Lymphedema Advocacy Group

Advocacy Handbook

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www.LymphedemaTreatmentAct.org

info@LymphedemaTreatmentAct.org

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I. About the Lymphedema Advocacy Group

The ***Lymphedema Advocacy Group*** (LAG), founded in 2010 by Heather Ferguson, is an all-volunteer organization made up of patients, caregivers, healthcare professionals and industry partners. Our mission is to advance lymphedema care in the United States by advocating for improved insurance coverage for the diagnosis and treatment of the disease.

The Lymphedema Advocacy Group works to increase awareness of and education about lymphedema among lawmakers, insurance providers and other relevant entities. We support attempts to improve insurance coverage at both the state and federal levels and encourage all members of the lymphedema community to become active participants in this process. Current board member biographies can be read on the *About Us* page of our website.

II. How Should I Use This Handbook?

There is no one-size-fits all approach, but the intent of this handbook is to provide individuals a resource from which they can draw inspiration and direction to launch their grassroots advocacy efforts.

This document will be updated as needed, and the most current version can always be viewed and downloaded from this page of our website – http://lymphedematreatmentact.org/advocacy-handbook/.

Together we can extend our reach, pass the Lymphedema Treatment Act, and help the millions of Americans with lymphedema. We are grateful for your participation!

III. Step 1 - Writing your Members of Congress

It's easy to send a letter using the submission forms on our website. Make sure to personalize the template.

Go to the "Contact Your Senators" and Contact Your Representative" pages under the "How You Can Help" menu on our website.

Several weeks after submitting your letter you will probably receive a polite "form letter" response. Most read as follows:

It will name the bill, then the committees it was referred to.
It will go on to tell you a bit about lymphedema and about what the bill would do.
And it will conclude by saying something to the effect of
keeping your thoughts in mind should the bill come to the floor for a vote.

Do not be satisfied with this noncommittal reply.

Simply keeping the constituent's thoughts in mind does not help us to pass the bill. As a first step, you should continue to urge your members of Congress to sign on as a cosponsor. **Persistence is the key!** You will usually have to make contact with an office multiple times before getting results.

Cosponsoring the bill is an important initial step, but it's not the only way in which we need their support. Thousands of bills are introduced in Congress each year, and only a very small percentages are acted on. Once a member of Congress has cosponsored the bill, we need them to work with congressional leadership to ensure that it is brought to a vote.

IV. Step 2 - Calling your Members of Congress

You will be amazed at what a huge difference phone calls can make!

Congressional offices receive hundreds, even thousands of emails each day, but far fewer phone calls.

CALLING INSTRUCTIONS:

- **Go to the "Contact Your Senators" and Contact Your Representative" pages under the "How You Can Help" menu on our website.**
- All needed phone numbers and a script are provided.
- It is likely that you will be transferred to voicemail, so have a concise, pre-planned message ready. Be sure to ask for a return call and leave your number.
- The goal is to speak with the **Health Legislative Aide**, but it is unlikely he or she will be available at the time you call. Ask for a call back.

TIPS FOR SPEAKING WITH THE HEALTH LEGISLATIVE AIDE:

- Prior to the call, review the FREQUENTLY ASKED QUESTIONS section included under "Step 4 – Meeting with your Members of Congress."

- When speaking to the **Health Legislative Aide**, remember that the most important thing to convey is why passage of this legislation is so important to you, and how it would improve your quality of life (or that of your patients, loved one, etc.). Your personal stories are the most important and persuasive tools we have! Be brief and to the point, showing why the legislation is needed.

- **Make sure to conclude by asking when and how you can expect to hear from them regarding your Representative's/Senator's decision to cosponsor, or whatever action it is you are asking them to take.**

V. Step 3 - Contact Congress via Social Media

Any current social media actions can be found on the "Contact Your Senators" and "Contact Your Representative" pages under the "How You Can Help" menu on our website.

VI. Step 4 - Meeting with your Members of Congress

Remember that we are here to help you prepare for these meetings! After you have reviewed the information below, if you would like to speak with us further to ask questions, get additional pointers or just get more comfortable, we would be happy to hear from you. Just contact us via email at info@LymphedemaTreatmentAct.org.

