National Lymphedema Conference

Calgary • October 23 - 24, 2015

CLF CANADIAN LYMPHEDEMA FRAMEWORK
PCL PARTENARI CANADIEN DU LYMPHOEDÈME

Alberta Lymphedema Association

UNIVERSITY OF CALGARY

Speaker Biographies and Session Descriptions

National Lymphedema Conference
Coast Plaza Hotel & Conference Centre
Calgary, Alberta
Canada

Message from the Scientific Committee

Welcome to the 2015 National Lymphedema Conference. Health professionals, researchers, patients and community leaders from Alberta and across Canada gathered in Calgary to learn from international experts in lymphedema research, diagnosis, treatment and self-care. We were excited that this joint conference took place in Alberta, as this province is currently leading the country in lymphedema research, provincial care and advocacy success.

With a focus on education, research and partnerships; the key objectives of this conference were to:

- provide a forum to educate attendees about lymphedema, its causes and treatments
- update attendees on research initiatives and scientific advances in the field of lymphedema
- promote partnerships between clinicians, researchers, patient advocacy groups and industry
- showcase Alberta's leading edge clinical and research work and recent advocacy successes

We hope you left this conference not only equipped with new learning, but new connections and new friends.

Dr. Pierre von der Weid and Dr. David Keast
Conference Scientific Committee Co-Chairs

Scientific Committee members:
Dr. Anna Towers
Dr. Margie McNeely
Dr. Roanne Thomas

Planning Leads:
Anna Kennedy
Diane Martin

Message from our Lead Sponsor

Congratulations to everyone who helped make this year's event possible.

Lymphedema affects many people of all ages, including approximately 350,000 Canadians. Yet this condition remains under-recognized, under-treated and underfunded. As lead sponsor of this event, the Canadian Breast Cancer Foundation is pleased to support this important survival issue to improve diagnosis and treatment of this condition, which is so prevalent among people experiencing breast cancer.

The Canadian Breast Cancer Foundation is the leading community-driven charity devoted to funding relevant and innovative research and supporting and advocating for the breast cancer community. Since 1986, CBCF has invested over $300 million in the breast cancer cause. In that time, breast cancer mortality rates have declined by 44% and we are proud to be part of that success story. But much remains to be done to realize our vision of creating a future without breast cancer, and we believe your work at this conference helps us take another step toward a future where the lives of people experiencing breast cancer and lymphedema is improved.

Lynne Hudson

CEO, Canadian Breast Cancer Foundation

2015 Conference Exhibitors

3M Canada
www.3M.ca/SkinWound

Alberta Lymphedema Association
www.albertalymphedema.com

BiaCare
www.biacare.com

BSN Medical – Jobst Inc.
www.bsnmedical.ca

Canadian Breast Cancer Foundation
www.cbcf.org

Canadian Lymphedema Framework
www.canadalymph.ca

CB Medical
www.cbmedical.ca

Compassionate Beauty
www.compassionatebeauty.com

Dr. Vodder School International
www.vodderschool.com

International Lymphoedema Framework
www.lympho.org

Juzo
www.juzo.ca

Klose Training and Consulting
www.klosetraining.com

Lenita Barrett, BA, RMT
www.hunterhornmassage.com

Living Better with Lymphedema
www.livingbetterwithlymphedema.com

Linotrade Ltd.
www.lympholino.com

Lohmann & Rauscher
www.lohmann-rauscher.us

Lymphedema Depot
www.lymphedemadepot.com

Medi-Valco
www.valco.ca

Moments Massage & Manual Lymphatic Drainage
www.momentsmassage.ca

Pascoe Canada
www.pascoe.ca

Solaris
www.solarismed.com

The Canadian Bandage Shoppe
www.cdnbandageshop.com

Wear Ease, Inc.
www.wearease.com

Wellspring – Calgary
www.wellspringcalgary.ca

Opening Plenary Session – Friday October 23, 1:30-3:00pm

Session Title

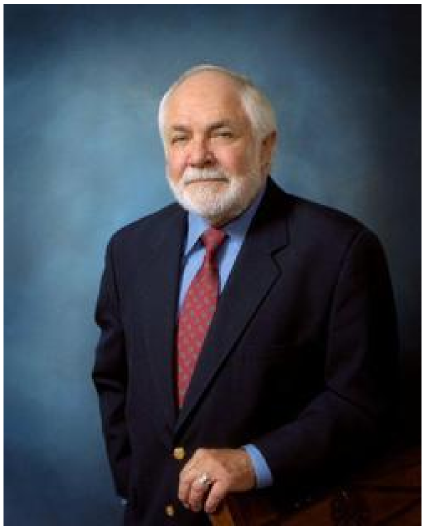
Lymphatic Filiariasis – Lessons from Haiti
Opening Plenary Session: Friday, October 23 at 1:30pm
Learning Stream: 2 and 3

Session Summary and Goals

In developed nations, both primary and secondary lymphedema are managed with protocols based on Complex Decongestive Physiotherapy. It becomes more complex in resource poor nations. The management of Lymphatic Filiariasis remains a global medical urgency. This presentation will discuss current continuing education and management initiatives in Haiti.

Objectives.

1. Introduction to The Bring hope to Haiti Medical Mission
2. Review the pathology and management of lymphatic filiariasis.
3. Appreciate the challenges of providing effective lymphedema therapy in resource poor nations.



Dr. John Macdonald practiced thoracic surgery in Ft. Lauderdale, Florida from 1971 until 1999. Over the past 20 years, Dr. Macdonald has been extensively involved in the clinical and research aspects of wound care and lymphedema. He has lectured extensively both in North America and internationally and has authored numerous articles and text chapters relating to both lymphedema and wound related lymph stasis. In 2002 he was appointed to the faculty of the Department of Dermatology and Cutaneous Surgery at the University of Miami, Miller School of Medicine. Dr. Macdonald is the founder and past secretariat for the World Alliance for Wound and Lymphedema Care (WAWLC) based in Geneva, Switzerland.

In the first two days post-earthquake, January 12, 2010, Dr. Macdonald established the wound care program in the University of Miami, Project Medishare, Hatian Relief Tent Hospital in Port-au-Prince. He is currently the Medical Director of the Wound and Lymphedema program now located at the Hospital Bernard Mevs in Port-au-Prince, Haiti.

Opening Plenary Session – Friday October 23, 1:30-3:00pm

Session Title

How Big is the Problem? LIMPRINT
Opening Plenary Session: Friday, October 23 at 1:30pm
Learning Stream: 2 and 3

Session Summary and Goals

Despite the complex issues associated with the management of Lymphoedema there is a paucity of evidence describing the prevalence and incidence of the problem throughout the world using standard methodologies. Until recently most research had focused exclusively on breast cancer related lymphoedema and other cancers. However over the last 10 years there has been a growing recognition that chronic oedema is a much wider, heterogeneous population and that broader public health definitions should be defined to capture the extent of the problem. The definition of chronic oedema present for more than 3 months has been used to capture the diverse aetiologies associated with the formation of chronic oedema, these include the following; primary lymphoedema due to lymphatic dysplasia; secondary causes including cancer treatment or invasive tumour, venous disease, trauma, immobility, obesity and filariasis in endemic areas such as India and Africa. There is considerable morbidity associated with the condition.

LIMPRINT is an international, multi-site project to determine the prevalence and functional impact of lymphoedema/chronic oedema in the adult population of member countries of the International Lymphoedema Framework.

The LIMPRINT study forms an important part of the guiding principles of the International Lymphoedema Framework (ILF). The ILF is a UK charity and its aim is to improve the management of chronic oedema and related disorders worldwide through the sharing of expertise and resources, and by supporting individual countries to develop a long-term strategy for the care and management of chronic oedema. The ILF comprises member countries that subscribe to the ideals of the ILF and have developed their own independent National Lymphoedema Framework (NLF). A NLF is a partnership of stakeholders within a given country who are dedicated to improving chronic oedema care.

A fundamental aim of the ILF is to support countries in the development of data to establish the size of the problem of chronic oedema. Such data are essential in supporting the introduction of evidence-based practice and enabling each NLF to argue for appropriate financing and reimbursement. LIMPRINT is an international epidemiological research study that aims to provide an opportunity to not only gather data that will benefit individual chronic oedema services, and the countries in which these services are located, but will also enable an international perspective by using a single central on-line database. The acronym LIMPRINT stands for **L**ymphoedema **IM**pact and **PR**evalence – **INT**ernational and is representative of the aim of the study, which is to determine the impact and prevalence of chronic oedema at a national and international level.

Limprint has been used this year during the development stage to describe the profile of patients within a large UK Lymphoedema service with over 3200 patients. It has also been used to undertake a population based study in Copenhagen where patients were sought from all clinical areas coming in contact with patients and included a clinical assessment of all patients within the two hospitals serving the area. The study is now running internationally and the progress of this work will be discussed during this presentation.

Dr. Christine Moffatt is professor of Clinical Nursing Research at the University of Nottingham School of Nursing, Midwifery and Physiotherapy. She is also nurse consultant at the Royal Derby Foundation NHS Trust Lymphoedema service in which she leads a research team as well as undertaking a clinical consultancy role. Christine is currently joint Chairperson and Director of the International Lymphoedema Framework. She has undertaken extensive research in lymphedema and wound care running national and international clinical trials.

Plenary Session A2 – Friday October 23, 3:30-4:45pm

Session Title

Care for Non-cancer/Primary Lymphedema: Lower Limb
Opening Plenary Session: Friday, October 23 at 3:30pm
Learning Stream: 2 and 3

Session Summary and Goals

A series of case studies will be introduced for an interactive session on challenges we face in treating lymphedema and how to deal with this.

Dr. Christine Moffatt is professor of Clinical Nursing Research at the University of Nottingham School of Nursing, Midwifery and Physiotherapy. She is also nurse consultant at the Royal Derby Foundation NHS Trust Lymphoedema service in which she leads a research team as well as undertaking a clinical consultancy role. Christine is currently joint Chairperson and Director of the International Lymphoedema Framework. She has undertaken extensive research in lymphedema and wound care running national and international clinical trials.

