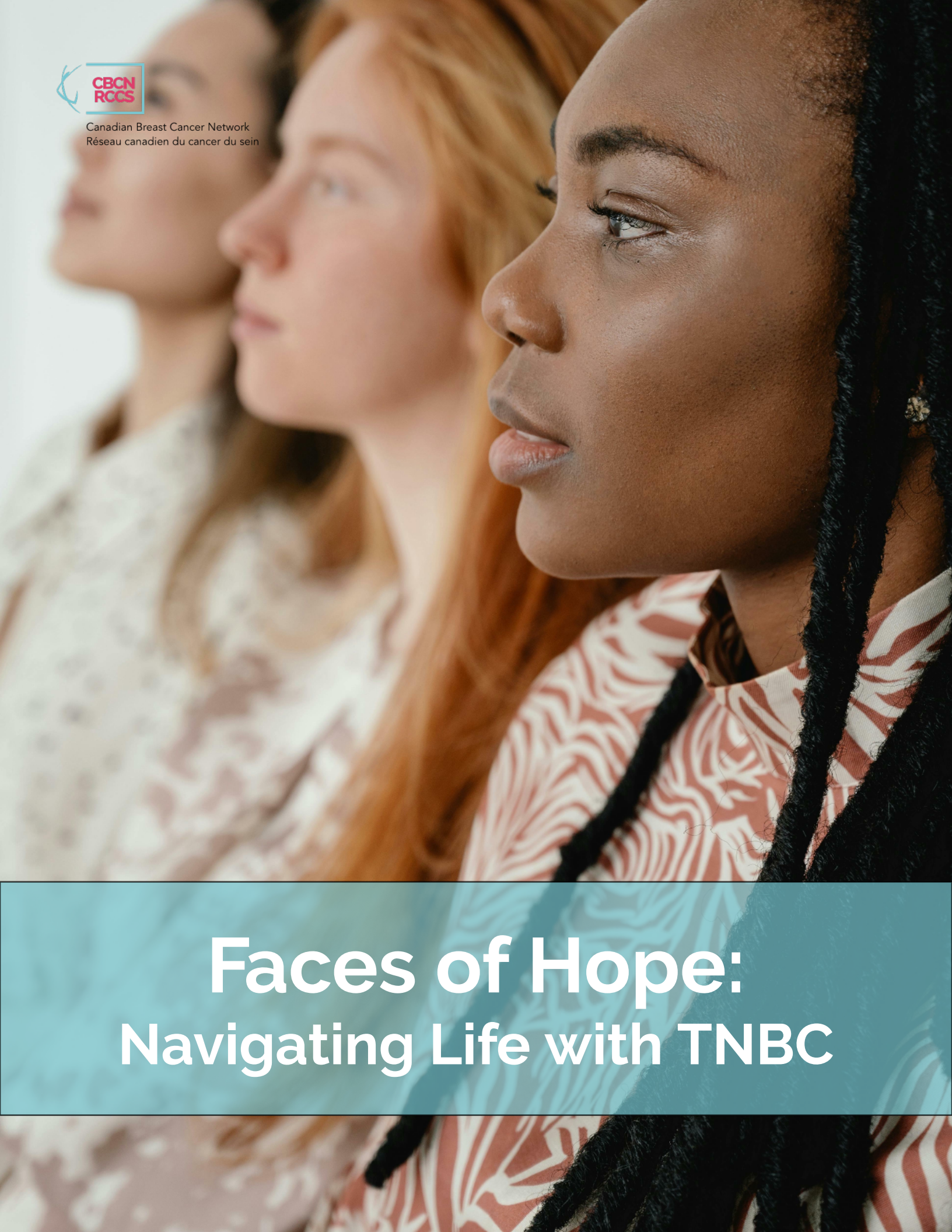

Canadian Breast Cancer Network
Réseau canadien du cancer du sein

Faces of Hope:
Navigating Life with TNBC

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Introduction

Being diagnosed with triple-negative breast cancer (TNBC) can bring plenty of difficult emotions—fear, sadness, uncertainty. However, one emotion often left unspoken is hope. When discussing this subtype of breast cancer, words like “aggressive,” “high-risk,” and “limited treatment options” often dominate the conversation, naturally triggering fear or sadness. Fear that the cancer might spread, or that treatments may not work as expected. Sadness knowing that TNBC affects only 10-20% of breast cancer patients, or that multiple rounds of chemotherapy may be in your future. But amid these challenges, there is also hope. Hope lies in the tireless efforts of researchers striving to develop more effective treatments. Hope in finding meaningful connections with others who are navigating a similar path.

Faces of Hope: Navigating Life with TNBC offers essential information on triple-negative breast cancer, personal stories from women who have faced this disease, and practical tips for self-advocacy. Drawing from the Our Voices Blog, this magazine seeks to provide that crucial sense of hope, helping you live well with or beyond TNBC.

TNBC is more common among young women, Black and Hispanic women, and individuals with BRCA mutations. Here are some additional resources to support and address your unique needs:

TNBC Specific:

CBCN’s TNBC Hub

Triple Negative Breast Cancer Foundation

Young Women:

CBCN’s Never Too Young Handbook

Rethink Breast Cancer’s Virtual Support Groups

Black Women:
Every Breast Counts
Olive Branch of Hope
African Cancer Support Group

Hispanic Women:
Latin Association for Breast Cancer

Hereditary Breast Cancer:
CBCN's Hereditary Breast Cancer Syndrome Factsheet
Facing Our Risk of Cancer Empowered (FORCE)

One Woman's Mission to Transform Breast Cancer Care in Canada

By Dawn Barker

Who is Dawn Barker? Dawn is a new-age renaissance woman, a difference maker, and a catalyst for change. Her passion for improving the well-being of her community has always been at the core of her life's mission, and she has dedicated herself to making a tangible difference for those around her.

Born proudly in Barbados, Dawn began her professional journey in the health insurance industry. However, as she witnessed the healthcare struggles of her loved ones, particularly her own family, Dawn felt a deep calling to shift her focus from the corporate world to a more hands-on approach. Her decision to pursue a Healthcare Aid Certification was driven by a desire to care for those who couldn't care for themselves, a desire born from personal experience.

Dawn's mother endured a lengthy 12-year battle with multiple myeloma, a struggle that deeply impacted Dawn and solidified her resolve to make a difference in healthcare. Sadly, after losing her mother at the age of 62, she faced yet another devastating loss just four years later when her father passed away after a brief battle with esophageal cancer.

The loss of loved ones is an experience that leaves a lasting void, one that is deeply felt but hard to describe. As author Jamie Anderson said it like this: "Grief, I've learned, is really just love. It's all the love you want to give but cannot. All of that unspent love gathers in the corners of your eyes, the lump in your throat, and in the hollow part of your chest. Grief is just love with no place to go." Dawn's personal journey through grief gave her a deeper

understanding of the need for compassion, support, and most importantly, advocacy—particularly when navigating the often complex and impersonal healthcare system.

