

# Lung Cancer Voice

**Fall 2008**

## Research. Awareness. Change.

Notice anything different about our look? Since its founding, the National Lung Cancer Partnership's logo has always included three words to describe the organization: Women. Research. Change. As you'll see at the top of this page, those words have evolved into Research. Awareness. Change. Why these words? The Partnership's mission is to decrease deaths due to lung cancer and help patients live longer and better through research, awareness and advocacy. Much of what we do as an organization is directly tied to raising the profile of this disease and to educate people that anyone can get lung cancer. By funding research and raising awareness, we will effect change and the words beneath our logo now fully reflect our mission.

### Research.

We believe that the single most important thing we can do to improve the outcome for patients with lung cancer is to support the research that will eventually lead to better methods of lung cancer detection, treatment, and care. We already have a model of how research investments can succeed: breast cancer. Breast cancer advocates have successfully garnered billions of dollars for

research over the last three decades. In that time period we have seen the 5-year survival rates for breast cancer increase from 75% to 89%. Death rates from breast cancer have decreased, and more and more people are living with this disease. For lung cancer, the 5-year survival rate has only increased from 13% to 16% over the last thirty years. This is the reason that funding research into this devastating disease is one of our primary goals.

### Awareness.

Many American women think breast cancer takes more of their lives than does lung cancer. They're wrong: lung cancer takes almost twice as many women's lives as breast cancer. But, the perception is that breast cancer is a bigger threat because of the *awareness* about the disease that's been created. Prostate cancer is similar: men are very aware of it, so there's a perception that it's a major killer. The truth is, lung cancer takes over three times as many men's lives as prostate cancer. By raising awareness of lung cancer we can get people to talk with their doctors and get doctors to talk with their patients. We

can help people and their doctors be aware of the symptoms and understand that the disease can happen to anyone, young or old, female or male, smoker or not. With greater awareness we can help end the stigma of lung cancer, so lung cancer patients and their families can feel supported instead of shunned. And, of course, if we increase awareness, we can increase research funding.

### Change.

Remember the minimal change in the 5-year lung cancer survival rate achieved in the last 30 years? We have to change that number a lot more if we're going to bring hope to the newly-diagnosed. We have to change the status quo of the federal and private funding levels if we're going to reduce the number of people dying from this disease. We have to change the perception of the public of this disease being "someone else's problem." This is what we're here to do. By giving your time, effort, energy and support, we will continue to be able to keep moving forward. Together, we'll knock lung cancer off its #1 cancer-killer spot.

## Lung Cancer Advocacy Summit Engages and Energizes



**Advocacy Summit Participants**

The National Lung Cancer Partnership sponsored the first ever Lung Cancer Advocacy Summit on May 27-29 in Chicago, IL. This workshop provided training and guidance to 50 grass-roots lung cancer advocates. The goal of the Summit was to empower advocates by giving them tools, knowledge, and courage to go back to their communities and take action. The Summit brought together a diverse group of people, including 30 lung cancer survivors, as well as caregivers, family members and friends. Some participants were seasoned lung cancer advocates with years of experience, and some were just beginning their journey into advocacy.

The topics discussed at the Summit were: understanding lung cancer; how to be your own health advocate; becoming a lung cancer consumer advocate; how to de-stigmatize the disease; engaging the media; raising lung cancer awareness in your community; and how to navigate the legislative process. Dr. Joan Schiller, President of the Partnership, also presented a seminar on the future of lung cancer research. Participants were excited to learn about the latest developments in treatment and current clinical trials. They also heard about novel treatments that researchers and physicians are looking forward to introducing in future years.

Discussions during the Summit clearly identified that the major concern of advocates is the lack of lung cancer research funding. Equally important is raising public awareness about the disease. To educate the public and aid in increasing research funding, many Summit participants are distributing lung cancer educational materials to their local hospitals, medical centers, and clinics. Others are planning *Free to Breathe*® 5K runs or other events in their communities. Several people also volunteered to serve as patient advocates for the National Lung Cancer Partnership's grant review committees.

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Support Research, Awareness and **Change**

If you weren't able to participate in the 2008 Lung Cancer Advocacy Summit, save the date for April 23-26, 2009 in Dallas, TX! Information about the 2009 Summit will be posted on our website, **NationalLungCancerPartnership.org**, in December, 2008.

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# Letter from the President



Joan H. Schiller, MD

It is Lung Cancer Awareness Month again, a time for reflection and contemplation. We have heard from many of you about the hope you feel, given the progress we've seen in the last year, as well as the frustration that progress for the disease isn't being made faster.

In one respect, this year was historic: The Stand Up to Cancer fundraiser, televised on all three of the major networks in September, raised more than 100 million dollars for cancer research. It's not clear how many of those dollars will directly impact research into the nation's #1 cancer killer, but general cancer research advances brought by this investment are likely to eventually yield advances for lung cancer. What is important to understand is how this amount of philanthropic giving and the research it can fund compares to the dollars already being spent on research by our government.

