



FDA Panel Votes to Remove Avastin for Breast Cancer Treatment

Kathleen Harris, NBCC Field Coordinator-WI

On July 20, 2010, ODAC, the FDA's Oncology Drugs Advisory Committee, voted 12-1 to remove Avastin as a first line therapy in combination with various chemotherapies for patients with metastatic breast cancer. Though the drug did show an increase in progression-free survival, it did not show an increase in overall survival for these patients. Clinical safety data showed a higher incidence of serious adverse events that required medical interventions, hospitalization, or resulted in death.

In February 2008, the FDA granted accelerated approval for Avastin to be used in combination with another drug to treat metastatic breast cancer-cancer that has spread to other parts of the body. This decision was based on the results of a single clinical trial known as E2100. The findings showed progression-free survival of about five months, but did not significantly extend patients' lives.



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The FDA made this decision despite the fact ODAC voted 5-4 against approval of the drug for breast cancer in 2007.

Data recently submitted to the FDA from two ongoing Phase III trials (AVADO and RIBBON 1) failed to confirm the results of the E2100 trial. In the two new trials, the delay in tumor progression was much shorter, up to three months in one trial and less than one month in the other.

On July 23, 2010, the National Breast Cancer Coalition (NBCC) responded to ODAC's vote on Avastin saying: "NBCC made the case in 2008 that accelerated approval for Avastin was lowering the bar on drug approval. There was no evidence the drug extended the lives of breast cancer patients, and some evidence it increased the risk of harm....The data show that Avastin should no longer be used in the treatment of breast cancer."

However, the drug Avastin is still available to doctors for off-label use to treat breast cancer. Unfortunately, women are still being recruited to participate in 87 new trials testing Avastin in patients with this disease.

NBCC believes there is no reason to continue to subject women to this drug in clinical trials. Quality of life issues are important. Family members and friends who have cared for loved ones know that at the end-of-life, quality of life matters.

Drugs given accelerated approval by FDA are rarely removed, but there is evidence that may change. The FDA is expected to make a decision by September 17, 2010.

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Moving? Please send your address changes to:

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President's Letter

As President of WBCC, I am very proud of the progress we have made as an organization. WBCC continues its unwavering commitment to halting the alarming incidence of breast cancer in Wisconsin. Our mission is to bring Wisconsin voices together to Stand Up and Speak Out about breast cancer through education, collaboration and legislation.

In the last few years, we have witnessed continued growth in both prominence and recognition. We have continued to increase our collaboration with other breast cancer organizations. While we are certainly different in our methods, one common pursuit unites us all, an end to breast cancer. We are members of the board of directors of the National Breast Cancer Coalition. As a member of the National Breast Cancer Coalition, WBCC actively pursued passage of health care reform that included meaningful changes for breast cancer patients, survivors and their families. With the passage of this health care reform, we have been actively educating people in Wisconsin as to what health care reform could mean to their families.

This legislation opens the door to coverage for those who have not been able to receive it due to a pre-existing condition. For many women in Wisconsin with breast cancer and their families, it means they will no longer have to worry about losing their insurance coverage if they lose their job. So much has been accomplished, but Wisconsin Breast Cancer Coalition understands that there still remains so much to do as long as breast cancer continues to prevail.

Bonnie Anderson



WBCC Honors Long Time Volunteer, Linda Zella Weide

Dawn Anderson, WBCC Executive Director

On August 16, a packed church gave a standing ovation to Linda Zella Weide, recognizing the lives she had touched, the impact she had made, and the remarkable woman she was. Linda passed away on July 29 after a 17-year fight to the finish with breast cancer. Her loss, to her family, her friends and this organization, is still hard to bear, but because we all knew Linda, we are forging on - as she would want us to. Her battle cry, written on a Relay for Life Luminary many years ago was: "This &*!*\$ disease is gonna regret picking me!" We intend to carry on with that spirit and fight.

Linda came to the WBCC as a Survivor Artist for the first Rare Chair Affair in 2000. She continued as an artist, as a co-chair, and as a mentor to subsequent Survivor Artists over the years through the event's 10-year anniversary last year. During that time, she also was a member of our Board of Directors and a Sherry Kohlenberg Scholarship recipient - joining us in Washington DC to take her story to the halls of congress. She spoke at numerous WBCC events including Neroli Spa's Girls Night Out events and the Raw Beauty Fashion Show.

