

Making a Difference Through Grassroots Advocacy



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Advocacy In Action



Grassroots advocacy begins with you.

Telling your story to the right people can be impactful and help to improve lives. Whether you are a patient, family member, caregiver, healthcare provider, or an advocacy organization, your voice can and will make a difference.

In this guide you will learn about:

1. The importance of advocacy in healthcare
2. The basics of advocacy
3. Becoming an advocate

As you read through this guide, keep your own story and experiences in mind. Your voice and the collective voices of those with common interests can impact important healthcare issues and change lives for the better.



Advocacy is Critical in Healthcare

Healthcare involves a myriad of complex issues. The best healthcare programs work to ensure excellent care, access without disparity, and affordable costs. Advocacy to help ensure that policies and regulations have the outcome that elected officials and regulators intend is important to ensuring patients receive the healthcare they need.

Since the implementation of the Patient Protection and Affordable Care Act (ACA) in 2010, there has been a growing emphasis on measuring patient experiences and using that information to improve care. There is a growing emphasis on measuring patient experiences and a shift to value-based care. It is critical for patients to be educated and engaged in their own healthcare decision-making and to share their stories with others to continue to drive a patient-centered approach to healthcare delivery.

Will My Voice Matter?

Your voice and views are important and your story matters. Personal stories are much more memorable and impactful than lengthy or dry reports. Through your advocacy on a particular policy change, you have the ability to shine a spotlight on an issue that is not well-understood or previously may have received little attention.

Policymakers look for ways to better understand the healthcare issues important to their constituents, and regulators are often open to learning how the law and policies they implement have an impact on patients. They often cite the voices of constituents and advocates as examples of why policy should change. Your specialized, direct experience is key to helping them do just that.

The Basics of Advocacy

Generally, advocacy is any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others. In the legislative and regulatory arenas, your approach may be in the form of personal advocacy, grassroots advocacy, or both. As a constituent – generally defined as a citizen living in the state, district, or community of an elected official – your elected officials at all levels should pay attention to your needs and those you advocate for.

You, a family member, a close friend, a co-worker, or a healthcare professional can all be **personal** advocates. In essence, personal advocates can help ensure a patient understands the different types of medications prescribed, assist in tracking the side effects of medications, and listen closely when meeting with members of the patient's healthcare team. They can also help a patient understand their

rights, and personal advocacy may even include contacting public officials to help ensure those individual rights are upheld.

Grassroots advocacy is an opportunity to engage others to help educate and influence key decision makers about the ways healthcare policy affects individuals or groups of people. This collective action may effect change at the local, state, or national level, by engaging on issues directly with elected officials, regulators, and other policy makers.

The Difference Between Advocacy and Lobbying

All lobbying is advocacy, but not all advocacy is lobbying.

As noted above, advocacy is any action that speaks in favor of, recommends, or argues for a cause, or the process of publicly supporting or defending on behalf of self or others. Lobbying involves activities

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in support of, or opposition to, a specific legislative or regulatory proposal, most often utilizing resources such as the salary of the individual doing the lobbying. While it may be permissible for an advocacy organization to participate in some form of lobbying, lobbying activities are governed by federal and state law. And, the IRS has strict rules about what percentage of an organization's budget can go toward lobbying activities without losing its non-profit, 501 (c)(3) status. Before engaging in any sort of paid lobbying activities, you should familiarize yourself with federal and state laws to ensure you are in compliance.

Legislative vs Regulatory Advocacy

Once a legislative body passes a bill and it is signed by the Executive (President or Governor), it becomes law. Federal, state, and local government agencies may then create rules or regulations through which those laws are implemented.

The Difference Between Statutes, Regulations, and Policy Guidance

On both a federal and state level, a law is referred to as a “statute”, either passed by Congress or the state legislature. A “regulation” or “rule” is adopted by an administrative agency to outline how a statute will be enforced or implemented.

Whether you advocated for the passage of legislation or argued in opposition to it, it is important to pay attention to the regulatory process to help ensure the regulations are in concert with the language and intent of the statute.

In addition to adoption of specific rules, regulatory agencies often create broad policies, or “policy guidance” on critical issues, providing another opportunity to advocate for changes to policies that aren't necessarily bound by either legislation or regulation.



The Levels of Advocacy

Each level of advocacy below has the potential to build a foundation for another level – expanding your reach and impact.

For examples of advocacy across federal, state and local levels, refer to the section, “Examples of Successful Advocacy Efforts by Patient Organizations” (See page 42).



Local Community Advocacy

Local community advocacy involves bringing attention to a particular issue that might affect others within your neighborhood, town, or community. Collaborations on a local level can help influence both the development and implementation of public policies.



State Advocacy

There are also opportunities to engage with elected officials and regulatory agencies at the state level. Research to identify if any state-level advocacy organizations or associations are already tackling your issue before starting this journey on your own.

As a state resident, you are a constituent to whom elected officials have a direct responsibility. State regulatory agencies perform their role through state health departments, state insurance agencies, state medical and pharmacy boards, and other agencies. Even one advocate’s voice can make a difference within these agencies and boards.



Federal/National Advocacy

Advocacy at the federal or national level is an important way to impact change in federal laws and policies. On a legislative front, successful advocacy can be accomplished both on Capitol Hill in Washington, D.C. and in your elected official’s home state or congressional district office where elected officials and their staff regularly meet with constituents to hear their stories or concerns.

To learn more about advocating with federal and state legislators and within federal and state regulatory bodies, reference the chapters on Engaging with Elected Officials and Engaging with Regulators.



Becoming an Advocate

The odds are that you are already an advocate in certain areas of your life. Have you ever helped or encouraged someone to learn more about a particular issue? Have you supported the needs and rights of others? If so, you have advocacy experience!

When you are advocating for a change in healthcare laws or regulations, some basic tools and approaches will help you get started.

Developing an Advocacy Plan

Your legislative advocacy plan is a road map to your goal and should align with your mission. Begin your effort by defining priorities, understanding how they may be impacted by the passage or defeat of legislation. Outline the ways you and your organization (and its individual members) might work with elected officials to help ensure your issues are addressed.

Setting Goals & Priorities

Aim high! Your goals may take time to achieve, but if your mission is clear, you have a better chance of getting there. Set both long-term and short-term goals – it may require a year or two to achieve healthcare legislative or regulatory success. Your goal might be to simply increase awareness about an issue, to secure increased funding for a cause, or to set the stage for another objective altogether. It is important to have your priorities well-defined before you begin to engage others.

There are a few key questions you should consider in writing your plan:

1. What is your primary goal: To encourage legislators to write and propose a new law or policy? To change existing laws and policies? Or just to be aware of the impact of a certain disease and the challenges patients and caretakers face? Specify your “ask” of policy makers.

2. Who is your target audience? Are there specific legislators or regulators you should talk with – based in your state or elsewhere in the country?
3. What will be the best way to reach them?
4. How often do you plan to reach out, and how will you follow-up?
5. Are there other allies or advocates you can join with or enlist to help get the message across and encourage action?

In the resources section of this chapter you will find tips to help you develop and define your advocacy plan. “A Planning Guide for your Advocacy Efforts” (See page 8 in the Resources section).

Working Collaboratively

By thinking, planning, and working together, groups of advocates can achieve goals that individuals may not be able to accomplish by themselves. Working with others can increase the volume of your voice amid a competitive environment for attention.

Working collaboratively will also combine different perspectives from a variety of individuals or groups, lending credibility and strength to your message and goal. In any collaborative effort, it is important to identify others who share an interest in your issue and investigate whether collaboration makes sense.

Before you consider a collaborative effort, identify your strengths, resources, and areas of expertise, and consider the benefits of working with other individuals or groups.



Be sure to consider a full range of potential collaborators, including both large and small organizations and specialized constituencies. Groups beyond the healthcare and patient advocacy world may also have a strong interest in your issue. For example, business organizations and labor unions may be aligned with your goal for healthcare access, coverage, transparency, or many other pursuit.

Engaging Effectively with Others

Before you consider a collaborative effort, identify your strengths, resources, and areas of expertise, and consider the benefits of working with other individuals or groups.

Considerations and questions for developing successful collaborations:

- What do you bring to the collaboration? What do you hope to gain from the collaboration?
- Do you share common goals and expectations? Will this collaboration allow you to stay true to your mission?
- What potential conflicts might arise and how will they be addressed?
- Have you established a clear understanding of roles and responsibilities?
- Will you be able to trust and openly communicate with your potential collaborator(s)?

Research online to learn more about established advocacy organizations that might be tackling an issue that is important to you or a loved one. Often local and national advocacy organizations track specific healthcare issues and publish their activities on their websites. Seek out organizations that have a successful track record of looking out for the best interests of patients.

Conclusion

Your efforts to create change are important and worthwhile. Through advocacy you have the chance to improve your own life and the lives of others.

The good news is that you have already taken the first step: understanding what advocacy is and how to go about it effectively. Your involvement is crucial to ensuring that healthcare policies and initiatives are meeting the healthcare standards that patients deserve.



A Planning Guide for Your Advocacy Efforts



1. Define Your Mission

- Understand your vision and mission
- Identify the relevant key issue(s)
- Assess your areas of strength, resources, and expertise



2. What is Your End Goal?

- Define your primary goal: new law or policy, change existing laws or policies, raise awareness



3. Do Your Research

- Are there other organizations or associations tackling this issue?
- Do you have the resources available to accomplish the goal?



4. Define the Target Group

- Specific legislators or regulators (local or elsewhere)



5. Collaboration

- Other patients or advocates
- Media (e.g., newspapers, radio stations)
- Local community leaders and constituents
- Are there potential organizations / collaborations to form?



6. Develop Your Message

- Consider the amount of time you'll have to deliver the message
- Develop clear and specific talking points with a specific ask
- Determine who will deliver the message



7. Effectively Deliver Your Message

- In person or virtual meeting (i.e., arrange a meeting with a policymaker on an issue, influence a state proclamation)
- On the phone (i.e., Getting a certain number of advocates to participate in a call in)
- Email
- Letter (i.e. Submitting comments to a regulatory agency)
- Mobilizing others through social media (E.g., Twitter, Facebook)



8. How Will You Measure Success?

- Did you achieve your goal?
- If not, how will you modify your approach?
- What will you do differently next time?
- Was it a success?



Engaging with Elected Officials and Regulators



Successful advocacy requires careful thought and planning to develop your strategy prior to mobilizing individually or as a team, and engaging in advocacy efforts.

In this guide you will learn about:

1. The legislative process
2. How to know your elected officials
3. The basics of regulatory advocacy
4. How to effectively communicate
5. Tools for individual advocacy
6. Tools for group advocacy
7. The importance of follow-up
8. How to remain encouraged and optimistic!

Understanding the Legislative Process

Gaining an understanding of how laws are made will help you determine where your advocacy efforts can have the greatest effect. Although there may be slight differences, the basic steps in the legislative process all begin with an idea. The idea doesn't have to come from an elected official; it can come from an advocate or an advocacy organization. If you can gain the support of elected officials with your idea, they can take action through drafting or revising a bill.

