A STORY HALF TOLD:

From Overwhelming to Empowering

A Look at Hereditary Breast Cancer and Genetic Testing

BREAST CANCER:
A STORY
HALF
TOLD
A Focus On Metastatic Disease

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Pfizer

Foreword:

In 2014, Pfizer launched *Breast Cancer: A Story Half Told* to uncover misperceptions and spotlight real-life stories of people living with metastatic breast cancer (MBC). But, as the patient stories told us, everyone living with MBC is not the same. The intention of *Story Half Told* was to get the general conversation started. Today, we need to move the conversation forward to continue shedding light on specific aspects of living with MBC that remain untold.

While all patients with MBC face a complex and difficult journey, those whose disease can be attributed to inherited genetic mutations could face unique challenges. These can include, but are not limited to, lack of access to support services, genetic counseling and information about available treatments specific to inherited breast cancer. Importantly, it also can include the weight of knowing that others in their family may be at risk.

As we learn more about the biology of breast cancer, it becomes clear that we need to address the unique needs of this community—especially as, currently, only 15 percent of all eligible patients with MBC undergo genetic testing to determine if their cancer is hereditary.[1] This may be attributed to a variety of logistical, emotional and informational barriers, in addition to the complexity of the guidelines that recommend who should receive genetic testing. It is clear that we need to raise awareness of the importance of genetic testing and its role for risk mitigation, prevention and treatment planning for people living with breast cancer.

To foster progress for this patient population, Pfizer partnered with 10 patient advocacy organizations as well as other multidisciplinary experts to better understand patients' needs. Together, our aim is to address the barriers to genetic testing and the information gaps that may exist. This addendum represents our pathway to progress, an effort that will take time and collaboration. It is intended to embrace and empower MBC patients with inherited genetic mutations as a key part of the larger breast cancer community.

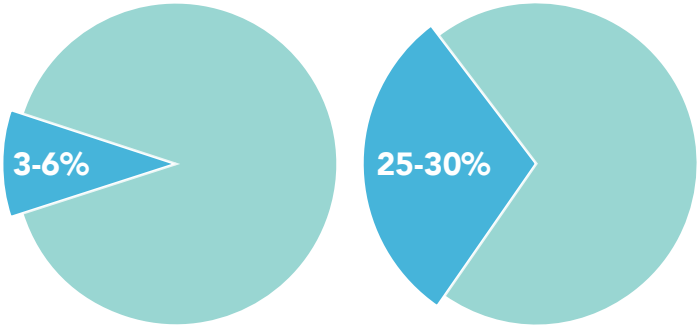
Lynn McRoy, MD, FACS
Vice President, Breast Cancer
Medical Lead, Pfizer Inc.

Story Half Told Founding Member Tarah, who passed away from MBC in October 2019, is pictured here with her mother and two children.

Understanding Hereditary Breast Cancer

Some breast cancers are caused by genes with mutations, or changes, passed down from either parent to their daughters or sons. Although there are several inherited genetic mutations linked to breast cancer, *BRCA1* and *BRCA2* are the most studied and the most common.

Mutations in *BRCA1* & *BRCA2* are responsible for approximately



3-6% of all breast cancers[2-5]

25-30% of hereditary breast cancer cases[6]

The average age for a breast cancer diagnosis is 62[7]

People with inherited mutations in *BRCA1/2* are often younger, and may be diagnosed in their 30s-40s[8]

It is important for a person with MBC to know their hereditary mutation status because it can help shine a light on important considerations[9,10]:

FAMILY IMPACT

THERE IS A 50% CHANCE

that first-degree relatives—children, siblings or a parent of a person with hereditary breast cancer—have the same mutated gene, increasing their risk of getting breast or other types of cancer.[11] Other, more distant relatives also are at risk of carrying the mutation.[12]

DISEASE MANAGEMENT

KNOWING *BRCA1 & BRCA2* MUTATION STATUS

in addition to other disease variables, including hormone receptor status and HER2 status, is important for patient empowerment and treatment planning, leading to more productive discussions with doctors, genetic counselors and family members.

