

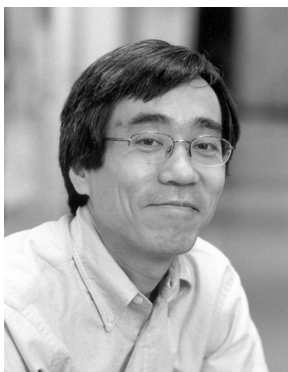


PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

FALL 2007



How Your Participation Will Contribute to Knowledge on Diet and Cancer

Larry Kushi, ScD, Principal Investigator

Perhaps you've read the latest on how diet may influence the chances of developing cancer – or how what you eat may (or may not)

decrease the likelihood of recurrence rates after a cancer diagnosis. In December 2006, it was reported in a study called WINS – the Women's Intervention Nutrition Study – that among women with early-stage breast cancer, a low-fat diet appeared to decrease the chances of having a breast cancer recurrence. But more recently, in July 2007, results from the WHEL Study – the Women's Healthy Eating and Living Study – made the news, saying changing your diet by including more fruits and vegetables appeared to have no impact on breast cancer recurrence. What is a person to make of this conflicting information, and how does your participation in the Pathways Study advance knowledge in this area?

Earlier this month (November 2007), you may have read that the World Cancer Research Fund International (WCRF) and the American Institute for Cancer Research (AICR) released a major compendium and review that provides the latest evaluation of the evidence relating diet to cancer. They released a series of guidelines related to food, nutrition, physical activity and cancer prevention. These updated guidelines, based on an exhaustive review of the medical literature relating diet and cancer, are similar to those that were released by American Cancer Society (ACS) in December 2006. Since I write this article prior to release of the WCRF/AICR recommendations, I'm unable to quote those directly. However, the ACS guidelines are readily available online through the American Cancer Society website and through a link from our study website (<http://www.dor.kaiser.org/studies/pathways>).

The ACS Committee on Nutrition and Physical Activity Guidelines for Cancer Prevention, which I chaired, was

composed of about two dozen leading researchers and other experts in this field from throughout the U.S. It also included representatives from the American Heart Association, the American Diabetes Association, the National Cancer Institute, and the Centers for Disease Control and Prevention, in order to ensure that these guidelines, while specific to cancer and released by the ACS, were also consistent with other organizations' messages about diet and health.

These guidelines promote maintaining a reasonable body weight – that is, avoiding weight gain that results in substantial overweight or obesity, engaging in regular physical activity, and consuming a diet that emphasizes plant foods and minimizes animal foods. As both the ACS and the WCRF/AICR reports note, the suggestion that these actions can decrease the likelihood of developing cancer, is based on a large body of evidence.

However, what about people who develop cancer, including you, the many women who are participating in the Pathways Study? The ACS had a companion report published at the end of 2006, which presented a "Guide to Informed Choices" concerning nutrition and physical activity for people with cancer. I co-chaired the committee that wrote this report. In this ACS report, and in the WCRF/AICR report, it is acknowledged that there is little research that has been conducted that can support recommendations concerning what types of dietary habits can favorably influence cancer prognosis. This is where you come in.

Aside from the WINS and WHEL studies, there are very few studies that have addressed the question of whether dietary habits, physical activity patterns, or use of alternative therapies after a diagnosis of cancer may impact cancer recurrence and survival. The Pathways Study is one of the

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Pathways Phone Faces

Here are pictures of our Pathways staff you may be speaking with on the telephone.

CHRISTINE BONNELL

is trained in Anthropology and is the mother of two energetic boys ages four and one. In her spare time, she is also a documentary photographer.



GERALDINE CARRILLO

is a Hodgkin's Lymphoma survivor and a meditation teacher at the Gnostic Movement center in Berkeley.

SARAH KRATHWOHL

is a life-long vegetarian who has recently taken up sewing and is looking forward to this winter's snowboarding season.



KATY LEUNG

is an avid and adventurous fruit and vegetable eater. She volunteers at a local food pantry and in the nutrition department in the San Francisco Chinatown Public Health Center.

MIKE PELAYO

is an Oakland A's fan and conversely is a San Francisco 49ers supporter.



