November is Lung Cancer Awareness Month

Lung Cancer Awareness Month (LCAM) is a national campaign dedicated to increasing attention to lung cancer issues and ending the stigma of lung cancer. The best way to accomplish that is by spreading the word about lung cancer. And the best way to do that is through the work of local volunteer advocates and grassroots activity with the Lung Cancer Alliance (LCA) as the central point of organization and information — the destination for everything needed to make LCAM a success. As you read this, Lung Cancer Awareness Month is already underway. It is hard to believe that the LCA has been in Washington, D.C. for almost a year now. We’ve established our new headquarters and we’re ready to take the next step — moving to a high level of public awareness and grassroots advocacy.

Volunteer advocates are meeting a primary objective by making LCAM official across the nation. Susan Levin, a New Jersey advocate, is coordinating LCA’s nationwide efforts. She was successful in making New Jersey the first state to enact legislation to permanently declare November LCAM and is determined to see it happen in every state. She helps local advocates in other states re-create her success by proposing state-level bills with the help of their state representatives so that LCAM can be official in perpetuity. Volunteers across the country have successfully obtained LCAM proclamations (22 obtained and 15 pending at press time). If you would like to help achieve this in your state, please contact LCA.

Presenting the human side of lung cancer is powerful. With that in mind, the LCA has launched the Faces of Lung Cancer campaign which allows people to upload photographs of them or loved-ones who have been diagnosed with lung cancer. The Faces of Lung Cancer will create a powerful tool promoting awareness of the vast number of lives affected by this disease.

LCAM is a good opportunity to get media coverage. The LCA encourages and supports local advocates who speak to the media in their home towns and states and share their stories along with facts and statistics about lung cancer. LCA helps volunteers with that eternal question, “How do I begin?” and provides them with the process for getting their voices heard. To learn how to effectively contact the media, including how to write a letter to the editor, check out the LCA website.

Each year more and more events are being held during November to raise money for lung cancer research and promote awareness. Many of these events are now in their second and third years. It is exciting to see grassroots activity increasing across the country.

Local advocates have organized walks, runs, lectures, and golf tournaments, among other events, all dedicated to raising money for and increasing awareness of lung cancer. These events are listed in detail on the LCA website. Check it out and attend an event in your area, or better yet sponsor one of your own. There are guides on our website on how to organize your own event.

There are other ways to spread the word. If you enjoy working on your computer, buy some business card forms and print a message or statistic about lung cancer on business cards. Examples are: “November is Lung Cancer Awareness Month,” “Support Lung Cancer Research,” or “Lung Cancer kills more people than breast, prostate, colon, and pancreas cancers.”

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Since our last newsletter went to print, the country was rocked by the news of Peter Jennings’ death and Dana Reeve’s lung cancer diagnosis. Why? Because these diagnoses didn’t fit neatly into the box that has shaped most people’s awareness of the disease.

The realities of lung cancer are complex and little understood. Sadly, most are not aware that the majority of newly diagnosed cases of lung cancer are in former smokers – many who quit decades ago – and never smokers. The stigma and long-held misperceptions attached to this disease have contributed to the lack of awareness as well as to lung cancer receiving far less funding for research and treatment than the astonishing incidence and mortality statistics would suggest. Which is why one of the Lung Cancer Alliance’s key initiatives since writing to you last was to file an Amicus brief, or “friend of the court” brief, before the United States District Court in the case of United States of America, Plaintiff, v. Philip Morris Inc., et al.

As background, the Government filed suit against Philip Morris and ten other tobacco related companies for violating the Racketeer Influence and Corrupt Organizations (RICO) statutes. The case is still pending before the court.

Our Amicus brief strongly supports the marketing restrictions, disclosure and smoking cessation remedies that have been proposed by the United States and also agrees with tobacco control intervenors that these remedies should be strengthened. We felt, however, that the proposed remedies were incomplete because they did not require the tobacco companies to adjust their behavior toward a population directly harmed by the tobacco companies’ decades-long efforts to deny, conceal, and obfuscate the hazards of cigarettes for financial gain. This is the population, certainly numbering in the millions, who will develop lung cancer as a result of inhaling cigarette smoke.

We argue that the tobacco companies persistently denied the health impact of smoking and the addictive nature of nicotine and deliberately hid their own research into these areas. As a result the defendants – very successfully – sold the American public on the belief that smoking is a matter of free choice – not addiction. What was deliberately implanted in the public’s mind is the essence of the “stigmatization.” “Adult free choice” is really “adult addiction” – and thus lung cancer is blamed on the victim. Moreover, we believe that this stigmatization has directly and indirectly caused the under-funding of lung cancer research.

