How a Nonprofit Maintains and Builds Relationships: The Role of Social Capital and Rhetorical Identification

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HOW A NONPROFIT MAINTAINS AND BUILDS RELATIONSHIPS: THE ROLE OF SOCIAL CAPITAL AND RHETORICAL IDENTIFICATION

A Thesis
Presented to
the Graduate School of
Clemson University

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
Professional Communication

by
Megan Eunice Garver
May 2012

Accepted by:
Dr. Susan Hilligoss, Committee Chair
Dr. Huiling Ding
Dr. Cynthia Haynes
The focus of this study is to investigate how one affiliate is situated in a particular context in order to understand, modify, and maintain its mission in the community, a process that this affiliate calls “community impact.” The study of this Susan G. Komen affiliate will provide insight into how nonprofits build social capital in order to convince a target audience to invest, whether through volunteering, partnering, or donating monetarily. Further, this study will examine how relationships are created, as well as maintained, and the role of identification within these partnerships. Lastly, this study will explore how a nonprofit localizes a value. Whether it is marketing a brand to a particular audience, or stepping into the role of developing a CIP, professional communicators need to understand how to develop, utilize and maintain relationships, as well as understand the process of localization, whether it is localizing a product or a value. Studying the development of a successful CIP will offer an understanding as to how these affiliates operate, how they accomplish their mission, how they implement their program in order to create community impact and how they assess their own success.
DEDICATION

I dedicate my thesis to my parents, Patty and Rob Garver. It was through their faith and relentless encouragement that allowed me to type the very last word of this thesis and smile with pride at what I had accomplished. I also dedicate my thesis to Earlean Tabb – my pseudo grandmother and four year Breast Cancer survivor. Her story and love provided the momentum for this piece of work.
ACKNOWLEDGMENTS

I was fortunate enough to have the “Dream Team” of support systems, and heading up the offense was my mentor, my encourager, my critic, my think tank, my committee chair: Dr. Susan Hilligoss. I cannot thank her enough for her patience. She held my hand through this process, gave me a kick-start when I needed it, and if it weren’t for her words, “all writing is good writing,” I do not think this thesis would be complete.

I can honestly say that I would not be in this program had it not been for Dr. Huiling Ding. Her focused attention has been consistent from the first time she emailed me about my application and has carried on through my entrance into the field of professional communication, to my final piece of work for this program. She has pushed me to become better academic and writer. Thank you for your faith in me and my work.

I have my sanity to thank to Dr. Cynthia Haynes. She provided me with much needed “zen moments,” as well as encouragement that all the revisions, frustrations, sleepless hours and anxiety are a part of the thesis writing process. Her faith in me has calmed me during my doubtful moments and helped me get to the bright light at the end of the tunnel (which is thankfully not a train coming at me).

To my rock, my confidant, my fiancé: Brad Carlson – I thank you. I am sure you will lose your mind if I utter the words “thesis” one more time, but I am so fortunate to have had someone by my side assuring me that I could do this; and if that encouragement failed, at least make me laugh. I could not have done this without your support, patience and uncanny ability to listen to the same complaints and fears over and over again.
I must thank the “star” of my thesis: EGC. Although I cannot state her name, I cannot thank her enough for allowing me to be a part of her work. I truly admire her dedication, creativity and passion towards Komen’s mission, and I am so thankful for the professional and personal relationship that we built over the course of my study, as well as the opportunity to study a Komen affiliate at the ground level. I hope I can do justice to what she has done within her service community, and may a piece of her commitment and work live on in this thesis.

I would like to thank my family for giving me perspective, encouragement, and blissful moments that could distract me from impending deadlines and piles of work. I would also like to thank my MAPC family. We have encouraged and motivated each other during this process, and I am so fortunate to have known each of them and been influenced by their work and creativity.

And finally, to my English 103 students: although they may not know it, their faith in me as their teacher and mentor re-instilled my own faith in my abilities as a student and writer. Here’s to growing, learning and continuously thanking the people who got us to where we are.
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CHAPTER ONE

INTRODUCTION, LITERATURE REVIEW AND METHODOLOGY

Introduction

In an economic climate such as this one, and in a nation where organizations such as the Bill and Melinda Gates Foundation and mission trips overseas exist, many organizations are searching for more efficient and effective ways to increase the visibility of their mission, and professional communicators holding positions of public relations and communication specialists in these nonprofits seek better ways to promote a nonprofit’s cause. The field of nonprofits identifying and addressing the needs within a community is indeed vast; and further, the range of size, scope and approach of these nonprofits only adds to the complexity of this area of study. However, there is one organization that has made leaps and bounds in the nonprofit world, prompting the selection of this organization. This nonprofit has made its color a trademark, a ribbon a fashion statement, and a race a household name: Susan G. Komen for the Cure.

Susan G. Komen for the Cure is a nonprofit organization whose mission is to rid the world of breast cancer forever. There are 120 Komen affiliates stationed across the United States and function as an extension of the organization that is based out of Dallas, Texas. These affiliates have the role of identifying the breast health need in their surrounding communities and addressing these needs. Through a holistic approach, they provide services from speaking engagements, providing educational materials, grant
funding, and serving on boards and committees who also serve the breast health community. Their mission is to ensure that all women in their area are getting the education, screenings, treatment assistance and survivor support they need.

Susan G. Komen for the Cure has received a four-star rating from Charity Navigator, which is the highest rating a nonprofit organization can receive (“Susan G. Komen for the Cure”). They have received this rating since 2007, as far back in the history of the rating of a nonprofit organization as Charity Navigator will allow. Charity Navigator was founded in 2001 and has become the nation's largest and most-utilized evaluator of charities. Charity Navigator's rating system examines two broad areas of a charity's financial health – how responsibly it functions day to day as well as how well positioned it is to sustain its programs over time (“Susan G. Komen for the Cure”).

As of 2011, Komen is ranked in the top ten by Harris Interactive in a study of 1,151 brands, in the categories of the most trusted nonprofit organization and brand equity (“Harris Poll Finds”). Harris Interactive is a custom market research firm, is known primarily for the Harris Poll, works in a wide range of industries, including healthcare, and is a member of the US National Council of Public Polls, the British Polling Council, and the Council of American Survey and Research Organizations. Susan G. Komen has also been ranked number two, behind St. Jude’s Research Hospital, as the most trusted nonprofit organization the United States (“Harris Poll Finds”).

In the spring of 2011, I interned with a Susan G. Komen for the Cure affiliate, here referred to as Komen Midwest, and in preparation for the internship, I developed a pilot study using qualitative methods, chiefly interviews of four members associated
with this nonprofit organization. At the time, the affiliate was engaged in a major exercise to assess and expand its program, called a Community Impact Program (CIP). A CIP is an action plan designed to address particular problem areas within a community and engage a public in a specific cause and action. The CIP is situated as a document that enables people to act, while still allowing for further development and creation. The CIP also functions as a timeline and motivator for ensuring that certain objectives are accomplished in a measurable and timely manner. While the CIP is not the sole focus of this study, it was a prominent concern in the mind and activities of the affiliate staff member responsible for achieving the mission goals, the Education and Grants Coordinator (EGC) and likewise, a major part of my internship and interaction with her.

The focus of this study is to investigate how one affiliate is situated in a particular context in order to understand, modify, and maintain its mission in the community, a process that this affiliate calls “community impact.” The study of this Susan G. Komen affiliate will provide insight into how nonprofits build social capital in order to convince a target audience to invest, whether through volunteering, partnering, or donating monetarily. Further, this study will examine how relationships are created, as well as maintained, and the role of rhetorical identification within these partnerships. Lastly, this study will explore how a nonprofit localizes a value. Whether it is marketing a brand to a particular audience, or stepping into the role of developing a CIP, professional communicators need to understand how to develop, utilize and maintain relationships, as well as understand the process of localizing a value. Studying the development of a successful CIP will offer an understanding as to how these affiliates operate, how they
accomplish their mission, how they implement their program in order to create community impact and how they assess their own success.

**Literature Review**

Because of the nature of this case study exploring a field that has little relevant qualitative research on small nonprofits’ communication and workplace strategies, this literature will address the various components that make up a community impact program developed by Susan G. Komen: social capital, managing stakeholders, collaboration, relationships and alliances (networks), and instilling values within a community (drawing from research based in globalization). In doing this, this literature review will create a framework of understanding the nature of the organizational communication used in order to create and develop this CIP, the strategies implemented during the developmental process of a CIP and provide a launching pad in addressing the research questions driving this study.

**Theoretical Framework**

For my theoretical framework, I draw on Bourdieu’s concept of “social capital.” Recent research has applied social capital theory to corporations, such as Lyon’s study on Enron and how social capital was both accrued individually through Skillings’ “smart” ideas and acquired as a group via Enron’s re-branding. Social capital theory has also been applied to nonprofits, such as Keyes’ study investigating the role of social capital in shaping nonprofit’s partnerships with other organizations (Keyes 203). Social capital theory has been successfully applied to this area of interest; and therefore, I will implement Bourdieu’s concept of social capital being “the aggregate of the actual or
potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition . . . which provides each of its members with the backing of the collectively-owned capital” to this workplace case study (51). The volume of social capital a person or organization possesses depends on the size of the network (51). A network is not a natural given; instead, it is the product of the organization’s/institution’s effort to build lasting, useful relationships that can secure material or symbolic profits (52). The reproduction of social capital is the “continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed” (52). Social capital, therefore, is a means of increasing a nonprofit’s equity, whether real or symbolized, via building and maintaining relationships, as well as through identifying and demonstrating public needs.

The first strategy, building and maintaining relationships, allow for an increase in the recognition of a nonprofit’s values. For example, if a nonprofit creates a relationship with a corporation, the public will now associate the nonprofit’s cause with not only the nonprofit itself, but will now associate the nonprofit’s mission with the corporation. Therefore, both the nonprofit and the corporation have “collectively owned capital” through the established partnership that encourages the “continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed (51-52).

The second strategy, identifying public needs, establishes the nonprofit’s goodwill towards the community by demonstrating to the public their genuine care and interest in the community’s wellbeing, thus establishing them as a credible nonprofit that can be trusted. This builds social capital by the community trusting the nonprofit and building a
relationship with them via using their services, supporting their mission, and even becoming a part of the organization through volunteering; and thus, again, increasing the recognition of the nonprofit’s values and/or cause. This increases their network, which thereby increases their social capital (51). The social capital can be real, through donations or increases in accessible resources (result of the new partnerships), or symbolized through the increase of recognition.

Lin reviews the concept of social capital and argues that this theory will be based on the understanding that social capital is gained from embedded resources in social networks (28). Lin outlines the elements of social capital: flow of information, social ties exerting influence on agents within the network, social ties being viewed as “social credentials, some of which reflect the individual’s accessibility to resources through social networks and relations,” and social relations reinforcing identity and recognition (31). After an extensive review of social capital and its various definitions, Lin offers a useful model for theorizing social capital (41). This model consists of three blocks of variables in causal sequences. Lin describes that “one block represents preconditions and precursors of social capital … another block represents social capital elements, and the third block represents possible returns for social capital” (41). This model will be a useful application in evaluating how social capital is accrued in nonprofits.

In addition to social capital theory, I will also incorporate Burke’s identification theory, specifically using Cheney’s *The Rhetoric of Identification and the Study of Organizational Communication*. For the purposes of this study, I focus primarily on Burke’s concept of consubstantiality, the overlap in ideology between and individual and
a group, where values become congruent, and the individual adopts the organization’s interests (146). Further, I focus on Burke’s identification strategy: common ground. This strategy involves when the “rhetor equates or links himself or herself with others in some overt manner” (148). This theory will offer a means of understanding how identification is facilitated during the establishment, as well as the maintenance, of relationships, as well as its relation to a nonprofit accruing social capital.

**Managing Stakeholders and Networks in Nonprofits**

Nonprofits, as well as corporations, must manage multiple stakeholders when addressing a community’s needs. A stakeholder is a group or individual who has an interest, investment, or stake in an organization. For example, women diagnosed with breast cancer would be considered a stakeholder of Susan G. Komen for the Cure. Many researchers have explored how nonprofits manage stakeholders and common problems that they encounter. Balser and McClusky examine the correlation between how nonprofits manage stakeholders and the overall effectiveness of nonprofits. They select three nonprofit organizations to demonstrate that nonprofits that rely on a “consistent, thematic approach to managing stakeholder relations are evaluated as more effective than organizations that use a less consistent approach” (296). Ospina et al., on the other hand, explore how nonprofits manage expectations of stakeholders and maintain accountability (6). This study was limited in scope and primarily focused on the board’s relationship with the nonprofit organization, which my study will look beyond the board relationship and explore other collaborative relationships and their role within Komen Midwest creating impact in communities.
Herman and Renz continue with the focus of board relationships with nonprofits and investigate the relationship with board practices and board effectiveness and their relationship with nonprofits (148). Herman and Renz offer an interesting perspective of how to evaluate effectiveness. They propose a move away from the foundationalist approach and instead suggest that “in a social constructionist view … judgments of effectiveness are effectiveness … there is no effectiveness until someone ‘calls’ it” (150-1). Although this helps bypass the issue of measuring effectiveness, they fail in providing groups or organizations that “call” the boards’ practices they selected effective. Without this, their study is simply based on their idea of what effective is. They conclude that nonprofit organization effectiveness is strongly related to board effectiveness and that many boards do not fully meet their responsibilities (158). The evidence to support the first conclusion is weak because of the fact that they did not compare an effective nonprofit organization and an ineffective nonprofit organization; therefore, one cannot assume that the board’s effectiveness is related to nonprofit organization effectiveness.

Other researchers have investigated stakeholders in a broad sense of it representing an entire network. Plastrik and Taylor’s study does this by detailing the balancing act that organizations must perform when networking – an area that much literature has ignored. They identified three areas of tension: identity (serving networks without losing the organization identity), governance (balancing freedom and control of other stakeholders), and adaptation (balancing change without entering into chaos) (11). Taliento and Silverman highlighted problems that nonprofits typically have to address, and these consisted of: CEO having less authority, a wide range of stakeholders,
measuring performance, communication within the nonprofit and to the public and scarce resources (6). I will observe these areas of tension and problems within my own study.

**Measuring Collaboration and/or Effectiveness of Networks**

Frey builds upon past collaboration models represented in the current literature in hopes of offering a model for measuring collaboration in shared organizational efforts that are formed through grant-funded initiatives (384-6). Based on Hogue’s model of levels of community linkage, Frey developed “five levels of collaboration and their characteristics,” which consisted of the following stages: networking, cooperation, coordination, coalition, and collaboration (387). From this model, Frey developed a complex collaboration map. Although the map is difficult to read, Frey argued that “whatever the method, collaboration maps allow for interpretations of collaboration from a variety of perspectives” (389). I, too, will incorporate collaborative maps within my own study.

Provan and Milward attempt to give a more comprehensive look and, rather than focusing on one stakeholder, explore the relationship of all “network constituents” and their effectiveness as it relates to the overall effectiveness of the nonprofit (414). They identify difficulties in measuring effectiveness and offer a model of evaluation that has three levels of analysis: community, network, and organization/participant levels (415). They provide a check-list that organizations can reference to determine whether they are being effective. This list consists of: flow of agencies to and from the network, range of services, broad web of ties, and strength of relationships (418).
Networking: Building Relationships and Establishing Alliances

Austin’s study describes how past literature has focused on the relationship between nonprofits and the government and how there is little literature of alliances between businesses and nonprofits. She fills this gap by exploring how alliances between corporations and nonprofits arise and evolve, while also focusing on factors that contribute to their viability (70). Austin’s findings are illustrated via a “collaboration continuum (CC)” in which the collaborations are defined in three stages: philanthropic (relationship is largely charitable), transactional (resource exchanges focused on specific activities), and integrative (the partners’ missions, people, and activities begin to merge into more collective action and organizational integration) (71). The collaboration continuum highlights Austin’s idea that the viability of a relationship between a nonprofit and a business relies on an equal “give and take” between the two groups and a continual exchange of information and knowledge (71). This concept relates to Bourdiue’s building of social capital relying on the “continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed” (52). Berger et al. builds upon Austin’s study by primarily focusing on Austin’s third stage: integrative (59). Berger et al. outlines six predictable problems that nonprofits could encounter in social alliances: misunderstandings, misallocation of costs and benefits, mismatches of power, mismatched partners, misfortunes of time, and mistrust (61). Both these studies highlight the importance of nonprofits networking, thus proving support for the findings in my study.
Seitanidi and Ryan explore the increased interaction between profit and nonprofit sectors, otherwise known as corporate community involvement (247). They highlight how Austin’s map, although useful, fails to differentiate between forms of interaction between corporations and nonprofits; and thus their study will fill this gap and examine the limitations of the varying relationships. Because of the scope of this study, I am primarily concerned with Seitanidi and Ryan’s concept of partnership, which they define as “symmetrical relations; transfer of resources (in cash or in kind) in order to address collaboratively a social issue” and that this takes place in Austin’s third stage: integrative (249). During my study, the education grants coordinator made a push towards building partnerships with corporations, and I further explore this concept.

**Localization**

Localization is a term frequently referenced within the field of global/international communication. The traditional sense of localization is taking a product and adapting it to another country and/or region. In other words, making a product fit its environment. The connection from product to community impact program may appear to be a leap, but in fact is extremely applicable. This particular nonprofit affiliate is responsible for 21 counties. Each county has different demographic, economic, and religious backgrounds. Thus, the program has to be adapted to each county in order for it to be successful. Current research has not only overlooked localization within a county, or even state, context; but further, there is a gap in research concerning how to localize a value, such as healthcare. This study addresses this gap and draws on research in the field of global communication.
Huatong Sun explores the concept of localization, specifically user localization of mobile messaging technology. Sun highlights how technical communicators tend to believe that poor usability is associated with poor popularity; however, this does not seem to be the case concerning text messaging, which is “a hard-to-use technology with inherent limitations enjoying a huge market success (670).” She notes that when users are the designers (as with text messaging), localization becomes inherent in the developmental process because users will naturally adapt a product to their context. This concept will be applied to this study, and I will determine to what degree the public (the users) are co-designers of this community impact program.

**Methodology**

I performed a case study with an ethnographic approach on a Susan G. Komen affiliate, referred to as Komen Midwest. Following Katz, I employed both observation and textual analysis and applied several theoretical perspectives. The selection of this affiliate was a result of my internship and pilot study, a circumstance which allowed me access to this organization. Before the study commenced, I received IRB approval, gained permission from the executive director of the affiliate, assured the staff members that their identity, beyond that of a Susan G. Komen affiliate, would remain confidential, and informed them of the purpose and benefits of the study.

**My Role**

As a participant observer, I worked with Komen Midwest for three months. I partnered with the Education and Grant Coordinator (EGC), who is head of developing the community impact program, and therefore, had access to board meetings, emails, and
meetings with physicians, grantees and potential corporate partners concerning the development of the 2011 Community Impact Program. Additionally, I continued to have email and phone contact from the end of the internship until the completion of the written findings of this study, as the completion of the first set of objectives for the affiliate’s community impact program would be outside the timeframe of this study.

**Data Collection**

Field notes were taken and recorded daily during observed meetings, observational interviews, which, as defined by Susan Katz, consists of informal and often spontaneous conversations (32); and, as Katz advises, these notes were taken during different points of the day (29). Further, avoiding Katz’s concern regarding “observer effect,” which she defines as “the tendency for participants to respond (during interviews) and act (while being observed) as they think the observer wants” (29), I followed Doheny-Farina and Odel’s advice and remained on-site for long periods of time, ranging from five to eight hours (29). In accordance with Katz, when taking notes, I identified the number of participants, the ethnicity and gender of participants, location, date, the exchange of dialogue between the participants, as well as how participants interacted and reacted during encounters with EGC, and how long conversations lasted (30). My focus was on developing a thick description of the affiliate, as well as a thorough understanding of what occurred during EGC’s interaction with other individuals/partners concerning the development of the CIP.

In addition to my field notes, I also gathered documents created for the CIP, such as a PowerPoint presentation, drafts of the CIP, the “toolkit” (defined later in Chapter
Five), as well as emails exchanged between grantees and EGC, ED and EGC, and emails between potential partners and EGC. The result was approximately 40 pages of single-spaced field notes. The documents included five e-mails; a 31-slide PowerPoint presentation and revision; four revisions of the CIP action plan; numerous documents reproduced for grantees and other partners. However, because of the time constraints of this study, only my field notes and selected documents were used for analysis.

Findings, Theory, and Analysis

Following Thompson and Rothschild’s *Stories of Three Editors*, I, too, developed stories for analysis from my field notes and selected e-mails and other documents. By drawing from multiple data sources and implementing multiple theoretical frameworks, I achieve triangulation, thus increasing the study’s validity (Katz 37).

Five months after the study had been completed, I read through my field notes repeatedly, first to refresh my memory, and then to identify patterns. However, similar to Katz, the readings provided me with a thick description of Komen Midwest and the participant, EGC; “however, it did nothing to relieve the chaos” resulting from the mass of collected materials (35). Thus, taking Lee Odell’s advice, I composed free writes in the form of stories of significant moments throughout the developmental process of the CIP (35). Katz, using this approach herself, defines this as a “messy holistic approach” (36); however, the stories successfully composed a window into the developmental process of a community impact program and provided a unit of analysis (CIP). Indeed, each story brought forth strategies that EGC implemented, detailed how partnerships were created, as well as maintained, highlighted networking and collaborative moments, and explained
how and where communication took place during the stages of the CIP. Similar to Thompson and Rothschild walking through how editors revise a piece of work, the affiliate stories provided a window into the ways that EGC creates community impact, the CIP being only a component of this effort.

After I developed the stories, I then selected the documents for analysis. My criteria for selection involved identifying documents that directly related to the stories I had created. Thus, I selected an email EGC sent to a potential corporate partner, BigCorp (detailed later in Chapter Four), an email ED sent to EGC regarding corporate partners, the “toolkit” (defined later in Chapter Five), and the PowerPoint presentation and revision that EGC gave at Lunch and Learns. Each of these documents revealed whether written documents differed from or reflected the same strategies and themes identified within the stories.

Falling between the local/emergent and the elite/a priori axis within Deetz’s “Contrasting Dimensions from the Metatheory of Representational Practices” diagram (11), the findings of this study are guided by Bourdieu’s social capital theory, as well as Burke’s identification theory; and thus, subsequently, the stories were analyzed by determining how social capital was maintained, or accrued, with each encounter, as well as the role of identification between EGC and the participants (the guiding question being: How did EGC help facilitate this identification?). In addition to social capital and identification theory, I also applied the global communication concept of localization, determining how Komen Midwest was localizing a value. After the stores were analyzed,
I then proceeded to read through each story’s analysis, synthesizing main ideas and identifying major themes.

This study aims at addressing the following questions:

- How do regional affiliates, a smaller unit of a nonprofit operating within a community, accomplish their mission; that is, how do they create community impact of the nonprofit’s mission?
- How do regional affiliates implement a program and how do they assess the impact of that program?
- How do regional affiliates maintain and build relationships?
- How do regional affiliates, while assessing their impact, move forward with their program in order to reach a population that they have not reached in the past?

Limitations

With a study consisting of an ethnographic approach, it is of no surprise that a primary constraint to this study was time. In fact, Susan Katz, in her opening remarks concerning ethnographic research, details these very problems, suggesting that the amount of time, patience and faith it takes to hold onto the hope that out of the ashes of a chaotic, mass of research will arise a phoenix: “a window into the lives and work of people within a specific organization or culture with a level of detail that is not otherwise available” (23), is the primary difficulty concerning ethnographic research. Therefore, I was only able to analyze selected documents, rather than all documents collected. Further limits of this study will be discussed in Chapter Six.
Preview

The upcoming chapters of this thesis develop as follows: Chapter Two, a former study that foreshadows EGC’s reliance and emphasis on collaboration. Chapter Three and Four offer a thick description – Chapter Three being distinguished by static observations, and Chapter Four consisting of the developed stories. Chapter Five is the analysis of the stories and selected documents, and the thesis concludes with Chapter Six.
CHAPTER TWO

FORMER STUDY

Introduction

Prior to my internship with Susan G. Komen for the Cure, I conducted a study using qualitative methods in which I observed an emphasis in networking, identifying community needs, and managing stakeholders during the process of developing a community impact program (CIP). Additionally, I discovered a correlation between an experienced education coordinator, the person responsible for developing the CIP, stressing networking, whereas comparatively, the novice education coordinators did not. This study foreshadows the importance of collaboration, as detailed later in Chapter Four and Five.

Methodology

Selection of Interviewees

Susan G. Komen for the Cure was selected for the same reasons detailed in Chapter One. The participants were selected via convenient sampling. My working relationship with my EGC provided three other names with whom she thought would be willing to give a brief interview. Convenient sampling had to be used because of the interviews aligning with a national conference in which all education coordinators had to be present in Dallas, Texas. Because of the time constraints of the study, my contact at the affiliate I would be working for allowed me to quickly access participants. The participants were contacted via email that detailed the goal on the research study and
informed them that the information they provided would not be revealed with their name or their specific (state) location.

**Data Collection of Interviews**

All interviews took place during the week of March 21, 2011. The interviews lasted between 15 and 20 minutes and were digitally recorded. The one interview was conducted face to face while the other three interviews were held via telephone. The interviews were then transcribed verbatim the same week as when the interviews took place. The opened questions allowed participants to naturally highlight the strategies they used rather than being led to the answer. Additionally, conducting interviews provided a perspective that would not be achieved through textual analysis alone. It should be noted that because of the time constraints of this study, only four participants were interviewed, providing only one experienced education coordinator (over four years of experience) and three novices (approximately one year of experience); and therefore, more participants are needed to confirm the findings. However, the findings start a dialogue as to how nonprofits localize their mission and support the exigency in exploring this topic further with future research studies.

