
Coalition for Genetic Fairness

November 4, 2003

Speaker Dennis Hastert
House 232 Capitol Building
United States House of Representatives
Washington, DC 20515

Dear Speaker Hastert:

On behalf of the Coalition for Genetic Fairness, the undersigned organizations, representing patients, people with disabilities, consumers, women, health and health professional and civil rights organizations and many others, we urge you to schedule immediate House action on S. 1053, the "Genetic Information Nondiscrimination Act." After years of hard work, the Senate passed S. 1053 on a nearly unanimous vote.

In strong support of this bipartisan legislation Senator Frist stated on the floor that, "... [I]f unchecked, the fear of genetic discrimination would have the potential of keeping people from participating in very useful research studies. As we greet the future, as we look at new technology, this is just one example of this body acting proactively, acting preemptively, so that such potential use in a discriminatory fashion of medical advances is kept from hurting the American people. We must take care to protect our body politic, and this legislation does just that."

Genetic testing can improve our lives by providing information on how we can prevent future health problems, and cope more effectively with unavoidable conditions. But the ability to predict disease through genetic testing and family history opens the door for genetic discrimination, particularly in employment and health insurance.

We ask you to schedule a vote on S. 1053 before the end of this year. If you need additional information please contact Vanessa Lopes at the National Partnership for Women & Families at (202) 986-2600. We look forward to continuing to work with you so that we can ensure individuals and families have the rights they need and deserve and we can recoup the investment that we have made in mapping the human genome.

Sincerely,

National Partnership for Women & Families
Alpha 1 Advocacy Alliance
Alpha-1 Association Caring Voice Coalition, Inc.
Alpha-1 Foundation

Sent in care of the National Partnership for Women & Families
1875 Connecticut Ave; Suite 650 Washington, DC 20009

American Academy of Family Physicians
American Academy of Pediatrics
American Association for Clinical Chemistry
American Association for the Study of Liver Diseases
American Association of Medical Colleges
American Association of People with Disabilities
American Cancer Society
American Civil Liberties Union
American College of Medical Genetics
American Diabetes Association
American Jewish Congress
American Nurses Association
American Psychiatric Association
American Public Health Association
American Sickle Cell Anemia Association
Association of Women's Health, Obstetrics and Neonatal Nurses (AWHONN)
Autosomal Recessive Polycystic Kidney Disease & Congenital Hepatic Fibrosis Alliance
Birt Hogg Dube Family Alliance
B'nai B'rith International
Breast Cancer Resource Committee, Inc.
Canavan Foundation
Cancer Awareness Program Services, Inc.
Cancer Research and Prevention Foundation
Cardiac Arrhythmias Research & Education Foundation
CARES Foundation, Inc. (Congenital Adrenal Hyperplasia Research, Education, and Support)
Center for Patient Advocacy
Central Conference of American Rabbis
Coalition of Heritable Disorders of Connective Tissue
Cooley's Anemia Foundation
Cornelia de Lange Syndrome Foundation
Crohn's and Colitis Foundation of America
Cure FD (Familial Dysautonomia) Foundation
Cystic Fibrosis Foundation
Cystinosis, Research Network, Inc.
Digestive Disease National Coalition
Dystonia Medical Research Foundation
Easter Seals
Epilepsy Foundation
Federation of American Societies for Experimental Biology
FORCE: Facing Our Risk of Cancer Empowered
Freeman-Sheldon Parent Support Group
Genetic Alliance
Gluten Intolerance Group
Hadassah, the Women's Zionist Organization of America
Hemophilia Federation of America
Hermansky-Pudlak Syndrome Network, Inc.
Hunters Hope Foundation
IDEAS (IsoDicentric 15 Exchange, Advocacy & Support)
Immune Deficiency Foundation
Incontinentia Pigmenti International Foundation
Jeffrey Modell Foundation
Juvenile Diabetes Research Foundation
K-T Support Group
Late Onset Tay-Sachs Foundation
March of Dimes
National Association of Protection and Advocacy Systems

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National Association of Social Workers
National Ataxia Foundation
National Marfan Foundation
National Niemann-Pick Disease Foundation, Inc.
National Organization for Rare Disorders (NORD)
National Ovarian Cancer Coalition
National Society of Genetic Counselors
National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD)
National Women's Health Network
National Women's Law Center
Oncology Nursing Society
Ovarian Cancer National Alliance
Pediatric/Adolescent Gastroesophageal Reflux Association, Inc – PAGER
Pulmonary Hypertension Association
PXE International
Sjogren's Syndrome Foundation
Spina Bifada Association of America
Spondylitis Association of America
STAR Foundation
Support)
Susan G. Komen Breast Cancer Foundation
The Arc of the United States
The Arc of Utah
The Dysautonomia Foundation National Foundation for Ectodermal Dysplasias
The Foundation for Nager and Miller Syndromes
The National Workrights Institute
The Society for Women's Health Research
The Society of Gynecologic Oncologists
Tourette's Syndrome Association
Trisomy 18 Support Foundation
Tuberous Sclerosis Alliance
UJA – Federation of New York Women's Public Policy Task Force
Union of American Hebrew Congregations
United Cerebral Palsy
VHL Family Alliance