



Living Beyond Breast Cancer

Joint Statement on the Breast Cancer Education and Awareness Requires Learning Young (EARLY) Act of 2009 (H.R. 1740, S. 994)

By Young Survival Coalition®, Susan G. Komen for the Cure® Advocacy Alliance, Living Beyond Breast Cancer® and Breast Cancer Network of Strength®

Each year, almost 24,000 women under age 45 are diagnosed with breast cancer in the U.S., and almost 3,000 women under age 45 will die of the disease this year. ⁱ Today there are more than 250,000 breast cancer survivors in the U.S. who were diagnosed at age 40 or younger.ⁱⁱ The biology and psychosocial needs of young women with breast cancer often differ from their older, post-menopausal counterparts. While a diagnosis of breast cancer is devastating at any age, it is especially so for young women. A breast cancer diagnosis at the very beginning of a woman's adult life can derail her career path, affect her ability to bear children, impact her ability to partner and for many, lead to premature death.

A shared goal of our organizations is to increase the quality and quantity of life for young women with breast cancer. We believe the Breast Cancer Education and Awareness Requires Learning Young Act of 2009, or EARLY Act (H.R. 1740, S. 994), which focuses on women under age 45, will help fulfill this goal.

The Breast Cancer Education and Awareness Requires Learning Young Act of 2009, referred to as the "EARLY Act," was originally introduced in the U.S. House (H.R. 1740) in March 2009 by Debbie Wasserman Schultz (D-FL), Sue Myrick (R-NC), Donna Christensen (D-VI) and Rosa DeLauro (D-CT). In May 2009, a similar version was introduced in the U.S. Senate (S. 994) by Amy Klobuchar (D-MN) and Olympia Snowe (R-ME). The bill's sponsors have worked closely with our organizations' staff and scientific advisors, as well as others in the cancer community, to develop and enhance the language. Senator Klobuchar's version of the bill reflects this ongoing conversation by increasing the targeted age to under age 45, emphasizing evidence-based messaging and adherence to the peer-reviewed guidelines developed by the National Comprehensive Cancer Network (NCCN). This paper is based on the Senate version of the bill, which the House bill will be changed to reflect during markup. The EARLY Act would create:

- A public health campaign to teach young women that breast cancer can and does occur in young women, but more importantly to help them establish good breast health habits to follow as they mature;
- An education campaign to increase awareness among health care providers that breast cancer occurs in young women and knowledge of the risk factors for breast cancer in young women; and
- Support services for young women with breast cancer.

The EARLY Act does not:

- Advocate that women under age 40 have regular screening mammography; nor,
- Promote breast self examination as the only means for breast cancer detection.

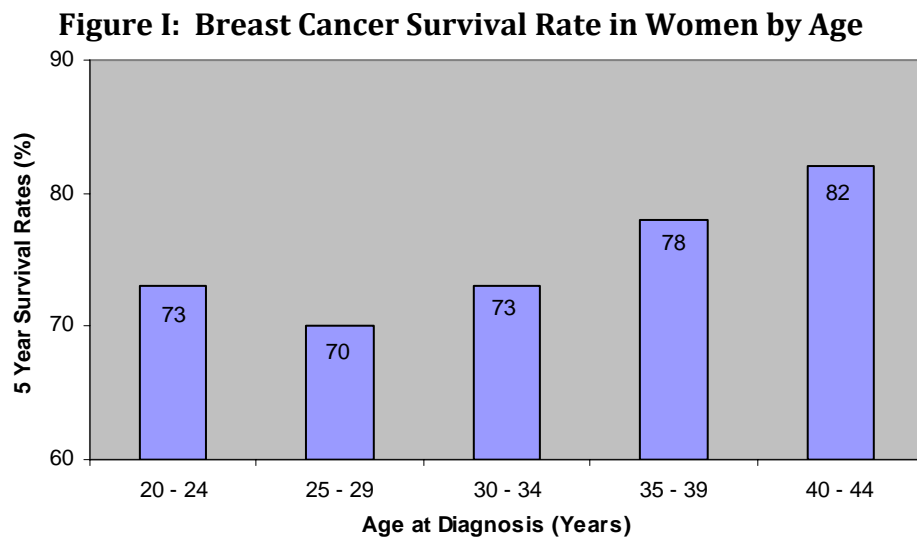
This position paper discusses (1) breast cancer in young women, (2) the level of knowledge among young women about their risk of breast cancer and programs that target young women, (3) the level of provider education about breast cancer in young women and (4) the need for support services for young women with breast cancer.

