**Public Relations Campaign for the**

**By: Alex Bosacker, Hannah Fox, Lynh Nguyen,**

**Kenzie Willaert and Danielle Williams**

**Message Clarification:**

The National Society of Genetic Counselors has asked us to respond to one group of stakeholder’s concerns regarding the new development of at-home genetic testing. In an effort to create the best public relations campaign possible, we would like to gather more information from the National Society of Genetic Counselors. Information obtained from the following questions would allow us to target the most effective audiences, focus on an ideal angle and work towards the NSGC’s specific goals.

1. Since the rise of at-home genetic tests, have you run campaigns with a similar goal in mind? If so, what were the successes and failures of those campaigns?
2. What is your budget for this campaign?
3. What is the deadline you would like this campaign to be executed by?
4. What are the specific stakeholders NSGC is concerned about?
5. How do you predict at-home tests will influence the field in the long run?
6. Does NSGC want to publish something on the website as a response to the situation? Would NSGC want to publish a press release?
7. Should NSGC supply their employees and stakeholders with “talking points” explaining their position on the topic? How would NSGC use internal communications to execute this discussion efficiently?

**Potential Stakeholders:**

*Stakeholder One:* White women, 50-70 years old, living in Illinois, Washington, New York, Massachusetts, Vermont, New Hampshire, New Jersey, Connecticut, Delaware, Hawaii, or Rhode Island, United States

Profile: “Shelby” is a white woman who lives in Illinois, United States, which is one of the states the Center for Disease Control and Prevention cites as one of the states with the highest incidence rates in the United States. She is a lawyer for a prestigious law firm and has been working there for 25 years, since she was 30 years old. Shelby resides in a high-income neighborhood and her office is also located in a wealthy part of Chicago. Shelby’s mother was diagnosed with breast cancer at age 40, and her aunt died from breast cancer two years earlier. Shelby is now concerned that she may have inherited genes that would increase her risk of developing breast cancer. According to an article published by Health.com aiming to inform women of their risk level, if you have two or more relatives with breast cancer or a relative diagnosed under the age of 50, you have a significantly higher risk of inheriting gene mutations known to cause breast cancer. Shelby is an important target audience because according to The Center for Disease Control and Prevention, white women have historically been more at risk for being diagnosed with breast cancer as opposed to other ethnicities. Given this information, in conjunction with her family health history, this makes Shelby an ideal candidate for genetic testing.

Sources:

“Breast Cancer.” *Centers for Disease Control and Prevention,* Centers for Disease Control and

Prevention, 15 June 2016. Accessed 3 December 2017.

Sepulveda, Meghann. “Genetic Counseling: Is It Right for Me?” *Azcentral,* 6 Oct. 2017. Accessed

3 December 2017.

*Stakeholder Two:* African American women, 30-50 years old, living in Alaska, Michigan, Ohio, Arkansas, Louisiana, Mississippi, Georgia, South Carolina, West Virginia, Virginia, or Maryland, United States

Profile: “Amanda” is an African-American woman living in Michigan, United States. She is a receptionist in the oncology unit at the local hospital near her house. The hospital and her house are both located in a low-income neighborhood of Detroit. To get more hours and increase her income, Amanda frequently picks up overnight shifts at the hospital and helps overnight visitors check-in. While working at the oncology desk, she notices that patients being seen by breast cancer specialists have a similar demographic to her. Amanda starts to do some research on her risk level, and discovers on the American Cancer Society website that individuals who work overnight shifts are more likely to develop cancer. She also comes across an article by the Center for Disease Control and Prevention and sees a statistic stating African-American women are more likely to die from breast cancer than women of other ethnicities. Amanda is an important target audience because she has multiple risk factors. With a less disposable income, it is important for Amanda to take the necessary prevention steps early to avoid extra costs later on.

Sources:

“Breast Cancer.” *Centers for Disease Control and Prevention,* Centers for Disease Control and

Prevention, 15 June 2016. Accessed 3 December 2017.

