

Spirit & Breath

Lung Cancer Alliance

Fall 2007

NO MORE EXCUSES. NO MORE LUNG CANCER

November is Lung Cancer Awareness Month

November 1, 2007 marks the start of Lung Cancer Awareness Month (LCAM), a national campaign dedicated to increasing attention to lung cancer and the need for increased funding for research and early detection. We need the help of volunteers and advocates across the country to make this LCAM the most successful yet!

One of our primary goals for 2007 is to make LCAM official across the country. Advocates in Wisconsin, West Virginia, California, Georgia and beyond have obtained proclamations from their governor's officially declaring November, Lung Cancer Awareness Month. **At press time over 25 governors have issued proclamations. Our goal is to get all 50 states!** Contact LCA to see how you can help us do it!

LCA has launched a National Public Awareness Campaign featuring Hall of Fame Shortstop Cal Ripken, Jr., Hall of Fame Quarterback Troy Aikman, and Emmy award winning Sportscaster Joe Buck. The television version of these ads will be featured on the Jumbotron in Times Square in New York City throughout the entire month! We need your help to keep the momentum going on a local level. **Please contact your local media and ask them to run these PSAs, which can be accessed via our website, throughout the month.** Media outlets are required to run a certain amount of public service announcements, so be sure to share your connection to the disease and explain the importance of getting out such an important public health message.

What else can you do during LCAM and beyond? Go to physicians' offices, local clinics, pharmacies, and other community organizations and ask to display information about lung cancer. LCA can provide the materials. Write a letter to the editor of your local newspaper or community bulletin sharing your story and explaining the importance of spreading the word about the need for increased funding for lung cancer research and early detection. Host an event in your home town to raise awareness for the disease.

LCA is open to hearing any other suggestions you have to help us empower patients, elevate awareness and change health policy. For more information about LCAM or any LCA initiatives, please contact Kay Cofrancesco, kay@lungcanceralliance.org, 202-463-2080. ■

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You Can Make A Difference!

Every day we receive inquiries from family members and friends asking "what can I do to help?". What they don't realize is that they have already taken a huge leap forward simply by contacting us. Serving as volunteer advocates and providing donations are certainly the traditional means of support that remain critical for mission success.

However, we are increasingly contacted by individuals who want to host their own lung cancer awareness event but are unsure how to get started. Look no further as we now have the tools to help you brainstorm

ideas and customize your very own program. Whether to recognize and empower loved ones or simply to bring hope – you can make a difference – and it is not as daunting a task as you may think.

Just ask Debbie Potash-Turner. After losing her mother and a friend to lung cancer, a friend broached Debbie with the idea to put together a bike-a-thon in their honor. Debbie jumped on the suggestion and after contacting us, organized a volunteer committee. She quickly realized that just about everybody she spoke to also shared a **continued on page 3**

LETTER FROM THE PRESIDENT



Dear Friends,

To quote Helen Keller, "The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of tiny pushes of each honest worker". I share this quote because it is illustrative of lung cancer advocacy today. Our "movement" is a growing number of passionate, energized, informed, committed and effective individuals banding together across the country to reverse the stigma and neglect too long attached to lung cancer.

Since the successes of the breast cancer and HIV/AIDS movement are often cited by our stakeholders I thought I would share a brief history which I hope will help put the progress lung cancer's movement has made in a short period of time into context.

The breast cancer movement began to take shape in two 15 year stages; the first starting in 1974 and the second in the beginning of the 1990's.

Breast cancer became "public" in 1974 with First Lady Betty Ford's announcement about her diagnosis and treatment. That opened the floodgates. For the first time, women with breast cancer began openly talking about their own experiences, speaking out as survivors rather than staying hidden as victims. Women began having mammograms, realizing that breast cancer may, in fact, be treatable rather than being a death sentence. They became active participants in their screening and treatment decisions.

Public awareness grew and the breast cancer movement continued to gradually coalesce during the 1980's. But, the dominant public health issue of that decade became HIV/AIDS, which engendered a new form of political activism, including "in your face" militancy staged to capture public attention and other aggressive tactics new to the more sedate world of health policy.

Breast cancer activists took notice and in the 1990s the second wave of the breast cancer movement turned decidedly more political. Over the ensuing 15 years support organizations and tens of thousands of activists from all over the country banded together and were eventually able to put enough pressure on Congress to increase government sponsored breast cancer research from \$90 million a year to \$800 million a year and to make mammograms available to all women, even free of charge for those who could not afford them.

