

Stay tuned...

Today's webinar, ***Understanding the Unique Needs of Young Women Affected by Breast Cancer***, will begin shortly.

Wednesday, May 8th
Noon-1pm EDT

Co-hosted by:



Welcome

Webinar Overview

1. Welcome and Introduction
2. Living Beyond Breast Cancer Overview
3. Young Women's Initiative Overview
4. Results from LBBC's National Needs Assessment of Young Women
5. Young Survival Coalition Overview
6. Young Survival Coalition's Research Think Tank
7. Questions and Answers from Audience



LBBC History and Overview

LBBC empowers all women affected by breast cancer to live as long as possible with the best quality of life.

- National nonprofit founded in 1991 located in suburban Philadelphia
- Among the first to fulfill the need for breast cancer-related information, connection and support after treatment
- As the need for specialized services increased, LBBC expanded to assist women at all stages of diagnosis, treatment and survivorship
- Tailored programs and resources for young women, women living with metastatic breast cancer and African-American and Latina women



LBBC Programs

- Three national conferences
 - Annual Fall Conference (Oct 26-27, 2013, Philadelphia, PA)
 - C4YW (Feb 21-23, 2014, Orlando, FL)
 - Conference for Women Living With Metastatic Breast Cancer (Spring 2014, Philadelphia, PA)
- Monthly Webinars
- *Insight*, LBBC's educational newsletter
- Over 15 publications covering diverse breast cancer topics
- Survivors' Helpline, peer-to-peer telephone support
- Training and resources for healthcare providers
- Lbbc.org, our interactive website



LBBC and Healthcare Providers

- Order bulk publications
- Sign up for our monthly healthcare provider e-blast
- Participate in LBBC's monthly webinars
- Refer patients to LBBC's programs
- CEU credits for social workers (expanding to other disciplines in future)



Young Women's Initiative

- LBBC launched the Young Women's Initiative (YWI) in Nov 2011.
- YWI is funded through a 3-year cooperative agreement with Centers for Disease Control and Prevention.
- Expands and strengthens LBBC's existing programs for young women while developing new programs and resources for this community.
- In the first year, we conducted a comprehensive national needs assessment in preparation for program expansion in years 2 and 3 of the grant.



Living Beyond Breast Cancer's National Needs Assessment of Young Women Affected by Breast Cancer

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Founding Director

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Department of Population Sciences

City of Hope

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Breast Cancer and Young Women

- The impact of breast cancer among young women has increased in public awareness and is gaining significance in public health, research and clinical practice.
- 10% of breast cancers are diagnosed in women ≤ 45 years. Ethnic minority women are more likely to be diagnosed at younger ages.
- Each year 24,000 women are diagnosed with breast cancer under the age of 45.
- Younger women face specific medical challenges related to breast cancer and its treatments, including endocrine changes that result in early menopause and infertility; and skeletal-muscular changes that can result in bone and heart concerns.
- Unique psychosocial and quality-of-life issues, including greater fear of recurrence, anxiety and depression, and phase-of-life concerns such as parenting, marital stability, career and identity development issues.

