



***Challenges and Opportunities in Using Newborn Screening Samples  
for Translational Research: A Workshop***

**May 24, 2010**

**The Keck Center of the National Academies  
500 Fifth Street, NW  
Washington, DC 20001**

**MEETING OBJECTIVE**

To examine and explore the access to, use, and storage of dried blood spots which have been collected for newborn screening purposes through questions such as:

- What are the benefits of making these resources available for translational research?
- How do we protect the privacy and rights of individuals while allowing access to newborn screening samples?
- How can we make these samples available without compromising the main function of the newborn screening program?

**8:00 – 9:00 A.M. WORKING BREAKFAST**

8:00 – 9:00 A.M. Working Breakfast

**9:00 – 9:10 A.M. PUBLIC WORKSHOP BEGINS — KECK 100**

9:00 – 9:10 A.M. **Welcome**

*Wylie Burke, Roundtable Chair, and Professor and Chair of  
the Department of Bioethics and Humanities,  
University of Washington*

**9:10 – 10:30 A.M. CURRENT STATUS REGARDING STORAGE OF NBS SAMPLES**

9:10 – 9:30 A.M. **Current state practices and policies**

*Alissa Johnson, Johnson Policy Consulting*

9:30 – 9:50 A.M. **Rationale for storing newborn screening samples**

*Kenneth Pass, Senior Research Scientist, New York State  
Dept. of Health Wadsworth Center*

9:50 – 10:20 A.M. **Discussion**

**10:20 – 10:30 A.M. BREAK**

**10:30 – 12:20 P.M. RESEARCH OPPORTUNITIES ON NBS SAMPLES**

10:30 – 10:50 A.M. **Continuum from service to research**

*Anne Comeau, Deputy Director  
New England Newborn Screening Program;  
Associate Professor, Department of Pediatrics,  
University of Massachusetts Medical School*

10:50 – 11:10 A.M. **Opportunities for broader research**

*Sharon Kardia, Professor and Chair of Epidemiology;  
Director, Public Health Genetics Program; Director,  
Life Science and Society Program; Co-Director,  
Center for Genomics and Public Health School of  
Public Health, University of Michigan*

11:10 – 11:30 P.M. **Implications of dataset linkage**

*Michele Caggana, Deputy Director Division of Genetics;  
Chief, Laboratory of Human Genetics; Director,  
Newborn Screening Program; Head, Genetic Testing  
Section, New York State Department of Health  
Wadsworth Center*

11:30 – 12:20 P.M. **Discussion**

**12:20 – 1:20 P.M. WORKING LUNCH**

12:20 – 1:20 P.M. **Working lunch**

**1:20 – 3:45 P.M. SURMOUNTING CHALLENGES**

1:20 – 1:40 P.M. **Importance of retaining the core mission of newborn screening programs**

*Alan Fleischman, Medical Director, March of Dimes  
Foundation*

1:40 – 2:00 P.M. **Balancing issues from the patient/parent perspective**

*Sharon Terry, President and CEO, Genetic Alliance*

2:00 – 2:20 P.M.     **Legal issues related to the usage of newborn screening samples**  
*Ellen Wright Clayton, Rosalind E. Franklin Professor of Genetics and Health Policy; Director, Center for Biomedical Ethics and Society, Vanderbilt University*

2:20 – 2:40 P.M.     **Informed consent and stewardship**  
*Kelly Edwards, Associate Professor Department of Bioethics and Humanities, University of Washington School of Medicine*

2:40 – 3:30 P.M.     **Discussion**

**3:30 – 3:45 P.M.     Break**

<b>3:45 – 4:45 P.M.     WEIGHING THE VALUE</b>
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3:45 - 4:45 P.M.     **Panel discussion examining the potential benefits that could be derived from the use of dried blood spots for translational research versus the issues that need to be overcome**  
*Ann Waldo, Senior Counsel, Genetic Alliance*  
*Michele Caggana, New York State Department of Health Wadsworth Center*  
*Alan Fleischman, Medical Director, March of Dimes Foundation*

<b>4:45 – 5:30 P.M.     SUMMARY AND WRAP UP DISCUSSION</b>
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4:45 – 5:30 P.M.     **Summary and wrap up discussion**  
*Wylie Burke, Roundtable Chair and Professor and Chair of the Department of Bioethics and Humanities, University of Washington*