



April 2023 - July 2023  
Topic #7:  
Newborn Screening



It's **TIME** to **KICK-off** Topic #7:  
**Newborn Screening**

For the next 4 months we will explore the topic of  
NBS in various ways:

- April:** Newsletter (you are reading that now!)
- May:** Webinar (**coming up on May 16th, register [HERE](#)**)
- June:** Check your Snail Mailbox for some MAIL!
- July:** Family Centered Perspectives & Conversation

Please take ONE hour (or more!) to review the resources in this newsletter  
and please **TAKE THE SURVEY** below!

**We thank you for taking TIME 4 GENETICS!**

Take our Newborn Screening Knowledge Survey before we  
begin this topic!



**Register NOW!**

**May 16, 2023**

*(at 11am PT, noon MT, 1pm CT, and 2pm ET)*


**Webinar:  
60 Years  
of Newborn Screening  
in a Nutshell**

*CME and CEU is available*




JOIN US FOR THE TIME 4 GENETICS WEBINAR:

**60 YEARS OF  
NEWBORN SCREENING  
IN A NUTSHELL**



**May 16, 2023**  
*(at 11am PT, noon MT, 1pm CT, and 2pm ET)*



Guest Presenter:  
Dietrich Matern, M.D., PH.D.  
Clinical Biochemical Geneticist  
Director, Biochemical Genetics Lab,  
Mayo Clinic

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To register please click: [here](#)

For a clickable and ready to share PDF version of this flyer please download: [here](#)

[Register Here](#)

**Resources for TOPIC #7:  
Newborn Screening**

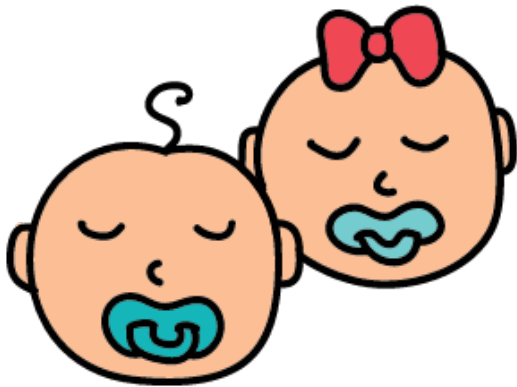
We encourage you to take an hour (or more!) to read the information below. Feel free to forward and share this newsletter with your staff and colleagues.

# What is Newborn Screening?

from HRSA

"Newborn screening (NBS) includes a series of tests: [Blood Spot Screening](#), [Pulse Oximetry Screening for critical congenital heart disease](#), and [Hearing Screening](#). However, it is more than only these tests. NBS is an interconnected system of organizations, programs, and experts who work together to make sure that caregivers and health professionals have information they need to understand NBS and know where to find more information when needed."

[HRSA Website on NBS](#)



**News Article and Video**  
that explains what the **RUSP**  
(Recommended Uniform Screening  
Panel) is and how NBS conditions  
lists vary by State.

**Death by ZIP Code: How state  
borders dictate critical  
screening for newborns**

*Chairman of federal advisory panel says there's  
no health-based reason not to have uniformity*

<https://www.wsfa.com/2023/03/27/death-by-zip-code-how-state-borders-dictate-critical-screening-newborns/>

[Find out what your  
State screens for](#)



**CME on NBS (free)**

**State of Newborn Screening  
in the Mountain States: A  
NewSTEPs Summary**  
*From MSRGN's 2022 Genetics Summit*

**access recording [here](#)**

**Patient Centered Newborn  
Screening Communication**  
*From our sister region  
(Midwest Regional Genetics Network)*

**access recording [here](#)**

**Register for the May 16  
Webinar (CME  
available!)**



## 2 Journal Articles to read

### Article #1: Newborn Screening

Expands: Recommendations for  
Pediatricians and Medical Homes—

#### Implications for the System

Read this publication [here](#).

Pediatrics (2008) 121 (1): 192–217.  
<https://doi.org/10.1542/peds.2007-3021>

### Article #2: Infants with Congenital

Diseases Identified through Newborn  
Screening—United States, 2018–2020

Read this publication [here](#).

Int. J. Neonatal Screen. 2023, 9(2),  
23; <https://doi.org/10.3390/ijns9020023>



## ACT SHEETS

*Your Guide to  
WHAT TO DO NEXT  
after you receive an  
ACTIONABLE NBS RESULT in  
your office!*

### View the ACT SHEET Library [here](#)

Searchable ACT sheet link [here](#)

The ACMG ACT Sheets and their accompanying algorithms are a great resources for health care providers looking for information on genetic conditions (identified through newborn screening and beyond) to help inform clinical decision making.

For each marker(s), there is 1) an ACTION (ACT) sheet that describes the short term actions a health professional should follow in communicating with the family and determining the appropriate steps in the follow-up of the infant that has screened positive, and 2) an algorithm that presents an overview of the basic steps involved in determining the final diagnosis in the infant.

# DATA TIME!

**Don't Forget!**

**Data from Topic #6  
(Cerebral Palsy)  
is DUE NOW!**

**Download the Zip Code  
Collection Tool Here**

**(by 5/15/23)**

We are all done with topic #6! We hoped you enjoyed the Cerebral Palsy topic area.

Please **email Kristi** any zip codes (**download tool here**) of those patients with whom you utilize any of the Time 4 Genetics information, resources, and tools! You can also include any zip code of patients you used Topic #1 (Red Flags), Topic #2 (Developmental Delays), Topic #3 (EDS) or Topic #4 (Genetic Testing), Topic #5 (Autism) info for as well!

**Take Topic #6 Survey  
(Cerebral Palsy) Here**

**Email Kristi with your  
Zip Code Data**

If you have not yet had a chance to provide feedback on topic #6 through the **evaluation/survey**, please do so. **WE HAVE GREATLY SHORTENED THE SURVEY** and it should only take you about 2-4 minutes to complete!

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THANK  
*you*

This publication and Time 4 Genetics initiative are supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000 with 0 percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](http://HRSA.gov).

Mountain States Regional Genetics Network  
**[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)**



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