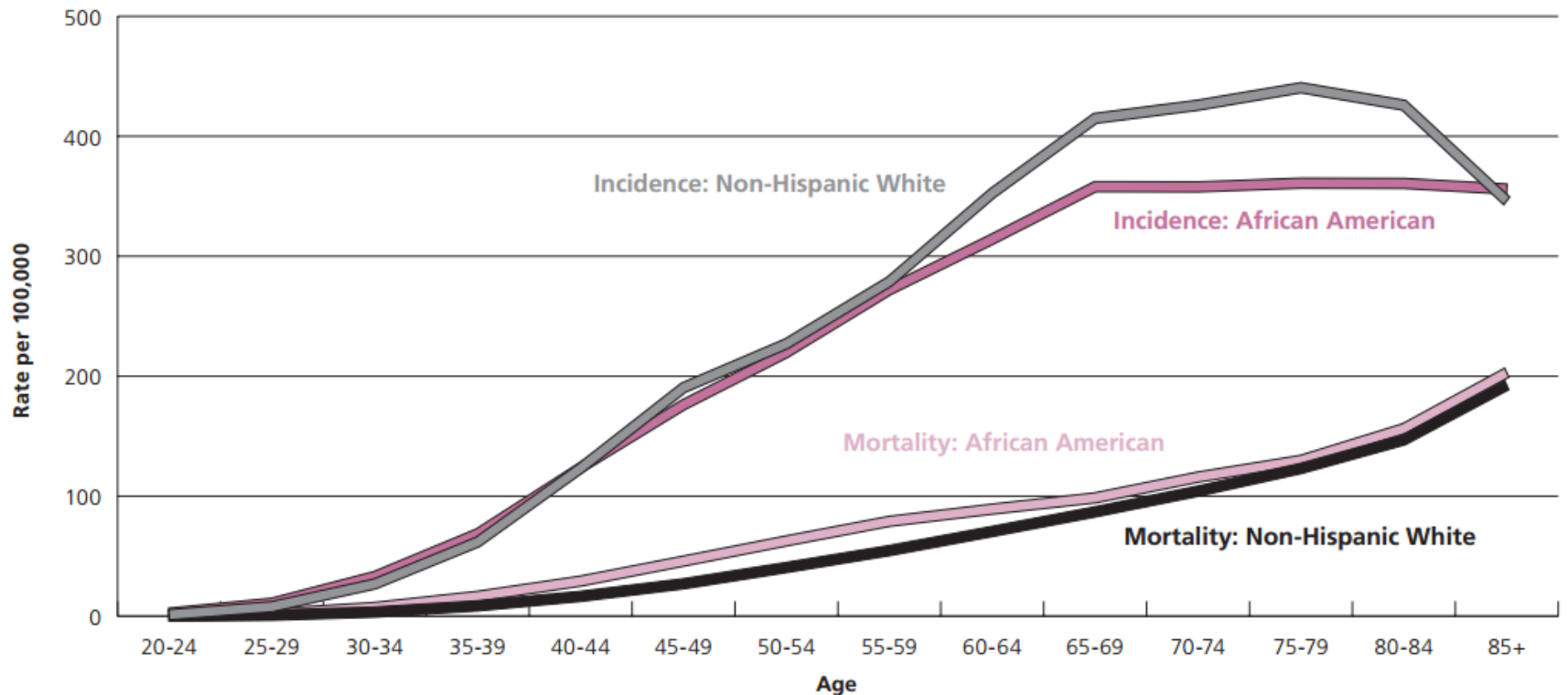
(American Cancer Society Breast Cancer Facts and Figures;
Howard- Anderson, J, et al., (2011) JNCI)



YOUNG
WOMEN'S
INITIATIVE

The logo features the word "YOUNG" in a large, bold, orange font with a butterfly icon integrated into the letter "O". Below it, the words "WOMEN'S" and "INITIATIVE" are stacked in a smaller, bold, purple font.

