

STARTING A SUPPORT GROUP FOR WOMEN WITH A HEREDITARY BREAST  
CANCER PREDISPOSITION

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# STARTING A SUPPORT GROUP FOR WOMEN WITH A HEREDITARY BREAST CANCER PREDISPOSITION

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Genetic testing for a hereditary breast cancer predisposition has been available since 1996. Since then, many at-risk individuals have pursued testing for a variety of reasons including medical management, surgical decision-making, and family planning. However, as a result of the ability to learn one's cancer risk, women often struggle to incorporate this information into their lives and are faced with complex decision-making. Providing comprehensive services for this population that address these concerns is a matter of public health importance. This study documents the process of designing a support group for women who have tested positive for a hereditary breast cancer predisposition. Thirty-three women who have previously tested positive for mutations in *BRCA1*, *BRCA2*, or *PTEN* were invited to participate in a monthly support/discussion group and were sent questionnaires and informed consent documents for study participation. Nineteen of the thirty-three (57.6%) women responded, five (27.8%) were group participants and fourteen (72.2%) were non-participants. The questionnaire addressed experiences with cancer, management decisions, risk perceptions, existing levels of support, causes of anxiety, and communication with family members. As hypothesized, group participants had higher perceptions of breast cancer risk, lower confidence in medical management decisions, and less support from family and friends than non-participants. In addition, group participants were more likely to be younger, to

have received their results 1-2 years ago, to not have a personal history of cancer, and to experience greater overall anxiety. Factors influencing perceived breast cancer risk and the need for support services included the number of first or second degree relatives with breast cancer, whether the relative was deceased or alive, the election of preventative surgery, and the time elapsed since result disclosure. Other findings included correlations between (a) perceived breast cancer risk and both perceived ovarian cancer risk and need for a support group, (b) perceived ovarian cancer risk and anxiety about talking with one's partner, and (c) all items addressing sources of anxiety. This study provides information that can potentially aid public health professionals who work with high-risk women and who are organizing or designing support services for women with a hereditary breast cancer predisposition.

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## **PREFACE**

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Lastly, I would like to dedicate this work to the women that shared their Wednesday nights, their Panera, and their heart-felt stories with me. I will take the accounts of their life experiences with me and feel blessed to have had the opportunity to gain such insight into the lives of patients.



## **1. INTRODUCTION**

This investigation was undertaken to examine the utility of a support group for women who have tested positive for a hereditary breast cancer predisposition. Testing for gene mutations associated with increased breast cancer risk have been clinically available since 1996. As a result, an emerging population of individuals is forming who are equipped with detailed information about their risk to develop breast cancer. This population is now faced with complex decisions with respect to surveillance and risk reduction techniques. In addition, as with all genetic diseases, a hereditary breast cancer predisposition has implications for other family members. Therefore, in addition to difficult medical decisions, these women often have to deal with issues such as the communication of genetic information to at-risk family members, the possibility of having transmitted the predisposition to children, and the guilt that may be associated with discovering that other family members also have the increased cancer risk. Even though support groups, in general, are widely available for a variety of diseases, groups tailored to women with a hereditary breast cancer predisposition are rare.

Women with a hereditary predisposition who have a personal history of breast cancer may be served by one of numerous breast cancer support groups. Such a support group may address their needs because women are often more concerned about an actual diagnosis of breast cancer and the subsequent follow-up, treatment, and prognosis, rather than a genetic test informing them that they are at an increased risk for breast cancer.<sup>1</sup> However, a woman with a diagnosis of breast cancer faces very different issues if found to carry a hereditary breast cancer predisposition. When compared to other women with

breast cancer, the woman with a hereditary predisposition has an increased risk for contralateral breast cancer and an increased risk for ovarian cancer.<sup>2,3</sup> Therefore, she may have difficult decisions to make regarding what course of medical management are compatible with her comfort level. Reports in the literature state that psychological support is important for high-risk women faced with difficult medical management decisions.<sup>4</sup> In addition, women may encounter issues regarding a genetic condition in the family, such as those previously mentioned, and may feel guilt or anger toward inheriting such a predisposition.

Women who have not yet developed breast cancer but have been found to have inherited a predisposition have even fewer available support services. In addition to not qualifying for group membership, support groups for women with breast cancer or breast cancer survivors do not address the specific needs or issues of a woman with a hereditary predisposition. The need for comparable support services for women with a hereditary breast cancer predisposition is supported by studies that have shown a positive genetic test for a breast cancer predisposition ignites a psychological response similar to that of a breast cancer diagnosis.<sup>5</sup> This need is compounded by the issues that face unaffected women. After testing positive for a hereditary breast cancer predisposition, women without a prior diagnosis are faced with many of the same medical management decisions mentioned above. However, in this context, the decisions address cancer prevention rather than management. Therefore, women may struggle more with their decisions because they involve weighing the chances to develop cancer with their comfort to undergo preventative interventions in the absence of a cancer diagnosis. In summary, there is a need for support services that are specific to this population of women.

To date, the research conducted on this population indicates that most women will not require additional support services, but that a “significant majority” will.<sup>6</sup> More research efforts are needed to further clarify what percent of women with a hereditary breast cancer predisposition require additional information or support services. In addition, since current studies indicate that not all women with a hereditary breast cancer predisposition will need additional support, healthcare professionals may benefit from research aimed at determining what characteristics are associated with a greater need for such services. Therefore, reports in the literature express a need for identifying subgroups of individuals who undergo genetic testing that may be vulnerable to experiencing testing-specific concerns.<sup>7,8</sup>

Given the unique issues and needs of women with a hereditary breast cancer predisposition, a support group was established in the summer of 2004 at Allegheny General Hospital to address some of these concerns. This study is designed to document the process of starting that group, to investigate differences between the women that elected to participate in the support group versus those who declined participation, and to explore what factors influenced a woman’s perceived breast cancer risk and need for a support group. It was expected that the support group participants will have more anxiety about their risk, less confidence in medical management decisions, and less support from other sources; and that factors such as a personal history of cancer, a strong family history of cancer, or a lack of preventative surgery are likely to increase a woman’s perceived cancer risk or need for support.

## 1.1. SPECIFIC AIMS

Specific Aim 1: To document the process of developing a support group for women with a hereditary breast cancer predisposition.

Hypothesis: Given the unique challenges associated with carrying an inherited breast cancer predisposition, a support/discussion group can be established to address the needs of women with a mutation in the *BRCA1*, *BRCA2*, or *PTEN* genes.

Plan: An examination of the various characteristics of self-help and support groups was performed. Group characteristics include the format of sessions, membership criteria, group leadership, and details such as when and where to meet. The process for designing and organizing a support group to meet the needs and expectations of the women with a hereditary breast cancer predisposition was documented.

Specific Aim 2: To explore the reasons why women with a hereditary breast cancer predisposition choose to participate in a support group or decline involvement.

Hypothesis: Women who chose to participate in a support/discussion group for those with a hereditary breast cancer risk are more likely to have more anxiety about their risk, less confidence in their medical management decisions, and less support from other sources when compared to non-participants.

Plan: A questionnaire was mailed to study participants. The characteristics of women who chose to participate in the support group and those who decline participation will be analyzed. These two groups of women were compared based on a variety of characteristics, such as differences in perceptions of cancer risk and current levels of support.

Specific Aim 3: To examine a variety of factors that might affect a woman's perceived cancer risk and need for a support group.

Hypothesis: Factors such as a personal history of cancer, a strong family history of cancer, or a lack of preventative surgery are likely to increase a woman's perceived cancer risk or need for support.

Plan: The questionnaire responses of all study participants will be analyzed to see what factors are most influencing the perceived risks and level of support. This will be done through correlation studies and subdividing the population based on the various characteristics to identify which factor is having the greatest impact.

## **1.2. B. BACKGROUND AND SIGNIFICANCE**

### **1.2.1. Self-Help vs. Support Groups**

Self-help and support groups are often comprised of individuals who are in a similar situation or who face the same issues. These two terms are often used interchangeably and the similarities between the two mean that research and theory on the one are often

applicable to the other. However, the terms “self-help” and “support” group can be distinguished by subtle differences. The distinction between these two types of groups lies in the role of professionals in group activities, the size of the organizations membership, the extent and type of the group’s change orientation, and the degree of local group autonomy.<sup>9</sup>

### **Definitions**

A self-help group is defined as a supportive, educational, usually change-oriented mutual-aid group that addresses a single life problem or condition shared by all members. Leadership of these groups often comes from within the members and professionals are rarely involved in the group’s activities, unless they participate as members. A membership criterion for the group is having the problem, situation, or identity in common with the other members. The meetings are often structured and task-oriented. They may involve the use of specific methods of help for the shared problem or condition.<sup>9,10</sup>

A support group is defined as a group that meets for the purpose of giving emotional support and information to persons with a common problem. There is less of a focus on individual and social change and more of a concentration on support and education. Leadership of these groups is often by professionals. They are also usually linked to a social agency or a larger, formal organization. Membership criteria may exclude individuals not served by the sponsoring organization. The meetings are often unstructured.<sup>9</sup>

### **Continuum of Services**

An alternative description of self-help and support groups is that they exist at opposite ends of a continuum. This continuum spans the distance between the definitions provided above and many existing groups share some features of both types of groups. As the concept of a continuum suggests, even though a group's primary focus is to educate, some aspects may have an impact on personal growth or change. Conversely, groups whose primary focus is to empower participants towards personal change or growth may also, in some fashion, provide information. In actuality, it is likely that the majority of existing groups have aspects fitting into the definition of both support and self-help groups. This overlap allows for the collective discussion of groups that provide support and self-help services.<sup>9</sup>

#### **1.2.2. History of Self-Help and Support Groups in the U.S.**

In this country and around the world, the majority of documented self-help or support groups were amongst those dealing with substance-related addiction.<sup>11</sup> Even though the start of Alcoholics Anonymous (AA) in 1935 is often referred to as the origin of self-help in this country, various accounts of such groups exist that predate AA. As early as the 1730's, Native Americans were forming abstinence-based mutual aid societies.<sup>12</sup> Early immigrants also witnessed a succession of self-help organizations such as the Washingtonians of the 1840s, the Ribbon Reform Clubs of the 1870s, and local groups such as the Dashaways in San Francisco (1859) and the Drunkard's Club in New York City (1871).<sup>13</sup> As time passed, substance control self-help groups were established that addressed different subgroups of people (based on sex, age, ethnicity, etc.), different

objectives, different problem areas, and that served various locations, both domestic and international.

Then in 1935, with the formation of Alcoholics Anonymous by William Wilson and Robert Smith, self-help groups took on a new level of recognition and availability. This is in part due to the long-standing success of AA, which is attributed to its framework of recovery (Twelve Steps) and set of organizational principles (Twelve Traditions).<sup>10</sup> The legacy of AA still continues and today it is comprised of approximately 100,000 registered groups with more than two million members in over 150 countries. In addition, the success of this organization and perceived effectiveness in helping those with addiction has led to the development of additional organizations such as Narcotics Anonymous and Women for Sobriety.

Although not as visible as Alcoholics Anonymous, other self-help or support groups have been in existence in this country since its very beginnings. The history of support groups stems back to the mid-1800's when immigrants arriving in the United States sought out others with a common ethnic background for advice and support in finding their ways in a new place.<sup>14</sup> Groups formed that addressed feelings of isolation, language problems, and intolerance. The Pan-Hellenic Union was formed for a Greek community and mutual help societies were organized for Jewish ghettos of major cities.<sup>10</sup> The support networks existed until immigration slowed at the onset of World War I and then sprung up again with successive waves of immigration. This led to the establishment of support networks for Hispanic, Asian, and Russian immigrants to this country.<sup>15</sup>

Through the years, groups providing help and support services have been established to meet the ever-changing needs of society. Self-help organizations for individuals with



physical and mental health concerns surfaced in the 1950's and 1960's. Some of the larger and better-known self-help groups related to healthcare that began during this time include the National Hemophilia Foundation founded in 1948, the Association for Retarded Citizens founded in 1950, the Muscular Dystrophy Association of America founded in 1950, the United Cerebral Palsy Association of American founded in 1954, and the National Cystic Fibrosis Foundation founded in 1957.<sup>16</sup>

Contributions to the success of the self-help movement were also made by health care professionals. Most notably, Karl Rogers and his teachings aided to shift the way professionals viewed and approached patients. The teachings of Rogers contain a basic sense of trust in the patient's ability to move forward in a constructive manner if the appropriate conditions fostering growth are present. To apply these teachings to healthcare involves assuming that patients have the ability to help themselves and that they are able to make their own decisions. This approach to dealing with patients was in contrast to the accepted practice of directing patients regarding their medical management. As a result of this shift, many health care fields attempted to offer non-directive services to patients and empower them to be proponents of their own health.<sup>17</sup>

Patients began to act as consumers who asked questions of healthcare professionals and were actively involved in their medical decision making. During the 1970's, this movement lead to an expansion of group therapy and support options for patients. Furthermore, this shift in the delivery of medical services created an environment in which self-help and support were viewed as necessary components of health care.<sup>9</sup>

Another proponent of this movement was Surgeon General C. Everett Koop, MD who offered to support these organizations. In 1987, under his leadership, a workshop entitled

“Self-Help and Public Health” was conducted. The following is a quote from the minutes of the workshop:

"My years as a medical practitioner, as well as my own first-hand experience, have taught me how important self-help groups are in assisting their members in dealing with problems, stress, hardship, and pain.... Today, the benefits of mutual aid are experienced by millions of people who turn to others with a similar problem to attempt to deal with their isolation, powerlessness, alienation, and the awful feeling that nobody understands."<sup>18</sup>

This workshop emphasized the tremendous impact of self-help groups and led to recommendations for increasing self-help activities that combine the efforts of the formal healthcare system with the efforts of individuals and small groups. As a follow-up to the encouragement of Dr. Koop, the National Council on Self-Help and Public Health was established. This organization is a federally funded group of self-help policy specialists.<sup>16</sup>

### **1.2.3. Genetic Support Groups**

Throughout the evolution of self-help groups and support networks, many organizations, such as some previously mentioned, have been established to deal with the issues surrounding genetic diseases. The occurrence of a genetic disease may have a strong impact on an individual because genetic diseases usually have an effect throughout a person's life and may involve complex scientific concepts. This may cause affected individuals to develop a sense of hopelessness or confusion if explanations are not provided to the patient. Patients may also experience a sense of hopelessness because currently there are no cures for genetic diseases. In addition, genetic diseases can have a strong impact because they rarely affect just one person, but usually have ramifications

for an entire family. The family dynamics associated with genetic disorders can involve a complex system of intense emotions such as fear, guilt, or blame. These groups have a unique capacity for reducing isolation among individuals and families with genetic disorders.<sup>19</sup>

Support groups for families dealing with genetic disease have been established for various reasons and by people impacted by the disease. These groups are referred to as “support” groups because their primary function is often to provide educational and supportive services, however these groups often serve a variety of purposes. Many organizations were originally formed to raise money to support treatment, research, and public education. The formation of other groups may be aimed at filling in gaps in modern healthcare to provide more personalized treatment with a focus on daily living.<sup>19</sup>

The formation of genetic support groups may also occur in response to the barriers to sufficient genetic information that individuals may experience after a diagnosis. The barriers encountered include limited professional knowledge about the disorder, difficulties knowing where to go to get desired genetic information, financial costs, lengthy travel time to major medical centers, and a lack of flexibility in scheduling appointments.<sup>24</sup>

