

Asian & Pacific Islander National Cancer Survivors Network: Cancer Strategies to Reach Underserved AAs and NHPIs

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February 20, 2014

- APINCSN Background
- Challenges
 - APINCSN initiatives
- Strategies to engage with AAs and NHPIs
- Q & A



Asian & Pacific Islander National Cancer Survivors Network (APINCSN)

www.apincsn.org

APINCSN is a network of cancer survivors, their family members, health care providers, researchers, health advocates, community members and organizations concerned about cancer and survivorship in the AA and NHPI communities.



Co-founded in 1998 by cancer survivors Susan M. Shinagawa and the late Rev. Frank Chong



Please join the Network if you are not a member yet!

www.apiahf.org/apincsn/membership

APINCSN Membership

A total of **1153 individuals and organizations** are currently members of the APINCSN.

Programs
Policy and Advocacy
Impact
Engagement

- ▶ API National Cancer Survivors Network
- ▶ **Membership**
- ▶ National Advisory Council
- ▶ eNewsletter
- ▶ Speakers Bureau

Cancer Resources

- ▶ CATCH Leadership Training
- ▶ Breast Cancer Awareness for Tongans Project
- ▶ Filipino Community Cancer Collaborative

Organizational Capacity Building
Funded Initiatives

[Home](#) ▶ [Programs](#) ▶ [Engagement](#) ▶ [API National Cancer Survivors Network](#) ▶ [Membership](#) ▶ [Become a Member of APINCSN!](#)

Become a Member of APINCSN!

The Asian & Pacific Islander National Cancer Survivors Network (APINCSN) is striving to break the isolation that many cancer survivors feel when they are first diagnosed and going through treatment.

Help us build our network!

If you are an Asian American, Native Hawaiian and Pacific Islander cancer survivor, family member or friend of a cancer survivor, health care provider, researcher, advocate or community member who is concerned about cancer in the Asian American, Native Hawaiian and Pacific Islander communities you can become a member of APINCSN.

BECOME A MEMBER OF APINCSN:

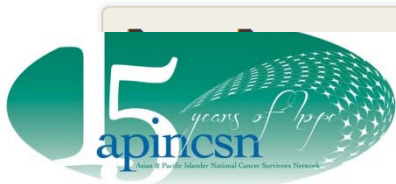
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Name *



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-  Asian & Pacific Islander National Cancer



APINCSN stakeholders

- AA and NHPI cancer survivors & their family members
- Health care providers
- AA and NHPI community-based organizations addressing cancer and cancer survivorship;
- Researchers
- AA and NHPI cancer support group facilitators;
- Cancer advocates
- Cancer programs at local, state, and Pacific Island Jurisdictions health departments.



Challenges

- Lack of health coverage and access
- Lack of linguistically and culturally competent care
- Insufficient data collection and reporting
- Cultural beliefs that complicate the diagnosis and treatment of cancer



How do we address these challenges?

- CATCH Trainings to **improve delivery of services** and **increase awareness of issues** faced by cancer survivors.
- Supporting cancer survivors by providing **access and referrals** to: cancer resources and in-language materials, peer and community support, and survivorship services
- Advancing **awareness through data and communications** opportunities –among the general public, policy makers, survivors, providers, and others of cancer survivorship and its impact.
- Responding to **technical assistance** requests