Where Are We Now? The Current Genetic Testing Landscape

> We're used to thinking about cancer genetic testing in terms of predicting future risk, stepping up surveillance, deciding about surgery or risk to one's children. Thinking about genetic testing to guide treatment options requires a significant shift from the future to the present, and it challenges us to rethink opinions we may have already formed about the pros and cons of genetic testing."
>
> **—Karen Hurley, PhD, Cleveland Clinic, Clinical Psychologist**

According to epidemiologic studies and national guidelines, people with any of these criteria* should speak with a cancer genetics professional about getting a blood test to see if their breast cancer carries a hereditary mutation[13-15]

AGE
Diagnosed with breast cancer before age 50

MULTIPLE BREAST CANCERS
Primary cancer in both breasts or a second primary cancer in the same breast

TRIPLE-NEGATIVE BREAST CANCER
Diagnosed with triple-negative (ER-/PR-/HER2-)† breast cancer before age 60

METASTATIC BREAST CANCER
People diagnosed with HER2-negative MBC who are eligible for single-agent therapy

HERITAGE
Ashkenazi (Eastern European) Jewish, African American or Hispanic heritage, among others[15]

FAMILY HISTORY
Relatives with ovarian, pancreatic, or metastatic prostate cancer, or breast cancer diagnosed at an early age

*These are just some of the criteria that should be considered. Individuals should consult their healthcare provider or a cancer genetics professional for more information.
†ER: estrogen receptor; PR: progesterone receptor; HER2: human epidermal growth factor receptor 2

Genetic testing for breast cancer is undergoing a shift from a risk management tool to a tool that also may help guide treatment decisions. NCCN Clinical Practice Guidelines In Oncology (NCCN Guidelines®) help inform healthcare professionals about which patients already diagnosed with any stage of breast cancer are recommended to receive genetic counseling and/or testing. NCCN Guidelines® include factors such as age, family history and ethnicity/heritage. Separately, the National Comprehensive Cancer Network® (NCCN®) updated the NCCN Guidelines for Breast Cancer in 2018 to recommend germline *BRCA1* and *BRCA2* testing for patients with HER2-negative metastatic breast cancer who are eligible for single-agent therapy.[13,15]

The shift to more widespread testing for MBC is supported by a recent community-based study. Researchers found that rates of *BRCA* mutations are similar in patients with breast cancer at any stage, who met age, family history and ethnicity risk criteria for genetic testing developed by NCCN, compared to those who did not. According to the study, based on these risk factors alone, the researchers estimated that as many as **40 percent of patients with inherited genetic mutations may be missed.**[16]

Genetic testing rates are low among people with breast cancer[17]

In addition, a large national study published in the *Journal of Clinical Oncology* in 2017 found more than 35 percent of patients with breast cancer at all stages (more than 1 million people) were eligible for genetic testing according to the NCCN Guidelines. Yet, of these individuals, only 29 percent discussed it with their healthcare provider, 20 percent were advised to test and just 15 percent underwent testing.[17] In medically underserved populations with breast cancer in the U.S., these rates may be even lower. A recent study found that while testing rates have steadily increased to 15 percent, a review of select medical records of patients who met Medicare criteria for test coverage found that less than 10 percent of treating physicians documented a need for genetic services for these patients, and none recorded referrals to genetic counseling.[18]

Healthcare professionals agree that genetic testing does not occur on a widespread basis. Findings from a 2017 survey of 95 community oncologists conducted by the Association of Community Cancer Centers (ACCC) showed **87 percent of respondents reported that fewer than half of their patients with MBC have ever had germline *BRCA1/2* mutation testing.**[19]

Partnering to Foster Progress

On June 3, 2018, a multidisciplinary roundtable of experts comprised of genetic counselors, psychologists, oncologists, nurse navigators and advocacy group leaders—some of whom are patients themselves—came together to share their expertise and perspectives about the challenges and barriers to genetic testing. The group's aim was to derive recommendations to address the barriers that prevent patients with MBC from getting tested and ways to increase testing rates.