She was awarded a CBE in the 2006 New Year's Honors List and made a life fellow of the Royal College of Nursing that same year. She has received several life time achievement awards in recognition of her work, the most recent being presented by the World Union of Wound Healing Societies in June 2008. In December 2008 she received a Nursing Times Diamond 20 Award as one of the 20 most influential nurses in the last 60 years.

Plenary Session A3 – Friday October 23, 3:30-4:45pm

Session Title

ALA Advocacy to AHS Action: Sharing ALA's approach to advocating along with AHS's approach to clinical services for lymphedema
Plenary Session: Friday, October 23 at 3:30pm
Learning Stream: 2 and 3

Session Summary

This 60 minute session will tour professionals from the beginning to the current state of Lymphedema services provided by AHS. Beginning with what advocacy means and sharing of Alberta Lymphedema Association's approaches to advocacy. Alberta Health Services will then share the historical approach to Cancer Care's Lymphedema service within Oncology Rehab, followed by tips on the process to launch a new clinic, such as the non cancerous clinic in Calgary; ending the tour with a service delivery approach and results for patients receiving treatment for noncancerous or primary lymphedema

This session is jointly presented to demonstrate the cycle of advocacy from the Alberta Lymphedema Association and wholesome approach to lymphedema care in Alberta Health Services. Diane Martin is the President of the Alberta Lymphedema Association; Dr. Margie McNeely is a Physiotherapist and associate professor with the Faculty of Rehabilitation Medicine, UofA with a passionate history of lymphedema care and research in Cancer related lymphedema; Lisa Warner is the Director of Allied Health in Calgary Zone with AHS, launching the latest noncancerous lymphedema treatment clinic; and Heather Watt is an Occupational Therapist with Allied Health CRIS in Edmonton Zone where she has passionately treated non cancerous lymphedema patients for the past 5 years.

Diane Martin

Dr. Margie McNeely

Heather Watt

Plenary Session A4 – Friday October 23, 3:30-4:45pm

Session Title

Workshop of Aqua Lymphatic Therapy for Health Professionals
Plenary Session: Friday, October 23 at 3:30pm
Learning Stream: 2 and 3

Session Summary

ALT is a method that uses the physical properties of the water to achieve the same goals as CLT (Complex Lymphatic Therapy). A combination of exercises, self- massage and gradient pressure are achieved in one session of 45 minutes. The ALT was studied in two randomized control trials and was found to be a safe method with immediate positive effect on edema and long term positive effects on pain, grip strength, quality of life and disability in women who suffer from mild breast cancer related lymphedema.

A one hour workshop that begins with a 15 minutes of theory and explanations on the principles of ALT, the sequence, pace, ways of movements through the water etc. 45 minutes of practicing a full session of ALT for arm lymphedema.

Dorit Tidhar is a physiotherapist who was trained in lymphedema therapy by Prof. Judith Casley-Smith in 1999 and was certified by her as a teacher in Self -Management and Exercise for Lymphedema in 2003. Dorit designed a program of Aqua Lymphatic Therapy to help people who suffer from lymphedema maintain and improve the results of conventional treatment and conducted a randomized controlled trial as part of her Master’s degree in Tel Aviv University in Israel, to examine this method. She is now working in Maccabi healthcare services as the national director of lymphatic therapy services.

Opening Plenary Session – Saturday October 24, 8:30-10:00am

Session Title

Advances in Lymphatic and Lymphedema Research Plenary
Session: Saturday, October 24 at 8:30am
Learning Stream: 1, 2 and 3

Session Summary

I will present the lab and the lymphatic imaging suite and present progress we are making in getting a better understanding of the mechanisms of lymphatic vessels functions. In particular we are getting a better grasp on how lymphatic function and in particular the ability of lymphatic vessels to drain lymph is modified in inflammatory situations and diseases. I will demonstrate the relevance of these studies to lymphedema, because inflammation is present in the edematous limb and is a critical player in driving the condition towards a chronic disease. I will finally present the lymphedema research and education program we are developing in Calgary and what it may mean to lymphedema patients.

Pierre-Yves von der Weid, PhD, is Associate Professor at the Cumming School of Medicine, University of Calgary, where he studies the roles and functions of the lymphatic vessels in health and disease. He graduated with a diploma degree and a PhD in Biological Sciences from the university of Geneva, Switzerland. He then spent his postdoctoral fellowship time in Newcastle, Australia, Strasbourg, France and Geneva, before obtaining a Faculty position in Calgary. The particular interest of his research group is to investigate the functions of the lymphatic vessels and the influence inflammation has on these functions. He is currently leading the Lymphedema Research and Education Program in the Snyder Institute for Chronic Diseases at the University of Calgary, an Alberta initiative philanthropically supported by the Dianne and Irving Kipnes Foundation.

Plenary Session B1 – Saturday October 24, 10:45am-12:00pm

Session Title

Self-Managing Lymphedema: Take control
Plenary Session: Saturday, October 24 at 10:45am
Learning Stream: 1 and 2

Session Summary

Due to the chronic nature of lymphedema, it takes a good self management plan to live with this condition and keep it from deteriorating. This presentation will compare the similarities and differences between managing limbs with cancer related lymphedema or non-cancer-related lymphedema. Areas of discussion include risk reduction, skin care, garments, exercise, self-bandaging, self/simple MLD, and good medical team/family/peer support. Objectives: 1.Self-care techniques for upper and lower limbs, cancer-related lymphedema vs noncancer-related lymphedema 2.Demonstration of self-bandaging of an upper limb and lower limb. 3.Provide an opportunity for audience input on other unique self-care tips.

Lori Radke is a physiotherapist that has worked in Alberta for more than 25 years since graduating from the U of A in 1988. She gained experience with edema management on the Home Care Skin and Wound Care team in Calgary and oncology experience on the Palliative Home Care team. She became a certified Lymphedema therapist and started the Rehabilitation Oncology program at the Tom Baker Cancer Center in 2009.

Elizabeth Girling BScOT, IIWCC, CLT is the Clinical Lead for the Calgary Ambulatory Lymphedema Service (CALS) at the Sheldon M Chumir Health Centre. This program opened January 20, 2014 offering services to those with primary and secondary non cancer related lymphedema. She is also an active participant of a Lymphedema Patient Advisory.

Plenary Session B2 – Saturday October 24, 10:45am-12:00pm

Session Title

Workshop on measurement using bioimpedence and perometry
Plenary Session: Saturday, October 24 at 10:45am
Learning Stream: 2 and 3

Session Summary

The session will discuss the theory and metrics associated with newer technologies used in evaluating limb lymphedema. The session will also include a practical workshop on the use of perometry and bioimpedance analysis for measuring lymphedema. In the workshop, we will demonstrate use of the devices, and discuss measurement procedures to ensure optimal accuracy and reliability, as well as how best to interpret the findings. Attendees will have the opportunity to gain experience using the devices.

Margaret (Margie) McNeely is an Associate Professor in the Department of Physical Therapy at the University of Alberta in Edmonton, Canada. She currently holds a joint appointment in the Department of Oncology and performs clinical research in the Rehabilitation Medicine Department at the Cross Cancer Institute. She is also the Director of the Cancer Rehabilitation Clinic at the University of Alberta. Dr. McNeely's research interests are in the area of cancer rehabilitation and exercise. Her research to date has focused on upper limb dysfunction and cancer-related symptoms of pain, fatigue and lymphedema.

Plenary Session B3 – Saturday October 24, 10:45am-12:00pm

Session Title

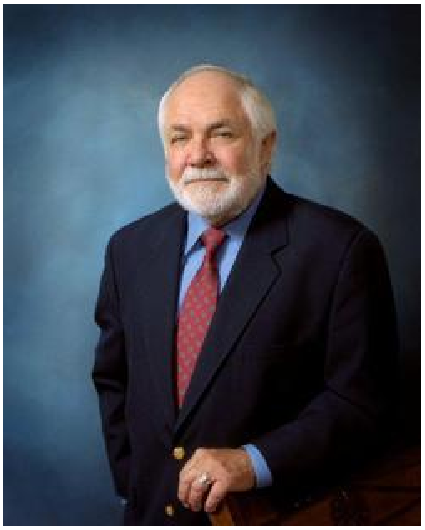
Wound Healing and Lymphedema
Plenary Session: Saturday, October 24 at 10:45am
Learning Stream: 2 and 3

Session Summary and Goals

Effective wound care can be defined by five basic principles. Control of peri wound edema / lymphedema is one of these principles. Edema and lymphedema are not the same. In order to effectively control edema and lymphedema one must appreciate the anatomy and physiology of the lymphatic system. Understanding the importance of lymphatic pathology and the physics of compression is the most neglected of the five principles. This presentation will address this problem.

Objectives:

1. Know the difference between edema and lymphedema.
2. Appreciate the pathophysiology of lymph stasis and the chronic wound.
3. Understand the effect of compression on the venous, arterial and lymphatic system.



Dr. John Macdonald practiced thoracic surgery in Ft. Lauderdale, Florida from 1971 until 1999. Over the past 20 years, Dr. Macdonald has been extensively involved in the clinical and research aspects of wound care and lymphedema. He has lectured extensively both in North America and internationally and has authored numerous articles and text chapters relating to both lymphedema and wound related lymph stasis. In 2002 he was appointed to the faculty of the Department of Dermatology and Cutaneous Surgery at the University of Miami, Miller School of Medicine. Dr. Macdonald is the founder and past secretariat for the World Alliance for Wound and Lymphedema Care (WAWLC) based in Geneva, Switzerland.

In the first two days post-earthquake, January 12, 2010, Dr. Macdonald established the wound care program in the University of Miami, Project Medishare, Hatian Relief Tent Hospital in Port-au-Prince. He is currently the Medical Director of the Wound and Lymphedema program now located at the Hospital Bernard Mevs in Port-au-Prince, Haiti.