Community Advocacy & Training on Cancer and Health (CATCH) Training

DAY 1

***Module I:**
Intro to AA & NHPI
Communities
Cancer 101 in AAs & NHPIs

Module II:
Communications
on Cancer and Social Media



DAY 2

Module III:
Data 101

Module IV:
Policy & Civic Engagement



DAY 3

Module V:
Ethnic -and Language-
Specific AA & NHPI Cancer
Support Groups



Outreach

	LOCATION	PARTNER ORGANIZATION	# TRAINED	DATE
1.	San Jose, CA	Yu-Ai Kai	27	May 1- 3, 2009
2.	Orange, CA	St. Joseph Comprehensive Cancer Center	20	July 9 – 11, 2009
3.	Philadelphia, PA	American Cancer Society – PA	20	Nov. 6 – 8, 2009
4.	Phoenix, AZ	Asian Pacific Communities in Action	27	April 8 – 10, 2010
5.	Minneapolis, MN	Minnesota Cancer Alliance & Vietnamese Social Services of MN	30	March 24 – 25, 2011
6.	Houston, TX	Asian American Health Coalition and Hope Clinic – Light and Salt Association	24	April 14 – 16, 2011
7.	Cleveland, OH	Asian Services in Action	18	Nov. 17-19, 2011
8.	Salt Lake City, UT	National Tongan American Society	27	May 2-4, 2012
9.	Salt Lake City, UT	National Tongan American Society - CATCH TOT	37	May 15-17, 2013
10.	Kona, Hawai'i	Department of Health Comprehensive Cancer Control Program and the Office of the Mayor, Hawai'i County	28	June 19-21, 2013
	TOTAL	9	258	



CATCH



CATCH Training of Trainers (TOT)

- 37 trainees from 21 organizations representing 9 states: CA, WA, PA, OH, AZ, TX, MI, NY, UT .
- 18 organizations applied for mini-grant funding of \$500 to support projects in cancer education, awareness, and survivorship.
- These projects reached over 1600 individuals.





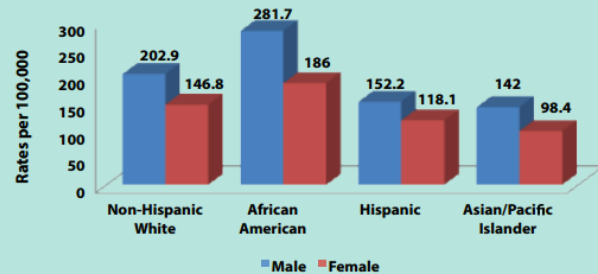
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Cancer Health Briefs

CANCER MORTALITY BY RACE/ETHNICITY & SEX: 2009, CALIFORNIA^[7]



Source: California Cancer Registry, California Department of Public Health

MOST COMMON CANCERS AND NUMBER OF NEW CASES BY SEX & RACE/ETHNICITY: 2006-2010, CALIFORNIA^[7]

C&R = colon and rectum, NHL = Non-Hodgkin lymphoma

Group	Male					Female				
	1	2	3	4	5	1	2	3	4	5
Cambodian	C&R 69	Liver 57	Lung 46	Prostate 32	NHL&Oral 21	Breast 66	C&R 60	Lung 42	Liver 33	Cervix 26
Chinese	Prostate 1,996	Lung 1,394	C&R 1,215	Liver 720	Bladder 436	Breast 2,854	C&R 1,220	Lung 1,012	Uterus 544	Thyroid 464
Filipino	Prostate 2,342	Lung 1,272	C&R 1,034	Liver 419	NHL 410	Breast 3,838	C&R 1,053	Lung 926	Uterus 868	Thyroid 807
Hawaiian	Prostate 76	Lung 37	C&R 36	NHL 16	Bladder 16	Breast 101	Lung 28	C&R 27	Uterus 27	Thyroid 14
Japanese	Prostate 700	C&R 538	Lung 391	Bladder 203	Stomach 188	Breast 1,279	C&R 571	Lung 442	Uterus 226	Pancreas 179
Korean	C&R 447	Prostate 420	Stomach 356	Lung 339	Liver 252	Breast 829	C&R 415	Stomach 262	Lung 242	Thyroid 188
Laotian	Lung 56	Liver 49	C&R 30	Prostate 21	NHL&Oral 20	Breast 50	C&R 30	Liver 27	Lung 18	Thyroid 15
Pacific Islander	Prostate 104	Lung 71	C&R 39	Liver 26	Oral 21	Breast 190	Uterus 83	Lung 45	C&R 38	Ovary 29
South Asian	Prostate 554	C&R 179	Lung 147	NHL 117	Bladder 100	Breast 774	C&R 151	Uterus 135	Thyroid 133	Ovary 90
Vietnamese	Lung 678	Liver 623	C&R 523	Prostate 517	Stomach 182	Breast 973	C&R 405	Lung 345	Thyroid 251	Liver 202
Non-Hispanic White	Prostate 69,893	Lung 31,208	C&R 23,527	Bladder 19,109	Melanoma 19,099	Breast 74,789	Lung 30,516	C&R 22,289	Uterus 13,991	Melanoma 12,352

Source: American Cancer Society, California Department of Public Health and California Cancer Registry, California Cancer Facts and Figures 2013.