Now let's relate this to lung cancer advocacy. It took 30 years for the breast cancer movement to come together and realize its successes to date. Yet in only three years, with less than 1% of breast cancer's advocacy army, public awareness about lung cancer is growing and legislation relating to lung cancer is moving in five state legislatures and the Congress. Cal Ripken, Jr., Troy Aikman and Joe Buck joined our national "Face in the Fight" campaign. Dana Reeve's sister has joined our board.

Lung cancer is starting to get more accurate media attention. The stigma of smoking, still ever present, is gradually being lifted. The public is becoming aware of the massive under funding of the disease, now hitting more non-smokers and former smokers than current smokers, and the research has evolved to now offer early detection for those at elevated risk for lung cancer.

Our "army" may be much smaller than the breast cancer movement, but our goal is not. We are combining national awareness, political advocacy and grassroots networking in tandem to propel lung cancer's movement forward at warp speed. We cannot do it without the incredible willing hearts, minds and hands of our extraordinary advocates across the country. Together we will make lung cancer a national public health priority and end its reign as the biggest cancer killer. We are turning the tide.

A large, elegant handwritten signature in black ink, which reads "Laurie Fenton". The signature is written in a cursive style with long, flowing lines.

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**LUNG
CANCER
ALLIANCE**

You Can Make A Difference!

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personal connection to this disease. "It was like a domino effect – once I started talking about it I realized, sadly, that it's everywhere. The good news was that people really wanted to do something to help. They simply had never been asked."

Debbie and her committee took this positive feedback and turned it into the "First Annual Bikathon" in Dutchess County, New York. Not only did they have 55 riders participating and another 25 joining in for lunch in the inaugural event, Debbie and her committee also raised over \$18,000 for LCA's unique patient support and advocacy programs. "This is so much more than we could have hoped for. It was a great day with entire families participating and

Whether to recognize and empower loved ones or simply to bring hope—you can make a difference—and it is not as daunting a task as you may think!

sharing their stories. We need to keep talking about it and not let anyone forget that this is a disease as deserving as any other." Due to its tremendous success, the Bikathon will be an annual event which they fully expect to get bigger and better every year.

Richard Heimler was also amazed at the outpouring of support from his community. A survivor and LCA advocate, Richard was honored when his Temple Beth Rishon in Wyckoff, New Jersey dedicated their annual benefit walk to his fight against lung cancer. Little did he know that it would result in the largest amount ever raised in the event's five-year history. "The fact that this walk raised three times more than any previous walk humbles and amazes me. With minimal effort, we made history and those much needed funds are now helping LCA help others."

These are just a couple of stories from the dozens of individuals who put



Rhea Finkelstein, Michele Kraushaar, Carson Wood, Debbie Potash-Turner, Lyn Leventhal and missing from photo but part of committee is Judy Ward.



Richard Heimler and LCA President and CEO, Laurie Fenton Ambrose at the walk in May.

together innovative events on our behalf every year. Each event was successful because the large numbers impacted by this disease, the common misperceptions, and general lack of understanding became a wake up call -- lung cancer is the underdog and the call to action is clear. The hard part is making the decision to do something – once you get started you will be pleasantly surprised by the outpouring of interest and support.

If you would like more information about hosting your own event or would like to brainstorm some ideas, particularly as Lung Cancer Awareness Month approaches in November, please

contact Emily Eyres at eebres@lungcanceralliance.org or call 202/463-2080. We have some new tools to help you get started and can also put you in touch with others that have planned similar events.

We could fill volumes of newsletters with all the stories of other action-minded individuals who have hosted events or carried out innovative fundraisers to help advance our mission. Due to our space limitations, we simply cannot feature all of them but please know that we are ever grateful for your support. We will continue to feature other events in future editions of the newsletter. ■

Joe's House Can Help

What is Joe's House?



Joe's House is a housing resource for cancer patients and their families who must travel away from home for medical treatment.

The Joe's House directories contain over 950 lodging facilities located near hundreds of cancer treatment centers in 40 states.

How can Joe's House help?

Temporary housing options near medical facilities vary widely from city to city. Joe's House brings them together in one easy-to-access resource. It consolidates networks that provide housing to those traveling for medical reasons such as Ronald McDonald Houses, Hope Lodges, hospitality houses, hotels, motels, homes, and apartments.

The resources on Joe's House sometimes provide free lodging or often heavily discount their rates for those traveling for treatment. Where no discount existed, Joe's House has frequently been able to broker reduced rates.

Who is behind Joe's House?

