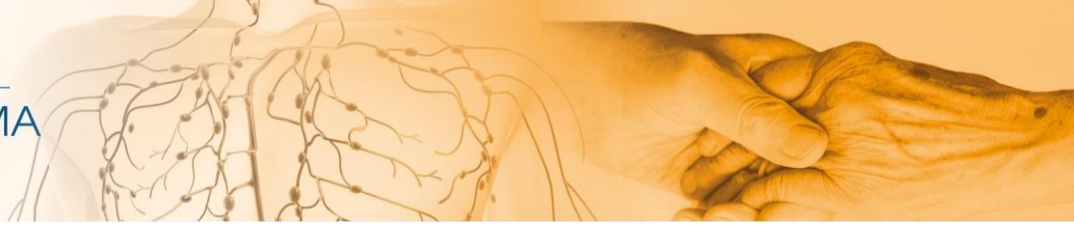


# National Lymphoedema Framework Annual Reports June 2018

## Contents

Canadian Lymphedema Framework (CLF), Canada .....	2
National Lymphoedema Framework Ireland (NLFI), Ireland .....	3
Italian Lymphoedema Framework, (ITA.L.F), Italy.....	4
ILF Japan (ILFJ), Japan .....	5
NLNet, the Netherlands.....	6
Lymphoedema Association of South Africa (LAOSA), South Africa .....	7
Swiss Lymphoedema Framework (SLF), Switzerland .....	8
Anatolian Lymphedema Association-ALA (Turkish Lymphedema Association) .....	9
American Lymphoedema Framework Project (ALFP), USA .....	11



## Canadian Lymphedema Framework (CLF), Canada

### Key accomplishments June 2017 – May 2018

Now in its 9<sup>th</sup> year, the staff and volunteers of the Canadian Lymphedema Framework have just completed another year of great accomplishments:

#### Education

##### Delivered 2019 bilingual national conference

- 325 participants from 10 countries
- Invited speakers: Dr. Tobias Bertsch, Dr. Alex Munnoch, Prof. Christine Moffatt and Dr. Isabelle Quéré
- Special paediatric lymphedema workshop led by Dr. Isabelle Quéré and Dr. Catherine McCuaig
- Hospital round table discussion on treatment protocol
- One day concurrent course for primary care nurses: Diagnosis and Treatment of LE

##### Published four issues of *Pathways* magazine

- Summer 2017, Fall 2017, Winter 2018 and Spring 2018
- Contributors from Canada, Netherlands, USA, Britain and Scotland
- Topics included surgery, exercise, skin care, patient-centred approaches, research advances and case studies

##### Produced French version of patient education pamphlet

- 20 page booklet highlighting self-care and compression bandaging
- Now available in both of Canada's official languages

##### Launched Resource Toolkit for health professionals

- PowerPoint presentation template for nurses orientation
- Slide bank of photos for presentation use

##### Collaborated with BSN for educational webinars

#### Advocacy/Awareness

##### Engaged in awareness across Canada

- Collaborated with 8 provincial associations on a 2 page insert on lymphedema in *MacLean's*, Canada's largest news magazine with 2.4 million readers
- Included article by actress Kathy Bates (LE&RN ambassador for lymphedema in the USA)

#### Research

##### LIMPRINT

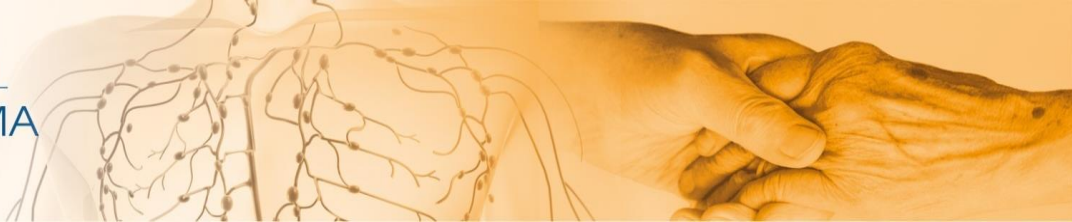
- Participated in International Lymphoedema Framework's prevalence study
- 68 participants followed in London, Ontario
- one of only a few sites using all the LIMPRINT tools
- mostly lower-limb, non-cancer related – high levels obesity and mobility issues