The most common cancers in male Asian American, Native Hawaiian, and Pacific Islander (AA and NHP) groups are prostate, lung, and colorectal. Koreans have a greater propensity to be diagnosed with stomach cancer than other AA and NHP groups. For all AA and NHP females, breast cancer is the most common, followed by lung, colorectal, uterine, and cervical cancers.

POPULATION CONCENTRATION^[5]

In 2010, Los Angeles County had the largest number of Asian Americans, Native Hawaiians, and Pacific Islanders among counties statewide. However, San Francisco and Santa Clara Counties had the largest proportion of Asian Americans, while Sacramento and Alameda Counties had the highest concentration of Native Hawaiians and Pacific Islanders. Asian Americans in Santa Clara, Orange, and Alameda Counties followed Los Angeles County in size, while Native Hawaiians and Pacific Islanders in San Diego, Sacramento, and Alameda Counties followed Los Angeles County in size.

Source: Asian Pacific American Legal Center, A Community of Contrasts Asian Americans, Native Hawaiians and Pacific Islanders in California.

LANGUAGES SPOKEN

Asian Americans, Native Hawaiians, and Pacific Islanders speak over 100 languages and dialects. In California, 52.53% (790,403) of native Asian Americans and 8.75% (274,678) of foreign-born Asian Americans speak English only. Of Asian Americans who speak other language(s) besides English, 17.74% (126,679) of native Asians and 55.74% (1,595,757) of foreign-born speak English not well or not at all. In contrast, 62.34% (61,732) of native Native Hawaiians and Pacific Islanders and 11.39% (4,208) of foreign-born Native Hawaiians and Pacific Islanders speak English only. Of Native Hawaiians and Pacific Islanders who speak other language(s) besides English, 17.55% (6,545) of natives and 39.16% (12,819) of foreign-born speak English not well or not at all.

Source: U.S. Census Bureau, 2009-2011 American Community Survey

INCOME

Group	Median Family Income	Per Capita Income
AA	\$83,558	\$31,300
NHPI	\$64,939	\$21,832
White	\$72,912	\$32,262
CA	\$67,745	\$28,504

Source: U.S. Census Bureau, 2009-2011 American Community Survey

Asian Americans (AAs) have the highest median family income of all groups, but have a lower per capita income than whites. Native Hawaiians and Pacific Islanders (NHP) median income is lower than the state median, and they have the lowest per capita income. AAs and NHPs income levels may be due to more individuals living in AAs and NHPs households than there are in white households. However, the number of poor (below 200% of Federal Poverty Level) AAs and NHPs increased 50% and 138% between 2007 and 2011.

Source: Asian Pacific American Legal Center^[6]

EDUCATIONAL ATTAINMENT

Population 25 years and over	CA	AA	NHPI
Less than high school diploma	19.19%	14.20%	15.64%
High school graduate (includes equivalency)	20.90%	14.79%	30.65%
Some college or associate's degree	29.78%	22.69%	38.59%
Bachelor's degree or higher	30.14%	48.32%	15.12%

Source: U.S. Census Bureau, 2009-2011 American Community Survey

A large proportion of Native Hawaiians and Pacific Islanders (NHPs) are high school graduates (30.65%) and have completed some college or associate's degree (38.59%). 15.12% of NHPs attain at least a bachelor's degree compared to 30.14% of Californians. While 14.20% of Asian Americans (AAs) have less than a high school diploma, 48.32% of AAs have a bachelor's degree or higher.

HEALTH INSURANCE COVERAGE

Group	Number of Individuals Uninsured	Percent
AA	703,834	14.43%
NHPI	27,564	19.37%
White	3,782,313	16.46%
CA	6,694,764	18.20%

Source: U.S. Census Bureau, 2009-2011 American Community Survey

Native Hawaiians and Pacific Islanders (NHPs) express the greatest uninsured population (19.37%) in California. Asian Americans (AAs), Native Hawaiians, and Pacific Islanders account for 10.92% of the total uninsured population, which means that more than half of those who are uninsured are AAs and NHPs.

