

Like David Bloom, many of us may be at risk for DVT and not know it. Some risk factors include: acute medical illness such as cancer, certain heart or respiratory diseases, prior DVT, increasing age, obesity, major orthopedic surgery, pregnancy, restricted mobility and paralysis. DVT can be prevented through maintaining a healthy lifestyle, including a fitness program and a healthy diet. Further, during periods of prolonged immobility such as airplane travel, stretch your legs as often as possible.

As Chairman of the Labor, Health and Human Services, and Education Appropriations Subcommittee, I led the effort to double funding for the National Institutes of Health (NIH) over 5 years. Funding for the NIH has increased from \$11.3 billion in fiscal year 1995 to \$28.5 billion in fiscal year 2005. In 2004, the NIH, through the National Heart, Lung, and Blood Institute, provided \$6.1 million for DVT and PE research. The NIH is also advancing research of this condition through a recently formed international partnership working to prevent and control blood clots, and improve therapies for conditions such as heart attacks, strokes, deep vein thrombosis and pulmonary embolisms.

Together with Melanie Bloom, widow of David Bloom, and the more than 35 leading health organizations in the Coalition to Prevent DVT, we are working to help raise awareness of this condition. To increase public awareness of this serious, yet preventable condition, I urge my colleagues to support this legislation to designate March 2005 as Deep Vein Thrombosis Awareness Month in honor of David Bloom's memory.

AMENDMENTS SUBMITTED AND PROPOSED

SA 13. Mr. ENZI proposed an amendment to the bill S. 306, to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

TEXT OF AMENDMENTS

SA. 13. Mr. ENZI proposed an amendment to the bill S. 306, to prohibit discrimination on the basis of genetic information with respect to health insurance and employment; as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) **SHORT TITLE.**—This Act may be cited as the “Genetic Information Nondiscrimination Act of 2005”.

(b) **TABLE OF CONTENTS.**—The table of contents of this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

- Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
- Sec. 102. Amendments to the Public Health Service Act.
- Sec. 103. Amendments to title XVIII of the Social Security Act relating to medigap.

Sec. 104. Privacy and confidentiality.

Sec. 105. Assuring coordination.

Sec. 106. Regulations; effective date.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

Sec. 201. Definitions.

Sec. 202. Employer practices.

Sec. 203. Employment agency practices.

Sec. 204. Labor organization practices.

Sec. 205. Training programs.

Sec. 206. Confidentiality of genetic information.

Sec. 207. Remedies and enforcement.

Sec. 208. Disparate impact.

Sec. 209. Construction.

Sec. 210. Medical information that is not genetic information.

Sec. 211. Regulations.

Sec. 212. Authorization of appropriations.

Sec. 213. Effective date.

TITLE III—MISCELLANEOUS PROVISION

Sec. 301. Severability.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract a particular disorder. New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.

(2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic “defects” such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to “correct” apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

(3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.

(4) Congress has been informed of examples of genetic discrimination in the workplace. These include the use of pre-employment ge-

netic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.

(5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections. Moreover, while many States have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME SECURITY ACT OF 1974.

(a) **PROHIBITION OF HEALTH DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION OR GENETIC SERVICES.**—

(1) **NO ENROLLMENT RESTRICTION FOR GENETIC SERVICES.**—Section 702(a)(1)(F) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(a)(1)(F)) is amended by inserting before the period the following: “(including information about a request for or receipt of genetic services by an individual or family member of such individual)”.

(2) **NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.**—Section 702(b) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(b)) is amended—

(A) in paragraph (2)(A), by inserting before the semicolon the following: “except as provided in paragraph (3)”; and

(B) by adding at the end the following:

“(3) **NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.**—For purposes of this section, a group health plan, or a health insurance issuer offering group health insurance coverage in connection with a group health plan, shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(b) **LIMITATIONS ON GENETIC TESTING.**—Section 702 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182) is amended by adding at the end the following:

“(c) **GENETIC TESTING.**—

“(1) **LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.**—A group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) **RULE OF CONSTRUCTION.**—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;