Not only are genetic support groups formed for various reasons, they are also organized by a variety of individuals. This may include patients, parents, spouses, and healthcare professionals, such as doctors, genetic counselors, nurses, and social workers. For example, one of the first organizations for individuals and families with genetic disorders is Little People of America (LPA), which was founded by actor Billy Barty in 1957. Starting with 21 individuals of short stature, LPA now has more than 5,000 members

from across the United States and involvement with similar organizations in Canada, Europe, and Asia.<sup>16</sup>

#### **1.2.4. Growing Popularity**

Today, support groups, in general, serve various populations who are searching for a common bond with others in a similar circumstance. This growing trend is reportedly underestimated by the public and health professionals alike. Support and self help groups blend very smoothly into city and small-town subcultures. The group participants themselves are often unaware of the rapidly increasing phenomenon. Participants often see themselves more narrowly as part of their specific group rather than contributing to a national movement.<sup>20</sup>

Emerging technologies and the ability to detect and test for various genetic disorders has increased the number of and need for self-help and support groups that address the specific needs of a family with a genetic disorder. Therefore, many support groups are emerging that deal with genetic disorders, assist patients and their families in learning new information, and help them understand the impact of such information on day-to-day living. However, even though these services are continually being developed, they may not be available for all individuals in need of services. Support services for genetic conditions face the challenge of reaching potential participants, especially since there may not be a large number of individuals with the same condition living within close proximity. Therefore, networks have been established to help individuals with rare genetic disorders connect with other affected families.<sup>16</sup>

One such network is the Genetic Alliance, which was founded in 1986. The Genetic Alliance is an international coalition comprised of more than 600 advocacy, research and healthcare organizations that represent millions of individuals with genetic conditions and their interests. The Alliance works to promote healthier lives by fostering the integration of genetic advances into quality and affordable healthcare, public awareness and consumer-centered public policies.<sup>21</sup>

Another example of a network of support services is The National Organization for Rare Disorders (NORD) which was founded by Abbey Meyers in the 1980's. The NORD has developed into a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.<sup>22</sup> Today, the NORD's Organizational Database provides information on more than 2,000 disease-specific and umbrella organizations, support groups, clearinghouses, registries and government agencies that serve the needs of the rare disorders community.<sup>23</sup>

#### **1.2.5. Services Provided by Genetic Support Groups**

Genetic support groups are continuing to play a vital role in the health care of an individual. Directors of genetic support groups indicate that these organizations not only provide their members with a wide range of supportive services but also address other needs of the individual as well as the public and health professionals. In a survey of 43 directors of national or international organizations, the variety of services provided to members was emphasized. When listing general service activities provided, membership

education about the medical care, treatment, and research of a specific disorder was the most performed service. Ninety-three percent of directors reported that their organization frequently performs this service. Other frequently performed services include educating health professionals and the public about the disorder and helping affected individuals adjust to the personal and emotional impact of the disorder.<sup>24</sup>

Similarly, organization and group participants cite the varied services offered. In a survey of 88 members of genetic support groups conducted at a national conference on such groups, the services reported to be frequently performed by the majority of groups included (1) education of members, (2) self help/peer counseling services, (3) public education about the disorder, and (4) education of health professionals about the impact of the disorder. Other services include fundraising for medical/genetic research, fundraising for services, advocacy efforts for all affected or individual members.<sup>19</sup>

Group participants acknowledge the importance of relationships with healthcare professionals, but also indicate the presence of services that their groups can provide, which professionals cannot. Group participants consistently recognize that support groups have something to offer that can not be duplicated by even the most well-intentioned professional. They emphasize the unique benefits of support and empathy that come from one's peers.<sup>19</sup>

Furthermore, research involving group participants also provides insight into what services are lacking from existing healthcare providers. Participants in genetic support groups report that, although they obtain genetic information from a variety of professional and informal sources, many of them experience barriers to obtaining sufficient genetic information. In a survey of 931 members of genetic organizations, the

respondents were given a list of 20 services that might be utilized in coping with the ramifications of a genetic disorder and asked which were needed, and if so, whether or not the service was received. Thirty-five percent of group members indicated that supportive counseling was a service often needed but not received, which was the highest percentage for any of the 20 services.<sup>24</sup>

In addition, genetic support groups do not only offer assistance to their members, but have the ability to provide services to others. These groups often serve the public and health care professionals by being a source of education. In the previously mentioned survey of 88 group participants, respondents were asked to list the services that they provide to health care professionals. The most frequent responses included the dissemination of information, sensitization to problems and accomplishments of affected individuals and their families, participation in and support for research, assistance in fundraising for research, and provision of support services for other patients.<sup>19</sup>

#### **1.2.6. Genetics of Hereditary Breast Cancer**

Breast cancer is a relatively common occurrence, affecting about 1 in 8, or 13%, of women that live to the age of 85. In the United States, it is estimated that during 2005 approximately 211,240 women will develop breast cancer, and 40,410 women will die from the disease. In addition, 1,690 new cases and 460 deaths due to male breast cancer are predicted.<sup>25</sup>

Most cases of breast cancer are sporadic occurrences, in which damage to the DNA is acquired. Acquired changes in the DNA sequence may be due to mistakes in cell replication or due to environmental exposures that cause DNA damage. However, it is

estimated that 5-10% of female breast cancer cases are the result of inherited changes in the DNA that are transmitted from parent to child and are therefore present from birth as germline mutations. Inherited mutations in tumor suppressor genes result in a predisposition to developing cancer. Several genes have been identified that confer an increased risk for breast and other cancers when an individual inherits a mutation. Of the breast cancer occurrences that are associated with hereditary predispositions, 52% are due to a mutation in *BRCA1*, 32% are due to a mutation in *BRCA2*, and 16% are due to mutations in other genes, such as *PTEN* and *TP53*.<sup>26</sup>

Mutations in these genes increase a woman's breast cancer risk up to 10-fold over the general population. For example, mutations in the *BRCA1* or *BRCA2* genes increase a woman's lifetime risk of developing breast cancer up to 85% compared to the population risk of 12%.<sup>27,28,29</sup> *PTEN* gene mutations increase a woman's risk for breast cancer to 25-50%, and *TP53* gene mutations carry a 90% lifetime risk of cancer.<sup>30,31,32</sup> In addition, these women often develop cancer at young ages and may develop multiple primary tumors in their lifetimes. For example, mutations in *BRCA1* and *BRCA2* also increase a woman's risk to develop ovarian cancer to 27- 44% compared to the general population risk of approximately 1.5%.<sup>27,28</sup> Even though there is an increased risk for other cancers associated with mutations in these genes, this study focuses on the unifying characteristic which is a predisposition to breast cancer.

#### **1.2.7. Genetic Counseling for Hereditary Breast Cancer**

Cancer genetic counseling is available to individuals with a significant history of cancer. The goal of cancer genetic counseling is to inform patients about the inheritance and



implications of hereditary cancer predispositions. Cancer genetic counselors also inform patients of the associated risks of a particular cancer syndrome and discuss any relevant testing options.

The patients referred to cancer genetic counselors may or may not have a personal history of breast cancer. Rather, these patients are referred due to a combination of personal and family characteristics that suggest an underlying predisposition to breast and/or ovarian cancer. Characteristics that are suggestive of an inherited predisposition include the presence of multiple affected generations, pre-menopausal breast cancer, bilateral breast cancer, or breast and ovarian cancer.

After the referral, the process of genetic counseling may take place in several steps. First, a patient will meet with a genetic counselor. During this first meeting, the patient's personal and family medical history will be reviewed, with special attention paid to the details that are indicative of a hereditary breast cancer predisposition. Then basic information regarding the occurrence of cancer (hereditary vs. sporadic) is discussed. The basic function of genes and the role that certain genes play in cancer development is also reviewed. Depending on the predisposition syndrome suspected, the non-functioning gene and associated cancer risks are discussed. This initial session may also involve a description of the testing procedure and the implications of the possible results. To aid in the decision-making process, the genetic counselor will often provide an estimate of risk assessment, or the likelihood that a mutation conferring a cancer predisposition would be identified. This discussion also involves the provision of information regarding medical management decisions that may be faced in light of the results from a genetic test.

In some situations, after the initial meeting, the patient may elect to pursue genetic testing for a particular cancer predisposition syndrome. On the other hand, in some situations, the rest of the genetic counseling process may take several meetings. The patient may try to gather more family information, medical records, or information about insurance coverage. In either situation, the genetic counselor will work with the patient to provide the most accurate information based on the available family and medical history. The counselor will also keep an open line of communication with the patient in order to keep him/her updated and informed about pertinent research studies and emerging genetic testing opportunities.

As a part of clinical practice, if genetic testing is pursued, the test results are disclosed to the patient in person by their genetic counselor. With the information gained from the genetic counseling meetings and genetic test results, individuals are often faced with multiple decisions concerning the prevention and early detection of cancer. Options include prophylactic surgery, extensive cancer surveillance regimen, and the task of informing relatives about their potentially increased cancer risk. Because clinical cancer genetics is rapidly advancing, future communications are encouraged. Often a long-term relationship exists between the genetic counselor and patient. This relationship allows the counselor to share new information or details about new research. Likewise, patients contact the genetic counselor with questions, concerns or updates regarding their personal or family histories of cancer.

### **1.2.8. Impact of Genetic Testing for a Hereditary Breast Cancer Predisposition**

When women test positive for a hereditary breast cancer predisposition, they are then faced with many decisions regarding their medical management. Women often choose between pursuing increased surveillance, chemoprevention, or preventative surgery. For breast cancer surveillance, the American Cancer Society recommends yearly mammograms and semiannual clinical breast exams starting at age 25.<sup>33</sup> For chemoprevention, Tamoxifen may be taken to reduce the risk for breast cancer by as much as 50%, especially in women that carry a mutation in *BRCA2*.<sup>34</sup> And lastly, women may pursue prophylactic mastectomy to reduce their risk for breast cancer by 90%.<sup>35</sup>

In addition, a woman with a hereditary predisposition, depending on the gene involved, may also have an increased risk for ovarian cancer. For women with *BRCA1* or *BRCA2* mutations, the current recommendation by the American Cancer Society is to have the ovaries removed around the age of 35 or when a woman is done having children. This recommendation stems from the fact that surveillance for ovarian cancer, consisting of a transvaginal ultrasound and the CA-125 blood test, only detects about half of the cases of early stage ovarian cancer. In addition, these women may consider the use of oral contraceptives which can reduce the risk for ovarian cancer by 50% when taken for at least five years in a pre-menopausal woman.<sup>36</sup>

In addition to decisions regarding her personal medical management, a woman who tests positive for a hereditary breast cancer predisposition also has to deal with the ramifications for the rest of the family. A positive test result means that a woman's siblings and children all have a 50% risk of also carrying the hereditary predisposition.

Therefore, women who test positive may be faced with issues related to sharing information within the family and anxiety regarding having other people tested.

#### **1.2.9. Self-Help and Support Services for Women with a Hereditary Predisposition**

Current literature reports few supportive medical services exist for women who have tested positive for a hereditary breast cancer predisposition. Women are often provided information regarding their cancer risks and options but are then left to make many difficult decisions on their own. While it is important for women to make the appropriate medical choices, the effect of this information on their life is often overwhelming and emotionally draining. The lack of emotional and informational support must be filled through the collaborative efforts of genetic counselors, social workers, and other health professionals. This team must work together to develop innovative support services to meet the needs of this high-risk patient population.<sup>6</sup>

Previous studies do concede that the majority of people carrying a *BRCA1* or *BRCA2* mutation do not require support group interventions. However, these studies have found that a proportion of these patients desire some type of support service. In a study of 79 women with a *BRCA1* or *BRCA2* gene mutation, 19% participants felt that they needed more support than was received. Also, 68.4% felt a support group was necessary for *BRCA* mutation carriers.<sup>37</sup>

Current literature does not provide a sufficient number of reports regarding support groups for this specific population. One group conducted a study to explore how genetic testing had affected people found to have a *BRCA1* or *BRCA2* mutation and their

families, and to determine whether there was interest in a peer-support group. Nine of the 24 (38%) study participants felt that they would benefit from a support group. This study concluded that a “significant minority” of people carrying a *BRCA* mutation desired a support service. The authors indicated that the organization of support groups for individuals with hereditary cancer predispositions should be a priority for clinical cancer genetics programs providing genetic testing.<sup>6</sup> This literature and its recognition of the need for additional research on support services for women with a hereditary breast cancer predisposition spurred the efforts to start a support group and examine the process.

## **2. EXPERIMENTAL DESIGN AND METHODS**

### **2.1. PARTICIPANTS**

Of the 33 women who were contacted, 19 elected to participate in the study. Of the 19 study participants, 5 women decided to also participate in the support group and 14 decided to participate in only the study and not the support group.

These study participants were recruited from the population of female patients of the Cancer Center at Allegheny General Hospital, who have previously tested positive for a hereditary breast cancer predisposition. The participants originally received genetic counseling because of a family or personal history of breast cancer. They pursued genetic testing in a CLIA-approved laboratory and received a positive result for a *BRCA1*, *BRCA2*, or *PTEN* mutation. This information was disclosed to the patient in person by the genetic counselor at Allegheny General Hospital.

Inclusion criteria were female age over the age of 18 years with a previous genetic test which indicated the presence of a mutation causing a hereditary breast cancer predisposition. Race, ethnicity, and pregnancy status were not used as inclusion or exclusion criteria. Due to the effect of these mutations on specific cancer risks, men were excluded from the current study.

### **2.2. PROTOCOL**

The experimental plan was followed as approved by the Allegheny General Hospital Institutional Review Board and the University of Pittsburgh Institutional Review Board (Appendix A). A schematic flowchart of the protocol may be found in Appendix

B. The current study reports on the initial phase of a larger study being conducted at Allegheny General Hospital. The overall study is aimed at evaluating the formation, as well as the utility, of support services for this population.

### **2.2.1. Interest Survey (Prior to this Study)**

Due to an interest in talking with others or obtaining additional support services expressed by a patient of the Cancer Genetics Program at Allegheny General Hospital, an interest survey (Appendix C) was distributed to thirty-three women who had previously tested positive for a hereditary breast cancer predisposition. Patients were asked whether or not they had been provided with enough medical information to make decisions with healthcare providers and with enough information about emotional support options. They were also asked about their interest in speaking with other women who have a hereditary high risk for breast cancer. The interest survey also addressed details of potential group meetings, such as location, time, and topics to be discussed.

### **2.2.2. Organization of Support Group**

As a result of the interest expressed in the initial survey, arrangements were made to have an organizational meeting in the Meditation Room of the Cancer Center at Allegheny General Hospital. Those in attendance decided to have monthly meetings and discussed various topics of interest. Other details of the group's organization were discussed, such as requirements for participation. The participants felt it would be beneficial to limit regular attendance to women in the same situation, those with positive genetic tests for a

hereditary breast cancer predisposition. However, they also expressed interest in designating certain meetings for participation of family members and support persons.

### **2.2.3. Recruitment of Study Participants**

The subject population was contacted via telephone by their genetic counselor and informed of the opportunity to participate in a research study. The genetic counselor explained the purpose of the study and addressed questions from potential participants. If the potential participant indicated an interest in the study, a packet containing the informed consent document (Appendix D), questionnaire (Appendix E), and a pre-addressed stamped return envelope was mailed to her. Upon receipt of the informed consent and the initial questionnaire, the participant was enrolled into the study.