Linda was first diagnosed at age 42. Over time, the cancer metastasized steadily - but she kept finding new treatments, new clinical trials. Through the years, she was blessed to see her children graduate from high school and college, and then get married. The icing on the cake for her was being around to enjoy her three grandsons. She often remarked that each one of these milestones was an answered prayer.

The WBCC as an organization and I, personally, will miss her always. We will be honoring Linda at the 2010 Rare Chair Affair on October 2. Her children are compiling a book of memories about Linda for her grandchildren. If you are one of the many people whose life was touched by her, please send your story or memory to RememberNana@gmail.com.



11th Annual Rare Chair Affair

Ashley Dietrich

The Wisconsin Breast Cancer Coalition will be hosting its annual Rare Chair Affair on Saturday, October 2, from 6 pm to midnight. The event, held in the stunning atrium of Milwaukee's U.S. District Courthouse on Wisconsin Avenue, will feature a silent auction, hors d'oeuvres and cash bar followed by the main event: live auction of beautiful and unique chairs artfully painted by breast cancer survivors. Proceeds from the auction will help the Wisconsin Breast Cancer Coalition in its mission to unite Wisconsin voices to stand up and speak out about breast cancer through education, collaboration and legislation. This exciting event is being planned by Milwaukee's own David Caruso of Dynamic Events. "It would be fabulous to gather a crowd of WBCC friends to celebrate the mission of the organization in a fun and colorful way," says Caruso. "This party is going to provide the energy, financial support and recognition to allow the Coalition to do inspiring things throughout the next year. The event is full of first-time surprises and is sure to delight and dazzle all party goers. I look forward to seeing everyone there!"



Photos taken by: Erin Calfa Weide – CALFPhotography

Rare Chair Affair
October 2, 2010

Reform Moves Ahead: A Patient's Bill of Rights

Kathleen Harris, NBCC Field Coordinator-WI.

We heard YOUR story. And we heard the stories of hundreds of women and men diagnosed with breast cancer across the country and in our state who were unable to get the care they needed when they needed it because they were uninsured or underinsured. Some were denied health care insurance because of a pre-existing condition, or had their insurance cancelled when they became sick due to lifetime limits on care. Many lost their coverage due to annual dollar limits on what an insurance company will pay for their health care. In 2006, several hundred women and men told their stories at NBCC's Personal Stories event convened by the Wisconsin Breast Cancer Coalition (WBCC) in Milwaukee, WI. We heard their voices loud and clear.



On June 22, 2010, the three-month anniversary of the enactment of the Affordable Care Act, President Obama announced a "Patient's Bill of Rights." The rules "will put an end to some of the worst practices in the insurance industry and put in place the strongest consumer protections in our history - finally what amounts to a true Patient's Bill of Rights," Obama said, where he spoke in the East Room.

Americans have been fighting for a true patient's bill of rights for many years. In 2001, the McCain - Edwards - Kennedy bipartisan Senate patient bill of rights legislation and its house equivalent were

nearly adopted, but were halted when the events of September 11th changed the nation's agenda.

Since its inception in 1991, the National Breast Cancer Coalition (NBCC) has had guaranteed access to quality care for all as one of its top priorities. WBCC joined NBCC in 1994 and worked with NBCC on this effort all the way through the process, up to the enactment of the law. Both the NBCC and WBCC continue their efforts in the state-level implementation phase.

Most of the provisions of the new Patient's Bill of Rights go into effect on September 23, 2010.

For more in-depth information about the Patient's Bill of Rights and other provisions of the Affordable Care Act, go to: www.HealthCare.gov.

A short summary of the PATIENT'S BILL OF RIGHTS follows.