Currently, the National Cancer Institute (NCI) provides 4.8 billion dollars in cancer research support (with \$243 million for lung cancer research). The breast, prostate, and ovarian cancer research programs supported by the Department of Defense (DOD) add another \$228 million to the federal research investment in cancer. In 2009, the DOD will finally begin funding lung cancer research with a \$20 million investment. The Centers for Disease Control and Prevention (CDC) spent \$306 million on cancer prevention and control (with \$0 for lung cancer, excluding tobacco prevention and cessation programs). Earlier this year, several major cancer organizations were asked by congressional leaders how much money it would take to really make a difference in the "war on cancer." Their answer: 355 billion dollars. Our government isn't remotely prepared to spend this amount of money on cancer research, treatment and care. But, it is clear that the status quo – even with the augmentation of research dollars from the Stand Up to Cancer initiative – is not going to lead to the research advances needed to stop this disease.

So, in the meantime, we need to continue to work hard to raise awareness of lung cancer, as that will raise the funds available to combat it. Our *Free to Breathe*® events around the country are bringing lung cancer awareness to local communities, and shedding light on the "invisible cancer." Our public service announcement (PSA) campaign is getting attention for lung cancer as a disease that can happen to anyone, even young, never-smoking women. Our research grants and awards, although currently a small addition to the funding stream, are nonetheless providing hope to the scientists and doctors fighting lung cancer on the front lines that they will be able to continue to perform their research and make those leaps needed to advance the cause. Our second Lung Cancer Advocacy Summit (the first of which is reported on in this issue of the *Lung Cancer Voice*) will be held in Dallas, TX in April, 2009 to train advocates to actively participate in awareness- and fund-raising initiatives, as well as how to talk to their government representatives.

One 2008 Summit alumna wrote to Dr. John Neiderhuber, head of the NCI, to ask how she

could make a difference. His reply is indicative of everything we at the Partnership are striving for:

"You asked me how research advocates in the lung cancer community could help to make a difference. While many of the current research limitations are scientific issues that you may not be able to impact directly, patient advocates do make a significant difference through their tireless effort to ensure science is patient focused and reasonably funded. Additionally, I believe lung cancer advocates make a difference by promoting public awareness about lung cancer and lung cancer research. Through increased awareness and understanding of this disease we can build a cadre of researchers from a variety of disciplines focusing on innovative approaches to intervene in the disease process, changing the outcome for all. We must strengthen the pipeline of lung cancer scientific investigators by promoting, inspiring and supporting high-achieving young people in science and medicine and inform the public about how the scientific process works and the opportunities presented through our greater understanding of the biology of cancer."

We may not all agree on how the NCI spends its money, but I think we can all agree with the sentiment of Dr. Neiderhuber's statement. The Partnership will continue to push for more federal funding for lung cancer research, while raising funds to support that research ourselves in the meantime. We thank each and every one of you for what you are doing to promote lung cancer awareness and increased research funding, and we look forward to celebrating Lung Cancer Awareness month next year with even more positive news.

Sincerely,

Joan Schiller  
Chief, Division of Hematology and Oncology  
Deputy Director, Simmons Comprehensive Cancer Center

Andrea L. Simmons Distinguished Chair in Cancer Research

## New Board Member, Lorraine Pastore

The National Lung Cancer Partnership is very pleased to welcome Lorraine Pastore, MBA, to our Board of Directors. Lorraine has personal connections to lung cancer and valuable business experience. We look forward to working with her to achieve our mission.

## Congratulations!

Ellen R. Gritz, Ph.D., member of the Partnership's Board of Directors and Scientific Executive Committee, was selected as the recipient of the 2008 Alma Dea Morani, M.D. Renaissance Woman Award from the Foundation for the History of Women in Medicine. Dr. Gritz was honored at an awards ceremony on October 1, 2008, at the College of Physicians in Philadelphia.



National Lung  
Cancer Partnership

RESEARCH. AWARENESS. CHANGE.

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# Advancing Lung Cancer Research

## National Lung Cancer Partnership Annual Meeting 2008

The Partnership's Annual Meeting, *Lung Cancer 2008: Progress and Promise*, was held on May 30 in Chicago, IL. The goal of the Annual Meeting is to highlight recent advances in lung cancer research and bring together patient advocates, researchers, clinicians and allied healthcare professionals.



**Dr. John Niederhuber, National Cancer Institute (NCI)**

### The status of NCI's lung cancer program

The Partnership was privileged to welcome Dr. John Niederhuber, Director of the NCI, as the keynote speaker for our 2008 Annual Meeting. He discussed the funding climate and the NCI overall budget, which has remained virtually unchanged since 2004 and is not expected to see a major increase in 2009.

Despite these budget constraints, the NCI has recently funded \$13 million in research projects addressing the role of inflammation in lung cancer and established a research program to identify and characterize lung cancer stem cells, which are thought to play a role in the initiation and metastasis of cancer. The NCI has invested in The Cancer Genome Atlas project, which is analyzing the DNA genome sequences of three different cancer types (including squamous cell lung cancer) to improve the diagnosis and treatment of cancer. NCI is also continuing to promote the study of biomarkers as a tool for improving early diagnosis, patient management, and accelerating drug development for lung cancer.

At the end of Dr. Niederhuber's address, the audience asked him pointed questions about the disparity in lung cancer funding compared to other cancer types. In response, he stressed that NCI is committed to supporting the best science and that if a great scientific opportunity is presented, he will find the money to fund it. He also urged both the advocates and the scientific community to increase awareness of these issues and to generate interest within Congress.