Access 21 health briefs here:

<http://bit.ly/CancerHealthBriefs>

Moving Against Cancer Webinar Series



MOVING AGAINST CANCER: Working with Local Coalitions

This **webinar** will present to advocates, health care providers, researchers, and cancer control staff current strategies in working with underserved and emerging Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) populations. This webinar will provide unique and valuable information on cultural issues in cancer care, AA and NHPI cancer demographics, best practices, identification of culturally appropriate resources, and will highlight local organizations in Georgia, the Center for Pan Asian Community Services, Inc. (CPACS) and the Georgia Cancer Coalition.

Objectives:

To increase your knowledge and understanding about how to work with cancer coalitions in your community.

To increase your understanding about Asian American and Native Hawaiian and Pacific Islander cancer trends in the Southeast.

REGISTER TO THE WEBINAR NOW!

<https://www2.gotomeeting.com/register/602274954>



MOVING AGAINST CANCER: Social Media as a Communications Strategy

This **webinar** will help you learn and gain an increased understanding of how to use social media to raise awareness on your advocacy priorities, amplify your community voices, and reach policy makers. This webinar will highlight strategies by presenting real world examples and sharing information on best practices challenges. Webinar attendees will receive a resource guide to help develop a social media strategy following the webinar.

Objectives:

To learn how to use social media to engage audiences.

To see examples of how other public health / cancer organizations are using social media.

To develop strategies for social media to augment public health policy and advocacy priorities.

REGISTER TO JOIN THE WEBINAR NOW!

<https://www2.gotomeeting.com/register/131738346>

August 17, 2012 at 10am PST, 1pm EST, 11am CST



MOVING AGAINST CANCER: Survivorship Support Groups & Resources

This webinar will share information on culturally and linguistically tailored cancer support groups and its role in addressing disparities impacting cancer prevention, screening, treatment, and survivorship among Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) populations particularly in the New England region. This webinar will also identify cultural issues and best practices in cancer care, share AA and NHPI national cancer demographics, and highlight local cancer coalitions and initiatives in Massachusetts.

Objectives:

To increase your knowledge and understanding about the important role of survivors and support groups in addressing health disparities that impact cancer prevention, screening, treatment, and survivorship.

To encourage participants to dialogue on cancer survivorship needs for the Asian American, Native Hawaiian, & Pacific Islander communities.

REGISTER TO JOIN THE WEBINAR NOW!

