

**Case Study of the
Breast Cancer Services Project**

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Executive Summary

In 2005 a group of concerned citizens and organizations launched an effort to improve access to social supports for survivors of breast cancer living in Austin. The project was born when its founder asked, “What can our community do to better support breast cancer survivors?” She invited representatives from a number of health and social service agencies and nonprofits to participate in a focus group to discuss their programs and identify service gaps. From that first meeting, it was apparent that 1) gaps existed, 2) some of the participants did not know each other, and 3) much could be gained from increasing communication. An informal group was forged, and within months a formal effort emerged, called the Breast Cancer Services Project. Through thoughtful discussion and information-gathering about current services, needs, and models, the group determined that it should focus on creating better systems and piloting new efforts that could further strengthen collaborative services to help breast cancer survivors.

In spring 2006, the Entrepreneurs Foundation adopted the Breast Cancer Services Project as a Leadership Project, providing funding and guidance as the project moved from an informal collaboration to a more focused initiative. The goal was refined: Strengthen collaborative services to better support breast cancer patients and survivors, and incubate new ideas that are good candidates for collaboration. The foundation helped the group by hiring and supporting paid staff to coordinate activities, and by investing in pilot programs that would ultimately be spun off back to other institutions for sustainability.

Among the ideas that were incubated was a meal delivery service for breast cancer patients undergoing treatment and their families. This pilot program was successful and a permanent program will be implemented. The team also launched cooking classes for breast cancer patients to learn more about nutrition. The group developed guidelines for patient navigation services and a greater presence on the web—ideas that will be implemented by partners in the collaboration. In addition the group identified funding opportunities. They organized a bicycle ride fundraiser for breast cancer services that will be held annually and established an emergency support fund called the B Club. The group also began efforts to secure public funds from local governments for breast cancer services. These new sources of funding will help to address remaining service gaps and will continue to build a more comprehensive service continuum.

In all, more than 25 organizations participated in the project. With a founder from the outside as a catalyst, the effort gained momentum as groups got to know one another and began working collaboratively. Through the process, groups that once felt competitive for scarce resources began to realize the mutual benefits of working together, and to see opportunities for increased funding for new initiatives that survivors need.

The project ended in early 2009, and was largely successful in meeting its objectives and realizing its goal of creating a better continuum of services. Pilot projects are now owned by collaboration partners and the effort has resulted in community members, health care providers, social service organizations, and local foundations all working together to develop an outcomes-based approach to addressing the local issue of breast cancer services. This model of bringing groups together should appeal to business-minded philanthropists and foundations in its value of maximizing resource use and attracting new funding for community initiatives.

Need for Breast Cancer Services Project

The Breast Cancer Services Project was created because of a belief by local community leaders that it was not easy for many of the women in Central Texas diagnosed with breast cancer to find and take advantage of support services they needed during their treatment, such as meals for themselves and their families, childcare, and transportation to medical appointments.

In the Austin area (Travis, Hays, and Williamson Counties), 806 women were diagnosed with breast cancer in 2008,¹ and thousands more are survivors from previous years. About 40 percent of all female cancer survivors had breast cancer.² National statistics show that breast cancer is the most common cancer diagnosis in women after skin cancer, and that one in eight women will be diagnosed with breast cancer during her lifetime.³ Thus virtually everyone will eventually be affected in some way by breast cancer, among friends and family if not personally.

Survivors, family members, and friends are the primary organizers of grassroots social services in the Central Texas community, but there has been no public money provided to supplement the personal and foundation funding raised. Medical advances have resulted in breast cancer increasingly being a chronic disease instead of a terminal disease; therefore there are many more women than in the past living with the disease or its after-effects, and needing various support services along the way. Without a coordinated effort, the service continuum is fragmented and harder to access.

Women with breast cancer often need assistance to gain access to treatment, stay in treatment, and recover well. Besides their medical care, they face challenges such as:

- employment rights;
- transportation difficulties;
- navigation/case management;
- physical and emotional support;
- caring for family;
- maintaining a household; and
- proper nutritional intake.

Along with the physical and emotional burdens of breast cancer and complicated medical treatments, these challenges can overwhelm even the strongest women and their families. Many women are unable to access support services, and as a result often do not receive appropriate medical care. The result is significant challenges for the family, costly late-stage medical care, worse health, and increased mortality.⁴

The leaders of the Breast Cancer Services Project learned about these issues and created a community collaboration not to provide medical care for breast cancer patients, but to help provide or make sure they can access all the other services they need while undergoing medical care. The founders recognized an unmet need for a mechanism to better connect patients and survivors to information and a continuum of services during and after treatment.

Objectives of Project

The goal of the Breast Cancer Services Project was to create an effective, long-term, community-based solution to an identified need, with community and provider input and with measurement and evaluation.