### Radon and COPD: lung cancer risk factors

Dr. Jonathon Samet, Johns Hopkins University, gave a historical background on radon as a risk factor for lung cancer. From early studies reviewing deaths in underground mine workers, to results of exposure to uranium mining during the era of the Manhattan Project, it has long been known that radon, a natural breakdown product of uranium, is a cause of lung cancer. He encouraged everyone to test their homes for radon, and if radon levels are too high, to get a radon-eliminating pump.

Dr. James Jett, Mayo Clinic, described the relationship between chronic obstructive pulmonary disease (COPD) and lung cancer. Most people with COPD have a history of smoking, as do lung cancer patients. The presence of COPD vastly increases the risk of developing lung cancer. Although COPD cases in women are rapidly rising, which cannot be fully accounted for the number of female smokers, COPD is less likely to be

diagnosed in women. A spirometry test, which measures an individual's lung capacity, can be administered to screen for COPD. Dr. Jett also stressed the importance of spirometry in properly evaluating lung cancer patients who also have COPD prior to surgery or radiation. If the estimated post-treatment lung function will be too low for the person's daily activities, other treatment options must be considered.

### Sex differences in lung cancer survival and treatment

Dr. Kathy Albain, Loyola University Chicago and Vice President of the Partnership, reviewed current research on the difference in survival between men and women with non-small cell lung cancer (NSCLC). For many years researchers have known that women with NSCLC tend to survive longer than men.

Recently it became clear that age also influences survival in women; women over 60 survive longer than younger women. Further studies suggest that women's estrogen levels may be the determining factor; women with lower estrogen levels survive significantly longer than women with higher estrogen levels.

Dr. Albain also reviewed several studies examining whether targeted treatments for lung cancer have greater benefit in women. The results are mixed; some drugs show greater benefits in women, such as vandetanib, which is still in clinical trials. However, another targeted drug, bevacizumab (Avastin®), showed no benefit to overall survival in women but it did increase survival for men. Why these drugs appear to behave differently in men and women continues to be an active area of research.

Dr. Albain contends these data do not mean men and women with lung cancer should be given different treatments. However, the data do justify certain clinical trials be conducted with just women, and all phase III trials should analyze outcomes by the sex of the participants.

### Guilt, shame and stigma: effects on lung cancer patient care

Dr. Joan Schiller, University of Texas Southwestern and President of the Partnership, described studies designed to look at psychological and social aspects of patient and primary care physician attitudes about lung cancer.

The first study was designed to measure the guilt and shame felt by lung cancer patients as compared to patients with other types of cancer. Through surveys completed by stage IV lung, breast and prostate cancer patients, they found that lung cancer patients were more likely to feel cancer-related self-blame than breast or prostate cancer patients. Furthermore, lung cancer patients who identify past behavior (e.g. smoking) as a cause of their cancer were more likely to have higher rates of guilt, shame, anxiety and depression.

In the second study, researchers randomly sent one of two surveys to primary care physicians depicting a clinical scenario with either a breast cancer patient or a lung cancer patient and asked the physician to answer questions about how they would treat the patient described in the case. The results implied that lung cancer patients might be receiving less aggressive treatment than patients with other types of cancer. Dr. Schiller also suggested there may be a subconscious bias in the referral patterns of primary care physicians when treating patients with lung cancer.

### The future of lung cancer treatment – cancer stem cells & personalized therapy

Dr. John Minna, University of Texas Southwestern and the Partnership's Scientific Executive Committee, discussed the newest advances in cancer stem cell research. Cancer stem cells are thought to be a critical part of the tumor and may keep dividing to generate new tumor cells and metastatic cells. Dr. Minna described current efforts to isolate and study these cancer stem cells with the hope of identifying specific characteristics that may be exploited as targets for new lung cancer treatments.

Drs. Frances Shepherd, Princess Margaret Hospital in Toronto, Gerold Bepler, Moffit Cancer Center, Anil Potti, Duke University, and David Carbone, Vanderbilt University, described advances towards personalized therapy in lung cancer – using the tools of molecular biology to try to best match specific treatments with individual patients. The panelists described their searches for gene and protein signatures that may be able to be used as markers to predict how individual patients will respond to a treatment, or even if a treatment might cause more harm than good.

Details of these latter presentations will be reviewed in an upcoming article in the *Journal of Thoracic Oncology*. We will announce the publication of this article as soon as it is available.



**Dr. Suzanne Dickerson and Dr. Grace Dean**

### Lung Cancer Nursing Research Grant Award Winners

The Oncology Nursing Society Foundation and National Lung Cancer Partnership are pleased to announce Grace Dean, PhD, RN and her co-investigator, Suzanne Dickerson, DNS, of the State University of New York (SUNY), University at Buffalo School of Nursing as the winners of our first co-sponsored Lung Cancer Nursing Research Grant. The goal of this award is to advance the science and practice of oncology nursing in lung cancer.

Drs. Dean and Dickerson were awarded this 2-year, \$50,000 grant for their proposal titled, "Sleep-Wake Disturbances in Lung Cancer: A Mixed Method Study." The stress and anxiety of lung cancer itself, as well as treatments given to combat the disease, can significantly disrupt patients' sleep patterns, which can further complicate their treatment. The purpose of this study is to collect information on sleep disturbances, daytime sleepiness and overall sleep quality in individuals before, during and after treatment for non-small cell lung cancer. By better understanding the sleep disturbances lung cancer patients experience, this research aims to improve sleep and overall quality of life for lung cancer patients throughout their treatment and beyond.

