

Lung Cancer Connection

Spring 2011 Newsletter



A Message From LCC's Co-Founders Cheryl Lamprecht & Myrtle Chidester

Dear Friends,

What an amazing past few months it's been for Lung Cancer Connection and lung cancer advocates everywhere. Over 1,000 people took part in LCC's 2nd Annual 5K Fun Lung Run/Walk on November 6, 2010. Thanks to the hard work and generosity of everyone involved, we raised a total of more than \$70,000, far surpassing our goal of \$50,000. All donations will be used to further LCC's mission to fund lung cancer research and provide support and educational programs for those affected by lung cancer in St. Louis.

We were also excited in November by the results from the National Lung Screening Trial, sponsored by the National Cancer Institute. The latest NLST study showed a 20 percent reduction in lung cancer deaths for high risk patients whose disease was first detected using low-dose helical CT scans (also known as spiral CT), compared to patients who were screened with standard chest X-rays. These findings further confirm the fact that early detection is essential for effectively treating lung cancer, and ultimately saving lives. LCC hopes you will join us in lobbying state and federal lawmakers for insurance coverage of CT scans, so more people will be able to access its lifesaving potential. The importance of CT scans is further explored in an article on page 4 from our guest medical advisor, Daniel Luedke, M.D.

LCC Sponsors New Support Group

One of the most highly desirable but least available resources for lung cancer patients is the opportunity to connect with others who share their questions and concerns about managing this devastating illness. In an effort to fill the void of information and assistance, this spring Lung Cancer Connection will begin sponsoring a new lung cancer networking group at the Cancer Support Community of Greater St. Louis (formerly known as The Wellness Community).

The monthly meetings will utilize a new discussion format to address both the medical treatment questions and emotional health needs of lung cancer patients. An oncology nurse, familiar with the lung cancer disease process, will guide the first half of each 90-minute session. The latter half of the meetings will be facilitated by a licensed clinical social worker, experienced in helping patients handle

the mental challenges of living with a lung cancer diagnosis. Lung Cancer Connection hopes to foster a dynamic, informative, and compassionate networking environment that will strengthen and inspire patients on their lung cancer journeys.



Deb Zimmerman, Charli Prather of the Cancer Support Community, and Myrtle Chidester

The Lung Cancer Monthly Networking Group will meet on the first Thursday of each month, beginning April 7, 2011, from 6 p.m. to 7:30 p.m. Meetings, which are free and open to patients and their caregivers, will be held at the Cancer Support Community, 1058 Old Des Peres Road, St. Louis, MO 63131. Registration is not required. For more information call 314-238-2000.

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Mark your calendars for **May 21, 2011**, when LCC will host its **2nd Annual Patient Education Seminar**. Our featured speaker will be Howard (Jack) West, M.D., director of the Thoracic Oncology program at the Swedish Cancer Institute, located in Seattle, Washington. Dr. West is a world-renowned oncologist and clinical researcher, and he will offer tremendous insight into various complex medical issues that lung cancer patients face on a daily basis. You will find more information about Dr. West and the seminar on page 5.

Finally, we are so happy to welcome two new members to the LCC board: Rita Russell and Deb Zimmerman. Both Rita and Deb bring compassion and dedication to LCC's mission, and we are proud to have them lend their time and talents to the cause. And as always, we are extremely grateful to all of you for your continued encouragement and support. Thank you.

-- Myrtle and Cheryl

Support

Education

Research

Hope

Faces of Lung Cancer: Tammy Yvette Jewell Miller

LCC Donation Coordinator

In February 2008, I noticed I was coughing more frequently than usual. But I wasn't worried. I had suffered from seasonal allergies most of my adult life and this cough did not seem any different from my past experiences. At age 42, I was a nonsmoker, I exercised, and I loved to get outdoors. A couple of months passed and I went about my daily life with the coughing continuing off and on.



Tammy Miller

In April of 2008, my husband and I took a trip to Jamaica where we had a wonderful time. Although I was feeling tired and needed to take lots of naps, I thought my fatigue was due to my aortic stenosis (narrowing of the heart's aortic valve), a condition I had lived with for several years. However, prior to my trip the cardiologist told me that my heart was okay and wouldn't need surgery in the near future. After returning home, I decided to get to the bottom of my cough. My primary care physician ordered a chest X-ray which showed what appeared to be pneumonia in both my lungs. I was puzzled by this diagnosis because I had always believed that symptoms of pneumonia included fever and coughing up sputum. I told myself, though, "Well, I am not the doctor, and my physician has much more experience with this sort of thing." So I followed the doctor's orders, completed a round of antibiotics, and went back to my everyday life. But the cough continued.