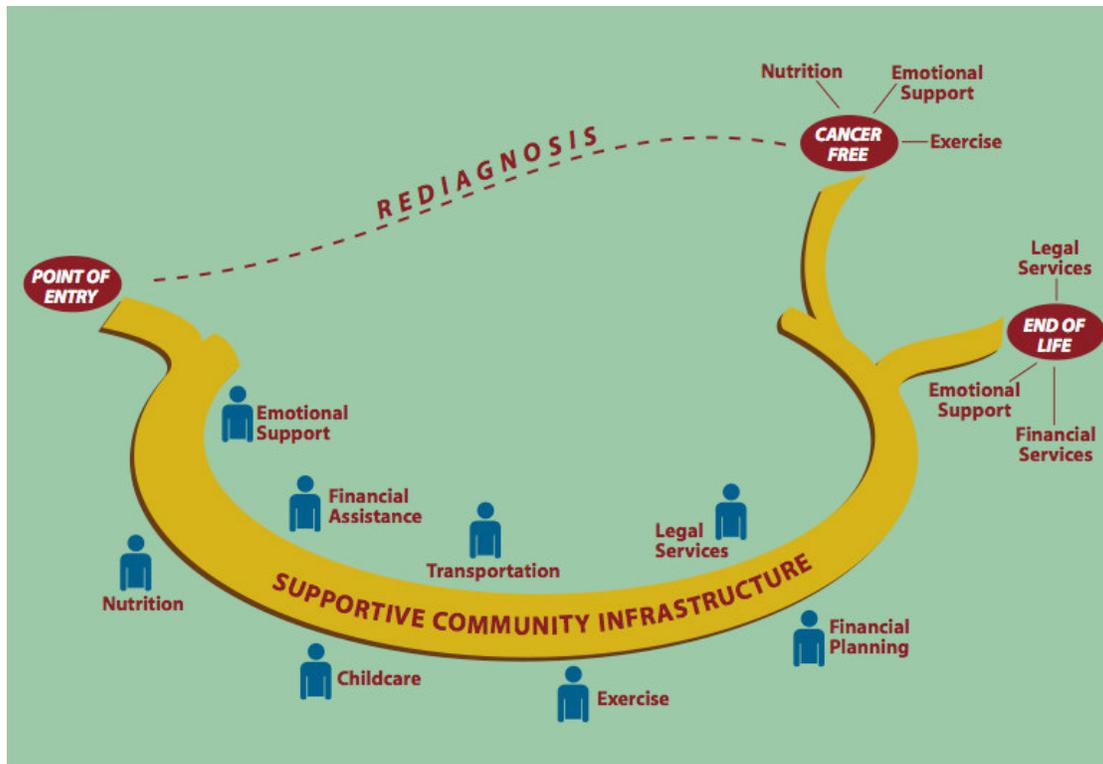
The three main objectives for the project were to:

1. Create and build the best continuum of care for women with breast cancer and their families in Central Texas;
2. Incubate or otherwise support new services to address gaps while supporting existing services; and
3. Leverage scarce financial resources with additional public and private funding.

These long-term objectives were addressed by organizing and reaching quarterly milestones that moved the plan forward—integrating resources of existing programs as well as creating new programs as needed. The group selected several key gap areas to pursue: food and nutrition assistance, patient navigation, access to information, childcare, emergency funding, transportation, and legal services.

See Figure 1 for a diagram of the envisioned support services continuum for breast cancer patients.

Figure 1. Support Services Continuum for Breast Cancer Patients



Source: Developed by the Breast Cancer Services Project and drawn by Mark Willenborg, KVUE, Austin, Tex., 2007.

History and Growth

The project was born in 2005 when its founder asked, “What can our community do to better support breast cancer survivors?” She had friends who had been diagnosed with the disease and she was frustrated by the lack of available support services and information for them, as well as by not being able to easily find volunteer opportunities to help breast cancer patients the way people could sign up with local organizations to help AIDS patients. She invited representatives from a number of health and social service agencies and nonprofits, including some entirely dedicated to breast cancer survivors, to participate in a focus group to discuss their programs and identify gaps in services. From that first meeting, it was apparent that 1) gaps existed, 2) some of the participants did not know each other, and 3) much could be gained from communicating more closely.

From that point, an informal group was forged. Within months a formal effort emerged, called the Breast Cancer Services Project, with more than a dozen organizations represented, and with concerned citizens and community leaders joining the effort. The group began asking and gathering information on a host of questions, including:

- In the continuum of care, what service gaps existed? That is, what needed services did not exist or were difficult to access?
- How can volunteers be deployed to help patients in treatment?
- What services could be strengthened by collaborating?
- What could be learned from promising practices elsewhere?
- What specific, achievable objectives could the group accomplish, both to serve survivors and advance working collaboratively?

The group committed to developing a project to improve the resources for local women diagnosed with breast cancer. The project raised a small amount of funding from two local hospital foundations and hired Greenlights for NonProfit Success, a local nonprofit organization that helps other nonprofits improve their programs, to facilitate their meetings and to identify the needs of breast cancer patients in Central Texas, the services currently available to them, and where the gaps were. The resulting report in March 2006 was used by the group to set goals and to help inform a series of planning meetings.

In March 2006, the Entrepreneurs Foundation, a Central Texas nonprofit that helps entrepreneurs and start-up companies become more involved in the community, agreed to adopt the Breast Cancer Services Project as a Leadership Project of the foundation, which helped it to move forward. The Entrepreneurs Foundation raised additional funding to complete payment to Greenlights and to support expansion of project activities, which included objectives of building relationships among the participants and creating a resource guide.

In June 2006, the foundation’s executive director reviewed the group’s progress and suggested that the group define a set of concrete objectives. Participants agreed to hire staff to complete the breast cancer resource guide. The staff member coordinated completion of resource guide, conducted benchmarking of programs in other areas, and recommended that the group focus on addressing service gaps rather than organizing a conference or forum as had been discussed.

At a meeting in November 2006, the staff person and a subcommittee of service providers identified a food and nutrition assistance program and improved patient navigation as priorities. Previous benchmarking had identified business models for these services. The council noted that benchmarking had not found a comprehensive continuum of social services for breast cancer patients anywhere, and they wanted to create the first such program in Austin. Discussion also focused on developing a vision and clear objectives. By the end of 2006, long-term objectives for the project were established (see Objectives section). The group reaffirmed the focus on projects that would address gaps concerning 1) food and nutrition, 2) patient navigation, 3) access to information, 4) childcare, 5) emergency funding, 6) transportation, and 7) legal services.