We hope the court will favorably consider our argument and allow our remedy, which seeks monies to fund independent research and early detection programs, be granted. You can review the entire Amicus brief on our website.

In addition, we will continue our work with Congress to secure additional dollars for lung cancer research and early detection funding. Lung Cancer Alliance remains committed to taking action to reverse these lethal and stigmatized trends.

(As of this writing, the United States District Court had not yet ruled on our brief.)
Together, Facing Lung Cancer

The Lung Cancer Alliance (LCA), in partnership with Genentech and OSI Pharmaceuticals, has created the educational program called Together, Facing Lung Cancer. The program was created to provide lung cancer patients and caregivers with the latest information about treatment and to discuss the importance of personal support networks when facing a cancer diagnosis. A personal support network can include an oncologist, surgeon, nurses, and other specialists including social workers as well as family members, friends, and community resources. Another important goal of the program is to instill hope, including the hope that lung cancer can become a chronic, manageable disease while work continues on finding a cure.

Each of the 2005 events was held at a major cancer center in the United States. The program began in Tampa in June and traveled to different seven cities winding up the 2005 schedule in Pittsburgh on November 10th. Dr. Jimmie Holland, a noted psycho-oncologist and author of The Human Side of Cancer, Living with Hope, Coping with Uncertainty, was a featured speaker at each of the events. Dr. Holland is chair of Psychiatric Oncology at Memorial Sloan-Kettering Cancer Center and is recognized internationally as the founder of psycho-oncology, a subspecialty of oncology that deals with the psychological impact of cancer on individuals. Following Dr. Holland to the platform at each event was a lung cancer specialist representing the local cancer center who spoke about recent treatment advances, detailing how important it is for the patient to take an active role in identifying and working with a personal support team. Laurie Fenton, President of LCA, ended the speakers’ portion of the evening by providing information about LCA’s patient services and advocacy.

November is Lung Cancer Awareness Month

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combined.” Distribute these cards just as you do your own business cards or put one in each correspondence you send, including holiday cards.

The LCA is committed to advancing a lung cancer research public policy agenda. Lung cancer receives only a fraction of the federal research funding—just 1/9 the amount of that for breast cancer. This affects survival. Two of the simplest, yet most powerful things you can do during LCAM are to sign the petition to make lung cancer a national public health priority and send a letter to Congress asking for an increase in lung cancer research funding. To sign the petition, go to the LCA web site, click on Take Action/Get Involved, then on Advocacy, and choose Sign the Petition. Take the petition to your local cancer center, hospital, or clinic and ask others to sign it. The web-site also includes a sample letter to Congress and tips for writing your own letter. Finally, LCA will unveil its first-ever Progress Report On Lung Cancer in time for LCAM. This report will provide an annual baseline on important measures such as the rates of lung cancer, smoking rates, lung cancer research dollars per death and other key indicators. This “Report Card” will become the annual benchmark for evaluating progress towards eradicating lung cancer. It will be rolled out with a concerted media campaign.

Remember, you are the power behind awareness. Use your power. Speak up during Lung Cancer Awareness Month and throughout the year. ■

Come join Lung Cancer Alliance staff and volunteers at the Thomas G. Labreque Foundation’s inaugural Washington, DC race. The Thomas G. Labreque Foundation was founded in 2002 by the Labreque family in honor of Tom. They also initiated the Thomas G. Labreque (TGL) Classic, "Run as One" event with the hopes of raising lung cancer awareness and research dollars to find a cure. The TGL Classic Road Race, on Sunday, November 20, will benefit lung cancer research and awareness. Visit tglclassic.com for registration information and course details. You may register online until Wednesday, November 16.
Advocacy 2006

This year the Lung Cancer Alliance (LCA) completed its transition to Washington, D.C., establishing itself in its national headquarters near the White House. The LCA realized that to be successful in influencing and changing public policy, it needed to be at the center of that activity. As a new year approaches, LCA will, as it has done since its inception, carry on its mission of advocacy on behalf of lung cancer patients and those at risk for the disease by continuing to push for federal commitments to lung cancer research and early detection. But, as the new ad campaign “No More Excuses. No More Lung Cancer.” has so clearly shown, LCA is gearing up to make 2006 a defining moment in the way lung cancer is understood by the public and by policy makers.

