

# Critical Congenital Heart Disease Newborn Screening: Recognizing US Successes and Identifying Next Steps

September 21, 2018

American College of Cardiology's Heart House  
2400 N St NW Washington, DC 20037

8:00 – 8:30 am

Registration

8:30 – 9:05 am

Welcome:

- American College of Cardiology CEO, *Tim Attebery, MBA, FACHE*
- Co-Chairs, *Gerard Martin, MD & Matt Oster, MD*
- Parent Perspective, *Michele Coleman*
- Early Investigator statement, *Robert Koppel, MD*
- Comments, *Michele Puryear, MD, PhD & Alex Kemper, MD, MPH, MS*

## Stakeholders Work Group: Where are we now? Where are we going? (Q&A to follow)

9:05 – 9:25 am

*USA Implementation Roadmap, Gerard Martin, MD*

9:25 – 10:10 am

*Outcomes Report: Measuring Success, Matt Oster, MD*

10:10 – 10:55 am

*Protocol Differences & Impact, Andrew Ewer, MD*

10:55 – 11:05 am

*HRSA Role & Update, Deboshree Sarkar, MPH*

11:05 – 11:45 am

*NewSTEPS/Public Health Report, Lisa Hom, RN, Esq., Marci Sontag, PhD & Amy Gaviglio, MS, LCGC*

11:45 – 12:15 pm

*Global Implementation Overview & Impact, Annamarie Saarinen*

12:15 – 1:00 pm

Lunch and group photo

## Data and Gaps Discussions

1:00 – 2:00 pm

**Data & Quality Improvement Opportunities**

*Reporting/data – equity, minimum data set, state barriers, funding support  
Short & long term follow-up*

2:00 – 3:00 pm

**Protocol – Rescreens & Timing**

*Implications for special populations and impact on vulnerable populations  
Discussion on how to best improve sensitivity*

3:00 – 4:00 pm

**Global Implications & Efforts**

*How to strengthen impact of screening globally and optimizing the additional value of detecting non-cardiac conditions*

4:00 – 4:30 pm

**Wrap-up**

*Discuss meeting outcomes, recommendations and next steps*

## Reception

4:30 – 6:00 pm

Welcome

Parent Story, *Karin Ryan*

Keynote Speaker, *Patrick Hope, Virginia House of Delegates 47<sup>th</sup> District*

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