

# Lymphedema

## MATTERS

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ONTARIO  
RESOURCES

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### NEXT STEPS AT THE LAO

Looking back on this the latest quarter of 2019 triggers tremendous feelings of satisfaction! It was three years ago that the LAO Board of Directors wrote into the Strategic Plan that advocacy for those suffering from lymphedema, struggling to be diagnosed and finance their treatment and self-care education, would become a significant goal of the Lymphedema Association of Ontario.

It was realized then that information about our Lymphedema community in Ontario was needed to inform an advocacy platform. To this end, the time-consuming work of creating, administering, analyzing and summarizing two large surveys of the population was undertaken by this author, as the LAO Advocacy Chair.

The Therapist Survey revealed the dynamics of 2,686 anonymous Ontarians being treated for lymphedema by certified lymphedema therapists. The Person with Lymphedema/Caregiver/Therapist questions were answered by greater than 200 individuals. All of this contributed important human experience, bringing the LAO Advocacy platform alive, so we could accurately speak about the perspectives and concerns of Ontarians who live with lymphedema.

With that work largely completed it is time to report to our readers that LAO representatives have entered Queen's Park on 3 different occasions. We have had satisfying experiences meeting Minister Christine Elliott in an informal meeting where it was asked, and she agreed to a future private meeting. We have also met and talked with the Parliamentary Assistant to the Health Minister and many other MPPs who have listened intently to the concerns expressed regarding those struggling with lymphedema in Ontario.

A highlight of the Queen's Park experiences has been the May 30th invitation by the Canadian Cancer Survivor Network to discuss lymphedema at an All Party Cancer Caucus. Although the theme of these CCSN caucuses has been Cancer Rehabilitation programming, this session evolved into an hour-long opportunity to talk about lymphedema of all causes, as the meeting time was longer than expected. The meeting was attended by many MPPs from all four political parties. LAO Treasurer Rob Caparelli contributed his moving video testimony of his late father's experience with severe lymphedema. We received excellent feedback from the MPPs that we had laid out our material extremely well, helping them to develop a good understanding of a topic that they knew very little about. There have also been good opportunities on two occasions now to have substantial conversations with Ms Robin Martin, MPP and Parliamentary Assistant to the Minister of Health.

The advocacy work is ongoing, and changes will not happen overnight. However, it is important to inform readers that there are many at the government level who know very little about lymphedema and we must all be engaged to improve this situation. It is highly rewarding to realize our conversations have been appreciated by all MPPs, and we look forward to future discussions. Additionally, as this unfolds we will be looking next to our Ontario population to provide us with their stories through letters that we can present to our Health Minister when we meet with her and continue to ensure the story of the Ontario lymphedema population is heard at Queen's Park.

As the Advocacy Chair of the Lymphedema Association of Ontario, I express extreme gratitude to all who offered perspectives of working or living with lymphedema in Ontario. These stories breathe real life into the Advocacy Platform.. This continues to help others understand what we live daily as lymphedema patients or caregivers and healthcare providers. It is an amazing privilege as a Board Director to see the fruits of this hard work that started three years ago advance to this stage, where informing those who need accurate information about this chronic condition, the needs, barriers to care and life difficulties of the lymphedema population, is now taking place at Queen's Park.

This progress truly represents the very significant and constructive way that we have all worked steadily together as a provincial community to improve the situations and lives of all those who live with or work with lymphedema in Ontario. Thank you to all!

**DEBBIE CIOTTI-BOWMAN**

PRESIDENT AND ADVOCACY CHAIR



ADVOCACY CHAIR ADDRESSING MPPS



MPPS EXPERIENCE SELF-BANDAGING



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## CHANGING AND EVOLVING ROLES AT THE LAO

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Change and evolution are constant in the universe, and there is no exception to this in the world of the LAO!

After two successive terms as a Board Director in the Office of Treasurer, we accepted the resignation of Ben Ciallella in late Spring of this year. Ben has served continuously for 6 years, keeping watch over our finances. Fellow Directors will remember Ben as an optimistic individual, greatly supportive of the various activities undertaken by each member of our Board, and possessing a keen understanding of the LAO mission. In a crossover time period between both Directors, we welcomed Rob Caparelli, Board Director and our new Treasurer, and we are most grateful for the sharing of financial talents of both of these wonderful people!

After 1.5 years as President of the LAO, Pouya Arefi announced his intention to move south of the border to the US to further his education. Pouya brought his unique insights based on his recent health economics education to our discussions and initiatives. Although his time with the

LAO was brief, we thank him for his informative service to the LAO Board! Debbie Ciotti-Bowman stepped into the role of President after Pouya's resignation.