American Cancer Society. “Breast Cancer Facts & Figures 2015-2016.” *Atlanta: American Cancer*

*Society, Inc*. 2015. Accessed 4 December 2017. .

PARKER-POPE, TARA. “Tackling a Radical Gap in Breast Cancer Survival.” *The New York Times,*

The New York Times, 20 Dec. 2013. Accessed 4 December 2017.

*Stakeholder Three:* Genetic Counselors, 25-35 years old, living in Ohio, U.S.

Profile: “Adam” is a graduate from The Ohio State University. He resides in Ohio, United States and is 27 years old. Adam has begun his career as a genetic counselor. He has noticed a decline in business since the stamp of approval passed allowing companies like “23andMe” to sell at-home genetic testing kits. This concerns Adam because he worries consumers are not properly educated to interpret their results on their own. The company he works for has a strict policy that their clients are unable to view their results without a counselor present to avoid miscommunications. He believes the at-home tests jeopardize this important step in genetic testing and he fears companies selling direct-to-consumer products are not under strict enough government oversight. According to Onet\*, the state of Ohio will not see as much growth in the field of genetic counseling compared to the rest of the nation. Counselors like Adam are important to consider because their financial stability and career aspirations can be drastically affected by Genetic testing companies such as 23andMe.

Sources:

“Summary Report for: Genetic Counselors.” O\*NET OnLine, 5 December 2017.

Accessed 7 December 2017.

Kathryn T Hock, et al. “Direct-to-Consumer Genetic Testing: An Assessment of Genetic Counselors'

Knowledge and Beliefs.” Genetics in Medicine, vol. 13, no. 4, 2011, pp. 325–332. Accessed

6 December 2017.

*Selected Target Audience:* Stakeholder Two

For this project, we have selected Stakeholder Two because we believe that this demographic will benefit the most from the development of direct-to-consumer genetic tests. According to a study by The Jama Network in 2013, “12.6% of black patients did not have evidence of receiving any treatment for their breast cancer, compared with 5.9% of whites.” With that being said, the black populations have lower survival rates as compared to the white populations. We believed this target audience who previously feel and believed visiting a genetic counselor was unnecessary or too expensive, may reconsider if their at-home test notifies them that they are at heightened risk or a disease such as breast cancer. Therefore, we decided to focus on African American women ages 30-50 years old with low-income and also are exposed to multiple risk factors.

Jeffrey H. Silber, Paul R. Rosenbaum, Amy S. Clark, Bruce J. Giantonio, Richard N. Ross, Yun Teng,

Min Wang, Bijan A. Niknam, Justin M. Ludwig, Wei Wang, Orit Even-Shoshan, Kevin R. Fox.

Characteristics Associated With Differences in Survival Among Black and White Women With

Breast Cancer. *The JAMA Network.* The JAMA Network. 31 July 2013. Accessed 7 December

2017.

**Angles:** The NSGC’s current position statement on direct access to genetic testing, states they support each individual’s right to make informed decisions regarding different types of genetic tests. Based on this stance and the information we have gathered, we have formulated two possible angles.

*Angle One:* Any consumer who is interested in getting a genetic test in order to discover risks of developing cancer should begin with the at-home test kit. After the at-home test, genetic counselors are an essential resource to aid direct-to-consumer genetic testing. At-home test kits and professional genetic tests can work together in order to provide better service for the clients. Direct-to-consumer test kits are advantageous for genetic counselors because they can get a partial genetic profile of a patient before coming into the office. This increases familiarity of the counselor with the patient prior to their first meeting. At-home genetic tests are simpler compared to professional tests. In addition, at-home tests can focus on a few of consumer’s specific concerns while professional tests with a genetic counselor are more advanced. Moreover, laboratories across the U.S are starting to “offer genetic testing for breast cancer risk, making it likely that the test and others could become more affordable and more widely available” (Pollack). With that being said, at-home testing is a great service to use prior to contacting a genetic counselor. However, women with increased risk to gene mutations should be directed to a genetic counselor for further information on testing (Han). Furthermore, benefits of getting a genetic test include discovering about an inherited gene and taking appropriate steps before cancer develops (Myriad).

