



Lymphedema Matters

Association of Ontario

Spring 2019 | Ontario Resources

Volume 22 Issue 2

Making a Difference in 2018



INFORMATION LINES

160 have been provided with direct assistance through the info-line and emails



WEBSITE

33,242 have viewed/utilized the Ontario map of certified LE therapists posted on our website



AWARENESS/EDUCATION

7 awareness/educational events hosted, attended, presented at or exhibited (including BRA Day and Oncology Day)



ADVOCACY

> 185 survey responses analyzed as part of a comprehensive research initiative to explore the evidence that supports funding models for lymphedema



PAMPHLETS

3042 LE information pamphlets distributed to hospital clinics/libraries, providers and members



NEWSLETTERS

2535 Pathways LE magazines and LAO's *Lymphedema Matters* newsletter inserts distributed to hospital clinics/libraries, providers and members

For all of us at the LAO, it has been an honor to serve and support the lymphedema community in 2018, and we are excited to carry this momentum into the new year. Therefore, as we reflect on the past year, we would like to extend our sincere appreciation for a year of achievements, changes, and memories.

Each year, the LAO works to build on its efforts to provide resources and services for its members and create positive change for the community at large. As a core function of the organization, we continue to provide direct assistance through our Infoline. We are also excited to see a significant increase in use of the LAO's Map of Certified Lymphedema Therapists; ensuring up-to-date access to LE professionals across Ontario. We encourage you to utilize these resources and reach out to the LAO with any inquiries you may have.

In 2018, the LAO also identified awareness and advocacy as one of its primary pillars of focus. Over the past year, great strides were made in expanding networks, increasing exposure, developing evidence, and building partnerships to support systematic change for the lymphedema community. In addition to attending several conferences and education sessions, the LAO has completed analysis of over 185 responses to a community survey aimed at gaining further insight into the state of lymphedema care in Ontario. Moving forward, the LAO will continue to expand its presence at key awareness sessions and develop an evidence-based approach to advocacy. There has also been an increase in the distribution of LAO informational resources to clinics, hospitals, and providers, with the goal of ensuring increased awareness in care provision.

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Luigi Caparelli: unwavering hero in the face of lymphedema

When Luigi was diagnosed with stage three colorectal cancer 11 years ago (January 2008), we were devastated. Shocked. Scared. Did I mention devastated? The diagnosis was unexpected and debilitating. This is not what is supposed to happen to a healthy, fit, 47 year old man, in the prime of his life. Luigi had been athletic growing up and continued to be active in his adult years. He was a regular runner and an avid skier who had no difficulty keeping pace with the best skiers on the slopes. He didn't smoke and he was certainly a healthy eater.

As the initial shock of the seriousness of the diagnosis slowly dissipated, Luigi faced the challenges of the treatment plan his doctors had provided in typical Luigi fashion—methodically and with quiet, but fierce, determination. He read, researched, and educated himself to the point where he could easily converse with and quiz his doctors (I'm sure they loved appointments with him). He underwent a month of daily radiation, followed by a serious and complicated surgery, a long recovery and then two months of aggressive chemotherapy. The surgery resulted in the removal of a significant number of lymph nodes on the left side of his body. We were told that this was necessary because the cancer had spread beyond the lining of his colon. At the time, we certainly did not give the removal of these lymph nodes too much thought.

The prognosis was not good—he had, we were told, two to three years left to live. But the cancer had no idea who it was up against. Luigi beat those odds and was cancer free for just over four years, after completing the initial round of treatment that lasted for the good part of a year. For the next several years, Luigi continued his fierce battle with cancer. His journey was not an easy one. It was more like a wild roller coaster ride; marked by highs and lows depending on what his ongoing and regular cancer follow-ups found.

Throughout the years, he continued to be on various chemotherapy treatments, rarely going longer than a couple of weeks between treatments. One of the most astounding parts of Luigi's journey was that only his close friends and family members knew that he had cancer and that he had chemotherapy drugs flowing through his system, three days every two weeks. Luigi refused to succumb to the effects of his chemotherapy. He continued to work—running his own successful businesses that he had established. But more importantly, he focused on his family—his two sons, Robert and Michael, and his



The Caparelli family (with the two newest additions, Jessica & Leslie), celebrating Luigi's youngest son's engagement to Jessica.

wife, Terri. Luigi's family was his "raison d'être"—his reason to fight. He wanted to live, as he often said, "as normal a life as possible" despite having cancer. He rarely complained (even though he had good reason to) and continued to live life to the fullest extent possible, always surrounded by his family and friends.

