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Stakeholders Applaud Passage of Law Banning Genetic Discrimination in California

Sacramento, Ca. – Patient advocacy organizations, healthcare professional groups, and biotech industry stakeholders are celebrating the passage of California’s Safeguarding Genetic Information Act (AB 1798), a new law that will prohibit life, long-term care, and disability insurers from using genetic test results to determine policy eligibility, premiums, or benefits. The law will help ensure that Californians carrying inherited gene mutations that increase their risk of diseases such as ALS, Alzheimer’s, cancer, or other genetically linked health conditions can pursue genetic testing to better understand their health risks without fear of discrimination.

“This law ensures that Californians are not penalized for taking proactive steps to understand their health,” said Assemblymember Lori Wilson, who authored the legislation. “Genetic testing should lead to better health, not to higher premiums, reduced benefits, or denial of coverage.”

California Insurance Commissioner Ricardo Lara, who sponsored the legislation, said: “Genetic testing should empower people to take charge of their health, not give insurance companies a new tool to discriminate. With the signing of the Safeguarding Genetic Information Act, California is drawing a clear line: Your medical data belongs to you, not to life and disability insurers. By stopping the unfair use of genetic data for underwriting, we are ensuring that life-saving preventive care and early detection never come with the penalty of higher costs or denied coverage.”

Genetic testing is increasingly important across healthcare. It provides critical insight into disease risk, empowering people to pursue prevention, risk reduction, and early intervention. It can also inform diagnosis and treatment by identifying individuals who may benefit from targeted therapies. In research and clinical trials, genetic and biomarker testing play integral roles in advancing our understanding of how genetics and genomics influence disease predisposition and type, as well as therapeutic dosage and response.

The insurance industry has also expanded its use of genetic information. Life, long-term care, and disability insurers use genetic test results to deny coverage or charge significantly higher premiums. Historically, these insurers relied on an individual’s personal and family health history to make underwriting determinations. Now, they also consider genetic test results, refusing to underwrite people with inherited mutations associated with an increased risk of disease—even if the applicant is healthy.

Passed in 2008, the Genetic Information Nondiscrimination Act (GINA) is a federal law that prohibits health insurers and employers from discriminating against an individual based on their genetic information or family health history. However, GINA's protections do not extend to other types of insurers.

Other countries such as Canada, the U.K., and most recently Australia, have laws banning genetic discrimination in life and other types of insurance. In the United States, Florida is the only other state with a comparable law. California's new law is unique, however, because it permits the use of genetic test results if they benefit the patient. For instance, if an individual has a family history of cancer and they test negative for genetic mutations that increase cancer risk, that may improve their odds of securing a policy with a lower premium.

"Surveys have consistently shown that fear of insurance discrimination is a significant barrier to genetic testing," stated Melanie Lendnal, Executive Vice President and Chief of Advocacy at The ALS Association. "For people at risk for ALS, that fear can stand in the way of accessing information that could connect them to research, clinical trials, and emerging therapies. No one should have to choose between understanding their genetic risk and protecting their future. We are proud to have helped lead this effort and hope California's example becomes a model for the nation."

"Carrying a genetic mutation associated with hereditary disease does not mean the individual has or will be diagnosed with that disease; it only indicates an increased risk," asserted Lisa Schlager, Vice President of Public Policy at FORCE: Facing Our Risk of Cancer Empowered. "In the case of cancer, this knowledge provides an individual with the opportunity to be proactive with their health, pursuing measures to prevent or detect cancer early, when it is easier to treat. We should reward people—not penalize them—for seeking out this information."

Gregory Mohl, a post-doctoral scholar at the University of California, San Francisco, and advocate for the bill, explained, "Encouraging broader uptake of genetic testing will accelerate scientific innovation. Genetic testing helps researchers develop personalized cell and gene therapies to treat cancer and rare diseases. It can also help us understand why certain medicines may not work or may cause serious side effects in people with certain genetic variants, such as APOE4 and some anti-amyloid therapies."

A broad range of stakeholders applaud the new law and hope it will serve as a model for other states—and ultimately, for federal reform.

Organizations supporting this effort include these and many others:

AliveandKick'n • ALS Association • ALS Network • American College of Medical Genetics and Genomics • American Kidney Fund • The Association for Frontotemporal Degeneration • Association for Molecular Pathology • Biomarker Collaborative • Bleeding Disorders Council of California • The Bonnell Foundation: Living with Cystic Fibrosis • California Rare Disease Access Coalition • CancerCare • Colon Cancer Coalition • Dialysis Patient Citizens • Exon 20 Group • Families Fighting Hereditary Cancer • Fight Colorectal Cancer • FORCE: Facing Our Risk of Cancer Empowered • GeneDx • Genetic ALS & FTD: End the Legacy

• ICAN, International Cancer Advocacy Network • jscreen • Les Turner ALS Foundation • Let's Win Pancreatic Cancer • Lupus and Allied Diseases Association, Inc. • Lynch Syndrome Awareness and Education • Male Breast Cancer Global Alliance • MET Crusaders • National Patient Advocate Foundation • National Society of Genetic Counselors • NothingPink • NRG1 Energizers • Oncology Nursing Society-San Diego Chapter • Ovarian Cancer Research Alliance • PDL1 Amplifieds • PWSA | USA • Rare Access Action Project • RARE Foundation • Susan G. Komen • Sharsheret | The Jewish Breast & Ovarian Cancer Community • Spondylitis Association of America • Stupid Cancer • Tigerlily Foundation • ZERO Prostate Cancer

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