Plenary Session B4 – Saturday October 24, 10:45am-12:00pm

Session Title

15 Minute Exercise Session with Music
Plenary Session: Saturday, October 25 at 10:45am
Learning Stream: 1, 2 and 3

Session Summary

Exercise plays an important role in the treatment of lymphedema. My experience has shown, however, that patient compliance is often limited because the traditional exercise program is too long. I came to this conclusion during my interventions with pediatric patients of different age groups, who had primary lymphedema, and, most recently with adults who present with secondary lymphedema, following cancer treatment. To improve compliance, I am proposing a sequence of 5 exercises that should be taught and adapted to the patient's needs. This set of exercises takes approximately 12 minutes to complete. This program is based on Casley Smith's exercise sequence as well as on my training in RPG (Postural Re-education). The pacing of the exercises and the completion of the sequence is facilitated when set to music.

Marie Jutras is a physiotherapist at The Lymphedema Support Centre of the Quebec Breast Cancer Foundation. She worked at the pediatric lymphedema clinic of the St. Justine Hospital Center from 2012 to 2014.

Lunch Session 1 – Saturday October 24, 12:00pm

Session Title

Making Compression Work for You
Lunch Session: Saturday, October 24 at 12:00pm
Learning Stream: 1, 2 and 3

Session Summary

This session will explore the challenges and benefits of using compression therapy as part of self-management for lymphoedema. The session will draw on commonly experienced problems faced by patients and how solutions can be successfully achieved.

Dr. Christine Moffatt is professor of Clinical Nursing Research at the University of Nottingham School of Nursing, Midwifery and Physiotherapy. She is also nurse consultant at the Royal Derby Foundation NHS Trust Lymphoedema service in which she leads a research team as well as undertaking a clinical consultancy role. Christine is currently joint Chairperson and Director of the International Lymphoedema Framework. She has undertaken extensive research in lymphedema and wound care running national and international clinical trials.

She was awarded a CBE in the 2006 New Year's Honors List and made a life fellow of the Royal College of Nursing that same year. She has received several life time achievement awards in recognition of her work, the most recent being presented by the World Union of Wound Healing Societies in June 2008. In December 2008 she received a Nursing Times Diamond 20 Award as one of the 20 most influential nurses in the last 60 years.

Lunch Session 2 – Saturday October 24, 12:45pm

Session Title

Let's Talk Lymphedema – Making a Difference in the Lymphedema Community
Lunch Session: Saturday, October 24 at 12:45pm
Learning Stream: 1, 2 and 3

Session Summary

A young person inspired to make a change in the lymphedema world began her journey at the age of 8. Now at the age of 17, Catharine Bowman has started to make a difference in the lymphedema community. During this session, Catharine will discuss her journey as a student researcher and lymphedema advocate. Catharine will touch upon the perspective of family members living with lymphedema, her current work as a researcher and advocate, and her hopes and plans for the future within the lymphedema community. Catharine's journey provides a refreshing outlook on getting involved and making a difference for the face of lymphedema on a global scale.

Catharine Bowman is a high school student from Hamilton Ontario with a profound interest in lymphedema research. For two years, Catharine has dedicated her efforts toward exploration of a potential pharmacological treatment for lymphedema, working in laboratories at University of Calgary and McMaster University. Catharine's original research was inspired by her mother's struggle with secondary lymphedema. Since then, Catharine has presented her research across North America at International science events, and has been able to act as a lymphedema advocate, gaining the attention of medical professionals and scientists. Catharine is humbled to be able to advocate for those affected by lymphedema.

Plenary Session C1 – Saturday October 24, 1:45am-3:00pm

Session Title

Exercise – Debunking the Myths
Plenary Session: Saturday, October 25 at 1:45pm
Learning Stream: 1, 2 and 3

Session Summary and Goals

The first published studies challenging the myth that vigorous upper body exercise may increase the risk of breast cancer related lymphedema or worsen symptoms for those already affected appeared over 15 years ago. The original research by McKenzie in 1998 and Harris and Niesen-Vertommen in 2000 looked at the sport of dragon boat racing and inspired a new generation of research debunking the myths and outlining how exercise could be used in the treatment of lymphedema. This session will discuss the evolution of research on the role of exercise in the etiology and management of lymphedema.

The learning objectives are to:
1) Examine the progression of research on the role of exercise and lymphedema;
2) Describe the current state of knowledge;
3) Discuss how this research can be translated into clinical practice; and
4) Identify what additional research is needed.

Dr. Kristin Campbell is a physical therapist and Associate Professor in the Department of Physical Therapy at the University of British Columbia in Vancouver, BC. Her research interests are focused on the role of physical activity across the cancer experience, namely in prevention, rehabilitation from cancer treatments, and cancer survivorship. Dr. Campbell is the author of over 75 peer reviewed articles and academic book chapters, and Dr. Campbell participates on national and international advisory boards and grant review panels on cancer prevention, rehabilitation and survivorship.

Plenary Session C2 – Saturday October 24, 1:45am-3:00pm

Session Title

Psychosocial impacts of Lymphedema: Mindfulness practices potential role in facilitating wellbeing
Plenary Session: Saturday, October 24 at 1:45pm
Learning Stream: 1, 2 and 3

Session Summary

Psychosocial impacts of lymphedema have been understudied but include: body image concerns, damaged self-esteem, relationship issues, feelings of loss of control, fear and depression (Moffatt et al, 2003; Persoon et al, 2004; Briggs and Fleming, 2007). Mindfulness meditation and associated practices have demonstrated meaningful benefits to sufferers of a wide range of medical conditions (see e.g.Khoury, B. et al Clinical Psychology Review. 33(6):763-71, 2013) but have not been studied specifically for effects in lymphedema patients. This presentation will provide a rationale for the use of mindfulness practices, outline promising applications to the challenges of lymphedema and provide direct introductory experience of these practices.

Dr. Michael Speca is Adjunct Associate Professor of Psychosocial Oncology at the University of Calgary. He counsels patients and families at the Tom Baker Cancer Centre and facilitates several group support programs including the Mindfulness Based Stress Reduction program which he co-founded. His research examines the effectiveness of psychosocial interventions for reducing distress and improving quality of life.

Dr. Speca has written several book chapters on mindfulness in the context of illness. In 2011 with Linda Carlson he published: Mindfulness Based Cancer Recovery: A Step-by-Step MBSR Approach to Help You Cope with Treatment and Reclaim Your Life published by New Harbinger.

Plenary Session C4 – Saturday October 24, 1:45am-3:00pm

Session Title

Healthy Steps (Lebed) Exercise
Plenary Session: Saturday, October 24 at 1:45pm
Learning Stream: 1

Session Summary

Objective: To share the experience and benefits of the Healthy-Steps™ program as an interactive session. Focus will be on how the Healthy-Steps™ program helps those with lymphedema.

Benefits include:
- Increases range of motion
- Stretches out scar tissue
- Provides support in the reduction of lymphatic swelling through different movement modalities, which will be explained
- Improvement of self-image
- Provides a support network
- Most importantly – it's FUN.

Plan of the Session:
- A brief history of the Healthy-Steps™ program
- A sample active class that is offered at Wellspring Calgary to those with cancer.
- A question & answer period to end the session

Barbara Cunnings-Versaevel is a long term Stage 3 breast cancer survivor (since 1990) and professional dancer/teacher of Healthy-Steps™ and her own program, Moves In Rhythm. Barbara, is a Cancer Survivor Mentor and publisher of an online magazine, the Cancer Help Hub. She is a co-founder of Wellspring Calgary, a community cancer support center and author of her upcoming book 'The Path to Wellness After Cancer: Insights of a Long Term Cancer Survivor'. Barbara is an advocate of Lymphedema education and has available her free report 'Lymphedema – A Risk Forever: What you NEED to KNOW before it's too late'.

Plenary Session C5 – Saturday October 24, 1:45am-3:00pm

Session Title

Workshop of Aqua Lymphatic Therapy for Patients
Plenary Session: Saturday, October 24 at 1:45pm
Learning Stream: 1

Session Summary

ALT is a method that uses the physical properties of the water to achieve the same goals as CLT (Complex Lymphatic Therapy). A combination of exercises, self- massage and gradient pressure are achieved in one session of 45 minutes. The ALT was studied in two randomized control trials and was found to be a safe method with immediate positive effect on edema and long term positive effects on pain, grip strength, quality of life and disability in women who suffer from mild breast cancer related lymphedema. 40 minutes of practicing a session of ALT for leg lymphedema, followed by 40 minutes of practicing a session of arm ALT for lymphedema. Patients will be measured before and after a session to explore whether the ALT session was beneficial.

Dorit Tidhar is a physiotherapist who was trained in lymphedema therapy by Prof. Judith Casley-Smith in 1999 and was certified by her as a teacher in Self -Management and Exercise for Lymphedema in 2003. Dorit designed a program of Aqua Lymphatic Therapy to help people who suffer from lymphedema maintain and improve the results of conventional treatment and conducted a randomized controlled trial as part of her Master's degree in Tel Aviv University in Israel, to examine this method. She is now working in Maccabi healthcare services as the national director of lymphatic therapy services.

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Conference
Calgary • October 23 - 24, 2015

Co-hosted by the Canadian Lymphedema Framework *and the*
Alberta Lymphedema Association *in collaboration with the* University of Calgary.

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NATIONAL LYMPHEDEMA CONFERENCE
OCTOBER 23-24, 2015
ORAL AND POSTER ABSTRACTS

ABSTRACT #1

A macroscopic vision for the prevention of lymphedema

Lina Demanins BSc O.T. CLT
Montreal, Quebec

The prevention of lymphedema in the community and in patients within the hospital setting is becoming a major element of concern for lymphedema therapists and other involved medical practitioners. Patients are often referred many years after the initial onset of symptoms and present with complications from a lack of adequate treatment. From an occupational therapy point of view, the purpose of this poster presentation, is to stimulate health professionals in these centers of practice to improve their modalities of evaluation and intervention regarding clients at risk of developing lymphedema. The intention this global perspective is to focus on adequate screening and timely intervention.

