

Lung Cancer Connection

Spring 2012 Newsletter



A Message From LCC's Co-Founder Cheryl Lamprecht

It is with the heaviest of hearts that I write this message alone for the first time. Myrtle Chidester, my dear friend and Lung Cancer Connection CEO, passed away in February after a valiant battle against this insidious disease. Myrtle's lung cancer fight began in June 2005, when she was diagnosed with Stage IV non-small cell lung cancer. From the moment that she learned of her illness, Myrtle was determined not only to regain her own health, but also to improve outcomes for other lung cancer patients and their families.

In 2008, when our paths crossed and we shared our stories, Myrtle and I quickly decided that no one should have to go through their lung cancer experience alone, as we had done. Thus, the idea of Lung Cancer Connection was born. It took us almost a year to settle on a mission, legalize all the paperwork, and attract the interest of enough people in the community to make the organization viable, but in 2009 LCC was officially launched.



Myrtle worked tirelessly to keep the group going, despite the sometimes debilitating challenges that she endured due to chemotherapy and radiation treatments. I recall many occasions when Myrtle would be confined to her bed, yet still have her laptop open doing some type of work to help LCC reach the many hundreds of people affected by lung cancer in St Louis.

Today Myrtle may be gone from our presence, but she will NEVER be forgotten. Her legacy lives on through all of us, LCC volunteers and supporters alike, and in her memory we will continue to work as fervently as she always did to advocate for new and better treatments and, some day, a cure for lung cancer.

We will still pass out our LCC bags to newly diagnosed lung cancer patients and their families. We will have our 3rd Annual Lung Cancer Education Seminar on May 19th. Grants to fund medical research will continue. The Lung Cancer Networking Group at the Cancer Support Community will carry on. Our education scholarships for medical professionals remains in force. And, of course, our very successful 5K Fun Lung Run/Walk will remain a constant, to be held this year on November 3rd.

Myrtle was and will always be a hero to the lung cancer community. Her leadership, dedication, and devotion to LCC's mission will forever guide our

LCC Presents Free Education Seminar

Lung Cancer Connection is proud to announce its **3rd Annual Lung Cancer Education Seminar, on Saturday, May 19th, 8:30 a.m. to 12 noon, at the Sheraton Westport Chalet.**

Four prominent St. Louis physicians and a respected social worker will headline the presentation, offering important information on lung cancer research and treatment, as well as the management of psychological stresses caused by the disease:

- Dr. Daniel Luedke, medical oncologist, will speak on Early Detection Lung Cancer Screening.
- Dr. Brian Meyers, thoracic surgeon, will discuss the Role of Surgery in Early Lung Cancer and the Importance of Clinical Trials.
- Dr. Jaymeson Stroud, radiation oncologist, will address Radiation Therapy in Lung Cancer.
- Dr. James Beattie, medical oncologist, will talk about New Advances for the Treatment of Lung Cancer.
- Kevin Ferris, social worker, will discuss Coping with Anxiety and Stress: A Mindful Approach for Those Affected by Lung Cancer.

A Q & A period featuring the presenters and lung cancer survivors will close out the seminar.

Although this is a free event, registration is required. To sign up, please call 314-740-0300, or visit the LCC website at: www.LungCancerConnectionInc.org

framework as we expand our reach throughout the St. Louis area. LCC will carry on the work that Myrtle began, and we will champion the dream of stronger lung cancer awareness that she held so deeply in her heart. — Cheryl

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Faces of Lung Cancer: Allison Haake

As told by her mother, Kathy Haake



Allison Haake

Allison Marie Haake, daughter, sister, granddaughter, niece, cousin, and friend, is a face of hope, courage, resiliency, love, faith, and one that reflects inner peace and beauty. Allison is also one of the many faces of lung cancer.

The possibility of such a diagnosis was not something we would have ever imagined as Allison, a 21-year-old, healthy college student, began to exhibit signs of fatigue, persistent coughing, and cold and flu-like symptoms.

We considered many possibilities as she talked on the phone about how she felt. When Allison came home from school in Chicago to catch up on rest, relaxation, and home cooked meals, at times she felt out of sorts. But in a matter of a few hours, she would return to normal energy levels and find motivation again.

