

**Written Testimony to the House Labor-Health and Human Services-Education
Appropriations Subcommittee
Regarding Fiscal Year 2010 Funding for the National Spina Bifida Program**

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Funding Request Overview

The Spina Bifida Association (SBA) and the Spina Bifida Foundation (SBF) respectfully request that the Subcommittee provide the following allocations in Fiscal Year (FY) 2010 to help improve quality-of-life for people with Spina Bifida:

- \$7 million for the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) to support existing program initiatives and allow for the further development of the National Spina Bifida Patient Registry.
- \$4.818 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects.
- \$25.623 million to strengthen the CDC's National Birth Defects Prevention Network.
- \$77.059 million for the CDC's National Center on Birth Defects and Developmental Disabilities.
- \$405 million for the Agency for Healthcare Research and Quality (AHRQ).
- \$33.349 billion for the National Institutes of Health (NIH) to support biomedical research.

As you may know, a bipartisan group of 21 Representatives have submitted a letter to the Subcommittee in support of a \$7 million FY 2010 allocation for the National Spina Bifida Program; this effort was spearheaded by Representatives Bart Stupak and Chris Smith, co-chairs of the Congressional Spina Bifida Caucus.

Background on Spina Bifida

On behalf of the more than 185,000* individuals and their families who are affected by Spina Bifida – the nation's most common, permanently disabling birth defect - SBA and SBF appreciate the opportunity to submit written testimony for the record regarding FY 2010 funding for the National Spina Bifida Program and other related Spina Bifida initiatives. SBA is a national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. The Spina Bifida Foundation assists SBA in its fundraising and advocacy efforts. SBA and SBF stand ready to work with Members of Congress and other stakeholders to ensure our nation mounts and sustains a comprehensive effort to reduce and prevent suffering from Spina Bifida.

* At the First World Congress on Spina Bifida Research and Care in March 2009 representatives from the CDC reported on new data indicating that there are an estimated 185,000 individuals living with Spina Bifida in the U.S.

Spina Bifida, a neural tube defect, occurs when the spinal cord fails to close properly within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy – as the fetus grows – the spinal cord is exposed to the amniotic fluid, which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild – with little or no noticeable disability – to severe – with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most people with it suffer from a host of physical, psychological, and educational challenges – including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living into adulthood and increasingly into their advanced years. These gains in longevity, principally, are due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our nation and people with Spina Bifida now face new challenges – education, job training, independent living, health care for secondary conditions, and aging concerns, among others. Individuals and families affected by Spina Bifida face many challenges – physical, emotional, and financial. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a national resource that provides them with the support, information, and assistance they need and deserve.

As is discussed below, the daily consumption of 400 micrograms of folic acid by women of childbearing age prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. However, 1,500 babies are still born each year with Spina Bifida, and, as such, with the aging of the Spina Bifida population and a steady number of affected births annually, the nation must take additional steps to ensure that all individuals living with this complex birth defect can live full, healthy, and productive lives.

Cost of Spina Bifida

It is important to note that the lifetime costs associated with a typical case of Spina Bifida – including medical care, special education, therapy services, and loss of earnings – are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare programs. The emotional, financial, and physical toll and costs of Spina Bifida on the individuals and families affected are extraordinary. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save – and improve – lives.

Improving Quality-of-Life through the National Spina Bifida Program

SBA has worked with Members of Congress to help improve our nation's efforts to prevent Spina Bifida and diminish suffering – and enhance quality-of-life – for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. The CDC's National Spina Bifida Program works on two critical levels – to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the individuals affected by Spina Bifida. Moreover, the National Spina Bifida Program works to improve the outlook for a life challenged by this complicated birth defect – principally, identifying valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need.

The National Spina Bifida Program serves as a national center for information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergies, obesity, skin breakdown and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida – and their caregivers – are properly educated and taught what they need to know to maintain the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the 185,000 individuals living with Spina Bifida with the goal being living well with Spina Bifida.

