



# Give Lung Cancer a Face and a Voice

Every day, we hear stories from people living with lung cancer about the negative stigma associated with the disease. Stigmatization and prejudice are often based on two factors: ignorance and impersonalization, or “facelessness”. While people have heard of lung cancer, many have little knowledge about the disease, or worse yet, have incorrect notions about the disease. Ignorance often leads to fear, which is expressed as prejudice. Understandably, the stigma associated with lung cancer has caused many people living with the disease to remain silent. However, we’ve all heard the old adage and have certainly experienced its truth at some point: **“The squeaky wheel gets the grease.”** So, be sure your voice is heard – Anyone with lungs can get lung cancer!



## Send us your video story

Make a short video about your lung cancer experience (2-3 minutes). We will post it on our site.

## Call your elected officials

Call your state and local elected representatives. Tell them you want lung cancer moved to the top of their health agenda.

## Write your elected officials

You can begin with the simple act of writing your state and local elected representatives. Tell them you want lung cancer moved to the top of their health agenda. It is a simple way to start. We’ve found that email works best.

## Visit your elected officials

A short visit with your elected officials’ offices at home or in DC can make the biggest impact. **Tell them what matters to YOU!** They want to hear from you. You vote for them.

**Change cannot occur without your help. Persistence is the key if we want change.**

Caring Ambassadors Program Advocacy Tool Kit Give Lung Cancer a Face and a Voice



# Grassroots Advocacy

## Advocacy Begins When Someone Says “No”.

*You don't have to be a policy expert to advance grassroots advocacy. Lung Cancer grassroots advocacy is based on championing our cause, giving people a voice, and building relationships.*

**Collect stories.** Capture the stories and experiences of individuals who call lung cancer Helplines, take classes, attend support groups, or volunteer. Personal stories are invaluable in portraying the many faces of lung cancer and the real-life impact of funding and policies to policy makers and community leaders.

**Cultivate leaders.** Recruit state advocacy network leaders and local or regional advocacy representatives to coordinate efforts and relay grassroots feedback on issues and priorities. Consider contracting with a professional lobbyist. Create ad hoc workgroups with interest and expertise in specific issues.

**Inspire action.** Motivate grassroots advocacy with concise and compelling messages, essential information, and a clear request, or “ask”, to inform policy makers on priority issues. Recruit members to fill hearing rooms and attend events. Suggest wearing a particular color and sitting together for impact.

**Provide training.** Develop members’ skills and confidence of advocates in how to tell their stories effectively, how to meet with elected officials, and other related topics.

**Promote connections.** Let members know that their state and federal policy makers are there to represent them and need to hear from them regularly. Encourage members to meet with their elected officials both during legislative session and in the interim about lung cancer priority issues.

**Track legislation.** Closely follow priority legislation throughout the legislative sessions, including budgets for lung cancer services and treatment. Pay particular attention to upcoming hearings as opportunities for grassroots action. Track additional cancer-related legislation as needed.

**Speak up.** Submit written testimony to legislative committees. Offer to provide oral testimony from a consumer or family perspective before a hearing is held. Ensure representation of lung cancer’s interests on important advisory groups or committees. Bring attention to how decisions will affect people living with lung cancer.

**Work with the media.** Establish relationships with key reporters and editorial boards by providing facts, “real life” examples and an appeal for action on lung cancer issues. Prompt additional coverage by following up on news stories and events to help shape public attitudes about cancer issues.

**Stay positive.** Remind members to stay positive and not give up when they get a negative response. **Advocacy begins when someone says “no.”** Keep in mind that our goal is to build connections with elected officials. Time and trust help build support for lung cancer.

## Command Attention



# What Influences a Legislator?

*Important items to keep in mind when lobbying elected officials*

Elected officials are, first and foremost, politicians. If an elected official is up for re-election, they are often more willing to listen to interests outside their norm. The issues of a special interest group are important to them because they need that support to win re-election. One of the easiest and most direct ways to get to know and influence a legislator is to help them; this can be accomplished by volunteering on their campaign. Although assisting a politician does not ensure that they will always vote your way, it allows you to spend time with them and their staff. Building and maintaining working relationships is always important.

