

# Spirit & Breath

Lung Cancer Alliance July 2006

NO MORE EXCUSES. NO MORE LUNG CANCER

## Nancy Michener: Passion and Determination

**W**e want to pay tribute to an amazing woman, Nancy Michener, who died from lung cancer on June 16, 2006 following a seven year battle. Nancy, a resident of Pasadena, CA, was Co-Chair of the California Steering Committee of the Lung Cancer Alliance. As the first LCA State Committee to get up and running, California largely exists because of Nancy. Her fellow committee members have said, "We exist because of her organization and dogged determination."

Nancy was diagnosed with non-small cell lung cancer at age 44 in 2000. At that time, she had a lobectomy. Three years later, the cancer returned. Prior to her initial diagnosis and between then and recurrence, she was very active and had even completed a 100 mile ride on a tandem bike with her husband. Nancy worked as a real estate appraiser for 30 years and ran her own practice for 7 years.



Survived by her husband, Stuart, Nancy was preceded in death by her only daughter Alison in March 2006. Alison died in a tragic accident a month before her graduation from Brown University with a degree in Biology.

Nancy turned her personal struggle into a mission to educate others, even after Alison's death. She befriended

many lung cancer patients, and challenged politicians, medical professionals and charitable organizations to focus on the disease itself rather than smoking. Unflinchingly, Nancy used her steely determination to demand that lung cancer be respected as a disease – deserving of the same compassion and public health support as all other cancers. She expressed this beautifully and purposefully – not just because of her own personal battle – but because she knew this battle would help tens of thousands of others.

Nancy joined LCA-CA in July 2005 and agreed to obtain a Lung Cancer Awareness Month proclamation. Nancy stepped up to be the California co-chair because she saw it needed to be done

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#### Dear fellow survivors, family and friends,

Nancy Michener was such a wonderful advocate and leader. She was fearless in confronting the scions of the public health establishment in California who are only interested in tobacco cessation programs and who felt "justified" in excluding any funds for lung cancer research and early detection in the upcoming tobacco tax initiative. She railed against their discriminatory attitude and actually started to turn the tide. I admired her greatly.

The Lung Cancer Alliance California Committee under Nancy's co-chair Joyce Neifert faces a tremendous challenge in getting the California Legislature and the Governor to support a set aside of at least 1% - just 1% - of all tobacco tax money for lung cancer research and early detection.

They need help. They need advocates willing to speak out, like Nancy, and demand more for lung cancer as a disease.

The Lung Cancer Alliance needs help to carry out this "no less than 1%" campaign in all the states. We cannot do it without you. We especially need people with press backgrounds, legislative and public relations experience and/or organizational skills. Even if you can only make some calls from home, we need you.

Call, write, email.... we CAN turn the tide. We CAN make lung cancer a national public health priority. NO MORE EXCUSES. NO MORE LUNG CANCER.

— Sheila Ross

## LETTER FROM THE PRESIDENT



**W**e are making exciting progress in establishing a network of state LCA chapters – a critical element in our fight against lung cancer. Just as we are elevating public awareness at a national level and educating federal public policy makers on the need to increase funding for research and early detection – so too must we act in concert at the state level.

This effort began in March when we gathered advocates from across the country to talk about LCA's goals and activities at our first advocate conference in Washington, DC. We discussed what it takes for a "movement" to be successful and how important it is to engage interested hearts, hands and minds at state and local levels. Armed with ideas and clearer understand-

ings, LCA state committees – under the direction of newly appointed state committee chairmen – began their organizational efforts. Georgia, Massachusetts, California, New York, are leading the way, with aggressive interest in Illinois, Wisconsin, Maine, Vermont, Florida, Michigan, Connecticut and Delaware. Others are starting to come forward and we are encouraging our patients, caregivers and families to get active and get involved. The stronger these state organizations, the faster we can move on reducing lung cancer mortality, securing more effective treatments and making early detection a reality for everyone at risk.

The states have two main sources of revenues related to tobacco products. The states collect about \$7 billion a year in state tobacco taxes (not be confused with federal tobacco taxes which go to the federal government).

