

# Breast Cancer Reference Guide: A Guide to Giving



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## Overview.

Breast cancer is the second most common cancer among American women (after skin cancer) and the second leading cause of cancer deaths (after lung cancer). 1 in 8 women will develop breast cancer in her lifetime. The American Cancer Society estimates that in 2013, over 232,000 women will be diagnosed with invasive breast cancer and about 39,600 will die from the disease.

This document provides a reference guide to ten of the leading organizations with substantial portfolios in breast cancer research. All organizations are based in the United States, with geographical scopes ranging from global grant making to state-focused initiatives.

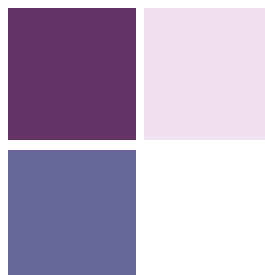
The organizations represented include public, corporate, community-based foundations and charities. The profiles are arranged by research expenditures (largest to smallest). Each organization is profiled to provide a full picture of size, research portfolio, historical funding, and research impact.

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## Research Footprint.

Each organization administers a diverse portfolio of grant programs, ranging from research on the cause of breast cancer and understanding risk factors to developing new treatments through clinical trials. These funders approach scientific research differently, and many offer a variety of awards and fellowships to researchers on a diverse range of breast cancer-related topics. When making a gift to medical research, there are many factors to take into consideration. Key factors include *research phase* (basic, preclinical, clinical), *research focus* (etiology, prevention, diagnosis, developing new therapies, or understanding disease progression, etc.), and the construction of or contribution to *research infrastructure* (lab technologies, tissue repositories, databases, etc.).

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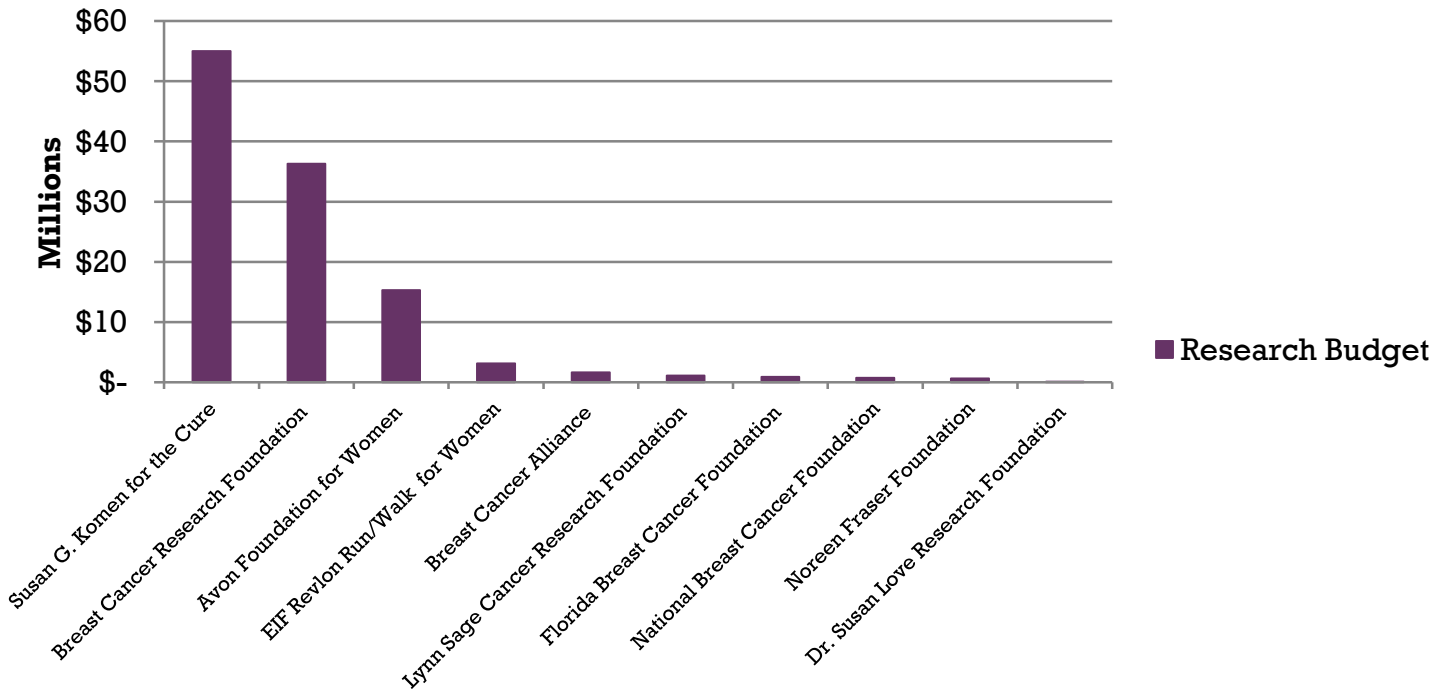
## + Profiled Organizations: Key Statistics

