Newborn Screening Resource Roadmap

What it is and how to use it

RARE FOUNDATION

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.

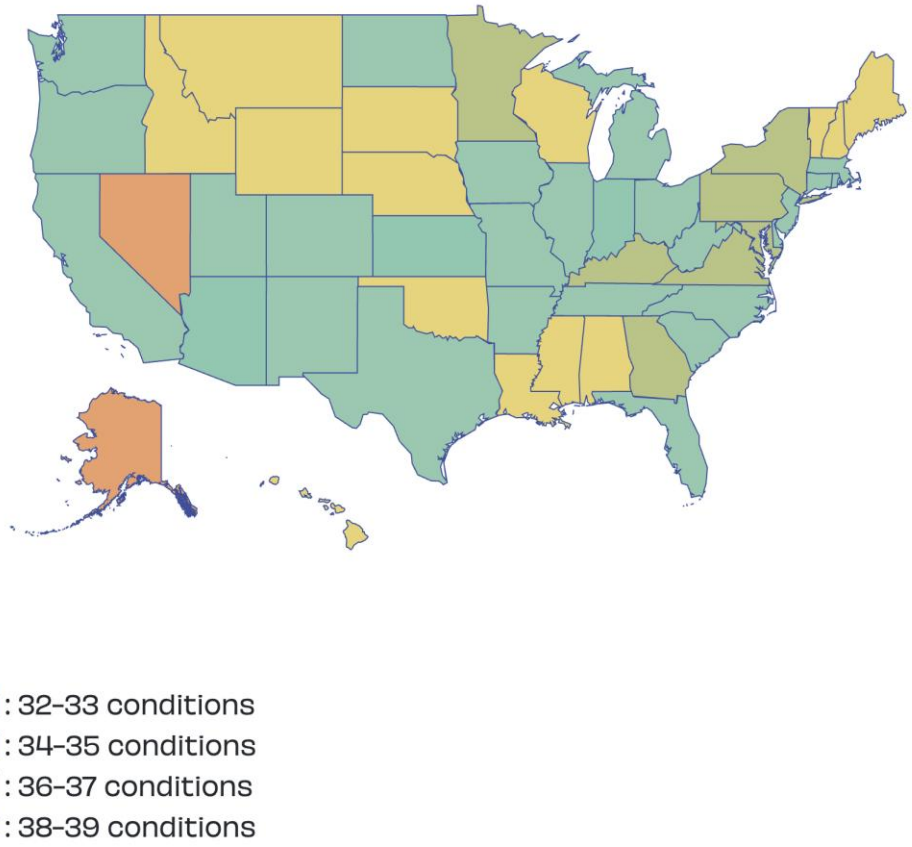
RARE FOUNDATION

What Does Newborn Screening Look Like Now?

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

We want to create resources to:

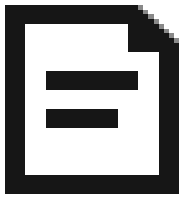
- Accelerate progress to align more states with RUSP
- Educate NBS advocates about processes for adding tests for new conditions to screening programs



RARE FOUNDATION

Everyone Has Different Needs

Programs and policies are in flux
Provide a source for the latest processes and policies