THE PATIENT'S BILL OF RIGHTS

PRESIDENT OBAMA ANNOUNCED A NEW PATIENT'S BILL OF RIGHTS MADE POSSIBLE UNDER HEALTH REFORM-A BASIC SET OF CONSUMER PROTECTIONS

1. **Prevents insurance companies from canceling your policy if you get sick.** Right now, insurance companies can retroactively cancel your policy when you become sick or your employer made an unintentional mistake on your paperwork.
2. **Stops insurance companies from denying coverage to children with pre-existing conditions.** Beginning in September, discrimination against children with pre-existing conditions will be banned—a protection that will be extended to all Americans in 2014.
3. **Prohibits setting lifetime limits on insurance policies issued or renewed after Sept. 23, 2010.** No longer will insurance companies be able to take away coverage at the very moment when patients need it the most. More than 100 million Americans have health coverage that imposes lifetime limits on care.
4. **Phases out annual dollar limits on coverage over the next three years.** Even more aggressive than lifetime limits are annual dollar limits on what an insurance company will pay for your health care. For the people with medical costs that hit these limits, the consequences can be devastating.
5. **Allows you to designate any available participating primary care doctor as your provider.** You'll be able to keep the primary care doctor or pediatrician you choose, and see an OB-GYN without referral.
6. **Removes insurance company barriers to receiving emergency care and prevents them from charging you more because you're out of network.** You'll be able to get emergency care at a hospital outside of your plan's network without facing higher co-pays or deductibles or having to fight to get approval first.

The Patient's Bill of Rights starts to take effect September 23, 2010.

For more information go to: www.HealthCare.gov

Wisconsinmade.com Supports Breast Cancer Awareness Month

WisconsinMade.com, an Internet-based specialty food and gift store, is donating 10 percent of its Internet sales to the Wisconsin Breast Cancer Coalition the week of October 11-20 to commemorate Breast Cancer Awareness Month and support the fight against breast cancer. Customers who place an order at www.wisconsinmade.com will see a portion of their purchase donated to help fund breast cancer research and advocacy efforts.

“The Wisconsin Breast Cancer Coalition has contributed so much to raise breast cancer awareness and advocacy in the State of Wisconsin,” said Linda Remeschatis, WisconsinMade.com owner and breast cancer survivor. “I’m pleased to be able to support this great Wisconsin organization for nine years now and help them fight breast cancer.”

About WisconsinMade.com

The web-store showcases over 2500 products made with pride and passion by more than 250 Wisconsin artisans. Visitors to Wisconsinmade.com find hand-crafted art for the home and office created in multiple media by Wisconsin artisans; books written by Wisconsin authors; CD’s produced by Wisconsin musicians; Wisconsin-sports apparel; gift baskets, and gourmet foods. Wisconsinmade.com receives national attention for the regional-specialty foods it delivers, such as the championship Wisconsin cheeses, meats, cranberries, maple syrup, and gourmet pastries identified with Wisconsin’s ethnic heritage. Wisconsinmade.com delivers the best of Wisconsin to the rest of the U.S.A.

About the Wisconsin Breast Cancer Coalition

The Wisconsin Breast Cancer Coalition brings Wisconsin voices together to stand up and speak out about breast cancer with:

- Education – Spotlighting critical breast cancer issues
- Collaboration – Empowering through strategic alliances
- Legislation – Influencing policymaking

The Wisconsin Breast Cancer Coalition is a statewide organization that is recognized as the premier resource on breast cancer policy issues. Since it was founded in 1994, the WBCC has initiated programs meant to reach the people of Wisconsin directly, partnered with other organizations to affect changes in policy that have significantly increased funding for research on both the state and national level, and worked to improve access to quality care and treatment for all people. Our collective voice in Wisconsin will make a difference. Visit our website, www.standupandspeakout.org for more information.

Announcing National Breast Cancer Coalition

Project LEAD Workshop: September 24-26, 2010 in Minneapolis, MN

Kathleen Harris, NBCC Field Coordinator-WI.

The new Project LEAD® Workshop is an introductory level, two and a half day workshop that will teach the basics of breast cancer science and the biomedical research process, how to more accurately understand scientific information in the news, and how to become a more effective breast cancer advocate in your community. Promising workshop students interested in moving to the next level of research advocacy will be encouraged to apply to the Project LEAD Institute.

Become an NBCC member with an annual fee of \$35 and attend for free! Includes all workshop materials and meals for 2 ½ days. Scholarships are also available for parking and lodging. Register online at StopBreastCancer.org/ProjectLEAD.

