



Annual Report Projects and Activities

April 2009 - March 2011



CANADIAN LYMPHEDEMA FRAMEWORK



proud partner of the
International Lymphoedema Framework

The Face of Leadership

Executive Committee

Dr. David Keast,
Dr. Anna Towers,
Anna Kennedy,
Rachel Pritzker and
Christine Moffatt (*small photo*)



Administrative support:
Jill Allen, Pamela Hodgson

CLF Advisory Board

Martina Reddick, Cathy McPherson, Janet McFarland,
Kim Avanthay, Linda Venus, Roanne Thomas-MacLean, Janice Yurick, Robert Harris

How to reach us

Canadian Lymphedema Framework

4161 Dundas Street West, 1st Floor
Toronto, Ontario M8X 1Y2 ♦ 416-410-2250
canadalymph@live.ca ♦ www.canadalymph.com

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Welcome Address

It is with pleasure that we write a brief note of introduction for the first report of the Canadian Lymphedema Framework. Our friend and colleague, Dr. John Macdonald often calls lymphedema the "Hidden Epidemic". Non-cancer related lymphedema in the industrialized countries, such as Canada, is under recognized and even more, poorly treated. Even for cancer related lymphedema, treatment is under resourced.

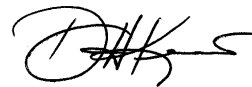
The Canadian Lymphedema Framework was formed in 2009 with the vision that "comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada". In two short years the CLF has achieved many milestones including incorporation as a not-for-profit corporation with charitable status, holding a Stakeholder's meeting, conducting a survey of lymphedema care providers to determine the "Lymphedema Landscape", and forming key working groups of dedicated and hard working individuals to move our agenda forward.

The CLF is an organization that not only includes clinicians, researchers and educators, but most importantly persons living with lymphedema.

Our work is detailed in the following report and we encourage you to read it carefully.



Anna Towers
MDCM, FCFP
McGill University Health
Centre
annatowers@muhc.mcgill.ca
CLF Co-Director



David Keast
MSc, MD, FCFP
Lawson Health Research Institute
david.keast@sjhc.london.on.ca
CLF Co-Director

Registered as the Canadian Lymphedema Framework
Charitable Registration **85160 1260 RR0001**

CLF Mission and Vision

The CLF is an academic and patient stakeholder collaboration that is part of an international initiative which aims to promote research, best practices and lymphedema clinical development, worldwide. The CLF is modelled on, and has a partnership agreement with, the International Lymphoedema Framework, and through them links with other national frameworks.

CLF Philosophy

- Effective treatment is based on best practice guidelines
- Lymphedema treatment must be fully covered or reimbursed
- Patient views are integral to all development of care
- Contributing to the rapidly growing evidence base is paramount
- International collaboration will increase global awareness of the importance of lymphedema in healthcare
- Investment in lymphedema will lead to new product development

CLF Mission

The Canadian Lymphedema Framework (CLF) will work to improve the management of lymphedema and related disorders in Canada. In collaboration with the International Lymphedema Framework (ILF) and the American Lymphedema Framework Project (ALFP) we will contribute to the global international advancement of lymphedema care.

Goals of CLF

- Raise the profile of lymphedema and related disorders nationally and internationally
- Define and promote best practices in risk reduction, early diagnosis and treatment of lymphedema
- Develop a Lymphedema Minimum Data Set for Canada to improve lymphedema outcomes
- Take a leadership role in defining and promoting education for health care professionals, patients and the general public
- Define research strategy for Canada and facilitate collaboration among researchers
- Place lymphedema and its management as a priority on regional, provincial and national health care agendas
- Address issues of inequity of provision

Who We Are

The Canadian Lymphedema Framework (CLF) was officially launched on February 6, 2009. It is modeled on and aligned with the International Lymphedema Framework (ILF) that began in 2002 as a collaboration among health professionals, community based organizations, patients and industry partners, to improve the standards of lymphedema management in Great Britain.

The CLF executive committee's leadership is headed by Dr. Anna Towers and Dr. David Keast, as Co-Directors, in collaboration with **Christine Moffatt**, Executive Director of the ILF.

Anna Towers, MDCM, CCFP is recognized as a leading lymphedema expert in Canada and is Director of the Interdisciplinary Lymphedema Program at McGill University Health Centre, Montreal, Quebec. She is Associate Professor of Oncology at McGill University and sits on the International Advisory Committee for the International Lymphoedema Framework.

David Keast, MSc, MD, FCFP is Founding President of the Canadian Wound Care Foundation and Centre, and Director; Aging, Rehabilitation and Geriatric Care Research Centre of the Lawson Health Research Institute, London, Ontario. He was appointed to an international working group to produce a white paper for the World Health Organization on the management of lymphedema in countries with scarce resources.

Patients are represented on the executive by **Anna Kennedy**, Executive Director of the Lymphedema Association of Ontario (Toronto, Ontario) and by **Rachel Pritzker**, President of the Lymphedema Association of Quebec (Montreal, Quebec). Anna and Rachel bring relevant patient experience, as well as both organizational and business skills to the team.

