



# Critical Congenital Heart Disease (CCHD) Stakeholders Meeting: State Implementation

February 27-28, 2014

Association of Public Health Laboratories

Silver Spring, MD



**This meeting is jointly sponsored by NewSTEPs  
and  
The Pediatric Congenital Heart Association**

**About NewSTEPs:**

NewSTEPs (Newborn Screening Technical assistance and Evaluation Program) is a national newborn screening program designed to provide data, technical assistance, and training to newborn screening programs across the country and to assist states with quality improvement initiatives. NewSTEPs is a comprehensive resource center for state newborn screening programs and stakeholders.

**About PCHA:**

The Pediatric Congenital Heart Association's (PCHA) mission is to "Conquer Congenital Heart Disease." PCHA was founded on the key purpose to be the resounding voice of the pediatric congenital heart population through collaboration in education, research and advocacy. PCHA's goal is to reduce the impact of congenital heart disease while striving to realize a world free from it.

## BACKGROUND

Critical Congenital Heart Disease (CCHD) Newborn Screening was added to the Recommended Uniform Screening Panel (RUSP) in September of 2011. CCHD is the second point of care newborn screen to be added to the RUSP, joining early hearing loss. As newborn screening programs work towards implementation of screening for CCHD using pulse oximetry, many new tools and resources have been developed. NewSTEPS is partnering with state newborn screening programs and federal agencies interested in CCHD to provide and share CCHD resources, as well as to offer technical assistance.

## PURPOSE

The purpose of this meeting is to share solutions for CCHD newborn screening implementation among state newborn screening programs and pertinent stakeholders in order to support ongoing state implementation of screening and to facilitate quality data collection and interpretation across the United States.

## OBJECTIVES

1. Provide input and offer expert guidance on implementation of CCHD
2. Identify Quality Improvement initiatives in CCHD implementation
3. Develop a toolkit of solutions to common barriers identified in CCHD newborn screening implementation

## CONTACT

Thalia Wood, MPH  
Specialist, NewSTEPS  
Email: [Thalia.Wood@aphl.org](mailto:Thalia.Wood@aphl.org)  
Phone: 240.485.2701

# AGENDA

## DAY 1

<b>9:00–9:30 am</b>	Arrival/Coffee
<b>9:30–10:00 am</b>	Welcome and Introductions: <i>Jelili Ojodu, Amy Basken</i> <ul style="list-style-type: none"><li>• Health Resources and Services Administration Welcome: <i>Joan Scott</i></li><li>• The Centers for Disease Control and Prevention Activities Update: <i>Stuart Shapira</i></li><li>• Meeting Overview: <i>Marci Sontag</i></li></ul>
<b>10:00–10:45 am</b>	State Model Practices and Successes in Implementation, Legislation and Approval <ul style="list-style-type: none"><li>• Minnesota Experience: <i>Amy Gaviglio, Annamarie Saarinen</i></li><li>• Utah Experience: <i>Harper Randall</i></li><li>• New England Experience: <i>Monica McClain</i></li></ul>
<b>10:45–11:00 am</b>	Break
<b>11:00–11:45 am</b>	Challenges/Solutions: Legislation/Approval (work groups)
<b>11:45–12:15 pm</b>	Report Out from Work Groups
<b>12:15–1:00 pm</b>	Lunch (provided)
<b>1:00–2:30 pm</b>	State Model Practices and Successes in the Area of Data Collection, Surveillance <ul style="list-style-type: none"><li>• Recommended Minimum Data Set: <i>Lisa Hom</i></li><li>• National Children’s Data Transfer from the Oximeter Device: <i>Lisa Hom</i></li><li>• Using the Dried Blood Spot Cards to Collect Data: <i>Alyssa Yang</i></li><li>• Virginia Work with Electronic Birth Certificates: <i>Kathleen Moline</i></li><li>• Utah Experience Linking to Birth Defects Registry: <i>Lorenzo Botto</i></li><li>• Michigan Options for Data Reporting and HL7 Messaging: <i>Janice Bach</i></li></ul>
<b>2:30–3:15 pm</b>	Challenges/Solutions: Data Collection (work groups)
<b>3:15–3:30 pm</b>	Break
<b>3:30–4:00 pm</b>	Report Out from Work Groups
<b>4:00–4:30 pm</b>	State Model Practices and Successes in Remote Hospitals/Home Births/Telemedicine <ul style="list-style-type: none"><li>• Lessons from Wisconsin: <i>John Hokanson</i></li><li>• Lessons from Minnesota: <i>Lazaros Kochilas</i></li></ul>
<b>4:30–5:00 pm</b>	Challenges/Solutions: Telemedicine (work groups)
<b>5:00–5:30 pm</b>	Report Out from Work Groups
<b>5:30 pm</b>	Action Item Review and Wrap Up: <i>Marci Sontag</i>

