

10 Tips to Guide Newborn Screening Advocacy

There are few things in life more precious than the life of a newborn child. Every child deserves the healthiest start to life possible by identifying treatable conditions as early as possible. That is the purpose of newborn screening (NBS) programs.

This sounds straightforward, but the details surrounding NBS programs are complex and multifaceted. The NBS Resource Roadmap is designed to support you in your advocacy for expanding NBS programs in one or more states. You might find the following tips helpful as you review the various steps in the Roadmap, engage with the resources, and advocate for progress.

1. **Take stock of what you know about NBS and what you need to learn.**

Orienting to any new topic takes some upfront investment to learn the lay of the land and become familiar with terms used, key players, and places where you can engage with others. Keep a running list of questions you have and topics you want to learn more about. Bookmark resources you anticipate needing to reference.

2. **Prepare to listen and collaborate.**

The ways NBS is handled at the federal level and in some states are undergoing rapid change. Information – even from authoritative sources – may be outdated or subject to more updates. The best way to stay current is to remain open to new information, check your sources, and actively work with and learn from others who have experience in NBS.

3. **Assemble the facts to support your interest in expanding NBS.**

NBS programs have been built on a foundation of science, public health, and policy. Decisions about expanding these programs rely on evidence that begins with having a deep understanding of the disease or condition of interest and how the NBS program operates in a particular state. Research both topics before taking action. Start by reading the state(s) of interest's [existing newborn screening legislation](#).

4. **Act with purpose and integrity.**

You may be motivated to advocate for the expansion of one or more NBS programs based on a personally relevant experience. When you engage with others to advocate for change, your actions can affect the families of all babies born in the state(s) you interact with – a weighty responsibility. Being truthful and treating others with respect will help build your reputation as a credible and creative problem-solver.

5. **Build a network of allies.**

There are many different [groups of people involved and invested in NBS programs](#), and you're bound to need – and benefit from – help along the way. Share what you learn with others, tap into their experiences, and provide mutual support. Work together when goals align and respect independence when your objectives differ. Focus on advancing

sound policy and action and avoid being drawn into partisan or political matters.

6. **Be generous with credit and thanks.**

Stay humble and recognize other community members' contributions. Saying "thank you" is an easy (and free!) way to reinforce the power of individual and collective contributions to progress. Expressing gratitude can also be a powerful antidote when you're feeling angry, frustrated, or anxious about a particular setback in your advocacy work.

7. **Adjust and pivot when necessary.**

Speaking of setbacks, there are times when you may find that circumstances or processes have changed, and you have to regroup and plot a new path forward. Take stock of lessons you've learned and the people you've met who may have insights that can help identify a fresh approach.

8. **Pace yourself to go the distance.**

It can take months or years to gather and/or generate the evidence and policy support needed to successfully add a new condition to an NBS program. There are times when tight deadlines or urgent opportunities demand total focus, so remember to prioritize other responsibilities, interests, and self-care between those sprints in this marathon.

9. **Do no harm.**

It can be easy to lose sight of the big picture when focused on achieving a well-intentioned goal. Check in with yourself and trusted colleagues every so often to reassess the benefits of proposed change(s) and the potential for harm. Look for ways to reduce risks or strains that might be felt by individual stakeholders and the system as a whole.

10. **Celebrate small wins.**

As outlined in this Resource Roadmap, the process of expanding NBS is the culmination of many, many small steps. Taking time to appreciate milestones crossed, new connections formed, and incremental progress is vital fuel for the journey. Recognize new knowledge and skills you've gained, and draw on that personal growth as a new superpower!