



National Lymphoedema Framework Annual Reports June 2019

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American Lymphedema Framework Project (ALFP), USA

Latest steps

- Launched ALFP stakeholder therapist survey electronically in Fall 2018 from the ALFP website with boosts from lymphedema organizations, training schools, and other key partners
- Aggregated and summarized survey findings in Spring 2019
- Comparing findings across the therapist surveys finding (Summer, 2019)
- Reporting survey findings in 2019 at the ILF-ALFP meeting in Chicago, IL (Anderson presentation)
- Establishing a plan to regularly monitor stakeholder perspectives in the years moving forward
- Communicate these finding through presentations, manuscripts, social media, and health policy briefings (Journal of Lymphoedema, Summer 2019; Midwest Nursing research Society, poster presentation, April 2019)
- Stakeholder open-space meeting to review priorities at ILF-ALFP meeting on Friday, June 14, 2019
- Participated in distributing ILF-COM oedema/lymphedema survey in the U.S. in 2019 (poster prepared for ILF 6/19)





Canadian Lymphedema Framework (CLF), Canada

Key accomplishments June 2018 – May 2019

The CLF is proud to be entering its 10th year of operation. **10 Years Strong** is the theme for a year-long celebration of our successes. Below are examples of key activities in the previous 12 months.

EDUCATION

Published four issues of *Pathways* magazine

- High profile authors from Canada, USA, Australia, Scotland, Wales, Israel
- Articles on advocacy, educational, research, surgery, case studies and self-management

Produced second edition of patient education booklet

- 20 page booklet updated to include 4 extra pages on self-care and compression bandaging
- Now available in both of Canada's official languages (English and French)



Comprehensive website

- Updated summer of 2018 with links to patient videos and resources for health professionals
- Over 100 pages of educational content – all reviewed and rated by an education committee before posted to the website

ADVOCACY/AWARENESS

Published Lymphedema Awareness Calendar

- 12 months of inspiring personal stories of promoting self-management of lymphedema
- Fundraiser for both the CLF as well as regional associations

Exposure in Canada's national news magazine

- Media collaboration with actress Kathy Bates profiling her personal story within a two-page spread featuring lymphedema in prestigious *Macleans* magazine



RESEARCH

Outcome Measures

- Disseminated ILF Outcome Measures survey through the network of regional associations
- Strong response with 713 respondents (64.73% were patients)

LIMPRINT

- Completed analysis of Canadian Core Tool data and did comparison with international data
- Presented material orally regional conference and prepared poster for 2018 ILF conference.

PARTNERSHIPS AND SUSTAINABILITY

Industry Partners

- Collaborated with BSN for educational webinars
- Partnership with Mediven for exclusive sponsorship of 2019 Lymphedema Calendar
- Continued industry sponsorship of *Pathways* magazine



Affiliate Partners

- Implemented new funding model - allocating an affiliate fee to independent regional lymphedema associations to support the “umbrella” model of providing national support
- Hosting quarterly cross Canada calls –connecting nine regional associations

International Lymphoedema Framework

- Collaboration with ILF through Canadian representation on their board and helping to organize their 2019 conference

Other Country Frameworks

- Working closely with our colleagues at the American Lymphedema Framework Project in ILF 2019 conference planning

SUMMARY

As a charitable organization, the CLF is still in its infancy. However with hard working volunteers, strong partnerships and continued industry support, it has grown to be a credible and reputable organization – establishing once voice for lymphedema in Canada.



Partenariat Français du Lymphoedème (PFL), France

The french framework called Partenariat Français du Lymphoedème or PFL has been promoting actions along with the patients support group AVML “Association Mieux Vivre son Lymphoedème” and the national scientific societies, namely SFL « Société Française de Lymphologie » and SFMV « Société Française de Médecine Vasculaire ». International actions have been undertaken with other frameworks, the Italian and the Japanese ones particularly.

