American Lymphedema Framework Project

The ALFP is a partner of the International Lymphoedema Framework

This report was produced in affiliation with the University of Missouri
American Lymphedema Framework Project

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Mission

The mission of the American Lymphedema Framework Project (ALFP) is to improve the management of lymphedema and related lymphatic disorders in the United States while contributing to global international improvement in this field. This will be achieved by defining best practices and developing a minimum data set to improve lymphedema outcomes. The ALFP will establish a leadership role in lymphedema risk reduction, treatment, education, health policy, and research. These outcomes will be achieved through a partnership among all lymphedema stakeholders.

The American Lymphedema Framework Project is a national multidisciplinary collaborative initiative developed under the leadership of Jane Armer, PhD, RN, FAAN, Director, and Joseph Feldman, MD, CLT-LANA, Co-Director, along with Christine Moffatt, PhD, RN, Clinical Director of the International Lymphoedema Framework (ILF) project, and Janice Cormier, MD, MPH, Executive Committee member. The ALFP is composed of nationally recognized clinical experts and investigators in the field of lymphedema. Headquarters for the ALFP are located at the University of Missouri Center for Lymphedema Research, Practice, and Health Policy (CLERPHP).

ALFP Steering Committee Members and ALFP Support Staff - 2009
Organizational Tree

- Director
- Co-Director
- International Advisory Board
- Executive Committee
- Industry Consortium
- International Lymphoedema Framework
- MU Center for Lymphedema Research, Practice, & Health Policy
- Steering Committee
- Stakeholders
- Researchers
- Third-Party Payers
- Industry Representatives
- Healthcare Professionals
- Patient Advocacy Groups
- Professional Organizations
- Best Practices Document
- Minimum Data Set
- Health Policy, Legislation, Reimbursement Committee
- Research & Dissemination Committee
- Minimum Data Set Committee
- Best Practices Document Committee
- Communication & Website Committee
- Stakeholder & Industry Relations Committee
Steering Committee

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Goals

The purpose of the ALFP is to improve clinical outcomes in patients with and at risk for lymphedema and related disorders. The four major goals of the ALFP, as outlined in the ALFP Business Plan, will advance the mission of the ALFP. The four goals and highlights of the progress achieved to date toward attaining these inaugural goals are summarized below.

   1.1. The revision and update of the U.K. Best Practices Document is currently underway. Working meetings of the ALFP Steering Committee took place in April and August 2009 to move this document forward. A literature search for the update began in October 2009 by an experienced reference librarian at the University of Missouri Health Sciences Library.
   1.2. Developed partnership with the American Cancer Society, which provided support for the initial Ad Hoc Steering Committee planning meeting, October 2008, Atlanta, Georgia; the ALFP National Stakeholders Conference, March 2009, Chicago, Illinois; and subsequent meetings to move forward the goals of the ALFP, including the update of the Best Practices Document.
   1.3. Developed additional partnerships with industry members to support existing evidence-based programs, to consult on development of further evidence-base, and to develop new approaches for diagnosis and treatment of lymphedema.

2. Develop methods for evaluating patient-based outcome measures by guiding the development of an ILF/ALFP Minimum Data Set (MDS) for the study of lymphedema outcomes nationally and worldwide.
   2.1. Under the guidance of Dr. Chi-Ren Shyu, the MDS Committee, and the Executive Committee, the ALFP has designed and developed methods for data collection via an internet-based information technology system. The beta test of the system will take place in a pilot study to be conducted in 2010.
   2.2. NIH grant preparation and submission for support of MDS project.
   2.3. Developed partnership with the American Cancer Society which provided support for the initial Ad Hoc Steering Committee planning meeting, October 2008, Atlanta, Georgia; the ALFP National Stakeholders Conference, March 2009, Chicago, Illinois; and subsequent meetings to move forward the goals of the ALFP including the development of the MDS.

