

Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

First Meeting

June 7-8, 2004

Ronald Reagan Building and International Trade Center
Washington, DC

Agenda

Monday, June 7, 2004

9-9:30 a.m.	HHS Welcome and Introductions Dennis Williams, Ph.D., M.A. Deputy Administrator Health Resources and Services Administration
9:30-10 a.m.	Roundtable Introductions
10-10:15 a.m.	Break
10:15-11 a.m.	Ethics Rules for Special Government Employees on Advisory Committees Jennifer L. Jordan Ethics and Personnel Security Specialist Health Resources and Services Administration
	Pam Kelley Ethics and Personnel Security Officer Health Resources and Services Administration
11-11:30 a.m.	Charge to Committee Review of Charter R. Rodney Howell, M.D., Chair Professor Department of Pediatrics The University of Miami School of Medicine
11:30-noon	Delivering Genetic Services to Children in a Clinical Setting R. Rodney Howell, M.D.
noon-1 p.m.	Lunch (on own)
1-2:30 p.m.	Overview of Newborn Screening Programs: State of the States Newborn Screening Task Force Report GAO report Marie Y. Mann, M.D., M.P.H. Genetic Services Branch Maternal and Child Health Bureau Health Resources and Services Administration
	Bradford Therrell, Ph.D. Director National Newborn Screening and Genetics Resource Center University of Texas Health Science Center at San Antonio

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2:30-3:15 p.m.

Federal Agency and Liaison Briefings

Elizabeth Edgerton, M.D., M.P.H.
Director of Clinical Prevention
U.S. Preventive Services Task Force
Agency for Healthcare Research and Quality

Coleen Boyle, Ph.D.
Associate Director
Science and Public Health Team
Centers for Disease Control and Prevention

Jennifer Howse, Ph.D.

President
March of Dimes

3:15-3:30 p.m.

Break

3:30-5 p.m.

Federal Agency and Liaison Briefings E. Stephen Edwards,
M.D.

Past President
American Academy of Pediatrics

James Collins, M.D.

Chair
Secretary's Advisory Committee on Infant Mortality
U.S. Department of Health and Human Services

Reed Tuckson, M.D.

Senior Vice President
Consumer Health and Medical Care Advancement
UnitedHealth Group
Secretary's Advisory Committee on Genetics, Health, and
Society

U.S. Department of Health and Human Services

5 p.m.

Adjourn

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Tuesday, June 8, 2004

8:30-9:30 a.m.	Federal Agency and Liaison Briefings Duane Alexander, M.D. Director National Institute of Child Health and Human Development National Institutes of Health Peter van Dyck, M.D., M.P.H. Associate Administrator Maternal and Child Health Bureau Health Resources and Services Administration
9:30-10:30 a.m.	Standardization of Guidelines and Practices for Newborn Screening Programs Michael Watson, Ph.D. Executive Director American College of Medical Genetics
10:30-10:45 p.m.	Break
10:45-noon	Discussion
noon-1 p.m.	Lunch (on own)
1-2 p.m.	Public Comment
2-3 p.m.	Committee Business Future Agenda Priority Issues
3 p.m.	Adjourn