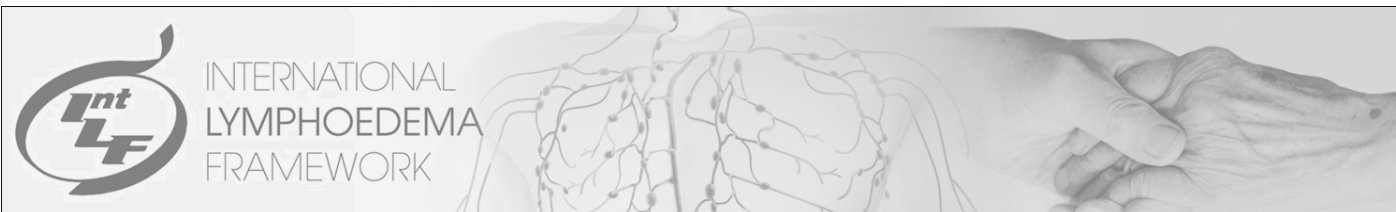


# Global Collaboration on Lymphedema Management

A synopsis of the International Lymphedema Framework Conference

By Anna Kennedy



The first International Lymphedema Framework conference was held in Ascot, England from April 21-23, 2009. The theme of the three day program was to achieve lymphedema care improvements globally through effective service development. Experts in the field of lymphedema management from 20 countries came together to discuss and share their experiences.

## A global problem

Representatives from international health organizations such as WHO (World Health Organization), GAELF (Global Alliance to Eliminate Lymphatic Filariasis), Handicap International and ISL (International Society of Lymphology) presented an overview of the global challenges of lymphedema in developing countries. A montage of video clips demonstrated the extent of the epidemic with more than 120 million people worldwide affected by lymphedema and 40 million incapacitated or disfigured by the condition. In India alone more than 23 million people are living with lymphedema filariasis where access to treatment is extremely difficult. And in Brazil, the living conditions among the poor exasperate lymphedema management because the rain, mud and lack of washing facilities make skin hygiene and effective compression bandaging almost impossible. I have tremendous respect for Dr. John MacDonald, Professor Terence Ryan, Dr. Pierre Brantus and all involved with international organizations and initiatives to bring training and programs to manage the

huge problem of lymphedema, filariasis and other skin conditions to developing countries.

It was inspiring to hear Dr. Bose showcase their pilot program in India using simple diet, exercise, yoga, skin care and teaching family members to apply manual lymph drainage.

***It was humbling to think that their approach could be adapted for developed countries such as Canada***

**Inequality in reimbursement** in developed countries was a universal theme. Five different countries presented how lymphedema treatment is or is not being funded within the context of their health care systems. Most countries experience great disparities between districts, provinces or regions and further inequality to access depending on whether the lymphedema is acquired at birth or due to cancer. On the whole, secondary lymphedema patients who contracted lymphedema due to cancer fare better than other lymphedema patients. This inequity needs to be addressed and hopefully with global collaboration we can help each other influence our individual country health policy advisors for equal access to appropriate treatment for **all** lymphedema patients.

## Lymphedema Patient Support

I was extremely excited to meet the heads of patient support networks from other countries such as Sweden, Israel, England and

the United States. The conference organizers have already committed to more opportunities at the next international conference for formal collaboration sessions to share ideas about programs, educational materials, conferences, memberships, fundraising ideas and advocacy initiatives.

## Global village showcase

Various products including compression bandaging, garments and hand held lasers for lymphedema were showcased in the exhibit hall. However many of the exhibitors were companies that specialize in the European market and don't yet have immediate plans to enter North America.

## UK Lymphedema Framework

An outline of the Framework project was presented along with some early clinical results. There is growing consensus that non cancer related lymphedema is being under assessed in terms of prevalence.

Dr. Vaughan Keeley outlined the need for reassessing lymphoedema classification and the current limitations.

## Effective compression

Professor Hugo Partsch introduced the science of lymphedema bandaging and effective compression. Some key points he included were that resting pressure may be too high in nighttime for compression stockings and that inelastic products produce more massaging of the lymphatics. I

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liked his analogy of our tissues being a sponge that expand with liquid and his recommendation that MLD should always be followed by bandaging to keep the "sponge" from expanding.

