

THE BCH-SBPR: A MULTI-DISCIPLINARY REGISTRY COLLECTING LONGITUDINAL DATA ON PATIENTS WITH SPINA BIFIDA

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Introduction. In the U.S. alone, approximately 1500 infants are born with SB each year. An estimated 166,000 individuals with SB live in the United States.

Background. The BCH-SBPR was established in August 2015 to help increase knowledge about new procedures, surgeries and treatment options, growing up with Spina Bifida, and to guide healthcare practices by prospectively studying a cohort of children born with this condition.

Objective. The objective of this project is to collect comprehensive longitudinal clinical data (demographics, treatments, and outcomes) from a multi- disciplinary clinic on patients with SB.

Design: Prospective longitudinal design. Data collection will occur every six months.

Methods. Study subjects include children whose ages range from birth to 35 years with one of the following six SB diagnoses: Myelomeningocele, Meningocele, Lipoma of Spinal Cord, Fatty Thickened Filum, Split Cord Malformation, and Terminal Myelocystocele will be eligible to participate.

Results. 653 patients were enrolled in this registry. 635 patients were enrolled in this registry. 66 patients were randomly selected to conduct a descriptive analysis. The mean age was 9.7 (7.63 SD). The majority of the patients' age were between 5 and 13 years old (40 %). The female participants (58.3 %) were slightly more than male participants (41.7%). The majority was white (56.7%) and None-Hispanic or Latino. 40% of the patient relaid on public insurance. 70% had an MMC and 30 non-MMC diagnoses. The majority of the patients were geographically located in Massachusetts (63.2.%). Therefore, further analysis of descriptive and inferential statistics will be conducted early August 2017.

Conclusion. This Registry will provide valuable longitudinal clinical data from approximately 700 patients with SB conditions. The collected data will be used for quality improvement and research projects.

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