**Data Analysis of Interviews**

I performed axial coding using episodic units on the four interview transcriptions and the preliminary coding categories were: networking, stakeholders, branding, identifying need, and planning/administration. As the coding progressed, I observed when categories were being discussed and what the interviewer would associate with the category. Thus, sub-categories developed. Stakeholders first developed into two
categories based off Ospina’s concept of nonprofit managers responding to downward pulls (agents that depend on the nonprofit) and upward pulls (agents that the nonprofit depends upon). Therefore, I developed a stakeholder “downward pull” category that consisted of: providers, volunteers, board members, grantees, businesses, and hospitals; and a stakeholder “upward pull” category which consisted of community members requiring Susan G. Komen services. Within the “downward pull” category, I developed a category in which the interviewees were describing managing the stakeholders, for example, describing having open communication with a stakeholder, and another category in which the interviewees were describing requiring the stakeholder of a particular action, for example, using volunteers to go into the community to conduct surveys. Figure 1 illustrates the coding categories and the emphasis that is placed in particular areas regarding the development of community impact programs.

**Figure 1: Definitions, Examples, and Number of Episodic Unit Occurrences of Coding Categories**

<table>
<thead>
<tr>
<th>Category</th>
<th>Color, Description, and Example from Transcripts</th>
<th>Number of Episodic Unit Occurrences out of total 134 Episodic Unit Occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholder (downward pull)</td>
<td>Light blue Stakeholders that Komen relies on (board members, volunteers, grantees, hospitals, etc.) that Komen uses. Ex. We pass along information to our grantees, so hopefully it will filter down from them to the community.</td>
<td>22</td>
</tr>
<tr>
<td>(stakeholders being used)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stakeholder (downward pull)</td>
<td>Dark Blue Stakeholders that Komen requires (community members requiring Susan G. Komen services)</td>
<td>18</td>
</tr>
<tr>
<td>(being managed)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
relies on (board members, volunteers, grantees, hospitals, etc.) that Komen manages. Ex. And once they’re an official Komen grantee, I kind of do all of the interfacing between our organization and them and basically treat them as an extension of Komen ___ and the community.

<table>
<thead>
<tr>
<th>Stakeholder (upward pull) (stakeholder being managed)</th>
<th>Pink</th>
<th>17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholders that rely on Komen (community members that require breast health services) that Komen manage. Ex. Doing education sessions on breast cancer 101, health fairs . . .</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stakeholder (upward pull) (stakeholder being used)</th>
<th>Purple</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholders that rely on Komen (community members that require breast health services) that Komen use. Ex. Well, in both communities we’re going to be using community members to get the message out.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Networking</th>
<th>Green</th>
<th>29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building relationships Ex. Talking with and connecting with other affiliates and talking with other education people.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Branding</th>
<th>Red</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spreading their message of breast cancer awareness Ex. I always say we’re taking out bran and infiltrating the communities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Color</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Identifying Need               | Yellow| Identifying the needs in the community  
Ex. In our community survey, we realized here’s still a lot of women that don’t know the appropriate ages to get screened and also just don’t know about the resources that are available. |
| Planning/Administration        | Grey  | Planning data collection or developing annual reports  
Ex. A big piece of all the things I do in the office is a lot of administrative work … so I do everything from backing contacts and looking at the reports of the grantees. |
| Professional Development       | Dark red| Training and anything related to developing their role as an education coordinator.  
Ex. I literally had a stack of flashcards with all the terms so that I could make sure I was conversational in breast health. |

**Findings**

Because of the substantial size of the appendix, coded transcripts are not included; and therefore, my findings do not reference specific transcripts. The coding categories in Figure 1 highlight the strategies that are implemented when a nonprofit is localizing their
mission in a community. Additionally, the coding categories confirm the strategies identified in the literature and also add additional strategies, such as identifying community needs. The number of episodic unit occurrences for each category demonstrates which strategies are emphasized over others, suggesting that some strategies are more important than others. For instance, branding and networking are mentioned throughout the interview more than planning/administration, thus suggesting that branding and networking are more of an integral component of localizing a nonprofit’s cause than planning/administration; and therefore, these two strategies should more emphasize during this localization process.

All participants, when describing the process of developing a community impact program (CIP), primarily focused on discussing the importance of networking and identifying needs within the community. As Figure 1 illustrates, these two areas of focus are a significant component in developing a CIP. The interviews, however, illuminated who they are seeking to build relationships with. For instance, one Participant A stated:

I chair the breast cervical cancer committee, and obviously my specialty is breast, but I co-chair it with someone that is over the government’s breast and cervical program, so her specialty is more on cervical cancer. And someone said to me, “Oh, Komen, you can come to things like this?” And ultimately, cervical cancer and breast cancer affect women, so while it doesn’t kind of fit in a nice pretty box with a bow, it’s going to those and networking and knowing that the same people who are treating cervical cancer are the same people who are trying to treat women with breast cancer. Or the same people trying to get them a pap smear is
the time they need to be getting a breast exam. So it would make sense to go to
things like that.

This statement reflects Austin’s idea that nonprofits are seeking relationships outside
other nonprofits. By doing this, they expand the boundaries of their network; allowing
them to have a wider base in which they can infiltrate their message and brand, have a
continuous exchange of information and recognition of what their mission is, thus
implementing Bourdieu’s concept that larger networks reproduce more social capital
(51).

All four interviews emphasized building relationships and networking within the
community. Participant A stated, “Those relationships are vital to our success, they just
are. We only have so far that we can go. The Komen name is wonderful and it gets you
in and it definitely helps. But you have to be willing to build out of those relationships
and work on them.” This statement suggests that Komen has not only recognized the
importance of networking, but that they relationships are an integral component to their
success.

As demonstrated in Figure 1, identifying needs was closely behind networking in
terms of areas of emphasis when developing a CIP. I observed a move from raising
money and allocating it in a general area, and instead, a move towards identifying the
needs of the community and figuring out how and where the money should be spent.
One participant detailed four different data collection methods they used to identify the
needs, and some of those methods broke off into even more specific ways to identify
needs. High risk communities were consistently brought up as the focus for the CIP
programs. For instance, if there was a high mortality rate in three counties, the education coordinator would mention how they were focusing their efforts on those specific communities. Participant B described how one community had the resources but didn’t utilize them because of their culture, whereas another community couldn’t access the resources; therefore, the message to these two communities might be the same of “get screened” but, as my participant said, “the approach [to these two communities] might be similar, but the conversation will be different.” The targeting of communities parallels with Ospina’s findings that nonprofit managers focus on one area within a community in order to maintain accountability and manage stakeholders’ expectations (16).

Managing stakeholders was also a highly emphasized strategy and relates to Balser and McClusky’s findings that a successful board is an integral component in a successful nonprofit. This study broadened Balser and McClusky’s scope by focusing on all stakeholders; however, the results of the high number of occurrences of managing stakeholders correlate with their findings. Additionally, Participant A stated that she was balancing trying to meet the board’s expectations while maintaining her freedom in choosing the course of actions that she thought would meet the overall goal. These actions conflicted with what the board wanted her to do and she explained how she had to compromise and meet the board half way. This relates to Plastrik’s balance of governance and balancing freedom with control from other stakeholders (11).

Branding was primarily focused on informing the public of their services and increasing breast cancer awareness by “spreading their [Komen’s] message within their community.” There was only one comment in which an education coordinator actually
described the brand of Komen when she was discussing going into the community and increasing awareness and informing the public that “we are more than just a race.”

Although networking was highly emphasized, the education coordinators did not associate their partners as part of the Komen brand in their interview. Additionally, only one participant used the word ‘brand,’ when discussing the development of the CIP.

**Figure 2: Comparing Novice and Experienced Education Coordinators**

The difference in experience levels correlated between a difference in areas of emphasis in networking and using stakeholders, as illustrated in Figure 2. The selected interviewees resulted in only one experienced education coordinator and three novices; therefore, the correlation is not strong but should be noted nonetheless. As illustrated in Figure 2, networking was a more emphasize strategy in comparison to the novice...
education coordinators. This suggests that networking has been proven as more of a useful tool towards establishing a foundation onto which a community impact program can be built upon.

**Discussion and Conclusions**

The pilot study offered itself as a platform for my study of a Komen affiliate to build upon and confirm patterns identified. The stressed areas of networking, identifying needs and branding contribute to Susan G. Komen’s accruing of social capital. With each new partnership, Komen establishes a wider base to reach with their message/brand, acquires new knowledge and business strategies, and their identity becomes a greater entity in which the public can then begin associating Komen with multiples areas of interest, rather than only associating them with a race or breast cancer awareness. By doing this, Komen increases their social capital by having a large network of partnerships.

Social capital, then, becomes an integral component in engaging a community in a nonprofit’s mission and/or cause. For instance, one participant stated in an interview, “Those relationships are vital to our success, they just are. We only have so far that we can go. The Komen name is wonderful and it gets you in and it definitely helps. But you have to be willing to build out of those relationships and work on them.” This statement references Bourdieu’s concept that networks are not a given, but that you must work at them in order to achieve the continuous exchange of information and recognition (51). Bourdieu suggests that working on a network and building relationships is important because it builds social capital. Additionally, this relates to Austin’s study that
networking is a continuum of collaboration and that this act takes constant maintaining and work (70). Thus, by Komen emphasizing that their success depends on their network suggests that their success a directly dependent on their accrual of social capital.

Social capital also becomes a means of localizing a product, or in this particular case, a mission. By establishing partnerships, identifying the community’s needs, thereby demonstrating to the community their credibility and overall care and interest, and branding, Komen has multiple levels in which they investigate and asses the community in which they hope to motivate and engage the targeted public. This avoids one of Berger’s identified common problems that nonprofits encounter when networking: mistrust. As demonstrated, this builds social capital, and through this accruing of social capital, Komen localizes their mission because they have a complete picture of the community.

Although this study was limited by time constraints, the findings suggest that social capital is an integral component when a nonprofit localizes their cause. But further, the process of a nonprofit taking their brand abroad and localizing their cause in a community is analogous to a corporation localizing a product; and therefore, this study suggests that the building of social capital is integral in the success of a nonprofit or corporation. The practical implications of this study suggest that nonprofits and corporations should invest in ways to improve how they build social capital.
CHAPTER THREE
DEFINING THE SUSAN G. KOMEN FOR THE CURE AFFILIATE: A THICK DESCRIPTION

Introduction

This chapter gives a thick description of Komen Midwest. First, I define the role of all Komen affiliates, and then I move into the Komen Midwest affiliate and describe the location and staff positions, the grantee partners, and affiliate partners. The last part of the chapter describes a typical day in the office, as well as an off-site visit for EGC, under the heading of “Office Shoes” and “Travel Shoes.”

Affiliates’ Role

Susan G. Komen for the Cure currently has 120 affiliates stationed across the United States that function as an extension of the organization that is based out of Dallas, Texas. These affiliates have the role of identifying the breast health need in their surrounding communities and addressing these needs. Through a holistic approach, the affiliate in this study provides educational services from symposiums, webinars, distributing educational materials, grant funding, corporate wellness programs and serving on boards and committees who also serve the breast health community. An affiliate’s mission is to ensure that women in their area are getting the education, screenings, treatment assistance and survivor support they need.

Affiliates operate under the model of a funding agency. Each year affiliates distribute 25% of its revenue, money they secured from the Race for the Cure and other major fundraisers, to fund breast cancer research, and the remaining 75% to support their
local service area and the surrounding nonprofit organizations that are concerned with the breast health in their community (komen.org). These organizations, heretofore referred to as grantees, report to the affiliate via quarterly reports, emails and in-person meetings and demonstrate how the Komen funds are contributing to meeting the breast health need in their area. However, as this study will demonstrate, the selected affiliate in this study, Komen Midwest, is moving beyond this typical funding agency model of simply distributing funds to grantees; and instead, reaching out to communities to identify the priority, breast health needs in the community, developing wellness programs and partnering with corporations in order to reach out to a population that had, in the past, not been addressed.

**Affiliate Location and Staff**

The affiliate was located within the state’s capitol and had recently undergone a move in which their offices went from being located in the downtown district to a set of suburban office buildings located in a large, populous county that was centrally located to the counties they served and near suburbia. Other occupants within this building consisted of a cooking institute, another nonprofit organization, and a law firm.

The Komen affiliate was located on the seventh floor and, as illustrated in Figure 1, consisted of: a reception area, kitchen, conference room, storage closet, four offices and four cubicles.
The space accommodated the five staff members: Executive Director (ED), Education and Grants Coordinator (EGC), Communications Director (CD), Finance Manager (FM) and Administrative Assistant (AA). The EGC was stationed in the office next to the conference room and next to ED, who was located in the corner office, and FM was in between the ED and the CD. The EGC’s office had more Komen memorabilia than the other offices (paintings on the wall, plaques, and pictures of past Race for the Cures, etc). The other offices had a few family pictures on their desk or wall, as well as one or two pieces of Komen merchandise.

It should also be noted that this particular affiliate combats the typical image that people invoke when they think of Susan G. Komen. This common image would consist of a world of pink; this, and a multitude of Race for the Cures. It is only in the world of
pink hats, pink calendars, pink shorts and a race that raises millions of dollars on a yearly basis that Komen can exist. Few can argue against the global success of Susan G. Komen and how it has taken its brand and made it as well known as the Nike swoosh. However, what my experience with Komen Midwest offers is a look beyond the pink walls and into the heart of this organization: mission. It is with Komen Midwest where I walked into a corporate office with not an ounce of pink paint, and five women who were too busy to decorate and line the walls with Komen merchandise.

During office hours, all of their doors were open and often the staff members would walk into each other’s office to ask questions or, on more than one occasion, simply yell from their office. The only meetings that I witnessed take place between the employees in the conference room was during staff meetings (which occurred every Monday) and when the EGC, ED and myself had a meeting concerning corporate partnerships.

The dress code ranged between staff members, and it is evident that strict standards concerning attire are not in place. ED and EGC were consistently in casual, professional outfits (black pants, skirts, etc.). FM, although part-time, would frequently wear suits to work. CD, thirty years of age and the youngest member of the group, often wore casual clothing in comparison to the other employees; for instance, she often wore black pants with flip flops.

The affiliate’s five staff members were all female and Caucasian. Because of the small size of the affiliate, each member reported to the Executive Director (ED). ED reported to the board and was responsible for the financial security of the affiliate and
provided operational oversight. My experience with ED was limited; however, I did observe that ED rarely left the affiliate and held most of her meetings with potential partners in her office. EGC stated that this would hopefully change when ED hired new personnel to assist with her administrative work, thus allowing ED to get outside the office and network and partner with corporations who could offer sizable donations to the affiliate.

Both ED and EGC reported the board, and the entire staff met with the board once a month and occasionally had social gatherings at a board member’s home. The board consisted of approximately twenty-five professionals in the affiliate’s area. Board members ranged from lawyers, to members of a hospital foundation, to employees of an accounting firm. Members could serve for two consecutive years. It was unclear how the affiliate recruited board members, as well as why the professionals decided to become a part of the affiliate’s board.

The Communications Director (CD) was responsible for all external communications to the public, such as maintaining the affiliate’s web site and Facebook page and also coordinated all third party partnerships. These relationships consisted of companies that wanted to have a fundraiser, contributing a percentage of the funds to the Komen affiliate, and use Susan G. Komen’s brand in their publicity. Additionally, the CD also assisted in heading major events that the affiliate hosted, such as the Pink Tie Ball, and coordinating those efforts.

The Financial Manager (FM) had a part-time role at the affiliate and was the bookkeeper for the organization. She sent out monthly reports concerning the budget and
communicated with the other staff members about their budget. The AA had the responsibility of coordinating all the volunteers, attending health fairs, answering incoming phone calls, and sat at the front of the office to greet visitors.

EGC was responsible for implementing all mission outreach and breast health programs, managing a two million dollar budget to be allocated to approximately seventeen grantees, being responsible for educating the community about breast cancer through interactive presentations and health fairs, and serving on committees and organizations who also assisted the breast health community. Over the course of this study, I worked closely with the EGC and could understand, further, the extent and multitude of her obligations and the priority and role of the CIP within those responsibilities. After the board formed a community impact committee, EGC had a close, working relationship with the board by reporting to them, hosting meetings, and also requesting their presence at grant site visits. In addition to collaborating with the board, EGC also collaborated with ED; and therefore, this study will highlight the interactions between ED and EGC concerning the development of the CIP, as this was a significant factor in decisions that were made regarding the CIP.

**Affiliate Grantees: The Traditional Komen Outreach**

Grantee relationships are established through EGC’s efforts of advertising grant opportunities on the affiliate’s web site, along with announcing available grants during collaborative meetings with organizations (potential grantees). There are a significant number of grantees that consecutively receive grant funding each year; however, the amount of funding they receive is susceptible to change, and this depends on the amount
of revenue gained from the Race for the Cure, as well as a grantee successfully demonstrating the need for the applied amount of funding. EGC stated that most grantees did not receive the full amount of funding requested because of the increase number of organizations applying for grants, as well as the current, economic climate.

For the year 2011, the affiliate “received 29 applications totaling $2.4 million in requested funds to provide services in [their] 21-county service area. The selection committee consisted of 15 community members who prioritized the applicant programs based on the needs outlined in our most recent Community Profile, which is conducted biannually” (komen___org). The affiliate was able to award $1.6 million to 17 grantees. The services these grantees provide include, but is not limited to, screening services, breast health education, services specifically targeting African American, Hispanic and incarcerated women, clinical breast exams, patient navigation (helping women through the diagnosis and treatment process), and ultrasounds.

The selected grantees consisted of: breast health programs at hospitals, health clinics, and nonprofit organizations concerned with breast health education and assisting women financially. The size of the grantee organization ranges; for instance, a hospital grantee is clearly larger than a rural, health clinic. Further, many nonprofit organizations had areas of service that did not relate to breast health, such as a current grantee whose main role is functioning as a food pantry for a community; and along with this service, providing wellness programs, one of the programs relating to breast health, as well as hosting a health clinic that offers breast exams and a mobile mammography unit once a month. However, disregarding the actual size of the organization, the number of people
directly associated with and responsible for the breast health program receiving the grant funding typically consisted of three to six people.

The location of grantees ranged. Two hospital grantees were located in rural areas an hour away from the affiliate’s location and one hospital grantee was located downtown, approximately twenty minutes from the affiliate. Nonprofits and health clinics less than thirty minutes from the affiliate were either in an urban area and/or a low-income community. If they were located over thirty minutes from the affiliate, then they were in a small, rural community.

Consistently, grantees had the overall goal of increasing the number of women taking care of their breast health. Hospital grantees accomplished this goal with a program focused on decreasing the number of women cancelling appointments, providing recently diagnosed women with a nurse navigator to help guide them through the process of treatment, and functioning as a resource of financial assistance information for women who cannot afford breast exams and/or treatment. For nonprofit organizations, their mission was twofold: first, increase the number of women educated in their breast health, thus motivating them to get a mammogram and a breast exam. Second, increase the number of women getting a breast exam or mammogram by providing easy access to these services at a low cost. The second objective for nonprofit organizations is also the mission for health clinic grantees.

**Affiliate Partners: The New Direction at Komen Midwest**

During the former study detailed in Chapter Two, EGC described that when she became a part of Komen Midwest, there had been an education and grants person in
place; however, there was no focus on relationship-building and networking outside of the Race for the Cure; and instead, the affiliate relied only on volunteers to assist with mission and community impact. The first year EGC figured out her role and what her job looked like, with a strong focus on education. EGC stated that she began developing partnerships approximately a year ago when she and the board began strategic planning and discussions concerning driving awareness outside of their county and the seven contiguous counties. It is then that EGC “looked outside who she was and what her position should really be responsible for,” and began networking in the cancer arena.

Four partnerships were established a year ago. One partnership was with an advocate group, The Breast and Cervical Cancer Coalition, and they approached EGC, requesting her presence and input during monthly meetings. Another partnership was with the State Health Department’s Data Coordinating Committee, and they, too, extended a membership request to EGC. She also formed two of her own initiatives: the Disparity group and the Funders Forums. The disparity group met once of month and consists of nurse navigators (nurses responsible for helping recently diagnosed women through the treatment and post-treatment process), project directors of organizations, and members of the breast and cervical cancer committee. EGC explained that she was observing that there were many people in local communities working towards the same cause; however, there was no avenue for them to come and work together. EGC believed that they could be more productive and powerful if they could collaborate on various projects that they would otherwise be trying to accomplish on their own. Thus, she started the disparity group in which they would do just this: outline their agendas,
network and collaborate. The Funders Forum consisted of Komen affiliates reaching across three different states and met approximately every two months. EGC explained that this was another opportunity for people working on the same cause to collaborate, share ideas, assist others when needed, and network. The name for this group derived from the idea that all Komen affiliates fund grantees; however, it should be noted that the focus of this group is not on funding, but rather collaboration.

Corporate relationships in the affiliate’s service area were a new endeavor for EGC and were mandated by the CIP. As this was a new development, the relationship between Komen and the corporations originated from a Google search targeting all corporations within target counties outlined in the Community Profile. From there, emails were sent to Human Resource representatives requesting a meeting and briefly informing the organization of the objective EGC hoped to achieve by partnering with them. The overall goal of the corporate partnership was to develop, or revise, a wellness program; and further, have a “lunch and learn” at the organization that focused on introducing breast health information for the employees and employers and encouraging them to take preventative measures.

**Office Shoes**

At 8:30am, EGC walks through the marble lobby, rides the elevator up to the sixth floor, and opens the glass doors (an alarm signaling her arrival), to the Susan G. Komen office. The AA greets her and after a few minutes of socializing, EGC drifts back to her office. While turning on her computer, she shifts piles of paper on her desk that accumulated from the previous day. Her eyes scan the list of emails to respond to, grabs
her rectangle notepad, and begins making a “to do” list for the day (the list usually sits casually by her phone). The list consists of people she needs to contact, items she needs to accomplish for upcoming meetings (for example, developing interactive activities for a breast cancer awareness event), and any meetings she has scheduled that day.

With the “to do” list outlined, she begins responding to emails. CD briefly pokes her head through EGC’s door, and they discuss various personal issues, such as their family or EGC’s preparation for the Susan G. Komen’s 3-Day, and then transition to what they are working on that day. A phone call interrupts their discussion, and CD slips out and returns to her office. A work routine emerges for EGC: email responses, phone call meetings, email responses, phone call meetings. Occasionally, EGC leaves her office and, standing in the open doorway of another office, asks a co-worker a question: Has this been done yet? How do you feel about ‘X’? The impromptu office meetings typically last for a few minutes and EGC returns to her routine of communicating with various stakeholders.

On a day when EGC has a visitor, which is rare because EGC’s face-to-face meetings are typically offsite, AA greets the visitor at the door. AA confirms who the visitor needs to meet with and notifies EGC via the office phone system. EGC comes out to greet the visitor and directs him or her back to her office. EGC’s door remains open, and the visitor takes a seat in front of her desk (where there are two chairs that sit close to each other). I did not take part in her office meetings; therefore, I was not able to observe the structure, the questions asked and the formality of the discussion.
Travel Shoes

Most off-site meetings during my internship consisted of grant site visits, as these occur during second quarterly reports (the halfway point for grantees using their Komen funding), these reports occurring during the summer. Grant site visits happened at least twice a week, and at times, there would be more than one off-site meeting per day. These meetings allow EGC to address any problems that arise and to make sure grantees are properly spending their funding. Regardless of the scheduled time of an off-site meeting, EGC visits the affiliate office first, usually to remind fellow employees where she will be and to respond to any emails, and she then leaves for her meeting. After checking in at the office, EGC takes her personal car and travels to either a grantee or an advocate meeting, such as a meeting with the Data Coordinating Committee.

EGC takes two documents with her: the grantee’s file (containing past reports) and her large, spiral notebook. This notebook contains all her notes from past meetings, things that she needs to accomplish for future meetings, and any ideas that she has for current projects. This notebook is taken everywhere she goes and is always opened during a meeting – ready for her to take notes or look up any information she needs. On the way to meeting, EGC debriefs me on the organization: how they became a grantee (which consisted of the services they provide and what target population they were serving), past problems, current directors, and the status of her relationship with the grantee. There were very few grantees where EGC implied an unhealthy relationship. Weak relationships for EGC consisted of poor communication on the grantee’s part, as well as failure to collect data on the grantee’s end and improper spending. Improper
spending sometimes involved a grantee not spending the amount of Komen dollars they should be. EGC explained this is problematic because that funding could be funneled to other grantees; and thus, improper spending results in money wasted.

Once we arrive at the grantee site, the visit begins with quick introductions of everyone present. It was typical for hospital grantees to have their nurse navigator, project director and a board member present. Other grantees typically had their project director, other program employees, such as outreach coordinators, and a board member present. After introductions, we take a tour of the facility. This was primarily done in order for me to get a feel for what the program offered to the public as EGC had already toured most of the organizations. We then gather in a conference room, and EGC begins the meeting by going through the organization’s grant report and highlighting areas of concern. Some typical questions EGC asked were: How many women have you served from your county? What is the primary demographic that you are seeing/serving? How are you tracking the women you are serving? Are you doing follow-ups? What are you doing to capture existing patients at the hospital? How do you feel the program is progressing? What can I [EGC] do for you and your program?

After EGC finishes her line of questions, she allows me to take over the meeting and ask them questions specifically pertaining to the CIP. My line of questions typically followed an explanation on a presentation I was working on and how I was having difficulty constructing an argument that would combat a woman’s particular reason for not getting a mammogram, which consisted of: I can barely afford a mammogram, if diagnosed with breast cancer, how can I pay for treatment? I would then ask the grantees
how they go about addressing this reason. I asked what barriers they were observing, for example, women not being able to get off of work, and how they were addressing these barriers. Additionally, I asked follow-up questions to the discussion between EGC and the grantee. For example, if a grantee explained they were investing in more advertisement for their program, I would ask what avenues they had chosen for their ad to be displayed and why, what the message consisted of in their ad, and their overall reason for investing in advertisement.

At the end of each site visit, EGC and I would re-group back in her car, or at the office, and discuss what information the grantees had provided and how it could be useful and or applicable to the CIP. Often, we would note a recurrence of a particular problem, for instance, grantees complaining about funding, or women not coming in for screenings because they did not deem it as a high priority. This provided confirmation as to what the CIP needed to accomplish in the target areas.
CHAPTER FOUR

STORIES OF KOMEN MIDWEST: OUTREACH COMMUNICATION
RELATIONSHIPS

Introduction

In this chapter, the thick description continues in the form of stories. These stories are about relationships maintained on and off-site. The organization of the stories follows the office and travel shoes classification and begins with stories based in the Komen Midwest Office and, beginning first with the story: Grantees Proving Partnerships, transitions to stories that took place outside the office. The stories, aligned with the development of the CIP, consist of EGC’s interactions with participants.

