Factors influencing uptake of bilateral prophylactic mastectomy between the ages of 20 and 30 years in unaffected women with a BRCA1/BRCA2 mutation

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Meera Mitchelle Clytone

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ABSTRACT

Factors influencing uptake of bilateral prophylactic mastectomy between the ages of 20 and 30 years in unaffected women with a *BRCA1/BRCA2* mutation

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Meera M. Clytone

It has been established that deciding to undergo a bilateral prophylactic mastectomy is a complex step for any individual. Studies have highlighted various factors such as family history of cancer and altered body image concerns that could play a role in this decision-making. However, there still is not enough evidence elaborating thoughts of women who undergo this surgery between the ages of 20 and 30 years. The purpose of this study was to explore the decision making of these young women. We conducted the study through an anonymous survey (FORCE) and received 27 responses. All the women reported to have a significant family history of *BRCA*-associated cancers. Most women had met with a genetic counselor/geneticist soon after being identified with a germline mutation, and found it helpful. We observed that women in this cohort (1) had a family history of cancer and death due to cancer (2) had a realistic understanding of the lifetime risk of breast cancer due to *BRCA1/BRCA2* mutation (3) faced concerns pertaining to their ability to breastfeed, potential impact to sexual relationships and altered body image (4) consider screening techniques to induce some level of anxiety (5) considered information from surgeon/plastic surgeon very helpful in their decision-making. This data highlights some of those concerns of this cohort and supports the need to address psychosocial concerns of women making the decision of undergoing a bilateral prophylactic mastectomy.
Keywords: Young women, HBOC, breast cancer, cancer risk, bilateral prophylactic mastectomy, unaffected carriers, factors influencing decision making, family history, BRCA mutation positive
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INTRODUCTION

Identification of a pathogenic variant in the BRCA1 or BRCA2 gene confirms the diagnosis of Hereditary Breast and Ovarian Cancer (HBOC) syndrome (Mauer, 2016). The lifetime breast cancer risk in women with a germline BRCA1 mutation is between 56% and 72% and the risk of ovarian cancer is between 40% and 67% (Metcalf K., 2010). Similarly, the lifetime risk for breast cancer in women with a germline mutation in BRCA2 is between 38% and 85% (Metcalf K., 2010) and the risk of ovarian cancer is up to 18% through the age of 70 years (Chen, 2007). Navigating options for management of lifetime cancer risks is crucial for individuals identified with a germline BRCA1 or BRCA2 mutation. A thorough discussion of high-risk breast management options includes breast screening for early detection, usually beginning by age 25; consideration of chemoprevention for lowering breast cancer risk with tamoxifen; as well as the option of bilateral prophylactic mastectomies (BPM). BPM may reduce the lifetime risk of developing breast cancer to <5% (Meijers-Heijboer, 2001). Management of ovarian cancer risk includes a bilateral salpingo-oophorectomy (BSO) after child-bearing is complete, or by age 40 and consideration of oral contraceptives before undergoing BSO (NCCN Clinical Practice Guidelines in Oncology (NCCN), 2017). Alongside offering management options, addressing questions and validating psychosocial concerns is also recommended to ensure well informed decision making and emotional health (NCCN Clinical Practice Guidelines in Oncology (NCCN), 2017).
Deciding to undergo a BPM is a complex and often a lengthy process (McQuirter, 2010). Multiple factors influence a woman’s decision and one of these factors includes the age at which genetic testing was done. Previous studies have identified that family history of cancer diagnosis and death due to cancer, fear of potential impact on sexuality, body image concerns, desire to breastfeed future children, and fear of cancer may influence a woman’s decision of choosing between BPM and screening techniques (McQuirter, 2010) (Brunstrom, 2016).

In clinical practice, both high-risk breast screening and BPM options are discussed with patients. Surgical discussions can involve multi-disciplinary consultations should include the potential risks and benefits of surgery and breast reconstruction options. Studies also report that the rates of bilateral and contralateral prophylactic mastectomy have increased among women with a newly diagnosed breast cancer (Komenaka, 2015) (Rosenberg, 2015). Contralateral prophylactic mastectomy is the surgical removal of an unaffected breast to reduce cancer risk, after the diagnosis of a unilateral breast cancer (Rosenberg, 2015). One study reported that the uptake of contralateral mastectomy in women with ductal carcinoma in situ solely, which is a particular pathology of breast cancer, had increased by 148% from 1998-2005 (Tuttle, 2009). A study carried out in 2010 to include all the Danish women who were BRCA positive, had a 50% uptake of BPM by a 10-month follow-up (Skytte, 2010). Even though this rate is potentially different in various countries, it supports the increasing acceptance of BPM as a management tool.

Researchers found that cancer distress post-surgery was heightened in women who had a family history of cancer compared to those who had a limited family history (Metcalfe K., 2004). One study from Denmark found that younger women chose BPM more often than the older women suggesting age being a possible factor influencing uptake (Skytte, 2010). Another study also showed that psychological distress and body image are issues that could be assessed before
undergoing BPM, so that women who are vulnerable to distress post-surgery, could have a planned coping mechanism with assistance (Heijer, 2012).

Due to the consistent fear of developing cancer, lifetime risks have been shown to be perceived higher than usual in conjunction to seeing a close family member suffer (Covelli, 2015). An important factor that drove women to opt for a prophylactic mastectomy included the intense news such as receiving a diagnosis of breast cancer, or a positive $BRCA$ test result of a family member (McQuirter, 2010). Additionally, in instances of partnerships, a significant other’s perspective and role in decision making for prophylactic surgeries has been highlighted (Mauer, 2016). It is justified to mention that the choice is highly personal. This could weigh in differently for women between the age group of 20 and 30 years, who are in the prime time of their life potentially planning to settle down, in terms of career, and personal life.

Deciding whether to undergo a prophylactic mastectomy or screening, or get no screening at all is a topic that has been addressed in various approaches. Scientists have seen that the decision-making is a result of a stepwise integration of intuitional processes with individual contexts and experiences (McQuirter, 2010). A retrospective study of women who underwent prophylactic mastectomy showed that age of the patient, having a family member pass away before the age of 50 years, and undergoing prophylactic oophorectomy play an important role in the decision making (Dana, 2016). Evidence has indicated the importance of not only accurate risk assessment but also appropriate genetic counseling addressing individual issues (CM, 2016).