Breast Cancer in Young Women

According to the American Cancer Society, about 250,000 breast cancer cases will be diagnosed in the U.S. this year, of which about 10 percent will be diagnosed in women under age 45.ⁱⁱⁱ While 24,000 may seem small compared to the total number of women diagnosed annually, it is a significant number — especially when compared to other cancers. After all, breast cancer is the leading cause of cancer deaths in women under 40.

iv

Breast cancer in young women tends to be more aggressive and it tends to be diagnosed at later stages than for older women. In fact, according to cancer statistics presented by the National Cancer Institute, the 5-year relative survival rate is lowest in women diagnosed with breast cancer before age 40 (82 percent) compared to women diagnosed at ages 40 and older (89 percent).^v When the numbers are separated by age, the disparities in survival rates among younger women become more stark.^{vi} (See Figure I.)

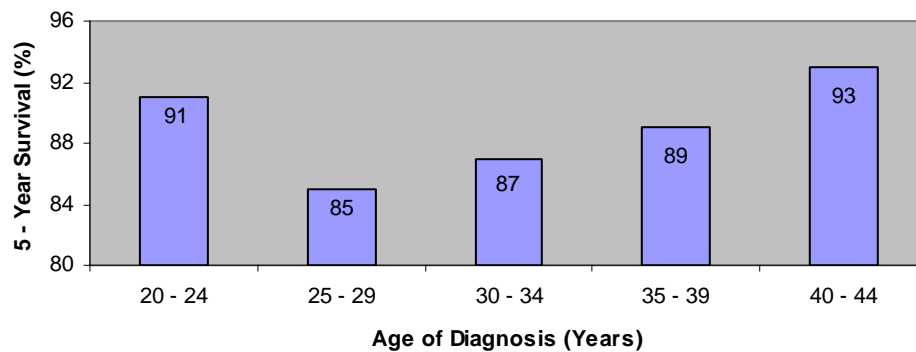


Source: Bleyer A, O'Leary M, Barr R, Ries LAG (eds): *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD 2006. Available online at <http://seer.cancer.gov/publications/aya/>

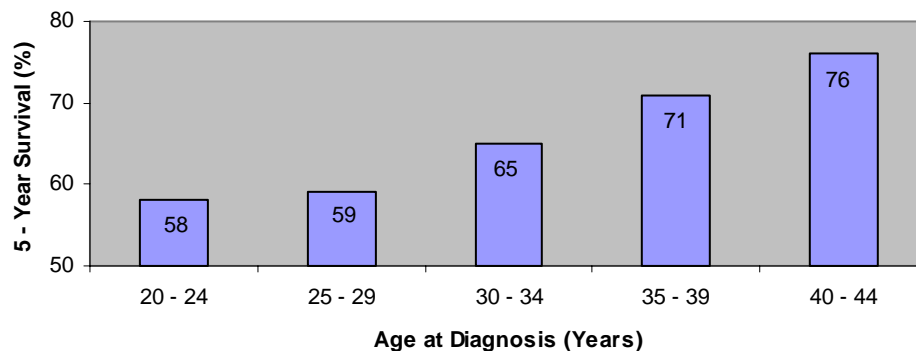
As can be seen in Figures II, III and IV, the decreased survival rates in young women are generally present at any stage of diagnosis, whether the breast cancer is localized to the

breast, regional (cancer has spread beyond the breast to the lymph nodes), or metastatic (cancer has spread to other organs).

