

Congress of the United States
Washington, DC 20515

March 15, 2018

The Honorable Tom Cole
Chairman
Subcommittee on Labor, HHS, and Education
U.S. House Committee on Appropriations
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS, and Education
U.S. House Committee on Appropriations
2413 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

As co-chairs of the Congressional Childhood Cancer Caucus, we commend your efforts in prior years to help the mission of families, researchers, and advocates affected by pediatric cancer. As the Committee considers the fiscal year (FY) 2019 Labor, Health & Human Services, Education and Related Agencies Appropriations bill, we ask you to review our funding priorities as well as specific requests for report language related to childhood cancer.

NIH and NCI Funding

We support robust funding for the National Institutes of Health (NIH) and the National Cancer Institute (NCI) and emphasize the importance of a greater focus on pediatric cancer research.

Childhood Cancer Funding

Within these funds, we are committed to working with Congress and the National Institutes of Health to ensure that childhood cancer becomes a higher priority. Each year in the U.S. an estimated 15,780 children are diagnosed with cancer. Approximately 1 in 285 children in the U.S. are diagnosed with cancer before their 20th birthday. Annually there are more than 300,000 children diagnosed with cancer worldwide. Unfortunately, cancer remains the most common cause of death by disease for children in America.

We have made significant advances to develop better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for too many children there is no available cure. Two-thirds of children treated for childhood cancer will suffer long-term effects from treatment including loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

To ensure that childhood cancer is a top priority for the NIH, we respectfully request that the Committee include the following report language in the FY 2019 Labor, Health & Human Services, Education and Related Agencies Appropriations bill.

National Cancer Institute: Children's Oncology Group

The Committee continues to support the important work of the Children's Oncology Group and we encourage the NCI to continue to maintain their important role in drug development. Pediatric cancer patients and their families rely heavily on the trials run by the Children's Oncology Group. The vast majority of childhood cancer patients are enrolled in trials conducted by the Children's Oncology Group and advances in treatment are dependent on their ability to conduct trials quickly and enroll as many pediatric patients as possible.

National Cancer Institute: Office of Cancer Survivorship

The Committee recognizes that the Office of Cancer Survivorship (OCS) is important for the leadership it provides in research on a wide range of cancer survivorship topics. However, the Committee recognizes that the needs of childhood cancer survivors are unique. By 2020, there will be at least 500,000 childhood cancer survivors in the U.S. Two-thirds of childhood cancer survivors suffer from at least one health problem – late effect – caused from their treatment. The Committee urges the OCS to provide a special focus in the area of childhood cancer survivorship. We encourage new NCI research requests regarding children surviving after treatment on emerging targeted and immunotherapies as well as a standard of care. The Office should work quickly to analyze secondary prevention strategies that go beyond the standard and routine therapies of diet, exercise and tobacco avoidance and focus on specific needs for childhood cancer survivors such as psycho-social treatments.

National Cancer Institute/Food and Drug Administration: Collaboration Between Agencies regarding Pediatric Investigation of Appropriate New Drugs

The Committee recognizes that Title V of FDARA amended PREA to support the early evaluation of potentially effective drugs by requiring pediatric investigation of appropriate new drugs intended for adults with cancer. The law directs the FDA, in collaboration with the NCI, to establish, publish, and regularly update a list of molecular targets considered on the basis of data the Agency determines to be adequate, to be substantially relevant to the growth or progression of pediatric cancers, and that may trigger the requirement for pediatric investigations. The Committee encourages the FDA and the NCI to continue to collaborate with the patient community, providers, and manufactures, and conduct a transparent and inclusive process to implement FDARA in a timely manner.

Thank you for your consideration and continued support in the fight against childhood cancer.


Sincerely,

A handwritten signature in blue ink that reads "Michael T. McCaul". The signature is fluid and cursive, with the first name being the most prominent.

Michael T. McCaul (R-TX-10)

A handwritten signature in blue ink that reads "Jackie Speier". The signature is cursive, with the first name being the most prominent.

Jackie Speier (D-CA-14)

A handwritten signature in blue ink that reads "Mike Kelly". The signature is cursive, with the first name being the most prominent.

Mike Kelly (R-PA-03)

A handwritten signature in blue ink that reads "G. K. Butterfield". The signature is cursive, with the first name being the most prominent.

G. K. Butterfield (D-NC-01)