Administrative support is provided by **Pamela Hodgson**, MSc, RMT, a certified lymphedema therapist and research assistant to Dr. Towers, and by **Jill Allen**, RN, WOCN/ET, located in London, Ontario.



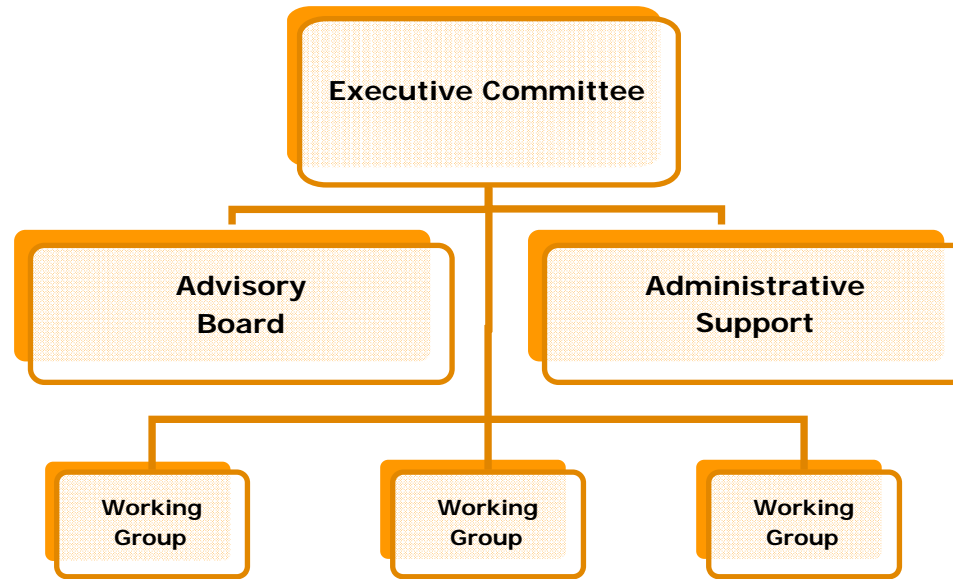
Advisory Board

The founding Advisory Board of eight volunteers covers the country from Newfoundland and Labrador to British Columbia and includes two patient representatives, a researcher, two educators, two therapists and a policy maker. The Advisory Board meets by teleconference a minimum of 4 times per year in addition to one in-person meeting. Advisory Board members participate in one of the three working groups and also advise the CLF Executive regarding strategic plans and activities.



Kim Avanthay Manitoba	Mother of a young child with lymphedema and a patient advocate
Robert Harris British Columbia	Director and Senior Instructor, Dr. Vodder School-International Educator and RMT
Jan McFarland Ontario	Director of Toronto Lymphocare, Educator and lymphedema therapist
Cathy McPherson Ontario	Website manager of Lymphovenous Canada and Policy Advisor lymphedema patient
Martina Reddick Newfoundland and Labrador	Lymphedema nurse practitioner Cancer Care Program, Eastern Health Region
Roanne Thomas-McLean Saskatchewan	Associate professor, Sociology, University of Saskatchewan, lymphedema researcher
Linda Venus Manitoba	Senior Director, Public Affairs and Cancer Control, Cancer Society and lymphedema patient
Janice Yurick Alberta	Physiotherapist in the lymphedema program at Cross Cancer Institute, Edmonton

Our Structure



Linkage - International Lymphoedema Framework

The Canadian Lymphedema Framework has an informal agreement with the ILF to share their core fundamentals which are to:

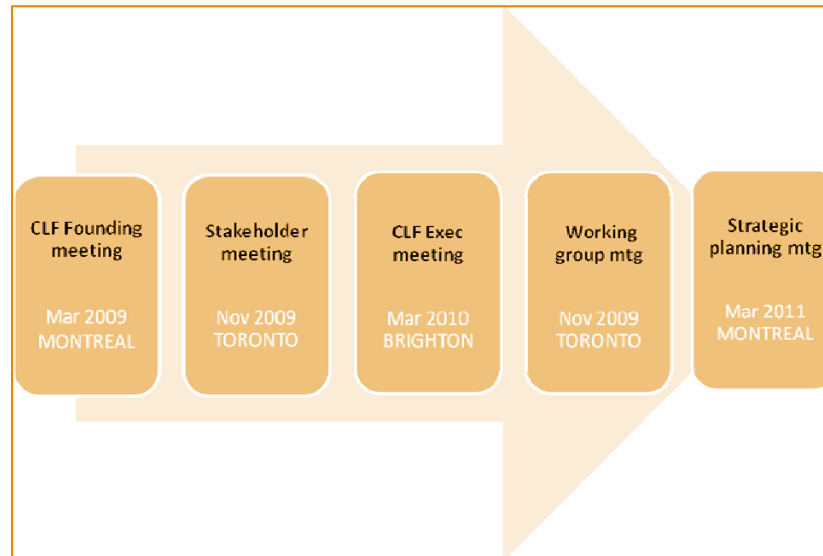
- place patients at the heart of our projects
- maintain collaborative and multi-disciplinary partnerships between ALL lymphedema stakeholders in Canada
- contribute to ongoing lymphedema research and work towards implementation of best practice
- support essential international collaboration

Additionally the CLF is expected to contribute to the ILF Best Practice Document, the lymphedema dataset, research projects and to identify and map lymphedema practitioners in Canada by carrying out the ILF practice survey in Canada.