Questions such as the following will be addressed:
What means do you use in your area of practice for the prevention of chronic edema and lymphedema?
Do you have the professional knowledge to provide an initial screening of your at-risk patients?
What are your abilities in transmitting your acquired knowledge to others?
How do you motivate others in an interdisciplinary team in regards to developing a lymphedema prevention program?

On a macroscopic level, for patients with latent stages or edema manifestations, adequate knowledge and early detection by any health professional in their area of practice may prevent the development of lymphedema, aggravation of symptoms and complications.

This should become an objective and responsibility for all implicated health professionals.

ABSTRACT #2

More than Just A Brightly Coloured Tape: The Role of Kinesiotape in Lymphedema Care

Using kinesiotape for lymphedema management and treatment is being a recognized and promising method to be used by both the therapist and the patient themselves for achieving outcomes and a means of self-management. This presentation will give an overview of kinesiotape and provide clinical case studies of kinesiotaping for lymphedema and their associated outcomes. After the brief review of literature, a demonstration will be done to illustrate the application of kinesiotape on a client, where the benefits of using kinesiotape will be highlighted.

The objectives of this presentation are the following:

1. Illustrate through clinical case studies, how kinesiotape has been used to help manage lymphedema.
2. Give a demonstration on the application of kinesiotape.
3. Acknowledge the use of kinesiotape as a new therapy tool and self-management tool for individuals with lymphedema (or family members) to use in conjunction with their treatment

Francois Gagnon, CLT, MES, KTP, HBPE
Credentials: Certified Lymphatic Therapist; Certified Medical Exercise Specialist; Kinesiotape Practitioner
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Founder & Chief Lymphatic Therapist @ All Points Integrative Wellness, a private practice in Calgary, AB
*Regards kinesiotaping, have been using kinesiotaping since 2013 and well versed in its various applications from Lymphedema to Orthopaedic & Neurologic applications.

ABSTRACT #3

Something more ...Moving Beyond Treatment of Lymphedema

While there has been best practices and guidelines established by international and national organizations for the treatment of lymphedema to be utilized by public and private clinics, there is something more to consider ...
... to optimize results in improving quality of life among individuals with lymphedema and even their families, healthcare providers and clinics need to be incorporating a style of self-management that will help to empower, motivate, and increase engagement in lifelong self-care activities for lymphedema as well as overall quality of life.

The objectives of this presentation are the following:

1. Provide a historical review of what has been done with respect to self management and lymphedema,
in order to broaden knowledge base;

2. Show the type(s) of self-management models that have been used and where they have been used (i.e. Chronic Disease Management) and how this can be applied to lymphedema care;

3. Display the evolution of self-management to a more engaging and empowering model;

4. Present the future advancement of self-management and where it will be found Presenter Information:

Francois Gagnon, CLT, MES, KTP, HBPE
Credentials: Certified Lymphatic Therapist; Certified Medical Exercise Specialist; Kinesiotape Practitioner
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Founder & Chief Lymphatic Therapist @ All Points Integrative Wellness, a private practice in Calgary, AB

ABSTRACT #4

National Lymphedema Conference Abstract Submission

CONTEXT: Development of first Regional Lymphedema Clinic at Windsor Regional Cancer Clinic. Clinic is led by a Registered Nurse who is also a Certified Lymphedema Therapist. The importance is centered on complete patient care through their cancer journey.

OBJECTIVE: Educate patients on prevention, treatment and maintenance of Lymphedema Regionally.

DESIGN: Beginning of patient education classes held once a month with video conference to Regional sites. Referral processes to Lymphedema clinic when patients have developed Lymphedema or greater health teaching is required/requested.

SETTING/PATIENTS: All patients in community are able to come to general education classes held monthly at the Cancer Centre, but only active Cancer Center patients are able to be seen in Lymphedema Clinic for assessment.

CONCLUSION: The hope of this newly developed clinic is to have resources within our Community/Regionally for education, prevention, and treatment options. Education to community Physicians and Surgeons will provide information to their patients at risk to our Education Days.

Karie Gignac, RN, CHPCN, Certified Lymphedema Therapist

ABSTRACT #5

15 MINUTE EXERCISE SEQUENCE WITH MUSIC

Marie Jutras

Exercise plays an important role in the treatment of lymphedema. My experience has shown, however, that patient compliance is often limited because the traditional exercise program is too long. I came to this conclusion during my interventions with pediatric patients of different age groups, who had primary lymphedema, and, most recently with adults who present with secondary lymphedema, following cancer treatment.

To improve compliance, I am proposing a sequence of 5 exercises that should be taught and adapted to the patient's needs. This set of exercises takes approximately 12 minutes to complete. This program is based on Casley Smith's exercise sequence as well as on my training in RPG (Postural Reeducation). The pacing of the exercises and the completion of the sequence is facilitated when set to music.

Marie Jutras is a physiotherapist at The Lymphedema Support Centre of the Quebec Breast Cancer Foundation. She worked at the pediatric lymphedema clinic of the St. Justine Hospital Center from 2012 to 2014.

ABSTRACT #6

The clinical and organizational challenges in creating a multidisciplinary clinic for the management of pediatric lymphedema

Marie Jutras PT, CLT, Chantal Lapointe PT, CLT, Catherine C. McCuaig Md. Dermatologist, Lorraine Miuse SW, Sandra Ondrejchak N.

Lymphedema in children and adolescence is a rare condition that is not easily understood. The incidence of childhood lymphedema is 1/6000, according to the International Lymphoedema Framework, making it sometimes difficult to establish a diagnosis. This chronic and progressive condition has a definite impact on a child's quality of life. Motor development, body image, social interaction and vocational training, later on, can be affected by the presence of lymphedema.

The complexity of its symptoms as well as the presence of associated conditions create a challenge when evaluating and treating lymphedema in pediatrics. A multidisciplinary team approach would better address these issues and provide the best possible care for these clients.

This team should include: a physician specialized in lymphoedema, a coordinator, a nurse, an occupational therapist, a physiotherapist with experience in lymphedema, a psychologist, a social worker, a trained technician in pressure garment fitting and adjustment and, when the need is present, professionals from other disciplines.

Some of the challenges associated with the management of pediatric lymphedema includes the choice of compression modalities, the compliance of the child and his/her family in controlling lymphedema and the professional costs that could be incurred in order to answer to the complex, varied and long term needs of these clients.

Creating a multidisciplinary clinic for the evaluation and management of lymphedema in pediatrics is not an easy project. The success of such a clinic relies on the collaboration of qualified professionals in order to offer the best evidence-based practice for these clients.

Chantal Lapointe is a physiotherapist at St. Justin e University Hospital Center in Montreal. She is presently pursuing a master's degree in rehabilitation medicine at the University of Sherbrooke in Quebec. Since October 2014, she has been involved in the evaluation and follow-up of children with lymphedema.

Marie Jutras is a physiotherapist at The Lymphedema Support Center of the Quebec Breast Cancer Foundation. She collaborate to implant a clinic for the evaluation and follow-up of children with lymphedema at St. Justine University Hospital Center in 2012-2014.

ABSTRACT #7

PREVALENCE AND CHARACTERISTICS OF LYMPHEDEMA IN AN OUTPATIENT CHRONIC WOUND MANAGEMENT CLINIC

Authors:
Keast D. H, Wang W.

Context:
Chronic edema/lymphedema is under-diagnosed and under-treated in Canadian health care.

Objective:
The purpose of this study was to determine the prevalence, clinical characteristics, and treatment practices of lymphedema in a wound care clinic at a Canadian tertiary care teaching hospital.

Design:
Lymphedema patients were identified using an administrative database of ICD-9 diagnostic codes of the most responsible diagnosis for the clinic's patients. A retrospective chart review of 326 patients, treated between May 2006 and July 2014, was then performed. Basic demographic data, comorbidities, concomitant medications, lymphedema characteristics and treatments were extracted to an Excel spreadsheet.

Setting:
Outpatient chronic wound management clinic in a tertiary care teaching rehabilitation hospital

Results:
Lymphedema patients represented approximately 20% of the clinic's total volume. The mean age at diagnosis was 67±15.5. 23% of patients were already being followed by the wound clinic for a different condition at time of diagnosis.

The vast majority of patients had secondary lymphedema (96%). The most common possible etiologies were chronic venous disease (75%), non-cancer surgery (61%), and obesity (45%). Cancer treatment was a factor in only 10% of patients.

The most common treatment modality prescribed at first visit and most recent follow-up were compression bandages (84%) and compression garments (63%), respectively. On average, patients had 7± 3.3 comorbid conditions and took 8±4.6 concomitant medications. The most common comorbidities were venous disease (73%), hypertension (60%), and obesity (46%).

Conclusions:
A significant portion of the clinic's patients had lymphedema. Secondary lymphedema unrelated to cancer treatment was very common, possibly due to lack of dedicated treatment programs for these patients. Treatment practices at the clinic followed the best practice guidelines of using bandages for initial treatment and garments for maintenance.

ABSTRACT #8

Subcutaneous needle drainage of lymphedema in palliative care: a case series

Landers A, Towers A, Bitzas B, Thomson M, Tradounsky G

Context:
Palliative care patients with advanced cancer may develop marked lymphedema of the lower limbs, abdomen and genitalia, often of mixed etiology.

This type of lymphedema can markedly reduce quality of life (QOL). Standard decongestive therapy may be inadequate in advanced cancer patients, and is not always readily available. Draining the fluid through the placement of subcutaneous needles is a technique that has been described in a few, small case series as being of significant benefit for symptom control. The largest case series reported to date involved only 8 patients. In addition it is not clear if and how this procedure affects QOL and whether there are any negative outcomes.

Objectives:
To explore the safety and effectiveness of subcutaneous needle drainage for palliative patients with malignant lymphedema. This presentation will also review the scientific literature on this method.

Design:
This is an international group recruiting a case series of 48 patients, 24 in each of two centres: Nurse Maude Hospice, New Zealand and 3 palliative care units in Montreal, Canada.

