



## New LAO President

Dear LAO members, colleagues, and the lymphedema community at large,

Each year, the Lymphedema Association of Ontario works to strengthen its capacity to provide resources and services for its members. At the LAO, each board member and volunteer is committed to ensuring all individuals living with



Pouya Arefi, LAO President

primary or secondary lymphedema in Ontario receive care that is accessible, equitable, and appropriate. Therefore, it is with great pleasure that I

introduce myself as the incoming LAO president, and I am honoured and humbled to serve you, alongside the rest of the board.

As my first official introduction, I would like to provide a brief background about myself and my vision for the organization. I have extensive background in not-for-profit organizations, systems-level health policy, and I am currently pursuing a Master's in Global Health.

Currently, I serve as a Board Director for the Asperger's Association of Ontario, a general member of the annual Party for Pain planning committee in support of Hamilton Health Sciences Michael G. DeGroot Pain Clinic, and I am also working on a sustainable outreach program aimed at delivering oral health care to developing nations. My experience in health systems and work with patient-representative groups, combined with my aspiration to seek improvement in lymphedema services inspired me to assume the Presidency role.

Given the current political climate and the growing body of evidence on the epidemiology of lymphedema, I believe

that we are well positioned to engage and lobby for action that could fund and support access to health services for those living with lymphedema.

We recognize that this is no simple undertaking, and will require expanding lymphedema education, awareness, research, and advocacy. Therefore, the LAO has taken steps to gain further insight into the state of lymphedema care in Ontario through patient and therapist surveys, and we are pleased to share the results of the Ontario Lymphedema Therapist Survey with you in this issue.

In an effort to expand our capacity to raise awareness and improve member information, the LAO is strengthening its networks by working to establish an advisory group. This group, composed of medical and non-medical professionals, will consult on health issues, advocacy efforts, and specialty inquiries.

Above all, the LAO is committed to transparency in its efforts to serve you. We always welcome questions, comments, and inquiries of all kinds that allow our members to be more involved with their organization, and allow us to improve the services that we provide!

I look forward to working with the Board, for and with you.

Pouya Arefi ■

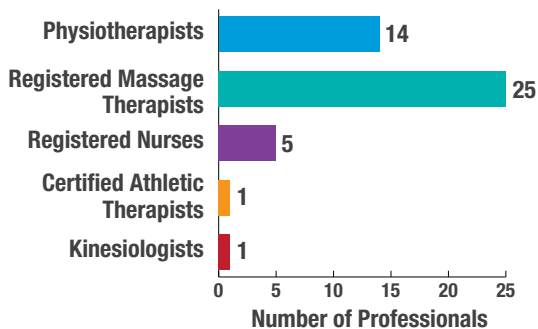
# Therapist Survey

By Debbie Ciotti-Bowman and Pouya Arefi

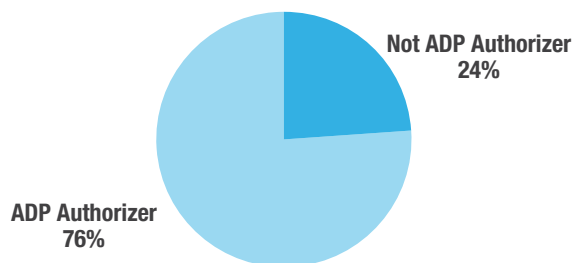
The LAO board of directors recognizes the importance and value of patient and professional member engagement in its strategic efforts. As detailed in our last issue, we have taken steps to gain further insight into the current state of lymphedema care in Ontario through both a member and therapist survey.

The Therapist Survey, distributed in 2017, provides the board with information and feedback that helps to improve our understanding of those living with and receiving treatment for lymphedema in Ontario. Questionnaires were sent out to 76 therapists certified to treat lymphedema, who are currently listed with the LAO. With 42 of 76 therapists responding to the survey, we achieved a 55% response rate, illustrating the overall dynamics of 2,689 anonymous Ontarians receiving treatment for lymphedema. This article presents the data obtained as a result of the survey, with the purpose of providing brief commentary on our analysis of implications for lymphedema care and future advocacy work.

## Professional Respondents



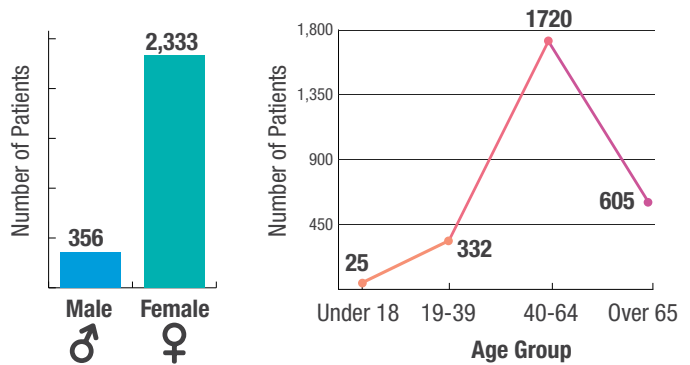
Note: Some respondents are educated in more than one professional discipline.



