

# ywbcpr

Volume Three: April 2008

## The Young Women's Breast Cancer Program

Siteman Cancer Center at Barnes-Jewish Hospital  
and Washington University School of Medicine



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*Dear Friend,*

We are pleased to share with you our third edition of YWBCP, the Young Women's Breast Cancer Program's annual news magazine.

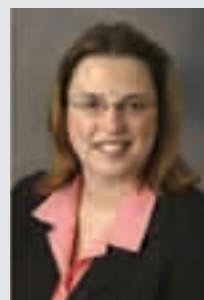
In this expanded edition, Dr. Julie Margenthaler focuses on the medical management of young women with breast cancer. Many questions remain regarding how young women should be treated and followed. Further research is needed to identify consensus guidelines for the care of women diagnosed at a young age. Stephanie Carson shares information about living with metastatic disease and programs available to women with advanced breast cancer. Jennifer Staed and Mary Griser offer their story of living beyond breast cancer at a young age and Wendy Reyes tells us how her life has changed since her Mother was diagnosed.

We are blessed to work with so many young survivors to develop and expand our program over the last seven years. With their guidance, we have created several different types of programs to meet the diverse needs and busy schedules of young women. The St. Louis Komen Affiliate has generously supported and partnered with us to reach out to young survivors in the community. All young women with breast cancer and young survivors are invited to attend any of our free programs. A calendar of events is listed on the back page and detailed information about our comprehensive program can be found at our website, ywbcp.wustl.edu.

There have been many advances in the treatment and support of women with breast cancer. Young women have not benefitted equally from this progress. We believe we can change this fact. We believe we can improve the medical care and support of young women with breast cancer and their families. Join us in making this progress possible.

Jen Ivanovich

# Medical Management



## *Medical Treatment and Follow-up of Women with Breast Cancer*

Julie Margenthaler, MD  
Department of Surgery  
Washington University School of Medicine



Breast cancer research has led to improvements in the treatment of women with breast cancer. In recent years, there has been a movement toward less invasive surgery, increased use of hormonal based therapies, the development of additional chemotherapy regimens, and introduction of Herceptin® and aromatase inhibitors, with an overall increase in the breast cancer survival rate. There is good reason for optimism as we care for women with breast cancer.

Sadly, this optimism is not shared equally among all women. When considered by age, the survival rate is much lower for women diagnosed <40 compared to women diagnosed after menopause. Targeted guidelines to distinguish the care of young women from older women do not exist. Most clinical guidelines are based on studies of women diagnosed after 50 because these women are the majority with breast cancer. For any major clinical improvement, the question is, will young women also benefit and will this benefit be equally significant?

The purpose of this article is to provide a brief overview of the approach to diagnosis, treatment and follow-up of women with breast cancer with consideration of issues specific to young women.

### *Initial Diagnosis*

A woman undergoes an extensive evaluation to determine the type and extent of the breast cancer after a biopsy confirms the diagnosis. Additional imaging, with an ultrasound

or breast MRI, may be performed to better characterize the size and location of the tumor and evaluate if the surrounding lymph nodes appear to be enlarged, a feature suggesting cancer has spread to the lymph nodes. A breast surgeon will perform a thorough physical examination to help determine surgical options and evaluate any symptoms suggestive of metastatic disease. The medical oncologist may order additional blood tests such as a complete blood count (CBC) or blood work to examine liver function and bone metabolism. Specific studies of the biopsied tumor are performed to determine the type of breast cancer (e.g. ductal v. lobular) as well as the estrogen, progesterone receptors and HER2/neu status. In women who are found to have cancer in the lymph nodes, or who have concerning physical examination symptoms/findings, CT scans and a bone scan are performed to determine if the cancer has spread outside of the breast and lymph nodes. In combination with a woman's current health status and previous medical diagnoses, these multiple studies and evaluations are used to determine the most appropriate treatment.

Chemotherapy results in a state of menopause that is generally reversible following the completion of chemotherapy, although this varies widely. Therefore, young women may also undergo a fertility evaluation prior to the initiation of chemotherapy and can choose to have egg cells extracted and frozen to allow for the possibility of future pregnancies following chemotherapy.

### *Initial Treatment*

#### **Stage 0, DCIS, non-invasive breast cancer**

Surgical removal with or without radiation therapy is the primary treatment for ductal carcinoma in-situ (DCIS). In general, all young women who are able to undergo lumpectomy, will also require radiation therapy following surgery. For those women who are unable to have a lumpectomy or who choose mastectomy, radiation therapy is usually not necessary unless the cancer is very close to the edges of the breast tissue removed. If the DCIS is positive for estrogen receptor (ER) and progesterone receptor (PR), treatment with tamoxifen is also typically recommended.

