

**New York State - 2024 Joint Legislative Budget Hearing: Health Committee
Funding for Adolescent and Young Adult Cancer
Submitted by Lauren Spiker, Executive Director
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Summary Statement

The needs of adolescents and young adults (AYAs) with cancer have long been underrecognized and underserved. New data indicate an alarming increase in incidence for this population which has serious medical, societal, and economic implications for New York State. Funding is necessary to develop a comprehensive and coordinated delivery-of-care system to mitigate the impact of this serious threat to the population health and wellbeing of New York residents.

Background

Approximately 90,000 adolescents and young adults (AYAs), aged 15-39, are diagnosed with cancer each year in the United States. Over 5,000 of these young people reside in New York State. Caught in “the great divide” between pediatric and adult medicine, this segment of cancer patients experiences a serious gap in age-appropriate, coordinated services and support. No longer children but often, not yet fully independent, self-supporting adults, AYAs have unique challenges which continue to be inadequately addressed, compounding the devastating impact of cancer. Consequently, this vulnerable age group has seen comparatively little improvement in survival relative to younger and older cancer patients, and are at high risk for recurrence and secondary cancers. Additionally, they suffer from complicated, and often life-long, treatment-related late effects, emotional and psychological distress, social isolation, diminished education and career opportunities, and serious financial hardship.

In the 53 years since the National Cancer Act of 1971 was enacted, enormous effort and financial resources have been directed to childhood cancer research, accounting for the dramatic improvement in survival for children. AYAs, however, have been relegated to what’s been referred to as “no man’s land”, despite the fact that three times as many young people are diagnosed in the second fifteen years of their life, as compared to the first fifteen. Statistics from the New York State Cancer registry bear this out. In the last 5 years, 641 children, aged 0-14, were diagnosed per year, on average, in New York State. In the same period, 1,960 young people living in New York, between the ages of 15-29, heard the words, “You have cancer.”

Problem

The incidence of cancer in young people has been growing at an alarming rate over the last ten years and, as reported in a recent 2023 study, cancer in young adults, aged 30-39, is growing by the largest percentage, nearly 20%. The increasing cancer burden among young adolescents and young adults, referred to as the “early-onset cancer epidemic” in a 2022 report, caused the National Cancer Institute to consider this issue a research priority. Projections reported in a 2023 study indicated that, globally, the incidence and deaths of early-onset cancer would increase by 31% and 21% in 2030, respectively.

While AYA cancer mortality rates in the United States have fallen, on average, about .9% over the last ten years, and 5-year survival for many AYA cancers is improving, AYA survivors are at a much higher relative risk of secondary malignancies as compared to younger or older cancer survivors.

This global trend has important medical, societal, and economic implications to the health of New York State's young people and its overall population wellbeing. In New York State alone, over 500 young people between the ages of 15-39 die each year from this dreaded disease, leaving 5,000 future community leaders and contributors with life-long, and complex, cancer-related challenges. The impact of this growing problem will result in even further diminished capacity and lost potential of young talent, stressed family, healthcare, and social services systems, weakened community health and vibrancy, and overall rising costs.

Funding Need

Improving outcomes and quality of life for adolescents and young adults with cancer must be a funding priority for New York State. The needs of this under-represented group who are our future, must be thoroughly identified, thoughtfully analyzed, and diligently attended to across a broad spectrum of disciplines – medical, social, financial, educational, and economic.

The challenges facing this population are complex as cancer interrupts many normal, and important developmental milestones – determining self-identity, solidifying personal goals and aspirations, attending school, starting careers, family planning, achieving financial stability. Managing the transition from pediatric care to adult medical models is hampered by siloed hospital systems, ineffective continuity-of-care planning, and providers uneducated about the challenges facing this 'in-between' group of cancer patients and survivors. In the public sector, far less is understood about how to help this group navigate life after cancer. Contrary to some life challenges, cancer is never really over for AYAs. Survivorship comes at a high cost, a cost, ironically, that survivors will bear for many decades with no clear guidance or support.

A starting point to mitigate this growing problem is development of a comprehensive and coordinated delivery-of-care system through which adolescents and young adults with cancer can access support designed to meet their myriad and complex challenges. Such a system, once piloted and tested, would be scalable across New York State, and ultimately nationwide.

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