



Report from National Framework networking meeting

7 June 2018 (ILF 2018 conference, Rotterdam, the Netherlands)

Participants:

- American Lymphedema Framework Project (ALFP), USA: Jane Armer
- Canadian Lymphedema Framework (CLF), Canada: Anna Kennedy, David Keast
- Danish Lymphoedema Framework (DLF), Denmark: Susan Nørregaard; Tonny Karlsmark
- Dutch Lymphoedema Network (NLNet), the Netherlands: Wouter Hoelen; Anita Ootjers
- Italian Lymphoedema Framework (ITALF), Italy: Sandro Michelini; Marina Cestari
- National Lymphoedema Framework Ireland (NLFI), Ireland: Meadh Sweeney, Norah Kyne
- Swiss Lymphoedema Framework (SLF), Switzerland: Anna Sonderegger
- Chair: Neil Piller (ILF Board of Directors)
- ILF Secretariat: Jan Kristensen, Anne Wad

The ILF Board of Directors was very pleased to welcome representatives from a wide range of National Lymphoedema Frameworks (NLFs) at this year's ILF conference in Rotterdam. With this meeting, the ILF wishes to recognize and encourage the work of the NLFs and to give frameworks the opportunity of sharing their thoughts and influence the future work of the ILF.

Objectives of the meeting

- Introduce and update from frameworks on news and current projects
- Update on the collaboration between the frameworks, the ILF Board and the secretariat, including news about new frameworks admitted since last meeting in June 2017
- Share experiences and lessons learned
- Discuss new initiatives and how to strengthen the collaboration further

Achievements experienced

- Children's and patients' camps organized in several countries
- Prevalence studies/surveys conducted in several countries
- Ability to influence the regional political level (CA)
- National reimbursement policy implemented (IT)
- Participation in elaboration of national guidelines (DK)
- Successful use of mobile device for sharing of patients' experiences (USA)

Challenges experienced

- Integration of stakeholders with different agendas
- Influence the political level regarding patient advocacy (reimbursement of garments)
- Identify models for collaboration with industry and sponsors.



Proposed Actions

ILF:

- Share summaries of annual reports on ILF website
- Consider sharing tools and inspiration regarding how to collaborate and engage with industry and stakeholders e.g. through open space meeting or similar.

NLFs:

- Submit outstanding annual reports on activities June 2017 – May 2018 and future annual reports according to written request by the ILF secretariat during March-April 2019
- CLF to share slides on prevalence data from across Canada.

Highlights of oral reports from all countries/frameworks represented. All full reports submitted prior to the ILF Rotterdam conference will be made available on the ILF website.

American Lymphedema Framework Project (ALFP):

- Systematic reviews have been made directly available from the ALFP website.
- A mobile device for sharing of experiences between patients have been developed (awaiting major funding to progress).
- ALFP is collaborating with Canadian “SOCIDO” providing weekly reports about new publications.

Canadian Lymphedema Framework (CLF):

- CLF has no members, but acts as an umbrella organisation to all the provincial lymphoedema associations (which have members), providing them with standardized health professionals and patient education material. CLF is focusing on providing data and advocacy tools for the provincial associations in order for them to advocate for better regional reimbursement. The CLF focuses primarily on lymphoedema, not lipedema.
- CLF has estimated chronic oedema/lymphoedema across Canada. Their estimate focus closely at morbidly obese persons amongst which estimated lymphoedema prevalence is 45% (Some of Christine Moffatt’s data show even higher prevalence). Anna Kennedy will share the slide showing their estimate with participants.

Danish Lymphoedema Framework (DNL/DLF):

- DNL/DLF is a small framework with only four members, but they are representing key professions / associations.
- DNL/DLF has been able to make a change as they were contacted by the Danish health authorities and invited to engage in the elaboration of national guidelines for treatment of chronic oedema of the lower extremities.
- A biennial seminar is being organized by the framework. The next one is on 11 October 2018 in Copenhagen with national and international speakers.
- DNL/DLF has participated in the LIMPRINT studies.



- A children's prevalence study is being conducted.
- It has been a wish to create and publish a journal but there are not enough human resources to do that.

Dutch Lymphoedema Framework (NLNet):

- NLNet embraces 1,800 members and is involved in problems faced by patients with garments.
- NLNet works on getting a task force together to address the need for more focus on patient advocacy. Most research is focused on lipoedema patients.
- NLNet has made a first experience with a weekend getaway for children (without parents). In general there are lots of activities taking place in the Netherlands for people living with lymphoedema.

Italian Lymphoedema Framework (ITALF):

- The ITALF annual conference is being organised in December 2018. Vaughan Keeley will be invited as a speaker.
- A patient camp will be arranged in Piemonte for patients with secondary lymphoedema similar to last year.
- Based on the publishing of guidelines at the ILF 2018 conference in Siracusa, it has been decided that patients can have two garments a year reimbursed across all of Italy.

Swiss Lymphoedema Framework (SLF):

- SLF was created earlier this year. SLF sees themselves as an umbrella organization for a lot of small associations and networks. The framework is still facing challenges in terms of integrating all relevant stakeholders and would like to discuss with other framework representatives approaches to achieving the aim of including all groups. In response meeting participants recommended to move forward and invite all important groups to participate in SLF. By the SLF showing leadership other groups may choose to follow the SLF, or choose to do their own individual activities.
For a small association in Switzerland it is not possible to change anything at the political level. Thus, a framework is necessary to move things forward.

National Lymphoedema Framework Ireland (NLFI):

- NLFI is a quite new association which started out by engaging in the LIMPRINT study.
- The framework is one of the first experiences in Ireland of having different professions sitting together on the same board.
- NLFI has two main objectives:
 - 1) A one-day camp for 10 children and parents on 20 October 2018. The camp will focus on education. There will be one volunteer therapist present per child.
 - 2) Invitation of different professionals in order to increase the number of stakeholders engaged in the framework.
- Meadh Sweeney and Norah Kyne were interested to know how other frameworks collaborate with companies without favouring some. The ILF model of industry partner meetings was explained. Based on this it was discussed to consider an open space meeting for frameworks for sharing of models for collaboration with industry etc.