BEYOND THE BLOODSPOT:
HOW WILL EMERGING TECHNOLOGIES SHAPE DETECTION AND CLINICAL CARE?

WASHINGTON DC | AUGUST 20, 2013

9:30 AM – 10:00 AM  Registration and Continental Breakfast
10:00 AM – 10:15 AM  Stakeholder Impact and Approaches
10:15 AM – 11:15 AM  How Are Clinical Questions Driving Expansion?
11:15 AM – 12:15 PM  Technology: The Driver or the Passenger?
12:15 PM – 1:00 PM  Lunch Break (lunch provided)
1:00 PM – 2:00 PM  Public vs. Individual Interests
2:00 PM – 3:00 PM  What can Whole Genome Sequencing Learn from Existing Population-Based Screening?
3:00 PM – 3:45 PM  Testing and Screening Beyond Newborn Screening
3:45 PM – 4:15 PM  Neonatal Screening and Sequencing: The Future is Now
4:15 PM – 4:30 PM  Final Summary Discussion

HOSTED BY:
Genetic Alliance

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CENTERS FOR DISEASE CONTROL AND PREVENTION
9:30 AM - Registration and Continental Breakfast

10:00 AM - Stakeholder Impact and Approaches
Engaging patients, clinicians, and other stakeholders in the manufacturing, policy, and service dialogue to envision a sustainable and responsible screening system.

Speaker:
Natasha Bonhomme, Genetic Alliance

10:15 AM - How are Clinical Questions Driving Expansion?
What are the clinical questions that should be driving the increase in the number of conditions screened? How is the process for condition expansion (state and national) incorporating clinical outcomes? Are there other examples of public health screenings derived from undefined clinical expectations?

Speakers:
Nancy Green, Columbia University
David Kaufman, Genetics and Public Policy Center

11:15 AM - Technology: The Driver or the Passenger?
Is technology driving newborn screening or are newborn screening needs driving technology? What have we learned from the technology expansion early in this century?

Speakers:
Teresa Finitzo, Oz Systems
Dan Didier, Life Technologies
Vamsee Pamula, Advanced Liquid Logic Inc.
Frank Adamo, PerkinElmer

12:15 PM - Lunch Break

1:00 PM - Public vs. Individual Interests
What consent models exist that balance public health objectives and individual rights? How does direct-to-consumer testing impact this balance? What happens when data are not pulled back into the public health system?

Speakers:
Carrie Blout, Johns Hopkins Medical Institutions
Ellen Wright Clayton, Vanderbilt University
Aaron Goldenberg, Case Western Reserve University

2:00 PM - What can Whole Genome Sequencing Learn from Existing Population-Based Screening?
As the dialogue about what whole genome sequencing can bring to screening continues, what can be learned from established population-based screening programs? How do the experiences of these programs play into this next phase of clinical care?

Speakers:
Bartha Maria Knoppers, McGill University
Robert C. Green, Harvard Medical School
Anne Comeau, New England Newborn Screening Program / University of Massachusetts

3:00 PM - Testing and Screening Beyond Newborn Screening: How do Advances in Prenatal Testing Impact Screening of Newborns?
How is the discussion about what should be detected during the newborn phase impacted by advances in prenatal screening and diagnosis? How can we connect the topics of screening and diagnosis across these parts of the life course?

Speaker:
Arthur Beaudet, Baylor College of Medicine
Siobhan Dolan, Albert Einstein College of Medicine / Montefiore Medical Center

3:45 PM - Neonatal Screening and Sequencing: The Future is Now
How is the federal government investing in the future of screening? What are the emerging trends in technology and how are they connecting to clinical care?

Speakers:
Tiina Urv, National Institute of Child Health and Human Development
Anastasia Wise, National Human Genome Research Institute

4:15 PM - Final Summary Discussion

#beyondbloodspot