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Washington, DC: Hailing President Clinton as forward thinking, Alliance of Genetic Support Groups\* Executive Director Mary Davidson joined him at the White House today to support legislation protecting the privacy of genetic information and prohibiting health insurance companies from discriminating against healthy people on the basis of their genetic inheritance.

"The Alliance of Genetic Support Groups wholeheartedly supports the scientific work of the National Human Genome Research Institute," said Davidson. "We are thrilled with rapid advances in mapping gene locations and related diseases. With each step forward, we come closer to prevention, treatment and cures," she emphasized.

"With all the wonderful scientific advances, however," Davidson cautions, "comes increasing potential for misuse of genetic information and the potential for harm, along with hope and promise. Genetics will be the civil rights issue for the twenty-first century. In making a public commitment to ban health insurance discrimination based on genetic inheritance, President Clinton is looking ahead to the twenty-first century. Soon we will be able to decipher the genetic composition of each individual at a glance and we will likely discover that we all have some potentially deleterious genes. Without legal protections, every one of us and our families could be at risk of genetic discrimination."

"Consumers live in constant fear that we will not be able to get the medical care we need when we get sick. Many families have had to face the grim option of letting loved ones die or bankrupting the family to pay medical costs because their health insurance was canceled. This legislation, which will help prevent insurers from denying coverage to families because of genetic inheritance, is another step closer to protecting children, adults and families already living with genetic diseases."

"The Kassebaum-Kennedy Bill passed in the 104th Congress made an outstanding first step toward preventing insurers from utilizing preexisting conditions clauses -- and including genetic diagnosis in that definition -- to deny coverage for people who are changing jobs or health insurance policies. The Alliance of Genetic Support Groups strongly supports the expansion of these civil rights protections to all Americans, including prohibitions against genetic testing as a condition of coverage, limits on disclosure of results to third parties, and standard utilization of informed consent so that consumers can know and understand their rights and obligations."

\*The Alliance of Genetic Support Groups is an active champion for genetic and medical privacy, protection against genetic discrimination, and access to affordable and quality health care. Representing a coalition membership of more than a million families, genetics professionals and members of genetic support groups, the Alliance of Genetic Support Groups provides information, referral and support to people with genetic conditions and educational services to professionals and the public. Our toll-free help line (1 800 336-GENE) serves as a direct link to families who are struggling with these critical civil rights issues and looking for information, referral, peer support and community resources.