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February 2, 2021

The Honorable Charles Schumer
U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Nancy Pelosi
U.S. House of Representatives
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Kevin McCarthy
U.S. House of Representatives
2468 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker Pelosi, and Minority Leader McCarthy,

On behalf of the Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, we write today urging you to prioritize people impacted by cancer as you consider the next COVID relief package and any future efforts to address the pandemic.

As the largest provider of social and emotional support services for people impacted by cancer, and the largest nonprofit employer of psychosocial oncology professionals in the United States, CSC has a unique understanding of the cancer patient experience. We provide \$50 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. In addition to our direct services, our Research and Training Institute and Cancer Policy Institute are industry leaders in advancing the evidence base and promoting patient-centered public policies to ensure that the patient voice is at the center of the national dialogue.

The high number of cancer patients and survivors in the United States –1.8 million new cancer diagnoses estimated in 2020 and more than 16.9 million Americans with a history of cancer – emphasizes the urgency of our requests below. (ACS, 2020). We respectfully request that you incorporate the following priorities that will provide the assistance necessary to help promote the health, safety, and economic well-being of people impacted by cancer throughout the COVID-19 pandemic and beyond:

Access to Care

Individuals impacted by cancer must have access to timely, high-quality, and comprehensive health care. The Affordable Care Act (ACA) was a critical policy shift that improved our nation's health care coverage landscape. The gains made by the ACA must be protected and improved upon. Patients should have access to the full range of essential health benefits without any restrictions due to a pre-existing condition. Any impediments must be addressed so that patients can efficiently enter and navigate the health care system to find an appropriate health care provider within their geographic area.

Access to comprehensive health care for patients with cancer is even more important now during the pandemic. However, the growth of less than comprehensive insurance plans on the market, like short-

term limited duration (STLD) and association health plans (AHP), have caused a significant increase in uninsured and underinsured rates over the last few years, leaving cancer patients at risk of paying higher out-of-pocket costs and obtaining inadequate coverage. These plans are not governed by federal rules regarding what they must cover, meaning many plans may not cover essential health benefits including emergency services, mental health care, prescription drugs, and COVID-related services. Congress should take immediate action against non-compliant plans by working with the Department of Health and Human Services (HHS), the Department of Treasury, and the Department of Labor to revise standards for STLDs and AHPs and to strengthen standards for short-term policies to limit their sale to consumers.

Medicaid

Expand State Medicaid Program. Medicaid plays an important role in providing affordable healthcare coverage for cancer patients with low incomes. The significance of the Medicaid program for cancer patients has grown over the past year as Medicaid enrollment continues to increase because of the COVID-19 pandemic and the resulting economic downturn (Rudowitz et al. 2020). The ACA expanded Medicaid eligibility for low-income adults, up to 138% of the federal poverty level. To date, 38 states and the District of Columbia have expanded Medicaid, and over 12 million people have gained coverage as a result (Kaiser Family Foundation, 2019). Research has shown an association between Medicaid expansion and early-stage colorectal, lung, breast, and pancreatic cancer diagnoses, when cancer is often more treatable (Jemal et al., 2017). Medicaid expansion is also instrumental in addressing health disparities—a 2019 study found that states that expanded Medicaid under the ACA reduced racial disparities in timely treatment for African American cancer patients (Adamson et al., 2019). The COVID-19 pandemic has illuminated disparities in health care, especially in the 12 states that have not expanded Medicaid. We urge Congress to encourage the remaining 12 states to expand Medicaid by providing 100 percent Federal Medical Assistance Percentages (FMAP) for the first three years that states expand their Medicaid programs. This financial incentive was available to states that expanded their programs back in 2013.

Strengthen State Medicaid Programs. Research suggest that states expect Medicaid enrollment to sharply increase in fiscal year 2021 (Rudowitz et al. 2020). Recognizing the significant impact this rise in enrollment will likely have on state budgets, it is critical that increased federal support be made available. CSC supported the authorization of 6.2 percentage point increase in the FMAP in *The Families First Coronavirus Response Act* (FFCRA). We urge Congress to raise the cumulative FMAP increase from 6.2 to at least 14 percentage point to help states pay for increases in enrollment and declines in revenues during the economic downturn caused by the pandemic. Further, we recommend that Congress preserve the Maintenance of Effort (MOE) requirements for the enhanced FMAP that prevent states from imposing more restrictive eligibility standards or increased cost-sharing during the public health emergency.

