

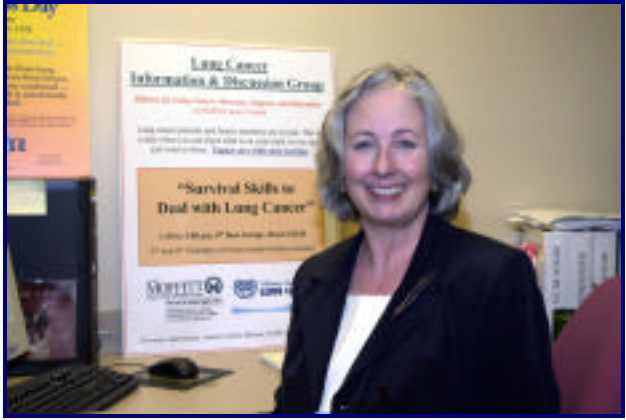
# Spirit & Breath

ALCASE • Winter 2004



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Cynthia Shimizu, Oncology Social Worker

## The Comfort of Kindred Spirits: Lung Cancer Support Groups

by Cynthia Shimizu, LCSW

Living with lung cancer is a challenge. It affects every aspect of your life: how you spend your days and nights, how you think and feel, and how you get along with family and friends. It has the power to get you thinking about matters of life and death, and rethinking what is valuable and important to you. People may offer help, but if you are uncomfortable accepting help, you may have difficulty navigating the many changes taking place in your life. The stress of living with lung cancer can develop into *distress*. Support groups can help you alleviate some of your stresses before they turn into distress.

### What is a cancer support group?

Cancer support groups are designed for people living with cancer and/or family members affected by cancer. People living with cancer, either directly or indirectly, share common experiences. Participants find it helpful to “compare notes” with others and learn how others have handled similar circumstances. By sharing experiences, group members come to realize the changes taking place in their lives are quite normal. Learning that others have similar experiences and emotions helps alleviate feelings of loneliness and isolation. Support groups give you an opportunity to share your personal story and to both give and receive care and support.

Group meetings are often facilitated by social workers or other professionals. The facilitator ensures that certain ground rules are followed by the group. One important ground rule is maintaining participants’ confidentiality. Meetings generally last for 60 to 90 minutes, and take place

weekly, biweekly, or monthly. Meetings typically start with participants introducing themselves and then various topics are discussed spontaneously as the conversation evolves.

### How do support groups help?

Researchers have reported that most medical treatment does not meet the psychosocial needs of patients and peer support can help meet these needs.<sup>1</sup> Support groups complement medical treatment by adding dimensions of care that are best provided by others with similar needs.

Support group members report that participation helps enhance their understanding of cancer, cancer treatments, and the emotional rollercoaster they experience. People attending support groups often note decreased stress levels when group members share advice and offer emotional support. Participating in a support group to share with and learn from others may have a direct impact on how you take care of yourself and whether you seek additional advice and care from your health care team.

### Why are lung cancer-specific support groups valuable?

The experience of living with lung cancer, as opposed to other cancers, is unique due to some pertinent issues. Lung cancer-specific support groups offer an educated and fair perspective on these issues, which can be a positive, rewarding experience.

An *undeserved* stigma is often attached to having lung cancer based on what we now know about the effects of smoking cigarettes. Many people with lung cancer feel guilty when they hear other people say, “You did it to yourself,” or “You should have known better.” The truth is that smoking cigarettes is not simply a matter of individual choice. We grew up surrounded by the glamour of smoking as portrayed in television, movies, and product

advertising. Many of our family members and friends smoked. Meanwhile, tobacco companies secretly engineered cigarettes to be highly addictive. Smoking is a worldwide social, cultural, and public health issue, so if you are a current or former smoker and now have lung cancer, you are certainly not alone. Every person with lung cancer *deserves* the best medical care possible.

Lung cancer still has a relatively poor prognosis.<sup>2</sup> Every year, lung cancer kills more people than breast, ovarian, prostate, and colorectal cancers *combined*. There is no FDA-approved screening test for lung cancer, and 85% of cases are diagnosed in later stages of disease when it is most difficult to cure.

There are fewer research dollars spent per patient for studying lung cancer than for many other common cancers. In 2001, the National Cancer Institute (NCI) estimated only \$1,312 was spent per lung cancer death compared to \$11,704 per breast cancer death and \$8,190 per prostate cancer death.<sup>3</sup> This has a direct impact on the type of screening, treatment, and care people with lung cancer receive.

### What else do people with lung cancer talk about?

The scope and depth of group discussions depend on the interests of the people attending the meetings. There is a broad range of topics. Some are common themes that are easy to talk about while other topics are more emotionally challenging.

Common themes discussed in lung cancer support groups include:

- finding information and resources to help deal with lung cancer
- working together with your doctor and other members of your health care team
- living well by maintaining balance in your life
- managing stress
- eating well
- managing the side effects of treatment

More challenging issues that may arise in discussion groups include:

- talking with the young children in your life about your cancer
- enhancing spiritual/religious well-being
- dealing with emotions such as anger, fear, and depression
- planning ahead with advance directives for your future health care
- coping with relationship stresses that arise from your cancer

### How do I find a lung cancer support group?

The ALCASE Internet site at [www.alcase.org](http://www.alcase.org) provides a list of lung cancer support groups that meet face-to-face, as well as a few on-line support groups. In addition, the ALCASE Phone Buddies Program (800-298-2436) can pair you with another lung cancer survivor, so that support is only a phone call away. Cancer Care, Inc. (800-813-4637 or [www.cancercares.org](http://www.cancercares.org)) periodically offers lung cancer support groups that take place over the telephone. The American Cancer Society (800-ACS-2345) can tell you about additional resources available in your area. Often, oncology nurses and social workers are also good sources of information about local support groups.

### You are not alone.

Knowing you are not alone and that others experience the same kinds of struggles you do can help take the edge off some of the many challenges you face with lung cancer. There are many adjustments to make and talking with others who have walked in your shoes can provide guidance about what to expect and survival skills to help you cope. Peer support also offers hope and encouragement, which are so important for living well with lung cancer.

