



Be-Well Study

Bladder Cancer Epidemiology, Wellness and Lifestyle

Summer 2016 Newsletter

Vol 1

Thank you for joining the Be-Well Study

Thank you for joining the Be-Well Study. With your help and ongoing participation in the study, we hope to find out more about factors that may influence the return of bladder cancer. In the upcoming years, we will follow you to gather information about your diet, quality of life, medication use, and other lifestyle factors.

The Be-Well Study is a collaboration between Kaiser Permanente researchers from the Division of Research in Oakland, CA and the Department of Research & Evaluation in Pasadena, CA, along with Roswell Park Cancer Institute in Buffalo, NY and the University at Buffalo in New York. Together, we are developing the largest and most comprehensive study of bladder cancer survivorship.

The study launched in January 2015 and will continue under current funding through May 2019. To date, 468 participants from areas throughout the Northern California and Southern California regions have enrolled in the study. Participants range from 21 to 93 years in age, with 78% male and 22% female, 79% White, 8% Hispanic, 6% Black, 5% Asian, and 2% Other.

We will continue to keep you updated on the study's progress through periodic newsletters. ■

We are grateful for your role in the Be-Well Study. All of you add meaning and diversity to our study, and contribute your unique perspective to the information we are gathering. Thank you for participating!

Background on Bladder Cancer

Bladder cancer is among the 10 most common cancers in men and women in the United States and globally. In 2016, nearly 75,000 new cases are expected in the United States alone, with over 16,000 deaths from this disease. Generally, bladder cancer is 3-4 times more common in men than in women. However, women are more likely to present with advanced tumors and have worse prognosis. The incidence and mortality rates of bladder cancer remain mostly unchanged over the past 30 years. Therefore, new research efforts are needed in the field.

Approximately 90 to 95% of bladder cancer cases in the United States originate from cells that line the inner surface of the bladder. These cells are exposed directly to the urine and numerous potential carcinogenic chemicals discharged into the urine. Therefore, it is well known that bladder cancer is associated with carcinogen/chemical exposures related to lifestyle, environment or occupation. Cigarette smoking is the leading cause of bladder cancer and is estimated to be responsible for 50% of bladder cancers in men and 25% in women. Many epidemiological studies consistently show a 2- to 4-fold increased risk of developing bladder cancer in cigarette smokers compared with nonsmokers, and the risk increased by 5-fold in heavy smokers. An increased risk in bladder cancer is also found among workers in manufacturing dyes, rubbers, textiles, paints, leathers, and aluminum. Some other conditions such as chronic urinary infections, the use of cyclophosphamide, exposure to arsenic, and previous radiation therapy have also been linked to higher risk of bladder cancer. These risk factors are known to contribute to bladder cancer development. Whether these factors affect bladder cancer prognosis remains unclear.

Unlike many other cancers, most bladder cancers (70~80% of cases) are diagnosed at an early stage, called non-muscle invasive bladder cancer. At this stage, bladder cancer is treatable with a favorable 5-year survival rate. However, the cancer has a high recurrence rate (50-80%) that requires life-long surveillance. Some cancers may progress to muscle invasive stage, which requires removal of the bladder (e.g.

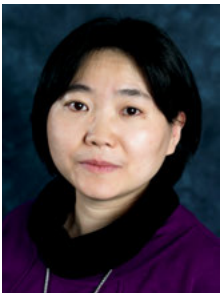
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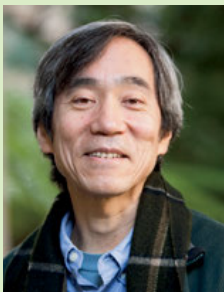
Meet the Be-Well Study Principal Investigators



Marilyn Kwan, PhD - Marilyn is one of the Principal Investigators of the Be-Well Study. She is a Research Scientist II at the Division of Research, Kaiser Permanente Northern California with expertise in cancer epidemiology. Her current research focus is breast and bladder cancer prognosis and survival. She also studies the long-term health effects of cancer treatment in breast cancer survivors. Her devotion to Be-Well comes from the fact that bladder cancer is an understudied Top 10 cancer which can impact patient's quality of life and has high cost of clinical care. In her free time, she enjoys taking her 9 year old daughter and 7- year old son to the movies and park, exploring new restaurants with her husband, and doing CrossFit at her local gym.



Li Tang, PhD - Li is one of the three Principal Investigators of the Be-Well Study. She is in charge of the Be-Well research activities at Roswell Park Cancer Institute in Buffalo, New York. She is an Associate Professor in the Department of Cancer Prevention and Control, and her expertise is in Nutritional and Molecular Epidemiology. Her research is focused on gene-diet interactions that may affect cancer treatment and prognosis. In addition to epidemiology, she has over ten years of experience in laboratory-based research in bladder cancer. She is devoted to translating laboratory research findings into health practice and guidance. Her goal is to provide evidence-based recommendations for cancer survivors. Like many other working moms, she maintains a fast-paced after work schedule, taking her 9-year old daughter to various after-school activities. She also reserves family fun time with her daughter and husband and preserves a little private time for herself for reading and crafting.



Lawrence Kushi, ScD - Larry is the Director of Scientific Policy at the Division of Research, Kaiser Permanente Northern California, and one of the Principal Investigators on the Be-Well Study. He has extensive experience conducting cohort studies, and is a well-recognized leader in the nutritional epidemiology of cancer. He is currently the PI of two prospective cohort studies that are based in KPNC, the CYGNET Study, examining predictors of early sexual maturation in 444 girls and the Pathways Study, examining lifestyle and molecular factors in breast cancer prognosis and which has enrolled 4,505 women. The Pathways Study serves as a model for various aspects of the Be-Well Study, including recruitment methods. He is also PI of the Cancer Research Network, which provides infrastructure support for cancer research in integrated health care settings. He enjoys hiking and camping, and watching his daughter perform in the Off Broadway show "Fuerza Bruta".



