

## Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: trastuzumab deruxtecan (Enhertu)

Indication: Anticipated indication is as monotherapy for the treatment of adult patients with unresectable or metastatic HER2-low (IHC 1+ or IHC 2+/ISH-) breast cancer who have received a prior chemotherapy in the metastatic setting or developed disease recurrence during or within 6 months of completing adjuvant chemotherapy. Patients with HR+ breast cancer should additionally have received or be ineligible for endocrine therapy.

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 all stages of breast cancer together through our private and public social spaces, as well as in-person events
- Rethink runs patient retreats and facilitates peer-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. 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 that channel. We listen, learn, and engage 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

Rethink also benefits from regular knowledge exchange with our Scientific Advisory Committee, which includes some of the leading clinician scientists in Canada who treat breast cancer.

For this submission, we have drawn on our general observations and insights gathered through programming and meetings with breast cancer patients as described above. 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.

In addition, we drew on recent in-depth one-on-one interviews in November 2022 with three Canadians who have HER2-low metastatic breast cancer: **Kelly**, who is currently being treated with Enhertu through a clinical trial, **Diane**, who is currently paying out of pocket for Enhertu, and **Rosilene**, who is HER2-low and having had progression in January after three years on endocrine therapy and a CDK 4/6 inhibitor, hopes Enhertu will be an option in the future. We also interviewed **Mary**, a woman living in the United Kingdom whose access to Enhertu came through a clinical trial.

**Please read testimonials from Diane and Kelly 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 who don't have cancer, 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.

In terms of a metastatic diagnosis, processing the reality of a life-limiting diagnosis is extremely difficult, especially for the young patients in our community and the emotional impacts on quality of life cannot be understated. Moreover, many develop brain metastasis, which is difficult to treat and has a heavy symptom burden with both physical impacts and often changes in mood, personality and thinking. These cognitive and psychosocial challenges negatively impact both the patients and their caregivers who often take on an overwhelming number of responsibilities. Other symptoms of metastatic breast cancer depend on the sites of the metastasis and include fatigue, shortness of breath for lung metastasis, pain and bone fractures for bone mets, as well as nausea, headache and of course challenges doing normal daily activity. Rethink's MBC Advisory Board strongly believes in the benefit of metastatic patients accessing palliative/supportive care services early to help address these symptoms.

The HER2-low metastatic breast cancer patients we interviewed shared the different ways their metastatic diagnosis has impacted their day-to-day life:

**Kelly** is 54 years, married and stepmother to two young adult children.

Before her metastatic diagnosis, Kelly was a marathon runner, socially active and worked full time and was a part-time university student. It was always a life dream of hers to get a university degree and just before her early breast cancer diagnosis, she had enrolled as a part-time student in disabilities studies. She was loving it so much that she set her sights on a master's degree. Kelly and her husband used to love going out for dinners and socializing with friends, but she now finds socializing more difficult because sometimes just focusing during the conversations is too draining. She walks to stay as active as she can but is no longer running. And due to the fatigue from treatments for her metastatic breast cancer, Kelly had to stop working. For her, that has been "A big, big, big change. I feel like the psychology of it is...I feel very isolated sometimes at home during the day. I really miss the social component of work." Unfortunately, fatigue from treatment made it too difficult to concentrate and focus on her university course work and paused her studies in 2021. In 2022, she had to accept the reality that she would not be able to resume her studies and made the difficult decision to formally withdraw from her program.

**Diane** is 47 and has been married to her high-school sweetheart for 20 years. Diane is an only child, and she is primary caregiver to her parents who are in their mid-eighties with health problems.

Diane had returned to work after a medical leave for treatment of her early breast cancer. She was ramping up slowly and had just started working full-time hours again, when she found out she was metastatic. She left her job because "It's like my full-time job became being a patient....your life just stops as you know it." For Diane, the diagnosis brought on "depression and anxiety... just this feeling of dread and anxiety, but I just hid from...from everyone. I would always just try to kind of put on this brave face." A big part of how a metastatic diagnosis has impacted Diane is "feeling guilty about things and being a burden on people." She discussed feeling guilt about causing her husband too much worry and stress and talked at length about the worries she has for her aging parents. As an only child and primary (sole) caregiver to her parents, Diane says, "I just felt like it was too much to tell them...after the first diagnosis, they were, you know, just totally shocked and it was just tears every time I would talk to my mom. And this went on and on and then December, the second diagnosis. I mean, I had to tell them because I was having this big surgery, but I couldn't...I couldn't then say 'Oh, and by the way it's also spread to my bones.'"