Young adulthood, as a phase of development might be the most crucial time to study the impact of genetic testing (Werner-Lin, 2008). For an unaffected woman to choose BPM when she is young, body image is potentially a factor to think about for personal or professional reasons (Heijer, 2012). One study looking at the uptake of BPM noted that significantly more women who
underwent BPM had lost their mothers to cancer than the women who had not (Singh, 2013). This may also relate to the age at which the individual lost her mother, if she was an adolescent, or a teenager, or too young to remember. The same study also suggested that women who already had children were more inclined to take up BPM. It is logical to think that an individual who perceives herself to be at a very high risk of developing breast cancer would want to do everything possible to reduce the risk. A study focused on reproductive decision brought out the voices of a few women facing the dilemma following a positive genetic test result, and one of them stated,

“I decided to have children before mastectomy because I wanted to breast feed…it’s always at the back of your mind I suppose.”

This highlights the fact that parity could be something young women think through before deciding regarding prophylaxis (L.S.Donelle, 2013). Being in a stable romantic relationship could indicate a partner’s role in the decision making. When looking at male attitudes on their partners getting a BPM, most tend to state that there was not much difference in the level of attractiveness with respect to before and after surgery (Mauer, 2016). However, for an unaffected woman to choose BPM when she is young, body image is potentially a factor to think about for personal or professional reasons (Heijer, 2012).

An interview based study in the UK looked at experiences of women who underwent BRCA testing before the age of 30 years. They found that removal of uncertainty and increases sense of control, along with family obligations were the main reasons that motivated them to undergo testing (Brunstrom, 2016). Although the women reported having no regrets about having been tested at a young age, they felt their mutation status and circumstances forced them into a tight spot of deciding for or against a BPM (Brunstrom, 2016).
Studies performed in the context of decision making for prophylactic surgeries have recognized some important factors that go into it. However, because age has been shown to be an important factor, it is important to determine what 20-30-year-old unaffected female BRCA mutation carriers consider when they are faced with this choice. No studies pertaining to BPM for young adults have looked particularly at potential professional influence, the influence of the individual’s relationship status, and the effect of family history. It is also important to recognize if pre-surgical discussions of BPM have been limited primarily to a physician or surgeon, or whether a genetic counselor or other support persons such as other BRCA carriers were also consulted. In addition, how women perceive the efficacy of screening techniques such as breast MRI or mammogram in early detection of cancer may be an influencing factor in their decision to pursue BPM. With this thesis, we attempted to incorporate these factors and look at the experiences of BRCA carrier females who elect BPM from the young adult perspective.
METHODS

The Brandeis University Institutional Review Board reviewed and approved this study.

Recruitment and sample

Unaffected women with a germline mutation in BRCA1 or BRCA2, and either underwent a BPM between the ages of 20 and 30 years, or are currently deciding to opt for one and are in their 20s were invited to participate in a confidential and anonymous survey. The survey was designed using both open and closed ended questions. A survey link was sent out on the E-newsletter and the Facebook page of the Facing Our Risk of Cancer Empowered (FORCE) group. All participants who completed the survey were offered a chance to enter a drawing for one of three $50 Amazon.com gift cards.

Data collection

Data was obtained using an anonymous survey created through Qualtrics. The main areas of focus were-

1. Family history
   a. Having lived with/lost a relative diagnosed with cancer and degree of relationship to that individual
   b. Ages of respondent and family member at the time of loss

2. Social history
   a. Relationship status at the time of decision-making
   b. Partner’s influence on the decision, if applicable
c. Parity/Desire to have more children
d. Breastfeeding ability concerns
e. Altered body image concerns

3. Profession related factors
   a. Field/Practice or area of study
   b. Potential impact of surgery on profession/performance

4. Awareness/Information level
   a. Perception of lifetime cancer risk
   b. Sources of information (i.e. resources and individuals)

The survey was voluntary and anonymous. It consisted of 74 questions including 5 open-response questions. Anticipated time required to complete the survey is somewhere between 15-20 minutes. Respondents had the option of not answering any of the survey questions or exiting the survey at any time. All raw and analyzed data was securely stored with access granted only to the principal investigator and the student researcher.

Data Analysis

Statistical analysis was performed using SPSS, a statistical software package. Microsoft Excel was used to manually analyze open-ended questions to identify themes.
RESULTS

Demographics of participants

There were 38 participants. After excluding incomplete and ineligible responses, data from 27 participants were used. All 27 women fell in the age range of 25-37 years, and the age range of when they underwent the bilateral prophylactic surgery was 23-30 years. The difference between current age and age at the time of BPM was an average of 4 years. 13 out of the 23 participants took 6 months or less in deciding to get a BPM, and 9 participants took 7 months to 2 years.

Influence of family history of cancer

We asked participants about their family history of breast, ovarian and other cancers. 25 out of 27 respondents said yes to having a family member diagnosed with breast cancer with 54 total family members reported to having had cancer.

Fig(1). Influence of family history of breast cancer
44/54 family members’ cancer diagnosis was an important factor in these women’s BPM decision making(Fig.1). 15/18 (83%) of respondents whose mother or sibling was diagnosed with breast cancer mentioned that it strongly or very strongly influenced their choice of BPM. Some women reported this to be the major driving force. One of the participants voiced,

“I am also sad my mom died when I was so young and want to do everything I can to avoid leaving my own kids too soon”.

Another participant elaborated stating,

“Put it in terms of life or death: have the surgery and probably live longer, don't have the surgery and probably die sooner. I didn't want to wait to get cancer only to have to fight cancer and worry about it coming back.”

7 out of 18 women (38%) whose mother/sibling was diagnosed with breast cancer were aged 10 or less years at the time of the family member’s diagnosis. One such woman’s words were,

“I think the greatest factor was my mother's early death at 36 from breast cancer. Losing a parent had a huge impact on me, and I was almost obsessed with avoiding that risk and putting my husband and future children through that sort of pain.”