Strategic Planning

The first two years of the CLF was with a significant amount of time spent laying the groundwork and planning the vision, mission, goals, structure and work plans for the organization. This included becoming incorporated and finally being granted charitable status.

The process took place with considerable amount of input from all stakeholder groups, advisory board and CLF Exec, in collaboration and direction from the International Lymphoedema Framework.



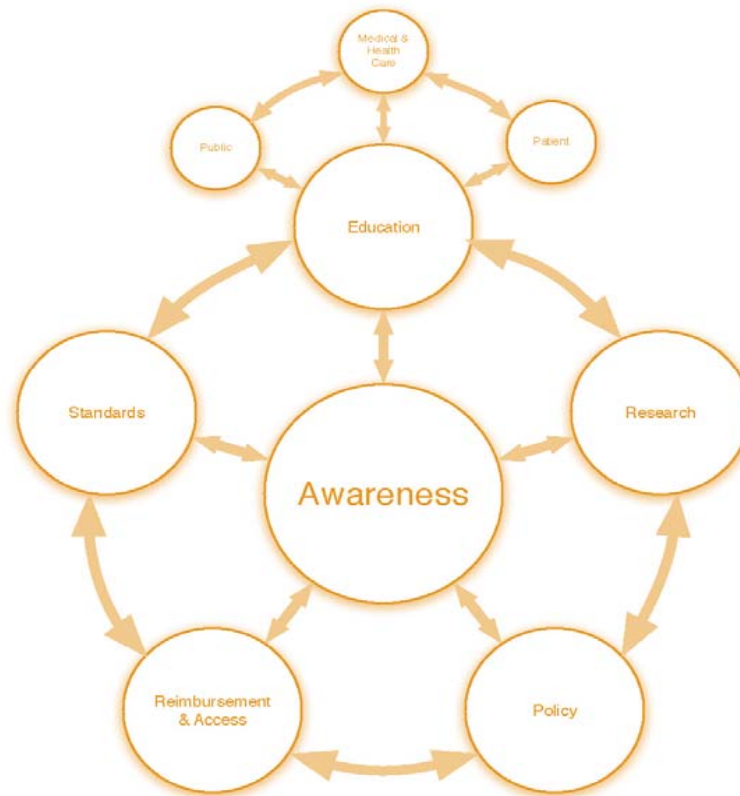
Stakeholder Meetings

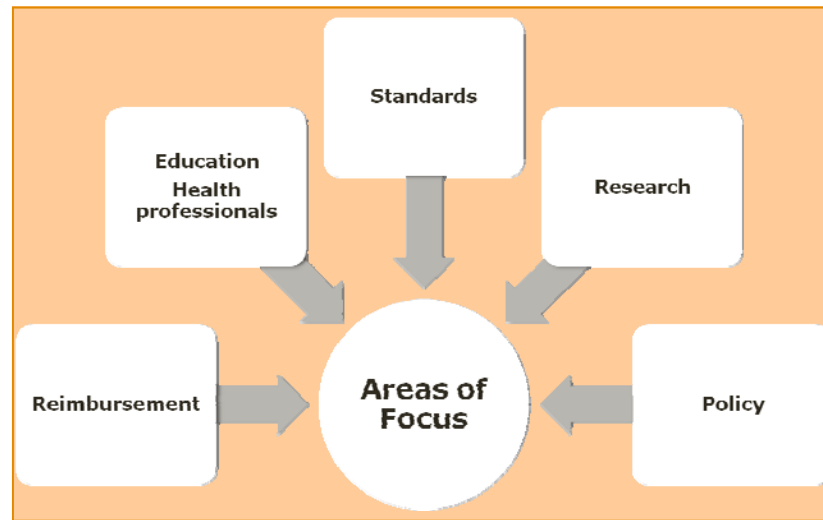
The CLF believes that only through partnerships with all stakeholders can the lymphedema agenda in Canada be advanced. Accordingly, as a first step, the CLF Executive Committee obtained a knowledge translation linkage grant from the Canadian Breast Cancer Research Alliance and secured funds from industry, in order to invite key lymphedema stakeholders from every province and territory to a National Stakeholders Meeting. The meeting was held November 6, 2009 in Toronto. One hundred and eight participants met to discuss the issues and set the research and development agenda for lymphedema management in Canada.