#### **Stage I, II, or III, invasive breast cancer**

The focus is to treat for cure by working to eliminate the cancer from the breast and surrounding area with surgery and radiation (local control) and to destroy any cancer that has spread outside of the breast with chemo and/or hormonal therapy (systemic control).

Treatment often begins with surgical removal of the tumor. Individual preference is an important consideration. Why? Studies of women with stage I and II breast cancer have shown there is no difference in survival between women who undergo mastectomy + lymph node removal compared to women who undergo lumpectomy + lymph node removal + radiation therapy. The risk of recurrence in the breast or chest wall is equal between these two treatments and is approximately 5-10%,

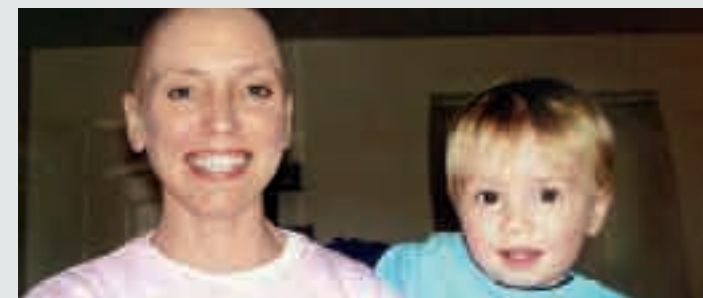
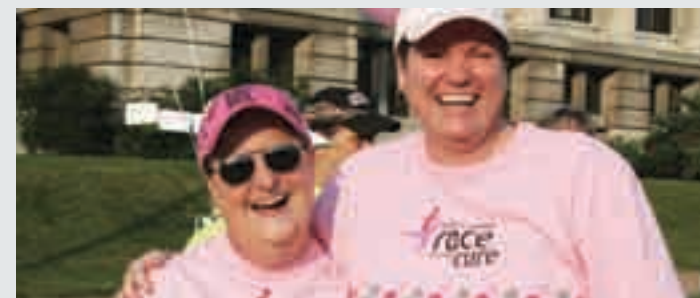
though the majority of studies were performed in women older than 40 years. Young women <40 years have a higher recurrence rate and lower survival when compared to older women with the same disease stage. The reason for this difference is not known but may be attributable to more aggressive tumor biology, age, or an inherited gene mutation.

The most important factor in determining stage and survival is the absence or presence of cancer in the axillary (arm pit) lymph nodes. In the past, the only method available to determine this information was to remove all of the axillary nodes. However, approximately 80-85% of women with breast cancer do not have cancer in the axillary lymph nodes and the removal of all lymph nodes is excessive. This led to the development of a technique called the sentinel lymph node biopsy. The idea is every breast cancer will travel to one or a few lymph nodes first before spreading to the rest of the axillary lymph nodes. If the sentinel lymph node is negative, then the rest of the lymph nodes are also negative and do not need to be removed. The risk for nerve injury and lymphedema is very low (and nearly 0%) for sentinel lymph node biopsy which is a huge benefit to all women with breast cancer. Removal of the sentinel lymph node is the preferred method for sampling the lymph nodes to determine if cancer has spread. Sentinel lymph node removal is not used for women who have enlarged or suspicious axillary lymph nodes. Subsequent removal of the axillary lymph nodes is also performed if the sentinel lymph node is positive for cancer.

Chemotherapy is necessary for the majority of young women. It can be given in the adjuvant setting (after surgery) or in the neoadjuvant setting (before surgery). Most women receive chemotherapy after surgery. However, for many young women, neoadjuvant chemotherapy can be very useful. Those who benefit from neoadjuvant chemotherapy include women who desire breast conserving therapy, women with large, aggressive tumors, and women who have large lymph nodes. There are multiple chemotherapy regimens now available and the treatment choice is based on many factors including a woman's age, overall health, and number of positive lymph nodes.

A woman's age, tumor size, number of positive lymph nodes and disease stage are used to predict the likelihood of recurrence. Tumor gene analysis is a new tool also used to help predict the likelihood of recurrence for women with early stage breast cancer. One example, Oncotype Dx® assay, may be used for women with stage I or II, estrogen receptor positive breast cancer with no positive lymph nodes. The expression of 21 genes is examined in the tumor sample and this information is used to predict tumors more likely to recur and consequently identify women with early stage breast cancer who may benefit from chemotherapy.

Herceptin® (Trastuzumab) is used in combination with chemotherapy to treat tumors which show over expression of the HER2/neu receptors. Nearly 35% of all



breast tumors show over expression with an associated higher likelihood for recurrence. Herceptin® reduces the likelihood of recurrence and has been a major advancement in the treatment of women with HER2/neu positive tumors. Tykerb® attacks the receptors found inside the tumor and currently provides an additional therapy for women with metastatic, HER2/neu positive breast cancers.