In both her parents' experiences, they often felt dismissed or overlooked by healthcare professionals. This sense of being unseen ignited a fire in Dawn to stand up for others and advocate for more equitable care. However, it wasn't until her own health was on the line that Dawn realized the power of self-advocacy.

> ***"Ironically, she had requested breast cancer screening twice before her diagnosis, only to be denied both times.***

In 2017, Dawn received her own life-changing diagnosis: triple-negative breast cancer (TNBC), an aggressive form of breast cancer. When diagnosed with this type of breast cancer, the message of hope is often lost amidst the urgency of treating an aggressive form of cancer. Being told things like, "survival rate is low, recurrence is high", "it's harder to treat", "chemotherapy regimen is very aggressive", "the side effects are quite harsh", "typically, the cancer may return in the first 5 years following treatment" can leave a person feeling helpless. Thankfully, 7 years later Dawn is here to share her story as a source of inspiration.

Ironically, she had requested breast cancer screening twice before her diagnosis, only to be denied both times. She was told, "Not until you're 50," a reflection of the standard guidelines that do not always account for the realities faced by younger women or racialized communities. Dawn's experience highlights a critical gap in the healthcare system: there is a lack of education and awareness around how breast cancer often presents earlier and more aggressively in racialized women, particularly Black, Indigenous, and People of Color (BIPOC).

Dawn's advocacy stems from her desire to ensure that others do not face the same barriers. She wants women to know that there are potential benefits in conducting a breast cancer risk assessment earlier than the

guidelines suggest, especially for BIPOC women. Above all, she emphasizes that informed decision-making is a right that everyone should exercise.

Through raising awareness, relentless advocacy, and initiating positive dialogues aimed at systemic change, Dawn's ultimate goal is to ensure better representation in healthcare nationwide. She envisions leading organizations, researchers, and government institutions toward the collection of race-based health data to close existing gaps. Dawn is calling for a provincial cancer action plan which includes training and equipping those that serve patients to better understand the tailored care and education required to adequately support our diverse nation. By doing so, she hopes to create a healthcare system where earlier detection, personalized treatment, and equitable care become the norm—ensuring that no one is overlooked or screened too late.

Dawn's advocacy led to the creation of **NUY50**, a movement born out of adversity, grief, and a desire to spark meaningful change. NUY50— standing for "Not Until You're 50"— reflects Dawn's experience of being denied breast cancer screening between the ages of 40 and 42, only to be diagnosed two years later with TNBC. NUY50's mission is to raise awareness about the importance of self-advocacy and push for more research into breast cancer, particularly in women under 50 and those from BIPOC communities.

Dawn Barker's story is one of resilience, courage, and a commitment to improving the lives of others. Her message is clear: "Don't wait — ADVOCATE!"©

TNBC: Who's at Risk?

Research shows that some people have a greater chance of developing triple-negative breast cancer (TNBC) if they are subject to certain risk factors. These risks include:

- Age: Premenopausal women and those under the age of 50 have an increased risk of TNBC.
- BRCA1 gene mutation: About 70 percent of the breast cancers diagnosed in women with an inherited BRCA1 mutation are TNBC.
- Ethnicity: Black and Hispanic women have a higher rate of TNBC.
- Breast density: Higher breast density is associated with increased risk of TNBC, especially among premenopausal women.

How is it treated?
Treatment can be difficult for this type of breast cancer. Without receptors, triple negative tumors do not have the proteins they need to respond to common breast cancer treatments like hormone and

targeted therapy, which are used for hormone-positive or HER2-positive breast cancer.

Chemotherapy and immunotherapy are the primary systemic treatment options for triple negative breast cancer. Unless the tumour is too extensive, TNBC that is in stage I through stage III is treated with chemotherapy (with or without immunotherapy) followed by surgery. If there are still cancer cells remaining when the surgery takes place, more chemotherapy is often needed. Stage IV TNBC treatment often depends on the patient's specific circumstances: the presence of a BRCA gene mutation, which proteins the cancer cells do have, and other factors. Luckily, the treatment options for TNBC continues to expand thanks to new and emerging research from clinical trials.

What does the research say?

A 2021 study by researchers in the Perelman School of Medicine found that Black women were almost three times more at risk for TNBC, which often has poorer outcomes. The significance of the risk found in this study was important because researchers had carefully adjusted for breast cancer risk factors in a screened population, and the size of the sample was meaningful; the group included 29,822 (or 15 percent) Black women.

Additionally, it was discovered that triple negative breast cancers were less likely to be detected through screening and more likely to be diagnosed as interval cancers. According to the Canadian Partnership Against Cancer, "Interval cancers are cancers that are diagnosed after a negative screening test, but before a participant is due to come back for their next screen".

In a separate study, the same researchers looked at more risk factors among Black women. They found that both breast density and obesity were more strongly associated with TNBC than other subtypes among this group.

Another US study from 2021 compared treatment and mortality rates between Black and white women with breast cancer. According to the study, Black women were:

- Younger when diagnosed with breast cancer
- More likely to live in areas with the lowest incomes

Black women were 31% less likely to have surgery, and 11% less likely to have chemotherapy than white women, although triple-negative breast cancers in Black women were:

- More likely to be advanced
- More likely to be larger than 5 cm
- More likely to have spread to the lymph nodes

Taking many demographic, socio-economic, and other factors into account, researchers still found that Black women were 28% more likely to die from triple-negative breast cancer than white women. When adjusted to take the breast cancer characteristics into account, Black women were still 16% more likely to die from triple-negative disease than white women.

> ***Understanding these risk factors is crucial for early detection and intervention.***

It's important that more Black women participate in clinical trials and other studies for breast cancer, as well as other diseases. A Canadian meta-analysis of 2000 studies done between 2003 and 2018 revealed that only 23 of them focused on Black Canadians. This limited data means that inequalities can't properly be addressed, which contributes to systemic racism and inequitable care in the Canadian health care system.

While TNBC presents significant challenges, there is reason for hope. Understanding these risk factors is crucial for early detection and intervention. Clinical trials and research are expanding treatment options, offering better outcomes for patients. While limited, emerging research on disparities in TNBC diagnosis and treatment, particularly among Black women, highlights the importance of addressing systemic inequities in healthcare access and participation in clinical trials. Increased awareness, advocacy, and inclusivity in research can lead to improved outcomes and equity in breast cancer care. Regardless of race or socioeconomic status, all Canadians should have equal opportunities for early detection and effective treatment.

Breaking Barriers in Triple Negative Breast Cancer Care

If you've been with us for a while or if you have Triple Negative Breast Cancer (TNBC) you know that this subtype is considered more aggressive and has fewer treatment options than other subtypes of breast cancer. By now, you're also likely aware of the risks associated with TNBC.

In 2023, we launched a report that identifies the educational, informational, and support needs of Canadians diagnosed with TNBC. Since then, we've dedicated significant time to raising awareness about its findings, including targeted advocacy for improvements in key issues affecting TNBC patients or those who are at elevated risk of developing TNBC. Our advocacy focuses on three main issues: awareness and education, improving access to and understanding of genetic testing, and expanding demographic health data collection.

If you're reading this, it's because you recognize that these issues directly impact you, and CBCN is committed to keeping you informed about how we're advocating for these critical matters to be addressed.

