

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

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Humphrey Building/HHS Headquarters Room 800  
200 Independence Avenue SW, Washington, DC  
September 13–14, 2012

**Thursday, September 13, 2012**

## ***COMMITTEE BUSINESS***

8:30 A.M. – 9:00 A.M.

### **Administrative Business**

- Approval of Minutes from the May 2012 Meeting
- Committee Correspondence

Joseph Bocchini, MD  
Committee Chair

## ***UPDATE ON RUSP CONDITIONS***

9:00 A.M. – 9:15 A.M.

### **Newborn Screening Case Definitions – Update**

Jelili Ojodu, MPH  
Director, Newborn Screening and Genetics  
Association of Public Health Laboratories

9:15 A.M. – 9:30 A.M.

### **Newborn Screening Quality Indicators**

Jelili Ojodu, MPH  
Director, Newborn Screening and Genetics  
Association of Public Health Laboratories

## ***PUBLIC CONSIDERATION AND CONDITION NOMINATIONS***

9:30 A.M. – 9:45 A.M.

### **Public Comment**

9:45 A.M. – 10:00 A.M.

### **BREAK**

10:00 A.M. – 11:00 A.M.

### **Final Condition Review Matrix**

Alex Kemper  
Condition Review Workgroup  
*\*Vote whether or not to accept the condition review matrix*

11:00 A.M. – 11:45 A.M.

### **Adrenoleukodystrophy – Nomination and Prioritization Report**

Fred Lorey, PhD  
Committee Member  
*\*Vote on whether to move ALD forward*

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11:45 A.M. – 12:15 A.M.

## **Update on Pompe Nomination**

Alex Kemper, MD

Condition Review Workgroup

12:15 P.M. – 1:30 P.M.

## **LUNCH**

1:30 P.M. – 2:30 P.M.

## **Ethical Issues – ELSI and the Advisory Committee**

Jean McEwen, JD, PhD

Program Director

Ethical, Legal, and Social Implications Program,

NHGRI/NIH

2:30 P.M. – 2:45 P.M.

## **BREAK**

2:45 P.M. – 5:00 P.M.

## **Subcommittee Meetings**

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

**Friday, September 14, 2012**

## ***ADVISORY COMMITTEE, SUBCOMMITTEES, WORKGROUPS REPORTS***

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  
Beth Tarini, MD, MS, FAAP  
Organizational Representative
- Subcommittee on Follow-up and Treatment  
Carol Greene, MD  
Organizational Representatives

10:00 A.M. – 10:15 A.M.

## **BREAK**

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10:15 A.M. – 11:00 P.M.

***Multistate Analysis of Single Tests or Routine Second Testing in Newborn Screening for Hypothyroidism and Congenital Adrenal Hyperplasia - Update***

Stuart Shapira, MD, PhD  
Medical Officer, Pediatric Genetics Team  
NCBDDD, CDC

11:00 A.M. – 11:45 A.M.

***CDC Recommendations for Good Laboratory Practices in Biochemical Genetic Testing and Newborn Screening for Inherited Metabolic Disorders***

Bin Chen, PhD  
Division of Laboratory Systems, National Center for Preparedness, Detection, and Control of Infectious Diseases, Coordinating Center for Infectious Diseases, CDC

*\* Vote on SACHDNC product support*

11:45 A.M. – 12:15 P.M.

**Prenatal Family History Project – data and report**

Joan Scott, MS, CGC  
Executive Director of NCHPEG

12:15 P.M. – 1:30 P.M.

**Lunch**

1:30 P.M. – 2:00 P.M.

**Carrier Screening Draft Review**

Meredith Weaver, PhD, ScM, CGC  
SACHDNC Carrier Screening Taskforce

## ***PERTINENT MEETING UPDATES***

2:00 P.M. – 2:30 P.M.

**IOM Meeting Summary: Assessing the Economics of Genomic Medicine**

Catherine Wicklund, M.S., C.G.C.  
Committee Member

2:30 P.M.

**ADJOURN**