

# network news

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# Letter from the Chair of the Board of Directors

This issue of *Network News* is all about research. We start with a feature on cutting-edge therapies for hormone receptor positive breast cancer. This is the most common type, accounting for more than 70 percent of all breast cancers.

We continue our look at promising treatments with an article on immunotherapy, a novel series of therapies that harness the power of the patient's own immune system to combat cancer, as well as an article on radiosurgery, a type of radiation that is an alternative to surgery and is especially useful for hard-to-access tumours in the brain and elsewhere.

On a practical note are articles on returning to work after breast cancer treatment and on the steps to take if you experience febrile neutropenia, a side effect of chemotherapy that affects a type of white blood cell.

We close with an inspiring story of a family and community that came together to raise awareness and funds for the breast cancer cause.

As you can see, CBCN has been busy with its mission to provide a national network, to educate and inform, and to advocate on your behalf. We hope you find the magazine informative and enjoyable.



Warm Regards,

A handwritten signature in black ink that reads "Cathy Ammendolea".

Cathy Ammendolea, CBCN Board Chair

The Canadian Breast Cancer Network publishes a free monthly e-newsletter, *Outreach*, that highlights current programs, resources & activities for breast cancer survivors and patients. **SUBSCRIBE TODAY**



# Hormone receptor positive breast cancer

What it is. How it's treated. Upcoming research.

The more we learn about breast cancer, the more we realize just how complex a disease it is. What we do know is that it's not just one disease but that there are various types of breast cancer, which determines how doctors treat the disease.



The most common type of breast cancer is hormone receptor positive breast cancer (HR+); this accounts for more than 70 percent of all breast cancers. If your breast cancer has a significant number of receptors for either estrogen or progesterone, it's considered hormone receptor positive. HR+ breast cancer is usually treated with hormone therapies after surgery, chemotherapy, and radiation. These therapies help prevent the cancer cells from getting the estrogen they need to grow.

Hormone therapies are designed to work in two ways: they either lower the amount of estrogen in your body or they block the hormone receptors on the cells to prevent the hormones from binding to them.

There are a variety of therapies that are used to block estrogen; the most popular types include:

**Selective estrogen receptor modulators (SERM's):** These drugs block the estrogen receptors in breast cancer cells and stop the estrogen from binding to the cancer cells. Tamoxifen is the most common SERM; it can help reduce the risk of the cancer returning or developing a new cancer in the other breast. Tamoxifen is usually taken for 5 to 10 years and can be started either before or after surgery.

# HR+ cont'd

## **Estrogen-receptor downregulators (ERDs):**

This is another type of therapy that sits in the estrogen receptor in the breast cell and prevents the estrogen from attaching to it. Fulvestrant (Faslodex) is an ERD that is used to treat metastatic HR+ breast cancer. Fulvestrant is usually used when drugs like tamoxifen or an aromatase inhibitor stop working.

**Luteinizing hormone-releasing hormone agents (LHRHs):** These therapies shut down the ovaries and stop them from producing estrogen. This type of treatments can be

used in premenopausal women with early-stage HR+ breast cancer. Drugs that are LHRHs include goserelin (Zoladex), leuprolide (Lupron), and triptorelin (Trelstar).



## Some therapies work by lowering estrogen levels in the body:

**Aromatase inhibitors (AIs):** These drugs stop estrogen production in post-menopausal women. These are only helpful to women whose ovaries aren't working, since they block an enzyme, called aromatase, in fatty tissue. There are three main AIs used in the treatment of breast cancer: letrozole (Femara), anastrozole (Arimidex), and exemestane (Aromasin). Usually AIs are taken after tamoxifen for 5 years and research has shown that taking AIs instead of just taking tamoxifen is more successful in helping reduce the risk of the cancer recurring. Given that AIs eliminate estrogen, this can sometimes have an impact on bone health, which may lead to your physician prescribing medications to help strengthen your bones, such as bisphosphonates or denosumab.

**Targeted therapy:** There is also a targeted therapy available for metastatic hormone receptor positive breast cancer called everolimus (Afinitor). This type of treatment is a signal transduction inhibitor. It stops a protein called mTOR from working properly. mTOR controls other proteins that can trigger cell growth, so this treatment helps to stop the cancer from growing, or can help slow it down.

