



Lymphedema Matters

Association of Ontario

Summer 2018 | Ontario Resources

Volume 21 Issue 3

President's Message



Pouya Arefi, LAO President

Dear LAO members, colleagues, and the lymphedema community at large,

We are fast approaching the summer months and I am hoping that

everyone is looking forward to taking a well-deserved break from the cold season that we have had this year, like I know I am!

Here at the LAO, we are looking forward to the next few months, as we work to plan new events and build on our existing initiatives. The LAO continues to work on expanding and restructuring the board in an effort to strengthen its capacity to provide services and resources to members. Therefore, I am pleased to introduce our newest board member, Ana Stosic, as she transitions into her role assuming responsibility for overseeing event planning and volunteer recruitment.

In March of each year, lymphatic disease advocates come together in an opportunity to raise awareness about lymphedema across the globe, recognizing important days of awareness, be it Lymphedema Awareness Day, World Lymphedema Day, or Lymphedema Awareness month.

At the LAO, this represents a time of outreach and engagement, and we are pleased to have obtained a proclamation declaring Lymphedema Awareness Day from the City of Toronto. We would also like to acknowledge and commend all others around the province and across the country who worked persistently to raise awareness about lymphedema, not just during the month of March, but all year round. It is important that the lymphedema community unites and engages through these awareness activities, and the LAO has always made an effort to connect its members with local and provincial initiatives through social media and email outreach.

In addition to raising awareness, the LAO has always acknowledged the importance of original evidence in seeking change for the lymphedema community and were pleased to share the results of the Ontario Lymphedema Therapist Survey with you in the past issue. Building on this work, the LAO released a member-survey to gain further insight into lymphedema care in Ontario. We are currently working on processing the data to share with you in the coming months and would like to sincerely appreciate everyone who responded.

In the next couple of weeks, members will be receiving more information on the details of our Annual General Meeting (AGM) and fundraising walk. In an effort to ensure accessibility for all individuals across the province, the LAO will be hosting a virtual AGM this year. Once the platform is finalized, we will ensure that all members receive detailed information on how to access and participate in the AGM virtually.

This year, we are also excited to announce that the LAO will be participating in the Scotia Bank Charity Challenge on October 21, 2018 as part of the Scotiabank Toronto Waterfront Marathon. Given its magnitude and reach, this event provides an opportunity not only to fundraise but also raise awareness amongst thousands of attendants. We will be sending more information in the next couple of weeks and we highly encourage all members to consider joining the LAO team by either walking or running! We will also continue to provide the platform for members to incorporate a virtual and remote walk for those unable to attend the event in Toronto.

Above all, we always welcome comments and inquiries of all kinds that allow our members to be more involved with their organization and allow us to improve the services that we provide!

I look forward to working with the Board, for and with you.

Pouya Arefi ■

Spotlight on Primary Care Oncology Day

By Debbie Ciotti-Bowman

On March 28, 2018, the LAO's Advocacy Co-Chair Debbie Ciotti-Bowman and its President Pouya Arefi attended the Mississauga Halton Central West Regional Cancer Program's Primary Care Oncology Day as exhibitors in order to engage with primary care physicians and nurses, about the status of lymphedema in Ontario.

Offered as a Continuing Medical Education Event (CME) in conjunction with Cancer Care Ontario, the day was a tremendous opportunity for the LAO to engage with a significant number of primary care physicians and nurses to discuss the needs and concerns of Ontarians living with this chronic condition, and what their health-care providers can do to help them.

Physicians and nurses frequented the LAO's exhibit space, inquiring how they could access help for their patients, seeking confirmation on whether or not the Ontario Health Insurance Plan (OHIP) paid for lymphedema therapy, and how they could make referrals for their patients for appropriate therapy. Their concerns were confirmed when they heard that OHIP does not finance therapy and self-care education programs for lymphedema patients; with the difficult reality being that most often the patient is left to seek out the certified therapist and then must privately pay or have access to private insurance benefits to cover their life-long therapy needs.

10 Things I Want My Physician to Know About LE

To download and print, go to

https://lymphaticnetwork.org/documents/Ten_Things_Flyer.pdf

The event also provided an opportunity to discuss results of the Therapist Survey recently conducted by the LAO which anonymously illustrates the overall dynamics of 2,686 Ontarians with lymphedema who are receiving treatment, and the common concerns of Ontario lymphedema therapists regarding patients' inability to pay for adequate care for this incurable condition. Debbie and Pouya were also pleased to distribute the flyer entitled "10 Things I Want My Physician to Know About Lymphedema" recently created by the Lymphatic Education and Research Network in the United States and made available to the public for distribution.

Besides having their patient management questions answered, some physicians participated actively in discussion with the LAO's representatives, offering suggestions to solve the dilemma of the lack of awareness and financial support of organized lymphedema care in Ontario. It has been suggested by some primary care physicians that the LAO approach the Family Practice Residency programs of universities to present lymphedema and lymphatic system information in face-to-face sessions



Debbie Ciotti-Bowman at Primary Care Oncology Day Conference

with Family Practice residents who are about to graduate to independent medical practice. It was the opinion of the physicians recommending this, that MDs at this stage of their residency programs would indeed be attentive to presentations because many are seeing patients with lymphedema and do not know what to do to help them.

Additional physician recommendations included considering outpatient clinics that deal with particular diseases that may lead to lymphedema such as cancer, diabetes, cardiac and vascular disease clinics as potential locations for lymphedema programs to deliver therapy and teaching of self-care management. One physician suggested that companies that sell compression garments to lymphedema patients become engaged in helping to fund a provincial pilot project program for delivering organized care and self-management education to diagnosed lymphedema patients in these potential settings.

