

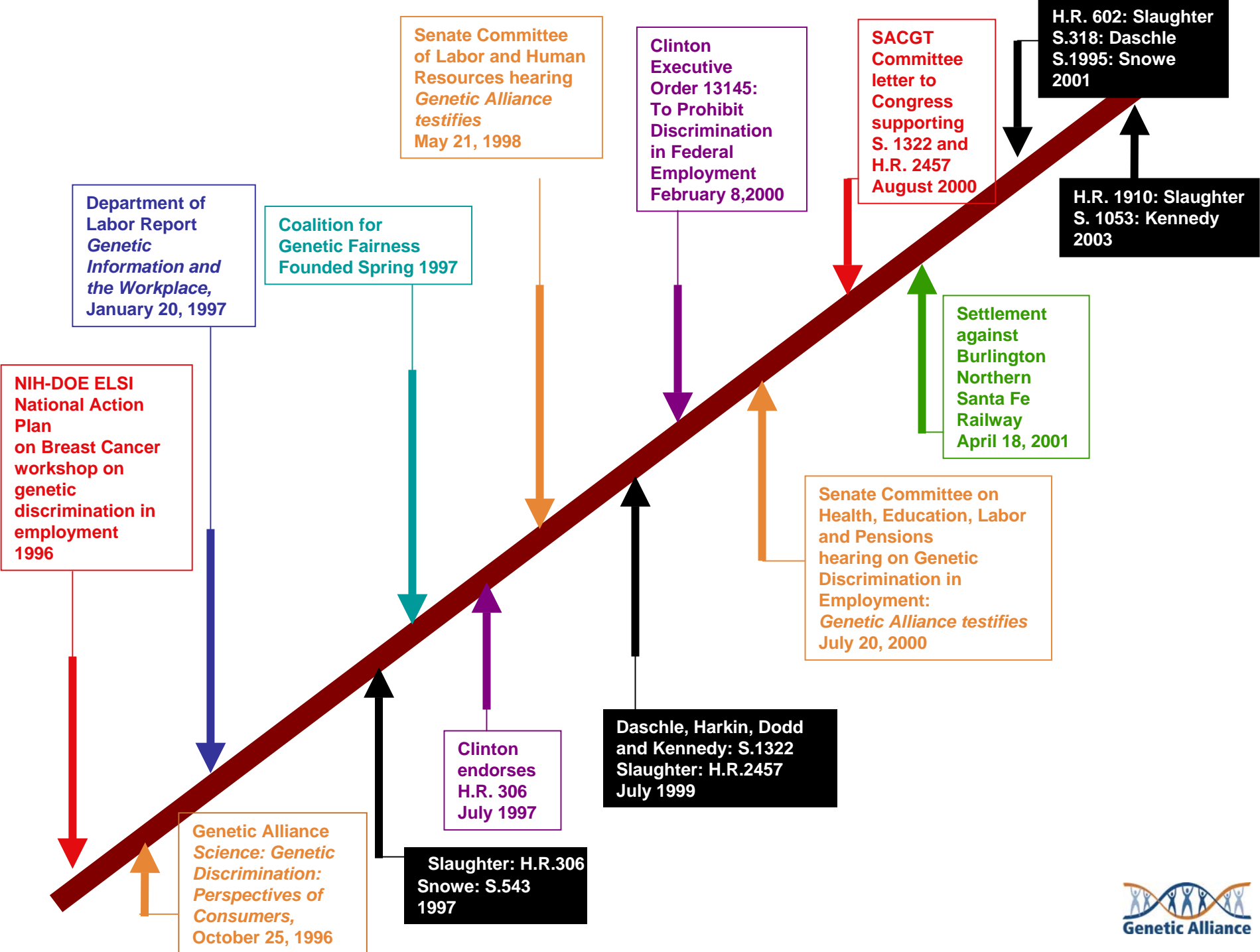
# **Genetic Information Nondiscrimination Update**

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**Chair, Coalition for Genetic Fairness**





# 109 Congress

- :: February 16, 2005: President Bush – full support – Statement of Administrative Policy.
- :: February 17, 2005: S.306 passed Senate – unanimous vote of 98-0.
- :: March 10, 2005: H.R.1227 was introduced and referred to the Committees on Energy and Commerce, Education and Workforce, and Ways and Means.
- :: Today: H.R.1227 has 170 total sponsors (94 Democrats, 75 Republicans, and 1 Independent)

# What has CGF been doing?

- Supporting Representatives Judy Biggert (R-III.), Anna Eshoo (D-Calif.), Bob Ney (R-Ohio) and Louise Slaughter (D-N.Y.) in increasing Republican sponsorship.
- Engaging the Chamber of Commerce, the National Association of Manufacturers, and the Society of Human Resource Managers in a dialogue that aims to establish an understanding among all parties.
- Working with companies and trade associations: IBM company policy, BIO's letter of support to Anna Eshoo

