

10 YEARS

abcd
after
breast cancer
diagnosis

a decade of
the power of one-to-one

6737 W. Washington Street
Suite 3265
West Allis, WI 53214

Mentors Matter
& Mentor Matters

Summer 2010 Volume 4 Issue 2

Dear Friends of ABCD,

Twelve months ago, we were launching a year-long celebration of “A Decade of the Power of One-to-One.” Now, we are well into the first year of “Decade Two.”

When ABCD was founded, the non-clinical support needs of breast cancer patients were recognized as significant only in limited circumstances. Today responding to those needs is seen as vital to successful implementation of Wisconsin’s Comprehensive Cancer Control Plan.

Much has changed in ten years. But some things remain the same; it is a long journey between the time of diagnosis when you hear the words, “you have breast cancer” and the completion of treatment and then the five-year anniversary of diagnosis. And, of course, that anniversary is but one milestone.

Yet, since 1999, it is a journey that women (and men) do not need to take alone because at ABCD’s core we remain steadfast and true to our founding philosophy: *patients, families and friends affected by breast cancer should have available compassionate, reliable, personalized support. For free.*

ABCD’s approach to one-to-one mentoring remains distinct, but we could not be happier that today personalized support is more widely valued for cancer patients. We collaborate with others serving those impacted by breast cancer and are humbled to work with, learn from, and support our partners from small community organizations to large service providers – anyone whose priority is support for breast cancer survivors.

The news and stories in this issue of *Mentor Matters* illustrate how ABCD complements the work of others, collaborates in ways customized to each community it serves, and commits itself for the long haul.

As we begin “Decade Two” we renew our promise to provide personalized support to people affected by breast cancer -

- * Breast cancer patients who request a mentor or mentors
- * Patients’ loved ones whose journey can be lonely in its own way
- * Mentors – compassionate survivors – who deserve focused training and professional support
- * Breast health professionals, volunteers, and advocates – who commit themselves to making life with breast cancer a little less scary

We renew our promise and belief in – the power of one-to-one.

Kathy Ehley
President

Ginny Finn
Executive Director

BOARD OF DIRECTORS

Kathy Ehley
President

M. Kathleen Eilers
Vice President

Gael Garbarino Cullen
Secretary

Jill Newman, C.P.A.
Treasurer

FOUNDER
Melodie Wilson
1950-2009

Bonnie Anderson
Elizabeth Brenner
Therese Burkhart
Hon. Lisa Neubauer
Wayne C. Oldenburg
Theresa Reagan
Nancy J. Sennett
Julie Tynion
Mark S. Young

STAFF

Judy Mindin
Outreach and Operations
Coordinator

Jackie Adams
Program Coordinator

Ginny Finn
Executive Director

ABCD Partners & Collaborators

Carla Harris, RN, BSN: An ABCD Healthcare Partner



Carla Harris

As Oncology Community Outreach Coordinator with Columbia-St. Mary's Hospital, Carla Harris is never really "off duty." She works diligently to assure all her breast cancer patients have access to quality clinical care and sensitive, personalized support. And, Carla is a long-time partner in spreading word of the power of one-to-one.

With over 20 years of nursing experience, Carla knows first-hand how important reliable support can be for a breast cancer patient. "Cancer can make you feel like you have no control over your life. The complexities of the journey can range from stressful to overwhelming," she notes. "One-to-one support from an ABCD mentor is really valuable, keeping patients, and their loved ones, focused on healing."

Beyond her formal duties, Carla is an active volunteer in the breast cancer community. She gives her time generously to ABCD and the Sisters Network-Milwaukee, among others.

Recently, she participated in a focus group assessing potential improvements to ABCD's mentor training curriculum. Carla actively recruits new mentors for the program, too.

"I can confidently recommend ABCD's services because I know the mentors are trained to focus on the needs of those they serve," Carla reports. "Plus, mentors are supported by ABCD with ongoing training and staff consultations. Partnering with ABCD is just one more way I help my patients."

Face to Face Arrives in Green Bay Area

On Thursday, April 22, ABCD held its first Green Bay-area "Face to Face" event at the Triumph Cancer Resource Center (TCRC), a new community-based support hub for those touched by cancer. The center's founder is Kay Van Boxel, an ABCD Family & Friends mentor.