Radiation therapy follows chemotherapy and surgery to eliminate the primary tumor from the breast and the surrounding area. Studies among women with four positive lymph nodes have shown radiation improves survival and thus is always recommended for these women. Radiation therapy is strongly considered among women who have fewer positive lymph nodes. Women who undergo lumpectomy for small tumors with no positive axillary lymph nodes may have the option of brachytherapy, a new treatment in which catheters are placed in the breast tissue cavity where the original tumor was located. Radiation is delivered directly to the cavity through the catheters, in a shorter period of time and with fewer side effects than traditional radiation therapy.

Endocrine therapy with Tamoxifen® or aromatase inhibitors (AI) is used for women with estrogen receptor positive tumors and is currently prescribed for five years. These types of therapies block the production of estrogen and have been proven to reduce the likelihood of breast cancer recurrence. Hormonal based therapy is recommended for women of any age. Tamoxifen is generally

prescribed for pre-menopausal women, and aromatase inhibitors are generally prescribed for post-menopausal women.

### Stage IV, metastatic breast cancer

The focus for women diagnosed with stage IV breast cancer is to treat and stabilize the cancer for as long as possible. Sadly, metastatic breast cancer is not curable but can be treated for many years. The focus of the initial treatment is to treat the cancer that has spread rather than immediately focusing on cancer found in the breast.

### Medical Follow-up

The American Society of Clinical Oncology has published medical follow-up guidelines for women with breast cancer. These recommendations are considered voluntary and individual follow-up is determined by the woman and her oncology team.

- Mammography screening, if bilateral mastectomy is not performed, is recommended within 6 months following completion of radiation therapy.
- Ongoing follow-up with physical examination and evaluation of symptoms suggestive of recurrence is recommended every 3-6 months for the first 3 years, every 6-12 months for the 4th and 5th year, and annually thereafter.

- Blood work including tumor markers is not routinely recommended unless a woman has symptoms suggestive of recurrence such as abdominal or bone pain, new breast lumps, continual headaches, or shortness of breath.
- Annual gynecologic follow-up is recommended for every woman and is especially important for women taking Tamoxifen®, as an increased chance for uterine cancer is a proven risk.
- Young women who have undergone chemotherapy or ovarian removal may consider regular evaluation of their bone health including bone density testing. Daily calcium intake and regular weight bearing exercises, as directed by your physician, may also be considered.
- Genetic testing has been used in the surveillance and surgical management of women with breast cancer and her family. Studies have been initiated to evaluate if tumors for women with specific inherited gene mutations are more sensitive to certain types of chemotherapies. In the future, genetic testing may be used not only to aid in making surgical decisions but also aid in chemotherapy choices.

Survivorship care plans have recently been advocated to be included in the follow-up of all people with cancer. The plan, written by a member of the oncology team, includes a summary of the diagnosis, screening evaluations, treatments, side-effects

experienced and contact information for the oncology team members. The plan also includes information about the long-term effects of treatment, recommendations for continued surveillance, and promotion of healthy lifestyle choices. One goal is to increase the cancer and medical literacy of people who have been diagnosed as they plan their medical follow-up as cancer survivors.

We encourage young women to ask the simple question at each follow-up appointment, what are the new advancements for women diagnosed with breast cancer at a young age? This simple question reminds your health care team to consider the differences that exist among younger women and to constantly evaluate your medical planning in light of the age you were diagnosed.

For additional information about the treatment and follow-up of women with breast cancer check out the National Cancer Institute website, [www.cancer.gov](http://www.cancer.gov), the Susan G. Komen for the Cure website, [www.komen.org](http://www.komen.org), and the American Cancer Society site, [www.cancer.org](http://www.cancer.org).

### References

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Harris, L. et al. American Society of Clinical Oncology 2007 update of recommendations for the use of tumor markers in breast cancer. *Journal of Clinical Oncology* 2007 25:5287-5311.

Ganz, P. and Hahn E. Implementing a survivorship care plan for patients with breast cancer. 2008. *Journal of Clinical Oncology* 26:759-767.

## Did you know?

You can request a copy of your pathology reports and medical records.