The following are important to keep in mind when lobbying elected officials:

## The Issue:

- Merits of the issue
- Impact on his/her district
- Possible job loss

## Political Considerations:

- Upcoming election/lame duck
- Campaign contributions
- Commitment of an interest group – single issue voters?
- President, Governor, or Mayor
- Scorecards

## Legislative Considerations:

- Committee chairman
- Committee assignments
- Trade offs with fellow legislators
- Position of others in state or district delegation
- Lobbying by other legislators
- Staff advice
- Position of Political party

## Cost:

- Impact on economy or businesses
- Too much government interference
- Opponents have more clout than proponents
- Lack of knowledge
- Executive branch position

## Media:

- News articles/stories
- Editorials
- Letters to the Editor
- Opportunity to gain press attention

## Personal:

- Personal experiences and feelings
- Family members, friends, especially children
- Impact on self or others important to legislator
- Alma mater

## Outside Influences:

- Constituent contacts – grassroots
- General public sentiment
- Celebrities, sports figures
- Chance encounters with people



# Tips for Writing Congress

## A Well -Written Letter Has Impact!

*People who think members of Congress pay little or no attention to constituent mail are plain wrong. Concise, well thought out personal letters are one of the most effective ways Americans have of influencing lawmakers. But, members of Congress get hundreds of letters and emails every day, so a personal letter that is clear and concise is what will be read and remembered.*

### ALWAYS

- ✓ Be courteous and respectful without "gushing"
- ✓ Address only a single topic or issue
- ✓ Introduce yourself and provide your contact information
- ✓ Clearly and simply state the purpose of your letter
- ✓ Keep your letter short – one page is best
- ✓ Use specific examples or evidence to support your position
- ✓ Close by stating what you want done or recommend a course of action
- ✓ Thank the member for taking the time to read your letter

### Components of an Effective Letter

1. Elected official's contact information
2. Salutation
3. Introduction
4. Purpose of letter
5. Bill number and name, if applicable
6. Evidence and/or examples (i.e. data)
7. Personal story/connection
8. Requested action (i.e. support/reject)
9. Thank you
10. Personal Contact information (including City, State, Zip code)

See

*"Write Your Elected Officials"  
for a sample*

### IF YOU CAN

- ✓ Email your letter rather than sending it snail mail
- ✓ State any professional credentials or personal experience you have, especially those pertaining to the subject of your letter
- ✓ If a certain bill is involved, cite the correct title or number whenever possible
- ✓ Include a personal story explaining why the subject is important to YOU
- ✓ Connect your story to the person you are writing – identify shared background, experience, etc...

### NEVER

- ✓ Use vulgarity, profanity, or threats. Don't let your passion get in the way of making your point
- ✓ Fail to include your name and address, even in email letters
- ✓ Demand a response

### Addressing Members of Congress

#### To Your Senator:

The Honorable (full name)  
(Room #) (Name) Senate  
Office Building  
United States Senate  
Washington, DC 20510

#### To Your Representative:

The Honorable (full name)  
(Room #) (Name) House  
Office Building  
United States House of  
Representatives  
Washington, DC 20515

Dear Senator:

Dear Representative:

#### Cite these legislation identifiers when writing to members of Congress:

House Bills: "H.R. \_\_\_\_"  
House Resolutions: "H.RES. \_\_\_\_"  
House Joint Resolutions: "H.J.RES. \_\_\_\_"  
Senate Bills: "S. \_\_\_\_"  
Senate Resolutions: "S.RES. \_\_\_\_"



# Write Your Elected Officials

**Write your state and local elected representatives.  
Tell them you want lung cancer in women  
moved to the top of their health agenda.**

SAMPLE LETTER

May 9, 2019

The Honorable John Adams  
United States Senate  
400 Hart Senate Office Building  
Washington, DC 20515

1

2

3

Dear Senator Adams: [or Representative for House]

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My name is Jane Doe. I am a case manager at the Health Matters Clinic in Any town, USA. I encourage you to cosponsor *Women and Lung Cancer Research and Preventive Services Act of 2021 (S. 699/ H.R.1800)*. This important legislation is in response to evidence that lung cancer is the leading cause of cancer death among women, and a higher rate of lung cancer for women who were never smokers compared to men.

6

According to the American Cancer Society, in the United States, approximately 171 women die each day of lung cancer. An estimated 62,470 women will die of lung cancer in 2021.

The Women and Lung Cancer Research and Preventive Services Act of 2021 creates an Interagency review to evaluate and identify opportunities for the acceleration of research on women and lung cancer, greater access to preventative service, and strategic public awareness and education campaigns.

Additional research strategies, including clinical trials, are necessary to explore the differences in lung cancer risk factors, incidence, and treatment response in women, and to address the disparate impact of lung cancer on women who have never smoked.