## **2.3. Data Analysis**

The questionnaire responses were analyzed to explore the differences between participants and non-participants and to determine what factors most influence a woman's perceived risk and need for support services. To explore the differences between participants and non-participants, two-sample t-tests assuming unequal variance were performed on all numeric data, specifically age and rankings regarding risk perception and sources of anxiety. In addition, the categorical data was analyzed using chi-squared tests.

To determine the factors most influencing a woman's perceived risk and need for support services, the population was stratified based on various characteristics and t-tests assuming unequal variances were again performed on the means between the stratified groups. For variables in which there were more than two possible responses, ANOVA



analysis was applied. In addition correlation studies were performed on numeric data. With respect to family history, correlation studies were performed between perceived cancer risk and both the total number of family members with breast or ovarian cancer and the number of alive or deceased relatives with breast and/or ovarian cancer. Lastly, correlation studies were performed on all rankings provided by the group participants on issues regarding risk perception, medical decision making, current levels of support, and issues of anxiety. The results of the analyses are described in the next section.

### **3. RESULTS**

#### **3.1. SPECIFIC AIM 1 - GROUP ORGANIZATION**

An initial step in the organization of a support or self-help group is identifying a gap in the current services provided to a particular population and individuals who would benefit by services offered by such a group. The need for additional support services for women with a hereditary breast cancer predisposition has been indicated in the literature.<sup>1,6</sup> In the formation of the group presently discussed, a gap in services was identified by a former patient of the cancer genetic counselor at Allegheny General Hospital. This patient expressed great interest in speaking with other women dealing with the decisions, issues, and concerns associated with a breast cancer predisposition.

This, coupled with the awareness of healthcare professionals of the complex issues facing women with a hereditary breast cancer predisposition, urged the cancer genetic counselor to conduct a survey of the patient population regarding interest in forming a support group. The responses to the survey indicated that there was a need. The counselor decided to undertake the organization of a support group for this particular population, women with a hereditary breast cancer predisposition.

According to the literature, a healthcare professional considering the organization of a support or self-help group is encouraged to identify a core group of individuals who represent those for whom the group is intended. In most situations, there is an agreement that this core group intends on participating in the group and aiding in its initial organization and function. It is advised that this core group be involved in planning and

deciding issues such as those discussed below. In this situation, the core group had already been identified through the interest survey; and it consisted of women with a positive genetic test for a hereditary breast cancer predisposition. These women were invited to a meeting at Allegheny General Hospital to discuss the organization and function of the intended support group. Five women were present at the organizational meeting.

The following is a discussion of the decisions to be made when starting a support or self-help group. Information regarding the various group characteristics was drawn from “Self-Help and Support Groups” by Linda Farris Kurtz, “Starting & Sustaining Genetic Support Groups” by Joan O. Weiss and Jayne S. Mackta, and “Group Therapy for cancer Patients” by David Spiegel and Catherine Classen.<sup>9,16,38</sup> The benefits or limitations of the various group characteristics are discussed below, as well as the manner in which each characteristic was addressed and decided upon in the current group setting.

### **3.1.1. Open-ended or closed group**

Many, if not most, support groups are open-ended, meaning that new members join regularly while returning members may drop out or attend sporadically. Open-ended membership ensures that individuals who seek out a support group will be able to receive those services as needed, instead of waiting until a new session or series begins. This method may enhance group membership and allows for group members at various stages in their coping process to interact with one another. On the other hand, a closed group provides for greater closeness of the group members and encourages members to share experiences since there will be no first-time attendees. Also, in the case of informational

group meetings, a closed group helps prevent the chance that a participant's major questions or concerns will have already been addressed in a previous session. However, as previously indicated, a closed group format can reduce the number of participants. It is estimated that only about 60% of group members will continue participating after the closure of a group with this format.<sup>9</sup>

In the current study, the decision regarding open-ended or closed membership was posed to the attendees at the organizational meeting. The women in attendance indicated that they favored an open-ended group membership. A driving force in this decision was the desire for all women with a hereditary breast cancer predisposition to have these support services available, especially since these predispositions are rare and services for this population are limited.

### **3.1.2. Size of the group**

Depending on the specific issue being addressed, size may or may not be an issue. A benefit of a larger group is that a wider range of experiences will be represented and participants may be more likely to encounter an individual who is dealing with or has previously dealt with their particular problem or issue. Group participants may also feel less isolation by realizing the number of individuals in a similar situation. On the other hand, smaller groups often lead to more intimate relationships between group members. Also, group members may receive more attention and are more likely to have their specific concerns addressed on the level of the entire group. Smaller groups better serve the needs of individuals who have felt alienated or over-looked by other sources of support services.

As previously mentioned, the size of the group is directly related to the membership criteria and whether the group is open or closed-ended. The number of group participants is rarely a predetermined number, but rather an indirect result of decisions made about the basic structure and function of the group.

In the current study, the size of the group was not discussed in the organizational meeting. The group members seemed to understand that there would inherently be a relatively small number (perhaps 6-10) of participants due to the rarity of gene mutations causing a hereditary predisposition to breast cancer.

### **3.1.3. Establishing membership criteria**

Support groups depend upon members who share the same problem or concern. Having the same primary concern is the essence of support groups and is typically the first criterion of group membership. This characteristic also is affected by the size of the group, with loose criteria encouraging larger groups and stricter criteria often leading to the formation of smaller groups. With this in mind, it is important to refrain from numerous eligibility restrictions as this may hinder the intended formation of a group. It is also important to have criteria that keep the group from becoming unmanageably large or from possessing members with very different issues. Larger groups may be managed by sub-dividing or forming small clusters of participants that share more characteristics and concerns in common.

In the current study, the goal was to organize a group for woman carrying a hereditary breast cancer predisposition. At the organizational meeting, the question of membership criteria was posed to those in attendance. It was decided that the group would be limited

to those who have tested positive for a hereditary breast cancer predisposition. This decision was made to ensure that the group could focus on the issues specifically facing this population, instead of those for individuals who tested negative or were considering the decision to undergo testing. For this same reason, those in attendance decided to limit the membership to women who have tested positive, even though men can also carry a gene for a hereditary breast cancer predisposition. Although male carriers also have a slightly increased risk for certain cancers when compared to the general population, the women at the organizational meeting felt that the issues and concerns of male carriers are very different. The highest risk for male breast cancer is 3-6%, which is associated with mutations in *BRCA2*.<sup>39</sup> Since males have a much smaller risk to develop breast cancer, they are not faced with the same decisions regarding their cancer risks and medical management. Overall, even though those at the organizational meeting decided to limit the membership to women with a positive genetic test for a hereditary breast cancer predisposition, they expressed interest in designating certain meetings to which carrier males, non-carrier family members, and other support individuals could be invited to attend.

Furthermore, the group at the organizational meeting decided to not limit membership based on the length of time since receiving test results. Even though this will lead to having group members who may be dealing with slightly different issues, it was decided that any woman with a hereditary breast cancer predisposition should be able to utilize the supportive services of the group.

#### **3.1.4. Meeting location**

The location of group meetings is also a critical issue in the formation of a support group. Support groups often meet in the sponsoring agency. In some situations a more neutral meeting place may be desirable. If the decision regarding location is made collectively, it may encourage group members to feel more ownership over the group. However, the meeting place should be accessible to all potential members and offer them safety and convenience with no disturbances by other events. In the absence of extenuating circumstances, the meeting location should ideally remain the same.

In the current study, meeting location was first addressed on the interest survey that was distributed prior to the decision to form a support group. Because of the possibility of negative feelings or a stigma that patients may associate with the Cancer Center at Allegheny General Hospital, the women were given several options for meeting locations. Most respondents indicated that the hospital was a convenient meeting location. However, there were women interested in participation that live a considerable distance from the hospital. Unfortunately, there was no location able to serve all interested women and those living relatively far outside the city were not able to participate in the support group.

In response to the indications of potential participants, the organizational meeting and most support group meetings were held in the Meditation Room in the Cancer Center of Allegheny General Hospital. The Meditation Room is a small carpeted room with about twelve chairs and windows along one wall. The group participants sat along the two sides room and speakers often projected presentations onto the wall at the end of the

rectangular room. Those in attendance felt the room was a very suitable meeting place and all subsequent group meetings were held in the room.

### **3.1.5. Leadership**

Leadership roles in many support groups are held by a variety of individuals including affected individuals, parents, or professionals. This is usually determined by the goals of the group and how the group was originally organized. Organizations aimed at dealing with psychological and emotional stress related to a condition are often led by an affected individual or a parent of an affected individual. This ensures that the leader of the group has personal experience with the issues faced by the group members. These groups are often formed when affected individuals or families seek out others in a similar situation for support. Organizations aimed at providing support through information are often led by healthcare professionals who are specifically trained in the shared condition. In this situation, professional leadership ensures that group members receive accurate information or referrals to organizations or other professionals who can address a specific issue. These groups are often formed when patients seek out additional help and support from their healthcare provider. In a study of genetic support groups, participants saw the efforts of their organizations as part of partnership with professionals and called for more active involvement by professionals.<sup>19</sup>

In the current study, the original idea to form a support group for this population arose when a former patient approached the cancer genetic counselor about her desire to speak with other women in her situation. The genetic counselor then decided to hold the organizational meeting. At that meeting, the issue of the involvement of the genetic



counselor in the group was raised. The members were asked whether her presence would affect their group experience, especially since she was a part of their experience with the genetic testing process. The group members responded by indicating that they viewed the genetic counselor as a valuable source of information and an asset to the group. The genetic counselor, with the help of an oncology nurse, has since assumed the co-moderator and organizational roles associated with the group. However, decisions regarding topics for discussion and guest speaker selection have been made based on the consensus of the group.

#### **3.1.6. Frequency of group meetings**

The frequency of group meetings may appear to be a less important detail of the formation of a support group. However, this characteristic is also related to the goals and needs of the group members. Groups for individuals in a serious crisis may better serve its members through frequent meetings, such as biweekly, weekly, or even more often. Frequent meetings may be unfeasible for group members due to their schedules or the distance to the meeting location. For many groups, frequent meetings will reduce the number of members at each meeting.

In the current study, the decision regarding the frequency of group meetings was posed to those in attendance at the organizational meeting. The group expressed interest in having monthly meetings, and thus far the group has had a meeting every month except for during the holiday season.

### **3.1.7. Duration of group meetings**

The duration, or the length of time over which the group meets, is also dependent on some of the other group characteristics and has the potential to influence membership. Groups that meet frequently and address very specific issues may have a set schedule of topics to discuss and therefore plan to only meet for several weeks. Groups with short durations are also more likely to be closed groups. Groups that meet for an extended amount of time usually have open membership and are more flexible about the topics discussed. Groups with longer durations are usually able to address a variety of issues and better serve individuals with extensive needs.

In the current study, the duration of the group was not determined prior to the group's formation. This study documents a first attempt at forming a support group for women with a hereditary breast cancer predisposition. Therefore, the group members are encouraged to provide feedback about what topics, if any, still need to be addressed. The general plan is to continue the group as long as there is interest and topics to be addressed. Thus far, an end to the current support group meetings has not been designated.

### **3.1.8. Group meeting format**

The format of the various group meetings has a strong impact on the function of the group and on the ability of group members to achieve their goals. If group members are primarily seeking supportive services, they may best be served by meetings with a discussion format in which they have the opportunity to reach out and share their experiences with others. Research has shown that peer discussion groups were helpful for women who lacked support from their partners or physicians but were harmful for

women who had high levels of support.<sup>40</sup> Therefore, group members who are primarily seeking information may best be served by meetings with a lecture format in which guest lecturers with information about a specific concern of the group participants can be invited to speak. In the cancer literature, education groups seem to be more effective than peer discussion groups.<sup>41</sup>

At the organizational meeting, two main themes emerged regarding the motivations of the women to join a support group. The first goal of the potential participants was to gain more information about hereditary breast cancer predispositions, including cancer screening, prophylactic surgeries, research, and others. The second goal was to speak with other women about their experiences and learn how they were able to make medical management decisions. Therefore, it was decided that the basic format for the group meetings would be to have informational lecturers speak about a specific topic and then allow time for the group participants to discuss the topic with one another and the speaker.

### **3.2. SPECIFIC AIM 2 - PARTICIPANTS VS. NON-PARTICIPANTS**

#### **3.2.1. Demographics**

Thirty-three women were invited to participate in the current study. Previously, all 33 women were invited to participate in a monthly support/discussion group. Five (15.2%) women accepted the invitation to participate in the group. As for this study, 19 (57.6%) of the thirty-three women who were contacted elected to participate, 5 (27.8%) were group participants and 14 (72.2%) were non-participants. The age of study participants ranged from 20 to 75 years, with a mean age of 45.8 years. The mean age of

group participants was 38.4 years, and the mean age of the non-participants was 48.5 years. Using a one-sided t-test, the difference between the mean age of group participants and non-participants is significant with a p-value of 0.03. Table 1 illustrates the age distribution of group participants and non-participants. It also shows the number and percentages of participants and non-participants with regard to marital status and educational level. A higher proportion of non-participants were married and had completed high school as their highest level of education, however these trends were not statistically significant.

**Table 1. Demographic information**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>Age</b>			
<30	0	1 (7%)	1 (5%)
30-39	3 (60%)	5 (36%)	8 (42%)
40-49	2 (40%)	1 (7%)	3 (16%)
50-59	0	2 (14%)	2 (11%)
60-69	0	4 (29%)	4 (21%)
≥70	0	1 (7%)	1 (5%)
<b>Marital Status</b>			
Single	3 (60%)	2 (14%)	5 (26%)
Married	2 (20%)	10 (71%)	12 (63%)
Divorced	0	1 (7%)	1 (5%)
Widowed	0	1 (7%)	1 (5%)
<b>Education Level*</b>			
High School	1 (20%)	7 (54%)	8 (44%)
Prof. Training	1 (20%)	2 (15%)	3 (17%)
Undergraduate	2 (40%)	4 (31%)	6 (33%)
Graduate	1 (20%)	0	1 (6%)

\* Percentages are based on the number of study participants that responded to the question.

### 3.2.2. Genetic Testing

As indicated in Table 2, the majority (84%) of the study population previously tested positive for a mutation in *BRCA1*. No women with *TP53* mutations were in the study population. Table 2 also displays information about the duration of time that has passed since the study participants received the result from their genetic test. It is important to consider that the cancer genetic counselor currently at Allegheny General Hospital has been employed for almost four years. This investigation examines her former patients, which explains why study participants were given the time interval options listed below. Group participants seemed to be more likely to have received their results more than a year ago. However, this finding was not statistically significant.

**Table 2. Gene Involved and Time since Results were Received**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>Gene Tested</b>			
<i>BRCA1</i>	3 (60%)	13 (93%)	16 (84%)
<i>BRCA2</i>	1 (20%)	1 (7%)	2 (11%)
<i>PTEN</i>	1 (20%)	0	1 (5%)
<b>Time since Results were Received</b>			
< 6 months	0	5 (36%)	5 (26%)
6 months – 1 year	1 (20%)	4 (29%)	5 (26%)
1-2 years	3 (60%)	5 (36%)	8 (42%)
> 2 years	1 (20%)	0	1 (5%)

### 3.2.3. Personal Cancer History

Even though it was not statistically significant, non-participants were more likely than group participants to have had a previous breast cancer diagnosis. However, this trend was not observed when considering ovarian cancer. No group participants have been diagnosed with both breast and ovarian cancer, whereas three non-participant women have been diagnosed with both cancers.