<https://www2.gotomeeting.com/register/174356938>

July 25, 2012 | 10:00am PST | 1:00pm EST



Technical assistance

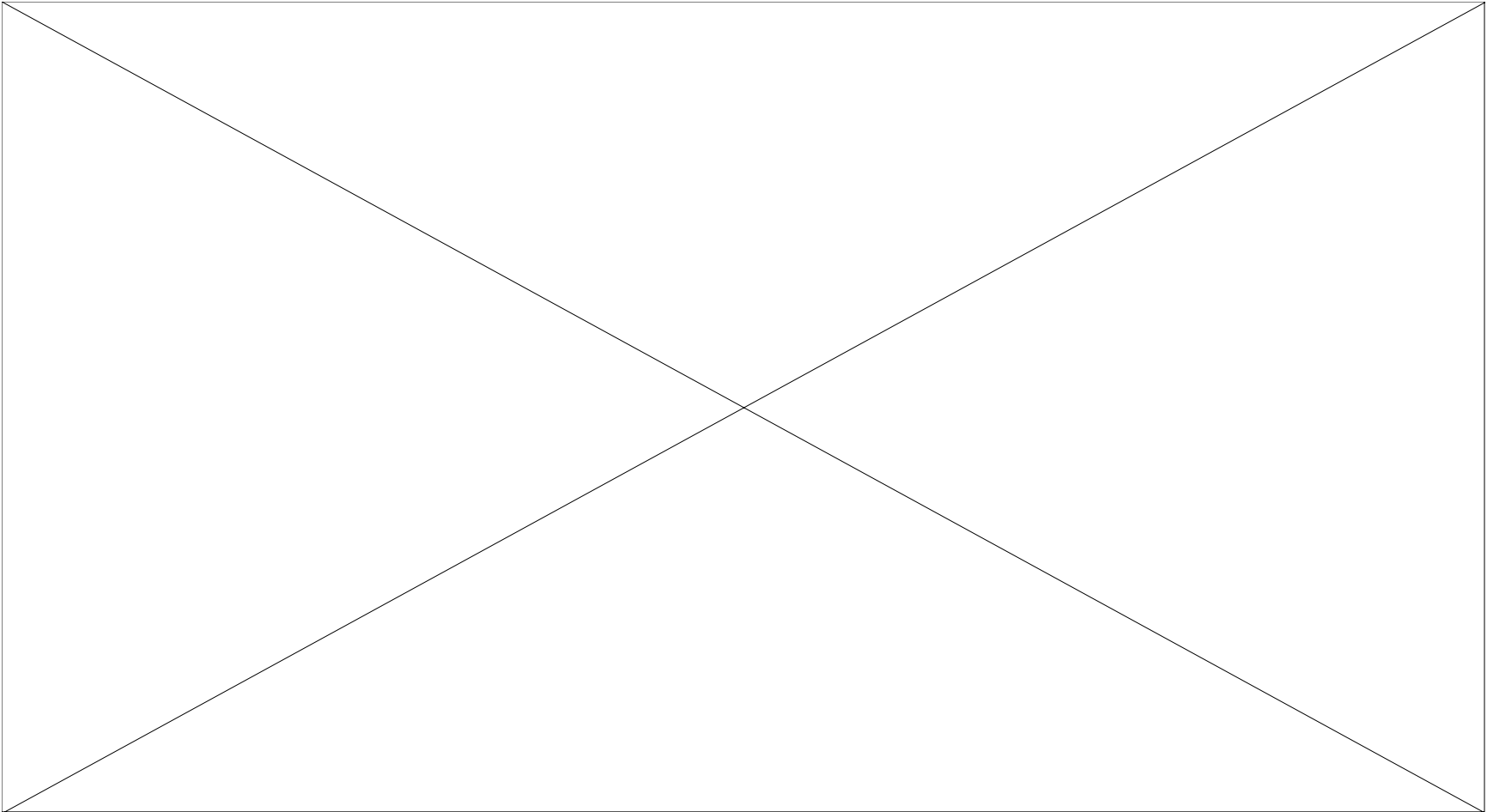
- Tailored cancer education materials (translations)
- Program planning and support
- Resource referrals & navigation
- Cancer support groups
- Speaking engagements, presentations
- Promoting advocacy and leadership

200+
TA hours



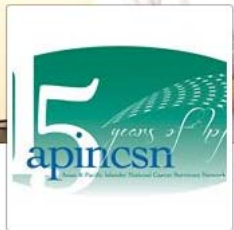
What are specific strategies to engage with AAs and NHPIs?

Identify leaders in the community



<http://www.youtube.com/watch?v=WOaKtrcjILQ>

Promote your brand



**Asian & Pacific
Islander National
Cancer Survivors
Network (APINCSN)**
210 likes

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Community [?]
Become a member by visiting:
<http://www.apincsn.org/membership>

About



Have vocal and visible leaders





Tell their story

"Before health care reform, I was unable to afford my prescription medications because my cancer medications were not on my insurer's approved drug list. The drugs I must take to treat my cancer cost \$40+ per capsule and I presently take 4 per day, though this may soon increase to 6. At present, the cost of my medication is nearly \$5,000 per month, or \$60,000 per year. Despite knowing that this medication was necessary to save my life, [my previous insurer] repeatedly declined further support. My parents, of course, did whatever they could to find the funds to pay for my treatments. In fact, my father sold our family home, which he had lived in for 50 years, to make certain we had the money for my medicine.

