

### Midwives, Did You Know ...



The ideal time to gather the bloodspot newborn screen is **24-48 hours after birth**, **regardless of feeding status**. There have been a lot of advances in technology and testing methods.



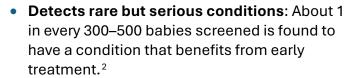
Having a family member hold the baby on their shoulder (belly on shoulder) makes gathering the newborn screen easier for you, baby, and the parents. It allows gravity to work and secures the baby. This approach also allows touch to soothe the baby. Nursing may also help<sup>1</sup>. Also, based on social media posts, some families don't like seeing midwives squeeze the foot. Putting the baby on the shoulder helps avoid that.



A lot goes into the family's decision to do a newborn screen. Below is a table with statistics to help you have that discussion if you want.



# Why families may want to do the screening



- Timely treatment: Some conditions need intervention within days or weeks to prevent death or significant impairment
  - **Prevents serious health outcomes**: Early detection can prevent intellectual disability, seizures, coma, or death.<sup>3</sup>

**Most babies get normal results:** Over 99% of babies screened have normal results.<sup>4</sup>

**Fast and low-risk**: Just a few drops of blood collected in a quick heel prick.

 Reassurance: Most affected babies have no family history.<sup>5</sup>



# Why families may be hesitant about doing the screening

- Avoids blood draw and discomfort for the baby (though mild and short-lived)
- Conditions screened for are rare: Approx. 0.2–0.3% chance, but consequences can be severe. 6
- Avoids anxiety from false positives (1–2% may initially suggest a problem that later turns out normal).<sup>7</sup>
- Specimen storage/privacy concerns:
   In North Dakota, specimens are destroyed after 30 days. No research is done on the blood spot specimens prior to destruction<sup>8</sup>.



#### You Can Help Families Whose Child Has an Abnormal Newborn Screen

- If you are working with a family whose child has a positive newborn screen, you or the family can go to Baby's First Test (<a href="https://babysfirsttest.org/">https://babysfirsttest.org/</a>) to learn more about what to do. Families can also use this website.
- It is important for families to get diagnostic testing as quickly as possible. If you are not the pediatrician, you can work with them to help the family. If you are the pediatrician, your local newborn screening follow-up program is there to help you help your patients.

This guide was made in collaboration with several state newborn screening programs and several midwives and was edited to reflect North Dakota.







#### **References**

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<sup>&</sup>lt;sup>1</sup> https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2019/05/newborn-screening-and-the-role-of-the-obstetrician-gynecologist

<sup>&</sup>lt;sup>2</sup> CDC – "Newborn Screening Saves Lives" <a href="https://www.cdc.gov/newbornscreening/index.html">https://www.cdc.gov/newbornscreening/index.html</a>

<sup>&</sup>lt;sup>3</sup> March of Dimes – "Newborn Screening Facts" https://www.marchofdimes.org

<sup>&</sup>lt;sup>4</sup> Canadian Paediatric Society – "Newborn screening in Canada" <a href="https://cps.ca/en/documents/position/newborn-screening-in-canada">https://cps.ca/en/documents/position/newborn-screening-in-canada</a>

<sup>&</sup>lt;sup>5</sup> American Academy of Pediatrics – "Understanding Newborn Screening" https://www.aap.org

<sup>&</sup>lt;sup>6</sup> CDC - "Newborn Screening Saves Lives" https://www.cdc.gov/newbornscreening/index.html

<sup>&</sup>lt;sup>7</sup> Newborn Screening Ontario – <a href="https://www.newbornscreening.on.ca">https://www.newbornscreening.on.ca</a>

<sup>8</sup> https://ndlegis.gov/prod/acdata/pdf/33-06-16.pdf