Sources:

Han, Xuesong and Ahmedin Jemal. "Recent Patterns in Genetic Testing for Breast and Ovarian Cancer

Risk in the U.S." American Journal of Preventive Medicine, vol. 53, no. 4, Oct. 2017, pp. 504-507. Accessed 5 December 2017.

Pollack, Andrew. "After DNA Patent Ruling, Availability of Genetic Tests could Broaden." *New York*

*Times*, June 14, 2013, New York Times. Accessed 3 December 2017.

“Genetic Testing 101.” *Myraid Genetics | Patients & Families.* Accessed 7 December 2017.

*Angle Two:* Collaboration between licensed genetic counselors and direct-to-consumer companies poses many potential risks including decline in revenues and profits due to potential clients choosing to invest in direct-to-consumer tests rather than visiting a genetic counselor. Possible complications of collaboration could be that there is a lot of room for error and misinterpretation if a consumer doesn’t know how to interpret results of an at-home genetic test. Furthermore, if a patient takes a flawed at-home genetic test and goes to a genetic counselor for interpretation, the magnitude of the blame is ambiguous and it is impossible to determine where the responsibility lies. There is a lot of room for improvement with at-home genetic tests and genetic counselors should wait until there is more verifiable hard evidence to support the accuracy of direct-to-consumer tests.

Sources:

Budman, Simon H. “CONSUMER GENETIC TESTING POSES MANY RISKS.” *Boston Globe,* Feb 16,

2003, Global Newsstream. Accessed 7 December 2017.

Gray, Stacy W., et al. “Personal Genomic Testing for Cancer Risk: Results From the Impact of Personal

Genomics Study.” *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology.*, vol. 35, no. 6, pp. 636–644. *Scopus,* 20 Feb, 2017. Accessed 6 December 2017.

Robinson, Ann. “DNA-Testing Kit 23andme: Patient-Powered Healthcare or Just Confusing?” *Factiva,*

12 Jan. 2016. Accessed 5 December 2017.

*Selected Angle:*For this campaign, we have chosen to adopt angle one. We believe direct-to-consumer tests have the potential to give consumers a small snapshot, but not the full picture. However, women with low-income, like our target audience, are a perfect match for us to incorporate at-home genetic testing kits into the genetic counseling process. Based on results, the patient can make a more informed decision regarding whether or not further testing is a good option for them. We reached this determination based on research collected by companies like Myriad Genetics. This notion was further supported by the evidence we found which we present to you in the following information section.

**Information:**

***Item One: Journalistic***

*Information:* Genetic Counseling; Is it Right for Me?

This source is important to the development of our campaign because it outlines the intricacy of genetic testing. The short clip on the article explains the intricacy of genetic testing and also how the accuracy of genetic testing has improved throughout time. This relates to how the advantage of genetic counselling is providing individualized treatment plans and identifying how family risks affect prevention methods. In the past, for breast cancer specific genetic testing, it was commonplace to only examine the BRCA1 and the BRCA2 genes. As genetics has advanced, although these two genes do have an important influence, over 20 other gene mutations have emerged that are also linked to breast cancer whereas past trend results have relied too heavily on family history being the primary risk factor. Given the early stages of at home-testing, it is clear that visiting a genetic counselor will yield a more comprehensive genetic profile and a more accurate risk assessment. The article urges that results from genetic testing contribute to prevention and early detection. In addition, the article also discusses the complexity of results, which is a reasonable concern for consumers considering at-home testing. Lastly, in an attempt to inform consumers of their risk, the article highlights individuals who should consider genetic testing. In their recommendation, they included people who have two or more relatives on the same side of the family who have the same types of cancer, a relative who was diagnosed with cancer before age 50, and individuals of Ashkenazi descent.

