

Young Women United Against Breast Cancer<sup>SM</sup>

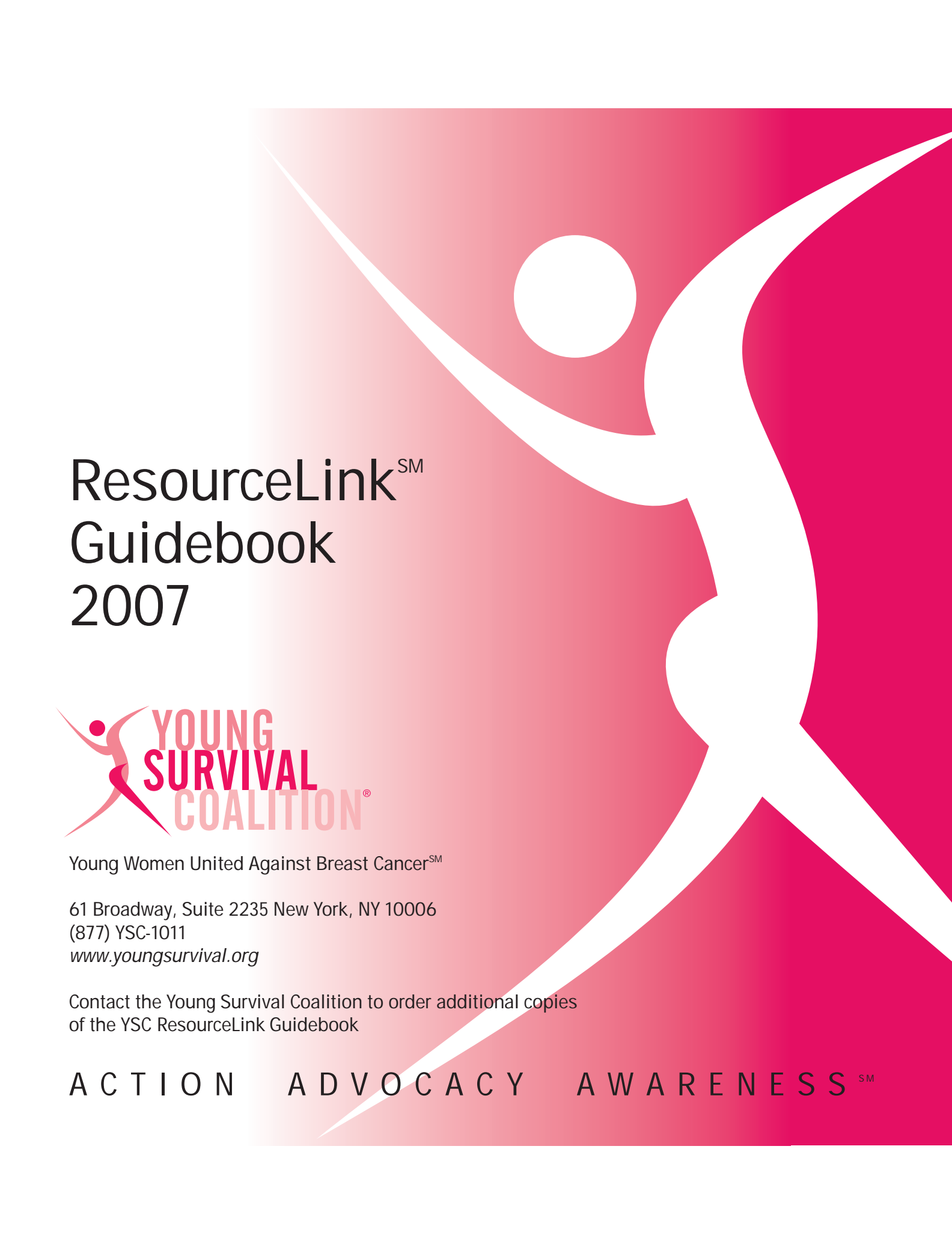


# ResourceLink<sup>SM</sup> Guidebook 2007



ACTION    ADVOCACY    AWARENESS<sup>SM</sup>

Young Survival Coalition® and YSC ResourceLink<sup>SM</sup> are registered service marks of the Young Survival Coalition. The *YSC ResourceLink Guidebook* is copyrighted by the Young Survival Coalition, all rights reserved.