In addition, the states receive funding from a settlement negotiated with four big tobacco companies as a result of a lawsuit started ten years ago. The Master Settlement Agreement (MSA) reached in 1998, divvies up \$206 billion among the states according to a percentage formula based on population and other factors, and spreads out the payments over 25 years. Some states elected to mortgage the payments for an up-front lump sum but most will continue to receive funding for many years to come.

Each state legislature determines how to use those funds. Sadly, in practically every case, the state legislatures missed this opportunity to use any of this "new found" money for lung cancer. Instead, funds have been earmarked for other diseases with large grass roots organizations, highway projects, deficit reductions, state government salaries, and even golf courses.

You can find out more information on the MSA and how your state has used those funds by visiting <http://www.gao.gov/new.items/d01851.pdf> for the first report in 2001 and <http://www.gao.gov/new.items/d05312.pdf> for the 2004 and 2005 updates.

Our goal is for LCA advocates to meet with the governors and legislatures in each state to explain why this is unacceptable and why lung cancer should receive AT LEAST 1% of ALL state tobacco tax and MSA funds – more is certainly better – but at least 1%. As our slogan says: NO MORE EXCUSES. NO MORE LUNG CANCER. Once we have spread the word, let the governors and the state legislatures explain to the public and the press why they couldn't even give 1% to help cure the biggest single cancer killer.

Please help us with this initiative. Every voice counts. We would like to see organizations started or about to start in every single state by November – Lung Cancer Awareness month.

All of us at LCA send our best wishes to all of you!

## Spirit & Breath

Published by  
**Lung Cancer Alliance**  
888 16th St. NW, Suite 800  
Washington, DC 20006

July © 2006 Lung Cancer Alliance.  
Lung Cancer Alliance is a not-for-profit 501(c)3 organization.  
To receive a sample copy, contact LCA at (800) 298-2436, (202) 463-2080, or [www.lungcanceralliance.org](http://www.lungcanceralliance.org)

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### Acknowledgements

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**Writing Assistance**  
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**Layout**  
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**Printing**  
Westland Printers

**Logo Design**  
Spectrum Science



# Washington News

## Legislation

Since LCA's last newsletter, we have worked with federal legislators to introduce two pieces of legislation. The first was a Resolution that declared lung cancer a major national public health priority and called for a 50% reduction in mortality within nine years. The Resolution was noteworthy in that it was introduced in both houses of Congress, in the Senate by Senators Hillary Clinton (D-NY) and Chuck Hagel (R-NE) and the House, by lung cancer survivor Representative Clay Shaw (R-FL). The Senate passed the Resolution in early May 2006.

LCA also

- Participated in a coalition supporting increased federal funding for health, including the National Cancer Institute
- Made important strides to enlist congressional support in the battle against lung cancer
- Reinforced the importance of retaining federal funding for translational research

In late May, Rep. Shaw introduced a House bill, the Medicare Lung Cancer Screening Benefit Act of 2006, which, if passed, would include lung cancer screening as a Medicare benefit for those at high risk of developing the disease, including those with:

- A family history of lung cancer
- A significant smoking history
- Exposure to toxic agents veterans were exposed to
- A significant exposure to radon, asbestos, beryllium, uranium, secondhand smoke and other known carcinogens
- Previous lung disease

The possible screenings could include:

- a low dose computerized axial tomography scan;
- sputum analysis;
- fluorescent bronchoscopy; and
- such other tests, and modifications to tests, as the Health & Human Services Secretary chooses.

## National Cancer Institute

In the March 2006 edition of Spirit & Breath, we told you that we would monitor the National Cancer Institute's Lung Cancer Integration and Implementation (I2) Team.

We have done that to encourage National Cancer Institute's (NCI) commitment to lung cancer research. In May, we read the Director's Update in the NCI Cancer Bulletin. John E. Niederhuber, MD, is Acting Director of NCI. The Update, titled "New Focus on Lung Cancer Research," appeared to signal a change in the commitment to the I2.

