Taking It to the Streets: Breast Cancer Advocacy in Your Community... and Beyond

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My Journey
from
Cancer Patient/Survivor
to
Cancer Thriver/Advocate
to
Community Health Activist

Speaking Truth to Power
“The journey toward advocacy is often triggered by tragic experience. Health problems force us to quickly understand that our health is both personal and political.”

“Advocates tend to work outside of the system. ...(they) have the freedom to agitate for the advancement of agendas outside of the interests of a powerful few.”

“A public health advocate needs to be a good listener and messenger. She delivers the message from the people to the institutions of power in a way they can hear.”

First Three Steps on the road to Becoming a Cancer Survivor/Advocate
My Journey from Cancer Patient & Survivor to Cancer Thriver & Advocate

**Step 1: Sharing my personal cancer story**

**Individuals and communities:**
- Women (in general) and young women (specifically)
- Asian and Pacific Islander women
- Asian and Pacific Islander communities
- Other women and communities of color

**Professional Associations & Service Clubs**
- University of California, San Diego Women’s Caucus
- UCSD Pan Asian Staff Association
- Staff Subcommittee of the UCSD Chancellor’s Affirmative Action Advisory Committee
- San Diego Junior League
- Women’s Clubs, Kiwanis Club, Soroptimists International
- Local university sororities
- Local high school Key Clubs

**Step 1 (cont.): Sharing my personal cancer story and advocating on behalf of communities of color, poverty and oppression with:**

**National / State / Regional / Local mainstream cancer service and advocacy organizations**
- American Cancer Society
- Susan G. Komen Breast Cancer Foundation
- National Coalition for Cancer Survivorship
- LiveSTRONG (the Lance Armstrong Foundation)
- The Breast Cancer Fund
- California Alliance of Breast Cancer Organizations
- Breast Cancer Action
- and many others

**Local, Regional and National Community-Based Health & Social Justice Organizations**
- Union of Pan Asian Communities, San Diego
- NAACP, San Diego Chapter
- Health Education Council, Sacramento, CA
- Papa Ola Lōkahi, Native Hawaiian
- Association of Asian Pacific Community Health Organizations
- Intercultural Cancer Council
- National Hispanic Medical Association
- Asian & Pacific Islander American Health Forum
- Summit Health Institute for Research & Education, Inc.
- Out of Many, One

**Step 1 (cont.)**

**Sharing my personal cancer story with:**

**Those who can influence and implement necessary changes to the system**
- Cancer clinicians (e.g., oncologists, family physicians, nurses, social workers, psychologists, and other healthcare providers)
- Cancer researchers (basic/laboratory researchers, clinical researchers, behavioral researchers, etc.)
- Funders of cancer education and support programs
- Funders of cancer research programs
- Legislators and health policy makers (city, county, state, national, agency directors and administrators, etc.)
Step 2: Listening to & learning from others
(very important!)

- Cancer Survivors
  - Breast cancer survivors
  - Survivors of other cancer types and sites
  - Survivors from diverse communities
    (based upon race, ethnicity, age, gender, sexual orientation, educational attainment, ability/disability, geographic/regional/neighborhood residency, nativity, immigrant/refugee, language proficiency, socioeconomic status, religion, cultural affiliation)
- Male and Female
- Family members
- Caregivers
- Survivors of cancer patients who have passed on (families, friends, colleagues, caregivers, communities, etc.)

Step 2 (cont.): Listening to & learning from others

Those who work with or on behalf of cancer patients/survivors and their families:

- Community leaders and gate keepers
- Cancer health service agencies and advocacy organizations
  - Administrators / Managers / Board Members
  - Staff who work directly with cancer patients/survivors in communities
  - Community volunteers and survivor/advocates
- Health care entities (hospitals, clinics, offices), including their providers, administrators and staff
- Biomedical and behavioral cancer research entities, research investigators and staff

Step 3: Working together to provide for the needs of cancer patients and families, and fill gaps in care and services

- Help to educate and bring cancer awareness to members of my own and other communities
- Advocate on behalf of all underserved communities
- Encourage survivors and families to share their stories with their communities and others (as appropriate)
- Facilitate, support and promote appointment of under-represented cancer survivors and advocates to cancer advisory and research councils
- Advocate on behalf of un-/underrepresented communities for a “seat at the table”
- Facilitate, support and promote Community-Based Participatory Research and Community-Based Participatory Programs

RECAP: Step 1

- Keep Talking (to anyone who will listen!)
- Keep lines of communication open with those who are not yet ready to hear your cancer message.
RECAP: Step 2

Always remember the importance of LISTENING!

