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Federally Funded Cancer Research: Coordination and Innovation

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Thank you Chairman Chaffetz, Ranking Member Cummings, and Committee members for the invitation to join you to discuss innovation and coordination in federally-funded cancer research.

My name is Mary Beckerle and I serve as CEO and Director of Huntsman Cancer Institute at the University of Utah. I also oversee a research laboratory at HCI that has been funded by the National Institutes of Health (NIH) for over 25 years. My work is focused on fundamental aspects of cell biology and the application of this knowledge to a bone cancer called Ewing sarcoma. I also served last year on the NCI's Cancer Moonshot Blue Ribbon Panel.

Huntsman Cancer Institute (HCI) is one of 69 National Cancer Institute (NCI)-designated cancer centers, the highest designation possible for a cancer research institution. NCI-designated cancer centers undergo rigorous peer review by national cancer experts and thought leaders and must demonstrate depth and breadth of cancer research that spans from bench to bedside. Simply put, the goal of the Cancer Centers Program is to accelerate scientific discovery to improve cancer prevention and treatment. The Cancer Centers Program provides a national network for innovation and coordination that promotes collaboration and synergy to make the whole greater than the sum of the parts.

HCI is the only NCI-designated Cancer Center in the five-state Mountain West, which represents 17% of the continental landmass of the United States. The area we serve includes Utah, Nevada, Montana, Wyoming, and Idaho. Cancer patients and their families come to HCI from this entire region and beyond to access advanced cancer knowledge and care, including clinical trials that explore the most promising new cancer treatments. HCI is a hub for innovative cancer research with over 475 active research projects, which collectively were supported with \$62.9 million in research grant and contract funding in 2016.

Research is our best defense against cancer. Everything we know today about caring for people with cancer is built on decades of research, including basic discovery science, which provides the foundation on which the cancer prevention and treatment strategies of today – and tomorrow – depend.

We are in an incredibly exciting and promising time in cancer research, and our national investment is having an impact. Consider the following:

- The cancer death rate has declined by 1 percent each year for more than two decades, resulting in more than 1 million lives saved.
- The number of cancer survivors in the USA has quadrupled since the 1970s, reaching 15.5 million this year.
- According to the most recent [AACR Cancer Progress Report](#), in just the last 18 months, the FDA has approved 17 new drugs to treat a variety of cancers. These treatments are saving and improving lives, and they only exist because of research.

In addition to the tremendous health benefits of the federal investment in cancer research for the health of our citizens, this investment also contributes to our economy and helps to retain our nation's prized status as the world leader in science and innovation.

Despite our great progress, we have **much more to do**. Cancer is complex: cancer research has taught us that cancer is not a single disease as originally envisioned when the War on Cancer was initiated in 1971 during the Nixon administration, but rather is a collection of more than 200 different diseases.

Cancer remains the major medical challenge of our time: today, one of every four deaths in our country is caused by cancer; we lose one person every minute of every day to this disease. Cancer is the **number one** cause of disease-related death among children in the USA. This year, in the United States alone, nearly 1.7 million people will receive a cancer diagnosis.

Today, I want to share some concrete examples about how one federally funded Cancer Center, Huntsman Cancer Institute, is making a difference for cancer patients and their families. I will describe how our goals are coordinated with national strategic cancer priorities, as well as aligned with the cancer burden in our State and region.

Cancer Genetics and Colon Cancer:

At HCI, a major focus is cancer genetics. HCI is the steward of the Utah Population Database, the largest genetic database of its kind in the world, with over 25 million records. In a way that fully protects individual privacy, information in the database, including “family trees”, can be linked to clinical records, so we can detect cancer that runs in families and study cancer in the population of an entire State. This has allowed Utah scientists to discover the genes responsible for many inherited cancers, including colon cancer, breast and ovarian cancer, and melanoma.

What does this mean for patients? Consider this story about a Utah man named Gregg Johnson and his family history of colon cancer.