A First Story: Accommodating the Board – We Need Measurables

During a meeting between EGC and me about outlining the CIP, EGC states that each focus area of the CIP must be SMART – sustainable, measurable, achievable, realistic and time. This term that EGC frequently references is essentially the foundation for every objective that EGC creates – asking herself: Can we actually achieve this? What is the time frame of this objective? How can we ensure that the result from the objective is sustainable? And the most important aspect: How can we measure this change? Taliento and Silverman highlighted measuring effectiveness as a common problem that nonprofits had to deal with and address (6), and this was also a concern with EGC. In part, the driving force for the focus on measurables was encouraged and demanded by the board. I observed this in phrases similar to: The board is going to ask us how long this will take. The board is going to want to know how many partnerships we want to create
in a community. We need to create a timeline for the board as they will want to know when we are accomplishing certain objectives (Appendix B). This moment clearly highlights the EGC accommodating the board’s request, thus suggesting that the success of a project, such as the CIP, cannot be achieved without adhering to the board’s demands.

SMART, then, also filtered into how EGC interacted with grantees. A primary concern for EGC was the data/records that grantees kept on the women they were serving – numbers on demographics, women served, as well as how they were tracking the women to ensure that a follow-up would occur. Additionally, a common statement of EGC’s was: we have to demonstrate the need. When this statement was used with grantees, it insinuated that their data was responsible for this demonstration. It is not only clear that agreement was shared between EGC and the board on the importance of measureables; but further, that this shared value influenced how EGC interacted with grantees, and as illustrated later, with other partners as well.

**Stories: Partnerships**

Partnerships were a significant focus during the study. These stories describe moments where Komen Midwest staff members discuss corporations the affiliate should pursue as a partner, revealing the criteria for a partnership, as well as highlighting that not all corporate relationships are considered beneficial to a nonprofit.
Appropriate Relationships – Can Hooters be a Partner?

During a staff meeting, CD brings up how Hooters is becoming involved in the breast cancer awareness movement. She asks, “What about Hooters? Would that not be a good partnership” (Appendix B)?

ED replies, “We don’t need permission from headquarters, but I don’t think people would go for it. Not a good association” (Appendix B). CD disagrees, and ED brings up KFC and explains that when Komen created a partnership with KFC, that people were upset that Komen had partnered with an organization that does not promote healthy eating. ED suggested that perhaps they would do something with Hooters in October, but to not have an extensive partnership with them, and CD nods her head and says that she thinks this would be a good idea.

Most importantly, this story illustrates that not all partnerships are appropriate for Komen Midwest, as some partnerships can be detrimental to the identity (ethos) of the affiliate. Therefore, Komen Midwest must be careful with whom they choose as a partner. The KFC example highlights how the chosen national partnership that headquarters had established has a direct impact on the decisions that affiliates make. ED treats the failure of KFC as a personal, affiliate experience; and thus allows it to dictate how they operate. Further, this discussion emphasizes the hierarchical order and where the ultimate approval lies: with ED. Although the discussion included moments of each individual staff member’s input, this does not dissuade ED’s original decision. This was a recurring pattern and will be highlighted in other ED interactions with EGC.
Assumed Relationships – Let’s Look for Contact Resources

After a consensus is made concerning the Hooter’s partnership, EGC instructs me to update the staff on the status of the CIP. I inform them that the outline has been completed, and that I will begin the process of researching partnerships, specifically corporate. Staff members suggest looking at Race for the Cure team captains from last year’s race as a good place to start in terms of locating a contact for these corporations. Team captains are simply the representative of a group of people running in the race. Many companies put together a group to run in the race, choosing one employee as the team captain. Thus, team captains are considered/become a contact source for Komen Midwest. This is an instance of the affiliate assuming a relationship has been established with an individual and/or an organization, with the basis for this partnership consisting of the person’s/company’s involvement in a Komen event.

The majority of the corporations that sponsored a race group were located in the same county, Midwest County, as the Komen affiliate’s location. EGC concluded that the large number of corporations within the affiliate county confirms that Komen’s presence outside the contingent counties is significantly weaker. The number of corporations in Midwest County is data that EGC presents to the board to support her efforts in establishing partnerships outside Midwest County.

Stories: Networking and Collaboration

During my study, EGC emphasized the importance of networking and collaboration with people throughout the community. She stated that it was of the utmost importance that Komen have a presence in any group, organization, task force, coalition,
etc. that is focused on breast health. She explained that not only is this crucial for Susan G. Komen promoting their brand, but furthermore, the Komen presence increases the opportunity for learning about what is currently going on in the breast health community and allows for collaborative opportunities. She stated that she would not be able to do her job without her partnerships, and that one partnership can lead to several others. Therefore, EGC has joined, co-chaired and chaired multiple breast health initiatives.

Networking and collaboration took place both in and outside of the affiliate office.

**Funders Forum — Who is our African-American Representative?**

The Funders Forum is a group EGC created that consists of Komen affiliates located in three states, including the affiliate’s state location. EGC explained that the Funders Forum was another opportunity for people working on the same cause to collaborate, share ideas, assist others when needed and network. The name from this group derived from the idea that all Komen affiliates fund grantees. The meeting took place at the Komen office in the conference room. Approximately, 20 people were present and all were female. There was one male invited as a guest and his daughter was recently diagnosed with cervical cancer.

One agenda item during the meeting was about reaching the African-American Community and trying to determine why African-Americans have a higher rate of later stage diagnosis in comparison to Caucasians. EGC explained to the group that there is no data about diagnostics and whether they are falling out of the continuum of care. She added that she did not know if it is a good use of affiliate money to put together 900 education packets and go to churches. “I want measurables,” she said. “It’s a huge
problem and frustration, and I just wanted to hear your thoughts,” she concluded to the group (Appendix B). This reflects one of the focuses of the CIP in targeting certain populations; and again, references EGC’s value of objectives being “SMART.”

A member asked EGC who made up the focus group that was addressing this problem, specifically asking, “Is it smart African Americans” (Appendix B). EGC responded by saying she had surgeons, lawyers, etc. Another member explained that their data showed that it is a cultural thing, and that we have to have a cultural shift. EGC added that her focus group wanted to use a polished newscaster to be one of their ambassadors and added, “But she is not relatable” (Appendix B). A member wrapped up the discussion by explaining that the focus group has to figure out what works for each individual community. This discussion introduced the importance of who needed to be going into the target communities, something that had not been highlighted previously. This suggests that the “face” of the group going into the target area is just as important as the message they bring, reflecting the importance of establishing a credibility that is relatable to the audience. This story will be analyzed in Chapter Five.

_The Data Coordinating Committee Meeting – Let’s Use Infographics_

The Data Coordinating Committee meeting took place downtown in the state department building. The committee members at this meeting consisted of state department epidemiologists, director of the _____ State Cancer Registry, comprehensive cancer control coordinator, and research coordinators, as young male, Kevin, possibly an intern, who was responsible for updating the web site and assisting with the presentation of cancer data to the public. The chair of the committee, a State Department employee
(unsure of his status), asked EGC to share with the group her difficulty with finding data concerning African-Americans and when they fall out of the continuum of care.

Towards the end of the meeting, Kevin introduced his Prezi presentation, “Information is Beautiful,” with the purpose of illustrating to the committee the various approaches in which the State Health Department could present cancer data to the public. Kevin offers the use of infographics as one of the strategies to help convince an audience to understand cancer data, and therefore take action in terms of getting a mammogram, physical, etc. His example of describing how many times the Midwest [NFL] Stadium would be filled with the rate of breast cancer diagnosis in “Midwest State” directly relates to the concept of localization. By taking a monument that is culturally pertinent to the people of “Midwest State”, Kevin adapts the delivery of cancer information to fit the culture, thereby increasing the likelihood of the cancer data making an impact and potentially resulting in people taking action to combat the cancer statistics, and thus successfully localizing a value within a culture.

EGC not only states that she would like to implement infographics within her own presentation that she gives during Lunch and Learns, but she is interested in updating her PowerPoint to a Prezi. Immediately following the Data Coordinating Committee meeting, EGC goes to her office and beings learning the basics of Prezi, as she had never heard of this software before this meeting. EGC’s actions reflect the collective capital nature of her relationship with the data committee, and because of this partnership, she is able to gain new resources; and further, improve her presentation by focusing on localizing the information to adapt to the affiliate’s particular, target population.
Although EGC’s role was minor during this meeting, this encounter demonstrates a breaking of the boundaries of the precursor for establishing partnerships: an association with Susan G. Komen (as outlined in previous stories); and instead, EGC developing relationships with advocate groups that have an interest, disregarding the extent, with breast health and breast cancer in the affiliate’s service area. Indeed, this is a significantly broader category; however, as illustrated, this partnership allowed EGC increase her resources.

**Incentive Meeting: Interaction between EGC and ED**

EGC organized a meeting in the conference room with ED, CD and I in order to discuss what incentives we could offer in order for corporations to be our partner. The first part of the meeting established the goal of the corporate partnerships, the Lunch and Learns and the wellness program. Additionally, we discussed a wellness program model that was highlighted during a grant site visit and how to establish this company as our first partnership in the CIP.

The meeting moved towards developing a plan of creating corporate partnerships. EGC stated, “What we’re doing is demonstrating the need and meeting with the corporations over three meetings. The first meeting we’ll establish a rapport, the next meeting we will outline the wellness program and the Lunch and Learn, and the third will be the Lunch and Learn” (Appendix B). ED advised us to cut out one meeting. ED explained, “They’re busy and they’ll want to meet once and figure out what you want from them. Also, in terms of models, you may want to Google places to work, or something like that, and see how other people are doing it” (Appendix B).
EGC agreed and explained that we were in a place where we had to determine what the incentives were going to be. ED advised us not to use the name “Pink Partners,” a name that EGC had previously mentioned, and to think of a name that implied what the corporation does/did. ED informed us that we could recognize them on the Komen Midwest website and take out an ad in a local newspaper in October 2012. EGC asked if they could be recognized at the Circle of Hope, an event that recognizes corporations and individuals that have helped with Komen’s mission, and ED said that we could. ED also said that we could also make them a plaque and added that our sponsors love them (Appendix B).

Towards the end of the discussion, ED advised us that if we had a company that did not offer health insurance, then we would be going up against a lot and to keep that in mind. She suggested that perhaps instead of a Lunch and Learn, we could put together a health fair and get local hospitals to give free blood pressures, etc. EGC was hesitant with the time commitment that would be involved; however, told ED that she would consider it as an option.

The interaction between ED and EGC demonstrate the chain of command, but further, it reflects the knowledge ED has of corporate relationships and how this is needed to be implemented within the CIP. There was little discussion after each suggestion ED made, which suggests that few staff members question the ED’s authority. This is important in the fact that the ED had little interaction with EGC and myself during the developmental stages of the CIP; however, ED’s comments overruled anything that EGC and I had agreed to previously. Additionally, because EGC requested ED to come
to this meeting, it indicates how EGC values ED’s expertise with corporations, as well as the necessity of including ED on decisions concerning EGC’s actions with partners.

**Disparity Meeting – Agenda Accomplished**

At 9:00 a.m., EGC and I meet at a local nonprofit that is approximately twenty minutes from the Komen office and is located in a small, street-front office. The meeting’s location changes every time, with each member taking turns hosting. Upon entering, I meet the guest speaker, Gary, an oncologist at a hospital that EGC knows personally and collaborates with on multiple projects, and begin meeting a few of the women who work at nonprofits and hospitals.

At the start of the meeting, we introduce ourselves. There are approximately 20 people present, all females (excluding Gary). The group consists of program directors of nonprofits, nurse navigators, as well as other nonprofit representatives. One of the program directors present is a current grantee. We are seated in somewhat of a circle in the middle of the office.

Gary begins the meeting and states that he has pushed their agenda and that there will now be evening mammograms that women can get. These sessions will happen on the 2nd and 4th Wednesday of every month from 12-8pm. It will be full service, including biopsy, mammogram, oncologist consult, and there will be free valet parking. There are five sites and he hopes to alternate them in order that every Wednesday has a late-night service. Gary states that resistance to this agenda primarily came from the radiologists. However, he continues, they are now full partners and there is a strong commitment to this program.
A member asks, “Is the goal of what this hospital is doing is to be where women go to get care that you are the hospital people think of, or is it to standardize care and hope that other hospitals will follow” (Appendix B)? Gary responds with, “I think it’s both. We obviously want to be number one and that’s why we’re doing this because it needs to happen. It’s in demand, and it should have been done years ago. However, I think hospitals will have to follow in order to compete” (Appendix B).

Gary ends his lecture, and EGC directs the meeting on to agency updates. Going around the room clockwise, each woman updates the group of women on current events such as: webinars, medical advisory board meeting, Pink Ribbon Connection meeting, a fashion show event fundraiser, a health fair, a race, and open enrollment information for a cancer prevention study headed by the American Cancer Association.

After updates, EGC asks for the people presenting case studies to do so. The case study portion consists of members explaining a specific problem they are having difficulty addressing in order to seek the advise/input from other disparity members. Two women, Barbra and Jill, present their case study. Barbra discusses how she has a 75 year old, Tammy, who cannot read, write, and does not have a car, a phone, and has not been to see a doctor in at least 20 years. Barbra, through a person describing this case to her, gets Tammy screened and discovers that the breast cancer is so severe that it has now spread to her skin. Barbra explains that Tammy has no way to see doctors/pay for the bills. Barbra asks for advice as to how to handle the situation. Members offer information on free cell phone and car services. Another member asks Barbra to contact her directly and see if she can find funding for this woman.
Jill discusses how she has created a support group that allows women with breast cancer to come together to have fun and relax through activities such as yoga. Jill was excited about this idea; however, she is having difficulty getting women to come to the meetings. EGC is the first to respond and states that this goes back to women not allowing themselves to come first and this only confirms the notion that we must change women’s behavior in regard to how they value themselves. Other members nod in agreement and Jill seems comforted in the fact that other women seemed to have experienced a similar response to groups such as the one she created.

**Stories: Grantees as Networking Partners for EGC**

These stories describe EGC’s interactions with grantees and are significant in that they demonstrate how a grantee functions as a networking partner by developing new relationships for Komen Midwest, highlight a moment in which EGC had an issue with a grantee, and reflect similar values outlined in “partnership stories” where a grantee decides whether a partnership with a hospital will be beneficial or not.

**Grantee Offering a Corporate Partnership – BigCorp as a CIP Partner Model**

A site visit with a grantee in a target county illuminated how organizations were communicating with their public; and further, allowed for a moment where the grantee offered EGC the name of a company who could be a model for future corporate partnerships. This particular grantee is a health clinic that is located in a small, rural county located approximately forty minutes away from the affiliate’s office. The meeting took place in the office of the program director, Lauren. Prior to becoming a program director, Lauren was a nurse; and therefore, along with her director duties, serves as one
of the two women who give clinical breast exams on a daily basis. The meeting also included a nurse navigator, Katie.

At the start of a grantee site visit, I ask Lauren and Katie to tell me about their program. Katie describes that they have mammogram assistance, health exams, nurse practitioners once a month, and an exam room (breast exams costing ten dollars). She continues, “Our county is extremely poor. We have a 13% unemployment rate and 65% of children are on free lunch in our school system” (Appendix B). The executive director adds that a benefit of being in a small county is that word of mouth spreads quickly and works in their favor. They often advertise their services by posting flyers in Wal-Mart, the farmers market, and the post office (Appendix B).

During the meeting, EGC asks, “Did you see more late-stage diagnosis with the underinsured” (Appendix B)? The executive director is unsure if they have that data; however, the nurse adds that she knows of at least two off the top of her head and says that they could look into developing that data. EGC states, “It would kind of show what we think we know, and it’s hard to get that data from a hospital” (Appendix B). This is just one instance of EGC focusing on the data and making sure that Komen can demonstrate the need within a target population. This aligns with EGC’s SMART mantra and stays consistent with her focus on evidence to justify the decisions she makes, as well as EGC accommodating the board.

Later in the meeting, the executive director states that they are having issues with women diagnosed with breast cancer and not wanted to participate in things like the Race for the Cure. EGC nods her head and says, “It’s their way to deal. You know, ‘it
happened to me, but it doesn’t define me” (Appendix B). Here is a moment in which EGC demonstrates her expertise knowledge in this field, which not only consists of breast cancer knowledge (the latest research, the right people to contact for an issue), but also consists of the behavior of women who are, or have been, diagnosed with breast cancer. It is a case of EGC knowing her audience and offering her partners into this insight. Although this knowledge does not help this grantee necessarily fix this problem, I did observe the two women become relaxed, as opposed to anxious, when they realized this was a common issue/reaction.

Towards the end of the meeting, EGC tells me to inform the two women about the CIP and the work I was doing, specifically, the strategy of reaching out and attempting to establish corporate relationships. When I finish my explanation, the executive director informs us that BigCorp is a large employer in their county and that during the month of May they offer free mammograms to their employees. EGC is excited and tells me that we need to contact them. She informs the two women that this corporation could be our first partner – a model for other companies to observe and hopefully emulate.

This discovery moment was significant in several ways. First, it demonstrated that grant site visits provide more than just face-to-face interaction. It is instead a collaborative moment in which EGC can gather information as to what is going on in the community; and further, enlist the help of the grantees to help with components of the CIP. Second, it reflected EGC’s value of collaborative work and how it is crucial to the success of the CIP. Third, it brought forth the importance of discussing community impact with a grantee. EGC informed me that grant site visits were primarily used as a
means to check up on an organization; however, because of the development of the CIP, community impact had been brought to the forefront of everything EGC was doing. These findings emphasize what was first described in the beginning section of this study: that the CIP acts as a catalyst for community impact. Without the development of the CIP, it is likely that the discovery of this company would have never happened.

*Grantee Creating a Partnership – An Amish Relationship*

We arrive at one of the hospital grantees, located in a small, rural county and approximately an hour from Komen’s office. The hospital is nice, small and almost seems out of place in the midst of the run-down town. At the start of the visit, we are given a tour of the facility in which Komen dollars are being used by the foundation president of the hospital (it is unclear whether he has any healthcare background), Brian, and a nurse navigator, Shelly. After the tour, we are brought to a conference room for a discussion about any problems they are having. The foundation president prior to Brian had recently retired, and EGC was curious how the transition was taking place. Brian informed EGC that everything was going smoothly, and he could not think of any problems regarding the transition that they needed to discuss. EGC informed me that the hospital was close to an Amish population, a population that she was concerned about reaching. One of EGC’s first questions was, “Tell me about how you are working the Amish population? I understand that you guys are playing basketball with them” (Appendix B)?

Brian replied, “It was actually the person before me who played basketball with the Amish father, but we still maintain contact with them” (Appendix B).
EGC asked whether they had noticed a difference in Amish seeking clinical breast exams, and Shelly informs EGC that one woman came in to get her mammogram. EGC seems excited and asks Shelly whether she thinks the woman would be willing to have Komen to do an article about her. Shelly replied, “I feel conflicted doing a story when they’re so private. I don’t want to turn them off” (Appendix B).

EGC said, “I understand. Feel her out and we’ll go from there. The fact that you’re building these relationships is great – just share the information and demonstrate the need.” The foundation president then turns to the nurse and says, “Ask _____ to take me there, and we can continue building that relationship” (Appendix B).

I observed the foundation president take a more active interest in the Amish population after seeing EGC’s excitement over the one Amish woman visiting the hospital. EGC’s active interest in this community encouraged the president to continue maintaining the Amish relationship; thus allowing Komen to maintain this relationship as well.

**A Problem with a Grantee – Show Me the Data**

The occurrence of EGC having a problem with a grantee was few and far between. However, there was one particular site visit that EGC warned me that she was not thrilled with the new program director’s efforts and did not feel they were spending their money wisely. This was unfortunate, EGC explained, because this grantee was addressing one of their target populations: African-American women. Therefore, EGC said she would have an extremely difficult time letting the grantee go, and she did not think they could afford to do so. On the way to the site visit (which was located
downtown in a seven-story, office building) EGC stated, “They [the nonprofit organization] record how they are spending money on visit reminders through the mail, but I don’t know if that’s really working. They don’t have the numbers to show me that it is” (Appendix B). She went on to say that she did not think they were really investigating the best methods to engage African-American women. EGC ended our conversation in the car by stating that she was not looking forward to this visit.

Inside, we went to the fourth floor and were told to wait for the program director. The office building was old and musty, but the organization seemed to have a significant amount of office space with one conference room, a reception office, and at least two other offices that I noted. We waited for at least five minutes and EGC started to become irritated. The program director, Pam, greeted us and told us that the conference room was not quite ready, but that we could start the visit by talking with Angela, one of their employees, in her office (Appendix B).

Angela was the only Hispanic woman, as the rest of the employees were African American, and her job was to call women and remind them of their appointments, as well as send reminders via the mail, and maintain records. Angela’s English was not at a high level, and during our brief meeting with her, she was often confused as to what EGC was asking her.

EGC seemed annoyed that the meeting was not starting with Pam, but was interested in seeing the records being kept on the women. Angela walked EGC through her routine, and EGC asked Angela if she was keeping records on whether the woman had already had a mammogram, their age, etc. Angela said she had not, but that she could
make a new entry in her form. EGC became increasingly annoyed and stated to Angela that she had already requested this data be kept on record and did not understand why it had not been implemented within their record tracking system. Angela nodded her head.

The program director came into Angela’s office and announced that the conference room was ready. Angela sat next to me, and next to Angel were two employees, the external advisor (Trisha, who had retired from project director), and Pam. EGC, excited to see Trisha, quickly exchanged greetings and asked Trisha what projects she was working on. Trisha told EGC that she was working on a project to get rural women access to health care. EGC said, “I really want to talk to you about … what prompted you to do this” (Appendix B). Trisha said that it was a target population that she has wanted to help for quite some time. She explains that right now she has lay health advisors speaking with these women in rural areas. EGC asks, “How do you ensure that these lay health advisors aren’t giving medical advice” (Appendix B)?

Trisha nods her head and explains that Pam conducts site visits as well as a training workshop for these advisors. EGC seems satisfied and directs her attention to Pam, asking her, “Talk to me about follow-ups. I need to see the measureables and getting that data” (Appendix B). Pam discusses their record keeping and tells Angela to take notes on the information they need to keep on record and send to EGC.

EGC then asks a question that I had not heard her ask at a single, site visit, “What does a day look like for you” (Appendix B)? (This question becomes clear when we are driving back to the Komen office and EGC states that she does not understand what Pam does with so many employees under her and with little data to justify her extensive staff).
Pam begins to explain her day, but shifts to what the entire program is doing. In front of us on the table, there was a small binding of papers that outlined their program. This was the first time a grantee had done this, and the presentation was professional. EGC thumbed her way quickly through the package and did not seem impressed by this gesture.

Towards the end of the meeting, EGC explains the problem she is having with gaps in the data for African-American women and asks, “What is your perspective/feedback? And we’re doing some town forums and would love your partnership” (Appendix B). Pam nods her head and tells EGC that she will ask her nurses about the data as well as assisting the forums.

EGC ends the meeting asking if there is anything she can do and Pam tells her that they will talk later. In the car on the way back to Komen, EGC tells me how she is disappointed in the organization because of their potential to make an impact; however, currently, she does not feel that they are. She tells me that she will visit them more often in order to keep track and determine if progress is being made. This story will be analyzed further in chapter 5.

**A Grantee Problem – Should the Grantee Partner?**

A meeting with a grantee was scheduled last minute because of a grantee concern about a partnership with another hospital. The grantee explained to EGC that another program director from a hospital had approached her with a potential collaboration. The grantee looked over the proposal and did not see the link between her hospital and theirs, and for the most part, felt that the other hospital was looking for a place to dump their
nursing students. Additionally, the data the other hospital supplied did not match up with what the grantee had been observing in her own hospital, which led her to believe that the other person was trying to force a partnership (Appendix B).

The grantee told EGC that she knew that collaboration and networking were a vital component to their program; however, she was weary partnering with this particular person because of the program director’s personality, as well as her methods of gathering data. Furthermore, the other person (who initiated the potential partnership) had demanded records of the grantee that the grantee was not comfortable giving. EGC advised the grantee that if the partnership did not make sense, and did not enhance the current program, then she should not do it. EGC explained that although she is a proponent for collaboration, there is a time and place, and if you are not comfortable with your partner, you should not force the partnership. The grantee agreed and said she would look over the proposal again and decide. Although this was a fairly short meeting, it was significant because it demonstrated that nonprofits have to be selective in their collaborative partnerships (Appendix B).

These stories offer a window in the variety of partners and relationships Komen Midwest maintains and builds in or to create community impact, how EGC interacts with her partners, as well as EGC’s and Komen Midwest’s values concerning partnership criteria and measurable. The following chapter will examine these stories through the lens of Bourdieu’s social capital theory, Burke’s rhetorical identification theory, as well as the global communication concept of localization.
CHAPTER FIVE

DISCUSSION

Taking a leaf out of Thompson and Rothschild’s *Stories of Three Editors*, Chapters Three and Four offers a compilation of stories that help compose a window into the developmental process of a community impact program (CIP). Indeed, each story brings forth strategies that EGC implemented, details how partnerships were created, as well as maintained, highlights networking and collaborative moments, and explains how and where communication took place during the stages of the CIP. Similar to Thompson and Rothschild walking through how editors revise a piece of work, the affiliate stories provide a window into the ways that EGC creates community impact, the CIP being only a component of this effort.

Falling between the local/emergent and the elite/a-priori axis within Deetz’s “Contrasting Dimensions from the Metatheory of Representational Practices” diagram (11), the findings of this study are guided by Bourdieu’s social capital theory, as well as Burke’s identification theory; and thus, subsequently, the stories detailed in Chapter 3 are analyzed by determining how social capital was maintained, or accrued, with each encounter, as well as the role of identification between EGC and the participants (the guiding question being: How did EGC help facilitate this identification?). In addition to social capital and identification theory, I also describe the role of the global communication concept: localization. This chapter is organized by the five themes that emerged from analysis: Accommodating the Board, Not All Partnerships are Valuable,
Common Ground Strategy, Social Capital through Partnerships, and Localization through Partnerships.

