



Canadian Breast Cancer Network
Réseau canadien du cancer du sein



Living in the Now, Looking to the Future: mBC & Clinical Trials



TABLE OF CONTENTS

2

What Are Clinical Trials and Are They Right for Me?

7

The Four Stages of My Stage Four mBC

16

Metastatic Breast Cancer has Made Her a Fighter

19

Losses from mBC: Vision and Fertility

26

Debunking Common Myths About Clinical Trials

33

A Rare Triple Negative Case

36

60 To 0 In Seconds – Being A Breast Cancer Patient

What Are Clinical Trials and Are They Right for Me?



According to a [2017 study](#), less than 5% of adult cancer patients enroll in cancer clinical trials. This may be because many cancer patients are not aware of clinical trials, do not know how to enroll in them or are concerned that they are unsafe. In this article, we explain what clinical trials are to provide you with the right tools to decide whether you should enroll in a clinical trial.

What are clinical trials?

Clinical trials provide doctors with a way to closely monitor and test the best treatment, medical procedure or therapy for various diseases. These research studies improve standard of care as they can lead to newer and better ways to treat diseases with less side effects than the current treatments that are available. After a treatment is studied in preclinical trials using cells in petri dishes or animals, the next step is to study them in [clinical trials using people](#). These trials help to determine [how well a treatment works](#) in comparison to currently available treatments and if it is safe for people.

There are various ways to study the effects of a treatment, the most common ways being through

Clinical trials provide doctors with a way to closely monitor and test the best treatment, medical procedure or therapy for various diseases.

interventions and observational trials. During interventions, the treatment being studied is administered to a patient to compare its effects to treatments currently available. Patients are put in one of two groups, an experimental group or a placebo group (also called the control group), usually without knowing which group they are in. The group of patients in the experimental group receive the treatment being studied and their side effects are closely monitored by the researchers and doctors in charge of the study. The placebo group, on the other hand, does not receive the treatment but instead continues to receive the current standard of care. During observational trials, there is no administering of the treatment that is being studied, instead, patients are simply 'observed' to determine their risk factors in getting a disease.



The four phases of clinical trials

Clinical trials happen in four phases. In *Phase 1*, the treatment in question is tested on just a few people to determine its safety, associated side effects and the best dosage to use. The treatment being tested then moves unto *Phase 2* where it is tested on more people. Once again, its safety is tested, and doctors continue to try to determine the right dosage to administer and try to understand how good the treatment is at treating the disease. Following that, the treatment is generally administered to thousands of people in *Phase 3* while doctors continue to look at how effective it is and what its side effects are. *Phase 3* also includes comparing the treatment being tested to the current standard of care. Once the treatment has been approved for use, doctors and researchers identify any other risks, benefits, and other uses for the treatment in *Phase 4*.

Why should I participate in a clinical trial?

Clinical trials help to improve the standard of care by introducing more options to treat, as well as to reduce the risk of diseases. They do this by allowing doctors and researchers to test what works and helps them decide whether the benefits of a new treatment are worth the associated side effects. Since patients are monitored during clinical trials, you can be sure that any side effects that come up during the trials will be attended to right away.

Although it is not to be expected of all clinical trials, some may compensate all or part of a patient's participation. Be sure to confirm exactly what will and will not be paid for before enrolling in a clinical trial.

How can I participate in a clinical trial?

There are many ways to learn more about clinical trials that are available to you. The first step would be to speak with your doctor or healthcare provider as they may be aware of some. However, that is not the only avenue. Clinical trials take place at various places, from cancer centres to universities to hospitals. Therefore, you can reach out to these institutions to ask about possible clinical trials that you may be eligible for. In addition to this, Clinical Trials Ontario has a [website](#) that lists all clinical trials that are available in Canada. Their website pulls information from [ClinicalTrials.gov](https://clinicaltrials.gov), a database that lists clinical trials from around the world, including Canadian trials.

Since clinical trials are heavily regulated, there may be specific patient characteristics they may only be interested in at the time, so be sure to confirm that you fit all eligibility criteria.

Other resources to find clinical trials available to you include:

[OncoQuebec](#)

[Canadian Cancer Trials](#)

[It Starts With Me](#)



The Four Stages of My Stage Four mBC



by Leanne Pierce Schneider

One night in July 2015, I went to sleep, and everything was fine. When I woke up, it was obvious that everything was not fine. My left breast was swollen, inflamed and painful. I was shocked and worried, but tried not to overreact. Then I started making excuses. Maybe my period was coming. Maybe it was cellulitis. Maybe it was a clogged milk duct. Maybe it was. Maybe it. Maybe...

I was in the USA at the time, showing horses on the American Quarter Horse show circuit. I went to a walk-in clinic and the doctor I met with suggested I return to Canada and have my doctors investigate further. I was traveling in the USA without health insurance. Not being an alarmist, I could sense that this doctor thought it might be serious. I also started thinking back on my time spent in the USA that year. Compared to the previous years, this one was filled with an overwhelming fatigue. It was unlike anything I had ever experienced. And the random pains made riding difficult.

I returned to Canada and immediately went to the hospital. From there, everything happened very quickly. Within 10 days and after many tests, I was given the diagnosis of Stage 3 Triple Positive Invasive Lobular Carcinoma.

The bottom fell out of my stomach.

The bottom fell out of my world.

I remember wishing that the bottom would fall out of the floor and the hole would swallow me whole.