## What's new in research for HR+ breast cancer?

Breast cancer research continues to help us better understand this very complex disease and different ways to attack the cancer. Research for HR+ breast cancer has led to an increased understanding of how we can better target certain pathways and proteins. Two targets that have been identified in recent years are the cyclin-dependent kinase 4 and 6 (CDK 4/6) pathway and the phosphatidylinositol-3-kinase (PI3K) pathway. By better understanding these pathways, their role in cell growth and cancer progression, a variety of therapies have been developed to target them as a treatment for HR+ breast cancer.

### **CDK 4/6 Inhibitor**

CDK 4/6 Inhibitors are used to treat cancer by preventing the over-proliferation of cancer cells; these drugs help to establish cell cycle control by inhibiting the CDK 4/6 pathways. Several CDK 4/6 Inhibitors have been developed and investigated through clinical trials in recent years, including palbociclib (Ibrance), ribociclib, and abemaciclib. Palbociclib is currently approved by Health Canada for HR+ metastatic breast cancer and is in the review process to be added to the provincial formularies; there are various clinical trials looking at its possible use for early stage breast cancer. Ribociclib and abemaciclib are not yet approved by Health Canada as they are still being investigated through clinical trials; both have clinical trials in Canada in the metastatic setting.

### **PI3K Inhibitor**

A variety of PI3K Inhibitors are under investigation for HR+ breast cancer. This pathway is one of the most frequently altered pathways in cancer and research is showing that inhibiting this pathway can reduce tumor growth. Buparlisib, taselisib and alpelisib are all PI3K Inhibitors that are currently being investigated through clinical trials in the metastatic setting. While none of these treatments are approved by Health Canada, there are ongoing clinical trials in Canada that are available to patients who meet the criteria.

For more information about clinical trials for the treatments listed above as well as for other breast cancer clinical trials visit

[www.canadiancancertrials.ca](http://www.canadiancancertrials.ca).

# Ask an expert: febrile neutropenia explained

Febrile neutropenia, or FN, is a common and potentially serious side effect of chemotherapy treatment.

Neutrophils are a type of white blood cell responsible for helping fight germs and infections. Neutropenia means that there are fewer neutrophils than normal in your blood and many people with lymphoma have neutropenia at some point during treatment<sup>1</sup>. Febrile neutropenia means that you have a fever and a very low neutrophil count in your blood.

The primary symptom of FN is an elevated temperature of more than 38 degrees centigrade. Fever is often the first sign of infection and if the neutrophil count is very low, there is a greater chance of serious infection compared to having a fever with a normal or near-normal neutrophil count. All patients should have clear instructions on who to call and what to do in case a fever develops while on chemotherapy. The only way to know if a patient has FN is for a blood test to be done at the time of a fever.

Other symptoms that may occur as a result of FN and increase the risk of complications can include<sup>2</sup>:

- chills
- sweating
- cough or shortness of breath
- sore throat or sores in your mouth
- redness or swelling around sores on your skin or redness and swelling of your skin
- trouble urinating and/or increased frequency or burning with urination
- vaginal discharge or itching
- flu-like symptoms such as body aches and extreme tiredness

Here, we ask three experts to explain FN, what it is, how it can impact treatment outcomes, and how it can be effectively managed. Our experts are:

Dr. Daniel Rayson, MD, FRCPC Oncologist, QEII Health Sciences Centre Halifax, Nova Scotia	Dr. David MacDonald, MC, FRCPC Hematologist, QEII Health Sciences Centre Halifax, Nova Scotia	Dr. Jawaid Younus, MD, FRCPC Oncologist, London Health Sciences London, Ontario
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## WHAT CAUSES FN?

FN can arise as a consequence of most chemotherapy regimens across all cancer types. The risk of developing FN depends mostly on the intensity of the chemotherapy treatment and the health of the patient's bone marrow, where neutrophils are produced. The elderly and those who are sick from their cancer or other medical conditions are most susceptible to complications from FN.

- Dr. Rayson

## HOW COMMON IS FN?

I often see FN in my practice, and it is more common than the published rates suggest. The good news is that it can be treated and sometimes the risk can be reduced with medication.