During the last two weeks of June, while I was away on another trip, I noticed a rattling/crackling sound coming from my chest while I was sleeping. Since I was feeling short of breath as well, I wondered if I was suffering from asthma. After I returned home, I went back to see my physician. Again he told me that I had pneumonia, but I was sure I did not. I begged him to examine me more closely and listen specifically for the sounds coming from my lungs while I was lying on my back. After he did, he said, "I have never heard anything quite like this." He ordered me to undergo a lung function test and CT scan. While driving home after the tests, I received a call from my doctor. "Go back to the Emergency Room immediately," he said. "You either have lung cancer or Tuberculosis, and you must be quarantined if it is the latter." I was in shock. But cancer was not my main worry – I just knew I did not have cancer. I believed I had Tuberculosis. For months I had been coughing, and I was so scared and worried that during all that time, I had been infecting my friends, family, and coworkers.

After more tests a few days later, my doctor informed me that I did not have TB. I was so relieved to know that I had not infected other people that the realization that I had lung cancer did not automatically sink in. I heard the doctor say cancer, but at the time it didn't seem like a big deal. After a biopsy of my lymph nodes, I was diagnosed with stage IV adenocarcinoma. Both of my lungs had multiple tumors. The cancer was in lymph nodes in my chest and I had one brain tumor. At the time I remember thinking, "Well, this is just a large bump in the road." I knew my life was going to be inconvenienced, and it was not going to be a picnic to take chemotherapy, lose my hair, be sick, and experience a lot of side effects. But not once did it ever occur to me that the cancer was so serious that I would die from it. I just wanted to begin my treatments so I could finally get better.

Since September 2008 I have been on continuous chemotherapy. I had stereotactic radiation to my brain tumor and to the larger tumor on my right lung. I have undergone several thoracentesis procedures, and I've been hospitalized several times for infections, blood clots in my lungs and legs, and other medical problems stemming from chemotherapy. I am glad to report that over time, all of my tumors have slowly become smaller.

In November 2009, my husband and I attended a lung cancer education seminar where for the first time I met volunteers from Lung Cancer Connection. "This is what I have been looking for!" I told my husband. "Someone who knows how we feel and is working to change public perception of lung cancer." With the strength and encouragement of my husband, a few days later I walked in the first Lung Cancer Connection 5K fun run/walk, and I ran in the second annual 5K in 2010.

What shocked me most about having lung cancer is how unsympathetic society is to lung cancer patients. People with lung cancer are treated as if they deserve their cancer, as if it was self-inflicted. There is very little public support for lung cancer patients and their families. Research into better treatments and tests for earlier diagnoses is grossly underfunded. If I had been diagnosed sooner, I may have been declared cancer-free by now.

The above picture of me was taken in Jamaica. It is still hard to believe that just a few months afterward I was diagnosed with stage IV lung cancer.

Lung Cancer Connection is a
non-profit 501 (c) (3)
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Cancer Center Receives Lung Cancer Connection Research Award

In October of 2010, Lung Cancer Connection selected Saint Louis University Cancer Center to receive a \$3,000 research grant. The funds will be used to complete a study titled "Optimal Management of Early Stage Non-Small Cell Lung Cancer Surgical and Radiotherapy Options," which compares the effectiveness of surgery versus radiotherapeutic treatment in patients with early-stage non-small cell lung cancer.

A key principle of LCC's mission is to help raise funding for lung cancer research to levels that are comparable to other common cancers. As such, LCC is thrilled to significantly increase the amount of research money it will donate this year to \$15,000.

Applications for the 2011 LCC research grant will be accepted through August 31st. All projects submitted for consideration must focus on some compelling aspect of lung cancer research. The award recipient will be announced in October. For more information, please e-mail Myrtle Chidester at Myrtle@LungCancerConnectioninc.org



Cheryl Lamprecht, Myrtle Chidester, and John Dombrowski, M.D. and Mark Varvares, M.D. of Saint Louis University Cancer Center

Spectacular Turnout for 2nd Annual 5K Race

With your help, we did it again in 2010! On November 6th, Lung Cancer Connection's extraordinary community of supporters and volunteers came together at Creve Coeur Lake Memorial Park to honor friends and loved ones affected by the disease.

