# LYMPHOEDEMA FRAMEWORKS:
# A PATIENT CENTRED APPROACH

## 2nd ILF CONFERENCE
## BRIGHTON, UK 22 - 25 MARCH 2010

INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

www.lympho.org

Belong Together

# Welcome to the 2nd ILF Conference

***by Christine Moffatt***

## Welcome

It is with great pleasure that we welcome you to the 2nd ILF conference held this year in Brighton, UK. Delegates are coming from far and wide, representing many different countries and disciplines. We are pleased that in addition to the professional elements of the conference we are also able to host a patient conference within this programme under the direction of the Lymphoedema Support Network .

We are particularly delighted to welcome our national framework partners who have worked so hard in the last year, both in their own countries, and also in contributing to this conference and to the documents we will launch during this event. Without their work the ILF would not exist and we are grateful for their enthusiasm and commitment to the vision of the ILF.

This event symbolises the passion that many of us feel in striving to improve the care of patients throughout the world and the desperate need for recognition of this neglected problem. We hope that you will enjoy the different aspects of the conference and will be able, through the interactive sessions, to ensure your voice is heard and understood.

The last year has been a challenging year for the ILF and we are grateful for the many people who have supported and encouraged us, in particular our partners in industry, without whose support this conference would not be possible. In the coming year we plan a major review of the Best Practice Document with a launch at our next conference. This work is being very ably led by the American Lymphedema Framework Project in partnership with the ILF.

**We hope you enjoy your time in Brighton and return energised to work together for a better life for our patients.**

Belong Together

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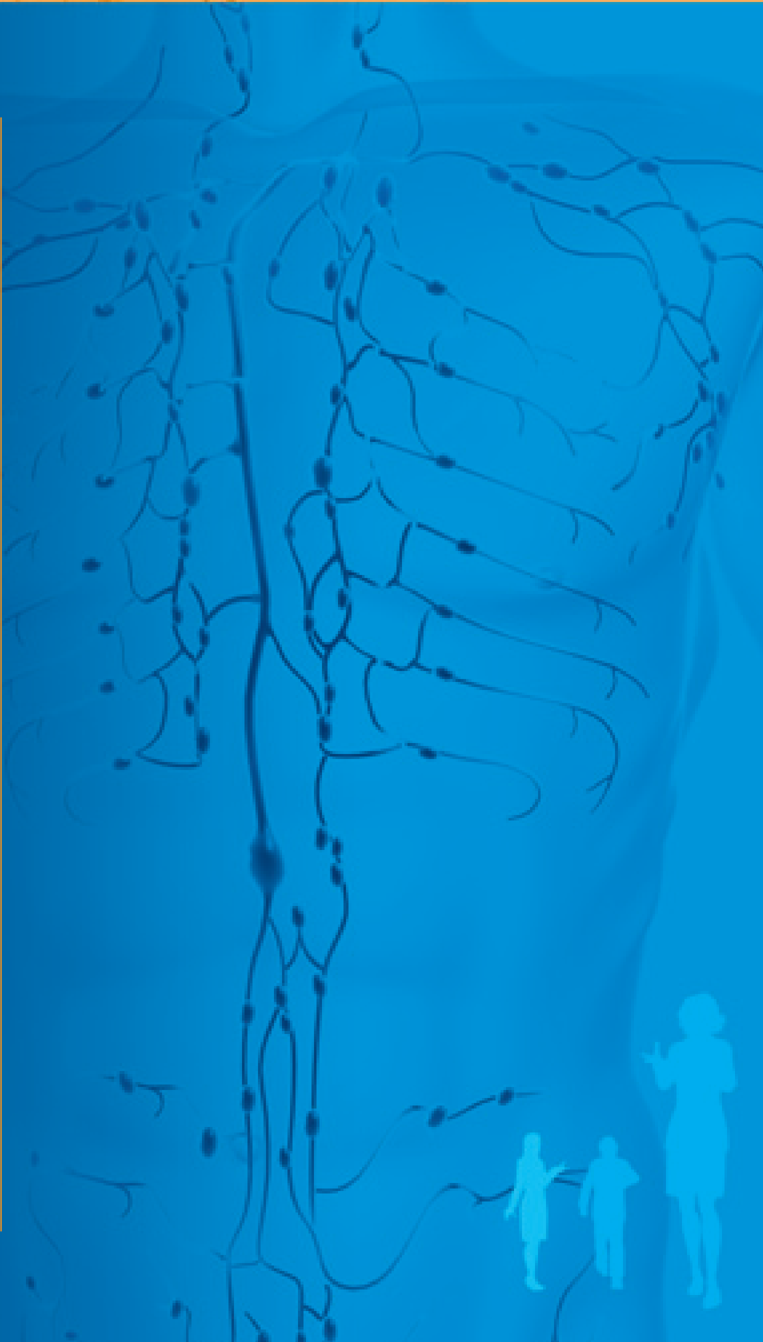


# Programme

## MONDAY

| | |
|---|---|
| 9.00 - 10.00 | Registration |
| 10.00 – 18.00 | ILF Open Space meeting : « The international challenges of improving the management of lymphoedema locally ». |
| 18.00 – 19.30 | National Lymphoedema Frameworks dinner |

## TUESDAY

| | |
|---|---|
| **9.00 – 12.00** | **Registration** |
| 12.00 –12.15 | **Opening Remarks** – *C. Moffatt* |
| 12.15 –12.30 | **Outcomes emerging from the Lymphoedema Frameworks Research** – *P. Franks* |
| 12.30 – 15.15 | **Session A** The Filariasis Patient |

**12.30 - 13.15**

**Plenary Session**

- ***J. McDonald:*** WAWLC
- ***N. Stout / P. Brantus:*** Bridging the gaps
- ***N. Tarur:*** Morbidity Control

**GLOBAL VILLAGE OPENING**

**13.45 - 15.15**

| **Interactive Sessions** | | | **Skills Development Workshops** | |
|---|---|---|---|---|
| **A1** | **A2** | **A3** | **A5** | **A6** |
| WAWLC: The World Alliance for Wound and Lymphoedema Care<br>*J. McDonald* | Bridging the gaps<br>*N. Stout, P. Brantus* | Lymphatic Filariasis Morbidity Control: Presentation of cases<br>*K.S. Bose, N. Tarur* | Overview of Exercise and Movement in Lymphoedema<br>*K. Johansson, A. Cheville, J. Hidding, L. Jönsson* | Overview of Diagnostics and Measurement in Lymphoedema<br>*N. Piller* |

| | |
|---|---|
| 15.15 – 15.45 | **Exhibition + Posters** |
| 15.45 – 18.00 | **Session B** Patients Empowerment |

**15.45 - 16.30**

**Plenary Session**

- ***A. Wallace:*** Patient Support Network 📙
- ***A. Kennedy:*** Lymphoedema Frameworks 📙
- ***S. Thiadens:*** Patients Advocacy

**16.30 - 18.00**

| **Interactive Sessions** | | | **Skills Development Workshops** | | |
|---|---|---|---|---|---|
| **B1** | **B2** | **B3** | **B5** | **B6** | **B7** |
| How to develop a Patient Support Network<br>*A. Wallace, K. Friett* | National Lymphoedema Frameworks - The Way Forward<br>*A. Kennedy* | Patient Perspective: a global Advocacy Coalition<br>*S. Thiadens, B. Weiss* | Yoga from India<br>*K.S. Bose, M. Vivekananda* | Children with lymphoedema - incidence and treatment<br>*E. Földi, H. von Zimmerman* | IPC: unravelling the facts from the fiction<br>*C. Saggers* |

| | |
|---|---|
| 18.00 – 19.30 | **Dinner** |

📙 Launch of ILF document

# Programme

## WEDNESDAY

**8.00 – 10.15** **Session C** Children with Lymphoedema

**8.00 - 8.45** **Plenary Session**
- ***P. Mortimer:*** Genetics
- ***I. Quéré:*** ILF Document: «Care of children with lymphoedema»
- ***J. Todd:*** Management

**8.45 - 10.15**

**Interactive Sessions**

| **C1** | **C2** |
|---|---|
| Case Studies of Children with Lymphoedema<br>*P. Mortimer* | Management of lymphoedema in children and young adults<br>*I. Quéré, J. Todd, P. Sanderson* |

**Skills Development Workshops**

| **C5** | **C6** | **C7** |
|---|---|---|
| Moving the pregnant patient<br>*M. Lauret-Romers* | Managing complex Skin problems in lymphoedema<br>*D.Doherty* | Writing for publication<br>*D. Glover* |

**10.15 – 10.45** **Exhibition + Posters + Judging of posters** *by Prof P. Franks and ILF Board*

**10.45 – 13.00** **Session D** The Bariatric Patient

**10.45 - 11.30** **Plenary Session**
- ***E. Földi:*** Conservative management
- ***B. Terry:*** Surgical approach
- ***M. Flour:*** Skin changes in the bariatric patient

**11.30 - 13.00**

**Interactive Sessions**

| **D1** | **D2** | **D3** |
|---|---|---|
| Complex case management using conservative approach<br>*E. Földi, S. Ellis* | Complex case management using surgery<br>*B. Terry* | Complex psychosocial and clinical problems in the management of morbid obesity<br>*M. Flour* |

**Skills Development Workshops**

| **D5** | **D6** | **D7** |
|---|---|---|
| Exercise for lymphoedema treatment<br>*A. Hendrickx* | The role of Negative Pressure Wound Theraphy<br>*D. Keast* | Treating the bariatric patient<br>*A. Wright, G. Close, K. Rutjens, P. Jamieson* |

**13.00 – 14.45** **Lunch + Exhibition**

13.15 - 14.45 **Breast Cancer Symposium** *Chair: Prof P. Mortimer, J. Cormeir, P. Lievens, J. Armer, K. Kitamura, K. Johansson, R. Peleg*

**14.45 – 17.00** **Session E** Risk Reduction

**14.45 - 15.30** **Plenary Session**
- ***J. Armer:*** Motivational interviewing
- ***N. Stout:*** Compression as prevention
- ***J. Cormier:*** Metrics of measurement

**15.30 - 17.00**

**Interactive Sessions**

| **E1** | **E2** | **E3** | **E4** |
|---|---|---|---|
| Motivational Interviewing – Role playing<br>*J. Armer, C. Brooks, B. stewart* | Compression as prevention<br>*N. Stout* | How should Lymphoedema be measured ?<br>*J. Cormier, J. Feldman,* | Meditative Exercise<br>*M. McClure* |

**Skills Development Workshops**

| **E5** | **E6** | **E7** |
|---|---|---|
| Group processes in self management<br>*H. Venema, T. Zee, E. Brower* | Footwear solutions for swollen feet<br>*M.J. Geyer, S. Cavanaugh* | Tissue Dielectric constant : a novel tool for oedema assessment<br>*A. Immonen* |

**17.00 –18.30** **Exhibition + Posters**

17.15 - 18.30 **Lipoedema Symposium** *Chair: I. Forner-Cordero, G. Szolnoky, S. Norton, K. Havens-Galer*

**19.30 – 24.00** **Conference Dinner + Awards + Barn Dance**

## THURSDAY

8.00 – 10.15

### Session F
Surgery in the management of Lymphoedema

8.00 - 8.45
**Plenary Session**

- ***A. Munnoch:*** Surgical Management of Lymphoedema
- ***R. Baumeister:*** Microsurgery using Lymphatic Grafts
- ***H. Brorson:*** Liposuction
- ***C. Campisi:*** Microsurgery

8.45 - 10.15
**Interactive Sessions**

**F1**
Discussion on the role of surgery and its integration into practice
*A. Munnoch, H. Brorson, R. Baumeister, C. Campisi*

**Skills Development Workshops**

**F5**
Pilates for Lymphoedema
*C. Pike*

**F6**
Education forum
*M. Sneddon*

**F7**
Compression bandages and movement
*T. Zee, N. Kool, G. Derijk, G. Strik, E. Wijbenga*

10.15 – 10.45 **Exhibition + Posters**

10.45 – 13.00

### Session G
The Palliative Patient

10.45 – 11.30
**Plenary Session**

- ***A. Towers:*** Communication and psychosocial issues
- ***V. Keeley:*** Advanced cancer ***D. Keast:*** Woundcare
- ***J. Simmons:*** Palliative document 📙
  ***A. Cheville:*** Creative CDT

11.30 - 13.00
**Interactive Sessions**

**G1**
« What do I say ? » - Communication and psychosocial issues in palliative care – related lymphedema.
*A. Towers*

**G2**
Assessment of oedema in advanced cancer
*V. Keeley*

**G3**
Creative CDT techniques in palliative care patients with lymphedema
*A. Cheville, S. Norton*

**G4**
Managing fungating wounds
*D. Keast*

**Skills Development Workshops**

**G5**
Salsa for Lymphoedema
*C. Pike*

**G6**
ILF Minimum Dataset
*P. Franks*

**G7**
Innovative treatment of Lymphoedema patients
*F. Schingale, H. von Zimmerman*

13.00 – 14.30 **Lunch + Exhibition**

14.30 – 17.00

### Session H
Dogma vs Science in compression for chronic oedema

## Joint ILF/ICC Meeting Plenary Session

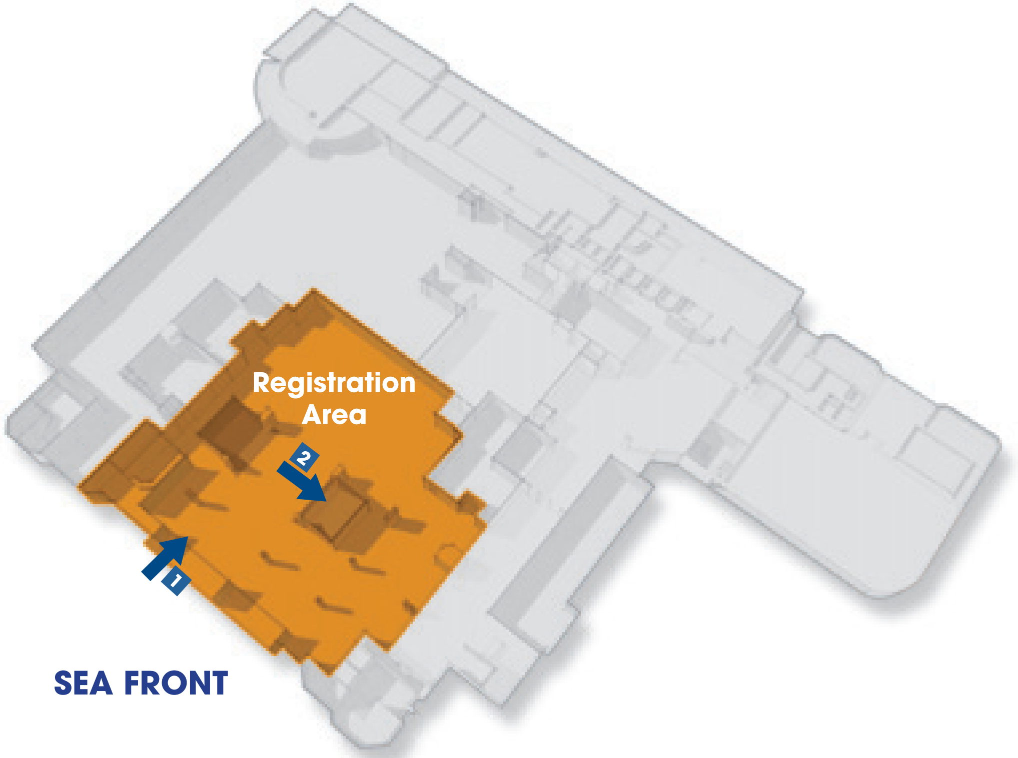
- ***P. Mortimer:*** Chronic oedema
- ***M.J. Geyer:*** Limb oedema due to immobility
- ***I. Forner-Cordero:*** What is the evidence that compression is helpful in chronic oedema ?
- ***M. Clark:*** Limb volume reduction in the clinic
- ***M. Neumann:*** Inelastic is more effective than elastic compression in reducing capillary filtration rate
- ***R. Damstra:*** Volume reduction of the lymphoedematous arm depending on compression pressure
- ***H. Partsch:*** Volume reduction of the leg depending on pressure and compression material in connection with body position and exercise

17.00 – 17.30 **Close of conference** *C. Moffatt*

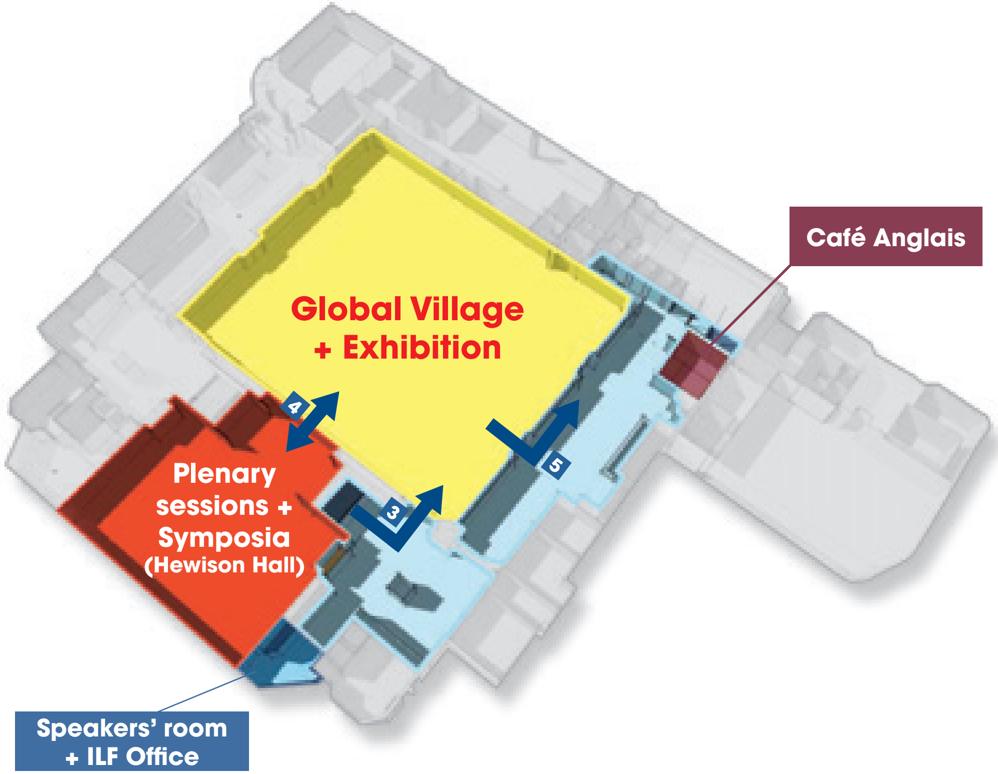
📙 Launch of ILF document

# Plan of Brighton Centre

## Ground floor



## First floor



**1** Access to Registration
**2** Access to First Floor
**3** Access to Global Village and Exhibition
**4** Access to Conference
**5** Access to East Wing for Breakout sessions

# General Information

## Conference Address

The Brighton Centre
143-145 King's Road
Brighton
BN1 2GR
**Tel : 01273 290 131**

## Access to the Brighton Centre

Access is through the main entrance on King's Road (Sea Front).

The doors will open 30 minutes before registration and conference programme begins. (See Conference Hours)

For security reasons and access to all areas of the Conference, official badges must be worn at all times.

