

Lymphedema Matters

Association of Ontario

Winter 2019 | Ontario Resources

Volume 22 Issue 1

LAO & LYMPHEDEMA AWARENESS

Quite a quarter!

First off, Maddie Simone, RMT, organized her 2nd Annual Lymphedema Awareness Walk on September 23rd in LaSalle Ontario. We want to thank Maddie, for organizing the event and Diane Lieder, who coordinated a raffle at the event. Maddie has also been asked to speak and answer questions at the Windsor Regional Hospital on November 27.

Furthermore, the Guelph Lymphedema Movement held their event, LYMPHEDEMA 101: A Learning & Social Evening, on October 1st. We want to recognize Hannah Sennit for all her efforts in educating people within the lymphedema community in the Guelph area.

On October 17th, Tony Wight, LAO Board Director, organized a booth at the Breast Reconstruction Awareness (BRA) Day Event at downtown Toronto. He was accompanied by LAO Advisory Committee members Ann DiMenna, PT, and Charlotte Schultz, former LAO Board Director. Thank you!

Shortly after, on October 20th, Ramona Herman, RMT hosted her second LE and LAO awareness event this year. She manned a booth at the Cancer Care Symposium in North Bay.

Lastly, the LAO participated in the Scotiabank Toronto Waterfront Marathon to raise LE awareness on October 21st. ■



Ramona Herman, RMT, CDT, at the Cancer Wellness & Awareness Day Event & Cancer Care Symposium, North Bay

LE Awareness in North Bay ON!

On Saturday October 20, 2018 in North Bay, Silver Linings held their 2nd annual "Cancer Wellness & Awareness Day" event for local cancer resources in our community. The day had speakers, products, services and support groups all in one location. The goal was to help inform patients, survivors, their families and the community about what resources are available locally.

This year, the wellness and information day ran in conjunction with the Nipissing Cancer Care Symposium and they expected to see up to 100 doctors attend.

This year's event featured over 50 booths. Representing the North Bay Lymphedema community, we had LAO member Susan

Woodman, RMT, CLT-LANA, with a booth educating patients about lymphedema and treatment options. Jody Gagnon from Robinson's Pharmasave had a table that focused on lymphedema products for patients to see. Jody is also a certified fitter and was able to help educate about the ADP process. I had my table set up to educate patients as well. Half of the table was dedicated to the Lymphedema Association of Ontario and had issues of the *Pathways* magazine as well as the LAO lymphedema information brochure.

Last year's event attracted over 400 people. Although the attendance numbers are not finalized yet for this year, I can say it was a great day and lots of connections in the community were made by all.

Ramona Herman RMT, CDT ■

Why Do I Walk/Run for LE & LAO?

"I just participated in our 2nd LaSalle Lymphedema Walk to raise awareness for lymphedema. I was diagnosed just over 2 years ago with Primary Lymphedema. I suffered for over 40 years with no diagnosis. Without my therapist, Maddie Simone, and Facebook Lymphedema groups, I would not have gotten this under control. We do need our doctors educated on lymphedema!"

—Diane Lieder, LaSalle Walk

2018 Lymphedema Awareness Walks

2nd Annual

Lymphedema Awareness Walk LaSalle/Windsor

Another wonderful day in LaSalle for the 2nd annual Lymphedema Awareness Walk! We had over 30 people join us for our fundraising fun this year and raised \$4000!!! Amazing swag bags were given to all participants and volunteers (thanks to Lymphedema Depot, Juzo, Jobst, the Verge Real Estate Group, and Cheung Trading Company Limited). We had performing dogs from Four Wheels Four Paws making our event so much fun!!

Thanks to our awesome volunteers! Thank you Diane Lieder for putting together another superb raffle draw! Congratulations to our top fundraiser two years running! Mrs. Margaret Broenink raised an incredible \$775 this year! A big thank you to our main sponsor Active Body Physical Therapy and mini sponsor Rob's Whole Health Pharmacy!

It feels so wonderful to be helping people with lymphedema each day! I've been a Certified Lymphedema Therapist for seven years and I love putting together this event! Raising funds to help the Lymphedema Association of Ontario create awareness and resources for lymphedema is an incredible feeling. Thank you for all your support this year!