**Theme One: Accommodating the Board**

*Accommodating the Board – We Need Measurables*

This story opened up Chapter Four and thus will open up Chapter Five as well, because the value of accommodating the board is demonstrated in almost every EGC-Participant interaction. EGC focused on collecting data in order to demonstrate the need. The reasoning behind this attention to data collection was twofold: First, the demonstration of need was used by EGC to justify her actions within a community. Second, quantifying the need allowed EGC to measure her progress, thus accommodating the board’s demands of measurable objectives.

As described in Chapter Four, an instance of EGC focusing on measurables is seen in how she interacted with grantees by asking for their data/records on the women they were serving and demanding that they keep an updated records system. Because measurables were a value to the board, they became a value for EGC, which thereby resulted in the grantees valuing measurables; and thus, a framework of Burke’s concept of consubstantiality is demonstrated. The espousal of values strengthened the connection between the partners and resulted in the individual organizations feeling united by one identity.
Theme Two: Not All Partnerships are Valuable

**Appropriate Relationships – Can Hooters be a Partner?**

The Hooters and KFC story developed into two highlighted moments: general, financial partnerships for Komen and partnerships for the CIP based on assumed relationships. This story took place during a staff meeting; thus, the participants in this encounter consisted of EGC, ED, CD, FD, and AA. CD initiated the discussion of the Hooters partnership with the intent on gaining a new, prospective partnership that had been overlooked in the past. For CD, Hooters was a logical partnership because the corporation had already implemented a “Save the Ta-Tas” fundraiser; therefore, CD’s thinking was: Komen should get a piece of the action, in other words, have access to part of the monetary funds collected. Thus, the collective capital would involve both economic as well as social. Clearly, Komen would benefit from the collective, economic capital, while Hooters would primarily benefit from sharing the social capital, although one could assume that economic capital would increase by Hooters including the name Susan G. Komen in their fundraiser.

It is this shared social capital in which ED announced her negative opinion of the partnership. For ED, the collective social capital, and thus the collective shared values, do not align with the affiliate and would result in the public questioning their values. The open discussion of corporations misusing their brand/logo, as well as ED’s concerns, echoes Plastrik’s area of tension: identity expansion causing a loss of control of the organization’s identity. Further, it demonstrates how social ties reinforce identity and public recognition (Lin 41). This also relates to Burke’s concept of consubstantiality, in
which two individual units are viewed as one and the same. For the public, the (potential) transformation of Komen’s identification, then, is catalyzed by the association of Hooters to the affiliate.

The KFC example that ED offers demonstrates how a nonprofit’s social capital can become damaged from an “inappropriate” partnership; that is, a partner whose values are so far off the spectrum that it results in the public’s confusion of the values of the initiator of the partnership, in this case, Susan G. Komen. Because of Komen consistently promoting a healthier lifestyle, e.g., Race for the Cure and Yoplait yogurt, the partnership with KFC was confusing to the public and resulted in them questioning the values of Komen by asking: Does Komen truly care about the health of women? Again, the public’s questioning is a result of consubstantiality, which then relates to social capital and how these two organizations now share the same values. ED’s example encourages staff members to come to the following conclusion: Yes, Komen must be concerned with how to increase their monetary funds; however, the affiliate has to choose appropriate partnerships in order to avoid risking their reputation, i.e., their identity. The cost of damaging their identity outweighs any gain in monetary assets.

**Assumed Relationships – Let’s Look for Contact Resources**

The story, Assumed Relationships, is based on the continued discussion after the decision about the Hooters partnership was made. The conversation led into potential partners for the CIP. Immediately, staff members advised me to look at Race for the Cure team captains as a place to start gathering prospective partners. Here, Lin’s model, A
Theory of Social Capital, comes into play with the three divisions: precursors, social capital elements (network and resources) and possible returns (41).

**Figure 4: Model of Social Capital with Team Captains**

Because of the conclusion from the Hooters and KFC discussion, Figure 4 illustrates that the employees retracted to a “safer place” for gathering possible partnerships. The precursor/determining factor for a safe partnership became individuals/organizations previously involved with Komen, e.g., Race for the Cure Team Captains. Not only is this selection logical; but further, it demonstrates the affiliate having a concern for finding “appropriate” partnerships, not just partnerships that would guarantee some kind of increase in their monetary funds.

*A Grantee Problem – Should the Grantee Partner?*

The story, A Grantee Problem, involved a grantee, EGC, myself and was scheduled because a grantee had a concern about a partnership with another hospital. Although this story was brief, it did highlight a moment in which EGC did not endorse
collaboration; but rather emphasized that organizations need to be selected with whom they partner with and that not all relationships are beneficial. This relates back to the previous story in which ED discouraged the partnership with Hooters. Thus, it is evident that the same standards Komen holds for their partnerships apply to their partners as well as; thus further illustrating the nature of collective assets within Bourdiue’s social capital framework, because if an inappropriate partnership hurts a Komen Midwest partner, this results in the inappropriate partnership hurting Komen Midwest.

**Theme Three: Common Ground Strategy**

*The Funders Forum – Who is our African American Representative?*

The Funders Forum: Who is our African American Representative? Story took place at the Komen office and involved 20 representatives from Komen affiliates based in three states, including the affiliate’s state location, as well as EGC, the creator of the advocate group, CD and ED. The goal of this meeting is for EGC to understand problems that affiliates are addressing, tactics that affiliates use that EGC may consider implementing herself, and extending her network.

EGC devoted a portion of the meeting for members to present their community profile, a two-year needs assessment demanded by Komen Headquarters that gives a synopsis of the breast health in an affiliate’s service area. This highlights how EGC facilitates the identity of the organization. First, the completion of the community profile, a two year process, is a momentous accomplishment for all affiliates; and therefore, is a moment in which EGC employs the common ground strategy, specifically recognizing individual contributions (Cheney 151). Giving praise to member’s work allows EGC to
encourage members to recognize shared values, which is already taking place with the
gathering of these affiliate representatives. The recognition of values, then, follows this
pattern: Komen Headquarters’ value \(\rightarrow\) EGC value \(\rightarrow\) Funder Forum value. As
demonstrated, this clearly relates to Burke’s concept of consubstantiality.

Although it may seem evident that of course all Komen affiliates share the same
values, this is not always the case. For instance, EGC had mentioned that many affiliates
did not have their community profile approved, revealing to EGC that affiliates were not
taking the proper time and care to accurately determine the breast health need in a
community. Thus, EGC’s devoting time to highlight the community profiles reflects her
value of this needs assessment; and thus convinces members to share this value.

Further, by EGC taking the time to ensure that each representative has an
opportunity to share their findings, relates to another sub-tactic of the common ground
strategy: expression of concern for the individual (Cheney150). This strategy encourages
members to feel that their findings are of value; and therefore, convinces them that they
are an integral component of the group. As an essential member of the group, affiliates
feel a stronger connection to the group, resulting in EGC successfully facilitating the
identification of the Founders Forum.

**Grantee Offering a Corporate Partnership – BigCorp as a CIP Partner Model**

This story took place during a grantee site visit at a health clinic located in a
small, rural county, approximately forty minutes from the affiliate’s office. The
participants included the program director, Lauren, a nurse navigator, Katie, EGC and
me. The site visits offer gains for both parties. On EGC’s end, the grantee offers her a
window into that county: their needs and what is occurring in that community. An instance of this window opportunity happened at the beginning of the site visit when Lauren details the economic climate of the county. EGC can evaluate the progress of the program and determine whether the allocation of Komen dollars is necessary to certain aspects of the program. EGC also secures face-to-face time with the grantee, and she has stated that this is a crucial component in maintaining her relationships with her partners. On the grantee’s end, the visit provides the organization to show their progress and justify their funding, address problems such as needing more funding for certain areas of the program and discuss upcoming events in hopes that EGC will be able to take a part.

The progression of the meeting revealed EGC relying once on the identification strategy: common ground. For instance, Lauren’s problem of women refusing to participate in events similar to the Race for the Cure EGC handles by claiming that this is a frequent problem that many organizations, including their own, have to address (Appendix B). Lauren takes comfort in knowing that this is a shared burden, and as a result, EGC facilitates the identification and strengthens the relationship between the two organizations. Further, EGC employs the common ground strategy, specifically the tactic category of expression of concern for the individual, by instructing me to inform the women of the new approach of establishing partnerships with corporations in order to not only keep them informed of Komen’s progress in the area of mission, but to also seek their input. EGC seeking Lauren and Katie’s input encourages them to consider themselves as integral components to the CIP, and thus the Komen organization, hence the desired result of this tactic category of the common ground strategy.
Grantee Establishing a Partnership – An Amish Relationship

The Amish story occurred during a grantee site visit at a hospital, in a small, rural county approximately an hour from the affiliate’s office. The participants included the foundation president of the hospital, Brian, a nurse navigator, Shelly, EGC and me. EGC initiated the discussion by highlighting one of hospital’s accomplishments: a partnership with the Amish community; and consequently, EGC employs the tactic of the common ground strategy – recognition of individual contribution. I observed the foundation president take a more active interest in the Amish population after seeing EGC’s excitement over the one Amish woman visiting the hospital (Appendix B); and accordingly, this tactic achieves its goal of convincing the agent (the foundational president) to continue the action that resulted in EGC’s praise. Because of EGC’s facilitation of this identification, which results in the hospital and the affiliate being substantially “one,” EGC encouraging the president to maintain the Amish relationship results in the affiliate maintaining this relationship as well. The implementation of this strategy reaffirms the shared values between the hospital’s program and Komen, and thus strengthens the connection between the two organizations. This outcome only occurs because of the affiliate’s and hospital’s values merging as one, or in Burke’s terms: consubstantiality. If the partnership is a value for EGC, then it becomes a value for the hospital.

Disparity Meeting – Agenda Accomplished

EGC created the disparity group in order to offer more opportunities for organizations and individuals to collaborate and network. The participants involved in
this particular meeting were the guest speaker, Gary, an oncologist, program directors of nonprofits, nurse navigators, as well as other nonprofit representatives. With a group consisting of diverse individuals, in terms of job affiliation, the role of identification is a significant, contributing factor in establishing the unity between group members. Gary’s opening comments that he had successfully “pushed their agenda” reflects the group’s shared values and objectives with Gary’s involvement in the group resulting in the group’s agenda becoming his agenda. Gary’s description of the evening mammogram program allowed the group to visibly comprehend the impact they had created, thus establishing a moment in which their contribution is recognized – a tactic category of the common ground strategy and convinces group members to continue with their actions.

The case study portion of the meeting further reflects how the group is substantially “one” with the notion of: your problem is our problem, and promotes the united identity of the group. Further, it opens the floor to input from all group members to collaborate and contribute to the solution of the problem; therefore encouraging members to perceive themselves as integral components of the disparity group, and thus this segment that EGC implemented within the meeting becomes a common ground strategy: expression of concern for the individual (Cheney 151). Finally, the case studies also offer EGC a window into the needs of particular, target communities that she would not otherwise know. Therefore, because of EGC’s efforts to network and build her relationships, thereby building her social capital, EGC can adapt, or localize her approach within each community.
Incentive Meeting – EGC and ED Interaction

As will be demonstrated in the analysis of this story, EGC’s use of common ground strategy also functions as means of approaching an organization and convincing them to become a partner. The incentive meeting took place in the affiliate conference room and involved ED, CD, EGC and me. The goal of this meeting was to brainstorm different incentives to offer corporations in order to convince them to partner with the affiliate; but additionally, allow ED to observe the progress of the CIP and attain her approval for the incentives. CD was included with her experience in third party fundraisers, as well as her communication experience.

EGC informed ED and CD that the first corporation had been selected because already had in place a wellness program that allowed all of their female employees to get a free mammogram during work hours in the month of May. EGC explained that she wanted to establish this company as the first partnership in order to offer them as a model to other companies and would approach the company by commending them on their efforts. Thus, EGC’s first strategy in approaching this organization is through the common ground strategy: recognition of individual contributions (Cheney 151). From here, EGC would continue with the common ground approach and transition into the espousal of values by stating to the employer: You care about your employees, therefore Komen cares about your employees, thus adopting their values (Cheney 151). One of the incentives was promotion of the partnership and the employer’s efforts to help with the breast health movement via newspapers, thus resulting in EGC implementing yet another tactic category of the common ground strategy – praise by outsiders. The public
applauding their efforts further solidifies their partnership and the identity that they now share together.

EGC also informed ED and CD about the “toolkit” she would take when she met with corporations. The toolkit consisted of individual information of the county that the corporation was located, as well as information about the affiliation and fundamental, breast cancer information (Field Notes 34). The goal of the toolkit was twofold: first, demonstrate the need within their community. Second, EGC demonstrates due diligence by showing the company that Komen had taken the time and interest to examine the particular needs of their community. This relates to the common ground, category tactic: expression of concern for the individual (Cheney 51), except in this case the company is treated as an individual unit. Further, EGC demonstrating to the corporation that she had identified community’s needs, establishes the nonprofit's goodwill towards the community by demonstrating to the public their genuine care and interest in the community's wellbeing, thus establishing them as a credible nonprofit that can be trusted. This builds social capital by the community trusting the nonprofit and building a relationship with them via using their services, supporting their mission, and even becoming a part of the organization through volunteering; and thus, again, increasing the recognition of the nonprofit’s values and/or cause. This increases their network, which thereby increases their social capital (51).

**A Problem with a Grantee – Show Me the Data**

As stated in Chapter 4, EGC rarely had an issue with a grantee; however, the analysis of the Problem Grantee story will highlight how EGC’s approach to the
organization alters when her expectations are not met. I did not observe this difference in approach until I applied Burke’s identification theory and compared my findings to my findings of EGC’s other encounters with partners. Thus, although this story is about a moment in which EGC did not implement common ground theory, it is still a critical moment that must be highlighted to further understand how and why EGC uses the common ground strategy.

The meeting involved the following participants: Angela, a records keeper, Pam, the program director, Trisha, the previous program director and currently the external advisor, and two other employees whose positions were not defined. Our encounter with Angela revealed that the organization had not been tracking the number of mammograms a woman had received, or not received, before coming to grantee’s program. For EGC, the data collected is a means of demonstrating the need; but further, it also provides a window in the needs of a target population. Thus, with this lack of information, the grantee was failing on producing the gains necessary for the partnership to sustain itself as the “collective assets” were limited to EGC.

I observed the meeting having an “us versus them” tone, as EGC continuously asked “offense” questions concerned with the progress of their program, and the grantee responded from a “defense position” in order to justify the organization’s actions, or lack of action in this particular case. Over the course of the meeting, EGC did not implement a single identification strategy. The meeting had the feeling of: What are you (the grantee) doing?, rather than a united front of: How can we improve what is happening in this
community? This demonstrates the disjointedness of their relationship and how the two organizations were failing to share the same values/objectives.

**Email: Setting up a Meeting with BigCorp**

After the incentive meeting, EGC sent an email to the President and Vice President of BigCorp requesting a meeting. The email was divided into three, long paragraphs. The first paragraph EGC recognizes the efforts of BigCorp and their health initiative with their employees, thus implementing the common ground strategy: recognition of individual contribution. EGC also describes the work of Komen Midwest’s two year needs assessment, which establishes Komen Midwest’s goodwill towards BigCorp by demonstrating their genuine care and interest in the community's wellbeing, thus establishing them as a credible nonprofit that can be trusted. This encourages the building of social capital by BigCorp trusting the nonprofit and building a relationship with them via supporting their mission and hosting a Lunch Learn, and thus, again, increasing the recognition of Komen Midwest’s values and cause (Bourdieu 51).

In the second paragraph, EGC describes the findings of the two year needs assessment, the community profile, detailing that many women do not get mammograms because of their job and fearing loss of employment and/or decrease in pay. She continues, “As a result, we are currently developing a program in which we reach out to corporations and promote a wellness program that allows women to do and get a mammogram during work hours without receiving any job related consequences…” Here, EGC successfully aligns Komen Midwest’s values with BigCorp’s values, as BigCorp has already implemented a program similar to the one EGC describes. Thus,
EGC communicates with BigCorp the same way as she does with her current partners: Your values are our values; thus, a use of common ground strategy (Cheney 151). This creates a strong, logical appeal in which EGC promotes the idea that BigCorp and Komen Midwest are practically partners with their espousal of values.

The third, and final paragraph EGC states, “Because of your initiative, we would like to recognize you and hold you as a model for other corporations to observe and hopefully emulate”; thus, again, recognizing their accomplishments and employing the common ground strategy, thereby encouraging BigCorp to continue their actions that received Komen’s praise. Further, EGC treats BigCorp as an expert through not only describing that they will be held as model for other corporations, but also by stating that she would like to “discuss your wellness program that you currently have in place, what has worked and hasn’t worked, and discuss possible ways in which we can recognize your efforts” (Appendix C). EGC seeking BigCorp’s input encourages them to consider themselves as integral components to Komen Midwest’s mission, and thus the Komen organization, hence the desired result of this tactic category of the common ground strategy.

**PowerPoint Presentation: Given at Lunch and Learns**

Prior to the start of my internship, EGC created a presentation titled: BC101 (date of the creation of the PowerPoint is unknown) and gave this presentation at Lunch Learns. The PowerPoint included 31 slides and consisted of the following format: Komen information (seven slides) → Breast Cancer information/education (18 slides) → diagnosis and treatment options (three slides) → how to get involved and additional
resources (two slides). The primary strategy EGC used to facilitate a partnership between her audience and Komen Midwest is observed within the first seven slides. Even in the original slide deck, EGC establishes the goodwill of Komen and demonstrates how they raise their money, how they spend their money, and which grantees were awarded Komen funding, as illustrated in Figure 5 (Appendix C).

**Figure 5: Slide Thumbnail of Komen Midwest’s Use of Funds**

EGC appeals to the ethos of Komen, thus encouraging the target audience to trust the information in the following slides, as well as trust Komen as an organization.

In the middle of my internship, EGC asked me to revise the presentation, stating that she did not feel that it was succeeding in motivating women to go and get a mammogram; but rather, the presentation was simply a list of slides filled with breast cancer information, and therefore, not entirely persuasive for her audience. This reflects EGC’s belief that the presentation lacked such strategies. She instructed me to make the following revisions: incorporate a slide devoted to the mortality rate within eight counties, as well as the percentage of women who had not received a mammogram in the last twelve months in the same eight counties; incorporate slides that address reasons as
to why women do not get a mammogram (based on the findings in the community profile); and a section towards the end of the presentation that was devoted to how the women could assist in not only improving their breast health, but also helping Komen’s mission.

EGC’s first revision allows her to demonstrate the need within the target audience’s community. Further, EGC demonstrates due diligence by showing the audience that Komen had taken the time and interest to examine the particular needs of their community. This relates to the common ground, category tactic: expression of concern for the individual (Cheney 51), where EGC communicates to her audience that they are a priority and deserve Komen Midwest’s focus and attention. The facilitation of identification is twofold: first, EGC convinces her audience that if Komen Midwest cares significantly about their breast health, then so should they. Indeed, a direct appeal to logos also functions as another use of common ground strategy: espousal of values, as EGC develops a partnership and a shared identity between herself and her audience (Cheney 151). Additionally, the demonstration of need within the individual counties establishes the nonprofit’s goodwill towards the community by demonstrating to the public their genuine care and interest in the community's wellbeing, thus establishing them as a credible nonprofit that can be trusted.

EGC’s second revision relates to the common ground strategy, expression of concern for the individual, and this is illustrated in each slide addressing a reason women give for not getting a mammogram. For instance, one slide states: “I don’t have the time to get screened,” and then presents a brief argument to convince women that time should
not be an excuse. This encourages the audience to feel that EGC knows their priorities, as well as their barriers; and therefore, they feel as if they are a priority and are of significant value to Komen Midwest, rather than a statistic number. This builds off of the trust established in the previous slides, thus strengthening the connection between the audience and Komen Midwest. EGC continues to facilitate identification with the remaining slides.

EGC’s third revision was a slide that read: How you can help increase resources and help end breast cancer forever. Following this slide was a range of information from early detection plans to different fundraising ideas, as well as how much $100 supports towards breast health services. Here, EGC treats her audience as an integral component in creating impact in their community by making a call to action. This solidifies the partnership as EGC concludes her presentation with her audience joining her mission. Thus, EGC’s priorities become the audience’s priorities, creating an espousal of values that EGC hopes results in women seeking breast health services. Clearly, these revisions align with the identification strategies outlined with EGC’s face-to-face meetings with her grantees and potential corporate partners as well.

**Theme Four: Social Capital through Partnerships**

*Incentive Meeting – Interaction between EGC and ED*

EGC started the incentive meeting by stating that the purpose of the corporate partnerships for the CIP was to extend their network in order to increase the number of women educated in breast health, rather than the common goal being to partner with a corporation in order to increase monetary funds. EGC did state that the an increase in
donations could occur, but that this would happen as a result of the revised, or newly developed, wellness program, as well as the Lunch and Learn. Here, EGC is focusing on building the affiliate’s social capital (her network) and increasing public recognition. The public will see these partnerships, whether through the newspaper or viewing a plaque in the corporate office, and will encourage the public to see Komen’s mission, rather than their exposure only consisting of the Race for the Cure (a concern that EGC voiced wanted to combat). This directly correlates with EGC facilitating the identity of Komen within her service area by concentrating on the visibility of Komen’s mission.

Grantee Establishing a Partnership with a Target Population – An Amish Relationship

The Amish story revealed that the accrual of social capital was a direct result EGC promoting the idea that the hospital’s partners are Komen’s partners, relating to the affiliate’s and the hospital’s “collective assets”; and therefore, when the hospital gains a partnership, it results in the affiliate gaining a partnership, thus extending the affiliate’s network, and therefore increasing Komen’s social capital.

Bourdieu’s framework of social capital is clearly demonstrated: with each connection/partnership that is created, a new one can be formed; thus increasing the social capital; and further, highlighting the “collective social capital” nature of partnerships with organizations. As emphasized by Lin, these partnerships must be maintained in order for social capital to continue to persist and accrue. EGC frequently stated the importance of maintaining these relationships and claimed that a key component of maintenance is face-to-face time. This commitment not only maintained
EGC’s relationship with the grantee, but it also resulted in retaining the Amish relationship.

*The Funders Forum – Who is our African American Representative?*

The establishment of the Funders Forum group expands Komen Midwest’s network, thereby increasing their resources, i.e., affiliate contacts, events developed by other affiliates that are shared during the meeting (offering an opportunity for Komen Midwest to emulate), and ideas suggested to address problems happening within target populations; thus, Komen increases their social capital. Additionally, the partnership with the other affiliates encourages the “continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed (Bourdieu 51-2) and thus reaffirms the affiliate’s identity.

Using Lin’s model, Figure 6 outlines the flow of social capital with the partnerships with the other affiliates.

*Figure 6: Model of Social Capital with Komen Representatives*
As the other stories highlight, mobilization took place when EGC reached out and established the group, thus extending her network. The returns can be illustrated in a moment when Lisa, a Funders Forum member, detailed the success of their Volley for the Cure fundraiser, additionally describing the process of developing this event, which then allows other affiliates to take this idea and implement it within their own service area, thus resulting in affiliates potentially increasing their monetary funds.

**Data Coordinating Meeting – Let’s Use Infographics**

The Data Coordinating Committee meeting took place downtown in the state department building. The committee members at this meeting consisted of state department epidemiologists, director of the Midwest State Cancer Registry, comprehensive cancer control coordinator, and research coordinators, as young male, Kevin, possibly an intern and responsible for updating the web site and assisting with the presentation of cancer data to the public. EGC had two purposes for being a member of this coalition: networking and informing the committee of the lack of breast cancer data concerning African-American women.

Although EGC’s role was minor during this meeting, this encounter demonstrates breaking the boundaries of the precursor for establishing partnerships: an association with Susan G. Komen (as outlined in previous stories); and instead, developing relationships with advocate groups that have an interest, disregarding the extent, with breast health and breast cancer in the affiliate’s service area. Indeed, this is a significantly broader category; however, as EGC points out, all of these group members are still working towards similar goals: helping diminish the breast cancer rate. Thus, this is yet another
moment of EGC expanding her network, and consequently, increasing the affiliate’s social capital.

**Email: Year Round Partners**

ED forwarded an email to EGC that detailed a discussion thread concerning corporate partners for affiliates. The initiator of the email was from an executive director of a Nebraska Affiliate and sent this email to a Komen affiliate, executive director list serve. The Nebraska executive director asked, “Does anyone have an Affiliate Sponsor level for companies that support the Affiliate year-round?” An executive director from a North Carolina affiliate responded and described a “Partner” status (a year-round partner) program in which a corporation receives this status by sponsoring two major events, as well as doing one substantial mission activity. A mission activity, the executive director explained, could include: “public education campaigns for customers (good for retail), employee education campaigns that go beyond the basics (example: a factory gave an extra day off for employees who used it to get mammograms), and hosting an event for service providers.” ED then forwarded this email to EGC and me and said, “Please read about NC’s year-round partner program and what they include in it for mission activities. I think this might be awesome for the community outreach plan” (Appendix C).

The Year-Round Partner email is significant in a number of ways. First, this email was forwarded to EGC July 14\textsuperscript{th}, less than ten days after the incentive meeting. Therefore, this moment becomes similar to the discovery moment of BigCorp. Because of the focus on the CIP, and EGC collaborating with ED and including her in the discussion of incentives, ED receives this email, and with community impact at the forefront of her
mind, forwards this email to EGC. Thus, again, the CIP acts as a catalyst for community impact; without the CIP, ED might not have given as much attention to the email; and further, send it to EGC.

Second, this is the only email I had access to that demonstrates ED’s interaction with EGC via email. Although the message is brief, it does reveal a lack of any implementation of identification strategy. ED’s message reflects a “command tone” with the use of “Please read” and “I think.” ED does not ask EGC’s thoughts on this program, as this move would have incorporated common ground and encouraged EGC to believe that her opinions were important; and therefore, that she has a vital role in the decisions made concerning the CIP.