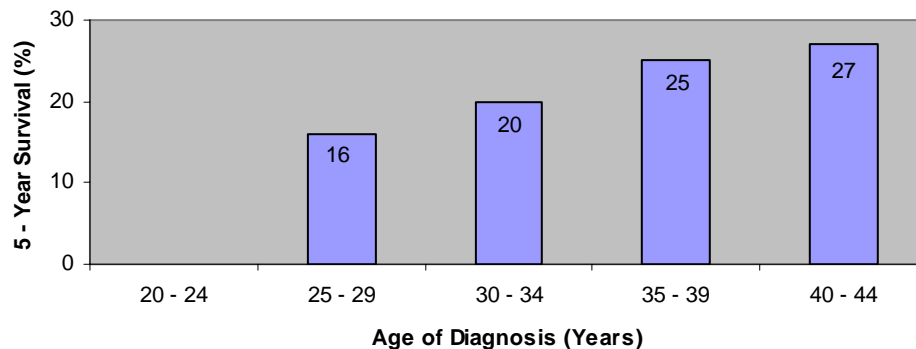
**Figure II: Breast Cancer Survival by Stage and Age at Diagnosis
Localized**



**Figure III: Breast Cancer Survival by Stage and Age at Diagnosis
Regional**



**Figure IV: Breast Cancer Survival by Stage and Age at Diagnosis
Metastatic**



Source: Bleyer A, O'Leary M, Barr R, Ries LAG (eds): *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD 2006. Available online at <http://seer.cancer.gov/publications/aya/>

Biology of Breast Cancer in Young Women. Breast cancer in young women tends to be a more aggressive disease. A recent study by Anders et al found that women age 45 and younger are more likely than women age 65 and older to have:^{vii}

- Higher rate of triple negative breast cancer,^{viii}
- Higher grade tumors,
- Larger tumor sizes, and
- Higher incidence of lymph node involvement

Ultimately, women age 45 and younger have a lower disease free survival rate than women age 65 and older — women under age 40 had an even worse disease free survival rate than women age 40 to 45.^{ix}

There are also racial and ethnic disparities in types of breast cancer among younger women. Many sociopolitical factors contribute to health disparities by race and ethnicity, including access to health care and behavior. Yet, at least some of the differences in health outcomes are related to differential incidence of breast cancer subtype by race and ethnicity. The Carolina Breast Cancer Study, an examination of breast cancer subtypes by race, showed that 39 percent of pre-menopausal African American women had generally more aggressive triple negative breast cancer versus 16 percent of non-African American women of all ages.^x This highlights the particular risks young African American women face when diagnosed with breast cancer.

Genetic Testing and Breast Cancer in At-Risk Populations. Genetic testing provides people the chance to learn if their family history of breast cancer may be due to a BRCA1 or BRCA2 mutation. However, only 5 to 10 percent of breast cancers are related to an inherited genetic mutation.^{xi} Most breast cancers, even in young women, are not related to a clear inherited genetic mutation in BRCA1 or BRCA2, but for people who have these mutations, the risk of breast cancer is greatly increased. In these cases, there are certain steps people can take to try and decrease this risk. Although it is widely advertised, genetic testing is only recommended for people who have the following:

- A strong family history of breast cancer at an early age
- A family history of breast and ovarian cancers
- A family history of male breast cancer
- Ashkenazi Jewish heritage who also have some family history of breast or ovarian cancer

Although BRCA testing requires just a blood sample, many risks and benefits should be considered before being tested. Because of the potential physical, emotional and financial impact of knowing one's genetic status, testing for the BRCA mutation is recommended **only** after genetic counseling for people with strong family or personal history of breast cancer — race or ethnicity alone is not a reason for pursuing genetic testing.