## ILF Office

The ILF Office is by the Hewison Hall (See plan on page 7)
Telephone :
**+ 44 (0)798 048 3545**
Throughout the Conference, the office or telephone will be manned betwen 08.00 and 20.00

## Catering

### Monday

10:00 – Open Space Room – Welcome Tea/Coffee
13:00 - Open Space Room - Finger Buffet
16:00 – Open Space Room – Tea/Coffee Break
18:00 – Open Space Room – Dinner

### Tuesday

15:15 – Global Village/Exhibition – Tea/Coffee Break
18:00 – Global Village/Exhibition – Hot Fork Buffet

### Wednesday

10:15 – Global Village/Exhibition – Tea/Coffee Break
13:00 – Global Village/Exhibition – Lunch Bags
17:00 – Global Village/Exhibition + East Wing – Tea/Coffee Break
19:30 – Hewison Hall – Conference Dinner and Barn Dance

### Thursday

10:15 – Global Village/Exhibition – Tea/Coffee Break
13:00 – Global Village/Exhibition – Lunch Bags

**During the Conference, except during the breaks, snacks and drinks can be purchased from « Café Anglais » on the first floor (See plan on page 7).**

## Certificate of Attendance

This will be found with your registration information envelope.

## Chairperson and Speakers

Please ensure that you are available in your presentation room at least 10 minutes prior to the start of the session. Please note questions from Plenaries will be dealt with in the Interactive sessions.
Please see Speakers' Room for check-in procedure for slides.

## Conference hours

### Monday :

09:00 -10:00 – Registration.
10:00 – 18:30 – Open Space Meeting.

### Tuesday

09:00 – 12:00 – Registration
12:00 – 18:00 - Conference

### Wednesday

08:00 – 18:30 – Registration/Conference

### Thursday

08:00 – 17:30 – Registration/Conference

## Exhibition hours

**The Exhibition Hall will be open :**

| | |
|---|---|
| Tuesday : | 13:15 – 19:30 |
| Wednesday : | 08:00 – 18:30 |
| Thursday : | 08:00 – 14:30 |

# General Information

## Global Village

The Global Village is the « heart » of the Conference. It is the ideal place to meet other members of the lymphoedema community, make sure you visit it regularly.

## Interactive Sessions and Skills Development Workshops

Interactive Sessions and Skills Development Workshops will be held in the East Wing (See plan on page 7)

Access to the different Sessions will be clearly indicated. If you have any questions, please contact a member of ILF Staff.

After each Interactive Session, a brief report will be posted in the « Keep up with the Conference » area. Answers to Question Cards will also be shown.

## Internet Café

An Internet Café is available in the Exhibition Hall.

## « Keep up with the Conference » area in the Exhibition Hall for :

Reports from the Interactive Sessions

Answers to Question Cards processed during Interactive Sessions

## Mobile phones

Delegates are asked to switch off mobile phones when in the sessions.

## Plenary Sessions & Symposia

All Plenary Sessions and the Breast Cancer Symposium will be held in Hewison Hall.

The Lipoedema Symposium will be held in the East Wing.

Plenary Sessions will not include time for questions. These will be dealt with at the following Interactive Session. If you are unable to attend the Interactive Session, please make use of the Question Cards provided in your delegate bag. Cards should then be placed in the ILF box in the Global Village and answers will be posted in the « Keep up with the Conference » area.

## Posters

Posters will be on display in the Exhibition Hall throughout the conference and can be set up after 13.15 on Tuesday.

Display boards will be available in the Exhibition Hall. Equipment for setting up the posters can be obtained from the ILF team at the registration desk.

Posters will be judged on Wednesday morning (10.15-10.45) and we request that you are available by your poster to answer any questions at this time. An award for the best poster will be presented at the Conference dinner.

Posters should be removed at the end of the conference.

## Speakers Room

All speakers are asked to check their slides into the Speakers' Room located next to the Hewison Hall at least 3 hours prior to the presentation, having checked presentation times with the final programme. A technician will assist you in transferring your presentation into the central server and you will be able to check the slides. Personal laptops cannot be used.

Unauthorised photography, audio taping, video recording, digital taping or any other form of duplication is strictly prohibited in conference sessions unless agreed with the ILF beforehand.

## Visit Brighton

Brighton's Visitor Information Centre is located in the :

Royal Pavilion Shop

Royal Pavilion

4-5 Pavilion Buildings

Brighton BN1 1EE

**Opening Hours:** Daily, from 10:00 to 17:00

# Exhibitors

### 3M

**3M Skin and Wound Care division is a global supplier of single-use medical supplies to simplify and improve skin health and the treatment of wounds. With specific expertise in skin and wound care, we provide products, services and solutions for medical professionals in hospitals and community settings.** These products provide cost –effective solutions and are supported by educational services, professional and technical support as well as ongoing research and development.

The 3M Skin Health range of trusted products focuses on both acute wound and chronic wound care, providing innovative solutions, including dressings and barrier film, for the prevention of skin breakdown and management of wounds, to help avoid associated patient discomfort and cost.

Compression Bandages

The original Coban™ self-adherent bandage sticks only to itself and not to skin or hair. Used for compression bandaging, strains and oedema control, the original Coban™ bandage is also suitable for securing dressings and devices.

Compression bandaging has been the mainstay of treatment of venous ulcers for over 15 years. Coban™ 2 Layer Compression System is entirely latex-free and is designed to provide easier application for clinicians and improved comfort for patients. This encourages better concordance and increased mobility and activity, resulting in a more efficient and cost-effective treatment regime.

### BSN medical

**BSN Medical is a world class medical devices company, offering unique, high quality product and therapy solutions to patients and clinicians in the areas of compression therapy, wound care, and orthopaedics.**

Linking up many years of clinical expertise with unique manufacturing competence, we are able to offer a wide range of products for the management of lymphoedema.

**JOBST® OPAQUE, JOBST® BELLAVAR®, and JOBST® READY-TO-WEAR ARMSLEEVE and GAUNTLET** together form a selection of ready-to-wear circular knit garments, available in a range of compression classes, for upper and lower body applications.

The **JOBST®** Surgical Vest helps manage post operative oedema and reduce tension on surgical incisions. The vest minimizes haematoma formation, and holds implants and surgical dressings in place.

The **JOBST® ELVAREX®** range of flat-knitted garments provides a custom fit solution to ensure a precise anatomical fit for more serious and complicated lymphoedema and for limbs with irregular shape. A recent addition to the range is the **JOBST® ELVAREX®SOFT SEAMLESS FOOTCAP** which is the world's first flat knit compression footcap offering unrivalled patient comfort and optimum oedema management. Also recently added is a selection of **JOBST® ELVAREX® SOFT** Custom Fit Armsleeves and Hosiery which provide proven efficacy whilst offering softness and ease of donning.

Raising the Standard Of Lymphoedema Education is the mission statement of the newly established **JOBST® Academy**. In addition to free Lymphoedema Study Days where delegates receive a free Interactive Training in Lymphology CD, BSN Medical now offers a specialized training module in The Management of Lymphoedema of the Lower Limb that is accredited by the Thames Valley University.

To find out more about **JOBST®** products for the management of lymphoedema and the educational opportunities offered by the **JOBST®** Academy, visit the BSN stand.

® Trademarks of BSN Medical Ltd

### HADDENHAM

### Haddenham Healthcare

Problem Solving Compression Therapy

**Haddenham Healthcare is an independently owned company specializing in the treatment of lymphoedema.** Haddenham is a market leader in UK, and is now rapidly developing partnerships in international markets. Haddenham focus is on providing innovative and problem solving solutions to assist lymphoedema therapists in treating their patients - helping achieve clinical effectiveness and patient compliance.

Haddenham offers a complete range of compression garments to treat Lower limb, Upper Limb and Mid-Line Oedema – with wide selection of highly innovative fabrics, styles, colours, and options. Additionally Haddenham offer easy to use technical devices - such as Lower Level Laser and the unique LymphAssist Intermittent Pneumatic Compression system.

Solutions for treating bariatric patients include the FarrowWrap and Eto range of garments, as well as all the made to measure options available.

Treating children with lymphoedema with made to measure garments, be that circular knit, flat knit or Gottfried garments, consider a FarrowWrap or Kinesiology taping and of course don't forget their skin care!

Haddenham Microfine Toecaps – An off the shelf solution for treating toes!

**Drop by the Haddenham Stand to find out more and don't forget to attend 'Treating the Bariatric Patient' break out session…**

### medi

**medi is an international organisation manufacturing compression garments with offices in 12 European countries as well as production sites in the USA and Germany. The "medi" product is known in over 125 countries worldwide.**

Our special knowledge in Lymphoedema has led to the development of products which are as effective as possible yet are compatible with the everyday lives of lymphoedema sufferers.

With mediven flat knit options you can offer your patients high quality garments with an exceptional degree of versatility. You may already be familiar with our mediven esprit flat knit armsleeve and glove which provide high working pressure but remain soft and comfortable due to the two way elastic stretch.

mediven forte is the first seamless two way stretch hosiery garment offering maximum compression and stability which is also available as made to measure.

Quality products are the key to ensuring treatment is a lasting success.

You are cordially invited to attend the medi sponsored teaching session on Thursday morning after Plenary session G when Dr Shingale from Germany will be presenting innovative treatments of Lymphoedema patients that could be used in the Palliative care setting.

**medi UK Ltd**
**Plough Lane**
**Hereford**
**HR4 OEL**

**T: +44 432 373500**
**E: enquiries@mediuk.co.uk**

## JOURNAL OF Lymphoedema

**The Journal of Lymphoedema (JOL) provides peer reviewed evidence-based information for clinicians involved in all aspects of lymphoedema care.** Now entering its fifth year, the journal's biannual publications have helped to put lymphoedema on the map, contributing to the development of clinical practice and disseminating original research.

The journal is aimed at lymphoedema experts but retains an emphasis on patient involvement — the views of those with the condition are heavily represented in the peer-reviewed content, with a focus on physical and psychosocial issues.

The journal also provides guidance on service development in different healthcare settings across the world, both in developed and developing countries.

The journal's editorial board includes clinicians, academics and representatives of international lymphology groups, ensuring that the journal's content is truly representative.

The journal's recently launched website, www.lymphormation.org provides fully interactive education and information to keep lymphoedema clinicians abreast of the latest developments, both nationally and internationally.

In association with JOL, two unique conferences are to be held in Ascot on 20-22 April 2010 — Lymphoedema 2010 and Management of Skin Changes in the Lower Limb. These events provide an excellent opportunity to access the latest clinical information as well as network with colleagues from around the world.

Visit the Wounds UK stand to find out more about JOL and our conference.

## The National Lymphedema Network

**NLN**
**NATIONAL LYMPHEDEMA NETWORK**

**The National Lymphedema Network (NLN) is an internationally recognized non-profit organization founded in 1988 to provide education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphedema.**

The NLN is supported by tax-deductible donations and is a driving force behind the movement in the U.S. to standardize quality treatment for lymphedema patients nationwide. In addition, the NLN supports research into the causes and possible alternative treatments for this often incapacitating, long-neglected condition.

## h&r healthcare

delivering innovation

**H&R Healthcare Ltd are distributors of the highest quality medical devices sourced from leading manufacturers throughout the world.** We represent world class companies in Advanced Wound Management and Compression Hosiery.

**sorbion**
health needs care

Advanced Wound Dressings using Hydration Response Technology.
**www.sorbion.com**

**CAROLON**
graduated compression

Carolon are a world-leader in the manufacturer of medical hosiery, and are market leaders in the USA and Japan.
**www.carolon.com**

## SIGVARIS

LIFE FOR LEGS

**Sigvaris are the world leaders in Medical Compression: and the innovators.** in 1959 we invented the first modern compression stocking for Dr Sigg who was studying varices - hence the name SIGVARIS.

2009 saw us introduce 7 innovations in the compression garment arena - more than every innovation of other companies added together. Sigvaris Advance armsleeve was however the culmination of 3 years work.

Sigvaris Advance can truly be seen as the product of patients and nurses - every stage of the product's development has been suggested and tested by patients and nurses, and for the first time we can show with our clinical data that it reduces oedema whilst being soft and comfortable. It is bacteriostatic and unlike products with silver in them does not kill the good bugs on the skin or harm the environment when being washed. It has the newest grip top on the market for added comfort and reduction of allergy and is made of modal fabric, to keep you warm in winter and cool in summer. **Our goal was two fold, to help current sufferers and perhaps produce a sleeve that was comfortable enough to enable it to be used in the prevention of lymphoedema.**

## LSN

THE LYMPHOEDEMA SUPPORT NETWORK
*because lymphoedema matters*

**Lymphoedema can be a frightening and isolating condition and The Lymphoedema Support Network is the only national Charity in the UK providing information and support for those living with or affected by the condition.** Our youngest member is just three months old and our oldest well into their eighties! We run a telephone information and support telephone line, a website containing articles, patient experience stories and much more, produce a quarterly newsletter and a range of 22 fact sheets covering topics as diverse as reducing the risk of lymphoedema, holidays and travel and the management of cellulitis in lymphoedema. We work to raise awareness of lymphoedema, campaign for better national standards of care, support professional as they establish and develop services and, in partnership with other organisations, carry out research into best practice for the treatment of lymphoedema regardless of cause. The LSN work in partnership with the International Lymphoedema Framework Project and have run concurrent patient conferences alongside each of their conferences and wish them every success at Brighton and beyond.

## The Lindsay LegClub Foundation

**The aims of the Lindsay Leg Club Foundation (CRN 1111259) include both the dissemination of the principles of the socioeconomic Leg Club® model and the spread of Leg Clubs throughout the UK.** These principles and the benefits of community and patient led treatment have now been accepted at the top level of NHS with its policy to introduce commissioning of services to third parties.

As a Foundation we have experienced unfaltering public support: patients, volunteers and communities, and commendable (unconditional) support from the Foundations corporate Health Care partners. The Foundation has continuously worked in partnership with members of the public, Expert Patient groups, the Department of Health policy developers, NHS managers and Healthcare professionals with an aim to raise awareness of preventative management of all aspects of lower limb related problems. We have also promoted good practice by forging relationship with nursing and professional organisations / societies, patient and industry groups and in 2008 became an associated member of the European Wound Management Association (EWMA), iLegx and the Knee Foundation.

As part of the Third Sector, the Foundation firmly believes that the social Leg Club model of care can form the basis for the treatment of all chronic conditions in the community not just leg conditions.

**PULSE PRESS is an integral part of the MJS Group which has been producing IPC equipment for over 30 years.** The PULSE PRESS range of IPC offers the widest choice of garment styles and sizes available in the world. There are single, three, six and twelve chamber pumps and garments to suit every eventuality. In total we produce 48 different types of garments which range from a small stump up to the trouser garment.

New for 2010 are the children's garments and also the extra large bariatric garment range. These specialist patient areas are further supported with a custom made garment service.

All PULSE PRESS equipment is designed and manufactured in the UK. This total control allows us to quickly turn customer feedback into the real world products we produce for patients care.

The majority of IPC equipment produced by MJS Group is exported.

In the USA the 'Presssion' brand is supplied by DJO. MJS Group produces this equipment range for distribution into the USA and Canadian market place.

In Germany the 'Hydropress' brand has been produced by MJS Group for over twenty years and continues to be an influential supplier to their lymphedema patients.

**Advancis Medical is a UK based company offering a choice of dressings to promote progressive and acceptable healing throughout all phases of the wound healing process.** Our dressings are professional wound care products and provide solutions to wound management challenges. There are three categories:

**Activon® medical Manuka honey:** Advancis Medical is the leading medical honey product company and the first to introduce Manuka honey as a medical device. The Activon dressings: Activon Tulle®, Algivon®, Activon Tube® and Actilite® are antibacterial, debride and deslough, combat malodour and promote healing, the range now includes a moisturising balm with Activon honey called Actibalm®.

**Silfix® soft silicone:** This range comprises of Silflex®, Episil®, Episil Absorbent®, Advasil conform®, and Eclypse Adherent®. These are atraumatic wound dressings, addressing the issue of pain at dressing change. Wound contact dressings, absorbent and non-absorbent that protect the wound. The Silfix® range now includes Siltape® and Eclypse Adherent Sacral®.

**Advanced wound care dressings**

Other Advancis dressing technologies include high exudate management, fluid management, de-sloughing and moisture balance dressings in the form of Eclypse, Advadraw, Advadraw Spiral, Advazorb Plus and Adva-co. This now includes the innovative Eclypse Boot, a full lower leg absorbent dressing.

**Tel: 01623 751500 - Email: info@advancis.co.uk**

**www.advancis.co.uk**

**Credenhill, the leading specialist distributor of compression hosiery, is attending the ILF Conference for the first time this year.**

On their stand you will be able to see the new VENOSAN® 7000 range containing the revolutionary SeaCell® active fibres which have antibacterial and antifungicidal actions.

They will also be displaying application aids including the newly launched Dot Gloves from VENOSAN® and the EasySlide which is also available on FP10.

The Credenhill Made To Measure service is accessed by health professionals throughout the UK and offers a bespoke service designed to meet the needs of your patient – to learn more about how this service can provide for your clinic or hospital please visit us.

We will also be highlighting our retail website, **www.daylong.co.uk.** Here you will find a range of brands under one website, offering patients a real choice and value for money for all their compression hosiery needs.

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**PROMOTING PROFESSIONAL LYMPHOEDEMA SERVICES**

**The British Lymphology Society (BLS) is a medical charity, drawing its members from health care practitioners and Lymphoedema Therapists who are engaged in the treatment of Chronic Oedema and Lymphoedema.** The objectives of the Society are:

1)To advance education and knowledge in the field of lymphology and related subjects.

2)To foster interest in and co-ordinate a strategy for improving the management of chronic oedema, particularly Lymphoedema.

3)To produce and maintain a register of specialist centres in the UK and Ireland.

4)To benefit patients by improving the knowledge, expertise and skills of health care professionals treating them.

This year's BLS Annual Conference will be held in Manchester Town Hall from 3-5 October. Conference will highlight the increasing range of disciplines and treatment methods that play a role in the management and treatment of Lymphoedema. The keynote speakers will be Dr Andrea Cheville from Mayo Clinic, USA; and Dr Kathryn Schmitz from the University of Pennsylvania. Both will be addressing the Conference key themes – Prevention and Provision.

**For information about joining BLS and/or attending the Conference e-mail info@thebls.com – or visit the BLS website www.thebls.com**

**ImpediMed is a global company with offices in Australia, the USA, and the UK, which develops bioimpedance devices with a focus on medical applications for use in a variety of healthcare segments that are non-invasive, compact and portable, highly accurate, fast, simple to operate, and considerably cheaper than most existing alternatives.**

ImpediMed's L-Dex® devices are the only FDA, CE and TGA cleared devices that offer simple point of care, standardized and objective metrics to aid in the clinical assessment of lymphoedema. They enable medical professionals to provide preoperative clinical assessments and ongoing monitoring of patients for early signs of lymphoedema. This allows early, simple, cost effective treatment that can assist in preventing the progression of lymphoedema to irreversible forms, helping to improve the quality of life of patients and easing the substantial financial burden on patients and governments.