*Ms. Cynthia Shimizu is an oncology social worker at H. Lee Moffitt Cancer Center & Research Institute in Tampa, Florida.*

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3 National Cancer Institute 2001 Fact Book at [www.cancer.gov/admin/fmb/2001factbook.pdf](http://www.cancer.gov/admin/fmb/2001factbook.pdf).

## Spirit & Breath

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Please direct all questions about content to Tina M. St. John, MD, ALCASE Medical Editor at [info@alcase.org](mailto:info@alcase.org).



There is always hope.

## From Where I Stand with Mary Shipherd

Mary Shipherd is a dynamic 79-year-old lung cancer advocate. Having survived two surgeries for lung cancer, Mary became “a one-person effort” to raise the public profile of the disease during Lung Cancer Awareness Month (LCAM) in November 2003. She persuaded her county commissioners and Georgia Governor Sonny Perdue to issue LCAM proclamations. The local newspaper featured an article about Mary along with a list of signs and symptoms of lung cancer. Mary was also interviewed by several radio stations in her area throughout the month. Mary set up an information display in the lobby of a nearby hospital, and personally staffed the table for four days. She distributed more than a dozen LCAM Hope posters, and gave a presentation about lung cancer to the Georgia Cancer Coalition.



Widowed since 1994, Mary has a supportive circle of friends and a lively sense of humor. She lives on a small island off the Georgia coast enjoying her closeness with nature. In addition to Mary’s budding lung cancer activism, she is supporting efforts to renovate a nearby Coast Guard station. Mary is dedicated to personal physical fitness and says, “There are all sorts of things you can do to strengthen the body and feel better.”

Mary shared these thoughts during a recent interview with ALCASE.

*I am a lung cancer survivor. Fourteen years ago I was diagnosed with lung cancer. Yes, I was a smoker. The upper and middle lobes of my right lung were removed [after my diagnosis]. My recovery was painful but uneventful. I returned to work as a human resources manager after six weeks and didn’t retire until May of 1998 at age 75.*

*In January 1999, my routine chest x-ray showed a suspicious nodule in my left lung. A CT scan confirmed the nodule. I was stunned. I hadn’t smoked in ten years and I thought I was free of cancer. Because of my age and my earlier loss of some of my [right] lung, I was considered a high-risk surgical candidate. Arrangements were made for me to go to Savannah for pulmonary and surgical evaluation. Based on very limited testing, I was advised that I was not a surgical candidate because any further lung reduction could leave me unable to manage my day-to-day activities, including self-care. None of what I heard was acceptable to me — I became my own advocate. I arranged an appointment with a pulmonologist and thoracic surgeon at the top clinic in a major city. After extensive testing and surgical consultation, the good news was that my lung function after surgery should allow me to manage comfortably.*

*I had two diverse opinions, and it was recommended that I get a third. Arrangements were made for me to go to yet another city to see a thoracic surgeon. He agreed with the most recent findings, so I gave the go ahead and surgery was scheduled.*

*I have never felt so alone as I did when I said goodbye to my friends and boarded the plane the day before my surgery. The upper lobe of my left lung was removed and again the diagnosis was adenocarcinoma. It was a second primary tumor, not a recurrence of my first cancer. After eight days in the hospital, I was transferred to a rehabilitation facility for twelve days. Rehab continued in my home.*

*When I look back, it all seems very strange. At the time, I seemed numb to what was happening to me. It was as though I was a robot — getting everything done but with little feeling. I brought legal documents up-to-date and even wrote a brief obituary. My friends prayed for me but I seemed unable to pray, even though I often felt the Lord’s presence.*

*My second lung cancer almost “took my breath away.” Exercising on a regular basis had been part of my routine for more than a decade. As soon as I was physically able, I started going to a fitness center again. Exercising to keep what was left of my lungs functioning at their maximum level was critical to my recovery. People laugh when I tell them, but I purchased two train whistle toys and kept one upstairs and one downstairs. I had to inhale deeply and exhale strongly to make them blow and it helped me. Also, a friend gave me small bag filled with sand, and I would lie on my back, put it on my diaphragm, and practice just breathing in and out, to strengthen those muscles. The body is remarkable in its ability to adapt and compensate for trauma inflicted upon it. Mine responded well to my efforts.*

*I don’t walk as fast on the treadmill as I once did, but I can often walk a 26-minute mile. I am at a gym three times a week using the equipment and participating in a Body Flow Class. A year ago, one hour of Tai Chi three times a week was added to my schedule.*

*I am glad to have found ALCASE. I tracked them down after seeing a television show where the lung cancer ribbon pin was mentioned.*



## Lung Cancer Research Supplement

by Tina M. St. John, MD

Several interesting new findings have been announced by the lung cancer community in the last few months. While it is tempting to see some of it as “bad” news, in reality, everything we learn about lung cancer adds to our understanding of the disease – and that’s a good thing.

Some of the most recent news from the lung cancer research community is summarized below.

### **Trastuzumab (Herceptin®)**

#### **Adds Little to Effects of Standard Chemotherapy for Advanced NSCLC**

Researchers from Germany have announced results from a phase II clinical trial that studied the effects of trastuzumab (Herceptin®) in combination with standard chemotherapy for the treatment of advanced NSCLC. The study of 100 people found the addition of trastuzumab led to no significant improvements over chemotherapy alone.<sup>1</sup> While the results were disappointing, researchers stated there may still be a role for trastuzumab (a monoclonal antibody) among people whose lung cancer expresses very high levels of HER-2.

#### **Low Tar Cigarettes Do Not Decrease Risk of Lung Cancer**

A large study involving over 940,000 participants found the risk of lung cancer is the same among people who smoke medium tar, low tar, and very low tar cigarettes.<sup>2</sup> These findings are contrary to tobacco companies’ advertising of “light” and “ultra light” cigarettes. Dr. Michael Thun of the American Cancer Society said, “There was not a shred of evidence of reduced risk [with low tar cigarettes].” However, investigators did note a higher risk for lung cancer among people who smoked unfiltered cigarettes compared to those who smoked filtered cigarettes. All findings were the same for men and women.

