



Karen Saylor, MD, President | Jeffrey S. Barkin, MD, President-Elect | Erik N. Steele, DO, FAAFP, Chair, Board of Directors
Andrew B. MacLean, JD, CEO | Dan Morin, Director of Communications & Government Affairs

TO: The Honorable Heather Sanborn, Chair
The Honorable Denise Tepler, Chair
Members, Joint Standing Committee Health Coverage, Insurance and Financial Services

FM: Dan Morin, Director of Communications and Government Affairs

DATE: April 7, 2021

RE: **Support**
LD 1085, An Act Relating to the Use of Genetic Information for Insurance Purposes

The Maine Medical Association is the state's largest professional physician organization representing more than 4300 physicians, residents, and medical students across all clinical specialties, organizations, and practice settings.

The MMA supports LD 1085, An Act Relating to the Use of Genetic Information for Insurance Purposes, sponsored by Representative Hymanson for the following reasons:

- Not all genetic tests available today have high predictive power.
- Predisposition does not necessarily mean that the disease will develop.
- Genetic testing should only be performed for medical purposes, and not to generate information for insurance.
- The goal of genetic research is to improve health and to reduce morbidity and mortality.
- The effectiveness of current genetic testing depends on the type of genetic disorder.
 - Chromosomal (e.g., Down's syndrome, leukemia, and lymphoma)
 - Single-gene (e.g., cystic fibrosis and Huntington's disease)
 - Multifactorial diseases (e.g., breast cancer, ovarian cancer, heart disease, diabetes, multiple sclerosis, and Alzheimer's)
- The pursuit of accurate risk classification for insurance should be balanced with issues of accessibility, privacy, and equity.

The first federal law to address genetic discrimination was the Health Insurance Portability and Accountability Act (HIPAA) of 1996. The Americans with Disabilities Act (ADA) prohibits employment discrimination based on a disability; however, it is not clear whether the ADA protects against genetic discrimination in employment decisions.

The Genetic Information Nondiscrimination Act of 1997 (GINA) [Public Law 110-233] protects individuals from genetic discrimination by health insurers and employers. While GINA provides some important protections, the American Medical Association examined the law and identified some gaps. Most notably, the federal law “leaves individuals vulnerable to discrimination in areas such as life, long-term care and disability insurance, and does not extend to certain sectors of the population.”

A similar bill to LD 1085 passed in Florida last year and multiple states are trying to expand federal protections regarding discrimination based on genetic and family health history information.

Maine Medical Association members believe that the lack of protections for the insurance types covered in LD 1085 may lead to widening health care disparities. Minority and underrepresented populations worried about discrimination may not avail themselves of new genomic tests for health purposes fearing that they may be discriminated against when they try to obtain insurance. Or they may not try to purchase these insurance types due to fear that they might be asked to undergo some type of genetic testing. In the end, MMA’s Legislative Committee felt LD 1085 was important to their patients and determined this bill fits under already determined MMA Board legislative priorities concerning patient privacy as well as health equity and systemic discrimination.

We urge the committee to vote Ought to Pass and are available to provide any additional information prior to the work session and intend to again be in virtual attendance.