##### Established updated prevalence estimate for lymphedema in Canada

- New standardized chart and accompanying references for use in presentations and advocacy efforts
- More than 1 million Canadians living with lymphedema and/or chronic edema (for 36 million population)

##### Conducted reimbursement survey

Detailed results showing inequity across provincial health care in reimbursement – to support local advocacy efforts



## National Lymphoedema Framework Ireland (NLFI), Ireland

### Report 1<sup>st</sup> June 2017 - 31<sup>st</sup> May 2018

In the past year NLFI held four board meetings and two teleconferences. We were delighted to be among the nine countries that presented data for LIMPRINT during the conference in Siracusa with three of our members attending the conference, bringing feedback to all. During 2017 we secured sponsorship from six medical supply companies, they have been provided with an ad on our website. Our chairperson Meadbh Mac Sweeney volunteered in the International Children Lymphoedema camp in Italy and we arranged sponsorship for two Irish children to attend this camp.

Since January preparations have been made to run a Children's Lymphoedema Camp in Clonmel in October 2018. We are in the process of securing sponsorship for this camp and have also applied for a grant to help with costs. A flyer has been launched on our website and Facebook page. This fun interactive camp will be the first of its kind in this country to address both the physical and mental difficulties brought about by lymphoedema in children. It will include a group educational session, a movement class, one to one education with therapists (for the children and parents) and an aqua lymphatic class with lunch and refreshments included. It will be officially opened by Prof. Peter Mortimer and we hope to host a minimum of ten children (5-16years). We have also invited representatives from the HSE and ILF. All volunteers and therapists for the camp are in the process of completing a Children's First programme and obtaining Garda clearance.

We have extended our stakeholdership during the year and eleven invitations have just been sent to new interested stakeholders.

Towards the end of 2018 and 2019 our focus will be on developing lymphoedema education programmes to present to nurses/GP's and healthcare workers in Ireland. It is hoped we can contribute to standardizing information and lymphoedema care across the country.



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

### Short Report of ITALF Activities 2017-2018

In the last year, also in light of the approval of the new rules on health care for patients with lymphedema issued by the Italian Ministry of Health on our solicitation and with our collaboration, ITALF has promoted more initiatives of dissemination and information in events open to health workers, patients, peoples, voluntary associations, companies and politicians, in various regions of Italy, and precisely: Sicilia, Calabria, Puglia, Marche, Basilicata, Campania, Umbria, Lazio and Piemonte. A number of participants between one hundred and fifty and three hundred peoples joined the events

Among other initiatives:

- ✓ The organization of a Campus for 20 patients with primary and secondary lymphedema aged between 19 and 75, held in the first week of August 2017 on the slopes of Mountain Pollino, in Basilicata. During the Campus, there were several activities of assistance, education, information and ludic aspects that aroused great satisfaction among the participants and the volunteer workers who collaborated (Physiotherapists, doctors, psychologists).
- ✓ On 7-10 June 2018, a new Campus is scheduled in Piemonte Region, with health operator volunteers from the municipality of Alba, aimed at patients with secondary lymphoedema
- ✓ On July 8-15, the replication of the initiative last year on Pollino Mountain.

Also other 'political' initiatives have been undertaken:

- ✓ In Italy, patients with cancer disease benefit from the exemption from sharing health care, both for diagnostic investigations and for therapies. We have identified, however, about 15,000 subjects judged healed by the tumour, who have lost the exemption, but who remain with the secondary lymphedema caused by the tumour without more protection. We have reported the problem to the Ministry of Health that is providing to solve the problem with dedicated codes.
- ✓ We have also officially interested the National Social Security Institution (INPS) so that patients with primary and secondary lymphedema can benefit from reduced monthly working hours to be treated and in the specific judgment of disability and handicap.

The Heads of the Authority are preparing a document to be sent to the commissions, judging during the visit, which will be reviewed by us before the officialization.

