

Arthritis Foundation Advocacy Toolkit



Arthritis
Foundation®

Welcome . . .

. . . to our Advocacy program!

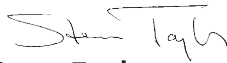
We are so thrilled and honored to have you participate in our advocacy program. -- There's a lot to do to make sure all people impacted with arthritis can achieve their Ideal Model of Care, so I hope you are ready! Our Advocates throughout the years have been pivotal in passing state and federal legislation to help all arthritis patients achieve better access to care.

Advocacy may seem intimidating, but it really is just telling your story! Your patient experience is valuable, meaningful, and impactful. You are the expert in your arthritis experience, and you should feel confident sharing how better health care policies will help your patient experience.

Now, you're not alone. Our national advocacy team, fellow veteran Advocates, and me, your President and CEO, are here to support you. We believe that by being on the journey together, we can accomplish great things!

Once again, welcome to our advocacy team. Your dedication to the mission is inspirational and we are so grateful to have you.

Let's advocate for arthritis!



Steve Taylor
Arthritis Foundation CEO

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Advocacy 101

What Is Advocacy?

Arthritis Foundation Advocates are a driving force in effecting positive changes for those living with arthritis. Advocacy is often seen as daunting and inaccessible, but it is much easier than you might imagine. At its core, advocacy boils down to something as straightforward as sharing your own story. It's your story that wields the power to make a lasting impact.

Whether you are attending the Advocacy Summit in Washington, DC, or engaging with your state representatives, your voice in the fight for arthritis-related matters across the nation is essential to making medications more affordable, funding new research and ultimately finding a cure.

The Arthritis Foundation is committed to turning these challenges and priorities into action through our state and federal advocacy programs.

Levels of Advocacy

There are many ways to get involved with Arthritis Foundation advocacy! We offer levels of advocacy that you can opt into.

Advocate: Advocates may utilize online platforms, emails, texts, social media and phone calls to advocate. They are also able to be active in local markets through advocacy. The time commitment is up to two hours per month.

Ambassador: Ambassadors are online, telecommunication and in-person advocates. Ambassadors may utilize online and telecommunication platforms as they engage directly and consistently with advocacy efforts. Ambassadors also may recruit Advocates in their state, be involved with their State Advocacy Committee, coordinate in-person meetings with legislators and attend State Lobby Days. Veteran Ambassadors are mentors to newer Ambassadors and help guide them through the process of sharing their story and feeling confident doing so. The time commitment is up to three hours per month.

Platinum Ambassador: Platinum Ambassadors are our highest-level Advocates. Platinum Ambassador is an earned title as a leader in our advocate community — they volunteer to lead advocacy committees, serve to help guide national advocacy projects, coordinate state lobby days, write testimony and participate in op-eds. The time commitment is up to four hours per month.

Junior Ambassador: Junior Ambassadors are 13- to 17-years-old and share their personal arthritis story at Arthritis Foundation programs and events, meetings with elected officials and other events. Junior Ambassadors are able to meet their peers virtually and train with Arthritis Foundation staff and volunteers. The time commitment is up to one hour per month.



Ways to Get Involved

There are many ways to get involved with advocacy both in person and online. Advocacy looks different for everyone, but we encourage you to explore areas you are interested in.

Ways to get involved may include:

- Taking action through the Action Center
- Responding to an Action Alert
- Attending State Lobby Days
- Attending a Town Hall with a state or federally-elected official
- Attending the Advocacy Summit
- Attending and fundraising for local market events, such as creating a Jingle Bell Run or Walk to Cure Arthritis team
- Joining a State Advocacy Committee
- Creating a Twitter profile to connect with state and federal officials



Media Advocacy

Letter to the Editor

Letters to the editor are published on the editorial page of a newspaper or other printed or digital communications vehicle.

Writing a letter to the editor is an effective way to briefly respond to an article or editorial that was previously published or to provide your opinion on current events, such as new legislation or the actions of your elected officials. When you communicate your opinion in a well-written piece, you can help inform, and even influence, the public regarding issues that are important to you.



Writing Tips

DO YOUR HOMEWORK. Check the publication's website for guidelines on letters to the editor so you can make sure your letter meets any outlined requirements. Each media outlet will have its own word/character count requirement and submission procedures.

KEEP IT CONCISE. Focus on just one major concept or idea and limit your letter to between 200 and 250 words.

OPEN WITH TITLE REFERENCE. Note the title of the article or editorial you are responding to and when that piece was published. You can express your opinion, contribute to the discussion by offering more information or point out inaccuracies in an article.

AVOID MAKING PERSONAL ATTACKS. Instead of emphasizing that a reporter, editor, expert or other individual was wrong, use your letter as an opportunity to educate the community on the facts that support your position.

KEEP IT SIMPLE. Remember, not everyone will have read the piece you are responding to or be familiar with your topic. Keep your writing simple and avoid acronyms and complicated language.

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July 19, 2023

To Whom It May Concern,

I am the father of a 13-year-old child with juvenile idiopathic arthritis and we live in Atoka, Tennessee. Alison was diagnosed with juvenile arthritis in every joint in her body at the age of 5. For all people with arthritis, and in particular my child who has JA, access to innovative medications, such as biologics, can be the difference between her being in a wheelchair or walking to school. I am asking you to pledge your support for people with arthritis by committing to support legislation that will limit out-of-pocket costs for medications.