Virginia P. Quinn, PhD - Virginia is a behavioral scientist and health services researcher at Kaiser Permanente Southern California (KPSC) with a focus on cancer-related prevention and care. She has worked for many years with Dr. Ronald Loo, the KP Inter-regional Chair of Urology and one of our physician advisors for the Be-Well Study, on the California Men's Health Study (CMHS). The CMHS is a longstanding collaboration between KPSC and KPNC that impaneled a cohort of over 84,000 male members of the health plans. She is the KPSC site principal investigator for the Cancer Research Network, and also a co-investigator on the Population-based Research Optimizing Screening through Personalized Regimens (PROSPR) network, a major research effort funded by NCI.

Spotlight on Be-Well Recruiters/Interviewers



Alexander Carruth - Alex was born in Scotland and immigrated to the United States 32 years ago. He has been working at Kaiser Permanente for almost 8 years, benefiting and enjoying the diversity of research projects in the Department of Research & Evaluation. Alex has a strong background in Behavioral Science, and prior to joining Kaiser Permanente worked in the Epidemiology Department at the Los Angeles County Department of Health for 14 years where he recruited and interacted with diverse populations from all over Los Angeles County. In his spare time, Alex enjoys horseback riding, tennis, cycling, swimming, running, travelling and gardening. In 2015, Alex competed in a Triathlon.



Adriana Martinez - Adriana graduated from the University of California, Berkeley in 2014 with a degree in Integrative Biology. She joined Kaiser's Division of Research shortly thereafter in June 2014. Adriana has been one of the primary interviewers for Be-Well study since it began last year, and prior to the Be-Well study she also conducted phone interviews with participants on a breast cancer survivorship study. Adriana thoroughly enjoys the time she spends interacting with participants, and helping them further cancer research. In her spare time, Adriana enjoys the outdoors and spent a few days camping in the Grand Canyon last spring.



Virginia Pozo - Virginia has been working at Kaiser Permanente Division of Research for the last 10 years. She had primarily been working on a breast cancer survivorship study, but was happy to join the Be-Well Study soon after it started last year. Besides scheduling appointments for the study she also conducts some of the phone interviews. Virginia is originally from Costa Rica but now calls San Francisco home, where she lives with her husband Rick and 2 year old daughter Maria. She likes living in the Bay Area because of it's cultural diversity, great food, wonderful museums and easy access to the great outdoors. In her spare time Virginia enjoys working on a variety of art and crafts projects.



Timothy Stirton - Timothy has a long history in research including 20 years in various capacities at the University of Southern California Keck School of Medicine. He recently returned to Kaiser Permanente's Department of Research & Evaluation after a 3 year hiatus to help recruit participants for the Be Well Study. Timothy's previous experience included recruiting participants for studies on childhood diabetes, melanoma skin cancer prevention, and obesity prevention for families. He enjoys fieldwork and lists among his most interesting assignments, a study on the behaviors of homeless men on LA's Skid Row and another study looking at how families transitioned from Section 8 vouchers to after leaving public housing. In his free time, Timothy is an avid hiker, enjoys trekking in the Sierra Nevada, and is a volunteer docent at the Los Angeles Zoo. ■

A Word of Thanks from our Clinician Advisors

On behalf of the KP Northern and Southern California urologists involved in bladder cancer care, we would like to extend our heartfelt thanks for your participation in this important study. We are extremely excited to partner with you and the Be-Well research team to increase our understanding of bladder cancer and help improve bladder cancer research and clinical care. ■



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Southern California

Background on Bladder Cancer *Continued from the page*

cystectomy) and results in compromised quality of life and worsened survival. The major goal for care of non-muscle invasive bladder cancer is to prevent recurrence and progression, and to improve survival. Currently, following resection of the primary tumor, non-muscle invasive bladder cancer is often treated with intravesical Bacillus Calmette-Guerin (BCG) or chemotherapeutic drugs such as Mitomycin C, depending on tumor stage and grade. These agents are administered into the bladder via transurethral catheter to enhance effectiveness and reduce systemic toxicity. Besides the treatment options, little is known about the role of lifestyle and/or dietary factors, which may affect treatment outcome and influence disease recurrence and survival.

The Be-Well (Bladder Cancer Epidemiology, Wellness and Lifestyle) Study is designed specifically to bridge the knowledge gaps stated above. Funded by the National Cancer Institute, the Be-Well study collects detailed information on occupational history, diet, and lifestyle, and collects blood, urine and saliva samples from patients with newly diagnosed non-muscle invasive bladder cancer. By analyzing these samples and data, we are hoping to find answers to two key questions: Are there any biomarkers or genetic factors that can be used to predict risk of disease recurrence, and survival? Does the choice of lifestyle influence effectiveness of treatment, prognosis, overall health, and quality of life? Your participation will make a difference in the lives of people, like yourself, with bladder cancer. ■

Be-Well Study - Who Is Participating

Baseline Interview

468 Participants

Urine Samples Received

300 Participants

Blood Samples Received

312 Participants

New Contact Information?

In order to keep in touch with you, we must have your latest contact information. Please let us know if your phone number or home address has changed. You can reach us by calling our toll-free number at (800) 627-2067 or at Be-Well@kp.org.