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.

https://disabilityadvocacynetwork.org/app/make-a-call?2&engagementId=506895
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?