Arthritis impacts hundreds of thousands of children nationwide. Alison's life changed when she was able to get excellent medical care and medication that helps her lead a normal life. Without her medication, she needed help dressing herself, tying her shoes, brushing her teeth and fastening her seatbelt. She did not play outside with her sisters because her joints hurt. She cried and complained of pain every day. Because of her medications and excellent medical care, Alison now leads a normal life. She attends Brighton Middle School, rides her horse on the drill team at Old West Special Trails, volunteers with Trailblazers to help those with special needs experience equine therapy, and loves to play outside with her sisters and her dog. Biologics, although very expensive, changed her life. Please support legislation that will limit out-of-pocket costs for these important life-changing medications.

Sincerely,

K Moschitta

K Moschitta

Keith Moschitta Atoka, Tennessee

Op-Ed

An op-ed is published opposite the editorial page and is a way for you to provide your opinion on current events in greater detail. Anyone can submit an op-ed, and doing so allows you to teach your community about issues that are important to you and shape public opinion. This document provides a list of suggestions to keep in mind as you write your op-ed.



Writing Tips

KEEP IT RELEVANT. Write and submit your letter as quickly as possible so that it's still newsworthy. If it has been more than a week since the original article or column appeared, it is too late to submit your letter.

MAKE IT RELATABLE. Explain how your topic impacts your community and, if possible, include an example from your personal experience. Use your letter to tell your personal story and engage your audience.

CLOSE WITH KEY TAKEAWAYS. Make sure to close your letter by restating your position and making your argument clear. Include your name, address and phone number, as well as any relevant academic degrees to demonstrate your qualifications to the media outlet. If you are writing on behalf of an organization, be sure to include the name of that organization in your letter.

HAVE SOMEONE REVIEW YOUR WRITING. Make sure your writing is clear and effective. If your letter to the editor is published, send a copy to your elected official's office.

“Be logical with biologics”

By Nikki Domers

Four years ago, my whole world changed when my daughter, Peyton, was diagnosed with juvenile rheumatoid arthritis (JRA). As a parent, you never want to see your child in pain. Seeing Peyton struggle with arthritis — with no way to relieve it — is one of the worst feelings that I have ever experienced.

We are fortunate that we could surround Peyton with the best health care team we could find. Through their coordinated efforts, we came across a biologic medication that effectively alleviated her symptoms.

While biologic medications are complicated and often injected or infused at hospitals, they also can be very effective in providing relief. As the science and our understanding of these medications continue to improve, new biologics and highly similar biosimilar medications are starting to provide new and additional treatment options.

As the name suggests, biosimilars work in similar ways to a biologic medication but, because of the unique nature of this class of medication, cannot be considered identical or a generic version of biologics.

As the Ohio legislature considers House Bill 505, which will facilitate the distribution of biosimilar medications and establish protocols for when substitutions for biologics are made, this distinction becomes crucial for patients like Peyton.

For example, a biosimilar may have been tested for one or two disorders, but not specifically with juvenile arthritis in mind. Therefore, if a pharmacist substitutes a biosimilar medication for a prescribed biologic, it could have adverse side effects for Peyton or not work at all, putting her joints and eyes at risk for further damage. It is essential that her health care team is aware so that they have a complete picture and accurate record of her treatment.

Don't get me wrong, the development of biosimilars is a hugely important milestone for those suffering from chronic and debilitating diseases. Having more options for treatment can mean the difference between pain and relief.

Due to the nature of biologics, patients sometimes have to be switched to other treatments to ensure efficacy and minimize potential negative side effects. For example, after years of success with the first biologic that Peyton was prescribed, she needed to be switched to another one because, like other patients, Peyton has developed antibodies to the first biologic, making it ineffective for her.

Having biosimilar medicines will provide additional options for patients to consider, but how these new biosimilar medications are dispensed and recorded will play an important role in achieving best possible treatment outcomes.

Because of the complex nature of the diseases being treated by biologics, it is crucial that the medical team is aware of any substitutions. Even small changes can affect treatment. Prescriber communication allows for the patient and doctors to proactively monitor for any potential adverse events and ensure that the new drug is working with the same efficiency without causing undue harm to the patient.

I am completely in support of biosimilars. I want to ensure that Peyton and other patients relying on these medications are set up for success so that they have the chance to gain some relief.

Domers lives in Barberton. She is an Arthritis Foundation Ambassador for Ohio

Social Media

Social media is the creation and exchange of ideas on a website or application (app). It ranges from putting a photo on Instagram to tweeting your ideas or messages to your elected official.

Why Do We Use Social Media?

Social media is instantaneous. There is no faster way to reach millions of people with your message. Social media also levels the playing field. Anyone can connect with politicians, celebrities and other important figures through social media.

What Does Advocacy Have to Do With Social Media?

One of the best ways to spread your message and reach prominent figures is through social media. The Arthritis Foundation supports using social media in advocacy efforts. Do you tweet healthy recipes and exercise tips? Do you share articles about arthritis on Facebook? If so, you're an Advocate.

Facebook

facebook.com/arthritis.org

Users create personal profiles, add friends, exchange messages and post photos, videos and updates. Professional figures or organizations have special profiles called pages, which users can "like." When users like a page or add a friend, their updates will appear on the newsfeed.

What You Can Do:

- "Like" the Arthritis Foundation and other health and wellness organizations on Facebook. You'll get frequent health and wellness updates on your newsfeed.
- Share relevant posts on your wall for your friends to see and learn from.
- Post about a topic you care about on your own page, or your elected official's Facebook wall.
- Ask your elected officials to "friend" you on Facebook.

Best Practices:

- Don't just post. Comment and share posts from other individuals or organizations you find interesting.
- Be sure to "tag" relevant individuals (like the Arthritis Foundation and your elected officials) in your posts.
- Use "hashtags" so more people can find your posts. Example: #Arthritis #AdvocateForArthritis

Possible Positive Outcome: The Articles And Advocacy Information You Share May Encourage Others To Become An Advocate.

