

# Bush Signs Bill to Prohibit Genetic-Information Bias

MARY ELLEN SCHNEIDER  
New York Bureau

Patients will soon be able to undergo genetic testing without fear of discrimination from either their health insurers or their employers, thanks to a new law signed by President Bush.

The Genetic Information Nondiscrimination Act (H.R. 493), which passed both houses of Congress by wide margins, prohibits health insurers from using genetic information in determining eligibility or setting premiums and forbids employers from using that information for decisions about hiring, firing, job assignments, or promotions. The law also prohibits health insurers and employers from requesting or requiring that individuals take a genetic test. The health insurance provisions in the law will go into effect in 12 months, and the employment provisions will take effect in 18 months.

"Genetic testing holds great promise for improving public health, and patients must be able to trust that their genetic information will be protected from inappropriate and discriminatory uses," Dr. Edward Langston, board chair of the American Medical Association, said in a statement. "This new law will allow patients to take advantage of scientific advances in genetics, such as screenings and therapies, without worrying that their personal health information could be used against them by insurers or employers."

"No one should have their health insurance or employment removed from them based on the potential for having a disease," said Dr. James King, president of the American Academy of Family Physicians. Although there is not yet a lot of genetic testing being done, the laws gives physicians and patients a greater level of comfort in ordering tests when early treatment or prevention strategies could benefit the patient, he said.

"Today, the genetic revolution in health care can truly begin," Dr. Renee R. Jenkins, president of the American Academy of Pediatrics, said in a statement. "For the first time since the development of genetic tests, parents can rest assured that they and their children will not lose their health insurance or their jobs just because their genetic makeup says they are at risk for a specific disease."

Supporters of the law are hailing it as the first civil rights legislation of the new millennium. In practice, experts say that it will mean that patients who might have been hesitant to undergo testing for fear of discrimination may be more willing. Some patients who would be good candidates for genetic testing have been refusing the tests, or in some cases taking them under an assumed name, said Sharon Terry, president of the Coalition for Genetic Fairness and CEO of the Genetic Alliance.

The frequency of genetic discrimination has been difficult to document, but it's clear that fear of discrimination has been a barrier to genetic services for some pa-

tients, said Dr. Matthew Taylor, director of adult clinical genetics at the University of Colorado in Denver. For example, last year the Genetics and Public Policy Center at Johns Hopkins University, Baltimore, conducted a survey of 1,199 U.S. adults on genetic testing and discrimination. The researchers found that 92% of respondents expressed concern that the results of a genetic test for disease risk could be used against them in some way.

One of the biggest impacts of the law may be its potential to alleviate concerns about genetic discrimination among both patients and physicians, Dr. Taylor said.

Another area where the law is likely to have a significant impact is in research. Many informed consent forms for clinical trials include statements warning participants that they could be discriminated against on the basis of their genetic information, according to Ms. Terry. The Coalition for Genetic Fairness plans to mount an educational campaign to make patients and physicians aware of the new protections in the law in the hopes of increasing participation in research, she said.

The new federal law is essential to help to "close the gaps in protection" among the various state laws, according to Naomi Senkeeto, a health policy analyst for the American College of Physicians. The new law is similar to policy positions outlined in an ACP monograph issued earlier this year. In fact, the law includes all of the provisions that the ACP monograph recommended. The law also adds a specific prohibition against issuers of Medigap policies using genetic information to adjust price or condition eligibility.

The law was a long time coming, according to supporters. Legislation on genetic nondiscrimination was first introduced in 1995. The bill has had broad support in Congress for many years but couldn't get to the House floor under the Republican leadership, according to Susannah Baruch, associate director of the Genetics and Public Policy Center at Johns Hopkins University. The other change that propelled the legislation forward was the explosion in the number of genetic tests available, she said.

About 1,200 genetic tests can be used to identify thousands of health conditions, according to the Coalition for Genetic Fairness. Only about 100 genetic tests were available a decade ago.

Over time, the legislation has garnered support from a broad coalition of groups, including the health insurance industry. "With this landmark bipartisan legislation, Congress and the President have taken strong action to prohibit discrimination based on a person's genetic makeup and to protect patients' privacy as they pursue genetic evaluations," Karen Ignagni, president of America's Health Insurance Plans, said in a statement. "This legislation also ensures that patients can continue to benefit from health plans' innovative early detection and care coordination programs that improve the safety and quality of care."