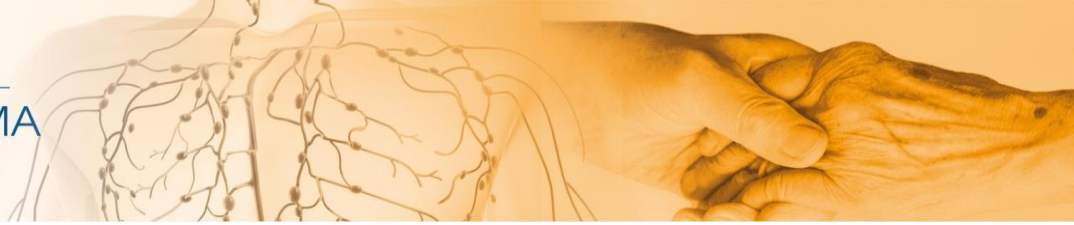
Together with the Association of patients SOS Lymphoedema, we are also organizing a national network of 'patronage', present in the territory that will take care, free of costs, to follow the paperwork necessary to patient care.

We are also preparing a detailed information leaflet explaining to patients, family doctors, caregivers and health professionals how to deal with and solve the problems of the daily life patients suffering from lymphoedema.

Next National ITALF Congress will be held in Genoa the 30 November and 1 December 2018.

<b>Comitato Esecutivo</b>
<b>Presidente:</b> Dr. Sandro Michelini (RM)
<b>Consiglieri:</b> Dr. Franco Forestiere (SR) Vice Presidente
Dr. Domenico Perrone (LE) Segretario
Dr. Marina Cestari (TR) Tesoriere
Dr. Massimo Favini (MI) Dr. Bertelli Matteo (BS)
<b>Comitato Scientifico</b>
<b>Coordinatore:</b> Dr. Maurizio Ricci (AN)
<b>Comitato Tecnico</b>
<b>Coordinatore:</b> Dr. Piantadosi Angela (NA)
<b>Sede Sociale:</b> Via Unione Sovietica 1 Siracusa <a href="http://www.italf.org">www.italf.org</a>

Dr. Sandro Michelini  
President of ITALF



## ILF Japan (ILFJ), Japan

A short report on the important activities of the International Lymphoedema Framework Japan in 2017.

Important activities in 2017 include organizing the annual conference, publishing the open access journal “Lymphoedema Research and Practice”, and renewing the website [www.ilfj.jp](http://www.ilfj.jp)

Professor Junko Sugama from Kanazawa University, a member of the board of directors of ILF Japan, organized the seventh annual conference from the 14<sup>th</sup> to the 15<sup>th</sup> of October 2017 in Kanazawa City.

The key theme of the conference was “Progress of Nursing Science by Multidisciplinary Innovation”. The conference was held in conjunction with two other domestic scientific and practical conferences: The 5<sup>th</sup> Annual Meeting of The Society for Nursing Science and Engineering, and the 11<sup>th</sup> Annual Meeting of the Society of Nursing Practice.

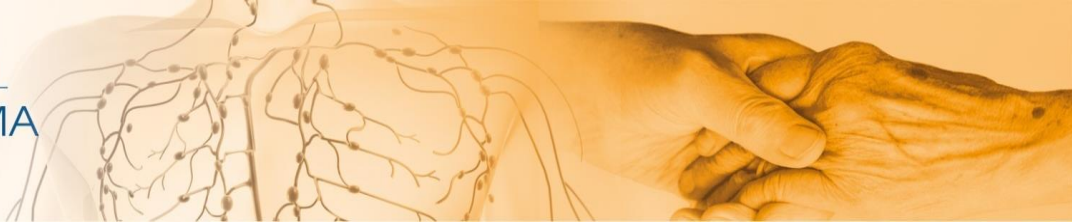
During the conference, Professor Christine Moffatt provided a special lecture entitled “Development of New Global Partnerships through the LIMPRINT study” and Professor Isabelle Quéré supervised young Japanese researchers to progress the study of oedema. 150 free papers were presented and discussed during the conference.

Secondly, ILF Japan has been publishing original articles and review articles in our open access journal. It covers all aspects of prevention and treatment of chronic oedema. Two research articles and two contributing papers are published in the current issue (vol. 5. no.1; <https://www.ilfj.jp/pdf/toukou-5-1.pdf>).

Last year, Japanese members attended the ILF conference in Syracuse, Sicily to present our recent activities regarding technology-based skin and wound assessment by Professor Hiromi Sanada and Dr. Gojiro Nakagami from the University of Tokyo. Professor Junko Sugama and Dr. Misako Dai from Kanazawa University reported the prevalence study of oedema in Japan, and they were awarded for their significant contribution to the LIMPRINT project.

