

## Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: pembrolizumab (Keytruda)

Indication: Pembrolizumab in combination with chemotherapy for the treatment of adult patients with locally recurrent unresectable or metastatic TNBC who have not received prior chemotherapy for metastatic disease and whose tumors express PD-L1 (CPS ≥10) as determined by a validated test.

Name of Patient Group: Rethink Breast Cancer

Author of Submission: MJ DeCoteau

### 1. About Your Patient Group

Rethink Breast Cancer (Rethink) is a Canadian charity known for making positive change. Rethink educates, empowers and advocates for system changes to improve the experience and outcomes of those with breast cancer, focusing on historically underserved groups: people diagnosed at a younger age, those with metastatic breast cancer and people systemically marginalized due to race, income or other factors. We foster spaces to connect, listen, empower and rethink breast cancer, together. Rethink's strategic priorities and organizational direction are guided by the unique, unmet needs identified by breast cancer patients and their families.

#### Programs and Activities

- Rethink Breast Cancer builds community, bringing patients with various stages of breast cancer together through our private and public social spaces as well as in-person events
- Rethink runs patient retreats and provides peer-support and professional support
- Rethink creates and runs education forums and conferences
- Rethink creates support and education tools, resources and content
- Rethink funds and supports breast cancer research

You can find out more by visiting:

[Rethink Breast Cancer Instagram](#)

[Rethink Breast Cancer Website](#)

## 2. Information Gathering

For over 20 years, Rethink has been working closely with breast cancer patients in Canada. We learn from and listen to the community to understand their values, priorities, and pain points to help drive change and system improvements. Each year, we learn from the patients with whom we serve, survey, and collaborate. We learn from the 40 individuals that we work extremely closely with as key patient advisors; the 100+ patients that share their stories on our blog; the 500+ patients that participate in our virtual support groups; the 1,600+ members of our private peer-support network; the 30,000+ people that have joined our Instagram community; and the 150,000+ individuals reached each month through the reach of that channel. We listen, learn, engage, and have conversations in all these spaces.

Rethink Breast Cancer has several important patient advisory boards and working groups that offer experience-focused insights on issues related to those affected by and concerned about breast cancer, including:

- Metastatic Breast Cancer Advisory Board
- Early Breast Cancer Advisory Board
- Equity, Diversity and Inclusion working group
- Triple Negative Breast Cancer working group (all stages)

For this submission, we have drawn on our general observations and insights gathered through programming and meetings with breast cancer patients as described above. In particular, we have drawn on our close work with our **Metastatic Breast Cancer Advisory Board** who we meet with bi-weekly.

We have also drawn on the results from an online survey with **78 metastatic breast cancer patients** conducted by Rethink Breast Cancer to document the lived experience of patients and caregivers. Patients completed the survey between September 2018 and April 2019.

Recent Zoom interviews have also informed this submission. We held a focus group with 7 patients from our **Triple Negative Breast Cancer Working Group** on March 3, 2022. We also conducted in-depth one-on-one interviews in June 2022 with two Canadian patients who are both metastatic triple negative breast cancer patients: **Jen**, who has experience with Keytruda through a clinical trial. And, **Kim**, who sadly has been unable to access Keytruda via trial because she was initially started on a CDK 4/6 inhibitor for HR responsive metastatic breast cancer before her cancer care team discovered her hormone receptor status had changed to

triple negative. This prior treatment in the metastatic setting excludes her from all trials for Keytruda. We also have drawn on notes from a meeting with **Shayla**, a 26-year-old Canadian triple negative breast cancer patient, and on-going correspondence with her. Rethink met with her via Zoom in early 2021 approximately four months after her diagnosis and corresponded with her regularly via email and Instagram private messages until her death eight months later.

**Please read testimonials from Jen and Kim in Appendix B.**

### 3. Disease Experience

Most people in the Rethink community are diagnosed at a younger age. When young people get breast cancer it may be more aggressive, which can lead to tougher treatments. In addition, those diagnosed in their 20s, 30s and early 40s face age-specific issues such as fertility or family-planning challenges, diagnosis during pregnancy, childcare, impact on relationships, body image, dating and sexuality, feeling isolated from peers, career hiatuses, and financial insecurity. The physical and emotional toll that a breast cancer diagnosis and treatment takes on a young person's life is devastating and traumatic. Of all breast cancers diagnosed in Canada, up to 15% will be triple negative breast cancer (TNBC), which is a more aggressive form, more often occurring in young people, and has a high risk of recurrence or presentation as stage IV at diagnosis.

