LANCE ARMSTRONG
FOUNDATION
LIVESTRONG

Parliament of Australia – Senate Community Affairs Committee
Inquiry into Services and Treatment Options for Persons with Cancer
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Testimony of Doug Ulman
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Thank you very much for giving the Lance Armstrong Foundation (LAF) this opportunity. As the Director of Survivorship Programs at LAF, I would like to comment on the state of cancer survivorship activity in the United States and offer some thoughts on your priority discussion areas.

LANCE ARMSTRONG FOUNDATION BACKGROUND

The LAF believes that in your battle with cancer, knowledge is power and attitude is everything. Founded in 1997 by cancer survivor and cycling champion Lance Armstrong, the LAF provides the practical information and tools people living with cancer need to live strong. We serve our mission through four core program areas:

Education - The LAF informs cancer patients, health care professionals and the public about the physical, emotional and practical issues that people face in their battle with cancer. We provide the information and resources people need to live strong.

Advocacy - The LAF represents people living with cancer on Capitol Hill. We are increasing awareness, encouraging the government to take action, and addressing the health policy concerns of people and their families battling cancer.

Public Health - The LAF plans, develops and funds programs that provide after-treatment support and services for people living with cancer and their families.

Research - The LAF supports scientific and clinical research that seeks to better understand cancer's physical, emotional and practical effects and the challenge of living with the disease.

U.S. CANCER BURDEN AND THE NEED

Cancer affects a staggering number of people in the United States, both individuals diagnosed with the disease and their families and friends. The following statistics give some perspective on the U.S. cancer burden:

- More than 10 million cancer survivors today (new data this month)
- More than 1.3 million people will be diagnosed with cancer this year
- 3 out of 4 families will help care for a family member with cancer

- 60% of adults diagnosed with cancer today will be alive 5 years from now
- 70% of children under the age of 14 diagnosed with cancer today will be alive 5 years from now
- 1 in 3 people will be diagnosed with cancer during their lifetime

To better understand the needs of those whom we serve the LAF conducted a survey of more than 1000 cancer survivors in November of 2004. Information and results of the LIVESTRONG Poll are listed below:

- Nearly half (**49%**) of people living with cancer feel their non-medical – emotional, practical and physical – cancer needs are currently unmet by the healthcare system.
- Among those who felt non-medical cancer needs were unmet, **70%** said their oncologists did not offer any support in dealing with the non-medical aspect of cancer, such as infertility, depression and fear of recurrence.
- The other **30%** said their oncologist was willing to talk about these issues, but did not have enough information or experience to really help them out in this area.
- The critical need for non-medical support is evidenced by the fact that more than half (**53%**) of respondents said they agree that the practical and emotional consequences of dealing with cancer are often harder than the medical issues.
- One third (**33%**) of people living with cancer said some or very few resources were available to meet their emotional needs directly connected to the cancer, compared to **28%** for practical issues, like finance and work, **23%** for physical issues and **14%** for medical issues.
- **78%** of respondents said they did not seek out the services of a counselor, social worker, psychologist or psychiatrist as a result of having cancer.
- People living with cancer are optimistic about life. Nearly three out of every five (**59%**) of the respondents say they expect to die from something completely different than cancer.
- People living with cancer also say their lives have changed as a result of the disease, with **57%** agreeing that cancer may leave their body, but it will always be a part of their life.
- Cancer has had a positive effect on the lives of some. Almost half (**47%**) agreed that dealing with their cancer diagnosis forced them to focus and they feel they're leading a better life now.
- More than half want to share their experience with others. **56%** agreed that they now take a more active role in speaking up about cancer and urging people to get screened.

SELECTED LAF PROGRAMATIC ACTIVITIES

National Action Plan for Cancer Survivorship: Advancing Public Health Strategies

The LAF recently joined forces with the Centers for Disease Control and Prevention (CDC) to lead a public health effort to address the issues faced by the growing number of cancer survivors. Our collaboration, *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*, charts a course for the public health community to more effectively and comprehensively address cancer survivorship with the goal of improving the quality of life for survivors, including:

- Preventing secondary cancers and recurrence of cancer whenever possible.
- Promoting appropriate management following diagnosis and/or treatment to ensure the maximum number of years of healthy life for cancer survivors.
- Minimizing preventable pain, disability, and psychosocial distress for those living with, through, and beyond cancer.
- Supporting cancer survivors in accessing the resources and the family, peer, and community support they need to cope with their disease.

LAF Community Grant Program

The LAF seeks to help develop innovative projects that encourage survivors to live strong through the physical, emotional and practical challenges of their survivorship. Since its inception, the LAF has helped provide services to more than 50,000 people by providing funding and practical advice to more than 100 programs across the country. From programs that provide art therapy to programs that use yoga to improve strength, flexibility, endurance and mental health, the LAF continues to fund initiatives that help cancer survivors live strong. I will give two examples of programs that LAF recently funded:

> **Women & Infants Hospital of Rhode Island - Providence, Rhode Island**
> The Women & Infants Hospital of Rhode Island developed the ESCAPE (Empowering Survivors of Cancer through Awareness, Prevention, and Education) program to provide advocacy, education and support for cancer survivors and their family members. A community grant from the LAF helped create the new position of patient advocate. Working with cancer survivors ranging in age from 20 to over 90, the patient advocate ensures that patients and families understand late effects of treatment, cancer recurrence, follow-up care and monitoring of cancer, to optimize quality of life.
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> **American Indian/Alaska Native Cancer Pain Education Curriculum Train-the-Trainer Program -- The UnBroken Circle - San Francisco, CA**
> This grant allowed the printing and dissemination of a three-module American Indian/Alaska Native Cancer Pain Education Curriculum and its associated materials to tribal health programs nationally. The LAF funds made the material widely available to tribal health organizations, tribal health consortiums and Native cancer survivor support groups who were in the position to train trainers, educate their constituents and communities about cancer pain, and advocate for optimal pain management for Native cancer survivors experiencing pain.

LAF Survivorship Center Network Initiative

To help accelerate the pace of progress in addressing the needs of the growing survivor community, the LAF plans to establish a network of Cancer Survivorship Centers intended to serve as comprehensive, one-stop sources of information, care, and services for cancer survivors, family members, and service providers. The proposed network represents a web of collaborative entities comprising of Centers of Excellence in Cancer Survivorship, located at National Cancer Institute-designated comprehensive cancer centers. Linked to these Centers of Excellence will be community-based cancer centers and programs, including those located in traditionally underserved areas, which provide direct services to individuals living with, through, and beyond cancer in their communities. The goals of this initiative are to:

- Increase the quality of life for people living with, through, and beyond cancer;
- Catalyze the transformation of the manner in which cancer survivors are treated and served;
- Contribute to the development of an integrated, coherent body of knowledge about survivorship and its treatment and service requirements;
- Contribute to the development of evidence-based interventions capable of enhancing the health and well-being of cancer survivors;
- Significantly increase: (i) the quality and integration of the full range of survivorship services; (ii) accessibility to these services through community-based centers; and (iii) the degree to which survivorship care and services complement primary cancer treatment and care; and

- Contribute to the development of insurance policies, reimbursement mechanisms, and other financial strategies for covering the costs of survivor care and services and for sustaining the life of survivorship centers over the long term.

CONCLUSION

The cancer survivorship movement needs to continue to raise awareness of the issues impacting the millions of cancer survivors worldwide. This will ultimately lead to additional research, programs and public policy change which will increase the quality of life for those with cancer.

Thank you once again for the opportunity to address you today. I am more than willing to answer any questions that you might have.

Thank you.