Paid Leave

Expand EPSLA and EFMLEA. Patients with cancer are more vulnerable to COVID-19 than those in the general population. COVID-19 patients with cancer have higher risks in all severe outcomes, with hematologic, lung, and metastatic cancer patients having the highest frequency of severe events (Dai et al., 2020). Cancer survivors currently undergoing active treatment are also at increased risk of more severe COVID-19 disease than people without a history of cancer (Penn Medicine News, 2021). Furthermore, caregivers and others in close contact with cancer patients are thought to be the most likely source of transmission to their loved ones. (NCCN, 2021).

CSC recognizes the worthy goals of the *Expanded Paid Sick Leave Act* (EPSLA) and the *Emergency Family and Medical Leave Expansion Act* (EFMLEA) created under the statutory provisions of the

FFCRA. However, both did not include populations at high risk of severe illness from COVID-19 as advised by the Centers for Disease Control and Prevention (CDC) to continue to shelter in-place to protect their health during the pandemic and failed to extend protections for a sufficient period. The number of people who have contracted COVID-19 and subsequently died has skyrocketed since the CDC first issued the advisory. No person recognized by the CDC as being at greater risk of severe outcomes (including death) from COVID-19 should be expected to return to work after the conclusion of a two-week period when the threat remains in place and continues long after the conclusion of that period.

In addition, the EPSLA did not include coverage and protection for individuals and family members living in the same household that are the most likely source of transmission to their loved one (NCCN, 2021). The lack of coverage for individuals who live with significant health conditions such as cancer leaves them facing a devastating choice: place their health or their loved one's health at risk by going back to work or lose their job and likely their health insurance. Similarly, the EFMLEA's limited support to only those with children or adults with disabilities, whose local school district or usual care providers are closed due to the pandemic for up to 10 weeks, neglected vulnerable populations that deserve and require support throughout the pandemic. We respectfully ask Congress to reauthorize the EPSLA and the EFMLEA, and extend coverage under both to include cancer patients, survivors, their caregivers, and working household members.

Expanded Unemployment Insurance

People impacted by cancer have been in the untenable position of accepting a job that literally risks their life, or that of their loved ones, or forfeiting unemployment insurance essential to keeping a roof over their heads, putting food on the table, and purchasing life-saving medications. President Biden recently signed an executive order asking the Department of Labor to consider clarifying that workers who refuse unsafe working conditions can still receive unemployment insurance (The White House Fact Sheet, 2021). We strongly urge Congress to expand unemployment benefits for individuals who are at increased risk of severe outcomes from COVID-19, their caregivers, and household members so they can continue to be eligible to receive expanded federal benefits if a job places them at increased risk of exposure to COVID-19.

Access to COVID-19 Vaccines

As referenced above, cancer patients are at increased risk of severe outcomes when exposed to COVID-19 (ASCO, 2020) and recent findings indicate that cancer survivors not currently undergoing active treatment are also at increased risk of more severe COVID-19 disease (Penn Medicine News, 2021). This heightened vulnerability calls for the prioritization of cancer patients and survivors above the general population in COVID-19 vaccine distributions plans. Furthermore, caregivers and others in close contact with cancer patients are thought to be the most likely source of transmission to their loved ones. Therefore, caregivers and household/close contacts of those undergoing cancer treatment should also receive the vaccine when possible (NCCN, 2021). Additionally, regarding the administration of the vaccine, all COVID-19 vaccination sites must be safe for high-risk patients. We request that Congress fully fund the purchase, distribution, and administration of COVID-19 vaccines and all necessary medical supplies required to expeditiously vaccinate people impacted by cancer.

Clinical Trials and Research

The COVID-19 pandemic has jeopardized hard fought gains in cancer research. From 1991 to 2017, the cancer death rate declined by 29% with the largest single-year drop (2.2%) from 2016 to 2017 (ACS, 2020). But safety restrictions and lock downs necessitated by the COVID-19 pandemic suspended or terminated many clinical trials (Health Affairs, 2020). Suspended or terminated trials delay the discovery of new treatments and therapies. Clinical research usually precedes clinical practice so the impact of this current disruption in trials could be felt for years to come. (Medscape, 2020). We urge Congress to increase federal funding for the National Institutes of Health (NIH) and the National Cancer Institute

(NCI) to restart cancer clinical trials as they are essential for discovering new ways to detect, diagnose, and treat cancer.