# AGENDA

## DAY 2

<b>8:00–8:30 am</b>	Arrival/Coffee
<b>8:30–9:15 am</b>	State Model Practices and Successes in the Area of Data Interpretation and Quality Improvement (QI)/Quality Control (QC) <ul style="list-style-type: none"><li>• Children’s National Medical Center on False Negatives (Delayed Diagnosis): <i>Gerard Martin</i></li><li>• The New England Experience with Surveillance: <i>Monica McClain</i></li><li>• Data Interpretation, the New Jersey Experience: <i>Kim Van Naarden Braun</i></li></ul>
<b>9:15–10:00 am</b>	Challenges/Solutions: Data Interpretation, QI/QC (work groups)
<b>10:00–10:15 am</b>	Break
<b>10:15–10:45 am</b>	Report Out from Work Groups
<b>10:45–11:15 am</b>	State Model Practices and Successes in Neonatal Intensive Care Unit (NICU) Protocols <ul style="list-style-type: none"><li>• NICU Protocols in Wisconsin: <i>Alyssa Yang</i></li><li>• NICU Approach in New Jersey: <i>Jean Grazel</i></li></ul>
<b>11:15–12:00 pm</b>	Challenges/Solutions: NICU Approach (work groups)
<b>12:00–1:00 pm</b>	Lunch (provided)
<b>1:00–1:30 pm</b>	Report Out from Work Groups
<b>1:30–2:30 pm</b>	State Model Practices and Successes in Education <ul style="list-style-type: none"><li>• New Jersey’s Training Tools for State Implementation: <i>Jean Grazel</i></li><li>• Virginia’s Experience with oOline Educational Modules: <i>Tamara Eberly</i></li><li>• Wisconsin Shine Project and Other Educational Initiatives: <i>John Hokanson</i></li></ul>
<b>2:30–3:00 pm</b>	What’s Next? What Do We Need to Move Forward? <ul style="list-style-type: none"><li>• Case Definitions</li><li>• Refining the Screening Algorithm</li><li>• Other</li></ul>
<b>3:00–3:15 pm</b>	Action Item Review and Wrap Up: <i>Marci Sontag</i>
<b>3:15 pm</b>	Adjourn

# SPEAKERS

## **Janice Bach, MS, CGC**

Janice Bach is state genetics coordinator and manager of the Genomics and Genetic Disorders Section at the Michigan Department of Community Health. She has worked in public health genetics for more than 30 years, and in her current role serves as project director for Michigan's HRSA-funded CCHD newborn screening demonstration program.

## **Amy Basken**

Amy Basken is president/CEO of the Pediatric Congenital Heart Association. As the mother of a child with a heart defect, Basken has had the privilege of spending the last nine years leading congenital heart disease advocacy efforts for many of the largest national congenital heart disease organizations, coalitions and consortiums. Her accomplishments include the introduction, passage and funding of the Congenital Heart Futures Act, the development and growth of the Congressional Congenital Heart Caucus and coordinating national messaging for the CCHD Screening movement.

## **Lorenzo Botto, MD**

Lorenzo Botto is professor of pediatrics at the University of Utah, blending clinical and public health service to children with birth defects and genetic conditions. He is trained in medical genetics, pediatric cardiology and epidemiology. Outside of the clinic, his work focuses mainly on the epidemiology and prevention of congenital heart defects.

## **Tamara Eberly, PhD, RN**

Tamara Eberly currently serves as the newborn screening education project manager for the University of Virginia School of Medicine Office of Continuing Medical Education. In her position, she coordinated the implementation of the web-based CCHD Newborn Screening Education program. Eberly holds a Master of Nursing and a PhD in Higher Education.

## **Amy Gaviglio, MS, CGC**

Amy Gaviglio, a graduate from the Genetic Counseling Training Program at the University of Michigan, has been employed by the Minnesota Department of Health, Newborn Screening Program for the past six years. In that role, Gaviglio oversees follow-up of newborn screening results, aids in statewide educational efforts on newborn screening and genetics and works on genetics-related policy in the state. She has interests in public health genetics and genomics and ELSI issues in biobanking.

## **Regina Grazel, MSN, RN, BC, APN-C**

Regina Grazel is the project coordinator for the New Jersey Department of Health Critical Congenital Heart Disease Screening Program. As a HRSA grantee for the CCHD screening demonstration project, Grazel was hired by the New Jersey Chapter of the American Academy of Pediatrics, a sub-grantee of the NJ DOH. She is a perinatal clinical nurse specialist with 30 years of experience educating nurses and caring for post-partum mothers, well babies and NICU infants. She is certified as an Advanced Practice Nurse and holds several other clinical designations including board certified high-risk perinatal nurse, Neonatal Resuscitation Program (NRP) regional trainer, National Association of Neonatal Nurses (NANN) neonatal developmental care specialist and certified breastfeeding counselor.

## **John Hokanson, MD**

John Hokanson is pediatric cardiologist at the University of Wisconsin-Madison and director of the echocardiography laboratory at the American Family Children's Hospital. He has a research interest in cardiac transition physiology and the diagnosis of critical congenital heart disease in newborns. He is the principal investigator of the Wisconsin SHINE Project.

