CANCER NATION

POLICY ROUNDTABLE EXECUTIVE SUMMARY

FALL 2025

WeAreCancerNation.org

CANCER NATION POLICY ROUNDTABLE

November 5, 2025 | Washington, DC

Since 1986, Cancer Nation has been a trusted source in the cancer community and a leading voice in the field of cancer survivorship. For more than 20 years, Cancer Nation has hosted twice-yearly policy roundtables, convening diverse stakeholders to discuss pressing cancer policy issues.

Cancer Nation convened another successful roundtable on November 5, 2025, hosting a compelling series of panels and guest speakers discussing critical issues in quality cancer survivorship care.

Keynote Address: Cancer Policy Update

Scott Gottlieb, MD
Former Commissioner, U.S. Food and Drug Administration

In his keynote address, former U.S. Food and Drug Administration Commissioner Dr. Scott Gottlieb reflected on the scientific, regulatory, and institutional foundations that have enabled transformative cancer innovations, while warning that many of those foundations are now under significant strain. Drawing on his forthcoming book on the forty-year development of chimeric antigen receptor T-cell therapy, Gottlieb highlighted that breakthrough cancer treatments are rarely the result of singular discoveries, but instead emerge from decades of incremental, publicly supported research, sustained federal investment, and close collaboration between academia, industry, and regulators.

He emphasized the central role of physician-scientists and long-term funding commitments in translating scientific insights into lifesaving therapies. Gottlieb expressed deep concern about the erosion of federal public health institutions, particularly the Food and Drug Administration, citing the loss of experienced career staff, politicization of agency leadership, and weakened regulatory processes. He argued that strong career leadership within federal agencies is essential for effective policymaking, implementation, and scientific integrity, warning that top-down, politically driven approaches produce superficial policies that lack durability. He also discussed the risks of replacing evidence-based regulatory processes with narrative-driven decision-making, using recent food policy actions as an example of announcements outpacing enforceable regulation.

The keynote underscored that diminished institutional capacity has real consequences for patients, including delayed approvals, reduced access to innovation, and widening inequities, especially for those relying on Medicaid or living in rural or underserved communities.

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Gottlieb cautioned that rebuilding federal scientific capacity will take years, if not decades, and urged policymakers to prioritize oversight, sustained investment, and protection of career expertise. As he stated, **"The degradation of our public health institutions is generational and rebuilding that capacity will take a very long time."**

Key Takeaways

- Preserve career leadership and scientific independence at federal health agencies. Effective health policy depends on experienced career leaders who can implement durable, evidence-based regulation. Politicization and workforce attrition weaken regulatory capacity, slow innovation, and undermine public trust.

- Long-term federal investment is essential to medical innovation. Breakthrough therapies, including chimeric antigen receptor T-cell treatments, are the result of decades of sustained public research funding and stable regulatory infrastructure. Budget uncertainty and workforce losses threaten future cures and U.S. scientific leadership.

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Survivor Perspective

Tom Warren, Head and Neck Cancer Survivor

Tom Warren's survivor perspective grounded the policy roundtable in the lived realities of cancer diagnosis, treatment, and survivorship, highlighting gaps in communication, long-term care, and patient support that policymakers must address. Diagnosed with angiosarcoma in late 2018, Warren described undergoing aggressive, lifesaving treatment, including extensive surgery, chemotherapy, and proton radiation; that resulted in lasting physical, neurological, and professional consequences.

While his care team acted decisively to save his life, Warren emphasized that patients are often told the truth about treatment without being fully prepared for the long-term and permanent effects, such as chronic pain, neuropathy, disfigurement, and loss of employment and identity. He underscored the importance of whole-person care, survivorship planning, and transparent communication about long-term outcomes so patients can make informed decisions and prepare for life after treatment. Warren also highlighted the critical role of self-advocacy and access to information, noting that not all patients have the resources or support to navigate complex systems alone. As he stated, **"I would not have changed my treatment plan, but I wish I had known the whole truth."**

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Medicaid: What's Next After the One Big Beautiful Bill Act?

- Catherine Finley, Partner, Thorn Run Partners, Modern Medicaid Alliance
- Lydia Isaac, PhD, MSc Vice President, Health Equity & Policy, National Urban League
- Anushree Vichare, PhD, MPH, MBBS Associate Professor, Milken School of Public Health, George Washington University

The panel provided a detailed examination of recent Medicaid policy changes enacted through the legislation commonly referred to as the "One Big Beautiful Bill," emphasizing the scale, timing, and real-world consequences for patients, providers, and states.

Panelists underscored that nearly one trillion dollars is projected to be removed from the Medicaid program, fundamentally reshaping health care financing and access nationwide. Key provisions discussed included the introduction of nationwide work requirements, changes to provider taxes, limits on state-directed payments, increased cost sharing for low-income beneficiaries, and more frequent Medicaid eligibility redeterminations. Although many provisions are phased in over several years, speakers stressed that states are already planning for budget shortfalls, which will likely lead to reduced benefits, lower provider payments, and constrained access to care—particularly for cancer patients who rely on Medicaid across the continuum of screening, diagnosis, treatment, and survivorship.

Panelists highlighted that administrative complexity, rather than employment status, is the primary driver of coverage loss under work requirements, citing evidence from Arkansas and Georgia where large numbers of eligible individuals lost coverage despite working or qualifying for exemptions. Workforce impacts were a central theme, with data showing declining participation of primary care and oncology providers in Medicaid due to low reimbursement and high administrative burden, threatening access in rural and underserved communities. Equity concerns were repeatedly emphasized, noting disproportionate harm to low-income, rural, and racial and ethnic minority populations.