In addition, Pfizer in partnership with seven breast cancer advocacy groups commissioned an online survey* of 1,001 U.S. breast cancer patients at all stages to[20]:

- Assess knowledge about hereditary breast cancer and genetic testing
- Understand the barriers to genetic testing
- Assess the emotional implications, available resources and unmet needs among the subset of patients with hereditary breast cancer

The key findings from these collective activities, paired with additional published research, follow.

Story Half Told advocacy partner organizations who fielded the online survey to their members included:

-BreastCancer.org

-Living Beyond Breast Cancer

-Metastatic Breast Cancer Network

-Young Survival Coalition

-Cancer Support Community

-METAvivor

-The Male Breast Cancer Coalition

*The online survey evaluated hereditary breast cancer and genetic testing resources and knowledge in 1,001 women and men with breast cancer in the U.S., aged 18 or older. The survey was commissioned by Pfizer and facilitated by seven breast cancer advocacy organizations that distributed the survey through their online and social channels in June 2018. The results of this survey were reflective of the membership of these organizations.

Patient and Healthcare Provider Barriers to Genetic Testing

> Barriers to genetic testing are multi-layered, from the systemic to the highly personal, and our solutions need to be flexible enough to address these multiple layers. Barriers can also be interpersonal—one person's access to testing can affect another relative's awareness that she might be at risk."
>
> —Karen Hurley, PhD, Cleveland Clinic, Clinical Psychologist

BARRIERS TO GENETIC TESTING

LOGISTICAL

1 Referrals treated as optional by some physicians

2 Limited access to genetic counseling

3 Financial/insurance concerns

EMOTIONAL

1 Patients are overwhelmed at initial diagnosis

2 Patients have concerns about family implcations

INFORMATIONAL

1 Confusion around testing

2 Lack of tailored genetic testing resources

3 Rapidly evolving field; challenges staying up to date for physicians

LOGISTICAL BARRIERS

1 Referrals for genetic testing can be treated as optional by some physicians

> We need to turn it from being optional to one more piece of the puzzle, one more diagnostic test."
>
> —Mary Freivogel, MS, National Society of Genetic Counselors, Cancer Genetic Counselor

There are several reasons that may prevent physicians from recommending testing. A genetic test is not required to diagnose breast cancer. This issue warrants further exploration, as research suggests that lack of recommendation from a doctor is a primary reason many patients with breast cancer are not tested.[17] What can add to this dynamic is the requirement of informed consent for genetic testing—a document signed by the patient stating that she or he has been fully informed of the benefits and risks of the test.

This observation was supported by the Pfizer survey that found among patients with breast cancer who had not received genetic testing, **31 percent of the 224 respondents stated that they didn't receive testing because no one recommended it to them.**[20]

2 Local access to genetic counselors is limited

Story Half Told participant Tarah speaking with a genetic counselor

With specialized training in medical genetics and counseling, genetic counselors play a unique and critical role in helping to determine whether genetic testing is appropriate, which test is right for a particular patient, interpreting genetic test results and supporting patients in navigating the implications of that information. However, there are simply not enough genetic counselors to meet this need for all who want or need their services.

> "[In addition to counseling about being tested], genetic counselors wear that other hat of offering the patient our hand and saying 'I'll be there for you. I'll explain these results to you. You don't have to take the burden on to explain them to your family. I'll be your advocate through this process.'"
>
> —Sandra Brown, MS, LCGC, St. Joseph Hospital Center for Cancer Prevention and Treatment, Cancer Genetic Counselor

There are only 773 certified genetic counselors in the U.S. who specialize in cancer, and they are spread disproportionately across the country. Some states like Missouri, Wyoming and Mississippi have five or fewer genetic counselors.[17,21]

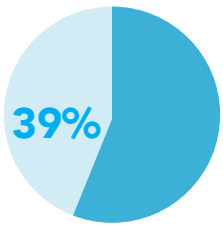
The roundtable discussions indicated a need for tools to help identify patients who may require support. And, based on the discussion, one thing is clear: there is a growing need to expand the number and type of healthcare professionals who can provide these services including genetic counselors, medical geneticists, trained physicians or advanced practice professionals.[22]

