

UP TO DATE INFORMATION ON LUNG CANCER

New Lung Cancer Research Program at the Department of Defense

One of Lung Cancer Alliance's (LCA) top priorities was realized this fall when a brand new lung cancer research program at the Department of Defense (DOD) was approved by Congress and \$20 million appropriated to get it started in 2009.

"LCA is deeply grateful to Congressman John Murtha (D-PA, 12th), the chairman of the House Appropriations Subcommittee on Defense, Senator Daniel Inouye (D-HI), the Chairman of the Senate Appropriations Subcommittee on Defense and Senator Thad Cochran (R-MI) the highest ranking minority member of the full Senate Appropriations Committee for their leadership in making this happen,"

said Laurie Fenton Ambrose, LCA's President and CEO.

Congress first began funding medical research programs through DOD with a \$25 million appropriation for breast cancer research in 1992. Now called the Congressionally Directed Medical Research Program (CDMRP), this DOD portfolio has grown to over 40 disease specific research programs, including breast cancer, ovarian, cancer, prostate cancer, autism, diabetes and HIV/AIDS and has received \$4.8 billion in funding over the past fifteen years. To date \$1.8 billion has been earmarked for breast cancer. Without a specific program linked to it, lung cancer research has received only a small amount of sporadic funding over the years.

"Thanks to Chairman Murtha, we now have our own legs to stand on—a designated lung cancer research program within DOD, \$20 million to launch it this fiscal year and the ability to expand this amount going forward as the program grows," Fenton Ambrose said.

Having DOD involved is going to make a big difference in lung cancer research. "DOD is mission-oriented. With this separate funding stream they can focus on putting together a program that will make maximum use of those funds. And, importantly, DOD knows how to push the envelope on imaging technology that is critical in diagnosing lung cancer early, treating it and expediting the development of more effective therapies." ■

IN THIS ISSUE

Letter from the President	2
LCA Patient Support	3
Dimes for Joan	4
Resource Corner	5
LCA Welcomes Newest Board Member	5
Faces of Lung Cancer	6
A Policy to Fight Lung Cancer	7

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LCA Salutes Congressman John Murtha for New Lung Cancer Research Program at the Department of Defense



Congressman John P. Murtha (D-PA, 12th)

U.S. Representative John P. Murtha has dedicated his life to serving his country both in the military and in the halls of Congress. He has had a long and distinguished 37-year career in the U.S. Marine Corps, retiring from the Marine Corps Reserve as a colonel in 1990 when he was awarded the Navy Distinguished Service Medal by the Commandant of the U.S. Marine Corps. The first Vietnam War combat Veteran elected to Congress, he has been serving the people of the 12th Congressional District of Pennsylvania since 1974.

continued on page 4



Dear Friends,

November is Lung Cancer Awareness Month and I would like to highlight “Awareness” in this newsletter as developments to end lung cancer as we know it continue to unfold at an exciting pace and will continue on after November and into 2009.

First, I want to report that LCA achieved its highest priority this fall. We set a goal day one, when we first opened our doors in Washington, DC four years ago, to secure a new pipeline for lung cancer research. I am so proud to share that WE DID IT – all of us – as we now

have signed into law the first-ever \$20 million line-item for lung cancer research managed within the Department of Defense. Simply put, this is a “shot in the arm” to badly needed research as lung cancer’s pipeline has been massively under funded for decades. Something had to change – and this is exactly the course correction needed. Let’s hope history repeats itself because this is how breast cancer jump started its efforts to see significantly improved survival rates today. We will work to ensure lung cancer charts a similar course.

Second, LCA helped shepherd another critical element of an over arching strategy to increase public health funding for lung cancer. The United State Senate again assumed a leadership role and introduced last June S.3187, the “Lung Cancer Mortality Reduction Act of 2008”, legislation to give authority to lead federal agencies, Departments of Defense, Veterans and Health and Human Services, to craft a broad and comprehensive plan to address lung cancer.