**Table 3. Personal Breast and/or Ovarian Cancer History**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>Breast</b>			
Yes	1 (20%)	8 (57%)	9 (47%)
No	4 (80%)	6 (43%)	10 (53%)
<b>Ovarian</b>			
Yes	1 (20%)	3 (21%)	4 (21%)
No	4 (80%)	11 (79%)	15 (79%)
<b>Breast and Ovarian</b>			
Yes	0	3 (21%)	3 (16%)
No	5 (100%)	11 (79%)	16 (84%)

### 3.2.4. Family Cancer History

No significant differences were found between group participants and non-participants in whether or not they have 1<sup>st</sup> or 2<sup>nd</sup> degree family members with breast cancer (Table 4), ovarian cancer (Table 6), or another type of cancer (Table 8). Furthermore, among study participants with affected family members, no trends were apparent in the average number of 1<sup>st</sup> or 2<sup>nd</sup> degree relatives with breast cancer (Table 5), ovarian cancer (Table 7), or other types of cancer (Table 9).

**Table 4. Number (and Percentages) of Women with a Relative with Breast Cancer**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Breast Cancer (Alive)</b>			
Yes	2 (40%)	10 (71%)	12 (63%)
No	3 (60%)	4 (29%)	7 (37%)
<b>1<sup>st</sup> Degree Relatives with Breast Cancer (Deceased)</b>			
Yes	3 (60%)	4 (29%)	7 (37%)
No	2 (40%)	10 (71%)	12 (63%)
<b>2<sup>nd</sup> Degree Relatives with Breast Cancer (Alive)</b>			
Yes	2 (40%)	3 (21%)	5 (26%)
No	3 (60%)	11 (79%)	14 (74%)
<b>2<sup>nd</sup> Degree Relatives with Breast Cancer (Deceased)</b>			
Yes	4 (80%)	10 (71%)	14 (74%)
No	1 (20%)	4 (29%)	5 (26%)

**Table 5. Average Number of Affected Relatives with Breast Cancer**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Breast Cancer (Alive)</b>	1.00	1.00	1.00
<b>1<sup>st</sup> Degree Relatives with Breast Cancer (Deceased)</b>	1.00	1.75	1.43
<b>2<sup>nd</sup> Degree Relatives with Breast Cancer (Alive)</b>	1.00	1.00	1.00
<b>2<sup>nd</sup> Degree Relatives with Breast Cancer (Deceased)</b>	3.25	2.2	2.50

**Table 6. Number (and Percentages) of Women with a Relative with Ovarian Cancer**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Ovarian Cancer (Alive)</b>			
Yes	1 (20%)	4 (29%)	5 (26%)
No	4 (80%)	10 (71%)	14 (74%)
<b>1<sup>st</sup> Degree Relatives with Ovarian Cancer (Deceased)</b>			
Yes	1 (20%)	4 (29%)	5 (26%)
No	4 (80%)	10 (71%)	14 (74%)
<b>2<sup>nd</sup> Degree Relatives with Ovarian Cancer (Alive)</b>			
Yes	1 (20%)	1 (7%)	2 (11%)
No	4 (80%)	13 (93%)	17 (89%)
<b>2<sup>nd</sup> Degree Relatives with Ovarian Cancer (Deceased)</b>			
Yes	3 (60%)	7 (50%)	10 (53%)
No	2 (40%)	7 (50%)	9 (47%)

**Table 7. Average Number of Affected Relatives with Ovarian Cancer**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Ovarian Cancer (Alive)</b>	1.00	1.00	1.00
<b>1<sup>st</sup> Degree Relatives with Ovarian Cancer (Deceased)</b>	1.00	1.25	1.20
<b>2<sup>nd</sup> Degree Relatives with Ovarian Cancer (Alive)</b>	3.00	1.00	2.00
<b>2<sup>nd</sup> Degree Relatives with Ovarian Cancer (Deceased)</b>	2.66	1.57	1.9



**Table 8. Number (and Percentages) of Women with a Relative with Cancer Other Than Breast or Ovarian**

	<b>Group Participants</b>	<b>Non- Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Other Cancer (Alive)</b>			
Yes	2 (40%)	4 (29%)	6 (32%)
No	3 (60%)	10 (71%)	13 (68%)
<b>1<sup>st</sup> Degree Relatives with Other Cancer (Deceased)</b>			
Yes	0	5 (36%)	5 (26%)
No	5 (100%)	9 (64%)	14 (74%)
<b>2<sup>nd</sup> Degree Relatives with Other Cancer (Alive)</b>			
Yes	4 (80%)	2 (14%)	6 (32%)
No	1 (20%)	12 (86%)	13 (68%)
<b>2<sup>nd</sup> Degree Relatives with Other Cancer (Deceased)</b>			
Yes	3 (60%)	7 (50%)	10 (53%)
No	2 (40%)	7 (50%)	9 (47%)

**Table 9. Average Number of Affected Relatives with Cancer Other than Breast or Ovarian**

	<b>Group Participants</b>	<b>Non- Participants</b>	<b>Total</b>
<b>1<sup>st</sup> Degree Relatives with Other Cancer (Alive)</b>	2.5	1.5	1.83
<b>1<sup>st</sup> Degree Relatives with Other Cancer (Deceased)</b>	0	1.4	1.4
<b>2<sup>nd</sup> Degree Relatives with Other Cancer (Alive)</b>	1.25	1.0	1.17
<b>2<sup>nd</sup> Degree Relatives with Other Cancer (Deceased)</b>	3.33	2.14	2.5

### 3.2.5. Result Disclosure and Family Communication

Overall, the group participants and non-participants were evenly distributed as to whether or not they were the first person in their family to undergo genetic testing (Table 10). The majority of all study participants indicated that they were accompanied to the disclosure of their test results and that they preferred accompaniment. The majority of both participants and non-participants indicated that other family members have been tested and that there is reciprocal communication with the family members regarding test results.

**Table 10. Genetic Testing, Result Disclosure, and Communication with Family Members**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>First in Family to be Tested</b>			
Yes	2 (40%)	7 (50%)	9 (47%)
No	3 (60%)	7 (50%)	10 (53%)
<b>Accompanied to Disclosure*</b>			
Yes	2 (40%)	10 (83%)	12 (71%)
No	3 (60%)	2 (17%)	5 (29%)
<b>Prefer Accompaniment*</b>			
Yes	3 (60%)	11 (85%)	14 (78%)
No	2 (40%)	2 (15%)	4 (22%)
<b>Other Family Members have been Tested</b>			
Yes	4 (80%)	14 (100%)	18 (95%)
No	1 (20%)	0	1 (5%)
<b>Talk with Relatives Regarding Results</b>			
Yes	5 (100%)	14 (100%)	19 (100%)
No	0	0	0
<b>Relatives Talk with You Regarding Results*</b>			
Yes	3 (75%)	13 (93%)	16 (89%)
No	1 (25%)	1 (7%)	2 (11%)

\* Percentages are based on the number of study participants that responded to the question.

### 3.2.6. Risk Reduction

No statistically significant differences were found between group participants and non-participants regarding their decisions for risk reduction medical interventions such as mastectomy or oophorectomy (Table 11). However, a higher percentage of non-participants than group participants have had an oophorectomy. The majority of group participants and non-participants have decided against the use of Tamoxifen or oral contraceptives. No study participants indicated that they were unsure or still considering these chemoprevention techniques. One group participant and no non-participants indicated the use of other risk reduction interventions. The group participant indicated that she uses holistic medicine options to reduce her cancer risk.

**Table 11. Risk Reduction Decisions**

	<b>Group Participants</b>	<b>Non-Participants</b>	<b>Total</b>
<b>Mastectomy</b>			
Yes	2 (40%)	5 (36%)	7 (37%)
Unsure	1 (20%)	2 (14%)	3 (16%)
No	2 (40%)	7 (50%)	9 (47%)
<b>Oophorectomy</b>			
Yes			
Therapeutic	1 (20%)	3 (21%)	4 (21%)
Prophylactic	2 (40%)	8 (58%)	10 (53%)
Unsure	0	1 (7%)	1 (5%)
No	2 (40%)	2 (14%)	4 (21%)
<b>Tamoxifen</b> *			
Yes	2 (40%)	0	2 (11%)
No	3 (60%)	13 (100%)	16 (89%)
<b>Oral Contraceptives</b> *			
Yes	0	2 (15%)	2 (12%)
No	4 (100%)	11 (85%)	15 (88%)
<b>Other</b> *			
	1 (100%)	0	1 (100%)

\* Percentages are based on the number of study participants that responded to the question.

### 3.2.7. Risk Perception and Support

Study participants were asked to rank various characteristics such as their perceived cancer risks and current levels of support on a scale from zero to ten (Table 12). Study participants made rankings by placing marks along a line representing a continuum of emotion or concern. For the perceived cancer risk, the continuum ranged from “not a concern” (0) to “certain will be affected” (10). For the other items, the continuum ranged from an absence of the item (0) to complete or absolute presence of that item (10). Group participants had slightly higher perceived cancer risk ( $p=0.17$ ) and a higher need for a support group ( $p=0.054$ ). They also reported slightly lower perceived ovarian cancer risk ( $p=0.41$ ), confidence in decisions ( $p=0.46$ ), control over cancer risk ( $p=0.15$ ), and support from family and friends ( $p=0.19$ ).

**Table 12. Mean Rankings ( $\pm$  standard deviation) Regarding Risk Perception and Support**

	<b>Group Participants</b>	<b>Non- Participants</b>	<b>Total</b>
<b>Perceived Breast Cancer Risk</b>	8.82 ( $\pm$ 1.78)	7.78 ( $\pm$ 2.44)	8.07 ( $\pm$ 2.28)
<b>Perceived Ovarian Cancer Risk</b>	5.13 ( $\pm$ 4.86)	5.71 ( $\pm$ 3.73)	5.55 ( $\pm$ 3.93)
<b>Confidence in Decisions</b>	7.41 ( $\pm$ 2.41)	7.52 ( $\pm$ 2.00)	7.49 ( $\pm$ 2.05)
<b>Control Over Cancer Risk</b>	3.02 ( $\pm$ 3.31)	4.85 ( $\pm$ 2.77)	4.36 ( $\pm$ 2.95)
<b>Support from Family and Friends</b>	7.25 ( $\pm$ 2.32)	8.37 ( $\pm$ 2.28)	8.07 ( $\pm$ 2.28)
<b>Need for a Support or Discussion Group*</b>	5.85 ( $\pm$ 2.61)	3.31 ( $\pm$ 2.91)	3.98 ( $\pm$ 2.99)

\* Indicates a significant difference between the means ( $p<0.10$ ).

### 3.2.8. Sources of Anxiety

The study participants were asked to rank their anxiety levels regarding communication with others and regarding medical decision-making. Study participants made rankings between zero and ten by placing marks along a line representing a continuum. For these items, the continuum went from “comfortable” (0) to “very anxious” (10). In general, the group participants had more anxiety than non-participants regarding all the items addressed. Group participants appear to have greater anxiety associated with talking to their children; however, this was based on a very small number of group participants that have children and was not statistically significant.

**Table 13. Mean rankings ( $\pm$  standard deviation) Regarding Sources of Anxiety (0=comfortable  $\rightarrow$  10=very anxious)**

	<b>Group Participants</b>	<b>Non- Participants</b>	<b>Total</b>
<b>Talking with Relatives and Having Them Tested</b>	2.88 ( $\pm$ 2.19)	1.68 ( $\pm$ 2.55)	2.00 ( $\pm$ 2.46)
<b>Talking with Children</b>	5.56 ( $\pm$ 4.75)	1.39 ( $\pm$ 2.52)	2.08 ( $\pm$ 3.14)
<b>Talking with Partner</b>	2.16 ( $\pm$ 3.06)	0.53 ( $\pm$ 0.48)	0.80 ( $\pm$ 1.20)
<b>Decisions About Screening or Prevention</b>	2.21 ( $\pm$ 2.09)	1.42 ( $\pm$ 2.49)	1.63 ( $\pm$ 2.36)

### **3.3. SPECIFIC AIM 3 – FACTORS AFFECTING PERCEIVED RISK AND SUPPORT**

#### **3.3.1. Risk Perception and Need for Support using Categorical Information**

Study participants were asked to rank their perceived cancer risks and need for support on a scale of zero to ten by placing marks along a line representing a continuum. For the perceived cancer risk, the continuum went from “not a concern” (0) to “certain will be affected” (10). For the need for support, the continuum ranged from “no need” (0) to “absolutely necessary” (10). Table 14 displays the differences in perceived breast cancer risk and need for a support group when the study population was stratified based on demographic and medical history information.

Women with *BRCA2* mutations reported a statistically significant higher need for support and the participant with a *PTEN* mutation reported a lower perceived cancer risk. Higher levels of both perceived breast cancer risk and need for support were reported by women who received their test result over one year prior to the formation of the support group. In addition, women without a personal history of breast cancer reported higher breast cancer risks perceptions than women with a previous diagnosis. The perceived breast cancer risk of those women who have not pursued preventative surgery was slightly higher than women who have had a mastectomy or oophorectomy, whereas women reporting that they were unsure about the decision regarding preventative surgery indicated the highest perceived cancer risk.

**Table 14. Mean rankings ( $\pm$  standard deviation) of Perceived Breast Cancer Risk and Need for Support when Stratified by Demographic and Personal History Information**

	<b>Perceived Breast Cancer Risk</b>	<b>Need for a Support or Discussion Group</b>
<b>Marital Status</b>		
<b>Single</b>	8.06 ( $\pm$ 1.53)	3.04 ( $\pm$ 2.37)
<b>Married</b>	7.91 ( $\pm$ 2.73)	4.24 ( $\pm$ 3.46)
<b>Divorced/Widowed</b>	8.92 ( $\pm$ 1.53)	4.75 ( $\pm$ 0.92)
<b>Educational Level</b>		
<b>High School</b>	8.17 ( $\pm$ 1.18)	3.18 ( $\pm$ 3.16)
<b>Professional Training</b>	9.61 ( $\pm$ 0.60)	4.31 ( $\pm$ 2.40)
<b>College/Grad. Degree</b>	7.57 ( $\pm$ 3.33)	5.19 ( $\pm$ 3.00)
<b>Gene Involved**</b>		
<i>BRCA1</i>	8.09 ( $\pm$ 2.39)	3.36 ( $\pm$ 2.64)
<i>BRCA2</i>	8.90 ( $\pm$ 1.56)	8.85 ( $\pm$ 1.63)
<i>PTEN</i> <sup>+</sup>	6.00	4.10
<b>Time Since Results Received</b>		
<b>&lt;6 months</b>	7.46 ( $\pm$ 1.01)	1.78 ( $\pm$ 2.11)
<b>6 months - 1year</b>	7.03 ( $\pm$ 4.34)	4.50 ( $\pm$ 3.47)
<b>1-2 years</b>	8.96 ( $\pm$ 1.46)	5.11 ( $\pm$ 2.90)
<b>&gt;2 years</b> <sup>+</sup>	8.11	3.24
<b>Breast Cancer Diagnosis</b>		
<b>Yes</b>	7.64 ( $\pm$ 2.95)	3.30 ( $\pm$ 4.39)
<b>No</b>	8.49 ( $\pm$ 1.37)	4.73 ( $\pm$ 3.01)
<b>Ovarian Cancer Diagnosis</b>		
<b>Yes</b>	8.24 ( $\pm$ 1.26)	4.39 ( $\pm$ 3.25)
<b>No</b>	8.02 ( $\pm$ 2.53)	3.83 ( $\pm$ 3.01)
<b>Mastectomy</b>		
<b>Yes</b>	7.33 ( $\pm$ 3.11)	4.69 ( $\pm$ 3.54)
<b>Unsure</b>	9.34 ( $\pm$ 1.06)	3.68 ( $\pm$ 1.26)
<b>No</b>	8.23 ( $\pm$ 1.64)	3.52 ( $\pm$ 3.11)
<b>Oophorectomy</b>		
<b>Yes</b>	7.92 ( $\pm$ 2.49)	4.08 ( $\pm$ 2.80)
<b>Unsure</b> <sup>+</sup>	10.00	2.70
<b>No</b>	8.05 ( $\pm$ 1.76)	3.93 ( $\pm$ 4.38)
<b>Overall</b>	8.07 ( $\pm$ 2.28)	3.98 ( $\pm$ 2.99)

<sup>+</sup> No standard deviation provided because the observation is based on one study participant.