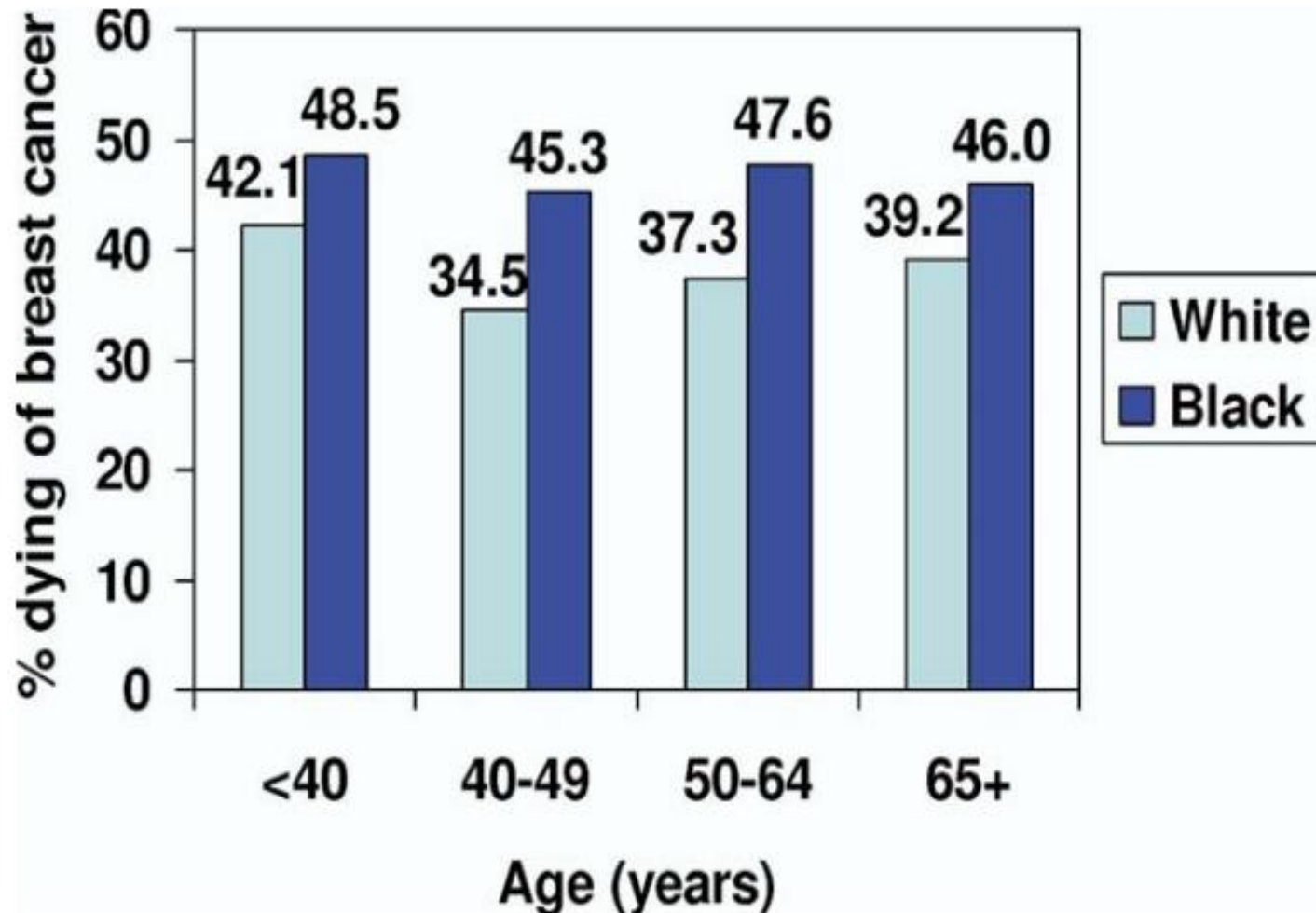
Age-specific Female Breast Cancer Incidence (2004-2008) and Mortality (2003-2007) Rates



Sources: Incidence: North American Association of Central Cancer Registries. Mortality: National Center for Health Statistics, Centers for Disease Control and Prevention, as provided by the Surveillance, Epidemiology, and End Results Program, National Cancer Institute.

American Cancer Society, Surveillance Research, 2011

Proportion of women with Stage III breast cancer who died of BCA, by age and race, SEER, 1988–2003.



National Needs Assessment

Goals:

- To assess the informational and support needs of young women affected by breast cancer
- To evaluate subgroup differences in regard to ethnicity, stage of breast cancer, time since diagnosis and age at diagnosis
- To identify existing gaps in programmatic needs for young women



Assessment Components

1. 12 key informant interviews were conducted with healthcare providers and cancer advocates who work closely with young women.
2. 4 focus groups with women diagnosed before age 45 (N=33). Each group was stratified by time since diagnosis and stage of breast cancer. The groups were divided by:
 - Diagnosed less than one year ago with early-stage breast cancer
 - Diagnosed 2–5 years ago with early-stage breast cancer
 - Diagnosed more than five years ago with early-stage breast cancer
 - Diagnosed with metastatic breast cancer
3. Environmental scan and gap analysis of 29 organizations
4. National survey of young women (N=1,473)



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Formative Focus Groups

Demographic Information of Focus Group Participants

- 33 women participated in four groups
- Average age 40 (age range: 30 to 64 years)
- 25% African American, 9% Latina, 3% Asian, 62% white
- Participants from all four regions of the United States



YOUNG
WOMEN'S
INITIATIVE

The logo features the word "YOUNG" in a large, bold, orange font with a stylized "O" containing a female symbol. Below it, "WOMEN'S" is written in a bold, purple font, and "INITIATIVE" is in a smaller, purple font at the bottom. The entire logo is set against a white rectangular background.

