



Reflecting on 2017

As we transition to 2018, I'd like to take a moment to reflect on the experiences of our board over this past year.

As still a somewhat new board, we gathered early in the New Year to complete a strategic planning session to decide on our key goals for this year. As a very small volunteer group, we decided it best to focus on attainable goals aligned with our skill sets in order to achieve results for our membership in Ontario.

Our goals were clear, we wanted to:

- Focus on expanding our membership
- Create an advocacy strategy
- Represent the LAO at industry events
- Continue maintaining the helpline and connecting individuals to resources
- Increase communication with our members and the lymphedema community throughout Ontario
- Raise enough funds to ensure the organization is financially sustainable

Despite some setbacks, including the departure of our president, our board continued to excel in our drive to help patients across the province. Highlights include a reduction in our patient membership fee to a cost of \$28, the creation of a therapist and patient survey to get a better picture of needs in Ontario,

increased reach on the LAO's social media channels, the distribution of this newsletter in electronic format, interactive dialogue with an abundance of requests for information received through the helpline, representation at a number of events, another successful AGM event, and support of our fundraising efforts.

Based on these successes, we feel that the LAO continues to be in a good position to attain our future goals. We are delighted to share that we have also recently recruited a new board member, Pouya Arefi who we will further introduce in our next issue. Our drive for recruitment is never over, however! We have an open invitation to join our efforts as a patient or health professional, as we are currently drafting terms of reference for a medical advisory board.

Having just attended the National Lymphedema Conference I truly feel that the future is bright. There is more discussion than ever, and having joined the provincial associations meeting held during the conference, it is evident across the country that the critical importance of advocacy has never been more imperative.

Even if you are unfamiliar with social media, I invite you to take a look at our social media channels for updates from

the conference. We shared a live video of the conference's poster presentations on Facebook, but on Twitter specifically I documented each session that I attended, with photos of slides and key talking points in order to share this information with the lymphedema community. Please take a look at www.twitter.com/lymphontario. You can also view the entire conference agenda and program, including session descriptions and speaker biographies at <http://canadalymph.ca/conference/program/>.

Personal Reflection

I'd like to end in sharing an experience I had at the conference that was profound for me personally. I have lived with primary lower extremity lymphedema for nearly 20 years. The first time I ever met others with lymphedema was when I decided to join the LAO board. How refreshing and awakening it was! Despite this big step I've admitted to myself that I have been somewhat in denial about my condition as I have not been practicing the type of self-care that is required to effectively manage this condition. A hectic career and a long commute should not be an excuse.

One of my personal goals in attending the National Lymphedema Conference this weekend was to get MY life back in check. During a session by psychologist Dr. Marc Hamel about building resilience and learning strategies to cope with lymphedema, I asked how he motivates his patients to maintain

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LAO Annual General Meeting

The LAO held its AGM on Sunday, September 24 at Swansea Town Hall in Toronto. We were excited and pleased to have members from many regions of Ontario in attendance and engaging



Hans-Jörg Clausmeyer, Compression Therapy Expert

in discussions around the operation of their Association. In addition, we were very happy to have the generous support of our sponsors and exhibitors that contributed greatly to making this event engaging for our members.

Moreover, a summary of the financial statement and the operations of the

LAO was presented, and we were pleased to inform members of the year's fundraising success, as well as the success of key services like the telephone/email Helpline, which services over 40 calls per month.

Furthermore, the Advocacy Committee provided a summary of important work that has been conducted over the past year. This included key surveying data of therapists in Ontario, educational and awareness initiatives, and active participation and advocacy in conferences and programs.

The afternoon was concluded with a guest talk by Hans-Jörg Clausmeyer, a compression therapy expert for more than 25 years. Hans detailed the approach to patient care for those receiving complex decongestive therapy at the renowned Foeldi Clinic in Germany. It was intriguing to gain insight into the way in which countries in Europe, such as Germany, provide coverage for higher level care for lymphedema patients. This includes complex decongestive therapy as well as education that promotes self-

management and a healthy lifestyle. Unfortunately, this spectrum of care is not organized and/or reimbursed for delivery to patients in Ontario and most areas in Canada. Therefore, this presentation highlighted the importance for Canadians with lymphedema to unite and speak out for provision of higher level care for patients living with this incurable chronic condition across the country.

Unfortunately, due to the extreme heat and humidity, reaching nearly 40 degrees Celsius, we decided to cancel the accompanying walk. Nonetheless, we would like to thank everyone who attended and phoned-in, as well as everyone who signed up to talk and raise awareness for Lymphedema!

By board directors Cindy DeGraaff, Liisa Morley and Pouya Arefi ■



Pouya Arefi - LAO Board Director
Debbie Ciotti-Bowman - LAO Board Director





Carol Houston - LAO Member, Charlotte Schultz - LAO Board Director and Susan Simons



Cindy DeGraaff, LAO Secretary



Ben Ciallella, LAO Board Treasurer



Michael Baldon, Barbara Shaw and Elaine Bladon, LAO members from Kitchener/Waterloo



Raffle time!!

Advocacy and Education Recent Events

By board director Debbie Ciotti-Bowman

At the annual AGM this past September, the LAO Board of Directors was pleased to present the results of the *Ontario Lymphedema Therapist Survey*. The survey was targeted to lymphedema therapists, and invitations were sent out to 76 listed therapists in Ontario. Of the 76 invitations, we received a total of 42 responses, achieving a 55% overall response rate. The responses reflected therapist accounts of 2,600 Ontario patients (anonymous), and allowed for an improved understanding of overall lymphedema trends and characteristics in Ontario. We are extremely thankful to our Ontario therapists for their time and effort in completing the survey, which provides us with great insight into the state of lymphedema care in Ontario. We will be publishing an article with the survey questions and results in our Spring 2018 Newsletter for your reading interest.

We have now launched our *Ontario Lymphedema Member Survey*, which aims to gather additional information about patient experience, and may be completed by the individual experiencing lymphedema or on their behalf (by a family member or caregiver). The survey also includes two questions for healthcare providers/therapists (including retired practitioners who previously worked with lymphedema patients), and we encourage all to participate.

This new survey was included in our last newsletter and is inserted again in this issue on page 8. Alternatively, the survey can be found on the home page of our website www.lymphontario.ca where it may be completed and submitted electronically. We greatly encourage everyone touched by lymphedema, whether you are a patient, family member of someone with lymphedema, caregiver etc, to complete this survey as it will provide important information that will inform and assist the Board in effectively advocating for Ontarians living with this difficult and chronic condition. Thank you so very much for your interest and your support! ■

Thank You 2017 AGM/Walk Supporters

RAFFLE DONORS



Ann DiMenna of Markham Lymphatic Centre

- **Markham Lymphatic Centre:** One set of Nordic walking poles and a Fleece Jacket
- **Custom Comfort:** Two \$100 certificates
- **David's Tea:** Gift Basket
- **Shopper's Markham:** Gift Basket

VOLUNTEERS

Thank you to all our volunteers including, all board members, Kristen and Chantel Altomare-Ciallella, Dominic Vilolante, Robbie Alvarez and Dan Bowman.



Shopper's Markham Gift Basket Winner

EXHIBITORS



Debra Hemming



Tammy and Katrina Jeffery



Bonnie Baker and John Mulligan RMT



Rosalind Tucker (Left)

EVENT SPONSORS

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2017 LE Awareness and Charity Walk

LaSalle/Windsor Team for Lymphedema Awareness!

We'd like to share our thanks with Maddie Simone and Diane Lieder for their outstanding efforts in raising awareness for lymphedema and funds for the LAO!

On September 24, 2017 Maddie, Diane and friends organized a walk for individuals in the LaSalle/Windsor/Essex area to create more awareness for lymphedema in this region.

Maddie has been a Certified Lymphedema Therapist for nearly 6 years and describes her care of lymphedema patients as her passion in life.

"I don't have lymphedema myself, however I do have a genetic heart condition that makes me vulnerable

to spontaneous aortic rupture," says Maddie. "I live with that fear every day. I have lost both of my brothers whom both had this condition as well. My lymphedema work is in their honour and has become my incredible passion for my work."

Diane is a client of Maddie, and is an incredible advocate for lymphedema. In addition to hosting the walk in September, Diane also organized a fundraiser in Chatham earlier this year in support of the LAO.

"Diane is a wonderful client and friend. She worked very hard in putting together the raffle draw and a huge portion of the funds raised came from her incredible team who all came from Chatham," says Maddie.

In all, 33 individuals traveled from Guelph, Chatham, LaSalle and surrounding areas to take part in the walk, which in total raised over \$3,495 that will go towards supporting the LAO connect patients with resources across Ontario.

By Maddie Simone and Liisa Morley ■

Top Fundraisers

LaSalle/Windsor—\$3,495

- Margaret Broenink – \$580
- Diane Lieder – \$510
- Maddie Simone – \$300

Ontario—\$2,885

- Charlotte Schultz – \$980
- Tammy Jeffery – \$830
- Debbie Ciotti-Bowman – \$200

Kitchener/Waterloo—\$1,290

- Alexis Bladen – \$500
- Michael and Elaine Bladen – \$350
- Barbara Shaw – \$200

Total Raised \$7,670



The Team LaSalle/Windsor—Walk included 33 participants and raised \$3,495!

Recent Awareness Events

June 30

Lecture and Demonstration on Lymphedema at Centennial College

Advocacy co-director Charlotte Schultz participated in a lecture and demonstration on lymphedema. It was a class with mature third year students. Charlotte has been invited to attend a subsequent session in November.

September 7

Managing Lymphedema at Sunnybrook

Charlotte also attended this event and it also was very well received and attended.

September 26

Garment Discussion at Custom Comfort

Charlotte Schultz represented the LAO again by attending a Q&A session on LE garments and, on behalf of the LAO, presented Hans-Jörg Clausmeyer a little gift and thank you letter for speaking at our AGM.

October 8

CIBC Run for the Cure in Markham

Charlotte Schultz represented the LAO by tending the Markham Lymphatic Centre booth at the CIBC Run for the Cure in Markham with Ann DiMenna. 1700 runners/walkers had registered—it was a very busy day.

October 18

Life After Breast Cancer Event, Hamilton

Advocacy co-director Debbie Ciotti-Bowman represented the LAO at Hamilton Health Sciences' Life After Breast Cancer event held at the Hamilton Convention Centre on October 18, 2017. Debbie was there to encourage discussions to create awareness about lymphedema. The day had a host of excellent speakers and resources including information about lymphedema.



Charlotte Schultz and Ann DiMenna at CIBC Run for the Cure, Markham



Hans-Jörg Clausmeyer and Charlotte Schultz at Garment Q&A at Custom Comfort



Debbie Ciotti-Bowman at Life After Breast Cancer Event, Hamilton



Anne Blair RN

1947 - 2017

The LAO would like to offer condolences to the family of Anne Blair, a passionate advocate for lymphedema, who we were saddened to learn passed away on June 29, 2017.

Anne Blair was an extremely compassionate and caring RN who worked for Sunnybrook Health Sciences in the oncology program at the Odette Cancer Clinic, where she worked for over 30 years before her retirement in 2012. Anne immigrated from Ireland with her family, and received her nursing education at the Toronto East General Hospital. A major focus of Anne's care included patients with breast cancer. She worked tirelessly as an RN consultant to doctors to advise about lymphedema and best care plans for their patients with the condition, and to patients of the cancer clinic who had the diagnosis of secondary lymphedema.

With the backing of the nursing administration and surgeon Dr. Glen Taylor, a lymphedema clinic was established in the 1990's, likely the first of its kind in Canada. Patients were assessed and teaching provided regarding self-care and management, with referrals made to therapists and garment fitters in the community.

Anne encouraged fellow colleagues in all cancer sites and the clinic grew to include patients with various cancers. Anne fielded many calls from professionals and patients eager for support and knowledge.

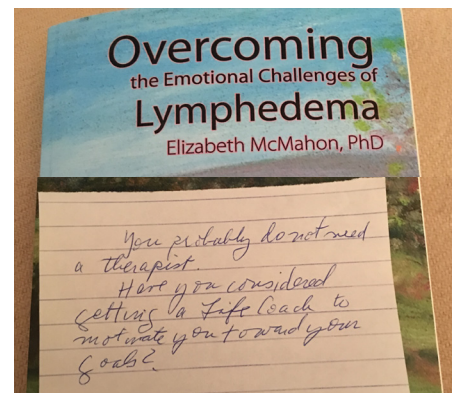
Anne became a member of the LAO board in 2000 and hosted all its board meetings from then on until the LAO opened up its first office on Dundas Street. Serving on the board until 2009, Ann started out on the conference planning sub-committee and served as Vice-President for several years.

Anne was a keen advocate for lymphedema care, and her compassionate care, support and friendship are greatly missed. We would like to ask the lymphedema community to join us in acknowledging Anne for the many years and hard work she put in to getting lymphedema on the map, and her work with LAO. We'd also like to thank Susan Bowles and Anna Kennedy for sharing insight on Ann's career and legacy in order for us to share this memoir with our membership.

By board director Liisa Morley ■

Continued from front page...

their self-care regiment. Of course, he basically told me the answer I already knew, I just have to do it! During another session that day, a sweet elderly lady traveling with a walker wheeled up to where I was sitting and said that she had to leave but that she wanted to share something with me. I was a bit puzzled as she dropped a little piece of paper in front of me. Did she think I was one of the organizers accepting questions for the final plenary session? I then looked down at the piece of paper as she strolled away, and I realized it was meant for me, and managed to squeak out a thank you. I was so touched that she took the time to share these words of advice and encouragement. When the conference ended I took a look at the books for sale. Upon flipping through "Overcoming the Emotional Challenges of Lymphedema," I immediately landed on a page about setting and prioritizing my personal goals. It was serendipity! I'm not sure who this earth angel was, but if she is out there reading this, thank you!



Lymphedema is a life-long chronic condition with no cure. While struggling with this reality is difficult, I'm so encouraged by all of the wonderful people I've met on my journey who always go the extra mile to raise each other up and to give us the strength to hang in there! I'm so grateful for this opportunity. To all of my fellow lymphies, thank you for the love and support. We'll get through this together!

By board director Liisa Morley ■

Let's Get Social!

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[@lymphontario](#)

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[LymphedemaAssociationofOntario](#)

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LAO Member Survey

As a newer Board of Directors for the Lymphedema Association of Ontario (LAO), we have a list of questions about the dynamic of the people we are trying to serve and assist.

We invite you to read them over, and share your answers with us so that we can effectively strategize about best ways to serve people living with lymphedema and/or their caregivers here in the province of Ontario.

1. Please choose all that apply to how you would identify your connection to lymphedema:

- Person with lymphedema
- Caregiver, family or friend of a person with lymphedema
- LAO member
- Doctor specializing in lymphedema care
- Therapist certified in lymphedema care (choose one or more qualifications below)
 - Physiotherapist
 - Massage therapist
 - Occupational therapist
 - Nurse
- Other _____

2. What lymphedema-related issue do you feel is most pressing in Ontario? _____

The following questions 3-18, are for lymphedema patients OR their family or caregiver to answer on their behalf:

3. What type of lymphedema do you have? Primary Secondary

4. What are the main causes of your lymphedema if it is secondary? _____

5. If your lymphedema is secondary to cancer surgery and/or radiation, was it explained to you that this might be a possible side effect?

- Yes No Comments: _____

6. What part or parts of your body are affected by lymphedema?

- Arm Leg Other: _____

7. How long have you had lymphedema? _____

8. How old are you? _____

9. Are you male or female? Male Female

10. Are you able to find the care you need to be able to effectively manage and control your lymphedema?

- Yes No Comments: _____

11. If you answered no to question 10, why did you not receive such care?

- Lack of financial resources
- These treatments are not available in my area
- I was not aware of the existence of this therapy
- Other: _____

12. What does your self-care and/or your therapist-care consist of, to effectively manage your lymphedema?

13. Have you been treated by a lymphedema therapist certified in combined decongestive therapy (bandages, manual lymphatic drainage, specific exercises)?

- Yes No Comments: _____

14. If you answered yes to question 13, do you consider this therapy to be essential and effective for lymphedema management?

- Yes No Somewhat

15. Do you have private insurance to cover your treatment costs, or do you have other methods to cover your financial costs of treatment?

16. How often do you wear compression garments and/or night garments? (ie 75% of the time, 100% of the time, etc)

| | Never | 25% | 50% | 75% | 100% |
|----------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Compression Garments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Night Garments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. Have you ever had cellulitis or skin infections that have required antibiotics because of your lymphedema? Yes No

18. If you get cellulitis often, how often? _____

19. Healthcare Professional Member comments for the LAO Board:

20. Name (optional) _____

21. Address/Region (optional) _____

22. I would like someone to contact me regarding LAO Board and/or volunteer opportunities.

Phone: _____ email: _____

Please complete, scan and email to accounting@lymphontario.ca

or mail to: Lymphedema Association of Ontario
299-3044 Bloor St. West, Toronto, ON M8X 2Y8

A link to fill out and submit this survey is also available on our home page at www.lymphontario.ca.


We would like to thank all who have already submitted this survey.


In Ontario, *Pathways* magazine is distributed by the Lymphedema Association of Ontario to active members.

LAO membership sign up or renewal options:

Membership includes an annual quarterly subscription to *Pathways*

 **Online:** Go to www.lymphontario.ca

 **Phone:** Call 416-410-2250 or **1-877-723-0033**

 **Mail:** Please make your cheque payable to: **Lymphedema Association of Ontario**. Call or email us for membership forms.

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Mailing Address: 299-3044 Bloor St. W., Toronto, ON M8X 2Y8 Canada
info@lymphontario.ca | **1-877-723-0033** | 416.410.2250

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