The initial staff member was made the permanent director of the project. Once the director was on board, the council and foundation staff began to explore potential partners for the two priority projects, the food and nutrition program and a patient navigation system. These and other programs that were undertaken are discussed in the Processes and Programs section below.

In 2007 and 2008, more than 50 people from over 25 organizations participated in the Breast Cancer Services Project on the Advisory Committee, Operations Committee, and work groups (more details about the committees and processes can be found in the following section). The organizations represented included nonprofit service providers, hospitals and other medical providers, local and state government agencies, and university departments (see Appendix A for partial list). In the fall of 2008, it was decided that the project had served its purpose and that the service organizations were working together on addressing gaps and could carry the new programs forward without the Entrepreneurs Foundation, the Project Director, and the original founders, so funding for administration of the project was set to end in February 2009.

Processes and Programs

The purpose of the Breast Cancer Services Project was to find better ways to coordinate community efforts to meet the unmet needs of breast cancer patients. A process was developed for project partners to discuss needs and goals, and several programs were created by project participants and partners to address these. The programs were incubated but not owned by the project, and thus the ongoing management of them was handed over to other organizations as detailed below for each program.

The project's Advisory Council met quarterly and consisted of approximately 30 individuals from various organizations, including the original founder of the project and the Executive Director of the Entrepreneurs Foundation. The council had the following responsibilities:

- developing vision;
- recommending policy;
- giving strategic advice;
- providing program concepts;
- improving networking and membership; and
- suggesting participation in work groups.

The project's Operations Committee consisted of approximately 10 people from various organizations, including the Project Director, the original founder of the project, the Executive Director of the Entrepreneurs Foundation, and representatives from area hospitals, the American Cancer Society, Komen for the Cure, the Breast Cancer Resource Center, and several others. This committee met monthly and was responsible for:

- staff management;
- operating, fiscal, and strategic decisions;
- grants and funding; and
- setting the agenda for Advisory Council meetings.

Various workgroups were established to work on the development and implementation of programs that the council and committee decided were priorities. These included the Gaps, Communications, Meals Project, Patient Navigation, and Fundraising workgroups, as well as others as needed. The membership of these consisted of Breast Cancer Services Project participants as well as other people brought in as needed for their expertise in areas such as data management, public relations, and Website development. The workgroups met monthly as needed and reported to the Operations Committee. Work was also done via e-mail, and the Project Director helped to coordinate the communications and activities of the workgroups, committee, and council, as well as sending project updates, taking meeting minutes, helping to establish agendas, and helping to keep participants focused on the goals.

Although the stated priorities were food and nutrition assistance, patient navigation, access to information, childcare, emergency funding, transportation, legal services, and housing assistance, not all of these issues were addressed by the end of the project. Programs on childcare and transportation were left for the future and legal services were provided by another agency. The programs and initiatives that were developed are discussed below.

Breast Cancer Resource Guide

The Breast Cancer Resource Guide was the first initiative completed by the project, due to the need for a comprehensive, up-to-date guide to available service. A few similar local guides existed but had not been updated in several years. After research and benchmarking, the Project Director completed the first version in October 2006, and it is reviewed and updated quarterly by the nine partner organizations listed in the first section of the guide.

The guide is published in PDF format in both English and Spanish, and is available online at <http://www.breastcancerservices.org>. The Breast Cancer Resource Center is taking over ongoing updating and publication. In addition to being online, hard copies of the guide are printed each time it is updated, and it is distributed to about 20 medical offices and service agencies by the partner organizations.

Food and Nutrition Assistance Program

A key priority was developing a food and nutrition assistance program for women undergoing breast cancer treatment. The idea was enthusiastically embraced by the Capital Area Food Bank and its Chief Operating Officer. The food bank nominated one of its lead sponsors, the HEB

grocery store chain, to be a partner, and the Entrepreneurs Foundation nominated a private chef as another partner. The pilot program described below took place in 2007, and as of this writing a permanent program has not started yet due to the food bank COO leaving and other factors, but there appears to be a willingness to continue the program.

Objectives for a food and nutrition program included: 1) optimizing nutrition during a patient's treatment, 2) alleviating financial burdens, 3) easing concern for survivors and family, and 4) mitigating loneliness and anxiety. After the Project Director reviewed programs in other cities and consulted local nutritionists and oncologists, the team evaluated menus, costs, delivery models, food preparation logistics, and opportunities for volunteer labor, and decided on a pilot program with weekly meal preparation and delivery.⁵

The team established criteria for participation in the pilot program, targeting low-, middle- and high-income clients, and noting a desire for ethnic diversity and to assist single mothers. Patients had to be in treatment (such as chemotherapy or radiation) or in the first two months after treatment, and for patients who qualified, food for their children and caregivers in the household was also provided free of charge. Partner agencies nominated patients, and their physicians had to approve their enrollment after reviewing the menus. The team created two options for meal delivery, volunteers and a paid delivery service, and included groceries as well as cooked meals for no charge. Dietary requirements and preferences were accommodated as much as possible.