Participants were representative of all key stakeholder groups: lymphedema therapists (25.9%), patients and patient advocates (16.6%), industry (14.8%), physicians (11%), nurses (9.25%), researchers (6.5%), government/policy makers (4.6%) educators (3.7%), and other (7.4%).

Participants worked first in small and then larger groups to build consensus about the priorities, barriers and resource issues facing the lymphedema community. One group summed up the state of affairs as a “vicious circle of lacks”. The central problem to standardized lymphedema care is the global lack of awareness of lymphedema as a chronic medical condition, among health care professionals, policymakers, funders and the general public.

The Lymphedema Web of Awareness





All the documents produced at the meeting, as well as a final report, are posted on the CLF website (www.canadalymph.ca)

Early in 2010, following the stakeholder meeting recommendations, the CLF Executive developed a three-year Road Map outlining activities, target groups and immediate and intermediate outcomes related to the key areas identified. In the spring of 2010 the executive invited eight volunteers, representing different professions and stakeholder groups across the country, to form an Advisory Board to counsel and inform the executive and to assist in advancing the strategic plan. With input and validation from the Advisory Board members, the CLF executive decided to focus on three key issues: education, research and partnership development/fundraising. Accordingly an invitation went out to Canadian stakeholders inviting volunteers to join one of three working groups.

On November 19, 2010, over 30 volunteers from across the country gathered in Toronto at their own expense for a second stakeholders meeting. After a short plenary session, participants spent the rest of the day in one of the three working groups, discussing issues, determining priorities, setting out working relationships and mandates for each group.

CLF working group members are individuals who volunteer their time to work on projects for at least one year.

CLF Education Committee Report

The CLF education committee met via teleconference on the following dates; January 13, February 24, March 15 and April 14, 2011. This large working group consisting of 17 active members. Hard work and dedication was not lost on this group and much has been accomplished in a very short time frame.

Accomplishments:

- Information on curriculum was collected and collated on the three major private lymphedema schools in Canada; Integrated Lymphatic Drainage; Dr. Vodder and Casley-Smith as a first step to address the need for Canadian educational standards.
- Power Point Presentation slides were gathered from committee member volunteers and compiled in to a resource library of 355 slides for future presentations to health care professionals to promote consistency in education.
- A survey/questionnaire was developed to send to universities across Canada to determine what is currently included in the under-graduate health sciences curricula on lymphedema. This survey was distributed to 100 schools and programs across Canada with 12 respondents to date. Another distribution is planned for early May of 2011.

The CLF Executive acknowledges and greatly appreciates the efforts of the volunteer members of the Education Working Group:

Chair: Martina Reddick

Linda (Koby) Blanchfield, Michael Eid, Adriana Golob, Robert Harris, Pamela Hodgson, Michelle Horst, Pamela Hilliard, Leslie Hutchings, Nadine Maraj-Niri, Jan McFarland, Edith Mulhall, John Mulligan, Casi Shay, Dorit Tidhar, Anna Towers, Janice Yurick

Research Working Group Report

The Canadian Lymphedema Framework (CLF), Research Working Group (RWG) held its first meeting in Toronto on November 19, 2010 and has since participated in 4 one-hour teleconference meetings. Attendance has been excellent with over 90% members present for each call. All meetings have been conducted with a planned agenda, documentation of minutes and plans of action identified. All members have worked to move our actions forward to accomplish our goals.

To date, we have drafted a broad mandate that the group accepted as a living document open to regular review. Terms of Reference prepared by the CLF executive for CLF working groups were discussed and we agreed that a three-year term will give stability and time for our group to initiate and develop projects. We have created a summary template and are collecting information on lymphedema studies taking place in Canada. We are also developing a comprehensive list of Canadian researchers from multiple disciplines who work in the area of lymphedema. We aim to create an extended Research Advisory Network (RAN) to assist us in developing and promoting funded research projects and have prepared a draft letter of invitation and discussed a selection process for such a group. We are investigating the cost of communicating via webcasting/webinar as a possible means of communication once this larger group is established. We also plan to access the CLF website to upload or link to current Canadian research, thus creating a database for people doing or looking for research on lymphedema in Canada.

The RWG recognizes that the prevalence study planned by the CLF will be the immediate focus of a major research project. This group however, will also continue to explore possible avenues of funding that may be available for smaller projects. Attracting researchers who have been successful in obtaining grants is of prime importance.

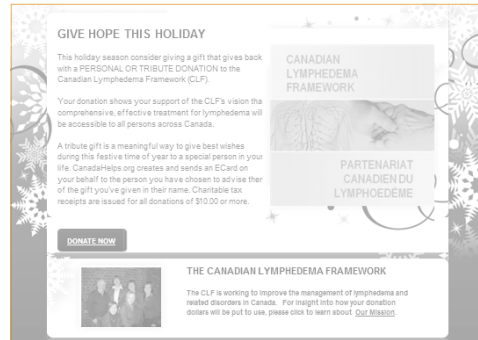
The CLF Executive acknowledges and greatly appreciates the efforts of the volunteer members of the Research Working Group:

Co-Chairs: Bev Lanning, Roanne Thomas-MacLean
Sylvia Crowhurst, Pamela Hodgson, Miles Johnston, Winkle Kwan, Margie McNeely, Cathy McPherson, Deborah Ruskin, John Semple, Andrea Tilley, Anna Towers

Partnership Development and Fundraising Report

This group is charged with developing partnerships with industry, corporate donors and potential grantors for the purpose of supporting the operations and goals of the CLF by building financial sustainability for long-term success.

