Metastatic Breast Cancer
MBCalliance
together we are stronger than the disease

THE METASTATIC BREAST CANCER ALLIANCE:
A STORY OF *SUCCESS* IN ADVOCACY

BY SUNNY SEA GOLD

While the large-scale breast cancer picture has brightened over the past 30 years, there is one group of patients who aren't faring much better than they used to: those with metastatic [met-uh-STAT-ic] breast cancer, in which the disease has spread from the breast to distant sites such as the bones, lungs, or brain.[1] Metastatic patients have a median survival time of just three years—a statistic that, although improving, hasn't changed dramatically in two decades.[2,3] More than 40,000 people are projected to die of metastatic breast cancer in 2016.[4] Despite these sobering facts, only about 7 percent of the total funds invested in breast cancer research over the past 10 years were specifically allocated for metastatic disease,[5] and patient information and support haven't been keeping up with demand.

The *Metastatic Breast Cancer Alliance*—a coalition of nonprofit groups, individuals with metastatic breast cancer, and pharmaceuticals and biotechs—was founded in 2013 to improve, and ultimately transform, the lives of people living with metastatic breast cancer. In a few short years, the *Alliance* has already made such strides in creating tools for patients and advancing research on metastatic breast cancer, that organizations focused on other disease states are looking to mimic the group's model.

THE POWER OF COLLABORATION

The concept of the *Alliance* began as many good ideas and collaborations do, during congenial chats over dinner or between sessions among advocates who met at breast cancer conferences and other events. Eventually, a core group of these advocates decided they could do more for people living with metastatic breast cancer *together* than they could in their separate groups, and they asked pharmaceutical company Celgene to help bring the fledgling coalition together for an inaugural meeting in 2012. "The organizational representatives included four women who were living with metastatic breast cancer, including myself," says Shirley Mertz, president of the nonprofit Metastatic Breast Cancer Network. “We shared why we felt our needs were unique; the idea that we’re *always* in treatment and we always need support, and that for years that has not been fully recognized. Most large breast cancer organizations have primarily been focused on either awareness or supporting those with early-stage disease.” But studies suggest that even when found and treated early, 20 to 30 percent of all breast cancers will eventually metastasize.[6,7]

“Representatives from 11 organizations, large and small, all with different missions and varying perspectives, came to that first meeting to talk about metastatic breast cancer and what we might do together to fight this disease,” says Kimberly Sabelko, managing director of strategic partnerships and programs for Susan G. Komen. “I think most of us went into that meeting with some reservations about the idea of so many different organizations doing something collaborative and meaningful, but we left with a great deal of hope that we could indeed put our collective resources, expertise, time, and energy to bear on metastatic breast cancer.” The founding members had a shared sense of urgency in this mission. “Surveys had already shown that women and men living with metastatic disease had very different needs from those with early breast cancer, and that few organizations were offering programs and services tailored to these needs,” says Musa Mayer, a breast cancer survivor and longtime patient advocate. “Even at that early stage, we found we could set aside our differences to focus on the common purpose we all agreed was so desperately needed. That meeting was a powerful experience. It was the start of the *Metastatic Breast Cancer Alliance.*”

Originating Members of the Metastatic Breast Cancer Alliance

AdvancedBC.org
Metastatic breast cancer
Information and support for patients, family members and friends

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Celgene

FORCE
Facing Our Risk of Cancer Empowered

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SHARE
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Young women facing breast cancer together.

Collaboration has been the cornerstone of the *Alliance* from the very beginning. Breast cancer research and advocacy can be competitive arenas, with nonprofits going after the same fund-raising dollars, labs applying for the same grants, and pharmaceutical companies competing for profits in the marketplace. “This competition can be a barrier to progress,” says Stephanie Reffey, managing director of evaluation and outcomes at Susan G. Komen, and co-chair of the *Alliance* research task force. “While the nature of competition is to hold some information close, we are all, at the end of the day, working toward saving lives and improving the quality of life for breast cancer patients,” she says. “Collaboration is so important for metastatic breast cancer because so many groups have bits of information and different constituents and expertise in certain areas. By bringing groups with different strengths together, we’ve been able to make progress in areas much more quickly than would have been possible independently.”