#### **Surgeons’ Lung Cancer Experience Linked to Outcomes for People with Limited, SCLC**

A study presented at the Society of Thoracic Surgeon’s annual meeting in January 2004 found surgeons specializing in lung cancer were more likely to achieve a successful resection of limited small cell lung cancer than surgeons who did not specialize in lung cancer. While postoperative, in-hospital deaths were the same in both groups (3%), people operated on by lung cancer specialists survived significantly longer than those whose surgeon was not a lung cancer specialist (18 versus 8 months). Although the study was relatively small (70 patients), the findings are important for people considering surgical treatment for SCLC.

#### **New England Journal of Medicine Publishes Study Showing Survival Advantage with**

#### **Postoperative Chemotherapy for People with Resected NSCLC**

A large study of 1,867 people who had undergone a complete resection for NSCLC randomly assigned participants to either observation or postoperative (adjuvant) platinum-based chemotherapy. The published results, which were previously reported at cancer meetings in 2003, showed people assigned to chemotherapy had a significantly higher 5-year survival rate (44.5%) than those assigned to observation (40.4%).<sup>4</sup> The authors concluded, “... our results strongly support the use of three or four cycles of cisplatin-based chemotherapy after complete surgical resection in patients with non-small-cell lung cancer.”

#### **Treatment Outcomes Similar for Chemotherapy Plus Surgery Versus Concurrent Chemoradiotherapy for Stage IIIA NSCLC**

A recent study at the University of Texas M. D. Anderson Cancer Center compared the outcome of preoperative (induction) chemotherapy followed by surgery (C/S) to concurrent chemoradiotherapy (CRT) among 107 people with stage IIIA NSCLC. Researchers found no significant differences between the two treatment groups in terms of local control, survival time, 5-year overall survival, distant metastasis-free survival, and disease-free survival.<sup>5</sup> The authors suggested that recent advances in radiation-based treatment have resulted in similar outcomes with CRT compared with modern induction chemotherapy plus surgery.

#### **Study Finds Mediastinoscopy Superior to PET for NSCLC Staging**

Investigators at Duke University Medical Center compared the accuracy of positron emission tomography (PET) to mediastinoscopy for the mediastinal staging of 202 people with NSCLC. Participants first underwent a PET scan followed by a mediastinoscopy. Results of the two procedures were then compared. Of the 65 people with positive results by PET, only 29 (44.6%) had positive results by mediastinoscopy. Of the 137 people with negative PET results, 16 (11.7%) had positive results by mediastinoscopy.<sup>6</sup> Based on their findings, the authors concluded, “PET neither confirms nor excludes involvement of the mediastinum in patients with NSCLC. Cervical

mediastinoscopy with lymph node biopsy remains the standard for mediastinal staging.”

### **Preliminary Results of Phase II Study of Docetaxel (Taxotere®) plus Enoxaparin (Lovenox®) Suggest Possible Role in Metastatic NSCLC**

Activation of coagulation (blood clotting) appears to play a role in tumor progression. Enoxaparin (Lovenox®) is an anticoagulant that was tested in combination with docetaxel in this trial among 15 people with stage IV NSCLC. Eight patients on the drug combination had an objective response (53%) and four had stable disease.<sup>7</sup> The median time to disease progression was 5 months and the median survival time was 11 months. Based on these preliminary results, the authors concluded the combination of docetaxel plus enoxaparin is safe and well tolerated in people with advanced NSCLC. They also stated the data suggest that enoxaparin may prolong the time to disease progression. Additional research is needed to determine if enoxaparin may improve treatment outcomes among people with advanced NSCLC.

### **Advanced Age Does Not Preclude Surgery for Lung Cancer**

A study from Johns Hopkins that examined the outcomes for 68 people in their eighties who underwent surgery for NSCLC found that 1-, 3-, and 5-year survival rates were comparable to those of younger patients when matched for stage, performance status, and respiratory (breathing) function.<sup>8</sup> These data support earlier studies that have concluded chronological age alone is not a contraindication to surgical treatment of lung cancer.

### **New Practice Guideline Recommends Etoposide-Cisplatin as the Preferred Chemotherapy Regimen for People with Limited-Stage SCLC Undergoing Concurrent Radiotherapy**

Cancer Care Ontario recently conducted a review of 50 randomized trials conducted from 1985 through 2002 addressing the first-line treatment of limited small-cell lung cancer. Based on the evidence from these studies, the new practice guideline recommends etoposide-cisplatin is the preferred chemotherapy regimen for people with limited-stage SCLC when concurrent thoracic radiotherapy is used.<sup>9</sup> The guideline further states that it is reasonable to offer the alternation of etoposide-cisplatin with cyclophosphamide-doxorubicin-vincristine, provided the administration of radiotherapy concurrent with an anthracycline (such as doxorubicin) is avoided. Guideline authors also

note the use of maintenance chemotherapy is not indicated for people with limited SCLC. While clinical trials of other chemotherapy regimens are important in the search for more effective treatment options, this guideline gives both doctors and patients a thorough review of the evidence to date.

### **Second-Line Docetaxel (Taxotere®) Improves Survival and May Improve Quality of Life in NSCLC**

A phase III trial comparing second-line docetaxel (Taxotere®) versus best supportive care among 204 people with NSCLC found docetaxel improved survival and showed a trend toward less deterioration in quality of life (QOL).<sup>10</sup> There was a significant difference in favor of docetaxel in terms of patient-reported pain, and trends in favor of docetaxel regarding appetite and fatigue.

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## Celebrating ALCASE Phone Buddies with Don Laughery

Don Laughery is a true “tell it like it is” Texan. He has spent the last 13 months fighting lung cancer, and is eager to share his experiences with others — especially those recently diagnosed with the disease. “I know that when a person is diagnosed, they are scared to death,” says Don. “I want to be there for that person, who like me, is staring at the ceiling at three o’clock in the morning and feels like they don’t have anyone to talk to.” Don is one of the more than 200 volunteers for ALCASE Phone Buddy Program. Each day (and night), these volunteers bring hope, information, and understanding into the lives of people facing lung cancer.

Don’s journey began in January 2003. After some dental work, he “started to get fat.” Swelling in his face and neck failed to go away with antibiotics, and spread to his chest. “One Sunday I went out to ride my horse and noticed that my shirt didn’t fit real good,” said Don. He went to see his doctor the next day. A chest X-ray showed several tumors. Don was immediately sent to the emergency room, where he met with an oncologist and a radiologist who confirmed a diagnosis of small cell lung cancer.