Enthusiasm for the event was high as over 1,000 racers, including 24 teams of walkers and runners, made their way around the park.

KMOV Channel 4 news anchor Jasmine Huda served as honorary chairperson for the race, kicking things off with an inspiring message about the challenges of fighting lung cancer and the hopes for improved treatments in the future.



Thanks to our Wonderful Sponsors

Energizer, SSM Cancer Care, Saint Louis University Hospital, Saint Louis University Cancer Center, Emerson, Midwest Chest Consultants, St. John's Mercy Hospital, Missouri Baptist Medical Center, St. Luke's Hospital, Brown & Crouppen P.C., Beck and Allen Cabinetry, Instant Imprints-Chesterfield, Siteman Cancer Center, Sandberg Phoenix & von Gontard P.C., The Delmar Gardens Family, Altair Travel and Cruises, Morrison Travel & Cruise, Sowers & Wolf, and Lisa Brauch Niemeier Family & Friends

SAVE THE DATE: NOVEMBER 5, 2011
3rd ANNUAL 5K FUN LUNG RUN/WALK

Support the Cure: Buy Lung Cancer Jewelry

Mary Scannell, volunteer coordinator for Lung Cancer Connection, is using her creative talents to raise lung cancer awareness. When Mary lost her husband to lung cancer eight years ago, she noticed a distinct lack of jewelry supporting lung cancer patients and lung cancer research. Although bracelets and necklaces were widely available for most other cancers, Mary was disappointed to discover that lung cancer jewelry was hard to find. She decided to address the disparity by designing bracelets, necklaces, key chains, and bookmarks that are lung cancer specific. Each exquisite piece is handmade by Mary and fashioned in Sterling Silver, Pearls, and Swarovski Crystals. Prices range from \$15 to \$30, with Mary generously donating 100% of the proceeds to Lung Cancer Connection. If you would like to purchase some of Mary's unique accessories, please call 636-329-8790 for more information.



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Lung Cancer Connection Guest Advisor

Q & A

Dr. Luedke, Lung Cancer Connection was so excited to learn of the preliminary results of the NLST. Would you explain the results and how you think it will impact lung cancer mortality? How do you think this revelation has been accepted in the cancer community?



Dr. Daniel Luedke

Screening for lung cancer saves lives! On Thursday, November 4, 2010, the results of the National Cancer Institute sponsored National Lung Screening Trial (NLST) were released. This was a randomized trial involving more than 53,000 current and former heavy smokers (defined by 30 pack-years) ages 55 to 74. None by definition had signs or symptoms of lung cancer.

One-half underwent screening

with chest X-rays (known to have at best a modest ability to detect early lung cancer). The other half underwent screening with low dose helical computed tomography (CT). Three screening tests were done in each group, one at baseline and two annual studies. Once detected, cancers were treated by currently recommended procedures according to the stage of the disease. Data were analyzed and after five years the mortality rate from lung cancer was reduced by a whopping **20%**. All-cause mortality was reduced by 7% (death due to any factor, including lung cancer).

Until the results of the NLST were released, debate raged throughout the scientific community as to whether screening CT scans actually reduced lung cancer mortality. Large population based trials led by the International Early Lung Cancer Action Program (I-ELCAP), as well as similar trials conducted in Italy, Japan and, China all claimed to show that screening CT scans of the chest saved lives. But none of these trials carried the scientific muscle of a large, well-designed, randomized trial that was the hallmark of the NLST.

What all of these trials now tell us is that if caught early, when the lung cancer is very small and in its earliest stage, before it has any symptoms and before it has had a chance to spread to other parts of the body, lung cancer is a very curable disease.

The best analogy I can think of is screening mammography for breast cancer. It too saves lives and reduces mortality from breast

cancer by diagnosing very small breast cancers, many before they can be felt and before they have spread. But everybody knows that. And the reaction among women has been extraordinary. Mammography is now included as part of an annual well-woman examination in those over 40 years of age. It is covered by most health insurance carriers and for those uninsured, charitable organizations provide the test free of charge. Millions of women get their annual mammogram.