How could this happen to me? I had no family history of cancer. I lived a very healthy lifestyle, as an equestrian athlete. I tested negative for all genetic mutations.

What did I do wrong? Why did my body betray me? I was only 48 years old.

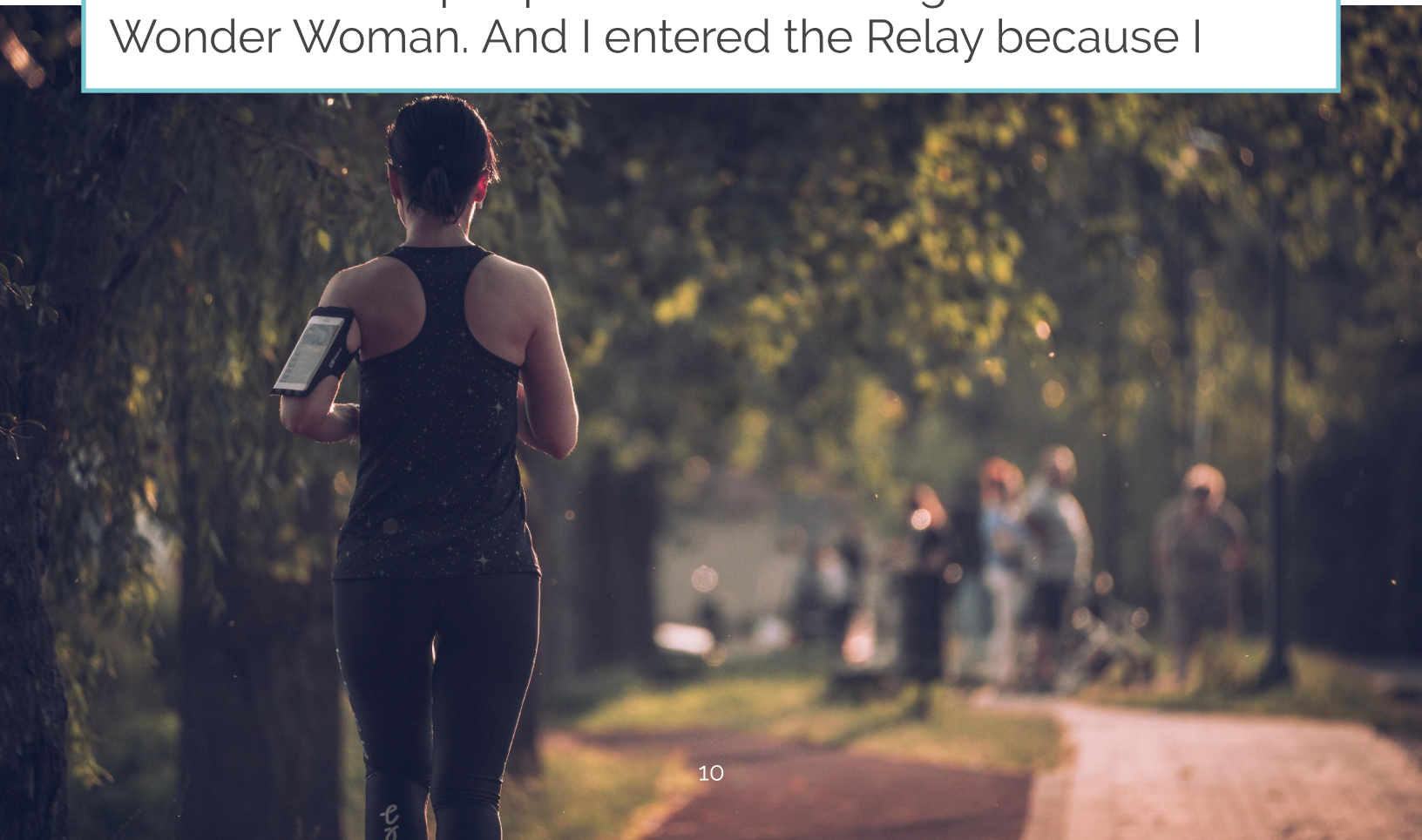
I began treatment within weeks, after initially declining all treatments. I went from being suicidal to trying to be inspirational. I looked for ways to share my experiences with others, to encourage them and be a beacon of hope. But also acknowledging that cancer is ugly, brutal and a nightmare. I acknowledged my feelings of anger, sadness, and depression.

I struggled with wanting to keep silent about my diagnosis, because I was ashamed, and I didn't want to answer questions or see the looks of pity on people's faces. But that went against my nature as an open book,

***What did I
do wrong?
Why did my
body betray
me? I was
only 48
years old.***

outgoing, heart on my sleeve type of person. And then I realized how many people I was helping by sharing my story. I was getting messages from friends and complete strangers. They were telling me that I was putting into words what they could not. That I was helping them to understand what their family members and loved ones were going through. That they were learning so much about cancer, from an insider's point of view. I used social media, writing, and face to face conversation as a way to communicate my experiences. Cards, letters, and gifts started arriving in my mailbox.

In 2016, after my completion of brutal chemotherapy and a mastectomy, that left me with lymphedema and PTSD, I entered a team, Wonder Woman and the Amazons, in our local Relay For Life. I gave my team this name because people started referring to me as Wonder Woman. And I entered the Relay because I



wanted to give back to the Canadian Cancer Society, who had done so much for me and others in this province. And then I was asked to be a guest speaker at that event. I was humbled, honoured and thrilled.