### About the pictures in this edition.

*The beautiful women and their families shown in this edition are members of our young women's breast cancer program.*

### Acknowledgements

*Our community program is coordinated through Washington University School of Medicine, Siteman Cancer Center and Barnes-Jewish Hospital and is funded in part by a generous grant from the St. Louis Affiliate of the Susan G. Komen For the Cure Foundation. We are pleased to partner with the Affiliate to offer programs that meet the unique needs of young women with breast cancer.*

# program *NEWS*

Jennifer Staed, Co-Director

*"I have never been in a room with any survivor who is near my age."*  
*I said this comment for the first time five years ago when I attended my first Young Women's Symposium. I have heard it from other young survivors this past year. I have heard it during monthly YWBCP meetings for yoga or education, and I heard at two national conferences that I attended. As a young survivor, I think finding other young women who share my unique fears, hopes, and challenges has been a key to my well-being. That is the main reason I chose to get involved in the Young Women's Breast Cancer Program.*

In August I traveled to the Susan G. Komen for the Cure Annual Mission Conference to represent the Young Women's Program. Members of the new Komen Young Women's National Advisory Council were available for questions. These young women from around the nation are dedicated to helping the Komen organization engage the next generation in the breast cancer fight. They are committed to our cause. The face of breast cancer is changing, and as young women are recognized we hope that more will be learned and shared about the very different disease breast cancer is when it strikes a young woman.

In February, I attended the annual Young Survival Coalition conference in Florida (thanks to a grant from the St. Louis Affiliate of Susan G. Komen for the Cure). There I found 600 other young survivors. As we participated in discussions, shared meals, and learned new forms of exercise I gained a greater understanding of the burden of breast cancer on women even younger than I was at diagnosis. My age of 33 at diagnosis seemed so young to me, until I met more women diagnosed at the age of 25, 24, or 23. Many young survivors talked of their feelings of alone-ness and isolation as they received well-meaning but meaningless advice from older survivors who could not imagine what was going through the minds of their much younger counterparts. As I talked about the YWBCP in St. Louis, I was proud to explain the energy of the group and the diverse programs that are offered each month. As young women we have great challenges: we are more often diagnosed with more aggressive disease and we have family and career opportunities to consider. Yet, banded together, we can support one another and draw attention to our unique needs. We can use our energy and connections to demand more research dollars and attention to quality of life. As Jen says, we believe change is possible!



## kids column



**Wendy Reyes,**  
age 13

We were both scared and sad when they explained to us my mom was diagnosed. My dad and mom told my sister and me she was diagnosed with breast cancer. My sister was 8 and I was 10 when we were informed about it. We both cried because we were scared. She has been diagnosed for almost three years now. We did not know what to think about it. Is this the last time we were going to see her? Is she going to be okay? How long is she going to have this cancer? These questions were on my mind for a while and they were making me sad, confused, and scared.

I was scared and sad when she had to go in for surgery. I was surprised that she came home without one breast and started to lose all of her hair. Also, I was sad for my mom when she started to wear scarves and hats. Then when she had to go out, she had to wear a wig.

When we went to the St. Louis Komen Race for the Cure for the first time, I was shocked of how many people were there. My mom invited a couple of her friends to walk with us. We walked for about two hours and thirty minutes. We had sore feet and the back of our necks were in pain. We made it to the finish line and then my mom started to cry. Then my dad started to cry and hugged her. My sister and I cried too. The following year we went for a second time and we brought our family (uncle, aunt, and two of our cousins). We took a lot of pictures when we were there. Then we got to the finish line again and two football players gave my mom a rose. Then my mom started to cry and my dad did the same thing again, hugged her and cried. This time we finished in about one hour and fifty minutes. All of us walked to support my mom.

Few months later, my sister and I went to a "H.U.G.S." (help us give support) program. We talked about our loved ones who have breast cancer and wrote a booklet about what we think and feel about breast cancer. Then we went to another program called "Bear Essentials". We talk about what is breast cancer. Also we make things and send them to people and put a smile on their faces when we do. It was fun when we send all of those nice things to them.

These two years have been a good experience for my sister and I because we both have learned what breast cancer is and it also prepared us if it happens again. Well, now I am happy she is okay. We are all happy she is okay. "My mom is a fighter and strong!"

# Research Update

Breast cancer takes a great toll on young women. It is the most common cancer diagnosis among women 19-39 years of age. Nearly 12% of all women diagnosed with breast cancer each year are younger than 45 years of age. Sadly, young women have the highest rate of breast cancer recurrence and the lowest overall survival.

These troubling facts are shared among other young adults with cancer. In 2006, the National Cancer Institute and the Lance Armstrong Foundation joined together to develop a Young Adult Oncology Progress Review Group. A first of its kind, the group was comprised of over 100 healthcare professionals, young survivors, health services experts, and others to draw attention to the medical care and unique issues of adolescents and young adults with cancer. (see [http://planning.cancer.gov/disease/AYAO\\_PRG\\_Report\\_2006\\_FINAL.pdf](http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf))

The improvements in survival among young adults compared to children and adults over 45 years of age are striking. See graph below.

Children and adults over 40 years of age have seen an increase in cancer survival from 1975-1998. In contrast, an increase in survival for individuals 15-39 years of age has lagged far behind. Furthermore, no improvement in survival has been achieved for individuals 25-35 years of age for over twenty years!