Dr. Niederhuber said he'll be "creating a base of scientific cohesiveness within the Institute around lung cancer, and will host regular meetings with extramural lung cancer researchers and advocates about our progress in this area and our future agenda" and calling this the "NCI Lung Cancer Program (LCP)."

While heartened to read that "the central focus of this program will be to support "research into early detection and treatment" because NCI believes this "most likely to provide more immediate benefits for lung cancer patients," we were concerned that NCI may have changed course again.

LCA queried Dr. Niederhuber after reading this and said "As advocates, we must let you know that this only reinforces the perception the NCI considers lung cancer not worthy of greater attention with a sense of urgency." We have requested a meeting with Dr. Niederhuber to discuss this directly and will have more to report later. We will query on the specifics of exactly how much money will be devoted to this program, is the program focused on what will be most helpful in real time, and how advocates will be involved. (The NCI had previously promised \$41.75 million over five years for the I2.) We will keep you apprised of developments.

In addition, the Lung Cancer Alliance responded to two studies in the Journal of the National Cancer Institute (JNCI).

The first, titled, "Lung Cancer Death Rates in Lifelong Nonsmokers," was published on May 17. It was based on analyses of data previously collected by

the American Cancer Society. In this paper, the authors show that the death rates among nonsmoking men are higher than among nonsmoking women. They did this in order to counter observations by clinicians and other research

**"Simply put," Fenton continued, "no matter how you interpret statistics, the fact is that this mortality rate is not acceptable. The National Cancer Institute must make lung cancer a national public health priority just as the Senate called for in recently passed legislation."**

indicating that lung cancer death rates were higher in nonsmoking women than men. LCA responded to the publication of this study with a press release.

The press release included the following from Laurie Fenton: "For people diagnosed with lung cancer – whether they are smokers, former smokers, or have never smoked – only 15% will survive five years and most will die within the first year after diagnosis." "Simply put," Fenton continued, "no matter how you interpret statistics, the fact is that this mortality rate is not acceptable. The National Cancer Institute must make lung cancer a national public health priority just as the Senate called for in recently passed legislation."

The paper contained a new finding, that the lung cancer death rate of African American non-smoking women is higher than of white non-smoking women. Ms. Fenton observed, "I am also pleased to see that the paper acknowledges the intolerable and under-researched disparity in lung cancer mortality among minorities, and we hope that this will lead to concrete steps by NCI to address the issue."

The second study, titled "Extended Lung Cancer Incidence Follow-up in the Mayo Lung Project and Overdiagnosis,"

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# Advocacy Conference

**O**n March 26-28, LCA held its first ever Advocacy Conference for State Committees.

Representatives from over a dozen states attended.

|             |               |
|-------------|---------------|
| Maryland    | Delaware      |
| Illinois    | Florida       |
| Wisconsin   | California    |
| New York    | Pennsylvania  |
| Georgia     | Massachusetts |
| Connecticut | Iowa          |
| New Jersey  |               |

The Conference began with a dinner when participants shared their stories and reasons for involvement in lung cancer advocacy. For some who had corresponded by email, it was the first opportunity to meet in person. There was not a dry eye in the room and we were all inspired for the next day's activities. The day's major activity was training. We heard from Jane Reese-Coulborne about the breast cancer movement and Tom Sheridan about the AIDS movement. We learned about developing a message and a strategy to communicate messages. Advocates were trained in how to build momentum at the state level. Advocates were also treated to a talk on lung cancer by LCA Board Member Dr. James Mulshine.

The LCA's office is located in a building belonging to the Motion Picture Association of America (MPAA). The MPAA generously hosted a dinner for the meeting attendees. Before dinner, American Legacy Foundation (ALF) President and LCA Board Member Dr. Cheryl Heaton addressed the group about ALF's activities. During dinner LCA advocates were joined by attorney Sean Donahue who talked about LCA's Amicus Brief (visit [lungcanceralliance.org](http://lungcanceralliance.org) for more information).