BECKY ROGOT

is a newbie gardener who somehow always has spare seeds, cuttings, and pinchings in her pockets.



Survivorship: Moving Beyond Diagnosis and Treatment

by Keren Stronach, MPH

What is survivorship? For me, the concept of survivorship is embodied in the story of Itzhak Perlman, a famous violinist.



Childhood polio left Perlman able to walk only with the aid of crutches. Yet his musical ability transcends any physical challenge. One evening, only a few bars into a performance of a very difficult violin concerto, one of his violin strings broke. The orchestra immediately stopped and the audience held its breath while all waited to see if perhaps an assistant would bring a different violin or a new string. But Perlman, after a moment's pause, put the violin to his chin and indicated to the conductor to continue. Now, everybody knows that you can't play a violin concerto with only three strings. But on that night, Perlman refused to know that. He refingered the entire concerto for a three stringed violin. At the end of a long standing ovation, Perlman said, "You know, sometimes it is the artist's task to find out how much music you can still make with what you have left."

Most of us emerge from the cancer experience different than we were, with "changed instruments". The question is how to make as much music as we can, given who we are today – after breast cancer diagnosis.

I often liken being diagnosed with cancer to being an immigrant in a new land, dealing with new terminology, new rules, uncertainty... How we respond to this new land is very individual. Some of us emerge profoundly changed, while others go back to life as it was. Both are equally valid. Below are some suggestions that other cancer survivors have found helpful in coping with the post-cancer experience.

Finding Meaning in Our Stories

How we interpret our experience and the meaning we impart to it has a lot to do with how we experience it. If we have a small sore and we find out it is cancerous, our experience of it will be very different than if we know it's just a pimple that will heal. So, how we understand our experience not only determines our emotional and physical reaction to it, but also influences how we heal and move beyond it. Although we cannot change the fact that we have cancer, we can reframe it and wring as much meaning out of the experience as we can. It is never too late, and reframing our story can be done in many ways – through writing, art, meditation, contemplation, or sharing our stories in a supportive setting.

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The Breast Cancer Advocacy Movement: From Awareness to Research

Janice Marie Barlow, RN
Executive Director, Zero Breast Cancer
Community Advocate:
Pathways Study



A diagnosis of breast cancer offers a chance for all of us to pause, reflect, and see where we can personally contribute to improving our knowledge about breast cancer and our care of those whose lives are affected by this disease. By participating in Pathways, one of the largest prospective studies focused on lifestyle and genetic factors that may influence survival and reduce risk of recurrence in women with breast cancer, you are making a meaningful and lasting contribution to the rich history of breast cancer advocacy.

For the past thirty years, courageous breast cancer survivors and advocates in the United States have significantly influenced breast cancer awareness, patient rights, and treatment options. Through activism and fundraising, advocates have ensured that millions of dollars are being directed to scientific research. Breast cancer activists have earned a “voice at the table,” shaping the research agenda, influencing funding priorities and actively participating in breast cancer research studies whose findings will lead to more informed decision making and evidence-based public policy.

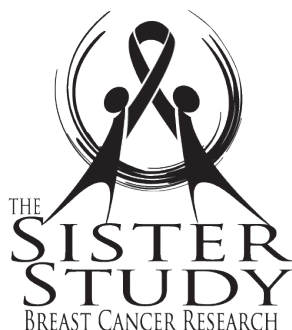
As a result of breast cancer advocacy, a more collaborative and participatory model of research has emerged. This model acknowledges and values the special kinds of knowledge that each and every one of you brings to the Pathways Study; knowledge based on personal histories, lifetime experiences, and cultural perspectives that will ensure the results are relevant to those most likely to benefit from the findings. This study offers a unique opportunity for researchers, breast cancer advocates, and study participants to join together to create new hope and optimism for women with breast cancer. ❧

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first to be designed specifically to examine these issues, and your participation is crucial to its success. To be able to answer these questions, we need your involvement.

We need your participation not only in the baseline interview when you enrolled in the study, but also in follow-up questionnaires and telephone interviews. So, please bear with us as we contact you for follow-up questionnaires. Without your participation, we would not be able to answer questions such as whether changes in dietary habits after breast cancer can influence breast cancer recurrence or survival rates.