A few organizations decided to step away before the formal launch because their missions didn’t align with the *Alliance* and, in some cases, because of the level of collaboration expected, says *Alliance* director Katherine Crawford-Gray. “But frankly, our success comes from the fact that our members play nicely in the sand box!” says Crawford-Gray. “Even though it can be hard sometimes, they know that coming together will give us all greater success than what any one group could do on its own.”

Another key difference between the *Alliance* and many other advocacy coalitions is that the pharma members don’t just supply financial support—their representatives have real seats at the table and do real work in the committees. Crawford-Gray credits this all-around hands-on approach with sparing the *Alliance* the failure so common to start-up organizations or coalitions like the *Alliance*. “We went through all the birthing pains of a start-up, but we had an important commitment from the core of members, which was that everyone had skin in the game,” she says. “The nonprofits didn’t have to pay dues, but everyone had to *work*. Each organization had to sign up at least one person to be in a working group—no one sits back or is passive.”

"I tend to believe that everything is about relationships," says Christine Benjamin, breast cancer program director at SHARE Cancer Support, a founding *Alliance* member organization. "So, the more you come to know someone, the more you have a rapport with someone, the more it affects the business you do together and the referrals you make. I can feel confident telling one of our SHARE constituents to call another organization in the *Alliance* because I know that he or she will be taken care of."

Early representatives of MBC Alliance members, March 2014

From bottom right: Katherine Crawford-Gray, MBC Alliance Project Director; Christine Benjamin, SHARE; Elly Cohen, BreastCancerTrials.org; Jo Dulay, Genentech; Janine Guglielmino, Living Beyond Breast Cancer; Jane Levy, Cancer Care; Elyse Spatz Caplan, Novartis Oncology; Michael Zincone, Pfizer; Musa Mayer, AdvancedBC.org; Julissa Viana, Cara Thompson, Celgene Corporation; Margaret (Peg) Mastrianni, Breast Cancer Research Foundation; Christine Wilson, Triple Negative Breast Cancer Foundation; Shirley Mertz, Metastatic Breast Cancer Network; Stacy Lewis, Young Survival Coalition; Katherine O'Brien, Virginia (Ginny) Knackmuhs, Metastatic Breast Cancer Network; Megan McCann, Young Survival Coalition; Catherine Ormerod, Living Beyond Breast Cancer; Lisa Schlager, Facing Our Risk of Cancer Empowered (FORCE); Kimberly Sabelko, Susan G. Komen; Marc Hurlbert, Avon Foundation for Women; Virginia (Ginny) Mason, Inflammatory Breast Cancer Research Foundation; Hayley Dinerman, Triple Negative Breast Cancer Foundation; Diane Rose, FORCE; Susan Brown, Susan G. Komen; Allison Harvey, Cancer Support Community; Stephanie Reffey, Susan G. Komen; Kerry Gruninger, SHARE; Jane Perlmutter, Consultant; Amy Bonoff, Dr. Susan Love Research Foundation | Photographer: Yasmeen Anderson Photography | Early members absent from photo as of March 2014:Christine Verini, Eisai; Kelly P. Hodges , Sisters Network® Inc.; Hope Wohl, Breastcancer.org; Elda Railey, Mary Lou Smith, Research Advocacy Network

LAYING A SOLID STRUCTURAL FOUNDATION

Over the next few months, the early organizers met again and again—they drafted mission and vision statements for the new coalition, agreed on a governance approach, and then recruited an experienced volunteer leader as the first elected chairperson: scientist Marc Hurlbert, chief mission officer of the Breast Cancer Research Foundation, and former executive director of the Avon Foundation Breast Cancer Crusade. The founders also determined that, in order to keep up momentum and further unite the membership, the group needed an administrative home base and funding to hire a dedicated program director.

