

UP TO DATE INFORMATION ON LUNG CANCER

The Lung Love Project

LCA's most recent initiative with a focus on educating and connecting lung cancer patients, survivors, their loved ones, and health care professionals. Comprised of three core components, **The Lung Love Project** addresses the needs of those touched by lung cancer by providing personalized educational materials and support services.

Lung Love Life

The Lung Love Project began in September 2009 with the launch of **Lung Love Life**, a formal and targeted outreach program aimed at providing medical institutions and cancer centers across the country educational materials about lung cancer and LCA's support services.

Leading the program is LCA's Manager of Community and Support Services Miguel Vélez. First, Miguel created a database of approximately 4,500 hospitals and major cancer service providers, with a special emphasis on

those with lung cancer programs and a multidisciplinary approach to patient care. Next, he began reaching out to a key contact person at each institution—building relationships with nurse navigators, social workers and hospital resource centers throughout the country.

Now, Miguel sends those contacts a packet of LCA materials and encourages them to request more as needed. Finally, he will follow up systematically to maintain contact and a steady flow of materials to all institutions. With 52% of the U.S. covered as of June 2010, LCA is more than half way to meeting



its goal of reaching out to all 50 states, Washington, DC and Puerto Rico.

"Lung Love Life is the focal point for our outreach," said Miguel. "We want to make sure that from the moment of diagnosis, lung cancer patients and their caregivers and loved ones have information available to them—about the disease itself and available support programs."

In addition to raising awareness of LCA and our services Miguel is also identifying lung cancer specific oncology programs across the county, which will allow LCA to better assist the hundreds of callers to our toll-free information line (800-298-2436) each month.

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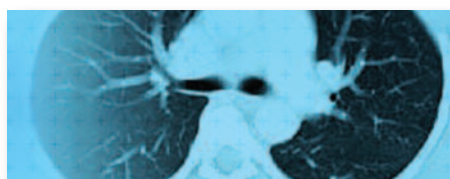
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LCA Launches Give a Scan

First Patient Driven Open Access Website for CT Scans and Clinical Data

This June, LCA launched **Give a Scan**—the first open access website for CT scans and clinical data donated by lung cancer patients. LCA developed the Give a Scan program to empower patients to accelerate the research for lung cancer screening,



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"The imaging is critical in the diagnosis, treatment and follow-up of lung cancer patients, and imaging holds enormous potential for speeding the development of targeted drugs and monitoring the effect of personalized treatments."

— Daniel C. Sullivan MD



Dear Friends,

It has been a busy spring and promises to be an even more active fall! We are excited about recent developments that have further advanced our mission and expanded the growing network of voices calling for a more compassionate and comprehensive plan of action for the lung cancer community. Let me share the details.

LCA has partnered with Brigham and Women's Hospital Connors Center for Women's Health and Gender Biology, a Harvard Medical Affiliate, to present "***Out of the Shadows: Women and Lung Cancer***," the most current and compre-

hensive report to date on the impact of lung cancer on women. Presented in layman's terms, this highly regarded report tells women what they need to know – and what they can do to ensure lung cancer no longer remains a hidden disease.

Since its release in late April, "*Out of the Shadows*" has gained traction and exposure on Capitol Hill, throughout the medical community and in the national press. "*Out of the Shadows*" has also been embraced by leading national women's health and social justice organizations that have come together to urge increased support, fairness and equality for women affected by lung cancer. Given the content and widespread distribution of "*Out of the Shadows*," there promises to be never before seen media coverage of the issues surrounding women and lung cancer, especially during November, Lung Cancer Awareness Month.

LCA continues to see more support for the Lung Cancer Mortality Reduction Act—first ever authorizing legislation establishing a multi-agency, comprehensive program targeted at lung cancer! In 2010, due in large part to the efforts of our state chapters and grass-roots networks across the country, we have gained 13 new House co-sponsors for a total of 56 and 5 new Senate co-sponsors! Representatives John Yarmuth (D-KY) and Gwen Moore (D-WI) and Senators John Kerry (D-MA) and Olympia Snowe (R-ME) are the most recent leaders to acknowledge the need for increased lung cancer research funding.