Like Kelly, Diane talked a lot about the physical and emotional isolation of her illness. She is home alone much of the time, which is a change from her lifestyle before her metastatic diagnosis when she worked and enjoyed dinners out and travelling with her husband and their friends. She would love to get a dog as a companion, but her worries and uncertainties about her future are roadblocks to getting a puppy. There's an emotional component to her isolation too caused both by the disappointment in not being able to do things she used to do as well as the gap in understanding she experiences from non-cancer peers and friends who just don't understand the reality of her diagnosis. "It was our 20th anniversary, and it would have been great to travel back to somewhere we'd enjoyed before but there was so much going on and like I said, you know, I had like full brain radiation just a month before so not being able to, not be able to plan things like that. I have friends that are you know, they plan all their travel like a year or more out and they're like, 'oh, you know, do you want to sign up for Hawaii? Hawaii 2023? Hawaii 2024? You should go to Italy in May. We should do all this.' Like yes, I would love that but when.... I don't know."

**Rosilene**, age 51, is from Brazil and lived and worked in the US before meeting her Canadian husband and settling down in Vancouver. They have one daughter who is 8 and three big dogs. Prior to her breast cancer diagnosis, Rosilene had an accomplished career in a leadership role as a professional engineer. Rosilene has a degree in Civil Engineering, an MBA in Industrial Administration and a PhD in Computational Mechanics and carried a lot of responsibility in her successful 21-year career. It's been a huge shift to go from a high-powered career to being an MBC patient, but Rosilene applies

some of her skill set to research and decision making around her treatment options. Her career plans had previously shifted a couple years earlier with the birth of her daughter, who they discovered was having some developmental delays, which eventually led to a diagnosis of autism.

Rosilene was diagnosed de novo metastatic breast cancer in December 2018. Her tumours were ER+PR+HER2- and her treatments were letrozole and Ibrance (palbociclib) then anastrozole combined and Ibrance (BC Cancer considers this to have been one line of treatment; letrozole and anastrozole are both aromatase inhibitors, and although side effects can be a bit different, they are considered equivalent). In 2020, she found out via a new biopsy she was HER2-low.

In January 2022, Rosilene had progression and needed to decide what to do post Ibrance. She had been following Enhertu results and explored accessing it through a clinical trial – specifically the Destiny Breast-04 and Destiny Breast-06 trials – but she did not meet qualifications. In the meantime, she qualified for the FINER study – a trial aiming to find out if cancer will remain under control for longer in patients given ipatasertib and fulvestrant, compared to fulvestrant on its own – which she joined.

In recent weeks, Rosilene has been presenting some new symptoms and had another CT scan and ultrasound – she’s currently waiting for the results. When they discussed the possibility of progression, her oncologist mentioned Enhertu as a future possible treatment.

Rosilene continues to actively follow the MBC research space, considering what could be her next treatment when and if she needs it – and as a person living with HER2-low MBC she is eagerly awaiting the availability of Enhertu. She said, “It’s been quite tough, trying to plan to help my daughter, but she is my motivation to try to survive.”

**Mary** is 57 years old and lives in London, England. She is a fitness coach and Pilates instructor – she was at her healthiest when she was diagnosed with primary (early stage) breast cancer at age 42. She was later diagnosed with secondary (metastatic) breast cancer in 2014 at age 49.

When Mary was initially diagnosed with MBC her daily life wasn’t too affected – she was working full time and her mental and physical fitness levels were manageable and doable despite the the side-effects of different treatments. “I guess exercise and my job has always kept me in good stead,” she shared. However, in recent years, she’s noticed that her energy levels have dropped, as well as her cognitive skills. And, due to all the hospital appointments, she is unable to work like she used to.

Her greatest concern is running out of treatment options and her body weakening. She shared, “Death never used to scare me, but seeing my mother at the end of her life earlier this year has

made me question my own. Dying in pain and discomfort frightens me, and of course, the thought of leaving my family.”

#### 4. Experiences With Currently Available Treatments

For metastatic HER2-low patients who have progressed, remaining options are standard chemotherapy such as eribulin, capecitabine, gemcitabine, nab paclitaxel or paclitaxel. These treatments 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. These chemotherapies are what metastatic breast cancer patients dread as their remaining options.