We are honored that you have joined the Pathways Study, and recognize your precious time and the potential burden of the data collection requests we have made of you. Thank you once again for inviting us into your lives and making the Pathways Study a part of your breast cancer experience. ❧



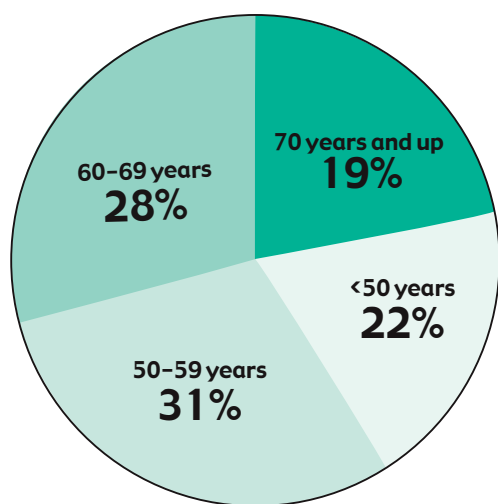
Conducted by the National Institute of Environmental Health Sciences, the Sister Study is committed to enrolling a diverse population of women to ensure the results represent and benefit all women. Is breast cancer caused by something women come in contact with at work, at home, in their communities or in the personal products they use? That's what the Sister Study is trying to answer. The Sister Study needs 50,000 **women whose sisters had breast cancer** to enroll now, to help discover the environmental and genetic causes of breast cancer. For more information visit www.sisterstudy.org or www.estudiodehermanas.org. Call toll-free 1-877-4SISTER. Deaf/Hard of Hearing call 1-866-TTY-4SIS.

Woman by woman...Sister by sister...We can make a difference.

Pathways Update – Who Is Participating?

Pathways began in January 2006 and as of November 2007 has over X (to be determined) participants drawn from across Northern California, including Fresno, the Bay Area, the greater Sacramento area, Santa Rosa, and Stockton. Women of all ages and with all stages of disease are participating in the study.

Our study population, in terms of age:



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

We are grateful for your role in Pathways. All of you add meaning and diversity to our team, and contribute your unique perspective to the information we are gathering. Thank you for participating.

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Befriending One's Emotions

Cancer and its aftermath bring up many uncomfortable emotions. Just as writing, art, and meditation can prove useful in infusing meaning into our experiences, we can utilize these media to express these emotions as they come up so as to move through them more effectively. Talking to friends, a therapist, or support group also may be a means of befriending our emotions – even the more difficult ones such as sadness, grief, anger – we can grieve our losses and come to accept the truth of things as they are.

As one wise survivor said “If I can simply feel my experience as it is – pain, grief, happiness, loss, fear, pride, joy – I will move through that experience, whatever it is. If I fear my emotions and thoughts, I will be stuck in fear.”

Knowing That Everything Changes

The skin that wraps and protects us today is made up of different cells than the skin we had last year, and the pain that we are experiencing today will be different than that which we will experience a week from now, a month from now, and a year from now. Knowing that our experience is constantly evolving can help us to approach the unpleasant emotions of life with curiosity and with openness and can also help us carry our pain and discomfort more lightly.

Connecting with Others

Just as cancer can help us know ourselves better, it can also deepen our relationships with friends and with other survivors. By coming to accept our own vulnerabilities and shortcomings, we may be more accepting of the same in others. By taking the risk and asking for help when we need it, we may also open the door to new connections. And by recognizing our shared humanity, vulnerability, beauty and strength, we can sometimes deepen the bonds of friendship and have more rewarding relationships.

Living Life with a Capital “L”

Having cancer can prod us to re-evaluate our lives. As Howard Thurman said, “Ask yourself what makes you come alive, and then go and do that. Because what the world needs is people that have come alive.” Although we would never choose cancer, we do have a choice about how we respond to it. And we can use our awareness of mortality to live each day in fear, or to live each day more completely.

For me, survivorship presents the challenge of living that duality, living fully and richly while knowing that I am mortal; using this awareness to live each day as if it was my last and to make plans as if I still have all the time in the world. In the words of Juan Ramon Jimenez, “I do not cut my life up into days but my days into lives, each day, each hour, an entire life.” ☒