Since the initial formation and meeting of the group in Toronto on November 19, 2010, we have had four teleconference meetings. To facilitate our discussions and decision making, we adopted the terms of reference presented to us from the CLF Executive.



One of the first initiatives was a holiday email fundraising campaign in December, 2010 called “Give hope this holiday”, inviting people to give an online personal or tribute donation to the CLF through Canadahelps.org.

Our first fundraising campaign in 2011 was sending personalized letters through Canada Post requesting support for an initial start-up contribution. The targeted individuals were heads of 250 organizations that included health professionals in various disciplines or community support groups that deal with lymphedema or cancer.

Key initiatives the group will be working on after the ILF conference are: developing a fundraising strategy and toolkit to present to possible funders, working on a CLF permanent website and targeting corporate donors. We enthusiastically welcome representatives from industry and those with fundraising experience to join our group.

The CLF Executive acknowledges and greatly appreciates the efforts of the volunteer members of CLF Partnership Development working group:

Chair: Bonnie Baker

Kim Avanthay, David Keast, Anna Kennedy, Claire Ann Deighton-Lamy, Rachel Pritzker, Linda Venus

Assessing the Lymphedema Landscape

A key priority identified at the stakeholder meeting was the need to assess the current status of lymphedema care in Canada. With the generous support of 3M Canada, the CLF commissioned a research company to conduct an online survey of Canadian health professionals currently providing lymphedema care.

Research objectives

The research objectives were to understand

- the level of lymphedema training and certification,
- the profile of care setting in hospital clinics and private practice,
- types of lymphedema treated,
- and services and treatments provided.



Online survey of health professionals

In the spring of 2010, health professionals across Canada providing lymphedema care were invited to participate in an online survey. The invitation was disseminated and cascaded through community organizations as well as both provincial and national professional

associations in nursing, physiotherapy, occupational therapy and registered massage therapy. 239 respondents from across the country completed the survey: 47% were licensed/registered massage therapists (RMTs), approximately 29% were physiotherapists (PTs), and approximately 19% were nurses. The remaining 5% were mainly occupational therapists and fitters.

Training

There were some surprising results. While most respondents had received training from a certified school, not all had.

Only about half the nurses treating lymphedema patients had taken post graduate training for lymphedema.

Most therapists complete recertification every two years, but some reported that recertification was not required at their school. Many take additional training in hands-on-care, while fewer are trained in exercise or psychosocial issues specific to lymphedema patients.

Care settings

According to the survey, lymphedema is mainly managed in a private practice setting (59%) by mostly massage therapists (90%) and a third of nurses and physiotherapists. Hospital clinics represent one third of the care settings where physiotherapists (55%) and nurses (33%) provide the majority of care. Only 5% of the total sample practise in a hospital clinic dedicated to lymphedema, the rest are in oncology, multidisciplinary, physiotherapy and other clinics where positions are part-time only. Both in hospital and private practice, health professionals and therapists teach patients about lymphedema risk reduction and management, and in many hospital clinics this education is the primary intervention. As there is no standardized patient educational material for lymphedema in Canada, it is not surprising to find that 65% of respondents reported creating their own information sheets.

Measurements and clinical guidelines

Circumferential measurements are used by 90% of respondents to assess lymphedema, and 35% also reported using photographs. An alarming 8% reported not using any type of measurement at all with their lymphedema patients.

Approximately 40% of survey participants reported following the International Best Practice Guidelines and 26% reported not following any clinical guidelines for lymphedema.

Referrals

Referrals for lymphedema therapists were reported from a wide range of medical professionals and specialists, with family physicians being the most common (75%). About one-quarter of referrals are from a provincial lymphedema association and many are self-referrals, indicating that an initial diagnosis and assessment for lymphedema is still difficult to come by for many Canadians.

Types of lymphedema treated

Participants reported that 70% of their lymphedema patients are secondary-cancer related, 13% are primary lymphedema patients and 17% secondary non-cancer related. 60% of patients seen have upper extremity lymphedema, 30% have lower extremity, and the majority of the remainder is truncal. More nurses than other professionals see patients with lower extremity lymphedema. Most lymphedema patients are adults (71%), 25% are seniors, 3% are children or adolescents.

Phase 2 of the research study will take place in 2011, focusing on reimbursement from provincial healthcare and insurance companies.

