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July 16, 2021

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

Dr. Eric Lander
Director, Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Avenue, N.W.
Washington, DC 20504

Dr. Francis Collins
Director, National Institute of Health
9000 Rockville Pike
Bethesda, Maryland 20892

Dear President Biden, Dr. Lander, and Dr. Collins:

I am writing on behalf of GO2 Foundation for Lung Cancer, which has the mission of transforming survivorship by saving, extending, and improving the lives of those vulnerable, at risk, and diagnosed with lung cancer.

We would like to thank the administration and express our support for President Biden's thoughtful and timely proposal to create a new entity, the Advanced Research Projects Agency for Health (ARPA-H), within the National Institutes of Health (NIH), "to develop breakthroughs—to prevent, detect, and treat diseases like Alzheimer's, diabetes, and cancer." We must underscore the specialized needs of the tens of millions of people living with and at risk for lung cancer and call attention to the specific actions needed to support the lung cancer community among other diseases and conditions.

This year, an estimated 235,760 new cases of lung cancer are expected, and an estimated 131,880 lives will be lost due to lung cancer. Despite recent breakthroughs in lung cancer—treatments targeted to specific genetic mutations, cutting-edge immunotherapies, and life-saving screenings—lung cancer remains the leading cause of cancer death among men and women, and every racial and ethnic group in every state nationwide. Historically patients with lung cancer have experienced an exceptionally low survival rate (five-year survival rate of just 22%) due to the overarching stigma and lack of early detection and effective treatment options.

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Lung cancer is not just one disease but many diseases, often with a high rate of mutations or tumor changes, affecting our civilian and military population. Research shows that there is a disparate impact of lung cancer on women, in particular on younger women who have never smoked. A comprehensive federal research strategy is needed to explore the differences in women with respect to lung cancer risk factors, incidence, and histology, along with a response to treatments; expand or improve access to lung cancer preventative services; and bring a public awareness and education campaign to increase the percentage of those screened for lung cancer.

Within ARPA-H, we can reimagine the vision to eradicate deaths and suffering from lung cancer and better the health and welfare of the American public. This supports GO2 Foundation's vision of doubling survivorship by 2025. We agree with the idea inspired by the Defense Advanced Research Projects Agency (DARPA) to design ARPA-H to be flexible, nimble, and undeterred by the possibility of failure, which has driven breakthrough advances for the Department of Defense (DOD) for more than 60 years.

With ARPA-H, we believe we will see a transformative shift in the management of recalcitrant cancers and in patient quality of life during treatment, and increased survivorship. The Recalcitrant Cancer Research Act statute defines the deadliest or recalcitrant cancers as those with a five-year survival rate below 50%, which includes brain, esophageal, liver, lung, ovarian, pancreatic, stomach, and mesothelioma cancers. To realize the outstanding potential for ARPA-H, we recommend a broad project portfolio that can significantly impact human disease by focusing on the following principles:

- **Improving early detection of disease**—The majority of diseases that afflict Americans offer opportunity for more prevention and/or intervention when detected early in pre-disease or early-disease settings. Cancer and heart disease are two key areas where early detection can lead to a significant improvement in outcomes. Investment in new platforms and models of risk and early disease detection could have significant impacts on the overall health of the population, across many disease areas.
- **Further advancing precision medicine**—Precision medicine utilizes a person's genetics, environment, and lifestyle to help determine the best approach to prevent or treat disease. In disease areas such as cancer, precision medicine has already improved how we diagnose and treat certain segments of the patient population. However, there is more work to be done. This is an area where broad, risk-taking innovative approaches could dramatically impact health care. Innovative clinical trial designs and infrastructure that reach and enroll more members of disease communities will be critical in advancing this goal. There is a need to streamline clinical trial regulatory processes to make them less burdensome and to accelerate community accrual through incorporation of newer concepts such as just-in-time designs and increased telehealth utilization. Notably, equity in precision medicine is a huge issue. We do not understand how factors such as race and ethnicity affect the best approaches to prevent and treat disease across most disease areas and current clinical trials are not designed to enroll equitably across many different demographic areas.

- **Increasing community engagement & access to care**—Research innovations do not improve lives unless implemented correctly in all communities throughout this country. We saw this clearly with the urgent need to roll out COVID-19 vaccines efficiently into diverse communities of different racial, ethnic, religious, socioeconomic, and subgroups across the United States. Innovations across all disease areas are facing the same challenges; current technologies that we know are lifesaving are not equitably available in all communities. There are barriers at many levels of implementation. New platforms and models are urgently needed to properly engage patients early on in research and innovation and then appropriately address barriers to ensure access. In addition, secure but flexible data sharing that allows all stakeholders, including patients, to access the medical data that they need remains a key priority.
- **Improving quality of life**—As we improve treatments for diseases such as Alzheimer's, heart disease, diabetes, and cancer, new issues arise for patients who are living with these conditions as more chronic, long-term diseases. Both physical side effects and emotional issues such as anxiety and depression can reduce quality of life and even work productivity. The time for significant focus on broad innovation in this space has arrived. Examples could include improving supportive care agents and mechanisms or technologies and platforms for simplified disease/recurrence monitoring. New, bold advances would ensure optimal patient experience and support health-related quality of life along with physical, cognitive, and emotional functioning.

In conclusion, we share our [letter to Congress](#) that contains our specific responses and recommendations to the questions asked in the 21st Century Cures 2.0 Discussion Draft: Sec. 501. Advanced Research Projects Agency for Health (ARPA-H) Proposal.

We look forward to working with your offices to further develop and implement ARPA-H. We respectfully request to be included in any stakeholder or community discussions with your staff to learn more about your vision and plans, and to exchange ideas and perspectives to improve outcomes for the lung cancer community. Please have your staff contact Elridge Proctor, Senior Director, Government Affairs with any questions or information at 202-669-5547 or Eproctor@go2foundation.org.

With Sincere Regards,



Laurie Fenton Ambrose
Co-Founder, President & CEO
GO2 Foundation for Lung Cancer

cc: Xavier Becerra, Secretary of Health & Human Services
cc: US House Representative Diana DeGette
cc: US House Representative Fred Upton

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