**Consistently setting new standards for lymphoedema care, Activa Healthcare continues to develop its range to provide the best products and treatments.**

Our nationwide lymphoedema training team provide practical training on full leg and arm bandaging using Actico cohesive, inelastic bandages. The cohesiveness of the bandage is designed to make the bandages stay put asthe limb volume decreases. Now with Mollelast digit bandage available on FP10, the team are pleased to train on finger and toe bandaging as well.

Actilymph hosiery has the compression values and stiffness to control oedema. The Actilymph range provides the clinical effectiveness demanded by healthcare professionals and also the comfort, fit and appearance patients prefer. By listening to the ever-changing needs and requirements of nurses and their patients, Activa recently introduced the longer length ActiLymph armsleeves and also now provides black ActiLymph hosiery in addition to the already popular sand colour.

**Activa are proud to be involved with the International Lymphoedema Framework and we look forward to meeting you on our stand.**

**EWMA is a multidisciplinary umbrella organisation linking European wound management associations together.** EWMA works to promote the advancement of education and research into the management of wounds.
Key activities include:
**1)** Development and coordination of a network of 46 national wound management associations in 35 European countries as well as international partner organisations. **2)** Educational activities including: a/ Development and maintenance of an education curriculum; b/ The EWMA University Conference Model (EWMA UCM) offering a teaching programme for wound management students during the EWMA conference; c/ The Teach the Teacher lifelong learning education programme for teachers of nursing students. **3)** The EWMA conference that annually, next in Geneva 26-28 May 2010, gathers more than 2,000 clinicians and other stakeholders for scientific discussions, industry presentations and educational activities.
**4)** Collaboration between clinicians, industry and policy decision-makers to create consensus and support implementation of recommendations for clinical trials. **5)** Advisory role in the Eucomed Advanced Wound Care Sector Group (www.eucomed.org). **6)** Research projects such as the Eastern European Leg Ulcer Project contributing to improving the evidence base for wound management activities in Europe.

**Delfin Technologies develops, produces and markets specialized instruments for skin and edema measurements.** Current products include the VapoMeter for TEWL measurements, the MoistureMeter SC for skin surface hydration measurements and the MoistureMeter D for tissue water changes in the deeper layers of the skin and subcutis.
Delfin instruments are scientifically validated and well established and they are renowned for their accuracy, reliability and user-friendliness. Customer organizations span over 30 countries on six continents and include universities, hospitals and other research organizations as well as pharmaceutical companies and testing laboratories.
The MoistureMeter D is a water-specific instrument for the local and non-invasive measurement of tissue water. The measurement is based on dielectric constant values that are directly proportional to the amount of water in the skin. The tissue dielectric constant (TDC) value is used in lymphedema research and increasingly also in the clinical setting and the assessment of lymphedema treatment efficacy.
The MoistureMeter D includes the main unit and four differently sized probes that measure to different depths of the tissue. The instrument also features wireless data collection to an easy-to-use computer program.
**www.delfintech.com**

# 2011 ILF CONFERENCE

## First Announcement

Date & Location for the 2011 ILF Conference will be announced during the Conference Dinner on Wednesday evening.

**We are particularly proud to announce that the 2011 ILF Conference will be centred around the launch of the**

## 2nd Edition of the Best Practice Document for the Management of Lymphoedema.

**More details available soon on www.lympho.org**

## World Alliance for Wound and Lymphedema Care (WAWLC).

*Dr J. McDonald,*

*Department of Dermatology and Cutaneous Surgery. Miller School of Medicine, University of Miami, USA*

**The mission** of WAWLC is to work in partnership with communities worldwide to advance sustainable prevention and care of wounds and lymphoedema in settings with limited resources. The objectives of the initiative:

1. To raise awareness of the importance of chronic wounds and lymphoedema, and their economic and social impacts.
2. To develop global policy on modern wound and lymphoedema management.
3. To support countries to develop the capacity necessary to utilize current knowledge on wound and lymphoedema in the care of patients.
4. To contribute to strengthening the health systems in affected countries in order to achieve objective #3.
5. To support research aimed at improving the management of wound and lymphoedema.

In pursuit of its mission, the WAWLC will focus on people, health and social systems, education, best clinical practices and research.

Its work will focus on six key pillars:

1. Advocacy
2. Resource mobilization
3. Global coordination and networking
4. Country support
5. Effective interventions and research
6. Monitoring and evaluation

**More information on www.wawlc.org**

## Bridging the Gap for Intervention: An International Construct

*N. Stout*

*Physical Therapist and Lymphedema Specialist. National Naval Medical Center, Bethesda, USA.*

*Dr. P. Brantus*

*Handicap International, France*

**Objective:**

- To highlight a basic construct for lymphoedema management from a societal perspective, relevant to the international community
- To demonstrate basic principles of lymphoedema management and their relevance to treating lymphoedema in all settings
- To outline an optimal approach for implementation of a comprehensive lymphoedema management program and to demonstrate to attendees how this can be modified to accommodate their unique setting.

**Method:** This session will highlight a construct for lymphoedema management that emphasizes basic principles of care including; skin hygiene, elevation, mobility, compression and education. Basic models for treating lymphoedema should emphasize a community-based intervention that is prospective in nature, ongoing and targets patients at highest risk for the development and/or progression of the disease. The construct can be modified and implemented regardless of the geographical or socioeconomic surroundings. Recommendations for health care provider education and dissemination of information will be provided.

## Rolling Out Filarial Lymphoedema Morbidity Control Treatment to Endemic Regions of India

*N. Tarur*

*Institute of Applied Dermatology, Kerala, India.*

**Objective:** Filarial lymphoedema, which leads to chronic disability, is endemic in 20 Indian states. Disabled patients from remote areas don't get access to morbidity control treatment. To fill this gap, Institute of Applied Dermatology (IAD) is rolling out its innovative low cost integrated treatment, that has proved effective in 1000 patients.

**Method and Results:** We propose a low cost, home based protocol integrating the best from Indian systems of medicine (Ayurveda, Yoga) and Biomedicine. Trained Skin Care Nurses in collaboration with local social empathetic groups are enabling effective penetration. Rollouts have already been launched in 2 endemic regions.

Rollouts, targeted to penetrate high density endemic regions, comprise four iterative phases:

1. Survey and education.
2. Health camps act as large scale generic counseling, communication, and motivation platforms. The establishment of peer groups; individual counseling for chronic patients; mass dissemination of easy self care activities like limb elevation, skin wash, phanta soaking, Yoga.
3. Multiple 14 day treatment workshops for 25-30 patients. Entire treatment protocol is provided with the support of a family member, thus enabling them to continue self care treatment at home.
4. Periodic follow ups and patient peer group discussions.

In this whole initiative, resource generation to treat poor patients remains a challenge.

**Conclusion:** Treatment methods will fit any environment: whether academic medical center or remote village. Each treatment component is cheap, easily provided after brief training, culturally sensitive, and capable of widespread compliance.

# Interactive Sessions and Skills Development Workshops

## TUESDAY
## SESSION A

| 13.45 - 15.15 | A1 | A2 | A3 | A5 | A6 |
|---|---|---|---|---|---|
| Title | **World Alliance for Wound and Lymphedema Care (WAWLC)** | **Bridging the Gap** | **Lymphatic Filariasis Morbidity Control: Presentation of cases** | **Overview of Exercise and Movements in Lymphoedema** | **Overview of Diagnostic and Measurement in Lymphoedema: Do you really know what you are measuring?** |
| Speakers | ***J. McDonald***<br>*Department of Dermatology and Cutaneous Surgery, Miller School of Medicine, University of Miami, USA* | ***N. Stout****<br>***Dr P. Brantus**** | ***Dr K.S. Bose****<br>***N. Tarur**** | ***Dr K. Johansson****<br>***J. Hidding*****<br>***Prof A. Cheville*******<br>***L. Jönsson******** | ***Prof N. Piller.*** *Director, Lymphoedema Assessment Clinic, Department of Surgery. School of Medicine Flinders University, South Australia* |
|  | **The objective of this Interactive Session is to encourage discussion on:**<br>**1)** Exactly how lymphedema teaching will be part of WAWLC.<br>**2)** Ideas as to how to address specific lymphedema problems in resource poor nations.<br>This Interactive Session will also be the opportunity to present some of the Haitian experience and the associated importance and significance of the WAWLC. | **The aim** of this session is to examine the common problems and solutions that exist in the management of Lymphoedema in developed and developing countries.<br>**The objectives** of the session will include discussion on the following areas :<br>**1)** How can the principles of Lymphoedema management be translated into different health care settings<br>**2)** What methods of assessment of health outcome could be developed that would contribute to a better global understanding of Lymphoedema<br>**3)** How can the international community of ILF support this work in developed and resource poor countries.<br>**The outcomes** from this session will contribute to the development of a minimum data set that can be used globally and the development of models of care transferrable to other health care settings. It will also inform the strategy the ILF will take in seeking to support the work in developing countries.<br>*Physical Therapist and Lymphedema Specialist, National Naval Medical Center, Bethesda, USA.<br>**Handicap International, France | **The objective of this Interactive Session is to present cases of Lymphatic Filariasis morbidity Control programmes.**<br>The expected discussions are:<br>**1)** Objectives of the programmes<br>**2)** Treatment methods<br>**3)** Access to management<br>**4)** Cost of management<br>**5)** Education, compliance and cultural issues<br>The expected outcomes are an exchange of ideas and solutions between participants but also a contribution to the development of ILF's Developing Countries Strategy (see abstract 1 p34).<br>*Principal, Administration & Communications, Institute of Applied Dermatology, Kerala, India.<br>**Institute of Applied Dermatology, Kerala, India. | **This session will consist of the following presentations:**<br>**1)** A review of evidence by A. Cheville (see abstract 2 p34)<br>**2)** A prospective study of leg lymphoedema exercise by J. Hidding (see Abstract 3 page 34)<br>**3)** A prospective study of weight bearing exercise for Breast Cancer Related Lymphoedema by K. Johansson (see Abstract 4 page 34)<br>**4)** A prospective study of pole-walking for Breast Cancer Related Lymphoedema by L. Jönsson (see Abstract 5 page 35)<br>*Lymphedema Unit, Lund University Hospital, Lund, Sweden.<br>**Zutphen, The Netherlands, Board member of NVFL.<br>***Associate Professor of Physical Medicine and Rehabilitation. Mayo Clinic, Rochester, USA.<br>****Lund University Hospital, Lund, Sweden. | **The objectives of this session are to:**<br>**1)** Indicate how the various measurement types can help in differential diagnosis between oedema, lymphoedema and other tissue swellings.<br>**2)** Show the pros and cons of the variety of types of measurement of lymphoedema<br>**3)** Indicate the importance of accurate and appropriate measurement of the progression of lymphoedema and of its treatment outcomes.<br>**4)** Help improve awareness that limb changes following treatment may be more than just fluid and that a poor outcome as measured by some change parameters may be a good one when measured using others.<br>**5)** Help you answer the questions:<br>- What should I measure? Fluids, fats, fibre, circumference or volume? The signs of a failing lymphatic system? Where and how the lymphatic system has failed?<br>- What is the right measurement tool for my situation? (Sole practitioner, Multi-disciplinary Unit, Hospital based).<br>- How can I get maximum clinical value out of my measurement with minimum time and effort?<br>**The session will consist of:**<br>**1)** Background Lecture<br>**2)** Demonstration of measurement of whole body bio-impedance.<br>**3)** Demonstration of measurement of segmental (limb) fluids.<br>**4)** Demonstration of measurement of local area fluids.<br>**5)** Demonstration of tissue tonometry and visco-elasticity.<br>**6)** Demonstration of limb volume and limb circumference determinations.<br>Subject to limitations of the equipment and time there may be an opportunity for workshop attendees to use some of it to gain a better appreciation of what each can offer. |

## Patients Support Network

*A. Wallace*

*Chair Lymphoedema Support Network, UK*

Brighton 2010 sees the launch of the ILFP/LSN focus document `Elements of an effective National Patient Organisation'. The LSN is the only National Lymphoedema Patient Support organisation in the UK and since its inception in 1991 has grown from a group of seven members with big ideas, to the UK's leading lymphoedema charity, still with big ideas. The LSN firmly believe that patient groups can make a real difference to the quality of life and levels of care that individuals with lymphoedema can achieve and that everyone living with the condition has the right receive support, information and to have a voice that is heard. This session will highlight what the LSN does to try and achieve this and the elements that have led to the LSN being recognised as the largest provider of information and support for lymphoedema patients in the UK. This is not to say we always get it right or have completed our task but rather that we hope sharing our successes, challenges and mistakes will allow others interested in developing their own groups to gather information, be encouraged and take something from our journey to assist them in theirs.

## Patient Empowerment: National Lymphoedema Frameworks

*A. Kennedy*

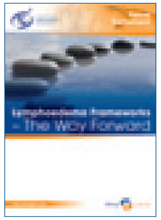
*Chair Lymphovenous Association of Ontario, Canada*
*Canadian Lymphedema Framwork Executive Committee member*

What started as a UK initiative in 2002, the International Lymphoedema Framework (ILF) is gaining momentum by sharing their expertise and resources to support National Frameworks around the world in developing their own long term strategies to improve the management of lymphoedema and related disorders in their respective countries.

Within the last 3 years alone, there are now more than eight countries in various stages of their framework development. The ILF believes that setting up and implementing a National Lymphoedema Framework is an evolutionary process with a unique formula involving a partnership of stakeholders and a proven methodology that includes 10 steps for success.

While each National Lymphoedema Framework is unique, what binds them together is the shared objectives of raising the profile of lymphoedema, placing lymphoedema management as a priority on national health care agendas, advocating for reimbursement of care and implementing and evaluating lymphoedema best practices. Each country belongs to the international lymphoedema community that collectively strives to improve the evidence base for treatment and ultimately improve the lives of lymphodemea sufferers worldwide.

Collaboration is at the heart of the ILF philosophy with each participating country contributing to global initiatives by sharing their knowledge and supporting the set up and work of other country frameworks. This interactive session, hosted by a member of the Canadian Lymphedema Framework, will introduce the ILF Frameworks Document, a 10 step approach to developing a national framework, followed by individual National Frameworks sharing their achievements, challenges and initiatives.



## Patient Perspective: A Global Advocacy Coalition

*S. Thiadens*

*Executive Director of National Lymphedema Network.*

**Objective:** Historically, patient viewpoints have been represented by doctors and other health care professionals. In the late `90's lymphedema (LE) activists began to rally and follow the successful models of other diseases.

**Method:** LE patients play a pivotal role by advocating for healthcare access and quality, research and patient rights. As a result of the activities of some inspiring passionate patient advocates, LE has come to the forefront in medical communities around the United States. LE advocates organize yearly Lymphedema D-days, support groups , write legislation, educate other patients and healthcare providers.

**Results:** Meaningful changes have been brought about by dedicated lymphedema advocates in areas of basic research, legislation, quality of Lymphedema care, outreach and support. Through persistence and belief in their ability to change the system, a handful of LE advocates have been instrumental in securing lymphedema treatment mandates in two states and have introduced a comprehensive lymphedema diagnosis and treatment mandate bill in the US Congress.

**Conclusion:** Ultimately a small group of passionate patient advocates have made a huge impact on the awareness, education and patient rights in the US. The time is here to join forces with all LE communities around the globe.

# Interactive Sessions and Skills Development Workshops

| 16.30 - 18.00 | B1 | B2 | B3 |
|---|---|---|---|
| Title | **How to develop a Patient Support Network** | **Lymphoedema Frameworks – The way forward** | **Patient Perspective: A Global Advocacy Coalition** |
| Speakers | ***A. Wallace*** *Chair Lymphoedema Support Network.*<br>***K. Friett*** *Chief Executive Lymphoedema Support Network.* | ***A. Kennedy***<br>*Chair Lymphovenous Association of Ontario. Canadian Lymphedema Framework Executive Committee Member.* | ***S. Thiadens***<br>*Executive Director of National Lymphedema Network.*<br>***B. Weiss*** *Lymphedema Patient Advocate.* |
| | **The objectives of this session are for delegates:**<br>- To understand the strategies to develop the elements of an effective National Support Network.<br>- To participate in open and realistic discussion about their own experiences and challenges in relation to developing National groups.<br>- To explore the potential of an International Lymphoedema Patient Groups Alliance, identifying advantages, challenges, possible models, and next steps.<br>**Session outline:**<br>**1.** Introduction<br>**2.** The LSN Story<br>**3.** Growing Membership<br>**4.** Managing the Organisation<br>**5.** Partnership working<br>**6.** Producing information<br>**7.** Income generation<br>**8.** Campaigning<br>**9.** Open table discussion<br>**10.** Potential of an International Lymphoedema Patient Group Alliance.<br>The document "Elements of an effective National Patient Organisation – The Lymphoedema Support Network" will be launched during this session. | **The objectives of this session are for delegates:**<br>- To understand the development process of a National Lymphoedema Framework.<br>- To hear the challenges and achievements of existing or scheduled Lymphoedema Frameworks.<br>- To share their experience.<br>The session will consist in a series of presentations from different countries, illustrating the different steps in the implementation of a Lymphoedema Framework.<br>**These presentations will be followed by a general discussion on the need:**<br>- To raise the profile of lymphoedema,<br>- To place lymphoedema management as a priority on national health care agendas,<br>- To advocate for reimbursement of care,<br>- To implement and evaluate lymphoedema best practices.<br>The document "Lymphoedema Frameworks – The Way Forward" will be launched during this session.<br>The following abstracts will be presented during this session:<br>Abstract 6, page 35<br>Abstract 7, page 35<br>Abstract 8, page 36 | **The objectives of this Interactive Session are:**<br>**1)** To review some of the lymphedema advocacy successes in the U.S<br>**2)** To discuss how they may be applied globally.<br>**The expected discussions are:**<br>- The International Lymphedema Advocacy Coalition (ILAC) which was formed in 2001 as an offshoot to the NLN and had the vision of bringing LE to the forefront around the globe. At that time 13 countries participated in a survey and expressed interest in a global coalition.<br>- The challenges of building a Global Programme.<br>- The concept of "Expert patient/advocate".<br>It is expected that one of the main outcomes of this Interactive Session will be the set-up of an ILF Patients' Advocacy Committee. |

| 16.30 - 18.00 | B5 | B6 | B7 |
|---|---|---|---|
| Title | **Yoga from India** | **Children with lymphoedema – Incidence and Treatment** | **IPC: Unravelling the Facts from the Fiction** |
| Speakers | ***Dr K.S. Bose*****[*]**<br>***Mr K. Vivekananda*****[**]**<br>***Mr Naveen K. Tarur*****[**]** | ***Prof E. Földi,*** *Földiklinik, Hinterzarten, Germany*<br>***H. von Zimmerman,*** *BSN Medical.* | ***C. Saggers,***<br>*Pulse Press, MJS Group, Barton-le-Clay, UK* |
| | The objective of this Skills Development Workshop is for delegates to understand the role and potential benefits of yoga in the management of lymphoedema.<br>Following the presentation of footages on yoga practice by patients, delegates will have the opportunity to practice yoga themselves.<br>[*] Principal, Administration & Communications, Institute of Applied Dermatology, Kerala, India.<br>[**] Institute of Applied Dermatology, Kerala, India. | The impact of lymphoedema on a child can be particularly traumatic, and the treatment options selected should therefore be tailored to cover all physical and psychological aspects of care.<br>The choice of compression garments will be very much dependent on the patient's individual circumstances.<br>There is now a wide selection to choose from; ready-to-wear, custom-fit, circular-knit, flat-knit – and indeed, within each of these general categories, further options to consider. For example, Jobst® Elvarex® custom-fit flat-knit garments are now available with or without latex, and in softer fabric options, particularly suitable for younger patients. Today, there are an increasing number of options available to treat children with lymphoedema. Working together, the Clinician and patient and carer can select the optimum solution and monitor / adjust accordingly. This session aims to discuss the incidence of lymphoedema, amongst children, the treatment options available, and the ideal choice of compression garments.<br>**This session is sponsored by BSN Medical.** | **The objective** of this Skills Development Workshop is for participants to learn more about Intermittent Pneumatic Compression (IPC).<br>The following questions will be raised during this session :<br>**1)** Why use gradient sequential Compression with IPC ?<br>**2)** Are Custom-made IPC garments needed ?<br>Participants will also have the opportunity to try and practice on the Pulse Press range of IPC Systems.<br>**This workshop is sponsored by Pulse Press.** |

**08.00 - 08.45**

# Plenary Session C: Children with Lymphoedema

## The Genetic Basis of Lymphoedema in Children

*Prof P. Mortimer,*

*Professor of Dermatological Medicine, St Georges Hospital, London, UK.*

Lymphoedema in children is usually caused by a fault in the development of the lymphatic system. Lymphatic vessels fail to form, or work, properly. This usually has a genetic, but not necessarily inherited, basis. The identification of causal mutations for different forms of lymphoedema and then understanding the mechanistic fault provides the opportunity for corrective treatments in the future.