The fluctuating symptoms concerned us enough that we decided several doctor visits were in order. Each time Allison went to see her physician, a different type of antibiotic was ordered, rest was encouraged, and for a short period of time, she would manage. That is, until she could not do so any longer. After eight weeks of on-again, off-again symptoms and taking various prescription medications, Allison walked to a hospital to get emergency treatment. Admitted initially for pneumonia, a chest scan revealed a lung mass, and on October 17, 2006, doctors diagnosed Allison with small cell lung cancer. Seventy-seven days later, cancer had weakened nearly every crevice of her body, and took her physical form from us. Allison Marie Haake died at age 21 on January 9, 2007.

I must emphasize that those eleven weeks were spent focusing on living, not dying. Living came to hold a new definition for Allison, and for all of us who loved her. We did not read statistics, and if somehow they were shared with us, we would remind Allison that these were not written for her. There were no studies on 21-year-olds with lung cancer. In fact, for a while doctors from various hospitals around the country were unsure about the lung cancer diagnosis, because Allison matched no criteria for "typical" lung cancer patients. Some physicians speculated that perhaps it was Ewing's sarcoma or another cancer that could be successfully treated, so that in time Allison could resume her normal life. However, none of that was to be. After several consultations, and under the purview of various oncologists, the diagnosis was reaffirmed: small cell lung cancer.

I could begin here and share the journey from a mother's perspective, from my breaking heart, to the years filled with grief, attempting to live strong and true for my daughters, my family, myself. I could share in vivid detail what life has been like since I buried my own child. How I look into the eyes of my husband and older daughter and feel their pain, trying to ease it, but knowing that I never can. I could share how each day, in these five years, I have shed tears because Allison died, but I also choose to smile because she lived. I could share so much, but this is Allison's story. My story is different. I did not receive the cancer diagnosis. I did not sit for hours in the chemotherapy chair or find myself needing more and more radiation just to sustain life. This is not my story, yet somehow it is.

From the moment of diagnosis, Allison would not allow lung cancer to define her. She was not insulted when others asked her if she smoked. She was not upset when folks attempted to find some reason for her cancer. Though she could not comprehend it, she didn't question what was hers to accept. Her response gave us our mission. We took our cues from her, and we supported her in every way as she went about her job of healing. *(continued on page 3)*

Lung Cancer Connection is a

non-profit 501 (c) (3)

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Her trademark smile rarely wavered as she faced the most aggressive chemotherapy from the first day, asking that all treatment protocols that could possibly help be administered to her. Allison carried Bible scriptures in her pocket to radiation treatment. Together, she and I would memorize them the night before, so that if she got scared, she would have something to lean on. She learned about God's medicine compared to man's medicines and held stock in both. She loved and trusted her oncologist, Dr. Luedke, and her chemotherapy nurse, Lucie, and even when her prognosis became dire, she never faltered in her respect for them and her appreciation for how well they treated her.

Once Allison knew lung cancer was nothing she had brought on herself, she faced each new day as though it were her best one ever. She could fight the fight, come up for air, and fight some more. After all, she was 21 years old. "Strong as a horse," her doctor would say. "The ping pong ball that keeps bouncing back." She was a nonsmoker, and she was never exposed to second-hand smoke in our home. Allison did, however, share with me that during her late teens, she had smoked some cigarettes when she was out socially with friends. After she admitted this to her doctor, he gently smiled and shook his head, and showed her a picture of her lungs that looked, in his words, like "that of a 60-year-old smoker." "You would have had to smoke many packs a day since the age of two for your lungs to even resemble this," Dr. Luedke said. "And even if you did, Allison, you would not deserve this."

I must admit that I was perplexed, maybe even irritated, when the first question many people asked Allison or us was, *Did she smoke?* -- as if this gave a license to the disease. I wanted to scream, and still do at times, upon hearing the question over and over again. But over time I have learned that just like we had been, many people are uneducated about lung cancer and its staggering statistics. Sadly, our family has now learned more than we ever imagined, and since Allison's death, our education has not stopped. Anyone can read statistics, but connecting them to Allison — a vibrant, energetic, healthy, sports playing, teacher bound, young woman who had her whole life ahead of her — reveals more than any numbers can say.

Allison had planned to become a teacher. Her smile widened in the presence of children and she was on her way. I believe that Allison would have been an amazing teacher, but I also believe that God must have had deeper, more meaningful plans for her. Lung cancer abruptly invaded her life and changed her course. Her family prefers to say that we didn't lose Allison to lung cancer. Cancer did not take her from us. She did not die, except in the physical sense. Allison Haake left a legacy, a smile that is etched in our hearts for eternity, and a glow that guides her family to do what we must to live each day.