* Source accessed by: Client Website → Newsroom tab

Sepulveda, Meghann. “Genetic Counseling: Is It Right for Me?” *Azcentral,* 6 Oct. 2017. Accessed

3 December 2017. Accessed 6 December 2017.

*Interviewee:* Susan Gubar

Susan Gubar is a renowned author and professor at Indiana University. She has been living with cancer for a decade and has written multiple articles about her experiences. Her article “The Haves and Have-Nots of Cancer Care” fit perfectly into our target audience research. The article gives background information about the differences in care that women receive based off their income. With the changes that the federal government has been pushing for, affordable care options such as Planned Parenthood could potentially no longer be available to women for things like cancer screening. This creates an even bigger divide between the haves (high-income) and have nots (low-income) regarding proper healthcare.

* Source accessed by: Assignment document linking to The New York Times → Health → Search Terms: “Breast Cancer” → “The Haves and Have-Nots of Cancer Care”
* Interviewee’s Email: gubar@indiana.edu
* Interview Questions:

1. Many people hold misconceptions regarding the services that Planned Parenthood provides, where do you think this misconception comes in regarding cancer care through Planned Parenthood?
2. You mention the importance of prevention and early detection for all women regardless of income, what are your views on how genetic testing could be incorporated into these goals?
3. How do you see the recent changes relating to Planned Parenthood impacting rates of cancer diagnosis and death among low-income women?

Gubar, Susan. “The Haves and Have-Nots of Cancer Care.” *The New York Times*, The New York Times,

30 Mar. 2017. Accessed 5 December 2017.

***Item Two: Public-Sector***

*Information:* Center for Disease Control and Prevention - Breast Cancer

The Centers for Disease Control and Prevention Breast Cancer page has vital information relating to both our audience and our angle. The basic information page cites that women’s risk of acquiring breast cancer in the last decade has not changed. Encouraging genetic testing may provide to be a great step in decreasing the prevalence of this disease because many of the signs and symptoms of breast cancer are not excessively clear. The CDC notes that rate of occurrence and death vary between different races and ethnicities. Historically, white women have the highest rates of incidence, while African American women have consistently shown high mortality rates due to breast cancer. These two trends helped us construct our audiences. Given the disadvantage African American women face regarding breast cancer, the CDC has launched their own mass media campaign to combat this trend. Their campaign is highly focused on knowledge of disease and awareness of screening for African American women to work towards early detection. In addition, the CDC website offers a plethora of information for consumers, including symptoms, risk factors, and explanations of the disease, screening, and treatment. This information will be critical while developing the knowledge portion of our campaign.

* Source accessed by: Database: The Leadership Library → Search Term: “Breast Cancer” → Linked to “Federal Government” →  “National Breast and Cervical Cancer Early Detection Program”

“Breast Cancer.” *Centers for Disease Control and Prevention,* Centers for Disease Control and

Prevention, 15 June 2016. Accessed 3 December 2017.

*Interviewee:* Marsha B. Henderson - Assistant Commissioner for Women’s Health

As the Director of the Office of Women’s Health for the U.S. Food and Drug Administration, Marsha Henderson is the perfect interviewee for the public sector. The primary goal of this office is to “protect and advance the health of women” in accordance with FDC policy. Henderson lead the development of the FDA’s Take Time to Care Program. Take Time to Care is focused on providing women with easily accessible health information. The FDA collaborates with a variety of other individuals and organizations including other professionals in the medical field, universities, other government institutions and health organizations. One specific aspect of Take Time to Care is the Pink Ribbon Sunday Program. The Pink Ribbon Sunday Program uses events and social media to educate the public about the importance of mammograms and detecting breast cancer early. The program was originally targeted at Hispanic and African American churches due to the disparity in influence by breast cancer in these populations. This program is highly focused on community outreach and collaboration, making them a perfect candidate to potentially partner with in the knowledge stage of our campaign.

* Source accessed by: Database: Hoover → Search terms: “FDA” → Link to FDA website
* Interviewee’s email: Marsha.Henderson@fda.hhs.gov
* Interview Questions:

1. Where do you see the new technology of direct-to-consumer genetic testing fitting into the current landscape of women’s health, specifically regarding breast cancer?
2. As medical technology advances and more money is invested into mapping of the human genome, how have you seen the field of oncology transition from treatment to prevention?
3. How do you think the Pink Ribbon Sunday Program has impacted the prevalence of breast cancer?

