

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Reply To:
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July 20, 2004,

The Honorable Sam Johnson
Chairman
Employer-Employee Relations Subcommittee
Committee on Education and the Workforce
U.S. House of Representatives
Washington, D.C., 20515

Dear Chairman Johnson:

The American Academy of Pediatrics urges prompt passage of federal legislation that would prevent genetic discrimination, thereby allowing continued progress in prevention efforts through genetic screening and ensuring that all children have access to health insurance coverage. The American Academy of Pediatrics is an organization of 60,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health and well being of all infants, children, adolescents, and young adults.

The American Academy of Pediatrics strongly supports efforts to enhance, improve and expand the ability to provide newborn screening, counseling and health care services. Advances in genetic research promise great strides in the diagnosis and treatment of many childhood diseases, detected as early as the newborn period or later in childhood. With early identification and timely intervention, we have the ability to significantly reduce morbidity, mortality and associated disabilities in infants and children affected with certain genetic, metabolic and infectious conditions.

With these opportunities, however, we also have a responsibility to ensure that careful consideration is given to the testing and screening of children so that emerging technologies are used in ways that promote the best interest of patients and their families. Potential benefits of genetic screening and testing are limited by the risks of harm that may be done by gaining certain genetic information, including potential for discrimination by insurers and employers. For this reason the American Academy of Pediatrics supports passage of legislation that protects children and families from genetic discrimination.

Furthermore, the American Academy of Pediatrics is concerned that genetic discrimination is a barrier for families to access health insurance for their children. More than 9 million children are currently uninsured in this country, and millions more are underinsured. We will never achieve our goal of ensuring that every child has health insurance coverage if genetic discrimination is permitted. The American Academy of Pediatrics therefore urges Congress to pass legislation that protects American families from genetic discrimination.

Sincerely,

Carden Johnston, M.D., FAAP
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