X (Formerly TWITTER)

@ArthritisFdn

Users send out short (280 characters or fewer) posts. Posts can be published on the feed for followers to see, or posted directly at individuals, for only them to see.

What You Can Do:

- Follow @AFAAdvocacy, the @ArthritisFdn and other health and wellness organizations on X.
- Reshare posts you like about arthritis and management techniques.
- Tag your elected official an advocacy issues you care about.

Best Practices:

- If your posts begin with a X handle, use a period before the handle if you want all of your followers to see it. Without the period, it will only be sent to your elected official. Example: .@congressmember please vote for a bill that caps copays and makes medications more affordable! #advocateforarthritis
- Less is more. Posts that don't use all 280 characters get more traction.
- Make it a conversation. Don't just post to post. Favorite and reply to posts you find relevant and interesting.
- If you want to add a thought when resharing, click "Repost" then "Quote"
- Use hashtags so more people can find your posts. Example: #Arthritis #AdvocateForArthritis
- Use a link shortener like .bitly to save characters.

Possible positive outcome: enough posts could educate your elected official about what matters to his/her constituents.

Youtube

[YouTube.com/ArthritisFDN](https://www.youtube.com/ArthritisFDN)

Users upload, view and share videos.

What You Can Do:

- Subscribe to the Arthritis Foundation to watch the latest recordings of our advocacy webinars like Ambassador Briefings or the Advocate Webinar Series.
- Create videos that allow you to share your personal arthritis story in support of a particular bill.
- Ask your elected officials to support arthritis-related legislation in your area.
- Comment on videos you like.

Best Practices:

- When uploading videos, use lots of relevant tags so people can find them. 0 Tag the elected officials you want to target – most have YouTube accounts. 0 Share your playlists on other social networks like Facebook and X.

Possible positive outcome: a state legislator supports legislation in your state based on your appeal.

Instagram

@arthritisfoundation

Users take photos, apply filters and often share them on other social networks like Facebook and X.

What You Can Do:

- Follow @arthritisfoundation on Instagram, your elected officials and other arthritis advocates
- Post photos of yourself with your elected official.
- Take photos of your arthritis management methods, like cooking a healthy meal or exercising.
- Favorite and comment on photos you like.
- Post photos and videos in your Instagram Story.

Best Practices:

- Use a variety of filters to catch eyes.
- Tag relevant individuals or organizations in your posts and Stories.
- Share your photos on Facebook and X for maximum effect.
- Use hashtags so more people can find your posts. Example: #Arthritis #AdvocateForArthritis

Possible positive outcome: the photo from your last meeting with a legislator may inspire someone to #advocateforarthritis!



Engaging With Elected Officials

Calling Elected Officials

It's often appropriate and important for constituents to contact their elected officials in support of or in opposition to an issue or piece of legislation. Calling your member of Congress or state legislator is an effective way to advocate, especially when they are making a policy decision, an important vote is coming up or you'd like to see action on a piece of legislation.

The arthritis foundation can put you in touch with the specific staff member you need to speak with about an issue. Contact advocacy@arthritis.org for more information.

Before The Call

It is essential to be prepared when you call your elected official's office. This draft call script will help you frame your remarks. It's equally important to do some research before contacting your elected official's office. Try to find out their position on the issue so you can either thank them for their support, encourage them to change their position or provide further information. Be sure to have resources in front of you (such as a fact sheet and a copy of the legislation) so you can answer questions if necessary. Tailor this script to your specific advocacy needs.

Follow-Up

You should always send a follow-up thank-you note or email, regardless of what was discussed in your phone call. If you offered to send your elected official's staff member additional information about your issue, you should include:

- Your contact information, including full name, address, email and phone number
- The issue or bill (including name and number) you would like to address
- Your position on the issue or bill
- Supporting facts
- Personal story (if applicable)
- The action you would like your elected official to take on the measure (like co-sponsoring a bill, voting in favor of or in opposition to a bill, moving a bill out of committee or taking a particular position on an issue)
- A sincere thank you and an offer to serve as a resource



Remember: the arthritis foundation advocacy & access team is always available to support you! Send your questions to advocacy@arthritis.org and we will connect you with the right resources to make the greatest impact possible.

Draft Call Script

Introduction

When you call your elected official's office, a receptionist will answer the phone. Ask the receptionist to connect you with the legislative aide who handles health issues, using this script:

Hello my name is name

And I am a constituent of Senator/Representative

May I please speak with the legislative aid who handles issues related to healthcare/arthritis

NOTE: If the legislative aide is not available, ask for their email address so you can follow up on your inquiry. You may also be asked if you'd like to leave a voicemail. Legislative staff differ

in their preferred ways to receive communications. You should accommodate their preference.

PAUSE FOR FEEDBACK

Hello my name is name

And I am a constituent of Senator/Representative

I am calling today about bill name/bill number/issue

Which I am an advocate for/against

Do you know if Senator/Representative is in favor of or in opposition to this issue?

NOTE: The legislative aide may tell you immediately whether your elected official supports or opposes the measure. If they are in agreement with you, thank them for their work on the issue and offer to serve as a resource. If they are in opposition to your position, tell them you would still like the senator/representative to consider your position.

IN FAVOR of your position

Thank you for that information. I'm pleased to hear that Senator/Representative is supportive of this position. May I give you my contact information so I can serve as a resource on this issue?

PAUSE FOR FEEDBACK

Thank you for your time and work on this issue.

NOT IN FAVOR of your position

Thank you for that information. May I ask why the Senator/Representative takes that position?