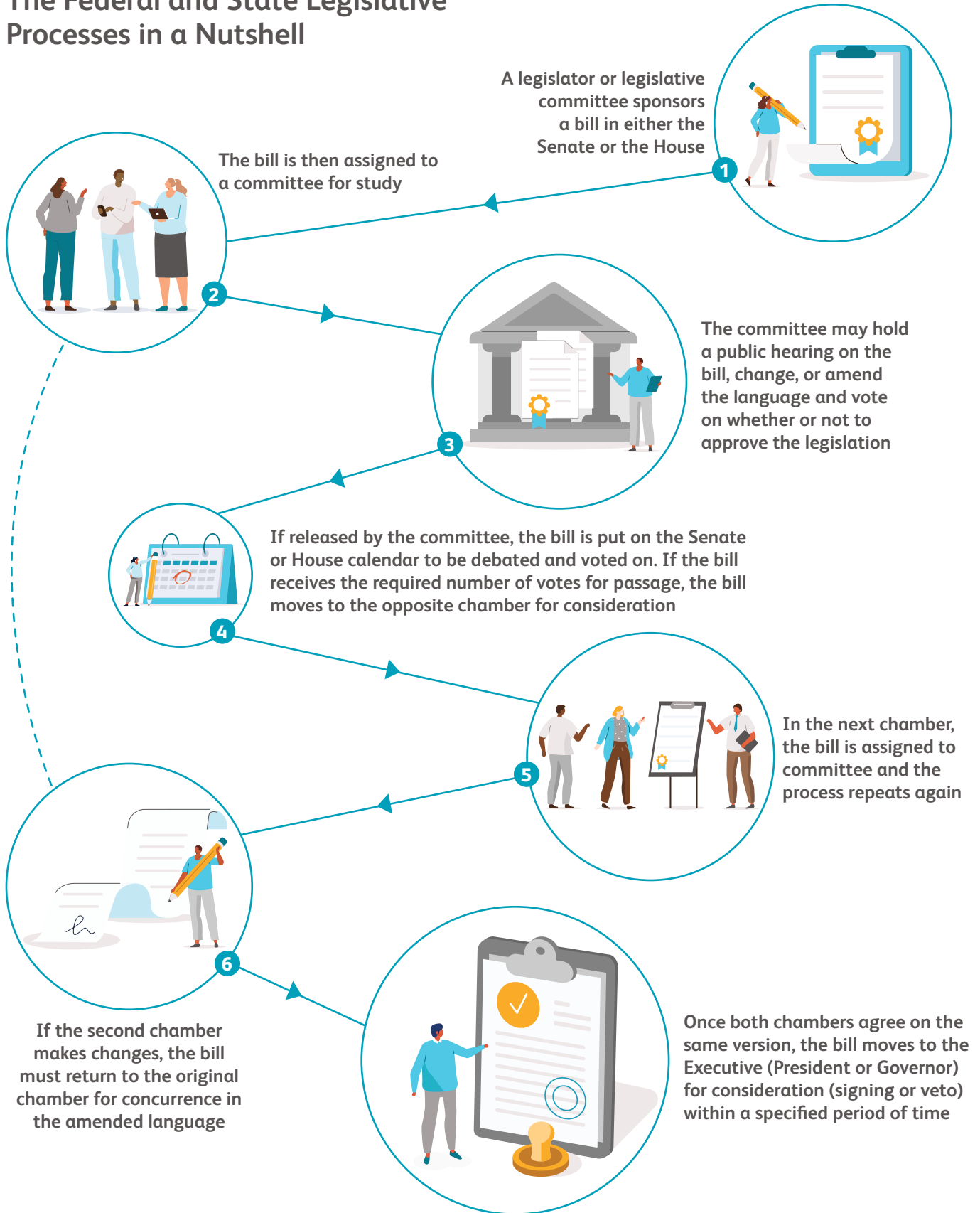
The process for the passage of a bill is similar at the federal and state levels. Ultimately, a bill passed by Congress is signed (or vetoed) by the President; a bill passed by a state legislature is signed (or vetoed) by the Governor.

Congress and most state legislatures are structured similarly, with a House of Representatives and a Senate (except for Nebraska, which has only a State Senate). Just as in Congress, state legislatures have committees that focus on specific topics such as healthcare, insurance or consumer protection policies. As bills move through state legislatures or Congress, they are informed by the expertise of committee members to determine how policy should be addressed. These committees are informed by advocates like YOU and can make adjustments and changes to a bill before it is voted on.

To learn more about your state legislature's specific structure, visit: openstates.org/find_your_legislator/ and enter the name of your state.



The Federal and State Legislative Processes in a Nutshell



Getting To Know Your Elected Officials

Building a strong relationship with your elected officials and their staff is an important aspect of advocacy. Before any meetings, do your research. On your elected official's website, you can learn more about their positions on particular issues and different pieces of legislation. They may also have a campaign website on which they post additional information about their goals and priorities in support of their election to office.


Learn the key facts about your prospective audience:

- Their political party – however, you should recognize the importance of bi-partisanship and legislators in both parties (and

independents) – both sides are usually needed to support a bill

- How long they've been in office and what motivated them to run for election
- Their priority issues of concern and legislation they have sponsored or supported in the past
- Their specific committee assignments
- Caucus memberships (such as the Congressional Black Caucus, Cancer Caucus or other issue-based caucuses)
- Their professional background and family life

Take the time to learn as much as possible. Not only will they appreciate your knowledge of their positions on certain issues, but you'll be in a better position to frame your priorities in a way that will resonate with them.



Building a strong relationship with your elected officials and their staff is an important aspect of advocacy. Before any meetings, **do your research.**

The Basics Of Regulatory Advocacy

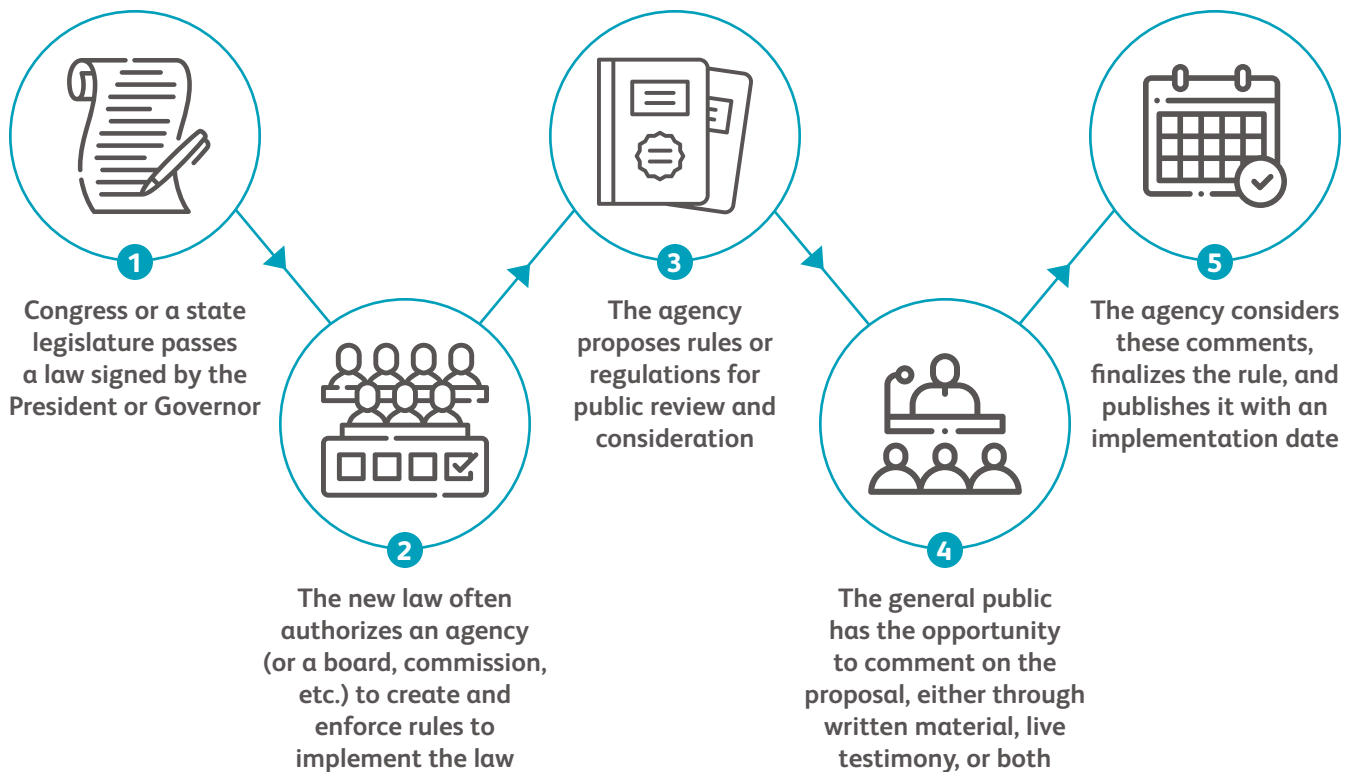
Regulatory advocacy can help to educate regulatory agencies to help ensure that enacted laws are implemented as Congress or a state legislature intended.

Now more than ever, it is important to ensure that the patient voice is represented in all facets of healthcare regulation. At a minimum, regulatory advocacy should focus on patients' healthcare rights that work to ensure the delivery of safe and effective quality healthcare.

A summary of federal and state regulatory agencies is in the Resources section at the end of this chapter. (See page 26 in the Resources section.)

Rulemaking Process Overview

The rulemaking process is similar at both the state and federal level.



NOTE: Neither a federal nor state agency is required to make any changes to a proposed rule based on the comments they have heard/read from the public, but they may be required to address them in the final publication.



Communicating Effectively

How and when you say something is as important as what you say. The effectiveness of your communication will depend on your style of writing or speaking, tone, sense of purpose, and clarity.

Developing Your Key Messages and Talking Points

A key message should articulate your goal in one sentence or thought. Keep it straightforward, strong, and concise.

Your message should always include:

- The issue
- Who it impacts
- The ask – what do you want to happen, and what change are you advocating for?

For more tips on developing your message, refer to the resource and support tool, “Develop Key Messages” (See page 29 in the Resources section).



Telling Your Story

You have a clear sense of your mission and goals. You are ready to reach out to legislators, staff, or regulators. How can you ensure you will be heard? The story of those who can speak from personal experience is one of the most effective ways to educate and engage people on a personal, emotional level.

Legislators and regulators will always remember a personal story over data points and facts because they are relatable and inspire feelings and emotions that help increase recall. You may have similar experiences remembering a friend's personal story years after they relayed it to you. Keep in mind that regardless of their position, elected officials and regulators are people with personal lives, families, and friends they care about, just like you.



Organize Your Thoughts

Before you can begin to tell your story, preparation and careful planning are important. Consider both your own individual story, as well as that of others who may be impacted by changes in policy or regulations. As you advocate for something or someone, the story you tell is likely part of a larger one.

