

Lung Cancer Connection

Summer 2013 Newsletter



A Message From LCC's Co-founder & CEO Cheryl Lamprecht

It's difficult to believe that it's been five years since Myrtle Chidester and I had the vision to start a group for lung cancer patients and their families in St. Louis. After almost a year of planning, filling out government forms, designing a logo, choosing a name, creating a mission statement, and going through a myriad of other steps required to start a nonprofit organization, our baby, Lung Cancer Connection, was born in May 2009.

Because of the amazing growth that LCC has experienced over the past four years, much has changed regarding our operating framework. One of the most significant changes is the addition of Alison Underwood to Lung Cancer Connection's board of directors, as head of strategic planning. Since joining the board last fall, Alison has been instrumental in spearheading our efforts to reflect on what LCC has accomplished thus far, analyze what we would like to do in the future, and design a strong strategic plan for achieving those objectives going forward.

Already we've outlined some specific goals for this year, including changing the venue of November's annual fundraising event from Creve Coeur Park to Forest Park; increasing the number of participating teams and bringing back the 5K run; expanding Lung Cancer Connection's profile in St. Louis through increased corporate partnerships and new marketing/advertising efforts; strengthening our relationships with hospitals and cancer centers; and growing our volunteer base and creating more opportunities for ongoing participation. On page 6, you'll find details about new LCC volunteer committees and the many ways that you can share your time and talents with us to help keep our efforts strong.

As always, we are extremely grateful for your support which makes all of Lung Cancer Connection's initiatives possible. We invite you to contact us with your thoughts and suggestions, and we encourage you to join us in taking action to erase the stigma of lung cancer and to find better treatments and a cure for all patients.

— Cheryl

LCC Awards Grants for Research, Screenings, and Support



Ramaswamy Govindan, M.D., Cheryl Lamprecht, and Bob Zimmermann

Research

In October 2012, Lung Cancer Connection awarded our first Myrtle Chidester Memorial Grant to Dr. Ramaswamy Govindan of the Washington University School of Medicine.

Dr. Govindan is using the \$25,000 gift to jumpstart a pilot lung cancer research study on small cell lung cancer (SCLC). "Relapsed small cell is a tough disease to treat and no one has studied comprehensively the molecular changes," says Govindan.

Although impressive advances have been made in recent years in the molecular treatment of non-small cell lung cancer, virtually no progress has been made in SCLC, which accounts for nearly 15% of all lung cancers. Patients with metastatic SCLC often respond well to chemotherapy initially, but the disease almost always recurs, and when it does, it is resistant to chemotherapy.

Dr. Govindan believes the lack of progress in SCLC treatment is due in large part to the limited knowledge of molecular alterations in recurrent SCLC. His new study, which is actively recruiting participants, will examine five patients with relapsed SCLC, and investigate

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Lung Cancer Facts

- The dearth of research funding has impeded progress in developing new treatments for lung cancer. Lung Cancer Alliance reports that in 2012, the U.S. government spent \$231 million on lung cancer research. Funding for breast cancer research totaled over \$1 billion.
- Only 15% of lung cancer is diagnosed at its earliest and most treatable stage. Unlike the mammogram for breast cancer detection, there is no approved screening test for early lung cancer detection in all people, no matter their smoking history.
- The ribbon color for lung cancer awareness is white or pearl.

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Faces of Lung Cancer: Avril Moore

As told by her daughter, Debbie Schroeder



Avril Suzanne Moore

There is no true face of cancer. It can affect anyone at anytime. My mother's face still shows itself to me so vividly that I can't believe she is gone. I see her face smiling at my daughters with the true love of a grandmother. I see her loving face as she cuddled her dog. Her content face as she napped on her favorite couch when she visited our home in Kentucky was always so comforting to see. My mother was a sister, grandmother, aunt and friend to so many. I am sure that the face they remember is just one of the many she showed.

In January 2010, my mother began having cold-like symptoms that consisted of coughing and fatigue. After just a few weeks of this, she visited her family doctor who began treatment for a simple cold. When this treatment failed to help, many other strategies were tried in order to help the coughing. This regiment of trial and error continued through the spring and summer with little to no relief of the coughing. Mom continued to try to live her life normally but found that the coughing and fatigue were very limiting to her very active life style. By August a more thorough exam was performed and stage four lung cancer was diagnosed.