## Launch of the ILF focus document : "Care of Children with Lymphoedema".

*Prof I. Quéré,*

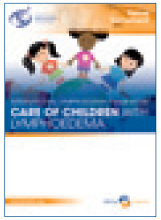
*Professor of Vascular Medicine, Montpellier 1 University, Montpellier, France.*

Childhood lymphoedema is a rare, orphan disease that has received little attention outside a small number of specialist centres.

Its management is made particularly difficult by a lack of awareness concerning the treatment of this disease among the general practitioners, paediatricians and geneticists responsible for its diagnosis.

As a consequence, it was considered essential, during the first conference of the ILF, to launch an international campaign to raise awareness. The ILF focus document "Care of Children with Lymphoedema" is a first step aimed at highlighting the major areas and topics essential for the optimisation of lymphoedema management and quality of life in children. It presents clinical aspects of the disease in children, describes the impact of lymphoedema on the quality of life of affected children and their families and tries to identify the organisation required to optimise care; finally it addresses some of the questions most frequently asked by affected children, their families and healthcare professionals.

This document is a working document designed to be the first in a series of publications leading to the establishment of a Consensus Document on Best Practice in the Management of Children with Lymphoedema.



## Managing the child with lymphoedema

*Dr J. Todd,*

*Physiotherapist Consultant in Lymphoedema, Leeds Teaching Hospitals NHS Trust, UK.*

This presentation will provide an overview of methods used to treat the child with lymphoedema, with an emphasis on working with parents and families in the development of treatment programmes.

### Management strategies and child development

Treatment approaches will be set within the context of child development and discuss how treatment goals can be achieved within this framework. There will be an opportunity to explore questions and challenges to treatment – especially as the child reaches teenage years. Current best practice will be explored, as well as products that are available to help in the treatment of the child with lymphoedema.

### Evidence based practice?

To date, there is little evidence on which to develop best practice in the management of the child with lymphoedema. The C2 Interactive Session will provide the opportunity to explore some of the unanswered questions. This will include working towards a consensus on the goals and priorities to work towards

### Conclusion

The C2 Interactive session will discuss lymphoedema treatment approaches within the context of a child development framework. Although evidence to support best practice is limited, there will be an opportunity to explore current practice and identify areas for future work and service development.

| 08.45 - 10.15 | C1 | C2 |
|---|---|---|
| Title | **Case Studies of Children with Lymphoedema** | **Management of Lymphoedema in Children and Young Adults** |
| Speakers | ***Prof P. Mortimer***<br>*Professor of Dermatological Medicine, St Georges Hospital, London, UK* | ***Dr J. Todd**** <br>***P. Sanderson***** <br>***Prof I. Quéré****** |
| | This Interactive Session will consist in the presentation and discussion of a series of cases of lymphoedema among children.<br><br>**Please note that participants in this session are more than welcome to bring some specific children cases for discussion.** | This Interactive Session will be the opportunity for the speakers to expand and exchange with the audience on the following subjects:<br><br>**J. Todd:** Adaptation of treatment to the child development – evidence based practice ? - service development.<br><br>**I. Quéré:** Quality of life – psychosocial issues (see Abstract 9 p36).<br><br>**P. Sanderson:** Challenges for clinicians to engage young patients (see Abstract 10 p36).<br><br>This Interactive Session should be one of the first steps towards the future publication of an ILF Consensus document on the Best Practice for the Management of Lymphoedema in Children and Young Adults.<br><br>*Physiotherapist Consultant in Lymphoedema, Leeds Teaching Hospitals NHS trust, UK<br>**Manager, Mercy Health Lymphoedema Clinic, East Melbourne, Australia<br>***Professor of Vascular Medicine, Montpellier 1 University, Montpellier, France. |

| C5 | C6 | C7 |
|---|---|---|
| **Moving the Pregnant Patient** | **Managing Complex Skin Problems in Lymphoedema** | **Writing for Publication** |
| ***M. Lauret-Roemers***<br>*oedema physiotherapist, oncologyphysiotherapist, Utrecht, The Netherlands.* | ***D. Doherty***<br>*Clinical nurse specialist, St Georges Hospital, London, UK.* | ***D. Glover,***<br>*independent medical editor and writer. Managing editor, ILF.* |
| **Subject:** Pregnancy, varices and lymphoedema: Causes, consequences and physiotherapeutic strategies.<br>**Introduction:** Pregnancy is a risk factor in developing varices. Within 5-20% of pregnant patients develop varices during their pregnancy. The patient can suffer from pain, paresthesia and painful contractions in the legs during the night, and oedema in the foot, ankles and legs is a very known complication. The complaints are very similar to the Chronic Venous Insufficiency of the legs, and often other signs of venous pathology are found. During the pregnancy, there are a lot of hormonal changes. Therefore the quality of the blood vessels, the blood pressure, the bloodcirculation and also the lymphdrainage change.<br>**Aim:** making clear:<br>**A)** influence of pregnancy on getting varices or oedema<br>**B)** the role of the oedema physiotherapist :<br>***1)*** prevention and treatment of varices and oedema<br>***2)*** self management for the pregnant patient?<br>***3)*** The importance of good garments<br>***4)*** exercises for pregnant patient with varices or oedema<br>**Methods:** This workshop will focus on how varices appear during pregnancy, how hormonal changes influence the blood circulation and lymph drainage, why it is so important to use good garments for the legs, and performance of exercises with these groups of patients. In the last part of the workshop, participants will do the exercises in order to experience the movements and the discomfort of a pregnant belly. | **The objective** of this Skills Development Workshop is to address a range of skin management issues: dry skin, hyperkeratosis, folliculitis, papillomatosis, lymphorrhoea, eczema/dermatitis and fungal infections.<br><br>**Outcomes:** Principles o maintaining good skin integrity, identifying varying skin presentations with lymphoedema, management of presenting skin conditions. | Participants will be given an overview of the principles of both medical and non-medical writing. Specific attention will be paid to case study presentations and the writing of research papers.<br><br>The general `do's and don'ts' will be presented, and reflected in examples taken from medical and other literature.<br><br>A brief overview of the medical publishing process will also be given. |

10.45 - 11.30

# **Plenary Session D:** The Bariatric Patient

## The Bariatric Patient: Complex case management - chances and limitations of the conservative approach

*Prof E. Földi, Prof M. Földi, T. Bertsch*
*Földiklinik, Hinterzarten, Germany.*

**Background:** The prevalence of obesity is constantly increasing in the western hemisphere. In the same way, the prevalence of accompanying diseases, such as obesity related secondary lymphedema, is also increasing. According to previous data, the success of dietary approaches to severe obesity (BMI > 40) is limited. Therefore, the development of a complex case management, including conservative and in selected cases surgical measures, is necessary.

**Objective:** We established an interdisciplinary case management approach for patients with severe obesity in our specialized Hospital for lymphology.

**Methods:** Patients are admitted to the Földiklinik for the diagnosis and treatment of lymphedema. In patients diagnosed with lymphatic diseases and severe obesity, i.e. BMI > 40, we apply a multimodal, interdisciplinary diagnostic and treatment approach. Diagnostics include a thorough history-taking, a general medical, endocrinological and metabolic check-up, as well as a psychological and psychosocial evaluation. According to the specific finding in the patient, the conservative treatment includes: medicamentous treatment of underlying respective accompanying diseases, nutritional coaching, physiotherapy and supervised sport programs, complex decongestive therapy, and psychological support. In patients without specific contraindications, bariatric surgery is suggested to the patients after a successful conservative pretreatment.

**Results:** The preliminary results will be demonstrated.

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## Surgical approach to Lymphoedema in Severe Obesity

*Prof B.Terry,*
*Associate Professor of Surgery. University of Missouri Medical Center. Columbia. USA.*

Lymphoedema is a comorbidity of severe obesity and is acquired. It is a product of the duration of severe obesity and the cardiac response to that disease. An understanding of the pathophysiology of the cardiac response is the result of work by JK Alexander and FH Messerli. One can then be guided in management knowing these principles.

Cellulitis and ulcers, necrotizing fasciitis and sepsis, become mortal threats and challenge conservative management with compression techniques which must continue unceasingly.

Increased blood volume with high flow requirements require greatly increased cardiac output. This leads to LV chamber dilation and eccentric hypertrophy. At some point in time LV wall tension causes afterload pressures equal to the 4th power of the LV radius. Pulmonary dysfunction and dependent edema occur and with time lymphoedema appears by peripheral obstruction (also central) plus inflammation effects.

Alpert, MA ; and Terry, BE have demonstrated in severely obese patients who sustained surgical weight loss that the cardiomyopathy reverses. This answers the dilemma in treating the acquired lymphoedema of severe obesity. Indeed if surgical therapy is accomplished before the late stage of lymphoedema this comorbidity can be prevented.

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## Skin Changes in the Bariatric Patient

*Dr M. Flour,*
*University Hospital Leuven, Belgium*

**Objective: Are there specific parameters to identify/classify the skin changes in morbidly obese edematous patients ?**
Lymphedema is a common feature in obese patients, including thickening of the skin, papillomatosis, deep skin folds with intertrigo. Is this true secondary lymphedema due to impaired lymphatic drainage or is there more to consider ?

**Method: Literature review of pathophysiology of these tissue alterations**
Literature reviews on obesity-induced tissue changes and their physiopathology were compared to those in true chronic lymphoedema.

**Results: Obesity may induce skin changes very similar to those seen in chronic lymphoedema**
Skin changes described in obese patients include thickened skin with marked dermal edema, obesity-associated lymphoedematous mucinosis, severe localized lymphoedema forming large pedunculated masses, and a chronic inflammatory state in the fat and other tissues with perivascular inflammatory infiltrate manifesting clinically as a cellulitis with characteristic peau d'orange.

**Conclusion: Management of morbidly obese patients with lymphoedema is a multidisciplinary project**
Weight loss is the major objective, as well as follow-up by an endocrinologist for treatment of hyperandrogenism, insulin resistance, and other metabolic disturbances. Adequate shoe ware and insoles will support mobilisation, like compression treatment which is a real challenge on obese limbs. Personal hygiene and prevention of infection are points of primary concern.

# Interactive Sessions and Skills Development Workshops

| 11.30 - 13.00 | D1 | D2 | D3 | D5 | D6 | D7 |
|---|---|---|---|---|---|---|
| Title | **Complex Case Management using Conservative Approach** | **Complex Case Management using Surgery** | **Complex Psychosocial and Clinical Problems in the Management of Morbid Obesity** | **Exercise for Lymphedema Treatment** | **Managing Wounds in the Patient with Oedema: The Role of Negative Pressure Wound Therapy** | **Treating the Bariatric Patient** |
| Speakers | ***Prof E. Foeldi**, Medical Director, Foeldiklinik Hinterzarten, Germany.*<br>***S. Ellis**, Nurse Consultant Lymphoedema, St Georges Hospital, London, UK.* | ***Prof B. Terry,***<br>*Associate Professor of Surgery, University of Missouri Medical Center, Columbia, USA.* | ***Dr M. Flour,***<br>*University Hospital Leuven, Belgium.* | ***A. Hendrickx*, N. Kool** , G. de Rijk***, T. Zee******* | ***Dr D. Keast***<br>*Lawson Health Research Institute, London, ON, Canada.* | ***A. Wright*, G. Close**, K. Rutjens***, P. Jamieson******* |
|  | The objective of this session is for delegates to understand and discuss the challenges, the possible results, but also the limitations in the complex case management of the Bariatric patient using conservative approaches.<br>The session will consist of the presentation and discussion of several cases. | The objective of this session is to discuss, using case presentation, the role that surgery plays in the treatment of patients with lymphoedema and morbid obesity. The session will consider the risks as well as the potential benefits and the importance of multi-disciplinary working. | **Objective of the session:**<br>To discuss - in an interactive way - the several aspects of morbid obesity, lymphedema and related problems. Clinical cases will be presented to introduce a general discussion.<br>**Expected discussions:**<br>Personal hygiene, being dependent on others for basic activities of daily living, finding clothes, risk of social isolation especially for young people, finding a job, mobility and the lack of it, skin problems and complications, bad habits and compensational behavior, general health concerns, challenges for care givers, compliance issues…<br>**Expected outcomes:** Inform and get informed on how to solve some of these challenges, take home some ideas for your practice. | **Introduction:** Exercise and movement is one of the key elements of successful treatment of Lymphoedema. Exercise can have different objectives like increase in range of motion, increase in muscle strength etc. Exercise that focus on improvement of function of lymphatics should involve the same parameters as manual lymphatic drainage. The lymphatic system is well organised in the skin, where manual lymphatic drainage grips are usually preformed. Exercise that enhances movement of the skin in a similar way MLD does, will stimulate pump function of lymphatics.<br>**Aim:** This workshop will give a clear idea of exercises that could help patients with arm- or leg lymphoedema. Health care professionals will be able to inform and advise their patients in performing exercises that could be beneficial for their lymphoedema.<br>**Method:** In this workshop we will demonstrate how to perform exercises with these characteristics. Participants will do the exercises in order to experience the movements.<br>* Physiotherapist at Nij Smellinghe hospital Drachten, Netherlands / ** Physiotherapist-teacher physiotherapy HvA, Amsterdam, Netherlands / *** Physiotherapist-teacher physiotherapy HU, Utrecht, Netherlands **** Physiotherapist, De behandelbank Arnhem, The Netherlands | **Objective:** By the conclusion of this presentation the participant will be able to discuss the role of negative pressure wound therapy in the management of wound in the patient with oedema.<br>**Discussion:** In this interactive workshop an approach to chronic wound management will be described. The role of negative pressure wound therapy will be discussed focusing on the 2008 Consensus Statement published by the World Union of Wound Healing Societies. Using specific case based discussions the participants will have an opportunity to explore negative pressure wound therapy in relation to patients with wounds and oedema. | **Objectives of the session :**<br>- To explore treatment options available,<br>- To discuss methods tried by participants and the outcomes achieved,<br>- To share knowledge,<br>- tTo learn new techniques for fitting this group of patients in graduated compression garments.<br>**This session is sponsored by Haddenham Healthcare**<br>*MD Haddenham Healthcare<br>**Clinical Manager Haddenham Healthcare<br>***Clinical Specialist, Varodem<br>****Sales, Haddenham Healthcare |

## Advances in the Surgical Treatment of Breast Cancer and its Impact on Lymphedema

*Dr J. Cormier[1], Dr K. Hunt[2], and Prof J. Armer[2]*

*1University of Texas M.D. Anderson Cancer Center, Houston, TX, USA. 2University of Missouri Sinclair School of Nursing, Columbia, MO, USA.*

**Objective:** The treatment of breast cancer has evolved significantly over the last 30 years. The objective of this review is to examine the impact of changes in surgical treatment on the incidence of lymphedema.

**Results:** Patients with invasive breast cancer can be effectively treated with breast-conserving therapy, which includes segmental mastectomy followed by radiation therapy to the breast, or total mastectomy with or without axillary lymph node dissection (ALND). Both mastectomy (and breast conserving therapy) and ALND contribute to the development of lymphedema. The addition of radiation treatment to a dissected axilla significantly increases the incidence of subsequent lymphedema up to 45%. Sentinel lymph node (SLN) biopsy is a technique that is used to identify patients with nodal metastases in order to spare those with negative SLNs from ALND. Reported estimates for lymphedema incidence following SLN biopsy are 6%. However, follow-up is short in the majority of SLN studies. The technique of axillary reverse mapping (ARM) has recently been introduced to identify the lymphatic drainage of the arm in order to preserve those lymphatics during the SLN biopsy procedure. Evaluation of this technique is ongoing.

**Conclusion:** Contemporary surgical treatment for breast cancer has become less invasive, likely resulting in a reduction in the risk of developing lymphedema. However, with the overall increasing number of breast cancer survivors, clinicians must remain vigilant in the early detection and referral of patients showing early signs of lymphedema. Furthermore, as advances in cancer treatment emerge, their impact on lymphedema must continually be examined.

## The Pathophysiology of Breast Cancer Related Lymphoedema

*Prof P. Mortimer,*

*Professor of Dermatological Medicine,*
*St Georges Hospital, London, UK.*

Lymphoedema following breast cancer treatment (BCRL) is caused fundamentally by interference to lymph drainage routes through surgery and/or radiotherapy but the exact mechanism is unclear. BCRL is considered due to obstruction of lymph drainage at the axilla but recent research suggests the pathophysiology is more complicated. Women who develop the highest lymph flows post surgery are most at risk of developing subsequent arm swelling. We propose that some women have a constitutive/genetic predisposition to BCRL through higher lymph flow `exhausting' lymphatic vessel pumping.

## Subjective oedema : does it exist ?

*Prof P. Lievens, A. Tassenoy, J. Lamote,*
*Research Unit of Lymphedema of the Vrije Universiteit, Brussels, Belgium.*

Depending on the measurement technique and the definition of oedema, literature mentions an incidence of arm swelling after axillary lymph node dissection for breast cancer from 10 to 37%. The subjective sensation of oedema is described in 54% of these patients.

**Aim:** The purpose of our research is to examine whether structural changes occurred in the subcutaneous tissue that could explain these subjective complaints.

**Method:** Two female cadavers with unilateral breast amputation and axillary dissection were studied. The dermal and the subcutaneous layer of both arms were visualized with high frequency ultrasonography, magnetic resonance imaging and spectroscopy and tissue biopsies were taken for histological evaluation.

**Results:** Ultrasound imaging shows a hyperechogenic sub cutis and a slightly increased thickness of the dermal and subcutaneous layer. The fat-to-water relationship in adipose cells is higher at the operated side measured by MRS. Tissue dissection revealed structural adipose tissue changes, confirmed by microscopically sample evaluation.

**Conclusion:** The complaints that patients have, even if there is no measurable oedema, can be explained by important changes of the subcutaneous tissue.