The next day's training focused on reaching out to the media. Next, the group traveled to Capitol Hill. During lunch, the group received surprise visits by Senators Chuck Hagel (R-Nebraska) and Hillary Clinton (D-New York) who described their passion about changing



**Deb Benton and Dave Grant attend the Advocacy Conference**

the lung cancer situation in the United States. Senator Clinton announced her and Senator Hagel's introduction of LCA's Senate Resolution. Later, advocates met as a group with Rep. Clay Shaw who is a lung cancer survivor. These three Congresspeople are responsible for introducing Resolutions

into Congress directing the President to make lung cancer a national public health priority.

On May 2, the Senate approved SR 408 unanimously.

Following the conference, the State Committees got to work. Please contact LCA if you'd like to become involved. ■

## Washington News

**continued from page 3**

appeared on June 7th in the Journal of the NCI. The Mayo Lung Project was a study designed in the 1960's and conducted from 1971-83. In the original study, participants were given given x-rays and sputum tests either every four months or the same tests annually. For this paper, the researchers measured lung cancer mortality among the participants from 1971-1999. Although this paper was about x-rays and sputum analysis, the authors generalized their findings to the lung cancer screening debate of today and end the paper by saying "The question thus remains as to whether early detection of lung cancer through mass screening results in a net benefit to the public's health." Laurie Fenton responded by saying "That's

exactly what was said by the opponents of mammography screening 30 years ago," Fenton pointed out, "yet this is even more ludicrous. First of all, the study they refer to is forty years old and was so badly designed that it has already been repudiated by the experts years ago."

"Secondly, the study focused on x-rays not CT scans which, it is widely agreed, more accurately detect lung cancer tumors. I do not know why NCI would spend badly-needed funding to rehash an old meaningless study when so much needs to be done on lung cancer." In closing, we called upon the NCI to address lung cancer with a sense of urgency and commitment. ■

# State Committee Updates

## California

Lung Cancer Alliance California recently suffered the tremendous loss of Co-chair Nancy Michener, who succumbed after a 7-year battle with the disease. However, the committee is determined to advance the work Nancy began and has been moving ahead with their advocacy efforts.

The committee worked with Senator Wes Chesbro on a successful effort to obtain a resolution declaring every November Lung Cancer Awareness Month. The resolution carried nearly the exact language proposed by the committee, in stark contrast to the proclamation issued by the governor's office last year which set off a firestorm of public protest by the California advocates.

Several members met with state leaders of the American Lung Association of California (ALAC) last year to discuss key issues. ALAC is part of a coalition which has placed a proposed \$2.60/pack tobacco tax increase on the upcoming November ballot with very minimal funding for "lung cancer and other lung diseases." California's advocates are fighting to secure at least 1% (2.6 cents) for lung cancer.

LCA-CA recently participated in the American Thoracic Society International Conference in San Diego on May 20-23. Advocates handed out literature and interacted with the medical community raising awareness of lung cancer issues.

## Florida

The Florida group obtained proclamations from the State of Florida and three localities-Weston, Hollywood, and Sunrise. They have appeared in articles in the Miami Herald, the Naples Daily News, and the Weston Gazette.

They are working on recruiting others to their campaign to direct 1% of state tobacco money to lung cancer research.

What could we do with \$9,686,200? The State could direct those dollars to universities and hospitals for research into early detection and better treatments. We could build on the landmark legislation passed in 2006. Sponsored by State Senator Burt Saunders, R-Naples, the Bankhead-Coley Cancer Research Law will allocate \$9 million to fund biomedical research in Florida, with recurring funding at \$9 million for the next 4 years under the Department of Health. This law never mentions lung cancer, even though lung cancer is the leading cause of cancer death in Florida. Florida has the second-highest lung cancer burden in the US.

## Georgia

The Georgia State Committee operates on a business model. There's an Executive Committee and the following subcommittees: financial/fundraising, medical, advocate, political, and coming soon, media. The Committee includes Jacqueline Patrick, Councilwoman of Woodstock (an Atlanta suburb) and Lung Cancer Alliance Medical & Scientific Advisory Board Member Dr. Michael Smith.

Georgia obtained a proclamation marking Lung Cancer Awareness Month (LCAM) for 2005 and then ensured passage of a resolution making every November LCAM. Georgia Governor Sonny Perdue signed the 2005 proclamation in his office, joined by officials, including from CDC and Senator Isaacson's office.