\*\* Indicates a significant difference between the means ( $p < 0.05$ ).

### 3.3.2. Correlation Studies

A correlation study was performed to examine the impact of the number of 1<sup>st</sup> or 2<sup>nd</sup> degree relatives with a diagnosis of breast, ovarian, or some other type of cancer on the risk perception of the study participant (Table 15). For the correlation studies, perceived breast cancer risk had a significant correlation to perceived ovarian cancer risk ( $p=0.08$ ). A significant correlation existed between perceived breast cancer risk and the number of first or second degree relatives with breast cancer ( $p=0.01$ ).

**Table 15. Correlation Values between Perceived Cancer Risk and Number of Relatives with Breast, Ovarian, or Some Other Type of Cancer**

		Perceived Breast Cancer Risk	Perceived Ovarian Cancer Risk	Relatives with Breast Cancer	Relatives with Ovarian Cancer	Relatives with Other Cancer
Perceived	Breast	1.00				
Cancer Risk						
Perceived	Ovarian	0.43*	1.00			
Cancer Risk						
Relatives	with	0.56**	0.16	1.00		
Breast Cancer						
Relatives	with	0.32	0.17	0.67***	1.00	
Ovarian Cancer						
Relatives	with	0.01	0.10	0.53**	0.59***	1.00
Other Cancer						

\* Indicates a significant correlation ( $p<0.10$ ).

\*\* Indicates a significant correlation ( $p<0.05$ ).

\*\*\* Indicates a significant correlation ( $p<0.01$ ).

Similarly, correlation studies were conducted on the perceived cancer risk and the number of living or deceased relatives with breast or ovarian cancer (Table 16). A significant correlation existed between perceived breast cancer risk and the number of deceased relatives with breast or ovarian cancer ( $p=0.05$ ).



**Table 16. Correlation Values between Perceived Cancer Risk and the Number Relatives (Alive or Deceased) with Breast or Ovarian Cancer**

	Perceived Breast Cancer Risk	Perceived Ovarian Cancer Risk	Alive Relatives with Breast or Ovarian Cancer	Deceased Relatives with Breast or Ovarian Cancer
Perceived Breast Cancer Risk	1.00			
Perceived Ovarian Cancer Risk	0.43*	1.00		
Alive Relatives with Breast or Ovarian Cancer	0.23	0.16	1.00	
Deceased Relatives with Breast or Ovarian Cancer	0.45*	0.09	0.31	1.00

\* Indicates a significant difference between the means ( $p < 0.10$ ).

Correlation studies were performed on the rankings that study participants provided on issues regarding cancer risk, medical management decisions, support levels, and sources of anxiety (Table 16). Significant correlations were present between all items addressing sources of anxiety ( $0.087 \geq p \geq 5.38 \times 10^{-8}$ ), indicating that individuals with anxiety about one issue often have anxiety about a variety of other issues. In addition, significant correlations were observed between control over cancer risk and both anxiety regarding talking with children ( $p=0.040$ ) and anxiety about screening or prevention decisions ( $p=0.027$ ). Other significant correlations existed between perceived breast cancer risk and perceived ovarian cancer risk ( $p=0.080$ ), perceived breast cancer risk and need for a support group ( $p=0.077$ ), and perceived ovarian cancer risk and anxiety about talking with partner (0.055).

**Table 17. Correlation Values for Numeric or Ranked Items**

	Breast Cancer Risk	Ovarian Cancer Risk	Confidence in Decisions	Control Over Cancer Risk	Support from Friends and Family	Need for a Support Group	Anxiety about Talking with Relatives and Having Them Tested	Anxiety about Talking with Children	Anxiety about Talking with Partner	Anxiety about Screening/ Prevention Decisions
Breast Cancer Risk	1.00									
Ovarian Cancer Risk	0.43*	1.00								
Confidence in Decisions	-0.20	-0.14	1.00							
Control Over Cancer Risk	-0.16	-0.03	0.36	1.00						
Support from Friends and Family	-0.10	-0.11	0.41*	0.33	1.00					
Need for a Support Group	0.43*	-0.19	-0.03	-0.31	0.19	1.00				
Anxiety about Talking with Relatives and Having Them Tested	-0.04	-0.10	-0.37	0.22	-0.30	-0.04	1.00			
Anxiety about Talking with Children	0.37	0.12	-0.23	0.48**	-0.08	0.23	0.61**	1.00		
Anxiety about Talking with Partner	0.32	0.45*	-0.17	0.32	-0.23	0.13	0.44*	0.93***	1.00	
Anxiety about Screening or Prevention Decisions	0.01	-0.01	-0.16	0.50**	0.10	-0.08	0.57**	0.89***	0.51**	1.00
Age	-0.28	-0.35	0.38	-0.21	0.21	0.32	-0.20	0.05	-0.23	0.10

\* Indicates a significant difference between the means ( $p < 0.10$ ).

\*\* Indicates a significant difference between the means ( $p < 0.05$ ).

\*\*\* Indicates a significant difference between the means ( $p < 0.01$ ).

## **4. DISCUSSION**

The goals of this investigation were fulfilled and insight was gained into the development of a support group for women with a hereditary breast cancer predisposition. The documentation of the organizational process may be used as a reference for others who embark upon a similar endeavor. Critical information was obtained about the characteristics of women who chose to participate in a support group for hereditary breast cancer predispositions. This may help healthcare professionals identify a subset of the population that are most likely to require additional support services. Lastly, insight was gained about the specific factors that are most likely to affect a woman's perceived breast cancer risk and need for a support group. This information can aid in the development of support services.

### **4.1. Specific Aim 1: Group Organization**

Aim:

To document the process of developing a support group for women with a hereditary breast cancer predisposition.

Hypothesis:

Given the unique challenges associated with carrying an inherited breast cancer predisposition, a support/discussion group can be established to address the needs of women with a mutation in the *BRCA1*, *BRCA2*, or *PTEN* genes.

Outcome:

With the assistance of the potential participants and by drawing on the current literature, decisions were made regarding the initiation and organization of a support group for women with a hereditary breast cancer predisposition. Group characteristics include the

format of sessions, membership criteria, group leadership, and details such as the frequency and location of group meetings.

#### Implications:

The documentation of this process hopes to provide insight to other healthcare professionals or individuals who elect to pursue the task of organizing a similar support group. Ideally, individuals involved with the initiation and organization of a support group for women with a hereditary breast cancer predisposition will also have a core group of potential participants from which to gather information regarding the desired group characteristics.

It was found that, for the most part, the various decisions required in this process are directly related to the overall goal of the group. Therefore, establishing the main objective of the group is a vital step in group organization and subsequent decisions are likely to fall into place. In the present study, the potential participants indicated the presence of two main desired functions of the support group; to receive scientific and medical information and to discuss decision-making and management with other women who have a hereditary breast cancer predisposition.

In general, some of the decisions regarding the initiation and organization of support group appear to have little significance on the function of the group. However, these details, such as the location and time of the meetings, are likely to influence group participation. For example, the location of the group meetings affected the ability for some women to participate. Two non-participants in the support group indicated on the study questionnaire that they would have participated in a support group if it met at a location closer to their home.

#### **4.2. Specific Aim 2: Participants vs. Non-Participants**

**Aim:**

To explore the reasons why women with a hereditary breast cancer predisposition choose to participate in a support group or decline involvement.

**Hypothesis:**

Women who chose to participate in a support/discussion group for those with a hereditary breast cancer risk are more likely to have greater anxiety about their risk, less confidence in the medical management decisions, and less support from other sources when compared to non-participants.

**Outcome:**

As hypothesized, group participants had a slightly higher perceived breast cancer risk ( $p=0.17$ ), lower confidence in medical management decisions ( $p=0.09$ ), and less support from family and friends ( $p=0.19$ ). Also, as expected, the group participants reported a significantly higher need for a support group ( $p=0.054$ ) and lower control over their cancer risk ( $p=0.15$ ). Group participants reported a slightly lower perceived ovarian cancer risk ( $p=0.41$ ). However, this finding was not statistically significant and therefore, there is not sufficient evidence to reject the original hypothesis.

Other findings include the fact that group participants were significantly younger than the non-participants ( $p=0.03$ ). Higher proportions of group participants were single and had pursued a level of education greater than a high school diploma. Participants were more likely to have received their results 1-2 years ago and were less likely to have had a previous cancer diagnosis. Group participants were less likely than non-participants to

have had an oophorectomy and more likely to have taken Tamoxifen. Regarding anxiety-causing issues, the group participants had more overall anxiety than non-participants regarding all the items addressed.

#### Implications:

The finding that group participants perceived a higher breast cancer risk than non-participants supports the current literature regarding the motivations of women with hereditary breast cancer predisposition to seek additional support services.<sup>42</sup> Perceived risk has consistently been shown to be a primary factor for motivating women to seek out support services. Therefore, supplemental support services for this population should address the risk perceptions of women with a hereditary breast cancer predisposition and provide education regarding risk reduction options. In addition, healthcare professionals should be aware when a patient is experiencing distress due to her perceived breast cancer risk and recognize that she may require support services.

We hypothesized that support group participants would be more likely to report lower levels of existing support. The hypothesis was made based on the assumption that people with a lower level of support from other sources would be more likely to participate in a support group. This trend was, in fact, observed in the study population. Therefore, there is not sufficient evidence to reject the original hypothesis. However, this finding actually contradicts some reports in the literature. One study addressing participation predictors for psychosocial telephone counseling following *BRCA1* and *BRCA2* testing indicated that participants had greater perceptions of social support. A suggested explanation for this finding was that the existing support systems of mutation carriers was present but may not be able to adequately address the issues associated with a *BRCA1* or *BRCA2*

mutation. Also, in these situations, once emotional support is offered by one's family or friends, the individual may experience greater comfort, ease, and social acceptability in regard to seeking other support services.<sup>42</sup>

One of the most striking differences between group participants and non-participants was that participants were significantly younger. Thus far, this finding has not been reported in the literature addressing distress and support groups for women with a hereditary breast cancer predisposition. There are several possible explanations for this finding. With the growing popularity of support organizations and trends in public health awareness, there may be fewer stigmas associated with seeking support services or, in general, with openly discussing a diagnosis of cancer. Alternatively, younger women found to have a hereditary breast cancer predisposition may experience greater distress directly related to their age. With a 2-3% risk per year associated with mutations in *BRCA1* or *BRCA2*, a young woman may experience more distress as a result of having more years of potential lifetime ahead of her as opposed to an older woman who has already lived through some of her cumulative risk for breast cancer.<sup>29</sup> Another possible explanation is that younger women, because they have lived through a smaller amount of their cumulative breast cancer risk, are less likely to have a personal history of breast cancer. As discussed later, women with a hereditary breast cancer predisposition who have not had a diagnosis of cancer experience higher levels of distress.<sup>43</sup> Regardless of the cause, the fact that younger women were more likely to seek additional support services should be considered by healthcare professionals dealing with this subset of the population.

Reports in the literature have also indicated a greater interest in support group participation after time has passed since the reception of a positive test result, similar to the results obtained in this study. In one study, participants expressed a need for additional genetic counseling after the initial “crisis” period caused by the genetic test result.<sup>19</sup> In the current study, group participants were more likely to have received their test results a year or more prior to the formation of the support group. This finding has significant implications for individuals providing services to women with a hereditary breast cancer predisposition and suggests that there may be a need to re-contact patients about support services at a later date instead of providing referral information at the time of their result disclosure. Perhaps patients would better be served if genetic counselors developed a standard method for re-contacting patients once they have had time to process their genetic test result. This could be done by composing letters after the initial session that would be sent after a year. These letters could encourage patients to contact their genetic counselor if they have any questions or if there have been any changes to the family history.

Group participants were less likely to have a personal history of breast cancer than non-participants. This counter-intuitive relationship between group participation and the absence of a cancer diagnosis is supported by the existing reports in the literature which indicate that the highest levels of test-related distress occur among mutation carriers with no history of cancer or cancer-related surgery.<sup>43,44</sup> Two suggested explanations were provided for these findings. First, women with a previous diagnosis or a cancer-related surgery initially perceived a higher likelihood that they were mutation carriers and may have consequently been less surprised by their results. Second, given their medical



history, it is possible that women with a previous diagnosis experienced greater cancer-related stress in the past and have placed the genetic test within a context that reduced its psychological impact.<sup>43</sup> Furthermore, because of the stress associated with a cancer diagnosis, those with a previous diagnosis may not identify with unaffected individuals or may seek support from groups that are focused on women who have or had a breast cancer diagnosis rather than a group focused on the predisposition to cancer. In general, unaffected women who elect increased surveillance over preventative surgery may require additional information and support services.

With respect to cancer-related surgery, group participants were less likely than non-participants to have pursued prophylactic oophorectomy. Possible explanations for this finding include the younger ages of the group participants or that distress related to the decision to undergo prophylactic oophorectomy motivated the women to seek additional information or support. In the current study, this trend was not observed with respect to prophylactic mastectomy.

The finding that group participants reported greater overall anxiety than non-participants suggests that the anxiety these women are experiencing is most likely a direct motivation for seeking additional support. In the current study, group participants reported greatest anxiety regarding discussing their results with their children. This information may not be an accurate reflection because it is based on the small number of group participants that have children. However, existing literature does indicate that women with a hereditary breast cancer predisposition who have young children were more likely to suffer long-term distress, suggested to be attributable to feelings of guilt and anxiety about their children also carrying the mutation.<sup>44</sup> Therefore, recognition of this source of

anxiety should also be incorporated when identifying women with a hereditary breast cancer predisposition who would most likely benefit from additional support services.

#### **4.3. Specific Aim 3: Factors Affecting Perceived Risk and Support**

Aim:

To explore what issues need to be addressed by support groups by gaining insight into what factors are affecting a woman's perceived cancer risk and need for a support group.

Hypothesis:

Factors such as a personal history of cancer, a strong family history of cancer, or a lack of preventative surgery are likely to increase a woman's perceived cancer risk or need for support.