Focus Groups – Recurrent Themes

- Described their needs as unique compared to older women.
- Reported concerns with healthcare providers who did not understand their unique needs as younger women.
- Difficult to find quality survivorship programming for young breast cancer survivors.
- Sought emotional support from counselors, friends and family, but generally not from organizations.



Focus Group Differences

Newly diagnosed:

- Expressed a need for breast cancer information to be tailored to their life stage.

Mid-term and long-term:

- Lack of support and information at the end of treatment and the need for more information on long-term side effects and other survivorship concerns.

Women Living with Metastatic Breast Cancer:

- Focused more on their experience as women living with metastatic breast cancer more than on their experiences as younger women.
- Significant financial impact on them and their families.

National Survey of Young Women

- To increase the diversity of perspectives included in the needs assessment, LBBC launched a national survey of young women affected by breast cancer in April 2012.
- Survey was available online and in a paper format.
- The online survey was open for 5 weeks.



National Survey of Young Women

- Survey domains included:
 - Demographic factors
 - Breast cancer treatment
 - Social support
 - Common side effects
 - Use of and interest in breast cancer education programs
 - Fertility preservation, breast reconstruction and genetic testing decisions



Participant Demographics

Participant Demographics						
	Total Sample (n=1473)	European American (n=923)	African-American (n=114)	Latina-American (n=59)	Asian-American (n=38)	Native-American (n=8)
	Total (%)	Total (%)	Total (%)	Total (%)	Total (%)	Total (%)
Current Age						
21-29	29 (3)	20 (2)	4 (4)	5 (9)	0 (0)	0 (0)
30-39	304 (27)	249 (27)	24 (21)	20 (34)	11 (29)	0 (0)
40-49	593 (52)	478 (52)	63 (56)	22 (38)	22 (58)	8 (100)
50-59	175 (15)	142 (16)	17 (15)	11 (19)	5 (13)	0 (0)
60+	34 (3)	29 (3)	5 (4)	0 (0)	0 (0)	0 (0)
Education						
<HS	5 (1)	3 (1)	0 (0)	2 (3)	0 (0)	0 (0)
HS	82 (7)	68 (7)	8 (7)	3 (5)	0 (0)	3 (38)
Some College	299 (26)	236 (25)	37 (32)	18 (31)	4 (10)	4 (50)
College Graduate	417 (36)	349 (38)	38 (33)	20 (35)	9 (24)	1 (12)
Graduate Degree	338 (30)	267 (29)	31 (28)	15 (26)	25 (66)	0 (0)
Income						
<\$25k	109 (10)	77 (8)	18 (16)	10 (18)	2 (6)	2 (25)
\$25-34k	59 (5)	42 (5)	13 (12)	4 (7)	0 (0)	0 (0)
\$35-49k	115 (11)	78 (9)	19 (17)	10 (18)	6 (18)	2 (25)
\$50-74k	231 (21)	188 (21)	27 (24)	8 (14)	6 (18)	2 (25)
\$75-99k	182 (17)	150 (17)	15 (14)	8 (14)	7 (20)	2 (25)
\$100-149k	224 (20)	198 (23)	12 (11)	11 (20)	3 (8)	0 (0)
>\$150k	170 (16)	148 (17)	7 (6)	5 (9)	10 (30)	0 (0)
Relation status						
Married/committed	838 (74)	707 (77)	57 (50)	40 (69)	29 (76)	5 (63)
Divorced	106 (9)	79 (8)	16 (14)	7 (12)	2 (5)	2 (25)
Widowed	12 (1)	8 (1)	3 (3)	0 (0)	0 (0)	1 (12)
Separated	24 (2)	19 (2)	3 (3)	1 (2)	1 (3)	0 (0)
Single	159 (14)	108 (12)	35 (30)	10 (17)	6 (16)	0 (0)

Note: Numbers in the group categories do not add to the total number of participants because of missing data.

