

2019 National Lymphedema Conference

Education, Research, Partnerships



Toronto once again welcomed the National Lymphedema Conference and it's more than 300 registrants, guests and speakers including patients, family, health care professionals and researchers. There was representation nationally from eight provinces, as well as international participation from the United States, the Netherlands, France, Poland and Austria. The Exhibit Hall had 25 companies displaying their products and services. This event was hosted by the Canadian Lymphedema Framework (CLF) and marked 10 years of their work in advocating for and raising awareness of lymphedema.

Prior to the start of the conference, there were industry symposiums taking place as well as meetings of the committees of the CLF. All of the provincial lymphedema associations were represented and met to network and share ideas for awareness and advocacy. This was the last conference with **Anna Kennedy** as CLF Executive Director as she is passing the reins to **Katerina Ilievska**, (see page 25).



Day 1 – Dr. Pierre-Yves von der Weid, the opening speaker, provided an update on the ongoing research being done at the University of Calgary that looks at changes in gut lymphatics when chronic inflammation is present and how lymphatic dysfunction can affect the immune system, fat digestion and deposition, and be linked to other diseases. His team is looking at how chemical mediators impact this process and will lead to a better understanding of these relationships.

Susan Harris, PT, the second plenary presenter, was one of the original breast cancer survivor dragon boat team members, and was involved in a study that broke the myth of limiting vigorous exercise after breast cancer surgery. She reported that this myth still persists. Citing numerous studies that support improved lymphedema outcomes with exercise groups, she encourages cancer

survivors to lead active lives. There are now 226 breast cancer survivor dragon boat teams in 25 countries.

Breakout sessions targeted to patients included the topics of psychosocial aspects of living with a chronic condition, relaxation therapy, nutrition and diet plus exercise sessions including yoga and aqua lymphatic therapy in the pool.

Jan Weiss, PT, provided a workshop on differential diagnosis of vascular impairments and associated edema management. Swelling is the common symptom for chronic arterial insufficiency, chronic venous insufficiency (CVI) and lymphedema. Examples of quick assessment tips:

- swelling, thin and hairless skin, wounds on foot and ankle may be Peripheral Arterial Disease (PAD)
- swelling, tight skin, dark staining of skin may be CVI
- swelling, stemmer sign positive, skin may maintain elasticity in the early stages may be lymphedema

CDT therapists may be the first to see these signs and it is essential that physicians and therapists work together so that the proper tests and diagnoses are done for these patients.

Dr. David Keast provided an excellent review on how to assess chronic wounds. Often associated with venous impairments these require a large amount of time and resources to manage. He stressed the need to talk to the patient, understand the underlying cause of the wound and any other risk factors before touching the wound. The treatment plan: 1) first treat the cause 2) the wound and 3) the patient. He stressed the importance of compression therapy and reviewed the

protocols of debridement, infection control and moisture for the skin to repair the barrier. If the wound does not respond then further investigation is required.

Jean LaMantia, winner of this year's poster presentation, explored nutritional recommendations in the management of lymphedema. She argued that nutrition has a role in lymphedema management and that Registered Dieticians could take a bigger role in lymphedema care. She suggests that weight management (rather than weight loss), a low salt and low fat diet, reducing long chain fatty acids, following an anti-inflammatory diet and not restricting fluids or protein, may be helpful.

Paediatric lymphedema occurrence is 1:6000 and is considered to be a vascular malformation. **Dr. Catherine McCuaig** of St. Justine Hospital in Montreal discussed the genetics of primary lymphedema and presented some case studies of infants with



primary lymphedema, describing the challenges of correct diagnosis; in implementing effective treatment, and the need for psychosocial support. She also highlighted the need for a multidisciplinary management team of physicians and lymphedema therapists for this group of patients.

Skin care is another component of lymphedema management and Dr. McCuaig gave an overview of best practices in this session. She stressed the balance in maintaining skin integrity and its barrier function. She reviewed a number of product characteristics, listing the positives and negatives of humectants, occlusives and emollients, highlighted the importance of neutral pH products with nothing abrasive or drying, and the need to keep the skin moisturized. She spoke of the cutaneous microbiome being *in* the skin as well as *on* the skin and the transdermal. Lymphedema causes stretching of the skin, which leads to inflammation of the surface and dryness

that creates a portal for bacteria into the body. Lymphedema also causes poor removal of fluid and debris from the skin, which can lead to more inflammation and poor immune response.

