

**Statement by the Deadliest Cancers Coalition on FY 2022 Appropriations for the National Institutes of Health and the National Cancer Institute**

**Submitted for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies**

On behalf of the Deadliest Cancers Coalition, a collaboration of national nonprofit organizations and industry focused on addressing issues related to our nation's most lethal cancers, we submit this statement in support of strengthening the federal investment in deadliest cancers research conducted and supported by the National Institutes of Health (NIH) and the National Cancer Institute (NCI). For Fiscal Year 2022, we respectfully request \$46.111 billion for the NIH's base program budget level, including \$7.9 billion for the NCI, as well as the funding needed to establish a new Advanced Research Projects Agency for Health (ARPA-H) that includes a focus on finding tools to help patients diagnosed with one of the deadliest cancers. We further request report language in the LHHS bill that continues to hold NCI accountable for making progress on the goals and ideals of the Recalcitrant Cancer Research Act (RCRA).

In his recent address to Congress, President Biden called for an "end to cancer as we know it". As the national coalition that represents the cancers for which we've seen the least amount of progress, we wholeheartedly endorse this statement. We deeply appreciate Congress' continued strong leadership in support of cancer research through the steady increases you have provided to the NIH and NCI over the last six years. Funding for the existing components of the NIH and NCI is a critical component of making the goal of "ending cancer" a reality, which is why we have joined with our partners in the One Voice Against Cancer Coalition to support the funding requests for NIH and NCI listed above.

We also support President Biden's call for a new ARPA-H that has an initial focus on cancer and other diseases for the purpose of driving transformational innovation in health research and speeding application and implementation of health breakthroughs. As representatives of patients who have been diagnosed with our nation's most lethal cancers and those who currently have the fewest early detection and treatment options available, we believe that ARPA-H has the potential to provide a vital bridge between this dearth of effective tools and the improved survival rates that are so desperately needed.

The discussion between physicians and patients diagnosed with a deadliest cancer are currently focused on end-of-life instead of exploring treatment options that will provide the best quality of life and the extension of life. These cancers exemplify areas where medical practice would be dramatically changed through the technologies and platforms that could be developed under ARPA-H. For these reasons, we urge Congress and the Administration to ensure that ARPA-H focuses on the hardest problems and areas where medical practice will be dramatically changed, including the deadliest cancers, as it develops authorizing language.

We know that this Subcommittee will face many difficult decisions as it is developing the FY 2022 Appropriations Bills. As you are considering these bills, we further encourage you to structure ARPA-H so that no funding is diverted from the core mission and budgets of the NIH and NCI, but also allows for true innovation.

It is also essential that critical stakeholders in the cancer community be involved at the earliest outset in the design, structure and budget of these endeavors. "Cancer" is not one disease, so it is therefore vital that stakeholders representing the range of the "cancer

experience” be involved in these efforts. For this reason, the Deadliest Cancers Coalition respectfully requests to be involved in the process, starting in the initial phase.

The deadliest cancers offer a powerful example of the need for continuing the path of sustained and robust increases for the NIH and NCI. While the overall five-year relative survival rate for all cancers combined has risen from 50 percent when the War on Cancer was first declared in 1971 to 67 percent today, we have seen relatively little success in improving survival for the deadliest cancers. Multiple myeloma is one of the few “success” stories among this group as the five-year survival rate was 34 percent when the coalition was founded in 2008 and is now 54 percent.

Next year (2022) will mark the 10-year anniversary of the passage of the RCRA, which requires that the NCI develop long-term strategic plans for addressing recalcitrant cancers beginning with pancreatic adenocarcinoma and small-cell lung cancer. The NCI has made progress in implementing the statute, particularly with respect to pancreatic adenocarcinoma and small-cell lung cancer. As a result of report language in the FY 2020 and FY 2021 LHHS Appropriations bills, NCI has also begun a scientific-framework-like process for glioblastomas and gastroesophageal cancers. However, there is much work to be done to ensure the goals of the legislation are met for all recalcitrant cancers. It is therefore crucial that Congress continue to shine a light on all recalcitrant cancers so they do not slip back into the shadows and so progress on implementing the RCRA for all of the deadliest cancers continues.

The Deadliest Cancers Coalition deeply appreciates the inclusion of report language focusing on these cancers in years past, including the FY 2021 language that reiterated Congress’ intention that NCI develop a scientific framework using the process outlined in the

RCRA for stomach and esophageal cancers and directed the NCI to identify future goals for each of the deadliest cancers in the fiscal year 2022 CJ.

We are seeking language in the FY 2022 LHHs Appropriations bills that continues to hold NCI accountable to the FY20 and FY21 language and the goals and ideals of the RCRA. Given that NCI has been responsive, to some degree, when Congress directs them to focus on specific cancers, we ask the language identify liver cancer as the next focus area. We are asking that the language specifies that the process should include cholangiocarcinoma, which is cancer that originates in the bile duct, but is grouped together with liver cancer, but want NCI to have flexibility on which other liver cancer subtype(s) should be included.

In addition, we continue to believe that it is critical that NCI stipulates how it will continue the goals of the RCRA to develop and implement strategic plans for the full range of recalcitrant cancers. The 2012 legislation was first introduced by Representatives Anna Eshoo and Leonard Lance and Senator Whitehouse and gained significant bi-partisan support because it was clear that just following “standard procedure” with respect to recalcitrant cancers was not working and there needed to be a specific focus on determining research priorities for these diseases. That need has not diminished.

The Deadliest Cancers Coalition was founded because we believe in a future in which there is no form of cancer for which a diagnosis is an automatic death sentence. All cancer patients should be able to select the best treatment option for them in consultation with their physician from a variety of effective treatments. Unfortunately, this year, approximately 44 percent of all cancer-related deaths will be due to one of the deadliest cancers, which means that we clearly have a long road ahead of us before that future is more than a dream. We

therefore urge the Subcommittee to continue its leadership to ensure that NIH receives \$46.111 billion for the NIH's base program budget level for FY 2022, including \$7.9 billion for the NCI, as well as the funding needed to establish a new ARPA-H that includes a focus on the deadliest cancers. We further urge you to continue to hold the Institute accountable to making progress on the deadliest cancers through report language in the FY 2022 bill.