Awareness and Education

Awareness of TNBC is alarmingly low. A staggering 70.6% of triple negative breast cancer patients who responded to our TNBC survey had not heard of the term at the time of their diagnosis. Most (76.8%) were informed of the aggressive nature of the disease following diagnosis. Given that a breast cancer diagnosis is already a scary thing to face, one can only imagine the additional shock and surprise this news would bring. It paints a concerning and overwhelming picture of what their future might hold, leaving room for anxiety and grief in an already uncertain time. Improving awareness gives voice to those with TNBC and serves as an advocacy tool to drive research forward toward the development of new, effective treatments.

There has also historically been a lack of information and resources dedicated to people with TNBC. We know, from our 2023 survey, that patients with TNBC prefer to receive information tailored to their triple negative subtype (94.3% of survey respondents), but these resources have been difficult to find (74%). Support was similarly lacking; 66.2% of TNBC patients found it was not easy or only somewhat easy to connect with other patients with triple negative breast cancer. This is why we created and launched our new TNBC hub, dedicated to providing information and ways to find support.

Genetic Testing

Understanding individual risk factors can be very challenging, especially when people don't know where to start. Most cancers are caused by an accumulation of damage in our bodies caused by the normal aging process and environmental factors like exposure to certain chemicals and radiation, to name a few. However, for some people, changes in certain genes, known as pathogenic variants (or

"There has also historically been a lack of information and resources dedicated to people with TNBC.

mutations) that are passed down through families, can increase their risk of developing breast cancer. Two of the most well-known pathogenic variants associated with breast cancer are on the BRCA1 and BRCA2 genes, which can increase a person's risk by 45 to 85%. TNBC is associated with BRCA mutations; between 10 to 30% of individuals diagnosed with TNBC will have a BRCA mutation. This association makes testing for hereditary breast cancer an important step for individuals diagnosed with TNBC.

Access to genetic testing, however, has its challenges. Eligibility guidelines can be difficult to find and vary by province. Someone may be eligible in one province, but a person with a similar personal and family history may not be eligible in another province. Given the high association between TNBC and BRCA1 and 2 gene mutations, a triple negative diagnosis *should* qualify patients for testing, but this varies by age depending on province. What is also unclear is exactly how long a person waits to see a genetic counsellor to begin the process of genetic testing. Furthermore, accurate health system-level private testing can cost hundreds of dollars, while cheaper alternatives are often inaccurate and misleading. CBCN is engaging with stakeholders to ensure that genetic test eligibility is equitable across Canada and that public-facing information on genetic testing eligibility is available in all jurisdictions.
Finally, understanding personal risk factors is complicated. To address

this, we recently created a factsheet to help individuals learn more about this type of breast cancer and the steps to take to determine if they qualify for hereditary cancer testing. Hereditary risk is one of several risk factors for developing breast cancer. That's why everyone should speak with their healthcare provider to understand their individual risk, especially if you've been diagnosed with triple negative breast cancer.

Demographic Health Data Collection

In addition to equipping patients with the right information, we need to ensure our healthcare system is collecting the right data. We know that TNBC is more likely to impact young women, as well as Black and Hispanic women but this data is based on US statistics. Even the statistics we have on the association between BRCA mutations and TNBC, mentioned earlier, is primarily based on international data. Too much of the data we currently use is not based on Canadian information and, therefore, may not accurately reflect the Canadian population. If we start collecting health data on race, ethnicity, and Indigenous identity, it will greatly improve our understanding of breast cancer in Canada. This call for the collection of race and ethnicity data is in line with the Canadian Cancer Society's and the Canadian Partnership Against Cancer's Pan-Canadian Cancer Data Strategy.

Our work is far from over, but we are committed to making meaningful strides for those affected by triple negative breast cancer. By continuing to raise awareness, pushing for accessible and equitable genetic testing, and advocating for comprehensive demographic health data collection, we aim to create a future where every person diagnosed with TNBC has the support, resources and care they need.

> ***"Everyone should speak with their healthcare provider to understand their individual risk.***

Triple Negative Breast Cancer: Shoulda, Woulda, Coulda and a TIP

By Ann Hill

If you're going to be told you have breast cancer, you want to be able to say, "They caught it early." With Triple Negative Breast Cancer (TNBC) - an aggressive, difficult to treat type of breast cancer - early detection is especially important.

At 53, breast cancer was not on my mind. I was fit and active with a healthy diet, weight, and lifestyle. No concerns with my family history or things like Hormone Replacement Therapy (HRT). Yes, I had the odd alcoholic drink. Yes, I had taken the pill years earlier, but even with these factors, my risk of getting breast cancer was considered below the norm for someone my age. And, following guidelines, I started getting regular screening mammograms when I turned 50. I was covered. Or so I thought.

In late 2016 I had a "clear" mammogram. Just six months later I was told I had Stage 3 TNBC. I was blindsided and, I'll admit, a bit angry. As a project manager who specializes in risk management, part of me also hung my head in shame. I realized that I didn't know nearly enough about breast cancer, its many types, or all the other risk factors. I quickly learned that early detection depends on so much more than just passively showing up for a mammogram every two years. My story is one of hindsight and is full of, what I call, SWC (Shoulda, Woulda, Coulda) moments.

SWC #1. Self-exams.
Confession time. After that "all clear" mammogram, I was somewhat lax about self-exams. I felt snug and safe in my comfortable, yet eventually false, sense of security. I *shoulda* continued doing regular self-exams. When I finally did one six months after that mammogram, I felt the lump in my right breast.

SWC #2. Talk to your doctor.
I didn't know that my family doctor got a detailed radiologist's report after each mammogram, or that it said, "Heterogeneously dense breast tissue. Mammographic sensitivity may be reduced." I learned that both tumours and dense tissue appear white on a mammogram. Meaning, if a tumour was present (which it was), there was less chance it would be seen. I wish my doctor had told me about this risk. If she had, maybe I *woulda* requested other imaging tests, like an ultrasound, which is better at "seeing" a tumour in dense breast tissue. Maybe I *woulda* been more diligent in my self-exams. Maybe my cancer *coulda* been caught earlier.

SWC #3. Trust your gut.
After going through all the diagnostic tests (another mammogram, ultrasound, and biopsy), the doctor told me it was cancer. He also felt an enlarged lymph node in my right underarm but said, based on the ultrasound, he wasn't concerned. What? I'm not a doctor, but this lack of concern about an enlarged lymph node in conjunction with a cancer diagnosis seemed odd. I *shoulda* trusted my gut and pressed him on this. It came back to haunt me later.

