



# *Breast Cancer Care & Research Fund*

## **Community Activism:**

### **How We Started and Our Involvement in Research and Public Policy**

**Michele Rakoff**

Patient and Research Advocate

### ***All In Our Lifetime: Journey Into Activism***

***Dedicated to all of the women and men who took action  
to end breast cancer and those who continue!***



# Are We Making Progress?

## Incidence

Estimated chance that a woman in the U.S develops  
invasive breast cancer (NCI)

1975- 9.09%      2016- 12.4%

**2017- 255,120 new invasive cases in US**

**63,410 new in situ cases in US (ACS, 2017)**

## Mortality

**2017- More than 1,400 women will die each day(ACS)**

**2017- More than 522,000 will die worldwide (GloboCan,  
2012)**

**2016- 3,560,570 women alive in the US  
with a history of breast cancer(ACS 2016/2017)**



# Our Story Begins 40 Years Ago

## The Year is 1974

### Rose Kushner

Journalist turns Breast Cancer Advocate

She changed the standard of breast cancer care

National Alliance of Breast Cancer Organizations

cofounder(1990)



## Cancer in the White House 1974-1987

- **Betty Ford** (1974) public announcement because of Watergate
- **Happy Rockefeller** (1975) VP's wife
- **Nancy Regan** (1987) chose a mastectomy even though lumpectomy plus radiation (when appropriate) showed equal survival



# **We Tell Our Stories**

**(Hamilton, the play)**

## **The Year is 1984**

- Announcement of the disease HIV/AIDS**

## **The Year is 1987**

- AIDS Coalition to Unleash Power (ACT UP)**

## **The Year is 1988**

- A breast cancer diagnosis changes everything**



# Breast Cancer Organizations founded by advocates

ASC founded in 1913 by physicians was the only established cancer organization

- **1978-Y-ME-** **Ann Marcou (d.), Mimi Kaplan (d.)** began as a hotline operated out of Marcou's Chicago-area home and a support group that met at a local YWCA
- **1978- SHARE-** breast and ovarian cancer support programs
- **1982- Komen- Nancy Brinker**, dedicated to her sister Susan Goodman Komen who died of her disease at 36, focus on awareness and early detection- has developed into education, advocacy and research. Komen Tissue Bank in Indiana- asking well women to donate tissue for research.
- **1990- NABCO-** **Amy Langer, Rose Kushner (d.)** alliance of organizations focusing on support, education and developed into political action-no longer in operation
- **1990- (Breast Cancer Fund) Breast Cancer Prevention Partners-** **Andrea Martin (d.)** science based advocacy organization that works to prevent breast cancer by eliminating exposure to toxic chemicals and radiation
- **1990-Breast Cancer Action-** **Eleanore Pred (d), Susan Claymon (d.), Barbara Brenner (d.)** to achieve health justice for all women at risk of and living with breast cancer.
- **1990-CABCO-** Coalition of Breast Cancer Organizations in CA focusing on breast cancer public policy issues
- **1990-Helen Mautner Project-** **Susan Hester**-envisioning a health care system that is respectful of and accessible to all without regard for their sexual orientation, gender identity, or gender expression.



# Breast Cancer Organizations

## founded by advocates (continued)

- **1991- National Breast Cancer Coalition- Fran Visco-** focus on public policy and advocacy, is governed by a grassroots Board of Directors who represent organizations that reflect the diversity of breast cancer.
- **1991- Living Beyond Breast Cancer- Marissa Weiss-** To connect people with trusted breast cancer information and a community of support.
- **1991-Women of Color Breast Cancer Survivors Support Project- PJ Viviansayles (d.), Beverly Rhines (d.)** provided emotional support and crisis intervention for women of color breast cancer survivors and their significant others; education and public policy.
- **1993- Silent Spring- founded by MA Breast Cancer Coalition-**study links between the environment and women's health, starting with breast cancer.
- **1994-Sisters Network, Inc.- Karen Jackson** leading voice and only national African American breast cancer support organization in the US.
- **1996-Nueva Vida- Carolina Hinstrosa (d.),** educate, support Latino families and to advocate and facilitate the timely access to state of the art cancer care
- **1996-Zero Breast Cancer (Marin Breast Cancer Watch)** promotes breast cancer risk reduction through translation of scientific research and evidence-based recommendations that support health and wellness at key stages of life.
- **1998- Young Survival Coalition- Roberta Levy Schwartz, Lanita Moss, Joy Simha-** is the premier organization dedicated to the critical issues unique to young women who are diagnosed with breast cancer