My mother's best friend and I were with her when we visited the oncologist for the first time. He was a lovely, gentle man who shared information freely and was very clear about her cancer. Mom did not like to talk about statistics because they were not about her and her cancer. She felt as though hers was a unique case with her own treatment plan, and I believed her doctor felt the same. Of course, we were all devastated when we heard that the cancer was treatable but not curable. The first thing mom wanted to know was, "What do we do next?" She was ready to fight this disease and live as long as she possible could.

Throughout Mom's treatment, she joined a number of groups for support, including Lung Cancer Connection. Since I was living out of state, a dear friend of hers joined her at these meetings in order to provide chauffeuring and support. This particular group provided Mom with education and love and was a great help to her through her journey. She believed in this group, and her friends did the Lung Cancer Connection walk to help raise money for the great things this group does to help others. Although Mom was unable to walk in the event in the fall of 2011, she supported her friends by showering prayers and love upon them.

In early November 2011, the cancer began to win the battle my mother had so eloquently fought. In the face of adversity, my mother showed strength and faith to such an extent that I was overwhelmed. I was so proud of the way she handled every battle in this horrible war. It was a struggle every day, but she persevered until she could not any longer. On December 11, 2011, my mother lost her fight. Although the loss will always be a part of who I am, I will always remember that who I am is because of who she was.

Lung Cancer Connection

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www.LungCancerConnectionInc.org

a 501 (c) (3) nonprofit organization



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Join the Movement! Support Lung Cancer Connection

- "Like" Lung Cancer Connection on Facebook for links to important news about the latest in lung cancer research and treatments.
- LCC gratefully accepts donations by mail or online through our website.

- Order flowers from Walter Knoll Florist, and the company will donate \$2.00 to LCC for each purchase. Just look for the "Lend a Hand" link on the WKF website, and choose Lung Cancer Connection from the list of participating charities.

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all 20,000 of their genes using a genetic sequencing approach that was pioneered at Washington University. Through exploration of the genomic landscape of the SCLC tumors, Dr. Govindan hopes his research will eventually lead to an understanding of the SCLC's molecular foundation and ways to combat its resistance to follow-up treatment.

Screenings

Last year, LCC awarded a \$5,000 grant to the SSM St. Joseph Foundation to support 50 free lung cancer screenings for high risk individuals who could not afford to pay for the screenings themselves. Because the need for screenings is so great in our community, in 2013 LCC increased the amount of our gift to \$10,000, which will pay for 100 screenings. Early lung screenings can make a significant difference in detecting cancer at its earliest stage, which has a significant impact on the effectiveness of treatment. LCC funded screenings are available at the St. Joseph Health Center (St. Charles) and the St. Clare Health Center (Fenton). For further information, contact the SSM Lung Health Nurse Navigator at 1-877-947-LUNG.

Support

Lung Cancer Connection is committed to increasing disease awareness so that individuals and families will be empowered on their lung cancer journeys. Since 2011, LCC has sponsored the Lung Cancer Networking Group at the Cancer Support Community. And again in 2013, LCC donated \$5,000 to fund the group for another year. The goal of the networking group is to provide a nurturing environment to learn and discuss coping skills, disease management, and quality of life during and after treatment, so that no one faces lung cancer alone. Meetings are held on the first Thursday of each month, 6 p.m. to 7:30 p.m. Call the Cancer Support Community at 314-238-2000 for more information.



Lung Cancer Heroes Promote Awareness and Change

You might think you don't have the time or ability to be a lung cancer advocate, but everyone can do something in their own special way to elevate awareness, erase the stigma, or raise funds for research. Two friends of Lung Cancer Connection were surprised to discover just how successful their efforts could be when they helped organize fundraisers in their community. Our hats are off to these lung cancer heroes!



Rick and Dawn Madigan



Kathy Haake and Jackie Weintrop

Childtime Center

In August 2012, LCC volunteer Dawn Madigan lost her husband, Rick, to lung cancer. Knowing how devastating Rick's passing was for the family, Childtime day-care center in Arnold, MO, (where two of Dawn's grandchildren attend) decided to honor his memory by donating the proceeds from their annual holiday festival to Lung Cancer Connection.