**Parity and desire to breastfeed future children**

Out of the 24 women that answered questions on parity and future children, 5 (20%) already had children at the time of surgery, of which 3 wanted to have more children in the future, and 2 did not. When the 3 women who wanted to have more children in the future were asked about their thoughts on breastfeeding, they reported neutrality and probable concerns. Both women who did not want to have more children expressed breastfeeding concerns, and implied that they were more
comfortable undergoing a BPM as they were done with having children and did not have to worry about their ability to breastfeed future children. One of the women mentioned:

“Breast feeding was important to me and I was lucky enough to have had all my kids when I found out I was positive. Otherwise, I may have waited longer.”

19 out of the 24 women (80%) who answered this set of questions reported that they had no prior children. 13 of these 19 women, said they desired to have more children, and 11 (84%) of those 13 expressed probable to definite breastfeeding concerns. The questions were exploring respondents’ views on wanting to breastfeed future children, and if that desire made them rethink their decision of undergoing BPM. For women who already had children the survey asked if not having to worry about breastfeeding in the future made breastfeeding less of a concern when deciding to undergo BPM.

Influence of relationship status at the time of decision making, concerns to body image and sexuality

18 out of 24 (75%) women were in a committed relationship at the time of surgery. Of the 18, 14 stated that their at-the-time partners were somewhat or very involved in the decision-making process. Additionally, 17 out of the 18 (94%) women reported that their partners were very supportive in their decision to get the surgery. On being asked if these 18 women were worried about the surgery affecting their relationship, 11 women (61%) said probably or yes.

6 out of 24 women (25%) said that they were not in a committed relationship while making the decision to undergo surgery, and were not asked questions pertaining to the partner as mentioned above. All 24 women were asked if they anticipated altered body images with or
without reconstruction, to which 22 (91%) expressed probably or definite concerns. Furthermore, on being asked if these women were thinking about potential effects of the BPM on their sexual relationships, 20 (83%) said that they at least had some concerns. One participant mentioned,

“I’m a teacher, and I worried that I would look strange to my students coming back from the surgery with no breasts and limited mobility. It ended up not being a problem at all, although I never told them what my surgery was for."

Lastly, under this segment, women were asked if they thought about what it would be like to divulge information pertaining to the BPM to a future partner, and 9 out of 24 (37%) said they were somewhat or very concerned about the disclosure.

**Perceived lifetime risk of cancer**

On being asked what lifetime breast cancer risk was told to them by their genetics healthcare provider, all 23 women who answered the question had a realistic view of the lifetime risk of cancer. They reported values between 60 and 89% after being offered choices in a scale from 0 to 100%.

![Fig(2). Lifetime breast cancer risk perception among participants](image-url)
**Interaction with a person with a similar experience**

22 out of the 24 respondents (91%) for this section said that they reached out to another individual who underwent a BPM too. Of these, 20 individuals reported somewhat to extremely satisfactory experience and 2 reported a neutral experience. Of the 22 women, 16 (73%) said that hearing another person’s positive experience influenced their decision making. One woman stated,

>“After seeing her great results and happiness with her results, I begin to think more positively about the process and the potential for me to look normal afterwards.”

Another woman mentioned how even talking to women within her family about BPM helped motivate her to make a choice for herself,

>“Yes, my mother underwent BPM and BSO after aunt had 2nd diagnosis of BC and tested positive for BRCA1. Went to FORCE conference to learn about my options after I tested positive. Extremely helpful for me to hear and SEE all my options.”

**Interaction with genetic counselor/geneticist**

21 out of 23 respondents that answered this section reported that they met with a genetic counselor or a geneticist after being identified with a BRCA mutation. Some respondents elaborated in the open-ended section regarding their genetic counseling experience and one of the participants said,

>“I met with an amazing genetic counselor who explained how I inherited this gene and laid out my options. She also referred me to some excellent doctors with lots of experience in BRCA1.”

However, another respondent seemed to have a different experience,
“I was told I had to for insurance purposes. She didn't tell me anything I didn't already know or couldn't have found out easily. I didn't think it was very useful, and I didn't really like the way she handled my testing.”

**Perceived effectiveness of screening techniques**

On a scale of not effective to extremely effective, when asked how the respondents felt about the available screening techniques for breast cancer, 21 out of 23 who answered the question (91%) said they thought the techniques were at least moderately effective. However, 16 out of 21 (76%) also reported that the screening techniques caused at least some anxiety in them. One respondent elaborated on her screening experience:

“In 2015 I had my first MRI. It showed a few areas of concern that lead to biopsies. Both sites were deemed fine, just remnants of breastfeeding my daughter and having has mastitis. After that I decided I didn't want to wait until 35 or 40 for my PBM and go through screenings every 6 months just waiting for a BC diagnosis. I booked my survey (surgery) for 1 month later.”

**Insurance coverage**

When asked about insurance coverage for the procedure, 20 out of 23 (86%) women who answered stated that they received full coverage for the BPM. A 27-year old respondent said,

“I was under the age of 26 and unemployed which, thanks to the ACA, made me eligible to remain on my parents' military health insurance: TRICARE. Since my parents lived near a military base and our PCP and all procedures were at a military hospital, we essentially had no co-pay/pharmacy fees.”
Another respondent said,

“Because I had a job with excellent medical coverage and sick leave, I opted to have the surgery right away. Since my lifetime cancer risk was high, I knew I wanted to have a mastectomy. I figured I should do it while I knew I could get time off work and my insurance would cover it 100%”

**Additional factors**

<table>
<thead>
<tr>
<th>Factors</th>
<th>Number of responses reporting “A great deal” or “A lot”</th>
<th>Total number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifetime cancer risk</td>
<td>20(100%)</td>
<td>20</td>
</tr>
<tr>
<td>Effectiveness of screening strategies</td>
<td>11(55%)</td>
<td>20</td>
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<tr>
<td>Participant’s feelings towards screening techniques</td>
<td>13(65%)</td>
<td>20</td>
</tr>
<tr>
<td>Information from written material, websites/books/articles</td>
<td>10(53%)</td>
<td>19</td>
</tr>
<tr>
<td>Information from a surgeon</td>
<td>16(80%)</td>
<td>20</td>
</tr>
<tr>
<td>Information from GC/Geneticist</td>
<td>13(65%)</td>
<td>20</td>
</tr>
<tr>
<td>Information from a plastic surgeon</td>
<td>15(75%)</td>
<td>20</td>
</tr>
<tr>
<td>Information from a family member</td>
<td>12(60%)</td>
<td>20</td>
</tr>
<tr>
<td>Information received from support groups/chat rooms</td>
<td>9(47%)</td>
<td>19</td>
</tr>
</tbody>
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Table(1). Influence of various factors in the BPM decision-making
Participants were asked to rate a list of factors influencing their decision to pursue BPM from “no influence” to “a lot” of influence. The factors with greatest influence were lifetime cancer risk, information from plastic surgeon and information from surgeon. Less important ones were information from support groups/chat rooms, information from a primary care provider, and from disclosure of Angelina Jolie’s BPM. A 33-year old participant made it a very black and white choice by saying,

“Put it in terms of life or death: have the surgery and probably live longer, don't have the surgery and probably die sooner. I didn't want to wait to get cancer only to have to fight cancer and worry about it coming back.”

