Assessing the Experience of Parents of Newborns Diagnosed with a Condition through Michigan’s Newborn Screening Program

2019 Newborn Screening and Genetic Testing Symposium
April 9, 2019

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Newborn Screening Process: Blood spot to diagnosis

1. Baby is born
2. Blood spot sample taken
3. Sample picked up from hospital
4. Sample arrives at lab
5. Laboratory runs tests
6. Lab contacts follow-up team with abnormal results
7. Follow-up team contacts PCP/hospital about abnormal NBS result
8. Parents contacted about abnormal results
9. Parents meet with specialist to confirm diagnosis
Assess parent experiences

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Parents learning NBS results and receiving confirmatory diagnosis

- **Parent contacted**
  - In-person, over the phone, letter
  - By PCP, PCP office staff, specialist

- **Specialist appointment scheduled**
  - By PCP office or parent

- **Specialist visit for confirmatory testing**
  - Extra tests completed
  - Infant diagnosed or ruled-out
Assessing parent experiences with NBS process

- Survey parents of infants diagnosed with a condition identified through NBS

**Goals:**
- Receive feedback from parents about their experience with NBS
- Identify areas of success and areas that need improvement within the NBS process
- Develop resources and educational materials
- Improve overall NBS experience for future families

- This study was approved by the MDHHS Institutional Review Board
Methods

- Follow-up team inputs limited contact info into Access database
  - Births from Jan 2017, June 2017, January 2018 – November 2018
- Introductory letter mailed
  - Parents contacted up to three times by phone
  - Phone survey completed or message left if no answer
  - Called during different days and times
- Closing letter and hard-copy survey sent if no contact after three attempts
- Results recorded in Access database
Survey Content

• 3 sections
  – Introduction
    • Confirms parent contact, asks if willing to participate
  – Learning the NBS results
    • How they were told, who told them, did they get enough info, satisfaction, feedback for improvement
  – Follow-up testing and visit with specialist
    • Scheduling appointment, information received, address any barriers, feedback for improvement
Survey Results

- **Response rate**
  - 111 parents contacted
    - 56 completed the survey (50%)
      - 68% over the phone
      - 32% returned hard copy survey
  - 6 refused (5%)
Conditions represented in survey respondents

- Amino Acid Disorders: 4 Completed, 10 Contacted
- Cystic Fibrosis: 8 Completed, 15 Contacted
- Endocrine Disorders: 37 Completed, 64 Contacted
- Hemoglobinopathies: 3 Completed, 14 Contacted
- Partial Bio: 4 Completed, 8 Contacted

Completed and Contacted counts for each condition.
Key results – Learning NBS Results

- NBS awareness
  - 84% of parents aware of NBS before receiving their child’s result

- 86% of respondents received NBS results by phone or in-person
  - If received specific information on condition
    - More than half of respondents felt it was just the right amount
    - More than one-third felt they didn’t receive enough
  - More than half satisfied with how NBS results were delivered
Parent feedback: Learning NBS Results

Positive feedback
- Speed of results
- Liked communication of results by PCP
- Good information provided

Areas for Improvement
- Improve condition specific knowledge for those delivering results
- Provide more information to families
Parent feedback: Diagnosis with Specialist

Positive feedback:
- Wonderful specialists, good communication and wealth of knowledge
- Good schedule coordination, flexibility and availability of specialists
- 95% of parents received enough information to care for their newborn with a NBS condition

Areas for Improvement:
- ~40% with barriers: majority with issues with distance to specialist or insurance
- Arranging visit with specialist: quicker scheduling to first visit
Overall NBS Experience

Areas for Improvement

- Prenatal and PCP education
- Strengthen communication between follow-up, PCP, specialist and parents
Next Steps

- Internal NBS education workgroup
- Developing educational products
  - Roadmap
  - Positive NBS fact sheet
- Expand prenatal education
- Summer health education intern
- Continue administering survey
- Examine results by condition to identify specific issues by disorder
Acknowledgements

• Anders Evenson, BA, Public Health Associate
• Mary Kleyn, MS, NBS Section Manager
• Isabel Hurden, MPH, NBS Epidemiologist
• Karen Andruszewski, BS, NBS Quality Assurance Coordinator