# Stories of Strength



Deborah Fuderer

## A Survivor's Story

Deborah Fuderer is an 11-year stage IV non-small cell lung cancer survivor! She is a founding member of National Lung Cancer Partnership's Board of Directors and was instrumental in the development of the Partnership's *Look Deeper* public service campaign.

### Q: When were you diagnosed with lung cancer? What were the circumstances?

A: I was diagnosed with stage IV non-small cell lung cancer in October of 1997. I had discovered a lump below my waist. After a couple of weeks, I decided it was time to go and see the doctor. The lump was surgically removed and examined. I received a call a couple days later from my primary doctor to tell me that what was removed was metastatic cancer. He told me he needed to do more tests to find the primary tumor. The test results came back: I had stage IV non-small cell lung cancer. The doctor told me my prognosis was only 3 to 8 months, but he referred me to an oncologist to get a treatment plan.

My oncologist laid out a treatment plan that included several surgeries along with a very aggressive chemotherapy schedule. I wondered, given the prognosis, why should I put myself through all this? I came very close to turning down treatment, but when I looked in my daughter's eyes, the thought of having to leave her and my husband made me realize I needed to try to do something. Eleven years later, I'm so glad I ultimately listened to my heart!



Dr. Lawrence Einhorn

## A Physician's Perspective

Dr. Lawrence Einhorn is a professor at the Indiana University School of Medicine, and the Lance Armstrong Foundation Chair in Oncology. A pioneer in testicular cancer research and treatment, and Lance Armstrong's oncologist, Dr. Einhorn began focusing

his attention on lung cancer several years ago. Dr. Einhorn is a valued member of National Lung Cancer Partnership's Scientific Executive Committee.

### Q: What inspired you to enter lung cancer research and treatment?

A: Lung cancer remains the number one cancer killer in both men and women in the United States. I have a passion for improving the quality and length of survival in patients with malignant disease.

### Q: What advances in lung cancer research have made you hopeful as an oncologist?

A: The explosion of knowledge about a cell's most basic processes – and what goes wrong in these processes that leads to cancer – has been nothing short of phenomenal. However, these laboratory advances have not translated to a miracle treatment for lung cancer. I predict that instead, these research advances will bring us personalized treatment for lung cancer in the next several years. Unfortunately, at the present time,

### Q: Do you talk openly with others about having lung cancer? What is the reaction you get when you talk about having lung cancer?

A: I wasn't as open about my diagnosis earlier, but have gotten over my fears about what other people might think of it. I had smoked on and off since college and had been smoking for about 20 years when I was diagnosed. I received very mixed reactions when I was diagnosed and going through treatment. I lost a close friend because she blamed me for the diagnosis. I was hurt by her actions and tried to explain to her that no one deserves cancer. I generally get asked if I had been a smoker and I ask them back, "Does it matter?" Most people aren't expecting that, and don't know what to say in return.

### Q: How has having lung cancer changed your life?

A: I appreciate the small gestures of life, and am less materialistic. I have been able to spend quality time with my family and have been around for my daughter and now my granddaughter. I am an advocate for lung cancer because I know how under-funded and under-supported this cancer is. Because of the lack of support groups that were available to lung cancer patients at the time of my treatment, I developed and currently run a cancer program for the employees at my company in order to help them with support, referrals, benefits assistance, and resources.

### Q: What is the biggest issue associated with lung cancer diagnosis, treatment, and/or research you wish you could change?

A: I wish I could change the stigma surrounding the disease. People do judge you, and don't support lung cancer patients as much as other cancer patients. I want someone to look at me as a person, and not judge me. I want people

stage IV metastatic disease still remains a largely incurable disease. However, with personalized therapy we see the future possibility of giving the best possible therapy to each individual patient, and therefore the hope for added quality and length of life.

***“Lung cancer research is grossly underfunded compared to other cancers. The National Lung Cancer Partnership is one of the few organizations that direct their entire research and educational efforts towards lung cancer. This organization will continue to be important by funding junior investigators and fostering and stimulating their interest in lung cancer research.”***

### Q: What role do you see the Partnership playing in the future of oncology?

A: The greatest challenge for physicians and researchers is that we need better therapy for all stages of lung cancer. Lung cancer research is grossly underfunded compared to other cancers. The National Lung Cancer Partnership is one of the few organizations that direct their entire research and educational efforts towards lung cancer. This organization will continue to be important by funding junior investigators and fostering and stimulating their interest in lung cancer research.

diagnosed with lung cancer to get the respect they truly deserve. But also, we absolutely need more dollars for research. Lung cancer research is not where it should be, and therefore the available treatments are limited. We need to pump more federal and private dollars into lung cancer research. The Partnership's research grant program is vitally important to the lung cancer research community.

### Q: What advice would you give to others recently diagnosed with lung cancer?

A: The advice I'd give to a newly diagnosed patient is: don't give up hope! A lung cancer diagnosis is devastating, but the drugs are better than when I was originally diagnosed. Get a couple of medical opinions, then take that information and decide what will be the best plan for you.