When it comes to a diagnosis of metastatic TNBC, it commonly affects the bones, lungs, liver and brain with significant symptoms, having a devastating impact on the day-to-day life and quality of life of patients and their families. Despite this intense disease burden, the aspect of the illness we primarily see and hear about from metastatic triple negative patients is a deep desire to defy the odds and be an outlier, to live longer than the median overall survival of 12 to 14 months. Metastatic TNBC patients know their tumour lacks the three most common receptors that most game-changing metastatic breast cancer therapies target. For the most part, when we meet metastatic triple negative patients, they are angry, devastated and, sadly, gone too soon.

On November 7, 2020, Shayla shared:

*"This is the post I prayed I would never have to write. There is no right time or easy time to tell my friends and family this. I feel like I have failed both myself and everyone around me. I have received the worst imaginable diagnosis—metastatic stage 4 breast cancer. I had a routine CT*

*scan recently that show my cancer has come back and has now spread, creating multiple tumours in my lungs within just a few short months of being told “no evidence of disease.” I had no symptoms. There is no cure for my disease. I was given the prognosis based on the grim statistics that I have approximately one year to live.*

*Canada says there is little they can do for me. Even though I live where health care is “covered” and have Alberta Blue Cross with a great medical plan – the medications I need to keep me alive will not be offered by the government or my insurance. How is this right?! These medications are thousands and thousands a month, and to get the needed treatment in the States will be unimaginable numbers. Our system is so flawed and Canada is so behind with treatment approvals and options. There is so much more hope and promising treatments available in the States, right across the border.*

*I am a very proud person. I have always been independent and have worked hard for what I have. But I know I need help now, and am humbly asking you to help me fight this life-robbing disease. It has already taken so much from me...My career and the life I worked hard for, my ability to have children and have my own family, my appearance, my sanity, and now my chance to grow old. Until I die I will be forever battling this disease chasing medications and treatments.*

*I have already gone through days and days of despair, the crying, the “why me,” and now I’m angry and I want to fight. With help I will undergo treatments and trials and do whatever I have to do to help in finding a cure to kill this relentless disease.*

*I am pleading with you to help me share this, even if you can’t donate. I am not ready to die yet. I need more time.”*

Shayla died November 9, 2021, just a year and two days after sharing news of her metastatic diagnosis on Instagram.

Shayla documented her one-year experience with metastatic TNBC through vulnerable, raw posts to her Instagram. She documented the incredible physical pain she endured both from her symptoms due to the metastases to her lungs, bone and brain and due to various treatments to address them—two gamma knife radio surgeries, thoracentesis procedures for fluid on the lungs. She also shared the incredible emotional pain and trauma of her experience. Her desire to extend her life is threaded through so many of her posts.

While Shayla is one patient story, her prioritization of controlling her disease and goal of staying alive as long as possible is something we have seen and heard in the community quite often. Overwhelmingly, the most important thing, as shown in our 2018–2019 survey of 87 metastatic (MBC) patients is controlling disease and extending life expectancy. This suggests that patients value long-term health outcomes over immediate concerns like reducing symptoms or managing side effects. (See the full survey results, along with methodology in Appendix C.)

Comments from MBC patients surveyed included:

- Symptoms and shrinking the cancer is the most important thing. Living well is the next most important thing.
- Keep me alive for my kids.
- I want to live, LIVE and enjoy my life for many more years and not be so afraid

In our interview, Kim, age 38, expressed a desire to live long enough to access better treatments than current standard of care in Canada.

Kim said:

*“I know my situation is a bit different because I started out as hormone positive and I flipped to TNBC, but it was really scary because I instantly thought about lack of treatment options, more aggressive disease, and it’s really terrifying, so I think it was already very difficult to navigate going through an MBC diagnosis but then being diagnosed with TNBC is just really overwhelming. There’s so much we don’t know about TNBC and I think that’s a lot of the reason too why we’re in this spot of trying to find more treatment options...I just hope that I’ll be around long enough to be able to see those changes come down and to see stuff come to research and see it be accessible to patients across Canada.”*

In our interview, 37-year-old Jen reflected on how she felt when she got the news of her metastatic TNBC diagnosis.