Don’s treatment was aggressive, combining chemotherapy and radiation together. “It kind of beat me up,” says Don of his treatment. “The skin on my chest just split open; it was like raw meat. But I knew the treatment was my best option. I was in good physical shape when the whole thing started and I didn’t have any serious complications.” However, Don experienced both depression and anxiety during treatment. “I told my doctor I was really depressed – not just about the cancer. I felt as if it had taken my life away. I couldn’t ride horses. I couldn’t weld. And there was no way anyone would hire me.” Don’s doctor put him on anti-depression medication. “They say that a lot of overcoming cancer is mental, so if a patient is unhealthy mentally and it is not treated, then they are really missing out,” said Don. He credits his doctor for being receptive and sensitive to his distress.

After completing the chemoradiotherapy, Don had gamma knife surgery (stereotactic radiosurgery) for a metastatic brain tumor. He is now taking a second chemotherapy regimen. He reports that all the large tumors have dissipated and he has just a few “spots” on his right lung.

Don is eager to reach out to others. Don said of being an ALCASE phone buddy, “I feel like I am going to prolong my life. If during that time I can help or answer questions to help others not to be so scared, then I want to do that.”

If you or someone you love would like to be matched to a phone buddy like Don, please call ALCASE today at 800-298-2436.

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For additional information, call 214-818-7462 or logon to the conference Internet site at:

[www.curetoday.com/patientmeeting/index.html](http://www.curetoday.com/patientmeeting/index.html)

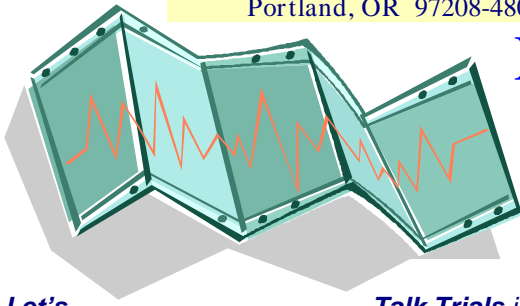


Thank you to everyone who contributed to ALCASE in 2003. Your donations matter. They help us maintain our Internet site, answer our Hotline, and mail information about our programs directly to the people who call or write us. Your contributions are essential to our work with thousands of patients and families. With your financial support, our Washington, D.C. representative raises lung cancer issues with health policymakers nationally.

We accept contributions by check and credit card. We also welcome donations of common stock and gently used vehicles. Call us for details.

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# Let's Talk Trials: Eligibility Criteria

by: Tina M. St. John, MD

**Let's** *Talk Trials* is a series of articles that address some of the most common questions people with lung cancer have about clinical trials. This is the second article in the series. If you have suggestions about what clinical trial topics you would like to see discussed in future issues of **Spirit & Breath**, send us an e-mail at [info@alcase.org](mailto:info@alcase.org) or give us a call at 800-298-2436.

All clinical trials have **inclusion and exclusion criteria**. Inclusion and exclusion criteria are sometimes talked about together as **eligibility criteria**. The purposes of these criteria are to:

- insure that all the study participants are similar enough to allow the investigator's to answer the trial's study questions
- limit the medical risks to study participants

Clinical trials are designed to answer specific study questions. In order to answer the study questions, investigators must limit the variability of factors other than those being studied. This helps ensure that at the end of the trial, the results observed are related to the factors being studied and not variation in the study participants. **Inclusion criteria** define who will be included in a study. Common inclusion criteria for lung cancer trials are listed below with examples of each criterion.

- **the type of lung cancer**  
small cell, non-small cell, bronchioloalveolar
- **the stage of the disease**  
stage I-IV for NSCLC  
limited or extensive for SCLC
- **treatment history**  
no previous chemotherapy (chemonaive)  
one previous chemotherapy regimen  
previous treatment with a specific drug or regimen

**Exclusion criteria** define specific circumstances or situations that would prevent a person from participating in a given trial. Some common examples of exclusion criteria in lung cancer trials include:

- **metastasis**  
Some studies exclude anyone with distant metastasis. Others exclude only people with metastasis in specific sites such as the brain or the liver.
- **medical conditions**  
Depending on what is being studied in the trial, people having certain medical conditions other than lung cancer may be excluded from a trial. For example, if a drug is being tested that is expelled from the body by the kidneys, people with kidney disease may be excluded from the trial.
- **performance status**  
Clinical trials can sometimes be demanding in terms of visits to the doctor, filling out paperwork, or keeping a diary. Therefore, the study sponsors sometimes exclude people who may find the demands of the trial too taxing.
- **previous treatments**  
First-line treatment trials are designed for people who have had no previous therapy for their disease. Therefore, anyone who has had previous therapy is excluded from a first-line treatment trial. Second-line treatment trials allow previous therapy, but may excluded people who have had certain types of therapy.

To understand how inclusion and exclusion criteria work, let's consider an example. Researchers have discovered a new drug. They want to design a study to find out if the drug helps prevent the spread of lung cancer to the brain. The investigators need to make sure the people participating in the study do not have any evidence of brain tumors before entering the study. Therefore, evidence of one or more brain tumors by CT or MRI will be one of the exclusion criteria for the study. Because the presence of brain metastasis that may be undetectable by CT or MRI could influence the results of the study, investigators may decide to exclude people with metastatic disease in *any* location as another way of limiting the chances of enrolling people who may have undetectable brain metastasis. Let's say the new drug being studied is eliminated from the body by the liver. To protect people who may have liver disease from potential harm due to the study drug, they may also be excluded from the study. Possible inclusion criteria for our example may be biopsy-proven lung cancer, no previous chemotherapy, and good performance status.

People with lung cancer who are interested in participating in a clinical trial are sometimes frustrated when they find they are not eligible for a specific trial because of inclusion or exclusion criteria. While this experience can indeed be frustrating and disappointing, try to keep in mind that these criteria are absolutely necessary to ensure the safety of the participants and the reliability of the study results.

In general, the lower the phase of the study, the less stringent the inclusion and exclusion criteria are. Conversely, the higher the phase of the study, the more limiting the inclusion and exclusion criteria are. In other words, phase I trials are usually least restrictive and phase III trials are usually the most restrictive in terms of inclusion and exclusion criteria. This rule of thumb may help you in your search for a clinical trial that suits your situation, needs, and desires.