Mobilizing the grassroots movement in the fight against lung cancer is one of the primary goals for 2006. It is through the committed work of a grassroots “army of activists” that we can make lasting change in public opinion and public policy. The dedication of a network of individuals who are profoundly concerned about lung cancer issues will ultimately change public opinion and advance a lung cancer public policy agenda. To this end, LCA will hold a spring advocacy conference in Washington, D.C. where it plans to gather committed advocates from across the nation who will become the initial voices of an organized grassroots movement. The advocates will be trained in ways to increase awareness at the congressional level, and push Congress to increase funding for lung cancer research. During the conference advocates will hand carry signed petitions to Congress, calling on the president of the United States and the members of Congress to make early detection, treatment, and chemoprevention of lung cancer a national public health priority and calling for adequate new funding to increase the overall 5-year survival rate to at least 50 percent by 2010.

(You can sign the petition by going to http://www.lungcanceralliance.org/involved/sign_the_petition.php)

Now that the LCA is established at a national level, the next organizational goal is to create chapters throughout the U.S. and ultimately in each state.

Now that the LCA is established at a national level, the next organizational goal is to create chapters throughout the U.S. and ultimately in each state. These local chapters will be charged with monitoring statewide activities with respect to lung cancer. It is important that watchdogs for lung cancer interests are present at the state level, since some legislative changes can only be enacted at this level. Local constituents can obtain bills proclaiming November Lung Cancer Awareness Month through the state government and through letter writing and personal visits to legislators. Evaluating a state’s budget and cancer plan for inclusion of lung cancer research and early detection are important state-level goals. State chapters will track and monitor money from the master settlement between state attorneys general and the tobacco industry to ensure that settlement money is being channeled into lung cancer research and programs that will benefit those diagnosed with or at risk for lung cancer, addressing an important political issue. Certain health care issues can also be addressed at the state level including available health insurance, adequate health care, and access to clinical trials and the best possible medical treatment for all who are diagnosed with lung cancer. It is through this type of grassroots organization – from national, to state, to local, and ultimately to the individual – that the most effective and successful political movement is achieved.

Another 2006 goal is to continue to enhance lung cancer patient support programs. LCA hopes to build on the success of the Together Facing Lung Cancer seminars which began in June 2005 and traveled to seven different cities in the U.S. These seminars provide patients and caregivers with the latest information in the treatment of lung cancer and ways to create a personal support network which can dramatically help patients and family members cope with a diagnosis of lung cancer.

2006 promises to be a year of organizational milestones for LCA in its ultimate goal of eradicating lung cancer. No more excuses. No more lung cancer!
Veterans Day is November 11, falling about midway through our observance of Lung Cancer Awareness Month. As we take the time to honor those men and women who have nobly fought and died for our country, we also recognize our living veterans. Veterans Day is also a reminder that veterans are affected even more by lung cancer than the rest of the population.

Several studies have shown that veterans have a significantly higher death rate from lung cancer than the general population\(^1\),\(^2\),\(^3\) Study after study has shown that our veterans have a higher "ever smoked" rate (74.2%) than the civilian population (48.4%), which is not surprising since the Department of Defense gave away cigarettes and even included them in K rations until 1976.\(^4\) Cigarettes are still sold tax free at PXs and rumors have been rampant about the easy availability of cigarettes in Iraq.

CA Salutes U.S. Army Sgt. First Class (ret) Dave Grant of Baraboo, Wisconsin for his support, advice and very active advocacy since he was diagnosed at Stage IV in 2001. Dave, along with Estrea Janoson, founded the Survivors for Lung Cancer Awareness message board (lungcancersurvivors.org).

He spent 16 years of his 20 years with the Regular Army as a Medical Laboratory Specialist, and a Nuclear Medical technologist. He is currently in clinical trials. Keep up the fight, Dave!

CA salutes Jim Curtis of West Virginia and Amman Williams of Washington State.

Although Jim Curtis, who served in the U.S. Army from 1962 to 1965, did not serve in any major conflicts, many of the troops he trained went to Vietnam. But in 2001, war of a different kind came to him. At the age of 55, he was diagnosed with Stage IV NSCLC. It was the week after Memorial Day. Curtis confronted his enemy with chemotherapy and participated in a clinical trial. Because it was a double-blind study, he was not told what drug he had received.