A little less than a year after the founders' first exploratory gathering, the *Alliance* had already grown to include 15 nonprofits, plus four additional pharmaceutical industry members at the formal launch: Eisai, Genentech, Novartis, and Pfizer.

With the staff, structure, and guiding principles of the *Alliance* in place, it was time to take action toward directly impacting the lives of people living with metastatic breast cancer. But before the group could decide what to *do*, the members had to know what was already being done. "From the outset it was important to us that the *Alliance* not duplicate the work of any of our members," says Crawford-Gray. "We weren't going to be creating patient hotlines or disease information brochures—our member groups were already doing that. But we could actively help their work advance. Together we could grow the reach of those services so that more patients are served." In order to understand the current state of metastatic breast cancer research and advocacy, a steering committee undertook an almost yearlong landscape analysis study. "It looked at where funding was being directed, where clinical trials were taking place, the epidemiology of the disease, the quality-of-life needs of patients and whether they'd changed over the last decade, and it looked at information and support services of our members at that time to see where there were gaps and duplications," says Crawford-Gray. "Understanding the landscape was important so we could determine what areas needed our collaborative efforts in order to bring about change."

"The group was able to complete the study on a shoestring budget," says research task force co-chair Reffey, "because it was mostly done by members on a volunteer basis. We all pitched in and got it done, because we felt it was so important to have that information so we could move forward thoughtfully and with a complete picture of the current environment," she says. "The resulting report is a valuable resource, not only to the *Alliance* but to the research and advocacy community as a whole."

MAKING AN IMPACT ON METASTATIC BREAST CANCER

After the landscape analysis was completed in late 2014, the *Alliance* adopted these three data-driven goals and divided members into three main working groups, or task forces, each of which works on projects addressing one of the goals:

1. Advance progess in research that will extend and improve the lives of those with metastatic breast cancer
2. Help inform and empower people living with metastatic breast cancer by making disease and treatment information clearer and easier to find, and facilitating better communication between patients and health care teams
3. Increase public understanding and awareness of metastatic disease in order to reduce stigma

