January 2012 Vol. 1 Issue 1

### **The Lung Cancer Study Team**

**Diptasri Mandal**, PhD, is the Principal Investigator of the Genetic Epidemiology of Lung Cancer Study. She is also a Professor in the Department of Genetics at the Louisiana State University Health Sciences Center in New Orleans.

**Jill Hutchinson**, BA, is the Study Coordinator.

**Angelle Bencaz**, MSPH, is a Research Associate.

**Emily Nykaza** and **Matthew Haskins** are Visiting Student Interns.

### **Lung Cancer Study Updates**

The information you donated on family health helps us to make important strides and discoveries. We are now one step closer to fully understanding why lung cancer is found more often in certain families.

What is it about certain people that make them more likely to develop lung cancer? Smoking does not fully explain the answer to this question, since some people who have never smoked are also diagnosed with lung cancer. Part of the answer comes from the study of genes. Think of a gene as a book that gives your body instructions on how to work. Everything from the color of your hair to how you breathe comes from the instructions in your genetic library. Our study found that light smokers with a certain variation of genes are as likely to develop lung cancer as heavy smokers with the same gene variations.

You can read the details of our study's findings published in the April 2010 issue of *Cancer Research*. The title of the paper is "A Second Genetic Variant on Chromosome 15q24-25.1 Associates with Lung Cancer."





From left to right: Jill Hutchinson, Diptasri Mandal, Matthew Haskins, guest, Emily Nykaza

#### **Local and National Network**

Our study's goal is to determine the genetic pathways of lung cancer in different populations and subgroups. Through a local surveillance network of 34 hospitals across 24 parishes in Louisiana, we are dedicated to making major contributions to the field of research and to eventually reducing disparity in lung cancer diagnosis. Our study is also part of a network of researchers across the United States called the Genetic Epidemiology of Lung Cancer Consortium (GELCC) (see last page for list of GELCC members).

#### **How the Network Works**

Researchers at each site of GELCC collect data from the study participants. Participants provide us with demographic and smoking history data, as well as biological samples (blood, saliva, or tumor tissue). All donations are securely stored with coded numbers. By collecting data from several sites, researchers can analyze a large database of DNA and behavioral profiles and, ultimately, locate the genes that increase the risk of lung cancer in families that have more than one case of lung cancer.

"Our research has shown that RGS17 is a likely susceptibility gene, but there is still work to be done. The next step is to determine exactly what is happening at the RGS17 site and, after that, to develop a genetic screening test and more focused drug treatments," explains Dr. Mandal.

January 2012 Vol. 1 Issue 1

### **Efforts to Fight Lung Cancer**

Lung cancer research will lead to better prevention and treatment strategies. Currently, it receives fewer dollars in federal funding than other cancers. The Lung Cancer Study continues to be a voice for lung cancer survivors and their families in several ways. We invite you to join us and learn more about local and national efforts to fight against lung cancer.

#### **Local Efforts**

Start lacing your shoes to prepare for a 5 kilometer (approximately 3.1 miles) race! The 4<sup>th</sup> Annual Free to Breathe 5k Run–Walk is planned for March 24<sup>th</sup>, 2012, in Lake Charles, Louisiana. For more information on this exciting event, please contact Jackie Ford at 608-316-3786 or visit the website <u>FreeToBreathe.com</u>.

If you are interested in helping yourself or others quit tobacco, call local non-profit Quit With Us, LA at 1-800-QUIT-NOW or visit them online at <u>quitwithusla.org</u>. You will find new methods and a friendly staff who will happily help you to achieve your goals. Free online counseling is also available.

#### **Shout Out!**

Our research team is proud to acknowledge Dr. Brian Boulmay, one of our collaborating physicians. In August, the American Cancer Society presented him with a Spirit Award at the annual Hope Gala.

#### **National Efforts**

Want to know what is happening around the nation with lung cancer advocacy? Visit <a href="https://www.lungcanceralliance.org">www.lungcanceralliance.org</a> to learn about events, news, and opportunities to support lung cancer causes around the country.

"How do I know lung cancer? Because I lost my mother to this disease four years ago. Like most people, I had no idea about this disease. I didn't think it could happen to young, non-smoking women like my mom."

-Julia Gaynor, Charleston Patch

#### **Support for Survivors and Their Families**

A survivor refers to any living individual with a cancer diagnosis. Below is a list of resources and support services for cancer survivors and their families.

- For cancer information, answers, and support, call the American Cancer Society 24 hours a day, 7 days a week at 1-800-277-2345.
- The Hope Lodge provides free overnight lodging for out-of-town cancer patients seeking care in the New Orleans metropolitan area. Call 1-800-ACS-2345 for more information on eligibility.
- Road to Recovery is a service of the American Cancer Society that provides free transportation to and from appointments for cancer patients. Call 1-800-227-2345 to find out if Road to Recovery is available in your community.
- You may have many questions after getting a cancer diagnosis. I Can Cope online classes are a free, self-paced option to learn more about cancer. You can take them in the privacy of your home or location of your choice at a time that is convenient for you. To take an online class, go to www.cancer.org/onlineclasses.