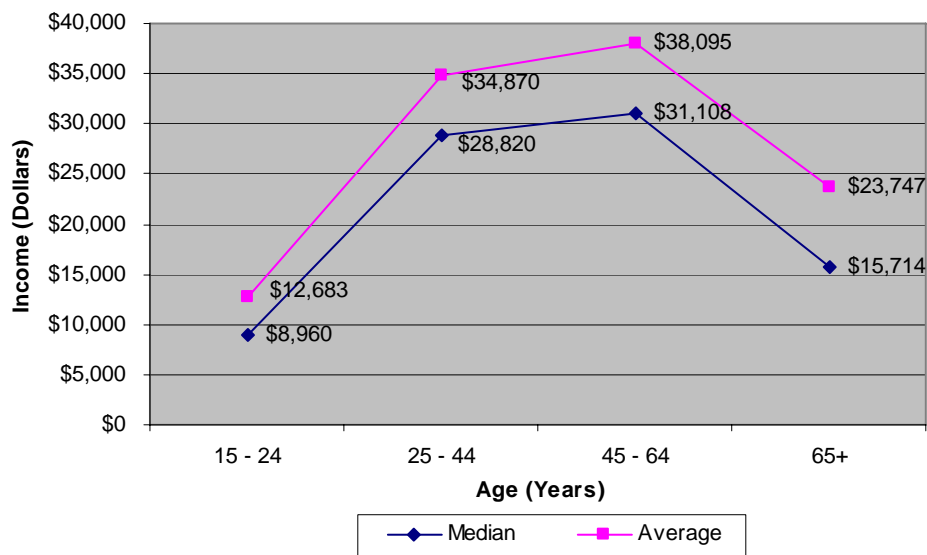
Psychosocial and Socioeconomic Issues for Young Women with Breast Cancer.

Breast cancer in young women comes at time of great change in a woman’s life. Careers, dating, fertility and child rearing are high priorities for most young women.

A cancer diagnosis has particular implications for young women in the beginning stages of their careers. The rigors of cancer treatment may force a person to cut back working hours or leave the workforce entirely, which will set back their efforts to establish themselves professionally. Further, when a young cancer survivor re-enters the workforce, she will have less work history to reference when seeking employment than someone who leaves the workforce at an older age. People with less work experience or inconsistent work patterns are likely to earn less and are at a disadvantage when competing for jobs and career advancements in today’s highly competitive employment market.

Figure V presents median and average incomes for women in different age brackets. From a career perspective, women from age 20 to 45 are in the beginning stages of their earning capacity. As the figure shows, income increases dramatically for women during this time period from \$12,683 to \$34,870.

Figure V: Income Distribution Among Women



Source: U.S. Census Bureau

Unemployment is a significant issue with young breast cancer survivors. A review of cancer survivors and unemployment studies showed that in the United States cancer survivors are 1.37 times more likely to be unemployed than the rest of the population, with increased risk for survivors of breast cancer, gastrointestinal cancer and cancer of the female reproductive organs.^{xii} This trend is borne out in the Young Survival Coalition’s 2009 Constituent survey of its survivor base conducted in May of this year, which showed that the unemployment rate among young cancer survivors is a startling 22 percent.^{xiii}

Further corroborating the potential disruptive effect of breast cancer in young women, the survey showed that within the first two years after diagnosis:

- 5 percent were involuntarily laid off
- 16 percent had their employment hours reduced
- 13 percent felt discriminated at work because of their breast cancer diagnosis

Another primary concern for young women being treated for breast cancer is loss of fertility. The early menopause that can be caused by chemotherapy can be very difficult for women who had hoped to either have a first child or add to the family they already have. Chemotherapy and tamoxifen can each damage the ovaries, causing irregular periods or stopping periods altogether.

By age 40, more than 95 percent of women have completed childbearing.^{xiv} One of the key decisions a young woman has to make as her breast cancer treatment plan is developed is whether or not she wishes to have children. A recent study conducted by the Young Survival Coalition and the Dana Farber Cancer Institute revealed that:^{xv}

- 48 percent of the women had at least one child prior to their breast cancer diagnosis
- 56 percent of the women reported they were considering having additional children
- 39 percent of the women surveyed indicated they were either concerned or very concerned about the impact of chemotherapy on their fertility
- This concern increased depending upon the age at diagnosis, marital status and number of prior pregnancies and live births
- 29 percent of the women reported that their fertility concerns impacted their chemotherapy decision

There are several steps women can take that may help preserve their ability to have children after treatment. Because of these unique needs and challenges, it is critical that young women receive the support services they need so that they can successfully navigate through their breast cancer diagnosis. This is one reason why the EARLY Act's grants for support services targeted toward young women diagnosed with breast cancer are so important.

