Signed. Sealed. Delivered!
Breast Density Notification Act Becomes Law

Turning Awareness Into Action

We did it! The PA Breast Cancer Coalition's Breast Density Notification Act is now law. With Governor Tom Corbett's signature, the bill requires mammography facilities to notify women who have dense breast tissue. Dense breast tissue increases a woman's risk of being diagnosed with breast cancer at a later, more dangerous, less treatable stage.

This victory would not have been possible without the leadership of bill sponsors Senator Robert Mensch and Representative Karen Boback and all of the work of PBCC advocates throughout Pennsylvania who contacted their state legislators asking support for this legislation. Thank you for helping the PBCC take another step forward in finding a cure for breast cancer now...so our daughters won't have to.

PBCC 20th Anniversary Conference: Celebrating Achievements and Working Toward a Cure

The 20th Anniversary PA Breast Cancer Coalition Conference was the perfect balance of reflecting on the past, celebrating the present and working toward the future in breast cancer awareness, outreach and advocacy here in Pennsylvania.

The 2013 Potamkin Prize winner Dennis Slamon, M.D., world-renowned for the discovery of Herceptin, presented his workshop during the opening session. Conference guests spent the rest of the morning in workshops or browsing the exhibitor hall.

The Pink Ribbon luncheon brought everyone together to hear from 2013 Pink Ribbon Awardees Jeanne Schmedlen and Mindy Gray as well as Conference Honorary Chair First Lady Susan Corbett. Governor Tom Corbett made a surprise appearance to congratulate the PBCC on its 20th Anniversary, and PBCC President & Founder Pat Halpin-Murphy took the opportunity to ask the Governor to sign the Breast Density Notification Act into law once it reached his desk.

See more Conference Coverage inside!

Sponsors - page 4; Pink Party - page 7
President’s Corner

Breast Density Notification Act Will Save Lives

Imagine being told you have Stage 3 breast cancer just months after having a ‘normal’ mammogram. For far too many women, this nightmare scenario becomes a reality due to dense breast tissue that they don’t even know that they have. Often this dense tissue hides tumors in mammograms, leaving women in the dark about their breast cancer until it has progressed to a late stage and becomes more difficult to treat.

Now, with the Breast Density Notification Act, mammography facilities are required to tell women if they have dense breast tissue and possibly offer information on additional screening options. This disclosure provides women with the knowledge they need to seek additional screening or pay particularly close attention to changes in their breasts in order to be aware of anything that may not have been detected by a mammogram. It gives a woman information that could ultimately save her life.

Cindy Spinello, a breast cancer survivor who faced a late-stage diagnosis due to dense breast tissue, spoke at the signing of the Breast Density Notification Act. She said, “Early detection saves lives and there is nothing more valuable than the gift of life.” It is both Cindy’s and our hope that this legislation will help educate women about what dense breast tissue means and how it can impact their health.

I am so grateful to bill sponsors, Senator Robert Mensch and Representative Karen Boback, as well as Governor Tom Corbett and all Pennsylvanians who called or emailed their legislators urging support for this life saving legislation.

Our next step is to educate the public about this important law. Please help us spread the word so that women with dense breast tissue will no longer be left in the dark.

New Board Member

Bradley P. Shopp has been named to the PBCC Board of Directors. Brad is a partner at Feinberg Shopp Associates and a longtime friend of the PBCC. For years, he has worked pro bono on the PBCC’s behalf to help secure funding. He brings to the board a career in government relations with an emphasis in healthcare consulting and advocacy. “I am most honored to be appointed to the PBCC’s Board of Directors and I look forward to working closely with Pat Halpin-Murphy, my fellow Board Members and the PBCC staff to spread the word and increase the visibility of this incredibly worthwhile organization,” Brad said. Welcome, Brad!

Your state tax refund TODAY can ensure her tomorrows.