Focus only on the highlights of your story – the meaningful parts that enable a listener to connect with you. Your story includes who you are and your situation, the impact on you and those around you (as well as other patients and caregivers), and why this matters. In-depth stories about the details of your treatment process may be less impactful than offering short anecdotes and a clear picture of how the situation impacts you (and others), and how you feel about that.

Practice telling your story in 10 minutes. Then practice telling it in five minutes. Finally, try to communicate it in two minutes. Some of your greatest moments in advocacy might stem from a personal story you reduced to a two-minute discussion at a coffee shop or in an elevator!

It may be helpful to record a short video of yourself telling your story with your mobile phone, and then share the clip with friends and family. They can offer feedback and you will become more comfortable telling your story in front of others.



Speak From the Heart

It is not necessary to use official-sounding phrases or big words. The best stories will be told in your own words, the way you would say them to a friend. The facts are important, but so are your emotions and the human story that goes along with them.

Emotions and personal experiences are relatable, memorable, and take the issue out of the realm of “theoretical” challenges.



Make the Ask

At the conclusion of your story, always plan to ask your listener to do something. When speaking with elected officials, your ask might be for their vote on a piece of legislation, or simply for them to learn more about an issue. Your ask may be as simple as “Please consider my point of view.”

When communicating with other patients or caregivers, your ask might be to work together to form a group or coalition. Regardless of with whom you are communicating, be prepared to ask them to contribute to solving the problem and engage!

Tools for Individual Advocacy Communication

Officials care about what their constituents have to say. How you communicate with them is vital in bringing attention to an issue that they may not be aware of or adding weight to their commitment on relevant legislation.

A mix of tools – meetings, emails, social media posts, and other tactics can be particularly effective in extending the reach and impact of your message. In the resources section of this chapter you will find tips to support with local media: Local Media Roadmap (See page 30 in the Resources section).

Meeting with Legislators or Regulators: In-Person or Virtual

In-Person Meetings

Face-to-face meetings with elected officials and/or their staff are often a very effective form of communication. A personal connection engages them in a way no other form of communication can. You can set up your own meetings by calling your elected official's office directly.

Keep in mind that meetings with staff are extremely valuable. They are typically the individuals who brief the legislator and can become your own advocates within the office.

Virtual Meetings

Today, virtual meetings through Zoom, Skype, or other platforms, are popular and effective ways to meet. These platforms allow you to add other advocates to the call, bolstering your share of voice. They also enable contact with your elected official or staff no matter where they are – at the state capitol or at home in their legislative district.

Get ready to meet!

Once you have set a meeting date, begin your preparation. Organize your thoughts, practice your story, and develop key talking points. Most importantly, remember this is not a political meeting – leave party politics out of your conversation. The elected official should remember you and your story, not your political affiliation.

Develop an agenda for your meeting, be it in-person or virtual.

Sample meeting agenda:

- Introductions and appreciation for their time
- Explain purpose of meeting including clearly stating your ask
- Share your story
- Answer questions openly and honestly – ask their advice!
- Repeat your ask and request their support for your position
- Leave behind or email written information that outlines your story, provides additional facts, and includes your contact information
- Thank them for their time

Follow up: Do not underestimate the impact one effective meeting and follow-up with those individuals afterwards can have on the legislative process. (See the tips on follow-up later in this section).

Go!

It's time to put your plan in action. Keep in mind that your approach may evolve over time, and you are not required to use every tool. Choose what makes sense for you and/or your team.

Traditional Phone Calls

Contacting your elected official on the phone is easier than you might think. If you are trying to connect with someone in Congress or in your state legislature, visit their website to find their contact information.

While speaking directly with your elected official is ideal, discuss your issue and ask with a staff member if the legislator is unavailable. Office staff are very important, so get to know them well! They have the ear of the elected official and can help facilitate your interactions.

Mail and Email

Writing a letter or an email to an elected official can also be an effective form of communication.

Your letter or email should have 6 basic elements:

1. Appropriate address and salutation (if email, include issue or bill number in the subject line!)
2. A request for their attention and action on a specific issue

3. The relevant bill number if one exists
4. The basics of your story
5. An offer to serve as a future resource

Social Media

The importance and prevalence of social media has changed the way we communicate with each other, the way we learn about events and news, and how we live our daily lives.

Virtually all elected officials use social media to keep a finger on the pulse of what is happening in their districts and states. There are tips on page 32 about communicating and staying connected through social media platforms like Facebook, Twitter, YouTube, and Instagram.

Keep in mind that the most effective and shared social media posts include images or short videos. You can track the effectiveness of individual posts and different channels (see the Resources section at the end of this chapter).



Before you make a call to an elected official's office, be clear on the following:

- Why you are calling
- The issue you are calling about
- What you would like them to do

Tips for successful social media advocacy campaigns:

1. Schedule your campaign around timely events that bring attention to your issue.
2. Build context into your message – a bill may go into consideration by elected officials soon, or a policy has been proposed, and advocates may need to act now.
3. Tag the campaign with relevant hashtags (#) that represent your topic, as well as the channel address (usually with a @ sign at the beginning) for key influencers, legislators, policy-makers, and journalists to help attract their attention.
4. Break down large issues or asks into smaller amounts of content or action items – this will help you fill your strategic plan calendar and give your audience manageable actions to take.
5. Remind your audience that their voice matters in creating change or bringing attention to your issue.
6. Actively follow other accounts that are relevant to your cause – this may encourage those individuals or organizations to follow you in turn.
7. Be persistent – your audiences need to see your message at least once or twice a day, and remember that evenings and weekends typically see an uptick in the number of people on social media channels.
8. Promptly respond to any questions or comments you receive, and “like” the ones that support your message. It’s best not to be drawn into an argument with a respondent – usually no response is the best option. If they post inaccurate content, you can respond with relevant information or data, and leave it at that.
9. Track your metrics such as “likes” and “shares” – this data can help you know where your message is gaining traction and where you may need to invest more effort.



If you are working with a group, consider creating a social media plan, best practice summary, and sample posts. Examples of these documents are available in the Resources section of this chapter.

Social media does not replace other channels of communication. But, it's a fast and important means of communication and follow-up, and can effectively support other efforts.

In the resources section at the end of this chapter (see page 32) you will find:

- Sample social media campaign plan and best practices
- Sample social media posts
- Social media channel guide and tip sheet

Op-Eds

An op-ed is an opinion column written for a newspaper and/or web publication appearing opposite the editorial page. The best op-eds are both compelling and balanced with factual information. Write clearly and concisely while assuming the reader knows nothing about your issue. Your op-ed should focus on one point and have one objective to help readers understand why this issue should matter to them. Every newspaper will have guidelines on how to submit an op-ed (such as length and format) which is generally available on their website.



Tips for writing a great op-ed:

- Create an eye-catching, accurate headline. For example:
Good headline: *Cancer patients need Senator _____'s help to get quality healthcare.*
Bad headline: *How advocacy can make a difference.*
- Tell your story to establish your connection to the issue
- Get to the point quickly – do not make the reader wait
- Feature 2 or 3 main talking points
- Close with a powerful conclusion and request for specific action

Live Testimony

Live testimony at a public hearing can educate elected officials and regulators about how a law or regulatory decision (or revision to one) may affect you and other patients. Legislative committees and regulatory bodies hold public hearings, and they are an important opportunity for advocates to have their voices heard.

By visiting the website for your local or state government, you can find a list of upcoming public hearings on key policy areas. Some may require registering in advance to provide testimony.

Tips on giving live testimony:

- State your name and, if appropriate, any relevant organizations you are affiliated with.
- Incorporate your personal story into the message and why the issue is important to you.
- Support your story with facts.
- Be specific about what you are asking government officials to do.
- Stay calm and professional – heartfelt emotions are wonderful; angry or argumentative testimony may ultimately be less successful.
- Repeat your ask and thank them for the opportunity to speak.

Tools For Group Advocacy Communication

As we've discussed, groups and collaborative relationships amplify your message and support your goal.

While groups can also use all the tools outlined in the personal advocacy section above, there are some tools and activities that are particularly effective for groups.

In the resources section of this chapter you will find tips to support with local media: Local Media Roadmap. (See page 30 in the Resources section.)

Legislative Call-Ins

If advocates can't make the trip in person to meet with their legislators, your organization can arrange for a legislative "call-in." You can encourage anyone involved with the cause to call assigned legislator offices on a specified day to ask for support on a particular issue or cause. This type of call-in can be effective in raising the impact and increasing awareness of an important issue.

Tips for Legislative Call-ins:

1. Set a Goal

- An example of a goal could be to flood members of Congress with phone calls about your issue or to educate key legislators and staff about your platform.

2. Recruit and Support Callers

- Focus on callers from a specific legislator's state and/or district, then you can add callers from every state.
- Develop a list of talking points for callers. They should first identify themselves as a constituent followed by the talking points of why they are calling.
- Set the time: Hold it separately from a group lobby day (when in-person visits are

planned) to increase participation. The call-in can be one day or last an entire month.

3. Promote the Event

- Promote the call-in through call-to-action emails and social media posts.
- If possible, collaborate with other groups or organizations with an interest in the cause.
- Make the strongest showing you can – you may need hundreds of calls to have an impact on offices.

4. Track Your Progress and Follow Up

- Track your progress: Use online tools to update advocates. This will show which districts have called in and where you need to recruit more callers, including family and friends.
- Follow up: Have advocates follow up after the calls with a thank you call or note to the office for listening to their concerns. Repeat the ask at this time.

Social Media Sharing

Having a plan for other advocates to share tweets and posts with their followers as soon as the original is posted is a very effective way to increase the number of times an audience member will receive a message – strengthening their sense of the number of people behind a message and increasing recall.





Town Hall Meetings

“Town hall” or community meetings can help you increase the awareness of a healthcare issue by educating your community as a whole through the use of selected speakers, panelists, experts, and patient representatives. They may be in-person, or virtual. Here are some tips on setting up a town hall meeting:

- **Plan:**
 - » Develop a planning committee, objectives, agenda, and meeting materials to be distributed to attendees.
 - » Identify staff, speakers, panelists, moderators, and media spokespeople for your event.
 - » Find a location, set a day and time for your event, and create an invitee list.
 - » Or, if the meeting will be virtual, choose a platform like Zoom and distribute call-in information.
- **Promote:**
 - » Within your community: Post news of the event on social media with information on how to participate; place flyers around town and on message boards at local hospitals.
 - » With the news media: Create a press release, call local media outlets including TV and radio stations, and contact your local newspaper.
- **Execute:** Arrive early to set up a registration table with a sign-in list to get attendee contact information for use in the future. Identify staff to welcome attendees; start and finish on time; the same goes for virtual meetings – log on early and finish on time.
- **Follow up:** Send a thank you email to attendees with a summary of the event, including a list of speakers or participants, what was accomplished, and any action items or next steps.

Press Releases

You do not have to be a professional journalist to write and issue a press release. Think of it as a way to educate a reader or help another write an article about your event or issue. If written well, it might pique the interest of a newspaper or a news station to cover your event or story in more detail.

