

Childhood Cancer STAR Act Implementation

2022 CAC2 Annual Summit

Introductions

- NCI's Office of Advocacy Relations (OAR)
- Work with the pediatric advocacy community
- Collaborations with NCI's Office of Government and Congressional Relations (OGCR)

Overview



Childhood Cancer
STAR ACT
Survivorship Treatment Access and Research

- Bipartisan
- Introduced in 2017
- Signed into law in 2018

Co-Lead Sponsors

Senate



Sen. Jack Reed (D-RI)



Sen. Shelly Moore Capito (R-WV)



Sen. Chris Van Hollen (D-MD)



Sen. Johnny Isakson (R-GA)

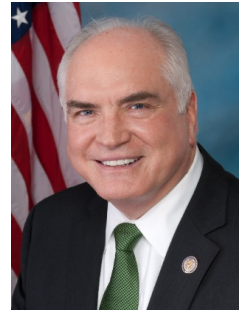
House



Rep. Michael McCaul (R-TX)



Rep. Jackie Speier (D-CA)



Rep. Mike Kelly (R-PA)



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

Overview

- Sec. 101. Children's cancer **biorepositories and biospecimen research**
- Sec. 111. Inclusion of at least one **pediatric oncologist** on the National Cancer Advisory Board
- Sec. 112. Sense of Congress regarding **pediatric expertise** at the National Cancer Institute
- Sec. 121. **Reporting** on childhood cancer research projects
- Sec. 202. Grants to improve care for **pediatric cancer survivors**
- Sec. 203. **Best practices** in survivorship care

Biobanking Progress (Sec. 101)

- **FY 2019:** May 2019 Biobanking Meeting, and immediate enhancements to COG Biobank
- **FY 2020:** New Biobanking Projects via supplement awards to COG and CCSS
- **FY 2021 and FY 2022:** Continuation of supplements to COG, including for tumor tissue collection at relapse and a partnership between COG Rare and Underrepresented Tissue Bank and CCDI Molecular Characterization Initiative

Childhood Cancer Data Initiative



STAR Act Research Efforts



STAR Act biobanking efforts include the *COG Rare Tumor Populations Biobanking Project* – working in partnership with the CCDI Molecular Characterization Initiative (MCI) to support specimen collection

Pediatric Oncology Expertise at NCI (Sec. 111 and Sec. 112)

- **National Cancer Advisory Board** (NCAB: Dr. Andrea Hayes-Jordan, UNC)
- **Board of Scientific Advisors** (BSA: Dr. Mary Beckerle, Huntsman; Drs. Les Robison and Martine Roussel, St. Jude's; Dr. Kevin Shannon, UCSF)
- **Clinical and Translational Research Advisory Committee** (CTAC: Dr. Smita Bhatia, UAB; Dr. Anne-Marie Lnagevin, UT San Antonio)
- **Board of Scientific Counselors** (BSC: Dr. Paul Spearman, Cincinnati Children's; Dr. Gail Tomlinson, UT San Antonio)
- **National Council of Research Advocates** (NCRA: Victoria Buenger, CAC 2, Texas A&M))
- **Frederick National Laboratory Advisory Committee** (FNLAC: Dr. Catherine Bollard, Children's National; Dr. Nilsa Ramirez, Nationwide Children's & CPG Biobank; Dr. Cheryl Willman, Mayo Clinic)
- **National Clinical Trials Network (NCTN) Steering Committees:** More than 40 subject matter experts with pediatric expertise serve across three relevant steering committees (Pediatric and Adolescent Solid Tumors, Brain Malignancies, Pediatric Leukemia and Lymphoma), including a patient advocate serving on each committee

Childhood Cancer Reporting (Sec. 121)

- NIH Pediatric Research Initiative Report to Congress
- NIH Triennial Report
- NCI research and portfolio updates via cancer.gov

Pediatric Survivorship Grants (Sec. 202)

- Childhood and AYA cancer survivorship research continue to be supported through requests for applications
- New initiatives through two funding announcements, with 17 awards issued from FY 2020 – 2021
- NCI supported AHRQ in developing a technical brief focused on innovative models of care, with an emphasis on adult survivors of childhood cancer

Pediatric Survivorship Grants (Sec. 202)

- Awards have covered a variety of issues affecting childhood and AYA survivors
- Many emphasize interventions for communities facing increased disparities
- Others investigate the utility of different technologies to deliver survivorship care

AHRQ Evidence Reports (Sec. 203)

- Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs (in progress)
- Models of Care That Include Primary Care for Adult Survivors of Childhood Cancer
- Disparities and Barriers for Pediatric Cancer Survivorship Care

Progress Recap

- New biospecimen research projects
- New efforts to support childhood and AYA cancer survivorship research
- Support for AHRQ's report on innovative models of care
- Leveraging pediatric expertise across NCI advisory groups and committees
- Formal and informal reporting on childhood cancer research activities

What about the Childhood Cancer STAR Reauthorization Act?

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Sen. Shelly Moore Capito (R-WV)



Sen. Chris Van Hollen (D-MD)



Sen. Lisa Murkowski (R-AK)

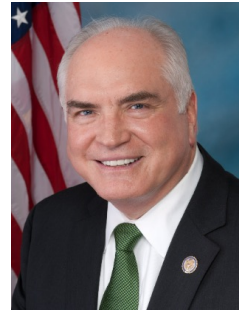
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Thank you!



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