Joe's House was started by Ann Calahan after her first husband, Joe Warnecke, died of cancer. Ann says, "I traveled for a number of years to Texas and New York with Joe when he was in treatment. Finding a place to stay was harder than it should have been. I spent a lot of time on the phone trying to find something close and affordable. As a hospitality executive, I knew there had to be a better way." Ann vowed to correct this problem and conceived the idea of a non-profit organization that would specialize in accommodations for traveling cancer patients. With the help of her

current husband, Don, Joe's House was founded in 2003 with Ann as President.

How do I access Joe's House resources?

It's easy! Those with internet access can go to www.joeshouse.org. Via the easy to navigate search options, you select by state, city, and healthcare facility. The lodging options list has information about the facility, including the type of lodging, the distance from the medical facility, and rate. Each option also has its own information page with specifics such as distance from the nearest major airport, available amenities, and how to get the reduced rate when available. OR call toll-free at **1-877-JOESHOU** (877-563-7468). LCA's Director of Patient Services, Maureen Rigney sits on the board of Joe's House. ■

The History of Lung Cancer Awareness Month and the "Little Man" Pin

In 1995, Peggy McCarthy founded the Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)--the predecessor organization to Lung Cancer Alliance. One of the first things she did was contact the head of American Cancer Society (ACS) in Atlanta and ask for their support in promoting Lung Cancer Awareness Day (LCAD). The Great American Smoke Out already existed and she thought the natural tie in would be a Lung Cancer Awareness Day the day before. ACS refused to help. Peggy moved forward with November 15th as LCAD for two or three years. Over time, the day turned into a week and now we have designated the entire month of November as Lung Cancer Awareness Month (LCAM).

Also in 1995, Peggy came up with a clear ribbon, at the suggestion of her daughter Susan who said it would represent the "invisible disease."

In 2005 when ALCASE in Washington State was dissolved and reborn as Lung Cancer Alliance in Washington DC, November was retained as LCAM.

By that time the public was being "over-ribboned" for so many causes that it was becoming confusing. It was also felt that a ribbon was too frivolous and too passive a symbol for the much stronger message that had to be conveyed—LCA and lung cancer advocates across the country would not allow the stigma, neglect, under funding and lack of public knowledge about lung cancer statistics to continue. With both feet firmly on the ground, right in the nation's capitol, and with hands on hips directly facing the health policy makers we say: "No more excuses. No more lung cancer."

Hopefully, as we begin to see real progress in treating and preventing lung cancer, or a significant change in how lung cancer is perceived, then one of those hands will start to raise up...first a little bit and then higher....and then maybe the other one....and then maybe one day—both.....! ■



Congresswoman Lois Capps Addresses Lung Cancer

Like many of you, my life has been forever altered by lung cancer.

Seven years ago, my daughter Lisa lost her fight against the disease.

Despite her healthy lifestyle Lisa was taken from us far too soon by this deadly disease. Sadly, our story is all too familiar for many families. Lung cancer is the number one cancer killer of both men and women of every race and ethnicity, causing more fatalities annually than breast, cervical, ovarian, prostate, colon, leukemia and brain cancer combined!

Lung cancer is deadly because it is difficult to detect. As was the case with Lisa, symptoms rarely appear before the cancer spreads beyond the lungs, making treatment difficult. In 1971 when Congress passed the National Cancer Act, the 5 year survival rate for lung cancer was 13%; today it is 15%. One

cause of this limited progress is the lack of funding for research. Despite the prevalence of the disease and its deadliness, lung cancer is the least funded of all major cancers.

We must work together to build awareness of the disease and the lack of funding. Congressman Ed Whitfield (R-KY), Delegate Donna Christensen (D-VI), and I introduced House Resolution 335, declaring lung cancer a public health priority and calling for a coordinated effort to reduce the lung cancer mortality rate by 50 percent by 2015. Similar legislation has been introduced in the Senate. Please encourage your Member of Congress and Senators to support House Resolution 335 and Senate Resolution 87. Building awareness is a critical first step in winning our fight against lung cancer. ■



California Congresswoman Lois Capps (D-23rd)

Senator Chuck Hagel Addresses Lung Cancer

Lung cancer is the most lethal form of cancer for men and women in the United States. The American Cancer Society estimates that in my state of Nebraska, over 900 people will die of lung cancer in 2007. We have made great advancements in prostate and breast cancer survival rates; we must commit ourselves to making the same progress in lung cancer survival rates.

In February, a bi-partisan group of senators joined me in re-introducing a Senate Resolution calling on the President to declare lung cancer a national public health priority by increasing funding for lung cancer research, developing early detection lung cancer screening programs and appointing an advisory committee to oversee and coordinate efforts to increase lung cancer survival rates. The legislation lays out a multi-agency action blueprint for reducing lung cancer's high mortality

by at least 50 percent within the next 10 years.