Implementing Best Practices

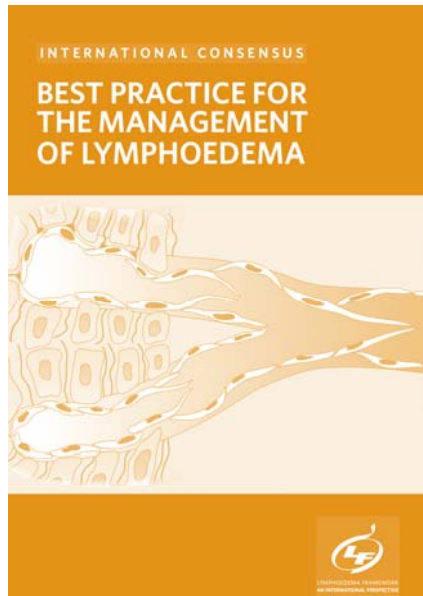
Lymphedema treatment continues to be primarily delivered through certified lymphedema therapists in the community. It is important to provide up-to-date evidence-based workshops and seminars for those lymphedema therapists working privately in the community, outside the research and teaching resources of the university and hospital-based system.

In Canada, lymphedema education for health professionals, for the most part, is being conducted by various organizations, including private lymphedema schools, lymphedema community associations (through conferences) and hospitals such as the MUHC lymphedema clinic.

Pilot Test—Educating Health Care Professionals in Montreal

The goal of the MUHC MGH Lymphedema Clinic over the next few years is to provide high quality continuing education programs for certified lymphedema therapists.

In 2010 three English pilot workshops were held on implementing international best practices, clinical decision-making and minimizing the risk of developing lymphedema, and one in French on implementing international best practices. Fifty certified lymphedema therapists attended the workshops and evaluated them as excellent or very good in terms of relevance of content, quality of sessions and overall rating.



The ILF Best Practice document is currently undergoing a comprehensive literature review with a second edition scheduled for release in 2011. A copy of the current edition can be found at www.lympho.org

Pilot Testing the ILF Minimum Data Set

At the McGill University Health Centre Montreal General Hospital Lymphedema Clinic, Dr. Towers pilot-tested the November 2008 version of the ILF minimum data set (MDS), using paper questionnaires, with 25 patients during 2009-2010. Those questions that complemented the existing clinical data entry and that were deemed most helpful were then integrated into the electronic database. The questions added were: How do you rate your overall health in the last thirty days, and two questions quantifying level of anxiety and depression. The database prepared by Dorit Tidhar, PT already had questions on function that are similar to the MDS questions. The clinic will proceed further, once the ILF's new version of the Minimum Data Set has been released.

Co-hosting the 2011 ILF Conference



The CLF submitted a bid to the ILF International Advisory Board in Brighton, March 2010 to host the next international conference in Toronto and were very pleased to have been awarded this honour. The CLF Exec has been working hard ever since in their role as co-host, along with the ILF and the Lymphedema Association of Ontario. Part of the vision was not only for lymphedema health professionals to meet and learn more from key world experts on lymphedema, but also to use the opportunity to target those health professionals that come across lymphedema in their clinical practice, but have never been trained and need a basic introductory course on lymphedema diagnosis and management.

A one-day primer day is targeted to these individuals as a separate conference stream. In addition, there is a four-hour session planned for physicians, facilitated by internationally renowned lymphedema experts, Prof. Neil Piller (Australia) and Dr. Vaughn Keeley (England). We look forward to welcoming old and new faces to this international event.

Contributing to Global Health Education

HVO is a network of health care professionals, organizations, corporations and donors united in a common commitment to improving global health through education. In June 2009, Dr. David Keast and Dr. Anna Towers, co-directors of the CLF, were sponsored by the Association for the Advancement of Wound Care Global Alliance (and coordinated by HVO), in cooperation with the World Alliance for Wound and Lymphedema Care, to perform a site visit to Mulago Hospital, and the regional Mbarara Hospital and associated nursing schools to assess the state of wound and lymphedema care in the Ugandan health care system.

At the two centres visited, lymphedema was not recognized as a problem seen regularly and filarial related lymphedema was seen as a problem affecting only the northern part of the country. The prevailing opinion was that lymphedema, because it was not painful, was under recognized. It was well advanced before seen in the primary care centres and at that point the fatalistic view that nothing could be done was prevalent among health care providers. The burden of chronic wounds related more to burns, trauma, post-operative difficulties, infection related problems, HIV related problems such as Kaposi's sarcoma, and skin malignancies.



The Site Visit Report documented a clear need for education and training in wound and lymphedema care. The report recommended a "train the trainer" approach so that faculty and clinicians at the national and regional level can, with

support, disseminate education to the community level. This would include basic preventative skin care; early recognition and treatment of lymphedema wound bed; preparation approach to managing skin breakdown; identifying the underlying causes; identifying patient and environmental factors which can impair wound healing; providing local wound care which involves, debridement, management of bacterial burden and managing moisture levels at the dressing/wound interface and Compression therapy. The report suggested an initial approach where the volunteer educators might provide one week of classroom training with a second week focusing on integration in to care by attending clinics and ward rounds with the trainees followed by Consolidation through a self learning project and a repeat visit in 6 months to consolidate learning.