Outcome:

Contrary to the original hypothesis, women without a personal history of breast cancer reported higher breast cancer risks perceptions than women with a previous diagnosis. As previously mentioned, this trend has been reported in the literature and several possible explanations were provided in the discussion for the previous specific aim.<sup>43</sup>

It was also hypothesized that women with a strong family history of breast cancer would have higher perceptions of their risk. A significant correlation existed between perceived breast cancer risk and the number of first or second degree relatives with breast cancer ( $p=0.01$ ). Whether the relative survived the cancer diagnosis also appeared to influence perceived risk because a significant correlation also existed between perceived breast cancer risk and the number of deceased relatives with breast or ovarian cancer ( $p=0.05$ ).

As hypothesized, the perceived breast cancer risk of those women who have not pursued preventative surgery was slightly higher than women who have had a mastectomy or oophorectomy. Furthermore, women reporting that they were unsure about the decision regarding preventative surgery indicated the highest perceived cancer risk.

Other findings include the fact that the higher levels of perceived breast cancer risk and need for support were reported by women who received their test result over one year prior to the formation of the support group. This finding and its implications were previously discussed.

Women with *BRCA2* mutations reported a dramatically higher need for support; however this information is based on only two study participants with *BRCA2* mutations. As would be expected because the lifetime risk for breast cancer is 25-50% as opposed to the 56-87% lifetime risk associated with mutations in *BRCA1* or *BRCA2*, the participant with a *PTEN* mutation reported a lower perceived cancer risk.

Correlation studies indicated a significant correlation between perceived breast cancer risk and both perceived ovarian cancer risk ( $p=0.08$ ) and need for a support group ( $p=0.07$ ). Perceived ovarian cancer risk correlated with anxiety about talking with one's partner ( $p=0.05$ ). Control over cancer risk was correlated with anxiety about talking with children ( $p=0.04$ ) and anxiety regarding screening or prevention decisions ( $p=0.03$ ). Strong correlations were also observed among all the items addressing sources of anxiety ( $p$  values between 0.087 and  $5.38 \times 10^{-8}$ ).

#### Implications:

Previously, the fact that women with a hereditary breast cancer predisposition and no personal history of cancer or a cancer-related surgery are more likely to seek additional

support services was discussed. Again, this contradicts the hypothesis which addresses factors that influence a woman's perceived breast cancer risk and need for support. In addition to identifying a subgroup of the population that would utilize services, this information should be used in designing subsequent support services. These services should address the factors increasing a woman's perceived risk and provide information about risk reduction techniques.

The hypothesis that an increase in perceived breast cancer risk is associated with having affected family members was supported by significant correlations between perceived breast cancer risk and both the number of first or second degree relatives with breast cancer and the number of deceased first or second degree relatives with breast or ovarian cancer. This finding also provides information for identifying a subset of women who are likely to need additional support services. In addition, this finding may have implications for the development of services. Group participants may have unique perceptions of cancer, alternative explanations for its occurrence, or strong emotions regarding its impact on the family that need to be addressed. However, interventions aimed at addressing the intense emotions surrounding the experience with cancer within the family may require careful planning or more personal interventions for certain participants.<sup>38</sup>

As hypothesized, women who have undergone either mastectomy or oophorectomy reported lower perceived breast cancer risks. However, when considering that mastectomy reduces the risk for breast cancer by 90% and that oophorectomy in a premenopausal woman reduces the breast cancer risk by 50%, a much larger difference in perceived breast cancer risk was expected.<sup>35,45</sup> Therefore, support services for this

population may be directed at exploring the reasons why women continue to have high perceptions of breast cancer risk after preventative surgeries. In addition, women who were unsure about the decision to undergo surgery reported higher risk perceptions than those who had made a decision, even if that decision was to not undergo surgery. This trend has been reported in a study indicating that persons with high levels of cancer-related stress who decline genetic testing may be at risk for depression.<sup>46</sup> In the current study, this finding is based on a very small number of participants; however it may represent an important motivation for women to gain information and explore the decisions that other women have made and therefore may be an important topic for support groups aimed at this population.

The fact that women with *BRCA2* mutations reported a statistically significant higher need for support may be an incidental finding due to the small number of study participants with *BRCA2* mutations. However, it may also indicate that women with less frequent genes mutations have an additional need for support. This idea is supported by the fact that the only study participant with a *PTEN* mutation was a group participant. Perhaps these patients encounter more individuals and healthcare professionals who are less familiar with this gene mutation and its associated ramifications. These patients may desire information specific to their gene mutation or to speak to someone in a similar situation.

In addition, the significant correlation between ovarian cancer risk and anxiety about talking to with one's partner suggests that women may benefit from support services that address these issues. A possible explanation for this finding in the literature is that women with higher perceptions of ovarian cancer risk may have difficulty talking to their

partner's about this subject because it affects their ability to have children and perhaps their mood, perceptions of femininity, or sexual identity; and perhaps because men may be less equipped or less comfortable to talk with women about their reproductive organs.<sup>47</sup> However, since a similar finding was not found with perceived breast cancer risk and anxiety about talking to one's partner, perceptions of femininity or sexual identity may not be relevant explanations. Instead, the fact that ovarian cancer is far more deadly than breast cancer may be related to the correlation between perceived ovarian cancer risk and anxiety about talking to one's partner.

Interestingly, one's control over cancer risk was correlated with anxiety about talking with children and anxiety about screening or prevention decisions. There is no apparent explanation for this finding and it is a challenge to interpret this information. However, perhaps women who feel more control over their cancer risk do so because they do not feel their doctors or other healthcare professionals are in control. This might explain their anxiety over the situation because they feel primarily responsible for their decisions and healthcare. Perhaps this causes anxiety about talking with their children because they do not want their children to worry about the decision making process.

#### **4.4. Limitations**

The primary limitation of this study is the small number of study participants, especially amongst support group participants. However, due to the fact that hereditary predispositions for breast cancer are relatively rare in the general population, this will most likely be a challenge for other individuals attempting to organize studies of support services for this population. In the current study, the small sample size negatively affects the ability to apply the findings to the overall population of women with hereditary breast cancer predispositions.

Factors which may have decreased the number of participants in this study are related to the recruitment and involvement of the study participants. This study did not offer any financial incentive for participation and therefore individuals may have declined to take part because they did not feel it would directly benefit them. In addition, the study utilized mailed questionnaires as a means of recruitment and participation. Therefore, potential participants may have not received the information or may not sufficiently understand the study to warrant participation. Lastly, potential participants may have been concerned about the privacy of their genetic information. Some women may not want anyone to know they have a hereditary predisposition, even other women who also carry a gene mutation.<sup>48</sup> To increase participation in similar research projects and protect an individual's privacy, web-based questionnaires may be utilized. As previously mentioned, this study utilized questionnaire responses to gather information and assess the perceptions of study participants. Therefore, a potential limitation exists in the fact that individuals may interpret a specific question differently. This limitation was indicated by the response of one participant to the open-ended questions at the end of the questionnaire. She felt the need to clarify her responses regarding issues of medical decision-making and anxiety about talking with her children. Her opinion that these issues should have been addressed through more specific questions suggests that perhaps other participants may have interpreted the question differently. This potential limitation illustrates the need to create very discrete and specific questions in clinical research and to utilize question formats that have been studied and are verified to be understandable. Research that requires participants to provide rankings may want to utilize the Likert scale of attitudes. Alternatively, other techniques for eliciting this information such as an open-ended interview might help clarify the opinions of group participants.

Another limitation of this study is the presence of a patient with a *PTEN* mutation, also known as Cowden syndrome. The cancer risks for this individual differ from those of the other group participants. Cowden syndrome has not been associated with an increased risk for ovarian cancer and it confers a 25-50% lifetime risk for breast cancer.<sup>30</sup> Therefore, the perceived cancer risks and the issues that a woman with Cowden syndrome faces may be very different from other women with a hereditary predisposition and her responses, when analyzed along with the women with *BRCA1* or *BRCA2* mutations, may skew the results.

## **5. FUTURE RESEARCH OPPORTUNITIES**

### **5.1. Current Project**

The current report discusses a portion of a larger study that is still being conducted at Allegheny General Hospital. The goal of this project is to contribute to the existing literature and help guide the development of support services for this population. The current study outlines the establishment of a support group for women with a hereditary breast cancer predisposition and analyzes the factors that affect a woman's perceived breast cancer risk and motivation for seeking additional support services. The larger study hopes to evaluate the utility of the existing support group.

#### **5.1.1. Follow-up Questionnaire and Evaluation**

To gain insight into the effect of the support group over time, all study participants will be asked to complete a follow-up questionnaire after six months of the support group's existence. The responses to the follow-up questionnaire will be compared to those from the initial questionnaire.



The possible changes over time between participants and non-participants will be explored. This will provide information about the benefit to group participants.

#### **5.1.2. Qualitative Information**

The questionnaires utilized in this study contained three open-ended questions for study participants to provide additional information or comments. The responses of the group participants and the non-participants can be found in Appendix F. These responses, along with the responses from the follow-up questionnaire will be examined for themes relating to personal experiences and the decision to join a support group. In addition to the follow-up questionnaire, the group participants will fill out an evaluation of the support group. They will be encouraged to provide information regarding ways in which the group could be more effective in meeting the needs of the participants. Overall, the follow-up questionnaire and the evaluation may provide information about issues that were not captured by the closed-ended questions.

### **5.2. Additional Projects**

#### **5.2.1. Women with a Hereditary Breast Cancer Predisposition**

Further research is needed on alternative methods for providing support services to this population besides group-based interventions. Due to geographic limitations to the delivery of services, research is needed on ways to reach more individuals such as web-based support forums or discussion groups. Other types of interventions with the potential to reach a larger population of women that require additional research are telephone counseling, telephone trees or group discussions, listserves, or newsletters.

### **5.2.2. Other Women Who Underwent Genetic Testing**

While the current study emphasizes the need for support services for women with a hereditary breast cancer predisposition, the existing literature also acknowledges complex issues faced by all women who undergo genetic testing.

#### **5.2.2.1. Women who Receive Negative Results**

At-risk women who test negative for a hereditary breast cancer predisposition may also require support services.<sup>2</sup> If a mutation is detected within the family, these women may experience guilt or strained relationships due to the fact that they do not have the same risks as other family members. If no mutation has been identified in the family, a woman with a negative test result may be left with unanswered questions and anxiety regarding the occurrence of breast cancer in herself or her family members. If a mutation has been identified within the family, a woman with a negative test result may experience guilt due to the fact that she did not inherit the mutation when other family members did.<sup>49</sup> For these reasons, research is needed on the perceptions and need for support of women who receive negative test results for mutations in breast cancer susceptibility genes.

#### **5.2.2.2. Women who Receive Indeterminate Results**

It is estimated that about 10% of Caucasian women and 30% of African American women will receive an indeterminate result when undergoing sequence analysis for *BRCA1* or *BRCA2*. This result indicates that a subtle gene change was identified but that it is unknown whether the change is a genetic variation or a harmful mutation. Initially, women who receive this result often do not receive any additional information about their cancer risks. More information may be obtained by the lab conducting the testing and these patients will be re-contacted if their gene

change can be classified as a harmful mutation or a benign genetic variation. Therefore, these individuals may be faced with making decisions, such as those regarding medical management or prevention, with uncertain information and no idea when more definite information will be available. Because of the prevalence of indeterminate results and the challenges faced by women who receive this result, research is needed to better serve the specific needs of this population.<sup>50</sup>

### **5.2.3. Partners and Family Members**

The current literature reports that the impact of genetic testing goes beyond the individual to the extended family and social context.<sup>51</sup> Therefore, future research endeavors are needed to address this impact and determine if support services are needed for partners and family members of women who are found to have a hereditary breast cancer predisposition.

#### **5.2.3.1. Spouses or Partners**

Spouses are confronted with many difficult issues and emotions when a wife or partner is found to carry a cancer-predisposing mutation. In a study of 59 spouses of mutation carriers, 43% of participants indicated that their greatest concern was the possibility of their partner dying of cancer. This was followed by the concern that their partner would develop cancer (19%) and the concern that their children might carry the mutation (14%). Overall, this study did not detect clinical levels of distress in the spouses of mutation carriers, but indicated that selected spouses may benefit from close attention and additional support. It also calls for further research to identify the spouses who may need support and to develop methods to provide additional support.<sup>52</sup>

#### **5.2.3.2. Male Carriers**

Furthermore, the current study did not incorporate information regarding men who carry mutations for hereditary breast cancer predispositions. Males who carry breast cancer susceptibility gene mutations also have increased risks for the development of various types of cancer when compared to the general population.<sup>39</sup> For example, studies have indicated a cumulative risk for all cancers of 32% by age 70 in men with *BRCA2* mutations.<sup>53</sup> In addition, a man that carries a mutation for a breast cancer predisposition may experience distress due to the societal stigmatization of breast cancer or due to guilt associated with a cancer diagnosis in his daughter.<sup>54</sup> In a study of 59 male carriers of *BRCA1* or *BRCA2*, 23% expressed a personal interest in a support group and 53% felt that a support group for male carriers was necessary.<sup>55</sup> However, because the associated cancer risks, management recommendations, and social issues are very different, the perceptions and needs for support of male carriers was not addressed in the current study. Therefore, research is needed on how to provide support services to this population.

#### **5.2.3.3. Women who Decline Testing**

In addition, studies have also indicated that women who report high levels of cancer-related distress but decline testing are more likely to become depressed than women who sought testing and obtained either a positive or a negative test result.<sup>46</sup> This may include women in families with an identified mutation or women with an increased risk for a hereditary breast cancer predisposition based upon family history. Due to the reported levels of distress, this population of women may have a significant need for support services specifically tailored to their concerns.

#### **5.2.4. Underserved Populations**

In the current study, the ethnic background and level of income of study participants was not ascertained. However, reports in the literature indicate that individuals from minority groups and from low socioeconomic levels are under-represented in the recipients of genetic services.<sup>56</sup> Due to this under-representation, research is needed to explore methods for distributing genetic services in a manner that will promote reception by individuals from all ethnic and socioeconomic groups.

##### **5.2.4.1. Minority Groups**

In general, support groups for breast cancer have an under-representation of people from minority groups. In addition, there is an under-representation of minority groups in the patient population of cancer genetic counselors and in studies aimed at identifying hereditary risk factors for cancer. These factors along with the higher rate of mortality related to breast cancer in the African American contribute to the need for better services for this population. Therefore, the development of more creative and flexible approaches to offering genetic services to these populations is a necessity.<sup>57</sup> One suggested strategy is to design support groups that better address the issues and concerns of the specific underserved populations. Research has been conducted about the differences in cultural perspectives regarding cancer and the use of support group. This research calls for a need to tailor support groups to meet the needs of participants in a culturally competent manner.<sup>58</sup>

In addition to being under-represented in support groups, women from minority groups, such as the African American population, are also under-represented in cancer genetic counseling and testing.<sup>59</sup> For example, one study reported that significantly fewer African-American women provided a blood sample for analysis after pretest education and/or counseling compared with the

Caucasian women.<sup>60</sup> Furthermore, the prevalence of mutations, such as those in *BRCA1* and *BRCA2*, are estimated to have equal frequencies in the African American and Caucasian populations even though African Americans reportedly account for only 3% of the population of women who have undergone genetic testing for *BRCA1* and *BRCA2*.<sup>61</sup>

Due to the under-representation amongst recipients of genetic services and the prevalence of hereditary breast cancer mutations in the African American and other minority populations, further research is needed regarding methods for increasing the reception of services such as cancer genetic counseling, genetic testing, and subsequent support group participation. This involves studying how genetics is perceived in minority populations and how to distribute appropriate information.