# What can the SACGHS do?

- Request a meeting with the CGF, Chamber and the National Association of Manufacturers
- Ask the Secretary to invite the same organizations, and the White House Domestic Policy Office to a meeting
- Remind the Secretary that as he works with Congress on getting the Genes and Environment Initiative (GEI) funded, that he should be explain to Congress the importance of HR 1227 to allay fears so that people feel comfortable participating in such research
- Make a clear and strong statement expressing concern about the chill on research and its impact on the investment made for biomedical research in this country, including the trend toward off shoring clinical trials by PhRMA/biotech companies
- Send its genetic discrimination report (the "phone book) to the new chairman of the Education and the Workforce Committee, Howard McKeon (R-CA)
- Members generate more activity within their constituencies as knowledgeable individuals and experts

# Coalition for Genetic Fairness

- 20th Century Fox
- Affymetrix, Inc.
- Alpha-1 Association
- Alpha-1 Foundation
- American Academy of Family Physicians
- American Academy of Pediatrics
- American Association for the Advancement of Science
- American Association of People with Disabilities
- American Cancer Society
- American College of Medical Genetics
- American Health Information Management Association
- American Jewish Congress
- American Medical Student Association
- American Occupational Therapy Association
- American Osteopathic Association
- American Society of Clinical Oncology
- American Society of Human Genetics
- Angelman Syndrome Foundation
- Angioma Alliance
- The Arc and United Cerebral Palsy Disability Policy Collaboration
- ARPKD/CHF Alliance
- Association for Molecular Pathology
- Association of American Medical Colleges
- Association of Women's Health, Obstetric and Neonatal Nurses"
- Basal Cell Carcinoma Nevus Syndrome Life Support Network
- Birt Hogg Dube Family Alliance
- Boston Jewish Women's Coalition on Breast Cancer
- Canavan Foundation
- Cancer Information & Support Network, Inc.
- CARES Foundation, Inc. [Congenital Adrenal Hyperplasia Research, Education & Support]
- Caring Voice Coalition
- The Center for Macular Degeneration at the University of Iowa
- Children's Cardiomyopathy Foundation
- Chromosome 18 Registry & Research Society
- Citizens for Quality Sickle Cell Care
- Coalition for Heritable Disorders of Connective Tissue
- Coalition for Pulmonary Fibrosis
- Cystic Fibrosis Foundation
- Debra of America
- DNA Direct
- Families of Spinal Muscular Atrophy
- Ferre Institute, Inc.
- Fight ALD
- First Genetic Trust
- FORCE: Facing Our Risk of Cancer Empowered
- Foundation for Children with Atypical HUS
- Foundation for Ichthyosis and Related Skin Types, Inc.
- Genetic Alliance
- Genomic Health, Inc
- Genzyme Genetics
- Health and Medicine Counsel of Washington
- Hemophilia Federation of America
- Hereditary Disease Foundation
- Hereditary Hemorrhagic Telangiectasia Foundation International, Inc.
- Hermansky-Pudlak Syndrome Network, Inc.
- Hunter's Hope Foundation
- IEEE-USA
- Inflammatory Skin Disease Institute
- International Essential Tremor Foundation
- International Premature Ovarian Failure Support Group, Inc.
- International Society of Nurses in Genetics, Inc.
- J. C. Venter Science Foundation
- Jeffrey Modell Foundation
- Jewish Federation of Metropolitan Chicago
- Klinefelter Syndrome & Associates
- March of Dimes
- Maryland Patient Advocacy Group
- Matthew's Mission
- Millennium Pharmaceuticals
- Mycosis Fungoides Foundation
- myDNA Media
- Myriad Genetics Laboratories, Inc.
- National Alopecia Areata Foundation
- National Association of Social Workers, Inc"
- National Coalition for Health Care Professional Education in Genetics
- National Eczema Association for Science and Education
- National Foundation for Ectodermal Dysplasias
- National Marfan Foundation
- National Organization for Rare Disorders
- National Partnership for Women and Families
- National Psoriasis Foundation
- National Society of Genetic Counselors
- National Tay-Sachs & Allied Diseases Association, Inc.
- National Workrights Institute
- NERGG, Inc
- PA Breast Cancer Coalition
- Pachyonychia Congenita Project
- Parent Project Muscular Dystrophy
- Pediatric Neurotransmitter Disease Association
- Periodic Paralysis Association
- Prevention Genetics
- Progeria Research Foundation
- Project DOCC - Delivery of Chronic Care
- PXE International
- Quest Diagnostics Nichols Inst.
- Religious Action Center of Reform Judaism
- Rett Syndrome Research Foundation
- Sjögren's Syndrome Foundation, Inc.
- Society for Women's Health Research
- Spina Bifida Association of America
- STAR (Supporting Those At Risk) Foundation
- Sudden Arrhythmia Death Syndromes Foundation

- Translational Genomics Research Institute (TGen)
- United Leukodystrophy Foundation, Inc.
- United States Costello Syndrome Family Network
- VHL Family Alliance
- The Women's Public Policy Task Force of UJA-Federation of NY
- XLH Network
- Zeta Phi Beta National Education Foundation