Knowledge Among Young Women about Breast Cancer Risk

A key question underlying the need for the EARLY Act is whether young women know they can get breast cancer. The 2009 YSC Constituency Survey of its survivor constituents asked this exact question of breast cancer survivors. An astounding 40 percent of young women with breast cancer responded that prior to diagnosis they did not know a young woman could get breast cancer.^{xvi}

Given the large proportion of women unaware that breast cancer can occur in young women, we believe this is an opportunity to teach young women good breast health habits that can be carried with them for a lifetime. And in addition to benefiting themselves the

information may also be shared with their mothers, grandmothers and older female relatives and friends.

Considerable time and effort is spent in the cancer community educating teenagers and young women about the issues of breast health and cancer in general. The Lance Armstrong Foundation offers a fully developed cancer education curriculum talking about cancer starting from the elementary school to the collegiate level.^{xvii} Susan G. Komen for the Cure and its Affiliates have granted almost \$3 million for secondary school breast health education programs over the past three years. Since 1990, Breast Cancer Network of Strength “Just for Teens” program has educated over 200,000 teens about the importance of breast health and awareness. The Young Survival Coalition has offered a high school and collegiate program since 2006 to educate young women about the issues of breast cancer in young women.

While breast cancer in young women can be scary, if it is handled in a factual and age-appropriate manner, it can give young women facts they can use for their lifetimes. The EARLY Act seeks to develop such a campaign with the advice of a council of medical professionals and advocates. The intent of this collaboration would be to give young women the most recent, evidence-based information about breast cancer in young women, of which a key component would be information about breast cancer screening.

Screening for breast cancer in young women. The EARLY Act has been subject to criticism because of the perception that the Act advocates the use of breast self-examination for early detection of breast cancer in young women, or that it encourages mammography be used to screen young women.

There is currently no effective method for screening young women for breast cancer. Because of the density of young women’s breasts, mammography is often ineffective. Similarly, breast density also impacts the effectiveness of breast MRI in young women, and MRIs are prohibitively expensive for routine screening. Not surprisingly, nearly 80 percent of young women ultimately diagnosed with breast cancer find their breast abnormality themselves.^{xviii} In the absence of an effective early detection methodology for young women, the best messages we can give them at this time is to “know your body,” be aware of the signs of breast malignancy and be aware of their breast cancer risks.

Our organizations have been in the forefront of advocating that breast self-examination should not be relied on as a screening methodology. We, like the other major cancer organizations and NCCN, advocate breast self-awareness. As part of self-awareness, a woman is encouraged to be aware of how her breasts normally look and feel — if a change is found, a young woman should seek the advice of a health professional. At the same time, young women are encouraged to know their risk including family medical history and personal risk factors, as well as get recommended mammograms and clinical breast exams at the appropriate age and time interval as directed by their health care providers. Breast self-examination should not be substituted for these other screening tests.

Both the American Cancer Society^{xix} and the authoritative National Comprehensive Cancer Network (NCCN) say women should be familiar with their breasts and promptly report changes to their health care provider. The NCCN goes on to say that periodic, consistent breast self-examination may facilitate breast self-awareness.^{xx} While it is entirely acceptable not to do regular breast self-exams or not to do it on a fixed schedule, if you do regular breast exams, you get to know how your breasts normally look and feel, and can more easily notice changes.

The Senate version of the EARLY Act proposes that the breast health program follow standard accepted guidelines from NCCN, which are developed and reviewed regularly by a multi-disciplinary group of breast cancer experts, and the House version will be changed to match, during the markup of the bill. Furthermore, a lack of cumulative answers for risk reduction and early detection methods for young women does not justify ignoring this population. Rather, the EARLY Act rightly bases outreach to young women on the recommendations of an advisory committee of breast cancer experts, so that as the science evolves — and new evidence-based methods are developed — so, too, will the messaging.

Finally, we believe more research is needed to find a cost-effective screening tool to diagnose breast cancer in young women.