PAUSE FOR FEEDBACK

Thank you for elaborating. I'd like to encourage Senator/Representative to support/oppose this issue because [Insert a brief summary of the issue/legislation and why you support/oppose it. Focus on how it affects your community. Use specific data points as well as a personal story if appropriate.]

PAUSE FOR FEEDBACK

I appreciate your time today and would like to follow up with additional information in writing. May I please have your email address?

Thank you for your time.

More Tips

Contacting your elected official's office for the first time can be a little intimidating. Follow these tips to settle your nerves and be the most effective Advocate you can be!

SHOW RESPECT. Treat staff with respect on the phone and in all written correspondence. Make sure you pronounce and spell the staff person's name correctly.

KEEP IT BRIEF. Staff members are very busy and will appreciate you getting your point across clearly and quickly during your call.

BE CONFIDENT. Legislative staffers want to hear from you so they can help the elected official make informed policy decisions. Tell a brief personal story about why you hold your position and why the elected official should consider the position you hold.

BE POLITE. Do not be defensive and do not attack the elected official or staff member.

DO YOUR HOMEWORK. Have supporting documents and data in front of you when you make your call. This can help with any questions they have.

BE HONEST. If you receive a question and don't know the answer, don't make one up. Tell the staffer you are happy to find the answer and will get back to them. If you don't understand something, ask for clarification.

MAKE YOUR ASK. Ask for a specific action from your elected official. Be clear about your request. Never leave a meeting without making a specific ask.

DON'T GIVE UP. If you don't get in touch with a staffer right away, keep trying.



Writing Elected Officials

Emails to your elected officials and their staff are important. Whether you have recently met with them or you are writing about an issue, email is the most efficient way to communicate your message. You can send a letter to your elected officials directly through our website in our Action Center.

It may take several weeks for the elected official to receive your letter due to security protocol. Call your elected official's office after a few weeks have passed to make sure the aide who handles the issue received your letter.

If you do not know the aide responsible for this issue, call the office and ask. Also find out about the elected official's position on the issue or how he/she will vote on the legislation or if they support or oppose the issue.



Writing Tips

ADDRESS YOUR OWN ELECTED OFFICIAL. Your elected official wants to hear from constituents about issues that matter and affect them. Only address someone who doesn't directly represent you if they are in a position of high leadership, such as the speaker of the House of Representatives, majority leader or committee chair.

KEEP IT BRIEF. Limit the length of your letter to one page and only focus on one issue or piece of legislation.

BE RESPECTFUL. Do not use harsh or aggressive language or make personal attacks.

OPEN WITH AN INTRODUCTION. Start your letter with a short personal introduction. Make sure to include whether you are writing as a constituent or on behalf of an organization (or both).

STATE YOUR PURPOSE. Be clear about your reason for writing. If you are discussing a bill, be sure to include the bill's name and number.

SHARE YOUR PERSONAL STORY. Your letter should include your personal story, specific examples and key points that demonstrate the importance of your issue and help your elected official understand why this issue matters and affects his/her constituents.

MAKE A SPECIFIC CALL TO ACTION. For example, "I ask that you vote for H.R. XXXX" – or "I urge you to support health care reform that includes greater access to affordable medication."

SAY THANK YOU. Close your letter by thanking your elected official for their time and offering to answer any additional questions or providing further information. Include your contact information and sign the letter.

[Date]

The Honorable [Name]

United States Senate

[Building and Office Number]

Washington, DC 20510

Dear Senator [name],

As an Advocate for the Arthritis Foundation, I want to thank you for being a champion for patient-centered step therapy reforms in Indiana. Step therapy, or “fail first,” is when insurers require patients to prove another medication is not effective before covering what a health care provider originally prescribed. It happens to thousands of patients across the country every day, but when it happens to your own daughter, you feel compelled to act.

At the age of 5, my daughter Amelia did as many other kids her age do – she jumped off a swing at a playground.

Following that jump, her knees swelled to the point where she could barely walk. Right then, we knew we were dealing with something much more than a swollen joint. Shortly thereafter, Amelia was diagnosed with juvenile arthritis. Now 8 years old, she is one of more than 6,000 children in Indiana living with and managing the disease. She’s an amazing little girl and does not let her condition stop her from doing what she sets her mind to. It’s been a battle from the start, with Amelia being put through step therapy by our insurance company.

Early in her treatment, Amelia had serious complications from her medication, and instead of agreeing to cover the medication her physician had originally prescribed, our insurance company forced her through painful testing to prove she was having nerve issues from the medication. That complication delayed her treatment by several months and forced her through painful procedures and side effects, at the tender age of 5. No child should have to go through that.

Thank you for your work on Senate Bill 41, recently signed into law by the governor, which established safeguards from the harmful impacts of step therapy for patients across Indiana just like Amelia. Because of you, she and thousands of others like her will have an easier path to the right treatment. Our hope is that other states follow Indiana’s lead and pass similar legislation to help protect patients from being put through unnecessary pain and suffering that can be avoided in the first place.

Sincerely,

J Jones

John Jones

[Mailing Address City, State, ZIP]

NOTE: Don’t forget to include your mailing address. It’s important for your elected official to know where you live.

U.S. Senators:

The Honorable [name]

United States Senate

[Building and Office
Number]

Washington, DC 20510

U.S. Representatives:

The Honorable [name]

United States House
of Representatives

[Building and Office
Number]

Washington, DC 20515

State Senators:

The Honorable [name]

[State] Senate

[Building and Office
Number]

[City, State, ZIP]

State Representatives:

The Honorable [name]

[State] House of
Representatives

[Building and Office
Number]

[City, State, ZIP]

Visiting Elected Officials

As a member of the Arthritis Foundation's army of Advocates, it is important to establish a relationship with your elected officials and their staff. A great way to do this is setting up a face-to-face meeting to discuss issues relevant to arthritis and share your personal story. While you can discuss specific legislation with your elected official, you don't have to start there. You can simply start a conversation based on an issue or concern you have. Use this guide when reaching out to your elected official's office to set up your meeting.