Tips on writing a great press release:

- Create an eye-catching, accurate headline. For example:
Good headline: *Advocacy groups join forces to help improve/save the lives of patients*
Bad headline: *Local group strives for change*
- Tell your story (briefly) and establish your connection to the issue
- Be clear on where the “news” is (press releases that repeat the same content over and over are less impactful than those that address recent events, or provide a new advocate quote or story)
- Use quotes from someone impacted personally by the issue (with their permission)
- Quote an elected official if they were involved (with their permission)
- Provide your contact information
- Tell the reader where they can go to learn more



Creating a Website and Social Media Pages

A website is not mandatory for your advocacy efforts, but it can help to have a central location to send other advocates and people interested in your mission. There you can provide information about your issues and resources, your contact information, and links to your social channels.

If you do not have experience setting up a website, companies like GoDaddy, Wix, among others offer simple platforms and tutorials for creating your own website.

Social pages for your group on Facebook, Instagram, Twitter, etc. are simple to set up. These sites generally offer instructions and customer service for help in set up.

The Importance of Follow-Up

Follow-up is crucial. Hearing a message multiple times is much more effective than only hearing it once. Communication with elected officials is tracked by their offices to keep a pulse on important things happening within their district and with their constituents. Phone calls about issues may be categorized, letters may be compiled, emails may be saved, and follow-up will be noted.

Following-up with your elected official or regulatory agency staffer may simply include a note thanking them for their time or a phone call to ask about progress with your issue. Follow-up ensures that the door stays open for future communication or interaction, their questions are answered, and your story and issue remain top of mind. Tell them you are looking forward to the next time you meet!

You can also follow-up with individuals in your community by sending additional information on the issue and news about next steps.

Remain Encouraged and Optimistic!

When you advocate, you are promoting change which may take time to achieve. Advocacy is hard work, and you may meet obstacles. Sometimes officials will tell you no, and at some point, it may feel like your voice is not being heard. Don't get discouraged! Focus on what you've accomplished and the impact you've made and let that be part of the inspiration behind your work.

Remind yourself for whom or what you are advocating, remembering the passion which drove you to take on the challenge in the first place. Allow this to fuel your continued effort. Think of advocacy like a GPS. You set your destination, and it provides options on how to get there. If you veer off track, you recalculate! You may follow a different path, but your goal remains the same.

Be sure to talk with other advocates and share your experiences, successes, and challenges. Look for ways to work together. Have a well thought out plan, understand the legislative process, and be persistent. You are making a difference!

Conclusion

Effective communication with elected officials is critical to advocacy success. Just like the legislative and regulatory process, advocacy is a process, and it may take time to see change.

Your elected officials will appreciate your first-hand insights as well as the increased understanding of how the policies they create affect patients' lives. You can help bridge the gap between them and their constituents.

It may help to carry something with you to look at and touch to remind you of why you spend your time and energy advocating. Maybe it's a picture of a loved one, a token from a patient not strong enough to fight with you, or something that just helps remind you of your mission.

Tell your story with every ounce of feeling and compassion you have. Use whatever helps give you strength and carry you forward, even when you think you've reached the end of a road. Advocate for change, stand up for those who can't, and work effectively to attract attention to your cause.



Remind yourself for whom or what you are advocating, remembering the passion which drove you to take on the challenge in the first place.

Federal Engagement Resources: Legislative

To learn more about your member of Congress: www.govtrack.us/congress/members

- Track social media (e.g. Twitter, Facebook, Instagram) and press releases
- Review committees they serve on & caucuses they have joined

To learn about Congressional House and Senate sessions:

- House schedule: www.house.gov/legislative-activity
- Senate schedule: www.senate.gov/reference/Index/Calendars_schedules.htm

To learn about important Congressional committees related to healthcare:

- House Appropriations appropriations.house.gov
- Senate Appropriations appropriations.senate.gov
- House Energy and Commerce energycommerce.house.gov
- Senate Health, Education, Labor & Pensions www.help.senate.gov
- Senate Finance www.finance.senate.gov
- House Ways and Means waysandmeans.house.gov
- House Budget budget.house.gov
- Senate Budget www.budget.senate.gov

To connect with your member of Congress on the phone:

- Visit the website below, for a listing of phone numbers for each member of Congress:
 - » Find senators' information: www.senate.gov/senators/senators-contact.htm
 - » Find representatives' information: www.house.gov/representatives/find-your-representative
- Call the Capitol! The switchboard will connect you to any of your members' offices, at 202-224-3121.

To learn about Congressional Caucuses:

- Congressional Caucuses: cha.house.gov/member-services/congressional-member-and-staff-organizations

You will also want to know if there is a Congressional Caucus that might help you advance your particular issue. For example, there is a Childhood Cancer Caucus, Congressional Caucus for Women's Issues, a Congressional Hispanic Caucus, a Congressional Caucus for Parkinson's Disease, and a Crohn's and Colitis Caucus. When you do your research online about your elected official, it will often list if they are a member of a Congressional Caucus.



Federal Engagement Resources: Regulatory

The Federal Register is a little bit like the newspaper of the federal government, and it is here that you can find proposed rules and public notices. To learn more about the Federal Register and the rulemaking process, visit: www.regulations.gov/learn

Healthcare Regulatory Agencies

Working at the pleasure of the President of the United States is an advisory board called the Cabinet. The Cabinet consists of 15 advisory bodies, one of which is the Department of Health and Human Services (HHS). HHS is the regulatory agency tasked with protecting the health of all Americans and providing essential human services. In addition to administering Medicare and Medicaid, HHS also oversees the Centers for Disease Control and Prevention, the U.S. Food and Drug Administration, and the National Institutes of Health. Some regulators are permanent government employees, and some are political appointees. www.hhs.gov

- Engaging with Department of Health and Human Services
www.hhs.gov/regulations/index.html

In total, HHS has 11 operating divisions. To learn about each agency and other relevant offices within HHS, visit: www.hhs.gov/about/agencies/index.html

HHS has 10 regional offices. To learn where these regional offices are located, visit: www.hhs.gov/about/agencies/regional-offices/index.html.

Federal Level Agencies

- **AHRQ** – The Agency for Healthcare Research and Quality’s mission is to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans.
www.ahrq.gov

- **CDC** – The Centers for Disease Control and Prevention works to protect America from health, safety and security threats, both foreign and in the U.S. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, the CDC fights disease and supports communities and citizens to do the same. For example, the CDC was one of the very first agencies to address and help educate the public about the Ebola Virus.
www.cdc.gov

- **CMS** – The Centers for Medicare and Medicaid Services (CMS) administers the Medicare program and works in partnership with state governments to administer Medicaid, the State Children’s Health Insurance Program (CHIP), and health insurance portability standards.
www.cms.gov
 - » Medicare is the federal health insurance program for people who are 65 or older and certain younger people with disabilities.
www.medicare.gov
 - » Medicaid provides free or low-cost health coverage to some low-income individuals, families and children, pregnant women, the elderly, and people with disabilities.
www.medicaid.gov

Did you know?: Medicare and Medicaid combined provide health insurance to one in four Americans.

CMS has 10 regional offices. To learn where these regional offices are located, visit: www.cms.gov/cms-locations

Submitting Comments to CMS
www.cms.gov/Medicare/Coverage/InfoExchange/publiccomments.html

- **FDA** – The U.S. Food and Drug Administration (FDA) is a federal agency within HHS that is responsible for protecting and promoting public health through the regulation and supervision of prescription and over-the-counter pharmaceutical drugs, vaccines, biopharmaceuticals, and medical devices. The FDA regulates drug safety, efficacy, and communication. They oversee the drug development process, they have the authority to regulate drug labels and promotional materials, they regulate drug studies and clinical trials, and provide drug approvals and/or denials.
www.fda.gov
Paths to Engaging with the FDA
www.accessdata.fda.gov/cder/sb-navigate/topic2/topic2/index02.htm
- **NIH** – The National Institutes of Health (NIH) is the nation’s medical research agency – making important discoveries that improve health and save lives. The National Cancer Institute (NCI) coordinates the National Cancer Program, conducts and supports cancer research, trains physicians and scientists, and disseminates information about cancer detection, diagnosis, treatment, prevention, control, palliative care, and survivorship. Under the NCI is the Office of Regulatory Affairs, which serves as a conduit between NCI and the cancer advocacy community.
www.nih.gov
Engaging the Office of Advocacy Relations at NIH
www.cancer.gov/aboutnci/organization/oar

State & Local Level Agencies

- **Department of Health/Human services** – Your state health departments are a part of the government which focus on healthcare issues important to citizens of your state. For example, the Departments of Public Health were responsible for the promotion of the flu vaccine, in that everyone six months of age and older should be vaccinated.

Many states have an office for the healthcare advocate. On their websites you will find information about your patient rights, including recent state and federal regulations, and resources for you to advocate on state healthcare issues. Engage with your state healthcare advocate to advance issues important to you.

To locate and learn about your state health department, visit: **www.statelocalgov.net/50states-health.cfm**

To locate and learn about your county health department, visit: **www.naccho.org/membership/lhd-directory**

- **Drug Utilization Review Boards** – Within each state’s health department, states are required to have a drug utilization review board or program that reviews and approves medications for patients. DUR boards may also require educational material be made available to patients on certain medications.

Similar to other state commissions and boards, the Drug Utilization Review Board meetings are open to the public. The board promotes patient safety through an increased review and awareness of outpatient prescribed drugs. Advocates have the opportunity to submit public comment on proposed rules and regulations to drug utilization review boards

- **State Health Insurance Commissioner** – the regulatory agency that oversees insurance within each state. All 50 states have State Insurance Commissioners, and they are true advocates for the people living within their state. They help enforce state insurance laws. For example, you can work with the office to file a complaint, appeal or report suspected insurance fraud.

To find the contact information for your state's health insurance commissioner, visit: content.naic.org/state-insurance-departments

The National Association of Insurance Commissioners (NAIC) is a standard-setting and regulatory support organization. These state regulators work through NAIC to establish standards and best practices and to coordinate regulatory oversight.

- **State Medical Board** – responsible for the licensing and regulation of all physicians within their state. To locate your State Medical Board, visit: www.fsmb.org
- **State Board of Pharmacy** – responsible for the licensing and registration of all pharmacies and pharmacists within their state. To locate your State Board of Pharmacy, visit: nabp.pharmacy
- **Pharmacy and Therapeutics Committees** – These committees are responsible for managing drug formularies within a healthcare system. Many P & T committees, on both the state and local levels, offer opportunities for patient advocate representation.

Develop Key Messages

Prompts to Develop Key Messages

A template that supports advocates/spokesperson(s) to craft key messages with their voice:

- I'm an [individual] advocate for:
I got involved because:
You too can get involved & here's how:

Optional organization specific prompts:

- We are a patient advocacy organization that:
Our mission is to:
We do this by:

Example Key Messages

Unpolished Example

Hello, I am here with a patient advocacy organization which cares about clinical trials for cancer. Today we are going around to offices to explain that clinical trials are very important. As a member of Congress, I hope you agree.