3. Establish national center(s) of excellence for lymphedema and related lymphatic disorders that will provide a forum for quality research and education programs. To move this goal forward, the ALFP:
   3.1. Conducted a successful national stakeholders conference, which took place in March 2009, bringing together diverse stakeholders in the field of lymphedema to collaborate on how to improve the management of lymphedema in the U.S.
3.2. Created and distributed a lymphedema therapist survey to assist with determining the size and complexity of the problem of lymphedema from all causes and the current management practices in the U.S.
3.3. Submitted three abstracts and for those accepted, made presentations or posters at national and international conferences.
3.4. Prepared, submitted, and published manuscripts summarizing the activities and findings of the ALFP.

4. Contribute to the mission and goals of the International Lymphoedema Framework (ILF) programs. The ALFP has made significant contributions to the goals of the ILF in 2009.
4.1. The ALFP Executive Committee was invited to serve on the international advisory board of the ILF.
4.2. The ALFP was well-represented with a booth at the 1st International Lymphoedema Framework Conference, Conference & Exhibition, Royal Ascot, U.K., 4/23/2009.
4.3. Several members of the Executive and Steering Committee presented their research and moderated sessions at the 1st International Lymphoedema Framework Conference, Conference & Exhibition, Royal Ascot, U.K.
4.4. ILF representation was secured for the ALFP executive, steering, and advisory committees.
4.5. The ALFP committed to preparing a half-day workshop session on risk reduction at the upcoming 2nd International Lymphoedema Framework Conference in 2010.
4.6. The ALFP Executive Committee participated in the program planning for the 2010 ILF 2nd International meeting.
4.7. The ALFP was consulted and assisted with the establishment of the Canadian Lymphedema Framework.

The ALFP has made considerable progress on each of these four goals. A more detailed summary is provided in the following pages.
Strategic Planning Meetings

To advance the mission of the ALFP, several strategic planning meetings have taken place with the support of the American Cancer Society. The initial Ad Hoc Steering Committee planning meeting took place in October 2008, in Atlanta, Georgia. In March 2009, a one-day ALFP National Stakeholders Conference took place in Glenview, Illinois. This Open Space meeting brought together stakeholders in the field of lymphedema and identified ways to improve management of lymphedema and care of patients in the U.S. In April 2009, members of the ALFP steering committee met for one day in Ascot, U.K., prior to the ILF Conference. This meeting allowed the ALFP to continue toward advancing important goals identified during the stakeholders conference.

Another strategic planning meeting with the ALFP steering committee took place in August 2009, in Columbia, Missouri. During this time, the update for the U.K. Best Practices Document for application in the U.S. was reviewed, draft revisions were presented and edited, and a protocol for the literature search was prepared. Also, a final review of the lymphedema therapist survey was completed, a timeline for conducting a systematic review on lymphedema risk-reduction was set, and guidelines for the minimum dataset were developed. At the International Society of Lymphology 22nd Congress in Sydney, Australia, September 2009, a steering committee meeting was held for ALFP members in attendance, other interested American delegates, and international advisory committee members. A timeline of past meetings and future planned meetings for advancement of the ALFP mission is below.

<table>
<thead>
<tr>
<th>2008 Fall</th>
<th>2009 Spring</th>
<th>2009 Fall</th>
<th>2010 Spring</th>
<th>2010 Fall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ad Hoc Steering Committee</td>
<td>National Stakeholders Meeting</td>
<td>Steering Committee Meeting at ILF Conference</td>
<td>Steering Committee Meeting at ILF Conference</td>
<td>Steering Committee Meeting at NLN Conference</td>
</tr>
<tr>
<td>Atlanta, GA</td>
<td>Glenview, IL</td>
<td>Ascot, U.K.</td>
<td>Brighton Centre, U.K.</td>
<td>Orlando, FL</td>
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</tbody>
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Best Practice Document

A major goal of the ALFP is to produce a second edition of the ILF Best Practice Document, as well as adapt the document for lymphedema management specific to the U.S. A preliminary review of gaps and updates to the 2006 ILF Best Practice Document has been completed by expert clinicians for application to the health care delivery system in the U.S. and worldwide. The ALFP has established a protocol for consensus in performing the update of literature for the ILF Best Practice Document from 2004-2009. This protocol is consistent with that used by the ILF in the development of the ILF Best Practice Document. Upon completion, the document will be reviewed and endorsement sought by the ILF and ALFP advisory committees. Two-thirds of the literature search was completed from October 2009 to December 2009 by an experienced research librarian from the University of Missouri Health Sciences Center. Review and selection of the literature by two independent reviewers is currently in progress. Completion of editing, printing, and distribution of the updated document is projected for early 2011 at the 3rd ILF international conference.