Treasurer's Report

Starting a new organization in an economic downturn is a challenge. However, with determination we forged ahead, trusting that others would share our vision and funding would follow. We are grateful to the McGill University Health Centre and the Canadian Association of Wound Care for contributing some initial funds in 2009 to help cover the associated costs of incorporating and building our structure.

With no public or government funding, the CLF relies solely on the generosity of donors, grants and corporate sponsorships for both ongoing operational costs and project related expenses.

Key expenditures over the last two years have been associated with the logistics of hosting national stakeholder meetings. We appreciate the vendors who sponsored the meetings and the participants from across Canada who all self-funded their own travel arrangements to attend.

The CLF is committed to transparency both in how we secure funding and spend resources. A full report of both 2009-2010 and 2010-2011 financial statements are available for viewing on our website.

As at March 31

Statement of Operations		Balance Sheet	
	2010		2010
Revenue	28,293	Assets	5,799
Expenses	25,271	Liabilities	2,777
Net income	3,022	Balance	3,022

Volunteer hours, difficult to capture in dollars and cents, remains the CLF's most valuable asset. None of the CLF work in the last two years would be possible without the countless work of many individuals; the CLF Executive, Advisory Board, working groups and stakeholder meeting participants. The value of their contributions as well as their passion and commitment to move the Canadian lymphedema agenda forward?...**priceless!**



Anna Kennedy
Executive Director, Lymphedema Association of Ontario
CLF Treasurer

Our Circle of Friends

A special thank you to the following individual donors, granting agencies and corporate sponsors for their financial support during the first two years of CLF's operation.

Granting Agencies

Canadian Breast Cancer Research Alliance (a Knowledge Transfer Linkage grant)

Corporate Giving

3M Canada
Bauerfeind
BSN Medical
Circaid Medical Products
Farrow Medical Innovations
Galien
Juzo
Linotrade Ltd.
Lymphedema Depot
Paradigm Medical
Pascoe Canada
Sigvaris Corp.
Solaris
Valco-Mediven



Donors - \$100 plus

McGill University Health Centre
Canadian Association of Wound Care
Dr. Anna Towers
Pamela Hodgson
Rachel Pritzker
Anna Kennedy
Jill Allen

Under \$100

Numerous contributions from individual donors

In-Kind Support

Lymphedema Association of Ontario
Lymphedema Association of Quebec
Melissa Coulson, Chartered Accountant
3M Canada

CLF Contributing to Publications

Peer-Reviewed Journals

Hack T., Kwan W., Thomas-MacLean R., Towers A., Miedema B., Tilley A., and Chateau D. Predictors of arm morbidity following breast cancer surgery *Psycho-Oncology* (2010) *Psycho-Oncology, Psycho-Oncology* 19: 1205–1212, Nov 2010

Thomas-MacLean R., Towers A., Quinlan E., Hack T., Kwan W., Miedema B., Tilley A. and Paul Graham. "This is a kind of betrayal": A Qualitative Study of Disability after Breast Cancer. *Current Oncology*. 16 (3) 26-32, 2010

Thomas-MacLean R., Spriggs P., Quinlan E., Towers A., Hack T., Tatemichi S., Miedema B., Kwan W. and Tilley A. Arm Morbidity and Disability: Reporting the Current Status from Canada. *Journal of Lymphoedema*, 5(2):33-38, 2010

Tidhar D. and Katx-Leurer, M. Aqua lymphatic therapy in women who suffer from breast cancer treatment-related lymphedema: a randomized controlled study. 2010. *Support Care Cancer*. 18, 383-92

Towers A., Hodgson P., Shay C. and Keeley V. Care of the palliative patient with cancer-related lymphedema. *Journal of Lymphedema*, 5(1), 72-80, 2010

Hodgson P., Towers A., Keast D., Kennedy A., Pritzker R., Allen J. Lymphedema in Canada: Developing a clinical, research and educational strategy. *Current Oncology*. In press.

Other Publications

Norton S. and Towers A. Adapting CDT in palliative patients. International Lymphedema Framework, *Palliative Care Template for Practice*, March 2010

Moffatt, C and Allen, J. Raising the profile of lymphedema in Canada and abroad. *Rehab and Community Care*. 2009. Vol 18.3. 10-14

Kennedy, A. and Hodgson, P. Moving towards Canadian standardization for training and care of lymphedema. *Rehab and Community Care*. 2010. Vol 19. 3. 10-14

Book Chapters

Towers A. "Diagnosing dying", Chapter in Rocker G, Puntillo K, Azoulay E and Judith Nelson J book *End of Life Care in the ICU*, Oxford, Oxford University Press, 2010, p.1-3, ISBN 978-0-10-923924