Apart from all the factors mentioned above, women reported family members to have a strong influence. A 31-year old woman said,

“My father put a lot of pressure on me to have the surgery. He was very concerned about what would happen if I chose to just wait and see.”

Other women pointed out the support they received from family. A 27-year old, whose mother was diagnosed with and survived a breast cancer diagnosis said,

“My mom was my biggest supporter and influencer. Seeing what she went through all those years made me realize I couldn't handle that myself.”

A 30-year old who had a family member diagnosed with breast cancer said,
“She had great results and more peace of mind. She was a person I could trust (my aunt). She had done a lot of the legwork with research. I went on to use her same surgeons for my procedure.”
DISCUSSION

This aim of this study was to explore factors that contributed to women undergoing a BPM in contrast to available breast cancer screening techniques such as mammograms, ultrasounds and MRIs. Since our target population were women who already have undergone the surgery, and not a comparative study of those who did and did not undergo surgery, it is not possible to juxtapose and infer what factors push women to or away from the decision of BPM. However, this study can serve to lend some voice to this narrow demographic group.

Young adults under the age of 25 are being described as being distinct from other age groups in terms of psychological needs at the time of risk assessment and surgical decision making (Werner-Lin, 2015). Of the 27 participants, 11 reported that they were identified with a BRCA1 mutation, and 15 reported to be carriers of a BRCA2 mutation. The youngest age of undergoing BPM in this cohort was 23 years, and 4 women fell in this sub group. 2 of the 4 respondents stated that their first degree relative had been diagnosed with breast cancer and passed away when the respondent was 10 years of age. This strongly affected their decision of BPM. It has been previously reported that family history is quite an important factor in choosing breast cancer surveillance (Covelli, 2015).

On similar lines, we noted that out of 27 participants, 25 of them said they had a family history of breast cancer. We also asked about the history of ovarian cancer in the family, and 12 out of 25 respondents answered positively. While 44 out of 54 family members who were diagnosed with breast cancer had a strong influence on participants’ decision-making, 6 out of 10
family members diagnosed with ovarian cancer had a strong influence on participant’s decision making (Fig. 1).

Lastly, under the family history umbrella we also asked if there was any other cancer history in the family. 21 out of 25 responded positively; 6 out of those had a family history of pancreatic cancer, and 6 had a family history of prostate cancer. Participants reported than 9 out of the 25 cancer diagnoses were a strong influence in their decision making. 3 out of those 9 were diagnoses of pancreatic cancer. It is important to note than not only a family history of breast cancer, but also other BRCA-associated cancers could be as influential in a person’s mind while deciding breast cancer risk management. Sometimes genetic testing and risk reducing surgeries are carried out more due to a parent’s anxiety rather than the young individual’s desire to act (Werner-Lin, 2015). This was expressed by one respondent,

“*My father put a lot of pressure on me to have the surgery. He was very concerned about what would happen if I chose to just wait and see. My sister would not talk to me about the surgery or the gene at all. My fiancee was very supportive in me choosing what was best for me.*”

The family history module gave us evidence that most women in our cohort reported significant family history of a BRCA associated cancer. We saw no significant differences in family history, body image and sexual relationship concerns and breast-feeding concerns between women who underwent the surgery before the age of 25 versus women who underwent BPM between the ages of 25 and 30 years.

Most women who were in a committed relationship when they were deciding to opt for a BPM mentioned that their partners were very supportive of them. It has been previously published that a significant other’s perspective is valuable and contributory to when as women chooses to get a BPM (Mauer, 2016). This also supports evidence that partners do not necessarily consider
there to be decreased attractiveness to be a concern as opposed to the cancer risks decreasing tremendously (Mauer, 2016). Despite having supportive partners, 11 out of 18 women expressed concerns of their relationship being affected due to the surgery. We did not dig deeper into if these women underwent reconstruction, or what kind of reconstruction they opted for. However, this could also be supported with the fact that 22 out of 24 women said they worried about there being a potential body image change post-surgery. This question was asked regardless of whether the respondent was planning to have reconstruction or not. A study reported that many women with BRCA mutations fear rejection after disclosing their mutation status to their partners itself (Mauer, 2016).

With respect to the impact of BPM on sexual relationships, 83% of women expressed fear, and this is supported by previous work. Thinking into the future, 63% of women said they were not very concerned about divulging this information to a future partner. Parity and desire to have more children was also hypothesized as an important factor. As expected, some women portrayed concerns of breastfeeding, and one of them even stated that she was lucky to have had all her children by the time she had to decide to get the surgery because breastfeeding was very important to her. This is important to note, because breastfeeding can be a crucial segment of parenting and motherhood for some women.

Apart from their own thoughts, we also inquired if our respondents reached out to other women who underwent a similar phase in life. All but two women sought out talking to an individual who had themselves undergone a BPM. This included family members, or individuals from a support group or a hospital program. This served as a very important step for them because all 16 women who answered positively to this segment, said they were very relieved to learn that other people have had good experiences and it in turn motivated them to opt for the surgery and
be relatively less anxious. Gestures such as sharing enthusiasm, recommending providers, clarifying doubts, helped these women cope with the dilemma.

On being asked about insurance coverage for the entire procedure, 21 out of 23 respondents mentioned that they received full coverage and this is an important factor, as these procedures are expensive if needed to be paid out of pocket. Hence, being on a family member’s health insurance, could also be convenient for considering the surgery at a younger age. Again, young adulthood in the United States is a dynamic time as individuals explore jobs/careers, education, and family building. The Affordable Care Act (ACA) allows young adults to remain on their parent’s health insurance until age 27. Young adults who are not employed and approaching age 27 face being uninsured or underinsured and therefore may experience additional financial pressure to undergo BPM at a younger age.