### Q: What advice would you give to the physicians and health care providers who deal with lung cancer patients?

A: I know many times a patient's prognosis isn't good, but I feel that lung cancer doctors generally need to instill more hope in the patient to strengthen their will to live. I often hear from other patients that their doctor seems to just go through the motions when discussing their diagnosis, treatment options, side effects, and everything else that goes along with a lung cancer diagnosis. The attitudes of the medical team should increase the hope for the patient and family. The stigma for a lung cancer patient is a burden itself, and it shouldn't be compounded by negative views of the disease from doctors. No one deserves to die.

To read more **Stories of Strength** and submit your own, visit the **Patients & Friends** section of our website, [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org).

The Partnership will continue to keep lung cancer as a disease of prominence, both for the public and funding agencies such as the National Cancer Institute.

### Q: What would you like patients to know about lung cancer treatment – now and for the future?

A: It is important for patients and their family members to realize that this is not a forgotten disease. There are exciting leads, but they can only be pursued through continued appropriate funding and research. Five years ago, when a patient had metastatic lung cancer and was treated with chemotherapy and then progressed, there was little, if anything, else that could be offered. Since then, the Food and Drug Administration (FDA) has approved several new agents that can be used in such a situation. Although these treatments don't afford a cure, they can all improve quality of life and prolong survival. Many new agents are in clinical trials and are showing great promise for certain patients.

### Q: What is the most important thing(s) you have learned from your patients?

A: Lung cancer is a formidable foe. As physicians, we see ordinary people struggling against extraordinary odds and still maintaining dignity, courage, and even a sense of humor. As oncologists, we make a covenant with our lung cancer patients that we will always be there for them and will continue to try to show the same kind of courage in treating this disease and developing more successful treatments as they demonstrate fighting their disease.

## Emotional Effects of Lung Cancer on Survivors and Their Spouses

Receiving a lung cancer diagnosis and undergoing treatment for it greatly affects the emotional health of the patient, as well as his/her family – particularly the spouse – and often negatively impacts the family's quality of life. Research shows that over 1/3 of patients and 1/3 of spouses experience psychological distress that is considered “clinically significant” around the time treatment starts.<sup>1</sup> Thus, it is important to consider the emotional well-being of both the patient and their spouse as they go through the cancer journey.

### Challenges for couples adjusting to lung cancer

Individuals facing cancer experience a range of psychological symptoms, including depression and anxiety, more often than people who do not have cancer. Cancer patients at highest risk for depression include those with a history of depression or alcoholism, advanced stage of disease, uncontrolled pain, or a cancer treatment regimen that produces depressive symptoms.<sup>2</sup> Many of these risk factors are present in individuals facing lung cancer.

Patients frequently report that their spouses are their greatest source of support. In fact, social support from spouses is an important predictor of a person's emotional adjustment to cancer and the stress that comes with it.<sup>3</sup> Significant stressors, such as cancer, force couples to deal with and discuss issues that are likely quite novel to their relationships. Couples may experience communication problems when facing lung cancer. Topics they may have difficulty talking openly about include continued tobacco use, cancer symptoms, the patient's prognosis, and the emotional effects of lung cancer on the spouse.<sup>4</sup>

Sometimes during times of stress, people cope in ways that are actually not constructive. They may avoid certain discussions in an effort to prevent conflicts, deny that a problem exists, spend time engaging in self-blame or blame over the cancer cause, vent their feelings in an unproductive way, or use substances such as alcohol, tobacco, or other drugs. Over time, these coping efforts may promote relationship conflict and psychological problems.

Many couples may cope in ways that aim to “protect” one another, but are actually counterproductive. For example, partners may emotionally withdraw from each other, refusing to ask for help or share feelings, thinking that they are protecting their spouse from the stress of their emotions. Or, they may avoid discussing certain topics thinking it will be too upsetting for their partners. Others may not know how to respond or act during a cancer-related discussion. Research shows that talking and sharing feelings facilitates a person's coming to terms with traumatic life events, such as cancer. When spouses do not know how to respond, or provide negative reactions when discussing cancer with their partner, they may unintentionally be hindering the emotional processing needed by both spouses to deal with the disease.<sup>5</sup> If partners discourage each other from expressing thoughts and feelings, both the patient and the spouse may avoid much needed discussions, which can actually increase their psychological distress.

### What can help couples cope with lung cancer?

Research suggests that using good active coping skills and having a reliable support system can help individuals adjust more effectively to stress. Additionally, healthy spousal communication is important, as it has been associated with less

distress and more relationship satisfaction in both cancer patients and their partners.<sup>6</sup>

There are several strategies couples can use to help them more effectively cope with lung cancer:

### Approach lung cancer as “our problem” rather than “his/her” problem or “my” problem.

- Make a list of questions and attend medical appointments together so you will have a shared understanding of what to expect.
- Problem-solve situations together. Write down how decisions will affect you both. Use this information to decide the best course of action.
- Sometimes priorities change after a cancer diagnosis. Write down your priorities as a couple to ensure that both of you are on the same page.
- As you learn information, share it with each other.
- Ask for each other's point of view.
- When necessary, help one another try to re-frame a problem positively and/or take a different perspective on stressful situations.
- Before cancer, both members of a couple have certain responsibilities (e.g., cooking, running errands, etc). After cancer, these responsibilities may need to change temporarily or permanently, depending on how the disease and treatment affect the patient. As a couple, decide how these responsibilities will change. It is sometimes helpful for patients to continue to assume some responsibilities, but to do so in a way that is less physically demanding.

