




Baby's First Test: An Educational Resource for Healthcare Providers

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Who We Are:
The Newborn Screening
Clearinghouse

The Newborn Screening Clearinghouse

Increasing Newborn Screening Awareness, Training, and Education through Engagement



- Newborn Screening Saves Lives Act 2008/2014
- Based on consumer focused newborn screening projects
- One stop shop for newborn screening information and education

Baby's First Test: What We Do

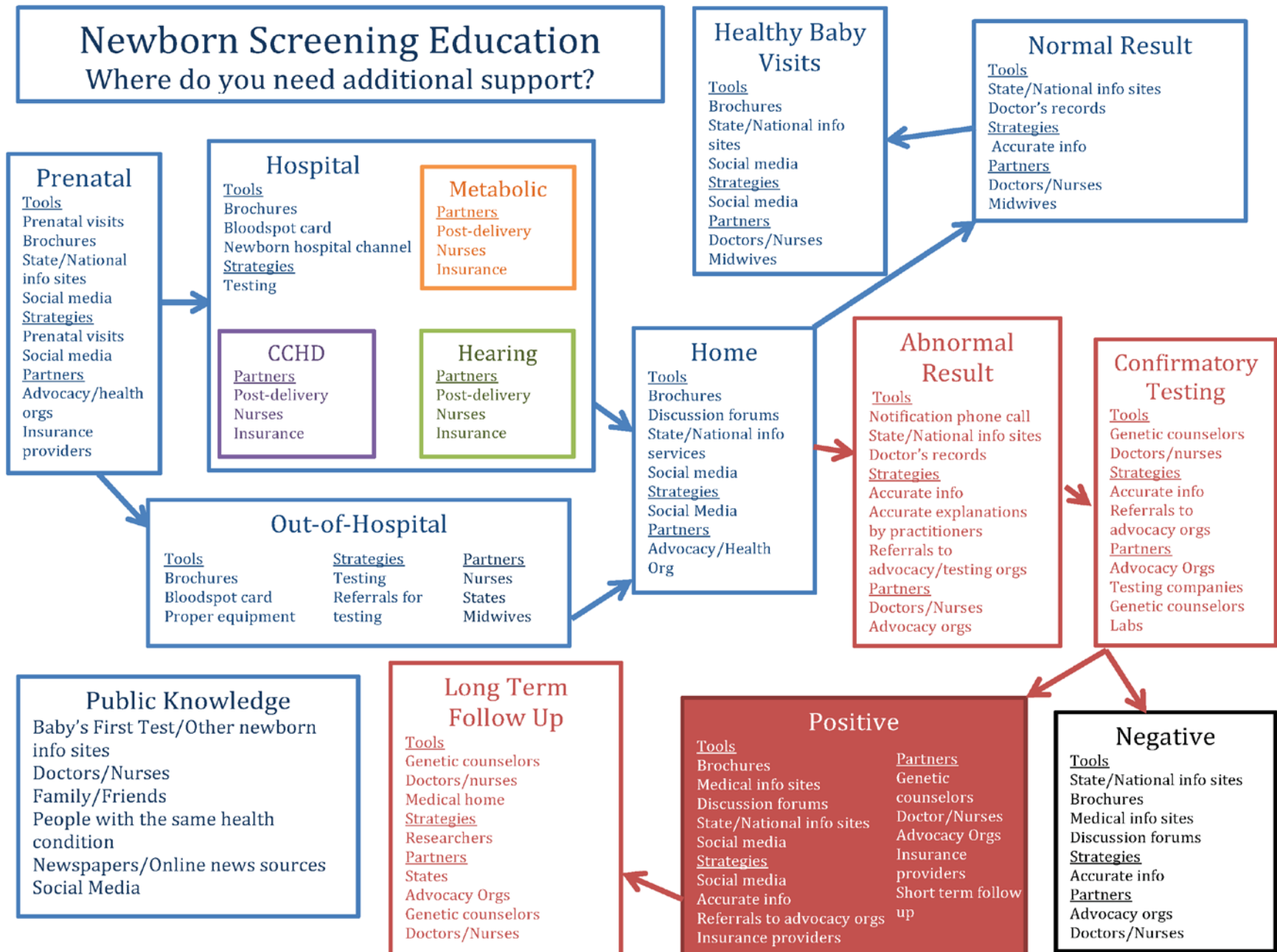
Baby's First Test houses the nation's newborn screening clearinghouse. As the clearinghouse, Baby's First Test connects parents and healthcare providers with extensive information and resources on newborn screening at the local, state, and national levels.