Finally, the email thread reveals the role of social capital in creating community impact. The list serve allows for executive directors to easily contact each other, seek advice, input; and therefore, offers an easy avenue for them to maintain their relationships with each other. The network of affiliate directors, then, provides opportunity for accrual of social capital by executive directors describing events/programs that they have implemented successfully; and therefore, allow other executive directors, such as ED, to emulate and use for their own affiliate. Here, an exchange of resources occurs; and thus, social capital is gained.

**Theme Five: Localization through Partnerships**

*Incentive Meeting – EGC and EGC Interaction*

The “toolkit” described previously in the Theme Four additionally relates to the concept of localization. EGC frequently stated how she did not want to walk into a
community and be viewed as the “expert.” For EGC, the title, expert, could be associated with her knowledge of breast health and breast cancer, but that this could not transfer over to her being an expert of a community. EGC viewed her connections with her service counties, whether a grantee or a corporate partner, as a window into that community. In other words, EGC approached her community partners as experts, asking them: what is happening in your community, tell me what you need, and how I can help. Accordingly, EGC treated the corporate partner as a co-developer in the CIP, and localization becomes inherent in the developmental process because the “user,” in this case the corporation, naturally adapts the CIP to fit their context (Sun 458).

**Grantee Offering a Corporate Partnership – BigCorp as a CIP Partner Model**

During the site visit, Lauren, the program director, describes how they advertise their services via Wal-Mart, the Farmer’s Market, and the post office, which reveals how their approach is tailored for a small, rural, farming community, as these are the places with the most traffic. Here, the role of localization is significant because Lauren’s advertisement approach is specifically designed not only for her community, but her available resources also influence her advertising strategy. Grantees located in more populated counties discussed marketing their services through their web site, newspapers, radio, etc. Here, it is evident that the differences in approach are based on the county’s economic climate and demographics, in other words, the cultural context.

As detailed previously in the Common Ground Strategy theme, Komen partnering with the grantee results in consubstantiality occurring, with the identities of both organizations merging as one; and consequently, the espousal of values takes place. Thus,
the actions of the grantee, which are actions directly related to localizing a value to fit their cultural context, become the actions of Komen. The grantee becomes a co-designer of the CIP, naturally adjusting the CIP to adapt to their community needs (Sun 458).

Data Coordinating Meeting – Let’s Use Infographics

Towards the end of the meeting, Kevin, possibly an intern and responsible for updating the web site and assisting with the presentation of cancer data to the public, introduced his Prezi presentation, “Information is Beautiful,” with the purpose of illustrating to the committee the various approaches in which the State Health Department could present cancer data to the public. Kevin offers the use of infographics as one of the strategies to help convince an audience to understand cancer data, and therefore, take action in terms of getting a mammogram, physical, etc. His example of describing how many times the Midwest [NFL] Stadium would be filled with the rate of breast cancer diagnosis in their state directly relates to the concept of localization. By taking a monument that is culturally pertinent to the people of “Midwest State”, Kevin adapts the delivery of cancer information to fit the culture, thereby increasing the likelihood of the cancer data making an impact and potentially resulting in people taking action to combat the cancer statistics, and thus successfully localizing a value within a culture.

EGC not only states that she would like to implement infographics within her own presentation that she gives during Lunch and Learns, but is also interested in updating her PowerPoint to a Prezi. Immediately following the Data Coordinating Committee meeting, EGC goes to her office and beings learning the basics of Prezi, as she had never heard of
this software before this meeting. EGC’s actions reflect the collective capital nature of her relationship with the data committee, and because of this partnership, she is able to gain new resources; and further, improve her presentation by focusing on localizing the information to adapt to the affiliate’s particular, target population.

**The Funders Forum – Who is our African American Representative?**

During the Funders Forum meeting, a discussion took place about how Komen should reach out to the African-American community. For starters, it is an interesting moment in which a group of all-white women discuss the best approach to convince a population of African-Americans to seek breast health services. The idea of finding the best, African-American ambassador for this movement, then, becomes the group of women selecting the most “ideal” candidates. “Ideal” is unclear, as one member considers it to be “smart” (doctors, lawyers, etc.), while EGC counters that a smart, newscaster is not relatable; and therefore, is not an ideal ambassador. Again, we are left asking: What is relatable and how is EGC determining this?

However, what is evident in EGC’s response is her facilitating the identity of the affiliate to the public. EGC’s comment that using a polished newscaster to be an ambassador for the movement would not work because she would not be relatable to the community relates to Burke’s consubstantiality, because if the women cannot relate to the spokesperson, then they cannot feel connected to the values/goals of Susan G. Komen – the ambassador and Komen become one and the same for the target community. This then relates to the concept of localization. The ambassador must be culturally pertinent (relatable) in order for Komen Midwest to successfully localize the value of breast health.
Another issue resulting from this discussion is the idea of Komen believing that African-Americans need a different approach to convincing them to seek breast health services than white women. This reflects African-Americans as “The Other,” and therefore requiring a different method for localization. It is unclear from my study whether different approaches are necessary, as well as more successful than one universal approach for white and black women; however, this needed to be noted, nonetheless.
CHAPTER SIX

CONCLUSION

Introduction

In this final chapter, I will first recap the major themes and relate them to rhetoric and professional communication issues. I will further outline the limitations of the study described in Chapter Two, offer directions for future research, and conclude by providing context for my thesis by briefly detailing the recent, national controversy concerning Planned Parenthood and Susan G. Komen, ending with EGC’s final remarks on the situation.

Recap of Major Themes

The five major themes in Chapter Five consisted of: Accommodating the Board, Not All Partnerships are Valuable, Common Ground Strategy, Social Capital through Partnerships, and Localization through Partnerships. Based on the current literature, as well as EGC’s actions, clearly a board has an influential role in the actions of a nonprofit. However, what is significant about EGC accommodating the board is how she accomplished it. Whether recognized or not, EGC’s actions reflected the values of the board in almost every encounter with a community impact partner. Thus, professional communicators need to be aware of the extent of how accommodation is achieved; and further, recognize that accommodation is taking place, because when consubstantiality occurs, it is difficult to question the shared values.
Current literature discussing nonprofit partnerships with corporations identify the clear benefits; however, few detail how a partnership can have a negative impact because of an organization’s ethos. Based on this study, as well as the current national controversy that recently took place involving Komen and Planned Parenthood, it is clear that professional communicators need to recognize that networking and building new relationships is not always beneficial for an organization, as it can result in damaging the social capital of an organization.

The significance of common ground theory for professional communicators is that this tactic is frequently implemented in order to maintain, as well as build partnerships. Because partnerships are an integral component in the success of an organization, clearly professional communicators need to understand how identification is achieved in order that organizations that are partnered feel united, rather than disjointed with their partner.

As demonstrated, social capital and localization play a crucial role in how nonprofits create community impact. Professional communicators need to understand that localization goes beyond localizing a product or restaurant, as frequently described in global communication literature, and that localization can extend into localizing a value. As demonstrated, localization cannot be achieved without an organization accruing social capital through partnerships; thus, localization and social capital exist in a symbiotic relationship.

**Limitations of the Study**

With a study consisting of an ethnographic approach, it is of no surprise that a primary constraint to this study was time. In fact, Susan Katz, in her opening remarks
concerning ethnographic research, details these very problems, suggesting that the amount of time, patience and faith it takes to hold onto the hope that out of the ashes of a chaotic, mass of research will arise a phoenix: “a window into the lives and work of people within a specific organization or culture with a level of detail that is not otherwise available” (23), is the primary difficulty concerning ethnographic research. The time restriction did not allow me to analyze all documents collected; and therefore, I was not able to explore further how EGC facilitated identification between CIP partners and the public through written documents.

Katz also details the inherent limitations in ethnography, and as my study consisted of an ethnographic approach, many of the same limitations exist. Because my audience, Komen Midwest, has had and will have direct access to my study, this put a considerable constraint on the findings I could report (Katz 38). Additionally, I only relied on my own perspective through my field notes; however, as Katz suggests, I allowed my participants to speak for themselves and included comments from other actors in addition to direct participants (Katz 39).

Further, my access to the organization was limited in some ways, the most significant of these being that I did not have access to all of EGC’s emails, as I only had the emails that I drafted for EGC, as well as emails EGC included me in the list of recipients. Because EGC conducts a significant amount of contact with partners via email, this is a considerable amount of communication that I was not able to observe.

Finally, my study is only focused on one member, of one affiliate, during a span of three months. This is limiting in a multitude of ways. First, the actual timing of the
study gave way to me being able to observe EGC’s face-to-face meetings with grantees; however, I was not able to observe how EGC maintains these relationships otherwise. Because EGC only visits with grantees once to twice a year, it would have been beneficial to observe other maintenance tactics employed by EGC, as well as how she facilitates identification through email, as this is her primary form of contact. Second, by only focusing on one member, I was only able to view the strategies/elements of the CIP through the lens of EGC. Further, I was not able to fully observe the role of ED and other partners in creating community impact. Finally, as previously stated in Chapter One, this affiliate clearly goes against the common image of Susan G. Komen for the Cure; however, this affiliate could clearly be an anomaly, and thus it would have been beneficial to observe multiple affiliates and how they create community impact.

**Questions/Directions for Future Research**

As previously described in the recap of themes, determining whether a partnership is beneficial or not is difficult. Future research should explore the criteria for successful relationships and whether or not they will be beneficial. For instance, at what point can two organizations not form a successful partnership because their values are too different?

Applying a Foucauldian lens to the ethnicity issue that emerged from the African American Representative Story would allow professional communicators to explore the following questions: Who has the right speak about an issue? How are “ideal representatives” created? Do nonprofits and/or corporations reinforce stereotypes with
the selection of their representatives? How does the role of “The Other” play into localization? What are the implications of treating a culture as “The Other”?

**Recent National Controversy**

Over the course of this study, a national controversy broke concerning Susan G. Komen for the Cure and one of their grantee partners: Planned Parenthood. As Chapter One detailed the common image of Komen (the world of pink), it is important to place my study in context of this recent, national controversy.

**Headlines**

On February 7, 2012, Washington Post’s headline was: “Komen Vice President Resigns as Details Emerge on Planned Parenthood Debate.” The article highlights the public relations nightmare that has ensued after Susan G. Komen for the Cure decided to bar funding from Planned Parenthood; and then deciding, after what many assume to be a result of political backlash and an attempt to “save face,” Komen restored funding for Planned Parenthood. Komen’s “flip-flop” nature, along with the idea of Komen clearly being influence by outside sources, such as politicians and anti-abortionist groups, has resulted in the public questioning the credibility of the organization.

The Post article further details affiliates scrambling as they try to handle the situation. The New York Affiliate postponed two of its events, stating that they were unsure of their abilities to fundraise. Komen members have left, including the vice president, and headquarters is quickly reviewing budgets for the new fiscal year as they are already preparing for a significant drop in revenue. Clearly, Komen’s damaged partnership with Planned Parenthood had a direct affect on Komen’s identity, and thus
their social capital, resulting in many people withdrawing their investment from the organization.

**EGC’s Final Statement on the Controversy**

Through an email exchange with EGC, I asked her about her feelings towards the national controversy, and if it had affected their affiliate. EGC’s response to this question will be the closing moment to this thesis.

*Komen HQ has made mistakes. Komen has let down it’s volunteers, supporters, survivors and affiliate network, and realize this and are making significant changes to ensure they rebuild the wonderful faith and support it has had in the past. But, our work at the affiliate level never changed. We raise, and grant our own dollars. The only money we receive from our National office is from Cause Related Corporate partnerships like Yoplait, and Ford. We haven’t funded a grant to Planned Parenthood since 2004, they haven’t applied since 2005. Yearly, we grant $1.6 million dollars so that the 30,000 women in Central “Midwest” receive the lifesaving clinical breast exams, mammograms, diagnostic testing, treatment support and patient navigation to help them survive a possible diagnosis of breast cancer. Since 2005 over 700 women have been diagnosed with breast cancer here in Central “Midwest” alone through Komen grant dollars. Without those dollars, those women wouldn’t be alive today. Our mission, our promise remains the same, to ensure all women have access to life saving breast health care, to fund research and to empower women....we can’t afford for it to not be.*
Works Cited


APPENDICES
Consent form for Participation in a Research Study  
Clemson University  
(Factors in Developing Successful Community Impact Programs)

**Description of the research and your participation**

You are invited to participate in a research study conducted by Megan Garver, a graduate student at Clemson University, under the direction of Dr. Susan Hilligoss. The purpose of this research is to identify the factors that should be considered when developing a successful community impact program.

Your part in the study will involve answering interview questions, and if possible, providing materials that you use when developing a community impact program. The interview will be held via telephone or face-to-face, and with your permission, digitally recorded to be transcribed at a later date.

The amount of time required for your participation is approximately 15-20 minutes.

**Risks and Discomforts**

I do not know of any risks or discomforts to you in this research study.

**Possible Benefits**

By participating in this study, you will help professional communicators better understand how to develop a successful community impact program.

**Protection of Privacy and Confidentiality**

Once I have your permission to do so, I will digitally record your responses to the interview questions. I will use this recording, along with any other materials you provide, to identify and provide a general guideline of factors that need to be considered when developing a successful community impact program. I will be taking excerpts of comments which you and other participants make and have these highlighted in the “findings” section of my paper.
Your name will not appear in the paper and I will do everything I can to protect your privacy and confidentiality.

**Voluntary Participation**

You may choose not to take part in this study and you may choose to stop participating at any time. You will not be punished in any way if you decide not to be in the study or to stop taking part in the study.

**Contact Information**

If you have any questions or concerns about this study, or if any problems arise, please contact Megan Garver at Clemson University at 205-960-2046. If you have any questions or concerns about your rights in this research study, please contact the Clemson University Office of Research Compliance (ORC) at 864-656-6460 or irb@clemson.edu. If you are outside of the Upstate South Carolina area, please use the ORC’s toll-free number, 866-297-3071.

A copy of this form will be given to you.
Interview Release Form, Clemson University

The signature below indicates my permission for Megan Garver to use the interview recorded for:

Factors to be Considered when Developing a Successful Community Impact Program on ______ (date) in which I served as a participant.

My name will not be reported in association with interview results nor will my name be included on the interview transcription. This interview recording may be used for the following purposes:

- Analysis of research and reporting of results
- Conference presentations
- Educational presentations
- Informational Presentations

I will be consulted about the use of the interview recording for any purpose other than those listed above.

There is no time-limit on the validity of this release nor is there any geographic specification of where these materials may be distributed.

This release applies to the interview conducted as part of this research study listed on this document only.

I have been given a blank copy of this release form for my records.

Name (please print) ____________________________ Date: __________________

Signature: ____________________________

Address: ____________________________

____________________________________

____________________________________

Phone: ____________________________ Email: __________________
Appendix B

Field Notes

May 16

9:00am
I walk in and I’m greeted by the receptionist (R), and I tell her I’m here for the education grants coordinator (EGC). She points to the back and says I can just go to her office. I walk to EGC’s office and she’s on her computer. We first talk about my semester, her current projects, and she tells me she wants to take me on a quick tour of the office.

9:30am
Tour of the office. There is a kitchen area, a large walk-in closet that has supplies, education materials, t-shirts, etc. There is a quadrant of cubicles by a large window, four physical offices, materials closet, a conference room, and then the reception area.
10:00am – Staff Meeting

10:00 am – Walk in and the executive director (ED), communications (C) and the receptionist (R) are talking about reports. The education grants coordinator (EGC) tells me they are talking about the Race for the Cure and wrapping up any loose ends. EGC asks ED about royalties. RD says it’s not official, but she thinks they went from 2.4 million dollars to 2.6 million dollars in money raised.
10:05 – ED turns to C and asks her to start us off. C asks EGC about the cost of materials that EGC sent her. EGC says she sent a report on bookmarks and shower cards. The finance person (F) says that they are expensive. EGC states that “I think those two items are crucial.” EGC continues that the cards are not only instructional, but that they also have the web site [she looks to their web site person (W)] and says, “And W has been really trying to push that.”

C says that it is cost related marketing versus education and asks if there is a difference between the two. Is there is difference between a speaking engagement and education.

W says that there is no difference and that EGC should be charging for her services. EGC says that she could not do that. No one would ever have her come speak.

C says that we need to be more discriminating towards 3rd part affiliates. We should have a $100 minimum to help cover materials cost. C talks about margents for cars and if it should be the image of a ribbon or something else. W says that he would put a ribbon on his car but not some random image with words on it.

C is done with her report and turns to R. R says that there is an Indians game this week. EGC asks R if she is going. R says yes, but just to make sure everything is okay. EGC asks if there will be survivors on the field. F says, “Well, it’s not our event.” And EGC replies, “Yes, that’s true. It’s a community thing.”

R continues and says there is a property meeting this afternoon and asks if there are any concerns she needs to bring up.

ED asks EGC, who is next to R, if she has anything to report. EGC says that we have a disparity meeting tomorrow and a webinar Wednesday.

EGC introduces W to me (who is the only male) and says, “This is _____ . He’s our diversity.” (Everyone laughs)
W says, “I’m the token male.” (More laughter)

C asks EGC how far she walked yesterday (EGC will be doing the 3 day 60 mile walk in August). EGC says she walked 13 miles in the rain. Everyone congratulates her and EGC tells W that she is done.

10:30 am
W says that he has nothing new to report. EGC asks, “What about the blog?” W says, “I think it’s a great idea.” There is a discussion about the blog and what purpose it would serve and whether they could keep up with it. They decide they would do it but for it to be a way to tell a story from a specific event.

10:40
F talks about t-shits.

10:50
Meeting ends and people comment that it’s a new record for how fast the meeting went.

I walk to Wendy’s office and she tells me that before I start on the community impact program, I should read through all the grant applications that got accepted so that I understand the programs that are being funded and how they relate to the community profile.

11:00-12:30 – grant reading
Notes on the grants:
They awarded a total of 1,616,625.13 dollars to 17 grantees. In general, there was more money allocated towards education purposes than screening. The programs they funded related to the profile in the fact that many of them focused on target populations (such as African Americans, Latinos, and incarcerated women).

12:30 pm – Meet with EGC
We discuss the grants and she tells me we have to focus on counties with no grantee. Then we discussed the community impact program. She said, “We need to get into these communities. What does that look like? We need to look at relationships, education, grants, and providers.” She then talked about how women don’t view their breast health as a priority. That if they have to schedule a mammogram and take their kid to the dentist, then the kid will come first and then maybe they’ll get the mammogram. She said we need to let women know that they can come first. Or to tell them that if they’re not healthy, their family isn’t healthy. We need to systematically change a behavior.

1:00pm
We go over my schedule for the summer and I leave for the day.

May 17

9:00am meet at an organization for the disparity meeting. I meet the guest speaker, an oncologist at a hospital, and meet a few of the women who work at nonprofits and hospitals.

9:05
We go around and introduce ourselves. There are approximately 20 people present. The doctor begins the meeting and says that he has pushed their agenda and that there will now be evening mammograms that women can get. They will happen on the 2nd and 4th Wednesday of every month from 12-8pm. It will be full service, including biopsy, mammogram, oncologist consult, and there will be free valet parking. There are 5 sites and he hopes to alternate them so that every Wednesday has late night service. He stated that most of the resistance came from the radiologists. However, now they are full
partners and that there is a strong commitment to this. The CEO of the hospital says that the mission is to make the hospital accessible and friendly. If there are patients without insurance, there is aid. June 8th will be the first clinic. There are 6 surgeon. It is not physician based, but instead, nurse based, where there will be a nurse navigator who walks the patient through the process. There will be a nurse navigator at each center. This will be instigating the continuum of care. There is a survivorship program that will provide support. The hand-off will consist of: nurse navigator → adult care nurse → survivorship program. A primary care doctor will oversee the survivorship program.

The doctor has also created a one year clinical fellowship in which a primary care doctor gets experience with oncology, radiology, etc. The graduate of this program will be the overseer of the survivorship program.

A women asks, “Is the goal of what this hospital is doing is to be where women go to get care, that you are the hospital people think of, or is it to standardize care and hope that other hospitals will follow. The doctor responds with, “I think it’s both. We obviously want to be number one and that’s why we’re doing this because it needs to happen. It’s in demand and it should have been done years ago. However, I think hospitals will have to follow in order to compete.”

10:00am

Doctor ends his lecture and it moves on to agency updates. We went around the room and each women updates the group of women what they have going on. Here is a list of what each women reported:

1) There is a webinar (CME credit for each one completed) – best practices
2) June 6 medical advisory board (new members) 10-12
3) Pink Ribbon Connection – this Thursday (addressing the fear of reoccurrence) Kim Ziner will be the speak (23 year survivor)
4) June 26 Pink Forever – fashion show supporting the emergency assistance fund. $50 and 11:30-3:30
5) A hospital in Greenville will also be starting evening hours one day a month. It costs 10,000 dollars a year for those extra 3 hours a month. They got a grant to cover the cost.
6) Health fair (august) – theme is locks for hearts (donate hair for cancer survivors)
7) Enrollment for cancer prevention study (American cancer association)
8) Pink Ribbon Rush (June 18, 5K)
9) Little Red Door event, July 9th, theme is: Get moving to beat breast cancer – register as individuals or teams
10) Skin cancer screenings happening this week
11) IU future scientists program (5 women in undergrad accepted to the program)

10:30am

EGC asks for the people presenting case studies to do so. The case study is when a women gives an example of something that is currently happening that she needs
assistance with. Two women present their case study. The first talks about a 75 year old who cannot read, write, doesn’t have a car, no phone, and hasn’t been to see a doctor in at least 20 years. She gets screened, the cancer is so severe that is has spread to her skin, and she has no way to see doctors/pay for the bills. The woman asks for advice as to how to handle the situation.

The other women talks about how she had a support group that allows women to come together to have fun and relax. However, she is having time getting women to come. EGC says that this goes back to women not allowing themselves to come first. This goes back to changing their behavior.

11:00am  Meeting ends and we drive back to Komen.

11:30 EGC tells me to go over breast health vocabulary before I start structuring the community impact program.

11:35-1:00 I read information of breast cancer and familiarize myself with vocabulary.

1:00 day ends

May 18

9:15
I meet EGC at Macy’s for her to give a presentation on the fundraiser event: Fit for a Cure

9:45
EGC gives presentation to the sales associates (approximately 20 people present) and opens with asking how many people attended the Race for the Cure and then asks how many people know the Race for the Cure. She then moves into how many women in her family have breast cancer and states that she can guarantee that each and every person will be directly or indirectly impacted by breast cancer. She then talks about her mother who does not have health insurance and needs to get screened – and that the money she helps raises helps women like her mother. She quickly talks about the event and how it will help people in their community.

The presentation lasts for approximately 5 minutes.

10:45
Arrive at Komen and go to EGC’s office to talk about the program. EGC tells me we have pilot communities identified in the community profile. We need to look at our areas of focus (education, relationships/partnerships, grants, and providers), and start outlining the program. Then I need to research who we can form relationships with – the board has compiled a list of corporations they personally know in the community, I can look at the
list of team captains in the Race for the Cure and see if they are associated with a
corporation and if the corporation is in a target community, I can look at RFA
applications for potential grantees, and then look at our sponsorships for the Race for the
Cure.

EGC tells me that the objectives for each focus area need to be SMART – sustainable,
measurable, achievable, realistic, and time.

11:15-12:30
I work on drafting the program and send the draft to EGC for a review.

12:30 – 1:00 EGC and I review the program. There are some areas I need to
expand/specify. The section under the Education focus area, “Localizing a
Value/Systematically Changing a Behavior,” needs to be revised because the goal seems
to be more of a measurable objective. She tells me to review the action plan in the
community profile and to make sure those objectives are present in the program.

May 19

9:00
I meet EGC at Komen and we drive to downtown for the “Midwest” Cancer Consortium.

9:45
We arrive at a conference room inn a hospital and find a seat next to a women who works
at another nonprofit an had been at the disparity meeting. As we sit there, a man sitting
across the row says hello to EGC and EGC says they need to get together and have a
meeting. She tells me that he is on the cancer coalition that she co-partners on.

10:00
The conference begins. The conference begins with a women giving a lecture titled
Utilizing Evidence Based Public Health Policy to Prevent and Control Cancer. The
speaker discusses factors that lead to legislators pushing public policy and the importance
of evidence based research and how this is not currently valued with legislators.

11:00
A lecture given titled Health Care Reform: Now What Do We Do? This lecture
attempted to break down the health care reform and what hospitals were transitioning to.

11:45 – 1:00 Lunch

1:00
A lecture was given titled *Tobacco-Related Policy: What’s Working at the State and Local Levels*. The speaker addressed how this past year they tried to push for smoke-free air but had failed because they would not push a bill that did not include bars.

1:30
On the same topic, another speaker got up and discussed a success story on how one county is now smoke-free thanks to a mother who was concerned for her children and their environment.

1:50 Break

2:00
The last and final lecture was titled *Physical Activity-Related Policy: Stories of Success*. This lecture discussed the implementation of a “Kids Fit” program in which children got to school early to have 45 minutes of activity.

3:00
Leave for the day

May 23

8:45
I get to work early to work on last minute revisions on the draft of the community impact program.

10:00
Staff Meeting

10:03
There is a conversation about a ticket issue and people not showing up to the Indian’s game when they said they would.

ED talks about Pink Honor Roll coming up and whether this should be mentioned in the newsletter. She says that there will be a board meeting tomorrow and that today she will be tallying the fundraising totals.

10:15
ED continues her report and says that they will be having an organizational audit in hopes that she can push for hiring two new people. She doesn’t think she can convince the board for two people because she has to show that she has the money to hire them – but
says that the board doesn’t realize that the staff members pay for their salary by increasing fundraising.

10:25
C says that she wants there to be a staff photo next Tuesday. There will be a mid June newsletter. She asks me if I would be interested in writing an article concerning a doctor and his research on breast cancer. C asks ED whether we should include Pink Honor Roll in the newsletter. ED says yes.

C says that the 3rd party guidelines have been updated with what we discussed in last week’s staff meeting.

10:28
Open discussion of organizations using Komen’s brand/logo without our permission and people thinking Komen is associated with those organizations (ON: relating to identify expanding and not having control)
C says that we need to crack down on logo use

10:30
R says that the Fit for the Cure was Friday and that there was low attendance. The Avon community fair is on Wednesday and that the board meeting is tomorrow.