**Heather** is a Canadian metastatic breast cancer patient that Rethink has worked with and engaged over many years. Heather was diagnosed with metastatic breast cancer 13 years ago and she has survived for so long by going to great lengths to avoid what she refers to as “the crappy weekly IV chemo.” She did this by accessing targeted treatments through clinical trials both in Boston and Toronto, going to great lengths including extensively researching options, advocating for herself, relocating her family when necessary and paying out of pocket for treatments. Why? Because, as Heather who is now on eribulin says, “On weekly IV chemo, your normal life pretty much ends. It requires two visits per week for either blood work or for the chemo. The rest of the week is managing side effects of nausea, fatigue, pain, worsening neuropathy. And that’s with me being in the cohort of people who ‘tolerates well.’”

**Rosilene** talked about the rapid decline she’s seen in the metastatic community once patients progress to having only standard chemotherapies as remaining options. She shared, “While your tumour is responding to endocrine therapy, you tend to be able to remain longer on the treatment and stable. Then when it starts to progress, and you need to go into chemo because you don’t have anything else, it’s just faster, you know, and things go down so quickly.”

Both of the Canadian patients we interviewed who are HER2-low and currently in treatment with Enhertu (Diane and Kelly) both went to great lengths to avoid standard chemotherapy, which would have been their next treatment option.

#### 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. It’s important that patients have

a clear understanding of trade-offs and are well prepared for common side-effects of a given treatment.

In our experience, working closely with many young metastatic breast cancer patients, we find most are willing to trade toxicity to control their cancer. In other words, they will choose to endure additional side-effects and impacts on quality of life from the toxicity of a stronger therapy to ensure they are doing everything they can to stabilize their disease. As Mary stated, “Weighing the benefits of a treatment versus side-effects is a personal choice. Quality of life is paramount, but I would encourage patients to always try a drug.”

In our interviews with metastatic HER2-low patients—both those who have been able to access Enhertu, and those who have not but hope the treatment will be available before they progress and have to face IV chemotherapies—the primary improvement they seek is to extend their life. Specifically, beyond what is expected with the current publicly-funded IV chemotherapy available and with a better quality of life. They also know a later-line therapy is likely not as easy to tolerate at their first-line MBC treatment was, but are anticipating better quality of life than on a weekly IV standard chemotherapy as noted in the previous section. The patients receiving Enhertu said they experience tiredness/fatigue, but both said it was manageable.

## 6. Experience With Drug Under Review

Rethink conducted in-depth interviews with HER2-low metastatic breast cancer patients who have experience with the drug under review.

**Diane** lives in Toronto and is paying out of pocket to access Enhertu for her HER2-low breast cancer.

Diane was diagnosed with early breast cancer in 2015 at age 40. She was diagnosed with MBC in September 2017 with a recurrence to her other breast and some mets in her bones. Her first line MBC treatment was letrozole and Ibrance (palbociclib). She experienced some bone progression in 2018 and began Verzenio (abemaciclib), and again in June 2021 and began capecitabine.

Three years after her MBC diagnosis, she experienced some brain mets and had radiation to the brain and moved onto the chemotherapy (IV taxol) in December 2021. In September 2022, a scan showed progression in her abdomen and that her ureter was being compressed. She had another surgery and knew she needed to change treatment again since the taxol was no longer working. She explored the option of a clinical trial and was excited to qualify; however, it was unblinded and after

getting the standard therapy arm, she made a last-minute decision to withdraw from the trial. She went back to her medical oncologist to discuss options and learned her one option was just another standard of care chemotherapy blend. Her concern was that if there was further progression, then it might be trickier to manage; it might mean another surgery if there's more progression to her abdomen and risk of further complications. She asked about Enhertu and was especially interested in hearing that those with brain metastasis were responding, saying "Since I have had four separate treatments for brain metastasis since last December, it just felt like a much better option right now than to wait and try to access it later and risk further progression on a new standard care chemo." Diane and her husband have made some adjustments to "make it work" and pay for Enhertu.

When asked, Diane says she is "Feeling great and received amazing news last week. My latest scans came back stable. Enhertu is working."