During the 12-week pilot program, from July to October 2007, 9,360 meals were delivered by 16 delivery volunteers to 15 families and 56 individuals (26 adults—patients and caregivers—and 30 children). There were 31 volunteers (mainly delivery drivers and food preparers) who donated over 1,044 hours. The total cost of the pilot including food and administration was about \$23,000.⁶

The average individual meal cost in the pilot program was \$1.80, and it was learned that higher-income participants are likely to be willing to pay at least twice the cost of meals in the future, thus providing additional funding for those unable to pay. In the 2008 budget for the full program (that was not implemented due to delays as noted above), revenue was predicted to be about \$4,000 higher than costs due to sliding-scale payments for meals, plus several grants.⁷

Cooking Classes

Another food-related program developed by the project is a series of cooking classes for breast cancer survivors who have completed treatment, since proper nutrition can contribute to recovery and help prevent recurrence. No local agencies provided a similar service, so the project approached the Sustainable Food Center, which has a cooking education program called The Happy Kitchen/*La Cocina Alegre*, and established a work team. This team created the pilot program and marketing strategy, guided curriculum development, secured funding, and performed an evaluation. The pilot program (consisting of two six-week series of classes, one in English and one in Spanish) took place in September and October 2008, and the next classes will start in June 2009. The plan is to continue to have classes regularly in both languages in Austin and several surrounding counties in Central Texas.

The Sustainable Food Center (<http://www.sustainablefoodcenter.org>) promotes eating locally grown food and improving access to nutritious affordable food for a healthier community and environment. It offers cooking classes and other programs to help address nutrition problems affecting low-income families and other at-risk populations, but it had never offered classes specifically for cancer survivors before. The classes offered hands-on demonstrations of healthy recipes and information about nutrition and food shopping, and included a bag of groceries at the end of every class so participants could cook the recipes at home.⁸ The cost for the series was \$30, but there were a number of full scholarships available for lower-income women.

In the pilot program, 21 women were served, which benefited 39 additional family members; 12 of these participants attended for no cost. The participants were referred by one of the participating social services agencies, and were from 18 different zip codes (a larger number than had ever been seen in previous classes). The classes were taught by trained facilitators. The total expense for the pilot program was \$12,100, which included groceries, staff, educational materials, and facilitator stipends.

In the survey at the end of the class series, 91 percent of participants said they were choosing more whole grain products, 91 percent were eating less packaged food, 81 percent were choosing leaner sources of protein, and 76 percent were eating more fruits and vegetables. One hundred percent of participants said they were either “very likely” or “somewhat likely” to continue to eat according to the Happy Kitchen nutritional standards, and 95 percent said that they would share what they learned with friends and family members.⁹

Patient Navigation

Exact definitions and models vary, but at a basic level “patient navigation” refers to helping patients navigate the medical and support services systems to find out about and access all the treatments and services they need in order to recover. An Institute of Medicine report states, “A patient navigator is a trained patient advocate and guide who helps individuals and their families navigate their way through the maze of doctors’ offices, clinics, hospitals, outpatient centers, insurance and payment systems, patient support organizations, and other components of the health care system.”¹⁰

In 1989, the American Cancer Society released a report on the barriers to cancer care for the poor, including financial, informational, and emotional barriers. In response to this report, the first patient navigation program was created at Harlem Hospital Center in New York City, where poorer breast cancer patients had a much lower five-year survival rate than average. The survival rate there greatly improved in the 1990s due to free screening, patient navigation, and improved outreach and education. Many patient navigation systems have since been implemented around the country serving different demographics, and results “suggest that navigation of services for patients diagnosed with cancer tends to significantly reduce patient anxiety, improve the timeliness of diagnostic resolution, and result in higher patient and provider satisfaction levels.”¹¹

Central Texas has some very good patient navigation programs and patient navigators/case managers at several area hospitals and nonprofits, but the capacity is limited and thus many women in the area are not able to be served.¹² There is no community-wide coordination of these services, and some women don't even know they exist, therefore the Breast Cancer Services Project saw a need to develop more comprehensive patient navigation services for breast cancer patients.

The project commissioned a patient navigation needs assessment from the University of Texas's School of Social Work,¹³ and the Project Director helped put together an inventory report of medical services, navigation services, and agencies in the five-county Central Texas area in 2008.¹⁴ The project considered implementing an extension to an existing program or possibly creating a new program in a county outside of Travis and Williamson Counties where there are fewer services. However, the Lance Armstrong Foundation is building a new headquarters building in east Austin that will have more space for programs, and the foundation wants to expand in the area of patient navigation, so the group decided to let this foundation take over the patient navigation program for breast cancer patients (as well as serving survivors of other cancers) since their funding is more sustainable. The project shared the needs assessment reports with the foundation and these will help to inform its plans in developing the appropriate services.

Bicycle Ride for Breast Cancer

Planning for an annual bicycle ride fundraiser has taken place for the last several years, and the first one is scheduled for October 10, 2009. It will be called the Texas Mamma Jamma Ride and will be produced by the same team who organizes the very successful Hill Country Ride for AIDS, an annual event that began in 1999 and has raised hundreds of thousands of dollars for agencies serving AIDS survivors in Central Texas. The purpose of the breast cancer ride is to generate significant and ongoing resources for local nonprofit agencies that provide social services to breast cancer survivors.

Similar to the AIDS ride, the member agencies must each donate a portion of the \$100,000 start-up capital needed for the first ride in order to be a beneficiary of the funding raised by the first ride and subsequent rides (with no further investment needed). The proceeds will be distributed according to the percentage of the start-up funding that the agency donated.