Minimum Data Set (MDS)

A second major goal of the ALFP is to assist the ILF with the development of the minimum data set (MDS) for clinical and research use nationally and internationally. The MDS will be used to evaluate patient-based outcome measures worldwide. Methods of data collection have been developed, including the design and testing of an internet-based information technology system under the oversight of Dr. Chi-Ren Shyu, Director of University of Missouri Informatics Institute, to serve as a platform for the collection and transfer of data. Methods are currently being developed to ensure effective quality data management and analyses of aggregated data from the MDS.

The ALFP has begun organizing a pilot test of the MDS. Two key variables: symptoms and limb volume, will be piloted among several test sites. Data on these two variables will be collected by clinicians and researchers. Among current sites planning to participate in the pilot study are Sister Kenny Rehabilitation Institute, Ellis Fischel Cancer Center, and NorthShore University HealthSystem. Federal funds have been sought through the National Institutes of Health G08 mechanism to support the development of the MDS in an accelerated timeline.
Lympedema Therapist Survey

During the October 2008 ALFP planning meeting, there was consensus agreement among attendees for the need to assess the current scope of practice in lymphedema treatment in the U.S. Through discussion among meeting attendees, a web-based survey of lymphedema therapists in the United States was determined to be the most feasible method of assessment at this time. This need also emerged as a priority during the Open Space meeting in March 2009. A timeline documenting the process of survey development, implementation, and analysis is displayed in Figure 1.

Beginning in January 2009, a lymphedema therapist survey was developed by the ALFP Research Committee, led by Electra Paskett, PhD, and Mei Fu, PhD, RN, with assistance by Radhika Ramachandran, research assistant at Ohio State University, and under the guidance of the ALFP Executive Committee. Additional review and revision occurred on March 15, 2009, during working group meetings immediately prior to the ALFP Stakeholders Conference. Electronic review led to multiple revisions and refinements. Beta testing occurred using a web-based survey in October 2009 with 22 participants, followed by further survey review and revision. The final survey design was completed at the end of October and invitations to complete the survey were sent via electronic mail on November 4, 2009. Lymphedema therapists were invited to take the survey directly from the ALFP stakeholder email list. Also, educators, industry partners, and other partnership organizations (such as the National Lymphedema Network and the Lymphology Association of North America) forwarded invitations to their mailing lists. The survey was available for completion from November 4 - November 20, 2009, with 419 respondents at the time of the survey closing. A complete analysis of the results will begin in January 2010; however, a preliminary descriptive analysis has been completed and the results are presented in Table 1.

**Figure 1.** Timeline for lymphedema therapist survey development, data collection, and analysis.
# Lymphedema Therapist Survey

<table>
<thead>
<tr>
<th>Total Completed Surveys</th>
<th>419</th>
</tr>
</thead>
<tbody>
<tr>
<td>States Represented</td>
<td>46</td>
</tr>
<tr>
<td><strong>States with highest number responses</strong></td>
<td>%</td>
</tr>
<tr>
<td>Florida</td>
<td>9.3</td>
</tr>
<tr>
<td>California</td>
<td>7.6</td>
</tr>
<tr>
<td>Illinois</td>
<td>7.6</td>
</tr>
<tr>
<td>Texas</td>
<td>7.1</td>
</tr>
<tr>
<td>New York</td>
<td>7.1</td>
</tr>
<tr>
<td><strong>Therapist background</strong></td>
<td>%</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>49.5</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>33.8</td>
</tr>
<tr>
<td>Massage Therapist</td>
<td>12.9</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>Therapist training consisting of 135+ hour course (1/3 didactic; 2/3 hands-on)</strong></td>
<td>%</td>
</tr>
<tr>
<td>Yes</td>
<td>93.0</td>
</tr>
<tr>
<td>No</td>
<td>7.0</td>
</tr>
<tr>
<td><strong>Practice setting</strong></td>
<td>%</td>
</tr>
<tr>
<td>Hospital-based outpatient clinic</td>
<td>64.6</td>
</tr>
<tr>
<td>Private practice</td>
<td>25.8</td>
</tr>
<tr>
<td>Hospital-based inpatient service</td>
<td>13.5</td>
</tr>
</tbody>
</table>