SWC #4. Take charge. Get copies of test results.
I had surgery to remove the lump and a sampling of lymph nodes. Three weeks later, my surgeon told me it was triple negative breast cancer. Stage 3. Positive lymph nodes. As I sat there in his office with my "deer in the headlights" stare, he said I would need chemotherapy. And radiation. Then, citing an urgent appointment, he simply got up and left the room. I was angry. And scared as hell. So, along with a referral to the oncology team, I left the surgeon's office that day with copies of all my test results and learned the following key things:

> ***I knew that, if I was going to beat this thing, I was going to have to take charge and do some self-advocacy.***

1. The biopsy report didn't call for testing of the hormone receptor status of the tumour. This test would have identified my cancer as TNBC, and aggressive, from the beginning. Why was this not tested? TNBC tends to occur more often in women under 50, in women of African American and Hispanic descent, and is a risk if a woman has the BRCA1 gene mutation. Because I didn't check any of these boxes, it was likely assumed (falsely) that I had a more common, less aggressive, hormone-driven type of cancer.
2. The pre-surgery ultrasound report said that the lymph nodes looked highly suspicious for cancer. My surgeon knew this before the surgery, yet told me the enlarged node was no concern. Why? Was he afraid of scaring me? Was it an oversight? (He didn't know the project manager in me doesn't like things sugar-coated or overlooked!)

By now there were too many SWCs for my comfort. I knew that, if I was going to beat this thing, I was going to have to take charge and do some self-advocacy.

SWC #5. Follow this TIP: be Thorough, Inquisitive, and Persistent.
Three weeks into chemotherapy, I felt a new lump in my right underarm. Aware of the aggressive nature of TNBC, my oncologist ordered an ultrasound which confirmed the cancer was in more lymph nodes. And there it was: I *shoulda* trusted my gut back when I was first diagnosed and pressed the doctor about that suspicious lymph node. Maybe this further spread to more lymph nodes *coulda* been avoided.

My cancer centre's tumour board recommended a second surgery to remove the remaining lymph nodes followed up by CT scans to see if it had spread further.

Distressing as this news was, it actually started a series of "early detection" wins that I chalked up to my new-attitude, take-charge TIP: be Thorough, Inquisitive, Persistent. I spent the time leading up to the second surgery finishing chemo and doing a lot of research. I learned about TNBC and the increased risk of recurrence. I learned that with dense breasts, the risk of developing a second (contralateral) cancer in the other breast is greater. And I listened to my fear that if a tumour developed, it may be missed again. So, for my second time under the knife, I requested, and received, a double mastectomy.

SWC #6. Be proactive.
After surgery, I was relieved to hear there was no sign of residual breast cancer. However, the surgeon did find some microcalcifications in the tissue plus some atypical spots on the skin, both of which can be early signs of cancer. The breasts and tissue were gone, but I decided to be proactive and met with a dermatologist. She found and biopsied three new suspicious spots on my back. Thankfully, they were early pre-cancerous. Doing regular skin exams are now part of my self-exam routine.

Around the same time, the post-surgery CT scans revealed some new and changing ovarian cysts. An OB/GYN was called in and, after an exam and discussion of my options, I opted to be proactive again and had my ovaries removed. It turned out there was some mild hyperplasia, which meant the cysts were not quite pre-cancerous but could become cancerous someday.

As the 4-year anniversary of my diagnosis approaches, my status is NED (no evidence of disease). My doctor tells me I am past the peak window for the TNBC to return or spread, but I know I'm never 100% in the clear so I stay on top of things by being Thorough, Inquisitive, and Persistent about my health.

Today, I have less body parts, but more peace of mind and confidence in what I've learned about what's needed of me – and my doctors – for early detection. For me, it was worth the trade-off. My daughters are benefitting from my SWCs. And the project manager in me is now holding her head high.

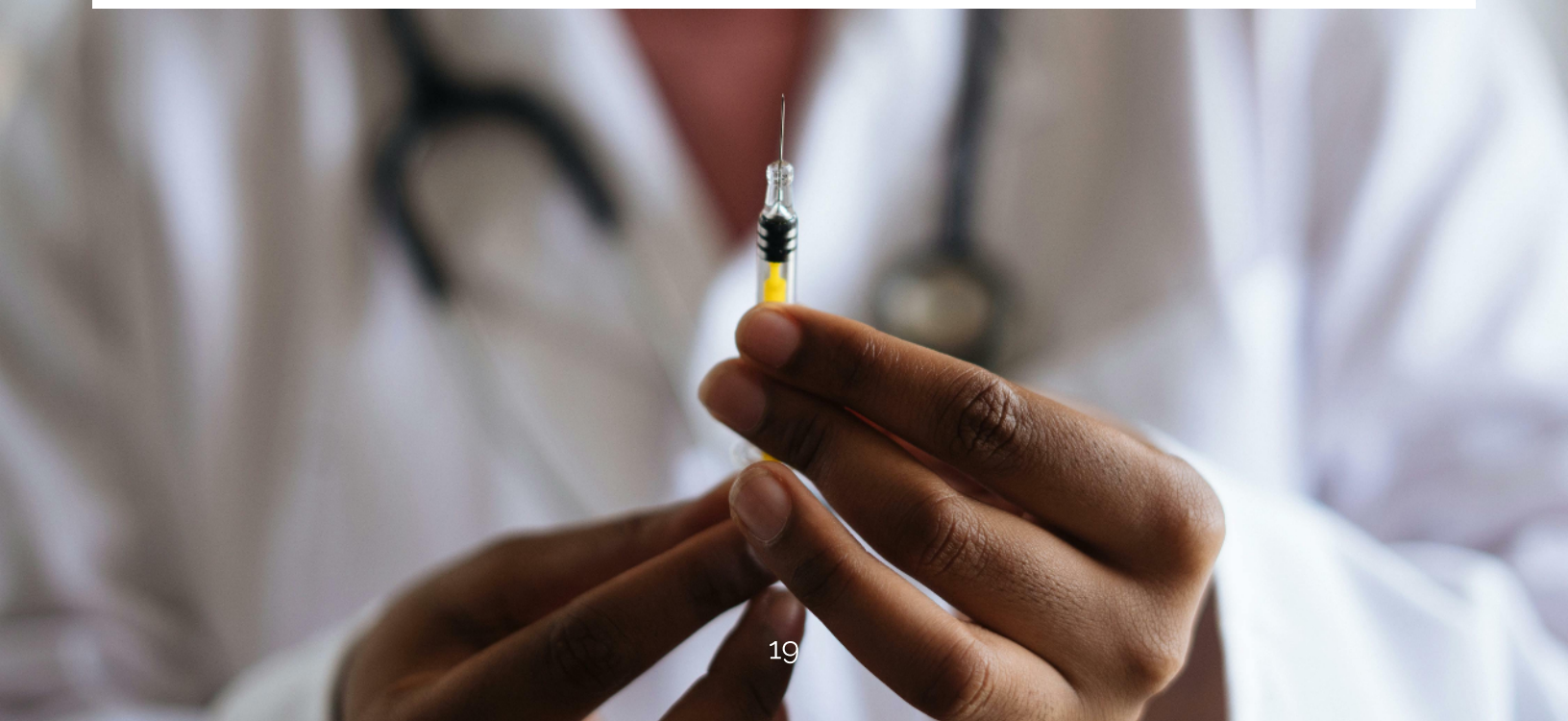
Immunotherapy and Breast Cancer Explained: Thoughts From a Researcher Who Has Also Had Triple Negative Breast Cancer

by Alyssa Vito

Traditional cancer therapies (such as chemotherapy and radiation therapy) have shown widespread success against various cancer types, but are known to have toxic, undesirable side effects as they do not selectively kill cancer cells and therefore actively damage healthy cells as well. This is where immunotherapy comes into play. Immunotherapy is a form of therapy that uses the body's own immune system to fight the cancer within it. Think of your body as a battlefield and your immune system the frontline of soldiers, ready to attack foreign invaders. The problem with cancer cells is that they are not easily recognized as foreign pathogens (such as viruses or bacteria) because they originate in the host's body and mutate from normal cells. It has long been postulated that the immune system could be used to target and kill cancer cells, but the process of figuring out how to harness this ability is not a simple task.