“Meet Marsha B. Henderson, Assistant Commissioner for Women's Health.” *U S Food and Drug*

*Administration Home Page*, Office of the Commissioner. Accessed 6 December 2017.

***Item Three: Private Sector For-Profit***

*Information:* Myriad Genetics

In 1994, the Myriad Genetics research team were the first people to isolate the BRCA1 gene that can cause an inherited form of breast and ovarian cancer. In October of 1995 Myriad was taken public and in December of 1995 they were able to isolate the BRCA2 gene mutation. In November of 1996, Myriad researchers conducted the first hereditary ‘molecular diagnostic’ tests for Breast and Ovarian cancer. Today, 96% of their profits come from specific diagnostic testing which tests an individual's chance of developing diseases over their lifetime. Myriad Genetics employs a perspective on at home genetic testing, very similar to our angle for this project. They focus on providing people with quality information and resources to help patients understand their risks and evaluate what steps should be taken as a result of genetic testing. When patients have this information, they are more aware of how to prevent the disease and more conscious of early signs and symptoms. In their mission to inform their consumers, they list risk factors of breast cancer, including history of ovarian cancer, Ashkenazi descent and family members diagnosed with breast cancer before the age of 50.

* Source accessed by: Database: Database: Hoovers → Search terms: “Genetic testing” → Refine by location: United States → Myriad Genetics website

“Genetic Testing 101.” *Myraid Genetics | Patients & Families.* Accessed 7 December 2017.

*Interviewee:* Augusta Broughton

Augusta is a scientific researcher for 23andMe in San Francisco, California. She specializes in “target validation and assay development” from the expertise she gained from her Molecular Toxicology and Public Health degree from University of California, Berkeley. We believe she is a valuable interviewee because of her familiarity with 23andMe’s research projects and types of genetic testing options. Additionally, she would be able to provide personal perspective and information regarding gene mutations and cell cycle regulation.

* Source accessed by: Database: Hoover → Search Terms: “23andme” → Refined by People & Contacts → Augusta Broughton
* Interviewee’s Linkedin: [www.linkedin.com/in/augustabroughton/](http://www.linkedin.com/in/augustabroughton/)
* Interview Questions:

1. What recommendations do you have for any client who is interested in taking a genetic test?
2. How has the genetic testing industry changed since the introduction of at-home genetic tests?
3. In your opinion, are there any disadvantages to the current genetic testing method? What should a client consider before deciding to conduct a genetic test either at-home or at the clinic?

***Item Four: Private Sector Non-Profit***

*Information:* Susan G. Komen

Susan G. Komen is a foundation founded by Nancy G. Brinker in honor of her sister, Komen, who was a cancer patient. The foundation is impacting the breast cancer industry through research, community health, global outreach and public policy initiatives. Thus, the Susan G Komen foundation is an important information contributor to the discussion about breast cancer, genetic testing, and gene mutations. One unique aspect of the Susan G. Komen Foundation is their special attention to Metastatic Breast Cancer. Metastatic Breast Cancer, also known as Stage 4 Breast Cancer, is when the cancer spreads from the breasts to other parts of the body and its most commonly develops after a person has been diagnosed and treated and the cancer comes back. Susan G Komen’s mission emphasizes that every day is important and they provide helpful treatment strategies that allow patients to manage a reasonable quality of life. Susan G Komen connects patients to clinical trials and new treatment opportunities and provide supportive counseling opportunities.

* Source accessed by: Database: GuideStar → Search Terms: “Breast Cancer” and “Cure” → Refined by Location: Texas → Linked to Non-Profit website

Learn About Genetic Testing for BRCA1 and BRCA2 Mutations at Susan G. Komen®. (n.d.). Retrieved

December 02, 2017. Accessed 7 December 2017.