When these data are examined by specific cancer type, we see there has been an increase in survival for young adults with breast cancer from 1975-1998 (graph not shown). However, this increase is nearly half of what has been realized for some groups of women who are diagnosed over 50 years of age.

The factors contributing to this lack of progress for young adults are many and are interconnected. There are limited research studies and clinical trials focused specifically on this age group with no infrastructure in place to conduct large national trials. Research funding to establish this infrastructure is difficult to obtain

because young adults represent a minority of individuals diagnosed with cancer. As with some young women with breast cancer, young adults often experience a delay in their diagnosis, resulting in a more advanced stage at the time of diagnosis. As they begin their careers, young adults often lack adequate health insurance resulting in less preventive care or delay in treatment. Clearly far more effort is needed to address the unique medical, psychological and family needs of young adults with cancer.

We find the survival statistics for young adults to be unacceptable and are working to change the outcome for young women with breast cancer. Our Young Women's Breast Cancer Research Program is dedicated to conducting research focused on breast cancer in young women.

Specifically, we are working to discover genetic factors that contribute to aggressive disease among young women. Why focus on the genetic aspects of breast cancer in young women? Young women have the highest rate of "genetic" breast cancer or the genetic contribution to their breast cancer. Large twin studies performed in Denmark suggest nearly one-third of all breast cancer has a genetic contribution. Ten genes have been identified to date that contribute to the development and progression of breast cancer. Some of these gene mutations are rare in the population and are associated with a high risk, while others occur commonly in the population and are associated with a low risk. It is estimated the ten genes identified to date only account for 20% of the genetic contribution. Consequently, there is a great deal to be learned about the genetic basis of breast cancer and young women have the most to gain from this knowledge.

By identifying these factors, we hope to identify targeted treatment options and contribute to the long term management planning of young women with breast cancer. Furthermore, identification of the genetic factors associated with breast cancer risk can be used to alter the medical care of daughters, siblings and other female relatives of young women with breast cancer, care which reflects their family based cancer risk.

We need your help to advance young women's breast cancer research. All woman diagnosed with invasive breast cancer <40 years are invited to participate.

Women who participate are asked to:

- Sign a consent form,
- Submit a sample of blood, drawn at the time of their follow-up appointment and shipped to us free of charge in the Fedex materials we provide,
- Release a copy of their cancer related records,
- Allow us to contact them about their family cancer history.

## Did you know?

Information about breast cancer research studies and clinical trials can be found at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and other studies for young women can be found at [www.youngsurvival.org](http://www.youngsurvival.org).

The parents and sisters of young women may also participate as controls, regardless if they have been diagnosed with cancer. They are asked to:

- Sign a consent form, and
- Submit a sample of blood.

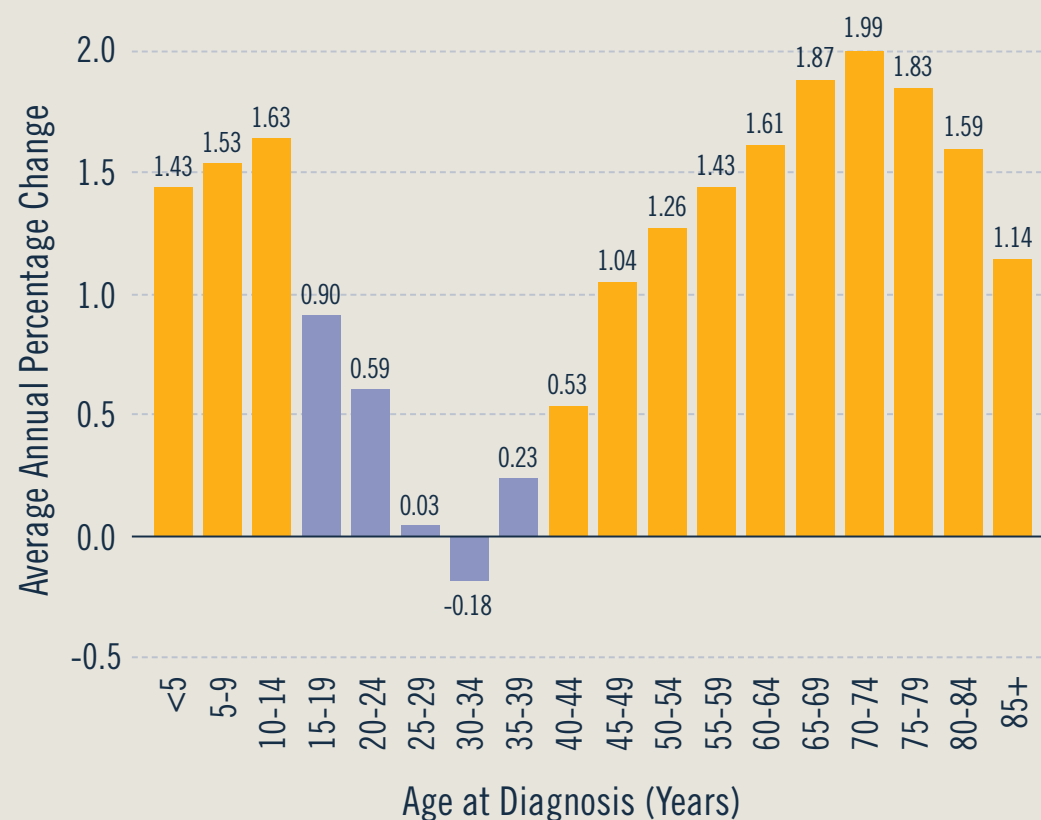
A woman may still participate if her parents are not living or choose not to participate.