Like the annual Milwaukee "Face to Face", participants and mentors gathered, shared stories and celebrated survivorship. This intimate evening included an introduction to the TCRC and an update on ABCD's plans for expanded services in Northeastern Wisconsin.

The evening also featured an outreach component, offering an overview of ABCD's services and anticipated plans to collaborate with TCRC in the coming year. ABCD welcomed area nurses and representatives from the Ribbon of Hope Foundation, which provides financial assistance to Brown County, Wisconsin, residents impacted by breast cancer.

As a result of the success of this event, new mentor training and Continuing Education for existing mentors have both been scheduled for fall at TCRC. New mentor training will be held on November 6 and 13, and all previously trained ABCD mentors are invited to join in on November 13 for special mentor update sessions. More information will be mailed out in October, or call the ABCD office if you have questions.



ABCD: Collaborating with the Community

Sisters Network – Milwaukee Holds Second “Side by Side – Reaching Out to U”

Sisters Network - Milwaukee, the local affiliate of the national African American breast cancer survivorship organization, held its second annual “Sisters Side by Side – Reaching Out to U” event on Saturday, June 12. Over three hundred attendees turned out for free clinical breast exams, breast cancer education and information about support services like ABCD.

Phyllis Holder, Sisters Network – Milwaukee President and an ABCD mentor led a team that recruited volunteers from several organizations, including ABCD mentors, to participate in this essential outreach to medically underserved members of the community. This year the event was hosted by House of Peace. ABCD Medical and Community Advisory Board members, Judy Tjoe, MD and Oza Holmes, RN were among the breast health professionals donating expertise. Over 300 people attended and over 100 received free clinical breast exams.



ABCD and the Pink Shawl Initiative - “Share the Care 2010”

For the third year in a row, ABCD reached out through its Pink Shawl/ABCD mentors at the annual “Share the Care” cancer education conference. This year held in Baraboo, Wisconsin, the conference provides cancer education to American Indian communities statewide. Founded in 2007, the Pink Shawl Initiative (PSI) works to raise awareness in and educate the American Indian community about breast cancer, providing support to those dealing with the disease. ABCD has been a supporter and collaborator of the PSI since its creation. The Pink Shawl/ABCD mentor team attending the conference and staffing a breast cancer education table was led by Deb Ushakow, Pink Shawl president and an ABCD Family & Friends mentor. For more information about the PSI visit www.dreamthecure.org

(artist credit: Dawn Dark Mountain)



ABCD Joins “Dia de la Mujer Latina” Organizing Committee

The American Cancer Society (ACS) invited ABCD and other community organizations to collaborate on this year’s “Dia de la Mujer Latina” breast cancer outreach event. A participant since 2008, this year ABCD staff met monthly with the rest of the organizing team, offering its expertise in one-to-one support and breast cancer awareness. In turn, ABCD continued to learn how to make its service to the Latina community more effective. While breast cancer was the event’s primary focus, this year it also included information about HIV/AIDS, diabetes, and heart disease.

Held Saturday, June 19, at South Division High School in Milwaukee, the event provided free breast health education as well as free clinical breast exams. Teams were on hand to coordinate referrals for follow up breast care if needed. ABCD Medical and Community Advisory Board member, Judy Tjoe, MD coordinated a team of volunteer physicians and clinicians from Aurora Health Care and the West Allis Health Department. ABCD mentor Emma Muniz and Outreach and Operations Coordinator Judy Mindin staffed the day-long information table.



Dia de la Mujer Latina

Continuing Education



Program attendees listen to presentation by Dr. Judy Tjoe.

Seventy-five mentors attended ABCD's winter Continuing Education program on Saturday, March 6 at M&I University in Brookfield. Designed to offer mentors the latest news in the breast cancer world, the program reflected one of ABCD's commitments to its mentor community.