3 Financial and insurance concerns

> "We still hear concerns from patients and providers that they are worried about genetic discrimination. It is important that we do a better job informing patients about their eligibility for testing and protections available to them."
>
> —Jennifer R. Klemp, PhD, MPH, MA, Associate Professor of Medicine, University of Kansas School of Medicine, Division of Oncology, Cancer Risk Counselor and Director of Cancer Survivorship, University of Kansas Cancer Center

For many patients with breast cancer, genetic testing is covered by their insurance provider, especially if they meet criteria under the NCCN Guidelines. Select policies have been updated to cover *BRCA1/2* gene testing as well as genetic counseling as part of the pretest process for people with breast cancer. Medicare also provides access to these services.[23] For those whose insurance will not cover testing, the out-of-pocket costs of genetic testing have decreased over the past few years with the introduction of many low-cost options. But, not all patients are aware of this and perceived cost is a deterrent to being tested.

In the Pfizer survey, among people diagnosed with breast cancer who had never been tested for hereditary disease (224 respondents), cited concerns with either cost or insurance coverage.[20]



Fear of discrimination by insurance companies is another obstacle that needs further discussion. The roundtable participants noted that some patients fear knowing their hereditary mutation status because they, or potentially their children, may not be insurable if they have a mutation. While laws and policies, such as the Genetic Information Nondiscrimination Act (GINA) of 2008, exist to offer certain protections against genetic discrimination,[24] there are some limitations; other policies can vary state by state. As such, more information needs to be shared with patients that answers critical questions related to insurance coverage and protections.

EMOTIONAL BARRIERS

1 Patients are already overwhelmed at time of initial diagnosis

The emotional impact of knowing one has a genetic mutation can be profound. Among the 297 patients diagnosed with hereditary breast cancer included in the 1,001-patient Pfizer survey[20]:

- **69 percent** felt that even after treatment they would not be normal because of their genetic mutation.
- **67 percent** reported feeling guilty that their children may have inherited the genetic mutation from them.
- **63 percent** reported being worried that sharing that their breast cancer is hereditary with family members may damage family relationships.

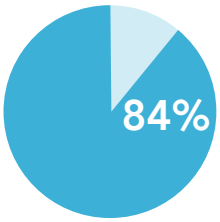
> "We ended up really talking with our physicians and nurses about how to tailor their conversations with patients in a supportive way that reinforced how important it was to make this appointment without delay."
>
> —Sandra Brown, MS, LCGC, St. Joseph Hospital Center for Cancer Prevention and Treatment, Cancer Genetic Counselor

> "It is important to reinforce the value of knowing whether one has a hereditary mutation. Genetic test results can impact risk, treatment decisions and has implications for their family."
>
> —Jennifer R. Klemp, PhD, MPH, MA, Associate Professor of Medicine, University of Kansas School of Medicine, Division of Oncology, Cancer Risk Counselor and Director of Cancer Survivorship, University of Kansas Cancer Center

2 Concerns about legacy and fears about impact of cascade testing on family

Once someone is determined to have an inherited mutation, they are a "proband"—the first person in the family who is known to have a mutation. Others in the family deemed to be at risk should then be tested, and this process—known as cascade testing—is repeated as more family members carrying the mutation are identified.

Passing on or sharing an inherited mutation is a significant concern among women and men with hereditary breast cancer.



of the 297 patients with hereditary breast cancer included in the Pfizer survey say they are worried that their children will get cancer by inheriting the same gene.[20]

Because patients with hereditary breast cancer are often diagnosed at a younger age than the overall breast cancer patient population, they may have young children who could face serious decisions (eg, cancer-prevention surgery) in the years to come.[8]

Evidence-based resources that help patients process the emotional task of thinking about their legacy exist, but may not always be accessible or offered to all patients who could benefit from them.