We all worked hard to communicate to our respective Senators the need for their co-sponsorship. We were able to enlist additional endorsement from key Senators but the clock ran out on the 110th Congress. But don’t worry, LCA is already hard at work lining up leaders in both the Senate and House of Representatives to reintroduce the “Lung Cancer Mortality Reduction Act of 2009” when the 111th Congress convenes in January. So stay tuned for new “calls to action”!

Lastly, we are enhancing our patient support initiatives to ensure that the lung cancer community has access to real time information and is efficiently and effectively linked to others affected by the disease. This newsletter will draw a brighter line on our hallmark programs and feature now enhancements underway to better support all those living with or at risk for the disease.

In closing, I cannot underscore enough how valuable your involvement and support is to our mission to reverse decades of stigma and neglect. Without it, we could not have achieved the successes to date – nor tackle the challenges we will continue to face tomorrow. Only together will we make the difference! From the entire staff at LCA – thank you for all you do and may you all have a healthy and happy New Year!

Sincerely,

Laurie Fenton Ambrose
President and CEO

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Lung Cancer Alliance Patient Support

LCA is the only national non-profit organization dedicated to patient support and advocacy for those living with or at risk for lung cancer. What does that mean to you? We focus 50 percent of our attention on political advocacy. Our Staff in DC and advocates across the country work with federal and state law makers to secure public health funding for lung cancer research.

The other 50 percent of our time is spent providing support and information for anyone touched by lung cancer or interested in learning more about the disease. Director of Patient Services, Maureen Rigney, LICSW, and Program Manager, Amy Pearson, MPH, manage and oversee the vast array of support services that we offer.

Meet Maureen Rigney and Amy Pearson



Maureen Rigney



Amy Pearson

Maureen joined us over three years ago with a Bachelor's degree in Psychology and a Master's in Social Work. Amy became a full time member of our staff a little over a year ago after first spending time as a volunteer and part time staffer. In addition to being fluent in Spanish, Amy holds a Bachelor's degree in Sociology and a Master's degree in Public Health.

Both Maureen and Amy have been personally touched by lung cancer; each losing a parent to the disease. So, in addition to the nearly 30 years of experience in providing direct social services, program and materials development and public health outreach that they bring to LCA, both provide the compassion and understanding that those touched by the disease need.

LCA Information Line (800-298-2436) and Educational Materials

We receive hundreds of requests for help and information every year from across the United States on our toll free information line, operating Monday through Friday from 9am to 5pm, Eastern Time. Every caller has a unique question and they vary greatly, so don't hesitate to call with any type of request. We will do our best to provide what you need and find the answers to your questions. Many callers seek current and reliable information on lung cancer, early detection methods, treatment options, symptom management and side effects of treatment. We can also provide information on finding clinical trials and second opinions, emotional support, smoking cessation, and resources for financial assistance.

To complement this Information Line, we offer free educational materials. With a wide variety of informational materials on hand, we are able to tailor our educational packets with information related specifically to the needs of each caller.

LCA Phone Buddy Program

The LCA Phone Buddy Program is the hallmark of our patient support portfolio. Started over ten years ago, our program is a great way for people dealing with lung cancer to connect with others who have gone through similar situations. Through our Phone Buddy network, a patient or caregiver is matched with a survivor with whom they can talk to for support, information and hope. The program is built around the selfless work of approximately 200 volunteers who represent all areas of the country and all stages of lung cancer.

How does it work? When someone calls the Information Line and asks to be matched with a Phone Buddy, the process starts with a series of questions. We try to get to know everything we can about the caller from diagnosis and treatment plans, to their current support system, to their specific needs and concerns. This

helps us best determine the most appropriate "match".

We match both current patients as well as caregivers based on diagnosis and treatment. While understanding that each person will have a unique experience with lung cancer, we feel that the specificity with which we match is extremely useful to both the person requesting the phone buddy and often to the volunteers as well. In some instances only a few phone calls are exchanged, but some Phone Buddy relationships last for years.