Requesting a visit is easy!

Each office has a preferred method of communication. Call the office of your elected official first and ask to speak with the scheduler. They may ask you to fax your request or send an email.

If you are scheduled to meet with a legislative aide, don't be offended. They are the issue expert and have great influence with the elected official. Though you may have scheduled your meeting with the elected official, he or she It's often easier to meet with the elected official in their district office. If you are scheduling a meeting with a member of Congress, try to meet when they are home (in-district), as their schedules are often more flexible then. U.S. senators typically have more than one office in their home state.

If someone will be joining you in your meeting, be sure you give the full names of all participants to the scheduler. Be clear about what you intend to discuss. Don't show up with surprise topics.

Phone Call Tips

- Keep it short and sweet (under five minutes).
- State your name and where you live.
- State the purpose of your call: scheduling a meeting with the elected official and/or relevant staff.
- Identify the issue.
- Briefly share why you care about the issue, including some background and supporting information.
- Tell them who will attend the meeting.
- Tell the scheduler how you can be reached (via email and/or phone).

Email Tips

- Keep it short and sweet (under four paragraphs).
- State your name and where you live.
- State the purpose of your letter: scheduling a meeting with the elected official and/or relevant staff.
- Tell them who will attend the meeting.
- Close with how you can be reached (via email and/or phone).

Elected Official Visit Tips

Use this list of tips to prepare for your meeting, which will help ensure you are ready to deliver a compelling message and make a positive impact.

Before The Meeting

CONTACT THE SCHEDULER. Reach out to your elected official's office to set up an appointment for a meeting. State the topic you wish to discuss at the meeting and who will be in attendance.

PRACTICE. Spend some time practicing what you will discuss with your elected official.

TALKING POINTS. Create clear, easy-to-understand talking points for yourself.

KEEP IT BRIEF. Don't overload the elected official or staffer with numerous concerns. Limit yourself to two main issues per meeting.

MAKE A LEAVE-BEHIND PACKET. Put together a packet of "leave-behind" information for your elected official and staff. Remember to bring extra copies of these materials for every staff person who attends the meeting. This packet should include relevant documents, such as:

- A fact sheet about your issue
- A copy of the legislation you are supporting/opposing
- Press releases, news stories or blogs about the issue
- Your business card or contact information

DO YOUR HOMEWORK. Before you go to your meeting, research your elected official to learn about their legislative background, including his or her committee assignments and voting record.

During The Meeting

BE ON TIME. Plan your visit ahead of time and know exactly where you are going.

DRESS FOR SUCCESS. Meetings with elected officials and their staff are typically formal and you should dress professionally.

BE CONFIDENT. You have a lot to offer, whether it's a personal story or just information on an issue. Elected officials and their staff members appreciate information from constituents.

KEEP IT BRIEF. Meetings with elected officials and their staff typically last between 15 and 20 minutes. You may also be asked to meet in an unusual place like a hallway or in cramped quarters. Try to not get distracted.

BE SPECIFIC. Request your elected official to take a specific action. For example, "I ask that you vote for H.R. XXXX."

DRIVE THE FOCUS OF THE MEETING. During your conversation, if the legislator or staff member goes off-topic, bring the discussion back to your issue.

- Quickly introduce the people at your meeting. Mention where they live and why they are attending.

"Before each meeting I am nervous and excited, but as soon as we say hello, it is as though they are your friend. and it is great to be able to share our arthritis journey with them and let them know how they can help us."

**– Staci Penner
Platinum Ambassador
Kansas**

- Explain your issue and highlight the top three points you'd like to get across.
- Share your personal story, along with specific examples and data to emphasize the importance of the issue or legislation you are discussing. Show your elected official why it's relevant to his or her constituency.

BE HONEST AND OPEN-MINDED. Be clear about your position on an issue, even if it differs from your elected official's view. Politely ask about your legislator's position on the issue you are discussing and why he or she holds that view. Your elected official might have a different position than yours, but by meeting with them, it's possible to soften or even change their views. Be open-minded and polite when responding to counter arguments. Your credibility is the most important asset you have – always tell the truth. If you are asked a question and don't have the answer, don't make one up. Tell the person who asks the question that you will find the answer and get back to him or her.

SHOW RESPECT. Use friendly language that makes everyone feel at ease. Remember, your elected official or his or her team may not be an expert on your topic. This is your opportunity to educate your representative on why your issue matters and how they can help.

BE SURE TO DELIVER ANYTHING YOU'VE PROMISED. If you've offered to send more information or materials to an elected official and their staff, do so promptly.

STAY ENGAGED. Take notes during your meeting so you can follow up, ask for clarity and provide more details about a particular talking point.

SNAP PICTURES. Take photos with the elected official and their staff. Photos are great for social media and outreach after the meeting.

SAY THANK YOU. Be sure to thank your elected official for meeting with you and for their attention to the issue.

DO NOT BE DISCOURAGED OR OFFENDED. It's OK if you meet with staff instead of the elected official, or if the meeting is postponed. Legislative schedules are incredibly busy, and sometimes it's more productive to meet with a staff member who is an expert on your area of focus.

After the Meeting

FOLLOW UP. Reach out to your elected official after the meeting by sending a thank-you email immediately and then a thank-you letter in the mail. If you promised to send additional information in your meeting, do so.

STAY INVOLVED. Showing your continued involvement after your meeting helps build a relationship with your elected official and his or her staff. Don't contact your elected official or their staff only when you are upset about an issue or need to request something. Thank them when they've done something you support.