#### **5.2.4.2. Low Socioeconomic Status**

Reportedly, individuals with a low socioeconomic status are also under-represented in the populations served by cancer genetic counselors.<sup>56</sup> This may be a result of a lower overall reception of medical services in this population coupled with a difficulty to obtain insurance coverage to cover the costs of genetic testing. For example, comprehensive sequence analysis for *BRCA1* or *BRCA2* costs approximately \$3000 and insurance policies such as Medicaid do not typically cover the test. Because of these reasons, women with a low socioeconomic status with a very suggestive family history or a mutation associated with a hereditary breast cancer predisposition may experience additional barriers to receiving both genetic testing and adequate support services. Therefore, further research is needed regarding methods to increase the reception of services.

## **6. SUMMARY**

Given the unique issues and needs of women with a hereditary breast cancer predisposition, a support group was formed to address some of their concerns. This study was designed to document the process of starting that group, to investigate differences between the women that elect to participate in the support group versus those who decline participation, and to explore what factors influence a woman's perceived breast cancer risk and need for a support group.

With the assistance of the potential participants and by drawing on the current literature, decisions were made regarding the initiation and organization of a support group for women with a hereditary breast cancer predisposition. Group characteristics include the format of sessions, membership criteria, group leadership, and details such as when and where to meet. The experience in this study reinforces the idea that organizational decisions should be made in conjunction with a core group of potential participants. In addition, the various decisions required in this process were directly related to the overall goal or function of the group. Therefore, establishing the main objective of the group is a vital step in group organization and subsequent decisions are likely to logically follow from that decision.

As hypothesized, group participants had a slightly higher perceived breast cancer risk, lower confidence in medical management decisions, and lower support from family and friends than non-participants. In addition, group participants were more likely to be younger, to have received their results 1-2 years ago, and to not have a personal history of cancer. Group participants were also more likely to experience greater anxiety, especially in regard to discussing their results with their children. With this information, healthcare professionals may better be able to identify patients who need support services.

Factors influencing perceived breast cancer risk and the need for support services included, as hypothesized, the number of first or second degree relatives with breast cancer, whether the relative survived the cancer diagnosis, and the election of preventative surgery. Furthermore, women reporting that they were unsure about the decision regarding preventative surgery indicated the highest perceived cancer risk. Higher levels of perceived breast cancer risk and need for support were reported by women who received their test result over one year prior to the formation of the support group. Other findings included significant correlations between (a) perceived breast cancer risk and both perceived ovarian cancer risk and need for a support group, (b) perceived ovarian cancer risk and anxiety about talking with one's partner, and (c) control over cancer risk and both anxiety about talking with children and anxiety about screening or prevention decisions. Strong correlations were also observed among all the items addressing sources of anxiety. Because this information provides insight into the factors associated with an increase in perceived cancer risk and need for support, it can be utilized to design support services for women with a hereditary breast cancer predisposition.

In conclusion, due to the limitations of this study, such as small sample size, it is not possible to generalize these findings to the needs of all women with a hereditary breast cancer predisposition. However, when considered along with the limited existing literature regarding support services for this population, the current study provides information about the process of forming a support group, the subset of patients who are most likely to participate, and the factors most influencing their cancer risk perception and need for support. This information can potentially aid individuals who are organizing or studying support services for women with a hereditary breast cancer predisposition.



## **APPENDIX A**

### **Letters of IRB Approval**



**ALLEGHENY  
GENERAL HOSPITAL**

WEST PENN ALLEGHENY HEALTH SYSTEM

320 EAST NORTH AVENUE, PITTSBURGH, PA 15212-4772

412-359-3156

**INSTITUTIONAL REVIEW BOARD #01  
DHHS/OPRR ASSURANCE #M1050  
(EXPIRES MARCH 23, 2005)**

September 28, 2004

Sheila Solomon MS  
Cancer Genetics Program

**RE: RC-3743 An Investigation into the Utility of a Support Group for Women with  
a Hereditary Breast Cancer Disposition**

Dear Ms. Solomon:

The Institutional Review Board (IRB) of Allegheny General Hospital is in receipt of the requested changes which were made to the above-referenced protocol.

The IRB has reviewed the information and determined that the above-referenced protocol is **approved**.

This protocol has been reviewed via the "*expedited review*" process and approved on its scientific, safety, ethical and socio-economic merits, and approved in accordance with Institutional, Federal and State regulations by the IRB. It is the responsibility of the investigator to obtain any other necessary approvals prior to implementation of the research (AGH and/or ASRI).

Your approved protocol will be subject to review within one year from the date of initial review by the IRB.

A stamped approved informed consent (dated 09/28/2004), (version September 2004) is attached for your use.

Sincerely,

Matthew R. Quigley MD  
Chairman  
Institutional Review Board  
MRQ/jss  
attachment

cc: Department Chairperson  
Administrative Vice President

APR-04-2005 MON 11:19 AM

FAX NO.

P. 02



## University of Pittsburgh

### *Institutional Review Board*

3500 Fifth Avenue  
Ground Level  
Pittsburgh, PA 15213  
(412) 383-1480  
(412) 383-1146 (fax)

#### MEMORANDUM

TO: Sheila Solomon, MS

FROM: Christopher Ryan, PhD, Vice Chair *CR/ky*

DATE: February 1, 2005

SUBJECT: IRB # 0410065: An Investigation into the Utility of a Support Group for Women with a Hereditary Breast Cancer Predisposition

The above-referenced proposal has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110 (7).

If applicable, please include the following information in the upper right-hand corner of all pages of the consent form:

Approval Date: February 1, 2005  
Renewal Date: January 31, 2006  
University of Pittsburgh  
Institutional Review Board  
IRB #0410065

Adverse events, which occur during the course of the research study, must be reported to the IRB Office. Please call the IRB Adverse Event Coordinator at 412-383-1504 for the current policy and forms.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month prior** to the expiration date noted above for annual renewal as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center) and FWA00000600 (Children's Hospital of Pittsburgh).

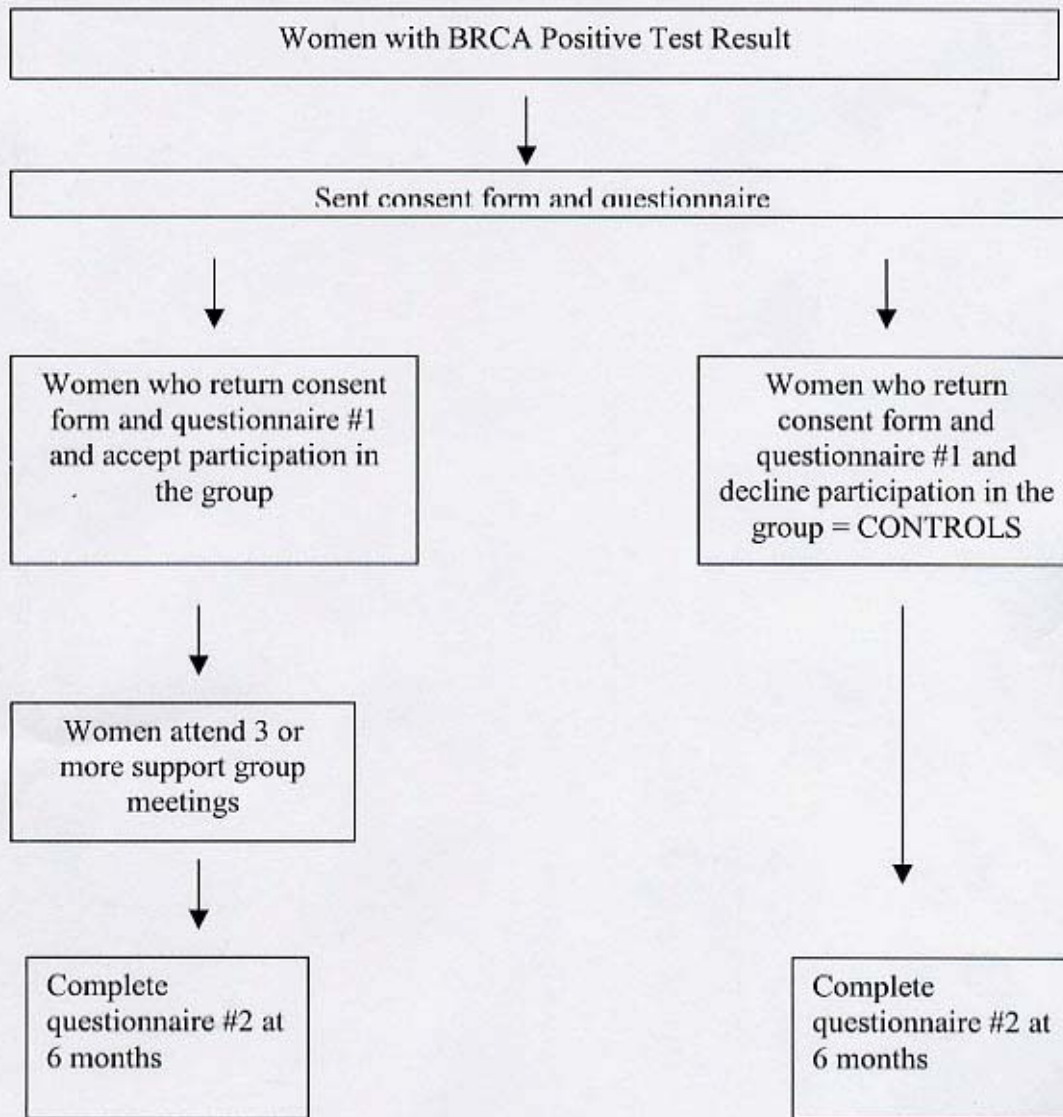
**Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.**

CR:ky

## **APPENDIX B**

### **Schema**

### SCHEMA



## **APPENDIX C**

### **Interest Survey and Cover Letter**



February 2004

Hello!

We are contacting you about a new opportunity for the patients of the Cancer Genetics Program. We are starting a support/discussion group for the many women who carry a gene mutation for hereditary breast cancer.

When we met with you to discuss your genetic test result, you were given a lot of information on prevention and early detection of cancer, however most of it was related to medical decision-making and not so much about the way the test result will affect all the other aspects of your life. Patients often find it helpful to speak with others who are in similar situations. It can be difficult to locate these people on your own and find the answers to your questions. From these questions and concerns from our patients, the idea to start a support group was born.

The group will plan to meet at Allegheny General Hospital and will be moderated by a clinical nurse specialist and genetic counselor. Before we organize the first meeting, we would like to hear from you. Please complete the attached questionnaire and return it to our office in the pre-paid envelope.

Thank you in advance. We hope this letter finds you and your family doing well and we hope to see you again soon!

Best regards,

Sheila Solomon, MS  
Genetic Counselor

Susan Ely, RN, MSN  
Clinical Nurse Specialist

Stanley Shackney, MD  
Medical Oncologist

Encl.: Questionnaire  
Return Envelope

1. The genetic counseling meetings provided me with enough medical information to make decisions with my healthcare providers (circle one).

Disagree   Neutral   Agree

2. The genetic counseling meetings provided me with enough information about emotional support options (circle one).

Disagree   Neutral   Agree

3. Are you interested in speaking with other women who have a hereditary high risk for breast cancer?

☐ Yes (skip to #5)

☐ No

4. If you answered "No" to #3, please share why you are not interested at this time: \_\_\_\_\_

5. Which of these meeting locations would be most convenient for you?

☐ AGH      ☐ North Hills

☐ South Hills      ☐ East End

☐ Downtown      ☐ Other: \_\_\_\_\_

6. How often would you like to meet?

☐ Every 2 weeks      ☐ Every 2 months

☐ Every month      ☐ Other: \_\_\_\_\_

7. When would you like to meet?

☐ Weekday evenings  
(Day: \_\_\_\_\_ Time: \_\_\_\_\_)

☐ Weekday afternoons  
(Day: \_\_\_\_\_ Time: \_\_\_\_\_)

8. What topics of discussion interest you? (check as many as you would like)

☐ Talking to relatives about my test and having them tested

☐ Talking to my children/my partner about my test

☐ Risk of developing cancer

☐ Screening/surgical options for me

☐ Effect of cancer/gene test on my life

☐ Genetic research and technology

☐ Treatments for breast cancer

☐ Other: \_\_\_\_\_

9. Optional

(If you are interested, please complete)

Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

If you have comments, ideas, or questions, please list them on the back of this sheet.

Please return this questionnaire in the enclosed pre-paid envelope.

THANK YOU!



## **APPENDIX D**

### **Informed Consent and Cover Letter**



## ALLEGHENY GENERAL HOSPITAL

WEST PENN ALLEGHENY HEALTH SYSTEM

320 EAST NORTH AVENUE, PITTSBURGH, PA 15212-4772

1-877-857-1889

### ALLEGHENY CANCER CENTER

**BREAST CARE CENTER**  
412-359-3636

**CENTER FOR  
COLON AND RECTAL  
SURGERY**  
412-359-3901

**HEMATOLOGY AND  
MEDICAL ONCOLOGY  
CENTER**  
412-359-6147

**LIVER CENTER**  
412-359-6738

**CENTER FOR  
LUNG AND THORACIC  
DISEASES**  
412-359-6137

**PROSTATE CENTER**  
412-359-3400

**RADIATION ONCOLOGY**  
412-359-3400

Dear \_\_\_\_\_

September 2004

Thank you for your interest regarding participation in a research study called **An Investigation into the Utility of a Support Group for Women with a Hereditary Breast Cancer**. As you know, women with hereditary breast cancer predisposition have increased risks for breast and possibly other types of cancer. The purposes of this study are 1) to better understand the needs of women with hereditary breast cancer susceptibility and 2) to describe the process of developing a support group for this group of women.

The study extends over a six-month period, and requires completion of a consent form, which is enclosed, as well as two short questionnaires. If you are interested in participating, please complete and return the enclosed consent form and complete the questionnaire. There are two copies of the consent form. If you choose to participate in the study, one copy must be signed and returned and the other copy is for you to keep for your records. The enclosed questionnaire is the first of two questionnaires that you will be asked to complete. Please fill it out to the best of your ability and feel free to provide additional comments.

Your participation in this study is strictly voluntary. Please understand that you will not be paid for participation in this research study. You can withdraw your consent and stop participating at any time. Your decision to participate, or not, will in no way effect your medical care. Participation may eventually be of direct benefit to you and your at-risk family members, as well as others with hereditary breast cancer predispositions.

All information collected from this study will be kept strictly confidential. This information will not become part of your personal medical record. This information will be available only to the study research team, and will not be released to any other party, except with your written consent.

The enclosed stamped envelope is addressed to the Cancer Center at Allegheny General Hospital. Please return the signed consent form and the questionnaire in this envelope.

We appreciate your time and willingness to participate in this study. If you have any questions, please contact Sheila Solomon, MS at 412-359-8064.

Sincerely,

Sheila Solomon, MS  
Genetic Counselor  
Allegheny General Hospital

Pamela Farnsworth, BS  
Genetic Counseling Intern  
University of Pittsburgh

Encl.



