

Beyond the Bloodspot: Education and Engagement Summit

Draft Agenda

Monday, June 5th (Day 1 of Summit)

- 7:30 AM **Breakfast and Registration Open**
- 8:30 AM **Welcoming Remarks**
- 9:00 AM **General Session (Panel)**
- *Lessons Learned Through Public Health & Newborn Screening Education and Engagement*
 - *The Why in Newborn Screening Education and Engagement*
 - *Spotting a Best Practice*
- 10:15 AM **Break**
- 10:30 AM **Breakout Workshops (1 hour each)**
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*
- 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*
- 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*
- 11:30 AM **Presentation/Report Back**
- 12:00 PM **Lunch** *(provided)*
- 1:00 PM **General Session**
Consumer Panel

2:00 PM

Breakout Workshops (1 hour each)

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*

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?*

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?*

3:00 PM

Presentation/Report Back

3:30 PM

Break

3:45 PM

Breakout Workshops (1 hour each)

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?*

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*

Workshop C: Education in a Crisis

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

4:45 PM

Presentation/Report Back

5:15 PM

Concluding Remarks

Dinner on your own

Tuesday, June 6th (Day 2 of Summit)

- 7:30 AM **Breakfast and Registration Open**
- 8:30 AM **Opening Remarks/Recap of Day 1**
- 9:00 AM **General Session (Panel)**
- *Evaluating Education & Engagement in Newborn Screening*
 - *Presenting Best Practices in Newborn Screening Education and Engagement from Day 1*
- 10:00 AM **General Session (Panel)**
- Challenges for (rapidly approaching) Future of Newborn Screening*
- Roundtable Discussions**
- Peer to peer discussion on needs and approaches to the evolving newborn screening systems in relation to:*
- Communication Technologies and Regulations
 - New Disorders
 - Privacy and Autonomy in Public Health
- 11:30 AM **Break**
- 11:45 AM **Presentation/Report Back**
- Educating in an Evolving System*
- 12:30 PM **Working Lunch**
- *Moving Forward: What's Next?*
 - *Recommendations for the Clearinghouse*
- 1:30 PM **Concluding Remarks**
- 2:00 PM **Conclusion of Summit**