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Secretary's Advisory Committee on Genetics, Health, and Society

Twentieth Meeting  
October 8-9, 2009  
Washington, D.C.

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DRAFT AGENDA

**Thursday, October 8, 2009**

8:30 a.m. – 8:45 a.m.            Opening Remarks  
   Steven Teutsch, M.D., M.P.H.  
   SACGHS Chair

**Genetic Information Nondiscrimination Act**

8:45 a.m. – 10:45 a.m.        Update on the Implementation of the Genetic Information Nondiscrimination  
   Act (Public Law 110-233)

8:45 a.m. – 9:30 a.m.        *Title I—Genetic Nondiscrimination in Health Insurance*

*Employment-based Group Market Provisions*

Amy Turner, J.D.  
Senior Advisor and Special Projects Manager  
Employee Benefits Security Administration  
Department of Labor

Russ Weinheimer, J.D.  
Senior Counsel, Office of the Chief Counsel  
Internal Revenue Service  
Department of Treasury

*Individual Insurance Market Provisions*

James Mayhew, J.D.  
Director, Division of Private Health Insurance  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services

*Privacy and Confidentiality*

Robinsue Frohboese, J.D., Ph.D.  
Principal Deputy Director

Christina Heide, J.D.  
 Senior Health Information Privacy Policy Specialist  
 Office for Civil Rights  
 Department of Health and Human Services

9:30 a.m. – 9:55 a.m. *Title II—Prohibiting Employment Discrimination on the Basis of Genetic Information*

Kerry Leibig, J.D.  
 Senior Attorney Advisor  
 Office of Legal Counsel  
 Equal Employment Opportunity Commission

9:55 a.m. – 10:45 a.m. *Committee Discussion*

10:45 a.m. – 11:00 a.m. BREAK

### **Gene Patents and Licensing Practices**

11:00 a.m. – 11:45 a.m. Overview of Report, Summary of Public Comments on Draft Report, and Session Goals  
 James P. Evans, M.D., Ph.D.  
 SACGHS Member

### **Public Comment Session**

11:45 a.m. – 12:30 p.m. LUNCH

12:30 p.m. – 2:00 p.m. Public Comments

### **Gene Patents and Licensing Practices**

2:00 p.m. – 3:00 p.m. Discussion of Final Draft Recommendations  
 Facilitators: Dr. Teutsch and Dr. Evans

3:00 p.m. – 3:15 p.m. BREAK

3:15 p.m. – 5:50 p.m. Discussion of Final Draft Recommendations (continued)

5:50 p.m. – 6:00 p.m. Closing Remarks – Dr. Teutsch

## **Friday, October 9, 2009**

8:00 a.m. – 8:10 a.m.            Opening Remarks  
    Dr. Teutsch  
    SACGHS Chair

### **Genomic Data Sharing**

8:10 a.m. – 9:00 a.m.            Discussion of Proposed Steps for the SACGHS Priority Topic on Ethical  
    Implications of Genomic Data Sharing  
    Charmaine Royal, Ph.D.  
    SACGHS Member

### **Genetics Education and Training**

9:00 a.m. – 9:30 a.m.            Update on the Draft Report on Genetics Education and Training: Literature  
    and Survey Findings  
    Barbara Burns McGrath, R.N., Ph.D.  
    SACGHS Member

9:30 a.m. – 10:00 a.m.            Committee Discussion of Draft Recommendations

10:00 a.m. – 10:15 a.m.            BREAK

### **Public Comment Session**

10:15 a.m. – 10:45 a.m.            Public Comments

### **Direct-to-Consumer Genetic Testing**

10:45 a.m. – 11:00 a.m.            Presentation of Revised Draft Paper on Direct-to-Consumer Genetic Testing  
    Sylvia Au, M.S., CGC  
    SACGHS Member

11:00 a.m. – 12:30 p.m.            Committee Discussion and Decisions Regarding Revised Draft Paper on  
    Direct-to-Consumer Genetic Testing

12:30 p.m. – 1:30 p.m.            LUNCH

### **Gene Patents and Licensing Practices**

1:30 p.m. – 2:45 p.m.            Reaching Consensus on Final Draft Recommendations and Draft Report  
    Facilitators: Dr. Teutsch and Dr. Evans

2:45 p.m. – 3:00 p.m.            Concluding Remarks – Dr. Teutsch  
    ADJOURN