- Dr. MacDonald

## HOW DOES FN IMPACT A PATIENT'S PROGNOSIS AND THEIR COURSE OF TREATMENT?

FN can impact a patient due to the need to delay treatment to allow the neutrophil count to recover. If someone has a complication or a serious infection due to FN, treatment may have to be changed or stopped altogether. In general, results from treatment are optimal when chemotherapy can be given at the original dose and on the planned schedule. Neutropenia and FN can cause both dose and schedule changes that have the potential to impact treatment results in some cases.

- Dr. Rayson

When a patient is at high-risk of developing FN or develops FN during treatment, their doctor will prescribe medicines to reduce the risk of infection, such as a G-CSF or antibiotics. These may help to maintain the patient's planned chemotherapy regimen. If the patient remains at high-risk of developing FN despite these measures, their doctor may need to adjust the patient's chemotherapy treatment, potentially delaying the patient's recovery.

- Dr. Younus

## FN cont'd

In my practice, for instance, if a patient remains neutropenic or they are still on antibiotics because they have had neutropenia or an infection, we give them a week off their chemotherapy and we reassess them a week later. Therefore FN can have an impact delaying a patient's chemotherapy schedule.

- Dr. MacDonald

### HOW IS FN IDENTIFIED AND TREATED?

It is crucial to be properly monitored by your healthcare team when receiving chemotherapy to watch for signs of FN. During the course of treatment patients should expect to have routine blood tests to measure levels of white blood cells<sup>3</sup>.

When a patient presents with a fever accompanied by symptoms of FN, healthcare professionals will take the patient's medical history, administer a physical examination, take blood to measure the patient's level of white blood cells (neutrophils), perform a chest x-ray and urine analysis to determine the site of infection. Patients may require routine injections of a drug that stimulates the growth and production of white blood cells and decreases the risk of FN. If necessary, antibiotics may also be used to treat the patient.

- Dr. Younus

Some patients are at a higher risk of developing FN, so it's important for chemotherapy patients to be closely monitored by their healthcare team and to watch for signs of FN. During the course of treatment, patients should expect to have routine blood tests to measure their levels of white blood cells. Typically though, cases of FN are more prevalent among patients with certain types of cancers, such as aggressive lymphoma. People who have a history of chronic lung disease and urinary tract infections specifically are the ones to be concerned about and we want to treat them.

- Dr. MacDonald

**When diagnosed with a low white blood cell (neutrophil) count, you may be more susceptible to germs and infection. It is important to report any signs of infection to your healthcare team. Below are a few tips to stay healthy during treatment.**



## Practice good personal hygiene

- Wash your hands frequently, especially before eating and after going to the bathroom
- Carry a small bottle of hand sanitizer to clean your hands if a sink is not available

## Protect your skin

- If your skin becomes dry or cracked, use moisturizing lotions to soften it and help it heal
- Clean any cut or scrape at once with warm water and soap

## Maintain good general health

- Get enough rest, eat a well-balanced diet, drink plenty of fluids, and get regular exercise
- Cook vegetables and wash and peel fruit to get rid of bacteria on their surfaces. Avoid uncooked eggs, raw or undercooked meats, poultry, fish, and seafood. These foods can contain harmful organisms<sup>4</sup>.

For more information about febrile neutropenia and the cancer journey, watch CBCN's video:



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# Immunotherapy: the new frontier in cancer treatment

Immunotherapy is a promising novel type of therapy that stimulates the body's own immune system to fight cancer.

## 1. monoclonal antibodies

There are several types of immunotherapy in use or being researched. One is **monoclonal antibodies**, which locate antigens on the surface of cancer cells and stimulate an attack on the cancer. They can also interfere with cell signalling and growth. Monoclonal antibodies approved by Health Canada for breast cancer include:

- Herceptin, Perjeta, and the antibody/chemotherapy drug combination, Kadcyla, which block the action of human epidermal growth factor receptor 2 (HER2) on tumour growth
  - Herceptin and Perjeta are approved for all breast cancer patients with tumours that overexpress HER2
  - Kadcyla is approved for patients with metastatic breast cancer that overexpresses HER2

Monoclonal antibodies currently being researched in breast cancer clinical trials include:

- CDX-011 (glembatumumab vedotin), which targets cellular proteins that enable tumours to metastasize. A [clinical trial](#) for this drug is recruiting patients in Montreal, Toronto, and Sault Ste. Marie, Ontario.
- MGAH22 (margetuximab), which blocks the effect of HER2 on tumour growth. A [clinical trial](#) for this drug is recruiting patients in Oshawa, Ontario and Moncton, New Brunswick.