“Whatever it was, it worked,” Curtis said. “I now have no tumor.”

Eighteen years after he had retired, Amman Williams, who had served 27 years in the U.S. Army (1953 to 1979), initially thought that the bouts of pneumonia he had suffered while on active duty had returned. But in 1998, doctors at Madigan Army Medical Center in Tacoma, Washington, determined that it was not pneumonia this time. It was lung cancer.

Luckily, the tumor was localized in his left lung. So, in June of that year, Williams underwent a lobectomy and has been cancer-free ever since.

Both Williams and Curtis share their stories of survival as LCA phone buddies. Their victories against lung cancer now serve as an inspiration and source of hope to others facing the disease.

“I’m very active in (the program). I’ve been doing it for a couple of years,” Curtis said. “It’s just a little something I can do to help people out.”

CA recently met with the president of the Vietnam Veterans of America and has meetings planned with the Veterans of Foreign Wars (VFW) and other veterans’ organizations to build collaborations. Please let us know if you would like to help.

REFERENCES

The Lung Cancer Alliance would like to express our sincere gratitude to our volunteers, who work tirelessly to offer support to lung cancer patients and their families.

We would specifically like to thank the Lung Cancer Hotline volunteers, Zhonghui Sun, Karena Smith, Dina Katsev Igoe and Shirley LaFevers, who regularly provide information and support to those affected by and at risk for lung cancer.

The motivation to become an LCA volunteer is often driven by personal experience with lung cancer. When Shirley LaFevers was first diagnosed, her search for lung cancer information came up cold. While other cancer organizations offered support and encouragement, lung-cancer specific information was difficult to find.

As a LCA Hotline volunteer, Shirley now provides information for patients in the same situation she found herself in years ago.

“Since I have worked as a Patient Advocate (at Johns Hopkins) for five years, I have talked with lung cancer patients, but on a small scale. Through the hotline, I am able to reach more people,” Shirley said.

Shirley and other volunteers offer answers to patient questions about their treatments, make referrals for support groups and financial assistance, and direct them to educational resources. But, perhaps most importantly, the volunteers provide a much needed source of hope.

“The recently diagnosed patients are devastated, as was I. I can give most of them hope and show them there is light at the end of the tunnel,” Shirley said.

“I keep the conversations up-beat, and I share the phrase I used each day as I trudged off to my radiation treatment, which was ‘I can do this.’”

“And I did.”

The LCA also thanks Meghan McArdle for research; Mike Fox-Boyd for manning the hotline this summer, as well as Anita Johnson; and Sherri Rauenzahn, Blain Farr and Patricia Tan for office assistance. Special thanks to Deborah Benton and Melissa Marino for contributions to this issue.

Not only is a lung cancer diagnosis an emotionally jarring event, but the medical bills and other costs too often drain a family’s finances.

The family of Jan Nadeau knew this all too well. Jan was diagnosed with Stage IV lung cancer two years ago and recently succumbed to her illness. Seeing the family’s struggle throughout Jan’s battle with the disease, Jan’s daughter Lisa and her partner Mary Novak wanted to help alleviate some of the financial stress and to raise awareness of lung cancer in their Minnesota community.

As avid runners, Mary and Lisa were already planning to run in the Grandma’s Marathon half-marathon event on June 18.

“We thought, let’s do it and try to raise awareness and money for the Nadeau family and for the Lung Cancer Alliance,” Mary said.

Calling their two-woman team ‘Running for Life,’ Mary and Lisa enlisted the help of the Grandma’s Marathon organizers, who helped distribute information about their fundraising effort to the local media. Donations poured in from family, friends and even complete strangers from across the country.

The ‘Running for Life’ team raised around $4000, which was split between the Nadeau family and LCA.

The success of their first event inspired Mary and Lisa to repeat it. Along with two other runners, they ran 10 miles on October 2nd, with all proceeds going to LCA. “Any race we run, we’ll run in honor of Jan,” Mary said.

People touched by lung cancer have been instrumental in raising awareness of the number one cancer in the United States.

In honor of their father, Joseph, who passed away in February of this year, Jeanette and Stephanie Marchiano have organized the first lung cancer awareness event in Folcroft, PA which was held October 8th.

“‘My father was a young man, only 53 when he passed of this horrible disease,’” said Jeanette.

“My sister, Stephanie, and I came up with the idea after my father passed. We wanted to join a run/walk…but we were absolutely shocked to see there was not one event concerning lung cancer in the Delaware County, PA area.”