Identification of the Out of pocket money paid for the treatment of lymphoedema in France

The results are now published. Thank to Grégoire Jenica Pastor, Mercier Mercier and all the patients who took part into the study.



Publication

Out-of-pocket payments, vertical equity and unmet medical needs in France: a national multicentre prospective study on Lymphedema. PLoS One 2019;14(5):e0216386.

Abstract

Out-of-pocket payments might threaten the vertical equity of financing and generate unmet medical needs. The main objective was to assess the vertical equity of outpatient out-of-pocket payments for lymphedema patients in France. Twenty-seven centres, among which 11 secondary care hospitals and 16 primary care practices participated in this prospective national multicenter study. We measured the lymphedema-specific outpatient out-of-pocket payments over 6 months. The vertical equity of out-of-pocket payments was examined using concentration curves, the Gini coefficient for income, the Kakwani index, and the Reynolds-Smolensky index. We included 231 lymphedema patients aged 7 years or more, living in metropolitan France, and being able to use Internet and email. After voluntary health insurance reimbursement, the mean out-of-pocket payment was equal to 101.4 Euros per month, mainly due to transport (32%) and medical devices (26%). Concentration curves indicated regressivity of out-of-pocket payments. Total out-of-pocket payments represented 10.1% of the income by consumption unit for the poorest quintile and 3.5% for the wealthiest ($p < 0.05$). The Kakwani index for out-of-pocket payments was equal to -0.18. Regarding outpatient health care, French lymphedema patients face significant and regressive out-of-pocket payments, associated with an increased risk of unmet medical needs. Such results shed light on significant socioeconomic inequalities and bring into question the current financing arrangements of outpatient health care in France. ClinicalTrials.gov ID: [NCT02988479](https://clinicaltrials.gov/ct2/show/study/NCT02988479).

Actions

Discussions are going on with the national healthcare authorities addressing the inequities issues through the experiment of an integrated clinical pathway that would increase access to good quality care and reduce the out-of-pocket load for patients.

Identification of the barriers and facilitators for self-management in children and young people with lymphoedema

The projects have been done during the organization of an educational holidays camp in collaboration with the Italian, Canadian, Irish Frameworks and the Turin CMIESI centre for rare diseases and ILF.



Lymphedema is both a chronic and a rare disease starting early during childhood or later in adults. Chronicity makes self-management a key component of a successful treatment over a lifetime. Rarity adds specific yet non explored issues. The aim of the ILF Children Project is to identify the barriers and facilitators for self-management in children, adolescents, parents and professionals as key deliverers of care. The strategy and first results as well as the ongoing projects will be described and discussed during the session.

Description and main results of the experiments

Along with educational sessions in specialized centres and educational holidays camps visual art methodology was used to explore how children and adolescents perceive their lymphedema and treatment and conceptualise the barriers and enablers. Younger children drew pictures and all of them were given cameras and asked to take pictures that depicted their experience of learning self-management of their condition. The analysis of the data produced information on normal versus altered life, living with lymphedema, perception of self and parents or professional's delivery of care, and gave insights into cultural differences in self-care.

The parental experience of caring for a child or adolescent with lymphedema and the daily challenges of self-management and self-efficacy were captured during three individual semi-structured focus undertaken in English, French and Italian with professional simultaneous translation. The same was done with professionals in order to understand how they understand and implement self-management strategies and the influence of their own self-efficacy beliefs on the process. Phenomenological analysis of the parents' data identified four superordinate themes; the journey, treatment management, independence and psychosocial impact. They included ten sub-themes; bandaging/compression, professional support, holistic care, fear, self-efficacy, acceptance, friendship, guilt, distress and hope. Professional data were equally complex, and seven subthemes emerged of which readiness to self-management with children, professional perspectives on self-management, emotional burden, views on complex decongestive therapy, ways to practice and sole practitioner versus multi-disciplinary teams. All these results will be presented and discussed during the session.

