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

Eighth Meeting  
October 19-20, 2005  
North Bethesda, MD

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### A G E N D A

#### Wednesday, October 19, 2005

8:30 a.m. – 8:35 a.m.            Opening Remarks  
   Cynthia E. Berry, J.D.  
   Acting SACGHS Chair

#### Large Population Studies Session

8:35 a.m. – 9:00 a.m.            Session Overview and Report from the SACGHS Task Force on Large  
   Population Studies  
   Huntington F. Willard, Ph.D.  
   SACGHS Task Force Chair

#### *Policy Perspectives from Members of the Scientific Community*

9:00 a.m. – 9:20 a.m.            Gerald R. Fink, Ph.D.  
   Professor of Genetics  
   Whitehead Institute for Biomedical Research  
   Massachusetts Institute of Technology

9:20 a.m. – 9:30 a.m.            Q&A

9:30 a.m. – 9:50 a.m.            Sharon Kardia, Ph.D.  
   Associate Professor of Epidemiology  
   Director, Public Health Genetic Program  
   University of Michigan School of Public Health

9:50 a.m. – 10:00 a.m.            Q&A

10:00 a.m. – 10:20 a.m.        Richard B. Marchase, Ph.D.  
   Vice President for Science Policy  
   Federation of American Societies for Experimental Biology

10:20 a.m. – 10:30 a.m.	Q&A
10:30 a.m. – 11:15 a.m.	Roundtable Discussion with Presenters Facilitator: Dr. Willard
11:15 a.m. – 11:30 a.m.	Public Comments
11:30 a.m. – 12:00 p.m.	Remarks of the Acting SACGHS Chair (continued) Ms. Berry
12:00 p.m. – 1:00 p.m.	LUNCH

*Exploring Mechanisms for Public Engagement*

1:00 p.m. – 1:20 p.m.	Joan A. Scott, M.S., CGC Deputy Director Genetics & Public Policy Center
1:20 p.m. – 1:40 p.m.	Toby Citrin, J.D. Adjunct Professor of Health Management and Policy Director, Michigan Center for Genomics and Public Health University of Michigan School of Public Health
	E. Yvonne Lewis Executive Director Faith Access to Community Economic Development
1:40 p.m. – 2:00 p.m.	Mary Woolley, M.A. President Research!America
2:00 p.m. – 3:00 p.m.	Roundtable Discussion with Presenters Facilitator: Kevin FitzGerald, S.J., Ph.D., Ph.D.
3:00 p.m. – 3:15 p.m.	BREAK

*Policy Perspectives from Members of the Bioethics Community*

3:15 p.m. – 3:35 p.m.	Henry T. Greely, J.D. Deane F. and Kate Edelman Johnson Professor of Law Stanford Law School
3:35 p.m. – 3:55 p.m.	Pilar Ossorio, Ph.D., J.D. Assistant Professor of Law and Medical Ethics Associate Director, Center for the Study of Race and Ethnicity in Medicine University of Wisconsin Law School

- 3:55 p.m. – 4:15 p.m. Troy Duster, Ph.D.  
Professor of Sociology  
Director, Institute for the History of the Production of Knowledge  
New York University
- 4:15 p.m. – 5:00 p.m. Roundtable Discussion with Presenters  
Facilitator: Ellen Fox, M.D.
- 5:00 p.m. – 6:00 p.m. Discussion of Next Steps, Work Plan and Final Work Product for Large  
Population Studies  
Facilitators: Dr. Willard and Ms. Berry

## Thursday, October 20, 2005

### Genetic Discrimination Session

- 8:30 a.m. – 8:45 a.m. Update on the Status of the Genetic Information Nondiscrimination Act  
of 2005 (S. 306/H.R. 1227)  
Sharon F. Terry, M.A.  
Coalition for Genetic Fairness
- 8:45 a.m. – 9:15 a.m. Public Attitudes toward Advances in Genetics, Genetic Privacy and the  
Potential Misuse of Genetic Information  
Ms. Christy White  
Cogent Research
- 9:15 a.m. – 9:30 a.m. Q&A and Committee Discussion

### Pharmacogenomics Session

- 9:30 a.m. – 9:45 a.m. Update from the SACGHS Task Force on Pharmacogenomics  
Emily S. Winn-Deen, Ph.D.  
SACGHS Task Force Chair
- 9:45 a.m. – 10:05 a.m. Update from FDA  
Steven I. Gutman, M.D., M.B.A.  
Director, Office of In Vitro Diagnostics  
U.S. Food and Drug Administration
- Allen Rudman, Ph.D.  
Associate Director, Office of Clinical Pharmacology and  
Biopharmaceutics  
Center for Drug Evaluation and Research, FDA
- 10:05 a.m. – 10:30 a.m. Q&A and Committee Discussion  
Facilitator: Dr. Winn-Deen
- 10:30 a.m. – 10:45 a.m. BREAK
- 10:45 a.m. – 11:00 a.m. Public Comments

- 11:00 a.m. – 11:25 a.m. Feasibility of Integrating Pharmacogenomics into Drug Development from an Economic Perspective  
Thomas A. Metcalfe  
Head of Biomarker Program  
F. Hoffmann-La Roche Ltd
- 11:25 a.m. – 11:50 a.m. Economic Challenges of Integrating Pharmacogenomics into Clinical Practice  
Kathryn Phillips, Ph.D.  
Professor of Health Economics and Health Services Research  
Director, Program in Pharmacogenomics and Population Screening  
University of California, San Francisco
- 11:50 a.m. – 12:15 p.m. Q&A and Committee Discussion  
Facilitator: Dr. Winn-Deen
- 12:15 p.m. – 1:15 p.m. LUNCH
- 1:15 p.m. – 1:45 p.m. Ethical and Social Issues Associated with Using Race and Genetics in the Study of Differential Drug Response  
Wylie Burke, M.D., Ph.D.  
Professor and Chair, Department of Medical History and Ethics  
University of Washington
- 1:45 p.m. – 2:15 p.m. Q&A and Committee Discussion  
Facilitator: Dr. Winn-Deen
- 2:15 p.m. – 3:15 p.m. Discussion of Next Steps, Work Plan, and Final Work Product for Pharmacogenomics  
Facilitators: Dr. Winn-Deen and Ms. Berry
- 3:15 p.m. – 3:30 p.m. Planning for March 2006 SACGHS Meeting and Concluding Remarks  
Ms. Berry
- ADJOURN