

FALL 2022

CANCER POLICY ROUNDTABLE

EXECUTIVE SUMMARY

National Coalition for Cancer Survivorship
8455 Colesville Rd, Suite 930
Silver Spring, MD 20910
www.canceradvocacy.org

Fall 2022

OPENING KEYNOTE

Congresswoman Debbie Wasserman Schultz (FL-23)

In the opening keynote, Congresswoman Wasserman Schultz (FL-23), a champion for cancer survivors and a survivor herself, shared her personal cancer experience and discussed her previous legislative successes that have directly impacted cancer survivors. She asserted, "confronting cancer head-on with an all-hands-on-deck approach is a personal and professional mission for me."

She also revealed exciting news about her forthcoming legislation that will directly benefit cancer survivors. Her comprehensive survivorship legislation, the Comprehensive Cancer Survivorship Act, has already garnered bipartisan support and will be introduced by the end of the year.

"Survivorship," she said, "like our health system, can no longer be viewed as one-dimensional," emphasizing the need for a comprehensive approach to helping survivors. Thus, her legislation will address the entire continuum of care to close many of the gaps patients face so that they may no longer feel like they are "lost in transition." Specifically, it will provide coverage for care planning services to address transition to primary care, develop comprehensive navigation services, establish workforce assistance grants, provide education and awareness through survivorship resources, and require study of the existing reimbursement landscape and development of an alternative payment model, among many other things.

In closing, Congresswoman Wasserman Schultz acknowledged the challenging work that lies ahead to pass this legislation and called on all members of the cancer community to lend their voices to this collective effort to improve the quality of life and quality of care for cancer survivors.



MID-TERM ELECTION UPDATE

Debra Curtis

McDermott+Consulting

Shelagh Foster, JD

Polsinelli

Lydia Isaac, PhD, MSc

National Urban League

Harry Spolidis

Polsinelli

Rodney Whitlock, PhD

McDermott+Consulting

Shelley Fuld Nasso

National Coalition for Cancer Survivorship



What to Expect for the Future of Health Policy

In our first panel, health policy experts offered their perspectives on the short- and long-term implications of the mid-term elections, with attention to how the election results will affect cancer survivors. Fortunately, the panelists unanimously agreed that future attempts to repeal the Affordable Care Act are unlikely. Acknowledging the anticipated difficulty of getting things done next Congress, there was some consensus that health care initiatives that are both bipartisan and preferably inexpensive will achieve the most success. Shelagh Foster, JD of Polsinelli offered hope for the cancer community, highlighting that many key issues, including prior authorization and appropriations, have strong bipartisan support.

Discussing health priorities for the next Congress, the panelists believed telehealth and Medicare Advantage plans could likely be a focus. They recognized the barriers that Medicare Advantage enrollees face, including delayed or denied care due to burdensome prior authorization processes, and briefly highlighted the opportunity for the Biden administration to pursue regulations that address prior authorization.

Lydia Isaac, PhD, MSc of the National Urban League cautioned that advocates may lose ground on equity initiatives as the policies implemented during the pandemic that positively impacted minority populations could be scrutinized or even rolled back. She called for a renewed focus on state-level efforts, emphasizing the need to prioritize access to care for individuals in non-expansion states which have some of the worst health disparities for communities of color.

MID-TERM ELECTION UPDATE

(continued)



Debbie Curtis of McDermott+Consulting offered assurances that opportunities exist to address these concerns, referencing the Biden administration's current regulatory efforts to ensure the unwinding of the Medicaid continuous enrollment requirement goes smoothly.

When asked how advocates can best support legislation that will benefit cancer survivors, the panelists encouraged advocates to keep working at it, continue building relationships with legislators, and share their personal stories. Debbie explained, "You have an amazing story to tell. We all know people who've been impacted by cancer. We all know the results. If you're treated better when you have cancer, you have access to the care that you need. There are ways to win these arguments, and there are ways to make investments that matter. And we've seen it happen before; it can happen again."



PALLIATIVE CARE IS SURVIVORSHIP CARE

Patricia Ganz, MD Stovall Award Winner



In this session, NCCS founding member and Stovall Award winner, Dr. Patricia Ganz, presented the many reasons why palliative care is integral to survivorship care. From the beginning of her career, Dr. Ganz recognized the importance of delivering palliative care to cancer patients from the time of diagnosis rather than waiting until the last few weeks of life to enhance their quality of life. She stressed that services such as care planning, palliative care, psychosocial support, prevention and management of long-term and late effects, and family caregiver support should be delivered to patients and their families throughout the entire continuum of care.



In her presentation, Dr. Ganz shared the three "p's" of survivor care: palliation, prevention, and health promotion. She emphasized the need to educate professional and patient communities so they understand the purpose and benefits of palliative care and cultivate specialists' interest in palliative care of cancer survivors. She acknowledged the importance of secondary prevention of cancer in survivors, noting that 15% of new cancer diagnoses are in individuals who have had cancer previously. Additionally, she highlighted how critical lifestyle modifications and surveillance can be to reduce the risk of a second cancer and other chronic conditions.

SURVIVORSHIP AND ADVOCACY

Alicia Staley Stovall Award Winner



In a personal interview, Alicia Staley, three-time cancer survivor, Stovall Award winner, and experienced patient advocate, traced her advocacy journey, acknowledging how her advocacy has helped support her as a survivor while her survivorship has helped drive and energize her advocacy. Diagnosed with cancer for the first time at just 19 years old, she never anticipated that she would become involved in cancer advocacy. However, after she was personally confronted with the complex and overwhelming environment that cancer survivors face, she openly questioned the lack of innovation in health care and was invited to join her first patient advisory board. She never looked back.



