

# 1<sup>st</sup> Meeting of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

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## Thursday, May 16, 2013

10:00 A.M. – 12:00 P.M.

### **Subcommittee Meetings**

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

12:00 P.M. – 1:00 P.M.

### **LUNCH**

1:00 P.M. – 1:05 P.M.

### **Welcome**

Joseph Bocchini, MD  
Committee Chair

1:05 P.M. – 2:00 P.M.

### **Subcommittee Reports**

- Subcommittee on Laboratory Standards and Procedures  
Susan Tanksley, PhD  
Organizational Representative
- Subcommittee on Education and Training  
Don Bailey, PhD, MEd  
Committee Member
- Subcommittee on Follow-up and Treatment  
Chris Kus, MD, MPH  
Organizational Representative

## Friday, May 17, 2013

10:00 A.M. – 10:30 A.M.

### **Public Comment**

10:30 A.M. – 12:30 P.M.

### **Final Evidence Review – Pompe**

Alex Kemper, MD, MPH, MS  
Condition Review Workgroup

Lisa A. Prosser, PhD  
Condition Review Workgroup

Jelili Ojodu, MPH  
Condition Review Workgroup

12:30 P.M. – 1:00 P.M.

### **LUNCH**

# 1st Meeting of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

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1:00 P.M. – 2:00 P.M.

**Committee Members Review, Discussion and Vote on  
Pompe**

Andrea M. Williams, BA  
Committee Member

Charles Homer, MD, MPH  
Committee Member

***\*Vote on whether or not to recommend addition to RUSP\****

2:00 P.M.

**ADJOURN**