

The AMBER Report

SPECIAL POINTS OF

Baseline Paper Published

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www.amberstudy.com

ISSUE 20

Message from the Investigators

The snow is melting, the days are longer and the birds are chirping! Spring is coming! We hope that you have continued to stay safe and healthy during these unprecedented times.

In this edition of the newsletter, we highlight details from the first baseline paper which was officially published in January! We profile a year 3 participant in Edmonton and post some thoughtful



reflections from a year 5 participant on her cancer diagnosis and participation in the study. Lastly, we highlight the exciting sport of Dragon Boating and how you can get involved! In total, 1353 participants

completed their Year I assessment. To date, 1042 participants have completed their Year 3 assessment and 722 participants have completed their Year 5 assessment.

APRIL 2022

We say it each newsletter, but thank you again for your commitment and participation to the study!

We welcome any suggestions for future newsletters.

AMBER Baseline Paper Published!

We are excited confirm that our first paper on the baseline data has been published! This paper outlines the characteristics of all study participants and how these compare to other study cohorts. The investigators are writing hard at work additional baseline papers to look at different aspects of the data collected at baseline. For example, they are examining how quality of life data are related to data collected during fitness testing.



In our last newsletter we mentioned that we had submitted a grant application to the Canadian Institutes of Health Research to acquire additional funding for analyzing the blood samples collected at baseline and at Years I and 3. Unfortunately, we were not successful, however, we will be applying again in Fall 2022.

We continue to move forward with cleaning and analyzing the Year I data. These data will be compared with the baseline data to examine changes in the variety of collected measures.

As well, we are working towards another huge milestone for the study as we reach the end of our Year 3 follow-ups and also complete the last health-related fitness appointments for all participants.

AMBER Participants

Hear from other participants in the study!

CALGARY

Read a letter we received from a Calgary participant who completed her Year 5 follow-up.

To AMBER Study Staff & Participants,

It took two & a half years after treatment to feel enough energy for more activity. This is not the norm. I just thought I would not be able to do activities I did previously and that after surgery there would be limited movement. Not true!



There are still (many) days where I tell myself that 10-15 minutes of activity outside is better than zero, and that gets me out the door. Doing stretches as I'm waiting or idle gets them done. Seeking the right help was also important. For me, that meant a good physiotherapist, counsellor & connecting with people who "get it".

Earlier in my participation in the study, I felt embarrassed at how little I was able to do comparatively. Taking new medications and gaining a lot of weight didn't help either. But the AMBER study made me take the time to reflect what/how/when I was eating, sleeping, moving, etc. I started to make changes, which included my mind set and inner dialogue.

As I am filling out my 5 year questionnaires, I truly see how far I have come, especially in the past two years. So thank you, AMBER Study, and all the best to each of the participants. It's never, ever too late to take better care of ourselves!

EDMONTON



Edmonton participant Elizabeth T-S.

We profile Elizabeth T-S.

Who completed her Year 3

follow-up in Edmonton.

I have joined the Remark 30

Center and I walk 30

minutes a day at the to

What has been a highlight of participating in the study?

Seeing the results of my exercise tolerance after the first & third year postop. This process was a great motivator for me. When I received my year 3 results, my scores were better than the first year.

Have you made any lifestyle changes after receiving the results of your AMBER study testing?

I have joined the Rec Center and I walk 30 minutes a day at the track. I didn't run before this time and now run two laps a day. I also do stretches daily, especially on my affected side.

Even in very cold temperatures, I walk every morning before breakfast which gives me an opportunity to greet the day, smell the freshness of the morning and enjoy the view. This is for my own mental health & wellbeing.

Is there a quote/saying that spoke to you during your cancer journey?

Every radiation treatment, I would repeat this scripture to calm myself: 'Do not be afraid, for I am with you. Do not be dismayed for I am your God. I will help you and strengthen you. I will uphold you in my righteous right hand' (Isaiah 41:10).

What is one thing you are looking forward to doing again once restrictions are eased?

Travelling! I love to go to tropical places with my family. I also want to start a trivia club.

Kinship and Exercise Out on the Water

Dragon boating originated in China more than 1500 years ago and came to North America in the mid-1980s. Boats are about 12.5m long and manned by 20 paddlers under the direction of a drummer, who beats out the pace, and a steersperson.

There are two teams in Alberta for breast cancer survivors to join: In Calgary - Sistership Dragon Boat Association and in Edmonton - Breast Friends Dragon Boat Racing Team. Teams are open to all age groups and no previous experience is required.

AMBER participant Joyce Z., who trains with the Breast Friends team in Edmonton, highlights what it is like being involved in this sport.

"Using the sport of dragon boating, this team proves that life can be full, vigorous and filled with joy after a diagnosis of breast cancer. The team mission is to encourage active lifestyles, raise awareness about breast cancer, encourage the pursuit of a cure, provide support and fellowship to each other and to have fun!

Breast Friends have supported each other through the pandemic by hosting virtual training and social events. We are stronger together."

Members train together nine months of the year, both in the gym and on the water. While fun is the key, so is competition. Breast Friends have been to festivals across Canada and have participated in survivor festivals around the world. The next international festival is tentatively scheduled for Spring 2023 in New Zealand. Breast cancer survivors at any age or any fitness level are welcome!







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AMBER Baseline Descriptive Paper

The first paper describing the full cohort of 1528 participants has been published! It was published in January in the journal *Cancer Causes & Control*. The aim of this paper was to describe the characteristics of the full AMBER study cohort and compare it to other studies. Below we highlight some of the findings.

Stay tuned for additional baseline papers that will further describe the data collected. In particular, we will be comparing the health and fitness related data to the information collected on the self-reported questionnaires. A copy of the full article can found at www.amberstudy.com under About the Study - Publications.

Average Age 55 years old

The average age was slightly younger than the base population of Alberta breast cancer survivors. This is likely due to the requirement for maximal fitness testing.



Fewer Co-morbidities

Compared to other study cohorts, participants were relatively healthier with few co-morbidities (on average 0.5 conditions/participant) at the time of diagnosis.

Family History of Cancer 29%

Nearly a third (29%) of participants had a mother, sister or daughter who had been previously diagnosed with any cancer.



Less Diverse

Participants were mostly white, married, well educated and had higher household incomes and partially representative of the entire breast cancer population in Alberta.

Fitness Level Fair

Based on age and gender fitness testing norms, the average cardiorespiratory fitness level was considered fair. Baseline physical activity levels were comparable to other studies.



Low Smoking Rates

Only 6% of participants were current smokers. This rate is lower than the Canadian population smoking prevalence level of 12.3%, but comparable to other breast cancer studies.

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