### **Finding a Trial That Suits You**

Eligibility criteria are an important filter in narrowing the search for a clinical trial that suits you. If you're looking for a clinical trial on the Internet, all of the major sites that list clinical trials include information about eligibility criteria. However, keep in mind that *all* the eligibility criteria may not be listed. This is important because the final word about whether you are eligible for a trial is made by the doctor who enrolls you into a trial. For some clinical trials, you may even need to undergo specific tests before a determination can be made about your eligibility for the trial. Knowing this ahead of time may help prevent you from experiencing possible surprises and potential disappointments.

### **Clinical Trials Information**

The Internet has become one of the best tools for finding clinical trials. Below are a few examples of reputable sites that offer clinical trial listings. All of the Internet sites listed allow you to search for clinical trials free-of-charge; some require registration. The National Cancer Institute (NCI) site and Clinical Trials.gov are operated with government funds. The other listed sites are privately operated.

#### **National Cancer Institute**

[www.cancer.gov/search/clinical\\_trials](http://www.cancer.gov/search/clinical_trials)

#### **Clinical Trials.gov**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

#### **Trial Check from the Coalition of National Cancer Cooperative Groups**

[www.trialcheck.org/cancertrialshelp/cancertrialshelp.aspx](http://www.trialcheck.org/cancertrialshelp/cancertrialshelp.aspx)

#### **Center Watch**

[www.centerwatch.com/patient/studies/area12.html](http://www.centerwatch.com/patient/studies/area12.html)

#### **Veritas Medicine**

[www.veritasmedicine.com/d\\_index\\_tc.cfm?did=17&cid=0](http://www.veritasmedicine.com/d_index_tc.cfm?did=17&cid=0)

#### **Cancer Consultants**

[cancerconsultants.com/patient\\_new/clinical\\_trials.php](http://cancerconsultants.com/patient_new/clinical_trials.php)

#### **Emerging Med**

[www.emergingmed.com](http://www.emergingmed.com)

If you prefer, you can call the NCI's Cancer Information Service at 800-422-6237 for information about lung cancer clinical trials.

COMING SOON... In the next issue of *Spirit & Breath*, *Let'sTalk Trials* will address informed consent and topics to discuss with your doctor before entering a clinical trial.



## RUN FOR THE LUNGS

### “Grandma’s Marathon”

by Lynn Johnson

**“One door closes and another opens.”** I never realized all the sayings my mom always used. But now I find myself repeating so many of her sayings – since she is no longer here to say them herself. My mom lost her life to lung cancer in 1996 at the age of 83. Losing her was difficult to deal with. Then in 2000, I lost my brother to lung cancer also. The door on both of their lives closed for me, but because of losing them, I became an advocate for lung cancer. So that is why I say another door opened for me.

In the fall of 2000, I began training for my first half marathon in Tucson and raising money for the Arizona Cancer Center. I wanted to find a way, though, to do something specifically for lung cancer. I learned about ALCASE and the Run for the Lungs Team, so I joined the Team for the San Francisco Marathon in 2001. What an emotional experience; I knew my mom and brother were there with me. They were the “wind beneath my wings.”

Most recently, I again raised money for ALCASE and went to Chicago for the 2003 Marathon. What an experience it was for me for several reasons! The weather was perfect. The spectators were awesome, and lined the entire 26.2-mile course. There are 40,000 participants in the Chicago Marathon, the largest in the world. I finished the race, breaking no records, but that was never my intention. The significance of the Chicago Marathon for me was the fact that I raised money specifically for lung cancer in the city where I was born and raised. My husband Michael and my daughters Jennifer (31), Melissa (19), and my three-year-old granddaughter were all there to support me. But to my surprise, my sister-in-law flew into Chicago the day before the marathon. She had worked out the surprise with my daughter. I was so shocked; she said since my brother could not be there to cheer me on, she felt she should be. What a great surprise!

My granddaughter was so excited about the marathon. She talked about it all the time saying that one day she would do a marathon with Grandma. Well, that happened sooner than any of us could have expected. As I was approaching the finish line, I saw my family in the crowd. I walked over to give everyone a hug. My daughter handed my granddaughter over the fence to me, and I gave her a hug. But instead of handing her back to her mom I said, “Alexis, are you going to finish this marathon with Grandma?” She was shocked. The announcer said, “Here comes Lynn Johnson from Tucson, Arizona! Did you carry that child with you the whole time?” My granddaughter had her picture taken with me at the finish line. It left such an impression on her that she is always pretending “marathon” since we have been home.

It was a wonderful experience; I hope to go back next year. And I will continue my mission to increase lung cancer awareness. Nothing can compensate for the loss of my mom and brother, but this is one way I can always keep their spirits alive.

So, to be like my mom and use another saying, **“When life gives you lemons, make lemonade.”**

To learn more about the ALCASE Run For The Lungs Team, logon to [www.alcase.org](http://www.alcase.org) and click on the runner’s photo.





## ALCASE Public Advocacy Update

Sheila Ross, ALCASE Washington, DC Representative

ALCASE is working hard to make inroads into public health policy with regard to lung cancer. The most significant breakthrough of 2003 was a meeting with the American Cancer Society (ACS) to discuss two critical issues:

- the stigmatization of lung cancer patients
- the need for more accurate information for the public and the medical community about identifying those at risk for lung cancer, screening, and treatment options.

ALCASE participated along with representatives from the National Cancer Institute, the CHEST Foundation, and the American College of Chest Physicians. The participants agreed that stigmatization of lung cancer patients must be stopped. It was further agreed that there continues to be a lack of clarity, even in the medical community, about lung cancer risk, especially for the persistent risk in former smokers. The medical community and the general public need to be better informed about lung cancer facts.

ALCASE thanks ACS for coming to the table to tackle these issues, especially Dr. Robert Smith, Director of Cancer Screening, and Wendy Selig and Mary Doroshenk of the national government relations office. We also want to thank the Oncology Nursing Society for their help in making this meeting possible.

Send ALCASE your ideas on what ACS and other organizations can do to help the lung cancer community. Your ideas will be shared at the next meeting in March 2004.