As Lydia Isaac, Senior Vice President for Health Policy at the National Urban League, highlighted, "There's no way you can take $900 billion out of a system and not impact everybody." **Panelists concluded that coordinated federal and state advocacy, paired with patient stories and data, is essential to mitigate harm and inform policymakers as implementation unfolds**.

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Safeguarding the Future: Federal and Academic Workforce Challenges in Cancer Research and Care

- Kalah Auchincloss, JD, MPH Founder, Auchincloss Legal Group
- Nikki Hayes, MPH Retired, Senior Public Health Advisor
- Ellen Lukens, MPH Managing Principal, Health Transformation Strategies

This panel examined growing challenges facing the federal academic and public health workforce and their long-term implications for research integrity, regulatory capacity, data reliability, and patient outcomes. Drawing on decades of service at the FDA, CDC, NIH, and CMS, panelists described an environment of leadership instability, workforce attrition, and constrained communication. Recent departures—often driven by early retirements, administrative pressure, or mission misalignment—have led to a significant loss of institutional knowledge critical to federal public health and regulatory systems.

Panelists highlighted concrete consequences already emerging, including slowed rulemaking, disrupted advisory committee processes at the Food and Drug Administration, reduced data transparency, and gaps in program continuity across cancer prevention, surveillance, and payment innovation. The discussion underscored that these disruptions are not abstract but directly affect patients, researchers, providers, and communities that rely on timely guidance, credible data, and stable federal partnerships. Speakers also warned that diminished workforce morale and uncertainty around incentives such as student loan repayment programs threaten the future pipeline of public servants.

A central theme was the critical role of storytelling, both patient stories and narratives about public servants themselves, in helping policymakers and the public understand what is at stake. As Nikki Hayes reflected, “In one day, I watched over a century of experience, expertise, and institutional knowledge walk out the door—and that was heartbreaking.” **Panelists concluded by urging continued engagement, data-driven advocacy, and visible support for remaining federal staff to preserve capacity during this period of transition and uncertainty**.

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Cancer Payment Reform: Balancing Access, Quality, and Cost

- Dave Adler, MA Vice President of Advocacy, ASTRO
- Roy Beveridge, MD Senior Strategic Advisor, Avalere Health
- Janette Merrill, DHA CHES Senior Director of Care Innovation, ASCO

This panel examined cancer care payment reform and how policymakers can better balance access, quality, and cost, noting that current oncology payment models often fail to reflect patient priorities or real-world care delivery. Panelists reviewed CMS and CMMI value-based initiatives, including the Oncology Care Model and Enhancing Oncology Model, which aimed to reduce fragmentation but have proven complex, administratively burdensome, and insufficiently patient-centered.

Dr. Roy Beveridge of Avalere Health highlighted that many quality measures reflect payer incentives rather than patient needs and can produce unintended consequences, such as reduced community-based access under the 340B Drug Pricing Program.

The discussion highlighted radiation oncology as a case study in the urgent need for reform. Dave Adler of the American Society for Radiation Oncology (ASTRO) explained that advances in technology now allow patients to receive fewer radiation treatments, improving convenience and outcomes but reducing revenue under fee-for-service payment structures. To address this mismatch, the proposed Radiation Oncology Case Rate (ROCR) model proposes episode-based payments aligned with clinical evidence, patient access, and long-term sustainability, particularly for rural and community practices facing steep capital costs.

Janette Merrill of the American Society of Clinical Oncology (ASCO) emphasized the importance of evidence-based guidelines, data collection, and flexible models that recognize differences across practice settings, citing innovative efforts to expand access in rural Montana. Across the discussion, panelists stressed that success should be measured not only by system savings, but by patient experience, affordability, and access to care close to home. As Janette Merrill shared, "**We found that patients who lived more than sixty minutes away were more likely to decline care, and that's a barrier payment policy has to acknowledge.**"

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Sharing Patient Stories on the Value of Research

- Laurie McGinley, Board Member, Patient Action for Cancer Research
- Kelly Cuvar, Board Member, Patient Action for Cancer Research

The panel on sharing patient stories examined how lived experience can be ethically and effectively integrated into advocacy, media engagement, and research decision-making. Panelists emphasized that patient stories are most impactful when strategically aligned with specific policy goals and paired with data, rather than shared broadly without context. Laurie McGinley, a former Washington Post health reporter and board member of Patient Action for Cancer Research (PACR), described how the organization was created to complement existing advocacy efforts by elevating patient stories that clearly connect cancer outcomes to sustained federal investment in research. She noted that many medical breakthroughs originate in federally funded studies, a link that is often difficult to convey without patient narratives.

Kelly Cuvar, a cancer patient, and long-term clinical trial participant, highlighted the unique sacrifices made by patients, particularly those with rare cancers, who volunteer their bodies for research. She stressed that storytelling should be intentional and voluntary, with patients retaining control over what they share and when. Across the discussion, panelists underscored the importance of transparency, informed consent, and trauma-informed approaches to avoid re-traumatization and unintended consequences. As Cuvar stated, **"The moment you're diagnosed with cancer, the first thing you lose is agency and telling your story, on your own terms, can be a way to build that back."**

Thank You to Our Sponsors

Cancer Nation is grateful to the partners whose support made the Fall 2025 Policy Roundtable possible. Their commitment helps ensure survivor voices are heard in critical policy conversations.

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