INFORMATIONAL BARRIERS

1 Lack of patient understanding and confusion around testing

> "The patient is the 'locus of control.' How do we take the person with the least amount of information and empower them with education and information to be active in shared decision-making?"
>
> —Jennifer R. Klemp, PhD, MPH, MA, Associate Professor of Medicine, University of Kansas School of Medicine, Division of Oncology, Cancer Risk Counselor and Director of Cancer Survivorship, University of Kansas Cancer Center

The lexicon of hereditary breast cancer is confusing and unfamiliar to patients. For example, inherited genetic changes are known as "**germline**," which can be detected using blood or saliva samples. Other types of genetic mutations, such as "**somatic**," or genetic changes due to factors such as aging and the environment, can also lead to breast cancer, but these are not inherited. Somatic changes to genes can only be detected using tumor samples. All genetic changes are either germline or somatic.

These words and the different methods for detecting genetic changes may be too technical for a person without some level of medical or genetics knowledge. In fact, the Pfizer survey found that while 88 percent of respondents reported knowledge of *BRCA1/2* mutations, 70 percent incorrectly believed that all *BRCA* mutations are inherited, supporting a need for more education.[20] Adding to the confusion are discussions around which test is appropriate for which patient (eg, single-gene tests versus multi-gene panel) and whether an at-home test may be an option. In addition, patients may not understand the purpose of different breast cancer tests, creating the possibility that they confuse another assessment, such as a test to determine hormonal status, with a genetic test.

Further complicating the matter is the fact that patients are not widely informed about the relationship between testing and treatment management decisions.

Despite the availability of treatments for specific forms of hereditary breast cancer, only

46%

of 1,001 breast cancer patients surveyed thought individuals would be tested to identify treatment options[20]

Further, among 696 people who had received genetic testing, only

37%

reported that they got tested to learn more about their breast cancer and how they could manage their disease[20]

2 There is a lack of current resources addressing genetic testing issues that are tailored to individual needs

> "Every patient is unique, and there needs to be a way to evaluate patients for what they want and when they want it—a way to titrate the information for that individual."
>
> —Mary Freivogel, MS, National Society of Genetic Counselors, Cancer Genetic Counselor

Many patients with hereditary breast cancer report needing additional guidance and resources to successfully navigate discussing the implications of hereditary disease with their children or family.[9] Among the 297 respondents diagnosed with hereditary breast cancer included in the 1,001-patient Pfizer survey, 68 percent reported that they don't know how to tell their family that they have a genetic mutation that may increase the risk of cancer for their children or siblings.[20]

In addition, each individual patient processes information in her/his own way. Some may want every detail about their diagnosis to feel more in control, and some may feel they are better off with less information. Cultural and religious differences may also influence how much information a patient wants or if they want to engage in discussion or seek information about testing at all.[25,26]

3 Staying abreast in a new and rapidly changing area of medicine can be challenging for both patients and HCPs

> "Genetics is something you have to keep up with. I feel like I have to read 20 articles a week just to keep up."
>
> —Sandra Brown, MS, LCGC, St. Joseph Hospital Center for Cancer Prevention and Treatment, Cancer Genetic Counselor

The genetics of breast cancer is a rapidly evolving field that necessitates collaboration among the whole healthcare team to ensure the sharing of up-to-date information to help identify patients for appropriate counseling and testing referrals. Guidelines are constantly being updated with new recommendations on which patients should be referred for genetic testing thanks to innovations in genetic testing and ongoing scientific discoveries. Further, given the complexity of the guidelines, sharing best practices on how to use and systematically implement the guidelines in a busy clinical setting may be warranted. Follow up among professionals is key as well, since research shows that between 40 percent and 50 percent of patients referred for genetic testing never participate in counseling and/or testing.[27,28]

Additionally, there is significant room for genetic counselors, psychologists and licensed social workers to share more psychosocial strategies with healthcare professionals to let them know what some of the emotional landmarks are and to provide basic skills on how to support someone confronted with genetic testing results.

Call to Action: Empowering a Path Forward for Hereditary Breast Cancer Patients with Metastatic Disease

Based on the challenges and barriers identified, the roundtable working group comprised of various breast cancer community experts proposes the following strategic recommendations for the breast cancer community.