We suggest that these complaints should be taken serious and that a preventive physiotherapeutic treatment should be standard procedure in order to prevent these tissue changes.

## Occurrence and Impact of Lymphedema Following Breast Cancer Treatment

*Prof J. Armer[1], Dr B. Stewart[1], and Dr J. Cormier[2],*

*1University of Missouri Sinclair School of Nursing, Columbia, MO, USA and 2University of Texas M.D. Anderson Cancer Center, Houston, TX, USA.*

Lymphedema is an under-recognized, progressive, life-long condition estimated to impact 2-3 million people in the United States alone, and secondary lymphedema following breast cancer treatment accounts for the majority of cases in the developed world.

**Objective:** To define the incidence, risk factors, symptoms, and quality of life (QOL) outcomes associated with various degrees of post-operative limb volume change (LVC) following breast cancer treatment in a cohort of survivors followed at a Midwestern USA cancer center.

**Methods:** A prospective cohort study was performed obtaining serial limb volume measurements using an infra red laser perometer on 269 women undergoing surgery for breast cancer. Four groups were created based on maximum LVC: none <5.0%, mild 5.0-9.9%, moderate 10.0-14.9%, and severe 15.0%. Symptoms (Lymphedema and Breast Cancer Questionnaire) and QOL (Functional Living Index-Cancer) were assessed at baseline and every three-to-six months and annually, respectively.

**Results:** Findings revealed 81 (30.1%), 70 (26.0%), and 14 (5.2%) survivors developed mild, moderate, and severe LVC, respectively. Increases in body mass index ($p<0.001$) and post-operative complications ($p=0.002$) were associated with increasing LVC. Lower QOL scores were associated with a moderate LVC (OR = 3.72, 95% CI, 1.29–10.73, $p=0.015$) and post-operative infections (OR=5.04, 95% CI, 1.73–14.70, $p=0.003$).

**Conclusions:** LVC at 5.0% occurs in up to 61.3% of breast cancer survivors and is associated with a significant increase in symptoms. These treatment outcomes significantly impact quality of life in cancer survivorship. Surveillance of at-risk persons for limb volume change and symptom experience beginning at time of treatment and regularly thereafter is recommended as the standard of care for breast cancer survivors.

## Multi-center Survey of Lymphedema following Breast Cancer Treatment

*Dr K. Kitamura*

*Vice Director, Kyushu Central Hospital, Fukuoka, Japan*

**Objective:** The aim of this study was to survey the incidence and risk factors of lymphedema through retrospective multi-center research. This study was granted by the Japanese Society of Breast Cancer.

**Method:** Lymphedema onset was defined as a 10 mm or more laterality on the affected arm in any one site. Between January 2007 and March 2008, 1379 post-mastectomy patients were collected from 51 domestic facilities. Four sites on both arms were measured in all patients. Questionnaires and medical card reviews were also performed. A Kruskal Wallis' test and a Logistic regression model were used for analyses.

**Results:** The mean onset period was 3.9 years. 51% of the patients were diagnosed with lymphedema. 21% of the patients with lymphedema experienced cellulitis and 53% of them had recurrent history. 49% of patients who had lymphedema did not recognize their onset. The incidence of lymphedema even in patients treated by sentinel node biopsy alone was 34.1%, and about 9.5% of them had evident edema. Multivariate analysis revealed that obesity, extended surgical procedures, no adjuvant therapy, regional irradiation and no prophylactic instruction were independent factors for lymphedema onset after breast cancer treatment.

**Conclusion:** These elements of our research and our social actions have led to the reimbursement of compression garments and bandages for postoperative patients with lymphedema after breast surgery since April 2008. Prophylactic instruction fee has also been approved.

## Arm Lymphoedema in a Cohort of Breast Cancer Survivors 10 Years after Diagnosis

*Dr K. Johansson[1], E. Branje[2],*

*1 Department of Health Science, Lund University, Lund, Sweden*
*2 Department of Oncology, Lund University Hospital, Lund, Sweden.*

**Introduction:** Arm lymphoedema is a frequent complication after breast cancer treatment. Early diagnosis and treatment is considered important for successful management of breast cancer related arm lymphoedema (BCRL). The purpose was to identify BCRL incidence, time of onset, progression/regression and associated factors 10 years after breast cancer diagnosis.

**Material and Methods:** Two-hundred-ninety-two patients treated with axillary node dissection and radiotherapy were included in this retrospective study. A total of 111 diagnosed with BCRL (incidence 38,7%). Of these women 98 were followed for up to 10 years after BCRL diagnosis. Forty consecutive patients registered with no BCRL were included in the control group. BCRL was defined as an increase in arm volume difference ≥5% and an increased thickness of subcutis. Follow-up was performed twice a year, including assessment of lymphoedema relative volume (LRV) by water displacement method and compression treatment. Additional intensive treatment was given if LRV increased by more than 5% since the previous visit or exceeded 20% in total.

**Results:** Mean LRV was 8,1±3,6% at diagnosis and 9,0±6,7% at last follow-up measurement (mean 48,9±39,2 months) with no significant difference. There was no difference in progression of LRV between groups with early versus late diagnosis (within or after 12 months postoperatively), small (5-<10%) versus large (≥10%) LRV at time of diagnosis, or regular (at least twice a year) versus non-regular treatment. More BCRL patients with large LRV at diagnosis (15,8%), exceeded LRV ≥20% during follow-up time, than patients with small LRV at diagnosis (10,1%).

**Conclusion:** BCRL can be identified at an early stage both in regard to time of diagnosis after operation and to edema volume, and that edema volume can be kept at a low level for at least 10 years. Small LRV at time of diagnosis appears to be more important for minimizing the progression of LRV than time of diagnosis after operation.

## Do Patients after Sentinel Node Biopsy require the same Physiotherapy Guidance as Patients after Axillary Lymph Node Dissection (ALND)?

*R. Peleg, Physical Therapy Department, Tel Aviv Medical Center, Tel Aviv, Israel.*

**Objective:** The most common breast cancer surgeries are complete mastectomy, or lumpectomy, including the axillary lymph nodes. Axillary lymph node dissection (ALND) is the standard treatment for staging the nodes and provides information necessary for determining the appropriate treatment. Accordingly, ALND constitutes the principal prognostic instrument for breast cancer patients. However, surgical removal of lymph nodes can have short-term and long-term effects on daily activity, including limited shoulder movement, weakened arm muscles on the affected side, lack of feeling or sensitivity (neuropathy), pain and lymphedema.

In recent years, a less invasive method has become widespread. In this procedure, the sentinel node biopsy, the first one to three nodes draining the lymphatic fluid from the area of the growth are removed and examined in the laboratory. If the sentinel nodes are free of cancer cells, there is a high probability that the other nodes are not cancerous and do not need to be removed.

**Method:** A literature search via PubMed (from 2000) was undertaken using the search terms sentinel node biopsy, morbidities, lymphedema and physical therapy guidelines.

**Results:** Indeed this method generates less complications and more rapid recovery after surgery. There are also indications of complications arising from removal of the sentinel node(s), particularly lymphedema.

**Conclusion:** Consequently, the question of whether a patient after such surgery requires the same physiotherapy guidance as a patient after ALND is important.

## Self-care Limitations related to Self-care Measures to Reduce the Risk of Lymphedema in Patients with Breast Cancer Surgery

*Prof J. Armer, Dr C. Brooks, and Dr B. Stewart,*
*University of Missouri Sinclair School of Nursing, Columbia, MO, USA.*

**Objective:** We will report the findings from the second (companion study) component of a Lance Armstrong Foundation (LAF)-funded pilot study that examined perceptions of limitations related to self-care measures to reduce lymphedema risk in breast cancer survivors. The original study examined the feasibility of an educational intervention to reduce the risk of lymphedema of post-breast cancer surgery survivors. The survivors participating in the LAF-funded pilot study reported inconsistency or inability in performing the self-care measures taught in the educational intervention.

**Methods:** The companion study was conducted with these participants to determine their perceptions of self-care competencies or power of self-care agency. Qualitative analysis of the data from this companion study was conducted to examine the specific limitations in performing lymphedema risk-reduction self-care measures.

**Results:** Findings from this companion study analysis indicated that the majority of factors limiting self-care were related to conditions and situations other than a lack of knowledge or skills in performing self-care measures. These conditions and situations include limitations related to energy, patterns of living, overriding competing interest in managing time for self-care measures, inadequate resources, and physical limitations.

**Conclusions:** These findings suggest a more comprehensive approach is needed if patients are to engage in self-care actions to reduce lymphedema risk. This includes understanding the concepts of self-care and personal support actions that can help nurses to design supportive-educative care systems that assist patients in over coming limitations in the estimative, transitional, and productive phases of self-care necessary to reduce lymphedema risk. Therapists and nurses need to be cognizant of the patient's needs for personal support to engage in result-achieving self-care. This includes needs for affirmation, comfort, tangible aid, empathy, and clarification, in addition to education about self-care actions. (See abstract 11 p36)

## Compression as a useful modality for Risk Reduction and to Prevent Early Stage Progression

*N. Stout,*
*Physical Therapist and Lymphedema Specialist. National Naval Medical Center, Bethesda, USA.*

**Objective:** To demonstrate the evidence-base of compression garments use in early stage lymphoedema.
To present early evidence that conservative compression interventions are an important tool in a comprehensive risk-reduction program.

**Method:** This session will highlight the importance of risk-reduction through ongoing prospective surveillance and monitoring of patients at risk for lymphoedema. Compression therapy may be a useful component of a risk-reduction program if the patient is diagnosed with sub-clinical or early lymphoedema. The compression recommendations will be outlined and the model for prospective surveillance highlighted.

## What are the Best Metrics for Lymphedema Assessment?

*Dr J. Cormier[1], Dr J. Feldman[2]*
*1University of Texas M.D. Anderson Cancer Center, Houston, TX, USA.*
*2 Prtzker School of Medicine, Chicago, USA*

**Objective:** It has been exceedingly difficult to establish methods for identifying and measuring lymphedema in the clinical setting that are objective, accurate, reproducible, and convenient.

**Methods of Assessment:** Diagnostic imaging as a direct measure of lymphatic flow (through lymphoscintigraphy) or tissue changes (through magnetic resonance imaging or computed tomography) has only proven useful in select cases. Indirect measures of limb volume change have been the most commonly used. Water displacement is cumbersome, and hygiene is an issue. Circumferential limb measurements are the most commonly used methods but protocols vary. Furthermore, there is little consensus on the optimal metric (cm or volume calculations) for reporting.
Several newer devices have been introduced for the assessment of lymphedema. The perometer is an optoelectronic volumetry device that uses infrared light and an array of optoelectronic sensors to assess limb volume by creating a two-dimensional silhouette of the limb. Bioelectrical impedance spectroscopy (BIS) is a new technique that measures the electrical resistance (impedance) of fluids in the tissues to determine extracellular fluid changes that precede volume changes. The results of BIS are expressed as impedance ratios. The tonometer is another device that measures the resistance of tissues to compression and quantifies compliance, which can then be correlated with limb swelling.

**Conclusions:** The varying incidence of lymphedema reported in the literature is in part due to inconsistent measurement. Each measurement approach and criteria has its own advantages and disadvantages, and researchers and clinicians should be aware of those issues when using them.

# Interactive Sessions and Skills Development Workshops

| 15.30 - 17.00 | E1 | E2 | E3 | E4 |
|---|---|---|---|---|
| Title | **Enhancing Supportive-Educative Nursing Systems to reduce risk of Post-Breast Cancer Lymphedema** | **Compression as Prevention** | **How should Lymphedema be measured?** | **Meditative Exercise** |
| Speakers | ***Prof J. Armer[1]***<br>***Dr C. Brooks[1]***<br>***Dr B. Stewart[1]*** | ***N. Stout***<br>*Physical Therapist and Lymphedema Specialist. National Naval Medical Center, Bethesda, USA.* | ***Dr J. Cormier,*** *M.D. Anderson Cancer Center, Houston, TX, USA.*<br>***Dr J. Feldman***<br>*2 Prtzker School of Medicine, Chicago, USA* | ***M. McClure***<br>*Magee Women's Research Institute, Pittsburgh, PA, USA.* |
| | **Objectives:**<br>**1)** Recognize competing philosophical frameworks of compliance, adherence, and practice of self-management.<br>**2)** Describe the role of motivational interviewing techniques in caring for patients with lymphedema.<br>**3)** Apply principles of motivational interviewing to a patient situation.<br>**Activities:**<br>**a)** Videotaped observation of motivational interviewing scenario.<br>**b)** Group discussion of cases of noncompliance, nonadherence, and sub-optimal self-management by lymphedema patients.<br>**c)** Role play of patient scenarios using motivational interviewing with two partners (therapist, patient, observer roles).<br>**d)** Large group discussion and reporting outcomes to group.<br>[1] University of Missouri Sinclair School of Nursing, Columbia, MO, USA. | The objective of this session is to develop the concept of Compression as a useful modality for risk reduction and to prevent early stage progression.<br>By the end of this Interactive Session, participants should have gained a much better understanding of the importance, the practicalities, and the challenges of :<br>**1)** Prospective surveillance<br>**2)** Monitoring of patients at risk<br>**3)** Compression recommendations. | **Objectives:** The objective of the session is to:<br>**1)** Examine the current metrics used in the assessment of lymphedema;<br>**2)** Discuss the advantages and disadvantages of the most commonly used approaches;<br>**3)** Contribute to the knowledge of members/participants of the application of various lymphedema techniques available.<br>**Activities:**<br>**a)** Survey audience members on currently used metrics<br>**b)** Demonstration of various measurement techniques<br>**c)** Topic of Interactive Debate – PRO / CON: Standardized circumference protocols should be adopted as the "gold standard" measurement tool for the assessment of lymphedema<br>**d)** Group discussion of the advantages and disadvantages of various techniques<br>**Outcomes:** Upon completion of this program, participants should be able to:<br>**1)** Understand the difference between accuracy and reliability and how this relates to measurement metrics;<br>**2)** Discuss the controversies in the assessment of lymphedema in clinical practice and research;<br>**3)** Describe the advances in the metrics of lymphedema assessment;<br>**4)** Understand the critical elements for the evaluation of new technologies as they emerge. | This session will start with the presentation of the Breast Cancer Recovery Programme© (BCRP©), an evidence based exercise/relaxation program for women with Breast Cancer Related Lymphedema (see Abstract 12, page 37) Participants will then have the opportunity to practice Meditative Exercise using the 17 minute FLOW BCRP video and related instructions.<br>A general discussion on the benefits, but also the limitations, of the BCRP© program will follow.<br>One of the expected outcomes of this session will be the wider dissemination of the BCRP© program. |

| 15.30 - 17.00 | E5 | E6 | E7 |
|---|---|---|---|
| Title | **Group Processes in Self Management** | **Footwear Solutions for Swollen Feet** | **Tissue Dielectric constant : a novel tool for oedema assessment** |
| Speakers | ***T. Zee****<br>***H. Venema*****<br>***E. Brouwer****** | ***Dr M.J. Geyer,*** *School of Health and Rehab, Sciences, University of Pittsburgh, Pittsburgh, USA*<br>***S. Cavanaugh,*** *Allegheny and Chesapeake Physical Therapy, Pittsburgh, USA.* | **A. Immonen,**<br>*Delfin Technologies, Kuopio, Finland.* |
| | **Introduction:** The course "teach the teacher in self management" organised and set up by the SLCN In the Netherlands trains therapists in organising group sessions for patients with lymphedema to enhance self management.<br>This workshop will emphasize on the group dynamic processes. The following items will be shown:<br>- What is the extra value of working in groups<br>- What are the do's and don'ts of working with a group<br>- Which attitude and behaviour does the teacher need to support this group process<br>- What is the need of communication (verbal and non verbal)<br>- How to handle critical questions en "difficult" patients<br>- How to handle emotions in a group session<br>**Aim:** The workshop will give health professionals a better understanding of the benefits of working with groups and how to create one themselves.<br>There will be enough time to exchange experiences and ask questions.<br>**Method:** By means of a short introduction and with the help of video moments about working with groups, showing in an interactive way all the above mentioned subjects. Participants will get some exercises to do and work in groups on the subjects.<br>*fysio- en oedeemtherapeut, De behandelbank Arnhem, The Netherlands / **coach/trainer, Trots Coaching, Groningen, The Netherlands / ***organiser and board member of the Dutch Lymphology Network and SLCN, Drachten, The Netherlands | **Objective:** To inform health professionals of the principles of foot assessment and footwear prescription.<br>Evaluation of the swollen foot and the provision of appropriate footwear is a critical component of lymphoedema patient management that is too often neglected, both during and after successful treatment. While ill-fitting shoes can be a curse to most, they are a frequent source of serious morbidity in those with lymphoedema.<br>**Method:** Interactive session with hands-on practicum. Step-by-step instructions will be provided for how to complete a comprehensive foot evaluation; evaluate a worn shoe; measure for shoe size; select an appropriate shoe; test for shoe fit and patient function; and achieve the best fit for a foot with special needs. A case-based review will be provided to reinforce the principles.<br>**Results:** the participant will be able to :<br>1) properly evaluate patients for footwear needs<br>2) provide a number of properly-fitting footwear solutions.<br>**Conclusion:** Don't forget the need for proper footwear in long-term lymphoedema management. Applying the basic principles of assessment and shoe fitting will prevent unnecessary morbidity and improve the function of patients with lymphoedema. | **Objective:** The objective of the workshop is to give the participants information of the use of tissue dielectric constant (TDC), an electrical parameter of a biological tissue and a measure of tissue water content in relation to lymphoedema and the local assessment of oedema.<br>**Discussion:** The TDC can be measured utilizing the novel MoistureMeterD device which offers localized and non-invasive measurements of virtually any body site. Study results and examples will be given on the variation of TDC values between body areas, on lymphatic and control arms and before and after lymphoedema treatment. The workshop participants will have the opportunity to perform hands-on measurements of TDC with the MoistureMeterD device. Emphasis will also be given to the assessment of how the TDC measurement could greatly benefit the lymphoedema community in terms of objective and practical measurements in comparison to current subjective means of measurement, for example girth measurements and water displacement methods.<br>**Outcome:** After the workshop the participants will have a good understanding how TDC measured with the MoistureMeterD could benefit lymphoedema research and potentially the clinical practice and the assessment of lymphoedema treatment efficacy.(see abstract 13 p37)<br>**This workshop is sponsored by Delfin Technologies.** |

## Clinical Manifestations and Diagnosis

*Dr I. Forner-Cordero*
*Physical Medicine and Rehabilitation specialist, University Hospital La Fe, Valencia, Spain.*

Lipedema is characterized by symmetrical swelling, pain and frequent hematomas in lower limbs which mainly affects women.

**Aim:** to perform a systematic review of the available literature about lipedema, given the lack of knowledge and little evidence about this disorder.

In my experience, from 843 patients seen in the unit since 2005, lipedema represents the 18.8% of the patients with lower limb edema. Diagnosis of lipedema is usually made clinically. Symmetric edema in lower limbs, with deposit of fatty tissue in the hips and legs, usually appears at puberty and often affects several members of the same family. The differential diagnosis has to be done with Lymphedema, obesity, lipohypertrophy and phleboedema. There are fundamental differences between Lymphedema and Lipedema: Lymphedema may be uni or bilateral, while lipedema is bilateral. In Lymphedema Stemmer sign is often positive, while in lipedema it's negative, the feet are spared and the fat deposits begin abruptly above the malleoli. Lymphedema is usually painless, whereas lipedema causes pain on palpation. Lipedema causes bruising easily. Complementary tests can provide data on the differential diagnosis of the lipedema and its severity: blood tests, Duplex ultrasounds and Lymphoscintigraphy.