SHARE Cancer Support volunteers, 2016

MEMBER SUCCESS STORIES: *ALLIANCE* MEMBERSHIP IS GOOD FOR PATIENTS *AND* ORGANIZATIONS

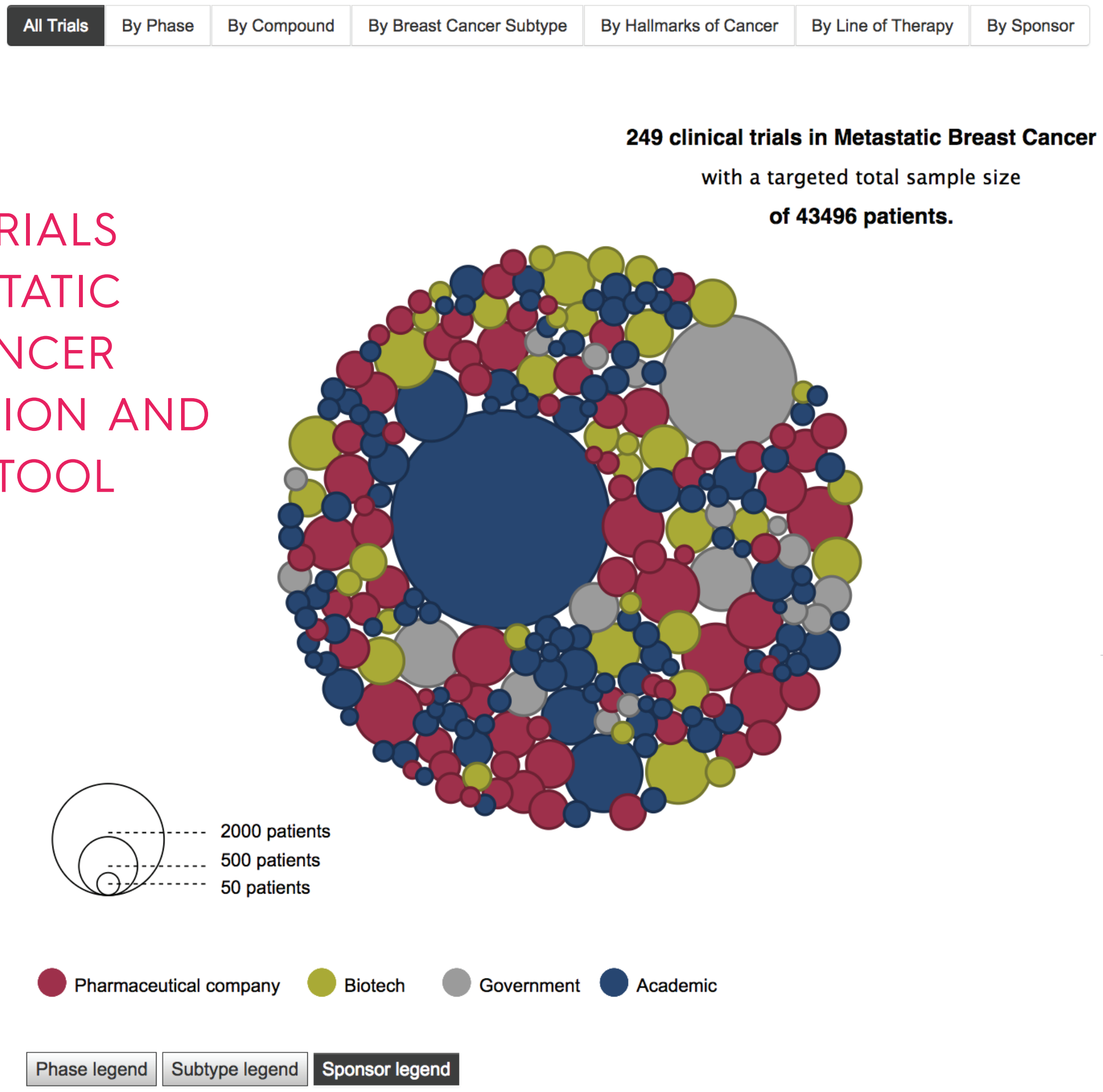
SHARE: QUADRUPLED THE USAGE OF THEIR TELEPHONE SUPPORT GROUPS.

The mission of nonprofit *Alliance* member SHARE is to support women affected by breast and ovarian cancers through educational programs, support groups, and advocacy. But, like many *Alliance* members have noted, while patient demand for services may be high, actual utilization can be frustratingly low. "We kept hearing from metastatic patients that they wanted and needed more support, so SHARE developed additional in-person and telephone support groups specifically for metastatic breast cancer," says Christine Benjamin, LMSW, SHARE's breast cancer program director. "But very few people were coming–for a year and a half we had just this core group of five or six women. After I shared this with the *Alliance*, all of a sudden people started calling to sign up for the groups. Every time we open up another slot, it fills to capacity. We now offer nine telephone and two in-person sessions each month, serving about 100 women."

Through a side collaboration with fellow *Alliance* member Living Beyond Breast Cancer (LBBC), SHARE has also expanded its pool of trained peer-support people. "If SHARE doesn't have a specific type of peer supporter for one of our constituents, we'll call the LBBC and say, 'This is what we're looking for, do you have anyone?' " says Benjamin. "It has really expanded our resources, with no additional staffing or costs."

In the area of research, the *Alliance* landscape analysis found that patients, researchers, and clinicians are often frustrated or confused by clinical trial information—an important gap to address as clinical trials are a part of treatment for many with metastasis. To address this challenge, the *Alliance* created a web-based Clinical Trials Visualization and Tracking Tool (known internally to some as the Bubble Project, since the graphics resemble a big bunch of interactive bubbles). Users can click-sort metastatic breast cancer trials by cancer subtype, compound, line of therapy, and other parameters, then hover over individual bubbles to get more information. "Since this is a source of trial information that focuses solely on metastatic breast cancer, it's easier to negotiate than going to clinicaltrials.gov, which contains trials about all types of cancer," says Mertz, co-chair of the research task force.

