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Young breast cancer survivors holding their age at diagnosis.

# press kit

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 /youngsurvivalcoalition

 @YSCBuzz

 YSC YoungSurvival

# YOUNG SURVIVAL COALITION - BACKGROUND

**Young Survival Coalition (YSC), headquartered in New York City, is the largest national 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 length of life for women who are diagnosed with breast cancer at the age of 40 or younger.

Three young breast cancer survivors founded YSC in 1998. All under age 35 at diagnosis, they were discouraged by the lack of information and resources available to young women, and they were concerned about the under-representation of this demographic in breast cancer research.

Unlike post-menopausal women who are overwhelmingly integrated into the design of clinical trials, young women diagnosed with breast cancer face higher mortality rates, fertility issues and the possibility and ramifications of early menopause.

YSC today has more than 160 Face 2 Face local networking groups nationwide and a vibrant online community board and Facebook community. The organization hosts the YSC Summit, the only national conference dedicated to the unique issues of young women with breast cancer. YSC also produces free educational resources, such as our navigator series, with useful information about every phase of treatment and survivorship. Visit [youngsurvival.org](http://youngsurvival.org) to learn more or order these or other YSC materials.

YSC seeks to change the face of breast cancer by: advocating for more research studies based on young women and breast cancer; educating young women about the importance of breast health; and serving as a support network to the 250,000 women living in the U.S. today who were diagnosed with breast cancer before their 41<sup>st</sup> birthday.

## YSC Offices

### HEADQUARTERS

80 Broad Street, Suite 1700  
New York, NY, 10004  
phone: 877.972.1011

### ATLANTA OFFICE

2300 Henderson Mill Road, Suite 311  
Atlanta, GA 30345  
phone: 404.250.6508

## WHAT WE DO – YSC PROGRAMS AND SERVICES

### YSC Conferences

These educational and inspiring conferences are for every young woman at any phase of the breast cancer experience, as well as their co-survivors. Find out more at [youngsurvival.org/conferences](http://youngsurvival.org/conferences).

#### YSC Summit – March 10-12, 2017 in Oakland, California

The largest conference in the world dedicated to young women affected by breast cancer. This three-day conference features inspirational speakers, workshops addressing the unique issues that young women with breast cancer face, and special wellness activities. Find the most up-to-date, evidenced based information and tools. It's also an opportunity to connect with a community of other young survivors and co-survivors.

[Learn more](#) about our upcoming YSC Summit.

### YSC Research Agenda

*YSC'S RESEARCH AGENDA ADVOCATES FOR ANSWERS*

YSC assembled a team of leading advocates, researchers and clinicians for an 18-month "Research Think Tank." YSC's goal is to drive real change by refocusing the research community on the tough questions that will ultimately improve and extend life for young women with breast cancer. To read YSC's Research Agenda and find out more, visit [youngsurvival.org/research-agenda](http://youngsurvival.org/research-agenda).

### YSC SYNC

YSC SYNC programs connect young women affected by breast cancer with **free** access to knowledge, experience, resources and support. Learn more at [youngsurvival.org/sync](http://youngsurvival.org/sync).

### Connecting Fellow Survivors

There are three easy ways for young women to connect with others who know what it's like to face breast cancer at a young age:

#### YSC Discussion Boards

The YSC discussion boards provide a forum for young women affected by breast cancer and their supporters. They can share experiences and information at any time of day or night. Connect online at [community.youngsurvival.org](http://community.youngsurvival.org).

#### YSC FACE 2 FACE Networking Groups (F2F)

YSC Face 2 Face peer-led networking groups bring together survivors in a local community. Groups can be based on location, similar diagnosis, interests or even age. To find a nearby YSC Face 2 Face group or learn how easy it is to start one, visit [youngsurvival.org/ysc-f2f](http://youngsurvival.org/ysc-f2f).

#### YSC SurvivorLink

YSC's SurvivorLink program allows young women to connect one-on-one with another young woman who shares a similar diagnosis, similar life experiences or concerns. To be connected, call YSC's toll-free number at 877.9721011, or email [resourcelink@youngsurvival.org](mailto:resourcelink@youngsurvival.org).

#### Online Video Support Groups

These facilitated online support groups allow young women affected by breast cancer to meet and share experiences no matter where they are. Participants meet monthly and can select from three different groups: In Treatment, Metastatic or and Under 30 group. To learn more visit [youngsurvival.org/sync/connect-online](http://youngsurvival.org/sync/connect-online).

## WHAT WE DO – YSC PROGRAMS AND SERVICES (Cont.)

### Educational Resources

YSC offers free resources unique to young women affected by breast cancer and those who care about them. Order and/or download materials for free through [youngsurvival.org](http://youngsurvival.org).