A second type of immunotherapy is **checkpoint inhibitors/immune modulators**, which are drugs used to power up the immune response, allowing the body to respond more aggressively to cancer.

## 2. checkpoint inhibitors

# Immunotherapy cont'd

Checkpoint inhibitors/immune modulators currently being researched in breast cancer clinical trials include:

- the anti-CTLA-4 antibody Yervoy® (ipilimumab). A [clinical trial](#) for this drug is recruiting patients in Toronto.
- the anti-PD-1 antibodies Keytruda (pembrolizumab, MK-3475) and Opdivo (nivolumab). A [study](#) of pembrolizumab for metastatic triple-negative breast cancer (TNBC) is recruiting patients in Kirkland, Quebec. A [study](#) of the effects of pembrolizumab in patients with advanced solid tumours, including TNBC, is recruiting patients in Toronto. A [study](#) of nivolumab monotherapy or nivolumab combined with ipilimumab in subjects with advanced or metastatic solid tumours, including breast cancer, is recruiting patients in Toronto.
- the anti-PD-L1 antibodies MPDL3280A (atezolizumab) and MEDI4736 (tremelimumab). A [study](#) of atezolizumab is recruiting patients in Alberta (Calgary and Edmonton), British Columbia (Kelowna, Surrey, and Vancouver), Nova Scotia (Halifax), Ontario (Kingston, Oshawa, Ottawa, and Toronto), and Quebec (Montreal and Quebec).

## 3. adoptive T cell transfer

A third type of immunotherapy is **adoptive T cell transfer**. In this approach, the cancer-fighting ability of T cells is enhanced. A patient's own immune cells are grown or changed outside of the body, and then re-infused back into the patient. The following types of adoptive T cell transfer are being researched for patients with breast cancer:

- tumour infiltrating lymphocytes (TILs) that are removed from a patient's tumour, boosted in the lab, then given back to the patient
- T cells genetically engineered to target several cancer-associated antigens

# Immunotherapy cont'd

## 4. cytokine therapy

A fourth type of immunotherapy is **cytokine therapy**. Cytokines regulate cellular communication and help control the activity and growth of immune system cells, as well as blood cells. Cytokines currently being researched in clinical trials of breast cancer include the following interleukins:

- Interleukin-2, an important growth factor for white blood cells
- Interleukin-7, an important growth factor for T cells and B cells

A fifth type of immunotherapy is **adjuvant immunotherapy**, which is a substance that is either used alone or combined with other immunotherapies to boost the immune response even more. One adjuvant immunotherapy being researched in breast cancer clinical trials is Indoximod, which blocks an immunosuppressive molecule produced by tumour cells.

## 5. adjuvant immunotherapy

### Side-effects

Because immunotherapy generally results in fewer side effects and less toxicity than chemotherapy, it can be tolerated for longer periods of time, alone or in combination with other agents. Resistance to immunotherapy is less likely because the immune system can target multiple cancer antigens simultaneously and adapt to changing cancer cells.

Immunotherapy can still cause a variety of side effects, including fatigue, nausea, mouth sores, diarrhea, high blood pressure, and fluid buildup, usually in the legs. Breast cancer patients may also experience vomiting, headaches, fever, chills, pain, weakness, and rashes. The side effects of immunotherapy generally become less severe after the first treatment.

### How to enroll in a clinical trial

You can find clinical trials advertised on [www.canadiancancertrials.ca](http://www.canadiancancertrials.ca) or [www.clinicaltrials.gov](http://www.clinicaltrials.gov); ask your doctor to refer you to a study.

# Radiosurgery: a precision healing tool

Radiosurgery is a treatment that delivers three-dimensional beams of high dose radiation to tumours as an alternative to surgery.

