

April 5, 2011

To: Sen. Susan C. Fargo and Rep. Jeffrey Sanchez
and members of the Joint Committee on Public Health

From: Jeremy E. Gruber, President
Council for Responsible Genetics

Senate Bill 1080, Legislation to Create a Genetic Bill of Rights

Introduction:

My name is Jeremy Gruber and I am the President of the Council for Responsible Genetics (CRG). Founded in 1983, CRG is a national non-profit organization based in Cambridge, Massachusetts that studies the social, ethical and environmental implications of genetic technologies. CRG represent the public interest and seeks to distribute accurate information on emerging issues in biotechnology. CRG also publishes a bimonthly magazine, *GeneWatch*, the only publication of its kind in the nation. Among other accomplishments, CRG played a leading role in enacting Massachusetts' current genetic nondiscrimination law and I worked closely with the late Senator Kennedy in leading the successful effort to pass the Genetic Information Nondiscrimination Act in Washington. CRG has assisted policymakers at the federal and state level to formulate policies on various topics related to genetics and has played a leading role in educating the public on issues ranging from forensic DNA databases to direct-to-consumer genetic testing, gene patents and worker safety in biological laboratories.

Testimony:

During the past several decades, our understanding of genetics has multiplied as procedures for identifying, analyzing and manipulating DNA have advanced. Among the many benefits of these efforts are the ways they may influence preventive health, reproductive planning and eventually therapies to cure illnesses with a genetic component. While no one can deny that this knowledge may be a blessing in finding cures to diseases with genetic origins, the immediate consequences of such advances have lead to a number of forms of individual discrimination. The ability to identify individuals based on genetic characteristics necessarily predates the ability to use this information in the treatment of the corresponding diseases. Furthermore, genetic information only indicates a predisposition or susceptibility to future illness; such information does not necessarily indicate when an individual will develop symptoms or how severe the symptoms will be. In fact, we are all at a significant absolute risk for common diseases whether or not our genetics indicates a slightly increased or decreased predisposition over the general population and such tests are often unreliable as a

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risk indicator when delivered without reference to family history, environment and lifestyle. Many people who test positive for genetic mutations associated with certain conditions will never develop those conditions at all. Many individuals identified as having a hereditary condition are, indeed, healthy. Genetic information does not necessarily diagnose disease.

Yet we have already encountered instances of genetic discrimination and abuse of genetic information. Consider the case of Burlington Northern Railroad, which conducted covert genetic testing on employees who had filed workers compensation claims for injuries resulting from working on the railroad tracks with heavy machinery. The employer attempted to deny millions of dollars for medical bills and disability by claiming those workers had a pre-existing condition to certain injuries. Or consider "Janet", a 51-year-old woman with a family history of breast and ovarian cancer. She was advised by a genetic counselor to consider genetic testing in order to guide her medical decision-making about preventative surgery. However, Janet knows that genetic privacy protections in our state are still limited. For now, she is delaying important decisions regarding genetic testing and potential medical intervention until comprehensive protections are in place.

Indeed, a recently released Cogent research survey found that the proportion of Americans who are concerned about how their genetic information would be stored and who would have access to that information, has climbed from 65% in 2006 to an all-time high of 71% in 2010. As public concern mounts with the growth of medical technology, it is crucial that restrictions be placed on the accumulation of genetic information by entities that would seek to leverage its predictive value for discriminatory purposes. Without meaningful privacy safeguards and protections against discrimination, the benefits of genetic testing will ultimately be lost as individuals avoid tests in the fear of adverse consequences

Massachusetts has a long and proud tradition of understanding and responding to these challenges. As a world leader in genetic research our state recognized early on both the potential for improvements in the human condition that such research offered as well as the potential for harm. In 1995, long before most states had studied this issue, this body created the Special Committee on Genetic Information Policy to do so. The Council for Responsible Genetics worked hard with the Committee and the entire legislature and in 2000, the state of Massachusetts passed the strongest law in the country safeguarding the confidentiality of genetic information and protecting against its misuse. Only eight years later did Congress catch up and pass similar legislation. I worked for 12 years leading that effort and working with the lead sponsor, the late Senator Kennedy. As the debate over federal legislation progressed, the Massachusetts law regularly served as a standard to aspire to.

