SUSAN MATSUKO SHINAGAWA

LIVESTRONG

Cancer Control Leadership Award Luncheon

July 1, 2010
12:45 – 2:15PM
Imperial Ballroom A
Hilton San Francisco
Union Square
Susan Matsuko Shinagawa is a true force of nature. Having undergone treatment following two primary and one recurrent breast cancer diagnoses, she is the personification of a cancer “Thriller.”

Susan’s personal cancer journey began in 1991 when she discovered a prominent breast lump during routine breast self-examination. Surgeons refused to perform a breast biopsy because Susan was “too young to have breast cancer,” had “no family history of cancer” and because, they said, “Asian women don’t get breast cancer.” Fortunately, Susan trusted her intuition and sought a second opinion. The biopsy showed what Susan suspected – infiltrating ductal carcinoma of the breast. She had breast cancer and was only 34 years old. Since then, Susan has challenged internal norms and exposed external stereotypes to become the nation’s leading Asian American cancer advocate, focused on cancer control, education and research, as well as healthcare access and parity for communities of color, poverty and oppression. Five years after her initial diagnosis, Susan was suddenly overcome with severe unilateral weakness and debilitating pain. Following seven weeks of diagnostic workups, she was given a presumptive, exclusionary diagnosis of recurrent disease presenting in her spine and was rendered permanently disabled. Soon thereafter, Susan added quality pain management, again focusing on communities of color, poverty and oppression, to her advocacy activities.

Susan is co-founder and immediate past chair of the Asian & Pacific Islander National Cancer Survivors Network, a program of the Asian & Pacific Islander American Health Forum. She completed a five-year term as National Community Director for the Asian American Network on Cancer Awareness, Research and Training (AANCART), a National Cancer Institute-funded Special Populations Network, and continues to volunteer as an AANCART representative on the Governing Committee of the Asian & Pacific Islander Cancer Education Materials (APICEM) web portal, a joint project of AANCART and the American Cancer Society, providing easy access to credible cancer education materials in multiple Asian and Pacific Island languages. Susan has been appointed to numerous governmental and nongovernmental advisory councils and review committees in the national/federal, state and local arenas, frequently serving in a leadership capacity. Among her current activities, she is one of only two community members on the Local Advisory Committee of the Comprehensive San Diego State University / University of California, San Diego Cancer Center Partnership [a National Cancer Institute (NCI)-funded Minority Institution/Cancer Center Partnership], and chairs the Partnership’s Community Liaison Subcommittee.

Susan served as the first elected chair of the Intercultural Cancer Council (ICC), a national cancer advocacy organization, from 1999 to 2001, and directed ICC’s 7th Biennial Symposium on Minorities, the Medically Underserved & Cancer in February 2000. During the Symposium, the ICC Executive Committee surprised Susan with a newly established award in her name, which has since been presented to deserving individuals at subsequent ICC symposia. Co-sponsored by the Lance Armstrong Foundation since 2008, this juried award was renamed the Susan Matsuko Shinagawa LiveSTRONG Cancer Control Leadership Award.

In recognition of her efforts to achieve equity across the cancer care continuum, Susan has been the recipient of more than 30 honors and awards, including the American Cancer Society’s prestigious Humanitarian Award (2000), the 2005 National Breast Cancer Awareness Month’s Honor Roll Award for Outstanding Advocacy on Behalf of Minorities, the 2006 Institute for the Advancement of Multicultural & Minority Medicine’s Eagle Fly Free Award, AANCART’s 2009 Christopher N.H. Jenkins Cancer Control Award, and the Prevent Cancer Foundation’s 2010 Prevention Laurel for Advocacy, awarded this past March.