Lastly, in early summer we sadly accepted the resignation of JoAnne Raditz, our Office Administrator and Graphic Artist. Most notably, JoAnne, who was contracted by the LAO for five years, kept the organization afloat, along with Ben Ciallella and Barbara Foster, in the years 2014 to 2016 which were filled with drastic changes for all. This represented a significant transitional period for the LAO. We will always be grateful to JoAnne for her deep empathy and concern for the lymphedema population of Ontario. We know this empathy greatly motivated her combination of LAO work and volunteer hours that she directed towards pursuing stability during this particular chapter of the organization's journey that was filled with drastic changes for all.

Thank you to all of these individuals who have brought their own unique gifts to carry out the mission of the Lymphedema Association of Ontario, where helping people live with lymphedema and raising awareness of this under-recognized disease is the primary focus of everything we do.

Periods like these points of change create quite a picture of the interesting mosaic of service that individuals have produced while carrying out various roles for the LAO. The organization expresses extreme gratitude for each of the above individuals' unique and important contributions that, when considered all together, have helped us fulfill the important mission and mandate of the LAO as time moves forward.

**DEBBIE CIOTTI-BOWMAN**  
PRESIDENT AND ADVOCACY CHAIR



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**LAO  
BENEFICIARY  
OF OTTAWA  
GOLD PLATE  
DINNER**

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On May 29, 2019 two of our Directors, Rob Caparelli, our Treasurer and Tony Wight, our Awareness Lead attended the annual Gold Plate Dinner in Ottawa. The Dinner has been a significant yearly event, organized by the Hellenic Community, to raise funds for a variety of charities and provide an excellent networking opportunity. Over 600 guests attended this year including large contingencies from the local Greek and Italian business communities. This year the LAO was designated as one of three beneficiaries of proceeds raised! We had become known to the organizers as Director Rob's late father, Luigi, had been active in the past in connection with the Dinner and suffered from lymphedema before he passed away last year.

We understand the Dinner was once again very successful and we are grateful to be receiving a portion of the proceeds. Director Tony was honoured to be the guest of the Caparelli family at the Dinner and at the organizers' invitation spoke to the gathering to express the gratitude of the LAO and also describe lymphedema as well as the goals and activities of the LAO.

**TONY WIGHT**, AWARENESS CHAIR  
**ROB CAPARELLI**, TREASURER



LAO REPRESENTATIVES - TONY WIGHT & ROB CAPARELLI



CO-CHAIRS, AIK ALIFERIS & NICK PANTIERAS WITH ROB CAPARELLI



MICHAEL CAPARELLI, TERRI CAPARELLI & ROB CAPARELLI

LYMPHEDEMA  
AWARENESS WALK

SCOTIABANK  
**CHARITY**  
CHALLENGE

SUNDAY  
OCT. 20, 2019



EVENT  
DETAILS

**MARATHON  
HALF MARATHON  
& 5K**

DATE:

SUNDAY,  
OCTOBER 20, 2019

TIME: 8:00AM

LOCATION:

TORONTO, ONTARIO, CANADA

The LAO will be participating in 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 2018 participants raised over 3.5 million for 191 community charities through the Scotiabank Charity Challenge at the Scotiabank Toronto Waterfront Marathon.

Raise support and awareness by walking, donating, fundraising, or sponsoring the LAO during the 2019 Scotiabank Toronto Waterfront Marathon!

**HOW YOU CAN PARTICIPATE:**

**SIGN UP AS A RUNNER/WALKER**

Register as a runner/walker through the Scotiabank Waterfront Marathon Website under the LAO. Runners will be provided with personalized information to fundraise in support of their walk and charity. [www.torontowaterfrontmarathon.com](http://www.torontowaterfrontmarathon.com)

**SUPPORT A RUNNER/WALKER**

Support an individual or team participating in the Scotiabank Waterfront Marathon.

**DONATE TO THE LAO**

Make a direct donation to the LAO on behalf of an individual or organization. Details are available on our website. [www.lymphontario.ca](http://www.lymphontario.ca)

**SPONSORSHIP**

Upon request, the LAO will provide a package for those interested in sponsoring the LAO in the Scotiabank Toronto Waterfront Marathon.

For more information please navigate to the Events tab on our website [www.lymphontario.ca](http://www.lymphontario.ca). You can also contact [events@lymphontario.ca](mailto:events@lymphontario.ca) with any inquiries, or any interest in leading an LAO walk in your area.



Scotiabank TORONTO  
WATERFRONT MARATHON

**FIND A LINK TO  
JOIN OR SUPPORT  
OUR WALK ON  
OUR WEBSITE AT  
[LYMPHONTARIO.CA](http://LYMPHONTARIO.CA)**