

The AMBER Report

ISSUE II

SEPTEMBER 2018

SPECIAL POINTS OF INTEREST:

- 1300th Participant!
- **Breast Cancer Awareness Month**

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> Check out our website!

> > Join our **Facebook** page!



www.amberstudy.com

Message from the Investigators

We hope that you have enjoyed the summer months and have been able to take time to relax with family and friends!

past June we This reached a new milestone in the study as we recruited our 1300th participant! To mark this achievement we profile two new participants who came in for their baseline testing on that day.

In this edition of the newsletter we touch on the topics such as getting a



good night's sleep and the process of moving forward after treatment.

We also highlight some of the events taking place for Breast Cancer Awareness month in October.

Currently the study has enrolled 90% of

the 1,500 participants we hope to recruit. As of Aug 31st we have enrolled 762 participants in Calgary and 588 in Edmonton. To date, participants have completed their Year I assessment, 487 particihave completed pants their Year 3 assessment and 115 participants have completed their Year 5 assessment.

Thank you again for your commitment and participation!

October is Breast Cancer Awareness Month

Highlighting some of the Calgary events taking place Calgary and Edmonton for BRA Day Breast Cancer Awareness Month.

BOTH

CIBC Run for the Cure Sept 30th

cibcrunforthecure.com



Oct 17th from 5 - 8:30 pm Foothills Medical Centre

https://www.eventbrite.ca/e/braday-calgary-tickets-493 I 0296424

Fashion with Compassion

In support of Breast Cancer Supportive Care Foundation Sept 23rd

bcscf.com/events/

Rethink Breast Cancer Boobyball

Oct 20th

boobyball.rethinkbreastcancer.com

Edmonton

Out of the Blues

Hereditary Cancer Fundraiser Sep 22nd

www.hbocsociety.org/out-ofthe-blues.html

Women of Song

Oct 13th

Newcastle Pub

www.yegwomenofsong.ca

Fashion with Compassion

In support of Sorrentino's Compassion House Oct 25th

www.fashioncompassion.ca

AMBER Participant Profiles

On June 26th we reached the milestone of **1300** participants! We profile two baseline participants who completed their testing that day!

CALGARY Participant

Why did you decide to take part in the AMBER study?

A curiosity and wanting to contribute any small part I can that may be of help to my daughter and other women in general.

What was your favorite part of the testing experience?

I enjoyed the physical testing. After receiving my results I hope to join the Alberta Cancer Exercise (ACE) program.



Calgary baseline participant Debra C.
with exercise testers
Nathaniel and Rebecca.

What were you hoping to gain from this experience?

Having a baseline or starting point and helping me see the direction I need to take.

What advice would you give to ladies newly diagnosed with breast cancer?

Reach out to others. Don't try to navigate this alone. Learn patience. You will meet a lot of really good and nice people.

Did you make any lifestyle changes after your diagnosis?

I am eating more vegetables, thinking twice about consuming sugar and reading labels more carefully.

What advice would you give other ladies who are thinking about joining the study?

Jump in with both feet! It is a small time commitment for the greater good of all.

EDMONTON Participant

What was your favourite part of the testing experience?

My favourite part of the testing experience was Diane, one of the exercise testers. She is so positive, caring and made the testing fun

How was your breast cancer discovered?

I had a massage and when I was getting dressed, my breasts were tingling and burning so I was rubbing them to relieve the feeling. It was then that I felt a lump in my left breast. I went home and asked my husband what he thought and he concurred with my diagnosis. I made an appointment for a mammogram and was able to get in right the next day. They asked me to come back for another mam-

mogram and then an ultrasound was performed. The radiologist advised that I had masses in both breasts and both lymph nodes and had to go for a needle core biopsy.

What kept you motivated during your treatment?

I started a Facebook page and a blog at the beginning of my journey. You really never know how many people you have in your life who care about you until you reach out. It was a huge comfort and motivator knowing that I had so many people in my corner praying, sending positive vibes, positive thoughts, positive juju, thinking about me, and checking up on me. My faith and my peeps were definitely a huge motivator in staying positive.

Being positive throughout this journey is what's going to get me to the other side.

Was there a quote or saying that spoke to you during your cancer journey or one that speaks to you currently?

"Don't panic. I'm with you. There is no need to fear, for I am your God. I'll give you strength and help you. I'll hold you steady and keep a firm grip on you. Isaiah 41:10."



Edmonton baseline participant Micheline D.

Moving Forward: Life After Treatment

It is not uncommon after treatment to experience an adjustment or transition period as one begins to move forward. This may be the first time that a woman has had time to step back and reflect on what she has gone through.