We will: 1. assess the effect of subcutaneous drainage on the volume of lower limb lymphedema (LLL), 2. Monitor for any complications, 3. Measure changes in QOL using a tool specific for lower-limb lymphedema (LYMQOL), 4. Monitor self-reported physical limitations due to the lymphedema and 5. Assess patients' perceptions of the procedure.

Results:
10 patients participated in a pre-pilot study in New Zealand: 6 objectively gained benefit and function, 1 had all scores get worse, 1 had mixed results, 1 died of unrelated renal failure after a few days, and 1 developed cellulitis. The formal study on 48 patients is in progress and available data will be presented.

Conclusion: This study may provide other options for the care of advanced cancer patients with uncontrolled LLL.

ABSTRACT #9

Title: **Clinician and Patient Reported Arm Dysfunction: Do they agree?**

Authors: Marie-Eve Letellier, Nancy Mayo
Affiliation; School of Physical and Occupational Therapy, McGill University, Montreal, Quebec

Context
Impairment, activity limitations and participation restrictions are well-known complication of (breast) cancer treatment. In most clinical settings, clinicians rate presence and severity of disabilities arising from oncological treatments based on observation and clinical examination, and do not necessarily consider the patient's point of view.

Objective
To estimate the extent of agreement between health professionals' (ClinRO) and patients' (PRO) ratings on disabilities associated with breast cancer (impairments, activity limitations and participation restrictions).

Design
Cross-sectional Methods
Health care professionals measured arm impairments, activity limitations and participation restrictions with the ICF Breast Cancer Core Set. Participants filled 5 outcomes measures targeting health aspects of QOL that were previously mapped to the ICF. Agreement between ClinRO and PRO was estimated with quadratic Kappa.

Participants
To be included in the study, participants had to have breast cancer as their main diagnosis, be at least 18 years old, and be informed and understand both the purpose and reason of the study. They were excluded if their surgery wound was not completely healed.

Results
245 paired clinician and participant completed outcomes measures. A total of 60 items mapped to 24 different ICF Breast Cancer Core Set codes, which provide 68 analyses for agreement. Impairment was better addressed with PROs (mostly poor and fair level of agreement); Activity limitations, both PROs and self-reported outcomes (SRO) (fair); Participation restrictions, PROs (fair).

Conclusion
Clinicians usually underestimate the symptoms and impairments of the patients, leading to a greater proportion of poor agreement. PRO's provide valuable information on impairments at the mental function level and pain. ClinRO's provide more valuable information on physically assessed impairments (edema). Activity limitations and participation restrictions, excluding reporting the difficulty aspect of various life situations, can be either SRO or ObsRO.

ABSTRACT #10

Title

Treating Breast-Cancer Related Lymphedema in a Hospital Setting

Authors: Marie-Eve Letellier, Anita Svadzian, Linda Henry, Chantal Turgeon, Artin Mahdanian, Sarkis Meterissian

Affiliation:
Cedars Breast Clinic, Royal Victoria Hospital, McGill University Health Center, Montreal, Quebec

Context
Due to the limitations imposed by a public hospital setting, it is not feasible to treat Breast-Cancer Related Lymphedema (BCRL) with daily Combined Decongestive Therapy (CDT), a common practice utilized in private institutions. Given this constraint, it is important to determine if CDT performed twice weekly combined with self-management strategies can also significantly reduce arm volume in BCRL patients.

Objective
To estimate the extent to which, in women with BCRL receiving conventional CDT or 2-layer compression bandaging twice per week, arm volume reduction obtained is similar to what is reported in the literature. The secondary aim will be to compare which method, the CDT or the 2-layer bandaging, resulted in a greater reduction in arm volume.

Design
Case Control study.
Setting Lymphedema services in a hospital based breast cancer center.
Participants All participants treated in our services for BCRL since September 2008 (opening of the lymphedema services) will be included in the analysis. Participants live in the greater Montreal area. They were treated (or will be treated) twice a week with either CDT or a 2-layer compression bandaging system and were instructed to perform daily self-management strategies (e.g. remedial exercises, self-massage).

Results
We hypothesize that we will obtain statistically similar levels of arm volume reduction to what is reported in the literature. In addition, we hypothesize that the 2-layer compression bandaging will obtain similar arm volume reduction than CDT; however, in a shorter period of time.

Conclusions
Finding solutions to treat BRCL in a public hospital setting is challenging. Patients express difficulty
1) Coming to the hospital,
2) Complying with the therapy itself. Ideally, a patient with BCRL should receive daily therapy, including at least compression. However, performing the compression aspect of the therapy twice weekly, in conjunction with self-management strategies, seems to be an effective method in reducing BCRL.

ABSTRACT #11

A comparison of three intervention methods for women with breast cancer related lymphedema

Anne Newman, Anna Towers, Leonard Rosenthall, Pamela Hodgson, Dorit Tidhar, Robert Kilgour

ABSTRACT
Rationale: The incidence of breast cancer-related lymphedema (BCRL) is approximately 30% for women who undergo breast cancer treatment (e.g. mastectomy, axillary node dissection and/or radiation treatment. The resulting physical symptoms, functional outcomes, and the need to wear compressive garments on a daily basis for prolonged periods of time place a persistent and significant burden on the quality of life of these survivors and creates the need for effective treatment interventions.

Objectives:
1) To assess the immediate and short-term effects in extracellular fluid (ECF) following a single bout of activity from three different interventions for BCRL (e.g., manual lymphatic drainage (MLD), aqua lymphatic therapy (ALT), and a Casley-Smith based exercise routine (CSER), 2) To determine which of the three interventions is most effective in maintaining or reducing limb volume over a 24 hour period.

Study Design:
A repeated measures crossover design ("3 treatments, 4 periods"). The four periods were: pre intervention, immediately post intervention, one hour post and 24 hrs post. Changes in limb volume were measured with circumferential measures and bioelectrical impedance spectroscopy (BIS).

Recruitment (n=19) took place at the McGill University Health Center (MUHC) Lymphedema Clinic between September 2011 and May 2012.

Results:
Of the three interventions, ALT was the only intervention that showed a significant ($p \leq 0.05$) decrease in ECF from baseline to 20-24hrs post-intervention, this finding should be viewed with some caution since this change appears to be mediated by a yet unexplained elevated baseline BIS value. When compared to the MLD, the ALT intervention demonstrated a consistent 3.31% greater ($p=0.038$) reduction in ECF volume over 24hrs. Comparing physical symptoms experienced by the participants across the three interventions, there were no significant differences found pre and post interventions.

Conclusion: For women with Stage II BCRL, ALT, CSER and MLD appear to be safe interventions. Despite the removal of compression sleeves for the 48 hour study period, no intervention led to an increase in ECF or physical symptoms.

ABSTRACT #12

Effect of early compression therapy on incidence of lymphedema in patients treated for gynecological cancer: a randomized trial

Anne Newman, Shirin Shallwani, Anna Towers, Shannon Salvador

Rationale: The incidence of developing lower limb lymphedema after treatment for gynecological cancers is estimated at 10% to 38%. The resulting persistent symptoms of swelling, achiness and difficulty walking have long-term impacts on mobility, self-image, and may also predispose patients to recurrent skin infections...These negative outcomes, which affect quality of life, and the cost of lymphedema management to the healthcare system, make it essential to identify strategies to reduce the risk of lymphedema development in this population.

Objective: to evaluate the effect of early compression therapy with individualized exercise on the incidence of lower limb lymphedema over12 months post-operatively in patients treated for gynecological cancer.

Study design: This is a pilot (n=50) randomized controlled trial, we will be recruiting patients with gynecological cancer treated at the McGill University Health Centre (MUHC) Royal Victoria Hospital and the Jewish General Hospital in Montreal, Quebec.

Inclusion criteria: Patients scheduled to undergo surgical lymph node dissection for gynecological cancer or having a diagnosis of one of the following: Grade 2 or 3 endometrial cancer, or high grade type (serous or clear cell); Stage 1b1 or stage 2a cervical cancer; Stage 1, 2or 3vulvar cancer

Exclusion criteria: Recurrent diagnosis of gynecological cancer; presence of distant metastases (stage 4 cancer); BMI≥35.

Procedures: At the MUHC Lymphedema Clinic, over a 12 month period, on five occasions a medical exam and bilateral limb measurements will be administered to assess for changes in limb volume and the possible onset of lymphedema. At four weeks post-operatively (T2) both groups will receive standard education on lymphedema risk reduction and the experimental group will receive individualized education on exercises and will be prescribed compression class 1 stockings.

Results: As recruitment is presently underway we expect to have preliminary results to present by October 2015.

ABSTRACT #13

Title:

Beyond edema: The symptoms, impact, and clinical implications of arm morbidity after breast cancer

Authors:

Elizabeth Quinlan, Anna Towers, Roanne Thomas, Thomas Hack, Winkle Kwan, Baukje Miedema, Andrea Tilley

Context:
Clinical expertise suggests that research focusing solely on swelling/edema after breast cancer may be limited in capturing the full range of arm morbidity experienced by women.

Objective:
Our team aimed to document the trajectories and impact of arm morbidity, including lymphedema, pain, and range of motion restrictions in Canadian breast cancer survivors over a 5 year period.

Design:
Mixed methods cohort study. Clinical assessments alternated with telephone assessments every 6 months.

Setting:
4 research sites – Fredericton, NB; Montreal, PQ; Winnipeg, MB; Surrey, BC.

Participants:
740 women who had Stages I-III breast cancer were enrolled 6-12 months post-surgery.

Results:
Analysis of self-reported swelling/edema proved to have a stronger relationship with pain, function, and quality of life measures than the clinical assessments during which circumferential measurements were collected.

Conclusion:
The findings suggest that arm morbidity has a significant impact on quality of life after breast cancer. Arm morbidity is not limited to lymphedema; therefore it is important that diagnostic tools include symptom specific questions. The findings also support the importance of early diagnosis and appropriate physical rehabilitation for arm morbidity. [project is complete]

ABSTRACT #14

A Prospective Surveillance Model for Early Detection of Breast Cancer-related Lymphedema

Authors:
Rafn BS, Hung S, Dingee CK, Kwan W, McKevitt E, Pao J, Kuusk U, Van Laeken N, Goldsmith C, Inglis F, McNeely M, Hoens A, Kristin L. Campbell

Topic: A program description of a study in progress.