ILF Japan is doing great work to move lymphoedema management forward!





## NLNet, the Netherlands

### Highlights 2017-2018

The Dutch Lymphoedema and Lipoedema Framework NLNet was founded with a primary goal of providing advocacy, education and patient support.

### Task Force medical devices for lymphoedema patients

Co-operating with the umbrella organizations of physical therapists, skin therapists, and suppliers of medical devices, the problems a large group of patients face when trying to get compensation for their medical devices are brought to the attention of VWS and the health insurance companies. The independent position of NLNet is of great importance and influence.

### Medical devices carousel

NLNet provides producers of medical devices with a platform in order to be able to introduce new materials to lymphoedema and lipedema patients. As the first carousel was a great success, two of these conferences will be held every year.

### Support groups for lymphoedema and lipedema patients

Meetings for lymphoedema and lipedema patients are held regularly in the various provinces. Many different subjects are discussed, like self-management, taking control of re-integration, and basic needs concerning lymphoedema and lipedema. Many people come to these meetings, showing that there is still a great need for information and peer support.

### Lipedema Expert Group

This group consists of medical professionals, therapists and patients. As lipedema has not been officially recognized as a disease, the group works hard at setting a standard of care and simultaneously creating awareness among primary health care providers.

### Meetings for fellow sufferers and exercise workshops

In 2018, there have been several 'fellow sufferers-cafes' and exercise workshops throughout the country. Here, patients are able to talk to each other about their condition and exercise together, in a safe environment. Locations for these meetings are usually medical offices or private practices affiliated with NLNet.

### Young adults platform

For the first time in the history of NLNet, a special weekend for young adults was held in 2017. A combination of information, contact with fellow sufferers, and a whole lot of fun made this weekend a great success!



## Lymphoedema Association of South Africa (LAOSA), South Africa

Thank you for the opportunity to inform you of what we have been up to. 2017-2018 was an exciting year for us, as we became a member of the International Lymphoedema Framework!

LAOSA's main vision during this time was to create awareness in the emerging field of lymphatic therapy in South Africa. As more therapists have been trained, our passion has been imprinted on their hearts and therapists have given a bit of themselves for the growth of awareness.

We have had a reshuffle in our executive committee, which saw Suzi Davey step down as president and Tamryn Vivian come in to take over the reins. Jen Dunn has swept in as secretary and a new research portfolio has been introduced with Colleen Marco graciously accepting the position. Maxine Blane continues as our marketing lady and Rogini Pillay and Natalie Elias handle all membership queries. Erika van Der Mescht heads up education and Isabeau Neethling manages our money as treasurer. Assisting to keep it all together and heading up our medical aid portfolio is Candice Kuschke. A quick thank you to this wonderful team!

In 2017, we presented and were invited to speak at 14 different events and conferences including the Wound Healing Association of South Africa conference and the SAPHEX conference (South Africa's largest pharmaceutical manufacturing event).

We also attended patient support groups and open day events at therapist's practices. LAOSA has a representative at the Christian Barnard Wound Care monthly ward rounds where patient care is discussed and lymphatic therapy is being introduced as an integral treatment option. We belong to the Cancer Alliance, which highlights various options available to cancer patients. Although Suzi Davey has stepped down as president, she has remained an executive committee member on the Limb for Life network and has invited the new president to attend future meetings.

Cape Town Breast Cancer Forum meetings held in Cape Town, represented LAOSA during steering committee meetings, engaging with medical practitioners. LAOSA was visible at all certification events run by the ILWTI Course nationwide and encouraged new therapists to become members of the association.

We had fun being invited to speak on air for a national radio station about lymphoedema and LAOSA was represented at the fifth world Physiotherapy Conference in Dubai last year November.

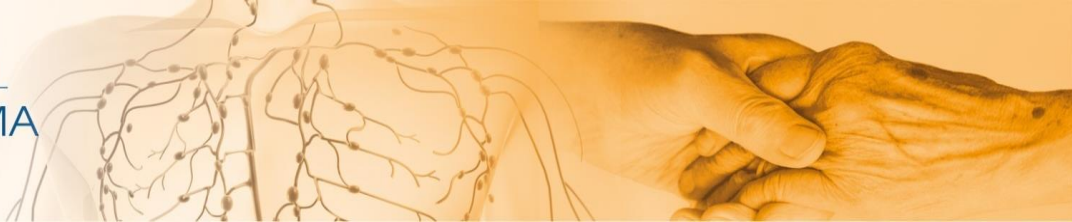
LAOSA also upgraded our accounting system to a formal system and provided training support for the treasurer, Isabeau Neethling.