## Aetiological and Pathophysiological Features of Lipoedema

*Dr G. Szolnoky*
*Dept of Dermatology and Allergology. University of Szeged, Szeged, Hungary.*

**Objective:** We intended to study the most prominent lipoedema hallmarks and their response to complex decongestive physiotherapy (CDP) therefore were interested to see the effects of CDP+intermittent pneumatic compression (IPC) on capillary fragility (CF) (an important factor in hematoma development) and pain. We also aimed to measure large blood vessel characteristics of lipoedema patients.

**Method:** CDP comprised once daily manual lymph drainage, intermittent pneumatic compression at 30 Hgmm pressure and multilayered short-stretch bandaging performed throughout a 5-day-course. Volumetry was performed in accordance with Kuhnke's disc model or optoelectronic measurement, CF was evaluated upon the count of vacuum suction method (VSM) induced petechiae and pain was measured with a 10-item questionnaire, Wong Baker Faces and visual analogue scale (VAS) prior and subsequent to therapy cycles. CF was also measured in lipoedema and obese persons. Aortic distensibility (AD) was calculated upon echocardiography.

**Results:** Decongestive therapy resulted in a significant reduction of limb volumes in both CDP and CDP+IPC groups, of the number of petechiae and pain severity ($p<0.05$; respectively). VSM might be an easy-to-use tool in differentiating between non-complicated obesity and lipoedema. There was a notable difference in AD between lipoedematous and control groups.

**Conclusion:** Beyond marked edema reduction, CDP considerably diminishes CF and pain in lipedematous legs which may also have on impact on further surgical treatment. VSM and and the measurement of AD might play a role in differential diagnosis.

## Understanding Lipedema; Adapting Treatment Thoughtfully

*S. Norton*
*CDT Clinical Instructor, Norton School of Lymphatic Therapy, Matawan, USA*

**Objectives:** *Following the completion of this session participants will be able to;*

- Appreciate lipedema as a multifaceted disease requiring therapeutic adaptations
- Differentiate pure lipedema, from lipo-lymphedema, lympho-lipedema, and lipedema with venous edema
- Adapt therapeutic modalites constructively based upon the clinical presentation
- Understand the psychological and emotional elements of lipedema which complicate treatment strategies.

**Method:** This presentation will be conducted with PowerPoint slides. At the discretion of the session chair, attendees will be given opportunites to ask questions of the speaker.

**Overview:** Lipedema is a poorly understood and distinct disease process which attracts patients to lymphedema clinics that offer services for limb reduction. Often times lipedema presents in combined forms such as lipedema with chronic venous insufficiency, lipo-lymphedema, lypho-lipedema or in pure form and as such must be addressed with appropirate therapeutic intensity and select modalities. With lipedema comes a predictable set of psycho-emotional stressors which create a personality type that must also be manged with sensitivity and care. This session will strive to clarify the role of conventional lymphedema therapy (modalites of CDT) in the care of this often combined lymphatic insuficiency.

## Food and Exercise – The Key to Living with Lipoedema

*K. Havens-Galer,*
*Patient with Lipoedema, UK*

**Objective:** *Making better choices for our health.*
I wish to share my personal journey in understanding the impact anti-inflammatory nutrients and pro-inflammatory anti-nutrients have on my body, and of the impact that my food choices have on my living with lipoedema. Coupled with the right types of exercise, the choice to make food and exercise the core of my treatment helps me take some control in life with positive results.

**Method:** *A personal recount of living with lipoedema.*
By discussing my history with lipoedema I hope to help the young sufferer; to educate them, to offer them hope and to give them the chance to make their own positive choices and, just maybe, alter the progression of this disease.

**Results:** *'You have ankles now!'*
Trust me, that's a big thing when you suffer with this condition. By making the choice to create a regime of functional weight training and anaerobic conditioning, coupled with a food intake of that is balanced, nutrient filled and anti-nutrient devoid, and undertaking necessary surgeries, I believe I look and feel the best I have in 20 years.

**Conclusion:** *It's not just a 'diet'; it's a way of life.*
I believe anyone facing any type of acute or chronic condition can take charge of their own health. Having taken many options in my fight with lipoedema, I have found the right nutrition along with the right kind of exercise is the key to managing my lipoedema.

## Surgical Management of Lymphoedema

*Dr A. Munnoch,*
*Consultant Plastic Surgeon, Dundee, Scotland.*

Debulking surgical procedures either excised all the lymphoedematous tissue (including skin) and covered the limb with skin grafts (Charles procedure or variants) or they excised some of the skin and subcutaneous tissue in a staged procedure, leaving lymphoedematous tissue behind (Sistrunk, Homans or variants). While Miller reported successful long-term results in 30 out of 38 patients, others have reported the adverse psychological impact of such extensive surgery & scarring on the patients (Young, BLS Meeting Oct 2009). The Charles procedure does have a role in the management of genital lymphoedema, with Modolin reporting successful results and improvement in function and QoL. While debulking surgeries still have a role in the developing world, far better results can now be obtained with liposuction.

Microsurgical techniques attempt to restore the lymphatic drainage. One such technique is lymph node transplantation (Becker and more recently Lin). A groin flap containing lateral lymph nodes is inserted into the axilla (Becker) or placed on the arm (Lin) with microvascular reconstruction of the artery & vein. No lymphatic surgery is undertaken. Both groups have described a reduction in limb volume, Becker reporting complete resolution of lymphoedema in over 50% of her patients, with the others showing improvement. Lin reported an average of 50% reduction in their patients. Lymphoscintigraphy has shown varied functionality of the transplanted lymph nodes. The number of patients reported is small, and the effectiveness of the surgery is not clear.

Current research may result in free lymph nodes being transplanted with lymphatic regeneration supported by angiogenic factors in the future.

## The Role of Liposuction in the Management of Lymphoedema.

*Dr H. Brorson,*
*Senior Consultant Plastic Surgeon, Malmoe University Hospital, Malmoe, Sweden.*

**The abstract for this presentation will be made available before the session.**

## Reconstructive Microsurgery in the Treatment of Lymphoedema using Lymphatic Grafts

*Prof. R. Baumeister,*
*University of Munich, München, Germany*

**Objective:** Most of the lymphedemas within Europe are caused by locally interrupted lymphatic vessels e.g. after surgery, radiation and trauma. Therefore like in other parts of the vascular system reconstruction using a bypass should be the treatment of choice.

**Method:** Advanced microsurgery enables us to perform lympho-lymphatic anastomoses and to use lymphatic vessels for bypass procedures. Lymphatic grafts can be harvested from the patients thigh in a length up to 30 cm.

In case of an interruption in the axilla the grafts are connected with ascending lymphatic vessels at the upper arm and descending lymphatic vessels at the neck.

In case of an unilateral edema of the lower extremity the grafts remaining attached at the inguinal lymphnode of the healthy leg are transposed to the edematous thigh via the symphysis and anastomosed there with ascending lymphatic vessels.

**Results:** From June 1980 through January 2010, 343 patients have been treated (195 lymphedemas of upper, 138 lymphedemas of lower extremities, 10 penile and scrotal lymphedemas).

A significant reduction in volume was seen also in long term follow-up studies over more than 10 years. A significant improvement of the lymphatic function was measured using lymphoscintigraphies, reaching also normal values in a specific group of patients. Long term patency of the lymphatic grafts could be demonstrated more than 10 years after surgery using indirect lymphography and Lymph-MRT.

**Conclusion:** Lymphatic autografts are able to improve significantly or even to restore the lymphatic flow.

## Microsurgery in the Treatment and Prevention of Lymphatic Disorders

*Prof C. Campisi, Prof F. Boccardo.*
*S.Martino Hospital. Genoa, Italy*

**Purpose:** To report a wide clinical experience in the microsurgical treatment of peripheral lymphedema, underlying the opportunity of an early treatment and prevention to obtain the best long term results.

**Methods:** More than 1800 patients with peripheral lymphedema have been treated with microsurgical techniques. Derivative lymphatic micro-vascular procedures recognize today its most exemplary application in multiple lymphatic-venous anastomoses (LVA), and particularly in the end-to-end telescopic technique, that allows to avoid any contact between lymphatics and the blood stream. For cases of such severity to contraindicate a lymphatic-venous shunt, reconstructive lymphatic microsurgery techniques have been developed (autologous venous grafts or lymphatic-venous-lymphatic-anastomoses - LVLA). Objective assessment was undertaken by water volumetry and lymphoscintigraphy.

**Results:** Subjective improvement was noted in 87% of patients. Objectively, volume changes showed a significant improvement in 83%, with an average reduction of 67% of the excess volume. Of those patients followed-up, 85% have been able to discontinue the use of conservative measures, with an average follow-up of more than 10 years and average reduction in excess volume of 69%. There was a 87% reduction in the incidence of cellulitis after microsurgery.

**Conclusions:** Microsurgical lymphatic-venous anastomoses have a place in the treatment of peripheral lymphedema and should be the therapy of choice in patients who are not sufficiently responsive to nonsurgical treatment. Improved results can be expected with operations performed earlier at the very first stages of lymphedema and the primary surgical prevention of secondary lymphedema.

# Interactive Sessions and Skills Development Workshops

| 08.45 - 10.15 | F1 | F5 | F6 | F7 |
|---|---|---|---|---|
| Title | **The Role of Surgery in the Management of Lymphoedema.** | **Pilates for Lymphoedema** | **Education Forum** | **Compression Bandages and Movement** |
| Speakers | ***Dr A. Munnoch[*]***<br>***Prof C. Campisi[**]***<br>***Prof R. Baumeister[***]***<br>***Dr H. Brorson[****]*** | ***C. Pike**, Lymphoedema Specialist Physiotherapist. Singleton Hospital. Swansea. Wales - Chair of the British Lymphology Society.* | ***M. Sneddon,** Head of School, Nursing & Health Care, University of Glasgow, Scotland* | ***N. Kool[*]***<br>***G. de Rijk[**], G. Strik[***],***<br>***E. Wijbenga[****],***<br>***T. Zee[*****]*** |
| | The objective of this session is for participants to understand and discuss the challenges, the possible results, but also the limitations in the use of the different surgery techniques for the management of lymphoedema.<br>It will consist in a series of case studies.<br><br>*Consultant Plastic Surgeon, Dundee, Scotland.<br>** Professor of Surgery, S. Martino Hospital, Genoa, Italy.<br>*** University of Munich, München, Germany.<br>**** Senior Consultant Plastic Surgeon, Malmoe University Hospital, Malmoe, Sweden. | This session is an introduction to what Pilates is, and how it could be of benefit to yourself and your patients. It's a simplified, very gentle exercise and movement routine that is aimed at improving a person's core strength and thus enabling better movement of the limbs.<br><br>The benefits for people with lymphoedema includes promotion of the central lymph pump by means of diaphragmatic breathing, and promotion of the muscle pump through the gentle action routine of the exercises. It is also very useful in encouraging your patient to try new positions especially following surgery and radiotherapy. | The objective of this session is to review the Challenges of building international standards of Education for Lymphoedema.<br><br>Participants will be asked to contribute to this Forum by describing existing Education Programmes, by exchanging on the pros and cons of international standards and by contributing to the definition on how to move forward the ILF project of building international standards of Education for Lymphoedema. | **Introduction:** Compression therapy is an essential part of successful treatment of lymphoedema. Using bandages is an accepted way to create pressure on an extremity. The use of devices to measure the amount of pressure that is created by a bandage is not common yet.<br>**Aim:** Participants can practices the skill of applying a short stretch bandage of the lower leg. Measuring the pressure will give more insight of the effects of the compression bandage. The alterations in pressure during movements will increase the insight in the significance of movement when compression therapy is applied to a patient.<br>**Method:** In this hands-on workshop a method of applying a bandage of the lower leg is demonstrated. Participants will practices this method on each other. There will be opportunity to measure the amount of pressure that occurs under the bandage and the alterations in pressure when movements of the lower leg are made.<br><br>*Physiotherapist-teacher physiotherapy HvA, Amsterdam, Netherlands / **Physiotherapist-teacher physiotherapy HU, Utrecht, Netherlands / ***Physiotherapist de Haak, Almere, Netherlands ***Nurse at dermatology department at Nij Smellinghe hospital Drachten, Netherlands / *****Physiotherapist, De behandelbank Arnhem, Netherlands |

10.45 - 11.30

# **Plenary Session G:** The Palliative Patient

## “What do I say?”: Communicating with Palliative Patients who have Lymphedema

*Dr A.Towers,*
*McGill University Health Centre, Montreal, QC, Canada.*

This presentation will start addressing the issues that will be developed during the G1 Interactive Session :

- Skills and attitudes for better therapist presence.
- Creation of a positive and healing relationship with patient.
- Palliative patients needs.
- What to say ?
- Use of silence.
- MLD as a communication tool. Challenges and stresses of dealing with palliative patients.
- Strategies for promoting health caregiver self care and stamina.

## Assessment of Oedema in Advanced Cancer

*Dr V. Keeley,*
*Consultant in Palliative Medicine, Derby Hospitals NHS Trust, Derby, UK.*

Oedema is reported to occur in about 20% of patients with advanced cancer. (Teunissen et al, 2007). However, it may only be one of a number of symptoms experienced by patients with advanced disease.

The oedema may be of complex multifactorial aetiology e.g. lymphatic damage from previous surgery/radiotherapy, metastatic lymphadenopathy, extrinsic venous compression (including vena caval compression), deep vein thrombosis, hypoalbuminaemia, immobility, anaemia, ascites, and drug effects. It can also be extensive (especially in advanced pelvic cancers) and associated with pain, recurrent cellulitis, lymphorrhoea and ulceration. It can have a significant impact on a patient’s quality of life (loss of independence and mobility; effects on body image; difficulty in micturition with genital oedema, etc.).

An understanding of the aetiology in each patient is important in determining the appropriate management.

Assessment should be aimed at:
seeking potential “correctable” or “improvable” factors e.g. anaemia, ascites, drug effects.
considering the overall symptom burden (other symptoms may be more important to the patient than the oedema).
understanding the patient’s priorities and wishes.
Taking into account the patient’s overall condition and likely prognosis (a complex prolonged treatment regimen may not be appropriate).

As a result of detailed assessment appropriate goals of treatment can be defined. For many patients, this is likely to be a “palliative” approach aimed at relieving discomfort, rather than an intensive treatment aimed at reducing limb volume.

It is particularly important in advanced disease that the likely benefit of treatment exceeds the burden.

## Managing Fungating Wounds: An Overview

*Dr D. Keast,*
*Lawson Health Research Institute, London, ON, Canada.*

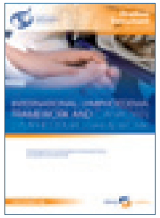
**Objectives:** By the conclusion of this presentation the participant will be able to describe an algorithm which can be used as a clinical decision support tool when managing fungating wounds in the palliative patient.

**Discussion:** The Wound Bed Preparations algorithm can be adapted for use with fungating wounds. Clinicians need to clearly establish diagnosis, address patient centred concerns such as odour, exudate, bleeding, wound related pain and cosmesis. Local wound care may involve debridement of non-viable tissue, managing bacterial loads and exudate management through effective dressing selection. A brief over view of strategies for each of these topics will be presented.

## Launch of ILF Document: « The Management of Lymphoedema in Advanced Cancer and Oedema at the End of Life »

*J. Simmons, Macmillan Lymphoedema Project Lead, The North London Cancer Network, and Education Project Officer, The British Lymphology Society*

This ILF Position Document aims to provide clear clinical advice on the management of oedema and its associated complications at the end of life. Specialist therapeutic interventions are defined, centred in the palliative care ethos of multidisciplinary care to reduce symptoms and associated psychological distress, improve quality of life and reduce the attendant risks.
Internationally, we need to develop minimum datasets to fully gauge the impact of oedema at the end of life and work with End of Life Care initiatives to ensure equitable access to treatment for all.
The goals of treatment within the palliative setting are different than traditional lymphoedema therapy. A careful balance must be maintained, treatments adapted and overall benefit to the patient carefully judged. Therapy must be patient centred and regular evaluation is vital for detection of new contraindications, such as development of thrombosis and changes in overall condition. The pain principles of the care approach are outlined in Box 1.
This document represents an international approach to standardising care for these patients. This document was led by the Canadian Lymphedema Framework in partnership with the ILF as part of a strategy to address all aspects of Lymphoedema management.



## Creative CDT

*Prof A. Cheville,*
*Associate Professor of Physical Medicine and Rehabilitation. Mayo Clinic, Rochester, USA.*

The palliative setting frequently requires creative adaptation of CDT due to co-existent symptoms, psychological distress and physical impairments. In addition, the overarching goal of palliative care is the best quality of life for the patient. The, at times, onerous demands of CDT may erode quality of life to an extent that the CDT outcomes do not justify the associated treatment burden.
This presentation will briefly outline the principal challenges to administering CDT in the palliative setting including but not limited to:

- realistic and human goal setting,
- symptom control,
- caregiver integration,
- neurological deficits,
- diagnostic ambiguity.

In addition, how the logistics of palliative care delivery may impact CDT feasibility will be addressed.
This brief talk will set the stage for the following interactive session during which we will pool experience to address the many challenges to controlling lymphedema in terminal illness.

