

## **Public Policy Agenda 112<sup>th</sup> Congress 1<sup>st</sup> Session**

Spina Bifida – a neural tube defect (NTD) – is the nation’s most common permanently disabling birth defect. The Centers for Disease Control and Prevention (CDC) calculates that there are approximately 3,000 NTD births each year, of which an estimated 1,500 are Spina Bifida. Due to the failure of the spine to close completely early in pregnancy, Spina Bifida impacts nearly every organ system and poses significant medical, physical, developmental, educational, and vocational challenges to the people who live with it.

The Spina Bifida Association (SBA) exists to enhance the lives of all individuals and families affected by Spina Bifida. To that end, the SBA respectfully calls upon Congress and the Administration to support increased funding and legislative, regulatory, and programmatic efforts to prevent Spina Bifida, reduce its myriad adverse complications, and improve quality of life for all individuals and families affected by this complex condition.

### **Prevent Spina Bifida and Reduce its Adverse Complications**

More than 65 million American women of child-bearing age are at risk of a Spina Bifida pregnancy; however, adequate daily consumption of folic acid helps reduce the risk of Spina Bifida and other neural tube defects by up to 70 percent. Despite the positive impact of folic acid consumption, recent research has shown that the number of Americans living with all forms of Spina Bifida may be as high as 166,000, which is significantly higher than previous estimates. These individuals need and deserve access to quality, comprehensive care and programs that help reduce and prevent the secondary effects of Spina Bifida and enhance quality of life. **Therefore, SBA calls upon Congress to provide the following allocations in FY 2012:**

- **\$6.25 million for the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities, within the CDC to enhance program activities to fulfill unmet needs.** This level of investment will allow the program to continue its current scope of work, increase its folic acid awareness/Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and sustain the National Spina Bifida Resource Center – all efforts to support daily living activities for individuals affected by Spina Bifida.
- **\$5.126 million for the CDC’s national folic acid education and promotion efforts for the prevention of Spina Bifida and other neural tube defects.** The CDC partners with SBA, and other national organizations to educate all women about the importance of consuming adequate daily levels of folic acid, so they can minimize their risk of a Spina Bifida pregnancy.
- **\$26.342 million to strengthen the CDC’s National Birth Defects Prevention Network, so that our nation can answer critical questions regarding the causes of birth defects and how they can be prevented or reduced.**
- **\$144 million overall funding for the CDC’s National Center on Birth Defects and Developmental Disabilities to increase the nation’s efforts to prevent and address birth defects and developmental disabilities.**

- **\$405 million for the Agency for Healthcare Research and Quality (AHRQ) to enable this important public health agency to engage in activities that improve health care quality.** Additional funding is needed to support AHRQ's efforts to validate quality treatment data measures for the National Spina Bifida Patient Registry, so that information can be gleaned to improve the provision of care given to individuals with Spina Bifida, helping them to live the healthiest and most productive lives possible.
- **\$35 billion (NOTE: pending Coalition for Health Funding recommendation) in funding for the National Institutes of Health (NIH) to support biomedical research.** NIH should expand applied and basic research efforts focused on improving the understanding of the etiology, prevention, cure, and treatment of Spina Bifida and its related conditions, including hydrocephalus (fluid build-up inside the skull), the neurogenic bladder, latex allergies, paralysis, and developmental delay.

**Enhance and Ensure Quality-of-Life for All Individuals Affected by Spina Bifida**

Care of persons with Spina Bifida is complex, involving different organ systems and, correspondingly, different clinical specialists. Thanks to advances in diagnostic equipment and testing, and other medical breakthroughs, people with Spina Bifida are living much longer than patients of previous generations. With this extended lifespan, however, individuals with Spina Bifida are facing new challenges – including unprecedented medical complications associated with aging.

**To address the myriad challenges that people with Spina Bifida face, SBA urges Congress to ensure that all children and adults with Spina Bifida have access to:**

- Appropriate, affordable, quality, comprehensive public and private health insurance coverage. To that end, SBA encourages Congress to reform the nation's health care system, sustain and expand the services and benefits provided under the Medicaid and the State Children's Health Insurance programs, and eliminate all pre-existing condition limitations under both group and individual health insurance.
- Durable/non-durable medical equipment and pharmaceutical drugs through all public and private health plans.
- Comprehensive information to prevent and reduce secondary effects and complications of Spina Bifida and improve quality of life.
- Federal employment, training programs, and related services.
- Health insurance that addresses the special and unique needs of individuals living with birth defects, mobility limitations, and other developmental and physical disabilities; no individuals with Spina Bifida should face pre-existing condition limitation exclusions.

In addition, SBA calls upon the Food and Drug Administration to establish folic acid fortification levels of corn products grown and consumed both domestically and internationally, to ensure that women of child-bearing age benefit from the advantages of folic acid contained in enriched foods.