Of greatest importance, LAOSA managed to complete a Position Statement on Lymphoedema Management. Our plans are to publish our statement in the Wound Healing Association of South Africa's Journal.

Our vision this year is to continue raising much needed awareness throughout the medical world as well as to the general public, and to provide support to both patients with lymphatic conditions as well as to the therapists who treat them.

Thank you for supporting our organisation.

Tamryn Vivian  
LAOSA President



## Swiss Lymphoedema Framework (SLF), Switzerland

### Activities of the Swiss Lymphoedema Framework June 2017 – May 2018

The Swiss Lymphoedema Framework (SLF) activities between June 2017 and May 2018 covered three important points:

**1. Forming a Board of Directors** -> <https://swisslymph.ch/en/about/1/board>

After the foundation in July 2016, one of the most important tasks was to develop the structures for an efficient functioning of the organization. One fundamental aspect was the establishment of an Executive Board. It is still not complete, but we are working on it. We try hard to find representatives from all relevant organizations and groups - not an easy task as most of the requested persons are already very strongly engaged in terms of time.

**2. Developing a website in four languages (D, F, I, E)** -> <https://swisslymph.ch/en>

With the basis of a successful fundraising among very committed physiotherapists we were able to create an informative website.

**3. Organizing an Open Space Meeting with the ILF** -> <https://swisslymph.ch/en/news/1/open-space-meeting-with-the-international-lymphoedema-framework>

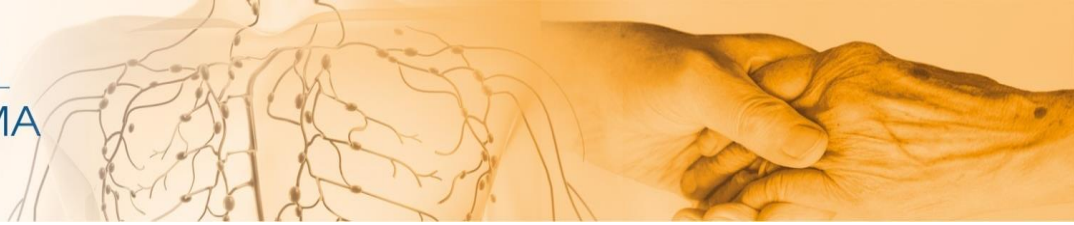
We had two main goals:

1. To bring all relevant stakeholders together to discuss the issues of major importance to them.
2. To fulfil one of the conditions to become a National Framework recognized by the ILF.