The Immune System

The cells of the immune system are continually monitoring our tissues and patrolling the body for foreign invaders. There are many different



types of immune cells that make up the complex immune response that keeps our body healthy. When a tumor is formed, the immune system reacts in a systemic manner. First, natural killer (NK) cells send stress signals when they detect damaged and cancerous cells. Dendritic cells (DCs) are then responsible for informing and activating other immune cells, such as cytotoxic T cells. Once activated, cytotoxic T cells act as border patrol agents, checking the antigens of every cell that passes by them. In this analogy, we can think of the antigens as passports. The cytotoxic T cells can sense that antigens on the tumor cells are "foreign" and "do not have the right passport". These cells are then signaled for destruction and the cytotoxic T cells and NK cells release proteins, which punch holes in the surface of the tumor cells causing them to die through a process called apoptosis.

As the tumor evolves, genetic changes occur that give some tumor cells a survival advantage over others. This results in what we call a "heterogenous tumor", meaning it is composed of multiple different types of tumor cells, each subtype having its own "passport" to identify it. While some cells may still be flagged as having the "wrong" passport and be killed by the immune system, others will mutate and evolve to no longer express the antigen that is sensed as being wrong by the killer immune cells. These cells are the driving force behind tumor persistence, and they evade immune-mediated killing with "fake passports". As the immune system continues to work and kill the cells it can recognize, the cells it can't sense become more prevalent and begin to form a tumor that goes fully undetected by the immune system.

Another trick of cancer cells is to actively supress cytotoxic T cells by expressing inhibitory molecules such as programmed death-ligand 1 (PD-L1). PD-L1 binds to the PD-1 receptor on T cells and deactivates them, stopping them from killing tumor cells. This is what we call an immune checkpoint. Tumor cells can also attract immune cells that supress the activity of other immune cells, in turn actually supporting tumor growth.

Checkpoint Blockade Therapy

There are various types of immunotherapies coming down the clinical pipeline. Some common ones that you may have heard of include

adoptive cell transfer (ACT), chimeric antigen receptor (CAR) T-cell therapy, checkpoint blockade therapy and oncolytic virotherapy. While some immunotherapies focus on enhancing and/or expanding the patient's own T cells to target the cancer cells, others focus on stopping T cell inhibitory pathways such as PD-L1.

Since the discovery of the PD-1/PD-L1 pathway by Dr. Tasuku Honjo in 1992, scientists have extensively studied checkpoints and the use of blocking antibodies to inhibit them. To show just how notable this discovery was to the field of oncology, Dr. Honjo was awarded the Nobel Prize for this finding in 2018. The award was shared with Dr. James Allison, who similarly uncovered the checkpoint pathway cytotoxic T-lymphocyte-associated protein 4, or CTLA-4. Antibodies that bind to either PD-1, PD-L1 or CTLA-4 have been used significantly in numerous clinical trials and with widespread success for many forms of cancer.

Unfortunately, not all patients will respond to these immunotherapies and some responses will be delayed or incomplete. One of the reasons for these differences in responses is that even patients with the exact same cancer, will still have individual expression levels of things such as PD-L1. As you can imagine, a patient

whose cancer has higher expression of PD-L1, will inevitably benefit more from anti-PD-L1 therapy. Though personalized cancer therapy is still in its infancy and we do not yet understand how to scale it up within reasonable time and financial constraints, the field of oncology is moving towards a point in which we will be able to fully dissect the immune markers for every single patient and then design personalized therapeutic regimens based on that immune environment unique to their cancer.

Breast Cancer Immunotherapy

Immunotherapy for breast cancer got off to a slow start. This is primarily because most breast lesions have low levels of immune cells and low expression of markers such as PD-L1. Additionally, breast cancers that are positive for the overexpression of hormonal biomarkers (such as the estrogen receptor or progesterone receptor) already have good targeted therapies available to them. Where we have seen the strongest emergence of immunotherapy for breast cancer is for the aggressive subtype, triple negative breast cancer (TNBC), which has been shown to express higher levels of PD-L1, when compared to other breast cancer subtypes. For this reason, we have begun to see improved clinical outcomes in TNBC patients treated with checkpoint blockade antibodies targeting the PD-1/PD-L1 pathway. It is however worth noting that in most breast cancer cases, this immunotherapy is still given in combination with chemotherapy or radiation therapy, which leads to a better response in some patients.

Will Immunotherapy Replace Current Treatments?

As scientists continue to explore ways of manipulating and enhancing the body's natural immune response, we see more immunotherapies emerging in both preclinical and clinical studies. For the time being, immunotherapies often need to be supplemented with additional standard therapies. However, given the favourable outcomes we have seen and the limited toxicity to the patients, it is plausible that in the future we will see immunotherapies as the sole, first-line treatment for many types of cancer.

My Perspective

Though most breast cancers are well managed by current treatments (surgery, chemotherapy and radiation therapy), patients endure aggressive, invasive procedures that result in any number of side effects including but not limited to infertility, nausea, hair loss and muscle atrophy. I myself can speak to these devastating side effects as I was only 23 years old when diagnosed with stage II TNBC. As a subtype of the disease classified as being inherently aggressive and with no clear hormonal targets for therapy, TNBC patients are often subject to an extremely intense treatment regimen. I had a partial mastectomy, 8 rounds of dose-dense chemotherapy and 33 radiation therapy treatments. While I can say that these therapies undoubtedly saved my life, I can also say that I will forever live with the long-term side effects they inflicted upon my body.

As a researcher in the field of immunotherapy I am excited and optimistic about the future of cancer therapy. Scientists around the world are studying the immune system in such minute detail that we are constantly uncovering new functions and possible areas for intervention in the complex innerworkings of the body. Like most researchers, I shy away from using terms such as “cure” when talking about the future of cancer research. I do not believe that there will be a singular “cure” for cancer. That being said, it becomes more evident every day that it is instead reasonable to think about a future where cancer can become a “manageable” disease. And that is exciting to me.

“As a researcher in the field of immunotherapy, I am excited and optimistic about the future of cancer therapy.