INSTRUCTIONS FOR SCHEDULING DISTRICT MEETINGS:

- To locate your Representative or Senators, and the phone number to his/her closest district office, go to www.house.gov/representatives/find or http://www.senate.gov/senators/contact/.
- There are various ways in which offices handle the scheduling of meetings. They will provide you with instructions for following their procedures.
- When you call, say that you would like to request a meeting with your Representative/Senator when he or she is in the district, to discuss a bill that is very important to you, the Lymphedema Treatment Act.
- You will often be told that your Representative/Senator will not have time to meet with you for weeks or months. In that case, ask if you could be put on a waiting list, and periodically follow up to check on and update your request.
- Ask for the Scheduler's email address, so that you can send him or her the same facts sheet about the bill that you sent the Health Aide. Also include a personal statement from you, highlighting why this is so important to you. If the scheduler has a better understanding of the reasons you want the meeting, the office will sometimes be more accommodating.

PREPARING FOR A DISTRICT MEETING:

- **Study the member of Congress' website.** Identify the issues that are important to him or her. Look for ways in which you can connect the reasons why he or she should support the Lymphedema Treatment Act to the ideals and issues that he or she values. Frame your reasoning so that he or she can relate to it on a personal level (as a mother, a doctor, a businessman, member of a health caucus, cancer survivor, etc.)

- **If possible, take with you a carefully selected group of people to the meeting*.** Ideally, they will be constituents, but they do not all have to be. Try to include a therapist, a fitter, and some patients. After these goals are met, try for diversity among the attendees, such as primary/secondary, upper/lower extremity, age, men and women, etc. Each person attending the meeting should represent a part of your total message, so you have a cohesive and persuasive presentation that comes from knowledge and from the heart.

  ** We can help you gather others to attend your meeting. Just contact us as soon as you have formally made the meeting request (you do not need to wait until you have the actual date) and we will reach out to others in your district.*

- **If you are not attending alone, all of your meeting attendees must coordinate with one another in advance of the meeting.** Plan who will talk about what, and in what order you will speak. You will not have time for redundancy, so you want to pack as much punch as possible into your finite amount of time. It's unlikely your meeting will unfold exactly as planned, but this preparation will serve you well.

- **Be ready to provide the following information in advance of the meeting:**
  - A list of who will attend, with their contact information and one sentence stating their relationship to the issue. (List constituents first, then others.)
  - An explanation that you are local patient advocates working with the Lymphedema Advocacy Group to support passage of the Lymphedema Treatment Act.
  - A brief, clear statement that your goal is for your Representative/Senator to cosponsor this bill.
  - Our Congressional Information Packet and any other materials you wish to utilize from this page on our website (*make sure all attendees have familiarized themselves with the information prior to the meeting*): http://lymphedematreatmentact.org/about-the-bill/lta-info-packet-for-congress/.

- **Bring the following materials with you:**
  - A printed copy of the Congressional Information Packet and any other materials you sent electronically in advance.
  - Any personal materials you may wish to have with you to help illustrate your message – photos, garments, bandages, nighttime compression devices, etc.

POINTERS FOR YOUR MEETING:

- **You will need to be brief and to the point.** You will have a finite amount of time; expect anything from 10-30 minutes.

- **Try to relax and just be yourself.** They do not expect you to be an expert. You are there to tell your story. Your personal experience is powerful and persuasive. Be direct and make eye contact.

- **Begin with a quick (2 minute or less) explanation about lymphedema,** how it should be treated, and what happens when it is not properly treated.

- **When sharing your personal story, be sure it serves the reason you are there:** They do need to know why it is essential for patients to have compression. They do not need to know your complete medical history.

- **Focus on the medical need, and stress that coverage for compression is the most conservative and cost-effective way to manage lymphedema.** Compression is an essential component of Complete Decongestive Therapy; it reduces the incidence of disease progression, complications and disability, thereby reducing the financial burden on the health care system.

- **Do show them your affected area(s), if able.** Wear your garments, show other treatment supplies (e.g., nighttime) & show photos (e.g., before and after treatment).

- **Cost is at the forefront of every Congress members' mind.** You will likely be asked what your compression supplies cost you (or your patients/loved ones). Remember that you will be more persuasive by stressing their medical need, not how much the compression supplies cost. Explain how proper treatment can save much human suffering as well as overall health care dollars.

- **At the beginning and again at the end of the meeting, clearly state what action you hope your Representative/Senator will take - cosponsor the bill, get it included in a vote, etc..** If they are unable to give you an answer then, ask when and how you should expect to hear of their decision.