She is happy with her decision so far saying, "I don't have any of the, you know, some of the symptoms could be like you know, breathing issues and this type of thing. I've had none of that, basically, I just feel a little bit tired that evening and then I'm fine. So, I've had no complications; it's just been smooth sailing." Diane also talked about how the thought of a break from the weekly IV treatments, which made it very difficult to support her parents needs such as getting them to their medical appointments, factored into her decision. She said, "The fact that the treatment is like once every three weeks instead of every week is great. I'm feel like I'm not there all the time. I mean I'm at hospital visits and doctor's visits but, you know, for other people! So, I've been feeling fine, like I have no issues with nausea. I mean, you know the long list of possible things that can happen once you've started; none of that has happened."

**Kelly** lives in Toronto and is accessing Enhertu through the clinical trial DB-06.

Kelly was diagnosed with stage 2b early breast cancer in December 2017 and did 8 rounds of ATC chemo and her lymph nodes were clear, so she did not have radiation. She was on tamoxifen for a while before switching to an aromatase inhibitor. Near the end of 2019, Kelly had a local recurrence to her lymph nodes that also led to the discovery of a single metastasis in her liver. She received her official diagnosis of metastatic breast cancer in March 2020, just as the world was shutting down. In the metastatic setting, she's been treated with fulvestrant and Ibrance (palbociclib) (because she had already received letrozole). She had liver ablation to address the lone liver met and the metastasis on her lymph nodes was surgically removed so she spent some time with no evidence of disease (NED) before progressing in April 2022. For the most part, she tolerated her first-line MBC treatments quite well, but she was plagued with neutropenia and fatigue and the disease has certainly impacted her day-to-day life.



Kelly was the one to ask about and proactively express interest in clinical trial opportunities.

She joined a Facebook group for Enhertu to learn more about what she might expect during the trial and saw some posts from people who were struggling with the side-effects but says “I didn’t let that sway me.” She admits that “I was quite worried that this might be very severe and change my quality of life quite a bit. A lot of people really struggle with the nausea it seems like on this drug and some people are saying that they’re in bed for like a week after treatments. Thankfully, I’m not in that category.” Kelly shared how she worked through these concerns and weighed the potential risks and benefits of her options. She said she talked a lot to the clinical trial coordinator and got answers and felt reassured. For her, she was actually more worried about the side effects from the control arm capecitabine than these potential side effects of Enhertu, saying “Xeloda would have been my drug had I not got on the trial drug. And I know people tolerate that very well but I’m a huge walker and walking is a big part of my mental health and my dog. I still walk every day, hiking in the summer as much as I can. And the thought of hand and foot syndrome scared me more to be honest. I thought if I lost my ability to walk because my feet were all blistered up that would hit me a lot harder than some nausea and fatigue. So, I guess between the two I was less scared for Enhertu.”

Because Kelly is part of the trial, she has scans every six weeks. Her last scan showed that all her mets are stable or had decreased. She said, “Being stable is what you hope for with MBC. If there is regression in some spots or they decrease in size, that’s a bonus.”

Kelly also shared that what will come after Enhertu is a bigger worry. She said, “Holidays are coming up now. Like I certainly don’t have a feeling that this is going to be my last Christmas....and I’m living fairly well on this medication although the fatigue is worse and I do have more nausea. But I believe my next treatment would be taxol and I had taxol when I had early-stage breast cancer. And with that came bone pain and I remember having to take, you know, at least for a couple of days after, having to take narcotics. And all these things are a part of my life now, knowing that that’s my next line, now I’m a lot more aware like “Okay, this is probably not my last Christmas but is this going to be the last Christmas that I have the energy to do all the decorating, to do all the baking and, you know, to do all that kind of stuff.”

**Mary** lives in London, England and her access to Enhertu came through a clinical trial.

Mary was first diagnosed with primary (early-stage) breast cancer in 2007 at the age of 42. She was later diagnosed with metastatic breast cancer in 2014 at age 49. Her status changed and hormone therapy wasn’t working. She said, “It was really tough because I was rapidly going through treatment

lines.” She was already HER2-low and at that time, there weren’t any targeted drugs available, and her oncologist knew little about this subtype.

Mary accessed Enhertu as part of a clinical trial and was stable for almost 1.5 years. She says, “For me the side effects are manageable. I had some fatigue and nausea in the first couple of cycles but those eased off. My mouth was sore and dry, but again, I managed to work through that...Enhertu gave me more freedom. I was able to still work whilst on Enhertu and that meant a lot to me.”

## 7. Companion Diagnostic Test

Nothing to report on this topic.