Well Crafted:

Hello, I am [name], a constituent of your district. As a 5 year cancer survivor, I am here with [association] and we are focused on the need for better funding for research to develop new treatments for cancer. Our patient advocacy organization supports clinical trial research funding and support patients in finding trials they may be eligible for in hopes to develop new treatments for cancer. We are asking Congress to take action now to approve new grants and funds for the lives of millions of patients like me. As a member of Congress, can I count on your support [Senator/Congresswoman]?

Well crafted pitch includes:

- Includes introduction and why you are involved
- Mentions appropriate organizational affiliations
- Outlines mission and importance of issue
- States a clear ask

Local Media Roadmap

Use this roadmap to guide you in your media outreach.

1

Research and Identify Media Target

- Browse local media websites and listen to their platforms; identify reporters covering industry/sector.
 - » Media has broadened greatly – be sure to consider a variety of mediums, including: print, radio, TV, blogs, podcasts, etc.
 - » Identify strategic opportunities to engage a features-style reporter as opposed to a reporter directly tied to your industry or sector – this could be most effective when discussing disease awareness/observances, seeking a profile on advocacy efforts, your community reaching a key milestone, etc.
- Understand current environment and what topics are timely.
- For a medium like radio, be aware of individual shows and which might be most interested in your news.

2

Develop Media Tools

- Answer the who, what, when, where, how of your story.
- Define story angle and develop talking points that communicate your story.
- Develop tools to help support engagement with media (i.e., email templates, content for social media platforms, etc.).
- Facilitate a mock interview to prepare for the questions and any time constraints of the interview.

3

Identify Opportunities

- Contact reporter around timely events (define cause + interest to their readers).
- Identify organizations, associations, and/or individuals within the community to support your cause.
- Identify spokesperson(s) to communicate point-of-view.
- Prep your team for media interactions. This should include:
 - » Information on reporter (a short bio and their recent stories, including those on this topic), angle, and potential questions.
 - » A message map – breaking down your talking points into sections with key points to help you pivot from one to the next (or back to where you want to be).
 - » It may be helpful to sketch out what you want the headline of the story to be – ask yourself what you need to convey in order for that headline to publish.
 - » Responses to anticipated follow-up questions from the reporter or other questions that arise following the interview itself.

4

Telling Your Story

Important tips

- Be clear about attribution – is this on the record, on background, off the record?
- Speak slowly and clearly.
- Be concise – this is especially true when providing a quote or speaking with a TV or radio reporter (know what your soundbite is).
- When you can, make things personal – share a personal reflection about why this news is so important or what this means at an individual level.
- If you're doing a virtual interview, ensure you're in a quiet and well-lit area (try to avoid sitting near a window).
- If you're doing an in-person interview, think about what you want to be “the backdrop” (the background can frequently be woven into a story) – this is critical if you're doing a TV interview or if the reporter plans to take photos to accompany their reporting.
- Have a member of your team with you – they can record the interview for archival purposes, assist with photo needs or other requests that may arise (ideally a communications staffer).
- If you don't know the answer to a question, let the reporter know that you'll be glad to get back to them with an answer.

Interview etiquette

- Dress appropriately – how you present yourself is often reflected in profile-style (and some news) stories.
- If you're doing a timed interview, be aware of the clock– consider having a team member keep track of the time and give you a signal when you need to begin wrapping up.
- Avoid arguing – if you are viewing an issue from different sides, calmly articulate your position and move on.
- Always thank the reporter for taking the time to speak with you and let them know how you can be a resource in the future (and how to get in contact with you / your team).

5

Other considerations:

- Consider the reporting timeliness of the media outlet you are targeting and any competing storylines the target reporter might be covering.
- Try to understand the outlet's style and approach to covering local news.
- Follow-up with the reporter to see if they need anything additional and when their story might run.
 - » Be sure to stay in touch so they view you as a resource for future stories.
- Be strategic in your communication timing (i.e., coordinate outreach around key awareness events).

Tips on Staying Connected via Social Media Channels



Facebook

Facebook is a social media platform with over 1 billion monthly users – even Congress has a Facebook page: [facebook.com/congressorg](https://www.facebook.com/congressorg) – and so do many elected officials. You can use Facebook to send messages and join in discussions by posting or commenting on their pages or using Facebook Messenger. Join Facebook at [facebook.com](https://www.facebook.com).



Twitter

Twitter is an important platform that allows you to share information through “tweets” with a limited number of characters (280). Many congressional offices have Twitter accounts, and you can follow them to see what issues they are working on. Twitter allows you to use hashtags (#) to help you align with others interested in your issue and to categorize topics that are important to you. If you see a post that you like or support, you can retweet it and immediately share it with your own followers. Join Twitter at twitter.com.

A post directed to an elected official could be as simple as: *“I am a constituent in your district, and I support bill number XXX for this reason. Please consider supporting us by co-signing.”* For a Twitter post, follow it with a relevant hashtag.

You can also send a DM or Direct Message to an official through Twitter and Facebook Messenger, and post images and videos on both platforms.



YouTube

YouTube is a video-sharing platform where you can post videos and view those of other individuals and groups. Many congressional offices have YouTube channels where they post important videos. If your Congressional office has a channel, you can subscribe to it to stay connected with them. Join YouTube at [youtube.com](https://www.youtube.com).

Here is an example of how you can keep up with your elected official via their YouTube channel: [youtube.com/user/RepJoeBarton](https://www.youtube.com/user/RepJoeBarton).

You can also create and post videos on YouTube through your own channel.



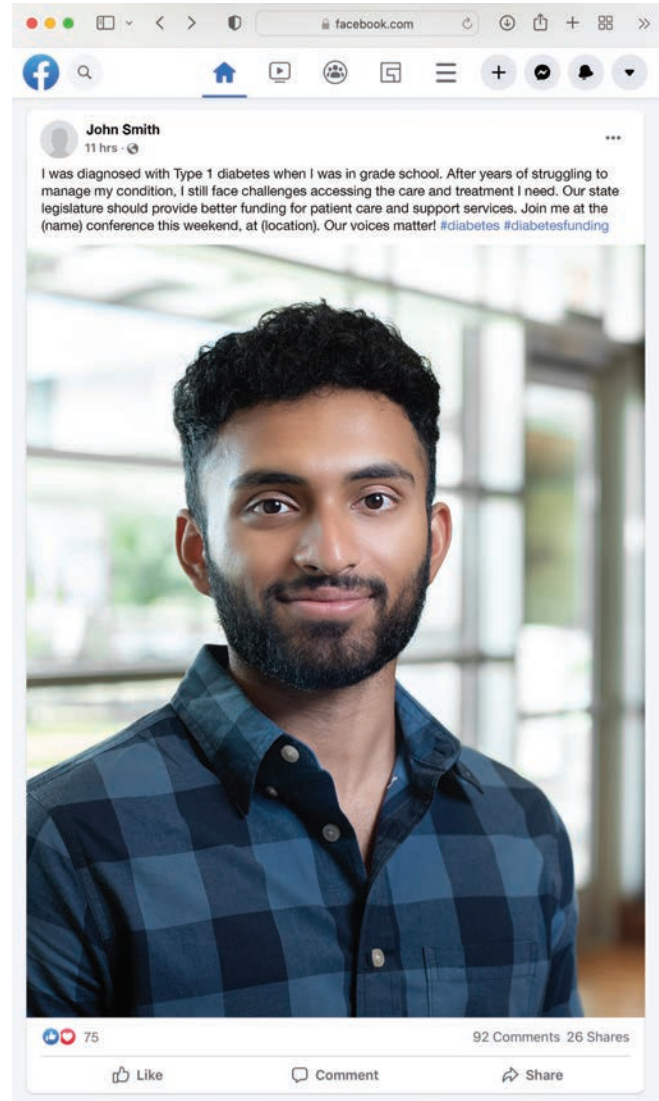
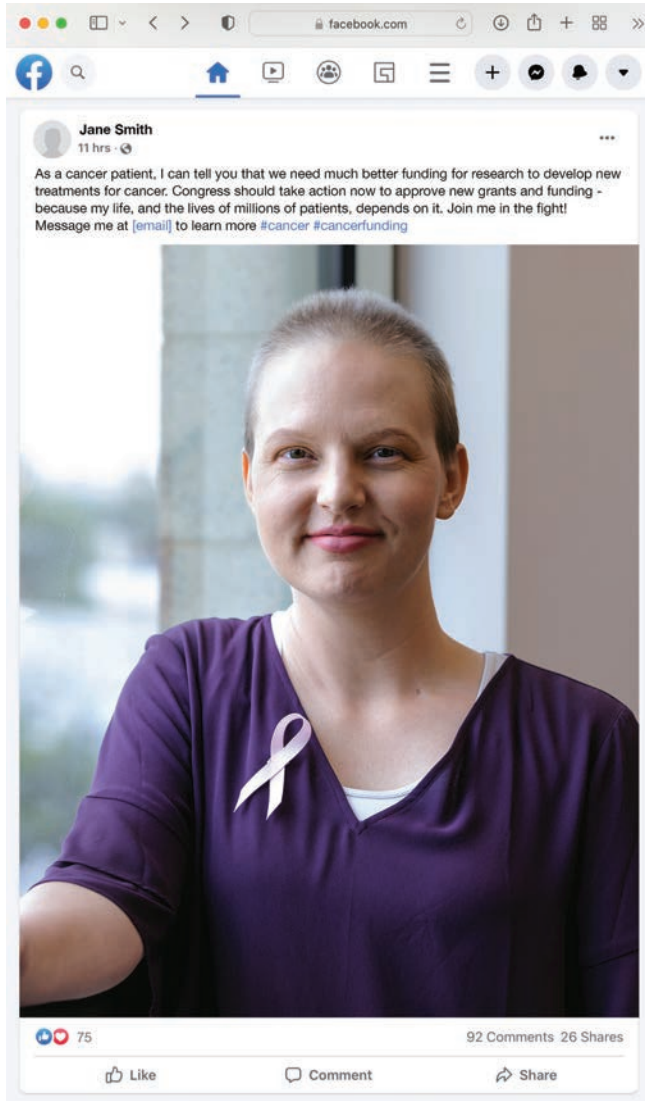
Instagram

Instagram is a rapidly growing image and video sharing platform. You can share pictures and videos with your followers or send them directly to individuals. Because Instagram is owned by the same company that owns Facebook, you can post stories to both platforms simultaneously. Join Instagram at [Instagram.com](https://www.instagram.com).

As you develop your social media content, please note that certain platforms may have character limits and/or other limitations.

