

# Lymphedema Advocacy A Role for Each One of Us

By Anna Towers

There is a great need to urge influential groups and policy makers to promote environments that will improve the management of lymphedema in Canada. The Canadian Lymphedema Framework (CLF) is committed to helping give a voice to all those affected by lymphedema.

If you are a patient, you and your family already have extensive expertise about your situation which can be tapped to persuade for change. You have a wealth of knowledge and are the best people to describe how lymphedema has impacted your life. Advocacy can involve telling your story to an elected politician, for example,

asking them to support the development of more lymphedema services.

In recent years licensing bodies for health professionals have stressed that advocacy is an important component of the practitioner-patient relationship. For physicians, for example, this duty applies not only to individual patients but also to communities. “Physicians have a responsibility to advocate on behalf of their patients to advance policies that promote the health and well-being of the public” states the Ontario College of Physicians and Surgeons.

However, health professionals receive little or no more formal training in advocacy than patients do. We all need to find our own sources, create fact sheets and then learn how to share this information with others.

We need to start saying yes to opportunities for getting our message heard in face-to-face meetings, in newspapers and magazines, via the radio, and on television. As we grow in our advocacy roles we need to focus on our goal and our message. This focus will go a long way to help counter shyness!

One challenge is that we are trying to convince people who may not have heard of lymphedema and /or who believe that it has nothing to do with them. They may falsely believe that lymphedema is a rare condition, or that there are other more urgent problems that need to be addressed. Becoming better advocates will help us overcome these obstacles.

## Step 1

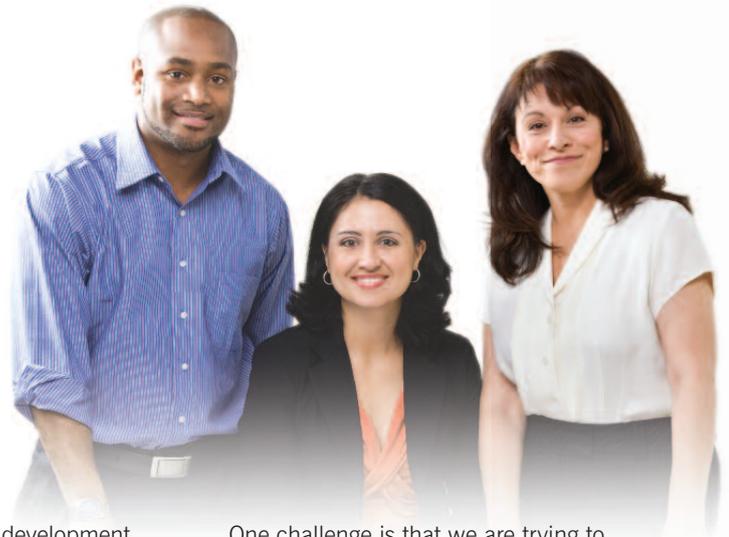
**Create a concise key message.** An example for patients and families might be: “Lymphedema is a common complication of cancer treatment and can lead to significant disability, as in our case. Yet why is lymphedema the only medical condition that is not covered by Medicare? These are the treatments that we require and need to be covered.”

## Step 2

**Target your audience and activity.** A prime time is to plan your activity during March, which is National Lymphedema Awareness month.

**Write a letter.** Outline a personal story, including photos of the patient, with one specific request, to be timed for delivery to the provincial Minister of Health and your local Member of Parliament.

**Arrange face-to-face meetings.** Go as a team of two (but no more than three



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persons) and decide who will say what. Bring background information. What exactly is it that you want the other person to do for you? Be prepared to state your case in five minutes.

**Seek media exposure.** Know which journalists or radio/TV hosts to contact. Send articles to your community and city newspapers. Ask for community radio announcements and request to be a guest or expert for a phone-in line or TV clip.



**Utilize social media.** Open up your social networks to the lymphedema cause by using facebook, twitter, YouTube and blogs to share your message with a vast number of people.

**Organize grand rounds or a conference.** Invite a key person and ask them for support in realizing a particular change.

**Start pilot projects.** No matter how small they may be; evaluate them, demonstrate their effectiveness, and then advocate for similar programs in the rest of the community.

**Invite advocacy experts.** These can be from other fields and organizations to give workshops on how to be persuasive.

**Gather and collate information.** Writers and researchers can help us collate material for handouts, write briefs and reports for advocacy activities and advocacy guides.

**Resources**

You can request a copy of the CLF 2009-2011 annual report to include in communication to MPs etc by sending a request to canadalymp@live.ca. Consider sending a copy of CLF's new magazine, *Pathways*, as well.

The Canadian Lymphedema Framework's Research Working Group, is planning studies to obtain more data on lymphedema in Canada. This information will be instrumental in advocacy activities. For now, provincial lymphedema associations can provide basic material to supplement your personal stories and help to advocate for issues like prevention, access to lymphedema treatment and reimbursement.

The CLF hopes to produce its own lymphedema specific "how-to" advocacy

kit in the future. In the meantime there are some excellent tips and ideas from the websites of other charitable organizations that lymphedema advocates can learn from:

- [www.schizophrenia.ca](http://www.schizophrenia.ca)
- [www.chpca.net](http://www.chpca.net)
- [www.thewpca.org](http://www.thewpca.org)
- [www.canceradvocacy.ca](http://www.canceradvocacy.ca)

The Cancer Advocacy Coalition of Canada, in particular, is a great leader in this arena and lymphedema advocates can receive inspiration from them. This organization produces regular Report Cards that highlight deficiencies in cancer care in Canada. However it is disappointing that lymphedema and the issue of cancer rehabilitation are missing from their reports. We have much work to be done to increase awareness!



The CLF welcomes any tips and resources that the Canadian lymphedema community might have to help us all become better advocates. We also invite you to share your stories of successful advocacy activities, events and pilot projects. *En avant!* **LP**

## Advocacy Work Across the Border



A patient advocate, Heather Ferguson is also a mother of Dylan, a young child with lymphedema. In 2009 Heather got a mandate passed in North Carolina requiring private insurance policies to cover all components of lymphedema treatment. In 2010 she secured her Congressman, Larry Kissel (left) as the sponsor for a federal bill that would improve coverage across the United States. Heather founded the Lymphedema Advocacy Group in 2011 to bring advocates together to focus on improving insurance coverage for treatment. Last November patient advocates from around the USA convened in Washington DC to visit hundreds of

House and Senate offices and conduct a Congressional Staff Briefing to educate legislators and staff.

"This has been a most remarkable journey," states Heather, "for myself, and all the advocates who have become involved. Getting even this far is what many people had formerly dismissed as impossible".

Heather hopes Canadians in the lymphedema community will be inspired to work for a change they feel is needed, and make a positive impact on their own lives and those of many other lymphedema sufferers. It's not easy, but it is worth it and YOU can make a difference. **LP**