Laurie Kingston, a metastatic breast cancer patient in Ottawa who has had radiosurgery for five brain tumours, has this to say about her experience: "The beauty of radiosurgery is that you need far fewer days of treatment (all but one of my tumours have required just one session) and because it is so precise, the same treatment can be used several times, aimed at various parts of the brain."

Radiosurgery requires extensive preparation. A few days before treatment, the patient is fitted with a custom-made mask, and a CT scan is taken to mark the mask and prepare the right points for radiosurgery. A radiologist works with a computer program to create a treatment plan. The plan ensures that the right dose of radiation reaches the exact tumour location and spares the surrounding healthy tissue.

Treatment takes place a few days later in a room with a bed and a radiosurgery machine. The patient is positioned on the bed, and the machine moves around her.

Laurie describes the experience.

"After the mask is fitted onto your head, it is bolted to the table. If it feels too tight, the technicians will adjust it - don't be afraid to speak up! It also helps to take a lorazepam or

similar relaxant to get through the process. If you don't have a prescription for this medication, you can ask your radiologist or the nurse who works with him. I certainly felt panicked the first time I had my face bolted to the table and it helped to calm down, even through artificial means."



*Patient Laurie Kingston wears a custom-made radiosurgery mask. It is bolted to the table during the procedure to prevent movement.*

## Radiosurgery cont'd

After the treatment, Laurie experienced some side effects. "I had a lot of swelling and headaches the nights after most sessions. These were addressed by taking a higher level of steroids

than had initially been prescribed. The first time I had the treatment was the hardest but I generally felt like I had the flu for a few days after each session. I had one tumour zapped over three sessions. In that area, I developed a bit of a burn and it was quite tender. However, I have had breast radiation (over 35 days) and this burn was really trivial in comparison."

A possible complication of radiosurgery is radiation necrosis (the growth of dead tissue). This can occur up to 18 months after radiosurgery, and may need to be removed through conventional surgery.

For Laurie, radiosurgery is a much better option than whole-brain radiation therapy. "I really felt that whole brain radiation (with all its accompanying side effects) was like using a sledgehammer when something much more delicate is available. My radiation oncologist told me that he typically only does whole brain radiation once on any given patient (some radiation oncologists will do twice but never more). I felt and still feel like this is a treatment that can be kept until we have run out of other options."

Laurie says that she feels extremely glad that radiosurgery was available for her. "Radiosurgery has been a helpful addition to the few tools available to address brain metastasis. The side effects are relatively minor and this treatment has done a good job for me of preventing recurrence and stabilizing those tumours that will not go away." For more information on radiosurgery, visit [cancer.ca](http://cancer.ca).

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# Returning to work after breast cancer treatment

By Patricia Stoop



When I completed my cancer treatment, I felt like I had stepped off a roller coaster, totally disoriented. I was out of shape, weak, and in constant pain. I felt emotional and feared recurrence. Yet the pressure was there to return to a “regular” daily life, including full time work. Was that possible? Who would help me?

I would like to share my story of returning to work after treatment with you. I blazed my own trail, created my own program. I called upon my experience as an occupational therapist (OT). I hope my story can help you.

## Background

Return to work is an issue for 60 percent of cancer survivors<sup>1</sup>. Up to 33 percent of survivors do not return to work<sup>2</sup>. Rehabilitation for return to work is recommended<sup>3,4</sup>. Cancer centres in Canada offer limited options. "Vocational reintegration is not a priority in medical treatment, as the primary aim focuses on survival<sup>5</sup>."

## Collateral damage

Collateral damage is a term used to describe the long term after-effects of cancer treatment<sup>6</sup>. Up to 75 percent of survivors complain of collateral damage<sup>7</sup>.

I experienced profound fatigue, cognitive challenges (“chemo brain”), weakness, pain, depression, and fear of recurrence. I attended a return-to-work information session. While helpful, it did not address many of my issues.

## Making the most of existing services

Occupational rehabilitation (OR) is 4 to 8 hours per day, up to 5 days per week, originally developed for work injuries. An OT, physical therapist (PT), and kinesiologist facilitate the program. Fitness routines, work simulation, and education sessions are provided.