## **Lisa A. Hom, RN Esq.**

Lisa Hom is the clinical program manager for the CCHD Screening Program at Children's National Health System. She and Gerard Martin lead the DC CCHD Screening Collaborative (a quality improvement demonstration project). Prior to starting her work at Children's National, she had the unique opportunity to work as a regulatory counsel, focusing primarily on healthcare issues at the state level, and as a pediatric intensive care nurse caring directly for children with CCHD.

## **Lazaros Kochilas, MD**

Lazaros Kochilas is a pediatric cardiologist and associate professor of pediatrics at the University of Minnesota. He is board certified in Pediatric Cardiology and Neonatal-Perinatal Medicine and holds a Master of Science in Clinical Research. His research focuses on the outcomes of children after interventions for congenital heart diseases and the role of a patient's genetic background. His professional services include participation in workgroups for defining strategies for implementing screening for CCHD at the state (Minnesota) and national level. Kochilas provides clinical services as a pediatric cardiologist at the University of Minnesota Amplatz Children's Hospital.

**Gerard R. Martin, MD, FAAP, FACC, FAHA**

Gerard Martin is the senior vice president of the Center for Heart, Lung and Kidney Disease and medical director for global services at the Children's National Health System in Washington, DC. He received his doctorate of medicine from SUNY-Upstate Medical Center. Martin is board certified in pediatric cardiology, a fellow of the American Academy of Pediatrics and the American College of Cardiology, and a member of the Society for Pediatric Research and the American Board of Pediatrics.

**Monica McClain, MS, PhD**

Monica McClain is a research associate professor in Health Management and Policy and the Institute on Disability at the University of New Hampshire. Trained in epidemiology, she has worked in evidence-based medicine and evaluation of genetic testing.

**Kathleen Moline, RN, BSA, MA**

Kathy Moline is the Virginia Department of Health's newborn screening supervisor and principal investigator of the CCHD HRSA Demonstration Project awarded to Virginia. As a registered nurse, she has worked in newborn screening since 2007.

**Jelili Ojodu, MPH**

Jelili Ojodu is the director of newborn screening and genetics at the Association of Public Health Laboratories (APHL). He has worked in newborn screening and genetics for the past decade with significant experience in strengthening public and private partnerships. Ojodu holds a Master of Public Health in Maternal and Child Health and a Bachelor of Science in the biological sciences.

**Harper Randall, MD**

Harper Randall is a board certified pediatrician and has been a medical director at the Utah Department of Health (UDOH) since 2006. She provides UDOH medical oversight for the Utah Newborn Screening Program and the Utah Birth Defect Program. She is the co-PI for the Utah Critical Congenital Heart Defect Screening Project grant. In addition, Randall is a practicing pediatrician in Salt Lake City.

**Joan Scott, MS, CGC**

Joan Scott is chief of the Genetic Services Branch in the Division of Children with Special Health Needs (DSCSHN), Maternal and Child Health Bureau (MCHB) at Health Resources and Services Administration (HRSA). She is a certified genetic counselor with over 35 years of experience in

clinical genetics, genetics education, laboratory medicine, the biotechnology industry and the ethical, legal, social and policy implications of genomics advances.

**Stuart Shapira, MD**

Stuart K. Shapira is the chief medical officer and associate director for science for the National Center on Birth Defects and Developmental Disabilities at CDC. He received his PhD in Genetics and his MD from the University of Chicago, and he completed a residency in Pediatrics and a clinical fellowship in Genetics and Metabolism at Boston Children's Hospital. Shapira's research activities include newborn screening, birth defects epidemiology and dysmorphology of autism.

**Marci Sontag, PhD**

Marci Sontag is the associate director of NewSTEPS and associate professor of epidemiology in the Colorado School of Public Health. She has worked in newborn screening since 1995 with significant experience in cystic fibrosis specific activities. Sontag holds a Master of Science in Biostatistics and a PhD in Epidemiology.

**Kim Van Naarden Braun, PhD**

Kim Van Naarden Braun is an epidemiologist with the National Center on Birth Defects and Developmental Disabilities at CDC, and a state assignee with the NJ Department of Health. She has worked in developmental disabilities epidemiology, newborn screening and maternal and child health at CDC in the Developmental Disabilities Branch for the past 15 years with expertise in surveillance of autism spectrum disorder (ASD), cerebral palsy, intellectual disability, hearing loss and vision impairment. She joined the Division of Family Services at NJ DOH in 2010 to work on a range of issues related to newborn screening, birth defects and ASD. Van Naarden Braun holds a PhD in Epidemiology.

**Alyssa Yang, MPH**

Alyssa Yang is a Class XI applied epidemiology fellow through CDC and Council of State and Territorial Epidemiologists (CTSE). She currently works in the Chronic Disease and Maternal Child Health Sections at the Wisconsin Department of Health Services. She received a Master of Public Health in Occupational and Environmental Epidemiology from the University of Michigan.

This meeting is supported in part by NewSTEPs under Cooperative Agreement #U22MC24078 from the Health Resources and Services Administration (HRSA). APHL is collaborating with the Colorado School of Public Health to implement NewSTEPs.