On opinions of being perceived differently at workplace, 11 out of 23 women stated that they certainly had concerns. One of them said she felt as though she would be “damaged or sick in some way”. Another participant was a dance teacher and felt nervous for her student and their parents to find out. This point to the fact again that the surgery comes with a long psychological thought process and distress that starts way before the actual surgery, and stays sometimes even long after the surgery is completed.

Most women (13/23) took 6 months or less after they found out that they were BRCA mutation positive to decide to undergo a BPM. A visit or two to a genetic counselor or geneticist was reported by 20 out of 23 respondents. 11 out of the 16 who left open ended responses stated that it was very helpful to meet with a specialist and look at all the possible options available.

Very importantly, all women had a realistic perception of the lifetime cancer risks they were dealing with. It is encouraging that they received these number from a healthcare provider,
and retained this information correctly, since we also need to consider that the average time between the participants getting the surgery and taking the survey was 4 years. It is interesting to note that even though these women had a fair understanding of their breast cancer risk, and yet they chose to go for the BPM and not any other breast cancer screening technique.

Breast cancer imaging have been known to induce some anxiety and sometimes even cause “scares” due to false positives on imaging that lead to a normal biopsy outcome. This trend was also seen in 17 out of 22 respondents, who reported that the screening caused them at least some anxiety. All 23 respondents perceived screening techniques to be at least moderately effective. It’s interesting to note that even though they thought the techniques effective, it caused anxiety, and they preferred to bring down the risk surgically rather than go through screening periodically and wait for a diagnosis. Some open-ended responses as mentioned previously highlighted this fact.

Lastly on a Likert scale we asked the respondents how much specific factors weighed in relatively in their decision-making. The most influential factors were lifetime cancer risk, and information from surgeon and plastic surgeon.

15 participants responded to the open-ended question of what other factors influenced their decision and 2 women reported the fear of death because they have lost a family member to cancer; 1 person mentioned breastfeeding concerns; 3 had had a previous scare and wanted to eliminate risk, and 5 were worried about not being around for family and kids. Given the small sample size, we cannot affirm that these are driving forces, but certainly is characteristic of women generally facing this decision.

Overall, this study brought attention to and reiterated that choosing to undergo a BPM is a complex process, and that the younger a woman is, there are generally more factors to consider. In such circumstances, it is important for genetic counselors and other healthcare providers such
as plastic surgeons, nurse practitioners, geneticists and oncology surgeons to bring up potential concerns when a client is considering different breast cancer surveillance options. The aim is to not confuse them with all the information, but support them in making an informed decision, from all the available options. BPM decision making comes with potential for many psychosocial concerns as mentioned during this presentation, which if talked about, would make the procedure smooth, and healing complete. It is valuable to note that despite having numerous concerns, and a realistic view of the breast cancer lifetime risk, these women chose to undergo the surgery at a very young age.

**Limitations**

One of the big limitations was the relatively small sample size, comprising only of 27 participants. This analysis is confined by number, and by access since all our participants were recruited through the FORCE group or Bright Pink, which may imply that they have had access to more information than a person only going to a hospital setting would have had. This brings in a sampling bias.

In asking about the respondents’ experience in interaction with other women who have undergone BPM themselves, all the answers were of having had a satisfactory feedback. The sampling bias gets extended to this segment as well, because the organization would not get a person in touch with someone whose experience with the surgery was not satisfactory. Another potential limitation is recall bias, since the average difference between the time BPM and taking the survey is 4 years. Lastly, interpretation and analysis was performed by one researcher, which may not have ensured neutrality in the identification of themes.

**Future directions**
This survey could be used to target a larger sample size, by considering more media for distribution. Through this, the findings of this study could be checked for consistency and standardization. As mentioned previously, this study only considered women who have already had a BPM, and not the ones that chose to not get the surgery. It would be interesting to see the difference in opinions between women in these two situations. Further exploration could be done as to what factors are most influential in making either decisions.

This study was limited to profiling of participants in the group, and not to go in depth of their emotional journeys through this procedure. Future studies in the form of interviews may be able to highlight the deeper issues and concerns. It might also be interesting to see on a larger sample size if there is any difference in the decision making based on if they had a BRCA1 mutation, and if the participants were told a different unrealistic lifetime breast cancer risk. Additional studies could develop more literature in this area that can be made available to women in the process of making their decision.
CONCLUSION

This study aimed to navigate the thought processes of women identified with deleterious BRCA mutations while choosing to undergo a BPM between the ages of 20 and 30 years, and identify common themes and ideologies among them. We observed that (1) all women had a first degree relative who had been diagnosed with breast, ovarian or pancreatic (or multiple) cancer; (2) all women had a realistic view of their lifetime breast cancer risks that fell between 60 and 89%; (3) women consider breastfeeding an important part of their motherhood, and might plan their BPM based on the timing of childbirth; (4) most women in this group had partners that were supportive of their decision, and this motivated them further to undergo the surgery; (5) women have concerns about the surgery impacting their body image and/or sexual relationships, and these concerns must be addressed to make their transition smoother; (6) women consider breast cancer screening techniques to be effective, but anxiety inducing.

As healthcare providers, we can meet their needs better by making sure to assess and address the various issues observed in this study in a timely manner. It may be prudent to attempt to get them thinking about implications of surgery while also trying not to confuse or overwhelm women during this sensitive phase. Furthermore, there is a need to develop more literature and resources for women so that they can have access to diverse information on BPM.

This study gave us results that support the findings from past literature. With this data, and further larger-scale studies on similar lines, we can hopefully develop standards of care and recommendations for improving services that support young women going through BPM.
Bibliography


APPENDICES

Appendix A: Recruitment notice

Welcome!

You are being asked to participate in this study because you are a woman identified with a $BRCA1$ or $BRCA2$ mutation and have undergone a bilateral prophylactic mastectomy between the ages of 20 and 30 years. As a part of my Master’s thesis at Brandeis University, I am hoping to understand the thought processes and important factors that come to play when women identified with a $BRCA1$ or a $BRCA2$ mutation face this difficult choice at young ages. We hope the findings from this study will serve as a resource to woman approaching a similar situation, and improve genetic counseling services in the future.