<http://www.youtube.com/watch?v=C3M7kPnUVWY>

Health care reform is important to me because thanks to [the Affordable Care Act], we were able change insurers. We now have insurance that covers much more of my prescription costs. I will also be able to remain on my parents' health insurance up to age 26."



Promote partnerships



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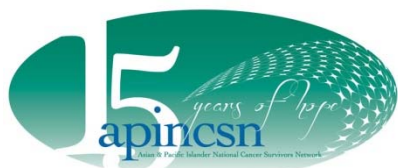
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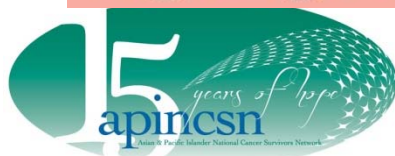
21 July 25, 2012 | 10:00am PST / 1:00pm EST



Work with your local media



Fighting for cancer health equity



yes! women

BETHENNY FRANKEL
FOR TURNING STREET-SMART IDEAS AND ELBOW GREASE INTO A MULTIMILLION DOLLAR BUSINESS

In her 30s, Bethenny Frankel was single and struggling. Her weight-loss book and her low-cal margarita idea had been shot down repeatedly. But Frankel, 40, wouldn't back down, spotlighting herself in Bravo's *The Real Housewives of New York City* and plugging away at her side projects. Her drive paid off: *Naturally Thin* became a 2009 best seller; this year, her Skinnygirl drink brand was bought for a reported \$120 million by Beam Global Spirits & Wine. Her secret? "Never assume anyone's smarter than you are. I knew if I wanted a drink like this, other women would, too." In 2010, Frankel wed, then gave birth to her first child at 39. Her book *A Place of Yes* came out in March, and she's now starring in and executive-producing the third season of her hit reality show *Bethenny Ever After*. Happily ever after, indeed.

GABRIELLE GIFFORDS
FOR RELENTLESS DISPLAYS OF OPTIMISM IN THE FACE OF UNSPEAKABLE VIOLENCE

We all know the backstory: On January 8, 2011, Arizona congresswoman Gabrielle Giffords was meeting with constituents in Tucson when a gunman shot her in the head. But Giffords, 41, has displayed grace and determination in the face of grave setbacks. Rather than hide while she regains her speaking skills and motor function—which could take months, if not years—she's jumped back into public life. In June, she was discharged from the hospital (she'll now have 24-hour help from a home-care assistant). Days afterward, she climbed 18 steps at a staff get-together; a week later, at an awards ceremony for her astronaut husband, Mark Kelly, she rose from her wheelchair to hug and kiss him. What's driving her is simple: "She loves her hometown and derives great strength from its people," says Kelly. "Gabby tells me that she wants to get back to Tucson and back to work."

SUSAN SHINAGAWA
FOR PUSHING THE MEDICAL WORLD TO FIGHT STEREOTYPES

At age 34, Susan Shinagawa felt a lump in her right breast. Her doctor told her not to worry, because she was young, had no family history, and, as he put it, "Asian women don't get breast cancer." Shinagawa wasn't convinced. A second doctor also brushed aside her concerns—only this time, "I wouldn't take no for an answer," says Shinagawa, who insisted on a biopsy. Days later, her hunch was confirmed: She had breast cancer. Her decision to listen to her intuition and not cave to doctors' stereotypes probably saved her life. Since then, Shinagawa has morphed into a one-woman awareness campaign: In 1998, she co-founded the Asian and Pacific Islander National Cancer Survivors Network, now more than 600 members strong.