If by sharing her story, we can inspire, educate, or teach someone something about this dreadful disease, then we know it would be pleasing to her. Perhaps people may begin to ask the right questions, increase research funding, eliminate the stigma, and look at lung cancer patients through loving eyes, with care and concern -- whether or not they may have smoked -- because they are human beings, deserving of all the respect given to anyone with any type of cancer diagnosis.

How our beloved Allison acquired small cell lung cancer, we will never know. There are no answers to some questions. We cannot control what is handed to us. What we can control, however, is our response. We can do our personal best to help others during similar battles, and we can persevere through trials and tribulations. We can support education and awareness groups, such as Lung Cancer Connection, Lung Cancer Alliance, and the National Lung Cancer Partnership. We can demand the right for everyone to breathe clean air. And we can also stop assuming that lung cancer is a smoker's disease.

I must believe that something bigger and better will come from this one life, this one face of many, this one smile. I must believe that Allison is proud, more than five years after receiving her lung cancer diagnosis, that her story is being shared, and that her message will be heard.

****PLEASE NOTE:** Jewelry maker Anna Ourth has created a lung cancer awareness necklace and earrings in honor of Allison. Anna will donate a portion of the sales of those pieces to Lung Cancer Connection.

To purchase the necklace, visit the website: <http://www.etsy.com/listing/94202300/allisons-hope-necklace-lung-cancer>

To purchase the earrings, visit the website: <http://www.etsy.com/listing/94202897/allisons-hope-earrings-lung-cancer>

LUNG CANCER FACTS

Between 20,000 to 30,000 people who have never smoked are diagnosed with lung cancer in the U.S. each year.

Lung cancer is the leading cause of cancer death in all ethnic groups.

Primary lung cancer starts in the lung. Secondary lung cancer (or lung metastases) starts in another part of the body and spreads to the lungs.

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Medical Therapy of Lung Cancer: Dawn of a New Era

I am very optimistic about the treatment options for patients with lung cancer today. Lung cancer research is progressing at an impressive pace with only one goal in mind: improving the outcomes of our patients diagnosed with lung cancer.



Dr. Ramaswamy Govindan

Our approach to the treatment of cancer has changed rather dramatically over the past decade. A quick 101 on cancer biology will help put things in perspective. Cancer results essentially from alterations in the functions of genes in the cells. Most of these alterations, or as we call it technically mutations, are acquired in the cells after we are born, and not passed on from one generation to another. In other words, they are not hereditary. The mutations transform a well-behaved normal cell to an erratic cell that becomes immortal and keeps growing, paying no attention to the normal tissue boundaries. We now have the tools and technologies to identify the alterations in the entire set of genes (genome) to understand what is driving the cancer cells to keep growing non-stop. We are getting better and better in developing designer drugs customized to block the functions of these renegade genes, in order to control the growth of cancer cells.

Lung cancer has been at the vanguard of this so-called targeted therapy revolution. It is now very clear that approximately 10% of patients in the United States with non-small cell lung cancer (NSCLC) have mutations in the protein called epidermal growth factor receptor (EGFR) in the tumor cells. Erlotinib (Tarceva) works very well, often dramatically, in this group of patients - more so than traditional chemotherapy regimens. Approximately 3% of patients with NSCLC have an alteration in one of the chromosomes in the tumor cell that brings two genes (EML4 - ALK) together to produce a new protein. This new protein transforms a normal cell into a cancer cell. The existence of the protein was first identified in the laboratory only in 2007. Quite remarkably, in a short span of just four years, a drug called crizotinib (XALKORI) has been found to be quite active

and has now been approved for use in the clinic. The fact that we can translate a research finding from a lab to a readily available option for treatment in the clinic in just four short years is certainly very encouraging. I personally think this is the way many drugs will be developed in the future.

By the way, lung cancer is not just one type of cancer. At the molecular level, there are probably at least 30 - 40 different types of lung cancer, each one driven by a different set of genes. Even though these different types of lung cancer may look the same through the CT scan images or even under microscope, the treatment approach will be customized based on which set of genes are altered. While we have known about these complexities for quite sometime, recent research has reinforced that view and has provided some clear directions. We have just begun to test a number of genes, so-called actionable genes, in the lung cancer specimens using a very modern technology called next generation sequencing, so that we could personalize therapy. We either use the information to use drugs like erlotinib or crizotinib approved for lung cancer, or to enroll our patients appropriately in one of the several ongoing trials of molecularly targeted therapies.