LCA Survivors Community

The LCA Survivors Community offers unique, round-the-clock online support for anyone who needs it. Open to patients, survivors, and caregivers alike, our community communicates through a web-based message board where participants can exchange experiences, provide support, celebrate the victories and truly empathize with each others' daily struggles with lung cancer.

By posting a message to our online community, a participant can get a response from any of the hundreds of frequent users. The value in this depth and breadth of experience is unrivaled for those who have access to the internet. Our community provides a connection and sense of empowerment and solidarity for lung cancer survivors and caregivers.

"When I was first diagnosed with Stage IV lung cancer in February 2008, I found the LCA Survivors Community. It is the single most valuable tool that has helped me cope with my diagnosis. Meeting and 'talking' to people like me, being able to ask questions or voice my concerns and having them addressed by others who know exactly what I am going through, getting support when I need it and having the opportunity to help others has been a tremendous help to my well being as I continue this battle. I have also met some extraordinary people and some good friends on this board that I

continued on page 6

Dimes for Joan

After Debbie Barrese's mother, Joan Furfaro, passed away from lung cancer nearly three years ago, she found great comfort in the dimes she would find in strange places. "Dimes would turn up when I needed her most or even when I thought to myself, 'Wouldn't she have loved to see this?'" Debbie says. "Dimes have been my comfort and source of connection to my mother in the time since she passed."



Debbie Barrese with her Dimes for Joan

After seeing a Today Show segment and recognizing one of the Lung Cancer Awareness advocates as her mother's nurse, she contacted the nurse to ask what she could do to help raise awareness. The nurse told her about LCA and encouraged Debbie to reach out to get more involved in raising awareness and honoring her mother. She took that advice and contacted LCA.

Soon after she reached out to LCA, an idea to raise money for lung cancer awareness was minted. Debbie wrote a letter to family members asking them to collect dimes in honor of Joan. Her family responded in ways Debbie never expected and for eight full months they faithfully gathered dimes for Joan.

At the annual family reunion, every family member handed over their dimes to Debbie. The family collected **9,524 dimes** in honor of Joan Furfaro!!! "I was blown away and I know Mom is very proud," said Debbie.

But, Debbie Barrese didn't stop there. This November, she partnered with her daughter Danielle and friends Jackie and Lynn Wolf to host a basketball Hoop-a-Thon in New Jersey that raised an additional \$5,000 for LCA.

Danielle has now caught the bug and now raises awareness on her own. Serving as Miss Delaware Coed 2008, Danielle gave LCA pins and awareness cards as gifts to the other pageant contestants, using her unique position to raise lung cancer awareness among young people.

LCA extends many thanks to Debbie and her family for their spirit, innovation and support. We can't wait to hear what they do next! ■

LCA Needs Your Help!



PHONEBUDDY

Would you like to help provide support to someone who is dealing with lung cancer? Consider volunteering as an LCA Phone Buddy.

We are looking for lung cancer survivors of all stages, whether in or out of treatment, of all treatment varieties.

We are also looking for caregivers with any type of caregiver relationship and any type of experience.

Please call us at 1-800-298-2436 or email info@lungcanceralliance.org if you are interested in more information!

continued from page 1

LCA Salutes Congressman John Murtha for New Lung Cancer Research Program at the Department of Defense

Congressman Murtha is highly respected for his first-hand knowledge of military and national security issues. He has been a trusted adviser to presidents of both parties and is one of the most effective advocates for our national defense. Currently the Chairman of the House Appropriations Subcommittee on Defense, he oversees appropriations for the Department of Defense, which includes the Air

Force, Army, Marine Corps, Navy, and the Intelligence Community.

Congressman Murtha's mission to improve access to preventative medicine, expand medical research, and ensure that health care is affordable has benefitted people across our country. He has been a founder and champion of the Congressionally Directed Medical Research Programs at the Department of Defense.