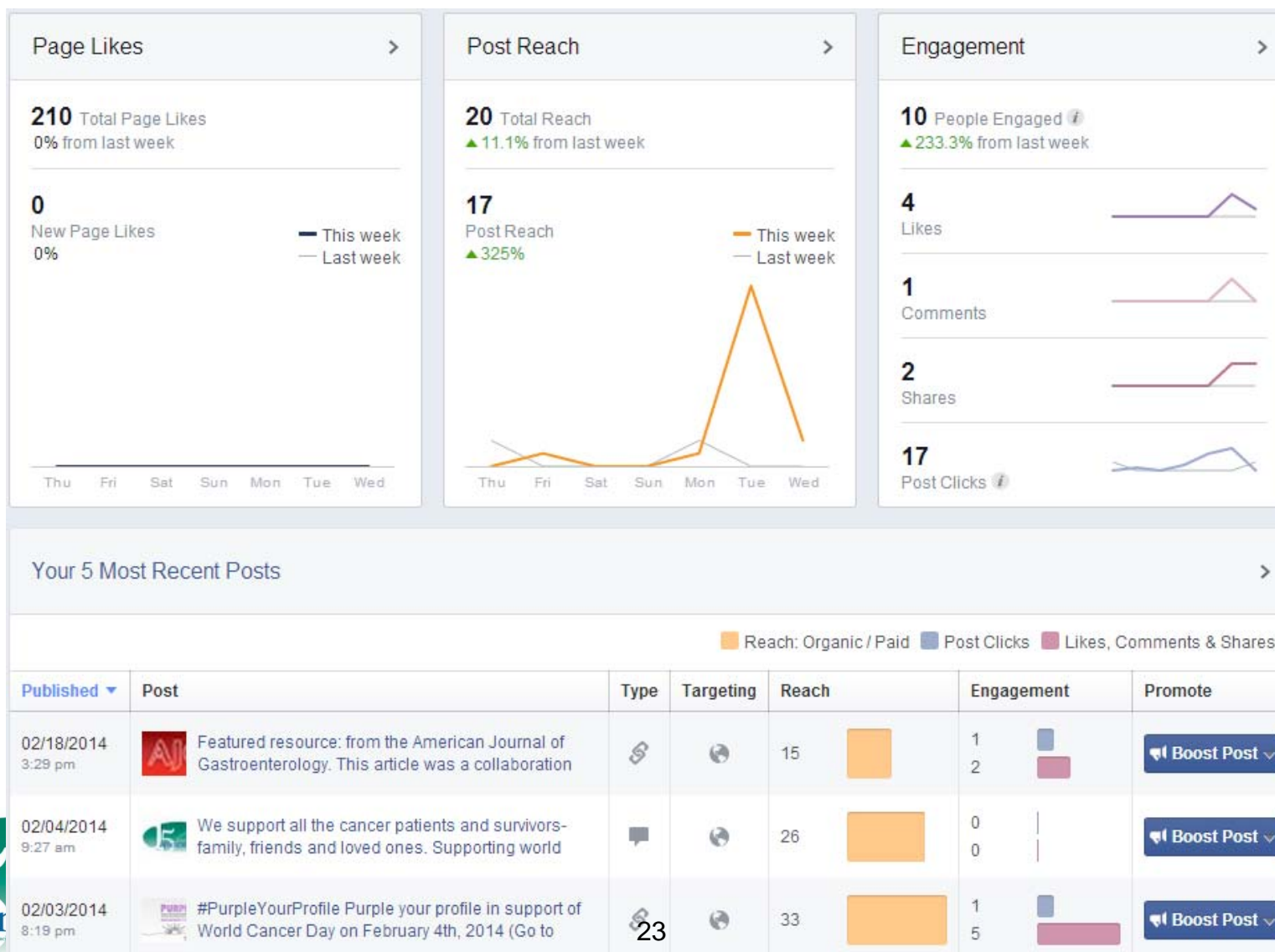
While breast cancer rates among women born in Asia are one-third that of Americans, they are quickly rising. Shinagawa, 55, who is Japanese American, wants to spread the word that Asian women do get the disease, and also buck the Asian belief that health problems should be kept private. "There's a Japanese concept called 'gaman,' which means you endure the unbearable silently," she says. "I share my story so people know it's OK to share theirs."

