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AACI Commentary

Finding a Path Forward Through Partnership, Persistence, and Purpose

By Danielle D. Leach, MPA

Danielle D. Leach, MPA, is principal of DDLeach Consulting.

Commentary Overview

- In this moment, AACI cancer centers have a unique opportunity to contribute to the future of pediatric/Adolescent and Young Adult (AYA) cancer research, policy, survivorship, and innovation.
- Recent executive actions and agency initiatives reflect a growing recognition that pediatric/AYA cancers require distinct strategies, sustained investment, and optimization of technologies where possible.
- Cancer centers can help create a path forward by supporting cross-age clinical trials, sharing regulatory and data infrastructure, improving access for AYA patients, and amplifying patient voices.

These are undeniably challenging times in health care. Yet, like the cancer patients and families we serve every day, the cancer community has never defined itself by obstacles. Instead, we persist, adapt, and find paths forward by staying anchored to a shared mission: creating cures and improving quality of life.

While most AACI member cancer centers do not directly provide pediatric and adolescent care, their leadership, research expertise, infrastructure, and convening power remain essential partners in improving outcomes. In this moment, cancer centers have a unique opportunity through collaboration and strategic engagement to contribute to the future of pediatric/Adolescent and Young Adult (AYA) cancer research, policy, survivorship, and innovation.

A Commitment Shaped by Personal Experience and Professional Responsibility

My commitment to advancing pediatric/AYA cancer cures and quality of life is shaped by both personal experience and professional responsibility, and by a firm belief that progress is possible, when partnership, persistence, and purpose align.

My sister was diagnosed with rhabdomyosarcoma as a young teenager and is now a survivor – living proof that research and innovation save lives. Years later, my son, Mason, was diagnosed with medulloblastoma at age three. Living through his diagnosis and treatment, and ultimately through his death, profoundly deepened my understanding of what families endure and what they need most: timely access to expert care, clear communication, and confidence that the system is working urgently and effectively on their behalf.

Professionally, my work has focused on advancing cancer research and policy, especially pediatric/AYA cancer, through patient advocacy, coalition building, patient engagement and government relations. I have seen how collaboration, particularly between research institutions, advocacy organizations, industry and policymakers, can translate into meaningful progress. Over the past decade, sustained advocacy has helped advance multiple pediatric/AYA cancer legislative and funding efforts, strengthening research investment, improving childhood cancer data collection, and elevating pediatric cancer as a national priority. Each success reflects a community unwilling to accept the status quo.

Still, significant gaps remain. No amount of funding will ever be enough until every child survives and thrives. Access to highly specialized pediatric oncology care remains uneven, often requiring families to travel long distances and navigate complex insurance and Medicaid policies. Survivors frequently struggle to access coordinated long-term follow-up care that addresses late effects of treatment and supports lifelong health.

Driving Progress at the Intersection of Policy, Data, and Innovation

Current legislative efforts discussed during a recent AACI Cancer Center Directors Town Hall meeting underscore both the challenge and the opportunity. Sustained, robust funding for medical research remains a top priority for our community and we collaborate with the larger cancer community on these efforts. Two of these priorities are the **Mikaela Naylon Give Kids a Chance Act** and **Accelerating Kids' Access to Care Act**. The Mikaela Naylon Give Kids a Chance Act seeks to expand access to innovative therapies for children with rare and aggressive cancers by ensuring pediatric relevance is considered earlier in the drug development process. This legislation seeks to expand access to targeted and combination therapies for children with aggressive cancers and reduces regulatory loopholes that allow pediatric studies to be delayed or avoided. The Accelerating Kids' Access to Care Act acknowledges the reality that children may need to receive care outside their home state and proposes a practical solution to reduce Medicaid enrollment barriers for specialized providers.