Susan is an often-invited speaker on cancer and pain issues germane to underserved communities, sharing her personal story and insights with diverse audiences, and has been featured in regional and national print, radio, television, film and internet-based media. Her story was the motivation behind the documentary film, “Mothers, Daughters, Sisters” (© Pacific Film Currents, 1999), which explored breast cancer experiences through the eyes of Asian American and Pacific Island survivors and family members. Susan uses her musical gifts to write original musical compositions and lyrics, often performing at meetings and conferences. “My Heroes”, written in 1993 during Susan’s recovery following completion of her first chemotherapy regimen, has been performed and used as the backdrop for numerous multimedia productions for the National Cancer Institute, Centers for Disease Control and Prevention, American Cancer Society, The Leukemia & Lymphoma Society, ICC, the Royal Canadian Mounted Police and numerous other groups.

Medically disabled since late 1996 and armed with grace and determination, Susan continues her volunteer advocacy activities from her home in San Diego County, California, where she lives with her husband, Rob Norberg, and their much-loved (Boxer) dog, Miya.

Susan’s cover photo taken by Richard J.P. Cavosora
SUSAN MATSUKO SHINAGAWA LIVESTRONG®
Cancer Control Leadership Award Luncheon

LUNCH

WELCOME FROM THE AWARD LUNCHEON CO-CHAIRS

Mary Bennett, MFA
Director of Grassroots Advocacy
American Pain Foundation

Andy Miller, MHES, CHES
Executive Vice President/Mission
Lance Armstrong Foundation

PRESENTATION OF AWARD

Susan Matsuko Shinagawa
ICC Past Chair
Breast Cancer “Thriver”
Honorary Luncheon Chair

Honoring
ZUL R.H. SURANI
Program Manager, Patient Education & Community
Outreach Center, USC Norris Comprehensive Cancer Center
Co-Founder & In-Kind Director, Saath USA

LUNCHEON KEYNOTE SPEAKER

Rosemarie Henson, MSW, MPH
Senior Advisor to the Assistant Secretary for Health
U.S. Department of Health & Human Services

MUSICAL SELECTION

“My Heroes” written and performed by Susan Matsuko Shinagawa

The Susan Matsuko Shinagawa LIVESTRONG® Cancer Control Leadership Award is sponsored by the Lance Armstrong Foundation and presented through the Intercultural Cancer Council’s Symposium Series.

The Susan Matsuko Shinagawa LIVESTRONG® Cancer Control Leadership Award is presented to an individual or group:
• whose demonstrated leadership in the area of cancer control goes beyond the expected to the exceptional, through the formulation and execution of policies, programs, partnerships and/or research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations
• who inspires others to aim high by his or her example
• whose esprit de corps brings greater recognition to the organization, program or message than to himself or herself
For the past 15 years, Zul Surani has served as a public health administrator, consultant and ardent advocate in the field of cancer prevention, control and survivorship. Zul currently manages the Patient Education & Community Outreach Center, and the Jennifer Diamond Cancer Resource Library at the USC Norris Comprehensive Cancer Center, University of Southern California. For the decade prior to this current position, Zul worked for the National Cancer Institute’s (NCI) Cancer Information Service (CIS) as the CIS Partnership Program Coordinator for Southern California. Through his work with CIS, he developed partnerships with Asian American, Native Hawaiian and Pacific Islander (NH&PI), African American, American Indian and Latino communities, linking them with external resources, as well as with each other, to grow and strengthen the communities’ involvement and input into local, regional, statewide and national cancer education, control and research programs.

In 1995, Zul helped start and managed the Mobile Mammography Community Outreach Program at the University of California, Los Angeles (UCLA), providing 16,000 mammograms and detecting 160 breast cancers over five years. In early 2000, he contributed to the development of the Digital Mobile Mammography Program at the University of California, San Francisco. The strong, collaborative partnerships he established with multiple Asian American and Pacific Islander communities and community organizations during this period continue to flourish today. Zul has also been a passionate and proactive advocate on behalf of underserved South Asian populations, calling for improved access to language appropriate health information and high-quality health care services. He played a key role in the concept development, planning and launching of the Community Health Action Initiative (CHAI), the nation’s first South Asian-focused, comprehensive health education and empowerment program, which received grants totaling $1.3 million from the Robert Wood Johnson Foundation and was subsequently nominated for RWJF’s Community Health Leadership Award.

