

August 24, 2011

Honorable Jerry Brown
Governor, State of California
State Capitol
Sacramento, CA 95814

Re: CRG Support for SB 559, the California Genetic Information Nondiscrimination Act (CalGINA)

Dear Governor Brown,

For over 25 years, the Council for Responsible Genetics has advocated for strong genetic nondiscrimination and privacy protections for all Americans. CRG first coined the term "genetic discrimination" and collected hundreds of examples of and performed some of the first case studies on it. CRG helped develop the first model legislation on genetic discrimination and I personally was a leader of the successful effort to enact the federal Genetic Information Nondiscrimination Act and a number of the state laws that preceded it. Nevertheless, current law is limited in its coverage; there simply is no comprehensive genetic privacy law in this country.

Today, the Council for Responsible Genetics urges you to sign SB 559, the California Genetic Information Nondiscrimination Act (CalGINA); historic legislation to protect against unfair genetic discrimination. By setting clear limitations on the use of personal genetic information in a variety of contexts unforeseen just a short time ago, including housing, education, life insurance, mortgage lending and elections, this bill represents an important step forward in ensuring that the genetic information of Californians is protected from misuse.

Ten years after the mapping of the human genome was completed, the genetic revolution has led to a tsunami of DNA data created by genetics research and the commercialization of such research. As more and more of this personal information becomes public knowledge, it can be bought and sold by any commercial interests interested in predictive information about an individual's future health status. The public must be assured that undergoing genetic testing will not endanger their economic security. Consider the case of Lawrence-Berkeley Laboratories, which for almost three decades gave its employees medical examinations that included tests for syphilis, sickle cell genetic markers and pregnancy without their knowledge. Such systematic violations of the expectations of people whose personal health information is being used without their consent is just wrong. It's a violation of basic human rights. Indeed, a recent survey by Cogent Research found that 71% of all Americans are concerned about access to and use of their personal genetic information.

The Council for Responsible Genetics urges you to sign SB 559, and confer upon California citizens the strongest protections in the country against genetic discrimination; placing California once again in its role as a leader in addressing the social and ethical implications of new technologies and biotechnologies in particular.

Sincerely,



Jeremy Gruber, President
Council for Responsible Genetics

CC: Gareth Elliott, Legislative Secretary, and Aaron Maguire, Deputy Legislative Secretary

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