### Engage in healthy relationship maintenance strategies.<sup>7</sup>

- Participate in activities together, e.g., household tasks; hobbies; leisure activities.
- Be positive whenever possible. Messages are often lost if everything said is negative.
- Assure your partner of your commitment to him/her and the relationship.
- Talk openly about your relationship with one another.
- Allow yourself and your spouse to seek support from others (e.g., family, friends). This will offer opportunities for both of you to seek other points of view. Additionally, letting others in allows family and friends to help with certain responsibilities, which may provide more time for you and your spouse to concentrate more effectively on each other and the things that are important to both of you.

### Learn and regularly practice healthy communication.

- Schedule time each day to talk. Pick a time that will have minimal disruptions.
- If communication problems are ongoing, discuss positive or neutral topics during the beginnings of your discussions.
- If discussions get heated, take a time out. Go in separate rooms and calm down. Afterwards, return and continue the discussion for the scheduled time.
- Avoid criticism, sarcasm, yelling, name-calling, and interrupting.
- Focus on the present topic. Don't bring up old arguments.
- Take time to discuss difficult topics and discuss only one topic at a time.
- Recognize that sometimes all your partner needs is for you to listen.

### Some problems are serious and may require a mental health professional for help, particularly when one or both of you:

- Have thoughts of hurting yourself or someone else.
- Feel depressed or anxious and it persists or interferes with your functioning in some manner.
- Physically or verbally threatens the other.
- Have problems with alcohol or other drugs.

The cancer journey is one of the most challenging anyone will face. Couples who face this challenge together, with a commitment to their relationship along with their commitment to battling the disease, are more likely to cope successfully individually, and together.

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### Ahor está disponible en español

The National Lung Cancer Partnership's video, *Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial*, is now available in Spanish! This video follows four lung cancer patients' in their personal experiences. To order copies of the Spanish or English version of the video, visit [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org).

### When the Doctor Becomes the Patient: A New Lung Cancer Voice

The Partnership is proud to introduce our new blogger, Lisa Woody! Lisa is a physician, so when she was diagnosed with stage IV lung cancer earlier this year, she knew the statistics. Read about Lisa's treatments, side effects, and her hopes and dreams at [NationalLungCancerPartnership.org/blog](http://NationalLungCancerPartnership.org/blog).

### In Memoriam



Anita Johnston

#### Anita Johnston (1930-2008)

We are deeply saddened by the death of Anita Johnston, who lived with lung cancer for 17 years. Anita was interviewed on National Lung Cancer Partnership's video, *Stories of Strength: Making the Decision to*

*Enter a Lung Cancer Clinical Trial*. She was a founding member of the Lung Cancer Online Foundation, served as a phone buddy through the Lung Cancer Alliance, and was an active member of CancerCare's lung cancer support groups. She inspired hope to many others through their battles with the disease. May her memory be a blessing.

# Upcoming Events



The National Lung Cancer Partnership's *Free to Breathe*® program raises awareness of lung cancer and gives people a chance to participate in a lung cancer event in their own community. Proceeds from the events fund the Partnership's research grant program and support efforts to educate patients and professionals and raise greater awareness of lung cancer.

In 2008, runs and walks were scheduled in 11 cities across the country. A national virtual run/walk will take place on November 1 this year to kick off Lung Cancer Awareness month.

Visit [FreeToBreathe.org](http://FreeToBreathe.org) to learn more, register, donate, and set up a fundraising page. Join us in one of the following cities:

- Dayton, OH - Saturday, November 1**
- Philadelphia, PA - Sunday, November 2**
- Raleigh, NC - Saturday, November 8**
- Greensboro, NC - Saturday, November 15**

### Great 108

The fourth annual Great 108 Yogathon will take place on **December 21** in the **North Carolina Triangle region**. Visit [NationalLungCancerPartnership.org/NC](http://NationalLungCancerPartnership.org/NC) for locations and more information.

To have quantities of this newsletter or our other educational materials delivered to your office or clinic for FREE, please email us at [info@NationalLungCancerPartnership.org](mailto:info@NationalLungCancerPartnership.org).



## ROSEANN'S GIFT

raising awareness and research funding  
to cure lung cancer

### Roseann's Gift

Kellie Lerner hosted the inaugural Roseann's Gift Cocktail Party in 2007 to raise funds for a research grant in memory of her mother, Roseann Safar. Mark your calendar for the second event on **November 11** in **New York City, NY**, and join Kellie as she continues raising awareness and money for lung cancer research!

# Past Events



Janice McQueen-Ward talks to a group at the United for Lung Health Federal Advocacy Day

### United for Lung Health Federal Advocacy Day - Washington D.C.

Kenda Schwarz, the Partnership's Director of Development and Outreach, and Janice McQueen Ward, Partnership Outreach Committee Member, joined other lung health advocates in Washington, D.C. in May to meet with congressional representatives to encourage them to support lung disease research, prevention and patient services programs.

### North Carolina Lung Cancer Partnership Inaugural Wine Reception - Durham, N.C.

The North Carolina Lung Cancer Partnership celebrated its formation as our first chapter with a wine reception at the Duke University Nasher Museum of Art in Durham, NC on June 14. More than 100 people attended the event and partook in fine food, fine wine, and fine art.