What has been the reaction to exciting results of the NLST, supported by a host of other studies like I-ELCAP? The American Cancer Society and The American Lung Association were tepid in their responses, citing reasons to be cautious about going forward with large-scale lung cancer screening. The health insurance industry has largely remained silent on the issue and does not provide coverage. Why? This is not a rhetorical question. Since the NLST closed to accrual (adding new patients), the number of lung cancer deaths in America has exceeded the casualties endured by both sides in the Civil War. And we have in our hands the CT scanner, which when properly applied, can reduce that mortality by at least 20%. I would invite you to learn more about the issues. Please go online to: <http://www.cancer.gov/clinicaltrials/noteworthy-trials/nlst> This will provide more information on NLST. You can contact I-ELCAP by googling their initials. SSM is an I-ELCAP member and you can get more specific local information by contacting Ellen Brennan, SSM Thoracic Nurse Navigator, at 636-947-5503 or 1-877-946-LUNG.

I would also invite you to become more involved as an advocate for lung cancer screening by contacting The American Cancer Society and The American Lung Association and ask WHY?

The take-home message I would leave you with is that when appropriately done, lung cancer screening by CT scan saves lives. I would go further—the screening chest CT scan is to lung cancer as mammography is to breast cancer. Both are life savers. But neither will save lives if they are not performed.

Dr. Luedke, a board certified medical oncologist, has been in practice for 33 years. He completed his medical oncology fellowship at Memorial Sloan-Kettering, one of the most prestigious cancer centers in the United States. His areas of interest include lung and breast cancers. Dr. Luedke has been honored several years in a row by his peers as one of St. Louis' Best Doctors.

Free Patient Education Seminar Coming



Dr. Howard (Jack) West

Lung Cancer Connection is proud to announce its 2nd Annual Patient Education Seminar on Saturday, May 21st, 8:30 a.m. to Noon, at the Sheraton Westport Chalet. Registration begins at 8 a.m.

Howard (Jack) West, M.D. is a lung cancer expert and Medical Director of the Thoracic Oncology Program at Swedish Cancer Institute in Seattle, WA. and leads several clinical trials in novel lung cancer therapies. He also founded and now serves as President and CEO of the Global Resource for Advancing Cancer Education (GRACE), a nonprofit dedicated to providing timely, free information directly from medical experts to patients and caregivers about the best cancer treatments available. GRACE provides educational content through its website (www.CancerGRACE.org) in the form of posted written summary materials, audio and video podcasts, and an interactive discussion forum in which patients and caregivers can ask

questions directly to oncologists and other medical professionals staff. Educational information provided through GRACE has now reached over 140,000 website visits in a month, by a cancer community that extends to over 130 countries around the world.

The seminar will also feature a discussion led by Kevin Ferris, MSW, LCSW. For over a decade, Kevin has worked in the St. Louis community as a clinical social worker, counseling individuals and family members facing life-threatening illnesses. Kevin has a vast amount of experience helping lung cancer patients deal with the emotional aspects of their disease, and her presentation at last year's seminar was wildly popular with the audience.

Lung Cancer Connection co-founder Myrtle Chidester will wrap up the half-day seminar with a presentation on things you can do to become a lung cancer advocate and increase public awareness of the urgent need for better research and a cure.

Although this seminar is **FREE**, pre-registration is required. To sign up, please call 636-329-8790 or visit the LCC website at www.LungCancerConnectionInc.org

A special note from Myrtle:

I was fortunate to find Dr. West's initial website, OncTalk, a few months after I was diagnosed in 2005 with stage IV lung cancer. Since then he has been an inspiration to me, and a source of power and strength through every up and down during my long journey with this disease. Now as president and CEO of GRACE, Dr. West continues on a daily basis to reach out to lung cancer patients and their families, giving them the most important gift of all: information and education about their disease. I firmly believe that part of my relatively long survival can be attributed to Dr. West and the information that he has shared, which has helped me become a more active participant in my treatment. I have no doubt that upon hearing Dr. West speak, you will be truly impressed with his knowledge and compassion for lung cancer patients.