Georgia's become very active in the Georgia Cancer Survivor Leadership, a group of twenty-one cancer organizations. They've discovered benefits of membership including visibility, credibility, and learning from others' experiences.

The Medical subcommittee and the Director were invited to the Center for Health Transformation where they met with founder Newt Gingrich.

The Georgians are planning their first annual celebrity golf tournament on October 23. Their sponsors include the Phoenix Corporation of Georgia, a developer, and other prominent builders. They have received interest from many potential participants and may extend the event to last for two days. In the future, they plan to hold spring and fall fundraisers.

## Massachusetts

It's only been ten months since Marianne Hall founded LCA MA and succeeded in petitioning Gov. Mitt Romney to declare November Lung Cancer Awareness month in Massachusetts.

Soon LCA MA will be mounting an all out campaign to demand 1% of Tobacco Settlement Fund and Excise Tax monies be directed to lung cancer – just in time for the gubernatorial election. Tara Zend procured the data and met with each of the Democratic contenders to lay the groundwork.

On May 21st, the first ever Netta's Run was held in Groveland, MA to raise public awareness about Lung Cancer. Maria Hurley founded the event in memory of her best friend Netta Sala, who lost her battle to lung cancer in April. Over 200 motorcyclists participated and Maria raised over \$7,000 for LCA. What a great tribute to both Netta and Maria. Maria plans to make this an annual event to raise even more awareness!

The group has made inroads to the Boston Globe; persuaded Cambridge Trust to 'grandfather' Harvard Square display windows for LCA; appeared on Fox25 TV News after the death of Dane Reeves. One member appeared in the north shore's Eagle-Tribune, another in "A Breath of Fresh Air" in The Island Packet, and a third with Dr. Pasi A. Janne in the Boston Globe.

## New York

The New York Chapter of the Lung Cancer Alliance has over 30 members. Our President is Pat O'Connell. We have a board meeting every six weeks at Memorial Sloan Kettering.

Our goals include asking state officials to consider a box on income tax returns for lung cancer donation, 1% of Master Tobacco Tax settlement and the Tobacco Tax devoted to lung cancer, political advocacy and media attention for lung cancer.

We are currently writing letters to the state and local legislators to make lung cancer a public health priority. We are asking that at least a minimum 1% of the Master Tobacco Tax Settlement and the Tobacco Tax be devoted to research for lung cancer early diagnosis and treatment. This includes Governor George E. Pataki, Mayor Michael Bloomberg and gubernatorial candidates for November 2006.

We also have a very positive relationship with the Capital Region of the LCA. This board, led by Phyllis Goldstein, is very energetic and passionate. They are dedicated to lung cancer advocacy with the governmental officials in upstate New York. ■

# Racing For Jim

In 2004 Jim Hawkins began working on his old Ford Mustang, getting it ready for road racing. In March 2005 he finished building his dream car and in April 2005 began attending racing school. In June 2005, Jim was diagnosed with late-stage lung cancer. He was only able to race his dream car twice. After his diagnosis he was never able to drive a car again. Jim battled his cancer valiantly, always determined to return to the racetrack. Sadly, it was a battle he could not win. Jim died on December 17, 2006 at the age of 41.

After Jim's death, his wife Sammi Hawkins wanted to do something to help others with the devastating disease of lung cancer. Sammi has a background in educational policy and thought "maybe I can put my policy experience to good use for lung cancer." Sammi remembered the Lung Cancer Alliance. "I was just so impressed with the Lung Cancer Alliance. I kept going back to the website when I was trying to find answers." So, Sammi decided to hold a fundraiser to honor her husband's memory and to raise money for lung cancer. "I literally put the fundraiser together in a week." Everything just seemed to come together. At first Sammi contacted the organizers of a local yearly golf tournament asking if this year it could be held in memory of Jim. But Jim wasn't a golfer and it didn't seem like a good fit. It was suggested that Sammi organize an event to do with



