

Lung Cancer Research Update

Volume 3

Greetings from the Principal Investigator and a Co-Investigator



Ping Yang, M.D., Ph.D.

Ping Yang, M.D., Ph.D., study principal investigator, is an epidemiologist with special training and experience in genetic epidemiology. Dr. Yang's long-standing research interest has been in the causes and outcomes of lung cancer.



Paul Scanlon, M.D.

Paul Scanlon, M.D., study co-investigator, is the director of both the Pulmonary Function Laboratories and the Pulmonary Clinical Research Center at Mayo Clinic. Dr. Scanlon is responsible for pulmonary function test-related aspects, including arranging the tests for patients.



Answers to questions frequently asked by participants in our study

Over the years, we have received many questions from people in our study about lung cancer and our research program. Here are answers to some of the most often asked questions:

“How do we get more public support and funding for lung cancer research?”

We agree about the importance of funding for research on lung cancer. This study is funded by the National Cancer Institute (NCI). The NCI web page, www.cancer.gov, gives the names of the NCI Director and Program Directors. You can write to them if you wish to advocate for public support and more funding for lung cancer research. They are responsive to the concerns of private citizens.

“Why did I get lung cancer - I quit smoking cigarettes 13 years ago?”

Based on our study results and data reported by other researchers in the literature, the largest proportion of lung cancer patients were former smokers. For example, among more than 5,000 lung cancer patients we saw at Mayo Clinic in a recent five-year period, roughly 90 percent have smoked cigarettes. Among patients who smoked, nearly 60 percent had quit and two-thirds of those had quit for over 10 years before their lung cancer diagnosis.

“Can you tell me more about what the current thinking is regarding preventing recurrence of large cell carcinoma?”

There is no absolute way to prevent recurrence, but we strongly encourage continuing not to smoke if you previously smoked, and eating a good diet with 5-7 servings of fruits and vegetables per day, as advised by the American Cancer Society.

“When will you have any feedback on the blood samples sent in for the study – my family members ask me when we will hear if our family is predisposed to lung cancer?”

To protect the privacy and confidentiality of every person involved in our study, we do not link test results to individuals in our study. Therefore, our study findings are not retrievable for each patient. If any major lung cancer gene is found, we will let the participants in our study know by an update such as this newsletter.

“Why are the same questions asked every year, e.g., ancestral background, etc., included without reference to the data already supplied and do you really think anybody remembers how many servings of any particular food they had before diagnosis compared to present?”

This is an important question raised to scientific researchers who enroll a large cohort (ranging from hundreds to thousands) of patients: how to optimize the content and customize the layout of a study questionnaire. Part of the goal of our research project is to look for factors that determine the health status and quality of life over time and that is the reason many questions are repeated year after year. This information may be important for developing prevention and intervention strategies for a healthy and better quality of life after surviving lung cancer. Meanwhile, our research team has been working hard to improve the issues that have been raised. For example, recognizing the difficulty in remembering food intake, we now only ask for the last year. We also will insert previously-supplied information for questions that typically do not change over time.

“Why do I have to keep donating blood for the study? Isn't once enough?”

We understand the inconvenience and sometimes redundancy patients go through when taking part in our studies. Participants are asked to provide a blood sample every year if possible, so the researchers can study the changes in biologic markers (genes and their products) to find out why some patients are living longer and are healthier than other patients.

“Why do you ask questions like: I am able to reach down deep into myself for comfort, I feel a sense of harmony within myself, and I know that whatever happens with my illness, things will be okay?”

These questions are in the spiritual well-being section. To date, there is limited information on health-related quality of life among long-term lung cancer patients in the following areas: physical, mental, emotional, social, and spiritual well-being. We realize that this section, which was adapted from a published instrument (*FACIT-Sp*), does not apply to every patient. For your information, the following is an article regarding the *FACIT-Sp* instrument. Please let us know if you would like a copy of this article.

Title: Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy–Spiritual Well-being Scale (FACIT-Sp), by authors Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Northwestern University, Center on Outcomes, Research and Education, Evanston, IL 60201, USA. Annals of Behavioral Medicine (2002, Volume 24 Issue 1, pages 49-58).