In 2004, Zul co-founded and continues to serve as the in-kind Director of Saath USA, a community service agency focused on cancer survivorship issues in underserved South Asian communities. Through Zul’s leadership, Saath has collaborated with the UCLA Jonsson Comprehensive Cancer Center, utilizing Community Based Participatory Research methodology to adapt evidence-based intervention programs for cancer control and survivorship for South Asian breast cancer survivors, for which the organization was honored with the 2009 Dr. Diane Fink Comprehensive Cancer Control Mobilization Award. Saath has also developed community-focused cancer education materials in several South Asian languages, and is now broadening its scope of services to include effective programs and tools in the early detection of cancer and cancer prevention strategies in South Asian community environments.

Zul was appointed to the National Advisory Council of the Asian & Pacific Islander National Cancer Survivors Network (a program of the Asian & Pacific Islander American Health Forum) in 2009. He is the current Chair Elect and serves on the Network’s Executive Leadership Team.

In recognition of his extensive professional and community service, Zul has been honored with the NCI’s 2006 Spirit of the CIS Award and the Susan G. Komen Breast Cancer Foundation’s Community Hero Award. He has also received awards from the American Cancer Society and the Aga Khan Education Board for USA.

Zul studied Public Affairs and Health Care Management at USC, where he received his Bachelor of Science Degree and is currently completing his Master of Public Health Degree in the USC Keck School of Medicine. Born in Kenya, Zul immigrated to the United States with his family as a child, grew up in Southern California and currently resides in Los Angeles. He is of Indian, Gujarati origin and is a Shia Ismaili Muslim.

Nearly two decades after Zul chose cancer control efforts as both his vocation and avocation, his mother, Rashida Surani, was diagnosed with late stage lymphatic cancer. Throughout her treatment, Zul was his mother’s constant companion and advocate. Zul’s life was forever changed when his beloved mother passed away on August 29, 2009, three short months after her diagnosis, at the age of 66. Zul has rededicated his life in her memory, making cancer his life’s work and cause.
Rosemarie Henson is currently the Senior Advisor to the Assistant Secretary for Health at the U.S. Department of Health and Human Services (DHHS). During Ms. Henson’s tenure with the Centers for Disease Control and Prevention (CDC), she directed multiple disease prevention and health promotion programs. Ms. Henson served for more than 5 years as the deputy director of the CDC’s National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). In partnership with the Center director, Ms. Henson shared the responsibility for overseeing the Center’s ten scientific divisions, and shaped plans, policies, and strategies to advance NCCDPHP’s multifaceted programs to prevent and control chronic disease.

From 2001 until 2004, Ms. Henson was director of CDC’s Office on Smoking and Health (OSH), the federal government’s lead organization on tobacco prevention and control. She launched CDC’s state-based National Network of Tobacco Cessation Quitlines; for the first time providing access to telephone counseling and local follow-up for all U.S. smokers. She played a pivotal role in leading CDC’s efforts to establish youth tobacco surveillance activities in 150 countries around the globe, and led the successful CDC tobacco-free campus initiative and the national strategy for the release of two landmark Surgeon General’s reports.

Prior to her service in OSH, Ms. Henson served as the deputy director of CDC’s National Center for Environmental Health and was chief of the Program Services Branch in NCCDPHP’s Division of Cancer Prevention and Control. She implemented the nation’s first-ever breast and cervical cancer early detection program, which, today, supports screening for millions of underserved women in all 50 states, the District of Columbia, five U.S. territories and 12 American Indian tribal nations.

Ms. Henson has been the recipient of several significant honors, including the prestigious 2007 Presidential Rank Award for Meritorious Service, the Surgeon General’s Certificate of Appreciation for Exemplary Effort in the development of the Surgeon General’s Report on the Health Consequences of Involuntary Exposure to Tobacco Smoke in 2006, and the 2004 Jeffery P. Koplan Award for Outstanding Leadership in global tobacco prevention and control.