Over 400 women from around the country have participated to date. We wish to invite 5,000 young women to join the study. Women who have had genetic testing may participate regardless of the test results.

A small amount of your time can go a long way in contributing to the investigation and advancement of care for young women with breast cancer. Contact Jen Ivanovich at 314-454-5076 or by email at [jen@ccadmin.wustl.edu](mailto:jen@ccadmin.wustl.edu) to learn more or to participate in this important research program.

## Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997

Reprinted from *Closing the Gap: Research and Care Initiatives for Adolescents and Young Adults with Cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group, page 17. Graph was created using SEER data.*



## References

Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer: Report of the Adolescent and Young Adult Oncology Progress Review Group.

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## Research Program Acknowledgements

We are sincerely grateful to the Barnes Jewish Hospital Foundation for their prior support and to the Mervyn and Ruth Golder Philanthropic Fund and Celebrate Fitness for their generous, ongoing support of our young women's breast cancer research program.



# Survivorship: information is power

Information about your cancer diagnosis and treatment is power in your hands. Having a summary of this information helps you to not only make informed decisions at time of treatment, but it can also help you in long-term follow up. If needed in the future, the information can help you identify the most appropriate approach to treating a recurrence. Specific details about your cancer diagnosis may also be useful for assessing the cancer risk of close relatives, such as your siblings or children. Use the table below as a guide for documenting information about your cancer diagnosis, treatment, and surveillance.



<b>Breast Cancer Diagnosis</b>	
Breast Cancer found in single breast or both breasts:	
<input type="checkbox"/>	right breast
<input type="checkbox"/>	left breast
<input type="checkbox"/>	both
Number and location of tumor(s)	
Was the breast cancer able to be detected on a mammogram:	
<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<b>Tumor Pathology</b>	
Type:	
<input type="checkbox"/>	Ductal carcinoma in-situ (DCIS)
<input type="checkbox"/>	Invasive ductal carcinoma
<input type="checkbox"/>	Invasive lobular carcinoma
<input type="checkbox"/>	Medullary carcinoma
<input type="checkbox"/>	Tubular carcinoma
<input type="checkbox"/>	Mucinous carcinoma
<input type="checkbox"/>	Inflammatory carcinoma
<input type="checkbox"/>	other:
Tumor(s) size:	
Tumor stage:	
<input type="checkbox"/>	Stage 0
<input type="checkbox"/>	Stage I
<input type="checkbox"/>	Stage IIA
<input type="checkbox"/>	Stage IIB
<input type="checkbox"/>	Stage IIIA
<input type="checkbox"/>	Stage IIIB
<input type="checkbox"/>	Stage IIIC
<input type="checkbox"/>	Stage IV

Estrogen receptor status:	
<input type="checkbox"/>	positive
<input type="checkbox"/>	negative
Progesterone receptor status:	
<input type="checkbox"/>	positive
<input type="checkbox"/>	negative
HER2NEU status:	
<input type="checkbox"/>	positive
<input type="checkbox"/>	negative
Oncotype DX results (if applicable)	
<b>Surgery Information</b>	
Type of surgery or surgeries and dates:	
Type of surgery on opposite breast (if applicable)	
Type of reconstruction (if any) and dates	
Sentinel lymph node biopsy:	
<input type="checkbox"/>	positive
<input type="checkbox"/>	negative
Axillary lymph node biopsy:	
<input type="checkbox"/>	positive (number with cancer _____)
<input type="checkbox"/>	negative (number without cancer _____)
List any complications including subsequent lymphedema	
<b>Chemotherapy</b>	
Names of chemotherapies given	
Total dose of anthracyclines (e.g. Adriamycin)	