The following year, I entered my team again. This time I was invited to be the Ambassador for the event. During these events, I was labeled as a “survivor” because I had been declared cancer free on March 1, 2016.

Then on April 4, 2018, I had a massive seizure alone in my kitchen. After it was over, I managed to call 911 and an ambulance came and took me to the hospital. The doctors performed a CT scan. The cancer had returned and metastasized to my brain. My daughter, who was sitting by my side, burst into tears. I let a few tears roll down my cheeks. But the sound of her crying and the thoughts of my new infant grandson, put me in a fighting spirit. I would prepare to face this challenge with determination, strength, focus, humour, honesty... while remaining true to my original goal of helping others.

That year, I was unable to enter my team at the Relay For Life. I was undergoing radiation treatment on my brain for the current tumours, as well as for new ones

The doctors performed a CT scan. The cancer had returned and metastasized to my brain.

that kept popping up. The treatment was easy and painless, but very fatiguing. The steroids prescribed to prevent the swelling of my brain wreaked havoc with my sleep. And the tumours in my brain wreaked havoc with everything else.

Also, in February of that year, my mother was diagnosed with Stage 3 lung cancer. She died on July 4, 2018. This was devastating to our family. But after months of counseling, it made me more determined than ever.

Even though I was now considered terminal, I still wanted to spread my message of hope.

My prognosis was 2-3 years. I was told to get my affairs in order and to start checking things off my bucket list. I am happy to say that I am now entering year 5. New drugs and treatments become available all the time. I have been on many. Some of them have been easy. Some of them have been absolutely intolerable.

In 2019, I again entered my team in the Relay For Life, although in a

My prognosis was 2-3 years. I was told to get my affairs in order and to start checking things off my bucket list. I am happy to say that I am now entering year 5.

much limited capacity. And without my mother, who had been an integral part of my team. I had to sit down often. I had to rest often. I had to leave earlier than I usually did. But I participated. I showed up.

I am still here, living my life. Although I am a different version of myself. The seizures and drugs have left me with mobility issues. I have to use a cane or walker or wheelchair. I fall often. I am frequently tired and weak. I have edema in my feet, ankles, and legs. I have had fluid around my lungs and in my abdomen. Some of my fingernails have fallen off. I have "Chemo Belly". I have Cushing's Syndrome from long term steroid use. I have gained over 100 pounds from the steroids and all of the drugs I'm on. As well as the lack of activity from the fatigue, weakness, and mobility issues. I have been hospitalized for a week with cellulitis and have had two more bouts with it. I have had blood clots in both arms and both lungs. I have bone mets in my spine, ribs, leg and hip. I have had mets on my ovary. I sometimes have problems breathing. I have trouble finding my words and speaking. I am not the Grandma I pictured myself to be. A "fun" Grandma. One who is full of energy, life, laughter, activity, always up for a new adventure. One who is able to play sports and ride horses with my grandson.

That is not who I am now. But I'm so grateful to be here and watch him grow up, as well as seeing many other milestones be reached. My daughter graduated from college in 2020, with Honours, as a Continuing Care

Assistant in the field of health care. I was here to celebrate that huge achievement with her. She got married last autumn. I was here to attend and help with the wedding and walk her down the aisle. I was here to see my grandson board the bus for his first day of school. And sit with my daughter on her front porch, waiting for him to get home, eager to hear all about his first day. We can't play sports, but we can play cards and board games. I was here to witness his very first time on ice skates and playing hockey. And I was able to attend every one of his soccer practices and games with our local Tim Bits. We can't run around the park, but I can push him on the swings. And he can push me in my wheelchair. We can't go for our usual 4km walks on the walking trails, but we can go for short walks on the nature trails and look at ducks, frogs, butterflies, bugs, mosses, lichens, pine cones and all the beauty of nature.

