

Southern Community Cohort Study

THE SOUTHERN COMMUNITY COHORT STUDY NEWSLETTER IS AN ANNUAL PUBLICATION FOR STUDY PARTICIPANTS.

Welcome to the latest edition of the Southern Community Cohort Study (SCCS) newsletter. We hope this newsletter finds you happy, healthy, and ready to participate in more SCCS-related studies!



The focus of this newsletter is to update you on the progress of the SCCS as well as to share information about upcoming research studies in which you will be able to participate.

The SCCS reached a major milestone in 2009. We began recruiting participants in March of 2002 and at the end of September 2009, we enrolled our last participant. It has been an incredible journey, and we are pleased to announce that 86,000 Southerners, like you, are SCCS participants and are helping researchers find the causes of cancer and ways to prevent cancer.

Since November 2008, the SCCS has been re-contacting participants through a short mailed questionnaire and/or telephone survey. We want to know how you are doing and if there have been any significant changes to your health. Some of you may already have heard from us. If you receive a questionnaire in the mail or a telephone call from us, please take a moment to answer the questions. If you have questions about the survey, call us at our toll-free number, 1 (800) 734-5057.

This newsletter is our way of keeping in touch and we love hearing from participants, so if you have ideas and stories for future newsletters or you have moved and your telephone or address has changed, please call us at 1 (800) 734-5057.

Thank you for your involvement in the SCCS. You are a valuable part of this study and are helping to fight cancer in the Southeast!

Your Study Team Leaders,

Dr. William J. Blot

Dr. Margaret K. Hargreaves

Dr. Lisa B. Signorello

SCCS Receives Supplemental "Stimulus" Funding from NIH to Study Cancer Survivors

Recognizing the importance of the SCCS as a resource to provide new information about the causes and outcomes of cancer, as well as to help inform the health care debate in the United States, the National Institutes of Health (NIH) recently provided additional funds to expand our research activities. The extra American Recovery and Rehabilitation Act (ARRA) funds will help several new activities to take place.

Beginning early in 2010, we will be calling participants who have been diagnosed with cancer since enrolling into the study. For persons with little or no health insurance, information on the paths they have followed in getting a cancer diagnosis and receiving appropriate treatment and follow-up care is lacking. Since a number of SCCS participants have limited health insurance (sometimes no insurance at all), the new interviews will provide some of the first detailed data on the steps taken, and the barriers faced, in this process. From this information we hope to learn more

about the gaps in America's healthcare system, and we hope to be able to suggest new approaches to improve cancer care for everyone.

During the new interviews we will also ask participants about the hospitals where their cancer was diagnosed and request permission to obtain copies of medical records, as well as tumor tissue specimens which the hospitals will have kept. The records we obtain will then be reviewed by our medical experts for the diagnostic and treatment details, and the tumor tissue will be stored at our SCCS Vanderbilt University labs and used for research, including genetic and molecular studies that may help us better understand how cancer starts and progresses.

If you are a cancer survivor and you are called by our research team, we hope you will take the time to join in this new survey. Your time and participation will greatly help us in our fight to conquer this illness, which causes suffering among far too many Americans.

Check Your Mail

In the next one to two weeks another group of SCCS participants will receive a follow-up questionnaire in the mail. You may also hear from us by telephone. The questionnaire is short and will give us an update on your current health status. You will receive \$10 for your participation.

We want to send a special thank you to the more than 29,000 participants who have already completed the follow-up questionnaire by mail or telephone. Following participants over time is a very important part of this study, and the SCCS study team hopes that, in the coming years, you will continue to share information about your health and lifestyle.

Thank you for your participation in the follow-up and commitment to this study.



An SCCS Research Update

The SCCS closed recruitment into the study on September 30, 2009 and began the phase of follow up of study participants. In any large population group like ours, a number of people will develop cancer and other diseases and a number of people will die. We will identify these occurrences and calculate rates of disease occurrence and mortality according to various participant characteristics, such as age, gender, race and lifestyle and medical factors. By comparing rates of cancer by various characteristics (for example, by weight comparing underweight vs. normal weight vs. overweight vs. obese), we can see whether such classifications are predictive of cancer risk. Researchers will then try to determine how and why such associations exist and what can be done to lessen the impact of the factor on cancer occurrence and outcome. Our scientific study team will be using the information you provided us to improve the understanding of the cancer process, with the ultimate goal of lowering the burden of this disease on current and future generations.

The major cancer among women is breast cancer. Several SCCS research projects aimed at understanding what triggers breast cancer and how it progresses are planned. Towards this aim, we are currently working on two sub-studies, for which we will be contacting some women.

