

## 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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