Improving Communication of Negative Newborn Screening Results

Whitney Thompson MPhil
Amy Gaviglio MS, CGC
Susan Berry MD
Positive newborn blood spot results in MN

- Presumptive positive and borderline results account for **2.5%** of results in MN

- Consistent and streamlined process for dissemination of positive results:
  - Program Genetic Counselors call infant’s primary care provider and notify appropriate specialists

- After phone notification, an informational packet is faxed:
  - Report
  - Family fact sheet
  - Medical fact sheet
  - Specialist contact list
What happens to the other **97.5%** of results

“A ‘negative’ result means that the screen was normal for that particular disorder and no additional follow-up is required.”

-MDH website
Why do negative results matter?

“A ‘negative’ result means that the screen was normal for that particular disorder and no additional follow-up is required.”

“Note: Because newborn screening is not diagnostic testing, false negative results may occur... Newborn screening should not replace diagnostic testing in any circumstance...”

-MDH website
False negatives in MN

1-2/year (reported)

• Most common:
  • Cystic fibrosis
  • Congenital adrenal hyperplasia

• Rarely metabolic

• Rarely of acute health impact
Leo’s story

“I do not remember ever receiving Leo’s results about the newborn screen until after his stroke. I remember being told no news is good news by someone from the hospital.”

– Leo’s mom
A quality improvement project has been initiated to assess:

• If families received and understood their normal screening results

• How negative newborn blood spot results are handled at several clinics in MN

• Where improvements are needed for the efficient and effective communication of negative results to providers and families
Do parents in MN receive negative results?

• Survey sent to parents 4 weeks after birth

• Chosen based on:
  • Negative blood spot screen results
  • Specified provider/clinic at time of birth

• To date (DOB 6/1-7/15 2017):
  • 799 surveys sent
  • 159 surveys received
  • Response rate: 19.9%
Percent of Newborn Blood Spot Results Received

- Yes: 46%
- No: 46%
- I Don't Know: 8%

n=159
Percent of Newborn Blood Spot Results Received at Each Clinic

- Clinic 1: n=18
- Clinic 2: n=35
- Clinic 3: n=2
- Clinic 4: n=50
- Clinic 5: n=40
- Other (Rural): n=14

Total: n=159
Clinics Summary

• **What’s working**
  • Have a designated person responsible for ensuring NBS results in chart
  • High continuity of care between midwives and providers at same clinic
    → more likely to have results in patient chart by 2-week visit

• **What’s not**
  • Require patients sign a release form before results retrieved
  • Lack of standardized/accurate materials in multiple languages
Method By Which Newborn Blood Spot Results Were Received

- At Clinic Visit: 41%
- Letter/Brochure: 28%
- Online Patient Portal: 24%
- Other: 4%
- Phone Call: 3%

n=78
Preferred Method to Learn About Newborn Blood Spot Results

- At Clinic Visit: 45%
- E-mail: 16%
- Online Patient Portal: 15%
- Letter/Brochure: 12%
- Phone Call: 8%
- Text Message: 2%
- Online Video: 2%

n=207
Reported Understanding of Screening Test vs. Diagnostic Test

- Yes: 120
- No: 20
- I Don't Know: 10

n=159
Survey Question: Were you satisfied with your experience getting your child’s newborn screening results? How could it be improved?
“I don't know if I ever received my child's newborn screening results. Since I don't remember getting anything I assume all is fine. However, the fact that I'm not sure I got results is a problem.”
“Send out the results. The test is taken but no one shares the results. That's annoying.”
“No, I didn’t receive any results. Assume that no news is good news! 😊”
“I asked about this at the 1 month check-up. Pediatrician said they received and ‘everything is normal’ but didn’t even tell me what was tested.”
“Pediatrician briefly mentioned my son’s results came back ‘good.’ It could be shared at appointment in better detail with a copy of results (PDF or paper). I’m not even sure what blood type my son is.”
Survey conclusions thus far

• Over 50% of parents did not receive or don’t know if they received their child’s newborn blood spot results

• Result reporting varies widely within each clinic examined

• Most common methods of result reporting are: in-person conversation with provider, letter in the mail, and online patient portal

• Most desired method to receive results is an in-person conversation with provider

• Many parents who received results are not satisfied with the manner in which they received them and/or the lack of information they received

• Majority of parents report an understanding of screening test vs. diagnostic test
What’s next

**Aim:** Initiate a conversation about newborn blood spot results between provider and parent at 2-week well-child visit

Development of a Maintenance of Certification course for providers detailing how to discuss negative newborn blood spot results

1 clinic in MN
→ Continue assessing with parental survey
→ Multiple clinics across MN
→ Regional network project
What’s next

“MDH Normal Result Family Fact Sheet”

• Given to parents by provider at 2-week visit when results are discussed
• Highlights limitations of screening test
• Notes symptoms parents should watch for despite normal blood spot results
• Provides resources that detail what was tested
• Translated into multiple languages

Normal Results: Blood Spot Screen Results Notification

The newborn blood spot sample was collected at birth and was normal (also known as negative) for the disorders on the MN newborn screening panel. This means that your baby is not likely for having one of the disorders on the screening panel. No further testing is needed at this time.

What is Newborn Blood Spot Screening?
Newborn blood spot screening is done by taking a few drops of blood from your child shortly after birth. Sometimes this test is called the “heel stick” or “24-hour test.” These drops of blood are used to fill spots on a filter paper card and are sent to the MN Newborn Screening Program to be screened for over 55 rare, but treatable disorders.

Why is this testing important?
This screen is often the only way to tell whether your child is at risk for one of these disorders. If found early, infants can be treated and lead much healthier lives than if found later in life.

What happens next?
Review your child’s newborn blood spot screening results with your child’s doctor. Newborn blood spot screening does NOT detect all disorders. Screening can still miss children affected by disorders on the panel. It is important for your child to receive regular checkups with a doctor and to watch for your child for health problems.

Resources

MN Newborn Screening Program: www.health.state.mn.us/newbornscreening/

Babys First Test: www.babysfirsttest.org

What to watch for in your child:

• Trouble breathing (very rapid or shallow breaths)
• Unusual shaking movements
• Difficulty waking up from sleep
• Severe or projectile vomiting

It is important to contact your child’s doctor or the hospital right away if your child has any of the symptoms listed above.
No news is *not* good news...
It’s time to start the conversation

In MN, **190** babies born/day ... That’s **190** conversations.
Comments or questions?

Whitney Thompson: thom2711@umn.edu

Amy Gaviglio: amy.gaviglio@state.mn.us

Susan Berry: berry002@umn.edu