

LTA Meeting Outline (aka **Outline**)

LTA Meeting Outline: This Outline is a tool you can use to study the issues and to plan your meeting. Topics below are organized to follow the **LTA Info Packet** * which you will print to use as a visual guide in your meeting.

Print: * **LTA Congressional Information Packet** (aka **Info Packet**)

(download from tab "About the Bill" on LTA website)

www.lymphedematreatmentact.org/about-the-bill/lta-info-packet-for-congress/

Use Outline as a study guide so you are able to flex on how you cover its points. Every meeting will flow differently. Members and/or staff will interact with questions, thereby directing the flow. Some will need more (or less) explanation on any of these topics.

Designate Team Member to record notes in the meeting so you can follow up effectively.

ESSENTIALS:

- Walk Member/staff through the **Info Packet**, using it as a visual guide
- Show Member/staff how the Info Packet includes the essential information they will need to understand (and cosponsor) the LTA
- Interject ideas from this Outline, when they are useful
- Leave the Info Packet with Member/staff after the meeting for further study

1. LEADER OPENS Meeting: Thanking them for meeting with your team

(Point to "facts" pgs. 1-2 Info Packet. Show House & Senate LTA Bill numbers)

- **STATE YOUR INTENTION:** We have come to discuss with you The Lymphedema Treatment Act, HR-1608 / S-2373. We ask you to cosponsor this bill, joining a large, bipartisan list of supporters in Congress. *(Share current # of House & Senate cosponsors. Note names from Member's state, party, committees, caucuses . . .)*
- **TEAM: BRIEF introduction** from each person with name, connection to lymphedema, personal perspective on the need for compression
- **Share brief perspective from which you will speak**, as a patient, parent, therapist, industry partner, state team member, organization leader, etc. *(Samples below)*

2. Set Info Packet on the table, turned it toward Member/staff • Use to guide meeting

(Show "Facts Sheet" pg. 1 • Save discussion of pg. 2 of Facts Sheet until para. 4 below.)

Use the front side of the "FACTS SHEET" to give overview of LTA essentials

- *(pg. 1, right column)* Point to summary of the essential problem for lymphedema patients & explanation of LTA as solution, under these headings:
 - About lymphedema • Why this legislation is needed • What this legislation will do
- **Explain** that lymphedema is **not** "disease-specific" because chronic LE swelling can result from dozens of different medical conditions and causes. (Some Members don't like supporting "disease-specific" legislation.)
- *(pg, 1, left column)* **Show list of major organizations** that endorse the LTA, and the **bipartisan teams of Lead Sponsors** in House and Senate. Show staff contacts.

3. (Show the Info-graphic, pg. 3 Info Packet, point to graphic & "causes")

Very briefly describe lymphedema, using "INFO-GRAPHIC" as visual guide:

- A swelling disorder caused by a damaged or malformed lymphatic system.
- It has many causes, including congenital defects, but most cases are caused by lifesaving cancer treatments that remove or damage lymph nodes & lymph vessels.
- Lymphedema is a chronic and potentially progressive condition.
- If untreated or undertreated it results in multiple complications including disfiguring and disabling swelling and life-threatening infections.
- *(Briefly point to facts on Info-graphic)* • Quick facts about lymphedema.
- 40% of breast cancer survivors develop lymphedema within 5 yrs of treatment.
- Compression is THE fundamental component of care for lymphedema
- This is why we ask your office to cosponsor this common sense, bipartisan bill.

(Point to these facts about lymphedema, numbers 4 & 5 on Info-graphic)

Briefly explain the role of compression. Medically-prescribed compression is the key component of lymphedema treatment, yet it is excluded from Medicare coverage due to a missing benefit category. **Say that the purpose of LTA is to close this coverage gap**

OPTIONAL: You may choose to include your brief stories HERE or wait until you finish showing the Info Packet, (see # 9 below) as seems appropriate.

4. *(Show pg. 2 Info Packet)* Return to the "**FACTS SHEET**" and point to back side, pg. 2 **Show critical information resources** for Member/staff to explore, including:
- HHS Secretaries' statements on why Congress must act • Supporting research • Major media story in Washington Post • PSA video with interviews of major leaders explaining need for LTA • Avalere Cost Analysis • Links to the names of the large, bipartisan group of cosponsoring Members of Congress in both House and Senate
 - **Why we need a law for Medicare to do this:** Mention that lymphedema community worked with CMS (Center for Medicare and Medicaid Services) for many years to find a non-legislative solution. Point to answers on need for change in law to Rep. Reichert from Cabinet Secretaries of HHS (Health and Human Services)
 - **Costs: IF ASKED** if we have **CBO score** (Congressional Budget Office cost estimate) **ANSWER: NOT YET**, but the House WAYS & MEANS staff is working with CBO to get it. Point out that we DO have an **Avalere Health score** to use while waiting for CBO score.