(most recent fiscal year)

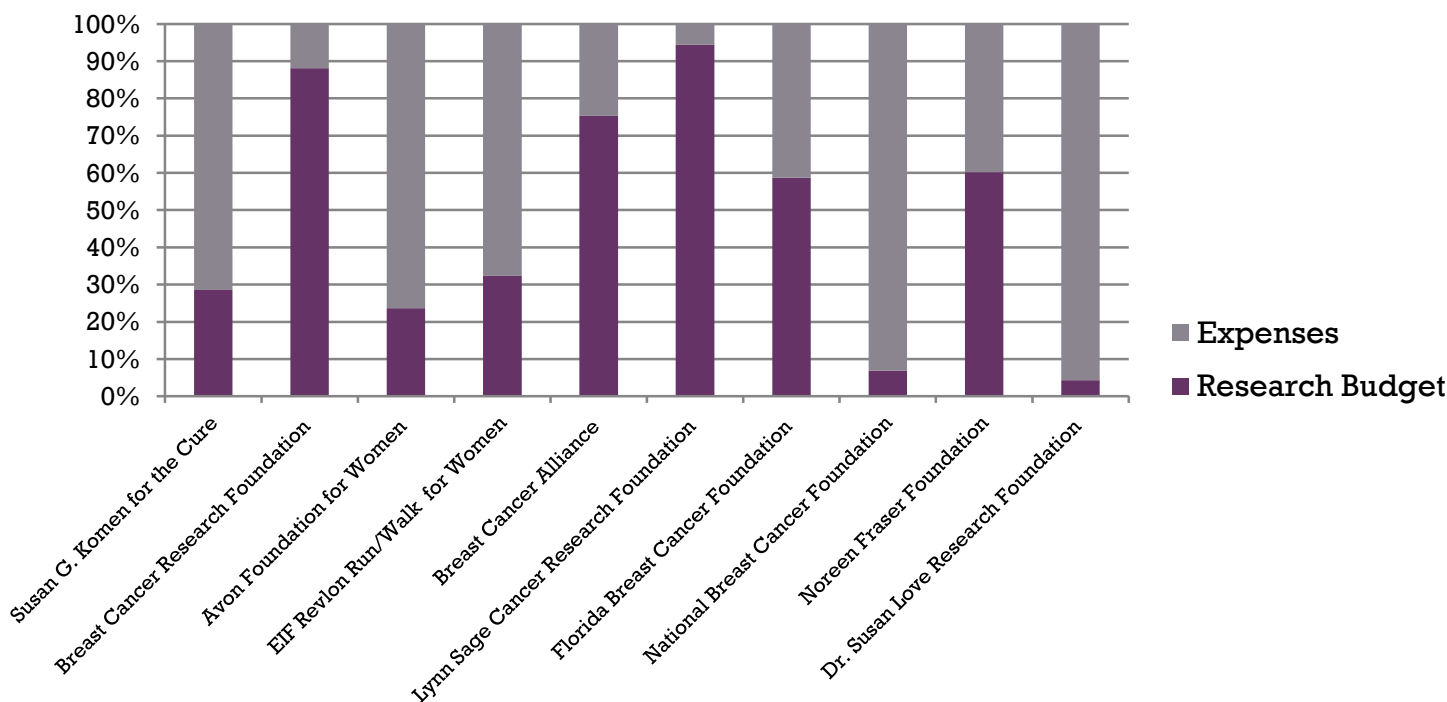
Organization	Full Time Staff	Research Funding Per Year	Number of Grants Per Year	Research as Percent of Expenses	Additional Services (E,S,T)*
<b>Susan G. Komen for the Cure</b>	280	\$55,000,000	80	29%	E,S,T
<b>Breast Cancer Research Foundation</b>	0 (75 volunteers)	\$36,307,750	149	88%	-
<b>Avon Foundation for Women</b>	0 (6400 volunteers)	\$15,283,500	35	24%	E,S
<b>EIF Revlon Run/Walk for Women</b>	-	\$3,122,386	4	32%	E,S
<b>Breast Cancer Alliance</b>	3	\$1,639,500	19	75%	E,S
<b>Lynn Sage Cancer Research</b>	0 (90 volunteers)	\$1,078,456	5	94%	-
<b>Florida Breast Cancer Foundation</b>	5	\$900,000	7	59%	E
<b>National Breast Cancer Foundation</b>	19	\$714,098	2	7%	S,T
<b>Noreen Fraser Foundation</b>	5	\$600,000	1	60%	E
<b>Dr. Susan Love Research Foundation</b>	15	\$90,000	6	4%	E