*Interviewee:* Lindsay Avner

After Lindsay Avner lost her great-grandmother, grandmother and watched her mom struggle through Breast Cancer, she decided to pursue genetic testing at the age of 22. After testing positive for the BRCA1 gene mutation, her genetic counselor explained she had an 87% chance of developing breast cancer in her lifetime and a 54% chance of developing ovarian cancer. After seeing the awful affects breast cancer had on her relatives, at 23 years old, Lindsay was the youngest person in the country to have a double mastectomy, which she did to reduce her chance of getting cancer later in life. After an enormous amount of support from women in her community, Lindsay created a website for women who were “high-risk” for breast cancer to connect with one another and exchange information. It wasn’t long before her website expanded into a full-fledged non-profit organization.

* Source accessed by: Database: GuideStar → Search Terms: “Genetic Testing at Home” and “Breast Cancer” and “Genetic Counselor” → Refined by Illinois → Linked to Non-profit website
* Interviewee’s LinkedIn: https://www.linkedin.com/in/lindsayavner
* Interview Questions:

1. Having watched multiple women in your life battle with this disease, how would you describe the potential impact of direct-to-consumer genetic testing in relation to women like yourself?
2. Given the high stakes involved related to health, what are some reservations you would have about using a direct-to-consumer genetic test as opposed to meeting with a certified genetic counselor?
3. On your webpage, you offer a link to “explore your genetics”, where you discuss in detail the role and tasks of the genetic counselor in the process. How do you think those roles and tasks could translate to be compatible with at-home genetic testing?

“Breast and Ovarian Health Organization.” *Bright Pink,* Bright Pink. Accessed 6 December 2017.

***Item Five: Scholarly***

*Information:* “The Risk of Breast Cancer in BRCA1 and BRCA2 Mutation Carriers without a First-Degree Relative with Breast Cancer”

Given the widely known fact that the development of breast cancer is linked to genetic mutations, specifically the BRCA1 and BRCA2 mutations, many women without a family history of breast cancer feel they are unlikely to develop the disease. This publication highlights why screening is important for all women, regardless of family history. The study found that women possessing either the BRCA1 or BRCA2 gene mutation faced similar risk factors, whether they had one first-degree relative with breast cancer or no first-degree relatives with breast cancer. People too often use their own family history as a representation of their own genetic factors and risk, leaving many women unidentified and unaware of their risks. As genetic testing becomes more affordable and prevalent, the researchers urge more women to be tested in order to identify all women who are at a heightened risk. This will lead to a transition from curing breast cancer to preventing breast cancer.

* Source accessed by: Database: Ovid Medline → Search terms: “BRCA1” and “BRCA2” → “The Risk of Breast Cancer in BRCA1 and BRCA2 Mutation Carriers without a First-Degree Relative with Breast Cancer”

Metcalfe, Ka, et al. “The Risk of Breast Cancer in BRCA1 and BRCA2 Mutation Carriers

without a First-Degree Relative with Breast Cancer.” *Clinical Genetics.*, 2017, pp.

Clinical genetics.2017. Accessed 3 December 2017.

*Interviewee:* Robert Green, M.D.

The New York Times Article “F.D.A. Will Allow 23andMe to Sell Genetic Tests for Disease Risk

to Consumers” cited Robert Green, an expert in the field of genetics. Given that this article was provided to us by our client, we felt it was vital to take a closer look at the individuals included in the article. Doctor Green is a medical geneticist and physician-scientist researching at Harvard University. He recently collaborated on a study titled “Utilization of Genetic Counseling after Direct-to-Consumer Genetic Testing: Findings from the Impact of Personal Genomics (PGen) Study”. Participants reported that 38% of customers reported they would have used a genetic counselor in person if it was an option.