The event was held on December 7 and featured a potluck dinner, pictures with Santa for the kids, and a silent auction. For the auction, Dawn weaved a basket filled with "Family Movie & Game Night" themed items. And her daughter-in-law, Ashley, who works for the Hertz Corporation, got the company to donate two free car rentals for the raffle.

We thank Dawn, Ashley, and the entire Childtime daycare family for their thoughtful and creative effort to support the important work that LCC does in St. Louis. Their hard work and dedication raised \$420 for Lung Cancer Connection.

Brentmoor Retirement Community

On February 20th of this year, LCC volunteer Kathy Haake was a guest presenter during a charity luncheon and game day event at the Brentmoor. Brentmoor marketing director Jackie Weintrop and event coordinator Phyllis Siegel were eager to give Kathy an opportunity to raise awareness about lung cancer, because they knew she had been deeply impacted by the disease.

In 2006, Kathy's daughter, Allison, was only 21 years old when she was diagnosed with small cell lung cancer. Sadly, just eleven weeks after she received that shocking news, Allison passed away. At the luncheon, Kathy and her family spoke bravely about Allison, sharing her life and lung cancer journey with the attentive crowd. Many of those gathered were so moved by Allison's story that they followed up with supportive e-mails to Kathy and donations to Lung Cancer Connection in Allison's memory. Gift baskets created by the Haake family and friends, Sephora, and Miss Jenn's Boutique were also raffled, with the proceeds going to LCC, as well.

We truly appreciate the Brentmoor community's effort to inspire hope and build support for everyone touched by lung cancer. The luncheon event raised \$875 for Lung Cancer Connection.

Lung Cancer Connection Advisor

Dr. Jaymeson Stroud

Radiation Therapy for Stage III NSCLC: A Moment of Truth



Dr. Jaymeson Stroud

Of all the major scientific discoveries in the 19th century, it has been said that the x-ray was the fastest to be applied to the medical field. Some scientists assumed at the turn of the century that over one hundred diseases would be cured with radiation therapy. But it wasn't long before they realized the corresponding dangers of the invisible, yet powerful, radiation

beam. Today, with over 100 years of radiation science behind us, our knowledge of radiation therapy for lung cancer continues to evolve and expand in the 21st century.

It is no secret that stage III non-small cell lung cancer (NSCLC) is a difficult malignancy to effectively treat. The three-year survival rate is around 30%, and approximately 30,000 patients are diagnosed each year in the United States. Historical studies in the medical literature show that increasing the dose of radiation directed at a lung cancer improves the chances of controlling that cancer. This is called a dose-response relationship.

A seminal article written by Dr. Carlos Pérez (Mallinckrodt Institute of Radiology), and published in 1980 in the journal *Cancer*, showed that local tumor control was 70% when the radiation dose was increased to 6000 cGy (centigray or rads), while lower radiation doses achieved control rates of only 40% to 60%. Thus, the standard dose of 6000 cGy for treating lung cancer has become widely accepted by radiation oncologists. Unfortunately, distant spread of disease is still common in over 70% of patients, necessitating intensification of medical therapy.

Radiation dose escalation continues to be a focus of study in the Radiation Therapy Oncology Group (RTOG) lung cancer clinical trials. Two such trials, RTOG 0235 and the recently reported RTOG 0617, seem to reveal conflicting data regarding intensification of dose and overall survival. Researchers from the RTOG 0235 study reported that a sub-analysis of their data showed a statistically significant improvement in survival in patients receiving at least 7,000 cGy of radiation, compared to those receiving a lesser amount.

Building on this positive result, researchers developed the trial RTOG 0617, which sought to confirm the RTOG 0235 results in a randomized controlled trial where patients would receive either 6,000 cGy or 7,400 cGy of radiation. Surprisingly, the results of RTOG 0617 revealed no increased benefit to patients receiving the higher dose. In fact, a very strong trend

toward a decrease in survival was actually observed in those patients who received 7,400 cGy of radiation. Though no obvious differences in toxicity were reported, further analyses continue.