Sammi Hawkins (r) honors the memory of her late husband Jim (l) with "Racing For Jim"

racing. So, Sammi contacted Jim's friend Dan Criss and asked if he would be willing to drive Jim's Mustang during the racing season. Dan readily agreed and the fundraiser Racing for Jim was born. During the races held at Waterford Hills Racetrack in Clarkston, Michigan, near Detroit this racing season, Dan will be racing Jim's beloved Mustang. Six road races are held throughout the season beginning in May and ending in September. During each race, points are earned and Dan's totals will be posted on the website racing4jim.com. Individuals can pledge a dollar amount for each point Dan earns or can donate a one-time dollar amount to the LCA. As it states on the racing4jim web site, we hope this fundraiser will be a great way to remember Jim, to know he's still out there racing, and to raise money for lung cancer -the cancer that kills the most Americans. - D.B. ■

# Crystal Ball

THE CRYSTAL BALL.....To those interested in helping fight Lung Cancer, to honor those who died from this horrible disease, those fighting it and to give hope to those living from cat scan to cat scan, there is glory in being alive and we will have a Crystal Ball. A twice lung cancer survivor who never smoked wanted to do something for Lung Cancer Alliance, to raise funds and awareness and to honor top lung cancer doctors in Boston.

The inaugural Crystal Ball, so named as it is clearly time to end this disease, will be held Saturday, October 21, 2006 at the Fairmont Copley Plaza, Boston. The event, founded by Gail & Glenn Matthews, LCA President Laurie Fenton and Terry Guiney, will honor seven of the area's top lung cancer doctors. Honorary Chairs include Jack & Eileen Connors, Senators Ted Kennedy and John Kerry, as well as Governor Mitt Romney, among others. The Ball will draw more than 500 leaders from the corporate, academic and medical communities – become a sponsor and jumpstart LCA's goals!

If you would like more information or to be a sponsor, please contact Stage One Productions, 781-828-5050, the event coordinator for the Crystal Ball. We welcome your support. ■

# Blog

LCA introduced a blog in March 2006 as its newest communications vehicle. A blog is a contraction of the words "web log" and is a form of online communication. They began as a way for people to comment on the news and other current affairs. Blogs continue to gain popularity on the world wide web among consumers and professionals in health areas.

The LCA blog enables lung cancer patients, their families, friends and caregivers to exchange information and develop concrete steps to take as a group to spread public awareness, educate public health policy

makers and advocate for more research, earlier detection and better treatments for lung cancer.

Categories include: Current Events, Policies Affecting Lung Cancer, Lung Cancer Awareness Month Activities. The content is currently maintained by LCA in DC. As the blog begins establishing regular readers, LCA will enlist the help of our state committees to contribute original content.

Please visit the blog at [lungcancerallianceblog.org](http://lungcancerallianceblog.org) and from [lungcanceralliance.org](http://lungcanceralliance.org) and pass the word! ■

# Strike Out Cancer

CA has teamed up with three Major League Baseball stars: Hall of Famer Paul Molitor, MLB All-Star Don Baylor, and MLB All-Star Eric Davis and four other cancer support organizations: The Wellness Community, CancerCare, breastcancer.org and Colon Cancer Alliance to “Strike Out Cancer.” Baseball Hall of Famer Paul Molitor’s family has had direct experience with lung cancer.

There will be events in ten cities, including four regional summits in Washington, DC, New York City, Houston, and St. Louis, many of them

at Major League games.

The events will be designed to encourage people to get information about new approaches to cancer treatment, side effect management, psychosocial support, and patient education.

The program includes a Strike Out Cancer Hall of Fame. Go online to nominate someone you know who is making strides to help people affected

The events will be designed to encourage people to get information about new approaches to cancer treatment, side effect management, psychosocial support, and patient education.

by cancer. It could be a survivor, caregiver, medical professional, etc. Your nominee could participate in a ceremony at home plate during one of the Strike Out Cancer events.

Visit [strikeoutcancer.com](http://strikeoutcancer.com) for more information. Sponsored by Genentech. ■

## Nancy Michener: Passion and Determination

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and someone had to do it. To obtain a proclamation, Nancy organized people to contact the Governor’s office on a daily basis. The proclamation, however, was re-written by the Governor’s administration and did not reflect the views of lung cancer advocates.