Intense research is ongoing here at Washington University in St Louis and elsewhere to comprehensively study the genomic landscape, to study thousands of common tumor types (including lung cancer), and to better understand tumor biology. St. Louis is at the epicenter of this groundbreaking research in cancer. The Genome Institute (TGI) at Washington University School of Medicine was the first in the world to ever study the complex portrait of cancer genome and has since studied several hundreds of tumor specimens from a variety of cancers. The basic idea is to understand the biology of cancer better in order to develop newer, more effective, and safer therapies for our patients with cancer. The work currently ongoing here and elsewhere will, for sure, transform our approach to lung cancer and improve the lives of our patients. I see a very bright future.

Ramaswamy Govindan M.D., an expert on lung cancer, is the co-director of the Section of Medical Oncology at Washington University School of Medicine and the co-chair of the Lung Cancer Disease Working Group for The Cancer Genome Atlas (TCGA) project.



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LCC Awards Screening Grant to SSM St. Joseph



Gaspere Calvaruso - SSM Cancer Care President and Service Line Executive, Dr. John Bedwinek - Radiation Oncologist, Aaron Robinson - SSM Cancer Care Executive Director, Myrtle Chidester, Cheryl Lamprecht, Dr. Dan Luedke - I-ELCAP Principal Investigator, Ellen Brennan - I-ELCAP Nurse Coordinator, and Dr. Jon Root - Thoracic Radiologist

Avril Moore lost her battle with lung cancer in December 2011, but her desire to promote early detection and better treatments for the disease lives on. Thanks to a generous donation from Avril's family, on February 6th Lung Cancer Connection awarded a \$5,000 grant to the SSM St. Joseph Foundation. The money will be used by St. Joseph hospitals, in association with the International Early Lung Cancer Action Program (I-ELCAP), to provide up to 50 free lung cancer screenings to high risk individuals, who are either uninsured or cannot afford to pay for the screening themselves.

The final results of the 2011 National Lung Screening Trial (NLST) showed 20% fewer lung cancer deaths among those who were screened using low-dose spiral CT scan as opposed to standard chest X-ray. The spiral CT is designed to detect lung cancer at its earliest, most treatable stage, thereby considerably increasing patients' chances of survival.

Lung cancer claims more lives each year than breast, colon, liver, kidney, and melanoma cancers combined, a fact due in large part to the limitations of early detection methods. Unfortunately, most common lung cancer symptoms, such as chronic coughing, chest pains, shortness of breath, or coughing up blood do not generally express themselves until the cancer has reached its latter stages, when the five-year survival rate is only 15%.

To qualify to participate in SSM Cancer Care's I-ELCAP study, you must:

- Be 40 years of age or older
- Have a history of smoking at least 20 packs of cigarettes per year
- Have no cancer history or be cancer free for at least 5 years
- Have not had a chest CT scan in the past 2 years
- Have no symptoms of unexplained weight-loss, worsening cough, cough producing bloody material, or persistent hoarseness

If you would like further information regarding free lung cancer screenings, please contact Ellen Brennan, SSM Thoracic Nurse Navigator, at 636-947-5503 or 1-877-946-LUNG.

LUNG CANCER FACT

Exposure to radon is the second leading cause of lung cancer, and the leading cause in people who have never smoked.

Third Time's a Charm! 2011 Fun Lung Run/Walk

On November 5th more than 1,000 runners and walkers filled Creve Coeur Park to create a loving community of support and hope for those affected by lung cancer. KTVI Fox 2 meteorologist Glenn Zimmerman served as honorary chairperson for the annual event, which raised over \$80,000.

Each November, in recognition of Lung Cancer Awareness Month, LCC holds a fun lung run/walk to unite people who are passionate about increasing public awareness of lung cancer and the vital need for more research dollars. Lung cancer is the nation's number one cancer killer, yet it receives much less research funding per death than most common cancers.

Join the movement! Help lung cancer patients live longer and enjoy better lives. Together we can inspire hope, raise awareness, and educate patients, health professionals, and the general public about the true facts of lung cancer.

**SAVE THE DATE:
NOVEMBER 3, 2012
4th ANNUAL FUN LUNG RUN/WALK**



**Thanks to our
Wonderful 2011 Sponsors**

SSM Cancer Care, Saint Louis University Hospital, Mari de Villa Retirement Community, Saint Louis University Cancer Center, Midwest Chest Consultants, Missouri Baptist Medical Center, St. Luke's Hospital, Koman Law Offices, Instant Imprints-Chesterfield, Siteman Cancer Center, The Delmar Gardens Family, Altair Travel and Cruises, Sowers and Wolf, LLC, Mercy Hospital, Deloris Green Russell Family & Friends, In Loving Remembrance of Allison M. Haake, By-Ron Entertainment, Little Debbie Snacks, Trader Joe's, and Starbucks.