Your responses to this online survey will be anonymous. This survey is expected to take an average of 10-15 minutes of your time. Participation in this survey is voluntary. We ask that you respond to all survey questions, however you may skip any questions that you are not comfortable answering or end your participation at any point.

This study involves minimal risk to participants. Some participants may experience some distress due to having to think back on their experience with decision making and going through the process of bilateral prophylactic mastectomy. Participants may however benefit from the feeling that their experience would contribute useful information to other women in a similar position and to the field of genetic counseling.

All participants who complete the survey will have the opportunity to enter a drawing for one of the three $50 Amazon gift cards. Your survey responses will not be connected to your email addresses. If you are interested, please enter your email address on a separate link as directed at the end of the survey. Your survey responses will not be connected to your email addresses. This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have any questions about your rights as a research subject, please contact the Brandeis Institutional Review Board at irb@brandeis.edu or (781) 736-8133.

If you have any questions, concerns or comments, please feel free to contact me by email at mclytone@brandeis.edu, or the Brandeis University faculty advisor, Gayun Chan-Smutko, at gchansmutko@brandeis.edu or 781-736-2336.

By clicking the Next button (>>, you acknowledge that you have read the information above and consent to participate in this survey.

Thank you in advance for your time and participation.
Facebook Group Post

Have you been identified with a BRCA1 or BRCA2 mutation?

Did you undergo a bilateral prophylactic mastectomy between the ages of 20 and 30 years?

If you answered yes to the above questions, you are invited to participate in an online research survey to explore the factors influencing a woman’s decision of undergoing a bilateral prophylactic mastectomy between the ages of 20 and 30 years. As a part of my Master’s thesis at Brandeis University, I am hoping to understand the thought processes and important factors that come to play when women identified with a BRCA1 or a BRCA2 mutation are faced with this difficult choice at young ages. This in turn would serve as a resource to women approaching a similar situation, and improve genetic counseling services in the future.

This anonymous survey will take an average of 10-15 minutes of your time. All participants who complete the survey will have the opportunity to enter a draw for one of the three $50 Amazon gift cards. Your survey responses will not be connected to your email addresses.

This study was reviewed and approved by the Brandeis University Institutional Review Board. If you wish to be a part of this study, please click the link provided below.

If you have any questions, concerns or comments, please feel free to contact me by email at mclytone@brandeis.edu, or my faculty advisor, Gayun Chan-Smutko, at gchansmutko@brandeis.edu or 781-736-2336.

Thank you in advance for your time and participation.

Click here to take the survey!

Sincerely,
Meera Clytone
Master’s Degree Candidate, Class of 2017
Genetic Counseling Program
Brandeis University
Blurb for the E-newsletter from Facing Our Risk of Cancer Empowered (FORCE)

We are conducting an online survey approved by the Brandeis University IRB to explore the factors influencing a young woman’s decision to undergo a bilateral prophylactic mastectomies (BPM). If you are a woman with a BRCA1/BRCA2 mutation, had a BPM between the ages of 20-30, please click HERE for more information!
Appendix B: Study instrument

Online survey

Welcome!

You are being asked to participate in this study because you are a woman identified with a \textit{BRCA1} or \textit{BRCA2} mutation and have undergone a bilateral prophylactic mastectomy between the ages of 20 and 30 years. As a part of my Master’s thesis at Brandeis University, I am hoping to understand the thought processes and important factors that come to play when women identified with a \textit{BRCA1} or a \textit{BRCA2} mutation face this difficult choice at young ages. We hope the findings from this study will serve as a resource to woman approaching a similar situation, and improve genetic counseling services in the future.

Your responses to this online survey will be anonymous. This survey is expected to take an average of 10-15 minutes of your time. Participation in this survey is voluntary. We ask that you respond to all survey questions, however you may skip any questions that you are not comfortable answering or end your participation at any point.

This study involves minimal risk to participants. Some participants may experience some distress due to having to think back on their experience with decision making and going through the process of bilateral prophylactic mastectomy. Participants may however benefit from the feeling that their experience would contribute useful information to other women in a similar position and to the field of genetic counseling.

All participants who complete the survey will have the opportunity to enter a drawing for \textbf{one of the three $50 Amazon gift cards}. Your survey responses will not be connected to your email addresses. If you are interested, please enter your email address on a separate link as directed at the end of the survey. Your survey responses will not be connected to your email addresses. This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have any questions about your rights as a research subject, please contact the Brandeis Institutional Review Board at irb@brandeis.edu or (781) 736-8133.

If you have any questions, concerns or comments, please feel free to contact me by email at mclytone@brandeis.edu, or the Brandeis University faculty advisor, Gayun Chan-Smutko, at gchansmutko@brandeis.edu or 781-736-2336.

By clicking the \textbf{Next} button (>>), you acknowledge that you have read the information above and consent to participate in this survey.

Thank you in advance for your time and participation.
Q1 Are you a female?
   ○ Yes
   ○ No

Condition: No Is Selected. Skip To: End of Survey.

Q2 Have you ever been diagnosed with breast cancer?
   ○ Yes
   ○ No

Condition: Yes Is Selected. Skip To: End of Survey.

Q74 Have you been identified with a germline BRCA1 or BRCA2 mutation? (Germline implying hereditary)
   ○ Yes
   ○ No

Condition: No Is Selected. Skip To: End of Survey.

Display This Question:
If Have you been identified with a germline BRCA1 or BRCA2 mutation? (Germline implying hereditary) Yes Is Selected

Q73 What gene mutation were you identified with?
   ○ BRCA1
   ○ BRCA2

Q4 Have you chosen to undergo a bilateral prophylactic mastectomy?
   ○ Yes
   ○ No

Condition: No Is Selected. Skip To: End of Survey.

Q6 How old were you when you underwent a bilateral prophylactic mastectomy? Condition:
How old were you when you underwent a bilateral prophylactic mastectomy? Is Less Than or Equal to 19. Skip To: End of Survey. Condition:
How old were you when you underwent a bilateral prophylactic mastectomy? Is Greater Than or Equal to 31. Skip To: End of Survey.

Q5 What is your current age?

