Meaningfully Engaging Families in Newborn Screening Education

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Adrianna (Annie) Evans, MPH
Program Development Specialist
Genetic Alliance
Who We Are

Expecting Health was founded by a group of women with a simple idea: families deserve and should expect more – more support, more guidance, better health.

Born from Genetic Alliance, Expecting Health shares science-based and policy-informed information that reflects the lived experiences of individuals and their families.
We know that education and support don’t start or end at childbirth. Instead, a whole new set of shared support and needs emerge.

**VISION**
At Expecting Health, we believe that **new and expecting families**, regardless of makeup, income, or background, should and deserve to expect health.

*We simply don’t think it needs to be this hard.*

**GOAL**
To bridge science-based information and real life strategies to help parents and parents-to-be make informed decisions.
Our Approach

- Engagement
- Technical Assistance
- Communications Science
- User Experience Testing
- Advocacy
Newborn Screening
Background
What is Newborn Screening?

- Newborn screening (NBS) is a state public health service that is performed soon after the birth of your baby (usually between 24-48 hours)
- While most babies are born healthy, some babies are born with serious, but treatable medical conditions. Newborn screening helps health professionals identify and treat these conditions before they make these babies sick.

These conditions can be present in any family, even those without a family history of them.

- To learn more about what to expect, check out our animated video on Baby’s First Test’s YouTube Channel: https://www.youtube.com/watch?v=6skxqLUjFDg
Three Parts to Newborn Screening

1. Blood Test
2. Pulse Ox
3. Hearing Test
Who is screened?
- Newborn screening reaches nearly all of the 4 million babies born in the U.S. each year.
- **You do not need to request it.** It is standard across hospitals in the United States. If you’re planning an out-of-hospital birth, families should ask their midwives about their newborn screening process to make sure they have proper equipment, etc.
- Most states only allow families to opt out for religious reasons.

What conditions will be my baby be screened for?
- It’s different in every state! Most states screen for **29 of the 35 conditions** recommended by the Secretary of Health and Human Services.

How is newborn screening paid for?
- Newborn screening is typically covered by insurance, but some states pay in cases where families are unable to.
- If you’re planning an out-of-hospital birth, ask your midwife. Some midwives offer it free within their packages.
Important Milestones

- **1960**: Dr. Robert Guthrie developed blood test for a metabolic condition called phenylketonuria (PKU)
- **2005**: Introduction of tandem mass spectrometry (MS/MS) allows for more conditions to be screened for in a single process
- **2008**: ACHDNC recommends ACMG’s Recommended Uniform Screening Panel (RUSP) to Secretary of Health and Human Services as the nation’s newborn screening standard
- **2008**: Newborn Screening Saves Lives Act of 2007 Signed
- **2014**: Newborn Screening Saves Lives Reauthorization Act Signed
Introduction to the Newborn Screening Family Education Program
VISION
All families have equitable access to newborn screening information and have confidence to participate in the newborn screening system.

GOAL
Within 5 years, create a comprehensive newborn screening training program for families that provides them with the information they need to self advocate, discover resources, and serve as leaders in the newborn screening system.
Program Overview

- **Steering Committee**
- **Training and Education Work Groups**
- **Needs Assessment**
- **Partnership Program**
  - Dissemination of Materials, Tools, and Training Program
- **Development of Materials and Tools**
- **Training and Learning Program**
- **Family Coaches**
  - Peer to peer involvement in Training & Learning Program
- **Ambassador Program**
  - All ambassadors must complete training and apply to program, provide community feedback. May become family coaches with more training

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**Training and Family Tools:**
- Online Learning Community
  - (for families to connect during & after training)
- Database of Trained Families

**Recruitment of Families**
Project Objectives

1. By 2023, increase by 20 percent from baseline, the **number of parents and families trained and educated** on the newborn screening system annually.

2. By 2023, increase by 15 percent from baseline, the **number of partnerships to increase awareness of newborn screening** and to facilitate the dissemination of materials to the target audiences.

3. By 2023, increase by 20 percent from baseline the number of families/parents trained that **report increased knowledge, skill, ability and self-efficacy** to serve as leaders on newborn screening systems-level teams.

4. By 2023, increase by 10 percent from baseline, the **outreach to medically underserved populations** and increase by 10 percent the **number of medically underserved individuals that are aware of newborn screening** and have access to information on the newborn screening system.
Opportunities for Families
Family Leadership in the Program

- Training and Learning Program
  - Ambassadors
  - Family Coaches
Investigating the Educational Needs of Families and Organizations
Methodology

Needs Assessment

Family
- Survey (in progress)
- Family Content Testing Group (not yet started)

Partner
- Survey (in progress)
- 1-on-1 Interviews (not yet started)
Reaching Families
Communication & Dissemination Methods

**Trusted Community Leaders**
- Family leaders
- Cultural brokers
- Home visitors

**Media**
- Social media
- Media campaigns
- Advertising

**Partnership Program**
- Local and national organizations
- Healthcare professionals
Partner With Us!

**We need help with:**
- Family recruitment
- Dissemination of materials

**We can help you with:**
- Family referrals
- Dissemination of your materials
Table Discussion

1. What are your NBS education needs?
2. What training recruitment methods work best for families in your network?
3. Are we planning the most effective recruitment methods for families?
4. How can this program partner with you to add to your NBS education efforts?
NBS Family Education Survey

*Share Your Voice and Enter to Win a $75 Gift Card!*

https://www.surveymonkey.com/r/GSF932T