Background: Early identification of lymphedema (LE) is key to effective management and symptom reduction. However, early detection of LE is a challenge: Pre-surgery arm volume is not commonly measured to provide a comparison; LE can be asymptomatic despite volume increases of up to 22% from pre-surgery values; and there is discordance between the presence of measured and patient-perceived LE. A prospective surveillance model (PSM), developed by researchers and clinicians assembled by the American Cancer Society, has been proposed to improve early detection of LE after breast cancer surgery. The framework includes an arm volume assessment pre-surgery and ongoing post-surgery assessments at key time points to detect LE and provide targeted delivery of physiotherapy when LE is identified.

Aim: Undertake the first randomized trial to test the PSM during the first 12-months after breast cancer surgery to improve early detection and treatment of LE.

Methods: Forty women, age 54 ± 8 years, scheduled for breast cancer surgery were recruited between February 2013 and August 2014 at a local hospital (83% unilateral surgery and 17% bilateral surgery). Participants were randomly assigned to either a prospective surveillance group or control group. Arm volume was measured with a perometer at pre-surgery and 12-months post-surgery. Women assigned to the prospective surveillance group also had arm volume assessed at 3, 6, and 9 months post-surgery. If a 200mL increase in volume was observed in the affected arm compared to pre-surgery, a physiotherapy intervention was prescribed. The primary outcome was LE prevalence at 12-months.

Perspective: This model has the potential to influence prevalence and severity of breast cancer-related LE. Our ongoing trial will evaluate the effects of PSM approach that includes surveillance and targeted rehabilitation interventions, on the prevalence of LE within the first 12 months after breast cancer surgery.

ABSTRACT #15

Abnormal lymphatic vessel morphology and dendritic cell delivery in murine Crohn's Disease

<u>Sonia Rehal</u>, Pierre-Yves von der Weid
Inflammation Research Network, Snyder Institute for Chronic Diseases, Department of Physiology & Pharmacology, Cumming School of Medicine, University of Calgary

Research-In-Progress

Context: Crohn's disease (CD) is a chronic intestinal inflammatory disease, commonly affecting the terminal ileum and which displays characteristic submucosal edema and chronic inflammatory cell infiltrate. Mesenteric lymphatic vessels play a critical role in normal gut host immune responses by tightly regulating dendritic cell trafficking to the mesenteric lymph nodes (MLNs). Our current understanding of this process during inflammation is incomplete.

Objective: The aim of this study is to examine in a unique mouse model of CD whether 1) the morphology of the mesenteric lymphatic vessel network changes and 2) lymphatic of DC trafficking to MLNs via chemokine signaling is altered.

Design: TNFΔARE mice were used at ~20 weeks of age, when CD-like inflammation was most evident in the terminal ileum. Disease severity was evaluated by weight loss, myeloperoxidase activity and histology. Lymphatic vessel diameter and patency were measured to assess lymphatic vessel morphology. Quantitative real time PCR (qPCR) and wholemount immunofluorescence were used to assess lymphangiogenesis and chemokine ligand expression, and flow cytometry was employed to determine levels of DC subsets during the disease.

Results: TNFΔARE mice demonstrate significant signs of inflammation, such as decreased body weight, increased histological damage and granulocyte infiltration, and marked increase in intestinal COX-2 mRNA level. TNFΔARE MLNs were grossly enlarged and obstructed lymph flow was not demonstrated. QPCR results revealed an overall increase in molecules needed for DC trafficking through lymphatic endothelium. Flow cytometry showed that DCs robustly accumulated in TNFΔARE MLNs, but remained at relatively stable levels in the inflamed lamina propria, suggesting increased trafficking to MLNs. Furthermore, changes in DC subsets occurred at the level of the ileum, MLNs and lymphatic vessels.

Conclusions: TNFΔARE mice displayed marked abnormalities of the lymphatic system as well as changes in DC populations. These findings suggest dysregulation of the lymphatic system in IBD pathogenesis.

ABSTRACT #16

Characterizing the lymphedema patient population: an overview of new referrals to a hospital-based specialized lymphedema clinic

Shirin Shallwani, Pamela Hodgson and Anna Towers

Context:

Lymphedema can have debilitating consequences on patient functioning and is costly to the healthcare system. However, little is known on the characteristics of the lymphedema patient population, particularly non-cancer-related cases.

Objectives

Our objectives were: a) to describe the lymphedema patient population referred to a specialized lymphedema clinic according to medical history, lymphedema characteristics and incidence of cellulitis infection; b) to compare these characteristics between patients with cancer and patients with non-cancer diagnoses.

Methods:

This was a retrospective cohort study of all new patients (n=429) with suspected diagnoses of lymphedema assessed at the McGill University Health Centre (MUHC) Lymphedema Clinic over a two-year period. The MUHC Lymphedema Clinic is a hospital-based ambulatory clinic. Patient data is compiled in an electronic Microsoft Access database.

Results:

The mean age of the patients was 61.6 years, 84% were female, 81% had a history of cancer and 94% had a relevant surgical history. Lymphedema characteristics were primary (7%) vs. Secondary (92%); upper body only (51%) vs. Lower body only (45%); and unilateral limb (74%) vs. bilateral limbs (25%). Incidence of cellulitis infections was: 0 (74%), 1-3 (17%), 4-6 (3%) and >6 (2%). Patients with non-cancer diagnoses (n=82) were significantly more likely than patients with cancer diagnoses (n=347) to have a history of cellulitis infection (44% vs. 17%; p<0.001), have bilateral (62% vs. 16%; p<0.001) and lower body (87% vs. 35%; p<0.001) lymphedema, be younger (57.1 vs. 62.6 years; p=0.002) and be male (30.4% vs. 11.8%; p<0.001).

Conclusions:

Most patients with diagnosed lymphedema are female with a history of cancer. However, patients with non-cancer diagnoses are likely to have an important history of cellulitis infection and bilateral lower body lymphedema; this sub-group is at great risk of missed and delayed diagnoses in the medical setting and of experiencing chronic issues with mobility, recurrent hospitalizations and poor quality of life.

ABSTRACT #17

The Incredible Shrinking Women

Tracy Smith BScPT
Tom Baker Cancer Centre Rehabilitation Oncology

An intensive trial of compression bandaging, by a therapist, twice a week for a month, can result in significant and sometimes staggering reductions in limb volume, when the affected limb has severe lymphedema. In some patient populations, lymphedema can progress quite rapidly without treatment, or without sufficient treatment and management.

In the following case studies, we would like to present two women, with different presentations of their lymphedema, who both responded well to compression bandaging. Both of these clients presented in an ambulatory rehabilitation clinic with their affected limb more than double in size to their non-affected limb.

In the first case study, the client recently moved to Canada from a country that she was not able to access any treatment for her arm lymphedema. The second client is someone who has been treating and managing her leg lymphedema for over 30 years and could no longer manage without assistance. Both clients are still receiving treatment and follow-up.

Currently, the client with arm lymphedema has been reduced from a limb volume difference of 102% to 36% with compression bandaging twice a week for approximately one month, and is now in a custom fit sleeve and glove. The client with leg lymphedema has reduced 6600 ml from a 21+L difference to just over 15L difference in 4 weeks of compression bandaging twice a week. The long-term goal for both clients is to have the smallest limb volume difference we can attain, and then to maintain their lymphedema with appropriate garments.

ABSTRACT #18

Clinical Case Study for 2015 National Lymphedema Conference
BRCA-related lymphedema and stubborn fibrosis lead patient to seek lymph node transfer

Submitted by: Katherine Styrchak, RMT, CLT-LANA
Wanda Guenther, RMT, MLD/CDT

Context:
We chose this case to present a fast-forming, stubborn, full arm and hand fibrosis in a patient with breast cancer-related lymphedema. It is of significance in that it highlights the challenges the patient and therapist faced when presented with severe fibrosis. It also highlights the patient’s frustration with the fibrosis, the reduced range of motion and the challenges to provide treatment while the patient tried to find a balance between treatment options and living her life. When presented with the option of a lymph node transfer and possibly improving her quality of life, the patient accepted. It is of significance that while the lymphedema was mild, the fibrosis affected her activities of daily living and was pivotal in her decision to have a lymph node transfer.

The objective of this presentation is to look at a case of breast cancer-related arm lymphedema with fibrosis which led the patient to undergo a lymph node transfer, and the consequences. The results of the lymph node transplant will be assessed at three, six and nine months.

Setting:
Therapy was provided by Dr. Vodder-certified MLD/CDT therapists. Treatment for the patient’s arm lymphedema took place at the Winnipeg Regional Health Authority's Breast Health Centre. Treatment for her leg lymphedema took place at a private practice clinic in Winnipeg.

Conclusion:
A case of mild breast cancer-related lymphedema quickly progressed to fibrosis which fluctuated between very firm and medium firm, and ultimately ended in a decision by the patient to undergo lymph-node transfer.

Challenges and options for treatment, as well as surgical outcome, will be discussed.

ABSTRACT #19

Clinical Case Study for 2015 National Lymphedema Conference
Breast cancer-related lymphedema in a male patient ends in disarticulation

Submitted by: Katherine Styrchak, RMT, CLT-LANA & Jen Dalke, RMT, CLT-LANA

Context:
We chose this case to show the fluctuations in a malignant lymphedematous arm and myriad techniques used in the management of this lymphedema. It is of significance in that it highlights the challenges the patient and therapists faced when presented with infections, DVTs, recurrent cancer, metastases and the difficulty in accessing lymphedema treatment when living in rural Manitoba. The case also highlights breast cancer in a male patient and subsequent lymphedema. Treatment was further challenged by the patient's anti-social nature, independence, and desire to be left alone. Malignant lymphedema requires treatment and management in palliative cases and can improve quality of life.