As a response to persistent concerns raised by the research community regarding the lack of clinical data and open access to patient CT scans, LCA began researching, developing and testing the feasibility of setting up a patient-driven process for donating CT scans to an open accessed website. After three years of work, LCA officially launched the **Give a Scan** program in June. **Give a Scan** is the world's first patient-powered open source database to increase and accelerate lung cancer research. This archive contains images and clinical data on lung cancer patients that will enable more researchers to focus on lung cancer and to accelerate progress in the early detection, diagnosis and treatment of lung cancer.

Planning is underway in earnest for our 5th annual Capitol Forum, LCA's signature national advocacy conference. This three day conference will bring advocates from all across the country to Washington, DC and provide valuable and memorable insights and training on key legislation that will bring increased compassion and support to people living with or at risk for lung cancer. We anticipate this to be even bigger and more effective for advocates than ever before.

These are some of the highlights of our on-going efforts to realize better outcomes for the lung cancer community. Thank you to each and every one of you for all you are doing to bring lung cancer "Out of the Shadows."

Sincerely,

Laurie Fenton Ambrose

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National Shine a Light on Lung Cancer Vigil Announced

The 2nd Annual National Shine a Light on Lung Cancer Vigil will be held on November 4, 2010!

Volunteers from across the country will be hosting and participating in vigils between the hours of 6-11pm EST. The goal of this year's campaign is to host 100 simultaneous vigils representing all 50 states and Washington, DC that will reach one million people.

Community-based vigils will coincide with LCA Chapter vigils already planned for Massachusetts, Georgia, California, New York and Kentucky. These estab-

lished vigils already attract hundreds of participants and will help build excitement around the National Vigil.

"Bringing a community together; bringing attention to a disease that has been overlooked and stigmatized; memorializing and honoring our loved ones and in the process helping change the face of this disease—this is what Shine a Light on Lung Cancer Vigils are



"As caregivers, patients, loved ones and or advocates, we've got to fight anyway that we can! The Shine a Light on Lung Cancer Vigil was a great catalyst for us to build a group of people willing to support lung cancer patients and help raise awareness in our community."

—Holly Michaelson, LCA-NY Co-Chair

all about," said Diane Legg, lung cancer survivor and LCA-MA co-chair.

The National Vigil brings together those interested in shining a brighter

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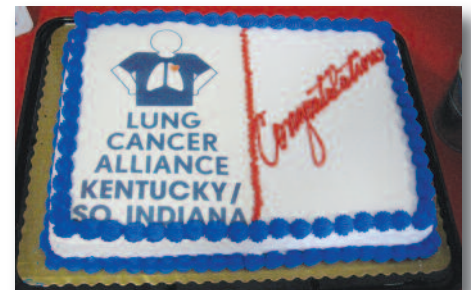
LCA Forms Fifth State Chapter

It is official! We are so pleased and proud to announce the formation of our fifth volunteer state chapter—Lung Cancer Alliance-Kentucky/Southern Indiana! Headquartered in Louisville, LCA-KY/So.IN was founded by Nancy Alvey, a lung cancer survivor; Goetz Kloecker, MD, an oncologist at the James Graham Brown Cancer Center and Colette McCoy, a passionate advocate for those touched by lung cancer.

For approximately nine months, the founders and now co-chairs of the chapter organized meetings, recruited survivors, caregivers and health professionals and spoke out generally

about lung cancer and LCA. Nancy is an articulate spokesperson for lung cancer survivors everywhere, sharing her story of survival and in doing so, providing hope for those newly diagnosed. She has willingly become the "Face of Lung Cancer" in Louisville. Through her doggedness and persistence, she also secured the support of her Congressman for the Lung Cancer Mortality Reduction Act!