WEST PENN ALLEGHENY HEALTH SYSTEM

APPROVED BY  
THE INSTITUTIONAL REVIEW BOARD  
OF  
AGH/ASRI

09/28/2004

DATE APPROVED

320 EAST NORTH AVENUE, PITTSBURGH, PA 15212-4772

1-877-857-1889

## ALLEGHENY CANCER CENTER

BREAST CARE CENTER  
412-359-3636

CENTER FOR  
COLON AND RECTAL  
SURGERY  
412-359-3901

HEMATOLOGY AND  
MEDICAL ONCOLOGY  
CENTER  
412-359-6147

LIVER CENTER  
412-359-6738

CENTER FOR  
LUNG AND THORACIC  
DISEASES  
412-359-6137

PROSTATE CENTER  
412-359-3400

RADIATION ONCOLOGY  
412-359-3400

Page 1 of 4

RC# 3743

September 2004

## INFORMED CONSENT FORM

### An Investigation into the Utility of a Support Group for Women with a Hereditary Breast Cancer Predisposition

#### Nature and Purpose of Study

Because you have tested positive for a hereditary breast cancer predisposition you are being invited to participate in a research study for patients of the Cancer Genetics Program at Allegheny General Hospital. About four months ago you received a letter regarding the start-up of a hereditary breast cancer support group being organized through our Program. Recently, you were contacted by your genetic counselor, Sheila Solomon, and expressed interest in participating in this study.

The purpose of this research study is to determine the utility of a support/discussion group for women with a genetic predisposition to breast cancer. To investigate this topic, women who tested positive for a hereditary breast cancer predisposition were invited to participate in monthly support/discussion group.

Those that chose to participate in the support group are meeting once a month to discuss various issues relating to their experience and obtain new health information about hereditary breast cancer and related topics. This research project will analyze various themes, discussions, and issues from the first six months of this group's existence. In addition, this study intends to explore the motivations and issues surrounding choosing or declining participation in the support group. Therefore, all women who were invited to take part in the support group are being invited to participate in this study.

#### Study Description

**Participating in the research project will involve completing two questionnaires.** The first questionnaire is accompanying this letter and the second questionnaire will be sent in six months. Each questionnaire will be mailed along with a self-addressed stamped envelope with which you can return the questionnaire. Each questionnaire should take approximately 10 minutes to complete.

Patient Initials \_\_\_\_\_



Right to Withdraw

Your participation in this research project is voluntary and if at anytime, you decide that you do not wish to participate in this study, you are free to withdraw at any time and this will not affect your access to medical care at Allegheny General Hospital in the future.

Risks

There are no foreseeable risks associated with this project, other than those that are related to the completion of any questionnaire. Completing this questionnaire may bring psychological effects regarding your test result. If at any time you feel you may benefit from counseling, please contact us at 412-359-8064. If an audit occurs, information may be shared with the Food & Drug Administration (FDA).

Benefits

In addition, there are no foreseeable personal benefits to completing the questionnaires besides any satisfaction gained from being able to express your opinions. Your participation has the potential to benefit other patients and healthcare professionals working in this field.

Confidentiality

Your participation in this study will remain confidential. This research study will not involve the use or disclosure of your identifiable medical information. You will be assigned an identification number which will only be known by the PI. All records from this study will be locked in a filing cabinet in the office of the PI. Your general medical record as well as your genetic testing information will not be used as part of this study, therefore the only information shared from your chart will be the fact that you carry a hereditary breast cancer predisposition. No personal or family medical history information from your chart will be used in this study.

Research Study Authorization of Protected Health Information & HIPAA Authorization

*In 1996 the government passed a law known as The Health Insurance Portability and Accountability Act (HIPAA), Public Law 104-191. This law, among other things will improve how your health care information is protected and kept confidential when it is shared with others. This includes both your medical records and insurance information as well as other personal health information. It also assures that everyone who shares this information will have to follow this law. This consent form describes to you how information about you may be used or shared if you are in a research study. It is important that you read this carefully.*

In order to participate in this research study, you must permit (allow) certain research records to be made about you in addition to the usual records the hospital and doctors create about your medical treatment. These research records will contain private medical and other information, which is protected by law. The researchers will only create the minimum amount of research records necessary to carry out the research.

Type(s) of research records that may be shared/copied is (are):

Tissue Samples: N/A

Medical Records: N/A

Lab Results: N/A

Participant Initials \_\_\_\_\_

Other (specify): Informed consent, Questionnaires

*In addition to using these research records to carry out the research and, perhaps, to treat you, the researchers will share portions of these research records to third parties involved in the research study. The third parties, who receive research information, may further share the information about you in accordance with their policies, practices and what the law requires. However, some third parties (such as the Sponsor) may not need to follow the HIPAA law. To the best of our knowledge, a complete and accurate description of who the third parties are and how they will use or share the information are as follows:*

<b>THIRD PARTY</b>	<b>PURPOSE</b>
Allegheny General Hospital Allegheny-Singer Research Institute Food & Drug Administration Department of Health & Human Services	May share this signed consent form and records that identify you to meet regulatory requirements or for purposes related to this research.

*The release of information described above will be the minimum necessary to abide by the law complete the research, and, perhaps, publish the research.*

*Unlike your medical records, you will not have access to research records made about you. Although every effort will be made to keep research records about you private, complete confidentiality cannot be guaranteed. Such research records may be subject to subpoena or court order. The researcher has set up safeguards to keep private information about you confidential.*

There is no expiration for this Authorization unless you revoke (cancel) it. You may revoke this Authorization by writing to the Principal Investigator. If you revoke your Authorization, you will also be removed from the study. Revoking your Authorization only affects the use and sharing of your information after the written request is received. Any information obtained prior to receiving the written request, may be used to maintain integrity of the study (for example account for reporting of side effects, sending information to the FDA for studies it regulates).

Principal Investigator Name & Address:

Sheila Solomon, MS  
Cancer Genetics Program  
5<sup>th</sup> Floor Cancer Center  
320 East North Avenue  
Pittsburgh, PA 15212

If you choose to not sign this Authorization, you will not be permitted to participate in this research study. In order to participate in this study, you must agree to share your information with the groups above. Upon completion of the study or if you withdraw from the study at any time, the research records about you will be kept by the researcher (s) and all of the information provided above will continue to apply to your research records.

Participant Initials \_\_\_\_\_



You give permission that your research records can be used and disclosed as described.

Costs Involved in Participation in this Study

There is no cost for you to participate in this study.

Compensation

You will receive no monetary compensation for participation.

You have been fully informed by \_\_\_\_\_ and you understand fully, that in the event of any (physical) injury, or injuries, resulting from research related procedures or protocols to which you have voluntarily and knowingly agreed to participate in, that no monetary compensation or free medical treatment will be made to you by Allegheny General Hospital or Allegheny-Singer Research Institute.

If at any time, you have questions or concerns about the proposed study please contact Sheila Solomon at (412) 359-8064 or ssolomon@wpahs.org. If you have questions about the rights of participants in a research study, please contact the Institutional Review Board of Allegheny General Hospital at (412) 359-3156.

You have had an opportunity to ask questions about this study and they have been answered to your satisfaction. You understand the purpose, procedure and benefits of this study that you have read or had read to you. You are over 18 years of age.

Sheila Solomon, MS  
Genetic Counselor  
Principal Investigator  
Allegheny General Hospital

Pamela Farnsworth, BS  
Genetic Counseling Student  
Co-Investigator  
University of Pittsburgh

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

Participant Initials \_\_\_\_\_

## **APPENDIX E**

### **Questionnaire**

### Questionnaire #1

Age: \_\_\_\_\_

**Marital status:**

- ☐ Single  
☐ Married  
☐ Divorced  
☐ Widowed

**Education:**

- ☐ High School  
☐ Professional Training  
☐ College Degree  
☐ Graduate Degree

**Gene Tested:**

- ☐ *BRCA1*  
☐ *BRCA2*  
☐ *p53*  
☐ *PTEN*

Do you have a personal history of breast cancer? Yes No

Do you have a personal history of ovarian cancer? Yes No

Number of relatives with breast cancer:	Alive	Deceased
1 <sup>st</sup> degree (parent, child, sibling)	_____	_____
2 <sup>nd</sup> degree (grandparent, aunt/uncle, niece/nephew, etc.)	_____	_____

Number of relatives with ovarian cancer:	Alive	Deceased
1 <sup>st</sup> degree (mother, sister, daughter)	_____	_____
2 <sup>nd</sup> degree (grandmother, aunt, niece, etc.)	_____	_____

Number of relatives with other cancer:	Alive	Deceased
1 <sup>st</sup> degree (parent, child, sibling)	_____	_____
2 <sup>nd</sup> degree (grandparent, aunt/uncle, niece/nephew, etc.)	_____	_____

Were you the first person in your family to be tested? Yes No

Did someone accompany you to the disclosure session? Yes No

Did/would you prefer to have someone with you? Yes No

Have other family members pursued testing? Yes No

Did you talk to relatives about your results? Yes No

Have relatives talked to you about their test results? Yes No N/A

**Have you decided on any of the following preventive interventions?**

Mastectomy (breast tissue removed)	Yes	No	Unsure
Oophorectomy (ovaries removed)	Yes	No	Unsure
Tamoxifen	Yes	No	Unsure
Oral contraceptives	Yes	No	Unsure
Other: _____	Yes	No	Unsure



**When did you receive your genetic test result?**

Less than 6 months      6 months – 1 year      1-2 years      More than 2 years

**How do you perceive the following?**

Please mark on the line corresponding to where on the range you think you belong.

Breast cancer risk	not a concern -----	certain will be affected
Ovarian cancer risk	not a concern -----	certain will be affected
Confidence in treatment/ prevention decisions	no confidence -----	completely confident
Control over cancer risk	no control -----	complete control
Support from family and friends	no support -----	total support
Need for a support/ discussion group	no need -----	absolutely necessary

**How much do the following issues cause you anxiety?**

Please mark on the line corresponding to where on the range you think you belong.

Talking to relatives about my test and having them tested	comfortable -----	very anxious
Talking to my children about my test	comfortable -----	very anxious
Talking to my partner about my test	comfortable -----	very anxious
Decisions about screening and prevention options	comfortable -----	very anxious

**Feel free to use the back for more room to answer any of these questions.**

What has your support been like? \_\_\_\_\_

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What do you think about participation in a support/discussion group for women with a hereditary breast cancer predisposition? \_\_\_\_\_

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Please share any other comments: \_\_\_\_\_

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## **APPENDIX F**

### **Open-Ended Responses**

## **What has your support been like?**

### Participants

From family and friends – excellent.

My family and friends have been overwhelmingly supportive; however, I had difficulty finding external support when I wanted to talk to people who had been through it.

I find that everyone's cancer experience must be different. At times I feel like no one could possibly understand what I have gone through or what I continue to go through. I feel like I have lost friends due to lack of support and due to their non-understanding of the emotional effects of this gene and this cancer.

Mixed. Some family members have been very supportive while others have been confrontational or unwilling to discuss risk options, etc. Generally this has fallen on the side of gender lines: females open to discussion, males unwilling to discuss, or critical decisions made related to testing and treatment.

Husband had cancer and thinks best if to not discuss it. Mom helps but still is so sad from my sister's death and me inheriting the gene. My dad has no clue. My doctor (holistic MD) is a huge help. She is very knowledgeable and offers preventative methods which help because my other doctors only offer surgery.

### Non-Participants

Enormous support and kindness from family and friends.

My family and friends have been very supportive and that means so much. It really helps you get through the difficult times.

My sister and daughter have been completely supportive. My husband doesn't understand the whole thing as well but is supportive as far as he is capable. Other family and friends don't seem to have much understanding at all – not very supportive.

My whole family is now in a family study. So needless to say, support is total.

Very good.

My sisters, husband, and children have totally supported me in mastectomy and reconstruction. All but one of my sisters have been tested.

Just had support of family and friends. Not afraid to discuss anything with anybody. Some people unsure, because they do not know a lot about it. (Unsure of how to support me)

I have had incredible support from family, friends, and the church.

Great support from family and friends.

Positive support from both family and OB/GYN doctor.

My family and doctors have been very supportive.

## **What do you think about participation in a support/discussion group for women with a hereditary breast cancer predisposition?**

### Participants

I think its great, but my situation is a little different than others. My risk is lower and I am prone to different things.

I think it is extremely beneficial. Since I have not yet had surgery for my ovaries, it has been educational for me to talk with those who've had more exposure to ovarian cancer. It has helped me to solidify my decision to have my ovaries removed.

I'm not big on "support" groups, however I find this discussion group to be beneficial and informative for any individual who faces the decisions associated with this gene.

Ambivalent. It's important to recognize that others share the same difficult decisions, emotions, sad family histories, but it is also very hard to be reminded of this again and again! Kind of like – I have enough to deal with, I don't need/want other people's miseries on top of my own.

Helpful to learn and see what others decided.

### Non-Participants

It would probably be helpful for most women. It helps to know that you are not alone in this situation.

I wish there had been such a support-discussion program available 20 years ago when I had my first breast cancer. I think it is very important for women just going through this to have the knowledge and experience from someone who has been there.

I would take part if the group were close to home.

If someone feels a need for a support group, then by all means go for it. I have all the support I need within my family and friends.

I would like to participate if it was in my area. I am willing to talk to others to help make a decision.

I think it would be a great idea, because I believe people going through the same thing have a better understanding. BRCA is not real common, and a lot of other people do not know what it is.

I don't feel that I need a support/discussion group.

I do not feel the need personally for a support group. I tend to discuss and deal with thing with a close group of family and friends. I think there are people out there who would benefit from

these types of groups. In the future if I or a member of my family would feel the need for this type of group, we would certainly seek it out.

I don't need it, but it might be a help for others.

I think that a support group is a great idea for women who do not have a family support group to help them.

I may frighten them – now 2<sup>nd</sup> treatments for ovarian cancer.

**Please share any other comments:**

Participants

Above I checked that I have complete confidence in the preventative decisions that I have chosen, however, I do not have confidence in treatments for breast/ovarian cancer that currently exist. That is why I had prophylactic surgery. I think this should be two separate questions. Also, my discomfort in talking to my children about the test results comes more out of the worry that I have for them. I am comfortable explaining the results, but am uncomfortable about my children having to face the same prospect in the future.

I would like to see more symposiums with this group and would like more expert opinions on the gene. It would be great if a genetic doctor could speak at one of the meetings.

I have been touched by the support group and time and effort that has gone into developing this support group. This is a group of kind and generous, and talented women! However, I keep asking myself where is it headed? What is the benefit for me? Since I am still not ready to undergo prophylactic mastectomy – and don't foresee that option in the near future – Do I want to keep being reminded of this? I generally leave the meetings feeling a bit depressed, and certainly anxious. Are those feelings worth the sense of solidarity?

I would like more discussions on prevention and positive thinking. Stress causes cancer. You need to be focused on the positives.

Non-Participants

I'm glad to have the opportunity to join such a group as I have had three cancer surgeries and hope my experiences can be of some benefit to others.

I have taken part in some discussions at [facingourrisk.com](http://facingourrisk.com). I attended a breast cancer awareness program at my local hospital and learned a few new facts from the speaker. I have also done some reading on the internet.

I am a 24 yr survivor of breast cancer. So be positive and never give up. My mother and 2 sisters died of ovarian and breast cancer. My daughter had a double mastectomy, chemo, and is alive and well. My son, throat cancer. He is alive and well. My youngest daughter is also carrying BRCA1 and recently had a mastectomy. My brother, throat cancer. Alive and well. His daughter, my niece, both breast and ovarian. Alive and well. There is hope and life with cancer.

I am so glad that I had the test and could have surgery before I got cancer.

I feel knowing that I have BRCA2 benefited me on making decisions about my life and contributed to a longer, healthier life.

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