

**SACGHS Efforts
on
Genetic Discrimination Issue**

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Session Overview

- Update on Recent Developments
- Presentation of the Analysis of Current Law
- Briefing from Rep. Biggert's Office
- Committee Discussion

Task Force Members

- Agnes Masny, Chair
- Cynthia Berry
- Barbara Harrison
- Debra Leonard
- Reed Tuckson
- Emily Winn-Deen
- Joann Boughman
- Robinsue Frohboese
- Peter Gray
- Tim Leshan
- Mildred Rivera

Congressional Developments

- Genetic Information Nondiscrimination Act of 2005 (H.R. 1227) introduced in the House March 10, 2005
 - Sponsored by Representative Judy Biggert (IL)
 - Key co-sponsors include Bob Ney (OH), Anna Eshoo (CA) and Louise Slaughter (NY)
 - A total of 101 co-sponsors
 - Currently, referred to Energy and Commerce, Education and the Workforce, and Ways and Means Committees

Congressional Developments

- Companion to S. 306 which unanimously passed the Senate in February (98-0)
- Differs from S. 306 in only one way
 - Since revenue measures must originate in the House, provisions amending the Internal Revenue Code were omitted
 - Provisions involved only church plans

SACGHS Correspondence to Secretary Leavitt

- Letter of May 3, 2005 and four enclosures
 - Compilation of Public Comments
 - DVD
 - Copy of AHIP's Letter of February 22, 2005 to Rep. Boehner
 - Analysis of Current Law
- Transmitted to the Secretary by the NIH Director

Content of SACGHS' Letter

- Urges the Secretary to exert influence and leadership to bring about the enactment of Federal genetic nondiscrimination legislation
- Reviews stakeholder perspectives gathered through outreach efforts
 - Patients, the general public and the Coalition for Genetic Fairness
 - Representatives of health insurance (AHIP) and business communities (Chamber of Commerce)

Content of SACGHS' Letter

- Suggests that perspectives of AHIP and the Chamber are complex and deserve further analysis
- Requests that the Secretary meet with three key stakeholder groups and other interested parties to advance consensus-building

Content of SACGHS' Letter

- Summarizes conclusions of the analysis of current law
 - No Federal laws directly or comprehensively address the issues raised by the use of genetic information
 - Current law and court decisions leave substantial gaps in coverage and offer inconsistent and uncertain safeguards at best
 - Current avenues for relief are uncertain and likely to lead to confusion as well as costly litigation

Perspectives on Genetic Discrimination

- Video highlighting the testimony received during the genetic discrimination session at the October 2004 SACGHS meeting