Colette and Dr. Kloecker worked behind the scenes speaking with colleagues to engage them in the mission of LCA and ensure their leadership within the chapter in the years to come. They organized meetings and



No celebration would be complete without cake!

spoke to anyone who would listen about becoming involved in the cause.

All of this came together on May 19, 2010 as a group of over 20 survivors, caregivers, nurses and oncologists met for the official LCA-KY/So.IN chapter kick off! Members of the state advisory board spoke and laid out the plans for the next six months for the chapter. LCA Staff members, Emily Eyres and Kay Cofrancesco joined the festivities as well.

We could not be more honored to have such a dedicated group of advocates engaged and committed to advancing LCA's unique mission. Great things are happening with this chapter and we are just getting started! For more information go to the chapter web pages: www.lungcanceralliance.org/kentucky. ■



LCA KY/So. IN Chairs, Advisory Board Members and volunteers at the kick off.

LCA Launches Team Lung Love: Endurance Training Program Brings Awareness and Support for Lung Cancer Nationwide!

On Sunday, May 2, 2010, runners and walkers from across the country made history by participating in LCA's first-ever **Team Lung Love**. Thirty-seven men and women (including three lung cancer survivors!!) crossed the finish line at the Cox Rhodes Races Marathon and Half-Marathon in Providence, RI. This race marked the launch of LCA's new endurance sports training program focused exclusively on raising awareness and support for lung cancer.

"Team Lung Love is a great way for survivors and anyone who's been touched by lung cancer to feel like they're doing something about this disease," says Team Lung Love National Coordinator Julia Gaynor. "It's also a great way to meet new friends, connect with others who've been touched by this disease and get



fit – all while raising funds for LCA to change this disease as we know it."

Team Lung Love marathon and half-marathon participants raise a designated fundraising minimum. The Providence team exceeded their fundraising minimum and brought in over \$60,000 to benefit LCA's patient support and advocacy programs.

Members of Team Lung Love receive coaching, race entry, hotel rooms and team branded race apparel. They're supported every step of the way with dedicated coaches and mentors, as well as volunteers who

cheer them on as they run or walk their race.

Karen Arscott, a four year lung cancer survivor from Waverly, Pennsylvania, walked the half marathon in Providence with her husband and sister by her side. "Before Team Lung Love, I felt really alone in my battle against lung cancer," she says. "Now I know there is an army forming and my family and I are part of it. I can't wait to do it again!"

The second Team Lung Love event took place just a month later in Albany, NY on June 5th with 17 walkers participating in the Freihofer's Community Walk. In just a few short weeks, these walkers raised close to \$3000 to support the LCA-NY Chapter.

Next up, marathoners, novice runners and walkers of all levels and ages are welcome to join Team Lung Love as we train for the Philadelphia Marathon, Half-Marathon or 8K on November 17, 2010. Team Lung Love is honored to have been selected as one of only ten official charity partners and our team will run along with 23,000 other runners at one of America's most prestigious running events.

In February 2011, Team Lung Love heads south to Austin, TX to participate in the Livestrong Austin Marathon and Half-Marathon!!! We hope to have over 100 teammates - including many survivors – travel for what should be an incredible weekend.

If you would like more information about joining Team Lung Love, please contact Julia Gaynor at jgaynor@lungcanceralliance.org. ■



Lung Cancer Survivors Jude Levi, Karen Arscott, Linnea Duff and Diane Legg after the Race!

Give a Scan

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diagnosis, treatment and drug development by providing researchers open and free access to critically important CT scans from a variety of lung cancer patients.

Give a Scan is the first publicly available archive that contains images and clinical data on lung cancer patients. All the data has been donated by patients in order to encourage more researchers to focus on lung cancer and to accelerate progress in the early detection, diagnosis and treatment of lung cancer which is now the leading cause of cancer death in the world.