C interjects and says, “What about Hooters? Would that not be a good partnership?
ED says, “We don’t need permission from headquarters, but I don’t think people would go for it. Not a good association.”
C thinks it would be fine. ED brings up the KFC example and suggests maybe just something in October and to not have an extensive partnership. C seems to think this would be a good idea.

10:40
EGC says she needs to talk with ED about developing small grants. She says she needs to start scheduling grant site visits.

10:45 It is F’s turn to give her report but ED asks her, “What is your process for resetting email passwords? There was an issue with EGC’s email and I need to know your process.”
There is a discussion on who needs to be in charge and where to keep your passwords so that they are accessible.

11:00 EGC asks me if I need to update the staff on my project. I tell them that I have an outline completed and that I’ll start researching partnerships. Staff members start talking about current partnerships and to look at Nestle and women’s networking groups.

11:10 Meeting ends.

11:15
I print two copies of the community impact program draft and go to EGC’s office to discuss revisions. EGC tells me to make the program more visual instead of using so
many bullet points. She asks me what our timeline is and I tell her I don’t know. She says that the board will need to see when we intend on accomplishing each objective and to develop a timeline that consists of everything I intend to accomplish during the summer and a more extensive timeline. Additionally, she informs me that at the board meeting she will be presenting this as the proposal to the community impact program.

12:00
I begin working on the revisions for the community impact program.

1:00
Leave the office for the day

5:00 – 11:00
Continue working on revisions

May 24

8:45
I arrive at the office and EGC, ED, and R are all talking by the reception desk. I greet them and go to my cubicle to continue working on a timeline.

9:00 – 11:30
As I work, all of the women work in their offices and occasionally walk into each other offices to talk about a particular project or email.

11:30
I walk into EGC’s office to discuss the final draft of the community impact program. We go through each section and address any problem areas. Overall, EGC likes the use of graphs and thinks it will go over well with the board. She thinks the timeline may be adjusted, but that for the most part, she will stick with the timeline.

1:00
Leave for the day

May 25

9:00
EGC comes to my cubicle and I ask her how the board meeting went, specifically the reception of the community impact program. She said that they were very impressed with the outlined program and that they had officially approved the community profile.
This means that EGC can now release the profile to the public. While we are talking, C drops by and tells me that she has sent me a list of all of the team captains and whether they are associated with a corporation.

9:10
EGC goes back to her office. I open the excel file that has the list of team captains and look at the name of the corporation and I then research what county the corporation is located in to determine whether it is in one of our 6 target communities; and therefore, be a potential partner. Only two corporations come up from the hundreds of names listed. Most corporations are located in the county that this Komen affiliation is located within. This is an issue that EGC has expressed she wants to address. She wants to increase the awareness of the Komen and the list of corporations located in one county illustrates awareness of Komen in only one area. I also look at a list of corporations that the board members had compiled where they have a personal contact at that company. After putting the lists together, there is only one county that does not have a corporation that we can partner with.

11:00
EGC asks me if I can begin emailing our grantees to set up site visits. She asks me to ask the grantees to try and have one of their board members present and that we will try and do the same. I send out an email to all 17 grantees requesting them to send me available dates.

11:30
I begin researching potential providers by first looking at the list the board members had compiled. I then researched nonprofits in each individual county.

1:00
I leave for the day

May 26

9:00
I walk in and all of the staff members are at the reception desk talking. I notice that all of them, except the ED, are wearing jeans.

9:10
I respond to grantee emails and begin making a list of scheduled appointments. The ED drops by my cubicle and asks whether I would be interested in going to the Indy race track. I laugh, because I think she is joking, and say, “Sure!”
9:15
EGC comes by my cubicle and asks if I am coming with the track with them. I ask them the time and what we are doing. EGC says that they were given tickets and that F backed out at the last minute; and therefore, they wanted me to come. A hospital had given them the tickets and EGC said that ED wanted her to schmooze with some of the people and talk up the mission at Komen. She tells me I can leave at 10:00 to go and get ready and to return at 12:00 to go to the track.

12:00
EGC, C, R, and I leave for the race track.

12:45
We arrive at a suite box and we are greeted by a hospital person. He shows us the food, the bar, and tells us we can take a tour of the pit and Gasoline Ally. We eat some food, have a drink, and talk with one of hospital officials there that seems to be the coordinator of the day. We all introduce ourselves and she talks a little bit about the day. She then tells us to continue to enjoy our meal.

1:30
EGC says she needs to schmooze with this person, so we walk to the bar where the main hospital person is, order another drink, and EGC talks with the women about Komen and our mission.

2:00-3:00
We mingle in the suite box and take a walk down to Gasoline Ally.

3:00
We leave the track and I leave for the day at 3:45.
May 30
9:00
I walk in and go to EGC’s office. We talk about our weekends and then move into what we have do this week. We look at the timeline I developed for the community impact program and decide that I need to begin compiling a list of potential partnerships with corporations, providers, and potential grantees. EGC hands me a list of corporations and providers that board members have personal links within that organization. EGC tells me to ask C for a list of team captains from the recent Race for the Cure and to see if any of them are with a corporation within our target communities.
I leave her office and stop by C’s office to ask her for the list of team captains. She tells me it will take a little bit of time because they do not have that as a separate spread sheet. She tells me she will give it to me today or tomorrow. I go to my cubicle and begin developing the contact by first starting with the board member’s list. There are a few communities that do not have a corporation listed. I begin using the Google search engine for corporations within the target counties.
10:00
Staff Meeting
(meeting hasn’t started, just casual conversation) R tells ED that she found the $1000 under Match, and doesn’t know why she put it under Match when it wasn’t a Match. ED says that we’ll write them a thank you note. R gives ED a magnet that we bought at the race track. ED asks C what she needs to wear for the staff photo.
10:05
ED says, “Let’s get started … and I don’t have anything.” “The Pink Honor Roll people have been identified. The prize is a mouse pad that we can design with the graphic. We will send them a picture of the mouse pad and see how many people want the prize.”
C – I do have stuff, I just don’t want to talk about it. EGC, we need to talk about Wal Mart. EGC asks if that is due this week and C says she got them a longer extension than that. C tells Web Guy that she needs to talk to him about the site and to make sure that her revisions were correct. C tells F that she needs to talk to her about purchasing a raffle license.
C points to R and says, “Your turn.”
10:10
R – Exciting news, my son gets home tomorrow from Afghanistan. (More talk about his visit home). R continues and says that there is a health fair and that she can’t find someone to fill a certain shift and asks ED if she can take the shift. ED says yes.
10:15
EGC - I don’t know what I have, I seem to still be on weekend mode. I can’t get in touch with John about the community impact program. So ED, if I have your permission, I’ll
go ahead and send the program to the committee without John’s approval. ED says yes. EGC continues that she is starting grantee site visits and says that she wonders if they are really that useful. ED says that she can stop. EGC says that she hopes that by bringing along a board member and by the grantee hopefully bringing a board member, that they can discuss the findings in the community profile, talk about the community impact program, and further establish the partnership. ED nods her head and agrees.

10:25
F says that she hasn’t gotten the cost but that she has toured the facility with the new renovations and that it looks great. F says it will be perfect for events.

10:30
Talk about newly purchased materials and pictures.

10:41
End of meeting
10:42
I walk back to my cubicle and continue researching corporations in the target communities.
1:00pm
I leave for the day

May 31
9:00
I walk in and go to EGC’s office. We talk about our weekends and then move into what we have do this week. We look at the timeline I developed for the community impact program and decide that I need to begin compiling a list of potential partnerships with corporations, providers, and potential grantees. EGC hands me a list of corporations and providers that board members have personal links within that organization. EGC tells me to ask C for a list of team captains from the recent Race for the Cure and to see if any of them are with a corporation within our target communities. I leave her office and stop by C’s office to ask her for the list of team captains. She tells me it will take a little bit of time because they do not have that as a separate spread sheet. She tells me she will give it to me today or tomorrow. I go to my cubicle and begin developing the contact by first starting with the board member’s list. There are a few communities that do not have a corporation listed. I begin using the Google search engine for corporations within the target counties.
10:00
Staff Meeting

(meeting hasn’t started, just casual conversation) R tells ED that she found the $1000 under Match, and doesn’t know why she put it under Match when it wasn’t a Match. ED
says that we’ll write them a thank you note. R gives ED a magnet that we bought at the race track. ED asks C what she needs to wear for the staff photo.

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ED says, “Let’s get started … and I don’t have anything.” “The Pink Honor Roll people have been identified. The prize is a mouse pad that we can design with the graphic. We will send them a picture of the mouse pad and see how many people want the prize.”

C – I do have stuff, I just don’t want to talk about it. EGC, we need to talk about Wal Mart. EGC asks if that is due this week and C says she got them a longer extension than that. C tells Web Guy that she needs to talk to him about the site and to make sure that her revisions were correct. C tells F that she needs to talk to her about purchasing a raffle license.

C points to R and says, “Your turn.”

10:10
R – Exciting news, my son gets home tomorrow from Afghanistan. (More talk about his visit home). R continues and says that there is a health fair and that she can’t find someone to fill a certain shift and asks ED if she can take the shift. ED says yes.

10:15
EGC - I don’t know what I have, I seem to still be on weekend mode. I can’t get in touch with John about the community impact program. So ED, if I have your permission, I’ll go ahead and send the program to the committee without John’s approval. ED says yes. EGC continues that she is starting grantee site visits and says that she wonders if they are really that useful. ED says that she can stop. EGC says that she hopes that by bringing along a board member and by the grantee hopefully bringing a board member, that they can discuss the findings in the community profile, talk about the community impact program, and further establish the partnership. ED nods her head and agrees.

10:25
F says that she hasn’t gotten the cost but that she has toured the facility with the new renovations and that it looks great. F says it will be perfect for events.

10:30
Talk about newly purchased materials and pictures.

10:41
End of meeting
10:42
I walk back to my cubicle and continue researching corporations in the target communities.
1:00pm
June 1

9:00am
I walk in and go to my cubicle. I continue researching providers within the target communities.

10:00
I print a draft and go to EGC’s office to show her what I have done. She looks over it and tells me that I should include not just include oncology radiologists but also radiologists. She gives me the name of a doctor she knows at a hospital I have listed and tells me to include that in the contact information. She tells me that for the counties I’m having trouble locating a hospital for, to just research for primary care and to list those contacts.

I leave her office and continue researching providers and potential grantees.

11:25
EGC drops by my cubicle and tells me that the co-founder of a popular woman’s undergarment company would be dropping by to have a meeting with her. I ask her what it is about and she tells me that she’s not quite sure, but that the person wants to “pick her brain.” She says she has had a good relationship with this person and although they are not a partner, she wants to help in any way she can because it is still helping the breast cancer cause. She asks if I need anything and I tell her that I’m going to continue researching and that we will hopefully have a completed list by the end of tomorrow.

1:00pm
I leave for the day.

June 2

9:00am
I walk and go to my cubicle to continue working on the contact list. EGC walks over and I ask her how the meeting with the co-founder went yesterday. She said it went great. She describes that’s he’s developing a web site that women can go to in order to talk with other women who have breast cancer/are survivors. He wants it to be a place where they can ask questions and find out information they normally couldn’t find. EGC says that the co-founder wanted to get in touch with physicians and give them a brochure to tell women about the site. EGC said that she told the co-founder that he needs to talk to the nurse because they are the one who is walking the patient through the entire process. EGC leaves and I continue to research and wrap up the contact list. The provider list is primarily of local hospitals. I then listed all oncologists, radiologists, oncology radiologists, primary care physicians, and breast surgeons/general surgeons. Potential
grantees were sometimes within a hospital or a small organization within the county that offered healthcare to uninsured/under insured persons who qualified. I also continue responding to grantee emails and setting up grant site visits.

12:00
I print two copies of the completed draft and present it to EGC. We look over it and she says it looks great. She tells me she is sending out the community impact program to the community impact committee and asks whether we should send this list as well. I tell her yes because I would like the board members to highlight any contacts they personally know and to add to the list. EGC tells that this sounds great and that I should draft up an email and send it to her for her to send to the board. Here is the email:

Hello Community Impact Committee,
I’m sure EGC has already informed you all, but I would like to take the time and formally introduce myself as your Community Impact Intern, Megan Garver. I have been working with Wendy on completing a draft of the Community Impact Program and compiling a list of corporations, providers, and potential grantees with whom we can partner with and establish a relationship.

Attached to the email you will find a draft of the Community Impact Program. Within this draft, you will find the overall approach/goal as to how we plan to infiltrate the Komen brand within the 6 target communities and a breakdown of the areas of focus, including a measurable objective, a detailed method as to how we plan to achieve our objective, and a list of goals. Additionally, I have developed two timelines: a timeline for what I hope to achieve during my internship and an overall timeline for the completion of the first implementation of the community impact program. The timeline is ambitious and includes each objective outlined in the program; however, it is certainly open for revision.

The other attachment consists of our contact list. After developing the draft of the community impact program, both EGC and I agreed that we needed to address each target community and identify corporations, providers and potential grantees. The list is a starting point and I hope to further develop our list of potential partnerships.

Please read through this list and highlight any corporations/individuals whom you know personally. Please provide any other corporations/providers/potential grantees that are not currently identified. And finally, please provide any contact information that is not currently available on the list. For example, the board provided me with a list of names from “Midwest” Health Arnett; however, I could not access their contact information online.

Thank you so much for your time and I look forward to hearing your feedback!

Best,
Megan

1:00pm
I leave for the day.
June 6

9:00am
I walk in and go to my cubicle. I begin revising the contact list. This past weekend I saw my mother, who is a primary care physician and told her about who we were contacting and why. She told that I needed to include gynecologists because they, too, also set up mammogram appointments. She also told me that only a few radiologists perform mammograms and to try to find out their specialty in order to narrow/refine my list. I take her advice and go to the “physician finder” on all the listed hospitals and add gynecologists and research radiologists.

10:00

Staff meeting

C shouts from her office that it’s ten and everyone begins to head to the conference room. I walk in and Web Site guy is there and he makes a comment that we should really switch up the seats. F and I laugh and ED says, “Okay, I’ll sit over here.” ED sits at the opposite side the room. R walks in and comments on the change of seats and takes ED’s usual seat. C walks in and says, “What is going??” We laugh and she takes a different seat. ED says that we’ll start differently and since R is sitting in her spot, that she should begin the meeting.

R: We have a health fair and I’m going to take the morning shift. She asks is we are doing the lunch at Joe’s Crab Shack.
F: Joe’s Crab Shack on July 7th?
C: Yes, I planned it for 3:30 and we could invite all staff like we did last year. We’ll include it in the newsletter.
F: With C’s help, we’re wrapping up the garbage for this year. Once we have that done, we can begin the 90 day report.
ED: I don’t think the 90 day report is due. (discussion about when the 90 day report is due)

10:20
EGC: My turn? We have grant visits this week. A few of the board members will be going with us. But right now it’s been difficult talking with them – I hardly ever get responses. We have two Thursday, so I will be out of my office all day. My garage sale fundraiser was not a success. No one really showed up and all I was given to sell from my mom’s friends was junk. But I do have a story. There was a women there who asked about Dusty Showers and I met him during the 3 day 60 mile walk and it turns out he has family here. (Discussion about Dusty Showers and his motives for doing the race)

Me: I wrapped up the contact list last week of potential corporations we can partner with in the 6 target communities. I thought I was done; however, I saw my mom this
weekend, who is a primary care doctor, and I told her what I was doing and how I had a list of 100 radiologists from just one hospital. She then told me that probably only three of them do mammograms/specialize in breast cancer. So I need to go back and narrow down our list of providers.

EGC: And to add, the corporations do not involve fundraising, or at least not initially. This is to reach out to them, talk about our mission, establish a relationship, hopefully hold a Lunch and Learn, and talk to them about establishing a wellness policy so that women can go and get a mammogram and not have any job related consequences – like loss of pay, because some of these cannot afford to lose that, or having to use their own vacation time. I was thinking we should talk to the marketing person first because that’s who is concerned with the image of the company to the public. And I think they could get us our in.

Web Guy: I think you need to talk to HR. They’re the ones who would be concerned with wellness programs, I don’t think HR is it.

ED: You need to be careful with who you chose to contact and make sure it’s the one who will get us in that door. We don’t want the assistant to HR, we want the VP, because the assistant will just say that she’ll get that to her boss and we’ll never hear from them. I also think HR is probably your best bet.

EGC: Yea, I just think marketing would get us to the right person, like the HR.

ED: And the board members provided us corporations, so we should talk to them because they have personal connections to these places.

Me: I did. In my email to them, I asked them to highlight any names/corporations they personally knew.

EGC: Right, and hopefully they will go on that visit with us. But right now, I’m getting no feedback from them and it’s frustrating because they’re supposed to be doing this with me. But it looks like it’s just me again.

ED: I know, well, you’ll just have to do what you did with the grant cycle.

EGC: I know.

10:30

ED: She asks me if I’m done and I say yes. She then continues and says that she spent last week revising the budget so that she would include two more staff members. I’ve been playing fast and loose with our allocations and I’ve decided that marketing is now mission.

C: Really? Why?

E: It doesn’t go against our 25%. I’ll be contacting other affiliations and seeing their model because they somehow manage to have a lot more staff members. I’m going to be gone Wednesday, Thursday, and Friday. And that’s it for me, Web Guy?

Web: I have a baby due in four weeks (laughter). The web site is pretty much done – I think C is happy with it (C nods head). I think we should do Save the Dates for the race so that we don’t have the issue of people signing up twice, because I think when we open up registration so early, people forget if they signed up and then we give away too many tickets. I think registration should open up a month before the race and then we can do a couple Save the Dates as reminders. (people agree) Also, we need to have a black back drop on the stage because last year’s was awful for pictures and video. (C agrees) And
that’s all I have.
10:45
C: I think everything was covers. My intern is having a meeting with ICAP. I have the survivor medals and I have two people quoting the mouse pads.
ED: Is that it for everyone?
Web: I have something. I was at the race event this week and it was a really poor event, in my opinion. I don’t think they raised anything and EGC, I don’t know if you want to send this along, but LRD’s presence was terrible and their was no real connection between the event and the mission. (EGC nods head)
10:55
C: Pink Honor Roll?
ED: M gave us a quote for the space and I thought it was ridiculously expensive.
[talk about different venues and catering and ED keeps talking about the price]
11:10
End of meeting

I tell EGC that I’m going to continue working on the list. EGC tells me to also look to see if the hospital has a breast cancer center and to try to find the nurse navigator and her contact information. I ask EGC if she had heard from any of the board members and she shakes her head ‘No’ and looks frustrated and annoyed.

1:00pm
I leave for the day and send EGC a revised contact list.

June 7

9:00-1:00pm
I work on the contact list and continue going through the hospitals and adding all primary care physicians and gynecologists.
EGC and I talk briefly, but she is busy with conference calls and I continue to research partnerships.

June 8

9:00am
I walk in to the office and go to my cubicle. EGC walks out of her office and asks me if I’ll be ready to go around 10:00 for our grant site visit. I tell her yes and respond to emails and look over the contact list for the next hour.
10:00am
We leave for our grant site visit. EGC explains to me that this is her fourth year doing this and that it can sometimes be boring going through the same tour. But, she explains
that this keeps her relationship with her grantees and that she can see how the program is doing, where it needs to improve, and where it has not been meeting the specifications identified in their proposed grant. She says she likes having face-to-face time with them.

11:30
We arrive to the hospital located approximately one hour from the affiliation. Although this is not one of our target communities, it is still a community that has a high mortality rate. We walk in to an office in the hospital and we are greeted by two women: the person in charge of the program (Participant A) and her board member (Participant B). We introduce each other and she asks EGC if she needs another tour of the facility. EGC says and explains that I need to get an idea for how these programs are run and what is included in the grant.

We walk through a waiting room, a reception area, and then we view two different screening areas, a changing room, and an office in which the doctor, nurse navigator, and the patient sit down and talk about a diagnostic screening that came back positive for breast cancer. There is a diagnostic center in which the patient views their image with a nurse and doctor. There are three nurse navigators (2 full-time and 1 part-time) and three general surgeons.

Participant A described the MAP program (mammogram assistance program), which is what the Komen grant is funding. It is for women who qualify (I think it is 210% below the poverty line), and if they do qualify, then a mammogram costs 5 dollars. EGC asks about further screenings and the cost of those. Participant A responds and says that the MAP only covers the first mammogram and not a diagnostic mammogram. However, the $5 does go back into the MAP. EGC asks about women who do not qualify and whether they turn them away. Participant A says they try not to turn people away and that sometimes the nurses put forth $5 and pay for the mammogram. She says that some people can’t even afford the five dollars.

Participant A explains that a barrier they have is getting people to the hospital. She says she tried multiple marketing tactics and nothing seems to be working. She thinks that a mobile unit would help.

EGC asks if the hospital could afford that. Participant says that they could not – not without grant funding.

EGC says that maybe two hospitals, a major hospital nearby, could share the unit. But EGC is unsure how she would divide the grant money and whether the hospitals could work together.

Participant interjects and says that they would definitely be willing to work with them and that’s it about serving the people.

Participant A explains that their partner, an organization that runs on all volunteers (VOL), can help with diagnostic mammograms and assist the patients that have too much of a financial burden. VOL has doctors, nurses, and pharmacists that are all volunteers. Furthermore, over two million dollars this past year was given out in donated medication.

EGC asks Participant A is she feels that the program is on track. Participant A: We’re running out of money.
EGC: That’s everyone story. So you make exceptions with the 200% below the poverty line? Since March, you’ve had 45 mammograms and you have allowance for 110. Has the foundation been covering the diagnostic?
Participant A: Sometimes.
EGC: How many people do you think you’ve served from _______ county?
Participant A: Ten, but that’s probably a big number.
EGC: But your Hispanic numbers are up.
Participant: Yea, we even saw an African American and an American Indian yesterday.
EGC: Wow, that’s great.
12:15
We head over to the VOL (a five-minute drive away from the hospital). It is located next to welfare housing and is in a small, one floor building. We walk in and there is a small waiting/reception area. We are greeted by a woman and she tells she will get the person in charge, Participant C.
We introduce ourselves to Participant C and he begins explaining the program. Half the patients from VOL are from the hospital. They offer clinical breast exams and a retired gynecologist comes in once a month.
EGC asks: What is the demographic that you mainly see?
Participant C: Very young and then very old.
EGC: City funding?
Participant C: Yes. We only have to pay $100 per month for this building, the city covers the rest and then gives us more grant money to operate.
EGC: Paid staff?
Participant C: Four full-time and four part time and we have volunteer nurse practitioners.
EGC: How many do you serve a year?
Participant C: 1000
EGC: Do you cut them off after a year or can you keep them as long as they need it?
Participant C: We can keep them as long as needed, but we encourage them to apply elsewhere with Medicare, etc. We want them to treat this as a last resort.
We tour the rest of the facility. There is a room where they keep refrigerated medicine, a few examination rooms, a pharmacy room, a break room, and one office.
1:30
We leave VOL.

June 9

8:15
EGC picks me up from my apartment and we head to work. We are carpooling today because we have two grant site visits and it will take most of the day.
9:45
We leave the Komen office and head to our first grant site visit, a hospital that has a program that helps women navigate through the process of getting screened, surgery, treatment, etc.

10:45
We walk into a small office and we are greeted by three women: a nurse navigator, a social worker intern, and I am unsure what position the third woman has. The director of the program (Participant D), who we are supposed to meet, forgot about the meeting and is not in the hospital. We have a conference call with her and the other women in the room.

11:00
Conference call
EGC: It’s been 6 months and I’m just checking in and seeing is you have any issues or have fixed the ones you’ve had.
Participant D: We have the referrals.
EGC: Real quick, let me explain to Megan the program. _____ captures the women and makes sure the women are following through. The education in place wasn’t about the follow through, so they’ve started revising that and the navigators working with the referrals and new patients.
Participant D: We trying not to let the women treat the ER as primary care. I’ve been trying to capture the existing _____ patients who have not gotten a mammogram but it has been an enormous challenge, but I will see what the clinic can do.
EGC: What are you doing to capture existing patients?
Nurse Navigator: I do think word is getting out that we have a nurse navigator (Komen grant pays for her salary).
EGC: Are you tracking this somehow to show your report?
Nurse Navigator: I have – tracking where the referral comes from then the progress.
EGC: How are the no-shows? Are they down?
Nurse Navigator: I think so, but I’ll see the raw numbers this weekend and I’ll be sure to get that to you.
EGC: Now do you (speaking to nurse navigator) see that when you call and remind them, that they show up?
Nurse Navigator: Yes.
EGC: Why isn’t there already something like that in place – like a postcard?
Nurse Navigator: They’re so transient.
EGC: Could you explain to Megan your position and this program.
Nurse Navigator: I work in two clinics and sit down with patients when they are being diagnosed with breast cancer. There is breast surgery and breast oncology and I work in both of those clinics. Right now our wait is 3-4 weeks for the initial consultation when someone is diagnosed with breast cancer. There was a woman who lived an hour away, got diagnosed, didn’t know what to do, so drove all the way here and we had to figure out who she could go see. We’re also having problems with the Department of Correction and not getting to see these women who need to get mammograms. I know they’ve been turned away before.
EGC: We found that in the community profile – incarcerated women is difficult and it’s an area we’re trying to fix.
Conference call ends and I go on a quick tour of the clinic. I view the waiting area, the infusion area (the incarcerated women are infused in a separate back room), and a donated supply room (blankets, wigs, toiletries, etc).
11:45
Leave and head to grant site visit number two.
1:30
We arrive to the site and are greeted by Participant E, the person in charge of the program. There are two small offices, on filled with cubicles, and the other has a physical office, two cubicles, and a large book shelf. We sit down and EGC asks about the program.
Participant E explains that the program is great; however, they are going through a lot of changed with their executive director leaving and she is retiring shortly. She explains that they have already burned through one of their grants and that she is using her emergency funds. She says money is short but that she will figure out and that she will certainly not turn anyone away.
The visit is pretty short and they primarily talk about the staff change and replacements.
2:15
Leave for the day.

