



INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK



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ILF Affiliates

Not yet an ILF affiliate? Registering as an affiliate of the ILF will ensure you are kept up to date with developments by being included on communications. Affiliates also benefit from reduced fees at ILF conferences, regular updates on activities and resources, opportunities to network with National Lymphoedema Frameworks and to influence future activities and direction of the ILF. Visit the ILF website now to complete and submit the form [here](#).

ILF Administration

All enquiries related to ILF administration and other ILF matters should be directed to Jan, whose contact details are as follows:

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LYMPHO NEWS Summer 2016

ILF's quarterly electronic newsletter

Welcome to the ILF Summer newsletter. Our goal is to keep you informed about the goals and activities of the International Lymphoedema Framework as well as the work of our national frameworks, partner organizations, affiliates and industry partners. We welcome readers to contribute ideas for updates or send us news that is relevant to share.

Best wishes,

Christine Moffatt and Neil Piller,
Co-directors of the ILF.

2016 Asia Pacific Lymphology Conference



2016 Asia Pacific
Lymphology Conference

Integrating the 11th Australasian Lymphology Association Conference
and the 6th International Lymphoedema Framework Conference

New Networks – New Solutions 26-28 May 2016 Darwin Australia



The 2016 Asia Pacific Lymphology Conference was deemed a great success. Under the theme “*New Networks, New Solutions*”, the conference was an integration of the 6th International Lymphoedema Framework Conference and the 11th Australasian Lymphology Association Conference. 356 delegates, 69 exhibitor registrants manning 29 trade booths, 11 sponsors and 66 patient day participants from 19 countries gathered to hear a large roster of presenters, including keynote and invited speakers Prof. Marlys Witte, Prof. Jean-Paul Belgrado, Prof. Terence Ryan, Dr. Karen Herbst and many more. There were also 46 poster presentations lining the conference centre hallways. Evaluations from participants were extremely positive. More than 93 percent stated that the conference was a worthwhile investment of their time and money.

“Please pass on my congrats to the ILF. I think it was one of the best conferences I’ve been to yet! A great combo! The breakfast meetings and workshops I went to were simply fabulous. It’s always a delight to be able to bring back news for patients, and renewed methodology. I’m still on a high!” - Statement from Conference delegate

A full view of the final program, all abstracts and photographs can be accessed on the [conference website](#).



There was great interest at the ILF exhibit booth. More than 30 people were eager to stay informed and keep engaged with the lymphoedema global community, and signed up to be an ILF affiliate. We urge all national framework countries to forward this newsletter on to their distribution list to promote individual affiliation with the ILF, which is free to join and offers benefits such as discounts on registration fees for international lymphoedema conferences.

Future ILF Conferences

A formal announcement was made to conference delegates in Darwin, regarding the locations of the next two international lymphoedema conferences.

In 2017 - the conference takes place from the 21-24 June and will be co-hosted by the Italian Lymphedema Framework (ITALF) in Siracusa, Sicily, Italy.



In 2018 - the conference will be co-hosted by the Dutch Lymphedema Framework and will be held in the Netherlands.



Key results of the ILF Board planning meeting

The ILF board of directors met for two days of planning, prior to the Darwin meeting. The priorities that were discussed for the coming two years were: Children's Strategy, Research Framework Document, Conferences, National Frameworks, Communication, LIMPRINT, Successful Outcomes Statement and Education Standards. Some of these projects are already complete, and will be shared with our affiliates via this newsletter as developments take place.

Industry Partners Networking Session

The ILF Board Directors were pleased to have the opportunity to share goals and project plans with some of our industry partners at a special Industry networking session in Darwin, Australia. We are grateful for the continued support of the following industry partners who share our vision of advancing lymphoedema care around the world:
Haddenham, Thuasne, 3M, BSN, Cizeta Medicali, Smith & Nephew and URGO.

Not yet an Industry Partner? [Email us now](#) to enquire about partnership, giving you access to significant advantages, including regular meetings with Directors and opportunities to be involved with specific global initiatives.

National Lymphoedema Frameworks Meeting

In recognition of the great work that is carried out by the individual National Lymphoedema Frameworks (NLFs), the ILF

Board of Directors is very keen to involve existing and developing NLFs in exploring ways of enhancing engagement with the Board and across the different NLFs. During the Darwin conference an interactive workshop for the leads of each framework was held, for the purpose of celebrating successes and sharing challenges and aspirations. Seven national frameworks from the following countries were represented at the meeting: Canada, Holland, Ireland, Italy, France and Belgium. Sweden and Singapore also had interested participants. A full report of the one-hour, interactive workshop will be made available for each country lead to share with their stakeholders.

Education Benchmark Standards (LEBS)

An ILF project developed by the Education Committee is aiming to ensure that all health professionals understand lymphoedema. International consensus has been achieved for Lymphoedema Education Benchmark Statements (LEBS) which comprise 6 basic statements in relation to professional knowledge and understanding of: 1) Anatomy and physiology, 2) Pathophysiology of lymphoedema, 3) Recognition of various causes of oedema, 4) Recognition of lymphoedema, 5) Patient education and support needs and 6) Components of treatment.