# Interactive Sessions and Skills Development Workshops

| 11.30 - 13.00 | G1 | G2 | G3 | G4 | G5 | G6 | G7 |
|---|---|---|---|---|---|---|---|
| Title | **"What do I say?": Communicating with Palliative patients who have Lymphedema** | **Assessment of Oedema in Advanced Cancer** | **Creative CDT** | **Managing Fungating Wounds: A Case Based Discussion** | **Salsa for Lymphoedema** | **ILF Minimum Dataset** | **Innovative Treatments of Lymphoedema Patients** |
| Speakers | **Dr A.Towers,** *McGill University Health Centre, Montreal, QC, Canada.* | **Dr V. Keeley,** *Consultant in Palliative Medicine, Derby Hospitals NHS Trust, Derby, UK.* | Dr A. Cheville*, S. Norton** | **Dr D. Keast** *Lawson Health Research Institute, London, ON, Canada.* | **C. Pike,** *Lymphoedema Specialist Physiotherapist. Singleton Hospital. Swansea. Wales - Chair of the British Lymphology Society.* | **Prof P. Franks,** *Centre for Research and Implementation of Clinical Research.* | **Dr F.-J.Schingale,** *Lympho-Opt Klinik, Pommelsbrunn-Hohenstadt, Germany* |
| | **Objective:** This workshop will help improve therapist and patient satisfaction and outcomes in dealing with lymphoedema patients who are at the end of life.<br>**Method:** Interactive workshop This workshop will examine skills and attitudes that will lead to better therapist presence when dealing with palliative patients who have advanced disease and who may have multiple causes of suffering. The types of questions we will examine are: What are the elements that facilitate the creation of a positive and healing relationship between therapist and lymphœdema patient in a palliative setting? What do these patients need from a health caregiver? What does a therapist say when faced with difficult existential situations?<br>We briefly review the literature on the needs, fears and expectations of palliative patients and their families, and we will discuss particular communication skills, including the use of silence and the use of MLD as a communication tool. We will examine the challenges and stresses of dealing with this population and review strategies for promoting health caregiver self-care and stamina. The workshop will offer opportunities for case discussion and self-reflection. | Participants in this session will have the opportunity to develop their knowledge and share their experience on :<br>**1.** aetiology<br>**2.** assessment of oedema in advanced cancer<br>**3.** treatment options and quality of life | **The objectives of this session are :**<br>to offer pragmatical and viable solutions to the myriad issues that confront clinicians endeavoring to manage lymphedema in the palliative setting.<br>to demonstrate the scope of Creative CDT in the management of Palliative patients with lymphoedema.<br>**The logistics of palliative care and why they matter in treating lymphedema will be discussed.**<br>Dr Cheville will outline practical strategies for managing symptoms, neurological impairments, psychological morbidity, and edema unrelated to lymphatic compromise, all of which may significantly impact the success of palliative CDT. The relevance of terminal disease to specific CDT components, e.g. MLD, will be discussed.<br>Dr Norton will share with the participants his knowledge and expertise in specific alterations to CDT by using case studies and practical demonstrations.<br>*Associate Professor of Physical Medicine and Rehabilitation. Mayo Clinic, Rochester, USA.<br>**CDT Clinical Instructor, Norton School of Lymphatic Therapy, Matawan, USA | **Objectives:** By the conclusion of this presentation the participant will be able to apply a clinical decision support algorithm to the management of fungating wounds in the palliative patient.<br>**Discussion:** In this session a case based approach will be used to discuss the management of fungating wounds specifically addressing:<br>**1.** Approaches to managing odour<br>**2.** Strategies to manage exudate<br>**3.** Managing bacterial loads in malignant wounds<br>**4.** Quality of life issues<br>**5.** The various types of wound related pain and how these can be controlled<br>**6.** The role of palliative chemotherapy and radiation treatment<br>**7.** Strategies to manage bleeding | Dancing is once again becoming a recognised form of exercise with an element of fun. The objective of this session is to demonstrate how lymphoedema patients of all ages and mobility abilities can participate in salsa sessions to improve their muscle pump and mobility, thus optimising lymph drainage.<br>Participants at this session will have the opportunity to practice salsa themselves. | ILF is currently developing a Minimum Dataset as a means of synthesizing current practice within a variety of geographical and clinical areas.<br>The ILF Minimum Dataset will be used to :<br>• Provide information on a large cohort of patients.<br>• Compare patients across different healthcare settings and geographical locations.<br>• Evaluate the clinical effectiveness of current/new services.<br>• Evaluate the cost-effectiveness of current/new services.<br>The objectives of this session are to share experience in the development and implementation of minimum datasets and to identify possible synergies between ILF and other organisations.<br>The expected outcome is a contribution to moving the ILF Minimum Dataset forward. | The objective of this Skills Development Workshop is to present innovative treatments of Lymphoedema patients that could be used in the Palliative care setting.<br>The expected discussions will be on the specific requirements of these patients in terms of management and the specific challenges of compression.<br>The expected outcomes of this session are a better understanding of the specific needs of the palliative patients and the opportunity to include these innovative treatments into the participants' practice. |

## Chronic Oedema

*Prof P. Mortimer,*
*Professor of Dermatological Medicine, St Georges Hospital, London, UK.*

Tradition teaches that 90% of tissue fluid is reabsorbed through the veins and the remaining 10% drains via the lymphatic. Recent evidence suggests this to be wrong and in most vascular beds (except gut and kidney) all interstitial fluid generally drains via the lymphatic. This indicates all chronic oedema represents lymphatic failure and treatment should always consider improvement in lymph drainage.

## Limb Oedema due to Immobility

*Dr M.J. Geyer*
*University of Pittsburgh, Rehabilitation Science & Technology Department, Pittsburgh, PA, USA.*

### Immobility and the challenge of chronic edema

Chronic lower extremity edema is a common, but often underestimated, secondary complication of immobility that has increased in conjunction with life expectancy for wheelchair-dependent persons. Prospective studies have shown that the presence of multiple secondary complications such as wounds, infections, and depression are strong predictors of premature death in wheelchair-dependent populations. Chronic edema exacerbates or may be the direct cause of multiple secondary complications.

All individuals who use wheelchairs as their primary means of mobility are at increased risk for development of chronic edema that may subsequently convert to lymphoedema. In addition to the usual factors contributing to chronic edema, wheelchair-dependent persons are subjected to chronic obstruction of lymphatic and venous flow due to excessive pressures from dependent limbs and improper wheelchair fitting. Lifelong control of chronic edema and prevention of associated complications in immobile persons presents unique challenges (loss of calf pump, loss of sensation, inability to apply bandages due to functional impairments, obesity, cost and limited availability of personal care assistants, etc.). Evidence for solutions to the challenges presented by disabled, immobile persons is unacceptably limited and further research is needed. This session will present the rationale for and the components of a research project focused on immobile persons with chronic edema currently being conducted at the University of Pittsburgh.

## What is the Evidence that Compression is Helpful in Chronic Oedema?

*Dr. I.Forner-Cordero,*
*Physical Medicine and Rehabilitation specialist, University Hospital La Fe, Valencia, Spain.*

Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values. Following the Oxford Center for Evidence Based Medicine, the studies can be classified, depending on their design, in five levels of evidence. The research in the long term effects of compression in chronic lower limb lymphedema is scarce. Most of the studies concerning the effects of compression are performed in venous disorders or breast cancer related lymphedema.

The aim is to summarize the evidence available in different aspects of compression therapy in chronic lower limb edema: systemic and local effects, effectiveness in volume outcomes and adverse effects.

## Limb Volume Reduction in the Clinic

*Dr M. Clark*

*Chief Executive, Lindsay Leg Club Foundation, UK.*

**Objective:** Stimulate discussion regarding practical issues in leg volume measurement

The measurement of changes in limb volume plays a key role in both research studies and in the documentation of the progress of treatment. However while the research community seeks accurate and reproducible measurements these may be harder to perform in a busy clinic environment. This presentation will review current methods for limb volume measurement and highlight their strengths and weaknesses. A currently on-going clinical trial will be discussed with regard to how limb volume measurements are being undertaken with the objective of discussing the compromise between the need for robust data and the challenges of collecting this in healthcare settings.

## Inelastic is more Effective than Elastic Compression in Reducing Capillary Filtration Rate

*Prof M. Neumann,*

*Erasmus MC, Rotterdam, The Netherlands.*

**The abstract for this presentation will be made available before the session.**

## Volume Reduction of the Lymphoedematous Arm depending on Compression Pressure

*Dr R. Damstra*

*Dermatologist, Nij Smellinghe hospital, Drachten, The Netherlands.*

**Background:** The purpose of this study was to determine whether there is a difference between low and high-pressure bandaging in terms of therapeutically intended volume reduction of the compressed arm.
**Method:** We designed an experimental, randomized and comparative study with 2 groups of each 18 patients. We studied the short-term relation between compression pressure at two sides of the arm during bandaging with high pressure (44-58 mmHg) and low pressure (20-30 mmHg) short stretch bandages.
**Results:** Median arm volume reduction after two and 24 hours was respectively 104.5 mL and 217 mL for group A and 56.5 mL and 167.5 mL for group B. There was no statistically significant difference between the volume changes in group A and group B. After 24 hours, edema decreased by median percentage of 9.2% in group A and 4.8% in group B (n.s.). Bandages in group A were better tolerated. The sub-bandage pressure drop in the first two hours was between 41% and 48% in both treatment groups at both measuring sites. After 24 hours, the pressure drop was between 55% and 63%. No proximal swelling above the bandage was observed.
**Conclusions:** Inelastic, multi-layer, multi-component compression bandages with lower pressure (20-30 mm Hg) are better tolerated and achieve the same amount of arm volume reduction as bandages applied with higher pressure (44-58 mm Hg) in the first 24 hours.

## Volume Reduction of the Leg depending on Pressure and Compression Material in Connection with Body Position and Exercise

*Prof H. Partsch*

*Professor of Dermatology, Vienna, Austria*

Leg volume changes have been measured using water displacement devices and tapes before, during and after compression in different settings. Some general conclusions drawn from these experiments:

- Compression stockings in a pressure range of 10-20 mm Hg prevent leg swelling due to long sitting and standing.
- In patients with proximal thrombosis leg circumference reduction in the first 3 days was 4,7% after inelastic bandages and 3,7% with compression stockings (n.s.).
- Volume reduction after application of strong, inelastic compression starts immediately, both in normals and in patients with lymphoedema evidencing a reduction of capillary filtration independent from lymphatic drainage. This leads to an instant reduction of compression pressure.
- In contrast to arm lymphoedema chronic oedema of the leg shows a greater reduction with 40 mm Hg pressure than with 20 mm Hg, both with sustained and intermittent compression.
- In patients with lymphoedema compression removes more water than protein.
- In spite of the stronger massaging effect of inelastic material on the soft tissue and on the venous pump sustained pressure exerted by elastic material is very effective, especially for the maintenance management of chronic oedema.

### Abstract 1 - Session A3 p15

## Case studies of self care & home based integrative treatment model for morbidity control of filarial lymphoedema

*Dr K.S. Bose*
*Principal, Administration & Communications, Institute of Applied Dermatology, Kerala, India.*

**Objective:** Transmitted by mosquitoes filariasis is endemic in 20 states causing disability and loss of $ one billion to rural India .Neglect, poverty and disability affects the quality of life of patients (QOL). We introduced a self care, locally available and home based treatment to over 1000 patients.

**Methods of treatment:** Patients and family members are introduced to integrative treatment following baseline counseling. A supervised treatment and training includes skin washing, Phanta soaking, oil massage, yoga exercises. Compression is used with long stretch bandages. The organized limb (mostly due to fibrosis) is subjected to heat treatment by spraying the steam from heated Ayurvedic medicinal water. Entry point care is done and oral ayurvedic medicines are prescribed. Periodic counseling with involvement of family members increases compliance to treatment.

**Results:** An average reduction in limb size of 20.04% in 14 days, 34.02% in 45 days, 46.57% in 90 days is noticed when the results are analyzed using the SPSS -16 software. The frequency of inflammatory episodes is reduced to 94.1%and reduction in Entry points to 18.73%% from 93.29% following three months of home based and self care. QOL scores are also improved by reduction in frequency of inflammatory episodes, Consuming antibiotics to prevent/treat ADLA and the number of entry points is prescribed according to need but mostly speedily reduced.

**Conclusion:** Compliant patients experience greatly increased QOL. Integrative treatment comprises components of Indian systems of medicine, yoga and breathing and compression methods. Repeated counseling focuses on entry point care and treatment compliance.

### Abstract 2 - Session A5 p15

## Review of Evidence on Exercise and Movements in Lymphoedema.

*Dr A. Cheville,*
*Associate Professor of Physical Medicine and Rehabilitation. Mayo Clinic, Rochester, USA.*

Widely varying recommendations with respect to exercise have historically been detrimental to patients' with lymphedema.

A lack of empirical data, a tenuous theoretical framework, and conflicting anecdotal experiences have been important contributing factors to this situation.

This talk will :

- briefly outline the rationale for past recommendations and how these recommendations may have negatively impacted patients.
- describe the expanding evidence base that suggests the need for an expanded and more empirically-informed role for exercise in lymphedema management beyond the remedial exercise performed in conjunction with CDT.

In recent years the first adequately-powered, randomized, controlled trials have yielded findings suggesting a pressing need to critically re-evaluate past beliefs.

These trials will be reviewed and their highlights summarized.

The talk will conclude with suggestions for the clinical implementation of these findings.

### Abstract 3 - Session A5 p15

## Effects of a training program in patients with lower leg lymphedema

*J. Hidding,*
*Zutphen, The Netherlands, Board member of NVFL.*

**Objective:** Limb function in lymphedema patients is generally poor. Studies about training in patients with lower limb lymphedema are rare. A countrywide training program started in September 2007 for specialized physical therapists with the objective to train patients with lymphedema in legs or arms in cardiopulmonary outcome and muscle strength in the affected area, with support of the Stichting Werkgroep Lymfoedeem (patient support group).

**Method:** The training program includes cardio pulmonary training up to 80% of maximum heart rate and muscle strength training, with accent on endurance (50-60% of 1 RM). Muscles that are expected to be important in lymph flow are part of the training program (in lower legs lymphedema gluteus, quadriceps en knee flexors).

**Results:** Only a few colleagues provided data over a longer period including 4 patients with lower leg lymphedema: Calculated volume of the leg decreased even after ending the training program: 802-2212 mls at 12 wks till 913-2237 mls at 6 months and 1941-2731 mls at 1 year; mobility of hip and knee flexion improved during the training; 6 min walking distance improved even after the training program ended; sensation of heaviness decreased an quality of life (RAND 36) improved.

**Conclusion:** Frequent wearing of stockings might be important to the decrease in volume. Endurance training of leg muscles and cardiovascular training seems to be a safe and effective intervention for patients with secondary lymphedema of the leg.

### Abstract 4 - Session A5 p15

## Effect of a high intensity arm exercise program on arm strength and lymphedema following breast cancer treatment.

*Dr K. Johansson, Lymphedema Unit, Lund University Hospital, Lund, Sweden.*
*P. Klernäs, Lymphedema Unit, Red Cross Hospital, Stockholm, Sweden.*

**Objective:** Reduced arm muscle strength and lymphoedema are common side-effects of breast cancer treatment. The aim of this study was to evaluate the effect of a high intensity arm exercise program on shoulder and arm muscle strength and lymphoedema.

**Method:** Twenty-three women with arm lymphoedema were included. All women were wearing a new compression sleeve before and during the study. A specially designed arm exercise program with weights, were carried through 3 times/ week over 12 weeks. Shoulder adduction(SA) and flexion(SF), and elbow extension(EE) and flexion(EF) were each performed for 4 sets (including 1 warmin-up) 10 repetitions. The training was set to 10 repetition maximum. Measurements were performed before a 2-week control period and before and after intervention. A control for arm volume measurements and training intensity scored on Borg scale were made every fortnight.

**Results:** No significant changes were found for any variables during the 2-week control period. Last week of intervention the mean weights were 3.0kg(SA), 3.0kg(SF), 4.2kg(EE) and 4.0kg(EF) with a mean score of 16.8(very strenuous) at Borg scale. After intervention an increase of strength were found in SA, SA, EF($p \leq 0.05$) and EE($p=0.016$) compared to before intervention. A reduction of arm volume difference in ml was found ($p=0.02$).

**Conclusion:** A high intensity arm exercise program can improve the arm strength without increasing the amount of arm lymphoedema.

**Abstract 5 - Session A5 p15**

## The effect of pole walking on arm lymphoedema, fitness and quality of life in women with breast cancer related arm lympoedema (BCRL).

*L. Jönsson, Lund University Hospital, Lund, Sweden,*
*Dr K. Johansson, Institution of Health Science, Lund University,Lund, Sweden*

**Objective:** The benefits of exercise are well documented for breast cancer treated women. However, there are few similar studies of women with BCRL. This study investigates the effects of pole walking on women with BCRL concerning; arm volume, body weight, cardiorespiratory fitness and health-related quality of life.

**Method:** Twenty women with unilateral arm lymphoedema took part in an 8 week intervention study consisting of pole walking for at least 30 minutes, 3-5 times per week, at 70-80% of maximum heart rate, preceded by a two week control period. Measurements of arm lymphoedema, body weight, fitness, and quality of life were performed before the control period, before and after intervention.

**Results:** After the intervention there was a significant decrease in total arm volume (p= 0,006) and lymphoedema absolute volume (p=0,052) of the lymphoedema arm and a tendency towards decrease in lymphoedema relative volume (p=0,058). There was a significant decrease in heart rate (p=0,003). No changes in body weight and health related quality of life was found. Both positive and negative influences on physical as well as psychological well-being were reported by the women.

**Conclusion:** Pole walking as cardiorespiratory fitness training results in a decrease in total arm volume and lymhedema relative volume of the lymphedema arm, a tendency towards decrease in lymphedema absolute volume and a decrease in heart rate for women with BCRL.

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**Abstract 6 - Session B2 p17**

## Swedish National Lymphoedema Framework

*M. Haag,*
*Svenska Ödemförbundet (Swedish Association of Lymphoedema),*

**Objective:** To implement comprehensive effective lymphoedema management for all persons irrespective of aetiology.

Sweden needs to improve accessibility and lymphoedema management.

**Method:** Define and promote best practices, raise the profile of lymphoedema,place lymphoedema and its management as a priority regionally and nationally.

SÖF has

- organized regional meetings to raise awareness of lymphoedema and to define stake holders for a NLF
- had meetings with politicians at regional and national levels to inform of cost-effective and QOL improvements for lymphoedema management
- published a report of a study identifying the need to improve lymphoedema management
- arranged a seminar with Professor Piller 2009 to increase awareness of lymphoedema..
- invited Professor Franks to the Swedish Annual Meeting of Medicine November 2009 as a guest lecturer.

**Results:** The involvement of the patients ensure that services meet their needs.

This work is a starting point to implement quality care for lymphoedema patients. There is no specialization in lymphoedema for medical professionals and no lymphologists exist. As the interest for lymphoedema is low, it is difficult to define dedicated and passionate stakeholders for the planning of the NLF. SÖF is in the process of translating »Best Practice for the Management of Lymphoedema » for converting it to Swedish conditions.

**Conclusion:** International collaboration is necessary to achieve improved lymphoedema management.

Best Practices change depending on research and positive treatment results. Collaboration with ILF is essential to improve lymphoedema management globally.

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**Abstract 7 - Session B2 p17**

## Progressing Lymphoedema Research: a New Zealand case study

*R. Campbell, R. Kirk, A. Hornblow,*
*M. Thompson, C. Lockie, and K. Koed*
*Institution: Health Sciences Centre, University of Canterbury, Christchurch, New Zealand.*

**Objective:** A comprehensive investigation was undertaken to determine international best practice, the New Zealand information base for Lymphoedema data, and service provision.

**Methods:** Data collection agencies within New Zealand were contacted to determine the scope of data collected on the burden of Lymphoedema in New Zealand. Electronic bibliographic databases were searched for key literature. The Ministry of Health and service providers were conducted for policy and service delivery information. Internationally recognized methods for undertaking systematic reviews of the literature were adopted. A comprehensive literature review was undertaken to determine what is known about truncal Lymphoedema.

**Results:** Key results include:

- Data on Truncal Lymphoedema were limited. No extensive cohort or longitudinal studies were found.
- Ministry of Health in New Zealand did not collect data on Lymphoedema.
- Ministry of Health in New Zealand collected data on death due to Septicemia.
- Breast cancer Foundation of New Zealand did not collect data on Lymphoedema as originally reported to research team by staff members.
- Further development of Lymphoedema services will depend on improved data collection and research into treatment effectiveness.
- Popularized articles were written targeting the general public to educate about Lymphoedema.

**Conclusions:** New Zealand has limited information on the national burden of Lymphoedema. There is potential to strengthen the information base by use of electronic health records and database collections. Improved information management is needed to strengthen service provision for Lymphoedema sufferers.

