



Meeting the Needs of Family Leaders Through Engagement, Education and Support

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“The most important voice in all of this - the people who are making decisions for your children - are the parents, because it's our lived experience.”



National Genetics
Education and
Family Support Center

Navigate Newborn Screening

 An Expecting **Health** Program

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What Does it All Mean?



- Family Engagement
- Family Support
- Family Leadership

Family Support and Where Families Find It

Parent to
Parent

Information

Existing
Communities

Professionals

Adults with
Lived
Experience



National Genetics Education and Family Support Center



Linking families to genetics



**Empowering Families:
Family Support, Family
Engagement, and Family
Leadership**

HRSA-Funded Genetics Programs



- National Genetics Education and Family Support Program (Family Center)
- Seven Regional Genetics Networks (RGNs)
- National Coordinating Center for the Regional Genetics Networks (NCC)

Program Aims



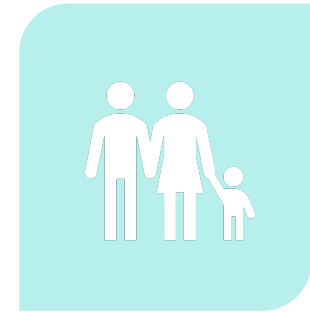
Provide culturally- and linguistically-appropriate education and resources on genetics and genetic conditions to families



Provide technical assistance to RGNs on how best to incorporate family leaders into their programs and reach underserved populations



Train individuals and families to become family leaders within the genetic health care delivery system and the Regional Genetics Networks (RGNs)



Provide support for individuals and families with, or at risk for, genetic conditions so that they can be equal partners in their health care

Family Center Resources



WEBSITE



PODCAST



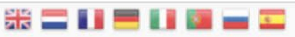
PEER
LEARNING



WEBINARS



LEADERSHIP
TRAININGS



Select Language ▾

Where are you in your genetics journey? ▾



Understand Genes and Genetics

Genes are the instructions for life as we know it.

[— Learn More Here](#)

— INDIVIDUAL

Resources for understanding and embracing your own capacity for leadership.



Finding the Win by Sarah Jacobs

“My husband, Adam, and I have two boys, Graham (10) and Dominic (6). Dominic has Dravet Syndrome. It is a rare and severe form of epilepsy that is lifelong and drug resistant...”

[Read More →](#)



Who is a Family Leader? With Jeannette Mejias

“Honor your process. It’s okay to not be okay. Then once you go through the stages, what’s next?”

[Watch The Video Here →](#)



Who is a Family Leader?

In this interactive virtual learning module, you will: Recognize who can be a family leader and how and where they demonstrate leadership, identify leadership characteristics and describe your own leadership in the context of being a family leader.

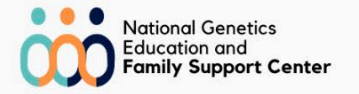
[Complete The Module Here →](#)



Menu

- Introduction
 - Welcome
 - Are leaders born or made?
 - Objectives
 - What makes a good leader?
 - Leadership Quality Review
- Objective One
 - Objective
 - Who can be a family leader?
 - Where do family members lead?
 - Family Leader Examples 1
 - Check for Understanding: Scenari...
 - Scenario 1
 - Scenario 2
 - Scenario 3
 - Scenario 4
- Objective Two

Who is a Family Leader?



Linked Together

A dynamic podcast series showcasing honest and open discussions about the issues that affect family leaders and what it means for families to drive systems change.



Linking families to genetics.



Peer-to-Peer Groups and Learning



**Family Center
Workgroup on Inclusion**



**Family Center Community
of Practice on Diversity,
Equity, and Inclusion**



Parent Leader Office Hours

Opportunities for Involvement



Inform

Stay up to date on the latest events, resources, and trainings by signing-up for updates or follow organizations on social media.

Connect

Connect with MGN for regional opportunities.

Join

Join the Family Center Community of Practice on Diversity, Equity, and Inclusion. –
4:00 – 5:00pm EST On the third Wednesday of every other month

Reach out

Reach out at mmartzke@expectinghealth.org





Stay Connected

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[@NationalFamilyCenter](https://www.instagram.com/NationalFamilyCenter)



National Genetics
Education and
Family Support Center



The Newborn Screening Family Education Program:

OUR VISION

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

OUR MISSION

To meet families where they are

A photograph of a man with glasses, a woman with curly hair, and a baby. The man is on the left, looking towards the woman and baby. The woman is in the center, smiling and looking down at the baby. The baby is on the right, looking up at the woman. They are all smiling and appear to be in a happy, intimate moment.

THE NEWBORN SCREENING FAMILY EDUCATION PROGRAM

1

FAMILY EDUCATION

Increase by 20% from baseline, the number of parents and families trained and educated on the newborn screening system annually.

