Committee on Oversight and Government Reform United States House of Representatives

March 29, 2017

Federally Funded Cancer Research: Coordination and Innovation

Testimony by Mary C. Beckerle, PhD

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Salt Lake City, UT

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 <u>AACR Cancer Progress Report</u>, 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 APC cancer pathway by many labs around the country. And, just last year, HCl 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 had 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 HCl 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 HCl 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.

Committee on Oversight and Government Reform Witness Disclosure Requirement — "Truth in Testimony"

Pursuant to House Rule XI, clause 2(g)(5) and Committee Rule 16(a), non-governmental witnesses are required to provide the Committee with the information requested below in advance of testifying before the Committee. You may attach additional sheets if you need more space.

Name: Mary C. Beckerle, PhD

Name of Entity	are testifying on behalf of and briefly describe your relationship with these entities. Your relationship with the entity							
Huntsman Cancer Institute	CEO and Director; Principal Investigator of NIH-funded laboratory							
2. Please list any federal grants	or contracts (including subg	rants or subcontracts)	you or the entity or enti	ties listed above have r	received since			
January 1, 2015, that are related								
Recipient of the grant or	Grant or Contract	Agency	Program	Source	Amount			
contact (you or entity above)	Name	Agency	Trogram	Source	Amount			
see attached								
. Please list any payments or co	ontracts (including subcontr	acts) you or the entity	or entities listed above	have received since Ja	nuary 1, 2015 fr			
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			Program	have received since Ja	Amount			
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foreign government, that are re Recipient of the grant or ontact (you or entity above)	Grant or Contract	earing.						

I certify that the information above and attached is true and corre	ct to the best of my knowledge.	
Signature Mary Bedard	Date: 03/28/2017	Page of

Committee on Oversight and Government Reform Beckerle Witness Disclosure Requirement – "Truth in Testimony" additional sheets

Please list any federal grants or contracts (including subgrants or subcontracts) you or the entity or entities listed above have received since January 1, 2015, that are related to the subject of the hearing.

Recipient of the Grant (Principal Investigator)	Grant or Contract Name	Agency	Program / Source	Project Number	Project Start Date	Project End Date	Project Title	Amount (Reporting reflects annual costs for calendar year 2016)
Beckerle M	Structure and Function of Stress Fibers and Cell Adhesion Sites	HHS	NIH / NIGMS	R01GM050877 -20	5/1/1994	11/30/2017	Structure and Function of Stress Fibers and Cell Adhesion Sites	\$51,152
Beckerle M	Cancer Center Support Grant	HHS	NIH / NCI	P30CA042014 -27	5/9/1997	4/30/2020	Cancer Center Support Grant	\$2,235,000
Beckerle M/ Sharma S	Experimental Therapeutics Clinical Trials Network (ETCTN)	HHS	NIH / NCI	P30CA042014 -27	5/1/2016	4/30/2019	Experimental Therapeutics Clinical Trials Network (ETCTN)	\$49,943
Beckerle M/ Agarwal N	Cancer Clinical Investigator Team Leadership Award (CCITLA)	HHS	NIH / NCI	P30CA042014 -27S1	7/8/2015	4/30/2017	Cancer Clinical Investigator Team Leadership Award (CCITLA)	\$16,667
Beckerle M/ Lopez A	Geographic Management of Cancer Health Disparities (GMaP)	ннѕ	NIH / NCI	P30CA042014 -27S2	7/8/2015	4/30/2018	Geographic Management of Cancer Health Disparities (GMaP)	\$249,799
Beckerle M/ Lopez A	Community Outreach Capacity through Community Health Educator (CHE) of the National Outreach Network (NON)	HHS	NIH / NCI	P30CA042014 -27S3	7/8/2015	4/30/2018	Community Outreach Capacity through Community Health Educator (CHE) of the National Outreach Network (NON)	\$123,315
Beckerle M/ Hashibe M	Promote Cancer Prevention and Control Research in Low and Middle Income Countries (CPCR)	HHS	NIH / NCI	P30CA042014 -27S4	7/8/2015	4/30/2017	Promote Cancer Prevention and Control Research in Low and Middle Income Countries (CPCR)	\$165,650

Beckerle M/ Werner T	Cancer Clinical Investigator Team Leadership Award (CCITLA)	HHS	NIH / NCI	P30CA042014 -27S5	5/1/2016	4/30/2018	Cancer Clinical Investigator Team Leadership Award (CCITLA)	\$59,998
Beckerle M/ Lopez A	Continuing Umbrella Research Experiences (CURE)	HHS	NIH / NCI	P30CA042014 -27S6	5/1/2016	4/30/2020	Continuing Umbrella Research Experiences (CURE)	\$113,250
Beckerle M/ Welm A	Administrative Supplements to Support Collaborative Research Efforts to Enhance Preclinical Trials Utilizing Patient Derived Xenograft (PDX) Models	HHS	NIH / NCI	P30CA042014 -27S7	5/1/2016	4/30/2017	Administrative Supplements to Support Collaborative Research Efforts to Enhance Preclinical Trials Utilizing Patient Derived Xenograft (PDX) Models	\$750,000

Biography for Mary Beckerle, PhD CEO and Director, Huntsman Cancer Institute at the University of Utah

Mary Beckerle, PhD, has served as Chief Executive Officer and Director of Huntsman Cancer Institute since 2006. Beckerle joined the faculty of the University of Utah in 1986, where she is a distinguished professor of biology and oncological sciences. She earned her PhD in molecular, cellular, and developmental biology from the University of Colorado at Boulder, and completed post-doctoral research at the University of North Carolina at Chapel Hill.

Beckerle's research has defined a molecular pathway that regulates how cells move throughout the body. The studies conducted in her laboratory have defined the molecular machinery involved in cellular events critical for tumor metastasis, organ formation, and wound healing. Her lab is focused on understanding the impact of this pathway on tumor progression, particularly in Ewing sarcoma, a rare but deadly cancer that typically strikes children and young adults. Her scientific work has been continuously funded by the National Institutes of Health (NIH) and the over 25 years. She leads a multi-investigator translational research grant focused on the development of a new therapy for Ewing sarcoma. She guided graduate education at the University of Utah as the director of the Interdepartmental Graduate Program in Molecular Biology for two years. In addition, Beckerle developed the Multidisciplinary Cancer Research Training Program at Huntsman Cancer Institute at the University of Utah and served for several years as the principal investigator of the National Cancer Institute (NCI) grant that supported this cancer-focused training initiative. Beckerle is the principal investigator of Huntsman Cancer Institute's NCI Cancer Center Support Grant (CCSG).

Beckerle previously served as president of the American Society for Cell Biology (ASCB), as Chair of the American Cancer Society Council for Extramural Grants. She currently serves on the Medical Advisory Board of the Howard Hughes Medical Institute, the NCI Initial Review Group (Subcommittee A) for Cancer Centers, and the Scientific Advisory Boards of the National Center for Biological Sciences in India, the Mechanobiology Institute in Singapore. She was selected by the National Cancer Institute to serve as a member of the National Blue Ribbon Panel on the Cancer Moonshot Initiative in 2016.

She received the Utah Governor's Medal for Science and Technology in 2001, the Sword of Hope Award from the American Cancer Society in 2004, and the Rosenblatt Prize for Excellence (the University of Utah's highest honor) in 2007. Beckerle was elected as a Fellow of the American Academy of Arts and Sciences in 2008.