Invited Presentations

Anna Towers

La compression médicale pour le lymphoedème et les problèmes veineux. Drummondville, Département de médecine générale CME, Jan 26, 2010

An integrated approach to lymphedema prevention and management, CanSupport, McGill University Health Centre, Montreal, April 13, 2010

New developments on disability, prevention and standards of care, Victoria BC Vodder School Refresher Course, Victoria BC May 9, 2010

Supportive care for cancer patients at the MUHC: fostering interdisciplinary synergies between clinical practice and research. Palliative Care Week presentation, McGill University, Montreal

What do I say?: Communication in palliative patients with lymphedema. Plenary presentation. 2nd International Lymphedema Framework Conference, Brighton UK 22-25 Mar 2010

Chair, Session on lymphedema and palliative care. 2nd International Lymphedema Framework Conference Brighton UK 22-25 May 2010

New developments on disability, prevention and standards of care, Victoria BC Vodder School Refresher Course, Stowe, Vermont USA, May 30, 2010

La compression médicale pour le lymphoedème et les problèmes veineux. St-Jean, Quebec, Département de médecine générale CME, Jun 17, 2010

Nouveaux développements en recherche sur le lymphoedème, Vodder Revision Course, Montréal, Québec Aug 30, 2010

New Developments in Research on Compression and Lymphedema, Conference of the Lymphedema Association of Quebec , Aug 30, 2010

Diagnosis and treatment of chronic edemas: the use of compression therapy. West Island Palliative Care Residence, Quebec. Oct 26, 2010

Best practice guidelines and the role of the Canadian Lymphedema Framework. Wound Care Course for Nurses. University of Victoria, British Columbia, Nov 1, 2010

Implementing Best Practice Guidelines for Lymphedema. Annual conference of the Lymphedema Association of Ontario. Toronto Nov 20, 2010

Decongestive therapies for lymphedema and self-management strategies. Annual conference of the Lymphedema Association of Ontario. Toronto Nov 20, 2010

Therapy of malignant lymphedema. Annual conference of the Lymphedema Association of Ontario. Toronto Nov 20, 2010

Expert panel on lymphedema management. Annual conference of the Lymphedema Association of Ontario. Toronto Nov 20, 2010

Invited Presentations

David Keast

Managing fungating wounds. 2nd International Lymphoedema Framework Conference. Brighton, United Kingdom. March 22-25, 2010.

Managing wounds in the patient with edema: The role of negative pressure wound therapy. 2nd International Lymphoedema Framework Conference. Brighton, United Kingdom. March 22-25, 2010.

World Alliance for Wound and Lymphoedema Care. Invited speaker at the "Chronic Wounds and Lymphedema: The Hidden Epidemic in World Health" Session 28 of the Symposium of on Advanced Wound Care (SAWC) Conference. Orlando, Florida. April 17-20, 2010.

Introduction to lymphedema management. Annual Wound Care Conference. Levis, Quebec. October 8, 2010.

Introduction to lymphedema management. 16th Annual Professional Wound Care Conference. Calgary, Alberta. November 4-7, 2010. Co-Presenters: DiCecca C, Keast DH

Canadian lymphedema framework – An overview of their plans and progress. Plenary Session. Education Information Awareness Comprehension Advancement Knowledge Lymphedema Conference. Toronto, Ontario. November 20, 2010.

Lymphedema Landscape: Results of the CLF's online survey of health professionals servicing lymphedema patients. Workshop. Education Information Awareness Comprehension Advancement Knowledge Lymphedema Conference. Toronto, Ontario. November 20, 2010.

Edema Management and Principles of Tissue Fluid Management. Invited speaker at The Winnipeg Regional Health Authority Advanced Wound Care Education Day. Winnipeg, Manitoba. April 11, 2011.

Venous Disease and Lymphedema. Invited speaker at The Winnipeg Regional Health Authority Advanced Wound Care Education Day. Winnipeg, Manitoba. April 11, 2011.

Anna Kennedy

Patient Empowerment: National Lymphoedema Frameworks. 2nd International Lymphoedema Framework Conference, Brighton UK 22-25 Mar 2010

Chair, Lymphedema Frameworks - The way forward. 2nd International Lymphoedema Framework Brighton UK 22-25 Mar 2010

The practicalities of incorporating self management techniques into daily living. (Co-facilitator with P.Hammond). Young Women Breast Cancer Survivors Conference, Toronto October 29-31, 2010.

By the Numbers

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**Countries with established or in-process
national lymphedema frameworks**

108

**Participants across Canada attending the first
lymphedema national stakeholders meeting**

239

**Health professionals who responded to the
CLF on-line survey**

2,000

**Estimated volunteer hours contributed by
CLF volunteers in 2009 and 2010**

40%

**Breast cancer survivors
who develop lymphedema**

\$3,000

**Average cost a patient incurs annually
for treatment of lymphedema**

0

**Provinces with full healthcare coverage
for lymphedema treatment**

250 million

**Estimate of lymphedema patients worldwide
according to World Health Organization**