A Focus on Breast Density

Recent studies have shown that women with “dense” breasts (breasts with a lot of ductal and connective tissue, rather than fat) are more likely to develop breast cancer. A mammogram is one screening tool used to find out if a woman has dense breasts because it is difficult to determine that on her own. A small number of women in the SCCS who reported having a mammogram within 2 years of joining the study have been selected at random

for a pilot study seeking permission to view their mammograms. SCCS scientists are not checking the mammograms for cancer. They are evaluating the normal features of the mammograms, specifically the density of women’s breast tissue, which can vary by racial or ethnic background, to better understand how these features may be related to future breast cancer risk. Our researchers hope that focusing on breast density will lead to improved strategies to catch cancers early and even prevent them from occurring.

Participation in this study is voluntary and requires having your mammograms reviewed for only this purpose. The study involves the completion of a short survey and a medical release form and returning these documents along with a signed consent form to our study team. Participants will be compensated for their time.

Attention Breast Cancer Survivors

Although it is known that people experience physical and functional problems (pain, fatigue, swelling, etc.) with breast cancer, there is limited information on whether the problems differ by racial or ethnic background and socioeconomic status. Little is also known about how women recover after breast cancer treatment.

Women who have been diagnosed with breast cancer are currently being contacted to help researchers understand what issues with physical functioning and well-being are common among breast cancer survivors. Participation in this study involves the completion of a short survey by telephone. Participants will be asked questions regarding their medical history, their breast cancer experience, and how easy - physically and mentally - it is to do everyday activities. With the information breast cancer survivors share, researchers hope to develop new ways to help women get better physically after completing cancer treatment.

SCCS Telephone Center

As noted on the first page of this newsletter, we will be mailing short follow-up questionnaires to many of you. We want to know how you are doing and if there have been any major changes to your health. Getting regular updates on our participants’ health will help us better understand the roles that genes and the environment play in the development of cancer.

We prefer that you send back a completed paper questionnaire, but if we don’t receive the questionnaire, we will try to call you. One of the interviewers from our Call Center at Vanderbilt University in Nashville, Tennessee will call you so that you can complete the short questionnaire over the phone. You will receive \$10 for completing the follow-up questionnaire.

The Vanderbilt Call Center is a busy place with many different kinds of projects, not only for the SCCS. Over 143,000 calls were placed for the SCCS from March 2009 through January 2010.

Keeping participant contact information up-to-date is a very important, but often difficult, part of the study. The Call

Center is contacting the friends and families of study participants when they find that a participant’s contact information is outdated. But you can call us too. If you have moved since enrolling in the study, call us, toll free, at 1 (800) 734-5057, and give us your new address and telephone number so we can update our records and stay in touch with you.

Following participants over time is an important part of this study. We need your participation (and current contact information!) to make it a success.

At right: Interviewers at Vanderbilt Call Center



Slimming Down a Family Favorite

Meatloaf is a regular feature on many dinner tables. It uses simple and affordable ingredients, and it is easy to prepare. For the most basic meatloaf, you only need ground meat, a few seasonings, and a binder (breadcrumbs and/or eggs) to hold it all together. Follow these simple steps to make a healthy, low-fat meatloaf a family favorite.

First, choose the main ingredient – the meat. Beef is a good source of protein and vitamins and minerals such as iron, zinc, and B12. Turkey and veal are rich sources of lean protein and B vitamins but are not high in iron. Avoid fatty ground meats such as “85% lean” ground beef because all of the fat will end up in your final product. Choose leaner cuts of meat such as 92% or 96% lean beef or ground turkey. Using lean meat, with a small amount of ground pork or veal, results in a moist, healthy meatloaf.

Next, add the binder. Use a ½ cup of dried breadcrumbs for every 1½ pounds of meat. Using egg whites reduces the fat in your meatloaf and holds it together just as well as the whole egg.

Finally, add seasonings to your meatloaf. Because lean cuts of meat are used in lower fat meatloaf, add slightly higher amounts of liquid flavorings like ketchup and salsa to keep the meatloaf moist.

Meatloaf leftovers can be crumbled in a taco or mixed with tomato sauce for a quick meat sauce for pasta.

Santa Fe Meatloaf

(adapted from *Cooking Light*)

Ingredients

- cooking spray
- ½ cup onion, chopped
- ½ cup red bell pepper, chopped
- 1 teaspoon chili powder
- 1 teaspoon ground cumin
- 4 garlic cloves, minced
- 1½ pounds ground turkey
- ½ cup dry breadcrumbs
- 1 cup mild chunky salsa, divided
- 1 teaspoon dried oregano
- 2 large egg whites
- 1 cup reduced-fat shredded Mexican-style four cheese blend



Becky Luigart-Stayner

Directions

1. Preheat oven to 350°.
2. Heat a large nonstick skillet over medium-high heat and coat with cooking spray. Add onion, bell pepper, chili powder, cumin, and garlic. Sauté until onion is tender. Remove from pan and allow mixture to cool slightly. Combine onion mixture, turkey, breadcrumbs, ½ cup salsa, oregano, and egg whites in a large bowl.
3. Place half of turkey mixture in an 8 x 4-inch loaf pan coated with cooking spray. Arrange cheese over top, leaving a ½-inch border around outside edges. Arrange remaining turkey mixture over cheese, pressing edges to pack. Spread the remaining ½ cup salsa over top of meatloaf.
4. Bake for 45 minutes to 1 hour. Remove from pan, cut into slices and enjoy!