7

Every day we witness the effects of lung cancer in women in our community. I have lost my aunt due to lung cancer. It was devastating to our family. It is imperative that we increase research to increase the longevity of women living with lung cancer.

8

We urge you to make lung cancer and lung cancer research a leading health priority in Congress by funding cancer research, prevention, and awareness activities. Please support *Women and Lung Cancer Research and Preventive Services Act of 2021 (S. 699/ H.R.1800)*.

9

Thank you for your time and your continued dedication to the people of Any Town and our health.

10

Sincerely,

Jane Doe  
Street address  
City, State, Zip Code  
Email or phone number





# Attending Town Hall Meetings

**A large and well-informed turnout at a town hall meeting or a community forum is an extremely effective way to send a strong message to your congressperson.**

You do not have to go to Washington DC to be effective in your federal advocacy efforts. A large and well-informed turnout at a town hall meeting or a community forum is an extremely effective way to send a strong message to your congressperson, the media, and the public (via the media or social media). If your lawmaker is supportive of your issue, a show of support helps to solidify their position.

Sometimes, lawmakers participate in events closed to the public, except by invitation. If you know of an event that you would like to attend but it is not open to the public, call the legislator's office and ask if you can attend. In general, when attending and speaking at town hall meetings, conduct yourself as you would when testifying at a hearing or meeting with your elected officials: courteously, professionally, and prepared to present evidence (facts or a personal story).

## Before the town meeting...

- ✓ Find out the legislator's schedule. Newspapers often publish these dates, or sometimes the lawmaker will send out a schedule to voters in their district. The most reliable way to find the schedule is to call their office.
- ✓ Try to recruit several others to attend the meeting with you. Inform them of the date, time, address, and nature and purpose of the meeting. If you have the time and resources, provide background information, a map to the site, salient points, and sample questions.
- ✓ Think about how the congressperson will likely respond to your questions and prepare in advance with answers and follow-up questions.

## At the town meeting...

- ✓ Keep your comments brief, clear, and to the point.
- ✓ If you attend with a group, wear stickers or buttons to identify that you are all in support of a common issue.



# Advocacy Resources

**Stay Informed!**

## [LungCan.org](https://lungcan.org)

The Lung Cancer Action Network (LungCAN®) is a collaborative group of lung cancer advocacy organizations that have come together to raise public awareness about the realities of lung cancer. Their intention is to increase funding for detecting, treating, and curing the disease.

LungCAN member organizations provide resources in a single place. Please use this website to access organizations that can help you find the information and assistance you need when you need it!

## [Congress.gov](https://www.congress.gov)

Find your Federal and State Elected Officials  
Track bills in Congress, your representative's voting history,  
upcoming committee meetings, and get alerts by email

## [Govtrack.us/start#states](https://govtrack.us/start#states)

Track bills in your state and get alerts by email

## [csg.org](https://www.csg.org)

Founded in 1933, The Council of State Governments is our nation's only organization serving all three branches of state government. CSG is a region-based forum that fosters the exchange of insights and ideas to help state officials shape public policy. This offers unparalleled regional, national and international opportunities to network, develop leaders, collaborate and create problem-solving partnerships.

## [WomeninGovernment.org](https://www.womeningovernment.org)

Women In Government Foundation, Inc., headquartered in Washington, D.C., is a national, non-profit, non-partisan organization of women state legislators that provides leadership opportunities, networking expert forums, and educational resources to address and resolve complex public policy issues to all 1,791 women state legislators.

## [NCCN.org](https://www.nccn.org)

National Comprehensive Cancer Network is a not-for-profit alliance of 31 leading cancer centers devoted to patient care, research, and education. NCCN is dedicated to improving and facilitating quality, effective, efficient, and accessible cancer care so patients can live better lives.

## [CDC.gov](https://www.cdc.gov)

### [Center for Disease Control](https://www.cdc.gov/cancer/lung/index.htm)

<https://www.cdc.gov/cancer/lung/index.htm>

See the government's facts and figures on lung cancer, order awareness posters, and more.

## Champion Scale Tool

Members of Congress (MoCs) don't often come into office as champions on lung cancer issues. The Champion Scale is a tool to help us move MoCs, step by step, toward becoming champions in Lung Cancer. Use this tool to assess decision makers, develop strategies, track learning and progress, and celebrate progress.