Maddie Simone RMT CLT ■

Top 3 fundraisers this year

Margaret Broenink \$775
Maddie Simone \$680
Diane Lieder \$665

SWAG DONORS

Lymphedema Depot, Juzo, Jobst, the Verge Real Estate Group, and Cheung Trading Co. Ltd.



Team LaSalle/Windsor - Over 30 people from LaSalle, Windsor, and Essex walked to raise awareness for lymphedema.



Maddie Simone RMT (right)—walk organizer and Diane Lieder (left)—raffle organizer



Margaret Broenink

"I walked because my daughter, Diane, was diagnosed over 2 years ago with Primary Lymphedema in both legs! I will continue as long as I am able."
—Margaret Broenink, LaSalle Walk

Margaret completed the 3K walk in LaSalle and is turning 90 years old in December!

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Rob's Whole Health Pharmacy

Lymphedema Awareness Walk Toronto

On October 21st 2018, the LAO held it's annual Lymphedema Awareness Walk. Organized in affiliation with the Scotiabank Toronto Waterfront Marathon (with over 22,000 participants supporting diverse charities), the LAO had representatives in the 5K, the half marathon and the full marathon! In total, \$7,615.00 was raised in support of lymphedema awareness through generous sponsorship, donations, and fundraising. Thank you to everyone who came out and raised awareness and support for lymphedema! We are looking forward to further success in our walk next year on October 20th 2019!

Ana Stosic, Event Organizer ■



Kamila and David at crack of dawn in TO



Teal umbrellas made quite a statement!



Dan—support person



Deb's Dash: Kamila (1/2 Marathon), David (5K Run), Alexander (1/2 Marathon), Jessie (Full Marathon) and Debbie (5K Walk)



Full marathon runner, Jessie McAlpine!



The 5K Walkers: Allan, JoAnne, Jaclyn, Paul, Pouya, Carol, Ana, Tony and Debbie



Tony and Debbie at the finish line!

"Every small step towards awareness or raising funds makes a huge difference. I ran to support the Lymphedema Association of Ontario. What a beautiful community of kindness, compassion and support! I'm grateful for an opportunity to run to challenge my body and mind while supporting a great cause with some amazing people."

—Kamila Matsyiakawiecz, Toronto 1/2 Marathon

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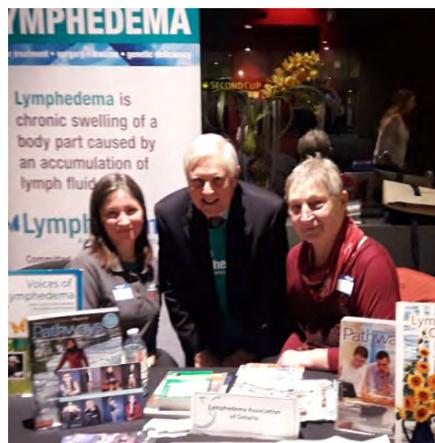
Breast Reconstruction Awareness (BRA) Day

By Tony Wight

Once again, the Lymphedema Association of Ontario (LAO) accepted an invitation by the Canadian Cancer Society to exhibit at the annual Breast Reconstruction Awareness (BRA) Day event. This was held in downtown Toronto, from 6 to 10 pm, on Wednesday, October 17, 2018 at the Glenn Gould Studio on Front Street. The LAO had quickly accepted as, based on our past experiences, we believed it would again provide an excellent opportunity to further our objective of improving the lives of people living with lymphedema, and those at risk, through increased awareness of the condition as well as information regarding treatment opportunities.

The LAO's exhibit booth was located in the lobby of the Glenn Gould Studio along with a dozen or so other exhibitors. Our booth was operated by two members of our Advisory Committee, Charlotte Schultz (a former LAO Board Director) and Ann DiMenna, PT, as well as Tony Wight, a new LAO Board Director. Speeches were presented by experts in the field during the evening and attendees visited the various exhibits both before and after the formal presentations, chatting with exhibitors, accepting a variety of informative handouts and enjoying refreshments provided in the lobby area.

The event was well attended. Many discussions were held by attendees with us and other groups. Several attendees, many of whom appeared relatively young, indicated that they were either breast cancer survivors, having had surgery or other treatments, or had received a recent diagnosis and were facing surgery or other treatments shortly. Several males also attended either in this capacity or as a member of an exhibitor team. Many health care professionals also attended.



Ann DiMenna, Tony Wight and Charlotte Schultz

We spoke with the full range of attendees. The level of their lymphedema knowledge varied. Some indicated to us that they were suffering from lymphedema, had heard about it and were concerned about getting it, or

knew of someone who has it. Many were attracted by our banner, poster and pamphlet displays. We proactively encouraged others to stop to receive our handouts and spend a few minutes chatting with us (most accepted our invitation). Our handouts included our pamphlet, current or back copies of *Pathways* magazine and our business card. Attendees seemed especially interested in *Pathways* insert, *Lymphedme Matters*, the LAO's newsletter and Ontario Resource Guide.

While several attendees displayed some knowledge of lymphedema, many others did not or were completely unaware of the condition. Those at risk for developing lymphedema, amongst others, were anxious to hear what we had to say about the condition, the need for early diagnosis, the types of treatment generally available and where to find treatment and related products. Attendees seemed grateful with the information and suggestions we gave and many indicated that, as a result of talking to us, they intended to do further research, using what we provided as the basis, and would consider calling our help line and accessing our website.

We believe this event was well worth attending and provided us with a meaningful opportunity to further our objectives. ■

Why Do I Walk/Run for LE & LAO?

"I chose to participate in this organization's fundraiser because lymphedema has had a unique impact on my family and my own life. After my mother's diagnosis with lymphedema, we became acutely aware of the challenges that this condition posed for her functionality and wellbeing. Through diligent maintenance and self-care, however, she has worked tirelessly to overcome these challenges so that she can be a force

for advocacy and support for others with lymphedema. I was honoured to have the opportunity to work with her and the LAO in this mission to raise awareness and funding to support those with lymphedema."

—David Bowman, Toronto Walk (5K Run)

"There is a great need for lymphedema research and advocacy within Canada. It is my hope that we will be able to raise funds for novel research and increase our current understanding of lymphedema not only within Canada, but for the global lymphedema population. Although I am currently living in Alberta, I am pleased to work with the LAO

and the Alberta Lymphedema Association (ALA) to promote and advocate for Canadian lymphedema patients. As a lymphedema researcher, it is my goal to contribute to the universal knowledge of lymphedema and quality of life of lymphedema for patients. I have begun to collaborate with the LAO on a new research endeavor associated with the LAO advocacy program. I greatly look forward to working with LAO board directors and members to improve the current status of lymphedema research within Ontario."

—Catharine Bowman, Toronto Walk Fundraiser ■

ADVOCACY Update

Juravinski Regional Cancer Center (JCC) has once again started lymphedema education sessions once a month. These sessions are open to patients and their caregivers who have been treated at the regional cancer center. A JCC Supportive Care program staff person also attended October's event to answer questions about accessing community services and funding through ADP for compression garments.

Debbie Ciotti-Bowman, LAO Board Director, was very happy to attend the October session. Debbie will be attending each monthly education session going forward, on behalf of the LAO network and as a cancer survivor who experiences leg lymphedema. Debbie was also able to discuss helpful lymphedema literature resources with the JCC librarian.

The October session was attended by 15 patients. Most attendees of this particular session were those who have experienced breast cancer related lymphedema or are at risk. It concluded with interesting general discussion about lymphedema and regional resources. This discussion included accessing certified therapists listed in this newsletter for early advice about lymphedema management, as well as cancer rehabilitation exercise programs in the Greater Hamilton Area. In particular, CanWell, a 12 week supervised exercise and education program for people who have been diagnosed with cancer and at any stage of their cancer treatment, was discussed.

It is excellent news to see this education program up and running again after a bit of a hiatus! It is of great assistance to patients at risk of, or who are experiencing lymphedema after their cancer treatment. Please call the Supportive Care Department at the JCC at 905-387-9711 ext 64315 for further information about these sessions if you are a patient of this regional cancer center and have lymphedema or have concerns about developing it.

By Debbie Ciotti-Bowman ■

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