



May 23, 2017

The Honorable Orrin Hatch  
Chairman  
Committee on Finance  
United States Senate  
Washington, DC 20510

Dear Chairman Hatch:

The National Coalition for Cancer Survivorship (NCCS) represents the nearly 16 million cancer survivors and their families in efforts to transform the cancer care system. Our vision is a health care system that supports cancer survivors and their families, that is affordable and accessible, and that considers individuals' goals and values. We appreciate the opportunity to offer our perspective on the American Health Care Act and Senate efforts to draft and approve health reform legislation.

Prior to enactment of the Affordable Care Act, Americans with cancer confronted serious obstacles in obtaining health insurance coverage because of their pre-existing condition – the condition of cancer survivorship. This was true for cancer survivors of all ages, including adult survivors of cancer that occurred in childhood. As a result of pre-existing condition exclusions and medical underwriting, some Americans with cancer experienced gaps in health insurance which resulted in delays in care and often compromised their health care outcomes. Cancer patients were among those most likely to shoulder significant medical debt and to be at risk of medical bankruptcy. Cancer survivors often found themselves in a form of job lock, pursuing and retaining employment for the availability of health insurance coverage instead of the professional opportunity.

Cancer survivors have benefited from important protections of the Affordable Care Act, including pre-existing condition protections, community rating, annual and lifetime cap protections, and essential health benefits. Young adult survivors of childhood cancer have benefited from Medicaid expansion, and those who are shy of Medicare – ages 50 to 65 – have more affordable insurance coverage because of community rating.

We are aware of certain Affordable Care Act marketplaces where there are limited or no insurance options. We also understand from the cancer survivors that we represent that some have experienced increases in their premiums and deductibles and still struggle with cost-sharing in their exchange plans.

We urge that the Senate, as it develops its plan, recognize the important protections offered by the Affordable Care Act and consider ways to stabilize a competitive and sustainable insurance market over the long-term without abandoning these protections. We realize the significant challenges, but we believe strongly that policy provisions exist to achieve these goals.

## **NCCS Principles for Health Care Reform**

NCCS recommends that the following principles should guide health care reform efforts:

- Protect the access of those with serious and life-threatening illnesses and chronic conditions to health insurance coverage.
  - Individuals who have had a cancer diagnosis should be protected from pre-existing condition provisions that might block their access to insurance altogether, delay access, or limit the scope of coverage available to them.
  - Pre-existing condition protections will only be meaningful if cancer survivors also are protected from medical underwriting and have access to plans that will cover the critical elements of cancer care.
- Ensure access to health insurance that is affordable.
  - Premium assistance should be income-based, to increase the ability of those with cancer and other serious conditions to purchase adequate health insurance.
  - Cost-sharing protections are critical, to protect access to care without bankruptcy.
  - Medicaid has served as a reliable pathway to care for many with cancer, and reductions in this program will disrupt access to care.
- Guarantee that health insurance coverage is adequate for delivery of quality cancer care.
  - Cancer care is complex, multi-disciplinary, and often delivered over a lifetime. Limits on essential health benefits, and annual or lifetime benefit limits, may make health insurance plans inadequate for cancer patients with complex needs.
  - Cancer patients who complete active treatment may experience late and long-term effects of cancer and cancer treatment; these individuals may require health care monitoring and significant health care for a period of years. Health insurance must be adequate to meet these needs.

## **Medicaid Per Capita Caps or Block Grants and High-Risk Pools**

We are especially concerned about proposals that would result in limits on the Medicaid program and that would force those with pre-existing conditions into high-risk pools. Proposals that are aimed primarily at reducing the cost of Medicaid run the risk of denying many cancer patients access to Medicaid or providing them access to Medicaid that is wholly inadequate for financing quality cancer care. We have evaluated high-risk pools in a number of states, and we find this model to be ineffective and unsustainable to provide the necessary care for cancer patients. There are challenges associated with isolating those with serious illnesses in high-risk pools, including the cost associated with maintaining a program adequate to meet the needs of those with serious diseases. Cancer patients who have relied on high-risk pools in the past offer mixed evaluations at best, and routinely note the limits in coverage and high costs that they experienced while in the high-risk pool. In short, we are concerned about the medium- to long-term viability of high-risk pools as a financing mechanism for those with serious illnesses.

## **Stabilizing Marketplaces**

We support efforts to stabilize fragile marketplaces, as a bridge to a major reform bill. Reinsurance or “invisible risk pools” will be an important element of market stabilization. Payments to issuers to cover higher-than-anticipated costs for certain enrollees may help to stabilize the markets by encouraging issuers to remain in the marketplaces and by stabilizing premiums and cost-sharing responsibilities. We caution that while we think the model of “invisible risk pools” – or reinsurance – may be a part of market stabilization, we remain opposed to high-risk pools as the sole means of providing those with serious health care needs access to financing of life-saving therapy.

## **State Innovation**

In our own work on cancer care innovation, we have supported initiatives that foster new approaches to care and experimentation by providers and health care systems. As a result, we appreciate the interest in fostering innovation by the states. However, we urge that providing state flexibility not simply be a means of eliminating access to care for millions of Americans. We also urge that state flexibility be permitted and encouraged in the context of basic protections for patients, including the essential health benefits that are necessary to ensure access to adequate and appropriate cancer care.

## **Senate Legislative Process**

We appreciate the opportunity to provide this information about the health care priorities of cancer survivors. We urge the Senate to proceed with a process for developing health care legislation that will include hearings, additional opportunities for public input, and committee deliberation and mark-up. This complex issue deserves no less than a process that fully engages all stakeholders in the health care system. The cancer survivors we represent are, understandably, frightened for their futures and worried about their ability to access health care. They are counting on their representatives in Congress to improve the health care system, not cause people to lose access to care.

Sincerely,



Shelley Fuld Nasso, MPP  
Chief Executive Office