



FACT SHEET
THE STACEY SCOTT LUNG CANCER REGISTRY
AT ROSWELL PARK CANCER INSTITUTE

- Roswell Park Cancer Institute (RPCI)—America’s first cancer center and an NCI-designated comprehensive cancer center—has initiated and is leading a collaboration of 11 leading cancer research institutions to create the first common registry of biological samples and data on patients considered at high risk for lung cancer. The initiative will be known as The Stacey Scott Lung Cancer Registry.
- All data comprising the Stacey Scott Lung Cancer Registry will be housed at Roswell Park Cancer Institute, headquartered in Buffalo, New York, for analysis.
- The primary goals of this registry are to help scientists describe the natural evolution of premalignant lesions that may lead to lung cancer, including the rate of progression/regression/persistence and speed of change over a 5-year period; to determine the role that these lesions play in the genesis of the disease; and to provide a critical source of comprehensive data for studies seeking to improve early detection and chemoprevention strategies.
- **Registry partner institutions are:**
 - Roswell Park Cancer Institute (headquartered in Buffalo, NY)
 - University of Colorado Cancer Center (Aurora, CO)
 - BC Cancer Agency (Vancouver, BC, Canada)
 - Fox Chase Cancer Center (Philadelphia, PA)
 - Franklin Square Hospital Center (Baltimore, MD)
 - Mayo Clinic (Rochester, MN, Jacksonville, FL, and Scottsdale, AZ)
 - New York University Medical Center (New York, NY)
 - Abramson Cancer Center of the University of Pennsylvania (Philadelphia, PA)
 - The Ohio State University Medical Center (Columbus, OH)
 - The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University (Baltimore, MD)
 - University of Chicago Cancer Research Center (Chicago, IL)
 - Vanderbilt University Medical Center (Nashville, TN)
 - Academic Hospital Vrije Universiteit (Amsterdam, The Netherlands)

A representative from the National Cancer Institute also will play an advisory role.
- Co-directors of the registry are Mary Reid, PhD and Alex Adjei, MD, PhD of Roswell Park Cancer Institute. Dr Reid, an Associate Professor in the Department of Epidemiology, Division of Cancer Prevention and Population Sciences, is one of the founders of the registry and will direct the project. Her research interests focus on the early detection and chemoprevention of lung and head and neck cancers, and the evaluation of genetic/epigenetic biomarkers of early lesions in high-risk populations. Dr Adjei is RPCI’s Senior Vice President of Clinical Research, Chair of the Department of Medicine, and the Katherine Anne Gioia Chair in Cancer Medicine. He is respected across the country for his innovative work in the fields of translational research, drug development and thoracic oncology.
- Principal investigators from each participating institution will recruit and screen those considered at high risk for lung cancer, including smokers, persons with chronic obstructive pulmonary disease (COPD), persons who have been exposed to asbestos and those who have previously had lung cancer. Clinical evaluations (including the results of bronchoscopies, spiral CT (SCT) scans and chest X-rays), and bronchial biopsy tissue specimens, blood, and sputum samples will be collected, as will data about participants’ medical histories, diets, and lifestyles. These patients will be monitored over 5 years of clinical follow-up. Using the registry, the rate of

pre-malignant lesion progression/regression/persistence will be calculated. Rates of change and persistence will be based on repeat clinical evaluations and will be calculated for the person (or whole field) and on a lesion-specific basis.

- The Stacey Scott Lung Cancer Registry at RPCI will help determine how genetic and protein biomarkers combine with epidemiological risk factors such as smoking and family history to predict the natural progression of these lesions into the development of lung cancer. This will be accomplished through the development of cooperative research projects utilizing the registry's data..
- The registry also will offer to researchers for the very first time a large and comprehensive pool of high-risk individuals for lung cancer who may be interested in volunteering for new chemoprevention clinical research studies to help create new and better treatment interventions. (For example, two clinical research studies coordinated by Roswell Park Cancer Institute and the University of Chicago are now in progress to administer calcitriol—a vitamin D compound shown to significantly enhance the antitumor effectiveness of certain drugs—to high-risk persons suffering from early-stage non-cancerous lesions.)
- Lung cancer is the leading cause of cancer-associated deaths in the United States and worldwide. Approximately 1.2 million people are diagnosed with lung cancer each year. More people die from lung cancer than from the four other major cancers combined (breast, colon, prostate, and cervical). The overall 5-year survival rate for lung cancer has remained at only 15% for the last 25 years, despite the integration of new chemotherapy agents into surgical and radiotherapy treatments.
- Approximately 25% of the US adult population actively smokes, while 40–50 million Americans are former smokers. Although reduction of cigarette smoking helps to reduce the risk of lung cancer, the risk for former smokers does not decrease for decades after smoking cessation. Currently, former smokers represent half of all new cases of lung cancer.
- The registry at RPCI is named in honor of Stacey Scott, a former resident of Tonawanda, New York (a suburb of Buffalo, NY). As an active, athletic, non-smoking young woman, Stacey would not have been considered at high risk for lung cancer. Yet, in May of 2005, after Stacey experienced fatigue and chest pain, tests confirmed the presence of malignant lung tumors. Stacey lost her battle with lung cancer on September 17, 2005, at the age of 38. Start-up funding for the initiative has been provided by Stacey's husband, William Scott, Jr., family members and friends, including the Scott Danahy Naylor insurance agency.
- Non-smokers like Stacey Scott represent approximately 10 to 15% of all lung cancer diagnoses. Among that group, women are two to three times more likely than men to get the disease. Conclusive data is not available on why, but hormones, second-hand smoke, diet and air pollution all are believed to be factors.
- Roswell Park Cancer Institute, headquartered in Buffalo, New York, is a leader of past cancer breakthroughs, including the first use of chemotherapy, the PSA test for prostate cancer, and photodynamic therapy (PDT). RPCI also has significantly contributed to the field of smoking-related cancer research. The Institute's cancer registry expertise began with the establishment of the international Gilda Radner Familial Ovarian Cancer Registry in 1981—a database of information on over 1,800 families from across the world with familial ovarian cancer. Information gleaned from the Gilda Radner Familial Ovarian Cancer Registry helped researchers identify the link between BRCA1 and BRCA2 and ovarian cancer in 1994.

Principal media interviews and video b-roll available with:

- Alex A. Adjei, MD, PhD / Roswell Park Cancer Institute
Co-Director (Science) of the Stacey Scott Lung Cancer Registry
- Mary Reid, PhD / Roswell Park Cancer Institute
Co-Director (Operations) of the Stacey Scott Lung Cancer Registry
- William Scott, Jr.
Husband of the late Stacey Scott
- **Additional interviews available with participating scientists from the 13 collaborating centers involved in the registry.**