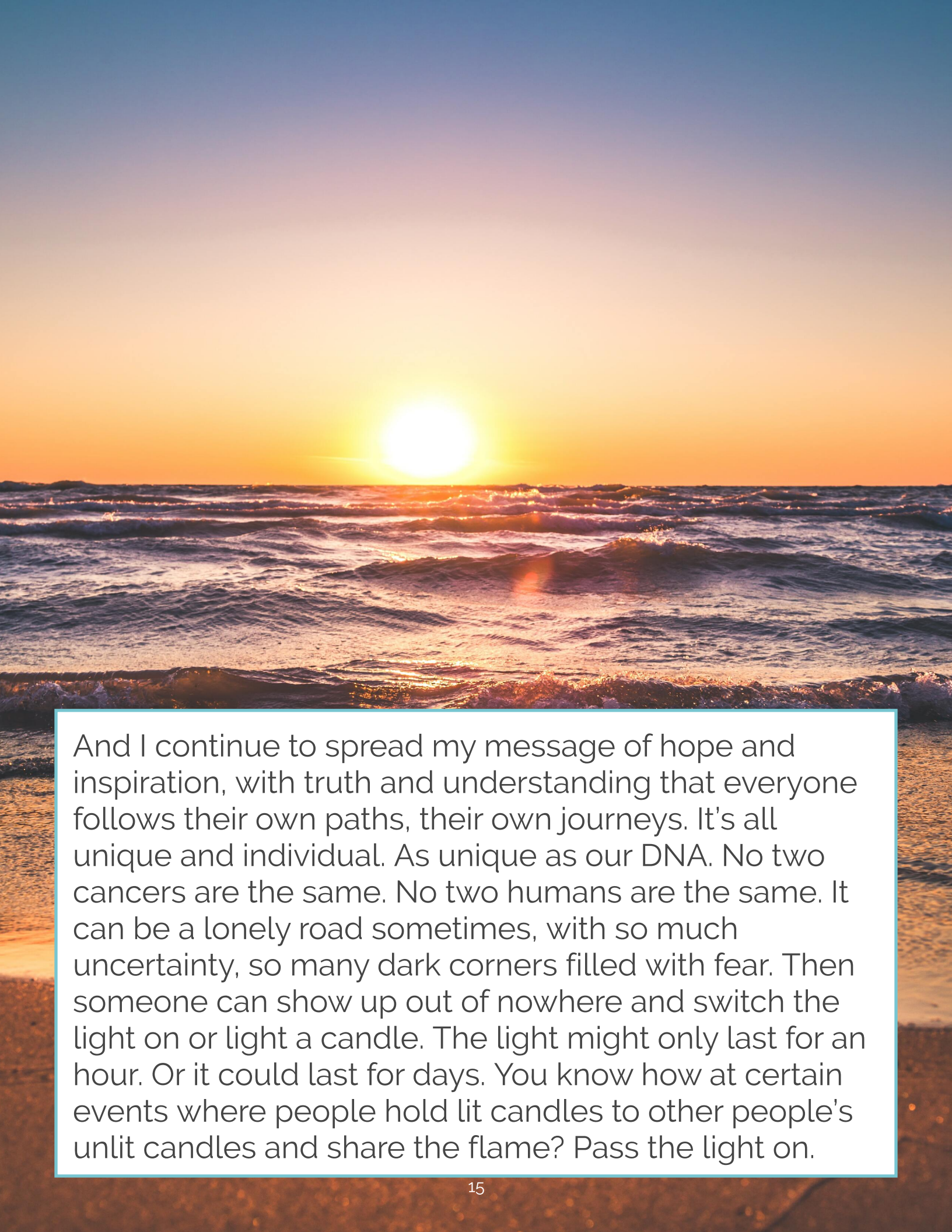
I realized after being diagnosed with Stage 4 MBC, that there are 4 stages that I've had to go through.

Acknowledgment

Acceptance

Adjustment

Adaptation



And I continue to spread my message of hope and inspiration, with truth and understanding that everyone follows their own paths, their own journeys. It's all unique and individual. As unique as our DNA. No two cancers are the same. No two humans are the same. It can be a lonely road sometimes, with so much uncertainty, so many dark corners filled with fear. Then someone can show up out of nowhere and switch the light on or light a candle. The light might only last for an hour. Or it could last for days. You know how at certain events where people hold lit candles to other people's unlit candles and share the flame? Pass the light on.



Metastatic Breast Cancer Has Made Her a Fighter

In August 2016, Erin Richard of Sydney, Nova Scotia was diagnosed with triple negative metastatic breast cancer. She was only 39 years old.

She was treated with mastectomy, radiation, and the chemotherapy drugs Adriamycin, Cytosin, and Taxol. The treatments made the tumours in her lung and lymph nodes shrink. She was then no longer receiving any kind of treatment as her condition was stable.

When Erin was diagnosed, she did not have a family doctor and had to go to the local walk-in clinic, which referred her to the Well Woman's Clinic. There, she received a mammogram and an appointment with a surgeon. It was not until May 2017 that she finally found

The oncologist encouraged Erin to stay positive and keep active. The prognosis of two to five years is only an average, and perhaps Erin could beat the odds.

a family doctor who was new to her area. "He is there for me any time even if I just want to talk," she says.

The hardest part of her cancer diagnosis was telling her 17-year-old son.

The best part was finding an extremely supportive oncologist who was always available to talk and answer questions. The oncologist encouraged Erin to stay positive and keep active. The prognosis of two to five years is only an average, and perhaps Erin could beat the odds.

Erin reached out to others for support. She managed to meet another woman with a similar age and diagnosis. She also found two Facebook groups helpful: Canadians with Metastatic Breast Cancer and Triple Negative BC Stage 4.

Cancer was hard on Erin's financial situation. She had to quit her job in fast food because it was too stressful. At first, she received Employment Insurance sickness benefits, but they only last for 15

weeks. When cleared to ease back into working, Erin was denied regular EI benefits. When her husband was laid off in December of 2016, they had to rely on credit cards and money they had been saving to buy a home. Fortunately, her husband was able to find new work, and they were able to pay their debts.

In response to these difficulties, Erin started a petition to extend EI sickness benefits to 52 weeks. She collected 1,167 signatures and delivered the petition to her Member of Parliament in September 2017.

Erin feels self-conscious about the changes in her body after a mastectomy. She hasn't had breast reconstruction, and she doesn't want to wear a prosthesis. When she buys sweaters, she makes sure they're loose-fitting.

She wishes that the public had greater awareness of metastatic breast cancer. She wants people to know that she can live well with this illness for several years.

Her greatest wish is to share in her son's achievements. "I got to make it to his high school graduation," says the proud mother. She looks forward to his accomplishments in the years to come.

Erin sees her breast cancer as giving her a vocation to help others like her. "Everything is going to be positive if I keep my faith and don't worry about tomorrow," she says.