## Patient Demographics

The data shows a sizeable gender disparity within individuals receiving care for lymphedema in Ontario, with females representing over 85% of the patients. Provided that arm lymphedema is the most common of the body areas treated for lymphedema, the higher prevalence in females can be attributed to treatment for female breast cancer. However, it is important to recognize that this is not mutually exclusive, and other factors may contribute to this gender disparity.

## Patient Demographics



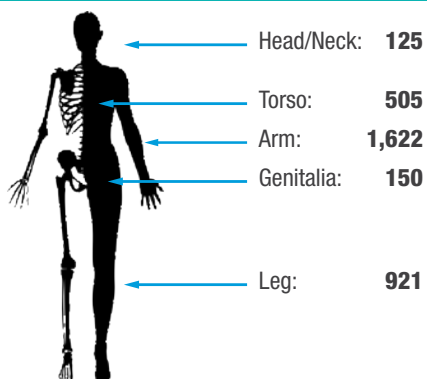
The majority of patients receiving care were found to be between the ages of 40-64, measured at close to 65% of all patients. The number of patients older than 65 that were receiving care dropped significantly when compared to those between 40-64, representing close to 22% of all patients. Taking into consideration the fact that lymphedema is incurable and a lifelong management issue for all that develop the condition, requiring consistent care to minimize swelling, inflammation and permanent tissue damage, this alarming drop calls into question the underlying causes that inhibit patients older than 65 from obtaining care. More specifically, there needs to be further research to examine whether a lack of, or minimal private insurance, and/or fixed income after 65 years of age may act as a barrier to access of care for this age group.

## Affected Regions and Causes

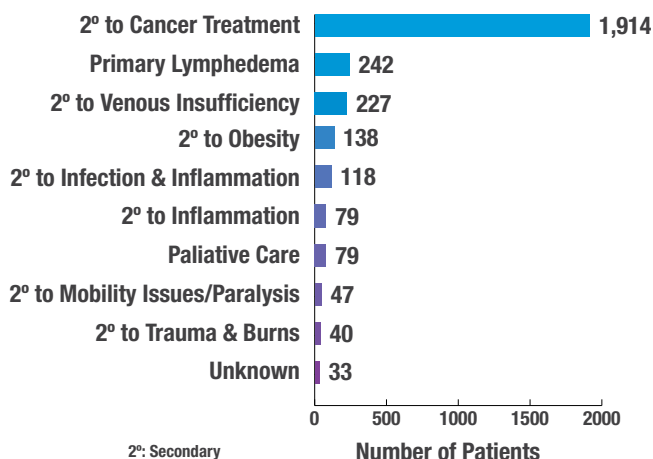
The body region affected by lymphedema was also assessed in the survey, with the arm observed to be most commonly affected, with over 60% of the patients being affected by arm lymphedema. The legs were the second most affected region, with 5.6 individuals affected by leg lymphedema for every 10 individuals affected by arm lymphedema. Of all regions, the head/neck and genitalia represented close to 10% of all patients, representing the lowest of all affected regions being treated by the 42 therapist respondents.

The results indicate cancer treatment as the highest reported cause for lymphedema, encompassing over 70% of all represented patients. Close to 10% of patients represented were shown to have primary lymphedema. Other reported conditions leading to lymphedema included venous insufficiency, obesity, inflammation/infection, palliative care, mobility issues/paralyses, and trauma/burns.

### Affected Regions



### Causes



With 2,917 reports of causes for lymphedema by therapist respondents out of the 2,686 patient population described in this survey, this illustrates that more than one cause for lymphedema may be observed in an individual living with the condition. It is interesting to observe the frequency of each diagnoses as noted by therapists in the Ontario survey, as they reflect the causes of lymphedema that are commonly discussed in North America.

## Frequency of Visits and Prevalence of Compression Therapy

The survey also assessed the number of treatments provided by therapists to patients each year. During the initial treatment phase of lymphedema, the majority of patients were reported by the therapists to be seen two to three times per week until swelling reduced/stabilized (535 patients as reported by 26 therapists).

During the maintenance treatment phase of lymphedema, the majority of patients reported by therapists were seen once a month (721 patients as reported by 30 therapists). This question was challenging for the therapists surveyed, as it required a closer and more detailed examination of patient history to inform visit frequencies.

We have provided readers with the two most predominant visit frequencies reported by therapists, offering a general idea of lymphedema patients' patterns of visits and needs for treatment.

In examining the prevalence of compression therapy, it was found that, on average, 82.77% of patients wore compression. While 11 of the 42 respondents reported that 100% of their patients wore compression, there were also reports below 50% and a few reports in the 60%-85% range. We did not inquire about the reasons in varied numbers between therapists. However, this may relate to factors such as patient comfort, overall compliance/manageability, cost, accessibility etc.

