

Update on SACGHS Task Force Efforts on Genetic Discrimination

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Presentation Overview

- Legislative Update
- Update on Report to Secretary
- Update on Fact-Finding Efforts
- Discussion of Next Steps

Task Force Members

- Agnes Masny, Chair
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- Barbara Harrison
- Debra Leonard
- Reed Tuckson
- Emily Winn-Deen
- Joann Boughman
- Robinsue Frohboese
- Peter Gray
- Tim Leshan
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Legislative Update

U.S. Senate

- Genetic Information Non-Discrimination Act of 2005 (S. 306)—Introduced February 7, 2005
 - Sponsored by Senator Snowe
 - Original cosponsors: Senators Frist, Gregg, Kennedy, Enzi, Jeffords, Dodd, Harkin, Collins, Talent, Bingaman, Hatch, Mikulski, Murray, and Clinton
- Nearly identical to the bill that passed the Senate in 2003 (S. 1053)

U.S. Senate

- Passed HELP Committee—February 9, 2005
- Debated on Senate floor—February 16, 2005
 - References to SACGHS’ support for legislation, Secretary Thompson’s response to SACGHS letter and October session
- Statement of Administration Policy issued February 16, 2005
- Passed full Senate—February 17, 2005 unanimously (98-0)

U.S. House of Representatives

- No bills introduced to date on genetic nondiscrimination

Update on Report to Secretary

Outcomes of October Session

- Compile testimony, public comments, and relevant scientific articles and submit to Secretary
- Gather information from stakeholders and facilitate stakeholder meeting
 - GINE Coalition, AHIP, Chamber, and Coalition for Genetic Fairness
- Facilitate DOJ/EEOC analysis of current law

Report to Secretary

- TF proposes in-depth report to the Secretary
 - Transmitting the public comments the Committee received at the October meeting
 - Discussing stakeholder positions
 - Providing an analysis of the adequacy of current law

Report to Secretary

Public Comments

- Public comments, written and oral, and relevant scientific articles collected by the Committee in October have been compiled
 - To inform the debate around the adequacy of evidence of the impact of genetic discrimination
- Consider DVD highlighting patient perspectives to enhance understanding of impact

Report to Secretary

Stakeholder Analysis

- Analysis would include:
 - Stakeholder positions
 - Points of agreement and disagreement among them
 - Possible points where consensus might be reached

Report to Secretary

Legal Analysis

- Legal analysis would be included as an appendix to the report
 - To inform the debate about the adequacy of current law

Update on Fact-Finding Efforts

Fact-Finding

- For the stakeholder analysis, discussions were conducted with:
 - America's Health Insurance Plans
 - U.S. Chamber of Commerce
 - Coalition for Genetic Fairness

U.S. Chamber of Commerce

- The world's largest not-for-profit business federation, representing:
 - 3,000,000 businesses
 - 2,800 state and local chambers
 - 830 business associations
 - 96 American Chambers of Commerce abroad
- Mission: To advance human progress through an economic, political and social system based on individual freedom, incentive, initiative, opportunity, and responsibility.

Chamber's Position on Genetic Discrimination

- Generally believes that employment decisions should be based on qualifications and performance, not on unrelated factors such as genetic predisposition
- Does not believe employers are currently engaging in genetic discrimination, though it does recognize that fear of potential discrimination may warrant a legislative solution

Chamber's Position on Legislation

- General concerns:
 - No record of employers discriminating, so the goal of legislation should be reducing employee fear of potential discrimination, not remedying past discrimination
 - Increases liability of employers and possibility of frivolous lawsuits
 - Current law provides appropriate protection of confidentiality of medical information, including genetic information

Chamber's Position on Legislation

- Specific concerns:
 - Damage provisions should be limited to equitable relief before a judge
 - One federal standard should preempt state and local laws
 - Definition of “family” should be limited
 - Study commission should be truly independent (not housed by EEOC) and should study the entire bill, not just disparate impact

GINE Coalition

- Group of employers, national trade associations, and professional organizations
 - formed to address concerns about workplace discrimination based on employees' genetic information as well as the confidentiality of that information
- Steering Committee:
 - US Chamber
 - Society for Human Resource Management
 - National Association of Manufacturers
 - HR Policy Association
 - College and University Professionals
 - Association for Human Resources

GINE Coalition's Position on Legislation

- No appreciable evidence of genetic discrimination in the workplace
 - Focus is on employment discrimination, not health insurance discrimination
- Concerns about:
 - Unintended consequences
 - Unnecessary regulation
 - Unwarranted litigation

Coalition for Genetic Fairness

- Group of advocates supporting Federal genetic nondiscrimination legislation
 - Educate Congressional policymakers and staff about the importance of legal protections for genetic information
 - Ensure passage of meaningful genetic nondiscrimination legislation

Coalition for Genetic Fairness

- Executive Committee:
 - Genetic Alliance, Hadassah, National Partnership for Women and Families, National Workrights Institute, ASHG, NSGC, Affymetrix, Millennium
 - Chaired by Sharon Terry, CEO and President of Genetic Alliance
- Membership being broadened to include :
 - Patient groups such as the American Cancer Society and the American Heart Association
 - Provider groups such as the American Academy of Pediatrics
 - Other pharmaceutical and health technology companies as well as broader employer groups

Coalition's Position on Legislation

- Predictability is key for both consumers and providers of health care as well as employers
- Lack of federal legislation creates an unfriendly climate for companies trying to develop new diagnostics and therapeutics in this nascent area
- Patients and providers must be willing to participate in research supporting the development of new products

Coalition's Position on Legislation

- Employers would benefit from predictability in this area
- Applicability of current law is murky
 - Creates uncertainties for employers about what they can and cannot do with genetic information
 - Especially problematic with respect to informally acquired information

Coalition's Legislative Efforts

- S. 306 has strong bi-partisan support
 - Support from Senate Republican leadership
- S. 306 has the support of the Administration
- Efforts now focused on the House

Coalition's Legislative Efforts

- Coalition is in discussion with a number of key senior House Republicans regarding introduction of Senate bill sometime in March
 - Goal is for one bill to be introduced in the House
- Will work with House Energy and Commerce and Education and Workforce Committees

Next Steps

- Committee approval of structure of report to the Secretary?
 - Should the Committee conduct a stakeholder meeting with the key stakeholders to further inform the report's analysis?
- Committee approval of DVD?
- Should a letter be written to the Secretary in support of S. 306?
 - Should it include public comments and DVD?