How Congress and State Legislatures Work

How A Bill Becomes A Law

This is the federal process; however, the same general steps also apply to state government.



THE BILL IS DRAFTED

A senator or representative drafts a bill or a joint resolution with the goal of passing it into law.



THE BILL IS INTRODUCED

The bill is introduced in the U.S. Senate or in the U.S. House (or both) and receives a number.



THE BILL IS REPORTED

The committee must approve the bill and send it to the House or Senate floor for debate.



THE BILL IS DEBATED

Members of Congress discuss why they support or oppose the bill.



THE BILL IS REFERRED TO COMMITTEE(S)

The committee members analyze and mark up the bill before it can be sent to the House or Senate floor.



THE BILL IS VOTED ON

In the U.S. House, the bill passes with a simple majority (218 of 435), as well as in the U.S. Senate (51 of 100).



THE BILL GOES TO CONFERENCE

If the House and Senate versions of the bill differ, a conference committee must work out those differences and draft a final bill for a vote.



THE BILL GOES TO THE PRESIDENT

The president must sign the bill into law.

Leadership of the Senate and the House

We work with the key committees and leadership in Congress to help build support for initiatives and pass legislation important to people with arthritis. If your members of Congress are represented in congressional leadership or on any of the committees, it's even more important to share your story! Learn more about key senators and

representatives in Congress below. For more detailed information about the functions of the key committees, visit the Glossary.

U.S. Senate

Majority Leadership

- Sen. Charles Schumer (D-NY), Majority Leader | @SenSchumer
- Sen. Richard Durbin (D-IL), Majority Whip | @SenatorDurbin
- Sen. Charles Schumer (D-NY), Democrat Conference Chair | @SenSchumer

Minority Leadership

- Sen. Mitch McConnell (R-KY), Minority Leader | @McConnellPress
- Sen. John Thune (R-SD), Minority Whip | @SenJohnThune
- Sen. John Barrasso (R-WY), Republican Conference Chair | @SenJohnBarrasso

U.S. House of Representatives

Majority Leadership

- Rep. Steve Scalise (R-LA), Majority Leader | @SteveScalise
- Rep. Tom Emmer (R-IL), Majority Whip | @GOPMajorityWhip
- Rep. Elise Stefanik (R-NY), Republican Conference Chair | @RepStefanik

Minority Leadership

- Rep. Hakeem Jeffries (D-NY), Minority Leader | @RepJeffries
- Rep. Katherine Clark (D-MA), Minority Whip | @WhipKClark
- Rep. Pete Aguilar (D-CA), Democratic Caucus Chair | @RepPeteAguilar

Key Committees and Their Role

Committees play a crucial role in making legislative bodies work well. When lawmakers join Committees, it helps them become experts in the areas they're responsible for. Committees keep an eye on the issues within their jurisdiction, identify and work through problems that should be addressed by the legislature, hold hearings to evaluate information, and importantly to mark-up and approve legislation to be voted on by the full chamber.

Below are brief descriptions of the major health-related Committees.

SENATE COMMITTEE ON APPROPRIATIONS: The U.S. Senate Committee on Appropriations is the largest Committee in the Senate and its role is defined by the U.S. Constitution, which requires "appropriations made by law" prior to the expenditure of any money from the federal Treasury. The Committee determines funding levels for government agencies on an annual basis. Appropriations are limited to the levels set by a budget resolution, drafted by the Senate Budget Committee. There are 12 subcommittees tasked with drafting legislation to allocate funds to government agencies within their jurisdictions.

- **Subcommittee on Labor, Health, Human Services, Education And Related Agencies (Lhhs):** This subcommittee has jurisdiction over the Department of Education, Department of Health and Human Services, Department of Labor and related agencies, and determines funding for arthritis research and programs across agencies like the Centers for Disease Control and Prevention and the National Institutes of Health.
- **Subcommittee on Defense:** This subcommittee has jurisdiction over the Department of Defense, which includes research funding for health conditions like arthritis.

SENATE COMMITTEE ON FINANCE: The Finance Committee has jurisdiction over taxation and other revenue measures, including those related to health programs. These health programs include Medicare, Medicaid, the Children's Health Insurance Program (CHIP) and other Health and Human Services programs financed by a specific tax or trust fund.

SENATE COMMITTEE ON HEALTH, EDUCATION, LABOR AND PENSIONS (HELP): The Senate HELP Committee has broad jurisdiction over our country's health care, education, employment and retirement policies, including the majority of public health programs.

HOUSE COMMITTEE ON APPROPRIATIONS: The House Committee on Appropriations has a role that is defined by the U.S. Constitution, requiring "appropriations made by law" prior to the expenditure of any money from the federal Treasury. The committee writes legislation that allocates federal funds to numerous government agencies, departments and organizations on an annual basis. Appropriations are limited to the levels set by a budget resolution, drafted by the Senate Budget Committee. There are 12 subcommittees tasked with drafting legislation to allocate funds to government agencies within their jurisdictions.

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- **Subcommittee on Defense:** This subcommittee has jurisdiction over the Department of Defense, which includes research funding for health conditions like arthritis.

HOUSE COMMITTEE ON ENERGY AND COMMERCE: The House Committee on Energy and Commerce is vested with the broadest jurisdiction of the Congressional Committees with responsibility over a broad portfolio of topics like consumer protection, food and drug safety, public health research, environmental quality, and interstate and foreign commerce. It also oversees multiple cabinet-level departments and independent agencies, including the Department of Health and Human Services, and the Food and Drug Administration.

HOUSE COMMITTEE ON ED AND WORKFORCE: The House Committee on Education and Workforce oversees employer-sponsored insurance and has jurisdiction over the Safe Step Act.