Scholarship deadline: August 27, 2010

Registration deadline: September 15, 2010



For more information contact: Programs Coordinator at 800-622-2838 or ProjectLEAD@StopBreastCancer.org
Don't miss this Project LEAD workshop!

Southeastern Regional Breast Care Fund (SRBCF)

Kim Melcher, Scholarship recipient

What is the Southeastern Regional Breast Care Fund?

A fund made possible through a unique partnership between the Wisconsin Breast Cancer Coalition and the Wisconsin Well Woman Program (WWWP). WWWP is a state program that provides free screening for uninsured or underinsured women. For the past ten years, this partnership has helped men and women in Southeast Wisconsin with financial support for their breast screening, diagnostic and treatment needs.

How does one get assistance from the fund?

Men and women are referred to their local coordinating agency (LCA) for the Wisconsin Well Woman Program. Each LCA assesses an individual's situation and utilizes the best available resources. If no resources are available for screening or diagnosis, the LCA will look to the Southeastern Regional Breast Care Fund for assistance. Assistance is dependent on the SRBCF availability.

The SRBCF goes beyond just providing financial support.

For those individuals in need of services, such as a screening mammogram, LCA and Fund administrators work together to provide in-kind coordination with providers of the Wisconsin Well Woman Program to perform needed services.

What is WBCC's role?

The Wisconsin Breast Cancer Coalition is the fiscal agent or sponsor of the fund. This means that the fund is "housed" under WBCC's non profit status in a segregated account. WBCC provides the oversight responsibility of the fund and has a designated volunteer who serves as the treasurer of the fund.

Where does the money for the fund come from?

Over the years, money for the fund has come from grants, donations and various fundraising events. For many years, funding was from a grant from the Milwaukee Affiliate of Susan G. Komen for the Cure®.

What is the future of SRBCF?

Stay Tuned! Strategic planning is underway. One thing that will remain constant, though, is the need for such a fund in the community and our need to keep money in the fund.

What are the highlights of SRBCF for 2010?

SRBCF is excited to continue partnering with Karen Dalessandro from FM106 for her Checkups for Chicks program. On October 22, 2010, Checkups for Chicks and Karen will be hosting a Marathon Mammogram Party at Aurora West Allis Medical Center. The goal is to provide 50-plus mammograms in party fashion to women who may not get a mammogram otherwise. To learn more about this party, tune in to FM106's morning show in September.

On October 20, 2010, The Woodhouse Day Spa® in Mukwonago will be hosting their 5th annual Breast Cancer Awareness Event. This is a great evening filled with complimentary spa services, food, education, raffles and silent auction. Proceeds from the event will benefit the SRBCF. Contact the spa manager, Kathy Busse, at 262-363-8878, to learn more.

How do I learn more about SRBCF?

Contact the fund administrator, Kim Melcher, at 414-328-7407 or kim.melcher@aurora.org.

Memorials and Honorariums



Often, when a loved one passes away, families want to honor them in a special way. Most non-profit organizations have memorial gift programs in which people can pay tribute to their loved ones by donating money to the organization in their family member's honor. The charitable gifts go to helping the cause and enhancing the care for future individuals.

Honor any loved one with a gift to WBCC. Individuals may donate a charitable gift in honor of their loved one and the revenue goes to supporting the WBCC and their mission. This can be done through their website or by mailing a donation.

The following individuals are recognized by donations made in their name to the WBCC:

Erin Marie Calfa
Tunisia Koonce

Lorraine Dillon
Sandra Torcarson

Kim Harris
Tina Dale-Koller

Jean Hedtche
Phylis Weiner

Thank you to all who honored these individuals with charitable gifts.

Wisconsin's Health Insurance Risk Sharing Plans (HIRSP)

Dawn Anderson, WBCC Executive Director

One of the key provisions of the comprehensive health care reform law is that by 2014, insurers in Wisconsin may no longer deny coverage to applicants because of a pre-existing condition, such as breast cancer. In the interim, there are options available.

