

Newborn Screening Saves Lives

We need a way to add new health conditions to the **federal newborn screening list**.



What is newborn screening?

It is a way to test every new baby for certain health conditions when they are 1-2 days old.

In the United States, we have an official list of conditions that doctors recommend babies be screened for as soon as they are born. There are almost 40 conditions on this list!

Why do we need newborn screening?

Newborn screening can:

- Find health conditions early
- Get babies treatments that can save their life
- Help parents learn how to take care of their baby's condition

If we don't screen to find certain health conditions early, babies with these conditions may:

- Have a disability that could have been prevented
- Become very ill
- Or they may even die

➔ **Newborn screening saves lives!**



“Screening” means testing for health problems **before** they show up. If doctors find a problem early, it can be easier to treat!

Remi's story



Hi! I'm Remi. When I was a baby, I got a little pin prick in my heel (I don't remember it, I was only 2 days old!) It was a test that all newborn babies get. It found that I had an invisible disease called PKU – even though I seemed perfectly healthy!

Without that test, my parents and doctor may not have known I had PKU until after the disease damaged my brain! It's ok though, my parents got me treatment and learned how to keep me healthy. I am 7 now. I'm so thankful my PKU was caught early!

Did you know?

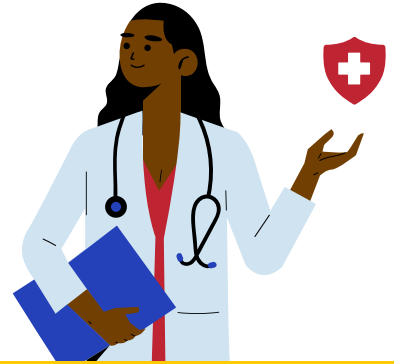
Four million babies are born in the U.S. each year. Newborn screening finds serious health conditions in 1 in every 300 of them! That's about 12,000 newborns each year who get life-saving treatments!

<https://www.cdc.gov/mmwr/volumes/69/wr/mm6936a6.htm>

Why do we need a way to add new conditions to the newborn screening list?

There are more conditions to add to the screening list that doctors could find and treat early. But right now, there is no way for people to suggest new health conditions to add to the list.

To help, you can talk to your lawmakers about **creating a way** for people to suggest health conditions that babies should be screened for.



What should I say to my lawmaker?

1

Tell them your name and your story about newborn screening, if you have one.

2

Tell them why newborn screening is important:

→ Newborn screening is important because it can:

- Get babies treatments early
- Avoid health problems later in life
- Prevent serious illnesses or disabilities
- **Save kids' lives!**

3

Tell them what we need:

→ "Because of recent changes, there is no way for doctors or patient organizations to suggest that a health condition be added to the federal newborn screening list.

I am asking that you create a way for people to suggest new health conditions for the screening list. With more conditions on the list, we can save more lives and money by finding and treating these conditions early."

4

Ask them, "What questions do you have for me?"

5

Say, "Thank you for your time!"

