

Wednesday, September 22, 2004	
8:30 a.m. – 9:00 a.m.	Continental Breakfast (for Committee Members and Speakers)
9:00 a.m. – 9:15 a.m.	HRSA Welcome Dennis P. Williams, PhD, MA Deputy Administrator Health Resources and Services Administration
9:15 a.m. – 9:30 a.m.	Opening Remarks and Welcome <ul style="list-style-type: none"> • Approval of minutes • Introduction of members (not in attendance at last meeting) <ul style="list-style-type: none"> ○ James Collins, MD ○ Derek Robertson, JD ○ Denise Dougherty, PhD ○ R. Rodney Howell, M.D., Chair The University of Miami School of Medicine
9:30 a.m. – 11:00 a.m.	American College of Medical Genetics “Newborn Screening: Toward a Uniform Screening Panel and System” Michael Watson, Ph.D. Executive Director American College of Medical Genetics <ul style="list-style-type: none"> • Decision Analysis <ul style="list-style-type: none"> ○ Case Studies: <ul style="list-style-type: none"> ▪ Lysosomal Storage Disease (no test but there is treatment) ▪ Medium-chain acyl CoA dehydrogenase deficiency (test and treatment) ▪ Cystic Fibrosis (test and treatment) ▪ Cystic Fibrosis (score) • Recommended Screening Panel
11:00 a.m. – 11:15 a.m.	Break
11:15 a.m. – 12:30 p.m.	Discussion
12:30 p.m. – 1:30 p.m.	Working Lunch (for Committee Members and Speakers)
1:30 p.m. – 2:30 p.m.	Use of MS-MS by State Newborn Screening Programs <ul style="list-style-type: none"> • State of the States • Barriers to incorporation of expanded screening with MS/MS Bradford Therrell, Ph.D. Director National Newborn Screening and Genetics Resource Center University of Texas Health Science Center at San Antonio

2:30 p.m. – 4:00 p.m.	<p>Financing Newborn Screening Systems- I—How States Finance their Systems</p> <ul style="list-style-type: none"> • State Financing Mechanisms Overview Kay Johnson, M.P.H., M.Ed. President Johnson Group Consulting Inc. • Panel-State Reports on Financing Mechanisms <ul style="list-style-type: none"> ○ New York Report Kenneth Pass, PhD Director of Newborn Screening Program Department of Health New York State ○ Mississippi Report Daniel Bender, MHS Maternal and Child Health Director Mississippi Department of Health
4:00 p.m. – 5:00 p.m.	Discussion
5:00 p.m.	Adjourn
Thursday, September 23, 2004	
8:00 a.m. – 8:30 a.m.	Continental Breakfast (for CommitteeMembers and Speakers)
8:30 a.m. – 10:30 a.m.	<p>Financing Newborn Screening Systems- II—The Benefit and Effectiveness of Screening</p> <p>Panel</p> <ul style="list-style-type: none"> • Office of Technology Assessment- 1986 Report on Newborn Screening Programs Judith L. Wagner, Ph.D. Scholar in Residence Institute of Medicine Julie Ostrowsky, B.Sc., M.Sc. Center for Infectious Disease Research and Policy and National Center for Food Protection and Defense University of Minnesota • Cost-Effectiveness Analysis of Newborn Screening Stephen Downs, M.D., M.S. Associate Professor and Director Children's Health Services Research Indiana University School of Medicine • Cost-Benefit Analysis of MS-MS in Newborn Screening in California George Cunningham, M.D., M.P.H. Chief, Genetic Disease Branch California Department of Health Services
10:30 a.m. –	Break

10:45 p.m.	
10:45 a.m. – 12:00 p.m.	Discussion
12:00 p.m. – 1:00 p.m.	Lunch (for Committee Members and Speakers)
1:00 p.m. – 2:00 p.m.	Public Comments
2:00 p.m. – 3:30 p.m.	<p>Committee Business</p> <p>Priority Issues</p> <ul style="list-style-type: none"> • Recommendations • Subcommittees • Working Groups <p>Future Meetings Agenda</p>
3:30 p.m.	Adjourn