Navigating the Stop Signs: A Story of Genetic Testing

By Quinn Obrigewitch

My mother was diagnosed with triple negative breast cancer at the age of 30, both of which are strong indicators of a genetic mutation. Triple negative breast cancer is a more aggressive and lesser-seen subtype of breast cancer that disproportionately targets young women and has fewer treatment options; often resulting in a more aggressive therapy process. This is all due to the unfortunate circumstance that triple negative breast cancer can be a hereditary pathology - commonly known as the Breast Cancer 1 (BRCA1) or BRCA2 mutations. Typically, mutations are not something to be wary of. In fact, they are a rather good thing. They are what make you different from your neighbour, or what has given you your beautifully coloured eyes, or what might be protecting you from a certain disease. Life requires genetic mutations to progress; the world adapts, and then we adapt, and the world adapts again in harmonious flux. However, people born with the BRCA1 or BRCA2 mutations are at a disadvantage against their environment.

The BRCA genes are tumour suppressor genes and can be thought of as the traffic officers of the body. In each hand, they hold one stop sign which signals to replicating cells that they have fulfilled their duty and can stop dividing. Sometimes, the environment gets too harsh, and a stop sign is lost. This is to be expected which is why there are two; BRCA1 and BRCA2 will still function normally following the loss of one stop sign. The mutation causes the loss of function of one stop sign in utero, meaning those possessing the BRCA mutations are only

equipped with one stop sign. Once that is lost, cells lose their guidance signal and begin to divide uncontrollably, thus resulting in a difficult-to-treat cancer which often occurs earlier in life.

With this knowledge, it is easy to understand the essential role genetic testing has in cancer diagnosis and prevention. In fact, genetic testing is what I consider having saved my life. My mother was quick to expose my sisters and me to the danger we may face in young adulthood following her diagnosis. She was never shy to tell us that we need to be vigilant, and our 18th birthdays were marked with the exciting milestone of now being legally old enough to request genetic testing for the BRCA mutation, as per the province of Alberta's cancer screening guidelines. I attended my older sister's appointment with her and had the opportunity to listen to the genetic counsellor speak. My sister and I were met with a warm, safe, and comfortable environment where we drew our family tree and learned all about BRCA, what it does and why the mutation is bad. The appointment only lasted one hour but we left with a wealth of new information, feeling both scared of what our bodies could do yet relieved that we had the opportunity to act before the cancer. I was so excited to tell my friends about their stop signs.

I had my 18th birthday in May of 2018 and had booked myself an appointment to see my family doctor the following week. I remember feeling excited, rather than scared, to request my genetic testing. I had enjoyed everything I learned at my sister's appointment a few years prior so much that I began actively volunteering with the local genetic counsellor, which mostly involved helping her organize her files. Nevertheless, I was looking forward to having her on my team and knew I could put my full trust in her to read my genetic background. My usual family doctor was on maternity leave at the time of my appointment, so I spoke with one who was standing in for her. I come from a relatively small town where everyone is quite well known to each other, so my mother's diagnosis, battle with cancer, and subsequent health advocacy beginning about a decade prior was no secret. I was in for quite a surprise when I went to speak with the interim doctor and not only had to regurgitate my entire family history of breast cancer and other cancers, but was also met with resistance; "Who is this "genetic counsellor" you keep asking for? I have never

heard of her; we don't normally have people requesting for genetic testing". I explained once again the breadth of my family history, my sister's referral, and how much I needed this test. I walked out of that health clinic with a newfound confidence in advocating for myself, a smile on my face, and a referral in hand.

My appointment was booked two weeks later and fell at the beginning of June. I met with the counsellor whom I had seen 100 times prior, yet I was incredibly nervous. I was so well versed in how these appointments go that at this point I could have recited it myself, but this whole situation was beginning to feel much more real. She asked me how I was feeling, to which I responded honestly, and I was sent away for my bloodwork. Genetic testing is typically done through blood sample analysis; however, it can be done through saliva samples or a cheek swab.

"The human genome can be thought of as chapters in a book, with every individual lineage holding its own, unique story.

The human genome can be thought of as chapters in a book, with every individual lineage holding its own, unique story. Searching for one gene in the entire genome is like sorting through the pages of a book. Upon the first time of reading the book, it can be difficult to decide where the chapter of importance will be, and so the length of the book must be read carefully and thoroughly. Once the book has been read and understood, a bookmark can be inserted into the desired chapter to make future searches easier and take less time.

My mother was the first one in my family to undergo genetic testing and patiently waited over the course of a year while her book was carefully read. My sister and I were graced with the fortune of my mother's bookmark,

and my results were delivered to me, by phone call, three months after my blood test, in September 2018. My genetic counsellor was the one to deliver the news, where she kindly asked me how I was feeling and if I would like any resources including BRCA1 support groups. I politely declined, as I felt the best people for me in that moment were my mother and sister, and that was the end of my journey with my genetic counsellor.

The following years were marked by routine cancer screening and decision making. I opted for prophylactic removal of my breast tissue to reduce my risk of breast cancer, and four years later I am happy to be living freely under normal-population cancer screening guidelines. Genetic testing offered me a brief window into my future by telling me I was missing a stop sign, where I was able to take action to keep myself as healthy as possible, for as long as possible; for the sake of myself, my friends, and my family. Two surgeries in exchange for more certainty, and all because of a silly little stop sign.

Getting Through My Worst-Case Scenario

By Rebecca Dahle

The worst weeks of my life had finally come to an end. It had been six weeks since my lumpectomy. Six terrifying weeks, living with many unknowns, in a state of complete disillusionment. But the wait was finally over because today I would meet my medical oncologist for the first time, she would go over my pathology report, and reveal my treatment plan. Going into the appointment I felt ready to face whatever would come my way. After experiencing the darkest days of my life, I had emerged feeling strong and optimistic. I had done a lot of research and decided that the odds were in my favour, I could beat this… unless I had triple negative breast cancer (TNBC), because that was a different story. However, I wasn't worried about that because I knew that TNBC only makes up 10-20% of breast cancers and that aside from my age, I didn't really have any risk factors. So, there I was, full of hope, when I was hit with what I had identified as the worst-case scenario. As soon as I heard "Your cancer is triple negative", I burst into tears. I don't remember much of the appointment after that.

I had a lot of time to think and question things between my lumpectomy and first appointment with my oncologist. I didn't have any experts to ask, so I turned to the internet. I know that Googling is one of the worst things you can do but my curiosity and need for answers got the best of me. Before I knew I had breast cancer, I didn't even know that TNBC existed. My mom, who was doing very well, had hormone receptor positive breast cancer and I, like many others, thought that was the only kind. I didn't spend a whole lot of time reading about TNBC, just enough to know that I didn't want it. I read that TNBC, which doesn't have

receptors for estrogen, progesterone, or HER2, is known as an aggressive form of breast cancer with few treatment options. I also read that it is the most likely to recur, usually somewhere else in the body, within the first five years after diagnosis. That's some scary stuff!

The hits didn't stop with my TNBC diagnosis. I was already aware that I would need radiation because I had chosen to have a lumpectomy over a mastectomy but I had hoped to avoid chemotherapy. It was another blow to find out that due to its aggressive nature, TNBC is almost always treated with chemotherapy regardless of the size of the tumour or extent of lymph node involvement.