Judy Tjoe, MD and ABCD Medical and Community Advisory Board member, and her colleague, Harpreet Parmar, MD, both of Aurora Sinai Medical Center, offered a look at screening and diagnostic testing. Their presentation included an update on the new U.S. Preventive Services Task Force mammography guidelines and the reasons those guidelines continue to provoke discussion within the healthcare community. The presentation also included a detailed review of how to read a pathology report. (*See sidebar.*)

A regular presenter for ABCD, Dr. Tjoe also has a faculty appointment at the University of Wisconsin – Madison. This session with Dr. Parmar, a senior internal medicine resident, was designed not only to offer helpful information to mentors, but also as a way to show the next generation of physicians the value of partnering with the community at the ground level.

Mentors also heard from Todd Dybul, certified yoga teacher/registered yoga teacher, and Mary Copps, retired occupational therapist and a breast cancer survivor, about yoga and Eastern movement practices that can help to improve the quality of life for patients and survivors. And, congratulations to Mary who completed mentor training in April!

ABCD would like to extend its thanks to:

- Medical & Community Advisory Board member Michele Nygro, metro Milwaukee district president, M&I Bank, and former ABCD participant Mary Hotchkiss, assistant vice president, M&I Support Services, for the invitation to present use M&I University. We also congratulate Mary on her commitment to becoming a mentor!
- M&I University staff Sara Albright and Debra Senglaub for making arrangements for our event.

A New Vocabulary – Lessons from a Pathology Report

*Have you heard these terms?
Your participants may have!*

- Tumor grade
- Tumor size
- Invasive vs. non-invasive
- FISH Test
- Oncotype DX
- BRCA1 / BRCA2
- Lymph node status
- Hormone receptor status
- HER2/neu status
- Tumor margins

ABCD has always gathered information from mentors and participants regarding their breast cancer diagnoses in order to make matches. As diagnostic tools have improved and doctors spend more time discussing test results and treatment options with their patients, our match process has become more and more refined in order to accommodate the information that our participants provide to us. We are continuously learning new terms, which we then incorporate into our mentor match process.

During our March Continuing Education program, keynote speaker Dr. Judy Tjoe shared a medical update on diagnostic testing and pathology reports with the ABCD mentors. If you missed it, check out some of the web sites listed below. They will help you keep up to date!

http://www.herceptin.com/pdf/pathology_report.pdf

(Developed by breastcancer.org)

<http://www5.komen.org/BreastCancer/ContentsofaPathologyReport.html>

http://www.breastcancer.org/symptoms/path_report/word_list.jsp

<http://www.cancer.org/Cancer/BreastCancer/DetailedGuide/breast-cancer-diagnosis>

<http://www.cancer.gov/dictionary>

Mona Hietpas: A Mentor's Story



Mona Hietpas

A PARTICIPANT BECOMES A MENTOR AND A CONTINUOUS LEARNER

We have all heard the phrase “making lemonade out of lemons” but have you ever heard of “making lemon meringue pie out of lemons?” Well that’s exactly how Mona Hietpas describes her journey of becoming an ABCD mentor. Diagnosed with breast cancer in August 2006, Mona dealt with the traumatic experience of her diagnosis, subsequent surgery and treatment with the help of an ABCD mentor and then sought to turn that experience into a sweet way to help others. Dessert, if you will.

In fall 2008, Mona went through the ABCD mentor training program and has since completed mentoring for three women. In addition, Mona is currently in a longer-term match, providing the one-to-one support of someone who’s “been there before – exactly there.” Mona has the benefit of a professional career that in some ways readied her to take on the role of mentor. As a retired social worker/psychotherapist, Mona knows what it is to attentively listen to others, to clarify and articulate someone’s thoughts and feelings and to create an intimate dialogue with empathy.

Mona believes that helping another woman talk out what is going on is crucial, making sure that emotional healing is part of the breast cancer journey as early as possible. Becoming an ABCD mentor has allowed Mona to use the supportive skills she learned professionally with a new, more personalized focus. That training combined with her own breast cancer experience, allows her to humbly share hope with others.