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2012 Thoracic Oncology Symposium Scholarship Applications

LCC is now accepting applications for its annual medical education scholarship. This year's recipient will attend the Chicago Multidisciplinary Symposium in Thoracic Oncology, September 6th through 8th, at the Chicago Marriott Downtown Magnificent Mile. St. Louis area medical professionals who have a strong desire to learn more about advances in care for lung cancer patients are encouraged to apply for the scholarship, which will cover conference registration fees, along with travel and housing costs.

The Chicago symposium is designed for oncologists, nurses, scientists, and other health care professionals interested in the treatment, screening, evaluation and management of thoracic cancers. Attendees will be given valuable information on the interdisciplinary approach in the treatment of thoracic cancers. Speakers will address a variety of strategies to treat lung and esophageal cancer, and other metastatic cancers of the chest, and they will present the latest developments in basic and clinical research that could be beneficial to patients.

To apply for the 2012 LCC Medical Education Scholarship, please visit the LCC website at www.LungCancerConnectionInc.org and download the application. The submission deadline is June 30, 2012.



Funding Programs

Lung Cancer Connection is funded entirely through donations. You can help us raise money for our services by participating in the following programs:

- **GoodSearch.** An Internet search engine that donates 1¢ to Lung Cancer Connection every time you perform a search using GoodSearch. And because it's powered by Yahoo!, you get proven results. The money GoodSearch donates to LCC comes from its advertisers, so you do not spend a dime! Go to www.GoodSearch.com and select Lung Cancer Connection as your preferred charity.
- **GoodShop.** An online shopping mall of popular stores, such as Macy's, Best Buy, and Amazon. Each purchase that you make via the GoodShop mall results in a donation to LCC averaging approximately 3% of the sale. And better still, many of the listed stores offer terrific coupons and deals! Go to www.GoodShop.com and select Lung Cancer Connection as your preferred charity.
- **GoodDining.** A dine out for charity program in which you can eat in or take out at thousands of restaurants nationwide, and earn LCC up to 6% in donations per dollar spent. Go to www.GoodDining.com to enroll in the GoodDining program.
- **Cell Phone Recycling.** If you have a cell phone that's no longer in use, take it to an LCC cell phone drop box, located at area cancer centers, and we'll collect it for recycling. Help decrease environmental pollution and raise money for LCC! For more information, call 314-740-0300.
- **Walter Knoll Florist's "Lend a Hand."** Every time you order flowers from Walter Knoll, the florist will donate \$2 to Lung Cancer Connection. Just go to www.WKF.com, look for the "Lend a Hand" link on the order form, and choose Lung Cancer Connection as your preferred charity.
- **Lung Cancer Connection also accepts donations through our website or mailed to: 1919 DeWitt Ridge Drive, Chesterfield, MO 63017.**

Strong Support for Networking Group

"First you get told you have lung cancer. And then you don't have anybody or anything to help you. That's pretty devastating. It feels like you're the only one going through this."

— Myrtle Chidester

When LCC co-founder Myrtle Chidester was diagnosed in 2005, there were no organized support groups for lung cancer patients in St. Louis. This spring marks the second year that LCC will sponsor the Lung Cancer Networking Group at the Cancer Support Community. The meetings, held on the first Thursday of each month, address both medical treatment questions and emotional health needs of participants. Torie Gettinger, the group's facilitator, says members find tremendous comfort in sharing issues that cannot be easily understood by others who are not on a lung cancer journey. "Almost every month, an individual expresses that he or she has been helped as a result of the group. Participants feel reassured that their concerns and questions are valid." For more information, call the Cancer Support Community at 314-238-2000.

Lung Cancer Jewelry



Do you have a hard time finding jewelry and accessories for lung cancer awareness? LCC member Mary Scannell is filling the void by designing handmade bracelets, necklaces, key chains, and bookmarks that are lung cancer specific. Each piece is fashioned in pearls and crystals, and comes with a beautiful ribbon charm. Prices range from \$15 to \$40, and all proceeds go to LCC. Call Mary at 314-565-2452 or email her at m.scannell@sbcglobal.net for more information.