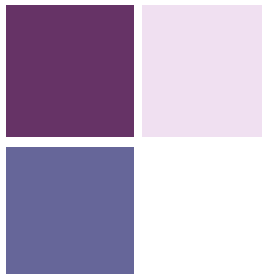
\* Education (E), Screening (S), Treatment (T)

## Breast Cancer Research Budget (most recent fiscal year)



## Breast Cancer Research Funding as Percent of Total Expenses (most recent fiscal year)





# + Profiled Organizations: Research Focus

## How have you been impacted by new research?

While individual research portfolios are summarized in the profiles, the chart below has been developed based on analysis of research portfolios. It serves as a comparative tool for understanding the scientific focus that different organizations are actively supporting. The areas of research focus are correlated with the patient pathway to help identify which areas of research impact different aspects of the patient experience.

Patient Pathway	Knowledge of Risk Factors	Preventative Measures	Screening & Detection	Biopsy & Diagnosis	Surgery	Treatment	Recurrence Prevention & Progression	—
Research Focus	The "Cause" Etiology	Prevention	Lab Tests & Tools	Biomarker Development & Detection	New Surgical Techniques	Novel Therapies	Recurrence	Scientist Career Development
Susan G. Komen for the Cure	Light Blue	Light Purple		Light Purple		Light Purple	Light Blue	Light Purple
Breast Cancer Research Foundation	Light Blue	Light Purple	Light Blue	Light Purple		Light Purple	Light Blue	
Avon Foundation for Women	Light Blue	Light Purple	Light Blue	Light Purple				Light Purple
EIF Revlon Run/Walk for Women			Light Blue	Light Purple		Light Purple		
Breast Cancer Alliance	Light Blue	Light Purple			Dark Blue	Light Purple		Light Purple
Lynn Sage Cancer Research Foundation	Light Blue	Light Purple	Light Blue		Dark Blue	Light Purple		Light Purple
Florida Breast Cancer Foundation	Light Blue					Light Purple		Light Purple
National Breast Cancer Foundation		Light Purple		Light Purple		Light Purple	Light Blue	
Noreen Fraser Foundation	Light Blue			Light Purple		Light Purple	Light Blue	
Dr. Susan Love Research Foundation	Light Blue	Light Purple	Light Blue	Light Purple				