## Children with lymphedema

There was a focus on pediatric lymphedema. The different presentations of childhood lymphedema (including the congenital and genetic components) were outlined by Professor Peter Mortimer and Dr. Jacqueline Todd shared the completed project on best practices for treatment of

lymphedema in children that will be released soon.

A mother of a child with lymphedema shared her family's experience of childhood lymphedema and tried to dispel the myth that there is no "pain" associated with lymphedema.

A great new book produced to help young children understand lymphedema and the impact to their bodies was showcased. For more information on the book please contact the LAO.

## Living with lymphedema

The Patient Support Network in the UK shared findings of their "Living with Lymphedema" survey with key themes that self help and education are essential to lymphedema management. Several lymphedema patients shared their journeys through diagnosis, treatment, acceptance of lymphedema in their lives.

## The Psychosocial impact of lymphedema

Professors Christine Moffat (UK), Mei Fu (USA) and Anna Towers (Canada) presented findings of psychosocial research, psychosocial adjustment to breast cancer diagnosis and treatment and psychosocial aspect of pain and functional problems associated with lymphedema. Since any chronic condition has a lot of psychosocial issues associated with it, lymphedema must be looked at in a holistic way. Some of the early research findings indicate that social support and quality of life is lower in lymphedema patients than the control group of non lymphedema people.

A clear pattern is emerging that one can't look at the physical component of lymphedema in isolation but needs to look at the whole person. Research needs to look at the longer impact of lymphedema as people reintegrate into the workplace. We need to address how lymphedema might affect paid and unpaid work and the financial status of individuals.

## Compression hosiery in upper body lymphedema

Christine Moffat introduced the template for practice and a review of the literature was provided by Karin Johansson (Sweden). Early diagnosis is most important to treatment and volume in lymphedema. Both Debra Doherty and Justine Whitaker presented the role of compression therapy and practical management of compression hosiery supported by case studies.



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## Predicting and preventing breast cancer related lymphedema

Professor Jane Armer (USA) shared what is known about predicting and preventing breast cancer related lymphedema. Prof. Neil Piller (Australia) shared the diagnosis and measurement challenges in early detection of breast cancer related lymphedema. He shared that the Lymphoscintigram is the only true measurement of what the lymphatics are doing and detecting lymphatic failure. All other tools merely measure the **signs** of lymphedema. Bioimpedance tools can measure lymphedema 10 months before the swelling even starts. Sarah Blackburn presented a policy perspective of predicting and preventing breast cancer related lymphedema in the UK.

## MLD in lymphedema practice

Several presentations covered the historical perspective of MLD, and explored clinical effectiveness of MLD and clinical outcomes and treatment interventions.

## Wounds and lymphedema

A growing development among lymphedema programs is to integrate them with wound care as some of the manifestations of severe lymphedema require the same treatment as wounds from other conditions. Several case studies of patients with complex wound and/or severe chronic oedema were presented.

## Canada Wide Update

Canadians showcased the lymphedema efforts in their country with the following: A poster on the Canadian Lymphedema Framework; the launch, missions and goals of this new entity. The CLF is now a federally incorporated entity and awaiting charitable status. Various lymphedema research being done in Canada was showcased in a collaborative poster created by Pamela Hodgson (please see page 24).

## Awards

The Gala awards ceremony was an effective way to acknowledge significant contributions to the field of lymphedema among LE

peers. Life time achievement awards went to Saskia Thiadens, Executive Director of the National Lymphedema Network (USA) and Professor Neil Piller (Australia).

## Closing Comments


It was promising to see distinguished lymphedema researchers, clinicians, doctors and patient advocate groups from around the world collaborating on universal issues about lymphedema. By the end of the conference several additional countries had signed up to initiate lymphedema frameworks including Australia, Israel, Sweden, Denmark, Slovenia and Ireland.



Plans are already underway for next year's conference which will build on what's already begun supported by ILF's theme "BELONG TOGETHER".


A concurrent international patient conference is also being considered.

*Five members of the Canadian Lymphedema Framework represented Canada at this conference.*



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