

National Spina Bifida Patient Registry at Vanderbilt Children's Hospital

- Although spina bifida is the most common permanently disabling birth defect in the United States, long-term medical outcomes are limited, and best treatment throughout the person's lifetime is not well defined. The Spina Bifida Program at Monroe Carell Jr. Children's Hospital at Vanderbilt sees a large population of pediatric spina bifida patients. By contributing our data to the CDC National Spina Bifida Patient Registry (NSBPR) and by using the registry to answer questions about best and most efficient treatment, we hope to improve both health care utilization and outcomes for spina bifida patients.
- Our overall goal is to prevent disease and progressive disability in individuals with spina bifida. Attaining this goal requires multi-disciplinary care because spina bifida affects multiple organ systems. Although providers from multiple disciplines often work together in the spina bifida clinics, clinical research in spina bifida is almost exclusively discipline-specific. Tethered cord syndrome occurs in 10-30% of patients with spina bifida and presents with changes in neurologic, orthopaedic, and/or urologic function. If left untreated, tethered cord syndrome can lead to permanent spinal cord damage. Diagnosis of tethered cord syndrome is based on qualitative assessment by the neurosurgeon. However, urinary symptoms are common, and a patient's initial complaint might be directed to a urologist. The development of a multi-disciplinary assessment tool may facilitate earlier diagnosis.

Specific Aim 1: To develop a multi-disciplinary quantitative risk assessment tool for evaluation of tethered cord.

Specific Aim 2: To identify populations at risk in adolescence (ages 10-19) and young adulthood (ages 20-24) for poor health outcomes.