* Source accessed by: Database: Scopus → Search Terms: “Genetic Testing” and “Direct to Consumer” → “Utilization of Genetic Counseling after Direct-to-Consumer Genetic Testing: Findings from the Impact of Personal Genomics Study”
* Interviewee’s email: rcgreen@bwh.harvard.edu
* Interview Questions:

1. How do you see direct-to-consumer genetic testing evolving in the next 10 years?
2. Do you view direct to consumer genetic testing as an opportunity or a threat to the field of genetic counseling and why?
3. Do you believe direct-to-consumer genetic testing should be limited to certain genetic markers or mutations? Why or why not?
4. Based on your experience in the field, what do you see as the biggest disadvantage for direct-to-consumer genetic testing?

Han, P. K. J., et al. "A Taxonomy of Medical Uncertainties in Clinical Genome Sequencing." *Genetics in*

*Medicine*, vol. 19, no. 8, 2017, pp. 918-925*, SCOPUS*, Scopus. Accessed 5 December 2017.

***Item Six: Informal***

*Information:* Nancy’s Point

Nancy Stordahl’s website is a valuable informal information source where audiences can learn and read a real-life story about breast cancer. In the blog post title, “Should Universal Testing for BRCA1 & 2 Mutations Be an Option for All Women?” Stordahl discusses the benefits of getting tested for cancer early. Additionally, the author believes that BRCA1 and BRCA2 testing should be available to everyone as a preventive measure because the symptoms can be misleading and could lead to a late-term diagnosis and become more severe cancer if patients are not aware they have the gene. Also, Stordahl suggests that genetic testing costs will decrease in the future and allow people to seek essential supplementary information from genetic counselors. Genetic counselors help relay valuable information to patients’ personal results and experiences, particularly treatment and prevention method recommendations. On the other hand, advice she gives to her audiences is that she wishes cancer testing was available when she was 30 years old so that she could have prevented cancer in advance. This blog post from Nancy Stordahl proves the importance of testing and how cancer could be preventive through early detection and genetic testing.

* Source accessed by: Goggle → Search Term: “Famous Breast Cancer Survivor Blog” → “10 Best Breast Cancer Blogs” → “Nancy’s Point”

Stordahl, Nancy. “Should Universal Testing for BRCA1 & 2 Mutations Be an Option for All Women?”

*Nancy’s Point,* 2 Oct. 2014. Accessed 1 December 2017.

*Interviewee:* Nicole McLean

Nicole McLean is a breast cancer survivor who started a blog post to discuss her breast cancer journey with her audiences. She is a valuable informal interviewee because she has experienced living with breast cancer. McLean is dedicated to sharing information about breast cancer to anyone who is interested. Also, she uses her blog posts as a way to inspire other cancer patients. Moreover, her insights as a cancer patient and survivor is valuable in order to obtain understanding about breast cancer, what genetic testing can do, and how breast cancer affects individuals.

* Source accessed by: Google → Search Terms: “Best Breast Cancer Blogs” → “Best Breast Cancer Blogs of 2017” → “My Fabulous Boobies”
* Interviewee’s email: nicole@myfabulousboobies.com
* Interview Questions:

1. How did breast cancer and the title of “breast cancer survivor” affect your life?
2. What do you think about genetic testing for breast cancer and early cancer detection?
3. What advice do you have for women who have a family history of breast cancer?

**Synthesis:**

* Breast cancer is a prevalent issue and there has been significant effort and investment to decreasing disease rates, but these efforts have had minimal effects.

1. Public Sector
2. Private Sector Non-Profit

* When breast cancer transitions from localized to metastasized, it becomes treatable but no longer curable, which highlights the importance of prevention rather than treatment.

1. Public Sector
2. Private Non-Profit

* Family history is repeatedly one of the most commonly cited elements to consider when determining if an individual is a good candidate for genetic testing

1. Scholarly
2. Informal
3. Journalistic
4. Private Sector for Profit
5. Public Sector

* Trends have shown that women overemphasized the influence of familial history when calculating individual risk.

1. Scholarly
2. Journalistic

* Signs and symptoms are not always clear, which may result in late diagnosis.

1. Public Sector
2. Informal

* Genetic testing can aid in prevention and early detection.

1. Journalistic
2. Scholarly
3. Private Sector for Profit

* Different subsets of the population experience varying incidence and mortality rates.