Losses from mBC: Vision and Fertility

By Ashley Blair Doyle

Five years ago, 2017, I had what I thought would be my last CT scan at the BC Cancer Agency. I was done. I busted out of there as if I was free, even though I had a mild concern about a weird, ongoing burp and GERD symptom. I was told this was anxiety and waited for the results thinking I would graduate from the cancer world. This was the assumption from my medical team and something I thought could be true since it had been five and a half years since my early-stage diagnosis. Even though the fear of recurrence existed, I held strong like my oncologist did.

But the way back to the agency for the scan news was quick and I received this instead: "There's something in your chest. Right in the center." It happened to be a metastatic cluster of lymph nodes behind my heart, pushed against my esophagus and trachea. The explanation behind my burping symptoms. This news was a complete derailment of my life. Back to cancer treatment for life. I felt massive grief and trauma of stage 4 breast cancer defining the rest of my life.

At the time of writing this, I'm on my sixth line of treatment. It's targeting my PALB2 mutation, also known as a HRD/homologous repair deficient cells which make clustering mistakes that are messing up my brain, left ear, left orbital and vision. I'm really grateful to get what I can, while I can, despite knowing and anticipating getting whooped a bit each time. The fatigue from treatment is insane and I'm still learning how to deal with medications for the side effects and pain.

There's been so much that has happened in the last five years. A lot stolen. A lot of heartbreak, fear, weight changes, pain, and side effects from treatments. Loss of vision and forced infertility are just a few of the ways stage 4 breast cancer has drastically altered my life.

Loss of vision

Recently, my vision in my left eye started to disappear slowly (70% visible). Then only a few days later, I lost about 70-80% of my vision. I can barely see a thing on my phone if I cover my good eye. When both eyes are open, my left peripheral only somewhat works a bit while the eyelid is drooped down and the whole eyeball is shifted left. The double vision that I was having earlier in the year before my treatment hasn't been as bad, but now, it's being able to see that is the problem.

Neck down, my CT scans show that I'm stable. But my brain MRI shows cancer progression. This progression is causing damage and nerve pain around my eye, as well as ear and temple pain. I feel so incredibly sad and worried. If only both my brain and full body could be stable together. I was offered brain radiation again and took it this time; treatments were from July 25th to August 4th. There are risks, possibilities that it won't work and that it could cause permanent loss of left eye vision with a 10% risk. But I'm trying anyway.

All of it feels so unfair. But despite all the pains, progression, and loss of my ability to see fully, I am doing all I still can.

These past few days have been so stressful, difficult, upsetting, and challenging. At this time, my left eye is completely closed because of a brain met spot pushing on my orbit 3rd nerve. I wear various things to cover the eye and I try to operate with the loss of vision. But it is challenging. I can't do my gardening, I need help walking in my yard and on walks, I need help with managing pills, pain, etc. All of it feels so unfair. But despite all the pains, progression, and loss of my ability to see fully, I am doing all I still can. Even if that means spending a lot of time resting, sleeping, and taking the slowest little walks with the people who care for me so much. Thank goodness for caregivers and animal love.

Cancer-forced infertility

It was Infertility Awareness Week a few months ago and the loss of not having a baby hit hard and the grief I felt, and still feel, is huge. Yet personally, I'm not truly infertile and repeated IVF is not a thing for me.

Cancer and treatments were what got in the way of my dream to be a mum and to see Mike as a dad. I did IVF preservation of 10 embryos in 2012 as a Plan B in case chemotherapy for early-stage breast cancer rendered fertility issues. It didn't. But having an estrogen fed (ER+)

breast cancer meant standard treatment of temporarily turning off ovaries with Zoladex injections and anti-estrogen pills for five years. That meant that there was no ability to try for a baby until I was finished five years of treatment. I finally reached the five-year mark in 2017 and within a month my cycle returned fast. I was told to wait six months for the drugs to be out of my system before trying to start a family. To feel safe, I asked for a CT scan when I hit that point and discovered I was living with stage 4 cancer in my lymph nodes and lung. My plans of parenthood were instantly derailed.

After a biopsy, it was confirmed that the rogue cells were ER+ fed again; the same initial cancer I had five and a half years earlier had returned. I was completely devastated. Not just because treatments would now be for life until death, but also because becoming pregnant was no longer an option. I immediately went back to ovarian suppression on Zoladex

To feel safe, I asked for a CT scan when I hit that point and discovered I was living with stage 4 cancer in my lymph nodes and lung. My plans of parenthood were instantly derailed.


and began my first line of treatment for incurable stage 4 mBC.

No more trying for a babe. No more future pregnancy plans. No more parenting opportunity. All attempts to carry a child were taken over by having metastasis and treatments to slow it. The 10 embryos that had been cryopreserved in 2012 were preserved in a slow freeze versus a fast freeze. Even our attempt in 2018 to have a surrogate bring one of our 10 embryos to life failed. Not one of them survived the slow freeze. I often think about the fast cryogenic method we missed.

The term "Infertility" to describe my case isn't exactly accurate. I could have had a family without a diagnosis at 28; had it not returned five and a half years later, and if we had the opportunity. Our ability to try was stolen. It was cancer-forced infertility. Cancer caused our loss to even try.

