

Beyond *the* Bloodspot: Education and Engagement Summit

June 5 - 6, 2017 • Washington, DC

Monday, June 5, 2017

Room Location: Phillips Ballroom
Kimpton Hotel Palomar

- 7:30 AM **Breakfast and Registration Open |**
- 8:30 AM **Welcoming Remarks |**
Natasha Bonhomme, *Genetic Alliance*
Joan Scott, *Health Resources and Services Administration*
- 9:00 AM **General Session |**
- Lessons Learned Through Public Health & Newborn Screening Education and Engagement**
Kristen Thompson, *Michigan Department of Health and Human Services*
- The Why in Newborn Screening Education and Engagement**
Kimberly Piper, *Iowa Department of Public Health*
- Understanding the Best Practice Continuum**
Kelly Umaña, *Association of Maternal and Child Health Programs*
- 10:15 AM **Break |**
- 10:30 AM **Breakout Workshops |**
The Who in Newborn Screening Education and Engagement
- Workshop A: Engaging Families**
Identifying potential best practices in getting messages to families and the public when there are “competing” priorities for their time
- Location:** Phillips Ballroom
Facilitators: Carol Johnson, *Iowa Newborn Screening Program*
Janice Freedman, *North Carolina Healthy Start Foundation*



Workshop B: Priority/Target Populations

Identifying priority populations and populations underserved by existing health and newborn screening systems; identifying potential best practices in reaching these populations

Location: Freer

Facilitators: Joyal Meyer, *North Dakota Department of Health*
María Isabel Frangenberg, *Family Voices National*

Workshop C: Engaging Health Educators & Health Professionals

Identifying how to form partnerships with health educators/professionals and have them be allies in educating about newborn screening

Location: Corcoran

Facilitators: Frederick Chen, *University of Washington*
Andrea Goodman, *Genetic Alliance*

11:30 AM **Workshop Report Back |**

12:00 PM **Lunch** (*provided*)

1:00 PM **General Session |**
Family Perspectives
Jackie Seisman, *Genetic Alliance*

2:00 PM **Breakout Workshops |**
The When in Newborn Screening Education and Engagement

Workshop A: Prenatal vs Postnatal

Identifying needs and approaches to educating in these timeframes – similar audiences, different priorities

Location: Freer

Facilitators: Sarah Verbiest, *UNC Center for Maternal and Infant Health*
Elizabeth Rochin, *Association of Women's Health,*
Obstetric and Neonatal Nurses

Workshop B: Training and Communications with Healthcare Providers

Identifying potential best practices that improve health professionals understanding of the newborn screening system; what do health providers need to know, and when do they need to share it with families?

Location: Phillips Ballroom

Facilitators: Johnna Watson, *Maryland Department of Health*
Stacy Hines-Dowell, *St. Jude Children's Research Hospital*



Workshop C: Short-term Follow-up

Identifying potential best practices in communicating with families; what should be focused on when follow up is needed but families are un/under informed?

Location: Corcoran

Facilitator: Amy Gaviglio, *Minnesota Department of Health*

3:00 PM **Workshop Report Back |**

3:30 PM **Break |**

3:45 PM **Breakout Workshops |**

The How in Newborn Screening Education and Engagement

Workshop A: Priority Setting in Education/Getting Buy-In

Identifying potential best practices in establishing buy-in for education; how do you prioritize education when it is undervalued or underfunded?

Location: Phillips Ballroom

Facilitator: Sondi Aponte, *Arizona Department of Health Services*

Workshop B: Access Issues

Identifying issues with accessing education and services within the health and newborn screening systems; identifying potential best practices in increasing access to education and services

Location: Freer

Facilitators: Luisa Soaterna, *ZERO TO THREE*

Amy Gaviglio, *Minnesota Department of Health*

Workshop C: Education in a Crisis

Identifying potential best practices when educating during a crisis; how do you engage with families?

Location: Corcoran

Facilitator: Alena Egense, *University of Maryland Genetics*

4:45 PM **Workshop Report Back |**

5:15 PM **Concluding Remarks |**

Natasha Bonhomme, Genetic Alliance

Dinner on your own



Tuesday, June 6, 2017

**Room Location: Phillips Ballroom
Kimpton Hotel Palomar**

- 7:30 AM **Breakfast and Registration Open |**
- 8:30 AM **Opening Remarks/Recap from Day One |**
Educating in an Evolving System
Natasha Bonhomme, *Genetic Alliance*
- 9:00 AM **General Session |**
- Evaluating Education & Engagement**
John Richards, *National Center for Education in Maternal and Child Health*
- Presenting Best Practices from Day One**
Natasha Bonhomme, *Genetic Alliance*
- 10:00 AM **General Session |**
Challenges for (rapidly approaching) Future of Newborn Screening
- Communication Technologies and Regulations**
Dixie Baker, *Martin, Blanck and Associates*
- Privacy and Autonomy in Public Health**
Bob Gellman, *Privacy and Information Policy Consultant*
Natasha Bonhomme, *Genetic Alliance*
- New Disorders**
Alex Kemper, *Duke University*
- 10:45 AM **Roundtable Discussions |**
Peer to peer discussion on needs and approaches to the evolving newborn screening systems in relation to:
- Communication Technologies and Regulations**
Room Location: Freer
- Privacy and Autonomy in Public Health**
Room Location: Corcoran
- New Disorders**
Room Location: Phillips Ballroom



- 11:30 AM **Break** |
- 11:45 AM **Roundtable Report Back** |
- 12:30 PM **Working Lunch: Moving Forward- What's Next?** |
Recommendations for the Clearinghouse
Jackie Seisman, *Genetic Alliance*
- 1:30 PM **Concluding Remarks** |
Natasha Bonhomme, *Genetic Alliance*
- 2:00 PM **Conclusion of Summit** |