Number of cycles and dates administered	
Growth factors recieved	
Blood Transfusions	
List any complications	
<b>Hormonal and other therapies</b>	
Type of endocrine therapy (e.g., Tamoxifen or aromatase inhibitor) date started, dosage, and date completed	
Herceptin®therapy date started, dosage, and date completed	
<b>Radiation Therapy</b>	
Type (e.g., whole breast versus brachytherapy)	
Dates administered (initiation and completion)	
Total dose administered	
Fields radiated	

<b>Additional testing (if performed):</b>	
MRI, CT, Ultrasound or Bone scan dates performed and results	
Tumor markers Name of marker and results	
Genetic testing Specific gene analyzed and results	
<b>Prior Health History</b>	
History of previous breast biopsies	
History of atypia or lobular carcinoma in-situ:	
<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
(If Yes, when diagnosed _____)	
History of fibrocystic breast disease:	
<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
History of medical or chronic illnesses	
History of surgical procedures	
Prior chest radiation treatment:	
<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
History of any type of cancer	

Family history of any type of cancer Type, age at diagnosis, and relationship to you	
<b>Healthcare Team</b>	
Name and contact information for each healthcare provider	
Surgeons:	
Medical Oncologist:	
Radiation Oncologist:	
Primary Care Physician:	
<b>Persistent Symptoms a Patient Should Report</b>	
New lumps	
Bone tenderness	
Pain	
Cough	
Shortness of breath	
Rash on breast	
Nipple discharge	
Unusual vaginal discharge or bleeding	

**Did you know?**

Nearly 12% of all women with breast cancer are diagnosed before their 45<sup>th</sup> birthday.

Our program website is [ywbcwustl.edu](http://ywbcwustl.edu)

## REFERENCES

Information compiled from: "My Breast Cancer Information" by members of the Young Women's Breast Cancer Program published in *The Woman is Stronger than the Disease: A Guidance Journal for Young Women with Breast Cancer*, 2004

Ganz, P. and Hahn E. Implementing a survivorship care plan for patients with breast cancer. 2008. *Journal of Clinical Oncology*. 26:759-767.

# Living with Metastatic Breast Cancer: helping each other along the way

Stephanie Carson, diagnosed at 29



## Did you know?

We have a research study focused specifically on young women with breast cancer.

All YWBCP events are offered free of charge.



*"Everyone's experience living with metastatic breast cancer is uniquely her own, as is everyone's experience in life."*

But that does not mean we cannot often benefit hearing what has helped others as it may give us a hint of what may benefit us and help us to heal from this disease, physically or mentally. During the past 4+ years living with metastatic breast cancer (MBC), I have been lucky enough to find a variety of resources which have helped me tremendously to move forward through the stages of this roller coaster ride disease. My wonderful friend Natalie (who I was lucky enough to meet at the YWBC symposium a couple of years back) reminded me recently that as important as the information being made available, the timing is also key in terms of how it is processed and received. We may think we've heard it all before, yet things can be seen in a different light depending on the stage we're in at any point in time. There have been so many avenues that have helped me to move forward through this disease and pick

me up when I've been in need of a physical or mental lift the past 4+ years. The support from my family and friends, as well as a wonderful and caring medical crew, has been invaluable. But in addition, it has been so beneficial to get to know other cancer patients through my medical center, the YWBCP activities and symposium, online support forums ([www.bcmets.org](http://www.bcmets.org), [www.youngsurvival.org](http://www.youngsurvival.org), [www.breastcancer.org](http://www.breastcancer.org), [www.her2support.org](http://www.her2support.org)), and other numerous resources made available to the cancer community. The resources themselves provide useful information, but there is also so much benefit in meeting other women through the resources.

Last spring I was lucky enough to participate in a retreat sponsored by the Young Survival Coalition specifically designed for young women living with MBC. Throughout that weekend, we all got to hear each other's stories, express our fears, deal with the associated losses of the disease, and learn strategies to move forward and continue to live a good life within the constraints of the disease. It was so comforting to meet other young women dealing with the tough situation of not being

able to have a child or allowed to adopt because our MBC diagnosis. The moms in the group were able to express their fears about not being there for their children to other moms who could understand. The difficulties of maintaining a romantic relationship or forming a new one given the constraints of the disease were discussed.

*"Those who had been living with MBC longer were able to give tips and strategies to those with less experience."*

Although I am not sure this particular retreat will be made available on a regular basis, from this experience, I encourage other women living with MBC to get out and utilize the resources made available to meet others in the situation. It can help immensely to combat isolation and deal with the real issues we face living daily with this disease.