We Do This By:

- ✓ Training Videos/Webinars
- ✓ Continuing Education Units
- ✓ Details on State Programs
- ✓ Information on 77 Conditions
- ✓ Educational Resources
- ✓ NBS Public Square
- ✓ Mobile App
- ✓ Consumer Task Force
- ✓ Challenge Awards
- ✓ Partnerships

Newborn Screening Education

Where do you need additional support?





Resources

Your State

Find a Condition

En Español

About Newborn Screening

Your Baby's Screening

Living With Conditions

Health Professionals

Programs and Policy

About Us

Search

What is Newborn Screening?

Many parents are unaware of the conditions included in screening, or that it varies from state to state. **Baby's First Test** brings together resources to help guide parents and health professionals alike.



What Your State Offers

Every state has its own Newborn Screening program. Learn about it.

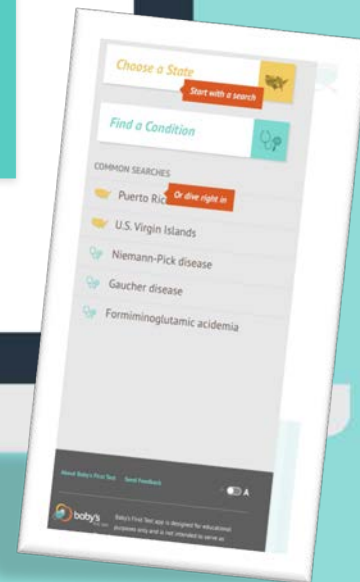
- Select State -



Find a Condition

Get information about the 77 screenable conditions.

Type a Condition



By The Numbers

37 Consumer Advocates

Since 2012, Baby's First Test has trained 37 Consumer Task Force members across 18 states.

100,000 Content Pages

Baby's First Test has over 100,000 pages of content, including information on 77 newborn screening conditions.

Over 2 Million Visitors

Since 2011, BabysFirstTest.org has had 2 million visitors with over 2.4 million sessions and over 4.1 million page views.

100% Increase in Visits

2016 brought nearly 795,000 visits from more than 660,000 users, averaging over 60,000 sessions per month and adding to the 1 million sessions on Baby's First Test since our launch in 2011.



Most Popular

Most Popular Content

1. Conditions Screened by State
2. Homepage
3. Screening Procedures
4. PKU
5. (other condition pages)

States

California, Texas, New York

Countries

United States (70%)

Also: UK, Philippines, India, Canada



Conditions



States



Support for Severe Combined Immunodeficiency

SUPPORT SERVICES

[ACCESSING CARE](#)[FAMILIES' EXPERIENCES](#)

Support groups can help connect families who have a child or other family member affected with severe combined immunodeficiency with a supportive community of people who have experience and expertise in living with the condition. These organizations offer resources for families, affected individuals, health care providers, and advocates.

- [Immune Deficiency Foundation](#)

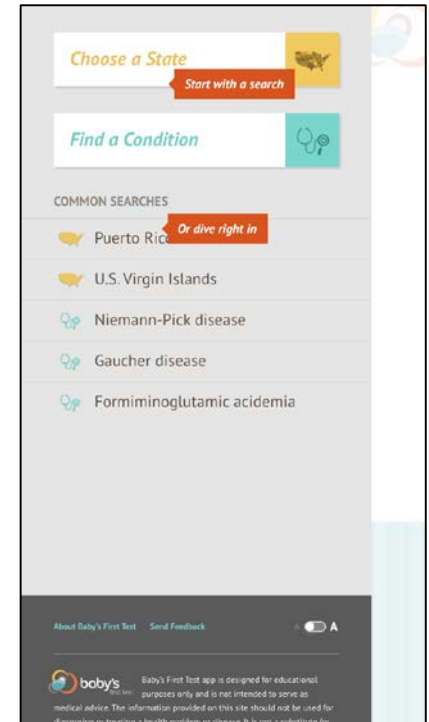
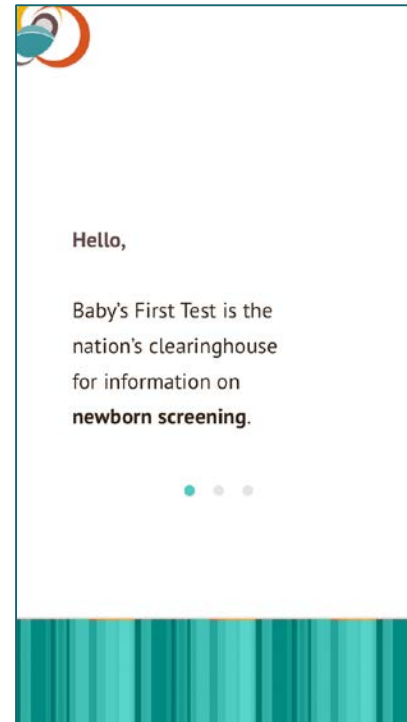
REFERENCES & SOURCES

