



SPINA BIFIDA
ASSOCIATION

Advocacy Priorities

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What exactly are we asking for?

- Fund the National Spina Bifida Program at the CDC
- Include the Disability Community in COVID-19 Relief Bills

National Spina Bifida Program Funding

- We are asking for \$8 million to fund the National Spina Bifida Program. It has been level-funded at \$6 million for the past six years. With this increased funding we will:
 - ✓ Fund research on sudden unexplained death in the Spina Bifida community
 - ✓ Determine the number of people living with Spina Bifida in the United States
 - ✓ Increase clinic participation in the National Spina Bifida Patient Registry

National Spina Bifida Program Funding

- We are asking for \$8 million to fund the National Spina Bifida Program. It has been level-funded at \$6 million for the past six years. With this increased funding we will:
 - ✓ Develop studies on social determinants of health within the Spina Bifida Registry participants
 - ✓ Create a protocol aimed at improving the health of those with Spina Bifida and Hydrocephalus
 - ✓ Research barriers to transition to adult care and analyze models for care delivery for adults with Spina Bifida

Include the Disability Community in COVID-19 Relief Bills

- We must ask Members of Congress to pass a bill NOW that addresses the specific and critical needs of people with disabilities, including:
 - ✓ Funding for a Medicaid grant program
 - ✓ Personal protective equipment (PPE) for direct support professionals.
 - ✓ Paid leave for caregivers.
 - ✓ Economic impact payments for all people with disabilities.

How do I ask for these things?

- Study a bit
- Find common ground
- Speak their language
- Remember they WANT to hear from you
- Don't assume
- Just tell your story...it's a good one!

Questions?