One way to enhance the knowledge base of Spina Bifida, improve quality of care, and save precious resources is to establish a patient registry for Spina Bifida. Plans are underway to create the National Spina Bifida Patient Registry. This registry is intended to determine the best clinical practices and the most cost effective treatment for Spina Bifida, as well as, support the creation of quality measures to improve overall care. It is only through clinical research towards improved care that we can truly save lives, while also realizing a significant cost savings.

In FY 2009, SBA requested \$7 million be allocated to support and expand the National Spina Bifida Program. In the final FY 2009 Omnibus Appropriations Act, Congress provided \$5.468 million for this program, following three years of essentially flat funding. SBA understands that the Congress and the nation face unprecedented budgetary challenges and, as such, appreciates this modest increase. However, the progress being made by the National Spina Bifida Program must be sustained and expanded to ensure that people with Spina Bifida – over the course of their lifespan – have the support and access to quality care they need and deserve. To that end, SBA respectfully urges the Subcommittee to Congress allocate \$7 million in FY 2010 to the

program so it can continue and expand its current scope of work; further develop the National Spina Bifida Patient Registry; and sustain the National Spina Bifida Resource Center. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from – and the costs of – Spina Bifida.

Preventing Spina Bifida

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women of child-bearing age are at-risk of having a child born with Spina Bifida, and each year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in an estimated 1,500 births. As mentioned above, the daily consumption of 400 micrograms of folic acid prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. There are few public health challenges that our nation can tackle and conquer by nearly three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 30 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age – particularly those most at-risk for a Spina Bifida pregnancy – consume adequate amounts of folic acid prior to becoming pregnant.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain a diet rich in folic acid. Since 1968, the CDC has led the nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. This public health success should be celebrated, but still too many women of childbearing age consume inadequate daily amounts of folic acid prior to becoming pregnant, and too many pregnancies are still affected by this devastating birth defect. The nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call – such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBA is the managing agent for the National Council on Folic Acid, a multi-sector partnership reaching more than 100 million people a year with the folic acid message. The goal is to increase awareness of the benefits of folic acid, particularly for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves, or those who have already conceived a baby with Spina Bifida). With additional funding in FY 2010, CDC's folic acid awareness activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide additional funding to CDC to allow for a targeted public health education and awareness focus on at-risk populations (e.g., Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$7 million FY 2010 allocation for the National Spina Bifida Program, SBA urges the Subcommittee to provide \$4.818 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects; \$25.623 million to strengthen the CDC's National Birth Defects Prevention Network; and a total of \$77.059 million for the National Center on Birth Defects and Developmental Disabilities.

Improving Health Care for Individuals with Spina Bifida

As you know, AHRQ's mission is to improve the outcomes and quality of health care, reduce health care costs, improve patient safety, decrease medical errors, and broaden access to essential health services. AHRQ's work is vital to the evaluation of new treatments, which helps ensure that individuals living with Spina Bifida continue to receive state-of-the-art care and interventions. To that end, we request a \$405 million FY 2010 allocation for AHRQ, so it can continue to provide guidance and support to the National Spina Bifida Patient Registry.

Sustain and Seize Spina Bifida Research Opportunities

Our nation has benefited immensely from our past federal investment in biomedical research at the NIH. SBA joins with other in the public health and research community in advocating that NIH receive \$33.349 billion in FY 2010. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the Subcommittee include language in the report accompanying the FY 2010 LHHS appropriations measure:

- Urging the National Institute of Child Health and Human Development (NICHD) to continue to support – and expand – a more comprehensive Spina Bifida research portfolio that focuses on addressing the myriad secondary effects and conditions associated with Spina Bifida;
- Commending the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for its interest in exploring issues related to the neurogenic bladder and to encourage the institute to forge ahead with its work in this important topic area; and
- Encouraging the National Institute of Neurological Diseases and Stroke (NINDS) to continue and expand its research related to the treatment and management of hydrocephalus.

Conclusion

Please know that SBA and SBF stand ready to work with the Subcommittee and other Members of Congress to advance policies and programs that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views regarding FY 2010 funding for programs that will improve the quality-of-life for the 185,000 Americans and their families living with Spina Bifida.