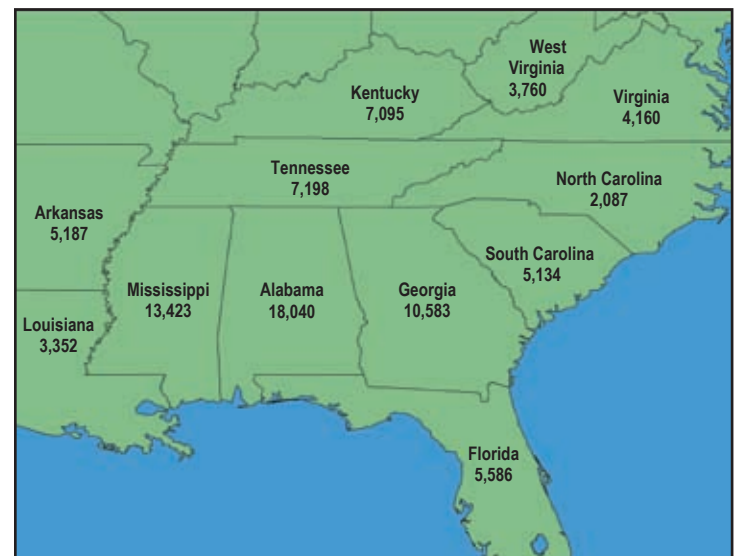
Study Snapshot

You are one of more than 86,000 participants across 12 Southeastern states who volunteered to join the Southern Community Cohort Study (SCCS). You are part of a landmark research study that hopes to address many unresolved questions about the causes of cancer and find ways to help prevent and reduce the burden of cancer. Two-thirds of this unique group of participants is African-American.

You completed a survey, either in-person at a community health center or by mail, and answered questions about health and lifestyle factors that may affect the risk of cancer and other diseases. Biological samples were collected from approximately 90% of SCCS participants. Almost 40,000 participants donated a blood sample, 40,000 a mouth/saliva sample, and nearly 24,000 donated a urine sample.

SCCS participants – Who are you?

	Men	Women
Number of Participants	34,948	51,075
Race/Ethnic Background		
African-American	23,164 (66%)	32,412 (63%)
Non-Hispanic White	9,918 (28%)	15,460 (30%)
Other	1,866 (5%)	3,203 (6%)
Average Age (years)	52	52
Average Height (inches)	5' 10"	5' 4"
Average Weight (pounds)	196	188
Smoking		
Current Smoker	52%	34%
Former Smoker	25%	22%
Never Smoked	23%	45%



Total number of SCCS participants by state.

Protecting Participant Privacy

With recent news reports about stolen computers and stories of identity theft and other breaches in confidentiality, you may wonder how the SCCS keeps your personal information safe.

In addition to following the guidelines set by the Health Insurance Portability and Accountability Act (HIPAA), the SCCS has always taken extra steps to protect the privacy of participants. Data and biological samples are never labeled with any personal information, such as name or social security numbers. Instead, all data are identified by ID number only. The information provided on all questionnaires (mailed, in-person, and over the telephone) and the results of laboratory analyses are confidential and not shared with family members, employers, insurance companies or other third parties. However, research data are shared with scientists we partner with to conduct some anonymous studies of cancer or other diseases. These data do not contain your name or other identifiable information.

Occasionally, study team members will be calling participants. The purpose of these phone calls is to collect information on your health, to update addresses and phone numbers, or to request consent to access additional health information, such as medical records and tumor tissue samples, for SCCS-related research studies.

Only a few members of the research team have access to your personal contact information for the purposes of mailing you

newsletters or follow-up questionnaires, and before reviewing pertinent medical records, written permission from study participants is always obtained. In summary, we protect the health information of participants as we would protect our own personal information.

If you have any questions or concerns regarding the security of the SCCS data, please call our toll-free number at 1 (800) 734-5057. Your confidence in the SCCS is extremely important to us, and we promise to work hard to maintain that trust.

Personal Information



During the course of this study, we have found some abnormal test results when conducting our laboratory research. We remind you that we do not contact participants regarding any individual results from the study. Therefore, please remember to get your yearly check-up and all recommended health screenings.

ADDRESS SERVICE REQUESTED

1455 Research Boulevard, Suite 550
Rockville, MD 20850



Presorted
First-Class Mail
U.S. Postage
PAID
Rockville, MD
Permit No. 800