CLINICAL TRIALS FOR METASTATIC BREAST CANCER VISUALIZATION AND TRACKING TOOL



249 clinical trials in Metastatic Breast Cancer
with a targeted total sample size
of 43496 patients.

The research task force has also begun tackling another major information gap: while some estimates suggest that up to 200,000 people are currently living with metastatic breast cancer, no one knows for sure.[7,8] That's because the National Cancer Institute SEER registry counts only those whose *first* diagnosis is metastatic breast cancer. It does not count the majority of cases in which patients receive a metastatic diagnosis years after having been treated for early-stage disease. "We have prevalence data for other diseases, why not metastatic breast cancer?" asks Mertz. "Don't we all matter?"

INNOVATIVE TOOLS FOR HEALTH CARE TEAMS TO COMMUNICATE WITH MBC PATIENTS ABOUT DIAGNOSIS AND TREATMENT

In another initiative, nicknamed the Dandelion Project, the *Alliance* information task force aims to improve communication between health care teams and patients—especially patients with low health literacy or language differences. "Understanding cancer terminology is like a foreign language to begin with," says task force chair Christine Benjamin. "So imagine if someone is trying to explain that to you in something other than your native language!" The main Dandelion Project tool is a set of cards and tear sheets that use pictures—and the metaphor of a dandelion and its seeds—to explain the difference between the four stages of breast cancer. The tool also shows patients where their cancer has spread, and educates patients further as to which type of breast cancer they have and the treatment options. The patient can also take the tools home to help explain things to family and friends. The Dandelion Project has already seen early successes with a poster accepted at the San Antonio Breast Cancer Symposium 2015, one of the premier international breast cancer meetings, and a pilot study is in the works during which the tools will be used in various health care centers around the country.

STEPS TO BUILDING A SUCCESSFUL COALITION

The Metastatic Breast Cancer Alliance gets many requests from organizations in the U.S. and abroad for insight and advice on how to duplicate the success of the organization. This step-by-step outline can help other groups interested in pursuing this advocacy model.

1. **Identify passionate people and organizations aligned toward the same goal.** Work together to develop a clear, concise vision and mission statement, so people can consistently and effectively articulate the group's purpose, needs, and immediate goals and objectives.

2. **Look for an administrative home to serve as the fiscal sponsor.** In order to raise funds, an alliance must either incorporate as an independent nonprofit or find a nonprofit to serve as fiscal sponsor and administrative home.

3. **Choose a strong, action-oriented leader.** Preferably one who has experience structuring coalitions or organizations, and can be seen by the group as a trusted party.

4. **Establish your existence in the world.** Do you have a brand image, a logo, a URL, an email address? After developing a clear mission and vision statement, the original steering committee quickly developed and agreed upon the *Alliance* logo and brand.

5. **Utilize experts when possible.** With support from original pharmaceutical partner Celgene, the *Alliance* hired a consultant to attend its first two meetings and help facilitate, synthesize, and clarify next steps, which included creating the vision and mission statements.

6. **Survey the current landscape.** Whether it's an official study or just a free online survey sent to colleagues and constituents, you must know what is missing in your specialty, and what the obstacles are, so you can define goals.

7. **Formulate a handful of main goals based on gaps in current services.** Duplication of existing resources in the field is a waste of time, money, and energy, and it's a major reason coalitions fail.

8. **Everyone works—no passive members.** Break members out into small task forces or working groups coalescing around each main goal in order to manage the workload for everyone involved. Being transparent about all processes and work groups is critical.

9. **If funding allows, hire a dedicated staffer.** As you grow, the workload will too. Things will move more quickly and members will stay more engaged when there's a designated person to handle scheduling, communication, financials, etc.

10. **Plan an early success to keep motivation high and garner increased visibility and build membership, if desired.** Other groups will become interested if they see your success, and they'll want to join together with you to add value to the work.

11. **Stay in contact often.** Use Skype, Google hangouts, conference calls, and webinars to have brief meetings and check-ins when members can't gather face-to-face. Create meaningful agendas so all members can engage and feel valued.