Congressman Murtha is currently the ninth most senior member of the 435 member U.S. House of Representatives. Of the nearly 10,000 men and women who have served in the U.S. House of Representatives since 1789, only 90 have served longer than he has. Congressman Murtha's many honors include the John F. Kennedy Profile in Courage Award. ■

Quitlines

What is a Quitline?

Quitlines are free telephone-based services available to any tobacco user wanting and needing help to quit. Tobacco users will receive information and support to make it easier for them to stop using tobacco products.

What is the National Network of Tobacco Cessation Quitlines?

Through a single toll free number, 1-800-QUIT-NOW (1-800-084-8669), the *National Network of Tobacco Cessation Quitlines* allows callers from anywhere in the United States to easily access the *Quitline* in their home state.

How can a Quitline help?

Recognizing the strength of the addiction, *Quitlines* provide individualized counseling, general information about tobacco use and the benefits to quitting and self-help materials. Services vary slightly from state to state, but most materials are available online. There are special services for teens

and pregnant smokers. *Quitlines* also provide help to friends, relatives and other members of the tobacco users' support team. Many offer services and information in languages other than English and can take calls from the deaf or hard of hearing.

How did the Quitline system start?

To ensure access to tobacco cessation services for all Americans, the US Department of Health set up the network of *Quitlines* in 2004. Federal funding supports all the lines in the United States.

How did the Quitline system start?

It's easy! Call toll-free to 1-800-QUIT-NOW (1-800-084-8669) from anywhere in the country. You will be automatically routed, by area code, to your free state *Quitline* where you can find out more about the tools and resources they offer. Or, you can visit www.naQuitline.org where you will find the World *Quitline* Map, with a detailed list of each quit line's service offerings. ■

Lung Cancer Alliance Welcomes Newest Board Member

January 1, 2009 marks the start of Admiral T. Joseph Lopez's, USN (Ret.) tenure as an LCA Board Member. Admiral Lopez, a native of Fayette County, West Virginia, joins the Board after a distinguished career in both the Navy and the private sector. He enlisted in the United States Navy in 1959 and was commissioned as an officer in 1964. He has earned a Bachelor of Arts (Cum Laude) in International Relations, and a Master of Science in Personnel Management from the U.S. Naval Postgraduate School.

During his naval career, Admiral Lopez commanded destroyers and destroyer squadrons in the Mediterranean and Red Seas. He commanded a River Assault Division in Vietnam and Cambodia. His principal assignments included tours as both Commander in Chief of U.S. Naval Forces, Europe and Commander in Chief Allied Forces, Southern Europe. In addition, he commanded all U.S. and

Allied Bosnia Peace Forces in 1996. He was also Deputy Chief of Naval Operations for Resources, Warfare Requirements and Assessments and Commander of the United States Sixth Fleet. Admiral Lopez is one of only two flag officers in the history of the Navy who have achieved four-star rank after direct commission from enlisted service.

In many of his career assignments he served in the same location as Rear Admiral Phil Coady, Former LCA Board Chairman. They became friends and remained in close contact. Prior to his passing, Rear Admiral Coady introduced Admiral Lopez to the LCA and was instrumental providing him the knowledge of LCA's mission and encouraging his involvement.

During his career, Admiral Lopez was awarded numerous medals and honors, including four Distinguished Service Medals and various other medals, ribbons and devices. He received



Admiral T. Joseph Lopez, USN (Ret.)

numerous honors from his home state including selection as the West Virginian of the year in 1998.

In addition to serving on LCA's Board, Admiral Lopez sits on the

Board of other institutions and organizations including the National Defense University, the National Youth Science Foundation, the Naval Postgraduate School, the Armed Forces Benefit Association, and the CNA Corporation. He is Chairman of Imagine West Virginia and served as Vice Chairman of the West Virginia University Board of Governors. Welcome to the LCA family, Admiral! ■

Lung Cancer Alliance Patient Support

wouldn't have otherwise met. I feel like the people on this board are my second family.”