But the universe had more in store for Luigi—another difficult challenge. In October 2015, Luigi and his wife, Terri, celebrated their 30th wedding anniversary on a cruise through the Panama Canal. During the last few days of their cruise, and upon their return home, Luigi had noticed slight swelling of his left ankle. At first we thought



Luigi Caparelli

it might have been a strained muscle, or possibly some kind of parasite. When the swelling showed no signs of subsidence yet continued to progressively worsen, the quest to uncover the cause began. Luigi was well-supported by his team of doctors and he was referred to many different specialists in the hopes of identifying the cause of his swollen ankle. After months of medical appointments and theories as to what was causing the swelling—which had by now spread up his entire lower leg—he was told that he had developed lymphedema; a condition which causes swelling as lymph fluid cannot flow normally and builds up in the soft tissues of a limb. Lymphedema usually occurs in parts of the body where lymph nodes have been removed or damaged by cancer treatment. Our new understanding was the "Aha" moment—not a good one. Years of cancer chemotherapy treatment coupled with the removal of a significant number of lymph nodes had led to yet another obstacle: lymphedema.

Being the "Dr. Spock" in the family, Luigi methodically educated himself on lymphedema and quickly realized that the condition would only get worse. What we did not expect nor anticipate was exactly how bad the lymphedema would get and the impact it would have on his quality of life.

Initially, the lymphedema was somewhat controllable through specialized massages—namely, lymphatic drainage therapy. These massages would temporarily reduce

the swelling. Elevating the leg also helped, but the swelling would often return within hours. As time progressed, so too did the swelling. Within months, the swelling had spread all the way up Luigi's leg. He could no longer get his foot into his regular shoe. He began to wear a compression "sock" to try and help control the swelling. The "sock" was thick, cumbersome, and covered his entire leg—right up to the top of his thigh. Initially, these therapies helped, but did not stop the progression of lymphedema. Throughout all these therapies and rigorous regimens, Luigi continued to live life to the fullest. He

wear the compression socks on both legs constantly. He could no longer wear his regular clothes and had to get custom made pants to fit his now elephant-like legs and waist. He had to give up wearing regular shoes. The realization that he would never ski again, because his feet would not fit into ski boots, was devastating.

Luigi did not give up even as the lymphedema continued to worsen. He continued to try to find a solution and eventually connected online with a long-time sufferer of lymphedema, who had had surgery to help alleviate the swelling. The

months of his life, the lymphedema was so bad that he could no longer bend his knees. He could not sit down at the dinner table to eat, so we would all gather around the counter for family dinners.

The lymphedema slowly but relentlessly eroded Luigi's quality of life and wreaked havoc on his physical and emotional well-being. Luigi was a proud man who never wanted to burden those he loved—even though those he loved, never felt he was a burden. Truthfully, the lymphedema was what really killed him, because it killed his spirit.



Both teams pose after the 1st annual Luigi Caparelli Memorial Hockey Game

In retrospect, not much attention is given to lymphedema because it is not considered life-threatening. When Luigi was diagnosed with cancer, none of the informative required reading warns you about the possibility of lymphedema. After all, lymphedema alone does not kill people, but cancer does—and you need to survive the cancer in order to get to the lymphedema.

There is no doubt in my mind that, for Luigi, the lymphedema was worse than the cancer that eventually took his life. Lymphedema is a horrible condition deserving of more attention. Due to this lack of attention, and general knowledge regarding lymphedema, Luigi's family, and close friends, have made it their goal to help educate the public and raise money for research so that others, sooner rather than later, will have a much better outcome than Luigi while dealing with this terrible disease.

This past holiday season, Luigi's sons, with the help of Michael's father-in-law, John Bertorelli, organized a friendly (although it turned out to be much more competitive than anticipated) hockey game - the 1st annual Luigi Caparelli Memorial Hockey Game. The outcome could not have been better. Through this event, we were able to raise nearly \$1,000 for the Lymphedema Association of Ontario, all in Luigi's name, and we are already looking forward to the next one.

by Ellie Weber, Luigi's sister ■

worked, travelled as much as possible (scheduling his life around the endless chemotherapy sessions), and spent time with his family and his unbelievably supportive and loving circle of friends. Luigi never lost his sense of humour, his curiosity about the world around him, his willingness to help others in his understated, and his humble manner. Luigi had an unquenchable thirst for knowledge and loved the written word. He was one of the most well-read people I've ever known and had the uncanny ability to remember and retain everything he read—God help you if you found yourself debating an issue with him, as he was likely to recall facts most of us had long forgotten or never retained.