After the ride events net \$400,000 or more, 20 percent of the net proceeds will go into a discretionary fund to be awarded to agencies wanting to expand and create new breast cancer support services (the remaining 80 percent will be distributed to the member agencies using the established formula taking into account how much they initially contributed). This will require that the agencies involved in the project continue to meet and collaborate to maintain and expand services, and a council will be formed with one representative from each beneficiary agency. There is a process in place for the founding agencies to vote in new investor agencies if deemed prudent. The Care Communities will serve as fiduciary agent for the rides.¹⁵

Early financial projections (from when the ride was initially going to begin in 2008) predicted an income from the first ride of \$400,000, consisting of rider donations, corporate donations, and other contributions. Total expenses were estimated to be \$200,000, consisting of production

costs and administrative and other contracted services. Therefore proceeds were estimated to be \$200,000 from the first ride, allowing each agency to double their initial investment (for example, if an organization put in \$15,000 of the \$100,000 start-up fund, it would received 15 percent of the proceeds, or \$30,000, in the first year).¹⁶ In subsequent years, administrative costs are projected to decrease, thus increasing the net revenue. Due to economies of scale, the Hill Country Ride for AIDS returned 77 percent of the donations to the agency beneficiaries in 2008, so it is hoped that the breast cancer ride can achieve similar efficiencies.

The website for the ride is not active yet as of this writing, but information about the ride will be posted online at <http://www.mammajammaride.org>.

B Club

The B Club is a program modeled after the Octopus Club (<http://www.octopusclub.org>), a grassroots organization that raises money for AIDS survivors in Central Texas needing immediate financial assistance. The parties and events are supported by volunteer hosts, so 100 percent of the funds donated by guests go to the program. The funding raised by the B Club is managed by the nonprofit Seton Fund, and the Seton Hospital network provides administration of the program after it was developed by the project and began raising funds in 2008. Volunteer leaders called Queen Bs and B Keepers help to coordinate the events and maintain a website (<http://www.bclubaustin.com>).

Every dollar raised by the B Club goes into the Breast Cancer Emergency Support Fund for short-term financial and social services support to breast cancer survivors needing immediate help with such things as rent or mortgage payments, utilities, food, transportation, and medications in order to successfully complete medical treatment. It can also be used to help with health insurance premiums and copays, including COBRA payments for up to six months for women on the verge of losing health insurance coverage due to their illness and being unable to work.¹⁷

The funds are distributed on a case-by-case basis after women are referred to the program by one of the participating agencies. Currently women must be referred, they cannot apply to the program directly and the program is not widely publicized to breast cancer patients, due to the fact that it cannot serve more people than it already is now with limited available funding. Seton also manages a similar emergency fund that is funded by Komen for the Cure, but that grant has restrictions on the geographic area a recipient can be from, so the B Club helps to serve those who do not qualify for help from the Komen program.

The B Club's emergency support fund has only assisted a few women so far since it started distributing funds in fall 2008, mainly due to the fact that it is the only funding that can be used for COBRA payments to continue health insurance coverage for patients, and those payments are expensive. This program fills an important need in the community, and it could help many more people at a critical time in their lives if it had more funding.

Web Portal and Data Mapping

Two more of the project's priorities were a community resource Website to provide information and access to services, and a data consortium where data on cancer incidence and provider locations could be mapped geographically by medical and social services providers to develop statistics for planning purposes. Workgroups were formed for these two areas and additional partners were engaged as needed. Several reports were commissioned regarding the content and strategy of the community Website.

After realizing the extent of time and funding that would be needed to successfully launch these programs, and after seeing a similar Website for data mapping in the Houston area maintained by St. Luke's Episcopal Health Charities (<http://www.slehc.org/chi/chis/BreastHealth>), the project decided to combine these two initiatives into one, and to consider expanding the St. Luke's Website for Central Texas instead of creating an all-new portal. The focus will initially be on data mapping for providers to use, and it will take more funding to add the community support resources to the Website. The lead organizations that will continue to work on this initiative are the Breast Cancer Resource Center and the Austin Affiliate of Komen for the Cure.

Outcomes and Accomplishments

The programs mentioned in the previous section are all accomplishments of the project. Some are farther along than others, but the overall achievement was getting agencies and individuals involved in breast cancer care and support services to meet each other and collaborate in a way that had never been done before in Central Texas. As stated previously, the three main objectives of the project were to:

1. Create and build the best continuum of care for women with breast cancer and their families in Central Texas,
2. Incubate or otherwise support new services to address gaps while supporting existing services, and
3. Leverage scarce financial resources with additional public and private funding.

Regarding *Objective 1*, the continuum of services has improved due to the group's planning and programs, but there is still progress to be made. The final outcome will be dependent on how well the partnering agencies keep working together and separately to increase and improve their services and make the continuum seamless so patients who need help do not fall through the cracks due to lack of support. This will probably always be a work in progress due to the ever-expanding population of Central Texas and the need for increasing funding to keep pace.

Objective 2 was met through the wide range of programs that were planned, piloted, and incubated by the project (though as stated above there is still a need for more support services to address the remaining gaps). Some of these are in development and others will be taken over by other agencies or developed/expanded at a later time as funding allows for an extension of services to more women and to more areas outside of Austin.

It is worthwhile to note the outcomes of one of the programs, the pilot program for food delivery, as it was well planned and measured and very successful in meeting its stated objectives. The

objectives were 1) optimizing nutrition during a patient's treatment, 2) alleviating financial burdens, 3) easing concern for survivors and family, and 4) mitigating loneliness and anxiety.