Members of Gregg’s family have a disease called “FAP”. Certain family members have inherited a gene mutation that means they almost certainly will develop colon cancer in their lifetimes. Sophisticated genetic testing has enabled us to identify which individuals in Gregg’s family are at high risk for colon cancer and ensure that they are advised about cancer screening options that can detect cancer early when it is treatable, or prevent the cancer from developing in the first place.

Back in Utah, Gregg Johnson is hoping to outlive his family history. He shared his story with Vice President Biden when the Vice President visited Huntsman Cancer Institute in 2016. Gregg stood before a diagram of his family tree and pointed to his grandmother and his mother, both of whom died of colon cancer when they were in their 40s. Gregg is now approaching 60 years of age, thanks to genetic knowledge and annual colonoscopies to find and remove pre-cancerous polyps. We call this general approach “precision prevention”. This is a promising area that was highlighted as a strategic opportunity by the Cancer Moonshot Blue Ribbon Panel.

Meanwhile, federal funding has continued to advance science to help families like Gregg’s by supporting the study of the FAP cancer pathway by many labs around the country. And, just last year, HCI scientists reported very promising results from a study of the first prevention treatment for these colon cancer families.

Thanks to collaboration and coordination, we are able to conduct cancer research across the entire State of Utah. Along with Intermountain Healthcare, HCI studied more than 2 million individuals in the Utah Population Database and determined how family history of colon cancer impacts individual risk. This research led to new guidelines for colon cancer screening based on family history of disease that have been disseminated worldwide. In another statewide study, we learned why some colon cancers are missed during regular colon cancer screening, a finding that has led to new colonoscopy guidelines.

Pediatric cancers:

In Utah, we have the youngest population in the country, thus we have a disproportionate burden of children’s cancers. At HCI we are testing an innovative new treatment for Ewing sarcoma, the second most common bone cancer in children and young adults. We are also addressing the long-term effects of pediatric cancer treatments that can compromise the quality of life of our growing childhood cancer survivor population. Parents of children with cancer are understandably desperate to know about the risk to their other children. Scientists at HCI have used the Utah Population Database to show that when one child in a family has an early onset cancer diagnosis, other family members do have elevated risk of developing cancer. This has led to new guidance for pediatricians and pediatric oncologists.

Federal funding for childhood cancers has led to dramatic improvements in the pediatric cancer five-year survival rate which has gone from 50% to about 80% since 1975. But there are still some childhood cancers for which progress has remained elusive, and cancer remains the leading cause of disease-related death in children. Here again, the Blue Ribbon Panel has put forward exciting proposals to accelerate progress in this

important area that will move be able to move forward if our national commitment for support of cancer research is sustained.

Cancer in underserved populations:

Finally, I will point out that even in this great nation, not everyone has equivalent access to the remarkable advances in cancer prevention and care. One underserved group that is not frequently highlighted is our rural and frontier residents. Ninety-six percent of the State of Utah is rural, with less than 100 persons per square mile, and 70% is frontier, with less than 7 persons per square mile. Recent research at HCI developed a new approach for remote symptom management to support cancer patients and their families that live far away from medical centers. This approach resulted in significant improvement in symptoms for patients in active treatment and also improved quality of life for the caregiver in the home. We have also tested a telephone-based method to deliver remote genetic counseling, effectively delivering information about inherited cancer risk outside of a major medical center.

Here I have described just a tiny amount of the important work going on at HCI as a result of federal funding for cancer research. This type of progress is replicated across our nation from sea to shining sea.

Our federal government has an unmatched and irreplaceable role in supporting cancer research. No other public, corporate, or charitable entity is able to provide the broad and sustained investment in research necessary to enable successes such as the ones I have noted today. Our continuing and future success requires an unwavering and bipartisan commitment from Congress and the Administration to continue to invest in life-saving biomedical research.

The need is great and the time is right. Research is the hope for the future.

I thank you for the opportunity to discuss this important national health issue and for your support of funding for the National Institutes of Health and the National Cancer Institute.