

# Lymphedema Matters

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## President's Report by Kim Gagan



It has been a very busy winter here at the LAO. I am happy to announce that we have successfully recruited a new Executive Director. We are very pleased to welcome Radosna Bijukovic to this position and the LAO.

Radosna's qualifications are very extensive. She started off her career as a registered nurse. She received her MBA from Queen's University and has held a myriad of consultant positions in the healthcare and business sectors. More recently, she was the Executive Director for West Toronto Support Services for Seniors and Disabled Adults. Following that, she managed the Geriatric Outpatient Department at the Centre for Addiction and Mental Health in Toronto. Her achievements in these various positions are extensive and we are fortunate to have such a highly qualified individual join the LAO. Radosna will start her new position with us effective April 1<sup>st</sup>.

I would also like to take this opportunity to thank the members of the hiring committee (Matthew Fawcett, Janice Goldberg, Ben Ciallella and Anna Kennedy) for all the time, energy and commitment that they devoted to this recruitment process. Your hard work is very much appreciated.

In addition to our new Executive Director, we hope to hire a Communication and Events Co-ordinator, in the near future. We said goodbye to Shannon Moore last year and have yet to find someone to fill her shoes permanently. We hope to have that position posted very soon. But the changes don't end there. We are also looking for new office space. Unfortunately, the place where we have hung our collective hats for the

last several years has been sold and will no longer be available effective this summer. It will certainly be a challenge to find a new location, but it is one that we are prepared to meet. The search is on and we will let you know our new co-ordinates as soon as they become available.

Finally, I will be stepping down as President of the Association. I have been serving in this role for the past several years and have been a Board member, off and on, since before our incorporation in 1997. The LAO has grown so much as an organization in that period of time. We started as a handful of patients and two physiotherapists, sitting around a kitchen table and wondering how we could launch an organization that would support lymphedema patients. At that time, there was no organization to support patients anywhere in Canada. We had no budget to speak of and no resources except our dedication and drive. Since that time, the LAO has grown into something quite remarkable and I am proud to have had the opportunity to be a part of this organization for nearly 18 years.

I have very much enjoyed my time on the Board, but I find that I must take a break in order to better balance my family and work commitments. I will certainly continue to be an active member of the LAO and look forward to a time in the future when I can once again rejoin the Board and contribute to this fantastic organization.

**"It has been an absolute pleasure to be associated with such an extraordinary group of people."**

# 2014 Lymphedema Honouree Professor Miles Johnston



Each year the Lymphedema Association of Ontario chooses a new honouree who we feel has worked hard to make a significant difference to the lymphedema community. We are pleased to announce this year's honouree, a long time supporter of the LAO.

**Professor Miles Johnston** received a B.Sc. (1974) in Physiology/Pharmacology at the University of Toronto and a Ph.D. in the Division of Experimental Pathology (Department of Pathology) at the same Institution in 1979. Following post-doctoral training at the Babraham Institute in Cambridge, England from 1979-1981, he returned to Canada to take up a faculty position at the University of Toronto. He was a Professor in the Department of Laboratory Medicine and Pathobiology and a Senior Scientist at the Sunnybrook Research Institute.

Although we wish him well in his retirement, we were sad when we learned his work ended December 2013.

Professor Miles Johnston devoted most of his 30 research years to studying the lymphatic system. Among his most notable research; autologous lymph node transplantation, lymphangiogenic therapy models to restore lymphatic function and development of an artificial lymph node. His most recent research involved studying the impact of radiation on lymphatic function. His tremendous contributions will have a lasting impact on how we understand and treat lymphedema in the future.

The LAO is grateful to Prof. Miles Johnston's support of the lymphedema community. He was our most frequent guest speaker (seven annual conferences), always willing to share his latest research with us. We never tired of his explanations of the lymphatic system. His enthusiasm and passion for the work he did gave us hope for the future. *He leaves big shoes to fill.*

## Incoming new Executive Director Report

by Radosna Bijukovic



My employment with the LAO officially started on April 1st - so by the time you read this newsletter I am just starting my journey with the LAO.

I will be transitioning into the position for the first few months with the support of Anna Kennedy and working together with the Board to chart our new strategies and plans for the coming years. It's a fresh start for the LAO and I am very privileged

to be part of the next phase of the journey. Some initial priorities include finding new office space, hiring support staff and developing a volunteer strategy to support the LAO's initiatives.

I am eager to learn about lymphedema and its impact on the people who live with it on a daily basis. I chose to work at the LAO because I want to contribute to an important cause and an organization with wonderful growth potential. I am looking forward to applying my skills, creativity and experience to benefit the LAO team, clients and community.