Medical Characteristics

Medical Characteristics						
	Total Sample (n=1473)	European American (n=923)	African-American (n=114)	Latina-America n (n=59)	Asian-America n (n=38)	Native-America n (n=8)
Stage at Diagnosis						
Stage 0	112 (10)	84 (9)	16 (15)	7 (12)	5 (13)	0 (0)
Early stage (I-III)	949 (85)	776 (86)	89 (82)	46 (81)	31 (82)	7 (87)
Stage IV (metastatic)	50 (5)	40 (5)	3 (3)	4 (7)	2 (5)	1 (13)
Age at Diagnosis						
<31	138 (12)	105 (12)	17 (16)	11 (20)	5 (13)	0 (0)
31-39	534 (48)	436 (48)	56 (51)	25 (46)	15 (40)	2 (25)
40-45	454 (40)	375 (40)	36 (33)	19 (34)	18 (47)	6 (75)
Years since diagnosis						
<1	222 (20)	175 (19)	23 (20)	17 (29)	6 (16)	1 (12)
1-2	295 (26)	242 (26)	28 (25)	13 (23)	9 (24)	3 (38)
3-5	174 (15)	141 (16)	13 (12)	7 (12)	9 (24)	4 (50)
>5	443 (39)	359 (39)	49 (43)	21 (36)	14 (36)	0 (0)
Type of surgery[†]						
Lumpectomy	470 (32)	369 (40)	57 (50)	19 (32)	20 (53)	5 (63)
Single mastectomy	296 (20)	230 (25)	39 (33)	14 (24)	12 (32)	1 (13)
Bilateral mastectomy	486 (33)	410 (43)	32 (28)	30 (51)	12 (32)	2 (26)
No surgery	20 (1)	17 (2)	2 (2)	0 (0)	1 (3)	0 (0)
Treatment[†]						
Chemotherapy	928 (63)	751 (81)	92 (81)	48 (81)	30 (79)	7 (88)
Radiation	705 (48)	575 (62)	72 (63)	30 (51)	22 (58)	6 (75)
Hormonal therapy	494 (34)	416 (45)	41 (36)	19 (32)	13 (34)	5 (63)
Other therapy	209 (14)	173 (19)	14 (12)	11 (19)	9 (24)	2 (25)

Note. Numbers in the group categories do not add to the total number of participants because of missing data.
[†]Participants checked all that applied.

How do young women want to receive information and support?

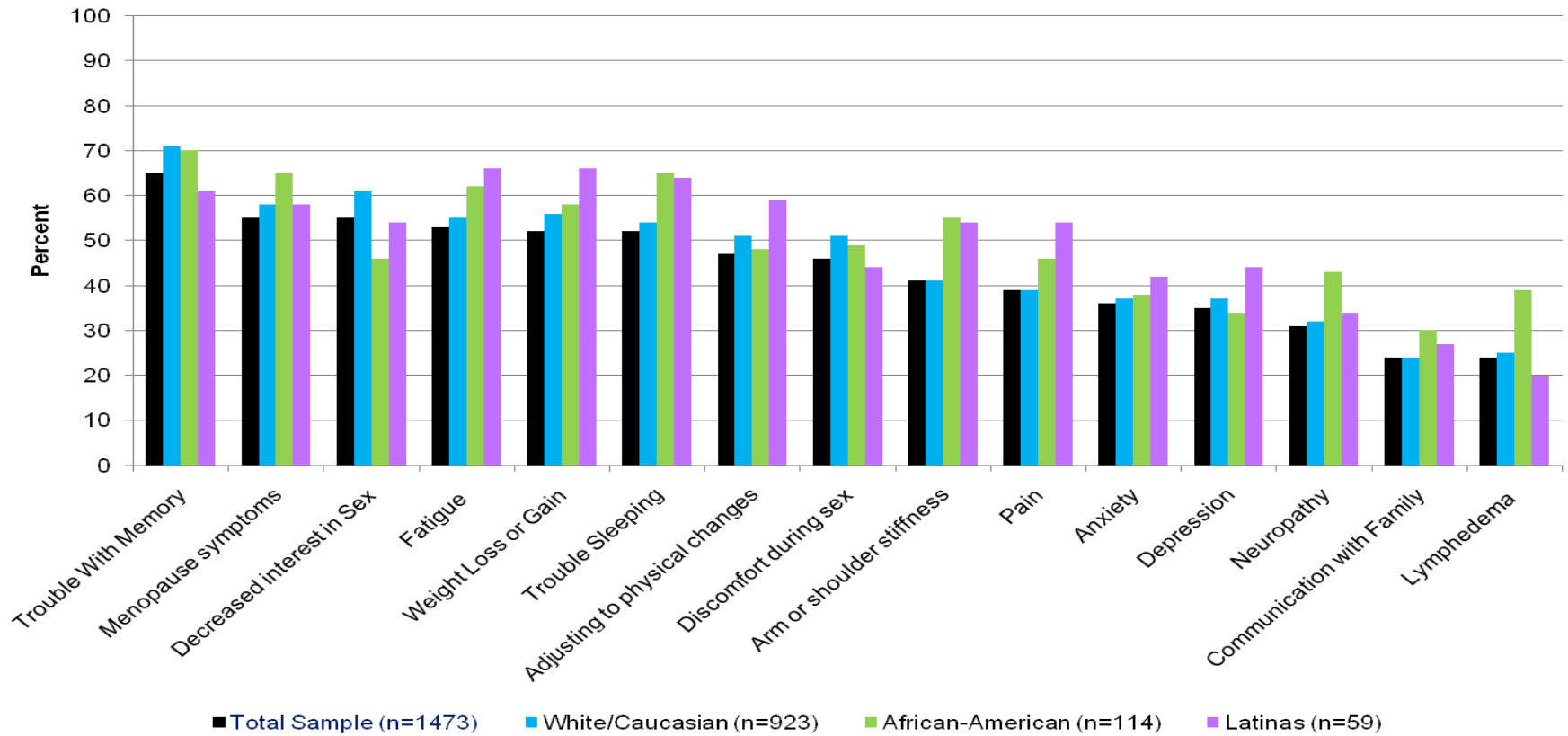
- 60% of young women indicated that it was very important to have emotional support services tailored to their needs as young survivors.
- 40% of women reported that it was not at all easy to find emotional support services tailored to their needs.
- 61% of African-American and 66% of Latinas indicated that it was very important to have emotional support services tailored to their needs as young women of color.