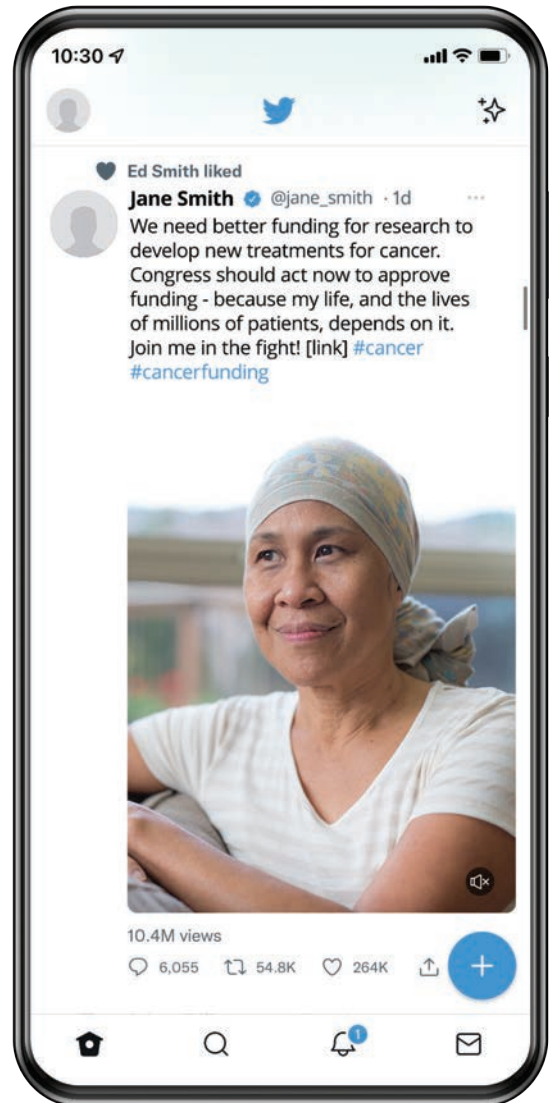
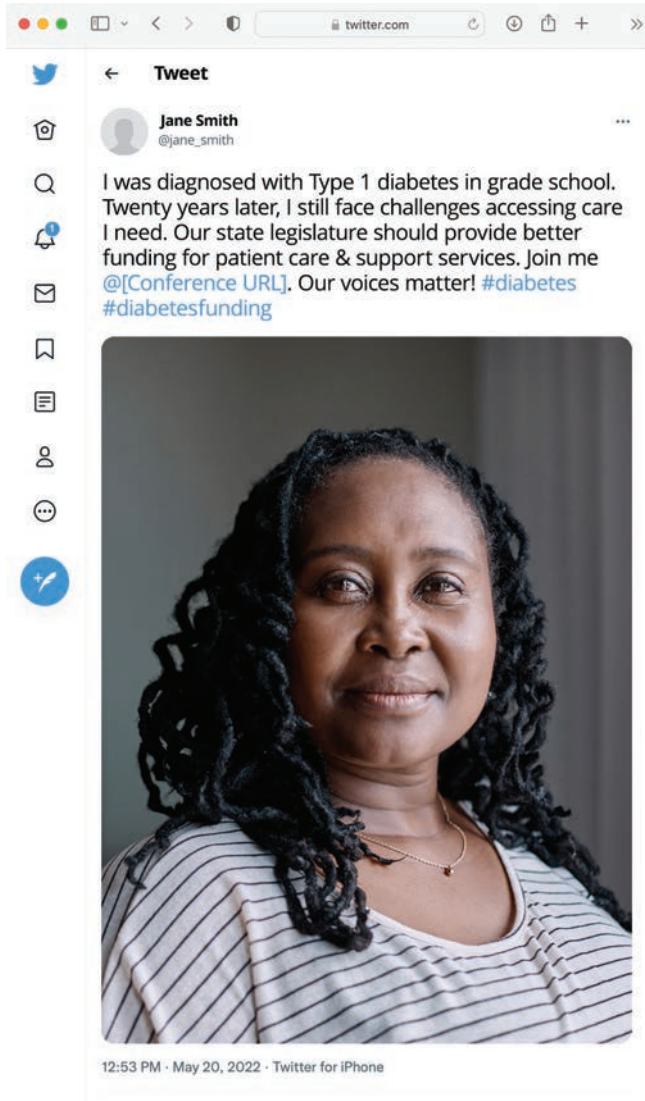
Sample Facebook Posts

- Facebook is one of the more established social media platforms.
- You can post content with links to other websites that provide additional information.



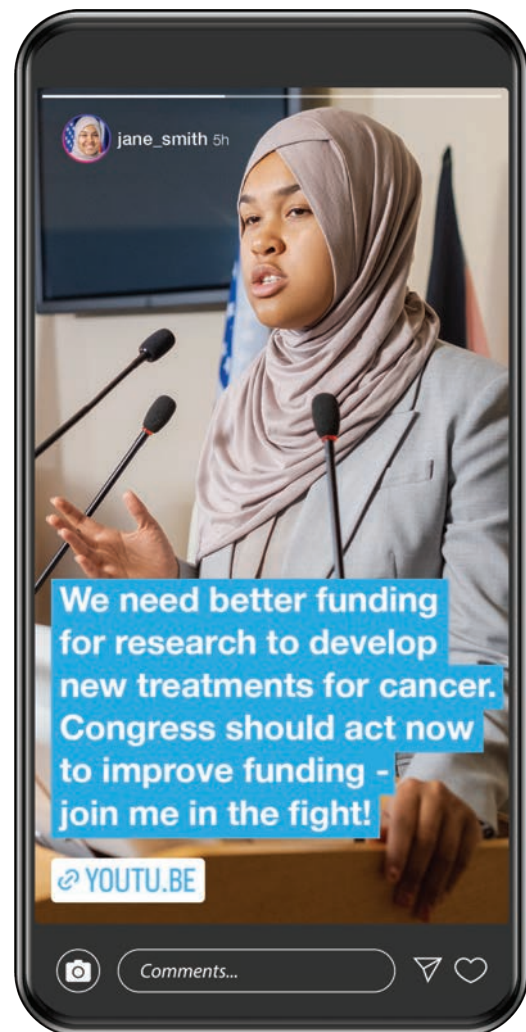
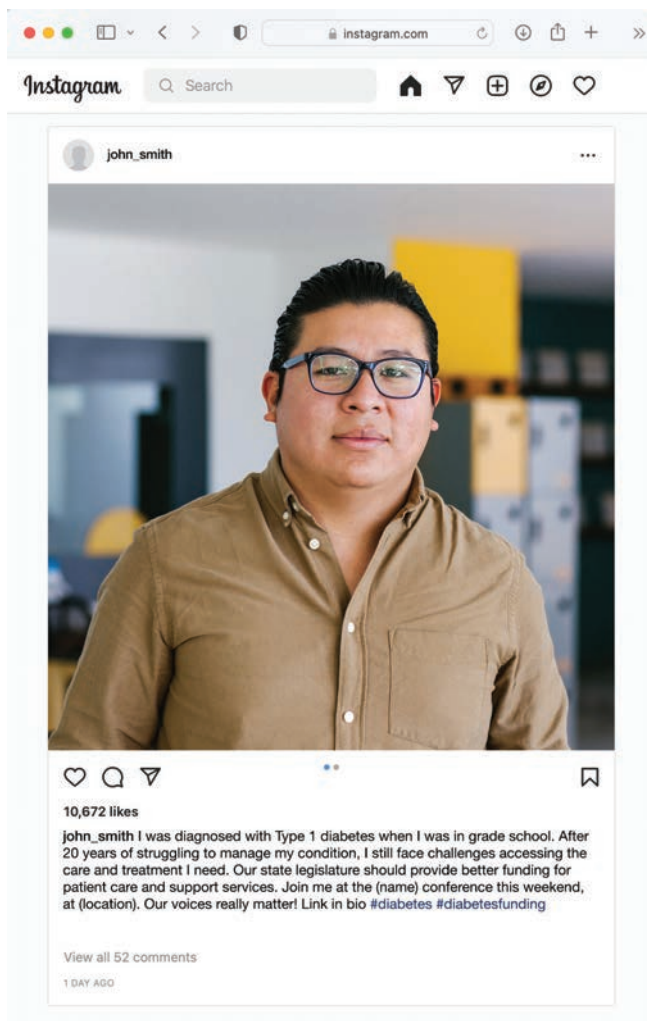
Sample Twitter Posts

- Twitter is meant for short and direct content (a tweet). There is a 280 character limit for every tweet.
- You can also repost a tweet (called a retweet) from fellow advocates or patient organizations.



Sample Instagram Posts

- Instagram has multiple ways to share content, such as posts, stories, and reels.
- Instagram posts do not have functional hyperlinks, but there are other options such as updating the link in your bio or sharing it on a Instagram Story.
- One way to increase viewership of a post is to leverage stories, which only run for 24 hours but can be used to link to other content, such as fundraising pages or Youtube videos.



Leadership In Grassroots Advocacy



Once you identify an issue or program that needs to change, develop a plan of action to motivate others to join in the effort. This is the first step in the advocacy process – but not a final stage. Educating yourself and other advocates on how to garner support of others will play a crucial part in your ultimate success. Your leadership can make all the difference.

This guide will help you do the following:

- 1. Develop collaborations with patient advocacy organizations and teams**
- 2. Engage your advocates throughout the year**
- 3. Remember to celebrate your successes**



The Importance of Getting Others Involved

Patient advocacy groups are considered key stakeholders in healthcare policies and regulations, scientific research, guideline committees, and patient education. Now more than ever, patient advocacy organizations are being asked and encouraged to play an important role in the healthcare process.

Part of your advocacy plan should include a strategy for engaging a broad base of individuals or groups. To do this, conduct research to identify individuals and groups who may have aligned goals or interests and develop a plan for how to best engage each of them leveraging your existing relationships or network. Once your mission and advocacy plan are in place, begin your outreach to the key stakeholders you've identified to get them involved in spreading your message.

Identify a core group of advocates (your ambassadors) within your organization and task them with helping to organize and broaden your group. Train your advocates on ways to educate others about the work you are doing and keep those messages short, simple, and personal.

Identify advocates and learn from them by asking them these five questions:

- 1. Why do they want to engage (and make a difference for themselves and/or others)? Do they believe in your mission?**
- 2. What made them interested in your cause and/or organization?**
- 3. Do they have ideas for activities and strategies you could develop together?**
- 4. How much time do they have to devote to working on the issue?**
- 5. What do they think is the best way to both obtain and engage other advocates?**

Keep in mind that:

- Only a small number of those you encounter are likely to support you
- Only a small number of those who support you will get involved
- Only a small number of those who get involved will become advocates
- The process usually takes time – it could take 2-3 years before change happens

Remain engaged and optimistic! Even just one committed individual can make a difference!

For resources and support tools to help you with engaging new advocates, refer to the “How-To Guide on Developing Other Advocates” at the end of this chapter.

Staying Engaged Throughout the Year

Advocacy is not a one-day affair. It is important that your grassroots advocacy efforts happen all year long. Whether you have 10 or 10,000 advocates, keeping them focused and engaged is essential. Here are some examples of how you can keep advocates active and connected to one another.

Local Events

Develop a toolkit for advocates to use at any hometown event, such as a local fair or a community event. This toolkit can include items like a sign with your organization’s name on it, printed education materials about your organization, and other takeaways helping people know where to go to learn more.

