



Teal on the Hill Advocacy Story Builder

1. Dramatic fact about you or your experience:

2. The problem:
 - Inadequate access to healthcare
 - Sudden unexplained death in adults with Spina Bifida
 - Difficulty transitioning from pediatric to adult care
 - Social barriers (accessibility, income, employment, housing)
 - Issues with durable medical equipment and other coverage
 - Other _____
3. The facts: The National Spina Bifida Program at the Centers for Disease Control focuses their work and research on impacting the issues faced by people living with Spina Bifida by: (choose the items that apply to the problem from question 2 on which you choose to focus)
 - Working to create a protocol aimed at improving the health of those with Spina Bifida and Hydrocephalus
 - Determining the number of people living with Spina Bifida in the United States
 - Funding research on sudden unexplained death in the Spina Bifida community
 - Working to increase clinic participation in the National Spina Bifida Patient Registry
 - Researching barriers to transition to adult care and analyze models for care delivery for adults with Spina Bifida
 - Develop studies on social determinants of health within the Spina Bifida Registry participants
 - Other _____
4. How does the problem impact me?

5. How does the problem impact you? (the congressperson, the community, society)

6. What is my ask? We are asking for \$9 million in FY 22 to fund the National Spina Bifida Program. This is a \$2 million increase over FY 21 and this small increase can make a large impact on people affected by Spina Bifida, including (insert closing sentence on how you will be directly impacted)