

The American Lymphedema Framework Project: An Untapped Resource for Oncology Clinicians and Cancer Survivors at Risk of and Living with Lymphedema

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Background

- The American Lymphedema Framework Project (ALFP) was founded in 2008 as the first invited national framework of the International Lymphoedema Framework (ILF) based in the UK.
- The ALFP's mission is to improve lymphedema management in the US and globally.
- Based on the ALFP stakeholder meetings, two ALFP goals were prioritized:
 - (1) Define lymphedema management Best Practices
 - (2) Develop a minimum data set (MDS) to support research to improve lymphedema outcomes.

Methods

- Multidisciplinary lymphedema stakeholders established the ALFP mission and goals through 'open-space' stakeholder meetings.
- In promoting evidence-based best practices, teams comprised of ALFP steering committee members and other lymphedema experts conducted 11 systematic reviews on lymphedema management.
- Collaboration with engineering/informatics experts established novel technological tools for lymphedema management and research.

Minimum Data Set

- The overall goal is to provide an operational cyber infrastructure that collects, organizes, and disseminates up-to-date LE information.



- The ALFP is currently accepting applications to join and use the minimum data set.

LYMPHOEDEMA Mobile Platform

- A low-cost, fast, reliable way to self-monitor limb volume via smartphone.



- In beta testing now, plan to expand sites soon
- Verify algorithm, simplify process, wrap in an app
- Eventually, make software freely available

Lymphedema Systematic Reviews

Surgery – Cormier, Rourke, Crosby, Chang
Annals of Surgical Oncology (2012)

Exercise – Kwan, Cohn
Journal of Cancer Survivorship (2011)

CDT – Lasinski, Thrift, Squire
PM&R (2012)



Pneumatic Compression – Feldman, Stout
Lymphology (2012)

Palliative Care – Beck, Wanchai
Journal of Palliative Medicine (2012)

Self-Management – Ridner, Fu
Nursing Research (2012)

Psychosocial Impact – Fu, Ridner, Hu
Psycho-Oncology (2012)

Economic Impact – Stout, Weiss, Shih
Lymphology (2013)

Non-CDT – Rodrick, Poage
PM&R (2014)



Botanicals – Poage, Rodrick
PM&R (2015).

Skin and Wounds – Fife, Farrow, Hebert
ADV SKIN WOUND CARE (2017)

- The ALFP Leadership is represented on each manuscript by Janice N. Cormier & Jane M. Armer, among others.

Look4LE & Sosido

- **Look4LE:** searchable database of 135-hr trained lymphedema therapists.
- www.alfp.org/resources/map/ available as iPhone & Android app
- **Sosido:** Partner for ALFP Research Network
- Receive alerts for new lymphedema publications in your email inbox!



Conclusions

- Through continuing multidisciplinary partnerships, ALFP has an established leadership role in lymphedema risk-reduction, treatment, education, and research.
- ALFP has made a major contribution toward addressing prioritized issues identified by stakeholders to move the lymphedema field forward.

Resources

- All ALFP-Supported Systematic Reviews are available at www.alfp.org/research.
- Look4LE is available on the web at www.alfp.org/resources/map (apps are linked there).
- Register as a trained lymphedema therapist at www.alfp.org/resources/registration
- Sign-up for Sosido alerts at www.alfp.org/sosido.
- Inquire about the Minimum Data Set or the LYMPHOEDEMA Mobile Device at alfp@missouri.edu.