As with other instances where outcomes have differed from expectations, this “moment of truth” has caused researchers and clinicians to step back and re-evaluate all aspects of radiation treatment planning. Is radiation dose escalation the answer to improved local tumor control for inoperable stage III non-small cell lung cancer? Possibly. But the answer depends, and here's why.

Radiation therapy fields for stage III lung cancer are on average about two to three times larger than typical radiation fields for other curable cancers. And although the dose limiting factor during treatment is typically due to radiation esophagitis (when the lining of a patient's esophagus becomes inflamed and sore during treatment), toxicity from damage to the heart and lungs can be seen much later.

What seems to be most effective in the treatment of NSCLC is radiation therapy that is individualized for each patient's specific anatomy, tumor type, and situation. In some patients, we can and should aggressively push the dose of radiation therapy, while avoiding impacting the critical internal organs. However, in other patients, that treatment plan may not be possible or appropriate.

Thankfully, modern advances in technology afford us more precise radiation therapy with treatment fields smaller than ever before. Four-dimensional CT scans can be employed to reduce treatment volumes by incorporating breathing motion. Image-guided radiotherapy opens the eyes of the treating physician to verify positioning, assess response, and even adapt treatment volumes based on daily pre-treatment CT scans. PET imaging provides a metabolic map whereby active cancer can be precisely targeted. Stereotactic radiation therapy and proton therapy are on the horizon as state-of-the-art techniques for pinpoint accuracy of high dose ablative radiation therapy, while sparing surrounding critical structures.

Harnessing these powerful tools of modern science enables the radiation oncologist to individualize each patient's care to maximize tumor control, while decreasing toxicity by sparing critical organs. As our understanding of the science of cancer and its various treatments increases with time and research, the need for customized cancer care becomes ever more vital in order to truly improve the lives of our patients.

Jaymeson Stroud, M.D., Radiation Oncologist at the David C. Pratt Cancer Center, Mercy Hospital St. Louis



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2012 Annual Walk Makes Noise for Lung Cancer in St. Louis



Theresa Meisenbacher and her team of supporters.

November is Lung Cancer Awareness Month, and on Saturday, November 3, 2012, over 500 people gathered at Creve Coeur Lake Memorial Park to participate in Lung Cancer Connection's 4th Annual Walk Around the Lake.

Cloudy skies and chilly temperatures didn't diminish the crowd's enthusiasm for the event, which attracted lung cancer survivors, family members, friends, and medical professionals. KMOV-TV News 4 meteorologist Kent Ehrhardt emceed the festivities, kicking off the morning with an inspiring message about the challenges of fighting lung cancer and the great progress that's being made to improve treatments. Other exciting speakers included Dr. James Beattie, SSM Cancer Care; Dr. Ramaswamy Govindan, Washington University School of Medicine; and Torie Gettinger, LMSW, the Cancer Support Community of Greater St. Louis.

Nearly \$80,000 was donated by contributors, including these top fundraising teams and their captains: #1 "Keith Campbell (Deeter)" - Mary Kay Wiesenhan; #2 "Tougher than Cancer" - Deb Zimmermann; #3 "Rally for Sally" - Debbie Dukeman; #4 "In Memory of Frank Schaefer" - Angie Schaefer; and #5 "Team Paglusch" - Kris Paglusch.

The LCC walk fundraiser is held each year to honor and support those affected by the lung cancer and to raise awareness about the devastating toll this disease takes on those in our community. One hundred percent of all contributions to Lung Cancer Connection are used to assist St. Louisians affected by lung cancer, support research, and fund education projects for patients, medical professionals, and the public.

Special thanks to our wonderful sponsors:

SSM Cancer Care, St. Louis University Hospital, St. Louis University Cancer Center, Cancer Treatment Centers of America, Midwest Chest Consultants, Siteman Cancer Center, Mercy Hospital, Kathy Rush, BJC HealthCare, St. Luke's Hospital, Delmar Gardens Family, Sowers & Wolf, LLC, Allison M. Haake Family, Deloris Green Russell Family, Bruce Streiff Family, happyMedium, Instant Imprints, Koman Law Offices, Little Debbie Snacks, Whole Foods, Starbucks, Einstein Bagels, Dierbergs, ByRon Entertainment, and the Kari James Dance Network

Save the Date!
Saturday, November 2, 2013
5th Annual LCC 5K Run/Walk at Forest Park!