Given that I was 39 at the time of my diagnosis and that TNBC is often associated with a BRCA mutation, I was also referred for genetic testing. After another excruciating eight week wait, I found out that I had tested positive for a BRCA1 mutation. I burst into tears yet again when I got that news. How could this be happening? Although my mom had been diagnosed with breast cancer two years before me, there was no other family history of the disease. My thoughts turned immediately to my four daughters. Now I was not only worried about myself but my innocent children who we now know have a 50% chance of also carrying the mutation.

Not only does a BRCA1 mutation confirm hereditary risk, it also comes with the recommendation to undergo further surgery. The lumpectomy that they recommended to me at first was no longer considered enough. I would need bilateral mastectomies to protect me against another breast cancer diagnosis down the road. What's more, not only was I going to lose my breasts, but also my ovaries and fallopian tubes and I was advised to have that surgery as soon as possible. BRCA1 carriers have up to a 45% chance of getting ovarian cancer and surgery to remove the ovaries and tubes is recommended between the ages of 35 and 40 or after childbearing is complete.

A cancer diagnosis in and of itself was already a worst-case scenario. At the beginning of my cancer journey, it felt like just when things couldn't get any worse, they did. As soon as I would get over one hurdle another would present itself. What I had a hard time getting over was hoping and praying for good news and getting the opposite, what I considered the worst case-scenario. There were many times that I lost

> *“I have learned so much about cancer, but more importantly, I have learned about myself and the value of relationships.*

all hope and believed that my life was doomed. I know that things could have been a lot worse. My mom, who was doing well and showing no signs of disease at the time of my diagnosis, died at the age of 62 while I was still in treatment. I'm still here and I have a lot to be grateful for. Although the road to recovery is long, I am a survivor and one day I will thrive again.

I've made it through chemo, radiation, four surgeries, being admitted to the hospital for six days due to a post-operative infection, a clinical trial, bone scans, ultrasounds, multiple biopsies, mammograms, MRIs, CTs, and a countless number of other things that my pre-cancer self could never have fathomed. I have learned so much about cancer but more importantly I have learned about myself and the value of relationships. I have faced matters of life and death and learned to grieve and comfort others who are grieving. I have overcome what in my mind was the worst-case scenario, and I am better for it.

For those who are newly diagnosed:

Don't Google. Really. Don't do it. All it ever did was scare me and almost none of what I read actually came to be.

Don't guess or try to predict an outcome. You can't tell the future. Don't worry until there is something to worry about.

Live in the moment. Take it one day at a time. It isn't just a cliché, it actually helps.

Even your worst-case scenario can be overcome. Don't give up.

Why it's Important to be Your Own Advocate

The Merriam-Webster dictionary defines 'advocate' as a verb that means "to support or argue for". 'Self-advocacy' is defined as "the action of representing oneself or one's views or interests". While the word, advocate might make us think of protests or political signs, that is not always the case. As someone with a breast cancer diagnosis, self-advocacy and being an advocate simply means being a part of your health care team. It means knowing yourself and speaking up for yourself to make sure that your cancer care needs are met. Self-advocacy is part of participatory medicine where "patients are actively working alongside their physicians to choose the best course of cancer treatment."

You might have been told before to self-advocate when you had certain concerns about your health when it comes to breast cancer and may have wondered what that looks like exactly. Here, we outline how

to become an advocate for yourself in order to ensure your needs are being met and your input is being considered.

Know Yourself

To advocate for yourself, you must first know yourself. This means reflecting on what's most important to you, what you value, what your priorities are as you consider treatment options, knowing your body, knowing what your normal is, and paying attention to your symptoms. It is easier to know when something is off if you are in tune with your body. When something feels off, it is important to pay attention to it. Make note of any symptoms you experience, take pictures if you're able to and speak to your doctor about them as soon as possible.

Do Your Research

Part of being an advocate for yourself is also knowing as much as you can about your breast cancer diagnosis and understanding what's most important to you as you make treatment decisions. Keep a record of your reports and take notes whenever you meet your doctor or visit your cancer care centre. Make sure your notes can be easily accessed at a later day by recording dates and times.

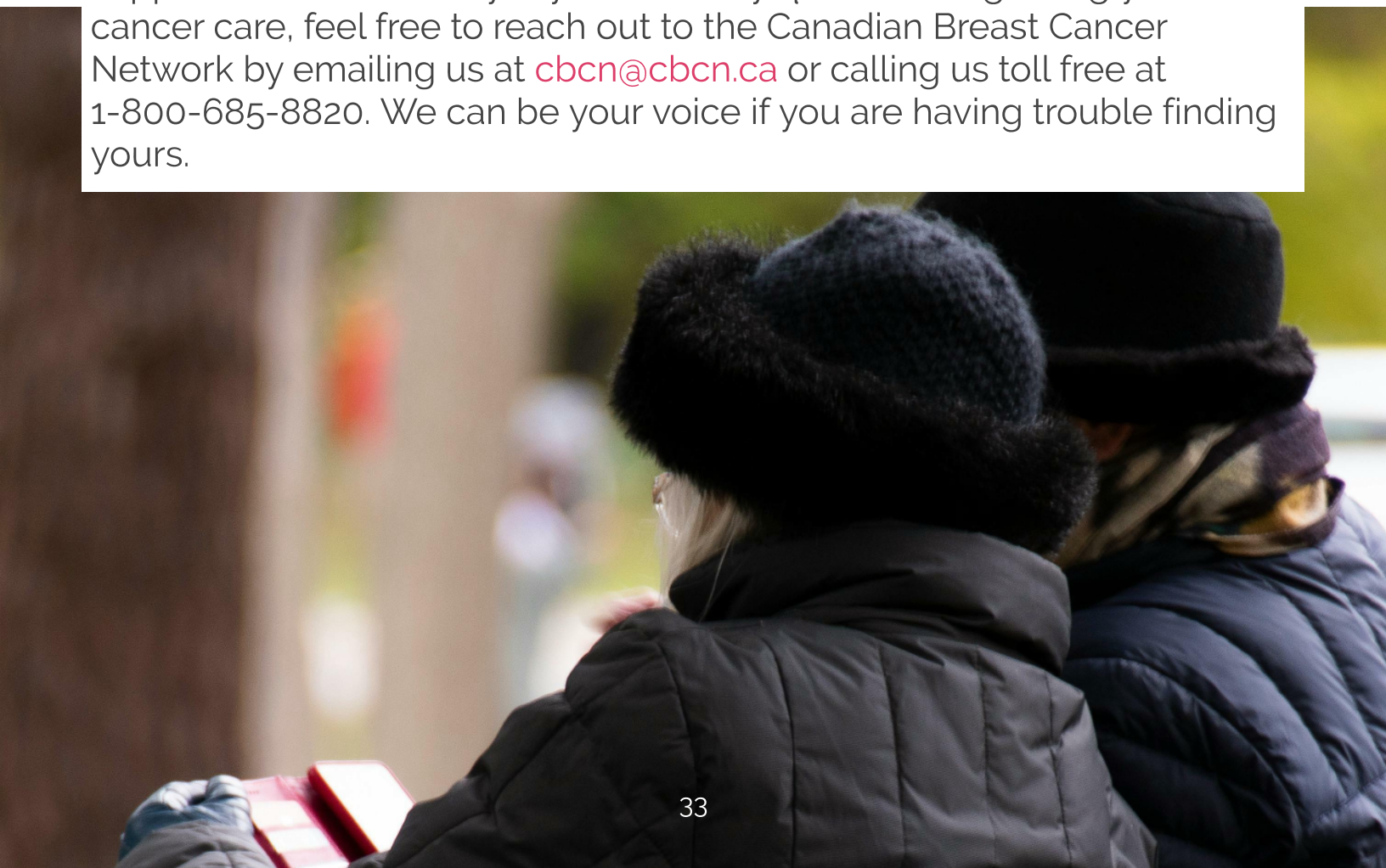
In addition to taking notes, ask your doctor questions and conduct research from credible cancer sources. If you have treatment or surgery decisions to make, it is important to find out what you can about your treatment options. Your doctor may provide you with several options so it's important for you to consider how these options, side effects and outcomes align with your priorities, values and overall goals of treatment. By doing this, you can weigh the pros and cons of each option to know what works best for you. When you are doing your research, write down any questions that come to mind and keep track of whether your research is answering them. Once you have conducted your research, any unanswered questions can be directed back to your doctor.