HOUSE COMMITTEE ON WAYS AND MEANS: The House Committee on Ways and Means has jurisdiction over taxation and Medicare.

State Legislative Process

Every state has a state legislature. Meetings vary state by state, with some states having yearly sessions and other states meeting bi-annually. Just like the federal legislature, the state legislature also has two houses: the House/Assembly and the Senate. State senators and representatives are elected by district, you have one state Senator and one representative who represents the district where you live. The number of state senators and representatives varies from state to state. Legislation passed by the state legislature only impacts your state.

The process of a state bill becoming a law is very similar to the federal process, however, the bill goes to the governor's desk for signature. Most bills become law on January 1 of the following year.



Glossary

Glossary

Glossary | Policy & Advocacy

ACT: Legislation (a bill or joint resolution) that has passed both chambers of Congress (or a state legislature) in identical form, been signed into law by the president (or the governor) or pass over his/her veto, thus becoming law.

ADVOCACY: The act or process of advocating or supporting a cause or proposal.

AFFORDABLE CARE ACT (ACA): A bill that was signed into law in 2010 by President Obama and consists of the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act of 2010. It reformed the American health care system to expand insurance coverage, reduce the cost of care and increase the quality of care.

AMENDMENT: A proposed change to a pending legislative text (e.g., a bill, resolution or other amendment).

APPROPRIATION: The provision of funds, through an annual appropriations act or a permanent law, for federal agencies to make payments out of the Treasury for specified purposes.

AUTHORIZATION: A statutory provision that obligates funding for a program or agency. The formal federal spending process consists of two sequential steps: authorization and appropriation.

BICAMERAL: Literally, “two chambers” in a legislative body having two houses (as in the House of Representatives and the Senate comprising the U.S. Congress or a state legislature).

BILL: A draft of a proposed law presented to Congress for consideration. Bills introduced in the House of Representatives begin with H.R., bills introduced in the Senate begin with S., and they are numbered in the order they are filed. State bills may begin with H.B. or S.B., depending on the state. Typically, federal bills are given hearings in their committees of jurisdiction, then they are “marked up” by the committees of jurisdiction before being placed on the calendar for a floor vote. Amendments to bills can be

CLOTURE: The method by which a supermajority (typically, three-fifths) of the U.S. Senate may agree to limit further debate and consideration of a question (e.g., a bill, amendment or other matters).

COMMENT LETTER: A formal letter to a federal or state agency commenting on a proposed or final rule or regulation. It is our formal opportunity to publicly state our views on an agency rule.

COMMITTEE/SUBCOMMITTEE: A panel (or subpanel) with members from the House or Senate (or both) tasked with conducting hearings, examining and developing legislation, conducting oversight and/or helping manage chamber business and activities.

CONCURRENT RESOLUTION: A form of legislative measure used for the regulation of business within both chambers of Congress, not for proposing changes in law. Depending on the chamber of origin, they begin with a designation of either H.Con.Res. or S.Con.Res.

CONFERENCE COMMITTEE: Temporary joint committee created to resolve differences between House-passed and Senate-passed versions of a measure.

CONSTITUENT: A member of a community or organization who has the power to appoint or elect.

CO-SPONSOR: Representatives or senators who formally sign on to support a measure. Only the first-named member is the sponsor, all others are co-sponsors, even those whose names appear on the measure at the time it was submitted.

FILIBUSTER: In the Senate, the use of dilatory or obstructive tactics to delay or block passage of a measure by preventing it from coming to a vote.

HEARING: A formal meeting of a congressional or state legislative committee (or subcommittee) to gather information from witnesses for use in its activities (i.e., the development of legislation, oversight of executive agencies, investigations into matters of public policy or Senate consideration of presidential nominations).

HILL BRIEFING: Capitol Hill Briefings are designed to educate members of Congress and their staff about a particular issue. Briefings make it possible for policymakers to hear directly from patients, providers, caregivers and other experts in the field.

JOINT RESOLUTION: A form of legislative measure used to propose changes in law or to propose an amendment to the U.S. Constitution. Depending on the chamber of origin, they begin with a designation of either H.J. Res. or S.J. Res.

LEAVE-BEHIND: Materials prepared specifically for a meeting with an elected official, which can include one-pagers, infographics, petitions, comment letters and other publications.

MARKUP: Meeting by a committee or subcommittee during which committee members offer, debate and vote on amendments to a measure.

MEASURE: A legislative vehicle: a bill, joint resolution, concurrent resolution or simple resolution.

ONE-PAGER: A summary of an issue, usually in the context of legislation, that defines an issue, a problem and the solution in the form of legislation or other policy proposal.

POLICY: A system of laws, regulatory measures, courses of action and funding priorities concerning a given topic promulgated by a governmental entity or its representatives.

POSITION STATEMENT: Actionable items that support legislation an organization is trying to advance.

PUBLIC LAW: A public law or joint resolution that has passed both chambers and has been enacted into law. Public laws have general applicability nationwide.

QUORUM: Minimum number of members a chamber (or committee) requires for the transaction of certain types of business.

RANKING MEMBER: The most senior (though not necessarily the longest-serving) member of the minority party on a committee (or subcommittee).

RECESS: A temporary interruption of proceedings in the House or Senate.

REGULATION: A regulation is a general statement

issued by an agency, board or commission that has the force and effect of law. Congress often grants agencies the authority to issue regulations. Sometimes Congress requires agencies to issue a regulation; sometimes Congress grants agencies the discretion to do so. Many laws passed by Congress give federal agencies some flexibility in deciding how best to implement those laws. Federal regulations specify the details and requirements necessary to implement and enforce legislation enacted by Congress.