Visit the [National Human Genome Research Institute](#) for more information on SCID

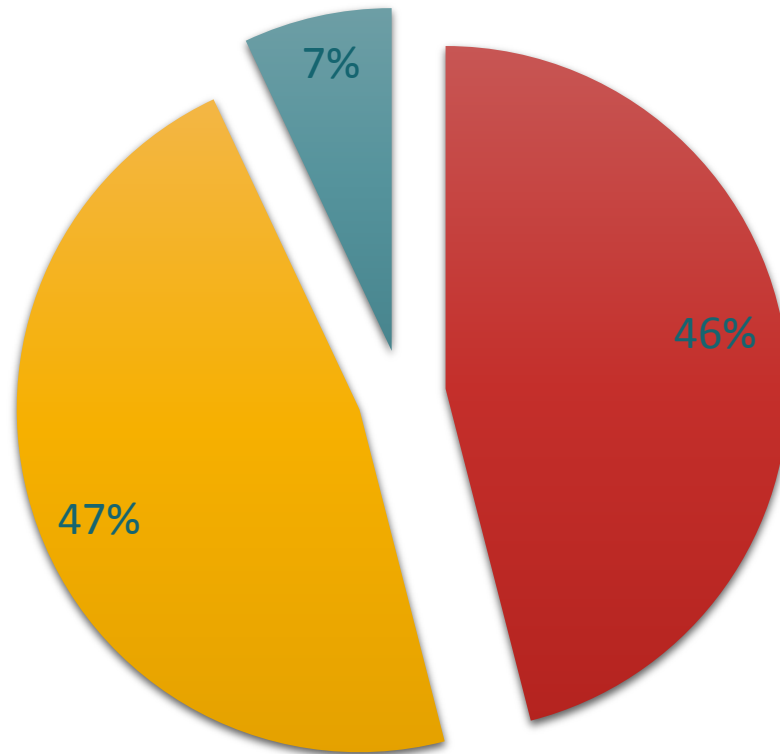
Going Mobile

- Mobile traffic more than doubled each year
- In 2016, more than 56% of traffic came from mobile devices
- Mobile and desktop users read the same content
- States and conditions were overwhelmingly popular

The Baby's First Test mobile app for iOS launched in 2015 and an Android version launched in 2016



Who's Visiting Baby's First Test?



19%
Parent with new
baby on the way

18%
Parent with new
baby

■ Family Members of Newborn ■ Healthcare Professionals ■ Advocate

	n=713	%
Family Members of Newborn	332	46%
Parent with new baby on the way	138	19%
Parent with new baby	130	18%
Family member or friend of someone with new baby	50	7%
Parent with older child diagnosed with disease	14	2%
If a parent with new baby: Baby's test results	127	38% of family*
Normal (in range/no evidence of medical condition)	64	50%
Out of range, waiting for more information	17	13%
Out of range, confirmed that baby has medical condition	12	9%
Have not yet received test results	26	20%
Don't Know	8	6%
Health Care Professionals	337	47%
Health care professional	262	37%
Researcher	50	7%
Lab personnel	15	2%
State health official	10	1%
If health care professional: Specific health profession	232	69% of HC prof*
Nurse	93	40%
Physician's Assistant/Nurse Practitioner	36	16%
Genetic Counselor	30	13%
Specialist	19	8%
Pediatrician	14	7%
Medical student	10	4%
Public health dept. employee	7	3%
Family Practice Physician	5	2%
Other (phlebotomist, pharmacist, midwife, paramedic health educator, administrators, neonatologist, ob/gyn)	18	8%
Advocate	44	7%
Advocate for newborn screening	44	7%



