

# Young Survival Coalition

## Federal Advisory Committee on Breast Cancer in Young Women

February 1, 2011

Joy Simha  
Co-Founder & Board Member  
16 year survivor, dx'd in 1994





# Introducing YSC

- We are the premier international organization dedicated to the critical issues unique to young women and breast cancer.
- We are a powerful community fighting breast cancer in young women.
- We believe no woman diagnosed under 40 should be left to face breast cancer alone.

# History

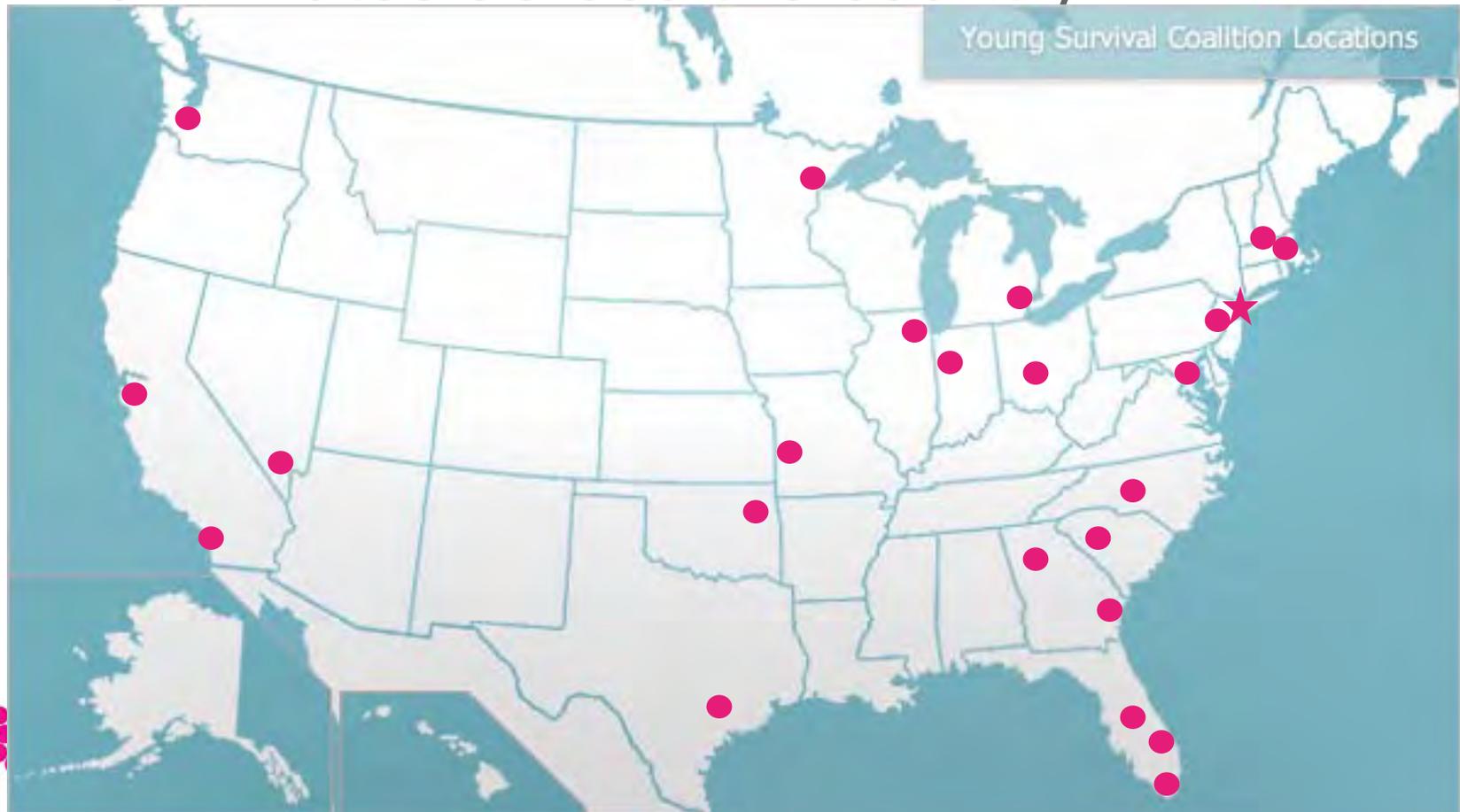
- Founded in 1998
- Three young women, each diagnosed with breast cancer under the age of 35:
  - Roberta Levy-Schwartz
  - Lanita Moss
  - Joy Simha



*Discouraged by the lack of information and research on young women diagnosed with breast cancer, they founded YSC and became a voice for thousands of young women who are diagnosed yearly with breast cancer.*

# The Organization

- Headquartered in New York City, NY
- 26 Affiliates across the country





# Strategic Goals

- By 2012, reach at least 60% of the young women newly diagnosed with breast cancer during the first year after diagnosis
- By 2012, reach at least 30% of all women who have been diagnosed 40 and under regardless of current age.