SIGN-ON LETTER: A joint letter with peer organizations to send to policymakers.

SPONSOR: A representative or senator who introduces or submits a bill or other measure.

STATUTE: The provisions in legislation once they become law, before they are implemented by the agencies and become regulations.

VALUE FRAMEWORK: Value models (also known as frameworks) have emerged as the latest tools to help health care stakeholders assess the value of new treatments. In 2015, four organizations – the American Society of Clinical Oncology (ASCO), the Institute for Clinical and Economic Review (ICER), the National Comprehensive Cancer Network (NCCN) and Memorial Sloan Kettering Cancer Center – released frameworks that developers have described as intended to support physicians and/or payers in assessing the value of treatments. While the subject of these initial models is drugs, models to evaluate other health care interventions are poised to proliferate given the heightened focus on value.

VETO: Presidential disapproval of a bill or joint resolution presented to him/her for enactment into law. If a president vetoes a bill, it can become law only if the House and Senate separately vote (by two-thirds) to override the veto. A similar process takes place in state legislatures with the governor having the power of veto.

WHITE PAPER: A government or other authoritative report giving information or proposals on an issue.

These definitions are drawn from the Library of Congress or U.S. Senate glossaries.

Glossary | Leadership Senate and House

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SUBCOMMITTEE ON LABOR, HEALTH, HUMAN SERVICES, EDUCATION AND RELATED AGENCIES (LHHS): This subcommittee has jurisdiction over the Department of Education, Department of Health and Human Services, Department of Labor and related agencies.

SUBCOMMITTEE ON DEFENSE: This subcommittee has jurisdiction over the Department of Defense, the Central Intelligence Agency and basic allowance for housing.

SENATE BUDGET COMMITTEE: The Senate Budget Committee determines fiscal priorities by creating the federal budget. Senate budget committees (including the House counterpart) are responsible for drafting Congress’ annual budget plan and monitoring action on the budget for the federal government. In addition, the budget committees have jurisdiction over the operation of the Congressional Budget Office (CBO).

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COMMERCE: The House Committee on Energy and Commerce is vested with the broadest jurisdiction of the Congressional committees with responsibility over a broad portfolio of topics like consumer protection, food and drug safety, and public health research, environmental quality and interstate and foreign commerce. It also oversees multiple cabinet-level departments and independent agencies, including the Department of Health and Human Services and the Food and Drug Administration.

SUBCOMMITTEE ON HEALTH: This subcommittee has jurisdiction over public health and quarantine; hospital construction; mental health; biomedical research and development; health information technology, privacy and cybersecurity; public health insurance (Medicare, Medicaid) and private insurance; medical malpractice and medical malpractice insurance; the regulation of foods, drugs and cosmetics; drug abuse; the Department of Health and Human Services; the National Institutes of Health; the Centers for Disease Control and Prevention; Indian Health Service; and all aspects of the above referenced jurisdiction related to the Department of Homeland Security.

HOUSE WAYS AND MEANS COMMITTEE: The House Ways and Means Committee is the chief tax-writing committee in the House of Representatives. The committee has jurisdiction over taxation, tariffs and other revenue-raising measures, as well as social security, unemployment benefits, Medicare, enforcement of child support laws, Temporary Assistance to Needy Families (TANF) and foster care and adoption programs.

SUBCOMMITTEE ON HEALTH: This subcommittee has jurisdiction over legislative programs providing payments for health care, health delivery systems or health research.

Glossary | Social Media

BITLY: Website that shortens and tracks click rates for URLs. (X/ (formerly Twitter)

BOARD: Where pins are placed. Boards have themes, like health and wellness, exercise clothes, workout tips, etc. (Pinterest)

COMMENT: A short remark posted to a social media post. Users comment positively on posts they like and offer constructive criticism on posts that fall short. (Facebook, Instagram, YouTube)

FAVORITE: To click the heart image under a photo or tweet. This means you like it. All favorite posts show up under the favorites section on your profile. (Instagram and X)

FILTER: An effect applied to a photo. (Instagram)

FOLLOW: When you follow someone, all of their posts will show up on your newsfeed. People who follow you are called followers. (Facebook, X, Instagram, Pinterest)

FRIEND: When you friend someone, all of their posts will show up on your newsfeed and vice versa. Depending on the individual, certain viewing privileges are granted to friends only. (Facebook)

HANDLE: A username. Example: @arthritisfdn (X)

HASHTAG: A type of tag used to find posts about a specific topic. Example: #arthritis#RA (Facebook, X, Instagram)

LIKE: To give something the thumbs up. On YouTube, you can also dislike. (Facebook, YouTube)

NEWSFEED (OR FEED): Where content from the organizations or people you follow, like or are friends with appears. (Facebook, Pinterest, X, Instagram)

PAGE: A profile for an organization or individual used for promotional purposes. You can like a page, but not friend it. (Facebook)

PIN: To add something to one of your boards. Posts on Pinterest are called pins. (Pinterest)

PLAYLIST: A compilation of related videos. (YouTube)

POST: To upload and share content to your profile. (Facebook, X, Instagram, YouTube)

PROFILE: Every user is given a main page called a profile. All of your posts show up on your profile. (Facebook, X, Instagram, Pinterest, YouTube)

REPOST: To share another user's content on the social media platform. (X)

SHARE: To repost another person's or page's content. (Facebook)

SUBSCRIBE: To view another user's content in your newsfeed. (YouTube)

TAG: To link to another user in your post. (Facebook, Instagram)

TAG: Tags are words related to a post that help users find them. (YouTube)

TWEET: A message posted on Twitter. (Twitter) Glossary | Coalitions



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