



Newborn Screening Family Education Program

May 2020 Meeting of Genetic Ambassadors

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A close-up photograph of a woman with dark hair, smiling warmly as she holds a newborn baby. The baby is wearing a white long-sleeved shirt and is looking towards the right. The woman's hands are gently cradling the baby's head and body. The background is softly blurred, showing what appears to be an indoor setting with a lamp.

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 Aims



Assess the newborn screening education needs of families and partners



Use evidence to create an online educational module



Disseminate the module through trusted partners/evidence-based methods



Perform QI on the program to create strategies that better serve different groups or reach underserved communities

Education

- Learn essential newborn screening information
- Receive informative, sharable materials
- Access online educational modules

Skill Building

- Develop storytelling skills
- Learn strategies for advocacy
- Learn how to use quality improvement



Field Learning

- Attend conferences
- Attend legislative meetings
- Connect with state newborn screening staff

Leadership

- Connect with legislative teams
- Become a family leader in the program
- Join our Family Training and Education Workgroup
- Join our Steering Committee

Newborn Screening Family Education Survey

In April 2019, we conducted a **survey** of families' needs and preferences for receiving a newborn screening education module.

The **Journal of Genetic Counseling** has accepted our manuscript on this survey for an upcoming Special Issue.

500 individuals participated in a part of the survey.

200 of those participants were living in HRSA-defined medically underserved areas.

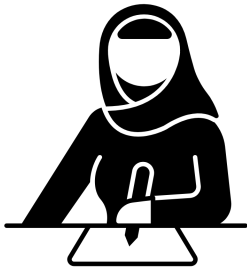
KEY TAKEAWAYS

Families living in medically underserved areas are generally **less aware** of newborn screening and do not receive education at the optimal time.

A newborn screening educational module is both **wanted and needed** by families living in medically underserved areas.

Navigate Newborn Screening

 An Expecting **Health** Program



Learn



Connect



Advocate

Access Navigate Newborn Screening at...

ExpectingHealth.myabsorb.com



We are looking for community
outreach partners!





Expecting Health

Connect

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Keep in Touch



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