

27th Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Hilton Alexandria Old Town Hotel, Alexandria, VA

May 17-18, 2012

Thursday, May 17, 2012

8:30 A.M. – 9:00 A.M.

Administrative Business

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

Joseph Bocchini, MD
Committee Chair

- Organization Representative Categories, Annual Report, Reauthorization Report, Policies and Procedures - Updates

Sara Copeland, MD
Designated Federal Official

9:00 A.M. – 10:00 A.M.

Subcommittee Priorities and Projects

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

UPDATE ON RUSP CONDITIONS

10:00 A.M. – 10:30 A.M.

Newborn Screening Case Definitions

Cynthia F. Hinton, PhD, MS, MPH
Centers for Disease Control - National Center on Birth Defects and Developmental Disabilities

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Thursday, May 17, 2012 *cont'd*

10:30 A.M. – 10:45 A.M. **BREAK**

PUBLIC CONSIDERATION AND CONDITION NOMINATIONS

10:45 A.M. – 11:00 A.M. **Public Comment**

11:00 P.M. – 11:45 A.M. **MPS I – Nomination and Prioritization Report**

Fred Lorey, PhD
Committee Member

** Vote on whether to move MPS I forward*

11:45 P.M. – 1:00 P.M. **LUNCH**

1:00 P.M.- 1:15 P.M. **Public Comment**

1:15 P.M. – 2:00 P.M. **Pompe – Nomination and Prioritization Report**

Nancy Green, MD
Nomination and Prioritization Workgroup
** Vote on whether to move Pompe forward*

2:00 P.M. – 5:00 P.M. **Subcommittee Meetings**

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

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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
Carol L. Greene, MD
Organizational Representative

10:00 A.M.- 10:45 A.M.

Discuss and Prioritize Subcommittee Plans and Projects

Joseph Bocchini, MD
Committee Chair

** Vote on priorities for the Subcommittees*

10:45 A.M. – 11:00 A.M.

BREAK

ADVISORY COMMITTEE, SUBCOMMITTEES, WORKGROUPS REPORTS

11:00 A.M. – 11:25 A.M.

Medical Home Manuscript from Follow-up and Treatment Subcommittee

Alex Kemper, MD, MPH, MS
Subcommittee Member

NCC Medical Home Workgroup

** Vote on SACHDNC product support*

11:25 A.M. – 11:45 A.M.

Medical Foods Manuscript from Follow-up and Treatment Subcommittee

Sue Berry, MD
Subcommittee Member

** Vote on SACHDNC product support*

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11:45 A.M. – 12:00 P.M.

Carrier Screening Taskforce – Update on the project and interval findings

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

12:00 P.M. – 1:00 P.M.

Lunch

1:00 P.M. – 1:30 P.M.

NBS Awareness Campaign Strategy Summit – Summary

Don Bailey, PhD, MEd
Committee Member

1:30 P.M. – 2:00 P.M.

Condition Review Process Report – Update
(Adding Public Health Impact)

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

PERTINENT MEETING UPDATES

2:00 P.M. – 2:30 P.M.

NIH Initiatives

Nutrition and Dietary Supplement Interventions for Inborn Errors of Metabolism (NDSI-IEM) and Phenylketonuria (PKU)
Meetings

Kathryn Camp, MS, RD, CSP
Scientific Policy Analyst, Office of Dietary Supplements
NIH

Melissa A. Parisi, MD, PhD
Chief, Intellectual and Developmental Disabilities Branch
NICHD/NIH

2:30 P.M.

ADJOURN