Day 2 – Dr. Machteld Huber, of the Netherlands who founded the Institute for Positive Health, began the day as the keynote speaker. She is challenging the World Health Organization's definition of health, which has not changed since 1948, despite changes in life expectancy and a shift in disease, from being mostly infectious to more chronic. Healthcare is more disease care and she suggests it is in need of a philosophical update. Her research looked at people in Blue Zones of the world – places where there are many people who live well into old age – and it was determined that in these areas, people prepared their own food, ate fresh, plant-based food and only ate until they were 80 percent



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satiated. They got plenty of exercise by moving naturally such as walking into their village regularly; made personal choices; and felt their life was meaningful even if they had a disease. They had a sense of coherence and comprehensibility and understood the situation in their own life. They felt connected and were not lonely. Dr. Huber noted that loneliness is more harmful to health than smoking.

Dr. Huber's team created a self-assessment tool, which looks at six dimensions of health. It is interesting that when given a choice, patients wanted to enrich or enhance areas where they scored higher but health care professionals wanted patients to focus on increasing their lower scores. It was found that when patients focused on enriching areas with higher scores, they scored higher in all areas. This suggested that this self reflection leads to a different conversation about what matters to the patient and is motivating, leading to small changes with positive effects to the whole person. Look for an interview with Dr. Huber in an upcoming issue of *Pathways*.



Berlang Persilus, a model and patient living with both Klippel-Trenanury and lymphedema was the lunchtime speaker. Her inspirational

message was on body image and being proud of who you are, despite how you look.

Pamela Hammond of Princess Margaret Cancer Centre Lymphedema clinic provided two sessions on self-care including self-massage. Their clinic has been teaching self-management since 2005 and continue to work to enhance

patient education. In the past three years they have seen a 20% increase in referrals.

Dr. David Keast presented the Canadian results of the Outcome Measures survey. The responses consistently focused on key areas of measurement including limb volume, quality of life, mobility, and episodes of cellulitis. He suggested that improvements in outcomes require an increase in patient and health care professional knowledge and improved reimbursement for treatment.

Dr. Anna Towers provided a workshop on palliative care and discussed the metastatic cancer patient and the difference in malignant lymphedema (tumour in the lymph system) vs. benign lymphedema. She stressed the importance of the palliative team and the need to continue Manual Lymphatic Drainage, exercise and bandaging and always keep the patient and family as part of the team.

There were a total of 15 oral abstract presenters with their work categorized in three different conference sessions: Research, Advocacy/International Work and Advancing Lymphedema Care. An additional 11 poster presenters displayed their work in the conference foyer throughout the conference.

Closing Plenary – Dr. Siba Haykal, a plastic surgeon at Princess Margaret Hospital, focused her presentation on surgery. The different types of microsurgeries she performs include lymphovenous anastomosis

(taking a functional lymph vessel and directing it into a vein and thus avoiding the blockage above) and lymph node transplant (where a lymph node is removed from one area and transferred to another to stimulate lymphangiogenesis and lymphovenous interface).

Patient selection is important with typically only stage 2 or 3 patients who have been assessed, and staged being eligible candidates. She stressed the need for conservative treatment before surgery and the need for compression post surgery, as this is not a cure. There are pre- and post-surgical protocols that the patient must be engaged in for optimal results. The research into the long term results of these surgeries is still ongoing, but to date, Dr. Haykal has seen a mean reduction in fluid of 35 percent over one year and more importantly an increase in quality of life.



Amy Beaith, a patient, provided her personal story of having surgery for lymphedema, after a lifetime of increasing problems with leg lymphedema that started at age five and worsened through university and again after having children. Her lymphedema was seriously affecting her quality of life due to both increasing volume and increasing incidents of cellulitis. She committed to a pre-surgery protocol followed by surgery where she had 2.5 litres of fluid and fatty tissue removed from

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Speakers, delegates, associations and organizers networking throughout the event.

her leg, a lymph node transplant and a lengthy post surgical protocol. She continues to follow a compression protocol and in 18 months has only had one episode of cellulitis. She finds she is able to be more active and is enjoying life more.

Marize Ibrahim, PT from Montreal provided a case series report of patient followup of LV and lymph node transplant surgery where short-term preliminary data showed an increase in lymphedema volume percentage in three respective operated limbs. This stressed the need for larger sample sizes and longer followup

to determine the long-term effect of surgical interventions on lymphedema. There was wonderful discussion throughout the conference amongst therapists, physicians, patients and families. There was so much to share and many thoughtful discussions took place. It was great having so many Provincial

Associations present so they could share their successes and strategies and to support the CLF in having a unified strong voice for lymphedema in Canada. Having opportunities to share strategies, advocate for and advance lymphedema care in Canada is so important, and this conference did just that. [LP](#)

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