When asked how she stays up-to-date with new aspects of breast cancer treatment, Mona points to ABCD’s Continuing Education Program. Mona knows she’s a “volunteer” and not a professional in her mentor role, but she likes to stay current with the kinds of treatment options her participants might be facing. Recently, Mona was mentoring an ABCD participant and found out about a kind of testing medical oncologists are using to more precisely determine the potential of recurrence and, therefore, the need for chemotherapy. This “onco-type testing” was not being used when Mona received treatment, but her participant had the benefit of this new approach. Fortunately, a recent ABCD Continuing Education session provided Mona with the opportunity to learn the exact nature of this new testing.

“I know I am and will always be a reliable mentor because ABCD keeps me informed on topics that are important and relevant in the world of breast cancer,” says Mona. She is also inspired by ABCD founder Melodie Wilson as she faced her own battle with recurrence with an attitude of grace and service. Like so many, Mona is humbled by her experience as a breast cancer survivor and appreciates ABCD’s effort to help her stay renewed as a mentor.

Mark your calendars: Continuing Education for Mentors

- Summer Session: Saturday, August 14, featuring Leslie Waltke, PT
- Special Fall Program, Wednesday, October 6, featuring a multidisciplinary panel of breast cancer experts

Please contact the ABCD office for details and to register.

News & Events

New Wisconsin Cancer Control Plan Prioritizes Formal Survivorship Services

Following guidance provided in recent years from the Centers for Disease Control and Prevention, the Wisconsin Comprehensive Cancer Control Program released its Comprehensive Cancer Control Plan for 2010-2015 at its annual summit on June 3. The plan continues to identify inequities in access to diagnostic and treatment programs, but has a new emphasis on survivorship issues. The annual summit was followed by an afternoon-long special survivorship forum, promoting formal efforts to improve support services for cancer patients and their loved ones over the next five years.

Key survivorship elements of the new plan include:

- Recognition that cancer survivorship begins at diagnosis, not after completion of clinical treatment.
- Emphasis on the needs of co-survivors (family, friends and caregivers of cancer patients).
- Acknowledgement that successful cancer treatments have increased the ranks of cancer survivors whose challenges evolve but do not necessarily disappear.

Seeking to dramatically improve survivorship care over the next five years, the plan notes a lack of uniform awareness by clinicians of the importance of support and uneven access to support services based on a number of factors, including economics and availability of services. It contains a number of recommendations for improving collaboration between healthcare providers and those that provide support services, including streamlining communications with the patient community. ABCD joined providers and other support organizations in developing elements of the plan's survivorship chapter and will continue to collaborate with them to assure that the support needed by people affected by breast cancer is easy to find, personalized and free.

April 2010: A New Class of Mentors Graduate



*Front row, from left to right: Annie Calteaux, Mary Braun, Ruth Reid, Tabitha Andrist, Catherine Becker, Pat Mize
Back row: Diane and Paul Augenstein, MaryAnn Lueck, Cheryl D'Amico, Mary Cops, Jack Congleton, Susane Cowans, Jody Furlong, Peggy Papenfus*

Two of our new April mentors are husbands of breast cancer survivors. Jack Congleton is married to Kathleen, who has been an ABCD mentor since 2006. Paul Augenstein joined his wife Diane to take the mentor training classes together.



Sisters and survivors Laura Sanders, left, and Therese Quinn also attended mentor training. Therese was an ABCD participant during her journey, and encouraged Laura to join her in becoming a mentor. Read more about their remarkable story at:

www.froedtert.com/HealthResources/ReadingRoom/IncredibleStories/CancerCenter/CancerDiscoveredBeforeWedding.htm

10th Annual Date with a Plate Sets Records



Blue Jeans and fabulous chefs were the hallmark of ABCD's 10th annual celebration of support – Date with a Plate. Held this year at the Garage on the Harley-Davidson Museum Campus thanks to presenting sponsor Harley-Davidson Foundation, Milwaukee's premier small plates event raised over \$100,000 for the first time and broke attendance records.