Jen shared:

*“...there was this pending feeling of what’s the point if I’m going to die and who knows what the shelf life is...just being diagnosed and told something like that is horrible. Just horrible. That’s the space that I lived in for a year.”*

#### 4. Experiences With Currently Available Treatments

In Canada, people diagnosed with metastatic TNBC, have lacked effective therapies for this aggressive disease. The standard of care for metastatic TNBC has been continuing chemotherapy until disease progression. The chemotherapies are given sequentially usually with diminishing responses with each line of therapy. Although initial lines of therapy may provide a few months of progression free survival, this decreases substantially with later lines.

In general, people with MBC must face the difficult reality of living a “condensed life” and have a sense of urgency and uncertainty. Over the past 5 or 6 years, the contrast between the experiences of members of the metastatic community who are TNBC and those who have other subtypes for which there are receptor-targeted treatments, has become more jarring. Patients with metastatic TNBC continue to die quite rapidly and, like Shayla, often have a very debilitating and symptomatic death.

How well are Canadian patients with metastatic TNBC managing their illnesses with current publicly funded treatments? Not well at all. They are dying quickly. The unmet need is colossal.

A common issue the community struggles with is the financial impact of a metastatic diagnosis due to not being able to continue working. Like Shalya, both Kim and Jen, had their careers impacted by their diagnosis.

Jen said:

*“I was an actor. I worked in film in Toronto. My husband’s a film director, I produce, and I act, and we were very involved in the film community here. I also work for a film festival that I help run every year. When I got the diagnosis, I completely panicked. I always had many plates spinning, many jobs on the go, wearing a lot of hats. When I got the diagnosis, I quit everything because I didn’t know what to expect. It sounded like, for a while there, that this would be my last year and that’s a pretty tough spot to be in. I was like, well, I don’t want to work, I’ll tell you that.”*

Kim said:

*“I think a lot of people who are going through treatment like myself are having to take off of work, go on long-term disability, some people may not even have insurance where they’re still*

*making a substantial wage at all, so to put a financial barrier in place for people who are trying to access life-saving treatments is just disappointing to think there's people out there who can't access this because they can't afford it. I fear that myself with other treatments too, am I going to be able to afford it if the province doesn't cover it? Is my lifespan going to be shorter because I can't access a potential treatment that could extend my life further?"*

## 5. Improved Outcomes

Each individual patient brings their own personal values and goals to their discussions with their oncology team. Communication and trust in their team is essential.

The growing gap in outcomes between metastatic TNBC patients and those of other subtypes has led to an amplification on-line by the TNBC patient community on the need for better, more effective treatments. Moreover, with new treatments for metastatic TNBC on the horizon, we experienced a spike in outreach from Canadian patients last year trying to access new treatments for metastatic TNBC such as Trodelvy and Keytruda. The primary improvement they were seeking in these desperate, urgent calls and emails was to extend life beyond the prognosis they faced given the treatments available to them in Canada at the time.

We asked Jen about her decision making regarding choosing to access Keytruda through a clinical trial:

*"I didn't know anything about clinical trials, or what standard of care meant. But after a bit of research, it seemed like the clinical trial was the way to go...One of my biggest fears was that Keytruda would attack another one of my organs. Because that seems to be a common-ish side effect with this drug and so that did end up happening in my case, but it attacked my thyroid and I've been told that if it's going to attack anything, the thyroid is the most correctable one for it to go for. My clinical trial nurse was amazing and was able to figure it out based off my side effects really quickly. I just thought I was feeling especially tired because I just started treatment. It was pretty early on. She was like, no, that's your thyroid, we're going to get you a thyroid doctor. They confirmed it was thyroid. So, I've been on thyroid medication, and it really levelled me out I was really closely monitored. I do have to take a little pill every day now likely forever which is weird, but a lot of people have thyroid issues, and I don't have any problems with it now so. That was one thing."*

While a dire prognosis of a year to live may be the reason metastatic triple negative patients prioritize life extension even against difficult side effects of treatment, this type of trade-off is something that we see in the broader MBC community. In our experience working closely with many young and metastatic people, they want new treatments that will extend their lives. “More time” is always a loudly expressed want and need. They also want stable scans showing disease stability. They want hope. The goal is to always have one more tool in the toolbox so that if there is progression, there is another effective treatment option. In terms of what is effective, they want a decent quality of life but are willing to make trade-offs and accept side-effects from treatment to control the cancer.