An early adopter of Twitter, she shared how social media helped her find other people like her, which in turn inspired her to create #BCSM, a global breast cancer community. She shared how her advocacy led to a career change, as she now works to bring patient insights to clinical trial design, centering clinical trials around the needs and experience of the patient. For example, she has recently worked to encourage industry stakeholders to reconsider their approach to sharing informed consent with patients, urging them to use digital platforms as educational tools to deliver complex information.

MEDICAL DEBT FOR CANCER SURVIVORS

Diagnosis: Debt

A reporting partnership between Kaiser Health News and National Public Radio, "exploring the scale, impact, and causes of medical debt in America."

Noam Levey

Kaiser Health News

Kristie Fields

PinkSlayer

Lauren Ghazal, PhD

University of Michigan

Tina Shih, PhD

MD Anderson Cancer Center

Shelley Fuld Nasso

National Coalition for Cancer Survivorship



Financial toxicity is a serious concern for cancer survivors, and medical debt is on the rise, with cancer survivors significantly more likely to have debt and to declare bankruptcy, compared to people without cancer. Diagnosis: Debt is a reporting partnership between Kaiser Health News (KHN) and National Public Radio, "exploring the scale, impact, and causes of medical debt in America." Over the past year, KHN Senior Correspondent Noam Levey explored medical debt through this series to better understand the scale and scope of the current problem. He found that medical debt in the United States is a much more pervasive problem than previously reported but has likely been underestimated because it can often be reflected in credit card balances, loans from family, and payment plans arranged with hospitals and providers. Currently, 100 million people in the US have some form of health care debt.

Noam shared that more than half of individuals with medical debt report having to make a difficult sacrifice, like cutting back on food and other essentials, moving in with friends and family, or taking on extra work. Medical debt can also serve as a barrier to accessing care. One in seven people report that they have been denied medical care because of the debt they owe. Additionally, individuals report that they avoided seeking care due to concerns they would go into debt or be sued by the hospital.



MEDICAL DEBT FOR CANCER SURVIVORS

(continued)

Medical debt can be particularly devastating for cancer survivors, as one in five people with cancer have more than \$10,000 in debt and 60% say they have had to use all or most of their savings. When reflecting on the results of his research, Noam said, “We have a health system that is generating debt on an industrial scale, and nobody else does it like this in the industrialized world.”

Next, Tina Shih, PhD of MD Anderson Cancer Center discussed her research on financial hardships, referencing her study that explored how long cancer patients experience high out-of-pockets health costs. She found that cancer patients still experienced higher than average out-of-pockets costs six years after a cancer diagnosis, with the elderly population, low-income individuals without Medicaid, and people in good health experiencing the greatest financial impacts.

Lauren Ghazal, PhD, FNP-BC of the University of Michigan, who is also a family nurse practitioner and young adult cancer survivor, shared more about her research on the financial hardships experienced by adolescents and young adults with cancer. Her research gathered insights on young adult cancer survivors who have to ask for money and crowdfund, which she refers to as “both shameful and necessary,” to pay for their cancer care. She said, “Even though financial toxicity is a great buzzword – it's a new, novel term – it's not a new concept. There have always been financial hardship issues for cancer survivors.”

Kristie Fields, founder of the cancer nonprofit PinkSlayer and member of NCCS Cancer Policy and Advocacy Team, shared her valuable insights as a cancer survivor, discussing her personal survivorship journey and the importance of family. When she was diagnosed with cancer after losing her job and experienced financial hardships first-hand, her family played a large role in providing financial and emotional support and helping her care for her children. Cancer patients, she said, “Shouldn't have to choose to go to treatment or eat or feed your family – that should be a no brainer.” Her experience led her to begin buying groceries, gas, and other necessities for cancer patients in her community. In 2016, she officially started her own cancer nonprofit to provide navigation, education, and support to cancer patients and their families.

To close the panel discussion, the panelists explored potential solutions to address medical debt. They agreed the Affordable Care Act has helped, particularly by covering preventive services, but does not address every issue, especially for cancer patients living in non-expansion states. Panelists expressed appreciation for the Inflation Reduction Act provision capping out-of-pocket drug costs for the Medicare population but recommended continued advocacy to extend this benefit to private insurance. The panelists also stressed the importance of advocating for yourself as a patient, financial navigation programs and financial counseling, patient navigation, openly communicating with your care team about expected cancer care costs, and capping out-of-pocket medical costs for all patients.

CLOSING KEYNOTE

Monica Bertagnolli, MD Director, National Cancer Institute

We were honored to have Dr. Monica Bertagnolli, National Cancer Institute's (NCI) new Director, attend the Fall 2022 Cancer Policy Roundtable and deliver the closing keynote. As a surgeon and oncologist for over 30 years, she worked with cancer survivors every day and understands that every survivor's experience is unique. She stressed throughout her speech the importance of and her dedication to keeping survivors front and center, by listening to and engaging them, when establishing NCI's research priorities and focus.

Dr. Bertagnolli celebrated the progress that has been made but acknowledged that many challenges remain for patients and survivors in the cancer journey. She affirmed NCI's commitment to improving care and quality of life for survivors through a broad range of research focused on, for example, disparities in childhood cancer, survivor outcomes, the impact of familial, socioeconomic, and other factors on health outcomes, and the development of targeted interventions to help reduce the burden of cancer for young survivors. She called for renewed focus on disparities in care for survivors, stressing the need to better understand where disparities are, why they exist, and how to eliminate them. This understanding, she said, is critical to ending cancer as we know it.



“Survivors are not just the products of their diagnosis. They are not what we have taken or what cancer has taken from them. They may be forever changed, but they are certainly whole.”

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