MoC Name: \_\_\_\_\_ Point Person: \_\_\_\_\_ RESULTS Group: \_\_\_\_\_ Issue: \_\_\_\_\_ Date: \_\_\_\_\_

### Tips for Getting Started with this Tool:

<input type="checkbox"/> Research the MoC's background and voting history on the issues at <a href="http://www.results.org">www.results.org</a> <input type="checkbox"/> Evaluate the MoC and determine where they are on the champion scale for each issue <input type="checkbox"/> <u>Always</u> make requests just above their current level to encourage them to move up <input type="checkbox"/> Use stories that personalize the issue & move the MoC emotionally	<input type="checkbox"/> When meeting, always begin by acknowledging them <input type="checkbox"/> Listen carefully to everything they say for clues about where they are on the champion scale
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Level Name, Objectives	Determining Their Level – They Might Say:	Moving Them to the Next Level:
<b><u>Level: 4 Champion</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Inquire on creating new legislative initiatives. <input type="checkbox"/> Help MoC see that his/her efforts as a Champion are worth while.	<input type="checkbox"/> "I will build the support and visibility needed to make sure this passes." <input type="checkbox"/> "I will walk this around the floor and make sure it happens." <input type="checkbox"/> "Can I count on the full support of your organization on this?" <input type="checkbox"/> "What do we need to do to make this happen?"	<input type="checkbox"/> Ask MoC to author and shepherd legislation through. <input type="checkbox"/> Enlist RESULTS staff & grassroots in achieving what MoC has set out to achieve. <input type="checkbox"/> Ask MoC to talk and/or write to leadership and report back. <input type="checkbox"/> Let MoC know he/she has support of entire organization (staff & network) when leading. <input type="checkbox"/> Encourage member to join key committees. <input type="checkbox"/> Hold regular meetings with key DC aide(s) every 1-2 months. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings. <input type="checkbox"/> Provide regular positive feedback on MoC's action via letters, events, and media. <input type="checkbox"/> Look for opportunities to put MoC in contact with people affected by the issues. <input type="checkbox"/> Demonstrate community support for his/her actions. <input type="checkbox"/> Offer to sit on their community advisory panels and to provide other input. <input type="checkbox"/> Offer to organize public events with the MoC (forums, radio, TV, etc). <input type="checkbox"/> Get member to draft or sign on to 4 or more opeds per year. <input type="checkbox"/> Ask member to speak on conference call, IC. <input type="checkbox"/> Ask MoC to initiate a sign-on letter on an issue. <input type="checkbox"/> Ask MoC to hold a briefing or hearing on an issue working with our DC staff.
<b><u>Level: 3 Leader</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Inspire MoC to become more by providing a vision of what it means to be a champion: using examples inside and outside of Congress. <input type="checkbox"/> Help MoC stake out his/her champion terrain on our issues.	<input type="checkbox"/> "I will get the support to help this pass." <input type="checkbox"/> "I will introduce this bill or be a co-leader on this letter." <input type="checkbox"/> "I will speak to leadership and let you know." <input type="checkbox"/> "I will speak on the floor about this." <input type="checkbox"/> "Yes, I will write an oped on this." <input type="checkbox"/> "Yes, I will offer the amendment." <input type="checkbox"/> "Yes, organizing a hearing would be a good idea."	<input type="checkbox"/> Ask MoC to talk and/or write to leadership and report back. <input type="checkbox"/> Let MoC know he/she has support of entire organization (staff & network) when leading. <input type="checkbox"/> Encourage member to join key committees. <input type="checkbox"/> Hold regular phone meetings with key DC aide(s) every 1-2 months. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings. <input type="checkbox"/> Offer to organize public events with the MoC (townhalls, forums, radio, TV, etc). <input type="checkbox"/> Provide regular positive feedback on MoC's action via letters, events, and media. <input type="checkbox"/> Look for opportunities to put MoC in contact with people affected by the issues including encouraging MoC to visit projects on the ground that address our issues. <input type="checkbox"/> Demonstrate community support for his/her actions. <input type="checkbox"/> Ask a colleague in MoC's state, caucus, interest group to join him/her in taking an action. <input type="checkbox"/> Offer to sit on their community advisory panels and to provide other input. <input type="checkbox"/> Get member to draft or sign on to 3 or more opeds per year. <input type="checkbox"/> Ask MoC to hold a briefing or hearing on an issue working with our DC staff. <input type="checkbox"/> Ask MoC to initiate a sign-on letter on an issue.