In Nebraska, we have a national leader in lung cancer detection. The University of Nebraska Medical Center (UNMC) has implemented the Nebraska Early Detection and Information Technology, or NEED-IT program. It is the first statewide effort to detect lung cancer in an individual at the earliest stages through CT scans provided by hospitals across the state. The leadership of UNMC through the NEED-IT program has been critical to the fight against lung cancer both in Nebraska and nationwide.

It is also necessary to emphasize the very important work organizations such as Lung Cancer Alliance are doing to educate America about lung cancer. By bringing people together to fight this dreaded disease, we can eliminate it. I will continue to work with my colleagues to find a cure for this lethal disease. ■



Senator Chuck Hagel (R-NE)

Advocacy

Across the country, LCA advocates have made great strides in empowering patients, elevating awareness, and changing health policy in 2007. For the first time in history, legislation funding lung cancer research and early detection pilot programs was introduced in five states; three state Report Cards evaluating the overall state of lung cancer will be released in November; and at press time over 25 states have officially declared November, Lung Cancer Awareness Month. LCA Field Directors, Ed and Linda Levitt have worked with advocates across the country to build the foundations, create the committees, and strengthen the strategic alliances needed as we all work to make lung cancer a national and state public health priority.

California

LCA-CA co-chairs Joyce Neifert and Mike Stevens rallied LCA-CA advocates to educate their state Senators and Assembly members to the need for increased research for lung cancer treatments and early detection. In response to this surge, State Senator Tom Torlakson (D-7th) introduced legislation creating the Lung Cancer Research Treatment Fund. In the words of Senator Torlakson's Chief of Staff "your efforts have made a difference." As the new legislative session begins, LCA-CA will continue to work with legislators and other public health organizations, including the Bonnie J. Addario Lung Cancer Foundation, to explore all options for securing funding for lung cancer research and support for early detection in the state of California.

In 2007, LCA-CA attended many conferences (the American Thoracic Society International Conference in May), symposiums, and special events (Strike Out Cancer in August) across the state to share information with medical professionals, public health leaders, and the general public at large.



Fall 2007—LCA-GA advocates at the signing of the proclamation with Governor Sunny Purdue (seated)

Connecticut

LCA-CT chair, Jude Levi and a core group of dedicated advocates saw legislation introduced in 2007. State Senator Mary Ann Handley (D-4th) authored a bill that called for funding of a lung cancer screening pilot program focused on those at high risk for lung cancer, especially minorities and those in underserved rural areas. Through this bill, Jude has brought lung cancer to the forefront of discussions in the state legislature and beyond. At a ceremony this month, Jude's dedication to raising awareness of lung cancer was recognized. A butterfly bush was planted in her honor at St. Frances Cancer Center in Hartford.

Georgia

In addition to guiding advocates across the country, Ed Levitt, LCA-GA Director, with the help of his Executive Committee, has expanded LCA-GA into a credible and sought after source for lung cancer information. After much hard work and time spent with physicians and staff, LCA-GA and

Wellstar Kennestone Hospital's six facilities and clinics have formed a partnership to launch the only lung cancer screening program for those at high risk in the state of Georgia. This program will be modeled after the protocols published in the New England Journal of Medicine in October 2006 by the International Lung Cancer Action Program (www.ielcap.org).

LCA-GA has a jam packed November! For the fourth straight year, LCA-GA advocates petitioned the Governor and obtained a proclamation officially declaring November, Lung Cancer Awareness Month (see photo above). To jump start activities, LCA-GA, Wellstar, and the Georgia Cancer Specialists will host the First Annual Lung Cancer Memorial Walk in Centennial Park in downtown Atlanta. They will also be releasing the 2nd Annual Georgia Report Card on Lung Cancer.

Maine

Deb Violette, LCA-ME Chair, has singled-handedly changed the face of

lung cancer in Maine. By attending meetings at the Department of Health, the Department of Education, and other various governmental agencies, Deb has formed a productive working relationship with her governor and other public policy and public health leaders. These relationships have led to Maine's legislature permanently designating November 1st, Lung Cancer Awareness Day as well as the planting of a tulip garden in the state capitol as a memorial for all Maine residents touched by the disease.