-- Myrtle Chidester

Local Nurse Wins Scholarship to Lung Cancer Symposium

Lung Cancer Connection awarded its very first education scholarship to Vanessa Blackburn, R.N., coordinator and manager of the Division of Hematology/Oncology at Saint Louis University School of Medicine. In December 2010, Vanessa used the scholarship funds to travel to Chicago to attend the annual Multidisciplinary Symposium in Thoracic Oncology. The three-day conference included sessions on the latest clinical and research findings on new radiation therapy, surgery, and chemotherapy used to treat lung cancer.

Lung Cancer Connection looks forward to awarding future scholarships to St. Louis-area medical professionals who are interested in learning about advances in care for lung cancer patients.

Funding Programs

Lung Cancer Connection is funded entirely through donations. We have several programs that help us raise money for our programs that you may be able to participate in.



• **LCC recycles used cell phones.** If you have an old phone that is no longer in use, bring it to a Lung Cancer Connection cell phone drop box. They are located at area cancer centers. For more information call 636-329-8790.

• **LCC participates in Walter Knoll Florist's "Lend a Hand" program.** Every time you order flowers from Walter Knoll, the company will donate \$2 to Lung Cancer Connection. Just look for the "Lend a Hand" link on the florist's website and choose Lung Cancer Connection from the list of participating charities.

• **Lung Cancer Connection also accepts donations made online through our website or mailed to 1919 DeWitt Ridge Drive, Chesterfield, MO 63017**

SSM Health Care Honors LCC Co-Founders

Spring 2011 Newsletter

Lung Cancer Facts

Lung Cancer Connection has been active in St. Louis for just over a year now, but already the grassroots organization is being recognized for its important work on behalf of thousands of local lung cancer patients.



Gaspere Calvaruso, Myrtle Chidester, Cheryl Lamprecht and James Beattie, D.O.

medical advisor Dr. James Beattie praised Lung Cancer Connection for its steadfast commitment to building a supportive and informed lung cancer community in St. Louis.

On January 14, 2011, Myrtle Chidester and Cheryl Lamprecht were shocked to become the first recipients of the SSM Cancer Center Community Advocate Award. Gaspere Calvaruso, president of SSM St. Joseph Health Center, presented the award to Myrtle and Cheryl at a surprise luncheon in their honor. Mr. Calvaruso commended the LCC co-founders for their dedication to eliminating the stigma of lung cancer and improving the lives of lung cancer patients. In their remarks, thoracic surgeon Dr. Keith Naunheim, and oncologist and LCC

◆ In 1971, the National Cancer Act marked the beginning of the War on Cancer. At that time, the overall 5-year survival for lung cancer was 13.6%. In 2008, the estimated 5-year survival rate for lung cancer will be 15%.

◆ Lack of funding for research has impeded progress in developing new treatments for lung cancer. According to statistics from the National Institutes of Health, government funding for lung cancer research continues to drop each year. In FY 2005, lung cancer received \$289 million in research funds. By FY 2008, funding for lung cancer research plummeted to \$169 million – a whopping 42% reduction!

◆ 1 in 5 women and 1 in 12 men diagnosed with lung cancer have never smoked.

Be sure and register for the Free 2nd Annual Spring Patient Education Seminar. Our special guest expert is Dr. Howard (Jack) West. The seminar is May 21, 2010 at the Sheraton Westport. Call 636-329-8790 for more information.



PriceWaterhouse Coopers Selects Lung Cancer Connection as Charity for the Month of January

Lung Cancer Connection is supported entirely through donations and there are many ways to raise funds as LCC member and PriceWaterhouse Coopers' Advisory Manager, Kathy Rush has done. Kathy's company supports charities through accepting donations from employees that authorizes them to wear jeans on Fridays. A big thanks to Kathy for the nomination and a great idea to raise much needed funding through bringing LCC to the workplace.

Lung Cancer Connection was the designated as charity of the month by PriceWaterhouse Coopers, due to a nomination by Kathy in honor of her 21-year-old niece who lost her battle with lung cancer nearly four years ago. Kathy and her family are helping to advocate for greater awareness about lung cancer and more research because of her niece, whose brave and courageous battle against this disease has inspired them to help others.

For more information about lung cancer or Lung Cancer Connection, visit our website , www.LungCancerConnectioninc.org Donations may be made online or checks should be payable to Lung Cancer Connection and mailed to 1919 DeWitt Ridge Drive Chesterfield, MO. 63017. Lung Cancer Connection, Inc is a 501 (c) (3) Nonprofit Organization.

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