The objective of this presentation is to look at a case of breast cancer-related right arm lymphedema in a 75 year-old male with an unexpected outcome: disarticulation.

Setting:
Therapy was provided by Dr. Vodder-trained MLD/CDT therapists. Treatment took place primarily at the Winnipeg Regional Health Authority's Breast Health Centre, located in Winnipeg, Manitoba. The Centre is a publicly funded, community based, multidisciplinary health facility, with a patient focused model of care on breast health concerns and cancers.

Conclusion:
A case of a male breast cancer patient presenting with right-arm lymphedema evolved into a malignant lymphedema with complications and was able to be managed for a time. Recurrent cellulitis, DVTs, METS and new cancerous lesions contributed to the patient's decision for a right arm disarticulation. Challenges and options for treatment will be discussed.

Abstract # 20

Modeling Chronic Disease Self-Management Support in Lymphedema Care

Aronela Benea, BScN, MScN, Pamela Hammond, RMT/CDT, MES; Aleksandra Chafranskaia, PT, MHSc; Stephanie Phan, OTRg.(Ont.), HBSc(OT); Jenifer Jones, PhD; Pamela Catton, MD, MHPEd, FRCPC

Context: A chronic condition like lymphedema has multiple implications on the patients’ physical and psycho-social wellbeing. Similarly to many other chronic conditions, lymphedema requires long term management. Self-management support is an essential component of the Chronic Care Model and an effective way of empowering patients to take an active role in the ongoing management of their condition. A self-management model of care for lymphedema secondary to cancer treatment has been successfully implemented at the Lymphedema Clinic, Princess Margaret Cancer Centre.

Methods: This presentation aims to provide health care professionals with an overview of self-management support in chronic diseases and the application of the self-management model to lymphedema care based on the experience of the Princess Margaret Lymphedema Clinic. Strategies to support self-management of chronic conditions as outlined in the Registered Nurses’ Association of Ontario guidelines and the Ontario Chronic Disease Prevention and Management Framework will be discussed in regard to lymphedema management.

Results: Health care providers working with lymphedema patients need to be able to provide appropriate self-management support. Various self-management support strategies and frameworks that have been used in other chronic disease populations are available for lymphedema clinicians.

Conclusion: Living with a chronic condition like lymphedema requires active participation of patients and families in their care and the adoption of specific self-management activities. Proper self-management support needs to be in place to empower patients to integrate lymphedema self-care practices into their daily life.

Abstract # 21

Lymphedema management strategies for Head and Neck Cancer patients: A case series using photographic surveillance

Rita Wannechko-Koening PT, BPT Cross Cancer Institute

Context: Lymphedema affecting the face and neck is a common side effect of surgical treatment for head and neck cancers. Lymphedema in this region can create body image distress and significantly impact the survivor’s neck mobility, ability to swallow and speak, and overall function. Lymphedema treatment methods such as compression therapy, manual lymphatic drainage and kinesiotape techniques are commonly used clinically. One of the challenges for the clinician is measuring lymphedema outcomes in the head and neck region following reduction treatment.

Objective: The main objective of this case series is to demonstrate the success of lymphedema treatment techniques through the use of before and after photographs.

Methods: Two survivors with head and neck cancer will be profiled in this case series presentation. Prior to the commencement of lymphedema treatment, survivors were encouraged to bring in their I-pads or cell phones to capture the images of their neck and facial swelling. Alternately, if these technologies were not available, formal photography was arranged through the medical audio-visual department. The chosen rehabilitation treatment was tailored to the individual survivor’s presentation and preferences. Photographs were retaken following reduction treatment.

Results: Through the use of this photographic measuring technique, we were able to evaluate the effects of the lymphedema treatment and inform our ongoing clinical treatment plan. Different combinations of compression therapy, manual lymphatic drainage and kinesiotape were effective in improving neck and facial swelling in survivors of head and neck cancer.

Conclusions: Photographic surveillance provides a means to visually document changes in facial and neck lymphedema over time, and can be a powerful motivator to the head and neck cancer survivor whose rehabilitation journey is often lengthy and riddled with setbacks.

ABSTRACT #22

Impaired Antigen Delivery during Edema Creates Immune Suppressive Environment by Remodeling Lymph Node Conduit System

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Interrupted lymphatic function inhibits the fluid drainage from the lymphatic system leading to fluid accumulation (edema). When lymphatic dysfunction is extreme, edema causes large swollen immobile limbs (lymphedema), fluid in the abdomen (ascites), fluid in the chest (pleural effusions), and can affect almost every organ in the body. In addition to causing organ dysfunction, discomfort and immobility, the edematous tissue is prone to infection. Currently, no well-established mouse model is available to study lymphedema except an artificial system of ablation of LVs in the tail of the mouse. The edematous and inflamed tissue condition caused by oxazolone skin sensitization induced inflammation (OX-inflammation) may serve as a simplified model to understand lymphatic function during lymphedema.

The **objective** of this study is to investigate the role of lymphatic function and immune regulation in normal and ox-inflammation.

Design: We use FITC or fluorescent dye labeled ovalbumin as model antigens to study antigen delivery to the draining lymph node at different time points after the induction of OX-inflammation. We use imaging technique to study antigen distribution in lymph node. We use FACS analysis to study dendritic activation in lymph node and T cell activation.

Results: We found that OX-inflammation significantly reduced antigen delivery to the lymph node when lymphatic function is interrupted. The interruption of antigen delivery likely due to altered lymph node microenvironment especially the lymph node conduit system. The reduced antigen delivery inhibits T cell responses.

Conclusions: The edematous condition caused by OX-inflammation impairs lymphatic function, reduces antigen delivery to lymph node and cause immune suppression to new antigen. This may explains why lymphedema patients are prone to infection.

ABSTRACT #23

Inhibition of lymphatic pumping by TNF-α – importance for lymphedema

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Research-In-Progress

Context: Lymphatic pumping is the main mechanism used for propelling lymph and immune cells from the peripheral tissues to lymph nodes and back to the blood stream. Decreased lymphatic pumping causes poor lymph drainage and accumulation of fluid, immune cells and macromolecules in the tissues, ultimately leading to lymphedema. Edema is one of the five cardinal signs of inflammation, and inflammation occurs in acquired lymphedema. Importantly, we have demonstrated that inflammation alters lymphatic pumping via increased production of nitric oxide (NO) and prostaglandins caused by the upregulation of the enzymes inducible nitric oxide synthase (iNOS), and cyclooxygenases (COX1 and COX2).

Objective: To further assess how inflammation impairs lymphatic contractile dysfunction, we investigated whether and how TNF-α, a potent pro-inflammatory cytokine upregulated in lymphedema, alters lymphatic pumping.

Methods: Rats were euthanized and the small intestine with its attached mesentery rapidly isolated. Mesenteric lymphatic vessels were dissected out, and incubated in physiological and sterile conditions for 24 h with TNF-α or vehicle with or without pharmacological inhibitors. Vessels were then mounted on a pressure myograph and contractile activity, induced by the luminal pressure, recorded.

Results: TNF-α significantly decreased lymphatic contraction frequency in a concentration-dependent manner. Contractile activity was restored following administration of PDTC, an inhibitor of NF-κB, a master regulator of inflammation acting downstream of TNF-α. Western blot analysis revealed an increase in phospho-IκB and quantitative real-time PCR showed upregulation of iNOS mRNA in TNF-α-treated vessels that was minimized in the presence of PDTC. Furthermore, pumping was reestablished by pharmacologically inhibiting the NO pathway, but not by inhibiting the prostaglandin pathway.

Conclusions: TNF-α decreases lymphatic pumping via activation of the NF-κB - iNOS - NO pathway and may contribute to the lymphatic dysfunction seen in lymphedema.

ABSRACT # 24

The Pharmacological Potential of Flavonoids as Novel Treatment for Chronic Lymphedema

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Research-in-progress

CONTEXT: Chronic lymphedema is an incurable, potentially disabling condition characterized by regional bodily accumulation of protein-rich interstitial fluid, affecting greater than 100 million people worldwide. Despite its prevalence, there is currently no pharmacological treatment for lymphedema.

OBJECTIVE: This ongoing experimentation examines the effectiveness of the flavonoid apigenin in ameliorating *in vitro* and *ex vivo*, the inflammation, lymphatic endothelial cell (LEC) proliferation and impaired lymphatic vessel contractility that accompany lymphedema.

METHODS: TNFα and COX-2 gene expression was measured by quantitative RT-PCR to evaluate the anti-inflammatory action of apigenin, administered at a concentration of a 0.2μg/mL, on rat mesenteric LECs and J774A.1 murine macrophages treated with 50ng/mL lipopolysaccharide (LPS) for 24 h. The effect of apigenin on lymphatic pumping was then assessed on isolated, pressurized rat mesenteric collecting lymphatic vessels under basal and LPS-stimulated conditions. Finally, a standard wound scratch assay was performed to assess the effect of apigenin on proliferation rates of control and LPS-treated LECs.

RESULTS: Concomitant administration of apigenin and LPS to primary LECs and J774A.1 macrophages for 24 h showed a decrease in COX-2 and TNFα mRNA expression compared to cells treated with LPS alone (n=2). A 24-hour LPS stimulation resulted in a decrease in contraction frequency of lymphatic vessels compared to sham vessels that was significant at 5mmHg and 7mmHg ($P<0.05$, n=6). In the presence of apigenin, the contraction frequency of LPS treated vessels did not significantly differ anymore from that of sham vessels (n=4). Apigenin also improved the proliferation rate of LPS-treated LECs following linear scratch wound (45% increase in proliferation, n=3).

CONCLUSIONS: These preliminary findings suggest favourable actions of apigenin in reducing inflammation, and positively influencing both LEC migration and lymphatic vessel contractility. Further testing is ongoing to validate these promising data for the development of a pharmacological treatment for chronic lymphedema.