As mentioned earlier, in our 2018-19 survey of 87 metastatic patients, we found that long-term health outcomes like controlling disease progression and extending life expectancy are considered more important than short-term outcomes like managing side effects and controlling symptoms. Patients were broadly willing to tolerate side effects for health benefits and overall, they were willing to tolerate new side effects from drugs that can control disease progression or prevent recurrence. (See the complete survey results and methodology in Appendix C).

It should be noted a number of respondents indicated this tolerance was not absolute - there was a limit to how much they could take. Some of the comments include:

- *I will take on the most shitty things this disease can through at me.....until I am ready to go. I love my life.*
- *I'll try so long as I can remain mobile and find joy in things.*

## 6. Experience With Drug Under Review

We felt fortunate to connect with and conduct an in-depth interview with Jen, a Canadian patient currently accessing Keytruda through a trial in Toronto.

Jen shared:

*“I was diagnosed when I was 37 in February of 2021 after having a lump in my breast that I had found the previous spring and had gone to get it checked out a couple of times, and my doctor at the time said it was something hormonal and it would go away. I don’t have history of breast*

*cancer in my family. Breast cancer wasn't anything close to my radar, so I kept waiting for it to go away. And it didn't by the fall so I ended up getting. Follow ups because of covid things were very slow and I was in another province for work actually when finally, I said ok it's time for me to really look into this because it's getting bigger and I'm starting to get freaked out about it. Still, cancer was not on my radar.*

*Fast forward a couple whirlwind appointments and a quick biopsy and I finally met the right doctor who was willing to give it to me. Even at that biopsy appointment they all said it's probably not, don't freak out. And then 2 weeks later I was pretty floored to find out I had cancer. And I was pretty floored 4 days later to find out it had metastasized to my lungs and possible spot on my sternum. So that was pretty horrifying, and to be in another province as well. Luckily, I was with my husband, and he was able to come with me to my appointments. I don't even really remember, it's kind of like a big black hole."*

*Clinical Trial Access for Keytruda:*

*"We quickly realized we needed to get back to Toronto and set up shop at PMH, where I was admitted and met with my oncologist and pretty instantly given the option of this clinical trial that I'm currently in....I didn't start treatment until 5 weeks after that because it's a lengthy process to meet the criteria for the trial, but my oncologists were confident from the beginning that I matched all the criteria. It was the longest 5 weeks of my life. My breast tumor at that time was measuring at almost 11cm. Within my first treatments it reduced in size by half. Within 6 months it was not traceable on scans whatsoever."*

*Response to Keytruda:*

*"So, I've been on this clinical trial now, Keytruda, it's a study that matched Keytruda with chemotherapy. So, I've been on 2 different kinds of chemo during this trial. I'm just over a year on the trial. I'm doing immunotherapy every 3 weeks and I do a small dose of carboplatin chemotherapy alongside that....As per some recent scans, what is still in my lungs they're not sure if it's just scarring from the disease, but there's been no progression whatsoever and the spot on my sternum is likely benign because it hasn't moved or done anything since my initial bone scan. So, I'm feeling like I'm really, really, really lucky and really hoping that things stay this way. I'm told the immunotherapy, because I've been responsive this long, it's showing it's doing its job and will keep the disease asleep for a very long time."*

Return to work:

*“Probably since the summertime I’ve been slowly peppering some of the work that I love to do back in which has been really nice because cancer as a full-time job is a lot mentally. I do a lot of production coordinating for film, and I was doing that from home right before I got diagnosed so one of the jobs that I was working on hired me back to do just some really mundane paperwork during this summer when they knew I was feeling a bit better. I was so excited to do the boring mundane stuff that I used to hate. I just wanted to be able to do anything else but think about when my next appointment and scan is. Since then, I went back to work for the film festival, I am a big part of that this year and I’m currently developing my own little TV show for Bell Fibe TV 1 that I plan on shooting this coming summer because I’m feeling great, and it was a project that I had to put down right after my diagnosis and something I wanted to do.”*

Finding a new normal and feeling hope:

*“I feel like I’m getting back into Jen 2.0 doing the things I really love to do versus everything all the time because I need to make all the money and please all the people. At least now my treatments are in a pretty regular routine so it’s just being able to work stuff around all of that and I kind of have a pretty good idea of how I’ll feel afterwards so I just don’t book anything for a day or two after that, and then I just go on with my life until the next appointment. The mental space I live in now versus a year ago is such a huge difference. I’m so grateful to somewhat be on the other side of that and just thankful. Living presently, but also being able to plan again is really nice.”*

## 7. Companion Diagnostic Test

It is essential that metastatic patients in Canada have immediate access to all the tests needed to determine the best treatment path. As mentioned earlier, lack of timely tumour testing has impacted Kim’s treatment options as a metastatic TNBC patient.