The children strategy

The key outcome from these studies is the development of a conceptual framework for understanding self-management for this population. Quality of life tools are already being developed into five different languages (English, French, Italian, German and Danish). The last stage of validation will use an electronic platform QOL questionnaire against the age specific KIDSCREEN tool on a dedicated electronic platform available through social media. Self- efficacy tools for parents and adults will be developed. ILF Recommendations for changes in clinical practice with lymphedema children and interventions to support self-efficacy are being developed with the close participation of ILF frameworks and specialized centres around the world.



AVML, PFL and Vascular and Lymphology department weekend for children with lymphoedema and their families

Isabelle Quéré, Chair of the Partenariat Français du Lymphoedème





National Lymphoedema Framework Ireland (NLFI), Ireland

Report 1st June 2018 - 31st March 2019

In the past year NLFI held five board meetings and three teleconferences. Our main focus in 2018 was the running of a one day children's lymphoedema camp in Clonmel on October 20th. We secured sponsorship from six companies to cover the cost of the camp, it was officially opened by Prof. Peter Mortimer and Dr. Rosemarie Watson from Our Lady's Children Hospital, Dublin. Through an application process we invited ten children with lymphoedema/lipoedema, their parents and siblings. This fun camp included a group educational session, Q&A session for parents with Prof. Mortimer and Dr. Markus Killenger (Dr. Vodder Clinic), movement/interactive classes, one to one bandaging/education with therapists and an aqua lymphatic class. Lunch, refreshments and goody bags were included on the day. Feedback from everyone that attended was extremely positive and encouraging.

Plans are in progress to run a similar children's camp this October and to run it alongside an education day for approximately thirty adults with lymphoedema/lipoedema. This day will give us an opportunity to share guest speakers, give our sponsors greater exposure to patients with lymphoedema and we hope that our therapists will again give one to one education/bandaging sessions.

We extended our stakeholdership during the year and were delighted to welcome five new stakeholders. Two of our stakeholders attended the 2018 ILF conference in Rotterdam bringing feedback to all. NLFI are now beginning the process of applying for charitable status.

This year we agreed that the Education Benchmark Statements would sit better with continuing or post graduate education in Ireland. Members are communicating with HSE working groups and with relevant professionals running University medical and nursing programmes, with a view to finding the best route forward.

We also contributed to Chronic Oedema Outcome measures with 127 responses from Ireland and look forward to receiving the results of the survey.



Italian Lymphoedema Framework, (ITA.L.F), Italy

Short Report of ITALF Activities 2017-2018

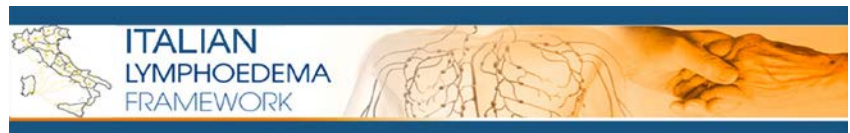
ITA.L.F. ACTIVITY SINCE JUNE 2018. CARRIED OUT AND PLANNED

