

Newborn Screening Resource Roadmap

What it is and how to use it

What is the RUSP?

Federal recommendations (RUSP) for NBS programs carried out individually by **states** led to wide variability in the conditions screened for by each state.

What is RUSP Alignment Legislation?

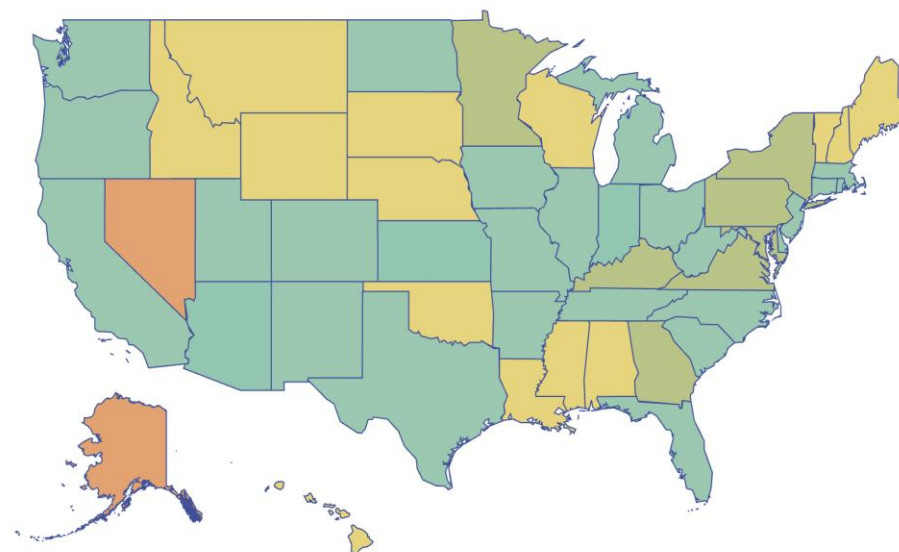
1. Requires the states to consider screening newborn babies for any disorder on the RUSP.
2. Implements a timeline for states to begin screening for new disorders added to the RUSP.
3. Ensures resources are available to facilitate the addition of new disorders.

What Does Newborn Screening Look Like Now?

68% of babies nationwide are born in RUSP-aligned states

We want to create resources to:

- Accelerate progress to align more states with RUSP
- Educate NBS advocates about processes for adding tests for new conditions to screening programs



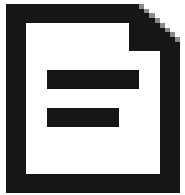
■ : 32-33 conditions
■ : 34-35 conditions
■ : 36-37 conditions
■ : 38-39 conditions