But more work is needed, Ms. Terry said. "This is a first-step bill for sure." ■

## POLICY & PRACTICE

### IAN Registers Nearly 24,000

The Kennedy Krieger Institute has announced that its Interactive Autism Network (IAN), the first U.S. autism registry, has registered nearly 24,000 individuals in its first year and is helping to facilitate approximately 75 research projects across the United States. As part of that total, 299 sets of twins have enrolled in the IAN research protocol, providing the largest collection of twins in published autism research. Twin studies provide an opportunity for researchers to investigate both genetic and environmental factors in autism, but studies historically have found it difficult to recruit twin sets, the institute said. Initial data from the registry indicated that living in a more rural state may delay the diagnosis of autism and limit access to private schools. In addition, another analysis of initial registry data showed that families of children with autism spectrum disorders (ASD) are using a number of autism interventions, ranging from therapy to medication to diet. The average number of simultaneous treatments was five, although half of those with an ASD receive four or fewer.

### CMS Softens SCHIP Policy

The Centers for Medicare and Medicaid Services will make it a little easier for states to expand coverage under the State Children's Health Insurance Program. States had expressed concern that they would not be able to achieve the required coverage for 95% of children in families with incomes at or below 200% of the poverty level before expanding SCHIP to children in families with incomes above 250% of the poverty level. In a letter to state health officials, CMS told states that they now may use "a variety of approaches," including state surveys, to prove they have reached the 95% threshold set by CMS for using federal money to expand SCHIP to families making more money. The agency also told state officials that children already enrolled in SCHIP, children in families with incomes at or below 250% of the poverty level, children whose enrollment costs are paid exclusively with state dollars, and unborn children are not subject to the threshold limits.

### Few Meet Activity Guidelines

Children who do not meet American Academy of Pediatrics guidelines for activity and screen time were much more likely to be overweight than children complying with both AAP recommendations, a study in *The Journal of Pediatrics* showed. The AAP recommends that boys take at least 13,000 steps a day, girls at least 11,000 steps a day, and all children limit their total screen time to 2 hours a day. Researchers from Iowa State University and the National Institute on Media and the Family studied 709 children aged 7-12 years. The children were asked to wear pedometers and track their screen time. Almost 20% of the children were overweight and fewer than half met both AAP recommendations. Those children who did not meet both recommenda-

tions were three to four times more likely to be overweight than children who complied with both recommendations.

### Poorer Children in ED More

Lower-income children made almost twice as many visits to hospital emergency departments as higher-income children in 2005, according to the Agency for Healthcare Research and Quality. AHRQ's analysis found that the rate of emergency department visits by children from low-income communities, where the average household income was under \$37,000, was 414 visits for every 1,000 children. For children living in a household where the average income was more than \$61,000, the rate was 223 visits for every 1,000 children. AHRQ also found that in 96% of all visits, children were treated—for problems such as respiratory conditions, superficial injuries, middle-ear infections, open wounds, and muscle sprains and strains—and released. The top reasons to admit children from the ED included pneumonia, asthma, acute bronchitis, appendicitis, dehydration, depression, and epileptic convulsions.

### Nearly One-Third on Drugs

Thirty percent of children under age 19 years were taking a prescription medication to treat at least one chronic health condition in 2007, according to Medco Health Solutions. Prescriptions for children most often involved asthma or allergy drugs, followed by drugs for attention-deficit/hyperactivity disorder. The number of girls taking ADHD medications rose 72% from 2001 to 2007. The pharmacy benefit management company analyzed a representative sample of 2.5 million people from its database. Overall, it determined that 51% of insured Americans—both children and adults—were taking at least one prescription medication in 2007. "These data do paint a pretty unhealthy picture of America," said Medco chief medical officer Robert Epstein, in a statement. "But there is a silver lining; they do show that people are receiving treatment which can prevent more serious health problems down the road."

### FDA Pushes for Event Reports

The Food and Drug Administration is working with a medical software firm to get more physicians to submit adverse event reports. Doctors who use Epocrates products have received a message on their personal digital assistant explaining how adverse event reporting works. "Physicians are on the front line when it comes to patient care, and working with Epocrates helps us remind them of safety and error reporting directly at the point of patient contact," said Dr. Norman Marks, medical director of the FDA's MedWatch program. "We want physicians to understand that by taking a few minutes to submit a report, that action may be the necessary first step that triggers an evaluation and action by the FDA and ultimately reduces the risk of patient harm."

—Jane Anderson