



SPINA BIFIDA
ASSOCIATION

A Congress Turned Upside Down



BEFORE COVID-19

- January until early March
- 2020 seen as time for limited legislative activity with most energy focused on election
- Limited agenda focused on appropriations as well as drug pricing and surprise billing

AFTER COVID-19

- Mid March onward
- Lawmakers consumed by COVID-19 response
- Significant legislative activity oriented toward pandemic response, particularly supporting health care providers and economic relief/stimulus
- Coronavirus and response dominate all things Washington

Good News on the Legislative Front

- Congress set to return to Washington on May 4
- FY 2021 Appropriations happening

What are Appropriations?

- Appropriations are annual decisions made by Congress about how the federal government spends some of its money.
- In general, the appropriations process addresses the discretionary portion of the budget (e.g. military spending, research funding, public health programs, etc) but excludes mandatory spending such as Medicare and Social Security, which is spent automatically according to formulas

How is the level of appropriations determined?

- Under current law, after the President submits his budget, the House and Senate Budget Committees craft a budget resolution that sets a total amount of money for the Appropriations Committees to spend
- Once they receive these allocations, the House and Senate Appropriations Committees set allocations to divide total appropriations among 12 subcommittees

What subcommittee is most relevant for Spina Bifida?

- The subcommittee on Labor/Health and Human Services and Education (informally referred to as Labor/H or Labor/HHS) is the subcommittee of most interest to the Spina Bifida community
- This subcommittee funds the Centers for Disease Control and Prevention (CDC) and the National Institutes for Health (NIH)
- Specifically, this subcommittee allocates dollars to the National Center for Birth Defects and Developmental Disabilities which houses the National Spina Bifida Program

Spina Bifida and Appropriations – A Brief History

- Funding for the National Spina Bifida Program has remained the same for the last six years (\$6 million)
- And really when the same dollar amount is provided for six straight years, the truth is that less money is given as there is no accounting for inflation
- Discouraging yes, but at least the program has not experienced cuts as many programs have over the last few years
- And last year we made great strides...

Appropriations – Fiscal Year (FY) 2020

- Good News: For the first time ever, the U.S. House of Representatives appropriated \$8 million to the National Spina Bifida Program
- This big bump was due in part to the excellent advocacy of Spina Bifida community
- Bad News: Sadly, the Senate appropriated only 6 million and the final number remained at that same level

Don't Despair – FY 2021 Happening Now!

- We've made great progress in our quest for additional funding for FY 2021
- We've requested 8 million; money that would be used for registry expansion, staffing and allow for focus on issues like sudden death and sepsis death in our community
- We've met with staff from 25 House and Senate offices, key committee staff and other friends
- We've submitted our appropriations forms (standard operating procedure) laying out our argument for increased dollars
- And this week we have the benefit of your help in the process

Senate & House Outreach

- Some of you will take part in phone meetings with Senate staff
- We have targeted those Senators on the Senate Labor/HHS Appropriations Subcommittee
- Reach out to your Member of Congress in the U.S. House of Representatives

We'll share how to reach out to your members of Congress later today.

Challenges to Advocating this Year

- Engaging on topics outside of the coronavirus response
- Threading the needle between focusing on our important priorities while being mindful of the bigger picture
- Making appropriate connections between Spina Bifida/CDC and COVID-19 concerns
- Recognizing challenges members and staff are facing

The Ask – Appropriations

- Please support an appropriation of 8 million dollars to fund the National Spina Bifida Program at the CDC for FY 2021
- This money will go a long way toward expanding the National Spina Bifida Registry, securing much needed staff and allowing for time and resources necessary to investigate many issues including the growing incidence of sudden death and sepsis death in our population

Looking Ahead

- Hopeful to have Congress turned right side up
- Hopeful that Appropriations bills will be voted on and we see an increase in funding
- Hopeful that other key pieces of legislation move toward passage