- 1) Italf has continued with free enrolments in the association; at present there are 370 subscribers (members) including medical doctors, physiotherapists, patients, companies and voluntary associations.
- 2) Currently, it is funded by small companies with interest in the sector and what remains from the budget of the National Congress.
- 3) In collaboration with the Directorate General of Legal Medicine of the Italian National Insurance Agency (INPS), it has drawn up a document safeguarding patients affected by primary or secondary lymphoedema which the agency has published on its own site and shared with all the "medical-legal commissions" on Italian territory responsible for assessing (and granting the consequent legal benefits) of the disability caused by the illness.
The concept has been accepted that if a sick person takes care of himself (with limited justified absenteeism in a month, as per legal provisions) this entails a minor cost for the state, both in terms of welfare and social security (perhaps the original document should be translated into English?).
- 4) In the summer of 2018, two campuses were entirely dedicated to patients (in the Basilicata region, where 18 patients and 6 operators participated, in full, and in the Piemonte region, where 15 patients with post-mastectomy lymphoedema participated partially).
- 5) The 4th National Congress of the association was organized (30th November and 1st December in Genoa) where, due to the numerous participations, over 100 participants, it was not possible to put them into practice with active participation. At the congress, some LIMPRINT data was presented by Christine Moffatt, and for the first time in Italy, an entire session was dedicated to Lipoedema, with the participation of the newly-founded association "Lipoedema Italia Onlus", with its President (doctor/patient Valeria Giordano) and other members of the Board of Directors.
- 6) Extensive emphasis was placed on ILF data collection with regards to a further survey, parallel to that of LIMPRINT, which takes the name of ILF SURVEY MONKEY. A personal appeal was sent to each member of the association through a message from the association using their "mailing list".
- 7) A small volume (70 pages), which is illustrative and popular, has been prepared in collaboration with "Associazione SOS Linfedema", (chaired by the patient Francesco Forestiere) called "Vivere e partecipare con il linfedema", (living and participating with lymphoedema), aimed not only at patients but also family doctors, companies, voluntary workers and specialists. The book contains elementary notions on lymphoedema and its "management" as well as all the regulations and assistance introduced in Italy over the past two years. 5000 copies of the book have been printed and an online version exists which can be entirely downloaded from the ITALF site and SOS lymphoedema sites.
- 8) The association is monitoring and intervening on an institutional level in the various Italian regions with regards to the implementation of the Ministry of Health guidelines with the consequent implementation and start up of the assistance activities provided for in the document itself. To this end, particular attention is being placed on the choices of regional references, which, in some cases, appear to be "improvised" and not "congruous" with the real experiences of the care centres, with



possible "damage" which can derive to the quality of assistance given to patients.

- 9) The next V National ITALF Congress is being organized (to which some ILF members will be invited), and it will be held in Naples on 18/19th October 2019.
- 10) Initiatives of the " Campus" type will also be funded this year, too, responding in a balanced manner and taking into consideration the requirements of all concerned, which will come from the territory in favour of the patients, and for the communication of information on the disease, both to patients as well as families.





NLNet, the Netherlands (Dutch Lymphoedema & Lipedema Framework)

Representation of interests: NLNet as a source of information

In 2018, many questions have been asked at NLNet, these were all answered. The question topics were mainly:

- Oedema in combination with another disorder and / or operation and what to do then
- Questions and results with regard to new developments
- Diet and self-management with lymph & lipoedema, what helps? Where can we learn something?
- How to treat oedema regarding areas such as face, scrotum, breast/chest area, etc.

Support groups activities 2018:

Support group meetings

NLNet Traveling Lottery Cafe

Product carousel

Regional Coordinators Day

Lymphedema

Quality standard Compression aids care

As a patient association, NLNet has taken the initiative from its independent position of representing the interests of the patient to address the issue of compression device care with health insurers and our ministry for health VWS.

Lipoedema

Expert group Lipoedema

The expert group of lipoedema met three times in 2018. There was great attention to the question of how to gain more awareness in the first line of healthcare; the general practitioner. The idea arose to make a pocket information card for this profession. This is expected to be realized in 2019. This card should also be available for dietitians and surgeons who have little knowledge of lipoedema.

Young people

Youth weekend

A successful Youth Weekend was organized for young people up to 25 years in 2018. During the weekend there were very nice pictures taken which demonstrate that you also can look beautiful with wearing compression garments!

Facebook page for young people with lip and lymphedema

A Facebook page has been created especially for young people with lip and / or lymphedema. This is a NLNet group.



Swiss Lymphoedema Framework (SLF), Switzerland

Activities of the Swiss Lymphoedema Framework June 2018 – March 2019

The period from June 2018 to March 2019 brought us two results, one rather negative (or at least difficult) and one clearly positive:

Difficult is that we are still searching for a board that would adequately represent the scattered lymph scene in Switzerland in a powerful umbrella organization - unfortunately with little success. It seems that any existing organization would prefer to work for itself rather than join forces - while the latter certainly would enhance the effective and nationally binding elimination of the still existing deficits in diagnostics and treatment.