Look for line 32 on your PA State Income Tax form and donate all or part of your refund to the PBCC’s Refunds for Breast and Cervical Cancer Research program.

pbcc.me/refunds
Survivor Spotlight
Kathie Thomas

Diagnosis & Treatment
I had a mammogram in September 2012 prior to having kidney surgery that did not show anything unusual. Then after I was home from the hospital for a few days, the surgeon called and said, “I hate to tell you this but you have a cancer that is estrogen positive.” It turns out there was a small tumor in my right breast next to the lymph nodes and the cancer had traveled through my blood system to the bones. So I went from being what I thought was healthy to having stage 4 breast cancer that had metastasized to my bones. It was devastating. How could this be? I thought I was doing everything you’re supposed to be doing. The oncologist explained that I had dense breasts and because of this, the mammogram didn’t detect the tumor. The bottom line is that I probably had this cancer for several years.

This began a series of appointments, seeing an orthopedic doctor and a breast cancer specialist to determine the course of treatment. My treatment course is radiation and a hormone blocker to try to stop my body from producing estrogen since this cancer thrives on estrogen. Once a month I also get an injection to help make the bones stronger. I was 62 years old and the orthopedist said that my bones were so fragile they could easily break at any time. With the type of cancer I have in stage 4 I will always be in some type of treatment to prolong my life. I still don’t understand why I was never told that I had dense breasts. That’s why I jumped on the bandwagon back in February to get the Dense Breast Notification Act signed into law.

A Simple Formula
My formula is a simple one. Positive attitude + a sense of humor + lots of prayers + family and friends for support = many more years of memories. My faith gets me through but in the beginning I couldn’t deal with the diagnosis and couldn’t even pray for myself. My goal though was to have at least one person in every state praying for me. I reached out by email to my friends and family and asked them to spread the word. Within two months I had all 50 states covered and then started to hear from people praying for me in other countries. Knowing that they are praying for me provides a sense of calm and peace that I need. Everyone has a crisis in life to deal with and mine just happens to be cancer.

In June I retired as a Special Ed teacher with the Capital Area Intermediate Unit. I have two grown children. I have a daughter who is married and a grandson who will be two years old on Christmas Day. My son lives in Philadelphia and is planning a December wedding. I like to travel and to eat in a variety of ethnic restaurants. I love being with friends, reading or playing games.

I see my battle with breast cancer as a journey. It’s a journey I’d definitely prefer not to be taking, but it has also provided opportunities. I’ve attended the PBCC conference, I was invited to the signing of the Dense Breast Notification bill, met the Governor and the First Lady. The wonderful people I’ve met along the way have been phenomenal. I’m very grateful that so many of the lemons that have been tossed my way have turned into lemonade.

“I thought I was doing everything you’re supposed to be doing. The oncologist explained that I had dense breasts and because of this, the mammogram didn’t detect the tumor.”
- Kathie Thomas

FREE Webinars
COMING SOON
Presented by PA Breast Cancer Coalition
Stay tuned in 2014 for topics and registration information!
Without the support of the sponsors listed below, the PBCC would not be able to have such a successful Conference. Thank you for your generous support. You truly make a difference in the lives of women across PA.

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What’s In a (DCIS) Name?

by BARBARA C. GOOD, PH.D., Director of the National Surgical Adjuvant Breast and Bowel Project (NSABP) Division of Scientific Publications

Many thousands of women have chosen mastectomy or double mastectomy when they are diagnosed with ductal carcinoma in situ (DCIS). Because the outcome of this finding is uncertain, some women choose to eliminate most of the chance they will develop invasive breast cancer by having their breast tissue surgically removed. But not all cases, some would argue not most cases, of DCIS proceed to invasive breast cancer. Lumpectomy, radiation and/or tamoxifen have been shown to treat DCIS effectively and allow a woman to avoid the more extensive surgery and reduce the risk of life-threatening disease.

This past July the National Cancer Institute brought together a panel of physicians and scientists from outside the organization that proposed a change to the way cancer is defined. In breast cancer, DCIS was specifically addressed. For many medical professionals, DCIS does not constitute a “true” cancer but is considered a forerunner to cancer, a sign that cancer may develop, or an indication that the woman who receives such a diagnosis has a predisposition to breast cancer. The thinking behind the panel’s proposed change was that perhaps eliminating the word “carcinoma” or not referring to DCIS as a cancer would lead fewer women to immediately assume the worst.