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I am a wife, mother, grandmother, friend, nurse, case manager, educator and author. But, because of a relatively small mass that appeared on a chest x-ray, I must now also view myself as a cancer patient.

As a healthcare consumer who has a diagnosis of lung cancer, I realized that all cancers are not created equal. My disease has few champions, no bright colored ribbons and, if there is a race to a cure, it is a triathlon not a sprint. Only a few national groups are available to support the needs of the lung cancer patient. My community did not offer any group that fostered physical or emotional support for those touched by this disease.

Because lung cancer is not generally identified through a specific annual screening regimen, there are no public service announcements that remind “at risk” patients to seek screening. We commonly discuss personal experiences regarding mammograms or Pap smears and even colonoscopies during polite conversations, but I have never heard anyone discuss the need or even the desire to be screened for a pulmonary tumor.

And, although lung cancer is the most common cancer treated in my community, I rarely meet other patients with a primary diagnosis of lung cancer. I find we are a quiet lot who are reluctant to discuss our illness. Maybe that is due to the ever-present question, “Did you smoke?” Whether past behavior and lifestyle decisions contributed to the development of the disease is really unimportant and immaterial. What is important is the great need for patient support and the advancement of research to find a way to conquer this disease.

Because my disease was identified before it became significantly advanced, I feel that I am one of a lucky few. To date, I have survived thoracic surgery, chemotherapy and radiotherapy. And, although I have been frustrated with some aspects of my care, I am still here to tell my tale.

I am grateful for the skill and expertise of every member of my treatment team. They have helped me to reach toward a goal of “managing,” if not conquering this disease. But, the journey towards survival has not been always been smooth. I find that not all members of my care coordination team have fought with the strength, intensity and enthusiasm that I would like them to display.

At times, I have felt alone in this battle and frustrated with the fight. I remain reluctant to make long term plans since there is a strong possibility that the disease will recur. I dread milestones since they are closely associated with regular testing that may identify an increase in disease activity. And, yes, at times, I am afraid of what that recurrence may mean.

But, I refuse to live in fear and, therefore, I am working to accept and live with this disease. My plan for living with lung cancer includes: telling my story to all who will listen; even if I have to answer the dreaded “smoking” question; contacting my elected representatives and demanding more funding for lung cancer research; and, enjoying today because not one of us knows how many tomorrows we will experience.

“Portions of this article were reprinted from PRIME, 2004, data on file.”
With hard work and determination, Jeanette and Stephanie organized their own event and formed the Joseph Marchiano Lung Cancer Research Foundation.

“We hope to raise awareness of this number one killer in the United States, to make it as common as the pink ribbon for breast cancer.” On October 8, Stephanie reports that “Even in the rain we had 142 people show up! It was a huge success in our book.”

The funds raised will be split between the Lung Cancer Alliance and Fox Chase Cancer Center in Philadelphia and will go toward research, education, increasing awareness and helping care for people with the disease.

“Our goal is that one day, maybe a family will not have to hear ‘there is nothing we can do,’ like we did,” Jeanette said.

Together, Facing Lung Cancer

efforts and encouraging participants to become advocates for lung cancer awareness. The final part of each evening included patient testimonials and a question and answer session during which the audience had access to the combined knowledge of the speakers, including oncologists from some of the best and most advanced cancer centers in the country.

With the success of the 2005 events, LCA plans to expand the program in 2006. In addition to large cities, the program will travel to smaller venues, becoming community based so that it can reach a larger population. The program is free and open to the public. More information can be found at www.togetherfacinglungcancer.com or by calling the Lung Cancer Alliance at 800-298-2436.

The LCA would like to thank the physicians who have participated in the 2005 Together Facing Lung Cancer Series:

George Simon, MD
Medical Oncologist
H. Lee Moffitt Cancer Center
Tampa, Florida

David Jablons, MD
Chief of Thoracic Surgery and leader of the Thoracic Oncology Program
UCSF Comprehensive Cancer Center
University of California at San Francisco

Alan Sandler, MD
Medical Oncologist
Vanderbilt-Ingram Cancer Center
Nashville, Tennessee

Paul Bunn, MD
Director of the University of Colorado Cancer Center
Denver, Colorado

Julie Brahmer, MD
Medical Oncologist
The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Baltimore, Maryland

Keep track of the news on our website lungcanceralliance.org