic technologies improve.

These wonderful and inspiring scientific advances of the Human Genome Project have accelerated the need for federal protections. With each step forward, we come closer to finding new treatments for genetic conditions and unlocking secrets about common diseases. Without federal protections, however, these advances can also bring us closer to the risk of misuse of genetic technologies and the potential for harm.

The Alliance of Genetic Support Groups affirms that the development of appropriate policy and legislation requires input from those most affected by these decisions and best able to foresee the impact of proposed legislation.

- The Alliance calls for the unequivocal prohibition of genetic discrimination of all kinds, including discrimination in employment, health insurance and education.
- The Alliance urges you to ensure that disclosure of genetic information not be a condition of employment, health insurance, or school admission.
- The Alliance affirms that genetic information is inherently personal and must be treated as confidential and proprietary.

Every American -- regardless of genetic inheritance -- deserves the protection that federal legislation alone can provide for this generation and for generations of Americans to come.