## 8. Anything Else?

A diagnosis of metastatic breast cancer is accompanied by a fear of running out of options. This is especially true for those with HER2-low metastatic breast cancer, as available lines of treatment have been limited – and patients are only left with weekly IV chemo treatment, and face harsh side-effects and a greatly diminished quality of life. The ability to now identify patients that are HER2-low and provide them with an effective and targeted treatment option is significant, and we hope that patients will be able to access this treatment without uncertainty or delay.

**We ask a few more minutes of your time to read profiles of two metastatic HER2-low breast cancer patients, Diane and Kelly, 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
AstraZeneca 2022				X
AstraZeneca 2021				X
Daiichi Sankyo 2022			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:** December 22, 2022

## Appendix B: Testimonials of the Unmet Need

Diane, 47 years old Living with MBC Paying for Enhertu out-of-pocket
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### ***When you are diagnosed with stage-4 metastatic breast cancer, your life as you know it stops. Completely.***

I'm Diane. I'm 47 years old and live in Toronto with my husband. We recently celebrated our 20th wedding anniversary – we were high school sweethearts who still live in the home we purchased together after university. After university, I ended up working at Princess Margaret Hospital doing administrative work in cancer research. When I turned 40, I was diagnosed with breast cancer for the first time. It was stage 2b and I had a single mastectomy. Almost two years later to the day, in a routine mammogram, they found a lump in my other breast. With the staging, they then found the cancer was in my bones. September 2017 was when my metastatic breast cancer (MBC) journey began.

I think it's important to share my reality of living with MBC to explain why Enhertu has been so important for me, and why accessing this drug is so important to people who need it. I was completely shocked to be diagnosed with MBC, as many of us are. I was still reeling from my initial diagnosis. I had just returned back to work full-time in July. I stopped that job when I was diagnosed and got a new one full-time job that I didn't choose: being an MBC patient. It means days of not just researching things, but also making really hard decisions and facing the realities of this diagnosis each and every day.

I have struggled with sharing my MBC diagnosis with my loved ones, because I feel guilty about being a burden on people. Of course, my husband and some close friends know, but there are a lot of people in my life that don't, including my parents. They knew I was diagnosed a second time, but not that it was MBC. I just felt like it was too much to tell them, knowing how hard my

first diagnosis was on them. I know they would be so devastated to learn about the MBC diagnosis. I worry it would cause them further health issues with the stress and weight of knowing. At the same time, I feel so guilty for not telling them.

To some people around me, including my parents, there was a while where I looked like I was fine, because MBC can be an invisible disease depending on treatment. But, behind the scenes, I have dealt with depression and anxiety. I didn't have any pain from the cancer, I felt well, so it was easier to hide my difficult reality. That changed last December when I had progression and had to start taking IV chemo. It became less invisible, but still, I hid it as I could.

This year in particular, being an only child has been really difficult as my parents continue to get older. They are in their mid-eighties and have had several health problems this year. I'm the only one navigating these challenges with them, while I'm also navigating my own MBC diagnosis. My parents rely on me for everything. They can't go to medical appointments on their own. I'm their contact for all their doctors. My oncologist has cautioned me that there needs to be some kind of plan because I'm faced with this diagnosis and if something happened to me, then what will happen to them? I hyperventilate when I think of that because I don't know. This weighs on me a lot. There's been times where I've had to cancel my own appointments, like with my psychiatrist last week, because my dad was in the ER. I feel like I put myself on the backburner all the time to make sure I'm limiting how much I'm burdening people around me.

In September 2022, a CT scan showed progression in my abdomen, and we had to come up with a new treatment plan. I had been on Taxol since December 2021. One option was another standard-of-care chemo, Eribulin, but we were worried about starting a different type of chemo because if there was further progression, it would be trickier to manage and may mean surgery, or further complications. I also knew that chemo likely meant side effects. Exploring all options, it was at that point when I was introduced to Enhertu and learned how amazing the results had been for some, including those with brain metastases like me.

As someone navigating MBC, there is so much I would do, so many lengths I would go to, to get more time. I considered going to the U.S. for this treatment when we considered options for accessing Enhertu. We decided to pay for it out of pocket here at home, which is a sacrifice I'm grateful we are able to make for now, and so I started it at the end of October 2022. Paying out of pocket for this treatment is almost like a Hail Mary situation. I've tried all different kinds of treatments. I'm kind of down the line here. Now is the time for me to do this. This is a ground-breaking treatment. I'm thankful that we're making it work, and I wish it was more accessible for people like me who need it, because I know this isn't a possibility for everyone.