Under the Give a Scan program, patients can donate their scans and other clinical information to LCA, which will de-identify the scans and upload the data to the new Give a Scan website. Interested researchers can then access these scans, free of charge, providing a crucial database of information unlike anything ever publicly available.

"Imaging is critical in the diagnosis, treatment and follow-up of lung cancer patients and holds enormous potential for speeding the development of targeted drugs and monitoring the effect of personalized treatments," said Daniel C. Sullivan MD, Professor of Radiology at Duke University Medical Center and Director of the Imaging Core, and Science Adviser to the Radiological Society of North America (RSNA).

You can make a positive impact on lung cancer research! With Give a Scan, patients are going to drive the change that will bring more researchers and more resources to the epidemic of lung cancer. For more information on the Give a Scan program or to learn how to donate scans, visit www.lungcanceralliance.org/giveascan ■

Ed Levitt

"I have stage IV lung cancer. It will only win if I let it. I believe attitude and involvement in the cause are everything in staying alive, and staying ahead of this lousy disease."



Ed with his wife, Linda at a gala last winter.

Prior to being diagnosed with stage IV lung cancer in 2004, my wife and I were making plans for our retirement. It was very important to us because my work kept me on the road 27 days a month for 20 plus years. I lived to work; some would say I was a workaholic.

When I wasn't focused on work, I was focused on exercise. At 61, I was in outstanding shape. I did smoke for a few years but that was 36 years ago. I thought smoking wasn't a problem because there is no cancer in my family and everybody smoked in the 50s and 60s.

It was at 61 that my life changed completely. I was getting off a plane and felt a severe pain in my right leg. As the days went on the pain grew worse. Towards the end of the trip, I could barely raise my leg to put on my pants.

I returned home and my wife insisted I go to the doctor. The doctor thought I had some inflammation due to over exercise. She prescribed some medication and sent me home. A week later, I revisited the doctor with a hard lump in my right groin.

She immediately gave me a chest x-ray, blood tests, a CT scan, an MRI and a bone scan. The CT scan showed lung and adrenal gland tumors. The bone scan showed tumors on my spine, ribs, neck and collar bone.

We met with the oncologist. He came into the office and said, "You have stage IV lung cancer. There is nothing we can do for you. Get your affairs in order and make funeral arrangements. You have about 30-60 days max."

I rarely cry, but I did then. I was scared. I was lost and did not know what to do. At that moment, my wife decided she was not going to take this lying down. Immediately she made an appointment for a second opinion. We met the second oncologist and after he reviewed my records I said, "Doc, is there any hope? Anything?" He just looked back at me and said, "There is always hope."

After many rounds of unsuccessful chemotherapy, my doctors put me on an experimental drug that stabilized my disease. Through it all I continued walking my dogs every day for at least four miles, rain or shine! I have remained active throughout the entire six plus years since my diagnosis. I credit my survival on that fact.

Once I felt that my lung cancer was under control, I decided I wanted to help myself and all lung cancer patients in the future. I researched lung cancer specific organizations and found LCA. My wife and I believe strongly in their mission. We work with them and four years ago founded the Georgia chapter of LCA.

I have given up on retirement because there isn't one for me. Instead my wife and I work together on my new life focus. We will fight this dreaded disease together with what time I have left.

I wake up each morning thanking God that I am alive. My aggressive business nature has helped me stay focused on a new end goal—to beat lung cancer and work towards finding a cure so that others can beat lung cancer too. ■

The Cancer Legal Resource Center

Helping with insurance coverage and other legal issues for those touched by cancer.

What is The Cancer Legal Resource Center?

Founded in 1997, *The Cancer Legal Resource Center* (CLRC) is a unique and valuable service that provides free, confidential information and resources on cancer-related legal issues. This national, joint program of the Disability Rights Legal Center and Loyola Law School-Los Angeles was created to assist patients, survivors, caregivers, health care professionals and others coping with cancer.

