U.S. Senate Committee on Health, Education, Labor and Pensions Cancer: Challenges and Opportunities in the 21st Century May 8, 2008

Written Testimony of Lance Armstrong Founder and Chairman Lance Armstrong Foundation

Mr. Chairman, members of the Committee, thank you for inviting me to testify before the Senate Committee on Health, Education, Labor and Pensions today. I am honored to be here with you. Chairman Kennedy, I applaud you and Senator Enzi for your leadership in renewing our nation's focus on cancer.

Much has happened in the 37 years since Congress passed the National Cancer Act. Chairman Kennedy, I know you played a key role in the passage of that historic legislation. Our National War on Cancer has made much progress since 1971. Thousands of lives have been saved and we have improved the lives of many more. Still, we can and must do better.

After I was diagnosed with cancer in 1996, I founded the Lance Armstrong Foundation (LAF), a 501(c) (3) national nonprofit organization based in Austin, Texas. The LAF engages Americans to pursue an agenda focused on preventing cancer, ensuring access to screening and care, improving the quality of life for people affected by cancer, and investing in needed research. The LAF is committed to making cancer a national priority through our advocacy initiatives.

The facts are staggering. 565,000 Americans will die of cancer in 2008 - more than 1,500 people a day. 1.4 million Americans will hear the words, "you have cancer" this year. Cancer is already the leading cause of death for Americans under the age of 85, but it is certain to become the leading cause of death for all Americans in the next decade as the "Baby Boomer" generation ages.

I was honored to be asked by President Bush to serve two terms on the President's Cancer Panel. The Panel was established by the National Cancer Act of 1971 to monitor the development and execution of the activities of the National Cancer Program, and report directly to the President. Before my second term expired this year, I had the privilege of working with national cancer experts such as Dr. Harold Freeman, Dr. LaSalle Lefall and Dr. Margaret Kripke. During my six years on the Panel, I contributed to the creation of four sets of recommendations to the President of which I am very proud. But I feel that as much as I contributed, I've learned even more in the process. Traveling the country as a member of the Panel, I learned that as a Nation, we know what it takes to save lives. But what we know and what we do are two different things.

Through my service on the President's Cancer Panel, I have seen firsthand the toll this disease takes on America and recognized it for the epidemic that it truly is. The recommendations made to the President by this Panel are ones that I stand behind and fully support. In fact, my foundation has made them cornerstones of our policy platform and our advocacy efforts. But sadly, one of my biggest frustrations throughout my service on the Panel is that very few of the recommendations we made ever came to fruition.

We have the ability and power to improve access to quality health care for cancer patients while lowering the personal costs of treatment. We can also cure many who have cancer and improve their quality of life.

Tragically, we do not use all available policy and regulatory tools at our disposal to optimize what we can control; nor do we deploy sufficient resources to stimulate scientific discovery and translation which hold enormous promise. Thanks to your leadership, we have an opportunity to renew our efforts in four key areas:

Access to Care

Nearly 47 million Americans lack health insurance, and about 16 million more are underinsured. Study after study has shown that those who lack insurance or are underinsured have higher cancer mortality rates than those who have insurance and therefore better access to care. Healthcare coverage and financial concerns should not dictate who lives, who dies, and who suffers unnecessarily. And yet all too often, it does.

Quality cancer care means ensuring that people with cancer have access to treatment that has been proven successful and is appropriate. It means services are delivered in a patient-centered, timely, and technically competent manner. And, it depends on good communication and shared decision making between the patient and provider in a culturally sensitive manner across the continuum of care and throughout the remainder of life. We do not take full advantage of what we already know about delivering high quality cancer care. It is fundamentally and morally untenable that a world class-athlete who has been diagnosed with testicular cancer should have a better chance of surviving than an African American resident of Harlem who has been given the exact same diagnosis. Yet minority and poor populations carry a disproportionate burden of the negligent cancer care in the United States - even when adjusting for socioeconomic factors.

Quality of Life

We must improve the quality of life for people affected by cancer. Providing access to quality cancer care and improving quality of life are intertwined.

In 1971, there were three million cancer survivors in the United States. At that time, cancer was largely a death sentence. Today there are 12 million Americans living with the disease. Addressing the needs of this growing population is critical.

Quality of life means different things to different people. Broadly speaking, quality of life for those living with cancer may encompass physical well being, including symptom management; psychological and social issues; emotional well-being; and spiritual considerations.

Cancer survivors should be provided access to treatment summaries and survivorship care plans. Patients starting treatment should be provided written documentation that details all elements of their treatment and those completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. These resources allow cancer survivors to play a critical role in their treatment decisions and provide much needed documentation of their treatment history. This service should be uniformly reimbursed by third-party payors of health care.

Psychosocial support is absolutely critical to the quality of life of cancer patients and survivors, yet the healthcare system's provision thereof often abysmal or nonexistent. We must ensure that clinicians incorporate psychosocial management as an integral part of treatment.

Cancer survivors are at increased risk of experiencing employment and insurance discrimination. Signing the Genetic Information

Nondiscrimination Act (GINA) into law will go a long way to provide protections against the use of genetic information in health insurance coverage and employment decisions. Even with the passage of GINA, the fact that cancer survivors are consistently denied health coverage due to pre-existing condition classifications must also be addressed.

