

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

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Webinar

FRIDAY, APRIL 19, 2013

## *COMMITTEE BUSINESS*

10:00AM – 10:30AM

### **Administrative Business**

- Approval of Minutes from the January Meeting
- Approval of the 2012 Annual Report to Congress

Joseph Bocchini, MD  
Committee Chair

Michael C Lu, MD, MPH  
Federal Ex-Officio Member – HRSA

## *UPDATE ON RUSP CONDITIONS*

10:30AM – 11:15AM

### **Lessons Learned from Early Hearing Detection and Intervention (EHDI) that may be applicable to Critical Congenital Heart Disease (CCHD) Screening - Update**

Chris Kus, MD, MPH  
Organizational Representative  
Subcommittee on Follow-up and Treatment

11:15AM – 12:00PM

### **Assessing the Impact of the NCAA Sickle Cell Trait Screening on State Newborn Screening Programs**

Beth Tarini, MD, MS, FAAP  
Organizational Representative

Anne Azrak  
Child Health Evaluation and Research (CHEAR) Unit  
Division of General Pediatrics  
University of Michigan

12:00PM – 1:00PM

**LUNCH**

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1:00PM – 1:30PM

## **Newborn Screening for Critical Congenital Heart Disease: An Update on CDC Activities**

Cindy Hinton, PhD, MS, MPH

Health Scientist

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

## ***PUBLIC CONSIDERATION***

1:30PM – 1:35PM

## **Pompe Condition Nomination - Update**

Joseph Bocchini, MD

Committee Chair

1:35PM – 2:00PM

## **PUBLIC COMMENT**

## ***ADVISORY COMMITTEE, SUBCOMMITTEE, WORKGROUP, OTHER REPORTS***

2:00PM – 2:10PM

## **BREAK**

2:10PM – 3:00PM

## **The Affordable Care Act and the Impact on Individuals with Heritable Disorders**

Meg Comeau, MHA

Director

Catalyst Center

Boston University School of Public Health

3:00PM – 4:00PM

## **Subcommittees' Updates - Current and Future Priorities and Projects**

- Subcommittee on Education and Training
  - Don Bailey, PhD, MEd  
Committee Member
  - Beth Tarini, MD, MS, FAAP  
Organizational Representative
- Subcommittee on Laboratory Standards and Procedures
  - Kellie Kelm, PhD  
Committee Member
- Subcommittee on Follow-up and Treatment
  - Carol Greene, MD  
Organizational Representative