Prior to joining CDC in 1990, Ms. Henson served in several public health leadership positions with the Massachusetts Department of Public Health in Boston. She earned her Masters in Public Health and Masters of Science in Social Work from Columbia University. Ms. Henson was appointed Senior Advisor to Howard K. Koh, MD, MPH upon his confirmation by the U.S. Senate as Assistant Secretary for Health, DHHS, in June 2009.
THE MANIFESTO
of the Lance Armstrong Foundation

We believe in life. Your life. We believe in living every minute of it with every ounce of your being. And that you must not let cancer take control of it. We believe in energy: channeled and fierce. We believe in focus: getting smart and living strong. Unity is strength. Knowledge is power. Attitude is everything. This is the Lance Armstrong Foundation. We kick in the moment you’re diagnosed. We help you accept the tears. Acknowledge the rage. We believe in your right to live without pain. We believe in information. Not pity. And in straight, open talk about cancer. With husbands, wives and partners. With kids, friends and neighbors. And the people you live with, work with, cry and laugh with. This is no time to pull punches. You’re in the fight of your life. We’re about the hard stuff. Like finding the nerve to ask for a second opinion. And a third, or a fourth, if that’s what it takes. We’re about getting smart about clinical trials. And if it comes to it, being in control of how your life ends. It’s your life. You will have it your way. We’re about the practical stuff. Planning for surviving. Banking your sperm. Preserving your fertility. Organizing your finances. Dealing with hospitals, specialists, insurance companies and employers. It’s knowing your rights. It’s your life. Take no prisoners. We’re about the fight. We’re your champion on Capitol Hill. Your advocate with the healthcare system. Your sponsor in the research labs. And we know the fight never ends. Cancer may leave your body, but it never leaves your life. This is the Lance Armstrong Foundation. Founded and inspired by one of the toughest cancer survivors on the planet. L I V E S T R O N G®

ABOUT THE LANCE ARMSTRONG FOUNDATION

The Lance Armstrong Foundation (LAF) unites people through programs and experience to empower cancer survivors to live life on their own terms and to raise awareness and funds for the fight against cancer. The LAF focuses on cancer prevention, access to screening and care, research and quality of life for cancer survivors. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF has raised more than $300 million for the fight against cancer. Join 70 million LIVESTRONG wristband wearers and help make cancer a national priority. Unite and fight cancer on LIVESTRONG.org.

"Speaking With One Voice"

The Intercultural Cancer Council (ICC) promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. Join the ICC National Network at iccnetwork.org.
My Heroes

Heroes are everywhere, they’re in the faces that we meet.
Heroes are here and there, they’re in the friendships that we keep.
Hands to hold when we feel all alone, help us to face the unknown,
Give us the strength to go on.
Smiles that light up the darkest of nights, tell us that we’ll be all right.
These are my Heroes.

Heroes are family. They love us more than we could know.
Heroes, you’ll always be nurturing minds and hearts that grow.
Silly jokes make us laugh till we cry, tears someone always wipes dry.
Friends who call just to say “hi”.
Hearts who give so that others can heal, caring we know that is real.
These are my Heroes.

Giving, and caring, and fighting to win.
Open my heart, let your love come on in.

Heroes, you’re in my heart. Give me the will to carry on.
Heroes, we’ll never part. You make each day a brand new song.
Dreams I dare to dream yet to unfold, life stories yet to be told,
Memories, sweet, made of gold.
No matter what my tomorrows may bring, I’ve got a song left to sing,
To you, my Heroes.

(Instrumental)
Giving, and caring, and fighting to win.
Open my heart, let your love come on in.

Heroes, you’re in my heart. Give me the will to carry on.
Heroes, we’ll never part. You make each day a brand new song.
Dreams I dare to dream yet to unfold, life stories yet to be told.
Memories, sweet, made of gold.
No matter what my tomorrows may bring, I’ve got a song left to sing,
For you, my Heroes. Thank you, my Heroes.
You are, my Heroes.

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