



# Lymphedema community organizations can drive change

## Engagement advances lymphedema care

### Advocating for increased awareness and care

By Anna Kennedy and Nicole Boulet

Lymphedema patients around the world can agree that their condition, although chronic and not altogether uncommon, is poorly understood by many patients and healthcare professionals alike. This misunderstanding stems from a general lack of awareness, resulting in both mismanagement of lymphedema and inadequate funding of lymphedema research and treatment. There is a huge need to raise the level awareness towards lymphedema and change how it is

diagnosed, treated and funded. Community organizations, such as the International Lymphoedema Framework (ILF), Canadian Lymphedema Framework (CLF), and provincial

associations are starting to fill this need by raising awareness and helping to drive change and advance lymphedema care not only in Canada, but across the globe.

Although it may be the most visible symptom, lymphedema is more than just a swelling problem. The impact lymphedema has on one's life is multifaceted, including

physical, functional, emotional, social and financial challenges. A majority of the lymphedema research trying to address some of these issues has been focused on breast cancer related lymphedema, but most researchers would agree that many of the effects on one's quality of life could be generalized to other populations as well.

Lack of awareness of lymphedema affects not only patients living with it, but also has an impact on research, policy, reimbursement & access, standards of care, and education of patients, medical and healthcare professionals, and of the public<sup>1</sup>.

Community organizations can work to improve the lives of lymphedema sufferers worldwide by advocating for the standards of care set by the ILF (Table 1), lobbying for reimbursement

of care, fighting to have lymphedema and its management as a priority on healthcare agendas, creating an international community that collectively strives to improve the evidence base for treatment and professional practise, and overall raising the profile of

TABLE 1

#### ILF standards of care<sup>2</sup>

- 1 Identification of people at risk or with lymphedema
- 2 Empowerment of people at risk or with lymphedema
- 3 Provision of lymphedema services
- 4 Provision of high quality clinical care for people with cellulitis
- 5 Provision of compression garments for people with lymphedema
- 6 Provision of multi-agency health and social care

lymphedema and related disorders.

Recent years have seen positive changes in relation to many of the advocacy efforts mentioned above. Seventeen years ago, the only organization in Canada was the Lymphedema Association of Ontario. Today, there are seven provincial associations, plus a Canadian umbrella—the Canadian Lymphedema Framework (CLF)—and an international framework—the International Lymphoedema Framework (ILF).

The ILF began the momentum for a coordinated global effort in the advancement of lymphedema care, in England in 2002. This organization serves as a dedicated platform for the global lymphedema



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she advocates a healthy lifestyle including daily exercise to manage her condition well.

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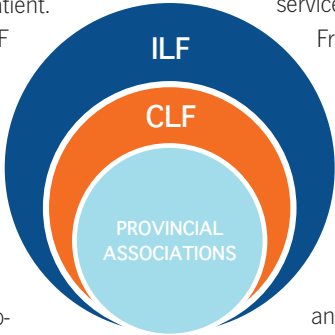
community. Currently, nine countries have Frameworks, including Australia, Belgium, Denmark, France, Greece, Holland, Japan, USA, and Canada—the third country to come on board. Several other countries are in the planning stages of developing Frameworks including some interest from developing countries that are looking for support from the ILF to start their own national Framework.

One of the ILF's main principles is that international collaboration is essential and that only a collaborative and multidisciplinary partnership between all stakeholders can lead to an improvement in the management of lymphedema. Of course, patients should be at the heart of the Framework Projects, with a dynamic process of ongoing research and implementing practice to improve the management of lymphedema, enhancing the lives of every lymphedema patient.

One measure taken by the ILF to advance lymphedema care is publishing Best Practice and position documents on the treatment of lymphedema, which are available free of charge in PDF format and can be downloaded from the ILF website [www.lympho.org](http://www.lympho.org).

One of the biggest challenges is to provide numbers of how many people are affected. An estimated 120 million people worldwide suffer from lymphedema, with approximately 300,000 Canadians living with the condition. To put this into perspective, in Canada there are only 100,000 people living with Parkinson's Disease, yet everyone knows about or has heard of this condition.

