



What Are SBA's Advocacy Priorities?

Spina Bifida affects about 166,000 individuals in the U.S. and over half are adults. It is a birth defect for which there is no cure. It results in a spinal cord injury before a baby is born. We need you to share your story with Members of Congress and ask to:

1. Increase funding for Spina Bifida Program at the NCBDDD at the CDC
2. Tell Congress to Include the Disability Community in COVID-19 Relief Bills

Fund the Spina Bifida Program at the NCBDDD at the CDC

THE ISSUE: The only place in the federal government that is specifically studying this complex condition for children and adults is the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention through the National Spina Bifida Patient Registry and the Spina Bifida Collaborative Care Network.

THE ASK: Support an \$8 million budget for the National Spina Bifida Program at NCBDDD. The program has been level-funded at \$6 million for the past six years. With increased funding we will:

1. Fund research on sudden unexplained death among adults in the Spina Bifida (SB) community
2. Determine the number of people living with SB in the US
3. Develop studies on social determinants of health within the Spina Bifida registry
4. Create a protocol for improving the health of children who have Spina Bifida with hydrocephalus
5. Research barriers to transition to adult care and analyze models for care

STATUS: At last year's budget cycle the House of Representatives passed the increase, however it did not pass in the Senate. With your help, we hope to gain an increase for FY 2021.

Tell Congress to Include the Disability Community in COVID-19 Relief Bills



THE ISSUE: Congress has passed several bills to respond to the coronavirus pandemic – but they have not addressed the **critical needs** of people with disabilities, their families, and the direct support professional workforce.

THE ASK: Ask Members of Congress to pass a bill NOW that addresses the specific and critical needs of people with disabilities, including:

1. Funding for a Medicaid grant program to support access to home and community-based services to limit the risk of people with disabilities being put into institutions and support the workforce. Congress should pass the Coronavirus Relief for Seniors and People with Disabilities Act.
2. Personal protective equipment (PPE) for direct support professionals. This is urgently needed to protect the health and safety of this critical workforce. Direct support professionals must be designated as essential workers so that they can get access to the PPE and medical supplies they need.
3. Paid leave for caregivers. As more people with disabilities lose their usual sources of care, family caregivers are scrambling and need access to paid leave and sick days to help their loved ones. Congress should include all family caregivers in the emergency paid leave provisions.
4. Economic impact payments for all people with disabilities. Tell Congress to pass H.R.6420, the All Dependent Children Count Act, and make sure that adults with disabilities who are claimed as dependents get their \$500 economic credit.