

# **TESTIMONY**

**Susan Kenyon Parsons, MD, MRP**

Member, National Cancer Legislation Advisory Committee  
Assistant Professor in Pediatrics, Harvard Medical School

\*\*\*\*\*

## **Hearing of the United States Senate Cancer Coalition**

National Cancer Legislative Advisory Committee Report  
Conquering Cancer: A National Battle Plan to Eradicate Cancer in  
Our Lifetime

October 10, 2001

**The Honorable Dianne Feinstein**  
**The Honorable Sam Brownback**  
**Co-Chairs**

**Testimony before the Senate Cancer Coalition**  
**Dr. Susan K. Parsons**  
**October 10, 2001**

I would like to extend my thanks to Senators Feinstein and Brownback and my colleagues on the National Cancer Legislation Advisory Committee for the opportunity to share these comments with you today.

For the past 25 years I have worked in the health care field, initially as a health economist and more recently, as a pediatric oncologist at the Dana-Farber Cancer Institute in Boston. My principal focus clinically is in pediatric bone marrow transplantation. My research focuses on the evaluation of quality of life for children with cancer and the long-term clinical and psychosocial sequelae of treatment. I have had the privilege of serving on NCLAC, leading discussions on the access and delivery of cancer care.

A national cancer program clearly must include an emphasis on biomedical research and the translation of new information from the laboratory to the bedside in addition to the delivery of quality care to all Americans with cancer. One of the biggest challenges in formulating cancer policy is to create the appropriate balance of resource allocation to allow the program to move forward in all of these areas. There is a long, contentious history of tension within and outside the cancer community about what is appropriate resource allocation.

As my colleagues have just articulated, there is no debate about the importance of scientific discovery and translation in our attempts to eradicate cancer. We must not lose sight, however, of the fact that every day people are living with and dying from cancer within an imperfect health care system.

Having just completed a month of clinical service, covering our institution's 13-bed intensive care level transplant unit, I would like to bring a human face to this discussion. Consider with me the case of one of my patients, a 10-year old girl with a recurrent brain tumor, fighting for her life after sustaining a severe complication of her transplant. This child lost her father, a non-smoker and marathon runner, to lung cancer when she was three years old. At the age of 6, her widowed mother was diagnosed with an inoperable brain tumor. Her mother died when this child was only 8. Ten months after her mother's death, orphaned by cancer, my patient was also diagnosed with a malignant brain tumor.

Although she responded favorably to initial treatment, her disease recurred this year. She underwent a bone marrow transplant in upstate New York. After developing a life-threatening complication, she was

airlifted to our center in Boston to participate in a Phase II clinical trial of an agent to treat this complication. This promising agent is already approved and widely available in Europe. Her care required extensive coordination among research pharmacists, specialty nurses, clinical subspecialists, and the clinical research team to provide life-saving treatment while also performing rigorous clinical investigation. I can personally attest to the complexity of her care, having spent the lion's share of the past month at her bedside.

What is striking about this case is not its uniqueness. This case exemplifies the points I would like to make about this report and these policy issues. Specifically, this case illustrates the need for improved access to care, a workforce adequate in number and training to address the complex nature of cancer care, and an appreciation of the long term effects of the disease and its treatment on people living with cancer.

- Access

While better understanding about the interactions between genetic and environmental factors, predisposing this child and her family to cancer is a pivotal part of the discovery process, that knowledge does not serve this child now. This child and the millions of other patients diagnosed each year require access to an expert health care system that can address the myriad issues that accompany the diagnosis of cancer.

This child, despite her tragic situation, was fortunate enough to have extraordinary family support and the resources to get the care she needed. With their help, she was able to find and participate in a promising clinical trial. Many others are not as lucky. Ensuring that Americans have adequate health insurance for the prevention, detection, and management of cancer is a cornerstone to making the progress outlined in this report. The most elegant solutions discovered cannot be applied without addressing the economic and geographic barriers to care faced by millions of Americans.

- Workforce

In addition to economic and geographic access, high quality cancer care requires sufficient numbers of adequately trained health care workers to provide this care. This workforce must include the full complement of physicians, nurses, pharmacists, psychosocial and resource specialists who can identify and manage the clinical, developmental and psychosocial factors influencing patients' ability to endure the diagnosis and its treatment. And what if the workforce isn't there? Current projections indicate that we are or will soon be facing this very real problem. Without an adequate workforce, we will be unable to take full advantage of our progress in scientific discovery.

- Quality of Life/Late Effects

As someone who works with children who survive their cancer and its treatment, I see on a daily basis the medical and psychosocial effects of their disease and its treatment. These physical, emotional and social challenges they face have lasting impact on them, their families, and their communities. More research addressing quality of life and symptom management across the age and illness continuum must also be included in funded cancer research mandate. The knowledge gained from research in these areas will guide the development of appropriate interventions and guidelines to ensure the highest quality cancer care delivered to those in need.

In closing, from my perspective as both a clinician-researcher and health economist, the recommendations of this report must be considered in their totality to realize the full potential of a national cancer program. Anything less would severely hinder our ability to eradicate this dreadful disease.