2

PARTNERSHIPS

Increase by 15% from baseline, the number of partnerships to increase awareness of newborn screening and to facilitate the dissemination of materials to the target audiences

3

FAMILY ENGAGEMENT & LEADERSHIP

Increase by 20% 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

MEDICALLY UNDERSERVED FAMILIES

Increase by 10% from baseline, the outreach to medically underserved populations and increase by 10% the number of medically underserved individuals that are aware of newborn screening and have access to information on the newborn screening system.

The primary focus of the The Newborn Screening Family Education Program is to educate, engage and train families.



OUR PROGRAM TODAY

>3M Families reached	>3000 Families trained	64 Org & Individual partners	10 Trained Ambassadors
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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.



The NBS Family Education Program

Navigate Newborn Screening
An Expecting Health Program

Awareness Campaigns

- *PRENATAL EDUCATION* INITIATIVES*
- *SOCIAL MEDIA**

Education & Training

- ONLINE LEARNING CURRICULUMS
- VIDEOS
- MICROLEARNING WEBPAGES/BUNDLES

Family Leadership

- NBS AMBASSADOR PROGRAM
- WEBINARS
- COMMUNITIES OF PRACTICE
- DISCUSSION GROUPS

EDUCATION IS MEETING FAMILIES WHERE THEY ARE

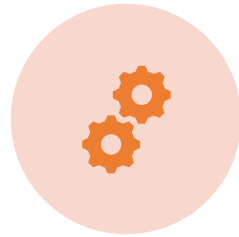
Key Strategies



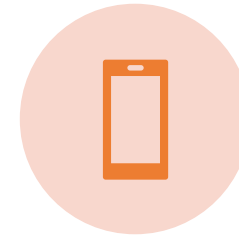
UNDERSTAND CULTURAL
PERSPECTIVES



LEVERAGE TRUSTED
HEALTH CARE PARTNERS



INCORPORATE INTO
EXISTING WORKFLOWS



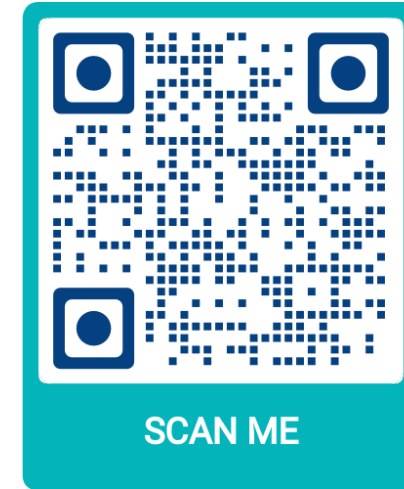
USE PRACTICAL
MATERIALS & RELATABLE
EDUCATIONAL MATERIALS



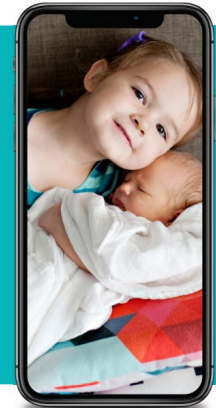
BE TRANSPARENT TO
BUILD TRUST

Engaging Families as Individuals:

- Educational Videos
- Online Learning Modules
- Learning “Flipbook”
- Dissemination Toolkits



**Navigate Newborn
Screening: A
Resource Sharing
Toolkit**



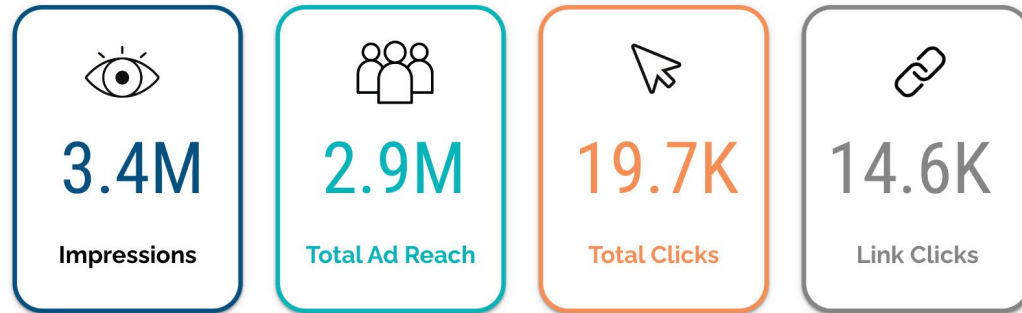
Navigate Newborn Screening
• An Expecting Health Program

Engaging Families as a Community:



Year 4 Social Media Campaign

*Data from March 4, 2022 - August 31, 2022

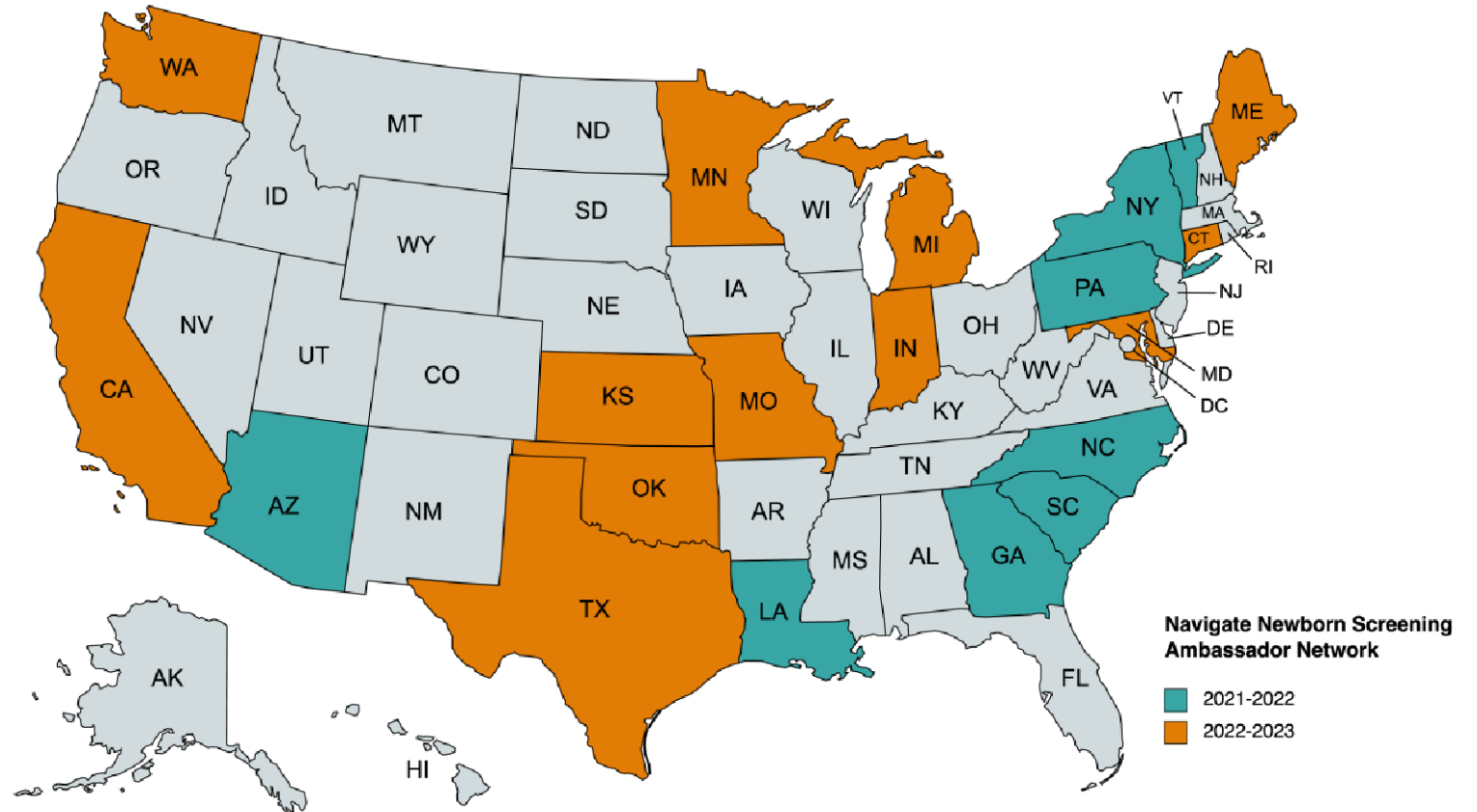


- Social Media Awareness Campaign
- Community Discussion Groups
- Communities of Practice
- Program Steering Committee
- Ambassador Program Development Task Force
- Training & Education Workgroup
- Education & Communication Workgroup

Engaging Family Leaders in the NBS System

Navigate Newborn Screening Ambassador Network

- Maple Syrup Urine Disease (MSUD)
- Congenital Cytomegalovirus (CMV)
- deaf/hard of hearing (D/HH)
- Sickle cell disease (SCD)
- Cystic Fibrosis (CF)
- Pompe disease
- Krabbe disease
- Guanadinoacetate methyltransferase deficiency (GAMT)
- Metachromatic leukodystrophy (MLD)
- Parents/Caregivers of CYHSN
- Doula
- Pediatric Nurse



What We Have Learned



Engaging families requires multiple strategies



Partnerships are critical to establishing trust



Involve families in all aspects of development

Stay Connected.



mraia@expectinghealth.org



www.ExpectingHealth.org



@ExpectingHealth



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