How can The Cancer Legal Resource Center help?

CLRC is the place to turn for help if you have any legal issues related to a cancer diagnosis, including insurance coverage, employment discrimination, access to health care and estate planning,

Through the toll-free Telephone Assistance Line (866-THE-CLRC) or the online and fax request form, you can find out about relevant laws and resources for your particular situation. In addition, CLRC can turn to its Professional Panel of attorneys, insurance agents, and accountants

for more in-depth information and counsel to callers as needed.

CLRC also offers educational materials; holds teleconferences, webinars, conferences and seminars; hosts workshops on cancer legal-related issues open to those affected by cancer, health care providers, and the general public.

How can I find out more about The Cancer Legal Resource Center?

It's easy! If you have internet access, you can learn more about CLRC and the services offered at www.cancerlegalresourcecenter.org or call toll-free at 1 (866) THE-CLRC (866-843-2572). ■

Meet LCA's Newest Employee

Denitra Kitchell is LCA's newest staff member. She moved from

Indianapolis, Indiana to begin work with LCA as the Development and Advocacy Specialist. A native to the Midwest, she has spent over half a decade volunteering for various health, community and outreach organizations. She earned a B.A. degree in Communication Studies from Indiana University Purdue University Indianapolis and hopes to continue study in the health field.

Through her work with advocates from across the country, she hopes to aid in the fight to end the negative stigma of lung cancer. Denitra has been somewhat of a convert; when she first thought of lung cancer, she held the belief that lung cancer was only caused by smoking. She has since learned this is not true and is jumping in with both feet to change the public perception of the disease and help show the true face of lung cancer. ■

"I am very happy to be here and can only hope I add something to LCA and advance its mission."

—Denitra



LCA Support Services

Lung Cancer Information Line:
800-298-2436

A credible source for information about all things lung cancer.

LungLoveLink

www.lunglovelink.org

An online support community for lung cancer survivors and caregivers.

Clinical Trial 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.

Upcoming Events

On the evening of November 4th, in conjunction with the National Vigil, LCA-MA will host its 4th Annual Shine a Light on Lung Cancer Vigil in Boston at the Prudential Building! Last year more than 300 people attended. Don't miss out on this exciting event! Find out how you can be involved at www.lungcanceralliance.org/massachusetts.

LCA-NY will also be hosting their Shine a Light on Lung Cancer Vigil in November in Albany, NY. If you are in the area and want to help or submit a picture for the tribute portion of the evening go to www.lungcanceralliance.org/newyork.

LCA-GA is hosting the 2nd Annual No More Excuses Run/Walk this November 6, 2010 outside Atlanta, GA! We are anticipating over 1500



runners and walkers to help us kick off Lung Cancer Awareness Month. For information on registration and sponsorship opportunities, go to www.lungcanceralliance.org/georgia.
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The Lung Love Project

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Lung Love Learn

Lung Love Learn is an educational brochure series addressing the wide ranging issues and concerns of lung cancer patients. The first brochure, published this past winter, introduced basic information about lung cancer to the newly diagnosed and their loved ones. Entitled *Lung Cancer: Understanding the Diagnosis*, this brochure provides a knowledge base and marks a starting point in a patient's quest for information. Hundreds of these brochures have already been sent out to cancer centers for patient distribution.

Up next for publication is a brochure that provides information specific to non-small cell lung cancer which accounts for approximately 87% of all lung cancer diagnoses. This brochure will be available by August 2010 and will be followed by a small cell lung cancer brochure.

As so many of those touched by lung cancer understand, there is often stigma associated with this disease. By the end of 2010, LCA will also produce and distribute a brochure about lung cancer stigma. This brochure will provide methods that patients and their loved ones may use to cope with the related stigma.