**Knowledge of Risk Factors** includes genetic and environmental factors  
**Preventative Measures** includes genetic screening, drugs, and surgery  
**Screening & Detection** includes mammogram, ultrasound, and MRI  
**Biopsy & Diagnosis** includes identification of molecular subtype and stage of disease progression  
**Surgery** includes mastectomy, partial mastectomy, lumpectomy, and reconstruction  
**Treatment** includes chemotherapy, hormones, targeted therapies, and immunology  
**Recurrence Prevention** includes radiation, adjuvant therapy, and second line treatment for progression

## Susan G. Komen for the Cure

CEO: Nancy Brinker  
5005 LBJ Freeway, Suite 250  
Dallas, TX 75244



*Susan G. Komen for the Cure is the largest non-governmental funder of breast cancer research.*

### + Scope

Geographic Scope: International  
Organization Type: Public Charity

### + Financials (FY2011)

Total Revenue:	\$208,956,027
Expenditures:	\$192,438,599
Research/Expenses Ratio:	29%

### + Research Portfolio (FY2011)

Research Funding: ~\$55,000,000  
Number of Grants: ~80

### + Funding History (1983-2011)

Research Funding: ~\$270,000,000  
Number of Grants: 500+

### + Research Focus

Komen is the largest non-governmental funder of breast cancer research. Originally, the organization focused its research strategy on understanding the basic biology of breast cancer, but now has expanded to include translational research, early detection, and prevention. In addition to its traditional grants process – which has programs both for research and training – Komen established Promise Grants in 2008 to encourage cross-disciplinary collaboration and translational-focused projects on incidence and mortality reduction. These grants support investigator teams of oncologists, surgeons, imaging specialists, etc. to converge around critical issues surrounding prevention, early detection, and treatment.

### + Research Impact

Former Komen grantees have played roles in discovering the gene mutation BRCA1 and telomerase (an enzyme instrumental in chromosome's ability to divide and replicate), and have participated in 7 clinical trials through Promise Grants, including therapies for ER-negative breast cancer, HER2-positive breast cancer, triple negative breast cancer, and inflammatory breast cancer.

## Breast Cancer Research Foundation

President: Myra J. Biblowit  
60 East 56th Street, 8<sup>th</sup> Floor  
New York, NY 10022



*The BCRF portfolio focuses on two main programs:  
identifying causes and developing new therapies.*

### + Scope

Geographic Scope: International  
Organization Type: Public Charity

### + Research Portfolio (FY2011)

Research Funding: \$36,307,750  
Number of Grants: 149

### + Research Focus

Research funds are not divided into programs, but focus on two wide areas – *Finding the Cause* (inherited susceptibility, environmental factors, irregular cell activities) and *Finding the Cure* (clinical innovations of existing therapies, prevention, risk recurrence identification, cancer vaccines, trial design, and personalized medicine).

### + Financials (FY2011)

Total Revenue: \$41,203,252  
Expenditures: \$41,186,344  
Research/Expenses Ratio: 88%

### + Funding History (1993-2011)

Research Funding: \$350,000,000  
Number of Grants: Unknown

### + Research Impact

BCRF researchers contributed to the development of Herceptin (trastuzumab), including coauthoring the 2001 *New England Journal of Medicine* article that described the value of trastuzumab and organizing clinical trials that showed that adjuvant trastuzumab can decrease the risk of recurrence for patients. BCRF researchers have also identified the process of metastasis, as well as identified additional inheritable mutations in the BRCA1/2 genes and created a comprehensive database of breast cancer genes.

## Avon Foundation for Women

President: Carol Kurzig, President  
1345 Avenue of the Americas  
New York, NY 10105



*The Avon Foundation mainly focuses on prevention, including etiology, markers, and progression.*

### + Scope

Geographic Scope: International  
Organization Type: Public Charity\*  
\*Corporate-sponsored foundation

### + Research Portfolio (FY2011)

Research Funding: \$15,283,500  
Number of Grants: 35

### + Research Focus

Currently, research focuses mainly on preventative or monitoring strategies, including environmental factors, potential viral causes, biomarker validation and validation of assays or diagnostics tests that can monitor changes over time. Avon also sponsors the Translational Breast Cancer Research Consortium – a 16 member collaborative research group that has a mission to conduct innovative clinical trials; the Susan G. Komen Foundation and Breast Cancer Research Foundation are also funders of this group.

