Strategies and Resources to Improve Communication of Out of Range Results

Carol Greene, MD
University of Maryland, School of Medicine

Natasha Bonhomme
Baby's First Test, Genetic Alliance

UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Genetic Alliance

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

Current Checklist: Content/Summary

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