#### **youngsurvival.org**

It's the most comprehensive resource for and about young women affected by breast cancer in the world. Find information on medical research and updates on clinical trials. Order and download fact sheets, learn about upcoming educational offerings and access podcasts on past topics.

#### **Navigator Series**

Written specifically for young women, these guides provide useful information about every phase of treatment and survivorship. It includes versions for newly diagnosed, post treatment, long term and those living with metastatic breast cancer. To download or order a free navigator, visit [youngsurvival.org/programs/learn/resourcelink](http://youngsurvival.org/programs/learn/resourcelink).

**YSC Newly Diagnosed Treatment Navigator** - A complete resource of key terms, questions to ask healthcare teams, insights and information for newly diagnosed women.

**YSC Post-Treatment Navigator** - This comprehensive guidebook includes what to expect and how to manage life after initial breast cancer treatment. Includes worksheets to create a survivorship care plan.

**Long-Term Navigator** - Developed specifically for young women with a history of breast cancer, this resource includes tips and information on how to manage long-term side effects and move forward with life after diagnosis and treatment.

**YSC Metastatic Navigator** - A guide to living with metastatic breast cancer, including treatment options, advice and tools to help women stay well informed and well organized.

#### **ResourceLink**

Includes hundreds of national and local resources in a print guidebook and a searchable online tool at [youngsurvival.org](http://youngsurvival.org). Also, you can call 877.972.1011 or email [resourcelink@youngsurvival.org](mailto:resourcelink@youngsurvival.org) for assistance.

#### **METSLINK: Young Women Living with Metastatic Breast Cancer**

MetsLink is a suite of free resources to help women take a proactive role with their healthcare team. Resources include:

- Online Discussion Boards - Dedicated metastatic group, 24/7
- SurvivorLink - One-on-one metastatic peer support
- Metastatic Navigator - Resources and information to guide young women facing stage IV breast cancer
- Dedicated workshops at our YSC Summit

### Virtual Programming and Online Chats

YSC offers virtual programming and chat forums for young women with breast cancer. Past podcasts are available on the [Transcripts/Audio Files](#) page of YSC's website. View additional videos and YSC news on YSC's YouTube channel – [YSC Young Survival](#).

## WAYS TO GET INVOLVED

### **IGNITE: Volunteers Making a Difference**

YSC's volunteer program offers a variety of new opportunities to raise awareness, educate, support and fundraise to support young women affected by breast cancer. Volunteers work alone or with friends, at school, work or elsewhere in the local community. Each volunteer activity comes with tools, resources and a how-to guide. Find out more at [youngsurvival.org/ignite](http://youngsurvival.org/ignite).

### **YSC Tour de Pink**

YSC Tour de Pink® is the only multi-day bike ride for breast cancer in the United States, and it raises awareness and funds for YSC to fulfill its mission. Growing from five participants in 2004 to more than 500 riders, YSC Tour de Pink has generated more than \$7 million and now includes three-day rides in the South and on both coasts. To learn more, visit [ysctourdepink.org](http://ysctourdepink.org).

## WHAT PEOPLE ARE SAYING ABOUT YSC

*“There is no other organization like YSC. They get what it’s like to be young and to have your entire world turned upside down by a breast cancer diagnosis. YSC has educated me so that I can be an advocate for myself and others. And I cherish the life-long friendships that I have made with other young survivors through YSC.”*

– Jennifer, diagnosed at 27

*“YSC gives us hope and allows us to carry on in our journey and believe that there is something better on the horizon for us. And that cancer isn’t the period, but just the start of a sentence.”*

– Victoria, diagnosed at 30

*“YSC meant I was not alone...No one knows what you are going through like another young survivor.”* – Sara, diagnosed at 29

*“I am so thankful for the Metslink resources and community. Because of YSC, I’ve been able to not only get the help from others who are metastatic, but also offer help to others in return. We can discuss treatment options and side effects, and also speak frankly and lift each other’s spirits when we need it most. I am thankful every day for YSC!”*

– Diana, age 40 at stage II diagnosis, 42 at stage IV diagnosis

*“Being able to spread the word about YSC has been a fantastic experience. I have been able to reach out to survivors and their families in not only my community, but the surrounding communities, as well.”* – Heather, YSC volunteer, diagnosed at 28

*“I would do anything for YSC because of the support they provided for my daughter.”* – Jose, volunteer and father of Kayla, who was diagnosed at 22

*“Riding Tour de Pink was something that I never would have attempted before cancer. I had something to prove. YSC helped me do just that.”*

– Barb G., diagnosed at 40

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# YOUNG WOMEN AND BREAST CANCER

Breast cancer in young women is not simply a disease diagnosed at a young age. Rather, it has biological characteristics and treatment concerns that differ from breast cancer diagnosed in postmenopausal women.