90-day supply of Medications

The heightened risk of cancer patients and survivors contracting COVID-19 and suffering more severe outcomes raises the urgency of ensuring all cancer patients, regardless of their type of insurance coverage, or lack thereof, have ready access to the medications necessary to treat their disease. Section 3714 of the *Coronavirus Aid Relief and Economic Security (CARES) Act* requires Medicare prescription drug plans and Medicare Advantage plans to allow fills and refills of covered drugs up to a three-month supply during the public health emergency. This helped minimize the potential exposure of these patients and their caregivers to the virus by limiting the number of trips to the pharmacy and helps ensure an extended supply of medication should these turbulent times result in periodic limited supplies of essential anti-cancer medication.

Moreover, the ability to afford a three-month supply of medications, whether in connection with the current requirements under Medicare Part D and Medicare Advantage plans, or when applied to other health coverage in the future, is intricately linked to patients' ability to benefit from this important policy. The high cost-sharing requirements of a 30-day supply of cancer medication is difficult for many patients, let alone an upfront payment for a 90-day fill or refill. To make the 90-day supply a viable option, all Medicare Part D, Medicare Advantage, state, and federally regulated plans should offer a pay over-time option. The even more limited financial resources of patients on Medicaid warrants the waiving of all cost-sharing requirements for Medicaid enrollees during the public health emergency. Congress should take action to encourage all health care plans, including Medicaid, to offer protections, and ensure affordability of these drugs for cancer patients. We also ask that payers be required to waive utilization management tools (e.g., prior authorization and step therapy) specifically designed to limit or restrict access to medications, especially high-cost specialty drugs for serious condition like cancer, during this public health emergency.

Oral Chemotherapy Parity

To limit cancer patients' potential exposure to COVID-19, many providers are encouraging their patients to remain at home as much as possible, leading them to prescribe oral anticancer therapies (self-administered) when available and medically appropriate. Unfortunately, insurance benefit designs currently impose higher out-of-pocket costs on patients for self-administered oral anticancer therapies covered under their prescription benefit than for IV therapies administered almost exclusively at an outpatient facility (e.g., infusion center) covered under the medical benefit.

There are ongoing efforts to address this outdated and counter-productive benefit design in the *Cancer Drug Parity Act*, S.741/H.R. 1730 introduced in the 116th Congress, but the urgency of the life-and-death dangers presented by the pandemic calls for Congress to act to require that oral and other cancer medications self-administered by patients require cost-sharing no greater than that for cancer medications administered by a health care provider. We urge Congress to include the *Cancer Drug Parity Act* in the next COVID relief package to help lower the risk and costs for cancer patients.

Telehealth and Telemental Health

The COVID-19 pandemic has highlighted the importance of access to telehealth and telemental services for patients, especially those living with cancer. In response to the pandemic, federal and state agencies provided new, and in some cases time-limited, flexibilities for telehealth and telemental services to enable patients to see providers from the safety of their homes to reduce disruptions to care. Additionally, the pandemic has imposed significant mental and physical health challenges on people. Feelings of anxiety, loneliness, and isolation experienced by many brought on by social distancing and other means to minimize contracting and/or spreading COVID-19 have been amplified for people impacted by cancer.

We strongly recommend that Congress permanently extend current flexibilities in telehealth services to ensure cancer patients can continue to safely access health care services now and beyond, including audio only telehealth which has been invaluable to individuals without broadband access, those without a device with visual capability, and those unfamiliar with or uncomfortable with technology. We also ask Congress to ensure that telehealth policies continue to offer no cost telemental health without pre-determined limitations throughout the public health emergency and beyond.

Conclusion

We appreciate your consideration of the extraordinary challenges facing cancer patients, survivors, and their loved ones caused by the COVID-19 pandemic. As Congress prepares to address the health and economic consequences the pandemic has imposed upon our nation and its people, we ask that the measures outlined above be included in the plan to move our nation forward.

Should you have any questions or would like to arrange a time to discuss these issues, please contact Phylicia Woods, Executive Director of the Cancer Policy Institute at the Cancer Support Community at pwoods@cancersupportcommunity.org.

Sincerely,



Phylicia L. Woods, JD, MSW
Executive Director – Cancer Policy Institute

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