Despite all this

While so much has been lost in the last five years, there's also been many good days and experiences too; great adventures, last minute trips, big YES decisions, really meaningful moments, creative projects, and impactful connections in the community. There has been hope, wishes, magic and releases. When I'm physically able, through brain mets, intense fatigue, treatment side effects, and visual struggles, I'll often make it outside in nature. For a different kind of rest. To escape. To take in all I can. Even if it's a challenge and

A photograph of a sunset over a field of tall grass. The sun is a bright, glowing orb in the center of the upper half of the image, casting a warm orange and yellow light across the sky. The grass in the foreground is dark green and slightly out of focus, with some blades catching the light. The background shows a distant horizon line under the sunset sky.

even when things feel difficult, I grasp onto life and breathe in every precious bit. So much matters, despite how much feels hard. Five years with stage 4 metastatic breast cancer and I'm still here today and holding on to being alive so hard. Holding on to all my loves, moment by moment, and every little piece that is still possible.



Debunking Common Myths About Clinical Trials

While you may be familiar with clinical trials, you may be hesitant about enrolling in one because of certain concerns that you may have. These concerns are valid, as many breast cancer patients have these same concerns. However, some of these concerns about clinical trials are ill-informed. In this article, we debunk some of the most common myths surrounding clinical trials. We hope that this will provide you with some fact-based information to make a more informed decision about whether or not clinical trials are right for you.

Myth #1: Once I begin a clinical trial I have to stay on it until the end.

Fact:

Participating in a clinical trial requires informed consent. That means that you will be given information about the treatment being studied and are kept informed during the study and once it is completed. While you must sign a consent form to indicate you are aware of the details of the study and so that you can participate in the study, you can decide to leave at any time, for any reason. Those in charge of the study will make sure that you can safely stop the study and you will then continue your regular treatment with your doctor or healthcare provider.

Myth #2: Clinical trials are a last resort for when I've run out of treatment options.

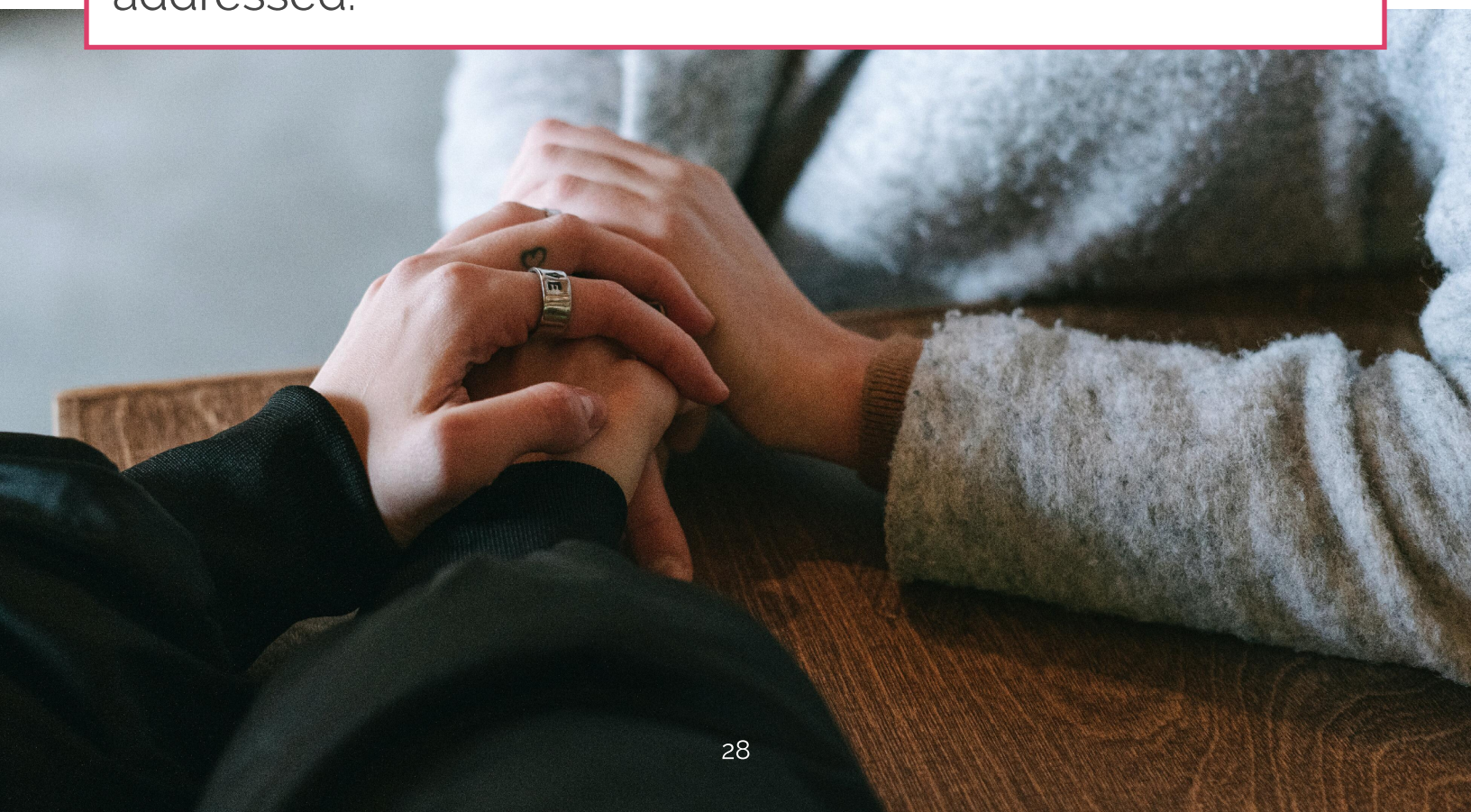
Fact:


Clinical trials are not just for those who feel like they have exhausted all other options. Instead, clinical trials can provide you with more and potentially better treatment than what is considered standard. Clinical trials also have very strict guidelines about who can participate; sometimes not receiving any other treatment is an eligibility criterion.