Q64 Has anyone on your father's or mother's side been diagnosed with breast cancer?
   ○ Yes
   ○ No
Display This Question:
If Has anyone on your father's or mother's side been diagnosed with breast cancer? Yes Is Selected

Q63 Which of your family member(s) were diagnosed with breast cancer? Select all that apply.
- Mother/sibling
- Aunt
- First cousin
- Grandparent
- Father/uncle

Q9 Did your (choice from Q.63) survive the cancer diagnosis?
- Yes
- No

Q10 How old was your (choice from Q.63) at the time of diagnosis?

Q11 How old were you when you first learned of your (choice from Q.63) ’s breast cancer diagnosis?

Q12 How strongly did your (choice from Q.63)’s history influence your decision of undergoing bilateral prophylactic mastectomy?
- Very strongly
- Strongly
- Neutral
- Not so strongly
- Not at all

Q55 Has anyone on your father's or mother's side been diagnosed with ovarian cancer?
- Yes
- No

Display This Question:
If Has anyone on your father's or mother's side been diagnosed with ovarian cancer? Yes Is Selected

Q56 Which of your family member(s) were diagnosed with ovarian cancer? Select all the apply
- Mother/sibling
- Aunt
- First cousin
- Grandparent

Q57 Did your (choice from Q.26) survive the cancer diagnosis?
- Yes
- No
Q61 How old was your (choice from Q.26) when diagnosed with ovarian cancer?

Q58 How old were you when you first learned of your (choice from Q.26) 's ovarian cancer diagnosis?

Q59 How strongly did your (choice from Q.26) 's history influence your decision of undergoing bilateral prophylactic mastectomy?
  - Very strongly
  - Strongly
  - Neutral
  - Not so strongly
  - Not at all

Q69 Has anyone on your father's or mother's side been diagnosed with any other cancer?
  - Yes
  - No

Display This Question:
  If Has anyone on your father's or mother's side been diagnosed with any other cancer? Yes Is Selected

Q70 Please state which cancer
  - Pancreas
  - Prostate
  - Peritoneal
  - Other. Please specify ______________________

Q71 Which of your family member(s) were diagnosed with this cancer? Select all that apply.
  - Mother/sibling
  - Aunt
  - First cousin
  - Grandparent
  - Father/uncle

Q65 Did your (choice from Q.71) survive the cancer diagnosis?
  - Yes
  - No

Q66 How old was your (choice from Q.71) when diagnosed with the cancer?

Q67 How old were you when you first learned of your (choice from Q.71)'s cancer diagnosis?

Q68 How strongly did your (choice from Q.71)'s history influence your decision of undergoing bilateral prophylactic mastectomy?
Q13 Were you in a committed relationship when deciding to undergo bilateral prophylactic mastectomy?
   ☐ Yes
   ☐ No

Condition: No Is Selected. Skip To: Did you worry about there being a cha....

Q14 How involved was your partner in your decision-making for the bilateral prophylactic mastectomy?
   ☐ Very involved
   ☐ Somewhat involved
   ☐ Neutral
   ☐ Not very involved
   ☐ Not involved at all

Q15 In your opinion, how supportive was your partner during the decision making process for the bilateral prophylactic mastectomy?
   ☐ Very supportive
   ☐ Somewhat supportive
   ☐ Neutral
   ☐ Somewhat unsupportive
   ☐ Very unsupportive

Q16 Were you concerned about the possibility of the bilateral prophylactic mastectomy affecting your relationship?
   ☐ Definitely yes
   ☐ Probably yes
   ☐ Neutral
   ☐ Probably not
   ☐ Definitely not

Q17 Did you have concerns about there being a change to your body image post bilateral prophylactic mastectomy, with or without reconstruction?
   ☐ Definitely yes
   ☐ Probably yes
   ☐ Neutral
   ☐ Probably not
   ☐ Definitely not
Q18 Were you concerned with the possibility of the bilateral prophylactic mastectomy affected your sexual relationships?
   ○ Definitely yes
   ○ Probably yes
   ○ Neutral
   ○ Probably not
   ○ Definitely not

Q19 How concerned were you about divulging information about your surgery to a future partner?
   ○ Very concerned
   ○ Somewhat concerned
   ○ Neutral
   ○ Not very concerned
   ○ Not concerned at all

Q22 Did you already have children when you were making the decision to have a bilateral prophylactic mastectomy?
   ○ Yes
   ○ No

Q27 Were you planning to have more children?
   ○ Yes
   ○ No

**Condition: No Is Selected. Skip To: Did the fact that you did not want ch....**

Q28 Was breastfeeding a concern for you while trying to decide about undergoing bilateral prophylactic mastectomy?
   ○ Definitely yes
   ○ Probably yes
   ○ Neutral
   ○ Probably not
   ○ Definitely not

Q29 Did your plans to not have additional children influence your choice of a bilateral prophylactic mastectomy?
   ○ Definitely yes
   ○ Probably yes
   ○ Neutral
   ○ Probably not
   ○ Definitely not

Q23 Were you planning on having any more children at this point?
   ○ Yes
Q24 Was breastfeeding a concern for you in trying to decide about undergoing bilateral prophylactic mastectomy?
- Definitely yes
- Probably yes
- Neutral
- Probably not
- Definitely not

Q25 Did the fact that you already had children, and not planning on more influence your decision to choose a bilateral prophylactic mastectomy?
- Definitely yes
- Probably yes
- Neutral
- Probably not
- Definitely not

Q30 While considering Bilateral prophylactic mastectomy, did you talk to any individual with a BRCA gene mutation who underwent a bilateral prophylactic mastectomy?
- Yes
- No

Q72 How did you know this individual?

Q31 For the person you had the most interaction with, what was the experience with this surgery like?
- Extremely satisfied
- Somewhat satisfied
- Neutral
- Somewhat dissatisfied
- Extremely dissatisfied

Q32 Did their experience with the surgery influence your decision?
- Yes
- No

Q34 How did their experience with the surgery influence your decision?
Q33 Did other interactions with family/friends/relatives influence your decision-making for the bilateral prophylactic mastectomy?
   ○ Yes
   ○ No

Condition: No Is Selected. Skip To: End of Block.