### LAO Board Directors Needed

Do you know someone who might want to join the Lymphedema Association of Ontario Board of Directors? We are currently recruiting for several Board member positions.

**Board Secretary** - using skills and board experience to record and distribute the minutes of teleconference calls and coordinate correspondence.

**Fundraising Chair** - supporting LAO staff and volunteers to organize our annual Charity Walk and additional new fundraising initiatives.

**Membership Chair** - experienced marketer to support our efforts to increase patient, professional and corporate LAO membership in Ontario.

**Advocacy Chair** - lend your talents and experience to liaise with government officials to promote accessible lymphedema treatment for all.

**Please consider volunteering your time and services to a great cause.  
WE NEED YOUR HELP!**

# “That’s the least of your worries”

## My lymphedema journey

by Susan Gamble



Similar to many people who suffer from lymphedema, the first step of my journey was hearing the dreaded word “carcinoma” from my doctor. There ensued a promptly arranged radical hysterectomy for uterine cancer, which successfully removed the offending tissue.

During surgery, 19 lymph nodes were removed from my pelvic area, all of which were thankfully negative. “That’s great news” I thought. Little did I know that those little nodes performed a very necessary function for my lymphatic system. They acted like traffic intersections. When the nodes are not there, a “traffic jam” is created. Unbeknownst to me, my lymphatic “traffic” was being severely affected.

So at my six-week check-up with my gynecological oncologist (who *should* know about lymphedema), I asked: “I have some swelling in my genital area. What could it be?” His verbatim response was: **“That’s the least of your worries!”** Unfortunately I did not have the presence of mind to retort: “If your genitals were swollen, I bet you would worry!”

So how was I diagnosed? By a different specialist? Actually by talking to my girlfriend in the US whose husband had cancer. They were warned about the potential for lymphedema. How I would love to have had *advance* warning of this condition rather than a specialist, of all people, who *totally* dismissed the problem.

So when I went for my next radiation checkup at the Sunnybrook Cancer Centre (Toronto) I asked the radiology oncologist what lymphedema is. Her reply? **“It’s just a posh word for swelling.”** This despite the fact that Sunnybrook has (as I later discovered) a Lymphedema Clinic! Fortunately the Clinic gave me a list of therapists who are specially trained to handle lymphedema and I picked one who makes in-home visits. I was fortunate enough to choose a really excellent woman whom I still see regularly for lymphedema massage.

**Little did I know that those nodes performed a very necessary function - acting like traffic intersections for my lymphatic system.**

A relevant part of my medical history is that as a result of radiation, I developed a bowel obstruction, necessitating further surgeries. Complications led to me having five bowel surgeries within 15 months, in addition to the hysterectomy. I learned recently that multiple abdominal surgeries can exacerbate lymphedema.

I have an extensive and apparently somewhat uncommon manifestation of lymphedema symptoms. I experience swelling from the waist down – abdomen, pubic and genital areas, both legs and even down to my toes. I also have ingrown toenails because the fluid retention has caused my toes to grow slightly around the nails, causing mild pain. I therefore see a podiatrist to get my toenails cut.

My therapist taught me and my husband how to bandage my legs at night. My husband has been a **wonderful** support during this whole journey, and he still bandages my legs when they get too swollen. At the appropriate time, my therapist also helped me find a specialist regarding compression garments. I wear custom made thigh-high stockings *and* what look like bicycle shorts – every day, year round. It gets rather hot in summer, but if I leave them off, my legs have a field day – they balloon in no time!

One unexpected aspect of lymphedema is that my legs don’t work nearly as well as they used to, even though they are not hugely swollen. I find stairs or going uphill a real challenge. So much so that we have moved into a bungalow. I’ve realized that the restrictions are totally disproportionate to the actual size of the swelling. (I am tall and slim, 5 ft. 7 ins. and 125 lbs. – so the swelling is quite noticeable to me). The swelling in the abdominal and pubic region makes bending over and kneeling almost impossible. So no more gardening, or bending to wipe up spills on the floor – oh bother! The saddest part of my lymph-edema is that it impedes my activities with my three young grandsons. I can’t lift them up, bend down and play with them, or run around outside with them.

**BUT** I’m here; the cancer has not recurred in five years; my lymphedema is under control (with the aid of massage, compression garments and occasional bandaging); I can still interact with my grandsons; I live in a bungalow which I love; and last but by no means least, I continue to enjoy being with my husband of 42 years – my best friend ever and my strongest supporter during this difficult journey.

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**Susan Gamble** was born and raised in England, and immigrated to Canada in her 20’s where she met her husband. She spent over 40 years in the marketing research industry, the last 25 of those in business with her husband and another partner. She has travelled to nearly 50 countries and was a keen hiker/trekker. Susan is now content to enjoy summers at their cottage in Haliburton.