Myth #3: I'll be treated like a guinea pig or a lab rat.

Fact:

Clinical trials in Canada must follow strict guidelines from Health Canada to make sure that patients are protected. Treatments being tested in clinical trials also undergo a preclinical trial (which can take years) where they are tested on cells in petri dishes or on animals to determine their safety, before they are tested on people. You must also provide informed consent, meaning that you will be given information before, during and after clinical trials. In addition to this, the quality of care is sometimes better than the standard of care. This is because patients in clinical trials are closely monitored and attended to so any issues that you have will be addressed.



A person wearing a white lab coat and purple gloves is holding a clear petri dish. The dish contains a pink agar surface. The background is a blurred laboratory setting with various equipment and a sink.

Myth #4: If I'm in the placebo group I won't be receiving any treatment.

Fact:

Being in the placebo group means that you are not receiving the specific treatment that is being tested. In most clinical trials, you are randomly placed in either the placebo group, also called the control group, or the experimental group, which is the group that gets the treatment that is being tested. If you are randomly assigned to the placebo group, you will simply be given the current standard of care. That means that regardless of what group you are placed in, you will always be getting treated.

Myth #5: My doctor will tell me which clinical trial to participate in.

Fact:

There are hundreds of clinical trials authorized by Health Canada every year. Your doctor or healthcare provider may be very familiar with the trials that are offered in the centre that they work in; however, there may be trials that aren't offered in the centre that they work in that may be beneficial for you. Some patients are also able and willing to travel to other cancer centres, cities and provinces to access a clinical trial; conducting some of your own research will allow you to understand if there are other trials outside of the centre that you're currently receiving treatment at that may be beneficial for you.

You can then discuss with your healthcare team whether or not these may be beneficial and how to enroll in trials outside of your current treatment centre. You can visit [Clinical Trials Ontario](#) or [ClinicalTrials.gov](#) to search which Canadian clinical trials you may be able to participate in.

Your doctor and/or healthcare provider are there to help you make an informed decision about whether (and which) clinical trial you should participate in. This means that they cannot force you to enroll in a clinical trial nor can they stop you from enrolling in a clinical trial.

Myth #6: Participating in a clinical trial is not safe.

Fact:

While clinical trials come with a unique set of risks, as with anything else, clinical trials are safe. The treatment in question first goes through years of testing in a preclinical trial that uses non-human subjects; the treatment is only tested in clinical trials on humans when it has been deemed safe to do so. The procedure to study a new treatment on humans is regulated by Health Canada and part of this process includes passing ethical standards judged via a research and ethics board. Those conducting clinical trials must submit a protocol, which is a detailed plan of what the clinical trial will consist of. Furthermore, if the clinical trial is not going according to plan or any safety issues come up, they will stop the testing.

Researchers do not only submit documentation to the government about their study but to patients as well. Patients receive informed consent with information about the study such as how long the study should take and potential side effects. Signing the consent form indicates that you have read it, not that you will stay in the study to the end; you can stop a clinical trial whenever you want and for whatever reason. Before signing a consent form, feel free to ask questions about any concerns you may have.



Myth #7: I can't participate in a clinical trial because of the stage of my cancer

Fact:

Each clinical trial has its own list of [eligibility criteria](#). This can be based on age, family history, medical history etc. Therefore, clinical trials are available for various types and stages of breast cancer. The best way to know if there is a clinical trial for your situation is to check with your doctor and/or healthcare provider and to also conduct research on your own starting with visiting [Clinical Trials Ontario](#) or [ClinicalTrials.gov](#).

A Rare Triple Negative Case



After chemotherapy, surgery, and radiation, I went ten and a half months progression-free.

By Erin Richard

Typically Stage IV triple negative breast cancer metastasizes to the bones, lungs, liver, and brain; however, mine is not in any of my organs. Mine was only in the left breast, both axillary lymph nodes, two on the left side of my neck, as well as two spots on my chest wall near the lung.

After chemotherapy, surgery, and radiation, I went ten and a half months progression-free. In November 2017, my doctor wanted another CT scan done because he slightly heard something when I breathed in again and my tumor markers were up. When I had my first surgery

back in March 2017, he told me not to get the lymph node removed on the right side even though it had shrunk less than 1 cm from chemo because he wanted an indicator if the cancer were to come back or spread. If he felt the lymph node, then he would know something has changed.

He hadn't felt any changes to my lymph node, but when the CT scan results came back in December, it showed a growth in the lymph node. He set me up to go to Halifax in January for a PET scan that only showed a growth in that same lymph node. On January 31, 2018, he set me up with my surgeon to have the lymph node removed, which ended up being a total of 16 lymph nodes removed and three were positive.

I also found out that my original pathology had been tested again because I recurred after only ten and a half months, less than the typical two years.

