

# CollegeNews

## ACMG-Supported Genetics Landmark Legislation to Move Forward

ACMG's mission includes the promotion of effective and fair health policies and to provide technical assistance to government agencies, professional organizations and other medical specialties in the area of clinical genetics. ACMG exists as members' advocate in Washington, DC to ensure the interests and concerns of our members are considered when lawmakers develop health policy. This advocacy role includes monitoring legislation and meeting with Congressional members and executive branch agencies to make our members' voices heard. Guaranteeing that policies are implemented in a responsible manner is crucial in a time when genomics is recognized as becoming increasingly important in field of healthcare. Please read below for a summary of some of the recent legislation that ACMG has worked to get passed into law.

### American College of Medical Genetics Applauds the Signing of the Genetic Information and Non-Discrimination Act of 2008 (GINA) Into Law

The American College of Medical Genetics (ACMG) enthusiastically applauds the signing into law of the Genetic Information and Non-Discrimination Act of 2008 (GINA). This legislation provides vital federal protections against the misuse of genetic information in employment and insurance decisions. The bill, HR 493 as introduced by Representatives Louise Slaughter and Judy Biggert, passed by an overwhelming 420-3 House vote last year. Senators Olympia Snowe and Ed-

ward Kennedy introduced a companion version of the bill, S 358, in the Senate last year. The bill was signed by President Bush on May 21.

"We believe that no American should have to choose between having a genetic test or participating in a research study that could be important to his or her life, or avoid a genetic test or furthering research to save a job or protect health insurance coverage," says ACMG's executive Director Michael S. Watson, FACMG. "Fear of discrimination, prejudice or economic consequences should not be a factor in whether someone has a genetic test that could improve or save their lives."

"We are pleased that GINA will set a minimum standard of protection for all Americans, such that they will no longer be dependent on a highly variable patchwork of state laws," says ACMG President Joe Leigh Simpson, MD, FACMG, FACOG. "As the medical genetics professionals on the frontline, we at ACMG are aware that the American public perceives genetic discrimination as a very real problem. This fear has already had chilling effects on the public's willingness to seek genetic services and to participate in clinical investigation that will lead to better understanding and treating the genetic components of human disease."

The American College of Medical Genetics had previously published *Points to Consider in Preventing Unfair Discrimination Based on Genetic Disease Risk: A Position Statement of the American College of Medical Genetics*, which can be viewed in the Publications/Policy Statements section at [www.acmg.net/](http://www.acmg.net/)

## American College of Medical Genetics Commends the Signing of the Newborn Screening Saves Lives Act

The American College of Medical Genetics (ACMG) applauds the signing into law of the Newborn Screening Saves Lives Act (S.1858) sponsored by Senator Christopher Dodd (D-CT) and 21 co-sponsors including ACMG's Maryland Senators, Barbara Mikulski (D - MD) and Benjamin L. Cardin (D - MD.) The bill, signed into law by President George W. Bush on April 24, will expand screenings of newborn babies for congenital, genetic and metabolic disorders and will authorize a grant program to expand the funding to state and local health agencies to provide screening, counseling and health care services to newborns and children having or at risk for heritable disorders. It also provides for funds for education and training of health care professionals in new technologies related to newborn screening and to develop and deliver educational programs about newborn screening counseling to parents, families and advocacy groups.

“This legislation will undoubtedly save the lives of many children,” says Michael S. Watson, PhD, FACMG, executive director of the ACMG, which recommends universal newborn screening for 29 treatable conditions. “Newborn screening is a vital public health program. Through early screening, diagnosis and treatment we can prevent the truly dire consequences of a number of treatable conditions. With the current expansion of newborn screening panels, it is estimated that about 10,000 of the 4.1 million babies born each year in the United States will be identified with one of the conditions for which treatment will have a significant impact on long-term outcome.”

“This bill places resources where they are needed to make the difference for families across every state in the US. Advances in technology have made it possible and feasible to test newborns for a number of serious or deadly conditions. With advances in genetic medicine, it is now possible to diagnose, and even more importantly, to treat more diseases than ever in history,” says Joe Leigh Simpson, MD, FACMG, FACOG, president of ACMG.

The legislation authorizes \$44.5 million in fiscal 2008 to fund the bill's various programs, with the amount increasing each year through 2012. To implement the bill fully, there will need to be funds appropriated.

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