FREQUENTLY ASKED QUESTIONS / TALKING POINTS:

Below are the most commonly asked questions by members of Congress and their staff - **make sure you review these prior to your meeting**. If you are asked any questions which you cannot answer, simply tell them you will get back to them. Then, email us at info@LymphedemaTreatmentAct.org and we will provide you with the answer or follow up with that office directly.

- **What will the law change?**

It will close the gap in Medicare coverage by enabling coverage for doctor-prescribed compression supplies under Durable Medical Equipment.

- **Is legislation really needed to get these items covered?**

Yes. The issue has been thoroughly researched by our Congressional champions. A timeline of their communications with HHS (Health and Human Services) and CMS (the Center for Medicare Services), can be found on this page of our website - https://lymphedematreatmentact.org/about-the-bill/lta-info-packet-for-congress/.

- **Does the bill have a Congressional Budget Office (CBO) score?**

No, not yet. Encourage them to contact our bill sponsors' office for questions about this. This contact information is on the front page (bottom left corner) of the Congressional Information Packet you should bring with you - https://lymphedematreatmentact.org/about-the-bill/lta-info-packet-for-congress/.

- **How will patients benefit?**

Untreated or inadequately treated lymphedema is progressive, leading to complications, comorbidities, loss of function, disability, and in some cases even death. Coverage for compression will enable patients to effectively manage this disease, thereby greatly improving their overall health and quality of life.

- **How will it affect healthcare costs?**

This bill will reduce the total healthcare costs associated with this disease by decreasing the incidence of complications, co-morbidities and disabilities.

If you need additional clarification or assistance preparing for your meeting, email us at info@LymphedemaTreatmentAct.org. We are eager to help you!

VII. Raising Awareness

- **Word of mouth** - talking to your family, friends, colleagues, etc.
- Social media - **Twitter** (https://twitter.com/LymphedemaAct) and **Facebook** (https://www.facebook.com/pages/Lymphedema-Treatment-Act).
- Distribute the various **educational materials** available through the Increasing Awareness page of our website - http://lymphedematreatmentact.org/increase-awareness/.

VIII. State Advocacy Teams

If you are considering joining your state's team, please visit the *State Teams* page of our website, where you can learn all about our teams and find a link to join yours - http://lymphedematreatmentact.org/state-advocacy-teams/.

If you are already a member of your state's team, we hope you will encourage others to join. This is a grassroots effort and we need your help extending our reach! Here are some tips for helping to grow your state's team:

- Remember that the goal for team membership is to have at least one person on your team from each Congressional district in the state.
- Ideal sources for locating new members include: support groups, lymphedema therapists, hospitals and clinics with lymphedema departments, garment fitters and providers, local cancer support groups, oncology groups, etc.
- While every new team member is valuable, constituents living in the districts of certain key members of Congress are particularly important. These Key Member districts are denoted in red on your team's contact sheet.
- Refer those who might be interested to the *State Teams* page of our website, at http://lymphedematreatmentact.org/state-advocacy-teams/, where they can access more information, including this Handbook.
- Remind potential members that the time commitment and level of responsibility is variable, so even if they can only do some of the tasks outlined in this handbook we still welcome their help in whatever capacity they can participate.

- **New team members must join by completing the sign-up form accessible via the *State Teams* page of our website; they cannot simply verbally join the team.** Please remind them that they must sign up to be in our database and receive state team communications. Anyone without Internet and/or email access can contact us to discuss alternative means of staying connected.
- If a prospective member has a question to which you do not know the answer, direct them to the *Contact Us* form on our website, or have them email us at info@LymphedemaTreatmentAct.org.

IX. Advocacy Trips to Washington DC

We organize annual advocacy trip to Washington DC. **No experience is required!**

We arrange for a group rate at an area hotel and provide you with all the materials and guidance you will need. Complete information is available on the *Lymphedema Lobby Days* page of our website - http://lymphedematreatmentact.org/lymphedema-lobby-days/.

Participants will meet with as many members of Congress from their state as possible. In order to achieve this a constituent has to request each meeting. Those individuals do not all have to come to DC. When scheduling the meeting, those who cannot attend will simply write to or call their Representative's DC office, state their inability to come to DC, and ask that others from their state be allowed to meet with his or her office on their behalf.

If you have never been on an advocacy trip to DC, we are not exaggerating when we say it will be an awe-inspiring experience. **We hope to see you in DC!**