I had a regional recurrence, which refers to cancer that reappears in your lymph nodes. Only 2 percent of breast cancer cases are purely a regional recurrence: one that isn't anywhere else in the breast area AND hasn't spread to other parts of your body. Very rarely,

Only 2% of breast cancer cases are purely a regional recurrence: one that isn't anywhere else in the breast area AND hasn't spread to other parts of your body.

recurring breast cancer will be found in the lymph nodes under your opposite arm, the arm on the side not previously treated.

The pathology report showed that I have two types of cancer. First it was triple negative, and now it is in my bloodstream and I have 5 percent HER2 positive. My oncologist indicated that I now needed chemotherapy because having it in my bloodstream meant that it could attach to any of my organs as quickly as days, weeks or months if not treated. Also, the 5 percent HER2 positive needed to be treated so it would not spread.

The treatment he prescribed was preventative chemotherapy with Herceptin and Perjeta. I did six rounds of the combination and now I am just on Herceptin and Perjeta indefinitely after a clear CT scan in August 2018.

I am doing great and feel well. I stay positive and active by walking every day.

Back in February 2018, I was involved in the Art of Living Program through my cancer center. In this program, I worked with an artist to help tell my cancer story through art. I was able to break my story down to a shorter, to-the-point narrative that explains my type of cancer and my experiences going through it.

Since then, I have been continuing to do paintings that I sell; with the money going to support the Cancer Patient Care Fund at my local cancer center.

60 To 0 In Seconds – Being A Breast Cancer Patient



By Bobbi Jo Beitz

I am a woman. I am active. I am a mom. I am also living with metastatic breast cancer, and I am living well.

I have been active all my life. I played a variety of sports ever since I was little, like competitive fastball and hockey. So, how could a super active, fit, and healthy individual, with no breast cancer or any other type of cancer in her family, all of a sudden be told she has stage IV breast cancer?

I first heard "you have metastatic breast cancer" on December 5, 2019. I had never even heard of metastatic breast cancer. I was scared and shocked. I asked the question no one has an answer to: "Why?" I felt like I was just given a death sentence. All I kept thinking about were my two girls – who were 15 and 11 years old at the time. I couldn't leave them! They're too young and they needed me as much as I needed them.

It all started with some numbness in my right heel. How odd! I chalked it up to years of competition and thought that maybe I was experiencing sciatica nerve issues.

I was scared and shocked. I asked the question no one has an answer to: "Why?" I felt like I was just given a death sentence.

Then the numbness crept upward into my “saddle” region. I was seeing a chiropractor at the time for some lingering back issues, so I mentioned the numbness to him. Thank goodness for his knowledge! He urged me to contact my family physician as he thought it might be a rare condition called “cauda equina.” In retrospect, I wish it had been. To add to my fear, I suddenly lost all strength in my right leg. I visited my family doctor, and she ordered an EMG (nerve test) and an MRI. After the loss of strength in my leg, those tests were now expedited. It was my family doctor that delivered the results of those tests – I had a 6.8 cm mass in my sacrum. What the heck? A mass? In me? Get it out!! Now.

I was scared, well, maybe even terrified.

That's when my dive into the medical world really began. I had an appointment for my first-ever CT scan which revealed a 2.3 cm lump in my left breast. I had breast cancer. I was scheduled for a biopsy and a mammogram. I was 49 years old at the time of diagnosis, and just weeks away from my 50th birthday. I wasn't sure if I was going to see that day.

One of the hardest parts of being diagnosed was telling my girls. I decided I was not going to hide anything from them. They were terrified, I was terrified, and I still have a hard time writing about it this without tearing up.

I am now on my fourth line of treatment. I am a veteran of CT scans and bone scans. I have had setbacks and some serious progression. I have heard the words “chance of paralysis” more than once. But I decided that I was not going to let cancer get me down. I was not

going to crawl under a rock and hide. Never! I'm not made that way. I have also had some really positive things happen to me since diagnosis: I have taken up a new sport and some new hobbies, I joined a dragon boat team made up of breast cancer survivors and thrivers, I've taken up photography and bird watching, and I've even started to learn to play the piano. I'm loving life!

Most importantly, I have shown my daughters that I am bigger than cancer. They see me going on with life and not letting cancer control me. I am teaching them about resilience in the face of fear.

My family and I have always been close and this diagnosis has brought us all even closer. I consider myself fortunate to have my amazing family. My siblings, my dad, my husband, and my daughters are with me for every appointment. We are all here for one another through good days and bad days. My oncologist has commented on my amazing support system. And while I have lost friends to this rotten disease, I have gained some new ones. My friends have become an extension of family for me; they are there with me too.

I know there will be a day when the medication stops working but I will face that day with the strength and will to live that got me through those first scary days. My family and I will face that day together.

I am Bobbi Jo. I am living with metastatic breast cancer. I love life. I am living well.

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!](#)

Subscribe to Our Newsletter

CBCN Connected is our monthly digital newsletter which gives updates on our activities, educational events, and resources. We also give updates on metastatic breast cancer with our mBC Connected newsletter.

[Subscribe to our newsletter today!](#)

Become a Supporter

No one should face breast cancer alone. Donations from you help to provide patients with a supportive community that she/he can turn to for quality information, education and support.

[Become a supporter today!](#)

Connect With Us!



[@theCBCN](#)



[@CBCNetwork](#)



[@CBCN](#)



[cbtn.ca](#)



[cbtn@cbtn.ca](#)