76 Health.com September 2011

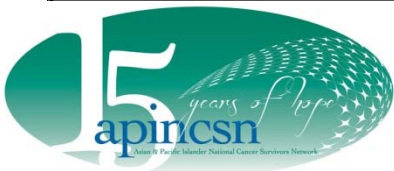
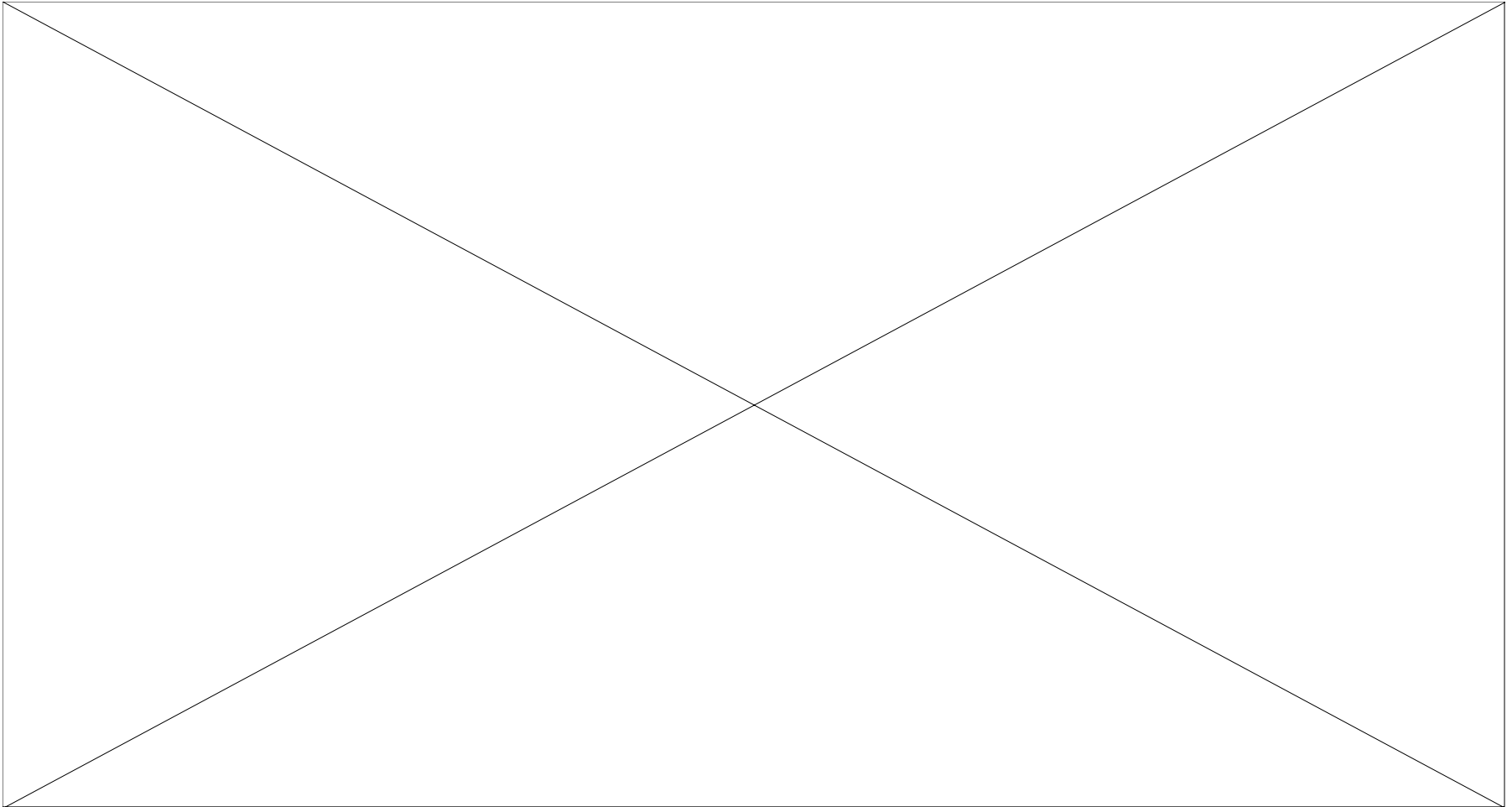
Photos: Frankel: Perry Negret/Corbis/Getty Images; Giffords: Courtesy of the Office of Congresswoman Gabrielle Giffords; Shinagawa: Courtesy of Susan Shinagawa



Track your effectiveness



Show everyone how to follow



<http://www.youtube.com/watch?v=fW8amMCVAJQ>

Thank You!

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