Kim explained:

*“It’s challenging when you do flip [from HR+ to TNBC] because they say it’s offered as a first-line treatment, but they don’t break it down to a first-line treatment per subtype or a first-line treatment for an MBC diagnosis in general. I think it’s a really unfair position to be in when*

*someone does flip like that because if I would have had the opportunity to have a biopsy from the get-go, it could have opened a lot more doors for treatment options so it's definitely a frustration that they don't take into account those unique situations where someone does flip. It should still be considered a first-line treatment in that specific subtype."*

Due to challenges with her liver biopsy, Kim was not accurately categorized as Triple Negative until several months after her metastatic diagnosis. She then faced an additional delay in determining her PD-L1 status, further testing which she advocated for herself.

*"When I had my biopsy done, it was tested automatically for the standard ER, PR, HER2 biomarkers but it wasn't until I found out it had flipped to triple negative that my oncologist requested the additional PDL1 testing after I pushed for it. This took an additional two weeks which delayed treatment options further. My understanding in talking to others is that the PD-L1 testing is not something that's covered everywhere in Canada."*

It will be important that testing for PD-L1 happen automatically and quickly as, unlike Kim, most patients processing the devastating news about their diagnosis, would not know to ask about it nor should the burden of asking and advocating for these tests be placed on patients.

We asked Jen what she knew about the types of tests she had done to determine her eligibility for accessing Keytruda.

Jen shared:

*"I've only just learned about PD-L1 scores as it suddenly keeps popping up in conversations about immunotherapy and I have been thinking, hey, how come I never heard about this before? All that was communicated to me when I was waiting to find out about the trial was that I was likely a good candidate, but I had to do a second biopsy (my first was conducted at another hospital) and wait to hear if I was accepted based on those results being sent to the study team, which took about five weeks. No one told me what I was being tested for, I just knew that I really wanted to qualify as fast as possible. The only effects associated with the testing was extreme anxiety and panic while I tried to stay patient. Luckily it ended up worth the wait for me, but that time period where I could feel the cancer growing and I just had to wait and wish were the most sleepless nights I've had since my diagnosis."*

## 8. Anything Else?

As we ponder “anything else,” we are struck by the juxtaposition of the three patients we particularly highlighted in this submission:

Shayla, diagnosed with metastatic TNBC in November 2020 in Edmonton. With only access to standard of care in Canada, she raised funds to pay for treatment in the US but sadly chose to pay out of pocket for Tecentriq, an immunotherapy that has since had its indication removed for breast cancer. Her debilitating and symptomatic year from the time of her metastatic diagnosis to death highlights what has been a common experience for young, triple negative breast cancer patients.

Kim, diagnosed with metastatic breast cancer in March 2021 but not identified as TNBC until many months later after a CDK 4/6 inhibitor failed to control her cancer. She is hoping to live long enough to access a new, innovative TNBC treatment; yet is struggling to remain hopeful about her outcomes. She is frustrated that her treatment with a CDK 4/6 inhibitor excludes her from accessing Keytruda as a first line treatment for metastatic TNBC. Her story highlights the importance of immediate biomarker retesting of metastatic tumours to ensure the patients receive the right treatment at the right time.

Jen, diagnosed with metastatic TNBC in Toronto in 2020 and able to access Keytruda through a clinical trial. She has returned to work and is feeling hopeful. Even thriving. Her story highlights what is possible when an innovative new treatment like Keytruda is made immediately accessible to metastatic triple negative patients who qualify for it.

Keytruda as an option for Canadian patients with metastatic triple-negative, PD-L1-positive breast cancer gives them what they have been asking for: to live longer and with disease stability that enables them to get out and live.

**We ask for a few more minutes of your time to read the truly powerful patient testimonials, which are included as Appendix B.**

## Appendix A: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH reimbursement review process, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.  
  
No.
  
2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.  
  
No.
  
3. List any companies or organizations that have provided your group with financial payment over the past 2 years AND who may have direct or indirect interest in the drug under review.