Massachusetts

LCA-MA co-chairs Diane Legg and Joanne O'Connor have spent much time at the State House in Boston over the past ten months. They have met with countless members of the assembly, testified in support of legislation that would permanently designate November as Lung Cancer Awareness Month, and worked with State Senator Susan C. Fargo (D-3rd Middlesex) as she penned legislation establishing the Commonwealth Lung Cancer Early Detection and Treatment Research Fund. At press time, the LCAM legislation vote and the introduction of Senator Fargo's legislation was just days away. LCA-MA will also introduce the First Annual Massachusetts Report Card on Lung Cancer in 2007.

New York

2007 was a productive year for LCA-NY advocates. Legislation creating the Lung Cancer Early Detection Research Pilot Program was introduced in both the New York State Senate and Assembly by Senator Elizabeth O'C Little (R-45th) and Assemblywoman Aileen M. Gunther (D-98th). S5369 was passed at the very end of the legislative session. LCA-NY Co-chairs, Pam Hicks and Phyllis Goldstein and other LCA-NY advocates met with high level officials from the New York Department of Health and the Governor's staff to encourage the inclusion of funding in the state budget for 2008. LCA-NY advocates have also secured positions on key committees within the New York state Cancer Consortium—a group of individuals and

LCA Faces of Lung Cancer

Phone Buddy Volunteer Eve Samuel



Eve Samuel, diagnosed with stage IIB NSCLC in 2003 at the age of 41

Lung Cancer Alliance recently received a \$2,500 grant from MetLife Foundation in recognition of the

accomplishments of Phone Buddy volunteer Eve Samuel, a MetLife associate.

Diagnosed with stage IIB NSCLC in 2003 at the age of 41, Eve has been an active Phone Buddy volunteer since 2004. Eve, an enthusiastic and delightful volunteer, is always there to give a new buddy a call to provide information, support and most of all, hope. She is one of 19 associates across the United States selected to receive the MetLife Volunteer Service Award this year.

Established in 1994, the award honors associates who have made a difference in their communities through volunteer work. Foundation President Sibyl Jacobson said, "MetLife and its associates have a long and active history of community involvement. The 19 associates recognized this year represent the best of this tradition."

"I am pleased to be able to help out as a phone buddy. We survivors share so many unique experiences in common and there is no substitute for one-on-one sharing with someone who has been there. These 'buddy' relationships are a way for me to give back a small part of what I so generously received from countless sources during my experience with lung cancer four years ago. The fact that my employer's corporate giving division chose to support this project gives me great delight," said Eve.

The Phone Buddy Program, the cornerstone of the LCA support services, is a peer-to-peer telephone/e-mail support network that matches patients and caregivers with others who have "been there". If you are a lung cancer survivor interested in volunteering, please contact Maureen Rigney, Director of Patient Services, at mrigney@lungcanceralliance.org. ■

organizations addressing the state's cancer burden by implementing goals and strategies listed in the New York state Comprehensive Cancer Control Plan.

Wisconsin

Wisconsin advocates Gayle Zinda and Adam Rizzo will release the First

Annual Wisconsin Report Card on Lung Cancer in November 2007. Gayle, a lung cancer survivor and proponent of early detection has spoken at hospitals, community centers, and other public venues throughout Wisconsin to share her story and offer encouragement to those living with lung cancer. ■

Lung Cancer Alliance is Pleased to Welcome Amy Pearson to Our Growing Staff!

Amy, who lost her mother to lung cancer in 2003, began volunteering with LCA in February 2007 and was hired as part-time Program Manager in May. Those who are active on the online LCA Survivors Community will recognize Amy as a moderator and involved community member. You may have talked to Amy on our toll-free information line where she provides information, support, referrals, and responds to requests for materials. Amy will also be developing new patient educational materials.

Amy brings a Master's degree in Public Health and expertise in the international community health

programs to the Program Manager position. Her experience as caregiver gives her particular insight as she provides psychosocial support to patients and their caregivers, and her international health experience gives her unique knowledge and perspective on cross-cultural issues in dealing with lung cancer.

Amy has also worked with immigrant health issues in Washington, DC and volunteers with the Wendt Center for loss and healing, a DC-based organization that provides mental health services, training, and education to ease the impact of illness, loss, and bereavement.

Welcome Amy! ■

LCA Support Services

Lung Cancer Information Line:
800-298-2436

A credible source for information about all things lung cancer.

LCA Survivors Community:
<http://lungcancer.clinicahealth.com>
An online support community for lung cancer survivors and caregivers.

Clinical Trials Matching Service:
800-698-0931

A pre-screening and referral service that identifies clinical trial options.

Phone Buddy Program:
800-298-2436

A peer to peer telephone support network for people with lung cancer and their caregivers.

Keep track of the news on our website lungcanceralliance.org



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