Treating Your Adenocarcinoma with Targeted Therapies

New guidelines jointly released in April of this year by the College of American Pathologists (CAP), the International Association for the Study of Lung Cancer (IASLC), and the Association for Molecular Pathology (AMP) call for all lung cancer patients with adenocarcinoma – irrespective of their smoking history – to be tested for both the epidermal growth factor receptor (EGFR) gene mutations and the anaplastic lymphoma kinase (ALK) gene rearrangements.

Adenocarcinoma is the most common type of lung cancer, accounting for about 60% to 70% of all cases. About 15% of these have the EGFR mutation, and about 5% have the ALK mutation.

As researchers have learned more about the changes in lung cancer cells that cause them to grow, new drugs such as Tarceva, Erbitux, and Xalkori have been developed to specifically combat these alterations. Unlike traditional chemotherapy, targeted therapies are designed to block the growth and spread of lung cancer cells by infiltrating proteins on cancer cells or normal cells that have been taken over by the tumor in its attempt to grow.

Because these targeted agents are orally administered and are less toxic than chemotherapy, patients generally have a much better quality of life while taking these drugs. EGFR-positive patients have shown a 70% response rate to treatment, while the ALK response rate is 60%. Both rates are higher than chemotherapy responses and last longer with less toxicity.

If you have advanced stage lung cancer, do not hesitate to speak with your physician about receiving testing for EGFR mutation and ALK rearrangement. Many major medical centers, including the St. Louis-based Siteman Cancer Center, offer molecular testing for lung cancer patients.

Even if test results show your tumor
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does not have known characteristics that can be matched to a targeted treatment currently available commercially or through clinical trials, molecular testing can still help you and your doctor decide on the right treatment option for you.

Make a Difference: Volunteer with LCC

Would you like to see more lung cancer specific events in St. Louis? Do you wish the media would publicize more stories about lung cancer survivors and the urgent need for greater research for a cure? Do you feel lung cancer patients and their caregivers deserve more support and compassion than they currently receive from the public, including some medical professionals? If you believe far more attention should be focused on lung cancer awareness, now is your chance to help make it happen.

These are exciting times for Lung Cancer Connection, and we are in great need of volunteers like you to be the driving force in our continued growth. Please consider volunteering for one (or

more!) of the following groups and helping us achieve our mission of support, education, research, and hope. Together, we can make Lung Cancer Connection a leading voice in the fight against lung cancer!

- **Patient Bags and Cancer Center Relationships:** Expand LCC's reach to lung cancer patients and families by supplying free lung cancer information bags to cancer centers.
- **Sponsorships:** Secure ongoing hospital, corporate, and small business sponsorships for long term sustainability.
- **5K Run/Walk 2013:** Grow the number of runners and teams participating in this year's fundraiser, and help organize volunteers and resources.
- **Fundraising Initiatives:** Facilitate ongoing fundraising opportunities with individuals and organizations that are interested in raising money on behalf of LCC.
- **Partnerships:** Establish working

relationships with other organizations dedicated to lung cancer advocacy and research.

- **Advisory Board:** Strengthen partnerships with medical advisors, and raise LCC's profile within the medical community.
- **Grants:** Identify projects worthy of receiving grants from LCC and connect with organizations that might offer grants to LCC.
- **Communications:** Develop a marketing and communication strategy that builds awareness of LCC through all forms of media, including the Internet.
- **Seminars:** Explore opportunities for presenting a yearly lung cancer information seminar that will address the needs of patients, as well as appeal to the general public.

To learn more about the important work that LCC is doing, please attend our monthly meetings, held every third Thursday at 6:30 p.m. Visit the LCC website for location details, or call Cheryl at 314-740-0300.



**Lung Cancer Connection
1919 DeWitt Ridge Drive
Chesterfield, MO 63017**

Save the Date!
Saturday, November 2nd

***Join us for the
5th Annual
Lung Cancer Connection
5K Run/Walk
at
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