# In the Room Where It Happened

## (Hamilton, the play)

### The Year is 1991

National Breast Cancer Coalition was formed

Advocates organized and educated ourselves on public policy issues, the science of breast cancer, and advocacy

Build relationships with local, state, and federal legislators

### Legislation and Research are Intertwined





# Legislation and Science

## Working Together

The Year is 1992/93

### Dept. of Defense Breast Cancer Research Program

- In response to the lobbying efforts of the breast cancer advocates, Congress authorized funds in support of new and promising research
- **Vision: To end breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers (advocates)**
- **\$3.28 billion (FY92-FY16) of new federal dollars for breast cancer research**
- **Due to the success and transparency, today there are 28 Congressionally Directed Research Programs**





# CA. Breast Cancer Act of 1993

## Meanwhile in California

- Advocates collaborated with Assemblywoman Barbara Friedman
- 2 cents tax on cigarettes
- ***Created***
  - ***California Breast Cancer Research Program,***
  - ***Breast Cancer Early Detection Program (Every Woman Counts)***
  - ***provided funding for the California Cancer Registry that funded the***
    - ***California Teacher's Study***, a prospective study of 133,000 teachers or administrators that continues today.



# California Breast Cancer Research Program (CBCRP)

- Established under the Breast Cancer Act of 1993.
- Advocates comprise 1/3 of the Advisory Council.
- Advocates participate in peer-review as well as programmatic review.
- ***Scientists are required to include advocates on all grant proposals.***
  - Includes active participation of advocate in all aspects of the grant.
  - Educates researchers about who and what is an advocate.



# California Teacher's Study

- *Prospective cohort study of 133,000 California teachers and administrators since 1995.*
- Consortium of investigators from CA DHS, City of Hope, Cancer Prevention Institute of CA, UC Irvine & USC.
- Includes advocates on the Scientific Task Force.
- Includes advocates on the Steering Committee,

A+



# What is a Research Advocate?

- ***Research advocates*** put a “human face” to the science.
- ***Research advocates*** are well trained and educated in the science of breast cancer.
- ***Research advocates*** need to be involved in every aspect of research as well as decision-making.



# Educate to Advocate

## *NBCC Project Lead*

- *Since 1995 has educated more than 2,000 breast cancer advocates on the science of breast cancer*
- Project Lead Workshops, Clinical Trials Project Lead, Quality Care Project Lead, International Project Lead  
Project Lead Institute
- **Other advocacy education programs followed**
  - AACR Scientist-Survivor Program
  - Komen Advocates in Science



# Federal and State Action

- **Federal legislation**
  - **1996-2000 Breast and Cervical Cancer Treatment Act** passes Congress and ratified by every state
  - **2008 Breast Cancer and the Environmental Research Act**
  - **2010-2017+ Affordable Care Act**
- **California legislation**
  - **2001 Patient Care Cost in Clinical Trials Act**
  - **2008 Biomonitoring Act**
  - **2012 Breast Density Notification Act**



# Breast Cancer and the Environment

## The Year is 2008

- Passage of the Breast Cancer and the Environmental Research Act
- Report of the Interagency Breast Cancer and the Environment Research Coordinating Committee(2013)
- **BCERP research**
  - **Effects of Endocrine Disruptors**
  - **Windows of Susceptibility that could be informative**



# Agencies with Advocates

- American Association of Clinical Research (AACR)
- American Society Clinical Oncology (ASCO)
- Agency for Healthcare Research and Quality (AHRQ)
- California Breast Cancer Research Program (CBCRP)
- Cochrane Collaborative (CUE)
- DoD Breast Cancer Research Program (DoD BCRP)
- FDA- Oncologic Drugs Advisory Committee (ODAC)
- Komen Tissue Bank (IU)
- Love Army of Women (AoW) & Health of Women Study (HOW)
- NIH, NCI , NIEHS
- Patient Centered Outcomes Research Institute (PCORI)
- San Antonio Breast Cancer Symposium (SABCS)
- SPORes & IRBs





# One Last Story the Activism Continues...

*Advocates are strategic, diligent, proactive*

**November 2017**

**National Defense Authorization Act FY 2018**

Congressionally Directed Medical Research  
Programs in jeopardy

Advocates once again work with Congress to  
save these programs

*We will continue until we prevent breast cancer and metastatic disease.*



# Advocate Impact

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

*Margaret Mead*

I am a “face of breast cancer”.

We must prevent breast cancer for my granddaughters and all the little girls of their generation!

*Michele Rakoff*