

ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN

Bethesda Marriott - Pooks Hill, 5151 Pooks Hill Road, Bethesda, MD 20814
February 26-27, 2009

THURSDAY, FEBRUARY 26, 2009

- 7:30A.M. - 8:30 A.M.** **CONTINENTAL BREAKFAST** (Committee Members and Presenters)
Bethesda Room – Level 1
- 8:30 A.M. - 8:45 A.M.**
(Salon A & B - Level 1) **WELCOME**
- **R. Rodney Howell, M.D.**
Committee Chair
 - Approval of Minutes from November 24, 2008 Meeting
 - Committee Correspondence
- 8:45 A.M. - 11: 15 A.M.** **SUBCOMMITTEE MEETINGS**
- **Follow-up and Treatment**
Salon A - Level 1
 - **Education and Training**
Chevy Chase Room - Level 1
 - **Laboratory Standards**
Potomac Room - Level 1
- 11:15 A.M. - 11:30 A.M.** **BREAK** (Committee Members and Presenters)
Bethesda Room – Level 1
- 11:30 A.M. - 11:45 A.M.** **UPDATE ON AMERICAN HEALTH INFORMATION COMMUNITY'S
NEWBORN SCREENING USE CASE**
- **Alan E. Zuckerman, M.D.**
Consultant, AHIC Personalized Healthcare Workgroup
Co-Chair CCHIT Interoperability Workgroup
Primary Care Informatics Program Director
Georgetown University School of Medicine
- 11:45 A.M. - 12:45 P.M.** **LUNCH** (Committee members and presenters)
Bethesda Room – Level 1

12:45 P.M. - 1:30 P.M.

DECISION CRITERIA AND PROCESS WORKGROUP

- **Ned Calonge, M.D., M.P.H.**
Committee Member

1:30 P.M. - 2:15 P.M.

EVIDENCE REVIEW WORKGROUP: FINAL DRAFT REPORT ON THE CANDIDATE NOMINATION OF SEVERE COMBINED IMMUNODEFICIENCY (SCID)

- **Ellen Lipstein, M.D.**
Fellow, Harvard Pediatric Health Services Fellowship
Center for Adolescent and Child Health Policy
MassGeneral Hospital for Children

2:15 P.M. - 2:30 P.M.

PUBLIC COMMENT ON SCID REVIEW

- **Jennifer M. Puck, M.D.**
SCID Nominator - Introduction
Department of Pediatrics
University of California – San Francisco
- **Mei W. Baker, M.D.**
Assistant Professor, Department of Pediatrics
Science Advisor, Newborn Screening Program
State Laboratory of Hygiene
University of Wisconsin – Madison
- **Barbara Ballard**
Parent and Administrator
SCID Network of Families
- **Marcia Boyle**
President and Founder
Immune Deficiency Foundation

2:30 P.M. - 3:00 P.M.

COMMITTEE DISCUSSION AND DECISION ON THE NOMINATION OF SCID TO THE RECOMMENDED UNIFORM SCREENING PANEL

- **Gerard Vockley, M.D., Ph.D. (discussant)**
Committee Member

3:00 P.M. - 3:15 P.M.

BREAK (Committee Members and Presenters)
Bethesda Room – Level 1

3:15 P.M. - 3:45 P.M.

NATIONAL INSTITUTES OF HEALTH REPORT:

- **Duane Alexander, M.D.**

Committee Member

- The Newborn Screening Translational Research Network
- Novel Technologies in Newborn Screening Initiative
- The National Children's Study

3:45 P.M. - 4:45 P.M.

**UPDATE ON HRSA AND CDC LONG TERM FOLLOW-UP
PROJECTS: INTERSECTING THE TRANSLATIONAL
RESEARCH NETWORK**

- **Anne Marie Comeau, Ph.D.**
Deputy Director
New England Newborn Screening Program
University of Massachusetts Medical School
- **Lisa Feuchtbaum, Dr.P.H, M.P.H.**
Research Scientist IV
Genetic Disease Screening Program
California Department of Health Services
- **Nicola Longo, M.D., Ph.D.**
Professor and Chief
Division of Medical Genetics
University of Utah
- **Michael Watson, Ph.D.**
Executive Director
American College of Medical Genetics

4:45 P.M. - 5:00 P.M.

DISCUSSION

5:00 P.M.

ADJOURN

FRIDAY, FEBRUARY 27, 2009

7:30 A.M. – 8:30 A.M. **CONTINENTAL BREAKFAST** (Committee Members and Presenters)
Bethesda Room – Level 1

8:30 A.M. – 9:45 A.M.
(Salon A, B & C - Level 1) **TRANSLATIONAL RESEARCH POLICIES: INTRODUCTION
TO INSTITUTIONAL REVIEW BOARDS, INFORMED
DECISION-MAKING AND CONSENT**

- **Jeffrey R. Botkin, M.D., M.P.H. - Moderator**
Department of Pediatrics
University of Utah School of Medicine
- **Edward Bartlett**
Division of International Activities
Office of Human Research Protection
- **Alan Fleischman, M.D.**
Committee Representative
Medical Director, March of Dimes

9:45 A.M. – 10:15 A.M. **COMMITTEE DISCUSSION**

10:15 A.M.—10:45 A.M. **BREAK** (Committee Members and Presenters)
Bethesda Room – Level 1

10:45 A.M. – 11:30 A.M. **RESIDUAL BLOOD SPOTS: POLICIES AND USES**

- **William Hannon, Ph.D.**
National Newborn Screening and Genetics Resource Center
- **Jeffrey R. Botkin, M.D., M.P.H.**
Department of Pediatrics
University of Utah School of Medicine

11:30 A.M. – 12:30 P.M. **LUNCH** (Committee Members and Presenters)
Bethesda Room – Level 1

12:30 P.M. – 1:30 P.M. **SUBCOMMITTEE REPORTS AND DISCUSSION**

- **Subcommittee on Laboratory Standards and Procedures**

Gerard Vockley, M.D., Ph.D.
Committee Member

- **Subcommittee on Education and Training**

Jana Monaco and Tracy L. Trotter, M.D., F.A.A.P.
Committee Members

- **Subcommittee on Follow-up and Treatment**

Coleen Boyle, Ph.D., M.S.
Committee Member

1:30 P.M. – 1:45 P.M.

PUBLIC COMMENT

1:45 P.M. – 3:00 P.M.

COMMITTEE BUSINESS

- **R. Rodney Howell, M.D.**

Committee Chair

- Agenda Items for the May 2009 meeting
- Calendar for the September 2009 Meeting
- President's Council on Bioethics: *The Changing Moral Focus of Newborn Screening*
- ACHDNC: Policies and Procedures for Operation and the Development of Recommendations for Screening Newborns and Children for Heritable Disorders and for the Heritable Disorders Program

3:00 P.M.

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