

Voices of Lung Cancer

**The Healing Companion:
Stories for Courage,
Comfort and Strength**

Edited by

The Healing Project

www.thehealingproject.org

“Voices Of” Series Book No. 1



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CancerCare

Diane Blum



Lung cancer is the most common cause of cancer death in the United States. Yet in 2000, a media survey by CancerCare confirmed that lung cancer was receiving far less coverage in print, broadcast, and online news than breast, colon and prostate cancers even though it claims more lives each year than these three other cancers combined. The survey also found that there were few celebrity spokespersons for lung cancer, few events to raise awareness, few first-person accounts about what it is like to live with the illness and little attention to progress being made in detection or treatment. Moreover, what little coverage there was of lung cancer was overshadowed by tobacco-related issues, something that both reflected and perpetuated a “blame the victim” attitude.

That same year, CancerCare launched Lung Cancer Awareness Week, a national campaign focused on disseminating information, erasing the stigma associated with lung cancer and increasing the overall understanding of the risks as well as the options available to patients diagnosed with this illness. Too often we saw how stigmatization led to isolation for people coping with lung cancer and frequently prevented them from understanding their treatment options. No matter what the cause of cancer—and keep in

mind that a high percentage of people diagnosed with lung cancer gave up smoking a long time ago—no one deserves to get it and everyone who does deserves to get the best possible treatment and care. They have a right to learn about resources available to them and their families, to ask for second opinions, to get help and to have hope.

It's been more than half a decade since *CancerCare's* media survey and the founding of Lung Cancer Awareness Week. In that time, we as a society have made great strides in providing comfort and support to people with lung cancer and their loved ones. This progress is the result of tireless efforts of many organizations and individuals dedicated to raising awareness and advocating for people with lung cancer. The media, too, is becoming a voice for this group. Newspapers and magazines have increased coverage of lung cancer issues, are less likely to focus solely on smoking and tobacco when reporting on it and offer more information on supportive care, clinical trials and research advances. As executive director of *CancerCare*, I've witnessed first-hand what the power of the media's attention can do to elevate national awareness and change public perception, and I have been fortunate to participate in the development of programs and services that share these goals.

In my position, I've been asked to support many publications aimed at people with cancer as well as books about cancer for the general public. I don't always take writers and publishers up on their offers, but once in a while a book comes along that not only really moves me, but also complements the mission of *CancerCare* to provide help and hope for all people affected by cancer. *Voices of Lung Cancer* is one such book. It is a rare tapestry of stories that illustrates the depth and variation of the lung cancer experience. The stories are written by people with cancer and by their spouses and partners, sons and daughters, brothers and sisters, caregivers and friends. The separate accounts weave together precious memories of life before cancer and tales of courage and strength in the face of diagnosis and treatment. Most of all, they

celebrate life and illustrate the love and support that carry us through adversity and give meaning to our lives.

If you or someone you love has lung cancer, always remember that there are others going through similar experiences that can provide inspiration and hope. These individuals, as well as many cancer organizations can offer valuable insight and information on practical issues such as treatment options, managing changes in your daily life caused by cancer, and caring for the needs of your family at this time. I hope that *Voices of Lung Cancer* gives you comfort and reminds you that you are not alone in fighting this illness.

Diane Blum is the Executive Director of CancerCare, a national nonprofit organization that since 1944 has provided free, professional counseling, education, financial assistance and practical help to millions of people affected by cancer. Co-founder of the National Alliance of Breast Cancer Organizations, Ms. Blum is a founder of National Breast Cancer Awareness Month and serves as Editor-in-Chief of People Living with Cancer, the patient education website of the American Society of Clinical Oncology (ASCO). Ms. Blum is the recipient of the Lifetime Achievement Award from the Board of Sponsors of National Breast Cancer Awareness Month, the Special Recognition Award from the National Coalition for Cancer Survivorship, the Republic Bank Breast Cancer Research Foundation Award and the Special Recognition Award of the American Society of Clinical Oncology.

Joan's Legacy

Susan C. Mantel



I come from one of those families that seem to be disproportionately affected by cancer—of all kinds, and with varying outcomes. I mention this because the prevalence of cancer in my life was a fact I only fully noted two years ago, shortly after I began working for Joan's Legacy: The Joan Scarangelo Foundation to Conquer Lung Cancer.

I was astonished that before joining Joan's Legacy, I knew so little about lung cancer, despite having had two uncles who were afflicted with it. The reality was that my family, like too many other families, did not have anyone with whom to share its experience, since 10 and 15 years ago people rarely spoke of their lung cancer. So in our isolation, we assumed that our experience was somehow unique, and we were left to make sense of it on our own, for better or worse.

Equally amazing to me is that Joan was one of more than 20,000 “never smokers,” 80% of whom are women, who get lung cancer each year. In fact, despite the widespread perception that lung cancer is a “smoker's disease,” more than 60% of patients diagnosed with lung cancer either never smoked or quit many years earlier. Although no one will claim smoking is good for you, the point is that smoking prevention and cessation programs will not cure

lung cancer. Only research into early diagnosis and successful treatment will do that.

To date, federal funding for lung cancer research has been woefully inadequate when compared to the amount of funding allocated for research into other forms of cancer. Currently, funding for lung cancer research is only \$1,829 per lung cancer death, compared to \$23,474 for breast cancer and \$14,360 for prostate cancer, both of which have early detection programs and highly successful treatments. This disparity highlights both lung cancer's lack of progress and the real impact that can be made with significant funding of research. This lack of attention to finding answers for those already affected by lung cancer inspired the brave founders of Joan's Legacy to undertake this huge challenge.

Now every day at Joan's Legacy, I am reminded that millions of other families have been affected by lung cancer as well, with about 164,000 new diagnoses each year. And I am inspired by the courage and wisdom of the many patients and families that I have the privilege of meeting every day.

No one deserves cancer, but everyone deserves support and love as they fight this challenging disease. All of us at Joan's Legacy are dedicated to funding research into earlier diagnosis and more effective treatment for lung cancer. We salute Debra LaChance and all who have shared their stories and are dedicated to making the voices of lung cancer heard.

Joan's Legacy: the Joan Scarangelo Foundation to Conquer Lung Cancer is a unique non-profit organization committed to fighting lung cancer by funding innovative research and by focusing greater attention on the world's leading cancer killer.

Joan's Legacy is named for Joan Scarangelo McNeive, a gifted writer, life-long New Yorker and nonsmoker who died at age 47 in 2001 after a valiant nine-month fight with lung cancer. The organization was founded by her family and many friends in response to

the lack of available treatments for lung cancer and the lack of research funding by private, charitable, or government sources. In its first five years, Joan's Legacy has become a leading resource in the search for new treatments and a cure for lung cancer.

In its fifth year, Joan's Legacy will have awarded more than \$2,000,000 in research grants to the finest cancer centers in the United States and will have helped raise awareness of lung cancer throughout the country. The first nonprofit in the U.S. to specifically identify inequities in research funding and cultivate lung cancer research with a special focus on non-tobacco-related issues in lung cancer, Joan's Legacy has quickly become recognized as the "venture capital fund" for lung cancer research in the U.S.

Susan C. Mantel is the Executive Director of Joan's Legacy, putting into action its development and growth initiatives and developing collaborations with like-minded organizations across the country to achieve the common goal of finding a cure for a disease that will take the lives of over 160,000 Americans this year.