### + Financials (FY2011)

Total Revenue: \$57,316,040  
Expenditures: \$64,517,679  
Research/Expenses Ratio: 24%

### + Funding History (1999-2011)

Research Funding: \$175,000,000\*  
Number of Grants: Unknown  
\*For 1999-2011 funding, pre-1999 numbers are unavailable

### + Research Impact

The Avon Foundation and the Dr. Susan Love Research Foundation partnered to launch the Love/Avon Army of Women in 2008. The goal of the partnership is to recruit one million healthy women (including high-risk women and survivors) to directly participate in research and challenge the scientific community to increase prevention research for healthy women. The group now includes more than 361,000 women who have indicated their willingness to learn about and take part in research studies. Additionally, an Avon grantee led the study that uncovered how BRCA1 mutations cause breast cancer.



# EIF Revlon Run/Walk for Women

President and CEO (EIF): Lisa C. Paulsen  
1201 West 5th Street, Suite T-700  
Los Angeles, CA 90017



*The EIF/Revlon research program focuses on prevention and developing less toxic treatments for breast cancer.*

## + Scope

Geographic Scope: National  
Organization Type: Public Charity

## + Financials (FY2011)

Total Revenue: \$6,073,033\*  
Expenditures: \$9,656,079\*  
Research/Expenses Ratio: 32%  
\* Based on Revlon event, not EIF total budget

## + Research Portfolio (FY2011)

Research Funding: \$3,122,386  
Number of Grants: 4

## + Funding History (1994 - 2011)

Research Funding: \$68,000,000  
Number of Grants: Unknown

## + Research Focus

The goal of Entertainment Industry Foundation's National Women's Cancer Research Alliance (NWCRA) is to accelerate promising research to develop less toxic treatments for breast cancer. NWCRA is researching the development of new treatments specifically designed for each sub-type of breast cancer. Institutions receiving continued support to advance this work are Cold Spring Harbor Laboratory, Harvard University, Jonsson Cancer Center (UCLA), University of Chicago and the National Breast Cancer Coalition.

## + Research Impact

EIF and its Women's Cancer Research Fund facilitated the Breast Cancer Biomarker Discovery Project, the first study of its kind conducted across labs sharing methods and data and using common blood and tissue samples to discover biomarkers that can detect cancer at an early stage when survival rates are highest. EIF grants also helped accelerate research for the cancer treatment Herceptin (trastuzumab).

## Breast Cancer Alliance

Executive Director: Yonni Wattenmaker  
48 Maple Avenue  
Greenwich, CT 06830



**Breast Cancer Alliance**

*Much of the BCA research has focused on strengthening the breast cancer surgery workforce.*

### + Scope

Geographic Scope: Mid-Atlantic\*  
Organization Type: Public Charity  
\*Within 200 miles of Greenwich, CT

### + Research Portfolio (FY2011)

Research Funding: \$1,639,500  
Number of Grants: 19

### + Research Focus

The organization funds training programs for breast cancer surgeons as well as research in diagnosis, etiology, immunology, genetics, therapies, prevention and clinical studies. The Breast Cancer Alliance disperses 75% of grant funds to research and 25% to early detection programs in neighboring communities.

### + Financials (FY2011)

Total Revenue: \$1,529,814  
Expenditures: \$2,177,322  
Research/Expenses Ratio: 75%

### + Funding History (1998 - 2011)

Research Funding: \$13,800,000  
Number of Grants: Unknown

### + Research Impact

Over the years, the Alliance has funded a variety of research grants and one-year post-graduate breast surgery fellowships at 25 of the nation's leading research institutions. The Alliance has been recognized for strengthening the breast surgery work force by funding fellowships specifically in the area of improving surgeon training.