1. Public Sector
2. Journalistic
3. Private Sector for Profit
4. Public Sector interviewee

* Mutations in the BRCA1 and BRCA2 genes play a crucial role in the likelihood of an individual acquiring breast cancer.

1. Scholarly
2. Private Sector for Profit
3. Informal

* As medicine and its technology is advancing, genetic testing is evolving in different ways, such as more advanced gene analysis and more cost-effective options.

1. Journalistic
2. Scholarly
3. Informal

* Genetic counseling has the potential to serve many different functions, such as choosing a treatment plan, assessing personal or family risk, contribute to family planning, or creating action plans.

1. Journalistic
2. Informal

**Recommendation Statement:**

Based on the information we have gathered, we have designed the following recommendation for the National Society of Genetic Counselors. Our recommendation provides a suggestion for how the NSGC can remain consistent with their current position statement on the topic while also adapting to the rising popularity of at-home genetic tests. We recommend a collaborative approach in addressing, and hopefully reducing the occurrence of Breast Cancer. Genetic counselors are the final step in a multiphasic strategy. The slogan of our campaign will be titled “Test for the Breast”.

The first step is to disseminate accurate and widely accessible information. While there have been many campaigns with this goal, medicine is ever-changing and it is important to keep women updated on new advancements and discoveries. In addition, existing campaigns have been segmented from one another. If organizations like Susan G. Komen, Bright Pink, and The Center for Disease Control and Prevention, united focus towards their common goal, it is likely they would have more fruitful results. In addition to breast cancer awareness and knowledge, this campaign would also spread information about the different forms of genetic testing. To begin, we would recommend creating campaign social media platforms, such as a Twitter account, to help easily reach our audiences. On the account, tweets would be sent out with statistics and information such as who should consider genetic testing and when. We would also encourage audience participation by inviting people to share their own stories with breast cancer and/or genetic testing and include #TestfortheBreast.

Our research has shown that, there is a push to increase the popularity of genetic testing to populations who may not have previously known about different options for genetic testing or did not have access to it. One factor influencing this trend is the decrease in cost of testing. Additionally, the research shows that if more women were to engage in genetic testing, more women who are at a high-risk for breast cancer would be identified and therefore more conscientious of their health, leading to prevention or early detection. Some proposals have suggested to offer testing for all women. The rapid increase in genetic counseling would result in overworked staff and clinics bring overridden with constant patients. One solution to this issue is our second step. The second step is to frame direct-to-consumer genetic tests as a stepping stone to a visit with a genetic counselor. This step would be ideal for populations at a disadvantage, such as our selected target audience. Currently, it might not be affordable for someone like Amanda to visit a genetic counselor. Rather, she could purchase a direct-to-consumer genetic test before determining if it is worth investing in a follow-up appointment with a genetic counselor.

In the final step, a patient worried about their results could meet with a genetic counselor to get clarification about misunderstandings, engage in further testing, and be informed about potential next steps. For example, if Amanda’s results show she possesses BRCA1, she may decide it is a good financial investment to visit a genetic counselor to learn more about her situation. Knowing tips for prevention and early detection would save Amanda money compared to treatment for more advanced stages of breast cancer. The interpretation of results and collaborative decision making is the biggest advantage genetic testing has to offer. Although direct-to-consumer tests allow consumers a concise genetic profile, it is limited and meeting with a genetic counselor can yield much more comprehensive results.

The benefits of this three-step strategy are two-fold. On one hand, genetic counselors maintain a growing and prosperous field, and on the other, the nation can begin to make strides in reducing the occurrence of breast cancer. It is important to note that breast cancer is only the beginning. Rather than seeing direct-to-consumer testing as a threat, genetic counselors should view this as an opportunity to expand the field to markets previously untargeted. Direct-to-consumer genetic testing is still in its early stages, leaving plenty of room for expansion and identifying other genetic mutations. As this occurs, the NSGC will be able to modify this campaign to apply to other diseases and reach another audience, continuing to further the growth of the field.