



PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

SPRING 2007

Creating a Landmark Study

Larry Kushi, ScD, Principal Investigator

First and foremost, on behalf of the investigators and staff of the Pathways Study, I would like to express our sincerest thanks for participating in this study. We know that there have been many changes in your life since your breast cancer diagnosis. We are grateful that, despite these circumstances, you have agreed to share your experiences with us and make the Pathways Study a part of your life's journey.



Back row (L to R): Christine Bonnell, Sarah Krathwohl, Becky Rogot, Marilyn Kivan, Keren Stronach, Larry Kushi; Front row (L to R): Josh Ergas, Geraldine Carrillo, Rosa Hippler, LaVallé Clark, Paola Taranta

When we first proposed the study to the National Cancer Institute, we were struck by how little information was known regarding the role of diet or other lifestyle factors in cancer prognosis. We felt strongly that the lack of research attention to these factors in this setting

needed to be addressed in a manner that could provide real information for women with cancer, their families, and their caregivers.

At the same time, we felt that we wanted to respect the unique individual circumstances of each study participant with breast cancer, and, in the absence of clear information, not suppose that a particular path was more beneficial than another. Thus, we proposed, and received funding, to conduct this prospective study in which we are collecting information on what you are doing, but are not asking you to follow a specific intervention or a specific course of action.

This particular study design involves a partnership between study participants and the research team. We are counting on you to provide accurate information about what foods you are eating, what supplements you are taking, what alternative therapies you may be pursuing, or what you feel about your experiences. This information, which we will be collecting every 18 months (and also at six months after your first

Your Contribution

—What Does It Mean?

Your continued participation in the Pathways Study is essential to improving our understanding of lifestyle factors that may influence survival. The follow-up questionnaires are just as important as the questionnaires that you answered in the initial interview. This is a survivorship study, so tracking your lifestyle and the changes you make over time is essential. As you know, we are looking at diet, physical activity, use of alternative and complementary care, and quality of life factors. We will be assessing patterns of behavior and teasing out which activities may have an impact on survivorship. In our analysis, we will be comparing subsets of women to see if particular groups benefit from specific lifestyle habits. For example, it may be possible that a particular diet may be more important for young women compared to older women, or for women who have estrogen receptor positive tumors compared to estrogen receptor negative tumors. Accurate information about your lifestyle patterns, along with information on your treatment choices and other characteristics, will help us examine what factors may influence survivorship. Thanks for taking the time to respond to the questionnaires, being part of the Pathways team, and making this study possible!

Additional Studies which Build on the Pathways Study: Lymphedema and Racial Disparities

Two additional studies have been funded that build on the main Pathways Study. Women who are enrolled in Pathways have an opportunity to participate in both of the studies described below. Certain eligibility criteria must be met in order for women to participate in the Racial Disparities study.



Communicating with Your Doctor *by Keren Stronach, MPH*

A relationship with a physician is a very personal one, and must be built on communication and trust. In choosing a doctor, the “chemistry” between the two of you must work. You must be able to trust, confide in, and tell your doctor about your health problems and symptoms. Your physician, in turn, should listen to you, give you options and feedback, and have your best interest in mind. Here are some things you can do to help build an effective partnership.

BE ORGANIZED

Doctors are busy people, so you need to know how to get the most from their limited time with you. Being organized and focused on the main issues you want to address will help tremendously. Think about questions you want to have answered in advance. Write those questions down and prioritize them, highlighting the main 3 or 4 issues that you want to discuss. Send a list of those questions to the physician in advance, if you think that would be helpful.

KEEP GOOD RECORDS

Provide your doctor with clear, accurate information about your symptoms and medications so that he or she can have the necessary information to accurately diagnose your condition and prescribe the appropriate treatment. Keep a list of the medications and supplements you are taking, a list of recent symptoms and the dates at which they occurred, and a list of names of the other doctors you are seeing.

The better you are able to communicate your needs and concerns to your doctor, the better he or she can respond.

SET THE TONE

Let your doctor know how much or how little you would like to participate in the decision-making process and whether you want very detailed information about all the treatment options or just general information. Also, be sure to inform your doctor of any cultural beliefs that may affect your treatment choices or preferences.

BE ASSERTIVE

There is virtually nothing that is more important than your health. Just as you would not purchase a car without asking questions, you should not be afraid to ask your doctor questions. If your concerns are not addressed to your satisfaction, you may need to be assertive. Let your doctor know that you still have questions and ask if an additional appointment can be set up, whether the appointment can be extended or if there are other staff members who can address your questions.

BE UNDERSTANDING

It is important to balance assertiveness with respect and understanding. Although it is important to let your physician know your needs or to voice dissatisfaction with your

communication, it is equally important to voice appreciation for the positive aspects of your communication and treatment! Also, keep in mind that many of your questions can be addressed by a nurse, a social worker or another staff member.

KNOW HOW TO KEEP IN TOUCH

Before you leave the appointment, find out what is the best way to keep in touch between office visits, whether through the nurse, via email or by leaving messages at the front desk.

IN A NUTSHELL ...

Before Your Visit

- Take a list of specific questions that you want answered to your appointment, making sure to list the most important ones first.
- Familiarize yourself with your medical history, so that you can convey it concisely to your physician. Writing out a brief synopsis that can be handed to a new physician can be helpful and can save time.
- Keep a symptom diary to track your symptoms and concerns. Convey these clearly to your physician.
- Keep a list of the medications and supplements you are taking, including dosage, and share any changes in what you are taking with your physician.
- Notify your oncologist or the scheduler ahead of time if you think the questions you have will take an extended period of time to answer. This will allow the staff to arrange the schedule accordingly.