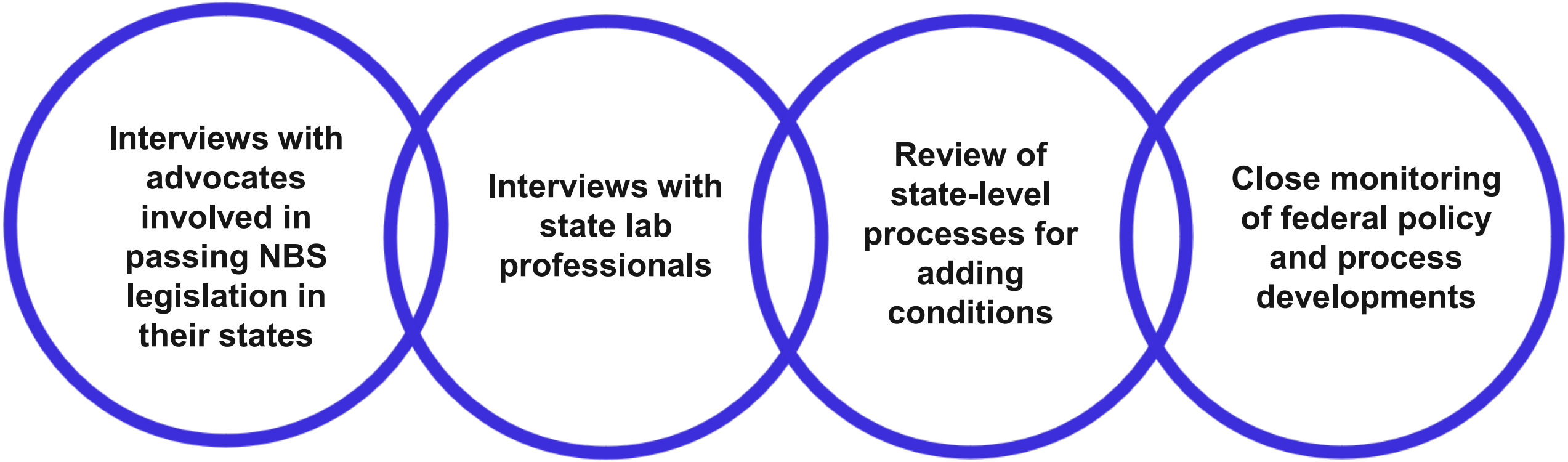


There are many existing resources
Help bring them together

It's a confusing landscape
Guide and encourage users through it

RARE FOUNDATION

Developing the Roadmap



RARE FOUNDATION

NBS Resource Roadmap

→ Orient people to key topics and resources related to newborn screening

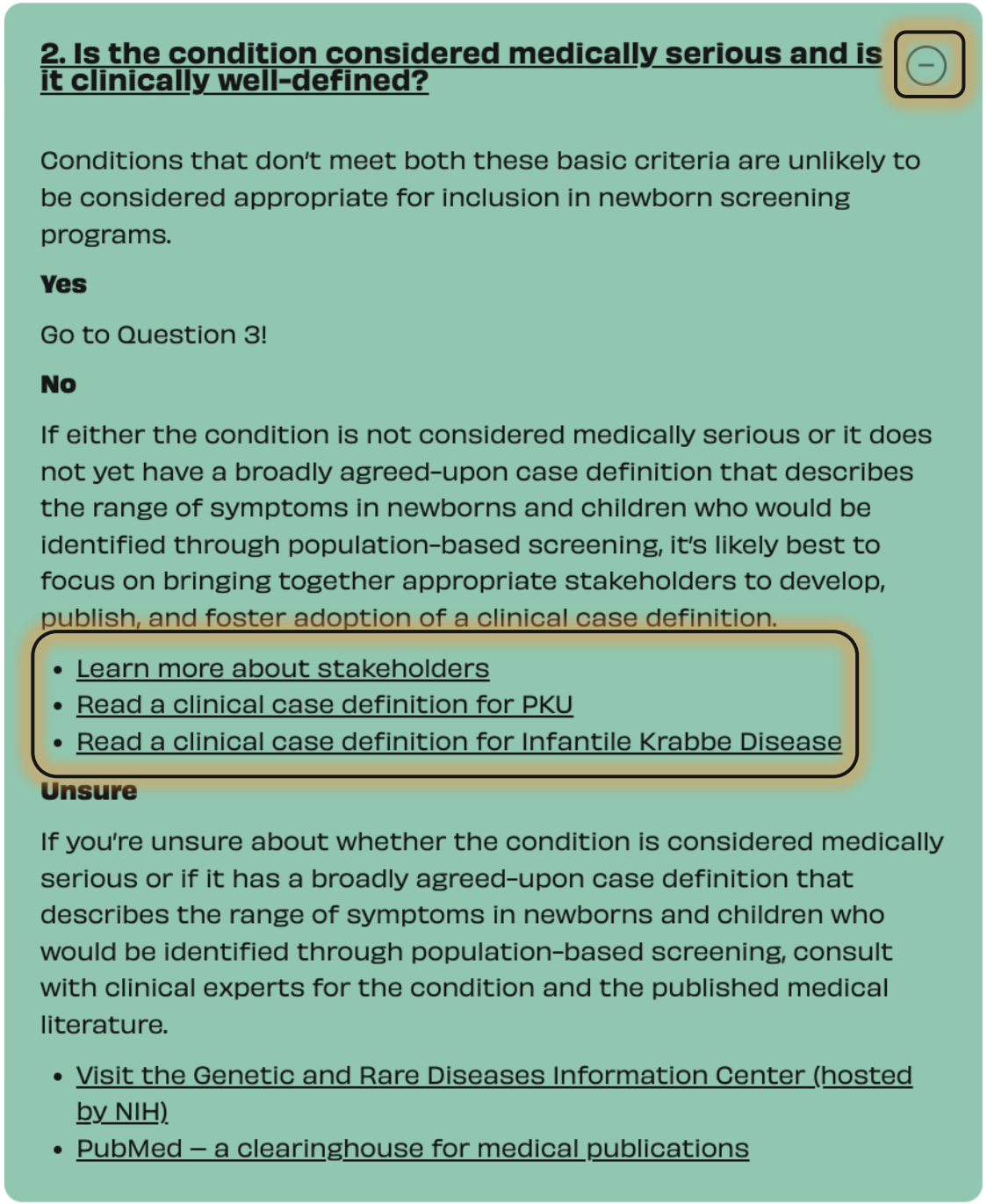
→ Prepare them to advocate effectively for NBS for one (or more) rare diseases in one (or more) U.S. states

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

RARE FOUNDATION

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.