Q35 Please elaborate

Q38 Did you think the bilateral prophylactic mastectomy might affect your job performance?
   ○ Yes
   ○ No

Q39 Did your insurance somewhat cover your bilateral prophylactic mastectomy charges?
   ○ Yes
   ○ Partially
   ○ No
   ○ Unsure
   ○ Insurance still in process

Q40 While trying to undergo a bilateral prophylactic mastectomy, did you think you it might affect the way you would be perceived at your workplace/school/college?
   ○ Yes
   ○ No

Display This Question:
   If While trying to undergo a bilateral prophylactic mastectomy, did you think you it might affect the way you would be perceived at your workplace/school/college? Yes Is Selected

Q41 How so?

Q42 Who, if any, from among your workplace did you inform about your surgery decision?
   ○ Supervisor/Colleagues
   ○ Colleagues
   ○ Employee(s) who report to me
   ○ Other ____________________

Q43 How involved were your colleagues in this decision-making?
   ○ Very involved
   ○ Somewhat involved
   ○ Neutral
   ○ Not very involved
   ○ Not involved at all

Q44 How long did you spend making this decision?
   ○ 0-3 months
4-6 months
7-9 months
10-12 months
13-18 months
19-24 months
More than 2 years

Q45 Did you meet with a board certified genetic counselor after your positive BRCA1 or BRCA2 results to discuss your options for screening or surveillance?
- Yes
- No

Display This Question:
If Did you meet with a board certified genetic counselor after your positive BRCA1 or BRCA2 results to discuss your options for screening or surveillance? Yes Is Selected
Q46 Please elaborate

Q47 What lifetime breast cancer risk estimate (%) did the genetic counselor/geneticist give you pertaining to the BRCA carrier status?

Please move the bar

Q48 How effective did you think breast cancer-screening techniques such as mammograms and breast MRIs were in detecting breast cancer early?
- Extremely effective
- Very effective
- Moderately effective
- Slightly effective
- Not effective at all

Q62 To what extent did breast cancer screening techniques such as mammograms and breast MRIs cause you anxiety?
- It caused a lot of anxiety
- It caused some anxiety
- It didn't cause anxiety
- It was somewhat reassuring
- It was very reassuring

Q50 Did you seek any resources after receiving your positive BRCA test results?
- Yes
- No

Condition: No Is Selected. Skip To: End of Block.
Q18 Please indicate your level of agreement, from strongly disagree to strongly agree, with the following statements in relation to your interactions with the [Answer from Q17].

<table>
<thead>
<tr>
<th>Statement</th>
<th>A great deal (1)</th>
<th>A lot (2)</th>
<th>A moderate amount (3)</th>
<th>A little (4)</th>
<th>None at all (5)</th>
<th>NA (6)</th>
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<tbody>
<tr>
<td>Lifetime risk of developing cancer</td>
<td>☐</td>
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<td>Effectiveness of early detection strategies such as mammogram and breast MRI</td>
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<tr>
<td>My feeling towards early detection strategies such as mammograms and breast MRIs</td>
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<td>Information I found in written material (such as websites, research/medical articles, books, magazines)</td>
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<tr>
<td>Information I received from my surgeon</td>
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<td>Information I received from my genetic counselor/geneticist</td>
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<td>Information I received from my plastic surgeon</td>
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<td>Information I received from ob/gyn</td>
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<td>Information I received from my primary care provider</td>
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<td>Information I received from support groups or chat rooms</td>
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<tr>
<td>Information I received from family member(s)</td>
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<tr>
<td>Information I received from my PinkPal</td>
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<tr>
<td>Disclosure of Angelina Jolie's bilateral prophylactic mastectomy</td>
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<tr>
<td>Information I received from a FORCE member</td>
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</tbody>
</table>
Q53 Please list any additional factors that were important in your consideration while making the decision to undergo a bilateral prophylactic mastectomy.

Q54 Would you like to enter a draw to win one of three $50 Amazon gift cards? Please note: Your contact information will not be connected to your survey responses if you select yes.
- Yes
- No

Condition: No Is Selected. Skip To: End of Survey.

RAFFLE SURVEY

Q1 Please provide your contact information below in order to enter the draw for one of three $50 Amazon gift cards. Note: Your contact information will not be connected to your survey responses

Q2 Name

Q3 Email Address
Appendix C: Permission letter

FORCE facebook page

Good morning! I am a second year genetic counseling student at Brandeis University, and working on a survey based thesis project to explore what factors go into decision-making for women who undergo bilateral prophylactic mastectomy between the ages of 20 and 30. I am in touch with the research coordinator from FORCE, who is sending out my survey with the monthly newsletter from FORCE. I am wondering if it would be possible to also put up the link on your facebook page. Since the inclusion criteria is quite precise, I am worried about not being able to reach out to enough women solely through one medium. The survey is completely voluntary and confidential, and no identifiers will be taken from the participants. Thank you for your time! I look forward to your response!

Best,
Meera

Hi Meera. You can post on our Facebook page but if you would prefer that we do it, please send me information or let me know who you are already working with at FORCE. Thanks.

Thank you for your response! I have been in touch with Sue Friedman from FORCE. I can also send you a blurp of what the project is regarding.

I'll touch base with Sue on it but feel free to post to our page.

Thank you very much! I will potentially post it sometime in the first week of April. By the time, if you are able to post it that works too.
November 29, 2016

Meera Clytone
Genetic Counseling Student
Brandeis University

Gayun Smutko
Thesis Faculty Advisor
Brandeis University

Facing Our Risk of Cancer Empowered (FORCE) hereby agrees to assist Meera Clytone in recruiting for a study of female HBOC families for her Master’s thesis project. We understand that the goal is to recruit as many members as possible with a positive BRCA1 or BRCA2 genetic test who meet the following eligibility criteria for this study: members who have undergone bilateral prophylactic mastectomies; members who are planning to pursue bilateral prophylactic mastectomies; are between the ages of 20 to 30. The goal of the survey is to assess the factors that go into the decision making process of bilateral prophylactic mastectomies in young female previvors.

Once the project has approval from the Brandeis University IRB, we will assist Meera in recruiting by sending notices with the monthly update emails to members of the FORCE group.

Sincerely yours,

Sue Friedman, DVM
Executive Director

16057 Tampa Palms Blvd. W, #373 Tampa, FL 33647 Tel: 866-288-7475 Fax: 954-827-2200

www.facingourrisk.org