# Returning to work cont'd

I attended an OR program close to work. My endurance, fitness, balance, and strength improved. I facilitated education groups to build cognitive skills. I participated in a gradual return to work. I also attended a healing retreat with the Callanish Society. I worked through

emotions and dealt with fears. When I arrived I felt like a patient and at the end I felt like a provider.

I returned to work successfully within three months of starting rehabilitation.

## Navigating the system

I requested a referral to rehabilitation through long term disability (LTD) benefits. I obtained letters of support from my doctors. LTD paid for the OR; Callanish offered financial assistance, and CPP Disability continued to pay benefits for six months after return to work. I was lucky to have good LTD benefits. In the resource list are some options for those without LTD.

If you cannot access formal rehabilitation programs, some practical ideas for preparing for return to work are:

- following a daily routine similar to that required for work; for example, sleep/wake routine
- participating in a structured or group fitness program
- volunteering; and/or
- returning to work gradually if your employer supports this. Start at two to three days a week for 4 hours and build up from there.

## Conclusion

With time, effort, and inside professional knowledge, I found there were services and funding available that addressed collateral damage of treatment and helped me return to work. I hope that my story helps you find support to return to work successfully.

*About the author: Patricia Stoop is an occupational therapist and metastatic breast cancer patient who lives in Whistler, British Columbia.*



# RESOURCES

The following resources may help you to prepare to return to work.

- **Cancer treatment centres:** Few clinics in Canada have rehabilitation or vocational consultants.
- **The British Columbia Cancer Agency** developed the following **manual**.
- **Long Term Disability:** LTD often has rehabilitation services available. Ask for a referral.
- **Private programs (OR, cancer rehab):** LTD may cover the cost. For example, visit Lifemark at <https://www.lifemark.ca/services/cancer-rehab>.
- **Private occupational therapy or physiotherapy** - sometimes funded by Extended Health Benefits.
- **CPP Disability Benefits** have rehabilitation benefits. See <http://www.esdc.gc.ca/en/cpp/disability/rehab.page>.
- **Employment Insurance (EI)** offers programs for retraining and education. See <http://www.servicecanada.gc.ca/eng/epb/ebsm/index.shtml>.
- **Provincial income support programs:** Each province has a different social assistance program. All have vocational rehabilitation. Contact your province's program for information.

Here are some resources for those with limited finances and no LTD/ CPP benefits.

- **Outpatient rehabilitation services** in your local hospital. OTs and PTs can help you attain the physical and cognitive tolerance for work.
- **Home care OT or PT** - contact your local health unit.
- **Cancer clinics** in Alberta and Ontario have rehabilitation in survivorship services.
- **Vocational counselling** is sometimes offered through patient and family counselling. **Callanish Society** offers scholarships to attend. See <http://www.callanish.org>.

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# Returning to work cont'd

# Advocates in action



Carmen and her family at the Pink Ribbon Project gala in 2015. From left to right: Doug Rutherford, Carmen Powell, Jody Rutherford, Tara Stogre, Ashley Williams

## By Carmen Powell

Director, Full Circle Foundation for Wellness [fcf4wellness@gmail.com](mailto:fcf4wellness@gmail.com)

My mom received her initial breast cancer diagnosis in 2002 at the age of 46. She bravely underwent a double mastectomy, chemo, and radiation and then put it behind her and continued her life as a wife, mother, educator, and eventual grandma. In 2013 we were shocked to learn that her cancer had returned as Stage IV, or metastatic breast cancer. Her cancer had metastasized to her bones and by May 2016, it had spread to her liver. These are the facts, and in all their heartbreaking unfairness, I cannot change or control them. What I can control is where I choose to focus my energy, and aside from spending every minute I can with my mom, I choose to focus my energy within my circle of influence.

In 2014, a group of dedicated friends and family members brought to life an idea for a gala event that would show our love and support to the women we love who have faced a breast cancer diagnosis, while raising funds and awareness for breast cancer. Since its inception, the Pink Ribbon Project gala has raised over \$61,000 for breast cancer, and has benefited both the Canadian Breast Cancer Foundation and the Canadian Breast Cancer Network. We are proud of the work that we have done through PRP but with the advancement of my mom's cancer, we set out to do more.