# Lynn Sage Cancer Research Foundation

Chair: Stephanie J. Lieber  
251 East Huron Street, Galter 3-200  
Chicago, IL 60611



*Lynn Sage Cancer Research Foundation operates the largest breast cancer research program in the Midwest.*

## + Scope

Geographic Scope: Midwest\*  
Organization Type: Public Charity  
\*Gives primarily in Chicago, IL

## + Research Portfolio(FY2011)

Research Funding: \$1,078,456  
Number of Grants: 5

## + Research Focus

The mission of the Lynn Sage Cancer Research Foundation is to support the understanding, research, and treatment of breast cancer in partnership with Chicago's Northwestern Memorial Hospital and the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. It now operates the largest breast cancer program in the Midwest. The Breast Cancer Research Program grants include funding for research on mammographic detection, immunotherapies, the causes of breast cancer, and surgical fellowships.

## + Financials (FY2011)

Total Revenue: \$973,025  
Expenditures: \$1,142,137  
Research/Expenses Ratio: 94%

## + Funding History (1985 - 2011)

Research Funding: \$14,000,000 +  
Number of Grants: Unknown

## + Research Impact

A Lynn Sage grantee discovered a link between FTO, the fat mass and obesity-associated gene, and an increased incidence of breast cancer. The lab focuses on investigating the biological components and pathways that control tumor metastasis and recurrence, which represent the two major obstacles in the successful treatment of cancer. Currently, the lab is investigating the role of several gene products in promoting epithelial to mesenchymal transition and breast cancer progression.

# Florida Breast Cancer Foundation

President and CEO: James Konschnik  
11900 Biscayne Blvd., Suite 806  
North Miami, FL 33181



*The Florida Breast Cancer Foundation is the largest philanthropic funder of breast cancer in Florida.*

## + Scope

Geographic Scope: Florida  
Organization Type: Community Foundation

## + Financials (FY2011)

Total Revenue: \$926,576  
Expenditures: \$1,532,026  
Research/Expenses Ratio: 59%

## + Research Portfolio (FY2011)

Research Funding: \$900,000  
Number of Grants: 7

## + Funding History (1993 - 2011)

Research Funding: \$2,700,000  
Number of Grants: Unknown

## + Research Focus

The foundation offers scientific and fellowship grants for researchers at Florida-based research organizations. Research grants go to basic, clinical and translational research, epidemiological studies research on environmental links, immunological research and other programs, particularly those involving multidisciplinary and/or multi-institutional collaborations.

## + Research Impact

A FBCF grantee discovered that micro environmental factors like stromal cells may play an active role in the procession of malignant breast tumors and others have identified possible environmental factors that lead to genetic changes that cause cancer.

# National Breast Cancer Foundation

CEO: Janelle Hail  
2600 Network Blvd., Suite 300  
Frisco, TX 75034



*The NBCF manages a limited research portfolio focused on targeted therapy for cancer initiating cells.*

## + Scope

Geographic Scope: National  
Organization Type: Public Charity

## + Financials (FY2011)

Total Revenue: \$11,922,622  
Expenditures: \$10,396,092  
Research/Expenses Ratio: 6.8%

## + Research Portfolio (FY2011)

Research Funding: \$714,098  
Number of Grants: 2

## + Funding History (2007 - 2011)

Research Funding: \$3,839,561\*  
Number of Grants: Unknown  
\*For 2007-2011 funding, pre-2007 numbers are unavailable

## + Research Focus

The foundation has focused on making large gifts to MD Anderson Cancer Center, Cleveland Clinic, and Worldwide Innovative Networking for research efforts focused on targeted therapy for breast cancer initiating cells (including gene therapy), therapeutic and preventative drugs for breast cancer, and the first clinical trial offering a choice of therapy guided by the biology to the majority of patients included in the study.

## + Research Impact

In the first year of the study on breast cancer initiating cells, substantial preliminary data was accumulated for targeted therapy for breast cancer initiating cells. The goal of targeted therapy is based on finding how breast cancer initiation cells can resist drug treatment, thus enabling researchers to develop clinical trials to suppress breast cancer initiation cells. Additionally, gene therapy researchers have found that therapy delivered directly to a particularly stubborn type of breast cancer cell caused the cell to self-destruct, lowered the chance of recurrence and helped increase the effectiveness of some types of chemotherapy.