Knowledge Among Providers about Breast Cancer in Young Women

One of the key aspects of the EARLY Act is provider education about breast cancer in young women and the unique challenges young women face. The issue is two-fold: (1) primary care providers have not integrated into their standard care screening for women at high-risk of breast cancer^{xxi} and (2) when presented with a young woman with a breast abnormality, breast cancer is too often overlooked or considered an unlikely diagnosis, resulting in delayed or missed diagnosis.

A recent multicenter study of young women diagnosed with breast cancer from Dana-Farber Cancer Institute found that nearly 25 percent delayed seeking medical attention and 25 percent experienced a delay in diagnosis *after* seeking medical attention.^{xxii} In addition, Oeffinger et al., recently studied the surveillance practices among women previously treated with chest radiation for childhood cancer — women at increased risk of breast cancer at a young age and for whom screening mammography is recommended starting at age 25 or eight years after radiation. Nearly two-thirds (63.5 percent) of those age 25 through 39 had not been screened in the previous two years, and the two most often cited reasons were their “doctor didn’t order it” (31 percent) and “I’m too young” (30 percent).

There are also legal and financial reasons for providers to learn more about breast cancer in young women. Delayed diagnosis and misdiagnosis of breast cancer in young women are frequent malpractice claims. In a 2002 Breast Cancer Study conducted by the Physician Insurers Association of America, the leading insurance trade association of medical professional liability companies, revealed, that 69 percent of the breast cancer malpractice claims were for women in their 40s and under and 33 percent of the claims were for women in their 20s and 30s.^{xxiii} The average size of the award for a woman in her 30s was

\$508,000. In 2006 in Massachusetts, a \$10.7 million malpractice award was awarded to a 38-year-old because of misdiagnosis by her gynecologist.

Based on both the malpractice information and existing studies, our organizations advocate for provider training that focuses on recognizing risk factors for early breast cancer and if they are presented with a breast mass to consider and appropriately rule out breast cancer according to standard guidelines such as those developed by the NCCN.

Conclusion

Breast cancer is relatively rare in young women. But when breast cancer is detected, prognosis is often worse than for older women. Younger women are often less likely to seek early medical attention, leading to later detection, which likely contributes to diagnoses at more advanced stages. In addition, breast cancer in younger women is also often a more aggressive disease than in older women, which is associated with worse survival rates for the same stage of disease at diagnosis. Evidence-based information is needed for younger women and their health care professionals to help detect their cancers early and give those who are diagnosed the greatest chance for survival.

About Us

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.

<http://www.youngsurvival.org>

The Susan G. Komen for the Cure Advocacy Alliance is the nonpartisan voice for more than 2.5 million breast cancer survivors and the people who love them. Our mission is to translate the Komen promise to end breast cancer forever into action at all levels of government to discover and deliver the cures.

<http://www.komenadvocacy.org>

Living Beyond Breast Cancer assists women at all stages of diagnosis, treatment and recovery. Our mission is to empower all women affected by breast cancer to live as long as possible with the best quality of life. We offer specialized programs and services for the newly diagnosed, young women, women with advanced breast cancer, women at high risk for developing the disease, and African-American and Latina women. We also offer programs for caregivers and healthcare professionals to help them better meet the needs of women affected by breast cancer.

<http://www.lbbc.org>

Breast Cancer Network of Strength®, formerly known as Y-ME National Breast Cancer Organization®, provides immediate emotional relief to anyone affected by breast cancer. The mission of Breast Cancer Network of Strength is to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.

<http://www.networkofstrength.org/>

ⁱ American Cancer Society, “Breast Cancer Facts & Figures 2007-2008.”

ⁱⁱ Young Survival Coalition estimates based on the 2000 U.S. Census data.