Over 700 guests enjoyed an evening of delicious samplings and select libations, distinctive deals (including the ABCD shop, silent auction, and Kesslers Diamonds "boutique"), and live music by Romarcus Jones and I-94. ABCD mentors joined in on the fun, attending the event free of charge in thanks for the gift of their personalized support of others. Leading a loyal team of ABCD DWP volunteers, were event Co-Chairs Gail Lione and Julie Tynion. Full credits can be found on ABCD's web site: www.abcdbreastcancersupport.org

In addition to celebrating ABCD's power of one-to-one, the evening had poignant moments, including a welcome by Harley-Davidson Motor Corporation CEO Keith Wandell, who along with his wife, Deb, served as Honorary Co-Chair of DWP 2010, and remarks by Wayne Oldenburg, husband of ABCD Founder Melodie Wilson. In tribute to DWP's 10th anniversary and to Melodie's legacy, Oldenburg pledged to match all winning auction bids at the event. His generosity and that of many others made it a night to remember.

Community Support for ABCD

ABCD's distinctive personalized information and one-to-one support for people affected by breast cancer is always free and always will be. Helping ABCD keep that promise are those who believe in ABCD's mission and show it by committing their own time and talents to create "third party events" – raising funds for and awareness of ABCD's services. Those that support our work this way – asking nothing of ABCD other than help spreading the word or providing program materials – provide priceless support and build momentum, one-to-one, in their own communities.

Recent third party events and independent efforts for ABCD include:

- * Cedarburg Junior Woman's Club's annual Wearable Art Show raised over \$6,000.
- * Valley of Wisconsin & Breckenridge Landscape who teamed together to design an Architectural Garden and auctioned it to benefit ABCD at the March Milwaukee Realtor's Home and Garden Show.
- * St. Robert's School – Shorewood, where students shared proceeds of the annual raffle with ABCD.
- * St. Francis Borgia Home & School Association – Cedarburg, Mother/Daughter breakfast, which included an ABCD information table and opportunities to make a Mother's Day donation to ABCD.
- * Face Off for Breast Cancer – Oshkosh, inaugural cancer fundraiser benefiting ABCD organized by John Davids, a Fox Valley Northwestern Mutual representative, to show support for his wife and others battling breast cancer.
- * Mission River Band & Fiddleheads Coffee Café Concert Series – Cedarburg, Mequon and Thiensville, raising over \$3,000 through the team work of this amazing local band and the folks at Fiddleheads.
- * Balistreri Owned & Operated Sendik's Food Market – eight Metro Milwaukee locations, together with their customers and employees, supported by ABCD volunteers, this family owned grocer promoted ABCD's services for three months and raised over \$54,000.

To you and others – thank you for supporting people affected by breast cancer by supporting ABCD and spreading the power of one-to-one!

10 YEARS

abcd
after

breast cancer diagnosis

*a decade of
the power of one-to-one*

6737 W. Washington Street
Suite 3265
West Allis, WI 53214



Mentors Matter Mentor Matters

ABCD

6737 W. Washington Street
Suite 3265

West Allis, WI 53214

Ph. 414.918.9222

920.471.0322

800.977.4121

Fax 414.918.9223

E-mail abcdinc@abcdmentor.org

www.abcdbreastcancersupport.org

Face to Face – Save the Date Saturday, September 11, 2010

M&I University will be the site for ABCD's annual Face to Face event – where participants and mentors gather and greet – sometimes meeting for the first-time, sometimes renewing old friendships – and get inside updates about what's new at ABCD. Special "treats" are planned for this year – so mark your calendar and plan to join us.

Upcoming Events— Save these dates too!

July 25	Stick it to Breast Cancer – Field Hockey Tournament to benefit ABCD at Hart Park in Wauwatosa. Visit www.sticktobreastcancer.webstarts.com
August 14	Continuing Education for Mentors – “The New Normal” - Living your Life after Breast Cancer.
September 26	Susan G Komen for the Cure – Southeast Wisconsin, Race for the Cure. To join ABCD's team: go to www.komenmilwaukee.org/komen-race-for-the-cure/race-information and complete the form.
October 6	Continuing Education for Mentors – Panel Discussion with a Multidisciplinary Breast Cancer Medical Team
October 23	Wisconsin Breast Cancer Coalition – Individual Advocacy Training. Interested? Visit www.standupandspeakout.org
November 6 November 13	New Mentor Training New Mentor Training & Continuing Education Both trainings located at: Triumph Cancer Resource Center, Green Bay/DePere www.triumphcrc.org
November 6, 13 & 20	New Mentor Training – Summit Place, West Allis