Guidelines to Consider When Creating a Newborn Screening Brochure

How Should Information be Presented?

- According to parents, the brochure’s format should:
  - Be short, simple, and concise
  - Use questions as headings
  - Use bullets when answering questions

- Parents would like the information in the brochure to:
  - Be descriptive, but easily understood
  - Include a single, general description of the screening disorders
  - Be minimal; more detail should be saved for brochures targeting families with abnormal results
  - Include the Newborn Screening Program’s contact information for those wanting more details

What Should the Brochure Look Like?

- Visually, parents would like the brochure to:
  - Be colorful (pastel colors were preferred)
  - Use real pictures instead of line drawings
  - Use pictures of people (pictures portraying newborns and caregivers were preferred)
  - Use pictures that are ethnically ambiguous (e.g.: the picture’s focus is on hands or feet rather than faces)
  - Use pictures that demonstrate a loving interaction between the newborn and caregiver

What Should the Brochure Avoid?

- Parents have told us to avoid:
  - Using pictures depicting the heelstick process; this was viewed as “scary” or “threatening”
  - Using the word “disease” (the words “condition” and “disorder” are preferred)
  - Using the word “heelstick;” many parents did not understand this word, or confused it with other tests using heelsticks
  - Using the word “metabolic” too often; this word was confusing to less educated parents
  - Describing each disorder included in a screening panel; this was viewed as overwhelming
  - Including too much information; parents who wanted more information indicated that they would contact the Newborn Screening Program
- Including unnecessary information (e.g.: list of states participating in the regional newborn screening program)

- State programs may want to include a list of the disorders screened by their program. This list should be placed at the end of the brochure.

Where Can I Get Other Ideas?

- Our Message Library and Graphics Library contain key statements and graphics that:
  - Have been approved by participating parents and our project Steering Committee
  - Are not copyrighted
  - Can be included or adapted to fit within your brochure

- You can also refer to the resources below for more ideas on formatting educational materials:

Who Developed These Guidelines?

- The Libraries were created by the Screening, Technology, and Research in Genetics (STAR-G) Project.

- The STAR-G Project is a multi-state project working to improve information about newborn screening and genetic testing.

- The project is supported by a grant from the Maternal and Child Health Bureau, Health Resources and Service Administration Genetic Services Branch, MCH Project #:1 H46 MC 00189-03.
How Were the Guidelines Developed?

- These Guidelines were developed using information from parents
- Parent input was collected through:
  - 3 focus groups in Alaska
  - 3 focus groups in California
  - 12 focus groups in Hawaii
  - 3 focus groups in Oregon
  - 4 focus groups in Washington
  - 1,413 completed surveys in California
  - 633 completed surveys in Hawaii
- Parents were of varying ethnic, educational, and socio-economic backgrounds

Where Can I Get More Information?

- For more information on our focus groups and surveys, please contact us through our website at www.newbornscreening.info.