With your help, the Quilt Study has made excellent progress. Since we began interviewing in late May of 2005, we have collected interviews for 1,435 of the study’s 2,336 cohort members. We very much appreciate the time each of you took to complete the interview and the effort you made to recall treatment and health events, some of which occurred many years ago. Your gracious participation demonstrates your commitment to furthering the research and understanding of breast cancer.

Thanks, also, to those of you who have returned completed consent forms for medical and pharmacy record review and/or tumor tissue acquisition. These forms are sent to participants after we have had the opportunity to review the completed Phase I Quilt interview.

While signing these consents is voluntary, obtaining medical record data and tumor tissue on as many women in the cohort as possible is critical to the success of the Quilt Study. The following is a description of the Quilt Study consent forms:

- **Provider Identification Form:** This form is pre-filled with names of hospitals, clinics, and physicians you reported in your interview. Please review it for accuracy. Add hospitals where you had breast cancer treatment, doctors you consulted with or who provided care for your breast cancer, and any doctors who provide your regular care, who are missing from this list.
- **Medical Record Review:** Reviewing medical and pharmacy records is one of the best ways we have of collecting detailed treatment and health history data, but we can only do so with your consent. Indeed, many of you remarked during your interview that we should review your medical records—and, with your consent, we will begin doing so in late Spring 2007.
- **Tumor Tissue and Pathology Review:** Almost all CARE and PACE cohort members gave consent for collection of their breast cancer tumor at the time of their original interview. The Quilt Study is now seeking that consent from EMF cohort members. Collected tumor samples will be analyzed for proteins and other features to further our understanding of their relation to risk of recurrence and/or treatment response.

### Authorization to Use and Disclose Health Information
A copy of this completed release (which addresses the security and privacy of health data) is needed in addition to a consent form when requesting either medical records or tumor samples.

- **Other Locating Information:** Providing the information requested on this form is very helpful to us if we have difficulty contacting you for Phase II of the study. As with all participant and study data, this information is kept strictly confidential and is accessible only to Quilt Study staff.

If you have questions about the consent forms described above, or have received your consent forms but have misplaced them, please call the study manager, Cecilia O’Brien at (206) 667-4630, or toll free at (866) 352-9525.

### What’s Next: Phase II

As you may recall, the Quilt Study is a two-phase research project. We are now inviting women who completed the telephone interview in Phase I to continue their participation in Phase II by completing a second telephone interview. This shorter update asks primarily about health events, medication use, and lifestyle factors since your first Quilt interview. It has fewer questions and covers a shorter time period than the first interview, it should take about 20 minutes to complete. Therefore, you have the option of completing this telephone questionnaire when the interviewer calls you, or you may schedule the interview for a later time at your convenience.

Obtaining completed interviews from as many women in the study cohort as possible is vital to the success of the Quilt Study. As the cohort is comprised of previously interviewed women who were diagnosed with breast cancer within specified dates and at specified ages within King, Pierce, and Snohomish counties, we cannot add women to the study who do not meet these criteria. Therefore, we will continue to seek cohort members who have not yet completed their first interview even as we enter Phase II.

We're on the Web at [www.fhcr.org/science/phs/quilt](http://www.fhcr.org/science/phs/quilt)

Here you’ll find an overview of the study, study newsletters, previously published article from the EMF, CARE and PACE studies, and links to other breast cancer sites our participants might find of interest.
Other Quilt Study Projects: When a cohort member is too frail due to health or memory issues to participate on her own, we seek a close family member to complete a modified version of the questionnaire. To demonstrate the validity of information obtained in this manner, we are conducting a small Reliability Study. In September 2006 we mailed to randomly selected cohort members who had already completed the first Quilt interview and asked them to participate by identifying one or more individuals, preferably a close family member, whom we could contact. This individual would be mailed a letter describing the Reliability Study and invited to participate by completing a “mock proxy” telephone interview.

Although a number of cohort members and their “proxy” have already participated, we will continue recruiting until we reach our participation goal. If you received a letter about the Reliability Study and have not responded, your interviewer will discuss this with you when she contacts you for Phase II. You may be included in the next random selection group, in which case you will be contacted later this year. While participating in the Reliability Study will greatly benefit our research, your participation is voluntary and you may decline the Reliability Study and still remain a participant in the Quilt Study.

Study Results: After the data collected in both Phase I and Phase II of the Quilt Study are reconciled and analyzed, we will send each participant the results of our key study objectives. While data collection will continue through 2008 and the analysis process for this large a study will be challenging, we are eager to share our findings with you as soon as possible.

Contacting Us

If you have any questions or concerns about the Quilt Study, please call the study manager, Cecilia O’Brien. When calling after hours, please leave a message including your name, phone number, and the best time to reach you at that number.

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866-352-9525 (toll free)

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Program Assistant: Vickie Blakey

Interviewers: Susan Ellingson; Eileen Louie; Georgene Ranney

Phlebotomist: Kevin Leach

Quilt Study: A Review

The Quilt Study is investigating outcomes in women diagnosed with breast cancer in middle age or older. Very little research has been done to explore why some of these women experience a recurrence of their cancer while others do not. To address this need, the National Cancer Institute awarded the FHCRC a five-year grant to study factors that may affect the risk of recurrence in women diagnosed with breast cancer at ages 45-79. The Quilt Study seeks to:

- Determine if selected exposures and lifestyle factors, both before and after diagnosis, increase or decrease the risk of recurrence;
- Investigate how exposures before diagnosis relate to specific tumor characteristics as a means to identify biologic pathways of disease progression; and
- Evaluate how selected proteins and other factors in tumor tissue, such as estrogen and progesterone receptors (ER/PR), relate to the risk of recurrence.

The best way to obtain the data needed for this study was to combine the participants and data from three studies conducted at the Center between 1993 and 1999: The Electric Power and Risk of Breast Cancer Study (EMF), the Women’s Contraceptive and Reproductive Experiences Study (CARE), and the Puget Sound Area Breast Cancer Evaluation Study (PACE). Our name, the Quilt Study, represents the merging of the eligible women, such as you, from these three previous studies into a new, larger study group or “cohort”. Collectively, the data from the original studies, the Quilt Study interviews, medical and pharmacy record review, and tumor tissue analyses, will create an important resource for our investigators as they seek answers to why some women experience a recurrence of breast cancer.

All information collected in the Quilt Study will be kept strictly confidential as provided by law. Our focus is on population-level research and, therefore, analyses are only relevant at the group level. Please see the Quilt Study Consent for additional information about the study and your rights as a research participant.