Nancy then eloquently led protests against the text of the proclamation, which was mostly about smoking. She didn’t hesitate to respond forcefully, but with grace. As a non-smoker, Nancy knew that all the tobacco control in the world wouldn’t have protected her from lung cancer. She wasn’t afraid of anyone, not the even the “Governator” of California (Arnold Schwarzenegger).

In other activities, she attended the Lung Spore meeting with her LCA-CA colleague and friend Sandy Britt; Nancy wrote to the LA Times to advocate that a proposed tobacco tax increase allocate part to lung cancer research; and was involved in meeting with leadership of California State American Lung Association. Nancy knew how to make a point in a way that people could hear it.

Even after losing her daughter, she never gave up, despite her loss and her own health challenges. She was going to fight, because she knew that her daughter wanted her to.

Nancy was a very good friend to others in the California committee and

supportive when they went through their illnesses and losses. On member described her as “one of the most thoughtful people I’ve ever met, just an extraordinary person.” Nancy had an amazing spirit and we will miss her greatly.

Fellow co-chair Joyce Neifert said Nancy was “the genesis, heart and soul of the CA Steering Committee” and that “Her bravery, grace and leadership have already begun to change the face of lung cancer in this state.”

### Nancy’s original announcement about the CA Proclamation:

“The good news is that Governor Schwarzenegger issued a lung cancer proclamation today, and it has been posted on his web site! ....

The bad news is that three of the four paragraphs of the proclamation are all about smoking which is exactly what we feared and fully expected. Nothing at all about screening, nothing at all about the majority of people diagnosed are not current smokers, nothing at all about compassion or advocacy for people living with lung cancer, nothing at all about this disease being severely underfunded given the huge numbers of people who suffer from it. Nothing at all about trying to change the way this illness is perceived by the public.

I ask you to contrast this proclamation with one the Governor issued in October declaring Breast Cancer Awareness Month in which he talks about the “devastating medical, emotional and financial effects” for this illness and talks both about screening and treatment. Once again, lung cancer is not worthy of the same language.

The stigma is alive and well in California.”

### Nancy’s follow-up, leading the charge for a rewritten proclamation:

“Like most cases in non-smokers, my doctors and I have absolutely no idea what caused my cancer. Do you know what? What caused my illness does not matter to me at all. What matters is that I have cancer: I need to be treated and I want to survive.

But, the real problem with the proclamation’s obsession with causes is that by the time a person has lung cancer it is far, far too late to worry about the reason they have it. As a never-smoker with terminal lung cancer, at this point I really could care less why I have it; it simply does not matter. I am also so very, very, very, very tired of answering the eternal question “Did you smoke?” The answer to the question does not change the terrible fact that I have cancer and am fighting for my life.” ■

# Phone Buddy Volunteers Needed!



## Why are volunteers needed?

Every day, the Lung Cancer Alliance receives calls from people wanting to talk about their experiences with lung cancer. Those requests come from the newly diagnosed, those struggling with a particular treatment or stage of illness, and family members/caregivers. They want to talk to someone who'll understand their experience.

After LCA receives a Phone Buddy request, we try to find someone on our list with similarities, starting with the type of lung cancer. We give close consideration to matching according to stage and treatment. We are often able to honor requests to match by gender and age group. To continue doing so, we need more Phone Buddy volunteers.

## What kind of Phone Buddies do we need?

We need volunteers who have been through their initial diagnosis and initial round of treatment and thus see their experience from some distance. Family members/caregivers whose loved one survived, as well as those who lost a loved one to lung cancer, are also needed as volunteers.

A Phone Buddy volunteer is someone who listens well and has compassion. A Phone Buddy volunteer has a basic understanding of the disease and currently available treatments. Phone Buddy volunteers offer support, encouragement, information, and above all, hope.

## How do I volunteer?

Call the LCA toll-free number or e-mail Maureen Rigney, Program Manager, at [mrigney@lungcanceralliance.org](mailto:mrigney@lungcanceralliance.org). ■



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