# Unique Challenges

- Approaching peak of earning potential
- Treatment impact on fertility
- Early onset menopause
- Dating and relationships
- Body image and self-esteem
- Diagnosed during childbearing years
- Parenting small children
- Access to targeted education and support

# Additional Challenges

- Healthcare team less familiar with young women and breast cancer
- Insurance
- Reconstruction
- Genetics and hereditary breast cancer
- Long-term survivorship issues

# What YSC is doing

- Building and informing a global virtual community

[youngsurvival.org](http://youngsurvival.org)

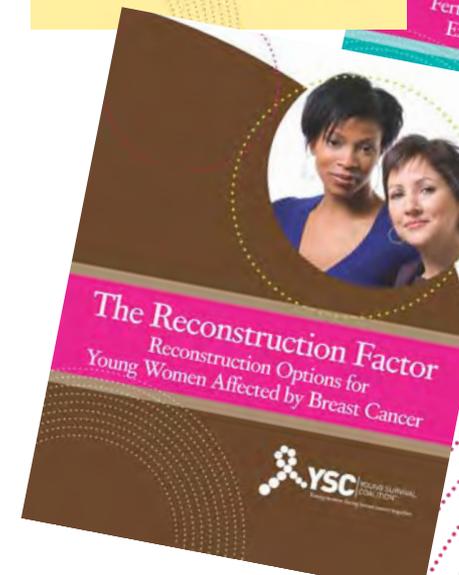
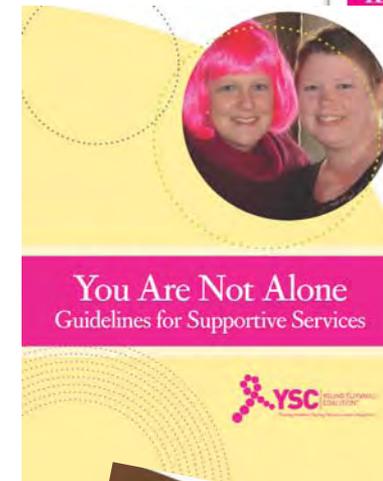


The screenshot shows the YSC (Young Survival Coalition) website homepage. At the top, there is a navigation bar with links for EN ESPAOL, Find An Affiliate, About YSC, FAQs, Newsroom, Contact, and SHOP. Below this is a search bar and social media icons. The main navigation menu includes PROGRAMS, BREAST CANCER IN YOUNG WOMEN, GET INVOLVED, PARTNERS & SPONSORS, COMMUNITY, and DONATE. The featured content includes a 'Featured Survivor Story' for Cassie, 34, with a 'Join Now' button and a 'ResourceLink' section. Below this are sections for 'SURVIVOR STORIES', 'INFO JUST FOR YOU' (with buttons for 'NEWLY DIAGNOSED', 'A SURVIVOR', 'A CAREGIVER', and 'A MEDICAL PROFESSIONAL'), 'YSC COMMUNITY FEED', 'ASK AN EXPERT', 'EVENTS', and 'FIND LOCATIONS'. The footer contains links for TERMS & CONDITIONS, PRIVACY POLICY, and SITE MAP, along with copyright information for 2008-2010.



# What YSC is doing: Empowering

- With information, resources and education
  - ResourceLink: information and resources
  - Local Education Events
  - Educational Videos, Audio Files, Teleconferences, Fact Sheets & Brochures
  - Ask-the-Expert Online Series
  - Adopt-a-Hospital Campaign



Young women facing breast cancer together.

# What YSC is doing: Connecting

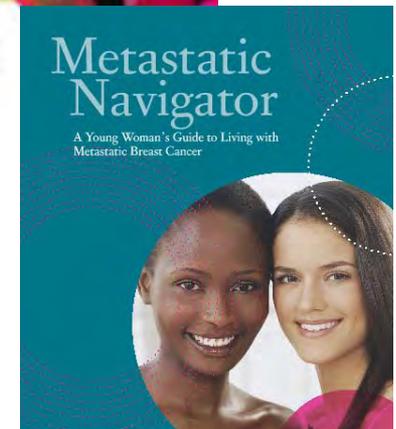
- Forming connections among young women



- SurvivorLink: telephone and email peer-to-peer support
- MetsLink: for young women living with metastatic breast cancer
- Annual Conference for Young Women Affected by Breast Cancer (C4YW)
- Local Support and education programs
- Online Bulletin Board Peer to Peer Support 24/7

# What YSC is doing: Providing

- Toolkits for healthcare and young diagnosed communities
  - Newly Diagnosed Resource Kits
    - Treatment Navigator
    - YANA DVD
    - Tote bag
    - Guidebook of resources
  - Metastatic Navigator
    - Comprehensive book
    - Forms
    - Accordion style filing folder
  - Post Treatment and Long Term Young Survivors in development
- In person, phone and online networking and support services



Young women  
facing breast  
cancer together.

# What YSC is doing: Advocating

- Standing up and Speaking out
  - Patient advocacy
  - Local, regional and national advocacy
    - Collaborating with others to strengthen the voice
    - Position Papers
    - EARLY Act
    - Working with key researchers and thought-leaders
- Working to inform and influence the medical and research communities
  - YSC Research Agenda and Think Tank Initiatives
  - Collaborating to train young women as advocates
  - Serving on Advisory Boards and Guideline Panels
  - National and international conference presentations

# Engaging Our Community Signature Events

In Living Pink

Tour de Pink





# Dedication

- **Randi Rosenberg**
- **Founding member**
- **Past President**
- **Diagnosed at 32**
- **Died at 44**
- **February 15, 2010**