Recent advances in technology have given radiologists and oncologists access to tools that can locate findings in patients that only a few years ago would have been overlooked or remained undisclosed. The term “overdiagnosis” is now sometimes used by physicians to indicate a situation in which a patient is informed of a “cancer” that may actually not yet be a cancer in strictest terms. The panelists gathered by the NCI were no doubt considering this when they made their recommendations.

Since Nancy Reagan’s mastectomy for DCIS in 1987, the percentage of women opting to undergo mastectomy for DCIS has risen. Numerous medical journals carried articles highlighting this trend, and some physicians became concerned that women choosing the route of mastectomy might be overreacting to the diagnosis they had received. Was there a way to help prevent what might be unnecessary major surgeries?

In an interview with PBS earlier this year, Larry Norton, M.D., from the Memorial Sloan-Kettering Cancer Center, noted that the future may hold ways of determining, through laboratory and molecular analysis, whether any given case of DCIS is likely to remain inactive or to develop into an invasive cancer. But for now, he said, there is no way to say with certainty which way any particular case of DCIS will go. Some cancers, such as certain prostate cancers, can be determined to be indolent and can be safely watched over long periods rather than being surgically removed. This is not currently true of DCIS. Physicians can sometimes tell whether a case of DCIS will become invasive but cannot now say with certainty that any given case of DCIS will remain DCIS.

Numerous editorials have appeared in the recent medical literature debating whether the name change proposed for DCIS by the NCI panel should be implemented (see, eg, Wickerham DL, Julian TB. Ductal carcinoma in situ: A rose by any other name. J Natl Cancer Inst 2013; 16;105(20):1521-2). Can women undergoing disfiguring surgical procedures for premalignant conditions or slow-growing cancers be discouraged from those actions by a change in medical terminology? Should they be? Can a name change remove the fear that a diagnosed case of DCIS may be one of the ones that proceeds to invasive cancer?

As Dr. Norton noted in his PBS interview, the real issue may lie not in terminology but in the type of communication that takes place between a patient receiving a diagnosis of DCIS and the physician giving it. Such a diagnosis needs to be delivered along with enough information to allow the patient to weigh the risks and benefits and to understand the implications of the road she’s taking. Until research provides us with the tools to define by molecular or laboratory methods what a given clinical finding will develop into, that is probably the best tool we have.

“Can a name change remove the fear that a diagnosed case of DCIS may be one of the ones that proceeds to invasive cancer?”

- Barbara Good, Ph.D.
Once again, teenager Maddy Vieth and her fellow swimmers at the Hershey Aquatic Club dove in to fundraising for the PBCC with their Breaststroke for Breast Cancer event! This year they swam their way to an incredible $12,000 donation. Since 2009, this event has raised over $40,000 for the PBCC. Many thanks to Maddy and the Hershey Aquatic Club for making such a splash for the PBCC!

Teams Take the Field Against Breast Cancer

Four school districts turned lessons in teamwork into lessons in giving when they turned events into fundraisers for the PBCC!

The Lower Dauphin High School football team held a ‘pink out’ game on October 18th. Players, cheerleaders and fans wore pink and they sold t-shirts. $4,900 was raised. Thanks to the community and coordinator Mandy Mease for their support!

Northern Lebanon Midget Football raised $1,529 from t-shirt sales. Erik Sechrist organized the effort with the help of other cheerleader dads. Thanks to the Vikings for their support!

In Centre County, girls took the field while boys cheered them on at Bald Eagle Area High School’s annual Powder Puff football game. Over $2,000 was raised from sweatshirt sales, local business support, and donations at the gate. Thanks to coordinator Sharon Nilson, our volunteers Lois and Michelle, and all who participated!

Boosters of the Red Land High School JV and Varsity soccer teams in York County coordinated a pink out game complete with a bake sale, t-shirt sales, raffles, concession sales and donations totalling $1,000. Way to go Red Land High!

Over 250 racing fans had the chance to walk the track at Pocono Raceway as part of Go Pink at Pocono 2. Bill Martel Racing presented the PBCC with a check for $5,000 from the event. Thanks to driver Kyle Martel and collaborators Rob Ziemba and Bill Martel Racing for putting together another great event!