Recent executive actions and agency initiatives reflect a growing recognition that pediatric/AYA cancers require distinct strategies, sustained investment, and optimization of technologies where possible. The White House Executive Order, **Unlocking Cures for Pediatric Cancer With Artificial Intelligence**, emphasizes artificial intelligence (AI), data sharing, and cross-agency coordination, and calls for a whole-of-government approach to unlocking cures and improving outcomes for children with cancer. The executive order reinforces the importance of modern data infrastructure through initiatives such as the **Childhood Cancer Data Initiative (CCDI)** and explicitly recognizes AI as a tool to accelerate discovery, improve diagnostics, and enable more precise, equitable care.

In addition, the Advanced Research Projects Agency for Health (ARPA-H) announced the **Pediatric Cancer eXpansion (PCX)** effort, a $50 million investment to build a national data and knowledge exchange network connecting pediatric hospitals and care centers, beginning with pediatric brain cancer. PCX will translate years of pediatric cancer research into faster, real-world impact by connecting hospitals through a secure, interoperable data network. By enabling real-time access to clinical, imaging, and genomic data – and beyond, PCX aims to reduce diagnostic delays and support more precise, timely care. Aligning PCX and CCDI with the **Children's Oncology Group (COG)** leverages proven clinical trial infrastructure, ensuring innovation will be scalable, evidence based, and embedded in everyday pediatric oncology care, ultimately accelerating cures and improving outcomes nationwide.

Adult cancer centers can strengthen this ecosystem through intentional collaboration: supporting cross-age clinical trials, sharing regulatory and data infrastructure, and improving access for adolescent and young adult patients who often fall between pediatric and adult systems to best optimize cures. As cancer research increasingly focuses on molecular drivers rather than age alone, increased collaboration between adult centers and COG institutions is not only beneficial, but necessary. Together, the executive order, CCDI, and PCX offer a glimpse of what is possible when policy, data, and innovation converge. At a time when health care systems face extraordinary pressure, these efforts provide cautious but credible hope—and a pathway forward—for advancing pediatric/AYA cancer research and improving outcomes for children and survivors alike.

Survivorship illustrates why strategic care and research partnerships across the lifespan matter. Today, more than 500,000 childhood cancer survivors live in the United States, many facing elevated risks of secondary cancers, cardiovascular disease, endocrine disorders, and cognitive and psychosocial challenges.

Adult cancer centers are often the primary point of care for survivors once they age out of the pediatric system. Transition of care models, AI-enabled risk stratification, shared survivorship care plans, and interoperable data systems can help translate decades of pediatric/AYA cancer research into lifelong quality of life and care.

In this environment, cancer center leaders can make a meaningful impact by focusing on three strategic actions:

1. Engage with federal innovation initiatives, including CCDI and PCX, by contributing expertise, infrastructure, and insights to improve cancer care throughout their lifetime
2. Collaborate with Children's Oncology Group institutions to strengthen pediatric and AYA clinical research, survivorship science, professional training, care transition and navigation, advocacy, and policy alignment
3. Partner with patient advocacy organizations to ensure pediatric/AYA cancer lived experience informs strategic initiatives, research priorities, policy engagement, and long-term outcomes

Moving Forward – Even When the Path is Uncertain

The pediatric/AYA cancer community understands adversity. Children and families show us every day what resilience looks like – how to move forward even when the path is uncertain. That same resilience must inspire us to engage where we can make a difference today.

By leaning into collaboration, aligning with federal innovation and AI-enabled research, and amplifying patient voices, cancer centers can help inform a credible path forward – one that delivers progress, access, and hope for children, adolescents, and young adults with cancer, and for survivors who seek to survive and thrive.

Our Mission

The Association of American Cancer Institutes (AACI) represents over 100 premier academic and freestanding cancer centers in the United States and Canada. AACI is accelerating progress against cancer by enhancing the impact of academic cancer centers and promoting cancer health equity.

About AACI *Commentary*

To promote the work of its members, AACI publishes *Commentary*, a monthly editorial series focusing on major issues of common interest to North American cancer centers, authored by cancer center leaders and subject matter experts.

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