ⁱⁱⁱ An estimated 192,370 new cases of invasive breast cancer are expected to occur among women in the U.S. in 2009. In addition to invasive breast cancer, 62,280 new cases of *in situ* breast cancer are expected to occur among women in 2009; of these, approximately 85 percent will be *ductal carcinoma in situ* (DCIS), for a total of about 250,000 cases, according to American Cancer Society, “Cancer Facts & Figures 2009.” Nearly 10 percent (23,790) of total new breast cancer cases were diagnosed in women under age 45 in 2007 — 16,150 invasive and 7,640 *carcinoma in situ*, according to American Cancer Society, “Breast Cancer Facts & Figures 2007-2008.”

^{iv} Ibid.

^v Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

^{vi} Bleyer A, O’Leary M, Barr R, Ries LAG (eds): *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD 2006. Available online at <http://seer.cancer.gov/publications/aya/>.

^{vii} Anders CK et al, “Young Age at Diagnosis Correlates with Worse Prognosis and Defines a Subset of Breast Cancers with Shared Patterns of Gene Expression”, *Journal of Clinical Oncology*, Vol. 26, No. 20, July 10, 2008, 3324-3330.

^{viii} A triple negative tumor is estrogen receptor-negative (ER-), progesterone receptor-negative (PR-) and HER2/neu-negative (HER2-). Because of their triple negative qualities, current treatment choices for these tumors are limited. Triple negative/basal-like tumors are often aggressive and are associated with a poorer prognosis compared to the estrogen receptor-positive subtypes.

^{ix} Anders et al, *Journal of Clinical Oncology*.

^x Carey et al, “Race, breast cancer subtypes and survival in the Carolina Breast Cancer Study,” *Journal of the American Medical Association*, Vol. 295, No. 21, June 7, 2006, pp. 2492-2502. Available online at <http://jama.ama-assn.org/cgi/reprint/295/21/2492>.

^{xi} National Cancer Institute. Genetics of breast and ovarian cancer (PDQ®). Available online at <http://www.nci.nih.gov/cancertopics/pdq/genetics/breast-and-ovarian/HealthProfessional/page1>.

^{xii} De Boer A.G.E.M., “Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression,” *Journal of the American Medical Association*, Vol. 301, No. 7, February 18, 2009, pp. 753-762. Available online at <http://jama.ama-assn.org/cgi/content/full/301/7/753>.

^{xiii} 2009 Young Survival Coalition Constituency Survey.

^{xiv} Centers for Disease Control and Prevention.

^{xv} See Partridge A.H, et al., “Web-based Survey of Fertility Issues in Young Women with Breast Cancer,” *Journal of Clinical Oncology*, Vol. 22, No. 20, October 15, 2004, pp. 4174-4183. Available online at <http://jco.ascopubs.org/cgi/content/abstract/22/20/4174>.

^{xvi} 2009 Young Survival Coalition Constituency Survey.

^{xvii} Learn more about the Lance Armstrong Foundation LiveStrong Young Adult Alliance online at http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661399/k.71A4/Young_Adult_Alliance.htm.

^{xviii} Based on a survey of 222 women under age 40 with recently diagnosed breast cancer in a prospective multicenter cohort study started in late 2006. See Ruddy K.J. et al, “Presentation of breast cancer in young women,” ASCO Meeting Abstracts 27: 6608. Available online at

http://www.asco.org/ASCOv2/Meetings/Abstracts?&vmview=abst_detail_view&confID=65&abstractID=34926.

^{xix} American Cancer Society, Breast Cancer Facts & Figures: 2007-2008.

^{xx} The National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of 21 of the world's leading cancer centers, develops valuable information for the numerous stakeholders in the health care delivery system. NCCN guidelines for screening and early detection of breast cancer can be found online at http://www.nccn.org/professionals/physician_gls/PDF/breast-screening.pdf.

^{xxi} Oeffinger, KC, et al, "Breast Cancer Surveillance Practices Among Women Previously Treated with Chest Radiation for a Childhood Cancer," *Journal of the American Medical Society*, Vol. 301. No. 4, July 2, 2009, p. 404-414. Available online at <http://jama.ama-assn.org/cgi/reprint/301/4/404>.

^{xxii} Ruddy et al, ASCO Meeting Abstracts.

^{xxiii} 2002 Breast Cancer Study conducted by the Physician Insurers Association of America.