

**ATTACHMENT M**  
Documentation Notice for HIPAA Accounting Form

*The Natural History of Spina Bifida in Children Pilot Project*

**Documentation Notice for HIPAA Accounting**

(To be placed in child's medical record.)

Information contained in this document can be used to comply with the Privacy Rule requirements as mandated by the Health Insurance Portability and Accountability Act (HIPAA) to account for disclosures of protected health information.

Disclosure date: \_\_\_\_\_

Name and address of recipient:

Natural History of Spina Bifida in Children Pilot Project  
c/o National Opinion Research Center  
1 N State ST FL 16  
Chicago IL 60602

**Purpose:** To date, there are no US population-based cohort studies on the natural history of SB. This is of importance because persons with SB often experience condition-specific difficulties and secondary conditions that detrimentally impact several aspects of their lives. Much still stands to be learned about the natural course of SB throughout the life span. The data collected in this project relate to medical concerns prevalent among individuals with spina bifida in the areas of neurology/neurosurgery, urology, and orthopedics; development and learning; nutrition and physical growth; mobility and functioning; general health; and family demographics. Participants consist of families with a child with spina bifida ages 3-, 4-, or 5-years of age.

**Description:** This document has been placed in the medical file as an indicator that information from this provider was used for the Natural History of Spina Bifida in Children Project. A copy of the medical records was made and relevant information will be abstracted. Information to be abstracted will include confirmation of patient characteristics (e.g., child's name, gender and birth date) and various information in the areas of neurosurgery, orthopedics, and urology (e.g., number of shunt revisions, number of urinary tract infections, number and type of equipment used, surgeries performed). All information collected is held in the strictest confidence and will be used only to generate statistical summaries. Following the data abstraction, the patient's medical records will be shredded. The information supplied is treated confidentially as specified by the Confidential Information Protection and Statistical Efficiency Act.