Each enrolled family completed entrance, midpoint, and exit surveys; 86 percent of patients cited satisfaction with nutritional improvements, while 92 percent of their families did so. From 57 percent scoring "good for you!" on the American Cancer Society smart eating quiz at the starting point to 82 percent at the midpoint, 100 percent scored this by the exit.

Regarding the objective of alleviating financial burdens, 100 percent of survivors (57 percent greatly and 43 percent somewhat) and 100 percent of families (67 percent greatly and 33 percent somewhat) cited the program as easing their financial burden. Regarding easing concerns for survivors and family, this was measured by asking about their ability to care for their family: 100 percent of survivors (82 percent greatly and 18 percent somewhat) and 100 percent of families (64 percent greatly and 36 percent somewhat) reported that the program eased their concerns.

Regarding the last objective of mitigating loneliness and anxiety, 86 percent of survivors (36 percent greatly and 50 percent somewhat) and 91 percent of family members (55 percent greatly and 36 percent somewhat) reported reduced feelings of loneliness. Enrollees were also asked about decreasing anxiety, and 100 percent of survivors (64 percent greatly and 36 percent somewhat) and 100 percent family (75 percent greatly and 25 percent somewhat) reported positively.¹⁸

Quantitative and qualitative evidence showed a positive effect on nutrition and health of participants, and hopefully this program can be expanded permanently to serve more survivors and families in need.

Objective 3 on gaining additional public and private funding was accomplished in several ways. Regarding public funding, the Travis County Healthcare District has agreed to fund a program at the Breast Cancer Resource Center, and funds should be distributed soon. There is ongoing discussion with the District on funding other projects as well. There is also a possibility of some of the partner agencies obtaining funding from the Austin/Travis County Health and Human Services Department, and meetings are being scheduled to introduce department officials to some of the agency heads.

Regarding private funding, the most significant outcome is the annual bicycle ride, which if all goes according to plan will provide a funding stream for member agencies for years to come, as well as more directly supporting expanded programs due to the portion of the revenue that will be set aside in a group fund earmarked for new services. The group of agencies will also need to continue to meet and collaborate due to this shared funding. The B Club program is also a source of new private funding that goes directly for emergency support services for survivors.

Overcoming Challenges

The Greenlights' needs assessment in 2006 identified several challenges that threatened the community's ability to collaborate to serve women with breast cancer, calling these "predictable and understandable, but problematic."¹⁹ These were the following:

1. Competition for scarce resources among service providers.
2. Conflicting accounts of how funders make decisions about funding local services.
3. Conflicting assumptions about how people with breast cancer want to be helped.
4. A pervasive sense of frustration that uninsured women are not getting care, much less the highest quality care.

Other issues were uncovered during interviews with participants. The overall biggest challenge was collaboration itself, not coming up with solutions to the issues. This is a common problem when bringing together groups of people from different organizations who have never worked together before and may offer similar services. Tensions were inevitable, though some may have been able to have been avoided if different tactics were taken. All participants had the best interests of breast cancer patients at heart and were learning as they went, and there were naturally different opinions of how the project should proceed.

The original organizers of the project were not from social service agencies already involved in serving breast cancer survivors, so this was different than a collaboration of only agencies would have been. "Outsiders" were asking the agencies to come together and telling them what needed to be done, creating trust and credibility issues. The project was initially driven by the founding leadership, but eventually the partner organizations felt more empowered to act and work together. It was also difficult to agree on priorities since each of the participants brought different perspectives and experiences. These issues were lessened over time as trust was built. Many meetings were held to discuss what the goals and priorities of the project should be. It helped to have neutral trained facilitators at some of the earlier meetings to help the group discuss and formalize the goals of the project.

In a social services arena such as breast cancer services, local agencies are often competing for the same dollars, and some agencies were worried that the project or any new programs would take away some of their grant funding or patient populations, or were threatened that others were coming into their "territory" to change things. Many wanted to work together but were protective of their organizations. This was addressed by ongoing dialogue with all participants, and by the realization that the Breast Cancer Services Project was not permanent and would not become a competing nonprofit agency, and instead would facilitate programs to be taken over by existing agencies. Some existing funding may have been redirected to the project's goals temporarily, but this should be more than compensated for by the new sources of funding that the project managed to create, both public and private.

It was difficult for representatives from some of the member organizations to attend many meetings and do extra work on top of their already full-time jobs, which is often a concern in any multi-agency collaboration. Though time management was a challenge, some did not want to miss any meetings so they would know what was going on and/or for fear that something might be decided without them that would not benefit their organizations early in the collaboration (a

trust issue). One thing that helped was to hire the Project Director full-time so she could devote more time to the project and move the programs forward, doing the research and coordination that many of the partners did not have time to do.

Overcoming the obstacles that are inherent in any collaboration and those that were specific to this collaboration took tenacity and the work of many dedicated volunteers who believed in what they were doing. Though there may have been disagreements along the way, patience and a passion for the cause by many participants helped the project to be largely successful in doing what it set out to do.

Lessons Learned and Conclusions

This section provides some conclusions based on interviews and project documents, and lessons that other groups wanting to do something similar in Central Texas or other communities can use to help shape their projects.

Collaborations of individuals and organizations are not always easy to forge or maintain due to differences of opinions, but when they work well, the synergistic effects facilitate accomplishments that could not have been done by the members alone. Some important considerations are how the organization will be structured, who “owns” it, and how it will be funded. Besides a shared vision, leadership and funding are fundamental to the success of a collaboration. It is important not to depend on only one leader or one source of funding. The goal is to get all the members engaged, and have all help provide funding or resources as needed for common objectives so all feel a part of it and it is sustainable. The leadership of this collaboration came from different backgrounds and had different views, but this dynamic tension was part of what made it work.