Overall, Debbie and Pouya appreciated attending this CME day as it provided a powerful platform to exchange information and engage in meaningful discussion with Primary Care health providers about lymphedema, the implications and the difficulties for Ontarians who live with this chronic condition. ■

Pink Crusaders Take on Lymphedema

By Judi Bonner

As a 13-year breast cancer survivor with lymphedema in my left arm, I was not aware that the Government of Ontario would cover 75 per cent of the cost of my compression garments through its Assisted Devices Program (ADP) until this was shared with me by a very knowledgeable massage therapist.

With the help of the well-informed team at Custom Comfort, I started wearing a compression sleeve, as well as compression stockings last year. They have been a godsend to me. I also started dragon boating with a breast cancer survivor team called the Pink Crusaders. Dragon boating is a fun sport and one of the fastest growing sports in Canada today.

In joining the Lymphedema Association of Ontario last year, I was fortunate to meet Ann DiMenna of the Markham Lymphatic Centre. With generous donations from both Custom Comfort and Ann DiMenna, the Pink Crusaders were able to purchase a pink tent for use at our numerous regattas last summer, and we will be able to purchase new hot pink t-shirts for our team this year.

I would like to thank the Lymphedema Association of Ontario for its great work, and Custom Comfort and Ann DiMenna for the support they have provided to our team.



The Pink Crusaders, a breast cancer survivor dragon boat team

We are always looking for new recruits for the team! The Pink Crusaders practice every Wednesday at the Balmy Beach Canoe Club at the foot of Coxwell Ave. in the Toronto Beaches from 7 – 8pm. We welcome any and all who would like to try out this fun sport! The first practice of the season will take place on Wednesday, May 2. Check us out at www.pinkcrusaders.ca or for more information, or email Judi at judi.the phoenix@gmail.com. ■

Celebrating Lymphedema Awareness

By Liisa Morley

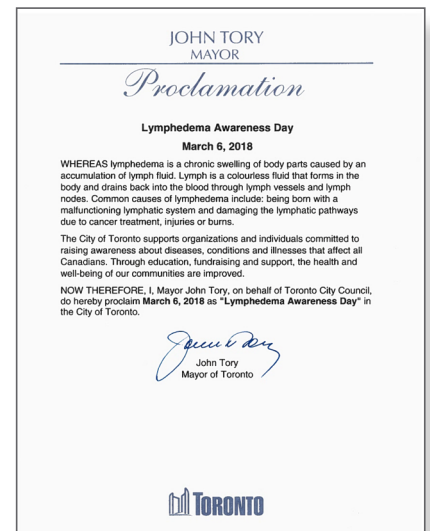
On March 6th, lymphatic disease advocates from around the world band together to mark a day of observance when the entire lymphedema community takes action to raise awareness of this under-recognized condition that currently has no cure, and the people who live with it every day.

We were thrilled to share that for the first time ever, the LAO had been successful in soliciting our province's capital to proclaim and observe Lymphedema Awareness Day on March 6, in the City of Toronto!

Municipalities across Canada, including the nation's capital of Ottawa, and others around the globe celebrated Lymphedema Awareness Day, and/or World Lymphedema Day. We were proud to join forces with lymphedema advocates, associations and networks from around the world to seize the opportunity of sharing our united voices in lead up to this important day, and throughout the month of March and beyond.

Several Ontario landmarks were periodically lit in teal to "Light It Up for Lymphedema," including the CN Tower, Niagara and Horseshoe Falls, the Peace Bride and Welland Canal Bridge 13. Be sure to check out LE&RN's website for a full-list and details of these and other international events at www.lymphaticnetwork.org/wld.

In addition, Canada's Calendar of Health Promotion Days documented March 6. Together, these awareness efforts are encouraging as the lymphedema community collaboratively advances the need for advocacy and research to make coverage and finding a cure a global priority. ■



SAVE THE DATE!

Scotiabank Charity Challenge

October 21, 2018, Toronto, Ontario

The LAO is joining forces with the Scotiabank Charity Challenge to create an opportunity for individuals affected by lymphedema to come together and join forces against this incurable disease, by raising both funds and awareness.

In 2017, participants raised \$3.5 million for 199 community charities through the Scotiabank Charity Challenge, which is offered through the Scotiabank Toronto Waterfront Marathon.



As Scotiabank covers all the fees associated with online fundraising, 100%* of the funds raised will go directly to your chosen charity.

Stay tuned and mark your calendars—we're busy getting everything prepared behind the scenes to bring you to the finish line! ■

RAM Rodeo, Rutherglen ON



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For details go to: www.rutherglenramrodeo.com

2018 Annual General Meeting

Virtual Meeting

June 19, 2018 | Virtual Meeting

Mark your calendars and join us at the LAO's 2018 virtual AGM!

We're looking forward to sharing our accomplishments over the past year as we continue to deliver on our mission to improving the lives of people living with lymphedema.

Due to the timelines associated with the production of this publication, registration details will become available directly from the LAO closer to the date. ■

Lymphedema Day at Custom Comfort

By Charlotte Schultz



Self-massage presentation for lymphedema patients at Custom Comfort

On Saturday, April 7th, certified lymphedema fitters and compression garment suppliers hosted a lymphedema information session for clients and others interested in learning about self-massage for lymphedema. The LAO's Advocacy Co-Chair Charlotte Schultz attended the event to raise awareness and engage with the participants on behalf of the LAO.

The session was organized by Custom Comfort at their Scarborough location with sponsorship from Juzo, a manufacturer of compression garments. The sessions were well attended, with the morning dedicated to arm lymphedema and the afternoon dedicated to leg lymphedema. Juzo had a product display and provided lunch. ■