On the other hand, it was very positive that we were able to participate in the ILF-COM project. At this point, we are eagerly awaiting the results.

Anna Sonderegger, Chair Swiss Lymphoedema Framework





Anatolian Lymphedema Association-ALA (Turkish Lymphedema Association)

Anatolian Lymphedema Association-ALA (Turkish Lymphedema Association) has been formed in July 2014 bringing together health care professionals and patients with lymphedema. Our goal is to increase the awareness and education among healthcare providers, patients and public, on the field of lymphedema. We also aim to help patients to reach early and efficient therapies and improve their quality of life.

ALA provides a platform for interdisciplinary branches and engages health professionals like physicians (PMR, Vascular surgeon, breast surgeon, gynecologist, oncologist, nuclear medicine) physiotherapists, nurses, psychiatrists and technicians; with the patients. Our mission is to be a collaborative association which strives to promote qualified lymphedema management, education, awareness and research in Turkey.

The Activities Performed between June 2018-May 2019

1. Annual Symposium of ALA was held between 5th-6th October 2018, in İzmir with multidisciplinary and International participation. Anatomy, pathophysiology, differential diagnosis, all aspects of treatment, prevention, lipedema, pediatric lymphedema, genital lymphedema, genetic of lymphedema were all covered in the sessions of this meeting. Also workshops have taken places on different topics comprising; complex decongestive therapy (CDT) for upper and lower lymphedema, ultrasound in diagnosis and follow-up of lymphedema and, kinesiotaping for lymphedema.
2. A half day Educational Meeting for patients and their families was also conducted as a part of this symposium. General information on skin care, treatment approaches, self-management techniques were undertaken. The questions and expectations of the patients were discussed together with the guidance of lymphedema specialists and other health professionals.
3. An Erasmus project (KA-104) with international stakeholders entitled as 'The Education of Parents having children with lymphedema' was submitted and the final decision is expected on August 2019.
4. Two Educational Courses for health professionals have been held:
 - a) Upper Extremity Lymphedema Rehabilitation Course, Ankara, 2th March 2019
 - b) Lower Extremity Lymphedema Rehabilitation Course, İzmir, 9th March 2019
5. Lymphedema Awareness Day, 6th of March 2019 was celebrated in Hacettepe University Conference Center, Ankara. An educational conference was held for the patients; the difficulties of the patients, expectations, state of play were also argued out. Presents like special pillows for upper extremity lymphedema patients, lymphedema bracelets and butterfly pins were given as a memorable gift.
6. Television program and broadcast announcements were carried out by the president and vice president of ALA-Professor Borman and Prof Ayhan, on the day and week of 6th March.
7. Newspaper report about 'Innovations in the field of Lymphedema Treatment' was published in one of the best-selling newspaper, on the Lymphedema Awareness Week. (7th of April 2019). The advanced pressure garment products, pneumatic compression pumps and materials for self-management, were discussed in this interview.
8. In Turkey; to take the title of 'Turkish' needs a lengthy and laborious process for the nonprofit associations and organizations. An organization or association does not have a right to use Turkey or Turkish Titles in forming an association. There are several criteria for submission to take 'Turkish' title: The time span of an association should be at least 2 years, should have performed at least 3 symposium or congresses, having at least 3 branch or offices, having enough number of members and having activities for community and health society and should have participate or represent international activities.



- ALA has prepared a master file and submitted last December to take the name of 'Turkish Lymphedema Association', to the Department of Associations. The supervisory authority approved the submission. We are waiting for approval of Turkish Ministry of Health Authority, as the final step.
9. We supported and donated the bandaging materials and compression garments of poor and needy 5 patients from the budget of ALA.
 10. The arrangements of the 1st Lymphedema Congress with international participation; which will be held in Istanbul between 11-13 October 2019, are going ahead. An educational program for patients and families will as well as workshops in main areas of lymphedema treatment will also take place in this congress.