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## Comments by Professionals/Therapists

The following is a selection of commentary by therapist respondents:

*"My frequency of follow up in the maintenance phase depends on how long the client has been in maintenance phase, how well controlled their edema is, and unfortunately, how often they can afford to come."*

*"How do you answer, "do people wear their sleeves" etc? There is such a wide variation. Ideally 24/7 but in reality there is a great discrepancy."*

*"I see clients in early stage / preventative care mainly..."*

*"I would like to see more therapist collaboration to bring our therapy to the forefront."*

*"I would like to see more therapist collaboration to bring our therapy to the forefront. Oncologists and radiologists need to refer to us to help their patients and not have the clients find us on their own."*

*"...the lymphatic drainage protocol and best practice guidelines that I utilize... are more contemporary—encouraging clients to engage in home program and exercise. More cost effective for the client and sustainable."*

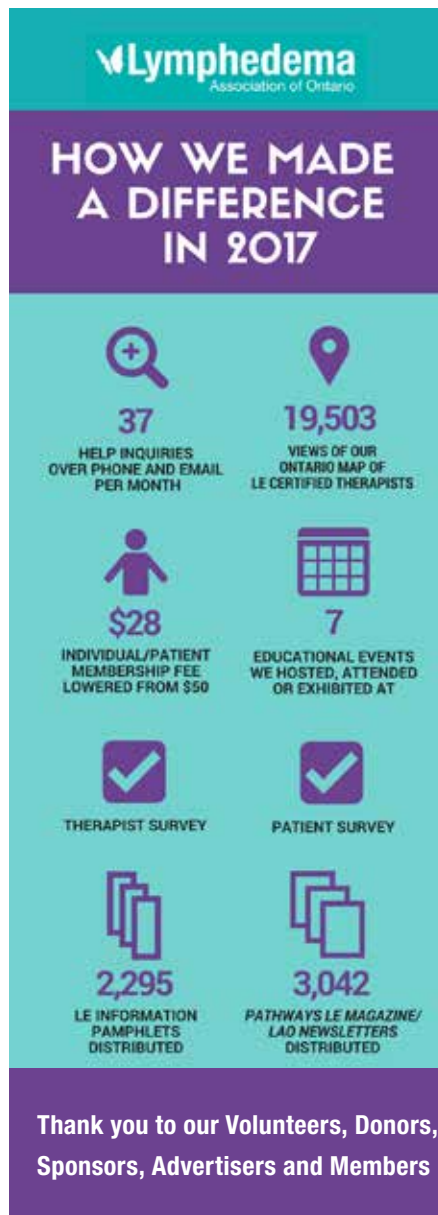
*"Cost of treatment and compression is a factor in patient compliance. Over the last year I have had two patients opt to do nothing due to the cost."*

*"Need manual lymphatic drainage (MLD) covered by OHIP and the clients need to have different kinds of compression depending on the day."*

*"Cost of treatment and compression is a factor in patient compliance."*

*"Other areas of interest may be how many clients are on social assistance or how many clients opt not to have treatment because they cannot afford it, or choose not to come as often because they cannot afford it. I would estimate that I have had a consult with approximately 40 clients that after education about lymphedema and compression, exercise and skin care opted to take care of it themselves because they could not afford treatment. Also, how many therapists co-ordinate care with local CCAC's to help clients? In addition, there is a cancer centre in my region that will see clients up to 10 times and then clients are referred to community therapists. Some areas do not have a regional program to help."*

We express our deepest gratitude to those who could provide this picture of Ontarians living with lymphedema by answering this survey. Our analysis efforts continue, and we ask those who have not yet completed the 2018 Patient Survey to do so by clicking on the link found on our home page at [www.lymphontario.ca](http://www.lymphontario.ca). Make your voice known in Ontario so that we can work together to help the citizens of this province affected by lymphedema! ■



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# ONTARIO LE SUPPORT GROUPS & PROGRAMS

## BRANTFORD

### LYMPHEDEMA AWARENESS GROUP MEETING

When: Friday April 27, 2018

Time: 10:00-1:00

Where: 4th Floor Board Room  
St. Josephs Lifecare Centre

### REGISTRATION IS REQUIRED

Call Pam Monarch at  
519-751-7096 x 3414

## BURLINGTON

905-332-6542 or  
info@headtofotoasis.ca

## KINGSTON

Breast Cancer Action Kingston

613-531-7912

admin@bcakingston.ca

www.bcakingston.ca

## KITCHENER/WATERLOO

Call Barbara Shaw

519-585-7748 for details on both  
Lymphercise Class & Support Group

## LASALLE/WINDSOR

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

## OSHAWA

Hearth Place Cancer Support Centre

Yoga for LE, Aqua Therapy for LE,

LE Education and Assessment Clinic

905-579-4833 Janette@hearthplace.org

www.hearthplace.org

## OTTAWA

Breast Cancer Action Ottawa

613-736-5921 or www.bcaott.ca

## PETERBOROUGH

Call Bridget at 705-876-3333 or  
Janice at 705-876-8561  
to register for a future meeting


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](http://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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