Story Half Told participant Michael (right), who is living with *BRCA2*-positive MBC, with his partner

1 Strategy

Empower patients with metastatic breast cancer by dispelling myths, addressing confusion and providing education to increase knowledge about hereditary breast cancer and normalize genetic testing for appropriate patients

Recommendations:

- Develop tailored materials that simplify the language around hereditary breast cancer and genetic testing (eg, germline and somatic mutations, etc.); create a strategy to reduce confusion
- Provide context and information about the importance of genetic testing after diagnosis and guide patients and their families to organizations with unique expertise in this area
- Address misperceptions and inform patients of the genetic testing and counseling coverage and protections available to them
- Create opportunities to share experiences and stories that increase awareness and combat the sense of isolation

> "Having the information itself can be empowering in that you can actually act on it. You can give them recommendations on what they can do to help their families, which they didn't have before."
>
> —Patricia Rodriguez, MD, Virginia Cancer Specialists, Vice President and Chief Health Equity & Inclusion Officer

2 Strategy

Reframe patient-physician discussions around genetic testing to be more empowering and actionable based on the latest research

Recommendations:

- Leverage existing resources and develop new training tools for healthcare professionals to help facilitate shared decision-making and genetic testing discussions in an emotionally supportive manner
- Encourage healthcare professionals to personalize and tailor education and counseling based on patient personalities, cultural and scientific literacy, as well as psychological readiness in order to motivate patients to ask questions and act
- Provide opportunities for healthcare professionals to stay abreast of the rapidly evolving cancer genetics landscape

> "Healthcare providers should communicate the message in a way that's not scary for the patient and consider that the patient is going into this with a fear of passing something along to their children and siblings. And not just check a box that they mentioned it once—they need to keep at it."
>
> —Stacy Lenarcic, MS, CGC, Levine Cancer Institute, Genetic Counselor

3 Strategy

Increase access to genetic testing and resources for patients with metastatic breast cancer

Recommendations:

- Integrate genetic testing as routine care for MBC; train members of the healthcare team on critical issues, including testing referrals, obtaining informed consent and discussing results
- Assess the need for genetic counseling for each individual patient and increase access to counseling services, including through telegenetics or telehealth tools
- Develop innovative practices to support cascade testing and notification of relatives to ease the emotional burden

> "We have to expand the number of people who are able to provide genetic counseling services. We also have to ensure physicians conducting genetic testing understand how to identify and refer patients with complicated cases to a genetic counselor."
>
> —Gena Volas-Redd, MD, Georgia Cancer Specialists, Medical Oncologist

Conclusion

The results of the Pfizer survey and roundtable discussion helped to define the barriers and areas of need related to genetic testing for patients with MBC. Furthermore, the insights provided by the multidisciplinary experts at the roundtable also led to the development of the three strategies laid out in the call to action:

- **Increase knowledge about hereditary breast cancer and normalize genetic testing for appropriate patients with MBC in ways that resonate with and empower this community**
- **Make patient-physician discussions about genetic testing more positive and actionable**
- **Increase access to genetic testing and resources for patients with MBC**

There is a need for continued discussion and consensus around this rapidly evolving area of medicine. No two patients are exactly alike. The more we can learn about their needs, obstacles and shared experiences, the more work we need to pursue to increase the availability of testing, resources and support. This is Pfizer's commitment.

Pfizer plans to work with our advocacy partners to support patients with hereditary breast cancer and help address their need for more information and support. We invite the broader breast cancer community and healthcare professionals nationwide to join us so these individuals have more places to turn, more resources and support, and know the breast cancer community is behind them.

Thank You

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- Adina Fleishmann, LSW, Sharsheret
- Shirley Mertz, Metastatic Breast Cancer Network (MBCN) and original *Story Half Told* Steering Committee Member
- Sue Friedman, FORCE: Facing Our Risk of Cancer Empowered
- Patricia Rodriguez, MD, Virginia Cancer Specialists, Vice President and Chief Health Equity & Inclusion Officer
- Karen Hurley, PhD, Cleveland Clinic
- Gena Volas-Redd, MD, Georgia Cancer Specialists

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