

FALL 2021 CANCER POLICY ROUNDTABLE: EXECUTIVE SUMMARY

OPENING KEYNOTE:

Congresswoman Debbie Wasserman Schultz (D-FL)

Congresswoman Debbie Wasserman Schultz (D-FL), a cancer survivor, joined NCCS to kick off our second Cancer Policy Roundtable of 2021. In the opening keynote, the Congresswoman shared her personal cancer survivorship story as well as her current efforts to pursue bipartisan cancer survivorship legislation.

When discussing her role as both a cancer survivor and member of Congress, she passionately stated, **“Just like your organization empowers survivors and helps them manage the emotional and practical and financial challenges of cancer, in my role as a federal legislator, I’m trying to change outdated policies, create new laws, shepherd new opportunities for leaders like yourselves to drive our mission home and make sure that we think about this approach in a very personal way, because there’s nothing more personal than fighting cancer.”**

To paint a clearer picture of the challenges cancer survivors face, Congresswoman Wasserman Schultz compared the journey to navigating a Swiss cheese minefield. In this analogy, she explained that cancer survivors spend most of their time on solid ground but eventually fall into a hole representing either insufficient information to navigate their cancer treatment and survivorship journey. She shared that the goal of her forthcoming legislation is to work with key stakeholders to identify where patients feel lost and address those gaps so cancer survivors no longer feel like they are lost in transition.

SESSION ONE:

Estamos Aquí: Cancer Survivorship in the Latinx/Hispanic Population

Narjust Duma, MD

Dana-Farber Cancer Institute

Rebecca Esparza

Cancer Survivor and NCCS Cancer Policy & Advocacy Team (CPAT) Member

Roxana J. Guerra

Living with Metastatic Breast Cancer

Shelley Fuld Nasso, MPP

National Coalition for Cancer Survivorship

NCCS's 2021 State of Cancer Survivorship Survey findings showed a higher burden of cancer across a range of physical, emotional, and financial measures for Hispanic/Latinx respondents. In this session, Shelley Fuld Nasso presented data from the survey and spoke with Dr. Duma and cancer patients and advocates about the needs and challenges facing the often-overlooked Hispanic/Latinx cancer survivors.

Dr. Duma opened her presentation with an explanation of the origin of this session's title, "Estamos Aquí," translated as "We are here," which represents the thought that Hispanic/Latinx cancer patients are often forgotten. She emphasized some of the major health disparities experienced within the Hispanic/Latinx community as well as critical facts about the population's culture, needs, and beliefs.

Dr. Duma explained that a critical issue for this population is their lack of utilization of palliative care. One study she shared found that only 2.2% of stage IV Hispanic/Latinx lung cancer patients were referred to palliative care, despite evidence that early integration of palliative care improves outcomes and even extends survival.

Additionally, she stressed that Hispanic/Latinx patients are largely excluded from clinical trials but are treated with therapies approved for a mostly white population.

SESSION ONE, CONTINUED:

Estamos Aquí: Cancer Survivorship in the Latinx/Hispanic Population

Dr. Duma attributed these problems to a number of factors. First, she argued, physician bias prevents providers from referring these patients to specific treatments because they believe patients are not interested. In reality, treatments like palliative care or clinical trials haven't been adequately explained to the patient, and they don't understand the potential benefit to their treatment. Moreover, language can serve as a barrier between physician and patient. Finally, the myth that members of the Hispanic/Latinx population are fatalistic and believe they were given cancer for a reason may lead providers to believe patients do not want to seek treatment. To address these issues, she recommended that physicians approach patients with cultural humility and include family in cancer treatment discussions.

Rebecca Esparza, two-time cancer survivor of 20 years and Roxana Guerra, who is living with metastatic breast cancer, shared valuable insights from the patient perspective. They agreed that family was important to the Hispanic/Latinx population and should be included in a patient's care planning. They also discussed reasons why the Hispanic/Latinx community was underrepresented in advocacy and why cancer was a serious burden for this population. Reasons included a lack of paid time off work, lack of access to childcare, the strong connection to family and the habit of putting the needs of family above their own, lack of financial resources, concern about legal status, the language barrier, and the stigma in their community associated with cancer.

To close, Rebecca and Roxana stressed the importance of self-advocacy as a cancer survivor, encouraging cancer survivors to be their own best advocate. Roxana also shared that her son was "mi motor," or motor that kept her going so she could continue to advocate for herself and see her son grow.

SESSION TWO:

The 25th Anniversary of the National Cancer Institute's Office of Cancer Survivorship

Emily Tonorezos, MD, MPH

Director, Office of Cancer Survivorship, National Cancer Institute

Dr. Tonorezos reflected on the past 25 years since the creation of the National Cancer Institute's Office of Cancer Survivorship and the office's impact on our understanding of the needs of cancer survivors and the delivery of survivorship care. She also shared more about her vision for the office as well as insights inspired by her experience and training in internal medicine.

Dr. Tonorezos explained that a growing population of people are living with cancer. Unfortunately, this population is often excluded from cancer survivorship research, which is why she stresses the importance of advocating for survivorship research for people with advanced and metastatic cancers.

She discussed the NCI's definition of cancer survivor, from the time of diagnosis through the balance of life. She acknowledged that every person who has received a cancer diagnosis may not identify as a survivor. In cancer research, however, the term "survivor" is used because it is difficult to determine when cancer treatment has ended. She argued that an individual does not need to be cured of cancer to be considered a survivor for research. Still, acceptance of the term "survivor" has increased over time. In NCCS's [2021 State of Cancer Survivorship Survey](#), we found that 85% of people surveyed identified with the term survivor, which included 63% of people currently in treatment.

Dr. Tonorezos identified the recognition and acknowledgement of the cancer survivor population as one of the biggest gains in the field of cancer survivorship. Yet, we still face a number of challenges.

SESSION TWO, CONTINUED:

The 25th Anniversary of the National Cancer Institute's Office of Cancer Survivorship

For instance, she discussed the difficult role of primary care physicians in providing survivorship care and the challenge of determining what cancer survivors need. She acknowledged that primary care providers are overwhelmed and grappling with COVID-19 but are willing to care for cancer survivors. However, they need actionable information to effectively treat survivors. She stressed that it is not the cancer survivor's responsibility to coordinate their own care and ensure they receive high quality care but should instead be the provider's responsibility.

Finally, when discussing equity for survivors, Dr. Tonorezos emphasized that the quality of a cancer patient's treatment should not depend on where they go for care, which is a current challenge, focus, and opportunity for the Office of Cancer Survivorship.



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 Roxana J. Guerra Living with Metastatic Breast Cancer	 Shelley Fuld Nasso, MPP NCCS CEO	 Emily Tonorezos, MD, MPH National Cancer Institute

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