



# Lymphedema Matters

Association of Ontario

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## President's Message



- **Debbie Ciotti-Bowman** - Director, Advocacy Committee Lead and Alternate for VP or President
- **Andrew Matta** - President, Fundraising Committee Lead
- **Barbara Foster** - Director
- **JoAnne Raditz** - LAO Manager, Graphics

What an exciting time for the Lymphedema Association of Ontario (LAO)! As we've shared recently, the association has been undergoing transformational changes that have brightened and inspired the future of the LAO!

To be able to embark on this journey to inspire change across the province, we needed to re-establish the foundation of the LAO, which for several years, has not had a physical place to call home...until now. On July 20th, we held our inaugural at-home board meeting, with all board members present in our new hometown of Milton, Ontario!

Having created the foundation of the association, the next item on the list was establishing our identity, which began with identifying roles for each of the board members. With that said, let me introduce the new and rejuvenated family of LAO:

- **Charlotte Schultz** - Director, Advocacy Committee
- **Cindy DeGraaff** - Secretary, Information/Education Line Coordinator
- **Ben Ciallela** - Treasurer
- **Liisa Morley** - Vice President, Communications Officer

Now that we have established a foundation and an identity, we can focus on building a great future together for the LAO. At our board meetings, we make a point of ensuring that the voices of patients are heard. Every email or concern we receive from members or patients across Ontario are taken very seriously. Our focus is to make sure patients are properly looked after, by applying the following; fundraising, advocacy and imposing changes across the province. We aim to be your vehicle in ensuring you have a voice, while raising awareness through ongoing education.

It's certainly an exciting time at the LAO, as eight people with great visions for the future have come together to discuss real opportunities and to spark change. However, just as Rome wasn't built overnight, LAO will need time to be nurtured as we establish a strong presence in Ontario. We ask you to be patient with us during this transition as we are all truly excited to be a part of this volunteer organization. With six of the eight of us having lymphedema ourselves, we have all experienced the challenges of navigating the healthcare system, and that is why we are so devoted to the LAO. This is personal for us!

We will be announcing some events and our AGM soon, so stay tuned! I am very excited about all of the hopes and dreams we have for the future. We're thinking big, but at the same time need to make sure we're being strategic with our plans to ensure the organization is sustainable! Furthermore, if you have an idea for an event, a fundraiser, etc, please do not hesitate to tell us. You are as much a part of this organization as we are!

In conclusion, I want you to know that we are here to spark change. We are here to raise voices, and to increase advocacy across Ontario. Far too many out there are suffering from this condition, and it's about time we stand up together to make necessary changes! ■

Andrew Matta, LAO President

### Let's Get Social!



Follow us on Twitter:  
@lymphontario



Like us on Facebook:  
LymphedemaAssociationofOntario

## DONOR SPOTLIGHT: Raising Awareness through Love and Music

Music is a language that connects to each of us through the heart.

On June 17 Leah Morise, a singer-songwriter in Fingal, Ontario held a concert fundraiser to raise awareness for lymphedema in honour of her mother Elaine, who has been battling the condition for years.



Leah contacted us before hosting the concert to let us know of her intention to donate all of the funds raised to the LAO in order to raise awareness about lymphedema.

Thanks to those who attended the event and those who donated through CanadaHelps. Leah and friends donated over \$1,400 to the LAO!

On behalf of all of the individuals we aim to serve across the province, thank you Leah for being a passionate advocate for this cause. Thanks also go out to Mike Bourgeault for his support and for playing at the show, as well as Jayne Bourgeault, Patt Durance and Welter Keirsebilck for donating the door prize.

As an organization run by volunteers we rely on the generosity of passionate individuals such as yourself who want to make a difference for others affected by lymphedema. We are grateful for your generous support. Together, we can do this!

Check out our Facebook page to view photos from Leah's concert and have a listen to her melodic folk/roots sound. Congratulations Leah on recently releasing your second album, Live At The House of Harmony! We are fans! ■

[www.facebook.com/Leah.Morise](http://www.facebook.com/Leah.Morise)



## Why advocacy is important to me

By Charlotte Schultz, Board Director,  
Lymphedema Association of Ontario

Lymphedema has been an unwelcome side effect of cancer treatment for me for the past six years. I developed lymphedema in my right arm during a flight from Toronto to Vancouver in 2010. I am a retired Registered Nurse and had ovarian cancer in 2002 and breast cancer in my left breast in 2003 and my right breast in 2007. During the flight where the lymphedema manifested itself, I wore compression sleeves on both my right and left arms and had manual lymph drainage prior to the flight. I had been aware of the risk of lymphedema and wearing compression sleeves and having manual lymph drainage were part of my regular "prophylactic" routine to hopefully prevent its onset.

The onset of my lymphedema has prompted me to want to be involved in advocacy as part of the Lymphedema Association of Ontario. As part of my advocacy I have two objectives. First, to raise awareness by meeting with leaders in both provincial and federal Health Ministries, hopefully including the Ministers, to educate and raise questions about funding for lymphedema research and care. My understanding is that lymphedema affects more patients than multiple sclerosis, muscular dystrophy, ALS, Parkinsons and AIDS combined. Personally, my lymphedema care costs are approximately \$3,000 per year which comes out of my fixed pension income. Ontario does not cover these costs but other provinces do, so why doesn't Ontario? Second, I am frequently sad, upset and shocked by the absence of knowledge of lymphedema in the medical community. There is minimal information in medical school curricula and to the best of my knowledge there is no centre for research, diagnosis, treatment

etc. in Ontario. Because of the lack of information and understanding the attitude of the medical community is often “be grateful you are alive, lymphedema is a small thing compared to the cancer you had”. This attitude is one of the most upsetting that I have encountered.

I hope that my advocacy will allow me to address and start to correct these problems. Thank you for allowing me to voice my opinions. We lymphedema sufferers need a voice and I am planning to use mine to benefit all of us. ■