Level Name, Objectives	Determining Their Level – What They Might Say:	Moving Them to the Next Level:
<b><u>Level: 2 Advocate</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Encourage MoC to consider taking individualized actions that go beyond the basics and demonstrate leadership. <input type="checkbox"/> Help MoC find and deliver on his/her passion around one or more issues.	<input type="checkbox"/> "I will talk to my colleagues & leadership and urge them to support this." <input type="checkbox"/> "I might be willing to write an oped on this." <input type="checkbox"/> "I would sign on to a letter supporting this and engage others." <input type="checkbox"/> "People in our community should know about this. "	<input type="checkbox"/> Ask MoC to talk and/or write to leadership and report back. <input type="checkbox"/> Let MoC know he/she has support of entire organization (staff & network) when leading. <input type="checkbox"/> Encourage member to join key committees. <input type="checkbox"/> Hold regular phone meetings with key DC aide(s) every 1-2 months. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings. <input type="checkbox"/> Provide regular positive feedback on MoC's action via letters, events, and media. <input type="checkbox"/> Look for opportunities to put MoC in contact with people affected by the issues including encouraging MoC to visit projects on the ground that address our issues.. <input type="checkbox"/> Demonstrate community support for his/her actions. <input type="checkbox"/> Offer to organize public events with the MoC (forums, radio, TV, etc). <input type="checkbox"/> Get member to sign on to 2 or more opeds per year. <input type="checkbox"/> Ask member to speak on conference call, IC. <input type="checkbox"/> Ask a colleague in MoC's state, caucus, interest group to join him/her in taking an action. <input type="checkbox"/> Ask the MoC to initiate their own "Dear Colleague" letter.
<b><u>Level: 1 Supporter</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Move MoC beyond taking basic action toward being vocal (in media, public, and hearings) and enrolling colleagues.	<input type="checkbox"/> "If it gets to the floor I will vote for it. You should talk to the MoCs who don't support this." <input type="checkbox"/> "I might co-sign an op-ed." <input type="checkbox"/> "Who else are you talking to?" <input type="checkbox"/> "I believe in this. We are on the same page." <input type="checkbox"/> "I will co-sponsor the legislation."	<input type="checkbox"/> Request regular meetings with key DC aide(s) every 1-2 months. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings. <input type="checkbox"/> Provide regular positive feedback on MoC's action via letters and media. <input type="checkbox"/> Look for opportunities to put MoC in contact with people affected by the issues including encouraging MoC to visit projects on the ground that address our issues. <input type="checkbox"/> Always ask that MoC do more than take the basic action (sign the letter <u>and</u> get committee colleagues to sign). <input type="checkbox"/> Demonstrate community support for his/her actions <input type="checkbox"/> Ask a colleague in MoC's state, caucus, interest group to join him/her in taking an action.
<b><u>Level: 0 Neutral--Uninformed</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Educate on issue or cause. <input type="checkbox"/> Determine and start to build areas of support. <input type="checkbox"/> Reach aides and decision-maker at emotional level <input type="checkbox"/> Get them to take an action.	<input type="checkbox"/> "Why should I support this?" <input type="checkbox"/> "Tell me more about this." <input type="checkbox"/> "Which other MoCs of Congress are supporting this?" <input type="checkbox"/> "Do you have more information?" <input type="checkbox"/> "What are you asking me to do?"	<input type="checkbox"/> Ask for action on their hot button topics. <input type="checkbox"/> Tell them stories that leave them moved by our issues. <input type="checkbox"/> Research MoC's interests and background to find ways to show how RESULTS aligns w/their interests. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings.
<b><u>Level: -1 Opponent</u></b>  <b>Objectives at This Level:</b> <input type="checkbox"/> Weaken their opposition; move them toward neutral. <input type="checkbox"/> Find common ground between your point of view and theirs. <input type="checkbox"/> Educate MoC on issues in way he/she can relate to.	<input type="checkbox"/> "I can't meet with your group." <input type="checkbox"/> "I won't/can't support this." <input type="checkbox"/> "It's not a problem" <input type="checkbox"/> "Your solution will not fix this." <input type="checkbox"/> "My constituents will not support this." <input type="checkbox"/> "We don't have money for that, it's not a priority."	<input type="checkbox"/> Get the ear of the key aide first <input type="checkbox"/> Share stories (DVD, spoken word) with MoCs and aides that leave them moved on the issues. <input type="checkbox"/> Research MoC's interests and background to find ways to show how RESULTS aligns w/their interests. Use his/her website and other sources. <input type="checkbox"/> Find foothold with one issue, or one aspect of one issue. <input type="checkbox"/> Be persistent about getting in front of MoC in meetings and public gatherings.

Notes: