



Lymphedema Matters

Association of Ontario

Summer 2016 | Ontario Resources

Volume 19 Issue 3

President's Message



Hello Everyone!

This is an inspiring time to lead the Lymphedema Association of Ontario (LAO) into a new era, as gradually more individuals are

globally joining the conversation about this unbearable condition. I am especially looking forward to encouraging change in the way we talk, treat, and manage lymphedema, both provincially in Ontario, and nationally in Canada.

I've lived with lymphedema since October of 2007, and since then, I've been fighting this battle. I have been fortunate enough to have friends and family that have helped me through the many ups and downs. I'm sure you'll agree that living with lymphedema isn't easy, and is not something to be overlooked, ignored, or pushed to the side.

Lymphedema isn't a mild condition to be taken lightly by the patient or the physician. It is not a condition that can be treated by taking a pill in the morning, and continuing about our day. It requires patience, pain tolerance, rest, good hygiene, bandaging and wrapping, compression stockings, as well as lymphatic drainage, among other things. It is a tough condition to handle, and for that, we should all be proud of fighting this battle every day.

It has been 20 years since the LAO was founded in 1996 when a group of patients

and family members came together to support one another. Twenty years later, that support system is still here! We are here to support each other, and we are here to guide one another in the journey of obtaining the best treatment. Moreover, we are here to serve you!

As we move forward to build on the commitment that started the LAO, the only thing that will be changing is the level of awareness for lymphedema as more voices unite. For the first time in history, World Lymphedema Day was declared on March 6th, 2016. This is just the beginning of something great, and for that, we should all be excited and looking forward to a brighter future.

I am thrilled to join my fellow board members, an active group of individuals who have been affected by lymphedema in their own ways, and who collectively have the talent and determination to lead this transition. We are honoured to work together to unite individuals battling lymphedema across Ontario. Together, it is our goal to ensure that ALL patients have the support they need to handle a condition like this.

Remember, this association is here to make sure YOU have a voice. You are a very important part of the Association. Join us. Become a member. And be a part of this great movement.

Wishing you all the best in your journey. Stay strong and be persistent.

Andrew Matta, President

My Inspiration

Last April, it was determined that the LAO could not sustain the cost of an executive director or renting an office plus, three board directors had resigned due to health conditions. Ben Ciallella and Barbara Foster asked me to stay on part time to manage the LAO for three months until they figured things out. After the office was dismantled, I started working from my home office.

Well it has been over a year! I want to thank Ben who overlooked as I found ways to cut costs, and worked with me to continue with the business side of the LAO. Barbara Foster went above and beyond throughout the year. When there was talk of not running or participating in any events because of the lack of manpower and funds, she disagreed. She was a team leader for the walk and organized a bake sale to raise money. She manned the LAO booths with me at various conferences to create awareness (one all on her own in Barrie). She kept pushing and making calls for a new Board of Directors. She answered the info line calls.

Barbara did all of this and continues regardless of her battle with cancer. Her optimism, determination and genuine concern for all the lost, confused and suffering people who have lived with or are starting their journey with lymphedema is so motivating—she was the reason I volunteered countless hours doing everything else besides the administrative work that it took to keep the LAO going. She is my inspiration not only at the LAO but to fight the many other personal obstacles that have come my way.

JoAnne Raditz, LAO Manager | Graphic Designer

Support Group Spotlight: Hearth Place Cancer Support Centre

As a drop in centre, with the comfort of a home-like atmosphere, Hearth Place Cancer Support Centre is committed to providing community support for patients and their families dealing with cancer through peer support, information, a resource centre, wellness programs and practical assistance. Located in Oshawa, Ontario, Hearth Place is a support centre where cancer patients and their families can come and share their experiences, find resources, and discover new ways to care for themselves and each other.

A local community cancer support centre LEAPS into action to support people living with lymphedema

Extension of Survivorship Program

As an extension to our survivorship programs for our members, we have been developing programs to address the late effects our members are experiencing. We found that very little information about prevention and risk assessment of lymphedema was being given to patients from the time of diagnosis, through treatment and survivorship. Information was not readily available in the community and many of our members had not heard of Lymphedema.

Responding to all the latest literature on best practices for education, assessment, treatment and management of lymphedema, Hearth Place is providing a number of support programs for its members.

Lymphedema Education and Assessment Program (LEAP)

On March 7, 2016, we opened the Lymphedema Education and Assessment Program (LEAP) to offer early and accessible education and assessment to those living with a cancer diagnosis. The focus is to provide individual education into risk reduction and self-care management. Ideally, assessments are done at the time of diagnosis, post cancer treatment, every six months for two years, and every year for three years.

LEAP services are provided by Jason Mandalentis RMT MLD/CDT ALT who witnessed his mother struggle with lymphedema and has a passion to ensure that women and men are educated and empowered to reduce their risk and effectively manage their lymphedema. All participants are provided with the findings and documents to be shared with other HealthCare Providers.

Aquatic Lymphatic Therapy Program

Members who have been through LEAP are then eligible to join our Aquatic Lymphatic Therapy Program. Developed by Dorit Tidhar, aqua lymphatic therapy is based on the principles of the Casley–Smith exercise program for lymphedema and is applied in an aquatic environment. The method enhances lymphedema therapy by combining the principles of lymphatic anatomy and physiology, with the effect of water immersion. This is a powerful tool for our patients who want to become more active and independent.

Yoga for Secondary Arm Lymphedema

Throughout the year, we also offer Yoga for Secondary Arm Lymphedema. An extremely gentle yoga program, it is designed specifically for those with, or at risk of developing, secondary arm lymphedema. Based on the research of Annette Loudon, MMedSc (President of the Australian Association of Yoga Therapists) it is the first time it has been offered in Canada. This program helps to prevent and alleviate the symptoms of lymphedema, teach techniques for coping with the emotional challenges of lymphedema, and provides tips for incorporating lymphedema exercise into daily life, a few minutes at a time.

Peer Facilitated Support

Monthly, we provide a peer facilitated support group to address the emotional impact experienced by our members who are at risk for or have swelling due to Lymphedema. Guest speakers, local resources and workshops demonstrating lymphatic drainage techniques are also provided.

We are encouraged by the response from our members who have had tremendous results from all the support programs and who feel listened to, supported and empowered by knowledge and a community of support.

Hearth Place is a local, non-funded charity who is very appreciative of the financial support from private donors, Ontario Power Generation, Lions Club and the Baagwating Community Association which has been dedicated specifically to this program for 2016. For more information, please visit www.hearthplace.org.

By Andrea Shaw, Executive Director of Hearth Place Cancer Support Centre, Oshawa Ontario.

AGM Highlights

On March 7, 2016, LAO held its 2015 Annual General Meeting by web conference; thanks to everyone who was available to join us.

- 32 voting members attended the AGM.
- Quorum was reached and the meeting was called to order at 7:05 p.m.
- The LAO's 2014-2015 financial statements were approved as presented by Ben Ciallella and independent auditor Mellissa Coulson.
- The slate of the new Board of Directors was approved as presented.
- The motion to renew two Board Members' second three-year terms was approved.

Following the business portion of the AGM, participants were fortunate to learn from two engaging presentations.

- Andrew Matta addressed the membership to relate his personal story with lymphedema and to share what has inspired him to seek election to the LAO Board.
- As an invited guest speaker, Catharine Bowman spoke about her involvement in the lymphedema community

as an advocate and high school molecular lymphedema researcher. Thanks for sharing your inspirational quest with us Catharine, and we wish you the best in your continued studies!

The full AGM agenda and supporting documents as presented at the meeting are available for viewing at lymphontario.ca.



Overall, it was acknowledged that this year marks the beginning of a new era for the LAO, with a new Board of Directors armed with a new set of skills and passion to advance the organization to its next level as the provincial voice and advocate for quality lymphedema knowledge and care.

Board of Directors

Returning LAO Board Directors

We are very fortunate that Ben and Barbara will continue to volunteer their skills to the benefit of the LAO.



Ben Ciallella • Markham • Treasurer since 2013

Ben is a Managing Director at the National Bank of Canada and lists his strengths as financial, leadership and strategic thinking. Ben first contacted the LAO for help in supporting a family member who has lymphedema. He subsequently became a board member in 2013 as Board Treasurer as a way of giving back to the lymphedema community.



Barbara Foster • Hawkestone (Barrie) • Director since 2013

Barbara recently retired as Vice President and Investment Advisor at TD Waterhouse and hopes to contribute her communication skills and board experience to the LAO. Barbara has served on various charitable committees and boards, such as the Women Entrepreneurs of Canada and the Advocacy Centre for the Elderly. She has personal experience as a lymphedema patient and is eager to help others.



Andrew Matta • Milton • President

Andrew is a pharmacist by profession who recently delivered the keynote address at the 2015 LE&RN Walk to Fight Lymphedema and Lymphatic Diseases in New York City. Andrew's road with lymphedema has been filled with ups and downs, and he is committed to bringing the struggles associated with lymphedema to doctors' attention. He looks forward to sharing his inspirational story about his leg surgery which has contributed to his lymphedema recovering remarkably to provide hope for others.



Liisa Morley • Hamilton • Director

Liisa is a Communications Specialist at PCL Constructors Canada Inc., Canada's largest construction contractor. With 12 years' experience as a professional communicator, Liisa has developed a sound understanding of the healthcare environment in Ontario, having led communications for the development and opening of a new hospital and cancer centre in St. Catharines. Diagnosed with primary lymphedema at the age of 20, Liisa has a personal interest in raising awareness of the condition and treatment of lymphedema, and looks forward to volunteering her professional skills to the LAO in the hopes of helping others grappling with this disease.



Cindy DeGraaff • Whitby • Director

As a social worker with over 20 years' experience in the non-profit sector, Cindy is looking forward to working with the LAO in achieving its vision of supporting and advocating for individuals living with lymphedema, as well as educating the professionals whose job it is to provide timely care to their patients. This is a cause close to her heart, as both Cindy and her husband are cancer survivors now living with lymphedema as a result of their treatments. She is excited about the possibilities for the coming year and looks forward to working with the Board and all the members of the LAO to shed light on this often misunderstood and misdiagnosed condition.



Debbie Ciotti-Bowman • Dundas • Director

Debbie is a cancer survivor and has lived with leg lymphedema for eight years after cancer surgery to remove the inguinal basin of lymph nodes in her left leg. She is married with four children between 17 and 26 years of age and has her BScN from McMaster University. Debbie's main concerns revolve around the lack of provincial health care coverage for the physical management of lymphedema and overall lack of awareness. She would like to see an increase in funding for molecular research into lymphedema in Canada, and believes that clarifying the molecular knowledge of the condition is the pathway for new treatment development to take place. Debbie strongly believes in keeping an inquiring, open mind as treatment options evolve and progress.



Charlotte Schultz • Markham • Director

Charlotte is a retired RN and a three time cancer survivor. Living with lymphedema since 2010, she is concerned and upset about the lack of medical care and research funding for post-cancer treatment and in particular issues related to lymphedema. In her experience she feels that most MD's are not knowledgeable about lymphedema diagnosis and treatment. She looks forward to supporting the LAO to act as both a resource for lymphedema sufferers and as an advocacy group to raise awareness of lymphedema among the public, medical and political communities.