On November 19, 2003, the first Congressional briefing on lung cancer was held on Capitol Hill. Over 70 people, including House and Senate health policy staffers, attended the two-hour event. Representative Amo Houghton (R-NY) and his wife Priscilla, a two time lung cancer survivor, spoke as did Dr. Jim Mulshine, a lung cancer expert from the National Cancer Institute and a long-time honorary member of the ALCASE Board. ALCASE thanks the Society for Women's Health Research and the American Cancer Society for cosponsoring this groundbreaking event.

ALCASE is working to build partnerships in the nation's capitol to raise awareness and help bring about changes in public health policy on lung cancer. At the recent cancer summit held by C-Change (the new name of the former National Dialogue on Cancer) Dr. Cheryl Heaton, president of the American Legacy Foundation, spoke out on lung cancer. Before a large audience of cancer specialists, health policy experts, and former President George Bush, Dr. Heaton pointed out that most people are unaware that each year, lung cancer kills far more women than breast cancer. By 2006, the number of women dying of lung cancer is expected to be double that of those dying of breast cancer. Public remarks such as this from leading cancer advocacy organizations go a long way toward helping make lung cancer more "visible."

We urge you to send Dr. Heaton a thank you note for her recent remarks. An electronic note can be sent to [info@americanlegacy.org](mailto:info@americanlegacy.org). Alternatively, a personal, handwritten note can be mailed to:

Dr. Cheryl Heaton, President  
American Legacy Foundation  
2030 M Street, NW, Sixth Floor  
Washington, DC 20036

On a sad note, my good friend and former fellow Capitol Hill staffer Marty Driesler died of lung cancer on November 30, 2003. Marty worked right up to the end to spur key members of the House of Representatives to action. With similar backgrounds and a shared love of politics, Marty and I enjoyed working together. I miss her greatly.

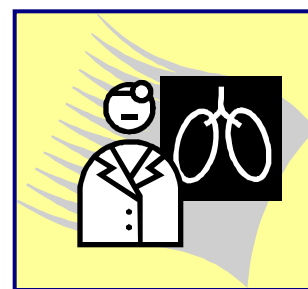
**Lung Cancer Fact: Every 3 minutes, someone in the U.S. dies of lung cancer.**

# CLINICAL PRACTICE GUIDELINES FOR LUNG CANCER:

## A description of their value and the process of development in Ontario, Canada

by **W.K. Evans, MD and Jean Mackay**

*Dr. Evans is the Chair of the Lung Disease Site Group and the Chief Medical Officer of Cancer Care Ontario in Toronto. He is also a member of the ALCASE Board of Directors. Jean Mackay is the Research Coordinator for the Lung Disease Site Group of the Program in Evidence-Based Care and is based at McMaster University in Hamilton, Ontario.*



The United States Institute of Medicine defines clinical practice guidelines as systematically developed statements designed to advise medical doctors and patients on the best evidence for treatment of a specific medical situation. Practice guidelines are compiled to help doctors and patients determine the best treatments for a medical condition based on the best available evidence. The need for such guidelines has grown in recent years as the volume of medical research continues to increase. There are currently over 20,000 medical journals publishing articles for the medical community. More than 500 medical articles are published each year in English alone about the treatment of lung cancer. Given this volume of information, it is difficult for individual doctors to find and evaluate all of the most recent treatment developments. Therefore, there is a need for practice guidelines that summarize and critically evaluate all the relevant data on specific treatment options and, where appropriate, combine the results from similarly designed clinical trials to determine what constitutes the current best evidence to guide clinical practice.

Practice guideline development is now an important part of the work of professional societies such as the American Society of Clinical Oncology (ASCO), government agencies such as the U.S. Agency for Healthcare Research and Quality (AHRQ) and the National Institute for Clinical Evaluation (NICE) in the United Kingdom, as well as international collaborations such as the Cochrane Collaboration. This article describes how Cancer Care Ontario (CCO) develops clinical practice guidelines and how they are disseminated for use by the cancer community.

CCO is an agency of the provincial government of Ontario, Canada. The agency is the principal advisor to the provincial government on all cancer matters. It operates a number of programs including the Program in Evidence-Based Care. This program develops clinical practice guidelines through 14 disease site groups (DSGs) including the Lung Cancer Disease Site Group (Lung DSG). The DSGs include different types of cancer doctors including surgeons, radiation oncologists, and

medical oncologists. Other people interested in guideline development are also included in the DSGs such as research coordinators, and importantly, patient representatives. The Lung DSG has 29 members from across Ontario including thoracic surgeons, radiation oncologists, medical oncologists, a medical sociologist, patient representatives, and two research coordinators. Except for the research coordinators, DSG members are unpaid volunteers. Meetings are conducted twice a year, but the guideline development work is continuous throughout the year. Each DSG decides on the guideline topics to be addressed. The choice of topics is largely driven by what new therapies or treatment approaches the DSG believes may have potential to improve patient survival or quality of life. Some guidelines are developed rapidly, as when a promising new treatment becomes available. When there has been no major advance in the treatment of a particular aspect of lung cancer, a guideline may be developed to review the existing data. The guideline development process in this case is likely to be more prolonged.

After a guideline topic is chosen, the research coordinators systematically review the medical literature on the topic. The review is often limited to English language publications. Electronic databases, reference lists of relevant articles, the proceedings of major cancer meetings, and reference lists of major review articles are often included in the search strategy to identify all available articles and information on the chosen topic.

The information gathered is reviewed based on preset criteria to determine its applicability to the guideline topic. The content of selected articles is summarized using a standard format. The summary of the evidence is then reviewed by the DSG members responsible for that guideline topic. A draft of treatment recommendations is prepared based on the summary. The recommendations are then discussed in an open meeting with all the Lung DSG members and modified as appropriate. When there is consensus on the evidence and its interpretation, a draft guideline is prepared called a

practice-guideline-in-progress (PGIP). It is sent to a large number of doctors in Ontario with an interest in treating lung cancer. These doctors are asked to complete a questionnaire about the PGIP, including questions related to:

- the need for a guideline
- the completeness of the literature review
- the clarity of the guideline recommendations

In addition, the doctors are asked if the practice guideline would be useful in their practices, and would they adopt it. Physicians also provide written comments that help the DSG clarify issues or improve on the interpretation of the data. This feedback is incorporated into the guideline, along with an explicit description of any changes made. A high percentage of doctors who provide feedback on PGIPs indicate they find the draft guideline recommendations clear (93-100%), the literature search relevant and complete (85-100%), and the PGIP recommendations should be approved as a practice guideline (61-89%).