Massachusetts citizens were granted these protections because well over ten years ago, this body recognized and appreciated that the potential for harm is great as genetic information, including both data derived from gene sequencing as well as supplemental family history and other personal and medical data, offers a wealth of details about the individual and their genetic relatives. Medical secrets are among the most sensitive we hold. It responded by ensuring that the citizens of Massachusetts were given back some control over their own DNA, ensuring that it was not used improperly by employers and health insurers and protecting its privacy.

Now, ten years after this legislation was passed and the mapping of the human genome completed, the genetic revolution has led to a tsunami of DNA data created by genetics research and the commercialization of such research. And the commercialization of genetics is well underway. 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. Current law does nothing to prohibit discrimination in life insurance, disability insurance, long-term care insurance, mortgages, commercial transactions, or any of the other possible uses of genetic information. The public must be assured that undergoing genetic testing will not endanger their economic security.

The Genetic Bill of Rights builds on the strong foundation of Massachusetts' current protections against genetic discrimination and misuse of genetic information by setting clear limitations on the use of personal genetic information in a variety of contexts unforeseen just ten years ago including protections against the use of genetic information in workers compensation claims and for marketing or determining credit worthiness. With the proliferation of genetic information, particularly in consumer contexts, this legislation sets strong standards on the disclosure of such data and ensures that genetic information and material are treated under state law in a manner similar to other medical records and creates a duty to report in the event of known security breaches or unauthorized use of personal information. Mistakes and other breaches of security are not uncommon. Just last year, the direct to consumer genetic testing company 23andMe accidentally sent data of up to 96 individuals to the wrong customers.

Indeed, as genetic research and commercial genetics applications have proliferated, narrow ethical precepts governing human subjects research have coupled with little to no regulation of commercialized genetics. This toxic combination has ridden roughshod over the reasonable expectations and the appropriate rights of the people whose data and materials are implicated. Take the case of the Texas Department of State Health Services which sent the genetic information of newborns to Texas A&M University for research without the parents consent. Some of those samples found themselves in an armed forces database. Or consider the case of members of the Havasupai tribe, a small, isolated community who gave DNA samples to researchers from Arizona State University to contribute to research that could help determine the cause of the tribe's very high rate of diabetes. Nothing much came of the diabetes study, but over a decade later, the Havasupai discovered that over 20 academic articles had been published based on studies conducted at the university using Havasupai DNA, studying an array of topics the tribe members never agreed to. Many members expressed their shock at such a betrayal.

Such systematic violation of the expectations of people whose DNA, and personal health information is being used without their consent is just wrong. It's a violation of basic human rights. Moreover, as commercialization of genetics has exploded, individuals are being denied the inherent monetary value of such information at the same time that personal genetic information is becoming widespread and our understanding of such data becomes richer and therefore increasingly valuable. The Massachusetts Bill of Rights represents a significant step forward in giving citizens back their autonomy by granting exclusive property rights to their own genetic information. Through property rights Massachusetts citizens will gain a series of rights regarding the control, possession and transferability of genetic information that are unavailable through privacy legislation alone; empowering individuals to have initial and on-going control over the use of their own genetic information. In turn, providing individuals with greater control over the use of their genetic information will, more practically, encourage otherwise reluctant individuals to participate in research by balancing their interests with the interests of those who seek to use such information for a variety of purposes.

For these reasons, the Council for Responsible Genetics urges the Joint Committee on Public Health to move quickly to pass a strong and comprehensive law providing property and privacy rights for genetic information and genetic material. The Genetic Bill of Rights, if enacted, would confer upon Massachusetts residents a significantly expanded set of rights than exist under current law and place Massachusetts once again in its rightful role as a national leader in addressing the social and ethical implications of new technologies and biotechnologies in particular. The Council for Responsible Genetics offers its expertise and assistance and welcomes the opportunity to work with this Committee and the legislature as a whole to meet the advances of the genetic revolution with a bill of rights for the next century.