We recently founded a non-profit organization that will give us more freedom to grow the Pink Ribbon Project, expanding our focus from

# Advocates in action cont'd

fundraising and awareness to include advocacy and education initiatives. When I was searching for inspiration to help shape the purpose and mandates of this new organization, I revisited a book that has always given me direction and that speaks to focusing our efforts on things we can actually change. "Proactive people focus their efforts in the circle of influence. They work on things they can do something about. The nature of their energy is positive, enlarging and magnifying, causing their circle of influence to enlarge<sup>1</sup>." With this as a guiding principle, the Full Circle Foundation for Wellness was born.

So what can we change? What lies within our circle of influence? Where are we focusing our efforts and how will that impact my mom and other Canadians living with metastatic breast cancer? With the guidance of CBCN, we are choosing to focus on gaining timely and equitable access to treatment for those with metastatic breast cancer. Focusing on this also means expending time and energy to educate others on what metastatic breast cancer is, what this diagnosis truly means, and why drug wait times matter.

This year's Pink Ribbon Project focused on education around Stage IV breast cancer. Through various media--print, social media, our foundation's blog, and educational materials at the event--we shared what we have learned about Stage IV and also where families affected by it can find accurate resources and supports. PRP also provided us a setting in which we could share the information from CBCN's report "[Waiting for Treatment](#)" and ask our guests to join us in requesting that the Alberta government commit to listing new treatments within defined time periods. Letters to both our provincial and federal health ministers are a jumping-off point that will lead us to our next step in seeing that our elected officials take real action. In the time between this PRP and the next, we will continue to work to have our concerns heard at both levels of government. As I write this article, I am preparing for a meeting with our local MLA to ask for his support and guidance in getting this issue brought to light. Our MP will be presenting a letter from us to our federal minister of health requesting that she lead the federal government to work with the provinces to renegotiate the Canada Health Accord with a provision to support increased funding for new treatments and the development of a national pharmaceutical strategy that will ensure that Canadians are able to access the effective medicines they need in a timely manner. A wait time of 2 to 4 years for metastatic patients to gain access to medications that could prolong their lives is unacceptable.

# Advocates in action cont'd



Members of the team who organized the Pink Ribbon Project gala in 2016. Front row, from left to right: Tara Stogre, Shanda Wood, Cody Shepherd. Seated: Brett Howe, Jenn Shepherd, Alexis Syvret, Nadia Muhieddine. Back row: Jaime Gossett, Ashley Williams, Krystie Olson, Dale Williams, Adam Powell, Kevin Gillett, Taylor Jacobson, Carmen Powell, Bret Howe.

For my mom and others, this is a life-or-death battle and one that we will continue to fight until we see real change.

On the particularly difficult days, like the day we learned of my mom's cancer spreading to her liver, I feel devastated. I feel my mind wandering to the worries of the future. How will I be able to exist in a world where my mom doesn't? How will I be able to take care of my children and fix their broken hearts when mine is shattered? I allow these thoughts only

on the truly difficult days and I let the grief pour out in a flood of tears that only stops when I have no tears left. Then I choose to put my energy elsewhere, back into something I can change and something that is in the present.

Educating those in power about metastatic breast cancer and how the drug wait times affect these patients is fully within my control. Demanding change is within my control. It's in your control, too. When we first connected with CBCN, I felt like a door opened and information came pouring in, giving us direction, support, and a way to take action. If you or a loved one is facing a metastatic breast cancer diagnosis, I urge you to get involved; get in contact with CBCN and see how you can affect change in your province. If you are in Alberta and want to join us in our efforts, please reach out to me. We can make a difference. We can prolong lives and ensure better quality of life. But we need access to every single tool available. For my mom and for all those facing metastatic breast cancer in Canada, we are here and we are fighting for you.

## References

1. Covey, S. (2004). The seven habits of highly effective people, p.83. New York, NY: Free Press.

*Network News* is published by the Canadian Breast Cancer Network (CBCN) to provide the breast cancer community with up-to-date and understandable information on issues at the national level, to promote education and awareness, and to highlight the concerns of Canadians affected by breast cancer.

We would like to thank the individuals who wrote and reviewed articles. We welcome your ideas, contributions, and letters, subject to editing and available space. The articles in this issue do not necessarily represent the views of CBCN but are the opinions of the authors. CBCN gives permission to copy with attribution.

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