

Act with Love™

FOR A FUTURE WITHOUT BREAST CANCER

Dr. Susan Love Research Foundation: *NextGen Public Driven Longitudinal Studies*

We believe to end breast cancer in the 21st century, research has to be democratized: fueled by consumer and patient participation at the intersection of life sciences, information technology, and medicine

Public Driven Research:

The Army of Women: The Army of Women (www.armyofwomen.org) is a registry of over 370,000 wo(men) with and without breast cancer who are willing to participate in research studies. All studies undergo review by advocates and scientists. Emails describing IRB approved research (not drug trials) are sent to all members of the Army of Women and members self-select which studies they want to participate in, and RSVP for further screening by the researcher. Army of Women members are encouraged to forward study emails to their network, increasing the viral penetrance of the call for subjects. Over the past 4 years, 71 studies have been launched and over 95,000 members enrolled in studies.

The Health of Women Study: The Health of Women (HOW) Study (www.healthofwomenstudy.org) is a large online cohort study aimed at finding the cause of breast cancer and predictors of long term survival. This study collects public reported health information via short themed modules on wo(men) over 18 with and without a diagnosis of breast cancer. Participation is via an online/mobile platform and not limited geographically. The HOW study is not being done on the participants but in partnership with them at every level, including crowdsourcing topics and questions the public thinks are important to cover. Launched in October 2012, there are over 40,000 participants who have both signed up and submitted their first module of health data.

Challenge:

To demonstrate that we can answer a neglected, publicly relevant, clinical question through the Army of Women and Health of Women Studies, allowing the public to accelerate phenotypic and genotypic data collection with data analysis through crowdsourcing. The potential project would focus on outliers: long term survivors of breast cancer who were not expected to survive according to current markers but did. We would recruit 1000 survivors who were 10 years out and have them enroll in HOW to collect phenotypic data and obtain blood for genotype analysis and when possible, the original biopsy/slides for analysis. The resulting data would then be put forth in a crowdsourcing challenge to determine the common data points predicting long-term survival of this high risk group.

Points for Discussion:

1. Funding
2. Mechanism for combining and sharing phenotypic and genotypic data
3. Mechanism for the public to obtain medical records and tissue
4. How to position the challenge and to whom

Over to You

D- NextGen Public Driven Longitudinal Studies

| <u>G</u> | <u>Organization</u> | <u>Last name</u> | <u>First</u> |
|-----------------|--|-------------------------|---------------------|
| D-Anchor | Sage Bionetworks | Bare | Chris |
| D | IBM | Bilal | Erhan |
| D | Fred Hutchinson Cancer Research Center | Clurman | Bruce |
| D | Stanford Center for Cancer Systems Biology | Gentles | Andrew |
| D | Sanofi-Aventis | Geoghegan | Cindy |
| D | Center for Cancer Systems Biology | Hill | David |
| D | UCSF | Dohan | Daniel |
| D | Consano | Lindquist | Molly |
| D | Fred Hutchinson Cancer Research Center | Logsdon | Ben |
| D-Lead | Dr. Susan Love Research Foundation | Love | Susan |
| D-Anchor | Sage Bionetworks | Nikolova | Olga |
| D | Dr. Susan Love Research Foundation | Sykes | Naz |
| D | Cancer Commons | Tenenbaum | Marty |



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NextGen Public Driven Longitudinal Studies

Dr. Susan Love, Dr. Susan Love Research Foundation

Project Overview- Major Themes

Start with the questions of the stake holders

What data: phenotype and genotype do we need to answer it?

How can that data be shared with the public and participants?

Available Tools

- Army of Women
- Health of Women Study

a program of the Dr. Susan Love Research Foundation

"We need to look at women with and without breast cancer to understand the molecular changes."

Kim Baltzell, PhD, University of California, San Francisco



DR. SUSAN LOVE RESEARCH FOUNDATION

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Army of Women?

- The Dr. Susan Love Research Foundation's Love/Avon Army of Women (AOW) Program is a groundbreaking online initiative launched in 2008 with the goal of recruiting one million women to participate in breast cancer research.
- The Army of Women connects a variety of breast cancer researchers with women who are willing to participate in a multitude of studies, especially those looking into the causes of breast cancer and how to prevent it.



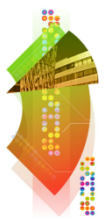
AOW: Who are They?

- More than 371,000 women recruited (and a few good men)
- 70% have never had breast cancer
- 30% are survivors or going through active treatment
- 67% have no first-degree family history
- 27% have one first degree relative who had breast cancer
- 5% have more than one first degree relative who had breast cancer



The Health of Women Study

- **The Health of Women (HOW) Study** is the offspring of the Army of Women.
- The HOW Study is a modular online longitudinal cohort study collecting information from participants around the country and around the globe using the internet and mobile technology
- The goal is to examine causes, treatment, and prevention of breast cancer.
- The HOW Study is open to all wo(men) over the age of 18.
- Launched in October 2013, 41,000 wo(men) have signed up and filled out the first module



Unmet needs and issues

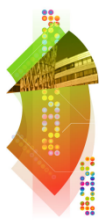
Technical, legal, data questions that arise in collecting data for studies that haven't been designed.

just in time tissue, gene, bank

How to maintain the trust

Feedback to participants

Level of instruction and moderation for participants



1-year vision for the future of this project

How do we get it funded

**Mechanism for combining and sharing
phenotypic and genotypic**

Mechanism for sharing data