

# 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*

**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, *Independent Contractor*

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 (Panel) |**
- 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**