Outside of asking your doctor questions and doing research, speaking to other breast cancer patients can provide you with valuable information. This can be as easy as joining an online breast cancer support community, such as our Canadian Breast Cancer Patient

Network. If you go this route, keep in mind that this is simply to get more information and to know about other options that may be available to you that your doctor may not have mentioned. What worked for one person may not be the best course of action for you and the information from these communities should not be used to substitute professional medical advice.

Have a Support System

While the term self-advocacy implies advocating for yourself, by yourself, it doesn't actually mean that you have to do it by yourself. A breast cancer diagnosis is overwhelming and distressing which means that constantly taking notes of everything might sometimes be too much to do alone. Whenever possible, try to bring a friend or family member with you. They can help you take notes. They also help to provide emotional support as self-advocacy can seem draining. A support system is also vital in practicing self-advocacy if you struggle with finding your voice and speaking up for yourself. A more outspoken family member or friend can give you a voice. While an individual or a few individuals are the ideal support system, organizations can also lend support in self-advocacy. If you have any questions regarding your cancer care, feel free to reach out to the Canadian Breast Cancer Network by emailing us at cbcn@cbcn.ca or calling us toll free at 1-800-685-8820. We can be your voice if you are having trouble finding yours.



To the Girl Standing in the Blue Hospital Gown, part 3

By Robyn Goldman

Adapted from social media posts originally shared on Robyn's Instagram which were written as diary entries to herself and to her followers as she documented her experiences after being diagnosed with Triple Negative Breast Cancer at 33 years old. This is part 3.

Day 93: January 21, 2022

Alex of Glow Up Wigs helped me with a wig and gave me some extra sparkle. I am overwhelmed with emotion and gratitude. Through my tears you saw my hurt, but you managed to capture my beauty and energy. Alex, you are incredible at what you do. When I look in the mirror now, my smile is bigger. Cancer cannot take that from me. I continue to love and accept every version of myself, and you have given me confidence when I needed it the most.

I have my golden crown.

Day 104: February 1, 2022

Holy crap… I have cancer?

It doesn't seem real sometimes, and I am still in shock. Like how? Why? In my head I scroll through these questions the same way I scroll for hours on social media. I know I'll never get the answer I am looking for and even if I do, will it make a difference?

This journey has been nothing short of a challenge for me. I'm halfway done, and I have another 4 rounds to go - this time with Taxol. While I

> *I am not a statistic, and those odds don't reflect who I am.*

celebrate a milestone of completing 4 rounds of the dreaded Red Devil, the happiness is very quickly replaced by the uncertainty of what's to come.

Working on my mental health has been the hardest part of this whole thing. There are (many) times the highs are weighed down by the lows. The loneliness I feel is harder than the treatment. If I'm not careful, the fear and uncertainty will take over.

This is trauma. This isn't a choice I made, I couldn't have avoided this, but I'll be damned if I let this take over. There is still beauty, beauty I didn't see before but beauty that is so clear now.

Day 134: March 3, 2022

Today is Triple Negative Breast Cancer (TNBC) Day.

134 days ago, I was diagnosed with cancer.

134 days ago, I was diagnosed with triple negative breast cancer.

134 days ago, my life changed.

134 days ago, I went down the google rabbit hole.

Google said the odds are against me. Google said that TNBC is one of the most aggressive types of breast cancer. Google said it's one of the harder cancers to treat. Google said that it's more likely to recur. What google didn't tell me, was that I am strong, brave, and fearless. Google didn't tell me that my family, friends, coworkers, and community will be there with me every step of the way. Google didn't tell me that I'll still be sexy and flirty! Google didn't tell me that I will continue to smile and laugh and that I will get through this. I am not a statistic, and those odds don't reflect who I am. I will celebrate every treatment, scan, and follow-up like it's a milestone. I will treat everyday like it is a win. This week I have had

bloodwork, an MRI, chemotherapy (for 5.5 hours), a mammogram, and ultrasound, all to prepare me for my next milestone March 15th - my last chemo treatment.

Day 146: March 15, 2022

I did it.

I rang the bell.

This isn't over yet; I still have surgery and radiation, but I am now 1/3 of the way done.

Day 172: April 10, 2022

Science said I probably had cancer back in 2019. I didn't know. To be honest, if you would have told that girl that in a few years she'll be

diagnosed with cancer, she wouldn't have believed you either. It's been almost a month since had my last round of chemotherapy. A month of riding this high. A month of celebrating that milestone. A month free from needles and appointments. A month of reflection. A month of worry and panic because you are in a state of limbo. A month of fear; has IT started to grow back since you aren't attacking it with lethal poison? A month of anticipating what is next and wondering if we have done enough. I am crashing from my high and draining the last bit of adrenaline left in my body, running on fumes. When I am still, I can feel the fear inside of me grow. Behind my smile, I am scared. Will this feeling ever actually go away? Or will I learn to just live with it the same way I will live with the scars it will leave on my body?

Day 186: April 24, 2022

Days since last chemotherapy: 40

Days since surgery: 10

I've had cancer for over 6 months now. It's hard for me to wrap my head around how much time that is and what I've lost. How many of those days I've cried. How many days I've wished I didn't have cancer and asking myself why? How many hours I have prayed for this to be over and imagining what that will look like, wishing to be normal. Sure, my lips have spoken those words, and my eyes have cried many tears. My body hurts from the new scars that cover my breast and the pain has taken me to places I've never been. Yet, the time I have lost, I will be gifted in years. I keep reminding myself that my body is more than the canvas for my hurt; it is the home to my heart. So, I am learning to soften the painful words that my lips sometimes speak and showering my eyes with the beauty that surrounds me.

If this is what my new normal looks like, then I'm okay with that.

Canadian Breast Cancer Network
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Order Our Resources

Finding reliable information on breast cancer can be overwhelming. We have produced various reports to help you understand your breast cancer diagnosis better. These resources are available online or in print.

Order our resources today!

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