# ResourceLink<sup>SM</sup> Guidebook 2007



Young Women United Against Breast Cancer<sup>SM</sup>

61 Broadway, Suite 2235 New York, NY 10006  
(877) YSC-1011  
[www.youngsurvival.org](http://www.youngsurvival.org)

Contact the Young Survival Coalition to order additional copies  
of the YSC ResourceLink Guidebook

A C T I O N    A D V O C A C Y    A W A R E N E S S <sup>SM</sup>

# TABLE OF CONTENTS

Welcome letter	4	5. Diagnosis	59
Young Survival Coalition mission	5	Biopsies	59
Disclaimer	5	How to find a breast specialist	60
<b>1. Young Survival Coalition Resources</b>	<b>6</b>	Pathology	60
Publications	6	<b>6. Treatment</b>	<b>61</b>
National programs	8	Treatment	61
Affiliates	9	Making treatment choices	61
<b>2. General Resources</b>	<b>11</b>	Working with your healthcare team	61
Personal stories	11	Diagnosis and treatment during pregnancy	62
Breast cancer information	14	Inflammatory breast cancer	62
Handbooks and workbooks	17	YSC Fact sheet: <i>Frequently asked questions</i>	
National breast cancer organizations	18	<i>about inflammatory breast cancer</i>	62
National cancer organizations	21	Recurrent breast cancer	64
National young adult cancer organizations	24	Advanced/metastatic breast cancer	65
Finding breast cancer resources online	24	Clinical trials	66
Local and statewide organizations		Breast surgery	67
and resources by state	26	Chemotherapy	67
International organizations:	43	Radiation	68
Europe	43	Complementary therapy	68
Australia	43	Treatment side effects	70
Canada	44	Managing side effects	70
Ireland	44	Fertility	71
New Zealand	45	Menopause	72
United Kingdom	45	Sexuality and intimacy	73
<b>3. Special Populations</b>	<b>46</b>	Body image	74
African American women	46	Breast reconstruction and prostheses	75
American Indian/Alaska Native women	47	Reconstruction	75
Asian American women	49	Prostheses	75
Jewish women	50	How to find post-mastectomy products	76
Latinas	50	Hair loss	76
Spanish language resources	51	Nausea	78
Women with disabilities	52	Fatigue	79
Women who partner with women	53	Lymphedema	79
<b>4. Genetics, Family History and Risk</b>	<b>55</b>	Managing lymphedema	79
YSC Fact sheet: <i>Frequently asked questions</i>		Osteoporosis	81
<i>about hereditary breast cancer</i>	55	Pain management	81
		Managing cancer pain	82

<b>7. Financial, Insurance and Legal Resources</b>	<b>83</b>	<b>11. Wellness and Moving Forward</b>	<b>129</b>
Financial assistance	83	Exercise, diet and breast cancer	129
Obtaining financial assistance	83	Exercise	129
National financial assistance	84	Nutrition	130
State and local financial assistance programs	87	Beauty and body image	131
Air transportation	101	Retreats and adventures	132
Drug assistance	102	Spirituality and religion	134
Scholarships and grants	104	Moving forward	135
Insurance assistance	106	Becoming a parent after breast cancer	136
Navigating your insurance plan	106	Follow-up medical care	137
Legal resources	107	Getting involved and advocacy	138
Employment resources	108		
<b>8. End of Life</b>	<b>110</b>	<b>12. Support Groups</b>	<b>140</b>
Dying well	110	How to find a breast cancer support group	140
Grief resources for adults	111	Support group listing	141
Grief resources for children	111		
<b>9. Family, Friends and Caregivers</b>	<b>114</b>		
Providing emotional support	114		
Resources for partners	115		
Partners coping with breast cancer	116		
Resources for single and dating women	117		
Resources for children	118		
YSC Fact sheet:			
<i>Helping children cope with breast cancer</i>	118		
Resources for parents of young women	125		
Resources for friends of young women	125		
<b>10. Living with Advanced/ Metastatic Breast Cancer</b>	<b>126</b>		
Coping and adjusting	127		
Caregivers	128		

All listed programs and resources are free unless otherwise noted.

 *Throughout this Guidebook, organizations, resources and support groups that focus specifically on young women affected by breast cancer are notated with this symbol.*

# WELCOME

Welcome to the first edition of the Young Survival Coalition (YSC) ResourceLink Guidebook.

If you are living with breast cancer, you are not alone. While breast cancer in young women accounts for a small percentage of all breast cancer cases, the impact of this disease is widespread: There are more than 250,000 women in the U.S. who were diagnosed with breast cancer at the age of 40 or under, and over 11,100 young women will be diagnosed in the next year. Despite all this:

- Many young women and their doctors are unaware that they are at risk for breast cancer.
- There is no effective breast cancer screening tool for women 40 and under.
- Young women are often diagnosed at a later stage than their older counterparts.
- There is very little research or educational material focused on issues unique to this younger population, such as fertility, pregnancy, genetic predisposition, the impact of hormonal status on the effectiveness of treatment, psycho-social and long-term survivorship issues, and higher mortality rates for young women, particularly for African Americans and Latinas.
- Young women diagnosed with breast cancer often feel isolated and have little contact with peers who can relate to what they are experiencing.
- As the incidence of young women with breast cancer is much lower than in older women, young women are underrepresented in many research studies.