Pain management and palliative care for cancer patients and survivors is in need of improvement. Pain is the number one symptom cited in cancer as well as a host of other diseases, yet it is continually left under-treated. The appropriate management of severe symptoms such as pain, nausea and vomiting is not only central to quality of life, but it also has implications for the efficiency of the health care system.

Cancer Management

Managing cancer involves activities that aim to prevent or cure cancer and increase survival and enhance quality of life for those who develop the disease. We must deliver the knowledge we have gained through research into strategies and services to the general public.

We can have a measurable impact if we just apply what we know. We have the tools to detect many of the more common cancers earlier, when they are most treatable.

The U.S. Preventive Services Task Force (USPSTF) first recommended that Americans 50 and older be screened for colon cancer in 1996. If colorectal cancer is discovered early, before it has spread, the fiveyear survival rate is 90%. If colorectal cancer is discovered after it has spread to distant parts of the body, only 10% of patients survive five years.

If all adults 50 and older were screened for colon cancer, we could save approximately 30,000 lives per year, cutting the death rate from this disease in half. Yet today, 12 years after the USPSTF first recommended this screen, we still have no federal screening program for low-income and uninsured Americans.

Timely and regular mammography screening would prevent up to 30 percent of all deaths from breast cancer in women over the age of 40. Pap tests and the widespread use of the HPV vaccine can prevent virtually all deaths from cervical cancer.

Yet today, the National Breast and Cervical Cancer Early Detection program, administered by the Centers for Disease Control and Prevention, only reaches 20 percent of eligible women between the ages of 50-64 with current levels of funding.

We also need a unified and evidenced-based national cancer prevention and cessation campaign to reduce the use of tobacco products. Almost one out of every three cancer deaths in the U.S. - 170,000 people a year - is the result of tobacco use. These deaths are entirely preventable.

Research

Simply applying what we already know about cancer prevention and early detection is not enough. For many Americans who die every day from terminal cancers, such as lung and pancreatic cancer, there is little known about how to effectively detect their disease early enough to decrease mortality.

For these people, research could provide the answer. We need to accelerate our investment in research on better detection methods for the deadliest cancers. We must improve treatment options so they will only attack the cancer cells and reduce the overall damage to the patient. And we need to develop treatments to control and manage cancer, much as high cholesterol and heart disease are managed conditions today. This is all within the realm of medical science, but it will take a renewed and constant effort to become reality.

Unfortunately, our Nation's commitment to cancer research has fallen flat over the past few years. National Cancer Institute (NCI) funding for cancer research has been level since 2005. I applaud the Senate for taking a bold step by passing the Harkin-Specter amendment to the Budget in March, supporting a 10% increase in funding for the National Institutes of Health (NIH) for FY 2009. It is my hope that this initial first step will allow Congress to get our national investment in biomedical research back on track through the appropriations process.

This is not a time when we should be decreasing our investment in extraordinary federal research opportunities. Federal investments in cancer research have yielded remarkable results. Several drugs developed and/or tested by NIH-supported scientists have been proven effective in treating and sometimes preventing certain types of cancer. New, more precise ways to treat cancer are also emerging, such as drugs that target abnormal proteins in cancer cells and leave healthy tissue alone.

Investing more money in cancer research is necessary, but not sufficient. We must also use strategies that improve the incentives for scientists, restructure the enterprise to encourage collaborative team science, and support best practices and common sense in clinical trials and the translation of discoveries into practice.

The federal government faces significant challenges in coordinating research to improve cancer treatment, building effective cancer prevention programs, deploying quality cancer care delivery systems, and paying for quality care for cancer patients who depend on federal health care programs.

In light of these challenges, we need a broad-based national cancer plan that aligns our research priorities with those for cancer prevention, early detection, treatment and survivorship. The NCI is doing great work in conducting cancer research, but our national plan must be broader than just cancer research. Too much knowledge sits on a shelf, never translated from the laboratory to the clinic. And effective evidence-based strategies for prevention and early detection remain underutilized costing America hundreds of thousands of lives.

Our national cancer plan should be a multi-disciplinary, cross agency approach that leverages the strengths of the various federal agencies and remains accountable for developing results in comprehensive cancer control and care. Ultimately, we need strong leadership that responds to the needs of the American public, can implement the plan, is backed with the resources to achieve the goals, and has the authority to facilitate communication and collaboration across diverse federal agencies that are engaged in cancer research, prevention, and care.

In 1999, after I won the Tour de France for the first time, I testified on Capitol Hill before the Joint Economic Committee about the promise of biotechnology. At that time, I indicated that I was a living example of what cancer research can do. If I had been diagnosed in 1971 rather than 1996, I would have likely died from the cancer that had invaded my body.

During that same hearing, my doctor, Dr. Larry Einhorn, testified that cancer was the scourge of the 20th century and if we don't accelerate our efforts, it will be the scourge of the 21st as well. Our national war against cancer has made some progress since I testified nine years

ago, but we still have a long way to go to eliminate suffering and death due to this disease.

It has been 37 years since the United States first declared war against cancer. I applaud the Committee for your interest in renewing the fight against this disease and look forward to working with you, Senator Hutchison and other Members of Congress on this effort. We have new knowledge and new tools ready for deployment. And through your leadership, we can change the way our country is fighting cancer in the 21st century.