January 2012 Vol. 1 Issue 1

#### **Collective Efforts in Research**

The National Institute of Health (NIH) manages the Central Database-Repository. The Central Database-Repository is similar to a library for highly qualified scientists. For the purpose of improving researchers' access to biological data and strengthening ability to make significant scientific discoveries, the Repository stores de-identified genetic information from NIH-funded studies. When any researchers outside our study team want to access the data, he or she will submit an application to the NIH for approval justifying their need to access the data. Names and other identifying information are never given to the Repository.

Our study has been funded by the NIH for over 15 years. During the past year, you may have received a form asking for consent to store your previously collected biological data in the Repository. If you would like to be re-mailed this form or prefer more information, please complete and send in the sheet attached to this newsletter or give us a call at our toll-free number.

#### Welcome to the Study

Our work could not continue without the dedication and commitment of Louisiana's physicians and health care professionals. We are excited to welcome the following members to our network of collaborating hospitals:

- Ochsner Cancer Institute
- Leonard Chabert Medical Center

#### Goodbye for Now!

Jill Hutchinson will be greatly missed as she transitions out of her position of Study Coordinator. For over 5 years, Jill has worked tirelessly to serve the goals and objective of the study. We are thankful for her service.

### Don't be a stranger!

Please continue to update us by calling 1-888-720-7757 or emailing <a href="mailto:LungCaStudy@Isuhsc.edu">LungCaStudy@Isuhsc.edu</a> with questions, updates, or concerns.

#### Who is eligible for the Lung Cancer Study?

 You or your family may participate in the study if your family has two or more cases of lung cancer.

OR

 You may serve in a control group if you have neither lung cancer nor a family history of lung cancer.

We maintain patient privacy and confidentiality. If eligible for the participation of entire family, no one in your family will be contacted without your knowledge and approval. Family participation is not needed for the control group.

#### **Breath of Fresh Air**

#### **Nondiscrimination Law**

The Genetic Information Nondiscrimination Act of 2008 protects people from discrimination based on their genetic information. This federal law prohibits insurance companies, employers, and other entities from using an individual's genetic information to make decisions or judgments. This powerful law provides specific guidelines and safety measures so that individuals can participate in research with total confidence.

#### **New Legislation**

The Lung Cancer Mortality Reduction Act is new legislation aimed at preventing lung cancer and reducing the amount of deaths to lung cancer. It calls for reforms to address all aspects of lung cancer at the state and federal levels. In the last two months, more members of both Houses of Congress have signed on as supporting this legislation.

We express our sincere appreciation if you have participated in the Lung Cancer Study. Thank you for taking the time.

The Lung Cancer Study Team

January 2012 Vol. 1 Issue 1

The Lung Cancer Study is part of the national network Genetic Epidemiology of Lung Cancer Consortium, GELCC:

Dartmouth-Hitchcock Norris Cotton Cancer Center

Karmanos Cancer Center

LSU Health Sciences Center-New Orleans

Mayo Clinic and Foundation

Medical College of Wisconsin

National Human Genome Research Institute

University of Cincinnati

University of Toledo Medical Center

#### Our local network of collaborators:

- Abbeville General Hospital
- Abrom Kaplan Memorial Hospital
- Acadia–St. Landry Hospital
- Acadian Medical Center
- American Legion Hospital
- Bunkie General Hospital
- Dauterive Hospital
- Doctor's Hospital of Opelousas
- Earl K. Long Hospital
- Franklin Foundation Hospital
- Iberia Medical Center
- Lady of the Sea General Hospital

- Lafayette General Medical Center
- LSU Lallie Kemp Regional Medical Center
- Medical Center of Louisiana–New Orleans
- Mercy Regional Medical Center
- Opelousas General Hospital
- Our Lady of Lourdes Medical Center
- Pointe Coupee General Hospital
- Prevost Memorial Hospital
- Regional Medical Center of Acadiana
- River Parishes Hospital
- St. Charles Parish Hospital
- St. Helena Parish Hospital

- St. James Parish Hospital
- St. Landry Extended Care
- St. Martin Hospital
- Savoy Medical Center
- Southpark Community Hospital
- Teche Regional Medical Center
- Thibodaux Cancer Care
- University Medical Center–Lafayette
- Washington–St. Tammany Medical Center
- Reliapath LLC
- Louisiana Tumor Registry



**Health Sciences Center** 

**NEW ORLEANS** 

School of Medicine Department of Genetics 533 Bolivar Street New Orleans, LA 70112

### **Participant Updates**

We always like to hear from the people who participated in the Lung Cancer Study. News about remission is rewarding to us on a personal level, and we sincerely hope that your family stays healthy and cancer-free. However, for the continued success of our research, it is important that you keep in touch with us and let us know about any newly diagnosed cases of lung, throat, or other types of cancers that are found in your family. Working with families in obtaining the most accurate information is a vital part of cancer research. The purpose of this form is for updates or changes in the health status of your family that you think we should know about.

#### To communicate with us:

• Please fill out and send in this form to let us know of any updates.

Dear Lung Cancer Study Team,
Here is some news about our family:
- <del></del>
Sincerely,
Print Full Name:
Your Address:
Your Phone Number(s):
Name of person this newsletter was sent to:
Please check the box if you would like to be on our list to receive regular correspondence from us (e.g. newsletters).
Please mail to: To call or email:



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Toll-free number: 1-888-720-7757 LungCaStudy@lsuhsc.edu