For these reasons the YSC encourages young women to become advocates for their own health and become educated about breast cancer. This Guidebook is meant to be a tool for young women, their supporters and healthcare professionals to access important information and resources.

In the pages of this Guidebook, you will find information and resources for young women affected by breast cancer, about young women affected by breast cancer, and those created by young women affected by breast cancer. But, do know that this book is also an incredible resource for all women who are diagnosed with breast cancer, and not just young women.

We created this Guidebook in the hopes that it will become your lifeline to all the resources, support, programs, educational services, treatment information and more that you need to navigate the continuum of your breast cancer experience—from diagnosis, treatment and post treatment to long-term survivorship.

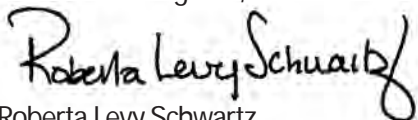
Here you will find:

- Local and national resources specifically for young women living with breast cancer from the YSC and other organizations.
- Local, statewide and national financial assistance resources for detection, diagnostic tests and treatment for breast cancer for those who are uninsured or underinsured.
- A list of over 450 breast cancer support groups either specific to young women or to special populations or a general breast cancer population where young women are significantly represented.
- Personal stories written by young women affected by breast cancer.

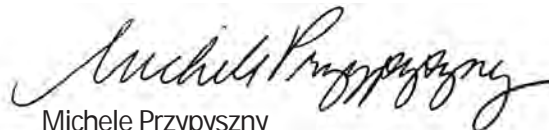
These pages bring to you a community of young women affected by breast cancer, so you have a place to turn and know that you are NOT alone.

We hope you will find this book to be as useful a resource as we do. And, as this book is the first edition of the ResourceLink Guidebook, we welcome your feedback as we begin to embark on the second edition. Please feel free to send us your comments and let us know if you can't find what you need. Contact us at [ResourceLink@youngsurvival.org](mailto:ResourceLink@youngsurvival.org) or (877) YSC-1011. Thank you for taking the time to help the YSC help those who need us most—young women affected by breast cancer.

Our warmest regards,



Roberta Levy Schwartz  
President, Board of Directors



Michele Przepyszny  
CEO

---

## YSC Mission Statement

The Young Survival Coalition (YSC) is the only international, non-profit network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer. Through action, advocacy and awareness, the YSC seeks to educate the medical, research, breast cancer and legislative communities and to persuade them to address breast cancer in women 40 and under. The YSC also serves as a point of contact for young women living with breast cancer.

## YSC Background

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

Unlike their post-menopausal counterparts, young women diagnosed with breast cancer face higher mortality rates, fertility issues and the possibility and ramifications of early menopause. The YSC seeks to change the face of breast cancer by advocating to increase the number of studies about young women and breast cancer and being a point of contact for other young women with breast cancer.

“ ‘Young women don’t get breast cancer’ is a refrain we hear frequently,” says Roberta Levy Schwartz, president of the YSC. “Yet, here we are, right in front of the medical and research communities representing the global voice of all young women living with breast cancer. If they begin studying breast cancer in young women, they may unlock the key to why all women are diagnosed with this deadly disease.”

Today, the YSC is a growing international group of thousands of survivors and supporters. The YSC is based in New York City and has eight affiliates and six community volunteer groups in the U.S. and countless volunteers across the country and abroad.

### Disclaimer:

This information is designed for educational, informational and community purposes only as a resource to young women and the people in their lives who are affected by breast cancer. For answers to specific health care questions or concerns, you should consult your health care provider, as treatment for each patient varies with individual circumstances. The content is not intended in any way to be a substitute for professional counseling or medical advice. You should not rely upon information found in this publication without seeking the advice of a qualified healthcare provider. The YSC does not endorse, recommend, or make any warranties or representations regarding any of the materials, products or information provided by organizations referred to in this guidebook.

### Conditions of use:

The *YSC ResourceLink Guidebook* is copyrighted by the YSC and is the exclusive property of the YSC, all rights reserved. Portions of the *YSC ResourceLink Guidebook* may be photocopied for non-commercial use, exclusive of republication. To receive permission to reprint or reproduce any portion of this Guidebook for any other purpose please contact, [ResourceLink@youngsurvival.org](mailto:ResourceLink@youngsurvival.org) or (877) YSC-1011.