

Thursday, July 21, 2005

8:30 a.m. – 9:00 a.m.

Continental Breakfast (for Committee and Ex-Officio Members)

9:00 a.m. – 9:15 a.m.

Opening Remarks and Welcome

Betty James Duke, Ph.D., Administrator
Health Resources and Services Administration
Department of Health and Human Services

9:15 a.m. – 9:30 a.m.

Committee Business

- Approval of Minutes
- Approval of Subcommittees' Charge

R. Rodney Howell, M.D.
Committee Chair

9:30 a.m. – 9:40 a.m.

American College of Medical Genetics (ACMG) Report—Update

Peter C. van Dyck, M.D., M.P.H.
Associate Administrator
Maternal and Child Health Bureau

9:40 a.m. – 10:15 a.m.

Committee Discussion on Public Comments to ACMG Report

R. Rodney Howell, M.D.
Committee Chair

10:15 a.m. – 10:30 a.m.

Break

10:30 a.m. – 11:45 a.m.

Committee Discussion on Public Comments to ACMG Report, continued

R. Rodney Howell, M.D.
Committee Chair

11:45 a.m. – 12:00 p.m.

State of the States

Bradford Therrell, Ph.D.

National Newborn Screening and Genetic Resource Center

12:00 p.m. – 1:00 p.m.

Working Lunch (for Committee and Ex-Officio Members)

1:00 p.m. –

2:30 p.m.

The Role of Evidence and Other Factors in Decision – Making

- **Evidence, Politics, Technological Change**
Annetine Gelijns, Ph.D. and Alan Moskowitz, M.D.
Columbia University
- **Making Policy When Evidence is Meager and in Dispute**
David Atkins, M.D.
Agency for Health Research and Quality
Chief Medical Officer
Director, Center for Outcomes and Evidence
- **Incorporating Evidence-Based Expert Opinion into the Decision – Making Process**
John McCormick, M.D.
Food and Drug Administration
Deputy Director, Office of Orphan Products Development

2:30 p.m. – 2:45 p.m. **Break** 2:45 p.m. – 5:00 p.m. **Committee Discussion on Decision – Making Process** 5:00 p.m. **Adjourn Friday, July 22, 2005** 8:00 a.m. – 8:30 a.m. **Continental Breakfast** (for Committee and Ex-Officio Members) 8:30 a.m. – 9:00 a.m.

American College of Obstetrics and Gynecology (ACOG)—Newborn Screening Policy

Anthony Gregg, M.D.

American College of Obstetrics and Gynecology

Committee on Genetics

9:00 a.m. – 11:00 a.m. **Committee Business – Subcommittee Meetings** 11:00 a.m. – 11:15 a.m. **Break** 11:15 a.m. – 12:00 p.m.

Committee Business – Subcommittee Reports

- **Education and Training**
Stephen Edwards, M.D.
Past-President
American Academy of Pediatrics
- **Follow Up**
Coleen Boyle, Ph.D., M.S.
Center for Disease Control and Prevention
- **Laboratory Standards and Procedures**
Amy Brower, Ph.D.
Executive Director
Third Wave Technologies
Medical Informatics and Genetics

12:00 p.m. – 1:00 p.m. **Working Lunch** (for Committee and Ex-Officio Members) 1:00 p.m. – 2:00 p.m.

Public Comments

2:00 p.m. – 3:00 p.m.

Committee Business – Discussion

R. Rodney Howell, M.D.
Committee Chair

3:00 p.m. **Adjourn**