

SPECIAL POINTS OF INTEREST:

- 1400th Participant!
- My Care Conversations App

INSIDE THIS ISSUE:

Exercise Specialist Profiles	2
My Care Conversations App	3
Lymphedema Study	3
1400th Participant!	4
Contact Information	4

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Message from the Investigators

We hope that you had an enjoyable holiday season and that you were able to take time to relax with family and friends!

This past December we were excited to reach a new milestone in the study since we recruited our 1400th participant. We are closing in on our goal of 1500!

In this edition of the newsletter, we profile two new Exercise Specialists who joined the AMBER team last year along with



our 1400th participant! We also highlight a new app designed by AHS for patients to use when visiting with their health care team.

Currently the study has enrolled 93% of the 1,500 participants we hope to recruit.

As of Dec 31st we have enrolled 794 participants in Calgary and 608 in Edmonton. To date, 1038 participants have completed their Year 1 assessment, 543 participants have completed their Year 3 assessment and 184 participants have completed their Year 5 assessment.

Thank you again for your commitment and participation! We welcome any suggestions for future newsletters!

Study Follow up

We are so thankful to all our participants who have participated in the AMBER cohort study. We understand that you agreed to participate at a difficult and overwhelming time in your life.

It is our goal to collect as much information as we can at each time point from all participants. The more information we are able to collect, the greater our ability will be to answer the research questions set out at the beginning of the study as well as to inform health practitioners and policy makers in the future.

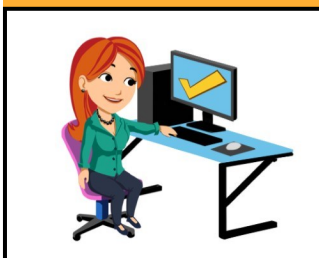
We understand that life is busy with various stressors and other commitments. Hence, we would like to encourage all of you to take time to complete the questionnaires at each time point as your information is very valuable to us.

Please know that the information we collect is not right or wrong, good or bad. We are trying to collect information that captures what you are doing and feeling. It is important to understand how you are coping from the time of diagnosis to the five year time point. As participants reach the five year mark, we cannot stress enough how important this last set

of questionnaires is for the completeness of our follow-up data on you. It helps us examine how things have changed for you over these five years and how these changes relate to your health and well-being.

We thank you again for your participation in the study and for the invaluable information that we have already collected.

Should you have any questions about any aspect of this study, please do not hesitate to contact our Study Coordinators in Edmonton and Calgary or the Principal Investigators for this project.



AMBER Exercise Specialist Profiles

Introducing two new Exercise Specialists who joined the AMBER team in 2018!

CALGARY

Nathaniel Minichiello joined the Calgary AMBER team in April of 2018. He has a MSc in Kinesiology from the University of Calgary.

What's your favourite holiday destination?

My favourite holiday destination is Boston. I go to Boston every year for the 4th of July as my Dad is from there and I still have a ton of family there. In April 2019 I will be going to run the Boston Marathon for my first time.

What is your favourite TV series?

My favourite TV series would have to be Game of Thrones. I have watched all



Nathaniel Minichiello
Calgary Exercise Specialist

of the episodes twice through and I just can't get enough of it.

What is your favourite book that you've ever read and why?

The best book I have ever read would have to be "Name of the Wind" by Patrick Rothfuss. It is well written and is a

mix of fantasy and adventure. My only complaint is that the third book of the trilogy has not been published yet so I'm becoming a little impatient about that!

Tell us about your pets?

I don't have any pets, but if I did I would have a dog, and I would name it Mookie after Mookie Betts, the greatest baseball player ever.

Who is the most famous person you have ever met?

While bartending in Calgary I had the opportunity to meet a couple of famous individuals on various occasions. I have met Martin Freeman, Colm Meaney and Common. They were all awesome.

EDMONTON

Jared Ferguson started working with the Edmonton AMBER team in April of 2018. He has a MSc in Kinesiology and Physical Education from McGill University.

What is your favourite TV series?

I seem to knock out a lot of great Netflix original series, so it is hard to pick a favorite. I found Bloodline to be really good. I enjoy basically any crime/drama/thriller-themed series.

In your opinion, what is one of Edmonton's best kept secrets, if you care to share?

Corso 32 in Edmonton. I don't think this place is really a secret, but it is by far THE best Italian cuisine I've had in Canada. I highly recommend it.

What do you usually eat or drink before and after a workout?

Before a workout I usually try and drink something caffeinated to get me energized and I'll eat a light, protein-based snack to tide me over until afterwards. Following a workout, I always get an additional serving of protein and something fruit-based to help kick-start the recovery process.

What's your favourite sport to watch live or on TV?

As a former player, hockey for sure. Sorry to all the Oilers and Flames fans out there... but I am a big Leafs fan.

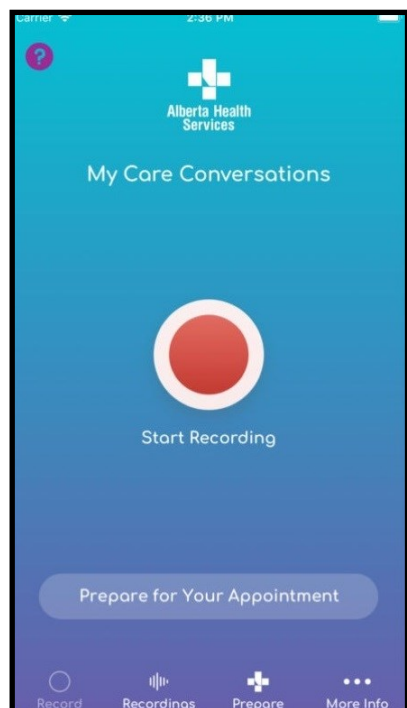
If you could pack your bags right now and go anywhere in the world for a week, where would you go?

During the winter I'd rather be anywhere hot. LA, Miami, the Caribbean, anywhere. During the summer months I'd choose somewhere in Europe.



Jared Ferguson
Edmonton
Exercise Specialist

“My Care Conversations” App



Patients and families report that clinic visits with their cancer care team can be stressful and overwhelming due to the amount of information provided along with the need to make decisions based on this information.

Research has shown that up to 80% of health care information discussed at clinic visits may be forgotten by patients. Being able to record and re-listen to appointments, along with sharing and discussing information with family and friends, can help reduce anxiety and improve recall of information when making an informed decision.

The My Care Conversations app was developed in partnership between CancerControl Alberta (CCA) and the Alberta Cancer Foundation (ACF).

It is free to download on the App Store (Apple devices) and on Google Play (Android devices) by entering and searching “My Care Conversations.”

The app has a built in tutorial that will walk you through the key functions of the app. There is also information about how to prepare for your upcoming appointment, make a high quality recording of your clinical conversation, re-listen to it after the conversation is done, and share it if you want.

For more information visit:

www.albertahealthservices.ca

and search My Care Conversations App

New Study on Lymphedema

A study out of the University of Alberta is showing positive results for women dealing with lymphedema. Dr. Margaret McNeely, an associate professor in the U of A's physical therapy department and investigator on the AMBER Study, is in the final stages of data collection for her study called “Night-time Compression for Breast Cancer Related Lymphedema (LYNC): A randomized controlled efficacy trial.”

The study investigated whether night time compression for breast cancer-related lymphedema improves arm lymphedema volume in breast cancer survivors. Along with the physical discomfort, patients dealing with lymphedema also have a higher risk of infection as bacteria can accumulate in the limb. It has been reported that 30% of women with lymphedema have problems with ongoing infections.

The study began in 2014 and completed data collection in December of 2018. Preliminary results are positive. The study suggests that women applying night time compression, either through the use of multi-layered bandaging or the use of a Velcro wrap system, along with the use of a daytime compression sleeve, have better control of their lymphedema compared to the use of a daytime compression sleeve only. As well, it appears that women who applied nighttime compression were found to have a reduction in limb volume of 15% compared to women who only used the daytime sleeve.



Final results of the study are yet to be published but will hopefully be used to guide practice and recommendations for those living with lymphedema.

1400th Participant!

On December 12th, 2018 the AMBER Study reached a new milestone and recruited our 1400th participant! Her name is Connie B. and she is from Calgary.

What were you hoping to gain from this experience?

I was hoping that this study may help in the future make things better and easier for other women to get through the experience. That they may find something they did not know before.

What was your favorite part of the testing experience?

My favourite part of the testing was meeting the wonderful staff, thanks to all.

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



Calgary participant Connie B. and Exercise Specialist Leanne Dickau

I have always been very active. I am now trying be more active again. I have a goal to be doing better at next year's testing as I have a bench mark to work with. I will be able to see my progression through my healing.

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

You will get through this. You never know how much love and support is out there till you go through this. Let this journey affect your life as little as possible and plow through.

Are there any programs/ resources you found helpful during your diagnosis/treatment?

I found a wonderful organization called Knitted Knockers who provided me with a free knocker. It helped me feel more balanced and showed me that people really care.

Is there anything else you would like to share about your breast cancer experience?

We need to be there for each other and connect with our support teams. The programs available will help us through. If you reach out there are so many out there to catch and support you.

AMBER Qualitative Sub-Study

We have recently received ethics approval to conduct a qualitative sub-study within the AMBER study. The sub-study will be conducted by Drs. Jeff Vallance and Lynn Corcoran who are co-investigators on the AMBER study. We will be interviewing AMBER participants over the phone or in person to understand your experience in the study.

Only a few participants will be contacted to ask for their potential participation. If you are contacted about this study, there is no obligation for you to participate and the data collected is separate from your current participation in the AMBER study. The information from this sub-study will help to inform us regarding retention and for developing studies in the future.

AMBER Study Contact Information

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