## THE FACTS

Despite common misconceptions, young women **can** and **do** get breast cancer. Here are the startling facts:

- Breast cancer is the most common cancer in women ages 15 to 39.<sup>1</sup>
- There is currently no effective breast cancer screening tool for women 40 and younger, most of whom have dense breast tissue that prevents routine mammograms from being a useful screening tool.
- Nearly 80 percent of young women diagnosed with breast cancer find their breast abnormality themselves.<sup>2</sup>
- The American Cancer Society projects 231,840 new cases of invasive breast cancer among U.S. women annually, as well as an estimated 60,290 additional cases of in situ breast cancer.<sup>3</sup>
  - It is estimated that 12,150 cases of breast cancer will be in women under age 40.<sup>3</sup> Approximately 26,393 women will be under 45 years of age when diagnosed.<sup>4</sup>
  - It is projected that more than 1,000 women under age 40 will die from breast cancer each year.<sup>3</sup>
- Young women are more likely to have aggressive subtypes of breast cancer, including triple negative and HER2+ disease<sup>5</sup>, larger tumor sizes and higher incidence of lymph node involvement.<sup>6</sup>
- Today, there are an estimated 250,000 breast cancer survivors living in the U.S. who were diagnosed at age 40 or younger.<sup>7</sup>

## THE ISSUES “COLLATERAL DAMAGE”

Young women diagnosed with breast cancer face myriad issues that may significantly impact their quality and length of life. These issues are often amplified for women diagnosed with metastatic breast cancer, including:

- **Lack of research:** As the incidence of young women with breast cancer is much lower than in older women, young women are often underrepresented in research studies.
- **Pregnancy:** Breast cancer is the most common form of cancer in women who are pregnant or have recently given birth<sup>8</sup>, occurring once in every 3,000 pregnancies.<sup>9</sup> An estimated 30 percent or more of all breast cancer in young women is diagnosed in the few years after a woman has had a baby.<sup>10</sup>
- **Early onset menopause:** Chemotherapy and hormonal treatments can sometimes bring on premature menopause, which can significantly impact quality of life.
- **Fertility:** Breast cancer treatment may affect a woman's ability and plans to have children.
- **Child rearing:** Many young women are raising small children while enduring treatment and subsequent side effects.
- **Financial challenges:** Breast cancer can dramatically impact a young woman's financial stability due to workplace issues, lack of sufficient health insurance and the cost of cancer care.
- **Body image:** It is challenging for some women to embrace their new body after breast cancer-related surgery and/or side effects of medically induced menopause.
- **Relationships and dating:** Whether married or single, intimacy issues may arise for women diagnosed with breast cancer.

### Citations

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## **YSC LEADERSHIP**

### **Jennifer Merschorf, Chief Executive Officer**

With more than 15 years of experience in both the nonprofit and for-profit sectors, Jennifer brings a new voice to philanthropy and a new style of nonprofit leadership. She has the ability to merge traditional business strategy and large-scale nonprofit training with innovative thinking and strategic planning.

Jennifer strives to be a strong voice for all young women facing breast cancer, ensuring that they know they do not need to face this disease alone. As a young breast cancer survivor herself (diagnosed at age 36), Jennifer understands the importance of ensuring all young women have access to YSC's unique resources

Originally from San Francisco, Jennifer began her career in corporate marketing and sales. She began her nonprofit career with the national Sierra Club, where she became a Director of Operations & Finance. Jennifer later served as the Director of Development for New Yorkers for Parks after relocating to New York City. Most recently, she was the Director of Finance for Soliya, an innovative international nonprofit focused on young adults.

Jennifer holds an MBA from the University of San Francisco and a BA from Washington State University. She also earned certification from National Breast Cancer Coalition's Project LEAD®, an educational course for breast cancer advocates.

### **Stacy Lewis, CHES, Chief Program Officer and Deputy Chief Executive**

Stacy bolsters YSC's ability to serve its constituents, bringing more than 12 years of experience creating, developing and running services and programs for those with special healthcare needs. Her primary goal is to enhance the organization's ability to run rewarding programs while leading new initiatives—including programs that address the needs of young women from diverse backgrounds and those living with metastatic disease.

Before joining YSC, Stacy spent five years as the deputy director and director of programs for SHARE: Self-help for Women with Breast or Ovarian Cancer. Before that, she served as the community executive and director of breast health for the American Cancer Society, Eastern Division. Stacy graduated from William Paterson University and earned credentials as a Certified Health Education Specialist (CHES) from the National Commission For Health Education Credentialing, Inc.