Another particularly good organization is the Metastatic Breast Cancer Network, who sponsors a yearly fall conference for

women living with MBC. I attended the conference at M.D. Anderson last November and was so impressed with the quality of information. The presentations were extremely informative, giving much of the latest research about MBC, not just the information made readily available to patients. It gave me so much hope to get up-to-date information in terms of treatments coming down the pipeline, research being conducted, more specific management of different aspects of the disease, and newer techniques in evaluating efficacy. I was quite pleased to bring back specific questions in terms of my own treatment to my oncologist and information to pass on to other patients. For more information about this conference and this organization dedicated specifically to those living with MBC, go to <http://www.mbcnetwork.org>.

The information that benefits one person may or may not benefit another. But, as we all share the concepts, resources, information, and advice that we have appreciated, we help each other to move forward and heal more than just physically in this disease.

## Giving Thanks



We come together in strength, support, and spirit to hold each other up.

We give thanks to the faith that drives us.

We give thanks for yesterday, we are patient for today, and we live for tomorrow.

We ask our hearts and minds be open to what touches us today.

We join together at different stages of our mutual journey - diagnosis, treatment, and survivorship.

We ask when we leave one another we take with us new knowledge, new relationships, and realization we are not alone.

We ask for peace with our bodies, confidence in healing, and hope in our hearts.

We ask those who have gone before to lift us with their presence and light.

We turn to them for our protection.

We ask for support and strength for our families, friends, and coworkers.

We pray to wipe their tears and celebrate this path.

We look to our higher power to help us understand what we have lost and what we have gained.

— Marsha Flowers & Mirna Rafael-Reyes



I think my journey is filled with mishaps and miracles. But, doesn't every young woman who is faced with a life altering event, feel that way? Come on now, which one of us actually thought well if I ever get breast cancer.... this is what I will do? My guess... not many, and certainly not me.

Up until May of 2006, at age 41, I was blissfully ignorant on breast cancer. Oh sure, I donated to the 3 day walk my friend Kristen did in honor of her friend's mother. I saw and heard about the pink Cardinal baseball bats, bought tons of pink stuff in October, and was sure to do my self-exam when I remembered. Hey, I was busy, wearing my many hats. I was a wife, mom, step-mom, friend, sister, daughter, and full time employee. My days were filled like so many others; I had work, more work, family time, football and volleyball games, grocery store, taxi driver, concession stand volunteer, and so on. Just like so many other women. I felt I was in general good health. I was running 3 to 4 times a week and eating well in an effort to lose weight and "be healthy." Life was busy, but good.

During my routine visit to my OB, I mentioned a "sore area" under my arm pit, my OB suggested a mammogram with an ultrasound just to "rule out" any potential issues. My first miracle was that even though this did end up being a "pulled muscle," the ultrasound showed a different area that was later diagnosis as Invasive Lobular Carcinoma.

## my journey

Was this a miracle or mishap? Just think, had I not complained about the pulled muscle under my arm, they would not have found my cancer so early! My ILC was closer to my chest wall and was not seen on the mammograms. Two surgeries, chemo, radiation and now hormone therapy have been my treatment plan.

So they say....don't sweat the small stuff. I think sweat and worry about whatever you want to, you are going to anyway. But do try and find a balance when possible. What I found helped me, was humor. Trying to gain a perspective on any given situation and trying to enjoy a sense of the ridiculous has also helped me. Of course, it doesn't always work, but sometimes it does. And for those moments, I thank God for my beautiful miracles.

I looked for and found help, encouragement, and support. I found our group, the YWBCP. When I was first diagnosis I found a message on a website talking about a Young Women's support group in St. Louis. I emailed the women directly, and asked if she could define "young." For although the few support groups I attended were very nice, I was having a hard time relating to the group members and their present life styles. Most of the members were older and enjoying retirement and grandkids. Even their individual treatments and protocols were different.

I was looking for someone who was worried about going to Parent Teacher conferences in a wig, or was worried about how heavy the case of Girl Scout cookies was and if it could be lifted safely. What should I explain to my five year old nephew when he asks why I don't have eyebrows anymore? Another of my miracles, I found our group. For a year and half, I have tried to attend at least one event per month. Who else can relate to chemically induced hot flashes? Yes, changing diapers while wearing prosthesis can be dangerous! What doctor when? Or NOW you have to eat healthy not because you want to lose weight or "be healthy" but because research has shown.... a link between diet and breast cancer. Oh yeah, like that's fair! Wouldn't it be nice if research could have shown a decrease in recurrence for all those women who ate at least 3 cookies everyday?

I go to group meetings because I am looking for something. Sometimes I am looking for sympathy, sometimes humor, sometimes serenity, and most times simply relief from my day to day. I found a group of women who can relate, who are just as disgusted as I with the unfairness of it all and yet are willing to laugh at the mishaps we have all encountered. These women help me find the balance I need to see and feel my beautiful miracles. Thank you all very much!

Mary Griser, diagnosed at 41