Community Fundraising

Design a fundraising event your advocates can hold locally, such as a barbecue or an evening at a local pizzeria. Sell tickets and a certain amount of the proceeds can go to your organization. Encourage your advocates to share their ideas and suggestions with you. It is an opportunity to hear from them, as they know what would work best in their local communities.

Research Advocacy Program

The more knowledge you have, the more effective you will be. Develop a research advocacy training program where interested advocates can learn more about the science of their disease to better represent other patients. Guideline committees and regulatory government agencies are often looking for educated patient advocates to sit on panels and represent the patient voice. Participation on those committees or panels can be the first step in the process of having your voice heard among other organizations, scientists, healthcare professionals, and government agencies.

Congressional District Meetings

For members of Congress, August is the Congressional Recess. This is a great point in your journey to help your advocates schedule meetings with their members of Congress, and the good news is, they won’t have to go far. Local district meetings hosted by legislators are invaluable to your success in legislative advocacy. Advocates who have met with their legislative leaders at home will tell you it is a different dynamic than Washington, D.C. and a great place to deliver important messages.



Volunteering

Keep a running list of ways advocates can volunteer for your cause and/or organization. Consider using volunteers to manage administrative duties for your annual fundraising campaign, or have volunteers share educational literature at their local hospital with other patients. The voice of an advocate may also be needed either at a legislative briefing or a regulatory hearing. Collect the names of those advocates willing to volunteer within these settings, so when the time comes, you will know who to call.

Advocacy Day

Organizing an advocacy day is a great opportunity to focus attention on your issue. Choose a particular day or align with an existing national disease recognition day. Schedule meetings with elected officials and equip your advocates with the messages you need carried.

Webinar Series

Webinars are a terrific way to rally and communicate with other advocates about what is happening within your cause and/or organization, while also serving as a wonderful resource or outlet for patients and advocates to hear from relevant healthcare professionals about their disease. You can also archive these on a website or YouTube channel so others can view them later.

Webinar Tip: www.gotomeeting.com has an easy to use program to host your webinars.

Social Media

Provide your advocates with suggestions on the best ways to use social media. Encourage them to post pictures or video clips from events, meetings, and to share news stories. You can provide sample posts, such as a text or video link, encouraging them to take action. Consider developing a social media calendar with pre-determined content and posts to share daily or weekly.



Public Meetings

Encourage your advocates to attend local legislative and regulatory meetings in their hometowns that are open to the public, or virtual meetings online. They can visit government websites for their county or state to learn about upcoming public meetings. You can help them by working together on crafting the appropriate message for each type of meeting.

Advocacy Scholarships

Tell your advocates that patient advocacy scholarships may be available. Very often companies and organizations will provide financial help and scholarships for patient advocates to attend scientific meetings to learn more about their disease.

Examples of scholarship programs:

- www.healthline.com/health/diabetesmine/innovation/patient-voices-contest
- www.cancer.net/research-and-advocacy/patient-advocates/conquer-cancer-foundation-patient-advocate-scholarship-program
- www.patientadvocate.org/connect-with-services/apply-for-a-scholarship
- www.aakp.org/press-release/scholarships-available-kidney-patients-national-meeting

Online Calendar

Developing an online calendar of events that your advocates can view and contribute to is another great way to keep them up-to-date about your organization's activities.

The Importance of Celebrating Successes

Success in advocacy isn't about just getting a bill passed into law or ensuring that law is implemented as intended (that is most beneficial for patients). Celebrating your ongoing work, milestones, and successes throughout the entire process is important.

Organizing a team and developing personal stories and messages IS success. Very little happens quickly in the legislative and regulatory arenas, so enter the advocacy process with a "never give up" attitude. When you celebrate your successes, you remind your advocates to focus on the positive and successful work you are doing.

Dedicate some of your communications efforts or a section of your website for success stories and testimonials – a place where they can go to learn about what other advocates have been up to and share what they have been doing. Make it easy! Create a template where they can enter basic information and allow for an area to share their experience.

To learn more about creating an online story template, reference the “Advocate Template for Sharing Stories and Successes” resource and support tool at the end of this guide.

What Success Can Look Like

- Writing an advocacy plan
- Finding other advocates to work with you
- Scheduling a legislative meeting to address an issue
- Raising awareness about your issue

- Gaining support for a piece of legislation or regulatory rule
- Speaking out on behalf of patients who need a voice
- Developing positive relationships with state legislators and their staff; when you need something, they will be there to help
- Educating elected officials and regulatory agencies about the importance of an issue and its impact on patients
- Testifying before a committee
- Securing a vote in support of your position
- Receiving a response to a submitted letter, social post, or email

Sharing your successes will unite your advocates, inspire them and remind them that you are making progress and working together toward one common goal.



Examples of Successful Advocacy Efforts by Patient Organizations

Federal

Alzheimer's Association advocates were able to obtain a \$300 million increase for Alzheimer's and dementia funding at the National Institutes of Health (NIH), bringing the annual federal investment to \$3.1 billion. [alz.org](https://www.alz.org)

American Cancer Society Cancer Action Network (ACS CAN) is a nonprofit, nonpartisan advocacy affiliate of the American Cancer Society that focuses on aggressive grassroots efforts, lobbying and media campaigns, and educating the public and media to make cancer issues a national priority. Their efforts have secured more than \$2.4 billion in appropriations at the state and local level, as well as a \$2 billion increase in medical research funding for the National Institutes of Health, including \$475 million for the National Cancer Institute. [acscan.org](https://www.acscan.org)

American Diabetes Association advocates are active on the Hill, participating in hundreds of meetings, briefings, events, and other actions in support of their legislative and regulatory priorities. In 2019, they achieved a \$600 million reauthorization of the Special Diabetes Program, which supports critical research toward better treatments, a cure for type 1 diabetes, and essential prevention and management programs for American Indians. [diabetes.org](https://www.diabetes.org)

American Heart Association advocates were leaders in the fight to end surprise medical billing. Their hard work came into fruition with the No Surprises Act, which established robust federal protections against surprise medical bills. [heart.org](https://www.heart.org)

American Lung Association advocates succeeded in raising the national age for sale of tobacco products, including e-cigarettes, to 21 as of 2019. They had previously laid the groundwork for the historic law by helping pass Tobacco 21 laws in nineteen states and hundreds of communities. [lung.org](https://www.lung.org)

Association of Maternal & Child Health Programs has been an active voice in the halls of Congress, urging for the inclusion of provisions from the Black Maternal Health Momnibus Act of 2021 in the Build Back Better Act. The first Momnibus bill was passed into law in November 2021, Protecting Moms Who Served Act, which created a \$15 million program to support maternal care at the Department of Defense and study what maternal health issues veterans are facing. Currently, they are leading advocacy campaigns to fund the Title V Maternal and Child Health Services Block Grant, reduce maternal and infant mortality in low-income communities and communities of color, and reauthorize the MIECHV Program. [amchp.org](https://www.amchp.org)

Diverse Elders Coalition successfully advocated for the reauthorization of the Older Americans Act (OAA) in 2020. The OAA is an invaluable law that helps millions of elders each year by delivering necessary services and support to older people nationwide at low or no cost. [diverseelders.org](https://www.diverseelders.org)

Leukemia Lymphoma Society advocates advanced health equity by helping to implement the Clinical Treatment Act, requiring Medicaid to cover care received during a clinical trial, thereby increasing trial access for more than 41 million people, including members of historically underrepresented racial and ethnic groups. [lls.org](https://www.lls.org)

National Council on Aging advocates have been improving the lives of older adults since 1950 and were instrumental in the creation of Medicare, Medicaid, and the Older Americans Act. They are currently leading advocacy efforts to expand federal funding for community-based falls prevention programs and to reduce Medicare prescription drug costs. ncoa.org

National Indian Health Board members advise the U.S. Congress, IHS federal agencies, and private foundations on health care issues of American Indians and Alaska Natives. Recently, they published a 2021 Legislative and Policy Agenda for Indian Health and a roadmap for the Biden Administration on how to advance American Indian and Alaska Native health. nihb.org

National Minority AIDS Council advances their legislative priorities by strategizing and meeting with members of Congress, as well as other public policy organizations with similar goals. They have successfully advocated for increased federal funding for HIV/AIDS treatment and research for decades. nmac.org

Sickle Cell Disease Association of America achieved a victory for the sickle cell community by working alongside Congress to pass the Sickle Cell Treatment Act of 2018. The bill represents a commitment by the government to continue much-needed research geared towards increasing the understanding of prevalence, distribution, outcomes, and therapies associated with sickle cell disease. sicklecelldisease.org

State

American Cancer Society Cancer Action Network (ASC CAN) brought together state advocates in support of legislation that would ensure biomarker testing coverage by more insurance plans, including Medicaid, when there is a clinical need. For many targeted therapies, it is critical patients and their doctors have access to precision medicine. Innovative testing can help determine the most effective medical treatment for these patients. This legislation was signed into law May 2022. ascan.org

Arthritis Foundation advocates led an effort, made up of more than 70 organizations to pass step therapy legislation in California. This bill requires health insurance companies to expeditiously grant requests for step therapy exceptions by establishing a set of standard exceptions to the protocol. arthritis.org

Black Women's Health Imperative evaluates and develops national and state policies to hold elected officials accountable for addressing issues most critical to Black women's health. Their policy wins include a New York state regulation that mandated insurers to cover 3-D mammograms with no out-of-pocket costs. bwhi.org

Oklahoma for Patient Access Coalition includes patient advocacy groups from across the state who were all advocating for the passage of a landmark bill focused on addressing co-pay accumulators in Oklahoma. When insurance companies refuse to count co-pay assistance program payments toward patients' out-of-pocket maximum, also known as co-pay accumulator adjustments, there is additional cost to the patient, putting patients at risk of not being able to afford their medicines. The state advocacy done by the 14 patient groups in Oklahoma led to the passing of this law in April 2021.

Local

Arthritis Foundation hosts hundreds of local walks in communities across the country with a goal to cure America's #1 cause of disability. Each Walk to Cure Arthritis and Jingle Bell Run raises awareness and funds for the foundation which supports effort in medical advancement, breaking down barriers in healthcare, and connecting the community. arthritis.org

Leukemia & Lymphoma Society hosts over a hundred Light the Night Walks every year bringing local awareness, hope, and connection. The funds raised can support research grants to develop new understanding and life-saving treatments for patients, as well as support for patients and their families. lls.org

Conclusion

Advocacy takes time, energy and effort. The more individuals engaged in your effort, the more efficient and expansive your work becomes.

The Bottom Line

Believe in your mission, and engage others who believe in it, too. Together you can change the future and improve the lives of patients in your community or even the nation as a whole.



Key Information for Sharing Successes and Stories

Success stories can be shared via newsletters, blogs, website, or social media

- Date
- Name
- County & State
- What was your goal?
- Did you achieve that goal?
- What happened? Share your story
- Follow-up necessary from a staff member of the organization?
If so, provide the contact information
- Your contact information, so other advocates can reach out to you and learn more

Appendix: Example Advocacy Material

Press Release

For Immediate Release: (Date)

Contact: (Contact Information)

Survey Finds Health Insurer Step Therapy Protocols Harm Cancer Patient Care; Organizations Urge Lawmakers to Establish a Fair and Expedited Override Process

(City, State) – Today (Organization) announced the findings of recently conducted surveys on health insurer step therapy protocols for prescription medications. Responses were received from cancer patients, caregivers, and physicians. The surveys found that existing insurer step therapy protocols delay patient care, increase stress and frustration, contribute to worse outcomes, and cost more out of pocket. Doctors reported step therapy requirements make it harder to treat patients, delay treatment, and are time consuming.

