

# 26<sup>th</sup> Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

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Park Hyatt Hotel, Washington D.C.  
January 26-27, 2012

Thursday, January 26, 2012

## ORIENTATION TO SACHDNC AND HHS

8:30 A.M. – 9:00 A.M.

### **Ethics for Special Government Employees**

Dheeraj Agarwal  
HRSA Office of Management/Division of Workforce  
Management

9:00 A.M. – 9:45 A.M.

### **Overview of the Health Resources and Services Administration and the Maternal and Child Health Bureau**

Mary Wakefield, PhD, RN  
Administrator, Health Resources and Services Administration

9:45 A.M. – 10:15 A.M.

### **Overview of SACHDNC legislation**

Beverly Dart, JD  
HHS Office of General Counsel

## COMMITTEE BUSINESS

10:15 A.M. - 10:45 A.M.

### **Committee Business**

- Approval of Minutes from the September 2011 Meeting
- Committee Correspondence

Joseph Bocchini, MD  
Committee Chair

10:45 A.M. – 11:00 P.M

### **BREAK**

11:00 A.M. – 12:30 P.M

### **Orientation to SACHDNC Current Charter, Processes and Procedures**

Sara Copeland, MD  
Designated Federal Official

*\*Vote on By-laws*

12:30 P.M. – 1:45 P.M.

### **LUNCH**

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**Thursday, January 26, 2012**

1:45 P.M. – 2:30 P.M.

**Nomination and Prioritization Workgroup Report**

Dietrich Matern, MD  
Committee Member

*\* Vote to move 22q11 forward*

2:30 P.M. – 2:45 P.M.

**Public Comments**

2:45 P.M. – 3:00 P.M.

**BREAK**

3:00 P.M. – 5:00 P.M.

**Subcommittee Meetings**

- Education and Training
- Follow-up and Treatment
- Laboratory Standards and Procedures

**Friday, January 27, 2012**

8:30 A.M. – 10:00 A.M.

**Subcommittee Reports**

- Subcommittee on Laboratory Standards and Procedures  
Fred Lorey, PhD  
Committee Member
- Subcommittee on Education and Training  
Don Bailey, PhD, MEd  
Committee Member
- Subcommittee on Follow-up and Treatment  
Coleen Boyle, PhD, MS  
Committee Member

10:00 A.M. – 11:00 A.M.

**Hyperbilirubinemia: Final report from Evidence Review Group**

Alex Kemper, MD, MPH, MS  
External Evidence Review Workgroup

Catherine Wicklund, MS, CGC  
Alexis Thompson, MD  
Committee Members

*\* Vote to move Hyperbilirubinemia forward*

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Friday, January 27, 2012

11:00 A.M. – 11:15 A.M.

**BREAK**

11:45 A.M. – 12:15 A.M.

**Report:** *Improving Data Quality and Quality Assurance in Newborn Screening by Including the Bloodspot Screening Collection Device Serial Number on Birth Certificates*

Brad Therell, PhD

National Newborn Screening and Genetics Resource Center

*\* Vote on SACHDNC product support*

12:15 P.M. – 1:15 P.M.

**LUNCH**

1:30 P.M. – 2:30 P.M.

**Report:** *Implementing Point-of-Care Newborn Screening*

Nancy Green, MD

Follow-up and Treatment Subcommittee

*\* Vote on SACHDNC product support*

**New Jersey – CCHD Implementation**

Lorraine Freed Garg, MD, MPH

New Jersey Department of Health and Senior Services

**Indiana – CCHD Implementation**

Bob Bowman, MS

Indiana State Department of Health

**Federal Plan of Action for CCHD - Update**

Coleen Boyle, PhD, MS

Committee Member

2:30 P.M.

**ADJOURN**