Reasons for Visiting Baby's First Test (HC & Advocates)

	HC Prof		Advocate		Total	
	n	%	n	%	n	%
Learn About Screening Tests						
Learn more about state testing available for medical conditions	221	26%	22	18%	243	25%
Compare my state requirements to other states	113	13%	19	15%	132	14%
Learn About Medical Conditions						
Get more information about a specific medical condition	90	11%	11	9%	101	10%
Get Tools For Communicating About Screening						
Get tools for communicating with parents	114	14%	10	8%	124	13%
Get tools for communicating with the public	51	6%	8	6%	59	6%
Get Current Information						
Check for policy changes	69	8%	15	12%	84	9%
Learn About Advocating For Newborn Screening						
Learn who to contact to advocate for newborn screening	36	4%	21	17%	57	6%
See if the website would be a good resource for parents	94	11%	12	10%	106	11%
Find Something Else						
Specified (find state contacts, get help evaluating results, storage of blood tests, find patient education materials, for training students, etc)	51	6%	7	6%	58	6%

Cells may not add up due to rounding, respondent refusal, or missing data



A Resource for Healthcare Providers

Learn, Connect, Share



The Public Square

An online space dedicated to ongoing conversations about newborn screening.

[JOIN THE DISCUSSION](#) 



National Maps

Newborn Screening is an evolving system that is different throughout the country.

[SEE THE MAP](#) 