Step therapy policies, also known as fail first policies, are a utilization management tool that health insurers commonly use to control spending on prescription drugs. These policies require that before the insurer will cover drugs prescribed by a physician, the patient must first try other (sometimes multiple), generally less expensive drugs to treat the patient’s condition to see if they will be effective. However, this process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations, which may ultimately lead to increased health care costs

“The survey findings are very disturbing. Patients are being forced to fail multiple times, sometimes for months at a time on ineffective medications before health insurers will cover the right medication to treat conditions,” stated (Organization, Title, Name). “Our members view it as central to our role to be advocates for our patients. Time is often of the essence for our patients with serious and debilitating illnesses. We need a clear, fair process that puts medical decision making back in the hands of physicians, so patients get the medications that most effectively address their needs.”

As supported by the (Organization) survey, step therapy restrictions are imposed by most health insurers and are applied to prescription drugs treating a wide range of diseases and conditions including autoimmune diseases, cancer, diabetes, HIV/AIDS, mental health, treatment of pain and many others. Patients need access to these medications without hurdles or delays. Legislation has been introduced in (State) to address this serious and widespread issue. The bill (name of bill) is sponsored by Senator (Name) and Assemblyman (Name) and would establish two simple patient protections:

- Ensure that step therapy protocols are based on widely accepted medical and clinical practice guidelines
- A clear and abbreviated process that prescribers may use to override a step therapy protocol in cases where evidence demonstrates that it is medically necessary
- A limit on the amount of time a patient can be required to try different medications

This legislation applies to commercial plans regulated by the State and is supported by (Organization) and a coalition of patient advocacy organizations, other health providers including (Organization) and others. It is currently under review in the Insurance Committee in each house.

Examples have been provided by advocacy and professional societies and have been de-identified. For illustrative purposes only.

Coalition Letter

(Date)

(Recipient Name & Address)

Dear (Name):

We represent an expansive and diverse group of patients and health care providers who share a common goal of improving the health of patients across the country. We are writing to express our support for federal step therapy reform legislation, which would ensure that patients with serious diseases, such as cancer, epilepsy, and diabetes, are able to access the medications they need without having to try another medicine and be forced to “fail first.”

This practice, commonly referred to as “fail first” or “step therapy,” is a utilization management tool that health insurers commonly use to control spending on prescription drugs. These policies require that before the insurer will cover drugs prescribed by a physician, the patient must first try other (sometimes multiple), generally less expensive drugs to treat the patient’s condition to see if they will be effective. However, this process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations, which may ultimately lead to increased health care costs.

Many states are taking steps to limit “fail first” practices by health insurers through state-passed legislation to reform and limit these harmful policies thereby helping to get the right medicines to patients faster. These step therapy practices are not limited by the state – the fail first protocols cross state borders and directly impact patients all across our country. And while many states are making great progress in protecting patients with state-regulated plans, more needs to be done at the federal level to close the gap for those patients on federally-regulated plans.

This year, (bill number), the Safe Step Act, was introduced in the U.S. Senate by Senator (name) and in the U.S. House of Representatives by Congressman (name), who understand the positive impact (bill number) will have on improving the health and welfare of millions of patients across the country.

We ask for your support of federal step therapy reform legislation as the best way to put health care providers and patients back in charge of their health care. It is a common-sense solution that establishes reasonable reforms and limits on step therapy practices and ensures that a health care provider’s professional judgment and a thorough review of a patient’s history are part of a successful health care equation.

On behalf of our members, which include patients, physicians, and other health care providers, we thank you for your review and consideration of federal step therapy reform legislation and respectfully request your affirmative support.

(Name)

(Organization)

Examples have been provided by advocacy and professional societies and have been de-identified. For illustrative purposes only.

Letter to a P&T Committee

(Name)

(Address)

Dear (Name):

Collectively, we are writing in regard to the (State Committee)'s planned review of oral oncology medicines during its scheduled (Date), meeting in (Location). We appreciate the P&T Committee not reviewing oral oncology drugs last year. As (Title) of (Organization), an organization representing physicians, nurses, and professionals all dedicated to the treatment of cancer, we are taking this opportunity to express our concern and the concerns of multiple statewide provider, patient and advocacy groups on the proposed review of oral oncology medications this year. (Organization) and the above-listed organizations are frequently called upon to comment on state-based policy and legislation.

Two years ago, the Committee recommended that all oral oncology drugs be designated as preferred on the Preferred Drug List (PDL) and that all would require prior authorization. We believe this is a reasonable policy to allow patients to have access to the best drugs available while ensuring effective utilization oversight.

Cancer therapies are not interchangeable. They often have different indications, different mechanisms of action and different side effect profiles. The physician takes several factors related to both the medicine and the patient into account when considering treatment options: evidence of the drug's efficacy and safety from the drug label and other published studies; patient tumor type, state of disease, biomarker status if applicable, and health status. Adding formulary status to the decision making process introduces non-clinical factors that may compromise quality patient care.

The federal government has explicitly endorsed oral cancer drugs as one of only six "protected classes" in the Medicare program. Federal law requires health plans to cover "all or substantially all" oral oncology medicines. The federal government has found that this class requires special protections given the life-threatening nature of cancer, and the lack of interchangeability among treatment options.

Cancer patients on Medicaid already have poorer outcomes compared to both commercially insured and the uninsured. Restricting access to necessary medication might only exacerbate these disparities.

Collectively, we urge the (Committee) to not restrict access to these life-saving drugs beyond what was determined in the last review. Respectfully submitted by the following patient and provider advocate organizations on behalf of their (State) chapters and/or constituents.

(Name)

(Title/Organization)

Examples have been provided by advocacy and professional societies and have been de-identified. For illustrative purposes only.

Written Comments to CMS

(Date)
(Name)
(Address)

Dear (Name):

We, the undersigned, write to express our concern that the recent proposed National Coverage Determination (NCD) on anti-amyloid monoclonal antibodies (mAbs) sets a precedent that could have far-ranging and damaging impacts on approval and access to new therapeutics across all disease areas. The draft NCD creates the potential for a new paradigm in which U.S. Food and Drug Administration (FDA) approval is not sufficient for access. It suggests that drug approvals, whether based on Accelerated Approval or on traditional approval to market, will be second-guessed by the Centers for Medicare and Medicaid Services (CMS) and made subject to a new set of requirements that may preclude patients from having access to an FDA-approved product for which they qualify.

The draft NCD sends a signal that the CMS can effectively set aside the FDA's approval of a new therapy and require a duplicative system for its own re-evaluation of the evidence upon which an approval is based. This proposed approach disregards the primacy of the FDA's jurisdiction as therapy regulator, its critical role in overseeing trial design (endpoint selection, methodology, target product profile, and biomarker selection, to name a few areas), and its benefit/risk determination based on significant scientific expertise in the relevant disease state. The unfortunate effect of the decision will be to prevent access for patients who meet the label criteria, especially those from racially, ethnically, or geographically diverse populations that have disproportionate challenges to accessing clinical trials. It creates a system that will thwart the very goal for diversity espoused by the agency.

We urge you to consider the implications of this draft decision. The NCD raises a number of questions that stand unanswered, including:

1. Does this determination create a paradigm where FDA approval is not sufficient for patient access?

While CMS states that, "Generally, an intervention is not reasonable and necessary if its risks outweigh its benefits," based on the proposed NCD, we are left unclear whether the converse remains the standard. Specifically, when the benefits outweigh the risks, as determined by the FDA, should this not be tantamount to a finding that the intervention is reasonable and necessary?

2. What is the role of Coverage with Evidence (CED) development? As stated by CMS, is it a tool that can be a bridge for patient access while additional evidence is generated?

Further CMS's own guidance provides, "CED will not duplicate or replace the FDA's authority in assuring the safety, efficacy, and security of drugs, biological products, and devices." How does this decision abide by and advance these principles for a CED?

The significant urgency, unmet need, and public health impact of our communities is matched by the potential for scientific discoveries that will transform health outcomes for millions of Americans. We must protect and preserve the processes enabling this progress, while also working towards collaborative solutions to address identified gaps in evidence. On behalf of millions of patients and caregivers living with different acute, chronic, common, and rare diseases, we ask you exercise the overarching jurisdictional authority inherent in your office as Secretary of Health and Human Services (HHS) to:

- Take steps to address the sweeping, negative impacts of this draft decision;
- Guide CMS and FDA to work in collaboration, not contradiction; and
- Direct CMS to issue a substantially revised NCD that:
 - Respects and relies upon FDA's review authorities; and
 - Assures coverage for beneficiaries who meet the FDA label requirements coupled with a robust post-market evidence generation strategy from various sources including the sponsors' post-market commitments that will deliver real-time, longitudinal data on the safety and efficacy profile across diverse populations for each drug in this class of disease-modifying therapeutics as these may come to market.

We are anxious to work with you toward these important and urgent goals.

Sincerely,
(Organizations)

Examples have been provided by advocacy and professional societies and have been de-identified. For illustrative purposes only.

Testimony to Congressional Committee

(Date)

Testimony of (Name)

(Title)

(Organization)

On House Bill (Number)

Thank you, Chairman (Name), Chairman (Name) and Members of the Committee on (Name) for the opportunity to testify this afternoon.

My name is (Name) and I am the (Title, Organization). (Organization) represents (number) members, comprised of cancer patients, caregivers, and physicians across the state. (Organization) is honored to testify today in (State) and represent our (number) members who are also constituents of the state.

I commend you for your consideration of House Bill (Number). In particular, I would like to applaud the work of Representative (Name) and you, Chairman (Name) for taking the time to learn about this complex issue, and leading this effort to provide the necessary pathway for patients to access biomarker testing which is an important step for accessing precision medicine, including targeted therapies that can lead to improved survivorship and better quality of life for patients.

As of 2018, over 50% of cancer clinical trials involved a biomarker and from 2015 to 2020, 60% of all FDA approved oncology medications required a biomarker test prior to use. However, in (state), not all communities can benefit from biomarker testing and precision medicine.

Insurance coverage for biomarker testing is failing to keep pace with innovation and advancement in treatment. In our state, (percentage) of commercial insurance plans are providing coverage that is more restrictive than the physician driven, National Comprehensive Cancer Network's treatment guidelines. Marginalized communities including communities of color and individuals with lower socioeconomic status are less likely to receive biomarker testing. Without action, this could increase existing disparities in cancer outcomes by race, ethnicity, income and geography.

We are extremely pleased to see House Bill (number) which improves access to biomarker testing. We are confident that we will pass groundbreaking legislation on which others states can model their initiatives.

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