

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:
 - *Clear and Simple: Developing Effective Print Materials for Low-Literate Readers*. National Cancer Institute.
www.cancer.gov/aboutnci/oc/clear-and-simple
 - Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*, 2nd Edition. L B Lippincott Company. 1996.
 - Gaston N, Daniels P. *Guidelines: Writing for Adults with Limited Reading Skills*. United States Department of Agriculture, Food and Nutrition Service, Office of Information.
www.cyfernet.org/research/writeadult.html
 - Lorig K. *Patient Education, A Practical Approach*. 3rd Edition. SAGE Publications. 2000.
 - Zimmerman M, Newton N, Frumin L, Wittet S. *Developing Health and Family Planning Print Materials for Low-Literate Audiences: A Guide*. Program for Appropriate Technology in Health (PATH). 1989.
www.path.org/files/DC_Low_Literacy_Guide.pdf

Who Developed These Guidelines?

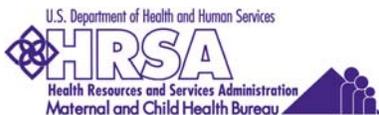
- The Libraries were created by the Screening, Technology, and Research in Genetics (STAR-G) Project.
- The STAR-G Project is a multi-state project working to improve information about newborn screening and genetic testing.
- The project is supported by a grant from the Maternal and Child Health Bureau, 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.



This project is supported by a grant from the Maternal and Child Health Bureau,
Health Resources and Service Administration, Genetic Services Branch,
MCH Project #:1H46 MC 00189-03 <http://mchb.hrsa.gov>