### Table 1: Financial Disclosures

Check Appropriate Dollar Range With an X. Add additional rows if necessary.

Company	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Merck (2021)			X	

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

**Name:** MJ DeCoteau

**Position:** Founder and Executive Director

**Patient Group:** Rethink Breast Cancer

**Date:** July 14, 2022

## Appendix B: Patient Profiles

Jen Pogue's profile:

In June of 2020 I discovered a strange lump in my breast.

The next 8 months of medical check-ins, misdiagnoses and dismissals ultimately led to the blow that was February 2021. After months of hearing, "Don't worry, it will go away, it's just hormone related," and, "You're too young, no cancer in your immediate family so don't sweat," to eventually, "You should do a biopsy just to rule out cancer," to the worst possible words I could hear: the mysterious lump was du novo stage 4 triple metastatic negative breast cancer (MTNBC) that had metastasized to my lung and sternum. Not only did I have one of the most aggressive types of cancer, it had already spread to my organs and spine.

I had recently turned 37, in the prime of my life, shortly after my second wedding anniversary with my amazing husband and the midst of trying to start our future family. And even in the middle of the pandemic, I was at the height of my career in the film and television industry, juggling multiple projects that I loved. I had no previous health conditions or qualms. I was, by all accounts, happy.

February 2021 changed all of that.

The weight of this shocking diagnosis completely knocked me off my feet. It turned my life upside down. As I learned more about breast cancer and what this kind of staging meant, it got even worse. Surgery and radiation were not on the table since it had already spread. Hormone therapy doesn't

apply to triple negative breast cancer since it won't respond. The very nature of MTNBC made the small lump aggressively grow to more than 11 centimeters in such a short time span. "The size of a baseball," as my husband put it. This was the very real weight and metaphorical heaviness that I carried.



My healthcare team said standard of care for stage 4 MTNBC was chemotherapy, but realistically it was just to slow the spread and would never fully stop it. Each chemo treatment has a shelf life of time until cancer will learn to work through it. Maybe 2-5 years of response for the most fortunate. I don't really know how one reacts to hearing you likely have 2-5 years left to live, that statement is so surreal. Every Google search, every blog post, every breast cancer survivor I reached out to for advice confirmed what I could not fathom: stage 4 MTNBC has no cure, just the faint hope that medicine can slow it down, through a barrage of quality-of-life compromising treatments, praying to get the maximum amount of time from each chemo course as you can.

**Living your life in this kind of existential dread is not living. Not knowing your un-confirmed departure date, but knowing you've already purchased a ticket is the most harrowing way to live. It is navigating a tornado of desperation, hysteria, grief, fear, resentment, and daily depression, all while grasping at straws of hope you can never really get a grip on. You mourn the loss of tomorrows and are incessantly plagued by the dark cloud of inevitability.**

I immediately left my jobs and unloaded all responsibilities I carried so I could focus on this one thing: to get better against all odds. In this, I acknowledge that I am in a privileged position of being a white cis-female with a loving family and supportive friends. I know not everyone has this economic privilege, and their MTNBC journey is even more difficult. This is why hope needs to be for everyone, but in cancer, it is so elusive and fleeting.

I began mourning my dreams for family planning and so much more. My loved ones and I started preparing for what now would likely be my so-called, short-term future, one that revolved around constant sickness and impeding frailness until the inevitable end... Until the very slight glimmer of hope that I desperately sought, showed itself.

In a miracle of timing, I was accepted into a clinical trial at Princess Margaret Cancer Centre



that studies that combination of chemotherapy (carboplatin and gemcitabine) + pembrolizumab (Keytruda) immunotherapy, which are intervened together on a regular schedule. As I came to learn, the goal of this study is for the less-harsh-on-your-body Keytruda to teach my immune system to fight new cancer cells on its own. A treatment so new that there are no survival rate statistics, but there are several patients who have gone through Keytruda trials and have been off any treatment entirely for a few years now, the nurses assured me. I cannot explain the kind of game-changing information this was to me; it changed EVERYTHING. Just knowing that the possibility of a treatment-free future was there again, no matter how long it was going to take, no matter the effects, was the fuel I needed to grin and bear, suit up and get to work at it.