Anna Sonderegger,

Chair Swiss Lymphoedema Framework

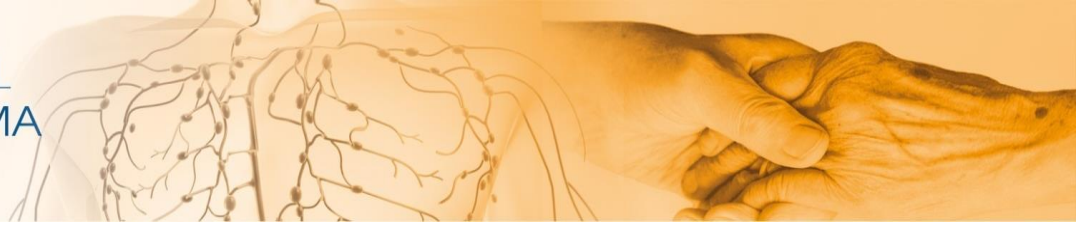




## **Anatolian Lymphedema Association-ALA (Turkish Lymphedema Association)**

### **The Activities Performed between June 2017- May 2018:**

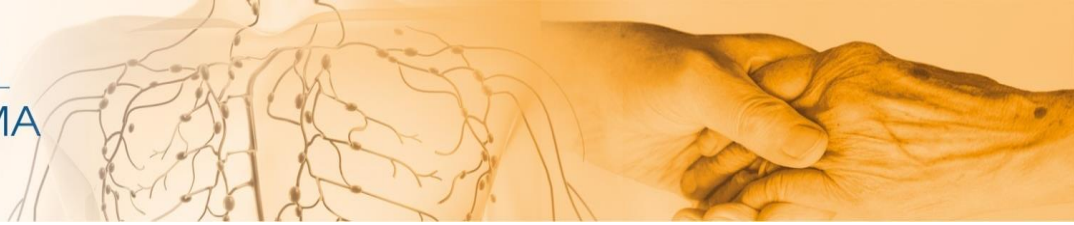
1. One branch and three representative offices of Anatolian Lymphedema Association (ALA) has been established in the late months of 2017. İzmir ALA Branch, İstanbul Representative Office, Erzurum Representative Office and Edirne representative Offices have begun to work under the umbrella of ALA.
2. Annual Symposium of ALA was held between 29-30 September 2017 in Ankara with multidisciplinary participation. Anatomy, pathophysiology, differential diagnosis, all aspects of treatment, prevention, lipoedema, paediatric lymphedema, genital lymphedema, kinesiotaping were all covered in the sessions of this meeting. In addition, workshops have taken places on different topics comprising; complex decongestive therapy (CDT) for upper and lower lymphedema, CDT for genital lymphedema and kinesiotaping for lymphedema.
3. 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.
4. Three Educational Courses for health professionals have been held:
  - a) Introduction to Lymphedema and Lymphedema Rehabilitation, Manisa, 2nd December 2017
  - b) Upper Extremity Lymphedema Rehabilitation Course, İzmir, 17th March 2017
  - c) Lower Extremity Lymphedema Rehabilitation Course, İzmir, 12th May 2017
5. Lymphedema Awareness Day, 6<sup>th</sup> of March, was celebrated both in Ankara and İzmir by the head office and İzmir branch. An education conference was held; 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 programme and broadcast announcements were carried out by the president of ALA- Professor Borman on the week of 6th March.
7. Newspaper report about 'Approach to Cancer-related Lymphedema' was published in one of the best-selling newspaper, on the National Cancer Week. (7th of April 2018)
8. As the reimbursement of compression garments was low or lacking in Turkish Health Insurance System, ALA prepared a file indicating the reasons for requisiteness of the reimbursement and brought up the suffering of these patients, and presented it to the Social Security Administration on June 2017. There have been several meetings and the resolution committee agreed on magnifying the reimbursement for grade 2 and 3 lymphedema patients. Now  $\frac{3}{4}$  cost of the compression garments are under reimbursement, since March 2018.
9. To take the title of 'Turkish' needs a lengthy and laborious process for the non-profit associations and organizations in Turkey. An organization or association does not have a right to use Turkey or Turkish as 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 month to take the name of 'Turkish Lymphedema Association', to the Department of Associations. The supervisory authority approved the submission and we are waiting for approval of Turkish Grand National Assembly.

10. We supported and donated the bandaging materials and compression garments of poor and needy four patients from the budget of ALA.
11. The arrangements of the third Lymphedema Symposium with Multidisciplinary and International Participation has been completed. Warm-ups are going ahead.





## American Lymphoedema Framework Project (ALFP), USA

### Annual report of ALFP accomplishments 2017 – 2018.

- 11th systematic review has been published in Summer 2017 on skin and wounds
- Leadership role in LE protocols at Gynecology Oncology Group, Alliance, CALGB with 5-year findings to be reported in 2018-19, including at the 2018 ILF meeting
- Collaboration with MSKCC, Dr Tim Whalen in Toronto, Mohammed in Saudi Arabia, Miriam in Ghana, Lize Maree in SA in sharing protocols.
- Currently updating CAM systematic review
- Leading development of clinical practice guidelines for Oncology Nursing Society in LE to extend and update Putting Evidence into Practice guidelines (Jane Armer, Marcia Beck, Mei Fu and others).
- Mentorship for students/fellows from high school, undergrad, PhD, post doc, research assistant professor in lymphedema research at Missouri and beyond
- Look4LE app currently has 1390 publicly viewable 135-hr trained therapists.
- Mobile app continues in development
- Minimum data set continues in development
- Sosido partnership connects LE researchers and other stakeholders.
- Partnership in co-hosting 2019 ILF in Chicago