Table 1. Preliminary descriptive summary of the ALFP lymphedema therapist survey findings
National Stakeholders Conference

The ALFP National Stakeholders Conference took place in March 2009, in Glenview, Illinois, with the support of the American Cancer Society. Over 70 stakeholders came together to identify issues in the field of lymphedema in the United States. Stakeholders included researchers, physicians, nurses, lymphedema therapists, other health care professionals, educators, industry representatives, and lymphedema patients/advocates. The Open Space method was the meeting format utilized during the conference. This method consisted of self-managed working groups where leadership was shared, diversity was encouraged, and personal empowerment was achieved1.

Priority issues identified in the field of lymphedema in the U.S. included the need to:

1) Address reimbursement challenges in lymphedema management and care
2) Promote research efforts to refine diagnostic standards and provide evidence for effective treatment
3) Improve patient support and education
4) Develop educational criteria for health care providers
5) Increase knowledge and understanding of lymphedema and related lymphatic system disorders in the U.S. and worldwide
6) Support evidence-based care
7) Further develop the credibility of the ALFP

A full report of the ALFP National Stakeholders was published in the fall 2009 issue of the Journal of Lymphoedema4 and selected findings were presented at national and international meetings.

Meeting Theme
“What can we do to improve the management of lymphedema and lymphatic system disorders in the United States?”1

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Medicare Evidence Development & Coverage Advisory Committee (MEDCAC) Meeting on Evidence-Base for Management of Secondary Lymphedema

On November 18, 2009, a Medicare Evidence Development and Coverage Advisory Committee (MEDCAC) full-day forum was held to discuss the evidence basis for the management of secondary lymphedema in the United States, the first time in MEDCAC’s ten-year existence that this subject was discussed. The open meeting featured a presentation of the Technology Assessment HHS/AHRQ commissioned from McMaster University Evidence-based Practice Center, Hamilton ONT Canada. Two lymphedema experts were featured as invited speakers at this meeting; they were Jane M. Armer, RN, PhD, FAAN, Professor of Nursing at University of Missouri and Director of the ALFP, and Stanley G. Rockson, MD, associate professor of cardiovascular medicine at Stanford University School of Medicine. Their task was to address the current state of research in lymphedema, focusing on the evidence base for diagnosis, measurement, and management of lymphedema, and to discuss the next steps for research. This was followed by scheduled public comments from 13 lymphedema experts from lymphedema and venous organizations.

The Expert Panel comprised ten voting members chosen from the eighty-eight permanent MEDCAC members plus a patient advocate, an industry representative, and three expert guest panel members whose votes were not counted in voting totals. The goal of the meeting was to present the best evidence on the measurement and diagnostic and treatment methods for secondary lymphedema, to question and hear testimony of the community of experts, and to vote on the adequacy of the evidence to support use of each method. In the afternoon, the Panel questioned the presenters and discussed the evidence, with the goal of eventually voting on a number of issues concerning their confidence in the adequacy of the evidence to support coverage of individual measurement and treatment modalities.

Janice N. Cormier, MD, MPH, and ALFP Executive Committee member, served as an expert guest panel member at the meeting. Several steering committee members and stakeholders of the ALFP also were in attendance and made presentations including Bob Weiss, MS; Paula Stewart, MD, CLT-LANA; Kathy Francis, MD; and Nicole Stout, MPT, CLT-LANA. In addition, several industry partners of the ALFP were in attendance including Jerry Mattys and Maggie Thompson of Tactile Systems Technology, Inc.; Kathy Weatherly of Solaris, Inc.; Jack Butler of ImpediMed, and Mary Schaeffer and Joe Tucker of 3M. The ALFP was well represented at this meeting and provided valuable input.

Meeting transcripts can be found at Centers for Medicare & Medicaid Services website (http://www.cms.hhs.gov/mcd/viewmcac.asp?from2=viewmcac.asp&where=index&mid=51&).
Communications with Stakeholders

The ALFP carries out regular communications with stakeholders of the ALFP. A stakeholder is any individual interested in increasing awareness and improving management of lymphedema in the U.S. and worldwide. Currently, stakeholders of the ALFP include researchers, physicians, nurses, lymphedema therapists, other health care professionals, educators, industry representatives, and lymphedema patients/advocates. A process has been developed for soliciting and accepting applications from interested stakeholders for membership to the Steering Committee.

Regular communications include the following:

- quarterly electronic updates are sent to interested stakeholders on January 1st, April 1st, July 1st, and October 1st;
- updates are sent to the quarterly National Lymphedema Network (NLN) newsletter;
- semiannual update to Journal of Lymphoedema; and
- regular follow-ups with industry partners.

Press releases, invited keynote and competitive abstract submissions for papers and posters at national and international professional meetings, ALFP exhibits at annual ILF conferences, invited presentations at local and regional professional meetings and classes, and development of manuscripts are strategies which have been utilized for dissemination of reports on ALFP activities and progress.

The ALFP expanded the organizational structure to include an industry consortium and an international advisory board with planned implementation in 2010. The industry consortium will give input and provide important feedback to the ALFP and to the other organizational partners of the ALFP. Collaboration and communication with these stakeholders is important to advancing the management of lymphedema and increasing awareness of the condition in the U.S. and worldwide.

The international advisory board consists of researchers, health care professionals, and patient advocates from around the world. This board will provide important feedback on the projects and goals of the ALFP. Input and feedback on the update of the Best Practices Document and development of the minimum data set are planned for 2010.
Publications

Refereed publications on the work of the ALFP:


Associated refereed publications increasing awareness of lymphedema:


**Conference proceedings on the work of the ALFP:**


**Conference proceedings increasing awareness of lymphedema:**


**Scientific review:**


**Scientific panel:**

Presentations

International/national presentations on the work of the ALFP:


Presentations where information on the ALFP was disseminated:


Associated presentations increasing awareness of lymphedema:


**Selected conferences and meetings attended in 2009 by ALFP representatives:**


**Honors:**

Armer, J.M. Margaret Allen Woods Outstanding Researcher Award Sigma Theta Tau Honor Society in Nursing, Alpha Iota Chapter, March 2009.


Armer, J.M. Extra-Ordinary Professor University of the Western Cape, South Africa, November 2009.

**Workshops Conducted**

Weiss, R. Conducted lymphedema therapist networking sessions on Medicare and Coding Problems at the Networking & Educational Seminar for Lymphedema Therapists in Scottsdale, AZ from February 6-8, 2009. (national)

**Abstracts submitted, not presented:**


Grants

Submitted grants:


Acknowledgements

On behalf of the American Lymphedema Framework Project team, our Executive and Steering committees, and all our existing stakeholders, we are deeply grateful for the support provided by the American Cancer Society, through The Longaberger Company, a direct selling company offering home products including handcrafted baskets made in Ohio, and the Longaberger Horizon of Hope Campaign, which provided a grant to the American Cancer Society for breast cancer research and education.

This support has enabled us to hold our initial Ad Hoc Steering Committee meeting in October 2008, our inaugural ALFP National Stakeholders Conference in March 2009, and subsequent meetings in April and August 2009 that have significantly helped move forward the mission and goals of the ALFP.

The ALFP Executive Committee: Janice Cormier, Joseph Feldman, Christine Moffat, and Jane Armer, with the 2009 Longaberger Horizon of Hope Basket, August 2009, Columbia, MO (basket courtesy of Marcia Beck).
Industry Partnerships: 2008-2009

On behalf of the American Lymphedema Framework Project team, our executive and steering committees, and all our existing stakeholders, we are deeply grateful for the support received from our industry partnerships. These supporters are not just financial sponsors, but partners in helping the ALFP to move toward achieving the mission to improve the awareness and management of lymphedema in the U.S.

**Founding Major Sponsor**
Tactile Systems Technology, Inc.

**Founding Contributing Stakeholders**
3M
CircAid Medical Products, Inc.
Farrow Medical Innovations
Bellisse
Solaris, Inc.

**Contributing Stakeholders**
Juzo
ImpediMed