The Practice Guideline Coordinating Committee, which is the final approval body for all CCO guidelines, then reviews the final guideline. The Committee includes clinical trial planners, oncologists, patient representatives, representatives from other provincial programs, and CCO administrators. Further modifications may be made to the guideline based on this review. Once approved by the Committee, the guideline is submitted for publication to a peer-reviewed medical journal and posted on Cancer Care Ontario's web site at [www.cancercare.on.ca/access\\_PEBC.htm](http://www.cancercare.on.ca/access_PEBC.htm).

As the medical literature continuously grows and new data becomes available, it is very important that guidelines be kept current. The policy of CCO's Program in Evidence-Based Care is to undertake a systematic review of the literature and incorporate relevant new evidence into the guideline annually. Of course, if new information that has an important bearing on the guideline emerges between annual reviews, updates can be initiated sooner.

The development of guidelines is a serious, labor-intensive activity. Patients should be aware that, just as the quality of medical literature varies, so too may the quality of practice guidelines. For those interested in determining the availability of guidelines on lung and other cancers, the National Guideline Clearinghouse in the US ([www.guideline.gov/resources/guideline\\_index.aspx](http://www.guideline.gov/resources/guideline_index.aspx)) and the Canadian Medical Association InfoBase in Canada ([mdm.ca/cpgsnew/cpgs/index.asp](http://mdm.ca/cpgsnew/cpgs/index.asp)) are good sources of information.



## INSIDE ALCASE

### ALCASE Internet Site Expands

The ALCASE Internet site at [www.alcase.org](http://www.alcase.org) has undergone several changes in the last few months. The redesigned site was launched in November 2003 during Lung Cancer Awareness Month. New features include:

- ***With Every Breath: a Lung Cancer Guidebook*** – a new book for people living with lung cancer
- ***Women and Lung Cancer*** – a new section that specifically addresses the needs of women with lung cancer
- ***Journal Highlights*** – an extensive list of recent lung cancer-related journal articles sorted by relevant topics
- ***Research Updates*** – summaries of recent developments in lung cancer care for people with lung cancer and their loved ones

We invite you to visit the site and let us know what you think of the redesign. Also, we are always happy to hear from you with suggestions for topics you'd like to see addressed on our Internet site or in ***Spirit & Breath***. Send us an e-mail at [info@alcase.org](mailto:info@alcase.org) or give us a call at 800-298-2436.

### Lung Cancer Awareness Month 2003 Events Observed Nationwide

Hope was the theme of Lung Cancer Awareness Month 2003. Hope helps us find our way through the most difficult situations. It can transform despair into courage and inspire a commitment to greater public action. Sparing people the devastation of lung cancer demands progress in both early detection and effective treatments.

ALCASE recognizes the many challenges associated with a lung cancer diagnosis. We salute all of you who are living with the disease, and the medical professionals, family, and friends caring for people with lung cancer. We support and applaud the growing local and national efforts to change the course of lung cancer. Together, we can make progress in our shared cause.

ALCASE sent Lung Cancer Awareness Month (LCAM) kits to thousands of medical facilities, lung cancer survivors, and patient advocates nationwide. Lisa DellaBella, who lost her father to lung cancer, designed the items in the kit including posters and freestanding counter displays with ALCASE brochures. Kits sent to survivors and family members were more personal with



bookmarks, magnets, and a window sticker. Lung cancer fact sheets and advocacy suggestions were sent with both types of kits. LCAM sponsors distributed tens of thousand of ribbon pins on informational cards.

ALCASE and Cancer Care cosponsored a telephone education workshop about lung cancer treatments. ALCASE, the American Cancer Society, and the Society for Women's Health Research co-hosted "What Women Don't Know about Lung Cancer," the first congressional breakfast briefing held on this topic. Cancer Care, the Oncology Nursing Society, and the CHEST Foundation clustered activities during one week in November. Several organizations featured lung cancer information on their Internet sites.

Patient advocates were involved in a variety of activities. In Illinois, a new advocacy volunteer planned and held an LCAM walk and rally. Activists also utilized the Internet sending electronic mail to their state and federal legislators urging them to allocate tobacco settlement funds for lung cancer programs and to increase federal fiscal support of lung cancer research. Responding to advocates' requests, governors in the following states issued proclamations for Lung Cancer Awareness Month: Arizona, Illinois, Kansas, Kentucky, Maine, Maryland, Massachusetts, North Carolina, Ohio, Tennessee, Texas, and Wisconsin. Lung cancer survivors were featured in many meetings held at hospitals and cancer clinics across the country. The need for greater public advocacy was often a key issue.

The media is another important way to increase public awareness of lung cancer and encourage compassion for people with the disease. ALCASE and volunteer activists made numerous media contacts and gave radio, magazine, and newspaper interviews. *The Boston Globe* and New York's *Newsday* newspaper ran stories about lung cancer research, and ALCASE placed display ads in five major newspapers. ALCASE is a founding member of the Global Lung Cancer Coalition whose theme for LCAM was "**No one in the world deserves lung cancer.**" Press releases and highlights from member organizations underscored the worldwide impact of lung cancer.

### Help Plan Lung Cancer Awareness Month 2004

We congratulate everyone who helped make Lung Cancer Awareness Month 2003 such a success. But now it's time to start planning for Lung Cancer Awareness Month 2004, and ALCASE needs the advice of lung cancer survivors, their families, and loved ones. Do you have ideas for awareness events, advocacy, or fundraising? Do you have ideas about how to increase lung cancer awareness in your community? Do you have an opinion about the materials ALCASE uses to help promote LCAM? How can we improve these materials in 2004? We want to hear from you today! ALCASE will decide on a theme for LCAM 2004 by April, so send in your suggestions and comments as soon as possible. Contact us by telephone at 800-298-2436, fax at 360-735-1305, mail at 500 W. 8<sup>th</sup> Street, Suite 240, Vancouver, WA 98660, or e-mail at [info@alcas.org](mailto:info@alcas.org) with "LCAM 2004" in the subject line.



## Symptom Management: Breathing Difficulties

by Tina M. St. John, MD

Breathing difficulty is a common and troublesome symptom of lung cancer. The medical term for breathing difficulty is **dyspnea**. Dyspnea includes difficult, labored, or uncomfortable breathing. People with dyspnea describe it as a feeling of air hunger. Dyspnea is triggered when the cells of the body are not getting enough oxygen. Sensations of dyspnea may include tightness in the chest, fast breathing, and/or shortness of breath. Dyspnea and the effects of having too little oxygen in the body can seriously affect your quality of life.

Lung cancer can cause dyspnea in several different ways including blockage of the airways by a tumor, fluid in or around the lungs, anemia, and muscle weakness. Dyspnea caused by partial blockage of a large airway may cause noisy breathing or wheezing. Dyspnea can also be caused by other medical conditions such as asthma,

chronic obstructive pulmonary disease (COPD), emphysema, pneumonia, or heart disease. Shortness of breath usually causes anxiety, which tends to make the problem worse. To treat dyspnea effectively, the underlying cause must be determined.

### **MEDICAL TREATMENTS FOR DYSPNEA**

The treatment recommended by your health care provider will depend on the underlying cause of the problem. Following are some of the treatments your doctor may recommend to help alleviate dyspnea.

#### **Supplemental Oxygen**

Supplemental oxygen increases the amount of oxygen taken in with each breath. This eases shortness of breath by providing the body with the oxygen it needs. Supplemental oxygen is moisturized to keep it from drying the airways.

#### **Medications**

A variety of breathing medications can be used to treat dyspnea. The choice of medications depends on the underlying cause of your symptoms. Drugs called bronchodilators open up the airways. Steroids are also sometimes used. Some medications are taken by mouth; others are inhaled. Pain can worsen dyspnea. Therefore, pain medication such as morphine sometimes helps alleviate severe dyspnea.

#### **Treating Airway Obstruction**

If one or more of your major airways is obstructed by a tumor, your doctor may recommend a procedure to clear the airway. The procedure recommended depends on the location of the tumor and other factors. Options include radiation therapy, dilation of the airway with a balloon, laser treatment, cryoablation (freezing the tumor), and photodynamic therapy (PDT).

#### **Treating Anemia**

Anemia is a shortage of red blood cells (RBCs) in the blood. Because RBCs carry oxygen to the tissues of the body, anemia can cause or worsen dyspnea. The cause of your anemia will be evaluated by your doctor and he or she will treat you accordingly. Severe anemia may require a blood transfusion. If the need for blood is not immediate, your doctor may recommend another form of treatment such as supplemental iron or an RBC growth stimulating drug such as Procrit® or Aranesp®.

### **SELF-HELP TECHNIQUES TO EASE DYSPNEA**

Some people with dyspnea find the following self-help techniques useful in controlling this troubling

symptom. While these techniques may help alleviate your shortness of breath, be sure to discuss your dyspnea with your health care provider. Dyspnea may indicate a serious underlying problem that requires medical treatment.

#### **Controlled Breathing**

Breathing normally takes place outside your conscious awareness. Focusing attention on breathing and doing it in a controlled way may help alleviate shortness of breath. Begin by taking a normal breath in through your nose. Count the number of seconds you inhaled. Breathe out through pursed lips for twice as long as you inhaled. Do not force the air; just breathe out in a controlled manner.

#### **Abdominal Breathing**

Abdominal breathing is a technique in which you use both your chest and abdominal (stomach) muscles to help you breathe more deeply. Babies and young children naturally breathe this way, which is why abdominal breathing is sometimes called baby breathing. As we grow older, we tend to change to chest breathing using primarily the muscles of the chest and the diaphragm (the large muscle under the lungs that separates the chest from the abdomen). Women are almost exclusively chest breathers whereas men tend to use both abdominal and chest breathing. With normal breathing, we typically use only 10-20% of our lung capacity. Abdominal breathing helps you use a much greater amount of your lung capacity with each breath.

Abdominal breathing is best learned while lying on your back with a pillow under your knees. Place one hand on your upper chest and the other on your abdomen below your ribs. Breathe out slowly through pursed lips. Squeeze your abdominal muscles upward and inward. Your abdomen will move inward toward your back. Breathe in through your nose. Your abdomen will rise. Once you have mastered abdominal breathing, you will be able to use it in any position. Abdominal breathing may greatly increase your ability to take in necessary oxygen. Some people with lung cancer have found this technique very helpful in reducing shortness of breath.

#### **Relaxation**

Relaxation can help reduce dyspnea in two different ways. When you are anxious, as people who are short of breath often are, you tend to take short, shallow breaths. Short, shallow breaths are not an effective way to breathe. When you relax, your breathing slows and becomes deeper. Deep breathing brings more oxygen into the lungs with

each breath. In addition, when you are anxious, your muscles are tense. Tense muscles use more oxygen than do relaxed muscles. Relaxing your muscles decreases their demand for oxygen, which helps reduce air hunger. People relax in different ways. Soothing music, dim lighting, or a warm bath works for some people. Other people practice techniques that can be used no matter where you are such as visualization or meditation.

### **Posture and Body Position**

Posture and body position can affect how deeply you breathe. Notice your posture. Slouching with your shoulders rolled forward prevents your rib cage from fully expanding with each breath. Try bringing your shoulders up and back. This opens the chest cavity and allows you to bring more air into the lungs.

Sit or lie down if you are short of breath. This decreases your need for oxygen to hold up your body weight and allows your muscles to relax. Sitting with your feet spread shoulder width apart while leaning forward with your elbows on your knees opens up the chest.

### **CONCLUSION**

Breathing difficulties can interfere with daily living and cause high levels of anxiety and fear. This common symptom among people with lung cancer can have many different causes. If you are having breathing difficulties, talk it over with your doctor right away. He or she will determine the cause of the problem and prescribe appropriate treatment. Effective treatment of dyspnea can greatly enhance your quality of life.

*This article is adapted from the information contained in Chapter 10 of the book, **With Every Breath: A Lung Cancer Guidebook** by Tina M. St. John, MD. The entire contents of the Guidebook can be found on the ALCASE Internet site at [www.alcase.org](http://www.alcase.org).*



**ALCASE**

Alliance for Lung Cancer Advocacy, Support, Education

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