Objectives have been set for each statement of standard. This should encourage educators to evaluate their education programme and its adequacy in relation to lymphoedema. For teachers who may lack knowledge themselves in this area, LEBS goes further by offering guidance on content and relevant points at which lymphoedema related information could be integrated into curricula. The ILF plans on-going development of free online resources to make this step as easy as possible, with minimal demand for extra curriculum time.

This is not a 'quick fix'. Registered health professionals will need to be educated for many years to come, but if future health professionals start their career with an understanding of the condition, are able to recognise it and provide appropriate advice and information on risk reduction, self-care and where to get help, we will have moved a long way!

Italian Lymphedema Framework (ITALF)

It has been little over a year since its inception (February 2015) but this new framework has been very busy. Just a sample of their activities and accomplishments are listed below:

2015 - In its first year the ITALF developed regional sections, and established important relationships with other scientific societies, patient and voluntary associations and companies interested in the lymphological sector. Today membership stands at more than 200 people and at least 20 stakeholder groups. They also launched their website (both Italian and English), delivered joint programming sessions for national congresses (Italian Society of Phlebology and Italian College of Phlebology) and held their own first national ITALF Congress (December 2015).

Advocacy efforts included a letter to the Italian Ministry of Health for assistance to all patients of lymphatic diseases and a letter to the Attorney for legal notice to institutional bodies.

2016 - participation in LIMPRINT started (July) with more than 100 clinical cases recorded in the first 15 days. They delivered a joint

session at the UIP Congress (April) and prepared informational material and training courses. The second national Congress is scheduled for November.

2017 - The ITALF is very proud to co-host the next ILF conference in Italy next year.



ITALF President Sandro Michelini shares these two very important messages:

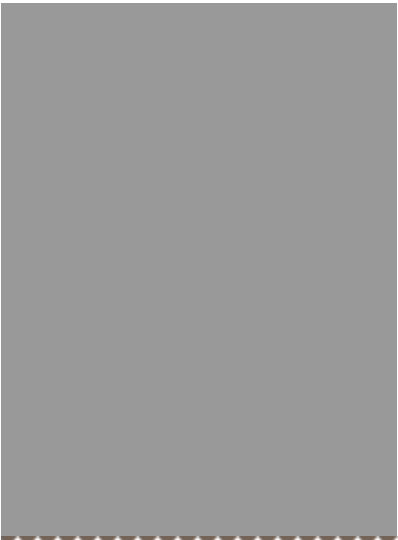
“1) The Italian Ministry of Health (with our close co-operation) has issued the 12 July 2016 Guidelines on Lymphedema and Lipedema. The primary lymphedemas joined the group of 'rare diseases'. Every Italian Region must now guarantee assistance both of primary and secondary forms of lymphoedema, in different care settings (up to hospitalization for more complex cases). The flat knitted compression garments are finally reimbursed by the public health system for both primary and secondary lymphedema patients. We are very happy for that development.

2) The ITALF work today is geared to increasing knowledge about the disease towards the primary care physician and to specialists. Once lymphedema was not known specifically. Today, thanks to the widespread dissemination of 'specific culture', there is also an abuse of the term and it happens more and more often, for example, that the same cardiologists for heart failure edema mistakenly should address patients to physical therapy cycles for lymphedema with consequent risk of deterioration of the clinical features. For this, having solved many practical problems of information and assistance to patients, we are now oriented towards general and other health care professionals because they can diagnosis and treat the problem better. Thank you for all you do as ILF. We are proud to bring our contribution/example”.

LIMPRINT

The ILF prevalence study LIMPRINT has continued to capture significant interest. The ILF is very aware that little is known of the current prevalence of lymphoedema/chronic oedema. Work undertaken by Christine Moffatt in 2003 showed an estimated prevalence of 1.3 people per 1000 adults within a London-based population. However, a number of factors including an aging population, obesity, and greater survival rates from cancer has led the ILF to believe that this estimate has since increased.

Four countries have already taken part in the study - Japan, Denmark, France, and the UK. Canada and Italy have recently started their data collection and following the Asia Pacific Lymphology Conference in Darwin (May 2016) two more countries have registered their desire to be part of the project. So far we have literally examined 12,000 people for chronic oedema/lymphoedema and wounds and we hope this figure will



rise to 15,000 by the end of the study. The study has been carried out in differing settings and of course, also in different cultures. Among the settings are hospitals, community, age-care facilities, lymphoedema services, and even in a prison. The ILF is recruiting new sites until December 2016, and hereafter the data will be analysed. The findings will be presented at the ILF 2017 Conference in Italy.

If you would like further information please contact the LIMPRINT Project Manager [Susie Murray](#).

WE WOULD LIKE TO HEAR FROM YOU.

As always, we encourage you to share your ideas, events and thoughts with us!