Strategies and Resources to Improve Communication of Out of Range Results

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Background

• Genetic Alliance and the University of Maryland School of Medicine, through a cooperative agreement with the Genetic Services Branch, MCHB/HRSA/HHS, is conducting a mixed-methods study to understand the impact of false-positive results and carrier identification on families as a consequence of newborn screening (NBS).

• Results from the study indicate that parents’ initial interaction with their pediatrician when receiving the abnormal NBS result may affect the emotional impact of that result on the family.

• Results lead us to consider several ways to improve the NBS experience for parents, including a ‘checklist’ or conversation aid.
Methodology: Overall

• A three tiered mixed-methods
• Throughout 2009 the research team conducted the first two tiers of the study: focus groups and semi-structured interviews.
• 3 focus groups
  – two with families in Michigan
  – one with families in Georgia,
• 18 semi-structured interviews with families in Maryland, Michigan, and Georgia,
  – 16 false positive newborn screen result
  – 2 identified as a carrier of a genetic condition through NBS.
Results

• Parents expressed a preference for receiving the NBS result directly from their pediatrician

• Parents with knowledgeable provider (about abnormal results) express satisfaction with their provider

• Structured questionnaires with a different sample of parents (Tier 3; in process) are being used to explore parents’ experience in relationship to their personal characteristics
What is the Need?

- An abnormal (out-of-range) NBS result is a significant challenge to parents; families told us they didn’t know what questions to ask
- Individuals/families vary in coping strategies including:
  - Variable interest in information
  - Variable access to information (e.g. novel strategies of access)
  - Differences in need for support and types of support accepted
- Providers are challenged to recognize families’ needs and help them sort through resources while trying to integrate this information into patient care
- Healthcare systems can use tools that facilitate communications for partnership of patients and providers to improve health care and the experience of families
Key Questions

• Would a check list for families after abnormal NBS helpful? (We think so!)
  – Is our current version useful?
  – How can it be improved?

• How would such a checklist be disseminated?
  – (in addition to posting on “Baby’s First Test”)

• How will providers be prepared to answer the questions prompted by the checklist?

• Would a checklist for providers be helpful?
Methodology: Family Checklist

• In the spring of 2010 the research team began to craft a “checklist” or conversation aid
• Created for parents to use with provider to steer discussion to meets parents’ informational and emotional needs.
• Input from counseling, education, and policy experts and from the Genetic Alliance Consumer Task Force on Newborn Screening
Challenges in Checklist/Resource Development

- **Terminology** – “Out-of-range result”, “abnormal result”, and “positive result” used interchangeably in the NBS system
- **Reading Level** – NBS and genetics concepts highly complex and difficult to convey
- **Length** – A comprehensive checklist detailing potential scenarios following an abnormal result may be longer than one page
- **Effectiveness** – Ideally, prior to dissemination, beneficial impact of the checklist should be documented
- **Dissemination** – To be useful, checklist must be available to the consumer at the time of learning the abnormal result – who is responsible?
- **Provider Role** – Checklist provides parents with the kinds of questions they should ask providers but not all providers will feel prepared to answer the questions
DON’T PANIC!

- Possible that your child has a treatable genetic condition – but much more likely that your baby is healthy and that a follow-up test result will be within a normal range.

Questions to ask your baby’s doctor (before more testing is done):

- For which disorder did my child have an abnormal result?
- What kind of test will the next test be, and how will I learn the results?
- Do I need to see another doctor?
- How should I prepare for the test? What do I need to bring?
- Should I try to find more information about the disorder? Can you tell me where to look?
Checklist Content/Summary: con’t

Things to do while waiting for the results:
  ▪ Consider how you cope with stressful situations, including speaking with others and searching for information.
  ▪ Ask your doctor: Is there anything I should be watching for in my child? Are there any precautions I should take?

Learning the follow-up test results and what they mean:
  ▪ **False-positive result**: Is my child really healthy? Why did this happen? Are there other parents who have gone through this?
  ▪ **Carrier identification**: Is my child really healthy? How did this happen? What does this mean for my family?
  ▪ **True-positive result**: Do I need to see a specialist? How can I keep my baby healthy? Will this affect my child’s ability to obtain health insurance coverage?
Future and Challenges

• Improving the checklist for families
• Checklist for providers?
• Need for broad and novel resource dissemination channels, mindful of time and economics
• Tools needed to help consumers filter the information they access (e.g. ATCG – Trust it or Trash it, informed providers)
• Providers must be adequately prepared to answer questions
• Research team recognizes the role of the Newborn Screening Clearinghouse
  – Channel for accessing NBS-related resources
  – Outlet for resource dissemination
  – Portal for provider education