RARE FOUNDATION

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

RARE FOUNDATION

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?

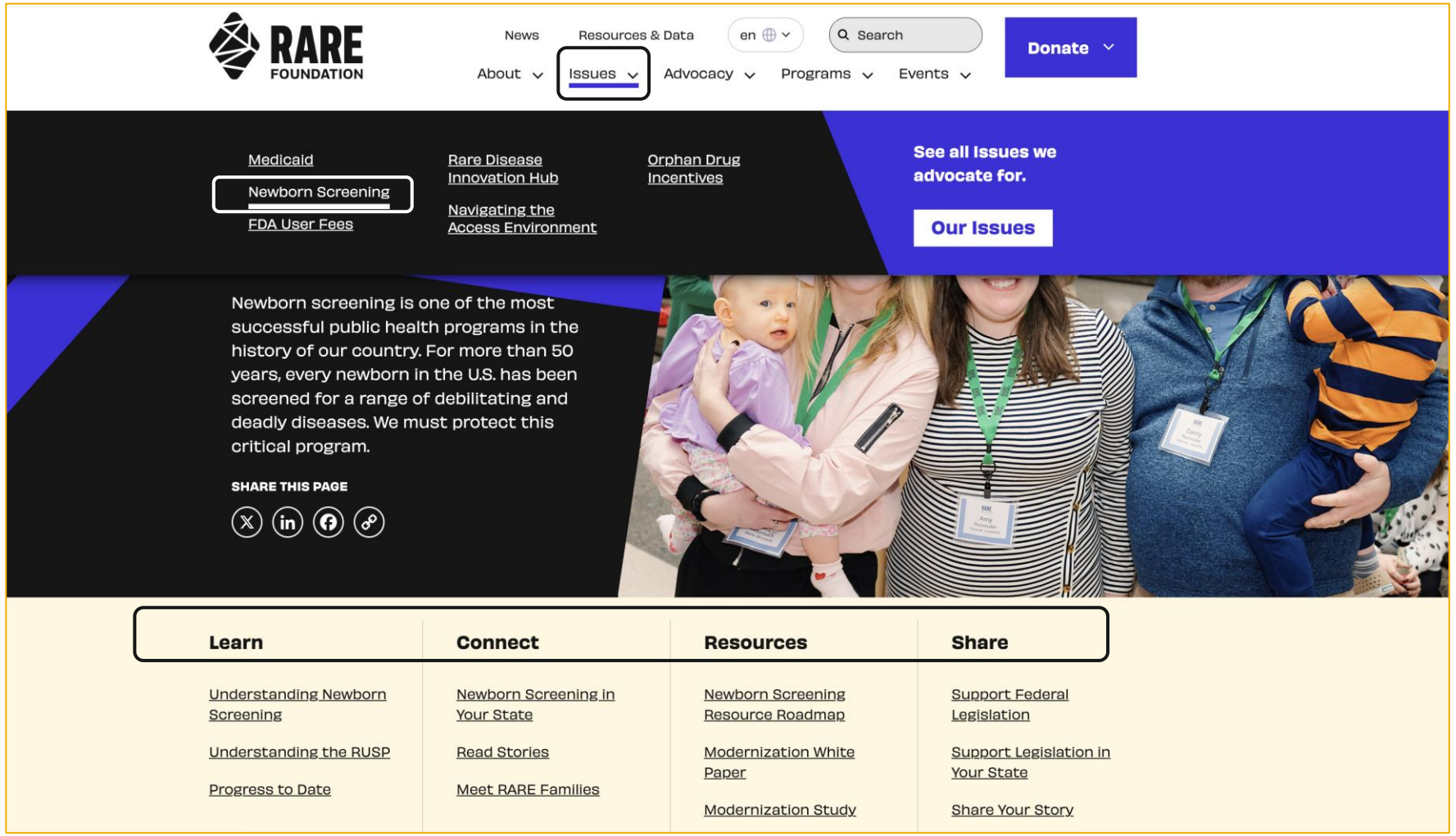
8. Are you familiar with your state's advisory councils, legislature, and calendar?

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?

RARE FOUNDATION

RARE Foundation Newborn Screening Resources



RARE FOUNDATION

Thank you!

RARE FOUNDATION