How do young women want to receive information and support?

- 50% wanted health and medical information in an online format and 20% preferred in person.
- 60% wanted emotional support to be delivered in person and 20% preferred online emotional support.
- 35% of women report that they seek information on breast cancer from any source on a weekly basis.



Current Side Effects



Interest in Breast Cancer Information

Top 10 Educational Topics of “High Interest”

1. Long-term health impacts	6. Exercise Treatment
2. New treatment and research	7. Breast cancer and the environment
3. Fear of recurrence	8. Managing weight gain
4. Nutrition and diet	9. Cognitive issues
5. Prevention of other illnesses	10. Communicating with healthcare team

Resources relevant to breast cancer and the environment was a topic of high interest but low availability by all respondent categories (75%).

Subgroup Differences:

- Breast cancer advocacy was of higher interest for women of color (33-40%)
- Sexuality and intimacy was of higher interest to women diagnosed under age 30 and long-term survivors (>5 years post diagnosis)
- Clinical research and future health planning were of higher interest for women living with metastatic breast cancer

Social Media Usage

- 66% of all women report regularly accessing the Internet through their cell phones.
- Facebook was the social media service that was the most used by respondents (86%).
- 58% of women who used social networking services reported sharing their personal experiences with breast cancer through social media.



Genetic Testing and Fertility Concerns

- 75% received genetic testing; African-Americans were less likely to receive genetic testing (61%).
- 50% reported seeing a genetic counselor or geneticist.
- 50% reported that fertility concerns was not discussed by their healthcare provider.
- Of those who discussed fertility with their providers, 30% initiated that conversation.



Needs Assessment Limitations

- National survey analysis only included online responses from women who had regular access to the Internet
- Limited ethnic, sexual orientation, education and diversity in sample
- Due to a lower response rate from minority women other than African-Americans, generalizability of findings to other minority young women with breast cancer is not possible.
- Relied on self-reported information.



Implications

- 1) Increasing Role of Technology especially in addressing informational needs
- 2) Face to Face support play an important component especially at the early phases, for women of color or advanced cancer
- 3) Age consideration hugely important, e.g., categories <33yrs, 34-40, 41-45
- 4) Stage at diagnosis and cancer progression must inform supportive care
- 5) Ethnicity, cultural and linguistic responsiveness facilitates acceptability and efficacy
- 6) Provider training critical – diagnostic and therapeutic care, genetics, follow-up care and surveillance, survivorship care
- 7) Role of advocates and peers to meet the needs of YWABC
- 8) Medical and supportive care needs intertwined, prognostic risk and anxiety, fear; fertility and sexual health tied to relational, social
- 9) Developing a shared care model, that includes oncology and primary care clinicians and to meet the medical and supportive care needs is urgent
- 10) The human, survivor and familial relation to care and service

