Navigate Newborn Screening: A Resource Sharing Toolkit
The Newborn Screening Family Education Program

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Newborn screening is more than a screen at birth, but a complex system with many stakeholders. We believe that families are integral to driving system change and supporting positive family experiences within the newborn screening system.

The Newborn Screening Family Education Program (Navigate Newborn Screening) is dedicated to developing opportunities for all families to learn about newborn screening and to develop training and educational resources that build confidence for families to become leaders in the newborn screening system.

We rely on partners like you to help us raise awareness for newborn screening and ensure all families have access to NBS education by sharing the resources in this toolkit with your friends, family and communities.
To create a landscape where all families have equitable access to newborn screening information
What's in the Toolkit?

01  TOOLS TO HELP RAISE AWARENESS OF NEWBORN SCREENING
02  TOOLS TO HELP EDUCATE & TRAIN
03  TOOLS TO HELP SUPPORT & ENGAGE FAMILIES
04  IMPORTANT DATES
Tools to Raise Awareness of Newborn Screening

- One Pagers & Flyers
- Office/Clinic Posters
- Social Media Graphics
What is NBS One Pager

Use this one page flyer to help families learn more about the basics of newborn screening. This short one-pager provides key point of NBS and guides families to the online learning curriculums available to dig deeper into NBS.

Share online

Link to your website, send in an email and/or share on social media

Print & Share

Send as a mailing, share at in-person events, distribute in prenatal, pediatric and specialty clinics

Customize

Want to add local or state specific information? Want to add your unique enrollment link or QR code? Reach out to mraia@expectinghealth.org to discuss.
Learn More Poster

This poster (16x 20 in) is designed to hang in waiting rooms, exam rooms, bathrooms, community centers and other family hubs so that families can learn more about newborn screening BEFORE they deliver their baby.

Hang it Up

Use this to hang in high traffic areas such as prenatal, pediatric and specialty care offices, community centers, WIC offices, etc.

Print & Share

Send as a mailing, share at in-person events, distribute in prenatal, pediatric and specialty clinics

Customize

Want to add local or state specific information? Want to add your unique enrollment link? Reach out to mraia@expectinghealth.org to discuss.
Social Media Graphics to Share

Learn about the test every parent can expect for their baby.

Download and share these graphics on your social media to raise awareness for newborn screening.

For more graphics, please email mraia@expectinghealth.org.
Social Media Graphics to Share

Learn more about newborn screening on the go.

Take your next step in navigating newborn screening.

Download and share these graphics on your social media to raise awareness for newborn screening.

For more graphics, please email mraia@expectinghealth.org.
Did you know there are three parts to newborn screening? 1) the blood test (or heel stick) 2) the hearing screen 3) pulse oximetry. Learn more about it in this free and flexible online learning module [INSERT YOUR UNIQUE ENROLLMENT KEY HERE] #NavigateNBS

Looking for FREE newborn screening information? Learn how to chart a course for a healthy baby through Expecting Health’s Navigate Newborn Screening educational module! Sign Up at [INSERT YOUR UNIQUE ENROLLMENT KEY HERE] #NavigateNBS

Each year, about 12,500 babies are born with one of the conditions included in state newborn screening panels. Sign up to learn more here [INSERT YOUR UNIQUE ENROLLMENT KEY HERE] #NavigateNBS

Not all states screen for the same newborn screening conditions. Learn why and how that may impact your family on Expecting Health’s Navigate Newborn Screening educational module. Sign up at [INSERT YOUR UNIQUE ENROLLMENT KEY HERE] #NavigateNBS

So much happens in the first few days of your child’s life... Get ahead by learning about newborn screening through Expecting Health’s Navigate Newborn Screening educational module. Sign Up at [INSERT YOUR UNIQUE ENROLLMENT KEY HERE] #NavigateNBS
Newborn screening is an essential public health service that screens babies for serious but treatable medical conditions. Learn more here: [INSERT YOUR UNIQUE ENROLLMENT KEY HERE]

Newborn screening is a connected system. It’s made up of diverse stakeholders who are committed to giving babies a healthy start! Share what newborn screening means to you #NavigateNBS

Newborn screening is life-changing. It detects babies who may be at a higher risk for certain health conditions. This allows doctors to start treatment as early as possible! What does newborn screening mean to you? #NavigateNBS

Newborn screening is a community. It’s filled with passionate family advocacy organizations and committed public health professionals dedicated to serving families. We wouldn’t be the NBS community without them! #NavigateNBS

What’s your newborn screening story? Share yours today to make a difference and remind other families they are not alone! https://expectinghealth.info/3gTKjH6 #NavigateNBS

Post and Share

Use these sample messages by copying it and posting it on social media!
Tools to Help Educate & Train Families

- Video Education Series
- Resources to support families with an out-of-range newborn screening result
- Online Training Curriculums
- Prenatal Education Resources
Video Education Series: "Journey Through Newborn Screening"

This 3-part video series includes short videos (~3 min each) covering introductory information to the importance of newborn screening. We encourage you to link on your websites, share with birthing centers and include as a resources when sharing newborn screening results.

This series includes the following three videos:
- The Patel’s Journey Through Newborn Screening
- The Cohen’s Journey Through an Out-of-Range Result
- Getting Involved in the Newborn Screening System

You can help families access these resources by sharing and posting using your unique enrollment key.

You Tube Playlist can be accessed here:
https://www.youtube.com/playlist?list=PL6M2gEwQoV25dRfVOrNK8BnC1Fm5wUCAK
Video Education Series: "Navigate Newborn Screening"

This 5-part education video series (~5-13 min in length) provides more in depth information about the value of newborn screening, the role state and federal partners play in determining screening panels as well as advocacy and storytelling in newborn screening.

This is a great resource to share with families as well as providers who are interested in understanding more about the newborn screening system.

- Share as a resource on your website
- Use as an onboarding tool for new program staff
- Use as content to facilitate community trainings and discussion groups**

**Discussion and evaluation questions are available upon request, Please email mraia@expectinghealth.org

You Tube Playlist can be accessed here: https://www.youtube.com/playlist?list=PL6M2qEwQoV25dRfVOrNK8BnC1Fm5wUCAK
Supporting Families through an Out-of-Range Result

Support families through an out-of-range newborn screening result. This video was designed to support families navigating this challenging time. Be sure to share the link with friends, families and local primary care providers, state newborn screening programs and any other family organizations.

To view and share The Cohen’s Journey Through an Out-of-Range Newborn Screening Result, visit: https://www.youtube.com/watch?v=cmWvANOISNk.
Online Training Courses

Based on feedback we've collected from over 500 families, we have created several online learning curriculums to help families learn more about the newborn screening system and gain skills to help them lead and advocate for their families.

Through our **learning portal**, families can access the following courses:

- **Navigate Newborn Screening**: An in depth training on the newborn screening system
- **Navegando por la Evaluación del Recién Nacido**: An in depth training for Spanish speaking families.
- **Navigate Newborn Screening Quick Bites**: Learn the most important information about how and why NBS occurs.

A log in will need to be created in order to access the modules. You can help families learn about these resources by sharing and posting the enrollment key through your regular communication channels (websites, newsletters, social media, etc).

To discuss using customized enrollment keys, please contact mraia@expectinghealth.org
Tools to Help Support & Engage Families

- Navigate NBS Ambassador Network
- Family Stories Video Series
- Tips to share stories
- Shareable Family Stories
A Resource For Expecting Families

We recognize that NBS education is not a one-time event and that to truly support families where they are, multiple strategies at multiple time points are needed.

With input from families and other newborn screening community experts, we created a learning book for families who are expecting a baby or planning a pregnancy to learn more about newborn screening prior to their delivery.

You can share a link to this digital book OR you can print these books to make available to families.

Navigate Newborn Screening Ambassador Network

Connect with our network of over 20 trained family leaders representing diverse perspectives and family experiences in newborn screening. Ambassadors are trained to connect with others, build awareness and knowledge of newborn screening, and serve as leaders throughout the system.

Ambassador are available to share their experiences with diverse audiences, engage in programs and project development as well as collaborate with other families or organizations to implement systems change programs.

To learn more about the Navigate Newborn Screening Ambassadors, visit: and download here:

https://www.expectinghealth.org/sites/default/files/inline-files/Meet%20Our%20Ambassadors%20Booklet_0.pdf
Family Perspectives You Can Share

Family Stories and lived experiences help us connect, learn and collaborate to improve systems. View and share this video series where some of the Navigate Newborn Screening Ambassadors share more about their experience and vision for the newborn screening system.

https://www.youtube.com/playlist?list=PL6M2gEwQoq5KoRw7oNh7QmK3cf1EoDL40
Tips to Share Your Story!

- Include the basics
- Be authentic
- Use images or video
- Choose one story to tell
- Aim for 250 words or less
- Include a call to action
Share Your Story!

Download & share these social media graphics OR create your own. Need help? Contact mraia@expectinghealth.org

"The words I’ll never forget were, "Your son tested positive for SMA on his newborn screening and without treatment most babies do not live past 8-18 months." I just sat there in disbelief... There are currently 3 FDA approved treatments for SMA - we chose the world’s one-time most expensive 2.1 million dollar infusion that took an hour to enter the body. Waylon has come such a long way and we continue to see progress daily, but our future is still so unknown. Treatments are currently changing the natural history of SMA and newborn screening is making it possible for babies with this disease to receive treatment prior to showing any symptoms, in turn meeting milestones like never before, which to me is breathtaking.

-Jessica B., mother of Waylon

Navigate Newborn Screening - An Expecting Health Program

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Share Your Story!

Download & share these social media graphics OR create your own. Need help? Contact mraia@expectinghealth.org

"The newborn screening was a huge help to prepare us for what he was up against in life. I’m grateful that we were able to get a head start on what we were going to face, because had we not known about Sickle Cell Disease we would have been lost. Every child cries and as we know every newborn does not come with an instruction manual, but being able to educate ourselves about his disease was truly a blessing.

-Chadd W., parent of a child with Sickle Cell Disease"
Share Your Story!

Download & share these social media graphics OR create your own. Need help? Contact mraia@expectinghealth.org

“While our family is grateful for newborn screening, we also hope to see changes in the system that allow for more babies to be identified and diagnosed at birth. We have become advocates for our son and for so many others like Elliott, who have genetic conditions, but that are not caught at birth. It is our hope that continuous review of the newborn screening system, along with improvements, be made so that no other family has to experience the pain of almost losing a child.

-Liz C., mother of Elliott
Need help getting started....
Share why Newborn Screening is Important to you!

Snap a family picture, share your story on social media, and include #NavigateNBS

Share your story with US!
Email it to: mraia@expectinghealth.org
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<td>Newborn Screening Awareness</td>
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Do you have any questions?

Feel free to reach out!

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