**When I finally started the clinical trial course in April 2021, the results from Keytruda were almost immediate: my then 11 cm primary breast tumor immediately shrunk 50% of what it was. Within 6 months, my CT scans could not trace the primary tumor whatsoever, and my lymph nodes and lung lesions had shrunk to practically nothing and stabilized. I was**

**eventually told that my spine lesions had likely become benign, and the scans were just picking up the scarring. These results revitalized me. I slowly felt human again, after months of being a pincushion.**

I'm now 16 months into the trial that will continue until September 2023, and the disease has stayed asleep and in ironic medical terms, *unremarkable*. My amazing team at Princess Margaret make no promises, but have stated, "This is the best possible response you could have hoped for." I'm far from my treatment-free goal, but the relief of having little to no side effects makes this prolonged process completely manageable. And there's that word again: I feel *hopeful*.

When I was originally diagnosed, my oncologist told me there was nothing I did to cause this, that I was just "lucky." I certainly didn't feel lucky to have been blindsided with a sudden disease this extreme, but luck showed itself with the opportunity for Keytruda. I now know how fortunate I am to have had access to this trial treatment exactly right when I needed it and have it as my first line of treatment before the trial doors shut. Lucky to have responded as rapidly as I did. Lucky to now sit in routine oncology appointments where we talk about my future and my options, rather than the prominent doom and gloom of early 2021. Lucky to remain relatively healthy and mentally strong as Keytruda has allowed me to bounce back to my pre-cancer days of running, biking, hiking, hosting friends, staying mentally engaged in my work, and much more. Lucky that Keytruda allowed me to move around my world with the same healthy appearance, rather than coping with extreme hair-loss or neuropathy or other adverse-chemo related side effects I hear about from many others. Beyond lucky to be back to some normalcy, having my working and everyday life scheduled around my treatments, rather than finalizing my goodbyes. Keytruda has been clinically, emotionally, physically transformative for me. And I feel this could be true for others too.



As one of the rarer forms of breast cancer, the MTNBC community is small, but has a mighty voice and presence. Through support organizations such as Rethink, online forums, and social media, I have connected to so many others at varying degrees of treatments who share very openly and honestly. As far as I've found, I am the only one I know who has access to

Keytruda in Canada, and has their sights set on a treatment-free future. I am both lucky and hopeful, when so many aren't either. While I personally and privately celebrate my wins, it's devastating to witness my MTNBC friends suffer through one ineffective chemo treatment to the next, while knowing first-hand that there's a Keytruda immunotherapy treatment that exists that could literally change their lives.

Hope should not be tied with how lucky you are.

In Canada, this "Universal Hope" should be accessible to all. And in the form of Keytruda immunotherapy as standard of care, this would give the metastatic triple negative breast cancer community the *hope* it deserves.

Jen Pogue

## Kim Angell's profile

My name is Kim Angell and I am a metastatic breast cancer thriver, patient advocate and avid hiker from Vancouver Island, BC. I was originally diagnosed with stage 2 hormone positive breast cancer in 2016 and was nearing the 5-year mark when my life came crashing down. On March 12, 2021, I found out the cancer had returned as metastatic with multiple lesions scattered through my spine, hips and ribs. I was young, healthy, and felt like I was just starting to put the thoughts of cancer behind me. Yet, suddenly I was now having to face my own mortality at just 38 years old.

My life quickly changed from being focused on advancing my career to focusing on keeping myself alive. I suddenly found myself entrenched in the world of MBC, educating myself on the disease, what treatments were available, finding connections and stories of hope from others while also being faced with the harsh reality as I watched this disease take their lives.



I was quickly thrown back into the life of a cancer patient, this time as a forever patient, and was put on what was considered to be the latest and greatest treatment for hormone receptor positive disease. I was encouraged by the advances in research and the fact that others like me were living with this disease for over 5+ years. A bittersweet glimmer of hope in the grand scheme of things.

As I went through a series of scans though following my diagnosis, I found out that the cancer wasn't just confined to the bones, it had now spread to my liver as well. I advocated to have a liver biopsy done to determine if the cancer was still hormone positive even though I was told that it was rare to lose receptors. After an unsuccessful biopsy attempt and more progression in my liver, they went in a second time and were able to finally get the sample they needed.