LungLoveLink

LungLoveLink is LCA's recently launched online community for those impacted by lung cancer. Whether you are a survivor (either out of treatment or currently in treatment), a caregiver, a family member or friend, a health care professional or a lung cancer advocate, LungLoveLink is a place for you to

"meet" others and share valuable information, resources and support.

LCA has moderated an online support community since 2006. By taking lessons learned from this experience, we launched LungLoveLink in April to continue the evolution of the online support community by combining message boards for support, while adding space for sharing resources, events and relevant news links.

The Support Forums include a range of topics including specific cancer types, caregiver issues, nutrition, and much more. There is also a space to honor the memory of loved ones lost to lung cancer. The Events Calendar is available for people all over the world to post lung cancer-specific events for those who want to participate. Tracking lung cancer "In the News" keeps the members of LungLoveLink informed on recent developments in lung cancer prevention, diagnosis, treatment, and support.

"The use of online communities for support is constantly changing," said Amy Pearson, Associate Director of Community and Support Services and LungLoveLink moderator. "We will continue to evolve in an effort to meet a wider range of needs for support and resources in the lung cancer community!" For more information and to find out if LungLoveLink could be a useful resource for you or a loved one, go to: lunglovelink.org ■

**Help us renew our
community outreach,
support services and
national awareness and
advocacy programs
for years to come!**

Join the lung cancer movement and meet your financial goals at the same time by making planned gifts to Lung Cancer Alliance. These gifts allow you to plan for your family's future while helping others impacted by this disease. You can do more than you thought possible and still receive favorable financial and tax benefits by*:

- Making charitable gifts from your IRA
- Donating gifts of stock
- Leaving Lung Cancer Alliance in your will
- Redefining life insurance policies

For more information on lasting legacies to continue our unique mission and make this disease a national public health priority please contact Emily Eyres at 202-463-2080.

* Please consult with your legal counsel, tax attorney and/or financial planner about these options today.

National Shine a Light on Lung Cancer Vigil Announced

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light on lung cancer. The vigils will range in size, location and agenda, but will all include the powerful stories of lung cancer survivorship. The vigils will provide information, support and hope for all of those touched by the disease. They can also act as a means for many to honor and memorialize their loved ones.

These vigils are an integral part of an extensive awareness effort to reduce the stigma of lung cancer and gather more people to support the cause. Many of the vigils will receive extensive media coverage on the local and national levels. They are kick offs to what promises to be the most recognized Lung Cancer Awareness Month to date!

We need your help to make this all happen! LCA has the tools for you to host your own vigil. We will provide you with materials, glow sticks and media contacts in your area and make it as easy as possible for you to raise awareness of lung cancer in your community. We also have an extensive website that lists all of the vigils across the country. Use this to sign up to be a vigil organizer, to volunteer to help an organizer or to attend a vigil in your area. Go to www.shinealightonlungcancer.org for more information. ■

Upcoming Events

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Members of Team Lung Love will be running the Philadelphia Marathon on November 21st. This will be the third event featuring Team Lung Love and we want to get 100 runners for this race. Join LCA staff and volunteers in the City of Brotherly Love this November.

The LCA-CA and LCA-KY/So.IN Chapters will also be hosting Shine a Light vigils this fall.

In addition, many people who have been touched by lung cancer hold events across the country to benefit LCA. Lorraine Julian is hosting a comedy event in Rochester, NY featuring internationally known comedian Rob Schneider in honor of her 41 year old sister, Renee on August 7th. This September 18th, Ken Wheatley of San Diego, CA will celebrate the life of his late wife, during the 1st Sheila Ann Wheatley Tennis Tournament. The 7th Annual Race for Breath will kick off November in Virginia Beach, VA on November 6th under the direction of lung cancer survivor Cathi Reade and founders Kelly Burke Jennings and Stacey Emanuel. For more information on these and other events please go to www.lungcanceralliance.org. ■

LCA's services are made possible by generous support from people like you. Please consider giving back, using the attached envelope, so that other may continue to receive these free services.



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