

Advocacy Accomplishments

November 2021

Childhood cancer advocates are making a big impact on Capitol Hill

- In three years, Congress passed two major pieces of childhood cancer legislation, and the National Cancer Institute created a new childhood cancer research initiative.
- The RACE for Children Act
 - In July 2017, Congress enacted the RACE for Children Act, changing the landscape of pediatric oncology clinical trials.
 - The RACE for Children Act requires companies to test adult cancer drugs in children if there is a substantially relevant molecular target.
- The Childhood Cancer STAR Act
 - In June 2018, Congress unanimously passed the Childhood Cancer STAR Act, the most comprehensive childhood cancer legislation ever considered by Congress.
 - The Childhood Cancer STAR Act focuses on creating and maintaining biorepositories at the National Cancer Institute, conducting nationwide childhood cancer surveillance programs, and developing best practices for long-term survivorship care.
 - STAR also authorizes \$30 million in new federal funding each year for five years.
- The Childhood Cancer Data Initiative (CCDI)
 - CCDI stemmed from President Trump's commitment in the 2019 State of the Union to fund \$500 million in childhood cancer research over 10 years.
 - The Director of the National Cancer Institute credited the overwhelming bipartisan support for the STAR Act with motivating the Administration to pursue CCDI.
 - CCDI focuses on the data needs for collecting, analyzing, and sharing data to address childhood cancer research.

What has the St. Baldrick's Foundation done?

- **We developed the Childhood Cancer STAR Act and crafted and implemented the strategy to get this bill signed into law:** While many people and organizations in the childhood cancer community contributed ideas, resources, and manpower to get the STAR Act across the finish line, St. Baldrick's compiled and synthesized the policy

ideas into one comprehensive legislative package, established relationships with key childhood cancer congressional champions, led the effort to build support for STAR on Capitol Hill, and negotiated final legislative language with congressional leadership.

- **We secured an historic federal funding increases for childhood cancer research for multiple years:** Just a few months after the Childhood Cancer STAR Act was signed into law in 2018, Congress provided \$30 million to fund the programs created by the STAR Act for its first year. At the end of 2019, Congress again provided \$30 million to implement the Childhood Cancer STAR Act for the second consecutive year and also provided \$50 million for the first year of the Childhood Cancer Data Initiative (CCDI). Combined, this \$80 million increase was the largest single-year federal funding increase for childhood cancer research in recent history. More excitingly, Congress again provided \$80 million in 2020 for childhood cancer research - \$30 million to implement the STAR Act for a third year and \$50 million to implement CCDI for a second year. St. Baldrick's was critical in making this happen by leading the childhood cancer community's advocacy strategy and working directly with policymakers to make the case for fully funding both programs.
- **We lead the Alliance for Childhood Cancer:** St. Baldrick's has co-chaired the Alliance for Childhood Cancer for more than 8 years. The Alliance is the voice of the childhood cancer community on Capitol Hill, and as co-chair, we set the policy agenda and lead the strategy to achieve those policy goals.