**Abstract 8 - Session B2 p17**

## Research Framework for Investigating Quality of Life in Lymphoedema Patients at Outpatient Services in Japan : a Progress of ILF Japan

*E. Kimura*

**Objective:** To present the current status of lymphoedema related issues and the progress of ILF-Japan project. It is estimated that 160 thousands lymphoedema patients are present in Japan. Since 2000, growing awareness on lymphoedema management has been occurred by research presentations or widespread media coverage. In 2008, Japanese Ministry of Health, Labour and Welfare approved the incentive insurance for 'Instruction of Lymphoedema care for cancer patients'. However, we face to following challenges; a lack of therapists and a difference in payment for receiving MLD due to non-insurance coverage.
In this situation, Prof. Moffatt was invited to Japan in 2009, introducing the UK Lymphoedema Framework Project. We launched ILF Japan to reveal the actual conditions of lymphoedema outpatient services at first.
The purpose of the research is to investigate the related factors for QOL of patients and to evaluate care outcomes at lymphoedema outpatient services.

**Method:** The data collection period is from Nov 2009 to Aug 2010. The participants consent to answer to the questionnaire including Minimum Data Set (demographic information, EuroQol, WHO Disability Assessment Schedule- [WHODAS-]), Hospital anxiety and Depression Scale (HADS), Abbreviated version of Coping Orientation to Problems Experienced (Brief-COPE) and The short form-36 (SF-36).

**Results:** We obtained provisional data by Dec 2009 including 73 patients (primary 19, secondary 54). Mean swelling duration was 6.92 years. The number of patients for each ISL classification was as follows; stage0 -1, stage -12, stage -37, stage (late)-20, and stage-3.

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**Abstract 9 - Session C2 p19**

## Experiences of Children with Lymphoedema

*Prof I. Quéré, Professor of Vascular Medicine, Montpellier 1 University, Montpellier, France.*

A pilot research with families willing to share their experiences was conducted in France and UK, leading to the first step towards the validation of a specific quality of life questionnaire.

**Methods:** Prospective descriptive qualitative study through individual interviews led by professionals. The focus was on pre-defined themes such as disease management, school life, experiences within the family, and psychological impact.
A questionnaire was then constructed and its feasibility tested in twenty children and young adults.

**Results:** Delay for the initial diagnosis and difficulty in getting answers were shared by all the families in both countries with different levels of anxiety. It seems to be linked more to the rarity of the disease than to the health care system itself.
Lymphoedema impacted on many aspects of family and school lives. Integration in school life depends mainly on the flexibility of the educational team and seems to have been facilitated by the laws on handicap integration in France.
All children expressed :
the feeling of being stigmatised by the swelling.
an ambiguous relationship with clothing (hiding lymphoedema while having to cope with it)
the constraints of the daily treatments

**Conclusion:** Children with lymphoedema share quite close experiences in UK and in France. The medical management is impacted by the rarity of the disease independently of the health care system. The psychological difficulties are very different from those described in adults with lymphoedema after cancer.

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**Abstract 10 - Session C2 p19**

## Engaging Young People :Challenges for Clinicians

*P. Sanderson, Manager, Mercy Health Lymphoedema Clinic, East Melbourne, Australia*

Lymphoedema can potentially affect the developmental processes of childhood and adolescence in areas of individualisation and socialisation. Developing self esteem and a healthy body image are challenging enough without the addition of a visible condition which may present limitations on activities and inhibit the development of independence.

The importance of a patient centred approach in providing treatment for young people with lymphoedema is essential. The young person with a chronic illness can benefit significantly from a trusting and therapeutic relationship with their health care professional.

Maximum participation in decision-making processes and involvement in peer support can empower young people to have greater control over their lives. How the clinician engages with the young person and their family is extremely important and will play a pivotal role in determining whether or not the young person will receive appropriate and timely intervention for their lymphoedema. In addition, the ongoing relationship built on trust, mutual understanding and respect can assist them to embrace the self management tasks that are inherent in living with lymphoedema. The clinician can expect resistance over the course of the young person's development so listening and understanding their experiences is paramount.

This paper will explore the challenges for clinicians of engaging with young people and the barriers that exist. Using two case examples of a young child and an adolescent, strategies for clinicians will be explored and outlined.

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**Abstract 11 - Plenary E p24**

## Enhancing Supportive-Educative Nursing Systems to Reduce Risk of Post-Breast Cancer Lymphedema

*Prof J. Armer, Dr C. Brooks, and Dr B. Stewart,*
*University of Missouri Sinclair School of Nursing, Columbia, MO, USA*

**Objective:** This study describes the use of participant feedback from a parent intervention study to plan an educational program for nurses and therapists to improve their supportive-educative nursing system when working with breast cancer survivors. Based upon feedback, the research team recognized that participants were not following the self-care intervention protocol. In order for nurses to help patients develop self-care agency (SCA) (Orem, 2001) to engage in actions to address self-care requisites associated with post-breast cancer surgery, these nurses needed to refine their intervention skills.
**Method:** An interview guide was developed based on Orem's (2001) power components. This guide consisted of open-ended questions to explore the essential capabilities of participants to engage in self-care actions. Questionnaires were mailed to 27 participants and telephone interviews were conducted for those who did not return the survey by mail. Data for 14 participants with a mean age of 60 who were 13 months beyond breast cancer surgery were analyzed and categorized using Crabtree and Miller's (1999) template analysis guidelines, categorizing data as related to the power components described by Orem. The focus was to explore the state of power related to self-care agency. Since our goal was to elicit information for developing the educational program to enhance the supportive-educative nursing intervention, data were not analyzed in the aggregate.
**Results:** The data revealed that participants were experiencing the most difficulty in four power components (Orem, 2001, p. 265): 1) ability to maintain attention and exercise requisite vigilance with respect to self as self-care agent, internal and external conditions, and factors significant for self-care; 2) ability to reason within a self-care frame of reference; 3) motivation; and 4) ability to consistently perform self-care operations, integrating them with relevant aspects of personal, family, and community living. Data from these power component categories (Orem, 2001, p. 265) were further refined and example statements included in the training materials.
**Conclusions:** Motivational interviewing (Miller & Rollnick, 2002) and solution-focused therapy (Berg & DeJong, 1996) were incorporated in the educational training for the research nurse team to strengthen nursing agency and improve supportive-educative nursing systems.

**Abstract 12 - Session E4 p25**

## The Breast Cancer Recovery Program, An Evidence-Based Exercise/Relaxation Program For Women With Breast Cancer Related Lymphedema

*M. McClure, R. McClure, R. Day, A. Brufsky,*
*Magee Women's Research Institute, Pittsburgh, PA, USA.*

**Objective:** This is a controlled, randomized study evaluating the efficacy of an exercise/relaxation program, the Breast Cancer Recovery Program© (BCRP©), in improving physical and emotional breast cancer related lymphedema (BCRL) symptoms through a «Circle of Healing» feed-forward strategy.

**Method:** Thirty-two women with BCRL were randomly assigned to either treatment (N=16) or control (N=16) groups. The treatment group completed a daily home program and ten, biweekly group sessions, including video exercise, relaxation techniques, and educational materials. The control group followed lymphedema medical team recommendations. Subjects were tested at entry, midpoint (2½ weeks), end of program (5 weeks), and 3-month follow-up. Tests included bioimpedance, girth (truncated cone volume), range of motion, weight, quality of life (SF36), mood (Beck Depression Inventory), and home program adherence.

**Results:** Mixed model repeated measure analysis of differences from baseline gave significant treatment main effects in decreased arm swelling measured by bioimpedance (p=0.05), active range of motion (p=0.03), mood (p=0.03), quality of life (physical function p=0.02), and wanted weight loss (p=0.04) with high treatment group adherence. Most treatment subjects with bioimpedance improvement also showed improvement in emotional measures; most controls did not.

**Conclusions:** This is the first evidence-based, controlled exercise/relaxation study demonstrating decreased arm swelling. The BCRP© is a safe and synergistically effective program for physical and emotional BCRL symptoms, demonstrating high exercise adherence.

**Abstract 13 - Session E7 p25**

## Tissue dielectric constant : A novel tool for local edema assessment

*[1]A. Immonen, [1]J. Nuutinen, [2]T. Lahtinen and [3]C. Budleigh,*
*1Delfin Technologies Ltd, Kuopio; 2Department of Physics, University of Kuopio, Finland; 3Psi-Ense, Dorking, England*

**Objective:** Tissue dielectric constant (TDC), an electrical parameter of a biological tissue, is a measure of tissue water content. We demonstrate that the TDC measurement is useful for local assessment of edema.

**Method:** A novel device MoisturemeterD (Delfin Technologies Ltd) generates and sends a high radiofrequency of 300 MHz into the skin and underlying structures oscillating water molecules of biological material. At 300 MHz, the EM field will oscillate both free and bound water molecules equally. This ensures that MoisturemeterD has equal access to tissue total water content. From this interaction the device can calculate the electrical parameter, the tissue dielectric constant (TDC), which is mainly dependent on tissue water content. The TDC of vacuum is 1 and water 79. Probes with different size enable local measurement of TDC at depths of interest.

**Results:** The TDC measurements have been used under a variety of conditions including skin irritation, breast edema during and after radiotherapy, hemodialysis, post cardiac surgery, weight loss, menstrual cycle and lymphedema where the TDC values depend on local tissue water content. Examples on the temporal development of edema in irradiated breast and the effect of manual and compression lymphatic drainage in reducing edema will be given.

**Conclusion:** MoisturemeterD is the first edema-specific instrument which has equal access to free and bound water components enabling easy, quick and local measurement of tissue water content. The results also suggest that high sensitivity may enable the detection of incipient edema.

**Poster 1**

## Assessment of Quality of life in lymphoedema patients: Validity and Reliability of the Swedish Version of the Lymphoedema Quality of Life Inventory (LQOLI)

*P. Klernäs,*
*Department of Physiotherapy, Institution of Neurobiology, Care Sciences and Society, Karolinska Institute, Stockholm, Sweden.*
*L. Kristjanson,*
*Professor, WA Centre for Cancer & Palliative Care, Curtin University, Perth, Western Australia.*
*K. Johansson,*
*Department of Physiotherapy, Institution of Health Science, Lund University, Sweden.*

**Introduction:** The Lymphedema Quality of Life Inventory (LQOLI) is an instrument developed for patients with different types of lymphoedema. It is divided into physical, emotional, social and practical dimensions and consists of 58 items, each with three sub items concerning life quality, daily life changes and difficulties. The purpose of this study was to adapt the Australian LQOLI to Swedish conditions and to test it for clarity, face validity, content validity, construct validity and reliability.

**Material and Methods:** The instrument was translated into Swedish according to international guidelines. Content validation was completed by experts (n=11) and patients (n=16) as well as test of "face validity". For construct validation the SF-36 (n=63) was used. Test-retest reliability was evaluated with lymphoedema patients (n=58) answering the questionnaire twice, within 3 weeks.

**Results:** Three items were added in the Swedish version of LQOLI (SLQOLI). The kappa coefficients in test-retest for all items and sub items varied (range=0.25-0.83). Construct validity showed moderate correlation with SF-36.

**Conclusion:** The Swedish version of the LQOLI is adapted and valid, with moderate reliability. It can be used in clinic to describe quality of life for patients with lymphoedema.

**Poster 2**

## LYMPH LISTENS: A community based report on living with lymphedema in Ontario

*A. Kennedy Chair Lymphovenous Association of Ontario.*

**Objective:** The Lymph Listens Report was a community based assessment by the Lymphedema Association of Ontario, with funding from the Canadian Breast Cancer Foundation – Ontario Chapter. It's objectives were to gain a deeper understanding of the needs of lymphedema patients and those at risk, the greatest gaps in servicing those needs and to develop a strategy of how the organization's programs and services could better align to support the lymphedema community.

**Method:**

- **Comprehensive surveys** were administered to those living with lymphedema
- **Group Consultations** took place with breast cancer survivors at risk for lymphedema
- **Interviews** were conducted with 18 representatives of the key stakeholder groups within the lymphedema community
- **Literature Review** of existing patient education material about lymphedema took place

**Results:** There is a lack of standardized patient education material on lymphedema, a need for more hospital based diagnosis and treatment centres, limited knowledge among health professionals about the treatment options and support services available for lymphedema patients and not enough certified lymphedema therapists to meet the number of patients in Ontario.

**Conclusion:** The lymphedema community is grossly underserviced. Armed with a better understanding of the lymphedema community in Ontario, the Lymphedema Association was better equipped to chart a roadmap for the years ahead that focused on the broader themes of

- Developing a comprehensive patient education
- Strengthening cancer community partnerships
- Reaching out to Health Care professionals and
- Advocating for better lymphedema patient care

**Poster 3**

## Lymphoscintigraphies in the management of lymphedemas and their health costs reimbursement in Belgium.

*Prof P. Bourgeois, Head of Clinic, Service of Nuclear Medicine; Université Libre de Brussels, Belgium.*
*J.-P. Belgrado, Institut des Sciences de la Motricité, Brussels, Belgium*
*C. Aerens, Institut Jules Bordet, Brussels, Belgium*

**Summary:** Limb edemas of lymphatic origin, either primary, or secondary, represent a chronic disease sometimes heavy to bear by patients who suffer from. These lymphedemas imply specific care by physical therapists trained to the use of different therapeutic approaches. Until a few years, only the treatments of secondary lymphedemas after radiotherapy and/or complete nodal dissection for cancer were reimbursed by the national health insurance system in Belgium. The introduction of the primary congenital lymphedemas as a disease also reimbursed raised several problems and led to a redefinition of these situations and of their cares. The definition and classification of the lymphedemas in view of the reimbursement of their treatments by the national health insurance system are now officially based (not only on the sole clinical history but) mainly on their clinical severity and/or also on the result of their lymphoscintigraphic investigation (according to a methodological protocol and to diagnostic criteria adopted at the national level). The reimbursements of the treatments by the physical therapists were also adapted and improved. The lymphocintigraphic investigations of the limb edemas became so essential in the management of the lymphedematous situations and in the reimbursement of their physical treatments in Belgium.

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**Poster 4**

## Skin Therapy as an added value in health care

*M. van Zanten*
*Skin and oedema therapist – University of Applied Science, Faculty of Health Care, Utrecht, The Netherlands*

**Objective:** To asses the added value of a skin therapist for post operative melanoma patients suffering from lymphoedema in Australia. Skin therapy was developed in the Netherlands to complement the work of medical specialists and deliver ongoing patient care. A skin therapist prevents, manages or cures skin disorders or underlying conditions.

**Method:** Practice orientated, qualitative research project based on interviews and literature research. Interviewee's were pre-selected on their medical or allied health profession.

**Results:** The majority of the respondents mention the rural areas as greatest challenge around skin health and lymphoedema treatments in Australia. Interestingly, in general there is a curiosity in the work of a skin therapist and most would think it could be effective in some way in Australia. Skin therapy can play a significant role in Australian health care by bridging the existing gap between specialists and patients needs.

**Conclusion:** The skin therapist could deliver preventive education, treatment and follow up care especially for the complex post-operative melanoma patient suffering from secondary lymphoedema. With these qualities the skin therapists could support the work of medical specialists and help address the long waiting lists for patient consultations, care and treatment.

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**Poster 5**

## A randomized, controlled crossover trial of vibration in women with breast cancer-related lymphedema.

*M. Dai,*
*Kanazawa University Graduate School of Medical Science, Japan.*

**Objective:** Simple lymphatic drainage (SLD) is commonly performed as a long-term self-help measure. However, as the effect of reducing affected limb volume for SLD cannot be fully implemented in comparison to manual lymphatic drainage, supportive therapy is necessary. Therefore, this study evaluated reductions in arm lymphedema using vibration as support for SLD.

**Method:** Subjects were outpatients with breast cancer-related stage II lymphedema. Participants were randomly assigned to receive a 4-week course of SLD with vibration or SLD alone. After at least a 1-week washout period, subjects underwent the same protocol using the opposite treatment. Vibration (47 Hz) was applied for 15 min twice daily using a portable vibrator (RelaWave Matsuda Micronics, Chiba, Japan). The outcome measure was excess limb volume, which was recorded at weeks 0, 4, 5, and 9 and calculated using the formula (Casley,1994). The protocol of this study was approved by the ethics committee of the Kanazawa University Medical Department.
Results: In total, 10 patients completed SLD both with and without vibration treatment. The age range of these patients was 41-65 years and the duration of lymphedema ranged from 1.5 to 38 years. Among these patients, 8 underwent axillary lymph node dissection. The mean relative reduction of excess limb volume was 5.6±3.5% with vibration and 0.6±2.6% without vibration (P=0.02).

**Conclusion:** These results suggest that vibration decreases the excess volume of breast cancer-related lymphedema and is a safe and effective for supporting SLD.

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**Poster 6**

## Using Traditional Acupuncture to Improve Wellbeing in Cancer Patients with Lymphoedema

*B. de Valois[1], T. Young[1], E. Melsome[2]; E. Maher[1]*

**Objective:** To investigate acceptability and effects of traditional acupuncture to promote wellbeing and improve quality of life for people with upper body lymphoedema.
**Method:** Breast (BC) and head and neck (NHC) cancer patients participated in focus groups to identify symptoms and discuss acceptability of acupuncture. An exploratory, single-arm observational clinical study measured the effects of treatment on symptoms prioritised by participants, using the validated, patient-centred, Measure Your Medical Outcome Profile (MYMOP). Acupuncture treatment did not aim to treat the lymphoedema and needling was avoided in the affected area. In follow-up focus groups, participants discussed acupuncture's effects and acceptability as an adjunct to usual care for lymphoedema.
**Results:** 27 BC and 8 HNC participants received 420 acupuncture treatments (maximum 13 per participant). BC participants prioritised lymphoedema- related symptoms (arm pain, heaviness, discomfort) as well as musculoskeletal and psychological symptoms (stress, anxiety, insomnia, distress). HNC participants prioritised musculoskeletal and psychological symptoms. MYMOP scores evaluated after 6 and 12 treatments showed significant statistical and clinical improvements. In follow-up, many participants reported that acupuncture improved their wellbeing, in turn enabling them to manage their lymphoedema more effectively. Acupuncture was well tolerated, with no significant adverse effects observed or reported.
**Conclusion:** Acupuncture appears to be a safe adjunctive treatment to usual care for lymphoedema. By reducing the symptom burden, acupuncture has the potential to help patients cope with their condition, and facilitate better self-management.
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# The ILF Objective:

## To improve the management of lymphoedema and related disorders worldwide

- To increase **awareness** by raising the profile of lymphoedema.
- To increase **knowledge** about lymphoedema by initiating and/or contributing to **Research Programmes.**
- To **disseminate** this knowledge by implementing an **international, not-for-profit, publications strategy.**
- To increase **understanding** of lymphoedema and its management by creating and/or contributing to the development **of Education Programmes.**
- To provide a cross cultural networking platform through an **Annual International Event** where all stakeholders will have the opportunity to contribute and influence the ILF agenda.
- To promote and document Best Practice with the development of an **International Minimum Dataset.**
- To facilitate and/or contribute to better **access to treatment** for patients worldwide.
- To promote and **support initiatives** whose goals are to improve the national/regional/local management of lymphoedema anywhere in the world.
- To help the Healthcare Industry understand the **real needs** of patients and practitioners, and develop and evaluate improved diagnostic tools and treatments.

**www.lympho.org**

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