Community members are very active in discussions and immediately reach out to those new to the community so they feel welcome. While high impor-



Susan Laurents,
Stage IV NSCLC
Community
member since
January 2008

tance is placed on allowing free and open conversation on all topics, our staff and community moderators constantly review postings to check for accurate information and to make sure participants follow the community guidelines which require full respect for each other, despite occasional differences in opinion.

We work hard to ensure that the community is a safe place where everyone can get the support that they need, whenever they need it. Anyone can visit the online community through our website, but in order to participate in discussion, you must be registered as a user. Registration is free and you can give as much or as little information as you wish. Please feel free to stop by!

Clinical Trials Matching Service (1-800-698-0931)

It is through research and patient participation in clinical trials that new drugs are developed and effective medication combinations are discovered. There are hundreds of lung cancer clinical trials and we provide a service to help all patients access this information and navigate the clinical trial enrollment system.

Our Clinical Trials Matching Service, powered by EmergingMed, provides a patient friendly mechanism to find available clinical trials. By calling the

toll free number, 800-698-0931, patients and caregivers will connect with a clinical trials specialist who will collect information about diagnosis and treatment history. The specialist will use this information to find specific clinical trials that the patient will be eligible for. In addition, the specialist also answers general questions about clinical trials, helps with enrollment and follows up with the patient or caregiver throughout the process.

It is also possible to create a profile through LCA's website to search for trials listed on Emerging Med's easy to navigate database of clinical trials. Regardless of a patient's diagnosis and treatment, it is important to know about all available treatment options including clinical trials.

In addition to our Clinical Trials Matching Service, we work with Emerging Med to publish a yearly newsletter describing promising research as presented at the American Society of Clinical Oncology (ASCO) Annual Meeting and in other research forums. *The New Directions* newsletter translates highly scientific information into language that can be understood by everyone.

In addition to these specific programs, we are often asked to review educational materials, clinical studies and other publications to ensure they

are patient friendly and patient relevant. We do our best to bring the “patient perspective” to the table each and every time we meet with other organizations, hospital representatives, scientists and the like to make sure that any decisions made are in the best interest of those we serve.

What's on the Horizon?

Maureen and Amy have a long wish list for expanding LCA's Patient Support Services. During 2009, we will expand the Phone Buddy Program to further meet the needs of callers and volunteers. We will also develop educational and awareness materials to meet the needs of the Spanish-speaking population.

Look for these enhancements and more in 2009!

Special Thanks to our Partners

Many of the materials we send out to the lung cancer community have been produced with the assistance of other non-profit organizations such as CancerCare, the Wellness Community and the National Brain Tumor Foundation. Through this collaboration, we have been able to provide the information so needed for patients and caregivers across the country. ■

The Emergency Economic Stabilization Act of 2008 Extends Tax-Free IRA Charitable Rollover Gifts Through 2009!

If you are aged 70 ½ or older you can make tax-free cash gifts totaling up to \$100,000 a year from your IRA to qualified charities like Lung Cancer Alliance. So many of you reach out to us wanting to give back in a meaningful way – and now you can with what you have saved in retirement assets. This act allows tax-free giving from your IRA through December 31, 2009. The gift must be made outright to Lung Cancer Alliance – it cannot be used to fund an annuity or other life-income gift. Other types of retirement plans (401k, 403b, and SEP accounts) are not eligible. Please consult with your tax advisor or accountant for more information about the program. ■

Dan Waeger, 25, Bethesda, MD

Over three years have passed since my diagnosis of non-small cell lung cancer. At the time of my diagnosis, I was 22 years old, in graduate school, coaching a Division One golf team, training for a marathon and looking forward to a career on Wall Street. My life was just taking off.

It was May 2005 and I was in the midst of taking final exams when I developed a persistent cough. Over a two week period, my symptoms worsened and I started feeling short of breath. I finally checked myself into the hospital and a few days later my doctor uttered those three words no one wants to hear—"You have cancer." Even worse-it was stage IV. As a 22 year-old non-smoker with no family history of cancer, the diagnosis was a shock.