Carlisle’s First Friday event kept businesses in the Cumberland County community thinking pink in October. Restaurants, shops and galleries opened their doors to the community and collected donations or held promotions to benefit the PBCC. $2,167 was raised! Special thanks to Kirsten Layser of Café Bruges for developing the event and to Karen Byers for organizing volunteers to help make the evening a tremendous success!

Due to the tremendous support we received from our Grassroots Partners this fall, we weren’t able to feature every event in this issue. Please check out our monthly e-newsletter PinkLink or the Spring 2014 FrontLine for more events!

Plant the seed in your community and watch it grow statewide - become a Grassroots Partner.

To find out how, call Kristen at 717-769-2301 or visit PABreastCancer.org
67 Women, 67 Counties Makes Stop for SEPTA in Philadelphia; Heads North to Montour County

Ride the Trail to a Cure and the Grey Mare Society teamed up for a triple crown of events this year. Linda Golden took the reins at the Clinton Anderson Ball Toss held at the Harrisburg Horse Show. Organizer B.J. Carey saddled up for the New Millford Ride at Pie in the Sky Orchard in Susquehanna County. JoAnn Gilkey finished strong as coordinator of the ride in Mt. Holly Springs, Cumberland County. In total, $17,000 was given to the PBCC to help serve women and their families battling breast cancer! We are grateful for the continued support of Linda, B.J., JoAnn and all who took part in these tremendous events!

Community Aid, Inc. donated $10,000 to the PBCC in keeping with their mission of “Neighbors Helping Neighbors.” Thanks to Executive Director Glenn Chandler, PR Director Bob Hauer, and all who helped to make the donation possible! You can support Community Aid by visiting their Central PA stores or donating your gently used clothing to one of their area drop-off bins.

For every vehicle sold at the Jack Giambalvo Family of Dealerships in York on certain days in October, the PBCC received $100, totaling $1,500! Thanks to Vice President of Operations, Tom Couch and Public Relations Manager Nicole Berkebile for getting customers revved up in support of the PBCC! We look forward to working with you again!

Pink Party Gets Celebrity Treatment in Harrisburg

With the help of celebrity hosts Nell McCormack Abom, with; Sue Campbell, WINK 104; Tammy Miller, Tammy Speaks, LLC; Alicia Richards, abc 27; Lesley Ridge, PBCC Board of Directors; Earl David Reed, 105.7 The X; and emcee Dave Marcheskie, abc 27!, the PBCC rolled out the pink carpet for the Pink Party celebration at the Harrisburg Hilton the evening prior to the PBCC Conference.

The PBCC honored Westmoreland Walks as the 2013 Shining Light Awardee for the organization’s long-standing support as a Grassroots Partner and ally in advocating for breast cancer survivors and their families.

The partygoers were also treated to a sneak peek of the 2013 Pink Glove Video Contest submission from Penn State Milton S. Hershey Medical Center as well as some live music and delicious refreshments.

Thanks to all who attended and contributed their time and energy to make the evening a night to remember!
Refunds for Research

Your state tax refund TODAY can ensure her tomorrows.

Can we count on you for $20 in honor of the PBCC’s 20th Anniversary?

We’ve come a long way in 20 years. From our supporting countless women and families through our programs and services to our patient and legislative advocacy, we have worked each and every day to find a cure for breast cancer now...so our daughters won’t have to.

WE NEED YOU to make a difference in someone’s life and help us continue our mission!

A gift of $100 will support a travel grant for an out-of-town woman to attend the PBCC Conference in Harrisburg.

A gift of $50 will pay to fill one Friends Like Me care package to let a woman who has just been diagnosed with breast cancer know she is not alone in her fight.

A gift of $20 to honor the PBCC’s 20th Anniversary will help support initiatives like our breast cancer research grants; the online course and webinars for survivors, nurses, social workers and advocates; and our personal one-on-one patient advocacy for women who, without that resource, might fall through the cracks in the medical system.

Thank you for all of the support you have provided over the years. We could never have made it this far without YOU.

Your donation really will make a difference in a woman’s life! To make an online gift please visit pbcc.me/give.