I have felt great on Enhertu so far, with no side effects other than feeling a bit tired the evening after my infusion. I can confidently say my quality of life has improved. The fact that this treatment is once every 3 weeks instead of every week is great because I have more time to do other things in my life. It's nice to have more time to myself. To be with my husband. To spend time with my parents.

On top of feeling great, I also received amazing news last week. My latest scans came back stable. Enhertu is working.

Enhertu has given me a sense of hope. I have a lot of hope that this is going to improve things for me. Looking at the studies, there is so much potential. If I were instead on a weekly chemo infusion with all the side effects of chemo, my quality of life would drastically diminish. Enhertu is giving me the potential gift of time. The stakes are high when you are living with an MBC diagnosis. To have more time is something that perhaps someone who isn't going through MBC wouldn't realize the importance of. But I can tell you, it is extremely important. People living with metastatic breast cancer need more time, and Enhertu can give some of us that.

Kelly C.M., 54 years old  
Living with MBC  
Accessing Enhertu in a clinical trial



***Not only is Enhertu tolerable, but it's working. It's keeping me well, giving me a better quality of life. When I'm doing well, I'm a better person and a better partner.***

My name is Kelly. I'm 54 years old and live in Toronto, Ontario. I'm married and have 2 stepchildren. I used to be a marathon runner. I was active. My husband and I would love to go out for dinners and see friends. This all changed when I was diagnosed with early-stage breast cancer, and then again with stage-4 metastatic breast cancer.

I was diagnosed the first time in 2017. Two and a half years later, I was diagnosed with MBC, in March of 2020 during the height of the COVID-19 pandemic.

When I had further progression in April 2022, my main motivation and goal was to keep fighting this disease. I had to advocate for myself to be able to access Enhertu for HER2-low metastatic breast cancer through a clinical trial. I asked my oncologist about clinical trials when we were figuring out a new treatment plan.

The reality of living with metastatic breast cancer for me is that I feel very isolated sometimes from the life I once had. I can't work, and I really miss the social component of that. I have things that I can do, but sometimes I know I just can't. Sometimes I'm just too tired.

Even with the fatigue, I think I still have a bit of healthy denial because I'm still relatively well considering my diagnosis. Plus, I had a year of No Evidence of

Disease, so while I knew there would be progression at some point, I still felt like it was far enough away that I could push it out of my mind, although it still consumes my day, every day. I'm certainly not at a point where I don't think several times a day that I have metastatic breast cancer.

And, even though I'm tired now on Enhertu, that is a manageable side effect for me. Xeloda would have been my treatment if I had not gotten into the clinical trial. I know people can tolerate that well, but walking and hiking is a huge part of my mental health care. I walk my dog every day, and hike in the summer as much as I can. The thought of a side effect like hand and foot syndrome scared me more than any associated side effects with Enhertu. If I lost my ability to walk because my feet were blistered, that would hit me a lot harder than some nausea and fatigue. So, between the two, I was less scared of Enhertu. And while I do experience fatigue on Enhertu, I can still walk, and that makes me happy.



Because I'm part of the trial, I have scans every six weeks. My last scan showed that all my mets are stable or had decreased. Being stable is what you hope for with MBC. If there is regression in some spots or they decrease in size, that's a bonus. After four treatments, I've already seen some of my spots become a few millimeters smaller, which is huge. My spots had a 20% decrease in size. Not only is Enhertu tolerable, but it's working. It's working better than what my next option would be. The longer that my disease is stable, the better off it is for my life expectancy, and I don't have side effects. For me, Enhertu is keeping me out of the hospital and it's keeping me well, giving me a better quality of life. When I'm doing well, I'm a better person and a better partner.

If the drug works even for a short period of time, it's huge in our lives. If you look at another 6 months when you have an MBC diagnosis is huge. The more drugs you have access to, the better it is because not everything works for everyone, and when they do work really well, it can be so transformative.





*Figure 1 Kelly on a bucket list trip to Iceland approx. 2 months after starting Enhertu*

The impact that hope can have on a person living with MBC is huge. As someone living with HER2-low metastatic breast cancer, Enhertu gives me that. When I'm on a drug that is working, I can live with hope. I can live less fearfully. I can have fun and make great memories, for at least one more year.

I hope Enhertu becomes more accessible, outside of a clinical trial, to the people like me who are HER2-low and need more time and more options to live a longer life, have stability and have a good quality of life because our lives matter.