

DEADLIEST CANCERS COALITION

May 7, 2021

President Joe Biden
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500

Dear President Biden:

On behalf of the Deadliest Cancers Coalition, a collaboration of national non-profit organizations and industry focused on addressing issues related to our nation's most lethal cancers, we are writing to thank you for your remarks in your address to Congress about ending cancer as we know it. As the national coalition that represents the cancers for which we've seen the least amount of progress, we write today to not only applaud your commitment, but to respectfully request a seat at the community table to develop the plans that will achieve this goal.

Funding for the existing components of the National Institutes of Health (NIH) and National Cancer Institute (NCI) is an important part of making this goal a reality. We were therefore pleased to see that your discretionary funding request for FY 2022 includes a strong commitment to cancer research, including \$51 billion for the NIH. We have joined with our partners in the medical and cancer research community to support \$46.111 billion for the NIH's base program budget level, including \$7.9 billion for the NCI.

We were particularly pleased that your ongoing leadership on cancer research innovation is continuing through your proposal to create a new Advanced Research Projects Agency for Health (ARPA-H) and that such funding will be in addition to NIH's base funding and not a reallocation from the current program. As noted in your proposed budget, ARPA-H will have 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 share your commitment to progress in this critical area. For this effort to be successful, it is essential that ARPA-H is designed and structured in a manner that ensures that funding is in no way diverted from the core mission and budgets of the NIH and NCI, but also allows for true innovation.

As you know well, the cancer community is diverse and has many voices. For the U.S. to truly end cancer as we know it and/or for ARPA-H to succeed, it is essential that critical stakeholders

in the cancer community be involved at the earliest outset in the design, structure and budget of these endeavors. For this reason, the Deadliest Cancers Coalition respectfully requests to be involved in the process, starting in the initial phase.

The Recalcitrant Cancer Research Act was enacted for the purpose of encouraging innovative research that would result in improving survival rates for our nation's deadliest cancers. **The statute defines the deadliest, or recalcitrant, cancers as those with a five-year survival rate below 50 percent and include brain, esophageal, liver, lung, ovarian, pancreatic, and stomach cancers, as well as mesothelioma.** While the NCI has taken critical steps in implementing this legislation and has made progress on developing new approaches and resources for some cancers, including pancreatic adenocarcinoma, small-cell lung cancer and glioblastoma, there is still much work that needs to be done for these and the other recalcitrant cancers.

ARPA-H has the potential to provide a vital bridge between the lack of tools and resources currently available to deadliest cancer patients and the improved survival rates that are so desperately needed. For that reason, we believe that ARPA-H should focus on the hardest problems and areas where medical practice will be dramatically changed. 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.

We are excited about the potential for ARPA-H to change outcomes for our nation's deadliest cancer patients. As a first step, we request a meeting with the appropriate individuals in your Administration to learn more about your plans and vision for ARPA-H and to share our perspective. Please contact Megan Gordon Don, Executive Director, at mgdon@mgdstrategies.com or 202.246.8095 with any questions or to set up a meeting.

Sincerely,

American Association for the Study of Liver Diseases

American Gastroenterological Association

Asbestos Disease Awareness Organization

Blue Faery: The Adrienne Wilson Liver Cancer Association

Cholangiocarcinoma Foundation

Debbie's Dream Foundation: Curing Stomach Cancer

Digestive Disease National Coalition

Esophageal Cancer Action Network

Global Liver Institute

GO₂ Foundation for Lung Cancer

Hepatitis B Foundation

Hope for Stomach Cancer

Mesothelioma Applied Research Foundation

National Brain Tumor Society

National Pancreas Foundation

Ovarian Cancer Research Alliance

Pancreatic Cancer Action Network

TargetCancer Foundation

cc: Xavier Becerra, Secretary of Health & Human Services
Eric Lander, Assistant to the President

Kei Koizumi, Acting Director & Chief of Staff, Office of Science & Technology Policy
Susan Rice, Director, Domestic Policy Council
Shalanda Young, Acting Director, Office of Management & Budget
The Honorable Patty Murray
The Honorable Richard Burr
The Honorable Patrick Leahy
The Honorable Richard Shelby
The Honorable Roy Blunt
The Honorable Anna Eshoo
The Honorable Brett Guthrie
The Honorable Dianne DeGette
The Honorable Fred Upton
The Honorable Frank Pallone
The Honorable Cathy McMorris Rodgers
The Honorable Rosa DeLauro
The Honorable Kay Granger
The Honorable Tom Cole
The Honorable Sheldon Whitehouse