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For My Son

BY RICHARD NARES

Livestrong Day

Looking from the airplane window as I traveled from San Diego to Washington, D.C., I reflected on my journey and its purpose to advocate on behalf of San Diego families, and all families whose children have cancer. My mind and heart filled with hope and anticipation as the reality sunk in that I had been chosen to participate in the Lance Armstrong Foundation's LIVESTRONG Day on Capitol Hill, a day in May when 100 survivors and co-survivors were given the chance to share our concerns and knowledge with elected leaders to influence national policymaking to improve the status of cancer research and survivorship.

The LAF has given me opportunities I never dreamed of to serve families impacted by cancer. I do this in honor of my son, Emilio, whom I lost to cancer six years ago. Indeed, my story is one of hope, courage, life, and death. But most importantly it is a story of the most profound love possible, the love of a parent for his child.

One year after I married my wife, Diane, our son Emilio was born. He was the center of our universe and together we filled our lives with play, laughter, and love. The amazing adventures that I have experienced in my life never came close to the great satisfaction of living with Emilio. From a young age he was bright and funny, clever, and kind—a little boy with the wisdom of a saint. Through his infancy and toddler years, we had the time of our lives.

In the winter before Emilio's third birthday he came down with frequent colds, which our friends and pediatrician assured us was quite common at that age. Our concern increased when a persistent fever wouldn't go away. At this time, bruises started developing on his arms and legs, and Emilio was lethargic and pale.

Blood tests were run immediately and on the afternoon of March 25, 1998, we found out Emilio had leukemia. Shock, fear, and bewilderment took over. I felt as if I was watching a horror film that had no volume. The following days brought an abundance of medical information and the beginning of chemotherapy. A new way of life was forcing itself upon us. I realized that I could no longer control the

situation. I could not protect my son from the suffering that awaited him.

Emilio's journey involved two relapses and three remissions. Finally, his only chance to survive was a bone marrow transplant, but we never found a matched donor. Desperate, we traveled to Boston Children's Hospital in the summer of 2000 to be part of a clinical trial with myself as Emilio's donor. Three months short of his sixth birthday, Emilio's organs began to fail. He lost his courageous battle on October 15, 2000.

From the onset of our journey, we had tremendous support, but Diane and I were deeply aware that many families don't have this support. In response, Emilio's legacy now lives on as the Emilio Nares Foundation (www.emilionaresfoundation.org). Our mission is to secure the best possible treatment and highest quality of life for children with cancer, with an emphasis on low-income patients. We have served more than 3,000 families and added nearly 5,000 new stem cell donors to the San Diego Blood Bank.

Back in D.C., the participants gathered, acknowledged our home states and exchanged stories. Speakers informed us of the current status of cancer survivorship in the United States. We learned of the budget cuts and arguments that existed regarding funding research for cancer.

Then May 17 arrived—LIVESTRONG Day. When I saw the California state flag in front of Rep. Susan Davis's office, I felt a rush of honor and excitement. With great relief, I soon learned that not only Rep. Davis, but also California Senators Dianne Feinstein and Barbara Boxer each shared a commitment and dedication to support the need to increase awareness of and funding for cancer research. Their goal is to make the government more responsible to the more than 10 million cancer survivors in this country.

That evening, as I traveled back to San Diego, I witnessed the most beautiful and inspirational sunset. At that moment, I understood that our work was deeply meaningful and that we all need to keep the inspiration alive and continue the fight.