My stomach dropped as I read the pathology report – the cancer had lost all hormone expression and I had now flipped to triple negative disease with a much poorer prognosis. **It's already hard enough going through this disease knowing the average median survival for MBC patients but knowing that I now had triple negative disease felt like an immediate death sentence. It's not only a more aggressive breast cancer subtype, but it also meant I no longer had access to targeted therapies such as CDK4/6 inhibitors and hormone therapies. My only option at this point was chemotherapy.**

Chemotherapy would kill the rapidly dividing cancer cells, but also kill other healthy cells. It brings side effects like the trauma of losing my hair, dealing with chronic skin and nail infections, and struggling to absorb any nutrients due to the lining of my gut being damaged from treatment – chemotherapy is not the option that gives me the best quality of life. All of this added to an already traumatic experience.



So, I tried desperately to get on a clinical trial but faced a series of roadblocks. Since I had been previously treated for MBC, I was excluded from numerous trials despite having a completely different subtype. I lost hope as the doors kept closing on me, feeling like I was being excluded from access to potentially life extending medications because of my own unique situation with MBC.

I began running out of time. The cancer was progressing rapidly in my liver and I risked it spreading elsewhere in my body being off treatment for weeks but what felt like an eternity. I ultimately had to accept the fact that I could not access these same treatments that others had access to in neighbouring countries due to the length of time that it was taking to be approved through our medical system and due to the restricting nature of the inclusion/exclusion criteria of these trials.

I often wonder if I had access to immunotherapy, if it would have provided another treatment option and extended my overall survival. Worrying with the limited amount of treatment options for MTNBC, that I will run out of treatment options one day. That my team will have to face me one day and tell me that they've done all they can do but there's nothing else available. It's a devastating reality knowing that I still have so much fight in me left but that I could reach the end one day because there was one less option to give me more time.

Kim Angell

## Appendix C: MBC Patient Survey Results

Information for this report was gathered through an online survey published in English and circulated through communications from Rethink Breast Cancer as well as the Rethink Network and other partner organizations. Messages were also posted on Facebook and Twitter as well as the Breastcancer.org, Cancer Connection and Cancer Survivors Network online discussion forums. 78 metastatic breast patients completed the survey between September 2018 and April 2019.

An independent contractor was hired to develop this survey and present the results. Survey questions were all reviewed by Rethink staff and Metastatic Patient Advisory Board prior to being posted online.

Rethink Breast Cancer asked respondents to evaluate the importance of different outcomes for their breast cancer treatment on a scale of 1 (not important) to 5 (very important). All the listed outcomes were considered important with no average scores lower than 4.4. However, controlling disease and extending life expectancy were rated as the most important results suggesting that patient values prioritize long-term health outcomes over immediate concerns like reducing symptoms or managing side effects.

Importance of outcome	1 - not important	2	3	4	5 - very important	Average
Controlling disease progression	0.00% 0	0.00% 0	0.00% 0	2.60% 2	97.40% 75	4.97 77
Reducing symptoms	1.30% 1	0.00% 0	12.99% 10	19.48% 15	66.23% 51	4.49 77
Maintaining quality of life	0.00% 0	0.00% 0	1.30% 1	12.99% 10	85.71% 66	4.84 77
Managing side effects	1.30% 1	1.30% 1	12.99% 10	19.48% 15	64.94% 50	4.45 77
Achieving NED (no evidence of disease)	1.32% 1	1.32% 1	1.32% 1	6.58% 5	89.47% 68	4.82 76
Extending life expectancy	0.00% 0	0.00% 0	0.00% 0	2.63% 2	97.37% 74	4.97 76

Comments included:

- Symptoms and shrinking the cancer is the most important thing. Living well is the next most important thing.
- Keep me alive for my kids.
- I want to live, LIVE and enjoy my life for many more years and not be so afraid.

When asked if they would be willing to tolerate new side effects from drugs that can control disease progression or prevent recurrence on a scale of 1 (will not tolerate side effects) to 10 (will tolerate significant side effects), respondents gave an average score of 7.5 (n=78) with only four respondents giving a score lower than 5. When asked the same question about new drugs that could prolong life expectancy, the average score was 7.7 (n=77) with only five respondents giving a score below 5. These results would support the conclusion that patient values prioritize long-term health outcomes.

However, it should be noted that a number of respondents indicated that this tolerance was not absolute - there was a limit to how much they could take. Some of the comments include:

- I will take on the most shitty things this disease can through at me.....until I am ready to go. I love my life .
- I'll try so long as I can remain mobile and find joy in things.
- I can tolerate side effects but I need it to be tolerable.
- If it means a longer, better life I would be willing.