Interest in the work and unique structure of the *Alliance* is high, and as membership continues to grow, the group plans to continue the same kind of data-driven, patient-led actions that have been successful thus far. By 2016, just three years after its official launch, the *Alliance* had grown by leaps and bounds to include upward of two dozen nonprofit members, plus 10 pharmaceutical and biotech partners. "We realize that right now our disease may not be curable, but what if we can contain it so that we could live with it for 20 or 30 years, as is the case now with people who have HIV/AIDS?" says Mertz. "I see the *Alliance* moving the dial forward, and I can't tell you the joy in my heart when I see progress being made for patients."

TRIPLE NEGATIVE BREAST CANCER FOUNDATION: INCREASED FUNDING TOWARD METASTATIC BREAST CANCER RESEARCH

Furthering research through funding and symposia is a major part of the mission of the Triple Negative Breast Cancer Foundation (TNBCF). But the vast majority of proposals the foundations received was for early-stage disease. "It's not that we didn't want to support metastatic projects, but we didn't have many of them applying for funding," says TNBCF executive director Hayley Dinerman. "The greater our involvement has been with the *Alliance* and the more we learn, the more we realized that we had to actively pursue that type of research." Rather than wait and see what kinds of grant requests would come in, this time around the TNBCF specifically stated that it was looking for metastatic triple negative projects—and in 2016 it has been able to allocate 48 percent of its research dollars toward metastatic triple negative research, says Dinerman. "Clearly announcing our intention made a difference and allowed us to really support important research in this area."

MEMBERS

ADVOCATE MEMBERS

abcd after breast cancer diagnosis
AVON Foundation for Women
BCRF Breast Cancer Research Foundation
BREASTCANCER.ORG REAL. ANSWERS.
BreastCancerTrials.org find a trial that's right for you
Cancer Action Network American Cancer Society
CANCERcare
CANCER SUPPORT COMMUNITY
Dr. Susan Love Research Foundation
FORCE Facing Our Risk of Cancer Empowered
hope scarves
INFLAMMATORY BREAST CANCER Research Foundation
LIVING BEYOND BREAST CANCER
The Male Breast Cancer Coalition
mbcn Metastatic Breast Cancer Network
MRS Metastatis Research Society
PAF Patient Advocate Foundation
Research Advocacy Network
SHARE
SHARSHERET
Sisters Network Inc.
Susan G. Komen
theresa's research foundation
Tigerlily Foundation
Triple Negative Breast Cancer Foundation
Triple Step Toward the Cure
Twisted Pink
YSC Young Survival Coalition
Canadian Cancer Survivor Network
The Cancer Couch Foundation

FOUNDING MEMBERS

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Celgene
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Genentech A Member of the Roche Group
Lilly | ONCOLOGY
NOVARTIS ONCOLOGY
Pfizer

SUPPORTER MEMBERS

CASCADIAN THERAPEUTICS
Genomic Health
MACROGENICS
R-PHARM US

PARTNERS

ACCC Association of Community Cancer Centers
Metastatic Breast Cancer Project

INDIVIDUAL MEMBERS

Eliza Adams, Deborah Collyar, Elizabeth Frank, Hester Hill Schnipper, Anne Loeser, Musa Mayer, Jane Perlmutter, Teri Pollastro, Kelly Shanahan

CREATIVE AGENCY

DDB Health

Sources:

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In Memoriam

Sarita Jordan
#MetastaticSayIt Campaign
Jun 19, 2016

Virginia "Ginny" Knackmuhs
Metastatic Breast Cancer Network
MBCA Executive Group &
Awareness Task Force
Aug 15, 2016

Holley Kitchen
#MetastaticSayIt Campaign
Jan 12, 2016

Amy Bonoff
Advocate
MBCA Research Task Force
Dec 17, 2015

Marcia Taylor
Living Beyond Breast Cancer
MBCA Research Task Force
Sep 26, 2015

Rochelle Shoretz
Sharsheret
MBCA Governance Working Group
May 31, 2015

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