- Listen to and learn from others.
- Be respectful
- Honor others’ experiences, cultures and traditions.
- Try to understand others’ perspectives, especially when they differ from your own.

Relativity

What you see depends on where you stand.

- Albert Einstein

RECAP: Step 3

Work collaboratively to best serve cancer patients, their families and communities, and fill in the gaps of unmet services and needs

- Educate
- Advocate
- Encourage
- Facilitate

An Important Tip: Leave your ego at home!

My Continuing Advocacy Journey

- Appointment to local, state (California) and national/federal cancer advisory and research councils
- Election to leadership positions in regional and national cancer organizations
- Speaking Invitations (local, state and national)
  - Conferences and training workshops
  - Testimony to governmental agencies and legislative bodies
  - Academic seminars
- Review grant applications for cancer research, outreach and education, health care service programs and support services
- Recipient of cancer leadership and advocacy awards
- Opportunities to network, mentor, and for continued learning
“Of all forms of inequality, injustice in healthcare is the most shocking and inhumane.”

- Rev. Martin Luther King, Jr.

March 25, 1966

Trends in Female Breast Cancer Incidence Rates* by Race and Ethnicity, 1975 to 2008


* Rates adjusted to 2000 U.S. standard population. Rates for AI/AN, AA/PI and H/L populations are 3-yr moving averages.

Trends in Female Breast Cancer Death Rates* by Race and Ethnicity, 1975 to 2007


Barriers contributing to the unequal burden of cancer in U.S. communities of color, poverty & oppression

Lack of:

- access to timely / quality cancer care
- health insurance
- health care “home”
- trust in health care systems, clinical researchers by some communities

- clinical trials, e.g., Tuskegee syphilis trial (1932-1972); Havasupai blood DNA studies (1990-2003); predatory drug trials in India’s poor by U.S./multinational pharmaceutical industry (2010-2013)
Barriers contributing to the unequal burden of cancer in U.S. communities of color, poverty & oppression (cont.)

Lack of:
- meaningful language access
- culturally competent cancer care
- race and ethnicity
- gender
- sexual orientation
- religious beliefs and practices
- socioeconomic status
- disaggregated cancer data by granular ethnicity
  - e.g., “Asian/Pacific Islander” (“API”)

The “API” Data Burden

U.S. breast cancer (and other health) statistics are most often collected and reported in the aggregate, as “API”. For breast cancer, this results in “API” women being reported as having among the lowest breast cancer incidence and mortality rates in the U.S.

U.S. Poverty Rates, 2000

% U.S. Totals by Race/Ethnicity¹, and Selected Asian Populations²,³

(Age-adjusted to the 2000 US Standard)


The policy / practice of collecting and reporting race and ethnicity cancer data in the aggregate obscures those populations with the highest (and the lowest) rates. Making cancer control, cancer research and grant funding decisions based on aggregate rates only serves to create greater disparities!

A Call to Action:
To eliminate health disparities in U.S. communities of color, poverty and oppression and achieve equality in cancer/health care across all U.S. tribal nations and organizations, and U.S. associated territories and jurisdictions!

A Call to Action
- Reveal and embrace community expertise
  - “If the problem is in the community, the solution is in the community.”
  - Gilbert H. Friedell, M.D.
- Public/Community Education & Awareness
- Healthcare Provider Education & Training
  - “Cultural Humility”
- Research & Programmatic Funding
- Public Policy & Legislation
- Accountability & Enforcement

“Knowing is not enough, we must apply. Willing is not enough, we must do.”

Goethe
“Change will not come if we wait for some other person, or if we wait for some other time. We are the ones we’ve been waiting for.”


[Last line excerpted from “Poem for South African Women”, by political activist, UC Professor, and poet, June Jordan, who died of breast cancer at the age of 65 on June 14, 2002.]

Thank you very much!

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