Eventually the lymphedema spread to his other leg and then his abdomen. He had to

specialized surgery was performed by the leading doctor in the field in Italy and it had reduced the swelling for this person by about 30%. The possibility of reducing

Truthfully, the lymphedema was what really killed him, because it killed his spirit.

the swelling by 30% was promising. Luigi further explored these prospects and found a doctor in Ottawa who was well versed on the surgery. Unfortunately, this surgery is not funded by our medical system. Luigi seriously considered the option of trying to have the surgery in Italy, but by this time (late summer of 2018), the cancer had progressed too far. During the last few

Ontario LE Support Groups & Programs

Brantford

Brantford Lymphedema Support Group

St. Joseph's Lifecare Centre: 99 Wayne Gretzky Parkway

Contact Pam Renneberg RMT (fka Monarch) for more information at 519-751-7096 x3414

Burlington

Burlington Lymphedema Support Group: Take control of your lymphedema—an information session.

Thursday, May 9th, 2019 at 7:30 p.m.

Head to Foot Oasis Wellness Clinic, 5115 Harvester Road (Unit 11A)

Topics that will be covered include:

- understanding lymphedema (education and awareness)
- manual lymphatic drainage (massage)
- exercise and rehab options
- pneumatic lymphatic pumps
- assistive device program information
- compression garment options
- cording and myofascial release
- lifestyle changes that can help manage lymphedema

Hosted by Jen Beck, RPT and Kim Gladman, RMT. Please RSVP to info@headtofootoasis.ca by May 1st, 2019.

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

Guelph

Guelph Lymphedema Movement: LYMPHEDEMA 101—a Learning and Sharing Social Evening

Monday, June 3rd 2019, 6-8pm

Guelph Community Health Ctr, Lower Level. 176 Wyndham St. N.

Email Hannah at lymph.guelph@gmail.com for more details

To RSVP go to [GuelphLymphedemaMovement.eventbrite.com](https://www.eventbrite.com)

Kingston

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 Office Hours: 12-4pm Tues-Fri

Kitchener/Waterloo

Kitchener/Waterloo Lymphercise Class and Support Group

Lymphercise Class

- Every Thursday Morning 10 to 11:30 a.m.
- 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

LaSalle/Windsor

Lymphedema Support Group & Social Walk

These groups are held from 11am-12pm at Active Body Physical Therapy located at 1765 Sprucewood Ave, LaSalle

Social Walk directly following weather permitting

2019 Schedule: February 10, March 10, April 7, August 11, September 8, October 6, November 10 and December 8

Hosted by Maddie Simone RMT CLT

For more information, email maddie.simone@yahoo.com.

Oshawa

Hearth Place Cancer Support Centre

Information, emotional and practical support for those with lymphedema, and those at risk. The group meets every third Thursday evening of the month, from 7 p.m. to 9 p.m.

86 Colborne St. West, Oshawa L1G 1L7

For more information or to register, call Hearth Place at 905-579-4833.

Ottawa

Breast Cancer Action Ottawa (BCAO)

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 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

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As we continue to recruit Directors, we also acknowledge the work and contributions of those who have been with the LAO throughout the years. As such, it is with a heavy heart that I inform you of Charlotte Schultz's resignation from the Board of Directors. Charlotte's dedication to supporting the lymphedema community has been a true inspiration to all of us at the LAO. We would like to formally acknowledge her unconditional



Charlotte Schultz

commitment throughout the years and her accomplishments in LE advocacy, awareness and especially education. I am

confident that Charlotte's contributions to the community will not end with her resignation from the board and her passion will continue to produce positive change in the community. It has been an absolute privilege to work alongside Charlotte and the LAO wishes her all the best moving forward.

Thank you to all the members, donors, and volunteers who supported our joint cause in 2018. We would not be able to succeed without your continued support and collaboration! We look forward to working together in 2019 and continue to encourage questions, comments, and inquiries of all kinds that allow our members to be more involved with the LAO and allow us to improve the services that we provide!

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

Pouya Arefi, Board President ■

Become a Corporate Member
and Help Support the
Lymphedema Association of Ontario

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.

Advertise to support the LAO

Lymphedema Matters is the official publication of the Lymphedema Association of Ontario. For advertising or advertorial queries contact the LAO at accounting@lymphontario.ca or **416-410-2250**

Disclaimer: The LAO does not guarantee, warrant or endorse any product or service advertised in this publication.

 **Lymphedema**
Association of Ontario

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