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Additional Studies which Build on the Pathways Study: Lymphedema and Racial Disparities *Continued from Page 1*

Racial Disparities in the Initiation and Intensity of Adjuvant Therapy for Breast Cancer.

This study, funded by the Department of Defense and led by researchers at Columbia University, is looking at a sub-sample of women enrolled in the Pathways Study. This study focuses primarily on differences in breast cancer treatment among women from different racial and ethnic backgrounds, why these differences exist, and the effect of these differences on survival. The Pathways Study will recruit a few hundred women for this study. Researchers at Columbia University will administer a baseline questionnaire and two follow-up questionnaires by



telephone. If your breast tumor is hormone-receptor positive, you will be contacted several more times over the course of the study for a 15 minute interview and asked to share your

experiences with hormonal therapy for the treatment of breast cancer.

Natural History and Cost Analysis of Lymphedema Secondary to Breast Cancer.

The American Cancer Society (ACS) has provided funding that enables us to research the natural history of lymphedema after breast cancer surgery, examine medical and behavioral risk factors of lymphedema, and estimate costs of treating lymphedema within Kaiser Permanente of Northern California.

Participation in the lymphedema study involves a brief self-administered questionnaire during the baseline interview and a set of questions as part of the mailed Pathways follow-up questionnaires. In addition, a specialized tape measure will be used to take measurements of the circumference and length of both arms so that lymphedema onset and progression can be assessed over time. Our interviewers will take the measurements during the baseline interview, and we will ask you to take the measurements (with the assistance of a family member or friend) during follow-up. You will be mailed the specialized tape measure and detailed instructions on how to take the arm measurements. If you have any questions please call our toll-free number at 1-866-206-2979, and we will be happy to assist you.

Creating a Landmark Study

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diagnosis), provides a record of each of your individual experiences.

The information you provide also forms the backbone of the research data from which we will discover insights that may help improve the prognosis of women with breast cancer. As one simple example, we will be able to examine whether women who take antioxidant supplements in the first few months or year after diagnosis do better in the long run – or not – than women who do not take those supplements.

When we began the study, we hoped that we would be successful in enrolling hundreds of women each year into this study. The more women we are able to follow, the more confident we will be that what we observe can be applied to other women with breast cancer. Thus, we are extremely grateful to you, and the contributions each and every one of you has made. Thanks to your dedication, at this time, just a little over a year after we began actively recruiting women into the study, we have enrolled over 800 participants into the Pathways Study.

Any progress we make in this study is a direct tribute to your dedication and our partnership in this adventure. We are on our way toward creating one of the landmark studies of the breast cancer experience, and hope that you feel as excited about your individual contributions to this research effort as we do when we receive the questionnaires and the information you provide.

In the coming months, we will be presenting updates on the study. Please keep an eye out for these talks, as they will be opportunities for you to get to know us and become more familiar with what we are doing. Thank you for responding to our follow-up questionnaires and providing information about your evolving experiences with breast cancer and beyond.

Your Input Is Valuable

Are there topics you would like to read about in future issues of the newsletter?

Do you have other comments you would like to share with us?

You can reach us through our website, **www.dor.kaiser.org/studies/pathways** or by calling our toll-free number, **1-866-206-2979**.

Pathways Update —Who is Participating?

Launched in January 2006, Pathways has a current enrollment of over 800 participants. Pathways participants are drawn from areas throughout the Northern California region, including Fresno, Sacramento, San Jose, the Bay Area, and Stockton. Women of all ages and with all stages of disease are participating in the study. About a quarter of the women are under age 51, nearly a third are between the ages of 50 to 60, a quarter are between the ages of 61-70, and the remainder are over age 71. In terms of race and ethnicity, 68% of the women identify themselves as white, 6% as Black, 9% as Asian, and 9% as Hispanic. American Natives (3%) and Pacific Islanders (0.5%) are also represented. The remainder identify as “other”.

*Thanks for joining Pathways,
adding to the diversity of our team,
and contributing your unique perspective
to the information we are gathering.*

Communicating with Your Doctor

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During Your Visit

- Tape-record your visit or bring a pencil and notebook so that you can take notes. You can also bring a trusted friend or relative to take notes for you.
- Keep the discussion focused on the main reasons for your visit, making sure to cover your main questions and concerns, your symptoms and how they are impacting your life.
- Ask for clarification if you don't understand what you have been told or if you still have questions.
- Ask for explanations of treatment goals and side effects.
- Many oncologists work closely with other team members. Be sure to ask if there is anyone else you should meet with.
- Let your doctor know if you are seeing other physicians or health care providers.
- Share information about any recent medical tests you have done.
- Let your doctor know how much information you want and if you have religious or cultural beliefs that will affect the type of treatment you want to get.
- Stand up for yourself or have a friend or family member advocate for you if your concerns are not addressed.
- Balance assertiveness with friendliness and understanding.

Adapted and reprinted with Permission of the Cancer Resource Center at UCSF.

A Blessing by James Wright

Just off the highway to Rochester, Minnesota,
Twilight bounds softly forth on the grass.
And the eyes of those two Indian ponies
Darken with kindness.
They have come gladly out of the willows
To welcome my friend and me.
We step over the barbed wire into the pasture
Where they have been grazing all day, alone.
They ripple tensely, they can hardly contain their happiness
That we have come.
They bow shyly as wet swans.
They love each other.
There is no loneliness like theirs.
At home once more, they begin munching the young tufts of spring in the darkness.
I would like to hold the slenderer one in my arms,
For she has walked over to me
And nuzzled my left hand.
She is black and white,
Her mane falls wild on her forehead,
And the light breeze moves me to caress her long ear
That is delicate as the skin over a girl's wrist.
Suddenly I realize
That if I stepped out of my body I would break
Into blossom.

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