Community leaders cannot do it all alone, and need the help of more people who care and who have the time, energy, and resources to assist in many aspects of a community project. The Breast Cancer Services Project had passionate leaders who recruited many other people willing to donate time and money to the cause. The well-placed connections of the leadership volunteers helped to draw in more funders and social service agencies. While this project demonstrates the power of collaboration, it is also a testament to the power of an idea. An outside founder, whose circle of friends and family had been touched by breast cancer, took the initiative to contact agencies and experts, whose assembly began the project. One person acting with curiosity and passion can catalyze a movement that brings forth community-wide support.

It was helpful that the project founders were neutral in that they did not care who did what in the agencies. They could step back and see the big picture and just wanted the agencies to work together more and address the gaps in services, and were willing to raise funds to help with that. So it is key in a venture like this that the strategy and goals envisioned by the leadership and the activities and needs of the local and grassroots organizations who are on the front line of services can meet in the middle and mesh in a way satisfactory to all. That seems to have happened in most aspects of this project, though there are some who feel that the project may not have obtained total buy-in from all participants.

Agencies may have a harder time at first seeing the value in collaboration since they are already offering their own services. They have their own goals and they are dealing with the day-to-day issues of their clients so it may be difficult to balance that with the big picture of the services continuum and what else needs to be done. But if they see value in it for their organizations, they will want to participate.

A collaboration needs a call to action, and while this collaboration was very passionate about what they wanted to accomplish in general at the beginning, it took a long time to narrow it down and agree on specific service gaps that could be met by new or expanded programs and to prioritize them, while trying to be mindful of not “reinventing the wheel” and doing things that were already being done.

It was extremely valuable to have a talented, dedicated Project Director and the participation of the Executive Director of the Entrepreneurs Foundation. Their perspective that was independent of the topic, their businesslike work style, and their time and resources helped evaluate options and move things along. It was helpful that the Entrepreneurs Foundation provided neutral funding not tied to any agency or existing grants. Some participants wished that there were even more business people involved to provide their expertise, and that they had gotten involved earlier in the process.

The Breast Cancer Services Project, started by a non-provider and funded partially by a business-related foundation, differs in membership and approach from some other collaborations such as the Breast Health Collaboration of Texas, which started in Houston in 2005 as a group of interested breast health advocates. The group began meeting in 2004 to plan a breast health summit, led by Komen for the Cure and The Rose, a Houston nonprofit breast cancer screening, diagnosis, and education center that already had good relationships with many providers (<http://www.the-rose.org>). The group decided to form a permanent collaboration, which is now applying to become a nonprofit organization. More than 60 organizations participate, and the collaboration’s mission is to “unite breast health advocates and providers to educate, advocate, and leverage resources in Texas.”²⁰ They have helped to advocate for millions of dollars for breast cancer screening and treatment, advocated for the passage of Proposition 15 for cancer research funding in Texas, developed the Breast Health Resource Mapping Project in collaboration with St. Luke’s Episcopal Health Charities, and hold an annual breast health summit, among other accomplishments.

The collaboration has members in other parts of Texas now besides Houston. The group would like to start some regional chapters, which Central Texas could become if desired. The Breast Health Collaboration of Texas focuses more on access to medical care, while the Breast Cancer Services Project of Central Texas emphasized access to the support services needed along with medical care, so each approach could complement the other and the collaborations could learn from each other.

It is remarkable how much was accomplished in a few years’ time by the dedicated and enthusiastic people in the Breast Cancer Services Project, originally called together by one person with an idea. Besides the individual programs that were initiated, the overall result of the project is new, lasting connections made between the local social service agencies, which will

help them and the community for years to come. The partner agencies plan to meet informally several times a year, maybe quarterly, to keep in touch, and will work together on the bicycle ride fundraising, which has the innovative component of the shared portion of funds for the group to control.

The project, which ended in early 2009, was successful and the programs it developed will be sustained due to the innovative collaboration of social entrepreneurs, business entrepreneurs, and service providers. This model resulted in community members, health care providers, social service organizations, and local foundations all working together to develop an outcomes-based approach to addressing a local issue. This approach appeals to business-minded philanthropists and foundations who want to see efficiency in projects they fund, and helps to attract new funding to social service initiatives. This project shows that instead of being concerned that the pie of funding is going to be sliced into smaller pieces if more people get involved in an issue, the pie can actually get larger with more for everyone to expand services and help more people, if groups can look beyond their organizations for opportunities to collaborate with one another.

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The opinions expressed in this case study are those of the author only, and not necessarily those of the people interviewed or the participants in the Breast Cancer Services Project or its programs.

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Interviews:

- Marion Cimbala, Breast Cancer Services Project Director
- Eugene Sepulveda, Entrepreneurs Foundation
- Chris Earthman, Aragona Family Foundation
- Nan McRaven, McRaven Consulting, and founder of the project
- Jan Hill, WR Starkey Mortgage
- Dawn Parsons, Seton Cancer Care Team
- Diana Phillips, Seton Hospital
- Diana Resnik, Seton Hospital
- Paula Harmon, St. David's Community Health Foundation
- Ramona Magid, Komen for the Cure, Austin Affiliate
- Vivian Smith, Breast Cancer Resource Center
- Hazel Barbour, former Komen board member
- Deborah Johnson, Komen for the Cure Headquarters (Dallas)

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Texas Mamma Jamma Ride Production Team. "2009 Ride for Breast Cancer, Beneficiary Collaboration Agreement." Austin, Tex., 2008.

