



Give Hepatitis a Face and a Voice

Each and every day, we hear stories from people living with hepatitis B and C about the negative stigma associated with the disease. Stigmatization and prejudice are often based on two factors: ignorance and impersonalization, or “facelessness”. While people may have heard of hepatitis, 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 HBV and HCV 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: Be sure your voice is heard! - **“The squeaky wheel gets the grease.”**



Send us your video story

Make a short video about your hepatitis 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 viral hepatitis 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 viral hepatitis 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.



Grassroots Advocacy

Advocacy Begins When Someone Says “No”.

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

Create an action network. Establish effective and timely means to reach hepatitis organization leaders, members, and allies for advocacy action. Email lists, text messages, phone trees, social media, and websites are options to explore. Develop capacity to identify and target members by legislative districts.

Collect stories. Capture the stories and experiences of individuals who call hepatitis Help-Lines, take classes, attend support groups, or volunteer. Personal stories are invaluable in portraying the many faces of hepatitis 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 hepatitis priority issues.

Track legislation. Closely follow priority legislation throughout the legislative sessions, including budgets for hepatitis services and treatment. Pay particular attention to upcoming hearings as opportunities for grassroots action. Track additional hepatitis-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 hepatitis’s interests on important advisory groups or committees. Bring attention to how decisions will affect people living with hepatitis.

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

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

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 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

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

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 viral hepatitis 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

Dear Senator Adams: [or Representative for House]

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3

My name is Jane Doe. I am an outreach worker at People Matter in Any town, USA. I encourage you to cosponsor *Liver Illness Visibility, Education and Research Act of 2019*. This important legislation is in response to evidence of liver cancer, hepatitis B as a major cause of liver cancer, and liver illness that disproportionately impact the Asian American and Latino communities.

5

In 2018, approximately 42,220 people in the United States will be diagnosed with primary liver cancer, and approximately 30,200 will die from the disease. Asian and Pacific Islander men and women are more than twice as likely to develop liver cancer compared to the non-Hispanic White population. The most common causes of liver cancer include Hepatitis B virus and Hepatitis C virus infection.

6

The Liver Illness Visibility, Education and Research Act of 2019 creates the following initiatives:

- Creates new Department of Health and Human Services (HHS) grant program for research into conditions known to increase an individual's risk of contracting major liver diseases, including liver cancer, Hepatitis B, and Hepatitis C.
- Creates new CDC grant program for liver cancer prevention activities (such as screenings, vaccination, and treatment for liver cancer, Hepatitis B, Hepatitis C, Nonalcoholic Fatty Liver Disease, and Cirrhosis of the liver)
- Creates new CDC grant program for liver cancer awareness activities, including production and distribution of public informational materials targeted towards communities at a higher risk for liver disease.

7

Every day we witness the effects of untreated treated hepatitis C in our community. I have lost a family member due to liver cancer and it is imperative that we stop the premature deaths associated with liver disease.

8

We urge you to make liver cancer and liver cancer research a leading health priority in Congress by funding liver cancer research, prevention and awareness activities. Please support *The Liver Illness Visibility, Education and Research Act of 2019*

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



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.



State Advocacy

Top Advocacy List for Making Change and a Lasting Impact on Hepatitis Policy

✓ Be Informed! Communicate with Policymakers! Vote!

- You're the Experts! Share Your Expertise! Testify!

✓ Join Local/State Hepatitis Task Forces

- If you do not have one, start one!
- Encourage Advocacy
- Policy Subcommittees
 - Work with other advocates and use the HHS Stakeholders' Workbook to make a plan and develop policies for your state. →

✓ Coalitions – Local, State & National

- Join and share your perspective with coalitions outside of hepatitis. *No one is immune to hepatitis.*
- Share hepatitis policy updates.

✓ Engage with your Medicaid and Insurance Agencies

- Testify at formulary meetings.
- Meet with your commissioner.
- Join the local care organization as a patient representative.

✓ Seek Gubernatorial and Mayoral Proclamations

- May is Hepatitis Awareness Month.

✓ Utilize Awareness Days

- Hepatitis, HIV, Immunization, Substance Use, etc.

✓ Engage with the Media

- Press Releases, Letters to the Editor, Featured Articles, Editorial Review Boards.

✓ Use Social Media

✓ Hold State of Hepatitis Forums

- Invite Policymakers – Highlight the Need.

✓ Hepatitis Advocacy/Lobby Day

- Descend on the State Capitol.
- Give awards to your Champions.
- Serve FOOD!



Your Hepatitis coordinator is a vital resource!

What programs are already in place?

What seems to be the natural "next step"?

Who are your community allies?

Who are your legislative champions?

What is realistic to expect?

Organize! Mobilize! Realize!

Do your Homework!



Advocacy Resources

Stay Informed!

[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.

[NVHR.ORG](https://www.nvhr.org)

Follow or join the National Viral Hepatitis Roundtable. Be a part of the national movement

The National Viral Hepatitis Roundtable is a broad coalition working to fight, and ultimately end, the hepatitis B and hepatitis C epidemics. We seek an aggressive response from policymakers, public health officials, medical and health care providers, the media, and the general public through our advocacy, education, and technical assistance.

[hepbunited.org](https://www.hepbunited.org)

Hep B United is a national coalition to address and eliminate hepatitis B, a serious liver infection that is the leading cause of liver cancer.

[hhs.gov/hepatitis](https://www.hhs.gov/hepatitis)

COMBATING THE SILENT EPIDEMIC OF VIRAL HEPATITIS

Follow the federal government's hepatitis action plan and get the latest updates from HHS.

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

[Center for Disease Control](https://www.cdc.gov)

See the government's facts and figures on hepatitis. Find your state Adult Viral Hepatitis Prevention Coordinator, order awareness posters, risk factor test and more.

Champion Scale Tool

Members of Congress (MoCs) don't often come into office as champions on hepatitis or liver disease issues. The Champion Scale is a tool to help us move MoCs, step by step, toward becoming champions on hepatitis B and C and Liver 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 www.results.org <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 |
|--|--|

| Level Name, Objectives | Determining Their Level – They Might Say: | Moving Them to the Next Level: |
|--|--|---|
| <p>Level: 4 Champion</p> <p>Objectives at This Level:</p> <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. |
| <p>Level: 3 Leader</p> <p>Objectives at This Level:</p> <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: |
|---|--|---|
| <p>Level: 2 Advocate</p> <p>Objectives at This Level:</p> <ul style="list-style-type: none"> <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. | <ul style="list-style-type: none"> <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 op-ed 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. " | <ul style="list-style-type: none"> <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. |
| <p>Level: 1 Supporter</p> <p>Objectives at This Level:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Move MoC beyond taking basic action toward being vocal (in media, public, and hearings) and enrolling colleagues. | <ul style="list-style-type: none"> <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." | <ul style="list-style-type: none"> <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. |
| <p>Level: 0 Neutral--Uninformed</p> <p>Objectives at This Level:</p> <ul style="list-style-type: none"> <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. | <ul style="list-style-type: none"> <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?" | <ul style="list-style-type: none"> <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. |
| <p>Level: -1 Opponent</p> <p>Objectives at This Level:</p> <ul style="list-style-type: none"> <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. | <ul style="list-style-type: none"> <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." | <ul style="list-style-type: none"> <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: