

Navigate Newborn Screening: A Resource Sharing Toolkit



Navigate Newborn Screening
& An Expecting **Health** Program

Toolkit Created by:

The Newborn Screening Family Education Program

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Help Us Raise Awareness for NBS Education

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.



OUR PROGRAM'S VISION:

To create a landscape where all families have equitable access to newborn screening information



What's in the Toolkit?

01 SHARING & SOCIAL MEDIA TOOLS

02 EDUCATIONAL RESOURCES

03 EMERGENCY PREPAREDNESS BUNDLE

04 IMPORTANT DATES

What is NBS One Pager

Use this 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.

Newborn screening is a 3-part test that checks babies to see if they are at increased risk of having a number of serious health conditions. Newborn screening includes a **blood spot** screen (heel prick test), a **hearing** screen, and a **pulse oximetry** (congenital heart disease) screen. These tests are given to all babies born in the United States, unless declined by a parent or guardian.

When will my baby receive newborn screening?

Babies receive newborn screening **24-48 hours after they are born**. Tests done outside of this time may be less accurate or need to be redone.

What conditions will my baby be screened for?

Every state requires newborn screening. Each state is different and decides which conditions will be included in their screen based on the recommended list provided by the United States Secretary of Health and Human Services. Newborn screening panels typically include hearing loss; critical congenital heart disease; and a number of metabolic, endocrine, hemoglobin, and other disorders.

Why is newborn screening important to me?

A baby can have the conditions included in newborn screening even if they look and act healthy at birth. **These conditions must be identified early and treated quickly** to prevent serious health outcomes, disability, and even death.

Learn more about newborn screening!

We have partnered with **Navigate Newborn Screening** to help families learn more about newborn screening and develop leadership skills with a **free**, online learning module. This learning module will teach you more about the newborn screening system and will help you develop skills and confidence to support your personal leadership journey.

How does it work?

To access the online module, scan the code in the corner with your camera. You will be taken to an enrollment page where you will be asked to enroll. Once you have enrolled, you can access all *Navigate Newborn Screening* courses. The module includes 5 base courses and 2 optional learning courses. Most courses take 5 minutes or less and can be easily viewed from your computer or phone.

Be sure to get your Completion Certificate!

Course completion certificates are available to individuals who complete online training. To receive a certificate, learners must view each of the 5 base courses and complete all learning checkpoints. Certificates can also be mailed upon request.

Scan here to get started!



If you have questions or want to learn more, please contact mraia@expectinghealth.org

What is Navigate NBS One-Pager

Use this flyer to share more about the importance of Navigate Newborn Screening with your friends, family, or in your communities

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? Reach out to mraia@expectinghealth.org to discuss.

Why Do Families Need Navigate Newborn Screening?

Newborn screening (NBS) is a health screen that checks for serious conditions at birth. NBS is a life-saving service, available to the nearly 4 million babies born in the United States each year. To better understand family preferences for NBS education, Expecting Health surveyed **819 participants** made up of parents, expecting parents, individuals with NBS conditions, or family members of individuals with NBS conditions.

LIMITED NEWBORN SCREENING AWARENESS


 **2 out of 3 participants** are aware of NBS.

 **1 out of 3 participants** aware of NBS can correctly identify a definition of NBS.

DISPARITIES IN NEWBORN SCREENING EDUCATION

Participants living in HRSA-defined medically underserved areas (MUA) may experience disparities in NBS education compared to those living in other areas.

 **55% of participants in an MUA** were previously aware of NBS compared to **67%** of those living in other areas.

 **50% of participants in an MUA** learned about NBS before birth - the optimal time - compared to **61%** of those in other areas.

FAMILY LEARNING PREFERENCES



An **online module** was the preferred format compared to other educational formats.



Family stories were considered very helpful to learn about NBS.



Participants use **social media** to connect with others about NBS and other health topics.

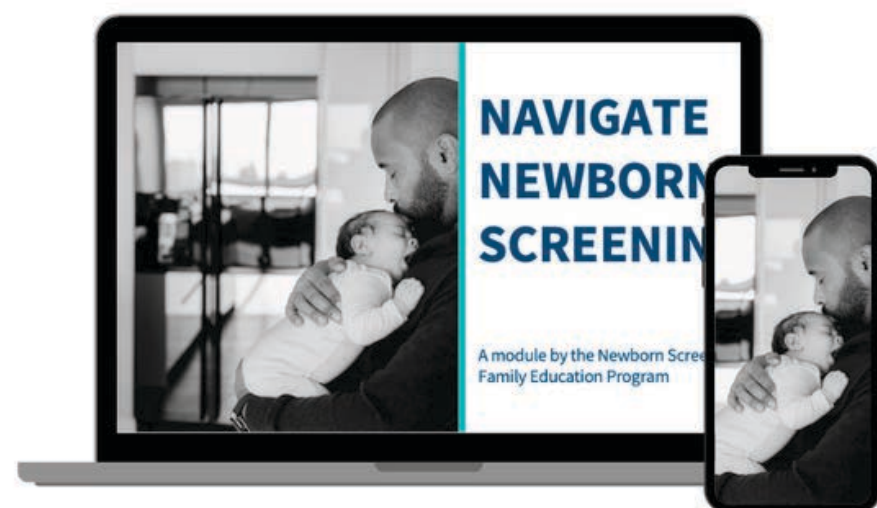
Informed by this data, Expecting Health developed *Navigate Newborn Screening*, a free online learning module that helps families just learning about newborn screening and provides opportunities to become leaders in the newborn screening system.

Sign up today: [EXPECTINGHEALTH.MYABSORB.COM](https://expectinghealth.myabsorb.com)

Have questions? Contact **Marianna Raia** at mraia@expectinghealth.org

Social Media Graphics to Share

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



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



This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant #UK5MC32105

Know early.
Know now.
Know newborn screening.

Get free information to promote a healthy start for your baby!



This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant #UK5MC32105

For more graphics, please email mraia@expectinghealth.org.

Social Media Graphics to Share

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

Learn more about newborn screening on the go.



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Take your next step in navigating newborn screening.



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For more graphics, please email mraia@expectinghealth.org.



Post and Share

Use these sample messages by copying it and posting it on social media!

- Did you know there are three parts to #newbornscreening? 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 #newbornscreening 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 #newbornscreening panels. Sign up to learn more here **[INSERT YOUR UNIQUE ENROLLMENT KEY HERE]** #2021NBS
- Not all states screen for the same #newbornscreening 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 #newbornscreening through Expecting Health's Navigate Newborn Screening educational module. Sign Up at **[INSERT YOUR UNIQUE ENROLLMENT KEY HERE]** #NavigateNBS



Post and Share

Use these sample messages by copying it and posting it on social media!

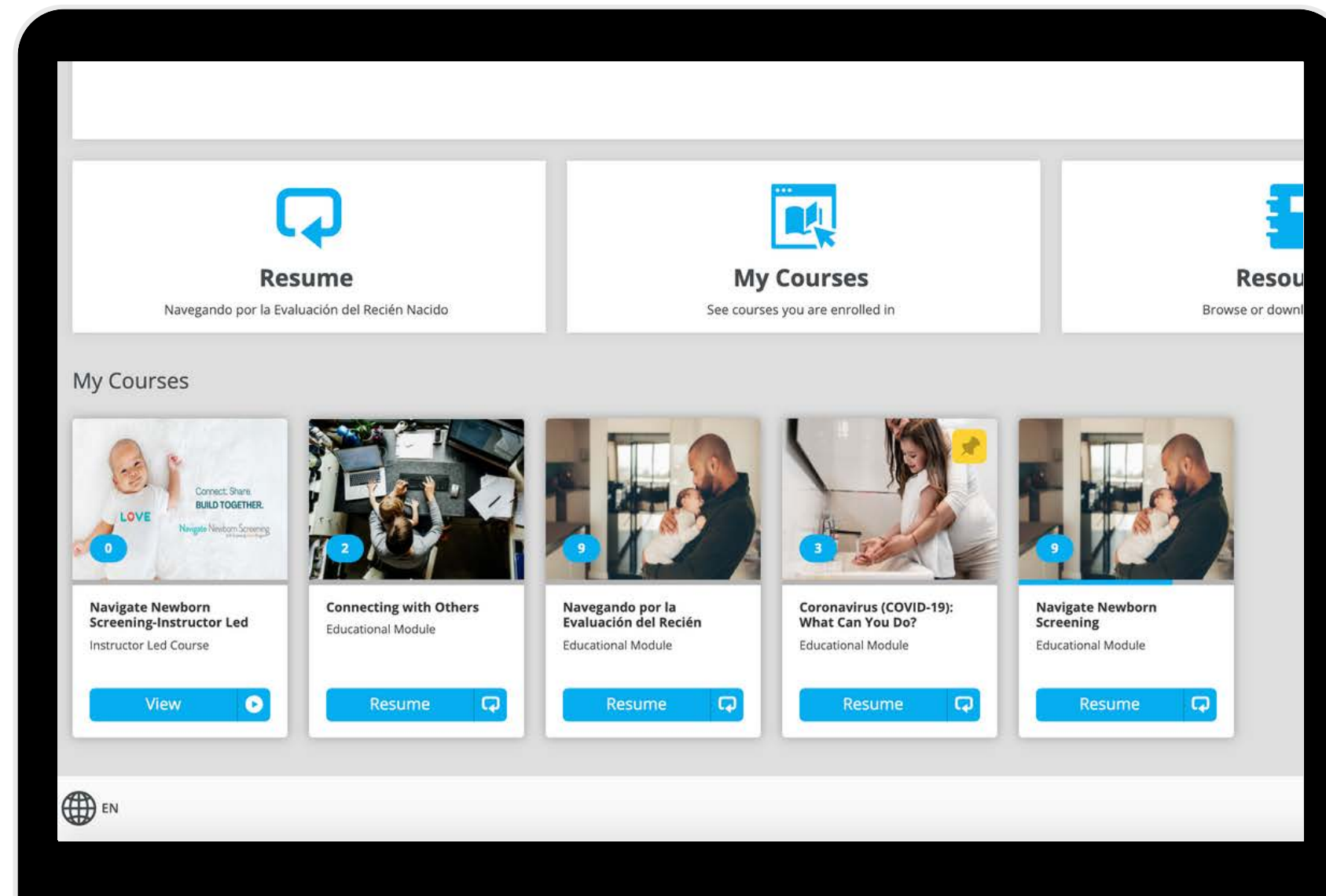
- **#Newbornscreening** is an essential **#publichealth** service that screens babies for serious but treatable medical conditions. Learn more here: [INSERT YOUR UNIQUE ENROLLMENT KEY HERE]
- **#Newbornscreening** is a connected system. It's made up of diverse stakeholders who are committed to giving babies a healthy start! Share what newborn screening means to you **#NavigateNBS**
- **#Newbornscreening** 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 **#newbornscreening** mean to you? **#NavigateNBS**
- **#Newbornscreening** is a community. It's filled with passionate family advocacy organizations and committed **#publichealth** professionals dedicated to serving families. We wouldn't be the NBS community without them! **#NavigateNBS**
- What's your **#newbornscreening** story? Share yours today to make a difference and remind other families they are not alone! <https://expectinghealth.info/3gTKjH6> **#NavigateNBS**

A Resource You Can Share with Families

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.
- *Launching in Feb 2022!* Navigate Newborn Screening Quick Bites (learn the most important information about how and why NBS occurs)

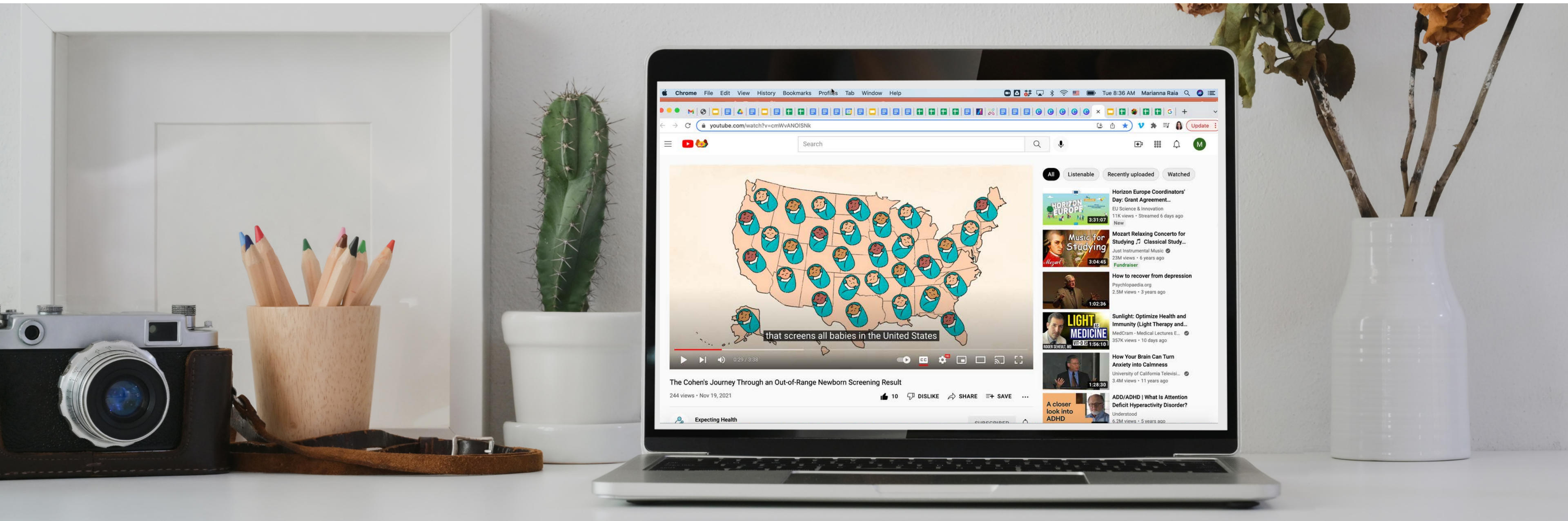


Use your unique enrollment key to help families gain access to our great online learning resources. Don't have a key?
Contact mraia@expectinghealth.org

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

A Resource You Can Share with Families

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=cmWvANOlSNk> .

A Resource You Can Share with Families

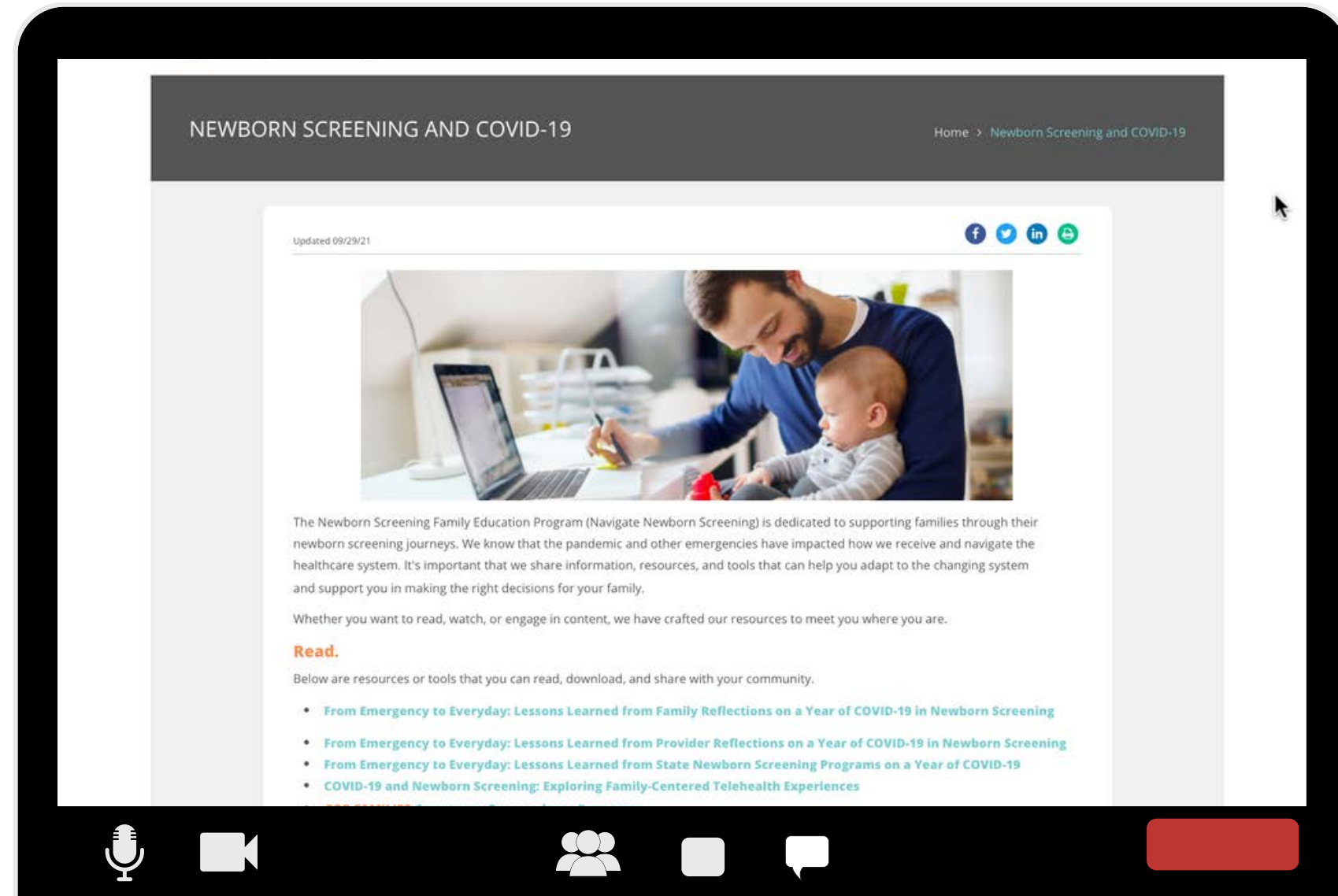
We know that the pandemic and other emergencies have impacted how we receive and navigate the healthcare system.

It's important that we share information, resources, and tools that can help families adapt to the changing system.

In this bundle you will find:

- Curated Resource Lists & One Pagers
- Recorded Videos & Webinars from families for families
- Online Curriculum for COVID & NBS

To view and share the **Emergency Preparedness Resource Bundle**, visit <https://expectinghealth.org/resources/newborn-screening-and-covid-19>.



A Resource You Can Share with Families



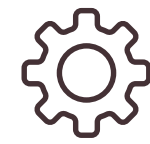
We recognize that NBS education is not a one time event and that to truly support families where they are, multiple strategies at multiple time points are needed.

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.

To view and share the **Navigate Newborn Screening Learning Book**, visit <https://www.flipsnack.com/navigatenewbornscreening/toolkit-flipbook-english-nov-2021/full-view.html>

Share Your Story!



Include the basics



Be authentic



Use images or video



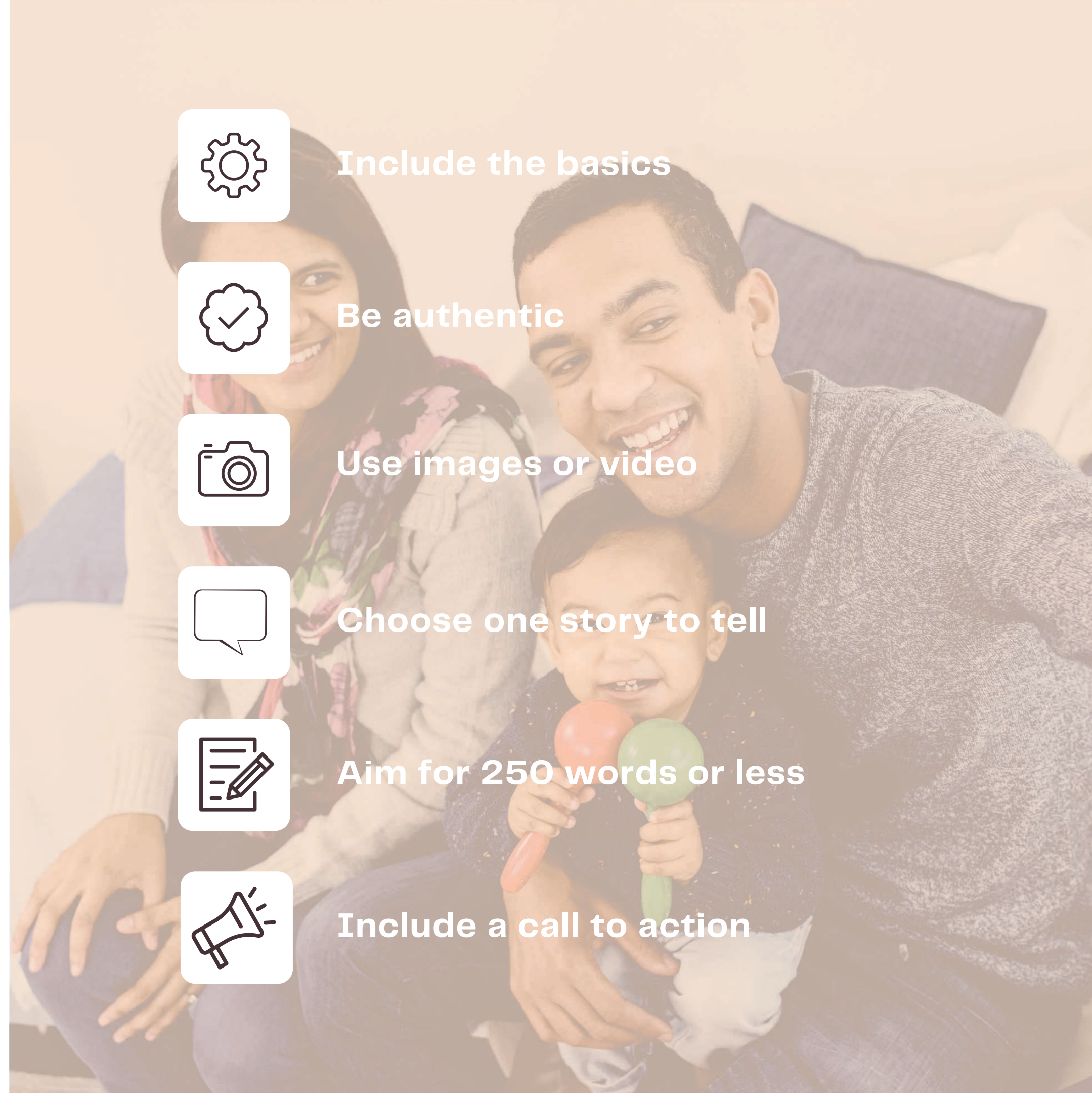
Choose one story to tell



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

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“

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

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“

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

IMPORTANT DATES



FEB

- Black History Month
- Rare Disease Day

MAR

- Public Health Week
- Purple Day for Epilepsy

APR

- National Autism Awareness Month
- National Public Health Week

MAY

- Public Health Genetics Week
- CF Awareness month

JUN-AUG

- Deafblind Awareness Week
- World Population Day
- SMA Awareness

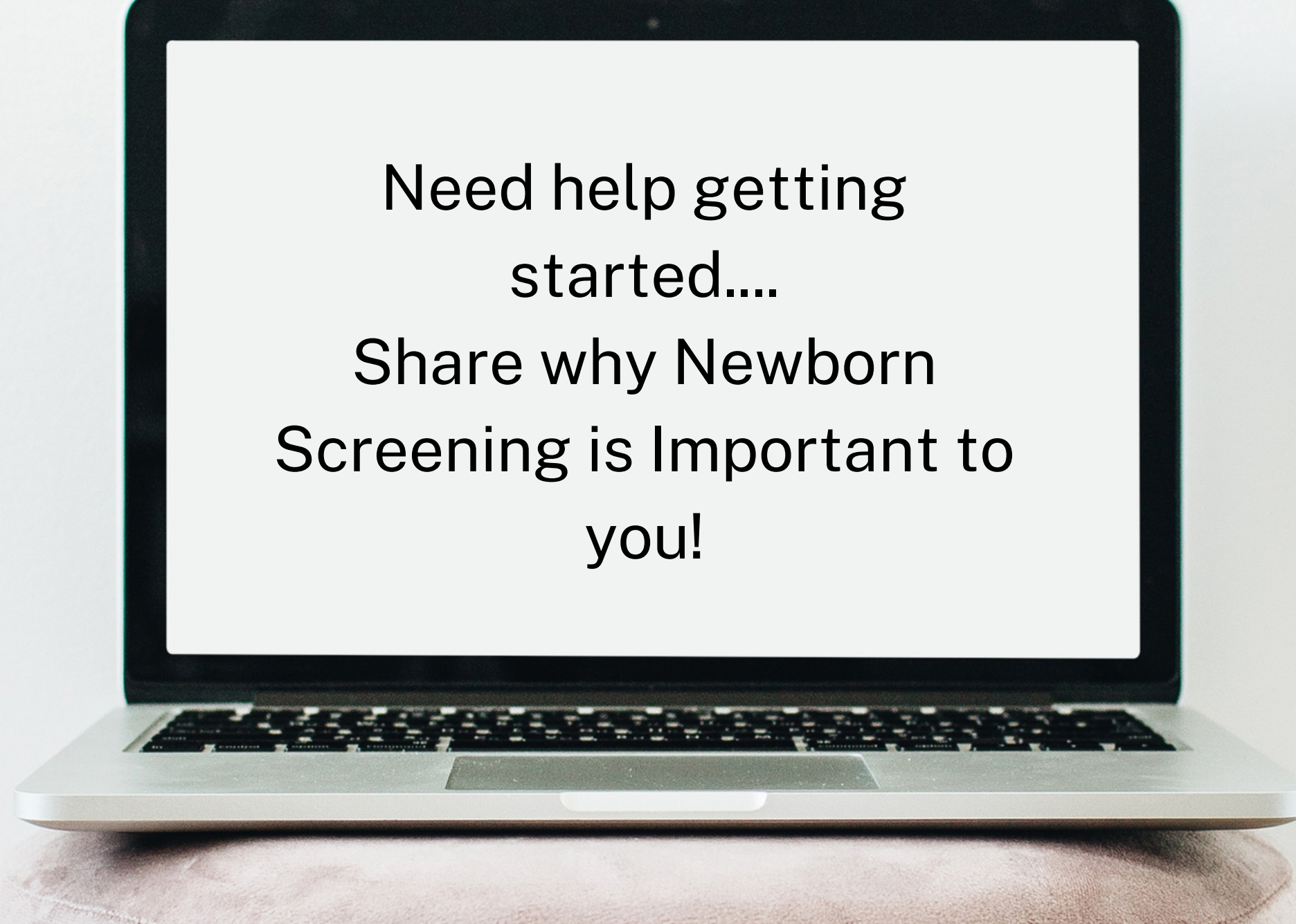
SEPT

- Newborn Screening Awareness
- Sickle Cell Awareness
- NBS Bootcamp

NOV

- Family History Awareness

Share Your Story



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**

Stay Connected.



www.ExpectingHealth.org



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MORE SUPPORT. MORE GUIDANCE. BETTER HEALTH

Do you have any questions?

Feel free to reach out!



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