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The American Society of
Pediatric Hematology/Oncology

ASPHO 2022 Legislative Priorities

The American Society of Pediatric Hematology/Oncology (ASPHO) is a multidisciplinary organization representing more than 2,000 members dedicated to setting, advocating for, and achieving the highest standards of care for children, adolescents and young adults with cancer or blood disorders and their families.

Advocacy for Cancer Programs

Support the Childhood Cancer STAR Act (P.L. 115-180): The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act — the most comprehensive childhood cancer bill ever taken up by Congress — was signed into law on June 5, 2018. The law expands opportunities for childhood cancer research, improves efforts to identify and track childhood cancer incidences and enhances the quality of life for childhood cancer survivors. Specifically:

- **ASPHO urges Congress to appropriate $30 million in Fiscal Year (FY) 2023 to fully fund the Childhood Cancer STAR Act.**
- **Please cosponsor H.R. 7630/S. 4120, the Childhood Cancer STAR Reauthorization Act, to allow STAR Act programs to continue for the next five years.**

Continued funding for the Childhood Cancer Data Initiative (CCDI): The CCDI is a dedicated federal investment of $50 million proposed to be extended annually for the next 10 years, with the first year of the initiative funded in December 2019. These funds will allow the National Cancer Institute to establish more efficient ways to share and use childhood cancer data. **ASPHO urges Congress to appropriate $50 million in FY 2023 to continue the CCDI.**

Increase funding for the Peer Reviewed Cancer Research Program and Support the Inclusion of Childhood Cancer Topic Areas: Childhood cancer affects families regardless of geographical location, occupation, or income, and impacts military families without prejudice. Cancer is tragically the leading disease killer of children, adolescents and young adults in the United States, with brain tumors being the leading cause of cancer death in children ages 0–19. The Peer Reviewed Cancer Research Program (PRCRP) at the Department of Defense funds vital research to enhance our understanding of deadly tumors and more broadly cancer in children, adolescents, and young adults so that treatments can be more effective and less harmful to children. **ASPHO urges Congress to extend PRCRP eligibility in FY 2023 to pediatric brain tumors, brain cancer neuroblastoma, as well as cancer in children, adolescents, and young adults. We urge Congress to support $130 million in funding for the program in FY 2023, a $15 million increase.**

Continued funding increases for the NIH and the NCI: We join with fellow leading national cancer organizations in requesting the following funding levels for medical research:

- **$4.089 billion increase for the National Institutes of Health (NIH) for a total of $49.048 billion.**
- **$853 billion increase for the National Cancer Institute (NCI) for a total of $7.766 billion.**

Advocacy for SCD Programs

Increase funding for the CDC Sickle Cell Data Collection Program: Sickle cell disease (SCD) is an inherited blood disorder that affects an estimated 100,000 Americans, with the burden falling predominantly on people of color, particularly individuals that are Black or African American and Hispanic American. Individuals with the disease produce abnormal hemoglobin which causes severe pain and can lead to strokes, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death. The Centers for Disease Control and Prevention's (CDC) Sickle Cell

Data Collection Program supports states in the collection and analysis of population-based surveillance data to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. **ASPHO urges Congress to provide $25 million in dedicated funding for the CDC Sickle Cell Data Collection Program in FY 2023.**

Continued funding for the HRSA Sickle Cell Disease Treatment Demonstration Program: This program at the Health Resources and Services Administration (HRSA) aims to increase access for individuals with SCD to quality, coordinated, comprehensive care by: 1) increasing the number of clinicians or health professionals knowledgeable about the care of SCD, 2) improving the quality of care provided to individuals with SCD, and 3) improving care coordination with other providers. This includes supporting a regional SCD infrastructure that includes components necessary for providing comprehensive services to individuals with SCD and their families. **ASPHO urges Congress to appropriate $7.205 million in FY 2023 to continue the HRSA Sickle Cell Disease Treatment Demonstration Program.**

Support the SCDCCA: The Sickle Cell Disease Comprehensive Care Act (SCDCCA) directs the Centers for Medicare and Medicaid Services (CMS) to create a demonstration program in up to 10 states to improve access to comprehensive, high-quality, outpatient care, including recommended clinical, mental health, ancillary, and support services, for individuals enrolled in Medicaid with SCD. **Please cosponsor H.R. 6216/S. 3389 to support the SCDCCA and access to SCD care.**

Funding for the ACA – CAPs

Support funding for CAPs: Established under the Affordable Care Act (ACA), Consumer Assistance Programs (CAPs) help consumers manage problems with their health insurance to increase insurance coverage and expand access to care. CAPs assist consumers in appealing, resolving, and tracking insurance disputes including surprise medical bills and claims denials. In addition, they help patients and consumers understand and navigate narrow networks, identify sources of charity care, and resolve issues related to advance premium tax credits. All CAPs help state residents who have private health insurance, and many CAPs also help state residents enrolled in public coverage. **ASPHO urges Congress to restore robust funding to CAPs in FY 2023.**

Advocacy for Physicians, Patients, and PHO

Support funding for PSLRP: The Pediatric Subspecialty Loan Repayment Program (PSLRP) received first-time funding of $5 million in FY 2022. This was a significant victory for the pediatric subspecialty and patient advocacy community. Additional funding of $30 million for PSLRP in FY 2023 is being requested to expand the program’s reach once HRSA completes implementation. This will allow HRSA to ensure more communities have access to subspecialty and child health care by addressing underlying economic factors that are driving subspecialty shortages so children can access the care they need. **Please support PSLRP funding in FY 2023.**

Cosponsor the Gabriella Miller Kids First Research Act 2.0 (H.R. 623/S. 1521): The Gabriella Miller Kids First Pediatric Research Program helps researchers uncover new insights into the biology of childhood cancer and structural birth defects, including emerging scientific opportunities, rising public health challenges, and knowledge gaps. Since the program was enacted, Congress has provided $75 million to childhood cancer and disease research, with funding set to expire in FY 2023. The Gabriella Miller Kids First Research Act 2.0 would redirect penalties levied against pharmaceutical manufacturers by the Securities and Exchange Commission for violating the Foreign Corrupt Practice Act towards the Kids First Pediatric Research Program at the NIH. With this legislation, penalties from pharmaceutical companies that break the law would be channeled directly to critical pediatric medical research. **ASPHO requests that your office cosponsors H.R. 623/S. 1521, the Gabriella Miller Kids First Research Act 2.0.**

Cosponsor the Research Investment to Spark the Economy (RISE) Act (H.R. 869/S. 289): Children with cancer rely on university-based laboratories and national laboratories to conduct vital research. The COVID-19 pandemic has caused severe disruptions to federally funded research, including pediatric cancer research and clinical trial enrollment. Due to federal guidelines adherence, many laboratories have been forced to minimize operations beyond “essential” work, delay research already underway, and postpone planned projects. These disturbances have created additional expenses which require supplemental funding to offset. The RISE Act provides $25 billion in needed relief to support independent research institutions, public laboratories, and universities throughout the country as well as provide needed regulatory flexibility so they can continue their work, including $10 billion for the NIH. **Please cosponsor H.R. 869/S. 289, the RISE Act, to stop further damage caused by the pandemic and allow our nation’s biomedical research cohort to get back to finding treatments and cures for children with cancer**.