Young Survival Coalition

*Focused on Meeting the Unique Needs of
Young Women with Breast Cancer*



CELEBRATING

15

YEARS

YOUNG WOMEN
FACING
BREAST CANCER
TOGETHER

1998 • 2013



Mission

Young Survival Coalition (YSC) is the **premier international organization** dedicated to the critical issues unique to **young women and breast cancer**. YSC works with survivors, caregivers, and the medical, research, advocacy and legislative communities to **increase the quality and quantity of life** for women diagnosed with breast cancer ages 40 and under.



Moving the Needle

Raising the bar on what we call success, we know:

- Young women are often over-treated
- Treatments have toxicities
- Toxicities impact quality and quantity of life
- We need evidence-based approaches

YOUNG SURVIVAL COALITION

RESEARCH
THINK  TANK

Driving the Agenda on Breast Cancer in Young Women

Young women
facing breast
cancer together.



Our Collective Goal

Drive real change in a smart and systemic way through refocusing the research community on the tough questions that will ultimately improve the quality and length of life for young women with breast cancer. The following six areas were identified for review:

- Factors that Increase the Risk of Breast Cancer in Young Women, including environmental
- Pregnancy and Breast Cancer
- Fertility
- Breast Cancer Treatment in Young Women
- Metastases
- Quality of Life and Survivorship

The Process of Progress

Phase I

Set up Think Tank
Invited Advocates & Medical Experts
Workgroups identified what we “know and still need to know” in six areas

Phase II

Came together to pool our knowledge
Recommended priority questions for YSC’s future research agenda & advocacy efforts

Phase III

Create and distribute summary report
Develop evidence based research agenda
Work with research, advocate and industry thought leaders to drive agenda

YSC Criteria for Priority Questions

Which research questions, if answered, would significantly impact the quality and quantity of life for young women diagnosed with breast cancer?

February 2013 – Phase II

- Fully collaborative process
 - Educated research advocates
 - Dedicated healthcare and research experts
- Phase I outcomes into Phase II presentations
- Informative and productive full-group dialog





Outputs to date

- Detailed Scope of Work
- Compiled Workgroup Preliminary Report
- Successful convening of 50+ project participants
- 20+ hours of audio files transcribed and under review
- Identification of suggested priorities
- Comprehensive outline of next steps





YOUNG SURVIVAL COALITION

RESEARCH
THINK TANK

Future Outputs

- Publish “State of the Research” on Young Women with Breast Cancer
- Educational initiatives
- Research Agenda focused on Young Women with Breast Cancer
- Move the agenda forward and monitor progress
- Collaborative work
 - Organizational partners
 - Industry partners
 - Providers
 - Constituents
- Appreciation to funders