(near bottom of pg. 2 Info Packet) Show link to the Avalere Cost Analysis. Point out that Avalere study shows bill's costs & potential hospitalization savings.

Offer to send "live" link to Avalere study in email to local staff (with cc to HLA in DC)

Or, staff may prefer to review online or download from tab "*About the Bill*" on **LTA website** www.lymphedematreatmentact.org/about-the-bill/lta-info-packet-for-congress/

5. *(pg. 4 Info Packet)* "**PATIENT NUMBERS**" DOCUMENT

- This very important page shows the number of Medicare beneficiaries in each state with diagnosed lymphedema who would directly benefit from passage of this bill.
- Connect bill to Members' own expressed interests & concerns about constituents.

6. *(pg. 5 Info Packet)* "**The FUNCTION OF COMPRESSION & Why Current Medicare Coverage of LE Treatment is Inadequate**"

- Call attention to this very useful explanation of LE treatment modes, including MLD,

- PT/OT & pumps. It describes the necessary role compression plays in treating LE.
- Medicare covers medically-prescribed PT/OT & pumps, which help to **reduce** swelling.
 - But the achieved **reduction** can only be **sustained** through **daily compression** use.

7. (pgs. 6-9 Info Packet) "EVIDENCE" Studies on Compression's EFFECTIVENESS (studies #1-6) & COST SAVINGS of Compression (studies #7-9):

- There is plenty of evidence showing the necessity & effectiveness of compression, including findings from a MEDCAC meeting & the CMS decision memo on pumps.
- The evidence clearly indicates that the use of compression reduces the incidence of complications and disease progression, which reduces overall healthcare costs.
- *(Point to Important last item, study #9):* Properly managing lymphedema is much more cost effective than paying for preventable complication. Study #9 cites a 12-fold reduction in hospitalizations when compression is used to treat lymphedema.

8. Show "ENDORSEMENT LETTERS" (pgs. 10-15 Info Packet)

POWERFUL SUPPORT for the LTA: LTA is strongly endorsed by bipartisan teams of LEAD SPONSORS in Congress & INFLUENTIAL ORGANIZATIONS such as American Medical Assn, American Cancer Society, American Physical Therapy Assn & Oncology Nursing Society

9. TELL YOUR STORY: Each person briefly explains what medically-prescribed compression has meant in own experience with lymphedema. 2-3 min each.

How compression helps. How lack of it causes harm. (Practice telling story at home until you can deliver it without reading.) **Write it out; leave with staff. Show your garments. Show your photos before & after compression. Make your story real.**

10. REPEAT "ASK": Ask Member to co-sponsor this bipartisan bill in House or Senate.

11. LEARN FROM THEM, TOO: Ask if they have any questions or feedback for us. Ask with whom you should follow up with email updates & info (i.e., HLA - Health Legislative Aide)

12. ASK FOR A PHOTO WITH MEMBER OR STAFF Get business card with job title from each person in meeting. Note of date you met & memory clues to conversation.

SAMPLES OF **OPENING TEAM INTRODUCTIONS** (para. 1, above. Different from full story in para 10.)

STATE TEAM context included showing how you represent yourself and all state advocates:

"I'm Mary Advocate, from Anytown, STATE. I'm a lymphedema patient. I developed this chronic condition XX years after having lymph nodes removed & radiated for lymphoma, a cancer of the lymph system. Insect bites on my leg caused the fragile lymph drainage system to break down. I was treated with good coverage for lymphedema treatment & compression until this year when I became a Medicare beneficiary. I also come today as part of the delegation representing the XX state team of advocates for the LTA. From my personal perspective & experience working with others, I see the dramatic challenge the missing Medicare coverage gives to lymphedema patients at a time when they enter retirement age."

WIDER context of your "connections," but very brief and focused:

"I'm Tom Advocate, from Anytown, STATE, where I work for a manufacturer of lymphedema compression garments. From my position, I see the critical needs patients have for these garments and the progressive disease that follows when they are not able to get them. I am part of the delegation representing the XX state team in these meetings and am also on the LAG board. I share the point of view of an industry leader devoted to serving the needs of these patients while providing manufacturing jobs in our region."