Previously suppressed emotions can come to the forefront and this can lead to feelings of isolation and discouragement. As well, women often contend with body image and self-esteem concerns as they adjust to what their breasts and body look like after treatment. Below we have highlighted some recommended tips and ideas to consider. For a more



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detailed resource, the National Cancer Institute has produced a publication called: "Facing Forward:

Life after Cancer Treatment."

It is available free online at:

https://www.cancer.gov/

publications/patient-education/

facing-forward

On Oct 26th, **CancerControl AB** is hosting their annual event called

"Living Your Best Life."

This event focuses on topics such as nutrition, mental well-being, and exercise for people who are finishing or have finished treatment.

To register, go to bit.ly/book-cancerpatiented

- **I. Managing Expectations:** Once treatment is complete you and your family may expect life to pick up again the way it was before. However, it is not uncommon for women to have feelings of depression and anxiety when treatment ends. The goal should not be so much of getting back to "normal" then it is in finding out what's normal for you now. Be patient as it takes time to feel like yourself again. Also, try to be gentle and gracious with yourself (or your loved one (s)).
- 2. Facing Fear: Once treatment is complete or you are discharged from your oncologist it may feel like your medical support is gone and you are left to fend for yourself. It is normal to worry about the cancer coming back, especially in the first year after treatment. Talk with your doctor or other health care professional to understand and be informed about what you can do for your health now. Search for services that are available to you. Seek ways to help yourself relax and try to look for the positive. If you are experiencing feelings of fear, anger or sadness find ways



to express these feelings. This can take different forms such as talking with family or friends, other cancer survivors, or a counsellor. It can also be as simple as taking the time to write your thoughts and feelings down in a journal.

3. Take care of Yourself: We have all heard it before but exercise, a healthy diet, sleep and limited alcohol can contribute to a healthy recovery. You may also find other services such as acupuncture, massage, yoga, meditation, or homeopathy may help to alleviate physical side effects from treatment and/or feelings of stress and worry.



- **4. Ask for Help:** While going through active treatment friends and family may help out with meals, errands, carpooling etc. When treatment ends this practical help often stops as well even though you may continue to deal with fatigue and other side effects. During the transition after treatment, don't be afraid to ask for help. Friends and family are often still wanting to lend a hand but need direction from you to know what you need and how to help as you start to recover.
- **5. Talk to Someone Who Gets It:** Whether online or face-to-face, connecting with other survivors can be very helpful. The AMBER Facebook

page was created for participants to interact and ask questions. Support groups moderated by a licensed professional can also be a good way to connect as well. These type of groups may not be for everyone, but you may surprise yourself.

6. Treat Yourself: Take the time each day to do something for yourself. This can be spending time journaling, going for a walk, meditating or deep breathing, reading a book etc. Ask your family for support to help make sure you follow through with whatever the activity is.

Getting a Good Night's Sleep



Sleep is important to conserve energy, maintain homeostasis and restore physiological processes that degrade while we are awake. It is reported that 30-80% of people with cancer experience sleep disturbances. Sleep disorders are linked to an increased risk of cardiovascular disease, diabetes, obesity, and depression. This is due to the body's response to a lack of sleep. Not having enough sleep can cause a decrease in resting metabolic rate and insulin sensitivity along with an increase in hunger and food intake. In turn, this lack of sleep can lead to weight gain and a decrease in activity.

What can we do to improve sleep?

- **I. Developing good sleep hygiene** It is important to have a regular schedule for going to bed and to avoid alcohol, caffeine and other stimulants before bed time.
- 2. Stimulus Control Go to bed only when you feel sleepy. Do not use your bed or bedroom for anything except sleep. Set your alarm for the same time each morning. Get up and go to another room if you have not been asleep for what feels like 20 minutes. Engage in relaxing activities such as light reading. Go back to bed when you feel sleepy or are ready for sleep. Repeat as needed.
- **3. Sleep Restriction Therapy** The goal is to limit the total time in bed to consolidate sleep and improve sleep quality. It requires keeping to a strict schedule of going to bed at a certain time and getting up at a certain time regardless of length or quality of sleep. Sleep is tracked in a daily sleep diary and time in bed increases or decreases based on sleep efficiency. It may take several weeks to see results. For more information on this therapy, contact your health professional.



4. Exercise - It has been shown that there is a positive trend between the amount of exercise you do and your sleep quality. Specifically, greater sleep improvements have been found with moderate to vigorous exercise, however, the specific dose, timing and type to optimally improve sleep remains unknown.

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