“How can you use answers to subjective questions to make valid conclusions about cancer?”

The “subjective” nature of the questions and answers on our questionnaire is driven by the knowledge gap in the published literature. We are hoping to help fill this gap by finding some answers to the questions: How are lung cancer survivors doing and what are their needs in health and quality of life? Our research team has been working hard to fill this gap while overcoming the shortcomings of the questionnaire.

“Have any new studies been found, for example, that shows if diet helps prevent cancer or if there are any new products out to prevent lung cancer?”

This is a very good question. Right now, there is not a “chemopreventive” agent that is routinely recommended to prevent lung cancer. However, this is an area of active research (including a large, multi-center trial that is being coordinated by Mayo Clinic Rochester), and we hope to learn more in this area over the next several years.

“How can I learn more about clinical trials available at Mayo Clinic?”

To get more information for specific types of studies, you may:

- Visit Mayo Clinic’s Clinical Trials Web site at <http://clinicaltrials.mayo.edu>.
- Send an e-mail to clinicaltrials@mayo.edu.
- Visit the Patient Education Center in the Siebens Building, Subway Level.
- Visit the Cancer Education Center in the Gonda Lobby.
- Call the Mayo Clinic Research Volunteer Program at 1-800-644-4542.

The following is an abstract from our research, in which many of you are participating. It was presented at the American Association of Cancer Research, Frontiers in Cancer Prevention, November 2006. In order to get definitive answers for these and other questions, we need to continue to enroll patients like you and follow up with you for many years.

Mayo Clinic staff involved in the study include:

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Characteristics of Long-term Lung Cancer Survivors

Background. People who survive beyond five years after a lung cancer diagnosis have been referred to as long-term lung cancer (LTLC) survivors. There currently is limited information about the health status, health behaviors, and quality of life (QoL) of LTLC survivors. In our multiple-dimension study, comprehensive analyses were conducted to capture the most important survival predictors. Our framework encompasses the following five dimensions: health and QoL (e.g., comorbid conditions and spiritual well-being), health-related behaviors (e.g., smoking status and physical activity level), disease and treatment related factors (e.g., adverse effects and disease recurrence), host-related factors (e.g., genotypes of oxidative pathways), tumor related factors (e.g., histology and markers of cell proliferation and apoptosis), as well as demographic variables.

Preliminary Results. Under the disease dimension, patients with any progression or recurrence were almost three times more likely to die within two years than those without progression or recurrence; under the treatment dimension, patients who had surgery were only 33 percent as likely to die within two years compared to patients without surgery; under the physical functioning dimension, patients who reported

being “unable to do work or could only do light work” had a 2.7-5.8 fold higher probability of dying within two years than those who were fully active; and under the host susceptibility dimension, patients with a GSTM1 positive allele (indicative of a higher anti-oxidative function) were four times less likely to die within two years than those with a null type.

Summary. In this initial analysis, we have shown the importance of all five dimensions, with varying magnitude, in predicting survival. New knowledge gained from our study may help lung cancer survivors, their healthcare providers, and their caregivers by providing evidence for establishing clinical recommendations to enhance their long-term survival and health-related QoL.



Meet the Study Coordinator

Sheila McNallan has been working on family studies for several years and is very experienced with the research activities involving patients and families. Her activities include interviewing patients, recruiting family members, coordinating mailings of consent forms, blood kits, medical release forms, and family packets. She also acts as a liaison between several departments that are supporting our research study.



Meet a Nurse Abstractor

Shawn M. Stoddard, R.N., is a research nurse, very experienced in finding relevant information in medical records. She is also responsible for requesting additional medical records outside of Mayo Clinic and death certificates whenever needed.

Thank you!

We know that you make a special effort to volunteer for this research study, and we want to thank you for your continued help!

Please feel free to contact our program coordinator, Sheila McNallan, at 507-266-1065 or 1-800-661-4939 with any questions, comments, or suggestions.



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