

# NEWBORN SCREENING EDUCATION RESOURCE LIST

## About Us

A critical component to the success of all newborn screening systems is ensuring that all families and providers supporting families have access to reliable, accurate and relevant newborn screening information. As the number and complexity of conditions included in newborn screening panels expands, access to diagnostic and preventive services and the dissemination of reputable information is critical. Engaging individuals with or those who are at-risk of developing these conditions, as well as their families and support teams in the newborn screening system is necessary to improve the overall system of care for families.

In 2023, The Newborn Screening Technical Assistance and Evaluation Program (NewSTEPS) established the Newborn Screening Follow-Up and Education Subcommittee. Nested under this new Subcommittee is the Education Workgroup, co-developed with Expecting Health. This workgroup provides expertise and input on education in support of NewSTEPS activities and provides additional technical support to ensure that all families have equitable access to newborn screening information and have confidence to participate in the newborn screening system.

This list of resources has been compiled by the education workgroup and highlights key topic areas important to supporting families and providers as they navigate newborn screening.

## Who Benefits from these Resources?

- ✓ Providers
- ✓ Families
- ✓ State Laboratories
- ✓ Follow Up Programs
- ✓ Advocacy Organizations
- ✓ and many more!

**These lists include a wide variety of resources. Use the icons to help you identify what type of resource may be most helpful to you.**



### Website

Includes websites and other digital resource pages.



### One Pager

Short, single-page resources that provide concise and timely information



### Video

Animated or other action videos which help inform and educate



### Toolkit

Collection of resources often providing best practices and implementation guidance



### Long-form Content

Includes webinars, recorded workshops and other resources that provide more in-depth training on a topic



### Book/Brochure

Short books and brochures that provide general and overview information



### Publication

Peer reviewed and published articles

# RESULTS COMMUNICATION RESOURCES

The following resources will support providers and families as they navigate delivering and receiving newborn screening results.



- [HRSA Communication Guide](#)
- [Plain Language Recommendations for Reporting Newborn Screening Results](#)



- [A Newborn Screening Education Best Practices Framework: Development and Adoption](#)
- [Communicating With Parents About Newborn Screening The Skill of Eliciting Unspoken Emotions](#)



- [The Patels Journey Through Newborn Screening](#)
- [The Cohens Journey Through an Out-of-Range Newborn Screening](#)
- [Getting Involved in the Newborn Screening System](#)
- [Heartland Regional Genetics Network Spanish Newborn Screening Video](#)



- [Understanding and Communicating Newborn Screening Results: A Toolkit by Baby's First Test](#)
- [Guide to Newborn Screening Results Portals](#)



- [APHL Hot Topic Webinar Series: Creating and Disseminating Newborn Screening Results Reports: Considerations & Strategies for Improvements](#)
- [Plain Language Recommendations for Reporting Newborn Screening Results](#)
- [First Contact: Communicating With Families](#)
- [Patient-Centered Newborn Screening Communication](#)

# EDUCATION RESOURCES FOR EXPECTING FAMILIES

The following resources offer support to providers and families who wish to raise awareness and education of newborn screening during pregnancy.



- [Newborn Screening Information for Providers: Prenatal Education](#): A website by the Minnesota Department of Health



- [Expecting Health's Prenatal Implementation Guide: A Toolkit for State's to Implement NBS education during pregnancy](#)
- [Navigate Newborn Screening Resource Toolkit](#)



- [Navigate Newborn Screening Learning Book](#)



- [Midwife Educational Videos](#)



- [A Blueprint for Success: A Guide to Implement Newborn Screening Education for Expecting Families](#)



- [Virginia Department of Health Newborn Screening Program Prenatal Outreach Brochure](#)

# RESOURCES TO SUPPORT NBS PARTNER ENGAGEMENT

The following resources offer support to providers and families who wish to raise awareness and education of newborn screening during pregnancy.



- [The Family Leadership HUB](#)
- [EBCD: Experience-based co-design toolkit.](#)
- [BabysFirstTest](#)
- [APHL NewSTEPS State Profile Page](#)



- [Co-designing Improved Communication of Newborn Bloodspot Screening Results to Parents: Mixed Methods Study.](#)
- [Understanding Family Engagement in Genetic Services](#)
- [Tips for Meaningful Participation by Parents in the EDHI system](#)



- [Short Term Follow Up Webinar: Collaborating with Families & Providers in Community Birth Settings](#)