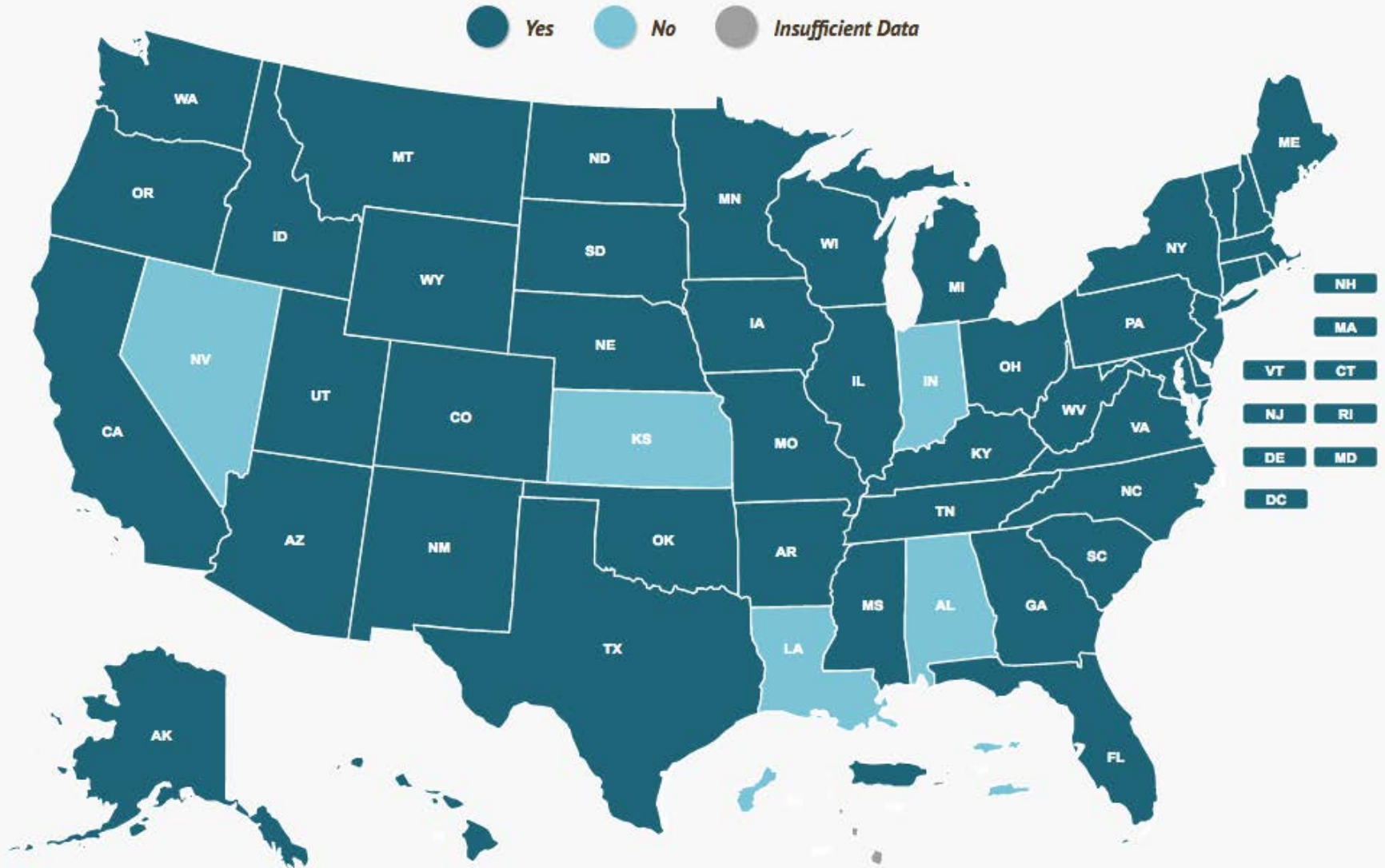


Resources

Educational resources from states and organizations across the U.S.

[VIEW RESOURCES](#) 

Interactive National Map - SCID





Health Professionals

Educational Resources

- Email
- Share This
- Print-friendly

Prenatal Providers

Pediatric Providers

Dried Blood Spot Storage and Usage

Trainings & Materials

Baby's First Test has teamed up with a number of wonderful organizations and institutions to provide a wide variety of educational trainings, promotional materials and resources geared towards both parents and providers. We are always adding more things so be sure to check back! If you would like to share how you have used some of these resources in your community, please email Natasha@BabysFirstTest.org.

TRAININGS AND RESOURCES

In this Section:

- ✓ TRAININGS
- ✓ NEWBORN SCREENING PROMOTIONAL MATERIALS
- ✓ RESOURCES FOR PATIENTS



Newborn Screening Education and Training Resources

Looking for educational materials about [newborn screening](#)? Starting in September 2016, Baby's First Test will be featuring fact sheets, videos, promising practices, and educational tools from states and organizations across the United States. Simply filter by resource type or audience, or search by keyword, to find resources that match your interest.

Interested in adding your educational resource, or not finding what you are looking for? Email resources@babysfirsttest.org for more information.



FILTER BY: [Clear Filters](#)



Type

- Fact Sheet
- Video
- Webinar
- Educational Tool

Created For

- Expecting Parents
- General Public
- Health Professionals
- Parents
- Policy Makers

Resource Key

-  Created by Baby's First Test
-  Created by a State Program

What Your State Offers

- Select State -



Find a Condition

Type a Condition






Newborn Screening Resources

What to Expect From Your Baby's First Test Infographic

Email

Share This

Produced by Baby's First Test 

TYPE: Educational Tool

PUBLISHED: Wednesday, August 24, 2016

DOWNLOAD NOW



Search
Educational
Resources

VIEW RESOURCES

What Your State
Offers

- Select State -



What to expect for your

The Public Square



The Newborn Screening Public Square is an online space dedicated to ongoing conversations about newborn screening. It's a commitment to **new ideas, knowledge sharing, and bringing together a range of communities** and experiences within newborn screening to **improve education and awareness.**





December 30, 2016

Anthony Steyermark

I agree with Kimberly Noble Piper about the importance of transparency and public trust in newborn screening. A specific extension of that is at the Population Level under Carrier, where some populations / communities may have a mistrust of government health programs, which makes it critical how the message of carrier status is delivered so that it is not misconstrued.

Also, it may be worth clarifying the "NBS State" stakeholder role. There is "Impact on state services (e.g. Medicaid, public school system)?", but this may not adequately capture the resources and services that an individual needs to reach their best possible outcome. This gets to the difference between available and accessible. While the availability of healthcare services (treatment, clinicians) is considered when exploring new conditions, the accessibility of services (local/state/federal) is rarely considered, and may lead to inequities at the individual and population levels.

Acknowledgements:

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Learn More

Visit BabysFirstTest.org for more information



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