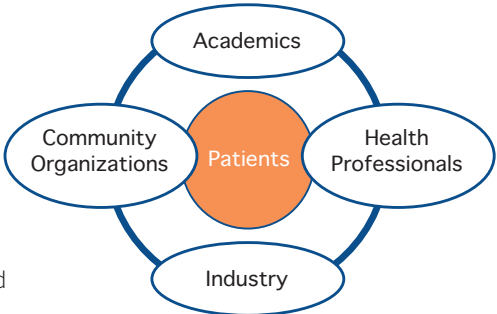
An exciting project currently underway by the ILF to address this challenge is LIMPRINT. This multi-country study is funded by 3M and will determine the impact and prevalence of lymphedema around the world. Christine Moffat, Chair of the ILF says "we will never change the face of lymphedema—if we can't supply the data." Collection of a global data set would allow us to accurately describe the prevalence and incidence of chronic edema, allowing us to bust widespread myths such as: "there is nothing that can be done for lymphedema." LIMPRINT is a population-



based study, examining the proportion of a population found to have lymphedema or chronic edema. It provides an important toolkit for countries to use to assess the number of patients with chronic edema and its impact on individuals and healthcare services. The Canadian Lymphedema Framework (CLF) is proud to be one of the five countries participating in this study. Founded in 2009, the CLF is a collaboration between academics, health professionals, industry, community organizations and patients. Patients are always at the heart of everything we do. Our mission is to make comprehensive and effective treatment for lymphedema and related disorders accessible to all persons across Canada.

The CLF structure is made up of an Executive Committee, Executive Director, a Communications Coordinator and three Working Groups. An Advisory Board, represented by a researcher, a clinician, a therapist and a patient, reviews strategy, policies and key projects. The strength of the CLF is our extremely committed volunteers, who are passionate and devoted to the CLF mission, donating their time and own funding for meetings.

One of our first initiatives in 2009 after the initial stakeholder meeting kickoff was a Lymphedema Landscape Study, funded by 3M Canada. Learnings from the stakeholder meeting and Landscape study are what drove the strategic plan and priorities for the CLF.



Other accomplishments achieved by the CLF since our inception include publishing standards for lymphedema training, delivering national conferences with core research elements, delivering patient education tools (including a new website, patient pamphlet and booklet) and publishing research repositories and national agendas.



The CLF sets an important example of how a new community organization can work with existing patient and clinical organizations to unite in one voice for furthering lymphedema care in Canada. It hosts quarterly teleconferences with all the provincial associations to exchange ideas, tackle issues and collaborate on national projects such as the *Pathways* magazine, patient education tools, and co-hosting of conferences.

The CLF is pleased to have received international recognition for its efforts in the lymphedema community at the 2014 International Lymphoedema Conference in Glasgow. The CLF was voted "Most Inspiring Organization" by conference delegates. The "Most Influential Organization" was awarded to the **Alberta Lymphedema Association** for their role in the recent change

in provincial health policy, which will now provide lymphedema care to all Albertans.

Other recent advocacy successes by Canadian community organizations:

**Lymphedema Association of Quebec and Alberta Lymphedema Association** – successfully advocated for increased provincial care

**Saskatchewan Lymphedema Association** – part of a Ministry of Health committee

**Lymphedema Association of Manitoba and BC Lymphedema Association** – established proclamations for March 6 awareness day

**Lymphedema Association of Ontario** – helped streamline the ADP reimbursement process

**Atlantic Clinical Lymphedema Network** – advocated for a hospital based lymphedema clinic

We can all be proud that the efforts of Canadian organizations are improving the lives of people living with lymphedema. What can you do to make a difference? Support your own provincial association with donations of money or time, subscribe to *Pathways* magazine, contribute an article to *Pathways*, or join a CLF working group. Any contribution, no matter how small, is a step towards improved lymphedema management for the future. We can all make a difference. **LP**

#### References

1. Hodgson, P., A. Towers, D.H. Keast, A. Kennedy, R. Pritzker, and J. Allen. "Lymphedema in Canada: A Qualitative Study to Help Develop a Clinical, Research, and Education Strategy." *Current Oncology* 18, no. 6 (2011): E260-264. Accessed July 10, 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3224034/>.
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