ABSTRACT # 25

Canadian Lymphedema Research Priorities: Results of National Surveys

Roanne Thomas, Anna Towers, Katie Armstrong

Project Status: Complete
Context: Lymphedema is a chronic condition, most commonly manifesting as swelling of one or more limbs. This topic is under-researched in comparison to other chronic illnesses and conditions. Considering the lack of research, it is important to identify research priorities within the realm of lymphedema. Our team consisted of members of the CLF Research Working Group.

Objective: The objective of this study was to identify lymphedema research priorities in Canada.

Design: The Delphi technique, utilized in this study, is used to generate consensus among people who are experts in a certain topic. It is used for determining or ranking priorities with multiple stages of prioritization. Two rounds of a Delphi Study survey were sent out to be completed online.

Setting: An electronic survey was sent to key stakeholders across Canada.

Participants: The first round of the Delphi Study Survey was sent out to 42 individuals considered to be lymphedema experts, including researchers, patients, advocates and health professionals (identified by the research team). Participants were chosen to give national representation. There were 33 respondents, and a second round of the survey was devised and sent out to respondents: 26/33 responded to the second round.

Results: The research priorities were ranked by respondents as follows (based on a weighted score):

1. Effectiveness of treatment modalities
2. Incidence and prevalence
3. Risk reduction
4. Quality of life
5. Scientific (laboratory) research
6. Economic impact

Conclusions: Although this Delphi study allowed for the ranking of research topics and identification of research priorities, all topics were considered important and demonstrate the need for further lymphedema research, as well as the need for increased funding for projects exploring this topic.

ABSTRACT #26

A Lymphedema Self-care Management Model for Cancer Survivors at the Princess Margaret Cancer Centre

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Background:

The Princess Margaret Cancer Centre Lymphedema Clinic, supported by an annual fund raising event, was established in 2005 to provide lymphedema self-management and care to patients with breast cancer-related lymphedema. The clinic has now expanded to all cancers and offers Princess Margaret patients with cancer-related lymphedema a personalized self-management care plan which includes education, comprehensive assessments, support, and training in lymphedema self-management skills and strategies.

Methods:

This clinic was developed based on The Chronic Care Model (Wagner EH 1998), cancer rehabilitation and wellness principles. Self-management skills' training follows International Lymphedema Framework guidelines (International Lymphoedema Framework 2006) and Combined Decongestive Therapy practices.

Results:

This self-management program is delivered by a transdisciplinary team and provides patients with the knowledge and skills needed to help manage the physical and psychosocial impact of lymphedema through multimodal educational resources and self-management tools, in-house and community support and services. Regular follow-up assessments and skill refresher classes address concerns that may occur over time, ensure ongoing support and foster adherence to self-management. Patients who experience pain and reduced mobility can be referred to Princess Margaret Function and Mobility Clinic, Toronto Rehabilitation Institute, Wellness and Exercise for Cancer Survivors program or one of our community partners. Following this model allowed us to facilitate care of over 1,637 lymphedema patients while being efficient and fiscally responsible

Conclusion:

Patients and their families can successfully develop self-care strategies and techniques for the self-management of lymphedema. Various programs and classes such as Lebed Healthy Steps, Relaxation sessions, Return to Work, Sex and Intimacy, What to do About Brain Fog, and Reclaim Your Energy have augmented our patient's lymphedema care.
Please note that this is an overview of our program.

ABSTRACT #27

"Today I understand it better": Evaluating Breast Cancer Patients' Success in Learning Lymphatic Self-Massage at the Princess Margaret Cancer Centre.

A. Chafranskaia, P. Hammond, P. Hansraj, L. Hawkins, A. Ross, S. Crowhurst, P.Catton, S. Phan and J. Nyhof-Young

The Princess Margaret Lymphedema Clinic provides patients with training and coaching in self-management and self-care skills based on Combined Decongestive Therapy (CDT) principles and International Lymphedema Framework (ILF) guidelines. Clinic staff observed that lymphatic self-massage (LSM) was not properly executed and/or not consistently maintained by a significant percentage of patients potentially limiting patient's ability to benefit from this program. As self-management is an integral component of chronic disease/condition management in primary health care, the LSM teaching program was explored.

This mixed method study evaluated the clinic's one-on-one LSM instruction interventions, its effect on patients' knowledge and adherence to LSM practice. Pre- and post-knowledge tests, structured demographic and self-massage questionnaires and semi-structured patient-feedback interviews were developed, administered and analyzed using basic descriptive statistics and descriptive thematic analysis.

This Lymphedema Clinic, supported by an annual fundraising event, is located in the Princess Margaret Cancer Centre.

Eighty-seven English speaking patients diagnosed with breast-cancer related lymphedema with a minimum of two one-on-one LSM coaching sessions were recruited from the lymphedema clinic. Patients receiving active treatment for malignancy at recruitment were excluded.

Pre/post test results (n=25) indicate that self-massage understanding improved (p=0.0001). Interviewed patients (n=18) reflected on their experiences with learning environment and made recommendations for program improvement. Motivators to LSM adherence included health literacy and establishing a daily routine; barriers included physical limitations. Quantitative data (n=87) indicated no significant correlation between social support and LSM adherence (p=1.0000).

Data provided a more comprehensive understanding of patients' needs and experiences of LSM instruction and adherence. Future research projects should focus on development of strategies to promote integration of LSM adherence into daily routine and program development to help patients overcome physical barriers to LSM adherence.

ABSTRACT #28

Empowering patients and professionals
– The collaboration to launch a unique Canadian lymphedema magazine

Kennedy A, Avanthay K, Martin D, McPherson C, Pritzker R, Ryan J, Tucker-Lloyd E, Wesley L

Introduction: *Pathways* is a full-colour 28-page national magazine published quarterly for the lymphedema community by the Canadian Lymphedema Framework (CLF) and its provincial affiliates. This publication is unique in targeting diverse lymphedema stakeholders: patients and caregivers, clinicians, product distributors and fitters, researchers and educators.

Context: A 2011 study by the CLF highlighted the need for increased education and awareness of lymphedema. Prior to the creation of the CLF in 2009, eight provincial/regional community organizations were already leading local efforts to educate patients and professionals.

Objective: To support the CLF's mission to improve the management of lymphedema in Canada and to disseminate lymphedema education and awareness nationally while incorporating customized local content.

Process: Under the leadership of the CLF, monthly cross-Canada calls were initiated. Over two years, all organizations contributed to the concept, design, branding and distribution of the magazine. Sponsoring companies provided financial support. An online evaluation is planned.

Results: In its first year of publication, *Pathways* surpassed initial targets of readership and industry support. Key objectives were met:

1) The CLF and its provincial affiliates have united in one official voice.
2) The magazine has provided the CLF with a sustainable revenue source to support its annual operating and project related costs.
3) The provincial lymphedema associations have a cost-effective tool that can boost their individual membership, attract local advertising revenues and support their provincial advocacy efforts.

Results of the online evaluation will be reported.

Conclusion: The development of *Pathways* provides a model of effective collaboration; several organizations, united in a single passion worked collectively to advance lymphedema education and awareness. Additional collaborative projects are currently under way.

ABSTRACT #29

Lymphedema Community Based Organizations Can Drive Change

Kennedy A

Presentation Objectives:

- Provide a Canadian and global perspective of the work being done in lymphedema community based organizations
- Showcase the changes that are evolving when dedicated and passionate volunteers work together to develop long term strategies
- Encourage conference delegates to become involved in the CLF or provincial association to help drive change

Context: The momentum started in 2002 with the inception of the International Lymphoedema Framework, a global platform for the lymphedema community. There are now nine countries currently with dedicated frameworks, united in their vision to change how lymphedema is diagnosed, treated and reimbursed around the globe. Canada was the third country to come onboard (2009) with the launch of the Canadian Lymphedema Framework. There are also seven provincial associations supporting the Canadian lymphedema community.

Joint Vision of all lymphedema based community organization:

- Raise the profile of lymphedema
- Place lymphedema and its management as a priority on health care agendas
- Lobby for financing of reimbursement of care and address issues of inequality of provision
- Improve the lives of lymphedema suffers worldwide – the patient is at the heart of everything we do
- International collaboration is essential – among academics, health professionals, community organizations, industry and patients

Key Initiatives:

ILF - LIMPRINT epidemiology project and Canada’s involvement on this research project
CLF – The focus on EDUCATION tools for health professionals and patients, RESEARCH agendas and initiatives and PARTNERSHIPS
PROVINCES – advocacy successes for reimbursement and awareness initiatives

Conclusion: Every Contribution Counts. It is the work of volunteers who are helping to change the face of lymphedema in Canada

ABSTRACT #30

Role of a Patient Volunteer in a Lymphedema Clinic

Pritzker R, Shay C, Hodgson P, Cama G, Towers A

Context

To provide supportive, compassionate quality care, a patient-centered approach involving multi-disciplinary care teams is promoted in hospitals across Canada. Team members increasingly include patient volunteers who play an important role in providing social support to other patients.

Background

The Lymphedema Association of Quebec (LAQ) is a non-profit charitable organization founded by patients in 1999 to address the needs of the lymphedema community.
In 2008, patient members of the LAQ began volunteering as part of the inter-disciplinary care team at the Lymphedema clinic of the McGill University Health Centre (now known as the Lymphedema Support Centre of the Quebec Breast Cancer Foundation).

Description

The multiple roles of the lymphedema patient volunteer are described and analyzed with reference to current literature. Roles at the Lymphedema Clinic include greeting patients, family and friends, listening to their needs and concerns, making them feel comfortable, offering support and providing valuable information about lymphedema, the LAQ, its programs and activities. Patients appreciate having the time and the opportunity to speak openly with a patient volunteer about their experience with lymphedema as well as cancer. Such peer contact has been found to be reassuring and validating for newly diagnosed and returning patients. Interviews with volunteers at the Lymphedema Support Centre of the Quebec Breast Cancer Foundation revealed that volunteers also find it an enriching experience for themselves.

Conclusion

Peer dialogue has been shown to be valuable in facilitating self-management programs in chronic illnesses. Patient volunteers can offer emotional and informational support that assists effective self-management, and serve as inspirational role models, providing examples of successful control of a chronic disease.

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