June 13-16

EGC is out for vacation. She told me to revise the education presentation. She explains to me that we need to have the presentation to encourage women to adopt a new behavior and value their breast health. She tells me that the current presentation does not do that.

EGC tells me to develop a pre-test and post-test to give to women at the Lunch and Learns (where we will deliver the education presentation at a corporation). She asks me to think about what information I think is important for women to know about their breast health and how we can evaluate a change in behavior/value.

I have been working on this for the past three days. Next week I will give what I have done and post the pre-test/post-test questions next week.

There was also not a staff meeting this week because both EGC and ED were out of town.

June 20

Staff Meeting
10:30
F: R can sit in the seat of honor (where ED usually sits) since it’s her birthday. (She places a balloon by her seat)
There is talk about the weather while everyone gets breakfast.

10:45
EGC: I had a frustrating meeting with a grantee.
ED: F and R filled me in a little.
EGC: Yea, they’re going after this national one million dollar grant and they want me to write a letter of recommendation and contract me to do their needs assessment. They had a timeline, grant writers. I thought were meeting to just “let’s see what this looks like,” but they were just “we’re doing this whether there is approval or not and we need you to do ‘X,’ ‘Y,’ and ‘Z.’ It was just really presumptuous.
ED: I would just smile sweetly and say that it’s great you’re going after this and that you’ll write them a letter of recommendation. After all, they are a grantee. But it is not your job to do a needs assessment. You work for Komen, so unless you want to do this after hours, you can’t do that.
EGC: No, I agree. Also, I haven’t gotten any emails from the board members. I will have Megan email them individually and see if we get some responses.
ED: And remember, I am happy to go to the corporations with you.
EGC: Right. Megan, do you have anything?
Me: I tell them about my engagement.

11:30
ED: Nothing too much to report. I got the go ahead to advertise for the development position. We need agreement on the job description. We need more money in the door. (Looks to EGC) You’re trying to go out and do community impact and have no money to do it. The race is down … I don’t know if it’s a trend.
F: Nothing for me.
R: Not a lot for me.

11:45
End of the meeting.
12:00
I leave for the day.

June 21

Site Visit
10am
We enter the facility, a small building (resembling a home), and we are greeted by a nurse navigator, an intern, and the woman running the grant for their program. The new executive director walks in, we introduce ourselves, and move to the back room. The place is small, old and everything seems cramped.
There is breakfast for us and once we get settled, the executive director tells us they are moving out of this building into a new one that will be free for two years.

EGC: What happens after two years?

ED: Hopefully free. We want to have a reception area, hoping to put in a library, a portioned room for volunteers, space for our clients, a room for work meetings, and more storage.

EGC: Now Participant F, how long have you been here?

ED: A year from August. Did you know we opened a satellite in ____ county and looking at opening another one in ______ county.

EGC: I knew about the first one. What are you doing in ______ county?

ED: It is an extension of the services we have here. We got free office space and trained 5 volunteers.

Participant G: People in ____ county mainly use us for gas. [more talk of a county that Komen does not cover]

Me: I am not familiar with this program as EGC, can you tell me about it and the services you provide?

Participant G: We reach out, we have three grants, we offer diagnostics, screenings, mammograms, education and outreach and reaching out to churches and community centers. We are more successful with clinic and hospital versus church.

Me: Why do you think that is?
Participant G: Not sure. I think women feel more comfortable in a clinic setting when having to expose themselves than in church. It might be too personal in a church.

Outreach Coordinator: Finding minorities in churches … we find a survivor to get us in there. We’ve tried different ways to reach out. We offered free food at a clinic and hardly anyone came out to participate. We ‘re running out of ideas – I thought the free food would work. but we’ll keep trying.

Navigator: We have town cryers that go to churches to town hall meetings to advocate and talk to women.
Board member (town cryer and survivor): It’s the fear. The fear that the husband won’t be there. If people have a really good support team then I think they will go and get screened and follow through, but I don’t know how to convince them of that.

Site Visit Number Two of June 21

EGC introduces me ED and their nurse.

Me: Can you tell me about your program?

Nurse: We have mammogram assistance, health exams, nurse practitioners once a month, exam room, breast exam ($10). Our county is extremely poor. We have a 13% unemployment rate and 65% of children are on free lunch in our school system.

ED: The good thing about a small county is that word of mouth spreads well and that works in our favor.

EGC: So you go to a Wal-Mart and you see people you know?

Participant H: Yea, that’s why you avoid the Wal-Mart (laughter)

EGC: Did you see more late stage diagnosis with the underinsured?

ED: I don’t if we have that data

Nurse: I know of 2 of the top of my head, so yea, we can look into that.

EGC: It would kind of show what we think we know and it’s hard to get that data from a hospital.

ED: We have had issues with women diagnosed with breast cancer and not wanting to participate in things like the Race for the Cure

EGC: It’s their way to deal, you know “It happened to me, but it doesn’t define me.”

Nurse: Mentality of what is far away and ______ is far away to these people. Post office is the best for the flyers because in parts of outlying towns they walk or drive to the post office.

ED: Farmers market also. ______ is a big employer and the month of May they offer free mammograms to their employees.

EGC: We need to contact them. We’re trying to make partnerships with corporations and establish a wellness program. So they could be our pink partner – the first.
Me: Yes, we could look at their model – see how they accomplish what they do.

EGC: Now how often is your clinical?

ED: Once a month.

Me: (I explain to them the education presentation I’m working on) How do you combat the reasoning of: I can’t even afford a mammogram, how will I afford treatment if diagnosed with breast cancer?

ED: It’s this idea that they’re invincible. They desire better for their family, so they’ll just keep on going because they don’t want to disrupt it.

Me: What are some ways you think we can motivate them?

ED: For me, its pictures, stories.

Nurse: But even then, we have women who won’t do anything about it even though they know they should. A few years ago a woman came in and she was diagnosed with breast cancer. She didn’t qualify for any coverage because even though she was well under the poverty line, she had a farm, which meant she had an asset. She said it was the only thing she had to leave her children and that she rather sacrifice herself then give up the farm – her legacy. And she did. She refused treatment.

Me: We keep hearing about this culture shift and I do wonder how we can get women to value their health – to see it as something worth fighting for. For instance, I never questioned college. It was never an option, of course I would go. Now, of course I had the financial ability, but so do some women and being able to afford health care. How do we get them to view a mammogram as, “Of course I’ll get one, no question.”

June 22

Funders Forum
11:00
EGC: We have a loose agenda. This will be time to talk and collaborate.
(We all introduce ourselves and get lunch)
Member 1: Volley for the cure. We need to look at the model in ___ and we should take the lead because it is a huge revenue.
ED: I know it’s a huge revenue in ___
EGC: (asks member 2) Are they doing breast health information at these events?
Member 2: I don’t know
EGC: I’ll get them some local information.
ED: Back to the side convo on volley for the cure
Member 1: Insurance. first step is to reach out to the president of the coaching association.
(More discussion of volley for the cure)
12:00 (next agenda item)
Member 3: National drag event, having a day there at the event to hand out educational material and maybe sell merchandise.
12:10 (next agenda item)
EGC: Providers breakfast. Some providers still don’t know who we are, what the MA12 program is, where the grantees are. I don’t know if this is something you are interested in and take this on the road and develop a program.
Member 4: Have you contacted the ______ Health Department?
EGC: I don’t know of any education workshops there. (To ED) Any thoughts?
ED: I don’t really see how this is a collaborative thing …
EGC: Well, creating a program, coming together and seeing what all we think providers should know.
12:30 (next agenda item)
EGC: A problem we’re having is reaching the African American community and trying to figure out the problem. There is no data out there about diagnostics and whether they are falling out of the continuum of care. I don’t know if it’s a good use of my money to put together 900 education packets and go to the churches. I want measurables. It’s just a huge problem and frustration. And I just wanted to hear your thoughts.
ED: What I’ve read is that there is no specific thing. But let’s be honest, we are a group of Caucasian women sitting here and we haven’t done anything. We’ve had small successes, but nothing big.
Member 4: Who’s in the focus group? Is it smart African Americans?
EGC: Yes. Surgeons, lawyers …
Member 1: Our data showed that it’s a cultural thing and we have to have a cultural shift, which I think is where your frustration is.
EGC: My committee wanted to use this polished, insured newscaster and she’s not relatable.
Member 5: We don’t know if this will back fire, but we’re going to have a mobile mammography unit and day care and things for the kids to do while mom gets her mammogram.
Member 6: I think you have to figure out what works for each individual community.
EGC: But we’ve removed all the barriers and they still don’t show up.
12:45 (next agenda item)
EGC: “Midwest” in Pink.
Member 2: We’re creating an ______ profile and combining our four affiliation executive summaries. We sent in a request and it took 3 months to increase the number of counties we cover.
1:10 (next agenda item – profile findings)
EGC: Let’s talk about finding and see if we see the same and also discuss our action plans.
Member 4: We use it for fundraising and show potential sponsorships what we’re doing.
Member 2: Rural and Hispanics were our target populations and selected 10 counties to target.
ED: Education alone won’t change behavior. You have to find the motivator.
EGC: We want navigators outside the hospitals and more through clinics to get a 360 view rather than just navigating through one system.

June 27

Staff Meeting
10:05
ED: Board meeting
C: (holds picture of an incision in her skin and a dime placed next to it) Donating breast tissue, I highly recommend it, they make it like a spa day
ED: Does it hurt?
C: The anesthetic does – first 2 needles are bad. I am talking with ____ for design and the mouse pads are good to go. I need to update the web site. Talking with Photo voice. Pictures that reflect what you are feeling through diagnosis, treatment. We could ask people what blank means to them, like Komen, and ask them to send in pictures. It can also be used for educational moments, like providers. In Ohio, they had a focus group of 6 and how they were diagnosed and four showed a phone, one showed a letter in the mail, and one was notified face to face.
EGC: This is something I’m really excited about. And we’re always looking for ways to spread the message. And we have C’s words and we can put images with them. Ohio’s didn’t go great because I think they primarily used insured women. I think we need to target African-Americans. Get the women who perhaps can vocalize.
R: So we need to get cameras to these people.
EGC: Disposable. We’ll use it for mission, not a research project like Ohio.
R: I think we need to make a packet for woman who call and are needing information.
EGC: We need to keep it minimal because they get inundated with materials.
F: I researched everything I could find.
EGC: It’s just what I’m hearing in community groups – everyone has resources, manuals, education materials. Ours would get lost in the pile.
R: They think of us first. Someone calls and I want to mail them something.
Web guy: We can put the information on the web site.
R: Great for people who have money …
ED: No, not just web, but that it should be there anyway
R: Okay.
C: I have no idea what happens to women have breast cancer but no treatment. Families bring them in because of the smell. I’m not saying we should do a terror ad, but …..
EGC: Women are already sacrificing themselves. There was a woman who would rather leave behind her farm to her children rather than sell it and pay for treatment. That was her only legacy and she didn’t want to give it up. There is no program out there for women like her who doesn’t qualify for Medicaid or B12.
C: Breast cancer is a death sentence, treatment is it.
ED: It still can be a death sentence, no guarantees - that’s the thing with these women. If you don’t have the money, there is nothing you or I can do for them.

EGC: That’s out hope in the next year or two to get a treatment program and catch these women, but right now we don’t have anything.

C: It just seems so hard trying to create a culture shift.

Me: It can be done though. This morning I was listening to NPR and they were talking about how women as young as 10 years old were getting pregnant. And organizations, like the Bill and Melinda Gates Foundation, are going in there and trying to get women to value their health, their bodies, to make themselves a priority. And that’s what we’re trying to do here, we just need the man power and time.

EGC: Yea, we’ve been talking and it’s realizing that you can’t treat these women as a homogeneous group. _____ county and _____ county will have different reasons. We need to stop going to communities (African-American) and telling them blank. We need to listen. _____ county has 65% of their children on a free meal lunch plan and they have 13% unemployment rate. We then know they’re not getting mammograms.

ED: That’s why we need more money in the door.

F: 90 day report is gone.

Web guy: Site is really close to done.

EGC: We’ll be cornering board members tonight at the social.

11:15 Meeting Ends

I walk to EGC’s office and she tells she has to go to a meeting. While she is gone, she wants me to put together a tool kit for when we go and visit corporations. She wants individual information for each county to present the corporation and show them how there is need. She wants basic information about our affiliation, Komen, what they do, and some breast cancer facts. She tells me to make it colorful and visual. She wants the majority of it done so that we can present it at the board social meeting tonight.

I work on this from 11:30-1:00.

6:00-8:30

We meet at the board’s president’s home and have drinks and eat dinner. I meet all the board members and we talk about my progress with the community impact program. Wendy campaigns for me to be hired on as mission.

June 29

Site Visit

We enter the building and we are greeted by the foundation president and the project director. There is a discussion of the movement of positions.

We take a tour of the facility. Radiology room, film mammography, every patient face to face and every diagnosis, oncology, resource center, oncologist Monday and Thursday, treatment rooms and a mixing rooms.
We sit down to have a discussion.
EGC: Tell me about how you are working with the Amish population and you guys playing basketball with them?

Foundation president: It was actually the person before me who played basketball with the Amish father but we still maintain contact with them.
EGC: Have you noticed a difference?

Nurse: We had one woman come in to get her mammogram.

EGC: Do you think we could do an article on her?

Nurse: I feel conflicted doing a story when they’re so private. I don’t want to turn them off.

EGC: I understand. Feel her out and we’ll go from there. The fact that you’re building these relationships – just share the information and demonstrate the need.

Foundation president: Ask _____ to take me there and we continue building that relationship.

EGC: Could explain briefly to Megan the program?

Nurse: We do education, screening, diagnostic – anything related to breast health. That’s what I like about the program, you don’t get trapped in one area. We get referrals from physicians and we also inform our providers of our services. Most women come in for a screening. Some don’t have a primary care physician, so I’ll set them up and get them a clinical breast exam.

Foundation president: We have a foundation in place as a resource for treatment. A man had cancer, couldn’t afford the treatment, raised the money to cover it, and the left over went into this foundation he created. We get the interest from the foundation and right now we have 3,000 for treatment money. We’re trying to make it fair for everyone in terms of who needs it.

Me: What barriers are observing that are difficult to remove or frustrations you have?

Nurse: It’s frustrating when you remove all barriers, like transportation and cost, and women still don’t show up. I’ll leave at least three messages. One woman needs a biopsy and refuses to come in.

EGC: Do you do mammogram reminders?

Nurse: I don’t, but someone does. I might start to do that though, thanks.
EGC: Well it’s so transient, it’s hard. What’s their reason for not showing up?

Nurse: Main one is taking care someone else.

Me: I’ve been working on a presentation that is trying to addresses the reasons as to why a woman won’t get a mammogram. And one slide I am having difficulty with is the reason that, “I can barely afford a mammogram, I can I afford treatment if diagnosed with breast cancer?”

Nurse: I approach it as there are facilities that can treat them, it’s just finding that person who can do the leg work. In the bigger facility it’s harder to navigate. But I have the time here, but that isn’t the case in the big hospitals.

EGC: We want a navigator in all 21 counties by 2013 and to have a treatment catchment program.

Nurse: That’s great!

Foundation president: We want to show what Komen is doing and show how the money is working. It’s not a competition is trying to get donations. It’s about helping each other out and working together.

June 30

Site Visit (one of the six target counties for the community impact program)

Tour – multipurpose room (resources, room for volunteers, educational materials for all types of cancer), wig room, board room, and a caregiver room filled with couches and artwork. In the back, there is a large warehouse filled with wigs, gift bags, blankets, jackets, merchandise, etc.

ED: It is completely comprehensive. We have kid care, transportation, taking clients if they’re scared of a mammogram, etc. We have to have a true understanding of breast health in order to be a true advocate. I’ve had to sit down with eight people, individually, and tell them they have breast cancer because they didn’t have a doctor. We are having a problem with the local hospital and there not being enough forms there.

EGC: I talk with ___ and get her up here to address the issue. I’m sending an email right now.

ED: Great. (to me) Clients have to volunteer 10 hours at the program.
EGC: That’s wonderful. Could I see the demographic information and have a copy of it – the last two years if possible.

ED: No problem.
(We head over to the board room to have a group discussion with the executive director, their nurse navigator, their outreach coordinator, grant writer and their board president)

Me: (I explain the presentation I’ve been working on and ask them for ways to combat women’s reasons for not getting a mammogram/treatment)

ED: Something for your presentation could be an airplane and the idea that before you take off they talk to the cabin pressure and if it changes, you have to put on your mask first before you put on your child’s. It’s the same idea with breast health. Women have to take care of themselves if they want to be able to take care of their family.

Me: That’s great!

Board president: Something that you might not realize is that we have a higher percentage of senior citizens in ____ county and many of them don’t have a gynecologist.

ED: Furthermore, it’s a culture thing. Many of them have this mentality that you don’t ask the doctor questions, you just do what the doctors says and nothing more. It’s a generation thing. Because older people don’t ask questions, we have to educate these women and empower them.

Board president: How many of these women will actually advocate for themselves?
ED: We advocate on college campuses because they just don’t know. We have to realize that people are different.

Board president: Have you been talking to physicians? I would like to know if they are asking women about whether they have gotten a mammogram.

EGC: We have to partner. We can’t tell them what they need to do because that’s how you get kicked out.

Grant writer: We need to show people that you’re [Komen] backing us, national program. I think that would mean a lot to people.

ED: Absolutely.

______________________________________________________________

July 5

Staff Meeting
10:15

ED: The only thing I need to tell y’all is … there is a group of people working on the Super Bowl and they are doing a fundraiser for the tissue bank and I’ve been asked to join the planning committee. They’re having a press conference next week. They’ll be having a gala in November. They’re having an awareness campaign. And my understanding is that Nancy Brinker will be here next week for the press conference.

EGC: Well that’s nice they notified us. It’s like we don’t exist.

C: EGC is shaking her head.

EGC: Well, it’s disappointing.

F: It is

ED: Once I get more information, we’ll reach out to our supporters and make sure that they know it’s not us, but that we support them. Out board president’s name is on the planning committee and I called her and she didn’t have a clue.

C: From a communications perspective, they can donate their dollars to us and their breast tissue to them. We need to funnel them to that breast tissue article I posted last week.

ED: It’s a great opportunity to network with those people who are supporting the breast tissue bank and get some leverage.

C: Pink tie ball might take a hit with their gala, but I don’t think so, as long as we have everything lined up.

EGC: It might be a good time to push the community profile and demonstrate the need and show how we are addressing those needs.

ED: Well that’s all I have, C?

C: Bra art will be coming and I’ll be delegating that. I met with the Zeta woman and discussed the money donated from Yoplait lids. Yoplait is now donating 15 cents, and 10 will do to us. Also, they’ll be calling October Breast Cancer Action Month, instead of awareness, which I think makes a lot more sense. That’s all I have.

R: We got the product key fixed and Unite to Fight is this weekend.

[Discussion about what to do with the left over Race for the Cure t-shirts]
EGC: (Recap on the site visits) We don’t have the data on African-Americans and when they get their first screening to diagnosis to treatment. The three day is coming.

Me: (Recap on site visits)

Meeting Ends at 11:30

Incentive Meeting

ED, C, EGC and myself meet in the conference room to discuss potential incentives for corporations partnering with us and developing a wellness program and allowing us to host a lunch and learn.

Me: When we visited ____ county, the executive director mentioned how the company, Draper, gave its employees free mammograms during the month of May. I did some research and it turns out that they have an award-winning wellness program. EGC and I talked and we think we should meet with them and have them be our first partnership. But they would serve as a model since they are doing what we want them to do already.

EGC: What we’re doing is demonstrating the need and meeting with the corporations over three meetings. The first we’ll establish a report, the next meeting we’ll outline the wellness program and the Lunch and Learn, and the third we’ll host the Lunch and Learn.

ED: I could cut out one meeting, or keep that in mind. They’re busy and they’ll want to meet once and figure out what you want from them. Also, in terms of models, you may want to Google places to work, or something like that. See how other people are doing it.

EGC: So that’s our plan, but we need incentives for them.

ED: Don’t use Pink Partners. We need a different name. And we can recognize them on our website. We can take out an ad in the ____ (a local newspaper) in October 2012 and recognize the corporations.

EGC: Maybe something in the ____ (another newspaper)

ED: Say that we have opportunities out there.

EGC: What about inviting them to the Circle of Hope?

ED: Yes.

EGC: (to me) Circle of Hope is recognizing corporations and individuals that have helped with our movement.
ED: Wouldn’t cost much to make a plaque. Our sponsors love them.

EGC: Do we use Pink Champion?

ED: Komen Champions – the name should imply what they do/did

Me: Are they allowed to put our name on their site?

ED: Yes.

EGC: They could have a link to our article that recognizes the corporations on their site.

Me: I think it would be great if we would track and display their progress. For instance, year one they develop a wellness program, year two they double the women who get a mammogram and start a Race for the Cure group, and so on. That way the public can see the progress/good and the corporations and compare themselves with others who are participating in this.

EGC: We need to go ahead and recognize Draper.

Me: And our web site can also serve as a model of the wellness program for other corporations to view. So if we contact one, we can direct them there before we even meet with them.

ED: If you have a company that does not offer health insurance, then you’re going up against a lot, so keep that in mind. Also, did you think that instead of a Lunch and Learn, you could put together a health fair and get hospitals in their to give free blood pressure, etc. Just a thought.

EGC: Maybe at the meeting we would bring in someone like Draper and have them tell the corporations how it is beneficial having a wellness program.

12:30 Meeting Ends

EGC asks me to draft an email to send to Draper.

1:00

Leave for the day.

July 7

Site Visit
(This visit included two grantees. One was a mobile mammography unit from a hospital that is funded by Komen and the other was a food pantry that hosts the mobile mammography unit and provides educational materials to the community)

(The people at the site visit include EGC, a member of our board, their executive director, two members of their board and myself)

The grantee that has the food pantry also hosts a clinic that has a wellness program and conducts clinical breast exams. They also provide transportation if the women cannot make it to their appointment. The mobile mammography unit is digital and immediately sends the mammogram to the hospital and the hospital will report whether there needs to be a diagnostic or not.

EGC: Their barriers are so different here because the people here are worried about putting food on the table, and that’s their focus.

Board member (grantee – professor at a university): I have ____ (the ED of the program) come and speak to my classes and inform young women.

EGC: (to me) Something we need to think about is reaching out to pharmacies. Proving educational materials at those locations.

Board member (grantee, professor): Pharmacies provide free cognitive services, they’re a good resource. (to EGC) There is a board that you should consider joining. It’s a think tank and it’s about getting things out of the city and reaching those women. The only way to hold people back is to not educate them.

EGC: I always talk about this program (the grantee we’re visiting) because they go to the population and they serve them. (to the ED) The biggest issue you’ve had are no-shows, correct?

ED: We’re at 90 (they’ve done 90 mammograms)

EGC: And your goal is 175.

ED: We’re doing good today. We had one woman call and say she couldn’t come and I told her that I would pick her up.

Board member (grantee, professor): And how often is the mobile mammography unit here?

ED: Typically once a month, but this month it is coming twice.

EGC: How many women to not go and get their diagnostic if notified that they need one?
ED: There was one out of 14 that refused to get a diagnostic. There was a total of 97 women who got mammograms and 14 were told they needed a diagnostic.

EGC: Any diagnosed?

ED: No.

[Tour of the Mobil Mammography Unit]

One mammography machine, 3 staff and they are out every day (sometimes Saturdays as well)

July 11
9:00

I walk in and go to EGC’s office. We talk about our weekends and what we have this week. The week is a lighter work load with only one site visit. She tells me to go through some emails and that we’ll discuss what I need to do for the day after the staff meeting.

10:00

Staff Meeting

ED: Press conference is Thursday at 2:45. I’ve been talking with the Nancy Brinker’s scheduler and she may or may not be there. I’m going to a super cure meeting tomorrow and that’s it for me.

EGC: Gotta get the grant checks. Komen on the Go is shaping up.

R: My volunteers want to know if they have to pay and parking.

EGC: I’ll ask during the conference call today.

Me: Nothing for me.

R: The health fair is coming up. There will be 1000 employees and four nonprofits, including ourselves. That’s it for me.

F: I’ll be in and out, but I have nothing to report.

Meeting ends at 10:30
EGC and I talk and she tells me to figure out what grantees we have visited and which ones we still have left. I work on this and report back to her. She tells me to email one of the four grantees we still have left and ask them to send us dates for a site visit. She says she has had some issues with them in the past and wants to make sure that they are on track.

EGC asks me to revise the timeline on the community impact program and adjust items as needed. We took out one of the three meetings for the corporations (as suggested by the ED) and have them being completed by October (with at least 6 partnerships established).

12:00

I leave for the day.

July 12

9:00am

I walk in to EGC’s office and we talk about our nights. I ask her what I need to do today and she says she needs to catch up on work and that I can use this day to print materials for my thesis.

The remaining hours I print out all materials that were used during the process of creating the community impact program.

1:00pm

Leave for the day

July 13

9:00am

I walk into EGC’s office and she tells me that we’ll be leaving for a meeting at the State Health Department downtown in ten minutes.

Data Coordinating Committee Meeting
10am

Introductions (research coordinators, cancer coalition director, epidemiologists, EGC and myself)

Epidemiology newsletter – (overview) discussing data limitations, how to detect incidence (he tried not to get too technical, but because this was in the epidemiology newsletter, he dived right in), and it is about a cancer cluster inquiry.

Cancer data update – social math (using a land mark, such as a football stadium, to represent the data so that people can visualize/relate the data to something) --> person leading the meeting states, “It is an innovative way of sharing data …. we want data to tell a story.”

EGC: There is a gap in the data with African-American women and why they have a greater percentage of women getting diagnosed with later stages of breast cancer in comparison to Caucasian women. Where are they falling out of the continuum of care? Screening to diagnostic? Diagnostic to treatment? Where is the gap?

Person leading meeting: And we don’t have a lot of data with patient navigation and we keep hearing talk of that at the state level.

Cancer epidemiologist for the state health department: What about Medicaid data?

Person leading meeting: We are looking there; however, there are cofounders that you can’t apply to the general population. But it will give us something and we are doing that, it’s just a slow process.