AVON
Foundation
for Women

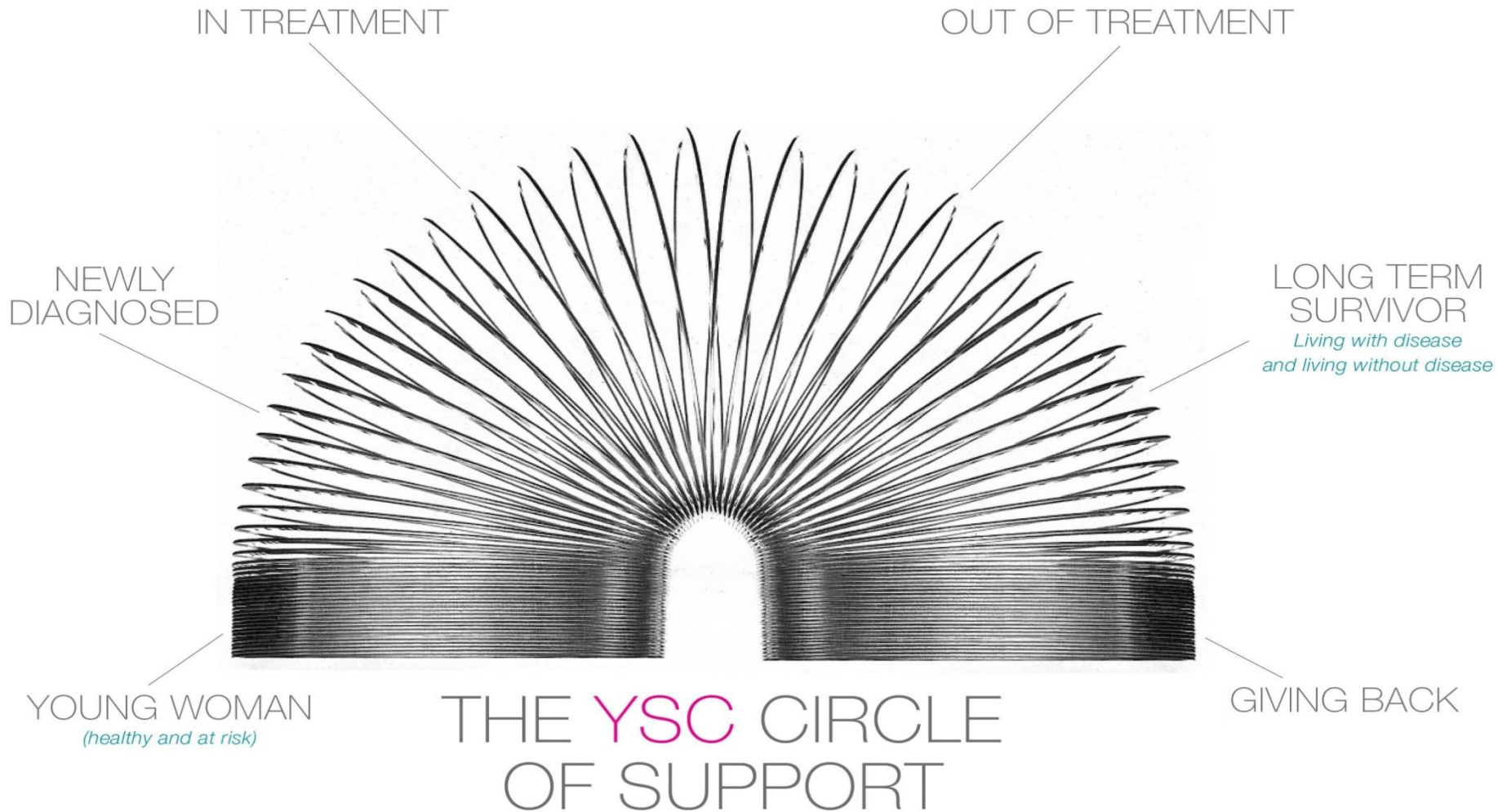
SUSAN G.
Komen
FOR THE
CURE



Young women
facing breast
cancer together.



The Home for Young Women



There is a place for every young woman with breast cancer at YSC.

Targeted Resources

- Newly Diagnosed Resource Kits
 - Three-ring binder, box, tote bag and evaluation
 - Comprehensive Treatment Navigator, brochures and resources



- Metastatic Navigator Resource

- Comprehensive, easy-to read 90+ page print resource reviewed by medical experts
- Forms
- Accordion style filing folder to facilitate organization
- Intuit Medical Manager software donated and available upon request

- What's Next? A Young Woman's Post-Treatment Navigator

- Targeted education and relevant resources,
- Robust glossary , removable Post-Treatment and Survivorship Care planning templates



- *Coming soon - Long-term Survivor's Resource*



*Connecting young survivors with **free** resources to educate, empower and support them during one of the most challenging times of their life.*

- **YoungSurvival.org** - Largest resource in the world for and about young women affected by breast cancer
- **Online Community Boards** - Forum for 24/7 support, from anywhere, even from your smartphone
- **ResourceLink** - Online database of national and local resources
- **SurvivorLink** - One-on-one peer support
- **Teleconferences & Webinars** - Topics designed for young women
- **FACE2FACE NETWORKING** - Equips young survivors to connect in their local communities



Young women
facing breast
cancer together.

Stay in Touch with YSC and LBBC!

Contact LBBC:

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Please submit your questions for the Q&A period.

Thank you for participating in today's webinar:

*Understanding the Unique Needs of
Young Women Affected by Breast Cancer.*

Please fill out the online webinar evaluation that will be
emailed to you at the end of today's program.

We appreciate your feedback!

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COALITION™
Young women facing breast cancer together.