### Lance Armstrong Foundation LIVESTRONG Summit: Making Cancer a National Priority

This July, Alice Yuroff, National Lung Cancer Partnership's Programs Manager, and three of the Partnership's 2008 Lung Cancer Advocacy Summit alumni attended the Lance Armstrong Foundation LIVESTRONG Summit. The participants learned how to effectively communicate with elected officials and community leaders, plan events, and effect change at a local level. The participants were asked to hold elected officials responsible for making cancer a national priority and to bring cancer issues to the forefront of the political discussion this election year.

### Hike for Lung Health - Chicago, IL

The National Lung Cancer Partnership is grateful to those who participated in the Hike for Lung Health on September 21 in Chicago, IL. The Hike for Lung Health is a multi-charity event sponsored by Respiratory Health Association of Metropolitan Chicago, benefiting several lung health organizations. A special thanks to our dedicated fundraisers!



Team Ali's Alliance in Los Angeles, CA

### Los Angeles, CA Free to Breathe®

The second annual *Free to Breathe*® 5K run/walk and 1.5 mile walk in Los Angeles, CA drew over 525 participants to the new location at Dockweiler State Park in Playa del Rey. Thanks to our participants, donors, fundraisers, and sponsors for helping make this event possible!



The McNamara Clan walks in Glastonbury, CT

### Glastonbury, CT Free to Breathe®

The second annual *Free to Breathe*® 3.5 and 1 mile walk in memory of Beth Kenny Foretic took place on September 21 at Glastonbury High School in Glastonbury, CT. Over 500 people joined the Kenny family in

remembering Beth and supporting other lung cancer patients and their families. Thanks to the Kenny family, their friends, participants, donors, fundraisers, and sponsors for making this event another success!



Madison, WI Free to Breathe® 5K participants

### Madison, WI Free to Breathe®

The first annual *Free to Breathe*® 5K run/walk and 1 mile walk in Madison, WI was held on September 27. Almost 300 people participated in raising awareness and funding for lung cancer. The proceeds from this event benefited National Lung Cancer Partnership and the University of Wisconsin Paul P. Carbone Comprehensive Cancer Center's "Creating Hope" lung cancer research campaign.

### Kansas City, MO Free to Breathe®

The first annual *Free to Breathe*® 5K run/walk and 1/2 mile walk in memory of Julia Miles was held on September 28 in Kansas City, MO. Approximately 500 people participated in raising awareness and funding for lung cancer programs. Special thanks to Jayne and Kara Hartwig and their family and team of volunteers for making this event successful!

### Providence, RI Free to Breathe®

The first annual *Free to Breathe*® fun run/walk was held on October 11 in Providence, RI. Special thanks to Daniel and Sheila Quелlette and their families for making this a great first-time event!

# Support Research, Awareness, and Change

## Lung Cancer Awareness Month

November is Lung Cancer Awareness month. What are you going to do to help raise awareness of the deadly impact of this disease? There are so many ways to raise lung cancer awareness – be creative because the more innovative an idea is, the more it will grab people's attention! Here are some suggestions for ways to get involved on a number of different levels.

**Help distribute National Lung Cancer Partnership's public service announcements (PSA)!** You can help the Partnership spread the message that lung cancer can affect anyone – at any age. Visit [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org) to view, listen to, and download the PSA campaign files and learn how you can spread the message about lung cancer and its risks.

**Write a letter to your editor!** Letters to the editor are one of the most widely read sections of the newspaper. The public is able to comment on a newspaper's coverage of an issue, and can influence future coverage. To have the best chance at getting published, remember to respond to a recent issue, article, editorial or column and be clear and concise in your writing.

**Set up a fundraising page on FirstGiving.com.** Are you participating in the *Free to Breathe*® Virtual Run/Walk? Or are you participating in another event? Do you want to gather donations to mark a special anniversary or honor a loved one? Set up a general fundraising page on [FirstGiving.com](http://FirstGiving.com) to benefit National Lung Cancer Partnership and ask your family, friends, co-workers, and acquaintances to donate to your cause!

**Sign the Partnership's online petition!** Go to [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org) to sign our petition calling on the federal government to increase lung cancer research funding. Forward the link on to your family and friends!

**Purchase, wear, or give as a gift lung cancer awareness jewelry and other merchandise!** A pair of Swarovski crystal earrings matches our exclusive Swarovski crystal bracelet and creates a lovely set. Wristbands and lapel pins are affordable, stylish ways to raise awareness of this "invisible cancer." Visit [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org) to view the merchandise and to place an order.



**National Lung Cancer Partnership**  
RESEARCH. AWARENESS. CHANGE.

## Memorial Giving:

Donations have been made in memory of the following people (May 2008 through August 2008):