The Happy Kitchen. "Cooking Class Series for Breast Cancer Survivors." Austin, Tex., 2008.

Endnotes:

- ¹ Texas Department of State Health Services, “2008 Selected Cancer Fact Sheets by Texas County.” Online at http://www.dshs.state.tx.us/tcr/factsheet_county.shtm. *Note:* Five counties—Travis, Williamson, Hays, Bastrop, and Caldwell—are often considered Central Texas for purposes of local programs, but current breast cancer cases were not available for Bastrop and Caldwell due to their smaller populations.
- ² Institute of Medicine, “From Cancer Patient to Cancer Survivor: Lost in Transition,” p. 33. Online at http://books.nap.edu/openbook.php?record_id=11468&page=33.
- ³ Breastcancer.org, “Breast Cancer Statistics.” Online at http://www.breastcancer.org/symptoms/understand_bc/statistics.jsp.
- ⁴ Cimbala, “Overview of Breast Cancer Services Project,” p. 1.
- ⁵ Sepulveda, “Social Entrepreneurship and Community Change,” p. 3.
- ⁶ Greenlights for NonProfit Success, “Nutritional Support Delivery Pilot Project,” pp. 3, 9.
- ⁷ Greenlights for NonProfit Success, “Nutritional Support Delivery Pilot Project,” pp. 10, 12.
- ⁸ The Happy Kitchen, “Cooking Class Series for Breast Cancer Survivors,” pp. 1-4.
- ⁹ Breast Cancer Services Project, “The Happy Kitchen/La Cocina Alegre Pilot Program for Breast Cancer Survivors,” pp. 4-10.
- ¹⁰ Institute of Medicine, “From Cancer Patient to Cancer Survivor: Lost in Transition,” p. 195. Online at http://books.nap.edu/openbook.php?record_id=11468&page=195.
- ¹¹ Jones, “Breast Cancer Patient Navigation Needs Report,” pp. 4-5.
- ¹² Jones, “Breast Cancer Patient Navigation Needs Report,” pp. 22-25.
- ¹³ Jones, “Breast Cancer Patient Navigation Needs Report.”
- ¹⁴ Cimbala and Worthy, “Central Texas Patient Navigation Needs Assessment: Service Delivery Inventory Report, Environmental Scan Report.”
- ¹⁵ Texas Mamma Jamma Ride Production Team, “2009 Ride for Breast Cancer, Beneficiary Collaboration Agreement,” pp. 2-5.
- ¹⁶ Breast Cancer Services Project, “Hill Country Ride for Breast Cancer (HCRBC),” pp. 1-3.
- ¹⁷ Breast Cancer Services Project, “B Club/Breast Cancer Emergency Support Fund,” pp. 1-2.
- ¹⁸ Greenlights for NonProfit Success, “Nutritional Support Delivery Pilot Project,” pp. 6-8.
- ¹⁹ Greenlights for NonProfit Success, “Lifelines: Preliminary Analysis of Central Texas Services Supporting Women with Breast Cancer,” p. 7.
- ²⁰ Breast Health Collaborative of Texas, “We are Committed To.” p. 1.

Appendix A. Medical and Social Service Organizations Represented in the Project

American Cancer Society (Andrea Taurins, Art Wolff, Karen Candelis, Villalaz)
Breast Cancer Resource Center (Marge Gallece, Alice Wilson, Ray Anne Evans, Barbara Formicelli, Shauna Martin, Vivian Smith)
Cancer Connection (Emmett Skiles, Karen Greif, Roni Kendall)
Care Communities (Carol Johnson)
City of Austin (Ella Pulga, Janet Pichette)
Community Action (Lydia Perez, Ana Sierra)
Indigent Care Collaboration (Ann Kitchen, Anjum Kurshad, Sandy Coe Simmons)
Lance Armstrong Foundation (Haley Justice, Sue Potts, Betty Otter-Nickerson, Andy Miller, Ruth Rechis Oelker)
Scott & White Hospitals (Pandora Ashley)
Seton Hospital, Seton Cancer Care Team (Dawn Parsons, Diana Resnick, Diana Phillips, Nidya Aponte)
St. David's (Paula Harmon, Vivian Smith, Nancy Etzold)
Support Source (of Hospice Austin) (Mark Mullinax)
Susan G. Komen for the Cure Austin Affiliate (Marianne Rochelle, Ramona Magid, Mary Moore Cavanaugh, Hazel Barbour)
Sustainable Food Center (Joy Casnovsky, Ronda Rutledge)
Team Survivor (Paula Harmon, Jan Hill)
Texas Oncology (Deborah Patt, MD, John Sandbach MD, Beth Hellerstedt, MD)
Texas Cancer Registry (Melanie Williams, Paul Betts)
Travis County Healthcare District (Christie Garbe, Elaine Carroll)
Texas Department of Health (Kenya Johnson)
WINGS (Terri Jones)
Wonders & Worries (Farya Phillips, Meredith Cooper)
Lone Star Oncology (Brian Shimkus MD, Glen Luepnitz)
United Way, Texas 2-1-1 (Holly Alexander, Amy Price)
UT Medical (Declan Fleming, MD)
UT School of Social Work (Barbara Jones, Annemarie Redelmeier)
UT School of Nursing (Mary Lou Adams)

Note: The people listed above do not reflect all of the individuals involved in the project, just those from medical and service organizations, in order to show the number of these organizations that participated.