Wisconsin established a Health Insurance Risk Sharing Plan (also known as HIRSP, or a "High Risk Pool") in 1979 to offer health insurance to Wisconsin residents unable to find adequate coverage in the private market due either to a medical condition or having lost their employer-offered group health insurance. Many states did not have a High Risk Pool for their residents – until now.

The new health care reform law requires states to establish a pre-existing condition insurance plan, and provides funding to do so. Wisconsin has been allocated \$73 million over the next three and a half years to operate the insurance plan on both state and federal levels, known in Wisconsin as the HIRSP Federal Plan.

Eligibility for the two programs is similar, except that the Federal Plan does not have a six-month waiting period for coverage of pre-existing conditions as WI-HIRSP does. However, under the WI-HIRSP, if an applicant is HIPAA eligible (that is, they have lost their employer-offered group health insurance, Medicaid or BadgerCare Plus, Medicare or another state's High Risk Pool coverage) then they too are exempt from the six month waiting period for coverage of pre-existing conditions.

Under both plans, applicants must have been uninsured for at least six months prior to application.



Premiums for the Federal Plan are slightly lower than the existing WI-HIRSP, however, if total annual household income is less than \$33,000, applicants may qualify for reductions in premiums, deductibles and drug out-of-pocket costs under the WI-HIRSP, which may make it less expensive than the Federal Plan. Wisconsin women are fortunate to have these two options for coverage available to them until the 2014 reform is in place.

The WBCC is pleased that the discriminatory practice of denying coverage to a woman because she has had breast cancer will eventually be prohibited. The HIRSP Federal Plan began accepting applications on July 15. Detailed information on eligibility criteria and premiums for both plans can be found at www.hirsp.org or you may call (800) 828-4777.

"Beyond The Pink Ribbon"™ Training Seminars: An Invaluable Resource for Breast Cancer Advocates

Katie Prown

Each year, the Wisconsin Breast Cancer Coalition sponsors half-day "Beyond The Pink Ribbon"™ training seminars for breast cancer advocates to learn more about leveraging the legislative process. Thanks to a grant from the National Breast Cancer Coalition, this year the WBCC was able to bring our BTPR training to Green Bay, and we will be returning on September 11th to provide an advanced training and leadership seminar for district leaders to learn state-of-the-art strategies for mobilizing their local communities.

The next BTPR will be held in Milwaukee on October 23rd (location to be announced). The Milwaukee training will be an excellent opportunity for advocates in Southeast Wisconsin to learn from legislators and seasoned activists about the best strategies for making our collective voices heard in Madison and Washington D.C., maximizing our impact at both the state and federal levels.

Please mark your calendars and plan to join us in October!

To find out more, call the WBCC Executive Director, Dawn Anderson at 414.963.2103 or send her an email at wbcc@standupandspkout.org.





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WBCC MISSION

The Wisconsin Breast Cancer Coalition brings Wisconsin voices together to Stand Up and Speak Out about breast cancer with:

- Education** – spotlighting critical breast cancer issues
- Collaboration** – empowering through strategic alliances
- Legislation** – influencing policy making.

TO CONTACT WBCC

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“Collective Voice” to go electronic!

For many years, supporters of the WBCC have automatically received our printed newsletter on a quarterly basis. As you can imagine, our list has become quite large, while printing and postage costs have increased. Our Board of Directors, in approving a new fiscal year budget, have made the decision to scale back our printing and postage costs and only mail printed newsletters as a benefit to dues paying members. The electronic format may allow us to do more frequent, time-sensitive issues going forward and will allow you to directly link to resources such as congressional offices. It's also easier for you to share with your friends and family!

If we have your email address in our database, you will continue to receive the newsletter in an electronic format quarterly. To ensure that you continue to receive this valuable source of information on breast cancer in Wisconsin, please send us an email at wbcc@standupandspeakout.org with your email address. You'll automatically be added to our email list beginning with the next issue.

Alternately, if you are not a member of the WBCC, and would like to receive printed newsletters, please consider supporting us with an annual membership of \$30. We'll send you a thank you gift and you'll be ensured free admission to our educational events such as “Beyond the pink ribbon” Advocacy Seminars and our Annual Meeting. You can join online at our website or by sending a check to PO Box 170031, Milwaukee, WI 53217.