From day one, I believed that having a positive attitude was the only way to succeed. When I was diagnosed, my college buddies gave me a green wristband that says "Waeger Will Win" and I wear it remind me of that attitude every day.

My favorite book is called "Good to Great" by Jim Collins. Reading the

book got me thinking about my own life and everything I've gone through. Three years ago, I knew my life was pretty GOOD so I was determined not to let this thing called "cancer" stop me from being GREAT. When you are faced with a potentially life threatening and debilitating disease you can feel sorry for yourself or stand up and fight. I knew I had no choice but to fight.

Every day presents some type of battle. From the nausea to neuropathy, from the sore throats to the moments of weakness where tears sometimes turn into puddles, I know that I have a long road ahead. For lung cancer survivors, we wonder whether or not that cramp in our side or the cough from a normal cold is the cancer coming back. Whether it's the chemotherapy or the mental stress of living with cancer, we



get knocked down a lot. However, as Rocky Balboa said, "It's not how many times you get knocked down, but how many times you get back up."

I've been knocked down a lot. I've received treatment every three weeks since my diagnosis. I've received radiation, undergone two major surgeries and another extended hospital stay for a suspicious virus. I've had every side effect you can imagine. But I know that I have to keep getting up. There is no other way to face cancer than with a "Will Win" attitude.

My fight is far from over. I hate to use words like "fight" or "battle"—because it seems cliché. But it really is a battle- not only for health, sanity, but a sense of normalcy. It is a battle I fight with passion. After all, I have a lot to do! I look forward to marrying my fiancé, Meghan, and starting our new life together, helping other young adult cancer survivors through my foundation, National Collegiate Cancer Foundation, and raising the awareness that lung cancer sorely needs. ■

A Policy to Fight Lung Cancer

Janice Woods is about to celebrate a milestone. She was diagnosed with lung cancer almost five years ago—and is still going strong. This year she decided to give back and support LCA's mission to eradicate this disease. When an old life insurance policy closed out this year, Janice received some extra income that she wasn't expecting. She decided to donate a portion of this money to LCA. "Lung cancer is an insidious disease that affects so very many people as well as their family and friends. I feel most fortunate at this point in my life and am so pleased that I was able to give back something to the LCA. They have sent me such informative literature over the years and were a tremendous support for my husband during my 'battle.'"

We are grateful to Janice. Her support allows us to help and empower others touched by this disease. For more information on life settlements and how they can be applied to further our programs, please contact Emily Eyres at 202-463-2080. ■

LCA Has Found a New Home!

After five years of sharing offices, moving from building to building and spending time in temporary office space, LCA has found a permanent home in Washington, DC. Located just a few hundred feet from the White House and the historic Lafayette Park, LCA's new offices, next door to the famed Hay Adams Hotel, occupy first floor space in the Motion Picture Association of America building. In fact, Laurie Fenton Ambrose and Sheila Ross work everyday from the very same office that was once home to MPAA President and Senior Executive, Jack Valenti!

My how LCA has grown! It was in the borrowed office space of Former LCA Board Chairman Steve Hart's law firm that LCA began more than four years ago. Laurie Fenton Ambrose, Sheila Ross, Kay Cofrancesco and Sarah Temin began their work for LCA in a 10x10 office. After the first month, they expanded into one of the firm's available conference rooms in order to have enough space to reach out to the hundreds of lung cancer patients and caregivers seeking support and guidance during that mission-defining first year.

LCA's new home is a beautiful space that will allow us to grow and expand in the coming years. In addition to its individual offices and ample storage units, the new space has been personalized with LCA colors and logos and infused with the new found spirit and enthusiasm of the staff here in DC. If you are ever in Washington, DC, please stop in and say hi! ■

LCA Free Support Services

Lung Cancer Information Line: 800-298-2436

A credible source for information about all things lung cancer.

LCA Survivors Community:
<http://lungcanceralliance.inspire.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 latest lung cancer news on our website www.lungcanceralliance.org



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