Everyone Has Different Needs



Programs and policies are in flux

Provide a source for the latest processes and policies



There are many existing resources

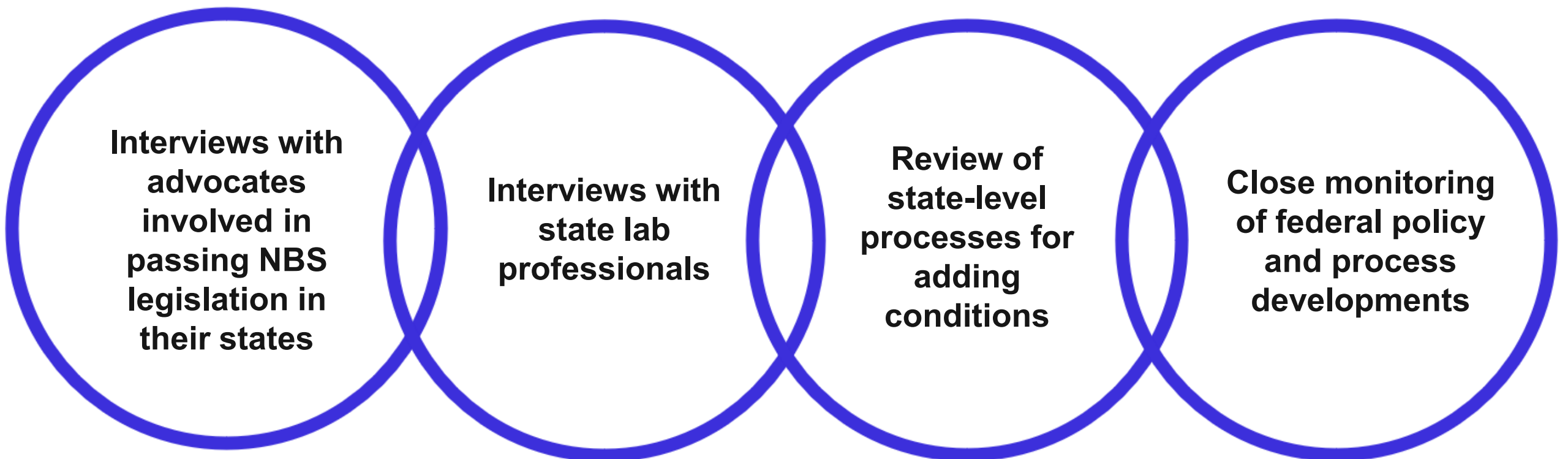
Help bring them together



It's a confusing landscape

Guide and encourage users through it

Developing the Roadmap



**Interviews with
advocates
involved in
passing NBS
legislation in
their states**

**Interviews with
state lab
professionals**

**Review of
state-level
processes for
adding
conditions**

**Close monitoring
of federal policy
and process
developments**

NBS Resource Roadmap

- Orient people to key topics and resources related to newborn screening
- Prepare them to advocate effectively for NBS for one (or more) rare diseases in one (or more) U.S. states

The user is posed a series of questions, and their responses direct them to resources and appropriate next steps.

1. Is the condition present in early childhood?



2. Is the condition considered medically serious and is it clinically well-defined?



3. Is there an immediate intervention or standard of care for babies with the condition of interest?



4. Is the condition listed on the federal newborn screening panel, referred to as "the RUSP"?



5. Is it currently being screened for by any US state?



6. Do you understand your state's process for adding new conditions?



7. How prepared are you to meet typical evidence requirements for adding a new test?



8. Are you familiar with your state's advisory councils, legislature, and calendar?



9. Have you identified other potential allies to support a request to add this condition?



10. Do you feel ready to submit a nomination or advocate for legislation to add this condition?



Expand each step by clicking the “+” button.

- ✓ Read the information under your answer and follow the links to discover additional resources to bolster your understanding.
- ✓ Follow the guidance and continue scrolling down through the steps. Mark your place for later reference if you need to take action before returning.

2. Is the condition considered medically serious and is it clinically well-defined?



Conditions that don't meet both these basic criteria are unlikely to be considered appropriate for inclusion in newborn screening programs.

Yes

Go to Question 3!

No

If either the condition is not considered medically serious or it does not yet have a broadly agreed-upon case definition that describes the range of symptoms in newborns and children who would be identified through population-based screening, it's likely best to focus on bringing together appropriate stakeholders to develop, publish, and foster adoption of a clinical case definition.

- [Learn more about stakeholders](#)
- [Read a clinical case definition for PKU](#)
- [Read a clinical case definition for Infantile Krabbe Disease](#)

Unsure

If you're unsure about whether the condition is considered medically serious or if it has a broadly agreed-upon case definition that describes the range of symptoms in newborns and children who would be identified through population-based screening, consult with clinical experts for the condition and the published medical literature.

- [Visit the Genetic and Rare Diseases Information Center \(hosted by NIH\)](#)
- [PubMed – a clearinghouse for medical publications](#)

Other Available Resources

- 10 Tips to Guide Newborn Screening Advocacy
- Newborn Screening Stakeholders
- NBS Pilot Study Overview
- Lab Barriers that Impact Implementation
- Unique Approaches to Expanding Routine NBS Panels: State Case Studies
- State-Based NBS Resources for Advocates
- Newborn Screening (NBS) Resource Roadmap
List of Resources embedded within the Roadmap

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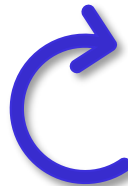
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Newborn screening is one of the most successful public health programs in the history of our country. For more than 50 years, every newborn in the U.S. has been screened for a range of debilitating and deadly diseases. We must protect this critical program.

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Thank you!