



Lymphedema Matters

Association of Ontario

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Expanding Our Leadership Reach

In a recent communication sent to our electronic mailing list, we announced that our President, Andrew Matta, made the personal decision to step down from his role as president and member of the Lymphedema Association of Ontario.

As a board that values transparency, we believe it is important to inform the lymphedema community of Andrew's resignation. We intend to move forward with recruitment efforts to solidify our board structure.

We wish Andrew continued health and happiness as he continues his personal journey.

To ensure that our commitment to the lymphedema community is unfaltering, our board is actively looking for a new president that will further our mission and provide leadership for the LAO's strategic direction.

Additionally, as a volunteer-run organization, the LAO is always looking to expand its capacity by recruiting new board members and volunteers with professional skill sets in fundraising, event management, administration, finance, healthcare management, and communications.

If you want to increase awareness for lymphedema and join a group of dedicated volunteers that are affected by this life altering condition, please contact us at info@lymphontario.ca. Make sure to describe your skill set and where you think you would be able to offer your support.

We have also begun to hear from the medical community regarding our interest in establishing a medical advisory committee. As we are not medical practitioners ourselves, their expertise and guidance will be invaluable in our effort to provide information about lymphedema and lymphedema resources in Ontario.

Whether your background of experience would suit the role of president, director, or medical advisor, I strongly urge you to please consider joining us. We are an energetic group of individuals brought together by this condition, and we are fighting for advocacy, awareness and change! Together, we are stronger.

By Liisa Morley ■

To my fellow members of the LAO,

I regret to inform you that, after careful consideration, I have chosen to step down from my role as the president of the LAO. My time spent on the board was nothing but an amazing, inspirational, and educational experience. I learned a lot about myself as well as the members suffering from lymphedema across Ontario. I may have stepped down from the LAO, but my passion for lymphedema has not been changed. I will continue to fight for this disease as long as I can, however I can. My position as president was challenging yet rewarding.

My fellow board members have been nothing but amazing. I learned a lot from each and every one of them. I urge you to participate in the fight against lymphedema with them; whether joining the board as a member or volunteer, your help will go a long way.

Yours truly,

*Andrew Matta,
Former LAO President*

Advocacy and Education

Recent Events

As part of our advocacy initiatives, we are committed to actively taking part in lymphedema related events, to help spread awareness and education. Our advocacy co-chair, Charlotte Schultz, recently participated in two events held at Sunnybrook Health Sciences Centre and Centennial College.

On May 25th Charlotte joined 132 individuals living with cancer-related lymphedema, and their loved ones, for an evening of learning. Hosted as part of Florence Winberg Education series at Sunnybrook's Odette Cancer Centre, the patient education evening featured practical strategies for living with lymphedema and tips on how to self-manage.

In addition to Charlotte's remarks on behalf of the LAO, presentations were delivered by Anne Dimenna, a physiotherapist, Jean LaMantia from the Markham Lymphatic Centre, and Ingrid White, a registered nurse from the Odette Cancer Centre, a patient advocate, and an educator from Sunnybrook.

A future session is being planned for September.



On June 30th, Charlotte joined 12 third-year registered massage therapy students at Centennial College's Morningside Campus to share information about lymphedema. As part of the program's curriculum, Centennial has integrated lymphedema lectures with hands-on demonstrations.

The college referred to the session as a welcomed opportunity to further lymphedema knowledge and introduce the LAO to its students. Charlotte has been invited, and looks forward to joining the college again in September to continue this rewarding work. ■

NEW Reduced Patient Membership Rate

With a goal of increasing our membership to connect with more patients across Ontario and to help ease the burden of costs associated with living with lymphedema, the LAO Board made the strategic decision to reduce our patient membership fee from \$50 to \$28 annually.

We feel this is in the best interest of connecting with more individuals across the Province. Professional rates will remain the same.

For more information on becoming a member, please go to: <http://www.lymphontario.ca/membership>. ■

New and Developing Support Groups/Programs

We are continually updating information about LE support groups/programs. We have heard about interest in Windsor, and have confirmed details about a group set to meet in Burlington. The Kitchener/Waterloo support group and lymphercise class have updated their contact information. Also, the Hearth Place in Oshawa is discontinuing their support group but added other programs for lymphedema. See details for all on page 3. ■



Barbara Shaw (left) and Elaine Bladen of the Kitchener/Waterloo support group

Ontario LE Support Groups & Programs

Brantford

Brantford Lymphedema Support Group

Meetings are held every second Friday of the month, 10am to 1pm, at St. Joseph's Lifecare Centre: 99 Wayne Gretzky Parkway, 4th Floor.

Registration Only—contact Pam Monarch to register at 519-751-7096 x3414

Burlington

Head to Foot Oasis Wellness Clinic LE Support Group

Meetings are held on various dates throughout the year at Head to Foot Oasis Wellness Clinic, 5115 Harvester Road, Burlington ON

Next Meeting: Lymphedema Awareness Night

Tuesday, November 7, 2017 at 7 p.m.

Spots are limited. Please RSVP by October 15 to secure your spot to: info@headtofootoasis.ca.

Goals of the session:

- What is Lymphedema?
- What are the signs and symptoms?
- Can I prevent Lymphedema from progressing?
- Treatment options
- Self-care options

For more information on future meetings please call or email: 905-332-6542, info@headtofootoasis.ca

Kingston

Breast Cancer Action Kingston

The Breast Cancer Action Kingston Lymphedema Support Group meets periodically during the year on an "as need" basis.

One-on-one support is available. Call to connect with a facilitator.

Exercise and Yoga programs including a lymphatic yoga class are available with a paid up membership.

For more information contact Breast Cancer Action Kingston 613-531-7912 • admin@bcakingston.ca • www.bcakingston.ca 110-650 Dalton Ave. Kingston ON K7M 8N7

Office Hours: 12:00 - 4:00 Tues-Fri

Please don't hesitate to contact us to tell us about your support program, or interest in getting one started!

Kitchener/Waterloo

Kitchener/Waterloo Lymphercise Class and Support Group

Lymphercise Class

- Every Thursday Morning 10 to 11:30 am
- Redeemer Church, 78 John St W, Waterloo, ON N2L 1B8
- Free classes with Free Parking

Kitchener/Waterloo Support Group

- Meets on various dates and locations

Please call Barbara Shaw at 519-585-7748 for details on both the Lymphercise Class and Support Group

LaSalle/Windsor

Active Body Physical Therapy LE Support Group

Coming soon. Will meet monthly.

Contact Maddie at 519-890-3068 or maddie.simone@yahoo.com

Oshawa

Hearth Place Cancer Support Centre

- 1. Lymphedema Education and Assessment Program (LEAP)**
 - by appointment, first and third Monday of each month, 9am to 4pm
- 2. Aqua Lymph Therapy (ALT)**
 - 6 to 8 week program—LEAP is a prerequisite
- 3. Yoga for Lymphedema**
 - 6 to 8 week program—open to all

86 Colborne St. West, Oshawa L1G 1L7

For start dates, more information and/or to register, call Janette at 905-579-4833 or email her at Janette@hearthplace.org.

Ottawa

Breast Cancer Action Ottawa

Workshops to learn about secondary lymphedema, how to self-monitor, important lifestyle recommendations, where to go for help and how to delay the onset or manage lymphedema.

The Fit and Fab Program is an exercise program designed for breast cancer patients to minimize and reduce the risk of lymphedema.

To register for the lymphedema workshop or exercise programs, please call Breast Cancer Action Ottawa at 613-736-5921 or visit www.bcaott.ca.

Peterborough

Peterborough Lymphedema Support Group

Please contact Bridget or Janice regarding registration for a future meeting: **Bridget - 705-876-3333 or Janice - 705-876-8561**

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: _____

Thank you for your time and effort which will ultimately help us all to work together most effectively to represent and advocate for the lymphedema population in Ontario.

Sincerely,

The Board of Directors of the Lymphedema Association of Ontario, Debbie Ciotti-Bowman, Charlotte Schultz, Liisa Morley, Cindy DeGraaff and Ben Ciallella

Sunday, September 24th, 2017

We are very busy organizing our second annual AGM & Walk Event. This event may have taken place by the time you receive this issue. We will have a detailed article in our Winter edition. We want to thank those that have stepped up early to lead a walk, exhibit or sponsor.

2017 LAO AGM SPEAKER

Hans-Jörg Clausmeyer

Compression Therapy Expert

2017 LAO WALK LEADERS*

- Maddie Simone RMT, Active Body Therapy, **LaSalle/Windsor**
- Barbara Shaw, **Kitchener/Waterloo**

2017 EVENT EXHIBITORS*

- Bonnie Baker and John Mulligan RMT, Lymphedema Depot

2017 EVENT SPONSORS*

GOLD



BRONZE



*at time of submission of this newsletter insert—please see our website for final list.