Joanne Marie Albarano	Jill Cotoia	Darleen Joyce	Melba Savage
Charles S. Anderko	Mary Cressler	Betsy Kemeny	Ramona Kay Schmidt
Phyllis Armstrong	Mary Lou Damm	Julie McMurray Kennedy	Charlotte L. Simpson
Mini Aycock	Mary Pat Darling	Terrelle Mattox Kerr	Susan L. Sipes
David Atkins	Mr. Devault	AJ Knowles	Leah Soto
Saul Bender	Karleen Dixon	Steve Kos	John Gregory Steele III
Fran Billsby	Jackie Dresler	Van Lamb	Maryann Strong
Susan Blevins	Carrie Linn Ernst	Joyce D. Lineberger	Sharon Smith
Donald Brennhofer	Lisa Strawn Foley	Mary Matthews	Dolat Virani
Paul Brennhofer	Beth Kenny Foretic	Pat McCue	Deanne Weiss
Shirley Brody	Sarah Farmer	Virginia McKinley	Roger & Maureen Woodson
Sue Brooke-Smith	Jay Freedman	Kim Medina	Anne Woolner
Robert Buchanan	Ruth Frerichs	Dorothy Wilma Mellody	
Marjorie June Buxton	Kara Gobron	Judy Meyers	
Bruno Ceschini	Shirley Guedon	Michael Mytilinaios	
Rheta Chernin	Naomi Gurse	Kenneth Ragland	
Jean E. Chipman	Margaret Hamilton	Patrick Redmond	
Francesca Combis	Janice C. Johnson	Joseph Roppolo	
Fran Cornell	Anita Johnston	Melanie Sattler	

## Lung Cancer Advocacy Summit, continued from page one

The advocates expressed a desire to increase their involvement with the National Cancer Institute (NCI), with the ultimate goal of increasing NCI funding for lung cancer research. Shannon Bell, Director of the Office of Advocacy Relations at the NCI, spoke at the Summit and participated in all the sessions. She promised an open, frank, and continuing dialogue with the lung cancer advocacy community.

Another priority for the advocates was to develop a clear, unified and consistent message. They identified the need for a 30 second "elevator speech" to help begin personal dialogues with the media and the general public and to allow the advocacy community to speak with one message and a unified voice. The key elements these speeches should touch on

are: Lung cancer is the number one cancer killer in America; Lung cancer research is under-funded; and Lung cancer can happen to anyone.

Several Summit alumni have already successfully engaged their local media and have been interviewed or had letters to the editor published. In addition, people are working to distribute the Partnership's public service announcements to local radio stations, newspapers and magazines.

The Summit fostered many advocates' interest to engage in the political process at all levels of government, especially at the state and local level. Many individuals expressed interest in working to get their states to include a lung cancer research check-off box on the state income tax forms to increase funding for research. Others are seeking to influence how their

## In the Press

The Partnership's print public service announcement has appeared in the following publications:

*City Woman Chicago* June issue, Chicago, IL  
*V Magazine for Women* June issue, Richmond, VA  
*Washington Woman* June issue, Bethesda, MD  
*Allure* August issue, Boston, MA subscribers  
*Glamour* August issue, Boston, MA subscribers  
*Self* August issue, Boston, MA subscribers  
*Wisconsin Counties Magazine* August issue, Madison, WI  
*Women's Health* September issue

The Partnership's radio public service announcement has been heard on the Georgia News Network and the Mississippi News Network, and in the following cities:

Atlanta, GA  
Boston, MA  
Chicago, IL  
Denver, CO  
Madison, WI  
Miami-Fort Lauderdale, FL  
Milwaukee, WI  
Minneapolis-St. Paul, MN  
Philadelphia, PA  
San Francisco, CA  
Seattle-Tacoma, WA

Carol McGarrahan of the North Carolina Lung Cancer Partnership was featured in a slideshow on *Fitness* magazine's website, [FitnessMagazine.com](http://FitnessMagazine.com).

Dr. Joan Schiller, Partnership President, and Charmaine Atkinson, Lung Cancer Advocacy Summit participant, discussed lung cancer patients' feelings of blame, shame and guilt in an interview for a Reuters article. Schiller and Atkinson believe that the stigma of a lung cancer diagnosis could affect doctor's attitudes and may prevent patients from pursuing lifesaving treatments.

The National Lung Cancer Partnership's *Free to Breathe*® 5K run/walks have been held in Los Angeles, CA; Glastonbury, CT; Madison, WI; Kansas City, MO; Providence, RI; and Tacoma, WA. Events are being held in Dayton, OH; Philadelphia, PA; Raleigh, NC; and Greensboro, NC in November. Each of these 10 events has received wide print, radio, television, and web coverage.

Partnership President, Dr. Joan Schiller, was quoted in *Nature News*, *The Boston Globe*, and a Reuters article about an experimental process that extracts lung cancer cells in a blood sample, which could potentially lead to a new lung cancer screening method.

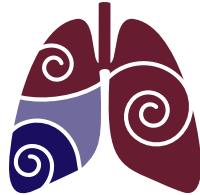
state uses tobacco tax and settlement income, with an attempt to divert a portion to lung cancer research. Some advocates have already written letters to their elected officials and are working to secure proclamations designating November as Lung Cancer Awareness month in their states.

Whether their plans are big or small, all the Summit alumni are making a real difference by raising awareness about lung cancer in their communities, which in turn will help increase research funding and bring about the change that is needed for future lung cancer patients and their families. If you would like to learn more about becoming involved in activities that Summit alumni are actively engaged in, visit our website, [NationalLungCancerPartnership.org](http://NationalLungCancerPartnership.org), or email [info@NationalLungCancerPartnership.org](mailto:info@NationalLungCancerPartnership.org).

# November is Lung Cancer Awareness month. What are you going to do?

If you're waiting for someone else to do something about lung cancer...Don't hold your breath.  
Look inside for what you can do.

.....  
National Lung Cancer Partnership is dedicated to decreasing deaths due to lung cancer, and helping patients live longer and better, through research, awareness and advocacy.



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