## Noreen Fraser Foundation

CEO: Noreen Fraser  
11693 San Vicente Boulevard, #194  
Los Angeles, CA 90049



*NFF supports a multidisciplinary and collaborative  
research portfolio for women's cancers.*

### + Scope

Geographic Scope: National  
Organization Type: Public Charity

### + Financials (FY2011)

Total Revenue: \$937,629  
Expenditures: \$997,143  
Research/Expense Ratio: 60%

### + Research Portfolio (FY2011)

Research Funding: \$600,000  
Number of Grants: 1

### + Funding History (2006 - 2011)

Research Funding: \$11,925,000  
Number of Grants: 4

### + Research Focus

The foundation operates a grants program primarily at UCLA that focuses on disease biology, new models of breast cancer (including tumor-derived mouse models), and the testing of new therapies.

### + Research Impact

UCLA scientists screened its panel of human breast cancer cell lines and found that ER+ breast cancer cells seem to be particularly dependent on cdk-4/6 function. Their research found that blocking it with a novel agent, a drug currently named PD 0332991 (which is a selective inhibitor of cdk-4/6) led ER+ breast cancer cell lines to stop growing. The results were brought to the clinic for Phase I and Phase II trials for women with advanced ER+ breast cancer. Because of the success of the research, a Phase III trial is now being planned, with a large pharmaceutical company dedicating \$190 million to further the study.

# Dr. Susan Love Research Foundation

President: Susan Love, MD  
2811 Wilshire Blvd., Suite 500  
Santa Monica, CA 90403



DR. SUSAN LOVE  
RESEARCH FOUNDATION  
MOVING BREAST CANCER BEYOND A CURE

*The Foundation's goal is to create a Pap-smear model for breast cancer.*

## + Scope

Geographic Scope: National  
Organization Type: Public Charity

## + Research Portfolio (FY2011)

Research Funding: \$90,000  
Number of Grants: 6

## + Research Focus

The foundation operates its own internal research program as well as funds external grants. Both programs focus on the intraductal area, as the foundation has identified the cells in that area as the source of breast cancer. The foundation's goal is to create a Pap-smear model for breast cancer that uses a blood or fluid test that can screen precancerous cells and identify the origination duct. With that knowledge, it also hopes to develop treatments that will allow for the cells to be treated with an agent, through the nipple. The foundation is currently funding breast cancer research focusing on the role of obesity in cancer, nipple aspirate fluid yielders, human papillomavirus subtypes in breast cancer, and different imaging tools for ductal areas including the ductoscope and 3-D lymphomatic anatomy imaging.

## + Financials (FY2011)

Total Revenue: \$1,940,545  
Expenditures: \$2,068,090  
Research/Expenses Ratio: 4.3%

## + Funding History (1998 - 2011)

Research Funding: \$4,100,000\*  
Number of Grants: Unknown  
\*Both internal and external research

## + Research Impact

The Dr. Susan Love Research Foundation and the Avon Foundation partnered to launch the Love/Avon Army of Women in 2008. The goal of the partnership is to recruit one million healthy women (including high-risk women and survivors) to directly participate in research and challenge the scientific community to increase prevention research for healthy women. The group now includes more than 361,000 women who have indicated their willingness to learn about and take part in research studies. Additionally, Love Foundation researchers found that the presence of atypical cells arising from an intraductal papilloma could be the source of false positive diagnoses in certain patients.

## On Process.

The information in this reference guide was acquired predominantly through desktop research. The final list of organizations for inclusion was identified using the Foundation Center's database, GuideStar, Charity Navigator, and other web-based searching techniques. In order to provide a compact guide, organizations with annual revenues under \$100,000 or local community-based groups were excluded from the final guide. Data fields in each profile (general information, size, financials and research funding, research portfolio, and research impact) were populated primarily from each organization's website. Financial information was taken from the most recent publically available IRS 990 forms, and grant information was taken from the most recent publically available IRS 990 forms, financial statements, and websites.



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