Discussion of cancer data

Prezi Presentation: Information is Beautiful, visualizing data

- data that tells a story, important with cancer data and making it more viable

- information graphs and using this to possible represent incidence

- visualizing cancer data so that people can better understand what they are looking at

11:15

Meeting Ends
On the way back to the office, I ask EGC how the meeting was. She said that these meetings allow her to continue building her relationships and networking and that without this, she could not do her job.

12:20

We arrive back at the office.

July 13

Site visit

Tour – transition to EMR, sit down with financial counselor, full time interpreters (2 now, hopefully 4), patient navigator (bilingual), outreach coordinator, prescription assistance coordinator

ED: promoting breast health awareness … shows an advertisement and it include the mention of free clinical breast exams and Susan G. Komen

EGC: Cost of the ad?

ED: 1000 for six months at the movie theater

Me: My question

EGC: Community profile … how well we’re known, but not outside the donut counties

ED: Promoting the CBE, medical director diagnosed and sharing her story. Outreach coordinator and helping patients navigate the system.

Director of Operations: We have the mobile mammography unit here

EGC: How often?

ED: 3 times a year. And then our health fair and outreach coordinator will sign them up for mammograms and refer them to _____ hospital if on Medicaid or us if they do not

EGC: Overview … what working and what’s not?

ED: The transition from EMR was difficult and we had to slow down our providers
EGC: I see you’re way down on exams

ED: First quarter hit us, but doubled in the 2nd

Director of Operations: More in depth exams

EGC: Do you find the computer a barrier to communication?

ED: We try for it not to be … we have touch screen and laptops, so they can face the patient

EGC: How have you done with BCEP dollars running out?

ED: We had our emergency fund and we adjusted

EGC: How many staff?

ED: 22 including our school program (school based clinic)

EGCC: Anything you need from me?

ED: Talk with you about the grant cycle

EGC: [Explanation of new grant cycle]

July 22

Site visit with Black Nurse Association

On the way to the site visit, EGC talks about her disappointment in this program. She wishes the old project director was still in place.

Wait on the project director. Meet records keeper. EGC not happy with how records have been kept.

Meet in the conference room. Records keeper, 2 nurses, external advisor and project director present. All workers black except for records keeper (Hispanic)

External advisor (use to be the project director) retired, working on project to get rural women accessing healthcare

EGC: I really want to talk to you about this … what prompted you to do this?
EA: It’s a target population that needs help.

[given an outline of the education program] They have lay health advisors

EGC: How do you ensure these lay ___aren’t giving medical advice?

EA: PD does site visits and they are trained

[discussion of follow up and EGC saying she needs to see measurable and getting that data]

EGC (to PD): What does a day look like for you?

PD: Describes part of her day but shifts to the entire program. Trying to engage the Latino/Hispanic population

EGC: Gaps in the data … what is your perspective/feedback? And we’re doing some town forums and we would love your partnership

PD: (Doesn’t answer first question) We’ll ask our nurses

EGC: Anything I can do?

PD: We’ll talk later

July 25

Staff Meeting

ED: Board meeting may be cancelled and EGC will be gone Wednesday to Dallas. Interviews for the development position this afternoon and tomorrow

EGC: Awareness campaign that a company does and we found out another affiliate does that and they call them year round partners

[.end of notes]
Appendix C

Gathered Documents

Site Visit Email (May 25, 2011)
(Email sent to grantees)

Hi ______ ,

My name is Megan Garver and I'm the Community Impact Intern at Susan G. Komen for the Cure working with Komen Midwest. We were hoping to schedule a site visit in which EGC, myself, and hopefully a member of our board would come. Please send several dates that would be convenient for you. Additionally, it would be great if a member of your board could be present during our visit as well so that we can strengthen our relationship with them and the community they serve. Thank you so much for your time and we look forward to hearing from you!

Best,
Megan

Megan Garver
Intern
Address
Email Sent to Board Members (June 2, 2011)
Hello Community Impact Committee,

I’m sure EGC has already informed you all, but I would like to take the time and formally introduce myself as your Community Impact Intern, Megan Garver. I have been working with EGC on completing a draft of the Community Impact Program and compiling a list of corporations, providers, and potential grantees with whom we can partner with and establish a relationship.

Attached to the email you will find a draft of the Community Impact Program. Within this draft, you will find the overall approach/goal as to how we plan to infiltrate the Komen brand within the 6 target communities and a breakdown of the areas of focus, including a measurable objective, a detailed method as to how we plan to achieve our objective, and a list of goals. Additionally, I have developed two timelines: a timeline for what I hope to achieve during my internship and an overall timeline for the completion of the first implementation of the community impact program. The timeline is ambitious and includes each objective outlined in the program; however, it is certainly open for revision.

The other attachment consists of our contact list. After developing the draft of the community impact program, both Wendy and I agreed that we needed to address each target community and identify corporations, providers and potential grantees. The list is a starting point and I hope to further develop our list of potential partnerships.

Please read through this list and highlight any corporations/individuals whom you know personally. Please provide any other corporations/providers/potential grantees that are not currently identified. And finally, please provide any contact information that is not currently available on the list. For example, the board provided me with a list of names from IU Health Arnett; however, I could not access their contact information online.

Thank you so much for your time and I look forward to hearing your feedback!

Best,
Megan

Megan Garver
Intern
Address
Email Sent to First Corporation (Model Corporation) to Establish Partnership (July 12, 2011)

Hello John & Terry,

Good Morning. I wanted to send you both an email and introduce myself to you. I’m EGC, the Grants & Education Coordinator at the Susan G. Komen for the Cure Midwest Affiliate. After a recent meeting with an organization in Midwest county, it was brought to our attention that you offer free mammograms to your employees during the month of May and, furthermore, offer wonderful healthcare benefits. Every two years, we complete a comprehensive need assessment that identifies current trends in mortality as a result of breast cancer, later diagnosis stages, and high rate of no mammograms in the last 12 months. This allows us to concentrate on the greatest needs in our 21 county service area, ensuring that the money we grant out is making the biggest impact. Annually we grant out $1.6 million dollars, some of which comes back to Midwest county, ensuring women without health insurance have access to breast screenings.

One of the biggest reasons we have found through this needs assessment, is that women do not want to take off work, fear the loss of employment, and loss of pay if they leave during the day to get their mammogram. As a result, we are currently developing a program in which we reach out to corporations and promote a wellness program that allows women to go and get a mammogram during work hours without receiving any job related consequences. Furthermore, we hope to host a Lunch and Learn at the corporation that would educate women on breast health. In return, we are working on ways in which to recognize these corporations via our web site, an advertisement in the Midwest Newspaper, a plaque that can be showcased in the corporation’s lobby and/or main office, and inviting corporations to our Circle of Hope in which we recognize people and organizations who have helped in our cause.

Because of your initiative, we would like to recognize you and hold you as a model for other corporations to observe and hopefully emulate. We hope that by partnering with corporations in our 21 counties, we can combat this movement and encourage women to value their breast health, but we cannot do this alone. Please let me know whom I should speak with in order to set up a meeting recognizing your efforts. I was hoping that I, my director and possibly a board member could meet with you or someone from your company, to discuss your wellness program that you currently have in place, what has worked and hasn’t worked, and discuss possible ways in which we can recognize your efforts. I also sincerely thank you for your efforts in valuing the health of your employees. I look forward to hearing from you about possible meeting times.

Very sincerely,
Email sent to me and [redacted] Regarding the Community Impact Program (July 14, 2011)

Please read about [redacted] year round partner program and what they include in it for mission activities. I think this might be awesome for the community outreach plan.

To learn more about Komen or to make a donation, visit our website at www.komenindy.org

From: [redacted]
Sent: Wednesday, July 13, 2011 2:09 PM
To: [redacted]
Subject: Re: [Edlist] Affiliate Sponsors

Very interesting idea! I especially like the mission angle.

Did she say how do they recognize or determine benefits for the Year-Round sponsors? Do they simply become part of the "Year-Round Partner" group or is there some other benefit or recognition for this group?

On Jul 11, 2011, at 9:05 AM, [redacted] wrote:

Here is an idea from one affiliate regarding "year round" sponsorship. I've gathered a couple of ideas.

From: [redacted]
Sent: Monday, July 11, 2011 7:43 AM
To: [redacted]
Subject: Re: [Edlist] Affiliate Sponsors

[redacted] has a "Partner" status that is open to any sponsor at any level. To be able to call themselves a "Year-Round Partner" they have to sponsor two major events/efforts (usually including the Race, but we have a few sponsors who can’t be part of the Race because of the national exclusivity clause for their industries) AND commit to doing one substantial mission activity.
Examples of "substantial mission activities" include: public education campaigns for customers (good for retail), employee education campaigns that go beyond the basics (example: a factory gave an extra day off for employees that used it to get mammograms), hosting an event for service providers (one sponsor hosted & paid for our grant-writing workshop for 60 potential grantees).

We actually don't affix a dollar minimum to this because many of our smaller partners were very interested in doing this as well. Sponsoring at least 2 events (we have one that does three) automatically increases their $5 commitment from wherever they were in the first place (we do often negotiate a "deal" where they get about 10% off the total published commitment). In the 3 years since we introduced this, we have gone from zero to more than 20 partners—each of which increased their race-only to partner commitments by 50-100%.

This model has worked VERY well for us... and we have had sponsors come to us unsolicited for more information on how to be a partner!

Executive Director
Susan G. Komen for the Cure, Affiliate

Our Vision is a World Without Breast Cancer
Join us for the Komen Race for the Cure, June 11, 2011!

From: [redacted]
Sent: Friday, July 08, 2011 4:43 PM
To: edlist@lst.komen.org
Subject: [Edlist] Affiliate Sponsors

Does anyone have an Affiliate Sponsor level for companies that support the Affiliate year-round?

Thanks!

Executive Director
Nebraska Affiliate – Susan G. Komen for the Cure

Our Vision: A world without breast cancer.
Slide 1

BREAST CANCER:
WHAT YOU KNOW CAN SAVE YOUR LIFE

EGC
Grants & Education Coordinator

__________ Affiliate of Susan G. Komen for the Cure

Slide 2

SUSAN G. KOMEN FOR THE CURE;
OUR PROMISE

To save lives and end breast cancer forever by
empowering people, ensuring quality care for all and
energizing science to find the cures.

The Komen Midwest Affiliate is one of 120 affiliates in
the nation and one of four affiliates in Indiana.

Slide 3

WHO ARE WE?

Susan G. Komen for the Cure was
founded in 1982 on a promise made
between two sisters — Nancy Goodman
Brinker and her dying sister, Susan
Goodman Komen. More than 25 years
later, Komen for the Cure is a global
leader in the fight against breast cancer
through its support of innovative breast
cancer research grants, meritorious
awards and educational, scientific and
community outreach programs around
the world. Through the National Network, corporate partners and
generous donors, Komen has raised
nearly 1.5 billion for the breast cancer
movement.
**Slide 4**

Komen Midwest Affiliate
- Race for the Cure: April 16
- 21 County Service Area
- Pink Tie Ball
- Pink Ribbon Celebration
- 1.6 Million dollars in grant money
- Education/Awareness

**Slide 5**

Komen Midwest Affiliate
- Mission Dollars
  - Local Education & Screening 75%
  - Research/Grant 25%
- Komen Research Grant 25%
- Mission Dollars

**Slide 6**

Komen Midwest Affiliate
- Use of Funds
  - Grants and Research 75%
  - Administration 5%
  - Race 13%
  - Fund Raising 4%
  - Sale 6%
Slide 7

Komen Midwest Affiliate of Susan G. Komen for the Cure

Slide 8

WHAT IS BREAST CANCER?
Breast cancer is not just one disease but a group of diseases. It occurs when breast cells that line the ducts become malignant (cancerous). Malignant tumors are made up of abnormal cells that grow without normal controls and invade normal breast tissue.

EGC’s Notes: This slide shows a drawing of the breast.
• Breasts are made up mainly of fat and breast tissue.
• Breast tissue is a network of lobules with cells that produce milk during breastfeeding, lobes, where the milk is stored and ducts that carry milk from the lobules to the nipple openings when a woman is breastfeeding.
• Most breast cancer starts in the ducts.

SHOW ribs, pectoralis muscle, fat on diagram
Many breast changes occur over a woman’s lifetime – at puberty, monthly during childbearing years and at menopause - that are normal.
**WHY SHOULD I CARE?**

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>New Cancer Cases</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin</td>
<td>31,400</td>
<td>3,880</td>
</tr>
<tr>
<td>Breast</td>
<td>207,090</td>
<td>39,480</td>
</tr>
<tr>
<td>Lung</td>
<td>105,770</td>
<td>71,080</td>
</tr>
<tr>
<td>Colon</td>
<td>54,430</td>
<td>24,709</td>
</tr>
</tbody>
</table>

(These numbers do not include basal and squamous skin cancer)

---

EGC’s Notes: This slide shows incidence and mortality of breast cancer compared to other types of cancer.

- More American women are diagnosed with breast cancer than any other type of cancer (aside from skin cancer), and breast cancer is second only to lung cancer in cancer deaths.
- Incidence rates fell in 2002 – 2003 (6.7%) and held for 2004 – the lowest rate since 1987. The largest decline was in women 50-67 years in ER+ breast cancer (14.7% compared to 1.7% in ER- breast cancer). This risk is for the population as a whole – the individual risk fell 1.7%.
- The cause for this decline has been linked with the decreased use of HRT – by the end of 2002, 20 million fewer prescriptions for HRT had been written for women in the U.S. – a decrease of 38%. The WHI study published in 2002 showed that the risk for BC outweighed the benefit of post-menopausal HRT.
- The mortality rate continued to decline, a trend for the last several years.
- Breast cancer does not know geographic boundaries – it is the leading cause of cancer among women in the world and the leading cause of cancer death among women in the world.
- Worldwide, one person is diagnosed with breast cancer every 30 seconds and one person dies of breast cancer every 90 seconds.
BREAST CANCER RISK FACTORS

- Getting Older
- Personal history of breast or ovarian cancer
- Having a mother, daughter, or sister who has had breast cancer
- Having a previous biopsy showing hyperplasia or carcinoma in situ
- Being under 30 at the time of your first period
- Starting menopause after 50
- Having an inherited mutation in the BRCA1 or BRCA2 breast cancer genes
- Having more than one drink of alcohol per day
- Taking birth control pills for 5 years or longer
- Never having children
- Currently or recently using combined estrogen and progesterone hormone replacement therapy (HRT)

NEW BREAST CANCER CASES BY AGE

EGC’s Notes: We’ll talk more about risk factors later, but here I would like to mention that the two most significant risk factors are being female and getting older.

- All women are at risk for breast cancer and as you can see on the graph, the majority of breast cancer cases occur in women over 50.
- Although rare, younger women can also get breast cancer.
- The lifetime risk of breast cancer calculated to the age of 85 years is 13 percent or one in eight.
- All women are at risk.

• SEER – Results from the Surveillance, Epidemiology, and End Results (SEER) program – collects cancer-related data on a large portion of the US.
Slide 15

### Mortality Rate

<table>
<thead>
<tr>
<th>Ind. Counties</th>
<th>Black</th>
<th>Other</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Henry</td>
<td>37.17</td>
<td>9.63</td>
<td>35.02</td>
</tr>
<tr>
<td>Grant</td>
<td>31.49</td>
<td>6.90</td>
<td>36.21</td>
</tr>
<tr>
<td>Brown</td>
<td>20.36</td>
<td>3.22</td>
<td>37.31</td>
</tr>
<tr>
<td>Tipton</td>
<td>8.46</td>
<td>3.22</td>
<td>30.38</td>
</tr>
<tr>
<td>Clinton</td>
<td>9.24</td>
<td>3.81</td>
<td>24.06</td>
</tr>
<tr>
<td>Marion</td>
<td>23.92</td>
<td>3.67</td>
<td>27.66</td>
</tr>
<tr>
<td>Delaware</td>
<td>28.42</td>
<td>3.73</td>
<td>30.02</td>
</tr>
<tr>
<td>Howard</td>
<td>27.07</td>
<td>4.82</td>
<td>27.83</td>
</tr>
<tr>
<td>State Total</td>
<td>127.29</td>
<td>73.66</td>
<td>102.32</td>
</tr>
</tbody>
</table>

age 65+

---

Slide 16

### No Mammogram Last 12 Months

<table>
<thead>
<tr>
<th>County</th>
<th>No Mammogram Last 12 Months</th>
<th>Uninsured Females 18-64</th>
<th>Incidence Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brown</td>
<td>38.1%</td>
<td>14.8%</td>
<td>130.68</td>
</tr>
<tr>
<td>Tipton</td>
<td>37.4%</td>
<td>7.6%</td>
<td>152.57</td>
</tr>
<tr>
<td>Clinton</td>
<td>38.4%</td>
<td>12.4%</td>
<td>137.10</td>
</tr>
<tr>
<td>Henry</td>
<td>38.0%</td>
<td>13.8%</td>
<td>124.51</td>
</tr>
<tr>
<td>Grant</td>
<td>39.5%</td>
<td>19.5%</td>
<td>131.04</td>
</tr>
<tr>
<td>Howard</td>
<td>37.5%</td>
<td>16.8%</td>
<td>143.75</td>
</tr>
<tr>
<td>Delaware</td>
<td>38.1%</td>
<td>24.3%</td>
<td>105.92</td>
</tr>
<tr>
<td>Marion</td>
<td>37.0%</td>
<td>17.3%</td>
<td>120.56</td>
</tr>
</tbody>
</table>

---

Slide 17

### TYPES OF BREAST CANCER

**In Situ (in SY- too)**

**Invasive Breast Cancer**

**Inflammatory Breast Cancer (IBC)**

In situ cancer means that the abnormal cell growth stays within the walls of the ducts or lobules. They are often called precancerous conditions because they can either develop into or affect the risk of getting invasive cancer. In situ cancers have not developed the ability to invade normal breast tissue nor to metastasize.

Invasive breast cancer means that the abnormal growth of cells has spread into nearby tissue. Invasive breast cancer is not the same as metastasis. Metastasis occurs when cancer cells break away from the original tumor and spread to other parts of the body.

Common sites for breast cancer metastasis:

- Lymph nodes
- Bones
- Lungs
- Liver
Inflammatory Breast Cancer (IBC) is an advanced and accelerated form of breast cancer usually not detected by mammograms or ultrasounds. Inflammatory breast cancer requires immediate aggressive treatment with chemotherapy prior to surgery and is treated differently than most common types of breast cancer. African Americans have a higher incidence of IBC.

**Typical Symptoms of IBC:**
- Swelling, usually sudden, sometimes a cup size in a few days
- Red, blue, or dark colored area (called erythema) sometimes with texture similar to the skin of an orange (called peau d'orange)
- Ridges and thinned areas of the skin
- What appears to be a bruise that does not go away
- Nipple retraction
- Nipple discharge, may or may not be bloody
- Breast is warm to the touch
- Change in color and texture of the areola
- Breast pain (from a constant ache to stabbing pains)

**Obvious Lump**

**Indentation**
CLINICAL BREAST EXAM (CBE)

- Your healthcare provider should perform your CBE during regular checkups.
- During the CBE, the doctor will look for breast changes such as size, shape & color.
- Your doctor will feel the entire breast and underarm areas for new lumps or changes.
- Ask any questions you have about doing BSE, common breast changes, or your personal risk.

MAMMOGRAM

- A mammogram (breast x-ray) is the best screening tool widely available for finding breast cancer early.
- It can find breast cancers before they can be felt.
- Mammograms use a very small amount of x-ray radiation.
- Starting at age 40, women should get a mammogram every year.
- If you are under 40 and have a family history of breast cancer or other concerns about your breasts, talk to your healthcare provider about your risks, when to start getting mammograms and how often to have them.
- Have your mammograms taken at the same place every year so that your x-rays can be compared. Or, pick up your previous mammogram films and take them with you so they can be compared with this year’s mammogram.
- If you do not receive your results in two weeks, call your doctor or the mammography center.

DIAGNOSTIC MAMMOGRAM

- A diagnostic mammogram is used to evaluate a woman with a breast problem/symptom or an abnormal finding on a screening mammogram. The diagnostic mammogram will be focused on the areas where there appeared to be abnormal tissue. It should be performed under the direct, on-site supervision of a board certified radiologist.
**Slide 27**

I DON’T HAVE TIME TO GET SCREENED

<table>
<thead>
<tr>
<th>Mammogram (15 min)</th>
<th>Driving Time (30 min)</th>
<th>YOUR LIFE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(graduation, family, vacations, anniversarys, grandchildren, weddings, birthdays, dinners with friends and family, etc.)</td>
</tr>
</tbody>
</table>

Approximately 1 hour

EGC’s Notes: Preventative care gives us a future.

**Slide 28**

I HAVE ENOUGH TROUBLE GETTING MY KIDS TO THEIR APPOINTMENTS, LET ALONE MY OWN

Think about the times you’ve had a cold or the flu and how your family managed: carpools, dinners, appointments, practices, rehearsals … If you are sick, then your family falls apart.

Early Detection: When breast cancer is confined to the breast, the 5 year survival rate is 98%

By getting a clinical breast exam, mammogram, and attending your follow-ups, you are putting your family (and yourself) first.

EGC’s Notes: “I don’t want to disrupt my family”

**Slide 29**

I DON’T HAVE THE MONEY FOR A MAMMOGRAM, LET ALONE MONEY TO PAY FOR TREATMENT IF I HAVE CANCER

There are resources and people who can help navigate the system

There are treatment options

You won’t be alone, you will have a support group.
Slide 30

Services: ORGANIZATIONS THAT RECEIVED CENTRAL INDIANA GRANTS

- Community Clinic
- Black Nurses Association
- Cancer Services of East Komen Midwest
- Cancer Services of County Regional Hospital Community Hospital
- County Memorial Hospital
- Fox Cities
- Regional Hospital
- Regional Hospital
- Regional Hospital

For more information: www.komen.org

Slide 31

WHEN THE DIAGNOSIS IS CANCER

1. Plan your journey: Go over your pathology & medical report with your doctor. From this time will determine the best course of treatment for you. Become an educated consumer and patient. After all, you will make the best treatment decisions for you.

2. Making treatment decisions: Two types of treatment: local & systemic. Local includes procedures involving only the breast and surrounding tissue. Lumpectomy, mastectomy, radiation. Systemic includes chemotherapy, hormone therapy and biologic therapy.

3. Know what to expect: Find out what you can expect during treatment, such as blood tests, and x-rays before treatment and what side effects you may experience.

4. Dealing with treatment: How long will treatment last? Eat well and get plenty of sleep. Join a support group and talk to others who are going through the same treatment as you.

Slide 32

CURRENT RESEARCH ON DRUGS & TREATMENT

Clinical trials are vitally important because they test the safety and potential benefits of new drugs and treatments and the effectiveness of new ways to diagnose, treat and prevent diseases. Some current drugs being researched:

- Anti-angiogenesis agents: These drugs work by preventing cancer cells from developing new blood vessels. Two drugs currently being tested are endostatin and angiostatin. Two other drugs thalidomide and anti-vascular endothelial growth factor antibody are being tested in women with advanced cancer.

- Selective estrogen receptor modulators: Estrogens promote the growth of breast cancer cells. SERMS work to block the effect of estrogen on breast tissue while still providing the beneficial estrogen to some other areas of the body.
There are different types of breast cancer as shown on the previous slide. In addition, every woman is unique. • For these reasons, there are different ways of treating breast cancer. They may include surgery, radiation therapy, chemotherapy, hormonal therapy, targeted biologic therapy – and most likely a combination of two or more. • Again, the most important message is that the earlier it is found, the more options and the more effective treatment is likely to be.
The Money from the Race goes to....

Screening:
$100.00 will pay for a mammogram
Clinical Breast Exams
MRI, Ultrasound & Biopsy

Treatment: Patient Navigation, some treatment

Education: Outreach to individuals

Support: Bras, Wigs, Prosthesis
Make A Difference

If 40,000 participants register for the Race, we will raise $1,120,000.

If 40,000 participants register and raise just $100 in donations, we will have an additional $4,000,000.

Fundraising Ideas

- **Power of 10**: Ask 10 friends for $10.
- **Office fundraisers**: A jeans day, open-toe shoe day, bake sale or chili cook-off.
- **Home parties**: Host a dinner party or barbecue with a small cover charge.
- **Garage sales**: Organize a personal or neighborhood garage sale, with a percent of proceeds benefiting your fundraising efforts.
- **Corporate matches**: Double your money by seeing if your employer or supporters have a match program.

WHAT CAN I DO FOR MY HEALTH?

**EARLY DETECTION & TREATMENT OFFER THE BEST CHANCE OF SURVIVING BREAST CANCER.**

**3-STEP EARLY DETECTION PLAN**

- **Breast self awareness**
- **Clinical Breast Exam (CBE)**
- **Annual Screening Mammography**
Slide 41

Monthly Breast Self Awareness

- Know your risk
- Get screened
- Know what is normal for you
- Make healthy lifestyle choices

Komen Midwest Affiliate of Susan G. Komen for the Cure

Slide 42

How to get involved in the breast cancer movement:

- Participate in events such as the Race for the Cure®, the Breast Cancer 3-Day, Passionately Pink to the Cure, Pink Tie Ball, which celebrates and honors loved ones touched by breast cancer while financially supporting Komen’s Promise.
- Become an activist through volunteer activities with the Komen Midwest Affiliate.
- Because of Komen’s corporate partners, people can purchase products that support Komen’s Promise. Without the funds from these partners, Komen for the Cure could not foresee the amount of work it does.
- Participate in early detection by accessing regular screenings and encourage the women around you to do the same.
- Schedule a presentation for your social group, work, home, or church to raise awareness about breast cancer.

Komen Midwest Affiliate of Susan G. Komen for the Cure

Slide 43

RESOURCES

Susan G. Komen for the Cure
1.800.I'M AWARE
www.komen.org

Komen Midwest Affiliate of Susan G. Komen for the Cure
317-638-CURE (2873)
www.komen.org

The American Cancer Society
1.800.ACS.2345
www.cancer.org

Komen Midwest Affiliate of Susan G. Komen for the Cure
Slide 44

REMEMBER

1 in 8
68 seconds
1 hour

Slide 45

QUESTIONS OR COMMENTS?

THANK YOU!!!!!!